frontiers | Frontiers in Education

ORIGINAL RESEARCH
published: 09 June 2022
doi: 10.3389/feduc.2022.867964

# The Inclusion of Children on the Autism Spectrum in the Design of Learning Technologies: A Small-Scale Exploration of Adults' Perspectives

**Bryan Boyle[1]* and Inmaculada Arnedillo-Sanchez[2]**

*[1] Department of Occupational Science and Occupational Therapy, University College Cork, Cork, Ireland, [2] School of Computer Science and Statistics, Trinity College Dublin, Dublin, Ireland*

This research explores the inclusion of children on the autism spectrum in the design of educational technology from the perspectives of adult co-designers. A group of five non-verbal children with a diagnosis of autism participated in a series of four design workshops over the course of 6 weeks. Using a participatory design approach, a small team of three teachers and two technology developers worked alongside the children to design a language development and literacy app for use in a special education classroom. The outcome of this process was a stand-alone education app that comprised many of the contributions made by children during the workshops. The inclusion of children with autism in technology design ensures the end-product reflects their education needs and requirements. Using a qualitative approach, this small-scale study sought to examine the participation of children with autism through the various stages of the design process from the perspectives of their teachers and technology designers. Data were collected through individual interviews and a focus group with teachers and technology designers. Three major themes emerged from thematic analysis: (1) valuing contribution; (2) the challenge of listening; and (3) ownership in outcome. Emerging subthemes highlight challenges described by teachers and designers in facilitating and maintaining meaningful participation in design activities and their efforts to address these. Findings emphasise the value of participation while questioning participatory practices for specific phases of design. The study explores the challenges of equalising power between adults and children with autism in participatory design projects. It uncovers tension between the desire to ensure the authentic participation of children with autism where communication and engagement is significantly compromised by the complexity of their disability. The small number of participants and the modest scope of this design project limit the generalisability of the findings. However, it points to the value of recognising children's contributions and the importance of striving to incorporate these in the final design artefact.

**Keywords: autism spectrum disorder, co-design, participatory design, learning technologies, disability**

**Edited by:**
*Fleur Heleen Boot,*
*Radboud University Nijmegen Medical Centre, Netherlands*

**Reviewed by:**
*Sofia Mavropoulou,*
*Queensland University of Technology, Australia*
*Sheila L. Macrine,*
*University of Massachusetts Dartmouth, United States*

***Correspondence:**
*Bryan Boyle*
*bryan.boyle@ucc.ie*

**Specialty section:**
*This article was submitted to Digital Learning Innovations, a section of the journal Frontiers in Education*

**Received:** *01 February 2022*
**Accepted:** *05 May 2022*
**Published:** *09 June 2022*

**Citation:**
*Boyle B and Arnedillo-Sanchez I (2022) The Inclusion of Children on the Autism Spectrum in the Design of Learning Technologies: A Small-Scale Exploration of Adults' Perspectives. Front. Educ. 7:867964. doi: 10.3389/feduc.2022.867964*

# INTRODUCTION

Autism Spectrum Disorder (ASD) is not a single disorder but a cluster of closely related disorders that share a common characteristics. It is considered a lifelong, neurodevelopmental disability and is characterised by the presence of persistent deficits in three core areas of functioning: social interaction; communication skills; and the presence of fixed or repetitive behaviours (Syriopoulou-Delli and Papaefstathiou, 2019). Autism, as it manifests in a child's social-communication skills and behaviours, is highly individualised and heterogeneous with symptoms presenting in a wide array of combinations and ranges of severity (American Psychiatric Association, 2013). There is a high degree of variability between those diagnosed with symptoms presenting across a broad range of severity. For instance, some children diagnosed with ASD may have above-average cognitive and verbal abilities. However, others may have profound deficits in behaviour, cognitive and language skills with the presence of psychiatric and medical comorbidities impacting significantly on their functioning and participation. Thus, some diagnosed with ASD can lead independent lives while others may see their quality of life and that of their families and communities significantly impacted (Howlin et al., 2004, 2013; Farley et al., 2009). As our understanding of autism as a spectrum conditions increases so does the debate concerning how best to refer to people with a diagnosis of autism. To this end while most adults prefer to be referred to as "autistic people", term most commonly used amongst health and education professionals is "children/people with autism" (Kenny et al., 2016). There is also a growing movement aiming to recognise autism as a human trait or characteristic equivalent to colour, ethnicity or sexual orientation. The "neurodiversity movement", as it has been referred to, aims to remove what is seen as "medical model" labels that serve to discriminate against and stigmatize people (Leadbitter et al., 2021).

Defined as a disability it's characterised by significant limitations in both intellectual functioning and in adaptive behaviour, which covers many everyday social and practical skills (Schalock et al., 2010). The heterogeneity of presentation of autism complicates the study of its diagnosis, prognosis and treatment interventions (Georgiades et al., 2013) and, it challenges researchers to devise methodologies that can match a diverse range of needs and preferences. For children with ASD a common comorbid condition is Intellectual Disability (ID). As many as 50–70% children with ASD also have intellectual disabilities, compromising their social, communication, cognitive, and adaptive skills (Matson and Shoemaker, 2009). This impacts their abilities to participate in research activities (Coons and Watson, 2013). One of the core features of ASD: impairment of communication; has a significant effect on a child's ability to partake in activities requiring face-to-face collaboration with others. Although deficits in language skills are not universal in autism, they are found in the majority of children with the disorder (Kjelgaard and Tager-Flusberg, 2001).

The potential technology can offer to support developmental, educational or therapeutic interventions for autistic children has been highlighted in the literature (Valencia et al., 2019). Previous studies have documented the efforts made by professionals to actively exploit the potential technology has to offer children facing the challenges posed by a disability such as autism to support education (Knight et al., 2013), development (Martolia and Gupta, 2020) and participation (O'Neill et al., 2017). Researchers, parents, teachers and others involved in supporting children on the autism spectrum increasingly recognise the potential computer-technology offers as an effective and efficient tool in research, education and treatment (Ploog et al., 2013). Research highlights the value of technology in areas including: communication (Logan et al., 2017), sharing interests with others (Kamps et al., 2015), self-regulation (Picard, 2009), and developing a sense of personal competence (Rapp et al., 2018). To this end, technology has demonstrated beneficial outcomes for children with autism in better understanding and recognising emotions and feelings (Schuller et al., 2013), developing cognitive flexibility (Pascualvaca et al., 1998), expressive and receptive vocabulary (Ploog et al., 2013), and reducing repetitive behaviours (Odom et al., 2003; Boyd et al., 2012). Applications focused on addressing key deficit areas for children with autism include improving communication skills (Bosseler and Massaro, 2003; Hetzroni and Tannous, 2004; Schlosser and Wendt, 2008; Hailpern et al., 2009), empathy and emotion recognition (Moore et al., 2005; Fabri et al., 2007), and social-interaction skills (Mesa-Gresa et al., 2018).

Designers of technology for children on the autism spectrum are challenged by several factors: (1) the heterogeneous nature and presentation of the condition; (2) the evolving, developmental nature of the disability (DiCicco-Bloom et al., 2006); and (3) the challenge presented by children with ASD in generalizing skills learnt using technology to naturalistic environments (Parsons et al., 2011). An increased recognition of the benefits that can be accrued from well-designed, purposeful technology for autistic people has led researchers and designers to explore the use of design methodologies that focus on reflecting inclusivity in their unique and individual needs in the final design outcome. In particular, there has been an increased recognition of the value of involving the child with ASD in the design process both, in terms of the outcomes of design and proving children with a feeling of ownership over the final product (van Rijn and Stappers, 2008; Frauenberger et al., 2011; Benton et al., 2014). A clear motivation for the active inclusion of children with autism in technology design is to ensure that the end-product accurately reflects the expressed needs and requirements of the child. It is anticipated that the needs of the child participating in the design process is representative of a broader population of children with similar needs and thus, the final design product will accurately reflect their collective needs. Including the proposed user of the eventual design outcome, offers the opportunity to build a technology based on real needs rather than assumptions. Thus, ensuring a higher chance of creating a successful and useful product.

