frontiers | Research Topics

Rural disability and community participation

Edited by
Catherine Ipsen, Jean P. Hall and John W. Lui

Published in
Frontiers in Rehabilitation Sciences

ISSN 1664-8714
ISBN 978-2-83250-662-2
DOI 10.3389/978-2-83250-662-2

About Frontiers

Frontiers is more than just an open access publisher of scholarly articles: it is a pioneering approach to the world of academia, radically improving the way scholarly research is managed. The grand vision of Frontiers is a world where all people have an equal opportunity to seek, share and generate knowledge. Frontiers provides immediate and permanent online open access to all its publications, but this alone is not enough to realize our grand goals.

Frontiers journal series

The Frontiers journal series is a multi-tier and interdisciplinary set of open-access, online journals, promising a paradigm shift from the current review, selection and dissemination processes in academic publishing. All Frontiers journals are driven by researchers for researchers; therefore, they constitute a service to the scholarly community. At the same time, the *Frontiers journal series* operates on a revolutionary invention, the tiered publishing system, initially addressing specific communities of scholars, and gradually climbing up to broader public understanding, thus serving the interests of the lay society, too.

Dedication to quality

Each Frontiers article is a landmark of the highest quality, thanks to genuinely collaborative interactions between authors and review editors, who include some of the world's best academicians. Research must be certified by peers before entering a stream of knowledge that may eventually reach the public - and shape society; therefore, Frontiers only applies the most rigorous and unbiased reviews. Frontiers revolutionizes research publishing by freely delivering the most outstanding research, evaluated with no bias from both the academic and social point of view. By applying the most advanced information technologies, Frontiers is catapulting scholarly publishing into a new generation.

What are Frontiers Research Topics?

Frontiers Research Topics are very popular trademarks of the *Frontiers journals series*: they are collections of at least ten articles, all centered on a particular subject. With their unique mix of varied contributions from Original Research to Review Articles, Frontiers Research Topics unify the most influential researchers, the latest key findings and historical advances in a hot research area.

Find out more on how to host your own Frontiers Research Topic or contribute to one as an author by contacting the Frontiers editorial office: frontiersin.org/about/contact

Rural disability and community participation

Topic editors

Catherine Ipsen — University of Montana, United States
Jean P. Hall — University of Kansas, United States
John W. Lui — University of Wisconsin-Stout Vocational Rehabilitation Institute, United States

Topic coordinator

Tracy Boehm Barrett — University of Montana, United States

Citation

Ipsen, C., Hall, J. P., Lui, J. W., Barrett, T. B., eds. (2022). *Rural disability and community participation*. Lausanne: Frontiers Media SA.
doi: 10.3389/978-2-83250-662-2

Table of contents

frontiers | Frontiers in Rehabilitation Sciences

TYPE Editorial
PUBLISHED 17 October 2022
DOI 10.3389/fresc.2022.1049578

Editorial: Rural disability and community participation

Catherine Ipsen[1]*, Jean P. Hall[2] and John Lui[3]

[1]University of Montana, Missoula, MT, United States, [2]University of Kansas, Lawrence, KS, United States, [3]University of Wisconsin–Stout, Menomonie, WI United States

KEYWORDS

rural, disability, participation, community living, disparities

Editorial on the Research Topic
Rural disability and community participation

by Ipsen C, Hall JP and Lui J. (2022) Front. Rehabilit. Sci. 3: 1049578. doi: 10.3389/fresc.2022.1049578

OPEN ACCESS

EDITED BY
Reuben Escorpizo
University of Vermont, United States

*CORRESPONDENCE
Catherine Ipsen
catherine.ipsen@mso.umt.edu

SPECIALTY SECTION
This article was submitted to Disability, Rehabilitation, and Inclusion, a section of the journal Frontiers in Rehabilitation Sciences

RECEIVED 20 September 2022
ACCEPTED 26 September 2022
PUBLISHED 17 October 2022

CITATION
Ipsen C, Hall JP and Lui J (2022) Editorial: Rural disability and community participation.
Front. Rehabilit. Sci. 3:1049578.
doi: 10.3389/fresc.2022.1049578

The barriers, needs, and opportunities of people with disabilities living in rural communities can be very different than those living in urban areas. This situation is problematic when concerns, approaches, and policies are defined through an urban lens, and overlook or disregard rural community values, systems, and decision-making. Rural research, innovation, and evidence-based practices are essential for understanding and addressing disability issues within the rural context.

The Rural Disability and Community Participation research topic contributes to the current science of disability and rehabilitation from a rural perspective. We know that rural people with disabilities experience a variety of social and economic disparities that affect and limit community inclusion and participation. These inequalities include access to education, employment, transportation, health care, and community services. Because people with disabilities and underserved rural populations are both considered health disparity groups, the intersection of these identities introduces compounded disadvantage.

For this special topic, we reached out to rural disability researchers across the US and internationally. We received nine articles that addressed disability disparities, community access, and infrastructure from rural perspectives.

The first three articles focused on the experience of rural disability and factors that predict or are associated with elevated rural disability rates. Ipsen, Ward and Myers examined 27 waves of U.S. National Longitudinal Survey of Youth data to explore how environmental factors over the life course, such as occupations, injuries, access to health insurance, and living in a rural location, predicted mobility disability at age 40 and age 50 Ipsen et al. (2022). After controlling for both socio-demographic characteristics and life events, they reported living in a rural community increased the odds of mobility impairment. These findings reinforce the value of consistent and adequate health care access and exploring additional rural community factors that contribute to disability.

Mashinchi, Hicks, Leopold, Greiman, & Ipsen used American Community Survey (ACS) 5-year estimates to conduct geographic analyses of disability rates for American Indians/Alaskan Natives (AI/ANs) living in metropolitan, micropolitan, and noncore counties Mashinchi et al. (2022). Generally, these data aligned with past studies indicating greater disability rates among AI/ANs compared to Whites. However, differences in disability rates between AI/AN and White racial groups were no longer present when comparing counties with a significant AI/AN presence (≥5% of the county population is AI/AN). The authors highlight the potential protective factors offered by sense of belongingness and cultural fit.

von Reichert explored disability from a household context using the 2015–2019 ACS Public Use Microdata Sample Von Reichert (2022). In addition to describing an innovative method for classifying cases across the rural-urban continuum, von Reichert found that living alone was more prevalent for people with disabilities living in rural areas and multigenerational households with disability were more common in large cities.

Other articles focused on rural participation from the lens of access to services in the community. Myers, Ipsen, and Standley explored 2017 National Household Travel Survey data to explore rural and urban differences in transportation patterns for people with travel-limiting disabilities Myers et al. (2022). Their paper examined differences between rural and urban drivers and non-drivers, types of transportation, and how adults with disabilities decide if they will give up driving. The results illustrate significant disparities in transportation options and offer policy and community insights for improving rural transportation systems.

Gimm and Ipsen used data from the National Survey on Health and Disability to explore rural and urban differences in both unmet and perceived need for acute and preventive services Gimm and Ipsen (2022). They found similar rates of unmet need across respondents from rural and urban locations, but significant differences in perceived need for preventive services. Specifically, rural people with disabilities reported not needing dental and mental health counseling at significantly higher rates than their urban counterparts. These differences highlight the impact of community norms and expectations in terms of rural health disparities.

Sage, Standley, and Mashinchi examined the rights of both disabled people and home-based personal care workers through the historical progression of federal policies and support of personal assistance services (PAS; Sage et al. (2022). Their paper explored the current and future implications on rural communities and highlighted the complex social justice issues that arise when trying to elevate the needs of different groups. This contextual work was complemented by a second paper by the same authors that surveyed consumers of PAS in five states to explore satisfaction with services and community participation outcomes among metro and non-metro respondents Sage et al. (2022). Overall, there were few rural and urban differences, and more research is needed to understand features of effective PAS delivery.

The final two articles focus on rural community infrastructure and strategies for measuring it. Seekins, Traci, and Hicks provided a process and strategy for assessing the accessibility of community space using Google Earth and Google Street View Seekins et al. (2022). Using existing Google imagery and an observation rating protocol, they assessed a total of 47 rural and urban communities and a combined 79 miles of community pathways to derive Community Access Scores (CAS) and Rule of Proportional Participation (RPP) rates. In general, rural communities had lower CAS scores and lower RPP rates, indicating participation limitations in both opportunities and use.

Finally, Hicks, Traci, and Korb compare disability simulations and I2audits for creating public awareness of access issues Hicks et al. (2022). Disability simulations ask participants to role-play different disability experiences, such as traveling in a wheelchair or wearing a blindfold. I2Audits involve a “shared discovery” of public access features with an interdisciplinary team of disability, public health, and public planning stakeholders. The authors conducted qualitative interviews with stakeholders who had participated in these strategies and concluded the I2Audits reduced feelings of stigmatization and provide opportunity for meaningful community dialogue.

Overall, rural disability research is varied in focus and approach. What is common across themes is the persistent disparity of health outcomes, lack of available resources, and feelings of uncertainty pervading an increasingly complex rural environment. Articles call for additional research to develop strategies to empower people with disabilities to meaningfully participate in their rural communities.

Author contributions

Ipsen drafted the introductory editorial. Hall and Lui provided feedback and comments. 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.

frontiers | Frontiers in Rehabilitation Sciences

MINI REVIEW
published: 25 April 2022
doi: 10.3389/fresc.2022.876038

Intersections of Personal Assistance Services for Rural Disabled People and Home Care Workers' Rights

Rayna Sage, Krys Standley and Genna M. Mashinchi*

The Rural Institute for Inclusive Communities, University of Montana, Missoula, MT, United States

It is very difficult to find and keep workers to provide home-based care for disabled people, especially in rural places. There is a tension between the rights of disabled people and the rights of home-based personal care workers. In this brief review, we explore the intersections of historical and social forces that shaped federal-level policies for both disability rights and the rights of personal care workers, as well as the current state of the policies. This paper provides a narrow focus on federal policies relevant to both groups, while also considering how the urbancentric nature of advocacy and policymaking has failed to address important issues experienced by rural people. In addition to briefly reviewing relevant federal policies, we also explore sources of support and resistance and how urbanormativity, ableism, and sexism intersect to influence how the needs of people with disabilities and their personal care workers are conceptualized and addressed. We conclude with recommendations for how to better address the needs of rural people with disabilities using home-based personal care services and the workers who provide them.

Keywords: disability, home care workers, policy, home-based services, community-based services

OPEN ACCESS

Edited by:
Jean P. Hall,
University of Kansas, United States

Reviewed by:
Joseph Caldwell,
Brandeis University, United States

****Correspondence:***
Rayna Sage
rayna.sage@umontana.edu

Specialty section:
This article was submitted to Disability, Rehabilitation, and Inclusion, a section of the journal Frontiers in Rehabilitation Sciences

Received: *15 February 2022*
Accepted: *31 March 2022*
Published: *25 April 2022*

Citation:
Sage R, Standley K and Mashinchi GM (2022) Intersections of Personal Assistance Services for Rural Disabled People and Home Care Workers' Rights.
Front. Rehabilit. Sci. 3:876038.
doi: 10.3389/fresc.2022.876038

INTRODUCTION

Personal Assistance Services, as part of Home and Community-Based Services funded through Medicaid, are critical for disabled people[1] to live, work, and recreate in their homes and communities (1). As part of these services, personal care attendants (PCAs—also referred to as personal care aides, personal attendants, and personal assistance service workers) come to disabled peoples' homes to assist them with tasks of daily living such as getting in and out of bed, toileting, meal preparation, housekeeping, transportation, and running errands. Distinct from home healthcare workers, who provide skilled nursing care, PCAs provide more basic care and, in most cases, are not required to have formal training. These services are clearly vital for the wellbeing of people with disabilities. Despite personal assistance services being among the fastest-growing employment sectors (2), these low-wage, low-status jobs are difficult to fill and maintain with qualified people, especially in rural places (3). Personal assistance care in rural areas is burdensome both for disabled people and PCA workers: many people with self-care disabilities live in places where personal care attendants are in short supply (4) and the unpaid commuting "windshield time" required in rural areas limits worker availability and adds mileage costs (5). PCA positions rarely come with benefits and often require workers to combine several clients to reach full-time

---

[1] The terms disabled people (identity first language) and people with disabilities (person first language) are used interchangeably to reflect the current preferences of advocates in the disability rights field.

status and earnings (6). Many of the positions are also physically demanding and PCAs experience high rates of injury and disability (7). Finally, like many care work positions, the vast majority of these jobs are occupied by women, women of color, and immigrants (4), who often face more exploitation than other workers. Despite the intertwined relationships that exist between the disabled people needing services and the workers providing them, advocates for these groups have not historically worked together to fight for protections and rights for both groups. This paper is a brief introduction to how the movements for disability rights and workers' rights evolved over the twentieth century, with a narrow focus on relevant federal policies. We recognize that these programs are executed and managed by states and that state implementation is heterogeneous. Given the brief nature of this focused mini-review, we are unable to speak to these between-state differences or the conflicts that have arisen due to the complexities of implementing federal policies at the state level, sometimes without additional federal support.

The disagreement regarding what policies are needed is embedded in the seemingly-competing goals of protecting both the "choice and control" (8) of disabled people and the labor policies needed to protect and promote workers' rights. On the side of protecting disabled people's autonomy, rural disability advocates recognized their unique needs were not always included in the dominant, urban-based movement for disability rights. This led to the formation of the Association of Programs for Rural Independent Living (9). However, there has been little organized support for rural PCAs. The goal of concurrently promoting and protecting both parties has historically been impeded by a belief among some disability rights advocates that if workers' rights and statuses are elevated, the autonomy of, and access to care for, people with disabilities will be demoted (10). To further understand the challenges of elevating and protecting both disabled people and workers, especially those living and working in rural areas, this paper (1) provides an overview of intersecting policies implemented since the 1930s, (2) considers the sources of supports and resistance in both movements, and (3) highlights the intersections of urbanormativity, ableism, and sexism in shaping policies and practices. This paper ends with a discussion of the current emerging opportunities in addressing the needs of both rural consumers and workers.

CHANGING POLICIES SINCE THE 1930s

While advocacy for disability rights has been formally happening for more than 150 years, advocacy at the national level for supports specific to being able to receive the care and services needed to stay in one's community and home have only come about more recently (11). The earliest policies focused on "protecting" non-disabled citizens from being exposed to people with disabilities (e.g., ugly laws). Many of these policies led to the hiding away of disabled individuals and kept them out of the labor market, with the exception of venues like "freak shows." People with disabilities have been incredibly marginalized throughout history, including being primary targets of the Eugenics movement. It is estimated that 60,000 disabled people in the United States were subject to forced sterilization during this period; worldwide, the number is over a half of a million (12, 13). Slowly, US policies have evolved to support greater integration of disabled people into society. However, policy nuances have resulted in less progress for disabled people in rural places. For example, employment provisions within the Americans with Disabilities Act (14) applied only to businesses that employed more than 15 people. Given employers in rural areas tend to be small businesses with fewer than 15 employees, rural disabled people benefit less from this policy than their urban counterparts (15).

Table 1 is a very brief overview of some of the key federal-policy-related events that impacted both the evolution of policies related to personal assistance services and home care workers' rights. For both people with disabilities and PCAs, the federal government's response to the Great Depression was a turning point, bringing some of the inequities and challenges faced by both groups to light. The Social Security Act (16) established formal federal funding (distributed to the states) for supporting people with disabilities, primarily in institutional or group living situations (10). Similarly, under the Roosevelt administration, the Visiting Housekeeping Program was established as part of The New Deal (17). This program put women, including many women of color, to work in other people's homes. Training centers for these programs were primarily located in urban centers, likely drawing labor-seeking women from the countryside. Despite the important gains made in passing the Fair Labor Standards Act of 1938 to protect workers from the most harsh and unsafe working conditions and to limit the standard work week, 86% of working women, including PCAs, were not included in the protections (17).

After a period of national focus on war efforts following the New Deal policies, changes for disability rights picked up again in the 1950s, but policy implementation impacting the work of PCAs stayed fairly mute until the 1974 amendment to the Fair Labor Standards Act. This amendment explicitly excluded domestic workers (including PCAs) from protections, designating their work "companionship services." During the 1950s, disability rights advocates gained ground in securing funding for basic living needs via Social Security Disability Insurance in 1956. Later advocacy by disability rights activists against institutionalization, and in favor of home-based services, resulted in amendments to the Social Security Act and new mandates throughout the 1960s and 1970s (see **Table 1**). During this time, however, there was little policy formation around the rights and working conditions of PCAs. Additionally, implementation of policies related to home-based services was slow, in part due to the growing power and influence of the nursing home industry (10). Though not perfect, formal programming and some fiscal supports were established during the 1960s and 1970s to meet federal mandates that Medicaid funding be used to support disabled people in their homes, rather than only in institutions. This would not become the Home and Community-Based Services program until 1983 when Congress added section 1915(c) to the Social Security Act (17), but these pieces of federal legislation and related policies provided important foundational support for today's systems.

TABLE 1 | Evolution of federal policies related to personal assistance services and home care workers' rights.

Home and community-based services	Home care workers' rights
• 1935—The Social Security Act established formal funding streams for supports for people with disabilities, primarily in institutional or group home settings[a]. • 1950—Social Security Act Amendment mandated Medicaid payment go directly to nursing homes, rather than beneficiary[a]. • 1956—Social Security Disability Insurance established to support low-income disabled people[a]. • 1961—Community Health Services and Facilities Act[a]. • 1962—President Kennedy formed a President's Panel to address federal policies for people with intellectual disabilities, including the need for workers to support and provide care for these people[b]. • 1963—President Kennedy asks Congress to address the mass institutionalization of people with disabilities[a] and signed into law an act that created a national network of University Centers for Excellence in Developmental Disabilities (UCEDDs), which support research, service, and training related to disability[b]. • 1970—Mandate for Medicaid to cover home-based care[a]. • 1973—The Rehabilitation Act prohibited discrimination against disabled people in the pursuit of employment and community participation by federally-funded entities and established nationwide centers for independent living[a]. • 1975—Social Security Act Amendment established first round of federal funding to incentivize states to move from institutional to home-based care[a].	• 1933—The Visiting Housekeeping Program was established as part of The New Deal[f]. • 1938—The Fair Labor Standards Act failed to include 86% of women, including home care workers, from protections pertaining to wages and work hours[f]. • 1961—Community Health Services and Facilities Act was passed, funding non-profit agencies to provide home-based PAS[f]. • 1964—Economic Opportunity Act authorized efforts to increase workers' wages[g]. • 1966—Economic Opportunity Amendment was created to fund training for those of low income to become trained home care paraprofessionals[g]. • 1967—Social Security Act Public Welfare Amendments were passed with a Worker Incentive Program to train housekeepers to aid older adults or individuals with disabilities. However, these jobs paid lower wages than did jobs for homemakers trained to aid in child care[h]. • 1974—Amendments were added to the Fair Labor Standards Act, providing wage and hour protections to domestic workers but not to home-based PAS workers due to a "companionship" exemption[i].
• 1990—The Americans with Disabilities Act guaranteed disabled people equal opportunities to employment, government services, and access to public buildings, including making modifications to avoid discrimination based on disability status[a]. • 1993—PAS were formally included in Medicaid regulations. States were explicitly allowed to provide PAS outside of consumers homes[a]. • 1999—The U.S. Supreme Court, in Omstead v. L.C., held that unjustified segregation of disabled people is unlawful discrimination under the Americans with Disabilities Act and that, under some conditions, public entities must provide HCBS to people with disabilities[a]. • 1999—Medicaid Manual Transmittal authorized additional assistance with instrumental activities of daily living, such as transportation services, and authorized some types of family members to become paid providers of PAS[a]. • 2001—The Real Choice Systems Change Grant Program was created through the Centers for Medicare and Medicaid Services to help states transform their long-term services and supports through awards to states to increase HCBS[a]. • 2005—Safe, Accountable, Flexible, Efficient Transportation Equity Act: A Legacy for Users provides for investment in and development of accessible transportation in rural areas, with impacts on rural people with disabilities and their service providers[c].	
• 2005—The Deficit Reduction Act created the Money Follows the Person Program in support of state efforts to rebalance their LTSS systems by providing financial assistance to support increased use of HCBS and reduction of institutional living facilities[a]. • 2014—Medicaid HCBS Final Rule defines requirements for person-centered planning and adds protections for service recipients[d]. • 2016—Medicaid Managed Care Final Rule required states to identify people with LTSS needs and required managed LTSS plans to follow the requirements of Medicaid's person-centered service planning[e].	• 2014—The Harris v. Quinn court ruling held that homecare workers experienced a violation in their first amendment rights when forced to pay union dues[j]. • 2015—Fair Labor Standards Act "companion exclusion" was revised and protections were extended to home care workers[i].

This table includes major federal policies relevant to personal assistance services and home care workers' rights. It is not a comprehensive policy review and does not include state policies. HCBS, home and community-based services; LTSS, long-term services and supports; PAS, personal assistance services.

[a] *Nielsen (37).*

[b] *Association of University Centers on Disabilities (38).*

[c] *Yusuf and Mahar (39).*

[d] *Centers for Medicare and Medicaid Services (40).*

[e] *Paradise and Muscumeci (41).*

[f] *Boris and Klein (17).*

[g] *Nittoli and Giloth (42).*

[h] *U.S. Senate Committee on Finance and U.S. House of Representatives Committee on Ways and Means (43).*

[i] *U.S. Department of Labor, Employment Standards, Administration, Wage, and Hour Division (21).*

[j] *U.S. Supreme Court (20).*

From the 1990s to present, policy changes have led to substantial advances in conceptualizing disability and associated civil rights for disabled people (see **Table 1**), such as the Americans with Disabilities Act of 1990, having Personal Assistance Services formally included in Medicaid Regulations in 1993 (17), the Olmstead decision by the Supreme Court in 1999 (18), and the development and evaluation of the Money Follows the Person Program of 2005 (19). Policies in support of workers' rights have expanded to include First Amendment Rights protections for PCAs (20) and the 2015 removal of the 1974 companionship exception from the Fair Labor Standards Act (21). To follow is a brief discussion of some of the people, organizations, and industries involved in supporting and resisting changes for disabled people and PCAs.

SOURCES OF SUPPORT AND RESISTANCE

On the surface, home-based services for people with disabilities received public support. For instance, social reformers Reverend Louis Dwight and Dorothea Dix were among the first advocates to publicly criticize the deplorable living conditions of institutionalized individuals in the mid to late 1800s (22). As public consciousness about dignity of life for disabled people was elevated, it seems very few believed disabled people *should* be living in such conditions. It is notable that these institutions were largely operated in rural locations in the United States and hidden away from urban centers. These institutions provided jobs and economic support in many rural communities. However, this commodification of care for disabled residents attracted for-profit companies into the industry (15). The movement to deinstitutionalize disabled people did not really take hold until the 1950s, following the foundational policies established in the amendments to the Social Security Act (23). Societal events leading up to these changes included the widespread effects of polio outbreaks in 1916 and between 1949 and 1952 leading to higher rates of disability (24) and the presidential election of Franklin D. Roosevelt (who used a wheelchair), which helped shift the ways in which Americans thought about physical and mobility-related disabilities. Although deinstitutionalization of disabled people eradicated many residential institutions, nursing homes—which are also disproportionately concentrated in rural places—have in some ways taken their places (15).

The nursing home industry, with strong lobbying abilities, resisted home-based services (10) and won most of the policy battles, garnering Congressional support in amendments to the Social Security Act until the 1970s when it was mandated that nursing home-level care for people with disabilities on Medicaid must be covered in-home, if a disabled person chooses in-home care. However, the systems to accommodate these choices would be long in the making. The nursing home industry also played a role in the continued exclusion of home-based PCAs from federally protected workers' rights, arguing they could not afford to adhere to the protections for their institutional-based workers who were also excluded (17). Instead, PCAs in the US were subject to unjust working conditions such not being able to receive phone calls or spend time with friends if they lived with the person for whom they provided services and unclear limits on how many hours they were allowed or required to work (25). Additionally, international workers' rights were not protected to ensure a pathway to achieving immigration status, and they were instead faced with having to comply with their employer or risk deportation (25).

Home care worker unions such as the Service Employees International Union grew exponentially during the last 20 years. This led to many key protections for unionized workers in select states (26). However, supporters of home care workers' rights have experienced setbacks to their efforts to improve working conditions and wages in recent years. In 2018, the U.S. Supreme Court prohibited home care workers unions from charging non-members fees. The following year, in 2019, a Medicaid policy change barred home healthcare aides working for Medicaid-funded facilities and agencies from having union dues automatically deducted from their pay checks (27). The inability to more easily pay union dues has led to less union membership, fewer resources, and less collective bargaining power. Perhaps due to the incredible harsh and negative impacts of worker shortages during the COVID-19 pandemic (28), there has been recent momentum in disability rights advocates joining forces with workers' rights advocates to fight for better compensation and work conditions.

INTERSECTIONS OF URBANORMATIVITY, ABLEISM, AND SEXISM

With more awareness and support, the Independent Living Movement took hold in the mid-twentieth century and was intimately tied to other civil rights movements. With a mantra of "nothing about us without us" to acknowledge the long paternalistic history of making decisions about disabled bodies *for* people with disabilities rather than *with* them (26), disability rights advocates continue to fight for justice and equity today.

Like many other social justice events, disability advocacy has largely taken place in urban areas [e.g., (28)]. With the exception of work done by the fairly small organization, the Association of Programs for Rural Independent Living, the Independent Living Movement has been fairly urbancentric with most activity happening on university campuses and in cities (8), making it difficult for rural disabled people to participate.

Given the urban focus of the Independent Living Movement, it is perhaps unsurprising rural-specific issues related to receiving personal assistance services have neither been sufficiently addressed nor researched thoroughly. Furthermore, in rural places, lack of affordable and accessible housing and limited availability of PCAs has led to unjust institutionalization of disabled people in nursing homes (15). Next, we briefly explore how ableism and sexism have played a role in the evolution of these policies influencing rural care work and those who need services.

From the beginning, there has been resistance to financially supporting people with disabilities at adequate levels. Some of this resistance is embedded in a cultural belief in rugged independence and self-sufficiency, which is more prevalent among rural citizens (11). Our country has a long history of having a weak safety net that is slow to kick in and quick to be pulled back (29). The evolving medical field and technology provided decision makers with new tools to determine who was "deserving" and "undeserving" of community living and services, as evidenced by the strict and extremely complex protocols established to determine eligibility for Social Security Disability Insurance (10). All of this, in addition to employment-based health benefits, contributes to keeping workers tied to the labor market.

The Visiting Housekeeping Program served as a catalyst for propelling PCAs toward a more formalized and professionalized occupation. However, it was met with resistance from the Southern textiles and manufacturing industry leaders because they argued that as they were getting back on their feet, they could not compete with subsidized wages provided by the government (17). This intersected with the restriction that only one person per family could be supported by Worker Progress Administration programs (which included the Visiting Housekeeping Program), which favored men (17). Finally, because care in the home was seen as less valuable than other labor, it was difficult for workers' rights advocates to gain any momentum toward better compensation and work conditions. This particular belief also helped fuel the resistance to workers' rights among people with disabilities who desired high degrees of autonomy and control in organizing their daily lives and services (30).

In terms of workers' rights, women in families with individuals with disabilities were historically and continue to be expected to provide family care for free, saving the government billions of dollars (31). In fact, currently 80% of care provided to people with disabilities and older adults is unpaid. Despite the majority of women being in the workforce by the late 1970s, family caregiving continues to be a social expectation, placing incredible burdens on many women (32). Even after the advent of Home and Community-Based Services, many states did not allow spouses or parents to be paid for providing care (33). These types of rules made it extremely hard for rural people needing services to find workers in their communities (4). However, today there is more momentum for creating better supports than has been seen for many, many years.

DISCUSSION

This paper highlights the complex social justice issues that arise when trying to elevate the needs of different groups that, at first, appear to have competing goals. This becomes even more complicated when we turn our attention toward the implications in rural places. The gains made by people with disabilities to have services that enable them to live, work, and recreate in community necessitate the commodification of other people's labor. In some cases, this means the autonomy of disabled people appears to be in conflict with the autonomy of workers, a conflict that is subsumed by a system that does not adequately support either group. For rural people with disabilities, current policies do not address the additional burden of rurality, including a lack of local workers (especially when spouses or parents are excluded from being paid caregivers), additional costs related to the lack of accessible, public transportation (34). For the workers who provide these essential services, workers' rights advocacy also has not addressed the additional burdens of "windshield time," car maintenance, and the costs of providing care in less accessible homes and communities with fewer services, for lower wages compared to what they can earn providing care in urban places (35).

Based on this review and the growing interest in finding ways to better support both people with disabilities and PCAs, we recommend organizations doing research in home-based services—such as the AARP Public Policy Institute—consider adding rural components to their very useful Long-Term Services and Supports Scorecard analyses (36). Topics to consider include adjustment of wages to better compensate rural workers, better compensation for vehicles and mileage, and incentivizing individuals in rural places to become PCAs. It is also recommended these organizations employ staff knowledgeable in the unique history of, and issues faced by, rural disabled people and service providers. We also recommend including rural voices of people with disabilities and PCAs in relevant policy discussions and decisions. Finally, in advocacy work, we encourage social justice advocates to consider making room at the table for rural people impacted by these issues in ways that do not exacerbate the burden of participation faced by many rural people (e.g., driving long distances to participate in advocacy events).

AUTHOR CONTRIBUTIONS

Idea for the paper was by RS. Writing, critical review of the paper, suggested edits, revisions, and responses to reviewers were distributed evenly between RS, KS, and GM. Final edits were done by KS and GM. All authors contributed to the article and approved the resubmitted version.

FUNDING

This work was supported by the Research and Training Center on Disability in Rural Communities (RTC:Rural) under a grant from the National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR; grant number 90RTCP0002), which was a Center within the Administration for Community Living (ACL), Department of Health and Human Services (HHS).

ACKNOWLEDGMENTS

The authors wish to thank Billy Altom for his consultation on rural disability history and Ashley Tamez Trautman for her feedback on an earlier version of this paper.

REFERENCES

1. Kaye HS, Harrington C. Long-term services and supports in the community: Toward a research agenda. *Disabil Health J.* (2015) 8:3–8. doi: 10.1016/j.dhjo.2014.09.003
2. U.S. Bureau of Labor Statistics. *Home Health and Personal Care Aides: Occupational Outlook Handbook.* (2021). Available online at: https://www.bls.gov/ooh/healthcare/home-health-aides-and-personal-care-aides.htm (accessed September 22, 2021).
3. Siconolfi D, Shih RA, Friedman EM, Kotzias VI, Ahluwalia SC, Phillips JL, et al. Rural-urban disparities in access to home- and community-based services and supports: stakeholder perspectives from 14 states. *J Am Med Direct Assoc.* (2019) 20:503–8.e1. doi: 10.1016/j.jamda.2019.01.120
4. Greiman L, Sage R, Chapman S, Wagner L, Bates T, Lissau A. *Personal Care Assistance in Rural America*. Missoula, MT; San Francisco, CA: University of Montana, Rural Institute and University of California San Francisco, Health Workforce Research Center (2021). Available online at: https://storymaps.arcgis.com/stories/836efdf9752d4f1c8d101181d7735c04 (accessed June 26, 2021).
5. Strong Towns. *The Bottom-Up Revolution Is... Helping Rural Residents with Disabilities to Thrive*. Strong Towns (2022). Available online at: https://www.strongtowns.org/journal/2022/1/6/billy-altom-bottom-up (accessed February 9, 2022).
6. Kim JJ. Personal care aides as household employees and independent contractors: Estimating the size and job characteristics of the workforce. *Innovat Aging*. (2021) 6:igab049. doi: 10.1093/geroni/igab049
7. Jang Y, Lee AA, Zadrozny M, Bae S-H, Kim MT, Marti NC. Determinants of job satisfaction and turnover intent in home health workers: the role of job demands and resources. *J Appl Gerontol.* (2017) 36:56–70. doi: 10.1177/0733464815586059
8. DeJong G. Independent living: from social movement to analytic paradigm. *Arch Phys Med Rehabil.* (1979) 60:435–46.
9. Association of Programs for Rural Independent Living. *Association of Programs for Rural Independent Living* (n.d.). Available online at: https://www.april-rural.org/index.php/about-us (accessed February 13, 2021).
10. Iezzoni LI, Gallopyn N, Scales K. Historical mismatch between home-based care policies and laws governing home care workers. *Health Affairs*. (2019) 38:973–80A–E. doi: 10.1377/hlthaff.2018.05494
11. Taylor S. *Beasts of Burden: Animal and Disability Liberation*. New York, NY: The New Press (2017). p. 272.
12. Roy A, Roy A, Roy M. The human rights of women with intellectual disability. *J R Soc Med.* (2012) 105:384–9. doi: 10.1258/jrsm.2012.110303
13. Tilley E, Walmsley J, Earle S, Atkinson D. 'The silence is roaring': sterilization, reproductive rights and women with intellectual disabilities. *Disabil Soc.* (2012) 27:413–26. doi: 10.1080/09687599.2012.654991
14. U.S. Equal Employment Opportunity Commission. *Fact Sheet: Disability Discrimination*. (1997). Available online at: https://www.eeoc.gov/laws/guidance/fact-sheet-disability-discrimination (accessed April 8, 2022).
15. Seekins T, Ravesloot C, Riggles B, Enders A, Arnold N, Ipsen C, et al. *The Future of Disability and Rehabilitation in Rural Communities*. Missoula, MT: RTC: Rural, Rural Institute, University of Montana (Foundation Paper No. 3) (2011). p. 22.
16. *The Social Security Act.* (1935). Available online at: https://www.ourdocuments.gov/doc.php?flash=false&doc=68&page=transcript# (accessed December 22, 2021).
17. Boris E, Klein J. *Caring for America: Home Health Workers in the Shadow of the Welfare State*. Oxford University Press (2015). p. 318.
18. *Olmstead v. L. C.* Vol. 527, U.S. (1999). p. 581. Available online at: https://www.law.cornell.edu/supct/html/98-536.ZS.html (accessed July 17, 2018).
19. *Money Follows the Person | Medicaid.* Available online at: https://www.medicaid.gov/medicaid/long-term-services-supports/money-follows-person/index.html (accessed February 11, 2022).
20. U.S. Supreme Court. *Harris et al. v. Quinn, Governor of Illinois, et al.* U.S. Supreme Court (2014). Available online at: https://www.supremecourt.gov/opinions/13pdf/11-681_j426.PDFhttps://www.supremecourt.gov/opinions/13pdf/11-681_j426.PDF (accessed February 11, 2022).
21. U.S. Department of Labor, Employment Standards, Administration, Wage, and Hour Division. *Application of the Fair Labor Standards Act to Domestic Service*. National Archives Federal Register (2001). Available online at: https://www.federalregister.gov/documents/2001/01/19/01-1590/application-of-the-fair-labor-standards-act-to-domestic-service (accessed February 11, 2022).
22. Minnesota's Governor's Council on Developmental Disabilities. *Parallels in Time: A History of Developmental Disabilities.* (2021). Available online at: https://mn.gov/mnddc/parallels/index.html (accessed December 8, 2021).
23. Torrey EF. *Out of the Shadows: Confronting America's Mental Illness Crisis.* Revised edition. New York, NY; Weinheim: Wiley (1998). p. 257.
24. Tucker J. *No Lockdowns: The Terrifying Polio Pandemic of 1949-52 – AIER*. Barrington, MA: American Institute for Economic Research (2020). Available online at: https://www.aier.org/article/no-lockdowns-the-terrifying-polio-pandemic-of-1949-52/ (accessed September 18, 2021).
25. Hondagneu-Sotelo P. Families on the frontier: from braceros in the fields to Braceras in the home. In: Suarez-Orozoco MM, Suarez-Orozoco C, Qin-Hilliard D, editors. *The New Immigration: An Interdisciplinary Reader.* New York, NY: Taylor & Francis (2005). p. 167–77.
26. Charlton JI. *Nothing about Us without Us : Disability Oppression and Empowerment*. Quest Ebook Central - Reader. Berkley, CA: University of California Press; ProQuest Ebook Central (1998). Available online at: https://ebookcentral.proquest.com/lib/msoumt/detail.action?docID=224299 (accessed February 14, 2020). doi: 10.1525/9780520925441
27. Quinton S. *Unions, States Confront Trump Home Care Worker Rule*. The PEW Institute (2019). Available online at: https://pew.org/2JDfNUB (accessed November 4, 2021).
28. Erkulwater JL. How the nation's largest minority became white: race politics and the disability rights movement, 1970–1980. *J Policy History*. (2018) 30:367–99. doi: 10.1017/S0898030618000143
29. Zinn H. *A People's History of the United States*. 6th ed. New York, NY: HarperCollins (2015).
30. Bagenstos SR. Disability rights and labor: Is this conflict really necessary? *Indiana Law J.* (2016) 92:277–98. Available online at: https://heinonline.org/hol-cgi-bin/get_pdf.cgi?handle=hein.journals/indana92§ion=9 (accessed December 7, 2021).
31. Chari AV, Engberg J, Ray K, Mehrotra A. The opportunity costs of informal elder-care in the United States: new estimates from the American Time Use Survey. *Health Serv Res.* (2014) 50:871–82. doi: 10.1111/1475-6773.12238
32. Hochschild AR. *The Managed Heart: Commercialization of Human Feeling, Updated with a New Preface*. Berkeley, CA: University of California Press (2012). p. 335. doi: 10.1525/9780520951853
33. AARP, the Commonwealth Fund, and the SCAN Foundation. *Advancing Action, 2020: A State Scorecard on Long-Term Services and SUPPORTS for Older Adults, People with Physical Disabilities, and Family Caregivers.* (2020). Available online at: http://www.longtermscorecard.org/2020-scorecard/preface (accessed December 8, 2021).
34. Sage R, Greiman L, Lissau A, Wagner L, Toivanen-Atilla K, Chapman S. *"It's a Human Connection…": Paid Caregiving in Rural America*. ArcGIS StoryMaps (2021). Available online at: https://storymaps.arcgis.com/stories/7f914cf2023c491bb780bae845253162 (accessed March 19, 2022).
35. Sage RA. Qualitative perceptions of opportunity and job qualities in rural health care work. *Online J Rural Nurs Health Care*. (2016) 16:154–94. doi: 10.14574/ojrnhc.v16i1.382
36. Reinhard S, Houser A, Ujvari K, Gualtieri C, Harrell R, Lingamfelter P, et al. *Long-Term Services and Supports State Scorecard 2020 Edition*. Washington, DC: AARP Public Policy Institute (2020). Available online at: http://www.longtermscorecard.org/~/media/Microsite/Files/2020/LTSS%202020%20Reference%20Edition%20PDF%20923.pdf (accessed March 17, 2022).
37. Nielsen KE. *A Disability History of the United States*. Boston, MA: Beacon Press (2013).
38. Association of University Centers on Disabilities. *AUCD History.* (2018). Retrieved from: https://www.aucd.org/emergingleaders/Learn/About-AUCD (accessed February 18, 2022).

