Research Topics

Break the stigma: autism

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Break the stigma: autism

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Editorial: Break the stigma: autism. The future of research on autism stigma - towards multilevel, contextual & global understanding

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Editorial on the Research Topic
Break the stigma: autism

Approaches to understanding and supporting autistic people in the 21st century have shifted from individual-level, often negatively valanced views, to an embrace of the fact that autistic people - like all people - exist in interaction with their context. Additionally, modern approaches have embraced neurodiversity, the idea that all people, regardless of neurocognitive abilities, have value, and highlights ways an individual is shaped in dialogue with their environment (1–4). However, the world is not built with neurodivergence in mind, and when individuals struggle, these difficulties are often pathologized - and stigmatized - across levels of societal experience: public, interpersonal, and internal (Bottema-Beutel et al.).

Historically, public portrayals of autism have been either minimal, caricatured, and/or stereotyped. Recently, there has been a shift, particularly in media, with an increase in portrayals that either offer a positive or more dimensional representation of autistic experiences (5–7). That said, the overall landscape remains far from balanced. For example, recent work shows that artificial intelligence-generated views and images of autism predominantly maintain a negative, stigmatized depiction of autism (8, 9), offering a data-driven mirror into public perceptions. It is notable, however, that some of the most effective instances of authentic portrayals have arisen from a *participatory* approach, whereby autistic people are either directly involved in the development of the characterization of a person's experience, and/or are the individuals representing (or represented in) those portrayals (10–12). Research has started to identify the impact of these portrayals on stigma, with initial evidence suggesting both increases and decreases in negative views (and self-views) of autistic people via these representations (7, 12–15). Thus, ongoing work should seek to examine the impact of different approaches to inclusion on the stigma that autistic people experience.

Stigma can also manifest in interpersonal relationships (e.g., family, classmates, work colleagues, other peers), in ways that can ultimately become enacted as prejudice. Thus, there is an urgent need to understand and address the ways in which interpersonal stigma is established and maintained (Marion et al.). Many established interventions designed to address stigma in social settings (e.g., peer relations) have used approaches that do little to address this outcome, and, at times, make it worse, leading to increased interpersonal victimization and risk of direct harm (16, 17). They often target the social behaviors of *autistic* people, with the aim of normalizing their behaviors to be more tolerable to non-autistic peers. This effect can then metastasize into systemic prejudice, wherein systems (e.g., employment, legal involvement) (18, 19) can themselves reflect these same expectations and values. Notably, recent work has begun to take a different path, seeking to provide psychoeducation to peers, colleagues, and the public about neurodiversity and the range of lived experiences these encompass (20–23). Intervention approaches have also started to take a more performance-based approach, aiming to advance each person's strengths and encouraging *choice* rather than behavioral normalization (24, 25). However, these approaches are often small-scale and consider only a subset of contexts, only beginning to scratch the surface of the need in this domain.

The culmination of these contextual forms of stigma for autistic people is that they can become internalized, and deeply impact how individuals view themselves. While the impact of internalized stigma is well-documented in other minoritized communities (26, 27), the consideration or prioritization of *any* subjective experiences *at all* has, until recently, been largely ignored in autism research. Several areas where work has started to take root include the impact on autistic identity formation and integration (28, 29), masking or passing as non-autistic (30, 31), minority stress (28, 32), internalized ableism (33), and distress experiences (34). However, other outcome domains, including shame, advocacy and self-advocacy, autistic community (35), and the perceptions of and prejudice towards other autistic people (i.e., lateral ableism) (36–38), have barely begun to be examined. Notably, these impacts represent areas that have long been advocated as an area of focus by the autism community, and many of the efforts to address autism stigma to date have largely been advanced by the efforts of autistic individuals, advocates, and scholars.

With the rise of the neurodiversity movement, many autistic people have realized a distinct marginalized identity, characterized by diverse strengths and challenges; this movement has also helped to identify acceptable unique supports to more inclusively address the needs of autistic individuals (17, 18). The autism research field, then, has finally started to recognize how the experience and impact of stigma and prejudice on autistic people can manifest in ways similar to (32) - and distinct from - that of other minority groups. This highlights the importance of learning from the diverse experiences of autistic people within and across cultures, communities, identities, and backgrounds, which could reinforce *or* bolster against adverse experiences of stigma and prejudice (28, 36, 39–43, Yoon et al.). More broadly, these developments highlight the importance of taking a capacious approach to addressing stigma and prejudice in this field, as represented by this Research Topic.

This work, then, can spur deeper investigations that can advance understanding and – ultimately – actionable findings that can continue to change the ways autistic people are viewed and supported in the community. Finally, we note that nearly all of these changes to date have been driven by the advocacy of autistic people at each of these levels, highlighting that, as ever, the best bulwarks against the effects of stigma remain the unified efforts of a marginalized community themselves. Therefore, it is our hope that this Research Topic can act as a catalyst and a call–to–arms for more dedicated research by both non–autistic and autistic researchers, clinicians, and other professionals alike, aiming to identify and address autism stigma and its impacts on autistic people and society around the globe, particularly in ways that continue to center the experience and contribution of autistic people, targeted efforts to address the breadth of stigma and prejudice experiences of autistic people of all backgrounds, and efforts to address existing stigma and prejudice within the autistic community, in efforts to reduce intra–community harms and increase collective action, thereby promoting a more equitable, inclusive world for all autistic people.

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ANG: Conceptualization, Writing – original draft, Writing – review & editing. MLM: Conceptualization, Writing – original draft, Writing – review & editing. AH: Writing – review & editing. NS: Writing – review & editing. CSMN: Writing – review & editing. MDL: Conceptualization, Funding acquisition, Writing – original draft, Writing – review & editing.

Conflict of interest

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References

1. Dawson G, Franz L, Brandsen S. At a crossroads–reconsidering the goals of autism early behavioral intervention from a neurodiversity perspective. *JAMA Pediatr*. (2022) 176:839–40. doi: 10.1001/jamapediatrics.2022.2299

2. Dwyer P. The neurodiversity approach (es): What are they and what do they mean for researchers? *Hum Dev*. (2022) 66:73–92. doi: 10.1159/000523723

3. Chapman R. Neurodiversity and the social ecology of mental functions. *Perspect Psychol Sci*. (2021) 16:1360–72. doi: 10.1177/1745691620959833

4. Dwyer P, Gurba AN, Kapp SK, Kilgallon E, Hersh LH, Chang DS, et al. Community views of neurodiversity, models of disability and autism intervention: Mixed methods reveal shared goals and key tensions. *Autism*. (2024). doi: 10.1177/13623613241273029

5. Lopez K. Why Pixar's First Non–Verbal Character In The Short "Loop" Was a Game–Changer (2020). Forbes. Available online at: https://www.forbes.com/sites/kristenlopez/2020/01/10/why–pixars–first–non–verbal–character–in–the–short–loop–was–a–game–changer/ (Accessed September 25, 2024).

6. Lawler K. *How "Everything's Gonna Be Okay avoids Hollywood's (and Sia's) pitfalls portraying autism* (2021). USA Today (Accessed September 25, 2024).

7. Jones SC, Gordon CS, Mizzi S. Representation of autism in fictional media: A systematic review of media content and its impact on viewer knowledge and understanding of autism. *Autism*. (2023) 27:2205–17. doi: 10.1177/13623613231155770

8. Botha M, Love J, Galbraith H, Pearson AD. (2024). Beyond white, boy, and blue: exploring prejudice and dehumanization of autistic people through artificial intelligence generated images. doi: 10.31219/osf.io/cxktf

9. Keyes O. Automating autism: Disability, discourse, and Artificial Intelligence. *J Sociotech Critique* (2020) 1:1-31. doi: 10.25779/89BJ-J396

10. Mittmann G, Schrank B, Steiner–Hofbauer V. Portrayal of autism in mainstream media – a scoping review about representation, stigmatisation and effects on consumers in non–fiction and fiction media. *Curr Psychol*. (2024) 43:8008–17. doi: 10.1007/s12144-023-04959-6

11. Orm S, Dean M, Fletcher–Watson S, Nordahl–Hansen A. Short report: Autistic adults' recommendations on how to improve autistic portrayals in TV–series and movies. *Res Dev Disabil*. (2023) 136:104484. doi: 10.1016/j.ridd.2023.104484

12. Jones SC. Hey look, I'm (not) on TV: autistic people reflect on autism portrayals in entertainment media. *Disability Soc*. (2024) 39:1484–501. doi: 10.1080/09687599.2022.2150602

13. Stern SC, Barnes JL. Brief report: does watching the good doctor affect knowledge of and attitudes toward autism? *J Autism Dev Disord*. (2019) 49:2581–8. doi: 10.1007/s10803-019-03911-7

14. Jones SC, Trott E, Gordon C, Milne L. Perception of the portrayal of autism in netflix's *atypical* within the autism community. *Autism Adulthood*. (2022) 5:76-85.. doi: 10.1089/aut.2022.0013

15. Groenendijk E, Van Heijst B, Geurts H. A co–designed psychoeducation for older autistic adults–a multiple case study. *Autism*. (2023) 27:1163–9. doi: 10.1177/13623613221138691

16. Pearson A, Rose K, Rees J. [amp]]lsquo;I felt like I deserved it because I was autistic': Understanding the impact of interpersonal victimisation in the lives of autistic people. *Autism*. (2023) 27:500–11. doi: 10.1177/13623613221104546

17. Gibbs V, Pellicano E. [amp]]lsquo;Maybe we just seem like easy targets': A qualitative analysis of autistic adults' experiences of interpersonal violence. *Autism*. (2023) 27:2021–34. doi: 10.1177/13623613221150375

18. Cooper D, Frisbie S, Wang S, Ventimiglia J, Gibbs V, Love AM, et al. What do we know about autism and policing globally? Preliminary findings from an international effort to examine autism and the criminal justice system. *Autism Res*. (2024) 17:2133-2143. doi: 10.1002/aur.3203

19. Black MH, Mahdi S, Milbourn B, Scott M, Gerber A, Esposito C, et al. Multi–informant international perspectives on the facilitators and barriers to employment for autistic adults. *Autism Res*. (2020) 13:1195–214. doi: 10.1002/aur.2288

20. Gillespie–Lynch K, Bisson JB, Saade S, Obeid R, Kofner B, Harrison AJ, et al. If you want to develop an effective autism training, ask autistic students to help you. *Autism*. (2022) 26:1082–94. doi: 10.1177/13623613211041006

21. Saade S, Bean YF, Gillespie–Lynch K, Poirier N, Harrison AJ. Can participation in an online ASD training enhance attitudes toward inclusion, teaching self–Efficacy and ASD knowledge among preservice educators in diverse cultural contexts? *Int J Inclusive Educ*. (2024) 28:161–76. doi: 10.1080/13603116.2021.1931716

22. Jones DR, DeBrabander KM, Sasson NJ. Effects of autism acceptance training on explicit and implicit biases toward autism. *Autism*. (2021) 25:1246–61. doi: 10.1177/1362361320984896

23. Dwyer P, Mineo E, Mifsud K, Lindholm C, Gurba A, Waisman T. Building neurodiversity–inclusive postsecondary campuses: recommendations for leaders in higher education. *Autism Adulthood*. (2022) 00:1–14. doi: 10.1089/aut.2021.0042

24. Lerner MD, Gurba AN, Gassner DL. A framework for neurodiversity–affirming interventions for autistic individuals. *J Consulting Clin Psychol*. (2023) 91:503–4. doi: 10.1037/ccp0000839

25. Gates JA, McNair ML, Richards JK, Lerner MD. Social knowledge & Performance in autism: A critical review & Recommendations. *Clin Child Fam Psychol Rev*. (2023) 26:665–89. doi: 10.1007/s10567-023-00449-0

26. Molina Y, Lehavot K, Beadnell B, Simoni J. Racial disparities in health behaviors and conditions among lesbian and bisexual women: the role of internalized stigma. *LGBT Health*. (2014) 1:131–9. doi: 10.1089/lgbt.2013.0007

27. Herek GM, Gillis JR, Cogan JC. Internalized stigma among sexual minority adults: Insights from a social psychological perspective. *J Counsel Psychol* (2015) 56:32-43. doi: 10.1037/2376-6972.1.S.18

28. Botha M, Gillespie–Lynch K. Come as you are: examining autistic identity development and the neurodiversity movement through an intersectional lens. *Hum Dev*. (2022) 66:93–112. doi: 10.1159/000524123

29. Perry E, Mandy W, Hull L, Cage E. Understanding camouflaging as a response to autism–related stigma: A social identity theory approach. *J Autism Dev Disord*. (2022) 52:800–10. doi: 10.1007/s10803-021-04987-w

30. Pearson A, Rose K. A conceptual analysis of autistic masking: understanding the narrative of stigma and the illusion of choice. *Autism Adulthood*. (2021) 3:52–60. doi: 10.1089/aut.2020.0043

31. Libsack EJ, Keenan EG, Freden CE, Mirmina J, Iskhakov N, Krishnathasan D, et al. A systematic review of passing as non–autistic in autism spectrum disorder. *Clin Child Fam Psychol Rev*. (2021) 24:783–812. doi: 10.1007/s10567-021-00365-1

32. Botha M, Frost DM. Extending the minority stress model to understand mental health problems experienced by the autistic population. *Soc Ment Health*. (2020) 10:20–34. doi: 10.1177/2156869318804297

33. Huang Y, Trollor JN, Foley KR, Arnold SRC. I've spent my whole life striving to be normal": internalized stigma and perceived impact of diagnosis in autistic adults. *Autism Adulthood*. (2023) 5:423–36. doi: 10.1089/aut.2022.0066

34. Lewis LF, Stevens K. The lived experience of meltdowns for autistic adults. *Autism*. (2023) 27:1817–25. doi: 10.1177/13623613221145783

35. Farahar C. Autistic identity, culture, community, and space for well–being. In: *The Routledge International Handbook of Critical Autism Studies*. London, England: Routledge (2022).

36. Giwa Onaiwu M. I, too, sing neurodiversity. *Ought: J Autistic Culture*. (2020) 2:58-67. doi: 10.9707/2833-1508.1048

37. Lateral ableism in the Autistic community (2023). Autistic and Living the Dream. Available online at: https://autisticltd.co.uk/2023/04/18/lateral–ableism–in–the–autistic–community/ (Accessed September 27, 2024).

38. Neumeier SAM, Brown LXZ. Beyond diversity and inclusion: understanding and addressing ableism, heterosexism, and transmisia in the legal profession: comment on blanck, hyseni, and altunkol wise's national study of the legal profession. *Am J Law Med*. (2021) 47:76–87. doi: 10.1017/amj.2021.3

39. Gillespie-Lynch K, Daou N, Sanchez-Ruiz M-J, Kapp SK, Obeid R, Brooks PJ, et al. Factors underlying cross-cultural differences in stigma toward autism among college students in Lebanon and the United States. *Autism* (2019) 23:1993–2006. doi: 10.1177/1362361318823550

40. Giwa Onaiwu M. They don't know, don't show, or don't care": autism's white privilege problem. *Autism Adulthood*. (2020) 2:270–2. doi: 10.1089/aut.2020.0077

41. Botha M, Dibb B, Frost DM. 'It's being a part of a grand tradition, a grand counter–culture which involves communities': A qualitative investigation of autistic community connectedness. *Autism*. (2022) 26:2151–64. doi: 10.1177/13623613221080248

42. Kim SY, Gillespie–Lynch K, Yoon W. A pilot mixed–methods evaluation of an intervention to reduce Korean undergraduates' stigma toward autistic people. *Res Autism Spectr Disord*. (2024) 113:102355. doi: 10.1016/j.rasd.2024.102355

43. Kim SY, Gillespie-Lynch K. Do Autistic People's Support Needs and Non-Autistic People's Support for the Neurodiversity Movement Contribute to Heightened Autism Stigma in South Korea vs. the US? *Journal of Autism and Developmental Disorders*. (2023) 53:4199–4213. doi: 10.1007/s10803-022-05739-0

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Editorial: Break the stigma: autism

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Editorial on the Research Topic
Break the stigma: autism

In this Research Topic we bring together a collection of research to *Break the Stigma* associated with autism, by exploring the impact of autism stigma and discussing the ways in which we can combat stigma.

Autistic individuals, transgender/gender non-conforming (TGNC) autistic people (Glaves and Kolman) and by extension, their caregivers (Clarke et al.) often experience victimization, bullying, and stigmatization. The pervasiveness of this stigma is evident when reviewing interviews of young autistic adults (Marion et al.) who all experienced stigma in the form of exclusion or isolation, with many also experiencing verbal bullying. However, this stigma is not reserved for autistic people. Twenty caregivers of profoundly autistic adults reported that they experienced at least one perceived stigma, characterized by negative responses or interactions with people in the community (Clarke et al.). These stigmatizing interactions were also reported with educators, peers (Marion et al.) and clinicians (Glaves and Kolman).

Stigma can be extremely impactful. For autistic people, stigma increases camouflaging behaviours aimed at concealing their autistic traits (Rivera and Bennetto), it interferes with their development of self-determination and autonomy (Thompson-Hodgetts et al.), it undermines their psychosocial well-being (Glaves and Kolman; Marion et al.), and it leads to adverse consequences such as suicidality (i.e., suicidal ideation, self-harm and suicidal attempts (Shaw et al.). Further, for parents of autistic children, stigma around bilingualism was shown to discourage families from raising their autistic child bilingually (Digard et al.).

Autism stigma has been also shown to significantly impede the integration of autistic individuals into society, a theme addressed by multiple studies in this special edition. Persistent barriers, inadequate support systems, and entrenched societal attitudes exacerbate this issue, as is often seen within education. For example, in South Korea, Yoon et al. highlight how systemic stigmatization in secondary education leads to bullying, trauma, and exclusion from further education and employment. The study emphasizes how societal values like elitism and meritocracy worsen these challenges, underscoring the need for targeted interventions.

This issue is not unique to Korea. Ahlers et al. explored the isolation of autistic students in self-contained classrooms in the U.S. and revealed that educators' attitudes contribute to this exclusion. They advocate for more inclusive practices that extend beyond physical integration and call for strategies to enhance educators' understanding of autism. One such strategy, investigated by Jenks et al. in the UK, is to run a training program for university staff aimed at debunking stereotypes and improving understanding of autism. Although quantitative measures showed limited changes, qualitative data revealed substantial benefits, particularly through including autistic perspectives. This approach enhanced staff's nuanced understanding and practical application in their interactions with autistic students.

Beyond education, integration barriers also exist in social service provision. Li and Qi examined the challenges faced by NGOs in China working with autistic children, noting how funding structures and interactions with funders impacted the effectiveness of inclusion efforts. This study provides valuable insights into the barriers in social service provision that hinder the integration of autistic children and suggests the need for more targeted and effective solutions.

In broader society, Boucher et al. explored how non-autistic adults quickly form negative judgments about autistic children based on brief interactions. They found that adults with higher social competence and explicit autism stigma were more likely to hold negative perceptions of autistic children. Similarly, Jones and Sasson found that college undergraduates often displayed patronizing and exclusionary attitudes towards autism. These studies underscore the need to address biases that contribute to social exclusion.

Collectively, these studies call for more focus on autistic strengths, inclusive practices, better-informed societal attitudes, and targeted interventions to support the integration of autistic individuals across various educational and social contexts. From initial diagnosis, clinicians should provide strength-based information to highlight autism strengths and reduce stigma (Woods and Estes). To provide more support to autistic people, Shaw et al. suggest a neurodiversity-affirmative approach to autism which may promote a more positive self-identity and improved mental health. Similarly, Riebel et al. highlight the role of promoting self-compassion in reducing the self-stigma and shame often associated with autism. Researchers also emphasized the need to provide more opportunities for autistic people to make choices and exert autonomy (Thompson-Hodgetts et al.; McVey et al.). For example, Glaves and Kolman advise that clinicians should take an intersectional perspective of their autistic clients' gender identities to reduce stigma and have a better understanding of the needs of the whole person. Providing adequate support and better educating autistic medical professionals may promote inclusion in the medical workforce (Shaw et al.).

Another salient theme in this Research Topic was the role of research(ers) in perpetuating autism stigma. As researchers, we need to explicitly address the link between ableism and poor autism science (Bottema-Beutel et al.). This means shifting away from research that reduces autistic people to their perceived deficits and instead focuses on how socially constructed views of "abilities" contribute to autistic people's "disabilities". This can be achieved by centering autistic voices (Kaplan-Khan and Caplan; McVey et al.; Caldwell-Harris et al.). *Comprehensive participatory research* promotes close collaboration with the autistic community and other autism stakeholders across all stages of research, allowing autistic people to share their perspectives and shape research priorities (Bottema-Beutel et al.; Kaplan-Khan and Caplan; McVey et al.). Researchers also need to leverage the unique contributions autistic researchers bring to autism research. For example, when qualitative interviews are conducted by autistic/non-autistic researcher dyads, autistic participants report increased connection and comfort (Kaplan-Khan and Caplan). Approaches like these that centre the autistic voice facilitate closer alignment and trust between autism research(ers) and the autistic community, promote novel research programs that are relevant to the priorities of autistic people, create more ethical and less ableist research practices, and ultimately culminate in reduced autism stigma.

Together the articles in this Research Topic stress the fact that researchers, clinicians, and society more broadly need to do a better job at advocated for the rights of autistic people. This starts with the understanding that autistic people are a marginalized population that experience discrimination (McVey et al.). It is not autism itself that leads to a poor quality of life, but instead, a lack of social support and acceptance. Social interactions are bidirectional, yet autistic people are under enormous pressure to learn about and accommodate the needs and preferences of non-autistic people (Schuck and Fung). We need to shift our focus away from the outdated notion that autistic people need to be fixed and instead place the onus on non-autistic people to learn about and accommodate the needs of autistic people (McVey et al.). By teaching and promoting neurodiversity, or the understanding that there are no "right" kinds of brains, non-autistic people can learn to accept and value autistic differences (Jenks et al.; Schuck and Fung; Davidson and Morales). Virtual autism acceptance programs for children (Davidson and Morales) and high schoolers (Schuck and Fung), and a training program for higher education staff (Jenks et al.), all demonstrated success in reducing stigma, but stigma reduction can also be achieved through greater social inclusion. For example, service dog placements were found to act as a social catalyst, decreasing experiences of judgement and stigma for autistic children by inviting others to approach and interact (Leighton et al.). By increasing non-autistic people's acceptance of individuals whose behaviours may not align with society's expectations, autistic people may garner more social support and ultimately experience an improvement in their quality of life.

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Why can't children with autism integrate into society in China? Study based on the perspective of NGO classification

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Introduction: In the field of protecting children with autism, NGOs have become a major force that cannot be ignored. Although NGOs for children with autism have expanded the number and improved the quality of the services they provide, a large number of autistic children still cannot achieve the goal of social inclusion in China. The existing literature has mostly tried to explain the reason from the perspective of the common characteristics of NGOs and has paid insufficient attention to the huge differences between these NGOs, so it is impossible to identify the obstacles that children with autism encounter accurately.

Methods: From the perspective of NGO classification, this study conducted an in-depth investigation of 4 NGO cases in City N, China, to show the impact of the difference of NGOs on the obstacles to the social inclusion of autistic children.

Results: The research has found that under the authoritarian regime, NGOs for children with autism that rely heavily on external funds include three common groups: government-oriented NGOs, foundation-supported NGOs, and individual-financed NGOs. The structural characteristics of the funders and their interaction with the NGOs for children with autism shape their different action logics, as the result that the desire of children with autism to integrate into society cannot be achieved as expected.

Discussion: The results of this study give more accurate insights into the barriers in social service provision for children with autism that impede their social inclusion and provide a reference for those seeking a solution to this problem.

KEYWORDS

children with autism, NGO classification, resource dependence theory, social integration, barriers

1. Introduction

Autism spectrum disorder (ASD) has become a key public health concern facing all countries around the world. In China, the prevalence of ASD has increased, the current incidence rate being 1 in 100. Statistics show that there are over 10 million Chinese with ASD, more than two million of whom are children under the age of 12, and the number is growing by over 100,000 a year, making autism the fastest-growing developmental disability (1). Moreover, the treatment of autism over the lifespan is currently the most expensive medical expenditure payment (2); however, with early diagnosis and intervention, these costs can be reduced by two thirds (3). Therefore, early intervention therapies for children with autism are crucially important.

Socially-oriented intervention therapies such as community integration and the resumption of valued life roles are critical for the health and well-being of children with autism (4). According to the United Nations *Convention on the Rights of the Child*, children with autism in this study refer to people with autism under the age of 18 (5). This stage is critical for cognitive function, social interaction, and personality development (6). At this stage, improving the ability of autistic children to take care of themselves, adapt to society, and participate in social life can create opportunities for subsequent inclusive education, employment, etc., thus substantially changing their future life (7–11). *The International Classification of Functioning, Disability and Health (ICF)* model provides a clear, comprehensive and universal concept of disability, namely impairment of body functions and structures, bad activities and limitation of participation (12). Among them, social inclusion is an important part of participation, reflecting the extent to which individuals can participate in social activities. For children with autism, social inclusion contains at least two meanings: one is that children with autism acquire equal attention from the social, political, economic and cultural life; Second, children with autism are socially accepted and have relationships of mutual trust, appreciation and respect in the family and among friends and communities (13, 14). Historically, treatment methods for children with autism in the world underwent a transition from biomedical specialties and institutionalized care in a closed environment to training of social skills, collaborative learning group activities and community-based living in inclusive environments (15–17). In China, the government has also clearly expressed its commitment to the full inclusion of children with autism into society. State laws and regulations, such as *the Law of the People's Republic of China on the Protection of Persons with Disabilities* (1990, 2008), *the Regulations of the People's Republic of China on the Education of Persons with Disabilities* (1994, 2017), and *the State Council on the Establishment of a Rehabilitation Assistance System for Children with Disabilities* (2018) all pay special attention to autism groups. Furthermore, programs such as "Colorful Dream" and "Learning in Regular Class" are also committed to providing integrated services for children with autism – China is establishing a rights-based social service system for autistic children with the goal of social inclusion (18).

The role of non-governmental organizations (NGOs) in providing social inclusion services to children with autism cannot be ignored. NGO is a form of organization which is independent of the government system, with non-profit, voluntary, organizational, autonomous, private and other attributes (19). In Western Europe, behind the state-centered "welfare state" is the supply of social welfare through the reality of government-NGOs partnership (20). Since the collapse of the Soviet Union, two parallel developments have also taken place in former Communist countries, namely, the systematic withdrawal of the state from the provision of social services and the increasing provision by NGOs in various fields (21). In the field of social services for autistic children, NGOs have been established to address government and market failures. For a long time, governments and markets have been criticized for their slow response and their lack of vision on rights, respectively (22–24). In China, the first NGOs for children with autism developed in the 1990s with the goal to speak for children with autism and their families and fill the gap in social welfare services from the nation and the market (25, 26). Encouraged by the Chinese authorities, NGOs have shown great development potential (27). Data from *Report on the Development of Autism Education and Rehabilitation Industry in China III* shows, from 2016 to 2019, the number of NGOs for autism increased by 12% from 1,600 to 1811, and service capacity increased by 30% from less than 200,000 to more than 300,000 (28). With the promulgation of the *Government Procurement Law of the People's Republic of China* (2014), it is increasingly common for governments to purchase social services from NGOs. NGOs have become the most important providers of social inclusion services for children with autism. Although all of the efforts of NGOs are for the well-intended purpose of giving children with autism equal rights, dignity, and respect, unfortunately, we were surprised to find, through long-term research, that the social inclusion aims undertaken by NGOs cannot be fulfilled.

Why are children with autism unable to achieve the goal of social inclusion through NGOs? There are a few direct and systematic responses to this question, and these researches start from one of three angles. First, the government's policy has produced the exclusion results. On one hand, most scholars believe that in countries represented by China, NGOs for children with autism are heavily controlled by the government (27), and official policies are mainly focused on children aged 0 to 6, thus leading to designated NGOs preferring to provide services for younger children instead of older children with autism (29). On the other hand, compared with Western Europe and North America, NGOs in developing countries are currently giving priority to service provision rather than to advocacy or the implementation of disability rights (30). Due to long-standing social barriers for people with disabilities, most NGOs assume that the cost of inclusive services is too high to justify; therefore, it is impossible to elicit sympathy to gain funding from the government (31, 32). Second, lack of money and human capital leads to poor service provision, especially in the case of NGOs that get no government support. Because of their unofficial status, the professional capacity of practitioners working in NGOs for children with autism is not certified and their pay is relatively low, resulting in a large loss of talent and thus affecting the effectiveness of services (33). In addition, in the poor charity environment in China, NGOs for children with autism can hardly acquire stable and institutionalized social funds to help these children (33). Third, the uniqueness of social inclusion service projects makes it difficult to implement. Compared with other interventions, social inclusion services often require cross-agency cooperation. However, evidence shows that different agencies are in a gaming environment, and the inconsistent goals make it difficult to implement and maintain cross-agency cooperation in social inclusion projects, which is prone to failure (34–36).

We do not deny the reasons proposed in the above literature, but our in-depth qualitative research indicates that the reality does not stop there. Existing studies, on the one hand, mostly explain the reason from the government-NGOs relationship approach, ignoring the perspective of NGO classification and the diversity of constraints based on this. That is, the current literature mostly explains from a single (category) case in an attempt to summarize the common characteristics of NGOs instead of the huge differences between them. In fact, various NGOs have different action logics. If we generalize NGOs, then it is impossible to accurately locate the underlying dynamic mechanism that explains why children with autism encounter obstacles to social inclusion. On the other hand, the current literature has discussed NGOs for autistic children in developed and developing countries, but has paid insufficient attention to this issue under the authoritarian regime, thus unable to reveal a variety of forms of control on NGOs for autistic children in China, and the exclusive behavior it produces.

Therefore, this study tries to explore the reasons why social inclusion is not achieved for children with autism as expected in the context of China from the NGO classification approach. We first explain the role, basic functions, and development difficulties (mainly in terms of funding) of Chinese NGOs for children with autism and then classify these NGOs according to their funding sources. After that, using case study method, four NGOs for children with autism in City N in China are investigated to examine the different action logics and consequences in terms of NGOs providing social inclusion for children with autism. This study is critically important to promoting the practice of public health services for children with autism and will effectively fill a gap in the current literature.

2. NGOs for children with autism in China and their classification

In 1993, the first autism educational organization was established by the mother of a child with autism simply because her child could not secure an educational placement in public schools (37). Since then, parents of children with autism and people with passion and charity have set up more and more NGOs to serve children with autism and their families (25, 38). In recent years, the Chinese government has relaxed requirements for a dual management system[1] and has been increasingly outsourcing social services (39), which has further stimulated the explosive growth of NGOs for children with autism. What's more, the number and proportion of social inclusion services for autistic children, such as integrated education, community rehabilitation, employment support, recreational and sports activities, and peer activities, are also increasing. Research shows that NGOs for children with autism are playing an increasingly important role in mobilizing resources, providing public services, and promoting social participation and inclusion for children with autism (40).

NGOs receive funding from various sources. Funders include the government, as well as other sources, such as social fundraising, sponsorship, and donations. At the same time, NGOs may obtain funding through market activity income (41). In addition, international assistance is also an important source of funding for NGOs in developing and underdeveloped countries (42, 43). According to statistics, in 2019/20, the largest source of income for NGOs in the UK was the public, including donations, legacies, charity stores, and membership fees, accounting for 51% of all income. Government support accounts for 26%, including grants and public service contracts. Other sources include the voluntary sector (9%), investment (9%), the private sector (4%), and national lottery (1%) (44). The Chinese people lack enthusiasm for the investment of NGOs, and the government is their main donor. According to data, nearly 50% of the funding of NGOs comes from financial allocations, 21.18% comes from membership fees, 6% comes from market income, 5.63% comes from sponsorship and project funds provided by enterprises, and 5% comes from other sources (45). Currently, compared to other countries, there are three trends in the funding of NGOs in China: (1) The Chinese government is increasingly using tangible support tools such as purchasing service contracts, tax preferences, and subsidies, among other means, to incentivize NGOs; (2) Private foundations have developed rapidly and have become increasingly active in supporting the development of grassroots NGOs; (3) Foreign funds are becoming increasingly unavailable. In particular, the implementation of the *Administration of Domestic Activities of Overseas Non-governmental Organizations* (2016) has led to NGOs for children with autism facing increasing challenges in attaining overseas funds, and the *Charity Law* (2016) has further restricted the channels for public foundations to engage in raising social funds in China (46, 47).

According to resource dependence theory, access to resources in such situations is crucial. Resource dependence theory is an important organization theory that studies the relationship between organizations and external resources and the environment, and its basic assumptions are as follows: (1) survival is what organizations focus most on; (2) for survival, organizations need to obtain external resources because no organization can be fully self-sufficient; (3) thus, organizations must interact with elements from the environment on which they depend, and these elements are often contained in other organizations; (4) the survival of an organization is based on its ability to control relationships with other organizations (48). NGOs must acquire the resources needed for survival, which can be achieved in the form of exchange, trading, or donation. In most cases, however, this is an asymmetric dependency relationship: The resources that the recipient needs to maintain its survival are in the hands of the sponsor, so the recipient must meet the requirements of the sponsor in order to obtain the resources, whereas the sponsor has the absolute power to reshape or constrain the recipient's behavior because of its unique advantages in terms of resources (49, 50).

Through literature review and field research, it is found that NGOs for children with autism rely most heavily and critically on the outside world for funds, which come from government, foundations, market income, donations from enterprises and individuals, self-financing by parents of autistic children, and so on[2]. Due to different funding sources and ways to serve sponsors, NGOs for children with autism have developed different models. Firstly, to promote social welfare, different government departments will provide different types of government assistance to NGOs (51). Among them, the government purchasing of services[3] "has become the most attractive tool" (52). Secondly, fundraising, sponsorship, and donations from the society also play an important role (53). In order to address the growing social demand and inequality, the government has encouraged the rapid growth and expansion of foundations by introducing of the *Foundation Management Regulations* (2004) and the *Charity Law*

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[1] Also known as the dual management examination and approval registration system, meaning that the establishment of NGOs needs to be approved by the competent business units and registration authorities. The system of direct registration was adopted in 2012, phasing out the "dual management system."

[2] NGOs for autistic children cannot collect membership fees.

[3] Government purchasing of services is an effective way to provide social services. By market mechanism, the provision of some public services directly provided by the government is entrusted to qualified NGOs, with the government paying the fees according to the contract.

(2016). Foundations have become one of the important sources of funding for NGOs (47, 54). The development of philanthropy has also stimulated the enthusiasm of some enterprises and individuals to donate money (55, 56). However, the object is selective, whether it is the government or social support. The two donor types have jointly created a result-driven and institutionalized environment in which NGOs easily lose sight of their missions and uniqueness (1), leading to an inability to meet the needs of autistic children and their parents. In the face of this situation, some parents of autistic children have voluntarily raised funds to establish grassroots NGOs to serve autistic children, to truly and effectively respond to their needs. In addition, market income is also one of the funding sources for NGOs for children with autism. However, families with disabled children generally have poor economic conditions and low effective market demand (57), so it often exists as supplementary funds for NGOs for autistic children. Based on this, we have selected three typical and common modes from these different types: government-oriented, foundation-supported, and individual-financed NGOs. What must be stressed is that we construct these ideal types in a taxonomic sense and try to explain their inherent operating mechanisms. However, in field research, the characteristics of NGOs are more complex: NGOs have the main characteristics of a certain ideal type but concurrently contain components of other types.

2.1. Government-oriented NGOs for children with autism

Government support generally includes two ways: government subsidies and government purchase of services. Among them, the government purchase of services, as a key measure of the government to promote the development of NGOs (58), plays a more important role. Most of these NGOs are designated units of government purchase services and have diverse and formal contractual relationships with the government. To gain support, NGOs' activities often focus on the government's priorities. In 2018, with the promulgation of *the State Council on the Establishment of a Rehabilitation Assistance System for Disabled Children (2018)*, local governments made great efforts to purchase rehabilitation services for disabled children, and data showed that more and more NGOs for autistic children had become designated units of the government purchase of services.

2.2. Foundation-supported NGOs for children with autism

Foundations, with their unique social mission, value proposition, and resource advantages, have been called a blessing for grassroots NGOs. In terms of the supply of funds, foundations provide NGOs with resources through project bidding or service purchases, and NGOs for autistic children also actively seek funds from foundations to meet their own needs. With China's support for the foundations, more and more foundations have emerged, such as the China Poverty Alleviation Foundation, the Nandu Public Welfare Foundation, the Tencent Foundation, the One Foundation, the Huiling Foundation for the mentally disabled, and so on. Such NGOs are deeply influenced by the principles of the foundations, and their services are also carried out in accordance with them.

2.3. Individual-financed NGOs for children with autism

These NGOs are mostly spontaneously established by parents to cope with the current lack of policy and professional support. In the survey, it is found that the parents of autistic children are more likely to gather together, and to spontaneously and actively establish various social groups and organize various activities to promote social inclusion to meet their children's needs. This is less common in other types of parents with disabilities. This is related to the rapid growth of autistic children in recent years, and the current social service support system cannot meet the needs of autistic children. They usually receive funds from parents, volunteers, or private donations for autistic children. Most of these organizations are relatively small and unregistered, aiming to carry out activities that mainstream NGOs cannot.

3. Method

This study adopted case study method to explore the differences in terms of the achievement of social inclusion for children with autism between NGOs supported by different sources of funds and the reasons for these differences. The detailed, nuanced case study approach, which focuses on the interdependencies of the various parts of an event and the ways in which these relationships occur, is well suited to answering questions left in the black box about how NGOs respond to different environmental pressures (59, 60).

3.1. Field access and sampling

We selected City N as the main research site. City N, the provincial capital of Province J, is situated in northeastern part of China. In 2014, there were over 20,000 children with autism in City N, with an incidence rate of 1 in 68. This figure is very high among Chinese cities, and the trend of increase is obvious. Therefore, the problem of autistic children has attracted considerable attention from the government, charitable foundations, and all sectors of society in City N. At present, City N is one of the places in China where NGOs for children with autism are developing quickly and are relatively mature. In terms of number and type, there are many NGOs for autistic children, and the difficulties NGOs encounter are very typical.

The field work for the study began in February 2021. With the help of the City N's Disabled Persons Federation (DPF)[4] and the recommendation of NGOs for autistic children and parents, the authors conducted an extensive preliminary survey of various NGOs

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[4] The China Disabled Persons' Federation, founded in March 1988, is a national organization for all persons in China who have diverse disabilities, with the guiding principles of representing, serving, and managing persons with disabilities. Local DPF have been established all over mainland China at the provincial, prefectural, county, and township levels, with the mission of promoting the full and equal participation of people with disabilities in society and of ensuring that people with disabilities share the material and cultural achievements of society.

TABLE 1 Cases of NGOs for children with autism.

Type	Government-oriented NGOs for children with autism	Foundation-supported NGOs for children with autism	Individual-financed NGOs for children with autism	
			Elite-funding-oriented NGOs for children with autism	Small-scale crowdfunding-based NGOs for children with autism
Name	AH	BI	CJ	DK
Date of establishment	2010	2003	2016	2015
Number of autistic children	Above 200	28	Above 200	Above 80
Work sites	A fixed place with full facilities	A fixed place with full facilities	Working in community	None
Service content	Exercise training, homework training, speech training, sensory training, physical therapy, music therapy, game class, etc.	Community living, evening family accommodation, pre-employment training, assisted employment, etc.	Community living, outdoor activities and socializing, integrated employment, skills training, etc.	Community living, social inclusion activities, art therapy, parent training, etc.

for children with autism in City N, classified the NGOs, and defined their typical characteristics. In order to ensure the category representativeness of the sample (61) and explore the significant differences between different fund-dependent NGOs, purposeful sampling was used in this study following three standards: the case (1) has typical characteristics of the NGOs for autistic children classified in this paper, that is relying on government funding (government-oriented NGOs), relying on foundation funding (foundation-supported NGOs), or mainly relying on self-raised funds (individual-funded NGOs); (2) has established for more than 3 years and have rich work experience serving children with autism (such NGOs can provide more information); and (3) has a relatively stable source of funds (in order to control the influence of capital changes and other factors on the results). Finally, we selected four NGOs for comprehensive observation and in-depth interviews: AH Rehabilitation Training School for Special Children (AH), a government-oriented NGO; BI Training Center for Special Children (BI), a foundation-supported NGO; CJ Social Work Service Center for Families with Mental Disabilities (CJ), an individual-financed NGO; and DK Services Center for Families with Mental Disorders (DK), an individual-financed NGO. In the investigation, we found that there were obvious differences in individual-financed NGOs due to the different composition of parents. To fully illustrate the complex characteristics of NGOs, we chose two cases[5]. Sample details are shown in Table 1.

3.2. Data collection and data analysis

With the assistance of the heads of the NGOs for children with autism, the authors collected ethnographic data from March to July 2021. Three different methods were adopted: participatory observation, in-depth interviews, and access to textual materials such as government planning outlines, statistical yearbooks, archives of NGOs, and other files. Ethical approval for this study was obtained from the Academic Committee of School of Philosophy and Sociology, Jilin University.

First, the first author conducted intensive participatory observations of each NGO, respectively, for 15 to 20 days in order to take a closer look at the day-to-day work of these NGOs, especially social inclusion service project application, social inclusion service supply, social inclusion service project assessment[6]. At the same time, the ethnographic field work also included participation in characteristic courses and social activities related to social inclusion, such as hiking, mountain climbing, film watching and so on. During that time, the staffs and parents generously shared their work experiences, feelings, and attitudes toward the social inclusion of children with autism with the researchers. These conversations were recorded as an important raw data source.

Second, we conducted 33 semi-structured one-to-one and one-to-many interviews (including 5 follow-up interviews). The interviewees included 21 NGO staff members (including 5 in AH, 6 in BI, 5 in CJ, and 5 in DK) and 16 parents of autistic children. In accordance with the principle of purposeful sampling, the inclusion criteria for interviews with NGO staff are: (1) the founders and principal managers of NGOs; (2) rehabilitators, special education teachers or social workers with more than 3 years of working

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[5] We found that there is a third type, namely, parent-buying NGOs for children with autism, but such organizations are rare. At the same time, parent-buying NGOs closely resembles the market: that is, charging low fees leads to survival difficulties, while charging high fees leads to market exclusion – consistent with previous literature. Thus, this paper will not go into details later.

[6] In China, social inclusion services for autistic children are provided through Project System, including the following links. The first is the project application. The NGOs shall formulate feasibility plans or application reports and submit them to the project sponsor. The second is the project approval. The project sponsor determines the funded project according to the application report and comprehensive consideration of other factors. The third is project implementation. NGOs provide corresponding social services according to project contracts. The fourth is the project assessment. In the process of project implementation and settlement, there will be multiple assessment at different phases from the project sponsor.

experience and rich experience in social inclusion services; (3) Consent to attend the interview. The inclusion criteria for parent respondents were: (1) the primary caregivers of autistic children; (2) Their children are aged 0–17 years old; (3) Receiving/having received social inclusion services at the four NGOs; (4) Enough Chinese fluency to participate in the interview process. In order to improve the reliability and validity, we fully consider the heterogeneous factors such as age, gender, education, occupation, position of NGOs staff interviewees, and also fully takes into account of variables control to family income, *hukou*, education level, age, gender, disability grade, disability type of the children with autism of parents' interviewees. The data collection process was achieved through semi-structured interviews, in which the NGO staff respondents were asked to answer questions about the NGO's funding sources, working modes, types of social inclusion service supply, coverage, and work barriers. Parents were asked to answer questions about their access to social inclusion services for autistic children, their experience of exclusion in social inclusion services, and their attitudes toward different NGOs. Before the interviews, participants were provided with information about the purpose of the study, the survey schedule, the duration of the study, and their rights and risks. The researchers conducted all of the interviews in Mandarin, transcribing the interviews verbatim into Chinese and selectively translating them into English as needed to present the findings. The whole research process strictly followed the requirements with regard to participant confidentiality, no harm, and informed consent.

Third, with the consent of the NGOs' leaders, we read some of their internal files. At the same time, we collected planning outlines and policy documents related to rehabilitation services for children with autism in City N to supplement the field data.

We integrated and analyzed data from different sources to form a consistent theme and reveal why children with autism are facing social inclusion difficulties in different categories of NGOs for children with autism. Our aims were to develop an extended case study of both theoretical and practical significance (62), to have a dialogue with the existing literature on the social inclusion dilemma for children with autism, and to offer certain recommendations on future rehabilitation policy practices for children with autism. Meanwhile, following the triangle method (60), the research team applied as many research techniques as possible, obtained information and materials from various data sources around the research topic, and compared the consistency and difference between the results to make the research conclusions more credible and accurate.

4. Findings

In government-oriented, foundation-supported, and individual-financing NGOs for children with autism, the structural characteristics of the funders and their interactions with the recipients shape NGOs' different action logics. Under the tension of the efficiency mechanism and rights protection mechanism dominated by NGOs' need for survival, there are various obstacles to the supply of services, such as group selection and service replacement, and consequently the aspiration to integrate children with autism into society cannot be achieved.

4.1. Government-oriented NGOs for children with autism

Government-oriented NGOs for children with autism establish close ties with the government mainly through the government's service purchasing system. Since 2009, the government has allocated financial expenditure to fund the Salvage Rehabilitation Project for Poor Children with Disabilities, and in 2018, it officially established a Rehabilitation Assistance System for Children with Disabilities, allocating special subsidies for rehabilitation training for children with disabilities, including autism. During this period, a large number of NGOs, such as AH, grasped the policy opportunities, becoming designated units for the purchase of rehabilitation services and experiencing rapid development. However, this approach is not always helpful. Influenced by the institutional heritage of omnipotent government, administrative power has long been centralized in China, while social forces are far from mature (63). The government decides the content and objectives of services, has complete bargaining power, and designs complex standards for strong supervision and strict assessment. As a result, under the institutional environment in China, the equal contractual relationship contained in the service purchasing system is in practice implemented on the basis of the principle "I (the government) pay, and you (the NGO) do the work" (64). Our research found that this unequal government-NGO relationship continues to produce and reproduce barriers that prevent children with autism from achieving social inclusion.

4.1.1. Age exclusion

NGOs for children with autism provide rehabilitation services for younger children with autism, thus the rights of older children with autism cannot be guaranteed. Under the authoritarian system, local DPF maintained the hierarchical relationship through bureaucratic management and strong assessment and supervision, rather than the original contractual relationship. In order to get funding, AH has had to become the "steward" of the local PDF, and thus it tends to implement the PDF's will. Lili, AH's Teaching Director, stated: "*At present, it is not up to us to decide. It depends on which areas the local DPF will invest more money in, and our focus will shift accordingly*" *(Interview with Lili, March 10, 2021)*. The rehabilitation training subsidy in City N is only provided to children with autism aged 0 to 6 years, and therefore most government-oriented NGOs have turned to providing social services for younger children with autism, so there is an obvious age exclusion. Many parents of children with autism commented on the lack of services for children over the age of seven (field notes, May 2, 2021). What is worse, under this top-down institutional structure, there is no space for bottom-up service users to exercise autonomy, and they cannot effectively fight for the rights of older children with autism.

4.1.2. Service type exclusion

The unequal bargaining power between funders and service providers limits the delivery of social inclusion courses. Here, unequal bargaining power means that the price is not regulated by the market but rather set solely by the government (64). In the local DPF's curriculum directory for NGOs, we clearly found the names of services and their prices: for example, "speech training, 30 yuan per class; sensory inclusion training, 40 yuan per class" (provided by the AH Archives, March 18, 2021). Because NGOs for children with autism are responsible for their own profits and losses, they prefer to provide services that are highly profitable. Unfortunately, social inclusion courses for children with autism only appear sporadically in the curriculum directory, and the prices for such courses are relatively low, which discouraged Ming, the principal of AH,

> Social inclusion is easier to say than to do. It does not mean taking them to normal society to play or letting them communicate with normal children. If we want to do good social inclusion, we must recruit workers with appropriate skills, find venues, and reset the training plan. Now with these little funds, we cannot do it. (Interview with Ming, March 13, 2021)

4.1.3. Reduced service quality

In order to ensure the effective implementation of tasks, the government has a strict, complex, and cumbersome assessment system. AH has incurred considerable management costs to comply with these systems and has correspondingly squeezed its investment in the service it provides. The assessment content of local DPF includes site setting, facilities and equipment, human resources, management system, quality control, etc., and the assessment means include data access, field observation, service effect evaluation, questionnaire survey, etc. AH therefore invested a lot of time and energy to meet the site settings, facilities and equipment, human resources, management system requirements, while ignoring the input of social inclusion services. What's worse, In China, the fund for each child with autism is provided through the local DPF in the place where the child's *hukou* is registered, and the criteria for receiving the fund vary from region to region. At a peak, AH will deal with the assessment and audit requirements of nearly 20 DPFs, and the labor cost of processing these materials will inevitably rise. Lili complained that *"the tasks that one staff member could accomplish in the past are now simply impossible" (Interview with Lili, March 10, 2021)*. Another issue is that the staff turnover rate is very high in NGOs for children with autism (33). The downward pressure of assessment makes the work team, which is already short of personnel, unable to focus on rehabilitation services; and this can be regarded as depriving children with autism of their rights.

4.1.4. Service content replacement

The assessment system also leads to a bias in course selection. AH is forced to replace those services that are not conducive to the assessment, and social inclusion services bear the brunt of this process. Actually, the varied assessment criteria of DPFs provide AH workers with their worst nightmare: they must comply with punitive rules to satisfy their sponsors. But these punitive rules do not always adapt to realities. In the face of the assessment dilemma, NGOs for children with autism often overlook, intentionally or unintentionally, some of the service needs that are not conducive to the assessment. High-demand social inclusion services have been replaced by mainstream services, such as ABA, because of their excessive complexity and uncontrollability. If they cannot replace courses, NGOs turn to changing the detailed content of courses. In one interview, Jun, a therapist, recalled a time when they "faked" classes,

> The DPF required us to have no fewer than four classes a day, but the teachers could not arrange them, so we set up an extracurricular activity class as a social inclusion class to solve the assessment. (Interview with Jun, March 17, 2021)

Not surprisingly, AH is often criticized by other NGOs for children with autism as being "utilitarian" and "indifferent." AH has to report annually to the local DPF on its customers' welfare qualifications and service use, and it obtains survival resources by relying on the government, which is an inevitable choice for its development. But in this process, the social inclusion progress of children with autism is hindered.

4.2. Foundation-supported NGOs for children with autism

The funding provided by foundations that support NGOs for children with autism has complementary advantages for both sides, each taking what it needs (65). Although presenting the appearance of friendly cooperation, the rational logic of the pursuit of profit maximization embedded in the power game leads to an unequal relationship between the two sides, where rich foundations with overwhelming power dominate the practices of NGOs for children with autism (66). The most important manifestation of this is project competition.

Projects are the life of foundation-supported NGOs, and their capacity to apply for projects directly determines their survival and development. Jiang, the principal of BI, showed that from foreign foundations to domestic foundations and then to charitable organizations on the Internet, the sources of funding have changed a lot. However, there has been no change in the method of open bidding for projects (Interview with BI President Jiang, April 4, 2021). In recent years, with policy restrictions, funding constraints, and the transformation of foundations, project applications seem to be getting harder and harder and competition is getting keener. In order to choose the final funding target, a foundation fully considers every project's advantages and risks, mainly referring to three standards: impact, implementation difficulty, and NGO's working experience (66). The strong competition has made it a priority for NGOs to meet the selection requirements of the foundations instead of the needs of children with autism. As a result, a large number of children with autism are excluded from the service system.

4.2.1. Impact rather than quality

Initially, foundations equate the impact of projects and NGOs with quality of service. However, in the process of making the impact quantitative, impact gradually becomes a rigid digital competition, losing the meaning of "quality." BI, originally established with the support of a caring person from Hong Kong, with most of its funds initially coming from foundations in Hong Kong. In recent years, they have begun to seek support from domestic foundations due to restrictions on overseas funds.

> Because of political security, it is difficult for foreign foundations to support us now. In the past two years, we stopped an important project supported by the Hong Kong Foundation. Currently, we mainly apply for funds from domestic foundations, some famous ones, such as Tencent Charity Foundation, One Foundation, etc. Nowadays, there are too many NGOs applying,

> and the competition in obtaining funds is becoming increasingly fierce. From the perspective of the foundation, they must also want to support those with strength and great social attention that can bring flow or help to the development of the foundation. (Interview with Jiang, April 4, 2021)

But they are often in a "helpless" state because of digital competition,

> On the Tencent 99 Charity Day[7], labor and wealth are wasted, completely losing their original intention. Now, to obtain funds, one has to donate steps and draw small red flowers. This consumes too much energy. If it were not for working with the ** Foundation and making participation mandatory, we would not have wanted to do it.. (Interview with Jiang, April 4, 2021)

Moreover, in order to expand its impact and improve the success rate of social inclusion programs, BI gives more attention to cultivating successful cases than to bringing universal benefits to children with autism. Koji, the program director at BI, is particularly focused on high-functioning children with autism because *"once their potential is played out, they will be the best advertisement for the institution" (Interview with Koji, April 6, 2021)*. However, the model of infinitely increasing the success of a small proportion of children with autism may bring about the concentration of resources and new forms of unfair resource distribution.

> I think the most serious problem is that the public has misconceptions about autistic children. They think autistic children will be gifted in some way, such as playing the piano, or drawing... However, very few autistic children are gifted. Most of them, like my child, cannot do anything, and it's difficult for them to take care of themselves. This misunderstanding is because these NGOs always favor and promote that type of children. The real-life of autistic children is not seen. (Interview with Pei, the parent of an autistic child, April 13, 2021)

4.2.2. Mild autism rather than severe autism

Faced with competition and assessment pressure from different foundations, foundation-supported NGOs for children with autism tend to select children with mild symptoms who are most likely to meet all the assessment criteria from foundations. For example, an integrated employment project for youths with autism is BI's most competitive project. In order to maximize funding, BI makes this project meet as many foundation standards as possible. However, different foundations have different requirements. In this case, foundation-supported NGOs for children with autism select children with a low degree of disability as it enables them to meet all requirements. While this is the best choice for BI, it results in the relentless rejection of a large number of children with severe autism.

> Children with mild autism are easier to manage and have better employment inclusion effects. Children with severe autism are difficult to manage and can hit you easily. Now, these children are so tall and powerful that you cannot control them. It's very difficult for us to do social inclusion services, and it's likely that we will not be able to do anything. (Interview with Koji, April 6, 2021)

4.2.3. A few rather than all

The competition mode, also known as the "survival of the fittest" mode, will eliminate many of the less developed NGOs and the children with autism they serve. NGOs that have already worked with foundations are well positioned as their capacity to provide services is recognized and there is an established trust mechanism and communication method between them and the foundations, all of which is extremely important for future cooperation. However, there is a paradox in this: The weaker NGOs in need of foundation support are more likely to fail to get support due to lack of ability, and this deprives the children with autism served by these NGOs of their right to receive social inclusion services. It means that weak foundation-supported NGOs for children with autism lack opportunities to improve their capabilities and also reduces the possibility of them obtaining resources, thus further limiting their survival and development and inevitably stifling their vitality and creativity.

The current situation is "the strong stronger, the weak weaker." Only when you develop and achieve something will the foundation be willing to invest in you. (Interview with Shui, April 11, 2021)

4.3. Individual-financed NGOs for children with autism

Individual-financed NGOs for children with autism are often set up spontaneously by parents with autistic children, rooted in the community, and financed through personal donations. These NGOs have emerged to express dissatisfaction with bureaucrats and experts (67). The birth of an autistic child often makes their parents second-class citizens, and children with autism's needs in terms of equal participation and social inclusion do not provoke a positive response from bureaucrats and experts, whose ignorant and indifferent attitude makes parents feel helpless (67). Parent-support organizations, on the other hand, provide an integrated environment in which children with autism and their parents can feel relaxed, which is more helpful for them (68).

Our research found that, unlike the other two types of NGOs, in individual-financed NGOs for children with autism, the funds basically come from parents and social donations and are jointly managed by the members. Generally, the core members who contribute the most decide on course themes and activity plans on the basis of their own needs and preferences. Due to the different economic and social backgrounds of the members and the different amounts of resources they have obtained, there are different individual-financed NGOs, the common ones being elite-funding-oriented NGOs and small-scale crowdfunding-based NGOs. The

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[7] In 2015, Tencent 99 Charity Day was launched by Tencent Charity Foundation, which is one of the most influential projects. Tencent Charity Foundation was founded in June 2007, which is the first national non-public Internet foundation. The foundation is committed to promoting the development of the public welfare industry through the Internet, especially the mobile Internet technology and services.

results of the field research showed that these two types of NGOs are unable to achieve good social inclusion for children with autism, but the specific reasons for this are clearly different.

4.3.1. Elite-funding-oriented NGOs for children with autism: multiple exclusions under elite power

The core members of elite-funding-oriented NGOs are mostly elite families. In CJ, the core members are mostly university professors, doctors, lawyers, and successful businessmen. They surpass most people in ability, insight, courage, property, cultural literacy, and many other aspects. For the rehabilitation of children with autism, they use their own money, knowledge, and social capital to establish mutual-aid organizations for parents and their autistic children and successfully attract other elite parents. They also make full use of their professional ability to undertake social inclusion projects such as "Light up the star," "*Yiqi* Travel," and "Friendly campus tour," which have become extremely popular across China. However, the strong personal characteristics and power advantages of elite groups inevitably produce social exclusion behaviors in the construction of inclusive social environments.

4.3.1.1. Interest priority

Elite-funding-oriented NGOs get a lot of attention and funding through personal networks or organizational influence through many enterprises. In order to protect the maximized profit of individuals and these enterprises, elite members often undertake some semi-inclusion or even non-inclusion activities. This approach is well suited to successful collaboration, but it does not fully achieve social inclusion. For example, Ken, the parent of an autistic child, made the following comments about movie watching activities,

> At CJ, communication activities will be organized between healthy children and parents, and autistic children like us. However, at this time, I feel we are like animals in zoos, for people from outside to visit and sympathize. (Interview with Ken, April 29, 2021)

This is far from what parents expect. What is more difficult for sensitive parents of autistic children to accept is that every time in such activities, they have to stand in a row, accept donations from kind-hearted individuals and enterprises, and force autistic children and their parents to take photos with some banners. As Ken said,

> This is using the kids totally as a promotional tool for profit. (Interview with Ken, April 29, 2021)

4.3.1.2. Elite capture

Although CJ says that it serves all children with autism and their families, the core members have more power in the NGO, leading to "elite capture" and generating inequality. Elite capture refers to the phenomenon whereby elites form an interest alliance and jointly monopolize public resources (69). In CJ, a small number of core members directly or indirectly decide the allocation of internal resources. Elite members and other families with more intimate relationships through blood, geography, and occupation are more likely to have access to social inclusion activities. This excludes families with weak social networks. Many parents of children with autism who want to participate in these activities say that they have been cheated in the face of widespread unfair distribution.

> In order to help my kid recover, we have participated in many activities from NGOs. I feel that these NGOs inside also have a circle, that is, there are close and distant relationships within them. Just look at CJ. When there are activities with no limit for the number of participants, my kid can participate. If it is a good activity with a limit of 20 or 30 participants, it will not be available for my kid. Only those inside the organization have the opportunity. (Interview with Yang, the parent of an autistic child, April 21, 2021)

4.3.2. Small-scale crowdfunding-based NGOs for children with autism: dilemma of survival with a lack of funds

DK is jointly established and maintained by parents of children with autism, but compared with an elite-funding-oriented NGO, it faces a relatively severe shortage of funds which has created a series of difficulties, such as a lack of management personnel, a shortage of professional talent, and project sustainability difficulties. Although the leaders of DK have made great efforts to maintain the operation of the organization, in terms of practical effects, they cannot provide professional, effective, and continuous services, which makes it difficult for them to have a meaningful effect on social inclusion.

4.3.2.1. Difficult to continue

Lack of funds leads to intermittent activities which fail to achieve the goal of long-term social inclusion. DK's director, Lee, told us confidently that *"you can do things with lots of money, and you can also do things without money" (Interview with Lee, May 2, 2021)*, and she listed DK's typical inclusion activities, such as collective life and art therapy. However, the reality is that many activities have been forced to terminate due to a lack of funding.

> *To be honest, we have a lot of good ideas. But often just because we do not have enough support, we cannot do it... Our lack of funds is the biggest problem. Without money, there is no way to organize activities and hire professional teams. Now, we mainly charge for some of our activities and get help from some kind-hearted people. And some volunteers come to help us organize our activities. But there is still a big gap in our expectations. (Interview with Jane, May 8, 2021)*

4.3.2.2. A vicious cycle

To make matters worse, inadequate funding creates a vicious circle, thus failing to improve the situation. DK has more than 220 members, but the economic situation of most of these families is average or even poor. The members are more conservative in their use of money, and most of them want to be free-riders. Deputy director Jane explained that the biggest problem with the DK is that,

> When it comes to low-cost activities, people are very much motivated. When the cost of a project is high and everyone needs to contribute money to carry it out, parents are on the fence. (Interview with Jane, May 8, 2021)

This creates a development dilemma: Due to inadequate funds, it is difficult for DK to provide services in a long-term and stable manner as this would require more parents to invest funds. But parents are less willing to spend money because they do not see any prospect of the project. Under this vicious circle, NGOs such as DK passively reject truly good social inclusion projects. Ming, the principal of AH, the government-oriented NGO, is not satisfied with DK's performance,

> *DK is still where it started after all these years. It has not had any success in training any children with autism. (Interview with Ming, June 2, 2021)*

We must admit that every type of individual-financed NGO is looking for ways to improve its own ability to survive in order to achieve the social inclusion of children with autism. However, whether NGOs have good funds or poor funds, it is difficult to achieve the established goals under the current environment.

5. Conclusion and discussion

Using the case study method and an NGO classification approach, this study answers the question of why, in China, a large number of children with autism fail to achieve the goal of social inclusion through NGOs. NGOs for autistic children, as important direct welfare providers, have a very critical impact on the future development of children with autism. Since the 1990s, Chinese parents who have children with autism and caring people concerned about autism have set up NGOs to provide services for these children. In the course of their development, these NGOs have become divided according to the different funding sources they rely on. This paper categorizes them as government-oriented NGOs, foundation-supported NGOs, and individual-financed NGOs. Through extensive and in-depth field research, we found that the structural characteristics of sponsors and their interactions with recipients shape their different action logics.

Specifically, the actions of NGOs for children with autism in an asymmetric dependence relationship with sponsors must meet the requirements of their sponsors. Therefore, the respective characteristics of the three types of NGOs for children with autism in the service field need to be redefined and examined. First of all, government-oriented NGOs for children with autism rely on government purchasing services to establish close ties with the government, but at the same time, being seen as the spokespersons of the local DPFs and the performers of administrative tasks, they do not play the role of protecting children with autism. In the face of the institutional environment constraints of the complete decision-making power, the absolute bargaining power, and the strict assessment power of the local DPFs, government-oriented NGOs prefer to simply fulfill tasks, which lead to issues of age exclusion, service type exclusion, the reduction of service quality, and the replacement of service content. Second, foundation-supported NGOs for children with autism need to win trust and support from foundations through project competition. However, the continuous competition leads to their paying attention to the "quantity" of influence rather than "quality" – the pursuit of numbers of retweets and likes replaces the substantive goal of realizing the social inclusion of children with autism. This study also found that faced with financial temptation from several foundations, foundation-supported NGOs tend to select children with mild autism to meet their assessment goals, leading to a large number of children with severe autism being ignored. While these stronger NGOs become the winners in this competitive environment, less developed NGOs and the children with autism they serve are left out of the service system. Finally, our interviewees provided clear evidence that leaders and core members are exceptionally important in individual-financed NGOs. These NGOs can be divided into two categories on the basis of the different identities of their core team members: elite-funding-oriented NGOs and small-scale crowdfunding-based NGOs. For elite-funding-oriented NGOs, the large influx of funds easily leads to interest priority and elite capture, resulting in unequal access to services for all members and even acquiescence to some exclusive behaviors in the construction of an inclusion environment. For small-scale crowdfunding-based NGOs, the financial difficulties they face means that their activities are always intermittent and they are unable to implement the most ideal social inclusion projects; such unsatisfactory results create a vicious circle and ultimately fail to meet the social inclusion needs of children with autism.

An increasingly important topic in regard to the current service provision for children with autism in China is how different types of NGOs can better provide social inclusion services. We have mapped out a tripartite interaction between service funders (governments, foundations, or individual donors), providers (NGOs), and service users (children with autism and their parents) and defined the roles and functions of these three parties in the area of social service provision. But the experience of NGOs shows that in a state of resource dependence, they inevitably give priority to the requirements of funders rather than responding to the needs of children with autism and their families. How to establish a tripartite two-way supply and demand closed loop and establish a more equal interactive relationship should be the focus of social services for children with autism in the future. This not only requires NGOs for children with autism to redefine their own roles but also, more importantly, taking the rights of children with autism and their families' needs fully into account.

From the perspective of NGO classification, this study found that different NGOs have different motivations for funding dependence, resulting in different exclusion of social inclusion services for autistic children. In China, the authoritarian government has had a huge impact on this result. In this study, the different interaction logics of funders and NGOs in specific environments should provide some reference for the provision of social services for children with autism in other countries in the future. At the same time, it must be admitted that this study has some limitations. First, only three common types of NGOs for autistic children were analyzed in this article. In fact, there are various types of NGOs for autistic children, which require a more comprehensive understanding. Second, there are few studies on relationship of autistic children with NGOs, making it difficult to obtain large amounts of information from previous studies. Third, this study is based on a qualitative field survey of one site, and so the representativeness and universality of its findings need to be further verified in future studies. Finally, we emphasize the potential replication of this study, but the applicability of its results to other countries needs to be demonstrated.

Data availability statement

The raw data supporting the conclusions of this article will be made available by the authors, without undue reservation.

Ethics statement

Ethical review and approval was not required for the study on human participants in accordance with the local legislation and institutional requirements. Written informed consent for participation was not required for this study in accordance with the national legislation and the institutional requirements.

Author contributions

ZL: conceptualization, methodology, investigation, writing – original draft, writing –revised draft, writing – revised draft, administration, and funding acquisition. CQ: conceptualization, methodology, investigation, writing – original draft, and supervision. All authors contributed to the article and approved the submitted version.

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Conflict of interest

The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

Publisher's note

References

1. China news. (2019). *There are more than 10 million autism, and about 2 million under the age of 12 in China*. Available at: https://baijiahao.baidu.com/s?id=1629661040786629738&wfr=spider&for=pc

2. Knapp M, Romeo R, Beecham J. Economic cost of autism in the UK. *Autism*. (2009) 13:317–36. doi: 10.1177/1362361309104246

3. Jaerbrink K. The economic consequences of autistic spectrum disorder among children in a Swedish municipality. *Autism*. (2007) 11:453–63. doi: 10.1177/1362361307079602

4. Heinemann AW. Putting outcome measurement in context: a rehabilitation psychology perspective. *Rehabil Psychol*. (2005) 50:6–14. doi: 10.1037/0090-5550.50.1.6

5. UNICEF. (1989). *Convention on the rights of the child*. Available at: https://www.unicef.org/child-rights-convention/convention-text.

6. Hillman CH, Biggan JR. A review of childhood physical activity, brain, and cognition: perspectives on the future. *Pediatr Exerc Sci*. (2017) 29:170–6. doi: 10.1123/pes.2016-0125

7. Chen YJ, Duku E, Zaidman-Zait A, Szatmari P, Smith IM, Ungar WJ, et al. Variable patterns of daily activity participation across settings in autistic youth: a latent profile transition analysis. *Autism*, Online ahead of print. (2023). doi: 10.1177/13623613231154729

8. Chen YL, Martin W, Vidiksis R, Patten K. "A different environment for success:" a mixed-methods exploration of social participation outcomes among adolescents on the autism spectrum in an inclusive, interest-based school club. *Int J Dev Disabil*. (2021):1–10. doi: 10.1080/20473869.2021.2001729

9. Chun J, Kuo HJ, Curtiss SL, Lee GK, Lee H, Awadu J. The interplay of supports and barriers during the transition to adulthood for youth on the autism spectrum. *Disabil Rehabil*. (2022):1–11. doi: 10.1080/09638288.2022.2112097

10. Landa RJ, Holman KC, O'Neill AH, Stuart EA. Intervention targeting development of socially synchronous engagement in toddlers with autism spectrum disorder: a randomized controlled trial. *J Child Psychol Psychiatry*. (2011) 52:13–21. doi: 10.1111/j.1469-7610.2010.02288.x

11. Trembath D, Waddington H, Sulek R, Varcin K, Bent C, Ashburner J, et al. An evidence-based framework for determining the optimal amount of intervention for autistic children. *Lancet Child Adolesc Health*. (2021) 5:896–904. doi: 10.1016/S2352-4642(21)00285-6

12. WHO. *International classification of impairments, disabilities and handicaps*. Geneva: World Health Organization (2001).

13. Boutot EA. Fitting in: tips for promoting acceptance and friendships for students with Autism Spectrum Disorders in inclusive classrooms. *Interv Sch Clin*. (2007) 42:156–61. doi: 10.1177/10534512070420030401

14. European Commission. *Joint report on social inclusion, directorate-general for employment and social affairs*. Brussels: European Commission (2004).

15. Dyson L. Strategies for and successes with promoting social integration in primary schools in Canada and China. *Int J Disabil Dev Educ*. (2012) 59:157–72. doi: 10.1080/1034912X.2012.676422

16. Majoko T. Inclusion of children with autism spectrum disorders: listening and hearing to voices from the grassroots. *J Autism Dev Disord*. (2015) 46:1429–40. doi: 10.1007/s10803-015-2685-1

17. Xu DZ, Hou J, Kong CH. Review of autism treatment theories and methods. *J Int Psychiatry*. (2009) 36:115–9.

18. Fisher KR, Shang X, Blaxland M. Review article: human rights based social policies – challenges for China. *Soc Policy Soc*. (2011) 10:71–7. doi: 10.1017/S1474746410000400

19. Salamon LM, Sokolowski SW, List R. *Global civil society: Dimensions of the nonprofit sector*. Bloomfield, CT: Kumarian (1999).

20. Salamon LM. Introduction: the nonprofitization of the welfare state. *Voluntas*. (2015) 26:2147–54. doi: 10.1007/s11266-015-9638-3

21. Cook LJ. New winds of social policy in the east. *Voluntas*. (2015) 26:2330–50. doi: 10.1007/s11266-015-9642-7

22. Fisher KR, Shang X, Li J. Accountability of children's services organizations in China. *Asian Soc Work Policy Rev*. (2015) 9:94–107. doi: 10.1111/aswp.12043

23. Liu DH, Li HZ. A study on the third sector in the context of government failure. *Law Rev*. (2005) 06:13–8. doi: 10.13415/j.cnki.fxpl.2005.06.003

24. McCabe H. Parent advocacy in the face of adversity: autism and families in the people's Republic of China. *Focus Autism Other Dev Disabil*. (2007) 22:39–50. doi: 10.1177/10883576070220010501

25. McCabe H. Bamboo shoots after the rain: development and challenges of autism intervention in China. *Autism*. (2013) 17:510–26. doi: 10.1177/1362361312436849

26. Shang X, Wu X, Wu Y. Welfare provision for vulnerable children: the missing role of the state. *China Q*. (2005) 181:122–36. doi: 10.1017/S030574100500007X

27. McCabe H, Deng G. "So they'll have somewhere to go": establishing non-governmental organizations (NGOs) for children with autism in the People's republic of China. *Voluntas*. (2018) 29:1019–32. doi: 10.1007/s11266-017-9879-4

28. China.org.cn. (2019). *Report on the development of autism education and rehabilitation industry in China III was released*. Available at: http://www.china.org.cn/chinese/2019-04/12/content_74673984.htm

29. Wu X. H. (2018). Suggestions on constructing the social welfare system for the elderly intellectual disabled people. Available at: http://aqxxgk.anqing.gov.cn/show.php?id=643705

30. Holland D. The current status of disability activism and non-governmental organizations in post-communist Europe: preliminary findings based on reports from the field. *Disab Soc*. (2008) 23:543–55. doi: 10.1080/09687590802328337

31. Grue J. False dichotomies of disability politics: theory and practice in the discourse of Norwegian NGO professionals. *J Lang Polit*. (2011) 10:109–27. doi: 10.1075/jlp.10.1.06gru

32. Niewohner J, Pierson S, Meyers SJ. 'Leave no one behind'? The exclusion of persons with disabilities by development NGOs. *Disabil Soc*. (2019) 35:1171–6. doi: 10.1080/09687599.2019.1664053

33. Fang W. Voluntary or professional: a case study on the NGO for children with autism. *J Soc Sci*. (2018) 03:73–81. doi: 10.13644/j.cnki.cn31-1112.2018.03.007

34. Glisson C, Hemmelgarn A. The effects of organizational climate and interorganizational coordination on the quality and outcomes of Children's service systems. *Child Abuse Negl*. (1998) 22:401–21. doi: 10.1016/S0145-2134(98)00005-2

35. Parsons BM. Local autism policy networks: expertise and intermediary organizations. *Educ Policy*. (2018) 32:823–54. doi: 10.1177/0895904816673743

36. Ziviani J, Darlington Y, Feeney R, Meredith P, Head B. Children with disabilities in out-of-home care: perspectives on organisational collaborations. *Child Youth Serv Rev*. (2013) 35:797–805. doi: 10.1016/j.childyouth.2013.02.003

37. McCabe H, Tian H. Early intervention for children with autism in the people's Republic of China: a focus on parent training. *J Int Spec Needs Educat*. (2001) 4:39–43.

38. Cotton JN, Edwards CP, Zhao W, Gelabert JM. Nurturing care for China's orphaned children. *Young Child*. (2007) 62:58–63.

39. Schmid H. The role of nonprofit human service organizations in providing social services: a prefatory essay. *Adm Soc Work*. (2004) 28:1–21. doi: 10.1300/J147v28n03_01

40. Ge ZM. An exploration of the standardized development of the self-organization for children with disabilities. *Shandong Soc Sci*. (2016) 07:60–6. doi: 10.14112/j.cnki.37-1053/c.2016.07.007

41. Clancey G, Westcott H. "This rabid fight for survival": small NGO manager's experiences of funding reform. *Aust J Soc Issues*. (2017) 52:163–79. doi: 10.1002/ajs4.9

42. Chaudhry S, Heiss A. Dynamics of international giving: how heuristics shape individual donor preferences. *Nonprofit Volunt Sect Q*. (2021) 50:481–505. doi: 10.1177/0899764020971045

43. Froelich KA. Diversification of revenue strategies: evolving resource dependence in nonprofit organizations. *Nonprofit Volunt Sect Q*. (1999) 28:246–68. doi: 10.1177/0899764099283002

44. NCVO. (2022). *UK civil society almanac 2022*. Available at: https://www.ncvo.org.uk/news-and-insights/news-index/uk-civil-society-almanac-2022/financials/where-do-voluntary-organisations-get-their-income-from/#/

45. Wang M. (2001). *NGO research in China: a case study*. NGO Research Center, Tsinghua University; Regional Development Center, United Nations.

46. Huang S. Ten years of the CRPD's adoption in China: challenges and opportunities. *Disabil Soc*. (2019) 34:1004–9. doi: 10.1080/09687599.2019.1604384

47. Kang Y. What does China's twin-pillared NGO funding game entail? Growing diversity and increasing isomorphism. *Volunt Int J Volunt Nonprofit Org*. (2019) 30:499–515. doi: 10.1007/s11266-018-00085-1

48. Pfefer J, Salancik G. *The external control of organizations: a resource dependence perspective*. New York: Harper and Row (1978).

49. Casciaro T, Piskorski MJ. Power imbalance, mutual dependence, and constraint absorption: a closer look at resource dependence theory. *Adm Sci Q*. (2005) 50:167–99. doi: 10.2189/asqu.2005.50.2.167

50. Wang JJ. The interactive mechanism on the NPO and government in Zhejiang: an analysis based on resource dependence theory. *Zhejiang Soc Sci*. (2008) 09:31–7. doi: 10.14167/j.zjss.2008.09.003

51. Shen Y, Yu Z. Government funding affects non-government revenues of social organizations: an empirical study of 3016 foundations in China. *Comparat Econ Soc Syst*. (2019) 204:128–37.

52. Zhang Y. Dependent interdependence: the complicated dance of government–nonprofit relations in China. *Volunt Int J Volunt Nonprofit Org*. (2015) 26:2395–423.

53. Wang M. *Introduction to non-profit organization management*. Beijing: China Renmin University Press (2002).

54. Yu X. Social entrepreneurship in China's non-profit sector. *China Perspect*. (2016) 2016:53–61. doi: 10.4000/chinaperspectives.7051

55. Li Y. A comparative study on the structure of charitable donations in China and America. *Gov Stud*. (2020) 196:81–7.

56. Zhang J. Competition, commitment and obedience: the motivation of charitable donations in Chinese enterprises. *Manage World*. (2013) 118–129+143

57. Qi CY, Wang Y. Why is rehabilitation assistance policy for children with disabilities deviated in supply-demand? A case study in mainland China. *Front Public Health*. (2021) 9:666333. doi: 10.3389/fpubh.2021.666333

58. Ministry of Finance of PRC. (2017). A guideline on supporting the development of social organizations through government purchase of services. Available at: http://www.mof.gov.cn/gkml/caizhengwengao/2017wg/wg201702/201706/t20170602_2614100.htm

59. Binder A. For love and money: Organizations' creative responses to multiple environmental logics. *Theory Soc*. (2007) 36:547–71. doi: 10.1007/s11186-007-9045-x

60. Yin RK. *Case study research: design and methods. 5th* ed. Newbury Park, CA: Sage Publications (2014).

61. Wang N. Representativeness and sampling logic in case studies. *Gansu Soc Sci*. (2007) 05:1–4.

62. Burawoy M. The extended case method. *Sociol Theory*. (1998) 16:4–33. doi: 10.1111/0735-2751.00040

63. Wu Y. Absorb and control: the logic behind social services purchase. *Acad Ther*. (2015) 06:64–73.

64. Zheng GH, Zhang Z. How social work agencies transform into labor companies: from the perspective of state-society relations. *Guangdong Soc Sci*. (2021) 04:194–210.

65. Li HR. Reciprocal logic between grant-making foundations and grassroots organizations: a case study of the China Foundation for Poverty Alleviation. *Expanding Horizons*. (2018) 01:109–15.

66. Luo C. *Analysis of effect and influencing factors of China's foundation funding grass-roots NGO*. Master dissertation. Wuhan: Central China Normal University (2020).

67. Schubert MA. Nurturing a self-help group: one professional's experience. *SAGE Open*. (2015) 5:215824401557493. doi: 10.1177/2158244015574939

68. Solomon M, Pistrang N, Barker C. The benefits of mutual support groups for parents of children with disabilities. *Am J Commun Psychol*. (2001) 29:113–32. doi: 10.1023/A:1005253514140

69. Laffont J, Tirole J. The politics of government decision-making: a theory of regulatory capture. *Q J Econ*. (1991) 106:1089–127. doi: 10.2307/2937958

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Service dogs for autistic children and family system functioning: a constant comparative analysis

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Introduction: Service dog placements for autistic children are growing in popularity, yet findings to date are mixed. Moreover, no study to date has examined these placements through the lens of a recognized theoretical model. The purpose of this study is twofold: to explore experiences reported by caretakers of autistic children involved in a service dog program, and to contextualize findings within an established theoretical framework.

Methods: A total of n=50 caretakers of autistic children (n=38 with and n=12 without a service dog) were recruited through the national non-profit service dog provider Canine Companions. Participants completed an online survey through Qualtrics which asked open-ended questions about their experiences, both negative and positive.

Results: Constant comparative analysis identified two high level themes, nested within a family systems approach framework: (1) Enhancing social functioning of the family system unit and (2) Fostering stability and strength within family system subunits. These themes interacted holistically to foster and reinforce family system resilience. Placements led to greater social inclusion for children and their families, acted as a highly individualized intervention, and decreased experiences of judgement and stigma. Perceived as members of the family, service dogs may coregulate with the autistic child and family members and can be a source of joyful connection within the family.

Discussion: Results highlighted the service dog's influence on the entire family (beyond the autistic child). Implications for service dog organizations suggest it may be helpful to account for family-wide impacts throughout the placement process. High standards on the part of provider organizations may minimize negatives, optimizing outcomes for both humans and canines. Ultimately, findings enrich our understanding of service dog interventions for autistic children.

KEYWORDS

assistance dogs, autism spectrum disorder, human-animal interaction, family systems approach, stigma

1. Introduction

In the United States, about one in 54 children are diagnosed with autism spectrum disorder (1). Autism spectrum disorder is a neurological condition characterized by both strengths and challenges. The diagnostic criteria for autism have tended to focus more on challenges including social difficulties, restricted interests, and repetitive behaviors (2). However, while the presentation of autism is highly heterogenous and unique to each individual, research has also identified a deep sense of pride within the autistic and neurodiverse community and highlighted strengths such as adaptability, creative thinking, individuality, and visuospatial processing (3, 4). The prevalence of autism is higher in males than females, and has been on the rise in recent decades (1). This increase has largely been attributed to a combination of increased awareness, broadened diagnostic criteria, and increased identification within under-diagnosed populations, rather than an actual rise in incidence (5). In the United States, it is estimated that for each autistic child, families spend an additional $3,930–$5,621 annually in healthcare costs relative to children without autism (6). Moreover, neurodiverse individuals frequently experience stigma which can have an even greater negative impact on functioning than the characteristics of their mental condition itself (7). A broad range of established, emerging, and unestablished interventions exist for autism to optimize functional outcomes and adaptive skills (8). For example, for individuals under 22 years of age, established interventions (backed by thorough research demonstrating effectiveness) include story-based interventions and behavioral interventions. Emerging interventions (with some research demonstrating effectiveness) include music therapy, picture exchange communication systems, and exercise; and unestablished interventions (with no sound research demonstrating effectiveness) include animal-assisted therapy, movement-based interventions, and concept mapping (9). Autism interventions should aim to promote an increase in quality of life, empowerment, and fulfillment (10).

One such complementary intervention is placement with a service dog trained to support autistic individuals. Service dogs can be trained in any number of tasks depending on the needs of the individual. Tasks may include providing calming deep pressure, facilitating social interactions, retrieving dropped items, and participating in structured therapies (11). According to Assistance Dogs International, the accrediting body for assistance dog providers, service dogs for autism are currently the third most common type of assistance dog after guide dogs and mobility service dogs (12). A total of 64 accredited organizations train these types of service dogs, up from 19 in 2014 – a more than 3-fold increase in less than a decade (13). In contrast to other types of service dog partnerships, in which the service dog handler is also the individual receiving assistance, service dog placements for autism often involve three parties: the autistic child, the service dog, and a caretaker (or "facilitator") who handles the service dog (11). The triadic (rather than dyadic) nature of these placements may lend additional complexity to the intervention; for example, the service dog's primary bond may form with the caretaker rather than the autistic child (14), and it can be difficult for the service dog to accompany or support the child in school settings given that the handler would not be present (15).

To date, while some types of service dog placements can be considered an emerging intervention (e.g., service dogs for PTSD in the realm of mental health), service dog placements for autistic children remain an unestablished intervention due to the limited evidence currently available. While a handful of studies have examined the biopsychosocial outcomes of this intervention and revealed encouraging findings, results overall have been inconsistent and mixed, particularly when comparing studies with quantitative versus qualitative designs (16, 17). Based on the existing research, benefits appear to consistently include enhanced safety of the autistic child, the dog's role as a social catalyst, improved emotional well-being, and enhanced self-regulation (16, 18–21). On the other hand, challenges can include increased burden in caring for the dog, canine behavioral issues, public access issues, and possible welfare concerns for the dog (14, 18, 22, 23). Perhaps unsurprisingly given the triadic nature of these placements, most studies identify impacts extending beyond the individual child to include the entire family, underscoring the importance of considering the family as a whole when evaluating outcomes (16, 22, 23). However, no study to date has attempted to examine this intervention in the context of an existing theoretical framework.

Thus, this study aimed to explore the experiences reported by caretakers of autistic children involved in a service dog program, including those with a service dog and those on a waitlist to receive a service dog. Using a qualitative approach, our goal was to contextualize findings within a broader established theoretical framework in order to develop a richer understanding of the service dog intervention for autistic children.

2. Materials and methods

This study reports a subset of qualitative findings from a larger mixed-methods, cross-sectional study. This study received ethical approval from the Purdue University Human Research Protection Program (IRB #1906022320). An exemption was obtained from the Purdue Institutional Animal Care and Use Committee (IACUC) since no interaction took place between the research team and any dogs.

2.1. Intervention

Service dog placements were made at no cost to the recipients by the non-profit organization Canine Companions, an Assistance Dogs International-accredited service dog provider in the United States and the largest service dog provider globally. Individuals with disabilities, or their caretakers, undergo a multi-step application process which includes submission of an application, reference forms from healthcare providers, a telephone interview, and an in-person interview (24). Eligible individuals are placed on a waitlist to receive a service dog. Canine Companions service dogs are Labrador Retrievers, Golden Retrievers, or Labrador/Golden Retriever Mixes purpose-bred for their role. Puppies are raised by volunteers for approximately 18 months before undergoing an additional 6–9 months of professional evaluation and instruction with Canine Companions training staff. Trained tasks include basic obedience (e.g., sit, down, loose leash walking), providing calming deep pressure, retrieving dropped items, and social greetings. As is common for this intervention, placements consist of a triad including the autistic child, the service dog, and a primary caretaker (often a parent) responsible for the service dog's care and management. Placements occur onsite at training centers, with caretakers receiving 2 weeks of hands-on instruction in the service dog's management, care, and safety. Canine Companions provides in-person and remote support throughout the duration of the placement.

2.2. Participants

A total of $n = 50$ caretakers (90% identifying as female) of autistic children were recruited through Canine Companions. Participants that completed the qualitative component of this study included $n = 38$

with a service dog and $n = 12$ without a service dog, but on the waitlist to receive one. All participants received unrestricted access to usual care. Among those with a service dog, time since placement ranged from 0.56–7.27 years ($M = 3.75$, $SD = 1.96$). Study eligibility criteria included (1) a community diagnosis of autism spectrum disorder, (2) the child being 5–17 years old, and (3) meeting provider eligibility criteria. Provider eligibility criteria included (1) child being at least 5 and caretaker at least 18 years old, (2) child having a disability, (3) needing a task (s) that a Canine Companions dog can provide, (4) child and caretaker cohabitating, and (5) caretaker being able to control, manage, and care for the dog.

2.3. Measures

Participants completed an online survey administered through Qualtrics experience management software (Qualtrics, Provo, UT) which included optional open-ended questions. Only the responses to open-ended questions are included in the present analysis. Participants waiting to receive a service dog were asked one open-ended question at the survey's conclusion: "Is there anything else you would like to share about yourself, [child's name], or your thoughts about a future [service dog]?" Participants with a service dog were asked six open-ended questions: (1) "What has [service dog's name] been trained to do (i.e., a specific behavior, alert, or command) that has helped the most?" (2) "What autism spectrum disorder symptom has [service dog's name] benefited or impacted the most with [child]?" (3) "How has [service dog's name] positively impacted you as a caregiver?" (4) "How has [service dog's name] positively impacted your family as a whole?" (5) "How has [service dog's name] negatively impacted you, [child], or your family as a whole? (6) "Is there anything else you would like to share about [service dog's name]?"

2.4. Analysis

We conducted a constant comparative analysis (25) to understand caretaker experiences and contextualize them within an established theoretical framework. Authors SL and LN read and re-read qualitative survey responses to identify similarities and differences and thereby develop initial categories (26). The team met regularly to discuss the analytic approach, align categories and codes, and identify areas requiring refinement. This iterative process continued until no new categories emerged [i.e., theoretical saturation, (27)]. Researchers then scanned literature containing potentially relevant theories and analyzed the fit of the coded data compared to theories. A single theoretical framework was identified (a family systems approach). This theoretical framework's major tenets were evolved in further detail from an etic perspective, extracting exemplar quotes from participant responses (28). Member checks were conducted to assess whether findings conformed to the lived experiences of caretakers of children with service dogs for autism (26).

3. Results

Constant comparative analysis identified two primary themes, consistent with a family systems approach (29): Theme 1. Enhancing social functioning of the family system unit, and Theme 2. Fostering stability and strength within family system subunits. Taken together, these themes contribute to building the resilience of the family system as a whole.

3.1. Theme 1. Enhancing social functioning of a family system unit

Caretakers described four ways in which the service dog improved the family system's functioning relative to other systems (i.e., on a macroscopic scale): As a social bridge, a social cue, a social buffer, and a social catalyst.

3.1.1. Subtheme 1.1. The service dog as a social bridge

First, the service dog acted as a social bridge for both the autistic child and their family, inviting others to approach and interact. One caretaker shared, "she's like a magnet, attracting all kinds of people over into our 'Sphere.'" It gave caretakers "joy to see [the service dog] attract other children." One participant shared an example of what this might look like in the context of school attendance:

> When [child] was actively attending public school … I would sometimes take [service dog] to campus and friends who would not usually engage with [child] would approach us and ask about [service dog]. This was a social bridge for [child] and other students who knew [child] was the girl with the "sweet dog."

The service dog's role as a social bridge not only attracted others, but also encouraged proactive connection with others for some children. As one caretaker shared, "[child] has been able to approach children and start conversations more easily because he starts conversations off about his dog."

3.1.2. Subtheme 1.2. The service dog as a social cue

Beyond inviting attention, numerous participants shared that the service dog's presence decreased stigma and judgement from others and increased their patience and tolerance. "People are more accepting of behaviors when he's around," shared one caretaker. Some autistic children use augmentative and alternative communication (AAC) devices to communicate, wherein a device (such as a tablet) can be used to generate speech. Added patience from community members was particularly helpful for these children:

> It's nice because the kids can pet the dog while [child] is answering questions. It takes a while to push the buttons to make a sentence. Kids wouldn't wait before the dog. It's almost like they want her to take her time so they can play with [service dog]. [Child] takes pride in it. We make all sorts of friends in line at Disneyland.

In some cases, the service dog's presence served to make the "invisible" visible, in a positive way:

> She is a quick indicator for people that there is a disability present, even if it's just momentarily invisible while [child] is sitting quietly

> on a park bench, and allows them the time to adjust their behavior and expectations.

This lessening of stigma served to decrease isolation for the autistic child, ultimately improving their well-being: "[Service dog] has … helped [child] interact with his environment more and become less isolated. [Child] is a happier child and feels more accepted in the world with [service dog] in his life!"

3.1.3. Subtheme 1.3. The service dog as a social buffer

Sometimes, the experience of interacting with the outside world was overwhelming for the autistic child. In these cases, the service dog provided a buffer and focal point, "directing [child]'s attention to [service dog] instead of overwhelming situations or places."

Sometimes, this buffering effect occurred passively through the dog's mere presence. As one caretaker shared, "[child] finds comfort in putting her hand on [service dog] when out in public." Another described that "having [service dog] always by his side directs [child]'s attention to [service dog] instead of overwhelming situations or places." Shared a third, "when you tell [child] about a hospital visit or a doctor appointment he is quiet for a minute then says can [service dog] come? And everything is better."

In other cases, the buffering effect was accomplished through use of trained tasks. "Deep pressure [helps] with sensory overload. [Service dog] will hug [child] or sit on her feet or lean against her when waiting in line at a store or at school," one participant shared. Another identified that "the commands that tell [service dog] where I need her to go are most helpful … These help me position her to best support [child] in specific situations or to be a 'buffer' between him and other people or activity."

3.1.4. Subtheme 1.4. The service dog as a social catalyst

For many families, the service dog acted as a social catalyst for community building. Above and beyond the dog's role as a social bridge (inviting approach and interaction on an individual level), the service dog contributed to greater participation within the community on a systemic level: "[Service dog] has made the family feel and experience life as 'normal' might these last 3 years. [Service dog] is such a people-dog, she just brings the joy out of strangers – and that's wonderful to be a part of." Thanks to the service dog, families were able to "attend baseball games and other places that [child] very well may not have done." By opening up the world for the autistic child, the service dog likewise opened up the world for the rest of the family:

> Knowing that [child] has a friend [service dog] and that [service dog] helps [child] access public places makes it so that I can access public places. Making sure that [child] is part of the community with the help of [service dog] rather than isolated in our home means everything!

In some cases, the service dog did not merely connect or re-connect families to the community; they were themselves a source of new community. As described by one participant, the service dog "has helped me join the world of dog people; gives me something to talk to others about which is helpful given that it's hard to engage socially."

3.2. Theme 2. Fostering stability and strength within family system subunits

Within the family system itself, service dog placements fostered greater stability and strength in four key ways: As a member of the family themselves and a catalyst for improved family interactions, by coregulating with family members, as a highly individualized intervention for the autistic child, and as a source of joy. Additionally, we found that the service dog's influence within the family was almost entirely positive for participants in this study, with a few specific exceptions. Finally, we identified that the service dog intervention's influence extended even before placement for families on the waitlist.

3.2.1. Subtheme 2.1. A catalyst for improved family interactions

Service dogs improved family system stability by smoothing interactions between family members. This influence occurred from within the family system: the service dog was, beyond a doubt, "not just a dog, [but] part of our family." In several families, the service dog was perceived as equivalent to a sibling:

> [Child] also sees [service dog] as a sort of brother, at times comparing herself to him in a mildly competitive sibling way—for instance, if [service dog] gets into poison ivy or mud in the back yard and gets "in trouble" for it, she will say '[Service dog], you are in trouble but I am not in trouble!

Family system structures shifted on a fundamental level to adjust for the addition of the service dog as a new family member. In many cases, this led to a direct transformation from imbalanced, unhealthy dyads between individuals (e.g., child-caretaker dyad, child-sibling dyad), to better-balanced triads with the addition of the service dog.

Perhaps most critically, the service dog enabled a diffusion of tension and restoration of healthier equilibrium in the relationship between child and caretaker. In many families, caretakers described sacrificing their own sleep or needs in their efforts to care for and meet the child's needs. The development of a caretaker-child-service dog triad is inherent to the structure of these placements, and this created space for the caretaker's needs to be met as well. "I feel like we are a team," shared one participant, "[service dog]'s always got my back and is there to help in any way she can." Another described that "because [child] has a best friend at home that she is engaged with, I have time to do household chores." A third shared, "[service dog] gives [child] a break which gives us a break." For several participants, this shift took place most notably in the domain of sleep:

> [Child] would not sleep. I would have to lay on her, practically on top of her to give her deep pressure. One night I thought a dog could do this and I could do the dishes and finish laundry instead of laying here and falling asleep before she did. [Service dog]'s main job was to get my girl to sleep … sleep is not our problem anymore.
>
> Having him with her at night meant I started sleeping through the night. I was up a couple of times a night with her before he came home with us and I cannot express how good it felt to start sleeping well.

The child-sibling dyad was also improved with the welcoming of a service dog to the family, creating "something positive and wonderful to bond over":

> He is also a significant support to our entire family and allows our three children to bond in ways they couldn't before we had [service dog]. They have their love for him in common, and this helps them connect. My other two have resentment towards [child] for the pain they feel he has caused them over the years.
>
> The joy I feel when I see the kids bonding over [service dog] remains even now that they are all essentially teenagers – they still interact with and chat about [service dog] pretty much daily, and this always brings a smile and a sense of relief and even hope for them staying connected as siblings in spite of our challenges.

Overall, for participants in this study, the service dog was a positive presence who drew focus away from challenges or negatives; loving the service dog was something the entire family had in common. "He brings us together as a family, because we all love him so much," shared one participant. Another described that "everyone loves to see [service dog] make [child] happy." The everyday routine surrounding the service dog supported a healthier family dynamic:

> Walking a dog, grooming her, playing fetch with her, dressing her up or just snuggling with her might not seem like a big deal, but all of it has had a strong impact on our family as a community in relationship with each other.

3.2.2. Subtheme 2.2. Coregulating with individuals to foster homeostasis

While relationships between family members partly influence family system stability, the well-being of individual family members is equally important. The service dog further increased stability by improving the well-being of individual members of the family through coregulation, or the development of a shared emotional system (30). Through this coregulation, the service dog fostered physiological equilibrium (homeostasis) thanks to their trained tasks, presence, calm demeanor, and intuition. Described one participant, "if any one of us is upset, [service dog] walks over and lays his head on our lap."

For the autistic child, the trained task of deep calming pressure was mentioned by far the most. "[Service dog] is trained to cover or visit to give deep pressure," explained one caretaker. "When [child] needs input or is upset he likes to have [service dog] lay or sit partially on him." In doing so, the autistic child was able to achieve "calm and peace," which for many caretakers "immediately reduced my stress levels enormously." Even beyond trained tasks, the service dog – as a source of calm themselves – was "generally a calming, co-regulating influence." One participant shared, "[child] calls him her patronus (Harry Potter reference) because every time she touches him he gives her joy. He is like an island of calm she can reach out to any time." Caretakers repeatedly described the role of the service dog's intuition in this relationship:

> The bond between [child and service dog] is amazing and it's so impressive to see how [service dog] knows when [child] needs him and he has to do his job. [Service dog] doesn't even need a command to help [child]. He will hear [child] crying or upset and he comes running to help. Our dog is amazing!!

Notably, although it was not a trained task for service dogs from this organization, multiple participants positively and specifically described the service dog licking away tears:

> [Service dog] is priceless in the hospital. A few times [child] hallucinated and he was the only one that could calm her down … When she is upset she runs to him, buries her head in his fur and cries and tells him how she is feeling … If she cries, he licks her tears off, which helps her a lot.

The service dog also coregulated and demonstrated emotional intuition with caretakers. As one participant shared, "[service dog] and I have a very, very special connection. He knows that he is [child]'s boy—but knows that I have his back, that I am in charge and that I will take care of all of us. [Service dog] has a tremendous calming influence on all of us." Another caretaker described that "he picks up on my stress. When I start to get upset he will come up and lick me or run and grab a toy from his basket to bring to me." This bond was motivating and rewarding to caretakers:

> He is love! He loves to cuddle and picks up on my emotions. He is motivation for getting out for walks because he is depending on me. He makes me feel good and accepted and important. When it's a bad day, he is always there for being cuddled and doesn't demand anything of me.

The positive impacts of the service dog's presence extended to the entire family. One caretaker described that the service dog "can sense when any of the children are having a bad day and she will love on them." Another shared that "the whole family just loves her. My younger daughter is less anxious, my husband loves to snuggle with her while we watch tv. She cheers up my mother-in-law when we visit her."

Finally, in three cases, the primary bond did not develop between the service dog and the child, but rather the service dog and a parent. Interestingly, in all three of these cases, the service dog took on a working role with that parent instead:

> My wife, who has a chronic health condition, spends the most time with [service dog] by far. … We both agree, as a "service dog," [service dog] is working her magic almost purely with [my wife] … who actually needs companionship and moral support. So, she's doing her job, but she's doing it in a way we hadn't originally planned.
>
> [Dad] is [service dog's] main handler and spends the most time with [service dog] when [child is] at school. He is retired due to disability. [Service dog] has helped him so much.

3.2.3. Subtheme 2.3. A highly individualized intervention

For most of the autistic children in this study, placement with a service dog was a highly individualized intervention that helped in targeted ways beyond coregulation, ultimately enhancing independence.

For some, the service dog gave the child a "sense of purpose and identity," teaching the child about "independence by helping with chores and feeding," increasing the child's "confidence and self-worth," and acting as a "motivating factor" to accomplish other tasks. For many children, having the opportunity to give the dog a command (i.e., cue to perform a task) was motivating: "[Child] will do almost anything just to be able to give [service dog] a command." For other children, benefits were seen in physical health: one caretaker shared that their child's "irregular gait and walking tempo has improved TREMENDOUSLY by walking with [service dog] on harness regularly." One child experienced improvement to sensory sensitivities "through touching [the service dog] and [the service dog's] care."

In several cases, benefits surpassed the service dog's original training. One caretaker shared, "[service dog] alerts me when [child] has a seizure – he is not trained for it – he just started doing it, but it is priceless and lets me grab her and set her down saving her injury." Another described the service dog helping the child fall back asleep at night, saying "I know he's not trained for that, but before we had him, she woke up often in the night. Now if she starts to stir, he cuddles up to her and often she goes back to sleep."

Above and beyond trained tasks, the service dog was also a "best buddy" to the autistic child, providing "unconditional love and friendship" where, in some cases, the child may have been isolated. As one participant shared, "[child] does not have the kinds of friends he can rely on, or hang out with outside of school. [Service dog] is his best friend and he considers her part of his family." Another described that for their child, the service dog "is her rock. When she is overwhelmed, she hides with him, he lays on her and she breathes. When she is in pain, he is the one who can help calm her down." For many children, the service dog was incorporated into every-day activities and conversations, just as a human friend would be:

> [Service dog] is [child]'s best friend. She talks with him ALL the time (even right now as I type). I mean ALL the time, whether he is with us or not. She explains about what it is like to be a human to him, tells him about social etiquette, tells him what different words mean, what are kind/mean and safe/unsafe behaviors, tells him about things she has experienced … she has a best friend who is very happy to hear all that she has to say.
>
> [Child] looks at [service dog] as his best friend. He wants to show her everything he does. He just wants to see her and know she is there for everything he does from getting dressed to making his bed.
>
> They sleep with either her legs over him or his arms around her shoulders or holding hands (it is adorable).

3.2.4. Subtheme 2.4. A source of joy, laughter, play, and calm

The service dog's presence within the household was a source of joy, laughter, play, and calm for families. Caretakers described positive changes in "the overall mood" of the family. As one participant explained, "she brings laughter, joy, playfulness, and a motivation to be active to each of us."

This joy stabilized and strengthened bonds between family members: "[Child] and I also laugh a lot about his antics—so he brings a lot of laughter into our home," one participant shared. Another described that "the whole family is happier having [service dog] around, even though he's [child]'s dog, his training makes him more sensible and he comforts and plays with everybody."

3.2.5. Subtheme 2.5. An almost entirely positive influence

While the service dog intervention can promote stability, it may also lead to added challenges. However, when asked about negatives, by far the most common response was that "there has been nothing negative" about having the service dog. "I honestly cannot think of one negative impact [service dog] has had on our family," shared a caretaker. One participant elaborated that they "expected an adjustment or change in routine when we graduated and it never happened. Things only got easier for us."

Of the challenges that some participants shared, a few consistent areas were mentioned. Most common was the volume of shedding: "The amount of HAIR [service dog] produces is incredible … really, I cannot believe it." "Really and truly, the only downside to [service dog] … is ALL THE DOG HAIR! If she did not shed so much, she would be pretty darn close to perfect." More broadly, for a minority of caretakers, the added responsibility could be a burden; as one caretaker described, "sometimes [service dog] feels like an added responsibility when things are hard around her (like if [child] has a seizure and needs medical attention)."

While no participants in this study described active financial hardship relating to the service dog, for some, the potential of future costs were a salient concern. One participant shared that as the service dog "is getting older, vet expenses are increasing a bit. Hopefully that will not become a major issue." In some families, this was an ongoing source of worry:

> I worry sometimes about the cost of medical care, should [service dog] fall ill. Of course we'd do anything for him, but I've heard stories from friends about the thousands they've had to pay for pet surgeries etc. Money isn't easy for us – [child]'s interventional treatments from age 5–9 were not covered by insurance.

Although for most participants the service dog partnership came with none, few, or only minor challenges, a sole participant shared that "the negative things about [service dog], have been bad enough at times, I just wish we had not gotten him. Thank goodness they are not thoughts I have often, but they are there."

Notably, the service dog's high degree of training and preparation for the role appeared key to the lack of negatives:

> [Service dog] is just such a love, she provides all the benefits of a regular dog but without any hyperness, overexcitement, barking, yipping, nudging, or all the things regular dogs do that could make that aversive to a guy like [child].
>
> [Service dog] is the dog love of my life, and I loved dogs before this, including doing years of rescue work. But despite all my

> knowledge, I could not have trained her this well. I think for me she provides all the benefits of a regular dog, plus without all the things that I could find aversive too.

The service dog's level of training was not only crucial to the lack of downsides, for some families, it was essential to their ability to achieve service dog partnership in the first place. As one caretaker shared, "we would not have been able to have a poorly trained dog in our home because it would scare [child]." Another described that "when we got [service dog] there was no way that we could have gotten a pet dog because I could never have trained it." The importance of the dog's training and suitability for the working role was not only important for the family, it was also important to the dog's welfare: "I think that [service dog] is trained to be with us, that we do not have to worry about him reacting to us in a bad way. He is always happy to see us and is gentle and calm and tolerates a lot of loud noises and sudden movements that might scare another dog."

3.2.6. Subtheme 2.6. Influence of the intervention for families on the waitlist

For families on the waitlist to receive a service dog, the intervention had an influence even prior to partnership by providing hope and excitement "at the prospect of what [a service dog] can offer." As one family shared, "the thought of receiving a [service dog] has given us such hope for the future." Another caretaker identified specific goals: "We hope that [child] really thrives in caring for his dog and taking responsibility to walk him every day. His goal is to master all the commands so the dog becomes his best friend." The decision to apply for a service dog was one founded in optimism and excitement for the future:

> We are a dog-loving family and have been on the lookout for getting an appropriate dog which will bring joy to the family and above all help [child] with the various social and emotional issues that she has. We are very excited that we have gotten the opportunity to get a [service] dog and strongly believe that it would change [child]'s life and ours too."

4. Discussion

The purpose of this qualitative study was to explore the experiences reported by caretakers of autistic children involved in a service dog program, and to contextualize results within a broader established theoretical framework. Through a constant comparative analysis, we identified that the experiences reported by caretakers were best explained through the framework of a family systems approach (29). Analyses revealed two primary themes. Theme 1, enhancing social functioning of the family system unit, included subthemes of the service dog as a social bridge, social cue, social buffer, and social catalyst. Theme 2, building strength and stability within family system subunits, included 6 subthemes: A catalyst for improved family interactions; coregulating with individuals to foster homeostasis; a highly individualized intervention; a source of joy, laughter, play, and calm; an almost entirely positive influence; and the influence of the intervention for families on the waitlist.

Previous literature has called for autism and disability research to take a family systems approach, recognizing that the well-being of an individual family member cannot and should not be fully disentangled from that of the family system [e.g., (29, 31)]. Family systems approaches incorporate family systems theory (32) to understand interfamilial processes and extend beyond these to understand the processes through which the family system interacts with external systems (communities, schools, other families, etc.) (29). The family systems approach conceptualizes these as microscopic and macroscopic lenses, respectively; from an ecological systems standpoint, the microscopic and macroscopic lenses can be considered to correspond to the micro-and meso-levels of a family ecosystem (33). Familial resilience is a key component of a family systems approach, impacting the family's ability to respond to challenges, balance the needs of individuals, maintain interfamilial bonds, and engage with their community. Our study extends family systems approaches (including familial resilience) to a new context: a service dog intervention for families with autistic children.

Results found that the service dog has an impact on the entire family (beyond the autistic child). This finding is well aligned with results previously reported in autism service dog literature (16, 34) and assistance dog literature more broadly [e.g., (35–37)]. Research has identified that these placements can strengthen interfamilial bonds, impact wellbeing of individual family members, facilitate resilience processes, and increase social participation for the entire family; however, they can also lead to new challenges. This highlights an important consideration for service dog provider organizations, which may focus primarily on the individuals involved in the triadic placement (the caretaker, who cares for and handles the service dog, and the autistic child). However, family unit makeup can vary widely, from single-parent-single-child families to many other forms and sizes of family units. For these families, interventions focused solely on the child and/or the parent are unlikely to be fully effective (38). Accordingly, provider organizations should recognize family-wide impacts and that familial resilience processes (i.e., the ability to balance stressors and marshal resources) can influence the family's ability to engage in an intervention at each step and thereby impact outcomes (39). Specifically, provider organizations should identify family unit makeup as part of the application process and incorporate the entire family into the intervention by setting expectations and accounting for each family member's needs within each treatment component.

4.1. Theme 1. Enhancing social functioning of the family system unit

The first theme, enhancing social functioning of the family systems unit, takes a macroscopic view to understand the service dog's influence on the family's interactions with other systems such as their community and social groups. We found that the service dog may enhance and even increase these interactions. This finding is particularly salient given research that families of autistic children may experience social isolation, driven by difficulties participating in social activities and a lack of understanding from members of the community with regard to behaviors common for autistic children (31). Social support is a known moderator of negative outcomes (including depression, social isolation, and relationship difficulties), wherein decreased social support can increase the negative impacts of parental stressors for families of autistic children (40). Notably, we also found that families with a service dog perceived decreased social stigma and judgement from community members, in line with prior findings in autism service dog literature (34, 36). Experiences of social stigma and social acceptance appear to vary based on the type of service dog interventions. For example, social acceptance and recognition are among the most common benefits reported by individuals with hearing dogs (41), but stigma and judgement are among the biggest *negatives* reported by veterans with service dogs for PTSD (37, 42). Although no participants in our study experienced this as a negative, one study has previously identified that the experience of increased public visibility may be unwanted for some caretakers (20). Given these differential findings, an interesting area of future research would be to examine the social stigma and discrimination experiences of handlers across different types of disabilities and service dog placements.

While service dogs for autism have frequently been discussed in the context of school [specifically, legal challenges and confusion in this context; e.g., (15, 43)], this topic was absent from our findings due to this population not being encouraged to engage in this practice. Given that this will likely continue to be an area of discussion given legal and logistical complexities, further research with more targeted questions is warranted to better understand the experiences of handlers of service dogs for autism with regard to school.

4.2. Theme 2. Building strength and stability within family system subunits

The second theme, building strength and stability within family systems subunits, takes a microscopic view to understand the impacts on and between individuals and family subunits. At a high level, the service dog was clearly identified as an individual family member themselves rather than a separate entity. Conceptualizing animals as individuals within a family unit aligns with a biocentric orientation that recognizes and respects the deep connections humans can form with other species (44). Through their position within the family system, we found that the service dog may contribute to strengthening and stabilization. In other words, the service dog may foster increased family resilience internally. Indeed, prior research examining pet dogs in a therapeutic context has identified that because of this familial integration, pets – and in this case, service dogs – can be important components of the family's healing team, strengthening family resilience (45).

Research suggests that an autism diagnosis can assist in developing resilience for families and that involvement of the entire family in interventions can lead to greater positive outcomes [e.g., (39, 46)]. Specific pathways for developing family resilience may include establishing routines, family time and togetherness, and social support (29, 47). These pathways map well onto a service dog intervention: routine can be created through the dog's day-to-day needs, and for some children, taking responsibility for the dog's care was a major benefit; the service dog was a source of joy, laughter, and play, thereby promoting togetherness and family time around the dog and dog-related activities. Finally, social support was improved through the dog's role as a social bridge and catalyst. This last element of social support speaks to the holistic interaction between Theme 1 and Theme 2, and further reinforces our recommendation that service dog providers account for the entire family unit throughout the service dog placement and ongoing support process. Similar recommendations have been made in the context of service dogs for veterans with PTSD, and it would be reasonable to consider that this may be a best practice for service dog interventions of any type (37).

When family systems theory was first developed, it was proposed that triads can be considered the fundamental family building block and that the addition of a third individual can help ease tensions within unbalanced dyads (32). This has interesting applications in the context of a triadic service dog intervention; this rebalancing process aligns well with observations from participants in this study who experienced a diffusion of tension between child and caretaker or child and siblings with the addition of the service dog. Moreover, the service dog appeared to coregulate with family members individually, acting as a homeostatic regulator helping achieve physiological equilibrium – a known phenomenon which has been described in pet dog literature more broadly (45). This occurred not only through the service dog's trained tasks (for the autistic child), but also through their presence and bond, echoing findings in service dog literature more broadly that speak to the importance of not only trained, but also untrained, behaviors (48).

In a few notable cases, service dogs in this study bonded not with the autistic child but with a parent. While prior literature has mentioned difficulties in child-dog bonding [e.g., (23)], these situations have previously been characterized as resulting from elements of the child's disability, such as motor control or communication difficulties. These stand in contrast to the current study; in each case the dog appeared to have developed a working relationship with a different family member. It's possible that the development of such a relationship directly interfered with bonding with the autistic child, but equally possible that in the absence of a strong bond forming between the service dog and the autistic child (for any number of reasons), the dog naturally gravitated towards another family member. An important line of future research will be to identify any factors – human or canine – that may be predictive of successful bonding between service dog and child, or whether there are cases where it is in fact *more* helpful for the service dog to form a primary bond with the caretaker instead. Some initial work has begun to characterize first interactions (49), and similar methods could be employed in a longitudinal design to begin identifying associations between early interactions and future bond strength. Ultimately, these findings could provide critical insights for service dog providers and health care practitioners to improve recommendations as to whether a service dog intervention would be appropriate, and if so, how to maximize efficacy.

It was apparent that placement with a service dog is a highly individualized intervention for autistic children. Given that the presentation of autism can itself be highly variable and unique to each individual, this is not surprising; however, it may shed some light on the disparities between qualitative and quantitative research findings on this topic (17). For example, if improvements are highly variable from domain to domain, standardized quantitative measures may result in null findings within a larger group. To account for this, future quantitative research should be thoughtful about measure selection and analytic strategy. Interestingly, when considering variation within the intervention, prior research on service dogs for autism frequently identify tethering (i.e., physically linking the autistic child to the service dog to prevent bolting or running away) as an important and necessary part of the intervention [e.g., (18)]. However, other research – including the present study – has identified benefits even in the absence of this task, which not all service dog providers train [e.g., (20)]. It is possible that individuals self-select when identifying a service dog provider based on their needs and the trained tasks offered, further underscoring the variable and individualized nature of the intervention.

Challenges raised in the current study included the service dog's shedding, the added burden of service dog-related responsibilities, and stress about potential future veterinary expenses. However, the notable lack of negatives reported by participants in this study appears to stand in contrast to prior research on service dogs for autism. Studies have highlighted issues including ongoing training challenges, public access issues, added burden of care, financial impacts, and difficulty bonding as negatives of service dog placements for autistic children (20, 34). This discrepancy may be due to the way that this study asked caretakers about drawbacks ("How has [service dog's name] negatively impacted you, [child], or your family as a whole"). Other studies have used open-ended text boxes to ask about "constraints of having a service dog" (22) or used semi-structured interviews to probe negative experiences in detail (18, 20, 23). Differences in experiences, including drawbacks, could also be due to differences across service dog providers. Adherence to high standards from service dog providers, including participation in accreditation processes, is important to minimize challenges experienced by autistic children, their families, and service dogs – ultimately optimizing outcomes and setting humans and canines up for success.

4.3. Limitations

Several limitations should be considered when interpreting these findings. This was a cross-sectional study, whereas both family systems and the needs of autistic children are known to evolve over time; thus, family functioning likely also evolves over time. Participants in this study were recruited from a single, United States-based service dog provider. While this increased standardization and homogeny of the intervention within this study, results may or may not be applicable to individuals participating in programs from other providers or in other countries. Additionally, surveys were completed by caretakers, and therefore responses reflect their personal experiences. It is possible that the autistic child or other family members would have shared different opinions or experiences if they had been the individual answering the questions. This study also did not examine the welfare of the service dogs themselves. Future studies should endeavor to include both human and canine outcomes, especially in light of findings that there could be welfare concerns in some cases (14). Finally, given that participants undergo a multi-step application process and 2 week, onsite training program as part of receiving the service dog, it is also possible that survey responses were influenced by the instruction and expectations set through interaction with the provider organization, and by the quality of the relationship between the two parties. In turn, it is likely that the provider's language and content are influenced by reports from past clientele.

4.4. Conclusion

This qualitative study of service dog placements for autistic children lends insight into the experiences of caretakers, children, and families involved in a service dog intervention. Overall, service dog placements appear to impact and foster resilience within the entire family (beyond the autistic child) and were best understood through the lens of a family systems approach framework. Placements led to greater social inclusion for families, acted as a highly individualized intervention for the autistic child, and decreased experiences of judgement and stigma. Perceived as members of the family, service dogs may coregulate with individual family members and can be a source of joy and positive connection within the family. The two themes (1. Enhancing social functioning of the family system unit and 2. Building strength and stability within family system subunits) interact holistically in that the family's resilience is strengthened through increased social support, fostering of homeostasis on an individual level, and increasing internal family stability. Implications for service dog organizations suggest it may be helpful to account for family-wide impacts throughout the placement process. High standards on the part of provider organizations may minimize negatives for children and their families, optimizing outcomes for both humans and canines. Overall, this study enriches and expands our understanding by extending a family systems approach in a novel context: that of a service dog intervention for families of autistic children.

Data availability statement

The original contributions presented in the study are included in the article/supplementary material, further inquiries can be directed to the corresponding authors.

Ethics statement

The studies involving human participants were reviewed and approved by Purdue University Human Research Protection Program (IRB #1906022320). The patients/participants provided their written informed consent to participate in this study. Ethical review and approval was not required for the animal study because an exemption was obtained from the Purdue Institutional Animal Care and Use Committee (IACUC) since no interaction took place between the research team and any dogs.

Author contributions

KR and MO contributed to the conception and design of the study. SL and LN conducted the data collation and analysis. SL wrote the first draft of the manuscript and SL, KR, LN, and MO contributed to the manuscript revision. All authors contributed to the article and approved the submitted version.

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Conflict of interest

The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

Publisher's note

References

1. Maenner MJ, Shaw KA, Baio J, Washington A, Patrick M, DiRienzo M, et al. Prevalence of autism spectrum disorder among children aged 8 years — autism and developmental disabilities monitoring network, 11 sites, United States, 2016. *MMWR Surveill Summ*. (2020) 69:1–12. doi: 10.15585/mmwr.ss6904a1

2. American Psychiatric Association. *Diagnostic and statistical manual of mental disorders, fifth edition. 5th* ed. Arlington, VA: American Psychiatric Association (2013).

3. Cooper R, Cooper K, Russell AJ, Smith LGE. "I'm proud to be a little bit different": the effects of autistic individuals' perceptions of autism and autism social identity on their collective self-esteem. *J Autism Dev Disord*. (2021) 51:704–14. doi: 10.1007/s10803-020-04575-4

4. Keehn B, Shih P, Brenner LA, Townsend J, Müller R-A. Functional connectivity for an island of sparing in autism spectrum disorder: an fMRI study of visual search. *Hum Brain Mapp*. (2013) 34:2524–37. doi: 10.1002/hbm.22084

5. Zeidan J, Fombonne E, Scorah J, Ibrahim A, Durkin MS, Saxena S, et al. Global prevalence of autism: a systematic review update. *Autism Res*. (2022) 15:778–90. doi: 10.1002/aur.2696

6. Zuvekas SH, Grosse SD, Lavelle TA, Maenner MJ, Dietz P, Ji X. Healthcare costs of pediatric autism spectrum disorder in the United States, 2003–2015. *J Autism Dev Disord*. (2021) 51:2950–8. doi: 10.1007/s10803-020-04704-z

7. Kapp SK, Gillespie-Lynch K, Sherman LE, Hutman T. Deficit, difference, or both? Autism and neurodiversity. *Dev Psychol*. (2013) 49:59–71. doi: 10.1037/a0028353

8. Will MN, Currans K, Smith J, Weber S, Duncan A, Burton J, et al. Evidenced-based interventions for children with autism spectrum disorder. *Curr Probl Pediatr Adolesc Health Care*. (2018) 48:234–49. doi: 10.1016/j.cppeds.2018.08.014

9. National Autism Center. *Findings and conclusions: National standards project, phase 2*. Randolph, Massachusetts: May Institute (2015) Available at: https://nationalautismcenter.org/.

10. Schuck RK, Tagavi DM, Baiden KMP, Dwyer P, Williams ZJ, Osuna A, et al. Neurodiversity and autism intervention: reconciling perspectives through a naturalistic developmental behavioral intervention framework. *J Autism Dev Disord*. (2022) 52:4625–45. doi: 10.1007/s10803-021-05316-x

11. Canine Companions. (2022). Skilled companions. *Canine Companions*. Available at: https://canine.org/service-dogs/our-dogs/skilled-companions/ (Accessed January 3, 2023).

12. Assistance Dogs International. (2022). Member program statistics. *Assistance Dogs International*. Available at: https://assistancedogsinternational.org/members/member-program-statistics/ (Accessed January 3, 2023).

13. Walther S, Yamamoto M, Thigpen AP, Garcia A, Willits NH, Hart LA. Assistance dogs: historic patterns and roles of dogs placed by ADI or IGDF accredited facilities and by non-accredited U.S. facilities. *Front Vet Sci*. (2017) 4:1. doi: 10.3389/fvets.2017.00001

14. Burrows KE, Adams CL, Millman ST. Factors affecting behavior and welfare of service dogs for children with autism spectrum disorder. *J Appl Anim Welf Sci*. (2008) 11:42–62. doi: 10.1080/10888700701555550

15. Hill DR, King SA, Mrachko AA. Students with autism, service dogs, and public schools: a review of state laws. *J Disabil Policy Stud*. (2014) 25:106–16. doi: 10.1177/1044207313477204

16. Berry A, Borgi M, Francia N, Alleva E, Cirulli F. Use of assistance and therapy dogs for children with autism Spectrum disorders: a critical review of the current evidence. *J Altern Complement Med*. (2013) 19:73–80. doi: 10.1089/acm.2011.0835

17. Sprod E, Norwood MF. What effect does participating in an assistance dog program have on the quality of life of children with autism Spectrum disorders and their caregivers? A systematic review of current literature. *J Soc Incl*. (2017) 8:27–41. doi: 10.36251/josi.122

18. Appleby R, Wright S, Williams L, Stanley M. Australian parents' experiences of owning an autism assistance dog. *Health Soc Care Community*. (2022) 30:e4113–21. doi: 10.1111/hsc.13805

19. Fecteau S-M, Boivin L, Trudel M, Corbett BA, Harrell FE, Viau R, et al. Parenting stress and salivary cortisol in parents of children with autism spectrum disorder: longitudinal variations in the context of a service dog's presence in the family. *Biol Psychol*. (2017) 123:187–95. doi: 10.1016/j.biopsycho.2016.12.008

20. Hellings D, Joosten A, Hatfield M, Netto J. Benefits and challenges of assistance dogs for families of children on the autism spectrum: mothers' perspectives. *Qual Health Res*. (2022) 32:1648–56. doi: 10.1177/10497323221111247

21. Smyth C, Slevin E. Experiences of family life with an autism assistance dog. *Learn Disabil Pract*. (2010) 13:12–7. doi: 10.7748/ldp2010.05.13.4.12.c7758

22. Burgoyne L, Dowling L, Fitzgerald A, Connolly M, Browne JP, Perry IJ. Parents' perspectives on the value of assistance dogs for children with autism spectrum disorder: a cross-sectional study. *BMJ Open*. (2014) 4:e004786. doi: 10.1136/bmjopen-2014-004786

23. Burrows KE, Adams CL. Challenges of service-dog ownership for families with autistic children: lessons for veterinary practitioners. *J Vet Med Educ*. (2008) 35:559–66. doi: 10.3138/jvme.35.4.559

24. Canine Companions. (2023). Application process. *Service Dog FAQs*. Available at: https://canine.org/service-dogs/assistance-dog-faqs/ (Accessed May 31, 2023).

25. Corbin J, Strauss A. *"Strategies for qualitative data analysis." Basics of qualitative research. Techniques and procedures for developing grounded theory*. Thousand Oaks: SAGE Publications, Inc (2008). 9781452230153 p.

26. Lindlof TR, Taylor BC. *Qualitative communication research methods*. Los Angeles, CA: SAGE Publications (2019).

27. Glaser BG, Strauss AL. *The discovery of grounded theory; strategies for qualitative research*. Piscatawaya, NJ: Aldine Publishing Co. (1967).

28. Miles MB, Huberman M. *Qualitative data analysis: an expanded sourcebook*. Los Angeles, CA: SAGE Publications (1994).

29. Cridland EK, Jones SC, Magee CA, Caputi P. Family-focused autism spectrum disorder research: a review of the utility of family systems approaches. *Autism*. (2014) 18:213–22. doi: 10.1177/1362361312472261

30. Butler EA, Randall AK. Emotional coregulation in close relationships. *Emot Rev*. (2013) 5:202–10. doi: 10.1177/1754073912451630

31. Tint A, Weiss JA. Family wellbeing of individuals with autism spectrum disorder: a scoping review. *Autism*. (2016) 20:262–75. doi: 10.1177/1362361315580442

32. Kerr ME, Bowen M, Kerr ME. *Family evaluation*. New York, NY: WW Norton & Company (1988).

33. Bronfenbrenner U. Ecological systems theory In: AE Kazdin, editor. *Encyclopedia of psychology*, vol. *3*. Washington, DC, US: American Psychological Association (2000). 129–33.

34. Burrows KE, Adams CL, Spiers J. Sentinels of safety: service dogs ensure safety and enhance freedom and well-being for families with autistic children. *Qual Health Res*. (2008) 18:1642–9. doi: 10.1177/1049732308327088

35. Bibbo J, Rodriguez KE, O'Haire ME. Impact of service dogs on family members' psychosocial functioning. *Am J Occup Ther*. (2019) 73:7303205120p1–7303205120p11. doi: 10.5014/ajot.2019.031690

36. Davis BW, Nattrass K, O'Brien S, Patronek G, MacCollin M. Assistance dog placement in the pediatric population: benefits, risks, and recommendations for future application. *Anthrozoös*. (2004) 17:130–45. doi: 10.2752/089279304786991765

37. Nieforth LO, Craig EA, Behmer VA, MacDermid Wadsworth S, O'Haire ME. PTSD service dogs foster resilience among veterans and military families. *Curr Psychol*. (2021):1–14. doi: 10.1007/s12144-021-01990-3

38. Rao PA, Beidel DC. The impact of children with high-functioning autism on parental stress, sibling adjustment, and family functioning. *Behav Modif*. (2009) 33:437–51. doi: 10.1177/0145445509336427

39. Gunty AL. Rethinking resilience in families of children with autism spectrum disorders. *Couple Fam Psychol: Res Pract*. (2021) 10:87–102. doi: 10.1037/cfp0000155

40. Dunn ME, Burbine T, Bowers CA, Tantleff-Dunn S. Moderators of stress in parents of children with autism. *Community Ment Health J*. (2011) 37:39–52. doi: 10.1023/A:1026592305436

41. Lalancette A, Tremblay M-A, Hotton M. The role and relevance of hearing dogs from the Owner's perspective: an explorative study among adults with hearing loss. *Audiol Res*. (2023) 13:64–75. doi: 10.3390/audiolres13010006

42. Leighton SC, Nieforth LO, O'Haire ME. Assistance dogs for military veterans with PTSD: a systematic review, meta-analysis, and meta-synthesis. *PLoS One*. (2022) 17:1–31. doi: 10.1371/journal.pone.0274960

43. Davidson JJ, Cumming TM, Strnadová I. Supporting service dogs in the classroom. *Interv Sch Clin*. (2020) 55:313–8. doi: 10.1177/1053451219881733

44. Melson GF, Fine AH. Animals in the lives of children In: AH Fine, editor. *Handbook on animal-assisted therapy: theoretical foundations and guidelines for practice*. San Diego, CA: Elsevier/Academic Press (2006)

45. Walsh F. Human-animal bonds II: the role of pets in family systems and family therapy. *Fam Process*. (2009) 48:481–99. doi: 10.1111/j.1545-5300.2009.01297.x

46. Bayat M. Evidence of resilience in families of children with autism. *J Intellect Disabil Res*. (2007) 51:702–14. doi: 10.1111/j.1365-2788.2007.00960.x

47. Kapp L, Brown O. Resilience in families adapting to autism spectrum disorder. *J Psychol Afr*. (2011) 21:459–63. doi: 10.1080/14330237.2011.10820482

48. Rodriguez KE, LaFollette MR, Hediger K, Ogata N, O'Haire ME. Defining the PTSD service dog intervention: perceived importance, usage, and symptom specificity of psychiatric service dogs for military veterans. *Front Psychol*. (2020) 11:1638. doi: 10.3389/fpsyg.2020.01638

49. Dollion N, Herbin A, Champagne N, Plusquellec P, Grandgeorge M. Characterization of children with autism spectrum disorder's interactions with a service dog during their first encounter. *Anthrozoös*. (2022) 35:867–89. doi: 10.1080/08927936.2022.2051932

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The experiences of autistic doctors: a cross-sectional study

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Introduction: Medicine may select for autistic characteristics. As awareness and diagnosis of autism are growing, more medical students and doctors may be discovering they are autistic. No studies have explored the experiences of autistic doctors. This study aimed to fill that gap.

Methods: This is a cross-sectional study. A participatory approach was used to identify the need for the project and to modify a pre-existing survey for use exploring the experiences of autistic doctors.

Results: We received 225 responses. 64% had a formal diagnosis of autism. The mean age of receiving a formal diagnosis was 36 (range 3–61). Most were currently working as doctors (82%). The most common specialties were general practice / family medicine (31%), psychiatry (18%), and anesthesia (11%). Almost half of those working had completed specialty training (46%) and 40% were current trainees. 29% had not disclosed being autistic to anyone at work. 46% had requested adjustments in the workplace but of these, only half had them implemented.

Three quarters had considered suicide (77%), one quarter had attempted suicide (24%) and half had engaged in self-harm (49%). 80% reported having worked with another doctor they suspected was autistic, but only 22% reported having worked with another doctor they *knew* was autistic. Having never worked with a potentially autistic colleague was associated with having considered suicide.

Most preferred to be called “autistic doctors” (64%). Most considered autism to be a difference (83%). Considering autism to be a disorder was associated with preference for the term “doctors with autism,” and with having attempted suicide.

Conclusion: Autistic doctors reported many challenges in the workplace. This may have contributed to a culture of nondisclosure. Mental health was poor with high rates of suicidal ideation, self-harm, and prior suicide attempts. Despite inhospitable environments, most were persevering and working successfully. Viewing autism as a disorder was associated with prior suicide attempts and a preference for person-first language. A neurodiversity-affirmative approach to autism may lead to a more positive self-identity and improved mental health. Furthermore, providing adequate supports and improving awareness of autistic medical professionals may promote inclusion in the medical workforce.

KEYWORDS

autism, autistic, doctors, cross-sectional, survey, medical education, wellbeing

1. Introduction

Autism refers to a set of lifelong differences in how people communicate, interact, socialize, and behave (1, 2). Autistic people have individual strengths and challenges, which can include hyperfocus, differences in sensory perception, special interests, and anxiety (3). The estimated worldwide (and UK) prevalence of autism is at least 1% (1, 4, 5). More recently, one study in Northern Ireland has found a 4.7% prevalence in school aged children (6). The rate of diagnosis has increased steadily in recent years, which correlates with better awareness of autism, increased screening, and more accuracy in diagnosis (1). There is a growing understanding that there are geographic and demographic disparities in rates of diagnosis, with women, socio-economically disadvantaged populations, and those in countries with less awareness or more stigma around autism all being significantly less likely to receive a diagnosis (1, 7). In addition, we have an incomplete understanding of those who may not receive a diagnosis but who self-identify as autistic, and these individuals are unlikely to be recorded in the prevalence data. In this paper we have chosen to use identity-first language ("autistic person" rather than "person with autism"). This reflects the preferences of our autistic authors and current research on the topic, which finds that autistic people generally prefer identity-first language (8, 9). We recognize that some readers will disagree with this choice, and we wish to affirm the ways that autistic people choose to identify or refer to themselves.

Historically, research on autism has focused on deficits and difficulties. In recent years, there has been increasing acceptance of the neurodiversity paradigm, which challenges this pathologizing approach with a recognition that autism is not an inherent flaw or disordered way of being (10). Instead, aligned with the social model of disability, this paradigm scrutinizes social, cultural, political, and environmental factors as causes of contextual disability that traditionally fuelled sentiments of disorder (11, 12). Thus, autism may be thought of as a common set of differences. The benefits of the neurodiversity paradigm are significant, enabling us to have a conversation that does not focus on deficits, emphasizes the importance of diverse and neurodiverse communities, and takes a wider perspective, thinking about how external factors impact the capabilities and success of each individual (13, 14). While we can still identify autistic populations and characteristics, this framing allows us to do so while acknowledging the wealth of neurological diversity that exists in the population we are talking about, and the external influences of our social world (15).

Medicine may select for some common autistic characteristics, including attention to detail, pattern recognition, and a conscientious work ethic (2, 3). As awareness and diagnosis of autism are growing, more medical students and doctors may be discovering they are autistic, and this may occur at any stage through their training or working lives. Some reach diagnosis following difficulties in stressful clinical environments, or highly demanding career paths – and that support from employers, including occupational health and professional supervisors is inconsistent, with some colleagues refusing to believe a qualified doctor could be autistic (16). This may reflect the insidious nature of stereotypes. Stereotypes surrounding autism permeate all facets of society, including the medical workforce (17). In a symbiotic fashion, such stereotypes may be both born of and act to reinforce the tragedy narrative surrounding autistic people (18). Being autistic in such an environment may foster internalized ableism and may promote a lack of disclosure. For example, a recent study found that only 63% of autistic adults in employment had disclosed being autistic (19). This may be of particular importance within the medical workforce, where we know that disclosure of disability more generally is scarce, through fear of being seen to show weakness (20, 21). In fact, in a recent sample of 6,000 American physicians, those with self-reported disabilities were significantly more likely to be abused both by co-workers and patients, including actual physical harm (22).

In recent years, we have seen a near-exponential rise in recognition of intersectionality and diversification within the medical workforce. This has been particularly evident within the UK, where both the General Medical Council and the Medical Schools Council have produced supportive guidance around diversity and inclusion (23, 24). Such guidance reinforces the rights and needs of autistic people in relation to reasonable adjustments to their education and work. In the UK, this is also mandated by law (25). In addition to matters of social justice, such guidance is also driven by the recognition of the fact that "a diverse population is better served by a diverse workforce that has had similar experiences and understands their needs" (23). Despite such positive steps, evidence suggests we may still have a long way to go in our drive for a truly inclusive workforce (26). A commitment to such change must set its sights on the longer term and must also consider cultural and systemic factors at all levels of medical education and training. The actual study of medicine is as much cultural as it is factual (27). Throughout their medical studies, students and trainees undergo a transition into this culture, finding their own place within the vast medical world, alongside its associated language and practices. Previous research has found that neurodivergent people may struggle during training, through experiences of bullying, othering, and falling victim of the competitive system (28–30). Such experiences have also been reported specifically by autistic medical students (31). To that end, improving the experiences of autistic (and of otherwise neurodivergent) people within the medical workforce is vital. However, no published research has explored the experiences of autistic doctors. Our overarching aim was, therefore, to explore the experiences of autistic clinicians and the benefits of participation in a supportive community of those with similar experiences. Here, we present an analysis of our quantitative findings. We intend to analyze and publish our qualitative data elsewhere.

2. Materials and methods

2.1. Study type

This is a cross-sectional study in the form of an online survey.

2.2. Ethics

This study was approved by the Health Service Executive North East Area Research Ethics Committee.

2.3. Study context

Autistic Doctors International is an online support group, which was founded by MD in 2019. Membership requires a medical degree (or to be in the last year of medical school) and either a formal diagnosis or self-identification as autistic. At the time of conducting this study, the group had over 500 members.

2.4. Survey design

The survey was adapted, with permission, from the Autistic School Staff survey (32), which had been developed in conjunction with a committee of three autistic school staff to explore the experiences of autistic school staff based in the UK. A team of five autistic doctors adapted the survey to an international medical context suitable for distribution to members of Autistic Doctors International. Changes to the survey included adapting questions to the medical field, adding several questions focused on medical school experience, specialty selection, and medical training experiences, and the addition of a section asking about participants' experiences with Autistic Doctors International.

The final survey included a mixture of open and closed questions along with Likert scale and multiple-choice questions. Free text boxes were included throughout. The survey consisted of 32 core questions, with additional questions contingent on participant responses. Including the contingent questions, there were 121 possible questions included.

2.5. Piloting and refinement

The survey was initially piloted with a small group of autistic doctors ($n = 7$). Following this, the survey was further refined. For example, consideration of gender was switched to a free text box. Other refinements included reorganization of sections to reduce redundant questions, improvements to the wording and language of some questions, and the addition of two free text boxes allowing users to clarify other responses. No core questions were added or removed at this stage, but the total number of possible questions was increased from 121 to 123.

2.6. Recruitment and data collection

This study was open to all members of Autistic Doctors International. Study invitations containing links to the online survey were shared with all members via Facebook and WhatsApp April–July 2022. The survey began with a participant information sheet. Following this, informed consent was received prior to progressing to the questionnaire.

2.7. Data sorting

Once data collection was complete, SS and AF individually reviewed the dataset. The wider research team then met to agree protocols for data sorting, such as those for converting qualitative responses about gender and countries into statistically analyzable formats. Responses to free-text questions on race/ethnicity, countries where training was received, time in practice, gender, level of training, and medical specialty were categorized.

2.8. Data analysis

Analyses were conducted by SS using Statistical Package for the Social Sciences (SPSS) 28. Descriptive statistics were used to explore frequencies. Chi-square was used to test for associations between categorical variables. Linear-by-linear association was also checked where appropriate. Significance was assessed at the $p < 0.05$ level.

3. Results

The survey received 225 responses. Whilst Autistic Doctors International member levels are fluid in nature, and spread across various platforms, this represents an approximately 40% response rate. Demographic details are outlined in Table 1.

Respondents resided in a variety of countries (Table 2). Most (61%) were living in the United Kingdom, followed by Australia (27%), the United States (16%), and Canada (11%).

3.1. Diagnosis

Most (64%, $n = 143$) had a formal diagnosis of autism. The rest self-identified as autistic. Of those with a formal diagnosis, the mean

TABLE 1 Demographic information.

	%	N
Current age		
20–29	12.9	29
30–39	36.2	81
40–49	29.5	66
50–59	14.3	32
60–69	5.4	12
70 or over	1.8	4
Total N =		224
Gender identity		
Female	81.3	178
Male	11.9	26
Non-binary, agender, or gender fluid	6.8	15
Total N =		219
Sexual orientation		
Straight	57.6	129
Bisexual	11.2	25
Asexual	8.5	19
Do not know	7.1	16
Gay/lesbian	5.8	13
Pansexual	4.5	10
Not listed	3.1	7
Prefer not to say	2.2	5
Total N =		224

TABLE 2 Current geographical locations.

Location	%	N
United Kingdom	61	136
Australia	12.1	27
United States	7.2	16
Canada	4.9	11
Ireland (Republic)	4	9
New Zealand	1.8	4
France	1.3	3
Romania	1.3	3
Denmark	0.9	2
Germany	0.9	2
South Africa	0.9	2
Austria	0.4	1
Brazil	0.4	1
Finland	0.4	1
Malaysia	0.4	1
Malta	0.4	1
Norway	0.4	1
Spain	0.4	1
Sweden	0.4	1
Total N =		223

age of receiving this was 36 (range 3–61). A few were diagnosed before the age of 18 (6%, $n = 8$).

One third (34%, $n = 74$) first suspected they were autistic when they were junior doctors/residents, and nearly one third first suspected when they were consultants/attendings or general practitioners (30%, $n = 65$). Some first suspected before they ever went to medical school (14%, $n = 30$), and a few first suspected whilst they were medical students (11%, $n = 23$).

3.2. Co-occurring conditions

Over a third had been diagnosed with generalized anxiety disorder (40%, $n = 91$) or depression (39%, $n = 87$). Nearly one third had also been diagnosed with ADD/ADHD (29%, $n = 66$). Almost one fifth had been diagnosed with post-traumatic stress disorder (18%, $n = 40$), over one tenth had been diagnosed with an eating disorder (13%, $n = 30$), and one tenth had been diagnosed with social anxiety disorder (10%, $n = 23$).

3.3. Medical school experiences

Most did not know or suspect they were autistic when at medical school (74%, $n = 164$). Of those who knew they were autistic, most did not disclose this to their medical school (72%, $n = 43$). Of those who did disclose, only half received adjustments (53%, $n = 9$). A quarter reported medical school taking them longer to complete than their peers (25%, $n = 57$). Of these, almost all felt being autistic played a part in that (89%, $n = 50$).

3.4. Current employment

Most were currently working as doctors (82%, $n = 183$). Some had previously worked as doctors but were not currently practicing (14%, $n = 32$), and a few had never worked as doctors after graduating from medical school (4%, $n = 9$).

At the time of completing the survey, almost half were consultants/attendings or general practitioners (46%, $n = 84$). Two fifths were currently trainees/junior doctors/residents (40%, $n = 73$). Some were non-training grade associate specialists (11%, $n = 20$) and a few reported other roles/routes (3%, $n = 5$). Of those with a childhood diagnosis ($n = 8$), seven were currently working as doctors with one yet to start.

Half were employed in a permanent position (51%, $n = 113$) and a quarter in a temporary position (27%, $n = 59$). A tenth were not currently employed (11%, $n = 25$), and a tenth were self-employed (11%, $n = 24$). Of those working, half were working fulltime (50%, $n = 96$) and half were working parttime (50%, $n = 97$).

One third were in general practice/family practice (32%, $n = 67$), nearly a fifth were in psychiatry (18%, $n = 37$), and a tenth were in anesthetics (11%, $n = 24$). A few were in internal medicine (6%, $n = 13$), pathology (4%, $n = 8$), or surgery (3%, $n = 6$). A range of other specialties were represented in smaller numbers, which were collected into an "other specialty" category (26%, $n = 54$).

Overall, three quarters usually enjoyed their work as doctors (74%, $n = 158$).

3.5. Autistic perspectives

Three quarters felt that being autistic helped them in their work as doctors (73%, $n = 133$). Three quarters also felt that being autistic hindered their work as doctors (73%, $n = 131$). Three quarters reported executive functioning challenges at work (77%, $n = 162$) and three quarters reported sensory issues being challenging at work (75%, $n = 156$).

Most preferred to be called "autistic doctors" (64%, $n = 145$), with less than a fifth preferring to be called "doctors with autism" (18%, $n = 40$). Most considered autism to be a difference (83%, $n = 187$), half considered it to be an identity (54%, $n = 122$), half considered it to be a disability (52%, $n = 118$), and only just over a tenth considered it to be a disorder (13%, $n = 30$). Considering autism to be a disorder was significantly associated with preference for the term "doctors with autism" ($p < 0.001$).

Four fifths reported having worked with another doctor they suspected was autistic at some stage in their career (80%, $n = 168$), but only one fifth reported having worked with another doctor they *knew* was autistic (22%, $n = 46$).

3.6. Disclosure at work

One third had disclosed being autistic to their supervisor/consultant (32%, $n = 73$), nearly a third had disclosed to their colleagues (30%, $n = 68$). One fifth had disclosed to occupational health (19%, $n = 44$) and nearly a fifth had disclosed to human resources (16%, $n = 35$). Nearly a tenth had disclosed being autistic to their patients (8%, $n = 19$). Nearly a third had disclosed to *no one* at work (29%, $n = 65$).

3.7. Reasonable adjustments at work

Less than half had requested adjustments in the workplace (46%, $n = 98$). Of those who had, only half had them implemented (49%, $n = 48$). Three quarters of those who received adjustments felt they were helpful in their jobs as doctors (75%, $n = 36$). Table 3 outlines changes that respondents felt would improve their ability to do their jobs.

3.8. Troubles at work

A quarter reported issues at work that had involved human resources or a disciplinary process (24%, $n = 50$). A tenth reported issues at work that had resulted in a formal regulatory/licensing process (9%, $n = 20$). Nearly a third reported issues at work requiring union or legal representation (30%, $n = 63$). While only 21% ($n = 47$) reported challenges in communication with patients, most reported challenges from the judgement or attitudes of other people at work (65%, $n = 137$). Approximately three-quarters experienced challenges in communication with peers (76%, $n = 161$), supervisors (74%, $n = 155$) and management (75%, $n = 157$).

3.9. Mental health

Half of our respondents had engaged in self-harm (49%, $n = 106$), three quarters had considered suicide (77%, $n = 166$), and one quarter had previously attempted suicide (24%, $n = 40$). Having engaged in self-harm was significantly associated with having considered suicide ($p < 0.001$) and having attempted suicide ($p < 0.001$). Considering autism to be a disorder was associated with having attempted suicide ($p = 0.019$, 43 vs. 21%).

Gender was associated with having engaged in self-harm ($p < 0.001$). Self-harm was reported by 73% of those identifying as non-binary, agender or genderfluid, 51% of those identifying as female, and 17% of those identifying as male. Having a formal autism diagnosis was also associated with having engaged in self-harm ($p < 0.001$). In addition, sexual orientation was also significantly associated with having engaged in self-harm ($p = 0.007$): pansexual (30%), straight (39%), bisexual (63%), gay/lesbian (69%), do not know (79%), not listed (86%).

Having requested adjustments at work was associated with having engaged in self-harm ($p = 0.039$), with only 42% of those not requesting adjustments having engaged in self-harm, compared with 50% of those who received adjustments and 64% of those who requested adjustments but did not receive them. Current grade was also associated with having engaged in self-harm ($p = 0.003$). Self-harm was reported by 64% of junior doctors/residents, 21% of non-training grade associate specialists, and 42% of consultants/attendings or general practitioners having completed training/been board certified ($p = 0.022$). The stage at which respondents first suspected they might be autistic was also associated with having engaged in self-harm ($p = 0.01$). Self-harm was reported by 77% of those who first suspected they might be autistic before medical school, 50% of those who first suspected at medical school, 46% of those who first suspected as junior doctors / residents, and 41% of those who first suspected as consultants/attendings or general practitioners having completed training / been board certified ($p = 0.023$).

Whether respondents were still working as doctors was associated with having *attempted* suicide ($p = 0.002$). Having attempted suicide was reported by 22% of those currently working as doctors, 75% of those having never worked as doctors, and 20% of those having previously worked as doctors but who were not currently practicing. Having never worked with another doctor who they suspected to be autistic was significantly associated with having *considered* suicide ($p = 0.022$, 90% vs. 73%).

There was an association between having previously considered suicide and respondents' views on whether Autistic Doctors International had been positive for their mental health ($p = 0.017$): strongly agreed it was positive (84%), agreed (67%), neither agreed nor disagreed (86%), disagreed (50%) ($p = 0.004$).

Having engaged in self-harm was associated with having disclosed being autistic to their consultant/supervisor ($p = 0.002$) and having disclosed to occupational health ($p < 0.001$). Having *not* disclosed being autistic to patients was associated with having engaged in self-harm ($p = 0.017$) and having attempted suicide ($p = 0.043$). Having disclosed being autistic to *no one* at work was associated with having never engaged in self-harm ($p < 0.001$) and having never considered suicide ($p = 0.011$).

3.10. Autistic doctors international

Most respondents found their membership personally beneficial (88%, $n = 196$). Almost all felt membership of the group was beneficial for autistic doctors in general (96%, $n = 216$). Three quarters felt membership had been positive for their mental health (72%, $n = 162$).

4. Discussion

Our findings tell the story of a diverse group of autistic doctors across the world who in many ways are thriving despite numerous barriers. Many discovered their autistic identity later in life, but few felt

TABLE 3 Changes felt to make their jobs easier/better.

Desired adjustment	%	N
A more manageable workload	50	112
Being able to be open about being autistic	49	111
A better work environment (e.g., with less noise and different lighting)	48	109
More autism understanding from colleagues	44	98
More flexibility from employers	44	98
More autism understanding from employers	42	94

comfortable disclosing this either in medical school or to future peers and employers. Disclosure to colleagues, supervisors, and human resources was uncommon, even though half of respondents reported that being able to be more open about autism would improve their work experience. This suggests the luxury of disclosure may be unavailable, excessively burdensome, or even harmful for many autistic doctors, despite the potential benefits that being open about their autistic status might bring. This mirrors the wider literature, which suggests that, whilst disclosure can be an appealing option for autistic employees, it is difficult to access in many workplaces and is often associated with stigma and discrimination from supervisors and co-workers (33). Our findings support previous calls for defined disclosure processes, supported by workplace to address stigma and provide accommodations (34, 35).

In our sample, half had engaged in self-harming behavior and over three quarters had considered suicide, compared with lifetime suicidal ideation rates of under 10% in the general population (36). Comparatively, the prevalence of suicidal ideation in the wider autistic population is also lower, sitting between 19.7 and 66% (37). Similarly, suicidal ideation in medical doctors, whilst well recognized as higher than the wider population, is also much lower – reported to be between 6.3 and 24.8% (38). It is therefore imperative to consider why the prevalence of suicidal thoughts may have been higher within our sample of autistic doctors. While we cannot draw a straight line that connects difficulties at work with high levels of self-harm and suicidal ideation, it is notable that, among those who requested adjustments in our sample, rates of self-harm were higher. This was particularly true for those who requested adjustments and did not receive them. We do see a pattern of those who did not disclose being less vulnerable to self-harm and suicidal ideation. This suggests the possibility that those who face more significant needs for support and accommodation are both less able to avoid disclosure and more likely to experience mental health difficulties. Whichever causality one chooses to follow, the process of disclosure itself must be accessible and positive. A world where doctors who seek adjustments are less likely to work and more likely to self-harm is not one that is helping autistic doctors to be healthy and productive contributors to the medical profession – potentially increasing health inequity through weeding out the benefits that autistic doctors bring to the profession for autistic patients (23). Furthermore, our finding that having never worked with another doctor they suspected to be autistic was associated with having considered suicide is important. Whilst this is an association and not a causation, this may provide some preliminary evidence to support the assertion that openly autistic role models play a key role within medical education and the wider medical workforce. As previously argued, "witnessing colleagues with whom we can identify and being able to learn from their successes and struggles may make the difference between leaving a career we dreamed of, or pursuing it, more aware of our strengths, our vulnerabilities and the right to advocate for accommodations" (18).

In this same vein, we see that those who found membership in Autistic Doctors International to be most positive were also more likely to have considered suicide. Given that there is clearly a significant set of barriers to disclosure for people with any level of adjustment needs, it is possible that these individuals might find membership in a group where they can comfortably disclose to be a positive experience. While Autistic Doctors International is unable to directly create adjustments in the workplace, it can be a way to find peer support and a welcoming community – exactly those things that may be lacking in a workplace with a culture of nondisclosure. Factors contributing to autistic people succeeding at work include peer support, provision of mentorship, and supportive communication (especially through an indirect platform, such as virtually) (39–42). Ideally, these positive factors would already exist in the medical workplace, but in this study, we see that many do not have access to these types of positive supports formally. Organizations like Autistic Doctors International, therefore, provide access to a supportive peer group and may help ameliorate any fear/damage introduced by workplaces that are not prepared to properly accommodate and embrace their autistic employees. This is in keeping with the wider literature, which shows that social support can be protective against emotional distress and burnout in medical students and doctors (43, 44). In the wider population, it has also been found to protect against suicide (45).

One result that is deserving of attention is that, among the relatively low number of respondents who disclosed their autistic status to patients, rates of self-harm were significantly lower. This is an area worth additional exploration. The wider literature suggests that disclosure of personal mental ill health or disability to patients is culturally frowned upon within medicine (46). Within our findings, it is not possible to assert causation here. One the one hand, respondents who experienced better mental health may feel more confident in disclosing to patients for patient benefit. On the other, could it be possible that a sense of camaraderie or acceptance with autistic patients in some way fostered improved mental health in our respondents? From another perspective, evidence suggests that autistic people are more comfortable in seeing a doctor whom they *know* to be autistic. In fact, one of the most common requests received by Autistic Doctors International is from autistic people asking for recommendations of openly autistic doctors they could approach for healthcare. Considering factors that may facilitate positive disclosure with patients, a better understanding of what makes these providers feel comfortable enough in their environment to disclose could help us support the creation of workplace environments that are more positive for the many other autistic doctors who do not feel similarly comfortable in disclosing. It is worth examining what is different about these workplaces – is it the patient population, a workplace culture of disclosure, a particular specialty that is more welcoming, or are there other factors that we can identify to create a set of best practices in supporting disclosure and mental health among autistic doctors?

Our respondents' preference for identity-first language and framing of autism as *difference* rather than disorder is in keeping with the wider autistic community perspective (9). One of our most striking findings was the association between the conceptualization of autism as disorder, the preference for person-first language and worse mental health as evidenced by previous suicide attempts. A growing awareness of the harm associated with a stigmatizing, deficit-based perspective on autism is leading to a re-framing towards a neurodiversity-affirmative approach, which may offer benefits in terms of mental health (47, 48). In our findings, we see the need for this approach to be adopted not just in patient care, but in how we think about employment in the medical profession. Most did not feel comfortable enough to disclose being autistic to others in the workplace. As a result, these people are consistently camouflaging or masking their autistic status, putting on a non-autistic façade for others in professional settings. Such practice takes a continual effort on the part of autistic people, and we know that masking can contribute to burnout, discontinuing employment, and even serious mental health issues and suicide (49, 50) – many of which are major issues within the medical workforce to begin with (51). To that end, suppressing one's autistic identity in this way may be deeply harmful. In the words of Maya Angelou, "there is no greater agony than bearing an untold story inside you" (52). To try and separate autistic doctors from 'their autism' is an impossible task, and yet this is essentially what we are asking them to do when we provide workplaces that cannot offer basic accommodations or make disclosure a realistic and supported option.

4.1. Strengths and limitations

This is the first study to explore the experiences of autistic doctors. It benefits from a participatory approach, whereby it was conceptualized and driven largely by autistic doctors. This allowed deeper insight into the needs and experience when designing the survey. The survey also benefited from being originally based on a previously developed study of autistic school staff (32).

During the analysis stage, we were informed that two respondents may or may not have completed the survey twice. We were, however, unable to confidently locate these potential duplicates. This is a limitation. The 14% ($n = 32$) who had previously worked as doctors but were not currently working may have stopped practicing at retirement age or may have ceased practice prematurely due to burnout or other reasons. Our survey did not discriminate between these groups, which is a further limitation. When interpreting our findings, it is also worth considering that we did not attempt statistical validation of our survey during its construction. It is also worth considering the limits associated with self-report data, and the fact that cross-sectional data cannot infer causation within associations.

Furthermore, it is important to consider our results in the context of our recruited sample. All participants were members of Autistic Doctors International at the time of completing the survey. The peer support focus of this group may impact the experiences reported. It is also worth noting that our survey was conducted online and in English. As such, this would have limited participation from those who do not read/write in English and from those without internet access.

Finally, it is vital to consider the potential implications of our findings themselves, given their striking nature – in particular, the preference for considering autism a difference, and the association between considering autism a disorder and higher rates of reported suicide attempts. As aforementioned, this insight holds the potential to influence positive change through supporting the adoption of neurodiversity-affirmative practices and identity-first language. Such impacts may include improved mental health and optimum outcomes for the autistic community more widely (47, 53). This is in line with our own philosophical positioning as the authors. However, also in line with our positioning, it is important that these findings around 'difference' are not mistaken as a dismissal of support needs or disability. The neurodiversity paradigm does not refute disablement, and indeed over half of our respondents identified as disabled. Instead, this paradigm shifts the focus of causation to external factors such as social, cultural, historical, political, and environmental causes (12, 47). To that end, we believe that a truly neurodiversity-affirmative approach should embrace difference through its aim to ameliorate such disablement, achieved through active inclusion and consideration of potentially ableist approaches – both on the ground and at higher, systems levels. From a reflective perspective, we feel this clarification is important to protect against potential misunderstanding of our findings. Otherwise, this risks the weaponization of heterogeneity being targeted against the autistic community, whereby a difference perspective might be mistaken as, or portrayed as, refuting disablement, thus creating a community fracture, and seemingly supporting functioning labels – i.e., the postulation that some of us are different and others are disabled. This risks either the downplay of support needs or the downplay of agency. Contrary to this, however, the high rates of mental ill health identified within this study do indeed evidence the importance of actively adjusting our educational and workplace systems within medicine to support autistic doctors who otherwise face a very real disablement.