Designing with children with autism is not a straightforward process. Typical design processes involve identifying the needs, demands, and opinions of users and often depend on interviews and discussion. The underlying assumption is that the representative user is both willing and able to communicate freely and transfer knowledge and opinion (Herriott, 2015). Efforts have been made to develop techniques and process to support designers in working with children with autism. Researchers have drawn on participatory design (PD) practice to inform bespoke methods for working with and including children with autism in design. Examples include work by Benton et al. (2012, 2014) in developing the IDEAS method and the D4D model. Further techniques and methods have been developed by Frauenberger et al. (2010) and Makhaeva et al. (2016). However, many such approaches continue to rely on verbal communication with and between participants throughout the various design phases.

In many situations, designers will depend on "proxy participation" relying on the knowledge and authority of other adults such as parents, teachers or other personnel (Boyd-Graber et al., 2006; Shen et al., 2016). The use of proxies, as an alternative to using challenging or difficult to access populations in user-centred design research, is not new and in some instances children themselves have been employed as proxies in design processes (Metatla et al., 2020). For instance, designers have sought to use neurotypical children as proxies to represent children with autism in design and development (Sofian et al., 2021).

Although the use of proxies may offer much to designers in terms of convenience, devolving decision making to an adult proxy is certainly problematic in terms of ensuring that there is a somewhat equitable distribution of power across the design team. The combination of lack of clarity regarding their role, unequal power relationships, difficulty in communicating ideas, and dealing with adults in a largely unfamiliar context present challenges requiring a balanced and empathetic approach (Frauenberger et al., 2011). In studies involving children with autism, adults familiar with participating children are often looked to support the decision making processes (Boyd-Graber et al., 2006; Boyle and Arnedillo-Sánchez, 2016; Shen et al., 2016). When designing with young children from populations where communication disabilities are common (e.g., autism), it is perhaps to be expected that designers will rely on feedback from proxies, such as parents, teachers, and care workers (Hamidi et al., 2017). An example of this can be found where researchers worked closely with a non-verbal autistic child and his mother during the development of an assistive communication app (Agarwal et al., 2013). Here, it is arguable that the mother plays both the role of proxy and user, as is often the case in such situations where it is reported that a parent will typically advocate on behalf of and otherwise represent their non-verbal child (Herriott, 2015). The advantage of such approach is that a proxy with sufficient knowledge of the child will be well-placed to recognise and convey the child's unique requirements. While research has shown agreement between proxy and self-responses in a research setting (e.g., Schmidt, 2014), little work has been done to explore the role of proxies in design studies (Boyle and Arnedillo-Sánchez, 2016). It is more common for researchers to consult with carers and family members because they prefer proxies who have most familiarity with the participants, even if this does come at the cost of specialist scientific knowledge of the participants' disability (Robb et al., 2021). Another approach, adopted by Boyd-Graber et al. (2006), involved using subject area experts such as Speech and Language Pathologists as proxies due to their familiarity with the child and their condition.

The aim of this research was to examine the perspectives of novice, adult designers who were tasked with collaboratively designing a learning technology with children on the autism spectrum. The study focussed on exploring their own participation in a design project and the roles and responsibilities they assumed in order to successfully complete the assigned design tasks. Furthermore, the research aimed to explore their perceptions of how the participation of children with complex communication and comprehension needs evolved through the various phases of a typical software design lifecycle.

## METHODOLOGY

Exploratory research is conducted when a problem or phenomenon has heretofore attracted little attention or study and describes "a broad ranging, purposive, systematic undertaking to maximize the discovery of generalizations leading to a description and understanding of an area of social or psychological life" (Stebbins, 2001, p. 3). Researchers explore in order to discover new knowledge about a group, process or situation. Qualitative methods for research in technology design have increased in popularity due to their suitability to capture the situated experience of those designing and, or using technology. The purpose of exploratory research enquiry is to find what is occurring in an area with little understanding, to seek new insights, to assess phenomena in a new light and to generate ideas and hypotheses for new research.

With a focus on the experiences of adult participants in a design project and their reflections of the participation of children on the autism spectrum, this study drew upon Grounded Theory to inform the theoretical sampling, systematic data collection practices and the use of multiple data sources until saturation was determined to have been achieved (Corbin and Strauss, 2012).

### The Co-design Process

This study took place at the Al Noor Centre in the State of Qatar. It is part of a larger study aimed at supporting the work of the Institute's team of Speech and Language Therapists (SLT) by assisting in the design of software resources to support the development and practice of prescribed, pre-verbal social interaction skills. Such a clinical focus would be typical of the therapeutic work SLTs provide to children with a range of complex disabilities. The overarching ambition was to install and make available the developed resources as an integrated virtual-learning environment providing technology enhanced, education and therapy opportunities for children availing of the centre's services. During the initial planning for this design project it was agreed that some of the children from the school would participate in the design of the technology they would eventually use in the school. Two mixed gender classes of children aged between 8 and 12 years were selected for participation in the design project. Only five, of the 15 children registered in both classes, were available to participate in the design project. The remaining seven children were not available to participate fully in all three workshops because of illness, absences from school or scheduling difficulties with other appointments such as on-going blocks of Speech and Language Therapy. Four male with a chronological age ranging from 8 to 11 years and a 10 year old female were participated in all the design workshops. All children had a diagnosis of ASD as confirmed by their school records.

A series of four collaborative workshops were designed to support two volunteer Computer Science students to design a software application to support letter identification and matching sounds with images of common objects. The volunteer students were recruited from a programme at a local University and took the role of "designers" for the project. They were tasked with developing and testing a prototype software application that met the requirements of the teachers involved and matched the needs of the children with autism that would use the software application. The teachers were tasked with supporting the designers through the process and ensuring the active participation of the children in all the workshops' activities.

Drawn from a similar theoretical and historical background as user-centred design, participatory design (PD) seeks to ensure that the prospective technology end-user is not just the focus of the design process but also an active contributor right through the process. PD offers designers a methodology for accessing the experience, needs, tacit knowledge and preferences of participants and seeks to bring this to bear on the design process. PD has increased in popularity in a range of research disciplines including human computer interaction, information systems and more recently the design of technology solutions for children with disabilities. The diversification in application of PD reflects recent, rapid technology developments across various domains and contexts (Halskov and Hansen, 2015). Within the context of this research, PD was adopted as the framework to support the active participation of children. The four collaborative workshops encompassed all the phases of the software design process but had different focus and objectives. Workshop one was structured to facilitate the gathering of user requirements data through observation, class based discussion and collaborative engagement in tasks with all of the children. Workshop two focussed on co-creating design artefacts with the children to incorporate these into the software design. Participating adults supported each child to engage in creative activities to generate audio and visual artefacts that could inform the design of the first proto-type. Activities during workshop two comprised drawing, colouring and sound recording with participating children using a range of supportive technologies and techniques. Workshop three focussed on the designers presenting a low-fidelity paper proto-type of the proposed visual interface for the software. During this workshop the adults presented the lo-fidelity proto-type to the children and gathered their reactions to the various elements of the proto-type and recorded their likes and dislikes to revise the design incorporating children's opinions. Workshop four focussed on presenting a fully functional prototype to the children and involved adults supporting the children testing the prototype and sharing feedback.