39. Yusuf J-E, Mahar K. Safe, accountable, flexible, efficient transportation equity act: a legacy for users. In: *Encyclopedia of Transportation: Social Science and Policy*. Thousand Oaks, CA: SAGE Publications, Inc. (2014). Available online at: http://sk.sagepub.com/reference/encyclopedia-of-transportation/n422.xml (accessed February 10, 2022).
40. Centers for Medicare & Medicaid Services. *Fact Sheet: Home and Community Based Services*. (2014). Available online at: https://www.cms.gov/newsroom/fact-sheets/home-and-community-based-services (accessed February 11, 2022).
41. Paradise J, Muscumeci M. *CMS's Final Rule on Medicaid Managed Care: A Summary of Major Provisions*. The Kaiser Commission on Medicaid and the Uninsured (2016). p. 20.
42. Nittoli JM, Giloth RP. *New Careers Revisited: Paraprofessional Job Creation for Low-Income Communities*. Social Policy (1998). Available online at: link.gale.com/apps/doc/A20575584/AONE?u=mtlib_1_1195&sid=googleScholar&xid=8b510b4e (accessed February 11, 2022).
43. U.S. Senate Committee on Finance and U.S. House of Representatives Committee on Ways and Means. *Summary of Social Security Amendments of 1967*. U.S. Government Printing Office (1967). Available online at: https://www.finance.senate.gov/imo/media/doc/PrtSSSummary2.pdf (accessed February 11, 2022).

Author Disclaimer: The research does not necessarily represent the policy of NIDILRR, ACL, or HHS and one should not assume endorsement by the federal government.

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.

frontiers | Frontiers in Rehabilitation Sciences

BRIEF RESEARCH REPORT
published: 27 April 2022
doi: 10.3389/fresc.2022.877555

Transportation Patterns of Adults With Travel-Limiting Disabilities in Rural and Urban America

Andrew Myers, Catherine Ipsen and Krys Standley*

The Research and Training Center on Disability in Rural Communities (RTC:Rural), Rural Institute for Inclusive Communities, University of Montana, Missoula, MT, United States

Introduction: Lack of transportation is a significant barrier to community participation for many disabled adults. Living in a rural area introduces additional transportation barriers, such as having to travel long distances to access services or socialize, and limited public transit options. While the importance of transportation access is clear, the mix of different transportation options used by people with disabilities to participate in their communities is less understood, particularly among those who do not or cannot drive.

Methods: We used data from the 2017 National Household Travel Survey to explore transportation behaviors among disabled adults in rural and urban areas and by four regions across the United States. We explored differences by transportation modalities (e.g., driver, passenger, public transportation, taxi/uber, walk) and trip purposes (e.g., social, independent living, healthcare, work). Our sample included 22,716 adults with travel-limiting disabilities.

Results: Several geographic differences emerged among non-drivers. Rural non-drivers were less likely to take any trip, particularly for social activities, and reported using less public transportation or walking/rolling than urban non-drivers. Further, respondents from the Northeast were more likely to report using public transportation and walking/rolling options, relative to the Midwest, South, and West. Overall, disabled rural adults reported lower odds of giving up driving, even after controlling for socio-demographic and health characteristics.

Discussion: These findings highlight the relative importance of different transportation modalities for participating in activities and the continued reliance upon personal vehicles, either as a driver or passenger, especially among rural disabled residents. Potential policy insights are discussed.

Keywords: transportation, rural, disability, community participation, independent living

Edited by:
Nuno Barbosa Rocha,
Polytechnic of Porto, Portugal

Reviewed by:
Linchuan Yang,
Southwest Jiaotong University, China
Ana Tsui Moreno,
Technical University of Munich, Germany
Steven Jones,
University of Alabama, United States
Beth Pfeiffer,
Temple University, United States

****Correspondence:***
Andrew Myers
andrew.myers@mso.umt.edu

Specialty section:
This article was submitted to Disability, Rehabilitation, and Inclusion, a section of the journal Frontiers in Rehabilitation Sciences

Received: *16 February 2022*
Accepted: *15 March 2022*
Published: *27 April 2022*

Citation:
Myers A, Ipsen C and Standley K (2022) Transportation Patterns of Adults With Travel-Limiting Disabilities in Rural and Urban America. Front. Rehabilit. Sci. 3:877555. doi: 10.3389/fresc.2022.877555

INTRODUCTION

Transportation is important for all people, and especially people with disabilities, because it facilitates access to community participation (1–3), a key outcome of rehabilitation (4). However, compared to people without disabilities, disabled people[1] experience limited access to transportation (5). More than 30 years since the Americans with Disabilities Act was signed into law, transportation is still a significant barrier to full inclusion in society for many people with disabilities (6). For example, ∼6 million Americans with disabilities have difficulty meeting their transportation needs (7). This problem is especially salient in rural areas where transportation options are more limited (8–12).

Eliminating barriers to participating in society is one of the core themes that underpin the disability rights movement and the Americans with Disabilities Act (1990) (13–15). As such, the concept of participation has emerged as a "gold standard" for measuring outcomes in rehabilitation (4, 16). For example, the Administration for Community Living is dedicated to the vision that "all people, regardless of age and disability, [. . .] live with dignity, make their own choices, and participate fully in society" (17).

Transportation influences the range of locations that an individual can access, and impacts the types of activities they can participate in (18, 19). More reliable and efficient transportation options can increase the range of available activities outside of the home, which is associated with increased levels of subjective wellbeing (20). Conversely, lack of transportation is a risk factor for social exclusion (21) and, in some analyses, has been found to be more impactful on how people spend their time than having a disability (22). For example, Marottoli et al. (23) found that adults over 65 who had stopped driving reported a substantial decrease in community activities even after controlling for socio-demographics and health factors. The importance of transportation for ensuring social inclusion for disabled people has been acknowledged by the United Nations Convention on the Rights of Persons with Disabilities, which identifies improvements in transportation as an opportunity to increase the social and economic participation of persons with disabilities around the world (24, 25).

In general, people with disabilities are less likely to take trips than people without disabilities; this is especially true of trips for social/recreational activities and for work (25). Disabled individuals are also less likely to travel in a personal vehicle than their non-disabled peers (26) which can restrict trip-taking behavior. For instance, Mitra and Saphores (27) found that households that do not have personal vehicles due to involuntary reasons (e.g., vehicle costs, inability to obtain insurance, or constraints due to health or age) take fewer trips. Additionally, those trips are characterized as being of shorter distance and longer duration than the trips taken by households with personal vehicles. For those who do not have access to a personal vehicle or cannot drive, including many people with travel-limiting disabilities, public transportation is instrumental to their community participation. Conversely, a lack of public transportation options can be particularly limiting.

Socioeconomic factors further exacerbate the personal and environmental factors that contribute to the experience of disability and can limit trip making. Disability prevalence is higher among people experiencing poverty (28) and poverty is increasingly connected to not owning a car or having access to a personal vehicle (29). Specifically, people with low incomes who own personal vehicles do so by taking on substantial economic burdens. Meanwhile, non-ownership of personal vehicles is increasingly associated with very low-income households. This latter association is especially true in places where the built environment is organized around personal vehicles (29), such as rural areas.

Transportation discrepancies in rural areas are exacerbated for disabled people. For instance, rural disabled people are more likely to report never using public transportation than urban disabled people (30). Among working-age disabled adults, those living in rural areas experience travel-related disabilities at slightly higher rates, but are also more likely to drive personal vehicles (31). Combined, limited public transportation services and geographically dispersed services mean that having transportation access via personal vehicle is more consequential. For example, having access to a personal vehicle in rural areas has been found to support health care utilization (8).

The United States Federal Transit Administration sponsors two separate funding mechanisms to support the transportation needs of people with disabilities and rural residents. The Enhanced Mobility of Seniors & Individuals with Disabilities program (§5310) allocates funding to states to support the transportation needs of people with disabilities and older adults (65+) where transportation is "unavailable, insufficient, or inappropriate." For rural areas, these funds are distributed via the states' departments of transportation (32). The Formula Grants for Rural Areas program (§5311) provides funding, as well as technical assistance, to support public transportation in rural areas with populations <50,000 "where many residents often rely on public transit to reach their destinations" (33). According to an analysis of 2019 National Transit Database revenue reports (34), \$327,637,963 was distributed *via* §5310 and \$770,713,023 was distributed *via* §5311. However, more than half of all rural counties, containing 3.6 million people with disabilities, did not receive funds from either of these programs[2] (35).

In summary, driving behaviors and federal funding for transportation vary significantly by geography and by disability status. While most rural Americans drive, many with disabilities cannot either because they have given up driving or because they do not have access to a vehicle. A study by Henly and Brucker (25) found that diver status was an important factor when analyzing the types of trips taken by people with and without disabilities—specifically, being a driver was associated with higher odds of taking any trip, but especially a social trip. The current paper

---

[1] We use the terms "people with disabilities" and "disabled people" interchangeably to reflect the current guidance of disability rights advocates in the field.

[2] National Transit Database reports are not comprehensive of all transportation funding. Only recipients of §5307 and §5311 funds are required to report to the National Transit Database, recipients of other funding mechanisms report optionally.

builds upon this line of research by exploring travel patterns among rural and urban disabled adults who do not or cannot drive. We conducted an exploratory study to examine how disabled rural adults get around, relative to disabled urban adults, and how transportation use varies across regions. In particular, we examined differences between people with disabilities who were drivers and those who were non-drivers. To explore these topics, we asked the following research questions:

1. What types of trips do disabled drivers and non-drivers take in rural and urban areas?
2. What types of transportation do disabled non-drivers use and how does this vary by region?
3. What factors predict the odds of giving up driving, among adults with disabilities?

METHODS

Data

We used data from the 2017 National Household Travel Survey [NHTS; (36)]. The NHTS is a cross-sectional survey conducted every 5–7 years to collect information about the types of trips and transportation modes used by the American public. It uses an address-based sampling frame designed to produce an equal probability sample of households, excluding group housing and institutional settings (e.g., prisons, dormitories). All respondents in a selected household complete a travel diary during a single day to document their travel behaviors. The 2017 NHTS includes 129,696 households, with 264,234 individuals and 923,572 trips. We analyzed data at the household level, individual level, and trip level to explore the travel behaviors of disabled adults in rural and urban areas throughout the U.S. The NHTS also includes weights to account for non-response and probability of being selected into the sample. More detailed information about weighting procedures can be found in the 2017 NHTS Weighting Report (37). An institutional review board approval was unnecessary because this is a secondary analysis of publicly available data.

Measures

Disability Status and Assistive Devices

The NHTS asks respondents if they have "a condition or handicap that makes it difficult to travel outside of the home" (i.e., travel-limiting disability). For this paper, we consider an affirmative response to this question as someone with a disability. However, disability is not a static characteristic, and several analyses describe changes in disability status over relatively short time frames, between 4 months and 1 year (38–40), which may reflect temporary injuries. The NHTS also asks respondents if their condition has lasted for <6 months, more than 6 months, or their entire life. To focus on individuals with long-term or enduring disabilities, we excluded those with a disability lasting <6 months. The NHTS also asks if they use any of the following: cane, walker, white cane, seeing-eye dog, crutches, motorized scooter, motorized wheelchair, manual wheelchair, or other. Individuals who reported using any of these items were coded as using assistive devices.

Gave Up Driving

If a respondent reports a disability (or is aged over 80), the NTHS follows-up with a question asking if they have "given up driving altogether." A "yes" response indicates that the person "has given up driving because of their disability." We use this variable as the outcome in our logistic regression analysis. Importantly, this variable is not mutually exclusive of actually driving on their travel diary day. In a subset of cases, individuals reported "having given up driving," but still drove. Presumably, some individuals who reported giving up driving may occasionally still need to drive, for example, if they have no alternatives or in an emergency. However, this is not clarified in any NHTS documentation.

Non-driver Status

The NHTS asks all respondents how many vehicles they have in their household. We defined "non-driver" status as including all individuals who reported giving up driving as well as individuals who can drive but do not have a vehicle in their household.

Trips

Respondents to the NHTS report every trip they take throughout their travel diary day. We used information about the main purpose for each trip to analyze the types of trips that individuals took. Each trip was assigned one purpose. "Social trips" includes recreational activities, exercise, visiting friends, and religious/community activities. "Independent Living trips" includes dropping off/picking someone up, errands, and buying meals. "Work trips" includes any trip for work or employment related activities among employed individuals. "Health trips" includes trips to the doctor's office, dentist or therapy. We excluded return trips to home and trips between different transportation modes (i.e., walking to bus stop). Types of trips were informed by another NHTS-focused study (25), however, we classified trips for healthcare purposes as a distinct category.

Transportation Modes

Trip records also include information about the type of transportation that was used. "Driver, personal vehicle" includes driving a car, SUV, van, truck or motorcycle. "Passenger, personal vehicle" includes riding in car, SUV, van, truck or motorcycle as a passenger. "Public transportation" includes public/commuter bus, paratransit/dial-a-ride, commuter rail, and subway/streetcar. "Taxi/rideshare" includes taxi, limo, and Uber/Lyft. "Walk/roll" includes walking and bicycle.

Self-Rated Health

The NHTS asks respondents to rate their general health as "excellent," "very good," "good," "fair," or "poor."

Geographic Variables

The NHTS uses the U.S. Census Bureau (41) classification scheme to code households as "rural" and "urban." Urban includes urbanized areas containing 50,000 or more people and urban clusters containing 2,500–49,999 people. Rural includes any population, housing, or territory not included in an urbanized area or urban cluster. The U.S. Census Bureau's four

TABLE 1 | Weighted sample characteristics.

	Overall	Rural	Urban	Sig.
Unweighted sample	22,716	5,544 (24.4%)	17,172 (75.6%)	
Weighted sample	22,827,651	4,211,445 (18.4%)	18,616,206 (81.6%)	
Age (mean, range)	66, 18–92	66, 18–92	66, 18–92	
Age category				0.691
18–64	54.8%	55.5%	54.7%	
65 and over	45.2%	44.5%	45.3%	
Female	58.2%	51.4%	59.7%	**≤0.001**
Race/ethnicity				**≤0.001**
White (non-Hispanic)	59.5%	80.9%	54.7%	
Black (non-Hispanic)	19.3%	8.7%	21.7%	
Asian (non-Hispanic)	2.3%	0.3%	2.7%	
Multi/Other (non-Hispanic)	4.6%	4.5%	4.7%	
Hispanic (any race)	14.3%	5.6%	16.3%	
Education				**≤0.001**
High school or less	50.4%	56.4%	49.1%	
Some college	31.1%	29.7%	31.4%	
Bachelor's degree or higher	18.5%	13.9%	19.5%	
Employed	12.4%	10.4%	12.9%	0.065
Household income				**≤0.001**
<\$15,000	30.2%	24.7%	31.5%	
\$15,000–24,999	16.4%	20.9%	15.4%	
\$25,000–34,999	13.0%	13.0%	13.1%	
\$35,000–49,999	12.0%	13.0%	11.8%	
\$50,000–74,999	11.5%	14.5%	10.8%	
\$75,000 and higher	16.8%	13.9%	17.5%	
Self-rated health				0.094
Excellent	2.6%	2.5%	2.6%	
Very Good	9.8%	10.1%	9.8%	
Good	28.8%	24.4%	29.8%	
Fair	37.9%	40.1%	37.4%	
Poor	20.8%	22.9%	20.4%	
Uses assistive device	58.6%	59.3%	58.4%	0.662
Lives alone	25.9%	18.0%	27.6%	**≤0.001**
Gave up driving	27.8%	24.7%	28.5%	**0.036**
At least one household vehicle	80.2%	93.5%	77.1%	**≤0.001**

P-values reported for Chi-Square tests between rural and urban columns. Bold indicates p-values < 0.05. Column totals may not sum precisely to 100% due to rounding.

regional classifications are also included in these data: Northeast, South, Midwest, and West.

Other Characteristics

NHTS data also includes information about age, race/ethnicity, sex (male & female only), educational attainment, household income, and total number of household members. The NHTS classifies individuals as "employed" if they are 16 or older and their primary activity in the last week was either "working" or "temporarily absent from work."

Analyses

We merged household-level and trip-level data with person-level data, to analyze travel patterns at the individual level. We used NHTS person-level weights for all analyses. All analyses were conducted with SPSS Complex Samples Module v. 28.0. Trip data was included as both summed variables (e.g., number of trips) and as dummy variables (e.g., took any trip of that type). We used Chi-square tests to compare variables between rural and urban respondents and across regions. We used a binomial logistic regression to estimate the odds of giving up driving. Pearson correlations between variables included in the regression did not indicate multi-collinearity (42).

Sample

Our sample includes adults (aged 18+) with a travel-limiting disability lasting for more than 6 months or their entire life (unweighted $N = 22{,}716$). **Table 1** provides demographic characteristics on key variables for the sample of adults with a travel-limiting disability, and for the rural and urban subsamples. Rural and urban statistical differences are also reported, and showed that rural respondents were less likely to be female, to live alone, and to be formally educated, and were more likely to be White and to have at least one household vehicle than urban respondents.

RESULTS

Trips Among Drivers and Non-drivers

We were interested in understanding how access to and ability to use a personal vehicle (drivers) shaped community participation for rural and urban people with disabilities, compared to those who could not drive or did not have access to a personal vehicle (non-drivers). We analyzed all data separately for working age (18–64) and 65+ respondents to account for age-based differences in activities (e.g., retirement). **Table 2** shows rural and urban analyses for drivers and non-drivers aged 18–64 and 65+. Rural and urban drivers reported similar frequencies of trips across independent living, health, social, and working domains for both working age and 65+ groups. Significant differences emerged when comparing rural and urban non-drivers, where rural working-age non-drivers reported significantly fewer trips overall, and fewer social and work trips. For those 65+ who were employed, rural non-drivers reported significantly fewer work trips.

Transportation Modes Used by Non-drivers

Those who have given up driving or do not have access to a personal vehicle must use other means to meet their independent living, health, social, and employment transportation needs. **Table 3** reports on the subset of non-driving rural and urban respondents to illustrate what transportation modes they used. Rural respondents were significantly more likely to ride as passengers in a personal vehicle, whereas urban respondents were significantly more likely to walk/roll or use public transportation.

TABLE 2 | Trips taken by drivers and non-drivers with disabilities, by rural/urban (weighted).

	Drivers, 18–64			Drivers, 65+			Non-drivers, 18–64			Non-drivers, 65+		
	Rural	**Urban**	**Sig.**	**Rural**	**Urban**	**Sig.**	**Rural**	**Urban**	**Sig.**	**Rural**	**Urban**	**Sig.**
Any trip	63.5%	67.4%	0.229	61.2%	65.1%	0.164	46.1%	59.3%	**0.030**	34.9%	40.2%	0.286
Independent living trip	44.9%	49.6%	0.176	46.4%	50.7%	0.154	35.8%	40.8%	0.405	24.2%	27.7%	0.476
Health trip	10.8%	11.4%	0.795	8.2%	11.2%	0.062	18.7%	13.2%	0.237	9%	9.5%	0.849
Social trip	22%	24.7%	0.380	23.4%	28.2%	0.086	9.7%	22.4%	**≤0.001**	12.2%	13.3%	0.691
Work trip (employed only)	47.3%	43.6%	0.678	46.5%	38.3%	0.398	16.8%	46%	**0.026**	2.7%	28.9%	**0.008**

P-values reported for Chi-Square tests between rural and urban columns. Bold indicates p-values < 0.05. Work trips include only respondents who were employed.

TABLE 3 | Transportation modes used by non-drivers with disabilities, by rural/urban and region (weighted).

	Non-drivers, over 18			Non-drivers, over 18				
	Rural	**Urban**	**Sig.**	**Northeast**	**Midwest**	**South**	**West**	**Sig.**
Passenger, personal vehicle	83.7%	47.8%	**≤0.001**	30.3%	54.9%	64.3%	50.2%	**≤0.001**
Walk/roll	10.1%	32.8%	**≤0.001**	50.1%	28.5%	17.6%	33.0%	**≤0.001**
Public transportation	6.2%	28.0%	**≤0.001**	36.3%	23.6%	21.5%	23.3%	**0.029**
Taxi/rideshare	1.2%	3.4%	0.093	4.8%	0.8%	3.6%	3.3%	0.200
Driver, personal vehicle	1.4%	3.1%	0.116	3.2%	6.5%	1.9%	1.0%	**0.043**
Other	5.5%	5.7%	0.964	4.4%	2.7%	5.6%	9.9%	0.087

P-values reported for Chi-Square tests between columns. Bold indicates p-values < 0.05. In a subset of cases, some individuals reported "having given up driving," but still drove on their travel diary day.

Regional differences showed that non-drivers with disabilities in the South were the least likely to use public transportation and most likely to travel as a passenger relative to other regions. This is contrasted by residents in the Northeast where over 1/3 (36%) of disabled non-drivers reported using public transportation.

Logistic Regression on Odds of Giving Up Driving

We conducted a logistic regression to explore factors associated with giving up driving. The dependent variable was a dichotomous variable where 1 = "gave up driving due to disability." Explanatory variables included socio-demographic, economic, health/function, and environmental variables. Socio-demographic variables included age (18–64 relative to 65+); sex (female relative to male), race (White, non-Hispanic relative to non-White), and education (some college or bachelor's degree or higher relative to high school education or less). Socio-economic variables included employment status (employed relative to not employed) and household income (<$35,000 relative to $35,000+). We measured health and function with two items. To assess health, we included indicator variables for fair, good, very good, and excellent health relative to poor health. To assess function, we included an indicator variable for using an assistive device. Finally, we included environmental variables including living alone relative to living with others, living in a rural location relative to an urban location, and living in the Northeast, Midwest, or West, relative to the South.

We hypothesized that younger age, employment, and living alone would be associated with lower odds of giving up driving due to higher need for reliable transportation. We also expected rural status would be associated with lower odds of giving up driving because there are fewer public transportation options and distances to services may preclude other transportation alternatives. We hypothesized that better health would also be associated with lower odds of giving up driving, because it may indicate less complex health issues. Similarly, we hypothesized that using an assistive device would be associated with higher odds of giving up driving because it may indicate more complex travel-limiting disabilities. We anticipated that living in the Northeast would be associated with higher odds of giving up driving, due to more transportation options. We controlled for several other sociodemographic factors, such as sex, race, education, and household income, but did not have firm hypotheses about how they would influence giving up driving.

Table 4 reports results from our logistic regression analysis. In general, model variables aligned with our stated hypotheses. However, living alone and variables to control for geographic region were not significant predictors. Having some college or bachelor's degree or higher was associated with lower odds of giving up driving, relative to those with high school education or lower.

We report Nakelkerke's (pseudo $R^2 = 0.112$) and McFadden's (pseudo $R^2 = 0.069$) model fit statistics. Pseudo R^2 statistics are not directly comparable to R^2 statistics, but range from 0 to 1 and provide a benchmark for evaluating alternate models (43). Pseudo R^2 values above 0.2 are considered to indicate good model fit. Although our model did not reach this threshold, fit statistics

TABLE 4 | Logistic regression on odds of giving up driving (weighted).

	OR	95% CI	Sig.
Socio-demographic			
Aged 18–64 (ref: aged 65+)	0.593	0.505-0.696	**≤0.001**
Female (ref: male)	1.084	0.922–1.275	0.329
White, non-Hispanic (ref: Non-White)	1.084	0.909–1.293	0.367
Education (ref: high school or less)			
Some college	0.644	0.534–0.777	**≤0.001**
Bachelor's degree or higher	0.659	0.534–0.812	**≤0.001**
Socio-economic			
Employed (ref: not employed)	0.433	0.312–0.600	**≤0.001**
HH income <$35 K (ref: household income $35 K+)	1.060	0.887–1.266	0.522
Health and function			
Self-rated health (ref: poor)			
Excellent	1.322	0.712–2.456	0.377
Very good	0.595	0.441–0.804	**≤0.001**
Good	0.505	0.404–0.630	**≤0.001**
Fair	0.644	0.528–0.785	**≤0.001**
Uses assistive device (ref: doesn't use)	1.733	1.465–2.050	**≤0.001**
Environmental			
Lives alone (ref: doesn't live alone)	0.847	0.698–1.029	0.094
Rural (ref: urban)	0.740	0.606–0.905	**0.003**
Region (ref: south)			
Northeast	1.048	0.812–1.338	0.707
Midwest	0.917	0.730–1.152	0.457
West	1.133	0.940–1.365	0.190
Intercept	36.266		**≤0.001**

Bold indicates p-values < 0.05. Nagelkerke pseudo $R^2 = 0.112$. McFadden's pseudo $R^2 = 0.069$.

are comparable to other transportation models focused on people with disabilities (25).

DISCUSSION

Prior analyses of the NHTS have explored travel behaviors among disabled and non-disabled adults (25, 26). We expanded upon this work by describing the travel patterns within this disabled population among drivers and non-drivers. Overall, we found no significant differences in trips between disabled drivers living in rural and urban areas. Differences emerged among non-drivers (aged 18–64) whereby those living in rural areas were less likely to take a trip for any reason, but especially for social activities and work, compared to their urban counterparts. Urban residents aged 65+ were also more likely than rural residents to take a trip for work. This may indicate that the dearth of public transportation options in rural areas (9, 12, 44) impacts non-drivers more than drivers, resulting in fewer trips.

Exploring transportation modes among non-drivers revealed that rural residents relied more upon riding as a passenger in a personal vehicle compared to urban residents who were much more likely to walk/roll and use public transportation. Regionally, respondents in the South relied more on riding as a passenger in personal vehicles and less on public transit. This could be explained by the fact that rural areas throughout the South are significantly less likely to receive either §5310 or §5311 funding (34). Simply put, public transportation infrastructure may be underfunded relative to the need. However, region was not a significant factor in the regression predicting odds of giving up driving, after controlling for other factors.

We also found that individuals with better health were less likely to give up driving than those in poor health, and those who used assistive devices (e.g., cane, wheelchair) were more likely to give up driving than those who did not. This is similar to findings from Han et al. (45) who found that more than 2/3 of adults in their study gave up driving due to physical and medical challenges. Clearly, health and function can impact transportation access, specifically, being able to drive. This is an important point because being able to get around independently impacts what people do. For example, Myers and Ravesloot (22) found that disabled adults who traveled independently reported more time working and less time watching television compared to disabled adults whose transportation was dependent on others (i.e., passenger in personal vehicle) or did not travel at all. For many, particularly those living in rural areas, independent transportation is primarily facilitated by driving personal vehicles. In this way, loss of driving may have a larger impact on people living in rural areas than in urban—and, as our results indicate, are less likely to give up driving. As such, more programs are necessary to provide adequate transportation service for non-drivers in rural areas (45).

Another barrier to transportation access is housing affordability. Several individuals interviewed by the Disability Mobility Initiative of Disability Rights Washington described how many of the places they can afford to live are severely underserved by public transit systems. Many of the neighborhoods where transportation is reliable and accessible are too expensive to live. This means that these individuals are faced with a difficult choice: to either live in an affordable home with limited transportation options or live in unaffordable home with better transportation options. However, financial necessities typically demand sacrificing transportation for housing (46). Indeed, Kramer (47) found that, after controlling for income and race in urban settings, public transit access decreased as home prices decreased. The association between housing and public transportation services offers future directions for this research.

Policy Insights

Overall, these results illustrate vast differences in transportation options for disabled adults living in rural and urban areas, particularly among non-drivers. We offer some policy insights that may help to begin addressing these inequities.

Transportation funding has historically favored urban areas. For example, a 1999 report by Seekins et al. (48) showed that urban areas, representing 75% of the total U.S. population, received approximately 94% of federal transportation subsidies.

This inequity persists today in how §5310 dollars are allocated. For instance, Myers and Lissau (34) reported that rural counties (i.e., micropolitan and noncore) receive approximately 5% of §5310 funds, despite the fact that these counties account for over 18% of the disabled population in the U.S. (49). We suggest that the Federal Transit Administration make expanding funding and program capacity in these rural areas a policy priority. Further, the condition that §5311 funds be allocated to rural areas "where many residents often rely on public transit to reach their destinations" seems paradoxical. Such language seems to suggest that transportation services must first exist in order to be supported by §5311. However, there are many rural residents in need of transportation in places where services are non-existent. Funding mechanisms that can not only help maintain rural transportation services, but *establish* them, would be invaluable.

Another approach may include collaborating with faith-based organizations (FBO) to provide transportation services in rural areas. In a survey of 288 rural FBOs, Seekins et al. (50) reported that ∼1/3 were willing to engage in providing transportation to people with disabilities, even people who were not members of their congregation. While the larger FBOs were most likely to own accessible vehicles, many of the smaller FBOs did not. Although, this approach is not without controversy regarding the separation of church and state. Nevertheless, the ubiquity of FBOs throughout rural America represents a potential partner in building cooperative transportation systems to serve disabled non-drivers (51).

Limitations

There are several limitations to this study. First, the NHTS only asks about disabilities that limit travel, which excludes individuals who may experience transportation barriers unrelated to having a disability, and those who have a disability but are not limited in their transportation. This is an important point because some disabled adults may not experience limitations in their travel if they have adequate supports, thus they would not be identified in these analyses. Second, the NHTS does not ask about trips that a person does not take or about difficulties experienced while traveling. Both can impact an individual's propensity to engage in community activities which may not be captured in these data. Finally, the NHTS does not ask about modifications to personal vehicles, which is critically important for understanding the supports that people with disabilities, specifically those who use assistive devices, need to drive themselves.

CONCLUSION

These findings highlight inequities across transportation access (drivers vs. non-drivers) and geography (in terms of rural vs. urban and region) among people with disabilities. Few differences appear to exist among those who can drive. However, without the ability to drive, rural residents are less likely to take any trip, but especially a trip for social or recreational activities. As such, disabled individuals in rural areas are less likely to give up driving than their peers in urban areas, even when they have difficulty traveling, potentially because doing so would significantly reduce their options for community participation. Overall, these findings indicate that more work is necessary to support disabled people who cannot or do not drive, particularly in rural areas where public transportation options are limited. To address these issues, we suggest that federal transportation funding be more equitable distributed to rural areas. Additionally, partnerships with faith-based organizations may be a potential partner toward building cooperative transportation systems.

DATA AVAILABILITY STATEMENT

Publicly available datasets were analyzed in this study. This data can be found here: https://nhts.ornl.gov/.

AUTHOR CONTRIBUTIONS

AM led the conceptual idea for the manuscript. The data analyses and tables were completed by AM and CI. All authors contributed to the writing, critical review, edits, and approval of the submitted version.

FUNDING

This work was supported by the Research and Training Center on Disability in Rural Communities (RTC:Rural) at the University of Montana Rural Institute for Inclusive Communities under a grant from the National Institute on Disability, Independent Living, and Rehabilitation Research (grant number 90RTCP0002). NIDILRR is a Center within the Administration for Community Living (ACL), Department of Health and Human Services (HHS). The research does not necessarily represent the policy of NIDILRR, ACL, or HHS and one should not assume endorsement by the federal government.