5. Conclusion

Autistic doctors reported many challenges in the workplace. This may have contributed to a culture of nondisclosure. Mental health was poor with high rates of suicidal ideation, self-harm, and prior suicide attempts. Despite inhospitable environments, most were persevering and working successfully. Viewing autism as a disorder was associated with prior suicide attempts and a preference for person-first language.

A neurodiversity-affirmative approach to autism may lead to a more positive self-identity and improved mental health. Furthermore, providing adequate supports and improving employer and peer awareness of autistic medical professionals may promote inclusion in the medical workforce. Employing a well-supported and neurodiverse set of medical professionals will mean that the diversity of the public is reflected in their medical providers, with likely improved patient outcomes. This is an area requiring further research to optimize the circumstances that lead to happier lives and more productive medical careers for this group.

> *"There comes a point where we need to stop just pulling people out of the river. We need to go upstream and find out why they're falling in."* (Demond Tutu).

Data availability statement

The raw data supporting the conclusions of this article will be made available by the authors, without undue reservation.

Ethics statement

The studies involving human participants were reviewed and approved by the Health Service Executive North East Area Research Ethics Committee. The patients/participants provided their written informed consent to participate in this study.

Author contributions

MD, LC, KR, AF, and WR: conception and design. AF, MD, LC, KR, WR, and SS: data collection, drafting manuscript, and agreeing final submission. SS: data analysis. SS, AF, MD, and LC: interpretation of results. All authors contributed to the article and approved the submitted version.

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Conflict of interest

SS, LC, KR, and MD are all leading members of Autistic Doctors International.

The remaining authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

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References

1. Royal College of Psychiatrists. *The psychiatric management of autism in adults (CR228)* United Kingdom: National Clinical Guidance (2020).

2. McCowan S, Shaw SCK, Doherty M, Grosjean B, Blank P, Kinnear M. Vive la difference! Celebrating and supporting autistic psychiatrists with autistic doctors international. *BJPsych Open*. (2021) 7:S40. doi: 10.1192/bjo.2021.157

3. McCowan S, Shaw SCK, Doherty M, Grosjean B, Blank P, Kinnear M. A full CIRCLE: encompassing autistic doctors in the Royal College of psychiatrists' college values and equality action plan. *Br J Psychiatry*. (2022) 221:371–3. doi: 10.1192/bjp.2022.14

4. Salari N, Rasoulpoor S, Rasoulpoor S, Shohaimi S, Jafarpour S, Abdoli N, et al. The global prevalence of autism spectrum disorder: a comprehensive systematic review and meta-analysis. *Ital J Pediatr*. (2022) 48:112. doi: 10.1186/s13052-022-01310-w

5. Zeidan J, Fombonne E, Scorah J, Ibrahim A, Durkin M, Saxena S, et al. Global prevalence of autism: a systematic review update. *Autism Res*. (2022) 15:778–90. doi: 10.1002/aur.2696

6. Rodgers H, McCluney J. *Prevalence of autism (including asperger syndrome) in school age children in Northern Ireland*. Northern Ireland: Information & Analysis Directorate Department of Health (2022).

7. Wiggins L, Durkin M, Esler A, Lee L, Zahorodny W, Rice C, et al. Disparities in documented diagnoses of autism spectrum disorder based on demographic, individual, and service factors. *Autism Res*. (2020) 13:464–73. doi: 10.1002/aur.2255

8. Monk R, Whitehouse A, Waddington H. The use of language in autism research. *Trends Neurosci*. (2022) 45:791–3. doi: 10.1016/j.tins.2022.08.009

9. Bottema-Beutel K, Kapp SK, Lester JN, Sasson NJ, Hand BN. Avoiding ableist language: suggestions for autism researchers. *Autism Adulthood*. (2020) 3:18–29. doi: 10.1089/aut.2020.0014

10. Introduction KS In: S Kapp, editor. *Autistic community and the neurodiversity movement*. Singapore: Palgrave Macmillan (2020). 1–19.

11. Shaw SCK, McCowan S, Doherty M, Grosjean B, Kinnear M. The neurodiversity concept viewed through an autistic lens. *Lancet Psychiatry*. (2021) 8:654–5. doi: 10.1016/S2215-0366(21)00247-9

12. Shaw SCK. *The impacts of dyslexia and dyspraxia on medical education* Brighton and Sussex Medical School. Brighton, United Kingdom (2021).

13. Pellicano E, Den Houting J. Annual research review: shifting from 'normal science' to neurodiversity in autism science. *J Child Psychol Psychiatry*. (2021) 63:381–96. doi: 10.1111/jcpp.13534

14. Stenning A, Bertilsdotter-Rosqvist H. Neurodiversity studies: mapping out possibilities of a new critical paradigm. *Dis Soc*. (2021) 36:1532–7. doi: 10.1080/09687599.2021.1919503

15. Baron-Cohen S. Editorial perspective: neurodiversity - a revolutionary concept for autism and psychiatry. *J Child Psychol Psychiatry*. (2017) 58:744–7. doi: 10.1111/jcpp.12703

16. Doherty M, Johnson M, Buckley C. Supporting autistic doctors in primary care: challenging the myths and misconceptions. *Br J Gen Pract*. (2021) 71:294–5. doi: 10.3399/bjgp21X716165

17. Magnin E, Ryff I, Moulin T. Medical teachers' opinions about students with neurodevelopmental disorders and their management. *BMC Med Educ*. (2021) 21:16. doi: 10.1186/s12909-020-02413-w

18. Shaw SCK, Grosjean B, McCowan S, Kinnear M, Doherty M. Autistic role modelling in medical education. *Educ Prim Care*. (2022) 33:128–9. doi: 10.1080/14739879.2021.1996277

19. Ohl A, Sheff M, Small S, Nguyen J, Paskor K, Zanjirian A. Predictors of employment status among adults with autism spectrum disorder. *Work*. (2017) 56:345–55. doi: 10.3233/WOR-172492

20. Miller S, Ross S, Cleland J. Medical students' attitudes towards disability and support for disability in medicine. *Med Teach*. (2009) 31:e272–7. doi: 10.1080/01421590802516814

21. Dennis A, Warren R, Neville F, Laidlaw A, Ozakinci G. Anxiety about anxiety in medical undergraduates. *Clin Teach*. (2012) 9:330–3. doi: 10.1111/j.1743-498X.2012.00569.x

22. Meeks LM, Conrad SS, Nouri Z, Moreland CJ, Hu X, Dill MJ. Patient and coworker mistreatment of physicians with disabilities. *Health Aff*. (2022) 41:1396–402. doi: 10.1377/hlthaff.2022.00502

23. General Medical Council (2019). Welcomed and valued: Supporting disabled learners in medical education and training [online]. Available at: https://www.gmc-uk.org/-/media/latest-welcomed-and-valued-full-guidance.pdf [Accessed January 20, 2023].

24. Medical Schools Council (2021). Active inclusion: Challenging exclusions in medical education [online]. Available at: https://www.medschools.ac.uk/media/2918/active-inclusion-challenging-exclusions-in-medical-education.pdf [Accessed January 20, 2023].

25. Great Britain. *Equality act 2010*. London: Stationary Office (2010).

26. British Medical Association (2020). Disability in the medical profession: Survey findings 2020 [online]. Available at: https://www.bma.org.uk/media/2923/bma-disability-in-the-medical-profession.pdf [Accessed January 20, 2023].

27. Shaw SCK, Anderson JL. Coping with medical school: an interpretive phenomenological study. *Qual Rep*. (2021) 26:1864–80. doi: 10.46743/2160-3715/2021.4443

28. Shaw SCK, Anderson JL, Grant AJ. Studying medicine with dyslexia: a collaborative autoethnography. *Qual Rep*. (2016) 21:2036–54. doi: 10.46743/2160-3715/2016.2570

29. Shaw SCK, Anderson JL. The experiences of medical students with dyslexia: an interpretive phenomenological study. *Dyslexia*. (2018) 24:220–33. doi: 10.1002/dys.1587

30. Shaw SCK, Anderson JL. Doctors with dyslexia: a world of stigma, stonewalling and silence, still? *MedEdPublish*. (2017) 6:29. doi: 10.15694/mep.2017.000029

31. Shaw SCK, Doherty M, Anderson JL. (2023). The experiences of autistic medical students: A phenomenological study. Medical Education. [Online]. Available at: https://onlinelibrary.wiley.com/doi/10.1111/medu.15119

32. Wood R, Happé F. What are the views and experiences of autistic teachers? Findings from an online survey in the UK. *Dis Soc*. (2021) 38:47–72. doi: 10.1080/09687599.2021.1916888

33. Lindsay S, Osten V, Rezai M, Bui S. Disclosure and workplace accommodations for people with autism: a systematic review. *Disabil Rehabil*. (2021) 43:597–610. doi: 10.1080/09638288.2019.1635658

34. Khalifa G, Sharif Z, Sultan M, Di Rezze B. Workplace accommodations for adults with autism spectrum disorder: a scoping review. *Disabil Rehabil*. (2020) 42:1316–31. doi: 10.1080/09638288.2018.1527952

35. Raymaker DM, Sharer M, Maslak J, Powers LE, McDonald KE, Kapp SK, et al. "[I] don't wanna just be like a cog in the machine": narratives of autism and skilled employment. *Autism*. (2022) 27:65–75. doi: 10.1177/13623613221080813

36. Nock M, Borges G, Bromet E, Alonso J, Angermeyer M, Beautrais A, et al. Cross-national prevalence and risk factors for suicidal ideation, plans and attempts. *Br J Psychiatry*. (2008) 192:98–105. doi: 10.1192/bjp.bp.107.040113

37. Cassidy S. Suicidality and self-harm in autism spectrum conditions In: S White, B Maddox and C Mazefsky, editors. *Oxford handbook of autism and co-occurring psychiatric conditions*. New York: Oxford University Press (2020). 349–68.

38. Ventriglio A, Watson C, Bhugra D. Suicide among doctors: a narrative review. *Indian J Psychiatry*. (2020) 62:114–20. doi: 10.4103/psychiatry.Indian JPsychiatry_767_19

39. Tomczak MT, Szulc JM, Szczerska M. Inclusive communication model supporting the employment cycle of individuals with autism spectrum disorders. *Int J Environ Res Public Health*. (2021) 18:4696. doi: 10.3390/ijerph18094696

40. Baldwin S, Costley D, Warren A. Employment activities and experiences of adults with high-functioning autism and Asperger's disorder. *J Autism Dev Disord*. (2014) 44:2440–9. doi: 10.1007/s10803-014-2112-z

41. Scott M, Falkmer M, Girdler S, Falkmer T. Viewpoints on factors for successful employment for adults with autism spectrum disorder. *PLoS One*. (2015) 10:e0139281. doi: 10.1371/journal.pone.0139281

42. Dreaver J, Thompson C, Girdler S, Adolfsson M, Black MH, Falkmer M. Success factors enabling employment for adults on the autism spectrum from employers' perspective. *J Autism Dev Disord*. (2020) 50:1657–67. doi: 10.1007/s10803-019-03923-3

43. Riley R, Kokab F, Buszewicz M, Gopfert A, Van Hove M, Taylor AK, et al. Protective factors and sources of support in the workplace as experienced by UK foundation and junior doctors: a qualitative study. *Br Med J Open*. (2021) 11:e045588. doi: 10.1136/bmjopen-2020-045588

44. Kilic R, Nasello JA, Melchior V, Triffaux JM. Academic burnout among medical students: respective importance of risk and protective factors. *Public Health*. (2021) 198:187–95. doi: 10.1016/j.puhe.2021.07.025

45. Kleiman EM, Liu RT. Social support as a protective factor in suicide: findings from two nationally representative samples. *J Affect Disord*. (2013) 150:540–5. doi: 10.1016/j.jad.2013.01.033

46. Karbouniaris S. Use of experiential knowledge by mental health professionals and its contribution to recovery: literature review. *J Recov Ment Health*. (2020) 4:4–19.

47. Shaw SCK, Doherty M, McCowan S, Eccles JA. Towards a neurodiversity-affirmative approach for an over-represented and under-recognised population: autistic adults in outpatient psychiatry. *J Autism Dev Disord*. (2022) 52:4200–1. doi: 10.1007/s10803-022-05670-4

48. Doherty M, Buckley C, Johnson M, Berney T, Davidson I. Autism in general practice. *Aust J Gen Pract*. (2021) 50:343.

49. Raymaker DM, Teo AR, Steckler NA, Lentz B, Scharer M, Delos Santos A, et al. "Having all of your internal resources exhausted beyond measure and being left with no clean-up crew": defining autistic burnout. *Autism Adulthood*. (2020) 2:132–43. doi: 10.1089/aut.2019.0079

50. Cassidy S, Bradley L, Shaw R, Baron-Cohen S. Risk markers for suicidality in autistic adults. *Mol Autism*. (2018) 9:42. doi: 10.1186/s13229-018-0226-4

51. Gerada C. *The wounded healer: Report on the first 10 years of practitioner health service*. London, United Kingdom: National Health Service (2018).

52. Angelou M. *I know why the caged bird sings*. United States of America: Random House (1969).

53. Bernard S, Doherty M, Porte H, Al-Bustani L, Murphy LE, Russell MC, et al. Upholding autistic people's human rights: a neurodiversity toolbox for autism research. *Autism Res*. (2023) 16:683–4. doi: 10.1002/aur.2907

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Combating stigma in autism research through centering autistic voices: a co-interview guide for qualitative research

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As autism has gained increased attention in the past few decades, autistic advocates have adopted the phrase "Nothing about us without us," illustrating the idea that autistic people should be centered in all conversations regarding autism. However, in a large portion of autism research, autistic people are still not meaningfully engaged throughout the research process, leading to continued stigma in research through biased methods. Thus, stigma about autism influences not only the content of autism research, but the ways in which neurotypical people conduct research alongside (or without) autistic people, ultimately resulting in less valid conclusions or research that actively harms the autistic community. One way to address this stigma is through involving autistic individuals as equal partners in the research process, such as by including autistic co-interviewers in qualitative studies of autistic people. In this perspectives piece, we will highlight the benefits of participatory research practices within qualitative research. Furthermore, we will outline methods for conducting co-interviews with autistic research partners and share insights from our experiences implementing this practice. We hope this piece provides researchers the practical resources and inspiration to continue working toward decreasing the stigma surrounding autism in research spaces.

KEYWORDS

stigma, autism, qualitative, co-production, participatory research

1. Introduction

Over the past decade, the growing neurodiversity movement has undeniably impacted the landscape of autism research. However, autism stigma and biases against autistic people nevertheless continue to influence current empirical work. The impact of autism stigma and biases (whether conscious or unconscious) in research is pervasive and insidious in ways that create a harmful feedback loop – biases against autistic people influence study methodology, in turn impacting study framing, outcomes, and conclusions, which then leads to further entrenchment of autism stigma and bias. To break this cycle, non-autistic researchers must take intentional and explicit steps to identify places of potential bias in their research and take corrective action. Whether the research is quantitative or qualitative, it is imperative for researchers to recognize the hidden ways in which subjectivity creeps into research that we perceive and present as "objective" (1).

One way to begin to address stigma within autism research is increased autistic involvement in every phase of the research process. In this perspectives piece, we will first provide brief descriptions of qualitative studies centering the autistic experiences and community-based participatory methods in autism research. We will then integrate these two methodologies by discussing the benefits of having autistic people as equal contributors on qualitative interview teams. Next, we will outline methods for developing and conducting co-interviews with autistic researchers[1] and non-autistic researchers, share insights from our experiences implementing this practice, and discuss some of the potential uses of this practice to reduce stigma against autistic people in autism research.

2. Centering autistic voices in autism research

Due to barriers that have historically and currently shut autistic people out of research spaces, many autism research teams are predominantly comprised of non-autistic researchers. The lack of autistic people on autism research teams poses a large risk of stigma against autism from the very inception of a research question. Put simply and generally, our lived experiences color and shape the questions and hypotheses we generate to learn more about autism. Non-autistic researchers, who have been trained extensively by other non-autistic professionals within the medical model of disability, undoubtedly have perspectives regarding autism that are biased by their experiences and include varying degrees of stigma about autism (2).

Addressing this stigma requires non-autistic researchers to put increased effort into providing opportunities for autistic people to share their perspectives and shape research agendas. One way to correct for this stigma is through an emphasis on qualitative research, in which autistic people are asked directly about their perspectives and lived experiences. The benefits of qualitative studies in autism research include gaining a deeper understanding of the autistic experience, developing more pertinent research questions, and deriving more accurate hypotheses (3). Suggestions and guidelines for conducting qualitative studies with autistic research participants are also available (4–6).

Literature on qualitative research and autism also includes recommendations to "involve stakeholders in some aspect of the research design and analysis" (6), emphasizing participatory methods in autism research. Comprehensive participatory research involves collaborating closely with autistic community members across multiple stages of research, including development, implementation, and dissemination (7, 8). Systematic reviews of such participatory research approaches in general healthcare research have established that such approaches offer a multitude of benefits (9–11). Applied to the field of autism research, these benefits can serve to decrease stigma in autism research, including closer alignment between the autism research and autistic communities (8), fostering novel and impactful programs of research (12), building trust between researchers and the autistic community (13) and conducting more ethical research practices in autism research (14).

As outlined above, we believe both qualitative studies and participatory methods independently serve important roles in decreasing autism stigma within autism research through centering autistic voices in both the research content and processes. We also posit that the combination of participatory methods and qualitative research can further decrease stigma and bias that can be present in autism research. Recent qualitative research exploring autistic adults' experiences being interviewed by an autistic researcher revealed that participants felt increased connection and comfort during the interview process because they were speaking with another autistic individual (15). These approaches can have positive impacts on the science of autism, increasing not only the rigor and validity of autism research, but also its relevancy and impact.

In particular, we propose and recommend a co-interview procedure for conducting qualitative interviews with autistic participants, wherein at least one interviewer is an autistic researcher who is involved throughout the study process. There are the notable benefits of having an autistic researcher interview autistic participants (15, 16); however, co-interview approaches offer some practical and accessibility considerations that may make a co-interview approach more feasible for study teams. For example, currently, due to systemic barriers to research participation, there are a limited number of autistic researchers with the necessary training (e.g., the Collaborative Institutional Training Initiative – CITI training) to participate in institutional research. Further, the diversity of perspectives and neurotypes within the interview team further serves to decrease stigma within autism research through fostering connections between autistic and nonautistic researchers. Co-interview methods also promote opportunities for nonautistic researchers to examine their own stigma through working closely and collaboratively with autistic researchers during the interview process.

A researcher's positionality (i.e., the researcher's world view and relationship to the research study itself) influences the qualitative research process in many ways (17), and this premise is central to our recommendations. Our own positionalities as non-autistic (EKK) and autistic (RC) coauthors, as well as our identities as White people who communicate primarily through verbal speech, shape the current perspectives piece. We believe that having diverse positionalities on the research team and during interviews with participants benefits qualitative research in numerous ways, many of which serve to reduce prejudiced beliefs against autistic people that can lead to discrimination in autism research. These benefits occur at multiple points throughout the qualitative research process: prior to conducting interviews, during interviews, and after interviews are completed. Below, we outline these benefits while offering guidelines for developing and conducing co-interviews for qualitative studies in autism research (see Table 1 for Summaries of Guidelines and Benefits).

3. Benefits of and guidelines for co-interview methods in qualitative autism research

Developing and implementing a protocol for co-interviews in qualitative autism research should be a collaborative practice at every stage. We highly recommend that before engaging in this type of work, all team members familiarize themselves with the principles of

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[1] Here, we mean 'autistic researcher' to refer to any autistic person who is engaged in research practices, regardless of their education, training, degree, or employment.

TABLE 1 Guidelines for co-interviews.

Timeline	Practice	Rationale
Before the interview	Interview protocol is written collaboratively with autistic researchers	- Reduces chance of bias in interview questions* - Increases understandability of interview questions for autistic participants* - Increases content validity of the interview through ensuring that questions tap into the into the intended constructs*
	Co-interviewers discuss interview flow, including who will begin the interview and who will ask which questions	- Establishes clear expectations for co-running the interview - Minimizes risk of misunderstandings/miscommunications during the interview - Promotes consistent interview procedures across participants
	Interview protocol and procedures are provided to participant prior to interview	- Facilitates accessibility of interview by giving participants time to think about and respond to answers prior to start of interview* - Decreases uncertainty of what participating in the interview will be like for the interviewee
During the interview	Co-interviewers introduce themselves to participant, stating relevant positionality for the interview	- Provides autistic participant with relevant information about the positionality of the researchers* - Increases knowledge equity in the interview – interviewee is provided with similar types of knowledge about interviewers, and they have about interviewee* - Knowledge that there is an autistic person on the research team can lead to increased levels of comfort for participants and elicit more authentic responses*
	Co-interviewers actively listen to interview partner and participant responses when they are not the “active” interviewer	- Ensures that interviewers are able to “step in” for each other at any point in the interview - Promotes interview continuity between questions (e.g., referencing previous participant responses in a subsequent question)
	Co-interviewers provide clarification and re-wording of interview questions when uncertainty arises	- Non-active interviewer may be able to re-word an interview question in a manner that is more accessible to the participant
	Co-interviewers are given opportunity to ask follow-ups to every interview question	- Co-interviewers may bring different perspectives on important areas of insight in the participants’ answers* - Provides opportunity for interviewers to clarify responses that may be potentially ambiguous in later data analysis
After the interview	Co-interviewers have dedicated time to debrief about and discuss the interview	- Promotes opportunities for co-interviewers to provide feedback to each other* - Co-interviewers given the opportunity to problem-solve any issues that arose during interview - Encourages a mentality of open communication and feedback across all team members*
	Thematic analysis completed in collaboration with autistic and non-autistic researchers	- Reduces chance of bias in interpretation of participant responses* - Allows for novel autistic insights into interview themes*

Rationale with asterisks* indicate justifications that serve to reduce stigma in qualitative autism research.

participatory methods in autism research (5, 8, 12, 13, 18) as well as best practices for qualitative research (19, 20). Here, we assume that the research teams have already developed their qualitative research ideas and questions. Additionally, we assume that these research ideas and questions have been developed collaboratively with autistic individuals.

The examples we provide are based on our team’s direct experiences of engaging in these processes. The goal of our study was to understand what daily living skills are most important to autistic adults, and how these daily living skills may or not be related to achieving their independence goals. Our study team included autistic and non-autistic researchers, as well as paid autistic consultants to review and provide feedback on our interview protocol. We (the co-authors of this piece) conducted all interviews with autistic participants.

3.1. Before the interview

Once study teams identify their primary research question, the next step is to collaboratively create the interview protocol. Questions for study teams to consider include how long the interview will be, how many questions are feasible in the allotted time, how to phrase questions to be maximally accessible for participants, and in what order questions would be most effective. Interview protocols should be drafted collaboratively with input from autistic and non-autistic researchers. This approach reduces the chance of unintentional, but potentially harmful, neurotypical biases in the interview questions.

For example, while developing the interview protocol, our research team engaged in multiple discussions around our conceptualization of "independence." We discussed how best to communicate that our question was not to probe for participants' levels of independence based on normative standards (i.e., living on one's own without daily supports), but rather based on participants' desired levels of independence (whatever those may be). Team members reflected on various ways that everyone receives support to live "independently" (e.g., hiring someone to do taxes, asking for help with home maintenance, etc.) and acknowledged that these supports change over time.

Including autistic researchers in the development of the interview protocol also increases the likelihood that the interview questions will be clear, understandable, and accessible to autistic participants (21). For example, while developing our daily living skills interview protocol, an autistic researcher suggested that asking participants to "describe a typical weekday" could be overwhelming or unclear for autistic participants without specifying an expected level of detail for the question. Relatedly, incorporating autistic perspectives into the creation of the interview protocol potentially enhances the content validity of the interview through ensuring that questions assess the intended constructs in autistic populations (22).

After the interview protocol is developed, co-interviewers should develop a plan for how interviews will be conducted. Aspects of the interview procedures that should be considered are who will begin the interview, which interviewer will ask each question, and how follow-up questions will be asked. We recommend that the interview procedure be written out for future reference. This practice establishes clear expectations for co-running the interview and minimizes the risk of miscommunications between the co-interviewers. Further, the process promotes consistent interview procedures across all participants. On our study team, we opted to alternate asking primary interview questions, ensuring that we each spent equal time in leadership and supportive roles.

To promote accessibility of the interview for participants, we recommend that the co-developed interview protocol and a description of interview procedures be provided to all participants prior to their interview. In our study, we provided participants a detailed description of the co-interview procedures, including brief co-interviewer biographies, instructions for the virtual interview platform, and communication options (e.g., video and audio, audio only, text chat). Providing descriptions of the interview procedure ahead of the study visit decreases uncertainty and ambiguity of what participating in the interview will be like, and allows participants take their time to process the questions and consider their responses. Further, providing co-interviewer biographies prior to the interview promotes transparency regarding the interviewer positionalities, allowing participants to consider their comfort level with the people they will be speaking with during the interview. If possible, we recommend that the interview questions and procedures be sent to participants at least 1 week in advance of the interview.

It should be noted that having two interviewers may increase the potential for participants to experience increased anxiety and/or sensory overload during the interview. Providing participants with the description of the interview procedures prior to the interview may help participants prepare for the interview experience and consider what accommodations they may find helpful ahead of the interview. For example, participants may request that all cameras are shut off during a virtual interview or may wear noise canceling headphones during in-person or virtual interviews to reduce sensory overload. Participants may also request to have a support person present during the interview to assist them as needed with social overwhelm or anxiety. In our experience, we have been able to make all accommodations that participants have requested, and this has led to increased rapport with participants.

3.2. During the interview

At the start of each interview, co-interviewers should introduce themselves to the participant, including any relevant positionality they want to share. For us, this practice included sharing our names, pronouns, institution/organization affiliation, and neurotype. Our goal in this practice was to increase equity in the types and levels of knowledge interviewees and interviewers had about each other. We believe that this introduction also implicitly communicated important team values to the participants – primarily that the study team valued neurodiversity and had taken explicit steps to attempt to decrease autism stigma and bias in our study.

Self-disclosure is a relatively common consideration in qualitative research (23), and can be a powerful tool for building rapport at the outset of the interview. Having an autistic researcher conduct interviews with participants communicated the team beliefs of valuing neurodiversity and autistic perspectives in research. Multiple participants made positive comments (e.g., "oh, that's really cool") when the autistic co-interviewer introduced themself at the start of the interview. Our hope is that this practice increased participants' level of comfort and allowed them to provide more authentic responses, promoting the validity of their answers that were used in the subsequent thematic analyses.

Related to the sensory overload consideration noted above, we recommend that at the start of the interview, researchers re-iterate that there are multiple participation methods available to the participant and offer any available accommodations to reduce sensory overload. It should be made clear to participants that they can change their communication methods at any point during the interview. Some accommodation options available to participants during virtual interviews include (1) choosing to have their cameras off (i.e., audio only), (2) asking interviewers to have their cameras off (to reduce visual overload), and (3) using exclusively chat (i.e., no audio or visuals) to conduct the interview. Some accommodation options available to participants during in-person interviews include (1) wearing noise canceling headphones to reduce auditory overload, (2) allowing participants to determine the seating arrangement and distance in the interview room, and (3) asking participants how they would like to communicate their responses (i.e., spoken responses or written/typed responses). Pre-emptive steps can also be taken to reduce sensory overload for autistic participants. For example, in our study, only the co-interviewer who was actively asking the participant question would have their microphone un-muted. The other co-interviewer remained muted until it was time to move onto the next interview question.

We recommend that co-interviews listen attentively throughout the entire duration of the interview (i.e., during both questions they ask, and ones their co-interviewer asks). This practice ensures that either co-interviewer could step in to lead at any point in the interview and promotes interview continuity and clarity of interview questions. For example, we regularly referenced aspects of participants' answers in subsequent interview questions. Further, during several interviews, we were able to provide clarification or re-wording for interview questions when the interviewee had questions about the item. Notably, different participants asked for clarification on different interview questions, and there was not a particular question (nor a particular interviewer) that interviewees found confusing. We both benefitted from each other's perspectives when rewording questions to the participant, making the interview more understandable and accessible.

In addition to alternating primary interview questions, we developed a method in which the interviewer who asked the primary interview item also asked any follow-up questions to the item. After an interviewer felt that they were ready to move onto the next question, we explicitly gave our co-interviewer the opportunity to ask follow-up questions for the current question [e.g., "(NAME), do you have any follow-up questions before we move on?"]. The co-interviewer asked any additional follow-ups before moving to the next interview question. This procedure ensured that we were each given opportunities to address aspects of every question, while also making an explicit "hand-off" so that we both had clear understandings of who was taking the lead during the interview. We found this practice incredibly valuable, as each of us brought different perspectives on important areas of insight in participants' responses. For example, on one occasion, our autistic co-interviewer (RC) asked a participant to clarify an important distinction about whether the participant's response about their independence goals was about a goal they personally valued, or whether the response was driven by the goal being valued by others (i.e., participant's parent). On another occasion, our non-autistic co-interviewer (EKK) asked a follow-up question that led the participant to share an important insight regarding the relationships between their levels of support, independence, and quality of life.

3.3. After the interview

In addition to the standard reflective practices regarding interview content after conducting a qualitative interview, co-interviewers may take time to reflect on the process of the interview after each participant. This practice gives the interviewers opportunities to provide feedback to each other and problem-solve and issues that may have arisen during the interview. For example, after experiencing technical/connectivity issues that resulted in poor audio-recording quality during an interview, we reflected on what types of technical challenges we could provide in-the-moment solutions for, and which we should opt to reschedule the interview. Our practice also gave us a space to reflect on ways that implicit bias or stigma may show up in our thoughts or actions, both personally and professionally. The space encouraged a mentality of open communication and feedback across team members that allowed for any mistakes to be pointed out, acknowledged, inspected, and corrected.

Collaboration with autistic and non-autistic researchers is also a crucial aspect of qualitative data analysis. Input from autistic researchers reduces that chance of neurotypical bias in interpreting participant responses. In our case, our team spent significant time reflecting on how normative views of what constitutes as "living independently" create stigma for autistic people who achieve desired levels of independence with various types of supports. Further, autistic perspectives allow for unique autistic insights into potentially novel themes in the interviews. For example, concepts like autistic burnout (24, 25), autistic inertia (26), and the double-empathy problem (27) were all introduced to the literature by autistic individuals.

4. Discussion

In this special issue on why stigma and bias surrounding autism are so detrimental to autistic people, we believe it is imperative to reflect how our own actions as researchers contribute to this problem. Research is necessary to establish strong evidenced-based ways to improve the lives of autistic people; however, autism research has undeniably caused harm to autistic people (1) and contributed to the levels of stigma and bias that autistic people continue to face today. Such experiences may lead people on the autism spectrum and their families to avoid participating in autism research altogether. This may be particularly true for autistic individuals with intersectional identities that face multiple types of stigmas, biases, and prejudices across personal and public levels (e.g., LGBTQIA+ autistic people, autistic people of color, autistic people from rural communities, non-speaking autistic people, etc.).

To help break this cycle, we believe it is essential for autism research to place an increased emphasis on centering autistic voices through qualitative research and participatory research methods. To our knowledge, this perspectives piece is the first to detail the benefits of and provide a guide for a co-interview approach to qualitative research. We believe that including diverse positionalities within the research team and during interviews with participants offers enormous benefit in decreasing potential bias and stigma in the research process while also increasing quality and rigor or qualitative science.

We recognize several considerations and limitations about our approach and experiences to date. First, as is true for other types of marginalized identities in research (28), it is important to consider the implications and potential burdens of encouraging people to identify themselves explicitly and publicly as autistic in positionality statements in autism research. Further efforts should be placed on creating environments to support autistic people interested in engaging in research and developing research cultures that address the concerns and needs of openly autistic researchers in an ongoing and transparent way.

Additionally, because this perspectives piece is written by two White researchers without intellectual disabilities who primarily use spoken language to communicate, we recognize that our recommendations likely contain biases that privilege certain kinds of knowledge and ways of communicating. Furthermore, our experience is limited to interviews with autistic participants who communicated primarily with verbal speech and did not have an intellectual disability. We acknowledge the important work that still needs to be done to include the voices of individuals – both researchers and participants – who are often left out of autism research, including, but not limited to, non-speaking autistics, autistic people with intellectual disability, autistic people of color, and autistic people with significant physical disabilities. We believe that additional qualitative work with these populations will be instrumental in progressing how research conceptualizes and studies topics that are priorities for these groups. We strongly urge researchers working in these spaces to adopt co-interviewing procedures when conducting their research.

We believe that the increased involvement of autistic people in autism research will help to reduce stigma surrounding autism in research spaces. While involvement can take many forms, in this guide, we provide rationale for and outline our practices of having autistic and non-autistic researchers co-interview autistic participants in a qualitative study. Our team included autistic and non-autistic researchers, as well as multiple paid autistic consultants who assisted us to develop our interview protocol. Based on these experiences, we found this collaborative approach reduced the chance of bias in interview questions, increased understandability of the interview questions for autistic participants, and provided multiple checks for our team to ensure our interview questions addressed our intended research questions. We hope this perspectives piece provides researchers the motivation, as well as some tangible steps, to reflect on the ways their research can benefit from the integration of autistic perspectives, both as qualitative research participants and as research collaborators.

Data availability statement

The original contributions presented in the study are included in the article/supplementary material, further inquiries can be directed to the corresponding author.

Author contributions

EKK and RC contributed to the conception of this perspectives piece. EKK wrote the first draft of the manuscript. All authors contributed to manuscript revision, read, and approved the submitted version.

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Conflict of interest

Author RC is employed by company Accessible Academia.

The remaining authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

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References

1. Botha M. Academic, activist, or advocate? Angry, entangled, and emerging: a critical reflection on autism knowledge production. *Front Psychol.* (2021) 12:727542. doi: 10.3389/fpsyg.2021.727542

2. Kapp SK, Gillespie-Lynch K, Sherman LE, Hutman T. Deficit, difference, or both? Autism and neurodiversity. *Dev Psychol.* (2013) 49:59–71. doi: 10.1037/a0028353

3. Bölte S. The power of words: is qualitative research as important as quantitative research in the study of autism? *Autism.* (2014) 18:67–8. doi: 10.1177/1362361313517367

4. Crane L, Sesterka A, Den Houting J. Inclusion and rigor in qualitative autism research: a response to Van Schalkwyk and Dewinter (2020). *J Autism Dev Disord.* (2021) 51:1802–4. doi: 10.1007/s10803-020-04634-w

5. Nicolaidis C, Raymaker D, Kapp SK, Baggs A, Ashkenazy E, McDonald K, et al. The AASPIRE practice-based guidelines for the inclusion of autistic adults in research as co-researchers and study participants. *Autism.* (2019) 23:2007–19. doi: 10.1177/1362361319830523

6. Van Schalkwyk GI, Dewinter J. Qualitative research in the journal of autism and developmental disorders. *J Autism Dev Disord.* (2020) 50:2280–2. doi: 10.1007/s10803-020-04466-8

7. Cornwall A, Jewkes R. What is participatory action research? *Soc Sci Med.* (1995) 41:1667–76. doi: 10.1016/0277-9536(95)00127-S

8. Fletcher-Watson S, Adams J, Brook K, Charman T, Crane L, Cusack J, et al. Making the future together: shaping autism research through meaningful participation. *Autism.* (2019) 23:943–53. doi: 10.1177/1362361318786721

9. Brett J, Staniszewska S, Mockford C, Herron-Marx S, Hughes J, Tysall C, et al. Mapping the impact of patient and public involvement on health and social care research: a systematic review. *Health Expect.* (2014) 17:637–50. doi: 10.1111/j.1369-7625.2012.00795.x

10. Concannon TW, Fuster M, Saunders T, Patel K, Wong JB, Leslie LK, et al. A systematic review of stakeholder engagement in comparative effectiveness and patient-centered outcomes research. *J Gen Intern Med.* (2014) 29:1692–701. doi: 10.1007/s11606-014-2878-x

11. Domecq JP, Prutsky G, Elraiyah T, Wang Z, Nabhan M, Shippee N, et al. Patient engagement in research: a systematic review. *BMC Health Serv Res.* (2014) 14:89. doi: 10.1186/1472-6963-14-89

12. Nicolaidis C, Raymaker D, McDonald K, Dern S, Ashkenazy E, Boisclair C, et al. Collaboration strategies in nontraditional community-based participatory research partnerships: lessons from an academic–community partnership with autistic self-advocates. *Prog Community Health Partnersh.* (2011) 5:143–50. doi: 10.1353/cpr.2011.0022

13. Gowen E, Taylor R, Bleazard T, Greenstein A, Baimbridge P, Poole D. *Guidelines for conducting research studies with the autism community*. Autism Policy & Practice (2019) 2:29–45.

14. Cascio MA, Weiss JA, Racine Ethe Autism Research Ethics Task Force. Person-oriented ethics for autism research: creating best practices through engagement with autism and autistic communities. *Autism.* (2020) 24:1676–90. doi: 10.1177/1362361320918763

15. Pellicano E, Lawson W, Hall G, Mahony J, Lilley R, Heyworth M, et al. "I knew She'd get it, and get me": participants' perspectives of a participatory autism research project. *Autism Adulthood.* (2022) 4:120–9. doi: 10.1089/aut.2021.0039

16. Grant A, Kara H. Considering the autistic advantage in qualitative research: the strengths of autistic researchers. *Contemp Soc Sci.* (2021) 16:589–603. doi: 10.1080/21582041.2021.1998589

17. Darwin Holmes AG. Researcher positionality – a consideration of its influence and place in qualitative research – a new researcher guide. *Education.* (2020) 8:1–10. doi: 10.34293/education.v8i4.3232

18. Pellicano E, Crane L, Gaudion K. *Participatory autism research: a Starterpack*. London: UCL Institute of Education (2017).

19. Malterud K. Qualitative research: standards, challenges, and guidelines. *Lancet*. (2001) 358:483–8. doi: 10.1016/S0140-6736(01)05627-6

20. O'Brien BC, Harris IB, Beckman TJ, Reed DA, Cook DA. Standards for reporting qualitative research: a synthesis of recommendations. *Acad Med*. (2014) 89:1245–51. doi: 10.1097/ACM.0000000000000388

21. Stacey R, Cage E. "Simultaneously vague and oddly specific": understanding autistic People's experiences of decision making and research questionnaires. *Autism Adulthood*. (2022):aut.2022.0039. doi: 10.1089/aut.2022.0039

22. Jones SC. Measuring the wrong thing the right way? Time to rethink autism research tools. *Autism Adulthood*. (2022) 4:104–9. doi: 10.1089/aut.2021.0050

23. Dickson-Swift V, James EL, Kippen S, Liamputtong P. Doing sensitive research: what challenges do qualitative researchers face? *Qual Res*. (2007) 7:327–53. doi: 10.1177/1468794107078515

24. Raymaker DM, Teo AR, Steckler NA, Lentz B, Scharer M, Delos Santos A, et al. "Having all of your internal resources exhausted beyond measure and being left with no clean-up crew": defining autistic burnout. *Autism Adulthood*. (2020) 2:132–43. doi: 10.1089/aut.2019.0079

25. Rose K. An autistic burnout: the autistic advocate. (2018). Available at: https://theautisticadvocate.com/2018/05/an-autistic-burnout/

26. Sparrow M. Autistic inertia: an overview: Unstrange Min. (2016). Available at: http://unstrangemind.com/autistic-inertia-an-overview/

27. Milton DEM. On the ontological status of autism: the 'double empathy problem. *Disabil Soc*. (2012) 27:883–7. doi: 10.1080/09687599.2012.710008

28. Massoud MF. The price of positionality: assessing the benefits and burdens of self-identification in research methods. *J Law Soc*. (2022) 49. doi: 10.1111/jols.12372

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Mindshift in autism: a call to professionals in research, clinical, and educational settings

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Autistic people often have poor outcomes over the life course, including in health, education, employment, and community inclusion. Many professionals working with Autistic adults in research, clinical, and educational settings devote their careers to trying to improve such outcomes. However, we maintain that real progress cannot happen without a fundamental mindshift. The status quo for professionals is to view autism as an illness. Instead, the neurodiversity movement encourages us to value and embrace autism as an aspect of human diversity and asks us to view Autistic people as a marginalized group that experiences significant disparities. While some professionals may be adopting language and concepts from the neurodiversity movement, we argue that making this mindshift fundamentally changes our practice across research, clinical, and educational settings. In this perspective, we call on professionals to embrace this mindshift to reduce discrimination and stigma, halt the spread of harmful ideologies, and help Autistic adults live fulfilling lives.

KEYWORDS

autism, stigma, discrimination, neurodiversity, disability justice

1. Introduction

Autistic adults are a marginalized group of people that experiences discrimination and stigma (1, 2). Like other marginalized populations, these factors lead to poor outcomes in health, education, employment, quality of life, and community inclusion (3–7). However, researchers, clinicians, and educators—as well as the general public—usually frame autism *itself* as the poor outcome rather than Autistic people as a disparity group (8, 9). Doing so can reinforce ableist views and result in even more discrimination, stigmatization, misrepresentation, dehumanization, abuse, harm, and traumatization (8, 10–12). Viewing autism as an illness can additionally communicate that Autistic people are inferior to allistic [i.e., non-Autistic neurodivergent and neurotypical people; (13)], which may result in internalized ableism in Autistic people (1, 2, 6, 11, 12, 14).

For years, Autistic self-advocates have attempted to de-pathologize autism through the neurodiversity movement (14, 15), which applies the social model of disability to reframe autism as an aspect of human diversity. Neurodiversity is defined as "variation in neurocognitive functioning" [Hughes (16), 3 as cited by Kapp (15)], and neurodivergence includes autism, attention-deficit/hyperactivity disorder (ADHD), and learning disabilities, among others (15). Thus, neurodiversity defines a group of people comprised of different neurotypes. Neurodivergent is defined as “having a mind that functions in ways which diverge significantly from the dominant society standards of ‘normal’” [Walker (17) as cited by Bertilsdotter Rosqvist et al. (18)] and thus refers to an individual. The neurodiversity movement “advocates for the rights of neurodivergent people, applying a framework or approach that values the full spectra of differences and rights such as inclusion and autonomy” [(15), 2]. This model asks us to switch our frame from autism as a deficit or pathology (15, 19) to Autistic adults as a marginalized population that experiences discrimination. This perspective allows for the needs of all Autistic adults (i.e., across all levels of support need and intellectual ability) to be viewed without discrimination or judgment (15) and highlights that all Autistic adults have a right to accommodations, supports, equitable access to society, and a high quality of life. This does not mean that autism is not a disability—Autistic self-advocates commonly identify autism as a disability [e.g., (20)]; this mindshift merely changes the way we view the needs of Autistic people from a medical model (where the individual is flawed and must be fixed) to a social one [where the setup of the environment determines whether a person struggles or succeeds; see Kapp (15)].

Professionals working with Autistic adults in research, clinical, and educational settings have a duty to make this mindshift to reduce discrimination and stigma, halt the spread of harmful ideologies, and acknowledge the trauma Autistic adults experience in academic and medical systems. Doing so fundamentally changes the way we conduct our work across research, clinical, and educational settings.

The purpose of this perspective is to describe the changes in our practice that result from embracing the paradigm of neurodiversity across research, clinical, and educational settings. We happily recognize the growing number of Autistic researchers, clinicians, and educators; and we primarily direct our recommendations toward allistic allies. In forming these recommendations, we bring professional experience in research (clinical and developmental psychology, public health, medicine, mental health services, systems science, implementation science, and community-based participatory research), clinical practice (clinical psychology and internal medicine), post-secondary education, and leadership. We also bring our personal lived experiences as Autistic, otherwise neurodivergent, or neurotypical people, family members, and activists.

2. Mindshift in action

2.1. Reframing goals

When we hold neurodiversity in mind, we are shifting our mental framework from fixing the Autistic person to helping them achieve a high quality of life. In research settings, this affects the questions we ask (e.g., “how can we remove systemic barriers for Autistic people?” instead of, “how can we change Autistic people to ‘fit’ into existing systems?”), the outcomes we measure (e.g., increased well-being instead of a reduction of autistic traits), and the grant funding sources we pursue (e.g., those that promote neurodiversity framing, include Autistic reviewers, support research conducted by Autistic scholars, and/or provide support for authentic Autistic engagement in the research). Within the clinic, this framework affects our case conceptualization [e.g., trauma-informed and strengths-based; (21, 22)], our treatment targets (e.g., driven by the client’s wishes, focused on promoting well-being as defined by the client), and our approach with clients [e.g., focus on treating co-occurring conditions and increasing function as opposed to treating autism itself; (20)]. Utilizing a collaborative goal setting model, such as shared decision making (23), with Autistic clients and, if applicable, their caregivers, can help us achieve these objectives as clinicians. As educators, the neurodiversity paradigm affects our educational support targets (e.g., encouraging personal interest and inspiration for learning through student-centered engagement and expression) as well as our measures of student progress and program success (e.g., evaluating student growth in knowledge and understanding over time, evaluating student preparation for next-level courses and/or job readiness).

2.2. Viewing supports and accommodations as a human right

From a neurodiversity-affirming perspective, we view supports and accommodations as a human right. That is, each Autistic person needs their own unique and tailored supports to achieve their goals. In this way, as researchers, we are likely to frame our research questions around the barriers and facilitators that hinder or support a high quality of life, to examine the effect of supports and accommodations, and to understand how barriers can be reduced or eliminated. As clinicians, we view supports and accommodations as falling under the purview of the Americans with Disabilities Act (24) and work to identify and provide appropriate, tailored, and responsive supports and accommodations for the clients with whom we work (25). This might include providing advance preparations for an office visit (26); considering sensory needs and adjusting our setting appropriately [e.g., dimming lights or providing natural lighting, ensuring access to a quiet space (27)]; changing how we communicate with clients to prioritize their receptive or expressive communication needs; using strategies to help clients tolerate examinations and procedures; supporting clients’ need for consistency or challenges with executive function; and considering the best way to incorporate caregivers while encouraging client-autonomy and shared-decision-making (25, 28). The AASPIRE Healthcare Toolkit[1] includes tools and resources to help healthcare providers make individualized accommodations and may help improve client-provider communication and reduce barriers to care (28). Within an educational setting, this means facilitating access to appropriate supports and accommodations for students in our classrooms and laboratories as well as bolstering their own self-advocacy (29). Because the process of obtaining accommodations can serve as a barrier to access for many Autistic students (30, 31), it may also be helpful to incorporate principles from Universal Design for Learning [UDL; (32, 33)] to create a more equitable learning environment. Although more research is needed to clarify the efficacy, scope, and implementation of UDL (34, 35), helpful strategies might include providing course materials in multiple formats, including written captions and alt text

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[1] www.autismandhealth.org

for videos and images, supplementing in-person handouts with online pdf versions, allowing for alternative participation modalities, providing written feedback at regular points throughout the semester, and including links and information related to accessibility resources within the course syllabi (33, 36). In addition to these strategies, further empirical work evaluating the efficacy of inclusive teaching practices, such as those outlined through validation theory (37), community pedagogy (38), and inclusive pedagogy (39), may help to develop "best practices" for supporting neurodivergent students in the classroom. Across these settings, our willingness to offer support and accommodations ensures Autistic people can more readily access clinical services and education and meaningfully participate in research.

2.3. Valuing Autistic people's lived experience

Marginalizing a group, by definition, de-centers that group's sources of knowledge; specifically, those with power to legitimize knowledge use it to devalue and dismiss the lived experience of the marginalized group while continuously reinforcing their own power and knowledge (40, 41). To disrupt this mechanism, it is essential to center Autistic people's lived experience as not just legitimate but as the central or primary source of knowledge about autism.

Taking a neurodiversity frame means centering Autistic people's lived experiences by listening to them, seeking to understand them, valuing them, and—crucially—actively rejecting conflicting narratives from those who do not have the legitimacy of lived experience no matter how powerful. In research, this means asking Autistic people what they would like to have researched and how and, if need be, pivoting research agendas to those priorities. Some scaffolding to do this in research includes using emancipatory research approaches to assemble teams that meaningfully include Autistic scientists and Autistic community members, ensuring their voices are prioritized as they play an active role throughout the entire research process, and compensating them fairly for their contributions (42–45). The practice of emancipatory participatory research further safeguards that the research is relevant to the Autistic community (9). Other scaffolding to do this work well and do it safely includes training researchers (including on how to work with diverse Autistic adults in trauma-informed and psychologically safe ways), providing adequate supports for Autistic co-researchers and collaborators, and securing sufficient funding (46). Further, valuing Autistic people's lived experience in research means providing the necessary accommodations to obtain direct report data from them, not from proxy reporters. We provide extensive resources for autism researchers who wish to use participatory approaches and create accessible study materials at www.aaspire.org/inclusion-toolkit.

Within clinical practice, we encourage providers to understand their client's whole and unique lived experiences, which requires humility, an awareness of intersectionality—that is, the unique experiences of those with multiple marginalized identities (47)—and a responsive style. A Rogerian person-centered approach may be helpful for promoting clinician authenticity, empathy, and positive regard (48). Within educational settings, valuing lived experiences includes training, hiring, and supporting Autistic educators, including Autistic co-facilitators and guest lecturers, involving Autistic people in curriculum development, and including written works by Autistic authors on course syllabi (49–51). Educators may also implement student-centered teaching approaches, creating an accepting environment where students feel comfortable sharing their emotions and experiences (52, 53). By creating space for students to voice their individual needs and concerns, and providing positive feedback, educators can also help to build confidence in Autistic students who have previously faced invalidation (37).

2.4. Using neurodiversity affirming language

One aspect of this mindshift is reflected in the language we use to talk about autism. Historically, language pertaining to autism has been largely informed by the medical model, but recent literature points to the need for autism researchers to move away from harmful, ableist language, and instead, center Autistic people's needs, preferences, and lived experiences (13). Bottema-Beutel et al. (54) as well as Botha et al. (10) provide detailed descriptions on how this can be accomplished. To briefly summarize, Bottema-Beutel et al. (54) ask autism researchers to identify language that may be patronizing, deficit-based, or otherwise ableist and replace it with nonableist terminology (e.g., specifically describing a behavior is an alternative to the term "challenging behavior" or using "co-occurring" instead of "co-morbid"). We believe these recommendations can and must be applied to clinical and educational settings as well by using nonableist and nonstigmatizing terms in spoken and written materials (e.g., therapy handouts or worksheets, course lectures and materials). When conducting autism diagnostic evaluations in clinical settings, this may include describing a client's challenges rather than their "deficits" (21). To take this even further, a clinician may consider how communication challenges may have more to do with the dynamic interaction between clinician and client, rather than a "deficit" seated within the Autistic person (55). Across research, clinical, and educational contexts, identity-first language ("Autistic person" as opposed to person-first language, "person with autism") is aligned with the neurodiversity movement, *and* it is important to note that there are individual differences in preferences [e.g., (56–58)]. We recommend using each person's preferred terminology.

2.5. Working within fundamentally ableist systems

As individuals, shifting our mental frame away from a medicalized way of viewing autism toward a social justice model affects our work, but does not in and of itself remove us from the fundamentally ableist systems in which we work. There are opportunities, however, to push back against and innovate these systems. As researchers, we advocate for community-driven research that centers autistic lived experience, reflects community priorities, and authentically includes Autistic people as both co-researchers and as research participants; further, the commitment to centering autistic priorities means doing so every time, including ending lines of research the community repeatedly has noted as harmful or ethically problematic (e.g., studies with potential for eugenic consequences). As clinicians, although we may be tethered to the Diagnostic and Statistical Manual of Mental Disorders [DSM-5-TR; (59)] for diagnostic purposes, we limit the inclusion of discriminatory and stigmatizing language within assessment reports and provide our clients and their families with explanations as to why this language is used (e.g., insurance requirements). We also routinely identify and name ableism and openly discuss it with clients as we talk with them about their health, healthcare, or wellbeing. Even though the educational classification system is focused on deficits, as educators, we can work to ensure that services are delivered in a manner that affirms diversity and makes learning accessible to all students (39, 60). Additionally, we offer emotional support, validation, and advocacy when indicated for Autistic students who are navigating these ableist systems; we also design our own classes to be universally accessible and to promote a culture of access, such that we reduce the burden of self-advocacy for all our students.

We also advocate directly for systems-level change. Within research, this may consist of requiring the inclusion of Autistic people on research teams, in the peer-review process, or on funding boards (43); requiring stringent reporting of conflicts of interest (61); and providing Autistic community members opportunities to voice their concerns without fear of retaliation. For clinicians, we advocate for clinic and/or hospital polices that allow for neurodiversity-affirming practices and documentation. As educators, we support trainings led by Autistic faculty, staff, and students to identify and understand their needs as well as promote autism knowledge and acceptance (62–64).

2.6. Leveraging greater systems change

Systems thinker Donella Meadows provides a framework for identifying and understanding leverage (i.e., places where a small change can create a large impact) within systems. The first level of leverage in the framework includes adjustments in numbers, buffers, and materials, such as increasing the number of Autistic scientists, clinicians, and educators, or increasing the capacity of research, clinical, or educational systems to support neurodiversity approaches. The next level of leverage changes the nature of relationships within a system (but not the system's structure itself), such as modifying how we use language on clinical reports or strengthening the connections between the Autistic community and the research community through participatory research models. These two levels of leverage, as outlined in the previous section, provide ways to push back against existing systems, and we are starting to see evidence of their success (65).

However, as we move into the future, it is both a challenge and an opportunity to consider how we can move beyond existing ableist systems and invoke the next two levels in the framework to remove sources of stigma all together. At the third level of the framework sits leverage that modifies the structure of the system—the flow of information through the system (including who can access it), the rules of the system, and the very way that the system is constructed (66). One place to look to for ideas in implementing interventions at this level of leverage is the Sins Invalid Disability Justice framework (67), which—contrasted with traditional disability rights that advocates inclusion within existing systems—encourages new structures to emerge from within Disability culture itself. Focusing on interdependence, intersectionality, and the inherent strengths, values, and resources of the community, Disability Justice provides a roadmap to creating inherently anti-ableist systems.

At the final level of Meadows' framework is leverage related to whole-system mindshifts. In order of least to greatest impact, they are, "3. [changing t]he goals of the system; 2. [changing t]he mindset or paradigm out of which the system—its goals, structures, rules, delays, parameters—arises; and 1. the power to transcend paradigms (66)." It is in this spirit that we encourage you to think about the potential for a neurodiversity mindshift. What happens when the goal is not normalization or even inclusion but celebration of Autistic bodyminds? What happens when our worldview inherently values neurodivergence? What happens when we have dismantled ableist systems of oppression to the point where Autistic people are no longer discriminated against at all?

3. Conclusion

In this perspective, we have shared practical considerations for the ways in which adopting the framework of neurodiversity shifts our work across research, clinical, and educational settings. Understanding that Autistic adults are a marginalized group of people that experiences discrimination and harmful outcomes drives us to shift our frame of mind from one based on a deficit model to one focused on centering the voices of Autistic people and providing appropriate supports and accommodations to help them thrive. Certainly, these recommendations are not a panacea, and there are many barriers to Autistic adults not addressed here. Nonetheless, we hope that you will consider how adopting the neurodiversity paradigm may help you to make immediate, tangible, and helpful changes to the way you conduct your research, interact with and support your clients, and engage and support students in their educational attainment.

Data availability statement

The original contributions presented in the study are included in the article/supplementary material, further inquiries can be directed to the corresponding author.

Author contributions

AM, DJ, DR, CN, and BM contributed to the conception of the manuscript. AM wrote the first draft of the manuscript. AM, DJ, TW, DR, and CN wrote sections of the manuscript. All authors contributed to the article and approved the submitted version.

Conflict of interest

The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

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References

1. Botha M, Dibb B, Frost DM. 'Autism is me': an investigation of how autistic individuals make sense of autism and stigma. *Disabil Soc*. (2020) 37:427–53. doi: 10.1080/09687599.2020.1822782

2. Botha M, Frost DM. Extending the minority stress model to understand mental health problems experienced by the autistic population. *Soc Mental Health*. (2018) 10:20–34. doi: 10.1177/2156869318804297

3. Botha M. Academic, activist, or advocate? Angry, entangled, and emerging: a critical reflection on autism knowledge production. *Front Psychol*. (2021) 12:4196. doi: 10.3389/fpsyg.2021.727542

4. Croen LA, Zerbo O, Qian Y, Massolo ML, Rich S, Sidney S, et al. The health status of adults on the autism Spectrum. *Autism*. (2015) 19:814–23. doi: 10.1177/1362361315577517

5. Howlin P. Adults with autism: changes in understanding since DSM-111. *J Autism Dev Disord*. (2021) 51:4291–308. doi: 10.1007/s10803-020-04847-z

6. Kapp SK. Social support, well-being, and quality of life among individuals on the autism Spectrum. *Pediatrics*. (2018) 141:S362–8. doi: 10.1542/peds.2016-4300N

7. Van Heijst BF, Geurts HM. Quality of life in autism across the lifespan: a meta-analysis. *Autism*. (2015) 19:158–67. doi: 10.1177/1362361313517053

8. Botha M, Cage E. 'Autism research is in crisis': a mixed method study of Researcher's constructions of autistic people and autism research. *Front Psychol*. (2022) 13:1050897. doi: 10.3389/fpsyg.2022.1050897

9. McDonald KE, Raymaker DM. Paradigm shifts in disability and health: toward more ethical public Health Research. *Am J Public Health*. (2013) 103:2165–73. doi: 10.2105/AJPH.2013.301286

10. Botha M, Hanlon J, Williams GL. Does language matter? Identity-first versus person-first language use in autism research: a response to Vivanti. *J Autism Dev Disord*. (2021) 53:870–8. doi: 10.1007/s10803-020-04858-w

11. Han E, Scior K, Avramides K, Crane L. A systematic review on autistic people's experiences of stigma and coping strategies. *Autism Res*. (2022) 15:12–26. doi: 10.1002/aur.2652

12. Turnock A, Langley K, Jones CRG. Understanding stigma in autism: a narrative review and theoretical model. *Autism Adulthood*. (2022) 4:76–91. doi: 10.1089/aut.2021.0005

13. Monk R, Whitehouse AJO, Waddington H. The use of language in autism research. *Trends Neurosci*. (2022) 45:791–3. doi: 10.1016/j.tins.2022.08.009

14. Walker N, Raymaker DM. Toward a neuroqueer future: an interview with Nick Walker. *Autism Adulthood*. (2020) 3:5–10. doi: 10.1089/aut.2020.29014.njw

15. Kapp SK. Introduction In: SK Kapp, editor. *Autistic community and the neurodiversity movement: Stories from the frontline*. Singapore: Springer (2020). 1–19.

16. Hughes J. M. F. (2016). "Nothing about us without us: increasing neurodiversity in disability and social justice advocacy groups." Autistic Self Advocacy Network. Retrieved July 21, 2016.

17. Walker N. Neurodiversity: some basic terms & definitions. (2014) Available at: https://neuroqueer.com/neurodiversity-terms-and-definitions/ (Accessed May 30, 2023).

18. Rosqvist B, Hanna MB, Hens K, O'Donoghue S, Pearson A, Stenning A. Cutting our own keys: new possibilities of neurodivergent storying in research. *Autism*. (2022) 27:1235–44. doi: 10.1177/13623613221132107

19. Kapp SK, Gillespie-Lynch K, Sherman LE, Hutman T. Deficit, difference, or both? Autism and neurodiversity. *Dev Psychol*. (2013) 49:59–71. doi: 10.1037/a0028353

20. Nicolaidis C. What can physicians learn from the neurodiversity movement? *AMA J Ethics*. (2012) 14:503–10. doi: 10.1001/virtualmentor.2012.14.6.oped1-1206

21. Brown HM, Stahmer AC, Dwyer P, Rivera S. Changing the story: how diagnosticians can support a neurodiversity perspective from the start. *Autism*. (2021) 25:1171–4. doi: 10.1177/13623613211001012

22. Urbanowicz A, Nicolaidis C, den Houting J, Shore SM, Gaudion K, Girdler S, et al. An expert discussion on strengths-based approaches in autism. *Autism Adulthood*. (2019) 1:82–9. doi: 10.1089/aut.2019.29002.aju

23. Slade M. Implementing shared decision making in routine mental health care. *World Psychiatry*. (2017) 16:146–53. doi: 10.1002/wps.20412

24. Americans with Disabilities Act. (1990). 42 U.S.C. § 12101. Available at: https://www.ada.gov/pubs/adastatute08.htm

25. Nicolaidis C, Kripke CC, Raymaker D. Primary care for adults on the autism spectrum. *Med Clin*. (2014) 98:1169–91. doi: 10.1016/j.mcna.2014.06.011

26. Nicolaidis C, Raymaker DM, Ashkenazy E, McDonald KE, Dern S, Baggs AEV, et al. 'Respect the way I need to communicate with you': healthcare experiences of adults on the autism Spectrum. *Autism*. (2015) 19:824–31. doi: 10.1177/1362361315576221

27. Strömberg M, Liman L, Bang P, Igelström K. Experiences of sensory overload and communication barriers by autistic adults in health care settings. *Autism Adulthood*. (2021) 4:66–75. doi: 10.1089/aut.2020.0074

28. Nicolaidis C, Raymaker D, McDonald K, Kapp S, Weiner M, Ashkenazy E, et al. The development and evaluation of an online healthcare toolkit for autistic adults and their primary care providers. *J Gen Intern Med*. (2016) 31:1180–9. doi: 10.1007/s11606-016-3763-6

29. Gillespie-Lynch K, Bublitz D, Donachie A, Wong V, Brooks PJ, D'Onofrio J. 'For a long time our voices have been hushed': using student perspectives to develop supports for Neurodiverse college students. *Front Psychol*. (2017) 8:544. doi: 10.3389/fpsyg.2017.00544

30. Lyman M, Beecher ME, Griner D, Brooks M, Call J, Jackson A. What keeps students with disabilities from using accommodations in postsecondary education? A qualitative review. *J Postsecondary Educ Disabil*. (2016) 29:123–40.

31. Nieminen JH. Unveiling ableism and disablism in assessment: a critical analysis of disabled students' experiences of assessment and assessment accommodations. *High Educ*. (2023) 85:613–36. doi: 10.1007/s10734-022-00857-1

32. Meyer A, Rose DH, Gordon D. *CAST: universal design for learning: theory & practice*. Lynnfield, MA: CAST Professional Publishing (2014).

33. Sewell A, Kennett A, Pugh V. Universal design for learning as a theory of inclusive practice for use by educational psychologists. *Educ Psychol Pract*. (2022) 38:364–78. doi: 10.1080/02667363.2022.2111677

34. Almeqdad QI, Alodat AM, Alquraan MF, Mohaidat MA, Al-Makhzoomy AK. The effectiveness of universal design for learning: a systematic review of the literature and meta-analysis. *Cogent Educ*. (2023) 10:2218191. doi: 10.1080/2331186X.2023.2218191

35. Capp MJ. The effectiveness of universal design for learning: a meta-analysis of literature between 2013 and 2016. *Int J Incl Educ*. (2017) 21:791–807. doi: 10.1080/13603116.2017.1325074

36. Milton D, Martin N, Melham P. Beyond reasonable adjustment: autistic-friendly spaces and universal design In: D Milton and N Martin, editors. *Autism and intellectual disabilities in adults Vol. 1*. Hove: Pavilion Publishing and Media (2016). 81–5.

37. Linares LIR, Muñoz SM. Revisiting validation theory: theoretical foundations, applications, and extensions. *Enroll Manage J*. (2011) 2:12–33.

38. Craven S. A pedagogy of community teaching critical social theory. *Transform J Incl Scholarship Pedagog*. (2020) 30:127–40. doi: 10.5325/trajincschped.30.2.0127

39. Florian L. Conceptualising inclusive pedagogy: the inclusive pedagogical approach in action In: J Deppeler, T Loreman, L Florian, R Smith and C Forlin, editors. *Inclusive pedagogy across the curriculum. International perspectives on inclusive education*, vol. *7*. Bingley: Emerald Group Publishing Limited (2015). 11–24.

40. Foucault Michel. (1980). *Power/knowledge: selected interviews and other writings*, 1972–1977. New York: Vintage.

41. Lukes S. *Power: a radical view*. London: Bloomsbury Publishing (2021).

42. Gillespie-Lynch K, Kapp SK, Brooks PJ, Pickens J, Schwartzman B. Whose expertise is it? Evidence for autistic adults as critical autism experts. *Front Psychol*. (2017) 8:438. doi: 10.3389/fpsyg.2017.00438

43. Nicolaidis C. What does inclusion mean in research and scholarship on autism in adulthood? *Autism Adulthood*. (2019) 1:79–81. doi: 10.1089/aut.2019.29001.cjn

44. Nicolaidis C, Raymaker D, Kapp SK, Baggs A, Ashkenazy E, McDonald K, et al. The AASPIRE practice-based guidelines for the inclusion of autistic adults in research as co-researchers and study participants. *Autism*. (2019) 23:2007–19. doi: 10.1177/1362361319830523

45. Shore Stephen M., and , Benevides Teal W, eds. (2018). "Autistic adults and other stakeholders engage together (AASET), engagement and compensation guide." Available at: https://www.pcori.org/sites/default/files/Engagement-Guide-as-of-122018-2.1.pdf.

46. Houting Jacquilineden, Higgins Julianne, Isaacs Kathy, Mahony Joanne, Pellicano Elizabeth. (2020). "'I'm not just a Guinea pig': academic and community perceptions of participatory autism research." *Autism*, 25: 148–163. doi: 10.1177/1362361320951696

47. Crenshaw Kimberle. (1989). "Demarginalizing the intersection of race and sex: a black feminist critique of antidiscrimination doctrine, feminist theory and antiracist politics." University of Chicago Legal Forum, 1989(1): Article 8. Available at: https://chicagounbound.uchicago.edu/uclf/vol1989/iss1/8.

48. Hume R. Show me the real you: enhanced expression of Rogerian conditions in therapeutic relationship building with autistic adults. *Autism Adulthood*. (2022) 4:151–63. doi: 10.1089/aut.2021.0065

49. Hall J, MacDonnell J, McConnell C, Jones J. Student–staff partnerships for diversifying and decolonising the higher education curriculum. *Equity Excell Educ*. (2022) 1:327–41. doi: 10.1177/27526461221109870

50. James W, Bustamante C, Lamons K, Scanlon E, Chini JJ. Disabling barriers experienced by students with disabilities in postsecondary introductory physics. *Phys Rev Phys Educ Res*. (2020) 16:020111. doi: 10.1103/PhysRevPhysEducRes.16.020111

51. Mbaki Y, Todorova E, Hagan P. Diversifying the medical curriculum as part of the wider Decolonising effort: a proposed framework and self-assessment resource toolbox. *Clin Teach*. (2021) 18:459–66. doi: 10.1111/tct.13408

52. Cotán A, Aguirre A, Morgado B, Melero N. Methodological strategies of faculty members: moving toward inclusive pedagogy in higher education. *Sustainability*. (2021) 13:3031. doi: 10.3390/su13063031

53. Moriña A, Orozco I. Planning and implementing actions for students with disabilities: recommendations from faculty members who engage in inclusive pedagogy. *Int J Educ Res*. (2020) 103:101639. doi: 10.1016/j.ijer.2020.101639

54. Bottema-Beutel K, Kapp SK, Lester JN, Sasson NJ, Hand BN. Avoiding ableist language: suggestions for autism researchers. *Autism Adulthood*. (2020) 3:18–29. doi: 10.1089/aut.2020.0014

55. Chapman R, Botha M. Neurodivergence-informed therapy. *Dev Med Child Neurol*. (2023) 65:310–7. doi: 10.1111/dmcn.15384

56. Buijsman R, Begeer S, Scheeren AM. 'Autistic person' or 'person with autism'? Person-first language preference in Dutch adults with autism and parents. *Autism*. (2023) 27:788–95. doi: 10.1177/13623613221117914

57. Keating CT, Hickman L, Leung J, Monk R, Montgomery A, Heath H, et al. Autism-related language preferences of English-speaking individuals across the globe: a mixed methods investigation. *Autism Res*. (2023) 16:406–28. doi: 10.1002/aur.2864

58. Taboas A, Doepke K, Zimmerman C. Preferences for identity-first versus person-first language in a US sample of autism stakeholders. *Autism*. (2023) 27:565–70. doi: 10.1177/13623613221130845

59. American Psychiatric Association. *Diagnostic and statistical manual of mental disorders*. *5th* ed. Washington, DC: American Psychiatric Association (2022).

60. Spratt J, Florian L. Inclusive pedagogy: from learning to action. Supporting each individual in the context of 'everybody. *Teach Teach Educ*. (2015) 49:89–96. doi: 10.1016/j.tate.2015.03.006

61. Bottema-Beutel K, Crowley S, Sandbank M, Woynaroski TG. Research review: conflicts of interest (COIs) in autism early intervention research – a meta-analysis of COI influences on intervention effects. *J Child Psychol Psychiatry*. (2021) 62:5–15. doi: 10.1111/jcpp.13249

62. Gillespie-Lynch K, Brooks PJ, Someki F, Obeid R, Shane-Simpson C, Kapp SK, et al. Changing college students' conceptions of autism: an online training to increase knowledge and decrease stigma. *J Autism Dev Disord*. (2015) 45:2553–66. doi: 10.1007/s10803-015-2422-9

63. Jones DR, DeBrabander KM, Sasson NJ. Effects of autism acceptance training on explicit and implicit biases toward autism. *Autism*. (2021) 25:1246–61. doi: 10.1177/1362361320984896

64. Jones DR, Morrison KE, DeBrabander KM, Ackerman RA, Pinkham AE, Sasson NJ. Greater social interest between autistic and non-autistic conversation partners following autism acceptance training for non-autistic people. *Front Psychol*. (2021) 12:739147. doi: 10.3389/fpsyg.2021.739147

65. Raymaker DM. Shifting the system: AASPIRE and the loom of science and activism In: SK Kapp, editor. *Autistic community and the neurodiversity movement: stories from the frontline*. Singapore: Springer (2020). 133–45.

66. Meadows DH. (1999). *Leverage points: places to intervene in a system*. Hartland VT: Sustainability Institute.

67. Berne P, Morales AL, Langstaff D, Invalid S. Ten principles of disability justice. *WSQ*. (2018) 46:227–30. doi: 10.1353/wsq.2018.0003

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Applications of identity-based theories to understand the impact of stigma and camouflaging on mental health outcomes for autistic people

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Autistic people have long been conceptualized from a deficit-based model of disability, but recent self-advocates and scholars have asserted the importance of recognizing autism as both a disability and an important part of a person's social identity. The autistic identity is subject to specific stigma and stressors beyond everyday discrimination and prejudice, which can have many downstream implications on mental health and well-being. Prior research on camouflaging has explained both quantitatively and qualitatively how autistic people conform to norms and mask their autistic traits to better fit in with non-autistic societal standards. Given this paradigm shift in understanding autistic peoples' lived experiences, researchers must also begin to reshape the theories guiding their work in order to improve diagnosis, intervention, and supports. This review examines the extant research on identity-related stigma and camouflaging and their subsequent impacts on mental health outcomes in autism. A model is proposed integrating identity-based theories—specifically the social model of disability, social identity theory, and minority stress model—to explain relationships across research areas and better explain the experiences of autistic people. We discuss how identity-based theories can be applied in autism research to better understand the impacts of stigma and camouflaging on autistic peoples' lived experiences and reduce disparities in their mental health outcomes.

KEYWORDS

autistic identity, minority stress, social identity theory, camouflaging, stigma, mental health

Introduction

Autistic people have various strengths and challenges in different domains such as language, social skills, executive functioning, sensory sensitivity, and focused interests and behaviors (1), and autistic traits can range in frequency and intensity across these areas (2). Since the turn of the century, advocacy efforts led by the autistic community have reshaped our understanding of autism, research priorities, and clinical practices (3) and have bolstered a sense of autistic identity and pride that confers a positive protective factor for self-esteem (4).

In addition to the strengths and challenges associated with autism, autistic people experience a multitude of mental health concerns at disproportionate rates to non-autistic people (5). While co-occurring psychopathology may result from within-person increased susceptibility [e.g., (6)], other external factors such as lack of accessibility to services (7), external stress (8), and discrimination based on disability status (9) can impact the likelihood of a person developing depression, anxiety, suicidality, or other mental health concerns. Stigmatization based on autistic identity can additionally contribute to stress and decreased mental health and well-being (10). Some autistic people may choose to hide their autistic traits and abide by social norms (known as camouflaging) to gain acceptance and avoid judgment from peers while others may experience prejudice and discrimination based on expressing their autistic characteristics and behaviors (11, 12).

It is crucial to understand how social dynamics influence how autistic people are perceived and treated by non-autistic people and subsequently, how autistic people act in response to this. Several social and identity-based theories have been proposed to explain how out-groups experience differential treatment or stress, including social identity theory (13) and the minority stress model (14); however, identity-based theories have not been commonly applied to research on understanding disabled peoples' experiences. Elucidating this process can help ascertain how to best support autistic people and mitigate stress. Additionally, this can assist in highlighting how caregivers and professionals can target and change more systemic structures that contribute to prejudice and stigma. Moreover, topics like improving access to healthcare and mental health support, the impact of co-occurring mental health diagnoses, and the effects of stressful social environments and discriminatory systems have been identified as a chief priority for future research (15, 16).

Aims

To our knowledge, there have only been two empirical studies examining the application of the minority stress model or social identity theory to understanding how stigma and camouflaging influence autistic peoples' mental health (10, 17). Thus, the primary aim of the present integrative theoretical review was to synthesize the research literature from the following areas: stigma, camouflaging autistic traits, models of disability, social identity theory, and minority stress model. Moreover, this review had the secondary aim of incorporating these areas together to advocate for further research on the impacts of minority stress on autistic peoples' camouflaging and mental health-related outcomes. In the sections below, we review stigma and camouflaging in autism and how we can use identity theories to better understand the subsequent difficulties and disparities and how to address them in structural systems and clinical practice.

Autism-related stigma

While developing a positive sense of autistic identity can have benefits for self-esteem and community belongingness, autism is still stigmatized by society. Stigmatization is often a result from the process of labeling or disclosing one's minority identity in a manner that negatively affects their mental health or emotional, physical, or social well-being. Autism stigma was originally conceptualized as the interplay between societally unacceptable social behavior with no noticeable physical markers of the disability and a general lack of public awareness about autism (18). As time progressed, additional research asserted that even with increased general autism knowledge, autism stigma evidently persisted (19, 20). This was posited to be primarily a result of autistic peoples' behaviors within social interactions that result from difficulties and differences within their verbal and non-verbal social communication skillset (21–23) and secondarily a contribution of the stereotypes associated with an autism diagnostic label (24–26).

For autistic people, labeling their autism may lead to comparisons to their non-autistic peers and subsequent meaning-making of those differences (27, 28). While autistic people may not initially assign negative attributions to their identity, societal norms and opinions can assign negative values to the labels and consequently propagate stigma towards this group of people (29). For example, one study demonstrated that non-autistic individuals rated 9 out of 10 descriptions of autistic people as negative (30), and another study elucidated that many of the core autism traits and characteristics were stigmatized by participants (21). Consequences from stigma can be pervasive and detrimental to the well-being and self-worth of the marginalized and stigmatized group (31). Research has found that the autistic community experiences many difficulties in different areas of well-being including physical and sexual victimization across the lifespan (32, 33), workplace discrimination (34), and social rejection (31). A systematic review and meta-analysis from Lai and colleagues (5) also assessed the co-occurrent rates of mental health diagnoses within the autism population and reported high prevalence rates for diagnoses including attention-deficit hyperactivity disorder, anxiety disorders, depressive disorders, and disruptive, impulse-control, and conduct disorders, among others. Cage and colleagues (35) found that decreased external and personal autism acceptance significantly predicted depressive symptoms, and decreased acceptance from others predicted greater stress. Furthermore, several recent studies have also directly linked autism-related stigma to decreased mental health and well-being (10, 17, 36).

A recent literature review created the first theoretical model of autism stigma and what may contribute to it, moderate it, and result from it (37). Their model asserted that autism stigma is predominantly influenced by a combination of others' interpretation of a person's autistic traits and a lack of public and professional understanding of autism. Additional suggested moderators included identity-based factors like gender, sex, and cultural factors, diagnostic disclosure and individual differences, and finally, the frequency and quality of contact with autistic people. While there is a rich breadth of literature that emphasizes the high levels of mental health co-occurrence and poor well-being outcomes for autistic people, this research area remains relatively new and understudied (37). There is a strong need for researchers to collaborate with autistic self-advocates on how to better examine how stigma subsequently impacts autistic peoples' thoughts and behaviors, identify the mechanisms that lead to autism stigma, and find creative solutions to decrease the perpetuation of autism stigma (38). An additional consideration is to conduct research on self-perceptions of peoples' autistic identity. For some people, autism can be an invisible disability which is defined as any combination of physical, mental, or neurological differences that cannot be seen by others but still impacts day-to-day life (39). Additionally, autism can be an invisible identity which is a social identity that cannot be easily determined from visible cues (40). Therefore, for people whose autism is both an invisible disability and identity, subsequent research should investigate how people may actively change how they present themselves to avoid any anticipated or internalized stigma (41, 42).

Camouflaging autistic traits

Individuals with more invisible stigmatized or minoritized identities typically choose one of two primary coping strategies: either disclose their identity or hide their identity from others (43, 44). Some may conceal their autistic identity by choosing not to disclose their diagnostic status, other people hide their autistic identity by abiding by social norms thus hiding (camouflaging) their autistic traits, and some may choose to utilize both strategies to avoid potential stigma [see (45) for a review]. Cage and Troxell-Whitman (46) found that having a stronger sense of autistic identity made autistic people less likely to engage in camouflaging behavior when they had greater disclosure. Camouflaging allows autistic people to minimize the differences between their behaviors and those of non-autistic people that they interact with on a daily basis (47–49). Some identified camouflaging strategies include suppressing self-stimulatory behaviors, mirroring non-autistic behaviors, acting as a social chameleon to adapt to different social situations, or using alcohol to feel more sociable.

Prior research has indicated that autistic people who experience identity-based stigma may camouflage their autistic characteristics or behaviors to assimilate to non-autistic cultural norms to achieve acceptance or success in different social spheres such as work, school, or relationships in addition to avoiding stigma (11). Despite potentially achieving this desired outcome (50, 51), autistic people have expressed that camouflaging can be highly stressful and anxiety provoking (11). Moreover, when people perceive that their autistic traits are flawed or faulty and need to be hidden, this can increase internalized stigma (49). Camouflaging in autism has additionally been linked to negative mental health and well-being outcomes including increased depression (36), suicidal thoughts and behaviors (52), increased stress and anxiety (53), and decreased sense of belongingness (54). A recent study by Perry and colleagues (10) found that while camouflaging did not mediate the relationship between autism stigma and decreased well-being, higher perceived stigma predicted greater reports of camouflaging which suggests that camouflaging is a response to stigma. An additional study by Bradley and colleagues (55) found that autistic people expressed utilizing camouflaging to cope with harmful societal labeling and a lack of acceptance and reported that extended periods of time spent camouflaging were exceedingly detrimental to their mental health despite the short-term positive impacts.

Camouflaging serves as a desirable option for autistic people to avoid differential treatment or prejudice, despite many reporting that they want to authentically present as themselves (47–49, 56). Based on the camouflaging literature, it appears that autistic people experience negative stereotypes and stigma regardless of their choice to either mask their autistic traits or disclose their autistic identity (47). These findings all suggest that many autistic people have rich self-perceptions and are keenly attuned to the consequences of appearing different than people across social contexts. The extant and growing research in both the camouflaging and stigma literature warrant the application of established theories that can help explain the integration of social identity, stigma and camouflaging, and stress and mental health outcomes.

Theories of disability

Professionals have predominantly used two models to help conceptualize the experiences of disabled people: the medical model and the social model of disability. These models provide frameworks for how professionals, caregivers, and lay people understand and interact with disabled people across various settings. Despite having very different conceptualizations, both models are still implemented today with the goal of supporting disabled peoples' quality of life.

Medical model of disability

Extant research has contributed to the understanding that the autism phenotype is exceedingly heterogenous; however, autism is often described using an etiological and deficit-based framework (57). Interventions often focus on only particular presentations of autism despite its heterogeneity, leading to difficulty with assessing intervention efficacy (58). This framework and conceptualization of autistic people is known as the medical model of disability (59). In the medical model, disability is defined as a pathological impairment within a person's cognitive, social, or physical functioning (60). The goal of treatment focuses on the amelioration or cure of the within-person disability. Upon its first introduction, the benefits of the medical model included a decreased sense of shame and stigma related to disability, increased trust in medical or clinical professionals in supporting disabled people, and increased medical and technological advances (60). The medical model promoted care and services for disabled people, but it did not originally include disabled people in decision making on intervention or policy.

In the present day, the model is still very present in medical systems, such as the Diagnostic and Statistical Manual of Mental Disorders (1), as it helps professionals identify specific areas where disabled people may need support, and in facilitating clear billable areas for insurance purposes (61). Additionally, many etiological theories of autism—both biological and psychological—have arisen from the medical model.

While aspects of the medical model continue to be used in current research and practice, the model itself has been criticized for emphasizing within-person deficits, prescribing methods to assimilate autistic people into engaging in more "societally acceptable," non-autistic norms, or in some extreme cases, aiming to cure or eliminate autistic traits altogether. Importantly, many autistic self-advocates have challenged the medical-focused conceptualization of autism. They maintain that, given autism's socially and behaviorally based diagnosis and interventions, understandings of autistic people should similarly account for social, societal, and behavioral influences (62).

Social model of disability

The social model explains how autism can be both a within-person disability that affects a person's daily functioning and a social identity that feels further disabling due to the limiting and biased beliefs of society (63). This model was developed by disabled people in the 1970s and 1980s in response to the civil rights and disability rights movements. Oliver (63) originally posited that disability is not solely a reflection of the deficits of an individual, but it results from a disabled person functioning within an unaccommodating environment or biased society. Furthermore, the social model asserts that everyday difficulties are not simply the fault of the individual but rather a broader failure of society to provide appropriate support or services to all people regardless of ability.

This environment paved a path for the emergence of the neurodiversity movement (64), a sociopolitical initiative ignited by autistic people communicating online and establishing a sense of community (3, 65). The movement's central premise holds that differences in neurological functioning and development are a part of natural human variation, and there is no one normal or healthy type of brain or one right style of neurocognitive functioning (66, 67). The goals of the neurodiversity movement align with the disability rights movement as they both aim to eradicate stigma associated with neurological differences. Moreover, this movement aims to communicate that there has been a long history of both medical and social misunderstanding and maltreatment of neurodivergent people that has caused a great deal of suffering for them (68).

Autistic self-advocates have been reframing their understanding of their disability through the social model of disability (69–71). Through this reframed understanding of autism as an identity inspired by the neurodiversity movement, autistic people may view their disability as a marginalized or minoritized identity in a similar way that people think of their race, sexuality, or gender (72–74). By situating their autism as both a disability and an identity, this conceptualization can allow autistic people to establish their own feelings and beliefs about their diagnosis which consequently gives them a greater sense of autonomy and dignity (75). Despite the strong self-advocacy for implementing the social model of disability, the medical model of disability remains pervasive in research and clinical practice which can cause discordance between the autistic community and non-autistic family members or professionals (76). The social and societal implications for differently conceptualizing and discussing autistic traits and people can lead to in-group and out-group thoughts and behaviors that may have direct implications on autistic peoples' self-perceptions and mental health.

Identity-based theories

The increase of focus on autistic community, identity, and pride should be reflected in the way non-autistic researchers and professionals conceptualize autistic peoples' experiences. The concept of social identity and its impacts is a complex, mechanistic relationship, and thus, this should be reflected in the way autistic identity and its correlates are studied. It is imperative to understand both how autistic people view themselves as well as how they are affected by non-autistic peoples' treatment of them. Two identity-based theories—social identity theory and minority stress model—can bridge the current gaps in the autism literature on identity, stigma, and camouflaging by accounting for these complex interactions in one framework. Furthermore, these theories can inform how unique identity-related stressors, internalized self-perceptions, and maladaptive coping strategies may decrease mental health and well-being in autistic people.

Social identity theory

Social groups, norms, and their interactions have direct effects on the disparities for marginalized people within education, healthcare, employment, and community environments (77, 78). While a person's social identity can give them a sense of belonging and understanding of themselves, it can also lead to the categorization of people within social dynamics (79). Social identity theory was first posited by Tajfel and Turner (80) to describe circumstances in which people see themselves as individuals or as members of a particular group. They additionally studied the consequences of a person's personal or social identity and how this impacts self-perceptions and group behavior (13, 81). In the seminal studies, participants were assigned to arbitrary and meaningless groups and asked to assign points to other participants. Results indicated that participants systematically chose to award points more often to in-group members than out-group members. The researchers inferred that the simple act of categorizing people into groups can sufficiently lead people to see themselves as group members rather than as separate individuals. In turn, group membership can help people define their personal identity and decide how they relate to those around them.

Tajfel and colleagues' initial studies asserted that group membership instills meaning in social situations, which inspired the development of social identity theory (13). This integrative theory combined cognitive processes and behavioral motivation, and initially focused on intergroup conflict and relations. Per the cognitive framework for social identity theory, the central psychological processes include social categorization, social comparison, and social identification. Social categorization refers to peoples' propensity to place themselves and others into social categories. Social comparison is when people assign a relative value to a particular group or member. Lastly, social identification occurs when people view others through the lens of themselves and how they relate to others. The three processes result in social identity, or one's knowledge of belonging to a specific group. Behavioral motivation is driven by both personal and group factors. Based on social identity theory, people attribute positive traits, attitudes, and behaviors as characteristic of their in-group members and less favorable qualities of the out-group. This difference in perception leads to disparities in outcomes, evaluation, performance assessment, and communication between the in- and out-group members.

Extant research has expanded upon the socially relevant outcomes resulting from social categorization including negative evaluations of out-group members (82), stereotyping (83), and lack of resource allocation to out-group members (84). Moreover, research has demonstrated that social identification can also be related to positive in-group bias (85). From both perspectives, the in-group treats the out-group poorly based on the motive to protect or enhance their own self-identity (13). While much of this early research focused on the in-group thoughts and behaviors, this treatment can infer a threat to the out-group members. Social identity threat is defined as the concern out-group members experience when the positive perception of their in-group is threatened by the presence of negative group stereotypes, devaluation of their members, or external stigmatization of their in-group (86). Prior research on social identity threat has demonstrated negative stereotypes towards women [e.g., (87)], older adults [e.g., (88)], immigrants [e.g., (89)], and people of low socioeconomic status [e.g., (90)], and these negative attributions can contribute to sustained inequality for marginalized groups in society. In addition to affecting performance [e.g., (91)], social identity threat can increase avoidance of or disengagement with a target domain [e.g., (92)] as well as be viewed as detrimental to the quality of one's social life (93).

Minority stress model

While social identity theory explains in-group and out-group thoughts and behaviors, it is necessary to further understand the impact that systemic factors have on marginalized groups, like autistic people, who are historically oppressed in education, workplace, clinical, and personal settings. The minority stress model supplements the social identity theory by outlining and explaining the disparities that exist specifically between stigmatized groups and majority groups (14). Meyer (14) coined the term, "minority stress," in response to conducting a literature review and meta-analysis on the prevalence of mental health concerns in lesbian, gay, and bisexual people and defined it as mental health problems that arise from prejudice, discrimination, or stigma that is present in hostile or stressful social environments. Additionally, the model asserts that stress processes exist both within an individual and as a function of the influences of broader social contexts. The model begins by situating minority stress within a person's environmental circumstances which overlaps with a person's minority status. Minority status has a direct relation to a person's self-perception or self-identification. Environmental circumstances can lead to experiencing stressors including general stressors as well as stressors unique to minority group members such as distal events like discrimination in education, the workplace, or healthcare and proximal events like expectations of rejection or internalized bias. Lastly, a person's minority identity can also moderate the impacts of stress in both positive and negative ways. Taken together, these processes all function to explain unique positive and negative mental health experiences for people with marginalized identities.

This framework functions on the basis that stigma and falling lower on the social hierarchy leads to a greater likelihood of experiencing greater stress or other mental health concerns while having less access to resources to cope with these occurrences (94). The additional presence of a tiered social structure facilitates discrimination and social exclusion which can add further stress to stigmatized groups. The model functions under four additional premises. The first principle states that differences between groups do not necessarily correspond to discrepancies when they are expected such as certain ailments more commonly occurring with older age. Second, social disadvantage does not need to affect the entire social subgroup, and if an individual person within that minority group does not experience it, it does not discredit the theory. The next premise is that the minority stress model applies broadly to social situations and overall health rather than to a particular disorder. Finally, the minority stress model specifically relates to sociological disadvantage influenced by external factors rather than representing a within-person difference or negative outcome.

The minority stress model has been historically implemented in the sexual and gender minority literature, which has demonstrated greater stress related to individuals' identities and higher instances of poor physical and mental health (14, 95–98). Health disparities have also been linked to identity-related stressors in other marginalized groups including Black Americans (8, 99), undocumented Latinx immigrants (100), and physically disabled people (73). It is notable that up until 2020, no research had been conducted to apply the minority stress model to people with any type of neurodivergent identity.

Applying identity-based theories to autistic people

Autistic people have qualitatively reported feeling different from others, lacking a sense of fitting in or belongingness, and feeling isolated and inferior to others [e.g., (101, 102)]; however, few studies have quantitatively assessed autistic identity and social categorization as catalysts for mental health or well-being (79, 103). Studies have demonstrated that autistic adolescents and young adults experience higher instances of depression resulting from feelings of loneliness (104, 105). Additionally, loneliness has been shown to be a strong predictor of depression in non-autistic populations [e.g., (106–108)]. While loneliness may appear conceptually similar to social identification, the two are separate constructs such that loneliness relates to a general disconnect between people whereas social identification relates more to feelings of belongingness to a particular group. Crompton and colleagues (109) conducted a qualitative assessment of autistic adults' belongingness with each other and their well-being. They found that autistic people reported that spending time with other autistic people provided a sense of belonging as they were able to be their authentic selves and felt understood by other autistic people, which participants believed was important for maintaining their well-being.

Cooper and colleagues (103) were among the first to use social identity as a primary variable assessed within autistic peoples' experiences. They asked autistic adults about their social identification with other autistic adults and its relation to self-esteem. Their path analysis results indicated that increased feelings of social identification with other autistic people predicted greater self-esteem towards their social group which in turn was predictive of greater personal self-esteem. When controlling for both forms of self-esteem as mediators, social identification was negatively associated with both anxiety and depression. Implications from this initial study indicate that feelings towards autistic people can influence both an autistic person's self-perceptions and mental health outcomes.

Maitland and colleagues (79) expanded on this work by assessing how to measure social identification in autistic people, how autistic people relate to other social groups, and finally, whether social identification associates with depression, anxiety, and positive mental health. They found that measures of social identification originally developed for non-autistic populations showed good reliability but yielded a different factor structure when applied to autistic people, suggesting that they may experience social identity differently, but can still accurately report on their feelings towards it. Their findings showed that some autistic people identified with other social groups such as autistic people, their family, and other groups they had frequent contact with (i.e., work, peer, and hobby groups), and some autistic people felt as though they did not identify strongly with any group. It is important to note that this study did not have a diverse enough sample to assess what other social identity groups they identified with, such as gender, sexuality, race, or ethnicity. Socially identifying as autistic did appear to have a protective factor as it was reported to relate to lower levels of depression and higher positive mental health. Again, this study tended to focus on autistic peoples' self-perceptions and belonging to their own group and less towards their feelings and perceptions of how non-autistic people perceive and treat them.

The current autism research informed by social identity theory has primarily focused on autistic group belonging and mental health. This does not account for the in-group and out-group dynamics and its subsequent impact on cognitive processes and behavioral motivation. Autistic people have been historically and systematically treated as an out-group, and thus, they likely experience being minoritized by society in social situations in similar manners to other marginalized groups. Therefore, the introduction and application of the minority stress model can supplement social identity theory research by framing autism as a minority identity that experiences specific stressors beyond being an out-group in social dynamics.

Several studies have demonstrated that autistic people are more likely than non-autistic people to have increased rates of physical and mental health concerns (34, 110–113), including greater rates of depression, post-traumatic stress disorder, and suicidality (111, 114, 115), which indicates a clear mental health disparity between the two social groups. Given this discrepancy, it is worthwhile extending the minority stress model to autistic people, since a tenet of applying the framework is that there must be documented disparities currently existing between the stigmatized and majority group (94).

Additionally, autistic peoples' experiences can be applicable to the model structure that Meyer (14) initially proposed. First, autistic peoples' neurominority status is intertwined with their experiences of identity-related stress in various social and environmental contexts (59). In line with the minority stress model, autistic people have expressed that holding a neurominority status relates to how they self-identify and see themselves (71). Moreover, autistic people experience unique minority stressors that extend beyond universal stressors such as prejudice from classmates in school settings (116), the workplace (56), and healthcare settings (117, 118). The final piece of the minority stress model in which social identity moderates stress has previously been absent within the autism literature.

Botha and Frost (17) conducted the first study to assess the impact of minority stress, above and beyond general stressors, and how it relates to autistic peoples' mental health experiences. Their study comprised autistic adults from the United Kingdom who answered questions regarding stress, discrimination, camouflaging, stigma, and well-being. All models controlled for the influence of gender and general stress exposure. Results for the first model indicated that lower social well-being was significantly predicted by greater levels of both expectation of rejection and behavioral concealment. Next, lower levels of emotional well-being were significantly predicted by greater levels of victimization and discrimination, everyday discrimination, expectation of rejection, and internalized stigma. Lower psychological well-being was predicted by greater levels of victimization and discrimination, everyday discrimination, expectation of rejection, and outness. Finally, greater levels of psychological distress were significantly predicted by greater levels of everyday discrimination, expectation of rejection, outness, and internalized stigma as well as having an official autism diagnosis.

While these results were preliminary, they suggest that the minority stress model could be applicable to understanding autistic peoples' mental health both theoretically and empirically (17). The findings support that autistic people experience unique stressors related to their identity that have an additive effect to other general stressors and make a strong argument that there is a need for this important research gap to be filled. Future directions of this research can more broadly explore and parse apart what the experiences of stigma, both external and internal, are like for autistic people, how their self-perception influences masking their autistic traits, how community connectedness or belonging could buffer mental health outcomes, and how other minority identities may have a "double discrimination" effect (119).

Autistic self-advocates and allies have been encouraging researchers to more broadly apply themes of acknowledging autism as an identity and minority status within research (15, 16); however, most of this research has been led by autistic researchers (17), who have reported that influential forces, like funding mechanisms and senior researchers, can make it feel emotionally taxing or professionally difficult to lead this research in a lower position of power (120, 121). Given that the use of the minority stress model to inform autism research is so nascent and led by members of the autistic community, non-autistic researchers in positions of power have the potential to positively impact and drive this research area forward to better understand minority stress in the same way that sexual and gender and racial/ethnic minority research has progressed. Moreover, conducting research that understands the impact of minority stress and how non-autistic people have intentionally or unintentionally perpetuated it dovetails well with a recent systematic review and meta-analysis on the interaction between non-autistic people's characteristics and their attitudes towards autistic people (122). Their results indicated that gender, knowledge on autism, quality of contact with autistic people, and how many times they have interacted with autistic people can significantly predict how positively or negatively they view the autistic community. More frequently implementing the minority stress model in autism research prioritizes the initiatives of autistic self-advocates and researchers while directly increasing our understanding of both internal and external stressors and how they impact a person's mental health and well-being.

The integration of social identity theory and the minority stress model interplay well together when investigating camouflaging, stigma, and mental health outcomes. Social identity theory asserts that groups use both individualistic and collective strategies to achieve a positive status (123). Camouflaging may serve as an individualistic strategy to separate from an autistic person's in-group and be accepted into the majority-status and non-stigmatized non-autistic out-group. Additionally, Botha and Frost's (17) findings demonstrate that autistic people have a stigmatized minority identity that is subject to specific stressors beyond everyday discrimination and prejudice. Therefore, a model integrating these two theories could examine the relationships between autism identity-related stigma and well-being with a mediating factor of camouflaging strategies while controlling for demographic factors and other general life stressors.

Discussion

The present integrative theoretical review proposes a reframing for our understanding of autistic people and their disparities in mental health outcomes. The integration and application of social identity-based frameworks shifts the locus of difficulties and negative outcomes from being predominantly within an autistic person to being a mutual interpersonal issue between both the autistic and non-autistic person. This shared breakdown in understanding was defined by Milton (124) as the "double empathy problem." This theory suggests that when people with different identities interact with each other, they may struggle to empathize with each other's perspectives or experiences. Recent research has begun to account for the impact that non-autistic people contribute to social interactions [e.g., (23, 125–128)]; however, this has not yet been more widely applied to how researchers frame mental health outcomes for autistic people, how the double empathy problem plays a role in camouflaging, or how systems can be changed to reflect this knowledge.

Implications for future research and practice

Suggestions for future research center around taking a more integrative and holistic approach to theories of autism. As previously mentioned, much of the current literature focuses on studying social identities, autistic traits, mental health, and camouflaging in separate studies. Across these studies, research has demonstrated that (1) social identity influences how autistic people view themselves and how others view them [e.g., (79)], (2) social exclusion can lead to poor mental health outcomes [e.g., (93)], (3) people with other marginalized identities have greater mental health concerns [e.g., (129)], (4) camouflaging to fit in can be physically and emotionally taxing [e.g., (11)], and (5) autistic people from other historically marginalized groups experience health disparities [e.g., (130–133)]. Future research is needed to integrate these areas; such research can account for these complex theories by utilizing more advanced statistical approaches like structural modeling and implementing person-centered approaches like mixed methods research. Additionally, non-autistic researchers should actively take an anti-ableist approach to their research by using more socialized frameworks of autism, including autistic people throughout their research process, and changing their language surrounding autistic people and their experiences (134).

This review also has important implications for intervention, education, and diagnostic practices, as well as broader implications for how professionals and lay people conceptualize and understand autistic peoples' experiences. First, education-based programs and interventions should be more widely implemented to reduce the identity-based stigma perpetuated by non-autistic people (135). These programs can address implicit bias, microaggressions, or outward discrimination in multiple settings and can assist with developing more equitable and sustainable disability policy. Multiple studies have demonstrated that stigma reduction programs can increase autism knowledge and reduce autism stigma at the individual level in non-autistic adolescent and young adult samples (136–139). At the systems level, stigma reduction programs can help reframe the conceptual view of autistic people to reduce stigma and camouflaging in the workplace, school, and other public settings (140). One such intervention that has been proposed focuses on educating non-autistic people on the social model of disability through placing less emphasis on assimilating autistic people to non-autistic cultural norms and practicing greater acceptance (62). Bottema-Beutel and colleagues (140) also recommended adapting social skills interventions to shift focus from using normative, non-autistic social interaction norms as target outcomes to appraising realistic social skills goals to communicate in a way that best fits each individual's needs and preferences.

Social identity and disability culture frameworks can also aid in addressing gaps in gold-standard diagnostic practices. The Autism Diagnostic Observation Scale-2 (ADOS-2) is a best-practice measure that focuses on behavioral observations to assign an autism diagnosis (141). Given that the measure can only be scored based on what is observed during the assessment, an ADOS-2 administrator cannot account for the presence and influence of camouflaging, and autistic people who engage in camouflaging may appear during the assessment as though they do not meet the diagnostic criteria for autism [e.g., (142, 143)]. Missing out on an autism diagnosis can lead to delaying access to supports or accommodations which can affect a person's feelings of competence, belonging, and autonomy (144). Additionally, limitations of behavioral observational measures due to camouflaging contribute to disparities in diagnostics for people of color or sexual and gender minority people which has negative implications for their mental health (132, 145, 146). One way to supplement the ADOS-2's observational approach is to include self-report measures of a person's perceived autistic traits, such as the Autism Quotient (AQ) (147), or camouflaging, such as the Camouflaging Autistic Traits Questionnaire (CAT-Q) (54). While caregiver-report measures can also assist in a more holistic diagnostic assessment, parents or caregivers may be unaware if their child engages in camouflaging. A prior study found that non-autistic children as young as 5 years old can reliably and validly report their health-related quality of life (148), and psychometric research has identified an approach to estimate the minimum age that children can self-report data of similar quality to their parents or caregivers (149). This approach can be taken to assess and potentially adapt the AQ or CAT-Q to determine what age autistic children can validly and reliably self-report their autism traits or camouflaging. Moreover, better professional development and education on stigma and camouflaging can improve diagnosticians' assessment and case conceptualization of clients.

This education can further benefit autistic people in therapeutic settings. Given the high co-occurrence of mental health concerns among autistic people, it is pivotal to change the stigma and barriers to systems of support. Brede and colleagues (150) found that the three most common themes among studies of mental health service experiences for autistic people included (1) a lonely, difficult service experience that can cause further harm, (2) a need for a more flexible and comprehensive approach to autistic mental health, and (3) listening to autistic clients, building strong and trusting rapport, and empowering their agency. In order to create safer and more trusting environments for autistic people to utilize mental health services, clinicians should actively work to dismantle their implicit biases that may unintentionally be harming autistic people and preventing them from seeking support. Additional exploration should focus on how to include autistic people with co-occurring intellectual disability or who are from historically marginalized racial, ethnic, or socioeconomic backgrounds to further identify even broader structural barriers to accessing equitable mental health care.

Chapman and Botha (151) emphasized the importance of clinicians adopting a neurodiversity-affirming therapeutic approach when working with autistic clients, as other classic theories of psychotherapy may not adequately capture an autistic clients' experiences or support their goals. Neurodiversity-affirming therapy encourages therapists to (1) reconceptualize dysfunction as external rather than within-person, (2) emphasize the importance of autistic community, acceptance, and pride, and (3) adopt a cultural humility for disability and neurodivergence. It is also important for therapists to recognize the deleterious effects that camouflaging may have on their clients' mental health (11), and to acknowledge the harmful impact of repeated experiences of stigma as a form of trauma when conceptualizing their clients' therapeutic goals (152).

Future directions

Future research and practice can integrate an identity-based theoretical framework with the autism and mental health literature to help providers and family members better understand and accommodate autistic people across their lifespan in multiple settings. As previously mentioned, very few studies to date (10, 17) have incorporated identity-based frameworks to understand autistic mental health, and the autism and stigma literature is less than 10 years old; therefore, this research area is relatively nascent in its development and dissemination.

Increasing inclusivity in stigma-related research

Despite the neurodiversity movement asserting the importance of all neurodivergent perspectives being included in research and advocacy, autistic people with co-occurring diagnoses remain underrepresented in the identity and stigma literature. The neurodiversity movement and the resultant sense of community has predominantly been facilitated through online communication (3). Additionally, many of the referenced studies included online surveys that required participants to read and complete self-report questionnaires and/or engage in interviews [e.g., (10, 17)]. The continued use of online platforms to conduct research allows for increased accessibility to participation for minimally speaking and non-speaking autistic people without co-occurring intellectual disability; however, many studies did not have participants self-report on their expressive language ability. To accurately capture the identities of autistic participants, studies should include additional demographic questions on expressive language and co-occurring diagnoses and increase the visibility and inclusion of autistic people with co-occurring conditions that may make it difficult to engage with online communities. It is also important to adapt or develop new assessments of perceived stigma and identity that can be completed by autistic people with co-occurring intellectual disability or cognitive or communication difficulties to capture their insights into their mental health experiences (153).

Incorporating mechanistic relationships

An additional limitation of much of the current literature is that it does not address potential mechanisms linking identity, camouflaging, and mental health outcomes. Future directions in this line of research should focus on taking a mechanistic approach to understanding the potential relationships between identity-based theories, camouflaging, and mental health outcomes. An initial area of exploration is the additional influences of other identities like race or gender. Autism research has traditionally comprised predominantly white, educated, higher socioeconomic status samples, and underrepresented autistic people with marginalized identities have often been excluded (154). Botha and Frost (17) acknowledged that they had too small of a sample size to further investigate the impacts of gender and race/ethnicity on experiences of camouflaging, identity-based stigma, and well-being. Additionally, follow-up research by Cooper and colleagues (155) assessed how autistic people relate to other social identity groups, namely gender. They found that autistic adults reported lower social identification with gender norms compared to non-autistic adults which is concordant with recent findings that autistic people are six times more likely to be transgender or gender diverse than non-autistic people (156). This may indicate that autistic people may more strongly identify with their identity than the social norms associated with it. Given these preliminary findings, future research must expand recruitment efforts to make autism research more accessible for and generalizable to autistic people of all backgrounds and lived experiences. A future direction of this research should include how demographic factors mechanistically play a role in affecting peoples' mental health and subsequently how therapy can be sensitive to the interplay of these experiences.

Another mechanistic approach would be to explore how other stress models may explain how autistic identity and community can relate to stress and health outcomes. One idea would be to explore how expressive suppression and cognitive reappraisal relate to camouflaging. Cai and colleagues (157) were the first group to examine emotion regulation as a transdiagnostic factor in autistic people. They found that autistic people using low reappraisal and high suppression were more likely to have higher depressive symptoms and lower well-being. Additionally, they found that continuously using suppression strategies could be buffered by continued use of reappraisal. Emotion regulation strategies may help to predict which people are more likely to engage in camouflaging and when camouflaging would more likely lead to negative mental health outcomes. For example, a study from van der Linden and colleagues (158) found that autistic people had stronger emotional stress reactivity in a negative stress model affect than non-autistic people in response to daily life stressors. Given that identity-based stigma can be a daily life stressor, this model may explain how those stressors can translate to the negative mental health outcomes seen in camouflaging and stigma studies. An additional theory not explored in the autism literature is how social allostatic load, or chronic stress-induced diminished regulatory systems, may affect stress within interpersonal relationships (159). Overall, it is crucial to understand both what leads autistic people to experience identity-based stigma, camouflaging, and negative mental health outcomes, as well as what maintains it.

Reconstructing stigma

Stigma research in autism has focused on stigma as one large construct (37). While it is important to know that stigma broadly has negative implications on health and well-being, different types of stigma may have different effects on subsequent coping strategies or outcomes. Research from Pryor and Reeder (160) separated stigma into four primary types: self-stigma, public stigma, stigma by association, and structural stigma. Researchers have translated this framework to other populations including people with HIV/AIDS (161) and people with fetal alcohol spectrum disorders (162). Turnock and colleagues (37) mention internalizing stigma and the effects of stigma on the systems in which autistic people exist; therefore, a next step in autism research is to separate the types of stigma and mechanistically understand what types of stigma trigger camouflaging or lead to more negative mental health outcomes.

Moreover, it is critical to draw a distinction between stigma and discrimination. Stigma focuses on the internalization of biases which can place the onus of change on the marginalized person. Discrimination and prejudice are constructs that put greater emphasis on the harmful impacts of oppressive systems, beliefs, and practices on marginalized peoples' well-being. In order to change the narrative surrounding autistic mental health and well-being, it is important that researchers do not conflate these separate experiences thereby drawing attention away from the detrimental impacts of external systems.

Modifying interventions and supports

Another way to support autistic people in improving their well-being is to improve upon current interventions and accommodations. It is critical to extend the extant research literature on stigma and mental health outcomes to identify ways to ameliorate negative experiences for autistic people. Strength-based interventions may provide an opportunity for clinicians to de-stigmatize identity-related deficits and focus on individual strengths (163). This can serve as a way for autistic people to collaborate on their therapy initiatives in a person-centered manner. Moreover, while strengths-based approaches have increased over the past several years, autistic and non-autistic researchers on an expert panel (163) identified that some current strengths-based approaches still stigmatize autistic people and have goals that are based on non-autistic social norms. Therefore, investigating how to destigmatize and improve the goals and structures of established interventions are important to the well-being of autistic people.

Conclusion

The present integrative theoretical review explores how social identity theory and the minority stress model complement the frameworks of the social model of disability and neurodiversity movement. Additionally, integrating these theories allows researchers to better understand the high rates of mental health concerns in autistic people and that camouflaging can contribute to these issues. Constructing an identity-based theory of stress and mental health concerns for autistic people helps understand and address other diagnostic and clinical disparities for autistic people with multiple minoritized identities. This framework can be further applied to educational, clinical, and diagnostic settings and have broader implications for how non-autistic people think about autistic people.

Author contributions

RR conceived the idea and drafted the first version of the paper. LB supervised the manuscript and contributed to the final version. All authors contributed to the article and approved the submitted version.

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Conflict of interest

The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

Publisher's note

References

1. American Psychiatric Association. *Diagnostic and statistical manual of mental disorders 5th Ed Text Rev*. Washington, DC: American Psychiatric Association (2022).

2. Masi A, DeMayo MM, Glozier N, Guastella AJ. An overview of autism Spectrum disorder, heterogeneity and treatment options. *Neurosci Bull*. (2017) 33:183–93. doi: 10.1007/s12264-017-0100-y

3. Kras JF. The "ransom notes" affair: when the neurodiversity movement came of age. *Disabil Stud Q*. (2010) 30. doi: 10.18061/dsq.v30i1.1065

4. Cooper R, Cooper K, Russell AJ, Smith LGE. "I'm proud to be a little bit different": the effects of autistic Individuals' perceptions of autism and autism social identity on their collective self-esteem. *J Autism Dev Disord*. (2021) 51:704–14. doi: 10.1007/s10803-020-04575-4

5. Lai MC, Kassee C, Besney R, Bonato S, Hull L, Mandy W, et al. Prevalence of co-occurring mental health diagnoses in the autism population: a systematic review and meta-analysis. *Lancet Psychiatry*. (2019) 6:819–29. doi: 10.1016/S2215-0366(19)30289-5

6. Unruh KE, Bodfish JW, Gotham KO. Adults with autism and adults with depression show similar attentional biases to social-affective images. *J Autism Dev Disord*. (2020) 50:2336–47. doi: 10.1007/s10803-018-3627-5

7. Whittle EL, Fisher KR, Reppermund S, Trollor J. Access to mental health services: the experiences of people with intellectual disabilities. *J Appl Res Intellect Disabil*. (2019) 32:368–79. doi: 10.1111/jar.12533

8. Meyer IH, Schwartz S, Frost DM. Social patterning of stress and coping: does disadvantaged social statuses confer more stress and fewer coping resources? *Soc Sci Med*. (2008) 67:368–79. doi: 10.1016/j.socscimed.2008.03.012

9. Kattari SK. Ableist microaggressions and the mental health of disabled adults. *Community Ment Health J*. (2020) 56:1170–9. doi: 10.1007/s10597-020-00615-6

10. Perry E, Mandy W, Hull L, Cage E. Understanding camouflaging as a response to autism-related stigma: a social identity theory approach. *J Autism Dev Disord*. (2022) 52:800–10. doi: 10.1007/s10803-021-04987-w

11. Hull L, Petrides KV, Allison C, Smith P, Baron-Cohen S, Lai M-C, et al. "Putting on my best Normal": social camouflaging in adults with autism Spectrum conditions. *J Autism Dev Disord*. (2017) 47:2519–34. doi: 10.1007/s10803-017-3166-5

12. Kapp SK, Steward R, Crane L, Elliott D, Elphick C, Pellicano E, et al. "People should be allowed to do what they like": autistic adults' views and experiences of stimming. *Autism*. (2019) 23:1782–92. doi: 10.1177/1362361319829628

13. Tajfel H, Turner J. An integrative theory of intergroup conflict In: WG Austin and S Worchel, editors. *The social psychology of intergroup relations*. Monterey, CA: Brooks/Cole (1979). 33–47.

14. Meyer IH. Prejudice, social stress, and mental health in lesbian, gay, and bisexual populations: conceptual issues and research evidence. *Psychol Bull*. (2003) 129:674–97. doi: 10.1037/0033-2909.129.5.674

15. Roche L, Adams D, Clark M. Research priorities of the autism community: a systematic review of key stakeholder perspectives. *Autism*. (2021) 25:336–48. doi: 10.1177/1362361320967790

16. Pukki H, Bettin J, Outlaw AG, Hennessy J, Brook K, Dekker M, et al. Autistic perspectives on the future of clinical autism research. *Autism Adulthood*. (2022) 4:93–101. doi: 10.1089/aut.2022.0017

17. Botha M, Frost DM. Extending the minority stress model to understand mental health problems experienced by the autistic population. *Soc Ment Health*. (2020) 10:20–34. doi: 10.1177/2156869318804297

18. Gray DE. Perceptions of stigma: the parents of autistic children. *Sociol Health Illn*. (1993) 15:102–20. doi: 10.1111/1467-9566.ep11343802

19. Park S, Lee Y, Kim CE. Korean adults' beliefs about and social distance toward attention-deficit hyperactivity disorder, Tourette syndrome, and autism spectrum disorder. *Psychiatry Res*. (2018) 269:633–9. doi: 10.1016/j.psychres.2018.08.023

20. Jensen CM, Martens CS, Nikolajsen ND, Skytt Gregersen T, Heckmann Marx N, Goldberg Frederiksen M, et al. What do the general population know, believe and feel about individuals with autism and schizophrenia: results from a comparative survey in Denmark. *Autism*. (2016) 20:496–508. doi: 10.1177/1362361315593068

21. Butler RC, Gillis JM. The impact of labels and behaviors on the stigmatization of adults with Asperger's disorder. *J Autism Dev Disord*. (2011) 41:741–9. doi: 10.1007/s10803-010-1093-9

22. Sasson NJ, Morrison KE. First impressions of adults with autism improve with diagnostic disclosure and increased autism knowledge of peers. *Autism*. (2019) 23:50–9. doi: 10.1177/1362361317729526

23. Sasson NJ, Faso DJ, Nugent J, Lovell S, Kennedy DP, Grossman RB. Neurotypical peers are less willing to interact with those with autism based on thin slice judgments. *Sci Rep*. (2017) 7:40700. doi: 10.1038/srep40700

24. Dickter CL, Burk JA. The effects of contact and labeling on attitudes towards individuals with autism. *J Autism Dev Disord*. (2021) 51:3929–36. doi: 10.1007/s10803-020-04840-6

25. Gillespie-Lynch K, Daou N, Obeid R, Reardon S, Khan S, Goldknopf EJ. What contributes to stigma towards autistic university students and students with other diagnoses? *J Autism Dev Disord*. (2021) 51:459–75. doi: 10.1007/s10803-020-04556-7

26. Russell G, Norwich B. Dilemmas, diagnosis and de-stigmatization: parental perspectives on the diagnosis of autism spectrum disorders. *Clin Child Psychol Psychiatry*. (2012) 17:229–45. doi: 10.1177/1359104510365203

27. Bagatell N. From cure to community: transforming notions of autism. *Ethos*. (2010) 38:33–55. doi: 10.1111/j.1548-1352.2009.01080.x

28. Miller D, Rees J, Pearson A. "Masking is life": experiences of masking in autistic and nonautistic adults. *Autism Adulthood*. (2021) 3:330–8. doi: 10.1089/aut.2020.0083

29. Aylott J. Autism in adulthood: the concepts of identity and difference. *Br J Nurs*. (2000) 9:851–8. doi: 10.12968/bjon.2000.9.13.5513

30. Wood C, Freeth M. Students' stereotypes of autism. *J Educ Issues*. (2016) 2:131–40. doi: 10.5296/jei.v2i2.9975

31. Mcleod JD, Meanwell E, Hawbaker A. The experiences of college students on the autism spectrum: a comparison to their neurotypical peers. *J Autism Dev Disord*. (2019) 49:2320–36. doi: 10.1007/s10803-019-03910-8

32. Cazalis F, Reyes E, Leduc S, Gourion D. Evidence that nine autistic women out of ten have been victims of sexual violence. *Front Behav Neurosci*. (2022) 16:852203. doi: 10.3389/fnbeh.2022.852203

33. Weiss JA, Fardella MA. Victimization and perpetration experiences of adults with autism. *Front Psych*. (2018) 9:203. doi: 10.3389/fpsyt.2018.00203

34. Baldwin S, Costley D, Warren A. Employment activities and experiences of adults with high-functioning autism and Asperger's disorder. *J Autism Dev Disord*. (2014) 44:2440–9. doi: 10.1007/s10803-014-2112-z

35. Cage E, Di Monaco J, Newell V. Experiences of autism acceptance and mental health in autistic adults. *J Autism Dev Disord*. (2018) 48:473–84. doi: 10.1007/s10803-017-3342-7

36. Cage E, Troxell-Whitman Z. Understanding the reasons, contexts and costs of camouflaging for autistic adults. *J Autism Dev Disord*. (2019) 49:1899–911. doi: 10.1007/s10803-018-03878-x

37. Turnock A, Langley K, Jones CRG. Understanding stigma in autism: a narrative review and theoretical model. *Autism Adulthood*. (2022) 4:76–91. doi: 10.1089/aut.2021.0005

38. Chown N, Robinson J, Beardon L, Downing J, Hughes L, Leatherland J, et al. Improving research about us, with us: a draft framework for inclusive autism research. *Disabil Soc*. (2017) 32:720–34. doi: 10.1080/09687599.2017.1320273

39. Hendry G, Wilson C, Orr M, Scullion R. "I just stay in the house so I Don't need to explain": a qualitative investigation of persons with invisible disabilities. *Disabilities*. (2022) 2:145–63. doi: 10.3390/disabilities2010012

40. Quinn DM, Earnshaw VA. Concealable stigmatized identities and psychological well-being. *Soc Personal Psychol Compass*. (2013) 7:40–51. doi: 10.1111/spc3.12005

41. Quinn DM, Chaudoir SR. Living with a concealable stigmatized identity: the impact of anticipated stigma, centrality, salience, and cultural stigma on psychological distress and health. *J Pers Soc Psychol*. (2009) 97:634–51. doi: 10.1037/a0015815

42. Quinn DM, Williams MK, Quintana F, Gaskins JL, Overstreet NM, Pishori A, et al. Examining effects of anticipated stigma, centrality, salience, internalization, and outness on psychological distress for people with concealable stigmatized identities. *PLoS One*. (2014) 9:e96977. doi: 10.1371/journal.pone.0096977

43. Clair JA, Beatty JE, MacLean TL. Out of sight but not out of mind: managing invisible social identities in the workplace. *Acad Manag Rev*. (2005) 30:79–85. doi: 10.5465/amr.2005.15281431

44. Han E, Scior K, Avramides K, Crane L. A systematic review on autistic people's experiences of stigma and coping strategies. *Autism Res*. (2022) 15:12–26. doi: 10.1002/aur.2652

45. Cook J, Hull L, Crane L, Mandy W. Camouflaging in autism: a systematic review. *Clin Psychol Rev*. (2021) 89:102080. doi: 10.1016/j.cpr.2021.102080

46. Cage E, Troxell-Whitman Z. Understanding the relationships between autistic identity, disclosure, and camouflaging. *Autism Adulthood*. (2020) 2:334–8. doi: 10.1089/aut.2020.0016

47. Botha M, Dibb B, Frost DM. "Autism is me": an investigation of how autistic individuals make sense of autism and stigma. *Disabil Soc*. (2022) 37:427–53. doi: 10.1080/09687599.2020.1822782

48. Leedham A, Thompson AR, Smith R, Freeth M. "I was exhausted trying to figure it out": the experiences of females receiving an autism diagnosis in middle to late adulthood. *Autism*. (2020) 24:135–46. doi: 10.1177/1362361319853442

49. Schneid I, Raz AE. The mask of autism: social camouflaging and impression management as coping/normalization from the perspectives of autistic adults. *Soc Sci Med*. (2020) 248:112826. doi: 10.1016/j.socscimed.2020.112826

50. Cook J, Crane L, Bourne L, Hull L, Mandy W. Camouflaging in an everyday social context: an interpersonal recall study. *Autism*. (2021) 25:136236132199264. doi: 10.1177/1362361321992641

51. Mogensen L, Mason J. The meaning of a label for teenagers negotiating identity: experiences with autism spectrum disorder. *Sociol Health Illn*. (2015) 37:255–69. doi: 10.1111/1467-9566.12208

52. Cassidy S, Bradley L, Shaw R, Baron-Cohen S. Risk markers for suicidality in autistic adults. *Mol Autism*. (2018) 9:42. doi: 10.1186/s13229-018-0226-4

53. Bernardin CJ, Lewis T, Bell D, Kanne S. Associations between social camouflaging and internalizing symptoms in autistic and non-autistic adolescents. *Autism*. (2021) 25:1580–91. doi: 10.1177/1362361321997284

54. Hull L, Mandy W, Lai M-C, Baron-Cohen S, Allison C, Smith P, et al. Development and validation of the camouflaging autistic traits questionnaire (CAT-Q). *J Autism Dev Disord*. (2019) 49:819–33. doi: 10.1007/s10803-018-3792-6

55. Bradley L, Shaw R, Baron-Cohen S, Cassidy S. Autistic adults' experiences of camouflaging and its perceived impact on mental health. *Autism Adulthood*. (2021) 3:320–9. doi: 10.1089/aut.2020.0071

56. Johnson TD, Joshi A. Dark clouds or silver linings? A stigma threat perspective on the implications of an autism diagnosis for workplace well-being. *J Appl Psychol*. (2016) 101:430–49. doi: 10.1037/apl0000058

57. Bunbury S. Unconscious bias and the medical model: how the social model may hold the key to transformative thinking about disability discrimination. *Int J Discrim Law*. (2019) 19:26–47. doi: 10.1177/1358229118820742

58. Ospina MB, Krebs Seida J, Clark B, Karkhaneh M, Hartling L, Tjosvold L, et al. Behavioural and developmental interventions for autism spectrum disorder: a clinical systematic review. *PLoS One*. (2008) 3:e3755. doi: 10.1371/journal.pone.0003755

59. Pellicano E, Dinsmore A, Charman T. What should autism research focus upon? Community views and priorities from the United Kingdom. *Autism*. (2014) 18:756–70. doi: 10.1177/1362361314529627

60. Olkin R. Could you hold the door for me? Including disability in diversity. *Cultur Divers Ethnic Minor Psychol*. (2002) 8:130–7. doi: 10.1037/1099-9809.8.2.130

61. Anderson-Chavarria M. The autism predicament: models of autism and their impact on autistic identity. *Disabil Soc*. (2022) 37:1321–41. doi: 10.1080/09687599.2021.1877117

62. Gillespie-Lynch K, Kapp SK, Brooks PJ, Pickens J, Schwartzman B. Whose expertise is it? Evidence for autistic adults as critical autism experts. *Front Psychol*. (2017) 8:438. doi: 10.3389/fpsyg.2017.00438

63. Oliver M. The social model of disability: thirty years on. *Disabil Soc*. (2013) 28:1024–6. doi: 10.1080/09687599.2013.818773

64. Singer J. Why can't you be normal for once in your life? From a "problem with no name" to the emergence of a new category of difference In: M Corker and S French, editors. *Disability discourse*. Philadelphia: Open University Press (1999). 59–67.

65. Dekker M. From exclusion to acceptance: independent living on the autistic spectrum In: SK Kapp, editor. *Autistic community and the neurodiversity movement*: Springer Singapore: Palgrave Macmillan (2020). 41–9.

66. Leadbitter K, Buckle KL, Ellis C, Dekker M. Autistic self-advocacy and the neurodiversity movement: implications for autism early intervention research and practice. *Front Psychol*. (2021) 12:635690. doi: 10.3389/fpsyg.2021.635690

67. Pellicano E, den Houting J. Annual research review: shifting from "normal science" to neurodiversity in autism science. *J Child Psychol Psychiatry*. (2022) 63:381–96. doi: 10.1111/jcpp.13534

68. den Houting J. Neurodiversity: an insider's perspective. *Autism*. (2019) 23:271–3. doi: 10.1177/1362361318820762

69. Bagatell N. Orchestrating voices: autism, identity and the power of discourse. *Disabil Soc*. (2007) 22:413–26. doi: 10.1080/09687590701337967

70. Elliman L. Asperger's syndrome-difference or disorder? *Psychologist*. (2011) 24:114–7. Available at: https://www.bps.org.uk/psychologist/aspergers-syndrome-difference-or-disorder.

71. Kapp SK, Gillespie-Lynch K, Sherman LE, Hutman T. Deficit, difference, or both? Autism and neurodiversity. *Dev Psychol*. (2013) 49:59–71. doi: 10.1037/a0028353

72. Jaarsma P, Welin S. Autism as a natural human variation: reflections on the claims of the neurodiversity movement. *Health Care Anal*. (2012) 20:20–30. doi: 10.1007/s10728-011-0169-9

73. Brown RL. Understanding the influence of stigma and discrimination for the functional limitation severity – psychological distress relationship: a stress and coping perspective. *Soc Sci Res*. (2017) 62:150–60. doi: 10.1016/j.ssresearch.2016.08.002

74. Altman D. Rupture or continuity: the internationalization of gay identities In: JC Hawley, editor. *Postcolonial, queer: theoretical intersections*. Albany, NY: State University of New York Press (2001). 19–41.

75. Dunn DS, Andrews EE. Person-first and identity-first language: developing psychologists' cultural competence using disability language. *Am Psychol*. (2015) 70:255–64. doi: 10.1037/a0038636

76. Bottema-Beutel K, Kapp SK, Lester JN, Sasson NJ, Hand BN. Avoiding ableist language: suggestions for autism researchers. *Autism Adulthood*. (2021) 3:18–29. doi: 10.1089/aut.2020.0014

77. Braveman P, Gottlieb L. The social determinants of health: it's time to consider the causes of the causes. *Public Health Rep*. (2014) 129:19–31. doi: 10.1177/00333549141291s206

78. Jetten J, Haslam SA, Cruwys T, Greenaway KH, Haslam C, Steffens NK. Advancing the social identity approach to health and well-being: progressing the social cure research agenda. *Eur J Soc Psychol*. (2017) 47:789–802. doi: 10.1002/ejsp.2333

79. Maitland CA, Rhodes S, O'Hare A, Stewart ME. Social identities and mental well-being in autistic adults. *Autism*. (2021) 25:1771–83. doi: 10.1177/13623613211004328

80. Tajfel H. Experiments in intergroup discrimination. *Sci Am*. (1970) 223:96–103. doi: 10.1038/scientificamerican1170-96

81. Tajfel H. The achievement of inter-group differentiation. In: *Differentiation between social groups: studies in the social psychology of intergroup relations*. New York: Academic Press (1978). 77–100.

82. Dovidio JF, Gaertner SL, Validzic A. Intergroup bias: status, differentiation, and a common in-group identity. *J Pers Soc Psychol*. (1998) 75:109–20. doi: 10.1037//0022-3514.75.1.109

83. Smith ER. Affective and cognitive implications of a group becoming a part of the self: new models of prejudice and of the self-concept In: D Abrams and MA Hogg, editors. *Social identity and social cognition*. Malden, MA: Blackwell Publishing (1999). 183–96.

84. Sidanius J, Pratto F, Mitchell M. In-group identification, social dominance orientation, and differential intergroup social allocation. *J Soc Psychol*. (1994) 134:151–67. doi: 10.1080/00224545.1994.9711378

85. Reynolds KJ, Turner JC, Haslam SA. When are we better than them and they worse than us? A closer look at social discrimination in positive and negative domains. *J Pers Soc Psychol*. (2000) 78:64–80. doi: 10.1037/0022-3514.78.1.64

86. Steele CM, Spencer SJ, Aronson J. Contending with group image: the psychology of stereotype and social identity threat. *Adv Exp Soc Psychol*. (2002) 34:379–440. doi: 10.1016/S0065-2601(02)80009-0

87. Murphy MC, Steele CM, Gross JJ. Signaling threat: how situational cues affect women in math, science, and engineering settings. *Psychol Sci*. (2007) 18:879–85. doi: 10.1111/j.1467-9280.2007.01995.x

88. Hess TM, Auman C, Colcombe SJ, Rahhal TA. The impact of stereotype threat on age differences in memory performance. *J Gerontol B Psychol Sci Soc Sci*. (2003) 58:P3–P11. doi: 10.1093/geronb/58.1.p3

89. Appel M, Weber S, Kronberger N. The influence of stereotype threat on immigrants: review and meta-analysis. *Front Psychol*. (2015) 6:900. doi: 10.3389/fpsyg.2015.00900

90. Croizet JC, Claire T. Extending the concept of stereotype threat to social class: the intellectual underperformance of students from low socioeconomic backgrounds. *Pers Soc Psychol Bull*. (1998) 24:588–94. doi: 10.1177/0146167298246003

91. Logel C, Peach J, Spencer SJ. Threatening gender and race: different manifestations of stereotype threat In: M Inzlicht and T Schmader, editors. *Stereotype threat: theory, process, and application*. New York: Oxford University Press (2012). 159–72.

92. Holleran SE, Whitehead J, Schmader T, Mehl MR. Talking shop and shooting the breeze: a study of workplace conversation and job disengagement among stem faculty. *Soc Psychol Personal Sci*. (2011) 2:65–71. doi: 10.1177/1948550610379921

93. Martiny SE, Nikitin J. Social identity threat in interpersonal relationships: activating negative stereotypes decreases social approach motivation. *J Exp Psychol Appl*. (2019) 25:117–28. doi: 10.1037/xap0000198

94. Schwartz S, Meyer IH. Mental health disparities research: the impact of within and between group analyses on tests of social stress hypotheses. *Soc Sci Med*. (2010) 70:1111–8. doi: 10.1016/j.socscimed.2009.11.032

95. Cochran SD, Mays VM. Relation between psychiatric syndromes and behaviorally defined sexual orientation in a sample of the us population. *Am J Epidemiol*. (2000) 151:516–23. doi: 10.1093/oxfordjournals.aje.a010238

96. Frost DM, Lehavot K, Meyer IH. Minority stress and physical health among sexual minority individuals. *J Behav Med*. (2015) 38:1–8. doi: 10.1007/s10865-013-9523-8

97. Gilman SE, Cochran SD, Mays VM, Hughes M, Ostrow D, Kessler RC. Risk of psychiatric disorders among individuals reporting same-sex sexual partners in the National Comorbidity Survey. *Am J Public Health*. (2001) 91:933–9. doi: 10.2105/ajph.91.6.933

98. Herek GM, Gillis JR, Cogan JC. Psychological sequelae of hate-crime victimization among lesbian, gay, and bisexual adults. *J Consult Clin Psychol*. (1999) 67:945–51. doi: 10.1037/0022-006X.67.6.945

99. Williams DR, Lawrence JA, Davis BA. Racism and health: evidence and needed research. *Annu Rev Public Health*. (2019) 40:105–25. doi: 10.1146/annurev-publhealth-040218-043750

100. Valentin-Cortes M, Benavides Q, Bryce R, Rabinowitz E, Rion R, Lopez WD, et al. Application of the minority stress theory: understanding the mental health of undocumented Latinx immigrants. *Am J Community Psychol*. (2020) 66:325–36. doi: 10.1002/ajcp.12455

101. Humphrey N, Lewis S. “Make me normal”: the views and experiences of pupils on the autistic spectrum in mainstream secondary schools. *Autism*. (2008) 12:23–46. doi: 10.1177/1362361307085267

102. Milton D, Sims T. How is a sense of well-being and belonging constructed in the accounts of autistic adults? *Disabil Soc*. (2016) 31:520–34. doi: 10.1080/09687599.2016.1186529

103. Cooper K, Smith LGE, Russell A. Social identity, self-esteem, and mental health in autism. *Eur J Soc Psychol*. (2017) 47:844–54. doi: 10.1002/ejsp.2297

104. Hedley D, Uljarevic M, Bury SM, Dissanayake C. Predictors of mental health and well-being in employed adults with autism Spectrum disorder at 12-month follow-up. *Autism Res*. (2019) 12:482–94. doi: 10.1002/aur.2064

105. Whitehouse AJO, Durkin K, Jaquet E, Ziatas K. Friendship, loneliness and depression in adolescents with Asperger's syndrome. *J Adolesc*. (2009) 32:309–22. doi: 10.1016/j.adolescence.2008.03.004

106. Cacioppo JT, Hughes ME, Waite LJ, Hawkley LC, Thisted RA. Loneliness as a specific risk factor for depressive symptoms: cross-sectional and longitudinal analyses. *Psychol Aging*. (2006) 21:140–51. doi: 10.1037/0882-7974.21.1.140

107. Jaremka LM, Andridge RR, Fagundes CP, Alfano CM, Povoski SP, Lipari AM, et al. Pain, depression, and fatigue: loneliness as a longitudinal risk factor. *Health Psychol*. (2014) 33:948–57. doi: 10.1037/a0034012

108. Luo Y, Hawkley LC, Waite LJ, Cacioppo JT. Loneliness, health, and mortality in old age: a National Longitudinal Study. *Soc Sci Med*. (2012) 74:907–14. doi: 10.1016/j.socscimed.2011.11.028

109. Crompton CJ, Hallett S, Ropar D, Flynn E, Fletcher-Watson S. “I never realised everybody felt as happy as I do when I am around autistic people”: a thematic analysis of autistic adults’ relationships with autistic and neurotypical friends and family. *Autism*. (2020) 24:1438–48. doi: 10.1177/1362361320908976

110. Baldwin S, Costley D. The experiences and needs of female adults with high-functioning autism Spectrum disorder. *Autism*. (2016) 20:483–95. doi: 10.1177/1362361315590805

111. Gillberg IC, Helles A, Billstedt E, Gillberg C. Boys with Asperger syndrome grow up: psychiatric and neurodevelopmental disorders 20 years after initial diagnosis. *J Autism Dev Disord*. (2016) 46:74–82. doi: 10.1007/s10803-015-2544-0

112. Kamio Y, Inada N, Koyama T. A nationwide survey on quality of life and associated factors of adults with high-functioning autism Spectrum disorders. *Autism*. (2013) 17:15–26. doi: 10.1177/1362361312436848

113. Hirvikoski T, Mittendorfer-Rutz E, Boman M, Larsson H, Lichtenstein P, Bölte S. Premature mortality in autism spectrum disorder. *Br J Psychiatry*. (2016) 208:232–8. doi: 10.1192/bjp.bp.114.160192

114. Kerns CM, Newschaffer CJ, Berkowitz SJ. Traumatic childhood events and autism spectrum disorder. *J Autism Dev Disord*. (2015) 45:3475–86. doi: 10.1007/s10803-015-2392-y

115. Mikami K, Inomata S, Hayakawa N, Ohnishi Y, Enseki Y, Ohya A, et al. Frequency and clinical features of pervasive developmental disorder in adolescent suicide attempts. *Gen Hosp Psychiatry*. (2009) 31:163–6. doi: 10.1016/j.genhosppsych.2008.12.003

116. Aube B, Follenfant A, Goudeau S, Derguy C. Public stigma of autism spectrum disorder at school: implicit attitudes matter. *J Autism Dev Disord*. (2021) 51:1584–97. doi: 10.1007/s10803-020-04635-9

117. Nicolaidis C, Raymaker DM, Ashkenazy E, Mcdonald KE, Dern S, Baggs AE, et al. “Respect the way I need to communicate with you”: healthcare experiences of adults on the autism spectrum. *Autism*. (2015) 19:824–31. doi: 10.1177/1362361315576221

118. Vogan V, Lake JK, Tint A, Weiss JA, Lunsky Y. Tracking health care service use and the experiences of adults with autism spectrum disorder without intellectual disability: a longitudinal study of service rates, barriers and satisfaction. *Disabil Health J*. (2017) 10:264–70. doi: 10.1016/j.dhjo.2016.11.002

119. Denise EJ. Multiple disadvantaged statuses and health: the role of multiple forms of discrimination. *J Health Soc Behav*. (2014) 55:3–19. doi: 10.1177/0022146514521215

120. Dwyer P, Acevedo SM, Brown HM, Grapel J, Jones SC, Nachman BR, et al. An expert roundtable discussion on experiences of autistic autism researchers. *Autism Adulthood*. (2021) 3:209–20. doi: 10.1089/aut.2021.29019.rtb

121. Jones SC. Let's talk about autistic autism researchers. *Autism Adulthood*. (2021) 3:206–8. doi: 10.1089/aut.2021.29012.scj

122. Kim SY, Song DY, Bottema-Beutel K, Gillespie-Lynch K, Cage E. A systematic review and meta-analysis of associations between primarily non-autistic people's characteristics and attitudes toward autistic people. *Autism Res*. (2023) 16:441–57. doi: 10.1002/aur.2867

123. Tajfel H, Turner JC. The social identity theory of intergroup behavior In: JT Jost and J Sidanius, editors. *Political Psychology*. New York: Psychology Press (2004). 276–93.

124. Milton DEM. On the ontological status of autism: the "double empathy problem". *Disabil Soc*. (2012) 27:883–7. doi: 10.1080/09687599.2012.710008

125. Chen YL, Senande LL, Thorsen M, Patten K. Peer preferences and characteristics of same-group and cross-group social interactions among autistic and non-autistic adolescents. *Autism*. (2021) 25:1885–900. doi: 10.1177/13623613211005918

126. Crompton CJ, Ropar D, Evans-Williams CV, Flynn EG, Fletcher-Watson S. Autistic peer-to-peer information transfer is highly effective. *Autism*. (2020) 24:1704–12. doi: 10.1177/1362361320919286

127. Heasman B, Gillespie A. Perspective-taking is two-sided: misunderstandings between people with Asperger's syndrome and their family members. *Autism*. (2018) 22:740–50. doi: 10.1177/1362361317708287

128. Sheppard E, Pillai D, Wong GT-L, Ropar D, Mitchell P. How easy is it to read the minds of people with autism spectrum disorder? *J Autism Dev Disord*. (2016) 46:1247–54. doi: 10.1007/s10803-015-2662-8

129. Mongelli F, Georgakopoulos P, Pato MT. Challenges and opportunities to meet the mental health needs of underserved and disenfranchised populations in the United States. *Focus (Am Psychiatr Publ)*. (2020) 18:16–24. doi: 10.1176/appi.focus.20190028

130. Ames JL, Morgan EH, Onaiwu MG, Qian YE, Massolo ML, Croen LA. Racial/ethnic differences in psychiatric and medical diagnoses among autistic adults. *Autism Adulthood*. (2022) 4:290–305. doi: 10.1089/aut.2021.0083

131. Bishop-Fitzpatrick L, Kind AJH. A scoping review of health disparities in autism spectrum disorder. *J Autism Dev Disord*. (2017) 47:3380–91. doi: 10.1007/s10803-017-3251-9

132. Hall JP, Batza K, Streed CG, Boyd BA, Kurth NK. Health disparities among sexual and gender minorities with autism spectrum disorder. *J Autism Dev Disord*. (2020) 50:3071–7. doi: 10.1007/s10803-020-04399-2

133. Malone KM, Pearson JN, Palazzo KN, Manns LD, Rivera AQ, Mason Martin DL. The scholarly neglect of black autistic adults in autism research. *Autism Adulthood*. (2022) 4:271–80. doi: 10.1089/aut.2021.0086

134. Botha M, Cage E. "Autism research is in crisis": a mixed method study of researcher's constructions of autistic people and autism research. *Front Psychol*. (2022) 13:1050897. doi: 10.3389/fpsyg.2022.1050897

135. Scheerer NE, Boucher TQ, Sasson NJ, Iarocci G. Effects of an educational presentation about autism on high school students' perceptions of autistic adults. *Autism Adulthood*. (2022) 4:203–13. doi: 10.1089/aut.2021.0046

136. Gillespie-Lynch K, Brooks PJ, Someki F, Obeid R, Shane-Simpson C, Kapp SK, et al. Changing college students' conceptions of autism: an online training to increase knowledge and decrease stigma. *J Autism Dev Disord*. (2015) 45:2553–66. doi: 10.1007/s10803-015-2422-9

137. Obeid R, Daou N, Denigris D, Shane-Simpson C, Brooks PJ, Gillespie-Lynch K. A cross-cultural comparison of knowledge and stigma associated with autism spectrum disorder among college students in Lebanon and the United States. *J Autism Dev Disord*. (2015) 45:3520–36. doi: 10.1007/s10803-015-2499-1

138. Ranson NJ, Byrne MK. Promoting peer acceptance of females with higher-functioning autism in a mainstream education setting: a replication and extension of the effects of an autism anti-stigma program. *J Autism Dev Disord*. (2014) 44:2778–96. doi: 10.1007/s10803-014-2139-1

139. Staniland JJ, Byrne MK. The effects of a multi-component higher-functioning autism anti-stigma program on adolescent boys. *J Autism Dev Disord*. (2013) 43:2816–29. doi: 10.1007/s10803-013-1829-4

140. Bottema-Beutel K, Park H, Kim SY. Commentary on social skills training curricula for individuals with ASD: social interaction, authenticity, and stigma. *J Autism Dev Disord*. (2018) 48:953–64. doi: 10.1007/s10803-017-3400-1

141. Lord C, Rutter M, DiLavore P, Risi S, Gotham K, Bishop S. *The autism diagnostic observation schedule, 2nd Ed (ADOS-2)*. Torrance, CA: Western Psychological Services (2012).

142. Lai MC, Baron-Cohen S. Identifying the lost generation of adults with autism spectrum conditions. *Lancet Psychiatry*. (2015) 2:1013–27. doi: 10.1016/S2215-0366(15)00277-1

143. Mandy W, Clarke K, Mckenner M, Strydom A, Crabtree J, Lai M-C, et al. Assessing autism in adults: an evaluation of the developmental, dimensional and diagnostic interview—adult version (3di-adult). *J Autism Dev Disord*. (2018) 48:549–60. doi: 10.1007/s10803-017-3321-z

144. Hus Y, Segal O. Challenges surrounding the diagnosis of autism in children. *Neuropsychiatr Dis Treat*. (2021) 17:3509–29. doi: 10.2147/ndt.s282569

145. Kalb LG, Singh V, Hong JS, Holingue C, Ludwig NN, Pfeiffer D, et al. Analysis of race and sex bias in the autism diagnostic observation schedule (ADOS-2). *JAMA Netw Open*. (2022) 5:e229498. doi: 10.1001/jamanetworkopen.2022.9498

146. Mandell DS, Wiggins LD, Carpenter LA, Daniels J, Diguiseppi C, Durkin MS, et al. Racial/ethnic disparities in the identification of children with autism spectrum disorders. *Am J Public Health*. (2009) 99:493–8. doi: 10.2105/ajph.2007.131243

147. Baron-Cohen S, Wheelwright S, Skinner R, Martin J, Clubley E. The autism-spectrum quotient (AQ): evidence from Asperger syndrome/high-functioning autism, males and females, scientists and mathematicians. *J Autism Dev Disord*. (2001) 31:5–17. doi: 10.1023/a:1005653411471

148. Varni JW, Limbers CA, Burwinkle TM. How young can children reliably and validly self-report their health-related quality of life?: an analysis of 8,591 children across age subgroups with the Pedsql™ 4.0 generic core scales. *Health Qual Life Outcomes*. (2007) 5:1. doi: 10.1186/1477-7525-5-1

149. Conijn JM, Smits N, Hartman EE. Determining at what age children provide sound self-reports: an illustration of the validity-index approach. *Assessment*. (2020) 27:1604–18. doi: 10.1177/1073191119832655

150. Brede J, Cage E, Trott J, Palmer L, Smith A, Serpell L, et al. "we have to try to find a way, a clinical bridge"- autistic Adults' experience of accessing and receiving support for mental health difficulties: a systematic review and thematic meta-synthesis. *Clin Psychol Rev*. (2022) 93:102131. doi: 10.1016/j.cpr.2022.102131

151. Chapman R, Botha M. Neurodivergence-informed therapy. *Dev Med Child Neurol*. (2023) 65:310–7. doi: 10.1111/dmcn.15384

152. Sweeney A, Clement S, Filson B, Kennedy A. Trauma-informed mental healthcare in the UK: what is it and how can we further its development? *Ment Health Rev J*. (2016) 21:174–92. doi: 10.1108/mhrj-01-2015-0006

153. Keith JM, Jamieson JP, Bennetto L. The importance of adolescent self-report in autism spectrum disorder: integration of questionnaire and autonomic measures. *J Abnorm Child Psychol*. (2019) 47:741–54. doi: 10.1007/s10802-018-0455-1

154. Rodgaard EM, Jensen K, Miskowiak KW, Mottron L. Representativeness of autistic samples in studies recruiting through social media. *Autism Res*. (2022) 15:1447–56. doi: 10.1002/aur.2777

155. Cooper K, Smith LGE, Russell AJ. Gender identity in autism: sex differences in social affiliation with gender groups. *J Autism Dev Disord*. (2018) 48:3995–4006. doi: 10.1007/s10803-018-3590-1

156. Warrier V, Greenberg DM, Weir E, Buckingham C, Smith P, Lai M-C, et al. Elevated rates of autism, other neurodevelopmental and psychiatric diagnoses, and autistic traits in transgender and gender-diverse individuals. *Nat Commun*. (2020) 11:3959. doi: 10.1038/s41467-020-17794-1

157. Cai RY, Richdale AL, Dissanayake C, Trollor J, Uljarević M. Emotion regulation in autism: reappraisal and suppression interactions. *Autism*. (2019) 23:737–49. doi: 10.1177/1362361318774558

158. Van Der Linden K, Simons C, Viechtbauer W, Ottenheijm E, Van Amelsvoort T, Marcelis M. A momentary assessment study on emotional and biological stress in adult males and females with autism spectrum disorder. *Sci Rep*. (2021) 11:14160. doi: 10.1038/s41598-021-93159-y

159. Saxbe DE, Beckes L, Stoycos SA, Coan JA. Social allostasis and social allostatic load: a new model for research in social dynamics, stress, and health. *Perspect Psychol Sci*. (2020) 15:469–82. doi: 10.1177/1745691619876528

160. Pryor JB, Reeder GD. Hiv-related stigma In: J Hall, B Hall and C Cockerell, editors. *Hiv/Aids in the post-HAART era: manifestations, treatment, epidemiology*. Shelton, CT: People's Medical Publishing House (2011). 790–803.

161. Bos AER, Pryor JB, Reeder GD, Stutterheim SE. Stigma: advances in theory and research. *Basic Appl Soc Psychol*. (2013) 35:1–9. doi: 10.1080/01973533.2012.746147

162. Roozen S, Stutterheim SE, Bos AER, Kok G, Curfs LMG. Understanding the social stigma of fetal alcohol spectrum disorders: from theory to interventions. *Found Sci*. (2022) 27:753–71. doi: 10.1007/s10699-020-09676-y

163. Urbanowicz A, Nicolaidis C, Houting JD, Shore SM, Gaudion K, Girdler S, et al. An expert discussion on strengths-based approaches in autism. *Autism Adulthood*. (2019) 1:82–9. doi: 10.1089/aut.2019.29002.aju

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Toward understanding and enhancing self-determination: a qualitative exploration with autistic adults without co-occurring intellectual disability

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Introduction: Self-determination is a fundamental human right positively related to quality of life. However, Autistic people are reported to be less self-determined than non-autistic people. We aimed to (1) understand what self-determination means to Autistic people from their perspective, (2) explore their perceptions of current barriers to being self-determined, and (3) learn from Autistic people about how they would like to be supported to be self-determined.

Methods: Semi-structured interviews were done with 19 Autistic adults without co-occurring intellectual disability. Data were analyzed by three Autistic and two non-autistic researchers through an iterative process of data familiarization, coding, and theme development, informed by reflexive thematic analysis. Autistic Community Partners (ACP) were also engaged throughout the study, and provided substantive feedback on all methods and results.

Results: Self-determination held the same meaning for Autistic people as non-autistic people. More specifically, participants discussed having the opportunity and support to make choices and decisions in life without unnecessary control from others. Experiences of self-determination were centered around: (1) lack of opportunity, influenced by ableist expectations and discrimination, and (2) executive processing differences that interfered with choice and decision-making. Desired areas of support related to providing opportunities to (1) make choices and exert autonomy, (2) be supported to unmask and be valued as one's authentic Autistic self, and (3) offering pragmatic support for executive processing differences.

Conclusion: Autistic adults desire to be self-determined and can flourish with support, as they determine to be appropriate, which might look different from support commonly offered or sought by non-autistic people. Although individualized support was discussed, the ideal desired support was for an inclusive society that values and respects their neurodivergence, rather than imposing ableist expectations. An inclusive society is only achievable through reduced (or eliminated) stigma and prejudice against Autistic people.

KEYWORDS

autism, self-determination, autonomy, stigma, opportunity, support, adulthood, qualitative

1. Introduction

Self-determination refers to one's ability to act as the causal agent in one's life, to have the capacity to choose and to have choices regarding one's quality of life free from undue external influence or interference (1–3). Self-determination is a fundamental human right, regardless of disability, as confirmed in the 2006 United Nations *Convention on the Rights of Persons with Disabilities* (4, 5) p. and ratified by Canada in 2011. Developing self-determination skills over one's lifespan enhances quality of life and supports positive employment experiences, independent living and community inclusion, including for Autistic individuals (2, 5–7). However, Autistic individuals experience less self-determination than their non-autistic peers, including peers with other developmental disabilities (5, 8–10). There is often an assumption that Autistic people without co-occurring intellectual disability have more positive outcomes than those with co-occurring intellectual disabilities across a variety of factors associated with self-determination in adulthood (e.g., functional independence, engagement in daytime activities, participation in paid employment, quality of life) (11). However, research evaluating the relationship between self-determination and intellectual disability has mixed results (11, 12).

Why might Autistic individuals, including those without co-occurring intellectual disability, be less self-determined than others? Having the capacity to be self-determined, usually attributed to personal abilities, is necessary. Furthermore, opportunities to be self-determined, usually attributed to external factors, is vital (3). However, autism stigma and prejudice influence perceptions of capacity and opportunities to be self-determined.

The capacity to be self-determined, such as one's knowledge and abilities to set goals, make choices, and monitor progress, as well as the ability to identify necessary supports and accommodations, or engage in supported decision-making, is essential to be self-determined (3, 13). Challenges with social-communication (based on standardized measures), depression, and differences in executive processing have been shown to predict lower self-determination in Autistic youth, including those without co-occurring intellectual disability (11, 13). Autistic people often rate their capacity higher than others (e.g., parents, teachers) (13). Discrepancies in reporting between stakeholders is common, and it remains unknown whether Autistic people overestimate their skills or others underestimate their skills (11). However, regardless of capacity, one cannot be self-determined without opportunities to do so. Having opportunities to be self-determined are also essential, yet Autistic people, including those without co-occurring intellectual disability, often lack opportunities to be self-determined across environments such as home and school (3, 11, 13, 14). Autistic people may need more support and practice to develop the skills necessary to be self-determined than non-autistic people, and evidence-based interventions to promote skills necessary for self-determination, such as those that teach self-advocacy, choice-making, goal setting and problem-solving, exist (3, 15). However, these interventions are uncommonly implemented (2, 10). Furthermore, in addition to capacity, or support for capacity, and opportunities to be self-determined in one's daily life, societal barriers exist that may preclude self-determination more broadly.

Stigma might significantly contribute to decreased opportunities for self-determination. Autistic people commonly experience stigma and prejudice, including discriminatory attitudes and actions (16). The pervasive nature of stigma has a profound impact on the lives of Autistic individuals, extending far beyond prejudice or discriminatory attitudes. This deeply ingrained societal bias can perpetuate misconceptions, stereotypes, and misunderstandings about autism, thereby perpetuating the cycle of stigma. For instance, in high school academic settings, Autistic people may encounter lowered expectations, inadequate support, and even discrimination through overt exclusion from mainstream classrooms due to misconceptions about their abilities (17). This lack of equal educational opportunities can severely hamper their self-determination by limiting their access to knowledge, skills, and resources necessary for personal growth and success (17). Stigma can also increase camouflaging, limit social connections, and negatively influence mental and physical health (16). Autistic people may internalize stigma, decreasing their feelings of self-worth (18).

1.1. Objectives of the study

To our knowledge, no study to date has explored nuances of the complex array of internal (e.g., personal characteristics) and external (e.g., opportunity, stigma) factors that influence self-determination, as well as desired strategies to support self-determination, from the perspective of Autistic adults without co-occurring intellectual disability. This study aimed to (a) understand what self-determination means to Autistic people from their perspective; (b) explore their perceptions of current barriers to being self-determined, and (c) learn from Autistic people about how they would like to be supported to be self-determined.

2. Methods

2.1. Theoretical and methodological approaches

This study is situated within an interpretive constructivist approach, which aims to understand and interpret participants' subjective experiences within an inherently complex social world (19). Within this paradigm, this work is strongly influenced by self-determination theory (SDT) (1) and the Social Model of Disability (SMoD) (20).

SDT acknowledges the influence of external regulatory mechanisms to enhance or hinder motivation, autonomy and choice. Ryan and Deci (1) suggest that three basic psychological needs must be satisfied for someone to be self-determined. The first need, autonomy, refers to having some choice or control over what happens or what one does. The second need, competence, refers to feeling capable and having a sense of accomplishment or mastery. Finally, the third need, relatedness, refers to belonging and connection to others, including support from others.

The SMoD offers a helpful critique against a deficit-oriented view of disability that was traditionally focused narrowly on physiological, anatomical or neurocognitive deficits. SMoD scholars and advocates, largely individuals who experience disability, seek liberation from identified stigma and oppression related to conceptualizations of disability and ensuing social exclusion and limiting social structures (20). They argue that disability is not located with the individual themselves but rather is "constructed" by social factors and impediments that restrict meaningful social engagement and participation and equitable access to opportunities.

This study was embedded within a larger study that utilized participatory research methods to address our research objectives specific to Autistic adults who do and do not experience co-occurring intellectual disability (21, 22). Engaging people from the Autistic community as part of the research team helped ensure that the research aligns with their needs and priorities, reduces translational barriers, and aims to disrupt ableism that has, historically, been prominent in autism research (23, 24). Autistic ($n=3$) and non-autistic ($n=2$) researchers and additional team members from the Autistic community ($n=4$; hereafter called 'Autistic Community Partners') were partners throughout the research process, from conceptualization to dissemination. Autistic Community Partners (ACP) met monthly with core research team members. They collaborated in designing the interview guide and recruitment strategies and throughout data analysis, interpretation, and dissemination. The ACP were fairly compensated for their time, as recommended by Nicolaidis and colleagues (22).

2.2. Positionality of the research team

Our team comprised three Autistic and two non-autistic researchers. STH is a non-autistic ally with over 20 years of clinical and research experience related to autism. JR is an Autistic Ph.D. candidate studying the self-determination of Autistic adults with intellectual disabilities. EC is a graduate student in counseling psychology and identifies as an Autistic lesbian woman. HB is an Autistic professor who researches thriving and belonging for Autistic people. AX is a non-autistic educator with more than 15 years of experience working with diverse groups of child and adult learners. Our team also included a robust team of Autistic community partners from diverse educational and demographic backgrounds. CD is an Autistic Registered Social Service Worker finishing a second Bachelor's degree in Disability Studies and Psychology. AL is an Autistic university alumnus with a Bachelor's degree in Computer Science. AK is an Autistic person, university student, and supporter for other Autistic people. AB is an Autistic person, a parent of an Autistic child, and an advocate for child and disability rights for people of all abilities. Given the researchers' diverse identities, the team co-analyzed all data and engaged in multiple discussions about potential biases and assumptions that may emerge due to their lived experiences. This process provided a system of peer examination that was crucial in making decisions on how to organize best and present the data, as well as provide relevant recommendations for improvement.

2.3. Inclusion criteria and recruitment

Ethical approval was obtained from the University of Alberta. All participants provided informed consent online and again verbally at the start of the interview. Inclusion criteria were (1) 18 years and older, (2) identifying as Autistic, including those who were diagnosed by a professional(s) and/or those who self-identify, (3) without a co-occurring intellectual disability (self-report), and (4) ability to complete an interview verbally or through text in English. Potential participants were recruited through email listservs and research recruitment webpages of autism support organizations in Alberta and through social media channels (e.g., Facebook pages) intended for the Autistic community (including open pages and closed membership for Autistic people). We aimed for a sample size of approximately 20 participants, which the team agreed would likely allow us to achieve data adequacy (25, 26).