## Ethical Considerations

A strict ethics protocol was developed collaboratively by both institutional parties participating in the study. Ethical approval was obtained from the Research Department at the Mada Qatar Assistive Technology Centre and from the Ethics Committee at the School of Computer Science and Statistics, Trinity College Dublin. Informed consent was obtained for all participants in both the design project and this research study prior to the commencement of the design workshops. The parents of children participating in the design workshops were provided with a written brief of the project, the implications of their children's participation and were informed of their right to withdraw their child at any time. The adult participants were also informed of the implications of their participation, the data management procedures that would be followed and their right to withdraw at any stage.

## Participants and Sampling

Morse (2015) stresses that determining an appropriate sample size for any study requires consideration of a broad range of factors including, but not restricted to: the topic under examination, the study design, the quantity and quality of the data gathered and the analysis conducted by the researcher. Due to the embedded nature of this study within a larger technology design project, participant selection was conducted using purposive, convenience sampling (Etikan et al., 2016; Creswell and Plano Clark, 2017). Participants were purposively selected for this study as they were considered to possess the knowledge and experience under investigation. Furthermore, the participants could be considered a "convenience" sample in that they were accessible to the researchers, they were involved in the broader project activities and were willing to participate in this study.

The characteristics of those involved across the larger project were such that they brought a range of perspectives and experience to the design process and their involvement was such that they were considered to have gained a degree of insight that would facilitate their reflective contributions to this study.

All five participants were actively involved across all design workshops previously described and had the opportunity to observe and support the participation of children with autism across all design activities. Of the five participants, two were teachers, both female, and worked full-time in a special education centre. Both participating female teachers had over 5 years' experience working directly with children with autism. The remaining male participant had 2 years' experience working in Special Needs Education and had only transferred to the school in the month previous to the commencement of the project. Teachers participating were aged between 25 and 32 years. The remaining two participants were students enrolled in an Master of Science programme in Computer Science at a local University who had both volunteered to participate as designers in the larger project. They too were involved in the design workshops described here. Both these participants were female aged 22 and

24 years and had no prior experience in software or technology design for children with disabilities and had no experience working directly with children on the autism spectrum.

## Data Collection

This study employed a semi-structured interview protocol designed by the researchers to elicit data from participants at key stages through the design process. This process allowed study participants to reflect concurrently on the participation of the children involved in the project through the various design stages.

To design the bespoke interview guide both authors followed the constructivist approach as recommended by Råheim et al. (2016). Thus facilitating the building of relationship between researcher and participants that would ensure the process of eliciting participants' experiences. Interviews were conducted face-to-face on an individual basis at three intervals during the design process. The first took place after the first workshop and the second took place a month later following the conclusion of the third workshop. The final round of interviews with participants was held immediately after the final workshop took place approximately 2 weeks later. Interviews were conducted in English and led by the first author while a research assistant was available throughout to provide Arabic translation support for participants if required. The first author had only limited fluency in Arabic and although all five study participants were bilingual the additional translation support allowed the researcher to understand some of the Arabic language interactions between study participants and the children with autism. All interviews and the focus group were recorded and transcribed immediately by the researcher and a bilingual research assistant.

In conjunction with the semi-structured interviews data was also gathered during a focus group with all participants. This focus group took place approximately one week following the conclusion of the final workshop and prior to the finalisation of the artifact designed. The aim of this focus group was to provide the entire group with an opportunity to reflect on the overall process and to discuss observations made by the researcher during the course of the design process. These observations were posed as open ended questions and aimed to provide an anchor to the emergent discussions. This approach ensured a focus on their experience of the design process was maintained while allowing open ended discussion and equitable opportunities for contribution to participants. The focus group was facilitated by the first author with a bilingual research assistant to support Arabic translation where necessary. The audio of the focus group was recorded in its entirety and was transcribed by the research assistant.

## Data Analysis

Braun and Clarke (2006) argue that thematic analysis is a useful method for examining the perspectives of different research participants, highlighting similarities and differences, and for generating unanticipated insight. Six phases were used to analyse the generated data. These included transcription and familiarisation with the data, generating initial codes, searching for themes, reviewing themes, defining themes and finally, writing the report. Initially the primary author read and re-read transcripts in collaboration with a research assistant fluent in both English and Arabic with a view to fully understanding and gaining familiarity with the transcribed text. A further reading and re-reading of the transcripts was conducted in order to identify initial codes. During this stage the interview transcripts and those from the focus group were examined separately. Following completion of coding of all relevant data, both the primary author and research assistant independently reviewed and analysed coded data by combining and collapsing multiple codes with a view to generating initial themes. Consideration was given to the iterative nature of the study and how participants' expressions of their experiences changed from the initial interview through to final focus group. Emergent codes were further analysed by both authors and a set of themes were then extracted and named through further review of the original data and through detailed discussion. Finally, the emergent themes and sub-themes were presented in an appropriate format for reporting.

## Trustworthiness and Rigor

The nature of the study ensured that the first author spent time in close proximity with participants as the design cycle unfolded (Elo et al., 2014). The iterative data gathering process described here provided opportunities for participants to reflect on the preceding rounds of data gathering and included a final session that involved peer debriefing for participants to ensure a further perspective on gathered data was possible (Nowell et al., 2017). A final process of member checking through the data analysis was not possible in this study as the two student volunteers were no longer available to the researchers following the conclusion of the design project.

Efforts made to ensure the validity of the results of this study required prolonged engagement with all data gathered to ensure accuracy and saturation (Houghton et al., 2013; Creswell, 2018). Furthermore efforts were made to triangulate the various data gathered and a data audit trail including records of the data, field notes, transcripts and generated design content was compiled through the study to ensure dependability.

# RESULTS

The analysis of all transcribed field notes, design content generated by participating children, interviews and focus group yielded a number of themes and subthemes that are outlined in **Table 1** below and in through subsequent sections.

## Valuing Contribution

The first theme emerging, "valuing contribution" reflects efforts by the adult participants to actively encourage the contributions of children with autism participating in the various workshops and design activities. Two subthemes were identified that describe how adults participating alongside the children sought to uncover meaning in the children's contributions and sought to understand these as representations of their lived experience.

**TABLE 1** | Summary of themes and subthemes extracted.

| Themes | Subthemes |
|---|---|
| (1) Valuing contribution | (i) Uncovering meaning<br>(ii) Design contributions as representations of participants |
| (2) The challenge of listening | |
| (3) Ownership in outcome | (i) How successful design equates with a need to communicate ownership<br>(ii) Collective ownership of the eventual design outcome |

## Uncovering Meaning

It was interesting to note how the two participating designers made every effort to uncover meaning from the contributions of participating children. They expressed a sense of obligation as designers to seek meaning in the drawings, sketches and sound recordings and spoke of how their discussions as designers focussed on inferring meaning from these.

This sense of obligation may have emerged from an increasing awareness on the part of the two designers that supporting co-creation for children with autism was not a straightforward process.

"*understanding and figuring it out meant that we had to start and think about the complicated way it was made, sometimes with a computer, sometimes with help, maybe with both, but everytime, making even a colour swatch was not straightforward.*"

The process of inference and meaning making that they reported required deliberate consideration of the context in which each child's contribution was created and how it was created. There was a clear sense that the contribution of each child could not be understood without understanding the process by which the child created it.

"*. . .I feel very strongly that each of these little things that were made represented the child's communication, something they wanted to say but couldn't and we had to try and see what that was, or no-one would know.*"

The children's teachers referred to themselves as "translators", aiding in the process of deciphering meaning, answering the designers' questions, drawing on their knowledge of each child to assist in elaborating meaning in contributions. Teachers did, particularly during the early stages of the design process, question the designers' need to understand the meaning of children's contributions. In some instances tried to gauge or speculate as to the children comprehension of the design process; "*did they know*" or if they fully understood the purpose of the activities they were engaged in. It did, however, appear that as the process continued and as both designers and teachers worked collaboratively to interpret and attribute meaning to the visual and auditory elements generated by the participating children.