REFERENCES

1. Altshuler AA. Transit subsidies: by whom, for whom? *J Am Inst Plan.* (1969) 35:84–9. doi: 10.1080/01944366908977578
2. Hammel J, Magasi S, Heinemann A, Whiteneck G, Bogner J, Rodriguez E. What does participation mean? An insider perspective from people with disabilities. *Disabil Rehabil.* (2008) 30:1445–60. doi: 10.1080/09638280701625534
3. Handy S. The road less driven. *J Am Plan Assoc.* (2006) 72:274–8. doi: 10.1080/01944360608976749
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. McDaniels BW, Harley DA, Beach DT. Transportation, accessibility, and accommodation in rural communities. In: Harley DA, Ysasi N, Bishop M, Fleming A, editors. *Disability and Vocational Rehabilitation in Rural Settings*. Cham: Springer (2018). p. 43–57. Available online at: https://link.springer.com/chapter/10.1007/978-3-319-64786-9_3 (accessed February 13, 2018).
6. National Council on Disability. *Transportation Update: Where We've gone and What We've Learned*. Washington DC: National Council on Disability

(2015). Available online at: https://www.bts.gov/archive/publications/special_reports_and_issue_briefs/issue_briefs/number_03/entire

7. U.S. Department of Transportation: Bureau of, Transportation Statistics. *Transportation Difficulties Keep over Half a Million Disabled at Home*. (2017). Available online at: https://www.bts.gov/archive/publications/special_reports_and_issue_briefs/issue_briefs/number_03/entire special_reports_and_issue_briefs/issue_briefs/number_ 03/pdf/entire.pdf–
8. Arcury TA, Preisser JS, Gesler WM, Powers JM. Access to transportation and health care utilization in a rural region. *J Rural Health*. (2005) 21:31–8. doi: 10.1111/j.1748-0361.2005.tb00059.x
9. Arnold NL, Seekins T, Nelson RE. A comparison of vocational rehabilitation counselors: rural and urban differences. *Rehabil Counsel Bull*. (1997) 41:2–14.
10. Bernier B, Seekins T. Rural transportation voucher program for people with disabilities: three case studies. *J Transport Stat*. (1999) 2:61–70.
11. Burkhardt JE, Nelson CA, Murray G, Koffman D. *Toolkit for Rural Community Coordinated Transportation Services*. Washington, DC: Transportation Research Board (TCRP No. 101) (2004). Available online at: https://www.nap.edu/read/13751/chapter/1 (accessed February 11, 2022).
12. Gonzales L, Stombaugh D, Seekins T, Kasnitz D. Accessible rural transportation: an evaluation of the traveler's cheque voucher program. *Commun Dev*. (2006) 37:106–15. doi: 10.1080/15575330.2006.10383112
13. Baird RM, Rosenbaum SE. *Disability: The Social, Political, and Ethical Debate*. Amherst, NY: Prometheus Books. (2008) 379 p.
14. Cardol M, Jong BAD, Ward CD. On autonomy and participation in rehabilitation. *Disabil Rehabil*. (2002) 24:970–4. doi: 10.1080/09638280210151996
15. Siminski P. Patterns of disability and norms of participation through the life course: empirical support for a social model of disability. *Disabil Soc*. (2003) 18:707–18. doi: 10.1080/0968759032000119479
16. Seekins T, Shunkamolah W, Bertsche M, Cowart C, Summers JA, Reichard A, et al. A systematic scoping review of measures of participation in disability and rehabilitation research: A preliminary report of findings. *Disabil Health J*. (2012) 5:224–32. doi: 10.1016/j.dhjo.2012.05.002
17. *About ACL | ACL Administration for Community Living*. Available online at: https://acl.gov/about-acl (accessed March 7, 2022).
18. Vilhelmson B. Daily mobility and the use of time for different activities. The case of Sweden. *GeoJournal*. (1999) 48:177–85. doi: 10.1023/A:1007075524340
19. Hägerstraand T. What about people in regional science? *Papers Reg Sci*. (1970) 24:7–24. doi: 10.1111/j.1435-5597.1970.tb01464.x
20. Bergstad CJ, Gamble A, Hagman O, Polk M, Gärling T, Ettema D, et al. Influences of affect associated with routine out-of-home activities on subjective well-being. *Appl Res Q Life*. (2012) 7:49–62. doi: 10.1007/s11482-011-9143-9
21. Kenyon S, Lyons G, Rafferty J. Transport and social exclusion: investigating the possibility of promoting inclusion through virtual mobility. *J Trans Geogr*. (2002) 10:207–19. doi: 10.1016/S0966-6923(02)00012-1
22. Myers A, Ravesloot C. Navigating time and space: how Americans with disabilities use time and transportation. *Commun Dev*. (2016) 47:75–90. doi: 10.1080/15575330.2015.1111399
23. Marottoli RA, de Leon CFM null, Glass TA, Williams CS, Cooney LM, Berkman LF. Consequences of driving cessation: decreased out-of-home activity levels. *J Gerontol B Psychol Sci Soc Sci*. (2000) 55:S334–40. doi: 10.1093/geronb/55.6.S334
24. Darcy S, Burke PF. On the road again: the barriers and benefits of automobility for people with disability. *Transport Res Part A Policy Pract*. (2018) 107:229–45. doi: 10.1016/j.tra.2017.11.002
25. Henly M, Brucker DL. Transportation patterns demonstrate inequalities in community participation for working-age Americans with disabilities. *Transport Res Part A Policy Pract*. (2019) 130:93–106. doi: 10.1016/j.tra.2019.09.042
26. Brumbaugh S. Travel patterns of American adults with disabilities. *Bureau Transport Statist*. (2018) 10:1–10. Available online at: https://www.bts.gov/sites/bts.dot.gov/files/docs/explore-topics-and-geography/topics/passenger-travel/222466/travel-patterns-american-adults-disabilities-11-26-19.pdf
27. Mitra SK, Saphores J-DM. How do they get by without cars? An analysis of travel characteristics of carless households in California. *Transportation*. (2020) 47:2837–58. doi: 10.1007/s11116-019-09994-6
28. Okoro CA, Hollis ND, Cyrus AC, Griffin-Blake S. Prevalence of disabilities and health care access by disability status and type among adults — United States, 2016. *MMWR Morb Mortal Wkly Rep*. (2018) 67:882–7. doi: 10.15585/mmwr.mm6732a3
29. King DA, Smart MJ, Manville M. The poverty of the carless: toward universal auto access. *J Plan Educ Res*. (2019) 1–18. doi: 10.1177/0739456X18823252
30. Clery E, Kiss Z, Taylor E, Gill V. *Disabled People's Travel Behaviour and Attitudes to Travel*. Department for Transport, London, United Kngdom. (2107) 47. Available online at: https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/647703/disabled-peoples-travel-behaviour-and-attitudes-to-travel.pdf
31. Myers A, Ipsen C, Smith L. *America at a Glance: How Do Working-Age Adults With Travel-Limiting Disabilities Get Around?* University of Montana Rural Institute (2020). p. 7. Available online at: https://scholarworks.umt.edu/cgi/viewcontent.cgi?article=1065&context=ruralinst_independent_living_community_participation (accessed February 14, 2022).
32. *Enhanced Mobility of Seniors & Individuals with Disabilities - Section 5310 | FTA*. Available online at: https://www.transit.dot.gov/funding/grants/enhanced-mobility-seniors-individuals-disabilities-section-5310 (accessed March 7, 2022)
33. *Formula Grants for Rural Areas - 5311 | FTA*. Available online at: https://www.transit.dot.gov/rural-formula-grants-5311 (accessed March 7, 2022).
34. Myers A, Lissau A. *America at a Glance: 5310 & 5311 Transportation Funding in Rural Counties*. Missoula, MT: The University of Montana Rural Institute for Inclusive Communities (2021). p. 6.
35. *American Community Survey 5-Year Estimates, 2015-2019. Table S1801*. U.S. Census Bureau (2020).
36. Federal Highway Administration. *2017 National Household Travel Survey*. Washington, DC.: U.S. Department of Transportation (2017). Available online at: https://nhts.ornl.gov (accessed February 14, 2022).
37. Dai Y. *Shelley Brock Roth Jill DeMatteis*. 2017 NHTS Weighting Report (2017). p. 53.
38. Myers A, Ward B, Wong J, Ravesloot C. Health status changes with transitory disability over time. *Soc Sci Med*. (2020) 244:112647. doi: 10.1016/j.socscimed.2019.112647
39. Ward B, Myers A, Wong J, Ravesloot C. Disability items from the current population survey (2008–2015) and permanent versus temporary disability status. *Am J Public Health*. (2017) 107:706–8. doi: 10.2105/AJPH.2017.303666
40. Sage R, Ward B, Myers A, Ravesloot C. Transitory and enduring disability among urban and rural people. *J Rural Health*. (2018) 35:460–70. doi: 10.1111/jrh.12338
41. Ratcliffe M, Burd C, Holder K, Fields A. *Defining Rural at the U.S. Census Bureau*. Washington, DC.: ACSGEO-1, U.S. Census Bureau (2016).
42. Coakes SJ. *SPSS: Analysis Without Anguish Using SPSS Version 17.0 for Windows*. 1st ed. Wiley (2009). 300 p.
43. Nagelkerke NJD. A note on a general definition of the coefficient of determination. *Biometrika*. (1991) 78:691–2. doi: 10.1093/biomet/78.3.691
44. Wood J, Brown J, Bond M, Suguri V, Florida State University, et al. Older adult transportation in rural communities: results of an agency survey. *JPT*. (2016) 19:154–67. doi: 10.5038/2375-0901.19.2.9
45. Han D, Lee Y, Yu J, Dejno C. How does driving status affect trip patterns among older adults in suburban and rural communities? *J Trans Health*. (2021) 21:101052. doi: 10.1016/j.jth.2021.101052
46. *Disability Mobility Initiative, Disability Rights Washington. Transportation Access for Everyone: Washington State*. (2021). Available online at: https://indd.adobe.com/view/dc0a72c0-2a05-4397-a17d-3aa0ecce4923 (accessed February 15, 2022).
47. Kramer A. The unaffordable city: housing and transit in North American cities. *Cities*. (2018) 83:1–10. doi: 10.1016/j.cities.2018.05.013
48. Seekins T, Spas D, Hubbard M. *Inequities in Rural Transportation*. Missoula, MT: The University of Montana Rural Institute for Inclusive Communities (1999). p. 4.
49. Leopold A, Greiman L. *America at a Glance: An Update on Rural-Urban Differences in Disability Rates*. RTC: Rural, University of Montana Rural Institute (2022).

50. Seekins T, Bridges S, Santa A, Denis D, Hartsell A. Faith-based organizations: a potential partner in rural transportation. *JPT*. (2008) 11:109–25. doi: 10.5038/2375-0901.11.1.6
51. Seekins T. *Models of Rural Transportation for People with Disabilities*. RTC: Rural, University of Montana Rural Institute (2007). p. 5.

Author Disclaimer: The contents and opinions expressed reflect those of the authors, and should not be considered an endorsement by the funding agency or the Federal Government.

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.

frontiers | Frontiers in Rehabilitation Sciences

BRIEF RESEARCH REPORT
published: 31 May 2022
doi: 10.3389/fresc.2022.863716

Events Across the Life Course Contribute to Higher Mobility Impairment Rates in Rural U.S.

Catherine Ipsen, Bryce Ward and Andrew Myers*

Rural Institute for Inclusive Communities, University of Montana, Missoula, MT, United States

Purpose: This paper investigates how life events such as injuries, health insurance coverage, geography, and occupation contribute to mobility disability rates over time. Findings can inform policies and practices to address factors that may contribute to disability in rural and urban areas.

Methods: We utilized 27 waves of the National Longitudinal Survey of Youth (NLSY) data from 1979 to 2016 to explore how past injury, occupation, health insurance coverage, and rurality predicted mobility impairment at ages 40 and 50 using regression analysis.

Findings: Rural respondents reported significantly higher rates of mobility impairment at age 40 and age 50 relative to people living in urban areas, and were more likely to report injury, work in high exertion occupations, and experience several pain-related health conditions. Using logistic regression and controlling for race and education, we found that people had higher odds of experiencing mobility impairment at age 40 if they reported a broken bone in the last 10 years, reported ever being knocked unconscious, had any workplace injury from 1988 to 2000, or lived in a rural area. People reported lower odds of mobility impairment if they had more consistent health insurance coverage over time. Further analysis showed that people consistently uninsured over time were 91% more likely to report mobility impairment at age 40 than those consistently insured.

Conclusion: A better understanding of environmental factors associated with disability such as access to insurance, risk exposures, resources, and other place-based behaviors can inform additional strategies for reducing the severity and duration of mobility disability.

Keywords: disability, injury, insurance, life-course model, rural

Edited by:
Mats Granlund,
Jönköping University, Sweden

Reviewed by:
Jacqueline Moodley,
University of Johannesburg, South Africa
Anna Karin Andersson,
Mälardalen University, Sweden

***Correspondence:**
Catherine Ipsen
catherine.ipsen@mso.umt.edu

Specialty section:
This article was submitted to Disability, Rehabilitation, and Inclusion, a section of the journal Frontiers in Rehabilitation Sciences

Received: *27 January 2022*
Accepted: *25 April 2022*
Published: *31 May 2022*

Citation:
Ipsen C, Ward B and Myers A (2022) Events Across the Life Course Contribute to Higher Mobility Impairment Rates in Rural U.S.. Front. Rehabilit. Sci. 3:863716. doi: 10.3389/fresc.2022.863716

People in rural areas of the United States (US) are more likely to experience disability (1, 2). For example, 16.6% of residents in nonmetropolitan counties reported a disability compared to 12% of residents in metropolitan counties (3). This difference appears to persist across the life span as rural residents across all age cohorts report disability at similar rates as urban residents who are, on average, 10 years older (4).

While disability rates are typically higher in rural US counties across all disability types and age cohorts, mobility disability is the most prevalent (3, 4). Approximately 9% of the rural US population reports serious difficulty walking or climbing stairs compared to 6% of the urban population (3). Mobility impairment is associated with economic and social impacts for individuals, families, and communities (5, 6). For example, people who report mobility impairment at age 40 work approximately half as many hours over the next decade as individuals who do not report mobility impairment (B. Ward, unpublished data, 2020).

In part, mobility disability is related to life events, such as prior injuries and lack of access to appropriate health care at the time of those injuries, which may be more common in rural areas. For instance, rural areas in the US tend to have more physically demanding jobs associated with workplace injuries (7), and rural individuals have lower rates of insurance coverage and less access to specialty medical care for addressing health issues as they arise (8–10). A better understanding of how life events shape future outcomes can help identify appropriate interventions, services, and accommodations in the workplace and in healthcare delivery.

We used data from the National Longitudinal Survey of Youth 1979 to explore how life events (i.e. injuries, health insurance coverage, geography, and high risk occupations) contribute to higher rates of mobility disability over time. Knowledge about specific upstream factors that contribute to downstream mobility disability can inform policies and practices that may mitigate the incidence and impacts of life events and promote overall wellbeing.

THE LIFE COURSE MODEL

The ecological model of disability describes disability as the outcome of dynamic interactions between a person and their environment (11, 12). The life course model can be used to operationalize the ecological model of disability by tracking individual and environmental interactions over time to predict downstream outcomes, such as chronic disease and disability.

Rather than focus on current conditions to explain health outcomes, the life course model attempts to understand how exposures or risks at different life stages influence health outcomes later in life. The life course model also explores how cumulative interactions between an individual and contextual settings influence the likelihood of developing non-communicable disease or disability (e.g., chronic pain, obesity, diabetes, cardiovascular disease, cancer, chronic respiratory disease, musculoskeletal disorders, and depression).

Within the life course model, Merlo highlights that those with similar socioeconomic factors experience similar outcomes (13). Geographic units of analysis such as neighborhoods, cities, or counties can be used to understand common or associated risk factors across different communities. For example, risk or exposure in a high resourced setting may result in a short-term or temporary impact, e.g., transitory disability (14), whereas the same risk or exposure in a low resourced setting might result in a precipitous decline in health or death (15). In other words, community context matters.

A simple life-course model of disability suggests at least three possibilities to explain persistent rural and urban differences in mobility disability rates (16–19). First, people in rural areas are more likely to acquire disability through injury or illness. This includes introduced risk from both behavioral norms and employment settings. For instance, people in rural areas self-report lower rates of seatbelt use, which translates into increased risk of car accident-related morbidity and mortality (20). Likewise, high-risk for injury occupations such as mining, logging, agriculture, and manufacturing are more prevalent in rural, relative to urban areas (7).

Second, people in rural areas do not achieve the same recovery from injury or illness as their urban counterparts due to compromised access to, or use of, health care. This can stem from a variety of factors including availability of specialized care, insurance coverage, and other community based psychosocial factors. It is well-documented that rural communities have lower rates of per capita specialty care and insurance coverage (8, 10). Additionally, they appear to utilize health care differently, which may introduce additional factors impacting disability outcome. For instance, Young et al., found significant rural-urban differences in worker's compensation healthcare claims after controlling for demographics, injury type, and severity (21). Specifically, rural workers used significantly fewer physical therapy services than their urban counterparts. Lower rates of health care utilization also resulted in different work disability durations for rural workers based on severity of injury. For more severe injuries, rural workers experienced longer work disability durations than urban workers. Conversely, for less severe injuries, rural workers had shorter work disability durations. Within the life course model, it is possible that lower rates of physical therapy services had direct impacts - longer duration of work disability for severe injury, and indirect impacts - incomplete recovery leading to higher rates of mobility impairment over time (21).

Finally, environmental factors in rural areas can impact disability outcomes as well. For example, rural communities typically have fewer employment choices that can accommodate functional limitations associated with disability (22). Inaccessible community infrastructure such as lack of sidewalks, limited public transportation, crosswalks without audio signals, or inaccessible buildings can create barriers to social participation and medical services (23–25). Fewer supports and lack of accessibility can introduce additional socioeconomic risks, such as declining wages, lost employment, and social isolation (26).

In this paper, we explore how life events such as occupation, injury, access to insurance, and geography predict disability status later in life. The findings make an important contribution to the field due to the longitudinal nature of the NYLS79 data and ability to explore cause and effects over time. While we know that rural people experience different rates of disability and health conditions, exploring the precursors to each over time provides a more nuanced understanding for addressing policies and practices that may improve quality of life.

METHODS

National Longitudinal Survey of Youth 1979 (NLSY79)

The NLSY79 is administered by the Bureau of Labor Statistics (BLS) to explore educational, labor force, and family experiences across the life span. The NLSY79 consists of a nationally representative sample of 12,686 US residents born between 1957 and 1964. Respondents completed their first wave of data in 1979, when they were between the ages of 14 and 22. Since that time, a subset of respondents have been resurveyed at multiple times to explore a range of life transitions related to education, residence, employment, income, family composition, and health (27). The NLSY79 was conducted annually from 1979 to 1994, and then bi-annually from 1994 forward. Some survey modules were asked consistently over time, while others were asked at specific points in time, such as when the respondent turned a specific age (e.g., 40+ and 50+ interviews).

Measures

For our analyses, we utilized 27 waves of data spanning 37 years between 1979 and 2016. Due to the length and complexity of the NLSY79 data, we only describe variables used in our analyses and how they were constructed. Several measures were calculated using data from the 40+ health interviews collected during the first survey administration after the respondent turned 40 years old. Other variables were drawn from multiple waves of data to construct proxy measures about experiences and conditions prior to age 40.

Disability

We used dichotomized variables to indicate mobility disability at age 40 and 50. Respondents were classified as having a mobility disability if they answered yes to "having a lot or a little trouble climbing several flights of stairs," as reported in the 40+ and 50+ health interviews.

Occupational Exertion by Age 40

We calculated a proxy variable for share of work history engaged in high exertion occupations by age 40. At each wave of data collection, the NLSY79 collects work history data since the preceding interview including time spent working in different occupations. We recoded NLSY79 occupation codes from different years into a consistent occupational coding scheme based on Pollard (28). Next, we identified high-physical exertion occupations based on questions included in two waves of data collection (1998 and 2000), which asked respondents two indicators of work intensity: (1) Does your job require lots of physical effort? [all, most, some, or none of the time], and (2) My job requires lifting heavy loads, stooping, kneeling, crouching, walking or other types of physical effort [rarely, a little, occasionally, most of the time]. We classified an occupation as high intensity if over 50% of respondents in that job category reported the job required high levels of physical exertion (i.e., reported physical effort all or most of the time AND required lifting etc. occasionally or most of the time). Based on this information, we computed the total time individuals spent in high exertion occupations (average weekly hours * number of weeks), divided by total number of hours worked to arrive at a share of time working in high exertion occupations. When weeks or hours were coded using a range, we used the low end of the range. This constructed variable ranged from 0 (never worked in a high-exertion occupation) to 1 (always worked in high-exertion occupation).

Injury

We used three variables to estimate injury, including broken bones, concussion, and workplace injury. The first two variables came from the 40+ interview, where respondents indicated if (1) they had broken a bone in the last 10 years, and (2) if they had ever been knocked unconscious. The workplace injury variable was derived from 9 waves of NLSY79 data representing 12 years (1988-2000) when respondents indicated if they had any workplace injury since their last NLSY79 survey. We used these data to create a binary variable equal to one if the respondent reported any workplace injury and zero otherwise.

Work Limitation

Each wave of the NLSY79 asks respondents whether a health condition makes them unable to work, limits the amount they work, and/or limits the type of work they can do. For each wave of data, respondents who answered yes to one or more of these questions were assumed to have a work disability. We created an indicator equal to one if a respondent reported a work limitation in any wave through the 40+ health interviews

Heath Indicators

The NLSY79 asked respondents about self-reported health problems and diagnosed health conditions at the 40+ health interview. *Self-reported* health problems included responses to the question "do you have any of the following health problems" and included an exhaustive list of conditions including joint pain and stiffness; asthma; back pain; problems with feet and legs; kidney or bladder problems; stomach or intestinal ulcers; high cholesterol; chest pain or abnormalities; low blood pressure; sinus problems or allergies; frequent indigestion or intestinal troubles; depression or anxiety; painful joints or bursitis; lameness or paralysis; trick or frozen shoulder, knee, or elbow; tuberculosis, jaundice or hepatitis; headaches, dizziness or fainting; eye trouble; ear nose and throat trouble; tooth and gum trouble; skin diseases; thyroid trouble; tumors or growths; deformities; loss of finger or toe; neuritis or nerve dysfunction; epilepsy; frequent trouble sleeping; frequent urinary tract infection; osteoporosis; hardening of the arteries; and anemia. *Diagnosed* health conditions were phrased "Has a doctor ever told you that you have X" and included high blood pressure or hypertension; diabetes; cancers; chronic lung disease, chronic bronchitis, or emphysema; heart attack, coronary heart disease, angina, congestive heart failure, or other heart problems; stroke; emotional, nervous or psychiatric problems; and arthritis or rheumatism.

Health Insurance

We utilized a proxy to estimate health care access over time. Starting in 1989, and in subsequent waves, the NLSY79 surveys

TABLE 1 | Urban and rural *t*-test comparisons of socio-demographics, mobility impairment, injury, work history, and insurance.

	Urban % or *M*	Rural % or *M*	*p*
Female	51.1%	50.0%	0.300
Education–high school graduate	42.2%	50.1%	***
Education–some college of more	48.7%	36.8%	***
White–not hispanic	47.4%	65.2%	***
A little or a lot of difficulty climbing stairs (age 40)	13.2%	17.3%	***
A little or a lot of difficulty climbing stairs (age 50)	24.0%	28.0%	0.004**
Broken bone in last 10 years (through age 40)	12.9%	14.9%	0.056
Ever unconscious (through age 40)	8.2%	10.2%	0.022*
Any workplace injury (1988–2000)	32.1%	35.3%	0.032*
Ever reported physical limitation restricts amount or type of work (through age 40)	43.2%	45.9%	0.073
Mean share of work-life in high physical exertion occupations (through age 40)	23.3	32.1	***
Mean share of observations with health insurance (through age 40)	80.6	76.7	***

Analyses of age 40 outcomes include 8,451 observations. Analyses through age 50 include 7,588 observations.
$^{*}p < 0.05$, $^{**}p < 0.01$, $^{***}p < 0.001$.

asked respondents if they had insurance currently. We calculated the share of "yes" responses across time periods to construct a variable capturing the share of time with health insurance up to age 40. Scores ranged from 0 (no insurance at any time period) to 1 (current insurance at every time period).

Rural Environment

Respondents were classified as living in rural or urban locations based on NLSY79 calculated urban-rural variables derived from Metropolitan Statistical Area (MSA) geo-codes. We defined residents as rural if they lived in a nonmetro area and urban if they lived in a metro area when they responded to the 40+ interviews. We also calculated the duration of rural residence, based on the share of data waves where the respondent was classified as living in rural areas by the 40+ interview. The average person living in a rural area at age 40 reported living in a rural area during 73% of their NLSY interviews between 1979 and 2016, while the average urban resident reported living in a rural area in 10% of their NLSY interviews. From this information, we determined that a dichotomous variable was appropriate for our analyses.

Participants

Our sample was limited to 8,451 respondents who responded to the mobility disability question "Do you have trouble climbing several flights of stairs?", and 13.7% reported mobility impairment at the 40+ survey. Participants were roughly split between male and females (51 vs 49%). Of these 30.7% identified as Black, 19.6% identified as Hispanic, and 49.7% identified as some other race (i.e., not Black, not Hispanic). Approximately 14% of the sample were classified as living in a rural location at the 40+ interview. People who reported living in a rural location at age 40 were significantly more likely to be non-black, non-Hispanic (47.4% urban vs. 65.2%).

Data Analyses

We downloaded NLSY79 data files into STATA V. 16 to construct case files and create model variables. We uploaded model variables into SPSS V. 25 to conduct analyses. Our analytical approach first explored differences in mobility impairment, injury, occupational exertion, health insurance coverage, and health conditions between people who lived in urban and rural locations. Then, we used logistic regression to explore how past injury, health insurance coverage, and rural residence predicted mobility impairment, after controlling for race and education.

RESULTS

Urban and Rural Comparisons of Life Events

Table 1 compares rural and urban rates of mobility impairment, and several explanatory variables including socio-demographics, injuries, workplace demands, and health insurance. Rural respondents were significantly more likely to report mobility impairment at ages 40 and 50, ever being unconscious, and ever suffering a workplace injury. They also reported a significantly smaller share of time with health insurance coverage. For instance, people who lived in urban areas reported health insurance coverage in 81 percent of their interviews through age 40, while people in rural areas reported health insurance coverage in 77 percent of interviews.

People in rural areas also spent significantly more time working in high exertion occupations. We explored how this might impact the probability of workplace injuries and found that a one standard deviation increase in share of employment in a high exertion occupation increased the odds of workplace injuries by 31%, using bivariate logistic regression.

Illness and Health Conditions

Like disability, life-events may shape the development of health conditions. **Table 2** includes comparisons of health

TABLE 2 | Health problem comparisons at age 40 ($n = 8451$).

	Urban %	Rural %	p	No Disability %	Has Disability %	p
Back problems	23.9	29.7	***	20.4	52.3	***
Joint pain/frequent leg cramps/bursitis	14.2	18.8	***	10.1	44.3	***
Frequent trouble sleeping	15.5	20	***	12.2	41.2	***
Ever had arthritis or rheumatism	11.2	14.8	***	8.1	34.1	***
Indigestion/intestinal/gall bladder problems	8.7	11.8	0.001**	7.1	22.3	***
Chest pain/pounding heart/other heart problems	5.4	7.9	0.001**	4	17.4	***
Depression/excess worry/nervous problems	12.7	15.9	0.003**	9.8	34.2	***
Diagnosed hypertension	16.7	20.3	0.003**	14.8	32.5	***
Frequent headaches/dizzy/fainting	10.5	13.3	0.004**	8.5	26.7	***
Ulcer	2.5	3.9	0.005**	1.9	7.9	***
Foot and leg problems	19.5	22.5	0.015*	14.1	56.7	***
Diagnosed stoke	0.8	1.3	0.047*	0.5	3.3	***
Kidney or bladder problems	4.5	5.7	0.063	3.4	12.8	***
Lameness/paralysis/polio	1.1	1.7	0.065	0.5	5.8	***
Diagnosed emotional/nervous problems	7.3	8.7	0.085	5.3	20.5	***
Severe tooth or gum trouble	6.1	7.4	0.1	5	13.9	***
Stomach or intestinal problems	5.2	6.3	0.106	3.9	14.4	***
Frequent colds/sinus/allergies	23.9	25.8	0.155	21.9	38.2	***
Diagnosed heart problems	2.8	3.5	0.194	1.9	9.1	***
Diagnosed chronic lung disease	2.8	3.5	0.206	1.7	10	***
Hardening of the arteries	0.3	0.5	0.213	0.3	0.6	0.049*
Osteoporosis	0.9	1.2	0.216	0.5	3.2	***
Diagnosed congestive heart failure	0.3	0.5	0.216	0.1	1.6	***
Neuritis	0.5	0.7	0.23	0.3	1.6	***
Frequent urinary tract infections	2.1	1.7	0.301	1.6	4.9	***
Skin diseases	2.7	3.2	0.304	2.4	5.1	***
Ear, nose, or throat problems	6.1	6.8	0.333	4.9	14.1	***
Scarlet/rheumatic fever, TB, jaundice, hepatitis	1.6	2	0.359	1.3	4.2	***
Diagnosed non-skin cancer	2.1	1.7	0.432	1.6	5.1	***
Thyroid trouble or goiter	3.7	3.3	0.47	3.1	6.7	***
Diagnosed diabetes	5.5	5	0.485	4.1	13.3	***
Eye trouble (not glasses)	5.2	4.8	0.553	3.8	14.2	***
Asthma	8	7.5	0.555	5.9	20.7	***
Anemia	5.3	4.9	0.564	4.1	12.1	***
Epilepsy or fits	1.1	1.2	0.66	0.8	3	***
High cholesterol	10.8	11.2	0.698	9.8	18.1	***
Low blood pressure	5.3	5.5	0.781	4.6	9.6	***

*$p < 0.05$, **$p < 0.01$, ***$p < 0.001$.

conditions between people living in rural and urban locations and for individuals with and without mobility impairment at age 40. Relative to urban people, respondents living in rural areas were more likely to report conditions like back problems, joint pain, trouble sleeping, and arthritis/rheumatism, which are often associated with more physically demanding employment (7). Comparatively, many conditions were not more common in rural areas, such as cancer, diabetes, asthma, chronic lung disease, anemia, or epilepsy. People with mobility impairment at age 40 reported significantly higher rates of every reported health condition than individuals who did not report mobility impairment.

Predicting Mobility Impairment With Logistic Regression

Table 3 shows a logistic regression predicting mobility impairment at age 40. After controlling for race/ethnicity and educational attainment, explanatory variables included indicators of past injury (i.e., broken bone in the last 10 years, ever unconscious, and any workplace injury), share of work-life in high exertion occupations, share of observations with health insurance, and living in rural at age 40. We checked model variables for potential multicollinearity and found none.

People who reported a broken bone, being knocked unconscious, or having workplace injury were 87, 48, and 41%

TABLE 3 | Logistic regression on mobility impairment at age 40 ($n = 8,451$).

	B	SE	p	OR	Lower	Upper
Not black, not Hispanic	−0.405	0.069	0.000	0.667	0.583	0.763
Education (Ref: no Ged)						
High school graduate	−0.445	0.100	0.000	0.641	0.527	0.78
Some college or more	−0.813	0.113	0.000	0.444	0.355	0.554
Broken bone in last 10 years at age 40	0.629	0.084	0.000	1.876	1.591	2.213
Ever unconscious by age 40	0.396	0.104	0.000	1.486	1.212	1.822
Any workplace injury by age 40	0.347	0.067	0.000	1.415	1.24	1.615
Share of worklife in high exertion occupation at age 40	−0.15	0.125	0.233	0.861	0.673	1.101
Share of health insurance up to age 40	−0.315	0.119	0.008	0.73	0.578	0.922
Rural residence at age 40	0.315	0.087	0.000	1.371	1.156	1.626
Constant	−1.22	0.134	0.000	0.322		

Nagelkerke R2 = 0.055.

more likely to report mobility impairment at age 40, respectively. After controlling for these injuries, the share working in high exertion occupations was not a significant predictor. Living in a rural location at age 40 increased the odds of mobility impairment by 37%, while share of health insurance coverage lowered the odds by 73%. Further analysis with bivariate logistic regression showed that people consistently uninsured over time were 91% more likely to report mobility impairment at age 40 than those consistently insured.

Table 4 shows the relationship between life course indicators by age 40 and reported impairment at age 50. Of the sample completing the NLSY at age 50 ($n = 7,588$), 15.8% became impaired between 40 and 50 (transitioned into disability), 4.6% reported impairment at 40 but not at 50 (transitioned out of disability), and 8.7% reported impairment at 40 and 50 (enduring disability). We report the odds of having a mobility impairment at age 50 for each of these groups, using the same explanatory variables as reported for mobility impairment at age 40.

Transitioned Into Disability Between 40 and 50

The first results column shows how conditions at age 40 predict who will become impaired between ages 40 and 50. The logistic regression was confined to the 6,575 people who did not have a mobility impairment at age 40. Evidence of injury increased the odds of becoming impaired by age 50, while more consistent health insurance coverage lowered the odds

Transitioned out of Disability Between 40 and 50

The second results column reports on those who reported mobility impairment at age 40 but did not report impairment at age 50. This logistic regression was confined to the portion of the sample who had impairment at age 40 ($n = 1,158$). In this model, predictors worked in the opposite direction, where reporting a broken bone at age 40 lowered the odds of not reporting mobility impairment at age 50 and having a higher share of insurance coverage at age 40 increased the odds of not reporting mobility impairment at age 50.

Reported Enduring Disability at Ages 40 and 50

The final column focused on the people who reported mobility impairment at both age 40 and age 50 (i.e., enduring disability). Conditions at age 40 strongly predicted consistent impairment. People who reported a broken bone or having workplace injury at age 40 were 69 and 45% more likely to report mobility impairment at age 50. Similarly, consistently having health insurance was associated with a 75% percent decrease in the odds of reporting consistent impairment.

DISCUSSION

A better understanding of disability and its precursors informs strategies for future interventions, and provides guidance for allocating health resources to those who may be more likely to experience disability across the lifespan. Data from the present study highlight contextual factors that may play a role in disability severity and duration, and how these factors vary across urban and rural locations. Specifically, rural respondents by age 40 had significantly higher odds of having a broken bone, concussion, or workplace injury in the prior 10 years than respondents from metro locations. Controlling for rurality revealed that these types of injuries were also significant factors on their own.

Many injuries occurred at the workplace and led to higher odds of mobility disability. This highlights the importance of workplace safety and safety culture to reduce accidents and the importance of effective medical care when injuries occur. Because workplace injuries did not happen uniformly across geography, it suggests rural and urban differences in injury treatment (21). One strategy to address this is to increase worker's compensation benefits immediately following injury (21, 29). Worker's compensation benefits typically cover medical costs to treat injury, temporary disability benefits to offset lost wages, and permanent disability benefits when workplace injuries lead to permanent impairment (30). Temporary disability benefits vary across states, but typically pay a portion of lost wages (e.g., 2/3 of wages) after a specified waiting period (e.g., one-week). Because people in rural areas experience higher rates of poverty, lower

TABLE 4 | Logistic regression models on mobility impairment at age 50.

	Model 1∆ (*n* = 6575)		**Model 2 + (*n* = 1158)**		**Model 3 □ (*n* = 7588)**	
	OR	**Sig**	**OR**	**Sig**	**OR**	**Sig**
Not black, not hispanic	0.677	0.000	0.794	0.097	0.809	0.015
Education (Ref: no Ged)						
High school graduate	0.742	0.006	1.165	0.447	0.623	0.000
Some college or more	0.545	0.000	1.363	0.163	0.456	0.000
Broken bone in last 10 years at age 40	1.277	0.012	0.687	0.033	1.697	0.000
Ever unconscious by age 40	0.940	0.613	0.684	0.088	1.423	0.007
Any workplace injury by age 40	1.214	0.005	0.941	0.655	1.453	0.000
Share of worklife in high exertion occupation at age 40	1.123	0.361	0.796	0.350	0.900	0.511
Share of health insurance up to age 40	0.568	0.000	1.741	0.030	0.573	0.000
Rural residence at age 40	1.147	0.140	1.032	0.858	1.339	0.008
Constant	0.545	0.000	0.311	0.000	0.214	0.000
Nagelkerke R^2	0.043		0.033		0.045	

∆Model 1 predicts people who transitioned into disability - did not report impairment at age 40 but did report impairment at age 50 (1,196 out of 6,575 possible).
+Model 2 predicts people who transitioned out of disability - reported impairment at age 40 but did not report impairment at age 50 (346 out of 1,158 possible).
□Model 3 predicts people with enduring disability - reported impairment at age 40 and age 50 (667 out of 7,588 possible).

wages, and fewer employment options, this may shape decision making to seek care and access temporary disability benefits (31). Providing more liberal payments for lost wages and removing waiting periods, may increase the probability of a more complete recovery (32).

Further analysis of the data showed that some injuries were independent of the workplace (i.e., not reporting workplace injury, but reporting broken bones and/or concussion). Different rural and urban prevalence rates may point to variations in behavioral norms and activities, including decision-making to seek care. We know that the rate of enduring disability (i.e., reporting disability at both age 40 and age 50) was lower for respondents reporting more instances of health care insurance coverage up to age 40. This evidence suggests that access to insurance is a particularly important factor for adequately addressing injury and lowering the odds of experiencing long-term disability and highlights the value of programs such as Medicaid expansion for the uninsured (33).

Other care-seeking factors are at play in rural communities. For instance, rural people have more limited access to specialty healthcare services, must travel further to access services, or may have privacy concerns related to healthcare visits (34). Policies and infrastructure to increase access to telehealth may be one strategy to reduce these types of care-seeking barriers. As telehealth access increases, additional variables that account for access to medical services and health seeking behaviors may provide additional information for understanding these impacts.

Onset of disability is associated with economic costs for individuals and families (5). For instance, a study using data from the Panel Study of Income Dynamics (PSID), reported that those with onset of chronic or severe disability between the ages of 18 and 65 experienced a 79% reduction in earnings and a 22% decline in food consumption 10 years later. However, this same study showed that negative economic outcomes were significantly moderated 10 years after onset for respondents with chronic but not severe, temporary, and one-time only reported disability (35). This suggests that interventions that can improve access for people with disabilities early-on (i.e., healthcare, Medicaid, workplace accommodations) may improve long-term economic outcomes.

These differences highlight the importance of addressing the onset of disability with appropriate medical access, behavioral, and social/community interventions. Looking at data using a life course model allows us to see how severe or chronic disability unfolds over time and offers opportunities to address risk and exposure incidents that reduce the incidence and severity of long-term disability. Additional research based on the life-course model could focus on additional risk and protective factors, such as adverse childhood events or childhood access to consistent healthcare.

LIMITATIONS

This paper and analyses were limited by the NLSY79 survey questions. First, the NLSY79 does not measure the varied experience of disability. Our analyses were focused on respondents reporting mobility impairment, defined as having a lot or a little trouble climbing several flights of stairs at the 40+ and 50+ health interviews. Disability rates, however, are higher in rural areas for multiple disability types, including hearing, vision, cognitive, ambulatory, self-care, and independent living disabilities (36). Similarly, many explanatory variables were proxies which may have under or over-estimated specific characteristics, such as health insurance coverage, duration of disability, and rural status. Despite imprecise measurement, however, the models provided consistent evidence about the relationships between environmental factors and subsequent disability experience.

CONCLUSIONS

The ecological model of disability posits that disability is the result of personal and environmental factors. The life-course model expands on this theory by highlighting how personal/environmental interactions across the life-course factor into the longer-term experience of disability. Better understanding of environmental factors such as access to insurance, risk exposures, resources, and other place-based behaviors inform additional strategies for reducing the severity or duration of disability.

DATA AVAILABILITY STATEMENT

Publicly available datasets were analyzed in this study. This data can be found here: https://www.nlsinfo.org/content/cohorts/nlsy79.

AUTHOR CONTRIBUTIONS

BW, CI, and AM developed the presented idea, discussed the results, and contributed to the final manuscript. BW and CI developed the theory and computations. CI and AM verified the analytical methods. All authors contributed to the article and approved the submitted version.

FUNDING

This work was supported by the Research and Training Center on Disability in Rural Communities (RTC:Rural) under a grant from the National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR; Grant number 90RTCP0002). NIDILRR is a Center within the Administration for Community Living (ACL), Department of Health and Human Services (HHS). The research does not necessarily represent the policy of NIDILRR, ACL, or HHS and one should not assume endorsement by the federal government.