2.4. Data collection

Semi-structured interviews, 30–60 min long, were done using Zoom ($n=17$; camera on: $n=16$; camera off: $n=1$), telephone ($n=1$), or email correspondence ($n=1$). Example questions from the interview guide are provided in Table 1. Questions addressed all three psychological needs outlined in self-determination theory, but focused more autonomy than on competence and relatedness because Ryan and Deci noted that support for autonomy often supports increased satisfaction for competence and relatedness (1). Based on our pilot interviews and feedback from our ACP, varying options for language were provided in the interview guide to increase clarity, including the option to use the broad term 'self-determination' or the terms 'choices' and 'decisions' as deemed appropriate in each interview.

Given the opportunity of an Autistic or non-autistic interviewer, 60% of participants chose an Autistic interviewer, and 40% of participants had no preference (thus were interviewed by a non-autistic interviewer). Interviews were recorded and automatically transcribed through Zoom ($n=17$; checked for accuracy against audio recording and cleaned when necessary), recorded with a digital audio

TABLE 1 Semi-structured interview guide.

Draft interview questions
1. Tell me about why you decided to participate in this study?
2. Do you get to make choices in your day?
3. What kind of choices are important to you?
4. Tell me about times when having a choice is not important to you.
5. What does self-determination mean to you?
6. What kind of support, if any, do you need/like for making choices or decisions/ to be self-determined?
7. Are there people in your life who let you make choices/be self-determined?
8. Are there people in your life who do not let you make choices/be self-determined?
9. Do people take your feelings/ideas/opinions seriously?
10.Do you feel accepted by the people around you?

recorder and transcribed manually ($n = 1$ telephone interview), or used text provided (email). All transcriptions were anonymized by removing names of people and organizations. All participants were from Canada or the United States for the feasibility of timing and provision of gift cards. A pseudonym was chosen by or assigned to each participant.

2.5. Data analyses

Once transcribed, data were analyzed by three Autistic and two non-autistic researchers through an iterative process of data familiarization, coding, and theme development, informed by reflexive thematic analysis, which is appropriate for research that desires to (1) create actionable outcomes, and (2) situate experiences in broader socio-cultural contexts (27).

Initial coding was an iterative process done in multiple stages. All transcripts were reviewed by four core research team members (STH, JR, EC, AX) to address research question #1 (What does self-determination mean to Autistic adults without co-occurring intellectual disability?). To address the second (barriers to self-determination) and third (desired ways to be supported) research questions, three team members (STH, EC, AX) coded all data using a color-coded spreadsheet. Then, two team members (JR, STH) embarked on initial theme development, informed by the basic psychological needs put forth in self-determination theory: autonomy (self-directed freedom), competence (confidence in one's ability), and relatedness (trusting and respectful relationships) (1). All codes from the spreadsheet were physically printed, and two team members used mind mapping to explore and understand relationships between ideas (28). Themes and subthemes underwent multiple iterations by the core research team and ACP. Numerous data excerpts supported the final theme and sub-theme development.

Rigor was demonstrated by established methods of trustworthiness and authenticity, including: reflexive journaling and dialog between team members, prolonged engagement by team members immersed in autism research, interdisciplinary team composition, and engagement of team members with lived experience (29).

3. Results

Participants included 19 Autistic adults (mean age = 34.8 years, range 18–62 years) who represented diversity across many demographic variables. See Table 2 for a summary of participant demographics.

Findings from our qualitative analyses, including conceptualizations of self-determination and developed themes related to barriers to self-determination and desired ways to be supported to be self-determined, are summarized in Figure 1 and described in detail below.

3.1. What does self-determination mean to autistic adults?

Self-determination held the same meaning for Autistic people as non-autistic people. More specifically, participants discussed *having*

TABLE 2 Participant demographics.

Age (years)	
Mean	34.8
Range	18–62
Identified gender (*n*)	
Woman	6
Man	6
Non-binary	1
Transfeminine	1
Autigender	2
No answer	3
Geographic location (*n*)	
Canada	11
USA	8
Who diagnosed? (*n*)	
Self-diagnosis	3
Health care provider	16
Educational attainment (*n*)	
High school	2
Current college student	2
Current university student	3
College diploma	3
Undergraduate degree	4
Graduate degree	5
Employment status (all that apply; *n*)	
Not employed	9
Employed full time (35–40 h/week)	3
Employed part time (20–30 h/week)	4
Full-time student	5
Part-time student	2
Living situation (*n*)	
On own	8
With others	11
Relationship status (*n*)	
Single	11
Partnered	6
Prefer not to say	2
Does your income meet your needs? (*n*)	
Not enough	5
Just enough	9
More than enough	5
Preferred terminology (n)	
Autistic person	13
Person on the autism spectrum	3
Person with autism	1
No preference	2

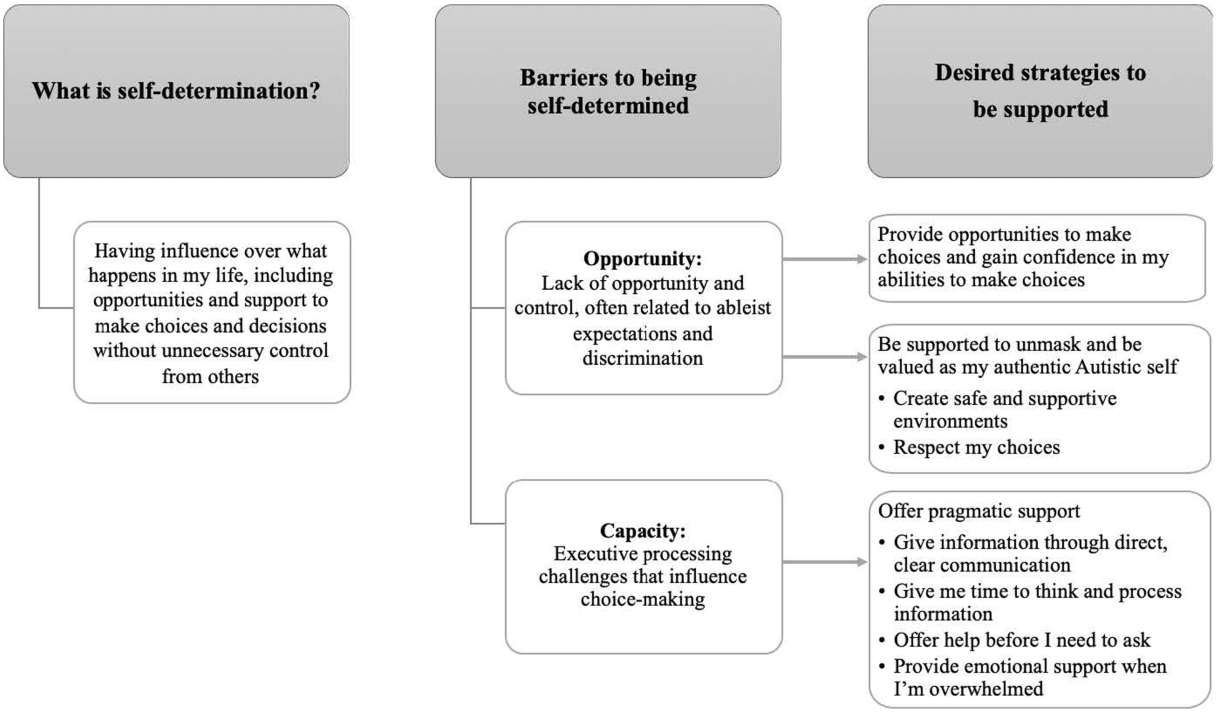

FIGURE 1
Summary of qualitative analysis.

influence over what happens in their lives, including opportunities and support to make choices and decisions without unnecessary control from others. For example, Freda passionately stated, "I'm in charge of me… everything that has to do with me. Choices about my own agency… and I include in that pleasure and wanting to be who I want to be, like presenting my true self." Kyle felt self-determination allowed him to flourish because it "is one path that allows a certain level of freedom or opportunities," and Stephen commented that it was essential to "actively participate in life, not just exist." Paul defined self-determination as:

> …a combination of a person's drive and ability to make choices. One who has a lot of self-determination is very passionate about the things they do and are able to make clear choices regarding their life…the ability to choose to do the things necessary for a happy, healthy life, but still maintaining success in their other affairs. It's a sense of functioning independently. This doesn't mean they need to do everything alone, but they are capable of functioning as an individual in their own way.

Multiple participants discussed how self-determination co-existed with meaningful relationships and partnerships, including family and parenting responsibilities. Although Kyle affirmed the value of freedom in making choices and decisions, he also acknowledged that interdependence is important because "having a group to lift you up or care for you is important for health and wellness." Veronica acknowledged that "of course, I work with my husband for our finances and where we want to live and that kind of stuff, but day-to-day I'm pretty free to do whatever I want … [and] being able to plan what happens to me during the day is important to me." Nancy, a married mother of four younger children, indicated that she adores parenting, but it required significant compromise:

> I get to make choices about my day-to-day stuff but it feels like those choices … [sighs] kind of get compressed when the kids get home… it's chaotic for even neurotypical people, but when you layer in, y'know, your obligation to your kids and also your own neurodivergence, it's a very hard balance.

When asked about what choices in life were most important, participants highlighted a variety of choices where they felt having autonomy was critical, including daily tasks such as sleep schedules and how one spends their free time and/or money, as well as longer-term choices such as "what I want to do with my life" (Stephen). Some participants, like Emma, felt "All of them…what I do with my time, what I spend my money on, where I go, all of that. It kind of determines how your life will go when you make those decisions." Notably, although no prompts were given related to specific areas in which participants wanted to feel a sense of autonomy, eight out of 19 participants commented that control over food was important. For example, Nayeli stated "Stuff around food! I have a lot of taste and texture stuff going on, so being able to choose what I can and cannot eat, that's important." Similarly, Dani commented that "It's definitely nice having control over what I eat…I like having control over my food." Furthermore, seven out of 19 participants commented that medical autonomy was essential. For example, Tia stated, "I want more medical autonomy, including being able to control the sharing of my information."

Overall, most, but not all, participants felt that they had opportunities to be self-determined in some areas of their lives.

However, all participants also expressed barriers to being self-determined related to their experiences as an Autistic person.

3.2. Barriers to being self-determined

Barriers to being self-determined crossed all three psychological needs outlined in Deci and Ryan's (1) self-determination theory, centered around both opportunity for and capacity to be self-determined. More specifically, experiences of self-determination were centred around: (1) lack of opportunity and autonomy, often related to ableist expectations and discrimination (autonomy, relatedness), and (2) executive processing differences that influenced choice-making (competence).

3.2.1. Theme 1: self-determination is thwarted by lack of opportunity and discrimination

While the participants in this study tended to define self-determination in the same way that non-autistic people do, most (*n* = 14) participants discussed experiences, past and present, of limited opportunities to be self-determined. Many of the factors that contributed to these limited opportunities were externally imposed upon our participants, based on ableist expectations for the choices one makes and discrimination related to the needs and abilities of Autistic people. Marcy's comment, which reflected comments by other participants, reinforces these experiences:

> I was expected to fit into a certain box and I wasn't given the choice to have anything different … My needs that I would try to speak up for were very quickly taught that they weren't acceptable needs to have, they were above and beyond …those lack of choices hurt me the most when I don't get to say 'hey wait, no. There's a person in here that is being deprived of a need'. If it was somebody else… nobody would be acting this way. If the lights are too bright and I'm asking for them to be not as bright, that's no different to me as somebody who's hungry and asking for food. But, to other people it's 'oh, you're just being spoiled. You just want it your way. It's not that big of a deal, you should just deal with it'.

Some participants felt that they were thwarted opportunities to be self-determined across all areas of life. For example, Nayeli expressed that "society and its push to make people like me fit in limits and does not let me make choices." Veronica stated, "neuro-typicals like to limit us because they cannot see what we are capable of. We're just trying to live our best lives and neuro-typicals keep telling us to stop." Other participants felt that they lived relatively autonomous lives as adults, but still expressed a lack of opportunity in daily choices, described as "limited options" (Tia), that "available choices seem constrained, limited, or come with predetermined outcomes" (Callie), or "not getting much of a say in how it looks or what it could look like… only related to already established routines" (Marcy). The lack of opportunity to be self-determined was frustrating for participants. For example, Emma expressed frustration at the lack of being given the opportunity to do daily activities that she knew she was very capable of doing, "I cannot choose what to eat … or how to spend my time, I'm, like'Oh, I want to do this, but I cannot.' It's very stressful." Kawhi reflected on negative experiences with self-determination when he was younger that strongly influenced his desire for autonomy in his current life,

> If the choice concerns me, I should have a part of it and I feel frustrated if it does not … it's the idea someone thought they could speak for me, neglecting the fact that I had my own voice and neglecting the fact that I have the ability to advocate and speak for myself. I see this thing where it's simply just disrespectful if someone does that … it's different if it's consensual but it's also something where it almost makes you feel lesser because that person sees it …that they can speak for you, even if they may not actually know you best.

The negative judgments of others related to participants' desires and preferences often led them to doubt their ability to make appropriate choices. In particular, four participants reflected that the lack of opportunities to be self-determined contributed to these doubts. For example, Kanti stated, "I was never really allowed to be an independent person, so I'm not a very secure person in my own judgment. Often there's a lot of imposter syndrome and such, so I'll fret about whether I'm making the right decisions." This sentiment was also echoed by Nayeli who said, "On one hand, making choices allows me to say 'no', but on the other hand, it can be anxiety provoking because I worry about making the wrong decision." The impact of restricted opportunities earlier in life on the confidence for autonomous decision-making can be clearly seen in Marcy's continued reflection, "now I feel like I have to have permission to do things … and I'm afraid if I just go forward …and do whatever I think to do, that I'm going to get in trouble for it, or misunderstand what I was supposed to do …" Their repeated experiences of being denied opportunity, including during their childhood, led to chronic feelings of self-doubt as shown by Marcy's next words, "So, with everything that I choose to do [as an adult], there's always that voice in the back of my head that's [saying], 'What if you are choosing wrong? What if this is going to end up going badly for reasons that you cannot anticipate until it will be too late?'"

It is noteworthy that three of the five participants who did not discuss a lack of opportunities to be self-determined throughout life were recently diagnosed Autistic. These participants felt that they were only given opportunities for autonomy in their lives because they did not have an autism diagnosis growing up. For example, Nancy stated that she thinks, "as soon as that label gets slapped on you, 'Oh, you are autistic', then they automatically start, y'know, just those stereotypes that people expect that, 'Oh all autistics must be the same, this is how you have to be treated.'" Similarly, Callie stated that she was "able to make choices in my day because most people aren't aware of my autism…when people know I am Autistic it creates problems."

Many (*n* = 13) participants also discussed how neuro-normative expectations and their fear of social censure/exclusion, led them to mask or camouflage obvious signs of their autistic traits or characteristics, despite their discomfort with doing so. For example, Alex emphatically stated that he "needs to mask to be respected … so the vast majority of us (Autistic people) always need to be masking," and Freda reported that they "do not feel safe unless they mask." Kawhi stated that his choice to mask or camouflage was a form of being self-determined because "choosing to mask … maintains equality and preserves an opportunity for me to show [colleagues] I can achieve." Tia agreed that masking was a form of self-determination, but also described that masking or camouflaging lead to "feel [ing] miserable all the time" because it meant "doing things that felt wrong and bad" to her. Further complicating the issue, some of the participants described that needing to mask their feelings of distress or discomfort (for example from sensory sensitivities) often hid their subjective experience from others. While this might be protective from social disapproval in the short term, it also meant that friends, family or colleagues might not truly understand their lived experiences, which impeded their ability to gain their support in their daily lives. For example, Tia described that she masked a lot growing up and as a result, her family "did not know that I could be experiencing reality in such a different way than them. Like that just did not occur to them…so I just stopped asking for help."

Overall, 17 of 19 participants discussed how ableist expectations and discrimination limited self-determination for Autistic people through limiting opportunities and/or decreasing one's confidence in their ability to make appropriate choices and decisions, and in limiting their ability to present as their authentic Autistic selves. In addition to these externally imposed barriers, all participants discussed how differences with various aspects of executive processing influence their capacity to be self-determined.

3.2.2. Theme 2: executive processing differences make choice and decision-making difficult

While all participants highlighted the importance and benefits of having the opportunity to make their own choices, all participants also discussed barriers to self-determination related to their perceived competence to make choices and decisions in daily life. Although, as previously discussed, some participants doubted their ability to make appropriate choices due to experiences with ableism and discrimination growing up, all participants did discuss challenges related to their executive processing abilities, which are necessary for goal-directed behavior. In particular, participants discussed challenges with emotional regulation, organization, initiation and planning, shifting attention, and flexible thinking as related to their competence to be self-determined. Of note, 11 participants were co-diagnosed with attention-deficit hyperactivity disorder (ADHD) and seven participants were co-diagnosed with anxiety disorder (five of whom were co-diagnosed with both additional diagnoses), and often attributed struggles to these co-diagnoses more than autism. However, all participants without these additional diagnoses also discussed the impact of executive processing differences on their ability to be self-determined.

Almost all participants ($n = 16$) felt that choice-making was overwhelming. In particular, 11 of these participants discussed that having "too many choices" was overwhelming. For example, related to multiple choices, James said "I have to be very careful with that. I hit 'decision paralysis' if I'm not careful. I tend to go into a loop in my brain over and over and over again, and have to find a way to step in and stop myself." Similarly, Nancy said, "I do not deal well with multiple choices …. I find that I get stuck in this indecision of not being able to make a choice at all, despite the options present." To support decision-making, Nayeli felt that she often made misguided choices because "I just pick something and hope it works because the decision-making choice is overwhelming." In addition to stress caused by the need to make choices, several participants described how stress from other areas of life made choice-making more difficult. For example, Paul, who had to navigate university exams, stated, "… it gets worse based on stress levels as well. So, like, the more stressed I am, the more I am unable to make those basic human decisions."

Three participants commented that making choices was difficult when there are many steps involved in a task or coming to a final decision, and they had to organize their thoughts or plan toward an informed choice. Keasik felt that "choice makes task initiation harder," and described the process of making choices as a 'tangled decision tree'. Using the example of a seemingly routine activity of daily living, she shared,

> I live alone… I have total autonomy. It's actually a little stressful because I have more choices than I want. Some decisions are so overwhelming, like, for example, the decision to clean my apartment. I would really like to clean my apartment, but there are a lot of things to do and where to start. It's so overwhelming that I just never start.

Four participants discussed experiences with inflexible thinking or being so detail-focused that it interfered with decision-making. For example, Kanti reflected that their need to learn everything about the options limited their ability to make seemingly simple choices, "my obsessiveness of autism means, like, I will read for a week which kind of hand mixer is best before making a decision … I cannot just make a snap decision and asking me to gives me anxiety." Reflecting on difficulties he has making decisions at work, Serge lamented, "Not everybody who has difficulties in a 'gray zone' is Autistic, but Autistic people will have challenges and count me in." To support his ability to determine the best course of action, Serge often relied on frameworks, policies and parameters to help guide him, yet, acknowledged that this strategy could lead to further problems due to a lack of flexible thinking: "Once I [use] a framework or policy or a parameter, maybe I stick to it too much, without giving [my attention] to new information, to new possibilities." Serge seemed to be highlighting that his executive processing differences could lead to challenges with decision-making in contexts where there may be ambiguity, uncertainty and/or conflicting factors; yet at the same time, one of his key strategies for navigating such circumstances (relying on frameworks/policies) could reinforce inflexible thinking, which in turn further hampered his ability to make the best decision. Veronica felt that she was able to make decisions, but had difficulties with changing her decisions, reflecting challenges with flexible thinking. She was fervent in her feelings that,

> "once I decide something, then I appreciate it if somebody doesn't try to change it. I'd rather know ahead of time if I need to think about it differently in order to come to my decisions about what I'm going to do. Being upfront … but it seems to me like neurotypical people put priorities opposite. I like to know what's important first and then I can make a decision that works for me. And when I've come to a decision and somebody tries to make me change my mind … it's the change part that's hard. The change is really hard."

Difficulties shifting focus were discussed by three participants. Both Freda and James used the term "hyperfocus" to describe their lack of choice in changing an activity. James unpacked this experience as he "hits the hyperfocus element of ADHD and autism fairly frequently …and [does not] have a choice in what I'm doing at a given time."

Despite our participants' unanimous agreement that they experienced challenges that decreased their opportunities and capacity to be self-determined, they offered many concrete strategies to support their and other Autistic people's ability to be self-determined.

3.3. How do you want to be supported to be self-determined?

Participants discussed that self-determination does not preclude their desire or need for support from others. Rather, obtaining support on one's terms enacts self-determination. They desired support across all three psychological needs outlined in Deci and Ryan's (1) self-determination theory, also centered around both opportunity for and capacity to be self-determined. Their desired strategies to increase opportunity reflected (1) opportunities to make choices (autonomy), and (2) to feel supported to unmask and be valued as their authentic Autistic selves (relatedness). Participants also identified numerous strategies that (3) could provide helpful pragmatic support with executive processing (competence).

3.3.1. Give me more opportunities to make choices

As indicated, a barrier to self-determination was a lack of opportunity, often due to a presumed inability to make appropriate choices. As such, many participants discussed a desire just to be given opportunities to make choices and exert autonomy, including having others adopt a presumed-competence approach, with their "choice actually listened to and validated" (Marcy).

As mentioned previously, many participants felt that decisions around food and medical autonomy were especially important. The desired strategies focused on respecting individuals' choices based on an appreciation for their unique sensory experiences, rather than assuming a lack of capacity to make appropriate decisions. For example, Nayeli's comment reflected the sentiment of multiple participants, when she said, "other people aren't the ones who have to live with my sensory stuff and anxiety, [so] I need to be able to accept and reject things on my own terms."

Many participants expressed a strong desire for others to demonstrate confidence in their ability to make choices, starting in childhood. For example, Dani discussed that as an adult, their parents have begun to "let me make decisions[they] do not always agree with my choices, [but] at this point, I've proven that I'm capable." However, they went on to reflect, related to their desired leisure activities that differed from what their parent perceived they should do, "when I was a younger adult my mom definitely struggled with some of the decisions I made and was not always super supportive…she was not a fan of them, and she made it very clear that she was not a fan of them, and it became sort of a source of strife." Therefore, participants also discussed the importance of ensuring that Autistic people, across the lifespan, are not told that their choices and desires are "wrong",[1] when they might just be different from what other people might have chosen.

3.3.2. Support me to unmask and be valued as my authentic autistic self

Along with the desire for others to validate their choices, participants expressed a strong desire to feel respected for their choices. This feeling inherently reinforced participants' desire to be valued as their authentic selves, including the nuances of their Autistic experience that might make them unique. Many participants expressed a desire for non-autistic people in their social and work networks to "just be comfortable with me being myself" (Stephen). Some participants, like Kanti, discussed how "neurodiverse advocacy is a passion of mine and I've been working toward presenting myself authentically as opposed to the homogenized acceptable version that I had been living most of my life." However, multiple participants felt that they could not "unmask" without support and validation from others. For example, Tia stated, "I have masked for so long that I do not know how to unmask around other people. I need support learning how to even unmask."

All participants wanted broad societal acceptance and inclusion. However, most participants discussed that, rather than waiting for broader societal change that embraces neurodiversity, they strive to or have already surrounded themselves with others who are supportive and on whom they can rely and feel emotionally safe to be their authentic selves. For example, Kanti went on to express that, in pursuit of their passion to live authentically, they "have worked very hard to build a community around myself of kind of like-minded people, so there's a certain kind of mutual understanding, and I find a lot of acceptance in that." Similarly, James appreciated support from "accepting others, like my family who I can rely on."

3.3.3. Pragmatic strategies for supporting executive processing differences

Even though the type of strategies that we asked about was open-ended, 13 of 19 participants articulated strategies that others could enact to accommodate their executive processing differences.

Many participants ($n = 11$) specifically identified a desire for others to scaffold choice and decision-making by providing clear and direct communication about their potential choices. For example, Freda stated that making choices is much less overwhelming with concrete support: "Pros and cons are great, like having more information about what the choices are is very helpful…[and] explanation for what happens after that," and several participants indicated a preference for having lists that clearly outline available choices. Freda also appreciated if others could help them "categorize choices so it's easier for me to understand and not feel overwhelmed," providing an example of categorizing mustard at the grocery store, "if it was all just mustard all mixed together [at the grocery store], that's overwhelming. But, if it's 'these are the Dijon, these are the ones that are spicy, these are the honey mustards', that is less overwhelming." Of note, Freda also articulated the importance of reinforcing the autonomy to make the choice to say "no," when they articulated how they "like being explicitly told that I can make the choice because I will default to what I'm told. I do not assume that I have a choice… literally just being told that I have the option to make a choice, and that I'm safe to."

Three participants specifically discussed that providing more time for them to come to a decision was very important. For example, Kanti expressed that "I appreciate not having to worry about a time…I'm able to make an educated decision when I can think fairly calmly, or as calm as I can get without having to worry about an extremely short time constraint." Marcy also articulated the benefits of being given "extra" time to evaluate options:

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[1] Our participants discussed experiences with daily choices, such as leisure (e.g., not wanting to participate in a sport) and self-care (e.g., food preferences) activities. We acknowledge that exerting parental control to try to keep one's children safe and healthy may be required by parents.

> I think that having more kind of time to process things would be really helpful because a lot of times what my first judgment call might be, is not what I end up like kind of sinking into as time goes on, and I process something. So, like having time to change my mind..and support around knowing the options, knowing that I have time to process the options, knowing that I can change my mind around the options, especially with new information coming in.

Tia's powerful statement reflected the benefits of offering support as part of fostering autonomy, and not as a way to exert external influence or interference, "I'm afraid of asking too much of people, but I *really* want people to offer help so it does not always feel like I'm asking. I guess I'm always afraid of, like, asking too much of other people." Offering this support without needing or expecting Autistic people to ask can help create opportunities for success, which is important to instill confidence in their ability to make appropriate decisions.

Participants frequently expressed a desire for pragmatic support, particularly regarding activities of daily living. Tia, for instance, mentioned that while she manages her own finances, her parents handle her car insurance because she dislikes "doing paperwork and filling out forms." Many participants ($n = 8$) sought support that would provide pragmatic emotional assistance during times of overwhelm. Kawhi articulated the usefulness of having a trusted person who can articulate their needs and communicate on their behalf when they are unable to do so. Similarly, Nayeli acknowledged her tendency to feel overwhelmed by certain decisions and expressed a strong desire for someone to be physically present to discuss the matter, emphasizing the importance of an unbiased approach. She explained that by the time she seeks support for decision-making, she is often in a state of distress, and therefore requires compassion, comfort, and guidance to navigate through those moments,

> definitely wanted somebody to be there in person and talk it over with and know that they don't have an agenda about getting me to choose a certain thing … because when I ask for support about making a decision then by that time I'm, like, having a meltdown pretty much, so, first of all, they need to be able to be compassionate and comforting about that meltdown and then help me through that.

4. Discussion

Self-determination is a basic human right that is associated with many positive outcomes that can improve one's quality of life. Unfortunately, research consistently shows that Autistic people experience less self-determination than non-autistic people, attributed to both decreased opportunity and capacity to be self-determined (3). Although self-determination involves causal agency, perceptions of self-determination are often based on reports from others, such as caregivers and educators, rather than the lived experiences of Autistic people (7, 30). This study aimed to (a) understand what self-determination means to Autistic people from their perspective; (b) explore their perceptions of current barriers to being self-determined, and (c) learn from Autistic people about how they would like to be supported to be self-determined.

Our participants identified that self-determination involves having influence over what happens in their lives, including both opportunities and support to make choices and decisions without unnecessary control from others. Not surprisingly, this conceptualization aligns with how self-determination is conceptualized for non-Autistic people (1–3). The foundational skills to self-determination, such as learning to make choices, express one's preferences, make decisions and set goals are generally fostered during childhood and become more refined in adolescence, especially when people are able to increase volitional and agentic actions (31, 32). Autistic young adults identified autonomous decision-making as a key desire in their transition to adulthood, yet one that was often thwarted because they felt micromanaged and were not granted decision-making authority or had their decisions questioned when made (14). Like the participants in the study by Cheak-Zamora and colleagues (14), our participants discussed challenges with executive processes that made some aspects of self-determination difficult. However, our participants often did not receive support with these challenges even when they asked for support.

The term autonomy, a component of being self-determined, is often misinterpreted as independence. However, making one's desires and needs known, including asking for support, *is* being autonomous (33). Like our participants, Shogren and colleagues (34) indicate the relevance of support to self-determination, as put in their succinct definition that self-determination is, "having opportunities and supports to make or cause things to happen in your life" (p. 289). Targeting support to specific areas of executive processing that interfere with choice and decision-making, while at the same time leveraging strengths in executive processes, enhances self-determination (34). However, it is notable that people who experience many other non-autism developmental diagnoses that are also associated with challenges in executive processing are often still more self-determined than Autistic people (5, 8–10, 35, 36). So, there must be something in addition to experiencing differences in executive processing that limited our participants' opportunities to be self-determined. Autistic people are among the most discriminated and stigmatized groups of people (37–40), which we suspect is the primary reason for decreased self-determination.

Stigma involves disapproval of someone because their social identity is perceived to deviate from social norms and values in a negative way (41). It results from negative attitudes (prejudice) and behaviors (discrimination) from others. Others, such as caregivers and educators, often rate the capacity of Autistic people to be self-determined as lower than Autistic people rate themselves (13). While these ratings might be well-informed or well-intentioned, they might also reflect discrimination against the inherent ability of Autistic people to be self-determined, contributing to the lack of opportunities provided. Given the lack of perceived capacity, parents may demonstrate overprotection of their Autistic children, which has been shown to predict poorer mental health as adults (42). Internalizing prejudice related to autism can lead to self-stigma, which is also associated with poorer mental health, decreased self-esteem and self-efficacy, and behavioral responses such as a lack of initiation to pursue meaningful opportunities (18, 43). Of concern, our participants did discuss examples that might indicate self-stigma, such as concerns over making the "wrong" decisions. However, similar to other research (14), they also recognized their ability to be self-determined when given adequate support with executive processing and opportunities to exert their autonomy. Our participants advocated for a 'presumed competence' approach while also being offered the support they need and desire to assist with choice and decision-making. These findings align with Webster and Garvis, whose participants appreciated a presumed competence approach to work out solutions independently, develop self-determination and feel successful (30). However, our findings also counter those of Webster and Garvis, whose participants felt most successful when they were able to act without support from others (30).

Autistic people use masking and selective disclosure to manage the impact of stigma (18). However, masking is associated with numerous negative outcomes for Autistic people, and while it can be an asset to decrease prejudice and discrimination, it can also reaffirm the stigma of being Autistic because it is used to hide 'flawed' or 'faulty' characteristics (44). Our participants used masking as a strategy to counteract stigma and enhance opportunities to be self-determined. Yet, they also discussed the negative implications of masking on their wellbeing and a desire to live in a society where they could "unmask" and be authentic. Our participants' desire to unmask differs from previous research in which Autistic men felt that learning to act in neurotypical ways (to mask) was a positive experience that enhanced autonomy, especially when they were "late-diagnosed" and had increased opportunities for this practice (30). Interestingly, our participants who felt that they were the most self-determined were also often "late-diagnosed." However, rather than talking positively about opportunities to develop neurotypical behaviors, they felt that they were more self-determined because they did not experience prejudice and discrimination associated with the label.

Consistent with other research (45), some of our participants felt that they were only given respect for their choices and decisions and opportunities to be self-determined because they did not disclose their diagnoses of autism to others. Their efforts, which reinforced ableist discourses that Autistic people should strive to "pass as normal," likely took away their autonomy to make decisions aligned with their Autistic identity. Parents, educators, professionals and others in general society should support Autistic individuals to become more self-determined by exploring positive aspects of their authentic Autistic identity, building on their strengths, respecting their desires and choices, and providing the support and opportunities they need to be successful in the choices and decisions they make (18, 46). Societal level and systemic changes aimed at reinforcing anti-ableist practices and policies are also necessary to broadly counteract autism stigma and enable Autistic people to feel safe to unmask. Empowering Autistic people as key consultants to ensure that these initiatives align with their needs and priorities is necessary and critical to their success (47).

4.1. Limitations

As with any research, our findings will not represent the experiences of all Autistic people. However, we do take comfort that our team engaged six Autistic (and two non-autistic) researchers throughout the research process. We believe that this team composition is fundamental given evidence that the lived experience of being autistic may offer unique insights and perspectives into our data that a non-autistic person might not perceive (48, 49). We also recognize that our participants learned about the study through electronic means of recruitment; therefore, Autistic persons without internet access were likely not represented in our study findings. Additionally, we did not ask about the cultural background of our participants, but we do know that they all lived in North America at the time of data collection. Culture can influence the degree to which people are supported to be self-determined (50). Therefore, our findings may not apply to Autistic people from cultures outside of those represented by our participants.

Our questions focused more on autonomy (choice-making) than the other psychological needs outlined in self-determination theory (competence, relatedness). Although our analyses included rich findings related to all areas, we acknowledge that the questions we asked may have swayed the results we found toward autonomy.

4.2. Directions for future research

Research specific to self-determination experiences for Autistic people, and especially based on the perspective of Autistic people, is relatively limited (7). Furthermore, research that garners the perspective of Autistic people with co-occurring intellectual disability and/or those who do or prefer to communicate in non-speaking ways is almost non-existent (51). Therefore, we strongly advocate for research that continues to garner perspectives on and desired support to be, self-determined from the perspective of Autistic people, and especially people with co-occurring intellectual disability and/or those who communicate in a variety of ways.

Although we garnered perspectives of people who felt varying degrees of self-determination, all of our participants felt thwarted to some extent. Research with Autistic people who feel a strong sense of self-determination is vital to provide a fulsome perspective on those experiences and insight into potential influences on positive experiences. This research could inform potential strategies and supports to enhance experiences for Autistic people more broadly.

Finally, given our perspective that stigma is a (the) major contributor to thwarted opportunities and adequate support for self-determination for Autistic adults without intellectual disability, there is a crucial need for the continued development and evaluation of anti-stigma initiatives related to autism. Furthermore, we advocate for the development and evaluation of these initiatives for Autistic people across the variability of intellectual ability and support needs. Anti-stigma interventions, such as autism-friendly spaces, increased inclusive media representation, and education training tools, do exist (16), but clearly, more work is needed given the ongoing pervasiveness of autism stigma.

5. Conclusion

Self-determination holds the same significance for autistic individuals as for their non-autistic counterparts. It encompasses making choices and decisions free from undue external influences. However, Autistic people live less self-determined lives than others, due to challenges posed by executive processing differences, limited opportunities and discrimination, influenced by stigma and ableist expectations.

Autistic adults desire to be self-determined and can flourish with support, as they determine to be appropriate, which might look different from support commonly offered or sought by non-autistic people. Autistic individuals desire support that respects their choices, validates their authentic selves, and provides pragmatic assistance, particularly in managing executive processing differences. Although individualized supports were discussed, the ideal desired support was for an inclusive society that values and respects their neurodivergence, rather than imposing ableist expectations. An inclusive society can only be achieved by reducing stigma and discrimination against Autistic people. Overall, addressing barriers at all levels, including societal-level approaches, and offering appropriate support can promote self-determination and empower autistic individuals in all aspects of their lives.

Data availability statement

The original contributions presented in the study are included in the article/supplementary material, further inquiries can be directed to the corresponding author.

Ethics statement

The studies involving humans were approved by Research Ethics Board, University of Alberta. The studies were conducted in accordance with the local legislation and institutional requirements. The participants provided their written informed consent to participate in this study.

Author contributions

ST-H contributed to all aspects of the study, including conception, design, data collection, analysis, interpretation and drafting of the manuscript. JR and HB contributed to conception, design, analysis, interpretation, and critical review of the manuscript. EC and AX contributed to data collection, analysis, interpretation, and critical review of the manuscript. CD, AL, AB, and AK contributed to design, analysis, interpretation, and critical review of the manuscript. All authors approved the submitted manuscript and agreed to be accountable for this work.

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Conflict of interest

The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

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References

1. Ryan RM, Deci EL. *Self-determination theory: basic psychological needs in motivation, development, and wellness*. New York: The Guildford Press (2017).

2. Shogren KA, Wehmeyer ML, Palmer SB, Rifenbark GG, Little TD. Relationships between self-determination and postschool outcomes for youth with disabilities. *J Spec Edu*. (2015) 48:256–67. doi: 10.1177/0022466913489733

3. Wehmeyer ML, Shogren KA, Little TD, Lopez SJ. *Development of self-determination through the life-course*. Netherlands: Springer (2017).

4. United Nations. *Convention on the rights of persons with disabilities*. Treaty Series, 2515, 3. (2006). 37 p.

5. Weiss JA, Riosa PB. Thriving in youth with autism spectrum disorder and intellectual disability. *J Autism Dev Disord*. (2015) 45:2474–86. doi: 10.1007/s10803-015-2412-y

6. Denney SC, Daviso AW. Self-determination: a critical component of education. *Am Second Educ*. (2012) 40:43–51.

7. White K, Flanagan TD, Nadig A. Examining the relationship between self-determination and quality of life in young adults with autism spectrum disorder. *J Dev Phys Disabil*. (2018) 30:735–54. doi: 10.1007/s10882-018-9616-y

8. Chou YC, Wehmeyer ML, Palmer SB, Lee J. Comparisons of self-determination among students with autism, intellectual disability, and learning disabilities: a multivariate analysis. *Focus Autism Dev Dis*. (2017) 32:124–32. doi: 10.1177/1088357615625059

9. Hodgetts S, Richards K, Park E. Preparing for the future: multi-stakeholder perspectives on autonomous goal setting for adolescents with autism spectrum disorders. *Disabil Rehabil*. (2018) 40:2372–9. doi: 10.1080/09638288.2017.1334836

10. Qian X, Shogren K, Odejimi OA, Little T. Differences in self-determination across disability categories: findings from national longitudinal transition study 2012. *J Disabil Policy Stu*. (2022) 32:245–56. doi: 10.1177/1044207320964396

11. Tomaszewski B, Kingler LG, Pugliese CE. Self-determination in autistic transition-aged youth without intellectual disability. *J Autism Dev Disord*. (2022) 52:4067–78. doi: 10.1007/s10803-021-05280-6

12. Cheak-Zamora NC, Maurer-Batjer A, Malow BA, Coleman A. Self-determination in young adults with autism spectrum disorder. *Autism*. (2020) 24:605–16. doi: 10.1177/1362361319877329

13. Tomaszewski B, Kraemer B, Steinbrenner JR, Smith DaWalt L, Hall LJ, Hume K, et al. Student, educator, and parent perspectives of self-determination in high school students with autism spectrum disorder. *Autism Res*. (2020) 13:2164–76. doi: 10.1002/aur.2337

14. Cheak-Zamora N, Tait A, Coleman A. Assessing and promoting independence in young adults with autism spectrum disorder. *J Dev Behav Pediatr*. (2022) 443:130–9. doi: 10.1097/DBP.0000000000001021

15. Morán ML, Hagiwara M, Raley SK, Alsaeed AH, Shogren KA, Qian X, et al. Self-determination of students with autism Spectrum disorder: a systematic review. *J Dev Phys Disabil*. (2021) 33:887–908. doi: 10.1007/s10882-020-09779-1

16. Turnock A, Langley K, Jones CRJ. Understanding stigma in autism: a narrative review and theoretical model. *Autism Adulthood*. (2022) 4:76–91. doi: 10.1089/aut.2021.0005

17. Hedges SH, Kirby AV, Sreckovic MA, Kucharczyk S, Hume K, Pace S. "Falling through the cracks": challenges for high school students with autism spectrum disorder. *High Sch J*. (2014) 2014:64–82. doi: 10.1353/hsj.2014.0014

18. Han E, Scior K, Avramides K, Crane L. A systematic review on autistic people's experiences of stigma and coping strategies. *Autism Res*. (2022) 15:12–26. doi: 10.1002/aur.2652

19. Markula P, Silk M. *Qualitative research for physical culture*. Basingstoke, UK: Palgrave Macmillan (2011).

20. Shakespeare T. The social model of disability In: LJ Davis, editor. *The disability studies reader*. *4th* ed. New York: Routledge (2013). 214–21.

21. Fletcher-Watson S, Adams J, Brook K, Charman T, Crane L, Cusack J, et al. Making the future together: shaping autism research through meaningful participation. *Autism*. (2018):943–53. doi: 10.1177/1362361318786721

22. Nicolaidis C, Raymaker D, McDonald K, Dern S, Ashkenazy E, Boisclair C, et al. Collaboration strategies in nontraditional community-based participatory research partnerships: lessons from an academic–community partnership with autistic self-advocates. *Prog Comm Hlth Partn*. (2011) 5:143. doi: 10.1353/cpr.2011.0022

23. Botha M, Cage E. Autism research in crisis: a mixed methods study of researcher's constructions of autistic people and autism research. *Front Psychol*. (2022) 13:1050897. doi: 10.3389/fpsyg.2022.1050897

24. Hacker K. *Community-based participatory research*. Thousand Oaks, CA: SAGE Publications Ltd. (2017). 139 p.

25. Levitt HM, Motulsky SL, Wertz FJ, Morrow SL, Ponterotto JG. Recommendations for designing and reviewing qualitative research in psychology: promoting methodological integrity. *Qual Psychol*. (2017) 4:2–22. doi: 10.1037/qup0000082

26. Vasileiou K, Barnett J, Thorpe S, Young T. Characterising and justifying sample size sufficiency in interview-based studies: systematic analysis of qualitative health research over a 15-year period. *BMC Med Res Methodol*. (2018) 18:148. doi: 10.1186/s12874-018-0594-7

27. Braun V, Clarke V. *Reflexive thematic analysis: a practical guide*. London: SAGE (2021).

28. Davies M. Concept mapping, mind mapping and argument mapping: what are the differences and do they matter? *High Educ*. (2011) 62:279–301. doi: 10.1007/s10734-010-9387-6

29. Charmaz K. *Constructing grounded theory*. London: Sage (2006). 208 p.

30. Webster AA, Garvis S. What does success mean for autistic men? A narrative exploration of self-determination. *Autism Dev Lang Impair*. (2020) 5:1–13. doi: 10.1177/2396941520945522

31. Palmer SB, Wehmeyer ML, Shogren KA. The development of self-determination during childhood In: ML Wehmeyer, KA Shogren, TD Little and SJ Lopez, editors. *Development of self-determination through the life-course*. Dordrecht: Springer (2017). 71–88.

32. Wehmeyer ML, Shogren KA. The development of self-determination during adolescence In: ML Wehmeyer, KA Shogren, TD Little and SJ Lopez, editors. *Development of self-determination through the life-course*. Dordrecht: Springer (2017). 89–98.

33. Wehmeyer ML, Shogren KA. Applications of the self-determination construct to disability In: ML Wehmeyer, KA Shogren, TD Little and SJ Lopez, editors. *Development of self-determination through the life-course*. Dordrecht: Springer (2017). 111–23.

34. Shogren KA, Mosconi MW, Raley SK, Dean EE, Edwards B, Wallisch A, et al. Advancing the personalization of assessment and intervention in autistic adolescents and young adults by targeting self-determination and executive processes. *Autism Adulthood*. (2021) 3:289–99. doi: 10.1089/aut.2021.0010

35. Rogers M, Tannock R. Are classrooms meeting the basic psychological needs of children with ADHD symptoms? A self-determination theory perspective. *J Atten Disord*. (2018) 22:1354–60. doi: 10.1177/1087054713508926

36. Spaniol M, Danielsson H. A meta-analysis of the executive function components inhibition, shifting, and attention in intellectual disabilities. *J Intellect Disabil Res*. (2022) 66:9–31. doi: 10.1111/jir.12878

37. Cooper KE, Smit L, Russell A. Social identity, self-esteem, and mental health in autism. *Eur J Soc Psychol*. (2017) 2017:844–54. doi: 10.1002/ejsp.2297

38. Khudiakova V, Chasteen AL. The experiences of stigmatization and discrimination in autistic people of different genders and sexualities. *J Interpers Relat Intergroup Relat Identity*. (2022) 2022:15. doi: 10.33921/isnu8742

39. Mazumder R, Thompson-Hodgetts S. Stigmatization of children and adolescents with autism Spectrum disorders and their families: a scoping study. *Rev J Autism Dev Disord*. (2019) 6:96–107. doi: 10.1007/s40489-018-00156-5

40. Pearson A, Rose K. A conceptual analysis of autistic masking: understanding the narrative of stigma and the illusion of choice. *Autism Adulthood*. (2021) 3:52–60. doi: 10.1089/aut.2020.0043

41. Goffman E. *Stigma: Notes on the management of spoiled identity*. Eaglewood Cliffs: Pretence Hall (1967). 168 p.

42. Lee JYS, Whittingham K, Mitchell AE. Childhood experiences of being parented, adult attachment, psychological inflexibility, social engagement, and mental health of autistic adults. *Res Dev Disabil*. (2022) 130:104343. doi: 10.1016/j.ridd.2022.104343

43. Corrigan PW, Watson AC. Understanding the impact of stigma on people with mental illness. *World Psychiatry*. (2002) 1:16–20.

44. Schneid I, Raz AE. The mask of autism: social camouflaging and impression management as copying/normalization from the perspectives of autistic adults. *Soc Sci Med*. (2020) 248:112826. doi: 10.1016/j.socscimed.2020.112826

45. Thompson-Hodgetts S, Labonte C, Mazumder R, Phelan S. Helpful or harmful? A scoping review of perceptions and outcomes of autism diagnostic disclosure to others. *Res Autism Spect Dis*. (2020) 77:101598. doi: 10.1016/j.rasd.2020.101598

46. Brown HM, Stahmer AC, Dwyer P, Rivera S. Changing the story: how diagnosticians can support a neurodiversity perspective from the start. *Autism*. (2021) 25:1171–4. doi: 10.1177/13623613211001012

47. Collis RB. Over and over and over: a continued call for autistic voices. *The Canadian J Autism Equity*. (2021) 1:18–22. doi: 10.15173/cjae.v1i1.4984

48. Finch TL, Mackintosh J, Petrou A, McConachie H, Le Couteur A, Garland D, et al. "We couldn't think in the box if we tried. We can't even find the damn box": a qualitative study of the lived experiences of autistic adults and relatives of autistic adults. *PLoS One*. (2022) 17:e0264932. doi: 10.1371/journal.pone.0264932

49. Gillespie-Lynch K, Kapp SK, Brooks PJ, Pickens J, Schwartzman B. Whose expertise is it? Evidence for autistic adults as critical autism experts. *Front Psychol*. (2017) 8:article 438. doi: 10.3389/fpsyg.2017.00438

50. Sheldon KM. The self-determination theory perspective on positive mental health across cultures. *World Psychiatry*. (2012) 11:101–2. doi: 10.1016/j.wpsyc.2012.05.017

51. Nicholas DB, Orjasaeter JD, Zwaigenbaum L. Considering methodological accommodation to the diversity of ASD: a realist synthesis review of data collection methods for examining first-person experiences. *Rev J Autism Dev Disord*. (2019) 6:216–32. doi: 10.1007/s40489-019-00164-z

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Anti-ableism and scientific accuracy in autism research: a false dichotomy

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It was recently argued that autism researchers committed to rejecting ableist frameworks in their research may sacrifice "scientifically accurate" conceptualizations of autism. In this perspective piece, we argue that: (a) anti-ableism vs. scientific accuracy is a false dichotomy, (b) there is no ideology-free science that has claim to scientific accuracy, and (c) autism science has a history of false leads in part because of unexamined ableist ideologies that undergird researcher framings and interpretations of evidence. To illustrate our claims, we discuss several avenues of autism research that were promoted as scientific advances, but were eventually debunked or shown to have much less explanatory value than initially proposed. These research programs have involved claims about autism etiology, the nature of autism and autistic characteristics, and autism intervention. Common to these false leads have been ableist assumptions about autism that inform researcher perspectives. Negative impacts of this work have been mitigated in some areas of autism research, but these perspectives continue to exert influence on the lives of autistic people, including the availability of services, discourses about autism, and sociocultural conceptualizations of autistic people. Examining these false leads may help current researchers better understand how ableism may negatively influence their areas of inquiry. We close with a positive argument that promoting anti-ableism can be done in tandem with increasing scientific accuracy.

KEYWORDS

autism, stigma, ableism, bias, anti-ableism

Introduction

Ableism and anti-ableism in autism research

Autism research has been criticized for being *ableist* (1–3). Ableism refers to a system of discrimination against people perceived to be disabled, based on socially constructed views of "normalcy, productivity, desirability, intelligence, excellence, and fitness" (4). A feature of this system of discrimination for autistic people is stigmatization, which can mean that autistic characteristics such as developing passionate interests on topics that others consider unusual or otherwise not adhering to social norms, are devalued in both interpersonal interactions and broader social contexts (5). Stigma is associated with less knowledge of autism, greater interest in curing and normalizing autistic people, and less familiarity with autistic people [e.g., not having an autistic family member; (6)]. Stigmatization can have significant negative impacts on autistic people's lives, such as lowered life expectancies, under-employment, and lowered quality of life (7).

Autism research focuses almost exclusively on autistic people's perceived deficits relative to non-autistic people, and researchers rarely acknowledge that autistic people have strengths and abilities in addition to impairments, and exist in contexts that enable or disable functioning. Autistic people are often inaccurately described as missing core human capacities (8), and as incapable of social reciprocity or contributing to shared culture (2). Deficit construals persist even when autistic people show strengths in domains that would otherwise be considered positive, such as transparency, rationality, and morality (9–11), and this framing is encouraged in common nosologies (e.g., the Diagnostic and Statistical Manual of Mental Disorders and the International Classification of Disabilities). Illustrating this issue, in a study investigating how almost 200 autism researchers construct autistic people, two-thirds of accounts included at least one dehumanizing, objectifying, or stigmatizing statement (2). Persistent negative evaluations of autistic people in the face of contrary evidence point to deeply ingrained social and cultural values about autism that influence researchers' interpretations of their findings.

There has been growing attention to how ableism in autism research impacts the scope and quality of research available (1–3, 11, 12). Exclusively focusing on deficits does not represent autistic people 12; or autism accurately; instead it reflects the interests of primarily non-autistic researchers. In contrast, autistic accounts of autism tend to be broad in scope, rather than deficit-focused (13), and co-produced work tends to advocate for a holistic approach to understanding autistic strengths and challenges (14, 15). Additionally, including autistic people in autism research is associated with lower odds of having ableist constructions of autism or autistic people (2, 16).

Backlash: rejecting anti-ableism in the guise of scientific accuracy

Many autism researchers have embraced calls to dismantle ableism in their work (17). However, others have asserted these efforts hamper scientific accuracy, particularly in regards to discourses and terminology used to describe autistic people (18). Their argument is that some autistic people– especially those who have accompanying intellectual disability, do not consistently use speech, and/or require substantial support– cannot be described without using terms such as "profound," "severe," and "problem behavior," which many autistic people and their allies find dehumanizing (3, 19). These terms are proposed to be fact-based, scientifically accurate descriptors that, if abandoned, would leave researchers unable to advance knowledge on issues important to this population. We have argued that these terms can be ableist when they reduce autistic people to perceived deficits, and when they are used without examining how social contexts contribute to disability (3, 20, 21). Important to this logic are theoretical commitments from sociolinguistic research traditions showing that *no* terms or discourses express value-neutral facts (22). Instead, language (including scientific language) is imbued with ideological and ethical dimensions.

Here, we extend our previous arguments by asserting that research underpinned by unexamined ableist ideologies has no claim to scientific accuracy. Instead, ableism is historically intertwined with research programs that were eventually debunked, or are now understood to have much less explanatory power than initially proposed. We explore three such programs, including: (a) etiology, identification, and prevalence; (b) descriptions and theoretical explanations, and (c) interventions.

False leads

Autism etiology, identification, and prevalence

Psychogenesis

Delineating causal mechanisms of autism and how they contribute to diagnostic prevalence have been top research and funding priorities (18). Psychogenic theories emerged early in the history of autism research, and stemmed from Freudian theories of psychosexual development. One version purported that mothers' rejection of their children resulted in insufficient parent–child bonding and caused their children to become autistic. Bettelheim's (23) iteration of this theory is most well-known, but Kanner (24) implied similar sentiments regarding the parents of autistic children (focusing most often on mothers) in his original case report. He later expounded a causal link between parents' behavior and their children's autism (25), writing how the "[m]aternal lack of genuine warmth is often conspicuous in the first visit to the clinic" (p. 422), and that children were "kept neatly in refrigerators which did not defrost" (p. 425).

Both Kanner and Bettelheim relied on ableists and misogynistic assumptions to connect mothers' behavior (their education, participation in work, and perceived warmth) to their autistic children's perceived aloofness. With more rigorous investigation, the notion that mothers' affect made their children autistic has since been widely rejected. For example, research has shown that autistic children are as securely attached to their mothers as typically developing children (26). To reflect updated research, a recently created and validated measure of autism knowledge regards autistic children showing affection, attachments, and empathy as facts (27). Essentially, the evidence for these ideas remained largely speculative and based exclusively on unsystematic and ableist clinical impressions of parents and their children—undermining any claims to scientific accuracy. Still, the damage this work caused families is well established, including for example the removal of autistic children from their homes at Bettelheim's recommendation (28), and further stigmatization of autistic people (29). Additionally, Douglas (30) argues that these theories have been repurposed from cause to cure, with mothers no longer being blamed for being the root of their child's autism, but instead blamed for their lack of recovery from it.

Toxicity and biogenesis

Psychogenic causal theories were eventually displaced by biogenic causal theories that focused on external toxins, with Bernard Rimland's ideas in particular gaining traction throughout the 1960s – 1990s. Rimland asserted that autism had biological origins similar to disorders like phenylketonuria, which is caused by a genetic inability to break down phenylalanine and, without treatment, leads to intellectual disabilities (31). Rimland either developed or promoted several biology-based theories, including that autism is caused by toxicity from sources such as vaccines (32), insufficient digestion of gluten and casein (33, 34), and heavy metals in the bloodstream (35). None of these theories were based on strong supporting evidence at the time Rimland proposed them, and are now widely considered debunked (36). Central to their proliferation are ableist and stigmatizing notions that autism is the result of biological "damage" that negatively impacts cognitive and social development, and that biological causes, if identified, could lead to simple to manage cures. Although these theories have been rejected by much of the scientific community, discourses about autism that invoke biological perturbations (often from external 'toxins') frame much of the professional and public understanding of autism, which can be a significant source of stigmatization.

Biomarkers

Autism is defined behaviorally and diagnosed observationally, resulting in significant variability in clinical evaluation and practice. To further standardize diagnosis and clinical trials, a major focus within autism research has been a search for quantifiable biomarkers to aid early detection and serve as targets for intervention. However, to date biomarker studies have produced inconsistent and contradictory results, leading a recent review to conclude that there is a biomarker "replication crisis" and "currently no response biomarker to inform ASD clinical trials" [(37), p. 23]. The search for autism-specific biomarkers is also complicated by its notorious heterogeneity that is not likely to be associated with a uniform underlying physiology (38).

Although biomarker research offers potential for identifying biological contributors to disabling medical conditions that disproportionately co-occur with autism (e.g., epilepsy, sleep disorders, digestive issues, hyperacusis), efforts to reduce autism itself to biology ignores the social and developmental contexts in which neurobiological differences manifest as social disabilities, and reifies deficit frameworks that presume disability is intrinsic to the individual. As these efforts continue, it remains incumbent on biomarker researchers to articulate how biomarkers will improve identification and clinical care, as biomarker testing is often more labor-intensive, more invasive, and less accessible to people in need than established methods. Further, biomarker researchers should address concerns from the autistic community about the underlying motivation for biological research funding [e.g., cure and prevent autism; (39)], which often comes at the expense of other funding and research needs prioritized by autistic people (40–46).

The autism epidemic

Rimland was among several researchers who made ableist claims that increasing numbers of autism diagnoses constituted an "autism epidemic" (3), and that increases in cases were due to environmental factors like toxins or vaccines. These claims lack empirical support, and systematic investigations into vaccines have not shown even correlational links to increases in autism prevalence (36). Current researcher consensus about changing prevalence estimates is that increases are due to differences in identification methods across survey years, greater awareness and improved differential diagnosis that enable appropriate identification of autistic people from minoritized backgrounds, and improved service access that incentivizes diagnosis (47–49). For example, a rise in autism diagnoses among United States children recently occurred particularly for historically underrepresented non-white children and girls (50). Researchers who continue to cleave to the notion of an autism epidemic tend not to sufficiently account for these alternative explanations. Still, claims of an autism epidemic continue to be promoted by a small group of researchers and influential public figures (51, 52).

The ableist ideologies that accompany concerns about an "autism epidemic" are readily apparent, and are mobilized in part to promote increased investment in cause/cure research. In an essay linking vaccines and autism, Rimland (32) quoted a parent of an autistic child who argued that parents would know – without autism awareness campaigns – if their child was "not talking yet and does not do anything except sit there flapping his hands" (p. 261). Rimland and the parent he quoted reduced autistic children to their non-normative behavior, and conveyed that more autistic people is cause for alarm.[1] However, recent estimates indicate that the vaguely-defined group of autistic children referenced in the parent's quotation do not account for a substantial portion of the increase in diagnoses (54). Researchers have also expressed alarmist, ableist concerns about the "economic burden" of autistic people [Blaxill et al. (55), in a recently retracted study]. However, recent efforts to model the cost of autistic people have been critiqued on methodological and ideological grounds because they inappropriately assume that autistic people's economic contributions are zero, that non-autistic people are cost-free, and that perceived financial cost is an informative marker for determining autistic people's right to exist (56). Once again, ableist assumptions about autism have undermined rigorous evaluation of available evidence on autism prevalence. These stigmatizing, ableist claims reach the consciousness of autistic people and may become internalized; as one autistic adult argued, vaccine-autism fears suggest society views having a deadly disease as worse than autism (57).

Characterizing and theorizing autism

Echolalia

Kanner (25) described echolalia in autistic children, which is the repetition of the speech of others, as a "…semantically and conversationally valueless or grossly distorted memory exercise" (p. 243). In the following decades, psychoanalytic and behaviorist researchers considered autistic echolalia to be non-communicative and inwardly focused. Interventions were developed to decrease its occurrence (58) under the ableist assumption that echolalia interferes with "real" social interaction and ultimately, social development (59). These conclusions did not stem from in-depth, systematic study of the social or interactional contexts in which echolalia was produced, the

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[1] Ableist panic of this sort came to a crescendo in the mid 2000's, with initiatives such as the "Ransom Notes" campaign launched by the New York University Child Study Center, where large billboard displays containing notes purporting to be from neurodevelopmental disabilities such as autism notified parents that they had stolen and harmed their children (49).

impacts of echolalia on interaction, or autistic people's input. Instead, they were based on clinical reports generated with seemingly *a priori* assumptions that the non-normative nature of echolalia was evidence enough that it was not worthwhile.

Autism researchers who studied language and communication *in context* soon took a more nuanced approach to conceptualizing echolalia, and proposed that echolalia could have communicative and interactive utility [see Gernsbacher et al. (59) and Sterponi and Shankey (60), for summaries], such as language-building imitation (61). Critical to these programs of research are theoretical commitments and methodological points of departure that seek to describe what autistic people *do* in interaction, rather than to seek out deficits by honing in on any form of conduct that appears to differ from a (usually idealized) non-autistic standard. For example, in their qualitative case study, Sterponi and Shankey (62) describe how an autistic child deployed echolalia in creative ways (e.g., by adjusting prosodic contours or adding/subtracting lexical items from the original utterance) to achieve a variety of interactional ends, such as redirection, expressing alignment, and projecting affective and epistemic stance. This research builds on prior systematic, empirical descriptions of autistic interactions showing the interactional relevance of echolalia (63–65) that sharply contrasts with previous, deficit-driven research that lacked a rigorous empirical basis.

Social motivation

In keeping with deficit-based descriptions, researchers have developed deficit-based theories to explain how features of autism (such as echolalia) develop and co-occur. The Social Motivation hypothesis purports that autistic people have an innately reduced interest in social interaction, and are instead inwardly focused, which stems from differences in neurobiology that affect the processing of social rewards (66). These early differences are thought to culminate in diminished participation in, and ultimately capacity for, social interaction with others. This theoretical framing has led to interventions designed to increase the "reward value" of early social interactions [for example via oxytocin administration, which has shown null or negative effects across several studies; see (21, 67)] in an effort to reroute social development to a more typical pathway (61, 68).

However, Jaswal and Akhtar (61) have pointed out three problems regarding the assumptions that underpin this theory: (a) autistic people express that they do desire interactions and relationships with others, (b) there are alternative explanations for the differences in social presentation evidenced by autistic people that do not assume reduced social motivation, and (c) social motivation is not a 'within-person' phenomenon; it involves one's social conduct, others' interpretations of their social conduct, and others' contingent social conduct based on those interpretations (69). Indeed, empirical work has found that autistic adult's social motivation has little predictive value for social interaction outcomes (70). Social motivation theories are one of many theoretical approaches that use deficit-based bridging assumptions to link deficit-based descriptions of autism (e.g., decreased eye-contact, differences in signaling emotion) to an explanatory framework, which can have stigmatizing effects on autistic people (10).

Broken mirrors

A related theoretical framework posits that autistic people lack neural activation in "mirror neuron" networks of the brain, which are purported to enable a simulated experience of others' actions by activating neural pathways during action observation that are also activated during action production (71). According to the theory, autistic people are unable to understand the goals, intentions, or affective motivations that underlie others' actions because the activation of these pathways are attenuated, and they do not have the simulated experience of producing an action when observing one. On this basis, autistic people's neurology was described as "broken" and in need of fixing to restore functioning (72). This theory rose to prominence in the early 2000s and led to interventions focused on improving autistic children's ability to imitate others, a skill thought to depend on and possibly enhance mirror neuron activation (73).

In a forum discussion of mirror neuron findings (74), Gernsbacher provides provocative counterpoints to this theory, noting that many of the findings showing decreased activation of mirror neuron networks in autistic as compared non-autistic controls have not consistently replicated. Indeed, many findings locating mirror neuron networks in non-autistic groups have not held up in meta-analytic investigations either. She also notes that the interventions that arose from mirror neuron theories have limited empirical support. Finally, Gernsbacher links the development of mirror neuron theories to explain autism to prejudicial bias (i.e., ableism). The ableism motivating this theory is especially apparent in the dehumanizing language used to articulate it, which included that autistic people lack a capacity central to human evolution.

Autism interventions

Young autism project

In the United States, applied behavior analysis (ABA) is a widely-implemented form of therapy for autistic people, popularized by Lovaas' Young Autism Project. ABA designed for autistic people was derived from similar, now disavowed, strategies used to prevent children from developing traits perceived to be inconsistent with their sex assigned at birth, and to prevent future same sex attraction (75, 76). Lovaas published a seminal study in the late 1980s claiming that autistic children who participated in intensive ABA therapy became indistinguishable from their non-autistic peers (77), but this finding has not replicated (78). Indeed, the vast majority of ABA studies do not meet basic quality standards such as randomization and masked assessment (79, 80), and those that do show only modest improvements in autistic children's cognitive development (a finding that also has not been replicated after more than 20 years). Despite the lack of high-quality evidence, many ABA providers have advertised their services as a gold-standard, scientifically-proven cure for autism (77).

Lovaas' ableist views about autistic people are familiar to researchers in academic traditions critical of ABA (1), but are rarely acknowledged by ABA proponents. For example, in interviews, Lovaas referred to autistic children as inhuman and promoted physical abuse–including making autistic people fear for their lives– as a means to promote behavior change (81, 82). Further, Lovaas' focus on encouraging autistic people to suppress autistic traits such as "stimming" (e.g., hand flapping, rocking, or repetitive vocalizations) so that they appear neurotypical further stigmatizes these behaviors, despite the fact that many autistic people describe stimming as an expression of joy or a valuable coping mechanism (83).

Defeat autism now! protocol

Consistent with his biogenic theories of autism causation, Rimland promoted the use of various therapies that he marketed as curative via his Autism Research Institute, through which he developed the Defeat Autism Now! (DAN!) protocol. This protocol was administered by DAN! doctors trained to implement strategies to remove toxins from the body, which were thought to be introduced through external influences such as diets and vaccines. Procedures included removing heavy metals from the bloodstream (i.e., chelation therapy), gluten-and casein-free diets, vitamin therapy, hyperbaric oxygen therapy, and the avoidance of childhood vaccines. These therapies were introduced with flimsy evidence of effectiveness, and insufficient attention to potential harms[2]– but Rimland felt that the need to decrease or cure characteristics associated with autism was so pressing that procedures with even just anecdotal or hypothetical support were worthwhile (84).

Subsequently, many studies have been published that refute the efficacy of these strategies (85–87), and calls have been issued for discontinuing their use due to significant harms, including death (88). While Rimland's approaches garnered contemporary criticism from many researchers, he gained significant traction with many medical providers and families, and is recognized as having enormous and enduring influence on the care autistic children receive [(84, 89, 90)]. An analysis of Google search data shows that these theories involving gluten and heavy metals still garnered significant public interest in 2019 (with renewed interest since the onset of the COVID-19 pandemic), and vaccines remain the topic most associated with questions relating to the cause of autism on Google (91).

Underlying the continued dissemination of these intervention programs are ableist ideologies positioning autism as such an undesirable state of affairs that: (1) any possibility to reduce its occurrence is worthwhile, regardless of a lack of evidence, and (2) there is no need to consider harms, because being autistic is worse than any potential harm (92). As a result of the poor science backing much autism intervention research, it is unclear if they have resulted in long-term positive impacts for autistic people (78, 79, 93), although it is likely that many of these programs contribute to stigmatization and trauma (94, 95).

Discussion

In this paper, we offer a counter argument to the insinuation that researchers have a choice between rejecting ableism and striving for scientific accuracy. In fact, history shows that ableism and poor autism science have gone hand in hand. Many autism research programs that have either been abandoned or have become much less influential may have gained initial traction because the ableist assumptions underpinning them were taken as givens, even though they were not backed by rigorous evidence. These include assumptions about the etiology and prevalence of autism, descriptions and theorizations about autistic people's social conduct, and ways to support autistic people. The assumed validity of these theories further encourages poor research practices and confirmation bias (e.g., elective reporting, p-hacking, hypothesizing after results are known, etc.). Until the field of autism research explicitly addresses the link between ableism and poor autism science, new programs of research will continue to emerge that have little to offer in terms of advancing knowledge, while also potentially causing significant harm–including stigmatization– to autistic people and their families (2).

Alternatively, recent efforts to reject ableism have led to promising empirical and theoretical advances, such as the program of research underpinned by the *Double Empathy Problem* (96–98), efforts to understand features of autism using neurodiversity frameworks (99–101), rigorous guidelines for conducting co-produced research with autistic people (102), pilot research on programs designed to reduce social stigma (103), and approaches to promote autistic flourishing that prioritize capabilities such as affiliation and health via systems change, rather than encouraging autistic people to "overcome" perceived deficits (104). Anti-ableist research on supporting autistic people in their daily lives also shows promise, such as efforts to improve quality of life measures that are specific and relevant to autistic people (105) research that can be used to rigorously test interventions that aim to improve their wellbeing. Each of these programs will need to be refined and improved over time through additional research, but illustrate the potential of anti-ableist work coinciding with scientific rigor. Ultimately, anti-ableism efforts may be a requirement for, rather than in conflict with, academic rigor.

Author contributions

KB-B proposed the manuscript, drafted the outline, wrote the initial draft, and edited the draft. SK contributed to the conceptualization of the manuscript, added to the outline, and edited the draft. NS contributed to the conceptualization of the manuscript, added to the outline, drafted text, and edited the draft. MG contributed to the conceptualization of the manuscript, and edited the draft. HN contributed to the manuscript outline, and edited the draft. MB contributed to the conceptualization of the manuscript, drafted text, and edited the draft. All authors contributed to the article and approved the submitted version.

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Conflict of interest

KB-B has previously received fees for consulting with school districts on intervention practices for autistic children and teaches courses on autism interventions in her role as an Associate Professor of Special Education. She has also accepted speaker fees to discuss her work on research quality, adverse events, researcher conflicts of interest as they pertain to autism intervention research, and ableist language. She also receives royalties for a co-edited book titled

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[2] In one study, Rimland reported that a drug he promoted was found to "induce adverse side effects in only about 19% of the children" [(78), p. 69], which he concluded was too low to take into consideration. He also asserted that high doses of vitamins did not have the potential for harm.

Clinical Guide to Early Interventions for Children with Autism, published by Springer. NS has previously received speaker fees to discuss his research investigating social cognition and interaction in autism, and to share his views on the state of autism research. SK has previously received research funds from the Autism Intervention Research Network on Physical Health, and teaches courses on neurodiversity studies and social construction of disability in his role as a university professor. MB has previously received speaker fees for discussing their research on ethics and autism research. They are also an advisor for Information Autism, and on an advisory board for an education service for Neurodivergent children, young people, and adults in Scotland.

The remaining authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

Publisher's note

References

1. Botha M. Academic, activist, or advocate? Angry, entangled, and emerging: a critical reflection on autism knowledge production. *Front Psychol.* (2021) 12:727542. doi: 10.3389/fpsyg.2021.727542

2. Botha M, Cage E. "Autism research is in crisis": a mixed method study of researcher's constructions of autistic people and autism research. *Front Psychol.* (2022) 13:7397. doi: 10.3389/fpsyg.2022.1050897

3. Bottema-Beutel K, Kapp SK, Lester JN, Sasson NJ, Hand BN. Avoiding ableist language: suggestions for autism researchers. *Autism Adulthood.* (2021) 3:18–29. doi: 10.1089/aut.2020.0014

4. Lewis T.L. (2022). Working Definition of Ableism. Talila A Lewis. Available at: https://www.talilalewis.com/blog (Accessed June 11, 2023).

5. Goffman E. *Stigma: Notes on the Management of Spoiled Identity.* New York, NY: Simon and Schuster. (1963).

6. Gillespie-Lynch K, Kapp SK, Brooks PJ, Pickens J, Schwartzman B. Whose expertise is it? Evidence for autistic adults as critical autism experts. *Front Psychol.* (2017) 8:438. doi: 10.3389/fpsyg.2017.00438

7. Turnock A, Langley K, Jones CR. Understanding stigma in autism: a narrative review and theoretical model. *Autism Adulthood.* (2022) 4:76–91. doi: 10.1089/aut.2021.0005

8. Gernsbacher MA. On not being human. *APS observer.* (2007) 20:5.

9. Gernsbacher MA, Dawson M, Mottron L. Autism: common, heritable, but not harmful. *Behav Brain Sci.* (2006) 29:413–4. doi: 10.1017/S0140525X06319097

10. Kapp S. How social deficit models exacerbate the medical model: autism as case in point. *Autism Policy Pract.* (2019) 2:3–28.

11. Rozenkrantz L, D'Mello AM, Gabrieli JD. Enhanced rationality in autism spectrum disorder. *Trends Cogn Sci.* (2021) 25:685–96. doi: 10.1016/j.tics.2021.05.004

12. Cowen T. Autism as academic paradigm. *The Chronicles of Higher Education* (2009). Available at: https://www.chronicle.com/article/autism-as-academic-paradigm (Accessed August 29, 2023).

13. Gernsbacher MA. On not being human. *Observer.* (2007) 20:5–32.

14. Sinclair J. Don't mourn for us. *Autonomy Crit J Interdisc Autism Stud.* (2012) 1

15. Russell G, Kapp SK, Elliott D, Elphick C, Gwernan-Jones R, Owens C. Mapping the autistic advantage from the accounts of adults diagnosed with autism: a qualitative study. *Autism Adulthood.* (2019) 1:124–33. doi: 10.1089/aut.2018.0035

16. Urbanowicz A, Nicolaidis C, Houting JD, Shore SM, Gaudion K, Girdler S, et al. An expert discussion on strengths-based approaches in autism. *Autism Adulthood.* (2019) 1:82–9. doi: 10.1089/aut.2019.29002.aju

17. Gernsbacher MA. The true meaning of research participation. *Observer.* (2007) 20:5–13.

18. Singer A, Lutz A, Escher J, Halladay A. A full semantic toolbox is essential for autism research and practice to thrive. *Autism Research.* (2023) 16:497–501.

19. Tan DW. Early-career autism researchers are shifting their research directions: tragedy or opportunity? *Autism Adulthood.* (2023). doi: 10.1089/aut.2023.0021 [Epub ahead of print].

20. Natri HM, Abubakare O, Asasumasu K, Basargekar A, Beaud F, Botha M, et al. Anti-ableist language is fully compatible with high-quality autism research: response to Singer et al. (2023). *Autism Res.* (2023) 16:673–6. doi: 10.1002/aur.2928

21. Kapp SK, Damian M, Sara R. Models of helping and coping with autism In: *The Routledge International Handbook of Critical Autism Studies.* Eds. D. Milton and S. Ryan Abingdon, Oxon: Routledge. (2022) 255–69.

22. Bloemmaert J. *Discourse: A Critical Introduction.* Cambridge, UK: Cambridge University Press. (2005).

23. Harris L, Gilmore D, Longo A, Hand BN. Patterns of US federal autism research funding during 2017–2019. *Autism.* (2021) 25:2135–9. doi: 10.1177/13623613211003430

24. Bettelheim B. *The Empty Fortress: Infantile Autism and the Birth of the Self.* New York, NY: Simon and Schuster. (1967).

25. Kanner L. Autistic disturbances of affective contact. *Nervous Child.* (1943) 2:217–50.

26. Kanner L. Problems of nosology and psychodynamics of early infantile autism. *Am J Orthopsychiatry.* (1949) 19:416–26. doi: 10.1111/j.1939-0025.1949.tb05441.x

27. Gernsbacher MA, Dawson M, Hill Goldsmith H. Three reasons not to believe in an autism epidemic. *Curr Dir Psychol Sci.* (2005) 14:55–8. doi: 10.1111/j.0963-7214.2005.00334.x

28. Gillespie-Lynch K, Brooks PJ, Someki F, Obeid R, Shane-Simpson C, Kapp SK, et al. Changing college students' conceptions of autism: an online training to increase knowledge and decrease stigma. *J Autism Dev Disord.* (2015) 45:2553–66. doi: 10.1007/s10803-015-2422-9

29. Crowell JA, Keluskar J, Gorecki A. Parenting behavior and the development of children with autism spectrum disorder. *Compr Psychiatry.* (2019) 90:21–9. doi: 10.1016/j.comppsych.2018.11.007

30. Douglas P. Refrigerator mothers. *J Mother Initiat Res Commun Involv.* (2014) 5:94–114.

31. Rimland B. Infantile autism: status of research. *Can Psychiatr Assoc J.* (1974) 19:130–3. doi: 10.1177/070674377401900203

32. Rimland B. The autism epidemic, vaccinations, and mercury. *J Nutr Environ Med.* (2000) 10:261–6. doi: 10.1080/13590840020013248

33. Lewis L. *Special Diets for Special Kids: Understanding and Implementing a Gluten and Casein Free Diet to Aid in the Treatment of Autism and Related Disorders.* Arlington, TX: Future Horizons (1998).

34. Reichelt KL, Ekrem J, Scott H. Gluten, milk proteins and autism: dietary intervention effects on behavior and peptide secretion. *J Appl Nutr.* (1990) 42:1–11.

35. Rimland B, Larson GE. Hair mineral analysis and behavior: an analysis of 51 studies. *J Learn Disabil.* (1983) 16:279–85. doi: 10.1177/002221948301600507

36. Taylor LE, Swerdfeger AL, Eslick GD. Vaccines are not associated with autism: an evidence-based meta-analysis of case-control and cohort studies. *Vaccine.* (2014) 32:3623–9. doi: 10.1016/j.vaccine.2014.04.085

37. Parellada M, Andreu-Bernabeu Á, Burdeus M, San José Cáceres A, Urbiola E, Carpenter LL, et al. In search of biomarkers to guide interventions in autism spectrum disorder: a systematic review. *Am J Psychiatr.* (2023) 180:23–40. doi: 10.1176/appi.ajp.21100992

38. Molloy CJ, Gallagher L. Can stratification biomarkers address the heterogeneity of autism spectrum disorder? *Ir J Psychol Med.* (2022) 39:305–11. doi: 10.1017/ipm.2021.73

39. Pukki H, Bettin J, Outlaw AG, Hennessy J, Brook K, Dekker M, et al. Autistic perspectives on the future of clinical autism research. *Autism Adulthood.* (2022) 4:93–101. doi: 10.1089/aut.2022.0017

40. Cage E, Crompton CJ, Dantas S, Strachan K, Birch R, Robinson M, et al. What are the autism research priorities of autistic adults in Scotland? *Psy ArXiv.* (2022). doi: 10.31234/osf.io/nbq8h [Preprint].

41. Dey I, Chakrabarty S, Nandi R, Shekhar R, Singhi S, Nayar S, et al. Autism community priorities in diverse low-resource settings: a country-wide scoping exercise in India. *Autism.* (2023):136236132311540. doi: 10.1177/13623613231154067 [Epub ahead of print].

42. Fletcher-Watson S, Apicella F, Auyeung B, Beranova S, Bonnet-Brilhault F, Canal-Bedia R, et al. Attitudes of the autism community to early autism research. *Autism.* (2017) 21:61–74. doi: 10.1177/1362361315626577

43. Frazier TW, Dawson G, Murray D, Shih A, Sachs JS, Geiger A. Brief report: a survey of autism research priorities across a diverse community of stakeholders. *J Autism Dev Disord.* (2018) 48:3965–71. doi: 10.1007/s10803-018-3642-6 Accessed August 29, 2023.

44. Pellicano E, Dinsmore A, Charman T. What should autism research focus upon? Community views and priorities from the United Kingdom. *Autism*. (2014) 18:756–70. doi: 10.1177/1362361314529627

45. Putnam OC, Eddy G, Goldblum J, Swisher M, Harrop C. How autistic adults' priorities for autism research differ by gender identity: a mixed-methods study. *Womens Health*. (2023) 19:174550572311603. doi: 10.1177/17455057231160342

46. Warner G, Parr JR, Cusack J. Workshop report: establishing priority research areas to improve the physical health and well-being of autistic adults and older people. *Autism Adulthood*. (2019) 1:20–6. doi: 10.1089/aut.2018.0003

47. Gernsbacher MA, Dissanayake C, Goldsmith HH, Mundy PC, Rogers SJ, Sigman M. Autism and deficits in attachment behavior. *Science*. (2005) 307:1201–3. doi: 10.1126/science.307.5713.1201

48. Harris E. Autism prevalence has been on the rise in the US for decades– and that's progress. *JAMA*. (2023) 329:1724–6. doi: 10.1001/jama.2023.6078

49. Mandell D, Lecavalier L. Should we believe the Centers for Disease Control and Prevention's autism spectrum disorder prevalence estimates? *Autism*. (2014) 18:482–4. doi: 10.1177/1362361314538131

50. Maenner MJ, Warren Z, Williams AR, Amoakohene E, Bakian AV, Bilder DA, et al. Prevalence and characteristics of autism spectrum disorder among children aged 8 years—autism and developmental disabilities monitoring network, 11 sites, United States, 2020. *MMWR Surveill Summ*. (2023) 72:1–14. doi: 10.15585/mmwr.ss7202a1

51. Dufault R, Lukiw WJ, Crider R, Schnoll R, Wallinga D, Hall-Lande J, et al. A macroepigenetic approach to identify factors responsible for the autism epidemic in the United States. *Clinical Epigenetics*. (2012) 4:1–12.

52. Miller M. E. (2015). The GOP's Dangerous 'Debate' on Vaccines and Autism Wash Post. Available at: https://www.washingtonpost.com/news/morning-mix/wp/2015/09/17/the-gops-dangerous-debate-on-vaccines-and-autism/ (Accessed August 29, 2023).

53. Kras JF. The "ransom notes" affair: when the neurodiversity movement came of age. *Disabil Stud Q*. (2010) 30:1065. doi: 10.18061/dsq.v30i1.1065

54. Hughes MM, Shaw KA, DiRienzo M, Durkin MS, Esler A, Deth R, et al. The prevalence and characteristics of children with profound autism, 15 sites, United States, 2000-2016. *Public Health Rep*. (2023):333549231163551. doi: 10.1177/00333549231163551 [Epub ahead of print].

55. Blaxill M, Rogers T, Nevison C. Autism tsunami: the impact of rising prevalence on the societal cost of autism in the United States. *J Autism Dev Disord*. (2022) 52:2627–43. doi: 10.1007/s10803-021-05120-7

56. Luterman S. (2021). Contentious Study Prompts Backlash from Autism Researchers. Available at https://www.spectrumnews.org/news/contentious-study-prompts-backlash-from-autism-researchers/ (Accessed May 30, 2023).

57. Botha M, Dibb B, Frost DM. " autism is me": an investigation of how autistic individuals make sense of autism and stigma. *Disabil Soc*. (2022) 37:427–53. doi: 10.1080/09687599.2020.1822782

58. Neely L, Gerow S, Rispoli M, Lang R, Pullen N. Treatment of echolalia in individuals with autism spectrum disorder: a systematic review. *Rev J Autism Dev Disord*. (2016) 3:82–91. doi: 10.1007/s40489-015-0067-4

59. Gernsbacher MA, Morson EM, Grace EJ. Language and speech in autism. *Ann Rev Linguist*. (2016) 2:413–25. doi: 10.1146/annurev-linguistics-030514-124824

60. Sterponi L, Shankey J. Rethinking echolalia: repetition as interactional resource in the communication of a child with autism. *J Child Lang*. (2014) 41:275–304. doi: 10.1017/S0305000912000682

61. Jaswal VK, Akhtar M. Being versus appearing socially uninterested: challenging assumptions about social motivation in autism. *Behav Brain Sci*. (2019) 42:1–73. doi: 10.1017/S0140525X18001826

62. Local J, Wootton A. Interactional and phonetics aspects of immediate echolalia in autism: a case study. *Clin Linguist Phon*. (1995) 9:155–84. doi: 10.3109/02699209508985330

63. Tarplee C, Barrow E. Delayed echoing as an interactional resource: a case study of a 3-year-old child on the autistic spectrum. *Clin Linguist Phonet*. (1999) 6:449–82.

64. Wootton A. An investigation of delayed echoing in a child with autism. *Language*. (1999) 19:359–81.

65. Clements CC, Zoltowski AR, Yankowitz LD, Yerys BE, Schultz RT, Herrington JD. Evaluation of the social motivation hypothesis of autism: a systematic review and meta-analysis. *JAMA Psychiat*. (2018) 75:797–808. doi: 10.1001/jamapsychiatry.2018.1100

66. Moerkerke M, Daniels N, Van der Donck S, Tibermont L, Tang T, Debbaut E, et al. Can repeated intranasal oxytocin administration affect reduced neural sensitivity towards expressive faces in autism? a randomized controlled trial. *J Child Psychol Psychiatry Adv*. (2023). doi: 10.1111/jcpp.13850 [Epub ahead of print].

67. Bradshaw J, Koegel LK, Koegel RL. Improving functional language and social motivation with a parent-mediated intervention for toddlers with autism spectrum disorder. *J Autism Dev Disord*. (2017) 47:2443–58. doi: 10.1007/s10803-017-3155-8

68. Gernsbacher MA. Toward a behavior of reciprocity. *J Dev Process*. (2006) 1:139–52.

69. Morrison KE, DeBrabander KM, Jones DR, Ackerman RA, Sasson NJ. Social cognition, social skill, and social motivation minimally predict social interaction outcomes for autistic and non-autistic adults. *Front Psychol*. (2020) 11:3282. doi: 10.3389/fpsyg.2020.591100

70. Rizzolatti G, Fabbri-Destro M. Mirror neurons: from discovery to autism. *Exp Brain Res*. (2010) 200:223–37. doi: 10.1007/s00221-009-2002-3

71. Ramachandran VS, Oberman LM. Broken mirrors. *Sci Am*. (2006) 295:62–9. doi: 10.1038/scientificamerican1106-62

72. Iacoboni M, Mazziotta JC. Mirror neuron system: basic findings and clinical applications. *Ann Neurol*. (2007) 62:213–8. doi: 10.1002/ana.21198

73. Gallese V, Gernsbacher MA, Heyes C, Hickok G, Iacoboni M. Mirror neuron forum. *Perspect Psychol Sci*. (2011) 6:369–407. doi: 10.1177/1745691611413392

74. Conine DE, Campau SC, Petronelli AK. LGBTQ+ conversion therapy and applied behavior analysis: a call to action. *J Appl Behav Anal*. (2022) 55:6–18. doi: 10.1002/jaba.876

75. Dawson M. The Misbehaviour of Behaviourists: Ethical Challenges to the Autism-ABA Industry Autism Crisis; (2004). Available at: https://www.sentex.ca/~nexus23/naa_aba.html (Accessed May 30, 2023).

76. Lovaas OI. Behavioral treatment and normal educational and intellectual functioning in young autistic children. *Journal of Consulting and Clinical Psychology*. (1987) 55:3.

77. Gernsbacher MA. Is one style of early behavioral treatment for autism 'Scientifically proven?'. *J Dev Process*. (2003) 7:19–26.

78. Bottema-Beutel K, LaPoint SC, Kim SY, Mohiuddin S, Yu Q, McKinnon R. An evaluation of intervention research for transition-age autistic youth. *Autism*. (2023) 27:890–904. doi: 10.1177/13623613221128761

79. Sandbank M, Bottema-Beutel K, Crowley S, Cassidy M, Dunham K, Feldman JI, et al. Project AIM: autism intervention meta-analysis for studies of young children. *Psychol Bull*. (2020) 146:1–29. doi: 10.1037/bul0000215

80. Chance P. A conversation with Ivar Lovaas. *Psychol Today*. (1974) 7:76–84.

81. Grant A. Screams, slaps, and love. *Life*. (1965):87–97.

82. Kapp SK, Steward R, Crane L, Elliott D, Elphick C, Pellicano E, et al. 'People should be allowed to do what they like': autistic adults' views and experiences of stimming. *Autism*. (2019) 23:1782–92. doi: 10.1177/1362361319829628

83. Rimland B. Controversies in the treatment of autistic children: vitamin and drug therapy. *J Child Neurol*. (1988) 3:S68–72. doi: 10.1177/0883073888003001S13

84. Shattock P. Bernard Rimland: Parent and practitioner revolutionising the treatment of autism. *The Guardian* (2006). Available at: https://www.theguardian.com/news/2006/dec/06/guardianobituaries.mainsection (Accessed August 29, 2023).

85. James S, Stevenson SW, Silove N, Williams K. Chelation for autism spectrum disorder (ASD). *Cochrane Database Syst Rev*. (2015) 5:CD010766. doi: 10.1002/14651858.CD010766.pub2

86. Mulloy A, Lang R, O'Reilly M, Sigafoos J, Lancioni G, Rispoli M. Gluten-free and casein-free diets in the treatment of autism spectrum disorders: a systematic review. *Res Autism Spectr Disord*. (2010) 4:328–39. doi: 10.1016/j.rasd.2009.10.008

87. Nye C, Brice A. Combined vitamin B6-magnesium treatment in autism spectrum disorder. *Cochrane Database Syst Rev*. (2005) 4:CD003497. doi: 10.1002/14651858.CD003497.pub2

88. Sinha Y, Silove N, Williams K. Chelation therapy and autism. *BMJ*. (2006) 333:756. doi: 10.1136/bmj.333.7571.756

89. Green VA, Pituch KA, Itchon J, Choi A, O'Reilly M, Sigafoos J. Internet survey of treatments used by parents of children with autism. *Res Dev Disabil*. (2007) 27:70–84. doi: 10.1016/j.ridd.2004.12.002

90. Jonkman KM, Back E, Staal WG, Benard L, van der Doelen DM, Begeer S. Alternative treatments for autism: prevalence and predictors. *Res Autism Spectr Disord*. (2022) 98:102046. doi: 10.1016/j.rasd.2022.102046

91. Saposnik FE, Huber JF. Trends in web searches about the causes and treatments of autism over the past 15 years: exploratory Infodemiology study. *JMIR Pediatr Parent*. (2020) 3:e20913. doi: 10.2196/20913

92. Dawson M, Fletcher-Watson S. When autism researchers disregard harms: a commentary. *Autism*. (2022) 26:564–6. doi: 10.1177/13623613211031403

93. Lord C, Charman T, Havdahl A, Carbone P, Anagnostou E, Boyd B, et al. The lancet commission on the future of care and clinical research in autism. *Lancet*. (2022) 399:271–334. doi: 10.1016/S0140-6736(21)01541-5

94. Anderson LK. Autistic experiences of applied behavior analysis. *Autism*. (2023) 27:737–50. doi: 10.1177/13623613221118216

95. McGill O, Robinson A. "Recalling hidden harms": autistic experiences of childhood applied behavioural analysis (ABA). *Adv Autism*. (2020) 7:269–82. doi: 10.1108/AIA-04-2020-0025

96. Crompton CJ, Ropar D, Evans-Williams CV, Flynn EG, Fletcher-Watson S. Autistic peer-to-peer information transfer is highly effective. *Autism*. (2020) 24:1704–12. doi: 10.1177/1362361320919286

97. Milton DE. On the ontological status of autism: the 'double empathy problem'. *Disabil Soc*. (2012) 27:883–7. doi: 10.1080/09687599.2012.710008

98. Sasson NJ, Faso DJ, Nugent J, Lovell S, Kennedy DP, Grossman RB. Neurotypical peers are less willing to interact with those with autism based on thin slice judgments. *Sci Rep*. (2017) 7:1–10. doi: 10.1038/srep40700

99. Gernsbacher MA. Diverse brains. *Gen Psychol*. (2015) 49:29–37.

100. Kapp SK. Empathizing with sensory and movement differences: moving toward sensitive understanding of autism. *Front Integr Neurosci*. (2013) 7:38. doi: 10.3389/fnint.2013.00038

101. Ratto AB, Bascom J, da Vanport S, Strang JF, Anthony LG, Verbalis A, et al. Centering the inner experience of autism: development of the self-assessment of autistic traits. *Autism Adulthood*. (2023) 5:93–105. doi: 10.1089/aut.2021.0099

102. Nicolaidis C, Raymaker D, Kapp SK, Baggs A, Ashkenazy E, McDonald K, et al. The AASPIRE practice-based guidelines for the inclusion of autistic adults in research as co-researchers and study participants. *Autism*. (2019) 23:2007–19. doi: 10.1177/1362361319830523

103. Gillespie-Lynch K, Bisson JB, Saade S, Obeid R, Kofner B, Harrison AJ, et al. If you want to develop an effective autism training, ask autistic students to help you. *Autism*. (2022) 26:1082–94. doi: 10.1177/13623613211041006

104. Pellicano E, Fatima U, Hall G, Heyworth M, Lawson W, Lilley R, et al. A capabilities approach to understanding and supporting autistic adulthood. *Nat Rev Psychol*. (2022) 1:624–39. doi: 10.1038/s44159-022-00099-z

105. Williams ZJ, Cascio CJ, Woynaroski TG. Measuring subjective quality of life in autistic adults with the PROMIS global–10: psychometric study and development of an autism-specific scoring method. *Autism*. (2023) 27:145–57. doi: 10.1177/13623613221085364

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Raising bilingual autistic children in the UK: at the intersection between neurological and language diversity

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Introduction: While research shows no negative effects of bilingualism on autistic children's development, due to misconceptions around both autism and bilingualism, bilingual parents and educational/clinical practitioners who advise them often express unfounded concerns that exposing autistic children to more than one language will cause confusion and developmental delays. To understand the reasons that drive these misconceptions, this study focuses on: identifying factors that impact family decisions about (not) raising autistic children bilingually; attitudes toward bilingualism expressed by the community, doctors, family members, and teachers; sources of information about bilingualism and autism available to families.

Methods: Through a mixed-method online survey, we explored these questions in 31 UK-based bilingual families with 34 autistic children (age M = 10.6 years; SD = 7.1).

Results: The families reported choosing bilingualism for their autistic child primarily so that the child can communicate with family and community members. Attitudes toward bilingualism in their networks were predominantly positive, with a large portion of individuals not having opinions possibly due to lack of information. Only about 1/3 of parents had access to information on bilingualism and autism, mostly found on the internet.

Discussion: We discuss these findings and offer future directions for research, practice, and battling stigmas around bilingualism and autism.

KEYWORDS

autism, bilingual, multilingual, neurodiversity, lived experience, family functioning, cultural minority, support

Introduction

At least half the world's population is estimated to be bilingual or live in a bilingual environment [(1), pp. 27–39], and logically, so should be half of the world's autistic population. While attitudes towards bilingualism in neurotypical individuals are generally positive (with variation across and within communities), attitudes are less positive when it comes to autistic people (2). Autism is characterised by specific patterns of social communication and interaction, and repetitive behaviour and/or restricted interests. These characteristics are commonly seen through a deficit, disability or impairment lens in comparison to neurotypical norms and expectations, resulting in stereotypes and stigmatisation of autism as a condition.

Some of the wrongly founded assumptions about autism include the idea that exposing autistic children to more than one language causes confusion or negatively affects cognitive development. This has been observed in professional practice among educators and clinicians, who likely with a good intent but due to the lack of information and/or the presence of stigma, tend to advise bilingual families with autistic children to raise their children monolingually [e.g., see Yu (3)]. Early work by Kay-Raining Bird et al. (4), which explored this topic, and which predominantly included respondents from the United States and Canada, found that bilingualism was often not recommended/favoured by practitioners when advising bilingual families about raising their autistic children. This has been replicated in several other studies predominantly in the Canadian context (2). The UK context, however, remains rather underexplored in this respect with exception of a few recent studies. Specifically, among 11 families of autistic children in England and 5 families in Wales, Howard et al. (5) found predominantly negative or lack of advice by practitioners or other family members regarding bilingualism. Furthermore, in their work with seven practitioners in England and six in Wales, Howard et al. (6) identified some concerns about bilingualism not being feasible for all autistic children, as well as concerns that bilingualism might hinder a pupil's literacy development and that language mixing might be cognitively demanding for an autistic child. As a result of these negative views regarding bilingualism in autism, many autistic children from bilingual families are denied access to learning their home language, and in turn, do not have the same opportunities to develop their cultural and linguistic identity as neurotypical bilingual children. Furthermore, since using the home language is essential for the participation of an autistic child in the family social life (7), the consequences of imposed monolingualism on an autistic child could have detrimental effects on communication and inclusion within a bilingual family or in fact community. Misconceptions about bilingualism and autism also play a role in a school context, where autistic pupils who need adjustments are frequently advised to drop language classes (8).

Contrary to concerns about exposing autistic children to more than one language, the growing body of evidence focusing on autism and bilingualism suggests that there are no negative effects of bilingualism on language or cognitive development [e.g., (9, 10)]. Research also suggests some tentative positive effects on cognition including facets of executive function skills [e.g., (11–13)] and crucially, in lived experiences. Specifically, parents describe increased familial connections and closeness when they are able to express themselves in their first language [e.g., (3, 14)] and autistic bilingual adults have expressed the benefits of bilingualism on domains such as widening access to work and social opportunities, social interactions, and self-understanding (15, 16).

The evidence of no harmful effects of bilingualism on development of autistic children suggests that the advice by practitioners not to expose autistic children to more than one language seems to be unfounded. Considering that there is a significant proportion of bilingual children in the UK [over 1.7 million pupils, equating to around 20% of school pupils (17)], as well as an estimate of more than 700,000 autistic individuals (18), it is crucial to better understand the views, attitudes and decision-making processes of parents regarding the linguistic environment for their autistic children. In the process, it is also vital to identify ongoing stigmas that might be present at the intersection of autistic and bilingual experiences. By using a questionnaire-based approach, comparable to Kay-Raining Bird et al. (4), and by expanding on the England- and Wales-based work of Howard et al. (5, 6) through the inclusion of participants from around the UK, the current research addresses the following questions:

1. What factors impact the decision-making processes around bilingual upbringing in UK-based bilingual families of autistic children?
2. What attitudes towards bilingualism do these families encounter among four main stakeholder networks (local community, doctors, family, and teachers)?
3. Where, if at all, do these families of autistic children find information about bilingualism and autism?

Materials and methods

Design and survey

The team developed an online, mixed-methods survey for UK-based bilingual parents of at least one child with a neurodevelopmental condition. The study received ethical approval from the School of Philosophy, Psychology and Language Sciences Research Ethics Committee from the University of Edinburgh, ethics approval number 22-2122.

Measures

The online survey was designed by the authors due to the lack of an existing tool to address the needs posed by the broader research project (on bilingual families, neurodevelopmental conditions, and COVID-19 effects on family language practices), which this study focusing specifically on bilingualism and autism was a part of. In designing the survey, the authors relied on their previous experiences of investigating bilingualism and neurodiversity. Furthermore, one of the authors recently participated in an international project which included a design of an online tool to document bilingualism in children [see (19)]. The survey included the following: (1) a section about parents' demographics, (2) a section about the first-born child including questions on their diagnoses (if any) and bilingualism (languages, exposure, and proficiency), (3) optional identical sections for up to seven other children if applicable, (4) a section about languages used with the child/ren, attitudes towards and the decision-making process concerning bilingualism, as well as about access to information on raising neurodivergent children bilingually, (5) a section on language use before COVID-19, (6) a section on language use at home during COVID-19, and (7) a section for any other comments. In this article we focus on data from all sections apart from those listed under (5) and (6). The survey is available on OSF at https://osf.io/gndb2/.

Procedure

Participants were recruited by circulating the study details and flyers via social media, UK-based charities related to neurodevelopmental conditions (e.g., autism, ADHD, dyslexia, and learning disabilities), as well as personal and professional contacts. As bilingual families with autistic (and neurodivergent) children are hard to recruit in the UK, it was decided that the best approach to obtain responses was to use every possible network through which prospective participants could be identified and recruited.

The online survey was hosted on a GDPR (General Data Protection Regulations)-compliant platform[1] and was active from December 2021 to June 2023. Respondents accessed the study via a general link to the online survey, which started with a participant information sheet and a consent form. Respondents were provided with the research team's contact details and were able to access the survey after providing informed consent. They were also informed that most questions were not mandatory, and respondents could choose not to answer them. Respondents were told that they could go back, or pause the survey, and that it would take between 10 and 30 min to complete depending on the number of children that they have in their family. Respondents were also informed that they had 2 weeks to contact the research team to withdraw their data from the study.

Analysis

The descriptive analysis of the quantitative data was conducted in R (version 3.5.3). Responses to the open-ended questions were used to qualitatively supplement quantitative data. All data was inspected both in R and in Excel.

Results

Participants

A total of 40 parents completed the survey, 31 of whom were parents of at least one autistic child. This research focuses on this sample of 31 respondents (mean age = 44.7 years, SD = 7.3, range = 32–69; 26 females, 4 males, 1 not disclosed) who together represented 62 children including a total of 34 with a clinical diagnosis of autism. Amongst the parents, two respondents chose to disclose a diagnosis of autism, and two a diagnosis of ADHD (mean age at diagnosis = 24.7 years, SD = 17.2, range = 5–37), while two self-identified as autistic. Some respondents also chose to disclose their partner's neurodevelopmental diagnoses: autism (2), ADHD (2), dyslexia (1), and learning disability (1). Respondents reported a total of 22 different first languages (Arabic, Bengali, Cantonese, Czech, Dutch, English, Finnish, German, Greek, Hebrew, Irish/Gaeilge, Italian, Japanese, Polish, Portuguese, Romanian, Russian, Scots, Slovenian, Spanish, Turkish, and Twi), and 21 different countries of birth (Bangladesh, Brazil, Czech Republic, Finland, Germany, Ghana, Greece, Hong Kong, Israel, Italy, Japan, Moldova, Netherlands, Poland, Russia, Saudi Arabia, Slovenia, Spain, Turkey, United Kingdom, and Venezuela).

Of the 34 autistic children represented (mean age = 10.6 years, SD = 7.1, range = 3–38; 7 females, 26 males, 1 non-binary), 21 only had a clinical diagnosis of autism, while 13 had both autism and one or more other clinical diagnoses: ADHD (5), developmental language disorders (6), dyslexia (1), dyspraxia (1), learning disability (5), or other neurodevelopmental conditions (4). Mean age at their first referral for their first neurodevelopmental assessment was 5.1 years (SD = 5.4, range = 1–30), and mean age when receiving their first clinical diagnosis was 6.4 (SD = 5.4, range = 2–30).

Language profiles of the children

Figure 1 shows the respondents' rating of their autistic children's oral expression and comprehension skills in: (a) English (green), (b) responding[2] parent's first (or main) language other than English (yellow), and (c) another language that the child is exposed to, which is either a language that they acquired from their other parent and/or from other interlocutors/contexts (purple). All 34 children had proficiency skills rated in English,[3] 29 had their language proficiency reported for the responding parent's first language other than English, and 9 children had proficiency reported in another language. About 50% of the children (*n* = 17) had English understanding and speaking skills similar to that of their same-aged peers, while some children had a few sentences or less in their comprehension (18%, *n* = 6) and expression (29%, *n* = 10) skills. Overall language skills were lower in their main non-English language (i.e., the parent's first language) compared to English, with 34% (*n* = 10) having similar comprehension skills as their peers, and 28% (*n* = 8) for expressive skills. However, many children had language skills of a few sentences or less in both comprehension (45%, *n* = 13) and expression (52%, *n* = 15). When it comes to children speaking an additional language (*n* = 9), 44% (*n* = 4) had comprehension skills similar to that of their same-aged peers, though most children (67%, *n* = 6) were reported to have expressive skills of a few sentences or less.

Decisions on bilingual upbringing

Quantitative responses

Of the 31 respondents, 27 reported their children were raised with more than one language at home, 26 reported that before their child's diagnosis they were planning to raise them bilingually, and 12 reported that receiving the diagnosis had led them to reconsider their decision. When asked to select the reasons that led them to decide what languages they would use with their child (Figure 2), most of these 27 respondents listed as a reason to choose bilingualism a wish for their child to understand their family at

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[1] www.onlinesurveys.ac.uk

[2] By responding parent we refer to the parent who completed the online survey.

[3] The comprehension skills in English were not reported for one child. Therefore, we have English expressive skills scores for all 34 children, while there are English comprehension skills scores for 33 participants.

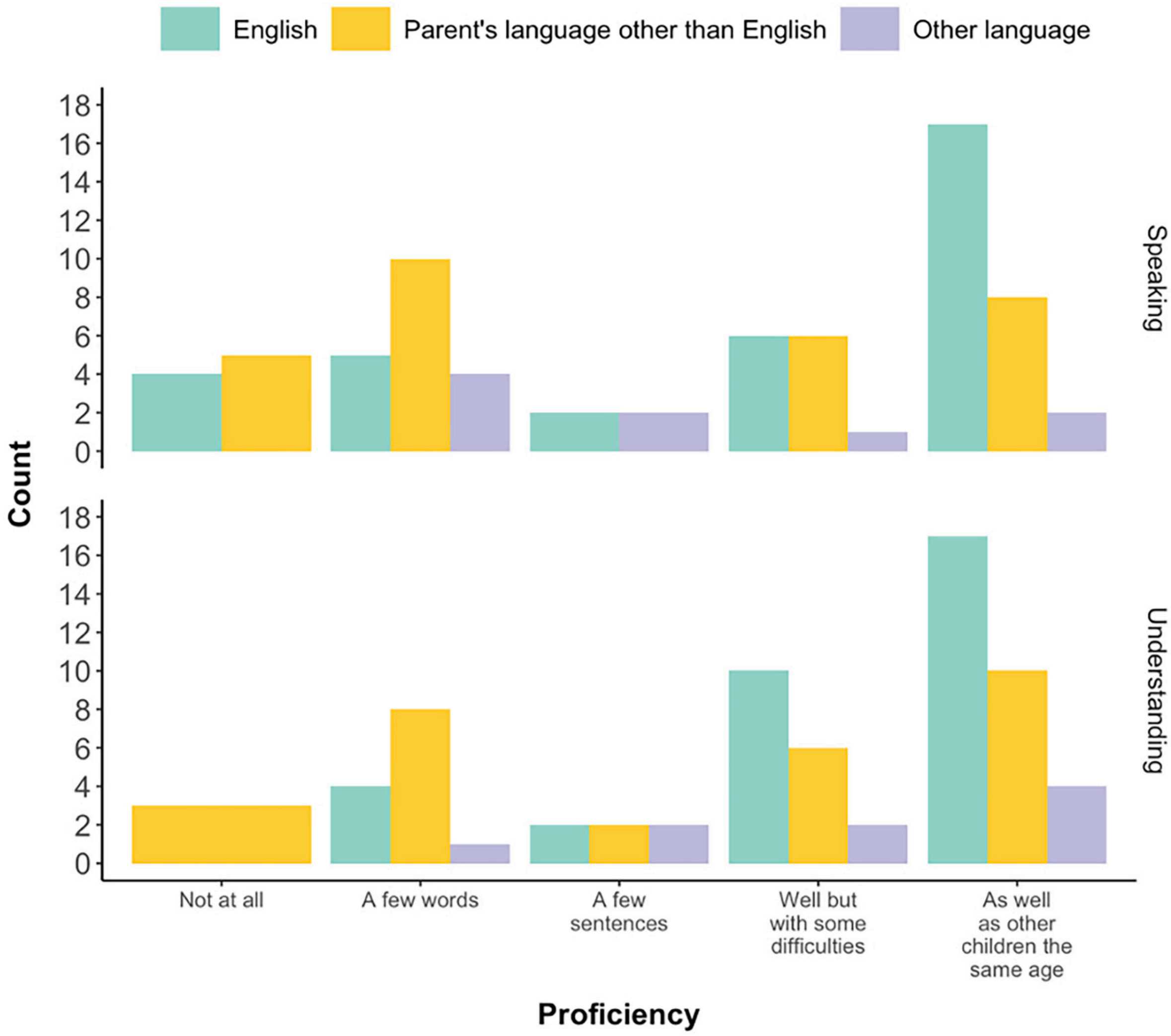

FIGURE 1
Parent-reported oral expression and oral comprehension skills of their autistic children in the languages they are exposed to. For each child, the proficiency scores were not necessarily provided for all three groups of languages presented in the figure: English (green), responding parent's language other than English (yellow), and other language that the child is exposed to (purple). This means that the proficiency of some children was rated for English and parent's language other than English only, while for some other children this included English and other language only. There were also trilingual children, for whom the rating was given for all three languages.

home (48%, $n = 13$), their extended family outside the home (63%, $n = 17$), and people in their community (37%, $n = 10$).

Qualitative responses

To supplement the counts presented in Figure 2, we looked at the open-ended questions regarding decisions on bilingual upbringing. Considering that the open-ended questions were optional and not frequent, we did not collect a number of qualitative responses deemed large enough to require a comprehensive coding approach. We therefore grouped and addressed these open-ended responses by looking at three cohorts of parents that emerged from our data based on the families' bilingual (or monolingual) practices. These included: (1) parents who do not speak more than one language with their child/ren, (2) parents who indicated that they speak more than one language to their child/ren and who *intended* to use more than one language with their autistic child/ren prior to their child/ren's diagnosis, and (3) parents who indicated that they speak more than one language to their child/ren and who *did not intend* to use multiple languages with their autistic child/ren prior to their child/ren's diagnosis.

The first focus was on responses from the four participants who do not speak more than one language with their child/ren. While three participants initially intended to use more than one language with their child/ren, they changed their minds upon their child receiving a diagnosis. The following clarifications were provided by two families:

> Parent 27: "My children 1st language is English although my husband and I speak French. My 1st born was exposed to our native languages, and we spoke to him in French. However, when we realised he had a language delay and was referred for an autism diagnosis, we decided to use English with him to help him 'catch up' on the use of English language." They further added that they "gave up on using our native languages

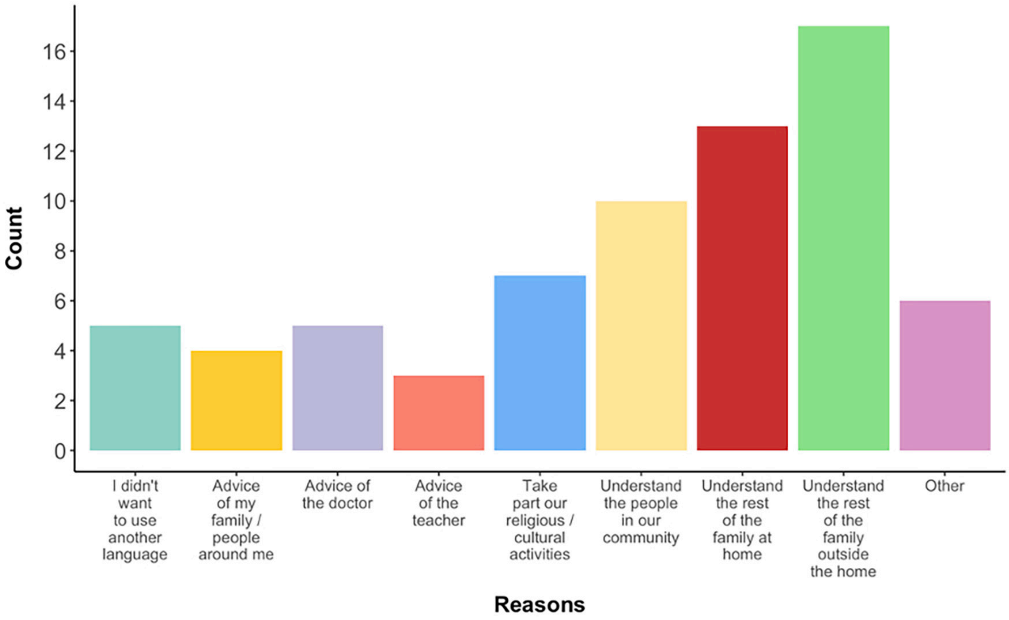

FIGURE 2
Respondents' reasons (in numbers) for choosing bilingual upbringing for their autistic children.

> in favour of English to help them develop language and communication skills used in the community they live in."[4]
> Parent 37: "Basically, our view is about practicalities. We live in an English-speaking country, and we decided that we should concentrate in it to make sure our children are able to speak the language in the country they live in. Besides, my wife and her family are native English speakers."

The second focus of responses included participants who indicated that they use more than one language with their child/ren and who intended to use more than one language with their autistic child/ren *prior* to their child/ren's diagnosis. From the 23 parents in this sample, six respondents changed the way in which they use their languages with their autistic child/ren after they received a diagnosis. These six parents provided the following clarifications:

> Parent 2: "Were advised to speak only Arabic with him. Then he joined English language nursery here at [anonymised]. We started to use more English, as we thought he might prefer English. I attended a seminar by [anonymised] and decided to speak both with him." This parent also clarified that "The father's Ph.D. topic has a minor in family language policy. I have decent information on how to raise my child bilingually. Yet I have to admit it didn't help much with my neurodivergent child."
> Parent 4: "Speech and Language therapist suggested our son with special needs couldn't learn the language as others so we should stick with one language with him."
> Parent 10: "We felt that there wasn't clear evidence from the speech and language therapist that using both languages at home was beneficial or on the other hand confusing for our son as already there was speech delay, and it is still the case."
> Parent 26: "At the beginning she wasn't speak any word and start to speak and language therapy in English. Unfortunately, I have to pick the English over the my mother tongue."
> Parent 35: "It's hard to know because of my child's language delay how much he understands. I have read leaflets that hearing two languages won't confuse him, but to me it already seems that English alone confuses him. His speech therapist did not know much about bilingualism and had no advice. (He has now been discharged anyway)."
> Parent 40: "Because the younger child is non-verbal, our communication has to be very simple. Another language is used sometimes is purely out of coincidence or that had been used since birth, which is also at a minimal level due to his understanding of the spoken word. For the teenager, I changed my mind about pushing him to learn my mother tongue because of his autism. I didn't want to give him extra pressure but my husband and I use Cantonese and French on some occasions for fun or for special greetings. This is so that our son can grow up knowing the existence of these languages esp Cantonese but he doesn't necessarily have to learn it, as long as he doesn't resent it is our aim. He loves French at school and has been learning Spanish, too. My own experience of living in [anonymised] has perhaps had an influence on him."

In the same cohort of 23 families, 17 decided to continue using multiple languages with their child/ren *after* a diagnosis was received. In addition to reasons summarised in **Figure 2**, several participants provided clarifications:

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[4] To preserve the authenticity of respondents' voices, we did not correct their writing into standardised English. Slight modifications were made only when we removed certain details for anonymisation purposes, which we indicated in square brackets.

> Parent 8: "I thought it could be an opportunity to have a job as a translator/interpreter if they want. It could be a backup job while they are looking for a their dream job or a source of additional income if needed."
> Parent 17: "Natural to speak whichever language best conveys the emotions and communications you aim to convey. i.e., what feels right."
> Parent 31: "Support their general development of language, and awareness that not everyone speaks English in the world."
> Parent 34: "The change to learn my language without accent and the fathers language without accent."
> Parent 36: "As a speakers of a minority language it was really important for me for reasons of emotion and identity and survival of our language too as well as all the above reasons. The children's father and I had both been brought up bilingually and had very positive experiences of this (and the support of our families)."

The final subset of responses included four parents who reported currently using more than one language with their child/ren but who did not intend to use multiple languages with their autistic child/ren *before* the diagnosis was received. Of these four families, three changed their mind after their child received a diagnosis, and one did not. From three parents who indicated changing the way in which they speak with their autistic child/ren after the diagnosis, one ended up opting for using English only while two parents opted in favour of bilingualism. Those two parents indicated the following:

> Parent 6: "We adjusted our communication in both languages. We made our sentences short and with clear instructions. Also we spoke slowly. In addition, we started speaking English to our children at home when doing homework or speech and language therapist therapies, and also in the public we tend to speak English more than Russian to share the common language environment and to include other people in our conversations with children."
> Parent 18: "I became more understanding of my child's needs."

Looking at the combination of quantitative (**Figure 2**) and qualitative responses, the reason for (not) choosing to raise autistic children bilingually varied widely. The findings are addressed in detail in section "Discussion."

Attitudes towards bilingualism

Respondents reported a similar pattern of attitudes from community members, clinicians, family members, and teachers, towards bilingual upbringing for autistic children (**Figure 3**). No respondents reported very unsupportive attitudes from either group, with most common attitudes being no opinion or a very supportive attitude across all groups of key partners. An overall positive ("a bit" or "very" supportive) attitude towards a bilingual upbringing for autistic children was reported from community members (18 respondents, 58%), clinicians (16 respondents, 52%), family relatives (20 respondents, 65%), and educators (18 respondents, 58%).

Sources of information regarding bilingualism

Ten respondents (32%) received information about raising autistic children in a bilingual context (**Figure 4**). The majority of participants had found information online (n = 6), or through support groups (n = 4). Few reported receiving information from their clinicians (n = 2) or teachers (n = 1). Of these 10 respondents, 5 indicated being aware of the research in this field.

Discussion

This study aimed to elicit the views of UK-based parents of autistic children who have the potential to be raised in a bilingual environment. In this section we first discuss three questions which were the focus of our study: the reasons why parents decided (not) to raise their child/ren in a bilingual environment, the sources of information that affected such decisions, and the influence of attitudes from various groups on the parental decision-making process. Following this, we summarise a desiderata for improved practice and discuss the feasibility of achieving these targets in the UK socio-political context. We also comment on the importance of moving away from the exceptionalism of bilingualism in order to prevent reinforcing myths/stigmas about both bilingualism and autism. We acknowledge the limitations of our study before closing with concluding remarks.

Reasons for (not) choosing bilingualism

The most common reason that parents listed for choosing a bilingual environment for their children was to provide additional opportunities for their children to better understand the family both inside and outside the home and to integrate with members of their community. This data demonstrates a somewhat obvious fact that bilingualism is likely a requirement for functional relationships within a local community and in family circles where more than one language is used. Consequently, advising against bilingualism can lead to a serious damage to family/community dynamics and wellbeing [for discussions on the importance of bilingualism for child wellbeing in general, see work by Müller et al. (20)].

As parents in the survey were asked this question in relation to all their children (including neurotypical children), it is likely that in some of these families who generally use multiple languages, they raised their autistic children monolingually for a variety of reasons. The questions regarding the influence of a diagnosis on parents' decisions to raise their children bilingually/monolingually helped to disentangle this. Six families indicated that they changed their child's linguistic environment following the diagnosis, although some did return to bilingualism – highlighting the dynamic nature of this decision-making process.

Open-ended responses further revealed several factors that affect parental decisions on bilingualism. These included advice from speech and language therapists (SLTs), situations in which SLTs did not feel confident in providing advice, or where access to language therapy was only available in the societal language. Parents also described their own concerns that hearing or speaking

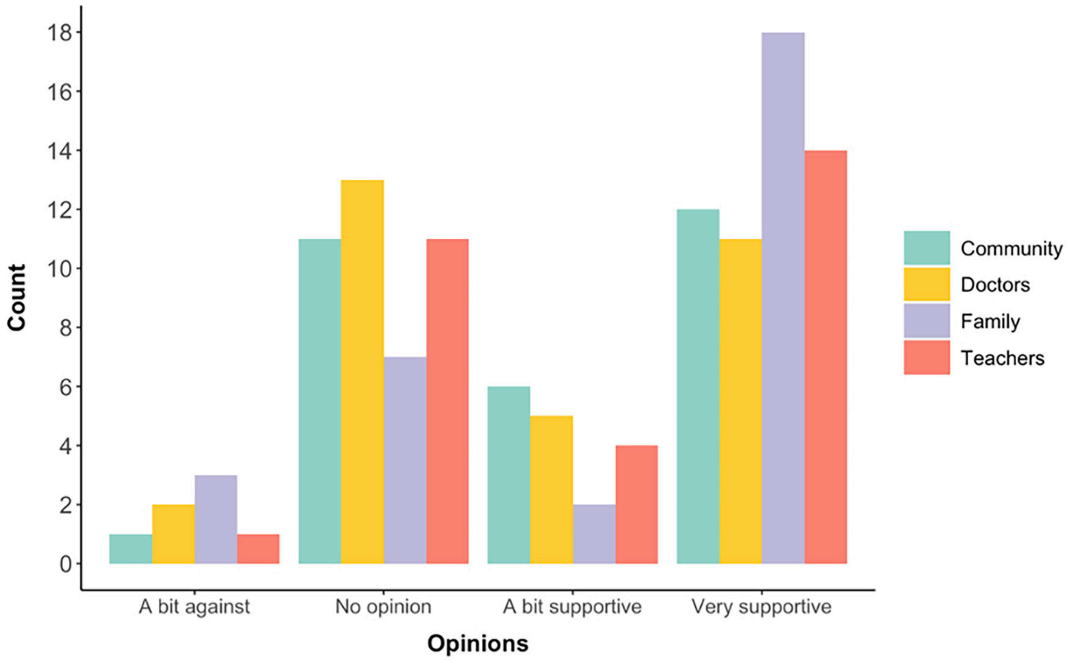

FIGURE 3
Attitudes towards a bilingual upbringing (in numbers) for autistic children reported for four cohorts (community members, clinicians, family members, and teachers).

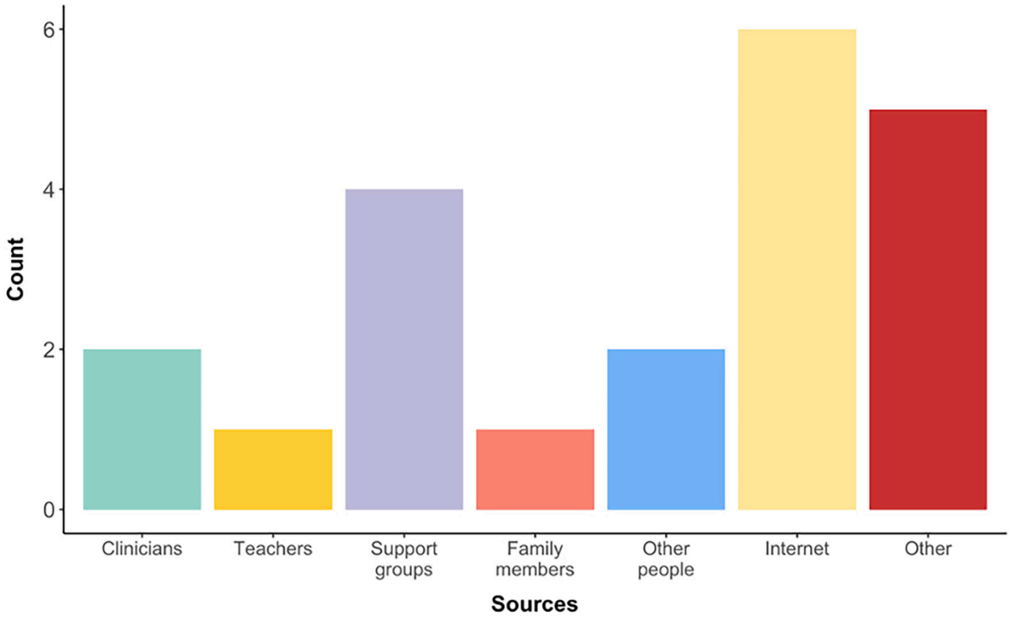

FIGURE 4
Sources of information regarding bilingual upbringing for autistic children. Selecting "Other" allowed for open entries, which were completed by respondents with "Books," "Speech and Language Therapists" (which could have been placed under "Clinicians"), "Webinar," and "Own research/publications."

more than one language could be confusing, and that for minimally verbal children, bilingual environments could cause additional pressure on the child using language in the future. Importantly, one of the respondents who returned to bilingualism with their autistic child reported that even though their partner knew about bilingualism from their own doctoral research, this knowledge did not help when raising their neurodivergent child. This point is addressed further below in the discussion.

This qualitative dataset of six families supplements the quantitative data presented. Although this is a small sample, the testimonies are in line with reflections from previous research from families with autistic children [e.g., (3–5)]. To understand the prominence of these concerns and to map the dynamic nature of decision-making about bilingual upbringing, a follow-up qualitative approach using semi-structured interviews could offer a more comprehensive understanding of the question which we focused on in this study [as per Howard et al. (5), for example].

Information available to parents and relevant stakeholders

As our data indicated that the advice about bilingualism somewhat affected parental decisions on raising their autistic children with(out) multiple languages, we now focus on the research question inquiring about available sources of information on bilingualism and autism. Only 10 respondents reported receiving information about raising their children bilingually. Even within this small cohort, the sources of information varied extensively, with the majority of individuals finding information online. This sets a significant task ahead when it comes to communicating scientific findings beyond academia.

What can be taken from the current findings is the following list of actions which would contribute to a more informed and accessible bilingual upbringing of autistic children: (1) a need to provide training for SLTs about the intersection of bilingualism and autism, and (2) a need to communicate relevant research to other key stakeholders (e.g., teachers, parents, and policy makers) in an accessible format. Pathways to undertaking these actions are many. We briefly discuss these points in relation to some relevant practices from the UK context.

When it comes to the training of future SLTs, as highlighted in Pert [(21), p. 204], including teaching on bilingualism and cultural diversity in the curriculum of pre-qualification SLT programmes would contribute to a solution. Indeed, the Royal College of Speech and Language Therapists[5] (RCSLT) curriculum guidance for the pre-registration education of SLTs contains bilingualism[6] as a content area integral to the development of future SLT skills (22). Anecdotally, we are aware that the contact hours dedicated to bilingualism in UK SLT programmes vary extensively – while some programmes dedicate a whole module to this topic, others have the topic integrated in various courses. Moreover, the increase in integrating the content on bilingualism in the UK SLT programmes seems to have occurred in the last few years. Unfortunately, we lack comprehensive information on how systematic this is across the UK universities. These speculative conclusions based on personal communication imply that SLTs who were trained in the last few decades might not have received the same amount of training on working with bilingual children as the newer generations of SLTs have/will. While this could be somewhat mitigated through continuing professional development (CPD) training, the availability or free access to relevant courses is not always guaranteed. We highlight that our conclusions on this point are based on anecdotal evidence. More research in this area and investment in training SLTs is necessary in order to improve the work of SLTs with bilingual families.

Bilingual parents of autistic children, as well as other relevant stakeholders, such as teachers and policy makers, are also in dire need for accessible information on interactions between bilingualism and autism. In a recent initiative from the University of Edinburgh and Queen Margaret University, accessible resources on autism and bilingualism have been produced in written format (in multiple languages) as well as in the form of a video (23, 24). Increasing such engagements of researchers with the relevant stakeholders could contribute to providing accessible state-of-the-art information necessary to inform choices about bilingual upbringing in autism. What is missing, however, is more extensive research and communication about not only the interaction of bilingualism and autism but also on how to raise autistic children bilingually in the UK context. Going forward, including parents and autistic individuals in the study designs could help direct research on community priorities and ensure the facilitation of access to bilingual environments as well as to strategies for bilingual upbringing.

Attitudes towards bilingualism

The study also explored the attitudes towards bilingualism and autism which parents of autistic children encountered among the local community, doctors, family members, and teachers. In the current sample, we identified a difference in attitudes towards bilingual upbringing in comparison to earlier work on this topic. For example, in an international study with most participants from Canada and the US, Kay-Raining Bird et al. (4) found that the majority of parents (regardless of whether they raised their autistic children monolingually or bilingually) received negative advice regarding bilingualism. More recently and in the UK context, Howard et al. (6) found that a group of practitioners expressed concerns about the feasibility of bilingualism for autistic children. Howard et al. (5) further confirmed this trend of negative advice regarding bilingualism and autism offered to parents by practitioners or family members. In the current sample, the majority of parents reported supportive attitudes regarding bilingualism from key stakeholder groups (local community, doctors, family members, and teachers). Importantly, while these groups had some instances of negative attitudes towards bilingualism, no group expressed strong negative views. The increase in positive attitudes in comparison to earlier literature on the topic could be partly due to the increase in the number of studies with autistic bilinguals over the last decade, and subsequently more research demonstrating a lack of negative effects of bilingualism. As Prévost and Tuller (10) report in their recent review of studies with autistic bilinguals, around half of the papers on the topic (11 out of 20) appeared in the last 3 years. We return to the discussion on the effect of bilingualism, particularly to the quest for bilingual advantage further below.

While the predominantly positive attitudes towards bilingualism in the current sample are welcome, we cannot claim with certainty that they can be generalised throughout the

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[5] The Royal College of Speech and Language Therapists is the professional body for SLTs in the UK.

[6] The RCSLT guidance uses the term multilingualism rather than bilingualism. As in this article we used the term bilingualism to refer to the knowledge/use of two or more languages, we chose to use the term bilingualism here for consistency purposes.

UK, especially bearing in mind our sample size. Additionally, to better understand any stigma associated with bilingualism, it is important to look beyond the specific research question that we focused on (i.e., attitudes towards bilingualism that bilingual families of autistic children encountered in their networks) and situate our research in the wider UK context. For instance, recent data from YouGov (25) indicated that about a quarter of 1,461 surveyed British participants expressed being bothered when they hear people speaking in a language other than English. Such a strong presence of xenophobic attitudes likely impacts views towards bilingualism across sectors, including in the stakeholder networks which we inquired about in the present study.

When it comes to the UK SLT practice in particular, Pert [(21), p. 198] notes that a negative attitude towards languages other than the mainstream ones (such as English or Welsh) is one of the factors likely related to predominantly English-only approaches to assessment and intervention. In interaction with other factors that come into play (e.g., the cost of interpreters in the SLT practice, the availability of resources in languages other than English, the working conditions of practitioners, etc.), this English-only SLT support can thus affect bilingual families' decision-making process about maintaining the use of more than one language with their autistic children.

A striking finding from this study is that within each of the four stakeholder groups (i.e., local community, doctors, family members, and teachers), there is a significant portion of individuals with no opinions on bilingualism (35, 42, 23, and 35% respectively). For comparison, Howard et al. (5) identified that no advice regarding bilingualism was the most frequent answer in their UK-based cohort of parents. Despite the increase in studies with autistic bilinguals (as pointed out above) and positive attitudes towards bilingualism which we identified, the significant number of parents reporting no opinions received across their networks could indicate that there is somewhat still a lack of easily available information on bilingualism. This is particularly worrying when it comes to teachers and clinicians, and it implies a need for providing resources and comprehensive training on bilingual development to these stakeholder groups, as has been suggested by Davis et al. (26), Pert [(21), pp. 204–206], and in our discussion above.

While the attitudes towards bilingualism in our sample are predominantly positive, the reality of raising autistic children bilingually remains challenging. As indicated by a parent in the current sample, attending a session on bilingualism can help them make decisions about raising their children bilingually. Nevertheless, as the same parent pointed out, even with relevant information, parents and autistic children still face challenges when it comes to a bilingual upbringing. These concerns corroborate those identified in a group of practitioners and parents in Howard et al. (5, 6), where the feasibility of bilingualism for all autistic children was found to be questionable. In addition to working on changing negative attitudes on bilingualism, stronger support services, such as the investment of government funding in the National Healthcare Service (NHS), in the education sector, and in local councils is necessary to ensure access to bilingualism for more autistic children, while acknowledging that individualised advice from clinicians and educators will still have to be given on a case-by-case basis (6).

Desiderata and challenging the status quo

The analysis of our dataset leaves us with the following desiderata for future practice: (1) a need for more comprehensive training/education of SLTs regarding bilingualism and autism, (2) a need to communicate research findings on autism and bilingualism to other relevant stakeholders in an accessible way (parents, teachers, doctors, and policy makers), (3) a need to confront stigmas about both autism and bilingualism and their intersection particularly in relation to negative attitudes and xenophobic views, (4) a need to support bilingual families with autistic children and provide them not only with information on the current research on the topic, but also with strategies and resources for bilingual upbringing. Achieving these targets requires an immense amount of work and collaboration by several groups of stakeholders, such as healthcare professionals, educators working in the primary, secondary and higher education context, policy makers, as well as families of children with autism. While our desiderata is a wish-list akin to suggestions from other work on the topic [e.g., (5, 6, 21, 27)], we find that it is important to address it by situating the findings of our research into the UK socio-political context in order to assess its feasibility.

First, we focus on working conditions of relevant stakeholder groups. A recent survey by RCSLT (28) indicated a national average vacancy rate in the SLT profession of 23%. The same report identified a need for improved workforce planning, a need to train more students, to retain and develop the workforce, as well as a need for improvement in funding. Whether this will change, ultimately depends on government support and funding given to both the health and the education services. In recent years, the austerity experienced across the UK resulted in industrial actions both in healthcare and education. The working conditions of teachers, health and support workers, as well as those in higher education who conduct research and provide training/teaching for future health and education workforce have significantly deteriorated. These conditions inevitably affect the quality of what is being investigated, communicated, taught and disseminated to stakeholders and families with autistic children. While our research-informed desiderata outlines necessities of the communities that we work with, solidarity and participation in the ongoing industrial actions as well as socio-political engagement are vital for systemic changes to take place – this is what will ultimately improve the quality of life of bilingual families with autistic children. Maintaining the *status quo* will not contribute to improving lives and breaking stigmas that both autistic and bilingual communities face, and particularly those at their intersection.

Moving away from the *status quo* will also be important to ensure changes in attitudes towards bilingualism and autism. Considering the presence of xenophobic views in the UK, maintaining the *status quo* as SLTs, researchers, teachers, and other clinicians makes us complicit with discrimination that affects bilingual families in general, as well as those with autistic children. A discussion on challenging *status quo* in relation to SLT practice in the bilingual context is offered in Pert [(21), pp. 198–215]. To those points, we add a need for participation in and solidarity with relevant industrial actions, as well as other forms of activism which will drive the long overdue systemic changes.

Avoiding the exceptionalism of bilingualism

The final point which we address goes beyond the scope of this study, but it is particularly relevant when considering access to information on bilingualism and autism. As it has been discussed above, the internet was identified as the most common source of information on the topic in our sample. When it comes to bilingualism in particular, the plethora of information available online and directed at the general audience can sometimes overestimate the implications of bilingualism as an experience and reinforce myths or even stereotypes about using multiple languages. An extreme example of lay interpretations of research attempting to make bilingualism sound attractive can be found in articles such as that by Riotta (29).

These attempts to present bilingualism as an exceptional experience are somewhat existent in our own work and research culture. They can be particularly problematic when it comes to investigating bilingualism, autism, and cognition. As mentioned earlier, work with autistic bilinguals indicates potential benefits in cognitive skills [e.g., (12)]. On the one hand, exploring possible cognitive benefits of bilingualism could be seen as an attempt to encourage families to preserve the use of multiple languages with their autistic children. Indeed, this has been observed in Howard et al. (5). On the other hand, while these investigations are likely well-intended, approaching bilingualism exploration with reference to monolinguals and identifying possible cognitive advantages could be seen as another way of attempting to justify the value of bilingualism in a space dominated by monolingualism-centred expectations – as if the bilingual experience does not have its own value and is not worthy of exploration unless it can offer particular cognitive advantages. Furthermore, these approaches could backfire and have a detrimental effect on the family decision-making process regarding preserving bilingual practice. For instance, if a study identifies that autistic bilinguals are significantly slower on a particular executive function task than autistic monolinguals, which might be translated to being 200 ms slower, is it worth dropping one language for the fear that bilingual exposure might have something to do with this? Specifically, is the cost of 200 ms on one executive function task more important for the wellbeing of an autistic child and their family than the ability to communicate with the family and their network of speakers by using all languages commonly present in their environment? The majority of our sample indicated that they chose bilingual upbringing for their autistic children in order to enable them to communicate with the family and the members of the local community. The importance of this has also been noted in previous work [e.g., (5, 7)]. The shift in research focus is therefore required, as our pursuit for cognitive advantages of bilingualism in autism inevitably contributes to the exceptionalism of bilingual experience and can have negative effects on family decision-making process and ultimately wellbeing.

The bilingual cognitive advantage quest in autism can also (unwillingly) contribute to reinforcing stigmas about autism. For instance, if the common assumption is that bilingualism improves specific aspects of cognition, it might mitigate certain difficulties in autism – therefore, it is good for autistic individuals. Such an approach is inadequate as it assumes that the cognitive profile of autism automatically equates to deficits and the almighty bilingualism is there to save the day. Most of us are guilty of approaching research on bilingualism and autism in such a way. Instead, we should explore whether the existing ways in which we tap into cognitive skills (which are primarily designed with a neurotypical individual in mind), are affecting how autistic individuals perform on these measures. Moving away from problematic designs could help us focus on investigations of bilingual experience in autism that reduce the stigmas of both being autistic and being exposed to more than one language as an autistic individual. Going forward it is necessary to centre participatory approaches – through which lived experiences of autistic individuals can be incorporated into the exploration of bilingualism – thus minimising biases that we as neurotypical researchers bring to the field. Importantly, as researchers we need to prioritise communicating findings beyond academia in a responsible way, to prevent situations in which our advice could contribute to stigmatising autism, and in relation to bilingualism lead families to drop one of their languages when there is no reason strong enough to do so. For further criticism of the bilingual advantage quest beyond the work in autism, see Leivada et al. (30). Rothman et al. (31) also offer a recent discussion on monolingualism-centred investigations of bilinguals which are important to consider in future research.

Limitations

One of the limitations of this study is what might be perceived as a small number of participants for broader generalisations. However, over half of the published studies on autism and bilingualism to date have included 20 or fewer autistic bilinguals (10). As autistic bilinguals represent a hard-to-recruit population in the UK, expectations of studies with larger samples are somewhat unrealistic without a longer period even for cross sectional data collection and collaborative efforts (10). We experienced this difficulty in the current study, as it took 18 months to collect responses from 40 families with children with neurodevelopmental conditions (including 31 bilingual families with 34 autistic children). Considering these circumstances, our sample is a significant contribution to the field of bilingual development in autistic individuals. As all respondents are based in one country, this also enables us to situate their experiences in a single context. We do note, however, that although larger samples can likely lead to more relevant conclusions for a larger proportion of the target population, significant variability in both bilingual and autistic experiences could be better captured with the addition of qualitative research. We have attempted to include this aspect in our survey by adding some open-ended questions, but offering opportunities for interviews or alternative modes of communication could improve future work in this area.

As the largest portion of our data collection period took place during the pandemic, an online survey was considered more practical rather than offering options for an in-person interview. The option of offering an online interview was considered, but as it would require asking for more commitment by the participant (e.g., finding adequate time for an online meeting that fits both the participant and the researcher), this option was not implemented. These restrictive conditions likely affected the number of recruited participants. Therefore, more inclusive participation approaches should be offered to prospective participants in future, not only to increase the participant numbers, but also to enable participants to choose a participation mode most suited to their needs.

A second limitation includes not compensating the respondents for their participation in the study. This was determined by limited funds available to the authors of the paper, some of whom were on precarious contracts during the time of the study design, data collection and analysis, and writing. On the one hand, as suggested by Pellicano et al. (32) in their recent discussion of data integrity from online studies on autism, the lack of financial incentive for participation may decrease the chances of recruiting any financially motivated study scammers. Nevertheless, the lack of participation reimbursement raises several issues, as pointed out in Pellicano et al. (32): a suggestion that participants' time is not valued, exploitation of the autistic community for research purposes, damaging trust between researchers and autistic communities, exclusion of lower-income participants, and bias towards more financially comfortable people and those with intrinsic interest in the research topic. Apart from expressing gratitude to our participants, we need to do better in future research and ensure just compensation for participation time.

Conclusion

This work expands on previous evidence regarding the decision-making process that bilingual families experience when raising autistic children. We provide evidence of increased positive attitudes towards bilingualism and autism in the UK context. Nevertheless, a significant portion of key stakeholder groups (clinicians, teachers, members of the family, and the local community) still lack accessible information on bilingualism and autism. We offer suggestions on how to move forward in this area of research and highlight the importance of abandoning the *status quo* across our professional sectors for systemic changes to take place. It is important to acknowledge that our work is situated in a Western-centric context and approach to thinking about bilingualism and autism. What is also necessary is the engagement with alternative approaches of how bilingualism is conceptualised and experienced, or rather engagement with individuals and communities whose views and experiences have previously been pathologized and pushed to the periphery [for relevant discussions in the educational and the clinical contexts, see García et al. (33) and Nair et al. (34)]. This change of perspectives will play a crucial role in reducing stigma around bilingualism, and ultimately about ensuring access to bilingualism for autistic people.

Data availability statement

The raw data supporting the conclusions of this article will be made available by the authors, without undue reservation.

Ethics statement

The studies involving humans were approved by the School of Philosophy, Psychology and Language Sciences Research Ethics Committee, University of Edinburgh. The studies were conducted in accordance with the local legislation and institutional requirements. The participants provided their written informed consent to participate in this study. Written informed consent was obtained from the individual(s) for the publication of any potentially identifiable images or data included in this article.

Author contributions

BD, EJ, DK, and RD: study conceptualisation, study design, and data collection. BD, EJ, and DK: data analysis. BD, DK, and RD: manuscript writing. All authors contributed to the article and approved the submitted version.

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Conflict of interest

The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

Publisher's note

References

1. Grosjean F. *Life as a Bilingual: Knowing and using Two or More Languages*. Cambridge: Cambridge University Press (2021).

2. Drysdale H, van der Meer L, Kagohara D. Children with autism spectrum disorder from bilingual families: a systematic review. *Rev J Autism Dev Disord.* (2015) 2:26–38. doi: 10.1007/s40489-014-0032-7

3. Yu B. Issues in bilingualism and heritage language maintenance: perspectives of minority-language mothers of children with autism spectrum disorders. *Am J Speech Lang Pathol.* (2013) 22:10–24. doi: 10.1044/1058-0360(2012/10-0078)

4. Kay-Raining Bird E, Lamond E, Holden J. Survey of bilingualism in autism spectrum disorders. *Int J Lang Commun Disord.* (2012) 47:52–64. doi: 10.1111/j.1460-6984.2011.00071.x

5. Howard K, Gibson J, Katsos N. Parental perceptions and decisions regarding maintaining bilingualism in autism. *J Autism Dev Disord.* (2021) 51:179–92. doi: 10.1007/s10803-020-04528-x

6. Howard KB, Katsos N, Gibson JL. Practitioners' perspectives and experiences of supporting bilingual pupils on the autism spectrum in two linguistically different educational settings. *Br Educ Res J.* (2021) 47:427–49. doi: 10.1002/berj.3662

7. Jegatheesan B. Multilingual development in children with autism: perspectives of south Asian Muslim immigrant parents on raising a child with a communicative disorder in multilingual contexts. *Biling Res J.* (2011) 34:185–200. doi: 10.1080/15235882.2011.597824

8. Essex J, MacAskill MG. Modern foreign language education for learners with additional support needs in Scotland. *Support Learn.* (2020) 35:440–53. doi: 10.1111/1467-9604.12325

9. Uljarević M, Katsos N, Hudry K, Gibson J. Practitioner review: multilingualism and neurodevelopmental disorders—An overview of recent research and discussion of clinical implications. *J Child Psychol Psychiatry.* (2016) 11:1205–17.

10. Prévost P, Tuller L. Bilingual language development in autism. *Linguist Approach Biling.* (2022) 12:1–32.

11. Montgomery L, Chondrogianni V, Fletcher-Watson S, Rabagliati H, Sorace A, Davis R. Measuring the impact of bilingualism on executive functioning via inhibitory control abilities in autistic children. *J Autism Dev Disord.* (2022) 52:3560–73.

12. Gonzalez-Barrero AM, Nadig AS. Can bilingualism mitigate set-shifting difficulties in children with autism spectrum disorders? *Child Dev.* (2019) 90:1043–60. doi: 10.1111/cdev.12979

13. Iarocci G, Hutchison SM, O'Toole G. Second language exposure, functional communication, and executive function in children with and without Autism Spectrum Disorder (ASD). *J Autism Dev Disord.* (2017) 47:1818–29.

14. Kim, HU, Roberti M. Tengo que habla español. Yo no entiendo ingles!": a qualitative case study on a bilingual child with autism spectrum. *J Spec Educ Apprenticesh.* (2014) 3:7.

15. Nolte K, Fletcher-Watson S, Sorace A, Stanfield A, Digard BG. Perspectives and experiences of autistic multilingual adults: a qualitative analysis. *Autism Adulth.* (2021) 3:310–9. doi: 10.1089/aut.2020.0067

16. Digard BG, Davis R, Stanfield A, Sorace A, Fletcher-Watson S. "The languages that you know draw the boundary of your world": a thematic analysis of the experiences of autistic bilingual adults living in the United Kingdom. *Autism Adulth.* (2022) 4:328–39. doi: 10.1089/aut.2021.0077

17. Department of Education. *Schools, Pupils and their Characteristics.* (2023). Available online at: https://explore-education-statistics.service.gov.uk/find-statistics/school-pupils-and-their-characteristics/2022-23#explore-data-and-files (accessed June 27, 2023).

18. National Autistic Society. *What is Autism?* (2023). Available online at: https://www.autism.org.uk/advice-and-guidance/what-is-autism#:~{}:text=Autism%20is%20a%20lifelong%20developmental,and%20children%20in%20the%20UK (accessed June 25, 2023).

19. De Cat C, Kašćelan D, Prévost P, Serratrice L, Tuller L, Unsworth S. How to quantify bilingual experience? Findings from a Delphi consensus survey. *Biling Lang Cogn.* (2023) 26:112–124. doi: 10.1017/S1366728922000359

20. Müller L-M, Howard K, Wilson E, Gibson J, Katsos N. Bilingualism in the family and child well-being: a scoping review. *Int J Biling.* (2020) 24:1049–70. doi: 10.1177/1367006920920939

21. Pert S. *Working with Children Experiencing Speech and Language Disorders in a Bilingual Context: A Home Language Approach.* Milton Park: Routledge Taylor and Francis Group (2023).

22. Royal College of Speech and Language Therapists [RCSLT]. *Curriculum Guidance for the Pre-Registration Education of Speech and Language Therapists.* (2021). Available online at: https://www.rcslt.org/wp-content/uploads/2020/08/RCSLT-Curriculum-Guidance-March2021.pdf (accessed July 23, 2023).

23. Digard BG, Davis R. *My Child is Autistic, should they Learn more than One Language?* (2021). Available online at: https://autism-bilingualism.github.io/resources/ (accessed July 24, 2023).

24. Digard BG, Davis R. *Autism and bilingualism. Can autistic people learn and use several languages?* (2023). Available online at: https://www.youtube.com/watch?v=oPctNHggQJI&t=1s (accessed July 24, 2023).

25. YouGov. *When in the UK, are you bothered when you hear those from a Non-English Speaking Country Talking to each other in their Own Language, or not?* (2020). Available online at: https://yougov.co.uk/topics/politics/survey-results/daily/2020/02/03/66818/3?utm_source=twitter&utm_medium=daily_questions&utm_campaign=question_3 (accessed June 25, 2023).

26. Davis R, Fletcher-Watson S, Digard BG. Autistic people's access to bilingualism and additional language learning: identifying the barriers and facilitators for equal opportunities. *Front Psychol.* (2021) 12:741182. doi: 10.3389/fpsyg.2021.741182

27. Davis R, Zaki FM, Sargent L. Autism and bilingualism: a thematic analysis of speech and language practitioners' experiences. *Open Sci Framew.* (2020). doi: 10.31219/osf.io/fcpk2 [Epub ahead of print].

28. Royal College of Speech and Language Therapists [RCSLT]. *Fail to Plan, Plan to Fail: Speech and Language Therapy Workforce Planning in England.* (2023). Available online at: https://www.rcslt.org/wp-content/uploads/2023/04/Workforce-planning-in-England.pdf (accessed July 24, 2023).

29. Riotta C. *People Who are Bilingual are Smart, Creative and Better lovers.* (2015). Available online at: https://www.elitedaily.com/life/culture/bilingual-people-smart-creative-lovers/1012727 (accessed June 27, 2023).

30. Leivada E, Rodríguez-Ordóñez I, Parafita Couto M, Perpiñán S. Bilingualism with minority languages: why searching for unicorn language users does not move us forward. *Appl Psycholinguist.* (2023) 44:384–99. doi: 10.1017/S0142716423000036

31. Rothman J, Bayram F, DeLuca V, Di Pisa G, Duñabeitia J, Gharibi K, et al. Monolingual comparative normativity in bilingualism research is out of "control": arguments and alternatives. *Appl Psycholing.* (2023) 44:316–29. doi: 10.1017/S0142716422000315

32. Pellicano E, Adams D, Crane L, Hollingue C, Allen C, Almendinger K, et al. Letter to the editor: a possible threat to data integrity for online qualitative autism research. *Autism.* (2023). doi: 10.1177/13623613231174543 [Epub ahead of print].

33. García O, Flores N, Seltzer K, Wei L, Otheguy R, Rosa J. Rejecting abyssal thinking in the language and education of racialised bilinguals: a manifesto. *Crit Inq Lang Stud.* (2021) 18:203–28. doi: 10.1080/15427587.2021.1935957

34. Nair KKV, Farah W, Cushing I. A critical analysis of standardized testing in speech and language therapy. *Lang Speech Hear Serv Sch.* (2023) 54:781–93. doi: 10.1044/2023_LSHSS-22-00141

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Gender diversity in autistic clients: an ethical perspective

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Autonomy and dignity are key ethical principles in psychiatric and psychological codes of ethics. Yet, when working with autistic individuals who are transgender/gender non-conforming (TGNC), non-autistic and cisgender clinicians can unintentionally take away client dignity and autonomy by disbelieving or stigmatizing clients' gender identities. Lack of awareness or discomfort around autism and gender dysphoria can lead clinicians to assumptions and interventions that damage both client rapport and client mental health; discouraging clients from being honest with clinicians about their mental health, and potentially leading to harm. Clinicians must take an intersectional view of their autistic clients' gender identities to reduce stigma and recognize the needs of the whole person. Facilitating access to gender-affirming care is an important part of caring for TGNC clients, including those who are autistic. The authors will discuss the ethical imperative to help autistic clients access gender-affirming care, while discussing common concerns clinicians have when helping autistic clients access this care, as well as the need to believe and support autistic clients when they share their gender identities with clinicians.

KEYWORDS

autism, gender dsyphoria, gender-affirming care, ethics, autonomy

1. Introduction

Multiple studies have shown that autistic individuals are more likely than the general populace to experience gender dysphoria (1–3). In this paper, we will use the term 'transgender and gender non-conforming' (TGNC) to encompass individuals whose gender identities differ from those assigned at birth. This term includes transgender, non-binary, two-spirited, and other non-cisgender identities. The co-occurrence of TNGC identities and autism spectrum disorder presents a challenge to clinicians as guidance related to working with TNGC, autistic individuals is still being created and debated; clinical consensus is forming, but is not well established (4).

2. Current climate and impact on providers

Many discussions about TGNC individuals and autism do not address a clinician's ethical duties to clients; this is complicated by the increase in threats to clinicians' abilities to treat TGNC children and adults in many states; as laws pass that ban gender-affirming care, many clinicians may be increasingly reluctant to provide gender-affirming care for autistic individuals, as doing so is potentially more complex than providing care to non-autistic individuals and might subject clinicians to legal action or ethical complaints.

An emergency order issued by Missouri's Attorney General (5) specifically bans providing gender-affirming care to patients until they have received "comprehensive screening" to determine if the client is autistic; this implies that if the patient is autistic, that treatment might be restricted or different than treatment for a non-autistic individual, raising ethical questions for providers, as well as concerns for potential loss of license when treating TGNC, autistic clients.

Arkansas' law attempting to restrict gender-affirming care for minors, now struck down, attempted to restrict access to gender-affirming care for children with any concurrent mental health conditions, explicitly including autism (6). Georgia's Senate Bill 140 (7), includes in its rationale for banning gender-affirming care that "gender dysphoria is often comorbid with other mental health and developmental conditions, including autism spectrum disorder," which heavily implies the co-occurrence must be due to either over-diagnosis or some form of pathology.

In this difficult political climate, with spotty or inconclusive guidance, what is appropriate for a clinician to do when an autistic individual presents with gender dysphoria? We would suggest looking to ethical principles to guide us. The ethical principle of autonomy holds "that all persons have intrinsic and unconditional worth, and therefore, should have the power to make rational decisions and moral choices, and each should be allowed to exercise his or her capacity for self-determination (8). This remains true, even for clients who have developmental or intellectual disabilities; indeed, the onus is on us, as professionals, to make sure we are fostering autonomy in persons with developmental or intellectual disabilities (9).

Further, without paying attention to the inherent dignity of each client, we encourage shame, which harms their mental health. If we as clinicians see autism as a culture, as many writers suggest we should (10–12), we must understand gender dysphoria as something that intersects with autism spectrum disorder, as the APA recommends clinicians understand how gender identity and culture intersect (13). Paying attention to the culture of a client restores dignity, as the client feels understood by their clinician (14).

3. Assumptions and concerns

When discussing gender dysphoria in autistic individuals, many writers express concerns that gender may be a passing special interest or obsession for their autistic clients (15, 16) or assume the clients are experiencing identity confusion due to social struggles (17–19). These concerns and assumptions seem to be rooted in stigma and the belief that either autistic clients cannot be genuinely TGNC or that the gender concerns must be part of another mental health disorder.

Clinicians often begin by treating gender dysphoria in autistic people as though it will pass, given time. However, in several case studies, the client's gender dysphoria did not pass (20–23). Autistic individuals who are TGNC report being told by parents, professionals and others that their desire to be another gender is a passing obsession (24), even when the individuals in question feel certain about who they are. In one case study (15), gender dysphoria lasted multiple years; the writer takes it as a victory that, in time, after multiple years, the individuals did stop asking to transition, although after reading the case report, one wonders if the clients just gave up in exhaustion, due to constant invalidation. In sum, in most case studies, gender dysphoria was not transitory.

A few case studies attempted to 'correct' children who endorsed being a different gender than the one assigned at birth through behavioral treatment or medication; Janssen et al. (20) report in a case study in which "dress in a masculine manner" was included in a treatment plan for a client who was assigned male-at-birth; despite the client's clear preference for feminine clothing and desire to be seen as female. In this case, attempts at behavioral correction caused the client distress while shifting to gender-affirming care helped the client feel comfortable in her body. Another case study (21) describes similar, unsuccessful, attempts to change gendered behavior using behavioral principles. Attempts to use behavioral principles to shift gender-related behavior is a form of conversion therapy that is proven to be harmful (25).

Notably, Applied Behavioral Analysis (ABA), a form of autism treatment associated with trauma symptoms in autistic people (26, 27), was created by Ole Ivar Lovaas, who was also a proponent of conversion therapy for LGBTQ people (28). Lovaas was involved in the "Feminine Boy Project" where one of Lovaas' graduate students attempted to "correct" children's "disturbed" gender expression; one participant committed suicide in adulthood and his family blamed his suicide on participation in the experiment (28, 29). Many autistic self-advocates and queer disability theorists highlight the way both ABA and LGBTQ conversion therapy disregard the "possibility of following the needs, wants, or inner experiences and desires of children labeled autistic or gender "disturbed." (30) Attempts to behaviorally "correct" gender should be viewed with suspicion for many reasons, including this disturbing history.

Landen & Rasmussen (31) and Perera (32) describe two separate cases of gender identity concerns in autistic children; both initially saw the gender identity concerns as part of OCD, but when treated with medication, other OCD symptoms receded, but the gender identity concerns remained. This suggests that defaulting to see gender identity as relating to OCD may not be an effective path to treatment.

The idea that social struggles could underlie gender identity struggles is intriguing. An autistic person might struggle socially and conclude that they are not the gender they were assigned at birth. In one case (19), social communication rehabilitation did temporarily stop requests for gender-affirming care, but the client still ultimately returned to requesting gender-affirming care. A clinician should, with careful questioning, be able to discern the difference between magical thinking that transition will resolve a client's social struggles and a realistic appraisal of the risk and benefits of gender transition.

4. Ethical context to objections

While many concerns about the authenticity of gender dysphoria in autistic clients come out of a place of care, they inadvertently ignore ethical concerns related to client autonomy and dignity. Indeed, it is striking how rarely ethical concerns are raised. One case study (33) states unambiguously that the clients "retain the right to self-determination." Some other articles do state autism should not be a rule-out for gender-affirming care, but without clear emphasis on ethics.

One anticipated objection to providing gender-affirming care is that clinicians also have the ethical duty to not cause harm. Given that some gender-affirming medical treatments do have risks as well as benefits, is leaving a client's gender dysphoria untreated the right choice? We would argue no, as untreated gender dysphoria raises the risk of suicide for clients and causes other, negative, mental health impacts, whereas gender-affirming care reduces the risk of suicide and negative mental health outcomes in the long and short term (34–37).

In addition, even if a clinician sees providing gender-affirming care as 'risk,' what is our right to decide what risks a client takes on? Some writers argue persuasively for the dignity of risk (38, 39): to allow clients to take on self-chosen, well-understood risk respects both their autonomy and their dignity and reduces stigma and shame. We remove dignity when we 'protect' clients from risks and we violate our ethical principles. Autistic clients themselves understand this; in a qualitative study (40), autistic, gender-diverse participants discussed the distress and indignity of having to rely on external supports which invalidate and question the client's right to make their own decisions due to the client's autism. Autistic clients should retain the same rights to autonomy and the same human dignity as non-autistic clients; to act otherwise is to perpetuate stigma.

5. Adopting a new lens

All clinicians could benefit from utilizing a perspective toward autistic and TGNC people similar to the perspective shared with many new therapists: stay curious and collaborate with the client. The context of a client's life and how they have come to their perspective can be just as important as the perspective itself.

If a clinician has questions about the validity of an autistic client's gender identity, then in the interest of maintaining client autonomy, clinicians must first ask themselves why they question that validity. Does the client's feelings about gender distress the client or distress the clinician? Are we helping the client investigate, or are we pushing them in a certain direction? Self-doubt can be a common topic for TGNC people for a variety of reasons, and it's vital to a client's autonomy and dignity that clinicians provide support or guidance without pushing them in any one direction.