It was evident, however, that despite their endeavours to attribute meaning to each of the children's contributions, the designers in this study did find the process challenging and somewhat beyond their expertise and experience. They both articulated how their participation in the co-design workshops and in seeking feedback on the first prototype made them aware of their own lack of expertise and experience working with and alongside children with significant communication challenges. Both designers highlighted their lack of experience as a limiting factor in the design process rather than questioning the suitability of including children with autism as design participants or partners.

## Design Contributions as Representations of the Participant

The value designers and teachers attributed to children's contributions was also demonstrated by their willingness to incorporate these into the overall design of the software under development. This was also evident in how the efforts to integrate these into the design changed how adult participants saw the design as representing the children.

During the early phases of the design process, participating teachers expressed a scepticism that designers' efforts to build an understanding of the children and their needs could be translated into a software solution. Through their reporting the teachers positioned themselves as the most valuable source for understanding the needs of the participating children. They cast doubts on how the various visual images generated during the second workshop in particular could be incorporated into the design, expressing they would be "*surprised if any or even one of these pictures*" were incorporated into the software design. However, this changed as the process progressed and in particular during workshop three when both designers presented a series of screenshots representing their ideas for the final software interface. Following this workshop, one of the teachers remarked that "*it was amazing what they did, really, we couldn't imagine how they did that*". Presentation of these prototype visual interfaces were instrumental in highlighting for teachers the value brought by the designers to the overall process.

Despite the challenges, both designers demonstrated a determination to incorporate as many of the visual and auditory expressions available to them. They described how they sought to incorporate the visual images and audio available to them in three ways. Firstly, to make use of the contributions as "design elements" such as, incorporating images created by children into the graphical interface as a background image or incorporated in another image. Secondly, they spoke of "*disassembling*" the children's contribution and sometimes taking a shape or colour or sound and using this in the design. Finally, they referred to a process of using the available contributions to guide their creativity as they worked to construct their prototype design:

> "*sometimes, it was looking at these pictures and images that were not clear to us in what they meant, but instead they were just like our inspiration, you know.*"

During the course of their elaboration on their efforts to incorporate individual children's visual and audio contributions, both designers described how it ensured that the eventual design outcome would represent the children participating both individually and collectively. They spoke of their role as designers changing from depending on traditional creativity to:

> "*making sure that I used the materials given to me by the children creatively.*"

Even though teachers were initially unsure whether it was possible to include children's contributions in the design outcome, they subsequently found their engagement with the designers helpful in understanding the mechanics of design. Therefore, they reported a residual sense that the efforts by the designers to incorporate children's generated design contributions may not be fully appreciated by the children themselves due to the limitations in their understanding brought on by their diagnosis. As one teacher described it:

> "*I feel it is a pity, I wish that [child] could understand how it is their work now that we can see on the screen and everytime to play with it, how much of him is in it.*"

Expressions of value were apparent in the efforts of both designers but also on the part of the teachers who grew through the process to understand how the creative expressions of children with significant challenges could be transformed into a design solution that meaningfully and sympathetically represented them.

## The Challenge of Listening

The second theme to emerge represents the challenges faced by adults in their efforts to support the participation of children with autism through the various stages of a design process.

The earliest phases of the overall design process were deliberately designed to provide novice designers with opportunities to better understand the requirements of the software to be designed and the needs of the users, namely children with autism, that would eventually use it. The designers participating did not have previous experience working with children with a disability and were unfamiliar with the workings of a Special Education environment. Their initial impressions of the task ahead of them was one of trepidation and a lack of confidence in their own abilities and skills. They felt that their lack of experience and expertise left them ill-equipped to engage with the children or with their teachers. It is unsurprising that what they perceived as their "*equipment*", the traditional tools of dialogue, questioning and observation were not suited to the group they were working with and did not serve to support them in identifying user-requirements that would underpin the software design.

"*nothing had prepared us for being in that classroom, I did not know what to say, when to speak, who to speak to or even when I was in the wrong place sometimes, after one day in the classroom I could only thing that we can never do this, no way.*"

All participants recognised the value, however, in spending time getting to know each other and getting to know the children in the class. Furthermore, there was a clear sense of the importance of understanding the space that the children inhabited and where technology fitted into the routine of the classroom. These early interactions were characterised by a sense of being overwhelmed on the part of the designers, and of the teachers being unsure as to what exactly their role was and how best they could support the children in getting to know the new people in the classroom.

The designers reported how reliant they were on listening in a traditional design project and how the absence of traditional dialogue between themselves and children who were functionally non-verbal stripped them of this key, operational tool.

Both teachers and the designers participating in this study recognised the need for a process of understanding each other's roles in relation to supporting the participation of children with autism through the design process. Both groups reported how they "*got to know each other*" and "*about each other*" through collaborations that had the participating children at the heart of them. They reported that much of their dialogue during the early stages of the process were focussed on the designers learning about children with autism in the most general terms with teachers reporting that the designers seemed overly concerned with whether or not particular behaviours, needs or characteristics were typical of autism or particular to the child. Teachers felt that in those early phases, the designers were not asking the correct questions and were relying on the teachers to make sense of what they were encountering. For their part the designers did accept that they felt discomfort engaging in conversation with children who were non-verbal which made them turn increasingly to the teachers for interpersonal engagement:

> "*. . .I was just out of my comfort zone and I realised that I needed to hear someone answering me when I was talking to them, I never realised that before, so it was easier just to talk about the children and not to them some of the time.*"

## Ownership in Outcome

The final theme from the data gathered from the adults participating in this study refers to participants' expressions of achievement in the successful generation of a design outcome and how this reflected the contributions of all participants. The teachers and designers reflected at times a pride in completing the design process and a need to appreciate the outcome in terms of what was achieved. An emerging subthemes reflected these by stressing the need to understand the successful outcome of a design process in terms of how invested the participants are in that outcome. A further subtheme reflected how the adults felt that it was not just the contributions of the children that ensured a successful outcome, but an increasing sense of the role they played themselves.

### How Successful Design Equates With a Need to Communicate Ownership

During the final phases of the design process, and particularly once the prototypes had been presented during the third workshop, there was clear increasing trepidation by the teachers and the designers with regard to what a successful outcome would be. Their vision in terms of what constituted a successful design outcome began to emerge during those final weeks where designers were working with the two teachers to understand the feedback they had gathered during the third workshop. The meaning making process they engaged in appeared motivated by their increasing concerns about what the actual outcome of the design would be. These concerns and trepidation suggest a growing investment by the adult participants in the prospective outcome of the design project.

Teachers were concerned about whether it was even possible to transform the information and experience gathered during the workshops into a meaningful software application. There were concerns their original ambitions: a software focus on providing learning opportunities for children with autism; may not be realised. Teachers feared the designers had become more concerned with ensuring the design outcome reflected the contributions of participating children than fulfilling the learning requirements outlined at the initiation of the project:

> "*I like what they have done [first prototype], but it is not like a learning software, I don't want to have this then have to buy other software, that would be a waste of time I think.*"

The designers on the other hand expressed concerns about how their design outcome would be perceived by the children. They expressed worries that the children would not like the software, would be unable to use it or would refuse to use it. Furthermore, it was clear that these concerns extended or accentuated their perceived lack of experience working with children with autism. The participants acting as designers in this project felt that if the software was not accepted or usable by the children, it would amount to failure on their part to successfully translate the contributions available to them into tangible design elements:

> "*I don't think we can make it clear enough, if we cannot show how it is part of them, then no-one will want to use it.*"

During the final phase of the process, particularly after the prototype presentation in workshop three, it emerged designers equated authentic representation of the participating children with their satisfaction of the outcome. To achieve this, they incorporated many visual and auditory elements created by children in workshop two in various elements of the software.