REFERENCES

1. Seekins T, Greiman L. *Map facts: disability in rural America*. Missoula, MT: University of Montana Rural Institute (2014). Available online at: https://scholarworks.umt.edu/ruralinst_independent_living_community_participation/8 (accessed March 8, 2021).
2. von Reichert C, Greiman L, Myers A, Rural Institute U of M. *The Geography of Disability in America: On Rural-Urban Differences in Impairment Rates. Independent Living and Community Participation.* (2014). Available online at: https://scholarworks.umt.edu/ruralinst_independent_living_community_participation/7
3. Lauer E, Boege S, Houtenville A. *Annual Disability Statistics Compendium: 2019*. Durham, NH: University of New Hampshire's Institute on Disability (2020) Available online at: https://disabilitycompendium.org/ (accessed October 14, 2020).
4. Sage R, Ward B, Myers A, Ravesloot C. Transitory and enduring disability among urban and rural people. *J Rural Health.* (2018) 35:1–11. doi: 10.1111/jrh.12338
5. Clarke P, Latham K. Life course health and socioeconomic profiles of Americans aging with disability. *Disabil Health J.* (2014) 7:S15–23. doi: 10.1016/j.dhjo.2013.08.008
6. National Bureau of Economic Research. *Annual Disability Satistics*. Cambridge, MA: National Bureau of Economic Research (2013). (Bulletin on Aging and Health). Report No.: 1. Available online at: https://www.nber.org/bah/2013no1/prevalence-and-economic-consequences-disability (accessed June 7, 2021)
7. Abdalla S, Apramian SS, Cantley LF, Cullen MR. Occupation and Risk for Injuries. In: Mock CN, Nugent R, Kobusingye O, Smith KR, editors. *Injury Prevention and Environmental Health*. 3rd ed. Washington (DC): The International Bank for Reconstruction and Development/The World Bank (2017). Available online at: http://www.ncbi.nlm.nih.gov/books/NBK525209/ (accessed September 23, 2020).
8. Gong G, Phillips SG, Hudson C, Curti D, Philips BU. Higher us rural mortality rates linked to socioeconomic status, physician shortages, and lack of health insurance. *Health Aff.* (2019) 38:2003–10. doi: 10.1377/hlthaff.2019.00722
9. Singh GK, Siahpush M. Widening rural–urban disparities in all-cause mortality and mortality from major causes of death in the USA, 1969–2009. *J Urban Health.* (2014) 91:272–92.
10. US Census Bureau. *Health Insurance in Rural America*. The United States Census Bureau (2019). Available online at: https://www.census.gov/library/stories/2019/04/health-insurance-rural-america.html (accessed September 23, 2020).
11. Centers for Disease Control and Prevention. *Social Ecological Model.* (2013). Available online at: https://www.cdc.gov/cancer/nbccedp/sem.htm (accessed April 13, 2019).
12. Shogren KA. A social–ecological analysis of the self-determination literature. *Intellect Dev Disabil.* (2013) 51:496–511. doi: 10.1352/1934-9556-51.6.496
13. Merlo J. Contextual influences on the individual life course: Building a research framework for social epidemiology. *Psychosoc Interv.* (2011) 20:109–18. doi: 10.5093/in2011v20n1a9
14. Myers A, Ward B, Wong J, Ravesloot C. Health status changes with transitory disability over time. *Soc Sci Med.* (2020) 244:112647. doi: 10.1016/j.socscimed.2019.112647
15. Hanson MA, Cooper C, Sayer AA, Eendebak RJ, Clough GF, Beard JR. Developmental aspects of a life course approach to healthy ageing. *J Physiol.* (2016) 594:2147. doi: 10.1113/JP270579
16. Bowen ME. Childhood socioeconomic status and racial differences in disability: Evidence from the Health and Retirement Study (1998–2006). *Soc Sci Med.* (2009) 69:433–41. doi: 10.1016/j.socscimed.2009.06.006
17. Freedman DVA, Martin LG, Schoeni RF, Cornman JC. Declines in late-life disability: the role of early- and mid-life factors. *Soc Sci Med.* (2008) 66:1588. doi: 10.1016/j.socscimed.2007.11.037
18. Laditka JN, Laditka SB. Unemployment, disability and life expectancy in the United States: a life course study. *Disabil Health J.* (2016) 9:46–53. doi: 10.1016/j.dhjo.2015.08.003
19. Rank MR, Hirschl TA. The risk of developing a work disability across the adulthood years. *Disabil Health J.* (2014) 7:189–95. doi: 10.1016/j.dhjo.2013.12.001
20. Beck LF. Rural and urban differences in passenger-vehicle–occupant deaths and seat belt use among adults — United States, 2014. *MMWR Surveill Summ.* (2017) 66:1–13. doi: 10.15585/mmwr.ss6617a1
21. Young AE, Cifuentes M, Wasiak R, Webster BS. Urban-rural differences in work disability following occupational injury: are they related to differences in healthcare utilization? *J Occup Environ Med.* (2009) 51:204–12. doi: 10.1097/JOM.0b013e3181917d8e
22. Lund S, Manyika J, Segel L, Dua A, Hancock B, Rutherford S, et al. *The Future of Work in American: People and Places, Today and Tomorrow*. McKinsey Global Institute (2019). p. 135. Available online at: https://www.mckinsey.com/featured-insights/future-of-work/the-future-of-work-in-america-people-and-places-today-and-tomorrow# (accessed September 24, 2020).

23. Myers A, Ipsen C, Smith L. *America at a Glance: How Do Working-Age Adults With Travel-Limiting Disabilities Get Around?* University of Montana Rural Institute (2020) p. 7. Available online at: https://scholarworks.umt.edu/cgi/viewcontent.cgi?article=1065&context=ruralinst_independent_living_community_participation (accessed September 2, 2022).
24. Myers A, Ravesloot C. Navigating time and space: how Americans with disabilities use time and transportation. *Community Dev.* (2016) 47:75–90. doi: 10.1080/15575330.2015.1111399
25. Seekins T, Arnold N, Ipsen C. Developing methods for grading the accessibility of a community's infrastructure. *J Urban Plan Dev.* (2012) 138:270–6. doi: 10.1061/(ASCE)UP.1943-5444.0000117
26. Shahin S, Reitzel M, Di Rezze B, Ahmed S, Anaby D. Environmental factors that impact the workplace participation of transition-aged young adults with brain-based disabilities: a scoping review. *Int J Environ Res Public Health.* (2020) 17:2378. doi: 10.3390/ijerph17072378
27. NLSY79 Data Overview : U.S. *Bureau of Labor Statistics*. Available online at: https://www.bls.gov/nls/nlsy79.htm (accessed October 14, 2020).
28. Pollard E. *A New Approach to Industry and Occupation Recoding in the CPS*. Technical Briefings (2019). Available online at: https://www.kansascityfed.org/publications/research/technicalbriefings/articles/2019/0624-new-approach-industry-occupation-recoding (accessed October 16, 2020).
29. Varacallo M, Knoblauch DK. Occupational Injuries and Workers' Compensation Management Strategies. In: *StatPearls*. Treasure Island (FL): StatPearls Publishing (2022).
30. Skowronski J. Hurt on the job? A state-by-state guide to workers' compensation. Policygenius (2018). Available online at: https://www.policygenius.com/personal-finance/news/state-by-state-guide-to-workers-compensation/ (accessed April 20, 2022).
31. Thiede B, Greiman L, Weiler S, Beda SC, Conroy T. *Six Charts That Illustrate the Divide Between Rural and Urban America*. The Conversation. (2017). Available online at: http://theconversation.com/six-charts-that-illustrate-the-divide-between-rural-and-urban-america-72934 (accessed February 13, 2018).
32. Ruser J, Pergamit M, Krishnamurty P. *Workers' Compensation "Reforms" and Benefit Claiming. U.S. Bureau of Economic Analysis, Washington DC.* (2004). Available online at: https://gsbww.uchicago.edu/labor/Ruser.pdf (accessed 2022 April 21).
33. Hoadley J, Alker J, Holmes M. *Health Insurance Coverage in Small Towns and Rural America: The Role of Medicaid Expansion*. Center For Children and Families (2018). Available online at: https://ccf.georgetown.edu/2018/09/25/health-insurance-coverage-in-small-towns-and-rural-america-the-role-of-medicaid-expansion/ (accessed February 13, 2019).
34. Rural Health Information Hub. *Healthcare Access in Rural Communities.* (2019). Available online at: https://www.ruralhealthinfo.org/topics/healthcare-access (accessed June 7, 2021).
35. Meyer BD, Mok WKC. *Disability, Earnings, Income and Consumption*. National Bureau of Economic Research (2013). Report No.: w18869. Available online at: https://www.nber.org/papers/w18869 (accessed June 7, 2021).
36. StatsRRTC. *2020 Annual Disability Statistics Compendium*. Annual Disability Statistics Compendium (2020). Available online at: https://disabilitycompendium.org/compendium/2020-annual-disability-statistics-compendium (accessed June 10, 2021).

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.

frontiers | Frontiers in Rehabilitation Sciences

BRIEF RESEARCH REPORT
published: 02 June 2022
doi: 10.3389/fresc.2022.876047

Exploring Metro and Non-metro Differences in Satisfaction With Services and Community Participation Among Low-Income Personal Assistance Service Users

Rayna Sage*, Krys Standley and Genna M. Mashinchi

Rural Institute for Inclusive Communities, University of Montana, Missoula, MT, United States

Personal assistance services (PAS) are supports provided by workers to assist disabled people with their activities of daily living. Access to in-home PAS allows people who need assistance with these activities to live in their own homes and communities, rather than moving to congregate living facilities. Because metro and non-metro areas differ in many ways, we explored the following research questions: (1) Are there differences between non-metro and metro PAS users?, (2) What factors are associated with satisfaction with services?, and (3) What factors are associated with satisfaction with community participation?. We randomly surveyed PAS consumers in five states about their experiences with PAS. To answer the first question, we compared metro or non-metro consumers using independent samples *t*-tests. We found few statistically significant differences between metro and non-metro respondents. To answer the second and third research questions, we conducted linear regressions predicting our dependent variables. In terms of satisfaction with services, our model explained very little of the variance, other than finding that being partnered or married was significantly, positively related to satisfaction with services. In predicting satisfaction with community participation, the model explained about a quarter of the variance, with having fewer disabilities and higher health status predicting more satisfaction. This research indicates that there are few differences between metro and non-metro low-income PAS consumers and that more research is needed to understand what factors are related to satisfaction with services and community participation in this population.

Keywords: personal assistance services, personal care attendants, people with disabilities, rural, urban

Edited by:
John W. Lui,
University of Wisconsin-Stout Vocational Rehabilitation Institute, United States

Reviewed by:
Zhuoying QIU,
China Rehabilitation Research Center/WHO Collaborating Center for Family International Classifications, China
Taslim Uddin,
Bangabandhu Sheikh Mujib Medical University (BSMMU), Bangladesh

****Correspondence:***
Rayna Sage
rayna.sage@mso.umt.edu

Specialty section:
This article was submitted to Disability, Rehabilitation, and Inclusion, a section of the journal Frontiers in Rehabilitation Sciences

Received: *15 February 2022*
Accepted: *27 April 2022*
Published: *02 June 2022*

Citation:
Sage R, Standley K and Mashinchi GM (2022) Exploring Metro and Non-metro Differences in Satisfaction With Services and Community Participation Among Low-Income Personal Assistance Service Users.
Front. Rehabilit. Sci. 3:876047.
doi: 10.3389/fresc.2022.876047

INTRODUCTION

For over ten million people with disabilities[1], paid in-home support through Personal Assistance Services (PAS) (1) makes living and working in their community possible. These services provide critical assistance with activities such as bathing, dressing, toileting, housekeeping, and meal preparation (2). With adequate PAS, disabled people can remain in their homes and communities (3) and have the energy to comfortably and safely work, volunteer, socialize, and connect with others in their communities (3, 4).

---

[1] we use "people with disabilities" and "disabled people" interchangeability to reflect the preferences of current disability advocates.

Despite the importance of these services and the fact that work in PAS is one of the fastest growing occupations (5), little is known about how satisfied people are with these services, especially low-income people in non-metro areas. Furthermore, despite the importance of community participation in the well-being of people with disabilities (6), little research has explored how satisfied rural disabled people are with their community participation. This exploratory study considers differences between metro and non-metro PAS consumers and examines predictors of satisfaction with services and community participation. Here we present a brief overview of existing literature regarding satisfaction with services and community participation, followed by a summation of the need for more rural-specific research and related research questions.

Satisfaction With PAS Services

There are a number of factors that have been explored in relation to satisfaction with PAS, but the majority have focused on issues around consumer choice and control in hiring, training, and maintaining their workers. Advocates during the Independent Living Movement in the 1970s and 1980s (7) pushed policymakers to find ways to move away from agency-controlled practices to consumer-directed models. Decades of research has established that consumer-directed programming is preferred over agency-based services (8, 9). Furthermore, some found high levels of satisfaction across different service delivery models, but elements of consumer choice and control (e.g., finding and hiring own aides, having the aide be a direct employee of the consumer, and more flexibility in who can be hired) were more related to satisfaction, regardless of the model (10). The most comprehensive research on the topic of self-directed models of care were related to the Money Follows the Person Demonstration Project (11), with research affirming that a move to more self-direction is associated with more satisfaction and less institutionalization. For example, across disability groups, moving out of institutions has been associated with more community participation and fewer barriers to community integration (12, 13). Despite challenges with community living, such as transportation barriers, Money Follows the Person beneficiaries have reported overall satisfaction with the program, including increased autonomy and overall well-being connected to living in their communities (14). Research on other models of care highlights how having more integrated services for consumers dually-enrolled in both Medicare and Medicaid led to higher levels of satisfaction with benefits and improved perceptions of quality of care (15). Finally, research into consumer characteristics such as race and gender of PAS users has found that Mexican Americans were more likely to have family caregivers than white consumers and that consumer race was not related to levels of satisfaction (16). Additionally, while satisfaction levels were similar across men and women, women were more likely to report problems with care.

Community Participation

Having the ability to participate in community is a component of functioning related to health (17) that has become a standard for outcome measurement in rehabilitation (18) and can therefore be considered vital for the well-being of disabled people. Rural people face additional barriers in community participation related to transportation and limited services (19), which means using more time, energy, and resources than urban people to accomplish these activities. Adding to the complexity of the situation, rural people are generally older (20), more likely to be single and live alone (21), and have a higher rate of disability (21) than urban folks.

In short, compared to their urban counterparts, rural people with disabilities are doubly challenged in realizing their community participation goals because of higher levels of environmental barriers such as inaccessible infrastructure and a lack of public transportation (6). It is unknown how these various factors interact and potentially impact the community participation of disabled people who live in rural areas and rely on PAS. While little research exists regarding rural and urban differences in how PAS are delivered and used, there is reason to believe that rural PAS consumers may be less satisfied with their community participation experiences.

In this exploratory study, we used data collected in early 2020 (pre-pandemic) in a paper-and-pencil mail survey of PAS consumers. We examined differences in non-metro and metro PAS consumers and what factors are related to satisfaction with services and satisfaction with community participation in order to improve our understanding of this unique and understudied rural population. More specifically, we addressed three exploratory research questions:

1) Are there differences between non-metro and metro PAS users?
2) What factors are associated with satisfaction with services?
3) What factors are associated with satisfaction with community participation?

METHOD

To answer these questions, we mailed a paper-and-pencil mail survey (copy of full survey available upon request) to 1,200 Consumer Direct Care Network PAS consumers in January of 2020. In addition to demographic questions and our variables of interest related to satisfaction with services and community participation, the survey also included questions on worker characteristics, health, electronic visit verification, and other topics relevant to PAS. We then conducted independent sample *t*-tests to explore metro and non-metro differences before constructing linear regression models to predict both satisfaction with services and community participation. To follow is a description of recruitment, measures, procedures, and analysis used.

Abbreviations: PAS, Personal assistance services; OMB, United States Office of Management and Budget.

Recruitment

At the time of this study, our partnering organization (Consumer Direct Care Network) was serving mostly self-directed Medicaid-funded consumers in 17 states. Based on feedback from our Rural PAS Advisory Board (consisting of seven stakeholders including consumers, service providers, and organizational staff), we decided to target consumers in five geographically and programmatically diverse states: Arizona, Alaska, Montana, Texas, and Wisconsin. While the majority of consumers in these states were in self-directed programs that allowed for consumer-based worker recruitment, hiring, and management, some agency-based programming continues to exist. Thus, based on 5-year estimates from Consumer Direct Care Network administrative data, we sampled each state differently to maximize rural and agency-based representation (see **Appendix A** for more information).

Procedures

After obtaining exempt status from the Institutional Review Board (IRB) at the University of Montana, we mailed pencil-and-paper surveys to 600 metro and 600 non-metro addresses across the five states. We used a Dillman multi-contact method (22), including a pre-notice letter, survey packet with $1 incentive, and follow-up postcard. Mailings were spaced approximately six days apart. Interested participants completed and returned the anonymous survey, which was expected to take 30 min. Research project staff were responsible for assembling the mailings and Consumer Direct Care Network staff applied mailing labels and mailed the materials to protect consumer confidentiality.

Of the 1,200 survey packets mailed out, 196 were returned because they were sent to undeliverable addresses, the person had died, or the person did not currently receive PAS. Surveys were returned by 190 participants, ten of which were omitted as they were completed by or for someone under the age of 18. This resulted in a response rate of 19%. Ninety percent of the respondents completed the entire survey. We received 96 non-metro and 85 metro responses.

Measures

Relevant to this study, the survey included measures of basic demographics, disability type, general health status, satisfaction with services, satisfaction with community participation, metro/non-metro status, and service type (self-directed or agency). To follow is a description of each of the measures.

Demographics

In open-ended questions, participants were asked to indicate their gender and answers were categorized into women and men. Age was also asked using an open-ended question and dichotomized to be working age [18–65] and non-working age (66 and older). We measured race using a check-all-that-apply option of American Indian/Alaska Native, Asian, Black/African American, Native Hawaiian/Other Pacific Islander, White, and Other (with space for a write-in answer). We also asked participants to indicate if they identified as Hispanic or Latino. Answers were then collapsed into a single dichotomous variable of White, Non-Hispanic and Non-White or Hispanic. Partnered-status was measured by asking if participants were single/never married, single/divorced or separated, widowed, married, or living with a serious partner. Partnered-status was then dichotomized as married/partnered or single. To measure income, respondents were provided seven categories of income ranging from <$10,000 to $100,000 or more. For this analysis, these categories were collapsed into a dichotomous variable of $20,000 or less and $20,001 or more.

Disability Type

Disability type was measured using the six-item set of dichotomous questions which are also asked in the American Community Survey (23). Respondents were prompted to indicate if they: (1) are deaf or have serious difficulty hearing, (2) are blind or have serious difficulty seeing, (3) have serious difficulty concentrating or remembering, (4) have serious difficulty walking or climbing stairs, (5) have serious difficulty dressing or bathing, or (6) have serious difficulty doing errands alone. We constructed a count variable of disability by adding responses to these six questions together to indicate multiple disabilities.

General Health Status

General health status was measured using a single item from the Health Related Quality of Life Scale (24): "Would you say that in general your health is: poor, fair, good, very good, or excellent?"

Type of Care Provider

We asked respondents to answer the question: "If you have more than one paid caregiver, who provides the MOST assistance?", to which they could select immediate family member, extended family member, friend or someone they knew before, someone they did not know, or fill in an "other" option. For this study, we dichotomized type of care provider as family (including family or extended family members) and non-family.

Satisfaction With Services

We used a 23-item modified version of the *Community Care for the Elderly (CCE) Client Satisfaction Survey* (25) converted to focus on PAS and added six related questions suggested by our Rural PAS Advisory Board members. The 23 items covered topics related to overall satisfaction, satisfaction with services, satisfaction with workers, and the impact of services on well-being, independent living, and community participation. The 23-item scale has a Cronbach's α of 0.92.

Satisfaction With Social and Community Participation

We used a four-item question set included in the PROMIS-29 scale (24) to indicate satisfaction with social and community participation. Respondents were asked to indicate on a five-point Likert scale (1 = never, 5 = always) how often they had trouble with: (1) doing all their regular leisure activities with others, (2) doing all the family activities they want to do, (3) doing all their regular work (including work at home), and (4) doing all the activities with friends that they want to do. Scores were reverse coded so that higher scores indicated more satisfaction. The 4-item scale has a Cronbach's α of 0.92.

Non-metro/Metro Status

Consumer Direct Care Network provided the research team with a list of de-identified zip codes of current self-directed and agency-based consumers. The zip codes were used to identify corresponding Rural-Urban Continuum Codes for each potential respondent. The research team created a cross-walk file based on guidelines provided by the Housing and Urban Development's Office of Policy and Development Research (26). This file was then used by Consumer Direct Care Network data analysts to assign non-metro and metro statuses. Non-metro status (Rural-Urban Continuum Codes = 4–9), based on the United States Office of Management and Budget's (OMB's) published standards that are applied to Census Bureau data, included any county with <50,000 people. Metro status was applied to Rural-Urban Continuum Codes of 1-3.

Program Type

As with non-metro/metro status, Consumer Direct Care Network data analysts matched consumer addresses with codes applied to the return envelopes to indicate self-direction or agency-based programming.

Statistical Analysis

We first used independent samples *t*-tests to compare non-metro and metro respondent characteristics and satisfaction with services and community participation to answer our first research question. We then tested two linear regression models to understand how geographic, demographic, program type, type of caregiver, multiple disabilities, and health status characteristics help explain differences in satisfaction with services and community participation to answer our second and third research questions.

RESULTS

Non-metro and Metro Similarities and Differences

Table 1 includes means for each variable by non-metro and metro status and *p*-values resulting from independent samples *t*-tests indicate significant differences. All PAS users in this sample had very low-incomes, with two-thirds of metro and one in four non-metro respondents reporting household incomes of $20,000 or less. In general, the majority of respondents were unpartnered. The vast majority of respondents were utilizing self-directed services and non-metro respondents were significantly more likely to be self-directed than metro (96% vs. 82%, $p < 0.01$). Overall, the most common disability types were serious difficulties walking or climbing stairs, dressing or bathing, and running errands independently. Metro respondents were significantly more likely to report serious difficulty dressing and bathing compared to non-metro respondents (82% vs. 66%, $p < 0.05$), while non-metro respondents were significantly more likely to report serious difficulty running errands independently (93% vs. 50%, $p < 0.05$). Finally, metro respondents had significantly higher number of disabilities compared to non-metro (3.56 vs. 3.06, $p < 0.05$).

TABLE 1 | Sample descriptive statistics by non-metro/metro status.

	Non-Metro	Metro	*p*
Women	66%	62%	0.603
Working age (18–65 years)	55%	62%	0.334
Married/partnered	10%	18%	0.167
White, non-hispanic	78%	66%	0.077
Household income $20,000 or less	76%	66%	0.166
Self-directed services	96%	82%	0.003
Paid family care provider	56%	54%	0.879
Disability			
Deaf	16%	22%	0.306
Blind/Low vision	19%	22%	0.614
Memory/Concentration	43%	57%	0.064
Walking/Climbing stairs	82%	80%	0.707
Dressing/Bathing	66%	82%	0.025
Running errands	93%	50%	0.028
Count of disabilities (mean, 0–6)	3.06	3.56	0.010
Health status (mean, 1–5)	2.48	2.32	0.311
Satisfaction with services (mean, 1–5)	3.96	3.85	0.259
Satisfaction with community participation (mean, 1–5)	2.65	2.37	0.263

Linear Regression Results

Prior to conducting the linear regression analyses, we completed Pearson's correlations for all variables. There were no strong correlations to indicate the existence of interacting variables or multicollinearity. To follow is a brief summary of the linear regression results for both satisfaction with services and satisfaction with community participation.

Satisfaction With Services

Overall, the linear regression model (see **Table 2**) predicting satisfaction with services was not statistically significant. The only variable in the model that was significant in relation to satisfaction with services was being partnered, which was positively related ($\beta = 0.586$, SE $= 0.233$, $p < 0.05$).

Satisfaction With Community Participation

The linear regression model (see **Table 3**) predicting satisfaction with community participation was statistically significant ($F = 4.37$, adjusted R-squared=0.26, $p < 0.001$), with the variables included in the model explaining 26% of the variance in satisfaction. In this model, the number of disabilities reported by the respondent was negatively related to satisfaction with services ($\beta = -0.227$, SE $= 0.085$, $p < 0.01$), while health status was positively related to the variable of interest ($\beta = 0.371$, SE $= 0.118$, $p < 0.01$).

DISCUSSION

In answer to our first research question, "Are there differences between non-metro and metro PAS users?", we found that consumers of PAS in metro and non-metro areas were very similar. The exceptions were that non-metro consumers were more likely to be self-directed and have serious difficulties

TABLE 2 | Linear regression predicting satisfaction with services.

	β	*SE*	*p*-value	VIF
Non-metro	0.060	0.154	0.696	1.269
Women	0.231	0.156	0.143	1.200
Working age (18-65 years)	0.214	0.163	0.194	1.311
White, non-Hispanic	0.137	0.159	0.390	1.137
Household income <\$20,000	0.080	0.189	0.672	1.648
Married/Partnered	0.586	0.233	0.014	1.531
Self-directed services	0.002	0.142	0.990	1.260
Paid family care provider	−0.028	0.063	0.662	1.068
Count of disabilities	0.269	0.234	0.254	1.349
Health status	0.002	0.142	0.990	1.545
Observations		88		
Adjusted *R*-Squared		0.06		
F-Value		1.54		

TABLE 3 | Linear regression predicting satisfaction with community participation.

	β	*SE*	*p*-value	VIF
Non-metro	0.200	0.221	0.367	1.272
Women	0.075	0.222	0.736	1.205
Working age (18–65 years)	0.192	0.239	0.423	1.357
White, non-Hispanic	0.027	0.231	0.906	1.123
Household income <\$20,000	0.132	0.272	0.628	1.736
Married/Partnered	−0.231	0.332	0.488	1.585
Self-directed services	−0.354	0.334	0.292	1.263
Paid family care provider	0.261	0.207	0.212	1.097
Count of disabilities	−0.227	0.085	0.009	1.271
Health status	0.371	0.118	0.002	1.506
Observations		96		
Adjusted R-Squared		0.26		
F-Value		4.37***		

$^{***}p < 0.001$.

running errands independently compared to metro respondents, while metro respondents were more likely to have serious difficulties dressing and bathing and reported more disabilities on average than non-metro respondents. Higher rates of self-direction among non-metro consumers makes sense in that agencies, like many organizations and businesses, tend to operate out of and in urban centers.

These findings may point to barriers in the geographic or built environments of non-metro communities (e.g., lack of public transportation, ramps, or automatic doors in public and private buildings as a potential barrier to people with mobility limitations) (27). This seems particularly relevant in relation to the higher rates of serious difficulties running errands independently among non-metro respondents, perhaps highlighting how some disabilities are a product of the environment and not necessarily traits unique to non-metro individuals. The higher rates of serious difficulties dressing and bathing among metro respondents may be related to how some people with disabilities move from more rural places to more urban places for better access to services (28–30).

To answer our second research question, "What factors are associated with satisfaction with services?", we found that our model was not effective in explaining variation in satisfaction. While we included variables indicated by previous research, only being partnered was significantly related to satisfaction with services. For the people in this study who are lower income and are receiving home-based services through Medicaid, rurality does not predict or relate to satisfaction with services, regardless of whether or not the care provider is a family member, or the type of program they are enrolled in.

To answer our third research question, "What factors are associated with satisfaction with community participation?", we found that our model was effective in explaining some of the variance in satisfaction with community participation, but many demographic factors, including rurality, were not significantly related to this type of satisfaction. Instead, the number of disabilities experienced by respondents, as well as health status, seem to be driving the significance of this model. This appears to indicate that degree of functional impairment bears on people's satisfaction with community participation. Existing research highlights there are no differences in actual community participation between metro and non-metro older adults, but closer proximity to certain environmental features such as neighborhood resources and public transportation increased social participation across geography (27).

Future Research Directions

Based on these findings, further research is warranted to better understand what factors are related to satisfaction with services and community participation. Although the 23-item measure of satisfaction with services had high reliability, a *post-hoc* factor analyses of the measure revealed that with more data, different aspects of satisfaction with services could provide a more nuanced understanding of PAS users' beliefs about the services they receive. Additional research is also needed to explore how PAS services might be organized or improved to overcome the unique environmental barriers in rural communities. Furthermore, additional research should seek to understand how to improve satisfaction with community participation for people with different disability types, especially disability related to mobility impairments and health status. Previous work suggests that pain, fatigue, and depression are negatively related to leaving the home (31) and thus, may also be important in satisfaction with community participation.

Limitations

Strengths of this study were its use of several complementary measures of demographics, disability type, general health status, satisfaction with community participation, metro/non-metro status, and self-directed/agency-directed PAS. The study further benefitted from the investigators' efforts to evenly sample metro and non-metro PAS users. Because this study relied on self-report data, reporting bias was a potential limitation. Additional limitations included small sample size and missing data, both of which were connected to a low survey response rate.

This response level suggests that PAS users are a challenging population to survey.

CONCLUSION

The present study explored the differences between metro and non-metro PAS users and further examined factors that might contribute to satisfaction with services and satisfaction with community participation. Despite many differences between metro and non-metro locations and access to resources, our findings found very few differences between metro and non-metro PAS users. However, of note, the significant findings related to non-metro individuals having serious difficulty running errands and being more likely to have self-directed services are in line with past literature and underscore the difficulty non-metro users experience when attempting to access the resources they need, whether that be through a lack of services available or through a lack of accessible transportation. Additionally, based on our findings, accessibility and access might further play a role in community participation, as those with fewer disabilities and higher health status were more satisfied with community participation. Inasmuch, access to resources to help with health and disability status, which are disproportionately fewer in non-metro areas, might affect not only health status, but also the ability to connect with others in the community. Thus, bridging the gap in accessibility to resources such as transportation and services might not only facilitate the ability of non-metro individuals to meet their basic needs, such as running errands and having access to services, but also to engage in their communities.

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 University of Montana Institutional Review Board, University of Montana. Written informed consent for participation was not required for this study in accordance with the national legislation and the institutional requirements.

AUTHOR CONTRIBUTIONS

RS conceptualized and designed the study and analyzed the data and subsequently revised the draft and created the tables. KS wrote the initial draft of the manuscript. KS and RS drafted the appendix. GM provided critical review of the paper and suggested edits. RS, KS, and GM contributed to the review and final edits. All authors contributed to the article and approved the submitted version.

FUNDING

This work was supported by the Research and Training Center on Disability in Rural Communities (RTC:Rural) under a grant from the National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR; Grant Number 90RTCP0002-01-00), which is a Center within the Administration for Community Living (ACL), Department of Health and Human Services (HHS). The research does not necessarily represent the policy of NIDILRR, ACL, or HHS and one should not assume endorsement by the federal government.

ACKNOWLEDGMENTS

The authors wish to thank Ari Lissau for collecting and cleaning the data used in this study, Catherine Ipsen for her critical feedback, and Justice Ender for his contributions in earlier phases of this project.

SUPPLEMENTARY MATERIAL

The Supplementary Material for this article can be found online at: https://www.frontiersin.org/articles/10.3389/fresc.2022.876047/full#supplementary-material

Supplementary Appendix A | More in-depth details about the sampling strategy.

REFERENCES

1. Kaye HS, Harrington C, LaPlante MP. Long-term care: Who gets it, who provides it, who pays, and how much? *Health Aff (Millwood).* (2010) 29:11–21. doi: 10.1377/hlthaff.2009.0535
2. U.S. Department of Labor Office of Disability Employment Policy. *Personal Assistance Services*. U.S. Department of Labor. (n.d). Available from: https://www.dol.gov/agencies/odep/program-areas/employment-supports/personal-assistance-services (cited Feb 11, 2022).
3. Chen YM, Berkowitz B. Older adults' home- and community-based care service use and residential transitions: a longitudinal study. *BMC Geriatr.* (2012) 12:44. doi: 10.1186/1471-2318-12-44
4. World Health Organization, UNESCO, International Labour Organization, International Disability Development Consortium. Personal assistance. In: *Community-Based Rehabilitation: CBR Guidelines*. Geneva: World Health Organization (2010). p. 7. Available from: https://www.ncbi.nlm.nih.gov/books/NBK310929/ (cited Feb 11, 2022).
5. U.S. Bureau of Labor Statistics. *Home Health and Personal Care Aides : Occupational Outlook Handbook*. (2021). Available from: https://www.bls.gov/ooh/healthcare/home-health-aides-and-personal-care-aides.htm (cited September 22, 2021).
6. Barclay L, McDonald R, Lentin P. Social and community participation following spinal cord injury: a critical review. *Int J Rehabil Res.* (2015) 38:1–19. doi: 10.1097/MRR.0000000000000085
7. DeJong G. *Defining and Implementing the Independent Living Concept*. USA: Jossey-Bass Publishers (1983). 4–27 p.
8. Carlson BL, Foster L, Dale SB, Brown R. Effects of Cash and Counseling on Personal Care and Well-Being. *Health Serv Res.* (2007) 42:467–87. doi: 10.1111/j.1475-6773.2006.00673.x

9. Harry ML, Mahoney KJ, Mahoney EK, Shen C. The Cash and Counseling model of self-directed long-term care: effectiveness with young adults with disabilities. *Disabil Health J.* (2017) 10:492–501. doi: 10.1016/j.dhjo.2017.03.001
10. Doty P, Kasper J, Litvak S. Consumer-directed models of personal care: lessons from Medicaid. *Milbank Q.* (1996) 74:377–409. doi: 10.2307/3350306
11. Fabius C, Shugrue N, Robison JT. Outcomes associated with home and community-based service use among older adults following a nursing home transition. *J Gerontol Soc Work.* (2020) 63:807–21. doi: 10.1080/01634372.2020.1830328
12. Coughlin R, Ward J, Denny-Brown N, Hagen B, Maurer K, Morris E, et al. *Money Follows the Person Demonstration: Overview of State Grantee Progress 2016*. Cambridge, MA: Mathematica Policy Research (2017). Available from: https://www.mathematica.org/-/media/publications/pdfs/disability/2017/mfp-2016-cross-state-report.pdf
13. Sheth AJ, McDonald KE, Fogg L, Conroy NE, Elms EHJ, Kraus LE, et al. Satisfaction, safety, and supports: Comparing people with disabilities' insider experiences about participation in institutional and community living. *Disabil Health J.* (2019) 12:712–7. doi: 10.1016/j.dhjo.2019.06.011
14. Kellett K, Ligus K, Robison J. *The Final Word: Connectitcut MFP Participants' Qualitative Feedback on Program Experiences—The Money Follows the Person Rebalancing Demonstration*. Farmington, CT: UConn Health Center on Aging (2018). doi: 10.1093/geroni/igx004.3072
15. Graham CL, Liu PJ, Hollister BA, Kaye HS, Harrington C. Beneficiaries respond to california's program to integrate medicare, medicaid, and long-term services. *Health Aff (Millwood).* (2018) 37:1432–41. doi: 10.1377/hlthaff.2018.0452
16. Mitchell JM, Kemp BJ. Satisfaction ratings and problems experienced with paid personal attendant care: ethnic comparisons. *Top Geriatr Rehabil.* (1999) 14:53–67. doi: 10.1097/00013614-199906000-00005
17. World Health Organization. *International Classification of Functioning, Disability and Health*. Geneva, Switzerland: World Health Organization (2001). 299 p. Available from: http://psychiatr.ru/download/1313?view=name=CF_18.pdf
18. Seekins T, Shunkamolah W, Bertsche M, Cowart C, Summers JA, Reichard A, et al. A systematic scoping review of measures of participation in disability and rehabilitation research: A preliminary report of findings. *Disabil Health J.* (2012) 5:224–32. doi: 10.1016/j.dhjo.2012.05.002
19. Mattson J. *Transportation, Distance, and Health Care Utilization for Older Adults in Rural and Small Urban Areas. Small Urban & Rural Transit Center Upper Great Plains Transportation Institute North Dakota State University*. (2010). Available from: https://www.ugpti.org/resources/reports/downloads/dp-236.pdf (cited February 11, 2022).
20. Smith AS, Trevelyan E. *In Some States, More Than Half of Older Residents Live In Rural Areas*. U.S. Census Bureau (2019). Available from: https://www.census.gov/library/stories/2019/10/older-population-in-rural-america.html (cited February 11, 2022).
21. Schroeder J, Henning-Smith C, Tuttle M. *Demographics and Disability Status of Adults Living Alone in Rural Areas*. University of Minnesota Rural Health Research Center (2021). Available from: http://rhrc.umn.edu/wp-content/uploads/2021/04/UMN-Policy-Brief_Demographics-and-Disability-Status-of-Rural-Adults-Living-Alone_3.23.21.pdf (cited February 11, 2022).
22. Dillman DA, Smyth JD, Christian LM. *Internet, Phone, Mail, and Mixed-Mode Surveys: The Tailored Design Method*. 4th ed. Hoboken, NJ: Wiley (2014) 528 p.
23. U.S. Census Bureau. *How disability data are collected from the American Community Survey*. (2017). Available from: https://www.census.gov/topics/health/disability/guidance/data-collection-acs.html (cited June 1, 2018).
24. Hays RD, Spritzer KL, Schalet BD, Cella D. PROMIS®-29 v20 profile physical and mental health summary scores. *Qual Life Res.* (2018) 27:1885–91. doi: 10.1007/s11136-018-1842-3
25. Office of Strategic Initiatives, Bureau of Planning and Evaluation. *Community Care for the Elderly (CCE) Client Satisfaction Survey*. Tallahassee, Florida: Department of Elder Affairs, State of Florida) (2016). Available from: http://elderaffairs.state.fl.us/doea/Evaluation/Client_Satisfaction_Survey_2016.pdf
26. Office of Policy Development and Research. *HUD USPS ZIP Code Crosswalk Files*. (2018). Available from: https://www.huduser.gov/portal/datasets/usps_crosswalk.html (cited January 8, 2021).
27. Levasseur M, Cohen AA, Dubois MF, Généreux M, Richard L, Therrien FH, et al. Environmental factors associated with social participation of older adults living in metropolitan, urban, and rural areas: the NuAge study. *Am J Public Health.* (2015) 105:1718–25. doi: 10.2105/AJPH.2014.302415
28. Rural Health Information Hub. *Healthcare Access in Rural Communities*. (2019). Available from: https://www.ruralhealthinfo.org/topics/healthcare-access (cited June 7, 2021).
29. Clawar M, Randolph R, Thompson K, Pink GH. Access to care: populations in counties with no FQHC, RHC, or acute care hospital. *NC Rural Health Research Program*. (2018) 3. Available online at: https://www.shepscenter.unc.edu/wp-content/uploads/dlm_uploads/2018/01/AccesstoPrimaryCare.pdf (accessed May 10, 2022).
30. Rural Health Information Hub. *Transportation to Support Rural Healthcare Overview*. (2022). Available from: https://www.ruralhealthinfo.org/topics/transportation (cited April 19, 2022).
31. Ravesloot C, Ward B, Hargrove T, Wong J, Livingston N, Torma L, et al. Why stay home? Temporal association of pain, fatigue and depression with being at home. *Disabil Health J.* (2016) 9:218–25. doi: 10.1016/j.dhjo.2015.10.010

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.

frontiers | Frontiers in Rehabilitation Sciences

TYPE Brief Research Report
PUBLISHED 02 August 2022
DOI 10.3389/fresc.2022.875979

OPEN ACCESS

EDITED BY
John W,
Lui, University of Wisconsin-Stout
Vocational Rehabilitation Institute,
United States

REVIEWED BY
Kylie Radford,
Neuroscience Research
Australia, Australia
Helen Russette,
Johns Hopkins University,
United States

*CORRESPONDENCE
Genna M. Mashinchi
genna.mashinchi@umontana.edu

SPECIALTY SECTION
This article was submitted to
Disability, Rehabilitation, and Inclusion,
a section of the journal
Frontiers in Rehabilitation Sciences

RECEIVED 14 February 2022
ACCEPTED 12 July 2022
PUBLISHED 02 August 2022

CITATION
Mashinchi GM, Hicks EC, Leopold AJ,
Greiman L and Ipsen C (2022) The
intersection of disability status and
rurality in American Indian/Alaskan
Native communities.
Front. Rehabilit. Sci. 3:875979.
doi: 10.3389/fresc.2022.875979

The intersection of disability status and rurality in American Indian/Alaskan Native communities

Genna M. Mashinchi*, Emily C. Hicks, Arin J. Leopold,
Lillie Greiman and Catherine Ipsen

University of Montana, The Rural Institute for Inclusive Communities, Missoula, MT, United States

There is a noteworthy gap in the literature regarding disability in rural American Indian/Alaskan Native (AI/AN) communities. This is significant, as many tribal lands are in rural areas and AI/AN individuals experience some of the highest prevalence rates of disability. To address this gap, we used descriptive statistics to examine the intersection of AI/AN and rurality in disability prevalence. Results indicate that rural counties have the highest prevalence of disability for both Whites and AI/ANs and that AI/ANs experience higher prevalence rates than Whites. However, further analysis indicates that county makeup (counties with high prevalence of AI/AN in the general population) moderated this relationship. Specifically, rural counties with populations of at least 5% AI/AN had lower prevalence of AI/AN disability compared to counties with populations with less than 5% AI/AN. Further analysis is needed to unpack this relationship, but results might suggest that AI/AN communities may feature resilient and protective attributes, moderating the amount of disability experienced in rural AI/AN communities.