Self-doubt of gender identity often occurs for a variety of reasons, and can often be a symptom of anxiety or depression related to untreated dysphoria, public stigmatization, or a lack of community support. Research related to internalized oppression corroborates that stigmatization and oppression often lead people to doubt themselves; one study (41) shows that autistic persons may be especially susceptible to internalized ableism and especially sensitive to stigma. Experiencing 'double minority' status as both autistic and gender-diverse almost certainly takes a toll on self-confidence. Strang et al.'s (24) study reports that many autistic, TGNC youth "are at risk for being misunderstood in terms of their gender and gender needs;" clinicians should take special care with this population to seek to understand first. Clinicians who discourage gender identity exploration may inadvertently contribute to these internalized feelings. We believe clinicians best maintain client autonomy by helping guide the client through their feelings, and supporting them to find the answer that's right for their specific circumstances.

It is also important for clinicians to maintain flexibility as they work with TGNC and autistic clients. Standard practices to alleviate anxiety may be less effective when a client's community or support system holds hostile views towards non-cisgender people, or when the client has had bad experiences with previous clinicians. Clients may hold back information in initial sessions, including their questioning of gender identity, until they can see that a clinician is safe to disclose to; clinicians can stigmatize clients by seeing this as insecurity in their choice, rather than as the client assessing the clinician before deciding if the clinician is safe. Clinicians can also signal their willingness to talk about gender by asking about pronouns and gender identity in intake documents and by not assuming a client is cisgender.

Clinicians also need to see autism as a culture; TNGC identities occurs within the cultural framework of autism. Autistic voices are just now 'joining' the academic discussion, to the joy of some and the frustration of others (42). With the increased focus on autism as an identity, not just a disorder, and the high concurrence of autism and TNGC identities, clinicians need to understand an autistic client's gender identity as part of their culture and make an effort to understand the norms of autistic culture, which often includes more space for non-cisgender identities. That does not, of course, remove our obligations for appropriate assessment and diagnosis, but we cannot discount autistic culture without discounting the dignity of our clients. We must cultivate cultural humility when approaching autistic culture, just as we would with any other culture.

We believe most clinicians would agree that our clients all come to see us with personal skills they have developed to navigate their lives. We must recognize that autistic TGNC clients also come with unique skills, and we encourage clinicians to actively affirm these skills throughout their work with their clients. Affirmation of self-advocacy skills, boundary setting, and, simply, believing the client, can be particularly bolstering for autistic TGNC clients learning to trust themselves and how they view the world. These clients will often experience less anxiety when they learn how to listen to and trust their instincts. We also view a client investigating their own symptoms to improve their own lives as an essential life skill that should be encouraged; this is the epistemic humility that Chapman and Botha (43) name as a key to doing neurodivergence-informed psychotherapy. This humility is a willingness to see the dignity and autonomy of autistic individuals and believe them when they share about their lives and perspectives, about gender and about autism. We affirm their dignity when we believe.

6. Considerations relating to TNGC, autistic children

Working with autistic TGNC children and teens requires navigating between a client's need for autonomy and potential parental anxiety about allowing a child or teen that autonomy. Younger clients may feel more pressure to stop or deny their gender questioning, or sound unsure of themselves discussing the topic, if they live in a home they perceive to be unsupportive; conversely, young children who socially transition and have supportive parents show no elevations in depression (35). One study of homeless or at-risk LGBT youth (44) found that LGBT youth made up 40% of their servicers' clientele and that 68% of those LGBT youth reported experiencing family rejection. Youth in a study (24) reported that "gender diversity obfuscated their ASD in the eyes of others due to common misunderstandings of what constitutes autism," which can lead to problematic reactions from others and distress in the client. A client assigned male at birth who transitions now faces, in addition to the struggles of being TGNC, the struggles of autistic women and girls, who often report high pressure to conform to gendered norms and greater judgment from female peers if they fail to meet those norms due to their autism (45).

We believe the best approach to building trust with these clients may be to show flexibility in places where, as a profession, we are often too rigid and fail to take into account the impact of autism on a client's narrative. If a client struggles to answer hypothetical questions or to imagine future scenarios, clinicians might find other ways to ask their questions; for example, the technique of asking a client to draw themselves was an excellent adaptation for an intellectually-disabled, autistic minor client in one study, yielding useful information (46).

Clinicians working with these populations could also benefit by finding and maintaining information sources based in those communities. A study argued that youth and parents could both benefit from hearing stories of and feeling connections to other TNGC people (47) and we concur with that assessment. We believe clinicians who take in information from TGNC communities will better serve their clients overall.

Parental involvement can often be crucial to a minor's mental health. When it comes to autism and gender, many parents are unsure whose advice to trust. Some parents may present with curiosity and desire to learn, while others may present as doubting of, or hostile to, their child's gender identity based on public information they have been given and the (lack of) support they have been offered. Kuvalanka (48) discusses ways in which parents feel supported and not supported by the larger systems in their children's lives; the importance of clinicians who can help families navigate systems cannot be overstated.

If parents express hostility and doubt about a child's gender identity, clinicians must offer education, referrals and support, while also believing the child in question. One of the writers of this paper (KJG) has navigated this situation multiple times; the vast majority of parents love their child and when given appropriate and kind support and information, do come to support their TGNC child in transitioning. If this does not happen, believing the child at least provides comfort and support to that child from a trusted adult.

Ehrensaft (49) proposed clinicians could work with parents to help their children navigate "gender mazes" by helping parents keep focus on their children's needs and desires. We believe mental health professionals are in a uniquely important position to provide trustworthy, accurate information that will help parents navigate these "mazes" and support their children.

We also believe that to work with these families in an evidence-based, ethical, effective manner, clinicians should understand the substantial research available that supports gender-affirming care for youth and adults; while much of it is not yet specific to the autistic and TGNC populations, that research is emerging. Clinicians should also name for parents that we do not need complete studies of autism and gender identity to affirm their child's gender identity; autistic children and teens are likely to respond to gender-affirming care the way non-autistic children and teens respond, and the evidence shows gender-affirming care benefits TGNC clients. A clinician who has accurate information will be better equipped to provide resources and support to parents to help them support their child and affirm that child's autonomy and dignity.

7. Conclusion

Autonomy and dignity are the antithesis of stigma and shame; yet for autistic and gender-diverse populations, shame and stigma can come from both their neurotype and gender identity, harming to the client. As clinicians, we must honor the dignity and autonomy of each client, believing each client, supporting each client and helping each client make decisions that are right for that client. We do this best when we acknowledge the social context in which we are working, a social context rife with transphobia and bias that can thwart our clients' autonomy and trample their dignity. As a profession, we can support, affirm and care for gender-diverse autistic clients by believing clients; in that way, we honor clients as autonomous, dignified human beings.

Data availability statement

The original contributions presented in the study are included in the article/supplementary material, further inquiries can be directed to the corresponding author.

Author contributions

All authors listed have made a substantial, direct, and intellectual contribution to the work and approved it for publication.

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Conflict of interest

The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

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References

1. Janssen A, Huang H, Duncan C. Gender variance among youth with autism spectrum disorders: a retrospective chart review. *Trans. Health.* (2016) 1:63–8. doi: 10.1089/trgh.2015.0007

2. Van Der Miesen AIR, Hurley H, De Vries ALC. Gender dysphoria and autism spectrum disorder: a narrative review. *Int Rev Psychiatry.* (2016) 28:70–80. doi: 10.3109/09540261.2015.1111199

3. Kallitsounaki A, Williams DM. Autism spectrum disorder and gender dysphoria/ incongruence. A systematic literature review and meta-analysis. *J Autism Dev Disord.* (2022) 53:3103–17. doi: 10.1007/s10803-022-05517-y

4. Strang JF, Meagher H, Kenworthy L, de Vries ALC, Menvielle E, Leibowitz S, et al. Initial clinical guidelines for co-occurring autism spectrum disorder and gender dysphoria or incongruence in adolescents. *J Clin Child Adolesc Psychol.* (2018) 47:105–15. doi: 10.1080/15374416.2016.1228462

5. Missouri Emergency Rule 15, CSR 60-17.010, experimental interventions to treat gender dysphoria. (2023). Available at: https://ago.mo.gov/wp-content/uploads/2023-04-13-emergency-reg.pdf

6. Arkansas Code Title 16, Chapter 114 protecting minors from medical malpractice act of 2023 protecting minors from medical malpractice act, (2023).

Available at: https://www.arkleg.state.ar.us/Bills/Detail?id=SB199&ddBienniumSession=2023%2F2023R

7. Georgia Senate Bill 140, GA SB140 (2023). Available at: https://legiscan.com/GA/text/SB140/2023

8. Varkey B. Principles of clinical ethics and their application to practice. *Med Princ Pract*. (2021) 30:17–28. doi: 10.1159/000509119

9. Lotan G, Ells C. Adults with intellectual and developmental disabilities and participation in decision making: ethical considerations for professional–client practice. *Intellect Dev Disabil*. (2010) 48:112–25. doi: 10.1352/1934-9556-48.2.112

10. Davidson J. Autistic culture online: virtual communication and cultural expression on the spectrum. *Soc Cult Geogr*. (2008) 9:791–806. doi: 10.1080/14649360802382586

11. Thibault R. Can autistics redefine autism? The cultural politics of autistic activism. *UC Irv J Tran*. (2014) 4:p57–88.

12. Dekker M. *On our own terms: emerging autistic culture*. AutScape.org (1999). Available at: http://www.autscape.org/2015/programme/handouts/Autistic-Culture-07-Oct-1999.pdf

13. American Psychological Association. Guidelines for psychological practice with transgender and gender nonconforming people. *Am Psychol*. (2015) 70:932. doi: 10.1037/a0039805

14. Jun H. *Social justice, multicultural counseling, and practice: beyond a conventional approach* (*2nd Edn.*). New York: Springer International Publishing (2018). 403–435.

15. Parkinson J. Gender dysphoria in Asperger's syndrome: a caution. *Austr Psychiatry*. (2014) 22:84–5. doi: 10.1177/1039856213497814

16. Gallucci G, Hackerman F, Schmidt CW. Gender identity disorder in an adult male with Asperger's syndrome. *Sex Disabil*. (2005) 23:35–40 doi: 10.1007/s11195-004-2078-4

17. Pasterski V, Gilligan L, Curtis R. Traits of autism spectrum disorders in adults with gender dysphoria. *Arch Sex Behav*. (2014) 43:387–93. doi: 10.1007/s10508-013-0154-5

18. Jones RM, Wheelwright S, Farrell K, Martin E, Green R, Di Ceglie D, et al. Brief report: female-to-male transsexual people and autistic traits. *J Autism Dev Disord*. (2012) 42:301–6. doi: 10.1007/s10803-011-1227-8

19. Lemaire M, Thomazeau B, Bonnet-Brilhault F. Gender identity disorder and autism spectrum disorder in a 23-year-old female. *Arch Sex Behav*. (2014) 43:395:398. doi: 10.1007/s10508-013-0141-x

20. Janssen A, Busa S, Wernick J. The complexities of treatment planning for transgender youth with co-occurring severe mental illness: a literature review and case study. *Arch Sex Behav*. (2019) 8:2003–9. doi: 10.1007/s10508-018-1382-5

21. Mukaddes NM. Gender identity problems in autistic children. *Child Care Health Dev*. (2002) 28:529–32. doi: 10.1046/j.1365-2214.2002.00301.x

22. Williams PG, Allard AM, Sears L. Case study: cross-gender preoccupations with two male children with autism. *J Autism Dev Disord*. (1996) 26:635–42. doi: 10.1007/BF02172352

23. Zupanič S, Kruljac I, Šoštarič Zvonar M, Drobnič RM. Case report: adolescent with autism and gender dysphoria. *Front Psych*. (2021) 12:671448. doi: 10.3389/fpsyt.2021.671448

24. Strang JF, Powers MD, Knauss M, Sibarium E, Leibowitz SF, Kenworthy L, et al. "they thought it was an obsession": trajectories and perspectives of autistic transgender and gender-diverse adolescents. *J Autism Dev Disord*. (2018) 48:4039–55. doi: 10.1007/s10803-018-3723-6

25. Forsythe A, Pick C, Tremblay G, Malaviya S, Green A, Sandman K. Humanistic and economic burden of conversion therapy among LGBTQ youths in the United States. JAMA. *Pediatrics*. (2022) 176:42. doi: 10.1001/jamapediatrics.2022.0042

26. Kupferstein H. Evidence of increased PTSD symptoms in autistics exposed to applied behavior analysis. *Adv Autism*. (2018) 4:16. doi: 10.1108/AIA-08-2017-0016

27. McGill O, Robinson A. "Recalling hidden harms": autistic experiences of childhood applied behavioural analysis (ABA). *Adv Autism*. (2021) 7:25. doi: 10.1108/AIA-04-2020-0025

28. Rekers GA, Lovaas OI. Behavioral treatment of deviant sex-role behaviors in a male child. *J Appl Behav Anal*. (1974) 7:173–90. doi: 10.1901/jaba.1974.7-173

29. Hughes S.A. Family of Kirk Murphey says "sissy boy" experiment led to his suicide. Washington post. (2011). Available at: https://www.washingtonpost.com/blogs/blogpost/post/family-of-kirk-murphy-says-sissy-boy-experiment-led-to-his-suicide/2011/06/10/AGYfgvOH_blog.html (Accessed August 8, 2023).

30. Gibson M, Douglas P. Disturbing Behaviours: ole Ivar Lovaas and the queer history of autism science. *Catalyst Feminism Theory Technosci*. (2018) 4:1–28. doi: 10.28968/cftt.v4i2.29579

31. Landén M, Rasmussen P. Gender identity disorder in a girl with autism--a case report. *Eur Child Adolesc Psychiatry*. (1997) 6:170–3. doi: 10.1007/BF00538990

32. Perera H, Gadambanathan T, Weerasiri S. Gender identity disorder presenting in a girl with Asperger's disorder and obsessive compulsive disorder. *CMJ*. (2003) 48:57–8. doi: 10.4038/cmj.v48i2.3374

33. Jacobs LA, Rachlin K, Erickson-Schroth L, Janssen A. Gender dysphoria and co-occurring autism spectrum disorders: review, case examples, and treatment considerations. *LGBT Health*. (2014) 1:277–82. doi: 10.1089/lgbt.2013.0045

34. Tordoff DM, Wanta JW, Collin A, Stepney C, Inwards-Breland DJ, Ahrens K. Mental health outcomes in transgender and nonbinary youths receiving gender-affirming care. *JAMA Netw Open*. (2022) 5:978. doi: 10.1001/jamanetworkopen.2022.0978

35. Turban JL, King D, Carswell JM, Keuroghlian AS. Pubertal suppression for transgender youth and risk of suicidal ideation. *Pediatrics*. (2020) 145:e20191725. doi: 10.1542/peds.2019-1725

36. Achille C, Taggart T, Eaton NR, Osipoff J, Tafuri K, Lane A, et al. Longitudinal impact of gender-affirming endocrine intervention on the mental health and well-being of transgender youths: preliminary results. International. *J Pediatr Endocrinol*. (2020) 8. doi: 10.1186/s13633-020-00078-2

37. Olson KR, Durwood L, DeMeules M, McLaughlin K. Mental health of transgender children who are supported in their identities. *Pediatrics*. (2016) 137:3223. doi: 10.1542/peds.2015-3223

38. Grinker RR. *Nobody's normal: how culture created the stigma of mental illness*. New York: W. W. Norton (2021). p311 p.

39. Perske R. The dignity of risk and the mentally retarded. *Ment Retard*. (1972) 10:24–7.

40. Cooper K, Mandy W, Butler C, Russell A. Phenomenology of gender dysphoria in autism: a multiperspective qualitative analysis. *J Child Psychol Psychiatry*. (2023) 64:265–76. doi: 10.1111/jcpp.13691

41. Botha M, Frost DM. Extending the minority stress model to understand mental health problems experienced by the autistic population. *Soc Ment Health*. (2020) 2020, 10:4297. doi: 10.1177/2156869318804297

42. Botha M, Cage E. "Autism research is in crisis": a mixed method study of researcher's constructions of autistic people and autism research. *Front Psychol*. (2022) 13:1050897. doi: 10.3389/fpsyg.2022.1050897

43. Chapman R, Botha M. Neurodivergence-informed therapy. *Dev Med Child Neurol*. (2023) 65:310–7. doi: 10.1111/dmcn.15384

44. Durso LE, Gates GJ. Serving our youth: findings from a National Survey of services providers working with lesbian, gay, bisexual and transgender youth who are homeless or at risk of becoming homeless. *UCLA: The Williams Institute*. (2012). Available at: https://escholarship.org/uc/item/80x75033

45. Milner V, McIntosh H, Colvert A, Happe F. A qualitative exploration of the female experience of autism Spectrum disorder. *J Autism Dev Disord*. (2019) 49:2389–402. doi: 10.1007/s10803-019-03906-4

46. Janssen A. Gender dysphoria and autism Spectrum disorders In: A Janssen and S Leibowitz, editors. *Affirmative mental health care for transgender and gender diverse youth: a clinical guide*. Cham, Switzerland: Springer International Publishing AG (2018). 121–8.

47. Bernal AT, Coolhart D. Treatment and ethical considerations with transgender children and youth in family therapy. *J Fam Psychother*. (2012) 2012, 23:5594. doi: 10.1080/08975353.2012.735594

48. Kuvalanka KA, Mahan DJ, McGuire JK, Hoffman TK. Perspectives of mothers of transgender and gender-nonconforming children with autism spectrum disorder. *J Homosex*. (2018) 2018, 65:6221. doi: 10.1080/00918369.2017.1406221

49. Ehrensaft D. *The gender creative child: pathways for nurturing and supporting children who live outside gender boxes*. New York: The Experiment (2016).

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The ethical imperative to honor autistic clients' autonomy in mental health treatment

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Autistic adolescents and adults commonly experience mental health concerns; however, mental health clinicians may hold implicit stigmatizing views of autism that contribute to case conceptualization and treatment goal setting that align more with caregivers' than clients' goals. This impingement on client autonomy is concerning, problematic, and potentially harmful for autistic clients who are of an age to set their own treatment agenda regardless of co-occurring intellectual disability and/or language delays. An application of the shared decision-making framework, an evidence-based tool for promoting client autonomy, can help to avoid these challenges in treatment. In this perspective, we use a case vignette as an anchor for discussing the imperative of honoring autistic clients' autonomy in mental health treatment and guiding shared decision-making to reduce stigma, promote autonomy, and increase collaborative care for autistic clients in mental health treatment.

KEYWORDS

autism, stigma, mental health, treatment, client autonomy

1. Introduction

Autonomy is a key principle in mental health practitioners' ethical codes (1–4). Yet, clinicians may hold implicit stigmatizing views of autistic adolescent and adult clients, especially those with co-occurring intellectual disability and/or language impairment. This harmful perspective may contribute to the assumption that these clients are unable to direct their own treatment and result in deriving treatment goals from caregivers', rather than clients', presenting concerns. This can be problematic, as autistic youth and their caregivers often have different goals for their future (5). This bias results in a disregard of the autonomy of these clients and can cause harm when case conceptualization, treatment goals and planning, and components of treatment are not well-matched to a client's wants, needs, or preferences and desires for their future. Additionally, thwarting an autistic client's autonomy may contribute to ongoing mental health challenges by contributing to a client's lack of agency and increasing their internalized ableism, infantilization, and learned helplessness. While working collaboratively with an autistic client in goal setting and treatment planning may require additional time and creativity, not doing so poses a significant ethical concern and can impair a client's ability to make progress, as they will likely be less willing to work towards goals they are not invested in meeting. Conversely, when clinicians work collaboratively with clients, clients are more likely to experience a sense of allyship with clinicians, an increased internal locus of control, and greater intrinsic motivation for skill building, leading to improved clinical outcomes.

In this perspective, we bring together our expertise as mental health providers and clinical researchers, as well as our lived perspectives as non-autistic neurodivergent and neurotypical allies of autistic people to discuss the imperative of honoring autistic clients' autonomy in mental health treatment. We acknowledge that mental health clinicians may themselves be autistic or otherwise neurodivergent, and while our guidance may be helpful to all, it is most intended for neurotypical clinicians. We use a case vignette as an anchor for discussing the imperative of honoring autistic clients' autonomy in mental health treatment and guiding decision-making. This vignette has been constructed by combining the experiences of numerous clients into one hypothetical case.

> *Jacob, a 16 years-old Black cisgender, heterosexual young man, is autistic, has a mild intellectual disability, and is clear about what he wants from therapy. "I want to have a girlfriend," he says. His parents tell you that that is not their goal: they want Jacob to be "less disruptive." Jacob's parents state that Jacob will "scream and shout" when he is upset or denied something he wants. These behaviors occur more at home than in other settings. When you try to talk to Jacob about his desire to date, his parents interject to tell you that Jacob does not need a girlfriend since, "it wouldn't be appropriate for him to date." In a one-on-one session, Jacob tells you that he is "really excited" to have sex, but when he got condoms from his doctor (following a conversation that Jacob initiated about safe sex), his parents took them away, saying pre-marital sex is a sin in their Christian faith.*

This scenario forces us to confront the complex issue of client autonomy when caregiver and client goals conflict. Jacob's parents are focused on his "disruptive" behavior. To Jacob, having a girlfriend is a meaningful goal. Many questions come to mind when considering how to address this conflict. How do we conceptualize the presenting concerns? With whose goals do we align? Who decides what therapy goals are appropriate and legitimate? What happens when an adolescent client and their caregivers disagree on goals for therapy?

We propose that supporting autonomy through the evidence-based framework of shared decision-making (6–8) can guide clinicians in working effectively with autistic adolescents and adults presenting for mental health treatment. Following Simon et al. (7) steps, this involves: (1) recognizing that a decision needs to be made, (2) identifying partners in the process as equals; (3) stating the options as equal; (4) exploring each person's understanding and their expectations; (5) identifying preferences; (6) negotiating options/concordance; (7) sharing the decision; and (8) evaluating decision-making outcomes. Shared decision-making relies on collaboration between clinicians, clients, and family members. Importantly, it centers the client's goals, preferences, and identities.

2. Centering autonomy

Greater levels of client autonomy are related to improved clinician-client communication quality (9, 10) and increased motivation, treatment participation and satisfaction, and quality of life (9–12). Decreased client autonomy, conversely, has been associated with higher levels of depression and anxiety symptoms (13). Pelletier et al. (12) identify that supporting a client's autonomy allows them to experience their behavior as caused by their own motives and goals (internal locus of causality). When clients perceive clinicians as more controlling and less supportive of their autonomy, clients report less motivation to "buy in" to treatment (12). When it comes to autistic clients, some researchers have spoken *against* promoting autonomy in therapeutic relationships (14, 15), despite literature that demonstrates substantial overlap between the needs of autistic and allistic clients in therapeutic relationship building (16). Outdated viewpoints such as this perpetuate the myth that autistic clients do not deserve autonomy in treatment and demonstrate the paternalistic attitudes that clinicians have historically taken toward autistic people, setting the stage for further exclusion of neurodivergent clients from models of therapeutic alliance. We propose that the application of shared decision-making, integrated with more progressive recent therapeutic considerations, supports a clinician in setting aside their own biases to meet their client as an equal in the treatment process.

Kinsella (17) provides a humanistic perspective and argues that it is a clinician's ethical duty to foster clients' autonomy. He states that an ethically-grounded practice requires believing that clinicians can nurture clients' autonomy by being adaptive and supportive of each client's strengths and needs. This can be done, not only by fostering autonomy where it exists, but also by promoting it where it is lacking. Additionally, Chapman and Botha (18) propose a neurodivergence-informed psychotherapeutic framework, arguing against default normalization and pathologization and for neurodivergent prosperity. One of the three themes they propose is for neurotypical clinicians to cultivate "epistemic humility"—the ability to change one's assumptions and biases through critical reflection—in order to foster a collaborative approach within the client-clinician dyad and respect the client's lived experience.

Bearing this in mind, when faced with Jacob's parents' requests to reduce his "disruptive behavior," we might ask ourselves, "What is happening, internally, for him when he behaves this way?" Jacob is likely distressed when he is "disruptive;" his behaviors can be seen as communicating that distress to his parents. To ignore Jacob's internal experiences is to overlook his valid frustrations, which disregards his personhood and autonomy.

As the name suggests, shared-decision-making centers around engaging the client in decision-making about their own treatment—a direct application of supporting client autonomy. The clinician empowers the client to make decisions by providing them with options, establishing and validating their expertise, and actively working to address misunderstandings when they arise. In Jacob's case, we would suspend the assumption about his inability to direct his own care due to his diagnoses of autism and intellectual disability. Rather than approaching Jacob's case from his parents' perspective of disruptive behaviors, a shared decision-making approach would support Jacob in communicating his perspective. By addressing the differing conceptualization of the presenting concern, we create the opportunity to discuss family dynamics and provide psychoeducation on appropriate teen autonomy and safe sex practices.

2.1. Supporting relatedness

While we may think of autonomy as pertaining to an individual, Kinsella (17) rethinks it as a reciprocal and relational process. He emphasizes the importance of a clinician replacing paternalism with a more egalitarian "relatedness." Chapman and Botha (18) emphasize that neurodivergence-informed therapy relies upon a relational model of mental health. From this view, the challenges an autistic person experiences are due to dysfunctions in the relationship or differences in communication, rather than dysfunction that is intrinsic to the autistic client. In Jacob's case, we can reflect on our own biases, neurotype, and communication styles to understand our role in relational dysfunctions that may occur in therapy, and we can view the concerns he and his parents raise as occurring within the context of their family system; that is, between Jacob and his environment, rather than as a flaw within Jacob himself.

Reconceptualizing the conflict between Jacob and his caregivers around the issue of premarital sex as relational can be beneficial in understanding how to engage in shared decision-making. For example, it is important to assess Jacob's feelings about premarital sex in terms of *his* faith—we should not assume Jacob shares his family's faith. In addition, if Jacob shares his family's faith, in which premarital sex is immoral, and Jacob's parents believe he cannot date or get married, Jacob may be in a double-bind: wanting sex, not considered competent to be married, but in a faith system that holds marriage is the only way one can have sex. This double-bind, a term from strategic family therapy (19), can cause a person to feel anger, rage and resentment as their autonomy is being denied. These may be some of Jacob's internal experiences when he exhibits "behavior problems."

Jacob's parents seem to be vocalizing distress by the idea of him dating; they find it "inappropriate." Almost all 16 years-old, including autistic and developmentally delayed 16 years-old, have sexual feelings [e.g., (20)]. If Jacob's parents deny him appropriate teen autonomy, Jacob may push back by acting out, which may cause Jacob's parents to see him as younger than his age. This circle of events occurs frequently in families with autistic teens and young adults, as parents fail to see their adolescent or young adult's behavior as age-appropriate bids for autonomy, instead viewing them as "childish" outbursts. Jacob's parents may be trying to protect Jacob from the risks of dating, but there is a dignity to risk taking—one that people with intellectual disabilities are often denied. "Perske (21) wrote, 'We have yet to completely evaluate what we do to the human dignity of (people with intellectual disabilities) when such relationships are denied.' To be a person is to strive and, at times, to fail. We deny personhood to those who we do not allow to fail" (22), p. 311.

Applying a model of shared decision-making inherently supports a relational and collaborative approach to care. Simon et al. (7) specifically propose steps to shared decision-making that address the concerns about relatedness discussed above, including developing a greater understanding of expectations and exploring the client's preferences, concerns, and goals. Shared decision-making invites ongoing communication from all parties to explore miscommunications or conflicting perspectives throughout treatment. It also creates a space to discuss the roles and responsibilities of all parties involved in treatment. Jacob's desire to date is normative and healthy, not pathological. As his clinician, we might offer psychoeducation on healthy relationships, how to set and hold to boundaries, or other information to support a client dating in healthy ways, but we would not take steps to deny Jacob's autonomy to date.

2.2. Validating identity

Race and ethnicity play an important role in the quality of the client-clinician relationship and treatment outcomes. Barzargan and colleagues (23) found that non-Hispanic Black and Hispanic clients had higher medical mistrust than non-Hispanic white clients of racial and ethnic minority backgrounds who report less respect and dignity in their treatment are less likely to follow medical recommendations (24). Trust, respect, dignity, and client-centeredness—treatment factors associated with racial and ethnic differences in the client-clinician dyad—are imperative to bolstering client autonomy.

Jacob's intersecting identities as a Black autistic young man are crucial for us to consider, especially when we do not share his identities or lived experiences. Given racism and racial stereotypes, Jacob's parents may have legitimate fears around him being perceived as the aggressor in a sexual relationship; to ignore this possibility is to place Jacob in danger. We could address this concern with Jacob by teaching him about consent, gaining clarity, and not making assumptions with romantic partners. Jacob has demonstrated responsible behavior about sex by seeking condoms and information about safe sex; highlighting this to his parents as a strength may help to alleviate some of their concerns.

Regarding his neurodivergent identity, Jacob and his parents may or may not see autism as something to celebrate. The common discourse about autism from a medicalized view may contribute to Jacob's parents' stigma and Jacob's own internalized stigma. His parents may wish to impose their treatment goals on Jacob out of fear that he cannot make appropriate decisions. Autism can be conceptualized as a "neurominority" (18)—an identity that is a source of pride, belonging, and competence. Connecting Jacob with resources and role models to support autistic joy and pride (18) may support his autonomy development, mental health, and wellbeing (25, 26). Additionally, educating Jacob's parents about autistic identity from a neurodiversity perspective may help to reduce stigma and set the stage for them to support Jacob in becoming an autonomous adult.

Without this neurodivergence-affirming lens, clinicians would be unable to engage in shared decision-making as they need to perceive their clients as equal partners in the process. Jacob showed mature judgment in seeking contraception from his doctor; noticing and praising that choice will foster his autonomy and help Jacob see himself as capable of making decisions that support his wellbeing. Jacob's parents might likewise be able to see how Jacob was being responsible by asking for contraceptives, even if they do not agree with Jacob having sex.

3. Conclusion

Promoting client autonomy is a key principle of care across ethics codes for various mental health practitioners (1–4). Most states allow minors to consent to their own outpatient mental health treatment and many have additional provisions of confidentiality and limited disclosures to legal guardians (27). While this level of autonomy and control over treatment is often the default for neurotypical minors entering therapy, autistic adolescents and adults, especially those with co-occurring intellectual disability and/or language impairments, are often not given the same opportunities. To promote the best possible outcomes in line with our ethical duties as mental health professionals, it is critical that we support the autonomy and dignity of risk of autistic clients.

For Jacob, we can promote autonomy, address the bias toward paternalization, and increase the quality of collaboration by following a model of shared decision-making [e.g., (6–8)]. By engaging clients directly in making choices about their treatment, respecting their experiences and intersecting identities, and working collaboratively across clients, clinician, and caregivers, outcomes for clients like Jacob can change dramatically.

> *Jacob's clinician laid out the conflict between Jacob and his parents and the fact that treatment goals were needed; Jacob and his parents agreed this was true and that they all wanted something to change.*
>
> *The clinician then explored with Jacob and his parents the meaning of their goals; Jacob's parents were able to discuss their worries for Jacob's future and how his outbursts lead them to fear for his safety, particularly as Jacob is a Black male. Jacob needed the context of this worry explained, but when it was, he began to understand his parents' fears.*
>
> *Jacob was likewise able to tell his parents he had always dreamed of being "married like you" which touched Jacob's parents deeply. Jacob likewise explained that he knew, from school, that sex was important to do "right," and that safe sex was "right sex." Jacob's parents were able to see the importance of dating to Jacob. They expressed the preference that Jacob wait to have sex until marriage, but also stated they were glad he was "thinking about safety." Jacob, for his part, was able to agree that less conflict at home would be good.*
>
> *Jacob and his parents negotiated an agreement: Jacob and his parents would work with the clinician to reduce conflict at home. Jacob's parents agreed that Jacob could date if he found a girlfriend.*
>
> *The end treatment goal prioritized reducing conflict. Jacob, understanding his parents' fears for his life, was more willing to work on reducing outbursts by using his coping skills, saying "I don't want to get shot." The treatment goals were reviewed after six months; at that time, Jacob's parents reported "less than one outburst a week" and Jacob was planning to ask a girl from his class to a church picnic.*

Furthermore, it is important to understand the role of identity in challenges to client autonomy. For Jacob, his various intersecting identities as a Black, cisgender, heterosexual autistic teen with an intellectual disability from a family with a religious background affect the way in which he is perceived and how his family or clinicians choose to interpret his behaviors. Historically, being autistic has been cited as a reason for excluding clients from shared decision-making regarding their care [e.g., (14, 15)]. Instead, we urge clinicians to engage in collaborative care that honors the autonomy and dignity of autistic clients. The shared decision-making model reminds us to respect the expertise and lived experience of our clients as equals in therapy, creating multiple points at which to engage in conversation about goals and motivations for treatment. This model helps ensure we are centering our clients' autonomy in a way that is relational and identity affirming.

Data availability statement

The original contributions presented in the study are included in the article/supplementary material, further inquiries can be directed to the corresponding author.

Author contributions

AM: Conceptualization, Writing – original draft, Writing – review & editing. KG: Conceptualization, Writing – original draft, Writing – review & editing. SS: Writing – original draft, Writing – review & editing. KC: Conceptualization, Writing – original draft, Writing – review & editing.

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Conflict of interest

The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

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References

1. American Counseling Association. (2014). *2014 ACA code of ethics*. Available at: https://www.counseling.org/resources/aca-code-of-ethics.pdf

2. American Psychiatric Association. (2013). "*The principles of medical ethics with annotations especially applicable to psychiatry*." Available at: https://www.psychiatry.org/file%20library/psychiatrists/practice/ethics/principles-medical-ethics.pdf.2013

3. American Psychological Association. (2017). "*Ethical principles of psychologists and code of conduct (2002, amended effective June 1, 2010, and January 1, 2017)*." Available at: https://www.apa.org/ethics/code/.2017

4. National Association of Social Workers. (2021). "*Code of ethics of the National Association of Social Workers*." Available at: https://www.socialworkers.org/about/ethics/code-of-ethics/code-of-ethics-english

5. Kirby AV, Diener ML, Dean EE, Darlington AN, Myers A, Henderson J. Autistic adolescents' and their parents' visions for the future: how aligned are they? *Autism Adulthood*. (2022) 4:32–41. doi: 10.1089/aut.2020.0061

6. Capers M. *Shared decision-making in mental health care: practice, research, and future directions*. Rockville, MD: U.S. Department of Health and Human Services (2010).

7. Simon D, Schorr G, Wirtz M, Vodermaier A, Caspari C, Neuner B, et al. Development and first validation of the shared decision-making questionnaire (SDM-Q). *Patient Educ Couns*. (2006) 63:319–27. doi: 10.1016/j.pec.2006.04.012

8. Slade M. Implementing shared decision making in routine mental health care. *World Psychiatry*. (2017) 16:146–53. doi: 10.1002/wps.20412

9. Schauer C, Everett A, del Vecchio P, Anderson L. Promoting the value and practice of shared decision-making in mental health care. *Psychiatr Rehabil J*. (2007) 31:54–61. doi: 10.2975/31.1.2007.54.61

10. Stacey D, Légaré F, Lewis K, Barry MJ, Bennett CL, Eden KB, et al. Decision aids for people facing health treatment or screening decisions. *Cochrane Database Syst Rev*. (2017) 2017:CD001431. doi: 10.1002/14651858.CD001431.pub5

11. Karver MS, Handelsman JB, Fields S, Bickman L. Meta-analysis of therapeutic relationship variables in youth and family therapy: the evidence for different relationship variables in the child and adolescent treatment outcome literature. *Clin Psychol Rev*. (2006) 26:50–65. doi: 10.1016/j.cpr.2005.09.001

12. Pelletier LG, Tuson KM, Haddad NK. Client motivation for therapy scale: a measure of intrinsic motivation, extrinsic motivation, and amotivation for therapy. *J Pers Assess*. (1997) 68:414–35. doi: 10.1207/s15327752jpa6802_11

13. Dwyer LA, Hornsey MJ, Smith LGE, Oei TPS, Dingle GA. Participant autonomy in cognitive behavioral group therapy: an integration of self-determination and cognitive behavioral theories. *J Soc Clin Psychol*. (2011) 30:24–46. doi: 10.1521/jscp.2011.30.1.24

14. Anderson S, Morris J. Cognitive behaviour therapy for people with Asperger syndrome. *Behav Cogn Psychother*. (2006) 34:293–303. doi: 10.1017/S1352465805002651

15. Forester-Miller H, Davis TE. (2016). *Practitioner's guide to ethical decision making (Rev. ed.)*. Available at: http://www.counseling.org/docs/default-source/ethics/practioner's-guide-toethical-decision-making.pdf

16. Hume R. Show me the real you: enhanced expression of Rogerian conditions in therapeutic relationship building with autistic adults. *Autism Adulthood*. (2022) 4:151–63. doi: 10.1089/aut.2021.0065

17. Kinsella M. Exercising leadership within the therapeutic alliance: an autonomy-grounded perspective. *J Humanist Psychol*. (2023) 63:103–25. doi: 10.1177/0022167818805568

18. Chapman R, Botha M. Neurodivergence-informed therapy. *Dev Med Child Neurol*. (2023) 65:310–317. doi: 10.1111/dmcn.15384

19. Weakland JH. The double-bind theory some current implications for child psychiatry. *J Am Acad Child Psychiatry*. (1979) 18:54–66. doi: 10.1016/S0002-7138(09)60477-5

20. May T, Pang KC, Williams K. Brief report: sexual attraction and relationships in adolescents with autism. *J Autism Dev Disord*. (2017) 47:1910–6. doi: 10.1007/s10803-017-3092-6

21. Perske R. The dignity of risk and the mentally retarded. *Ment Retard*. (1972) 10:24–7.

22. Grinker RR. *Nobody's normal: how culture created the stigma of mental illness*. New York, NY: W. W. Norton (2021).

23. Bazargan M, Cobb S, Assari S. Discrimination and medical mistrust in a racially and ethnically diverse sample of California adults. *Ann Fam Med*. (2021) 19:4–15. doi: 10.1370/afm.2632

24. Beach MC, Sugarman J, Johnson RL, Arbelaez JJ, Duggan PS, Cooper LA. Do patients treated with dignity report higher satisfaction, adherence, and receipt of preventive care? *Ann Fam Med*. (2005) 3:331–8. doi: 10.1370/afm.328

25. Botha M, Dibb B, Frost DM. 'Autism is me': an investigation of how autistic individuals make sense of autism and stigma. *Disabil Soc*. (2022) 37:427–53. doi: 10.1080/09687599.2020.1822782

26. Cage E, Di Monaco J, Newell V. Experiences of autism acceptance and mental health in autistic adults. *J Autism Dev Disord*. (2018) 48:473–84. doi: 10.1007/s10803-017-3342-7

27. English A, Bass L, Boyle AD, Eshragh F. *State minor consent laws: a summary*. 3rd ed. (2010). Chapel Hill, North Carolina: Center for Adolescent Health & the Law.

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“On an island by myself”: implications for the inclusion of autistic students in self-contained classrooms in public elementary schools

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Introduction: Autistic students have limited access to inclusive classes and activities in their schools. Principals and special education teachers who directly teach and administer programs for autistic elementary students can offer critical insight into factors, such as educators' attitudes, that may impact inclusive opportunities in schools. These attitudes may serve as barriers to or facilitators of promoting an inclusive school setting.

Methods: Semi-structured interviews with 26 elementary school principals and 26 special education teachers explored their experiences implementing evidence-based practices for autistic students (pivotal response training, discrete trial training, and visual schedules) in 26 self-contained classrooms in the United States. Autism-specific culture and inclusion emerged as a theme, which was analyzed for this paper.

Results: An inductive approach to thematic analysis revealed principals' and special education teachers' perspectives regarding the “autism-specific culture” in the school, including attitudes towards and inclusion of autistic students in self-contained classrooms in the broader school environment. Analysis of text related to “autism-specific culture” detailed aspects of inclusion, factors (i.e., barriers and facilitators) affecting inclusion, principals' and special education teachers' attitudes towards autistic students placed in self-contained classrooms, attitudes of other school staff towards teachers in self-contained classrooms, and recommendations to support an inclusive school environment for autistic students.

Discussion: Results suggest that valuing “equal” access to classes and activities for autistic students in self-contained classrooms may not be sufficient for promoting an inclusive school environment, Educators may benefit from targeted strategies to facilitate inclusion. Strategies range from supporting educators' attitudes and knowledge of autism to shifting physical aspects of the school environment (e.g., location of classrooms). Additional implications for supporting the true inclusion (i.e., inclusion that goes beyond physical inclusion) involves of autistic students in self-contained classrooms schools are discussed.

KEYWORDS

autism, inclusion, special education, elementary school, educators

Introduction

In the United States, the prevalence of autism spectrum disorder (ASD) has increased to about one in 36 children (1). With that, there is an increase in the rates of autistic students being served in public schools (2), the primary service setting for autistic youth (3). It is imperative to include autistic students in general education settings alongside typically developing peers (4–6). Nevertheless, across the United States, only approximately 30% of autistic students were served up to 80% of their day in general education settings (7). Self-contained classrooms (i.e., those that only serve students with disabilities) persist as a common placement (8). While placing students in the same location as peers is a necessary start to dismantle segregated placements and practices, placement alone is insufficient to realize the educational and social benefits of inclusion (9). Autistic students may be excluded from inclusive contexts associated with many factors, including low knowledge, negative attitudes, or stigma by school professionals or peers (10). Ideally, all aspects of the school are designed to support inclusion through its structure, norms, practices, and culture, to create the context for all students to participate in their classrooms and have a sense of belonging to their school communities (11–13). To improve inclusion rates and practices, educators' experiences and perspectives on stigmatization of autism and what can facilitate effective inclusion are needed.

A variety of educational placements

Students with disabilities should be taught with their non-disabled peers to the greatest extent possible and receive specialized intervention support that meets their needs (4). Although this has been written into law since 1975 (4), the predominant approach for placement of students has been exclusion, where students with disabilities are served in separate classrooms from their neurotypical peers. Educators often cite that the specialized service needs of students with disabilities [e.g., speech-language intervention, occupational therapies, behavioral therapy (14)] are challenging to integrate into general education settings (15, 16), and researchers have demonstrated that social stigma toward autistic students and those with other disabilities can impede inclusion (17, 18). The amount of time children with disabilities spend with their non-disabled peers placed in general education settings rests on a continuum of educational placements. On the two ends of this continuum are self-contained classrooms, where only students with disabilities are members, and general education settings, which predominantly include students without disabilities.

Self-contained settings usually have a lower student-teacher ratio and use personalized goals and curricula for students based on their needs; often, students may vary in grade level or age within this setting (19). Students' goals can cover various developmental domains (e.g., adaptive, social communication, physical, and cognitive) that influence their academic achievement. The rationale for serving students in these settings is that children may have more teacher attention and fewer distractions, though this often is not the case (19). Moreover, IEP quality has not been demonstrated to improve in quality by placement [i.e., self-contained vs. inclusive; (20)]. In contrast, general education settings focus on a general curriculum and standards that all students are expected to meet. Although general education classrooms include tailored support for students within multi-tiered systems of support, [MTSS (21)] a system of supports that provides specific practices based on students' level of need, standard educational perspectives are that there is less room for variation in the focal skill areas within general education classrooms (e.g., primarily academics with some social–emotional focus). There is a tension, however, that all students with disabilities should access the general curriculum and their neurotypical peers, which requires schools to offer alternative models.

To meet the expectations of supporting students with disabilities in their least restrictive environment, accessing the general curriculum, and balancing their support needs, U.S. public schools offer different models of inclusion that primarily relate to time spent in a general education classroom. These include: a) hybrid, which is some time in self-contained and some time in general education, b) push-in, which includes time in general education with special education service support, c) pull-out, which is time in a general education classroom and then the student receives special education service support in a separate setting, or d) inclusive classrooms, where students' individualized education program (IEP) services and goals are addressed in the general education classroom integrated into the classroom activities with their non-disabled peers (7).

Given the mandates of IDEA and the recognized benefits of inclusion, educators have increasingly sought alternative models to self-contained classrooms, intending to increase the access of students with disabilities to the general education setting and non-disabled peers. In an inclusive classroom model, the general classroom is set up with all students with and without disabilities in mind to provide both class-wide and individualized supports (22), which helps support autistic students' rightful presence in all spaces and meet legal expectations. Our co-author CE, an ASD advocate, defines inclusion as: "the ongoing process to remove institutional and structural barriers that have been in place for many years that prevent a more equitable educational outcome for ASD students. An important element of this definition of inclusion is that ASD students have a 'seat at the table' with effective parent/guardian advocacy for general education inclusion classes on their behalf." This definition aligns with some presented in the literature of equity-based inclusion, meaning all children receive the levels and types of support and instruction they need (22) and recognizes that barriers to attaining this level of inclusion remain in the school systems.

School staff and factors supporting inclusion

Moving the needle on inclusion in a way that aligns with this definition requires school staff to work across levels [e.g., student-level, teacher-level, school-level, district-level (23)]. Federal and state-level policies set the context and requirements for inclusion, but individual schools and classroom leaders create the conditions for inclusion. Within a school, the staff comprises general education teachers, special education teachers, related service providers (e.g., occupational therapists, speech-language pathologists), principals, and other administrators. To facilitate effective inclusion for autistic students, school staff need adequate resources, support, and collaboration across levels (24). Principals also play an essential role in providing the necessary implementation leadership [i.e., support of adopting new practices; (22, 25)] as well as make structural decisions (e.g., classroom space assignments, staff allocation, caseloads) to enact inclusion. Importantly, teachers identify that some of their primary strategies for including autistic students are advocacy within their school systems for training and resources and collaboration with other educators (26).

Malleable educator-level factors, such as their attitudes and stigma towards autism and inclusion, are likely instrumental in supporting autistic students' inclusive service delivery in general education classes. Educators describe that the inclusion climate and culture across their schools require disability awareness and education, often grounded in educators' positive attitudes (26). School staff's attitudes toward autism and the inclusion of autistic students is frequently identified as a barrier to inclusion (26) and influential to effective practices in inclusive contexts for autistic students (27). Similarly, for other groups of students with disabilities, such as attention-deficit/hyperactivity disorder (ADHD), educators' attitudes towards inclusion have been influenced by stigma associated with perceptions of the condition or difference [i.e., ADHD; (28)]. Thus, stigma toward autism and the inclusion of autistic students with non-disabled peers may continue to influence educators' attitudes and impede inclusion and student participation across all social contexts (28, 29). Importantly, principals' and teachers' attitudes also facilitate inclusion when they are accepting, favorable toward autism, and understanding of students' individual differences (30, 31). Therefore, school staff's individual attitudes and a collective positive culture toward autism and inclusion may be key to improving autistic students' access to inclusive classrooms.

Study purpose

In the last decade, the proportion of students with disabilities accessing general education classrooms has remained somewhat stagnant (32). The persistent need to support inclusion presents opportunities to learn from those who play key roles in supporting inclusive placements of autistic students [i.e., principals and special education teachers (31)]. Special education teachers who work primarily with autistic students in self-contained settings offer unique autism expertise given their daily classroom experiences and involvement in special education teams where placement decisions are made. As part of a larger mixed-methods study (33) aimed at understanding contextual factors that influence special education teachers' fidelity to implementing autism-focused evidence-based practices (EBPs), *autism-specific culture and inclusion* arose inductively. *Autism-specific culture and inclusion* refers to the attitudes, perspectives, and treatment of autistic students and staff who support them in self-contained classrooms and inclusion (or lack thereof) in general education classrooms and other school spaces (e.g., lunchroom) with non-disabled peers. In response to this, this qualitative study aimed to characterize how principals and special education teachers perceive the "autism culture" in their schools, as it relates to their and others' perspectives of autism and inclusive practices for autistic students in self-contained settings in public elementary schools. Thus, this paper describes principals' and special education teachers' perspectives regarding the "autism culture" in their schools and its implications for the inclusion of autistic students in schools with traditionally segregated autism-specific settings.

Materials and methods

Participants and setting

Data were drawn from a larger study that examines how contextual factors influence special education teachers' fidelity to three EBPs [i.e., discrete trial training, pivotal response training, and visual schedules (34–37)] for autistic youth (27, 33, 38). In brief, 26 schools with kindergarten through third-grade special education classrooms located in the northeastern United States were included in this study. Enrolled schools received training in three autism-focused EBPs based on the principles of applied behavioral analysis. At the start of the school year, teachers received training in the three EBPs, followed by monthly coaching in each of those EBPs. From January to April of the academic year in which data were collected, fidelity observations were conducted in special education classrooms. Teachers were then purposefully sampled based on their average levels of fidelity (i.e., high vs. low) across the three EBPs to participate in qualitative interviews during April and May of the same year. This paper reports on the qualitative interviews, and reporting is guided by the Consolidated Criteria for Reporting Qualitative Research (COREQ) guidelines [(39); see Supplementary File S1].

To capture a full range of teacher experiences related to individual- and school-level factors associated with EBP implementation, special education teachers with high (i.e., in the top tertile based on their average fidelity rating across EBPs) and low (i.e., in the bottom tertile across EBPs) fidelity were invited to complete interviews. Principals of each special education teacher also were invited to participate in interviews. Potential participants were invited via email. Interviews with participants from thirteen high-fidelity and thirteen low-fidelity classrooms were sufficient to achieve data saturation (40).

Participants included $n = 26$ principals and $n = 26$ special education teachers who completed qualitative interviews. Educator characteristics are presented in Table 1. Both principals (77%) and special education teachers (92%) were predominately female. Principals were racially and ethnically diverse with representation across Asian ($n = 1$), Black ($n = 12$), white non-Hispanic ($n = 10$), and Latine groups ($n = 4$); in contrast, special education teachers were predominantly white non-Hispanic ($n = 24$). Principals and special education teachers had equal education attainment levels spanning across college- and graduate/professional-level degrees.

Twenty-six schools were represented in the sample. One school had one principal participate, but the teacher declined the interview due to lack of interest. Twenty-three schools had one teacher, and one

TABLE 1 Principal and special education teacher characteristics.

	Principals (*n* = 26)		Teachers (*n* = 26)	
	n/*M*	%/*SD*	n/*M*	%/*SD*
Age	46.3	7.4	35.8	9.9
Gender				
Female	20	77%	24	92%
Male	6	23%	2	8%
Race/Ethnicity				
Asian	1	4%	0	–
Black	12	46%	2	8%
White Non-Hispanic	10	38%	24	92%
Latinx/Hispanic	4	15%	0	–
Education				
Bachelor's degree	2	8%	2	8%
Graduate/ Professional	23	88%	23	88%
Other	1	4%	1	4%
Years of experience	8.3	6.0	6.8	4.5

Race/Ethnicity reporting is non-exclusive, meaning summation of percentages is greater than 100%.

school had two teachers in the sample. One principal and one teacher were excluded from this analysis, as they did not mention *autism-specific culture* in their interviews.

Procedure

The senior author JL conducted individual, semi-structured interviews lasting 45–60 min with participating principals and special education teachers. Interviews were audiotaped and conducted at schools at a convenient time for participants. No field notes were made during interviews. Two parallel interview guides were developed using the Domitrovich et al. (23) multi-level framework. Questions were designed to elicit participants' experiences with the EBP implementation process in their school, perceptions of the school environment, and behaviors and practices from other school staff (e.g., leadership, general education teachers, support staff) that had facilitated or hindered EBP implementation (see Supplementary Files S2, S3 for the principal and teacher interview guides, respectively). Example items from the principal interview guide include: "Tell me how you *facilitate* or *support* your special education teachers' and classroom staff's use of these practices."; "Think about the autism support team at your school. Tell me about their relationships with the general education teachers and staff." Example items from the special education teacher interview guide include: "What has it been like for you to implement EBPs in your classroom?"; "Tell me what makes it difficult to use these practices in your classroom."; and "Tell me how the practices you use in your classroom fit within the school's main goals and purpose." Participants provided informed consent and were paid $50 for their time. The University of Pennsylvania IRB provided ethics approval for the study.

Research team and reflexivity

The senior author JL is female, and at the time of the interviews, she was an assistant professor and had no previous relationship with the participants. Participants knew that the interviewer was a Ph.D.-level researcher with expertise in the clinical care of autistic children. As a licensed psychologist and implementation researcher, JL values the use of EBPs for autistic youth and supporting the successful implementation and sustainment of EBPs for autistic youth in public school settings. The remaining co-authors were not involved in data collection or initial qualitative data analysis. However, all authors are researchers committed to increasing access to best practices for autistic youth. Two authors (KA, AH) contributed to the thematic analysis of the autism-specific culture data; both identify as female and are in clinical psychology. The remaining authors contributed to manuscript writing and represent the following disciplines: special education (MH), clinical psychology (DT), and public health (TH). One co-author identifies as autistic and contributed their lived experience with the special education system and inclusive practices (CE).

Data analysis

Semi-structured interviews were transcribed and uploaded to NVivo QSR 10 for data management. The coding scheme for the overall study was based in content analysis and developed using a systematic, rigorous, transparent, and iterative approach (41) and involved two stages. For Stage 1, the research team independently coded four transcripts to identify recurring codes and developed a preliminary codebook for principal and special education teacher interviews. As some codes were developed during the interview guide development and others arose from reading the transcripts, both a deductive and inductive approach were used (42). Two female research study coordinators with BA or higher degrees coded all data, and 20% of transcripts were selected randomly to calculate inter-rater reliability (43). Transcripts were randomly selected using a random number generator. Coders met regularly to discuss, clarify, and compare emerging codes and disagreements were discussed with the entire research team to reach consensus. Percent agreement was calculated based on the number of words agreed upon for Stage 1 coding. The average agreement for principal interviews was 97.04%, and for teacher interviews was 94.18%.

Stage 2 of the thematic analysis involved an iterative, inductive approach in which the segments of text related to autism-specific culture from Stage 1 were analyzed and coded to identify categories. The two female research study coordinators independently reviewed the segments of text from the autism-specific culture code to identify recurring themes (42). They met with the principal investigator (PI) to (a) develop a preliminary codebook integrating the identified themes, (b) operationally define each subcode, and (c) come to consensus on which subcodes to include in the final codebook. Lastly, the research study coordinators then coded all data, meeting regularly with the PI to discuss, verify, and compare subcodes and resolve any disagreements to attain consensus. Stage 2 inductive coding resulted in eight codes shared across principals and special education teachers with an additional two unique principal codes and two unique teacher codes. Codes were further organized into two broad themes regarding autism-specific culture. Specifically, the first theme was school staff's characterization of their schools' approach to inclusion, describing *inclusion philosophy*, *advocacy* for autistic students and the inclusion of these students, and ways in which autistic students are included (i.e., *academic inclusion* and *social interaction*). The second theme captured factors affecting autism-specific culture within schools, including facilitators of and barriers to supporting and including autistic students. For instance, both principals and special education teachers described *awareness* of and *attitudes* towards autistic students. Principals discussed *teacher/staff professional relationships* and their *[principal] involvement with autistic students* and special education teachers highlighted *teacher and staff support for inclusion* and *principal support for inclusion* as unique factors affecting autism-specific culture. Both principals and teachers identified *influences on inclusion* and the *location of the autism self-contained classroom* as components of autism-specific culture. Lastly, we also identified a third theme specific to special education teachers, including their recommendations regarding supporting autistic students and the inclusion of autistic students.

Results

Results are presented by theme and integrate principal and special education teacher perspectives. Table 2 presents the code definitions, and Table 3 includes example quotes that illustrate the *autism-specific culture and inclusion* subcodes.

Theme: approach to inclusion

Inclusion philosophy

Most principals described inclusion as "part of [their] vision" for autistic students in self-contained classrooms, such that they "want

TABLE 2 Code definitions.

Code/subcode	Definition
Autism-specific culture and inclusion	Attitudes, perspectives, and treatment of autistic students in self-contained classrooms and their special education teachers; Inclusion (or lack thereof) in classrooms and other school spaces (e.g., lunchroom, assemblies) with neurotypical peers (e.g., integration or segregation of autistic students; active and supportive involvement from non-special education staff, such as general education teachers, principals, other staff)
Inclusion philosophy	Approach, guiding principles, decision-making for inclusion and integration practices
Advocacy	Non-specific sponsorship, support, and advocacy for autistic students and inclusion practices; on the part of the participant or others
Academic inclusion	Inclusion practices specific to academic spaces and activities (e.g., general education classrooms; fieldtrips with neurotypical peers; elective classes)
Social interaction	Non-classroom social inclusion and engagement with neurotypical peers (e.g., at recess, during lunch, non-academic clubs)
Awareness	Knowledge, understanding, awareness of autism; autism self-contained classrooms; autistic students' needs and IEP goals (across greater school community, including general education teachers, staff, caregivers, neurotypical students)
Attitudes	Mode of thinking or feeling reflected in behavior toward autistic students in self-contained classrooms, teachers, classrooms; and inclusion and integration practices (across greater school community, including principals, general education teachers and students, staff)
Teachers/staff professional relationship (principal only code)	Special education teachers and general education teachers' relationship with one another; helping each other, collaborating (e.g., planning fieldtrip together, working together on inclusionary practices); negative, poor, underdeveloped relationships
Teacher/staff support for inclusion (teacher only code)	Non-special education staff support and participation (or lack thereof) in inclusion and integration practices; cooperation and collaboration across teacher roles (e.g., general education teachers planning with special education teachers); disregard or negative regard towards inclusion practices (e.g., general education teachers ambivalent towards having autistic students in their classrooms)
Principal involvement with autistic students (principal only code)	Principal-specific involvement, interaction, and engagement with autistic students in self-contained classrooms
Principal support for inclusion	Principal-specific sponsorship, advocacy, and participation (or lack thereof) in inclusion and integration practices
Influences on inclusion	Specific determinants (i.e., barriers of and facilitators to) of inclusion and integration practices not captured in other subcodes
Location of self-contained classroom	Physical placement of self-contained classroom(s) in the school building
Recommendations	Expression or call for change and suggestions to improve inclusion and school culture

IEP, Individualized Educational Plan; EBP, evidenced based practice.

TABLE 3 Example principal and special education teacher quotes by subcode.

Subcode	Principals	Special education teachers
Inclusion philosophy	"It started with that, with talking about what inclusion truly is, not just doing it for the sake of doing it, but with doing it purposeful and having – making sure there's an impact and making sure you can measure the growth." [P3700; Principal, Female, Professional Degree]	"I get to be in a bubble… but there's just so much going on outside of this bubble that we sort of get lost and left alone until there's a problem." [T217; Teacher, Female, Professional Degree]
Advocacy	"They know to call me because I need to see what this kid's skill level is, and I need to see from the door what do we need to do with you, the kid… he needs to be mainstreamed. Make sure that happens." [P500; Principal, Female, Professional Degree]	"I have a kid who is being mainstreamed pretty much the whole day and we came back from Easter break and then he did not wanna go back into the classroom at all. So I had to take over some of the reins myself where I was taking him around on my prep time and I was getting him back into the fray. I started out on the peripheral but then trying to phase [out my] support and get the one-on-one in there more." [T801; Teacher, Male, Professional Degree]
Academic inclusion	"In smaller settings we identify different children, and we slowly try to include them more and more into the Gen Ed schedule. So, when those children are integrated into the whole group setting in a General Ed setting, they are often responded to very favorably." [P4200; Principal, Female, Professional Degree]	"I wish there were more inclusion, but again, because there's so many kids here with high needs… inclusion is really tough to do." [T217; Teacher, Female, Professional Degree]
Social interaction	"Even if they are not ready for inclusion, maybe with their academics yet, then they at least get that social inclusion with age-appropriate peers." [P900; Principal, Female, Professional Degree]	"The kids know our kids. They come in and they help. They do reading with the kids. They come in and they work with the kids. They'll play on the computer with them. They'll invite us to come in and do things. So although it seems as though we are a self-contained quiet little room, we are really not. We go out to recess with the kids. We go out to prep with the kids. And like I said, I interact with the other kids in the other class and my kids interact with those kids too. That's the whole point of it." [T921; Teacher, Female, Other Degree]
Awareness	"When you walk in our school, one of the first things you see is our pillar that says Autism Awareness… And so we want parents and community people to know that we have students with autism in our building and that we are aware and we are trying our hardest to meet their needs and include them as much as possible." [P3700; Principal, Female, Professional Degree]	"People in this school, they are – what they know about autism is not really accurate… they are not really informed about the disorder, and I wanna bring autism awareness to the teachers in this school. Because I do not think everyone's as informed as they should be." [T3653; Teacher, Male, Professional Degree]
Attitudes	"[The autism self-contained classroom] just reinvigorates… because you do not get this all the time because it's a struggle. It's a daily struggle and sometimes it's two steps forward and then five steps backwards with some of the kids. So, it's just we feel very, if I can use the word blessed, to have our autistic children because as much as we feel that we have taught them, they have taught us so much more in so many ways that it's amazing. It's very gratifying as well." [P5700; Principal, Female, Professional Degree]	"[General education] teachers are really afraid of kids with autism. They hear autism, and they are like, 'Oh I cannot do that.' And they do not understand that at least five of my kids are better behaved than a challenging general education student." [T217; Teacher, Female, Professional Degree]
Teacher/staff professional relationships	"[Special education teachers] are including some of their children that are ready into regular Ed, so there's a lot of conversations that are occurring between our regular Ed teachers… how to support those kids, what do we need to make it work?" [P5200; Principal, Female, Bachelor's Degree]	N/A
Teacher/staff support for inclusion	N/A	"So my team meeting is actually with the other autistic support teacher. It's not with the kindergarten teacher. So I really do not have any planning – common planning time with them. They're both very friendly and I've talked to them, but very brief because we all have classes to attend to." [T538; Teacher, Female, Professional Degree]

(Continued)

TABLE 3 (Continued)

Subcode	Principals	Special education teachers
Principal involvement with autistic students	"So now we have breakfast every morning together just so that he could have a good day… and he told me today, 'I love you, you are the best principal,' and he says, 'because you have breakfast with me every day'… So you know, those things are rewarding to see the progress in the students and knowing where he's coming from, and knowing that I can make a difference in their lives… I try to keep that at the forefront." [P2900; Principal, Female, Professional Degree]	N/A
Principal support for inclusion	N/A	"My principals really encourage the learning support teacher to buddy with the [special education] teacher and to make inclusion work that way of kind of being that bridge in between." [T4257; Teacher, Female, Professional Degree]
Location of self-contained classroom	"Plus, their classrooms are on their age-appropriate floors and in their age-appropriate wing so that they get that exposure [to age-appropriate peers]." [P900; Principal, Female, Professional Degree]	"We're on the fourth floor. We're the only classroom up there. Um, we do have an art room and there is a media room. I'm not really sure what they do in that room but is pretty much just us on the fourth floor. So I kind of feel like we are isolated." [T1828; Teacher, Female, Professional Degree]
Influences on inclusion	"They are included to the degree that they can, although also being respectful of some of their limitations, if there's certain things that are not appropriate for them…if that was my child would not want them to be forced to do something just under the sort of umbrella of being included. So we try to be sensitive to that as well." [P5700; Principal, Female, Professional Degree]	"We do not get to go out to recess with the kids because it's just too many kids out there. The recess is K-5, so it's just way too many kids and there's only two or three staff members that monitor it and it's overwhelming. So I think that part makes me really upset because I would love to see their interaction. And when we have had the chance, they play so well that I think their growth would be so much stronger if we had that interaction." [T538; Teacher, Female, Professional Degree]
Recommendations	N/A	"It is little things like that, that could be addressed. You know, even if you put us on the second or third floor, I do not care, but at least, you know, I can go knock on a door next door just to say, 'Hey, neighbor'… But we are just up there alone." [T1828; Teacher, Female, Professional Degree]

Participant demographic characteristics and identification numbers are included in brackets; P, Principal; T, Special education teacher.

[autistic] students included wherever possible." In expanding on their philosophy towards inclusion, some principals highlighted that they supported inclusion as "appropriate for [students'] growth," such that students first need to "show that they are developmentally ready" for general education settings. Several principals described a goal of equality and a mission to treat their autistic students in self-contained classrooms "just like everyone else." For instance, one principal stated that they were "trying to make it not be the Gen Ed population and [special education or autistic] population. It's supposed to be, this is our [School name] population." Another principal added that treating students equitably means having similar opportunities:

> When I became an administrator, I was determined that there will be no special ed, gen ed. It's just a school. So my expectations don't waiver… everyone weighs in, different ways, but everyone is a part of it. My children with special needs are involved in any activity that we have at the school.

In addition, several principals described a need to be "purposeful" about inclusion, so "it's just a part of what [they] do." One principal added that there may need to be intentional strategies that facilitate inclusion, such as providing a student with limited language skills a whiteboard, so they have a way to communicate during a classroom discussion.

A few principals extended their inclusion philosophy to special education teachers, with one stating, "I want everyone to have relationships with everyone in my building. Because reality is we do not live in bubbles." Another principal acknowledged that special education teachers can feel "alienated" from the rest of the school and, therefore wants them to feel like "a part of the fabric of the school."

While one teacher specifically reported feeling included as "a part of the school," half of teachers who referenced *inclusion philosophy* identified feelings of isolation. Teachers described being "secluded," "left out," feeling like "a lone wolf," "in a bubble," or even forgotten. One teacher summarized, "We often refer to ourselves as Special Ed Island. We're off [isolated] and everybody else is their own thing" Another teacher stated that they do not feel intentionally left out, but they still end up on their own. In addition, some teachers described a lack of attention or prioritization of their autistic students or classrooms. For instance, one teacher noted that the school mission was created for general education students and, therefore, they had to "tweak it a little bit to work for [autistic students]." A few teachers described that their classrooms could follow along with the programming or curriculum of the rest of the school, and one teacher highlighted that there had been a recent "learning process" at their school in which the school is "coming around" to inclusion, such that each year they are being included in more activities than the previous year.

Advocacy

About half of principals (56%) outlined ways in which they advocate for their autistic students and special education teachers.

Several described "pushing for" inclusion and advocating for their students to have increased time in general education settings. Principals reported conducting classroom observations, setting individualized student goals, obtaining tools to support progress monitoring of included students, and working closely with special education teachers, who they describe as the strongest advocates for autistic students, to facilitate inclusion. Additional strategies that principals employed include purchasing materials to support the inclusion of autistic students in activities (e.g., noise canceling headphones, multisensory equipment) or advocating for additional staff at the district level.

Forty percent of teachers commented on ways in which they advocate for their autistic students or strategies that they feel worked well for autistic students (e.g., positive behavioral supports). Several teachers noted that they go out of their way to get to know general education teachers and have ongoing conversations about inclusion. One teacher described that they needed to be the driver of inclusion: "If I ask to be included, like I say… "Oh, we would really enjoy going on [field] trips with you." "Of course," they say, "absolutely." And they have included us in those [field] trips." Other teachers described their additional efforts to advocate for inclusion, such as taking their students to different general education art classes or encouraging students to sit with their autistic students at lunch.

Academic inclusion

Principals and special education teachers described what academic inclusion looks like for their autistic students in self-contained classrooms. Most principals (92%) detailed the academic inclusion of autistic students. Overwhelmingly, principals said that autistic students in self-contained classrooms have "as much inclusion time as possible," though principals typically qualified this statement to indicate that the level of inclusion "depends on the child." One principal summarized, "Now not all kids can, but if they can, we mainstream them." Principals reported a wide range of what inclusion looks like in their schools from autistic students participating in general education specials, such as art, to full inclusion. For instance, one principal described,

> We look at every kid and make sure they're getting the proper programming. We actually have [autistic] kids in our building who are not in [a self-contained] classroom at all and they never have been… And we say, all right, well, if we can do X, Y, and Z, we'll keep it going.

Principals also described various factors that support the academic inclusion of autistic students in their schools. For instance, some principals highlighted the importance of communication amongst teachers, with one principal noting that they have developed "a really good system of students passing in and out of classrooms," such that autistic students spend time in general education and general education students may receive support from the special education teacher. Relatedly, another principal gave an example of how teacher involvement supports academic inclusion:

> At that IEP meeting, the regular teacher was there with the parent, she was able to clearly speak to the parent about the child, where the weaknesses were, where her strengths were. So that makes parents feel good when a regular ed teacher comes in and treats your child like they're a member of their class. They don't see them as the girl in the [self-contained] class.

In addition, other principals emphasized the importance of a systematic approach to inclusion, such as starting gradually (e.g., one academic class) or using progress monitoring to monitor autistic students' IEP goals when in inclusive classrooms.

Of the special education teachers who mentioned academic inclusion (64%), a substantial minority (5 of 16) stated that they would like to see more inclusion of their students. One teacher described, "I feel like the inclusion process is not necessarily inclusive just because my kids are in the same space during [specials]… when they go to gym class, they do not do the stuff that the other kids are doing." Another teacher added, "At the beginning of the year I was told that my students would go on field trips with the first-grade classrooms. That has never happened." In contrast, some teachers noted examples of their autistic students being integrated into general education classrooms. One teacher described their school as "like Grand Central Station," such that students are frequently being "pushed in" to classrooms and coming and going from different classrooms. Another teacher highlighted that many of their students are academically ready for inclusion but other factors (e.g., behavior) interfere.

Social interaction

Principals and special education teachers identified social (peer) interaction as another aspect of inclusion for their autistic students in self-contained classrooms. Principals discussed ways in which they facilitated peer interaction for autistic students, noting that if autistic students were not ready for academic inclusion "then they at least get that social inclusion with age-appropriate peers." For example, several principals identified lunch and recess as important opportunities for autistic students in self-contained classrooms to spend time with their general education peers, with one principal changing the schedule to facilitate autistic students joining recess with the general education kindergarten class. Another principal described "reverse inclusion":

> In the lunchroom, the children from the typical classrooms are sitting with the children—autistic students—at their lunch tables, and they're just interacting and socializing. And the adults are helping to facilitate that when it doesn't come naturally. But for some, it's coming naturally. So that's been helping with the social skills.

Several principals emphasized that peer support is valuable for both general education students and autistic students. For instance, one principal described middle schoolers who were on the same floor as the self-contained classroom building "positive relationships" with the autistic students and volunteering in the classroom. Other principals noted partnerships between the autistic self-contained classroom and other grade level classrooms, including pairing students for specials or for joint field trips. One principal added that they give "friendship awards" for students "who have volunteered their lunch time to play and socialize with our [autistic] students." This principal described an increase in the collaborative spirit in the school, such that, "It's really nice to see the kids who have rallied around and taken that child under their wing to help them, to make sure that their transitions are smooth and that they do not get upset."

Thirty-two percent of teachers referenced social interaction with mixed descriptions in how often autistic students in self-contained classrooms were socially included with their general education peers. However, overall, teachers agreed regarding the importance of social opportunities for their autistic students, with one teacher stating, "The academic part is important, but also there needs to be a balance of what can they learn socially, and how can they learn with speaking to one another." Another special education teacher who lamented the lack of inclusion for their students said, "I think their growth would be so much stronger if we had that interaction," referencing joint recess. Other teachers reported positive social interactions between students, highlighting shared recess, lunch, and joint classroom time as opportunities for interaction. Teachers also described buddy systems in which general education students would come into self-contained classrooms to work with the autistic students or autistic students would join their grade level peers' classrooms at the end of the day for "[free] choice time."

Theme: factors affecting the inclusion of autistic students in self-contained classrooms

Awareness

While fewer than half of principals (44%) referenced awareness of autism and the autism self-contained classrooms in their schools, awareness was the most referenced topic (88%) by teachers. Of the principals who mentioned awareness, a few highlighted ways in which autism awareness is a value of their schools. For instance, one principal described specific autism awareness activities (e.g., selling t-shirts) at their school. Another noted that "almost all" of the school was aware of the autism self-contained classrooms, from parents to students to custodial staff. In addition, one principal stated that certain school practices, specifically creating grade level (e.g., Kindergarten to second grade) "communities," facilitated awareness of their autistic students and classrooms as "everybody [within the community] knows how everybody else operates." In contrast, some principals indicated that autism awareness is an area for growth in their schools, as only certain school staff (e.g., special education team, speech-language or occupational therapists) are aware of the autism self-contained classrooms.

Similarly, special education teachers identified specific school staff who may be aware of the autism self-contained classrooms in the school; however, the majority of teachers who mentioned awareness (81%) cited at least one misconception from colleagues regarding autism, the abilities of their autistic students, or the strategies used in their classrooms. For instance, one teacher described:

> I don't think that the rest of the staff necessarily understands what autism is or what it means for my kids…I think people are kind of just not holding them to the same kind of expectations in their [inclusion classes]… because people don't understand what autism is and that it's not necessarily an intellectual disability… I just wish that there was a little more awareness or training for our school staff.

Another teacher expressed upset at the implications of school staff's misconceptions and stigma of autism or students' potential:

> These are people that are in a teaching environment… And they can't understand it. So how is someone in the public supposed to understand what's going on? And I think it is harder with autistic children because they don't have [the] physical features that other children with special needs have… And it's hard to differentiate that when you're out in the public or in the hallway. They don't realize.

Relatedly, several teachers noted that general education teachers express surprise at the skill level or work accomplished by autistic students in self-contained classrooms, potentially because it did not match their preconceived stereotypes of autism. One special education teacher added that while their colleagues may notice and commend them on their students' behavioral gains, they do not notice autistic students' academic achievements:

> People will stop me in the hallway and be like, "Oh, your kids line up now, and they never used to do that before. That's great." … It's really only what they see, where I don't think that their academic progress is on anyone's radar besides mine.

When asked directly about general education teachers' awareness of the autism self-contained classrooms or strategies used, a common response from special education teachers was, "They do not know what I do." Moreover, several teachers described their colleagues' misperceptions of their jobs as "play[ing] all day long" or being "easy." Further, special education teachers indicated that it is challenging when their colleagues do not understand the strategies or purpose of the strategies employed in the autism self-contained classroom. For instance, one teacher described, "They'll [colleagues] say, 'Why is your room so dark? It needs to be brighter.' I'm like 'Well, it really causes sensory overload for a lot of the students to keep it so bright.'"

Attitudes

Nearly half of both principals (48%) and special education teachers (40%) referenced attitudes towards autistic students in self-contained classrooms or inclusion of these students. Several principals referenced that they "embrace" the inclusion model and are supportive of the autistic students in their school. One principal described that it is important to be aware and accept the differences of autistic students compared to non-autistic students, stating:

> Understanding that it may look very different than a typical first grade when you go in because the kids… they may be louder. They may need more transitions. The teacher may do things that may look a little different. But I think understanding that they're trying to meet the needs of their kids… I think it's just accepting that, as well.

A few principals acknowledged that this attitude is not universal, as school staff might become frustrated by specific students' behavioral challenges. However, many principals referenced general education students in their building being friendly, tolerant, and motivated to "help one another and be supportive."

Special education teachers echoed that students in general education settings largely had positive attitudes toward autistic students. However, teachers reported that while some general education teachers were respectful of their work, many had negative attitudes towards inclusion and practices used in autism self-contained classrooms. In a few instances, special education teachers discussed hearing exclusionary comments from colleagues such as, "They're your problem," and, "Your students cannot go into my room." In addition, some teachers were described as "afraid" of autistic students, sometimes due to interfering behaviors (e.g., biting, hitting), though several special education teachers attributed others' fears to lack of knowledge or understanding. For instance, one participant noted a shift in attitude resulting from increased exposure to working with autistic students:

> I think they [general education teachers] were scared at first. And then once they got to know the kids, they loved them. I mean, they're easy to love. So, I just – I feel like they were – they didn't know what to do at first. And then once they got to know them, everything started changing.

General education teachers also reportedly expressed resistance to strategies used by special education teachers, most prominently positive behavior reinforcement models, or the supports in place for the autism self-contained classrooms. One teacher stated that other teachers see their role as a "babysitter" and do not understand why they have additional staffing in their classroom.

Teacher/staff professional relationships (principal code) and teacher/staff support for inclusion (teacher code)

Most principals (76%) described ways in which teacher/staff relationships affect the autism-specific culture in their schools. Principals consistently highlighted communication, including formal and informal opportunities, as being helpful for supporting and including autistic students "so everybody's on the same page." Communication occurs across educator roles, though principals predominantly discussed the importance of communication between special education and regular education teachers. For instance, one principal described:

> [Special education teacher] works with [general education teacher] to provide the appropriate levels of support and understanding what they're doing so he can support [autistic students] when they come back in the [autism self-contained] classroom. And so really communicating around what the needs of kids are and how they can incorporate them into what they're doing in the regular education classroom so that he can incorporate that.

Principals noted that professional learning communities, grade group meetings, and other meetings as opportunities during which teachers and the principal can discuss student progress. One principal summarized:

> I think there's constant conversation and discussion about those students. It's not just, "Okay, your side's here, have a good year." There's constant community and discussion about those students, how well they're doing, what their needs are, what they're doing well, what they need support with.

Some principals observed poor relationships across roles, sometimes stemming from navigating interfering student behavior. Others noted limited formal time communication when structures are not in place for regular meetings; for example, there is not a regular meeting set up for special education teachers to communicate with other teachers.

Teacher/staff support for inclusion was one of the most frequently referenced (84%) domains by special education teachers. Teachers' perspectives were mixed in terms of their experiences of support in their schools. Several special education teachers indicated that supportiveness depended on the "comfort level" of the individual, and experiences ranged from positive to negative to ambivalent. While some teachers referenced being welcomed into general education teachers' classrooms, others described that they are just "on an Island by myself," with one special education teacher sharing that when they provided coverage for a classroom, they were mistaken as a substitute. Another teacher specifically summarized their experience of using positive behavioral supports in their autism self-contained classroom:

> I get a lot of flak from my coworkers and even at times from – not our principal, but other administrators because I don't use that negative punishment model. I use a positive behavioral support model… I get a lot of eye-rolling, I get a lot of you're too soft from people.

In addition, participants described valuing opportunities to have shared meetings with their same grade colleagues. However, scheduling was a tremendous barrier to support from other teachers. Though some special education teachers had brief meeting times, most said they were not given shared meeting times with their grade groups, felt left out during planning, or that shared meetings covered topics not applicable to autism self-contained classrooms.

Principal involvement with autistic students (principal code) and principal support for inclusion (teacher code)

Twenty percent of principals discussed ways in which they are involved with their autistic students or autism self-contained classrooms. Principals highlighted how they develop relationships and rapport with their students, including having breakfast with an autistic student and visiting and observing the autism self-contained classrooms. Some principals specifically described ways in which interacting with autistic students facilitates inclusion. For instance, one principal shared that they talk to all newly enrolled special education students, stating staff "know to call me because I need to see what this kid's skill level is, and I need to see from the door what do we need to do… [if he/she/they] needs to be mainstreamed." Another described their observations as key to identifying students for inclusion.

Of the special education teachers who referenced principal support for inclusion (32%), participants described both supportive and unsupportive administrations. Support included cultivating an inclusive environment through including autistic students in schoolwide events (e.g., assemblies), observing in the autism self-contained classroom, and encouraging teacher communication to be a "bridge in between" classrooms. Teachers who described unsupportive environments mostly highlighted being left alone. For instance, one teacher stated, "I do not get chastised by administration or asked to change my methods, I just do not get a lot of support." Other participants indicated that they would like the principal to be more participatory in their classrooms, including more frequent observations and getting to know the autistic students, and to facilitate teacher communication.

Location of autism self-contained classroom

Some of the principals (24%) and teachers (20%) highlighted the location of the self-contained classroom as either a facilitator of or barrier to the inclusion of autistic students. For instance, a few principals highlighted being intentional with classroom location, such as having autistic students in the "same hallway" as their general education peers. One principal described:

> Before I got here, it was like the special ed wing, like all special ed [classrooms] are in one area. And I said that was the first thing I needed to change in terms of putting all the different classes within the flow of the school and not separating them into one part of the building and acting like they're not there…That it's not like they're going through the back door. They're going through the same doors everyone else can.

Another principal referenced space issues as contributing to the autistic students being separated from their grade level peers. Notably, all the teachers who mentioned their classroom location indicated that they were "secluded," with one teacher stating, "We're just stuck over here in nowhere land by ourselves." Other teachers described that their self-contained classrooms were on a separate floor (e.g., basement, fourth floor) where there were no other classrooms.

Influences on inclusion

About half of principals (44%) and special education teachers (48%) noted factors that influence inclusion that were not captured elsewhere. Principals predominantly discussed facilitators of and barriers to inclusion specific to student characteristics and teacher/staff factors. Specifically, some principals noted that students' skills, including their communication, academic skills, and interfering behavior, affect inclusion. For instance, one principal stated that autistic students who are behind their peers in certain subjects "are not able to fit into the [academic] group[s] that the teachers have already established." Another principal noted that an autistic student's behavior had "become a danger to himself and others" and, therefore, they included him in classes in which they were less likely to see interfering behaviors. In addition, principals described ways in which teacher/staff factors affected inclusion. Principals noted that the personalities (e.g., kindness, calm) and techniques of teachers facilitated the inclusion of autistic students. For instance, one principal stated, "I have seen some positive responses from teachers and implementation of specific techniques and that has afforded us opportunities in some instances to include students." Several principals highlighted the value of having additional staff, such as a one-to-one aide or classroom assistant, to accompany autistic students between classrooms (i.e., general education and autism self-contained classrooms). One principal specifically referenced a district-level factor (i.e., lack of hiring) as a barrier to supporting the inclusion of autistic students.

Similar to principals, special education teachers also cited student and teacher/staff factors as influences on inclusion. Some teachers noted that some of "their autistic students are "academically on par and ready to be there [included in general education]," but their "behaviors" (e.g., tantrums) interfere. One teacher's perspective was that "functionally [their] students cannot do it [inclusion]" or referenced the "high needs" of the students as a barrier to inclusion. Other teachers emphasized that a facilitator of inclusion was having a classroom assistant or aide to support autistic students in settings in which they are included, though several teachers noted that their schools simply did not have the staffing for this. One teacher described that lack of staff support meant that it would be a tradeoff, such that if the classroom assistant accompanied the autistic students into general education classrooms, the special education teacher would then be the only adult in the autism self-contained classroom. Beyond staffing, participants also described lack of funding as a barrier to inclusion, such as not being granted funds for a bus for autistic students to join field trips. Another teacher summarized, "Trying to do a co-teaching model of inclusion is a big jump. It's huge. And I do not think anybody has the time, energy, or resources to head it up."

Theme: recommendations

A subset of special education teachers (36%) provided recommendations, which fell into three categories: specific recommendations for inclusion, recommendations for teachers, and recommendations for administration. In terms of inclusion, teachers primarily wanted their autistic students to receive more time in inclusive settings in general, whether this was an integrated classroom, shared recess time, or more integration during lunch time. One teacher noted that having more inclusion time also would facilitate collaboration between teachers. For instance, a participant stated:

> If I was included in grade group or – I think that would be very helpful. Then they would know what I was doing, and they would know how our schedule works, and they would understand it better. But we don't get the time at all to collaborate with the teachers."

For general education teachers, special education teachers recommended them spending more time getting to know the autistic students and treating them equitably. Behavior management training also was recommended, particularly for behaviors that interfere with inclusion. Administrative recommendations included moving the special education classroom, so it is not physically isolated, keeping class sizes small, supporting autism-specific staff development to reduce stigma and build skills specific to service autistic students, funding more classroom staff, and giving an equal amount of support to specialized classrooms as general education classrooms.

Discussion

The findings of this qualitative study shed light on the culture of inclusion of autistic children in public elementary schools in the United States from the perspectives of principals and special education teachers. In line with previous research [e.g., (9, 11, 12, 44, 45)], this study emphasized that inclusion goes beyond placement and academic integration alone, and revealed possible attitudes and stigma toward autism that may affect inclusion. Participants emphasized the need for proactive measures to facilitate the genuine and equitable social participation of autistic students in a manner that fosters positive experiences for them, with a specific focus on improving knowledge and attitudes toward autistic students. It is important to note that educators did not endorse one universal picture of autism in schools, nor did they propose one specific strategy to promote inclusion. Instead, our findings highlight that there are several different ways to be inclusive and that schools must take steps to promote inclusion in a way that is personalized for the unique needs of their setting, staff, and autistic students. Implications for how to support the inclusion of autistic students with a diverse range of strengths and support needs are described below.

A consistent theme that emerged from both principals and special education teachers was a strong desire for equality for autistic students in terms of similar physical placements and social and academic opportunities. Notably, a small group of principals also emphasized the importance of *equity* (i.e., each person has different circumstances and requires a different set of resources and opportunities to reach an equal outcome) as opposed to equality [i.e., each individual or group of people is given the same resources or opportunities (46)] in promoting inclusion, providing insight on an "ideal" when it comes to the culture of supporting autistic students in school. These participants emphasized that true inclusion requires a nuanced understanding of individual student needs and the provision of appropriate and individualized support. Going forward, inclusion efforts should not solely aim to treat all students equally, but rather create inclusive environments that equitably meet all students' needs and ensure autistic students' meaningful participation in the educational setting.

This study also confirmed the stigmatization experienced by autistic students in schools (10, 47–49). Participants cited autistic students' behaviors as one factor that interfered with inclusion. In the school environment, autistic children display behaviors, such as tantrums, aggression, and not following directions, at a higher rate than their neurotypical peers (50–52), which can be a driver of stigmatizing views. This stigmatization can contribute to the misperception that inclusion is only for "some" student and not "all," which further impedes achieving true inclusion. Our findings also revealed an additional layer of stigmatization experienced by special education teachers themselves, similar to "affiliate stigma" of parents of autistic children (17), highlighting the challenges they face in promoting inclusive practices. This mutual experience of stigmatization underscores the complexity of creating an inclusive environment and emphasizes the need for a comprehensive approach to promoting a culture of inclusion that addresses the systemic barriers faced by both autistic students and teachers. Participants in the study recommended additional training on disabilities and special education, as well as steps to promote awareness of disabilities and special education in schools to help reduce stigma, as school staff's attitudes have been shown to be barriers to inclusion (26). Additionally, research has found that interventions including psychoeducation, case vignettes, contact-based interventions, and bespoke stigma reduction interventions have helped to reduce stigma surrounding both autism and other developmental and mental health concerns in educational settings (53).

These themes support the overarching philosophy and goals of the IDEA and, more specifically, the expanded definition of the "least restrictive environment" for autistic students in educational settings in the last several decades, now being viewed as more of a "context" than a "place" (54, 55). Additionally, these views of inclusion parallel the perspectives of many autistic self-advocates themselves (see the aforementioned definition of inclusion by our co-author, CE). However, these models and ideals are still not widely applied throughout the public education system in the United States.

Practical recommendations

A key suggestion to promote inclusion put forward by participants is the implementation of a co-teaching model involving both special education teachers and general education teachers in the same classroom. Previous research has highlighted that among general education teachers, those who possess limited knowledge or training in special education tended to engage in inclusive practices less frequently (56). A more collaborative teaching approach may allow for the sharing of expertise, resources, and responsibilities, fostering a more inclusive learning environment for all students. However, it should be noted that although participants in the study stated that co-teaching would be a practical step to promote true inclusion, they also reported that actually initializing this model would be a "big jump." Previous research has highlighted similar educator attitudes in regard to initiating a co-teaching model; however, several studies have found positive administration support and specified professional training as helpful strategies to promote successful implementation (57–59).

In previous work in this area, teachers have frequently highlighted the absence of adequate training and resources as a major obstacle to establishing an inclusive classroom atmosphere and effectively addressing behaviors of autistic students that may interfere with classroom instruction (26, 60–62). The need for additional training in autism, inclusive practices, and inclusive teaching methods also was identified in the current study as a valuable strategy to promote inclusion. By enhancing educators' knowledge and skills in these areas, attitudes towards inclusion can be positively influenced, contributing to a more inclusive school culture overall (26, 63). An essential next step to promote inclusion is investing in professional development opportunities that address the specific needs of educators working with autistic students.

Educators in this study also highlighted the positive attitudes of neurotypical students at their school towards interacting with and supporting autistic students. School staff could capitalize on this openness by educating neurotypical students about neurodiversity and promoting positive and collaborative interactions with their autistic peers. Examples of this may include partner or group academic activities or setting up relationship building activities either during unstructured school time or after school extracurriculars (64). These approaches have the potential to create an inclusive school culture that values and celebrates differences.

Moreover, educators shared ways in which they consider individualizing educational support for autistic students' strengths and challenges in various academic, social–emotional, and behavioral realms in relation to "readiness" for inclusion. However, this notion somewhat contradicts the essence of true inclusion, which emphasizes providing the necessary support and accommodations to enable autistic individuals with a diverse range of strengths and support needs to succeed in the general education setting. The findings highlight the need to challenge and shift this narrative within schools, encouraging a paradigm that values neurodiversity and focuses on providing the appropriate support and models for autistic individuals to succeed in inclusive settings, rather than imposing readiness criteria that may hinder their inclusion (65). Approaches such as Universal Design for Learning (66, 67) and collaborative teaming (68, 69) have been used to create inclusive settings that can accommodate and serve all children. Additionally, behavioral interventions [e.g., RUBIES (70)] can help educators manage behaviors that they report prevent some autistic students from fully engaging in an inclusive classroom.

Limitations and future directions

It is important to note that this study focused specifically on the perspectives of elementary school principals and special education teachers in one geographic area in the United States. Future research should consider incorporating the viewpoints of other stakeholders, most importantly autistic students themselves, from more geographically diverse areas of the country. It also will be critical to survey stakeholders involved in middle and high school education for autistic students given the changes and challenges that occur in adolescence. Exploring these diverse perspectives will contribute to a more comprehensive and generalizable understanding of the culture of autism in schools and help inform the development of truly inclusive practices that consider the needs of a broader group of autistic individuals and their educators. In addition, while consistent with observed trends in public schools across the United States, the majority of principals and special education teachers in this study were female.

Conclusion

This study offers a window into educators' perspectives on and recommendations for improving inclusion in schools with self-contained settings and provides valuable insights for policymakers, school administrators, educators, and other professionals involved in the education of autistic students. To promote true inclusion, it is crucial to prioritize equity over equality, recognize and address social as well as academic inclusion, combat stigmatization of both autistic students and special education teachers, challenge readiness-based narratives, and embrace individualized approaches to support diverse learners. By doing so, schools can foster inclusive environments that celebrate neurodiversity and create opportunities for the academic, social, and emotional growth of all students.

Data availability statement

The raw data supporting the conclusions of this article will be made available by the authors, without undue reservation.

Ethics statement

The studies involving humans were approved by University of Pennsylvania IRB. The studies were conducted in accordance with the local legislation and institutional requirements. The participants provided their written informed consent to participate in this study.

Author contributions

JL is the principal investigator of the study, generated the idea and designed the study, and supervised the qualitative coding and data analysis. KA is the primary writer of the manuscript and summarized the qualitative data. MH, DT, CE, AH, and TH supported the writing of the manuscript. All authors contributed to the article and approved the submitted version.

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Conflict of interest

The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

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Supplementary material

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References

1. Maenner MJ, Warren Z, Williams AR, Amoakoehene E, Bakian AV, Bilder DA, et al. Prevalence and characteristics of autism spectrum disorder among children aged 8 years – autism and developmental disabilities monitoring network, 11 sites, United States, 2020. *Morb Mortal Wkly Rep Surveill Summ*. (2023) 72:1–14. doi: 10.15585/mmwr.ss7202a1

2. Cardinal DN, Griffiths AJ, Maupin ZD, Fraumeni-McBridge J. An investigation of increased rates of autism in U.S. public schools. *Psychol Sch*. (2021) 58:124–40. doi: 10.1002/pits.22425

3. Kang-Yi CD, Locke J, Marcus SC, Hadley TR, Mandell DS. School-based behavioral health service use and expenditures for children with autism and children with other disorders. *Psychiatr Serv*. (2016) 67:101–6. doi: 10.1176/appi.ps.201400505

4. IDEA. *(2004). Individuals with disabilities education act 20 U.S.C. § 1400*. Washington, DC: US Department of Education (2004).

5. Humphrey N, Lewis S. 'Make me normal': the views and experiences of pupils on the autistic spectrum in mainstream secondary schools. *Autism*. (2008) 12:23–46. doi: 10.1177/1362361307085267

6. Larcombe TJ, Joosten AV, Cordier R, Vaz S. Preparing children with autism for transition to mainstream school and perspectives on supporting positive school experiences. *J Autism Dev Disord*. (2019) 49:3073–88. doi: 10.1007/s10803-019-04022-z

7. U.S. Department of Education, Office of Special Education Programs, individuals with disabilities education act (IDEA) database. (2020). Available at: https://data.ed.gov/dataset/idea-section-618-data-products-state-level-data-files (accessed February 25, 2022).

8. Morningstar ME, Kurth JA, Johnson PE. Examining national trends in educational placements for students with significant disabilities. *Remedial Spec Educ*. (2017) 38:3–12. doi: 10.1177/0741932516678327

9. Simón C, Martínez-Rico G, McWilliam RA, Cañadas M. Attitudes toward inclusion and benefits perceived by families in schools with students with autism spectrum disorders. *J Autism Dev Disord*. (2022) 53:2689–702. doi: 10.1007/s10803-022-05491-5

10. Aubé B, Follenfant A, Goudeau S, Derguy C. Public stigma of autism spectrum disorder at school: implicit attitudes matter. *J Autism Dev Disord*. (2021) 51:1584–97. doi: 10.1007/s10803-020-04635-9

11. Goodall C. 'I felt closed in and like I couldn't breathe': a qualitative study exploring the mainstream educational experiences of autistic young people. *Autism Dev Lang Impair*. (2018) 3:239694151880440. doi: 10.1177/2396941518804407

12. Mesibov GB, Shea V. Full inclusion and students with autism. *J Autism Dev Disord*. (1996) 26:337–46. doi: 10.1007/BF02172478

13. Russell A, Scriney A, Sinéad S. Educator attitudes towards the inclusion of students with autism spectrum disorders in mainstream education: a systematic review. *Rev J Autism Dev Disord*. (2022) 10:477–91. doi: 10.1007/s40489-022-00303-z

14. Wei X, Wagner M, Christiano ER, Shattuck P, Yu JW. Special education services received by students with autism spectrum disorders from preschool through high school. *J Spec Educ*. (2014) 48:167–79. doi: 10.1177/0022466913483576

15. Koegel L, Matos-Freden R, Lang R, Koegel R. Interventions for children with autism spectrum disorders in inclusive school settings. *Cogn Behav Pract*. (2012) 19:401–12. doi: 10.1016/j.cbpra.2010.11.003

16. Sansosti JM, Sansosti FJ. Inclusion for students with high-functioning autism spectrum disorders: definitions and decision making. *Psychol Sch*. (2012) 49:917–31. doi: 10.1002/pits.21652

17. Turnock A, Langley K, Jones CRG. Understanding stigma in autism: a narrative review and theoretical model. *Autism Adulthood*. (2022) 4:76–91. doi: 10.1089/aut.2021.0005

18. Underhill JC, Ledford V, Adams H. Autism stigma in communication classrooms: exploring peer attitudes and motivations toward interacting with atypical students. *Commun Educ*. (2019) 68:175–92. doi: 10.1080/03634523.2019.1569247

19. Causton-Theoharis J, Theoharis G, Orsati F, Cosier M. Does self-contained special education deliver on its promises? A critical inquiry into research and practice. *J Spec Educ Leadersh*. (2011) 24:61–78.

20. Kurth JA, Lockman Turner E, Gerasimova D, Hicks TA, Zagona A, Lansey K, et al. An investigation of IEP quality associated with special education placement for students with complex support needs. *Res Pract Persons Severe Disabl*. (2022) 47:244–60. doi: 10.1177/15407969221134923

21. Sailor W, McCart AB, Choi JH. Reconceptualizing inclusive education through multi-tiered system of support. *Inc*. (2018) 6:3–18. doi: 10.1352/2326-6988-6.1.3

22. Choi JH, McCart AB, Sailor W. Reshaping educational systems to realize the promise of inclusive education. *Forum Intl Res Educ*. (2020) 6:8–23. doi: 10.32865/fire202061179

23. Domitrovich CE, Bradshaw CP, Poduska JM, Hoagwood K, Buckley JA, Olin S, et al. Maximizing the implementation quality of evidence-based preventive interventions in schools: a conceptual framework. *Adv Sch Ment Health Promot*. (2008) 1:6–28. doi: 10.1080/1754730x.2008.9715730

24. Roberts J, Simpson K. A review of research into stakeholder perspectives on inclusion of students with autism in mainstream schools. *Intl J Inclusive Educ*. (2016) 20:1084–96. doi: 10.1080/13603116.2016.1145267

25. Lyon AR, Corbin CM, Brown EC, Ehrhart MG, Locke J, Davis C, et al. Leading the charge in the education sector: development and validation of the school implementation leadership scale (SILS). *Implement Sci*. (2022) 17:48. doi: 10.1186/s13012-022-01222-7

26. Lindsay S, Proulx M, Thomson N, Scott H. Educators' challenges of including children with autism spectrum disorder in mainstream classrooms. *Intl J Disabil Dev Educ*. (2013) 60:347–62. doi: 10.1080/1034912X.2013.846470

27. Locke, J, Lawson, GM, Beidas, RS, Aarons, GA, Xie, M, Lyon, AR, et al. Individual and organizational factors that affect implementation of evidence-based practices for children with autism in public schools: A cross-sectional observational study. *Implement Sci*. (2019) 14. doi: 10.1186/s13012-019-0877-3

28. Toye MK, Wilson C, Wardle GA. Education professionals' attitudes towards the inclusion of children with ADHD: the role of knowledge and stigma. *J Res Spec Educ Needs*. (2019) 19:184–96. doi: 10.1111/1471-3802.12441

29. Carter R, Satcher D, Coelho T. Addressing stigma through social inclusion. *Am J Public Health*. (2013) 103:773. doi: 10.2105/AJPH.2012.301167

30. Holmes SC. Inclusion, autism spectrum, students' experiences. *Int J Dev Disabil*. (2022):1–15. doi: 10.1080/20473869.2022.2056403 [Epub ahead of print].

31. Horrocks JL, White G, Roberts L. Principals' attitudes regarding inclusion of children with autism in Pennsylvania public schools. *J Autism Dev Disord*. (2008) 38:1462–73. doi: 10.1007/s10803-007-0522-x

32. National Center for Education Statistics. (2020). Available at: https://nces.ed.gov/programs/digest/d21/tables/dt21_204.60.asp?current=yes (accessed June 10, 2023).

33. Locke, J, Beidas, RS, Marcus, S, Stahmer, A, Aarons, G, Lyon, AR, et al. A mixed methods study of individual and organizational factors that affect implementation of interventions for children with autism in public schools. *Implement Sci*. (2016) 11:1–9. doi: 10.1186/s13012-016-0501-8

34. Arick JR, Falco R, Loos L, Krug DA. *The STAR program: Strategies for teaching based on autism research*. Austin: Pro-Ed Publishing, Inc. (2004).

35. Dettmer S, Simpson R, Myles B, Ganz J. The use of visual supports to facilitate transitions of students with autism. *Focus Autism Other Dev Disabl*. (2000) 15:163–9. doi: 10.1177/108835760001500307

36. Schreibman L. Intensive behavioral/psychoeducational treatments for autism: research needs and future directions. *J Autism Dev Disord*. (2000) 30:373–8. doi: 10.1023/A:1005535120023

37. Smith T. Discrete trial training in the treatment of autism. *Focus Autism Other Dev Disabl*. (2001) 16:86–92. doi: 10.1177/108835760101600204

38. Williams, NJ, Frank, JE, Frederick, L, Beidas, RS, Mandell, DS, Aarons, GA, et al. Organizational culture and climate profiles: Relationships with fidelity to three evidence-based practices for autism in elementary schools. *Implement Sci*. (2019) 14. doi: 10.1186/s13012-019-0863-9

39. Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *Int J Qual Health Care*. (2007) 19:349–57. doi: 10.1093/intqhc/mzm042

40. Guest G, Bunce A, Johnson L. How many interviews are enough?: an experiment with data saturation and variability. *Field Methods*. (2006) 18:59–82. doi: 10.1177/1525822X05279903

41. Braun V, Clarke V. Using thematic analysis in psychology. *Qual Res Psychol*. (2006) 3:77–101. doi: 10.1191/1478088706qp063oa

42. Bradley E, Curry L, Devers K. Qualitative data analysis for health services research: developing taxonomy, themes, and theory. *Health Serv Res*. (2007) 42:1758–72. doi: 10.1111/j.1475-6773.2006.00684.x

43. MacPhail C, Khoza N, Abler L, Ranganathan M. Process guidelines for establishing intercoder reliability in qualitative studies. *Qual Res*. (2015) 16:198–212. doi: 10.1177/1468794115577012

44. de Valenzuela JS. Sociocultural views of learning In: L Florian, editor. *The Sage handbook of special education*. London: SAGE Publications Ltd (2007). 299–314.

45. Qvortrup A, Qvortrup L. Inclusion: dimensions of inclusion in education. *Intl J Inclusive Educ*. (2018) 22:803–17. doi: 10.1080/13603116.2017.1412506

46. Espinoza O. Solving the equity–equality conceptual dilemma: a new model for analysis of the educational process. *Educ Res*. (2007) 49:343–63. doi: 10.1080/00131880701717198

47. Broady TR, Stoyles GJ, Morse C. Understanding carers' lived experience of stigma: the voice of families with a child on the autism spectrum. *Health Soc Care Community*. (2017) 25:224–33. doi: 10.1111/hsc.12297

48. de Boer A, Pijl SJ, Minnaert A. Regular primary school teachers' attitudes towards inclusive education: a review of the literature. *Intl J Inclusive Educ*. (2011) 15:331–53. doi: 10.1080/13603110903030089

49. Lalvani P. Disability, stigma and otherness: perspectives of parents and teachers. *Intl J Disabil Dev Educ*. (2015) 62:379–93. doi: 10.1080/1034912X.2015.1029877

50. Hartley SL, Sikora DM, McCoy R. Prevalence and risk factors of maladaptive behaviour in young children with autistic disorder. *J Intellect Disabil Res*. (2008) 52:819–29. doi: 10.1111/j.1365-2788.2008.01065.x

51. Mazurek MO, Kanne SM, Wodka EL. Physical aggression in children and adolescents with autism spectrum disorders. *Res Autism Spectr Disord*. (2013) 7:455–65. doi: 10.1016/j.rasd.2012.11.004

52. Spaulding SA, Irvin LK, Horner RH, May SL, Emeldi M, Tobin TJ, et al. Schoolwide social-behavioral climate, student problem behavior, and related administrative decisions: empirical patterns from 1,510 schools nationwide. *J Posit Behav Interv*. (2010) 12:69–85. doi: 10.1177/1098300708329011

53. Waqas A, Malik S, Fida A, Abbas N, Mian N, Miryala S, et al. Interventions to reduce stigma related to mental illnesses in educational institutes: a systematic review. *Psychiatry Q*. (2020) 91:887–903. doi: 10.1007/s11126-020-09751-4

54. Crockett JB, Kauffman JM. *The least restrictive environment: its origins and interpretations in special education*. New York: Routledge (2013).

55. Rueda R, Gallego MA, Moll LC. The least restrictive environment: a place or a context? *Remedial Spec Educ*. (2000) 21:70–8. doi: 10.1177/074193250002100202

56. Van Reusen AK, Shoho AR, Barker KS. High school teacher attitudes toward inclusion. *High Sch J*. (2001) 84:7–20.

57. Brendle J, Lock R, Piazza K. A study of co-teaching identifying effective implementation strategies. *Int J Spec Educ*. (2017) 32:538–50.

58. Friend M, Barron T. Co-teaching as a special education service: is classroom collaboration a sustainable practice? *Educ Pract Reform*. (2016) 2

59. Scruggs TE, Mastropieri MA. Making inclusion work with co-teaching. *Teach Except Child*. (2017) 49:284–93. doi: 10.1177/0040059916685065

60. Anglim J, Prendeville P, Kinsella W. The self-efficacy of primary teachers in supporting the inclusion of children with autism spectrum disorder. *Educ Psychol Pract*. (2018) 34:73–88. doi: 10.1080/02667363.2017.1391750

61. Majoko T. Inclusion of children with autism spectrum disorders: listening and hearing to voices from the grassroots. *J Autism Dev Disord*. (2016) 46:1429–40. doi: 10.1007/s10803-015-2685-1

62. Segall MJ, Campbell JM. Factors relating to education professionals' classroom practices for the inclusion of students with autism spectrum disorders. *Res Autism Spectr Disord*. (2012) 6:1156–67. doi: 10.1016/j.rasd.2012.02.007

63. Vaz S, Wilson N, Falkmer M, Sim A, Scott M, Cordier R, et al. Factors associated with primary school teachers' attitudes towards the inclusion of students with disabilities. *PLoS One*. (2015) 10:e0137002. doi: 10.1371/journal.pone.0137002

64. Bolourian Y, Losh A, Hamsho N, Eisenhower A, Blacher J. General education teachers' perceptions of autism, inclusive practices, and relationship building strategies. *J Autism Dev Disord*. (2021) 52:3977–90. doi: 10.1007/s10803-021-05266-4

65. Acevedo SM, Nusbaum EA. Autism, neurodiversity, and inclusive education In: U Sharma, editor. *Oxford Encyclopedia of inclusive and special education*. Oxford: Oxford University Press (2020)

66. Carrington S, Saggers B, Webster A, Harper-Hill K, Nickerson J. What universal Design for Learning principles, guidelines, and checkpoints are evident in educators' descriptions of their practice when supporting students on the autism spectrum? *Int J Educ Res*. (2020) 102:101583. doi: 10.1016/j.ijer.2020.101583

67. Gargiulo RM, Metcalf D. *Teaching in today's inclusive classrooms: a universal design for learning approach*. Boston, MA: Cengage Learning (2022).

68. Bateman KJ, Schwartz IS, Gauvreau AN. It takes a team: working together to meet the needs of young children with autism spectrum disorder in an inclusive setting. *Incl Pract*. (2022) 1:132–8. doi: 10.1177/27324745221097354

69. Ryndak DL, Lehr D, Harayama N, Foster MH. Collaborative teaming for effective inclusive education for students with severe disabilities In: J McLeskey, F Spooner, B Algozzine and NL Waldron, editors. *Handbook of effective inclusive elementary schools*. England: Routledge (2021)

70. Bearss K, Tagavi D, Lyon AR, Locke J. Iterative redesign of a caregiver-mediated intervention for use in educational settings. *Autism*. (2022) 26:666–77. doi: 10.1177/13623613211066644

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Toward a more comprehensive autism assessment: the survey of autistic strengths, skills, and interests

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Introduction

Autism is primarily defined by its deficits in the Diagnostic and Statistical Manual of Mental Disorders (DSM-5) (1). However, autism can be defined as a natural, valuable part of human experience in which the ability to thrive depends on the match between the individual and their social context (2–8). Autistic strengths have been noted since autism was first defined (9). A growing body of literature has demonstrated how strengths in social communication, focused interests, stimming, sensory abilities, systems thinking, and cognition can be part of autism (10–13). Despite the neurodiversity movement, autism is still associated with stigma (14–16). Diagnostic evaluations often focus exclusively on problems without considering strengths (17, 18). Most questionnaires, observational tools, and interview questions tabulate problems to determine if someone is autistic, but they miss the comprehensive view of what it means to be autistic. The autism diagnostic evaluation is a critical time in a person's life, with some individuals referring to it as the most important experience of their life (19, 20). When an individual is first discovering they or their child is autistic, providing strengths-based information can provide an alternative to some of the stigmatizing messages they may have heard about autism. This can be shared in addition to a discussion about some of the anticipated challenges (21, 22). Autism-specific strengths-based measures that allow clinicians to assess for autistic strengths during diagnosis are needed. The Survey of Autistic Strengths, Skills, and Interests (SASSI, presented in the Supplementary Table 1) is a set of questions that can be integrated into the clinical interview with an adult or caregiver to explore and identify common autistic strengths. It is meant to be used along with a comprehensive battery that also includes challenges.

Social communication strengths

By definition, autistic people fail to conform to social norms, but a deficit-based diagnostic process can overshadow the value of nonconformity (16). Studies have shown that non-autistic people are more likely to conform to the majority by choosing an incorrect response if they think it is popular whereas autistic people tend to choose the correct answer even if that answer is unpopular. This autistic willingness to go against the crowd when correct has been demonstrated in autistic children (23) and adults (24). This research is based on small sample sizes, but many autistic activists cite their autism as giving them the strength to speak out (25). Non-autistic people tend to change their prosocial behavior (e.g., giving to charity) depending on whether they are being watched, whereas autistic people behave more consistently across contexts (26). In one study, autistic people were more likely to refuse to make an immoral choice (giving to a "bad charity") even if it benefitted them (gaining money). Non-autistic people changed their behavior depending on whether they were being watched, but autistic people were consistent (27). Many autistic people also identify honesty as an autistic strength (28, 29). Autistic people may be characterized as "lacking a filter," but being honest and direct saves time and allows for clearer understanding. Learning to express oneself directly can be an important intervention for neurotypical people (30). Autistic people point out that being guided by their own internal ethical compass and being less influenced by what other people think is a strength (31). However, autism stigma has led even this moral consistency to be conceptualized as a deficit [for an example, see (27)].

Need for solitude was one of the first characteristics identified as defining autism (32). This has been framed as a deficit, but enjoyment of solitude is also a strength. It is associated with lower levels of depression and anxiety (33). Experience sampling studies suggest that autistic people tend to enjoy solitude and may not feel lonely when alone (34). However, autistic people often highly value friendships as well. Making friends is a major developmental achievement of middle childhood (35). Friendship can protect against depression and anxiety (36). Some autistic people are selective in their friendships. They may keep their circles small (37, 38) and value friendships in which they can be authentic (38, 39). Autistic people often connect well across age groups (40–43). Research on the double empathy problem (44, 45), has shown that autistic people can often connect with other autistic people more effectively than non-autistic people can (46). Autistic pairs tend to have stronger rapport than mixed-neurotype pairs (47). Autistic people report experiencing relationships with other autistic people as highly satisfying and less tiring (48, 49). Autistic people also have a strong ability to connect with other autistic people online (50–52). Assessing a client's autistic friendships and online social network could inform ways to reduce the isolation autistic people sometimes experience (53), inform our understanding of social support networks, and identify support needed to further achieve satisfying relationships.

Focused interests and stimming

Focused interests can offer a sense of wellbeing (54–56), facilitate social connection (57), guide employment opportunities (58, 59), and strengthen academic skills and executive functioning (57, 60–62). Although the DSM-5 views "restricted interests" as deficits (1), clinicians can take a more wholistic view by identifying clients' interests and considering the potential opportunities they offer. Because autistic people tend to experience monotropism (63), they may be able to devote long periods of time to studying or talking about one subject, which often leads to expertise and mastery (64, 65). Some autistic people have animals as a special interest and many describe themselves as connecting well with animals (29). Interests can facilitate friendships, provide educational and vocational focus, as well as being pleasurable, so should be assessed directly.

Autistic people engage in repetitive movements primarily as a way to cope with intense thoughts or sensory experiences (66), but these are framed as deficits in part because engaging in unusual behavior is stigmatized (66, 67). Although some repetitive motor movements can indicate neurological problems (68, 69) or contribute to back pain or self-injury (70), they can also provide pleasure and serve a regulatory purpose. If clinicians can be mindful of our biases and ask about stimming from a positive perspective, we may help guide our clients to see the ways in which stimming helps them.

Sensory strengths

Autistic people often have sensory sensitivities, which may cause distress in certain environments. This, along with our profession's predisposition to view autism through a deficit-lens, has resulted in sensory sensitivities being framed as deficits on most questionnaires. This has limited research into whether sensory differences may also be strengths. Some previous studies have suggested that autistic people tend to perform more poorly on certain sensory tasks, such as identifying individual smells (71) and switching their attention between different sounds (72). Despite the challenges posed by sensory sensitivities, research has also reported autistic strengths, such as increased likelihood of perfect pitch (73), ability to identify smells that are mixed together (74), ability to recognize sounds that are mixed together (75), and performance on visual search tasks (76, 77). Attention to detail is one of the most prominent self-reported autistic strengths (29). These findings have led some researchers to refer to autistic people as perceptual experts (76). Sensory sensitivity itself may be linked to increased capacity. For example, autistic people who are more sensitive to sounds may perform better on tests of auditory capacity [ability to detect specific sounds mixed with multiple distracting sounds; (78)]. Sensory differences may also inform creative pursuits and coping strategies.

Asking clients about their positive sensory experiences can offer guidance in empowering clients to select and modify environments to support autistic flourishing. Most existing questionnaires and interview questions assess whether autistic people are bothered by sensory input, but very few tools assess sensory strengths. The Monteiro Interview Guidelines for Diagnosing the Autism Spectrum, Second Edition [MIGDAS-2, (79)] does assess sensory experiences that the individual enjoys and attention to detail. The SASSI offers additional assessment questions.

Systems and routine

From a young age, many autistic children line-up toys, gaze at them from different angles, and arrange them by color or shape. Some are drawn to pre-existing systems like alphabetical and numerical order (80). This has been framed as nonfunctional (1) and as obstructing or distracting from more productive types of play. A frequently cited paper introduces restricted interests and repetitive behaviors as constituting "a major barrier to learning and social adaptation" (81). Recent research has shown, however, that engaging in this autistic way of playing at preschool age is linked to improved nonverbal reasoning skills at school-age (82). In addition to bringing joy to autistic children, which in and of itself is a worthy goal (83, 84), this interest in systems means that many autistic people are good at creating their own systems for making their environments work (28). Many autistic people also thrive on routine (85), which can be an advantage in many environments.

Cognitive strengths

There is no one autistic profile when it comes to cognition, but there are certain strengths that seem to be associated with autism across the lifespan, and may appear even among autistic children classified as having intellectual disabilities or as being untestable (86, 87). Autistic people often outperform non-autistic people on tasks assessing visual-spatial reasoning [e.g., Block Design on the Wechsler tests, (88)], other nonverbal tasks that required identifying visual features embedded among other distracters [e.g., visual search tasks, (77, 89), and embedded figures tests, (86, 87)], and certain executive functioning tasks (90). Recent longitudinal research has shown that early performance on some of these specific types of tasks (e.g., embedded figures tasks) is linked to non-verbal intelligence as autistic children get older (82).

Discussion

Clearly autism is more than the set of deficits we have traditionally been taught to assess and evaluate. To move toward overcoming the stigma that permeates our diagnostic assessments we must expand and clean the lenses through which we view autism. Asking directly about autistic strengths can help us see our clients' experiences more clearly and make more effective recommendations to help them move forward while embracing who they already are. The SASSI is a newly developed tool meant to inspire future research on assessing autistic strengths. Future research could include focus groups or interviews with autistic adults to further refine the items, pilot studies with small groups of clinicians who can apply it to children and adults, and exploration of how it might be modified to include Likert scales. Our hope is that the SASSI can serve as a step toward inspiring future research and refining our diagnostic evaluations as we recognize together the value of expanding our conceptualization of autism.

Author contributions

SW: Conceptualization, Writing—original draft, Writing—review and editing. AE: Supervision, Writing—original draft, Writing—review and editing.

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Conflict of interest

SW has presented research on autistic strengths including the Survey of Autistic Strengths Skills and Interests at the University of Washington Autism Center and attendees paid UWAC to participate in the course and receive continuing education credits.

The remaining authors declares that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

Publisher's note

Supplementary material

The Supplementary Material for this article can be found online at: https://www.frontiersin.org/articles/10.3389/fpsyt.2023.1264516/full#supplementary-material

References

1. American Psychiatric Association. *Diagnostic and Statistical Manual of Mental Disorders*. 5th ed. Washington, DC: APA (2013). doi: 10.1176/appi.books.9780890425596

2. Anderson-Chavarria M. The autism predicament: models of autism and their impact on autistic identity. *Disabil Soc.* (2022) 37:1321–41. doi: 10.1080/09687599.2021.1877117

3. Chapman R. The reality of autism: On the metaphysics of disorder and diversity. *Philos Psychol.* (2020) 33:799–819. doi: 10.1080/09515089.2020.1751103

4. Dreaver J, Thompson C, Girdler S, Adolfsson M, Black MH, Falkmer M. Success factors enabling employment for adults on the autism spectrum from employers' perspective. *J Autism Dev Disor.* (2020) 50:1657–67. doi: 10.1007/s10803-019-03923-3

5. Gernsbacher MA. Toward a behavior of reciprocity. *J Dev Proc.* (2006) 1:139.

6. O'Neil S. The meaning of autism: Beyond disorder. *Disabil Soc.* (2008) 23:787–99. doi: 10.1080/09687590802469289

7. Rosqvist HB. Doing things together: Exploring meanings of different forms of sociality among autistic people in an autistic work space. *Alter.* (2019) 13:168–78. doi: 10.1016/j.alter.2019.03.003

8. Walker N. *Neuroqueer Heresies: Notes on the Neurodiversity Paradigm, Autistic Empowerment, and Postnormal Possibilities*. Fort Worth, TX: Autonomous Press. (2021).

9. Kanner L. Autistic disturbances of affective contact. *Nervous child.* (1943) 2:217–50.

10. Grant A, Kara H. Considering the Autistic advantage in qualitative research: the strengths of Autistic researchers. *Contemp Soc Sci.* (2021) 16:589–603. doi: 10.1080/21582041.2021.1998589

11. McCowan S, Shaw SC, Doherty M, Grosjean B, Blank P, Kinnear M. Vive La difference! celebrating and supporting autistic psychiatrists with autistic doctors international. *BJPsych Open.* (2021) 7:S40. doi: 10.1192/bjo.2021.157

12. Moore S, Kinnear M, Freeman L. Autistic doctors: overlooked assets to medicine. *Lancet Psychiat.* (2020) 7:306–7. doi: 10.1016/S2215-0366(20)30087-0

13. Warren N, Eatchel B, Kirby AV, Diener M, Wright C, D'Astous V. Parent-identified strengths of autistic youth. *Autism.* (2021) 25:79–89. doi: 10.1177/1362361320945556

14. Botha M, Dibb B, Frost DM. "Autism is me": an investigation of how autistic individuals make sense of autism and stigma. *Disabil Soc.* (2022) 37:427–53. doi: 10.1080/09687599.2020.1822782

15. Kinnear SH, Link BG, Ballan MS, Fischbach RL. Understanding the experience of stigma for parents of children with autism spectrum disorder and the role stigma plays in families' lives. *J Autism Dev Disord.* (2016) 46:942–53. doi: 10.1007/s10803-015-2637-9

16. Turnock A, Langley K, Jones CR. Understanding stigma in autism: A narrative review and theoretical model. *Autism Adulthood.* (2022) 4:76–91. doi: 10.1089/aut.2021.0005

17. Pellicano E, den Houting J. Annual Research Review: Shifting from 'normal science'to neurodiversity in autism science. *J Child Psychol Psychiat.* (2022) 63:381–96. doi: 10.1111/jcpp.13534

18. Urbanowicz A, Nicolaidis C, Houting JD, Shore SM, Gaudion K, Girdler S, et al. An expert discussion on strengths-based approaches in autism. *Autism Adult.* (2019) 1:82–9. doi: 10.1089/aut.2019.29002.aju

19. Arnold SR, Huang Y, Hwang YI, Richdale AL, Trollor JN, Lawson LP. "The single most important thing that has happened to me in my life": development of the impact of diagnosis scale—preliminary revision. *Autism Adult.* (2020) 2:34–41. doi: 10.1089/aut.2019.0059

20. Jones L, Goddard L, Hill EL, Henry LA, Crane L. Experiences of receiving a diagnosis of autism spectrum disorder: a survey of adults in the United Kingdom. *J Autism Dev Disord.* (2014) 44:3033–44. doi: 10.1007/s10803-014-2161-3

21. Abbott M, Bernard P, Forge J. Communicating a diagnosis of Autism Spectrum Disorder-a qualitative study of parents' experiences. *Clin Child Psychol Psychiatry.* (2013) 18:370–82. doi: 10.1177/1359104512455813

22. Makino A, Hartman L, King G, Wong PY, Penner M. Parent experiences of autism spectrum disorder diagnosis: A scoping review. *Rev. J Autism Dev Disord.* (2021) 1:1–8. doi: 10.1007/s40489-021-00237-y

23. Yafai AF, Verrier D, Reidy L. Social conformity and autism spectrum disorder: A child-friendly take on a classic study. *Autism.* (2014) 18:1007–13. doi: 10.1177/1362361313508023

24. Bowler DM, Worley K. Susceptibility to social influence in adults with Asperger's syndrome: A research note. *J Child Psychol Psychiat.* (1994) 35:689–97. doi: 10.1111/j.1469-7610.1994.tb01214.x

25. Rourke, A. Greta Thunberg responds to Asperger's critics. *Guardian.* (2019). Available online at: https://www.theguardian.com/environment/2019/sep/02/greta-thunberg-responds-to-aspergers-critics-its-a-superpower (accessed September 2, 2019).

26. Izuma K, Matsumoto K, Camerer CF, Adolphs R. Insensitivity to social reputation in autism. *Proc Nat Acad Sci.* (2011) 108:17302–7. doi: 10.1073/pnas.1107038108

27. Hu Y, Pereira AM, Gao X, Campos BM, Derrington E, Corgnet B, et al. Right temporoparietal junction underlies avoidance of moral transgression in autism spectrum disorder. *J Neuroscience.* (2021) 41:1699–715. doi: 10.1523/JNEUROSCI.1237-20.2020

28. Cope R, Remington A. The strengths and abilities of autistic people in the workplace. *Autism Adult.* (2022) 4:22–31. doi: 10.1089/aut.2021.0037

29. Russell G, Kapp SK, Elliott D, Elphick C, Gwernan-Jones R, Owens C. Mapping the autistic advantage from the accounts of adults diagnosed with autism: A qualitative study. *Autism Adult.* (2019) 1:124–33. doi: 10.1089/aut.2018.0035

30. Omura M, Maguire J, Levett-Jones T, Stone TE. Effectiveness of assertive communication training programs for health professionals and students: a systematic review protocol. *JBI Evidence Synthesis.* (2016) 14:64–71. doi: 10.11124/JBISRIR-2016-003158

31. Autistic Science Person. Autistic people care too much, Research says. *Neuroclastic.* (2020). Available online at: https://neuroclastic.com/autistic-people-care-too-much-research-says/ (accessed November 7, 2020).

32. Rowland D. Autism as an intellectual lens. *J Neurol Psychiat Brain Res.* (2020). 2020 doi: 10.37722/JNPABR.20201

33. Lin PH, Wang PY, Lin YL, Yang SY. Is it weird to enjoy solitude? Relationship of solitude capacity with personality traits and physical and mental health in junior college students. *Int J Environ Res Public Health.* (2020) 17:5060. doi: 10.3390/ijerph17145060

34. Chen YW, Bundy A, Cordier R, Chien YL, Einfeld S. The experience of social participation in everyday contexts among individuals with autism spectrum disorders: An experience sampling study. *J Autism Dev Disord.* (2016) 46:1403–14. doi: 10.1007/s10803-015-2682-4

35. Estes A, Munson J, John TS, Dager SR, Rodda A, Botteron K, et al. Parent support of preschool peer relationships in younger siblings of children with autism spectrum disorder. *J Autism Dev Disord.* (2018) 48:1122–32. doi: 10.1007/s10803-017-3202-5

36. Mazurek MO. Loneliness, friendship, and well-being in adults with autism spectrum disorders. *Autism.* (2014) 18:223–32. doi: 10.1177/1362361312474121

37. Sedgewick F, Hill V, Pellicano E. 'It's different for girls': Gender differences in the friendships and conflict of autistic and neurotypical adolescents. *Autism.* (2019) 23:1119–32. doi: 10.1177/1362361318794930

38. Sosnowy C, Silverman C, Shattuck P, Garfield T. Setbacks and successes: How young adults on the autism spectrum seek friendship. *Autism Adulth.* (2019) 1:44–51. doi: 10.1089/aut.2018.0009

39. Black MH, Kuzminski R, Wang J, Ang J, Lee C, Hafidzuddin S, et al. Experiences of friendships for individuals on the autism spectrum: A scoping review. *Rev J Autism Dev Disord.* (2022) 12:1–26. doi: 10.1007/s40489-022-00332-8

40. Pintsplease. Did you prefer the company of adults when you were a child? R/Autism. *Reddit.* (2022). Available online at: https://www.reddit.com/r/autism/comments/sj6uqt/did_you_prefer_the_company_of_adults_when_you/ (accessed March 7, 2023).

41. Bauminger N, Solomon M, Aviezer A, Heung K, Gazit L, Brown J, et al. Children with autism and their friends: A multidimensional study of friendship in high-functioning autism spectrum disorder. *J Abnorm Child Psychol.* (2008) 36:135–50. doi: 10.1007/s10802-007-9156-x

42. Daniel LS, Billingsley BS. What boys with an autism spectrum disorder say about establishing and maintaining friendships. *Focus Autism Other Dev Disabl.* (2010) 25:220–9. doi: 10.1177/1088357610378290

43. Petrina N, Carter M, Stephenson J. The nature of friendship in children with autism spectrum disorders: A systematic review. *Res Autism Spectr Disord.* (2014) 8:111–26. doi: 10.1016/j.rasd.2013.10.016

44. Milton DE. On the ontological status of autism: The 'double empathy problem'. *Disabil Soc.* (2012) 27:883–7. doi: 10.1080/09687599.2012.710008

45. Milton DE, Waldock KE, Keates N. Autism and the 'double empathy problem'. *Convers Empathy.* (2023) 16:78–97. doi: 10.4324/9781003189978-6

46. Crompton CJ, Hallett S, Ropar D, Flynn E, Fletcher-Watson S. 'I never realised everybody felt as happy as I do when I am around autistic people': A thematic analysis of autistic adults' relationships with autistic and neurotypical friends and family. *Autism.* (2020) 24:1438–48. doi: 10.1177/1362361320908976

47. Crompton CJ, Ropar D, Evans-Williams CV, Flynn EG, Fletcher-Watson S. Autistic peer-to-peer information transfer is highly effective. *Autism.* (2020) 24:1704–12. doi: 10.1177/1362361320919286

48. Crompton CJ, Sharp M, Axbey H, Fletcher-Watson S, Flynn EG, Ropar D. Neurotype-matching, but not being autistic, influences self and observer ratings of interpersonal rapport. *Front Psychol.* (2020) 11:2961. doi: 10.3389/fpsyg.2020.586171

49. Botha M, Dibb B, Frost DM. 'It's being a part of a grand tradition, a grand counter-culture which involves communities': A qualitative investigation of autistic community connectedness. *Autism.* (2022) 26:2151–64. doi: 10.1177/13623613221080248

50. Davidson J. Autistic culture online: Virtual communication and cultural expression on the spectrum. *Soc Cult Geogr.* (2008) 9:791–806. doi: 10.1080/14649360802382586

51. Kim SY, Bottema-Beutel K. Negotiation of individual and collective identities in the online discourse of autistic adults. *Autism Adulth.* (2019) 1:69–78. doi: 10.1089/aut.2018.0029

52. Ringland KE. A place to play: the (dis) abled embodied experience for autistic children in online spaces. In: *Proceedings of the 2019 CHI Conference on Human Factors in Computing Systems.* (2019). p. 1–14. doi: 10.1145/3290605.3300518

53. Umagami K, Remington A, Lloyd-Evans B, Davies J, Crane L. Loneliness in autistic adults: A systematic review. *Autism.* (2022) 26:2117–35. doi: 10.1177/13623613221077721

54. Grove R, Hoekstra RA, Wierda M, Begeer S. Special interests and subjective wellbeing in autistic adults. *Autism Resh.* (2018) 11:766–75. doi: 10.1002/aur.1931

55. Patten Koenig K, Hough Williams L. Characterization and utilization of preferred interests: A survey of adults on the autism spectrum. *Occupat Ther Mental Health.* (2017) 33:129–40. doi: 10.1080/0164212X.2016.1248877

56. Pellicano E, Fatima U, Hall G, Heyworth M, Lawson W, Lilley R, et al. capabilities approach to understanding and supporting autistic adulthood. *Nat Rev Psychol.* (2022) 1:624–39. doi: 10.1038/s44159-022-00099-z

57. Gunn KC, Delafield-Butt JT. Teaching children with autism spectrum disorder with restricted interests: A review of evidence for best practice. *Rev Educ Res.* (2016) 86:408–30. doi: 10.3102/0034654315604027

58. Jones SC. Advice for autistic people considering a career in academia. *Autism.* (2023) 23:13623613231161882. doi: 10.1177/13623613231161882

59. Kirchner JC, Dziobek I. Toward the successful employment of adults with autism: a first analysis of special interests and factors deemed important for vocational performance. *Scandin J Child Adolesc Psychiat Psychol.* (2014) 2:77–85. doi: 10.21307/sjcapp-2014-011

60. Tansley R, Parsons S, Kovshoff H. How are intense interests used within schools to support inclusion and learning for secondary-aged autistic pupils? A scoping review. *Eur J Special Needs Educ.* (2022) 37:477–93. doi: 10.1080/08856257.2021.1911520

61. Winter-Messiers MA, Herr CM, Wood CE, Brooks AP, Gates MA, Houston TL, et al. How far can Brian ride the daylight 4449 express? A strength-based model of Asperger syndrome based on special interest areas. *Focus Autism Other Dev Disabil.* (2007) 22:67–79. doi: 10.1177/10883576070220020701

62. Wood R. Autism, intense interests and support in school: From wasted efforts to shared understandings. *Educ Rev.* (2021) 73:34–54. doi: 10.1080/00131911.2019.1566213

63. Murray F. Me and monotropism. *Psychologist.* (2019) 32:44–8. Available online at: https://www.bps.org.uk/psychologist/me-and-monotropism-unified-theory-autism

64. Bross LA, Travers JC. Special interest areas and employment skills programming for secondary students with autism. *Teach Except Children.* (2017) 50:74–83. doi: 10.1177/0040059917730846

65. Laber-Warren E. The benefits of special interests in autism. *Spectrum.* (2021). doi: 10.53053/UVVZ8029

66. Kapp SK, Steward R, Crane L, Elliott D, Elphick C, Pellicano E, et al. 'People should be allowed to do what they like': Autistic adults' views and experiences of stimming. *Autism.* (2019) 23:1782–92. doi: 10.1177/1362361319829628

67. Charlton RA, Entecott T, Belova E, Nwaordu G. "It feels like holding back something you need to say": Autistic and Non-Autistic Adults accounts of sensory experiences and stimming. *Res Autism Spectr Disord.* (2021) 89:101864. doi: 10.1016/j.rasd.2021.101864

68. Martino D, Hedderly T. Tics and stereotypies: a comparative clinical review. *Parkinsonism Relat Disord.* (2019) 59:117–24. doi: 10.1016/j.parkreldis.2019.02.005

69. Shukla T, Pandey S. Stereotypies in adults: a systematic review. *Neurol Neurochir Pol.* (2020) 54:294–304. doi: 10.5603/PJNNS.a2020.0058

70. Minshawi NF, Hurwitz S, Fodstad JC, Biebl S, Morriss DH, McDougle CJ. The association between self-injurious behaviors and autism spectrum disorders. *Psychol Res Behav Manag.* (2014) 12:125–36. doi: 10.2147/PRBM.S44635

71. Sweigert JR, John T, Begay KK, Davis GE, Munson J, Shankland E, et al. Characterizing olfactory function in children with autism spectrum disorder and children with sensory processing dysfunction. *Brain Sci.* (2020) 10:362. doi: 10.3390/brainsci10060362

72. Emmons KA, Kc Lee A, Estes A, Dager S, Larson E, McCloy DR, et al. Auditory attention deployment in young adults with autism spectrum disorder. *J Autism Dev Disord.* (2022) 52:1752–61. doi: 10.1007/s10803-021-05076-8

73. Bradshaw J. Music, language and autism. *Tizard Learn Disab Rev.* (2014) 19:154–5. doi: 10.1108/TLDR-09-2013-0042

74. Walker SC, Williams K, Moore DJ. Superior identification of component odors in a mixture is linked to autistic traits in children and adults. *Chem Senses.* (2020) 45:391–9. doi: 10.1093/chemse/bjaa026

75. Remington A, Fairnie J, A. sound advantage: Increased auditory capacity in autism. *Cognition.* (2017) 166:459–65. doi: 10.1016/j.cognition.2017.04.002

76. Mottron L, Dawson M, Soulières I, Hubert B, Burack J. Enhanced perceptual functioning in autism: An update, and eight principles of autistic perception. *J Autism Dev Disord.* (2006) 36:27–43. doi: 10.1007/s10803-005-0040-7

77. O'riordan MA, Plaisted KC, Driver J, Baron-Cohen S. Superior visual search in autism. *J Exper Psychol.* (2001) 27:719. doi: 10.1037/0096-1523.27.3.719

78. Brinkert J, Remington A. Making sense of the perceptual capacities in autistic and non-autistic adults. *Autism.* (2020) 24:1795–804. doi: 10.1177/1362361320922640

79. Monteiro MJ, Stegall S. *MIGDAS-2: Monteiro Interview Guidelines for Diagnosing the Autism Spectrum*. Torrance, CA: WPS Publishing. (2018).

80. Mottron L. Should we change targets and methods of early intervention in autism, in favor of a strengths-based education? *Eur Child Adolesc Psychiatry.* (2017) 26:815–25. doi: 10.1007/s00787-017-0955-5

81. Leekam SR, Prior MR, Uljarevic M. Restricted and repetitive behaviors in autism spectrum disorders: a review of research in the last decade. *Psychol Bull.* (2011) 137:562. doi: 10.1037/a0023341

82. Girard D, Courchesne V, Cimon-Paquet C, Jacques C, Soulières I. Visual abilities and exploration behaviors as predictors of intelligence in autistic children from preschool to school age. *Autism.* (2023) 27:13623613231166189. doi: 10.1177/13623613231166189

83. McGuinness K. An evaluation of a tool, based on spoon theory, to promote self-regulation and avoidance of burnout in autistic children and young people. *Good Autism Pract (GAP).* (2021) 22:59–72.

84. Ratto AB, Bascom J, daVanport S, Strang JF, Anthony LG, Verbalis A, et al. Centering the inner experience of autism: development of the self-assessment of autistic traits. *Autism Adulth.* (2023) 5:93–105. doi: 10.1089/aut.2021.0099

85. Walsh L, Lydon S, Healy O. Employment and vocational skills among individuals with autism spectrum disorder: Predictors, impact, and interventions. *Rev J Autism Dev Disord.* (2014) 1:266–75. doi: 10.1007/s40489-014-0024-7

86. Courchesne V, Girard D, Jacques C, Soulières I. Assessing intelligence at autism diagnosis: Mission impossible? Testability and cognitive profile of autistic preschoolers. *J Autism Dev Disord.* (2019) 49:845–56. doi: 10.1007/s10803-018-3786-4

87. Courchesne V, Meilleur AA, Poulin-Lord MP, Dawson M, Soulières I. Autistic children at risk of being underestimated: school-based pilot study of a strength-informed assessment. *Mol Autism.* (2015) 6:1–10. doi: 10.1186/s13229-015-0006-3

88. Mitchell P, Ropar D. Visuo-spatial abilities in autism: A review. *Infant Child Dev.* (2004) 13:185–98. doi: 10.1002/icd.348

89. Joseph RM, Keehn B, Connolly C, Wolfe JM, Horowitz TS. Why is visual search superior in autism spectrum disorder? *Dev Sci.* (2009) 12:1083–96. doi: 10.1111/j.1467-7687.2009.00855.x

90. St John T, Woods S, Bode T, Ritter C, Estes A, A. review of executive functioning challenges and strengths in autistic adults. *Clin Neuropsychol.* (2022) 36:1116–47. doi: 10.1080/13854046.2021.1971767

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Negative first impression judgements of autistic children by non-autistic adults

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Introduction: Although autism inclusion and acceptance has increased in recent years, autistic people continue to face stigmatization, exclusion, and victimization. Based on brief 10-second videos, non-autistic adults rate autistic adults less favourably than they rate non-autistic adults in terms of traits and behavioural intentions. In the current study, we extended this paradigm to investigate the first impressions of autistic and non-autistic children by non-autistic adult raters and examined the relationship between the rater's own characteristics and bias against autistic children.

Method: Segments of video recorded interviews from 15 autistic and 15 non-autistic children were shown to 346 undergraduate students in audio with video, audio only, video only, transcript, or still image conditions. Participants rated each child on a series of traits and behavioural intentions toward the child, and then completed a series of questionnaires measuring their own social competence, autistic traits, quantity and quality of past experiences with autistic people, and explicit autism stigma.

Results: Overall, autistic children were rated more negatively than non-autistic children, particularly in conditions containing audio. Raters with higher social competence and explicit autism stigma rated autistic children more negatively, whereas raters with more autistic traits and more positive past experiences with autistic people rated autistic children more positively.

Discussion: These rapid negative judgments may contribute to the social exclusion experienced by autistic children. The findings indicate that certain personal characteristics may be related to more stigmatised views of autism and decreased willingness to interact with the autistic person. The implications of the findings are discussed in relation to the social inclusion and well-being of autistic people.

KEYWORDS

autism spectrum disorder, first impressions, autism bias, autism stigma, social competence

1. Introduction

Although many autistic children desire to make friends (1), they encounter difficulties when it comes to social isolation, exclusion, and victimisation more frequently than their non-autistic peers and children with other disabilities (2–5). The difficulties that autistic people face have been partly attributed to the stigma around autism. Stigma refers to a negative indicator or attribution attached to a particular characteristic or difference. This stigma may combine with negative attitudes towards this difference, contributing to the devaluation or discrimination against a person or a group (6). The stigma and negative perceptions towards autistic children may contribute to their exclusion by family members, teachers and peers in school, and people in their community. Autism stigma may lead someone to judge an autistic child and treat them differently. It is considered a stigma, even when these actions are not conscious and overt. For example, negative perceptions may contribute to non-autistic people misunderstanding autistic children's words or actions (7), telling autistic children to try to "fit in" (8), and, in more extreme cases, victimisation and violence (9). Repeated experiences of stigmatisation have a cumulative effect on the autistic person's wellbeing and contribute to the significantly higher rates of anxiety, depression, and suicidality in autistic people (10, 11).

First impressions are the rapid judgement of personality traits and social characteristics that are made after a brief initial exposure to a person or stimulus (12). Previous research studies indicate that non-autistic people form quick and strong negative first impressions of autistic people based on short de-contextualised videos (13–19). Participants in these studies watched 10-s videos, referred to as "thin-slices", created by Sasson et al. (14) of autistic and non-autistic adults. Participants then completed a questionnaire to record their first impressions of the person in the video, rating them on their traits (i.e., attractiveness, awkwardness, intelligence, likeability, trustworthiness, and dominance) and behavioural intentions towards them (i.e., willingness to live near, hang out with, comfort sitting next to, and the likelihood of starting a conversation with the person in the video). Across these studies, autistic adults were consistently rated by non-autistic adults as being more awkward and less likeable than their non-autistic peers, even though the non-autistic raters were not informed of the diagnostic status of the individuals in the videos (14–18). Similarly, non-autistic adults have reported a disinclination to interact with the autistic people in these videos. These negative first impressions, if they are indicative of the implicit negative attitudes held about autism, may contribute to the social exclusion experienced by autistic people.

It is likely that differences in the verbal and non-verbal behaviours of autistic adults are identified as peculiar by non-autistic raters, leading to less favourable ratings of autistic people. In a study by Sasson et al. (14), non-autistic adults formed less favourable first impressions of autistic adults compared to non-autistic adults when exposed to a sample of their social communication in audio and/or visual formats. However, when presented with a transcript of the same audio or visual recordings, there were no differences in their first impressions between autistic and non-autistic adults. Similar negative first impression formation was found in the ratings of children by non-autistic adults. Grossman (13) used recordings of autistic and non-autistic children across different audio and video formats, including audio only, video only, audio with video, and still images. After each recording of a child was presented, participants responded with "yes" or "no" to indicate their perception of whether that child was socially awkward. Participants rated autistic children as socially awkward more often than non-autistic children across all audio-visual formats.

Furthermore, these negative first impressions of autistic adults appear to be related to the characteristics of the non-autistic rater. Raters, who scored higher on a questionnaire assessing explicit stigma, rated autistic people in short video clips less favourably on characteristics such as awkwardness, attractiveness, trustworthiness, dominance, likability, and intelligence (16). In a similar study with high-school-aged non-autistic raters (ages 15–19 years old), a higher self-rating of social competence was associated with greater negative perceptions of autistic adults (15). Other characteristics, such as quality and quantity of previous contact with autistic people, were also related to raters' attitudes towards autistic people (20).

Although previous research studies have already documented negative judgements of autistic children by non-autistic adults (13), this study aims to explore the factors that contribute to these negative judgements by varying the audio-visual formats through which the autistic child is perceived and by assessing the characteristics of the non-autistic examiner. In light of negative perceptions of autistic adults and children by non-autistic perceivers increasingly being reported in recent literature, the current study examined the first impressions of autistic and non-autistic children by non-autistic adults using a "thin slice" paradigm [see Grossman (13) and Sasson et al. (14)]. This research extends previous rese by examining the potential effect of audio-visual mediums (i.e., the effect of auditory, visual, and content cues within a de-contextualised conversational segment) on the formation of first impressions of autistic and non-autistic children. The study also extends previous research by examining the potential effect of the non-autistic rater's personal characteristics (i.e., explicit stigma, social competence, autistic traits, and past experiences with autistic people) on the formation of first impressions of autistic children.

The following hypotheses were proposed: first, non-autistic adult raters would rate autistic children less favourably than non-autistic children when evaluating personal characteristics and behavioural intentions across different audio-visual formats. Second, the following relationships would be supported: higher levels of social competence and explicit stigma would predict more negative first impressions of autistic children, while higher levels of autistic traits and quality and quantity of past experiences with autistic people would predict more positive first impressions of autistic children. We also explored differences in first impression ratings across audio-visual mediums given the mixed results reported by other researchers [i.e., Grossman (13) and Sasson et al. (14)] regarding the effect of these mediums.

2. Methods

2.1. Participants

We extracted stimuli from a set of 52 semi-structured interviews with autistic and non-autistic children (ages 6–11 years old) discussing their interests (21). Before the interview, parents provided consent for their child's audio and video recordings, the use of these recordings for future studies, and for use in publication, while the children provided assent for the interview. For the current study, the inclusion of each stimulus was determined by calculating the longest utterances of each stimulus participant. This was defined as the child speaking to the interviewer for at least 8 s without disclosing any personally identifying information (e.g., their name), without pausing for more than 3 s, and without being interrupted by the interviewer. In addition to these criteria, the stimuli were excluded if the stimulus participant had a diagnosis of intellectual disability, stood up or was seated out of frame during their longest utterance, or wore clothing that obscured their face. After eligibility screening, a total of 30 interviews were edited and used in the current study.

Of the 22 excluded stimulus participants, 17 (12 autistic and five non-autistic) were excluded because they did not meet the utterance inclusion criteria. One autistic stimulus participant was excluded because they had a diagnosis of intellectual disability. Two (one autistic and one non-autistic) stimulus participants were excluded because they were not sitting within the frame of the camera during the interview. One non-autistic stimulus participant was excluded because they wore a mask for the duration of the interview. One autistic stimulus participant was excluded because the camera malfunctioned during the interview and, thus, no video was recorded.

Fifteen autistic (mean age = 8.84, SD = 1.68) and 15 non-autistic (mean age = 8.77, SD = 2.11) children served as stimulus participants. These stimulus participants did not significantly differ in age or IQ between groups and had a similar makeup of gender and cultural background (see Table 1). Caregivers of the autistic children provided a copy of their child's diagnostic report to confirm a diagnosis of autism spectrum disorder (ASD). To receive a diagnosis of ASD in the Canadian province of British Columbia, one must complete the Autism Diagnostic Interview-Revised (ADI-R) and the Autism Diagnostic Observation Schedule (ADOS-2). Additionally, they must meet the criteria outlined in the Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (22). All autistic children met these criteria.

Rating participants were recruited from introductory university psychology classes and were compensated with course credit. A total of 346 undergraduate students (ages 17– 49 years, mean age = 19.44, SD = 2.84) participated in the current study as raters. Participants were randomly assigned to one of five categories: audio with video (n = 93, mean age = 19.32, SD = 1.69), audio only (n = 62, mean age = 20.98, SD = 4.98), video only (n = 61, mean age = 19.05, SD = 1.86), transcript (n = 61, mean age = 18.70, SD = 1.23), and still image (n = 69, mean age = 19.19, SD = 2.75). Participants in each group were similar in their reported gender and cultural background (see Table 2). Two participants in the audio with video group and one participant in the transcript group self-reported a diagnosis of ASD. Therefore, they were excluded from the participant count and analyses. There were no other exclusion criteria for rating participants.

2.2. Materials

2.2.1. Demographic information

The demographic information of participants was collected using a parent-report questionnaire for child stimulus participants and a self-report questionnaire for adult rating participants. Questions on both versions of the form inquired about the participant's sex, date of birth, cultural background, family or individual income, parental or individual education level, physical and mental health conditions, and family history of ASD diagnoses.

2.2.2. Wechsler abbreviated scale of intelligence, 2nd edition (WASI-II)

The WASI-II (23) is a brief measure of cognitive ability for individuals aged between 6 and 90 years old. The Full-Scale IQ-2 (FSIQ-2), which measures verbal comprehension and perceptual reasoning, was administered to the child stimulus participants by graduate students in the Clinical Psychology program at Simon Fraser University. The reliability coefficient for the FSIQ-2 is good (0.93) for children aged between 6 and 16 years old. The WASI-II also has good interrater reliability for the Matrix Reasoning (0.99) and Vocabulary (0.95) subtests, which are used to calculate the FSIQ-2. The WASI-II was used in the current study to assess the equivalency of the intellectual ability of autistic and non-autistic child stimulus participants.

2.2.3. Social responsiveness scale, 2nd edition (SRS-2)

The SRS-2 (24) is a standardised parent-report measure of autism symptom severity. The SRS-2 contains 65 items scored on a 4-point Likert scale (1 = Not True to 4 = Almost Always True) and produces two domain scores (Social Communication and Interaction; Restricted Interests and Repetitive Behaviour) and a total score. Raw domain and total scores are converted into t-scores, with t-scores $\geq$76 indicating a severe range of symptom severity, scores 66–75 indicating a moderate range of symptom severity, scores 60–65 indicating a mild range of symptom severity, and t-scores $\leq$59 indicating that the person is within typical limits. The SRS-2 demonstrated high internal consistency (Cronbach's α =0.95) in a standardisation study with 1,014 children. In the current study, SRS-2 was administered to corroborate the diagnoses of the autistic stimulus participants and assess for group differences in autism symptom severity. The reliability of the SRS-2 total score was good (Cronbach's α = 0.977, McDonald's ω = 0.979) within the current sample.

2.2.4. Autism spectrum quotient (AQ)

The AQ is a self-report and parent-report measure of autistic traits (25). Fifty statements are answered on a 4-point Likert scale (1 = Definitely Agree to 4 = Definitely Disagree) and loaded onto five factors associated with autism: attention switching, attention to detail, social skills, communication, and imagination. The AQ self-report was administered to rating participants, and the parents of children aged 6–11 years old were asked to fill out the AQ-Child report (26). The sum of all questions yields the AQ total score, which provides an overall score of autistic traits for the individual, where higher scores represent a higher level of autistic traits. A cutoff score of 32 correctly identifies 80% of autistic adults (25) and 86% of autistic children (27). In the current study, the Autism Spectrum Quotient: Children's Version (AQ-Child) was utilised to confirm the diagnoses of participants with autism spectrum disorder and to compare the autistic traits between groups. The AQ self-report was administered to adults to evaluate the possible relationship between autistic traits and bias against autism. Four adult rating participants in

TABLE 1 Descriptive statistics and demographic information of stimulus participants.

Variable	Autistic ($n = 15$) Mean (SD)	Non-autistic ($n = 15$) Mean (SD)	*df*	*t*	*p*
Age	8.84 (1.68)	8.77 (2.11)	28	−0.097	0.923
WASI-II FSIQ-2	101 (16.57)	109 (11.83)	28	1.687	0.103
AQ Total Score	30.20 (6.24)	17.53 (8.20)	28	−4.758	<0.001
SRS-2 Total T Score	70.87 (11.24)	49.67 (10.73)	28	−5.283	<0.001
	n (%)	*n* (%)			
Gender					
Men	9 (60%)	8 (53%)			
Women	6 (40%)	7 (47%)			
Ethnicity					
East Asian	6 (40%)	5 (33%)			
Latin American	1 (7%)	2 (13%)			
White/European	8 (53%)	8 (53%)			

$n = 30$.
WASI-II FSIQ-2, Wechsler Abbreviated Scale of Intelligence, 2nd Edition, Two Scale Intelligence Quotient; AQ, Autism-Spectrum Quotient; SRS-2, Social Responsiveness Survey, 2nd Edition.

TABLE 2 Demographic information of rating participants.

Variable	Audio with video ($n = 93$) *n* (%)	Audio only ($n = 62$) *n* (%)	Video only ($n = 61$) *n* (%)	Transcript ($n = 61$) *n* (%)	Still image ($n = 69$) *n* (%)	Total sample ($n = 346$) *n* (%)
Gender						
Men	20 (22%)	11 (18%)	16 (26%)	13 (21%)	11 (16%)	71 (21%)
Women	73 (78%)	51 (82%)	45 (74%)	48 (79%)	58 (84%)	275 (79%)
Cultural background						
Black/African American	3 (3%)	4 (7%)	2 (3%)	1 (2%)	4 (6%)	14 (4%)
East Asian	17 (18%)	11 (18%)	11 (18%)	10 (16%)	9 (13%)	58 (17%)
Indigenous	1 (1%)	2 (3%)	5 (8%)	3 (5%)	4 (6%)	15 (4%)
Latin American	2 (2%)	1 (2%)	3 (5%)	3 (5%)	1 (1%)	10 (3%)
South Asian	16 (17%)	8 (13%)	5 (8%)	7 (11%)	10 (14%)	46 (13%)
Southeast Asian	6 (7%)	10 (16%)	4 (7%)	7 (11%)	7 (10%)	34 (10%)
West Asian	6 (7%)	5 (8%)	5 (8%)	4 (7%)	8 (12%)	28 (8%)
White/European	42 (45%)	21 (34%)	26 (43%)	26 (43%)	26 (38%)	141 (41%)
Autistic relatives						
First-Degree	2 (2%)	1 (2%)	0	1 (2%)	0	4 (1%)
Second-Degree	1 (1%)	0	1 (2%)	3 (5%)	2 (3%)	7 (2%)
Third-Degree	6 (7%)	3 (5%)	4 (7%)	2 (3%)	4 (6%)	19 (6%)

First-degree relatives included parents and siblings; Second-degree relatives included grandparents, aunts and uncles, and nieces and nephews; Third-degree relatives included first cousins.

the current study were found to have an AQ total score ≥32 (one in the audio with video group, one in the video only group, one in the transcript group, and one in the still image group). They were included in the analyses because they did not self-report a diagnosis of ASD. In the current study, the reliability of the AQ total score was acceptable for the adult rating participants (Cronbach's $\alpha = 0.714$, McDonald's $\omega = 0.721$) and child stimulus participants (Cronbach's $\alpha = 0.887$, McDonald's $\omega = 0.900$).

2.2.5. Multidimensional social competence scale (MSCS)

The MSCS is a 77-item questionnaire that assesses social competence across the following seven domains: social motivation, social inferencing, demonstrating empathic concern, social knowledge, verbal conversation skills, nonverbal sending skills, and emotion regulation (28). The MSCS is scored on a 5-point Likert scale (1 = Not True or Almost Never True to 5 = Very True or Almost Always True), where higher scores represent greater levels of social competence. The MSCS was previously found to have good internal consistency (Cronbach's α = 0.795) among a sample of young adults. The psychometrically validated self-report MSCS (29) was completed by rating participants in the current study to evaluate the possible relationship between the social competence of the rater and bias against autism. The reliability of the MSCS total score for the current study was good (Cronbach's α = 0.926, McDonald's ω = 0.931).

2.2.6. Quantity of contact

The quantity of previous contact with autistic people was assessed using a questionnaire originally developed by Holmes et al. (30) and adapted by Gardiner and Iarocci (31). Respondents answered yes or no to a series of 12 items that state varying degrees of closeness to an autistic person (e.g., "I have watched a movie or television show in which a character depicted a person with autism"; "I live with a person who has autism"; "I have autism"). The total number of "yes" responses served as the total quantity of contact score, ranging between 0 (no exposure) and 12 (exposure in many contexts). Following the procedures of Scheerer et al. (15) in the current study, participants who reported no real-world contact with an autistic person (i.e., "I have watched a movie or television show in which a character depicted a person with autism", "I have never observed a person that I was aware had autism", and "I have watched a documentary about autism") were classified as having no direct contact with autistic people. The quantity of contact measure was used in the current study to evaluate the possible relationship between the amount of past contact with autistic people and bias against autism.

2.2.7. Quality of contact

The quality of previous contact with autistic people was assessed using a questionnaire originally developed by McManus et al. (32) and adapted by Gardiner and Iarocci (31). Respondents answered six items using a 9-point Likert scale (1 = Strongly Disagree to 9 = Strongly Agree). This scale included items such as "Overall, I have had positive experiences with people with autism" and "The experiences I have had with people with autism have been fun". The sum of all six items yielded a total score ranging between 6 and 54. Following the procedures of Scheerer et al. (15) only participants who indicated some direct contact with autistic people on the quantity of contact questionnaire received a quality of contact score. The quality of contact measure was used in the current study to evaluate the relationship between the quality of past experiences with autistic people and bias against autism. The reliability of the quality of contact total score for the current study was good (Cronbach's α = 0.898, McDonald's ω = 0.915).

2.2.8. Social distance scale

The SDS is a self-reported measure of stigma towards autistic adults (33). Respondents answered six items on a 4-point Likert scale (1 = Definitely willing to 4 = Definitely unwilling), yielding a total score between 6 and 24. Higher total scores represent more autism stigma and greater social distance from autistic people. The SDS was used in the current study to evaluate the relationship between explicit autism stigma measured by this questionnaire and the autism bias score produced by the First Impressions Scale. The reliability of the SDS total score for the current study was good (Cronbach's α = 0.876, McDonald's ω = 0.881).

2.2.9. First impression scale

A modified version of the FIS created by Sasson et al. (14) was presented against each stimulus participant and completed by each rating participant as a measure of explicit biases about autistic children. Similar to the original FIS, the modified FIS in the current study contained a series of 10 statements rated on a 4-point Likert scale (0 = Strongly disagree to 3 = Strongly agree). Six statements related to the stimulus child's characteristics (i.e., awkward, confident, trustworthy, aggressive/dominant, likeable, and smart) and four statements related to behavioural intentions towards the stimulus participant (i.e., willingness to live next to the child, the likelihood of hanging out with the child if they were the same age, comfort level sitting next to the child, and comfort level having a conversation with the child). Statements were re-phrased from the original FIS to accommodate the discrepancy in age between the rater and the stimulus participant (e.g., changing "This person is probably as smart as I am" to "This child is probably smart" and changing "I would hang out with this person in my free time" to "I would hang out with this child if I was their age"). Higher scores are indicative of a more positive impression of the stimulus participant; therefore, "awkward" and "aggressive/dominant" items were reverse scored as these characteristics are associated with more negative first impressions. Consistent with previous research (11), an "autism bias score" was calculated by taking each participant's mean rating of each FIS item for autistic stimulus participants and subtracting it from that of the non-autistic stimulus participants; positive values indicate a bias against autistic stimulus participants (i.e., higher ratings of non-autistic stimulus participants).

In the current study, the reliability of the FIS was good, as assessed by Cronbach's α and McDonald's ω: audio with video format (α = 0.986, ω = 0.988), audio only format (α = 0.990, ω = 0.990), video only format (α = 0.984, ω = 0.985), transcript format (α = 0.981, ω = 0.984), and still image format (α = 0.982, ω = 0.983).