Designers and teachers were further concerned with the need for individual children to recognise their own contribution and the fact that these would not be apparent in the final design. Following the final demonstration of the working software application a designer noted:

> "*I spent the entire time really trying to show every child what they personally contributed and I almost forgot to show anyone how it all worked, I was more worried they wouldn't understand or get what they did.*"

The three designers in this project made it clear that they felt that the success of the design outcome was their responsibility, and they needed to convey their concerns with their lack of experience working with autistic children from the early stages of the project. Whereas the two teachers increasingly emphasised how each designer's knowledge and expertise was growing and expressed satisfaction that their discussions between the third and fourth workshops had a clear focus on what direction their design was taking and why this was this case. In probing the reason why there was such a focus on incorporating children's contributions in the eventual design outcome it was evident that the adult participants had begun to equate these with individual children's sense of ownership of the software application. It appears that both designers and teachers felt that if they could make it clear to children that they had a direct contribution to the software and acknowledge their investment in the process, it would increase ownership of the eventual outcome.

## Collective Ownership of the Design Outcome

All the adults participating in this design project were able to express retrospective satisfaction with the outcome. Overall, designers and teachers described the developed software in positive terms as "very useful" and "successful."

Furthermore, all the participants expressed their participation in the process as "unique," "a privilege," and "a good thing." In particular they highlighted how the collective nature of the activities throughout the process helped them to understand each other and to develop new perspectives. All participants attributed value to "designing together" and articulated they had a collective responsibility to ensure that this included the children as well as themselves. Some of the participants spoke of the challenges in continually checking that they were engaging in practices that encouraged the participation of children across the design activities:

> "*There was no guidelines for it, nothing that we could follow and it was easy sometimes, particularly in the early part, in the class just to forget or ignore the children and to just focus on what we were doing, but we knew we couldn't do that.*"

Study participants described feeling that there were times when they were unsure of the utility of facilitating children's participation in the various design activities. One of the teachers in particular reflected that it would be easier for the designers to simply consult with the teachers considering the marked communication challenges that were faced.

In exploring why all participants felt a responsibility to ensure children's inclusion in the design, both groups reported that they were motivated to do so because they recognised the very real danger that their involvement could not happen without the efforts of the adults in the project. All participants saw their efforts to support children's participation in the design as contributing to the eventual success of the project. Furthermore, they linked the participation of the children, and their efforts to support that, as a key factor in the children using the software application that emerged at the end of the project.

The two participating teachers commented that the process, not only produced a software application that matched their needs but also:

> "*all of the work together seemed to prepare each of the children for what would come at the end of the project, the anticipation made them excited to see it and use it when it came.*"

It was interesting to note, however, that the three designers signalled a disappointment that the satisfaction of the children participating was not as evident as they would have liked. They reflected that as designers they invariably seek affirmation of their work at the end of the process and acknowledged that in design projects with more complex end-users this is something that should not be expected. The two teachers participating also acknowledged this challenge highlighting their own concerns that regardless of the focus on showcasing each child's contribution, communicating such complex concepts in many cases may be beyond the children's understanding. Additionally, they commented on the communication challenges faced by the children in this study and how these impacted both theirs and the designers understanding and appreciation of how; (1) children participating understood their input into the final design, (2) understood how the various prototypes and elements that had been presented in the third workshop were realised as a functioning software application. The teachers suggested their disappointment that the communication challenges reduced the feedback that designers received. They further speculated that this might impact how they perceived the success of the project.

"*it is difficult, because working with children with limited communication you live with uncertainty, but when you put in such effort, you want to feel a clear reward for the effort.*"

For their part the designers indicated that they sought affirmation in their design from observations of the children using it rather than through verbal feedback. One of the designers went as far as to state that watching children use the software was more "a*uthentic*" than relying on more traditional expressions of feedback.

Despite the obvious challenges in communicating their collective appreciation of the design outcome and of each other, the adult participants in this study all suggested that they shared a tacit acknowledgement that the children had enjoyed being part of the design process and that this enjoyment translated into their understanding that it was "their software."

## DISCUSSION

Working with children with complex learning profiles poses a range of methodological, practical and logistical challenges for designers or researchers. The complexity was multiplied in this study by introducing what could be considered "novice designers" who collectively had to develop ways in which they could include children for which traditional forms of discursive engagement are not appropriate in design workshops. Furthermore, these two groups of adult participants had to contend with learning about autism as a condition, what was involved in a typical design process and perhaps most importantly, about each other. Design projects that are characterised as participatory highlight the concept of mutual learning as a core benefit of engaging in such projects (Robertson et al., 2014). Examining the processes of design and the experiences of the participants, it is reasonable to conclude that the design project reported here does indeed reflect many of the traditions and processes usually associated with PD. The exploratory nature of engaging in a design project for all of the participants necessitated the need to learn by doing, adopt creative and collaborative approach to problems that emerged and to foster meaningful communication between the various groupings that comprised the design team (Nesset et al., 2021). In this study, the early phases of the design process were characterised by mutual learning which matured so that the adult participants became increasingly aware of the role they could play in empowering the participating children. This suggests that the process was such that the adults participating in this design project actively shifted their focus from the outcome to the process itself, a characteristic that is inherent in PD (Bossen et al., 2016). As such, empowering the adults in this design to define and creatively shape their own participation and that of the children from one of designing *for* users to designing *with* users.

From a practical perspective, design research is heavily reliant on traditional, discourse based, collaborative data gathering processes such as observation, interviews, focus groups, questionnaires and simulation. For many children with complex disabilities, such as those participating in this study, the high level social and communication skills requires a full engagement with such data collection practices often resulting in researchers modifying and adapting their processes to meet the needs of participants.

It is clear from the study reported here, however, that creating the conditions to allow adult designers to support the participation of children with complex needs does not necessarily lead to successful, empowering and meaningful experiences for children. Both groups of adults were very clear in the early stages of the design of the limits of each other's knowledge and experience, but worked to collaborate to address the challenges that emerged, such as the challenges in understanding what it was that could be contributed by children with autism and how these could be translated into meaningful design contributions that reflected each participant. This combination of a lack of clarity regarding their role, unequal power relationships and difficulty in communicating ideas, is echoed in other design studies with children with autism where a balanced and empathetic approach was the key to its eventual success (Frauenberger et al., 2011). Working with children with atypical communication skills necessitates a complex process of decoding and interpretation by the communication partner (Frauenberger et al., 2010). There was a recognition by all adults that key to including children with autism in the design process was to support their participation in co-creation activities. Seeking understanding and meaning in those contributions and incorporating these into the software design was considered to have the greatest impact on the design. The experiences of those adults participating in this study, however, is similar to that reported elsewhere and attests to the value of such efforts while highlighting the difficulty in implementing this (Frauenberger et al., 2011). Other researchers have also suggested that overcoming these challenges may involve offering children with complex disabilities even greater capacity for participation in design activities, increased opportunities for expression and power in what has been referred to as a design after design approach (Brereton et al., 2015). The potential effectiveness of such iterative approaches are also highlighted elsewhere in studies with children experiencing similar challenges of communication and understanding (Hamidi et al., 2017).

The sense of collective ownership and investment in the final design outcome appears to bear out the assertions made in other studies that highlight the benefits to placing the child with autism at the centre of the design process, in terms of an improvement in the design outcome (Fletcher-Watson, 2014), mutual learning and empowerment (Bell and Davis, 2016).