KEYWORDS

disability, American Indian/Alaskan Native, rural, health disparities, health equity, social determinants of health

Introduction

Disabled people[1] have historically been stigmatized and marginalized throughout the United States (1). While important legislation such at the Americans with Disabilities Act, the Rehabilitation Act, and the Olmstead Decision have led to significant progress in increasing disability awareness and promoting full inclusion into American society (2), inequities in access and inclusion persist (1, 3). Marginalization is compounded for minoritized groups (e.g., American Indians/Alaskan Natives, Blacks, Hispanics) who also experience disability (4). In fact, data from four national population surveys conducted in 2015 revealed that minoritized individuals—such as individuals of an ethnic or racial minority—report disability at disproportionately higher rates than White individuals (4).

Despite increased disability awareness and literature regarding disparities faced by individuals with disabilities, there is a significant knowledge gap regarding disability

---

[1] The terms people with disabilities (person first language) and disabled people (identity first language) are used interchangeably to reflect the current preferences of advocates in the disability rights field.

among American Indian/Alaskan Natives (AI/ANs), particularly those living in rural areas. U.S. Census data indicate that 16% of AI/ANs report disability across counties, and that prevalence rates increase as counties become more rural (5). This finding aligns with descriptive statistics that show individuals in rural counties have higher prevalence of disability across racial groups, and that the most rural (non-core) counties have higher prevalence of disability, compared to less rural (micropolitan) and urban (metropolitan) counties (5). While the majority (63.5%) of AI/AN individuals reside in urban areas (6), the remaining rural population represents nearly one million (982,517) people with 17% (nearly 170,000) reporting disability (6).

The limited research looking at the intersection of AI/AN identity, disability, and rurality has focused on health outcomes, rather than environmental factors (7). This is problematic because disability is shaped by the interaction between functional limitation (e.g., difficulty walking, grasping, or concentrating) and environmental factors (e.g., community characteristics, access to resources, social stigmatization, and exclusionary policies). While symptoms of specific health conditions can result in a variety of functional limitations, it is the interaction of those limitations with the surrounding environment that produces the incidence and severity of disability (6, 7).

Community characteristics (e.g., sociodemographic and access factors) that rural AI/AN individuals encounter are critical to understanding the disability experience (8), and shape the need for studies examining disability disparity from a community-specific perspective. Of note, Henning-Smith et al. (9) examined premature death rates and the intersection of rurality and race in AI/AN, White, and Black communities from a county-level perspective. The authors found that rural counties with a majority of AI/AN residents experienced significantly higher premature death rates, even after adjusting for community-level covariates. However, disability rates were not examined.

We explored the prevalence of disability for the AI/AN population living in rural communities. Given past findings that AI/AN populations report higher levels of disability and disproportionately live in more rural areas—which also have higher prevalence of disability (5)—we hypothesized that there would be a positive association between AI/AN prevalence and AI/AN disability prevalence rates across geographic locations.

Methods

Sample

The study sample consisted of 3,220 counties across the United States and the unit of analysis was at the county vs. individual level.

Procedure

All data was from the American Community Survey 5-year estimates (2015–2019) (6). The American Community Survey is a cross sectional survey operated by the US Census Bureau. It uses an annual rolling sample, collecting data on 2.5% of the US population per year for an aggregated sample of 12.5% of the US population in the 5-year estimates. A 2015 report found that while there is increased room for estimate error for small geographies, the coefficients of variation for AI/AN communities were similar to others of similar sizes and deemed reliable (10).

Race/ethnicity was defined as the percentage of the county population of each racial category based on ACS data reports. We used AI/AN and White racial categories for these analyses.

We accessed 2018 cartographic boundary shapefiles for geographic analyses (counties, states, and tribal areas) from the US Census Bureau's geography downloads.

We created an AI/AN county makeup variable to analyze AI/AN populations more closely. This was a binary coded variable, such that counties with $\geq$5% of residents identifying as AI/AN were classified as having "high AI/AN" populations, and the remaining counties were classified as "remaining."

Disability was defined using the American Community Survey six question set asking about functional ability and supports. If a response was yes to at least one of the following six American Community Survey questions, we classified individuals as having a disability:

1. Are you deaf, or do you have serious difficulty hearing?
2. Are you blind or do you have serious difficulty seeing even when wearing glasses?
3. Because of a physical, mental, or emotional problem, do you have difficulty remembering, concentrating or making decisions?
4. Do you have serious difficulty walking or climbing stairs?
5. Because of a physical, mental, or emotional problem, do you have difficulty dressing or bathing?
6. Because of a physical, mental, or emotional problem, do you have difficulty running errands alone, such as visiting a doctor's office or shopping?

We classified counties as metropolitan, micropolitan, and non-core using the United States Office of Management and Budget (OMB) classification. OMB classifies counties as metropolitan and nonmetropolitan based on population data collected by the U.S. Census Bureau. The OMB defines metropolitan counties as counties with an urban core of over 50,000 people. Metropolitan counties are generally considered to be urban. Non-metropolitan counties are classified into two rural subclassifications: micropolitan counties, with urban

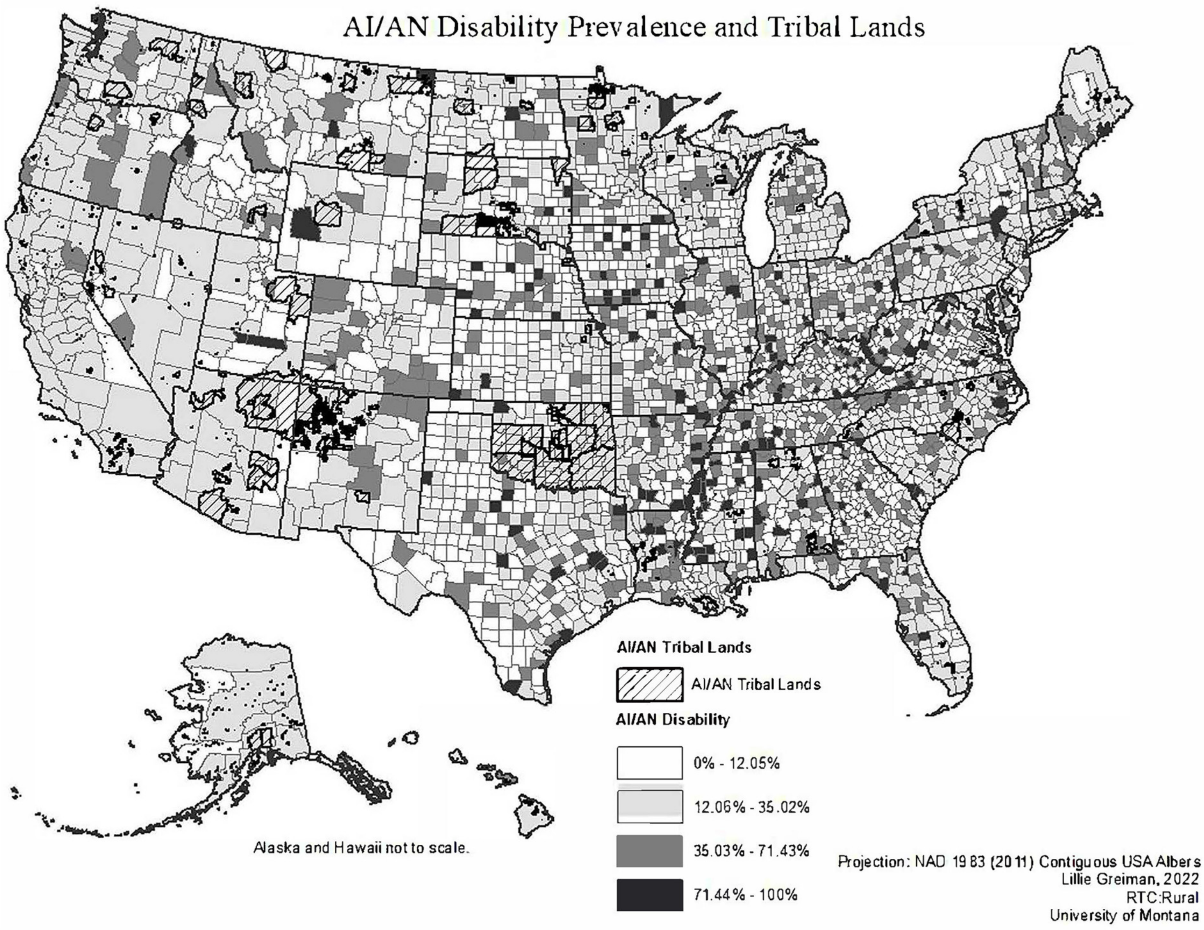


FIGURE 1
Map of AI/AN disability prevalence overlayed with AI/AN tribal reservation and trust lands.

populations between 10,000 and 50,000 people, and non-core counties as all remaining counties with urban cores <10,000 (11).

Data analysis

Analyses were conducted in ArcMap, Version 8.1 and IBM SPSS Statistics for Windows, Version 28.0. We used ArcMap to visually examine county-level geographic distribution of AI/AN disability prevalence. We used SPSS to run descriptive statistics, *t*-tests, and Pearson *r* correlations to explore the relationship between disability and rurality in AI/AN populations.

Results

Figure 1 illustrates the geographic variation in AI/AN disability prevalence with an overlay of Tribal Trust and Reservation lands. There does not appear to be any visual correlation or relationship between higher rates of AI/AN disability and counties overlapping tribal lands where a significant proportion of AI/ANs reside.

A Pearson *r* correlation analysis of counties revealed a significant negative correlation between the AI/AN concentration in the county population and the AI/AN county disability prevalence, $r(3{,}218) = -0.061$, $p < 0.001$. This finding indicates that higher concentrations of AI/AN in the county population were associated with lower rates of reported disability among AI/AN county residents.

Figure 2 shows a visual map representation of counties with high AI/AN populations. There were 211 counties with AI/AN populations of 5% or more. These counties are located primarily across the western United States with high concentrations in Alaska, Oklahoma, South Dakota, Montana, Arizona, and New Mexico.

Table 1 compares disability rates between “high” and “remaining” counties using group comparison *t*-tests

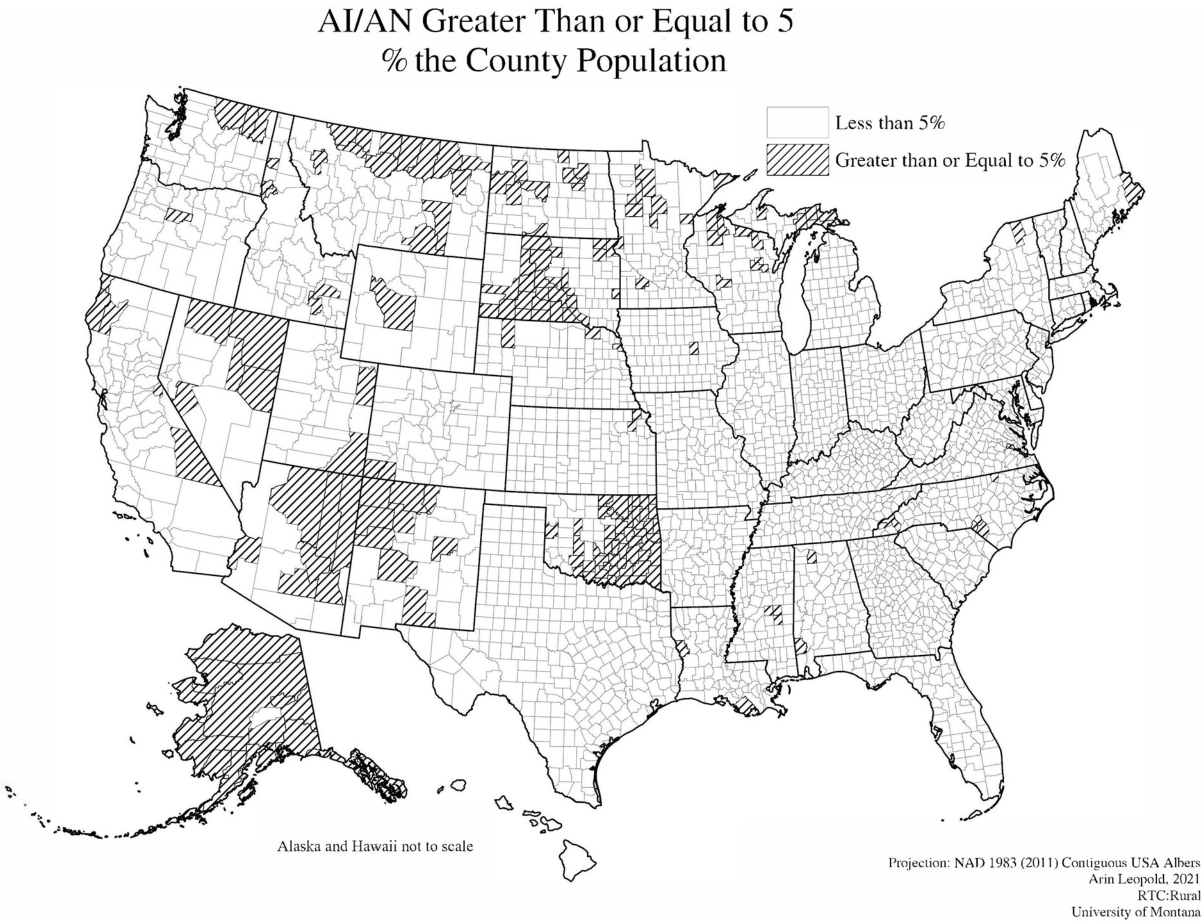


FIGURE 2
Map of high AI/AN counties.

based on prevalence of AI/ANs in the general county population. Results indicate that the disability prevalence for AI/ANs in metropolitan, micropolitan, and non-core counties with "high" prevalence of AI/AN populations (5% or more) had significantly lower prevalence of AI/AN disability relative to "remaining" counties. In fact, the prevalence of AI/AN disability in high AI/AN counties is equal to or lower than prevalence of White disability prevalence across metropolitan, micropolitan, and non-core county groups. In contrast, Whites in metropolitan counties with "high" prevalence of AI/AN populations had significantly higher prevalence of disability relative to "remaining" counties. Differences were not statistically significant for differences in micropolitan and non-core counties.

Table 1 also shows comparison across all counties (without grouping them based on concentration of AI/ANs). We used one-way ANOVA and *post-hoc* analyses to examine disability prevalence for AI/ANs and Whites across metropolitan, micropolitan, and non-core counties. Disability prevalence was significantly higher for AI/ANs living in non-core relative to metropolitan counties ($p = 0.005$) and micropolitan relative to metropolitan ($p = 0.008$), but not for non-core compared to micropolitan counties ($p = 0.744$). Disability prevalence was significantly higher for Whites living in non-core relative to micropolitan ($p \leq 0.001$) and non-core relative to metropolitan ($p \leq 0.001$), and micropolitan relative to metropolitan ($p \leq 0.001$). We also explored the interaction between county classification and proportions of AI/AN population. We found a statistically significant interaction between non-core and high AI/AN ($p = 0.003$). This suggests that although non-core counties have higher rates of disability, the interaction of non-core and high AI/AN significantly lowers the disability rate.

Figure 3 further illustrates Table 1 results in a bar chart format.

TABLE 1 *T*-test comparisons of disability prevalence among AI/ANs and Whites in “high” vs. “remaining” AI/AN counties[*].

	“High” AI/AN counties *M* [*SD*]	“Remaining” AI/AN counties *M* [*SD*]	*T*	*p*	All counties [†] *M* [*SD*]
AI/AN disability prevalence					
Metropolitan	16.4 [3.5]	21.0 [19.2]	5.31	$\leq$0.001	20.9 [19.0]
Micropolitan	16.4 [4.5]	24.4 [24.0]	6.80	$\leq$0.001	23.9 [23.3]
Non-Core	16.4 [6.9]	24.4 [29.8]	7.61	$\leq$0.001	23.6 [28.4]
White disability prevalence					
Metropolitan	16.8 [3.6]	14.8 [4.3]	2.98	0.006	14.9 [4.3]
Micropolitan	17.4 [4.6]	16.2 [3.9]	1.59	0.118	16.3 [4.0]
Non-Core	16.9 [5.7]	17.7 [4.7]	1.68	0.095	17.6 [4.8]

[*] “High” counties are characterized as having general populations with at least 5% AI/ANs, whereas “remaining” counties have populations with less than 5% AI/ANs.

[†] We used one-way ANOVA and *post-hoc* analyses to examine disability prevalence for AI/ANs and Whites across metropolitan, micropolitan, and non-core counties. Disability prevalence was significantly higher for AI/ANs living in non-core relative to metropolitan counties ($p = 0.005$) and micropolitan relative to metropolitan ($p = 0.008$), but not for noncore compared to micropolitan counties ($p = 0.744$). Disability prevalence was significantly higher for Whites living in noncore relative to micropolitan ($p \leq 0.001$) and noncore relative to metropolitan ($p \leq 0.001$), and micropolitan relative to metropolitan ($p \leq 0.001$).

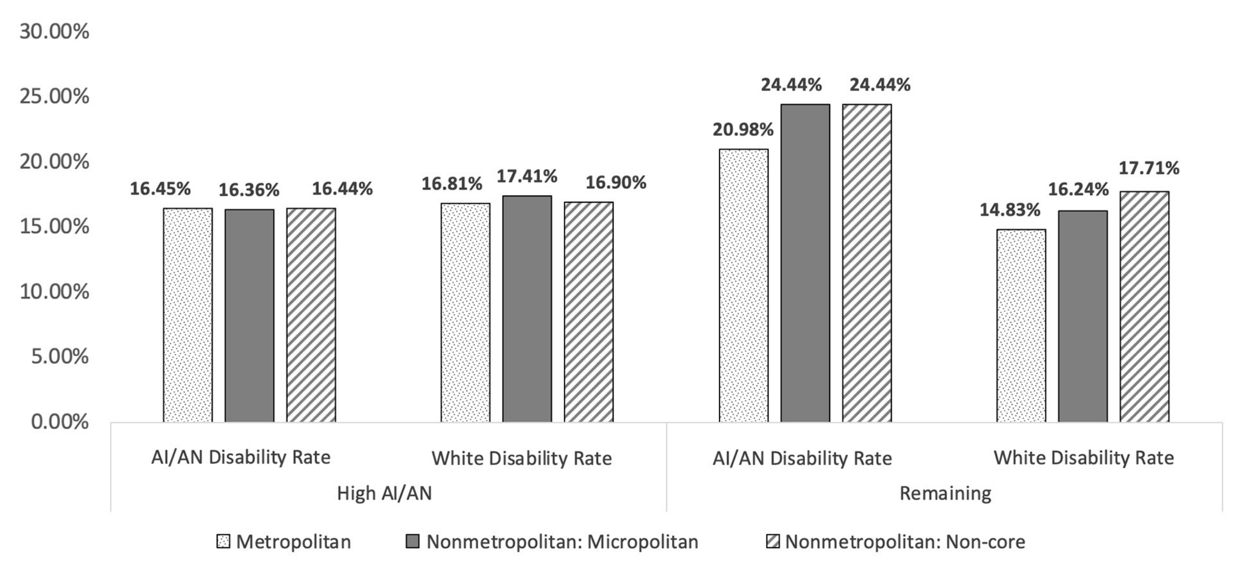


FIGURE 3
Comparisons of county makeup, county classification, and AI/AN disability rates.

Discussion

When examining counties all together, there were notable differences between the prevalence of disability in AI/AN and White racial groups, as AI/ANs reported disability prevalence rates of 20.9, 23.9 and 23.6% and Whites reported rates or 14.9, 16.2, and 17.6% across metropolitan, micropolitan and non-core counties. These data illustrate a common finding that disability rates are high among rural people and for AI/ANs relative to Whites.

However, closer examination of the data (see Table 1; Figure 3) are contrary to our proposed hypothesis and past research (5). Specifically, a different pattern of disability prevalence emerged in counties with higher percentages of AI/ANs in the general population. Across metropolitan, micropolitan, and non-core counties, the disability prevalence in AI/ANs was significantly lower in counties with “high” AI/AN populations ($\geq$5%) relative to counties with lower AI/AN populations (<5%). Additionally, reported disability prevalence rates in “high” AI/AN counties where actually lower for AI/ANs relative to Whites.

This finding may be due to two related hypotheses in the literature: (a) the belongingness hypothesis, which states that strong connections with others have strong effects on individuals, both emotionally and cognitively (12); and (b) cultural protective factors, in which the belonging aspect of being part of a culture and its traditions results in specific protective factors for those that belong, such as emotional wellbeing and resiliency in the face of negative outcomes (13–15). Previous research has found that a sense of belonging mitigates against negative life satisfaction that results from disability-related discrimination (16). In AI/AN communities, cultural traditions are reported to be protective factors because they provide a sense of purpose, a support system, comfort, companionship, and belongingness (17), which may lead to a reduced experiences of environmental barriers for those with health conditions, creating lower prevalence of disability. It is possible that the vehicle through which belongingness contributes to reduced disability prevalence is through mental health. Unfortunately, we were unable to examine the difference between race within specific disability type (e.g., mental illness, mobility difficulties) because we were working with county level prevalence data rather than individual-level data.

Further, the finding that AI/AN individuals living in high AI/AN counties experienced lower prevalence of disability, compared to White individuals, might illustrate that an intersectional protective factor may exist. Again, it should be noted that disability and health are not interchangeable terms. Disability is the interaction of environmental factors (i.e., inaccessible buildings, lack of public transport, exclusionary policies, and practices) and a functional limitation brought on by a health condition which results in disability (18). It is plausible that high AI/AN communities are more attentive to the environmental factors that impact community members with disability, thus creating fewer environmental barriers, and leading to lower prevalence of disability. Given that we did not use inferential statistics or an experimental design, the authors were unable to speak to causation or confounding variables, such as differences in federal- and state-level policies or differences between federal- and state-recognized tribal lands. Future research studies examining a possible protective factor should include these variables to fully examine this relationship.

Findings also suggest the importance of economic resource considerations. Rural counties generally experience sparse economic resources and opportunities (19). This leads to broad, community-wide health disparities due to a lack of funds for insurance, food, and other factors that impact health (3). This is in line with recent data from the U.S. Census Bureau that indicates that while generally, rural Americans experience lower household incomes than urban households, those living in rural areas have lower poverty prevalence than individuals in urban areas (20). Taken together, this suggests a protective factor of living in rural communities despite fewer economic resources. Protective factors may include a greater sense of community connectedness, support, and a lower cost of living in rural areas (21).

Limitations and future research

The present study includes limitations for consideration when interpreting results. First, the study used county level rates which limit the ability to draw conclusions based on individual-level factors. Second, there were few AI/AN individuals represented in several counties, which introduced higher margins of error for interpreting results. However, our findings do have important implications for public health policy. To reduce disability disparity in areas with lower prevalence of AI/AN individuals, economic resources and community factors must be considered alongside individual considerations in future research. Additionally, as disability prevalence rates were higher for rural areas compared to metropolitan and micropolitan areas, disbursement of resources to address environmental factors in rural communities must be considered.

Further, data that does exist is often from an individual and deficit-based perspective, which tends to place blame on AI/AN individuals for health disparities, rather than considering community contextual factors. Data equity should be encouraged by increasing community-focused, asset-based, and culturally responsive data gathering in AI/AN communities. Similarly, additional research is needed to understand the intersectional protective factors that exist for AI/AN individuals residing in counties with high AI/AN populations. Finally, our study could not explore the influence of culturally-specific and culturally safe health care provisions on the prevalence of disability. Future research should aim to examine this in the context of disparities for AI/AN individuals.

Data availability statement

This study used publicly available data. The metadata or the description of how we created variables will be included in ICPSR and will be available upon request.

Ethics statement

We used secondary data analyses from U.S. Census data and was thus exempt from review by the Institutional Review Board.

Author contributions

Data aggregation, data analysis and cleaning for the project was done by LG. The idea for the project was generated by LG and GMM. The writing was done by GMM, ECH, and LG.

The tables and figures were done by AJL, LG, GMM, and CI. Critical review of the paper, suggested edits, and review and final edits were done by GMM, ECH, LG, AJL, and CI. All authors contributed to the article and approved the submitted version.

Funding

This work was supported by the Research and Training Center on Disability in Rural Communities (RTC:Rural) under a grant from the National Institute on Disability, Independent Living, and Rehabilitation Research (grant number 90RTCP0002-01-00). NIDILRR is a Center within the Administration for Community Living (ACL), Department of Health and Human Services (HHS). The research does not necessarily represent the policy of NIDILRR, ACL, or HHS and one should not assume endorsement by the federal government. ECH receives/received support from Montana INBRE – an Institutional Development Award from the National Institute of General Medical Sciences of the National Institutes of Health under Award Number P20GM103474.

Acknowledgments

The authors thank the Rural Institute for Inclusive Communities for their support on this project.

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. Wang K, Ashburn-Nardo L. Disability stigma: Causes, consequences, and strategies for change. In: Dunn DS, editor. *Disability: Social Psychological Perspectives.* New York, NY: Oxford University Press (2019).

2. U.S. Department of Labor. *Laws and Regulations.* Available online at: https://www.dol.gov/general/topic/disability/laws (accessed February 8, 2022).

3. Committee on Community-Based Solutions to Promote Health Equity in the United States, Board on Population Health and Public Health Practice, Health and Medicine Division, National Academies of Sciences, Engineering, and Medicine In: Weinstein JN, Geller A, Negussie Y, Baciu A, editors. *Communities in Action: Pathways to Health Equity*. Washington, D.C.: National Academies Press (2017).

4. Goodman N, Morris M, Boston K, Walton D. *Financial Inequity: Disability, Race, and Poverty in America. National Disability Institute.* (2019). Available online at: https://www.nationaldisabilityinstitute.org/wp-content/uploads/2019/02/disability-race-poverty-in-america.pdf (accessed May 19, 2022).

5. Leopold A, Greiman L. *America at a Glance: An Update on Rural-Urban Difference in Disability Rates.* The University of Montana, Rural Institute for Inclusive Communities (2022). Available online at: https://scholarworks.umt.edu/cgi/viewcontent.cgi?article=1080&context=ruralinst_independent_living_community_participation (accessed June 2, 2022).

6. United States Census Bureau/American FactFinder. *S1810 Disability Characteristics*. Washington, D.C.: US Census Bureau's American Community Survey Office (2016). (2012 – 2016 American Community Survey). Available online at: http://factfinder2.census.gov (accessed February 8, 2022).

7. Institute of Medicine, Committee on Assessing Rehabilitation Science and Engineering. Disability and the environment. In: Brandt EN Jr, Pope AM, editors. *Enabling America: Assessing the Role of Rehabilitation Science and Engineering.* Washington, D.C.: National Academies Press (1997). p. 5799.

8. Kauffman and Associates, Inc. *Long-Term Services and Supports in Indian country: Issues affecting American Indians and Alaska Native Consumers With Disabilities*. Centers for Medicare and Medicaid Services (2014).

9. Henning-Smith CE, Hernandez AM, Hardeman RR, Ramirez MR, Kozhimannil KB. Rural counties with majority Black or Indigenous populations suffer the highest rates of premature death in the US. *Health Aff.* (2019) 38:2019–26. doi: 10.1377/hlthaff.2019.00847

10. United States Census Bureau. *2015 American Community Survey Research and Evaluation Report Memorandum Series #ACS15-RER-01*. United States Census Bureau (2015). Available online at: https://www.census.gov/content/dam/Census/library/working-papers/2015/acs/2015_King_01.pdf (accessed May 19, 2022).

11. U.S. Census Bureau. *Metropolitan and Micropolitan* . Census.gov. (2021). Available online at: https://www.census.gov/programs-surveys/metro-micro/about.html (accessed February 9, 2022).

12. Baumeister RF, Leary MR. The need to belong: desire for interpersonal attachments as a fundamental human motivation. *Psychol Bull.* (1995) 117:497–529. doi: 10.1037/0033-2909.117.3.497

13. Baumeister RF. Need-to-belong theory. In: *Handbook of Theories of Social Psychology*. London: SAGE Publications Ltd (2012). p. 121–40. Available online at: http://sk.sagepub.com/reference/hdbk_socialpsychtheories2/n32.xml (accessed February 3, 2022).

14. Burnette CE. Family and cultural protective factors as the bedrock of resilience and growth for Indigenous women who have experienced violence. *J Fam Soc Work.* (2018) 21:45–62. doi: 10.1080/10522158.2017.1402532

15. Child Welfare Information Gateway. *American Indian Resilience: Culture as a Protective Factor.* (2022). Available online at: https://www.childwelfare.gov/topics/systemwide/diverse-populations/americanindian/resilience/ (accessed February 8, 2022).

16. Daley A, Phipps S, Branscombe NR. The social complexities of disability: Discrimination, belonging and life satisfaction among Canadian youth. *SSM - Popul Health.* (2018) 5:55–63. doi: 10.1016/j.ssmph.2018.05.003

17. Teter T, Chapin J. *Culture is our Best Protective Factor and Healing Practice*. National Indigenous Wmen's Resource Center (2021). Available online at: https://www.niwrc.org/restoration-magazine/june-2021/culture-our-best-protective-factor-and-healing-practice (accessed February 8, 2022).

18. World Health Organization. *Disability and Health.* (2018). Available online at: https://www.who.int/news-room/fact-sheets/detail/disability-and-health (accessed August 13, 2020).

19. Krause E, Reeves R. *Rural Dreams: Upward Mobility in America's Countryside*. Center on Children and Families at Brookings Institution (2017). Available online at: https://www.brookings.edu/wp-content/uploads/2017/08/es_20170905_ruralmobility.pdf (accessed February 8, 2022).

20. Bishaw A, Posey KG. *Incomes and Poverty Higher in Urban Areas.* U.S. Census Bureau (2017). Available online at: https://www.census.gov/library/stories/2017/11/income-poverty-rural-america.html (accessed February 10, 2022).

21. Kurre JA. Is the cost of living less in rural areas? *Int Reg Sci Rev.* (2003) 26:86–116. doi: 10.1177/0160017602238987

frontiers | Frontiers in Rehabilitation Sciences

TYPE Original Research
PUBLISHED 05 August 2022
DOI 10.3389/fresc.2022.879193

OPEN ACCESS

EDITED BY
Jean P. Hall,
University of Kansas, United States

REVIEWED BY
Chia-Feng Yen,
Tzu Chi University, Taiwan
Zhuoying Qiu,
China Rehabilitation Research Center/WHO Collaborating Center for Family International Classifications, China

*CORRESPONDENCE
Meg A. Traci
meg.traci@mso.umt.edu

SPECIALTY SECTION
This article was submitted to Disability, Rehabilitation, and Inclusion, a section of the journal Frontiers in Rehabilitation Sciences

RECEIVED 19 February 2022
ACCEPTED 06 July 2022
PUBLISHED 05 August 2022

CITATION
Seekins T, Traci MA and Hicks EC (2022) Exploring environmental measures in disability: Using Google Earth and Street View to conduct remote assessments of access and participation in urban and rural communities.
Front. Rehabilit. Sci. 3:879193.
doi: 10.3389/fresc.2022.879193

Exploring environmental measures in disability: Using Google Earth and Street View to conduct remote assessments of access and participation in urban and rural communities

Tom Seekins, Meg A. Traci* and Emily C. Hicks

Rural Institute for Inclusive Communities, University of Montana, Missoula, MT, United States

The Americans with Disabilities Act has been in place since 1990. Yet, we still do not know the actual levels of accessibility in the nation, how access varies across communities or over time, or how it influences participation in community life. The present two studies explored the use of Google Earth (GE) and Google Street View (GSV) imagery as a database for examining the accessibility of rural and urban cities and towns in the United States. We developed procedures for selecting places in a community to observe multiple access features. Study 1 reports the findings from assessments of 25 communities across 17 states. We observed ≈50,000 m (31 miles) of pathways through the observed places. The Combined Access Score (CAS) averaged 65% across these communities. In Study 2, we evaluated 22 towns and cities in a large rural state. We observed ≈77,000 m (48 miles) of pathways through the Central Business Districts observed as core areas connecting people to community life. The CAS averaged 83.9% across these communities. We noted a Rural Access Penalty (RAP), such that rural areas tended to be less accessible, leading to less community participation. The method for using GSV to examine accessibility is discussed. This study demonstrates an inexpensive and reliable method for evaluating the accessibility of communities and participation in them. Future research should be conducted to gather a larger sample of communities in order to create a baseline from which to monitor changes in accessibility of infrastructure over time.

KEYWORDS
accessibility, participation, environment, rural penalty, behavioral ecology, disability

Introduction

The design and organization of a community's environment can significantly influence the degree to which people that experience mobility limitations associated with chronic conditions have opportunities to participate in community life (1–5). In the United States, several laws, policies, and programs focus on arranging the environment to increase participation. For example, the Americans with Disabilities Act (ADA) sets rules for employment, communications technology, and the built environment intended to promote participation in community life. Governments and private entities have invested significant resources to build public infrastructure that approaches universal access in rural and urban areas (6). Still, we know surprisingly little about the extent to which these efforts have succeeded or how they function across the 30,000 urban and rural communities in the United States.

Several scientists have demonstrated methods for measuring environmental factors affecting participation. For example, Carlsson and colleagues (7) developed a housing usability screening instrument that identifies housing accessibility problems. Whiteneck and colleagues (8) developed a self-report questionnaire (the CHIEF) to assess the frequency and magnitude of barriers that keep people from engaging in desired activities. Gray and colleagues (1, 9) have demonstrated a self-report protocol for recording the accessibility of environments people visit. Nary et al. (10) used direct observation to evaluate the accessibility of several fitness facilities. Others have used the Behavioral Risk Factor Surveillance System to assess the visitability of homes [e.g., 15] and have estimated the likelihood of a house being occupied by a person with a significant impairment during the lifetime of the house (11). Finally, Seekins et al. (12, 13) used data collected by direct observation of businesses randomly selected from those in a small city and all towns between 2,500 and 10,000 residents in Montana. Still, few of these have been taken to scale; perhaps, at least in part, because the methods would require significant resources and organization to collect data across distant sites.

Recently, several researchers have used Google Street View (GSV) to assess various characteristics of public spaces. For example, Ben-Joseph and colleagues (14) used GSV as a publicly available database to assess environmental conditions promoting health. Similarly, Rundle and colleagues (15) used GSV to assess characteristics of neighborhood vitality (e.g., aesthetics, physical disorder, infrastructure for travel, sidewalk amenities, and social and commercial activity). GSV has been used to examine disaster preparedness (16), pedestrian injury (17), and supportiveness of physical activity (18). In a recent review of over 600 papers that used street level imagery, Biljecki and Ito (19) found that most studies used GSV to describe the built environment for a range of purposes and concluded that street level imagery is "…now clearly an entrenched component of urban analytics and GIScience" (p. 1).