2.3. Procedures

2.3.1. Stimulus participants

The responses from stimulus participants that were used in the current study were elicited from one of two questions: "Tell me about your most favourite thing in the whole world." and "Is there anything else you want to tell me about [favourite thing]?" During the interviews, participants were asked to sit in a chair across a table and 3 ft to the right of the researcher. A camera was concealed behind the researcher in a box and out of view of the participant. A Philips Voice Tracer DVT1150 audio recorder was placed between the participant and the interviewer to record the audio. During the interviews, participants discussed their favourite interests and behaviours associated with the interest and told the interviewer a storey about their interests. Following the interview, participants completed the WASI-II, and parents completed a demographic questionnaire, the AQ, and the SRS-2. Children were compensated with a t-shirt and toy/object ($5 value), and caregivers were compensated with entry into a draw for a $100 gift card.

For the audio with video, audio only, and video only formats, recordings lasted between 8 and 14 s for each group, similar to the range of 9–14 s in the stimuli created by Sasson et al. (14). The transcript format had the typed content of the child's utterance. Transcripts of each interview were typed verbatim by two research assistants and was checked a final time by the first author. Transcripts included filler words (e.g., "Umm"), self-corrections (e.g., "that happen- didn't happen"), informal pronunciations (e.g., "kinda"), and mispronunciations (e.g., "fright" instead of "fight"). The still image format included the first frame of the video where the child's head was upright, and their eyes were completely open.

2.3.2. Rating participants

Participants reviewed a short description of the study ("You will be asked to make judgements about children observed through brief audio-visual formats as well as fill out questionnaires about your social behaviours and social motivation. The survey will take approximately 60 min to complete. You will be compensated with 2 credits for your participation"). If they chose to participate, they were shown the consent form on a Qualtrics web survey. After they completed the consent form, they were shown a separate Qualtrics web survey and randomly presented with one of the five audio-visual formats (audio with video, audio only, video only, transcript, and still image). Rating participants were not informed of the diagnostic status of participants. Each stimulus participant within that condition was presented one at a time in a random order. The FIS was completed by the rating participant for each stimulus participant. The rating participant then completed a demographics questionnaire, the AQ, the MSCS, the Quantity of Contact questionnaire, the Quality of Contact questionnaire (2), and the SDS. After completing the questionnaires, the participants were debriefed and compensated.

2.4. Analyses

Data were evaluated using SPSS Version 26. Descriptive statistics were reported for the main variables for child stimulus participants and adult rating participants.

To address our first hypothesis and assess whether the main variables (age, AQ total scores, MSCS total scores, quantity of contact score, quality of contact score, and SDS total scores) varied between ratings of audio-visual formats (audio with video, audio only, video only, transcript, and still image), one-way ANOVAs were conducted for each main variable. If the one-way ANOVA was statistically significant, Tukey's *post-hoc* analyses were conducted. If the assumption of homogeneity of variances was violated, Welch's ANOVA was used with Games-Howell *post-hoc* analyses. A Bonferroni correction was used for the one-way ANOVA analyses given the large number of comparisons ($\alpha = 0.0083$). To assess for potential differences in the trait and behavioural ratings of autistic and non-autistic stimulus participants across different audio-visual formats, a 2 (autistic vs. non-autistic stimulus participant group) by 10 (rating for each FIS question) by 5 (audio-visual format) 3-way mixed-model ANOVA was conducted. A Greenhouse-Geisser correction was used when the assumption of sphericity was violated.

To address the second hypothesis, a correlation analysis was conducted between the main variables.

To address our exploratory hypothesis to better understand the differences between different audio-visual format ratings, we conducted *post-hoc* analyses using paired sample *t*-tests following the three-way mixed-model ANOVA. To control for multiple comparisons, a Bonferroni correction was used ($\alpha = 0.005$).

3. Results

3.1. Descriptive statistics

Means and standard deviations of study variables were calculated for child stimulus participants and adult rating participants (see Tables 1, 3, respectively).

3.2. One-way ANOVA

A series of one-way ANOVAs were conducted to determine if age, AQ total scores (autistic traits), MSCS total scores (social competence), quantity of contact, quality of contact, and SDS total scores (explicit stigma) were different for raters across the five audio-visual formats. For the variable of age, homogeneity of variances was violated, as assessed by Levene's test for equality of variances ($p = 0.003$); therefore, a Welch's ANOVA was conducted. The one-way Welch ANOVA for participant age was significant [Welch's $F_{(4,158.876)} = 4.136$, $p = 0.003$]. A Games-Howell *post-hoc* analysis found that the audio only group was significantly older than the transcript group (Mean difference = 2.28, 95% CI [0.45, 4.10], $p = 0.007$). Other *post-hoc* comparisons did not survive correction for multiple comparisons ($p > 0.0083$).

For the variable of MSCS total scores, the homogeneity of variances was violated ($p \leq 0.001$). Welch's ANOVA was significant [Welch's $F_{(4,162.629)} = 5.467$, $p \leq 0.001$]. A Games-Howell *post-hoc* analysis found that the still image group had significantly higher total MSCS scores than the audio only group (mean difference = 20.85, 95% CI [8.37, 33.33], $p \leq 0.001$). Other *post-hoc* comparisons did not survive correction for multiple comparisons ($p > 0.0083$).

The assumption of homogeneity of variances was met for the one-way ANOVAs for autistic traits, quantity of contact, quality of contact, and SDS total scores. The one-way ANOVAs for total AQ scores, quantity of contact, quality of contact, and total SDS scores were not significant ($p > 0.0083$).

3.3. Three-way mixed-model ANOVA

A 2 (autistic vs. non-autistic stimulus participant group) by 10 (rating) by 5 (audio-visual format) mixed-model ANOVA was conducted (see Table 4). There was homogeneity of variances, as assessed by Levene's test for equality of variances ($p > 0.05$).

TABLE 3 Scores of rating participants.

	Audio with video ($n = 93$)	Audio only ($n = 62$)	Video only ($n = 61$)	Transcript ($n = 61$)	Still image ($n = 69$)	Total sample ($n = 346$)
Variable	Mean (SD)	Mean (SD)	Mean (SD)	Mean (SD)	Mean (SD)	Mean (SD)
Age	19.32 (1.69)	20.98 (4.98)	19.05 (1.86)	18.70 (1.23)	19.19 (2.75)	19.44 (2.84)
AQ total score	18.17 (4.87)	19.89 (4.38)	17.79 (5.27)	17.67 (5.05)	17.35 (5.66)	18.16 (5.10)
MSCS total score	295.16 (25.19)	285.18 (26.76)	295.26 (28.59)	293.79 (25.64)	3.6.03 (24.61)	295.32 (26.72)
Quantity of contact score	3.60 (2.15)	3.58 (1.82)	4.52 (2.17)	4.11 (2.17)	4.33 (2.05)	4.00 (2.10)
Quality of contact score	35.75 (9.95)	34.34 (8.70)	37.03 (10.65)	34.13 (10.20)	31.54 (11.83)	34.60 (10.42)
SDS total score	10.23 (3.72)	11.37 (4.08)	11.82 (4.06)	11.62 (4.10)	12.10 (4.77)	11.33 (4.17)

AQ, Autism-Spectrum Quotient; MSCS, Multidimensional Social Competence Scale; SDS, Social Distance Scale.

TABLE 4 Three-way mixed-model ANOVA.

	Sum of squares	*df*	Mean square	*F*	*p*	*Partial* η^2
Between-subject effects						
Condition	28.3	4	7.076	4.267	0.002	0.048
Error (Condition)	565.5	341	1.658			
Within-subject effects						
Stimulus group	5.585	1	5.585	77.77	≤0.001	0.186
Error (Stimulus group)	24.49	341	0.072			
Rating	573.3	3.544	161.8	321.1	≤0.001	0.485
Error (Rating)	609.1	1,208	0.504			
Stimulus group x Rating	2.578	5.834	0.442	16.07	≤0.001	0.045
Stimulus group x Condition	2.693	4	0.673	9.375	≤0.001	0.099
Rating x Condition	20.04	14.18	1.414	2.804	≤0.001	0.032
Stimulus group x Rating x Condition	2.868	23.34	0.123	4.47	≤0.001	0.05

n = 346.

Mauchly's test of sphericity indicated that the assumption of sphericity was violated [$\chi^2_{(44)} = 661.588$, $p \leq 0.001$]; therefore, a Greenhouse-Geisser correction was reported. There was a statistically significant three-way interaction between the stimulus group, audio-visual format, and rating [$F_{(23.335,1,989.287)} = 4.470$, $p \leq 0.001$, $\eta_P^2 = 0.050$]. The statistical significance of a simple two-way interaction was accepted at a Bonferroni-adjusted alpha level of 0.025. There was a significant two-way interaction between the stimulus group and audio-visual formats [$F_{(4,341)} = 9.375$, $p \leq 0.001$, $\eta_P^2 = 0.099$] and between the stimulus group and rating [$F_{(5.834,1,989.287)} = 16.067$, $p \leq 0.001$, $\eta_P^2 = 0.045$). There was a simple main effect of the stimulus group [$F_{(1,341)} = 77.774$, $p \leq 0.001$, $\eta_P^2 = 0.186$], rating [$F_{(3.544,1208.401)} = 321.079$, $p \leq 0.001$, $\eta_P^2 = 0.485$], and audio-visual formats [$F_{(1,341)} = 4.267$, $p = 0.002$, $\eta_P^2 = 0.048$].

3.4. Pearson correlation

Pearson's correlations were used to investigate whether the characteristics of raters across all audio-visual formats were associated with autism bias scores (see Table 5). Total AQ scores were negatively correlated with autism bias scores [$r_{(344)} = -0.276$, $p \leq 0.001$], indicating that raters with more autistic traits had a lower autism bias score. Similarly, quality of contact was negatively correlated with autism bias scores [$r_{(344)} = -0.221$, $p \leq 0.001$], indicating that raters who reported more positive past experiences with autistic people also had a lower autism bias score.

On the other hand, the total MSCS scores were positively correlated with autism bias scores [$r_{(344)} = 0.311$, $p \leq 0.001$), indicating that raters with higher social competence had higher autism bias scores. Similarly, total SDS scores were also positively correlated with autism bias scores [$r_{(344)} = 0.340$, $p \leq 0.001$], indicating that raters with higher explicit autism stigma had higher autism bias scores. Neither age nor quantity of contact were significantly correlated to autism bias scores.

3.5. *Post-hoc* paired sample *t*-tests

Follow-up paired-sample *t*-tests were conducted to elucidate the interaction effects. Based on the audio-visual format interaction, the stimulus group rated autistic children less favourably than non-autistic children in the audio with video [$t_{(92)}$

TABLE 5 Pearson correlations.

	1	2	3	4	5	6	7
1. Autism bias score	-						
2. Age	−0.008	-					
3. AQ total score	−0.276**	0.074	–				
4. MSCS total score	0.311**	−0.036	−0.447**	–			
5. Quantity of contact	0.094	−0.003	−0.040	0.050	-		
6. Quality of contact	−0.221**	−0.046	0.015	−0.160*	0.325**	-	
7. SDS score	0.340**	0.033	0.009	0.012	0.096	−0.081	-

n = 346. $^{*}p < 0.05$, $^{**}p \leq 0.001$.
MSCS, Multidimensional Social Competence Scale; AQ, Autism-Spectrum Quotient; SDS, Social Distance Scale.

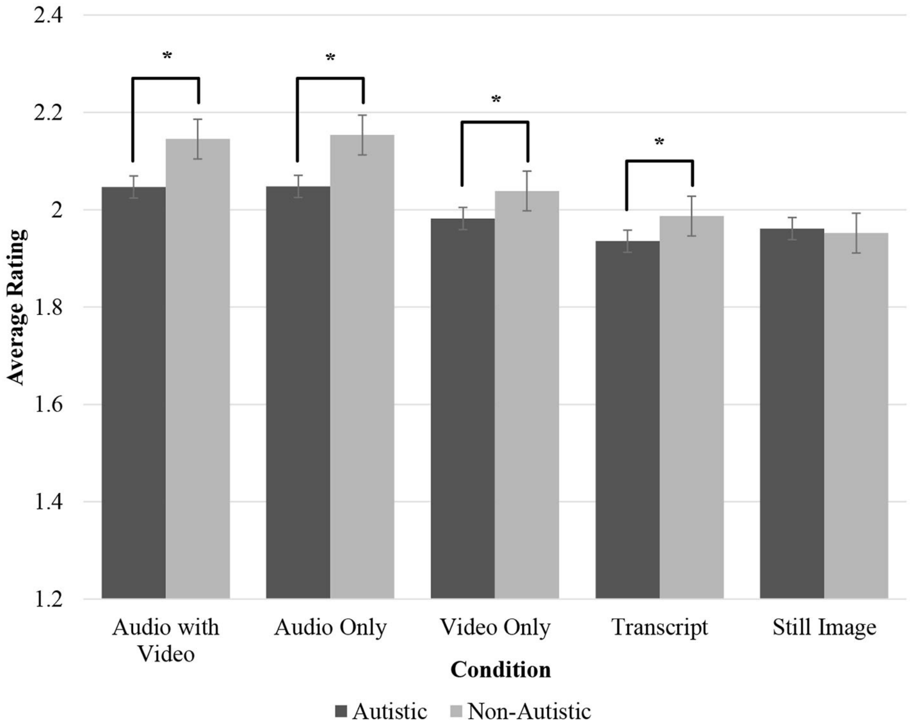

FIGURE 1
Average ratings of stimulus participants across conditions by group. The significance of the *post-hoc* paired-sample *t*-tests of the stimulus group by audio-visual format at $p \leq 0.001$ is indicated by an asterisk (*). Error bars represent standard errors.

$= -7.750$, $p \leq 0.001$, $d = 0.12$], audio only [$t_{(61)} = -5.909$, $p \leq 0.001$, $d = 0.13$], video only [$t_{(60)} = -3.213$, $p \leq 0.001$, $d = 0.12$], and transcript [$t_{(60)} = -4.173$, $p \leq 0.001$, $d = 0.10$] formats, but not the still image format [$t_{(68)} = 0.584$, $p = 0.281$, $d = 0.13$].

Similarly, autistic children were rated significantly less favourably than non-autistic children on ratings of awkwardness [$t_{(345)} = -4.315$, $p \leq 0.001$, $d = 0.27$], trustworthiness [$\mathrm{t}_{(345)} = -5.027$, $p \leq 0.001$, $d = 0.20$], aggression [$\mathrm{t}_{(345)} = -8.974$, $p \leq 0.001$, $d = 0.21$], likability [$\mathrm{t}_{(345)} = -6.595$, $p \leq 0.001$, $d = 0.20$], willingness to live near the child [$\mathrm{t}_{(345)} = -5.834$, $p \leq 0.001$, $d = 0.19$), willingness to hang out with child if they were the same age [$\mathrm{t}_{(345)} = -8.856$, $p \leq 0.001$, $d = 0.26$], comfort level sitting next to the child [$\mathrm{t}(345) = -5.357$, $p \leq 0.001$, $d = 0.19$], and comfort level conversing with the child [$\mathrm{t}(345) = -6.946$, $p \leq 0.001$, $d = 0.19$] but not for ratings of confidence ($p = 0.009$) or intelligence ($p = 0.008$) given the Bonferroni correction (see Figure 1).

The three-way interaction between stimulus group, rating, and the audio-visual format identified that autistic children were rated significantly less favourably in the audio with video format on awkwardness ($p \leq 0.001$), trustworthiness ($p \leq 0.001$), aggressiveness ($p \leq 0.001$), likeability ($p \leq 0.001$), and willingness to live next to ($p \leq 0.001$), hang out with the child if they were the same age ($p \leq 0.001$), sit next to the child ($p \leq 0.001$), and have a conversation with the child ($p \leq 0.001$) (see Supplementary Table S1). In the audio only category, autistic children were rated significantly less favourably on confidence ($p \leq 0.001$), trustworthiness ($p \leq 0.001$), aggressiveness ($p \leq 0.001$), likeability ($p \leq 0.001$), and willingness to live next to (*p*

≤ 0.001), hang out ($p \leq 0.001$), sit next to ($p \leq 0.001$), and have a conversation ($p \leq 0.001$). In the video-only category, autistic children were rated less favourably than non-autistic children on aggressiveness ($p \leq 0.001$), likeability ($p \leq 0.001$), and willingness to sit next to ($p \leq 0.001$) and have a conversation ($p \leq 0.001$). In the transcript condition, autistic children were rated significantly less favourably than non-autistic children on awkwardness ($p \leq 0.001$), trustworthiness ($p \leq 0.001$), likeability ($p \leq 0.001$), and willingness to hang out ($p \leq 0.001$). There were no significant differences in ratings of autistic and non-autistic children within the still image format.

4. Discussion

Previous research on first impressions of autistic children and adults indicated that autistic people are rated less favourably than non-autistic people following brief exposure to de-contextualised "thin slices" of social behaviour. The current study investigated the first impressions of autistic and non-autistic children across different audio-visual formats (i.e., audio with video, audio only, video only, transcript, and still image) as judged by non-autistic adults. The relationships between first impression ratings and the rater's own characteristics (i.e., autistic traits, social competence, quality and quantity of past experiences with autistic people, and explicit autism stigma) were also investigated.

Consistent with the first hypothesis, autistic children were rated less favourably than non-autistic children in terms of traits of the child and the rater's behavioural intentions towards the child. However, these first impression ratings of autistic and non-autistic children differed between audio-visual formats. Raters viewing the stimulus participants through audio with video and audio only formats rated autistic children less favourably on most traits and all behavioural intentions towards the child. In the category without audio information (i.e., video only format), there were fewer differences in ratings between autistic and non-autistic children and even fewer differences when raters evaluated the transcript of the conversation. No significant differences were found in the ratings of still images between autistic and non-autistic children.

The current findings partially replicate those by Sasson et al. (14) in ratings of autistic and non-autistic adults. In their study, non-autistic adults rated autistic adults more negatively in all formats of audio and/or visual information, including the still image format. However, Sasson et al. found no differences in ratings in the transcript format. They posit that these differences may have occurred due to the potential atypicalities in physical presentation, non-verbal communication, and paralinguistic features of speech, such as inflexion. Compared to non-autistic people, autistic people are more likely to have unusual prosody in their speech (34). In social interactions, the modulation of prosody is related to social competency, as normative social interactions often include the identification and transmission of nonverbal information such as emotions, attitudes, and intentions (35, 36). Raters in the present study might have identified the prosodic peculiarities of autistic stimulus participants when audio information was available, contributing to their more negative ratings of autistic children. However, paralinguistic features of speech are just one of several factors contributing to social competency, indicating that atypical prosody may be one of several mechanisms by which negative impressions are formed about autism.

Autistic children in audio-visual formats containing visual information, except for the still image format, were rated more negatively than non-autistic children in the current study. The physical movements and non-verbal communication patterns of autistic children were often observably different from those of non-autistic children, with characteristics such as reduced eye contact and gesture use (37). These differences may be perceived as peculiar by the rater and, thus, were rated more negatively than those with more typical non-verbal communication. A still image of a child may not provide enough information about that child's non-verbal communication for a negative first impression to be formed on that basis. However, Sasson et al. (14) found that autistic adults were rated more negatively than non-autistic adults in their still image condition. A similar rating between autistic and non-autistic children in the present study may be due to how the still images were created. Given that the still image was created using the first frame of the video where the child's eyes were open and their head was upright, aberrations of social communicative norms (e.g., looking down or away during a conversation) may have been missed. Future studies would benefit from using a random sampling of still images from across the video stimuli (instead of the first frame) to account for this potential limitation.

An interesting finding in the current study was the difference in ratings between autistic and non-autistic children in the transcript format. Autistic children were rated more negatively on awkwardness, trustworthiness, likeability, and willingness to spend time together. Given that the first impression stimuli were created from the interview of children talking about their interests, these findings might represent negative first impressions of how autistic children's interests were expressed, as the interests of autistic and non-autistic stimulus participants were similar in the current study. While an analysis of the content of speech is beyond the scope of the current study, autistic children have been found to use different "fillers" in language compared to non-autistic children, such as using "um" less frequently (38, 39). Autistic children may also have difficulties articulating a spoken narrative coherently and cohesively, with less complex language and greater repetitions in their speech than non-autistic children (40). As the raters in the current study viewed the verbatim transcriptions of the stimulus participants' speech, it is possible that these qualities of autistic children's speech were viewed as more awkward and negative than non-autistic children. Future research is needed to investigate negative attitudes towards autism and stigma based on the possible peculiarities in the content of speech and the discourse markers of autistic children.

Consistent with the second hypothesis, the rater's explicit autism stigma in the current study was found to be related to higher autism bias on the first impression task. These findings are similar to those of Morrison et al. (16). Using only the autistic adult stimuli by Sasson et al. (14), Morrison et al. (16) examined the characteristics of non-autistic college students on first impressions. They found that higher autism stigma measured by the SDS predicted less favourable ratings of autistic adults on most traits. Research by Aubé et al. (41) examining elementary school-age children's attitudes towards autistic children found high levels of explicit autism stigma in younger children but less explicit negative attitudes in older children. However, children across different elementary school ages held similar levels of implicit negative attitudes towards autism, measured by a faster spontaneous decision to avoid autistic children and approach non-autistic children when presented with videos featuring both autistic and non-autistic children. Implicit attitudes are evaluations arising from experiences which may occur outside of conscious awareness (42). Aubé et al.'s (41) findings indicate that, even if explicit attitudes improve, implicit attitudes may still remain. Educating people about autism can lead to improvements in explicit attitudes towards autism (15, 43), but implicit attitudes remain a better real-world predictor of non-deliberate and impulsive behaviour than explicit attitudes (44, 45). Unfortunately, implicit attitudes may be less susceptible to change by improving autism knowledge (46), which may explain why autistic people experience discrimination and victimisation despite greater societal autism knowledge and improving explicit attitudes towards autism (47, 48). Therefore, it is of interest for future research to examine the nature of implicit attitudes towards autism and explore the mechanisms by which implicit attitudes may be improved.

Consistent with the second hypothesis, higher social competence scores of the raters were associated with greater bias towards autistic children. Furthermore, higher levels of the raters' autistic traits were related to lower bias towards autistic children. Finally, across all raters, more negative ratings of autistic children were associated with higher levels of the rater's social competence and explicit stigma. In contrast, more positive ratings of autistic children were associated with higher levels of the rater's autistic traits and quality of past experiences with autistic people.

Individuals who self-reported greater social competence may be more perceptive to behaviours and parts of interactions that are divergent from the norm, such as peculiarities in body language and gaze, thereby leading to more negative evaluations. In contrast, individuals with greater autistic traits may be comparatively less perceptive to these social divergences. In addition, individuals with greater autistic traits may have a better implicit understanding of the experiences of children who also show such traits, potentially constructed or bolstered through personal experience. Therefore, they may be more empathetic, sympathetic, or less judgemental when perceiving others with similar experiences. Finally, there may be other unmeasured characteristics of individuals with autistic traits that positively influence their openness to differences of others more broadly.

It is worth noting, however, that a recent systematic review and meta-analysis on the characteristics of non-autistic adults on autism stigma by Kim et al. (20) found no significant correlation between the autistic traits of the rater and their attitudes towards autistic people. In the current study, higher autistic traits of the rater measured by their AQ were related to lower autism stigma measured by the autism bias score derived from the FIS; but AQ scores were not related to a measure of explicit autism stigma determined by the SDS. It may be that FIS is closer to an implicit measure of autism stigma, as the questions are less overt when querying for autism stigma than the SDS, and rating participants were unaware of the diagnostic status of stimulus participants. Previous research shows a relationship between AQ scores and implicit bias, where participants with higher autistic traits demonstrated less implicit bias towards autism (47).

Past positive experiences of raters with autism were related to lower bias towards autistic children in the current study, although the number of past experiences with autistic people was not. Negative evaluations of autistic people may be mitigated or improved by having more positive past experiences and by improving acceptance and openness towards autistic people (31). Simply having more experiences with autistic people may be insufficient to change attitudes towards autism if individuals still lack knowledge about autism or hold stereotyped or prejudiced views (49). Indeed, improving autism knowledge is related to lower bias towards autistic adults (15) and autistic children (50), stressing the importance of providing accurate autism knowledge in addressing autism stigma.

The overall finding that non-autistic adults hold more negative perceptions of autistic children than non-autistic children has implications for the acceptance and de-stigmatisation of autism within society. In the life of an autistic child, adults play a crucial role in nurturing and supervising many of the contexts in which the child interacts, such as the classroom and community spaces. Successful inclusion and acceptance of autistic children in these spaces depends on the de-stigmatisation of autism and the acceptance and humanisation of neurodiverse people. Autistic individuals in several studies have reported animosity, prejudice, and stigma against autism in general and against themselves as autistic people (11, 51, 52), which can have deleterious effects on mental health, self-perception, and wellbeing (53). For autistic children who are already vulnerable to social and mental health difficulties, enduring negative attitudes towards autism held by adults has the potential to undercut their dignity, growth, and participation in educational and social environments. Furthermore, attitudes held by adults can influence the formation of similar attitudes in children (54, 55), which may influence how children interact with disabled or otherwise different peers (56). Awareness of one's attitudes towards autism is an important step in addressing the transmission of negative attitudes to children and the possible consequences of the inclusion or exclusion of autistic children.

4.1. Limitations

A few limitations of the study are worth noting. First, it is unclear how these results translate to real-world interactions with autistic children. Although participants reported increased explicit autism stigma and a negative bias towards autism, other factors, such as the situational context and their relationship to the child, may more strongly affect the way an adult interacts with an autistic child.

Second, autism knowledge was not measured. The quality and quantity of past autism contact cannot be assumed to be equivalent having knowledge about autism. It is possible that certain raters in the current study were more knowledgeable of how autism presents in children, and thus, this knowledge may have influenced their first impression judgements. In previous studies, mixed results were found whereby one study showed an association between more positive attitudes towards autism and greater autism knowledge, (19) while another found no such association (50).

Third, the AQ self-report measure of autistic traits in the current study was normed on a predominantly male sample. Given that the current study's sample was predominantly female, the autistic traits of these participants may not have been sufficiently assessed. The development of more comprehensive questionnaires and diverse validation of existing measures may be of value for future research.

Fourth, the stimulus participants did not have intellectual disabilities, and they all used verbal language as a primary means of communication. Within the population of autistic children, approximately 38% have a co-occurring diagnosis of intellectual disability (57), and approximately 30% are non-speaking (58, 59). Therefore, the results of the current study are limited in their generalisability insofar as it only includes a particular presentation of ASD and does not include the wider range of abilities present in the diverse population of autistic children. It is possible that the stigma against non-speaking autistic children is greater than the stigma against speaking autistic children, given the importance verbal language has in social interactions. Alternatively, raters might more easily recognise a non-speaking child as autistic, which may potentially soften their first impression judgements. Future research should strive to include a more diverse and representative sample of autistic children with varying language and intellectual abilities to best understand autism stigma, as it affects all autistic children.

Finally, there is a possibility of selection bias in the current study's first impression stimuli compared to the greater sample of interviews by Boucher (21). The inclusion criteria for the stimulus participants required a specific set of criteria to protect the identity of the child and to ensure consistency between visual and audio formatting. The factors that excluded certain interviews (e.g., exiting one's seat and stepping out of frame when not appropriate to do so and speaking in single-word or brief phrases interrupting the recording of an 8 s clip) may have had an impact on first impression ratings. The relations between these behaviours and communicative norm violations in relation to the formation of first impressions and autism stigma could be examined in the future.

4.2. Conclusion

The study successfully isolated the effect of audio-visual formats (i.e., auditory, visual, and content cues within a de-contextualised conversational segment) and examined the effect of a number of the non-autistic rater's personal characteristics (i.e., explicit stigma, social competence, autistic traits, and past experiences with autistic people) on the formation of first impressions of autistic and non-autistic children. Our findings were generally consistent with those of previous studies, and the proposed hypotheses were supported. Our findings suggest that visual and auditory cues may trigger negative first impressions of autistic children in non-autistic adults but that the personal characteristics of the observer also play a role.

This study supports the robust nature of the negative first impression bias towards autistic individuals. Identifying which factors are most influential and how they may be addressed in prevention and intervention programs are important next steps in research aimed at counteracting harmful perceptions and attitudes about autistic people.

Data availability statement

The raw data supporting the conclusions of this article will be made available by the authors, without undue reservation.

Ethics statement

The studies involving humans were approved by Simon Fraser University Department of Research Ethics. The studies were conducted in accordance with the local legislation and institutional requirements. Written informed consent for participation in this study was provided by the participants' legal guardians/next of kin.

Author contributions

TB, NS, and GI designed the study. TB and NS created the novel stimuli and collected the study data. TB, JL, and NS conducted the analysis and interpretation of the data. TB wrote the first draft of the manuscript in consultation with JL, NS, and GI. All authors provided feedback on the manuscript and approved the final version of the manuscript.

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Conflict of interest

The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

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Supplementary material

The Supplementary Material for this article can be found online at: https://www.frontiersin.org/articles/10.3389/fpsyt.2023.1241584/full#supplementary-material

References

1. Cresswell L, Cage E. 'Who am I?': an exploratory study of the relationships between identity, acculturation and mental health in autistic adolescents. *J Autism Dev Disord.* (2019) 49:2901–12. doi: 10.1007/s10803-019-04016-x

2. Hebron J, Humphrey N, Oldfield J. Vulnerability to bullying of children with autism spectrum conditions in mainstream education: a multi-informant qualitative exploration. *J Res Spec Educ Needs.* (2015) 15:185–93. doi: 10.1111/1471-3802.12108

3. Käld E, Beckman L, Eapen V, Lin PI. Exploring potential modifiers of the association between neurodevelopmental disorders and risk of bullying exposure. *JAMA Pediatr.* (2022) 176:940. doi: 10.1001/jamapediatrics.2022.1755

4. Maïano C, Normand CL, Salvas MC, Moullec G, Aimé A. Prevalence of school bullying among youth with autism spectrum disorders: a systematic review and meta-analysis. *Autism Res.* (2016) 9:601–15. doi: 10.1002/aur.1568

5. Hwang S, Kim YS, Koh YJ, Leventhal BL. Autism spectrum disorder and school bullying: Who is the victim? Who is the perpetrator? *J Autism Dev Disord.* (2018) 48:225–38. doi: 10.1007/s10803-017-3285-z

6. Bos AER, Pryor JB, Reeder GD, Stutterheim SE. Stigma: advances in theory and research. *Basic Appl Soc Psych.* (2013) 35:1–9. doi: 10.1080/01973533.2012.746147

7. Berkovits LD, Moody CT, Blacher J. "I don't feel different. But then again, I wouldn't know what it feels like to be normal": Perspectives of adolescents with autism spectrum disorder. *J Autism Dev Disord.* (2020) 50:831–43. doi: 10.1007/s10803-019-04309-1

8. Perry E, Mandy W, Hull L, Cage E. Understanding camouflaging as a response to autism-related stigma: a social identity theory approach. *J Autism Dev Disord.* (2022) 52:800–10. doi: 10.1007/s10803-021-04987-w

9. Gibbs V, Pellicano E. 'Maybe we just seem like easy targets': a qualitative analysis of autistic adults' experiences of interpersonal violence. *Autism.* (2023) 27:2023–2034. doi: 10.1177/13623613221150375

10. Mournet AM, Wilkinson E, Bal VH, Kleiman EM. A systematic review of predictors of suicidal thoughts and behaviors among autistic adults: making the case for the role of social connection as a protective factor. *Clin Psychol Rev.* (2023) 99:102–235. doi: 10.1016/j.cpr.2022.102235

11. Turnock A, Langley K, Jones CRG. Understanding stigma in autism: a narrative review and theoretical model. *Autism Adulthood.* (2022) 4:76–91. doi: 10.1089/aut.2021.0005

12. Bar M, Neta M, Linz H. Very first impressions. *Emotion.* (2006) 6:269–78. doi: 10.1037/1528-3542.6.2.269

13. Grossman RB. Judgments of social awkwardness from brief exposure to children with and without high-functioning autism. *Autism.* (2015) 19:580–7. doi: 10.1177/1362361314536937

14. Sasson NJ, Faso DJ, Nugent J, Lovell S, Kennedy DP, Grossman RB. Neurotypical peers are less willing to interact with those with autism based on thin slice judgments. *Sci Rep.* (2017) 7:1. doi: 10.1038/srep40700

15. Scheerer NE, Boucher TQ, Sasson NJ, Iarocci G. Effects of an educational presentation about autism on high school students' perceptions of autistic adults. *Autism Adulthood.* (2022) 4:203–13. doi: 10.1089/aut.2021.0046

16. Morrison KE, DeBrabander KM, Faso DJ, Sasson NJ. Variability in first impressions of autistic adults made by neurotypical raters is driven more by characteristics of the rater than by characteristics of autistic adults. *Autism.* (2019) 23:1817–29. doi: 10.1177/1362361318824104

17. DeBrabander KM, Morrison KE, Jones DR, Faso DJ, Chmielewski M, Sasson NJ. Do first impressions of autistic adults differ between autistic and non-autistic observers? *Autism Adulthood.* (2019) 1:250–7. doi: 10.1089/aut.2019.0018

18. Alkhaldi RS, Sheppard E, Burdett E, Mitchell P. Do neurotypical people like or dislike autistic people? *Autism Adulthood.* (2021) 3:275–9. doi: 10.1089/aut.2020.0059

19. Sasson NJ, Morrison KE. First impressions of adults with autism improve with diagnostic disclosure and increased autism knowledge of peers. *Autism.* (2019) 23:50–9. doi: 10.1177/1362361317729526

20. Kim SY, Song D, Bottema-Beutel K, Gillespie-Lynch K, Cage E. A systematic review and meta-analysis of associations between primarily non-autistic people's characteristics and attitudes toward autistic people. *Autism Res.* (2023) 16:441–57. doi: 10.1002/aur.2867

21. Boucher TQ. *Investigating the Manifestation and Subjective Experience of Restricted Interests in Autistic and Non-Autistic Youth: An Interpretive Phenomenological Analysis* (Master's thesis). Burnaby, BC: Simon Fraser University. (2022).

22. American Psychiatric Association. *Diagnostic and statistical manual of mental disorders. 5th ed. text rev*. Washington: American Psychiatric Association Publishing. (2022).

23. Wechsler D. *WASI-II: Wechsler Abbreviated Scale of Intelligence (2nd ed.).* London: Pearson. (2011).

24. Constantino JN, Gruber CP. *Social Responsiveness Scale: SRS-2.* Torrance: Western Psychological Services. (2012).

25. Baron-Cohen S, Wheelwright S, Skinner R, Martin J, Clubley E. Evidence from Asperger syndrome/high-functioning autism, males and females, scientists and mathematicians. *J Autism Dev Disord.* (2001) 31:5–17. doi: 10.1023/A:1005653411471

26. Auyeung B, Baron-Cohen S, Wheelwright S, Allison C. The autism spectrum quotient: children's version (AQ-Child). *J Autism Dev Disord.* (2008) 38:1230–40. doi: 10.1007/s10803-007-0504-z

27. Wakabayashi A, Baron-Cohen S, Uchiyama T, Yoshida Y, Tojo Y, Kuroda M, et al. The autism-spectrum quotient (AQ) children's version in Japan: A cross-cultural comparison. *J Autism Dev Disord.* (2007) 37:491–500. doi: 10.1007/s10803-006-0181-3

28. Yager J, Iarocci G. The development of the multidimensional social competence scale: a standardized measure of social competence in autism spectrum disorders. *Autism Res.* (2013) 6:631–41. doi: 10.1002/aur.1331

29. Trevisan DA, Tafreshi D, Slaney KL, Yager J, Iarocci G. A psychometric evaluation of the Multidimensional Social Competence Scale (MSCS) for young adults. *PLoS ONE.* (2018) 13:11. doi: 10.1371/journal.pone.0206800

30. Holmes EP, Corrigan PW, Williams P, Canar J, Kubiak MA. Changing attitudes about schizophrenia. *Schizophrenia Bulletin.* (1999) 25:447–56. doi: 10.1093/oxfordjournals.schbul.a033392

31. Gardiner E, Iarocci G. Students with autism spectrum disorder in the university context: Peer acceptance predicts intention to volunteer. *J Autism Dev Disord.* (2014) 44:1008–17. doi: 10.1007/s10803-013-1950-4

32. McManus JL, Feyes KJ, Saucier DA. Contact and knowledge as predictors of attitudes toward individuals with intellectual disabilities. *J Soc Pers Relat.* (2011) 28:579–90. doi: 10.1177/0265407510385494

33. Gillespie-Lynch K, Brooks PJ, Someki F, Obeid R, Shane-Simpson C, Kapp SK, et al. Changing college students' conceptions of autism: an online training to increase knowledge and decrease stigma. *J Autism Dev Disord.* (2015) 45:2553–66. doi: 10.1007/s10803-015-2422-9

34. Asghari SZ, Farashi S, Bashirian S, Jenabi E. Distinctive prosodic features of people with autism spectrum disorder: a systematic review and meta-analysis study. *Sci Rep.* (2021) 11:23093. doi: 10.1038/s41598-021-02487-6

35. Peppé S, Cleland J, Gibbon F, O'Hare A, Castilla PM. Expressive prosody in children with autism spectrum conditions. *J Neurolinguistics.* (2011) 24:41–53. doi: 10.1016/j.jneuroling.2010.07.005

36. Scheerer NE, Aime H, Boucher T, Iarocci G. The association between self-reported camouflaging of autistic traits and social competence in non-autistic young adults. *Autism Adulthood.* (2020) 2:298–306. doi: 10.1089/aut.2019.0062

37. Trujillo JP, Özyürek A, Kan CC, Sheftel-Simanova I, Bekkering H. Differences in the production and perception of communicative kinematics in autism. *Autism Res.* (2021) 14:2640–53. doi: 10.1002/aur.2611

38. McGregor KK, Hadden RR. Brief report: "Um" fillers distinguish children with and without ASD. *J Autism Dev Disord.* (2020) 50:1816–21. doi: 10.1007/s10803-018-3736-1

39. Gorman K, Olson L, Hill AP, Lunsford R, Heeman PA, Van Santen JPH. *Uh* and *um* in children with autism spectrum disorders or language impairment. *Autism Res.* (2016) 9:854–65. doi: 10.1002/aur.1578

40. Kuijper SJM, Hartman CA, Bogaerds-Hazenberg STM, Hendriks P. Narrative production in children with autism spectrum disorder (ASD) and children with attention-deficit/hyperactivity disorder (ADHD): Similarities and differences. *J Abnorm Psychol.* (2017) 126:63–75. doi: 10.1037/abn0000231

41. Aubé B, Follenfant A, Goudeau S, Derguy C. Public stigma of autism spectrum disorder at school: Implicit attitudes matter. *J Autism Dev Disord.* (2021) 51:1584–97. doi: 10.1007/s10803-020-04635-9

42. Banaji MR, Roediger H III, Nairne J, Neath I, Surprenant A. "Implicit attitudes can be measured," in *The Nature of Remembering: Essays in Honor of Robert G Crowder.* (2001). doi: 10.1037/10394-007

43. Morris S, O'Reilly G, Byrne MK. Understanding our peers with Pablo: Exploring the merit of an autism spectrum disorder de-stigmatisation programme targeting peers in Irish early education mainstream settings. *J Autism Dev Disord.* (2020) 50:4385–400. doi: 10.1007/s10803-020-04464-w

44. Friese M, Bluemke M, Wänke M. Predicting voting behavior with implicit attitude measures: the 2002 German parliamentary election. *Exp Psychol.* (2007) 54:247–55. doi: 10.1027/1618-3169.54.4.247

45. Greenwald AG, Nosek BA, Banaji MR. "Understanding and using the implicit association test: I. an improved scoring algorithm": correction to Greenwald et al. (2003). *J Pers Soc Psychol.* (2003) 85:481. doi: 10.1037/h0087889

46. Jones DR, DeBrabander KM, Sasson NJ. Effects of autism acceptance training on explicit and implicit biases toward autism. *Autism.* (2021) 25:1246–61. doi: 10.1177/1362361320984896

47. Dickter CL, Burk JA, Zeman JL, Taylor SC. Implicit and explicit attitudes toward autistic adults. *Autism Adulthood.* (2020) 2:144–51. doi: 10.1089/aut.2019.0023

48. Lipson J, Taylor C, Burk JA, Dickter CL. Perceptions of and behavior toward university students with autism. *Basic Appl Social Psychol.* (2020) 42:354–68. doi: 10.1080/01973533.2020.1785468

49. Cage E, Di Monaco J, Newell V. Understanding, attitudes and dehumanisation towards autistic people. *Autism.* (2019) 23:1373–83. doi: 10.1177/1362361318811290

50. Cook A, Ogden J, Winstone N. The effect of school exposure and interpersonal contact on attitudes towards bullying and autism in schools: a cohort study with a control group. *Autism.* (2020) 24:2178–89. doi: 10.1177/1362361320937088

51. Botha M, Dibb B, Frost DM. "Autism is me": an investigation of how autistic individuals make sense of autism and stigma. *Disabil Soc.* (2022) 37:427–53. doi: 10.1080/09687599.2020.1822782

52. Underhill JC, Clark J, Hansen RS, Adams H. Exploring autistic college students' perceptions and management of peer stigma: an interpretative phenomenological analysis. *J Autism Dev Disord.* (2022) 22:1–13. doi: 10.1007/s10803-022-05867-7

53. Mazumder R, Thompson-Hodgetts S. Stigmatization of children and adolescents with autism spectrum disorders and their families: a scoping study. *Rev J Autism Dev Disord.* (2019) 6:96–107. doi: 10.1007/s40489-018-00156-5

54. Spiel EC, Rodgers RF, Paxton SJ, Wertheim EH, Damiano SR, et al. 'He's got his father's bias': parental influence on weight bias in young children. *Br Dev Psychol.* (2016) 34:198–211. doi: 10.1111/bjdp.12123

55. Degner J, Dalege J. The apple does not fall far from the tree, or does it? A meta-analysis of parent–child similarity in intergroup attitudes. *Psychol Bull.* (2013) 139:1270–304. pmid:23379964 doi: 10.1037/a0031436

56. Over H, McCall C. Becoming us and them: Social learning and intergroup bias. *Soc Personal Psychol Compass.* (2018) 12:e12384 doi: 10.1111/spc3.12384

57. Maenner MJ, Warren Z, Williams AR, Amoakohene E, Bakian AV, Bilder DA, et al. Prevalence and characteristics of autism spectrum disorder among children aged 8 years — autism and developmental disabilities monitoring network, 11 sites, United States, 2020. *MMWR Surveill Summ.* (2023) 72:1–14. doi: 10.15585/mmwr.ss7202a1

58. Norrelgen F, Fernell E, Eriksson M, Hedvall Å, Persson C, Sjölin M, et al. Children with autism spectrum disorders who do not develop phrase speech in the preschool years. *Autism.* (2015) 19:934–43. doi: 10.1177/1362361314556782

59. Rose V, Trembath D, Keen D, Paynter J. The proportion of minimally verbal children with autism spectrum disorder in a community-based early intervention programme: Proportion of minimally verbal children with ASD. *J Intell Disabil Res.* (2016) 60:464–77. doi: 10.1111/jir.12284

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A mixed method examination: how stigma experienced by autistic adults relates to metrics of social identity and social functioning

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A recent meta-analysis reveals almost half of autistic individuals experience some form of victimization in their lifetime, including bullying and other forms of stigma. Research among caregivers of autistic individuals demonstrates that stigma can have a long-lasting impact on other aspects of a social identity, such as self-esteem, but less research has specifically examined this among autistic adults themselves, in spite of research suggesting these are likely constructs that contribute to the internalization of stigma and subsequent mental health consequences. The current study used a mixed method approach to assess the relation between stigma and several components of social identity and social functioning. More specifically, among 45 autistic young adults, three dimensions of self-reported stigma (discrimination, disclosure, and positive aspects) were examined in relation to self-esteem, self-efficacy, social satisfaction and adaptive social functioning. Quantitative analyses revealed higher reported discriminative and disclosure stigma were significantly associated with lower self-efficacy. Increased experience with all types of stigma were associated with lower social satisfaction. Greater reported disclosure stigma was also associated with lower self-esteem. Qualitative interviewing among eight autistic young adults helped to better understand the nature of stigma and the impact of these experiences. Thematic analysis of the qualitative data revealed that all of the participants experienced stigma in the form of exclusion or isolation and that a majority also experienced verbal bullying. Many of the negative interactions came from educators, peers, and family members. Most participants indicated that these stigmatizing interactions directly contributed to decreased social satisfaction, diminished self-efficacy, and lowered self-esteem. A greater understanding of the negative consequences of stigma can inform efforts to increase awareness and acceptance of autism.

KEYWORDS

stigma, autism, social identity, self-esteem, self-efficacy, social satisfaction, neurodiversity

1. Introduction

1.1. Neurodiversity movement and stigma

The autistic community has been at the frontline of the neurodiversity movement, which emphasizes neurological differences as innate, attributable to the person, and simply part of a continuum of human diversity (1). The neurodiversity framework has the potential to reduce stigma [social exclusion due to differences that are perceived to deviate from societal norms; (2)], by explaining that the differences between neurotypical and neurodiverse individuals are due to biology and outside of one's control (3). This is particularly important to the autism community as these individuals are at heightened risk of experiencing stigma likely because of differences in social functioning and noticeable stereotyped behavior, paired with typical physical appearance (4, 5). Thus, autism allies support this movement to help both decrease the stigmatization of autism and increase the wellbeing of the autistic individuals through increased community acceptance and awareness that the concept of "typical" is driven by societal standards (1, 5).

As a result of the neurodiversity movement, more recent research has focused on the experience of stigma from the perspective of autistic individuals (6). This research reveals that in spite of greater societal acceptance of individual differences through the adoption of neurodiversity framework (7), many autistic adults continue to encounter stigma. Recent meta analyses revealed that 44 to 67% of autistic adults report experiencing stigma (8, 9). Several contemporary literature reviews reveal that autistic individuals continue to experience stigma in many different forms and from various sources (5, 10). However, much of the research included in these recent literature reviews and meta-analyses include data over a broad period of time, which in many cases can be over a decade old (5, 8, 10). Thus, more research needs to examine the current perspective of autistic individuals to better understand the contexts in which stigmatization continues to occur and the extent of consequences of experienced stigma (5, 10). To continue to make gains in stigma reduction, we need to better understand the types of stigma autistic adults continue to experience over time and the primary sources. As we continue working toward shifting societal attitudes, understanding the widespread impact that stigma has on neurodiverse individuals can also help inform approaches to mitigate some of the negative consequences (11).

1.2. Contextualizing experienced stigma

The hope is that an adoption of a neurodiversity framework will help to reduce stigma experienced by autistic individuals; however, to gauge success with shifting societal attitudes, research needs to focus on frequently assessing the continued scope of experienced stigma. Further, because research documents that parents might underestimate the extent their children experience stigma (12), it is crucial to specifically document the lived experience from the perspective of autistic individuals.

1.2.1. Perpetrators of stigma

A systematic review reported the majority of experienced stigma over the last decade has originated from peers, teachers, employers/co-workers, and family members (10). Many studies document that autistic individuals feel misunderstood, rejected, and/or excluded by peers. They also found teachers and employers often make false assumptions about an individual's abilities and needs. Similarly, a metanalysis focused on experiences of stigma in the form of bullying among autistic students and found these instances occurred most frequently in the inclusive classroom setting (8).

In addition to the individual level, autistic people report being impacted by stigma at a group or societal level. For example, media representations of autism are frequently negative, depicting individuals as dangerous and/or unloved (13). Additionally, one study suggested the news coverage of autism may be unintentionally stigmatizing autistic individuals by including stigmatizing cues, such as describing psychiatric symptoms or social skills deficits which distinguish autistic from allistic children, in more than two-thirds of media coverage (14). This same narrative extends into autistic adults, in which dehumanizing language continues to appear (15, 16).

1.2.2. Types of experienced stigma

Both qualitative and quantitative research provides evidence that autistic individuals have historically experienced stigma in alignment with most of the primary modalities of stigma defined in the literature [i.e., labeling, stereotyping, separation, status loss, discrimination and misuse of power; (17)]. For example, qualitative interviews documented that autistic individuals experienced stereotyping, exclusion, and discrimination (18). A systematic review examining the impact of stigma experienced by autistic individuals similarly found evidence for varying types of experienced stigma, including stereotyping, bullying, and judgment (10).

The vast majority of the literature focuses on bullying, which is discussed by most as "ongoing and deliberate misuse of power in relationships through repeated verbal, physical, and/or social behavior that intends to cause physical, social, and/or psychological harm" (8). This type of stigma can manifest as exclusion (19), but is often physical in nature (20). The quantitative research is clear that bullying occurs more readily among autistic individuals compared to those with other disabilities and compared to neurotypical peers (19). One study revealed that 36% of autistic individuals had some lifetime experience of bullying (19) and another documented that as many as 14% had experienced cyber bullying (12); however, a more recent metanalysis revealed pooled prevalence rates of bullying closer to 67% among autistic individuals (8). Additional qualitative research emphasized the pervasive nature of experienced stigma among autistic adults (18). These different types of methodological approaches help to reveal the importance of mixed methods in understanding more about the types of stigma that continue to occur and from what perpetrators. A greater understanding of what types of stigma persist can inform targeted approaches to diminish the negative impact of stigma still experienced by so many autistic adults.

1.3. Consequences of experienced stigma

Although the impact of experienced stigma is underrepresented in the literature for autistic adults compared to adults with other developmental disorders, a growing body of literature has also begun to document the myriad of negative consequences among autistic individuals. Growing literature has documented a relation between stigma and mental health in autism. For example, almost half of adults with Asperger's syndrome had long term sequelae from prior bullying, such as increased levels of anxiety (8). Additionally, there is a known relationship between higher levels of experienced bullying and victims' increased rates of depression, anxiety, suicidality, and other broad internalizing symptoms (12, 21). An illuminating recent study examined the time ordered relation between bullying and mental health among autistic adolescents and documented that bullying predicted internalizing mental health concerns one year later (22). Less is known about how these stigma experiences convey risk for mental health.

1.3.1. Stigma and social identity consequences

A systematic review examining the impact of stigma experienced by autistic individuals found evidence for a host of more nuanced negative outcomes including internalization of stigma, low self-esteem, negative self-labeling, and concealing their diagnosis (10). These more subtle negative consequences likely contribute to later negative mental health outcomes. Theory suggests that experienced stigma is internalized and converted into self-stigma, where autistic individuals begin to view themselves in a negative light as a result of their negative experiences with others (5, 23). Research documents that a meaningful number of autistic individuals experience this self-stigma [e.g., (23)]. In this process of internalizing stigma, autistic individuals then start to view themselves negatively, which results in increased experiences of shame and fear (5, 10). In alignment with the "Why Try? Effect" (24), among autistic individuals, this internalized stigma is thought to result in negative shifts in social identity (23). These impacted factors of social identity include self-esteem and self-efficacy. Self-esteem is defined as how much someone likes themself and is related to self-respect, worthiness, and adequacy (24, 25). Self-efficacy is how capable one believes themself to be of successfully accomplishing tasks, and social self-efficacy refers specifically to the completion of social tasks or interactions (26).

In support of this theory, a broader review revealed that internalized or self-stigma related to self-esteem and self-efficacy (27). Although not explicitly studied among autistic adults, self-esteem is documented as a mechanism by which stigma contributes to negative mental health outcomes among reviews examining the implications of experienced stigma among families of individuals with developmental delays and autism (28–30). Other aspects of one's identity, such as self-efficacy, have not been similarly examined but are also a likely additional mechanism.

1.3.1.1. Self-esteem and stigma

Although not directly testing the relation between stigma and self-esteem, a systematic review revealed a relation between self-esteem and social support and loneliness, two experiences related to stigma (5). Relatedly in qualitative research, caregivers of autistic children report that experienced affiliative stigma is directly related to self-esteem and that self-esteem mediated the relation between stigma and negative mental health consequences (31). The only known study to directly quantitatively test the link between stigma and self-esteem among autistic adults did not find significant esteem differences among groups that did and did not experience bullying but this is a topic that remains under-investigated (32).

1.3.1.2. Social self-efficacy and stigma

Although even less well examined in the literature, parents of autistic children report that experiencing stigma led them to feel embarrassed and feel less confident in their parenting (33). A later review identified parent confidence as a potential moderator between experienced stigma and parental mental health challenges (34). Only one known study specifically links self-efficacy related to socialization and stigma among autistic adults. In this study, a large majority of the autistic sample endorsed the item, "I can't contribute anything to society because I have autism," revealing signs of low social self-efficacy among autistic participants experiencing internalized stigma (35). In spite of these connections drawn between stigma and self-efficacy, no known research has directly examined the relation between these constructs among autistic adults using comprehensive assessments. Examining how stigma relates to social identity among autistic adults provides greater evidence for the importance of stigma reduction and provides insight into the process of how stigma internalization likely happens.

1.3.2. Stigma and social functioning

Social functioning is a broad concept comprised of multiple factors, including social satisfaction and adaptive social skills. Social satisfaction is often assessed by examining constructs such as loneliness, social adequacy, and peer relations/status (36). Examining how personally satisfied an individual is with their social interactions helps to understand one's own perception of social success (35). Measures of adaptive functioning help to examine social success from a more objective perspective through a comparison of population norms (37, 38). Adaptive behaviors are real-life skills one performs independently to succeed, and include social adaptive skills or practical behaviors that help an individual socialize in society [e.g., understanding social nuances; (37, 38)]. Socialization was found to be the most impaired adaptive domain among autistic participants (39).

1.3.2.1. Social satisfaction and stigma

In relation to stigma, most studies measure subconstructs of social satisfaction, such as loneliness or feelings of isolation [i.e., (36)]. Related to this, autistic participants in a qualitative study reported being outcasted by society due to their differences (18). Participants in this study also revealed that the internalization of this experienced stigma resulted in social isolation as a result of pressure to conform and subsequent avoidance of social situations to prevent judgment from others. An additional study demonstrated that experienced discrimination by autistic individuals resulted in an expectation of later rejection that likely renders an individual to feel more uncomfortable in social situations (40). All of these negative social experiences revealed through qualitative inquiry align with measurement items designed to quantify loneliness/social dissatisfaction (36).

One quantitative study examined the experiences of loneliness and bullying among autistic college students and found that many experienced bullying and reported limited social satisfaction [e.g., feelings of isolation, feeling left out and limited companionship; (19)]. Of note, this study did not examine a relation between these two constructs and both were measured with a limited number of items. Although these identified feelings of loneliness and isolation that arise as a result of stigmatization are likely to lead to low social satisfaction, this relation has not been specifically examined.

1.3.2.2. Adaptive social functioning and stigma

Autistic individuals' social adaptive functioning has served as a predictor of stigma in past research (33) and emerged as a meaningful predictor of bullying in a metanalysis (8). Yet, impaired social adaptive functioning might also be an outcome of experienced stigma. Autistic individuals are already at an increased risk for developing a co-occurring disorder, such as anxiety (41). Added social stress (e.g., bullying, stigma) can exacerbate or elicit internalizing problems for autistic individuals. Internalizing problems, such as social anxiety and social withdrawal, have been reported as outcomes in bully victims but also might lead to increased social challenges (42). A link between social anxiety and social self-esteem also suggests that higher levels of social fear, avoidance, and physiological reaction are associated with negative attitudes regarding themselves in social situations (43). Given these associations, this study aims to further examine the relationship between stigma and adaptive social functioning in autistic young adults.

1.4. Current study

Despite the progress made in increasing acceptance through the neurodiversity movement, autistic individuals still experience stigma; however, the extent of these experiences in more recent years are not fully documented as many of the published reviews and meta-analyses reflect experiences over a wider or dated time period. As such, using a mixed method approach, the current study documented a more recent perspective of the stigmatizing experiences experienced by autistic adults, including the types of stigma this population continues to endure and from what sources. This study also aimed to extend the research by examining in-depth potential social consequences of experienced stigma.

The quantitative component of this study measured the following:

(1) how several aspects of perceived/experienced stigma (discrimination, disclosure, and positive aspects of stigma) relate to social self-efficacy and self-esteem and
(2) how experienced stigma correlated with measures of social functioning, including self-reported adaptive social skills and social satisfaction.

Qualitative interviews were also conducted with autistic adults, to add more depth to the understanding of the extent and context of experienced stigma, as well as the perception of how stigma relates to social identity. Qualitative data allowed for:

(3) documentation of types of stigma experiences that autistic adults continue to experience and the reported sources of this stigma (44), and
(4) a better understanding of the specific ways in which stigma relates to social consequences from the perspective of autistic adults.

2. Materials and methods

2.1. Procedure

This study used a mixed-method complimentary design involving an initial quantitative component with a qualitative follow-up (45). A sequential sampling design allowed the researchers to gain a general understanding of the topic before following-up with a deeper exploration of the participants' experiences (46). This study was approved by the university's Institutional Review Board Committee. Autistic individuals were recruited for the study through various listservs (e.g., university disability resource centers nationwide, state Autism organizations, etc.) and other online advertisements. Fliers were handed out at autism-related events (e.g., conferences, walks, social skills groups), posted on campus buildings, and distributed to therapist offices in the local area.

2.2. Participants

The quantitative study included 45 autistic adults (23 males, 21 females, 1 gender not reported) from the United States. Initial screener questions required the participants to self-report if they had both a confirmed diagnosis of autism and were 18 years or older. The individuals' ages ranged from 18 to 58 years old (M = 25.12, SD = 9.50). Twenty-nine adults were enrolled in postsecondary education and 22 held jobs at the time of survey completion. Thirty-three percent of participants lived at home with family members, 33.3% lived independently, and 26.7% lived on campus in university housing. Race and ethnicity was inadvertently not collected as part of the quantitative data collection.

After collecting the battery of self-report surveys, participants were offered the opportunity to participate in an interview. Eight individuals participated in the qualitative follow-up study. Sampling stopped after thematic saturation was reached across interviews (47). Participants were between the ages of 19 and 40 (M = 25.13, SD = 8.06), primarily White (75%), and Non-Hispanic or Latino (88%). All participants had some college completed, with most individuals currently completing an undergraduate degree during the time of the interviews.

2.3. Data collection

2.3.1. Quantitative questionnaires

Participants completed five rating scales in addition to some demographic questions regarding their academic standing (e.g., graduation year, major) and living situation. Participants were given the option to complete the questionnaires in person or online. The rating scales took approximately 15 to 30 minutes to complete.

2.3.1.1. Stigma Scale

The Stigma Scale (48) is a 28-item measure that assesses perceived and experienced stigma in individuals with mental health disorders. In this study, the phrase "mental health problems" was replaced with "autism spectrum disorder" wherever it appeared in the measure. Autistic participants rated their perceived or experienced stigma on a 5-point Likert scale (0 = strongly disagree to 4 = strongly agree) in the following sub-scales: discrimination (12 items; Cronbach's $\alpha = 0.87$), disclosure (11 items; Cronbach's $\alpha = 0.75$), and positive aspects (5 items; Cronbach's $\alpha = 0.79$). The discrimination subscale assessed more overt types of experienced stigma, such as experienced hostility from others or losing opportunities due to others' biases. The disclosure subscale assessed negative experiences with disclosing an autism diagnosis or fear surrounding this process. The positive aspects examined any positive experiences as a result of having an autism diagnosis. For all subscales, higher numbers were associated with greater experienced stigma. This scale has high reported psychometric support (internal consistency $\alpha = 0.87$) (48). In the current study the internal consistency was similarly solid for the total stigma score (Cronbach's $\alpha = 0.85$), as well as for the individual subscales (see above).

2.3.1.2. Adapted rosenberg self-esteem scale

The Adapted Rosenberg Self-Esteem Scale (49) is a six item measure that assesses an individual's self-esteem and overall feelings of self-worth (25) using a 5-point Likert scale (1 = never true to 5 = always true). A higher score on this measure indicates greater self-esteem and feelings of self-worth. The adapted version of the scale was used due to its simplified wording and past use in the mental health context (49). This is one of the most widely used measures of self-esteem (50), with a excellent demonstration of psychometric support [i.e., (51, 52)]. In the current study, good internal consistency was reported (Cronbach's $\alpha = 0.82$).

2.3.1.3. Social self-efficacy subscale

The Social Self-Efficacy Subscale consists of six items derived from the Self-Efficacy Scale identified as a unique factor (53). This subscale is a self-report measure of one's social competence and the perception of success with completing tasks (54). The measure uses a 5-point Likert scale (1 = strongly disagree to 5 = strongly agree) with higher scores indicating greater self-efficacy. Previous studies demonstrate strong psychometric support for this measure (53). The internal consistency calculated for this sample (Cronbach's $\alpha = 0.65$), although considered in the low range by some, is considered in the acceptable range according to multiple psychometric experts for a psychological measure used in research [see (55) for a review].

2.3.1.4. Social satisfaction measure

The social satisfaction measure is a compilation of the social distress and companionship sections of the NIH Toolbox Social Relationships subdomain that assesses how fulfilling individuals find their relationships (56). Previous studies have established solid psychometric support for the measure (57). The measure consists of 22 items that factors onto four scales presented in the following order: friendship (5 items; Cronbach's $\alpha = 0.86$), loneliness (7 items; Cronbach's $\alpha = 0.95$), perceived rejection (5 items; Cronbach's $\alpha = 0.91$), and perceived hostility (5 items; Cronbach's $\alpha = 0.91$). The measure uses a 5-point Likert scale (1 = never to 5 = always), with a higher score indicating less social satisfaction.

2.3.1.5. ABAS-II

A widely used adaptive functioning measure, the Adaptive Behavior Assessment System (ABAS), assesses three constructs of adaptive behaviors: conceptual, social, and practical (58). The Social Domain of the Adaptive Behavior Assessment, Second Edition consists of 23 items and was used to measure participants' perceptions of social skills that help them function in daily living (59). The instructions specify that participants rate how often they perform the various social behaviors independently on a four-point scale (0 = not able to 3 = always). A social composite score was calculated and higher scores on the composite reflect more adaptive behavior skills based on participants' self perception. Prior studies have demonstrated high internal consistency for the Social domain (60). Similarly, high internal consistency for the Social domain was reported in the current study (Cronbach's $\alpha = 0.96$). In this sample, participant standard scores fell in the Extremely low range (0.4th percentile) indicating this sample had notable challenges with adaptive functioning compared to same aged peers.

2.3.2. Qualitative interview

Participants' met one-on-one with a researcher to complete a semi-structured interview that lasted between 45 minutes and 1 hour. An interview guide was created to establish consistency across interviews and to facilitate discussion with the participant. The guide included questions and prompts that related to experienced stigma and factors impacted by the stigma experienced (i.e., self-esteem, self-efficacy, and social satisfaction). Examples of questions asked include, "Can you tell me a time when you were treated unfairly?" and "When have the actions or words of others made you feel as if you can/can't interact well with people?"

Questions were derived from different published measurement approaches from both the qualitative and quantitative literature. Specifically, the interview included questions assessing experiences and feelings about receiving a diagnosis aligned with qualitative research examining similar questions (61, 62). Broader stigma questions were derived from the Discrimination and Stigma Scale [DISC; (63)], as well as The Stigma Scale (48). The inquiry about social satisfaction aligned with a qualitative interview assessing social experiences among autistic adults (56). Social identity theory was the framework to guide the second part of the qualitative interview. More specifically, the interview focused on two aspects of social identity theoretically impacted by the internalization of stigma: self-esteem and self-efficacy (23). Interview questions assessing self-esteem were derived from both a qualitative interview (61) and from the Rosenberg Self-Esteem Scale (49) and the self-efficacy conversation was guided by items on the Self-efficacy Scale (53).

This study was conducted by researchers who identify as non-autistic. As neurotypical researchers, we acknowledge our privilege in society and recognize the contrast between our experiences and the participants' experiences. Throughout the research process, we reflected on how our status in society could influence the development of interview questions, connection with participants, and interpretation of responses. Alignment with the neurodiversity mindset and a thorough knowledge of the autism stigma literature was used as a guiding tool throughout this study.

2.3.3. Analysis plan

All statistical analyses were conducted using SPSS software version 26. The statistical significance for the analyses were set at $p = 0.05$. Using two-tailed bivariate correlational analyses, we examined how three types of stigma were related to a range of social variables. More specifically, the three types of stigma (disclosure stigma, discriminative stigma, and positive aspects of autism) were included in all of the correlational analyses. We first examined how stigma was related to several components of social identity, including self-efficacy and self-esteem. Next, we examined the relation between stigma and social outcomes, including the four subdomains of social satisfaction (i.e., friendship, loneliness, rejection, and hostility) and the ABAS social adaptive functioning subdomain.

3. Results

3.1. Quantitative

3.1.1. Preliminary analyses

Both the stigma measure and all measures of social functioning demonstrated a normal distribution. For the quantitative measures, means and standard deviations for the current sample are reported in **Table 1**. This table also includes published means to allow for contextualization of the current data within the broader literature.

3.1.2. Correlation analyses

Table 2 presents the correlations between the stigma types and all social identity variables. For the social identity variables, analyses revealed individuals with lower reported self-efficacy had significantly higher reported discriminative and disclosure stigma (all p's $<$ or equal to 0.05). However, expressions of positive aspects of stigma were not significantly related to higher self-efficacy ($p = 0.19$). Additionally, lower self-esteem was correlated with greater reported disclosure stigma ($p < 0.5$) and positive aspects of stigma ($p < 0.5$), but it was not significantly associated with discriminative stigma ($p = 0.37$).

Regarding variables assessing social functioning, all four social satisfaction subdomain scores were significantly associated with higher discriminative stigma (all p's < 0.01). Similarly, higher disclosure stigma was significantly associated with lower social satisfaction in the subdomains of loneliness, rejection, and hostility (all p's < 0.05), but not friendship ($p = 0.32$). Positive aspects of stigma were significantly associated with the loneliness subdomain ($p = 0.04$), but not friendship, rejection, or hostility (all p's > 0.05). Lower adaptive social functioning was associated with positive aspects ($p = 0.01$), such that people with lower adaptive social functioning scores reported less positive experiences with their autism diagnosis.

3.2. Qualitative

The authors used a phenomenological approach in alignment with the social identity theory to understand the participants' lived experiences of personal stigma and explore how stigma related to their social identity (64). Past studies have examined the impact of stigma on autistic adults' identity and wellbeing [e.g., (18)]; thus, a blended approach allowed for both existing and developing codes to emerge. The authors transcribed verbatim audio recordings of the interviews, then coded responses by identifying and labeling recurring concepts (65) via NVIVO 10. A codebook was developed to categorize concepts derived from participants' responses into meaningful themes. The original version of the codebook aligned with the overarching structure of the interview. For example, this included sections aligning with general inquiry about stigma (i.e., types and sources) and then sections about each of the two social identity and social functioning domains. Code operational definitions were added and refined following consensus coding by two team members of several initial interviews. Additional codes were added throughout the coding process as relevant and the data was considered saturated after no novel themes emerged from the coded interviews. Questions about coding were reconciled through consensus conversations among team members.

3.3. Thematic analysis results

Four themes emerged from the data examined (1) type of experienced stigma, (2) source of stigma, (3) perceived reason for stigma, and (4) impact of stigma on multiple domains of social functioning. The terms 'some,' 'most,' and 'all' were used to quantify the number of participants who shared similar experiences. 'Some' is defined as less than or equal to half of the participants; 'most' is defined as more than half of the participants (i.e., 5 to 7); and 'all' is defined as all eight participants. Pseudonyms and non-binary pronouns (they/them/their) are used to personalize the responses and to maintain confidentiality.

3.3.1. Type of stigma

All participants expressed experiencing some type of stigma. Definitions of stigma from the literature highlight that stigma is experienced in six primary modalities including, labeling, stereotyping, separation, status loss, discrimination and misuse of power (17). Autistic adults in the current sample provided examples of experienced stigma across most of these modalities (see **Table 3**).

3.3.1.1. Stereotyping

Some participants shared experiences of others relying on stereotypes to make general assumptions about autism. For example, Kari explained a time they experienced stigma while having dinner with their ex-partner's family: "Umm his stepsister was talking about her ex-boyfriend or something and she was like... 'He had Asperger's like, that's why he was kind of weird,' and then his siblings started joking about it." Beatriz also explained how others minimized their autism because it did not align with other autistic exemplars they held (see **Table 3**).

3.3.1.2. Separation

When asked to describe a time participants were treated unfairly, all indicated experiences of separation or exclusion from the neurotypical society because of their behavior and/or autism diagnosis. Some individuals reported being made to feel as though they did not fit in with the neurotypical society. For example, Diya shared a time when

TABLE 1 Descriptive statistics of all quantitative measures.

Variables	Minimum	Maximum	Mean (SD)	Other published means (References)
Stigma				
Discrimination	2	44	22.02 (10.27)	29.1 (48)
Disclosure	3	41	20.67 (8.23)	24.7 (48)
Positive Aspects	0	18	6.96 (4.65)	8.8 (48)
Stigma Total	16	95	49.64 (17.00)	62.6 (48)
Social satisfaction				
Friendship	5	25	14.67 (5.37)	26.53 (57)
Loneliness	7	35	19.93 (7.88)	12.02 (57)
Rejection	5	25	11.02 (4.52)	16.93 (57)
Hostility	5	25	11.69 (4.81)	16.87 (57)
Self-esteem	11	30	21.80 (4.83)	23.44 (49)
Social adaptive functioning	0	13	4.97 (3.08)	9.9 (75)
Social self-efficacy	6	26	16.98 (4.36)	21.20 (75)

their classmates were talking about how one of their parents work with people on the autism spectrum, explaining how "they were really talking about them as (if they were) other people."

3.3.1.3. Discrimination

Some participants reported experiences of discrimination. Diya shared about an instance "at a camp that was meant for autistic people" when they felt discriminated against by camp staff: "They isolated me in the nurse's office and told me that I was using my disability as an excuse and I was trying to just get attention by hurting myself and it honestly made me feel worse." This form of stigma made Diya feel as if they was not seen as a person, and that they "were just looking at (them) because of (their). disability."

3.3.1.4. Misuse of power

Gabriel shared a more intense situation in which a teacher from their daughter's school got overly involved in the child's care because the teacher did not believe Gabriel and their partner could "protect" their daughter because they were autistic, or "disabled" as described by the teacher. Other examples discussed in more detail below involve the refusal to provide legitimate educational accommodations.

3.3.1.5. Overt bullying and abuse

In addition to these types of less overt aggressions, most participants in this sample also experienced more overt types of bullying and abuse, including both physical and verbal bullying/verbal abuse. Eric explained how their "hyper fixations" imposed on their conversations with others. They knew others would make "sly comments" about this which resulted in them wanting to "shut up and not talk to people and kinda be by myself." One participant experienced stigma in a physical manner. Ali explained: "I'd get beat up because people didn't- I mean- people hated me there in middle school and I think a lot of that just comes down to the fact that I was different, and they didn't understand that." Other examples shared by participants regard instances of verbal bullying, such as name calling and using "autistic" in a colloquial manner to refer to something defective (see Table 3).

3.3.2. Source of stigma

Overall, participants experienced stigma from nine different sources, including family members, peers, significant others, healthcare professionals, educators, employers, camp counselors, acquaintances, and strangers.

3.3.2.1. Educators

Most participants experienced stigma from educators and this was the most prevalent source among all reported. The type of stigma experienced by educators ranged from singling students out because of their autism diagnosis or observed symptoms, to minimizing the need for legally assigned accommodations. For example, Ali shared an instance in which an educator infringed upon the use of extra time:

> "Um and then there was one time sophomore year where I had like an accommodation to be able to stand in the back of the room if I just needed to like fidget or whatever and this one teacher called me out and in front of the class and he was in a pissy mood that day and just made me sit. . . it was just like I don't know kind of made me insecure (and) I know what works for myself why won't you let me. I clearly like wasn't distracting anyone."

Although many of the participants described experiencing stigma in high school and in their earlier developmental years, most of the participants reported still experiencing stigma in postsecondary settings as well. Hanna's experienced stigma from their research supervisor highlighted the lack of knowledge about autism even in higher education: "He still has a lot of like stigma that are not promotive to our relationship, such as um he doesn't understand how much variability there is among all the autistic people."

TABLE 2 Correlations between stigma and all social variables.

Variable	N	1	2	3
Stigma				
1. Discrimination	45	–		
2. Disclosure	45	0.44	–	
3. Positive aspects	45	0.14	0.23	–
Social satisfaction				
5. Friendship	45	0.50**	0.15	−0.02
6. Loneliness	45	0.52**	0.30*	0.30*
7. Rejection	45	0.56**	0.40**	0.20
8. Hostility	45	0.59**	0.33*	0.21
10. Self-esteem	45	−0.14	−0.33*	−0.44**
11. Social adaptive functioning	44	−0.11	−0.27	−0.40**
12. Self-efficacy	45	−0.43**	−0.37*	−0.20

$^{*}p < 0.05$ level (2-tailed). $^{**}p < 0.01$ level (2-tailed).

3.3.2.2. Peers

Most participants also experienced stigma from the peers at school. Stigma mainly came from acquaintances or classmates, including accounts of demeaning comments or physical bullying. One participant described experiencing stigma from a significant other after disclosing their autism diagnosis. Kari explained, “When I, you know, disclosed to him about it, you know, right after we’d started dating, he like thought that I was joking.” Kari further explained that their significant other would say things that implied that they couldn’t care for themselves because of their autism diagnosis.

3.3.2.3. Family members

Family dynamics varied across participants. Unfortunately, most participants described negative relationships with different family members, while some even explained experiencing stigma from their family. Eric shared that their parents would refer to their diagnosis in a “derogatory tone:” “They’ll say something like, ‘you know well I guess it’s your duh, duh, duh diagnosis acting up today.”

3.3.2.4. Community members

There were also accounts made by some participants of experienced stigma in the form of discrimination and misuse of power by community members, such as healthcare providers and employers. Gabriel explained how they were laid off from a job because of their request for accommodations:

> “The same employers that laid me off um for being disabled. They said it was because I had requested accommodations for being disabled. They didn’t say it was for being disabled, they said it was for requesting accommodations and I shouldn’t have requested accommodations. And um yeah that made me feel kind of ashamed.”

Additionally, some participants experienced stigma from acquaintances and strangers. Eric was a victim of stigma when playing Dungeons and Dragons, an online video game and someone used the term “autistic” colloquially to indicate something negative.

> “Like a month ago, um I’m in this group chat for dungeons and dragons and I only know like one person there and he invited me in, but you know I guess it’s like the internet thing to say oh no it’s autistic. And I’m like, ‘dude that’s—that’s not cool I have autism.’”

3.3.3. Consequences of stigma

3.3.3.1. Impact of stigma on self-esteem

All participants declared their social self-esteem was negatively impacted by experiences of stigma. Stereotypes about autism not only alter others’ understanding about autism, but it seemed that stereotypes also affected participants’ perceptions of themselves. Diya explained how a camp counselor’s negative views of their abilities to be independent impacted their self-esteem in the long-term, as they were questioning their ability to move away for college:

> “I just couldn’t do anything I guess um like I was- like the stereotypes of like autistic people were kind of playing through my head like I’m never going to be able to leave my parents I’m always gonna be stuck here um I can’t do college because it will be too overwhelming, and even though I knew all of those were lies like I was just really depressed and overwhelmed.”

Kari’s social self-esteem was also impacted by experienced stigma. They explained how their significant other’s negative perceptions of their abilities made them “feel like (they were) like less than a person.”

3.3.3.2. Impact of stigma on social self-efficacy

Participants reported variable self-efficacy in a range of situations requiring socialization, such as in the classroom, at a job, or in relationships. Most participants reported that experienced stigma had a negative impact on their self-efficacy in social situations. Ali explained how they tended to second guess or analyzed social situations after they occured. For example, when they “say something other people will laugh at and then a little bit later I’ll start thinking about how they’re probably laughing at me and not with me.”

3.3.3.3. Impact of stigma on social satisfaction

In general, most of the participants reported a mix of both social satisfaction and dissatisfaction depending on interactions with others. Social dissatisfaction was related to experienced stigma for most participants. For Kari, this decrease in social satisfaction was the result of discrimination and isolation from their team members:

> “I mean, people can tell that I don’t act normal and I think that I’m a pretty easy target. So people just in general weren’t super nice to me or like very encouraging. . . I mean it kind of just drove like a further wedge between me and all these other people like, even though I was on the team, I never really felt like I was a part of the team”

TABLE 3 Examples of participants' experienced stigma.

Theme	Example
Type of stigma	
Stereotyping	"And so there have been. . .plenty of people who I tell them my diagnosis and I get a 'oh I would've never known' or 'you're nothing like my cousin's sister's brother's ex's kid.' And I'm like 'cool it's because I'm not your cousin's sister's brother's ex's kid'. . . a lot of times it makes me feel like. . .I don't actually have autism but just that I'm not worthy of being part of like that community." (Beatriz)
Separation	"As far as responding to my diagnosis I mean I never tell anyone about my diagnosis except for like this because I know they will not respond well no one has ever responded well." (76) "I don't want to be like because I'm a student with accommodations or anything, but I was just like she's just making me feel kind of weird and it's like you're not treating other students like this." (Kari)
Discrimination	"Parents got involved. Mom says she's a nurse says, 'Oh he's gonna have a meltdown and you better not have that you know if y'all get married and then you have a child then you gonna take care of the child all your life because of the autism offspring.' Dad says, 'Oh you can't have a uh you can't be around him because he might not be able to have a job.'" (Fatima) "I wasn't allowed to talk about my disability at work which is kinda crazy because a lot of my students had disabilities themselves." (Gabriel)
Misuse of power	"Um I was laid off in (county) for being disabled as well because I needed accommodations for my visual processing disorder and so when they needed to lay off half their staff, they can't fire you for being disabled but when they have to lay off half their staff, then they can get away with it." (Gabriel)
Overt bullying and abuse	"One time we were like sitting in his truck and he was like, 'I'm sorry, but this truck is like actually autistic,' because his truck was acting up." (Kari) "Oh yeah, (laugh) I mean like I was picked on a lot in middle school so like then. Um my sister liked to call me freak for a while." (Beatriz)
Source of stigma	
Educators	"I was. . . working on a problem on the board and it was taking me a while and (teacher) actually called me a 'retard' in front of the whole class for it." (Ali)
Peers	"In high school. . .I was bullied a lot. 'You're different, you need to stop thinking about your future.' This that and the other because I said during my high school years I wanted to go for a Ph.D. and people looked at me like you're nuts. I know that was just my social peers." (Fatima)
Family members	"(My sisters) would belittle me about it a few times. Like whenever I was doing something- whenever I'd say something, they didn't agree with they'd just say, 'Oh he's insane.' And they would just totally discredit me because of (my diagnosis) and that made me feel ashamed that I had something that people could just do that with." (Ali) "My family. . . tried to convince me that. . . 'you can't be a medical doctor because your motor skills are bad.' Well, you know I always said. . .'let me prove you wrong' and I wasn't told until after I graduated with my uh bachelor's is that my parents both told me at graduation that 'we thought you were gonna flunk out the first semester and you gonna be moving back home.'" (Fatima)
Community members	"There's a really nice lady in my choir, she would tell me things like- but you have Asperger's not autism so you're safe." (Hanna) "Yeah when (ADA Coordinator) told me that I took her literally and I took her out of context and walked out on me, I feel very ashamed (of my diagnosis)." (Hanna)
Consequences of stigma	
Self-esteem	"I pretty systematically get rejected whenever I ask someone out and I don't know how much of that is autism and how much of that is other things. But yeah. That always makes me lose confidence in myself." (Ali) "It also made me feel really sad because I mean. . . It really hurt my self-confidence because I mean you're supposed to you know try to earn the respect of your teachers through your work, and they feel like I was just totally unable to do that." (Ali)
Social self-efficacy	"I realize that when other people respond to my autism diagnosis the wrong way, I usually spend a lot of time and effort in educating them 'laugh' Um, I don't think I stopped anything, I think I become more committed to making them understand that they can't say those things." (Hanna) "She (social skills tutor) you know did kind of like have a conversation with me and was like look like you do want to be careful with like who you share your diagnosis with in college um because people like do have biases and they do have stereotypes and you know you're going into a competitive field and you don't want that to be the first thing that people know about you. You want them to like make their own um opinions about you. So, I've definitely like been more hesitant to like share my diagnosis and I don't think that's something where I've been like ashamed of it I've just like I'm aware of the realities of the world and like not everyone like knows you know what autism is or what it means." (Beatriz)
Social satisfaction	"I often feel left out and alone being a grad student with autism." (Hanna) "I mean, people can tell that I don't act normal and I think that I'm a pretty easy target. So people just in general weren't super nice to me or like very encouraging. . . I mean it kind of just drove like a further wedge between me and all these other people like, even though I was on the team, I never really felt like I was a part of the team" (Kari)
Adaptive socialization	". . .the student alliance meeting. Um I only went to one of them at the beginning of the semester because it was kind of a social thing and I got uncomfortable with it, and I've been like too nervous to put myself back in that situation and go back there." (18002)

3.3.3.4. Impact of stigma on adaptive socialization

Many individuals indicated that lower adaptive social skills or autism symptoms contributed to an increase in stigmatization. For example, Fatima shared: "I'm just like not sure how to keep up with the conversation and butt in the conversation to make myself relevant and sometimes I end up feeling left out a lot." Additionally, some participants also reported that their other characteristics of autism or autism diagnosis were reasons why they experienced stigma. For example, Ali explained how they're "kinda like off in (their) own world sometimes" and can "sometimes. . .come across weirdly." Also, Fatima's parents discouraged them from becoming a "medical doctor because (their) motor skills are bad."

4. Discussion

This study provides a mixed method examination from the perspective of autistic adults on experienced stigma and how it relates to a range of social outcomes. Results from this study replicate previous research demonstrating that autistic individuals experience high rates of stigma (5, 10). Qualitative data helped to reveal that these individuals experienced a myriad of different types of stigma that come from a wide range of sources. This information documents that in spite of the significant strides made by the neurodiversity movement toward reducing stigma (3), most autistic adults in this sample report still experiencing stigmatizing interactions in recent years in employment, postsecondary education, and from peers. This study highlights the need for more specific trainings in workplace and educational settings to increase awareness of the different types of implicit and explicit stigma people often engage in and continue to grow alignment with a neurodiversity mindset to shift the culture toward more acceptance.

With regard to the negative consequences of stigma, the current study also expands the literature [e.g., (5, 35)] by specifically examining the relation between experienced stigma and components of the social identity theory thought to contribute to an internalization of stigma: self-efficacy and self-esteem. Quantitative results revealed individuals reporting higher amounts of experienced stigma had significantly lower self-efficacy and self-esteem. Delving into these associations in more detail, interviewees revealed that the misconceptions held by others about autism often resulted in them feeling more negative about themselves or "less than a person." Stigmatizing experiences resulted in low expressed self-efficacy in social situations and employment seeking. While not explicitly examined in this study, these findings help to elucidate how experienced stigma transitions to self-stigma and ultimately, mental health concerns among autistic individuals (5, 10, 23, 24, 28–30). Because systemic acceptance continues to spread at a pace that might be insufficient to help autistic adults that might have already endured a great deal of stigma, understanding more about the potential mechanism between experienced stigma and later mental health consequences helps to understand that more resources should focus at present on helping to bolster self-esteem and self-efficacy among neurodiverse populations.

This study also documented a link between experienced stigma and metrics of social functioning, such as social satisfaction and adaptive social skills. Although all of the research questions examining the true impact of stigma would benefit from longitudinal studies, the social success variables are most difficult to interpret with a cross-sectional, correlational design because it is likely that there is a cyclic pattern. Previous research has shown that social success is likely both a predictor of experienced stigma and an outcome [i.e., (4, 18, 21, 33)]. Qualitative data from this study reveal a similar pattern in that participants report that the different social abilities they possess contributed to greater experiences of stigma and that increased stigma led to less overall social satisfaction. This confirms the importance on conducting more longitudinal research in this area to better understand how stigma impacts quality of life.

The positive aspects subscale of the stigma measure did not align with the discrimination and disclosure subscales in terms of a relation with self-esteem and self-efficacy. As a reminder, on this subscale a higher score indicated that an individual had less positive experiences attributable to their autism diagnosis, which is an important, but much different, aspect of stigma compared to the others measuring more overtly negative experiences. Although we still anticipated that this metric would significantly relate to the social identity indices, it is likely that other participant characteristics not assessed in this study impacted this relation. For example, research shows that autistic adults that align with a neurodiversity movement mindset (3, 66) and those with a stronger affiliation to their autistic identity (67) have a more positive self-esteem and a positive social identity. Future research would benefit from including other protective and predictive factors in the model to determine among what groups and in what context stigma most likely leads to internalization and subsequent mental health concerns.

4.1. Limitations and future directions

There were several limitations of this study that are important to note. One key limitation is that primarily autistic individuals with higher cognitive abilities participated, such as those attending college or maintaining full-time employment. This limits the ability to generalize findings to the entire autism population, including those with lower intellectual functioning and proliferates the issue that autistic individuals with higher support needs are underrepresented in the autism literature (68). Because individuals with intellectual disabilities also face stigma in society (69), future research should also recruit participants with autism and co-occurring intellectual disability to understand if they have unique stigma experiences.

As participants were recruited through various methods to complete an online survey about autism and experienced stigma, selection bias could have influenced results (70). Perhaps only those who felt as if they experienced stigma participated in the study, leaving out others with different experiences. The nature of phenomenological research also limits the generalizability of findings (71). Although the qualitative interviews served as a follow-up to better understand and apply deeper meaning to the quantitative results (45), participants' lived experiences are unique to the individual and cannot appropriately explain all autistic adults' experiences.

Another limitation to the study is the lack of racial and ethnic diversity in the qualitative sample and a failure to document the demographic composition of the quantitative sample, which prohibited researchers from controlling for demographic factors in the analyses. The fact that mainly white, non-Hispanic autistic individuals participated in the qualitative interviews limits the understanding of intersectionality of identities. For example, Black autistic individuals experience racial discrimination from society, in addition to ableism from their community [see (72) for a review]. As the majority of the research has focused on the relation between cultural and affiliate stigma [e.g., (29)], future research should specifically explore stigma among autistic adults with a more diverse intersection of identities to better understand if different groups have unique stigma experiences.

Finally, there were limitations in the sample size and reliability analysis. Specifically, the small sample size of the quantitative study limited the ability to perform more complex quantitative analyses. Future research should employ methods that allow for an examination of social identity variables as mediators between stigma and reported symptoms of psychopathology and those that examine more cyclical patterns in how social ability might serve as a potential predictor and outcome of stigma. Most importantly longitudinal research is needed to really examine whether the experienced stigma over time is a causal factor in contributing to lower social identity and social success. Furthermore, the lower Cronbach's alpha that was calculated on the Social Self-Efficacy subscale limits our confidence that the subscale accurately measures social self-efficacy; however, a 0.6 alpha is considered moderately acceptable or satisfactory in some literature for the use of psychology measurement in research [see (55) for a review].

5. Conclusion

The pervasive and prolonged nature of stigma experienced by autistic individuals indicates that efforts to impart change continue to be insufficient. As rates of autism continue to rise and more supports are put into place, more autistic adults are predicted to enter post-secondary education or professional settings (73) thus, we need approaches to reduce stigma in childhood and adult context. By examining how stigma relates both social outcomes and core features of one's social identity we can continue to alert the public to the importance of engaging in stigma reduction efforts in educational institutions or workplaces and to develop and implement more appropriate support structures for autistic students or employees to mitigate these negative experiences. This research helps to underscore the importance of continued efforts to help improve societal attitudes about autism through great acceptance to reduce harmful stigma and to help mitigate the subsequent negative social consequences (7). Also, given that many autistic adults have already encountered stigma, understanding the extent of the consequences and how we might help to ameliorate these is essential.

Data availability statement

The raw data supporting the conclusions of this article will be made available by the authors, without undue reservation.

Ethics statement

The studies involving humans were approved by the University of Georgia Institutional Review Board. The studies were conducted in accordance with the local legislation and institutional requirements. The participants provided their written informed consent to participate in this study.

Author contributions

AM and AH contributed to the conception and design of the study. AH supervised AM during the development of the codebook and interview protocol. AM collected with majority of the quantitative and qualitative data, with help from KB, GT, and AH. KB, GT, and AH analyzed the quantitative data. KB and AH identified themes in the qualitative data. All authors wrote sections of the manuscript, contributed to manuscript revisions, and approved the submitted version.

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There is clear indication that autistic adults prefer identify-first language [e.g., (74)]. Despite the disagreement among professionals about the use of identify-first versus person-first language, we opted to use identify-first language (i.e., autistic individuals) to align with autistic adults' preference as the participants in this study. The use of this language is consistent with APA guidance https://apastyle.apa.org/style-grammar-guidelines/bias-free-language/disability#:$\sim$:text=Avoid%20language%20that%20uses%20pictorial,AIDS%E2%80%9D%20or%20%E2%80%9Cperson%20with%20a.

Conflict of interest

The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

Publisher's note

References

1. Taylor SJ, Brumby A. Correction to: Healthy minds in the twentieth century. In: Taylor SJ, Brumby A editors. *Healthy Minds in the Twentieth Century. Mental Health in Historical Perspective*. London: Palgrave Macmillan (2020). doi: 10.1007/978-3-030-27275-3_12

2. Goffman E. *Stigma: Notes on the management of spoiled identity*. Hoboken, NJ: Prentice Hall (1963).

3. Kapp SK, Gillespie-Lynch K, Sherman LE, Hutman T. Deficit, difference, or both? Autism and neurodiversity. *Dev Psychol.* (2013) 49:59–71. doi: 10.1037/a0028353

4. Gray DE. Perceptions of stigma: The parents of autistic children. *Sociol Health Illness.* (1993) 15:102–20. doi: 10.1111/1467-9566.ep11343802

5. Turnock A, Langley K, Jones C. Understanding stigma in autism: A narrative review and theoretical model. *Autism Adulthood.* (2022) 4:79–91. doi: 10.1089/aut.2021.0005

6. Leadbitter K, Buckle KL, Ellis C, Dekker M. Autistic self-advocacy and the neurodiversity movement: Implications for autism early intervention research and practice. *Front Psychol.* (2021) 12:635690. doi: 10.3389/fpsyg.2021.635690

7. Grinker RR. Autism,"stigma," disability: A shifting historical terrain. *Curr Anthropol.* (2020) 61:S55–67. doi: 10.1086/705748

8. Park I, Gong J, Lyons GL, Hirota T, Takahashi M, Kim B, et al. Prevalence of and factors associated with school bullying in students with autism spectrum disorder: A cross-cultural meta-analysis. *Yonsei Med J.* (2020) 61:909–22. doi: 10.3349/ymj.2020.61.11.909

9. Trundle G, Jones KA, Ropar D, Egan V. Prevalence of Victimisation in Autistic Individuals: A Systematic Review and Meta-Analysis. *Trauma Violence Abuse Online.* (2022) doi: 10.1177/15248380221093689 [Epub ahead of print].

10. Han E, Scior K, Avramides K, Crane L. A systematic review on autistic people's experiences of stigma and coping strategies. *Autism Res.* (2021) 15:12–26. doi: 10.1002/aur.2652

11. Kapp SK. *Autistic community and the neurodiversity movement: Stories from the frontline*. London: Palgrave Macmillian (2020). doi: 10.1007/978-981-13-8437-0

12. Hu HF, Liu TL, Hsiao RC, Ni HC, Liang SH, Lin CF, et al. Cyberbullying Victimization and Perpetration in Adolescents with High-Functioning Autism Spectrum Disorder: Correlations with Depression, Anxiety, and Suicidality. *J Autism Dev Disord.* (2019) 49:4170–80. doi: 10.1007/s10803-019-04060-7

13. Jones SC, Harwood V. Representations of Autism in Australian Print Media. *Disabil Soc.* (2009) 24:5–18. doi: 10.1080/09687590802535345

14. Holton AE, Farrell LC, Fudge JL. A Threatening Space?: Stigmatization and the Framing of Autism in the News. *Commun Stud.* (2014) 65:189–207. doi: 10.1080/10510974.2013.855642

15. Luterman S. *What it's like to be autistic at an autism research conference*. Stamford: Spectrum (2019).

16. Rose K. *Regarding the use of dehumanising rhetoric*. Consett: The Autistic Advocate (2020).

17. Zajicek AM, Koski PR. Strategies of resistance to stigmatization among white middle class singles. *Sociol Spectrum.* (2003) 23:377–403. doi: 10.1080/02732170309203

18. Botha M, Dibb B, Frost DM. "Autism is me": An investigation of how autistic individuals make sense of autism and stigma. *Disabil Soc.* (2022) 37:427–53. doi: 10.1080/09687599.2020.1822782

19. Jackson SLJ, Hart L, Brown JT, Volkmar FR. Brief report: self- reported academic, social, and mental health experiences of post-secondary students with autism spectrum disorder. *J Autism Dev Disord.* (2018) 48:643–50. doi: 10.1007/s10803-017-3315-x

20. McLeod JD, Meanwell E, Hawbaker A. The experiences of college students on the autism spectrum: A comparison to their neurotypical peers. *J Autism Dev Disord.* (2019) 49:2320–36. doi: 10.1007/s10803-019-03910-8

21. Zablotsky B, Bradshaw CP, Anderson C, Law PA. The association between bullying and the psychological functioning of children with autism spectrum disorders. *J Dev Behav Pediatr.* (2013) 34:1–8. doi: 10.1097/dbp.0b013e31827a7c3a

22. Rodriguez G, Drastal K, Hartley SL. Cross-lagged model of bullying victimization and mental health problems in children with autism in middle to older childhood. *Autism.* (2021) 25:90–101. doi: 10.1177/1362361320947513

23. Dubreucq J, Plasse J, Gabayet F, Faraldo M, Blanc O, Chereau I, et al. Self-stigma in serious mental illness and autism spectrum disorder: Results from the REHABase national psychiatric rehabilitation cohort. *Eur Psychiatry.* (2020) 63:e13. doi: 10.1192/j.eurpsy.2019.12

24. Corrigan PW, Larson JE, Rüsch N. Self-stigma and the "why try" effect: Impact on life goals and evidence-based practices. *World Psychiatry.* (2009) 8:75–81. doi: 10.1002/j.2051-5545.2009.tb00218.x

25. Rosenberg M. *Rosenberg Self-Esteem Scale (RSES).* Washington, DC: APA PsycTests (1965).

26. Chen G, Gully SM, Eden D. General self-efficacy and self-esteem: Toward theoretical and empirical distinction between correlated self-evaluations. *J Organ Behav.* (2004) 25:375–95. doi: 10.1002/job.251

27. Livingston JD, Boyd JE. Correlates and consequences of internalized stigma for people living with mental illness: A systematic review and meta-analysis. *Soc Sci Med.* (2010) 71:2150–61. doi: 10.1016/j.socscimed.2010.09.030

28. Cantwell J, Muldoon O, Gallagher S. The influence of self-esteem and social support on the relationship between stigma and depressive symptomology in parents caring for children with intellectual disabilities. *J Intell Disabil Res.* (2015) 59:948–57. doi: 10.1111/jir.12205

29. Mitter N, Ali A, Scior K. Stigma experienced by families of individuals with intellectual disabilities and autism: A systematic review. *Res Dev Disabil.* (2019) 89:10–21. doi: 10.1016/j.ridd.2019.03.001

30. Recio P, Molero F, Silván-Ferrero P, Nouvilas-Pallejà E. Perceived discrimination and emotional distress among family caregivers of children with physical disabilities: The mediational role of affiliate stigma and self-efficacy. *Am J Orthopsychiatry.* (2021) 91:367–74. doi: 10.1037/ort0000534

31. Zhou T, Wang Y, Yi C. Affiliate stigma and depression in caregivers of children with autism spectrum disorders in China: Effects of self-esteem, shame, and family functioning. *Psychiatry Res.* (2018) 264:260–5. doi: 10.1016/j.psychres.2018.03.071

32. Chou WJ, Wang PW, Hsiao RC, Hu HF, Yen CF. Role of school bullying involvement in depression, anxiety, suicidality, and low self-esteem among adolescents with high-functioning autism spectrum disorder. *Front Psychiatry.* (2020) 11:9. doi: 10.3389/fpsyt.2020.00009

33. Gray DE. 'Everybody just freezes. Everybody is just embarrassed': Felt and enacted stigma among parents of children with high functioning autism. *Sociol Health Illness.* (2002) 24:734–49. doi: 10.1111/1467-9566.00316

34. Papadopoulos C, Lodder A, Constantinou G, Randhawa G. Systematic review of the relationship between autism stigma and informal caregiver mental health. *J Autism Dev Disord.* (2019) 49:1665–85. doi: 10.1007/s10803-018-3835-z

35. Bachmann CJ, Höfer J, Kamp-Becker I, Küpper C, Poustka L, Roepke S, et al. Internalised stigma in adults with autism: A German multi-center survey. *Psychiatry Res.* (2019) 276:94–9. doi: 10.1016/j.psychres.2019.04.023

36. Asher SR, Hymel S, Renshaw PD. Loneliness in children. *Child Dev.* (1984) 55:1456–64.

37. Klin A, Saulnier CA, Sparrow SS, Cicchetti DV, Volkmar FR, Lord C. Social and Communication Abilities and Disabilities in Higher Functioning Individuals with Autism Spectrum Disorders: The Vineland and the ADOS. *J Autism Dev Disord.* (2007) 37:748–59. doi: 10.1007/s10803-006-0229-4

38. Sparrow SS, Cicchetti DV. Diagnostic Uses of the Vineland Adaptive Behavior Scales. *J Pediatr Psychol.* (1985) 10:215–25. doi: 10.1093/jpepsy/10.2.215

39. Tillmann J, San José Cáceres A, Chatham CH, Crawley D, Holt R, Oakley B, et al. Investigating the factors underlying adaptive functioning in autism in the EU-AIMS Longitudinal European Autism Project. *Autism Res.* (2019) 12:645–57. doi: 10.1002/aur.2081

40. Botha M, Frost DM. Extending the minority stress model to understand mental health problems experienced by the autistic population. *Soc Mental Health.* (2020) 10:20–34. doi: 10.1177/2156869318804297

41. Maskey M, Warnell F, Parr JR, Le Couteur A, McConachie H. Emotional and behavioural problems in children with autism spectrum disorder. *J Autism Dev Disord.* (2013) 43:851–9. doi: 10.1007/s10803-012-1622-9

42. Coelho VA, Romão AM. The relation between social anxiety, social withdrawal and (cyber)bullying roles: A multilevel analysis. *Comput Hum Behav.* (2018) 86:218–26. doi: 10.1016/j.chb.2018.04.048

43. Bowles TV. The focus of intervention for adolescent social anxiety: Communication skills or self-esteem. *Int J School Educ Psychol.* (2017) 5:14–25. doi: 10.1080/21683603.2016.1157051

44. Pearson A, Rose K, Rees J. 'I felt like I deserved it because I was autistic': Understanding the impact of interpersonal victimisation in the lives of autistic people. *Autism.* (2022) 27:500–11. doi: 10.1177/13623613221104546

45. Morgan DL. Practical strategies for combining qualitative and quantitative methods: Applications to health research. *Qual Health Res.* (1998) 8:362–76. doi: 10.1177/104973239800800307

46. Hesse-Biber SN. *Mixed methods research: Merging theory with practice*. New York City, NY: The Guilford Press (2010).

47. Saunders B, Sim J, Kingstone T, Baker S, Waterfield J, Bartlam B, et al. Saturation in qualitative research: Exploring its conceptualization and operation. *Qual Q.* (2018) 52:1893–907. doi: 10.1007/s11135-017-0574-8

48. King M, Dinos S, Shaw J, Watson R, Stevens S, Passetti F, et al. The Stigma Scale: Development of a standardised measure of the stigma of mental illness. *Br J Psychiatry.* (2007) 190:248–54. doi: 10.1192/bjp.bp.106.024638

49. Dagnan D, Sandhu S. Social comparison, self-esteem and depression in people with intellectual disability. *J Intell Disabil Res.* (1999) 43:372–9. doi: 10.1046/j.1365-2788.1999.043005372.x

50. Park J, Park E. The rasch analysis of Rosenberg Self-Esteem Scale in individuals with intellectual disabilities. *Front Psychol.* (2019) 10:1992. doi: 10.3389/fpsyg.2019.01992

51. Fleming JS, Courtney BE. The dimensionality of self-esteem: II. Hierarchical facet model for revised measurement scales. *J Pers Soc Psychol.* (1984) 46:404–21. doi: 10.1037/0022-3514.46.2.404

52. Sinclair SJ, Blais MA, Gansler DA, Sandberg E, Bistis K, LoCicero A. Psychometric properties of the Rosenberg Self-Esteem Scale: Overall and across demographic groups living within the United States. *Eval Health Profess.* (2010) 35:56–80. doi: 10.1177/0163278709356187

53. Sherer M, Maddux JE, Mercandante B, Prentice-Dunn S, Jacobs B, Rogers RW. The self-efficacy scale: Construction and validation. *Psychol Rep.* (1982) 51:663–71. doi: 10.2466/pr0.1982.51.2.663

54. Maddux JE, Sherer M, Rogers RW. Self-efficacy expectancy and outcome expectancy: Their relationship and their effects on behavioral intentions. *Cogn Therapy Res.* (1982) 6:207–11. doi: 10.1007/BF01183893

55. Ponterotto JG, Ruckdeschel DE. Perceptualand Motor Skills. *Percept Motor Skills.* (2007) 105:997–1014. doi: 10.2466/pms.105.3.997-1014

56. Salsman JM, Butt Z, Pilkonis PA, Cyranowski JM, Zill N, Hendrie HC, et al. Emotion assessment using the NIH Toolbox. *Neurology.* (2013) 80:S76–86. doi: 10.1212/WNL.0b013e3182872e11

57. Cyranowski JM, Zill N, Bode R, Butt Z, Kelly MA, Pilkonis PA, et al. Assessing social support, companionship, and distress: National Institute of Health (NIH) Toolbox Adult Social Relationship Scales. *Health Psychol.* (2013) 32:293. doi: 10.1037/a0028586

58. Harrison PL, Oakland T. *Adaptive Behavior Assessment System, Third Edition (ABAS-3): Manual.* Torrance, CA: Western Psychological Services (2015).

59. Richardson RD, Burns MK. Adaptive Behavior Assessment System (2nd Edition) by Harrison, P. L., and Oakland, T. (2002). San Antonio, TX: Psychological Corporation. *Assess Effect Interv*. (2005) 30:51-4. doi: 10.1177/073724770503000407

60. Oakland T. Adaptive Behavior Assessment System – Second Edition. In: Kreutzer JS, DeLuca J, Caplan B editors. *Encyclopedia of Clinical Neuropsychology*. New York, NY: Springer (2011). doi: 10.1007/978-0-387-79948-3_1506

61. Altman K. *College students on the autism spectrum: Social experiences and self-disclosure. (Publication No. 3573884).* Ph.D. Thesis. Philadelphia, PA: Chestnut Hill College (2013).

62. Johnson TD, Joshi A. Dark clouds or silver linings? A stigma threat perspective on the implications of an autism diagnosis for workplace wellbeing. *J Appl Psychol.* (2016) 101:430–49. doi: 10.1037/apl0000058

63. Brohan E, Clement S, Rose D, Sartorius N, Slade M, Thornicroft G. Development and psychometric evaluation of the Discrimination and Stigma Scale (DISC). *Psychiatry Res.* (2013) 208:33–40. doi: 10.1016/j.psychres.2013.03.007

64. van Manen M. From Meaning to Method. *Qual Health Res.* (1997) 7:345–69. doi: 10.1177/104973239700700303

65. Harding T, Whitehead D. Analysing data in qualitative research. In: Ellingson LL, Sotiri P editors. *Making Data in Qualitative Research*. London: Routledge (2020). p. 127–42. doi: 10.4324/9780429058240

66. Ferenc K, Płatos M, Byrka K, Król ME. Looking through rainbow-rimmed glasses: Taking neurodiversity perspective is related to subjective well-being of autistic adults. *Autism.* (2022) 27:1348–61. doi: 10.1177/13623613221135818

67. Cooper K, Smith LG, Russell A. Social identity, self-esteem, and mental health in autism. *Eur J Soc Psychol.* (2017) 47:844–54. doi: 10.1002/ejsp.2297

68. den Houting J. Neurodiversity: An insider's perspective. *Autism.* (2019) 23:271–3. doi: 10.1177/1362361318820762

69. Scior K, Werner S. *Intellectual Disability and Stigma: Stepping Out From the Margins*. New York, NY: Macmillan Publishers (2016). doi: 10.1017/9781108920995.011

70. Rubenstein E, Furnier S. Bias: The opportunities and challenges of surveys that recruit and collect data of autistic adults online. *Autism Adulthood.* (2021) 3:120–8. doi: 10.1089/aut.2020.0031

71. Mayoh J, Onwuegbuzie AJ. Toward a Conceptualization of Mixed Methods Phenomenological Research. *Article J Mixed Methods Res.* (2015) 9:91–107. doi: 10.1177/1558689813505358

72. Diemer MC, Gerstein ED, Regester A. Autism presentation in female and Black populations: Examining the roles of identity, theory, and systemic inequalities. *Autism.* (2022) 26:1931–46. doi: 10.1177/13623613221113501

73. Shattuck PT, Narendorf SC, Cooper B, Sterzing PR, Wagner M, Taylor JL. Postsecondary education and employment among youth with an autism spectrum disorder. *Pediatrics.* (2012) 129:1042–9. doi: 10.1542/peds.2011-2864

74. Taboas A, Doepke K, Zimmerman C. Preferences for identity-first versus person-first language in a US sample of autism stakeholders. *Autism* (2023) 27:565–70. doi: 10.1177/13623613221130845

75. Sherer M, Adams CH. Construct validation of the self-efficacy scale. *Psychol Rep.* (1983) 53:899–902. doi: 10.2466/pr0.1983.53.3.899

76. Ali A, Hassiotis A, Strydom A, King M. Self stigma in people with intellectual disabilities and courtesy stigma in family carers: A systematic review. *Res Dev Disabil.* (2012) 33:2122–40. doi: 10.1016/j.ridd.2012.06.013

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A mixed method comparison of stigma toward autism and schizophrenia and effects of person-first versus identity-first language

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Introduction: While stigma toward autistic individuals has been well documented, less is known about how autism is perceived relative to other stigmatized disabilities. As a highly stigmatized condition with similar social cognitive features to autism, schizophrenia may offer a useful comparison for stigma. Previous studies have found that autistic people may be perceived more favorably than those with schizophrenia, but little is known about the underlying volitional thoughts that contribute to differences in how these conditions are perceived.

Methods: The present study utilizes a mixed-methods approach, allowing for a detailed understanding of how young adults perceive different diagnostic labels. 533 college undergraduates completed questionnaires reflecting their perceptions of one of eight diagnostic labels: four related to autism (autism, autistic, autism spectrum disorder, or Asperger's), two related to schizophrenia (schizophrenia or schizophrenic), and two related to an unspecified clinical condition (clinical diagnosis or clinical disorder). Participants also completed an open-ended question regarding their thoughts about, and exposure to, these labels. Responses were compared across broader diagnostic categories (autism, schizophrenia, general clinical condition), with thematic analysis used to assess the broader themes occurring within the open-ended text.

Results: While perceptions did not differ significantly for person-first and identity-first language within labels, several differences were apparent across labels. Specifically, quantitative results indicated greater prejudice towards autism and schizophrenia than the generic clinical condition, with schizophrenia associated with more perceived fear and danger, as well as an increased preference for social distance, compared to autism. Patterns in initial codes differed across diagnostic labels, with greater variation in responses about autism than responses about schizophrenia or the general clinical condition. While participants described a range of attitudes toward autism (patronizing, exclusionary, and accepting) and schizophrenia (fear, prejudice, and empathy), they refrained from describing their attitudes toward the general clinical label, highlighting the centrality of a cohesive group identity for the development of stigma. Finally, participants reported a number of misconceptions about autism and schizophrenia, with many believing features such as savant syndrome to be core characteristics of the conditions.

Conclusion: These findings offer a more detailed account of how non-autistic individuals view autism and may therefore aid in the development of targeted programs to improve attitudes toward autism.

KEYWORDS

autism, schizophrenia, stigma, qualitative, terminology

Introduction

Stigma has traditionally been defined as the social discrediting and marginalization that occurs in response to negatively perceived attributes within a prevailing society (1), with more modern conceptualizations emphasizing the lower status and power afforded to stigmatized groups (2, 3). One marginalized group that continues to be stigmatized across many cultures (4–6), despite recent increases in acceptance and awareness (7), is autistic people. Autistic children and adults often behave and communicate in non-normative ways, and these differences are reliably rated by non-autistic observers as less socially appealing (8, 9). Attitudes about autism do vary among non-autistic people (10), with greater autism acceptance occurring among those with more autism knowledge and experience [for a review, see Kim et al. (11)], but non-autistic observers as a whole express a general reluctance to interact with autistic people (9). This process is mitigated somewhat but still persists when raters are informed that the person they are observing is autistic [(12); for a review see, Thompson-Hodgetts et al. (13)], or when they are first educated about autistic differences, neurodiversity, and inclusion (14–17).

Stigma toward autistic differences contributes to the social exclusion of autistic people (18), increases experiences of minority stress (19), affects mental health (20), and impedes personal and professional achievement (13). This stigma can also turn inward among autistic people (19) and contribute to conscious and unconscious concealment strategies to avoid victimization (21) that are mentally and emotionally taxing and associated with poor mental health outcomes (22, 23).

Although the nature, experiences, and consequences of stigma toward autism has received considerable attention (18), less is known about how autism stigma compares to the stigma associated with other specific clinical conditions, or perceptions of clinical conditions more generally. Charting responses to a generic, unspecified clinical condition may provide a baseline to extract aspects of stigma associated with autism, and comparisons to another stigmatized neurodivergent group can specify the aspects of stigma unique to autism that can be used to target prejudice or misconceptions that are specific to autism, inform knowledge-based interventions, and improve education and dissemination of autism-relevant information.

For instance, comparing autism-related stigma to stigma toward another stigmatized condition, schizophrenia, may be instructive. Like autism, schizophrenia is defined in part by social difficulties (24), is misunderstood in the general population (25, 26), and is associated with considerable stigma (27). Unlike autism, however, schizophrenia is often characterized by negatively viewed symptoms such as hallucinations and delusions. Exaggerated and distorted media portrayals (28) have reinforced stereotypes and misperceptions of people with schizophrenia as unpredictable and dangerous (29), which may contribute to fear-based stigma that is less present with autism (30). In truth, research indicates that non-clinical factors such as age and gender are stronger predictors of violence than schizophrenia (31), and those with severe mental illness are more often the victims of violence than the perpetrators of it (32).

Previous research comparing attitudes toward autism and schizophrenia suggests that stigma toward the two conditions often differs, and may relate to knowledge and stereotypes about the conditions (30). While the majority of adults can recognize the terms autism and schizophrenia, far fewer can accurately describe their characteristics (33). In particular, non-autistic people show large variability in their understanding of the causes, age of onset, and need for lifelong treatment associated with an autism or schizophrenia diagnosis (33), but tend to believe that autistic people are more capable of living a "normal" life than those with schizophrenia. In line with greater functional assessments, non-autistic people also report less stigma toward autism (34), perceiving them as intelligent and creative, while people with schizophrenia were more likely to be perceived as dangerous (30). The increased severity of stigma toward people with schizophrenia extends to social attitudes; while non-autistic people report a reluctance to interact with both autistic people and people with schizophrenia (30), this stigma is more severe and wider ranging for hypothetical interactions with a person with schizophrenia, extending to familial, workplace, and educational settings (33).

Most studies of stigma have used quantitative measures and scales to assess attitudes about autism and schizophrenia. Such approaches are useful for comparing individuals and groups of people on a uniform set of items, but they restrict responses to pre-determined questions and therefore may fail to fully capture conscious feelings. Complementing quantitative assessments with qualitative analysis in which participants describe clinical conditions in their own words allows for a richer view of how conditions are perceived. For instance, qualitative data can be used to assess specific patterns in how people stigmatize a condition instead of just quantifying degrees of stigma, help inform the underlying volitional thoughts that drive quantitative results, and determine whether emergent themes are consistent with survey data.

The present study utilizes a mixed-method approach that incorporates both self-report questionnaires and open-ended responses to understand how adults perceive autism-related diagnostic labels compared to schizophrenia-related labels, as well as general clinical labels. We hypothesized that participants would endorse more negative attributes and attitudes toward autism-related labels and a lower willingness to interact with individuals with these labels, compared to labels associated with a general diagnostic condition. However, based on previous data showing high levels of stigma toward individuals with schizophrenia, particularly around misperceptions (35, 36), as well as findings that autistic people are perceived more positively when they are labeled as autistic compared to when they are labeled as having schizophrenia (12), we hypothesized that autism-associated labels would be perceived more favorably than schizophrenia-associated labels.

It is also possible that differences in how conditions are described can affect stigma, with certain labels increasing the salience of difference, disability, or severity than others. Therefore, a secondary aim was to determine whether perceptions of clinical conditions vary between person-first (e.g., person with autism) and identity-first labels (e.g., autistic person) within diagnostic categories, as well as between different labels within the autism spectrum (e.g., Asperger's, on the spectrum). In general, autistic adults tend to prefer identify-first language, while professionals and practitioners continue to favor person-first language (37, 38). Within the diagnostic conditions, we expected more positive perceptions for the "person with Asperger's" label relative to other autism-related labels, as some findings have suggested that the Asperger's label is associated with less stigma and considered less severe compared to the autism label (39). We also explored whether person-first labels ("person with schizophrenia") would be perceived more positively than identity-first labels ("schizophrenic person") within the schizophrenia condition, as would be predicted by proponents of person-first language who seek to separate the person from a highly stigmatized condition (40). There is a lack of consensus on preferred technology among people with severe mental illness, with individual preferences often varying across situations and contexts (41), while clinicians often encourage person-first language in an effort to reduce stigma (42). However, because person-first language in practice is typically restricted to conditions that are stigmatized, such efforts may backfire and unintentionally accentuate stigma rather than reduce it (43). While previous literature has suggested an association between identity-first language and greater stigma (44), more recent findings suggest that it is the lack of an explicit diagnostic label, rather than the phrasing of the label, that elicits the greatest impact on stigma (45, 46). In particular, vignettes of people with schizophrenia were associated with greater fear, anger, blame, and perceived danger when a diagnostic label was not provided, while these responses did not differ significantly when person-first and identity-first labels were used (46). Likewise, videos of autistic adults are typically rated more favorably when the person's diagnosis is disclosed (12), regardless of whether person-first or identity-first language is used (10).

In order to emphasize a data-driven approach, no specific *a priori* hypotheses were generated for the qualitative portion of this study, though we expected differences in the themes used to describe diagnostic labels for autism, schizophrenia, and a general diagnosis.

Materials and methods

Participants

A total of 533 college undergraduates aged 18–63 ($M = 21.22$, SD = 5.67) were recruited from the University of Texas at Dallas. Four participants with an IQ below 80, as estimated by the Reading subtest of the Wide Range Achievement Test 3 [WRAT3; (47)], were excluded from analysis, resulting in a final sample of 529 participants ($M_{IQ} = 109.26$). Participants were predominantly female (78%) and a plurality were White (43%), with the remaining participants identifying as Asian (40%), Black (7%), American Indian/Alaska Native (1%), or other races (9%). To better approximate a general population sample, participants were not screened for psychological or psychiatric conditions. Participants received course credit for their participation. All aspects of this protocol were approved by the UT Dallas Institutional Review Board.

Procedure

After providing informed consent, participants completed the WRAT3 and several computerized questionnaires assessing their perceptions of different diagnostic labels, along with an open-ended question regarding their thoughts about, and exposure to, each label. Participants were randomly assigned to a survey condition in which the wording of each measure was modified to feature one of eight labels: four related to autism (AUT; person with autism, person with autism spectrum disorder, person with Asperger's, or autistic person), two related to schizophrenia (SCZ; person with schizophrenia or schizophrenic person), and two related to a general clinical condition (CDX; person with a clinical diagnosis or person with a clinical disorder). These labels enabled the comparison of perceptions of: (1) person-first relative to identity-first language; (2) autism-related labels to a distinct clinical condition also characterized by social difficulties, schizophrenia; and (3) autism and schizophrenia labels to a more general clinical condition. The inclusion of the general clinical label allowed us to determine whether autism and schizophrenia are perceived more positively or negatively relative to the invocation of clinical diagnoses more generally. Due to the larger number of autism-related labels relative to schizophrenia and general labels, the sample size of participants assigned to autism-related labels was larger than that of the other two categories ($N_{AUT} = 269$, $N_{SCZ} = 129$, and $N_{CDX} = 130$).

Measures

Stigma questionnaires

The attributes and reactions scale (AAR)

The AAR (35) is a five-point Likert scale originally designed to measure attitudes toward schizophrenia and depression. In the first part of this measure, participants were given eight stigma-related behavioral attributes (unpredictable, lacking self-control, aggressive, frightening, dangerous, needy, dependent on others, and helpless) and asked to rate the extent to which each attribute applied to a person with the assigned diagnostic label, with higher scores indicating greater agreement. Due to a technical error, ratings for "aggressive" were not collected. Responses were averaged across two subscales (35): perceived dangerousness and perceived dependency.

For the second portion of this measure, participants were given nine emotional labels (fear, uneasiness, feelings of insecurity, pity, empathy, desire to help, anger, ridicule, and irritation) and asked to indicate the degree to which they would respond in such a way toward a person with the given label, with higher scores indicating a more likely emotional reaction. Responses were averaged to form three subscales (35): fear, pity, and anger. The behavioral attributes portion of this scale showed strong internal consistency across all diagnostic categories ($\alpha_{AUT} = 0.819$, $\alpha_{SCZ} = 0.841$, and $\alpha_{CDX} = 0.811$), while the emotional reactions portion showed lower, but acceptable internal consistency ($\alpha_{AUT} = 0.701$, $\alpha_{SCZ} = 0.635$, and $\alpha_{CDX} = 0.648$).

The prejudice scale

The Prejudice Scale (36) is an 18-item scale developed to measure negative attitudes toward schizophrenia. The scale was adapted in this study by replacing "schizophrenia" with each of the eight tested labels. Participants were shown items reflecting prejudiced attitudes toward the assigned label [e.g., "(Label) patients/patients with (label) should be kept in hospitals"] and answered either "I agree" or "I disagree" for each statement. Scores of either 1 or 2 were assigned to each response based on agreement or disagreement, with higher scores indicating more negative attitudes toward the label. A total score was generated by summing individual item scores (36), with possible scores ranging from 18 to 36. Internal consistency for the overall measure was low to modest across groups ($\alpha_{AUT} = 0.433$, $\alpha_{SCZ} = 0.610$, and $\alpha_{CDX} = 0.426$).

The social distance scale (SDS)

The SDS (48) is a six item Likert scale developed to assess stigma toward autistic individuals and adapted here to include each of the eight labels. Participants were shown 6 items assessing their willingness to form hypothetical social relationships with a person with each label [e.g., "How willing would you be to make friends with a person with (label)?"]. Responses were scored on a four-point Likert scale, with higher scores indicating a lower willingness to interact. Scores on each item were summed to form a composite score, with possible scores ranging from 6 to 24. This measure showed strong internal consistency within each diagnostic category ($\alpha_{AUT} = 0.824$, $\alpha_{SCZ} = 0.803$, and $\alpha_{CDX} = 0.811$).

Open ended question

Participants were also given an open-ended question about their assigned label, which formed the basis for a qualitative analysis. Participants were asked "what do you think of when you hear the word(s) (label)?" Open-ended questions were administered privately via computer, and participants were given as much time to respond as needed. Responses ranged from 0 to 788 characters in length, with a mean length of 136.34 characters (SD: 111.03), and eight participants providing no response.

Analysis plan

Quantitative analysis

Preliminary one-way ANOVAs were conducted to determine where person-first and identity-first labels were perceived differently within each diagnostic condition. Summary scores on each of the three stigma questionnaires did not differ significantly between any of the 4 labels within the autism-associated labels, nor did they differ between the 2 schizophrenia-associated labels or between the 2 general clinical diagnosis labels (**Supplementary Figures 1–3**). Subsequent analyses therefore were conducted at the level of diagnosis (i.e., labels within each of the three diagnostic conditions were combined). A one-way ANOVA was then used to assess whether summary scores on the seven stigma measures differed for autism, schizophrenia, and a general clinical condition. Significant findings were followed up with *post hoc* Tukey tests for multiple comparisons. Due to the large number of analyses performed, the significance cutoff was adjusted to 0.01.

Qualitative analysis

Because quantitative results did not differ between the different labels for each condition, qualitative analyses focused on each condition collapsed across labels (for an overview of the most common codes for all 8 labels, see **Supplementary Table 1**). Specifically, a thematic analysis was conducted to gain further insight concerning perceptions of autism, schizophrenia, and a general clinical condition, and to highlight differences in how participants describe these conditions. This method was chosen due to its ability to provide a rich analysis of large qualitative datasets, as well as its recent use within autism research (49, 50). Responses to open-ended questions were aggregated and themes were identified and coded by the first author based on the six-step approach to thematic analysis outlined by Braun and Clarke (51, 52). First, all responses were given an initial read-through by the first author to gain familiarity with the data prior to coding. Next, initial codes for the data were generated in a data-driven fashion using QDA Miner (53). Initial codes were created by identifying frequently occurring patterns of responses across the dataset. Similar codes were then clustered and organized into themes and sub-themes, which were further refined and simplified to eliminate any redundancies and minimize overlap. Once finalized, themes were named based on the shared narrative they conveyed. Codes, themes, and sub-themes were reviewed by both authors, and consensus was reached for any areas of disagreement.

Results

Quantitative analysis

Means and Standard deviations (SDs) for the three label conditions are presented in **Table 1**. On the AAR, perceptions of danger differed significantly between diagnostic labels [$F_{(2,526)} = 19.77$, $p < 0.001$], with greater danger attributed to schizophrenia compared to autism ($p < 0.001$) and a general clinical condition ($p = 0.002$). A similar pattern was found for fear [$F_{(2,526)} = 22.56$, $p < 0.001$], with participants reporting greater feelings of fear in response to schizophrenia compared to

TABLE 1 Means and standard deviations (SD) for measures of stigma.

	Autism labels	Schizophrenia labels	General clinical labels
Perceived danger	2.42 [0.71]	2.93 [0.88]	2.61 [0.73]
Perceived dependency	2.77 [0.84]	2.75 [0.79]	2.91 [0.81]
Fear	2.05 [0.88]	2.68 [0.95]	2.11 [0.85]
Pity	3.58 [0.69]	3.56 [0.78]	3.66 [0.71]
Anger	1.34 [0.58]	1.35 [0.67]	1.37 [0.56]
Prejudice	22.10 [2.04]	22.07 [2.48]	21.27 [1.92]
Social distance	11.50 [3.33]	12.97 [3.37]	11.66 [3.28]

autism and a general clinical condition (*ps* < 0.001). Perceived dependency did not differ significantly across diagnostic conditions [$F_{(2,526)} = 1.63$, $p = 0.197$], nor did feelings of pity or anger (*ps* > 0.417).

Groups differed significantly for scores on the Prejudice Scale, [$F_{(2,526)} = 7.35$, $p = 0.001$]. Both schizophrenia ($p = 0.007$) and autism ($p = 0.001$) were associated with more prejudice than the general clinical condition, but prejudice did not differ significantly between schizophrenia and autism ($p = 0.988$). However, many group differences were present at the individual item level for this measure, with participants believing that people with schizophrenia are more dangerous, untrustworthy, and pose greater harm to children, and reporting greater opposition to having a relative marry a person with schizophrenia, compared to an autistic person (*ps* < 0.001) or a person with a general clinical condition (*ps* < 0.01). Compared to schizophrenia, participants also believed that autism was more visibly detectable, less likely to require hospitalization, had greater potential for treatment and recovery, and benefited more from psychotherapy and pharmacological interventions, and showed more favorable attitudes toward having an autistic neighbor (*ps* < 0.01). On the SDS, schizophrenia was associated with greater stigma [$F_{(2,526)} = 8.97$, $p < 0.001$], with participants endorsing a significantly larger social distance to schizophrenia relative to both autism ($p < 0.001$) and a general clinical condition ($p = 0.005$).

Qualitative analysis

Autism

A total of 88 initial codes were generated for autism, with each code occurring in <1–15% of cases. These codes reflected a wide range of perceptions, with the most frequently occurring codes (Table 2) focusing on poor social abilities (15%), a range of severities (10%), and dependence on others (10%). Initial codes and their context within the data were used to generate four themes: (1) perceived severity, (2) symptoms or features, (3) attitudes toward autism, and (4) representations of autism. Each theme was further divided into subthemes. Full themes and subthemes, along with representative responses, are reported in Table 3.

Schizophrenia

Open-ended responses for schizophrenia labels were used to generate 86 initial codes, which appeared within <1–38% of cases. Psychotic symptoms (38%), general mental illness (19%), and the need for treatment (13%) were among the most frequently occurring codes (Table 2). These codes and their associated responses centered around three general themes: (1) schizophrenia knowledge, (2) attitudes toward schizophrenia, and (3) representations of schizophrenia. These themes and their respective subthemes, along with representative responses, are reported in Table 4.

General clinical condition

Participant responses for general clinical labels produced 62 initial codes, which appeared within 1 to 63% of cases. References to brain or behavioral conditions (63%), autism (18%), and impaired functional abilities (15%) were among the most frequent codes for these labels. These codes and the responses in which they occurred were used to generate three broader themes: (1) clinical conditions, (2) symptoms or features, and (3) clinical pathology. These themes were divided into subthemes, which are reported in Table 5, along with representative responses.

Discussion

The current study used a mixed-methods approach to compare stigma between autism, schizophrenia, and a generic clinical condition. Quantitative results indicated greater prejudice toward autism and schizophrenia than the generic clinical condition, with schizophrenia differentiated from autism by being associated with perceptions of danger and fear, and a greater preference for social distance than from autism. Qualitative results supported and expanded these findings, with autism described in greater depth but with less cohesion than the other conditions, and schizophrenia more commonly described with references to danger and more frequent uses of derogatory terms for mental illness.

A secondary aim of the study was to compare stigma toward clinical conditions labeled with person-first language (e.g., "person with autism") relative to identity-first language (e.g., "autistic person"). Language choices for autism and other clinical conditions are often intensely debated and discussed, as use of person-first versus identity-first language can reflect ideological differences that may affect conceptualizations and biases (54). However, preliminary examination indicated that stigma did not differ between person-first and identity-first language, either for autism or schizophrenia, nor did it differ between different labels of the autism spectrum ("autism," "on the spectrum," "Asperger's"), and thus subsequent quantitative analyses were pursued after collapsing

TABLE 2 Frequently occurring initial codes.

Code	% cases
Autism labels (N = 269 cases)	
Poor social abilities	15.20%
Range of severities	10.40%
Dependent on others	10.00%
Intelligent	8.10%
Intellectual disability	7.80%
Misunderstand social cues	7.00%
Awkward	6.70%
General deficits	5.90%
General mental illness	5.60%
Difficulties understanding emotions of others	5.60%
Schizophrenia labels (N = 129 cases)	
Psychotic symptoms	38.00%
General mental illness	19.40%
Needs treatment	13.20%
Multiple personalities/dissociative	8.50%
Emotional instability	7.80%
Can be managed	7.80%
Unfairly stigmatized	6.20%
Crazy	5.40%
Brain disorder	5.40%
Can live a “normal life”	5.40%
General condition labels (N = 130 cases)	
Brain or behavioral conditions	63.10%
Autism	17.70%
Impaired functional abilities	15.40%
Depression	13.80%
Broad range/spectrum	13.80%
Diagnosed by a doctor	13.10%
Schizophrenia	12.30%
Needs treatment	8.50%
Anxiety	6.90%
Mania/bipolar disorder	6.20%
Dependent on others	6.20%
Personality disorder	5.40%
Developmental disability	5.40%
Physical impairment	5.40%
Not normal	5.40%

Text-based responses to an open-ended question about perceptions toward labels related to autism (ASD), schizophrenia (SCZ) or a general clinical condition (CDX) were analyzed using thematic analysis. Initial codes reported in greater than five percent of cases (N_{AUT} = 15 cases, N_{SCZ} = 7 cases, and N_{CDX} = 7 cases) are reported for each category. Initial codes were used to help generate themes and subthemes within the data.

across person-first and identity first-labels. The lack of a language effect here aligns with a previous study that found that referring to autistic people with person-first or identify-first language does not affect the first impressions they receive from non-autistic observers (12), as well as research suggesting that it is the lack of a label, rather than person-first or identity-first language, that most contributes to stigma toward schizophrenia (46). Broader language use surrounding disability, however, still influences perpetuation of stigma in other ways (54), and it is possible that the use of person-first and identity-first language may have differing effects on those to whom the label is attributed Because preferred terminology has been the subject of recent debate within disability communities, with the preferences of disabled people differing from those of clinicians and stakeholders (55, 56), future research examining the effect of person-first and identity-first language on self-esteem and internalized stigma may offer greater explanation to the potential impact of differing terminologies.

Although stigma did not differ among labels within each clinical condition, it did differ between the conditions themselves in a number of ways. First, autism and schizophrenia were ascribed more stigma than a generically labeled clinical condition. This suggests that autism and schizophrenia are more stigmatized conditions than clinical conditions are generally, with each exceeding the baseline of stigma attributed to a non-specified clinical status. However, stigmatizing attitudes may also be generated to a greater degree when a specific diagnostic label is provided compared to a generic one. Encountering the terms “autism” or “schizophrenia” may trigger certain stereotypes, encourage consideration of specific knowledge and (mis)information, and inspire personal reflection on experiences with each condition. In contrast, a generic clinical label may not be associated with specific enough experience or information to generate high levels of stigma. Supporting this interpretation, the thematic analysis of the qualitative data indicated that the general clinical condition did not elicit as many discernable attitudes or references to first-hand exposure as did participant descriptions of autism and schizophrenia. This suggests that discrete clinical labels may play a central role in the development of stigma by providing categories that can be linked to specific attitudes, information, and biases.

Second, both quantitative and qualitative analyses suggested important differences in the stigma ascribed to autism and schizophrenia. Descriptions of autism were more detailed and wide-ranging than those of schizophrenia, covering more concepts, characteristics, and attitudes. This may reflect greater familiarity with autism than schizophrenia, both interpersonally and from broader cultural messaging, awareness campaigns, and media portrayals. Given comparable prevalence estimates for autism and schizophrenia of about 1% (57, 58)—at least until recent reported increases for autism (59)—greater familiarity with autism is likely not driven by substantially higher cases of autism within communities than schizophrenia. Rather, it may reflect increasing awareness, acceptance, and inclusion of autism that has not occurred to the same degree for schizophrenia (60). This disparity in stigma may also be echoed in diagnostic disclosure decisions. Although disclosing one’s autism can be a fraught decision for many autistic people that often depends on many internal and external factors (61), disclosure of schizophrenia may be especially perilous given rampant biases, beliefs, and misinformation about the condition (62). Disparities in disclosure between the two conditions may in some respects be a reflection of disparities in the stigma attached to them.

TABLE 3 Themes and subthemes within open-ended responses for autism labels, with text examples.

Theme	Subtheme	Quoted example from responses
Perceived severity	Severe disability	"A person whose mental ability is limited and they rather depend on their parents."
	Minimal disability	"I think of a disorder that a person is born with. It doesn't mean that the person is less intelligent or strange. It just means that their brains make connections differently than most people's do."
	Range of presentations	"A spectrum of disability that mostly deals with communication skills, but also impacts other aspects of life. Can be incredibly mild, or require life-long care."
Symptoms or features	Social difficulties	"When I hear the word "autistic," I generally tend to think of people who have a hard time connecting to other people in a permanent fashion. They want to create bonds with other people but just don't know how to create and maintain these relationships"
	RRBIs	"I believe each person with autism has unique characteristics where they can fixate on one thing or have a specified routine everyday. it does not seem that they like change"
	Emotion and behavior dysregulation	"Cannot understand their own inward emotions from time-to-time and act on them appropriately. This may make the autistic person seem a bit impulsive or compulsive"
	Speech and communication difficulties	"Disorder that doesn't allow you to process or communicate the same way others do."
	Savant syndrome	"Have extraordinary memory about what they did or saw (such as immediately memorizing road signs or car types or people's names with faces)."
Attitudes toward autism	Exclusionary attitudes	"They seem to be more social but tend to not be always be wanted in social setting. They make people feel uneasy and not comfortable to be around"
	Patronizing attitudes	"Wants to be accepted and loved. But doesn't understand how to be accepted. Someone who wants to be just like everyone else."
	Autism acceptance	"I don't subscribe to the harmful stigmas associated with autism nor am I very fond of them, mostly because they dehumanize individuals who, at the end of the day, are human. Yes, their cognitive processes may be different, but that doesn't necessarily make them any less intelligent or any more piteous than people without autism."
Representations of autism	Personal contact	"I think of two people from high school, one whom I was great friends with, and one that was seen as an outcast of sorts."
	Media	"The famous woman who is autistic who was known for building the cattle processing machine that became something used nationwide in many farms."

TABLE 4 Themes and subthemes within open-ended responses for schizophrenia labels, with text examples.

Theme	Subtheme	Quoted example from responses
Schizophrenia knowledge	Accurate knowledge of symptoms, cause, and prognosis	"Treatable psychological disorder with potential delusions and/or hallucinations."
	Misperceptions of symptoms and cause	"When I hear the word schizophrenic I think of someone who has multiple personalities but is highly intelligent at one specific topic/interest."
Attitudes toward SCZ	Understanding and empathy	"They are not mean, dangerous people, but people who need to be helped and treated the way everyone should be treated."
	Fear or perceived danger	"I think violent, unpredictable, and intelligent mainly."
	Prejudice toward mental illness	"My first thought is 'crazy'."
Representations of SCZ	Personal contact	"My uncle. He was the only person who I had regular interactions with and he was diagnosed with schizophrenia during adolescence."
	Media	"I think of the TV show Criminal Minds because one of the characters mothers has schizophrenia."
	Classroom exposure	"When I hear schizophrenic, I think of a mental disorder that I learned about in psychology."

Over time, increases in disclosure can demystify clinical conditions, facilitate personal exposure, and help reduce stigma (63), yet findings from this study underscore reasons people may be hesitant to disclose a schizophrenia diagnosis. Although misconceptions were common for both autism and schizophrenia, with wide variability in participant understanding and acceptance of autism, schizophrenia was uniquely characterized by misinformation concerning propensity for violence and disparaging comments about mental illness. This pattern was especially prevalent within the quantitative data, with participants reporting similar levels of pity, anger, and perceived dependency toward both autism and schizophrenia, but associating schizophrenia with significantly greater fear, perceived danger, untrustworthiness, and potential to harm children. Perceived danger, which is more frequently attributed to schizophrenia than other conditions (33), is a strong predictor of stigma (64)

TABLE 5 Themes and subthemes within open-ended responses for general clinical labels, with text examples.

Theme	Subtheme	Quoted example from responses
Clinical conditions	Psychological conditions	"Any diagnosis from a psychiatrist in regards to normal brain health, e.g., autism, schizophrenia, mania, manic depression, MDD, etc."
	Physical disabilities	"Possesses lacking physical capabilities that undermine normal bodily expression."
Symptoms or features	Impaired adaptive skills	"I think of a condition upon an individual that presents a disadvantage to them in social, academic, and work related contexts in comparison to other individuals."
	Cognitive difficulties	"Somebody who has an impairment that limits their ability to "normally" respond to stimulus around the world. This can mean somebody who doesn't understand others, or somebody who doesn't respond to situations "normally," whatever that could mean in some situation."
Clinical pathology	Causes	"Clinical diagnosis' in my opinion are the result of stressful events in collaboration with genes, thus both have a hand to play in the onset of many disorders, but not all."
	Treatment	"I think of a disorder that requires treatment of some sort in order for the individual to maintain homeostasis within the realms in their lives."
	Prognosis	"Is able to live a normal life depending on how they learn how to adapt."

and may underlie the persistent stigma attached to schizophrenia (65). Indeed, while overall prejudice did not differ significantly between conditions, participants were more hesitant to interact with a hypothetical person with schizophrenia than an autistic person, even for less intimate interactions. This is consistent with previous literature reporting greater social distance for schizophrenia than autism (30, 33), and highlights the need for improved education and targeted initiatives to counter stigma about schizophrenia (66).

This study has several limitations that should be considered when interpreting the findings reported here. Most notably, the sample—while large—consisted exclusively of university students, who generally are more inclusive and progressive about disability and mental health differences than the general population (67, 68). Participants were also racially diverse, and younger and more educated than the general population. Because schizophrenia is often diagnosed in early to mid-adulthood (57), while autism is typically diagnosed in childhood (69), it is possible that participants may have had less exposure to schizophrenia than autism. However, many participants in both the autism and schizophrenia conditions described personal contacts with both autistic people and people with schizophrenia, and literature suggests that reported contact with autistic people and people with schizophrenia may occur at similar rates in adults (33). Therefore, it is uncertain whether exposure to the two conditions may have impacted the reported findings. Participants were recruited through the university's psychology research pool, meaning that the majority of these individuals were actively enrolled in a psychology course and may have been exposed to ideas about autism and schizophrenia through their coursework. This may explain the unexpected, but relatively frequent references to autism and schizophrenia in responses to the control labels. Thus, the stigma reported here for autism and schizophrenia may not reflect stigma in the population more broadly, and may be a conservative estimate of stigma that would be found in a more representative sample.

While the current study was underpowered to test for differences based on participant age, it is possible that these results may not generalize to an older sample of raters, and future research should aim to characterize the effects of age on perceptions of autism and schizophrenia. Further, this study should not be taken as a comprehensive examination of attitudes and beliefs about autism and schizophrenia. Although the mixed method approach used here provided deeper and more nuanced information concerning the nature of stigma attributed to the two conditions, the measures used were limited, and the lack of inclusion of other clinical conditions precluded the opportunity to examine how autism and schizophrenia are perceived relative to other types of disability and conditions. A within-subjects comparison of quantitative and qualitative accounts of stigma toward these labels may offer greater clarity regarding the relationship between one's perceptions of a label and their associated social attitudes.

These limitations notwithstanding, the current study provides quantitative and qualitative evidence that attitudes about autism and schizophrenia vary widely among participants. Although many emphasized the importance of understanding, acceptance, and inclusion, negative attitudes and misinformation were also common. In particular, results indicated that schizophrenia remains a highly stigmatized condition, driven primarily by participants' beliefs concerning danger and fear that was not present in attitudes about autism. Countering these misconceptions, reducing stigma, and promoting inclusion should be important priorities for educators and clinical practitioners.

Data availability statement

The datasets presented in this study can be found in online repositories. The names of the repository/repositories and accession number(s) can be found below: https://osf.io/3k6zj/?view_only=681901d6f3f44de1a5da2f021ce4f41b.

Ethics statement

The studies involving humans were approved by the University of Texas at Dallas Institutional Review Board. The studies were conducted in accordance with the local legislation and institutional requirements. The participants provided their written informed consent to participate in this study.

Author contributions

DJ: Conceptualization, Formal analysis, Funding acquisition, Methodology, Visualization, Writing—original draft, Writing—review and editing. NS: Funding acquisition, Project administration, Resources, Supervision, Writing—review and editing, Writing—original draft.

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Conflict of interest

The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

Publisher's note

Supplementary material

The Supplementary Material for this article can be found online at: https://www.frontiersin.org/articles/10.3389/fpsyt.2023.1263525/full#supplementary-material

References

1. Goffman E. *Stigma: Notes on the Management of Spoiled Identity. Stigma: Notes on the Management of Spoiled Identity - Erving Goffman*. New Jersey: Prentice Hall (1963).

2. Frost DM. Social stigma and its consequences for the socially stigmatized. *Soc Pers Psychol Compass.* (2011) 5:824–39.

3. Herek GM, McLemore KA. Sexual prejudice. *Annu Rev Psychol.* (2013) 64:309–33. doi: 10.1146/annurev-psych-113011-143826

4. Araujo AGR, da Silva MA, Bandeira PFR, Gillespie-Lynch K, Zanon RB. Stigma and knowledge about autism in Brazil: a psychometric and intervention study. *Autism.* (2023) doi: 10.1177/13623613231168917. [Epub ahead of print].

5. Kim SY, Cheon JE, Gillespie-Lynch K, Kim YH. Is autism stigma higher in South Korea than the United States? Examining cultural tightness, intergroup bias, and concerns about heredity as contributors to heightened autism stigma. *Autism.* (2022) 26:460–72. doi: 10.1177/13623613211029520

6. Obeid R, Daou N, DeNigris D, Shane-Simpson C, Brooks PJ, Gillespie-Lynch KA. Cross-cultural comparison of knowledge and stigma associated with autism spectrum disorder among college students in Lebanon and the United States. *J Autism Dev Disord.* (2015) 45:3520–36. doi: 10.1007/s10803-015-2499-1

7. White D, Hillier A, Frye A, Makrez E. College students' knowledge and attitudes towards students on the autism spectrum. *J Autism Dev Disord.* (2019) 49:2699–705. doi: 10.1007/s10803-016-2818-1

8. Grossman RB. Judgments of social awkwardness from brief exposure to children with and without high-functioning autism. *Autism.* (2015) 19:580–7. doi: 10.1177/1362361314536937

9. Sasson NJ, Faso DJ, Nugent J, Lovell S, Kennedy DP, Grossman RB. Neurotypical peers are less willing to interact with those with autism based on thin slice judgments. *Sci Rep.* (2017) 7:40700. doi: 10.1038/srep40700

10. Morrison KE, DeBrabander KM, Faso DJ, Sasson NJ. Variability in first impressions of autistic adults made by neurotypical raters is driven more by characteristics of the rater than by characteristics of autistic adults. *Autism.* (2019) 23:1817–29. doi: 10.1177/1362361318824104

11. Kim SY, Song DY, Bottema-Beutel K, Gillespie-Lynch K, Cage E. A systematic review and meta-analysis of associations between primarily non-autistic people's characteristics and attitudes toward autistic people. *Autism Res.* (2023) 16:441–57. doi: 10.1002/aur.2867

12. Sasson NJ, Morrison KE. First impressions of adults with autism improve with diagnostic disclosure and increased autism knowledge of peers. *Autism.* (2019) 23:50–9. doi: 10.1177/1362361317729526

13. Thompson-Hodgetts S, Labonte C, Mazumder R, Phelan S. Helpful or harmful? A scoping review of perceptions and outcomes of autism diagnostic disclosure to others. *Res Autism Spectr Disord.* (2020) 77:101598.

14. Jones DR, DeBrabander KM, Sasson NJ. Effects of autism acceptance training on explicit and implicit biases toward autism. *Autism.* (2021) 25:1246–61. doi: 10.1177/1362361320984896

15. Jones DR, Morrison KE, DeBrabander KM, Ackerman RA, Pinkham AE, Sasson NJ. Greater social interest between autistic and non-autistic conversation partners following autism acceptance training for non-autistic people. *Front Psychol.* (2021) 12:739147. doi: 10.3389/fpsyg.2021.739147

16. Scheerer NE, Boucher TQ, Sasson NJ, Iarocci G. Effects of an educational presentation about autism on high school students' perceptions of autistic adults. *Autism Adulthood.* (2022) 4:203–13. doi: 10.1089/aut.2021.0046

17. Gillespie-Lynch K, Bisson JB, Saade S, Obeid R, Kofner B, Harrison AJ, et al. If you want to develop an effective autism training, ask autistic students to help you. *Autism.* (2022) 26:1082–94. doi: 10.1177/13623613211041006

18. Turnock A, Langley K, Jones CRG. Understanding stigma in autism: a narrative review and theoretical model. *Autism Adulthood.* (2022) 4:76–91. doi: 10.1089/aut.2021.0005

19. Botha M, Frost DM. Extending the minority stress model to understand mental health problems experienced by the autistic population. *Soc Ment Health.* (2020) 10:20–34.

20. Mitchell P, Sheppard E, Cassidy S. Autism and the double empathy problem: Implications for development and mental health. *Br J Dev Psychol.* (2021) 39:1–18. doi: 10.1111/bjdp.12350

21. Han E, Scior K, Avramides K, Crane L. A systematic review on autistic people's experiences of stigma and coping strategies. *Autism Res.* (2022) 15:12–26. doi: 10.1002/aur.2652

22. Bradley L, Shaw R, Baron-Cohen S, Cassidy S. Autistic adults' experiences of camouflaging and its perceived impact on mental health. *Autism Adulthood.* (2021) 3:320–9. doi: 10.1089/aut.2020.0071

23. Cook J, Hull L, Crane L, Mandy W. Camouflaging in autism: a systematic review. *Clin Psychol Rev.* (2021) 89:102080. doi: 10.1016/j.cpr.2021.102080

24. Sasson NJ, Pinkham AE, Carpenter KL, Belger A. The benefit of directly comparing autism and schizophrenia for revealing mechanisms of social cognitive impairment. *J Neurodev Disord.* (2011) 3:87–100. doi: 10.1007/s11689-010-9068-x

25. Angermeyer MC, Dietrich S. Public beliefs about and attitudes towards people with mental illness: a review of population studies. *Acta Psychiatr Scand.* (2006) 113:163–79. doi: 10.1111/j.1600-0447.2005.00699.x

26. Link BG, Phelan JC, Bresnahan M, Stueve A, Pescosolido BA. Public conceptions of mental illness: labels, causes, dangerousness, and social distance. *Am J Public Health.* (1999) 89:1328–33. doi: 10.2105/ajph.89.9.1328

27. Corrigan PW. The impact of stigma or severe mental illness. *Cogn Behav Pract.* (1998) 5:201–22.

28. Stuart H. Media portrayal of mental illness and its treatments: what effect does it have on people with mental illness? *CNS Drugs.* (2006) 20:99–106. doi: 10.2165/00023210-200620020-00002

29. Vahabzadeh A, Wittenauer J, Carr E. Stigma, schizophrenia and the media: exploring changes in the reporting of schizophrenia in major U.S. newspapers. *J Psychiatr Pract.* (2011) 17:439–46. doi: 10.1097/01.pra.0000407969.65098.35

30. Jensen CM, Martens CS, Nikolajsen ND, Skytt Gregersen T, Heckmann Marx N, Goldberg Frederiksen M, et al. What do the general population know, believe and feel about individuals with autism and schizophrenia: Results from a comparative survey in Denmark. *Autism.* (2016) 20:496–508. doi: 10.1177/1362361315593068

31. Corrigan PW, Watson AC. Findings from the National Comorbidity Survey on the frequency of violent behavior in individuals with psychiatric disorders. *Psychiatry Res.* (2005) 136:153–62. doi: 10.1016/j.psychres.2005.06.005

32. Choe JY, Teplin LA, Abram KM. Perpetration of violence, violent victimization, and severe mental illness: balancing public health concerns. *Psychiatr Serv.* (2008) 59:153–64. doi: 10.1176/ps.2008.59.2.153

33. Durand-Zaleski I, Scott J, Rouillon F, Leboyer M. A first national survey of knowledge, attitudes and behaviours towards schizophrenia, bipolar disorders and autism in France. *BMC Psychiatry.* (2012) 12:128. doi: 10.1186/1471-244X-12-128

34. Williams K, Foulser A, Tillman KA. Effects of language on social essentialist beliefs and stigma about mental illness. In: *Proceedings of the Annual Meeting of the Cognitive Science Society*, 44. (2022). Available online at: https://escholarship.org/uc/item/92m9h735

35. Angermeyer MC, Matschinger H. The stigma of mental illness: effects of labelling on public attitudes towards people with mental disorder. *Acta Psychiatr Scand.* (2003) 108:304–9. doi: 10.1034/j.1600-0447.2003.00150.x

36. Hori H, Richards M, Kawamoto Y, Kunugi H. Attitudes toward schizophrenia in the general population, psychiatric staff, physicians, and psychiatrists: a web-based survey in Japan. *Psychiatry Res.* (2011) 186:183–9. doi: 10.1016/j.psychres.2010.08.019

37. Kenny L, Hattersley C, Molins B, Buckley C, Povey C, Pellicano E. Which terms should be used to describe autism? Perspectives from the UK autism community. *Autism.* (2016) 20:442–62. doi: 10.1177/1362361315588200

38. Taboas A, Doepke K, Zimmerman C. Preferences for identity-first versus person-first language in a US sample of autism stakeholders. *Autism.* (2023) 27:565–70. doi: 10.1177/13623613221130845

39. Kite DM, Gullifer J, Tyson GA. Views on the diagnostic labels of autism and Asperger's disorder and the proposed changes in the DSM. *J Autism Dev Disord.* (2013) 43:1692–700. doi: 10.1007/s10803-012-1718-2

40. Jensen ME, Pease EA, Lambert K, Hickman DR, Robinson O, McCoy KT, et al. Championing person-first language: a call to psychiatric mental health nurses. *J Am Psychiatr Nurses Assoc.* (2013) 19:146–51. doi: 10.1177/1078390313489729

41. Mizock L, Dilts G, Sotilleo E, Cherry J. Preferred terminology of people with serious mental illness. *Psychol Serv.* (2022) doi: 10.1037/ser0000717. [Epub ahead of print].

42. Granello DH, Gorby SR. It's time for counselors to modify our language: it matters when we call our clients schizophrenics versus people with schizophrenia. *J Counsel Dev.* (2021) 99:452–61.

43. Gernsbacher MA. Editorial perspective: the use of person-first language in scholarly writing may accentuate stigma. *J Child Psychol Psychiatry.* (2017) 58:859–61. doi: 10.1111/jcpp.12706

44. Fernandes PT, de Barros NF, Li LM. Stop saying epileptic. *Epilepsia.* (2009) 50:1280–3. doi: 10.1111/j.1528-1167.2008.01899.x

45. Noble AJ, Marson AG. Should we stop saying epileptic? A comparison of the effect of the terms epileptic and person with epilepsy. *Epilepsy Behav.* (2016) 59:21–7. doi: 10.1016/j.yebeh.2016.03.016

46. Masland SR, Null KE. Effects of diagnostic label construction and gender on stigma about borderline personality disorder. *Stigma Health.* (2022) 7:89–99.

47. Wilkinson G. *Wide Range Achievement Test 3 (WRAT3)*. Wilmington, DE: Wide Range Inc (1993).

48. Gillespie-Lynch K, Brooks PJ, Someki F, Obeid R, Shane-Simpson C, Kapp SK, et al. Changing college students' conceptions of autism: an online training to increase knowledge and decrease stigma. *J Autism Dev Disord.* (2015) 45:2553–66. doi: 10.1007/s10803-015-2422-9

49. Botha M, Cage E. Autism research is in crisis: A mixed method study of researcher's constructions of autistic people and autism research. *Front Psychol.* (2022) 13:1050897. doi: 10.3389/fpsyg.2022.1050897

50. Crompton CJ, Hallett S, Ropar D, Flynn E, Fletcher-Watson S. 'I never realised everybody felt as happy as I do when I am around autistic people': A thematic analysis of autistic adults' relationships with autistic and neurotypical friends and family. *Autism.* (2020) 24:1438–48. doi: 10.1177/1362361320908976

51. Braun V, Clarke V. *Thematic analysis: a practical guide*. London: Sage (2022) 1.

52. Braun V, Clarke V. Using thematic analysis in psychology. *Qual Res Psychol* (2006) 3.

53. Provalis Research. *QDA Miner. Provalis Research.* (2020).

54. Bottema-Beutel K, Kapp SK, Lester JN, Sasson NJ, Hand BN. Avoiding ableist language: suggestions for autism researchers. *Autism Adulthood.* (2021) 3:18–29. doi: 10.1089/aut.2020.0014

55. Beresford P. 'Mad', Mad studies and advancing inclusive resistance. *Disabil Soc* (2020) 35:1337–42.

56. Botha M, Hanlon J, Williams GL. Does language matter? identity-first versus person-first language use in autism research: a response to Vivanti. *J Autism Dev Disord.* (2023) 53:870–8. doi: 10.1007/s10803-020-04858-w

57. Saha S, Chant D, Welham J, McGrath J. A systematic review of the prevalence of schizophrenia. *PLoS Med.* (2005) 2:e141. doi: 10.1371/journal.pmed.0020141

58. Zeidan J, Fombonne E, Scorah J, Ibrahim A, Durkin MS, Saxena S, et al. Global prevalence of autism: A systematic review update. *Autism Res.* (2022) 15:778–90. doi: 10.1002/aur.2696

59. Shaw KA, Bilder DA, McArthur D, Williams AR, Amoakohene E, Bakian AV, et al. Early identification of autism spectrum disorder among children aged 4 years - autism and developmental disabilities monitoring network, 11 sites, United States, 2020. *MMWR Surveill Summ.* (2023) 72:1–15. doi: 10.15585/mmwr.ss7201a1

60. Grinker RR. Autism, "stigma," disability a shifting historical terrain. *Curr Anthropol.* (2020) 61:S55–S67.

61. Love AMA, Edwards C, Cai RY, Gibbs V. Using experience sampling methodology to capture disclosure opportunities for autistic adults. *Autism Adulthood.* (2023). [Epub ahead of print].

62. Hampson ME, Watt BD, Hicks RE. Impacts of stigma and discrimination in the workplace on people living with psychosis. *BMC Psychiatry.* (2020) 20:288. doi: 10.1186/s12888-020-02614-z

63. Rüsch N, Kösters M. Honest, open, proud to support disclosure decisions and to decrease stigma's impact among people with mental illness: conceptual review and meta-analysis of program efficacy. *Soc Psychiatry Psychiatr Epidemiol.* (2021) 56:1513–26. doi: 10.1007/s00127-021-02076-y

64. Gillespie-Lynch K, Daou N, Obeid R, Reardon S, Khan S, Goldknopf EJ. What contributes to stigma towards autistic university students and students with other diagnoses? *J Autism Dev Disord.* (2021) 51:459–75. doi: 10.1007/s10803-020-04556-7

65. Corrigan PW, Rowan D, Green A, Lundin R, River P, Uphoff-Wasowski K, et al. Challenging two mental illness stigmas: personal responsibility and dangerousness. *Schizophr Bull.* (2002) 28:293–309. doi: 10.1093/oxfordjournals.schbul.a006939

66. Morgan AJ, Reavley NJ, Ross A, Too LS, Jorm AF. Interventions to reduce stigma towards people with severe mental illness: Systematic review and meta-analysis. *J Psychiatr Res.* (2018) 103:120–33. doi: 10.1016/j.jpsychires.2018.05.017

67. Campbell C, Horowitz J. Does college influence sociopolitical attitudes? *Sociol Educ.* (2016) 89:40–58.

68. Scior K. Public awareness, attitudes and beliefs regarding intellectual disability: a systematic review. *Res Dev Disabil.* (2011) 32:2164–82. doi: 10.1016/j.ridd.2011.07.005

69. American Psychiatric Association. *Diagnostic and statistical manual of mental disorders: DSM-5 [Internet]*. Washington, D.C: American Psychiatric Association (2013).

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Reducing stigma toward autistic peers: a pilot investigation of a virtual autism acceptance program for children

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Inclusive educational practices can be beneficial for autistic children, especially when the general education classroom can better meet the child's academic and socio-emotional needs than a special education classroom. Unfortunately, autistic children may not thrive in general education classrooms if they are perceived negatively, subject to bullying, and are socially isolated and rejected by their typically developing peers. Autism acceptance programs may help address the root cause of these problems, autism stigma. Thus, this study evaluated the effectiveness of a virtual autism acceptance program presented to typically developing, 8–10-year-old children through remote learning technology. The 5-week, stakeholder-approved pilot program included a themed module each week (e.g., facts about autism and reducing stigma, sensory sensitivities, strengths of those with autism) presented through a variety of online educational materials. Pretest, posttest, and maintenance results showed that the program was effective in improving children's knowledge about autism, and children's attitudes and behavioral intentions toward their peers with autism. In addition to reducing autism stigma, study findings suggest that remote learning and virtual tools can be used to implement an efficacious autism acceptance program to children, allowing for greater and more cost-effective outreach to children and schools.