This research study, by virtue of the needs of the children at its core saw a high degree of involvement by adults. Both categories of adult participants, teachers and designers, varied in their experience and understanding of children with autism, thus presenting an opportunity to conduct a careful examination of how different stakeholders can best support a child with autism in the various activities that comprise a technology design project. Descriptions of the role that adults play supporting children in design are often generic however, what emerged over the course of this research were differences in the role based on each group's knowledge, expertise and skill working with children with autism. By combining two groups of "novice" designers with different backgrounds, expertise and approach the opportunity emerged to examine the relative contribution of both groups.

For designers with limited experience of working with children their responsibility in the early phases of a design project was to: (1) build rapport with participating children, (2) increase their understanding of children's needs and preferences in their own context and (3) organise their emerging understanding within the typical workflow of a design project. In these earliest phases of a project, the responsibility of those adults familiar with participating children was to: (1) ensure the comfort and safety of children was maintained in the midst of the change that was brought about when new people were brought in to their environment, (2) facilitate the building of rapport between children and these new unfamiliar adults and (3) begin a process of establishing the design project as a collective endeavour and to ensure that children were made aware that was happening and the ways in which they would be involved. As designers' understanding of the children's lived experience evolved and enhanced they required opportunities to discuss and reflect on the information that they encountered and relied on the expertise of the participating teachers to assist in the meaning making process. This collaborative meaning making is something that is also evident in other design studies (Scariot et al., 2012). As the design processes transition to the development of potential solutions participating adults play key roles in ensuring children with autism were supported in participating in this development. Those most familiar with children provide: (1) material support (through the provision of suitable technology), (2) physical support (through assisting with activities), cognitive support (by explaining the process and helping to finish activities) and (3) emotional support (through prompting, encouragement, motivation and withdrawal if required).

Finally, a key finding in this work emphasises the importance of creating a culture that supports the participation of children with autism; through valuing the contributions of children and respecting their decision making by creatively examining ways in which these can be represented in the final design outcome. For adults that seek to support and facilitate the participation of children with autism both in design projects and potentially beyond these, a key part of their role is to harness children's strengths and abilities and provide the required support that each child needs to participate to their full potential. This remains an area that would benefit from greater exploration. Bringing a broader range of perspectives across different experience with more experienced practitioners would add significant value to the existing knowledge in this area.

## LIMITATIONS

The modest scale and limited sample size represented in this study should be acknowledged. The nature of the conditions that presented to the authors was such that the design project in its entirety was conducted in a single location, in a single class with the staff and children usually located or situated in that class. By their nature, special education classes tend to be smaller than those in mainstream education settings with a high staff to student ratio. During the preparation for this study consideration was given to including children from different classes from the Centre. This was quickly ruled out following discussions with the school staff as it was felt that asking children who required consistency of routine to be expected to work with unfamiliar children and staff would be unfair and ultimately disruptive for them.

The numbers of adults participating in this study are small, as such it must be stressed that the findings presented here reflect the contributions of only five adults. The number is, however, reflective of many small-scale design projects that occur within organisations and learning institutions for children with autism where resources are often scare and innovation is sought from within (Lorenzo and Lorenzo, 2018). Similarly, the limited representation of the typical staff that would work alongside children in a Centre such as this were not included in this particular study as they participated in some of the other design activities and workshops that were being carried out as a series of events. Future studies should seek to capture a broader range of perspectives including those of therapists and healthcare practitioners, those involved in non-formal caring roles and children's parents and primary care-givers.

## CONCLUSION

This study, while recognising the size and scale of the design project reported here offers some new insights as to the experiences of adults serving both as active co-designers and facilitators for children with autism presenting with complex communication and cognitive needs. The themes that emerged from the analysis of data point to the motivation to engage with children with complex disabilities and ensure their active participation by focussing on: (1) developing a shared understanding of their lived experience, (2) supporting their capacity to contribute media and content to the overall design, and (3) ensuring that every effort was made to represent these contributions in the eventual design. The engaged and collaborative nature of the design process also contributed to a final, collective sense of ownership in the final outcome of the design and the reflections by the adult participants that the overall project was a success.

## DATA AVAILABILITY STATEMENT

The datasets presented in this article are not readily available because all original (anonymised) data has been retained in a secure online location as per the conditions of the Ethics Approval provided. No provision was made and no approval was granted to make the data available in an accessible public repository. Requests to access the datasets should be directed to BB, bryan.boyle@ucc.ie.

## ETHICS STATEMENT

The studies involving human participants were reviewed and approved by Trinity College Dublin, Department of Computer Science and Statistics Research Ethics Committee. Written informed consent to participate in this study was provided by the participants' legal guardian/next of kin.

## AUTHOR CONTRIBUTIONS

BB responsible for the day to day management of the project and for collecting, transcribing, and managing the data gathered. IA-S provided support through the analysis phase of this study and guided the BB's overall analysis and synthesis. BB contributed to led the authorship of the manuscript with the guidance of IA-S. BB and IA-S took responsibility for the overall design of this study and put in place the necessary framework for the execution of the project, were involved in applying for and obtaining the ethical approval from the host institution and the IA-S's University Ethics Committee, contributed to the article, and approved the submitted version.

## FUNDING

This research was supported by funding from the charity RESPECT and the People Programme (Marie Curie Actions) of the European Union's Seventh Framework Programme (FP7/2007-2013) under REA grant agreement no. PCOFUND-GA-2013-608728.

## ACKNOWLEDGMENTS

We thank the staff and children of the Al Noor Centre, Qatar for all their support and participation throughout these design studies.

## REFERENCES

Agarwal, R., Sampath, H. A., and Indurkhya, B. (2013). "A usability study on natural interaction devices with ASD children," in *Lecture Notes in Computer Science (including subseries Lecture Notes in Artificial Intelligence and Lecture Notes in Bioinformatics)*, eds C. Stephanidis, and M. Antona (Berlin: Springer).

American Psychiatric Association (2013). *American Psychiatric Association, 2013. Diagnostic and Statistical Manual of Mental Disorders*, 5th Edn. Washington, DC: APA.

Bell, A., and Davis, K. (2016). "Learning through participatory design," in *Proceedings of the 15th International Conference on Interaction Design and Children - IDC '16*, (New York, NY: ACM Press).

Benton, L., Johnson, H., Ashwin, E., Brosnan, M., and Grawemeyer, B. (2012). "Developing IDEAS: supporting children with autism within a participatory design team," in *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems*, (New York, NY).

Benton, L., Vasalou, A., Khaled, R., Johnson, H., and Gooch, D. (2014). "Diversity for design: a framework for involving neurodiverse children in the technology design process," in *Proceedings of the 32nd Annu ACM Conf Hum Factors Comput Syst - CHI '14*, (New York, NY: ACM).

Bosseler, A., and Massaro, D. W. (2003). Development and evaluation of a computer-animated tutor for vocabulary and language learning in children with Autism. *J Autism Dev Disord.* 33, 653–672. doi: 10.1023/b:jadd.0000006002.82367.4f

Bossen, C., Dindler, C., and Iversen, O. S. (2016). "Evaluation in participatory design: a literature survey," in *Proceedings of the 14th Participatory Design Conference: Full Papers*, (New York, NY: Association for Computing Machinery).

Boyd, B. A., McDonough, S. G., and Bodfish, J. W. (2012). Evidence-based behavioral interventions for repetitive behaviors in autism. *J. Autism Dev. Disord.* 42, 1236–1248. doi: 10.1007/s10803-011-1284-z

Boyd-Graber, J., Nikolova, S., Moffatt, K., Kin, K., Lee, J., Mackey, L., et al. (2006). Participatory design with proxies: developing a Desktop-PDA system to support people with aphasia. *Computer-Hum. Interact.* 2006, 151–160.