We report two studies aimed at developing methods and procedures for using GE and GSV, large geospatial digital data bases representing images of the physical structures on or near roadways in the United States, to assess the accessibility of communities. Study 1 reports the findings of assessments of 25 towns and cities in 17 states and the District of Columbia. Study 2 reports the findings from assessments of 22 towns and cities in one, large rural state developed within a state program of technical assistance to community action teams (CATs) working on community development plans.

Study 1

Researchers routinely monitor features of natural ecologies to assess the health of places and their populations (20). Cities and towns are ecological habitats for human populations. The accessibility of our cities and towns can affect the health and participation of people with disability. The aim of Study 1 was to explore procedures for conducting remote monitoring of the accessibility of communities of various sizes located at distance from the observer (21, 22). Such a monitoring system requires procedures for both selecting places to observe within a community and procedures for observing the features of those places. We chose GE and GSV as the source of data from which to extract observation to assess the accessibility of cities and towns.

Sample

We chose a convenience sample of 25 towns and cities in 17 states and the District of Columbia to evaluate. These were chosen in four groups; including (1) seven that were among the towns Seekins and colleagues (13) assessed; (2) 16 were hometowns of elected and appointed officials with jurisdiction over the Americans with Disabilities Act), (3) and two were chosen at convenience to explore more diverse communities. The cities and towns observed had populations ranging from 235 to 2.59 million ($mean = 181{,}030.60$, $SD = 521{,}819.36$). The locations observed in each town included access features of the sidewalks along ≈2,000 m around the city hall and the building entrance along 500 m of the selected sidewalks.

Procedures

Places observed

Seekins et al. (12, 13) assessed the accessibility of communities by directly observing the accessibility of businesses selected randomly from among all businesses in a community. In this study, we chose to assess the accessibility of a central area of incorporated cities and towns. While incorporated places vary in many ways, each has a city hall or comparable administrative office. We reasoned that the area around the city hall should be among the most accessible areas in any city or town. That area is often the civic center of a city or town around which commercial activities take place. The left panel of Supplementary Image 1 shows a Google Earth satellite view of such an area of one town.

The concept of accessibility includes elements of the built environment that support or hinder the participation of those with mobility impairments. Accessibility can be viewed from a legal or a functional perspective. A legal perspective specifies exact criteria to use in determining whether an arrangement complies with a law (e.g., 32″ doorways). A functional perspective assesses the "usability" of an environmental arrangement (e.g., 28). As implied, usability suggests a wider range of acceptable arrangements that still allow a person to achieve the aim, albeit with more effort (e.g., a ramp with a gentle slope vs. 1:12 slope ratio). Usability is more of a judgment of accessibility than a precise measurement of legal requirements. This study focused on assessing the usability of physical elements of the environment observable from images presented in GSV. In this work, we use the terms accessibility and usability interchangeably.

We used GSV to assess the usability/accessibility of sidewalk pathways and business entries. Brooke (23) suggests using a five-point Likert-type scale for assessing usability of any product. We derived an accessibility rating instrument for assessing the usability of the physical environment of cities and towns based on one developed by Seekins et al. (12, 13). Observers rated the usability/accessibility of curb cuts (CC) and sidewalk segments (SS), and entry ways (EW) and doorways (DW) of non-residential buildings using a five-point, anchored rating scale. The anchors included ratings of "0" or access failure, "1" for access risk, "2" for obstructed, "3" for poorly maintained, and "4" for a clear and accessible pathway. Each anchor included specific definitions for each feature with examples. If an image lacked focus sufficient to see a feature clearly, its accessibility was not rated, and a null symbol was recorded.[1]

An observer applied the scales to record observations of pathway usability along sidewalks on each side of the 1,000-m pathway for a total of about 2,000 m per place. They applied the scales to the buildings along the 250-m pathway for a total of about 500 m per place. They also tallied the number of people present as pedestrians, the number who used personal mobility devices (e.g., wheelchair, scooter, cane, guide animal, etc.), and the number using other wheeled devices along the 500-m pathway. We also noted features of access and public participation. Features included temporary obstacles, such as safety cones blocking the sidewalk, and permanent barriers, such as lamp posts blocking the sidewalk (see right panel of Supplementary Image 1). Finally, we collected pictures of unique arrangements, situations, and features.

As this exploratory research unfolded, we noted both new features that could be observed and new situations for scoring. When we adopted significant new measures or procedures, we rescored previously observed places.

Observational protocol

An observer secured the address of the city hall of each place, along with data on the population of the community to be observed from its official website. Then the observer opened the Google Earth program on a computer and entered the address into the search box. Once the city hall or equivalent place was located, the observer used GSV to mark the location of the nearest street intersection with the thumbtack tool. Next, the observer left GSV and oriented to the layout of the city using the Google Earth's satellite view. Beginning at the position previously marked, the observer used the pathway tool to draw a line of ≈1,000 m of roadway for observing the accessibility of the sidewalk system. The line was drawn from the target address down the center of the street leading toward the area of greatest development and looped back through the area to where it began, when possible. If a city boundary or natural end was encountered, or if there was limited street view availability, the line was extended in the direction of the next most developed area or until a total of 1,000 m was reached. A second line of 250 m was traced from the same starting point along the same pathway as the sidewalk segment for rating the accessibility of building entries and doorways, and for recording the people present. Finally, an image of the city with the path drawn was saved for reference.

Next, the observer navigated through the visual images presented by GSV on the computer screen, moving along the 1,000-m line rating the accessibility of each curb ramp (CC) and sidewalk segment (SS) on one side of the line. Upon returning to the beginning of the path, the observer followed the path again on the other side. Every curb ramp passed along the path of travel was rated. At each corner, each ramp or corner adjacent to the street was rated, progressing clockwise from the straight-ahead path of travel. Once the curb ramps were rated, the observer rated the accessibility of the segment of sidewalk on the line to the next intersecting street, alley, or other vehicular roadway. As such, observers rated ≈2,000 m (1.24 miles) of the sidewalk system, and the buildings and people along 500 m of those same sidewalks in each city or town. A complete observation—from preparing the observation files through rating a town's accessibility and participation, to saving and accounting for the data—took ≈2 h for each city.

Inter-observer reliability

Seekins et al. (12) reported inter-observer agreement that averaged 91% using the original, direct-observation protocol and measures. Seekinset al. (24) reported inter-observer agreement that averaged 84% across all GSV ratings of usability/accessibility, including 96% for curb cut, 89% for sidewalk segment, 80% for doors, and 50% for entryway ratings. Agreement on people observed was 93%. Correspondence between observations made using GSV and those made directly averaged 85%.

---

[1] A complete set of definitions and training materials may be obtained from the second author.

Data analysis

While this was an exploratory project, we were guided by a hypothesis that the population of a community (e.g., rural, or non-metropolitan status) would statistically predict accessibility, and that the accessibility of a community would predict participation by individuals using mobility devices. As data analysis proceeded, we recognized the possibility that several metrics, derived from the primary data might also be related to accessibility, participation, or to newly derived measures. These are described below.

The ratings of the usability/access features for a town or city were entered into an Excel spreadsheet. Ratings were converted to percentage scores for CC and SS along streets, and for doorways and entries of non-residential buildings. The scores for CC and SS combined into an average Pathway Access Score. The ratings for entries and doorways were combined into an average Building Access Score. Pathway and Building Access Scores were multiplied to create a Combined Access Score. These scores were calculated for each community and for all communities combined.

Similarly, we tallied the number of temporary and permanent obstacles observed in each community. We also tallied the number of people observed, the number of people using mobility devices, and the number of people pushing or pulling other wheeled devices. Again, these scores were calculated for each community and for all communities combined.

Derived variables

We also derived new measures from the data that led to additional hypotheses that we examined (see Table 1 for variable names and definitions). For example, we reasoned that the fewer the number of interruptions in any pathway, the more likely people with mobility devices would be present. Therefore, we explored three measures of such interruptions. First, we derived Access Risk and Access Failure Indices. Access Risk was scored as a "1" whenever a feature presented a potential danger of falling or getting stuck due to poor conditions of the feature (e.g., cracked sidewalk) or forcing a person to leave the sidewalk and enter the street in order to circumvent a permanent or temporary obstacle. Access Failure was scored as "0" whenever there was a barrier (e.g., telephone pole in pathway or no curb ramp) that would block a person using a mobility device from continuing along a Path of Travel (i.e., inaccessible) with no visible options. The Risk Index was derived by counting the number of ratings of "1" in either sidewalk or curb cut ratings observed per 1,000 m. The Access Failure Index was derived by counting the number of ratings of "0" in either sidewalk or curb cut ratings per 1,000 m.

Second, we reasoned that the experience of accessibility might be influenced by the proportion of risks and failures to the opportunities encountered in a given pathway rather than their simple frequency. We derived a Threat Access Ratio (TAR) by taking the inverse of the sum of the number of access risks and failures encountered as a proportion of opportunities (i.e., number of curb cut and sidewalk ratings). Similarly, we derived an Available Building Ratio by calculating the inverse of the number of buildings that were rated inaccessible to the total number of buildings.

Next, we plotted the scores for each measure across communities, rank-ordered by population. We examined the relationships between population and access using regression and Mann-Whitney *U* test, and we used Kendall's *t* to examine differences in access and participation. Alpha was set at 0.05.

The rule of proportional participation

In the process of examining the relationship between accessibility of a place and the presence of people who use mobility devices, we recognized the need for a standard metric to compare communities with varying populations. We developed the Rule of Proportional Participation (RPP), the idea that the proportion of people who use mobility devices present at any time in a given place ought to be proportionate to their prevalence in the population as a whole; environmental factors should explain deviations from this proportion. LaPlante and Kaye (25) report that rate as 4.5% of non-institutionalized individuals 6 years old and older. Table 1 lists and defines the RPP, as well as other terms for measures and outcomes reported here.

Results

Overall, we evaluated 25 towns and cities in 17 states and the District of Columbia. We observed ≈50 km (31 miles) of pathways through the observed places, including: 1,100 curb ramps, 513 sidewalk segments, and 233 buildings (with 225 entries and 194 doorways that were rated). The Combined Access Score averaged 65% across these communities, including an average Pathway Access Score of 67% and an average Building Access Score of 63%. Only one community received a perfect score across these categories.

Access and population

Because the population of the towns and cities varied by over 2.5 million, we assessed the relationship between the population of a community and the Combined Access Score (CAS) by plotting it on a logarithmic scale. Figure 1 portrays the data on a logarithmic scale for population ($R^2 = 0.69$). One box marks the point between places with a population below and above 10,000 (between non-metropolitan, non-core, and core-based counties) and another box indicates the point above the 50,000-population threshold (metropolitan counties). The towns under

TABLE 1 Definitions of selected terms and concepts.

Terms used	Definition
Public Participation	Presence of an individual in an open public space
Rule of Proportional Participation	The ideas that the proportion of people who use mobility devices present at any time in a given place ought to be proportionate to their prevalence in the population as a whole; environmental factors should explain deviations from this proportion
Pathway of Travel	A line between two points that a person might follow to get from one end to the other
Sidewalk Segment	That portion of a pathway from the edge of an intersecting motor way to the next intersecting motorway
Curb (Cut) Connector	A short ramp cutting through a curb or built up to it
Building Entryway	Any access point to a building or portion of a building or facility used for the purpose of entering. An entrance includes the approach walk, the vertical access leading to the entrance platform, the entrance platform itself, and vestibule if provided, the entry door or gate, and the hardware of the entry door or gate
Doorway	The entry door or gate, and the hardware of the entry door or gate
Pathway Access Score	The percentage of combined sidewalk and curb ramp ratings
Building Access Score	The percentage of combined entry and doorway ratings
Index of Building Access	The proportion of buildings which the entry and the doorway each receive an Access Rating of at least "1"
Combined Access Score	The percentage of the total possible points of all access ratings, including curb cuts, sidewalk segments, building entries, and building doorways
Temporary Obstacle	Obstructions to the path of travel that could be moved, such as a utility truck parked on a sidewalk to repair an overhead wire
Right of Way Obstruction	The permanent installation of a fixed object (e.g., fire hydrant) in a curb cut or sidewalk so that it blocks the passage along a path of travel
Permanent Barrier	A barrier in the path of travel that cannot be moved without significant effort, such as a utility pole placed in a curb cut
Access Risk	A feature of the pathway puts an individual at risk (e.g., forces one into traffic) to navigate a barrier and continue on the pathway
Access Failure	A barrier blocks progress along a Pathway of Travel (i.e., inaccessible)
Threat Access Ratio	The inverse of the proportion of Access Risks and Failures to the total opportunities for passage.
Access Island	Areas where there is good pathway and building access, but it comes to an abrupt end
Access Barren	An area in which both Pathway and Building Access Scores fall below 40%
Access Desert	Areas in which the Pathway Access Score exceeds 80% but the Building Access Scores fall below 40%
Rural Access Penalty	The discrepancy in accessibility found between urban and rural areas; cities above and below 50,000 population; and then above and below 10,000

50,000 averaged an access score of 42% while the cities above the 50,000-threshold averaged 76% [$U(N_{\text{MetropolitanCAS}} = 18, N_{\text{Non-MetropolitanCAS}} = 7) = 17$, $z = 2.83$, $p < 0.05$]. No town with a population <50,000 exceeded a CAS of 78%. All except one city with a population >50,000 exceeded a CAS of 80%.

Access features

We noted three new categories for classifying access features in a community. Figure 2 shows Access Islands (areas with highly accessible pathways and buildings), Access Deserts (highly accessible pathways but fewer than 40% of buildings are accessible), and Access Barrens (low pathway accessibility and low building accessibility).

We were also able to evaluate Access Risks and Failures associated with Permanent Barriers and Temporary Obstacles. Figure 3 portrays these features. Importantly, we observed 1.95 Access Risks and 1.40 Access Failures per 1,000 m of pathway. Many permanent obstacles appeared in the public right of way, labeled as Right of Way Obstructions.

Access and participation

We observed 561 people, an average of about 24 per community. The Rule of Proportional Participation (RPP) suggests that individuals who use mobility devices might be expected to be present in the same proportion as their prevalence in the population, or about 25 individuals. We observed 12 people using mobility devices, 48% of the RPP.

The Combined Access Score statistically predicted the proportion of people using personal mobility devices of all those observed ($r_T = 0.277$, 95% CI $= [-0.026, 0.58]$, $p = 0.036$). We noted consistent disparities between the levels of access and participation in non-metropolitan cities and those in metropolitan cities, which we labeled "Rural Access Penalty" (Figure 4). Importantly, participation averaged 27% of the expected rate under the Rule of

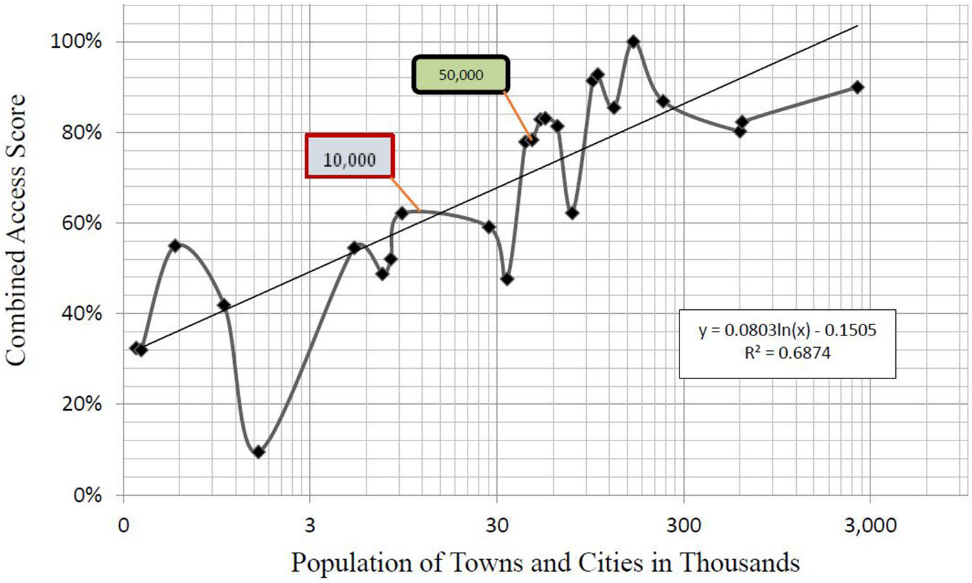


FIGURE 1

Access and Population—This figure displays the combined access scores of 25 cities and towns by the log of their populations. Populations account for over 60% of the variance in access. The points at which populations exceed 10,000 and 50,000 are marked.

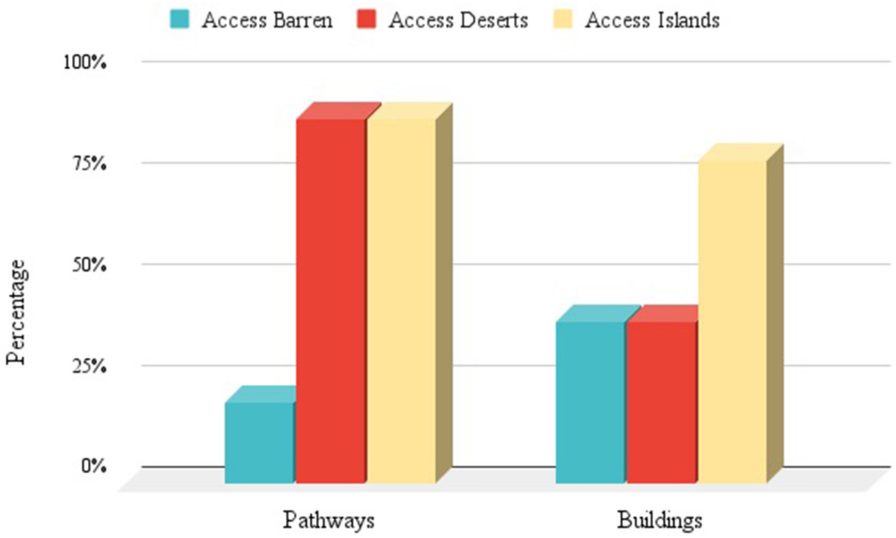


FIGURE 2

Three Derived Concepts—shows three concepts derived from the data, including Access Islands (yellow) in which pathway and building access are both high; Access Deserts (red) in which pathway access is high but building access is low; and Access Barrens (blue) in which both pathway and building access are low. In Access Islands, a person using a mobility device can move around most or all of an area and get into most or all buildings. In Access Deserts, one can move around most of an area but cannot get into many of the buildings. In Access Barren, it is difficult to move around an area or get into many buildings.

Proportional Participation in non-metropolitan areas and 51% in metropolitan areas. The finding of lower rates of participation in less accessible rural areas supports both the commonsense argument and our hypothesis that participation in events at a place may be influenced by the accessibility of the place. However, the small number of towns located in non-metropolitan counties (26) and the low levels of observed presence of people with mobility

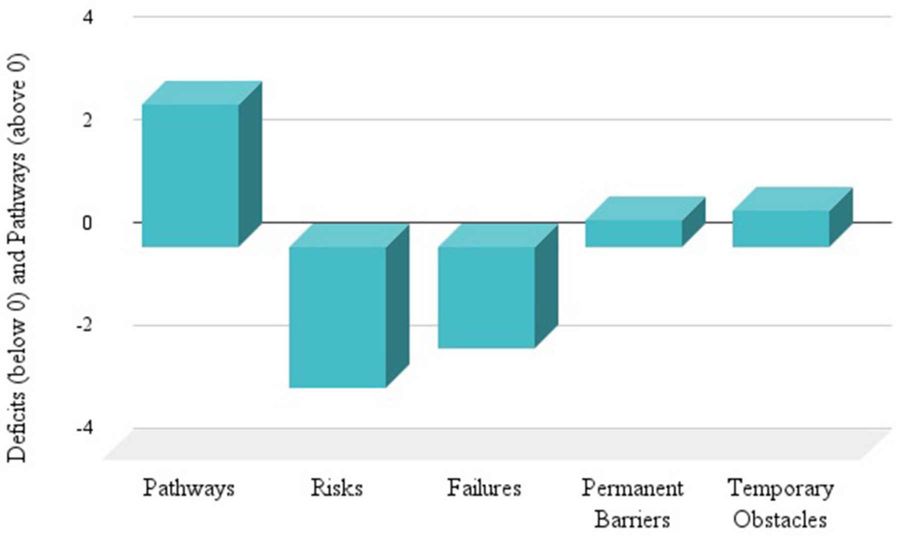


FIGURE 3
Comparison of Accessible Pathways and Features—shows the average pathway rating as a positive score and contrasts it to the average ratings of observed access risks and failures, permanent barriers, and temporary obstacles per community shows as deficits along the negative scale. Permanent barriers and temporary obstacles contribute to Access Failures. Access Risks and Failures reduce the Pathway Score.

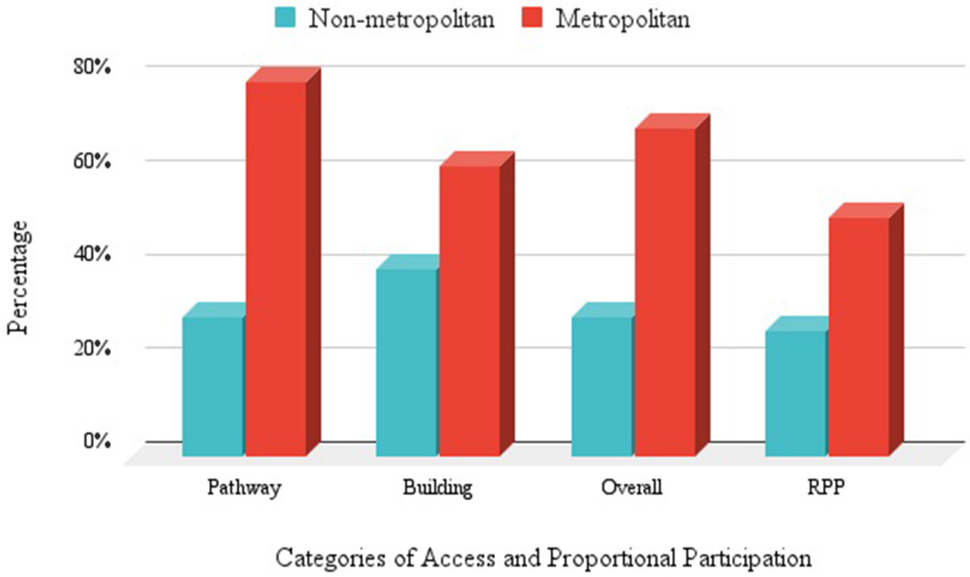


FIGURE 4
Rural Access Penalty and Rural Participation Penalty—shows non-metropolitan (blue) vs. metropolitan (red) access features (Pathways, Buildings, and Overall Scores) and participation as measured by the Rule of Proportional Participation (RPP). The metropolitan access and participation rates are consistently higher than non-metropolitan rates.

impairments in those places (1) yielded no statistically significant results.

Similarly, we reasoned that participation might be influenced by the number of impediments encountered. We derived a new score, the Threat Access Ratio, by calculating the inverse of the proportion of inaccessible buildings (i.e., rated "0" in doorway or entryway) multiplied by the inverse of the sum of the Access Risks and Failures as a proportion of observed opportunities. We examined the correlation between the Threat Access Ratio and the proportion of people using personal mobility devices to all those observed ($r = 0.23$, $p = <0.14$). While this derived measure is not significant in this sample, the sample is relatively small. A larger sample may show a relationship with this derived measure, and it would be worth considering it in the future.

Discussion

This study demonstrated a relatively inexpensive and reliable method for evaluating the accessibility of communities and participation in them. While limited in the sample, the results suggest that, on average, even the most public of civic places are not universally accessible; with public pathways averaging 67% and buildings just 63% on our Combined Access Score. Nonetheless, these data provide empirical support for the assertion that the accessibility of a place influences the rate of presence of people who use mobility devices. Further, these results suggest that the burden of inaccessible places may fall disproportionately on rural residents of non-metropolitan counties. Indeed, while the overall Participation Score is just 52% of the RPP, rural residents participate at half that rate. Given the discrepancy in accessibility, this finding presents evidence to support the existence of a Rural Access Penalty.

Of course, these data and findings need to be interpreted with caution. First, our sample was limited in the number of communities observed and the places within a community observed. A larger, stratified sample of places would be helpful to create an accurate baseline. Similarly, the locations observed within each place were for convenience. Here, we chose the city hall as an anchor point to trace a path of 1,000 m. The selection of the 1,000 m was standard but arbitrary. Further, it treated all towns and cities, regardless of population or size, as the same. Other means for selecting areas for observation might be considered. Especially for larger places, more locations or a larger area might be sampled to develop a representation of the community. Community functions are often organized by location. Most cities and towns create zoning to do this or to shape it. Even within zones, there may be distinct groupings around functions that might need to be sampled. Larger samples would allow researchers to test hypotheses contained in this study and a wide range of additional ones adequately.[2]

Study 2

Our experience in Study 1 suggested that the choice of community area to be assessed was inadequate and difficult to apply. The procedure oversampled places in small communities and under sampled features in larger communities. Moreover, the selection of areas in larger communities was arbitrary. Study 2 was designed to explore an alternative that involved assessing a community's central business district– a community's core area of public participation. Study 2 was conducted to support community action teams (CATs) working to advance community development opportunities.

Sample

We worked with 22 towns and cities in one large, rural state including two communities on American Indians reservations. Communities were selected based on their participation in a state Healthy Communities' program (27–30). Towns and cities organized CATs to participate in the program and support the implementation of related community action plans (CAPs). CATs included community decision-makers and were supported to include representation of disability advocates and partner organizations on the CAT or in the implementation of CAPs (31–33). The towns and cities varied in size, with populations under 5,000 people ($n = 7$), between 5,000 and 10,000 people ($n = 9$), between 10,000 and 50,000 ($n = 3$); and over 50,000 people ($n = 3$) (Median population size = 6,681). The total population across all towns and cities was nearly 394,000 people.

Procedures

Places observed

As an alternative to the methodology for selecting the area of a community to observe used in Study 1, we selected a standard unit area across communities and rated the accessibility of selected features of part or all of the area. Cities and towns are frequently organized around zones. For example, most communities in the United States include residential, commercial, industrial, and mixed zones. While a community may have several such zones, a community typically has one central business district (CBD) or downtown core. A community's CBD is its economic, cultural, governmental, and civic center. The core is characterized by multi-story buildings that primarily contain commercial, office, and retail land uses, as well as multiple surface parking lots and structures and institutional facilities. A limited number of residential structures are located in the CBD or downtown core, and those are typically multi-family. While the size and composition of a CBD vary from town to town, it is a recognizable unit. Moreover, the CBD is a focal point for participating in community life. As

---

[2] Based on these preliminary studies, we estimated that a sample of 2,219 communities in each population range (242 for communities over 49,999 people, 338 for communities between 10,000 and 49,999 people, and 1,639 for communities of <10,000 people) would provide a statistically valid representation of the 36,000 communities in the United States, sovereign American Indian reservations, and territories.

such, the accessibility of a CBD is central to the participation of people who experience disability. Also, the heathy community's program was promoting strategies and funding mechanisms targeting CBD policy, systems, and environmental changes, and we reasoned that CATs with accessibility assessments could support related community action plans that would have greater reach to people with disabilities. For these reasons, we chose to focus on assessing the accessibility of CBDs. The left panel of Supplementary Image 2 shows a CBD of a small town outlined with a yellow grid (Google Earth satellite view) and the right panel shows a GSV section of the CBD of another small town (GSV).

Measures and data collection

We used the same rating scale as we used in Study 1, with revisions to clarify scoring and the additional measures of sidewalk crossings (e.g., alleys and driveway that cross a sidewalk), street crossings (e.g., crosswalks), and railroad crossings, as well as counts of designated accessible parking spaces observed. We did not observe for temporary and permanent barriers. We calculated the same Access Scores for each of the features of each CBD. Access Scores included Pathway Access Scores overall and for curb cuts, sidewalk segments, sidewalk crossings, street crossings, and railroad crossings; Building Access Score overall and for building approaches and entries; Combined Access Score; and Designated ADA Parking Access Score.

Observational procedure

There is no universal list of downtown or CBD coordinates. Due to this situation, a general selection step was required for each community. Procedurally, an observer first entered the name of a city and the state into Map Quest (or Google equivalent) and selected the option to display the locations of all banks, libraries, post offices, pharmacies, drycleaners, museums, movie theaters, department stores, shopping centers and malls, florists, retail apparel stores, bookstores, office supply shops, parking garages, public transportation stations, and restaurants and bars. The image produced would suggest areas that may qualify as a CBD based on the density of businesses.

Next, the observer entered the name of the city and state into the Google Earth Search Bar. Once Google Earth presented the image of the city, the observer adjusted the elevation of the "eye altitude" to allow the entire city to be in view. Then, the observer scanned the geography for indicators of the CBD candidates. From above, these areas present images of groups of flat-top buildings that occupy relatively larger areas than the majority of structure in the city (i.e., residential structures). Typically, these areas have less visible vegetation (e.g., trees) and wider streets or roads. A downtown area can be distinguished from a commercial strip or industrial area by closer examination.

Additionally, the observer entered key terms in the search bar successively: city hall, downtown, and central business district. If any of these areas appeared in a candidate area and no other candidate area contained those terms, it was deemed as the CBD. If the search did not reveal any area as containing the search terms or if they were located in several different areas, a closer inspection of each candidate area was conducted to determine which area met the accepted definition of a CBD.

Finally, the observer established an observation grid. using natural boundaries (e.g., rivers, foothills) and constructed boundaries (e.g., streets, roads, and railroads) as guides to mark areas of transition from primary core activities from residential, mixed, and industrial activities. The grid was formed to maximize the inclusion of commercial, civic, entertainment, and governmental facilities but to minimize inclusion of residential areas, manufacturing, and industrial areas. In some instances, it is desirable to draw a sample from the grid. In this study, we made observations of the entire grid selected for each CBD. Once established, the grid was reviewed by a second researcher who could agree with the choices or modify them. Both agreements and modifications were monitored. All observers were trained to inter-rater reliability criterion to score environmental features as described above.

Results

Overall, we evaluated 22 towns and cities in a large rural state. We observed ≈77,000 m (48 miles) of pathways through the observed CBDs, and scored 4,474 pathway features (1,547 curb ramps, 1,542 sidewalk segments, 822 sidewalk crossings, 545 street crossings), and 4,479 building features (2,258 approaches and 2,221 doorways). GSV images were newest for the two most populous communities (dated 0–2 months prior to our observations), whereas images for the rest of the communities were older (dated 25–89 months prior to the observations).

The Combined Access Scores across CBDs averaged 83.9%, including an average Pathway Access Score of 85.2% and an average Building Access Score of 83.0%. No community received a perfect score across these categories. More than half (52.3%) of the smaller communities with populations under 10,000 ($n = 16$) had Combined Access Scores below the median (85.7%) while only a third (33.3%) of the communities with larger populations had Combined Access Scores below the median.

Community population size was positively associated with all Access Scores, but this relationship was significant only between population size and curb cut (CC) scores ($r = 0.42$, $p < 0.05$) and between population size and the accessibility of designated parking spots ($r = 0.46$, $p < 0.05$). The positive relationship between community population size and overall Pathway Access Scores was on trend toward significance ($r = 0.40$, ns). Figure 5 presents mean Access Scores for Pathway

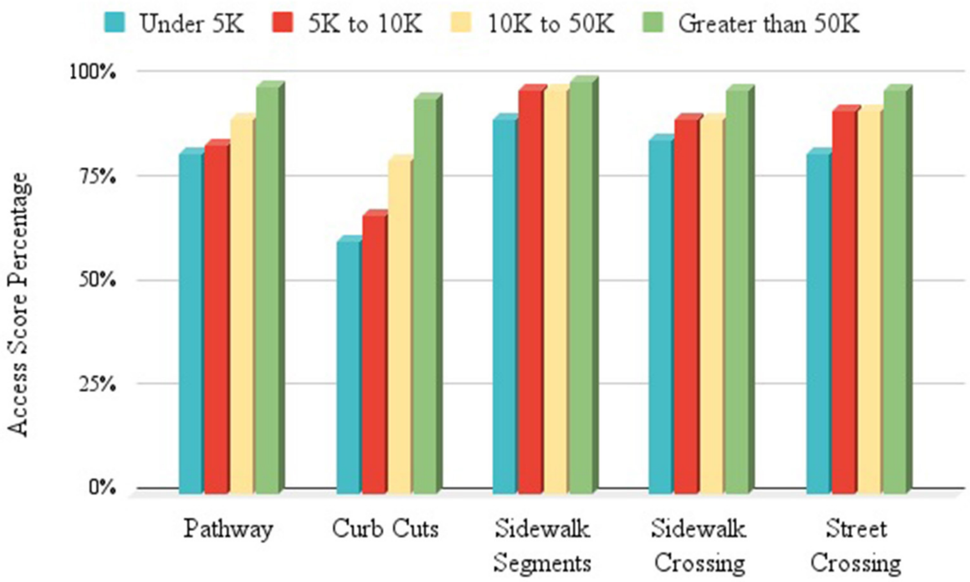


FIGURE 5
Access Scores by Community Population Groups—shows access feature scores (Pathway, Curb Cuts, Sidewalk Segments, Sidewalk Crossing, Street Crossing) by community population groups ranging from under 5,000 to >50,000 people. Communities with populations >50,000 score highest across all features.

features by four types of communities grouped by: populations under 5,000 people ($n = 7$); populations between 5,000 and 9,999 people ($n = 9$); populations between 10,000 and 50,000 people ($n = 3$); and populations over 50,000 people ($n = 3$). Communities with populations over 10,000 had CBDs with higher average Pathway Access Scores, while the groups with populations under 5,000 had CBDs with the lowest average Pathway Access Scores for any feature. Mean Pathway Access Scores that decreased with the population sizes of community groups indicated support for a Rural Access Penalty. Curb cuts in CBDs in small, rural towns (under 5,000) had the lowest average Pathway Access Score of all average scores.

In addition to rating the accessibility, the number of pathway and building risks and failures were derived from observations. Failures reflect ratings of "0" for any feature; meaning that feature created an insurmountable obstacle to proceeding. Risks reflect a feature scored as "1," a feature that exposed a person to a dangerous situation (e.g., divert into traffic), if they were to proceed. Figure 6 presents Pathway and Building Failure and Risk Scores by groups of communities ranging from under 5,000 to over 50,000 people. Failure and Risk Scores reflect the percentage of features that were scored a "0" (failure) and the percentages scored a "1" (risk) of the total number of features scored. The Building Risk Scores for the two more populous groups of communities were <0.1%.

Overall, 7.2% of the 4,474 features failed to provide an accessible pathway. Only 1.9% of pathway features presented a risky situation. The percentage of pathway features that failed exceeded 15% in six of the communities, all with populations under 10,000 people. One rural and one urban community presented a completely accessible (no Access Failures) CBD infrastructure.

Observers noted seventy-one designated parking spaces, receiving an average access rating of 1.96. Five of the spaces were observed to be in use. No designated spaces were observed in five communities.

GSV images showed people in only three CBDs (two rural and one urban community). Observers noted 56 individuals in the areas observed. Of those, 3.6% used a mobility device. The Rule of Proportional Participation suggests that 4.5% of those observed should be expected to use a mobility device or 2.52 individuals.

Discussion

The observation system focusing on a city's CBD performed well. Failure and Risk can be attributed, in part, to the location of the CBD. For example, one city's CBD is located on a major highway. When the highway was refurbished, the State and City arranged a complete rehabilitation of the sidewalks in the CBD. In addition to creating accessible pathways, the reconstruction was done in a way to bring the sidewalks very close to the level of many old buildings. As such, this improved the accessibility of both the public pathways and the privately-owned buildings.

FIGURE 6
Failure and Risk Scores by Community Population Groups—shows pathway and building failure and risk scores by community groups ranging from under 5,000 to over 50,000 people. Failure and Risk Scores reflect the percentage of features that were scored a zero (failure) and the percentages scored a one (risk) of the total number of features scored. The Building Risk Scores for the two more populous groups of communities were <0.1%.

Similar designs and arrangements have produced significant increases in accessibility in several small towns in the State.

A future direction is use of this method to evaluate change over time and implications of community action planning and related policy, systems, and environmental changes (34–37). For example, between 2013 and 2018, the communities in Study 2 participated in annual healthy community workshops, with half of these communities choosing to participate in multiple workshops. After the workshops, 10 communities developed and passed complete streets policies. Further, six communities created and implemented motorized transportation plans, and four designed non-motorized transportation plans. Other community plans were also developed, including downtown master plans ($n = 5$), growth policies ($n = 3$), and wayfinding plans ($n = 2$). Six communities generated both a complete streets policy and another community policy or plan, such as a transportation plan or wayfinding plan. As of 2018, there were 24 active transportation plans and policies in communities statewide, including complete streets policies and master plans (motorized and non-motorized transportation plans). Additionally, two of the communities were receiving technical assistance on the ADA through the U.S. Department of Justice's Project Civic Access, as a separate activity from the healthy communities program. Community leaders could use the current method to evaluate the impact of their community action planning on changes over time using available GSV data. e.g., within an inclusive, interdisciplinary audit workshop (38, 39). Indeed, the full version of Google Maps affords access to old street-level imagery from the GSV archives to support reviews of community change over time. These archives also would allow a closer study of imagery updates in rural and urban places.