KEYWORDS

autism, autism acceptance, stigma, remote learning, typically developing children, inclusive education, elementary school

Introduction

The prevalence of autism spectrum disorder or ASD, and its broad range of abilities and impairments (1, 2), present unique challenges to educational systems. This is especially true as the number of children with ASD, henceforth identified as autistic children using identity-first language, in general education settings has grown substantially over the past two decades (3–5). In the United States, this increase was due in part to the passing of the Individuals with Disabilities Education Act (6) and the No Child Left Behind Act (7) that mandated that children with disabilities, including autism, receive an education in the least restrictive environment to the maximum extent possible (8). This increase has also been a response to study findings showing that for a significant number of autistic children with average to above average intellectual ability, special education classrooms did not meet their educational or social–emotional needs (9, 10).

Benefits and costs of general education placement

Significant benefits of inclusive education for autistic children include increased instructional opportunities and the chance to develop age-appropriate and normalized academic skills, expanded opportunities to develop peer relations and enhanced socio-emotional functioning (9, 11, 12). For example, studies have shown that autistic children in general classroom settings exhibit significant improvements in academic achievement (e.g., math, language arts) when compared to their peers in more restrictive, specialized classroom settings (11, 13). Additionally, inclusion in general education classrooms can lead to improved social and emotional functioning in autistic children because it increases children's opportunities to interact with their typically developing peers and develop social skills in a classroom setting (14). Equally important, typically developing children benefit from having autistic children in the classroom as it can promote better understanding, knowledge, and appreciation of those with autism as well as other children who may be different from them (12, 15). For example, Noggle and Stites (16) followed three typically developing children for 1 year who were in inclusive preschool programs with at least 40% of the children in the classroom with special needs. All three children showed growth in social skills, improved understanding of human variability, and better acceptance of their peers with disabilities. The parents of one child reported that their child talked extensively about spending time with a visually impaired friend and another child learned that it was possible, and enjoyable, to play a game with someone with limited verbal abilities.

Inclusive education may also reduce stigma, including "autism stigma." According to Link and Phelan (17) seminal model of stigma, the development of stigma derives from the culturally driven detection and labeling of a difference between groups (e.g., non-autistic versus autistic). That is, perceived differences and an unfavorable distinction between groups can lead to negative labeling, social exclusion, and discrimination of a group (18).

Importantly, research on "autism stigma" suggests that contact with autistic people can reduce the stigma associated with autism. In adults, several studies have shown that knowing someone with autism was associated with more positive attitudes toward autism (19, 20), although the quantity and quality of the interactions mattered (18). In children, while inclusive educational practices may promote better attitudes between those with and without autism, inclusive educational practices alone may not be enough to ensure that an autistic child will thrive in a general education classroom (21, 22). In elementary school settings, parent and teacher reports show that autistic children are significantly more likely to be perceived negatively, be bullied through verbal and physical confrontations, and be socially isolated at school than their typically developing classmates [e.g., (23–28)]. It has been suggested that bullying and other inappropriate behaviors occur because autism is a "hidden disability." Lacking physical differences, typically developing peers may struggle to understand or emphasize with social and behavioral differences, making autistic children more susceptible to social rejection in and out of the classroom (29).

A lack of understanding toward their autistic peers may occur because typically developing children lack knowledge about autism. Studies have shown that typically developing children are often unable to define autism accurately and may hold erroneous beliefs about autism. For example, they may believe that autism is contagious or that all autistic people are the same (30–32). Additionally, they are often unaware of the challenges autism might pose for a child, including social-communicative issues (e.g., difficulty maintaining eye contact, the use of pedantic speech) and the sensory sensitivities associated with autism (8, 30). As Hebron et al. (33) note, behaviors of autistic students are often misconstrued by their peers in the classroom, with either negative attributions made about these behaviors or the belief that the behaviors of autistic students are fully within their control.

Thus, it is theorized that negative peer relationships in the classroom are due to the reciprocal effects of challenges associated with autism (e.g., social communication difficulties) *and* the lack of knowledge and understanding on the part of their typically developing peers that leads to autism stigma. According to the reciprocal effects peer interaction model (REPIM), a lack of understanding about autism, reduced acceptance of differences, and limited opportunities to learn about autism all contribute to bullying and social exclusion of autistic children and devalue the benefits of inclusive education for them (34).

The case for autism acceptance programs

In line with the REPIM approach, we believe that negative stigma and inappropriate behaviors toward autistic children in general education classrooms can be lessened through an efficacious autism acceptance program. Autism acceptance programs vary in formats and materials [see (21), for a review]. Most include an educational component to increase children's knowledge about autism and an attitudinal component to address negative beliefs about autism [e.g., (8, 31, 32)]. For example, Campbell et al. (30) found that a single presentation of autism awareness materials led to improvements in 9- and 10-year-old children's knowledge about autism at posttest and again 1 week later. Their program also led to improvements in children's attitudes about autism, particularly for those children with little or no knowledge about autism before the start of the session. However, Cremin et al. (21) note that apart from a handful of studies, autism acceptance programs are often plagued by the lack of theoretical grounding, the narrow or brief implementation of educational materials, and the lack of empirical assessment of children's learning.

Thus, our goal in the present study was to address these limitations through the pilot implementation of a 5-week autism acceptance program that made comprehensive use of educational materials organized into five themed modules. Each module was designed to increase children's knowledge about autism and improve their attitudes toward autistic peers. According to attitude change theory, increasing knowledge and improving attitudes toward a group not only results in less stigma toward a group but is essential for improving behavioral intentions and ultimately, behaviors toward others (35–37). This is also consistent with theories on stigma that assert that stigma toward a group is due to problems of knowledge (e.g., ignorance), negative attitudes (e.g., stereotypes), and discriminating behaviors (18). Simply put, this pilot program aims to provide a practical application of addressing stigma by increasing autism acceptance from non-autistic peers.

The present study

The autism acceptance program was created for this study and implemented during the pandemic (Fall, 2020) to typically developing 3rd and 4th grade children. All program materials were approved by stakeholders (i.e., parents of autistic children, autistic adults) and targeted children's knowledge about autism, and their attitudes and behavioral intentions toward autistic peers. To our knowledge, a completely virtual autism acceptance program, with all materials shared remotely by the facilitators, had not been developed nor assessed prior to this study.

Research questions and aims were as follows:

(1) Can a virtual autism acceptance program lead to significant gains in children's learning about autism, and maintenance of that learning, between pretest, posttest, and maintenance time points? Additionally, is there evidence that participating in the program leads to a reduction of autism stigma by promoting positive attitudes and behavioral intentions toward autistic children? It is expected that participation in the autism acceptance program will lead to increased knowledge about autism and more positive attitudes and behavioral intentions toward autistic children.

(2) Do children show learning of the information from each of the themed modules (e.g., facts about autism, strengths of autistic individuals, sensory sensitivities)? It is predicted that children should be able to learn from each of the modules equally well.

(3) Do study results show that a virtual autism acceptance program can be implemented successfully and be viewed favorably by children and school staff? That is, does the program show adequate feasibility (e.g., adherence to guidelines, attendance, lack of substantive problems) and acceptability (i.e., favorable perceptions from children and the teacher)? It is expected that the autism acceptance program can be implemented successfully through a virtual platform (Zoom).

Methods

Participants

Twenty-three typically developing children ($M_{age} = 8;09$, $SD = 0;08$, age range: 8 years; 02 months – 10 years; 07 months,) attending a private elementary school in a large city in the Midwest region of the U.S. participated. Children (18 males; 5 females) were in a hybrid classroom during the Covid-19 pandemic (Fall, 2020). With social distancing and mask policies in place, children at the school had the option of going into the classroom ($n = 17$) or engaging in remote learning from home ($n = 6$). Both 3rd ($n = 13$) and 4th ($n = 10$) grade children were combined in the classroom, given the small size of each grade at the school. In terms of race/ethnicity, approximately 87% were Latino/a, 10% were White or European American and 3% were Asian American or other. There no significant differences ($p > 0.05$) between students who chose in-person instruction at their school and students who participated in remote home learning in terms of age, race, or gender. All children in the classroom were fluent in English, as reported by the teacher. The teacher of the classroom regularly taught 3rd and 4th grade. She had been an elementary school teacher for 31 years and had taught all grades between pre-kindergarten through fifth grade, with the exception of kindergarten. The teacher was white and identified as cisgender female. She reported that she occasionally taught a classroom with an autistic child, but that none of the children in her current classroom were autistic. The latter point was supported by parent report and confirmed by the school. On the parent permission letter, parents were asked whether their child had been diagnosed with autism or had other special education needs. They were also asked about their children's exposure to autistic individuals and to describe the contact. According to the parents, none of the children had been previously diagnosed with autism or had other special education needs. Moreover, none of the children in the program had an Individualized Education Plan (IEP). The IEP is a written plan that specifies educational goals and services that a child with a disability requires in order to succeed in school.

Although over half of the children reported that they had heard of the word "autism" (57%) at pretest, none mentioned having any experiences with autistic children. Parent reports included as part of the parent permission letter confirmed children's responses. When asked about their children's exposure to autistic children or adults, none of the parents reported that their children knew an autistic child or autistic adult in any immediate capacity (e.g., family member, friend, current or former classmate). We saw no change in the parents' responses about their children exposure 1 year later in the parent permission letter completed for the maintenance condition.

In the pretest and posttest conditions, $N = 23$ was obtained following the removal of the data from three children who had significant missing data due to absences. Eighty percent ($n = 18$) of the children participated in the maintenance condition. Of those children not participating, two were no longer at the school, two did not turn in a parent permission slip, and one child was absent on the day of testing.

Materials

Autism acceptance program

Our virtual autism acceptance program consisted of five module sessions, each covering a different theme related to autism. The themes were (1) introducing the facts about autism and reducing autism stigma, (2) learning about the strengths of autistic peers, (3) understanding similarities and differences between typically developing and autistic children, (4) exploring the sensory world of autistic children, and (5) promoting kindness and friendship among typically developing and autistic children. These themes were selected with the goal of improving attitudes and behavioral intentions toward autistic peers. Previous research has suggested that educational components such as these can reduce autism stigma (18, 21). Each of the 5 weekly module sessions were approximately 35 min ($SD = 33–37$ min) in length.

Table 1 shows a more detailed description of the five modules, their goals and the activities presented in each module. All program materials and learning formats were implemented virtually and included online educational materials (videos and workbooks) available at https://researchautism.org/education/students-corner/kit-for-kids/#activitya, brief PowerPoint presentations, classroom discussions, interactive activities and public domain videos (e.g.,

TABLE 1 **Themes, activities and videos for each of the five weekly autism acceptance modules.**

Module	Goals for module	Worksheet activities/*Kit for Kids (KfK)*	PowerPoint presentations/ classroom discussion	*Autism Tuned In Videos*	YouTube videos
Module 1: "*Facts about Autism and Reducing Stigma*"	• Introductions • Overview of the program • Present facts about autism	• Children completed workbook p. 1–4 (KfK)	• Facts about autism • Discussion: Common misperceptions about autism.	*"Everyone is Unique"*; *"What Does That Mean?"*	"*Autism Explained*"
Module 2: "*Learning about Autism*"	• Learn about an autistic peer (Nick) focusing on his strengths	• Reading"*What's up with Nick?*" booklet • Workbook "*What's up with Nick?*"	• Discuss strengths of Nick and others with autism	*"What's Up with Nick?"*	"*A Sibling Story*"
Module 3: "*Similarities and Differences*"	• Embracing similarities and accepting differences between all children • Understanding the challenges of autism	• Activity: How are you similar or different from another? • Understanding how autistic peers are the same/different	• Brief PowerPoint presentation on topic • Children share likes and dislikes • Discussion: embracing differences between themselves and a friend or family member	"*Differences Are Ok*"; "*Get into the Act*"; "*Tuned in Together*"	
Module 4: "*Exploring Our Senses*"	• Exploring the sensory world of autistic children • Discuss sensory sensitivities	• Activity: Children share examples of sensory experiences they like and dislike. • Workbook p. 6–8	• Brief PowerPoint presentation on topic • Discussion: sensory world of autistic children	"*Spring into Action*"; "*Make it Better*"	"*Can you Make it End?*"; "*The Sensory Room: Helping Students with Autism Focus*"
Module 5: "*Encouraging Kindness*"	• Promote kindness and encourage friendship with autistic peers	• How to be a friend activity. • Workbook p. 9	• Brief PowerPoint presentation on topic. • Students share ideas about how to be friends with an autistic peer	"*Let us Be Friends*"	"*Do all autistic people think the same?*"

Information about access to Organization Autism Research (OAR) videos is on their website. All links to YouTube videos available from the first author. KfK: Kit for Kids (2021) materials and workbooks available on OAR website.

YouTube Kids). Videos matched the theme of the module and included, but were not limited to, one written and narrated by autistic children, another consisting of interviews with autistic children, adolescents and adults, a video dramatization of an autistic child experiencing sensory overload in a shopping mall setting (e.g., bright lights, loud music) and a video showing the calming benefits of a "sensory room" being implemented at an elementary school.

All educational materials used in the program were reviewed by 10 unpaid adult stakeholders before implementation. Four stakeholders were recruited from personal connections that included family and friends who are parents of autistic children ($n=2$) or are autistic adults ($n=2$). Six stakeholders were recruited from social media accounts (i.e., Instagram) with no personal connection to the researchers. Two were autistic adults and four were parents of autistic children. Stakeholders were sent an email or direct message briefly explaining the autism acceptance program, asking them if they would provide input on the program. If they responded affirmatively, an email was sent with a link to the videos and attachments of the documents used during the modules. Two stakeholders reviewed the materials of one module, with the modules randomly assigned. Stakeholders were asked to provide brief written comments via email and to determine whether any of the materials used in a module (e.g., videos, PowerPoint presentation, interactive activity worksheets) were unacceptable or needed revising. Based on their feedback, minor revisions were made to various documents (e.g., an activity worksheet) and one video was dropped from the program because several felt it did not differ sufficiently from the other videos shown in that module.

Measures

Autism knowledge measure

A paper and pencil "Autism Knowledge" questionnaire was constructed and included five different categories of questioning (see Table 2). This measure was adapted from the Knowledge of Autism scale (KOA) (39), although several changes were made. For example, on the KOA, children are asked true or false whether autistic students "cannot do normal activities that other people can do." To reduce reliance on true/false questioning and to be more in alignment with our program, this question was changed to read "*What are some things a child with autism might do or feel?*" with five statements following it such as "*A child with autism can be bothered by lights or sounds.*" Children were asked to put a check mark next to those statements that were correct. Statements following each question were either correct or were incorrect foils (e.g., "*A child with autism is usually very* *funny*."). In some cases, children were asked whether they agreed or disagreed with a statement (e.g., I do not know what a child with autism can do.") by placing a check mark next to it if they agreed (see Table 2).

Additionally, children were given one open-ended question, "*Can you tell me what you think "autism" is in the space below? If you do not know, please tell me that*." Children's responses to this question were scored by two independent coders as "correct" or "incorrect." Children had to give one to two characteristics about autism for their answers to be coded as correct. For example, one fourth-grade child wrote, "They have a hard time with eye contact and sometime rock in class." Incorrect responses were almost always due to children not answering it or writing, "I do not know.," although a few children gave incorrect characterizations (e.g., "They are sad.").

This measure served as a baseline (pretest), posttest and a maintenance measure. Cronbach's alpha conducted on the data from the Autism Knowledge measure at pretest ($\alpha = 0.81$), posttest ($\alpha = 0.90$) and maintenance ($\alpha = 0.79$) timepoints showed good reliability across the sample.

Module assessments

The researchers created five paper and pencil questionnaires in order to assess children's learning of information from each of the five modules (see Table 3). Questions were following by three to six statements that children had to decide were correct or incorrect. Specifically, children were asked to check all correct responses from an array of correct and incorrect (foils). Cronbach's alpha on the module assessments data ranged from adequate to good, $\alpha = 0.77–0.90$.

Feasibility and acceptability measures

A senior-level undergraduate student recorded how many children were in attendance and how often they participated in the activities at each session. She also kept track of technological difficulties and how much time each session took. After each session, the undergraduate student and the facilitators completed a checklist regarding how well they thought the various activities used in that day's session (module) were carried out. All of these activities comprised the feasibility measure. Acceptability was gauged with 3 to 4 item paper and pencil feedback questionnaires for each module. Children assessed how well they liked different activities during each module and, once completed, the program as a whole. Children were asked to respond using 3-point Likert scales with 1 = *did not like at all*, 2 = *liked somewhat*, and 3 = *liked a lot*. Children were also asked to rate the activities they liked the best and least from the program. Using a 16-item paper and pencil questionnaire, the teacher was asked to provide feedback on the individual modules, different activities of the program, and the program as a whole. She was also given space to provide open-ended feedback.

Procedure

Prior to the start of the study, all program materials and activities were reviewed and approved by the Institutional Review Board at the authors' university. Informed written consent from the school principal, classroom teacher, and parents, and verbal assent from the children were also obtained prior to the start of the program. One week before the program began, children were given the baseline assessment (pretest) to assess children's knowledge and attitudes (stigma) about autism.

Program facilitators (first and second author) were from a psychology department and included a faculty member and a doctoral student. An advanced undergraduate student completed the feasibility questions as described above. All were online at each autism acceptance session. For each of the five module sessions, the following protocol of activities was used: (1) greetings and the collecting of verbal assents, (2) a review of the previous module's material and introduction of the current module's theme through brief PowerPoint presentations and interactive activities, (3) playing videos that matched the theme of the module, (4) worksheet activities with follow-up discussions, and (5) a closing review of the module. Within 24 h after the module ended, the teachers were asked to provide the Module Assessment.

Although children were provided with a PowerPoint review of the previous week's material, children were not given direct feedback on their individual assessments from the modules. That is, the module assessments were not corrected and returned to the children. Moreover, no feedback was given on the pretest or the posttest questions and statements, in order to protect against children simply remembering how they had responded in the past.

The homeroom teacher was present at all sessions, during which time she connected to us via our Zoom link and made sure our program was broadcast to the classroom via a Smartboard (a large, projector-type screen). She also provided the link to the at-home children and their parents so that they could join from home. Due to the COVID-19 pandemic, all program activities were presented online, and hard copies of assessment tools (i.e., module learning and feedback forms) were delivered to a drop box outside the main office of the school because individuals not affiliated with the school were not allowed in-person visits.

Based on the instructions provided by the researchers, the teacher made sure that the children completed a module learning assessment within 24 h after each module was presented. At the same time, children completed a feedback form that gauged how much they liked specific activities (e.g., interactive activities, videos) from the module. After the final session, children completed an overall assessment (posttest) and the feedback form about the program. In the maintenance condition implemented 1 year later, children completed the posttest again and the behavior intention measure. After the initial posttest, children were given a gift bag that included a certificate of completion, school supplies and a book about autism, chosen by each child from a list of award-winning children's books on autism. Children were also given a small giftbag of school supplies following the maintenance condition.

Data analytic plan

All data analyses were conducted using IBM SPSS v28 (Chicago, IL). Cochran's Q tests were used to assess the first research question (Research Aim 1), "Can a virtual autism acceptance program lead to significant gains in children's learning about autism, and improvement in children's attitudes toward those with autism, from pretest to posttest and maintenance time points?" Significant findings were followed up with Dunn's procedure with Bonferroni correction to control for Type 1 error.

TABLE 2 Percentage of correct responses between pretest, posttest, and maintenance.

Question	Pretest% correct	Posttest % correct	Maintenance % correct	Cochran's Q		*Post hoc*			
				χ^2	p	Pr-Po	Pr-M	Po-M	η^2
1. General knowledge									
Have you heard of the word autism before?[a]	59%	–	–	1.32	0.250				
Can you tell me what you think autism is…	8%	73%	61%	13.00	0.002	0.562*	0.625**	0.063	0.28
Can you catch autism from another child like a cold?	76%	96%	94%	1.60	0.449	-	-	-	0.03
Do you think children with autism look different?	44%	59%	78%	2.60	0.273	–	–	–	0.05
Are all kids with autism the same?	72%	91%	100%	5.20	0.740	–	–	–	0.11
2. What are some things a child with autism might do?									
…can do well in school	44%	82%	89%	6.89	0.032	0.312	0.375*	0.062	0.15
…can be bothered by lights or sounds	68%	91%	100%	7.60	0.022	0.187	0.312**	0.125	0.17
…may find it hard to talk to you	76%	77%	89%	1.00	0.607	–	–	–	0.02
…may find it hard to make eye contact with you	68%	91%	94%	6.00	0.050	–	–	–	0.13
…I do not know what a child with autism can do	40%	100%	83%	9.25	0.010	0.438*	0.250	−0.187	0.20
3. Please tell me some other things a child with autism might do or be like									
…can be friendly	56%	91%	94%	9.00	0.011	0.375*	0.375*	0.000	0.20
…can be fun to be around	40%	96%	94%	10.89	0.004	0.437**	0.437**	0.000	0.23
…can be mean and difficult to be around	64%	73%	72%	2.00	0.368	–	–	–	0.04
…is usually very funny[b]	76%	36%	22%	10.8	0.005	0.001	−0.562*	−0.562*	0.23
4. What are some strengths or good things about having autism?									
…can often remember details well	20%	82%	72%	15.17	<0.001	0.562**	0.625***	0.063	0.33
…may be honest and direct when he or she speaks to you	52%	64%	72%	6.55	0.038	0.375	0.375	0.000	0.14
…can be smart	40%	82%	83%	9.50	0.009	0.500**.	437*	0.062	0.20
…will know lots of languages besides English[b]	72%	68%	67%	0.600	0.741	–	–	–	0.01
5. Friendships with children with autism									
Can you be friends with someone with autism?	88%	100%	100%	6.00	0.050	–	–	–	0.13
Can a child with autism be a good friend?	48%	96%	83%	11.40	0.003	0.437**	0.500**	0.063	0.25
Would you like to be friends with a child with autism?	76%	100%	100%	8.00	0.018	0.250	0.250*	0.000	0.17

Pr, pretest; Po, posttest; M, maintenance. [a]This question was only asked during pretest. [b]Questions were asked as foils. *$p < 0.001$, **$p < 0.002$. Bonferroni corrected error rate across all experiment-wise comparisons is $p < 0.002$. η^2 = eta squared, maximum-corrected measure of effect size (38). For section 5, at pretest and posttest $n = 22$ and $n = 17$ at maintenance.

TABLE 3 Assessment of children's retention from modules 1–5.

Topics and items	% Agree	% Disagree	One-way χ^2	p	Φ
Module 1: challenges associated with autism					
Sometimes makes noises in the classroom	82.4%	17.6%	7.12	0.001	0.65
Likes to sing and dance*	11.8%	88.2%	9.94	0.020	0.76
Needs to take a break in class	82.4%	17.6%	7.12	0.008	0.65
May rock back and forth	63.0%	37.0%	4.12	0.050	0.49
May flap arms	94.1%	5.9%	13.25	<0.001	0.88
May get up and do jumping jacks*	37.0%	63.0%	4.12	0.050	0.65
Likes to hit others*	18.8%	81.0%	6.25	0.010	0.61
Module 2: strengths associated with autism ($n = 21$)					
May speak directly and honestly with you	52.9%	64.7%	0.059	0.810	0.06
Can be a good friend	70.6%	29.4%	4.88	0.050	0.53
Might know a lot on a particular topic	76.5%	23.5%	4.77	0.030	0.53
Can be really mean*	11.8%	88.2%	9.94	0.002	0.76
Can be smart and do well in school	82.4%	17.6%	3.87	0.050	0.48
Might know a lot on a topic	64.3%	35.3%	1.47	0.230	0.29
Module 3: similarities and differences between children					
All children are similar and different from each other	78.0%	23.0%	7.12	0.008	0.63
Children with ASD only have things in common with other children with ASD*	11.1%	88.9%	10.89	0.001	0.78
Children with ASD can be both similar and different to others	66.7%	33.3%	14.22	0.001	0.89
Module 4: sensory experiences associated with autism					
Children with ASD experience sensory input the same as others*	26.0%	74.0%	4.84	0.050	1.18
A child with ASD may get upset by regular sounds.	53.3%	46.7%	2.73	0.100	0.43
Child with ASD can be overly-sensitive to sensory stimuli (e.g., smells, sights)	86.8%	13.3%	8.07	0.010	0.67
To a child with ASD, a smell may be bothersome…	80.0%	20.0%	5.40	0.020	0.67
Normal sounds can be too loud or annoying to a child with ASD	93.3%	6.7%	11.27	0.001	0.75
To a child with ASD, a normal light might be too bright	93.3%	6.7%	11.27	0.001	0.28
A child with ASD may be really bothered by "outdoor voices" when inside	86.7%	13.3%	8.07	0.005	0.63
It would be best to use indoor voices as children with ASD as they would be less bothered…	93.3%	6.7%	11.27	0.001	0.89
It is best to keep your hands to yourself with children with ASD…	93.3%	6.7%	11.27	0.001	0.002
Module 5: what would a good friend do? ($n = 22$)					
Ignore someone who is different*	95%	5%	16.20	<0.001	0.64
Ask someone what they like to do	100%	0%	–	–	–
Listen when someone is talking	95%	5%	16.20	<0.001	0.64
Make a face if someone acts different*	100%	0%	–	–	–

*Items used as foils to assess bias toward agreement in responding. Φ = Phi measure of effect size. Unless otherwise noted, $N = 23$.

To address our second research question examining whether children retained the material from the modules (Research Aim 2), one-way chi-square analyses were performed on children's responses from the individual module (1–5) assessments. Of interest was whether children were able to identify correct and incorrect statements in the assessment following each module. Finally, we addressed our third research aim and its questions regarding feasibility (i.e., Can a virtual program be implemented successfully?) and acceptability (i.e., Will children and the classroom teacher view the virtual program favorably?). In addition to children's learning, we also used positive change in attitudes and behavioral intentions as evidence of a reduction of autism stigma and as a way to judge the efficacy of the program.

No significant differences were found between children who connected with us remotely while in the classroom or at home. Therefore, the results reflect the aggregate analyses of responses. At the maintenance time point 1 year later, only 16 children (70%) participated. Two children were no longer at the school, three children were absent on the day of testing, and two children did not return a parent permission slip.

Results

Pretest, posttest, and maintenance assessment

In order to assess children's learning about autism and improvements in attitudes toward their autistic peers from pretest, posttest and maintenance time points (i.e., Research Aim 1), children were asked questions across the five module themes: (1) general knowledge ("*Can you tell me what you think autism is?*," "*Can you catch autism from another child like a cold?*"), (2) information about what an autistic child might do or be like (e.g., "*An autistic child can do well in school.*"), (3) strengths about autism (e.g., "*Can often remember details well.*," "*May be honest and direct when he or she speaks to you?*), (4) sensory sensitivities (e.g., "*An autistic child can be bothered by lights or sounds.*"), and (5) developing friendships with children with autism (e.g., "*Can a child with autism be a good friend?*," "*Would you like to be friends with a child with autism?*"). Table 2 presents the results of these analyses across time points including percentages of correct responses, *p*-values, *post hoc* analyses, and effect sizes.

As shown in Table 2, children exhibited learning of program material by responding more accurately at posttest and maintenance time points than at pretest. Children showed that they learned information from all five modules (see Table 2). However, the greatest increases in children's learning included general knowledge about autism [e.g., "*Can you tell me what autism is?*," $\chi^2(2) = 13.00$, $p = 0.002$, 8, 73, 61% pretest, posttest and maintenance percent correct, respectively], strengths about autism [e.g., "*Can often remember details well*," $\chi^2(2) = 15.17$, $p < 0.001$, 20, 82, 72% pretest, posttest and maintenance percent correct, respectively], and developing friendships with autistic children [e.g., "*Can a child with autism be a good friend?*," $\chi^2(2) = 11.40$, $p = 0.003$, 48, 96, 83% pretest, posttest and maintenance percent correct, respectively]. Importantly these findings, along with the remaining findings shown in Table 2, provide evidence that children not only learned the material from the modules but also retained what they learned 1 year later.

The open-ended question, "*Can you tell me what you think autism is in the space below?* "was scored by two independent coders. Coders agreed approximately 98% of the time, with disagreement settled with discussion. At pretest, a significant percentage of the children (92%) were not able to answer this question and either did not answer it, or said, "I do not know." The few children who answered it correctly at pretest, and the significantly greater numbers of children that answered it correctly at posttest and maintenance time points (see Table 2), had to give at least one or two characteristics that may be present in autism in order for their responses to be scored as correct, e.g., "They have a hard time with eye contact and sometime rock in class." Although none of the children mentioned that it was a "neurodevelopmental disorder" (information that was given in the program), most children were able to recall and give characteristics that were discussed during the program at posttest and maintenance conditions (see Table 2).

Individual modules assessment

Children's retention of information from each module (Research Aim 2) is shown in Table 3. Results showed that children displayed learning about the challenges associated with autism (Module 1), the similarities and differences between autistic and typically developing children (Module 2), and the sensory sensitivities associated with autism (Module 4). However, children were less accurate when asked about the specific strengths associated with autism (Module 3).

Also assessed was children's learning of material on ways for developing friendships (Module 5). However, when assessing children's learning from this module, we did not focus solely on making friends with autistic children. Instead, children were instructed, through the presentation of the videos and in our discussion, that making friends with autistic and typically developing children required the same skills and understanding (e.g., by getting to know them, by being tolerant of differences). Children's performance on the assessment of this material showed they retained it. These results are shown in Table 3.

Feasibility and acceptability

Finally, we were interested in whether a virtual program could be implemented successfully and be viewed favorably by the children and teacher alike (Research Aim 3). Feasibility checklists and recording of issues that occurred during the program showed only minor problems, such as an internet connection that briefly went out but was resumed within a few seconds. Moreover, checklists showed that the facilitators completed all scheduled activities for each module. In terms of acceptability, children reported that they preferred the videos (animated and real person) and interactive worksheets over other activities. However, children viewed the program and all its activities quite favorably (over 94% reported that they "really liked" the program and all of its activities). The teacher also had a quite favorable review of the program and its presentation of material through a variety of learning formats. When asked why she agreed to participate, she wrote, "*…children should know more about autism because of the likelihood of a child with autism being in one of their classrooms at some point.*" Moreover, she wrote, "*As a teacher, it is important for me, as well as all students in the classroom, to have the knowledge and the tools to be able to welcome a child with autism. Unfortunately, I have witnessed situations in which the teacher and the classroom were unprepared and so the child in the classroom did not thrive.*"

Discussion

Autism stigma that results in bullying and other inappropriate behaviors toward autistic children may occur because autism may be considered a "hidden disability." Lacking physical differences, peers may struggle to understand or empathize with social and behavioral differences. Moreover, as Turnock et al. (18) suggest, autistic individuals' "typical" appearance, coupled with autism-related behaviors, may elevate stigma. That is, socioemotional behaviors associated with autism may be taken as examples of social deviance rather than an underlying difference or difficulty. Others suggest that differences in socio-emotional functioning and social communication make autistic children more susceptible to social rejection and increase autism stigma (29). Consistent with the reciprocal effects peer interaction model (REPIM) (34), a lack of understanding about autism, reduced acceptance of differences, and limited opportunities to learn about autism all contribute to autism stigma. Importantly, the factors that produce autism stigma increase the chances that autistic children will experience bullying and social exclusion in their general education classrooms and devalue the benefits of inclusive education for them.

Thus, the overarching goal of the present study was to pilot test a virtual autism acceptance program based on REPIM principles that addresses negative stigma toward autistic children. Of interest was whether participation in the program led to significant gains in children's learning about autism and maintenance of that learning between pretest, posttest, and maintenance time points. Also examined was improvement in children's attitudes and behavioral intentions toward autistic children that were taken as evidence of the reduction of autism stigma.

In terms of overall learning, study findings showed that the program resulted in significant improvements in children's knowledge about, and attitudes toward, peers with autism between pretest and posttest time points. Moreover, children retained much of this information when assessed a year later. Highlights of the findings showed not only increases in children's general knowledge about autism, but also children's learning of information regarding the specific strengths of their peers with autism (e.g., can do well in school, can be smart, can remember details well), and the specific challenges associated with autism (e.g., may find it hard to talk to you or make eye contact with you; may experience sensory sensitivities). Previous research with adults has shown that by providing accurate information about the strengths and challenges associated with autism, and by emphasizing that the challenges are often out of the control of individuals, can autism stigma be reduced (18, 40).

Additionally, positive attitudes about, and behavioral intentions toward autistic children (e.g., can be friendly, would make a good friend) showed significant improvement following our virtual autism acceptance program. This corroborates research by Silton and Fogel (41), who showed that typically developing children were more motivated to play with an autistic child, or partner with them in an academic setting, following the viewing of videos that promoted positive attitudes toward autistic children. Finally, children were more likely to reject common misconceptions about autism, such as "autistic children only have things in common with other autistic children" or that "autistic children experience sensory input the same as others" following participation in the program. Thus, the results of our intervention are in line with approaches that autism stigma can be reduced by using educational tools to increase knowledge and attitudes about autism (18).

Although student feedback revealed that children preferred some formats (videos) over others (PowerPoint presentations), the children and the teacher had quite positive views of all presentation formats and the pilot program as a whole. Based on our findings, and consistent with universal design principles for learning, we would assert that successful autism acceptance programs should provide a variety of different learning formats regardless of mode of transmission (virtual, in-person). This enables multiple ways to learn the material and keeps the 5-week program interesting to children. Thus, our findings support slowly emerging evidence that autism acceptance programs are beneficial for reducing autism stigma through improvements in children's knowledge, attitudes and behavioral intentions toward their autistic peers (21, 30, 32).

Limitations and future directions

Although remote learning tools allowed us to present our program virtually, most schools in our area during the pandemic were not utilizing a hybrid model (i.e., students in the same class having the option to learn in-person or remotely from home). Thus, access to additional children was not possible. Moreover, this pilot study consisted of one group, with children serving as their own control (i.e., each participating child completed a pretest, posttest, and maintenance assessment of learning). Equally important, no autistic children participated in the study. Additionally, the teacher who allowed us to implement the program in her classroom had been teaching for over 30 years and was very supportive of the program. Thus, the results of this study may not be generalizable to other school settings, classrooms or the general population. In future research, it will be important to assess the efficacy of our virtual program across more classrooms, and to compare those results with in-person presentations of the program.

Additionally, while we took steps to decrease positivity bias in children's responding ("yes" to statements), or responding in a socially desirable way, we could not completely eliminate the possibility of these biases. However, children's performance at pretest, and their rejection of positive foils, argue against strong biases in their responding. Moreover, children were not given specific feedback on their responses on any assessments, although a review of the information from the preceding week's module was included the following week. Outcomes may have differed with specific feedback on assessments. Future research should also examine how participation in the autism acceptance program translates to real-life behaviors toward autistic children. Nevertheless, the preliminary and promising results of this pilot study suggest that behavioral change through autism acceptance programs is possible because positive change in behaviors cannot occur without first accurate knowledge about, and positive attitudes toward, others (37).

Conclusion

Preliminary findings from our autism acceptance program showed that a virtual program can address a lack of understanding about autism, reduced acceptance of differences, and limited opportunities to learn about autism in classrooms, factors that have all been shown to contribute to negative stigma associated with autism (34). Thus, online programs such as the present one may provide a new means for autism acceptance materials to be made widely available, expanding the number of schools and children that can be reached. Consequently, significant benefits for both typically developing and autistic children are possible through autism acceptance programs, enabling them to successfully navigate inclusive, general education classrooms together.

Data availability statement

The raw data supporting the conclusions of this article will be made available by the authors, without undue reservation.

Ethics statement

The studies involving humans were approved by the institutional review board at Loyola University Chicago. The studies were conducted in accordance with the local legislation and institutional requirements. Written informed consent for participation in this study was provided by the participants' legal guardians/next of kin.

Author contributions

DD: conceptualization, funding acquisition, methodology, project administration, supervision, formal analysis, writing–original draft, and editing and review of the manuscript. DM: project administration, data analyses, and writing–review and editing. All authors contributed to the article and approved the submitted version.

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Conflict of interest

The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

Publisher's note

References

1. World Health Organization. *International statistical classification of diseases and related health problems*. 11th ed World Health Organization (WHO) (2019). Available at: https://icd.who.int/browse11

2. American Psychiatric Association. *Diagnostic and statistical manual of mental disorders. 5th* ed. Arlington, VA: American Psychiatric Association (2013).

3. Samuels CA. Number of U.S. students in special education ticks upward. *Educ Week*. (2016) 35:1–12. Available at: https://www.edweek.org/ew/articles/2016/04/20/number-of-us-stuents-in-special-education.html

4. Sanford C, Levine P, Blackorby J. *A national profile of students with autism: a special topic report from the special education elementary longitudinal study*. Menlo Park, CA: SRI International (2008).

5. Snyder TD, De Brey C, Dillow SA. *Digest of education statistics 2015. 51st* ed. Washington, DC: National Center for Education Statistics, Institute of Education Sciences, U.S. Department of Education (2016).

6. Individuals with Disabilities Education Act of 2004. *Pub. L. No. 108–446 (2004). Kit for Kids* Organization for Autism Research (2021) Available at https://researchautism.org/education/students-corner/kit-for-kids/#activitya.

7. No Child Left Behind Act 2001. *P.L. 107–110, 20 U.S.C.§ 6319* (2002).

8. Scheil KA, Bowers-Campbell J, Campbell JM. An initial investigation of the kit for kids peer education program. *J Dev Phys Disabil*. (2017) 29:643–62. doi: 10.1007/s10882-017-9540-6

9. National Research Council. *Educating children with autism*. Washington, DC: National Academy Press (2001).

10. Starr EM, Foy JB, Cramer KM. Parental perceptions of the education of children with pervasive developmental disorders. *Educ Train Ment Retard Dev Disabil*. (2001) 36:55–68.

11. Grimm RP, Solari EJ, McIntyre NS, Zajic M, Mundy PC. Comparing growth in linguistic comprehension and reading comprehension in school-aged children with autism versus typically developing children. *Autism Res*. (2018) 11:624–35. doi: 10.1002/aur.1914

12. Pratt C. *So exactly what is the least restrictive environment?* Autism Support Network (2021) Available at: http://www.autismsupportnetwork.com/news/so-eactly-what-least-restrictive-enviornment-2236251.

13. Kurth J, Mastergeorge AM. Impact of setting and instructional context for adolescents with autism. *J Spec Educ*. (2012) 46:36–48. doi: 10.1177/0022466910366480

14. Chandler-Olcott K., Kluth P. (2021). *Why everyone benefits from including students with autism in literacy classrooms*. Available at: https://www.readingrockets.org/article/why-everyone-benefits-including-students-autism-literacy-classrooms

15. Mavropoulou S, Sideridis GD. Knowledge of autism and attitudes of children towards their partially integrated peers with autism spectrum disorders. *J Autism Dev Disord*. (2014) 44:1867–85. doi: 10.1007/s10803-014-2059-0

16. Noggle AK, Stites ML. Inclusion and preschoolers who are typically developing: the lived experience. *Early Childh Educ*. (2018) 46:511–22. doi: 10.1007/s10643-017-0879-1

17. Link BG, Phelan JC. Conceptualizing stigma. *Annu Rev Sociol*. (2001) 27:363–85. doi: 10.1146/annurev.soc.27.1.363

18. Turnock A, Langley K, Jones CRG. Understanding stigma in autism: a narrative review and theoretical model. *Autism Adulth*. (2022) 4:76–91. doi: 10.1089/aut.2021.0005

19. Nevill REA, & White, S. W. (2011). College students' openness toward autism spectrum disorders: improving peer acceptance. *J Autism Dev Disord* 41, 1619–1628. doi: 10.1007/s10803-011-1189-x

20. White D, Hillier A, Frye A, Makrez E. College students' knowledge and attitudes towards students on the autism spectrum. *J Autism Dev Disord*. (2019) 49:2699–705. doi: 10.1007/s10803-016-2818-1

21. Cremin K, Healy O, Spirtos M, Quinn S. Autism acceptance interventions for children and adolescents: a scoping review. *J Dev Phys Disabil*. (2021) 33:27–50. doi: 10.1007/s10882-020-09741-1

22. Pellicano L, Bölte S, Stahmer A. The current illusion of educational inclusion. *Autism*. (2018) 22:386–7. doi: 10.1177/1362361318766166

23. Cappadocia MC, Weiss JA, Pepler D. Bullying experiences among children and youth with autism spectrum disorders. *J Autism Dev Disord*. (2012) 42:266–77. doi: 10.1007/s10803-011-1241-x

24. Humphrey N, Hebron J. Bullying of children and adolescents with autism spectrum conditions: a 'state of the field' review. *Int J Incl Educ*. (2015) 19:845–62. doi: 10.1080/13603116.2014.981602

25. Hwang S, Kim YS, Koh Y-J, Leventhal BL. Autism spectrum disorder and school bullying: who is the victim? Who is the perpetrator? *J Autism Dev Disord*. (2018) 48:225–38. doi: 10.1007/s10803-017-3285-z

26. Kloosterman PH, Kelley EA, Craig WM, Parker JD, Javier C. Types and experiences of bullying in adolescents with an autism spectrum disorder. *Res Autism Spectr Disord*. (2013) 7:824–32. doi: 10.1016/J.RASD.2013.02.013

27. Maïano C, Normand CL, Salvas MC, Moullec G, Aimé A. Prevalence of school bullying among youth with autism spectrum disorders: a systematic review and meta-analysis. *Autism Res*. (2016) 9:601–15. doi: 10.1002/aur.1568

28. Zablotsky B, Bradshaw CP, Anderson C, Law PA. The association between bullying and the psychological functioning of children with autism spectrum disorders. *J Dev Behav Pediatr*. (2013) 34:1–8. doi: 10.1097/DBP.0b013e31827a7c3a

29. Ashburner J, Ziviani J, Rodger S. Surviving in the mainstream: capacity of children with autism spectrum disorders to perform academically and regulate their emotions

and behavior at school. *Res Autism Spectr Disord*. (2010) 4:18–27. doi: 10.1016/j.rasd.2009.07.002

30. Campbell JM, Caldwell EA, Railey KS, Lochner O, Jacob R, Shelby K. Educating students about autism spectrum disorders using the kit for kids curriculum: effects on knowledge and attitudes. *Sch Psychol Rev*. (2019) 48:145–56. doi: 10.17105/SPR-2017-0091.V48-2

31. Morris S, O'Reilly G, Byrne MK. Understanding our peers with Pablo: exploring the merit of an autism spectrum disorder de-stigmatisation programme targeting peers in Irish early education mainstream settings. *J Autism Dev Disord*. (2020) 50:4385–400. doi: 10.1007/s10803-020-04464-w

32. Ranson NJ, Byrne MK. Promoting peer acceptance of females with higher-functioning autism in a mainstream education setting: a replication and extension of the effects of an autism anti-stigma program. *J Autism Dev Disord*. (2014) 44:2778–96. doi: 10.1007/s10803-014-2139-1

33. Hebron J, Humphrey N, Oldfield J. Vulnerability to bullying of children with autism spectrum conditions in mainstream education: a multi-informant qualitative exploration. *J Res Spec Educ Needs*. (2015) 15:185–93. doi: 10.1111/1471-3802.12108

34. Humphrey N, Symes W. Peer interaction patterns among adolescents with autism spectrum disorders (ASDs) in mainstream school settings: a qualitative study. *Autism*. (2011) 15:397–419. doi: 10.1177/1362361310387804

35. Ajzen I, Fishbein M. *Understanding attitudes and predicting social behavior*. Englewood Cliffs, NJ: Prentice Hall (1980).

36. Antonak RF, Livneh H. Measurement of attitudes towards persons with disabilities. *Disabil Rehabil*. (2000) 22:211–24. doi: 10.1080/096382800296782

37. Triandis HC. *Attitude and attitude change: foundations of social psychology*. New York, NY: Wiley (1971).

38. Serlin RC, Carr J, Marascuilo LA. A measure of association for selected nonparametric procedures. *Psychol Bull*. (1982) 92:786–90. doi: 10.1037/0033-2909.92.3.786

39. Campbell JM, Barger BD. Middle school students' knowledge of autism. *J Autism Dev Disord*. (2011) 41:732–40. doi: 10.1007/s10803-010-1092-x

40. Kitchin JL, Karlin NJ. Awareness and stigma of autism spectrum disorders in undergraduate students. *Psychol Rep*. (2022) 125:2069–87. doi: 10.1177/00332941211014144

41. Silton NR, Fogel J. Enhancing positive behavioral intentions of typically developing children towards children with autism. *J Cogn Behav Psychother*. (2012) 12:139–58.

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Teaching higher education staff to understand and support autistic students: evaluation of a novel training program

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Background: Autistic students are particularly vulnerable to stressors within a university environment and are more likely to experience poor mental health than their non-autistic peers. Students' experiences of stigma from staff and peers, and the masking behaviors they deploy to minimize it, can also result in worsening mental health. Despite these concerns, there is a lack of tailored support for autistic students at university. The current project assesses a co-created training course for university staff focused on debunking stereotypes, educating about the autistic experience at university, mental health presentation among autistic individuals, and practical strategies to improve interactions with autistic students.

Methods: The Autism Stigma and Knowledge Questionnaire [ASK-Q] was administered before and after the training, to examine changes in trainees' understanding and acceptance of autism and autistic people. Post-training interviews and surveys were also conducted with trainees, covering the impact the training has had on their perceptions of autism, the strategies they found beneficial, and how they will use the materials in future.

Results: There were no statistically significant differences between pre- and post-training scores on the ASK-Q, likely due to ceiling effects as pre-training scores were high. Thematic analysis of interviews identified five themes: value of lived experience; developing nuanced, in-depth knowledge of autism; training as acceptable and feasible; links to professional practice; and systemic barriers.

Conclusion: Although ceiling effects meant there were no changes to participant's knowledge about autism and autistic people statistically, the qualitative data reveals the extensive benefits they gained from taking part in the training programs. Scoring highly on the ASK-Q did not mean that people could not learn important new information and benefit from the course. This more nuanced understanding of autism led to practical changes in their practice. Listening to and learning from autistic people was seen as particularly important, highlighting the value of co-production. Our results also emphasize the need for varied approaches to evaluating training effectiveness, as reliance on quantitative data alone would have missed the subtler, but impactful, changes our participants experienced. This has important implications for professional practice, both within higher education and more broadly.

KEYWORDS

autism, mental health, higher education, training, intervention, evaluation

1 Introduction

Contrary to historical assumptions that autistic people mostly had co-occurring learning difficulties and would not enter higher education (HE), it is estimated that 0.75% of the UK higher education (HE) population had a social or communication difficulty, a category which autism falls under (1). It is worth noting that the total number of autistic students in the UK is not formally tracked by any official body, despite the likely large and growing representation in HE. Increasing research around autism and autistic people in HE settings reflects a recognition among researchers of a need to support this growing population (2), who face additional and unique challenges in these spaces. While transitioning to university can be daunting for most people, autistic students are particularly vulnerable to challenges such as changes to routines, navigating unfamiliar environments, and higher academic or social demands (3).

1.1 University experience

Several studies have found that autistic students generally feel comfortable with the academic side of university, compared to other elements of university life (2, 4, 5), which are discussed later in this paper. Some autistic traits, such as attention to detail, strong memory, and different ways of thinking are considered particularly beneficial for university study (3, 4). It is also the case that the ability to focus on a topic more deeply, often one which is a special interest, can enhance students capacity to achieve. This is the case in earlier stages of education (6), and has been mentioned by autistic students themselves (7).

When academic problems do occur, however, this can be a source of emotional distress and anxiety (4, 8). Autistic students may face challenges in the academic setting due to specific autistic traits, such as organization and time management, motivation, and managing course load (2, 5, 9). In Gurbuz et al. (10), students described a difficulty with pacing themselves, sometimes fixating on one subject at the cost of others and the risk of burnout – the potential downside of the ability and desire to 'hyperfocus' on a topic or assignment of particular interest. Equally, the perceived pressure to perform in the same ways and to the same standards as neurotypical peers can have a major impact on autistic students, especially if faced with staff who do not understand the extent to which this is a challenge for them (5, 11).

Social communication differences, such as understanding social cues and unspoken social rules, can present a challenge for autistic students at university, as so much of both the formal and informal curriculum depends on these skills and unwritten rules (12). Many report feelings of isolation and loneliness, difficulty in making and keeping friends, social anxiety, and limited or impersonal interactions with their peers (2, 8, 11). Social events at university can often also be inaccessible, with crowded, overwhelming spaces and reliance on alcohol, especially during the first week, known as "Fresher's Week" in the UK (7, 13). As Fresher's Week is the time in which most students will get the chance to learn about and join university clubs and societies, many autistic students miss out on those opportunities. Having access to these societies is important, as many autistic students find it easier to interact with people in structured spaces centered around their interests (5, 12).

Outside of social aspects, the physical environment of university can also present difficulties. Loud or bright spaces or busy areas such as lecture theatres and labs can be difficult for students to work in (5, 12, 13). There are, however, solutions that are available in the short term, such as adjusting the lighting (12) and the provision of sensory-friendly spaces (11) – but students have reported difficulty in getting these changes or resources implemented (3). Larger-scale architectural issues, such as narrow, crowded corridors, are possible to address if future building plans are made with neurodiversity in mind.

1.2 Stigma and masking

Social communication differences and behaviors can become a source of stigma against autistic people (14). Non-autistic people are less likely to judge autistic people positively or want to engage with them socially (15). Experiences of stigma are commonly reported by autistic people (16–18), with significant negative impact on many areas of their lives.

Reacting to, or fearing, stigma is among the main reasons why autistic people engage in masking, or camouflaging (19, 20). Masking/camouflaging is adopting specific behaviors intended to help an individual fit into a neurotypical environment and hide their autistic traits or social differences (21). It is often not a deliberate choice made by an autistic person, but a response driven by anxiety (22) which can be exhausting and lead to burnout (23).

Masking can have immediate benefits in helping someone to fit in socially and can act as a protective factor against bullying or victimization (16, 24). Some practitioners may encourage masking as a tool for effective socializing (22) but this does not ultimately address the root cause of an unwelcoming environment (20).

The potential harm of suppressing natural behavior in this way has been documented extensively (19, 22, 25). People who frequently mask report losing their sense of self (19, 24) and a sense of disconnection from other people (22). It can also have the unfortunate consequence of the autistic person not being believed when they do reach out for support, because others do not consider them disabled and think that they are able to cope (19, 24). For autistic students, this can mean that it is harder for them to access the supports they are entitled to, or that they face disbelief from staff members when they request reasonable adjustments (7).

Autistic people are more likely to experience mental health conditions, such as depression and anxiety, across the lifespan (26). Anxiety can act as both a trigger and a consequence of masking (22) and extensive masking has been linked to increased rates of autistic burnout, depression, substance use, and suicidality (27–29). In the context of HE, a time associated with increased mental health issues in the general population (30, 31), this relationship may be especially intense as autistic young people attempt to mask their way through multiple new and challenging situations alongside managing independent living and academic pressures.

Indeed, Goddard and Cook (12) found that students were hesitant to disclose to peers who showed little knowledge of autism or relied heavily on stereotypes (such as rudeness, savant abilities, or not feeling emotion). This stereotyping was worsened, in the students' opinions, by poor media representations of autistic people. If an autistic student seems to be coping well academically, this can be misinterpreted by others to mean that they are not struggling socially (10).

1.3 Support

Universities will typically offer traditional academic supports to autistic students, such as extra exam time and separate testing locations. While these can be helpful, they are likely not sufficient for autistic students (8, 32, 33). As discussed above, non-academic concerns also need to be addressed, through options such as peer mentoring, psychological support, and support during the transition to university (5, 11, 32, 34). It is also the case that many autistic students will need individualized rather than generic support options.

Even where adequate supports are available, they are often only provided to students who have a formal autism diagnosis and who choose to disclose it (34, 35). This, however, is not a straightforward decision for students to make and many will wait until they are at a point of crisis before taking that step. They may not consider themselves disabled or in need of support, may be unsure of the process of disclosure, or their circumstances may change during their time at university (3, 4, 10, 35). Students without an official diagnosis may not have access to support at all (11) and those with a diagnosis may experience delays in getting the help they need (4, 9).

As addressing these barriers can be a deciding factor in students' success and wellbeing at university (3, 11, 33), the current work aims to help staff in becoming more proactive in offering support.

1.4 Need for staff training

In addition to the above-outlined aspects of being autistic in HE, many autistic students report negative interactions, or a lack of autism knowledge, among university staff (3, 7, 11, 12). Gelbar et al. (33) describe instances where even staff who studied or taught about autism still did not recognize that autistic students may be in their classrooms. This is not a problem unique to autistic students' interactions with teaching staff, but also takes place with respect to interactions with those services from whom autistic students might have expected more understanding, e.g., disability services and university mental health services (12, 33).

For students who anticipate, and fear, being treated differently (7, 10), infantilized (12), or considered incompetent (5), an expectation of lack of knowledge and understanding among university staff can prevent students who would otherwise access support from reaching out. Scott and Sedgewick (7) found that, when students were supported by knowledgeable staff with a positive attitude, they felt better supported with their mental health and more comfortable asking for accommodations. Staff with improved knowledge are also more capable of helping their students navigate support systems (4, 11).

Training courses have been shown to make a difference to knowledge and attitudes in university student populations, including around autism (36–38). Jones et al. (39) found that, while their training did not affect implicit bias, such as connecting labels related to autism with negative character traits, it did change explicit bias. This meant that, after the training, participants showed more interest in interacting with, and better first impressions of, autistic people, and were less likely to agree with misconceptions. Similarly, training for university peer mentors can lead to better working relationships between mentors and autistic students. Mentors reported that their new knowledge had been essential to their support role, demonstrating that providing information on autistic students' needs can be beneficial in helping them access support (38). Therefore, developing training for staff who work with autistic students in the very specific HE context has the potential to significantly positively impact outcomes, both academically and in terms of wellbeing. Participatory training designs, in particular, have been shown to be effective. Gillespie-Lynch et al. (36) ran two versions of a training course and found that, while both showed improvements in stigma, bias and autism knowledge in their sample, the participatory training had a greater impact. Even though the two courses were the same length, participants described the non-participatory version as too long. This suggests that hearing from autistic people, with their own personal stories, was more engaging, potentially resulting in the greater impact it had.

1.5 Current study

The current study evaluates a training course designed to address these issues for university staff. This was developed alongside a participatory advisory group (PAG) of autistic students and representatives from the National Autistic Society (NAS) and Spectrum First (an autism training provider). The training was also partly designed and co-delivered by an autistic academic (EJ). Further to this, the PAG suggested the content initially, approved the structure of the training, and recorded interviews sharing their own experiences with the course topics – in line with recommendations for such training to be participatory in nature from studies outlined above. The training was initially designed as a five-week online course, delivered via a virtual learning environment, with a time commitment of approximately 1–2 h per week. The training was partly delivered by an autistic individual and included panel interviews with autistic students, who discussed their own experiences relating to each week's topic. The order and content of the sessions is outlined below.

Session One: introduction to autistic traits, terminology, and theories, emphasizing heterogeneity and the need for individualized support.

Session Two: debunking stereotypes, understanding stigma, and autistic masking.

Session Three: mental health among autistic people, contributing factors, coping mechanisms, and impact on academic achievement.

Session Four: autistic experiences at university and support systems staff could access or signpost to.

Session Five: recap of potential challenges for autistic students and how to address these with reasonable adjustments and practical strategies for staff.

To complete the course, participating staff were required to watch a weekly pre-recorded lecture and a video interview with autistic students. Some weeks also had an activity (e.g., a quiz, a visual search task) and optional extra resources, involving YouTube videos, blog posts, journal articles and external websites. Finally, an optional weekly live session was held to allow participating staff to exchange thoughts on the week's topic, share resources and discuss strategies for engaging with autistic students. This version of the training was run over the summer break, a period in which academic staff tend to have more time available for professional development.

Due to further demand from staff who were not available over the summer, or who could not commit to the five-week course, the training was adapted to a single afternoon session delivered via

TABLE 1 Job roles of each training cohort.

Role type	Full course	Short course	In person
Accommodation	0	1	0
Administration	0	2	10
Careers services	0	1	0
Disability services	2	3	0
Library services	2	5	0
Research	0	0	1
Teaching	5	7	23
Wellbeing services	1	1	0
Other (e.g., technicians)	2	3	4
Other support staff	2	1	2
Total staff	14	24	40

TABLE 2 Course and evaluation completion rates for each course type.

	Full course	Short course	In person	Total
Registered for course	67	49	90	206
Completed training	42	32	52	126
Completed both questionnaires	25	24	40	89

Microsoft Teams. This version was run over three hours, with the lecture portion delivered live and using shortened clips from the prerecorded student interviews. Further sessions of this version of the training were also delivered in-person at one of the participating universities. Links to the optional extra resources from the longer course were provided after the short course sessions and all staff, regardless of the training version they engaged with, were given a document with key information for future reference.

The current work adopts a mixed-methods approach to address the following research questions:

1. Can training have an effect on autism knowledge and stigma among university staff?
2. Are there advantages to involving the autistic community in developing autism training?
3. How do staff feel that the training has affected their knowledge and practice?

2 Methods

2.1 Participants

Participants were staff from three different UK universities. The training was initially designed for academic staff with additional roles as personal tutors, who support students throughout the duration of their degree with academic, personal and professional development. As these tutors have frequent one-on-one meetings with their students and act as a first point of contact should any issues arise, the training was tailored toward them. However, enrolment was open to any student-facing member of staff and, due to their interest, the cohort was expanded to include staff in other roles, such as library and disability services (see Table 1). Staff were recruited through advertising sent out in department mailing lists and word of mouth. Through this method of dissemination, it is unclear how many people saw the advertisement, and it is therefore not possible to calculate uptake rates, or the percentage of staff who signed up for the course. More participants took part in the shortened version of the training and full completion rates are listed in Table 2.

Ethical approval was granted by the University of Bristol School of Education's Ethics Committee, and all participants were informed of the evaluation study and gave consent before beginning the training.

2.2 Materials

Demographic data was collected from all staff before they took part in the training, including age, gender, and role at the university.

All staff completed the *Autism Stigma and Knowledge Questionnaire* [ASK-Q (40)]; twice, pre- and post-training. In the ASK-Q participants select whether they "agree" or "disagree" with a set of 49 statements. Examples include "autism is preventable" or "autism is a developmental disorder." Their answers are scored as in/correct, for one point per correct answer, and a maximum score of 49.

Once the training was complete, staff from the five-week training were also emailed an invitation to participate in follow-up interviews, the questions for which had been reviewed by the PAG. The interview covered participating staffs' opinions about the course in general, what they found interesting and motivating, and whether it was easy to navigate. They were also asked how it differed from previous training they may have received, how much time they dedicated to the course, and what they learned. After the short courses, staff were asked to complete feedback surveys. For the first short course, this was a written version of the interview, but for the in-person course, this consisted of two open-ended questions ("which strategies do you think you will use from the course" and "do you have any feedback about the course?"). These changes were made in response to comments from participants about the feasibility of completing the longer feedback survey.

2.3 Follow-up data collection procedure

Prior to the interview, staff were sent a copy of the interview schedule and were given the opportunity to ask any questions. Staff had continued access to the course material to review it alongside the questions. Interviews were conducted online using Microsoft Teams with 12 staff members, with both audio and video being recorded with their consent. The system automatically generated a transcript, which was then checked for accuracy. Staff who took part in the interview were paid £20 for their participation. Similar processes were followed for the data from the feedback surveys. These were emailed to staff and were optional for them to complete. Staff were not paid for the surveys as the time commitment was significantly less, and many chose to complete anonymously meaning they could not have been contacted for payment. A total of 54 staff members completed the surveys.

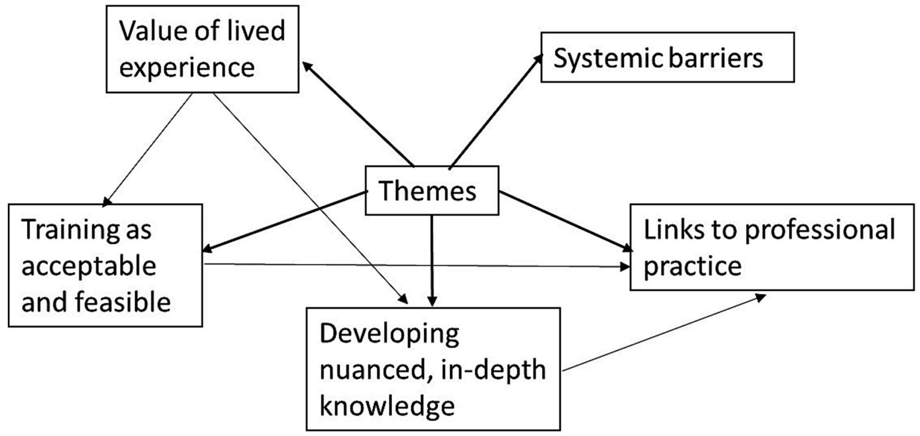

FIGURE 1
Visual representation of identified themes. Arrows in bold indicate the main themes, thin arrows denote other connections between themes.

Interview transcripts were analyzed using thematic analysis, as detailed by Braun and Clarke (41). The steps they recommend are as follows: familiarizing yourself with the data; generating initial codes; searching for themes; reviewing themes; and defining and naming themes. Two authors (FeS and EJ) coded all interviews, while all other team members were given a subset of six interviews that were selected at random. All team members initially coded independently of each other and once this had been completed, a consensus meeting was held to decide on the final themes and subthemes to be presented.

3 Results

3.1 Quantitative results

For the whole dataset ($n = 89$), there were no significant differences between ASK-Q scores before ($M = 41.16$, $SD = 2.84$) and after ($M = 41.52$, $SD = 2.77$) the training, $t(88) = -1.204$, $p = 0.232$.

For the full online version of the course ($n = 25$), there were also no significant differences between pre- ($M = 41.44$, $SD = 2.42$) and post-training ($M = 42.08$, $SD = 2.33$) scores, $t(24) = -1.104$, $p = 0.281$, indicating no change in knowledge or stigma levels among trainees.

There was a significant difference for the online short course ($n = 24$), with pre-training scores ($M = 41.24$, $SD = 3.82$) lower than post-training scores ($M = 42.42$, $SD = 2.59$), $t(23) = -2.429$, $p < 0.05$, indicating that trainees had gained knowledge and reduced stigma.

For the in-person version of the short course ($n = 40$), pre-training scores ($M = 40.93$, $SD = 2.38$) were higher than post-training scores ($M = 40.62$, $SD = 2.91$) but this difference was not significant, $t(39) = 0.648$, $p = 0.521$.

3.2 Thematic analysis

Five themes were identified in interviews with participating staff: *value of lived experience*; *training as acceptable and feasible*; *developing nuanced, in-depth knowledge*; *links to professional practice*; and *systematic barriers*. Please see Figure 1 for a visualization of themes and subthemes. Each participant has been given an ID reflecting their course type- "F" for full course (interview participants) and "S" for the short course (survey participants).

3.2.1 Value of lived experience

As mentioned earlier, the training was partly delivered by an autistic individual and included panel interviews with autistic students. Most of the interviewees mentioned this as a key benefit of the training, describing it as "*rare*" (F6), "*powerful*" (F2) and different from previous training they had received. This was echoed in the survey responses, where it was described as "*enlightening*" (S42) and "*a vital part*" of the training (S39). Several mentioned that it was a novel experience to take part in participatory training, and their appreciation for the work this represented from the autistic students and staff member. For example:

> *"I recognise there's a level of… emotional labour that's needed in that to kind of go 'here's my world, here's my experience, and here are the times where it sometimes is really difficult'" (F2).*
>
> *"was getting to know them and I felt quite a big responsibility to keep watching and keep learning from them, so that helped keep me motivated" (F6).*

The responses from staff who were interviewed also indicated a recognition that it may be more natural for students to cover up their traits when interacting in-person, and that seeing the autistic students and staff member discuss this explicitly was revelatory:

> *"People are talking about autism openly in those. That's almost like that's what we need to learn because no one does in real life because… that conversation does not really come up. And… the people have just been sort of told to hide it their whole lives anyway so… that's exactly what we need to see" (F7).*

Seeing the group of autistic people speaking with one another also helped dismiss stereotypes and incorrect expectations from staff. Finding students relatable was a key aspect of this process:

> *"they just seemed like normal people I'd wanna be friends with… I expect them to be obviously autistic and because those female ones were just chatting away laughing with you, I was like 'wait, what? You're like, you just seem like someone I'd meet at a party'" (F7).*

The inclusion of the phrase "*like normal people*" in the above quote suggests that some staff held ableist attitudes (i.e., that autistic students are not normal) which were being challenged by the inclusion of autistic people in the training. The issue of challenging existing perceptions is discussed further in Section 3.22.

One of the other key perceived benefits of having autistic students involved in the training was that staff were able to put their learning into perspective:

> *"sometimes training like this can be very abstract, so adding in those personal experiences and connections to the university was a nice touch" (S3).*

While the lecture material had discussed subjects such as masking and differences in communication styles, the staff who participated in the interviews reflected that these were better illustrated through listening to autistic individuals:

> *"They're telling you about all their struggles but then they seem quite confident the same time" (F7).*
>
> *"How they mask was really interesting and helps me see how different the experiences can be for different autistic people" (S4).*

Finally, staff expressed during the interviews that they had appreciated the personal nature of the student involvement:

> *"I did like getting to know the students… you could kind of get a picture of them which was lovely… but also getting sense of how different they were to each other." (F10).*

3.2.2 Developing nuanced, in-depth knowledge

One of the main themes identified in the responses from both those who participated in the five-week and single-session versions of the course was that the training had allowed them to develop more nuanced and deeper knowledge about autism and autistic HE students. While many had a high level of knowledge going into the training, as shown by the ASK-Q pre-test scores, they still felt that they had learned significant amounts, both in terms of new knowledge and practical strategies they could use.

3.2.2.1 Breaking stereotypes and changing views

While the student interviews helped to present a different image of autistic people than the images that staff on the course were familiar with, the course content itself was also built to debunk stereotypes. Examples brought up by staff during both interviews and surveys included misunderstandings of autistic communication styles and socializing, lack of knowledge of masking and autistic mental health, and thinking that individuals would be *"obviously autistic"* (F7). For example:

> *"[I had] slipped into that… Hollywood depiction of autism, you know the white male maths savant. This or the person who's just supremely non-communicative" (F11).*
>
> *"reinforcing that autism is not bad and does not imply cognitive inability" (S1).*
>
> *"it also promoted a lot of the positive traits that autistic people may have, which was nice because I feel sometimes training can focus more on the barriers and challenges without that balance" (S3).*

There was a range of existing knowledge about autism, and therefore stereotypes, within the group. For some staff, the lecture material was entirely new, although the majority had some prior experience. This meant that some felt that they were carrying no stereotypes:

> *"I never thought about these things to begin with even though I think I'm kind of [an] understanding person" (F7).*

While others described realizing that they did hold stereotypes, even if unconsciously or without malice:

> *"carrying some unconscious bias" (F3).*
>
> *"preconceived ideas about [autism]" (F4).*

Other staff, for whom the material was familiar, still recognized the benefit of the training in expanding their knowledge and bringing more nuance to the ways they thought about autistic students they encountered:

> *"If you went into it thinking well every autistic person's like Sheldon Cooper aren't they? It would absolutely change your thinking" (F2).*
>
> *"I would consider myself relatively well-informed about a lot of educational issues, but I was challenged (in a good way) by what was in the course" (S8).*

Some staff had previously taken the need for accommodations personally, or had been hesitant to engage with students whose requests they had previously interpreted as being rude:

> *"it's not a reflection on me when they are wanting more time or asking the questions in those ways it's a reflection on their needs" (F5).*
>
> *"I'd written them off as this rude person who I did not want to have to engage with and was annoyed if I saw them" (F7).*

Even staff who were knowledgeable about the presence of accommodations had struggled to appreciate their value, and were now beginning to understand the consequences of this:

> *"I've learned to appreciate it that actually there was some people that do need to have those recordings… being prevented from doing that, or dismissing it, or trying to stop it can actually be more detrimental to the relationship that we have with them" (F5).*

Participating staff noted the conscious effort it took to unlearn these assumptions, both consciously during the training and going forwards in their interactions with autistic (and potentially other neurodivergent or disabled) students:

> *"an element of having to sort of reprogram the brain a little bit. And that was definitely what was going on in those couple of weeks" (F4).*
>
> *"it wasn't something that is really at the forefront of my mind but… it's definitely something that I'll think more about and has changed my opinions and my views" (F12).*

3.2.2.2 Building on existing knowledge

Some staff, particularly those working within Disability Services or who were familiar with autistic people in their daily lives, were already knowledgeable about these stereotypes and their inaccuracies. For these individuals, the training provided an opportunity to revise or build on this existing knowledge:

> *"[it helped to] clarify certain things or… make it easier for me to explain things to other people" (F2).*
>
> *"reinforced and clarified what I knew" (S1).*

Some staff used the current training to update knowledge that may be outdated or applied to different settings, especially valuing the specific links to the HE context and the ability to compare to training they had on autism previously:

> *"nice to see some of the social changes and the language changes and you know to put it in the university context" (F10).*
>
> *"to see how maybe the advice on that manual is no longer valid or is valid still" (F4).*

3.2.2.3 Recognizing students' individuality

Through the training, staff were able to recognize that any adjustments or strategies learned were not "one-size-fits-all":

> *"It's not like all neurotypical people are the same and then all neurodivergent people are the same. It just sort of recognising those key differences but there's a huge variation within that" (F2).*

Throughout the training, staff were able to see the variability in autistic traits, both between people and within the same person in different settings:

> *"you could see differences in people, so some of them seemed a lot less talkative and a lot more like someone you would say 'ohh… they might have autism" (F7).*
>
> *"There are situations in which they… will potentially get themselves anxious, or overly anxious because of the situation they are in, which might not be a particularly anxious situation to somebody else" (F12).*

This highlighted the need to adapt strategies and adjustments to individual students, and the importance of working with autistic students to find what worked for them rather than assuming that the same approaches would work for everyone:

> *"there are other ways of working and if this one strategy does not work for them, maybe listen to what they are saying, hear what they are saying" (F1).*

3.2.3 Links to professional practice

Some participating staff intended to continue using the course content and extra materials for reference once the course was complete, to support their ongoing practice and interactions with autistic students in their work:

> *"there… to go back over and to…read and to dip in in over a period of time" (F1).*
>
> *"keep for when you come across a case of somebody who wants some support, and actually it's probably a fantastic resource set to have a look and go 'oh mental health'" (F9).*

Both the course materials and live session discussions allowed staff to become familiar with accommodations, and different ways of working, that could benefit autistic students. Across all versions of the training, staff noted specific options that they had not been previously aware of, such as a sensory room available at one of the university campuses. Many described a more general practice of simply checking in more often with students and being proactive in their approach.

A common change for staff was in the way they chose to communicate with students, such as providing more time to respond to questions and being more concise. They also discussed implementing their knowledge of conversational scripting and alexithymia into their interactions with students and support plans they pass onto other staff:

> *"…being aware not to ask very general things that could… elicit that kind of scripted answer… I've definitely mentioned that in a few… support plans that I've written and discussions I've had with students where they have spoken about sort of not being able to… get in touch really with how they are feeling and difficulty sort of describing it" (F2).*

Sensory and planning needs were also frequently mentioned by staff, such as reflecting more on the space in which they meet students, asking about sensory needs ahead of meetings, and preparing spaces:

> *"sometimes people have to go in and look beforehand and… check [a space] out and… walk through it and work out where… everything's going to be" (F5).*

Contributions made by several staff indicated that accommodations intended for autistic people, particularly in the environment, can be beneficial to the wider student population, for example.

> *"In providing a supportive, inclusive environment for the people that we work with and…for the students that access our facilities, actually we are making it more inclusive for everybody" (F5).*
>
> *"If you create a space that is good for neurodiverse people, it's self-fulfilling in the sense it's better for everybody. It's not that you have created a space that is brilliant for a minority but it's made it useless for everybody else" (F9).*

3.2.4 Systematic barriers

Many staff noted aspects of the structure of their universities that could cause further barriers for autistic students. 'Crunch points' around assessment deadlines (*"all of the assessments are due in at the same time,"* F2) and lack of adjustment to assessment requirements were seen as particular issues. The differences between the three institutions in terms of the visibility of neurodiversity, and support available, surprised some trainees – one university had Neurodiversity Champions, and staff there thought this should be standard across HE:

> *"I could not believe that in 2022 there was an institution that actually had not engaged with this… I think they were only really starting that engagement because they were thinking about the PR disaster that was facing them" (F4).*

Staff also often discussed the physical environments of university spaces, especially in relation to what they had learned about sensory sensitivities:

> *"we have got lots of people going in potentially who are neurodiverse and our facilities… probably were designed… in a decade where we literally did not give a crap about that sort of thing" (F9).*
>
> *"having someone in… the workshop doing mandatory workshop training who cannot take loud noises" (F4).*

Aside from problems directly impacting students, staff discussed systems that prevent them from being able to support students in the way that they would like, such as difficulties in accessing training and barriers to information sharing between relevant departments:

> *"in higher education sometimes people have very little time… we did not get great amount of support from our management about you know setting aside time to do it in" (F6).*
>
> *"it was interesting to see what academics were thinking and then disability staff were thinking and how those differed sometimes" (F6).*
>
> *"we can sometimes come up against sort of barriers or just people being difficult where we are trying to recommend adjustments and things and we are basically getting pushback from that… Sometimes it's perhaps they do not understand why it's needed and there's so much in the training that I think would explain why that's needed. And then sometimes I think it's a pushback because they do not quite know how to do it or they are worried they do not have time to do it" (F2).*

There were also concerns about being unaware of students' disabilities, which could be due to university policy around sharing this information:

> *"[the training] made me more aware about the very limited flow of information to the lecturers/staff about learning needs" (S44).*
>
> *"I think the students have the assumption that we know and actually we do not" (F11).*

Staff were aware that this issue could also be a result of disclosure decisions or a lack of an official diagnosis, often due to fear of the stigma that has been mentioned in many previous studies about autistic experiences:

> *"either [the students] or their families have been incredibly resistant to seeking a diagnosis… because of the stigma presumably and it's really not been helpful from the students perspective and actually when they do have a diagnosis and we are able to work with them" (F11).*
>
> *"[they] do not want to be that person who has to go and ask for help… you are spending the whole time trying to fit in and not asking for help" (F7).*

There was acknowledgement of the serious consequences of these barriers and a lack of student support, for example on mental health:

> *"something needs to be done because like autism does not cause mental health conditions. Being autistic in this world causes mental health conditions" (F2).*

3.2.5 Training as acceptable and feasible

Part of the evaluation of any training is feasibility, as it is important that participants on any course feel able to engage with the materials, complete the training, and that the level is appropriate for the length of the course. Participants on our course generally endorsed the training on these points, although there were more reservations about the short course than the full five-week version.

3.2.5.1 Accessibility

Staff appreciated the structure and delivery of the course, in both formats:

> *"both presenters did really well getting across a vast amount of information and context in a comparatively short space of time" (S4).*
>
> *"I knew what I was doing each week. That was really really helpful. And then it meant I knew that I was watching kind of the seminar part and then looking at the student voice and then attending the Q&A session. And then I kind of allocated a bit of time to look at the additional resources as well. So I quite liked that format that really benefited me personally" (F3).*

Staff also discussed how the course content was easy to understand and follow, crucial to the ability to engage with any training and conducive to the learning being retained:

> *"it would have been OK to come into it without so much baseline knowledge, because I think it kind of did work it from ground upwards" (F5).*
>
> *"it's level of pitch was really good" (F8).*

There were a few participants who highlighted that the short course (a single three-hour session rather than the five-week version) felt like it was missing some elements or that the level of content was high for the time allocated:

> *"[would like a] longer course to engage in depth with some of the theories underlying the content" (S50).*
>
> *"the length of the initial session… was quite a lot to take in one go" (S8).*

However, this did not appear to impact the accessibility of the course, with a number of staff describing it as clear and informative:

> *"it would be hard to cover all important information about autism in 30 h, so for the 3 h provided, I think this was an excellent summary" (S16).*
>
> *"A lot of time, effort, expertise and thorough research and consultation with autistic people (which some autism training really lacks!) has clearly been utilised well to deliver a clear, interesting and informative training program that would be accessible for all staff" (S3).*
>
> *"It's the best institutional training I've experienced" (S4).*

3.2.5.2 Flexibility and time management

The nature of many jobs meant that they were not always able to dedicate a large portion of their time to the course, especially if live discussion in the five-week version clashed with other commitments, which some explicitly lamented:

> *"[I] wanted to see what there was in terms of like the breadth of it, and maybe I did not have enough time to go into depth" (F1).*

However, the five-week course structure allowed staff to work at their own pace and fit the resources around their existing schedules, meaning that many still accessed the extra resources and optional readings:

> *"I wasn't sort of stressed trying to fit it in each week" (F7).*
>
> *"I particularly like the fact that it was self-directed time wise, because I could not necessarily do each week… I did two in one week" (F11).*

This flexibility provided more time for reflection for many, enabling them to think about the links between the learning and their professional practice:

> *"able to kind of pause it and kind of think about it and sort of make a few notes" (F2).*
>
> *"could go back and do something and then go forwards and then go ohh that connected you know" (F1).*

3.2.5.3 Range of resources

While some staff valued and enjoyed the range of resources provided outside the lectures, others found the amount offered overwhelming – especially those who had less time to peruse them. For some, this became discouraging as they felt that they were not making the most of the training or able to fully engage:

> *"we kind of learned about not overstimulating and not over informing. But yet there's all these resources to look at" (F12).*
>
> *"was just overwhelmed by the quantity which then made it get a little bit lower in the pecking order" (F8).*
>
> *"would feel a little bit guilty if I had not looked at everything" (F3).*

However, other staff emphasized that they *"did not feel pressured to have to go through everything"* (F2), something which was made explicit as part of the training. Additionally, many staff enjoyed the extra resources. The option to engage further, and to follow individual preferences on format (such as choosing to read blogs, or watch videos, or listen to podcasts) was mentioned as a specific strength of the training:

> *"it made the training… it sort of brought it to life with those different elements" (F3).*
>
> *"[I] liked the interplay of different resources…something to read, something to watch, something to hear, listen to" (F1).*
>
> *"I personally would not use the social media links… but I thought it was a nice thing to include as many others might find this really helpful" (S3).*

These external materials also provided a direction for further reading when staff had the time to research independently. Many did take up this opportunity, showing that the training became more than a tick box exercise and supported genuine engagement, further learning, and reflection about the topics:

> *"I did have one week where I got to look at the extra… YouTube clips and so on and they were very cool … autistic people kind of sharing their experiences." (F10).*
>
> *"I had the luxury of time. I think I did pretty much all of them and then fell down some Internet wormholes, you know following up on more off of that" (F11).*

> *"The presentations, they were really useful to sort of introduce all the concepts but it was more the YouTube videos and the interviews with the students that I thought really engaged me" (F7).*

4 Discussion

Autistic students are more vulnerable to stress both during the transition to university and once they are enrolled, and, because of stigma, may feel the need to mask their autistic traits at the cost of their mental health (19, 20, 22, 25). Despite their increased risk of difficulties, they may not be able to access suitable support at university (4, 8, 35). Many encounter staff who hold negative or inaccurate beliefs about autism and are therefore either unapproachable or not able to help (7, 11). The current study evaluates a training course designed to address these issues through improving staff knowledge about autism and thereby potentially make them 'safe people' for autistic students to talk to. Staff completed one of two versions of the training, a 10-h course delivered over five weeks (full course), or a 3-h course delivered in one session (short course). This is one of the first papers to report on autism awareness training specifically in the HE context, which is important considering the growing number of autistic students in universities.

Results from the ASK-Q (40) did not show a significant difference in autism knowledge and stigma for the training overall. This could be due to ceiling effects as pre-training scores for all staff were relatively high, with a mean score of 41 of a possible 49. The questionnaire itself was not tailored to the content of the course, so staff may have gained additional knowledge that was not represented by the measure. There was a significant difference for the online short course, which demonstrates that the training could have an impact on knowledge.

For one version of the training, the in-person short course, ASK-Q scores were lower post-training but the reasons for this are unclear. It may be the case that for some of the questions, the training content led staff to mistakenly change their answers. For example, the course covered stereotypes of autism and explained that not all autistic people are boys or men, as is often depicted in media (42). After learning this, trainees could have disagreed with the statement "autism is more frequently diagnosed in males than females," even though it is correct. Short course participants also had less time between taking the pre- and post-training questionnaires than their full course counterparts, potentially causing a lack of focus or interest in answering the same questions.

While there were no statistical changes in ASK-Q scores pre- and post-training, this does not mean that the training itself was ineffectual. Evaluation interviews and feedback surveys revealed a set of significant benefits and impacts for trainees on both versions of the course.

One of the leading points from the qualitative data was the value of hearing from autistic people themselves, supporting previous work that has suggested benefits of realistic representation and getting to experience participatory training (37, 39). For the current group of trainees, it meant that they were able to place their new knowledge into context. They were able to recognize that students are not usually able to be this open about their concerns and it solidified the idea of the autistic spectrum being much more varied than is generally assumed.

It should be noted that staff demonstrated some ableist beliefs in their post-training interview quotes. While the training did challenge these views, their presence has the potential to impact the approach taken by staff members (43) and whether students feel comfortable discussing their needs with those individuals (7, 11). For instance, one of the participants explained that they did not expect the autistic students to be "normal," incorrectly framing them as inherently "different" or "other" (44, 45), which could lead to gaps in support within a university context. Autistic people often experience being dismissed because they do not seem to be struggling (24). For students, this can occur because they are masking their autistic traits as well as other challenges such as academic concerns (3). If this continues, particularly for long periods of time (24), it can have a significant impact on mental health (19, 25, 28, 29). Staff therefore need to be more aware that students who appear to be coping may still need support, and this was recognized by those who completed the training.

As noted above, many staff were already familiar with autistic traits and had interacted with autistic students on a regular basis. However, these well-informed staff still felt that they were able to learn from the course. This more nuanced understanding included autistic masking, the recognition of students' individual presentations and needs, and options for new strategies and supports they could offer. Standard academic supports may not be sufficient for every autistic student (8, 35), and students themselves may not always be aware of supports available or whether they could be of use (4). Their implementation, therefore, relies on staff being proactive in suggesting them and being open to their use. This training improved staff awareness of the supports available, encouraged them to continue learning more and to share the information with colleagues, which could lead to an increase in uptake and therefore improvements in autistic quality of life and academic achievement in HE.

In addition to being aware of university-wide support options, staff also discussed their intentions to adapt their own practice. It has been shown that training that provided an increased understanding of autistic traits helped peer mentors take on approaches that worked for autistic students (39). Adaptations mentioned by staff in the current work included adjusting for social communication and sensory processing differences. The former can prevent students from being able to self-advocate (35), while the latter can make the physical environment of university overwhelming (5, 12). Individual staff making these changes, and potentially spreading them through word-of-mouth to colleagues, therefore has the potential to build better relationships between staff, students, and the university beyond the realm of the training.

The final theme from the qualitative responses was that of systematic barriers affecting autistic students – and staff in supporting them. While some of these – such as sharing good practice and encouraging staff to be more open to student concerns – could be addressed by this training, it needs to occur alongside more large-scale improvements. For example, future university buildings and renovations should be designed in an inclusive manner (12), and policy changes need to be made to improve access to support (46). Training may, however, improve the general inclusivity of campus life and supportive staff have been shown to make a difference to autistic students' experiences in meaningful ways (7).

Finally, feedback also considered the structure of the training itself. Staff generally found the course accessible and easy to manage, depending on the rest of their workload. There were varying opinions regarding the extra resources provided. While some staff appreciated the chance to dive deeper into the content, others felt overwhelmed and intimidated by the amount, despite these being optional. The time pressures that some staff experienced highlighted the need for university departments to prioritize this type of training and allocate more time for it to their staff. Issues around promoting and ensuring high rates of uptake in this kind of training are discussed in Section 4.2.

4.1 Implications for practice

Compared to the general student population, autistic students are less likely to complete their degrees (4) partly due to a lack of knowledge and support from staff (11). The results of this study indicated that, after training, staff felt more confident in recognizing and discussing individual students' needs. Universities could begin to address the gap in students' degree completion and improve support systems by introducing further training, and allocating sufficient time for staff to complete it.

Training of this nature can be delivered online, using pre-existing staff training platforms, which would make it simple for institutions to implement. Autistic people should be involved in the development of such training, as they are recognized as experts (47) and their lived experience was described by the current sample as particularly valuable. The course described in this paper is currently being adapted for use at other universities, in addition to charities and other groups responsible for supporting autistic people.

4.2 Limitations

This training course was offered on a voluntary basis for staff and required a time commitment either across the summer break or for a single afternoon session without alternative dates. Therefore, it is likely that those who completed the course recognized that they needed to learn more about autism and were motivated to do so. Previous studies (11, 24) suggest that some staff may assume that autistic people may not need support, or that they are unlikely to have autistic students in their classrooms (33). The people who are most in need of such training may not have felt the need or the inclination to attend. This means that the results may look very different, both in terms of the statistical outcomes and the qualitative evaluation, with a different cohort of trainees, something which would be important to test with future studies.

The ASK-Q (40) was not adapted for this training course. Many of the items include questions about children and early interventions that were not relevant for the university-based target group. While it was important to use a recognized and validated measure as an evaluation tool, this may have impacted the results as trainees would not have recognized what they had learned in the questions asked. Those whose scores got worse often changed to incorrect answers on items relating to common autism stereotypes which are based in truth, suggesting that the training did make them question their assumptions, but possibly did not reinforce new knowledge strongly enough. It may be that it is more appropriate for future evaluation studies to use or develop questionnaires which are more closely tailored to the population targeted with the training. It is also important to recognize that the disparity between the number who completed the training, and the number who completed the evaluation surveys, may have impacted the statistical results.

Finally, this study very much focused on attempting to change attitudes and support capacity at the individual, rather than systemic, level. While this is important and has the potential to improve the experiences of autistic HE students with individual members of staff, it does not address the wider systemic issues which have been identified both in previous literature and by the participants in this study. Future work should focus on improving HE systems, from application and transition from school through to assessment and transition into employment or further study. These are the areas with the potential to have larger-scale impact for a wider range of autistic and neurodivergent students overall.

4.3 Conclusion

Despite no statistically significant differences between pre- and post-training autism knowledge scores overall, staff still benefitted from the training. The qualitative data showed that even staff who previously had a high level of knowledge or experience working with autistic people were able to learn new information and develop a nuanced understanding of the autistic university experience. This emphasizes the need for multiple methods of evaluation, as a reliance on quantitative data would have missed this more subtle, practical impact.

Participants strongly valued learning from autistic students, which helped put their learning into context and further demonstrated the variance within the autism spectrum. This highlights the importance of both co-production and accurate representation. The training helped to make staff more aware of both existing supports for students and the systematic barriers they face. Trainees discussed plans to alter their approach to working with students, as well as recognizing the importance of sharing good practice. This may allow the course to have a wider, lasting impact through word of mouth and sharing resources with team members. Overall, the training was shown to be feasible and impactful, and shows the importance of HE staff receiving this kind of training to improve how they work with and support autistic students, with potential positive long-term impacts on quality of life and student outcomes.

Data availability statement

The raw data supporting the conclusions of this article will be made available by the authors, without undue reservation.

Ethics statement

The studies involving humans were approved by School of Education Ethics Committee, School of Education, University of Bristol. The studies were conducted in accordance with the local legislation and institutional requirements. The participants provided their written informed consent to participate in this study.

Author contributions

EJ: Data curation, Formal analysis, Investigation, Project administration, Writing – original draft, Writing – review & editing. FrS: Conceptualization, Formal analysis, Writing – review & editing, Methodology. MH: Conceptualization, Formal analysis, Resources, Writing – review & editing, Methodology. SB: Conceptualization, Formal analysis, Resources, Writing – review & editing, Methodology. TT: Conceptualization, Formal analysis, Writing – review & editing, Funding acquisition. HH: Conceptualization, Formal analysis, Writing – review & editing, Funding acquisition. SE: Conceptualization, Formal analysis, Writing – review & editing, Funding acquisition. FeS: Conceptualization, Data curation, Formal analysis, Funding acquisition, Investigation, Methodology, Project administration, Resources, Supervision, Writing – original draft, Writing – review & editing.

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References

1. Office for Students. (2022). Student characteristics data: Population data. Available at: https://www.officeforstudents.org.uk/data-and-analysis/student-characteristics-data/population-data-dashboard/

2. Davis MT, Watts GW, López EJ. A systematic review of firsthand experiences and supports for students with autism Spectrum disorder in higher education. *Res Autism Spectr Disord* 84 (June): Article 101769. (2021) 84:101769. doi: 10.1016/j.rasd.2021.101769

3. Hees V, Valérie TM, Roeyers H. Higher education experiences of students with autism Spectrum disorder: challenges, benefits and support needs. *J Autism Dev Disord.* (2015) 45:1673–88. doi: 10.1007/s10803-014-2324-2

4. Anderson AH, Carter M, Stephenson J. Perspectives of university students with autism Spectrum disorder. *J Autism Dev Disord.* (2018) 48:651–65. doi: 10.1007/s10803-017-3257-3

5. Bolourian Y, Zeedyk SM, Blacher J. Autism and the university experience: narratives from students with neurodevelopmental disorders. *J Autism Dev Disord.* (2018) 48:3330–43. doi: 10.1007/s10803-018-3599-5

6. Wood R. Autism, intense interests and support in school: from wasted efforts to shared understandings. *Educ Rev.* (2021) 73:34–54. doi: 10.1080/00131911.2019.1566213

7. Scott M, Sedgewick F. "I have more control over my life": a qualitative exploration of challenges, opportunities, and support needs among autistic university students. *Autism Dev Lang Impairments.* (2021) 6:239694152110104. doi: 10.1177/23969415211010419

8. Jackson SLJ, Hart L, Brown JT, Volkmar FR. Brief report: self-reported academic, social, and mental health experiences of post-secondary students with autism Spectrum disorder. *J Autism Dev Disord.* (2018) 48:643–50. doi: 10.1007/s10803-017-3315-x

9. Ying CR, Richdale AL. Educational experiences and needs of higher education students with autism Spectrum disorder. *J Autism Dev Disord.* (2016) 46:31–41. doi: 10.1007/s10803-015-2535-1

10. Gurbuz E, Hanley M, Riby DM. University students with autism: the social and academic experiences of university in the UK. *J Autism Dev Disord.* (2019) 49:617–31. doi: 10.1007/s10803-018-3741-4

11. Cage E, De Andres M, Mahoney P. Understanding the factors that affect university completion for autistic people. *Res Autism Spectr Disord.* (2020) 72:101519. doi: 10.1016/j.rasd.2020.101519

12. Goddard H, Cook A. "I spent Most of Freshers in my room"—a qualitative study of the social experiences of university students on the autistic Spectrum. *J Autism Dev Disord.* (2022) 52:2701–16. doi: 10.1007/s10803-021-05125-2

13. Lambe S, Russell A, Butler C, Fletcher S, Ashwin C, Brosnan M. Autism and the transition to university from the student perspective. *Autism.* (2019) 23:1531–41. doi: 10.1177/1362361318803935

14. Butler RC, Gillis JM. The impact of labels and behaviors on the stigmatization of adults with Asperger's disorder. *J Autism Dev Disord.* (2011) 41:741–9. doi: 10.1007/s10803-010-1093-9

15. Sasson NJ, Faso DJ, Nugent J, Lovell S, Kennedy DP, Grossman RB. Neurotypical peers are less willing to interact with those with autism based on thin slice judgments. *Sci Rep.* (2017) 7:40700. doi: 10.1038/srep40700

16. Cage E, Troxell-Whitman Z. Understanding the relationships between autistic identity, disclosure, and camouflaging. *Autism Adulthood.* (2020) 2:334–8. doi: 10.1089/aut.2020.0016

17. DeNigris D, Brooks PJ, Obeid R, Alarcon M, Shane-Simpson C, Gillespie-Lynch K. Bullying and identity development: insights from autistic and non-autistic college students. *J Autism Dev Disord.* (2018) 48:666–78. doi: 10.1007/s10803-017-3383-y

18. Turnock A, Langley K, Jones CRG. Understanding stigma in autism: a narrative review and theoretical model. *Autism Adulthood.* (2022) 4:76–91. doi: 10.1089/aut.2021.0005

19. Miller D, Rees J, Pearson A. "Masking is life": experiences of masking in autistic and nonautistic adults. *Autism Adulthood.* (2021) 3:330–8. doi: 10.1089/aut.2020.0083

20. Perry E, Mandy W, Hull L, Cage E. Understanding camouflaging as a response to autism-related stigma: a social identity theory approach. *J Autism Dev Disord.* (2022) 52:800–10. doi: 10.1007/s10803-021-04987-w

21. Cook J, Hull L, Crane L, Mandy W. Camouflaging in autism: a systematic review. *Clin Psychol Rev.* (2021) 89:102080. doi: 10.1016/j.cpr.2021.102080

22. Chapman L, Rose K, Hull L, Mandy W. I want to fit in… but I Don't want to change myself fundamentally: a qualitative exploration of the relationship between masking and mental health for autistic teenagers. *Res Autism Spectr Disord.* (2022) 99:102069. doi: 10.1016/j.rasd.2022.102069

23. Hull L, Petrides KV, Allison C, Smith P, Baron-Cohen S, Lai M-C, et al. "Putting on my best Normal": social camouflaging in adults with autism Spectrum conditions. *J Autism Dev Disord.* (2017) 47:2519–34. doi: 10.1007/s10803-017-3166-5

24. Bradley L, Shaw R, Baron-Cohen S, Cassidy S. Autistic adults' experiences of camouflaging and its perceived impact on mental health. *Autism Adulthood.* (2021) 3:320–9. doi: 10.1089/aut.2020.0071

25. Beck JS, Lundwall RA, Gabrielsen T, Cox JC, South M. Looking good but feeling bad:"camouflaging" behaviors and mental health in women with autistic traits. *Autism.* (2020) 24:809–21. doi: 10.1177/1362361320912147

26. Lever AG, Geurts HM. Psychiatric co-occurring symptoms and disorders in young, middle-aged, and older adults with autism Spectrum disorder. *J Autism Dev Disord.* (2016) 46:1916–30. doi: 10.1007/s10803-016-2722-8

27. Cage E, Di Monaco J, Newell V. Experiences of autism acceptance and mental health in autistic adults. *J Autism Dev Disord.* (2018) 48:473–84. doi: 10.1007/s10803-017-3342-7

28. Cassidy S, Bradley L, Shaw R, Baron-Cohen S. Risk markers for suicidality in autistic adults. *Mol Autism.* (2018) 9:42. doi: 10.1186/s13229-018-0226-4

29. Cremone IM, Carpita B, Nardi B, Casagrande D, Stagnari R, Amatori G, et al. Measuring social camouflaging in individuals with high functioning autism: a literature review. *Brain Sci.* (2023) 13:469. doi: 10.3390/brainsci13030469

30. Bewick B, Koutsopoulou G, Miles J, Slaa E, Barkham M. Changes in undergraduate students' psychological well-being as they Progress through university. *Stud High Educ.* (2010) 35:633–45. doi: 10.1080/03075070903216643

31. Thorley C. *Not by degrees: Improving student mental health in the UK's universities.* London: IPPR (2017).

32. Accardo AL, Jay Kuder S, Woodruff J. Accommodations and support services preferred by college students with autism Spectrum disorder. *Autism.* (2019) 23:574–83. doi: 10.1177/1362361318760490

33. Gelbar NW, Shefcyk A, Reichow B. A comprehensive survey of current and former college students with autism Spectrum disorders. *Yale J Biol Med.* (2015) 88:45–68.

34. Lei J, Calley S, Brosnan M, Ashwin C, Russell A. Evaluation of a transition to university programme for students with autism Spectrum disorder. *J Autism Dev Disord.* (2020) 50:2397–411. doi: 10.1007/s10803-018-3776-6

35. Nuske A, Rillotta F, Bellon M, Richdale A. Transition to higher education for students with autism: a systematic literature review. *J Divers High Educ.* (2019) 12:280–95. doi: 10.1037/dhe0000108

36. Gillespie-Lynch K, Bisson JB, Saade S, Obeid R, Kofner B, Harrison AJ, et al. If you want to develop an effective autism training, ask autistic students to help you. *Autism*. (2022) 26:1082–94. doi: 10.1177/13623613211041006

37. Gillespie-Lynch K, Brooks PJ, Someki F, Obeid R, Shane-Simpson C, Kapp SK, et al. Changing college students' conceptions of autism: an online training to increase knowledge and decrease stigma. *J Autism Dev Disord*. (2015) 45:2553–66. doi: 10.1007/s10803-015-2422-9

38. Hamilton J, Stevens G, Girdler S. Becoming a Mentor: the impact of training and the experience of mentoring university students on the autism Spectrum. *PLoS One*. (2016) 11:e0153204. doi: 10.1371/journal.pone.0153204

39. Jones DR, DeBrabander KM, Sasson NJ. Effects of autism acceptance training on explicit and implicit biases toward autism. *Autism*. (2021) 25:1246–61. doi: 10.1177/1362361320984896

40. Harrison AJ, Bradshaw LP, Naqvi NC, Paff ML, Campbell JM. Development and psychometric evaluation of the autism stigma and knowledge questionnaire (ASK-Q). *J Autism Dev Disord*. (2017) 47:3281–95. doi: 10.1007/s10803-017-3242-x

41. Braun V, Clarke V. Using thematic analysis in psychology. *Qual Res Psychol*. (2006) 3:77–101. doi: 10.1191/1478088706qp063oa

42. Jones SC, Gordon CS, Mizzi S. Representation of autism in fictional media: a systematic review of media content and its impact on viewer knowledge and understanding of autism. *Autism*. (2023) 27:2205–17. doi: 10.1177/13623613231155770

43. McVey AJ, Jones DR, Waisman TC, Raymaker DM, Nicolaidis C, Maddox BB. Mindshift in autism: a call to professionals in research, clinical, and educational settings. *Front Psych*. (2023) 14:1251058. doi: 10.3389/fpsyt.2023.1251058

44. Milton D, Sims T. How is a sense of well-being and belonging constructed in the accounts of autistic adults? *Disabil Society*. (2016) 31:520–34. doi: 10.1080/09687599.2016.1186529

45. Nachman BR, Brown KR. Omission and othering: constructing autism on community college websites. *Commun Coll J Res Practice*. (2020) 44:211–23. doi: 10.1080/10668926.2019.1565845

46. Margaret JVR, Liang B. Improving autistic students experiences in higher education: developing a community framework for individual autistic student and autistic community flourishing. *Autism in Adulthood*. (2023). doi: 10.1089/aut.2022.0079 [online ahead of print].

47. Gillespie-Lynch K, Kapp SK, Brooks PJ, Pickens J, Schwartzman B. Whose expertise is it? Evidence for autistic adults as critical autism experts. *Front Psychol*. (2017) 8:438. doi: 10.3389/fpsyg.2017.00438

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Autistic discussion forums: insights into the topics that clinicians don't know about

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Background: User-led autism discussion forums provide a wealth of information about autistic lived experiences, albeit oriented toward those who regularly use computers. We contend that healthcare professionals should read autism discussion forums to gain insight, be informed, and in some cases, to correct assumptions about autistic persons' lives and possibilities. But experts may be dismissive of user-led forums, believing forums to be filled with myths, misinformation, and combative postings. The questions motivating our research were: Do online forums raise issues that are educational for clinicians and other stakeholders? Are forums useful for those who do empirical research?

Method: Content analysis was conducted on 300 posts (62,000 words) from Reddit, Quora, and Wrong Planet. Forums were sampled to reflect broad topics; posts were selected sequentially from the identified forums. The authors read through posts in the Excel sheet, highlighting statements that were the main ideas of the post, to discern both broad categories of topics and more specific topics. We coded content pertinent to classic autism myths and analyzed attitudes towards myths such as 'lack emotion' and 'cannot form relationships.' To document whether forum posts discuss topics that are not widely known outside of elite experts, we compared discussion content to new material about autism contained in the March 2022 DSM 5 Text revision.

Results: Classic autism myths were discussed with examples of when elements of myths may be valid. Posters described cases where parents or therapists believed myths. Experts may believe autism myths due to rapid changes in diagnostic practices and due to their lack of knowledge regarding the characteristics of autistic people who have typical intellectual abilities. We conclude that forums contain high-value information for clinicians because all concepts in the DSM 5 text revision were discussed by posters in the years before the text revision appeared. Ideas that are only slowly becoming part of the research literature are discussed at length in forums. Reading and analyzing forums is useful for both clinicians and scientists. In addition, the relative ease of forum analysis lowers the bar for entry into the research process.

KEYWORDS

autism, user forums, content analysis, online spaces, diagnosis, myths and facts

Introduction

Health-related online discussion forums have grown in popularity as people learn from each other while sharing daily life struggles (1). How should experts in the field of autism, such as clinicians, therapists, educators, and researchers, view autism discussion forums? Forums are widely appreciated for giving voice to autistic people (2, 3). Online communities share discourses about how to develop an autistic identity, understand autism as a culture, and reframe deficit as difference (4). Discussion forums also provide practical implications for friends and family members (3–5). But are forums relevant to experts? Autistic people have long expressed frustration that autism is misunderstood (6, 7), as in this quote reported by Linton et al. (3): *That's why I say that 'experts' frequently do not get autism at all. They truly need our input. However, I also realize that they do not generally consider us a reliable source.* Consistent with this quote, researchers have argued that autistic people should be viewed as autism experts (8–10). The current paper examines whether online discussion forums provide relevant, timely, and insightful information not just for lay people but for experts.

Change in how autism is viewed has been rapid. Diagnosis has evolved, with growing numbers of people diagnosed in adulthood (6). With changes in diagnostic criteria, the majority of autistic people do not have an intellectual disability (11, 12). Current criteria appear to be male-centered leaving women undiagnosed (3, 13, 14). Autistic people are encouraged to seek employment, leisure activities, and fulfillment in life commensurate with their abilities (7, 15–18). Some research analyzes forums to characterize autistic perspectives (3, 4) but there is currently no systematic examination of whether the content of autistic forums is likely to be novel and revelatory for researchers and clinicians.

Analyzing forum content with quantitative and qualitative methods

Forum analysis refers to extracting information, both quantitative and qualitative, from online discussion forums. Both quantitative and qualitative analyses can be applied to discussion posts drawing on the techniques for analyzing any textual information (19). A quantitative approach is to count the frequencies of words or phrases; and interpret their significance (20). Qualitative approaches involve identifying consistent themes across several texts (21). We briefly review prior examples of forum analysis.

Giles and Newbold (1) examined the history of online self-help networks and online communities where people discuss their experiences of diverse psychiatric disorders. They discussed ethical considerations, methods for selecting forums, and analytical techniques. Using DSM-IV-related search terms, those authors constructed a large corpus of forum posts. Their specific research question was how users discussed the importance of having an official diagnosis. Healthcare professionals have traditionally been cautious about the value of user-led forums, as this can encourage self-diagnosis. Somewhat surprisingly, many users demonstrated a reverence for having an official diagnosis (1). Formal diagnoses allowed users to present themselves as part of an in-group with special authority to speak about their disorder or disability.

Interestingly, a later content analysis of autism discussion posts found a different attitude towards diagnosis. Sarrett (22) analyzed posts on Wrong Planet, a website designed to celebrate autism in all its diversity, hosting diverse forums as well as articles and videos about employment, schools, and parenting. Sarrett categorized comments according to their primary attitude: accept self-diagnosis, reject self-diagnosis, and middle-of-the-road. Those who rejected self-diagnosis were concerned about legitimacy, like the reports in Giles and Newbold (1). However, arguments for accepting self-diagnosis were plentiful (23) and focused on the difficulty of obtaining a diagnosis as an adult, skepticism about diagnostic practices, and being a self-expert.

Another noteworthy example of forum analysis examined Facebook groups for caregivers of Alzheimer patients. The authors used a careful longitudinal method to detect patterns in daily-life situations over a 6-month period. Caregivers most frequently discussed their exhaustion, desire to give up, and struggles in communicating with and obtaining help from family members, such as sharing care responsibilities. Another category was discussion of violent behavior by people with Alzheimer's dementia, a topic understudied by researchers.

Discussion forums have been analyzed for how they are used in positive and prosocial ways. This is particularly true of autism forums, as the internet has allowed the emergence of a vibrant autism community. Internet forums allow autistic individuals to connect with others not just for social support, but to organize and advocate for recognition of autistic cultural differences (2). An example is Parsloe's (4) analysis of The Aspies Central Website. She documented how users participated in and contributed to a worldwide shift in the understanding of autism from a biomedical to a cultural perspective. Forums have also been used as a source of data for basic science questions, including autistic person's religious beliefs (24) and special interests (25). A survey that asked autistic people to report their religious beliefs yielded similar results to quantitative coding of discussion forums where autistic forum users discussed their religious beliefs (24).

Dangers of discussion forums: misinformation, myths, and combative exchanges?

For autism discussion forums to be touted as a source of insight for clinicians, we must address the popular perception that social media sites spread fake news, false information, and rumors (5). Discussion forums allow large amounts of unverified information to spread rapidly (26), making this a concern in health-related fields (27). Autism myths have been featured for years in books and informational websites (28). Surveys reveal that both autistic and non-autistic people have uneven knowledge about autism (9, 29). If myths are discussed in online communities, it is important to learn if false information is shared. If myths are rebutted in online discussions, it would be useful to analyze whether the discussion about myths goes beyond information commonly known to experts.

Experts seeking insights will lack the motivation to read user-led forums if they have an argumentative or nasty tone, as has been reported for some online sites (30). Incivility has been noticed most strongly in political discussion forums, but anonymity on the internet could license sarcasm and mockery in a variety of online forums.

TABLE 1 Characteristics of posts selected with examples of questions.

	Number of posts	Average words per post	Number of threads	Example of the question starting a thread
Quora (8 forums)				
Autistic girls and women	50	142	16	How to get my parents to show me my autism diagnosis papers?
Exploring autism	20	254	8	Did you struggle with impostor syndrome after your autism diagnosis?
Autism awareness	20	245	3	Are people with high functioning autism more similar to neurotypical people than to people with low functioning autism?
Autistic people matter	15	170	9	Do autists have good intuition? it goes a bit against their rational, logical nature?
Asperger syndrome	15	424	2	Is it common for Aspies to suddenly withdraw from relationships?
High functioning autism	10	485	8	Do people treat you like you are an idiot because of your autism diagnosis even if you are actually smart?
Living with autism	5	425	4	Has Aspergers made employment difficult?
Autistic nerds and geeks	5	583	3	When should I tell my child they are on the spectrum?
				Total Quora posts: 140
WrongPlanet (3 forums)				
Women's discussion	25	131	11	Was Diagnosis a Life Changer?
Adult autism issues	25	215	18	Am I on the asexual scale because I've had relationships without wanting to have sex?
In-depth adult life discussion	10	330	7	Can autism be conditioned out of a person by corrective behavior?
				WrongPlanet posts: 60
Reddit (4 forums)				
Ask autistics	50	132	6	I have always had difficulties relating to romance in media.
Aspergers	25	104	2	I stopped masking, now i do not even remember how to.
Autism	20	269	17	I was diagnosed with Autism as a child but parents hid it from me. I found out when I was 19.
Autistic adults	5	57	4	Does anyone else get bothered by how empathetic they are?
				Reddit posts: 100
Total forums = 15		Total words in corpus: 62,000 Total posts: 300		

Rösner et al. (31) conducted an online experiment in which participants read a news article about marijuana legalization, followed by between zero and six uncivil comments. Exposure to even one comment with a hostile tone was sufficient to increase readers' negative cognitions. It is thus worthwhile to determine how often uncivil comments appear in autistic online discussion forums.

Motivation and overview of the current article

Our goal was to address whether forums are useful for clinicians, educators, and researchers. Our own reading of forums, including our prior forum analysis, suggested forums had potential as rich sources of insight, even for experts. But experts may be wary of user-led forums, given popular concerns that social media is filled with myths, misinformation and combative postings (5). Our first goal was to scrutinize posts to determine how often they contained misinformation and myths, and if present, how did other posters respond to these. We also wanted to establish whether discussion forums can provide insight to experts such as clinicians (9). Establishing whether posts are informative to experts has a subjective element since this depends on those experts' knowledge base and experience. What material could substantiate a subjective impression that discussion posts discuss up-to-the-minute issues? We tackled this by comparing discussion topics to newly revised material in the March 2022 DSM-5 Text Revision. If online forums, with material dated prior to March 2022, review the topics in this revision, it would lead credence to the claim that discussion forums frequently contain current, informative information.

Method

Selecting platforms, forums and posts

Reddit, Quora, and WrongPlanet were used as these are publicly accessible social media platforms (websites) with written postings in a question-answer format. Wrongplanet is a website serving the autistic community. Reddit and Quora are large websites that host a variety of forums focusing on specific topics, although the topic of a forum (usually identified by its title) can range from general to specific in content (see examples in Table 1). Our team was already familiar with the forums dedicated to autism on Reddit and Quora, from prior extensive forum analysis (32). We already knew the titles of many of the specific discussion forums that had been created by autistic individuals for sharing and information exchange for other autistic people. Because new forums can be created and old ones retired, we began by using the search terms *Reddit autism*, *Quora adults with autism, Quora autism in women.* A target of 300 posts was set as a number large enough to extract generalizations but small enough to be tractable. Table 1 lists the 15 forums selected, number of posts within each forum, and other relevant information, including examples of questions.

The researchers who selected forums and discussion questions were the two co-authors (TM and KB), who were students in the early days of the project, and 3 additional undergraduate lab members. The corpus of 300 posts was compiled before any hypotheses were made and before any decisions had been made about content to investigate. The goal was to compile a broad set of posts and discover the topics. The student-led team coordinated with each other on selecting forums and how to paste posts into an Excel spreadsheet for later analysis. The group agreed to select forums on highly general topics, since the goal at the beginning of the project was to compile forums covering broad, general topics. Forums devoted to broad, general topics are also the most frequently accessed and perused by users, so these are forums that are preferentially delivered in response to search queries. A corpus of broad, general topics will also resemble what ordinary internet users might experience if they decided to explore autism discussion forums. To convey to readers the meaning of "general topics," all of the forums used are listed in Table 1. Examples of more specific forums that were avoided are, from Reddit: Spicy Autism, Autistic With ADHD, and Autism Translated.

For each forum selected, team members agreed to start with the first discussion thread that they saw on the website, and to paste into the Excel sheet additional posts in the thread until the discussion thread was concluded, or until between 10 and 25 posts had been obtained from a selected forum. Posts were excluded if they had under 30 words or were clearly off-topic. Our corpus of posts was constructed in the spring of 2021 and reflected posts from November 2017 to April 2021. Posts from prior years were included because searches in web browsers, as well as Quora and Reddit algorithms, preferentially present posts that are highly accessed and highly up-voted.

It is typical to think of discussion forums as being short exchanges between numerous participants, mimicking a conversation. However, our corpus contained many lengthy posts which presented (or responded to) a unique question. These "one-off" posts are common at Quora. Quora specializes in short questions (usually just one sentence) which are then answered in-depth by a person with expertise in the topic. Answers are voted up by readers, leading to a single high-quality post being presented prominently on the Quora website.

Ethical concerns

The institutional review board at our university did not consider forum analysis to be human subjects research, because our team did not interact with any persons online. This stance is consistent with other research on forums (1, 33). Nonetheless, this is a grey area and norms may be changing. Some researchers post an introductory note to inform users that academic researchers are reading posts for research purposes (22). However, this practice infuses researchers' goals into the forum, potentially disrupting a space for autistic-only voices, and could load an additional set of expectations onto posters (34).

Content analysis

Broad topics

The authors read posts in the Excel sheet to identify what topics were being discussed. Like conventional content analysis (19), we grouped topics into categories and sub-categories. The authors discussed these categories during lab meetings and ultimately agreed on the presence of 10 broad topics. Categories, subcategories, and their frequencies are listed in Supplementary Table S1, available in the supplemental information. We also coded whether posters reported having an official diagnosis (22%), being self-identified (43%), being a parent (7%), not being autistic (2%), being neurodivergent (2%) or providing insufficient information to categorize (24%). The posts that contained no information had content consistent with identifying as autistic. Note that none of the posts discussed in the section on myths or DSM-5 relevance were made by parents or by people who identified as not autistic.

After conducting a content analysis of topics, our team had long discussions about the insightful ideas described in the corpus. It was at that point that we turned our attention to the idea of analyzing the 300 posts to address whether forums are useful for clinicians, educators, and researchers. The posts were not selected in advance to reference myths, or to reference topics discussed in the DSM 5 text revision.

Myths and misinformation

To determine whether forums contained any disinformation, we analyzed the corpus for references to myths about autism. Focusing on myths has the advantage that many websites exist which list myths in straightforward language. These websites also explain why these are myths and what facts are accepted by experts. We used the search term *autism myths* to identify lists of myths. We picked 2 websites due to their high scientific prestige: the Kennedy Krieger Institute, and the US Department of Health and Human Services. We included a third website, Autism Awareness,[1] due to its focus on education, its non-profit status, and because it was a reputable source outside of the US. Each website contained 5–8 myths, which we amalgamated together to create a master list of 17 myths either about autism or about autistic people (see Table 2). When we describe the myths, we retain the language *people with autism* as this terminology is used in the sources from which we derived the myths.

- *Six myths about autism*: Autism is a disease, is relatively new, can be cured, can be cured by special diets, is caused by vaccines, is caused by bad parenting.
- *Eleven myths about autistic persons*: Autistic people are generally or always nonverbal, savants, violent, lack emotions, lack empathy, have mental/intellectual disabilities, cannot stand to be touched, cannot learn, cannot form relationships, have no sense of humor, do best at jobs which entail repetitive tasks.

Combining three sources created a more comprehensive list than using a single source, and was consistent with statements used to

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[1] autismawareness.com.au/

TABLE 2 No posts endorsed myths but posters made three types of comments.

Total posts in corpus of 300	Myth	Elements of myth valid	Others believe myth	Challenge myth	Percentages (out of 52 posts with myths)
10	Lack empathy	5	1	4	19
10	Lack emotion	5	1	4	19
6	Cannot stand to be touched	6	0	0	12
6	Cannot form relationships	1	2	3	12
4	No sense of humor	3	1	0	8
4	Have intellectual disabilities	2	0	2	8
4	Best at repetitive tasks	0	0	4	8
2	Is a disease	0	0	2	4
2	Can be cured	0	2	0	4
2	All are nonverbal	0	2	0	4
1	Poor parenting	0	0	1	2
1	Autism is relatively new	0	0	1	2
0	Cured by special diets	0	0	0	0
0	Caused by vaccines	0	0	0	0
0	Cannot learn	0	0	0	0
0	Are violent	0	0	0	0
0	Are savants	0	0	0	0
Total 52	Total	22	9	21	

measure knowledge about autism in surveys by Gillespie-Lynch et al. (9) and Stone (35). Also pertinent are 10 myths in the book *Life on the autism spectrum: Translating myths and misconceptions into positive futures* (28). Their 10 myths were all in our set except Bennett et al. (28) included the myth of the autism epidemic. Bennet et al. (28) included refrigerator mothers while our list of myths referenced the more general category 'bad parenting.'

All posts were scrutinized for the presence of these myths or for anything else that seemed medically incorrect or non-standard. We also noted whether any posts contained hurtful comments or a generally angry or negative tone.

Comparing forum content to novel material on autism in DSM 5 text revision

We wanted to rigorously examine the impression that autistic people posting on discussion forms frequently have insights about autism that are not widely known to clinicians and researchers, thus demonstrating that autistic people sometimes have considerable expertise regarding autism, in addition to insider knowledge. To be representative of autistic interests and concerns, our corpus contained a variety of topics. We thus instead sought to demonstrate that autistic discussion forums contained a diversity of knowledge about autism that was not widely known to typical autistic experts.

Results

We first briefly address our broad analysis of the content of posts, before turning to the specific questions guiding the project.

Broad categories, topics, and sub-topics

Topics are categories summarizing content, whereas themes are more abstract concepts that include higher-level goals, feelings, and attitudes. We did not have any specific hypotheses about what topics would be discussed in forums. To provide context for our analyses of myths and the DSM 5 text revision, we briefly discuss content analysis of topics. Supplementary Table S1 lists the most common topics identified in the corpus. These are not surprising. Prior peer reviewers informed our team that documenting these topics did not constitute a contribution to the research literature, but we included them as Supplementary material for interested readers.

The most frequently discussed category of topics was *Autism as a Mental Health Condition*. The most common topics within this broad category were the diagnostic process, male/female differences, and sensory sensitivities. A second broad category was *Social Interaction*, where the most frequent topics were difficulty interacting with others, and relationship advice. Our third broad category was *Challenges*, which included the topics of achieving well-being and parenting, such as advocating for school services or learning about one's autism following a child's diagnosis. Our final category of topics was *Interests and Talents*, with the most common topics being special interests and artistic abilities. Special interests were dominated by entertainment and intellectual pursuits, such as psychology, science, and gender studies. Quotes for several topics were extracted to illustrate the quality and variety of posts; these appear in the Appendix (Supplemental materials).

In the next sections, we organize our results under subheadings corresponding to our main questions:

- Did posts contain misinformation and myths?
- Were posts angry or combative?
- Could forums provide insights for healthcare professionals?

Did posts contain misinformation and myths?

None of the posts advocated for the validity of autism myths, nor was medical misinformation found in the posts. Of the 300 posts, 52 posts made reference to at least some aspect of the classic autism myths, although in most cases the myth itself was not mentioned. None of the posts mentioned more than one myth (because the purpose of posts was not to discuss autism myths; another topic was foregrounded). We coded posts that referenced aspects of myths into the following three categories, corresponding to what seemed to be posters' purpose.

- to refute or challenge myths
- to discuss the ramifications of other people incorrectly believing myths.
- to discuss how elements of myths could be valid in some cases or could apply to themselves or could apply in restricted situations.

The quotes excerpted below cover all cases of each myth discussed in our corpus (with exceptions noted below).

Myth: autism can be cured

Two posts discussed other people who apparently believed this myth.

- *My partner once mentioned that he used to be autistic, but his real dad put him through conditioning to stop his autism from being an issue…* [continued in subsequent post after another post asked for details] *His real dad used to put loud static on headphones and force him to listen to it for hours at a time to reduce his sound sensory. He do not talk to his real dad anymore.*
- *Course now with what's happened with his grief and epilepsy his autistic traits are showing more often though his mum still claims he's cured and the traits are merely cause he's mirroring me.*

Myth: autism is caused by poor parenting

While no post endorsed this myth, one thread opened with: *Do you think there's a connection between autism and overprotective parents?* The eight responses rejected the idea of a causal link, as in this example: *Are you asking if overprotective parenting causes autism? If so, the answer ranges from No to Extremely Unlikely. Are you asking if autism causes overprotective parenting? If so, the answer ranges from Possible to Very Likely* (challenge myth).

Three of the 8 responses noted that overprotection could make their autistic characteristics worse. The most explicit example was: …. *it could make children less self-reliant, take opportunities away to practice social skills, prevent them from gaining life experience, reduce self-esteem, cause social anxiety and hamper the development of resilience, thereby making autistic symptoms more noticeable or making the transition to adulthood and independence harder.* These responses could be seen as 'elements of myths could be valid' (because a parenting practice was claimed to exacerbate autistic symptoms), but we decided not to code these responses in this way. Our reasoning was that the posts primarily concerned young adults complaining about parental over-protection. Parental over-protection is distinct in meaning from 'poor parenting' and "making autistic symptoms more noticeable" is distant from "causing autism."

Myth: people with autism are non-verbal

[Discussion with psychiatrist] *She told me that she no longer thought I needed to see a Neurologist and that people with autism are nonverbal and that I did not seem to be one of those kinds of people* (other people believing myths).

One poster described how her good verbal ability caused her mother to disbelieve her autism diagnosis. *My mother will not even read my autism diagnosis. She constantly compares me with people she works with* [in adult social care]*, saying I do not understand, they cannot even speak.... I think she is in denial* (other people believing myths).

Three posts referenced atypical speaking manner, which our team evaluated as distinct from being nonverbal and thus not endorsing elements of the nonverbal myth. These posts are nonetheless interesting as examples of autistic posters' concerns.

- *I was raised in Hong Kong, where no one knew about Aspergers 40 years ago, I was always being punished by acting and speaking not normal.*
- *I struggle with my tone in voice. I speak too fast or too slow. Too loud or too soft.*
- *He can seem "neurotypical" to those who do not know him because he looks "normal" and speaks "normally." Until he does not.*

This next quote probably meant "speaking rarely" rather than being nonspeaking: *I got away with not speaking because girls are allowed to be "shy."*

Myth: autistic people lack emotion

Posts discussed many commonplace aspects of human emotional life. The word *emotion* appeared 37 times in the 62,000-word corpus. Six posts discussed different facets of reduced levels of emotion. We thus labelled these as consistent with 'elements of myths could be valid in some cases.' We grouped the 6 posts into the following four categories.

- Not understanding emotion. *Not understanding your own emotions is a trait of autism, Emotional Intelligence is hard...*
- Not identifying emotions. *I cannot really decipher facial expressions. I am bad at reading emotions of others. (And my own).* *This quote includes a mix of statements about emotion. I feel emotions very deeply but have a hard time identifying what they are. And I can feel other people's emotions but also have trouble identifying them and what not. It's especially hard when they cry because I kinda just sit and stare and try to think of what to say and cannot so I end up looking like a jerk.*
- Not discussing emotions. *Deep emotional conversations about how much you mean to me are not the norm for aspies. We aren't good at explaining how we feel, either physically or emotionally.*
- Emotional shutdown. *Complete shutdowns when afraid or sad.* A second post combined over-emotion, dysregulation and

shut-down: *Why you have meltdowns and either lose your shit or just totally shut down.*

The following reports described having too much emotion, which goes against the myth. We thus included these as cases of 'challenging myth.'

- Emotion dysregulation. *Why you cannot control your emotions sometimes and you hate yourself for it*. Two additional posts also described dysregulation.
- Absorbing others' emotions (relates to empathy, see below). … *emotional 'sponge' (I would absorb others' feelings when they were sad or angry, thus acting like I was)*
- Social expectations for women to be emotional. *[It]costs all women a lot to be social and emotional shielding for everyone else, but when we are autistic the costs rise brutally fast.*

Myth: autistic people lack empathy

One poster recommended that non-autistic people should … *try to meet any autistic people without assumption of delayed emotions, or lack of empathy* (other people believing myths).

In discussing her own symptoms, one poster noted that her problem with empathy was *not so much issues with feeling empathy, but with expressing it.* Four other posts made similar statements (elements of myths could be valid in some cases).

In contradiction to the myth, three posters discussed having too much empathy.

A life of being taken advantage of, because you are so empathetic, even if you do not know how to show it, and you feel EVERYTHING. A life begging to know why you are different. Why you do not fit in.

Does anyone else get bothered by how empathetic they are? I've always been naturally empathetic and compassionate and not until I was around 19 did I really start to be able to turn that off. I still cannot control my emotions a lot but I've gotten a good enough handle on my empathy where I can tune into it if I want to or ignore it (usually).

While talking about how we feel can be hard, a lot of us are strangely empathetic. Like, painfully empathetic.

One poster argued that autistic people are natural empaths. *We spend our whole lives adapting to what people think we should be. We are human chameleons. In essence, we are empathic metamorphs (from Star Trek - Next Generation - The Perfect Mate episode), which is a being that can sense what people around her desire and react accordingly. It is pretty telling that at age 22, I identified heavily with this character. One often misunderstood trait of autistic, is our internal empathic accuracy. This means we make great social psychologists, or that we are great at predicting the thoughts and feelings of another person—we are actually better than non-autistics at this.*

Myth: autistic people cannot stand to be touched

Three posters mentioned dislike of being touched. One poster stated this about herself in response to a post asking people to share their autistic symptoms. *I hate being touched. Especially skin-to-skin contact.* A second post mentioned that "*avoids being touched by others*" *is a common sign of autism.* A third post responded to a request for signs that someone is autistic. The list of signs included: *dislike of touch, does not touch others and/or avoids being touched by others, sometimes physically moving the other person's hand to another part of the body (forearm instead of hand).*

Three additional posts discussed sensory sensitivity to things touching their skin, such as *wearing clothes inside-out so that seams will not be touching my skin*. One post conveyed the feeling to readers: *Imagine you are sunburnt from head to toe. Any touch is absolute torture. Then you have to wear that itchy, scratchy sweater that grandma knitted you last Christmas*. One post noted the impact on a spouse*: I am sensitive to texture and touch all over, it can be an issue with a touch oriented spouse. He is mindful of my sensitivities and I know he needs touch emotionally so we try to compromise.*

The six posts described here were examples of how elements of myths could be valid in some cases. Eight additional posts discussed sensory sensitivities but were not specific to being touched.

Myth: autistic people cannot learn

No post referenced this myth. The posts that came closest to it were two posts about being too tired or not motivated sufficiently to learn. One concerned how cognitive abilities may be altered due to stress associated with autism. *Most of us with autism are so stressed that our learning, memory, digestion, and healing circuits are closed.*

As would be expected in any vibrant and earnest discussion of human development, the corpus contained varied and complex references to learning, with 76 mentions of '*learn*' (and *learned, learning*). Example included: *meltdowns can appear at a young age…as a child gets a bit older they might learn that outward expressions of their distress are 'bad'…* We did not code these remarks as challenging the myth, because the statements referenced learning as what all humans do, with no implications for autism. An exception to this was a post that implicitly challenged the myth by noting the opposite of 'cannot learn': autistic learn quickly when interested. *Autists are very sensitive and learn very fast if we are interested in something* (challenge myths).

One post mentioned enjoyment in learning on one's own. *I learn new things on my own. Languages and information that I find to be interesting. I love to learn new things, and I believe that I have studied psychology and attachment styles on the same level as someone who chose such a path in terms of education. I speak 7 languages, and 6 are self-taught.*

Myth: autistic people cannot form relationships

One poster specifically condemned clinicians for believing this myth: *I had an assessment and was told I cannot be autistic because I'm married. Many women I know have been denied the diagnosis based solely on their ability to maintain some relationships* (other people believing myths).

One poster obliquely referenced the myth, while denying it, by writing: *But never pretend that a person who is autistic does not contribute hugely in a relationship* (challenge myth).

Posters discussed the difficulty of making friends: *Making platonic friends is something I find incredibly difficult*. Discussion also included challenges in romantic relationships: *Funnily my partner had the same problems; we are both autistic, both ADHD, and both started the relationship with rejection issues*. One poster referenced an extreme level of difficulty: *It's a life of loneliness and relationship problems you do not understand* (elements of myths could be valid in some cases).

The above quotes were the only ones that touched on autistic people have difficulties with relationships. Discussion of relationships were prominent across many different threads, figuring in 1 out of 6 posts, while the word *relationship* occurred 77 times in the corpus of 300 posts. Examples included: *How long into a relationship do I wait to tell my partner I'm autistic?* And: *Give the person more time and perhaps take a step back in your relationship* (*especially your physical relationship*). These rich discussions implicitly challenge the myth that autistic people cannot form relationships, but we did not tally them in Table 2 as they are typical for ordinary human conversation and did not intersect with statements about autism.

Myth: people with autism have no sense of humor

Three posters mentioned difficulty understanding jokes, which we coded as 'elements of myths could be valid in some cases.'

An autistic-identified woman wrote *when I make a joke,* [my autistic husband] *can think I am criticizing him.* A second poster mentioned struggling with jokes along with other aspects of language: *...as a girl I was pretty good at masking and only struggled with a few things such as figures of speech or certain jokes and especially rhetorical questions like what's the point of asking if you do not want an answer.* A third poster mentioned not understanding jokes in the same context of not liking other NT activities. *Do people treat you like you are an idiot because of your diagnosis even if you are actually smart? ... until I bust out with something pertinent to their discussion. Or some scientific gobbledygook that amazes them. I do not get some jokes, and I do not follow sports or watch much tv.*

School was a living hell for me and I've always been seen as the 'slow one' or the 'handicapped kid who did not get jokes' (other people believing myths).

Myth: autistic people do best at jobs that entail repetitive tasks

One post asked: *What kind of jobs do you have and what advice do you have about jobs for autistic people?* A second asked: *Why cannot some people with Aspergers hold paid jobs?*

Many posts discussed interview difficulties, social expectations, masking and job stress as reasons for not having a full-time job. No post in our corpus mentioned repetitive tasks or even a structured routine as a benefit. Four posts argued against structure and/or the drawback of conformity and job boredom. We thus coded these as 'challenge myth.'

- *I hate schedules with a passion, if you mean having a day heavily planned in advance. I find that I do well with one scheduled meaningful activity about every other day, and I build the rest of my activities around that as the mood strikes me.*
- *I managed to attend college and I've had plenty of jobs – so I've "managed" to fit myself into rigorous timetables but I think it's against my nature to work mere 9 h days. Having to work the same hours, everyday – every week – it seems like slow death by monotony to me.*
- *I would start out very excited to learn something new. Once I mastered the job, which did not take long, I would become bored.*
- *Employment has been a really hard road for me, I've spent so many years smashing up neurotypical social niceties, like I was driving a crazy clown car.... But if you want to join the monkey troop, you are going to have to make some compromises.*

Myth: autism is a disease

Autism is not a disease, it is simply a different way that some people's minds process the world around them (challenge myth).

You do not have autism, it is not a disease or mental illness. In order to avoid the stigma for both of you, say you are autistic (challenge myth).

Myth: all autistic people have mental/intellectual disabilities

Two posts discussed the general category of autism without intellectual disability, classified a 'challenge myth.'

- *Impostor syndrome is rampant ...that they are faking it... particularly prevalent in autism without intellectual disability* (challenge myth).
- *Until recently, autistic females without an intellectual disability were often misdiagnosed or overlooked* (challenge myth).

One post discussed autistic individuals with mental/intellectual disabilities.

- *My family does not want to understand my Autism, mental disabilities, and mental illness at all* (elements of myth could be valid).

How different types of disabilities intersect with autism was a frequent topic. The words *disabled*, *disability* and *disabilities* occurred 43 times in the corpus. Posters discussed what disabilities co-occurred with autism, whether autism is a disability, and topics related to the social mode of disability. They also discussed practical concerns such as insurance coverage, disclosing one's disabilities in the workplace and to friends, and general coping strategies.

Myths not discussed in the corpus

Five remaining myths were not referenced in our corpus. No posters mentioned special diets to ameliorate symptoms, although posts did mention sensory issues with food texture, digestive problems, and being picky about food choices. No posters said autism was relatively new or linked autism with vaccines, savants, or violence.

Were posts angry or combative?

In none of the posts did users mock, derogate, or criticize other posts. This relieves a concern raised by prior researchers (30, 31). On occasion, posters politely expressed their disagreements on specific topics. To illustrate the high level of civility we saw on the forums, we list here the strongest cases of disagreement in our corpus.

I disagree with those who say the only early intervention is ABA. There's also Floortime, which you have discovered.

*Autistics: what is your opinion on the sentence 'everyone has a little bit of autism'? I happen to disagree with a lot of people about whether there is such a thing as a little bit of autism. At times in my life I was accused of being a little autistic because, well, I *was* a little bit autistic...* [post goes on to explain more for 200 words.]

I absolutely disagree with those saying to get a doctor to give you an official diagnosis: it's not usually covered by insurance, it's expensive, most cannot diagnose adults, even fewer can diagnose females... [post continues with additional details for 100 words].

Could forums provide insights for healthcare professionals?

The corpus contained many posts illustrating the material that was new in DSM-5-TR. Illustrative quotes are listed in the righthand panel of Table 3, corresponding to each new DSM-5-TR concept. For example, in the first row, a new item in the DSM-5-TR was "More subtle overall deficits for individuals without intellectual or language impairments." This corresponds to growing awareness autism may be an appropriate diagnosis even without the obvious "classic" symptoms of eye contact, odd body posture, and atypical voice qualities (36). The quote concerns about preferring information-rich discussion while disliking gossip. This is "subtle" because this characteristic is not diagnostic of autism and occurs among non-autistic persons. Yet it can be seen as an impairment since the poster goes on to describe some distress, inviting the inference that this discomfort with gossip can at times impair a daily activity. The doctor referred to in row 2 was not familiar with evolving concepts of autism, since he did not know that an atypical communication style may go unnoticed in someone with overall good communication. Indeed, across the corpus of posts, distress and indignation at misdiagnosis or not being sufficiently impaired for a diagnosis was a frequent topic (see Table 1). The DSM-5-TR idea of less obvious restricted interests is also illustrated in our listing of common special interests from the corpus, in the final rows of Table 1, such as TV shows, psychology, and yoga.

Row 6 describes the new idea that the stress of social interaction may be exhausting and contribute to social impairment. Six posts describe the stress of social interaction in ways similar to the description in the DSM 5 text revision. Several referred to *social exhaustion*, a term used in online neurodivergent and therapy communities. For example, one thread opened with the question: *Do you experience less social exhaustion with a person overtime?* Responses to this thread shared experiences or provided advice, such as this one: *I know that I can actually crave spending lots of time with someone who I do not feel social exhaustion with – it's a rare experience, and thus valued highly. That being said, many autistic people need alone time to recharge or deal with sensory overload regardless.* Another post connected stress to ABA therapy (Applied Behavioral Analysis): *If she was raised with ABA she might just always be on high alert trying to read signals and react appropriately and it becomes an EXHAUSTING reaction.*

Row 7 lists the new idea in DSM-5-TR that theory-of-mind deficits are not present in all cases. The quote here provides insight into a phenomenon that is only starting to become known to clinicians: many autistic people with typical intellectual ability become good mind readers because they understand its necessity and apply themselves, and/or because understanding social rules becomes a special interest (37). The bottom section of Table 3 lists DSM-5-TR's overview of how autism may affect females differently from males. This topic has had a long life on discussion forums (3, 14). Consistent with this, one-fifth of posts in our corpus discussed or mentioned female-specific symptoms.

When forum posters are more knowledgeable about autism than some mental health professionals.

In the prior section, we reviewed posts that illustrated novel material in DSM-5-TR, although they were posted between 1 and 4 years prior to the publication of DSM-5-TR. Many other posts touched on aspects that are more subtle and detailed than what is contained in the DSM-5-TR yet ring true in terms of being consistent with other autistic writings such as autie-biographies (38, 39), autistic-authored blogs (40) and the authors' own knowledge of autistic people. We discuss 4 of these below.

Sobbing as a reaction to social or environmental stress

Misinterpreting crying as a sign of depression. *The one time I did go to a professional who could diagnose, the doctor told me I was depressed and gave me some Zoloft because I had a crying meltdown after she asked me about something that would obviously make me emotional (I am a little bit depressed but it's like the very bottom of the list of things I need to worry about).*

Asking for help

A theme the authors have frequently encountered on autistic discussion forums concerns the difficulty of asking for help. It likely makes sense to clinicians that asking for help will be challenging for persons with social difficulties, but clinicians may not have details about this challenge, nor recognize it as consistent with autism. Nor has this difficulty been discussed systematically in the research literature (see Discussion). For this reason, we cite this as a case where people on forums are more knowledgeable than mental health professionals. One of the quotes in our database explains why asking for help is challenging.

Question*: Do Aspies find it difficult to ask for or accept offered help and favours?*

Answer: *This was something that caused me a lot of trouble my entire life. It breaks down into a few problems. ....initiating social interaction... ....the chance of them actually helping me in the way I need is lower than the chances of me solving the problem without them or them making the problem worse if I ask. ....will see me as a burden if I ask for something. ...I'm still not super awesome at asking when I need something.* [Many useful details omitted for brevity.]

Bothered by illogical group dynamics; ethical high standards, politically idealistic

Not conforming to the hivemind/groupthink and seeing that the emperor has no clothes; being bothered by illogical group dynamics and detesting rude people (they are rude, because they think you are below them, while I think social hierarchies are usually not based on truths).

...Is overly strong-willed and can be demanding in her idealism….

We are loyal, we will not have an affair, or leave the other person.

Sensitivity and emotional intensity

The historic association of autism with lack of emotional responsiveness has made it hard for non-autistic people, including experts, to understand that 'highly sensitive person', and high emotionality, are common in autism. The following discussions were in our corpus.

Has intensity that makes her overly sensitive and relentless.

Over the years I have been diagnosed with depression, anxiety, and an eating disorder. I have been told I'm just "being sensitive" and that I do not "seem autistic."

Autistic people are highly sensitive, and so may bruise easily, causing them to close up from others to protect themselves.

TABLE 3 Comparing new concepts in DSM 5 TR to forum-analysis posts.

	Items excerpted from DSM-5-TR, in order of appearance in that document	Quotes from the corpus of 300 forum posts indicating a similar concern or issue
1	More subtle overall deficits for individuals without intellectual or language impairments	I'm exhausted by people and find talking to other women IRL particularly taxing because I hate socializing. I can carry out a conversation full of information or on an interesting topic, but if someone starts shit talking about their lover I just want to run headlong into a wall and die. *[This is an example of a subtle deficit because the posters' exhaustion may not be obvious to observers.]*
2	More subtle deficits in social communication for individual with better overall communication skills	I was not formally tested as, after a chat with me, the doctor said because I could hold a conversation I could not be autistic. I waited a year for that appointment.. *[The poster understands that her social deficits were more subtle than not being able to hold a conversation]*
3	Less obvious restricted patterns of behavior and interests if the interests are closer to age-typical norms	Most of my special interests are in *video games*, with collecting plushies, *cards, games* themselves and what not. Another one of them is car crashes... I do not know why I am so interested in them but I'm interested nonetheless. Also *animals [interests resemble those for NTs]*
4	Stress may result from consciously calculating what most individuals find socially intuitive	I spend the whole conversation *focused on what I'm supposed to say or do* and often cannot participate because I can only focus on that
5	Lower ascertainment of autism spectrum disorder due to less obvious symptoms in these [competent] individuals, perhaps especially in adult women.	What a mess unpicking all the damage health professionals have done. Gaslighting in the worst possible way. They convinced me I was just a crazy female and it was my fault I wasn't getting better because I wasn't trying. Even a spell in a psych ward. Not one male health professional ever considered ASD. I was way too smart, must just be manipulative like a typical BPD. Cruelty towards me cause the stigma of BPD.
6	Stress of social interaction may be exhausting; unable to concentrate because of the mental effort in monitoring social conventions	Interacting with my Neurotypical (NT) friends, is exhausting. I have to do what is expected (i.e., my duty as a friend). I have to appear happy, sad or angry, match my emotions with the group, at the same time help them solve a problem they are facing.. prefer interacting with Aspies ... does not exhaust me.
7	Self-esteem is adversely affected by being unable to be themselves	[Diagnosis] showed me that many of my issues were not caused by character flaws and being a weak person but I was born this way. That was a great help to my self esteem. It helped me understand myself both in knowing my strengths and weaknesses. They helped me avoid situations that are not good for me and seek situations that are good for me
8	Normal theory-of-mind [ToM deficits not present in all cases].	Like many women with autism, people and social rules are one of my special interests.
9	Executive function deficits are also common but not specific, as are difficulties with central coherence [Infer: executive function difficulties common but not invariably present.]	I'm extremely slow in making artwork. I love doing it, but I insist on getting good results, and that means taking a lot of time, experimenting on it.. Could the slowness be caused by poor fine motor skills, requiring extra caution? *[slowness may indicate an atypical form of executive dysfunction or atypical weak central coherence -- or something else]*
10	Living independently and working… able to find a niche that matches their special interests and skills and thus are productively employed.	I'm 38 now and I've been working for a professional services firm in what's now a well paid job for 11 years... The clincian said I wasn't autistic because I had a job and was living independently and was in a relationship….
Female characteristics		
11	In comparison with males with autism spectrum disorder females are likely to have…. [pertinent to 5 items below]	I wasn't diagnosed until adulthood. Autism often presents differently in women than in men. I think a lot of people have this idea of what autism looks like that is based on a "lower-functioning" man.
12	►Better reciprocal conversation.	In general, people like to talk about themselves, and they enjoy feeling as though others are listening.. that's part of how I'm perceived; people think I'm a good listener because I repeat back key things they say, and offer insight.
13	►More likely to share interests, to integrate verbal and nonverbal behavior, and to modify their behavior by situation, despite having similar social understanding difficulties as males	Yes, it is generally thought that autistic women are somewhat different from autistic men, and the differences overall make female presentation more subtle. But it's not that all autistic females have the exact same traits and all autistic males have the exact same traits. Traits will still vary on an individual basis and there may be some cross-over/overlap.
14	►Masking. Attempting to hide or mask autistic behavior (e.g., by copying the dress, voice, and manner of socially successful women) may also make diagnosis harder in some females.	Masking does not mean to act as if I am NT. Masking means to learn the skills that for others are intuitive. It's a superpower many of us here have. It comes easier to female aspergers than to male ones because our symptoms are different. Be proud of what you achieved. It does not mean hiding, it means overcoming by hard work.. NTs get gifted with what we have to learn. But we are better at learning things.
15	►Repetitive behaviors less evident	My stims are small -- small repetitive movements? (Foot/toe curls). I am easily overstimulated by light and noise
16	►Special interests may have a more social (e.g., a singer, an actor) or normative focus (e.g., horses)	I have always had special interests but because they are what you would consider "mainstream" or typical for a girl it also went under the radar.
17	Rates of gender variance increased in autism spectrum disorder, with higher variance in females compared with males	*[posed question]* How do I know if a woman has Aspergers/autism? What is the most common sign? *[response]* She was a tomboy or is gender fluid.

Discussion

No consensus exists among healthcare professionals or researchers about the value of online forums as sources of insight for professionals or as sources of data for researchers. We sought to remediate this gap in the literature for autism forums. Here we discuss the evidence that forums are useful for clinicians, educators, and researchers.

Discussion forums contain high-value information: evidence from the analysis of myths

Concerns about misinformation have been raised in prior research (27, 30). Form analysis of autism forums revealed the opposite: the content of these forums had minimal hostility and virtually no misinformation. Consistent with prior writings about the value of online communities (3, 4), family members, friends, and autistic individuals should feel confident that browsing and contributing to autism forums will be rewarding.

Our initial goal in searching for myths in the corpus was to substantiate and qualify our prior impression that autistic forums do not spread misinformation. During analysis of how aspects of myths were discussed, we became impressed with posters' knowledge about autism. Posts incorporated the "truth" section explained in the myth vs. truth sections of authoritative sources such as (9, 28). But the posts went beyond those by providing compelling examples that challenged myths but also dissected how elements of the myths could be valid in some cases.

Challenging myths

Posters frequently challenged myths by sharing examples that were the opposite of the myth. Key examples were being an emotional sponge, disliking the structure, and lacking learning opportunities in the workplace. Researchers could systematically address how often traits classically associated with autism manifest as both hypo- and hyper variants [see (41)]. This a relatively novel idea and mostly confined to research on sensory sensitivity (42), although scholars have discussed hypo- vs. hyper-arousal underlying social functioning (43). Bimodality in functioning is routinely discussed in autism discussion forums, in domains barely touched by scholars, such as language, face recognition, analytical intelligence, and memory.

Other people believe myths

Posters shared the distress, disappointment, and rejection experienced when other people, such as a parent, believed myths. Most striking of these concerned clinicians believing myths. We have seen no scholarship on clinicians endorsing autism myths or making diagnoses based on myths. Research on knowledge of autism has only been conducted on students and the general public (9, 29).

Clinicians may believe myths because of the enduring power of classic or profound autism, which is stereotyped as including traits such as "…impaired reciprocity, quality of eye contact, atypical vocal prosody, presence of motor mannerisms, and atypical gait or posture" [(36), p. 653]. Clinicians estimated such traits to occur in 40% of the autistic population, in the survey by De Marchena and Miller (36). Some respondents provided estimates as high as 90%. This survey indicates that some clinicians lack experience with the diversity of characteristics of autistic people, consistent with complaints in the current corpus about incorrect diagnoses. Future research can explore what proportion of clinicians believe myths and what this implies for diagnosis and intervention.

Elements of myths could be true in some cases

Posters discussed how elements of myths could be true in some situations. Consider posts explaining why autistic people may be perceived by others as lacking emotions. One post noted *We aren't good at explaining how we feel*. A second post explained that emotional shut-down is a coping strategy during emotional dysregulation. These explanations situate autistic people as similar to NTs, because NTs can suffer emotional dysregulation and may have difficulty explaining how they feel. In contrast, *lacks emotion* is alien and suggests a discontinuity with human experience.

Another nuanced treatment concerned dislike of being touched. The myth is widely held by the general public, as mentioned in a focus group conducted by John et al. [(29), p.14]: *the mother was adamant that the boy could not be autistic because he liked hugs*. The popular myth of autistic people not liking human touch may be conflated with social introversion to imply dislike of people (29). In contrast, in our corpus, posters attributed discomfort with human touch to sensory sensitivities. These thoughtful reports of touch sensitivity are pertinent to current scholarship since the role of touch-aversion in social interaction has broad implications for parenting and intervention (44).

Discussion forums as sources of insight for clinicians

Reading online forums can provide clinicians with rapid insight into the concerns of autistic individuals (33). This is important because posters provided examples of how their misdiagnosis occurred because professionals were not aware of autistic symptoms. The 'subtle deficits' included in the March 2022 DSM 5 text revision have been discussed in discussion forums for years (3, 45). We documented this by comparing novel elements of the DSM-5-TR to the topics in forums. All new points in the DSM-5-TR were discussed in the corpus of 300 posts.

The DSM-5-TR item in row 15 was curious to us. Women were viewed as having a set of favorable social abilities yet were still said to have "similar social understanding difficulties as males." This similarity remains an empirical question and one that is not supported by the quotes in our corpus discussing women's social abilities. "Similar social understanding as males" is at odds with the comments that clinicians decide not to diagnose women because their social abilities were too competent.

Consistent with the above, a common complaint in the autism community is clinicians not recognizing symptoms of autism in adult women (3, 4, 46). Although such symptoms are increasingly discussed by scholars (6, 47), forum posters complain that these details are unknown to some clinicians. For example, one poster observed that because she had a crying meltdown during her diagnostic interview, the clinician concluded she was depressed and prescribed Zoloft. A clinician could interpret a crying episode as a sign of depression if clinicians do not know that autistic women commonly report crying meltdowns due to the stress of being questioned by a doctor in a high-stakes assessment. Also helpful is awareness that a crying meltdown need not be florid but can manifest as quiet sobbing. Here we see forum posters discussing concepts in a more detailed manner than the partial attempt in the text revision. Posters reported crying meltdowns due to stressful social interactions, such as experiencing disapproval from authority figures, or being overwhelmed by sensory stimuli, as can happen in a crowded supermarket.

Emotional dysregulation is frequently discussed in the autism community as a neurodivergent characteristic, and has attracted the attention of scholars (48), but it is not a symptom in the DSM-5 definition of autism spectrum disorders. The DSM-5-TR does state that social interaction can be stressful and exhausting (row 6 in Table 3) but does not alert clinicians that emotional dysregulation can result. This raises the question of why emotional dysregulation is not noted as a common symptom in the DSM-5-TR. Is this omission because of the continuing prominence of the stereotype (or, myth) among medical professionals that autistic people are not emotional? The unfortunate result is that clinicians regard emotional dysregulation as pointing to anxiety, depression, or borderline personality rather than autism.

Discussion forums can inform diagnostic practices

The corpus contained many examples of topics that can extend the boundaries of professionals' knowledge about autism. Consider the difficulty in asking for help. How to teach autistic adults to ask for help is part of social skills training (49). Autistic individuals' reluctance to seek help has been noted when giving advice to police and has been identified in studies of the experiences of autistic college students (15, 17), and late-diagnosed autistic women (50). However, in each of the articles just cited, asking for help was included in a list of other challenges, and was not the focus of systematic exploration. Clinicians may not realize that asking for help is challenging for neurotypical-passing autistic adults.

One of the quotes in our database discussed why asking for help is challenging (see Results). When this quote was discussed with autistic acquaintances of the authors, one woman mentioned that her therapist was mystified by her difficulty in asking for help, which included making requests more broadly, such as asking her parents to buy needed items or asking for a raise at work. This therapist reportedly spent weeks in therapy trying to identify the traumatic event that prevented her client from making requests. Clinicians would benefit from knowing how asking for help requires navigating several social domains.

Forums can provide data relevant to research questions

Empirical research suggests autistic people are less selfish than neurotypical people (51), and value abstract moral rules over social expectations (52). These journal articles managed to cast their findings as consistent with autistic deficits, rather than traits to be admired. Little scholarly work exists on autistic people's preference for honesty, equality, and social justice, but these topics and their lived experiences are common in autism forums. A related example of a topic that pushes against the boundary of professional knowledge is autistic people's avoidance of hierarchical group dynamics. The social activist Greta Thunberg has remarked that her autism allowed her to care less about conforming to social norms [see (53)].

Our analysis suggests an abundance of material relevant to research questions.

Researchers can analyze the content of discussion forums using qualitative methods, like analyzing free responses in questionnaires. We list here specific topics from our corpus that have been insufficiently studied by researchers but are frequently discussed in online forums (see details in Supplementary Table S1 and Supplementary Appendix).

- The experience of receiving a diagnosis: what went wrong; were tests and observations appropriate for the client's age and intellectual abilities (3).
- The experience of disclosing one's diagnosis vs. masking: how are decisions made about 'pretending to be normal' (or disclosing) and what are the ramifications (54).
- Childhood experiences of either diagnosed or undiagnosed autism: how was one treated by family, friends, teachers and others?
- Life experiences and concerns of parents who realize they are also probably autistic once their child is diagnosed.
- Understanding the impact of psychiatric conditions that statistically co-occur with autism, such as ADHD, OCD, social anxiety, and anorexia.
- Understanding the impact of co-occurring symptoms such as motor clumsiness, poor face recognition, gut problems, irritable bowel syndrome, gender fluidity, and homosexuality.
- Handling diverse social experiences such as friendships, peer pressure, bullying, dating, marriage, parenting, school and work.
- The ongoing controversy over how to integrate autism without intellectual disability compared to classic or profound autism.
- Autistic characteristics often manifest at either the low or high-end of ability; many of these are discussed in forums although this topic rarely appears in the research literature

Limitations: the merits and disadvantages of forums

A primary limitation concerns the novelty of forum analysis as a research method. Forum analysis deserves to be a tool in researchers' toolbox, alongside interviews and surveys (34). Each method brings its strengths and weaknesses; those of forum analysis are summarized in Table 4. For example, the strengths and weaknesses of a convenience sample vs. a random sample are well-known. Consider the challenge of how to sample online forum posts, when there may be virtually unlimited content (55), or very rare content can be sought out with sophisticated data scraping techniques. Guidelines for analyzing frequent vs. rare content have

TABLE 4 Strengths and challenges of forum analysis as a research tool.

	Analyzing user-led discussion forums rather than surveys/interviews	
	Strengths	*Drawbacks and challenges*
Whose Agenda	The questions being answered are generated by forum users, not led by the researcher's agenda	Questions on forums may only partially overlap with researchers' questions
Demand Qualities	No researcher-induced demand characteristics	Posters' goals in writing on a forum can influence content
Amount of Data	Depending on the topic, large or even inlimited data	There may be no data if posters do not address the topic of interest to a researcher
Demographic	Posters choose to reveal what they decide is pertinent in their post or personal profile.	Insufficient details about background characteristics
Ease	Forums easy to find online	Need to learn about specific digital cultures
Payment	Funds not needed to pay participants	Posters may appreciate their ideas informing research; or may not appreciate that quotes are used in research; Researcher does not know which is the case.
Ethics	Ethics approval may not be required (gray area)	

not been rigorously presented or defended. A lesson from the current project is that a representative vs. semi-random sample of forum posts cannot be undertaken without considerable familiarity with the structure of the platforms to be analyzed, including how topics are offered up to browsers when using search tools.

Our corpus included a relatively small number of posts discussing DSM-5 diagnostic practices. This detracts from conclusion validity regarding the content relevant to myths and the DSM. But our primary purpose wasn't to analyze how autistic people discuss myths or diagnoses. Instead, our intent was to document whether myths are rare in forums. Content analysis revealed references to myths are uncommon, being mentioned in only 52 of 300 posts (17%). What is new, and mostly unknown in the research literature, is that when elements of myths were mentioned, discussion was insightful and nuanced.

The small number of posts relevant to DSM 5 is also a limitation. After being impressed with posters' insights, we decided to analyze the corpus for discussion of topics in the DSM-5-TR. Posters did insightfully discuss topics relevant to diagnosis. This is evidence that forums autistic posts can be instructive for clinicians. This sets an agenda for future work: obtain a larger, systematically constructed corpus by identifying relevant threads and/or posts via keyword searches.

Forum data does not provide researchers the same assurance as interview or survey data, where all participants have been systematically recruited to have diagnoses [or at least self-diagnosed; see (34)]. But forum analysis is not thereby inferior to traditional surveys and interviews. Surveys and interviews are oriented around researchers' agendas, have demand characteristics, and often have unknown self-selection biases (see Table 4). Many people participate in interviews for money. Online surveys that pay out money can be infected by AI bots whose free-response answers can be surprisingly sophisticated. One solution is to combine survey methods and forum analysis [e.g., (24), who investigated autistic people's religious beliefs].

Researchers might be wary of forum analysis because it may seem like a shortcut. Humans value outcomes requiring large effort [effort justification effect, (56)]. But the ease of forum analysis is a feature, not a bug. When readers experience skepticism while reading a forum analysis, they can take immediate action by going to the named forums (or similar ones). Readers can use the search terms provided in the method and determine for themselves whether the content is consistent with the authors' report.

Autism advocacy

We have established that autistic people have substantial expertise on autism, thus going one step beyond the important paper by Gillespie-Lynch et al. (9). The current article also showcased the benefits of forum analysis. Reading and learning from forums is an accessible route for non-experts and experts alike to learn about autistics who use social media, both for insights and as a source of empirical data (34, 55). Analyzing forums does not substitute for meeting autistic people, attending conferences created by autistic people, and collaborating with them as researchers (10, 57) but forums have a low bar for entry. They are accessible at no cost to anyone with internet access who can use a computer, an advantage for researchers without labs and grant funding. Despite being a low bar, forums are rich enough to reward scholars and researchers at any level of expertise.

Forums are especially rich with voices of women, as is apparent in the current corpus in forums specifically for autistic women, and themes in the posts (see Appendix). Sexism in society is evident when accomplished males like Elon Musk are commonly regarded as both autistic and highly intelligent, yet doctors tell women they are too smart to be autistic and therefore must have BPD (as in the illustrative quote in row 5, Table 3).

Autistic persons' positive attributes have been undervalued (12, 58, 59). So too with discussion forums. Let both prosper.

Data availability statement

The original contributions presented in the study are included in the article/Supplementary material, further inquiries can be directed to the corresponding author.

Ethics statement

Ethical approval was not required for the study involving human data in accordance with the local legislation and institutional requirements. The social media data was accessed and analyzed in accordance with the platform's terms of use and all relevant institutional/national regulations.

Author contributions

CC-H: Conceptualization, Data curation, Formal analysis, Methodology, Project administration, Resources, Supervision, Writing – original draft, Writing – review & editing. TM: Conceptualization, Data curation, Writing – original draft. KB: Conceptualization, Data curation, Writing – original draft.