Boyle, B., and Arnedillo-Sánchez, I. (2016). "Exploring the role of adults in participatory design for children on the autism spectrum bt - design, user experience, and usability: design thinking and methods: 5th international conference, DUXU, held as part of HCI international 2016, Toronto, CA," in *Design, User Experience, and Usability: Design Thinking and Methods DUXU 2016 Lecture Notes in Computer Science*, ed. A. Marcus (Cham: Springer International Publishing).

Braun, V., and Clarke, V. (2006). Using thematic analysis in psychology. *Qual. Res. Psychol.* 3, 77–101. doi: 10.1191/1478088706qp063oa

Brereton, M., Sitbon, L., Abdullah, M. H. L., Vanderberg, M., and Koplick, S. (2015). Design after design to bridge between people living with cognitive or sensory impairments, their friends and proxies. *CoDesign* 11, 4–20. doi: 10.1080/15710882.2015.1009471

Coons, K., and Watson, S. (2013). Conducting research with individuals who have intellectual disabilities: ethical and practical implications for qualitative research. *J. Dev. Disabil.* 19, 14–24.

Corbin, J., and Strauss, A. (2012). *Basics of Qualitative Research: Techniques and Procedures for Developing Grounded Theory*. 3rd Edn. Los Angeles, CA: Sage Publications.

Creswell, J. D. (2018). *Research Design*, 5Th Edn. Thousand Oaks, CA: SAGE.

Creswell, J. W., and Plano Clark, V. L. (2017). *Designing and Conducting Mixed Methods Research*. Thousand Oaks, CA: SAGE Publications Ltd.

DiCicco-Bloom, E., Lord, C., Zwaigenbaum, L., Courchesne, E., Dager, S. R., Schmitz, C., et al. (2006). The developmental neurobiology of autism spectrum disorder. *J. Neurosci.* 26, 6897–6906.

Elo, S., Kääriäinen, M., Kanste, O., Pölkki, T., Utriainen, K., and Kyngäs, H. (2014). Qualitative content analysis. *SAGE Open* 4, 1–10.

Etikan, I., Musa, S. A., and Alkassim, R. S. (2016). Comparison of convenience sampling. *Am. J. Theor. Appl. Stat.* 5, 1–4. doi: 10.11648/j.ajtas.20160501.11

Fabri, M., Elzouki, S. Y. A., and Moore, D. (2007). "Emotionally expressive avatars for chatting, learning and therapeutic intervention," in *Proceedings of the Human-Computer Interaction. HCI Intelligent Multimodal Interaction Environments, 12th International Conference, HCI International 2007*, (Beijing).

Farley, M., McMahon, W., Fombonne, E., Jenson, W., Miller, J., Gardner, M., et al. (2009). Twenty year outcome for individuals with autism and average or near average cognitive abilities. *Autism Res.* 2, 109–118. doi: 10.1002/aur.69

Fletcher-Watson, S. (2014). Evidence-based technology design and commercialisation: recommendations derived from research in education and autism. *TechTrends* 59, 84–88. doi: 10.1007/s11528-014-0825-7

Frauenberger, C., Good, J., and Keay-Bright, W. (2010). "Phenomenology, a framework for participatory design," in *Proceedings of the 11th Biennial Participatory Design Conference on - PDC '10*, (New York, NY).

Frauenberger, C., Good, J., and Keay-Bright, W. (2011). *Designing Technology for Children with Special Needs - Bridging Perspectives through Participatory Design*. Haryana: CoDesign.

Georgiades, S., Szatmari, P., Boyle, M., Hanna, S., Duku, E., Zwaigenbaum, L., et al. (2013). Investigating phenotypic heterogeneity in children with autism spectrum disorder: a factor mixture modeling approach. *J. Child Psychol. Psychiatry Allied Discip.* 54, 206–215. doi: 10.1111/j.1469-7610.2012.02588.x

Hailpern, J., Karahalios, K., DeThorne, L., and Halle, J. (2009). "Talking points," in *Proceedings of the 11th International ACM SIGACCESS Conference on Computers and Accessibility ACM*, (New York, NY).

Halskov, K., and Hansen, N. B. (2015). The diversity of participatory design research practice at PDC 2002–2012. *Int. J. Hum. Comput. Stud.* 74, 81–92. doi: 10.1016/j.ijhcs.2014.09.003

Hamidi, F., Baljko, M., and Gómez, I. (2017). "Using participatory design with proxies with children with limited communication," in *Proceedings of the 19th International ACM SIGACCESS Conference on Computers and Accessibility - ASSETS '17*, (New York, NY: ACM Press).

Herriott, R. (2015). The use of proxies: lessons of social co-design for inclusive design for people with cognitive disabilities. *J. Access. Design All* 5, 100–124.

Hetzroni, O. E., and Tannous, J. (2004). Effects of a computer-based intervention program on the communicative functions of children with autism. *J. Autism Dev. Disord.* 34, 95–113. doi: 10.1023/b:jadd.0000022602.40506.bf

Houghton, C., Casey, D., Shaw, D., and Murphy, K. (2013). Rigour in qualitative case-study research. *Nurse Res.* 20, 12–17. doi: 10.7748/nr2013.03.20.4.12.e326

Howlin, P., Goode, S., Hutton, J., and Rutter, M. (2004). Adult outcome for children with autism. *J. Child Psychol. Psychiatry* 45, 212–229. doi: 10.1111/j.1469-7610.2004.00215.x

Howlin, P., Moss, P., Savage, S., and Rutter, M. (2013). Social outcomes in mid- to later adulthood among individuals diagnosed with autism and average nonverbal IQ as children. *J. Am. Acad. Child Adolesc. Psychiatry* 52, 572–581. doi: 10.1016/j.jaac.2013.02.017

Kamps, D., Thiemann-Bourque, K., Heitzman-Powell, L., Schwartz, I., Rosenberg, N., Mason, R., et al. (2015). A comprehensive peer network intervention to improve social communication of children with Autism spectrum disorders: a randomized trial in kindergarten and first grade. *J. Autism Dev. Disord.* 45, 1809–1824. doi: 10.1007/s10803-014-2340-2

Kenny, L., Hattersley, C., Molins, B., Buckley, C., Povey, C., and Pellicano, E. (2016). Which terms should be used to describe autism? Perspectives from the UK autism community. *Autism* 20, 442–462. doi: 10.1177/1362361315588200

Kjelgaard, M. M., and Tager-Flusberg, H. (2001). An investigation of language impairment in Autism: implications for genetic subgroups. *Lang. Cogn. Process.* 16, 287–308. doi: 10.1080/01690960042000058

Knight, V., McKissick, B. R., and Saunders, A. (2013). A review of technology-based interventions to teach academic skills to students with autism spectrum disorder. *J. Autism. Dev. Disord.* 43, 2628–2648. doi: 10.1007/s10803-013-1814-y

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

Logan, K., Iacono, T., and Trembath, D. (2017). A systematic review of research into aided AAC to increase social-communication functions in children with autism spectrum disorder. *Augment Altern Commun.* 33, 51–64. doi: 10.1080/07434618.2016.1267795

Lorenzo, C., and Lorenzo, E. (2018). "When learning happens through a cycle of invention, design and digital fabrication as students bring their ideas to life," in *Proceedings of the INTED Proceedings*, (Hungary: CEU University).

Makhaeva, J., Frauenberger, C., and Spiel, K. (2016). "Creating creative spaces for co-designing with autistic children," in *Proceedings of the 14th Participatory Design Conference on Full papers - PDC '16*, (New York, NY: ACM Press).