Finally, Healthy People 2030 (40) has a *Community* goal to "Promote health and safety in community settings" that currently organizes 20 HP2030 objectives to achieve this goal. The current method could support partners working on these objectives to plan for increased accessibility of health promotion opportunities in community settings across their efforts. For example, the HP2030 *People with Disabilities* workgroup could provide leadership on how to integrate this method and similar tools into HP2030. Additionally, this workgroup could support increased use of environmental data across HP2030. Organizing for environmental interventions is necessary to eliminating health disparities experienced by people with disabilities within an ecological framework and the bio-psycho-social model of disability.

Conclusion

These two studies demonstrate a method for using GE and GSV to conduct distance observations of accessibility of rural and urban communities. Together, they suggest that disparities exist between rural and metropolitan cities, such that rural areas have poorer accessibility ratings, leading to decreased community participation. This disparity is termed as a "Rural Access Penalty." Continued monitoring and use of such data to plan and evaluate infrastructure investment of community accessibility, particularly in rural areas, is critical for community members' health and quality of life. Advocates may also find results from more cities useful.

These studies demonstrate the usefulness of GSV in measuring features of accessibility. This approach also produced operational definitions for several potentially useful concepts. Several of those either emerged from observation (e.g., Access Islands) or were derived by combining measures (e.g., Threat Access Ratio). Others were identified but are not reported here. This work suggests additional benefits to this scientific approach to monitoring accessibility and representing these concepts and related design considerations in planning for infrastructure development

It seems quite feasible that future research could develop an algorithm for noting and scoring accessibility features of images that would permit for computerized scoring of GSV images (41). This would increase the feasibility of nationwide accessibility assessments. An explicit partnership would be needed to replicate, routinely repeat, and expand this method systematically.

GSV has its limitations and drawbacks. First, GSV is limited to those aspects of the arranged environment that are detectable by visual inspection, and to measures derived from those observations. The level of observation limits analysis to the information captured by a car-mounted camera as it drives a route through a place. The time of day, the day of the week, and the season of the year are determined and may not reflect the needs of accessibility evaluations. Nonetheless, as in wildlife biology, multiple levels of analysis are used to assess the habitat of a population, the population in interaction with the habitat, and the behavior of individuals. Indeed, such an ecological model could be applied to organize the existing literature and guide additional research in the study of disability. As with the natural sciences, understanding at those levels could be integrated into public policy and practice, and serve as the basis of the development of the science.

Second, GSV has been criticized over concerns for privacy (42). In one case, Google was fined for intrusions in multiple states and countries and has since apologized for these actions. Further, Google has taken measures to protect privacy in GSV images, including blurring out the faces of individuals present and blurring license plates. The use of GSV imaging is legal, and studies using these images should engage in ethical measures to protect confidentiality by following ethnographic, observation, and participatory action research guidelines. When used ethically, GSV can benefit communities.

Third, GSV data represent static, one-time, cross-sectional observations. Participation is a dynamic process. As such, it requires a dynamic measure. Importantly, the environment is also in flux, and it too calls for measures across time. For example, the features of an arranged environment can interact. A curb ramp installed today may sit astride a water main buried directly below. A new building, a change in policy or practice, or simple routine maintenance may lead to the installation of a fire hydrant in the middle of the curb ramp tomorrow. Similarly, sidewalks deteriorate over time and their characteristics change. If viewed on typical periods familiar to rehabilitation researchers focusing on individual behavior, the arranged environment can be treated as relatively stable. Viewed from a perspective of natural resource management or civil engineering, the timeframe of the succession of flora or the lifetime of a bridge can be a 100 years.

This study, along with the research of others, demonstrates the value of scientific measurements of environment and participation. Society invests a great deal in scientific approaches to monitoring and managing the natural and constructed environment. For example, the U.S. Forest Service (43), the Fish and Wildlife Service (44), and the U.S Geological Service (45) collect a wide range of data from space and on the ground that permit analysts to assess the health of entire forests, including the moisture content of soils, the spread of diverse vegetation throughout habitats, as well as the populations and individuals that inhabit them (46). Similarly, the American Society for Civil Engineering (47) monitors the condition of America's infrastructure, including our bridges, dams, drinking water plants, levees, public parks and recreation facilities, schools, and transit systems. Findings from such programs are integrated into policy development, used for modifying program practices, and serve as a basis for improving science. Yet, there is no such program assessing the accessibility of our communities or participation in them. This lack of information hampers policy development and program practice.

The emerging science of the 21st century will be a science of the environment (48, 49). This movement has generally focused on models in which exposure to an environmental variable over time produces a disease response; however, this model can also be used to understand the impact of environmental risk and protective factors for community participation. Programs intended to evaluate the impacts of disability policies and programs have been scattered across Federal agencies, private organizations, and independent researchers with little integration of information (50–54). New technology provides a means for enhancing the scientific understanding of the effects of environmental factors on participation in community life. Future research may also use this technology to provide a foundation for assessing additional factors of environments (e.g., cognitive, sensory) and other areas (e.g., web sites and voting places). These data could be coordinated and consolidated by one central program with a responsibility for integrating it into public policy and practice, and into the development of the science. As such, there is both a need for and possibility of organizing a national laboratory on the environment and participation.

Data availability statement

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

Author contributions

Data collection and analysis for the project was done by TS and MT. The writing was done by TS, MT, and EH. Critical review and suggested edits were completed by all authors. All authors contributed to the article and approved the submitted version.

Funding

This research is supported by a grant from the National Institute on Disability and Rehabilitation research (NIDRR), U.S. Department of Education, #H133B080023. This project received additional support from the Research and Training Center on disability in Rural Communities (RTC:Rural) under a grant from the National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR; Grant number 90RTCP0002). NIDILRR is a Center within the Administration for Community Living (ACL), Department of Health and Human Services (HHS). This project also had support from cooperative agreements between the Centers for Disease Control and Prevention (CDC), U.S. HHS and the Montana DPHHS (DD16-1603; DD21-2103). EH receives/received support from Montana INBREŮan Institutional Development Award from the National Institute of General Medical Sciences of the National Institutes of Health under Award Number P20GM103474. The work does not necessarily represent the policy of NIDILRR, ACL, CDC, NIH or HHS and one should not assume endorsement by the federal government.

Acknowledgments

The authors wish to acknowledge the contributions of Julia Hammond, Brandon Rennie, Brice Lubitz, and Cathy Costakis. The authors thank the Rural Institute for Inclusive Communities for supporting this project and countless disability advocates for their leadership, work and guidance over the years. We also would like to thank Nancy Arnold and Catherine Ipsen for the original project idea and related contributions to the data collection methods.

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/fresc.2022.879193/full#supplementary-material

References

1. Gray D, Dashner J. CHEC it out & change it! A new tool for people with disabilities to improve community receptivity. [Webinar]. Associated Programs for Rural Independent Living Conversation Webinar; 2011.

2. 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

3. Kochtitzky CS, Frumkin H, Rodriguez R, Dannenberg AL, Rayman J, Rose K, et al. Urban planning and public health at CDC. *Morb Mortal Wkly Rev.* (2006) 55:34–8. Available online at: https://www.communitypsychology.com/

4. Seekins T, Shunkamolah W, Bertsche M, Cowart C, Summers JA, Reichard A, et al. A systematic scoping review of measures of participation in disability and rehabilitation research: a preliminary report of findings. *Disabil Health J.* (2012) 5:224–32. doi: 10.1016/j.dhjo.2012.05.002

5. Twardzik E, Clarke P, Judd S, Colabianchi N. Neighborhood participation is less likely among older adults with sidewalk problems. *J Aging Health.* (2020) 33:101–13. doi: 10.1177/0898264320960966

6. Access Board (USAB) | Spending Profile | USAspending; 2021 [cited 2022 February 10]. Available from: https://usaspending.gov/agency/access-board

7. Carlsson G, Schilling O, Slaug B, Fänge A, Ståhl A, Nygren C, et al. Toward a screening tool for housing accessibility problems: a reduced version of the housing enabler. *J Appl Gerontol.* (2009) 28:59–80. doi: 10.1177/0733464808315293

8. Whiteneck GG, Harrison-Felix CL, Mellick DC, Brooks CA, Charlifue SB, Gerhart KA. Quantifying environmental factors: a measure of physical, attitudinal, service, productivity, and policy barriers. *Arch Phys Med Rehabil.* (2004) 85:1324–35. doi: 10.1016/j.apmr.2003.09.027

9. Gray DB, Hollingsworth HH, Stark SL, Morgan KA. Participation survey/mobility: psychometric properties of a measure of participation for people with mobility impairments and limitations. *Arch Phys Med Rehabil.* (2006) 87:189–97. doi: 10.1016/j.apmr.2005.09.014

10. Nary DE, Froehlich-Grobe K, White GW. Accessibility of fitness facilities for persons with physical disabilities using wheelchairs. *Top Spinal Cord Inj Rehabil.* (2000) 6:87–98. doi: 10.1310/B9FH-7X8B-HUBR-3RHN

11. Smith SK, Rayer S, Smith EA. Aging and disability: implications for the housing industry and housing policy in the United States. *J Am Plann Assoc.* (2008) 74:289–306. doi: 10.1080/01944360802197132

12. Seekins T, Arnold N, Ipsen C. Developing methods for grading the accessibility of a communality's infrastructure. *J Urban Plann Dev.* (2012) 138:270–6. doi: 10.1061/(ASCE)UP.1943-5444.0000117

13. Seekins T, Arnold N, Ipsen C. Assessing and comparing the accessibility of community environments: a feasibility study. In: *Environmental Contexts and Disability* [Internet]. Bingley: Emerald Group Publishing Limited (2014). p. 55–70. (Research in Social Science and Disability; vol. 8). doi: 10.1108/S1479-354720140000008004

14. Ben-Joseph E, Lee JS, Cromley EK, Laden F, Troped PJ. Virtual and actual: Relative accuracy of on-site and web-based instruments in auditing the environment for physical activity. *Health Place.* (2013) 19:138–50. doi: 10.1016/j.healthplace.2012.11.001

15. Rundle AG, Bader MDM, Richards CA, Neckerman KM, Teitler JO. Using Google Street View to audit neighborhood environments. *Am J Prev Med.* (2011) 40:94–100. doi: 10.1016/j.amepre.2010.09.034

16. Rzotkiewicz A, Pearson AL, Dougherty BV, Shortridge A, Wilson N. Systematic review of the use of Google Street View in health research: Major themes, strengths, weaknesses and possibilities for future research. *Health Place.* (2018) 52:240–6. doi: 10.1016/j.healthplace.2018.07.001

17. Mooney SJ, DiMaggio CJ, Lovasi GS, Neckerman KM, Bader MDM, Teitler JO, et al. Use of Google Street View to assess environmental contributions to pedestrian injury. *Am J Public Health.* (2016) 106:462–9. doi: 10.2105/AJPH.2015.302978

18. Griew P, Hillsdon M, Foster C, Coombes E, Jones A, Wilkinson P. Developing and testing a street audit tool using Google Street View to measure environmental supportiveness for physical activity. *Int J Behav Nutr Phys Act.* (2013) 10:103. doi: 10.1186/1479-5868-10-103

19. Biljecki F, Ito K. Street view imagery in urban analytics and GIS: a review. *Landsc Urban Plan.* (2021) 215:104217. doi: 10.1016/j.landurbplan.2021.104217

20. Morrison ML, Marcot BG, Mannan RW. *Wildlife-habitat Relationships: Concepts and Applications*. Washington, DC: Island Press (2006).

21. Bromm KN. Lang, IM, Twardzik, E, Antonakos, CL, Dubowitz, T, Colabianchi, N. Virtual audits of the urban streetscape: comparing the interrater reliability of GigaPan® to Google Street View. *Int J Health Geograph.* (2020) 19:31. doi: 10.1186/s12942-020-00226-0

22. Hara K, Le V, Froehlich J. Combining crowdsourcing and Google Street View to identify street-level accessibility problems. In: *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems*. New York, NY: USA Association for Computing Machinery (2013). p. 631–40. doi: 10.1145/2470654.2470744

23. Brooke J. SUS: a "quick and dirty" usability scale. In: Jordan PW, Thomas B, Weerdmeester BA, McClelland AL, editors *Usability Evaluation in Industry*. London: Taylor and Francis (1996). p. 189–94.

24. Seekins T, Rennie B, Hammond J. Exploring the feasibility of using "Google Street View" to assess the accessibility of community environments: developing definitions and observational protocol for image recognition and classification. *Res Soc Sci Disabil.* (2014) 8:123–39. doi: 10.1108/S1479-354720140000008007

25. LaPlante M, Kaye S. Mobility device use and hearing impairments among individuals and households, 1990–2010. United States Access Board [cited 2022 February 10]. Available from: https://www.access-board.gov/pvag/

26. Frumkin H, Frank LD, Jackson R. *Urban Sprawl and Public Health: Designing, Planning, and Building for Healthy Communities*. Washington, DC: Island Press (2004).

27. Centers for Disease Control and Prevention. Community health assessment and group evaluation (CHANGE): Building a foundation of knowledge to prioritize community needs; 2013 [cited 2015 December 7]. Available from: http://www.cdc.gov/nccdphp/dch/programs/healthycommunitiesprogram/tools/change.htm

28. Centers for Disease Control and Prevention. ACHIEVE healthy communities; 2013 [cited 2015 December 7]. Available from: http://www.achievecommunities.org/

29. Sallis JF, Frank LD, Saelens BE, Kraft MK. Active transportation and physical activity: opportunities for collaboration on transportation and public health research. *Transp Res Part A Policy Pract.* (2004) 38:249–68. doi: 10.1016/j.tra.2003.11.003

30. Rimmer JH, Vanderbom KA, Bandini LG, Drum CE, Luken K, Suarez-Balcazar Y, et al. GRAIDs: A framework for closing the gap in the availability of health promotion programs and interventions for people with disabilities. *Implement Sci.* (2014) 9:100. doi: 10.1186/s13012-014-0100-5

31. Traci M, Cowan B. Accessibility under the big sky. *Commun Psychol.* (2005) 38:34–7. Available online at: http://www.msulocalgov.org/images/MTPolicyReview-2011-Fall.pdf (accessed July 27, 2022).

32. Traci M, Seekins T. Integration of chronic disease and disability and health state programs in Montana. *Disabil Health J.* (2014) 7:19–25. doi: 10.1016/j.dhjo.2013.10.006

33. Traci MA, Costakis C, Sutherland S, Laurin K. The Three Forks headwaters trail project: improving accessibility through community input and trail assessment. *Mont Policy Rev.* (2011) 15:15–9.

34. Center for Disease Control and Prevention. Community Health Assessment and Group Evaluation (CHANGE) tool; 2018 [cited 2022 February 13]. Available from: https://www.cdc.gov/nccdphp/dnpao/state-local-programs/change-tool/index.html

35. Eisenberg Y, Rimmer JH, Mehta T, Fox MH. Development of a community health inclusion index: an evaluation tool for improving inclusion of people with disabilities in community health initiatives. *BMC Public Health.* (2015) 15:1050. doi: 10.1186/s12889-015-2381-2

36. Eisenberg Y, Vanderbom KA, Harris K, Herman C, Hefelfinger J, Rauworth A. Evaluation of the reaching people with disabilities through healthy communities project. *Disabil Health J.* (2021) 14:101061. doi: 10.1016/j.dhjo.2021.101061

37. Center for Disease Control and Prevention. Reaching people with disabilities through healthy communities; 2020 [cited 2022 February 13]. Available from: https://www.cdc.gov/ncbddd/disabilityandhealth/reaching-people.html

38. Traci MA, Costakis C, Hoit A, Greiman L, Fenton M. (2018). Walkable rural communities for all: using inclusive, interdisciplinary walk audit workshops to achieve health equity. [Poster presentation]. APHA Annual Meeting, San Diego, CA.

39. Hicks E, Traci MA. "Sympathy" versus "empathy": comparing experiences of I2Audits and disability simulations. *Front Rehabilit Sci.* (Under review).

40. Office of Disease Prevention and Health Promotion. Community: Healthy People 2030; n.d. [cited 2022 February 13]. Available from: https://health.gov/healthypeople/objectives-and-data/browse-objectives/community

41. Weld G, Jang E, Li A, Zeng A, Heimerl K, Froelich JE. Deep learning for automatically detecting sidewalk accessibility problems using streetscape imagery. *Assets.* (2019) Paper Session 4, 196–209. doi: 10.1145/3308561.3353798

42. Zuboff S. *The Age of Surveillance Capitalism: The Fight for a Human Future at the New Frontier of Power. New York, NY: PublicAffairs* (2019).

43. United States Forest Service. FSGeodata Clearninghouse; n.d. [cited 2022 February 13]. Available from: https://data.fs.usda.gov/geodata/

44. United States Fish and Wildlife Service. Online Databases; n.d. [cited 2022 February 13]. Available from: https://www.fws.gov/info/databases2.html

45. United States Geological Survey. Data [cited 2022 February 13]. Available from: https://www.usgs.gov/products/data

46. Famiglietti JS, Devereaux JA, Laymon CA, Tsegaye T, Houser PR, Jackson TJ, et al. Ground-based investigation of soil moisture variability within remote sensing footprints during the Southern Great Plains 1997 (SGP97) Hydrology Experiment. *Water Resour Res.* (1999) 35:1839–51. doi: 10.1029/1999WR900047

47. American Society of Civil Engineers. Report card for America's Infrastructure; 2009. Available from: https://www.infrastructurereportcard.org/2009/sites/default/files/rc2009_full_report.pdf (accessed July 27, 2022).

48. National Academies of Science. The exposome: A powerful approach for evaluating environmental exposures and their influences on human disease. [Workshop]. International Agency for Research on Cancer; 2010. Available from: https://www.iarc.who.int/media-centre-iarc-news-59/ (accessed July 27, 2022).

49. Wild CP. Complementing the genome with an "exposome": the outstanding challenge of environmental exposure measurement in molecular epidemiology. *Cancer Epidemiol Biomarkers Prev.* (2005) 14:1847–50. doi: 10.1158/1055-9965.EPI-05-0456

50. Americans with Disabilities Act: Assessing the progress toward achieving the goals of the ADA [cited 2022 February 10]. Available from: https://www.aucd.org/docs/ADA%20Impact%20Report.pdf

51. Seekins T, Traci MA, Cummings S, Oreskovich J, Ravesloot C. Assessing environmental factors that affect disability: Establishing a baseline of visitability in a rural state. *Rehabil Psychol.* (2008) 53:80–4. doi: 10.1037/0090-5550.53.1.80

52. Iwarsson S, Ståhl A. Accessibility, usability and universal design: Positioning and definition of concepts describing person-environment relationships. *Disabil Rehabil.* (2003) 25:57–66. doi: 10.1080/dre.25.2.57.66

53. Centers for Disease Control and Prevention. Health Issues Related to Community Design; 2007 [cited 2022 February 10]. Available from: http://www.cdc.gov/healthyplaces/

54. Srinivasan S, O'Fallon LR, Dearry A. Creating healthy communities, healthy homes, healthy people: initiating a research agenda on the built environment and public health. *Am J Public Health.* (2003) 93:1446–50. doi: 10.2105/AJPH.93.9.1446

frontiers | Frontiers in Rehabilitation Sciences

TYPE Brief Research Report
PUBLISHED 09 August 2022
DOI 10.3389/fresc.2022.875978

OPEN ACCESS

EDITED BY
Kathleen Thomas,
University of North Carolina at Chapel Hill, United States

REVIEWED BY
Elena Vasilchenko,
FSBI Novokuznetsk Scientific and Practical Centre for Medical and Social Expertise and Rehabilitation of Disabled Persons, Russia
Zhuoying Qiu,
China Rehabilitation Research Center/WHO Collaborating Center for Family International Classifications, China

*CORRESPONDENCE
Catherine Ipsen
catherine.ipsen@mso.umt.edu

SPECIALTY SECTION
This article was submitted to Disability, Rehabilitation, and Inclusion, a section of the journal Frontiers in Rehabilitation Sciences

RECEIVED 14 February 2022
ACCEPTED 15 July 2022
PUBLISHED 09 August 2022

CITATION
Gimm G and Ipsen C (2022) Examining rural-urban disparities in perceived need for health care services among adults with disabilities.
Front. Rehabilit. Sci. 3:875978.
doi: 10.3389/fresc.2022.875978

Examining rural-urban disparities in perceived need for health care services among adults with disabilities

Gilbert Gimm[1] and Catherine Ipsen[2]*

[1]Department of Health Administration and Policy, George Mason University, Fairfax, VA, United States, [2]Rural Institute for Inclusive Communities, University of Montana, Missoula, MT, United States

Purpose: The purpose of this study is to parse out differences between unmet need and perceived need for health care services among rural and urban adults with disabilities in the United States. While unmet need focuses primarily on environmental factors such as access to health insurance or provider availability, perceived need relates to personal choice. This distinction between unmet and perceived need is largely ignored in prior studies, but relevant to public health strategies to improve access and uptake of preventive care.

Methods: Using Wave 2 data from the National Survey on Health and Disability, we explored rural and urban differences in unmet and perceived health care needs among working-age adults with disabilities for acute and preventive services.

Findings: Although we found no significant differences in unmet needs between rural and urban respondents, we found that perceived needs for dental care and mental health counseling varied significantly across geography. Using logistic regression analysis and controlling for observable participant characteristics, we found that respondents living in noncore counties relative to metropolitan counties were more likely to report not needing dental care (OR 1.89, $p = 0.028$), and not needing mental health counseling services (OR 2.15, $p \leq 0.001$).

Conclusion: These findings suggest additional study is warranted to understand perceived need for preventive services and the levers for addressing rural disparities.

KEYWORDS

rural, health care, unmet need, perceived need, preventive services, disability

Introduction

Timely access to preventive care such as regular check-ups, health screenings, immunizations, and dental care can lower the risk of developing health complications, identify emerging health issues, reduce the need for aggressive interventions, and lower overall health care costs (1–3). Despite these substantial advantages, however, many people choose to forego preventive care, particularly in rural places (4–6).

The decision to obtain preventive care depends on a variety of environmental and personal factors. Environmental factors are well cited in the literature, and include the cost of preventive care services, local availability of providers, health insurance coverage, as well as travel time and distance from a person's home to a provider facility to receive care (2, 7, 8). Many environmental barriers to services can be addressed through policy and funding initiatives, such as Affordable Care Act provisions to lower the out-of-pocket cost of preventive services (9). However, less straightforward are personal factors that influence decision making, such as trust of medical providers, ideology, self-reliance, and other behavioral norms (4, 10, 11). If patients do not perceive a need for preventive care, some policy efforts to increase access, such as expanding provider availability, may have limited effectiveness.

The purpose of this study is to parse out differences between unmet need and perceived need in a population of rural and urban adults with disabilities. While unmet need focuses primarily on environmental factors, perceived need relates to personal choice. This distinction is largely ignored in prior studies, but relevant to public health strategies to improve access and uptake of preventive care.

Background

In comparison to adults living in urban areas of the US, rural adults experience significant health disparities. In part, these disparities can be explained by a greater proportion of older adults (65 years or more) living in rural areas (12). After controlling for age, however, rural adults still experience higher rates of chronic conditions, mortality, and disability across the life span (12–14). Socio-economic factors play a role in disparities, such as lower median income, lower educational attainment, and higher poverty rates that impact access to services (15, 16). The literature documents economic-based considerations for delaying or not seeking services, such as high out-of-pocket costs and a lack of insurance coverage, which has a disproportionate impact on rural adults (8, 16).

Limited availability of rural health service providers also comes into play. In comparison to urban areas, rural areas generally have fewer per capita health care providers including physicians, surgeons, psychologists, counselors, dentists, dieticians, occupational therapists, physical therapists, and a host of allied-health professionals (16, 17). Although telemedicine has been touted as a solution to address provider shortages, rural people have significantly lower rates of broadband access, smartphones, and home computers, as well as an under-trained workforce for using telemedicine visits (16). When health care professionals are unavailable or alternatives such as telemedicine are inappropriate, rural residents incur additional opportunity costs to access care, such as securing reliable transportation and taking time off to travel to health care appointments (16, 18). In international studies, a lack of reliable transportation and financial barriers also contribute to disparities in accessing health care services for adults with disabilities (19).

Rural and urban disparities may also relate to differences in behavioral norms. Prior studies have shown lower rates of seat belt use and higher rates of smoking in rural relative to urban areas (10, 20). Higher rates of smoking undermines the argument that cost by itself is a driving factor in rural decision-making. Rural adults also have lower rates of vaccination, which has become particularly evident during the COVID-19 pandemic. In this case, public health efforts and free COVID-19 vaccinations nationwide have not translated into similar vaccination rates for adults in rural versus urban areas (21, 22).

A study exploring rural and urban differences in worker's compensation healthcare claims provides additional evidence regarding different rural and urban behaviors. After controlling for demographics, injury, and injury severity, Young et al. found that rural workers used significantly fewer physical therapy (PT) services than their urban counterparts, and experienced longer injury duration and risk of prolonged work-disability (11). Although access to PT services may drive some of these differences, cost was not a factor because worker's compensation covered medical costs.

We know that health behaviors shape and directly influence health outcomes (23). In the case of rural adults, less adherence to recommended preventive health practices translates into higher rates of health conditions, comorbidities, and mortality (10, 20). A reluctance to engage in preventive practices is particularly risky for people with disabilities, who often experience a thin margin of health (24). For instance, a recent study of National Longitudinal Survey of Youth 79 (NLSY79) data found that U.S. adults who experience a mobility impairment at age 40 had a higher incidence of health conditions or complications (e.g., arthritis, heart problems, depression, ulcers, intestinal problems, tooth and gum trouble, chronic lung disease, thyroid issues, asthma, diabetes, etc.), compared with those who did not report a mobility impairment. Furthermore, rates of health conditions or complications were significantly higher among rural people for many conditions (Ipsen et al., in press). For this reason, we are particularly interested in exploring rural and urban differences in unmet and perceived need for adults with disabilities. Also, prior studies have not been able to measure or assess perceived need using national surveys, which is a major gap in the literature. Therefore, this study aims to contribute new knowledge on differences in perceived and actual need among adults with disabilities living in rural and non-rural areas of the United States.

Methods

We used data from the second administration (Wave 2) of the National Survey on Health and Disability to explore unmet and perceived health care needs among people with disabilities. The NSHD was developed as part of a National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR) funded grant to learn how access to health insurance and services affects health and community living outcomes among people with disabilities.

Sample inclusion criteria

Data collection for Wave 2 of the NSHD was completed in February 2020, just before the start of COVID-19 lockdowns in the United States. The sample included adult respondents ($N = 2{,}161$) who were living in the United States, between the ages of 18 and 64 years, and answered yes to the question "Do you have a physical condition, mental illness, impairment, disability or chronic health condition that can affect your daily activities OR that requires you to use special equipment or devices, such as a wheelchair, walker, TDD, or communication device?" Most participants completed the NSHD questionnaire using an online Qualtrics survey, but all eligible participants had the option of completing the survey over the telephone, if needed.

Recruitment of participants took place in two ways. Targeted recruitment occurred through (1) direct email requests to past respondents who provided optional email contact information, (2) flyers distributed to conference attendees at six 2019 disability-focused conferences, and (3) recruitment materials shared through 73 disability-related organizations, groups, and/or service providers. Additional recruitment was conducted through an online platform called Amazon's Mechanical Turk (MTURK).

MTurk is an online marketplace where "requesters" can post a human intelligence task (HIT), such as completing a survey, and "workers" can pick up the HIT for a small payment. MTurk recruitment began with a brief online screening survey to identify respondents meeting inclusion criteria, who were then invited to take the full survey. To ensure data quality, researchers used vetted strategies including the use of MTurk approval ratings, cognitive checks, and hidden screening criteria to reduce false reporting (25–27). More complete descriptions of NSHD data-collection methods are available in past study publications (26, 27).

Measures

The NSHD is a comprehensive survey that covers multiple topics including health status, transportation, use of personal assistance services, community participation and social isolation, benefits, employment, insurance coverage, unmet needs, income, demographics, and multiple measures of disability. Survey measures specific to this paper are described below.

Socio-demographics

We used several variables to control for socio-demographic differences, including age, gender, race/ethnicity, educational attainment, marital status, and income. *Gender* options included male, female, and other (non-binary). The question for *race and ethnicity* asked, "which one or more of the following best describe your race and/or ethnicity?": American Indian/Native American, African American/Black, Asian, Hispanic, Native Hawaiian/Pacific Islander, White/Caucasian, and Other. These data were used to create African American/Black, Hispanic, Multi-Racial, and Other Race groups, with the remaining classified as White/not Hispanic. We collapsed seven *education* groups ranging from no formal education to graduate or doctoral degree into four including high school or less, some college, 4-year college, and graduate school for our analyses. The survey asked, "what is your current *marital status*?" with four possible responses: single-never married, single-divorced or widowed, married, and prefer not to answer. *Income* groupings were calculated based on three questions including number of people living in the household, state of residence, and household income. This information was utilized to provide household income as percent of the Federal Poverty Level (FPL). As informed by created variables within the NSHD dataset, we focused on four income categories including $<$ 138% of the FPL, 138–249% of the FPL, 250–399% FPL, and 400% or higher than the FPL.

Disability

We measured disability using the 6-item question set included in the American Community Survey (ACS), which includes the following yes/no questions: Are you deaf or do you have serious difficulty hearing? Are you blind or do you have serious difficulty seeing even when wearing glasses? Because of a physical, mental, or emotional condition, do you have serious difficulty concentrating, remembering, or making decisions? Do you have serious difficulty walking or climbing stairs? Do you have difficulty bathing or dressing? Because of a physical, mental, or emotional condition, do you have difficulty doing errands alone, such as visiting a doctor's office or shopping? (28). In our analyses, individuals who endorsed more than one functional difficulty were classified as having multiple disabilities.

Noncore, micropolitan, and metropolitan residence

The NSHD asked participants to provide their county of residence. County indicators were matched to Federal Information Processing Standards (FIPS) codes and classified using the Office of Management and Budget's (OMB) rural-urban classification scheme. Specifically, OMB classifies counties as (1) *metropolitan*, if they are located within an urban core of 50,000 of more people, or are an outlying county with close economic ties to an urban core (2) *micropolitan*, if they are located within an urban core of at least 10,000 but $<$ 50,000 people, and (3) *non-core*, all remaining counties (29). Both micropolitan and non-core counties are considered rural, but have unique characteristics related to health care access (30).

Unmet need and perceived need

The NSHD asked a series of questions to understand unmet need in the past 12 months for those with some type of health insurance plan. We focused on unmet needs related to a participant's self-reported access to doctors, specialists, prescription medications, dental services, and mental health counseling. NSHD questions on unmet need were phrased as follows: "in the past 12 months, have you been able to [see the doctors you need to; see the specialists you need to; get all the prescription medications you need; get the dental services you need; get the mental health services and/or counseling services you need]. There were four possible response options including "yes," "no," "I don't know," and "I did not need." While the "no" responses to questions on access to care reflected unmet need, the "I did not need" responses were used to measure and examine differences in perceived need.

Data analyses

Data was transferred from Qualtrics to STATA for analyses. We compared unadjusted responses to questions about unmet need by geographic area (i.e., non-core, micropolitan, metropolitan) using Chi-square statistics. We then used logistic regression to adjust for observable characteristics and examine factors significantly associated with a participant responding "I did not need" dental services or mental health services. We focused on these two services because they represented proxies for preventive care, as opposed to a measure of acute care from a primary care doctor or specialist, or medications obtained from a pharmacy to manage a chronic health condition.

Results

Our analytic sample included a total of 2,161 adult respondents (18–64 years) with disabilities. Of these, 6.3% were living in non-core rural areas, 11.1% were in micropolitan rural areas, and 82.6% were living in metropolitan urban areas. Table 1 reports sample demographics including age, gender, race/ethnicity, educational attainment, marital status, income level, and functional disability type by geographic area, and for the combined sample.

Unmet and perceived needs

Table 2 shows the unadjusted prevalence of unmet and perceived service needs by geographic area (non-core, micropolitan, and metropolitan). There were no statistical differences between non-core, micropolitan, and metropolitan respondents in terms of rates of unmet and perceived need for seeing a doctor, seeing a specialist, and getting needed prescriptions. However, perceived need, as measured by the "I did not need" responses, were statistically different for dental care and mental health care across non-core, micropolitan, and metropolitan groups. For dental care, 17.9% of non-core respondents indicated they did not need dental services, compared to 14.1% in micropolitan, and 9% in metropolitan. For mental health services, 46.7% of non-core, 43.5% of micropolitan, and 34.8% of metropolitan respondents said that they did not need mental health services.

Logistic regression models to predict perceived need

Given the unadjusted disparities observed in the perceived need for dental care and mental health services among non-core, micropolitan, and metropolitan respondents, we conducted multivariate analyses of these two outcomes. Table 3 reports results from a logistic regression to examine the likelihood of a participant saying they did not need dental care. After controlling for observable participant characteristics, we found that adults in non-core areas (OR 1.89, p =0.028) had significantly greater odds of not needing dental care compared to those living in urban areas (i.e., the reference group). Males (OR 2.07, $p \leq 0.001$) relative to females, individuals from lower income brackets (<138% FPL, OR 2.11, $p = 0.007$ and 138%-249% FPL, OR 1.93, $p = 0.020$), relative to the highest income bracket, and those reporting ambulatory disability (OR 2.22, $p \leq 0.001$) were also more likely to say they did not need dental care. Conversely, adults were less likely to say they did not need care as they become older (OR 98, p =0.044).

TABLE 1 Participant characteristics.

	Non-core ($N = 136$)	Micropolitan ($N = 240$)	Metropolitan ($N = 1{,}785$)	Full sample ($N = 2{,}161$)
Age (mean years)	41.3	42.4	41.6	41.7
Gender				
Male	39.0%	31.7%	32.6%	32.7%
Female	58.8%	67.5%	64.0%	64.1%
Other (Non-binary)	2.2%	0.8%	3.4%	3.0%
Race/Ethnicity				
White non-hispanic	83.0%	87.3%	79.7%	80.7%
African American	3.0%	2.5%	5.3%	4.8%
Hispanic	2.2%	0.4%	3.4%	3.1%
Multi-Racial	5.9%	6.8%	6.7%	6.6%
Other Race	5.9%	3.0%	4.8%	4.7%
Educational attainment				
High school or less	23.0%	18.8%	11.9%	13.3%
Some college	43.0%	49.2%	36.4%	38.3%
4-year college	26.7%	21.3%	27.7%	26.9%
Graduate education	7.4%	10.8%	24.0%	21.5%
Marital status				
Currently married	36.1%	35.9%	34.3%	34.6%
Living with partner	11.3%	13.9%	10.4%	10.8%
Divorced/widowed	14.3%	15.6%	14.1%	14.3%
Never married	38.4%	34.6%	41.3%	40.3%
Income level*				
less than 138% FPL	49.6%	43.2%	35.1%	37.0%
138%-249% FPL	24.1%	26.3%	22.0%	22.6%
250%-399% FPL	14.3%	14.8%	19.5%	18.6%
400% FPL or more	12.0%	15.7%	23.4%	21.9%
Functional disability type**				
Hearing only	1.5%	3.3%	4.0%	3.8%
Vision only	3.7%	3.3%	4.2%	4.1%
Cognitive only	32.4%	27.5%	26.9%	27.3%
Ambulatory only	18.4%	21.8%	17.8%	18.3%
Self-care only	4.4%	2.9%	4.4%	4.2%
Independent living only	26.5%	19.6%	18.7%	19.3%
Multiple disabilities	24.3%	28.0%	27.9%	27.7%

*FPL, federal poverty level.

**Disability type based on binary indicators from 6 categories in the American Community Survey.

Table 4 reports results from a logistic regression analysis that examines the likelihood of a participant saying they did not need mental health counseling in the past year. Adults in both non-core (OR 2.15, $p < 0.01$) and micropolitan (OR 1.56, $p < 0.05$) areas had higher odds of saying they did not need mental health services compared to those in metropolitan areas. Males (OR 1.03, $p \leq 0.001$), relative to females, and respondents as they became older (OR 1.03, $p < 0.001$) were also more likely to report not needing mental health care. Conversely, non-binary adults (OR 0.21, $p = 0.011$), relative to females, were less likely to say they did not need mental health services, as were respondents in the lowest income bracket (138% FPL, OR 0.65, $p = 0.011$), relative to the highest income bracket. In terms of disability, those with a vision disability (OR 2.00, $p < 0.05$) or ambulatory disability (OR 1.37, $p < 0.05$) had higher odds of saying they did not need mental health counseling, while those with a cognitive disability (OR 0.27, $p < 0.001$) and multiple disabilities (OR 0.63, $p < 0.01$) had lower odds of saying they did not need mental health services.

TABLE 2 Unmet and perceived service need (%), by geographic category.