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Conflict of interest

The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

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Supplementary material

The Supplementary material for this article can be found online at: https://www.frontiersin.org/articles/10.3389/fpsyt.2023.1271841/full#supplementary-material

References

1. Giles DC, Newbold J. Self- and other-diagnosis in user-led mental health online communities. *Qual Health Res.* (2011) 21:419–28. doi: 10.1177/1049732310381388

2. Jordan CJ. Evolution of autism support and understanding via the world wide web. *Intellect Dev Disabil.* (2010) 48:220–7. doi: 10.1352/1934-9556-48.3.220

3. Linton KF, Krcek TE, Sensui LM, Spillers JL. Opinions of people who self-identify with autism and Asperger's on DSM-5 criteria. *Res Soc Work Pract.* (2014) 24:67–77. doi: 10.1177/1049731513495457

4. Parsloe SM. Discourses of disability, narratives of community: reclaiming an autistic identity online. *J Appl Commun Res.* (2015) 43:336–56. doi: 10.1080/00909882.2015.1052829

5. Zhao Y, Da J, Yan J. Detecting health misinformation in online health communities: incorporating behavioral features into machine learning based approaches. *Inf Process Manag.* (2021) 58:102390. doi: 10.1016/j.ipm.2020.102390

6. Bargiela S, Steward R, Mandy W. The experiences of late-diagnosed women with autism spectrum conditions: an investigation of the female autism phenotype. *J Autism Dev Disord.* (2016) 46:3281–94. doi: 10.1007/s10803-016-2872-8

7. Brede J, Cage E, Trott J, Palmer L, Smith A, Serpell L, et al. "We have to try to find a way, a clinical bridge"-autistic adults' experience of accessing and receiving support for mental health difficulties: a systematic review and thematic meta-synthesis. *Clin Psychol Rev.* (2022) 93:102131. doi: 10.1016/j.cpr.2022.102131

8. Finch TL, Mackintosh J, Petrou A, McConachie H, Le Couteur A, Garland D, et al. We couldn't think in the box if we tried. We can't even find the damn box: a qualitative study of the lived experiences of autistic adults and relatives of autistic adults. *PLoS One.* (2022) 17:0264932. doi: 10.1371/journal.pone.0264932

9. Gillespie-Lynch K, Kapp SK, Brooks PJ, Pickens J, Schwartzman B. Whose expertise is it? Evidence for autistic adults as critical autism experts. *Front Psychol.* (2017) 8:438. doi: 10.3389/fpsyg.2017.00438

10. Thompson-Hodgetts S. Reflections on my experiences as a non-autistic autism researcher. *Autism.* (2023) 27:259–61. doi: 10.1177/13623613221121432

11. Katusic MZ, Myers SM, Weaver AL, Voigt RG. IQ in autism spectrum disorder: a population-based birth cohort study. *Pediatrics.* (2021) 148. doi: 10.1542/peds.2020-049899

12. Wright B, Spikins P, Pearson H. Should autism spectrum conditions be characterised in a more positive way in our modern world? *Medicina.* (2020) 56:233. doi: 10.3390/medicina56050233

13. Loomes R, Hull L, Mandy WPL. What is the male-to-female ratio in autism spectrum disorder? A systematic review and meta-analysis. *J Am Acad Child Adolesc Psychiatry.* (2017) 56:466–74. doi: 10.1016/j.jaac.2017.03.013

14. Sedgewick F, Hill V, Pellicano E. It's different for girls': gender differences in the friendships and conflict of autistic and neurotypical adolescents. *Autism.* (2019) 23:1119–32. doi: 10.1177/1362361318794930

15. Anderson AH, Carter M, Stephenson J. Perspectives of university students with autism spectrum disorder. *J Autism Dev Disord.* (2018) 48:651–65. doi: 10.1007/s10803-017-3257-3

16. Cope R, Remington A. The strengths and abilities of autistic people in the workplace. *Autism Adulthood.* (2021) 4:22–31. doi: 10.1089/aut.2021.0037

17. Ward D, Webster A. Understanding the lived experiences of university students with autism spectrum disorder (ASD): a phenomenological study. *Int J Disabil Dev Educ.* (2018) 65:373–92. doi: 10.1080/1034912X.2017.1403573

18. Webster AA, Garvis S. The importance of critical life moments: an explorative study of successful women with autism spectrum disorder. *Autism.* (2017) 21:670–7. doi: 10.1177/1362361316677719

19. Hsieh HF, Shannon SE. Three approaches to qualitative content analysis. *Qual Health Res.* (2005) 15:1277–88. doi: 10.1177/1049732305276687

20. Morgan DL. Practical strategies for combining qualitative and quantitative methods: applications to health research. *Qual Health Res.* (1998) 8:362–76. doi: 10.1177/104973239800800307

21. Braun V, Clarke V. One size fits all? What counts as quality practice in (reflexive) thematic analysis? *Qual Res Psychol.* (2021) 18:328–52. doi: 10.1080/14780887.2020.1769238

22. Sarrett JC. Biocertification and neurodiversity: the role and implications of self-diagnosis in autistic communities. *Neuroethics.* (2016) 9:23–36. doi: 10.1007/s12152-016-9247-x

23. Bachmann P. Caregivers' experience of caring for a family member with Alzheimer's disease: a content analysis of longitudinal social media communication. *Int J Environ Res Public Health.* (2020) 17:4412. doi: 10.3390/ijerph17124412

24. Caldwell-Harris C. L., Murphy C. F., Velazquez T., McNamara P. (2011). Religious belief systems of persons with high functioning autism. In Proceedings of the 33rd annual meeting of the cognitive science society 3362–3366.

25. Jordan CJ, Caldwell-Harris CL. Understanding differences in neurotypical and autism spectrum special interests through internet forums. *Intellect Dev Disabil.* (2012) 50:391–402. doi: 10.1352/1934-9556-50.5.391

26. Bode & Vraga. See something, say something: correction of global health misinformation on social media. *Health Commun.* (2018) 33:1131–40. doi: 10.1080/10410236.2017.1331312

27. Ghenai A, Mejova Y. Fake cures: user-centric modeling of health misinformation in social media. *Proceed. ACM Hum. Comput. Interact.* (2018) 2:1–20. doi: 10.48550/arXiv.1809.00557

28. Bennett M, Webster AA, Goodall E, Rowland S. *Life on the autism spectrum: Translating myths and misconceptions into positive futures.* Singapore: Springer (2019).

29. John RP, Knott FJ, Harvey KN. Myths about autism: an exploratory study using focus groups. *Autism.* (2018) 22:845–54. doi: 10.1177/1362361317714990

30. Castro T, Lucke U. Socialization of people with autism through social networks In: M Antona and C Stephanidis, editors. *Universal access in human-computer interaction: users and context diversity.* Brazil: Springer (2016). 193–202.

31. Rösner L, Winter S, Krämer NC. Dangerous minds? Effects of uncivil online comments on aggressive cognitions, emotions, and behavior. *Comput Hum Behav.* (2016) 58:461–70. doi: 10.1016/j.chb.2016.01.022

32. Caldwell-Harris C.L., McGlowan T., Garrity M., Chen S. (2023). *Autistic adults discuss their experience of foreign language learning: an exploration of the "different strategies" hypothesis* [Under review]. International Journal of Bilingual Education and Bilingualism. 1–28.

33. Zhao Y, Zhang J, Wu M. Finding users' voice on social media: an investigation of online support groups for autism-affected users on Facebook. *Int J Environ Res Public Health*. (2019) 16:4804. doi: 10.3390/ijerph16234804

34. Seale C, Charteris-Black J, Mac Farlane A, McPherson A. Interviews and internet forums: a comparison of two sources of qualitative data. *Qual Health Res*. (2010) 20:595–606. doi: 10.1177/1049732309354094

35. Stone WL. Cross-disciplinary perspectives on autism. *J Pediatr Psychol*. (1987) 12:615–30. doi: 10.1093/jpepsy/12.4.615

36. Marchena A, Miller J. Frank presentations as a novel research construct and element of diagnostic decision-making in autism spectrum disorder. *Autism Res*. (2017) 10:653–62. doi: 10.1002/aur.1706

37. Dachez J, Ndobo A. Coping strategies of adults with high-functioning autism: a qualitative analysis. *J Adult Dev*. (2018) 25:86–95. doi: 10.1007/s10804-017-9278-5

38. Hacking I. Autistic autobiography. *Philos Trans R Soc B*. (2009) 364:1467–73. doi: 10.1098/rstb.2008.0329

39. Van Goidsenhoven L. Autie-biographies': life writing genres and strategies from an autistic perspective. *Lang Liter Cult*. (2017) 64:79–95. doi: 10.1080/20512856.2017.1348054

40. Kim SY, Bottema-Beutel K. Negotiation of individual and collective identities in the online discourse of autistic adults. *Autism Adulthood*. (2019) 1:69–78. doi: 10.1089/aut.2018.0029

41. Schwartz Anna M., Caldwell-Harris C.L. (in preparation). *The missing pieces: Leveraging the pattern in the distribution of autistic heterogeneity*.

42. Elwin M, Schröder A, Ek L, Kjellin L. Development and pilot validation of a sensory reactivity scale for adults with high functioning autism spectrum conditions: sensory reactivity in autism Spectrum (SR-AS). *Nord J Psychiatry*. (2016) 70:103–10. doi: 10.3109/08039488.2015.1053984

43. Yi L, Wang Q, Song C, Han ZR. Hypo- or hyperarousal? The mechanisms underlying social information processing in autism. *Child Dev Perspect*. (2022) 16:215–22. doi: 10.1111/cdep.12466

44. Thye MD, Bednarz HM, Herringshaw AJ, Sartin EB, Kana RK. The impact of atypical sensory processing on social impairments in autism spectrum disorder. *Dev Cogn Neurosci*. (2018) 29:151–67. doi: 10.1016/j.dcn.2017.04.010

45. Kapp SK, Ne'eman A. Lobbying autism's diagnostic revision in the DSM-5 In: S Kapp, editor. *Autistic community and the neurodiversity movement: stories from the frontline* (2020). 167–94.

46. Self.Autism InWomen. (2022). Changes to the DSM-5. https://www.reddit.com/r/AutismInWomen/comments/t7gwz4/i_am_absolutely_furious_about_the_changes_to_the/ (Accessed September 17, 2022)

47. Lai MC, Szatmari P. Sex and gender impacts on the behavioural presentation and recognition of autism. *Curr Opin Psychiatry*. (2020) 33:117–23. doi: 10.1097/YCO.0000000000000575

48. Cai RY, Richdale AL, Uljarević M, Dissanayake C, Samson AC. Emotion regulation in autism spectrum disorder: where we are and where we need to go. *Autism Res*. (2018) 11:962–78. doi: 10.1002/aur.1968

49. Ozonoff S, Schetter PL. Executive dysfunction in autism spectrum disorders In: L Meltzer, editor. *Executive function in education: From theory to practice*. New York, NY, USA: Guilford Publications (2007). 133–60.

50. Gould J, Ashton-Smith J. Missed diagnosis or misdiagnosis? Girls and women on the autism spectrum. *Good Autism Pract*. (2011) 12:34–41.

51. Hu Y, Pereira AM, Gao X, Campos BM, Derrington E, Corgnet B, et al. Right temporoparietal junction underlies avoidance of moral transgression in autism Spectrum disorder. *J Neurosci*. (2021) 41:1699–715. doi: 10.1523/JNEUROSCI.1237-20.2020

52. Jaarsma P, Gelhaus P, Welin S. Living the categorical imperative: autistic perspectives on lying and truth telling–between Kant and care ethics. *Med Health Care Philos*. (2012) 15:271–7. doi: 10.1007/s11019-011-9363-7

53. Caldwell-Harris C.L., Schwartz Anna M. *Listening to autistic voices regarding competing for social status*. (2024).

54. Frost KM, Bailey KM, Ingersoll BR. I just want them to see me as... Me: identity, community, and disclosure practices among college students on the autism spectrum. *Autism Adulthood*. (2019) 1:268–75. doi: 10.1089/aut.2018.0057

55. Robinson K. Unsolicited narratives from the internet: a rich source of qualitative data. *Qual Health Res*. (2001) 11:706–14. doi: 10.1177/104973201129119398

56. Festinger L. *A theory of cognitive dissonance*. Stanford, CA: Stanford University Press (1957).

57. Raymaker DM. Shifting the system: AASPIRE and the loom of science and activism In: S Kapp, editor. *Autistic community and the neurodiversity movement: stories from the frontline* (2020). 133–45.

58. Gernsbacher MA, Yergeau M. Empirical failures of the claim that autistic people lack a theory of mind. *Arch Sci Psychol*. (2019) 7:102–18. doi: 10.1037/arc0000067

59. Nader AM, Courchesne V, Dawson M, Soulieres I. Does WISC-IV underestimate the intelligence of autistic children? *J Autism Dev Disord*. (2016) 46:1582–9. doi: 10.1007/s10803-014-2270-z

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Compassion focused therapy for self-stigma and shame in autism: a single case pre-experimental study

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Introduction: Exposure to public stigma can lead to the internalization of autism-related stigma (i.e., self-stigma), associated with negative health, occupational and social outcomes. Importantly, self-stigma is linked to shame and social isolation. Although elevated self-stigma has been reported in autistic adults, to the best of our knowledge, interventions designed to target this issue are lacking. Compassion is an effective way to reduce the emotional correlates of self-stigma (i.e., shame) and their impacts on mental health. However, no study has investigated whether compassion focused therapy (CFT) can effectively reduce self-stigma in autistic adults. The present study aims at investigating whether and how self-compassion improvement following CFT may reduce self-stigma and shame in an autistic individual.

Methods: A single case pre-experimental design (SCED) was used with weekly repeated measures during four phases: (i) pure baseline without any intervention (A), (ii) case conceptualization (A'), (iii) intervention (B) where CFT was delivered, (iv) follow-up without intervention (FU). The participant is a 46-year-old autistic man with high self-stigma and shame. Self-report measures of self-compassion and self-stigma and a daily idiographic measure of shame were used.

Results: There was a large increase in self-compassion between pure baseline (A) and the intervention phase (A'B) (Tau-U = 0.99), maintained at follow-up. Similarly, there was a moderate decrease of self-stigma (Tau-U = 0.32). In contrast, when we compared the whole baseline phase AA' (i.e., considering the conceptualisation phase as baseline) to the intervention (B), there was no change in self-stigma (Tau-U = −0.09). There was no change in self-stigma between the intervention (B) and follow-up (Tau-U = −0.19). There was a moderate decrease in daily shame reports between the baseline (AA') and the intervention (B) (Tau-U = 0.31) and a moderate decrease between the pure baseline (A) and intervention phase (A'B) (Tau-U = 0.51).

Conclusion: CFT was feasible for this autistic client and our results show that CFT led to the improvement of self-compassion. Changes on self-stigma measures were moderate. Self-stigma may need more time to change. Because self-stigma is involved in poorer social functioning and mental health in autistic adults, our results are promising and suggesting conducting more large-scale studies on CFT in autistic adults.

KEYWORDS

autism, self-stigma, self-compassion, CFT, shame, compassion focused therapy

1 Introduction

Autism spectrum disorder (ASD) is defined as a neurodevelopmental condition, characterized by difficulties with social communication and interaction, altered sensory processing and patterns of repetitive behaviors and intense interests (1). Recent worldwide estimations of autism prevalence indicates that approximately 1% of the population is autistic (2). Importantly, lifetime prevalence of anxiety disorders and depressive disorders in autistic adults are particularly high, ranging from 23 to 42% (3). This elevated prevalence of mental health difficulties in autistic people is thought to be partially explained by the high levels of bullying they experience (4–6) and by the frequent experience of non-acceptance from others (7, 8). Such discriminative behaviors, probably linked to autism-related public stigma, can increase the likelihood of using camouflaging behaviors to pass as non-autistic (e.g., masking) (9), which is associated with poor mental health and increased isolation in in autistic people (10, 11).

The process of stigmatization encompasses three facets, contributing to the discrimination experienced by targeted groups. The first one, public stigma, refers to the negative attitudes, beliefs, and stereotypes held by the general population towards individuals or groups who are perceived as different or deviating from societal norms (12); affiliative stigma designates the prejudice and discrimination experienced by individuals who are closely associated with a stigmatized person or group (13); finally, self-stigma refers to the internalization of societal stereotypes and negative beliefs by individuals who belong to a stigmatized group (14). Importantly, self-stigma has been shown to lead to a decrease in self-esteem, self-efficacy, and a heightened feeling of shame or self-blame (14).

The relationship between self-stigma, shame and poor self-esteem may be explained by the social mentality theory (SMT; (15)). SMT conceptualizes stigma as a social threat that challenges the social ranking of the stigmatized individual, engendering feelings of inferiority (15). Thus, the perception of being on a lower social rank, akin to self-stigma, can provoke feelings of shame (16). Shame is defined as a self-conscious emotion, involving worthlessness, powerlessness, and isolation. Usually viewed as one of the most intense and incapacitating self-conscious emotions, shame can be understood as a socially focused emotion, cued by threats to the social self or one's status (17). Given its socially threatening nature, shame comes with a willingness to escape the situation, hide, or conceal deficiencies (18–20). Thus, shame is seen as the emotional consequence of self-stigma, linking stereotypes to behavioral consequences (e.g., social isolation) (21).

While numerous studies have investigated self-stigma associated with mental illness, studies concerning self-stigma in autism are scarce (22–26). This may seem surprising given the high prevalence of self-stigma in autistic adults, which ranges between 15% (22) and 45.2% (27) according to recent estimations. Furthermore, few studies have investigated shame and its relationship with self-stigma in autistic people. In a recent study led by our team in a sample of 689 autistic adults, self-stigma was found to be highly correlated to shame and shame mediated the relationship between self-stigma and depression (27). These results highlight the need to develop and evaluate specific interventions to target shame and self-stigma in autistic adults in order to mitigate the negative outcomes associated with the internalization of autism-related public stigma (e.g., social isolation and depression). Yet, to the best of our knowledge, interventions targeting shame and self-stigma in autistic adults are lacking.

Self-compassion has been recently put forward as a potential buffer of the effects of public stigma on self-stigma and mental health (28). Self-compassion is defined as kindness and support towards oneself when experiencing suffering (29). Self-compassion involves responding to life's difficulties in three specific ways: (i) kindness as opposed to self-judgement, (ii) mindfulness as opposed to over-identification to painful emotions and thoughts, and (iii) common humanity as opposed to isolation, that is, perceiving one's suffering as an integral part of the human experience. In non-autistic samples, self-compassion has been strongly associated with numerous health benefits such as higher levels of happiness and well-being, better sleep quality and lower levels of depression, anxiety, stress and self-harm (30–33). In the context of self-stigma, increasing self-compassion may therefore contribute to the reduction of self-blame and act as a buffer of the negative effects of public stigma, by facilitating social resources and increasing the willingness to ask for help (28). In addition, self-compassion may foster self-perspectives that are more balanced, first, accepting both positive and negative aspects of self and, second, learning how to observe and let go of self-stigmatizing thoughts, emotions and behaviors. This may, in turn, mitigate the negative outcomes associated with self-stigma (34).

Some empirical results provide support to Wong et al.'s (28) model, which highlights the protective role of self-compassion. For instance, a correlational study found that self-compassion partially mediated the relationship between self-stigma relative to one's weight and negative health outcomes (e.g., somatic symptoms and quality of life) (34). Similarly, in another study, self-compassion was found to moderate the impact of HIV-stigma and negative affect (35). Furthermore, self-compassion has been found to moderate the relationship between public stigma and the anticipated self-stigma of help seeking when one has a mental health problem (36).

Despite the elevated prevalence of self-stigma and mental health difficulties in autistic individuals, few studies have investigated self-compassion in relation to autism. Recently, two online studies found that autistic participants reported significantly lower self-compassion levels than non-autistic adults. Interestingly, in both groups, those with higher levels of self-compassion had fewer depression symptoms

(37, 38). Moreover, autistic traits and self-compassion in both autistic and non-autistic individuals have been found to be negatively correlated (38), suggesting that low levels of self-compassion are related to the cognitive style found in autism (e.g., social difficulties and cognitive inflexibility). Relatedly, Cai and Brown's (39) review paper suggested that self-compassion may improve mental health in autistic adults through the modification of emotions (as an emotion regulation strategy). Consistent with this view, empirical results by Cai et al. (40) demonstrated that emotion regulation mediated the relationship between self-compassion and anxiety/depression in autistic adults. Thus, it is likely that self-compassion may help autistic adults regulate their feeling of shame associated with self-stigma.

Interestingly, self-compassion has been recently found to moderate the relationship between self-stigma and depression in autistic adults (27) suggesting that an intervention aiming at increasing self-compassion might be useful for reducing self-stigma. In particular, compassion focused therapy (CFT) seems relevant in the context of self-stigma as it has shown its efficacy for targeting shame and hostile self-to-self relationship (41). CFT is a biopsychosocial, evolution-informed psychotherapeutic approach that builds on traditional cognitive behavioral therapy (CBT) principles and blends empirical knowledge from affective neuroscience, social and developmental psychology (16). Theoretical benchmarks in CFT includes an understanding of how evolutionary processes have shaped our minds and brains to serve a variety of functions. CFT focuses particularly on *social mentalities,* defined by Gilbert (42) as patterns of brain activity organizing our relationships and social roles by shaping different parts of our minds, i.e., motives, emotions, cognitions and behaviors. Relevant examples of social mentalities are the caregiving and care-receiving mentalities in contrast to threat-giving and threat-receiving social interactions. This understanding of social mentalities is relevant to the experience of stigma which can be understood as a social rank (dominant-subordinate) relationship. Because CFT provides an understanding of the function of threat-based processes, specifically when threat-giving and threat-receiving social rank mentalities have been internalized and used to interact with oneself, this therapeutic approach seems particularly relevant to target self-stigma. Moreover, CFT has gathered a large body of evidence in the treatment of shame and self-blame in a wide range of clinical settings (43, 44). Given its focus on the psychological processes and affective aspects that can be found in self-stigma, CFT may be more effective than existing interventions for the reduction of self-stigma and shame (45). CFT has not yet been evaluated in autistic individuals. However, a recent paper has provided strong theoretical support for the clinical relevance of CFT for the treatment of shame-related problems experienced by autistic adults (46). Hence, through its focus on self-compassion, CFT is likely to improve mental health by specifically targeting shame and self-blame (27).

The present study aims at investigating whether and how self-compassion improvement following CFT may reduce self-stigma and shame in an autistic individual. To do so, using a single case pre-experimental design, we will investigate whether and how scores of self-compassion, self-stigma and shame measures evolve following CFT in an autistic adult presenting with high levels of self-stigma. Specifically, we hypothesize that self-compassion scores will increase post-therapy, while self-stigma and shame scores will decrease. Single-case experimental designs constitute methodologies of growing interest in rehabilitation settings. These methodologies are recognized as relevant to investigate parameters related to the efficacy of a new intervention in a small number of participants before running a larger group trial (47).

2 Materials and methods

2.1 Design

To be included, the participant had to be autistic, present with an elevated score on the internalized stigma of mental illness (ISMI-9) (>2.5; (48)), have an IQ within the normal range, and be willing to participate in CFT. The participant was recruited from the University Hospital of Psychiatry clinics following his participation in a dialectical behavior therapy (DBT; (49)) program. A single case pre-experimental design (SCED; (50)) was used with weekly repeated measures of self-compassion and self-stigma as well as a daily ideographic measure of shame, during four phases, i.e., (i) pure baseline, (ii) conceptualisation, (iii) active compassion focused therapy, (iv) follow-up. Table 1 provides a detailed description of the contents and the duration of each phase. Using the baseline as a benchmark, the participant functions as his own control and the primary analysis is a comparison of weekly measures during the baseline, and the subsequent phases. The conceptualisation phase consisted of individual sessions with the participant to establish a working therapeutic alliance, identify goals and conceptualize his difficulties according to the CFT formulation. The active intervention phase consisted of 20 weekly individual CFT sessions. Throughout the study duration, the participant responded to weekly measures of self-compassion and self-stigma and daily measures of shame through an online journal that he chose to design (instead of using a paper survey). All sessions were conducted by a clinical psychologist trained in CFT. Ethical approval was assigned by the French ethics committee (Comité de Protection des Personnes Nord Ouest II) - (2022-A02501-42). Written informed consent was obtained from the participant for the publication of any potentially identifiable images or data included in this article.

2.2 Measures

Acceptability of the intervention was measured via the assiduity in sessions and his adherence to in-between sessions practices. The participant designed an online journal which was shared with the therapist where he took notes of his home practices.

2.2.1 Self-Compassion Short Scale

Self-compassion was measured with the Self-Compassion Scale (51) in its short version (52). The French validation of the scale in its long version indicates good psychometric properties (Cronbach $\alpha = 0.94$) (53) consistent with the results of the English short version of the scale (Cronbach $\alpha = 0.87$) (52). The scale consists of 12 items. The responders are asked to indicate how often they act toward themselves in difficult times using a Likert-scale ranging from 1 ("almost never") to 5 ("almost always"). For example, item 2 states "I try to be understanding and patient towards those aspects of my personality I do not like." Only total scores were used in this study as recommended by Raes et al. (52). The total score was calculated as a

TABLE 1 Description of phases.

	Baseline		Intervention phase	Follow-up
	A: Pure baseline	A': Case conceptualization	B: Active CFT	FU: Follow-up
Contents	No sessions with therapist.	Sessions with therapist consisted of assessment, formulation, therapeutic relationship, safety and safeness, tasks and goals.	Sessions with therapist consisted of CFT for self-stigma including elements of compassion mind training and working with shame and self-stigma using the compassionate self.	No sessions with therapist.
Number of weeks	5	4	20	5

total mean after having reversed coded the negative subscale items (self-judgment, isolation, and over-identification).

2.2.2 Internalized Stigma of Mental Illness (ISMI-9)

Self-stigma was measured using the Internalized Stigma of Mental Illness Scale (ISMI) in its short 9-item version (54), it is an abbreviated version of the full 29-items designed to assess self-stigma among persons with psychiatric disorders (48). The scale is a self-report instrument with each item rated on a 1 (strongly disagree) to 4 (strongly agree) Likert scale. According to Ritsher and Phelan (48) a mean total score of >2.5 indicates high levels of self-stigma.

2.2.3 Daily reports of the feeling of shame

To further inspect the variations of feelings of shame on a daily basis, participant and researcher collaboratively decided to design a question aiming to assess shame. It was collaboratively decided to use the following question: *How often have I felt ashamed today?* The participant rated his feeling of shame on a Likert scale ranging from 1 (never) to 5 (most of the day).

2.3 Statistical analysis

The total scores calculated from the weekly measures of self-compassion and self-stigma were graphically displayed. Visual analyses focused on the following data features: level, trend, variability and overlap of data points (55). No visual aids were used in the process of visual inspection of the graphed data. The visual analysis of weekly measures were complemented with the use of statistical indicators. Tau was used when it was visually evident that there is no improving baseline trend, whereas Tau-U with baseline trend control was used when the visual analysis suggested the need to control for spontaneous improvement during the baseline.

Tau-U (56) has several versions, the simplest of which also quantifies overlap, but in a slightly different way as compared to NAP: if NAP is expressed in a scale from 0 to 100 and Tau is expressed in a scale from 0 to 1, $\text{Tau} = 2 * (\text{NAP}/100) - 1$ (57). This quantification is appropriate when there is no improving baseline trend. Given that there was no such trend for the shame data (unlike the measurements of self-compassion and self-stigma), we used Tau. Another version of Tau, Tau-U, allows quantifying monotonic baseline trend and correcting for this trend when representing the amount of nonoverlap. Therefore, we used Tau-U to evaluate the changes in self-compassion and self-stigma.

In addition to Tau calculations, we also used the percentage of goal obtained (PoGO) for self-compassion and shame in order to quantify to what extend goals were achieved (58). The set goals in the context of the calculation of PoGO was set *a posteriori*. Regarding daily reports of shame, the goal was set to 1 indicating "*I did not feel ashamed today*" and regarding self-compassion, the goal was set to 2.5 which corresponds to the benchmark from low self-compassion to moderate self-compassion (51).

The following comparisons were made: (i) A versus A'B phase, i.e., assuming that the conceptualisation phase A' is already an intervention because of the awareness and psycho-education it includes; (ii) AA' versus B, i.e., considering that the conceptualisation phase is part of the baseline because no active CFT ingredients are delivered; (iii) A'B versus FU and (iv) B versus FU.

2.4 Case illustration

2.4.1 Presenting problem and client description

Julian (a pseudonym) is a 46-year-old autistic man working as a free-lance web designer. He received an ASD diagnosis at age 41. In addition to ASD, Julian has been diagnosed with social anxiety and asthma. He currently takes no medication. Two years prior to his participation in CFT, he benefitted from DBT (59) which led to a significant reduction in self-harming behaviors and emotion dysregulation. However, Julian still struggles with a very depreciating self-image, feelings of inferiority and self-stigma since he has received the diagnosis of ASD (ISMI score of 3.3 at inclusion). Julian is divorced and has two children who are now adults. He lives alone and is involved in a romantic relationship. He reports suffering from loneliness and lack of friendships.

2.4.2 Intervention

2.4.2.1 Overview

To increase compassion for self, others, and the ability to receive compassion from others, the CFT therapist guides patients to develop feelings of warmth, safeness and soothing through compassionate mind training (16).

The intervention consisted of weekly, individual sessions of approximately 1 h. The content of the intervention was adapted from a group CFT program for self-stigma developed by our team, presented in Table 2 (45). However, since the therapy was conducted in an individual setting, it was possible to adapt the contents to individual situations. The twelve modules of the program were

TABLE 2 Content of modules and home practices of the COMPASS program (45).

Modules	Session title	Session content	Home practice
1	Welcoming and creating a safe place Definition of compassion and personal goals	Reflection on a safe place agreement for the therapy Exploration of what is (and what is not) compassion Short introducing to Soothing Rhythm Breathing (SRB)	Soothing rhythm breathing (SRB) (https://youtu.be/Md2c0h6bogE)
2	Compassion wisdom: the tricky brain and the social construction of self	SRB Tricky brain problem How and why we are different to other animals: our unique capacity for self-consciousness and self judgement ("not our fault") We are only one version of the infinite possible versions of self Understanding the influence of our social environment on our construction ("not our fault")	Soothing rhythm breathing (SRB) Identifying my own tricky brain loops
3	Compassion wisdom: Three emotional regulation systems	SRB Introducing the three circles model: threat, drive and soothing Evolutionary function of emotions	Soothing rhythm breathing (SRB) Drawing my three circles and identifying triggers
4	Compassion wisdom: stigma and self-stigma	SRB Introduction stigma and self-stigma Understanding the path from public stigma to self-stigma ("not our fault") through the social construction of self and the tricky brain Consequences of self-stigma through the lens of the 3-circle model	Soothing rhythm breathing (SRB) Filling the self-stigma model and tricky brain loops associated
5	Compassionate engagement: thinking, imagery and body postures can influence our physiology	SRB Introducing the mindfulness circle Thoughts and imagination can impact our physiology: experiencing with attention, postures, tones of voice, SRB Safe place imagery Ideal compassionate other imagery	Safe place imagery (https://youtu.be/Md2c0h6bogE)
6	Compassionate engagement: the compassionate self	Experiencing with the compassionate self (postures, tone of voice, feelings of warmth, actions)	Compassionate self-imagery (https://youtu.be/1KELVnBvvho)
7	Compassionate courage: multiple selves	Embodying the compassionate self to respond to the threat system thoughts and emotions	Compassionate self-imagery (https://youtu.be/1KELVnBvvho)
8	Compassionate courage: how to respond to the self-stigmatizing self	Exploration of self-stigma and self-critic: reasons to be and consequences Using compassionate self to respond to self-stigma	Compassionate self-imagery (https://youtu.be/1KELVnBvvho)
9	Compassionate courage: dealing with difficult emotions	Understanding of shame and guilt Responding to difficult emotions with compassion	Embodying compassionate self in everyday life
10	Compassionate courage: compassionate assertiveness	Understanding the components of compassionate assertiveness compared to submissive and aggressive expression Practicing compassionate assertiveness through role plays	Compassionately asking something we need
11	Compassionate courage: cultivating the compassionate self	Writing a compassionate letter Sharing of compassionate letters	Compassionate letter
12	Continuing my journey with compassion	Building my personal compassionate tool bag Plans for continuing practicing compassion Gratefulness and compassion wish	

conducted in 20 individual sessions. This program was built based on core CFT psychoeducation components and core experiential practices such as compassion focused imagery, chair work and letter writing. Details of the therapeutic sessions can be found in Table 2. Each session started with a soothing rhythm breathing practice and contained psychoeducation elements, socratic dialogue around a theme and in-session experiential practices such as compassionate imagery, role plays and chair work. The overall aim of the CFT program is to help the patient shift from a hostile and critical self-to-self relationship to a more compassionate relationship to self. Indeed, the participant develops a compassionate identity through which he can respond to parts of oneself that might suffer. During the therapy process, the clinician adapted CFT exercises to fit the interests of the participant (60). For example, the participant's interest in writing was used to create dialogues between different selves based on the CFT framework.

2.4.2.2 Case formulation (phase A')

The CFT case formulation is evolution-informed and helps creating a de-shaming and de-pathologizing understanding of one's difficulties. Specifically, psychoeducation in CFT involves elucidating the evolutionary origins of our brains, helping clients recognize that our brains are tricky and reassuring them that they are not to blame (61). Brain functions that were advantageous for our survival over millions of years can now pose considerable difficulties in our daily lives. For instance, our brains possess an inherent tendency to be hyper-aware of threats, guided by the principle "better safe than sorry." For a more comprehensive understanding of the evolution-informed psychoeducation in CFT, see Gilbert (62) for a review. Case conceptualization in CFT comprises an evolution-informed psychoeducation and entails an understanding of one's difficulties within this functional framework.

Using Socratic dialogue, the *fundamental fears* of Julian, consisting of external fears (i.e., in relation to how others perceive oneself; e.g., "fear *that others will make fun of me and reject me*") and internal fears (i.e., fears related to one's own perception of oneself; e.g., "*I am scared to fall apart*") were normalized through the exploration of *historical influences* (see Figure 1). In particular, the therapist explored early memories with an emphasis on experiences of warmth and safeness as opposed to memories of feeling threatened and ashamed. For example, as a child, Julian had a speech impediment which led to school bullying; he felt excluded and ashamed. Julian also reported the loss of his feeling of safeness following the divorce of his parents, as his mother left home while he had been sent away for holidays during the summer. Concerning feelings of warmth, Julian felt safety around his father and grandmother. Julian developed feelings of inadequacy and loneliness that might be explained by the school bullying he experienced and by the abrupt departure of his mother. Safety strategies were then identified as behaviors used to avoid or escape situations that may bring about his fundamental fears and other painful emotions. For instance, Julian often escaped social situations and fled home to find a place where he felt safe. Internal protective reactions include hypervigilance regarding his social behaviors (e.g., ruminations over how to react to prevent rejection and mockery from others). During the conceptualization phase, the therapist normalized these safety strategies as they were viewed through the lens of their protective functions. For example, monitoring his behaviors might have prevented further harm in the past (e.g., from bullies at school). However, these safety strategies have led to unintended consequences, e.g., fatigue. Interestingly, fatigue may be related to camouflaging, which is defined by Hull et al. (63) as coping strategies including "explicit techniques to appear socially competent and finding ways to prevent others from seeing their social difficulties." Camouflaging is highly prevalent in autistic adults and is associated with fatigue and negative mental health outcomes (64, 65). All of these can fuel the development of high standards towards oneself and a self-critical self-to-self relation. Indeed, Julian felt "*bullied at school and now I am my own persecutor.*" One of the purposes of collaborative case conceptualization is to de-shame those unintended consequences. Consistently, the CFT framework employs the terminology "*safety behaviors*" instead of "*dysfunctional behaviors*" to acknowledge that the patient is doing their best to feel safe. In other words, the patient is doing their best given the social construction of the self and the way the human brain evolved from an evolutionary perspective (i.e., in CFT, the human brain is called the "tricky" brain). In addition to the specific components of the CFT case conceptualization, the strengths of the participant were highlighted (66). The latter factors were related to important values such as creativity and love for the arts.

Following the case conceptualization, three therapeutic goals were identified: i.e., "be less self-critical towards and accept my imperfections," "start writing my novel," "connect with people."

2.4.2.3 Compassion focused therapy (during phase B)

The 20 therapy sessions were based on the group program developed by our team (Table 2). The program is a step-by-step manualized CFT treatment targeting self-stigma. In this study, the same treatment contents were applied, albeit more flexibly, to adapt to the participant's individual needs. The primary objective of the intervention was to assist the client in cultivating a caregiving and care-receiving mentality, which involved nurturing a compassionate mind or compassionate self. The compassionate self served as a foundation for the client to effectively respond to his emotions and experiences rooted in threat. Thus, the patient sought to foster his compassionate self, equipping himself with the necessary qualities and skills to incorporate compassion into his relationship with himself and with his recently discovered autistic identity. The intervention is illustrated through the presentation of some key therapeutic practices below. Based on the key adaptations suggested by Keenan et al.'s (60) first-hand account of DBT, the main adaptations of CFT for this specific person consisted of connecting the therapeutic tasks to his specific interests, that is, the arts (literature, classical music, and visual arts). Hence, the key practices outlined below were developed based on Julian's interests. Also, we provided Julian with a therapy booklet containing visual summaries of key psychoeducational contents and worksheets to guide him with his home practices.

2.4.2.3.1 First session: getting acquainted with compassion

Julian initially associated the words "*altruism, non-judgment, openness, empathy*" with compassion. After validating this intuitive wisdom, we explored the meaning of compassion through the recall of a memory where he felt willing to help someone. We specified the two psychologies of compassion, i.e., (i) sensitivity to suffering in self and others and (ii) engagement to alleviate and prevent suffering (16). Julian then provided a recent example where he acknowledged that he could understand the person's difficulties from a cognitive standpoint, which he called "*external knowledge*," but he explained how difficult it was to have "*internal knowledge*," that is, feel compassion. A metaphor to explain the difference between knowing and feeling was then used based on Julian's practice of music: "*I am a pianist, I could play cello or doublebass, I know how music works, but I am not a cello or doublebass player, I cannot feel the music on cello like I feel it when I play piano.*" This highlighted that one can practice feeling compassion just like one can learn to play a new instrument. At first, it might be difficult and require a deliberate effort but, with training, compassionate feelings may emerge. This first session helped to reinforce Julian's engagement in the therapy and his willingness to cultivate compassion.

2.4.2.3.2 Cultivating the compassionate self

Compassionate mind training is an essential component of CFT (67). To cultivate the evolved social mentality for caring and compassion, different practices with breathing, body posture, voice tone, and imagery were used. The objective was to build and train a compassionate self, able to give compassion to one's own suffering.

The first CFT technique used was Soothing Rhythm Breathing (SRB). SRB allows to experiment the connection between bodily sensations, emotions, and mental processes; this in turn helps to regulate arousal (see (68) for more details about SRB). SRB is a breathing method that permits to decrease respiration frequency and increase heart rate variability (HRV) (69). To do so, it was important that SRB was experienced as a technique that goes beyond mere relaxation; instead, it is aims to function as a cue to activate the soothing system while simultaneously regulating the threat system (70). Indeed, greater HRV is linked with reduced negativity bias and an enhanced willingness to embrace novelty (71). In Julian's case, a cognitive shift through SBR was reported after his second independent practice with this breathing method "*in a time of stress when many thoughts were present*," "*through breathing, the thoughts left, slowing down, as if we were stopping time*." After the first introduction of SRB, each session started with a SRB practice, which was progressively complemented with new learnings such as a soft internal voice tone or a friendly facial expression. Indeed, SRB constitutes the initial phase of most therapeutic tasks in CFT (68, 72). We used posture and breathing exercises to establish physiological safeness, fostering a compassionate mind. In session 3, Julian reported that he had turned to SRB spontaneously during a difficult situation where he felt tense and angry while he was driving home. Instead of stopping on the side of the road and taking a nap to calm down, he "*…used the vibrations on the steering wheel as an anchor that helped me to calm down*." He highlighted that this was very effective and soothing: "*this strategy of calm through breathing, while driving, is less risky than stopping on the side of the road to sleep*." Thus, there was generalization of new learning and SRB became a helpful strategy to regulate intense emotions. Based on the intuitive wisdom Julian showed in this situation, the therapist suggested that he could use the same strategy during other difficult situations. For instance, in the city, if intense tension arises, Julian usually sits down and plugs his ears. He dislikes this behavior and chose to practice SRB instead while holding a small object of his choosing (i.e., a specific rock), to feel "anchored' akin to the feeling he reported while touching the steering wheel. As the weeks went by and Julian continued to regularly practice SRB, he shared in week 21 (10th session of active CFT) "*I know it's there, I can activate it when I need*" and "*there is a part of me in this rock, the part that is wise and compassionate*."

Another fundamental technique in CFT consists of training the caring system through compassion focused imagery (e.g., compassionate memories, visualizing caring individuals, creating a safe place, imagining a compassionate color and a compassionate ideal person). These practices were first conducted in session and debriefed with the therapist who targeted the sensations and feelings during the practices. Julian was able to experiment further at home through audio recordings of the sessions or with videos made by the therapist (73). These practices increased his familiarity with the feelings and sensations associated with compassion. To facilitate the implementation of these practices, we relied on Julian's love for the arts. For example, Julian chose specific music pieces to accompany certain compassionate practices. His safe place was first chosen to be his grandmother's house, which was associated with warmth and feeling of safeness but also a sense of loss, grief, and deep sadness. After different explorations of potential safe places, Julian thought of an arts foundation he used to visit with his grandmother; this safe place helped him feel warmth, a sense of safeness and openness and he felt welcomed there exactly for the person he is. Julian discovered that looking at a picture of the arts foundation helped him to feel peaceful. Between-sessions practices consisted of SRB and compassionate imagery. Examples of his personal notes regarding these between-session practices are presented in Table 3.

In CFT, training of the compassionate mind can include role plays, chair work and embodiment practices. These were particularly difficult for Julian at first as they tapped on one of his fundamental fears, i.e., "*others will make fun of me*." To facilitate these practices, the therapist first asked Julian to choose an object that had special meaning for him and to bring it to the next therapy session. The therapist then interviewed Julian as he embodied the compassionate object (75). This allowed him to experiment embodiment practices in a safe and playful way as he embodied a toy from his childhood. This therapeutic task was also a way to experiment giving himself compassion through a third person perspective.

2.4.2.3.3 The multiple selves

Since the beginning of the intervention, Julian was introduced to the concept of having multiple selves, where each emotion was treated as a separate entity. For instance, when he expressed feeling sadness, the therapist acknowledged this as the expression of his "sad self." This approach aimed to foster a more relational perspective towards emotions, allowing the client to engage with them as distinct entities rather than becoming overwhelmed by them. Throughout sessions, the therapist guided Julian to identify, label and picture his different parts. The different selves were explored by the therapist with an attitude of curiosity. Here again, Julian was able to fully embody his different parts, e.g., "sad self," "angry self," and the therapist asked questions like "*Angry self, what would you like to say?*" "*how does the anger manifests in your body?*" "*What would you do if you could take control over Julian?*" This allowed Julian to become aware of different emotional parts within himself and to better understand the underlying motives and needs of each part. For example, we explored the "blaming self" that emerged during a difficult situation (i.e., Julian was not invited for the birthday of his friend) (*cf.* Table 4).

In CFT, a relational approach is used to explore the different parts of the self, akin to defusion described in mindfulness-based approaches (e.g., Acceptance and Commitment Therapy; (76)). In addition to defusion, in CFT, the therapist explores how the client would like to respond to the parts within himself to foster understanding and compassion. This allowed Julian to identify certain qualities ("*kindness, generosity, altruism, gentleness, understanding, tolerance and strength*"), which were then useful to guide him in constructing his compassionate self. This ideal compassionate self was further reinforced through imagery practices, role-playing and embodiment exercises, allowing him to immerse in the role and experience the compassionate attributes firsthand. Painful emotions were explored through the lens of the multiple selves and then integrated trough the compassionate self that validated the needs of each part.

2.4.2.3.4 Bringing compassion into daily life

As Julian's compassionate identity became more clear, other therapeutic tasks were included to embody his compassionate self in his daily life. This started at home while doing activities such as

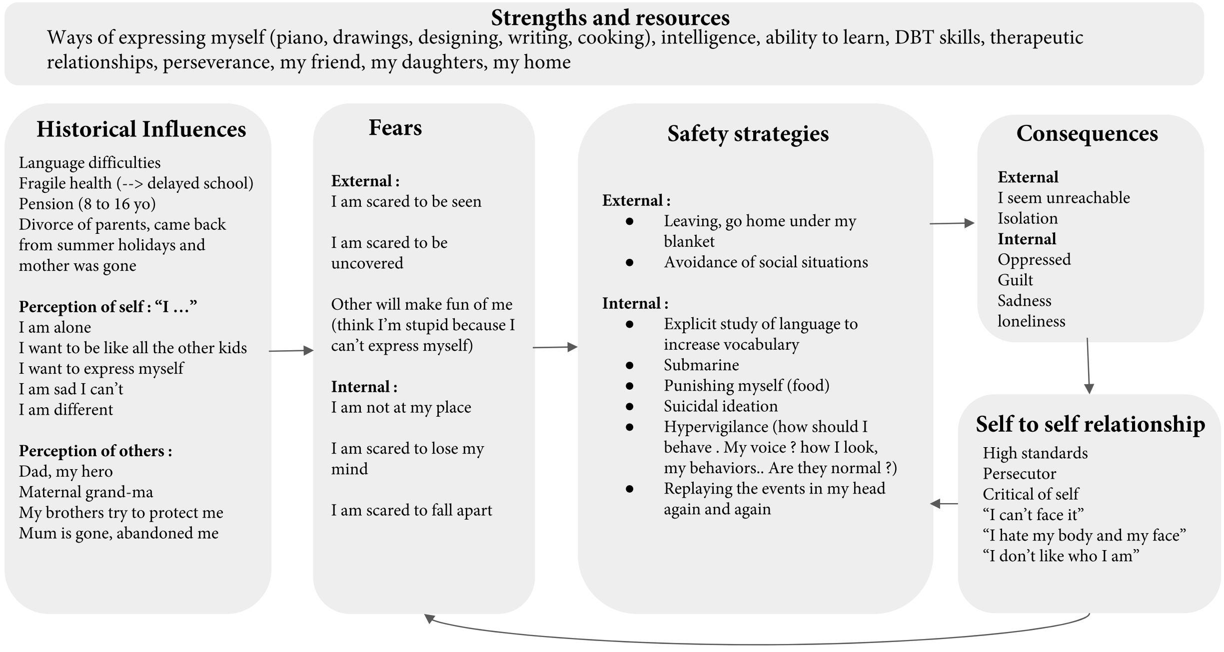

FIGURE 1
Conceptualization of Julian's difficulties.

TABLE 3 Compassionate object interview.

Aims	Relating to aspects of self as if he was the compassionate object. This experience of self as an external person permits to transfer interpersonal behaviors and competencies to self. It can increase the client ability to mentalise and generate self-compassion by focusing on self from an external perspective (74).
Therapist questions	How long have you been in Julian's life? What role do you have for Julian? What do you do for Julian? When does Julian turn towards you? When does Julian need you? Why are you so important for Julian? How do you feel about him? What do you wish for Julian? What would like him to know?

listening to music, playing the piano, or doing house chores. Julian deliberately changed his body postures and internal voice tone, mindfully observing his sensations, and looking at the world through the eyes of his compassionate self. After practicing at home, Julian was encouraged to practice outside. This was a stressful situation for Julian as he felt inadequate and feared the mockery and rejection of others. To embody his compassionate self, Julian shifted from the ashamed self to the compassionate self when going to the bakery and talking to the salesperson. He did so via the practice of SRB, intentionally changing his body posture and voice tone, he observed "*when I change my posture, others change too*." He also noticed that he felt more comfortable and talked more during the conversation. He still felt anxious but instead of having the "blaming self / the spear" run the show and make him feel inferior, the compassionate self encouraged him. Julian acknowledged that "*Compassion is part of me now*," highlighting how his compassionate self had been incorporated in his sense of identity.

2.4.2.3.5 Compassion for the stigmatized self

Julian's interest in writing was an important asset when the compassionate self was to give compassion to the stigmatized self. Indeed, one of the main practices of CFT is the compassionate letter writing (68). To do so, one writes a letter to oneself (i.e., the part who is suffering) through the lens of the part of the self who is wise, caring, and strong, i.e., the compassionate self. Before writing the letter, Julian first practiced SRB and immersed himself in a compassionate self-imagery. Then he identified the part of the self who was suffering, i.e., the stigmatized self, validated its suffering, shared his compassionate wisdom about humankind's tricky brains (i.e., "even though it is not my fault, it is my responsibility"), and showed support and willingness to change. This practice cued an important fear of compassion, which led Julian to postpone its writing. Some time was taken during sessions to identify key fears and resistances and to compassionately respond to them. Motivational interviewing techniques were used to help him activate his compassionate self and start writing (77). During this process, Julian noted "*Even if I do not act, I can see and identify how I can make progress and I stop bullying myself*." With the compassionate self, Julian wrote himself a letter that progressively became the novel he wanted to write for a long time (i.e., one of the therapy's goal). In week 25, he felt that "*The therapy allowed me to move forward and feel safe. My writing project takes up more and more space*." This highlights the importance in CFT of creating safeness and of cultivating the courage, through compassion, to achieve the goals of one's life worth living.

TABLE 4 Example of the blaming self.

The blaming self/"the spear"	
Sensations	Jaws are tensed, like having a spear through the chest
Emotion	Shame
Thoughts	I am not normal, and I deserve to be punished. I must isolate. I must harm myself
Behaviors	I cannot speak, urge to punch my hands into a wall
Underlying need	To be included and accepted

3 Results

3.1 Acceptability

The participant did not drop out of therapy, nor did he miss any session. Julian completed an online journal shared with the therapist where he took note of his practices of soothing rhythm and compassion focused imagery. In total, during the compassionate mind training phase and follow-up, he wrote 125 entries about soothing rhythm practices and several compassionate imagery practices such as the "safe place" and "compassionate color." In the journal entries, Julian wrote how he felt before, during and after the practices as well as any practice-related discoveries or comments. Example of journal entries of practices are presented in Table 5.

3.2 Self-compassion, self-stigma and shame

Figures 2–4 graphically display the participant's weekly measures of self-stigma and self-compassion and daily reports of shame.

3.2.1 Visual inspection

Visually, self-compassion increased while shame decreased across the pure baseline (A) and the conceptualization phase (A'). Regarding self-compassion during the active treatment period (B), there was some variability around scores of 1.5 to 1.8 until week 21 followed by a consistent increase of scores for 5 weeks up to 3 which then decreased slightly to reach a score of 2.2 at the end of the active treatment phase. Self-compassion increased again during the follow-up period and ranged between 2.5 and 2.8 during the 5-week follow-up period suggesting that the amelioration of self-compassion during the intervention was maintained post-therapy.

Regarding self-stigma scores, the trend is less straightforward than for self-compassion. Indeed, there is a large variability of self-stigma scores during the pure baseline period (A) making the changes in self-stigma across the subsequent phases difficult to interpret. In the conceptualization phase (A'), self-stigma progressively decreased but the variability of scores persisted, suggesting that the conceptualization phase had a small effect on self-stigma. During the active therapeutic phase (B) and the follow-up period, self-stigma scores continued to show great variations.

Daily reports of shame during the pure baseline period (A) indicate that Julian frequently felt ashamed. At the beginning of the conceptualization (A'), Julian reported a high level of shame which showed a sudden subsequent decrease. During the start of the active treatment phase (B), shame was reported to be more present than for the rest of this phase suggesting a decrease of shame during the CFT phase as compared to the baseline. This reduction of shame was maintained during the follow-up period.

3.2.2 Statistical analyses

Tau-U was calculated to investigate changes across the different phases. Results are given in Table 6 and interpreted according to Vannest and Ninci (78): A 0.20 improvement can be considered a small change, 0.20 to 0.60 a moderate change, 0.60 to 0.80 a large change, and above 0.80 a large to very large change. Statistical analysis indicates a large increase in self-compassion between the baseline (including the conceptualization phase) and the active treatment phase (Tau-U = 0.74). If the baseline phase is considered without the conceptualization phase, the change is very large (Tau-U = 0.99). These results suggest that self-compassion increases during the conceptualization phase even though there is no active compassionate mind training during the conceptualization sessions. There is no difference between the intervention phase and the follow-up (Tau-U = 0.00) suggesting that the amelioration of self-compassion is maintained after the intervention. Regarding self-stigma, there is a moderate decrease of self-stigma between the baseline (including the conceptualization phase) and the active treatment phase (Tau-U = 0.32). In contrast, when we compare the baseline without the conceptualization phase with the intervention phase (which includes the conceptualization), there is no change in self-stigma (Tau-U = −0.09). There is no change in self-stigma between the intervention and follow-up (Tau-U = −0.19). Regarding daily shame, there is moderate decrease in shame between the baseline including the conceptualization phase and the active treatment phase (Tau-U = 0.31) and a moderate decrease between the baseline (without the conceptualization phase) and the intervention phase including the conceptualization (Tau-U = 0.51).

The percentages of goals obtained were calculated for both self-compassion and shame (Table 7). Between baseline (including the conceptualization phase) and the active intervention phase, 64.91% of goal in self-compassion was obtained. When we include the conceptualization phase as part of the intervention, the percentage of goal is almost the same (62.49%). Across the intervention phase and the follow-up phase the percentage of goal obtained is very high: 143.10%. Considering that the goal was set as the benchmark between low self-compassion to moderate self-compassion, this result suggests that during the follow-up, self-compassion was consistently higher that the "moderate" cut-off. Regarding daily shame reports, the percentage of goal obtained is also very similar whether we include the conceptualization in the baseline or the intervention phase, respectively 90.21 and 92.51%. In the follow-up, the percentage of goal remained high suggesting that the effects of the intervention on daily shame reports remained stable during the follow-up.

4 Discussion

In this study, as recommended by recent literature referring to healthcare and rehabilitation, we used a single case pre-experimental design to evaluate the feasibility and efficacy of CFT for reducing self-stigma in an autistic adult (47). To do so, we investigated whether and how scores of self-compassion, self-stigma and shame measures

TABLE 5 **Examples of Julian's journal entries of compassion practices at home.**

Week number and period	Type of practice	How I felt before	How I felt during	How I felt after	Comments
Week 13 Compassionate mind training	Soothing rhythm breathing	Very angry	The first minutes are difficult	Relieved, soothed, calm	
Week 14 Compassionate mind training	Safe place	Tired, angry	It is difficult to keep focus	A little bit calmer	I cannot seem to choose my safe place, several images come to my mind
Week 22 Compassionate mind training	Safe place	Tensed	The successive heat waves we are experiencing at the moment allow me to give more reality to this place. I've often been there when it was hot, and very quickly, flagrances of pine and stones splashed by watering invade my thoughts	Happy and at peace	Now that I've identified my place of serenity, everything is much simpler
Week 27 Compassionate mind training	Compassionate self	Tired	I feel good and happy to practice this	Peaceful	I've just come from a nature walk, I'm sitting on a bench in the sun
Week 44 Follow up	Soothing rhythm breathing	Wilful	I think back to Marie's words before I left, and her encouragement, which for me was an expression of a certain kindness	I'm confident I'll have a beautiful day	I came across Agnes Obel's name in one of my music playlists, and I must confess to having been very moved by the memory of my first listen. This "incident" undoubtedly reconciled me with the practice of soothing breathing rhythms, the very thing I had long abandoned, so unable was I to find the answers to my inner suffering. Now I know that this name and the music behind it are like all the lights in the sky when the night is at its darkest

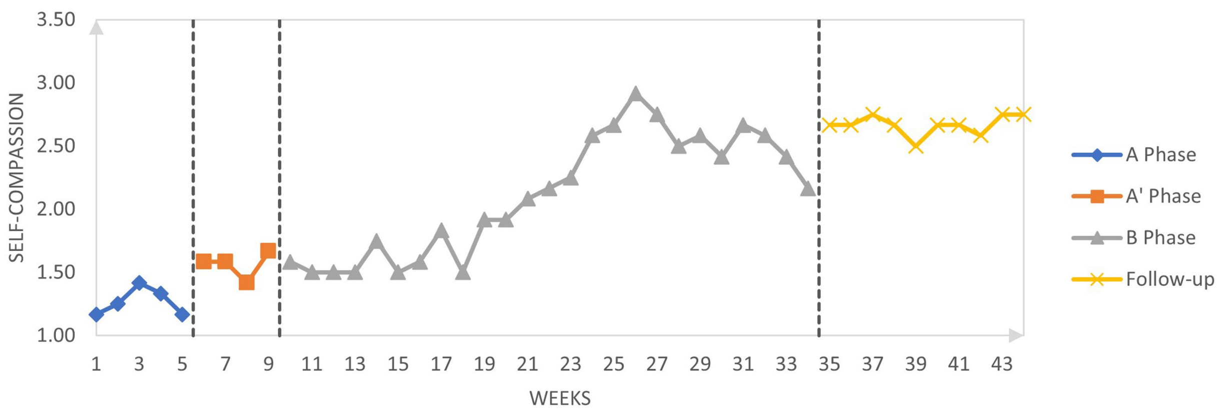

FIGURE 2
Weekly self-compassion scores across phases.

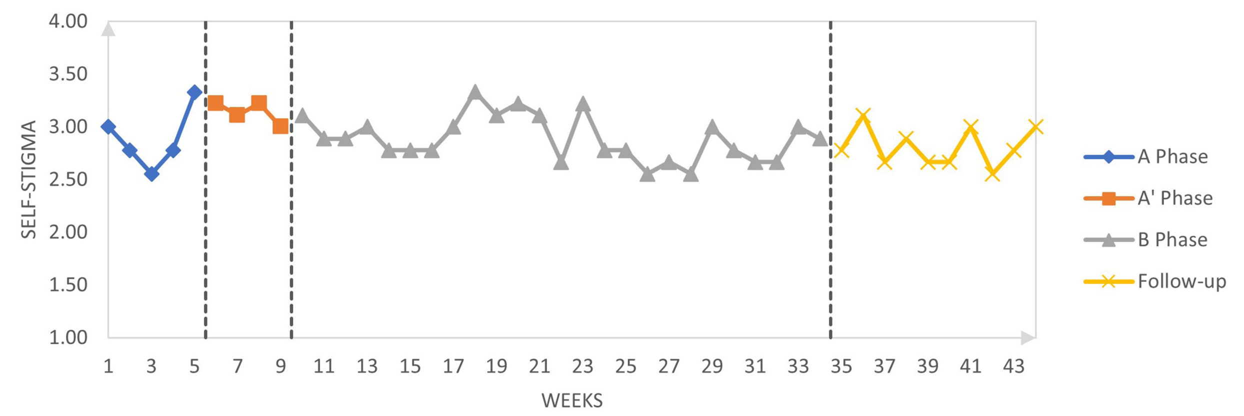

FIGURE 3
Weekly self-stigma scores across phases.

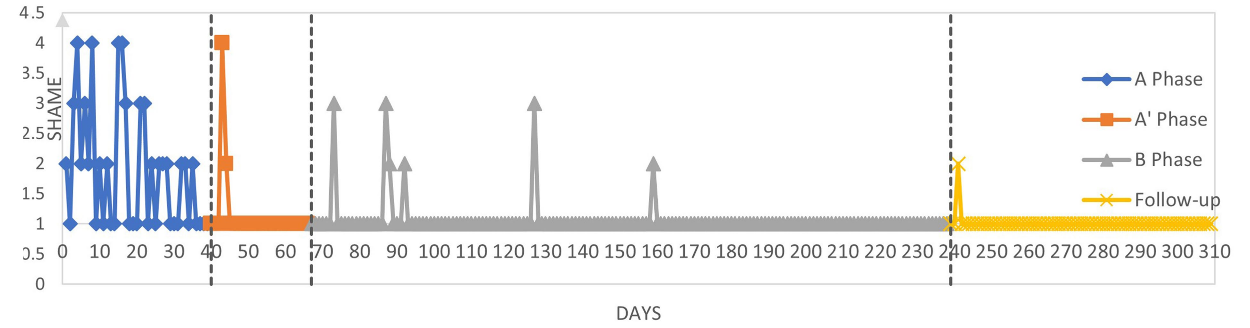

FIGURE 4
Daily reports of shame across phases: "How often I have felt ashamed today?".

TABLE 6 **Tau calculations for the weekly measures of self-compassion and self-stigma.**

	AA′ versus B	A versus A′B	B versus Follow-up**	A′B versus Follow-up**
Weekly self-compassion*	0.74	0.99	0.00	−0.08
Weekly self-stigma*	0.32	−0.09	−0.08	−0.19
Daily shame	0.31	0.51	0.02	0.03

*Tau-U was used in order to include baseline trend correction. **If intervention effects are maintained over time, a Tau/TAU-U close to zero is expected.

evolved through a baseline period, a conceptualization phase, CFT and a follow-up period.

First of all, we found that CFT was highly acceptable and feasible with this autistic client. Indeed, Julian was very diligent with session attendance and in-between sessions practices, with more than a hundred entries in his log of home practices across the intervention and follow-up phases. This result is important given that barriers to accessing care are numerous in this population, including clinician attitudes about autism and the importance of flexibility for the individualization of treatment (79). In addition, the individual format of the intervention allowed the therapist to adapt the sessions to better fit the needs of the participant. For example, the client's interests and passions were used in the therapeutic tasks, which may have contributed to increase the acceptability of CFT (60).

In terms of the efficacy measures, self-compassion increased throughout the conceptualization, CFT and follow-up phases. More specifically, self-compassion increased while shame decreased across the baseline and the conceptualization phase. This is consistent with the de-shaming function of case conceptualization in CFT (80). Indeed, the collaborative creation of a common understanding of the client's difficulties through a compassionate lens may have been effective in reducing shame (i.e., "we did not choose to have a brain that functions this way and can create difficult emotions and ruminations, nor did we choose the context in which we grew up"). In other words, the idea that "it is not my fault" brought about in the conceptualization phase might explain the reduction of shame found during this phase as opposed to the pure baseline phase.

In contrast to self-compassion, the self-stigma measure showed high variability during the baseline, making subsequent results and changes difficult to interpret. A moderate decrease in self-stigma was nevertheless found between the baseline and the intervention

TABLE 7 Percentage of goal obtained for weekly self-compassion and daily shame.

	AA′ versus B	A versus A′B	B versus Follow-up	A′B versus Follow-up
Self-compassion	Effect size estimate: 64.91 Standard error: 10.91 95% CI: [43.53, 86.29]	Effect size estimate: 62.49 Standard error: 8.61 95% CI: [45.61, 79.37]	Effect size estimate: 143.10 Standard error: 43.37 95% CI: [58.10, 228.11]	Effect size estimate: 136.02 Standard error: 33.07 95% CI: [71.20, 200.85]
Shame	Effect size estimate: 90.91 Standard error: 27.12 95% CI: [37.75, 144.07]	Effect size estimate: 92.51 Standard error: 25.30 95% CI: [42.92, 142.09]	Effect size estimate: 76.69 Standard error: 58.38 95% CI: [−37.74, 191.12]	Effect size estimate: 81.43 Standard error: 52.28 95% CI: [−21.04, 183.89]

phase, which was maintained at follow-up. Similar results were found on the daily reports of shame, consistent with the idea that shame is strongly associated with self-stigma in autistic and non-autistic people) (27, 81). The moderate changes in self-stigma might be explained by different factors. First, internalized stigma is the result of frequent and repeated exposure to stigmatizing attitudes and experiences of discrimination. Thus, although self-compassion significantly increased during treatment and this change was maintained at follow up, self-stigma may take more time to change, especially because public stigma remains prevalent. Relatedly, it is worth noting that, as the therapy advanced and self-compassion increased, the participant progressively exposed himself to social situations that he avoided before, momentarily increasing his anxiety, and feelings of inadequacy. Indeed, increased social exposure to a non-autistic world comes with a high risk to face negative attitudes from others (64), and this might explain the results found in our study. Another explanation is related to the scale that was used to assess self-stigma, i.e., the ISMI (54). Indeed, the ISMI was validated for measuring self-stigma related to psychiatric disorders, thus it is possible that the ISMI did not fully capture autism-related self-stigma.

Overall, our results suggest that self-compassion increased following CFT, but self-stigma decreased only moderately. We speculate that this is due to the persistence of autism-related stigma in our society. Hence, in addition to tackling self-stigma, it is crucial to address and fight autism-related public stigma within our societies. To achieve this, it is pivotal to implement anti-stigma programs targeting the general public, families of autistic individuals, teachers, and health practitioners. However, existing programs are scare, have shown limited effectiveness so far (82), and changing public attitudes takes effort and time. Some studies focusing on anti-stigma programs for autism have shown promising results but have been constrained by methodological limitations, such as short-term effects and lack of behavioral measures (83–86). Considering these challenges, in addition to working on reducing public stigma, this study demonstrates how CFT may decrease autism-related self-stigma and thus addresses one of the facets of the stigmatization process. By doing so, CFT could contribute to reduce the negative health consequences associated with stigma in autistic individuals.

From a qualitative standpoint, Julian reported that the therapy helped him become less self-critical and self-stigmatizing, suggesting that, from a subjective perspective, self-stigma decreased. Indeed, during the last sessions of the therapy, Julian shared that writing his novel meant that he was embracing who he was, i.e., "*I accept who I am*." He shared that his novel was now part of his life and contributed to "*his acceptance of his difference*," that is, he accepted and embraced his autistic identity instead of camouflaging it in most occasions or avoiding social situations. Consistently, he mentioned "*I show myself as I am, I have no more desire to be a chameleon because I know it's destructive, I have no more need to hide*" "*I'm naked, camouflage falls off, I am now more sensitive to my environment, I have not fallen back into the idea of being perfect, I have my flaws, they make up my personality*." He also noticed that he was more aware of his emotions "*My awareness and acuity when it's happening improved, there is now a real synchronization when it's happening, so I can see what I can use right away to be helpful*." Furthermore, Julian reported "*I can notice I've been hurt by someone and I'm able to ask for an apology, compassion goes in both directions*," suggesting that his self-compassion, but also compassion for others increased following CFT. Hence, the self-reported decrease in self-stigma through self-compassion seems to have allowed him to hide and avoid less while decreasing his use of camouflaging behaviors. In addition, he acknowledged that CFT also helped him become more aware of his emotions, a finding in line with previous studies using CFT (87). Both results are clinically important given that camouflaging, social isolation, and emotion dysregulation have been found to be involved in the high rates depression, anxiety and suicidality in autistic adults (7, 65, 88, 89).

As a pilot clinical study, this research presents with limitations. Firstly, the shift between the baseline and the intervention phase is not clear-cut, given that the conceptualization phase can be either seen as part of the baseline or the intervention. This is particularly the case in an A-B single case design such as ours. Further research should aim at replicating our results and explore changes across the conceptualization and active treatment phases possibly with a larger sample of autistic individuals. Moreover, to decrease the load on the participant, only selected measures of self-stigma, self-compassion and shame were used. However, given the link between self-stigma and mental-health, future studies should consider using measures of psychopathology (e.g., depression and anxiety scales) and quality of life to explore the effects of the intervention more broadly. Furthermore, because autism can take many shapes, further research should include larger scale studies involving a wide variety of autistic clients (e.g., multiple baseline SCED design and randomized controlled studies). Finally, research should investigate the types of adaptations of CFT required for autistic clients more broadly.

In conclusion, the present study adds to the CFT literature by demonstrating its acceptability and preliminary efficacy in reducing self-stigma in autistic adults. Given that self-stigma seems to be involved in the diminished social functioning of autistic adults as well as in the maintenance of co-occurring disorders, our results are particularly promising and point to the need to conduct more large-scale studies on CFT in autistic adults.

Data availability statement

The raw data supporting the conclusions of this article will be made available by the authors, without undue reservation.

Ethics statement

Ethical approval was assigned by the French Ethics Committee (Comité de Protection des Personnes Nord Ouest II) - (2022-A02501-42). The studies were conducted in accordance with the local legislation and institutional requirements. The participants provided their written informed consent to participate in this study.

Author contributions

MR: Conceptualization, Data curation, Formal analysis, Funding acquisition, Investigation, Methodology, Resources, Writing – original draft, Software, Visualization. AK-P: Methodology, Writing – review & editing, Supervision. RM: Methodology, Writing – review & editing. OR: Writing – review & editing. LW: Conceptualization, Supervision, Writing – review & editing, Project administration.

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Conflict of interest

The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

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References

1. Volkmar FR, Reichow B. Autism in DSM-5: progress and challenges. *Mol Autism*. (2013) 4:13. doi: 10.1186/2040-2392-4-13

2. Zeidan J, Fombonne E, Scorah J, Ibrahim A, Durkin MS, Saxena S, et al. Global prevalence of autism: a systematic review update. *Autism Res*. (2022) 15:778–90. doi: 10.1002/aur.2696

3. Hollocks MJ, Lerh JW, Magiati I, Meiser-Stedman R, Brugha TS. Anxiety and depression in adults with autism spectrum disorder: a systematic review and meta-analysis. *Psychol Med*. (2019) 49:559–72. doi: 10.1017/S0033291718002283

4. Bejerot S, Mörtberg E. Do autistic traits play a role in the bullying of obsessive-compulsive disorder and social phobia sufferers? *Psychopathology*. (2009) 42:170–6. doi: 10.1159/000207459

5. Hebron J, Humphrey N, Oldfield J. Vulnerability to bullying of children with autism spectrum conditions in mainstream education: a multi-informant qualitative exploration. *J Res Spec Educ Needs*. (2015) 15:185–93. doi: 10.1111/1471-3802.12108

6. Zablotsky B, Black LI, Maenner MJ, Schieve LA, Blumberg SJ. Estimated prevalence of autism and other developmental disabilities following questionnaire changes in the 2014 national health interview survey. *Natl Health Stat Rep*. (2015) 2015:1–20.

7. Cage E, Di Monaco J, Newell V. Experiences of autism acceptance and mental health in autistic adults. *J Autism Dev Disord*. (2018) 48:473–84. doi: 10.1007/s10803-017-3342-7

8. Jacoby EC, Walton K, Guada J. Community perspectives on adults with autism Spectrum disorder. *Occup Ther Ment Health*. (2019) 35:72–91. doi: 10.1080/0164212X.2018.1507774

9. Perry E, Mandy W, Hull L, Cage E. Understanding camouflaging as a response to autism-related stigma: a social identity theory approach. *J Autism Dev Disord*. (2022) 52:800–10. doi: 10.1007/s10803-021-04987-w

10. Cage E, Troxell-Whitman Z. Understanding the reasons, contexts and costs of camouflaging for autistic adults. *J Autism Dev Disord*. (2019) 49:1899–911. doi: 10.1007/S10803-018-03878-X

11. Mazumder R, Thompson-Hodgetts S. Stigmatization of children and adolescents with autism spectrum disorders and their families: a scoping study. *Rev J Autism Dev Disord*. (2019) 6:96–107. doi: 10.1007/s40489-018-00156-5

12. Pescosolido BA. The public stigma of mental illness: what do we think; what do we know; what can we prove? *J Health Soc Behav*. (2013) 54:1–21. doi: 10.1177/0022146512471197

13. Huang CH, Li SM, Shu BC. Exploring the relationship between illness perceptions and negative emotions in relatives of people with schizophrenia within the context of an affiliate stigma model. *J Nurs Res*. (2016) 24:217–23. doi: 10.1097/jnr.0000000000000124

14. Corrigan PW, Watson AC. Understanding the impact of stigma on people with mental illness. *World Psychiatry*. (2002) 1:16.

15. Gilbert P, Miles JNV. Sensitivity to social put-down: It's relationship to perceptions of social rank, shame, social anxiety, depression, anger and self-other blame. *Personal Individ Differ*. (2000) 29:757–74. doi: 10.1016/S0191-8869(99)00230-5

16. Gilbert P. Introducing compassion-focused therapy. *Adv Psychiatr Treat*. (2009) 15:199–208. doi: 10.1192/apt.bp.107.005264

17. Gilbert P. The relationship of shame, social anxiety and depression: the role of the evaluation of social rank. *Clin Psychol Psychother*. (2000) 7:174–89. doi: 10.1002/1099-0879(200007)7:3<174::AID-CPP236>3.0.CO;2-U

18. Gilbert P. The evolution of social attractiveness and its role in shame, humiliation, guilt and therapy. *Br J Med Psychol*. (1997) 70:113–47. doi: 10.1111/j.2044-8341.1997.tb01893.x

19. Gilbert P. What is shame? Some core issues and controversies In: P Gilbert and B Andrews, editors. *Shame: Interpersonal Behavior, Psychopathology, and Culture*. Oxford University Press. (1998) 3–38.

20. Tangney JP, Wagner P, Gramzow R. Proneness to shame, proneness to guilt, and psychopathology. *J Abnorm Psychol*. (1992) 101:469–78. doi: 10.1037/0021-843X.101.3.469

21. Schibalski JV, Müller M, Ajdacic-Gross V, Vetter S, Rodgers S, Oexle N, et al. Stigma-related stress, shame and avoidant coping reactions among members of the general population with elevated symptom levels. *Compr Psychiatry*. (2017) 74:224–30. doi: 10.1016/j.comppsych.2017.02.001

22. Bachmann CJ, Höfer J, Kamp-Becker I, Küpper C, Poustka L, Roepke S, et al. Internalised stigma in adults with autism: a German multi-center survey. *Psychiatry Res*. (2019) 276:94–9. doi: 10.1016/j.psychres.2019.04.023

23. Botha M, Dibb B, Frost DM. "Autism is me": an investigation of how autistic individuals make sense of autism and stigma. *Disabil Soc*. (2022) 37:427–53. doi: 10.1080/09687599.2020.1822782

24. Dubreucq J, Plasse J, Gabayet F, Faraldo M, Blanc O, Chereau I, et al. Self-stigma in serious mental illness and autism spectrum disorder: results from the REHABase national psychiatric rehabilitation cohort. *Eur Psychiatry*. (2020) 63:e13. doi: 10.1192/j.eurpsy.2019.12

25. McDonald TAM. Correction to: discriminative and criterion validity of the autism Spectrum identity scale (ASIS). *J Autism Dev Disord*. (2020) 50:340–1. doi: 10.1007/s10803-019-04228-1

26. Shtayermman O. An exploratory study of the stigma associated with a diagnosis of Asperger's syndrome: the mental health impact on the adolescents and young adults diagnosed with a disability with a social nature. *J Hum Behav Soc Environ*. (2009) 19:298–313. doi: 10.1080/10911350902790720

27. Riebel M, Bureau R, Rohmer O, Clément C, Weiner L. Self-compassion as an antidote to self-stigma and shame in autistic adults. (Submitted).

28. Wong CCY, Knee CR, Neighbors C, Zvolensky MJ. Hacking stigma by loving yourself: a mediated-moderation model of self-compassion and stigma. *Mindfulness*. (2019) 10:415–33. doi: 10.1007/s12671-018-0984-2

29. Neff KD, Kirkpatrick KL, Rude SS. Self-compassion and adaptive psychological functioning. *J Res Pers*. (2007) 41:139–54. doi: 10.1016/J.JRP.2006.03.004

30. Brown L, Houston EE, Amonoo HL, Bryant C. Is self-compassion associated with sleep quality? A meta-analysis. *Mindfulness*. (2021) 12:82–91. doi: 10.1007/s12671-020-01498-0

31. Cleare S, Gumley A, O'Connor RC. Self-compassion, self-forgiveness, suicidal ideation, and self-harm: a systematic review. *Clin. Psychol. Psychother*. (2019) 26:511–30. doi: 10.1002/cpp.2372

32. MacBeth A, Gumley A. Exploring compassion: a meta-analysis of the association between self-compassion and psychopathology. *Clin Psychol Rev*. (2012) 32:545–52. doi: 10.1016/j.cpr.2012.06.003

33. Zessin U, Dickhäuser O, Garbade S. The relationship between self-compassion and well-being: a meta-analysis. *Appl Psychol Health Well Being*. (2015) 7:340–64. doi: 10.1111/aphw.12051

34. Hilbert A, Braehler E, Schmidt R, Lowe B, Hauser W, Zenger M. Self-compassion as a resource in the self-stigma process of overweight and obese individuals. *Obes Facts*. (2015) 8:293–301. doi: 10.1159/000438681

35. Skinta MD, Fekete EM, Williams SL. HIV-stigma, self-compassion, and psychological well-being among gay men living with HIV. *Stigma Health*. (2019) 4:179–87. doi: 10.1037/sah0000133

36. Heath PJ, Brenner RE, Lannin DG, Vogel DL. Self-compassion moderates the relationship of perceived public and anticipated self-stigma of seeking help. *Stigma Health*. (2018) 3:65. doi: 10.1037/sah0000072

37. Cai RY, Gibbs V, Love A, Robinson A, Fung L, Brown L. "Self-compassion changed my life": the self-compassion experiences of autistic and non-autistic adults and its relationship with mental health and psychological wellbeing. *J Autism Dev Disord*. (2022) 53:1066–81. doi: 10.1007/s10803-022-05668-y

38. Galvin J, Richards G. The indirect effect of self-compassion in the association between autistic traits and anxiety/depression: a cross-sectional study in autistic and non-autistic adults. *Autism*. (2022) 27:1256–70. doi: 10.1177/13623613221132109

39. Cai RY, Brown L. Cultivating self-compassion to improve mental health in autistic adults. *Autism Adulthood*. (2021) 3:230–7. doi: 10.1089/aut.2020.0034

40. Cai RY, Love A, Robinson A, Gibbs V. The inter-relationship of emotion regulation, self-compassion, and mental health in autistic adults. *Autism* in Adulthood. (2023) 5:335–42. doi: 10.1089/aut.2022.0068

41. Goffnett J, Liechty JM, Kidder E. Interventions to reduce shame: a systematic review. *J Behav Cogn Ther*. (2020) 30:141–60. doi: 10.1016/J.JBCT.2020.03.001

42. Gilbert P. Social mentalities: a biopsychosocial and evolutionary approach to social relationships In: MW Baldwin, editor. *Interpersonal Cognition*. New York: The Guilford Press (2005). 299–333.

43. Craig C, Hiskey S, Spector A. Compassion focused therapy: a systematic review of its effectiveness and acceptability in clinical populations. *Expert Rev Neurother*. (2020) 20:385–400. doi: 10.1080/14737175.2020.1746184

44. Kirby JN, Gilbert P. Commentary regarding Wilson et al. (2018) "effectiveness of 'self-compassion' related therapies: a systematic review and Meta-analysis." all is not as it seems. *Mindfulness*. (2019) 10:1006–16. doi: 10.1007/s12671-018-1088-8

45. Riebel M, Rohmer O, Weiner L. Compassion focused therapy (CFT) for the reduction of the self-stigma of mental disorders: The COMpassion for psychiatric disorders and self-stigma (COMPASS) study protocol for a randomized controlled study. *Trials*. (2023) 24:393. doi: 10.1186/s13063-023-07393-y

46. Mason D, Acland J, Stark E, Happé F, Spain D. Compassion-focused therapy with autistic adults. *Front Psychol*. (2023) 14:1267968. doi: 10.3389/fpsyg.2023.1267968

47. Krasny-Pacini A, Evans J. Single-case experimental designs to assess intervention effectiveness in rehabilitation: a practical guide. *Ann Phys Rehabil Med*. (2018) 61:164–79. doi: 10.1016/j.rehab.2017.12.002

48. Ritsher JB, Phelan JC. Internalized stigma predicts erosion of morale among psychiatric outpatients. *Psychiatry Res*. (2004) 129:257–65. doi: 10.1016/j.psychres.2004.08.003

49. Linehan MM. *Skills Training Manual for Treating Borderline Personality Disorder*. New York: Guilford Press (1993).

50. Gast DL, Ledford JR. *Single Case Research Methodology*. *3rd* ed Routledge (2018).

51. Neff KD. The development and validation of a scale to measure self-compassion. *Self Identity*. (2023) 2:223–50. doi: 10.1080/15298860309027

52. Raes F, Pommier E, Neff KD, Van Gucht D. Construction and factorial validation of a short form of the self-compassion scale. *Clin Psychol Psychother*. (2011) 18:250–5. doi: 10.1002/cpp.702

53. Kotsou I, Leys C. Self-compassion scale (SCS): psychometric properties of the French translation and its relations with psychological well-being, affect and depression. *PLoS One*. (2016) 11:e0152880. doi: 10.1371/JOURNAL.PONE.0152880

54. Kratochwill TR, Hitchcock JH, Horner RH, Levin JR, Odom SL, Rindskopf DM, et al. Single-Case Intervention Research Design Standards. *Remedial Spec. Educ*. (2013) 34:26–38. doi: 10.1177/0741932512452794

55. Kratochwill T. R., Hitchcock J., Horner R. H., Levin J. R., Odom S. L., Rindskopf D. M., et al. (2010). Single-Case Designs Technical Documentation. What Works Clearinghouse. Available at: http://ies.ed.gov/ncee/wwc/pdf/wwc_scd.pdf.

56. Parker RI, Vannest KJ, Davis JL, Sauber SB. Combining nonoverlap and trend for single-case research: tau-U. *Behav Ther*. (2011) 42:284–99. doi: 10.1016/J.BETH.2010.08.006

57. Pustejovsky JE. Procedural sensitivities of effect sizes for single-case designs with directly observed behavioral outcome measures. *Psychol Methods*. (2019) 24:217–35. doi: 10.1037/met0000179

58. Ferron J, Goldstein H, Olszewski A, Rohrer L. Indexing effects in single-case experimental designs by estimating the percent of goal obtained. *Evid Based Commun Assess Interv*. (2020) 14:6–27. doi: 10.1080/17489539.2020.1732024

59. Bemmouna D, Coutelle R, Weibel S, Weiner L. Feasibility, acceptability and preliminary efficacy of dialectical behavior therapy for autistic adults without intellectual disability: a mixed methods study. *J Autism and Dev Disord*. (2021) 52:4337–54. doi: 10.1007/S10803-021-05317-W

60. Keenan EG, Gurba AN, Mahaffey B, Kappenberg CF, Lerner MD. Leveling up dialectical behavior therapy for autistic individuals with emotion dysregulation: clinical and personal insights. *Autism Adulthood*. (2023). doi: 10.1089/AUT.2022.0011

61. Gilbert P. A brief outline of the evolutionary approach for compassion focused therapy. *EC Psychol Psychiatry*. (2017) 3:218–27.

62. Gilbert P. Compassion: from its evolution to a psychotherapy. *Front Psychol*. (2020) 11:586161. doi: 10.3389/fpsyg.2020.586161

63. Hull L, Petrides KV, Allison C, Smith P, Baron-Cohen S, Lai MC, et al. "Putting on my best Normal": social camouflaging in adults with autism Spectrum conditions. *J Autism Dev Disord*. (2017) 47:2519–34. doi: 10.1007/S10803-017-3166-5

64. Bureau R, Riebel M, Weiner L, Coutelle R, Dachez J, Clément C, et al. French Validation of the Camouflaging Autistic Traits Questionnaire (CAT-Q)s. *J Autism Dev Disord*. (2023) 1–10.

65. Cook J, Hull L, Crane L, Mandy W. Camouflaging in autism: a systematic review. *Clin Psychol Rev*. (2021) 89:102080. doi: 10.1016/J.CPR.2021.102080

66. Dudley R, Kuyken W, Padesky CA. Disorder specific and trans-diagnostic case conceptualisation. *Clin Psychol Rev*. (2011) 31:213–24. doi: 10.1016/J.CPR.2010.07.005

67. Irons C, Heriot-Maitland C. Compassionate mind training: an 8-week group for the general public. *Psychol Psychother Theory Res Pract*. (2021) 94:443–63. doi: 10.1111/PAPT.12320

68. Gilbert P. An introduction to compassion focused therapy in cognitive behavior therapy. *Int. J. Cogn. Ther*. (2010) 3:97–112.

69. Laborde S, Allen MS, Borges U, Dosseville F, Hosang TJ, Iskra M, et al. Effects of voluntary slow breathing on heart rate and heart rate variability: a systematic review and a meta-analysis. *Neurosci Biobehav Rev*. (2022) 138:104711. doi: 10.1016/J.NEUBIOREV.2022.104711

70. Di Bello M, Ottaviani C, Petrocchi N. Compassion is not a benzo: distinctive associations of heart rate variability with its empathic and action components. *Front Neurosci*. (2021) 15:617443. doi: 10.3389/FNINS.2021.617443/BIBTEX

71. Petrocchi N, Cheli S. The social brain and heart rate variability: implications for psychotherapy. *Psychol Psychother Theory Res Pract*. (2019) 92:208–23. doi: 10.1111/PAPT.12224

72. Gilbert P. *Mindful compassion*. Hachette UK (2013).

73. Riebel M, Weiner L. Feasibility and acceptability of group compassion-focused therapy to treat the consequences of childhood maltreatment in people with psychiatric disorders in France. *J Nerv Ment Dis*. (2023) 211:393–401. doi: 10.1097/NMD.0000000000001603

74. Bell T, Montague J, Elander J, Gilbert P. "A definite feel-it moment": embodiment, externalisation and emotion during chair-work in compassion-focused therapy. *Couns Psychother Res*. (2020) 20:143–53. doi: 10.1002/capr.12248

75. Lucre K, Clapton N. The compassionate kitbag: a creative and integrative approach to compassion-focused therapy. *Psychol Psychother*. (2021) 94:497–516. doi: 10.1111/papt.12291

76. Hayes SC, Strosahl KD, Wilson KG. Acceptance and commitment therapy In: F Arthur, editor. *Encyclopedia Cognitive Behavior Therapy*, vol. 6. New York: Guilford Press (1999)

77. Steindl SR, Kirby JN, Tellegan C. Motivational interviewing in compassion-based interventions: theory and practical applications. *Clin Psychol*. (2018) 22:265–79. doi: 10.1111/cp.12146

78. Vannest KJ, Ninci J. Evaluating intervention effects in single-case research designs. *J Couns Dev*. (2015) 93:403–11. doi: 10.1002/JCAD.12038

79. Brede J, Cage E, Trott J, Palmer L, Smith A, Serpell L, et al. "We have to try to find a way, a clinical bridge" - autistic adults' experience of accessing and receiving support for mental health difficulties: a systematic review and thematic meta-synthesis. *Clin Psychol Rev*. (2022) 93:102131. doi: 10.1016/j.cpr.2022.102131

80. Heriot-Maitland C, Levey V. A case report of compassion-focused therapy for distressing voice-hearing experiences. *J Clin Psychol*. (2021) 77:1821–35. doi: 10.1002/jclp.23211

81. Hasson-Ohayon I, Ehrlich-Ben Or S, Vahab K, Amiaz R, Weiser M, Roe D. Insight into mental illness and self-stigma: the mediating role of shame proneness. *Psychiatry Res*. (2012) 200:802–6. doi: 10.1016/J.PSYCHRES.2012.07.038

82. Godeau E, Vignes C, Sentenac M, Ehlinger V, Navarro F, Grandjean H, et al. Improving attitudes towards children with disabilities in a school context: a cluster randomized intervention study. *Dev Med Child Neurol*. (2010) 52:e236–42. doi: 10.1111/J.1469-8749.2010.03731.X

83. Campbell JM, Ferguson JE, Herzinger CV, Jackson JN, Marino CA. Combined descriptive and explanatory information improves peers' perceptions of autism. *Res Dev Disabil*. (2004) 25:321–39. doi: 10.1016/j.ridd.2004.01.005

84. Ranson NJ, Byrne MK. Promoting peer acceptance of females with higher-functioning autism in a mainstream education setting: a replication and extension of the effects of an autism anti-stigma program. *J Autism Dev Disord*. (2014) 44:2778–96. doi: 10.1007/s10803-014-2139-1

85. Schachter HM, Girardi A, Ly M, Lacroix D, Lumb AB, Van Berkom J, et al. Effects of school-based interventions on mental health stigmatization: a systematic review. *Child Adolesc Psychiatry Ment Health*. (2008) 2:18. doi: 10.1186/1753-2000-2-18

86. Staniland JJ, Byrne MK. The effects of a multi-component higher-functioning autism anti-stigma program on adolescent boys. *J Autism Dev Disord*. (2013) 43:2816–29. doi: 10.1007/s10803-013-1829-4

87. Gilbert P, Simos G. (Eds.). *Compassion focused therapy: Clinical practice and applications*. Routledge (2022).

88. Cassidy S, Bradley L, Shaw R, Baron-Cohen S. Risk markers for suicidality in autistic adults. *Mol Autism*. (2018) 9:42. doi: 10.1186/s13229-018-0226-4

89. Conner CM, Golt J, Righi G, Shaffer R, Siegel M, Mazefsky CA. A comparative study of suicidality and its association with emotion regulation impairment in large ASD and US census-matched samples. *J Autism Dev Disord*. (2020) 50:3545–60. doi: 10.1007/s10803-020-04370-1

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A dual design thinking – universal design approach to catalyze neurodiversity advocacy through collaboration among high-schoolers

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Introduction: Neurodiversity describes the fact that humans all have different brains with unique qualities that contribute to society. Though understanding of neurodiversity is gaining traction among the general public, there remains considerable stigma and prejudice toward neurodiverse people. One way to combat these issues is to teach individuals about neurodiversity and encourage them to develop advocacy skills. Development of such knowledge is especially important for adolescents, as they have the capacity to make small (e.g., interpersonal interactions) and large (e.g., school-wide) impacts.

Methods: Eighty-nine high schoolers participated in a two-week virtual summer camp in 2022; research consent/assent was obtained from 19 (11 neurodiverse/neurodivergent). Campers learned about neurodiversity, Universal Design for Learning (UDL), and Design Thinking (DT) through lectures from researchers and neurodivergent people, as well as group activities and discussions. Campers worked in small groups to design a neurodiversity advocacy project based on the principles of UDL and DT. Each group was facilitated by camp counselors–some of whom were neurodiverse–who were all committed to neurodiversity advocacy. Participants completed questionnaires about autism, ADHD, and dyslexia pre- and post-camp. Some also completed optional post-camp interviews.

Results: Pre-camp stigma toward neurodiverse conditions was generally low. However, autism stigma was significantly higher than dyslexia stigma ($Z = -2.24$, $p = 0.025$). After camp, autism stigma decreased ($Z = -2.98$, $p = 0.003$;) and autism [$t(13) = 3.17$, $p = 0.007$] and ADHD [$t(13) = 2.87$, $p = 0.013$] knowledge improved. There were no significant changes in ADHD or dyslexia stigma or dyslexia knowledge. Participants reported enjoying collaborating with other campers and learning about UDL and DT. Thematic analysis of interviews generated four themes: Increased Understanding of Neurodiversity; Increasing Empathy and Becoming Less Judgmental; Creating a Neurodiverse Community; and More Awareness is Needed.

Discussion: This pilot investigation suggests that a virtual summer camp can be effective in improving attitudes toward and knowledge of neurodiversity. Qualitative analysis indicated participants became more accepting after the camp, both in terms of being less judgmental toward neurodiverse people and more self-accepting among neurodivergent campers. Future research should investigate the long-term effects of such a program, particularly with diverse samples of students.

KEYWORDS

neurodiversity, design thinking, universal design for learning, autism, ADHD, dyslexia

Introduction

What is neurodiversity?

Neurodiversity, at its most literal level, refers to the diversity of human neurobiology. Judy Singer, an Australian sociologist who coined the term *neurodiversity* in her 1998 thesis, likened neurodiversity to ecological diversity, highlighting that both conferred benefits to the human species and society (1). Apart from being a fact of biology, "neurodiversity" is often used when evoking the *neurodiversity paradigm* [or *approach* [es] (2)], which is a way of viewing the world in which there are no "right" kinds of brains, and people with different kinds of brains should be accepted and valued (3). Generally, people whose brains function within the norm and whose behavioral manifestations align with society's social expectations are referred to as neurotypical. In contrast, people whose brain functions and behavioral manifestations deviate from the societal norm are referred to as neurodiverse or neurodivergent. (Note that we will use "neurodiverse" and "neurodivergent" interchangeably throughout this paper to reflect the varying preferences of individuals who fall under the neurodiverse umbrella. Similarly, we refer to both "neurodiverse conditions" and "neurodivergences"). Examples of neurodiverse conditions include autism, attention-deficit/hyperactivity disorder (ADHD), dyslexia, and Tourette's syndrome.

The neurodiversity approach is in stark contrast to the medical model of disease/disability, wherein disability is located within an individual, who then requires treatment to ameliorate the disability or symptoms (4). For example, a child diagnosed with autism might be enrolled in therapy to get them to appear more like a typical child, for instance, by reducing their self-stimulatory movements and encouraging eye contact. While the neurodiversity approach is not synonymous with the social model of disability, it does have much more in common with it than the medical model. Under the social model, disability exists within society, and individuals with physical or psychological impairments are only disabled to the extent that society oppresses them (4). Thus, according to a strict interpretation of the social model, if society changes (for example, by creating curb cuts so wheelchair users can easily navigate sidewalks), the disability may no longer exist.

The neurodiversity paradigm aligns itself well with the social model of disability in multiple ways. For example, neurodiversity proponents highlight the ways in which societies are not created for neurodiverse people and thus contribute to their disablement (5, 6). They therefore stress the importance of environmental changes and accommodations in order to help neurodivergent people thrive. There are slight differences between the neurodiversity paradigm and the social model, however [though some do equate the two (6)]. In addition to being specifically focused on differing neurobiology (as opposed to any kind of disability, psychological or physical), there is room within the neurodiversity approach to support individuals above and beyond societal changes. This is especially true when those supports enhance quality of life (7). Indeed, some autistic people have echoed the common criticism of the strict social model that it can erase embodied feelings of disability (8, 9), for example, if someone has extreme sensory sensitivities. Similarly, Dwyer (2) argues that the neurodiversity approach shares similarities with the social-relational model of disabilities (10), where some individuals may benefit from both environmental accommodations and interventions targeted at the individual (though ultimately curing or normalizing should never be the goal). Some models of neurodiversity specifically center neurodivergent people's strengths (11), such that interventions and supports are tailored to capitalize on what the individual is interested in and/or already good at [see also (12, 13)].

Why is understanding neurodiversity important?

Neurodiverse people face tremendous stigma and prejudice in today's society [e.g., (14–16)]. Such stigma cuts across all neurodivergences, though each neurotype experiences this differently. For example, adults with ADHD report high levels of public stigma and expected discrimination (14). Autistic adults report having to navigate stigma and the stereotype that autism is "bad" (15). Teachers and parents are more likely to perceive disability and have lower educational expectations if a student is *labeled* as having a learning difference compared to matched students who are not labeled as such (16).

This stigma and prejudice lead to ableism, wherein those seen as less "able" than others are discriminated against. Because the neurodiversity approach is based on the acceptance of brain differences, it has the potential to address the ableism that has been perpetuated by the application of the medical model to neurodiverse conditions. According to Link and Phelan (17), stigma occurs when labels are applied to differences among people, and those differences are associated with negative stereotypes. This then allows the creation of an "us versus them" mentality, which ultimately can result in negative effects due to discrimination. Chapman and Carel (18) argue that stigma toward neurodivergent people has led to society discrediting, disenfranchising, and excluding them from what society considers a "good life."

Neurodiverse conditions are highly stigmatized, but many studies suggest that it is not neurodivergence (e.g., autism) itself that can lead to lower quality of life or well-being, but instead, lack of social support and/or acceptance (19–22). Nonetheless, many neurodiverse people are at risk of negative outcomes, likely due to these societal pressures and poor fit between individuals and their environments (2). For example, while some autistic people may prefer to interact with other autistic people (23), interactions with neurotypical people are inevitable at places like school and work. Thus, while young autistic people do report wanting and having friends, they also report difficulty trying to navigate neurotypical social norms, which can lead to feeling the need to change themselves in order to "pass" at being neurotypical (24, 25). Other research has found that young autistic people report experiencing neglect, rejection, and scorn at school (26), and are at high risk for bullying victimization (27). Adolescents with ADHD report being bullied, feel that society lacks empathy toward them (28), and are likely to experience peer rejection (29). Similarly, those with learning differences are more likely to struggle with interpersonal difficulties and report higher levels of loneliness and stress (see Al-Yagon and Margalit (30) for a review). Neurodivergent individuals may also be subject to self- or internalized stigma, wherein the stigmatized person accepts society's view of them and sometimes perpetuates the stigma toward themselves and others (31). One way of combating such internalized stigma is via self-acceptance, which has been linked with better mental health (19) and increased self-efficacy and self-regulated learning (32) in neurodivergent samples. Another way of relieving such stigma is self-compassion, which was found to be associated with higher psychological well-being and lower depression symptoms in both autistic and non-autistic adults (33). Thus, the adoption of the neurodiversity approach – which emphasizes acceptance – may hold promise for reducing stigma among neurotypical people, as well as reducing self-stigma among neurodivergent individuals.

Approaches to reducing stigma and prejudice

There are several approaches to reducing stigma and prejudice toward neurodivergent people. The ones highlighted below are awareness/acceptance programs, direct contact with neurodiverse people via inclusive settings, and programs specifically tailored to educate people about neurodiversity.

It should be noted that these approaches are in contrast to approaches that are solely focused on the autistic individual. For example, many intervention programs, including social skills programs, focus on teaching neurodiverse people skills that neurotypical people frequently use. For example, a host of social skills programs targeting autistic youth aim to increase their verbal and nonverbal initiations and responses to and engagement and sustained interaction with neurotypical peers [see Sutton et al. (34) and Whalon et al. (35) for two reviews of social skills interventions]. These are undoubtedly beneficial skills to learn, and reviews/meta-analyzes have found evidence of the benefits of these interventions (34–36). However, targeting only the neurodivergent child is an issue for multiple reasons. First, this implies that there is something inherently wrong with neurodivergence, which contrasts the tenets of the neurodiversity approach (2, 3). Second, teaching autistic individuals to act neurotypical in order to fit in can lead them to "mask" or "camouflage" their true selves (37, 38), which has been found to correlate with multiple negative mental health outcomes in autistic people (39, 40). Therefore, even if children could learn to perfectly enact every social skill in order to blend in with neurotypicals, this would likely have a negative effect on their quality of life. It should be noted, however, that "unmasking" can be viewed as a privilege not extended to non-White autistic people, who may feel that masking helps keep them safe, for example, with regards to Black autistic individuals who mask while interacting with the police (41). Lastly, focusing solely on the neurodivergent person ignores the fact that social interaction is a two-way street–why should, for example, children on the autism spectrum have to learn so much about neurotypical social interactions while neurotypical students are rarely expected to learn about the ways autistic people prefer to interact? This is an example of the double empathy problem (42), wherein a lack of understanding between different groups leads to mismatched expectations and difficulty in interacting. With regard to autistic people, they are expected to have enormous empathy for neurotypicals and accommodate their needs, whereas the reverse is rarely evident. As such, autistic people are often taught neurotypical social skills, but neurotypical people are rarely (if ever) taught about how autistic people prefer to interact socially. It is for these reasons that it is imperative that neurotypical people learn more about neurodivergent people.

Awareness/acceptance programs

While research suggests many youth and young adults have a basic awareness of autism (43, 44), there are still many reported inaccuracies [(45, 46); see (47) for a review]. Even in studies that have found high awareness and understanding of autism (48), such awareness is not necessarily from a neurodiversity perspective (e.g., there is little emphasis on acceptance of differing brains, masking, etc.). Similarly, there exist misconceptions and gaps in knowledge regarding ADHD (49), for example that ADHD is caused by sugar intake or failure to recognize the genetic heredity of ADHD.

Three reviews of autism acceptance/awareness/anti-stigma interventions for non-autistic peers were recently conducted (50–52). Programs reviewed in these studies varied widely, though all shared the goal of increasing understanding of autism. Some were short, one-off interventions [e.g., showing a video about an autistic child (53) or a self-paced online training (43)]. Other programs were longer, including those implemented in classrooms over a period of weeks (54). Overall, while many interventions reviewed show promise, especially with regards to self-reported knowledge about autism and, to some extent, attitudes toward autistic individuals, peers' behavioral intentions seemed less easily modulated across studies. It is also important to note that even when interventions purport to have the same goal (improving attitudes toward autistic peers), and even if they use the same outcome measures [e.g., the Adjective Checklist (55)], the effects of the intervention could vary drastically depending on the *framing* of the intervention. For example, Birnschein and colleagues (50) included peer-mediated interventions in their review. These kinds of interventions frame the neurotypical student as a helper, placing the neurotypical student in a position of power compared to the autistic peer. Similarly, Campbell and Barger (47) suggest that peer education and awareness programs be combined with peer tutoring or peer mentoring. Again, this frames autistic students as lacking and in need of help, as opposed to focusing on building reciprocal relationships between equals who have different interaction styles. Indeed, Morris et al. (52) point out that some awareness interventions may actually be inadvertently stigmatizing, and Cremin et al. (51) highlight that few such programs have assessed social validity.

Direct contact with neurodiverse people

Allport's (56) contact theory posits that contact between groups (i.e., a majority "in-group" and a minority "out-group") can reduce prejudice. Pettigrew and Tropp's (57) meta-analysis of studies based on contact theory found that direct contact with the out-group can reduce stigma and prejudice via increased empathy and decreased anxiety toward, and – to a lesser extent – knowledge of the out-group. When applied to neurodiversity, this would suggest that interacting with neurodivergent people can improve neurotypical people's attitudes toward them. Indeed, Rademaker et al.'s (58) review found that both contact with and information about peers with disabilities contributed to improved attitudes among non-disabled children in inclusive education settings. Another recent meta-analysis (59) also found that inclusive education led to improved social effects, such as greater peer acceptance and less prejudice. Studies that have specifically manipulated direct contact (e.g., by implementing a buddy system) have also shown promise in improving attitudes (60). However, inclusive settings nonetheless run the same risks as some of the aforementioned awareness/acceptance programs; that is, even when they recognize that inclusion leads to the possibility of being friends with disabled students, peers without disabilities often see themselves as helpers or facilitators (61). This could explain why there is some variation in the findings in the above meta-analyzes [e.g., (58–60)]. Social inclusion and contact by themselves are thus not enough to ensure positive attitudes develop [and could in some circumstances lead to an "us versus them" mentality (62)].

Interventions designed to promote neurodiversity

It has been argued that adopting the neurodiversity approach can have beneficial effects across a variety of contexts, including school (12), early intervention (63, 64), and even with regard to reducing stigma toward people with addiction issues (65). These arguments are bolstered by Kim and Gillespie-Lynch's (66) finding that those with less knowledge of autism and less endorsement of the neurodiversity movement report higher stigma toward autism. This stigma is not inconsequential—in Cage and Troxell-Whitman's (40) online survey study, feeling accepted by others was significantly related to reduction in depression and stress in autistic adults. Personal acceptance was also a predictor of depression and stress. Similarly, college students with learning disabilities reported greater academic self-esteem and greater career aspirations if they saw themselves through a neurodiversity lens as opposed to the medical model (67). Therefore, a great understanding of and positive attitude toward neurodiversity is likely to lead to greater acceptance (both external and personal) and well-being via a reduction in stigma.

Gillespie-Lynch and colleagues (46) created an online intervention to increase knowledge about autism and improve attitudes toward autistic people among college students. However, the authors recognized two important aspects of many previous interventions: (a) behavioral intentions often did not change attitudes toward autistic people, suggesting that neurotypical people were no more likely to want to hang out with an autistic person than prior to the intervention; and (b) the language used to explain autism in other studies may not be very useful in decreasing stigma [e.g., an autistic person described as having "something wrong with his brain" (53)]. The training included details regarding diagnostic changes from the DSM IV to DSM 5, issues of diagnosis in females, cultural factors including stigma, heterogeneity of intelligence in autistic people, etiology, empathy, challenges facing adults on the spectrum, and neurodiversity. Though the training was developed by a non-autistic researcher, the research team included an autistic scholar and self-advocate who provided feedback on the training. Stigma [assessed using an adapted version of the Social Distance Scale (68)] significantly decreased from pre- to post-test. At the item-level, there was significantly more willingness to collaborate with and marry/date someone on the spectrum after the intervention (though the item assessing stigma regarding romantic relationships was rated highest of all at both timepoints). Autism knowledge also increased after the training (with effect sizes larger than for stigma), though participants' open-ended definitions of autism did not improve. The same training was also successful at increasing knowledge and to some degree reducing stigma in a sample of Japanese college students (69).

While Gillespie-Lynch et al.'s (46) training utilized an inclusive, neurodiversity-affirming framework, the team still felt that the training was lacking autistic input. They therefore conducted a study looking at differences between a training that was developed with autistic individuals using a participatory framework and one that was developed primarily by non-autistic people (70). The non-participatory training was adapted from the initial 2015 training. The participatory training was developed with multiple autistic college students (including one non-speaking student) and included videos of the students throughout the training. While some of the information presented was similar to the non-participatory training, the participatory one especially emphasized topics that were of importance to the autistic students, such as gender and motherhood in autistic individuals. The two trainings were matched on length and number of videos (the non-participatory training included TEDTalks and other informational videos in place of the student videos). While both trainings resulted in increased knowledge, reduction in stigma, and improvements in attitudes toward inclusion, the impact of the participatory training was greater than that of the non-participatory one.

Several studies have documented the promise of teaching individuals about neurodiversity through the lens of Universal Design (UD) (71). UD is a way of designing products, spaces, and materials such that they are accessible to everyone from the get-go, as opposed to having to provide retrofits to ameliorate non-accessibility. When applied to learning, UD (or Universal Design for Learning; UDL) focuses on the fact that we all have different brains with different strengths (72), and no one-size-fits-all approach will work for all people, an approach that is very much in line with the neurodiversity perspective. In a study designed to improve the way university educators teach autistic students, Waisman and colleagues (73) developed an asynchronous, online training about autism and UD. After participants reviewed the two modules (one about autism, one about UD), their reported knowledge of autism improved, and stigma decreased. Most participants also felt that they understood more about neurodiversity after the training, and their definitions of autism were more in-line with the neurodiversity perspective.

Similarly, during the early days of the COVID-19 pandemic, Lambert and colleagues (74) taught math educators about UD in order to help them design educational materials that would be accessible while teaching online. Recognizing that the Universal Design for Learning framework lacks clear guidance on how to actually implement inclusive curriculum, Lambert and colleagues (74) also utilized the principles of Design Thinking (DT), which is a step-by-step, iterative approach to designing. The DT steps include empathize (what do my users actually need/want?), define (what exactly is the problem I am going to try to solve?), ideate (how might I solve this problem?), prototype (develop potential solutions), and test (how would this solution work for the users?). Participants not only learned about disability, UD, and DT, but they also designed hands-on projects in small groups. After the 6-week course, participants in Lambert et al.'s (74) study reported shifts away from deficit-conceptions of students with disabilities and recognized that a major key to working with disabled individuals was to listen to their needs (75).

Thus, didactic teaching about disability and neurodiversity, emphasizing intentional design, and giving opportunities to create tangible materials using the principles of UDL and DT appear to be effective ways of improving knowledge of and attitudes toward neurodiversity.

Current study

There is research to support a variety of interventions to reduce stigma and prejudice and improve the quality of life among neurodivergent people. These include awareness/acceptance interventions, inclusive environments that encourage direct contact among people with and without disabilities, programs that include explicit teaching about neurodiversity, and trainings that emphasize hands-on advocacy projects via UDL and Design Thinking. However, no studies have combined all of these approaches in order to teach *in-vivo* about neurodiversity advocacy while also providing direct contact with neurodivergent people. Adolescents are in a unique position to enact both formal advocacy (e.g., through school clubs or volunteer opportunities) as well as have a sustained direct impact on neurodivergent peers through day-to-day interactions at school. Learning about neurodiversity may improve such day-to-day interactions, and an understanding of how to apply UDL via Design Thinking might help more formal advocacy efforts.

The current multimethod study aimed to preliminarily assess the effectiveness of a two-week summer camp designed to improve high schoolers' attitudes toward and increase knowledge of neurodiversity. The camp consisted of both didactic sessions intended to teach participants about a variety of issues related to neurodiversity and a hands-on advocacy project. Similar to the Lambert et al. (74) study, the camp project incorporated principles of UDL and DT in order to guide participants in designing something that could benefit the neurodiverse community. The following research questions guided the study and its analysis:

- What impact does the summer camp have on participants' self-reported stigma toward and knowledge of neurodiverse conditions, such as autism, ADHD, and dyslexia?
- What do participants feel are the best parts of the camp? What suggestions do they have for the future?
- In qualitative interviews, how do participants discuss their experiences in the camp? What take-aways are there?

Method

Participants

Participants were recruited from the pool of high school students who had already signed up to participate in the Stanford Neurodiversity Project - Research, Education, and Advocacy Camp for High Schoolers (SNP REACH) in Summer 2022. Of the 89 campers (about one third neurodiverse), parental consent was obtained for 23 campers. Of those 23 campers, 19 (12 female, 5 male, 2 non-binary) agreed to participate (18 provided written assent; 1 participant who turned 18 years old after their parent consented provided written consent). Eight participants (42.1%) identified as Asian, five (26.3%) as White, three (15.8%) as Mixed Race, one (5.3%) as Hispanic, one (5.3%) as Middle Eastern, and one participant did not fill out the question about race/ethnicity. For both race/ethnicity and gender, participants were presented with multiple-choice options and asked to check off all that identified with; if "other" was chosen, participants could write-in how they identified. Participants ranged in age from 14 to 18. Eleven (57.9%) identified as neurodiverse/neurodivergent, with participants identifying as autistic ($n = 6$), as dyslexic ($n = 3$), having ADHD ($n = 6$), having dyscalculia ($n = 1$), and having dysgraphia ($n = 1$). Some participants had multiple diagnoses/identities. Three participants (including two who identified as neurodiverse and one who did not) indicated they had psychiatric conditions (depression and/or anxiety). Most ($n = 14$) indicated they had neurodiverse friends or family members; three indicated they did not, whereas two participants were not sure. See Table 1 for full demographic information. Because our research questions were focused on the overall effects of the camp (not differences between neurotypical and neurodivergent campers), and due to our small sample, the group of campers was considered one sample.

All 19 participants completed the baseline survey. Fourteen completed post-camp surveys (9 neurodiverse), and nine (4 neurodiverse) completed at least one interview. Most of the participants who completed an interview also completed the post-camp surveys, though two of the neurotypical participants who completed interviews did not, as they preferred to talk via Zoom than fill out online surveys.

Procedure

Approximately 2–4 weeks before the start of the camp, an email was sent to all campers and their parents inviting them to participate. The email included a link to an online consent form for parents to fill out. Once parents consented, parents were sent a link to the child assent form and asked to share it with their child. Once assented, participants were asked to fill out a series of questionnaires before the camp. All 19 participants filled out baseline questionnaires (though one did so during week 2 of the camp). During the two-week camp, participants did not complete any research activities. Immediately after the camp, participants who completed baseline questionnaires were asked to complete post-camp questionnaires; 14 campers completed post-camp questionnaires. They were again asked 3 months later (10 completed follow-up questionnaires). Participants were also asked to participate in optional Zoom interviews at both follow-up

TABLE 1 Participant demographic information.

	Neurodiverse campers (*n* = 11)	Neurotypical campers (*n* = 8)	All campers (*n* = 19)
Gender			
Female	5	7	12
Male	5	0	5
Non-binary	1	1	2
Diagnosis[a]			
Autism	6	0	6
Dyslexia	3	0	3
ADHD	6	0	6
Dyscalculia	1	0	1
Dysgraphia	1	0	1
Anxiety	2	1	3
Depression	0	1	1
OCD	1	0	1
Neurodiverse			
Personal Contact			
Yes	9	5	14
No	1	2	3
Unsure	1	1	2
Average Age	16.11	15.88	16.00

[a] Self-reported diagnosis (participants could choose from a list of potential developmental disability and mental health diagnoses or write-in something else).

timepoints. Nine campers (4 ND) agreed to the interview at one or both timepoints.

Intervention: SNP REACH

The SNP REACH is a summer camp for high schoolers to learn about neurodiversity and collaborate on neurodiversity advocacy projects. The camp was started in 2019. SNP REACH lasted 6 hours per day, Monday through Friday, for 2 weeks. In 2022, SNP REACH was conducted entirely online via Zoom and Canvas. There were two cohorts of participants, one with 42 campers and the other with 47 campers. In each cohort, campers were split into small groups of 7–8. Each group was assigned 1–2 counselors to help facilitate discussion and guide their projects. Counselors included high school students who attended SNP REACH in previous years, undergraduate and graduate students, and recent college graduates. Most groups had two counselors. Younger, less experienced counselors (e.g., high school students and undergraduates) were paired with those who were older and more experienced counselors so that each group was led by counselors with a wide range of expertise. In the groups where there was only one counselor, the counselor was more mature and experienced (e.g., a graduate student). Five of the twelve counselors identified as neurodiverse/neurodivergent. Because there were fewer neurodivergent than neurotypical camp counselors, most groups had two neurotypical counselors, whereas some had mixed-neurotype counselors. All were involved in neurodiversity advocacy in some capacity. All camp counselors received an 8-week training (1 h, once a week) on neurodiversity, UDL, and DT before the camp started. Camp counselor trainings were led by the senior author.

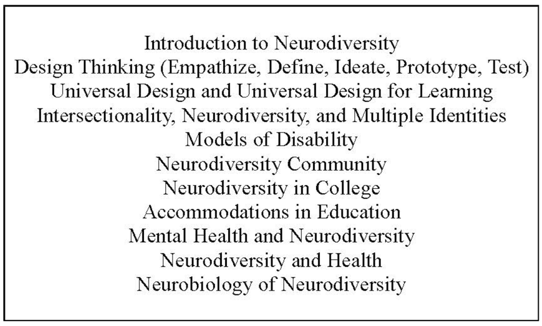
Day-to-day camp activities included large group activities such as expert lectures and workshops led by camp counselors as well as small group discussions and project work time (see Table 2 for an example camp day and Figure 1 for an overview of camp topics).

Expert lectures

One large group lecture was given via PowerPoint presentation daily at the beginning of camp. The initial lecture was given by Dr. Fung and focused on introducing campers to neurodiversity. Guest

TABLE 2 Example SNP REACH Daily Schedule.

Time	Activity	Delivered by	Format
9:00–9:10 AM	Daily check-in	Camp director	Large group
9:10–10:30 AM	Lecture: neurodiversity in college	Content Expert (e.g., adjunct professor and social worker)	Large group
10:30–10:40 AM	Break		
10:40–11:40 AM	Discussion/activity: accommodations in education	Camp counselor	Large group and small group break-outs
11:40 AM–12:25 PM	Lunch break		
12:25–1:25 PM	Project-based learning: design thinking: prototype	Camp counselor	Large group and small group break-outs
1:25–1:35 PM	Break		
1:35–2:35 PM	Student group work time	Facilitated by camp counselors	Small groups
2:35–3:00 PM	Wrap-up	Camp director	Large group



Introduction to Neurodiversity
Design Thinking (Empathize, Define, Ideate, Prototype, Test)
Universal Design and Universal Design for Learning
Intersectionality, Neurodiversity, and Multiple Identities
Models of Disability
Neurodiversity Community
Neurodiversity in College
Accommodations in Education
Mental Health and Neurodiversity
Neurodiversity and Health
Neurobiology of Neurodiversity

FIGURE 1
Topics covered at SNP REACH.

speakers gave the remaining lectures on topics such as inclusive playground design, disability law, lived experience of neurodiversity, neurodiversity advocacy, disability support for college students, neurobiology, and mental health. Experts included researchers and clinicians as well as neurodivergent students and advocates.

Workshops

Workshops covered topics related to the morning's lecture, including universal design for learning and accommodations, models of disability, health, and positionality. Additional daily workshops on the principles of design thinking were conducted in the afternoon. Most workshops were run by camp counselors. Workshops usually started by the camp counselor giving a short presentation to the whole group on an extension of the morning's lecture (e.g., a workshop on accommodations followed the morning's lecture on neurodiversity in college). After the short presentation, breakout rooms were utilized so that each small group could complete brief activities and answer discussion questions (e.g., in the context of the accommodations workshop, review different university Disabled Students' Program webpages, and discuss what kind of accommodations might work best for them). Workshops usually ended with each group sharing what they discussed with the entire camp.

Group advocacy project

The culmination of the camp was each group's neurodiversity advocacy project. The purpose of these projects was to give the campers the opportunity to apply what they were learning in a hands-on way that could be applied to real-world settings beyond the camp (e.g., at their school or in their own communities). Groups were instructed to follow the design thinking process to create a product to address an issue relevant to neurodiversity. Daily DT workshops throughout the camp guided campers through the design process. Additional time was given every afternoon for groups to work freely on their projects, facilitated by their counselors. After going through the first DT steps (empathize, define, ideate, prototype), groups were encouraged to test their prototypes with potential users. Many groups sent out their prototypes (including magazines, websites, cookbooks, etc.) to members of the Stanford Neurodiversity Project Special Interest Group to get feedback. All groups presented their projects to the whole group on the last day of the first week and the last day of the camp. Families were invited to attend final presentations on the last day of camp. Groups were encouraged (but not required) to continue their advocacy projects beyond the end of camp.

Measures

This study used multiple methods to answer our research questions: questionnaires (both standardized, validated instruments as well as open-ended questions about the camp, which were designed by the researchers) and qualitative interviews. Questionnaires were the same at all time points, with the exception of the open-ended questions. Interviews were only conducted at post-camp and 3-month follow-up.

Open-ended questions

Participants were asked open-ended questions such as: What was your favorite part of the camp? What was the most important takeaway from camp? Do you have any suggestions for how to improve the camp in the future?

Social distance scales

Three SDS's were included: one about autism, one about ADHD, and one about dyslexia. Each SDS contained 10 questions about whether one would be willing to participate in different activities (e.g., *I would be willing to have lunch with an autistic person*). The SDS was originally developed by Bogardus (68), though the current version was adapted by Gillespie-Lynch et al. (70) to focus specifically on autism. Half of the items were reverse-scored. SDS item scores ranged from −2 to 2, with higher scores indicating more stigma. The autism-focused SDS exhibited strong internal consistency across Gillespie-Lynch et al.'s three samples (α range = 0.85–0.90) (70); internal consistency was slightly lower in the current study (α =0.77). For the purpose of the current study, all items from Gillespie-Lynch et al.'s study were modified to also refer to individuals with ADHD and dyslexia. These SDSs had excellent internal consistency (ADHD: $\alpha = 0.94$; dyslexia: $\alpha = 0.91$).

Participatory autism knowledge-measure

The PAK-M was developed by Gillespie-Lynch et al. (70) and taps into not just common knowledge about autism (e.g., that vaccines do not cause autism) but also topics that were deemed important to autistic collaborators (for example, masking: "*Autistic people who hide their autism symptoms are more likely to experience mental health challenges than those who are comfortable with their autism*"). PAK-M item scores range from −2 to 2, with higher scores indicating more knowledge. Nine items were reverse-scored. The PAK-M exhibited satisfactory internal consistency (α range = 0.74–0.86) across multiple samples in Gillespie-Lynch and colleagues' study (70) and had similar internal consistency in the current study ($\alpha = 0.88$).

Scale of ADHD-specific knowledge

The SASK (76) is a 20-item instrument designed to assess understanding of ADHD. Each item is presented as a statement (e.g., *ADHD is a neurobiological, developmental disorder*) and participants can indicate whether they think the statement is true, false, or do not know. Items were scored a 1 if answered correctly and 0 for incorrect or "do not know" answers. Two items were removed for this study (*A combination of stimulant medication and behavior management is an effective treatment for ADHD; Teachers are often the first to recognize ADHD type behaviors and refer children for assessment*), as it was decided that these items were irrelevant for our adolescent sample. Of the 18 retained items, four items were reverse-scored. The SASK had satisfactory internal consistency in Mulholland's study ($\alpha = 0.88$) (76); it was almost as high in the current study ($\alpha = 0.75$).

Dyslexia knowledge scale

The 10-item knowledge subscale of Gonzalez's (77) dyslexia scale was used. Each item is presented as a statement (e.g., *Dyslexia is a learning disability that affects language processing.*) and participants indicate whether they think the statement is definitely true, probably true, probably false, or definitely false, with items scored on a scale of 1–4. Six items were reverse-scored. Gonzalez found the entire scale to have acceptable internal consistency ($\alpha = 0.70$) (77). Internal consistency for the knowledge scale in the current study was much lower ($\alpha = 0.54$).

Average scores for each instrument were obtained for each participant at pre-camp and post-camp.

Interviews

The post-camp interview focused on take-aways from the camp, how they saw neurodiversity advocacy as part of their life moving forward, things campers liked about SNP REACH, and suggestions for the future. Three-month follow-up interviews touched upon any neurodiversity-related activities since the camp ended and further reflections on the camp's impact. All interviews were conducted via Zoom by the first author.

Data analysis

Analysis of quantitative data

Questionnaire data was first assessed for normality. The Shapiro–Wilk test indicated that all three SDS's were non-normally distributed, whereas the knowledge scales were normally distributed. Thus, comparisons of baseline stigma and pre-post changes in stigma were assessed using Wilcoxon signed-rank tests, whereas pre-post comparisons of knowledge scales were assessed using paired samples t-tests. Due to the small sample and the exploratory nature of these analyzes, significance level was set at $\alpha = 0.05$ and was not adjusted for multiple comparisons. Cohen's d was used as a measure of effect size.

Analysis of qualitative data

Two types of qualitative data were generated. First, written responses to open-ended questionnaire items (e.g., What was your favorite part of the camp? What was the biggest takeaway? What could be improved in the future?) were reviewed for common answer choices (e.g., group work, advocacy project, etc.). These answers were then quantified by tallying the number of participants who gave the most frequent answers.

Second, interviews were analyzed using reflexive thematic analysis (78, 79). According to Braun and Clarke, thematic analysis includes the following six steps: familiarization, generating codes, constructing themes, revising themes, defining/naming themes, and producing the report. All interviews were recorded via Zoom and the interviewer (the first author) took notes during each one. The automated transcripts generated by Zoom were then reviewed and edited by the first author while watching and listening to each video recording. After this initial familiarization with the data, the first author then read through all interview transcripts and created an analytic memo about each interview (80). These memos were then reviewed altogether, and an initial coding scheme was developed based upon commonalities throughout the interviews. After codes were generated, they were then applied while re-reading each interview transcript. Code names and meanings were continually updated during the coding process. Themes were then generated based on the codes. All themes were then reviewed by the senior author for peer debrief in order to assess credibility of the findings. The extensive data familiarization process and comprehensive audit trail enhance the trustworthiness of the analytic process. Additionally, both authors exercised reflexivity by recognizing their own values and positionalities (see below for more information).

Author positionality

Both authors take a neurodiversity approach to working with neurodivergent individuals and conducting research. The first author, a recent doctoral graduate with a PhD in Education, identifies as female, White, and neurotypical. Her research interests center around the acceptability of interventions for autistic individuals and teaching the general public about neurodiversity. She has a background in delivering naturalistic developmental behavioral interventions with autistic children and their families. She also served as a camp counselor during the 2022 SNP REACH. The senior author is an academic psychiatrist specialized in autism and neurodiversity. He identifies as male, Asian, and neurodiverse. He is the father of a neurodiverse individual. He has 14 years of experience seeing patients on the autism spectrum. He is an active researcher, educator, and program developer in the fields of autism and neurodiversity. He is also the creator and director of SNP REACH.

Results

Quantitative data

At baseline, campers reported relatively low stigma toward the three neurodivergent diagnoses (on a scale of −2 to 2, where higher scores indicate greater stigma: autism: -1.67 (SD = 0.40), ADHD: -1.73 (SD = 0.52), dyslexia: -1.79 (SD = 0.40)). Though reported stigma was generally low, there was a significant difference between participants' autism and dyslexia stigma scores ($Z = -2.24$, $p = 0.025$), with participants reporting greater autism stigma. Other baseline stigma comparisons were not significantly different.

After the camp, stigma scores decreased for all three diagnoses compared to baseline. However, the decrease was only statistically significant for autism ($Z = -2.98$, $p = 0.003$; see Table 3). Knowledge of autism and ADHD also significantly changed, with participants reporting more knowledge after the camp [autism: t (13) = 3.17, $p = 0.007$; ADHD: t (13) = 2.87, $p = 0.013$]. Knowledge of dyslexia did not significantly change. Effect sizes for the significant changes ranged from $d = |0.77|—|0.85|$, indicating relatively strong effects.

Comparisons in pre-camp to post-camp changes in quantitative measures between neurodiverse and neurotypical campers are not

TABLE 3 Average questionnaire scores at baseline and post-camp.

	Pre-camp mean	Post-camp mean	Test statistic[a]	Effect size[b]
Autism SDS (Stigma)	−1.67	−1.84	−2.98*	−0.80
ADHD SDS (Stigma)	−1.71	−1.86	−1.22	−0.33
Dyslexia SDS (Stigma)	−1.80	−1.89	−1.84	−0.49
PAK-M (Autism Knowledge)	1.16	1.37	3.17*	0.85
SASK (ADHD Knowledge)	0.69	0.82	2.87*	0.77
Dyslexia Knowledge	3.17	3.13	−0.87	−0.23

*Significant at the $p < 0.01$ level. SDS = Social Distance Scale (measure of stigma). [a]For SDS's, test statistic is a Z-score; for knowledge scales, test statistic is a t-score. [b]Effect size for SDS's is calculated by dividing the test statistic by the square root of the number of participants ($n = 14$); for knowledge scales, effect size is Cohen's d. All SDS's and the PAK-M are rated on a scale from −2 to 2; the SASK is rated as a 0 or 1 and scores indicate average number of answers correctly answered; the dyslexia knowledge scale is scored from 1 to 4. Only data for the 14 participants who completed pre- and post-camp data is displayed here.

presented here due to the very small sample size in each group and the fact that this was not one of our research questions. However, these analyzes can be found in the Supplementary materials.

Qualitative data

Questionnaires

When asked what their favorite part of the camp was, 6/14 of the participants who filled out the post-camp questionnaires indicated their favorite part was collaborating, interacting, and/or discussing with their small group. Five individuals mentioned the lectures/speakers, three mentioned the group project, and two mentioned the final advocacy project presentations. When asked what the most important take-away from camp was, 7/14 participants indicated it was learning about UDL and DT, three indicated learning more about self-advocacy, and two indicated the strengths-based model.

Suggestions for how to improve the camp in the future included increased opportunities to get to know fellow campers, providing more guidance regarding the advocacy projects, and having more interactive sessions (as opposed to lectures) in the morning. Some participants also mentioned how it might be interesting to have an even greater diversity of speakers, such as having a young neurodivergent person plus their parent, an elderly neurodivergent person, and international neurodiversity advocates.

Interviews

Thematic analysis of the post-camp and 3-month follow-up interviews generated four themes: Increased Understanding of Neurodiversity; Increasing Empathy & Becoming Less Judgmental; Creating a Neurodiverse Community; and More Awareness is Needed. Each theme is discussed in more detail below.

Increased understanding of neurodiversity

> Five of the nine campers who completed an interview mentioned how the camp broadened their understanding of neurodiversity. This was an especially salient point, given that many of the campers were already familiar with neurodiversity before starting the camp. As one neurodivergent camper stated: I definitely feel like I learned a lot about a topic which I already kind of knew a large amount about…like the amount of difference there is between different types of neurodiversity – like one thing I really never actually heard of, which really surprised me that I had not heard of this, is nonverbal autism.

Another camper, who is neurotypical, mentioned how she realized how common different neurotypes were: "It definitely broadened in my view, beyond just ADHD and autism and to see how common it is and how many different ways it can manifest." An autistic camper also mentioned that her view of neurodiversity was broadened due to the interactions with other neurodivergent campers: "I'm just maybe a little more broadened a little bit just because I met more people and people with diverse conditions like, I met people other people with autism. And then I met people with ADHD, people with dyslexia, you know, people who do not have any brain differences."

Two campers mentioned how learning about neurodiversity from a factual, empirical standpoint was especially useful to their own conceptions of neurodiversity. For example, an autistic camper stated: "That's why like [the] lectures about the studies are so important, because they are like empirical facts, instead of like people's observations." Another camper described how he felt validated in his own ideas after hearing about neurodiversity in such a way:

> I feel like there were some ideas with support. I feel like I have a lot of like ideas, like – Oh, I have these ideas, they exist, but I do not have, like all this stuff to back them up. But I feel like now, I have a lot more to – like, I feel like I've definitely learned a lot, even if, like what I knew wasn't changed, I guess.

Another two campers mentioned how their perspectives were broadened due to discussions around different models of disability. One described how they "learned a lot about the different models [of disability] and why each one is, has its strengths and weaknesses." Another discussed how they thought "the main [takeaway] is just that things tend to be very oversimplified online and this camp really dove into like the depth of what we are talking about when it comes to, like the strength-based model."

Increasing empathy and becoming less judgmental

Seven participants touched upon the idea becoming more understanding. This theme was broken up into two subthemes: Increasing Empathy and Becoming Less Judgmental. Three participants mentioned how the design thinking concept of empathy was important when thinking about how to best support neurodivergent people. A neurotypical participant explained, “I think that goes with any sort of community that’s misjudged, just breaking down those misconceptions. And that’s the biggest thing. Because if everyone can empathize with each other, right, so many of our problems would be gone.” Another participant, who was autistic, described how empathy could be used to design products that are more accessible and useful:

> [The camp director] was wondering if we were actually addressing the pain points of neurodiverse students, so I learned that there’s basically, there’s no point of creating a product if it does not benefit the people you want to target. And you can think your product is all good and that it has the most advanced technology, but it does not end up benefiting the lives, or like addressing some of the suffering that people face on a daily basis, then there is no point of the product.

Similarly, another camper mentioned how they were rethinking the accessibility of some graphic design infographics they created over the pandemic:

> We have to factor in things like font, we have to factor in things like audio versions and whatnot and I realized like, these online materials, I thought were more accessible, because of their format of them being online - I thought they are accessible but turns out maybe they are not. … so I think that’s my main takeaway, like needing to reach out to more people to actually be part of the design process.

Five participants (four of whom were neurotypical) described becoming more understanding in terms of being less judgmental after the camp. One camper described how she learned to be more supportive of people’s special interests: “I know it’s like impossible to completely have no prejudice but whenever I talk to people, making sure that I do not just, do not be rude or, let us see, like when people are really passionate about something, let them talk about it, be a good listener.” Another camper explained how the camp has allowed her to be more understanding of a friend with ADHD who was panicking about a class project and mentioned that her ADHD medications had worn off an hour before: “I feel like before the camp, I would have probably thought of this in a negative way, like, “Oh, my gosh! She takes meds!” -- but now it’s just like, I do not think much of it, and I think it’s completely natural.”

Two participants who tutor younger children commented on how the camp taught them to individualize their teaching such that each child’s strengths can be supported. Another participant described how she incorporated the strengths of people with ADHD into a class presentation about psychiatric diagnoses.

Creating a neurodiverse community

Three of the four neurodiverse campers discussed how they felt the camp taught them something about themselves as a neurodiverse person and/or created a sense of community among neurodivergent people. For example, a camper with ADHD discussed how her self-advocacy skills grew: “I always get worried about, like, if I’m telling people I need something, am I inflicting it on other people? So that was definitely one big barrier that I overcame…I have the confidence to go to the teacher and say, “Oh, I would like more time on this because my extended time was not met all the way.””

An autistic participant described how he felt that the camp allowed him to be “more accepting of some of the weird ways that I act.” He explained how seeing that there are other people in the world like him boosted his confidence and encouraged him to try to mask his autism less, which led to positive outcomes: “When I try to mask less, then I was less stressed, and I was actually more confident in talking to people, which is kind of counterintuitive. But, yeah I was more confident, more happy talking to people.”

Participants also felt that the camp provided a sense of community for neurodivergent people. An autistic participant stated that the camp is “kind of geared toward people like me so they have kinda like more similar traits to me than compared to other camps, so I guess there was a closer community here.” Another autistic camper explained how she felt included in the camp in a way that she does not always at school: “But it was definitely nice being in a group, where I was included and I could actually talk to any people in here…sometimes in groups in the past, like at school, it’s been harder to be included because I’m, you know, the quiet one and it’s difficult when you are with people who will not pull their weight, or who will not let you contribute. But our group was thankfully really nice about letting everyone contribute.”

More awareness is needed

Six participants brought up how there is little awareness or understanding of neurodiversity in the general population. A neurotypical participant explained that most teens.

“Have not been taught whatsoever about the community. And so our perceptions are filled up by whatever media we take in, or whatever biases or stigmas we hear around us…So anything, anything history-related, advocacy-related, just some sort of education about it – I think it would get rid of some of these biases and fill in with actual positive, factual information that I guarantee you very few high schoolers have right now.”

Another participant explained how his plans to incorporate a mentorship program into an existing neurodiversity club at his high school seemed unlikely given the club’s low membership: “And it could also be that no one really knows what neurodiversity is, which is probably what it is…I think most people kind of know that neurodiversity exists. I think it’s more like putting a name to that idea, and really like, I feel like just getting people more accustomed to the topic.”

Several other participants also discussed how schools were a great venue for teaching about neurodiversity. One participant had given presentations about autism during school assemblies and was planning more for the future, with the hope that they would inform both students and teachers. Another participant mentioned how incorporating the camp content into schools would help reach a wider audience and increase its impact: “I do not know if you guys have some sort of initiative to bring it to schools, but if you could, that’d be so cool because…if you could like, really magnify it, I think there’d be a lot of students that could benefit from it.”

Discussion

According to pre-camp self-report, campers had relatively low stigma toward and high knowledge of three neurodiverse conditions that were seen as representative of the neurodiversity approach: autism, ADHD, and dyslexia. This is unsurprising, given that the campers self-selected into the camp based on an interest in the topic of neurodiversity. Nonetheless, there was a statistically significant decrease in autism stigma and increase in autism and ADHD knowledge from pre- to post-camp, though there were no significant changes in attitudes toward ADHD or knowledge of or attitudes toward dyslexia.

This finding could be explained by a variety of factors. First, there was more autism-specific (and to some extent ADHD) content in the camp, which is a likely byproduct of the neurodiversity movement being originally rooted in autism rights (81, 82). The significant decrease in autism stigma could also perhaps be attributed to the fact that stigma toward autism was higher than stigma toward dyslexia at pre-camp (autism and ADHD stigma was not significantly different, though it is possible that with more power from a larger sample, differences would have been detectable). This highlights that, even among teenagers who have an interest in neurodiversity, autism is perhaps especially misunderstood. This is in line with other research that autism is particularly stigmatized, even compared to other conditions (83, 84). Nevertheless, providing didactic instruction on neurodiversity and allowing participants to work together to create their own advocacy projects based on the principles of UDL and DT appeared to improve even the low level of stigma at pre-camp.

Additionally, the change in knowledge regarding autism could be attributed to the fact that Gillespie-Lynch et al.'s (70) autism knowledge measure was designed with an explicit neurodiversity perspective, whereas the other two instruments were not. This could thus provide evidence that the camp was successful in its goal of changing campers' conceptions of disabilities from a neurodiversity—as opposed to medical model—point of view. Nonetheless, knowledge toward ADHD also significantly increased even though the instrument was not designed with neurodiversity in mind. While dyslexia knowledge did not improve, it is possible that this was due to the fact that the measure exhibited poor internal consistency in this study. This could be explained by the fact that the instrument was originally designed for teachers; high school students may not have enough background knowledge about dyslexia, which could have led to guessing on certain questions (e.g., most campers did not know that dyslexia is more common in boys than girls). This suggests that future iterations of the camp and similar programs should take care to include more information on neurodivergences that are less commonly discussed in the public sphere, such as dyslexia. Additionally, more research is needed into the construct of dyslexia knowledge among adolescents and how to accurately measure it.

One of participants' favorite things about camp was interacting and working with others. Other future neurodiversity awareness/acceptance programs would thus likely benefit from interactive learning opportunities as opposed to only providing didactic instruction. Also, incorporating UDL and DT into the camp likely also impacted students' feelings toward neurodiversity. In fact, increased empathy was one of the themes generated from participant interviews, with some participants even directly pointing out the importance of the empathize stage of DT. This is in line with research with special educators that indicated that empathy – i.e., listening to your user's needs instead of assuming them – is a particularly compelling aspect of DT (74, 75). This perspective is distinctly different from other awareness campaigns that tell people how they should feel; instead, SNP REACH encourages campers to engage with and learn directly from neurodivergent people, keeping the focus directly on the user. Engaging with the principle of empathy thus likely allowed the campers to challenge their stereotypes and what they thought about neurodiversity. Additionally, many of the interactions between campers were likely cross-neurotype. In line with Contact Theory (52), prior research has shown that personal connections with disabled individuals is associated with more positive attitudes toward that disability (e.g. (85, 86)). It is thus likely that the camp's success in reducing stigma was in part due to the fact that a substantial portion (about one third) of campers were neurodiverse. The immersive experience may have allowed participants to more fully assimilate the information they were learning didactically. Thus, future programs aiming to improve attitudes toward neurodiversity should aim to include participants of all neurotypes.

The qualitative findings from this study are particularly encouraging, as participants discussed positive changes in multiple areas. Not only did participants discuss feeling that they understood more about neurodiversity, but they also mentioned how they felt less judgmental after learning more about neurodiversity. Multiple participants described specific, real-world instances where they felt that they were more understanding of neurodiverse peers than they would have been prior to the camp. It is likely that these improved attitudes led participants to better interactions with the neurodiverse people they came into contact with [similar to (87), where non-autistic and autistic people endorsed an increased desire to hang out with one another after the non-autistic people participated in an autistic acceptance training compared to those who did not participate in the training]. Increases in empathy also likely improved actual behaviors, as evidenced by the participant who mentioned knowing she needed to redesign club advertisements to be more accessible. SNP REACH thus has the capacity to change actual behaviors, as opposed to only changing attitudes or knowledge. This is promising, as behavioral intentions (i.e., reported likelihood of engaging in positive behaviors toward neurodivergent people) have shown less malleability than attitudes or knowledge [see, for example, Cremin et al. (51)] for a review of autism awareness interventions).

The other highly impactful aspect of the camp, according to post-camp interviews, was the increased personal understanding of neurodiversity reported by three out of the four neurodiverse campers who completed an interview. Campers specifically discussed building a community with people like them, learning self-advocacy skills, and learning how to unmask and accept oneself. This is a particularly important finding, given that disability identity is related to self-esteem (88). Furthermore, masking has been linked with mental health issues in prior research (40, 89); if a program like SNP REACH is able to thus reduce masking and decrease social anxiety, there may be long-term benefits to mental health.

Limitations

While the findings of this study are encouraging in terms of both reducing stigma toward and improving self-acceptance of neurodiversity, there are several limitations to consider. First, the study sample was fairly small, and our already small sample also experienced attrition from pre- to post-camp as the school year had started and campers were quite busy. It is thus difficult to extend our findings to other samples. We were also limited in the amount of subgroup analyzes we could do (e.g., differences between neurotypical and neurodivergent campers; differential effects of having a neurodivergent counselor). Additionally, it will likely be impossible for other people or organizations to exactly replicate our study, as the exact camp schedule with its specific speakers is unlikely to be duplicated. Also, while reflexive thematic analysis does not emphasize coding reliability (79), it is important to consider that other individuals with differing positionality may have extracted meaning from the qualitative interviews differently than the first author (who coded the interviews) and the second author (who reviewed the coding). Nonetheless, the mostly qualitative findings are not necessarily meant to be exactly replicated, and a camp of a similar nature could still be developed, particularly in other urban, diverse settings.

A perhaps more important limitation is the way our sample was recruited. All participants self-selected into the camp and had to partake in an application process. Therefore, all of our participants likely had knowledge of neurodiversity and at least some degree of interest in the topic. Thus, most of these highschoolers may be in less need of training on neurodiversity than those who did not sign up for the camp. It is therefore possible that the camp would not have had the same effect on students who were less familiar with or invested in the topic. Perhaps these students would have needed more background on neurodiversity and other models of disability, or perhaps an intervention that was spread over more than just 2 weeks. Therefore, as explicitly suggested by one of our participants, programs such as SNP REACH should be integrated into classrooms, where short- and long-term effects on all students (including those who are less motivated or knowledgeable) can be studied (see Alcorn et al. (90) for such a program that is being piloted in the United Kingdom). Similarly, all camp counselors were passionate about neurodiversity and highly motivated to support campers' learning. Therefore, the transferability of our findings to other settings is potentially limited, as we speculate that SNP REACH will result in more optimal outcomes when instructors and camp leaders are carefully selected, and a significant proportion of campers are neurodiverse and interested in neurodiversity.

Finally, all of our data collection tools assessed explicit stigma and attitudes. Research has shown that implicit attitudes toward disability (91) are more difficult to change. Future research on programs such as SNP REACH should therefore include measures of implicit stigma, such as the implicit attitude test (92) in order to tailor such programs to target less overt demonstrations of prejudice. Future iterations of this research could also employ a waitlist-control group, such that campers' pre- and post-camp changes can be compared to a control group who did not yet participate in the camp. It would also be helpful to understand how the effects of in-person SNP REACH might differ than virtual-delivery (as was the case in the current study).

Conclusion

In conclusion, using UDL and DT as a framework for teaching adolescents about neurodiversity appeared to be effective at improving understanding and attitudes. While stigma toward and knowledge of autism shifted more on quantitative measures than dyslexia (and to some extent ADHD), qualitative findings suggest that participants felt the camp affected their perspectives toward neurodiversity in general, specifically with regard to being less judgmental and, for neurodivergent campers, being more self-accepting. Future research must assess the long-term outcomes of such programs and find novel ways of recruiting a wider variety of participants.

Data availability statement

The raw data supporting the conclusions of this article will be made available by the authors, without undue reservation.

Ethics statement

The studies involving humans were approved by the Stanford University Institutional Review Board. The studies were conducted in accordance with the local legislation and institutional requirements. Written informed consent for participation in this study was provided by the participants' legal guardians/next of kin.

Author contributions

RS and LF both designed the study. RS collected and analyzed the data and drafted the manuscript. LF supervised the study, provided feedback on analyzes, and edited the manuscript. All authors contributed to the article and approved the submitted version.

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Conflict of interest

RS and LF were compensated for serving as either camp counselor or director of the Stanford Neurodiversity Project – Research, Education, and Advocacy Camp for High Schoolers (SNP-REACH). LF is also an Associate Editor of Frontiers in Psychiatry.

Publisher's note

Supplementary material

The Supplementary material for this article can be found online at: https://www.frontiersin.org/articles/10.3389/fpsyt.2023.1250895/full#supplementary-material

References

1. Singer J. *Neurodiversity: The birth of an idea*. Sydney: University of Technology (1998).

2. Dwyer P. The neurodiversity approach (es): what are they and what do they mean for researchers? *Hum Dev*. (2022) 66:73–92. doi: 10.1159/000523723

3. Walker N. (2014). Neurodiversity: Some basic terms and definitions. Available at: https://neurocosmopolitanism.com/neurodiversity-some-basic-terms-definitions/ (Accessed July 28, 2021).

4. Marks D. Models of disability. *Disabil Rehabil*. (1997) 19:85–91. doi: 10.3109/09638289709166831

5. Bailin A. (2019). Scientific American blog network. Clearing up some misconceptions about neurodiversity. Available at: https://blogs.scientificamerican.com/observations/clearing-up-some-misconceptions-about-neurodiversity/ (Accessed Jul 7, 2021).

6. Den Houting J. Neurodiversity: an insider's perspective. *Autism*. (2018) 23:271–3. doi: 10.1177/1362361318820762

7. Robertson SM (2009). Neurodiversity, quality of life, and autistic adults: shifting research and professional focuses onto real-life challenges. Disability Studies Quarterly. Available at: http://dsq-sds.org/article/view/1069 (Accessed Nov 20, 2019).

8. Ballou EP. (2018). Thinking Person's guide to autism. What the neurodiversity movement does–And Doesn't–Offer. Available at: http://www.thinkingautismguide.com/2018/02/what-neurodiversity-movement-doesand.html (Accessed Jul 30, 2021).

9. Crow L. (1996). *Including all of our lives: renewing the social model of disability*.

10. Reindal SM. A social relational model of disability: a theoretical framework for special needs education? *Eur J Spec Needs Educ*. (2008) 23:135–46. doi: 10.1080/08856250801947812

11. Fung LK. *Neurodiversity: From phenomenology to neurobiology and enhancing technologies*. Virginia, US: American Psychiatric Pub (2021). 332 p.

12. Armstrong T. Neurodiversity in the classroom: strength-based strategies to help students with special needs succeed in school and life. *ASCD*. (2012) 2012:195.

13. Donaldson AL, Krejcha K, McMillin A. A strengths-based approach to autism: neurodiversity and partnering with the autism community. *Perspect ASHA SIGs*. (2017) 2:56–68. doi: 10.1044/persp2.SIG1.56

14. Masuch TV, Bea M, Alm B, Deibler P, Sobanski E. Internalized stigma, anticipated discrimination and perceived public stigma in adults with ADHD. *ADHD Atten Deficit Hyperact Disord*. (2019) 11:211–20. doi: 10.1007/s12402-018-0274-9

15. Botha M, Dibb B, Frost DM. "Autism is me": an investigation of how autistic individuals make sense of autism and stigma. *Disabil Soc*. (2022) 37:427–53. doi: 10.1080/09687599.2020.1822782

16. Shifrer D. Stigma of a label: educational expectations for high school students labeled with learning disabilities. *J Health Soc Behav*. (2013) 54:462–80. doi: 10.1177/0022146513503346

17. Link BG, Phelan JC. Conceptualizing Stigma. *Annu Rev Sociol*. (2001) 27:363–85. doi: 10.1146/annurev.soc.27.1.363

18. Chapman R, Carel H. Neurodiversity, epistemic injustice, and the good human life. *J Soc Philos*. (2022) 53:614–31. doi: 10.1111/josp.12456

19. Cage E, Di Monaco J, Newell V. Experiences of autism acceptance and mental health in autistic adults. *J Autism Dev Disord*. (2018) 48:473–84. doi: 10.1007/s10803-017-3342-7

20. Kapp SK, Steward R, Crane L, Elliott D, Elphick C, Pellicano E, et al. 'People should be allowed to do what they like': autistic adults' views and experiences of stimming. *Autism*. (2019) 23:1782–92. doi: 10.1177/1362361319829628

21. Milton D, Sims T. How is a sense of well-being and belonging constructed in the accounts of autistic adults? *Disabil Soc*. (2016) 31:520–34. doi: 10.1080/09687599.2016.1186529

22. Renty JO, Roeyers H. Quality of life in high-functioning adults with autism spectrum disorder: the predictive value of disability and support characteristics. *Autism*. (2006) 10:511–24. doi: 10.1177/1362361306066604

23. Crompton CJ, Hallett S, Ropar D, Flynn E, Fletcher-Watson S. "I never realised everybody felt as happy as I do when I am around autistic people": a thematic analysis of autistic adults' relationships with autistic and neurotypical friends and family. *Autism*. (2020) 2020:8976. doi: 10.1177/1362361320908976

24. Black MH, Kuzminski R, Wang J, Ang J, Lee C, Hafidzuddin S, et al. Experiences of friendships for individuals on the autism Spectrum: A scoping review. *Rev J Autism Dev Disord*. (2022) 2022:1–26. doi: 10.1007/s40489-022-00332-8

25. Sosnowy C, Silverman C, Shattuck P, Garfield T. Setbacks and successes: how young adults on the autism Spectrum seek friendship. *Autism Adulthood*. (2019) 1:44–51. doi: 10.1089/aut.2018.0009

26. Ochs E, Kremer-Sadlik T, Solomon O, Sirota KG. Inclusion as social practice: views of children with autism. *Soc Dev*. (2001) 10:399–419. doi: 10.1111/1467-9507.00172

27. Forrest DL, Kroeger RA, Stroope S. Autism Spectrum disorder symptoms and bullying victimization among children with autism in the United States. *J Autism Dev Disord*. (2020) 50:560–71. doi: 10.1007/s10803-019-04282-9

28. Singh I, Kendall T, Taylor C, Mears A, Hollis C, Batty M, et al. Young People's experience of ADHD and stimulant medication: a qualitative study for the NICE guideline Ilina Singh et al. young People's experience of ADHD and stimulant medication. *Child Adolesc Ment Health*. (2010) 15:186–92. doi: 10.1111/j.1475-3588.2010.00565.x

29. Hoza B, Mrug S, Gerdes A, Hinshaw S, Bukowski W, Gold J, et al. What aspects of peer relationships are impaired in children with attention-deficit/hyperactivity disorder? *J Consult Clin Psychol*. (2005) 73:411–23. doi: 10.1037/0022-006X.73.3.411

30. Al-Yagon M, Margalit M. Social cognition of children and adolescents with learning disabilities In: HL Swanson, KR Harris and S Graham, editors. *Handbook of learning disabilities*. New York: Guilford Press (2013)

31. Livingston JD, Boyd JE. Correlates and consequences of internalized stigma for people living with mental illness: a systematic review and meta-analysis. *Soc Sci Med*. (2010) 71:2150–61. doi: 10.1016/j.socscimed.2010.09.030

32. Willoughby D, Evans MA. Self-processes of acceptance, compassion, and regulation of learning in university students with learning disabilities and/or ADHD. *Learn Disabil Res Pract*. (2019) 34:175–84. doi: 10.1111/ldrp.12209

33. Cai RY, Gibbs V, Love A, Robinson A, Fung L, Brown L. "Self-compassion changed my life": the self-compassion experiences of autistic and non-autistic adults and its relationship with mental health and psychological wellbeing. *J Autism Dev Disord*. (2023) 53:1066–81. doi: 10.1007/s10803-022-05668-y

34. Sutton BM, Webster AA, Westerveld MF. A systematic review of school-based interventions targeting social communication behaviors for students with autism. *Autism*. (2019) 23:274–86. doi: 10.1177/1362361317753564

35. Whalon KJ, Conroy MA, Martinez JR, Werch BL. School-based peer-related social competence interventions for children with autism Spectrum disorder: a Meta-analysis and descriptive review of single case research design studies. *J Autism Dev Disord*. (2015) 45:1513–31. doi: 10.1007/s10803-015-2373-1

36. Garrote A, Sermier Dessemontet R, Moser OE. Facilitating the social participation of pupils with special educational needs in mainstream schools: a review of school-based interventions. *Educ Res Rev*. (2017) 20:12–23. doi: 10.1016/j.edurev.2016.11.001

37. Cook J, Hull L, Crane L, Mandy W. Camouflaging in autism: a systematic review. *Clin Psychol Rev*. (2021) 89:102080. doi: 10.1016/j.cpr.2021.102080

38. Hull L, Petrides KV, Allison C, Smith P, Baron-Cohen S, Lai MC, et al. "Putting on my best Normal": social camouflaging in adults with autism Spectrum conditions. *J Autism Dev Disord*. (2017) 47:2519–34. doi: 10.1007/s10803-017-3166-5

39. Bargiela S, Steward R, Mandy W. The experiences of late-diagnosed women with autism Spectrum conditions: an investigation of the female autism phenotype. *J Autism Dev Disord*. (2016) 46:3281–94. doi: 10.1007/s10803-016-2872-8

40. Cage E, Troxell-Whitman Z. Understanding the reasons, contexts and costs of camouflaging for autistic adults. *J Autism Dev Disord*. (2019) 49:1899–911. doi: 10.1007/s10803-018-03878-x

41. Hammond TL. *Tiffy's "BIG" book of ABA+ race, intersectionality, parenthood, compliance, community, etc....* Fidgets and fries. Available at: https://www.fidgetsandfries.co/.

42. Milton DE. On the ontological status of autism: the 'double empathy problem'. *Disabil Soc*. (2012) 2012:8. doi: 10.1080/09687599.2012.710008

43. Dillenburger K, Jordan JA, McKerr L, Lloyd K, Schubotz D. Autism awareness in children and young people: surveys of two populations. *J Intellect Disabil Res*. (2017) 61:766–77.

44. Campbell JM, Caldwell EA, Railey KS, Lochner O, Jacob R, Kerwin S. Educating students about autism spectrum disorder using the kit for kids curriculum: effects on knowledge and attitudes. *Sch Psychol Rev*. (2019) 48:145–56.

45. John RP, Knott FJ, Harvey KN. Myths about autism: An exploratory study using focus groups. *Autism*. (2018) 22:845–54.

46. Gillespie-Lynch K, Brooks PJ, Someki F, Obeid R, Shane-Simpson C, Kapp SK, et al. Changing college students' conceptions of autism: an online training to increase knowledge and decrease stigma. *J Autism Dev Disord*. (2015) 45:2553–66. doi: 10.1007/s10803-015-2422-9

47. Campbell JM, Barger BD. Peers' knowledge about and attitudes towards students with autism Spectrum disorders In: VB Patel, VR Preedy and CR Martin, editors. *Comprehensive guide to autism*. New York: Springer (2014). 247–61.

48. Campbell JM, Morton JF, Roulston K, Barger BD. A descriptive analysis of middle school students' conceptions of autism. *J Dev Phys Disabil*. (2011) 23:377–97. doi: 10.1007/s10882-011-9234-4

49. Moldavsky M, Sayal K. Knowledge and attitudes about attention-deficit/hyperactivity disorder (ADHD) and its treatment: the views of children, adolescents, parents, teachers and healthcare professionals. *Curr Psychiatry Rep*. (2013) 15:377. doi: 10.1007/s11920-013-0377-0

50. Birnschein AM, Paisley CA, Tomeny TS. Enhancing social interactions for youth with autism spectrum disorder through training programs for typically developing peers: a systematic review. *Res Autism Spectr Disord*. (2021) 84:101784. doi: 10.1016/j.rasd.2021.101784

51. Cremin K, Healy O, Spirtos M, Quinn S. Autism awareness interventions for children and adolescents: a scoping review. *J Dev Phys Disabil*. (2021) 33:27–50. doi: 10.1007/s10882-020-09741-1

52. Morris S, O'Reilly G, Nayyar J. Classroom-based peer interventions targeting autism ignorance, prejudice and/or discrimination: a systematic PRISMA review. *Int J Incl Educ*. (2021) 1–45.

53. Swaim KF, Morgan SB. Children's attitudes and behavioral intentions toward a peer with autistic behaviors: Does a brief educational intervention have an effect? *J Autism Dev Disord*. (2001) 31:195–205.

54. Reiter S, Vitani T. Inclusion of pupils with autism: the effect of an intervention program on the regular pupils' burnout, attitudes and quality of mediation. *Autism*. (2007) 11:321–33. doi: 10.1177/1362361307078130

55. Siperstein GN. *Instruments for measuring children's attitudes toward the handicapped*. Boston, MA: University of Massachusetts (1980).

56. Allport GW. *The nature of prejudice*. Reading, MA: Addison-Wesley (1954).

57. Pettigrew TF, Tropp LR. How does intergroup contact reduce prejudice? Meta-analytic tests of three mediators. *Eur J Soc Psychol*. (2008) 38:922–34. doi: 10.1002/ejsp.504

58. Rademaker F, de Boer A, Kupers E, Minnaert A. Applying the contact theory in inclusive education: a systematic review on the impact of contact and information on the social participation of students with disabilities. *Front Educ*. (2020) 5:414. doi: 10.3389/feduc.2020.602414

59. Kart A, Kart M. Academic and social effects of inclusion on students without disabilities: a review of the literature. *Educ Sci*. (2021) 11:16. doi: 10.3390/educsci11010016

60. Lindsay S, Edwards A. A systematic review of disability awareness interventions for children and youth. *Disabil Rehabil*. (2013) 35:623–46. doi: 10.3109/09638288.2012.702850

61. Shogren KA, Gross JMS, Forber-Pratt AJ, Francis GL, Satter AL, Blue-Banning M, et al. The perspectives of students with and without disabilities on inclusive schools. *Res Pract Pers Sev Disabil*. (2015) 40:243–60. doi: 10.1177/1540796915583493

62. Scheil KA, Bowers-Campbell J, Campbell JM. An initial investigation of the kit for kids peer educational program. *J Dev Phys Disabil*. (2017) 29:643–62. doi: 10.1007/s10882-017-9540-6

63. Fletcher-Watson S. (2018). Is early autism intervention compatible with neurodiversity? DART. Available at: https://dart.ed.ac.uk/intervention-neurodiversity/ (Accessed Apr 23, 2020).