Martolia, D., and Gupta, R. (2020). Assistive technology for autistic children: a review. *Int. J. Curr. Microbiol. Appl. Sci.* 9, 2170–2175. doi: 10.20546/ijcmas.2020.907.253

Matson, J. L., and Shoemaker, M. (2009). Intellectual disability and its relationship to autism spectrum disorders. *Res. Dev. Disabil.* 30, 1107–1114. doi: 10.1016/j.ridd.2009.06.003

Mesa-Gresa, P., Gil-Gómez, H., Lozano-Quilis, J.-A., and Gil-Gómez, J.-A. (2018). Effectiveness of virtual reality for children and adolescents with autism spectrum disorder: an evidence-based systematic review. *Sensors (Basel)* 18:2486. doi: 10.3390/s18082486

Metatla, O., Read, J. C., and Horton, M. (2020). "Enabling children to design for others with expanded proxy design," in *Proceedings of the Interaction Design and Children Conference*, (New York, NY: Association for Computing Machinery).

Moore, D., Cheng, Y., McGrath, P., and Powell, N. J. (2005). Collaborative virtual environment technology for people with Autism. *Focus Autism Other Dev. Disabl.* 20, 231–243. doi: 10.1177/10883576050200040501

Morse, J. M. (2015). Analytic strategies and sample size. *Qual. Health Res.* 25, 1317–1318. doi: 10.1177/1049732315602867

Nesset, V., Davis, E. C., Stewart-Robertson, O., and Bible, J. B. (2021). Bonded design in the virtual environment: the transition of a participatory design methodology. *J. Doc.* Online ahead of print.

Nowell, L. S., Norris, J. M., White, D. E., and Moules, N. J. (2017). Thematic analysis: striving to meet the trustworthiness criteria. *Int. J. Qual. Methods* 16, 1–13.

O'Neill, T., Light, J., and McNaughton, D. (2017). Videos with integrated AAC visual scene displays to enhance participation in community and vocational activities: pilot case study with an adolescent with autism spectrum disorder. *Perspect. ASHA Spec. Interes. Groups* 2, 55–69. doi: 10.1044/persp2.sig12.55

Odom, S. L., Brown, W. H., Frey, T., Karasu, N., Lee Smith-Canter, L., and Strain, P. S. (2003). Evidence-Based practices for young children with autism: contributions for single-subject design research. *Focus Autism Other Dev. Disabl.* 18, 166–175. doi: 10.1177/10883576030180030401

Parsons, S., Guldberg, K., MacLeod, A., Jones, G., Prunty, A., and Balfe, T. (2011). International review of the evidence on best practice in educational provision for children on the autism spectrum. *Eur. J. Spec. Needs Educ.* 26, 47–63. doi: 10.1080/08856257.2011.543532

Pascualvaca, D. M., Fantie, B. D., Papageorgiou, M., and Mirsky, A. F. (1998). Attentional capacities in children with autism: is there a general deficit in shifting focus? *J. Autism Dev. Disord.* 28, 467–478. doi: 10.1023/a:1026091809650

Picard, R. W. (2009). Future affective technology for autism and emotion communication. *Philos. Trans. R. Soc. Lond. B Biol. Sci.* 364, 3575–3584. doi: 10.1098/rstb.2009.0143

Ploog, B. O., Scharf, A., Nelson, D., and Brooks, P. J. (2013). Use of computer-assisted technologies (CAT) to enhance social, communicative, and language development in children with autism spectrum disorders. *J. Autism Dev. Disord.* 43, 301–322. doi: 10.1007/s10803-012-1571-3

Råheim, M., Magnussen, L. H., Sekse, R. J. T., Lunde, Å, Jacobsen, T., and Blystad, A. (2016). Researcher-researched relationship in qualitative research: shifts in positions and researcher vulnerability. *Int. J. Qual. Stud. Health Well-being* 11:30996. doi: 10.3402/qhw.v11.30996

Rapp, A., Cena, F., Castaldo, R., Keller, R., and Tirassa, M. (2018). Designing technology for spatial needs: routines, control and social competences of people with autism. *Int. J. Hum. Comput. Stud.* 120, 49–65. doi: 10.1016/j.ijhcs.2018.07.005

Robb, N., Boyle, B., Politis, Y., Newbutt, N., Kuo, H. J., Sung, C. (2021). "Participatory technology design for autism and cognitive disabilities: a narrative overview of issues and techniques bt - recent advances in technologies for inclusive well-being: virtual patients, gamification and simulation," in *Recent Advances in Technologies of Inclusive Well-Being* eds A. L. Brooks, S. Brahman, B. Kapralos, A. Nakajima, J. Tyerman, L. C. Jain (Cham: Springer International Publishing).

Robertson, T., Leong, T. W., Durick, J., and Koreshoff, T. (2014). "Mutual learning as a resource for research design," in *Proceedings of the 13th Participatory Design Conference: Short Papers, Industry Cases, Workshop Descriptions, Doctoral Consortium Papers, and Keynote Abstracts*, (New York, NY: Association for Computing Machinery).

Scariot, C. A., Heemann, A., and Padovani, S. (2012). Understanding the collaborative-participatory design. *Work* 41(Suppl. 1), 2701–2705. doi: 10.3233/WOR-2012-0656-2701

Schalock, R. L., Borthwick-Duffy, S. A., Bradley, V. J., Buntinx, W. H. E., Coulter, D. L., Craig, E. M., et al. (2010). *Intellectual Disability: Definition, Classification, and Systems of Supports*, 11th Edn. Silver Spring, MD: American Association on Intellectual and Developmental Disabilities.

Schlosser, R. W., and Wendt, O. (2008). Effects of augmentative and alternative communication intervention on speech production in children with autism: a systematic review. *Am. J. Speech-Lang. Pathol.* 17, 212–230. doi: 10.1044/1058-0360(2008/021)

Schmidt, M. M. (2014). Designing for learning in a three-dimensional virtual learning environment: a design-based research approach. *J. Spec. Educ. Technol.* 29, 59–72. doi: 10.1177/016264341402900405

Schuller, B., Marchi, E., Baron-Cohen, S., O'Reilly, H., Robinson, P., Davies, I., et al. (2013). "ASC-Inclusion: interactive emotion games for social inclusion of children with autism spectrum conditions," in *Proceedings of the 1st Int Work Intell Digit Games Empower Incl (IDGEI 2013) held conjunction with 8th Found Digit Games 2013*, (Chania).

Shen, S., Doyle-Thomas, K. A. R., Beesley, L., Karmali, A., Williams, L., Tanel, N., et al. (2016). How and why should we engage parents as co-researchers in health research? a scoping review of current practices. *Heal Expect.* 20, 543–554. doi: 10.1111/hex.12490

Sofian, N. M., Hashim, A. S., and Sarlan, A. (2021). "Multimedia elements in designing mobile app interface for autistic children: proxy user perspective," in *Proceedings of the 2021 International Conference on Computer & Information Sciences (ICCOINS)*, (College Park, MD: AIP).

Stebbins, R. A. (2001). *Exploratory Research in the Social Sciences.* Thousand Oaks, CA: SAGE Publications, Inc. doi: 10.4135/9781412984249

Syriopoulou-Delli, C. K., and Papaefstathiou, E. (2019). Review of cluster analysis of phenotypic data in Autism spectrum disorders: distinct subtypes or a severity gradient model? *Int. J. Dev. Disabil.* 66, 13–21. doi: 10.1080/20473869.2018.1542561

Valencia, K., Rusu, C., Quiñones, D., and Jamet, E. (2019). The impact of technology on people with autism spectrum disorder: a systematic literature review. *Sensors (Basel)* 19:4485. doi: 10.3390/s19204485

van Rijn, H., and Stappers, P. J. (2008). The puzzling life of autistic toddlers: design guidelines from the LINKX project. *Adv. Human-Comp. Interact.* 2008:639435.

**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.