64. Schuck RK, Tagavi DM, Baiden KMP, Dwyer P, Williams ZJ, Osuna A, et al. Neurodiversity and autism intervention: reconciling perspectives through a naturalistic developmental behavioral intervention framework. *J Autism Dev Disord*. (2022) 52:4625–45. doi: 10.1007/s10803-021-05316-x

65. Sussman S. Commentary: addiction, stigma, and neurodiversity. *Eval Health Prof*. (2021) 44:186–91. doi: 10.1177/01632787211012036

66. Kim SY, Gillespie-Lynch K. Do autistic People's support needs and non-autistic People's support for the neurodiversity movement contribute to heightened autism stigma in South Korea vs. the US? *J Autism Dev Disord*. (2022) 53:4199–213. doi: 10.1007/s10803-022-05739-0

67. Griffin E, Pollak D. Student experiences of neurodiversity in higher education: insights from the BRAINHE project. *Dyslexia*. (2009) 15:23–41. doi: 10.1002/dys.383

68. Bogardus ES. A social distance scale. *Sociol Soc Res*. (1933) 17:265–71.

69. Someki F, Torii M, Brooks PJ, Koeda T, Gillespie-Lynch K. Stigma associated with autism among college students in Japan and the United States: an online training study. *Res Dev Disabil*. (2018) 76:88–98. doi: 10.1016/j.ridd.2018.02.016

70. Gillespie-Lynch K, Bisson JB, Saade S, Obeid R, Kofner B, Harrison AJ, et al. If you want to develop an effective autism training, ask autistic students to help you. *Autism*. (2021) 2021:41006

71. Hamraie A. *Building access: Universal design and the politics of disability*. Chicago: U of Minnesota Press (2017). 443 p.

72. Meyer A, Rose DH, Gordon DT. *Universal design for learning: Theory and practice*. Wakefield, MA: CAST Professional Publishing (2014).

73. Waisman T, Williams ZJ, Cage E, Santhanam SP, Magiati I, Dwyer P, et al. Learning from the experts: evaluating a participatory autism and universal design training for university educators. *Autism*. (2023) 27:356–70. doi: 10.1177/13623613221097207

74. Lambert R, Imm K, Schuck R, Choi S, McNiff A. "UDL is the what, design thinking is the how": designing for differentiation in mathematics. *Math Teach Educ Dev*. (2021) 23:54–77.

75. Lambert R, McNiff A, Schuck R, Imm K, Zimmerman S. "UDL is a way of thinking"; theorizing UDL teacher knowledge, beliefs, and practices. *Front Educ*. (2023) 8:293. doi: 10.3389/feduc.2023.1145293

76. Mulholland S. ADHD-specific knowledge and attitudes of teachers (ASKAT): development and validation of a new research instrument. *Int J Educ Res*. (2016) 77:109–16. doi: 10.1016/j.ijer.2016.03.010

77. Gonzalez M. Dyslexia knowledge, perceived preparedness, and professional development needs of in-service educators. *Ann Dyslexia*. (2021) 71:547–67. doi: 10.1007/s11881-021-00235-z

78. Braun V, Clarke V. Using thematic analysis in psychology. *Qual Res Psychol*. (2006) 3:77–101. doi: 10.1191/1478088706qp063oa

79. Braun V, Clarke V. Reflecting on reflexive thematic analysis. *Qual Res Sport Exerc Health*. (2019) 11:589–97. doi: 10.1080/2159676X.2019.1628806

80. Miles MB, Huberman MA, Saldana J. *Qualitative data analysis: A methods sourcebook*. Thousand Oaks, CA: SAGE Publications (2018).

81. Pripas-Kapit S. Historicizing Jim Sinclair's "Don't mourn for us": a cultural and intellectual history of neurodiversity's first manifesto In: SK Kapp, editor. *Autistic community and the neurodiversity movement: Stories from the frontline*. London, UK: Palgrave Macmillan (2020). 23–39.

82. Silberman S. *Neurotribes: The legacy of autism and the future of neurodiversity*. London, UK: Penguin (2015). 546 p.

83. Gernsbacher MA. Editorial perspective: the use of person-first language in scholarly writing may accentuate stigma. *J Child Psychol Psychiatry*. (2017) 58:859–61. doi: 10.1111/jcpp.12706

84. Werner S, Shulman C. Does type of disability make a difference in affiliate stigma among family caregivers of individuals with autism, intellectual disability or physical disability? *J Intellect Disabil Res*. (2015) 59:272–83. doi: 10.1111/jir.12136

85. Armstrong M, Morris C, Abraham C, Tarrant M. Interventions utilising contact with people with disabilities to improve children's attitudes towards disability: a systematic review and meta-analysis. *Disabil Health J*. (2017) 10:11–22. doi: 10.1016/j.dhjo.2016.10.003

86. Schwab S. The impact of contact on students' attitudes towards peers with disabilities. *Res Dev Disabil*. (2017) 62:160–5. doi: 10.1016/j.ridd.2017.01.015

87. Jones DR, Morrison KE, DeBrabander KM, Ackerman RA, Pinkham AE, Sasson NJ. Greater social interest between autistic and non-autistic conversation partners following autism acceptance training for non-autistic people. *Front Psychol*. (2021) 12:147. doi: 10.3389/fpsyg.2021.739147

88. Nario-Redmond MR, Noel JG, Fern E. Redefining disability, re-imagining the self: disability identification predicts self-esteem and strategic responses to stigma. *Self Identity*. (2013) 12:468–88. doi: 10.1080/15298868.2012.681118

89. Miller D, Rees J, Pearson A. "Masking is life": experiences of masking in autistic and nonautistic adults. *Autism Adulthood*. (2021) 3:330–8. doi: 10.1089/aut.2020.0083

90. Alcorn AM, McGeown S, Mandy W, Aitken D, Murray F, Peacock LJJ, et al. *A mixed-methods evaluation of the learning about neurodiversity at school (LEANS) Programme: teaching neurodiversity concepts in mainstream primary schools*. International Society for Autism Research Annual Meeting, Stockholm, Sweden. (2023).

91. Jones DR, DeBrabander KM, Sasson NJ. Effects of autism acceptance training on explicit and implicit biases toward autism. *Autism*. (2021) 25:1246–61. doi: 10.1177/1362361320984896

92. Greenwald AG, McGhee DE, Schwartz JLK. Measuring individual differences in implicit cognition: the implicit association test. *J Pers Soc Psychol*. (1998) 74:1464–80. doi: 10.1037/0022-3514.74.6.1464

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Understanding profound autism: implications for stigma and supports

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Introduction: Societal perceptions and lack of understanding of autism spectrum disorder can be stigmatizing for autistic individuals and their families. This may be particularly the case for individuals who meet criteria for profound autism. Despite the considerable service needs of this marginalized group, there is little data on the prevalence of profound autism, nor on the experiences of those with profound autism and their families.

Methods: The current study leveraged a mixed-methods approach to address these gaps. First, the prevalence of profound autism was examined in six samples—three from the United States and three from Western Europe. Second, inductive thematic analysis was used to code interviews from 20 caregivers of profoundly autistic adults.

Results: The prevalence of profound autism varied widely across the six samples—from 11% to 48%. There were also notable differences between samples in prevalence by gender, race, and ethnicity. Two overarching themes were identified via inductive thematic analysis: *Community Perceptions of Autism and Family Support Needs and Advocacy Challenges*. Though caregivers were not directly asked about stigmatization during interviews, 85% of caregivers reported at least one instance of perceived stigma.

Discussion: Future research should continue to examine the unique needs and stigmatization experiences of profoundly autistic individuals and their families across the life course.

KEYWORDS
autism spectrum disorder, profound autism, stigma and awareness, prevalence, mixed method, autistic adults, qualitative interview analysis

Introduction

Autism spectrum disorder (ASD), is a neurodevelopmental condition characterized by symptoms in two core domains: social communication difficulties (e.g., deficits in social–emotional reciprocity, limited use of eye contact, facial expressions and gestures, and difficulty maintaining relationships) and restricted, repetitive interests and behaviors (e.g., stereotyped motor movements, insistence on sameness, unusual and/or circumscribed interests, and unusual sensory interests) (1). Some individuals with ASD have average or above average IQ scores and strong language abilities. In contrast, others with autism have co-occurring Intellectual Disability (ID), limited or no use of spoken language, and require 24-h support. Importantly, the heterogeneity of autism is associated with differing needs, challenges, and strengths for individuals with autism and their families, including experiences of stigmatization.

The general public's understanding—or lack thereof—of the social communication, behavioral, and other differences associated with autism can be stigmatizing both for individuals with autism and for their families. Erving Goffman famously defined stigma as "an attribute that is deeply discrediting" (2). In other words, stigma encompasses disapproval of and discrimination against individuals who are perceived to meaningfully differ from societal norms. Goffman's argument that stigma could extend from those with "spoiled identities" to their families through what he called "courtesy stigma" has been used by many researchers as a springboard to the analysis of stigma experienced by parents of autistic children (3–6). One extreme example of autism courtesy stigma is the infamous "refrigerator mother" theory, in which parents of autistic individuals were thought to cause symptoms of autism through cold and insufficient caregiving (7). During the 1960s and 1970s—a period when there was virtually no empirically-based understanding of autism etiology—the refrigerator mother theory became widely accepted within the medical establishment, effectively labeling parents as the ultimate "scapegoats" for their children's challenges (8).

Experiences of stigmatization may be especially pronounced amongst individuals who meet categorization criteria for profound autism (i.e., having either substantial intellectual disability, no or very limited language, or both, after age eight; see *A Note on Terminology*, below) and their caregivers, given the nature and severity of impairment inherently associated with these criteria. On a basic level, we need to know what proportion of individuals with autism fit these criteria to understand how many individuals with autism and their families may be at risk for experiencing stigmatization due to symptoms of profound autism. Because many profoundly autistic people cannot easily advocate for themselves, we also need to engage directly with caregivers to understand the stigmatization experiences of these individuals and their families, and to establish research priorities for this vulnerable group.

A note on stigma

Scambler and Hopkins (9) clarified the difference between "felt" and "enacted" stigma: felt stigma describes the internalized negative feelings of the stigmatized, whereas enacted stigma refers to discrimination experienced by the stigmatized. From qualitative and quantitative studies, autistic individuals who are capable of advocating for themselves and their families have frequently expressed perceptions of both felt and enacted stigma based on their diagnosis, behaviors, language, or cognitive ability [for a review, see (10)]. These experiences can have notable impacts on mental health. Whereas reports of felt stigma—such as the embarrassment parents may conceivably feel when their autistic children have meltdowns—are rare, reports of enacted stigma are ubiquitous among caregivers of individuals with autism (3). Autistic children, particularly those with challenging behaviors, are implicitly and explicitly excluded both from private spaces, like family celebrations, and more public settings, such as restaurants, classrooms, and extracurricular activities (11–13). Further, caregivers of profoundly autistic adults—after decades of stigmatization and other negative experiences, and often in the face of limited adult services—may reduce efforts to find or create spaces in which their profoundly autistic loved one will be included (6). In short, enacted stigma is a considerable and ongoing challenge for profoundly autistic individuals and their families.

The lack of consideration of what constitutes appropriate supports to meet the needs and preferences of profoundly autistic individuals is another common form of stigmatization. The deinstitutionalization movement that began more than 50 years ago has had a tremendous effect on the types of services available to both autistic children and adults. A pervasive belief is that inclusive settings are always best for all disabled people, though empirical evidence supporting this view has focused on verbal autistic individuals with average or better cognitive abilities (14, 15). This bias has resulted in the shuttering of disability specific programs more broadly, from educational, to vocational, to residential settings (16). Inclusive options are appropriate for many autistic children and adults, who should, without question, be provided with whatever supports they need to thrive in the community. However, profoundly autistic individuals with severe cognitive impairments and sometimes dangerous behaviors–including aggression, self-injury, property destruction, pica, and elopement–may require structure, targeted instruction and behavioral support that can best be provided in intensive, disability-specific settings (17–19). The closure of many such programs has left families in crisis: parents repeatedly called to pick up their children at schools that cannot safely manage their behaviors; adults unable to obtain residential placement outside their parents' home because agencies are financially incentivized to choose the easiest clients; overburdened and unequipped emergency rooms struggling to manage the growing influx of profoundly autistic individuals with nowhere else to go (20, 21). Families can feel that their options for support are limited and may feel obligated to continue as 24/7 primary caretakers. While there are reported emotional and relational benefits to arrangements of extended care in the family home for autistic adults (18), some families report exhaustion, stress, helplessness, and social exclusion arising from the challenges of caregiving (22). In short, challenges associated with the stigmatization experiences of families caring for individuals with profound autism warrant further study.

A note on terminology

Diagnostic criteria for autism, particularly for subgroups or levels within autism, have changed several times in the history of this condition, with controversy for every attempt to subclassify what we now call ASD. These classification challenges and pursuant controversies are in part due to the heterogeneity seen in the presentation of autism. In efforts to reflect this, the 5th edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-5) and the 11th revision of the International Classification of Diseases (ICD-11), include specifiers and subcategories of autism. However, these classifications are rarely used in practice or in research (23). For example, DSM-5 introduced severity levels intended to indicate the degree of support required for individuals diagnosed with autism (1). These severity levels were not empirically validated, and in the years since their introduction, have not been consistently applied, though some school systems and insurance companies require their application (24, 25). Thus, challenges remain in parsing the autism spectrum to effectively indicate the capabilities and support needs of autistic individuals.

One recent effort to parse the differing needs, challenges, and strengths seen across the autism spectrum came from a commission from *The Lancet* on clinical research and care for ASD (23). Three authors of the current study (JM, MG, and CL) were also authors on *The Lancet* commission. *The Lancet* commission proposed a new term, profound autism, for individuals having either substantial intellectual disability (e.g., an intelligence quotient below 50), no or very limited language (e.g., limited ability to communicate to a stranger using comprehensible sentences), or both, after age eight, in addition to meeting criteria for autism. Given the wide range of needs of autistic people, the intent behind this term was to provide a clinically relevant way to identify autistic individuals who fit this profile to ensure their needs are not forgotten. Inherently, the nature and severity of impairment associated with profound autism criteria may place these individuals and their families at greater risk of experiencing stigma and marginalization.

New prevalence estimates from the Centers for Disease Control (CDC) found that over a quarter, 26.7%, of children with autism in the United States meet criteria for profound autism (26), suggesting that in the United States, a substantial minority of children with autism may be at increased risk of experiencing stigma due to the nature and intensity of their autism symptoms. Additional work is needed to further understand the prevalence of profound autism, particularly in clinical and community-based samples, so we can better understand what proportion of autistic individuals and their families may experience stigma related to profound autism. Such information is also critical to improving service planning for this population, as most profoundly autistic individuals cannot speak for themselves and are likely to need intensive support services for much or all their lives.

Prior to *The Lancet* commission, the term “profound autism” had been used by stakeholders, therapists, and researchers to broadly describe autistic individuals whose ability to live independently was significantly compromised [see (27)]. The term “severe autism” has also been used to similar effect (28). As part of *The Lancet* commission, a consensus of researchers and stakeholders—including autistic self-advocates and parents—proposed profound autism as an administrative term to clearly and efficiently indicate individuals with autism who need extensive functional assistance, specifically, “requiring 24 h access to an adult who can care for them if concerns arise, being unable to be left completely alone in a residence, and not being able to take care of basic daily adaptive needs.” [(23), p. 278].

There is disagreement in scientific and advocacy communities about the choice of the term profound autism, with some arguing it is “misleading and counterproductive” [(29), p. 94] to efforts of the neurodiversity movement to conceptualize and advocate for autism as an identity, not a disabling medical condition [see also (30)]. However, clear terms are needed to describe the extensive clinical needs of profoundly autistic individuals and their families. Reliable terminology is also necessary to support high-quality empirical investigations necessary to better understanding and supporting profoundly autistic individuals. With precise terminology, we can also start to develop and apply standard methodology for classification. This is an ongoing effort, particularly when classifying adults, because available measures for IQ and autism classification are typically adapted from assessments for younger children (31). Despite the controversy, the term profound autism has already been applied in a number of research studies [see (26, 32–35)].

The proposal of the term profound autism and subsequent debate has highlighted the current cultural politics of autism. The rise of the neurodiversity movement has changed how autism is discussed and conceptualized, both in public and academic circles, to emphasize the experiences and opinions of autistic individuals who speak for themselves. But the priorities, service needs, and life experiences, including experiences of stigmatization, of autistic self-advocates are frequently quite different from those of profoundly autistic individuals and their families. It is essential that elevating the perspectives of autistic self-advocates does not come at the cost of amplifying the stigmatization experienced by profoundly autistic people, who are often not capable of self-advocacy, as well as their families. Ultimately, the agreed-upon term to describe this subgroup of individuals with ASD is far less important than acknowledgement that this group has extensive service and daily life support needs—needs which are often not adequately met by existing services—and that the nature of profound autism puts these individuals and their families at increased risk of experiencing marginalization and stigma.

The current study

The current project consisted of two distinct but related goals. First, to better understand what proportion of individuals with autism may be at risk of experiencing stigma related to meeting profound autism criteria, we wanted to establish the prevalence of profound autism in a range of samples from the United States and Western Europe. Second, to better understand the stigmatization experiences of individuals with profound autism and their families, we wanted to directly ask caregivers of individuals with profound autism about their life and stigmatization experiences. Thus, the aims of this study were as follows:

1. To establish the prevalence of profound autism in six autism cohorts, three from the United States and three from Western Europe, and to examine variation in prevalence estimates by gender, race and ethnicity.
2. To qualitatively examine experiences of stigmatization, challenges, and service needs reported by caregivers of adults with profound autism in varying regions of the United States.

Given the disparate approaches required to accomplish each of these two aims, the method and results for Aims 1 and 2 are reported separately.

Aim 1: profound autism prevalence estimates

Method

Autism cohorts

Prevalence estimates of profound autism were calculated by gender, race, and ethnicity in six samples, three from the United States and three from Western Europe. All data included in the current project was de-identified, and all six studies were approved by their respective institutional review boards (IRBs). The U.S. samples included the Early Diagnosis (EDX) cohort, the Adolescents and Adults with Autism (AAA) sample, and the Rhode Island Consortium for Autism Research and Treatment (RI-CART) sample. The EDX cohort was initially recruited in the early 1990s and consists of 192 consecutive referrals to community-based clinics in North Carolina (58%) and the greater Chicago area (42%). Participants were initially seen between the ages of 2 and 3—data for the current analyses was collected when participants were approximately age 9. The AAA sample, initially recruited in the late 1990s, consists of 406 individuals with a preexisting diagnosis of ASD or a related condition (i.e., Asperger's Syndrome, Pervasive Developmental Disorder, Not Otherwise Specified [PDD-NOS]) aged 10 or older at the time of recruitment and assessment. Half the sample (49.6%) was recruited from Wisconsin, and the remaining half (50.4%) was recruited from Massachusetts. RI-CART is statewide community-based sample of individuals with autism living in Rhode Island and surrounding geographic regions [i.e., Southeastern Massachusetts, Northern Connecticut; (36)] initially recruited in the 2010s. Individuals of all ages who had a preexisting autism diagnosis or who were suspected of meeting criteria for an autism diagnosis by a community provider or family member were eligible to participate. 1,016 individuals who participated in RI-CART between the ages of 8 and 25 are included in the present study.

The Western European samples included the UK-based QUEST sample and the Special Needs and Autism Project (SNAP) cohort, and the Norwegian Mother, Father, and Child (MoBa) cohort. All three samples were initially recruited in the mid 2000's. QUEST is a community-based sample of 277 children living in one of two districts in London, Bromley and Lewisham (37). Notably, girls with autism were over-sampled within QUEST to allow for more robust sex comparisons (38). QUEST data for the current analyses were collected when participants were approximately age 13 (38). SNAP is a population-based study drawn from an initial cohort of 56,946 children living in South Thames, United Kingdom. A weighted epidemiological design was used to target a subsample of children considered most at risk for autism [see (39)]. A stratified subsample of 255 children (223 males) completed comprehensive diagnostic, IQ, and language assessments at approximately age 12 (40). Led by the Norwegian Institute of Public Health, MoBa is a population-based pregnancy cohort of 114,000 children born between 1999 and 2009. MoBa data for the current analyses were collected when participants were approximately age eight (41). Preliminary prevalence data from three of these samples (EDX, MoBa, SNAP) was included in *The Lancet* commission (23). Summary information on all six samples is included in Table 1.

Phenotypic characteristics

Individuals were considered as meeting criteria for profound autism if at age eight or older they had an IQ score of less than 50 and/or little to no spoken language. In the EDX, RI-CART, MoBa, QUEST, and SNAP samples, individuals were classified as minimally or nonverbal if they were administered an Autism Diagnostic Observation Scale [ADOS; (42)] Module 1 at or after age eight. In the AAA sample, individuals were classified as minimally or non-verbal based on scores from item 33 (Overall Level of Language) on the Autism Diagnostic Interview [ADI; (43)]. The EDX, MoBA, SNAP, and QUEST samples administered IQ assessments chosen from standardized hierarchies based on child age and ability at the time of assessment [see (40, 44, 45), and (46), respectively, for information on the specific IQ measures used in each sample]. In the RI-CART sample, IQ was determined via scores on the Kaufman Brief Intelligence Test, Second Edition [KBIT-2; (47)]. In the AAA sample, IQ was determined via scores on the Wide Range Intelligence Test [WRIT; (48)] and/or maternal report (49).

Demographic characteristics

Given the various geographic locations and time periods that participants were recruited, the proportion of participants from racially and ethnically diverse backgrounds, and the criteria used to classify participants as racially and/or ethnically diverse differs considerably across the six samples reported here. The proportions of male and female participants within each sample are also quite variable. In the United States, the EDX sample was 76% White, 23% Black, and 1% Other (1 Asian participant and 1 American Indian participant). Only 2% of EDX participants identified as Hispanic. Males comprised 82% of the EDX sample. The AAA sample was 94% White, 3% Black, and 3% Other (6 Asian participants, 2 American Indian, and 4 Other). Two percent of AAA participants identified as Hispanic. Males comprised 73% of the AAA sample. Finally, the RI-CART sample was 71% White, 3% Black, 8% Multiracial, and 5% Other, with 13% of the RI-CART sample not reporting their race or missing information on race. For ethnicity, 13% of the RI-CART sample identified as Hispanic, 73% identified as non-Hispanic, and 14% of the sample chose not to report their ethnicity or were missing information on ethnicity. Additionally, 84% of the RI-CART sample identified the native language of the primary caregiver as English, 5% Spanish, 0.6% Other, and 10% of the sample chose not to report caregiver native language or were missing that information. Males comprised 78% of the RI-CART sample (Table 1).

In Western Europe, the QUEST sample was 48% White, 28% Black African or Black Caribbean, 13% Multiracial, and 11% Other. QUEST did not collect information on participants' ethnicity, nor did SNAP or MoBa. Males comprised 58% of the QUEST sample. The SNAP sample was 95% White and 5% people of color. Ninety percent of the SNAP sample was male. Finally, the MoBa sample did not collect information on participants' race but did ask about the primary caregiver's native language. To be able to participate in MoBA, primary caregivers had to be able to read in Norwegian (41). Seventy-seven percent of the MoBa sample identified Norwegian as the native language of the primary caregiver, 21% identified a language other than Norwegian as the native language of the primary caregiver, and 2% of the sample chose not to report or were missing information on the primary caregiver's native language. Males comprised 78% of the MoBa sample (Table 1).

Analytic plan

The cohorts included in this project used different methods of sampling, recruitment, and behavioral assessment. Notably, only two of these samples, MoBa and SNAP, are population-based. Thus, prevalence estimates for each of the six samples were calculated and are reported separately. Prevalence estimates for profound autism and corresponding confidence intervals were calculated by sex and race/ethnicity. For samples that had limited numbers of racially and ethnically diverse participants (AAA, SNAP) or, the majority of

TABLE 1 Demographic characteristics of the six samples.

Sample	Geographic location	*n*	Sex		Race				Ethnicity		Caregiver native language[a]
			Male	Female					Non-Hispanic	Hispanic	
Adolescents and Adults with Autism (AAA)	Wisconsin, Massachusetts	406	297	109	**White**		**Black**	**Other**	398	8	–
					376		10	12			
Early Diagnosis Cohort (EDX)	North Carolina, Illinois, Michigan	192	158	34	**White**		**Black**	**Other**	188	2	–
					146		46	2			
Rhode Island Consortium of Autism Research and Treatment (RI-CART)	Rhode Island	1,016	795	221	**White**	**Black**	**Multi**	**Other**	740	131	856 English 46 Spanish 2 Portuguese 4 Other 106 Missing/ not reported
					722	34	81	47	145 missing or not reported		
					132 missing or not reported						
Norwegian Mother, Father, and Child Cohort (MoBa)	Norway	188	146	42			–		–		Norwegian: 144
											Not Norwegian: 40 4 Missing/not reported
Special Needs and Autism Project (SNAP)	South Thames, United Kingdom	155	139	16	**White**		**POC**		–		–
					147		8				
QUEST	London, United Kingdom	80	46	34	**White**	**Black**	**Multi**	**Other**	–		–
					38	22	10	9			

[a] For the MoBA sample only, caregiver native language was used as a proxy for measuring racial and ethnic diversity.

racially and ethnically diverse participants fell into a single racial category (Black—EDX), prevalence estimates are reported for white participants and participants of color. Because MoBa did not collect data on participant race and ethnicity, prevalence estimates are reported based on the native language of the primary caregiver (Norwegian/not Norwegian) instead. Both QUEST and SNAP provided comprehensive autism diagnostic and cognitive assessments to stratified subsamples—given this, both weighted and unweighted prevalence estimates and confidence intervals are reported for QUEST and SNAP (Table 2). Data management and analysis were conducted using Stata 17 and R version 4.3.0 (50).

Results

United States samples prevalence estimates

The proportion of individuals meeting one or both criteria for profound autism criteria was 57% (95% CI 49–64%) in the EDX sample. A higher proportion of females in EDX met profound autism criteria than males, although confidence ranges overlapped (70% vs. 54%, see Table 2 for confidence intervals). Moreover, a higher proportion of participants of color met criteria for profound autism in the EDX sample compared to white participants (69% vs. 52%). In the AAA sample, 35% (95% CI 29–42%) of participants met criteria for profound autism. The proportions of females and males who met profound criteria were quite similar, 37 and 35%, respectively. Whereas 20% of white participants in the AAA sample met profound autism criteria, only 10% of participants of color did, though confidence intervals overlapped (Table 2). Only 11% of the RI-CART sample met criteria for profound autism. A lower proportion of females met criteria than males, though again, confidence intervals overlapped (9% vs. 14%, Table 2). Thirteen percent of white participants in RI-CART met profound criteria, and 16% of participants of color met profound criteria—again, confidence intervals overlapped (Table 2).

Western Europe samples prevalence estimates

The weighted proportion of individuals meeting criteria for profound autism in the QUEST sample was 18%. Thirty-eight percent of both male and female participants in QUEST were classified as having profound autism. Higher proportions of Black African and Black Caribbean participants and participants who identified their race as Other (30% and 23%, respectively) met criteria for profound autism than white and multiracial participants (15 and 6%,

TABLE 2 Profound autism prevalence estimates by sample, gender, and race.

<table>
<tr><th colspan="2" rowspan="3">Sample</th><th colspan="8">Profound autism prevalence</th></tr>
<tr><th rowspan="2">Overall</th><th colspan="2">Gender</th><th colspan="5">Race</th></tr>
<tr><th>Male</th><th>Female</th><th>White</th><th colspan="4">People of color[a]</th></tr>
<tr><td colspan="2">Adolescents and Adults with Autism (AAA)</td><td>57%
(49 – 64%)</td><td>54%
(45 – 62%)</td><td>70%
(51 – 84%)</td><td>52%
(42 – 61%)</td><td colspan="4">69%
(55 – 81%)</td></tr>
<tr><td colspan="2">Early Diagnosis Cohort (EDX)</td><td>48%
(37 – 58%)</td><td>4%
(0 – 11%)</td><td>23%
(10 – 36%)</td><td>34%
(27 – 42%)</td><td colspan="4">70%
(55 – 81%)</td></tr>
<tr><td rowspan="2">Special Needs and Autism Project (SNAP)</td><td>Unweighted</td><td>23%
(16 – 30%)</td><td>22%
(16 – 30%)</td><td>25%
(7 – 52%)</td><td>22%
(16 – 30%)</td><td colspan="4">20%
(10 – 37%)</td></tr>
<tr><td>Weighted</td><td>20%
(10 – 36%)</td><td>21%
(10 – 39%)</td><td>15%
(3 – 50%)</td><td>25%
(3 – 65%)</td><td colspan="4">11%
(1 – 55%)</td></tr>
<tr><td rowspan="3">QUEST</td><td rowspan="2">Unweighted</td><td rowspan="2">31%
(21 – 43%)</td><td rowspan="2">26%
(14 – 41%)</td><td rowspan="2">14%
(7 – 26%)</td><td>White</td><td>Black</td><td>Multi</td><td>Other</td></tr>
<tr><td>29%
(16 – 30%)</td><td>45%
(24 – 68%)</td><td>10%
(0 – 45%)</td><td>33%
(7 – 70%)</td></tr>
<tr><td>Weighted</td><td>18%
(11 – 28%)</td><td>38%
(22 – 56%)</td><td>38%
(23 – 56%)</td><td>15%
(7 – 29%)</td><td>30%
(14 – 55%)</td><td>6%
(0 – 44%)</td><td>23%
(4 – 69%)</td></tr>
<tr><td colspan="2" rowspan="2">Rhode Island Consortium of Autism Research and Treatment (RI-CART)</td><td rowspan="2">11%
(8 – 15%)</td><td rowspan="2">14%
(10 – 19%)</td><td rowspan="2">9%
(4 – 17%)</td><td>White</td><td colspan="4">People of color[a]</td></tr>
<tr><td>13%
(9 – 18%)</td><td colspan="4">16%
(11 – 22%)</td></tr>
<tr><td colspan="2" rowspan="3">Norwegian Mother, Father, and Child Cohort (MoBa)</td><td rowspan="3">18%
(12 – 24%)</td><td rowspan="3">17%
(12 – 24%)</td><td rowspan="3">45%
(28 – 63%)</td><td colspan="5">Caregiver native language[b]</td></tr>
<tr><td>Native Norwegian speaker</td><td colspan="4">Non-native Norwegian speaker</td></tr>
<tr><td>23%
(17 – 30%)</td><td colspan="4">22% (11 – 39%)</td></tr>
</table>

[a] Due to limited numbers of racially and ethnically diverse participants (AAA, SNAP) or the majority of racially and ethnically diverse participants belonging to a single racial/ethnic group (Black, EDX), racial and ethnic prevalence estimates for these samples were collapsed into binary categories.

[b] For the MoBA sample only, caregiver native language was used as a proxy for measuring racial and ethnic diversity.

respectively), though confidence intervals overlapped (Table 2). In the SNAP sample, the weighted proportion of individuals with profound autism was 20%. A lower proportion of females met criteria than males (15% vs. 21%), though confidence intervals overlapped (Table 2). A larger proportion of white participants in SNAP met profound autism criteria than participants of color, though again, confidence intervals overlapped (25% vs. 11%). Both weighted and unweighted prevalence estimates for the QUEST and SNAP samples are reported in Table 2. Finally, in MoBa, 23% of participants met one or both criteria for profound autism. A higher proportion of females met profound autism criteria than males, although confidence ranges overlapped (45% vs. 17%, Table 2). Similar proportions of MoBa participants whose primary caregiver was a native Norwegian speaker and participants whose primary caregiver was not a native Norwegian speaker met criteria for profound autism (23 and 22%, respectively).

Aim 2: qualitative caregiver interviews

Method

Participants

A total of 20 caregivers of autistic adults (average age of autistic adult = 24.6) agreed to be interviewed. The autistic adults were mostly male (n = 18) and most were white (n = 18). Participating families resided in a wide range of geographic regions in the US, including West (n = 6), Northeast (n = 5), South (n = 3) and Midwest (n = 5). Additionally, one participating family resided in Canada. The majority of autistic adults were living in the family home (n = 16), with the remainder living in residential care, group homes, or a combination of family home and residential care. Families were eligible to participate if they were parents or legal guardians of a child over 18 with a diagnosis of autism spectrum disorder, if the child either had a co-occurring diagnosis of intellectual disability, had minimal communication capabilities and/or required extensive daily assistance. Within recruitment materials, the phrase "Autistic Adults with High Support Needs" was used, and families within interviews mainly used the term autism, but a small number (n = 4) also used "profound autism" or "severe autism" to describe their adult children's diagnosis and behavior.

Procedure

Caregivers of autistic adults were invited via social media to participate in interviews about their adult children's needs for quality of life and their family's needs and challenges related to caregiving an autistic adult. Purposive and snowball sampling techniques were used, specifically, posting flyers to community websites or groups specific to caregivers of autistic adults and by asking families to share the research flier with others. This study was approved by the Saint Mary's College of California Institutional Review Board, and written consent was obtained from all caregivers. The interviews were all conducted remotely via Zoom and transcribed by research assistants. Interviews lasted approximately 55 min. Caregivers were asked about their needs, community perceptions, and their adult child's needs in a semi-structured interview regarding quality of life. Some open-ended questions included, "How do people in your community view autism?," "Do you easily find support in your community for disabilities or autism?," and "Do you experience any negative reactions to autism in your community?." For the current study, only themes regarding family needs and community perceptions from the interviews are reported to gain a nuanced account of perceived stigma and marginalization. These themes were largely reflected in participant responses to questions surrounding community experiences when their adult was present and current family support needs. The second author analyzed the data using inductive thematic analysis by applying codes to data, developing a codebook, and constructing themes and subthemes in an iterative process in collaboration with trained research assistants (51). After the development of themes, the dataset was analyzed again and subthemes were then refined, recategorized, and renamed.

Researcher positionality

It is important to acknowledge the positionality of the qualitative coders for this research, as such factors may influence the analysis and interpretation of qualitative data. Specifically, it is important to acknowledge how the perspectives of the researcher may differ from the participants and the reader, and that these might influence data collection or interpretation in subtle but meaningful ways [see (52)]. The initial motivation for this protocol was to understand the lived experiences of autistic adults and their families with a focus on understanding factors related to quality of life. Participants were informed of the second author's experience with autism as a researcher before completing interviews. One research assistant involved in developing the qualitative portion of the current study identified as a sibling of individuals with profound autism.

Results

A detailed description of the themes, subthemes, definitions, and examples is presented in Table 3. All excerpts presented have been anonymized.

Community perceptions of autism

Perceived stigma

Caregivers reported a wide range of experiences in their communities and advocacy networks. Most notably, 85% of caregivers in the data reported some instance of perceived stigma, characterized by negative responses or interactions with community members. Of the individuals reporting stigma, many ($n = 10/17$) described a stigma event happening in childhood, with the remaining reporting instances of negative interactions in the community in the present day. Caregivers remarked about negative reactions from strangers within grocery stores, religious institutions, and other public locations. Other caregivers reported how others had negative reactions to the ways in which their children made noises, moved, or displayed aggressive behavior in public.

Incomplete knowledge of autism

Caregivers also reported hearing public conversations about autism that were not representative of individuals with lower cognitive abilities, limited communication, or behavioral concerns. Caregivers described frustration with social movements surrounding autism. For example, one mother of a son in his early twenties with profound autism stated:

> I think generally society has the wrong view of autism. They don't, they're not thinking about severe autism, like what [my son] has. They're thinking about, you know, The Good Doctor. And that really leaves [my son] out of the conversation. And the politicians, they won't listen to us … They'll only listen to the self-advocates; they won't listen to us. And…that's why I have to fight like hell for things that they should probably be giving me without a fight.

Caregivers also said that public conceptions of autism did not consider behaviors such as intense vocalizations or aggression as being related to autism. Instead, caregivers reported members of the public were more familiar with higher cognitive abilities and/or extraordinary talents being associated with autism. For example, another mother of a son in his early twenties with profound autism explained that she had to correct people during community interactions: "They'll often ask if he has some savant or particular talent."

Attempts to build community

Caregivers talked about attempts to establish routines and trusted social networks for their children. Many caregivers reported that their children liked to be around peers with whom they were familiar and benefited from integration into community events. For example, one mother explained "I think over like, 20 years, like, we do not get the same looks in church that we used to get, because we have been going for 20 years. So it's kinda [*sic*] like, 'oh, it's them.'"

Family support needs and advocacy challenges

Limited support for housing and activities

Caregivers described difficulties establishing appropriate activities or living situations for their adult children. Some families reported activities for their children had stopped because of the COVID-19 mitigation efforts, and that resumption of these activities was slow-going. One father explained that his son enjoyed walking around the community, but his residential program did not restart community outings for almost 2 years following COVID-19.

Many families also noted difficulties finding appropriate housing placements for their children or being on waitlists for residential care. One mother of a son in his early twenties with profound autism reported:

> In order to even be able to apply in our state for supported living homes, we had to submit his application to group family homes and get denied. He received over a dozen denials in one week.

TABLE 3 Caregiver perception and experience of stigma: themes, subthemes, definitions, and examples.

Themes	Subthemes	Definitions	Examples from transcripts
Community perceptions of autism	Perceived stigma	Caregiver reporting negative responses or interactions for community members witnessing behavioral problems in autistic adult at some point in development	"I've had people take video when he was having a meltdown in a public place. I've had people say that I wasn't controlling him. I've had people say I wasn't trying hard enough. I've had people saying I was trying too hard. It really runs the gamut." "I've had a few people tell me there are institutions for people like her. You know, other people look at you like she's some sort of alien. It's when you find other parents who have children with special needs, that you get the nice smile than the Oh, do not worry about it. It's okay. If she's humming." "I think we get more pity than, than, than people who are just unkind but there definitely are people you know, that stare and that, you know, aren't curious. They're just, they are muttering to themselves or whatever. They just want to, you know, if you are curious, fine, but just kind of, you know, the 20-year-old guy bouncing down the aisle in the supermarket wearing a Sesame Street shirt and knocking things over and bumping into people and stuff like that."
	Incomplete knowledge of autism	Caregiver reporting perceptions of autism in the community that is not representative of individuals with lower cognitive abilities, high support needs, and/or with more behavioral concerns	"I think generally society has the wrong view of autism. They do not, they are not thinking about severe autism, like what [my son] has. They're thinking about, you know, The Good Doctor. And that really leaves [my son] out of the conversation. And the politicians, they will not listen to us … They'll only listen to the self-advocates; they will not listen to us. And, and that sort of like, that's why I have to fight like hell for things that they should probably be giving me without a fight." "I think a lot of people just have no idea what it is. Because, you know, we go for walks, and [my son] is very vocal, he jumps around, he makes fast movements. I cannot, I feel like I cannot really take him out in public. Like, because he just, he just freaks people out. He gets people in people's face. And he's really hard to control. And he's bigger than I am. And he's stronger than I am. And unless it's an open space, it's really hard to take him out much." "People do not see behaviors as a part of autism. But unfortunately, it's, it's a very big part. It's just the unspoken part, you know, you do not see, you know, the morning news shows really doing it, they do the segments of, you know, the kid with special needs, who was chosen homecoming king, or, you know, they do not do you know, the parents that get beaten up one minute, but then are like, loved and hugged on the next."
	Attempts to build community	Caregivers describing attempts to establish community supports and routines for autistic adult	"I would say, we have tried to foster a community around him that's really supportive. So, all of our neighbors know him. And everybody, you know, says hi to him, and everybody kind of looks out for him. And that, that goes into the general community, for instance, like when he where he shops, and where he recreates and things like that, everybody knows him. And so, they are all very supportive of him." "I feel like it's kind of, and we were lucky too that my, my daughter who has autism was fully included. And so, she kind of grew up in a neighborhood school with peers and her sister and you know, so I think people are a lot more accepting than maybe elsewhere. There's definitely misconceptions about it. Definitely. When, when they were little, it was really hard to take them out in public, but we sort of have kind of worn people down, I think over like, 20 years, like, we do not get the same looks in church that we used to get, because we have been going for 20 years. So it's kinda like, "oh, it's them" you know, it's just kind of that kind of thing."

(Continued)

TABLE 3 (Continued)

Themes	Subthemes	Definitions	Examples from transcripts
Family support needs and advocacy challenges	Limited support for housing and activities, and healthcare	Caregivers reporting difficulties establishing appropriate placements and activities	"And we have asked to have him placed in a group home, but he has not been placed yet. The stress for us, is very dependent on his behavior. But he is still, even when he's having very good days, and he has many of those in a row, he's still very limited on what he will let us do. I mean, he does not want to go out and shop or go to any activity that does not really involve food. So, his dad and I are stuck at home, he does not travel well, he does not fly well. He does not, you know, unless it's Disneyland, he does not like to go anywhere." "I mean, so it's difficult, it really, we have had to sue and hire lawyers to get services and different places. You know, go to mediation, frequent meetings, that sort of thing. So, you really have to, we had to really fight for getting him services, and then we pay privately on our own when we did not feel like they were able to meet his needs." "What I would say when I look at some of these kids who are on the severe end of the spectrum like my son that, you know, I think a lot of people underestimate our kids and what they are capable of, including families. And I think part of that is that the professionals sometimes have lower expectations, and so I think what's really been important for us is to have these very high expectations and to always, you know, assume that [our son] can learn something, that he can do something.
	Frustration about health and healthcare experiences	Caregivers reporting difficulties finding competent healthcare services or challenging experiences with healthcare professionals	"It's really hard dealing with healthcare professionals, and how little they know about this disability and, or the Americans with Disabilities Act." "I think if I could do things differently over the years is that the medical professionals would do more tests instead of just saying, well, that's cause she's got autism, you know, and I mean, I think we put her through a lot of physical pain with, you know, the things that have been wrong with her physically, that she wasn't able to tell us."
	Inadequate services and staffing	Caregivers reporting understaffed placements, high turnover rates for staff, or difficulties finding adequate support personnel to accommodate needs	"Having to find a respite worker, there's nobody, really. Nobody that can handle autism. And I would just not feel comfortable having a stranger come in … because he can get angry very fast, and if he gets angry, he will hurt you. And I feel like I cannot put somebody through that. I mean, I'd feel really bad about leaving it. And then if they did something accidentally, and that they did not even know when they made him mad accidentally, then you know, they are in danger." "I'm just thinking lack of support as far as not being able to have enough staff to help us with him … having such a hard time finding staff since he's graduated from high school." "I could use another caregiver or two. But just have a hard time finding people, and then finding people that she would trust. She's been through a lot. So she does not trust a lot of people."

> And so as far as…the supported living homes, which are supposed to be for people like [our son], there's so few of them, and so many people that want to get in, and the homes choose the people they take.

The need for better opportunities for both activities and being around peers was frequently reflected on by caregivers.

Frustration about health and healthcare experiences

Families also reflected on challenges working with physicians or other healthcare professionals. Some caregivers reported difficulties getting accommodations during medical care visits, such as the presence of support staff. Others reported encountering professionals with limited awareness of autism or associated behaviors. One mother expressed frustration trying to get medical attention for her daughter in her late thirties with profound autism due to her inability to communicate pain: "the medical profession does not look further than just saying, well, she has autism. So that's why she has bad behavior." Another mother of a son in his early thirties reported frustrating experiences, noting healthcare professionals frequently, "have had no training in autism, and they do not know how to accommodate [my son], or necessarily do they want to, or feel they need to."

Inadequate services and staffing

Caregivers also described frustration finding appropriate staff for respite, in-home care, and/or high-turnover rates at day programs or residential programs. Some caregivers reported it was difficult to find staff that they and their adult children trusted. Others stated that they were worried what might happen when they were not present. For example, one mother of an adult in his early twenties noted both difficulties finding care staff and discomfort with leaving her son alone with unfamiliar staff:

> "Having to find a respite worker, there's nobody, really. Nobody that can handle autism. And I would just not feel comfortable having a stranger come in … because [my son] can get angry very fast, and if he gets angry, he will hurt you. And I feel like I can't put somebody through that. I mean, I'd feel really bad about leaving it. And then if they did something accidentally, and that they didn't even know when they made him mad accidentally, then you know, they're in danger."

Indeed, many families with an autistic adult living at home felt constrained in their ability to take breaks for themselves and to develop longer term plans for their children amid their own aging experiences without trusted support available.

Discussion

Stigma impacts individuals across the autism spectrum. For those who meet criteria for profound autism, marginalization due to communication challenges and considerable daily care needs may lead to distinct stigmatization experiences. However, to date, there is a relative lack of research on this group of autistic individuals and their families; as discussed below, this is a particular issue within Low- and Middle-Income Countries (LMICs). To better understand profound autism, we first examined the prevalence of profound autism in six distinct samples, three from the United States and three from Western Europe. To examine how stigma impacts the daily life experiences of profoundly autistic individuals and their families, we then conducted qualitative analyses of interviews with caregivers of adults with profound autism.

Though prevalence estimates vary across the samples reported here, in all six cohorts, profound autism represents a sizable minority of autistic individuals. These samples were recruited at distinct points in time, ranging from the 1990's (AAA, EDX), to the early 2000's (SNAP, QUEST, MoBa) and the mid-to-late 2010's (RI-CART). The samples initially identified three decades ago, in the 1990's, had the highest prevalence of profound autism—48% in the EDX sample and 35% in the AAA sample, respectively. In contrast, in the Western European samples, which were initially identified in the mid 2000's, the prevalence of profound autism hovered around 20% (QUEST, 18%; SNAP, 20%; MoBa, 18%). The most recently ascertained sample, RI-CART, had the lowest prevalence rate of profound autism—11%. Notably, RI-CART also differed from the other samples reported here in that it included individuals who received an autism diagnosis in adolescence or early adulthood as well as individuals diagnosed in childhood, as there was no age limit for joining the study (36). These results suggest that as the overall prevalence of autism spectrum disorder has increased, the relative proportion of autistic individuals meeting profound criteria has decreased (26, 53). In other words, individuals with fluent language and average or better cognitive abilities constitute an increasingly large portion of the autism population, at least in the United States and the United Kingdom. As access to assessment and treatment services and public awareness of autism has increased, identification of autistic individuals with relatively mild behavioral presentations has improved. This represents a substantial shift from the 1990's and 1980's, when it was widely accepted that at least half of people with autism spectrum disorder had a comorbid intellectual disability (40, 54).

A recent analysis from the CDC of population-based surveillance data collected between 2000 and 2016 found that approximately 27% of eight-year-olds with autism in the United States met criteria for profound autism (26). Notably, Hughes and colleagues found the prevalence of both autism spectrum disorder and profound autism increased from 2000 to 2016 (2023). However, the prevalence of autism spectrum disorder increased at a much faster rate—from 3.9 in 1000 children in 2000 to 14.3 in 1000 children in 2016—than the rate at which the prevalence of profound autism increased—from 2.7 in 1000 children in 2000 to 4.6 in 1000 children in 2016. These findings suggest that as clinical practice has evolved, the sensitivity for diagnosing individuals without significant cognitive or language delays has increased. The decrease in the relative proportion of autistic individuals meeting profound autism criteria may be an indirect result of this diagnostic shift.

In three of the six samples (AAA, EDX, MoBa), a higher proportion of females met criteria for profound autism than males, though confidence intervals overlapped. In two samples (RI-CART, SNAP) a higher proportion of males met criteria than females—though again, confidence intervals overlapped. Finally, in QUEST, an equal proportion of males and females met criteria for profound autism—importantly, females were over-sampled in the QUEST study (38). This contrasts with prior findings that females with autism are more likely to have comorbid intellectual disability and similar challenges than males (55–57) and differs from the recent CDC estimates, which found 31% of females met profound autism criteria, compared to 26% of males (26). Awareness of and diagnostic processes for autistic women and girls have changed markedly in recent years, with increasing numbers of females with average or better IQ and verbal abilities receiving ASD diagnoses, both in childhood and later in life (58–60). These shifts in the understanding of autistic women and girls may explain some of the differences seen across samples.

The prevalence rates by race and ethnicity also differed considerably across samples. In three of the six samples, a higher proportion of racial and ethnic minority groups (EDX, QUEST, RI-CART) met criteria for profound autism than white individuals, though confidence intervals for QUEST and RI-CART overlapped. In MoBa, the prevalence of profound autism between individuals whose primary caregiver was a native Norwegian speaker and individuals whose primary caregiver was not a native Norwegian speaker were almost the same, 23% for the former, 22%, suggesting that caregiver native language did not contribute to the likelihood of meeting profound autism criteria. A higher proportion of white participants met profound autism criteria in AAA and SNAP, though again, confidence intervals overlapped. Of the samples reported, AAA and SNAP had the fewest racially and ethnically diverse individuals (comprising 7 and 5% of all participants, respectively)—this may have contributed to the lower prevalence rates seen here. AAA was a convenience and volunteer sample, which may have contributed to the limited representation of minority families.

These results do not provide conclusive evidence for or against racial/ethnic disparities in profound autism. Notably, the recent CDC prevalence estimates of profound autism found higher proportions of children of color met criteria for profound autism than white children (26). The underlying prevalence rate of autism spectrum disorder in the population at large is not thought to vary by race or ethnicity—the same is thought to be true for profound autism (56, 61). Prior work suggests people of color are less likely to receive timely autism diagnoses than their white peers, which may translate to increased difficulty accessing diagnostic and treatment services (36). There is also evidence to suggest that children of color are more likely to receive a diagnosis of intellectual disability (ID) in lieu of (62) or in addition to (63) a diagnosis of autism compared to their white peers. Clearly, more work examining prevalence rates of profound autism in diverse racial and ethnic groups is needed.

Caregiver interviews highlighted experiences of stigmatization both from society at large, and from medical professionals and other service providers. Regarding the latter, caregivers frequently expressed frustration about the lack of adequate services for their adult children with profound autism. Families expressed frustration finding and maintaining support staff for adults living at home. Difficulties finding respite or other support staff were often reported in tandem with challenging behaviors such as aggression, which corroborates existing qualitative reports on the impact of aggression on experiences of isolation [e.g., (64)]. Families were frustrated by their interactions with medical professionals whom they described as unprepared or unwilling to accommodate the needs of their children. In other words, parents felt that stigmatization towards their adult children with profound autism results in poorer healthcare experiences for their autistic loved ones, as well as limited access to healthcare, residential, and other important services. Similarly in other qualitative reports, caregivers have advocated for all healthcare professionals to receive more autism-specific training, as well as for the use of more person-centered approaches in healthcare, with a particular emphasis on accommodations during visits (65).

Commonly, caregivers reported experiencing stigma in their communities in response to the behaviors of their children. Of particular concern, some families reported feeling they had limited access to their communities and peers for their adult children. Family isolation increases the risks for caregiver burnout and health complications associated with extended caregiving (18, 22). Within the current study, caregivers also frequently reflected on the benefits for their adult children being involved in their communities and with peers. Some caregivers even noted that consistent interaction with community groups, such as church parishes, was integral to reducing their and their children's stigma experiences over time. Developing opportunities for adults and their family members to increase community and peer engagement remains a critical goal for this population.

Perhaps one of the most frustrating and isolating experiences faced by the parents of profoundly autistic children is the stigmatization they experience within the autism community itself. The heterogeneity of the autism spectrum includes both married college graduates and severely cognitively impaired individuals who will require round the clock supervision for their entire lives. Given these disparate characteristics and the lack of effective labels to parse autism heterogeneity, it is perhaps little wonder that the opinions of families of profoundly autistic individuals and those of some autistic neurodiversity advocates who are capable of leading independent lives frequently differ.

Autistic self-advocates are important stakeholders in debates over policies that affect the autism community—as are the parents and caregivers of profoundly autistic individuals. Importantly, the increasing influence of the former should not come at the expense of the latter. Many individuals with profound autism, by the nature of their intellectual disability and/or limited language capabilities, cannot advocate for themselves. It is vital to acknowledge the invaluable role and enormous efforts of caregivers of children and adults with profound autism as their children's greatest advocates. Bioethics offers a robust literature on surrogate decision making, and the overwhelming consensus is that family members are the best representatives for incapacitated loved ones, both because they have the deepest understanding of their needs and preferences, and because they care most about their quality of life (66). Yet many neurodiversity proponents have advocated for changes–such as the elimination of words like "treatment," "severe," or "challenging behavior" from autism research and clinical practice (67–69)–without meaningful engagement with caregivers nor careful consideration of their articulated concerns for individuals with profound autism. Determining best practices for the most disabled segment of the autism spectrum will require extensive input from the families of profoundly autistic individuals. The consulting of neurodiversity advocates alone is not sufficient. Arguably, the more a particular policy affects profoundly autistic individuals, the more weight should be given to feedback from profoundly autistic individuals' parents, siblings, and other family members and caregivers.

Limitations

Our ability to calculate prevalence estimates of profound autism in the present study is inherently limited by the kinds of samples employed in these analyses. The current samples were drawn exclusively from High Income Countries (HICs) and most participants in all six samples were white. The relative lack of racial and ethnic diversity present in the samples described here, as well as discrepancies across samples in how participant diversity was described, limits our ability to adequately examine prevalence rates of profound autism by race and ethnicity. There is also considerable variability in the time periods during which these samples were collected, so the prevalence estimates reported here, particularly for the samples initially collected in the 1990s (AAA and EDX) are likely influenced by cohort effects. Importantly, only two of the six samples (MoBa and SNAP) were population-based, so it is impossible to draw conclusions from this work about the "true" prevalence of profound autism. There were also variations in the measures used across samples to characterize participant IQ and verbal abilities. These measurement differences may have contributed to the different prevalence estimates seen across the six samples.

The caregivers who participated in interviews for the current study are unique in many ways and not representative of the total population of caregivers of adults with profound autism. Although geographically diverse within the United States, most families were white, lived with their adult child, and had adult children diagnosed in early childhood. Further, it is not clear how much the experiences and priorities of families of adult individuals with profound autism overlap with, or are distinct from, the experiences and priorities of families of children with profound autism. Understanding the perspectives of caregivers should be seen as an ongoing effort, and further qualitative exploration into the needs of families of profoundly autistic individuals of all ages, particularly racially diverse and lower SES families, is a priority.

Future directions

Future work in more racially and ethnic diverse samples is needed to better understand potential disparities that may uniquely impact profoundly autistic individuals of diverse backgrounds and their families. More efforts to establish prevalence estimates of profound autism in LMICs may be especially critical. In LMICs, the relative percentage of autistic individuals who met criteria for profound autism may be higher, given the lack of available assessment and treatment services compared to HICs. In other words, individuals with autism and average or above average IQ and language abilities in LMICs may be less likely to receive an ASD diagnosis and associated services than individuals of similar characteristics in HICs. Accurate and reliable studies on the prevalence of ASD in LMICs are necessary so that health professionals and policy makers can develop strategic plans to meet the needs of autistic individuals (70). A recent review (71) found prevalence studies of autism have only been conducted in 34 countries. Most of the studies included in the review examined the prevalence of autism in HICs, which on average, report higher prevalence estimates of autism than LMICs (72). Access to ASD diagnosis, intervention, and support services is limited in LMICs, many of which do not have sufficient trained healthcare professionals who are familiar with autism to adequately meet service needs (73). Further, in some LMICs, autism and similar developmental conditions are perceived as evidence of demonic possession, curses, or other deeply stigmatizing religious or cultural omens (74, 75). This misinformation regarding the etiology of autism and subsequent stigmatization of people with autism and their families can be a substantial barrier to seeking diagnostic and treatment services in some LMICs.

In short, future work examining the prevalence of ASD, and the prevalence of profound autism specifically, in LMICs should be a priority. Accurate prevalence data in LMICs would underscore the need for policies and funding to improve access to diagnosis and intervention services for autistic individuals and their families. Such research could be also used to improve public awareness of the causes and characteristics of autism, which could in turn mitigate the stigmatization of autistic people and their families. Knowing the prevalence of profound autism specifically would allow policymakers in LMICs to estimate the percentage of the autism population that may need lifelong substantial support—imperative information to prepare public health and service delivery systems to provide adequate care to autistic individuals with the most intensive needs and their families.

Efforts to meaningfully divide up the autism spectrum have persisted for decades and will undoubtedly continue to persist well into the future. As outlined in *The Lancet* Commission, given the huge range seen in the needs and abilities of autistic people, the term "profound autism" was intended to efficiently identify autistic individuals with extensive and often lifelong daily care needs. Future research should also examine the potential utility of describing other subgroups within the autism spectrum. For example, despite not meeting profound autism criteria, some autistic individuals who have fluent language skills and mild or moderate intellectual disability still require substantial daily supports. Still other autistic people may require support in employment, education, and/or other areas of daily life, but are capable of substantial independence when appropriate supports are in place. Careful study is needed to examine and define additional subgroups of the autism spectrum. Ultimately, the goal of any such subgroupings should be to ensure that all individuals with autism and their families receive appropriate services and supports, given their specific abilities and needs.

More work is also needed to understand how stigma impacts access to appropriate diagnostic and treatment services for profoundly autistic individuals. Most individuals with profound ASD will need substantial daily support for much of their lives and will be unable to attain many normative outcomes parents hold for their young children, such as living independently, establishing careers, and having families of their own. Clear and accurate information about the prognosis of profound autism, though that information may be upsetting for parents to hear, is essential for clinicians to communicate to families so that they can prepare financially, mentally, and emotionally for the often-lifelong caregiving responsibilities required for profoundly autistic individuals. But when can clinicians feel confident that an individual meets profound autism criteria, and subsequently share this information with parents and caregivers?

The Lancet commission specified that the term profound autism should only be applied to individuals aged eight or older. The rationale for this stipulation was that language fluency and cognitive ability can develop rapidly in early childhood. An autistic child who has very limited speech at age three is unusual, but still may develop many language abilities by age four or five. In contrast, by mid-childhood both language fluency and cognitive ability are relatively stable, and substantial changes are much less likely to occur (44, 76, 77).

Nevertheless, Hughes et al. (26) used data on language fluency from as young as age four in their profound autism prevalence estimates and found less than a percentage point difference in their prevalence estimates with language fluency data from age five. More work is needed to establish an empirical basis for profound autism age criteria. Ideally, a data-driven balance should be struck between allowing sufficient time for an individual's language and cognitive abilities to develop and granting families as much time as possible to prepare for the extensive caregiving responsibilities profoundly autistic individuals require across the life course.

In the United States, all autistic children are entitled by law to appropriate educational support. However, that entitlement ends when autistic individuals age into the world of adult services. The adult services system is plagued by long waiting lists, staffing shortages and frequent staff burnout and turnover [American Network of Community Options and Resources (78)], as well as a fundamental lack of research about the value of different support models (16). Are the dispersed, community-based supports favored by many neurodiversity advocates appropriate for those with profound autism? Might some profoundly autistic adults achieve better outcomes in larger, more structured settings? How do we even define "better outcomes" for those who cannot necessarily articulate their needs and preferences (79, 80)? Additional research is needed to answer these and other pressing questions on how to minimize stigmatization, improve services access, quality of life, and community engagement for profoundly autistic individuals and their families.

Conclusion

As individuals with autism reach adulthood and avenues for services and community engagement decrease, stigmatization of individuals with profound autism and, notably, their caregivers, may only increase. By calculating the prevalence of profound autism and characterizing experiences of stigmatization and research priorities amongst caregivers of adults with profound autism, the current study enhances our understanding of this vulnerable subgroup of individuals with ASD. Future research should continue to examine the unique needs and stigmatization experiences of this group across the life course.

Data availability statement

The raw data supporting the conclusions of this article will be made available by the authors, without undue reservation.

Ethics statement

The studies involving humans were approved by University of California, Los Angeles Office of the Human Research Protection Program, IRB#19–000079. The studies were conducted in accordance with the local legislation and institutional requirements. Written informed consent for participation in this study was provided by the participants' legal guardians/next of kin.

Author contributions

EC: Conceptualization, Writing – original draft, Writing – review & editing. JM: Conceptualization, Writing – original draft, Writing – review & editing. AL: Writing – original draft, Writing – review & editing. MG: Writing – original draft, Writing – review & editing. SS: Conceptualization, Data curation, Writing – review & editing. CL: Conceptualization, Data curation, Funding acquisition, Supervision, Writing – review & editing.

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Conflict of interest

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The remaining authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

Publisher's note

References

1. American Psychiatric Association. *Diagnostic and statistical manual of mental disorders: DSM-5, vol. 28. 5th* ed. Leeds: Emerald (2014).

2. Goffman E. (1963). Stigma: notes on the management of spoiled identity. Touchstone. Available at: https://books.google.com/books?id=7CNUUMKTbIoC

3. Farrugia D. Exploring stigma: medical knowledge and the stigmatisation of parents of children diagnosed with autism spectrum disorder. *Sociol Health Illn*. (2009) 31:1011–27. doi: 10.1111/j.1467-9566.2009.01174.x

4. Gray DE. Perceptions of stigma: the parents of autistic children. *Sociol Health Illn*. (1993) 15:102–20. doi: 10.1111/1467-9566.ep11343802

5. Kinnear SH, Link BG, Ballan MS, Fischbach RL. Understanding the experience of stigma for parents of children with autism spectrum disorder and the role stigma plays in families' lives. *J Autism Dev Disord*. (2016) 46:942–53. doi: 10.1007/s10803-015-2637-9

6. Song J, Mailick MR, Greenberg JS. Health of parents of individuals with developmental disorders or mental health problems: impacts of stigma. *Soc Sci Med*. (2018) 1982:152–8. doi: 10.1016/j.socscimed.2018.09.044

7. Bettelheim B. *The empty fortress: Infantile autism and the birth of the self*. New York City, NY: Free Press of Glencoe (1967).

8. Schopler E. Parents of psychotic children as scapegoats. *J Contemp Psychother*. (1971) 4:17–22. doi: 10.1007/BF02110269

9. Scambler G, Hopkins A. Being epileptic: coming to terms with stigma. *Sociol Health Illn*. (1986) 8:26–43. doi: 10.1111/1467-9566.ep11346455

10. Han E, Scior K, Avramides K, Crane L. A systematic review on autistic people's experiences of stigma and coping strategies. *Autism Res*. (2022) 15:12–26. doi: 10.1002/aur.2652

11. Kanne SM, Mazurek MO. Aggression in children and adolescents with ASD: prevalence and risk factors. *J Autism Dev Disord*. (2011) 41:926–37. doi: 10.1007/s10803-010-1118-4

12. Laverty C, Agar G, Sinclair-Burton L, Oliver C, Moss J, Nelson L, et al. The 10-year trajectory of aggressive behaviours in autistic individuals. *J Intellect Disabil Res*. (2023) 67:295–309. doi: 10.1111/jir.13004

13. Laverty C, Oliver C, Moss J, Nelson L, Richards C. Persistence and predictors of self-injurious behaviour in autism: a ten-year prospective cohort study. *Mol Autism*. (2020) 11:8. doi: 10.1186/s13229-019-0307-z

14. Falkmer M, Anderson K, Joosten A, Falkmer T. Parents' perspectives on inclusive schools for children with autism Spectrum conditions. *Int J Disabil Dev Educ*. (2015) 62:1–23. doi: 10.1080/1034912X.2014.984589

15. Watkins L, Ledbetter-Cho K, O'Reilly M, Barnard-Brak L, Garcia-Grau P. Interventions for students with autism in inclusive settings: a best-evidence synthesis and meta-analysis. *Psychol Bull*. (2019) 145:490–507. doi: 10.1037/bul0000190

16. Mandell DS. A house is not a home: the great residential divide in autism care. *Autism*. (2017) 21:810–1. doi: 10.1177/1362361317722101

17. Griffith GM, Hastings RP. 'He's hard work, but he's worth it'. The experience of caregivers of individuals with intellectual disabilities and challenging behaviour: a meta-synthesis of qualitative research. *J Appl Res Intellect Disabil*. (2014) 27:401–19. doi: 10.1111/jar.12073

18. Krauss MW, Seltzer MM, Jacobson HT. Adults with autism living at home or in non-family settings: positive and negative aspects of residential status. *J Intellect Disabil Res*. (2005) 49:111–24. doi: 10.1111/j.1365-2788.2004.00599.x

19. Tichá R, Hewitt A, Nord D, Larson S. System and individual outcomes and their predictors in services and support for people with IDD. *Intellect Dev Disabil*. (2013) 51:298–315. doi: 10.1352/1934-9556-51.5.298

20. Handen BL, Mazefsky CA, Gabriels RL, Pedersen KA, Wallace M, Siegel M, et al. Risk factors for self-injurious behavior in an inpatient psychiatric sample of children with autism spectrum disorder: a naturalistic observation study. *J Autism Dev Disord*. (2018) 48:3678–88. doi: 10.1007/s10803-017-3460-2

21. Righi G, Benevides J, Mazefsky C, Siegel M, Sheinkopf SJ, Morrow EM, et al. Predictors of inpatient psychiatric hospitalization for children and adolescents with autism spectrum disorder. *J Autism Dev Disord*. (2018) 48:3647–57. doi: 10.1007/s10803-017-3154-9

22. Marsack-Topolewski CN, Church HL. Impact of caregiver burden on quality of life for parents of adult children with autism Spectrum disorder. *Am J Intellect Dev Disabil*. (2019) 124:145–56. doi: 10.1352/1944-7558-124.2.145

23. Lord C, Charman T, Havdahl A, Carbone P, Anagnostou E, Boyd B, et al. The lancet commission on the future of care and clinical research in autism. *Lancet*. (2022) 399:271–334. doi: 10.1016/S0140-6736(21)01541-5

24. Taylor LJ, Eapen V, Maybery M, Midford S, Paynter J, Quarmby L, et al. Brief report: an exploratory study of the diagnostic reliability for autism spectrum disorder. *J Autism Dev Disord*. (2017) 47:1551–8. doi: 10.1007/s10803-017-3054-z

25. Weitlauf AS, Gotham KO, Vehorn AC, Warren ZE. Brief report: DSM-5 "levels of support:" a comment on discrepant conceptualizations of severity in ASD. *J Autism Dev Disord*. (2014) 44:471. doi: 10.1007/s10803-013-1882-z

26. Hughes MM, Shaw KA, DiRienzo M, Durkin MS, Esler A, Hall-Lande J, et al. The prevalence and characteristics of children with profound autism, 15 sites, United States, 2000-2016. *Public Health Rep*. (2023) 3335492311635. doi: 10.1177/00333549231163551

27. Huang A. X., Wheeler J. J. (2006). High-functional autism: An overview of characteristics and related issues. Int J Spec Educ. Available at: https://www.semanticscholar.org/paper/High-Functional-Autism%3A-An-Overview-of-and-Related-Huang-Wheeler/aa6acda00913066177f44de30a0a9acd6547137b

28. National Council on Severe Autism (2021). NCSA position statement on diagnostic labels: the need for categorical recognition of severe autism in the DSM. Available at: https://www.ncsautism.org/dsm

29. Pukki H, Bettin J, Outlaw AG, Hennessy J, Brook K, Dekker M, et al. Autistic perspectives on the future of clinical autism research. *Autism Adulthood*. (2022) 4:93–101. doi: 10.1089/aut.2022.0017

30. Kapp SK. Profound concerns about "profound autism": dangers of severity scales and functioning labels for support needs. *Educ Sci*. (2023) 13:Article 2. doi: 10.3390/educsci13020106

31. Bal VH, Maye M, Salzman E, Huerta M, Pepa L, Risi S, et al. The adapted ADOS: a new module set for the assessment of minimally verbal adolescents and adults. *J Autism Dev Disord*. (2019). doi: 10.1007/s10803-019-04302-8

32. Greer BD. Barriers to accessing effective treatments for destructive behavior. *Policy Insights Behav Brain Sci*. (2023) 10:68–74. doi: 10.1177/23727322221144653

33. Hamdani Y, Kassee C, Walker M, Lunsky Y, Gladstone B, Sawyer A, et al. Roadblocks and detours on pathways to a clinical diagnosis of autism for girls and women: a qualitative secondary analysis. *Womens Health*. (2023) 19:17455057231163761. doi: 10.1177/17455057231163761

34. Smith JR, York T, Warn S, Borodge D, Pierce DL, Fuchs DC. Another option for aggression and self-injury, alternative benzodiazepines for catatonia in profound autism. *J Child Adolesc Psychopharmacol*. (2023) 33:109–17. doi: 10.1089/cap.2022.0067

35. Waizbard-Bartov E, Fein D, Lord C, Amaral DG. Autism severity and its relationship to disability. *Autism Res*. (2023) 16:685–96. doi: 10.1002/aur.2898

36. McCormick CEB, Kavanaugh BC, Sipsock D, Righi G, Oberman LM, Moreno De Luca D, et al. Autism heterogeneity in a densely sampled U.S. population: results from the first 1,000 participants in the RI-CART study. *Autism Res*. (2020) 13:474–88. doi: 10.1002/aur.2261

37. Salazar F, Baird G, Chandler S, Tseng E, O'sullivan T, Howlin P, et al. Co-occurring psychiatric disorders in preschool and elementary school-aged children with autism spectrum disorder. *J Autism Dev Disord*. (2015) 45:2283–94. doi: 10.1007/s10803-015-2361-5

38. Chandler S, Carter Leno V, White P, Yorke I, Hollocks MJ, Baird G, et al. Pathways to adaptive functioning in autism from early childhood to adolescence. *Autism Res*. (2022) 15:1883–93. doi: 10.1002/aur.2785

39. Baird G, Simonoff E, Pickles A, Chandler S, Loucas T, Meldrum D, et al. Prevalence of disorders of the autism spectrum in a population cohort of children in South Thames: the special needs and autism project (SNAP). *Lancet (London, England)*. (2006) 368:210–5. doi: 10.1016/S0140-6736(06)69041-7

40. Charman T, Pickles A, Simonoff E, Chandler S, Loucas T, Baird G. IQ in children with autism spectrum disorders: data from the special needs and autism project (SNAP). *Psychol Med*. (2011) 41:619–27. doi: 10.1017/S0033291710000991

41. Magnus P, Birke C, Vejrup K, Haugan A, Alsaker E, Daltveit AK, et al. Cohort profile update: the Norwegian mother and child cohort study (MoBa). *Int J Epidemiol*. (2016) 45:382–8. doi: 10.1093/ije/dyw029

42. Lord C, Rutter M, DiLavore PC, Risi S, Gotham K, Bishop S. *Autism diagnostic observation schedule: ADOS-2*. Torrance, CA: Western Psychological Services (2012).

43. Le Couteur A., Lord C., Rutter M. (2003). *The autism diagnostic interview-revised (ADI-R)* (pp. 659–685). Torrance, CA: Western Psychological Services.

44. Anderson DK, Liang JW, Lord C. Predicting young adult outcome among more and less cognitively able individuals with autism spectrum disorders. *J Child Psychol Psychiatry*. (2014) 55:485–94. doi: 10.1111/jcpp.12178

45. Surén P, Schjølberg S, Øyen A-S, Lie KK, Hornig M, Bresnahan M, et al. The autism birth cohort (ABC): a study of autism spectrum disorders in MoBa. *Nor Epidemiol*. (2014) 24:Article 1–2. doi: 10.5324/nje.v24i1-2.1757

46. Simonoff E, Pickles A, Charman T, Chandler S, Loucas T, Baird G. Psychiatric disorders in children with autism spectrum disorders: prevalence, comorbidity, and associated factors in a population-derived sample. *J Am Acad Child Adolesc Psychiatry*. (2008) 47:921–9. doi: 10.1097/CHI.0b013e318179964f

47. Kaufman AS, Kaufman NL. *Kaufman brief intelligence test. 2nd* ed. Circle Pines, MN: American Guidance Service (2004).

48. Glutting J, Adams W, Sheslow D. *Wide range intelligence test*. Wilmington, DE: Wide Range (2000).

49. Shattuck PT, Seltzer MM, Greenberg JS, Orsmond GI, Bolt D, Kring S, et al. Change in autism symptoms and maladaptive Behaviors in adolescents and adults with an autism Spectrum disorder. *J Autism Dev Disord*. (2007) 37:1735–47. doi: 10.1007/s10803-006-0307-7

50. R Core Team. *R: A language and environment for statistical computing*. Vienna, Austria: R Foundation for Statistical Computing (2021).

51. Braun V, Clarke V. Using thematic analysis in psychology. *Qual Res Psychol*. (2006) 3:77–101. doi: 10.1191/1478088706qp063oa

52. Darwin Holmes AG. Researcher positionality—a consideration of its influence and place in qualitative research—a new researcher guide. *Shanlax Int J Educ*. (2020) 8:1–10. doi: 10.34293/education.v8i4.3232

53. Fombonne E. Editorial: the rising prevalence of autism. *J Child Psychol Psychiatry*. (2018) 59:717–20. doi: 10.1111/jcpp.12941

54. Carpentieri S, Morgan SB. Adaptive and intellectual functioning in autistic and nonautistic retarded children. *J Autism Dev Disord*. (1996) 26:611–20. doi: 10.1007/BF02172350

55. Amiet C, Gourfinkel-An I, Bouzamondo A, Tordjman S, Baulac M, Lechat P, et al. Epilepsy in autism is associated with intellectual disability and gender: evidence from a meta-analysis. *Biol Psychiatry*. (2008) 64:577–82. doi: 10.1016/j.biopsych.2008.04.030

56. Elsabbagh M, Divan G, Koh Y-J, Kim YS, Kauchali S, Marcín C, et al. Global prevalence of autism and other pervasive developmental disorders. *Autism Res*. (2012) 5:160–79. doi: 10.1002/aur.239

57. Fombonne E, MacFarlane H, Salem AC, Zuckerman KE. Epidemiological surveys of ASD: current findings and new directions In: JL Matson and P Sturmey, editors. *Handbook of autism and pervasive developmental disorder: assessment, diagnosis, and treatment*. Berlin: Springer International Publishing (2022). 135–84.

58. Halladay AK, Bishop S, Constantino JN, Daniels AM, Koenig K, Palmer K, et al. Sex and gender differences in autism spectrum disorder: summarizing evidence gaps and identifying emerging areas of priority. *Mol Autism*. (2015) 6:36. doi: 10.1186/s13229-015-0019-y

59. Hull L, Petrides KV, Mandy W. The female autism phenotype and camouflaging: a narrative review. *Rev J Autism Dev Disord*. (2020):306–17. doi: 10.1007/s40489-020-00197-9

60. Jamison R, Bishop SL, Huerta M, Halladay AK. The clinician perspective on sex differences in autism spectrum disorders. *Autism*. (2017) 21:772–84. doi: 10.1177/1362361316681481

61. Mandell DS, Wiggins LD, Carpenter LA, Daniels J, DiGuiseppi C, Durkin MS, et al. Racial/ethnic disparities in the identification of children with autism spectrum disorders. *Am J Public Health*. (2009) 99:493–8. doi: 10.2105/AJPH.2007.131243

62. Polyak A, Kubina RM, Girirajan S. Comorbidity of intellectual disability confounds ascertainment of autism: implications for genetic diagnosis. *Am J Med Genet B Neuropsychiatr Genet*. (2015) 168:600–8. doi: 10.1002/ajmg.b.32338

63. Becerra TA, von Ehrenstein OS, Heck JE, Olsen J, Arah OA, Jeste SS, et al. Autism Spectrum disorders and race, ethnicity, and nativity: a population-based study. *Pediatrics*. (2014) 134:e63–71. doi: 10.1542/peds.2013-3928

64. Hodgetts S, Nicholas D, Zwaigenbaum L. Home sweet home? Families' experiences with aggression in children with autism spectrum disorders. *Focus Autism Other Dev Disabl*. (2013) 28:166–74. doi: 10.1177/1088357612472932

65. Mazurek MO, Sadikova E, Cheak-Zamora N, Hardin A, Huerta I, Sohl K, et al. They deserve the "same level of care that any other person deserves": caregiver perspectives on healthcare for adults on the autism spectrum. *Res Autism Spectr Disord*. (2021) 89:101862. doi: 10.1016/j.rasd.2021.101862

66. Buchanan AE, Brock DW In: DW Brock, editor. *Deciding for others: the ethics of surrogate decision making*. Cambridge: Cambridge University Press (1989)

67. Bottema-Beutel K, Kapp SK, Lester JN, Sasson NJ, Hand BN. Avoiding ableist language: suggestions for autism researchers. *Autism Adulthood*. (2021) 3:18–29. doi: 10.1089/aut.2020.0014

68. Dwyer P, Ryan JG, Williams ZJ, Gassner DL. First do no harm: suggestions regarding respectful autism language. *Pediatrics*. (2022) 149:e2020049437N. doi: 10.1542/peds.2020-049437N

69. Monk R, Whitehouse AJO, Waddington H. The use of language in autism research. *Trends Neurosci*. (2022) 45:791–3. doi: 10.1016/j.tins.2022.08.009

70. Salari N, Rasoulpoor S, Rasoulpoor S, Shohaimi S, Jafarpour S, Abdoli N, et al. The global prevalence of autism spectrum disorder: a comprehensive systematic review and meta-analysis. *Ital J Pediatr*. (2022) 48:112. doi: 10.1186/s13052-022-01310-w

71. Zeidan J, Fombonne E, Scorah J, Ibrahim A, Durkin MS, Saxena S, et al. Global prevalence of autism: a systematic review update. *Autism Res*. (2022) 15:778–90. doi: 10.1002/aur.2696

72. Talantseva OI, Romanova RS, Shurdova EM, Dolgorukova TA, Sologub PS, Titova OS, et al. The global prevalence of autism spectrum disorder: a three-level meta-analysis. *Front Psychiatry*. (2023) 14:1071181. doi: 10.3389/fpsyt.2023.1071181

73. Divan G, Bhavnani S, Leadbitter K, Ellis C, Dasgupta J, Abubakar A, et al. Annual research review: achieving universal health coverage for young children with autism spectrum disorder in low- and middle-income countries: a review of reviews. *J Child Psychol Psychiatry*. (2021) 62:514–35. doi: 10.1111/jcpp.13404

74. Papadopoulos C. (2016). Autism stigma and the role of ethnicity and culture. Network Autism

75. Tilahun D, Hanlon C, Fekadu A, Tekola B, Baheretibeb Y, Hoekstra RA. Stigma, explanatory models and unmet needs of caregivers of children with developmental disorders in a low-income African country: a cross-sectional facility-based survey. *BMC Health Serv Res*. (2016) 16:152. doi: 10.1186/s12913-016-1383-9

76. Pickles A, Anderson DK, Lord C. Heterogeneity and plasticity in the development of language: a 17-year follow-up of children referred early for possible autism. *J Child Psychol Psychiatry*. (2014) 55:1354–62. doi: 10.1111/jcpp.12269

77. Simonoff E, Kent R, Stringer D, Lord C, Briskman J, Lukito S, et al. Trajectories in symptoms of autism and cognitive ability in autism from childhood to adult life: findings from a longitudinal epidemiological cohort. *J Am Acad Child Adolesc Psychiatry*. (2020) 59:1342–52. doi: 10.1016/j.jaac.2019.11.020

78. American Network of Community Options and Resources. (2022). The State of America's direct support workforce crisis 2022 [policy brief]. Available at: https://www.ancor.org/wp-content/uploads/2023/12/2023-State-of-Americas-Direct-Support-Workforce-Crisis_Final.pdf

79. Lounds Taylor J. When is a good outcome actually good? *Autism*. (2017) 21:918–9. doi: 10.1177/1362361317728821

80. McCauley JB, Pickles A, Huerta M, Lord C. Defining positive outcomes in more and less cognitively able autistic adults. *Autism Res*. (2020) 13:1548–60. doi: 10.1002/aur.2359

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Korean autistic persons facing systemic stigmatization from middle education schools: daily survival on the edge as a puppet

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Introduction: Korean autistic persons who have endured an integrated secondary education system have been exposed to school bullying, causing trauma and stigma to them. It also blocks them from entering a tertiary education system and a decent work, resulting in a lower quality of life. However, research on how it affects autistic persons has not yet been conducted in Korea.

Methods: Fourteen adult autistic persons in the Republic of Korea participated in the semi-structured focused group interviews. Their conversations were analyzed through qualitative coding.

Results: The interview results show the rare voice of Korean autistic people. Although interviewees experienced physical, verbal, and sexual violence against them during the secondary education period, they could not get substantial assistance from schools and society. Interviewees agreed that bullying is inherent in the secondary education system of Korea, even in Korean culture. They experienced the cause of bullying being attributed to them as victims rather than perpetrators, and impunity is given to the bullying assailants. Early analyses of this article confirm that such experiences are combined with the sociocultural climate of elitism, meritocracy, and authoritarianism in the Republic of Korea.

Conclusion: The study confirmed that the autistic person's bullying experience does not come from the social inability of autistic people but the "profound" competition and discriminative atmosphere of the society. The result urges further studies on the bullying experience of East Asian autistic persons and the construction of Korean intervention strategies to prevent school violence against Koreans with disabilities, especially autistic pupils.

KEYWORDS

school bullying, stigma, autistic traits, objectification, authoritarianism, autism spectrum

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1 Introduction

Bullying, expressed as *Wangtta* in Korean and *Ijime* in Japanese, is an “intentional, repeated” (1) victimization of a person by others in thinkable various ways of humiliation (2) and objectification (3, 4), including abusive utterances, relational manipulation, exploitation (5, 6), physical hits, sexual harassment, and cyberbullying (7). Bullying can lead to eating disorders (8), obesity (9), further physical and psychological problems (10), social isolation (11, 12) or *hikikomori* (13), and even leads to victims’ murder or suicide (6, 14).

Most autistic people seemingly face school bullying from their “peers.” Park et al. (15) suggests that 67% of autistic secondary school pupils endure victimization, and 14% are related to perpetration and victimization in primary and secondary schools by meta-analysis. In addition, Maïano et al. (16) also suggest that 44% are related to victimization and 14% are related to perpetration and victimization. The result may be contradicted by Trundle et al. (17), who found the prevalence of bullying against autistic people at 44%. However, these results can be complementary because their analysis contained bullying in all ages. The results of meta-analysises suggest that most bullying experiences of autistic people may occur during secondary school.

Bullying against autistic people mostly occurs between the communication of autistic and allistic people. Autistic people seem to have a different interaction strategy due to the difference in brain neurology (18). Some autistic-suggested theories, like the double empathy problem (DEP) (19) and monotropism (20), support the theorem of neurodiversity. In addition, the neurodiversity model coincides with the human rights model of disability (21, 22), the legal approach to disability under international law, according to the UN Convention on the Rights of Persons with Disabilities (23).

The problem is that autistic perception and communication approaches and strategies are regarded as an impairment of social communication (24) or the “lack of theory of mind” (25). Therefore, what is going on with autistic students in secondary schools, which impacts significantly in their lives, has been ignored or has a low priority in autism research. For example, only 3% of research on autistic traits in America (2018) went to transition and adult issues (26).

Bullying in school against autistic persons and their negative experiences in the school affect their “prognosis.” For example, in 2022, only 16.8% of autistic pupils (402 persons) remained in regular classes in secondary schools in Korea; other Korean autistic students often go to special schools or special classes in schools (27). Therefore, most Korean autistic pupils cannot advance to the tertiary education system, especially graduate schools. Moreover, the employment rate of Korean autistic people in 2022 was 26.7% (28), much lower than the overall employment rate of 68.5% (29). Most autistic persons cannot advance into decent jobs or remain in low-salary jobs because they cannot get enough knowledge and skill(s) through the education system to work in companies, or many companies do not want to hire them (30). Therefore, most autistic people could not earn enough money to live well in the Korean society. Moreover, trauma and stigma resulting from bullying could trigger other mental health problems (10), a highly stigmatic disposition in Korea resulting in social exclusion (31).

Nevertheless, the research on bullying against autistic people is only at a starting point. For example, according to Park et al. (15:911), the number of research articles on bullying autistic people by January 2018 in English, Japanese, and Korean was 752, 227, and 20, respectively, which shows that academic concern lags in terms of the number of articles. Despite many researchers interested in autism in these countries, Korean articles focused on either autistic persons’ parents (32–34) or literature analysis (35) and quantitative analysis (36). The status proves the need for research on what is happening in the school life of autistic persons, especially on school violence against autistic pupils in their own words.

Therefore, we want to start answering this problem to find out what was happening in secondary schools in Korea. First, we want to clarify why bullying occurs from looking at the applied humanities and law studies viewpoint. Then, we will show the results from the focused group interview (FGI) with Korean autistic people.

2 Meaning of bullying against autistic people in the Korean society

2.1 Social environment where bullying takes place

Before discussing a Korean autistic person’s exposure to bullying, we need to understand the background that enables easy bullying against people with disabilities including autistic people.

Korea has a high-contextual (37) and “Confucian meritocracy” culture (38), which requires its people to be productive. The 12-year mandatory education, especially secondary education—constituted of middle schools and high schools—has been regarded mainly as preparatory courses for the College Scholastic Ability Test (CSAT) or *sunwng*, to go to “top universities” (39). The Korean government keeps CSAT day a special one, including making Notice to Airmen for blocking aircraft from airport runways and its airspace, during the hours when examinees hear Korean and English questions from speakers (39). To ensure that children and teens eventually enter higher-ranked universities, many parents require “their own” kids to learn a huge amount of knowledge before they officially enter even elementary school, especially in mathematics (39, 40).

The point system of CSAT utilizes the standard normal distribution (SD), which corresponds with the neuronormality (41) and medical model of disability. In the CSAT, examinees get higher scores when they are among the top 4% of examinees (the next grade is 11%) and get higher points if their standard deviation is higher. Under this system, examinees can get a third grade with just one failed question if more than 11% of the examinees in a test subject get a perfect score. Therefore, examiners must create extremely hard questions in the CSAT to make superiority and inferiority between examinees discernible, and the level of difficulty of CSAT has constantly increased to distinguish the “learning power” of examinees.

This “fierce competition” (42) is seen as important not only for the lifetime of an individual, but its importance reaches for family, community, and the nation. For example, many families see university as a predictor of their child’s position in the labor market, because admission to an “elite” university is assumed to ensure the highest career in Korea (42, 43). Moreover, the educational performance of schools has been thought to be evaluated with the average CSAT score of local high school pupils and how many pupils at a certain high school entered elite universities (44). The Korean government also refers to international educational exam results, such as the Programme for International Student Assessment as indicators of a country’s future (39).

Therefore, during the high school period, most pupils are forced to live an austere life to enter a better university. One of those practices is the night self-study or *yaja*, which is *de facto* mandatory studying (45, 46) that makes pupils study until 9 or 10 p.m. (47). During *yaja*, teachers round classes to supervise them to see whether they are studying or not. They punish any pupil who is away from their studies (45). Recently, some local education boards lifted night self-study as a mandatory program, but some schools and parents continue this program, fearing lower scores for their children (46).

Moreover, to make their kids more competitive than others and achieve a successful lifetime, most parents send their children to shadow education or *hagwons* (48). Many children participate in advanced education in a *hagwon* to preempt a higher place in the unending competition (40, 43, 48). According to a recent survey, 78.3% of pupils go to *hagwons*, and their parents spend around 4,100 USD equivalent value in a year (49), which has unexpectedly increased in some years (43). Moreover, overall expenditures for shadow education in 2022 are 19.9 billion US dollars (26 trillion won), which is 1.1% of the GDP in 2022 (49). In other cases, some schools operate small dormitories for honor class to encourage pupils in higher test points to “immerse in study” (40). Some schools oblige all pupils to enter the school dormitory and impose inhumane policies without consent or free will, which violates human rights (50).

These institutions affect Korean pupils negatively. According to Joo et al. (51), high school pupils in Korea usually go to sleep after midnight and wake up before 8 a.m., sleeping only 6 h a day. However, many pupils are encouraged to sleep less because they assume that to “save time for sleep” until some days from CSAT day is indispensable for those who want to advance to elite schools like *seoyeongo* (52), which is limited to 10,000 spots (53). The unofficial four-character idiom *sadangorag* (“four-pass five-fail”) defines their lifestyle (40): An examinee must sleep only for 4 h on weekdays to get into elite universities.

The negative effect of competitive education is clear: stress from learning (47) and excessive daytime sleepiness (51). Long learning time also lowers life satisfaction and school adjustment and induces depression (54), runaway, and suicidality (47). Most of all, the free will of pupils is ignored in this kind of mandatory education system, which violates the human rights of children (44).

In this very competitive system, anything disturbing their study, which is the reward strategy for the hardship of study or solution for the stress-resolving solution, is strictly prohibited. Especially, anything that would make secondary school pupils escape from “linear repetitions” (55), which, as Henri Lefebvre described as a *détournement* (56:17), becomes a sin.

For example, in 2011, the Korean government under President Lee, Myeong-bak enforced the reformed Youth Protection Act, supported by parent organizations, which imposed internet game providers blocking access from teenagers from midnight to 6 a.m. (57); the policy officially repealed in 2021 with unsuccessful effects, but it shows the authoritarian view of pupils, which ignores their human rights (58).

In addition, families, schools, and society condemn “examinees” enjoying cultural contents, such as K-POP (59), webtoons, web novels (*websoseol*), animé and *manhwa* (comics), and cosplay (60), because they oppose instrumentality of life (56). Indeed, some hook songs are called as a prohibited song for *sunwng*. Certainly, many pupils deviate from the prescribed meaning (56:21) and objectivity, but then their families and authorities punish them, forcing them to “stay still” until they graduate high school.

Moreover, some researchers even connect (social) communication with friends or using smartphones to “depression and suicidality” (61) because they reduce the time which is not related to “productive behavior”: Learning, eating, and sleeping are only allowed in high school period. This is the modernistic, and authoritarian viewpoint of life, and it has value for criticism in social studies.

The harsh education environment puts teenagers under utmost stress, which induces anger and rage (62, 63). In addition, many pupils construct a negative view of the society and the education system, which increases their rage (64).

Many Korean pupils in secondary education schools have extensive learning time, and, to them, a confrontational strategy by pupils is considered a sin; they are eager to search for objects to relieve stress, and it is bullying because it is the easiest way to relieve stress. This is the point that is usually overlooked in the (autistic) life experience of people in Korea.

2.2 Relationship between bullying and stigma in autistic people

As mentioned in the introduction, there is a strong link between autism and bullying, and the severity of the emotional impact has been documented in numerous studies (65). Hence, why is bullying so prevalent against autistic people? To find out the connection between bullying and autistic people, we want to take back from the notion of stigma, which has been confirmed by Erving Goffman (66), and the theme of this special issue.

Goffman’s concept of stigma is often understood to be limited to the phenomenon of discrimination itself, which occurs because a person with a disability has certain “attributes” that are understood by society as “stigma” and because the members of the society notice those traits (66). However, if we re-read Goffman’s discussion, we can see that the stigma phenomenon is a social construction that is shaped first and foremost by a society’s cultural system and its power system.

According to Goffman, stigma is only constructed through communication with others. For example, a person with disability who does not go to school may be protected by his/her family

(66:33). Police officers, on the other hand, can identify suspicious people by sight and use techniques such as framing and blackmail to incriminate them (66:75–76). Social stigmas, especially those imposed on people without disabilities, can be removed when the members of the society who knew them do not exist when they succeed in fleeing from their communities. Therefore, Stigmas can be reinterpreted as being formed when peers or communities find a reason to harm a person and then harass them for it, and the group accepts and shares this collective memory.

An important point is that stigma closely influences and is influenced by collective empathy (67) and operates particularly strongly where it is imbued with prescribed social meanings (68). For example, one might compare who is more actively engaged in society today, between contemporary people with disabilities and those of the "enlightenment era," where, as Foucault pointed out, the body was domesticated as a docile body, controlled by the power (69), and the society and intellectuals were controlled (70) to drive social progress. It should also not be denied that this exclusion was deeply connected to social evolutionary theory and eugenics, which sought to separate the "abnormal" from the "normal" to develop a "healthy" society (71).

From the late 19th century to the mid-20th century, American society, at the height of its modernity, had a policy of only accepting immigrants whose bodies and behavior did not exhibit "signs" that could be interpreted as stigma (72) to keep "unhealthy" outsiders out, and these noticing people were everywhere, spying on audiences at the entrances of theaters and shops and arbitrarily removing them (66:70). At the same time, the United States had a policy of thoroughly objectifying Black people (73): The effects of this racism continue to stress Black people in American society today (74).

Understanding this historical context, therefore, reveals that stigma is not expressed by the individual with stigma but by others who are "enabled" to read the individual's difference as an impairment and interpret it as a disability. This fact supports the social model of disability and, at the same time, challenges the medical model of disability, which is the dominant ideology through which autism is perceived.

Autistic people are officially represented as "persons with autism spectrum disorder" (24), which suggests that they are in disordered (therefore, that is out of the "order") status (75). The diagnostic criteria for this abnormality include intense interest and an inability to respond to "Social-emotional" communication and combines visual information other than speech (24). However, the diagnostic criterion is not fair, because the criteria are clinical views and prescribed from non-autistic perspectives such as the theory of mind or eye contact (25, 76), far from the social model of disability.

For example, the DEP by Milton (19) suggests that the social initiative problems of autistic people are not created because the autistic trait is not a deficiency of social communication abilities, but allistic (or neurotypical) people are unable to communicate in the autistic or neurodivergent communication system (77, 78). There is evidence supporting the DEP that shows that groups with and without autism have the same degree of social communication in each group (79–82).

However, because the way that autistic people communicate is different from what society has constructed, neurotypicals soon discover autistic people despite their masking strategy (83, 84), and these differences become a major reason for people without disabilities to withdraw from relationships with autistic people. Unfortunately, Goffman finds that discrimination based on difference is not only perpetuated by people with disabilities but also by various other stigmas of the time. According to Goffman, some people with disabilities could only exist in "public" as minstrels or clowns, and they were "encouraged to have a distaste for those of his fellows … without actually making a secret of their stigma … to show that despite appearances they are very sane, gentlemen deviants, nice persons like ourselves despite the reputation of their kind" (66:110–111). Those who ignore this "air" (85) and enter the space of the "normal" are subjected to the gaze of exclusion, and the stigmatized person is required to exist in a space where the "normal" is unable to see them (66:119-121).

Of all the ways that peers reject this "notification," violence is the most efficient, leaving an indelible mark on the victim while benefiting the perpetrator. Autistic people are less likely to have adequate coping skills for bullying (86), so pranks may be escalated to the point where they become gaslighted. Therefore, bullying and peer rejection of communication are risks that should be actively controlled, as they not only prevent well-meaning social communication initiatives in adolescent autistic people but also increase stress and the likelihood of psychiatric complications (65, 87).

However, we find indifference and lack of action on the part of educational authorities toward bullying against autistic people and the absence of sufficient methodologies for dealing with bullying. Here, we can find a system of stigmatization through bullying that prevents autistic people from participating in society. Autistic people who enter the secondary education system become targets of bullying because of their autistic behavior to regulate their stress or intense interest—neurodivergent expression. As the bullying continues, autistic people are disrupted from learning necessary for tertiary education and may end up being segregated in special classes or special schools, or they are forced to endure the violence on an ongoing basis. As a result, school violence against autistic people can be interpreted as being used as a tool to visualize or justify the stigmatization of autistic people.

2.3 Bullying in the law system of the Republic of Korea

School bullying attracted public attention around the turn of the 21st century in Korea. Then, the Act on the Prevention of, and Countermeasures Against, Violence in Schools (hereinafter the School Violence Prevention Act) came into force on 30 July 2004 (88). This act provides that perpetrators shall be subject to various sanctions or countermeasures, ranging from ordering an apology letter to victims to expulsion from schools by the decision of the autonomous committee for countermeasures against school violence (hereinafter the *hakpogwi*) established in individual schools, which is composed of teachers, representatives of parents and other experts. Such sanctions are supposed to deter school bullying because they may be recorded in the school performance record of the perpetrator. When school bullying conforms to either crime or juvenile delinquency, perpetrators may be subject to sanctions by the Juvenile Act. All these measures are punishment, which schoolteachers and police are usually reluctant to resort to as punishment for school bullying because it is likely to damage university entrance competition, which parents and children desperately cling to (89). Because of the reluctance of the committee to take appropriate countermeasures against school violence, the reformed School Violence Prevention Act in 2019 transferred the function of the committee to the level of the district office of education. Thereby, the sanction function is supposed to be removed from individual schools. But, still, the principal of the school has the right to close "slight school violence" cases (90, 91).

On the other hand, social welfare measures to prevent school bullying are lacking. Because perpetrators are likely to be victims of child abuse and neglect as well, a child protective agency might intervene to provide appropriate support and counseling to parents and children to prevent and mitigate potential school bullying as the consequent effect of abuse and neglect. However, such interventions are yet to be implemented.

3 Method

3.1 Procedure

To understand the bullying experience of autistic people in Korea, we adopted the focused group interview with ethnographic methodology. All autistic persons who identifies them as autistic, and speaks Korean, regardless of diagnosis, were eligible for participation in this research. Most participants were contacted through advertisements that were distributed in autistic and neurodivergent advocacy groups. Furthermore, we tried to find more potential participants in other areas, through the advertisement to welfare centers, organizations for people with disabilities, and academic associations in Korea.

The research process was designed to be two-step: Participants can select to come to Seoul or connect via an online meeting service, according to their allowance. After getting the informed consent in (electronic) documents, all participants will receive the semi-structured focused group interview, in which two to three autistic persons answer pre-defined and instant questions for 1 h and a half to 2 h. Examples of fixed questions are in Table 1. Then, selected participants who would have resilience or further important testimony move on to another focused interview.

The research could induce some traumatic reactions by the flashback of their bullying memories. Therefore, to verify the ethicality of the research process, the research process got ethical approval from the Institutional Review Board of Hanyang University (Approval No. HYUIRB-202303-005).

Fourteen participants participated in the first round, through three offline interviews and three online interviews. However, after we ended the first round, we found the utterances of participants constituted a theoretical saturation, because the number of participants was over the suggested sample size and the interview results constituted new concepts (92). Therefore, we received revision approval from the Institutional Review Board for closing out the research.

The interview audio files, which were recorded with the consent of participants, were transcribed into Korean, and, then, two reviewers reviewed the transcriptions independently, according to the triangulation methodology (93). Reviewers constantly find the meaning units from the transcriptions and sort them into categories according to their relativeness. The categories and the analysis of each researcher were compared in the meeting of researchers and triangulated with other reviews. After the reviewing, one reviewer compromised it as a document.

After the Korean analysis results were out, the results were circulated to participants to confirm the accurate reflection of their own experiences. All participants agreed to the results, with some edit requests. The request was applied to the result of this article.

3.2 Participants

Fourteen autistic persons gave researchers documented consent to participate in the research. The demographic characteristics of the participants are shown in Table 2.

All participants reported their autistic identity. However, only four persons were regarded as "people with autism spectrum disorder" by the Korean government, which is due to the rigid medical criteria of the Korean national disability registration system (94). Rather, more participants were self-diagnosed persons because they are unable to get a diagnosis for several reasons.

To secure the anonymity of the participants, we randomized each person's number in the following results.

4 Results

The results have been summarized into five general themes. These are (1) mainstream society that draws the line at outsiders; (2) surviving alone on the edge of school violence; (3) autistic traits

TABLE 1 Excerption of fixed interview questions.

- Exposure to violence and schooling experiences in secondary education
  - How did you feel when you first went to school?
  - Do you remember the first time you were exposed to school violence?
  - Do you remember any words from the other pupils?
  - What other challenges did you face in school?
- Coping with bullying
  - How did you deal with stress at that time?
  - Have you ever told a teacher or family member about bullying, and what was their reaction?
  - Did you have opportunities to consult about your bullying and school life?
  - Have you ever used a program such as "Letters to and from" or "Wee class" and what was your experience?
- Desire for support for bullying
  - What did you want most when you were a victim of bullying?
  - Based on experience, what interventions are needed for autistic students who are still experiencing bullying?
- What does secondary education mean to you?
  - What is the significance of secondary education in your life?
  - Where would you go if you had to go back and choose between a special school and a mainstream school?
  - What do you think where is the best school for autistic people?

TABLE 2 Demographic characteristics.

Categories	M or N (SD or %)
Age (n = 14)	30.29 (6.27)
Gender (women)	4 (28.6%)
Race/ethnicity	
Korean	14 (100%)
Education status	
Dropout of high school	1 (7.1%)
High school graduated	3 (21.3%)
University student	2 (14.2%)
Bachelor's degree	7 (50.0%)
Graduated school student	1 (7.1%)
Disability registration to the Korean government	
Autistic persons with ASD registration	4 (28.6%)
Autistic persons with mental disability registration	2 (14.3%)
Autistic persons without recognition	8 (57.1%)

as a playing object in malicious play; (4) bullying grows out of ableism and an authoritarian environment; and (5) the suggestions from personal experience.

The participants described their bullying experiences as struggling to survive on the fringes of the school system and enduring physical and verbal abuse such as bullying, ignoring, ostracizing, ridiculing, and teasing from mainstream social groups who drew the line to them as outsiders.

For them, school is a horrific hell, a traumatic space that gives them nightmares: They became toys for malicious play just because they "have autism." Participants found that the perpetuation of bullying in schools is fed by the nourishment of ableism, meritocracy, and authoritarianism, which suggests that bullying experience intertwines with meritocracy and authoritarianism in mainstream society. Concretely, in secondary schools, mediocracy is supported by schools, which routinized corporal punishment and gives impunity to perpetrators who are stronger than victims. Furthermore, schools had an authoritarian social culture that found problems in the victim rather than the perpetrator. The Summarized results are in Table 3.

4.1 Mainstream society draws the line at outsiders

Participants in the research remembered that the first thing that came to mind in their bullying experiences was people who labeled them as disabled. They recalled that they started to recognize their disability when they were called "mentally weak, sickly, and disabled", were ridiculed, and were ostracized by those who labeled them. As a result of this ridicule, teasing, and harassment, the research participants cognized that they were outsiders who could not be included in mainstream social groups. They remembered the experience that started in elementary school, and, as they moved to middle and high school, the level and methods of bullying became more intelligent and sophisticated.

For the study participants, bullying was explored as a never-ending nightmare that continued uninterrupted from elementary school to middle school to high school. Most of the participants in the study experienced verbal abuse from the mainstream social group as early as elementary school:

> "I got the most bullying in middle school. I cannot stop the list of them, let's just take one. When I went somewhere, they teased me by saying *byeongtta*. The meaning is stupid (*byeongsin*)—outcasted (*wangtta*). They teased me using those words." (P7)

The verbal abuse signals the notification of difference: "You are not like us." The attack fulfilled the role that ostracizes the outsider who cannot be included in the mainstream social group. Through the signal and ostracism, the study participants felt that they became passive recipients of warnings from the mainstream social group rather than they could find their identity. They also found that they were "trapped in a caged structure" where their disability was constantly recognized and confirmed by others and outsiders.

In addition, participants reported that perpetrators stressed their inferiority to perpetrate violence against them.

> "During the higher grades in elementary school, my father passed away. [peers] said, 'Did you have a father?'. Every year, I experienced school bullying, from the first day to the last day of school." (P9)

Their utterances further include not being able to go to university (P8) and having a smaller body size, showing the underlying logic of inferiority. It is also closely linked to what mainstream social groups consider to be the social markers of success, such as doing well in school, being physically superior, or coming from a rich or high–social status family.

Finally, they experienced ableism constantly throughout their schooling. Even when they talked about their hopes and dreams, like going to the Military Academy, mainstream social groups made fun of them or dismissed them as the future jobless, because of their disability. The participants described themselves as the oppressed person who had to live with disability hatred in the culture of mainstream social groups.

4.2 Surviving alone on the edge of school violence

Participants described that they survived alone on the fringes of school violence. They did not have any power to stop bullying against them. Moreover, participants could not have comfortable experiences, because some parents bothered them even in the family (P6), forcing them to survive: Their coping way was imagining a bleak future for the bullies (P3) or imagining a hero to save them.

> "Passing middle school period, what I desired was a hero. One of my desires was it. I wanted to become a member of the hero narrative, to rescue myself in this status: A prince. The prince. That prince, I always have had an imagination that superhero save me." (P13)

However, the hardest thing was the school: They thought the school itself was problematic. Schools were busy trying to please the mainstream social groups by giving lenient punishments to the bullying perpetrators while viewing victims as pitiful people with disabilities. They felt no advocacy system in the school could speak for them.

> "In an elementary school, there was a system of 'praise point passbooks.' [One day the teacher] openly gave them +20 points just because they have been continuing their friendship with me." (P2)

In addition, the clumsy intervention by teachers against the bullying made hostile relationships with peers and autistic pupils (P2 and P6). They felt that the school administration dealing with bullying was just for show, and there were no schools that advocated for victims, only problematic schools existed.

> "I was pushed to the TV cabinet and just kept being punched in the head and the forearms, and I was almost beaten to death with one punch, and that was before the summer holidays of my first year. As the punching continued, my homeroom teacher and their homeroom teacher came, and their teacher punished them. Even though their teacher was expected not to give them a grade, the teacher just made them clean the classroom for a week, and the next year they were in the same class as me." (P3)

The main reason for the forced survival of study participants was there was no advocate for them during their lives: neither in school nor in the family. In other words, they were forced to survive on the edges of school violence due to the absence of an advocacy system.

4.3 Autistic traits as a playing object in malicious play

Participants found that their traits were objectified and instrumentalized for bullying perpetrators' malicious play, along with full teasing and ridicule with stigmatizing labels such as "mentally ill," "sick," and "disabled," which came from the mainstream community. They remember that they lived with the bullying at schools every day: Some of the perpetrators even invaded their own houses.

> "[The perpetrators] came to my house, what were they doing in my house?…If I upload that to SNS like Twitter, if they do like this, they will be ostracized almost. It's a hamster, before me, they throw my hamster heavily, to kill [my hamster], not in their house, but in my house." (P1)

Some of the most difficult memories of bullying for participants were times when they were instrumentalized by perpetrators. Perpetrators utilize stimming behaviors, literal understanding of meaning, intense interests, obsessive-compulsive behaviors, and different sensories, which are part of the autistic traits (95, 96), as a trigger for bullying.

> "When I and my peers go somewhere, or I buy *tteokbokki* for them, then we get along anywhere. Let's take an example. If the friend said to me: 'How's using this big bear doll instead of the umbrella?' Then, I waded outside hugging the bear during huge rain." (P5)
> "There is a memory in elementary school, I just sat on my chair and kept writing sketchbook-like notes with strange figures and numbers. Then, they got the note and teased me [viewing the note]." (P2)
> "Usually, kids have a way of understanding things like reading atmosphere or context. And they could notice differences between jokes and truth. But I couldn't do that, that point made me the object of bullying when I was in elementary school." (P12)

Perpetrators treated participants as punching bags, playthings, and emotional outlets for their play or playfulness. They described being treated as puppets or seen as someone who deserved to be hit or sexually harassed (P12) because they were different. Moreover, these experiences were associated with social withdrawal, difficulty in interacting with people and maintaining trusting relationships.

> "[They] were making fun of me by drawing me as the subject of obscene graffiti, and when I made bad feelings, they got violent and punched me in the face. Someone who did not know how to control his/her sexual impulses embarrassed a classmate, and I got punched in the face, and from that, that's when most of the boys started using me as a punching bag." (P13)

This bullying pattern was important because it highlights how autistic people are perceived. When bullying perpetrators belonging to mainstream social groups treat autistic people as emotionless, objects of amusement, or instrumentalized them, it is more than an individual aberration. The undermining of the dignity of autistic individuals and their objectification as instruments of malicious play is a point where the fundamental problem of school education in Korean society is rooted, meaning that a more macro-level approach in a social structural context should be required.

Perpetrators of bullying from mainstream social groups were armed with a justification for the violence that they were different from the rest of the community. The difference is an instrument of violence against the research participants.

4.4 Bullying grows from ableism and an authoritarian environment

The social context of the participants' experiences of bullying was two axes: (a) meritocracy and (b) authoritarianism.

First, study participants described that, during the coping process, they experienced unfairness, including being treated as idiots by their classmates or teachers protecting the perpetrators. They cited the entrance examination–orientated education system as the reason for the school culture that produces school violence. Influenced by the Korean social climate that favors and respects meritocracy, teachers regard students who score well as model students, and they may not have deviant actions or cause trouble but disregard those who are not good at studying. Therefore, the natural perpetrators of bullying are those who study well and are more respected than the victims of bullying who do not study well, which blocks the victims from receiving adequate support from bullying.

> "The teachers took the perpetrators' side, because the victim did not study well, and the perpetrator was a model pupil." (P6)

Participants experienced bullying, were ridiculed, and were physically abused in a cultural climate that stigmatizes those who do not get good points as "stupid" (P10) due to the mainstream social mechanisms that have formed social standards and indicators in the center of those who succeed in elite universities. Moreover, one participant was scolded because they wept, which used to be prohibited in the Confucius society.

> "I cried a lot, a lot more than other students of my age: there were so many things to cry about. And then other teachers or my parents would take it very badly, and they would give me orders, instructions, to be more mature because I wasn't mature enough." (P13)

However, participants mentioned that their bullying experience was due to the CSAT-oriented Korean education system, where all pupils experienced CSAT stress and therefore used themselves as an outlet for entrance examination stress. This suggests that school violence is parasitic and reproduced by the nourishment of meritocracy among mainstream social groups. Participants perceived that, because the Korean society climate supports the logic of going to an elite university to become a successful person, the perpetrators, who are unable to resist this logic and are suppressed and controlled at home and school, instrumentalize bullying by targeting their autistic classmates as the victim to relieve their stress.

Second, participants pointed out the authoritarian social culture of Korea that justified corporal punishment (97) and inhumane communication at secondary schools, which international law prohibits (98). Participants reported that the school culture and atmosphere, which justifies corporal punishment for students, gives perpetrators of school violence a justification for their bullying.

> "It was a time when there was corporal punishment and all that kind of stuff, so it wasn't strange for violence in schools and its spaces to take place. So, it's kind of a cheesy thing to say. What are kids going to learn from that?" (P2)

The research participant referred to these behaviors as a microcosm of the society. This attitude was also reflected at home, where family members blamed the research participant, who was a victim of bullying, for the cause of bullying.

> "They didn't believe it, because they said that students who are good at studying never bully others. And when I talked about my bullying, everybody blamed me: they weren't blaming the perpetrators." (P13)

This phenomenon of placing the blame on the victim rather than the perpetrator was explored as a parasitic effect of the Korean society's authoritarian culture, in which the strong are empowered and recognized (P6). Participants thought that the prevalence of corporal punishment and control over the people of the nation during the Korean authoritarian governments became the soil of reproduction of bullying in the Korean society. In addition, they referred to the social viewpoint that dismisses bullying as fun, and mainstream social groups that assume that those who could not study well or were weak were looked down upon and trampled upon. Whoever's exam results are not good or weak, they are likely to be bullied.

> "Adults said that they were just having fun with me because they wanted to play. They're having fun, so why am I not happy? So, if I don't like it, who am I to judge them? It was my thought." (P4)

4.5 Suggestions from the experience

During the interview, participants suggested some coping methodologies: (a) strengthen the legal system, (b) increase disability sensitivity among mainstream social groups, (c) establish an autistic-centered self-advocacy system, and (d) establish a counseling system by professionals.

First, participants wanted to change the legal system regarding school bullying. Participants stressed that a current weak punishment system for bullying sends the message to perpetrators: "You can deal them with anything" (P13). They feared that the allowance of school gives legitimacy and perpetuates bullying. Therefore, they want strong punishments for perpetrators of bullying and to separate victims from the perpetrators, when the event is detected.

> "Even when the *hakpogwi* was called, the [punishment] in the school remained as education volunteering, one week of classroom cleaning, writing apology letters, and making apologies in the document. If the countermeasures against school violence had been fortified the same as now, teachers would have received a disciplinary measure for the concealment [of bullying], and [perpetrators] would have gotten additional punishment." (P3)

Moreover, they suspect that the Korean social climate does not favor confidentiality for those who report bullying. There is a report that teachers made public the bullying report to the class through homeroom time (P7). Therefore, they requested confidentiality for those who report bullying and a system to prevent victims from committing suicide. The system would be accomplished by thoroughly separating perpetrators and victims of bullying, but they did not experience that kind of help during their secondary education period (P13).

Second, participants mentioned how schoolteachers intervened by asking the mainstream community to pity students with disabilities (P7): They suggested enhancing disability acceptance among the mainstream community to decrease school violence. This is a point that is closely related to the mainstream community's inadequacy of education for autistic people.

In addition, the disability sensitivity of mainstream social groups should be raised, and schools should play a role as a support system for service programs such as social skills training and dialogue training for situations where autistic people have difficulty communicating with people without disabilities. Participants in the study wanted a diverse school where they could feel empowered and had an advocate on their side.

Third, research participants identified the need for a person-centered self-advocacy system as a response and solution to bullying. Participants mentioned the need for a support system for undocumented people with neurodivergence (P3), a self-advocacy support system to empower them (P14), access to specialized services to support their difficulties in communicating with allistic people (P1 and P3), an emotional community to connect with people, and a diverse school system to empower them.

Finally, participants in the study mentioned a specialist-based counseling support system on school violence. They mentioned the Wee class, an education program for separating bullied students in other classes could not help because it caused side effects such as stigmatization (P6). Therefore, they need support from the perspective of the victims: They reckoned that psychiatrists with expertise in neurodiversity would help, rather than psychological counselors.

In addition, they reported the mental trauma caused by school bullying is extremely painful due to avoidance of interpersonal relationships, schizophrenia, and depression (P4, P8, P9, and P14). It was explored that the establishment of a counseling system centered on experts is also necessary in terms of preventing these problems.

> "I don't even like to be around people because I don't have any good memories of synergy with people, so I can't fit into society and now I'm almost like a *hikikomori*, and now I'm studying for my GED. I meet people, but if I meet them publicly, I don't meet them privately, so honestly, I feel comfortable with that." (P9)

5 Discussion

The results are consistent with the findings of the literature review on bullying against autistic persons to which this study was pre-referenced, thus reaffirming the objectivity of the result.

First, the root cause of the bullying was autistic traits. Autistic behavior was perceived as odd because it deviated from the highly structured rules required in the high-contextual Korean society. Korean society, along with other East Asian countries (99), values the collective identity (37, 67) and has a high tendency to downplay behaviors that are visibly different from mainstream groups, influenced by allocentrism and self-other similarity (100) and cultural stereotyping (101). Therefore, autistic people have lost their Confucian *raison d'être* and are easily objectified, which further contributes to the stigmatization of autistic people in the Korean society.

It may have a relationship with autistic people's difference in cranial nerves of the brain neurodiversity (18). Some autistic-suggested theories, like the DEP (19) and Monotropism (20), support the theorem of neurodiversity. The problem is that neurodivergent perception and communication approaches and strategies are regarded as an impairment of social communication (24) or the "lack of theory of mind" (25) because they are no need for eye contact between autistic persons (81, 102). Therefore, it is usually considered a rude attitude to Korean allistic persons, which could justify "the correction" to unite autistic people to allistic persons: to keep neuronormality (41).

Second, the findings suggest that school bullying against autistic people is a social product rather than an individual fault. While participants reported trauma from the bullying, they also indicated that the roots of this violence lie in a variety of background factors, including societal discrimination against autistic traits, competitive schooling, and violence by schools (98). However, the Korean School Violence Prevention Act focuses on redressing school violence instead of preventing it and punishing perpetrators instead of providing relief to victims of school violence. In addition, the Ministry of Education has excluded pupils with disabilities who attend mainstream classes from the policy targets of the Comprehensive Plan for the Protection of Human Rights of Students with Disabilities released in 2018 (103). Therefore, the Korean government and society are also responsible for the prevalence of school violence against autistic people.

Third, there is a need to develop a distinct approach to autistic people outside of the Korean welfare system. In Korea, social services for developmental disabilities are provided for focusing on persons with intellectual disabilities, and there is still a lack of awareness about the bullying experiences and domestic abuse experienced by autistic people. However, it is known that the stigmatizing and traumatic effects of bullying have a profound impact on the lives of autistic people in the transition period, such as tertiary education and adulthood (104). Therefore, there is a need for a distinct policy outside the developmental disability frame, such as bullying of autistic and neurodivergent people who are excluded from registration. Moreover, Ministries of Education should develop education policies to enable autistic students into integrated education using universal designs and an interest-driven education system (105).

The findings also show the counterexample of the stereotypical portrayal of autistic traits. Autistic people are often portrayed as those who lack the theory of mind, do not have emotions, and cannot interact with society (106) because they are locked in their world. However, in the wake of the school violence, they were aware of the social attributes of the bullying, impressing their desire for counseling and improvement of the education system that was failing them.

The result negates previous research on teenage pupils' attitudes toward people with disabilities (107), where classmates expressed more prosocial expression toward autistic pupils as time passed. Moreover, the result shows the negative effect when education authorities have few interventions for allistic persons to accept autistic people and people with disabilities. However, proper interventions for the pupils may make a difference (108). Therefore, education authorities should make methodologies to include autistic pupils in the integrated class, including the initiative of friendship with allistic pupils (109).

There have been some improvements because the researchers and participants were in school. From 2010, corporal punishment by teachers in schools was criminalized by "progressive superintendents" (97), and excessive use of corporal punishment has since been weakened in regulations. In 2021, the Civil Act of Korea was amended to prohibit corporal and emotional punishment at home. However, conservative political parties, media, and NGOs still view the ban on institutional violence in schools as a weakening of their authority and have called for its full reinstatement to increase "study ability" alongside night-time independent study (110). Parents still justify corporal and emotional punishment when they do not feel a sense of parenting efficacy (111). Korean society must recognize this fact: Student violence is reproduced by school violence to reinforce school authority (12).

6 Conclusion

This study reaffirms existing research that impresses bullying against autistic persons, views bullying as a social construction (112), and sheds light on the low quality of life among autistic people in Korea.

In recent years, the airing of *The Glory* (2022) and the continuous revelation of allegations of bullying by children of candidates for high public office have led to a growing social consensus on punishing perpetrators of bullying in Korea. *The Extraordinary Lawyer Woo Young-woo* (2022) also mentioned bullying against autistic pupils through media, which Woo overcame. However, the bullying has been largely excluded from media coverages.

Korean secondary schools, where bullying against autistic persons in Korea mostly happens, promote a "profound" competition to advance to the tertiary education system. In this competition, autistic behavior is arguably redefined by some peers as a stigma rather than a diversity with the acquiescence of some school teachers. As a result, some autistic people remaining in mainstream classes in secondary schools are seen as abnormal; Even many autistic pupils who have attended mainstream classes in primary schools are pushed into special classes or special schools due to school maladjustment and bullying, resulting in the exclusion from education to take the CSAT. From the perspective of autistic people, excessive competition in the Korean secondary education system and school violence might cause irreparable damage to those autistic pupils, their low academic performance, in turn excluding them from post-secondary education and decent jobs (113).

Now we see an increasing number of autistic people entering higher education systems around the world (114), and some autistic experts and scholars are actively engaged in autism research and leading participatory research, as well as a surge in the number of autistic doctors and even psychiatrists (115). In this regard, the interdisciplinary findings of this study, based on the humanities and social sciences, reject the view that school violence against autistic people is fate and logical conclusion caused by their lack of social skills (116). The dehumanization of autistic people is a result of intentional or unintentional discrimination and stigma from society caused by the societal inability to accommodate them. The immediate demands of the study participants, which included the provision of a counseling system for victims of school violence and punishment of perpetrators, are the evidence of such accommodation, and the need for stronger countermeasures against school violence.

Nevertheless, many autistic-related parties stress that there are more important things to the "people with autism spectrum disorder" (117), like 24-h care for "people with severe developmental disabilities" (118); Such argument may block finding social stigma, barricades against autistic and neurodivergent people in the society, and eventually loses reciprocal benefit from an autistic-inclusive society. The result of this study reveals there are much more important problems for autistic people, suggesting further studies to figure out their current quality of life. We hope autism research shift its focus from the medical model of disability, which violates the Convention on the Rights of Persons with Disabilities, to the human rights model of disability (23).

The results also provide several insights for further research. First, the results of the study will justify further research needs on autistic bullying experiences, especially on the autistic person's lived experience outside the European and North American Countries (119) and by Autistic researchers (120, 121). We hope that this article facilitates further representative and comparative studies on Asia and other countries.

TABLE 3 The result from the FGI.

Subject	Sub-category	Meaning unit
Mainstream society draws the line at outsiders	**People who stigmatize**	Being treated like a psychotic Being teased as a *Byeongtta* ("disable-bullied") Become a target of rumored bullying by middle school Teased and ostracized for being disabled
	Logic of inferiority	Assaulted for being an inferior student who could not go to university Beaten because they were dwarfed by their physique Beatings for being disabled and not having a father
	Bullying and harassment based on disability prejudice	Called *aeja* ("disabled") because of low intelligence Ignored by teachers for having a disability, which led to students ignoring them as well
Surviving alone on the edge of school violence	**Surviving 1 day at a time**	Getting through the day without the strength to fight back Imagining a bleak future for the bully Imagining a hero to save me
	Schools in trouble	Teachers looking the allistic pupils A classroom teacher's lack of intervention leads to hostile relationships with classmates Victims of bullying are seen as pitiful person with disabilities School administrative support system that is only display for showing Lenient school punishments for perpetrators of bullying
Autistic traits as a playing object in malicious play	**Instrumentalization by bullies**	Being beated became daily routine I was so ashamed of the way bullies used to harass and placate me A classmate who bullied me in my own home with pride
	Instrumentalization by perpetrators	Being treated as a puppet Being used as a punching bag for my classmates' emotional outbursts Being hit repeatedly for looking up
	The logic of difference is used as a justification for bullying	The stimming becomes an excuse for bullying My unusual hobbies (interests) are used as an excuse for bullying Classmates who exploited my fastidiousness to emotionally abuse me Speaking differently than my peers is used as an excuse for teasing
Bullying grows from ableism and an authoritarian environment	**Bullying as a parasite on meritocratic nourishment**	Schools coddle academic perpetrators Oppressed students in a meritocratic school system use students with disabilities as an outlet for stress Targeted by perpetrators because of their inability to study
	Bullying as a parasite on authoritarian societies	A school culture where corporal punishment is the norm serves as a justification for bullying Older generations dismiss bullying as a prank Mainstream social groups assume that children are victims of bullying because they are unable to study and are weak
Suggestions from the experience	**Strengthening the legal system**	A weak legal system sends the message that "You can deal them with anything" Strong penalties for perpetrators of school violence are important Confidentiality for complainants and suicide prevention systems for victims are needed
	Increase disability sensitivity in mainstream communities	Training on disability sensitivity is needed Strict separation of perpetrators of bullying is important Teachers need to be trained in disability sensitivity Mainstream society needs to be educated on how to deal with people with ASD
	The necessity of the person-centered self-advocacy system	Service and support system for Neurodivergent persons without registration Training programs that give conversations with allistic persons Advocate to stand up for me The emotional community where one connects with other people The diversity-respected school system where I can feel empowered
	Access to a supportive, professionally led counseling system	Reformation of 'Wee project' that supports us from our perspective Need for a psychological counseling support system centered on specialists (psychiatrists) Need for a professional support system to prevent the development of interpersonal avoidance, schizophrenia, and depression due to mental trauma caused by school violence

Next, the study results suggest the connection between school bullying and emotional effects (122) and failure from the social lifecycle path, which is the need for wellness and a high quality of life for each autistic person. For example, Japanese researchers report a connection between autistic traits during *hikikomori* or isolated youth (123, 124), which could be a starting point for a study on the emotional effect of autistic persons with bullying experience.

Third, the results call attention to the relationship between bullying and the deprivation of self-determination rights of persons with an impairment in decision-making ability. "People with developmental disabilities", which 'the Act on Guarantee of Rights of, and Support for Persons With Developmental Disabilities' defines as autistic persons and persons with intellectual disabilities, can be easily placed under guardianship in Korea, which could lead to substituted decision-making (125). School Bullying tends to deteriorate their decision-making ability, making it hard to implement supported decision-making (126). Therefore, we need more research on the effect of school bullying on the decision-making ability of people with developmental disabilities.

Finally, the result urges fast and meaningful policymaking to the (Korean) government, which includes intervention strategies or possible revision of acts to prevent school violence against Koreans with disabilities, especially autistic pupils, according to their expected barriers (127).

The results from this research have some limitations: First, most participants relate to the Korean autistic community, which includes many self-diagnosed autistic persons. Therefore, someone might deny the quality of this research, according to the disability registration system and developmental disabilities dogma prevalent in Korea. However, there was no quality difference between reports from registered and "liminal" autistic persons. The result of the study reaffirms the viewpoint of other researchers on autistic traits and autistic advocators (22, 75, 128, 129) to include "people with social communication" disabilities and other self-diagnosed autistic persons into the whole number of autistic people.

One participant reported bullying at the workplace, which may induce post-traumatic stress (130). They said that workplace bullying was more severe. However, because the research focused on bullying in Korean secondary education, we did not hear the bullying in the transition and adult periods. We hope to continue further studies to fill up the cognitional hole of the unknown: the whole life of Korean autistic people.

As this study was conducted with adults, the length of time between the bullying incident and the interview may raise questions about the reliability of memory recall. However, many participants complimented the objectivity of this research, and the interviewers' comments provided constant reliability. Moreover, the difficulty of recruiting and interviewing adolescents requiring their parents' consent under Korean law and research ethics were factors that led us to limit the study to adults. We hope there will be an additional expansive study, including Korean autistic teenagers and adults under the Korean disability sphere.

Data availability statement

The original contributions presented in the study are included in the article/supplementary material. Further inquiries can be directed to the corresponding authors.

Ethics statement

The studies involving humans were approved by Institutional Review Board of Hanyang University. The studies were conducted in accordance with the local legislation and institutional requirements. The participants provided their written informed consent to participate in this study.

Author contributions

WY: Investigation, Writing – original draft, Writing – review & editing. JS: Investigation, Writing – original draft. CJ: Supervision, Writing – original draft, Writing – review & editing.

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Conflict of interest

The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

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References

1. Olweus D, Limber SP. bullying in school: evaluation and dissemination of the Olweus bullying prevention program. *Am J Orthopsychiatry* (2010) 80(1):124–34. doi: 10.1111/j.1939-0025.2010.01015.x

2. Juvonen J, Graham S. Bullying in schools: the power of bullies and the plight of victims. *Annu Rev Psychol* (2014) 65:159–85. doi: 10.1146/annurev-psych-010213-115030

3. Walton G. The notion of bullying through the lens of foucault and critical theory. *J Educ Thought* (2005) 39(1):55–73.

4. Lunde C, Frisén A. On being victimised by peers in the advent of adolescence: Prospective relationships to objectified body consciousness. *Body Image* (2011) 8 (4):309–14. doi: 10.1016/j.bodyim.2011.04.010

5. Olweus D. *Bullying at School: What we know and what we can do*. Malden: Blackwell (1993).

6. Barral E. *Otaku: les enfants du virtuel*. Paris: Denoël (1999).

7. Triantafyllopoulou P, Clark-Hughes C, Langdon PE. Social media and cyber-bullying in autistic adults. *J Autism Dev Disord* (2022) 52:4966–74. doi: 10.1007/s10803-021-05361-6

8. Wang W, Chen Z, Ding X. Cyberbullying victimisation and disordered eating behaviors: The mediating roles of self-compassion and self-objectification. *Appetite* (2022) 178:106267. doi: 10.1016/j.appet.2022.106267

9. Baldwin JR, Arseneault L, Odgers C, Belsky DW, Matthews T, Ambler A, et al. Childhood bullying victimization and overweight in young adulthood: A cohort study. *Psychosom Med* (2016) 78(9):1094–103. doi: 10.1097/PSY.0000000000000388

10. Chou W, Wang P, Hsiao R, Hu H, Yen C. Role of school bullying involvement in depression, anxiety, suicidality, and low self-esteem among adolescents with high-

functioning autism spectrum disorder. *Front Psychiatry* (2020) 11:9(9). doi: 10.3389/fpsyt.2020.00009

11. Bejerot S, Edgar J, Humble MB. Poor performance in physical education - a risk factor for bully victimization. A case-control study. *Acta Paediatr* (2011) 100(3):413–9. doi: 10.1111/j.1651-2227.2010.02016.x

12. Humphrey N, Lewis S. 'Make me normal': The views and experiences of pupils on the autistic spectrum in mainstream secondary schools. *Autism* (2008) 12(1):23–46. doi: 10.1177/1362361307085267

13. Krieg A, Dickie JR. Attachment and hikikomori: a psychosocial developmental model. *Int J Soc Psychiatry* (2013) 59(1):61–72. doi: 10.1177/0020764011423182

14. Holden R, Mueller J, McGowan J, Sanyal J, Kikoler M, Simonoff E, et al. Investigating bullying as a predictor of suicidality in a clinical sample of adolescents with autism spectrum disorder. *Autism Res* (2020) 13(6):988–97. doi: 10.1002/aur.2292

15. Park I, Gong J, Lyons GL, Hirota T, Takahashi M, Kim B, et al. Prevalence of and factors associated with school bullying in students with autism spectrum disorder: A cross-cultural meta-analysis. *Yonsei Med J* (2020) 61(11):909–22. doi: 10.3349/ymj.2020.61.11.909

16. Maïano C, Normand CL, Salvas M-C, Moullec G, Aimé A. Prevalence of school bullying among youth with autism spectrum disorders: A systematic review and meta-analysis. *Autism Res* (2016) 9(6):601–15. doi: 10.1002/aur.1568

17. Trundle G, Jones KA, Ropar D, Egan V. Prevalence of victimisation in autistic individuals: A systematic review and meta-analysis. *Trauma Violence Abuse* (2023) 24 (4):2282-96. doi: 10.1177/15248380221093689

18. Masataka N. Implications of the idea of neurodiversity for understanding the origins of developmental disorders. *Phys Life Rev* (2017) 20:85–108. doi: 10.1016/j.plrev.2016.11.002

19. Milton DEM. On the ontological status of autism: the 'double empathy problem'. *Disabil Soc* (2012) 27(6):883–7. doi: 10.1080/09687599.2012.710008

20. Murray D, Lesser M, Lawson W. Attention, monotropism and the diagnostic criteria for autism. *Autism* (2005) 9(2):139–56. doi: 10.1177/1362361305051398

21. Lawson A, Beckett AE. The social and human rights models of disability: towards a complementarity thesis. *Int J Hum Rights* (2021) 25(2):348–79. doi: 10.1080/13642987.2020.1783533

22. Dwyer P. The neurodiversity approach(es): what are they and what do they mean for researchers? *Hum Dev* (2022) 66(2):73–92. doi: 10.1159/000523723

23. United Nations. *The Convention on the Rights of Persons with Disabilities: training guide, UN. (HR/P/PT/2019)* (2014). Available at: https://digitallibrary.un.org/record/772770.

24. American Psychiatric Association. *Neurodevelopmental Disorders: Dsm-5® Selections*. Washington, DC: American Psychiatric Publishing (2015).

25. Baron-Cohen S, Leslie AM, Frith U. Does the autistic child have a "theory of mind"? *Cognition* (1985) 21(1):37–46. doi: 10.1016/0010-0277(85)90022-8

26. IACC (Interagency Autism Coordinating Committee). *2017-2018 IACC Autism Spectrum Disorder Research Portfolio Analysis Report*. Bethesda: U.S. Department of Health and Human Service Interagency Autism Coordinating Committee (2021). Available at: https://iacc.hhs.gov/publications/portfolio-analysis/2018/.

27. National Institute of Special Education. *Special School Statistics 2022* (2022). Available at: http://www.nise.go.kr/ebook/site/20220916_132651/ (Accessed July 1, 2023).

28. The Ministry of Employment and Labor. people with disabilities*, e-employment labor index* (2022). Available at: https://eboard.moel.go.kr/indicator/detail?menu_idx=73.

29. Statistics Korea. *Employment rate, jipyonuri (index world)* (2023). Available at: https://www.index.go.kr/unify/idx-info.do?idxCd=4212.

30. Kang D. Why would companies not employ people with disabilities in Korea? *Asia Pacif J Soc Work Dev* (2013) 23(3):222–9. doi: 10.1080/02185385.2013.818202

31. Kim K, Kim D, Shin Y, Yoo D. Social exclusion of people with disabilities in Korea. *Soc Indic Res* (2016) 129:761–73. doi: 10.1007/s11205-015-1123-2

32. Lee H, Lee Y. School bullying and students with autism spectrum disorders. *J Korean Soc Persons Autism* (2013) 13(3):53–80.

33. Lee K, Jung S. School violence experience and coping of students with high functioning autism spectrum disorders in inclusive education environment. *J Korean Soc Integr Med* (2016) 4(3):69–79. doi: 10.15268/KSIM.2016.4.3.069

34. Park I, Lee S. Analysis of bullying experiences and coping process for victimization in students with ASD based on the grounded theory. *J Emot Behav Disord* (2021) 37(1):1–27. doi: 10.33770/JEBD.37.1.1

35. Lee H. An integrated literature review on bullying issues related to students with autism spectrum disorders. *J Korean Soc Persons Autism* (2013) 13(2):89–109.

36. Hwang S, Kim YS, Koh YJ, Leventhal BL. Autism spectrum disorder and school bullying: who is the victim? Who is the perpetrator? *J Autism Dev Disord* (2018) 48:225–38. doi: 10.1007/s10803-017-3285-z

37. Kim D, Pan Y, Park H. High-versus Low-Context culture: A comparison of Chinese, Korean, and American cultures. *Psychol Market* (1998) 15(6):507–21. doi: 10.1002/(SICI)1520-6793(199809)15:6<507::AID-MAR2>3.0.CO;2-A

38. Kwon K. Towards Confucian democratic meritocracy. *Philos Soc Crit* (2020) 46 (9):1053–75. doi: 10.1177/0191453720948376

39. Kwon S, Lee M, Shin D. Educational assessment in the Republic of Korea: lights and shadows of high-stake exam-based education system. *Assess Educ* (2017) 24(1):60–77. doi: 10.1080/0969594X.2015.1074540

40. Hwang Y. Why do South Korean students study hard? Reflections on Paik's study. *Int J Educ Res* (2001) 35(6):609–18. doi: 10.1016/S0883-0355(02)00014-9

41. Mueller L. From neuronormativity to neurodiversity: Changing perspectives on autism. In: Milton D, Ridout S, Martin N, Mills R, Murray D, editors. *The neurodiversity reader*. Shoreham-by-Sea: Pavilion Publishing (2020). p. 94–105.

42. Kim S, Lee J. Private tutoring and demand for education in South Korea. *Econ Dev Cultural Change* (2010) 58(2):259–96. doi: 10.1086/648186

43. Schaub M, Kim H, Jang DH, Baker DP. Policy reformer's dream or nightmare? *Compare* (2020) 50(7):1066–79. doi: 10.1080/03057925.2020.1733797

44. Choi J, Kim B. A qualitative case study on the operational process of night self-study at general high schools. *J Learner Centered Curriculum Instruct* (2017) 17(4):375–403. doi: 10.22251/jlcci.2017.17.4.375

45. Kwon H, Kim N. English-learning students' Perception on the night self-study program at a Korean highschool. *J Educ Res* (2013) 21:45–74.

46. Jeong S, Na E, Kim Y, Suh J, Song C, Jeong D. The analysis of night-time self-study non-participatory students' Time utilization and academic performance. *Korean J Educ Res* (2020) 58(3):171–200. doi: 10.30916/KERA.58.3.171

47. Chae J. The impact of supplemental classed and night self-study in school on academic stress, subjective well-being, runaway from home, and suicidal impulse among high school students. *Korean J Soc Issues* (2008) 9(2):211–32.

48. Han S, Suh H. The effects of shadow education on high school students' creative thinking and academic achievement in mathematics: the case of the Republic of Korea. *Educ Stud* (2023) 49(2):314–33. doi: 10.1080/03055698.2020.1850427

49. Statistics Korea. *The result from 2022 elementary · middle · high personal education fee survey* (2023). Available at: https://kostat.go.kr/board.es?mid=a10301070100&bid=245&act=view&list_no=424071.

50. Finch J, Kim S. Thinking locally, acting globally: redefining traditions at the Korean Minjok leadership academy. *Korean Stud* (2009) 33:124–49. doi: 10.1353/ks.0.0028

51. Joo S, Shin C, Kim J, Yi H, Ahn Y, Park M, et al. Prevalence and correlates of excessive daytime sleepiness in high school students in Korea. *Psychiatry Clin Neurosci* (2005) 59(4):433–40. doi: 10.1111/j.1440-1819.2005.01396.x

52. Jeong J. The justice theory of N-po age and their efforts in the hell-Joseon. *Moonhwagwahak* (2016) 86:132–54. Available at: https://www.dbpia.co.kr/journal/articleDetail?nodeId=NODE06715957

53. Jung H. How cram schools perpetuate the cycle of poverty in South Korea. *The International Young Researchers' Conference, 2021* (2021) 10:16~17. doi: 10.34614/iyrc2021f22

54. Yang S, Cha H. Retrospective cohort study on Korean adolescents' sleep, depression, school adjustment, and life satisfaction. *Nurs Health Sci* (2018) 20 (4):422–30. doi: 10.1111/nhs.12425

55. Ford DR. Arrhythmanalysis and revolutionary rupture of dėtournement: lefebvre and the pedagogical rhythms of post-fordism. *Postdigit Sci Educ* (2023) 5:440–54. doi: 10.1007/s42438-021-00285-x

56. Stevens Q. *The Ludic City: Exploring the Potential of Public Spaces*. Abingdon-on-Thames: Routledge (2007).

57. Lee C, Kim H, Hong A. Ex-post evaluation of illegalizing juvenile online game after midnight: A case of shutdown policy in South Korea. *Telemat Inf* (2017) 34 (8):1597–606. doi: 10.1016/j.tele.2017.07.006

58. Choi J, Cho H, Lee S, Kim J, Park EC. Effect of the online game shutdown policy on internet use, internet addiction, and sleeping hours in Korean adolescents. *J Adolesc Health* (2018) 62(5):548–55. doi: 10.1016/j.jadohealth.2017.11.291

59. Han Y. Community of new taste: idol-fandom recognition struggle. *Humanit Contents* (2022) 67:127–47. doi: 10.18658/humancon.2022.12.127

60. Kim H. *Narrative Inquiry on Scientifically Gifted Elementary School Students' Loneliness, Dissertation for Cheongju National University of Education* (2015). Available at: http://www.riss.kr/link?id=T13837822.

61. Seo JH, Kim JH, Yang KI, Hong SB. Late use of electronic media and its association with sleep, depression, and suicidality among Korean adolescents. *Sleep Med* (2017) 29:76–80. doi: 10.1016/j.sleep.2016.06.022

62. Okayasu T, Takayama I. Psychological stress of victims and bullies in junior high school. *J Educ Psychol* (2000) 48(4):410–21. doi: 10.5926/jjep1953.48.4_410

63. Leung C, To H. The relationship between stress and bullying among secondary school students. *New Horizons Educ* (2009) 57(1):33–42.

64. Lee Y. The learning culture of Korean juveniles in the education system of competitive entrance examination. *Sociol Educ* (2000) 12(1):135–71.

65. Hamilton LD, Newman ML, Delville CL, Delville Y. Physiological stress response of young adults exposed to bullying during adolescence. *Physiol Behav* (2008) 95 (5):617–24. doi: 10.1016/j.physbeh.2008.09.001

66. Goffman E. *Stigma: Notes on the Management of Spoiled Identity*. New Jersey: Prentice-Hall (1963).

67. Reese G, Rosenmann A, Cameron JE. The interplay between social identities and globalization. In: *The Psychology of Globalization: Identity, Ideology, and Action*, vol. 4. Cambridge: Academic Press (2019). p. 71–99. doi: 10.1016/B978-0-12-812109-2.00004-5

68. Bizzari V, Brencio F. Psychiatric diagnosis as a political and social device: Epistemological and historical insights on the role of collective emotions. *Humanistic Psychol* (2022). doi: 10.1037/hum0000307. Advanced online publication.

69. Foucault M. *Discipline and Punish*. New York City: Vintage Books (1979).

70. Stewert D-L. Producing ‘docile bodies’: disciplining citizen-subjects. *Int J Qual Stud Educ* (2017) 30(10):1042–6. doi: 10.1080/09518398.2017.1312598

71. Kim E. *Curative Violence: Rehabilitating Disability, Gender, and Sexuality in Modern Korea*. Durham: Duke University Press (2017).

72. Nielsen KE. *A Disability History of the United States*. Boston: Beacon Press (2013).

73. Wilkerson I. *Caste: The Origins of Our Discontents*. New York City: Random House (2020).

74. Jacob G, Faber SC, Faber N, Bartlett A, Ouimet AJ, Williams MT. A systematic review of black people coping with racism: approaches, analysis, and empowerment. *Perspect psychol Sci* (2023) 18(2):392–415. doi: 10.1177/17456916221100509

75. Pukki H, Bettin J, Outlaw AG, Hennessy J, Brook K, Dekker M, et al. Autistic perspectives on the future of clinical autism research. *Autism Adulthood* (2022) 4 (2):93–101. doi: 10.1089/aut.2022.0017

76. Baron-Cohen S. *Mindblindness: An essay on autism and theory of mind*. Cambridge: MIT Press (1997).

77. Mitchell P, Sheppard E, Cassidy S. Autism and the double empathy problem: Implications for development and mental health. *Br J Dev Psychol* (2021) 39(1):1–18. doi: 10.1111/bjdp.12350

78. Crompton CJ, DeBrabander K, Heasman B, Milton D. and Sasson NJ Double Empathy: Why Autistic People Are Often Misunderstood. *Front Young Minds* (2021) 9:554875. doi: 10.3389/frym.2021.554875

79. Crompton CJ, Ropar D, Evans-Williams CVM, Flynn EG, Fletcher-Watson S. Autistic peer-to-peer information transfer is highly effective. *Autism* (2020) 24 (7):1704~1712. doi: 10.1177/1362361320919286

80. Crompton CJ, Hallett S, Ropar D, Flynn E, Fletcher-Watson S. ‘I never realised everybody felt as happy as I do when I am around autistic people’: A thematic analysis of autistic adults’ relationships with autistic and neurotypical friends and family. *Autism* (2020) 24(6):1438–48. doi: 10.1177/1362361320908976

81. Rifai OM, Fletcher-Watson S, Jiménez-Sánchez L, Crompton CJ. Investigating markers of rapport in autistic and nonautistic interactions. *Autism Adulthood* (2022) 4 (1):3–11. doi: 10.1089/aut.2021.0017

82. Crompton CJ, Sharp M, Axbey H, Fletcher-Watson S, Flynn EG, Ropar D. Neurotype-matching, but not being autistic, influences self and observer ratings of interpersonal rapport. *Front Psychol* (2020) 11:586171. doi: 10.3389/fpsyg.2020.586171

83. Kapp SK, Steward R, Crane L, Elliott D, Elphick C, Pellicano E, et al. ‘People should be allowed to do what they like’: Autistic adults’ views and experiences of stimming. *Autism* (2019) 23(7):1782–92. doi: 10.1177/1362361319829628

84. Miller D, Rees J, Pearson A. "Masking is life": experiences of masking in autistic and nonautistic adults. *Autism Adulthood* (2021) 3(4):330–8. doi: 10.1089/aut.2020.0083

85. Yamamoto S. *Study of Air*. Chiyoda: Bungeishunjū (1977).

86. Rex C, Charlop MH, Spector V. Using video modeling as an anti-bullying intervention for children with autism spectrum disorder. *J Autism Dev Disord* (2018) 48:2701–13. doi: 10.1007/s10803-018-3527-8

87. Konishi C, Hymel S. Bullying and stress in early adolescence: the role of coping and social support. *J Early Adolesc* (2009) 29(3):333–56. doi: 10.1177/0272431608320126

88. Kim N, Oh I. Analysis of stakeholders’ perceptions of zero tolerance policy for school violence in South Korea. *KEDI J Educ Policy* (2017) 14(1):61–78. doi: 10.22804/kjep.2017.14.1.004

89. Kim J-Y. Critical Review of the Act on Prevention of and Measures against School Violence through cases of the court precedent and objection procedure. *Korean Criminol Rev* (2017) 28(4):149–75. Available at: https://www.dbpia.co.kr/journal/articleDetail?nodeId=NODE07295765.

90. Korean Legistration Research Institute. *Act On The Prevention Of And Countermeasures Against Violence In Schools*. Available at: https://elaw.klri.re.kr/kor_service/lawView.do?hseq=55092&lang=ENG.

91. Lee J. Management Plan of the Amended School Violence Prevention Law. *Korean J Criminol* (2020) 32(1):159–91. doi: 10.36999/kjc.2020.32.1.159

92. Low J. A pragmatic definition of the concept of theoretical saturation. *Sociol Focus* (2019) 52(2):131–9. doi: 10.1080/00380237.2018.1544514

93. Santos KDS, Ribeiro MC, Queiroga DEUD, Silva IAPD, Ferreira SMS. The use of multiple triangulations as a validation strategy in a qualitative study. *Ciec Saúde Coletiva* (2020) 25:655–64. doi: 10.1590/1413-81232020252.12302018

94. Kim M, Jung W, Kim SY, Park JH, Shin DW. The Korea national disability registration system. *Epidemiol Health* (2023) 45:e2023053. doi: 10.4178/epih.e2023053

95. Hebron J, Humphrey N. Exposure to bullying among students with autism spectrum conditions: A multi-informant analysis of risk and protective factors. *Autism* (2014) 18(6):618–30. doi: 10.1177/1362361313495965

96. Murray D, Milton D, Green J, Berboets J. The human spectrum: A phenomenological enquiry within neurodiversity. *Psychopathology* (2023) 56(3):220–30. doi: 10.1159/000526213

97. Higginbotham S. “The cane of love:” Social and cultural reform of corporal punishment in South Korea. *Int Res Scape J* (2014) 1:9. doi: 10.25035/irj.01.01

98. Gershoff ET. School corporal punishment in global perspective: prevalence, outcomes, and efforts at intervention. *Psychol Health Med* (2017) 22(sup1):224–39. doi: 10.1080/13548506.2016.1271955

99. Atherton G, Morimoto Y, Nakashima S, Cross L. Does the study of culture enrich our understanding of autism? A cross-cultural exploration of life on the spectrum in Japan and the west. *J Cross Cultural Psychol* (2023) 54(5):610–34. doi: 10.1177/00220221231169945

100. Kashima Y, Yamaguchi S, Kim U, Choi S-C, Gelfand MJ, Yuki M. Culture, gender, and self: A perspective from individualism-collectivism research. *J Pers Soc Psychol* (1995) 69(5):925–37. doi: 10.1037/0022-3514.69.5.925

101. Cuddy AJ, Fiske ST, Kwan VS, Glick P, Demoulin S, Leyens JP. Stereotype content model across cultures: towards universal similarities and some differences. *Br J Soc Psychol.* (2009) 48(Pt 1)1–33. doi: 10.1348/014466608X314935

102. Senju A, Johnson MH. Atypical eye contact in autism: models, mechanisms and development. *Neurosci Biobehav Rev* (2009) 33(8):1204–14. doi: 10.1016/j.neubiorev.2009.06.001

103. Ministry of Education. *The announce of Comprehensive Plan for the Protection of Human Rights of Students with Disabilities*. Available at: https://www.moe.go.kr/boardCnts/viewRenew.do?boardID=294&levv=0&statusYN=C&s=moe&m=020402&opType=N&boardSeq=76216.

104. Pellicano E, Fatima U, Hall G, Heyworth M, Lawson W, Liley R, et al. A capabilities approach to understanding and supporting autistic adulthood. *Nat Rev Psychol* (2022) 1:624–39. doi: 10.1038/s44159-022-00099-z

105. Humphrey N, Hebron J. Bullying of children and adolescents with autism spectrum conditions: a ‘state of the field’ review. *Int J Inclusive Educ* (2014) 19(8):845–62. doi: 10.1080/13603116.2014.981602

106. Botha M, Dibb B, Frost DM. "Autism is me": an investigation of how autistic individuals make sense of autism and stigma. *Disabil Soc* (2022) 37(3):427–53. doi: 10.1080/09687599.2020.1822782

107. Cook A, Ogden J, Winstone N. The effect of school exposure and personal contact on attitudes towards bullying and autism in schools: A cohort study with a control group. *Autism* (2020) 24(8):2178–89. doi: 10.1177/1362361320937088

108. Reiter S, Vitani T. Inclusion of pupils with autism: the effect of an intervention program on the regular pupils' burnout, attitudes and quality of mediation. *Autism* (2007) 11(4):321–33. doi: 10.1177/1362361307078130

109. Winchell BN, Sreckovic MA, Schultz TR. Preventing bullying and promoting friendship for students with ASD: looking back to move forward. *Educ Training Autism Dev Disabil* (2018) 53(3):243–52.

110. Moon B, McCluskey J. School-based victimization of teachers in Korea: focusing on individual and school characteristics. *J Interpers Violence* (2016) 31 (7):1340–61. doi: 10.1177/0886260514564156

111. Hong K, Ahn H, Kim H. Influence of parenting self-efficacy and belief in corporal punishment on physical abuse of children in Korea. *Korean J Child Health Nurs* (2004) 10(4):479–87.

112. Morton HE. Assessment of bullying in autism spectrum disorder: systematic review of methodologies and participant characteristics. *Rev J Autism Dev Disord* (2021) 8:482–97. doi: 10.1007/s40489-020-00232-9

113. Chiang HM, Cheung YK, Hickson L, Xiang R, Tsai LY. Predictive factors of participation in postsecondary education for high school leavers with autism. *J Autism Dev Disord* (2012) 42:685–96. doi: 10.1007/s10803-011-1297-7

114. Nuske A, Rillota F, Bellon M. Transition to Higher Education for students with Autism: A systemic Literature Review. *J Diversity Higher Educ* (2019) 12(3):280–95. doi: 10.1037/dhe0000108

115. McCowan S, Shaw SCK, Doherty M, Grosjean B, Blank P, Kinnear M. A full CIRCLE: inclusion of autistic doctors in the Royal College Of Psychiatrists’ values and Equality Action Plan. *Br J Psychiatry* (2022) 221:371–3. doi: 10.1192/bjp.2022.14

116. Sterzing PR, Shattuck PT, Narendorf SC, Wagner M, Cooper BP. Bullying Involvement and Autism Spectrum Disorders: Prevalence and Correlates of Bullying Involvement Among Adolescents With an Autism Spectrum Disorder. *Arch Pediatr Adolesc Med* (2012) 166(11):1058–64. doi: 10.1001/archpediatrics.2012.790

117. Lord C, Charman T, Havdahl A, Carbone P, Anagnostou E, Boyd B, et al. The Lancet Commission on the future of care and clinical research in autism. *Lancet* (2022) 399(10321):271–334. doi: 10.1016/S0140-6736(21)01541-5

118. Hwang J. How must we prepare in the next decades when caring for those with developmental disabilities: “Grown up” (2018). *Soa Chongsonyon Chongsin Uihak* (2022) 33(2):55–6. doi: 10.5765/jkacap.220007

119. Zhang H, Chen C. “They just want us to exist as a trash can”: parents of children with autism spectrum disorder and their perspectives to school-based bullying victimization. *Contemp School Psychol* (2023) 27:8–18. doi: 10.1007/s40688-021-00392-3

120. Gibbs V, Pellicano E. ‘Maybe we just seem like easy targets’: A qualitative analysis of autistic adults’ experiences of interpersonal violence. *Autism* (2023) 27 (7):2021–34. doi: 10.1177/13623613221150375

121. Pearson A, Rose K, Rees J. ‘I felt like I deserved it because I was autistic’: Understanding the impact of interpersonal victimisation in the lives of autistic people. *Autism* (2023) 27(2):500–11. doi: 10.1177/13623613221104546

122. Stanyon D, Yamasaki S, Ando S, Endo K, Nakanishi M, Kiyono T, et al. The role of bullying victimization in the pathway between autistic traits and psychotic experiences in adolescence: Data from the Tokyo Teen Cohort study. *Schizophr Res* (2022) 239:111–5. doi: 10.1016/j.schres.2021.11.015

123. Katsuki R, Tateno M, Kubo H, Kurahara K, Hayakawa K, Kuwano N, et al. Autism spectrum conditions in hikikomori: A pilot case-control study. *Psychiatry Clin Neurosci* (2020) 74(12):652–8. doi: 10.1111/pcn.13154

124. Shimono Y, Hasegawa A, Tsuchihara K, Tanaka K, Matsuda Y, Kunisato Y. Longitudinal association between autistic traits and affinity for hikikomori in Japanese university students. *Curr Psychol* (2022) 41:8842–9. doi: 10.1007/s12144-020-01287-x

125. Yoon T. A study on effectiveness of cancellation right on the acts of vulnerable adult. *J Comp Priv Law* (2019) 26(2):43–75. doi: 10.22922/jcpl.26.2.201906.43

126. Kim MO, Park JH, Jung MA. Supported decision making experiences for people with developmental disabilities in rehabilitation center. *J Disabil welf* (2020) 50:169–97. doi: 10.22779/kadw.2020.50.50.169

127. Horgan F, Kenny N, Flynn P. A systematic review of the experiences of autistic young people enrolled in mainstream second-level (post-primary) schools. *Autism* (2023) 27(2):526–38. doi: 10.1177/13623613221105089

128. Sarrett JC. Biocertification and neurodiversity: the role and implications of self-diagnosis in autistic communities. *Neuroethics* (2016) 9:23–36. doi: 10.1007/s12152-016-9247-x

129. Park-Cardoso J, da Silva APS. Insistence on sameness for food space appropriation: An exploratory study on Brazilians with autism (self-)diagnosis in adulthood. *Autism* (2023) 27(4):938–51. doi: 10.1177/13623613221121417

130. Tehrani N. Bullying: a source of chronic post traumatic stress? *Br J Guidance Counsel* (2004) 32(3):357–66. doi: 10.1080/03069880410001727567

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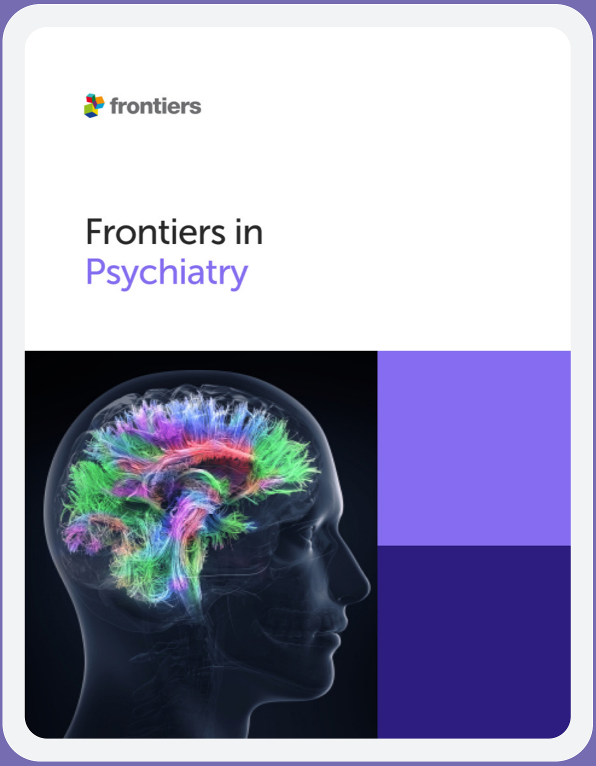

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