In the last 12 months have you been able to…?	Non-core ($N = 136$)	Micropolitan ($N = 240$)	Metropolitan ($N = 1{,}785$)	Chi-square p-value
See a doctor				
Yes	81.3	85.1	83.9	0.571
No	13.1	12.9	12.8	
Did not need to see a doctor	5.6	2.0	3.3	
See a specialist				
Yes	76.1	70.4	75.1	0.378
No	11.9	12.2	12.6	
Did not need to see a specialist	11.9	17.3	12.2	
Get needed prescriptions				
Yes	77.4	80.5	77.2	0.803
No	16.0	15.1	17.6	
Did not need prescriptions	6.6	4.4	5.2	
Get dental services				
Yes	50.0^{a}	55.2^{a}	60.6^{a}	**0.008**
No	32.1^{a}	30.7^{a}	30.4^{a}	
Did not need dental services	17.9^{b}	$14.1^{a,b}$	9.0^{a}	
Get counseling or mental health services				
Yes	34.3^{a}	38.9^{a}	45.0^{a}	**0.024**
No	19.0^{a}	17.6^{a}	20.3^{a}	
Did not need mental health services	46.7^{a}	$43.5^{a,b}$	34.8^{b}	

Each subscript letter (a, b) denotes a subset of 3 category population density categories whose column proportions do not differ significantly from each other at a 0.05 level.
Boldface indicates p-values < 0.05.

Discussion

The literature highlights the importance of regular health and preventive services for managing health care costs and outcomes (1–3), as well as disparities in health care access and utilization across rural and urban subgroups (6–8). Disparities in access and utilization appear to translate into higher rates of chronic health conditions, mortality, and disability for rural, relative to urban populations (12–14).

The literature points to several rural barriers to health care access including provider shortages, increased out-of-pocket costs, and time and distance to receive services (16–18). We anticipated these types of barriers would be captured by NSHD questions focused on unmet needs in the last 12 months for doctors, specialists, prescription medications, dental services, and mental health counseling. Contrary to expectations, however, unmet needs were similar across non-core, micropolitan, and metropolitan respondents.

When exploring the data further, we noted rural and urban differences in perceived need for services in the last 12-months related to dental and mental health counseling services, after controlling for differences in socio-demographic and disability characteristics. Dental and mental health counseling services are different from doctors, specialists, and prescriptions on certain dimensions. First, they have historically been excluded from most private health insurance plans. According to Fair Health, an advocacy organization for health care costs and coverage, most private health care plans do not cover dental services (31). Although coverage expanded for mental health counseling services somewhat due to the Affordable Care Act, prior to 2014 these types of services were often excluded from coverage (32, 33).

Because rural consumers experience higher rates of poverty, lower household incomes, and less disposable income to cover out-of-pocket costs, lack of current and past insurance coverage for dental and mental health services may contribute to the comparatively low ratios of per capita providers for these services (33). According to the National Center for Health Workforce Analysis, the lowest urban to rural ratios among 32 health care occupations were for dentists (0.61) and psychologists (0.45) (17). In this case, the perception of need may be shaped by long-standing provider shortages that have undermined both demand and expectations for receiving services.

TABLE 3 Multivariate analysis of dental care not needed ($N = 1{,}705$).

	OR	*p*-value	95% CI	
Geographic region (ref = metropolitan)				
Non-core	1.89	**0.028**	1.07	3.33
Micropolitan	1.58	0.059	0.98	2.53
Age (Years)	0.98	**0.044**	0.97	1.00
Gender (ref. = female)				
Male	2.07	**<0.001**	1.47	2.92
Other (non-binary)	1.30	0.636	0.44	3.84
Race/Ethnicity (ref. = white, non-Hispanic)				
African American	0.63	0.316	0.26	1.54
Hispanic	0.38	0.190	0.09	1.61
Multi-Racial	0.76	0.452	0.37	1.56
Other Race	1.37	0.418	0.64	2.91
Education (ref. = 4-year college)				
High school or less	1.32	0.315	0.77	2.26
Some college	1.07	0.752	0.71	1.62
Graduate school	0.70	0.196	0.40	1.20
Marital status (ref. = never married)				
Currently married	1.12	0.593	0.73	1.72
Living with unmarried partner	0.80	0.485	0.43	1.50
Divorced / widowed / separated	1.23	0.458	0.71	2.12
Household income (ref. = 400% FPL or more)				
<138% FPL	2.11	**0.007**	1.22	3.62
138%-249% FPL	1.93	**0.020**	1.11	3.35
250%-399% FPL	1.41	0.250	0.79	2.53
Functional disability type				
Hearing only	0.77	0.596	0.29	2.02
Vision only	1.27	0.561	0.56	2.87
Cognitive only	1.01	0.961	0.67	1.52
Ambulatory only	2.22	**<0.001**	1.43	3.44
Self-care only	0.36	0.062	0.13	1.05
Independent living only	1.02	0.940	0.66	1.58
Multiple disabilities only	0.76	0.278	0.46	1.25

Boldface indicates p-values < 0.05.

TABLE 4 Multivariate analysis of mental health care not needed ($N = 1{,}694$).

	OR	p-value	95% CI	
Geographic region (ref. = metropolitan)				
Non-core	2.15	**0.001**	1.37	3.37
Micropolitan	1.56	**0.011**	1.11	2.20
Age (Years)	1.03	**<0.001**	1.02	1.04
Gender (ref. = female)				
Male	1.43	**0.002**	1.14	1.81
Other (non-binary)	0.21	**0.011**	0.06	0.70
Race/Ethnicity (ref. = white, non-Hispanic)				
African American	0.72	0.239	0.41	1.25
Hispanic	1.06	0.858	0.55	2.04
Multi-Racial	0.89	0.610	0.58	1.38
Other Race	1.49	0.159	0.85	2.61
Education (ref. = 4-year college)				
High school or less	1.42	0.077	0.96	2.09
Some college	0.90	0.454	0.68	1.19
Graduate school	0.84	0.250	0.62	1.13
Marital status (ref. = never married)				
Currently married	0.87	0.300	0.66	1.14
Living with unmarried partner	1.12	0.561	0.76	1.65
Divorced / widowed / separated	0.90	0.563	0.63	1.28
Household income (ref. = 400% FPL or more)				
<138% FPL	0.65	**0.011**	0.47	0.91
138%-249% FPL	0.75	0.086	0.54	1.04
250%-399% FPL	1.26	0.153	0.92	1.73
Functional disability type				
Hearing only	1.29	0.348	0.76	2.21
Vision only	2.00	**0.010**	1.18	3.41
Cognitive only	0.27	**<0.001**	0.20	0.37
Ambulatory only	1.37	**0.041**	1.01	1.85
Self-care only	0.71	0.201	0.42	1.20
Independent living only	0.86	0.344	0.62	1.18
Multiple disabilities only	0.63	**0.002**	0.47	0.84

Boldface indicates p-values < 0.05.

Second, many dental services such as regular teeth cleanings and mental health counseling services to address health behaviors and depression are considered preventive, as opposed to generalized, acute care, which may shape overall consumption (34, 35). Douthit et al., conducted a literature review on rural health care access and highlighted various dimensions of health seeking behaviors. Among these dimensions were cultural perceptions related to accessing care, including delaying care until acute need (36), issues related to privacy when living in a smaller community, and health care consumption, in general (33). As one qualitative study excerpt highlighted "We have our ways. We're from a ranch…We don't use medical. We fix ourselves here" (37).

In particular to mental health counseling, evidence suggests self- and public-stigma undermines decision-making to seek services, particularly in rural communities (38). For instance, a study by Hammer et al. found that self-stigma about seeking counseling was significantly higher among rural men, relative to urban men across diverse socio-demographic backgrounds (39).

Together, these factors may shape decision making differently in rural and urban places, particularly related to perceived need. If preventive health care is not part of existing community norms or typical behavior, perceived need will likely be lower. It is likely that community behaviors develop over time, and environmental factors play a role. If providers are not available and time and cost burdens are high, low demand gets incorporated into the status quo. Goldberg et al. describes this in terms of "horizontal" communication, where people receive and incorporate behaviors based on examples from trusted and familiar sources including personal relationships, social networks, and communities (40).

These findings have important policy implications. Since most federal surveys with questions on health care access are limited to binary "Yes/No" categories without a third option for "not needing a service," a participant might indicate that they were able to access the care they needed (because they did not perceive or have a need). As a result, the estimated prevalence of having adequate access to care is likely to be misleading or overestimated. The addition of a third response category for "not needing a service" in federal surveys would be a valuable contribution by allowing researchers and policymakers to identify perceived need as a separate component and obtain more accurate measures of access to care.

Further study is needed about which personal and environmental factors play a key role in the lower rates of perceived need for dental care and mental health counseling among adults in rural areas compared to those living in urban areas. Findings from these future studies can also help inform public health efforts to increase the use of preventive care and raise vaccination rates in rural areas.

Study limitations

This study had several data limitations. First, the data were collected using online survey methods. Thus, the NSHD sample excluded rural and urban adults who had limitations in digital literacy or inadequate broadband access. As a result, these findings may not be generalizable to all adults with disabilities who are living in non-metro, micropolitan, and metropolitan areas. Second, the cross-sectional design of the study using Wave 2 of the NSHD does not allow us to make casual inferences. Instead, we can only identify associations between measures. Third, the NSHD used self-reported measures of access to care in the past 12 months, which may be subject to some recall bias and inaccurate responses.

However, a major strength of the NSHD is that it is a national survey that provides detailed information on health insurance and access to services among working-age adults with disabilities in the United States. Another strength is a novel response option that allows a participant to indicate their perceived need for a service. Other federal surveys only have a binary indicator (yes/no) in response to questions on access to services, which limits the ability to measure perceived need. To our knowledge, this is the first national study to assess perceived need for preventive services among working-age adults with disabilities.

Conclusion

Preventive services are vital to health management and health outcomes, particularly for adults with disabilities who experience higher rates of chronic health conditions. Unfortunately, preventive services are not consumed at similar rates by geographic area, leaving rural people with disabilities particularly vulnerable to negative health outcomes. We found strong evidence that the perceived need for dental services and mental health counseling was lower among adults in rural areas compared to those living in urban areas. Therefore, perceived need plays a role in examining the demand for preventive health services and highlights the strategic importance of considering differences in community values and norms when developing and implementing public health campaigns. While environmental barriers such as cost and provider availability influence unmet need, rural-urban differences in community norms and expectations also affect the demand for preventive services.

Data availability statement

The data analyzed in this study are subject to the following licenses/restrictions. These data are available upon request: University of Kansas Institute for Health and Disability Policy Studies, 2022. The National Survey on Health and Disability (NSHD) https://ihdps.ku.edu/nshd. Requests to access these datasets should be directed to Noelle Kurth, pixie@ku.edu; https://ihdps.ku.edu/nshd.

Ethics statement

The studies involving human participants were reviewed and approved by the University of Kansas Institutional Review Board. Written informed consent for participation was not required for this study in accordance with the national legislation and the institutional requirements.

Author contributions

GG organized the database and performed the statistical analysis. CI wrote the first draft of the manuscript. CI and GG contributed to conception, design of the study, contributed to all sections of the manuscript, and contributed to manuscript revision, read, and approved the submitted version.

Funding

This work was supported by the National Survey on Health and Disability (NSHD) as part of the Collaborative on Health Reform and Independent Living (CHRIL). CHRIL was funded by a 5-year Disability and Rehabilitation Research Program (DRRP) from the National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR, grant number 90DP0075-01-00). In addition, research for this manuscript was supported by the Research and Training Center on Disability in Rural Communities (RTC:Rural) under another NIDILRR (grant number 90RTCP0002-01-00). NIDILRR is a Center within the Administration for Community Living (ACL), Department of Health and Human Services (HHS). The research does not necessarily represent the policy of NIDILRR, ACL, or HHS, and one should not assume endorsement by the federal government.

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. Farley TA, Dalal MA, Mostashari F, Frieden TR. Deaths preventable in the U. S by improvements in use of clinical preventive services. *Am J Prev Med.* (2010) 38:600–9. doi: 10.1016/j.amepre.2010.02.016

2. Levine S. Health care industry insights: why the use of preventive services is still low. *Prev Chronic Dis.* (2019) 16:E30. doi: 10.5888/pcd16.180625

3. Okunev I, Tranby EP, Jacob M, Diep VK, Kelly A, Heaton LJ, et al. The impact of underutilization of preventive dental care by adult Medicaid participants. *J Public Health Dent.* (2022) 82:88–9. doi: 10.1111/jphd.12494

4. Sun Y, Monnat SM. Rural-urban and within-rural differences in COVID-19 vaccination rates. *J Rural Health.* (2021) 23:10.1111/jrh.12625. doi: 10.1111/jrh.12625

5. Matthews KA, Croft JB, Liu Y, Lu H, Kanny D, Wheaton AG, et al. Health-related behaviors by urban-rural county classification - United States, 2013. *MMWR Surveill Summ.* (2017) 66:1–8. doi: 10.15585/mmwr.ss6605a1

6. Casey MM, Thiede Call K, Klingner JM. Are rural residents less likely to obtain recommended preventive healthcare services? *Am J Prev Med.* (2001) 21:182–8. doi: 10.1016/S0749-3797(01)00349-X

7. Johnston KJ, Wen H, Joynt Maddox KE. Lack of access to specialists associated with mortality and preventable hospitalizations of rural Medicare beneficiaries. *Health Affairs.* (2019) 38:1993–2002. doi: 10.1377/hlthaff.2019.00838

8. Gong G, Phillips SG, Hudson C, Curti D, Philips BU. Higher us rural mortality rates linked to socioeconomic status, physician shortages, and lack of health insurance. *Health Affairs.* (2019) 38:2003–10. doi: 10.1377/hlthaff.2019.00722

9. USA.gov. *Preventive Health Services.* Available online at: https://www.healthcare.gov/coverage/preventive-care-benefits/ (accessed January 21, 2022).

10. Beck LF. Rural and urban differences in passenger-vehicle–occupant deaths and seat belt use among adults — United States, 2014. *MMWR Surveill Summ.* (2017) 66:1–13. doi: 10.15585/mmwr.ss6617a1

11. Young AE, Cifuentes M, Wasiak R, Webster BS. Urban-Rural differences in work disability following occupational injury: are they related to differences in healthcare utilization? *J Occup Environ Med.* (2009) 51:204–12. doi: 10.1097/JOM.0b013e3181917d8e

12. Coughlin SS, Clary C, Johnson JA, Berman A, Heboyan V, Benevides T, et al. Continuing challenges in rural health in the United States. *J Environ Health Sci.* (2019) 5:90–2.

13. Sage R, Ward B, Myers A, Ravesloot C. Transitory and enduring disability among urban and rural people. *J Rural Health.* (2018) 35: :460-470. doi: 10.1111/jrh.12338

14. Smith AS, Trevelyan E. *The Older Population in Rural America: 2012-2016.* Census.gov. (2019).

15. Long AS, Hanlon AL, Pellegrin KL. Socioeconomic variables explain rural disparities in US mortality rates: Implications for rural health research and policy. *SSM —Population Health.* (2018) 6:72–4. doi: 10.1016/j.ssmph.2018.08.009

16. Harrington RA, Califf RM, Balamurugan A, Brown N, Benjamin RM, Braund WE, et al. Call to action: rural health: a presidential advisory from the American Heart Association and American Stroke Association. *Circulation.* (2020) 141:e615–44. doi: 10.1161/CIR.0000000000000753

17. National Center for Health Workforce Analysis. *Distribution of U.S. Health Care Providers Residing in Rural and Urban Areas.* U.S. Department of Health and Human Services, Health Resources and Services Administration.

18. Rural Information Hub. *Healthcare Access in Rural Communities Overview.* (2021). Available online at: https://www.ruralhealthinfo.org/topics/healthcare-access (accessed April 19, 2022).

19. World Health Organization, World Bank, editors. *World Report on Disability.* Geneva, Switzerland: World Health Organization (2011). p. 325.

20. American Lung Association. *Top 10 Populations Disproportionately Affected by Cigarette Smoking and Tobacco Use.* American Lung Association (2022).

21. Myers A, Ipsen C, Lissau A. COVID-19 vaccination hesitancy among Americans with disabilities aged 18-65: An exploratory analysis. *Disabil Health J.* (2022) 15:101223. doi: 10.1016/j.dhjo.2021.101223

22. Branswell H. Rural-urban gap in some vaccination rates leaves health officials puzzled [Internet]. STAT. (2017).

23. Petrovic D, de Mestral C, Bochud M, Bartley M, Kivimäki M, Vineis P, et al. The contribution of health behaviors to socioeconomic inequalities in health: A systematic review. *Prevent Med.* (2018) 113:15–31. doi: 10.1016/j.ypmed.2018.05.003

24. Burns ME, Shah ND, Smith MA. Living at the thin margin of health: out-of-pocket health care spending by Medicaid beneficiaries with disabilities. *Health Aff (Millwood).* (2010) 29:1517–22. doi: 10.1377/hlthaff.2009.0147

25. Lund EM, Nadorff MR, Galbraith K, Thomas KB. *Using Amazon Mechanical Turk to Recruit Participants With Disabilities* London: SAGE Publications Ltd. 2018.

26. Arditte KA, Çek D, Shaw AM, Timpano KR. The importance of assessing clinical phenomena in Mechanical Turk research. *Psychol Assess.* (2016) 28:684–91. doi: 10.1037/pas0000217

27. Casler K, Bickel L, Hackett E. Separate but equal? A comparison of participants and data gathered via Amazon's MTurk, social media, and face-to-face behavioral testing. *Computers Human Behav.* (2013) 29:2156–60. doi: 10.1016/j.chb.2013.05.009

28. US Census Bureau. How *Disability Data are Collected from The American Community Survey* [Internet]. The United States Census Bureau. (2021).

29. Office of Management and Budget. 2010 Standards for deliniating metropolitan and micropolitan statistical areas. *Federal Reg*. (2010) 75: 37245–52. Available online at: http://www.whitehouse.gov/omb/fedreg_default/ (accessed July 20, 2020).

30. Jones C, Parker T, Ahearn M. *Taking the Pulse of Rural Health Care*. USDA Economic Research Service (2009).

31. Fair Health Consumer. *Choosing Your Health Plan: Healthcare Services Not Covered by Health Insurance*. Fair Health Consumer. (2022).

32. Norris L. *How Obamacare Improved Mental Health Coverage*. Healthinsurance.org. (2020).

33. Douthit N, Kiv S, Dwolatzky T, Biswas S. Exposing some important barriers to health care access in the rural USA. *Public Health*. (2015) 129:611–20. doi: 10.1016/j.puhe.2015.04.001

34. Assistant Secretary for Public Affairs. *Preventive Care*. HHS.gov. (2021).

35. Stubblefield H. *Preventive Dentistry*. Healthline. (2015).

36. Weeks WB, Bott DM, Lampkin RP, Wright SM. Veterans health administration and medicare outpatient health care utilization by older rural and urban New England veterans. *J Rural Health*. (2005) 21:167–71. doi: 10.1111/j.1748-0361.2005.tb00077.x

37. Willging CE, Salvador M, Kano M. pragmatic help seeking: how sexual and gender minority groups access mental health care in a rural state. *Psychiatric Ser*. (2006) 57:4. doi: 10.1176/ps.2006.57.6.871

38. Henderson C, Evans-Lacko S, Thornicroft G. Mental illness stigma, help seeking, and public health programs. *Am J Public Health*. (2013) 103:777–80. doi: 10.2105/AJPH.2012.301056

39. Hammer JH, Vogel DL, Heimerdinger-Edwards SR. Men's help seeking: Examination of differences across community size, education, and income. *Psychol Men Masc*. (2013) 14:65–75. doi: 10.1037/a0026813

40. Goldberg M, Gustafson A, Maibach E, van der LS, Ballew MT, Bergquist P, et al. Social norms motivate COVID-19 preventive behaviors. *PsyArXiv*. (2020). doi: 10.31234/osf.io/9whp4

frontiers | Frontiers in Rehabilitation Sciences

TYPE Original Research
PUBLISHED 12 August 2022
DOI 10.3389/fresc.2022.875966

Disability and the household context: Findings for the United States from the public Use Microdata Sample of the American Community Survey

Christiane von Reichert[1,2]*

[1]Department of Geography, Franke College of Forestry and Conservation, University of Montana, Missoula, MT, United States, [2]RTC: Rural at the Rural Institute for Inclusive Communities, University of Montana, Missoula, MT, United States

EDITED BY
John W. Lui,
University of Wisconsin-Stout Vocational Rehabilitation Institute,
United States

REVIEWED BY
Jacqueline Moodley,
University of Johannesburg,
South Africa
Daniel Mont,
Center for Inclusive Policy,
United States
Zhuoying Qiu,
China Rehabilitation Research Center/WHO Collaborating Center for Family International Classifications, China

*CORRESPONDENCE
Christiane von Reichert
c.vonreichert@umontana.edu

SPECIALTY SECTION
This article was submitted to Disability, Rehabilitation, and Inclusion, a section of the journal Frontiers in Rehabilitation Sciences

RECEIVED 14 February 2022
ACCEPTED 11 July 2022
PUBLISHED 12 August 2022

CITATION
von Reichert C (2022) Disability and the household context: Findings for the United States from the public Use Microdata Sample of the American Community Survey.
Front. Rehabilit. Sci. 3:875966.
doi: 10.3389/fresc.2022.875966

Introduction: Based on questions about impairments and activity limitations, the American Community Survey shows that roughly 13% of the U.S. population is experiencing disability. As most people live in households with other persons, this study explores disability at the household level. Considering the literature on household decision-making, solidarity, and capabilities in disability, this analysis of the household context of disability takes into account residential settings, household composition, and urban–rural differences.

Method: The 2015–2019 ACS Public Use Microdata Sample (PUMS), which shows persons with disability (PwD) and persons without disability (PwoD), also indicates household membership, used here to separately identify PwoD as those living in households with persons with disability (PwoD_HHwD) and those in households without any household member with disability (PwoD_HHwoD). Relationship variables reveal the composition of households with and without disabilities. An adaption of Beale's rural–urban continuum code for counties is used to approximate rural–urban differences with ACS PUMS data.

Results: Solo living is two times as common among persons with disability than among persons without disability, and higher in rural than urban areas. In addition to 43 million PwD, there are another 42 million PwoD_HHwD. Two times as many persons are impacted by disability, either of their own or that of a household member, than shown by an analysis of individual-level disability. For family households, differences in the composition of households with and without disabilities are considerable with much greater complexities in the makeup of families with disability. The presence of multiple generations stands out. Adult sons or daughters without disability play an important role. Modest urban–rural differences exist in the composition of family households with disability, with a greater presence of multigenerational households in large cities.

Discussion: This research reveals the much wider scope of household-level disability than indicated by disability of individuals alone. The greater complexity and multigenerational makeup of households with disability imply intergenerational solidarity, reciprocity, and resource sharing. Household members without disability may add to the capabilities of persons with disabilities. For the sizeable share of PwD living solo, there is concern about their needs being met.

KEYWORDS

disability, persons without disability in households with disability, single-person households, family solidarity, capability approach, urban-rural, American Community Survey, Public Use Microdata Sample (PUMS)

Introduction

Data from the American Community Survey (ACS) show that, based on physical impairments and functional limitations, nearly 43 million or 13% of the U.S. population experience disability. Disability rates vary by location and are generally lower in large metropolitan counties and a good deal higher in very rural counties and in the southern parts of the United States (1).

The ACS captures disability as a binary attribute of persons: persons with disability (PwD) and persons without disability (PwoD). Of persons with disability, 20% live solo and another 7% live in group quarters. However, most persons with disability live in households with other persons, predominantly in family households (2). In these residential settings, other household members may also experience disability, but more commonly, they are persons without disability. Without disability of their own, these persons nonetheless are impacted by disability through that of another household member. Quite likely, the lives of persons without disability in households with disability are different than the lives of persons without disability in households without disability, simply because of the nature and makeup of the household.

Microdata from the ACS show attributes of persons and household membership, and this allows for an analysis of disability of persons in their household context. Specifically, PwoDs are separated into two groups: those living in households with another household member experiencing disability (PwoD_HHwD) and those without other household members with disability (PwoD_HwoD). Using this distinction, and as laid out below, this analysis of ACS microdata reveals that, besides 43 million persons with disability of their own, there are over 42 million persons without disability living in households with disability.

There is good rationale for considering the household setting when examining disability, as household members live and act in the context of their household. Three conceptual approaches provide a background for this analysis: household decision-making, household solidarity, and capabilities in disability.

Decision-making is shaped by household membership, as highlighted by Becker (3, 4) and Mincer (5, 6). Households, especially family households, function as units with decisions made at the household level. Household decisions are centered on what benefits the household, even at the expense of an individual household member. Household decisions involve the use of time, labor force participation, migration, health, and more. For households with disability, the concept of household decision-making suggests that the needs of a household member with a disability could impact available options and choices for persons without disabilities in these households. Persons without disabilities in households with a disability may be involved in caregiving and could very well face different opportunities and make different choices than their counterparts in households without disabilities. Indeed, U.S. persons without disabilities in households with disability showed lower migration rates during young adulthood. As young adulthood is a period of peak migration, reduced migration rates during these peak years can translate into lower lifetime mobilities (7). In a literature review of young caregivers in Australia, Day (8) expressed concern about significantly reduced future life opportunities for this cohort, while acknowledging both the challenges and rewards that come with caregiving.

Solidarity in households, in particular family households, indicates that households are units of support. Households may exercise same-generation and intergenerational solidarity (9–12). Same-generation support between spouses and partners tends to be the norm. Siblings are also of the same generation. Intergenerational support (between generations) tends to go from parents to children (forward support to the next generation) or adult sons/daughters to elderly parents/parents-in-law (backward support to the previous generation). In

---

Abbreviations: RRID:SCR_011587 (U.S. Census Bureau), Resource Identification Initiative.

a household with disability, where support relationships are crucial, it has been shown children and young adults provide care for parents or grandparents, thereby reversing roles and the standard intergenerational directions of support. A 2019 survey conducted by the National Alliance of Caregiving and the American Association of Retired Persons reveals a growing number of teenage and young adult grandchildren (who could be resident members of the household or non-resident) are caregivers for grandparents (13).

As part of these solidarities, households/families also function as economic units: Household members living under the same roof can share their resources, such as income or housing assets, or split household expenses. Pooling of household resources may be especially relevant for persons with disability. Persons with disability face diminished opportunities to participate in the labor force (14). In addition to these indirect costs of disability, there are sizeable extra direct costs of living with a disability (15). Higher indirect and direct costs of disability, along with lower incomes (16), translate into a greater likelihood of being in poverty (17). In essence, persons with disability may have greater resource needs while faced with limited household resources to meet those needs. Additional members of the household could be positioned to fill that gap between needs and resources. Sen (18) referred to household resources as "commodities" and proposed a capability approach to human wellbeing, later adapted by Nussbaum (19), Mitra (15), Trani, and Dubois with co-authors (20, 21) and others to better and differently conceptualize disability.

"Capabilities" or practical opportunities make for a set of choices that affect people's "functioning" or actually achieving what they value. Besides "commodities," capabilities are shaped by the environments people live in and their personal characteristics, such as age, education, and impairments (15, 20). Disability results from deprivation in capability and/or functioning. Impairments are "potentially disabling" but only "actually disabling" if they restrict people's capabilities or functioning, meaning they bar people from doing what they would like to do or value [(15), p. 241]. In household settings, capabilities of individuals may be increased with others contributing or sharing their capabilities, such as caregivers (22). Beyond the household, members of the community people live in may also offer support. Consequently, individual capabilities can be enhanced and turn into collective capabilities [(20), p. 8, (23)].

The merit of the capability approach for this analysis lies in looking at the household as a unit for increasing capabilities and reducing potential disability. In other words, the presence of household members without disability quite likely improves the lives of persons with impairments or activity limitations. PwoD_HHwD provide PwD more opportunities to fully participate in their community. At the same time, the presence of household members with disability also affects in major ways the capabilities and functioning of persons without disability sharing the household.

ACS microdata on disability used in this research do not offer explicit insight on household decision-making, household support, and impacts on lives based on capabilities and functioning. However, the large sample of the ACS Public Use Microdata Sample PUMS can be used to identify the residential setting (group quarter, solo, family households, and non-family households with two or more people) of PwD and PwoD and to describe in depth the composition of households with or without members with disability. The relationships between household members (reference person, spouse/partner, son/daughter, elderly parent/parents-in-laws, and grandchildren) with or without disability indicate caregiving relationships and resource sharing with the potential to affect capabilities and functioning. Capabilities made available through household members can expand opportunities for persons with impairments and functional limitations, thereby increasing activity and favorably affecting community participation.

Using a three-way classification of disability (PwD, PwoD_HHwD, and PwoD_HHwoD), this research sets out to identify the residential setting for persons with and without disability, describe the composition of households with and without disability, with special emphasis on family households, and present data for the nation and separately for areas along the urban–rural continuum.

The merit of this analysis lies in expanding the analysis of disability by considering the household context, to better identify the scope of disability and the residential setting in which it occurs, with a focus on the composition of family households where over 80% of the U.S. population live.

Beyond analyzing national-level data, an analysis of urban–rural differences in residential settings and household composition is called for because of sizeable differences in the rural–urban disability rates. Higher rates of disability in rural than urban areas were found to be accompanied by a shortage of formal support and caregivers in rural areas (24). This service gap may lead to a greater need for household members (as well as non-resident family and friends) to provide support and caregiving to persons with disability. Supportive rural environments may reduce restrictions in the lives of people with impairments and activity limitations by supplementing individual capabilities with collective capabilities. Alternatively, if collective capabilities are limited, rural people with impairments may lead more restricted lives, especially if living solo.

Methods

This descriptive analysis is based on the Public Use Microdata Sample (PUMS) of the 2015–2019 American Community Survey (ACS) (2). Five-year data are used to benefit from the larger sample size, which consists of over 6.2 million households (HH) with nearly 15.2 million people plus 750,000 persons in group quarters (GQ). By applying person weights to extrapolate from persons in the sample to the U.S. population, the 2015–2019 ACS PUMS puts the U.S. population at 325 million.

Based on the ACS definition of disability, there are nearly 43 million persons with disability in the United States and a disability rate of 13%. In the ACS, disability is a binary variable (present or absent, 1 or 0) based on self-reported binary responses to four impairment questions (ambulatory or walking, cognitive, vision, and hearing) and two functional limitation questions (self-care and independent living). Disability is deemed to be present if a person answers affirmative to at least one of the six questions. Multiple affirmative responses are quite common (two or more impairments or limitations account for 75% of persons with disability), with ambulatory impairment and independent living limitation being the most common combination followed by independent living limitations and cognitive impairment. There is some overlap in the ACS questions with the six questions from the Washington Group on Disability Statistics Short Set (WGSS) (seeing, hearing, walking, cognitive-remembering, self-care, and communication) (25). However, in contrast to the binary measure of the ACS, the WGSS uses a Likert scale to develop a disability score, therefore an ordinal measure of disability. The WGSS, developed for international use in general population surveys or censuses, where a limited number of questions can be asked on a wide range of attributes, was designed to capture the majority of people with activity limitations that most often restrict participation (26). The WGSS is informed by the World Health Organization's 2001 International Classification of Functioning, Disability, and Health ICF [(27), p. 5]. The ICF presents disability as impairments giving rise to activity limitations and participation restrictions [(15), p. 238].

Disability definitions have changed and are evolving (15, 20, 28, 29), demonstrating that disability is multifaceted and complex. While ACS questions and definitions on disability cannot fully capture that complexity, the ACS questions have merit as shown by their overlap with the Behavioral Risk Factor Surveillance System (BRFSS) (30), the nation's premier health-related survey. Importantly, the ACS is, by design, a very large sample of the U.S. population with an extensive set of variables. Variables include household membership and household relations used here to analyze residential settings and household composition. In contrast to smaller surveys which work well at the national level, the sample size of the ACS further allows a breakdown of rural–urban differences in disability and household composition. Disability as a three-way (PwD, PwoD_HHwD, and PwoD_HHwoD), not binary (PwD and PwoD), classification of persons in households relies on three variables of the ACS: the serial number of the household a person belongs to (SERIALNO), the relationship variable which shows the relationship of household members to the reference person (person who answered the survey, presumably the "householder," RELSHIPP), and the disability variable (DIS) (31). The reference persons may also live solo (single-person household). Populations in institutionalized and non-institutionalized group quarters are identified as well, but not considered to be members of a household.

These variables make it possible to separately identify persons without disability (PwoD) as those living in households of two and more with (1) another person/s with disability (PwoD_HHwD) or (2) other household members without disability (PwoD_HHwoD). Household affiliation, relationship, and disability variables are used to identify the residential setting, and the composition of households with and without disability. Table S1 in the Supplement illustrates the process of transitioning from the binary disability variable of the ACS to a three-way classification of disability at the household level used here. The three-way classification allows pinpointing who persons with disability live with and how the household compositions differ for households with or without disabilities. Additional variables, such as marital status, subfamilies, or race, were consulted as well for select data queries.

To explore urban–rural differences in household compositions, a measure of urbanity–rurality is needed. ACS PUMS data are released for Public Use Microdata Areas (PUMAs), sizeable areas with a population of at least 100,000. In large metropolitan (metro) areas, PUMAs consist of census tracts, while in smaller metro and nonmetropolitan (nonmetro) areas, PUMAs contain one or several counties. However, PUMAs are not published showing a measure of urbanity or rurality. The Census Bureau also designed MIGPUMAs, to track migration, (as well as POWPUMAs, to track places of work) using counties as building blocks (32). For counties, two widely used urban–rural classifications exist: the metro-micro-noncore classification of the Office of Management and Budget (33) and the rural–urban continuum or Beale code of the Economic Research Service (34). The urban–rural measure employed here builds on the Beale code of counties that make up MIGPUMAs weighted by county populations. The urban–rural code assigned to MIGPUMAs consists of eight categories, ranging from most highly urbanized (large metro) to most rural (nonmetro-highly rural). While an approximation, the urban–rural continuum code of MIGPUMAs derived from county Beale codes does well in replicating the urban–rural distribution of the resident population and disability rates of counties shown in ACS 2015–2019 summary data (35).

Results

Overview: Residential settings of persons with or without disability

Nearly 43 million (13%) Americans with disability live in various types of residential settings: in non-institutionalized and institutionalized group quarters, in single-person (solo) households, or in households of two or more persons as family or non-family households.

Population shares and disability rates vary by residential setting. Persons in group quarters account for <3% of the U.S. population but close to 7% of persons with disability due to disability rates of 18% in non-institutional group quarters and 54% in institutional group quarters. Persons in single-person households represent 10% of the U.S. population, but 20% of persons with disability, making solo living twice as common among persons with disability, thereby upping the disability rate of solo households to 26%, twice the U.S. average. Family households account for 81% of the U.S. population, and non-family households account for 6%, with disability rates around 11% (Please see Table 1).

Table 1 also shows summary data for PwD and PwoD_HHwD by residential settings (PwoD_HHwoD account for the remainder and are not shown to avoid redundancy). There are 42 million PwoD_HHwD, which per definition only include households with two or more persons. Their number is just slightly less than the number of PwD in the United States. In family households, however, the number of PwoD_HHwD is at 40 million larger than the number of PwD at 29 million.

By recognizing persons without disability in households with disability, disability—either their own disability or that of a household member—affects more persons than binary measures of disability capture. ACS PUMS data show there are twice as many persons impacted by disability at the household level than disability rates for individuals suggest. The three-way classification of disability shows up as especially important in family households where disability experiences are widely felt and broadly shared.

The household literature suggests that individual members of a household may be tied in their decisions to household needs and act out of solidarity with other household and family members. In households, especially in family households with disability, the needs of PwD may influence everyday living and major household decisions. In this context, PwoD_HHwD feel the impact of disability through the presence of another household member with disability, and their life is shaped by disability at the household level. This analysis shows that the number of PwoD_HHwD is sizeable.

Residential settings of persons with or without disability along the urban–rural continuum

Urban–rural differences in rates of disability are well recognized with higher rates of rural than urban disability. The 2015–2019 ACS PUMS data put disability rates in large metropolitan areas at 11% with rates stepping up for smaller metro and larger nonmetro areas and rising further to 18% for highly rural areas, much above the national average of 13% (see Figure 1 below).

While this geographic pattern is not that evident for the relatively small group quarters population (not shown in Figure 1), urban–rural differences are very much apparent for solo households, where disability rates of single-person households are 23% in the most highly urbanized areas and 34% in the most rural areas. These high disability rates of solo households are striking but especially concerning for highly rural areas, where health and social services tend to be limited and formal caregiving is disturbingly low (24). Higher rural disability rates could stem from rural areas being nonetheless more amenable to solo living of PwD as they may receive support from non-resident families, friends, and neighbors. There also could be the benefit of lower rural housing costs keeping housing affordable and within reach of a person with disability, even if single. In other words, individual capabilities could be increased through "collective capabilities" [(20), p. 398, (23)] based on support-based relationship or through a more favorable bundle of resources or "commodities" (15, 18). Both would increase capabilities, improve functioning and create incentives for living in supportive, and lower-cost rural communities. Alternatively, solo persons with disability in rural areas may not have these benefits while seeing limited other options such as living in group quarters or with family. Group quarters may be less available or hardly affordable, or close family members may have moved away, and solo persons' opportunities to move nearer to them may be constrained.

The rise of disability rates with increasing levels of rurality also holds for family and non-family households (Figure 1). Also noteworthy is the somewhat higher rural share of PwoD_HHwD in family households. Their greater share may be a benefit to these households as persons without disability may be tasked to provide informal support for family members with disability if service infrastructure and formal support are limited in more rural places. A rural focus on familism, age structure, and composition of household members could also come into play.

For non-family households, there is an even bigger increase in disability rates between urban and rural households. However, the number of non-family households is relatively small overall and particularly small in rural areas.

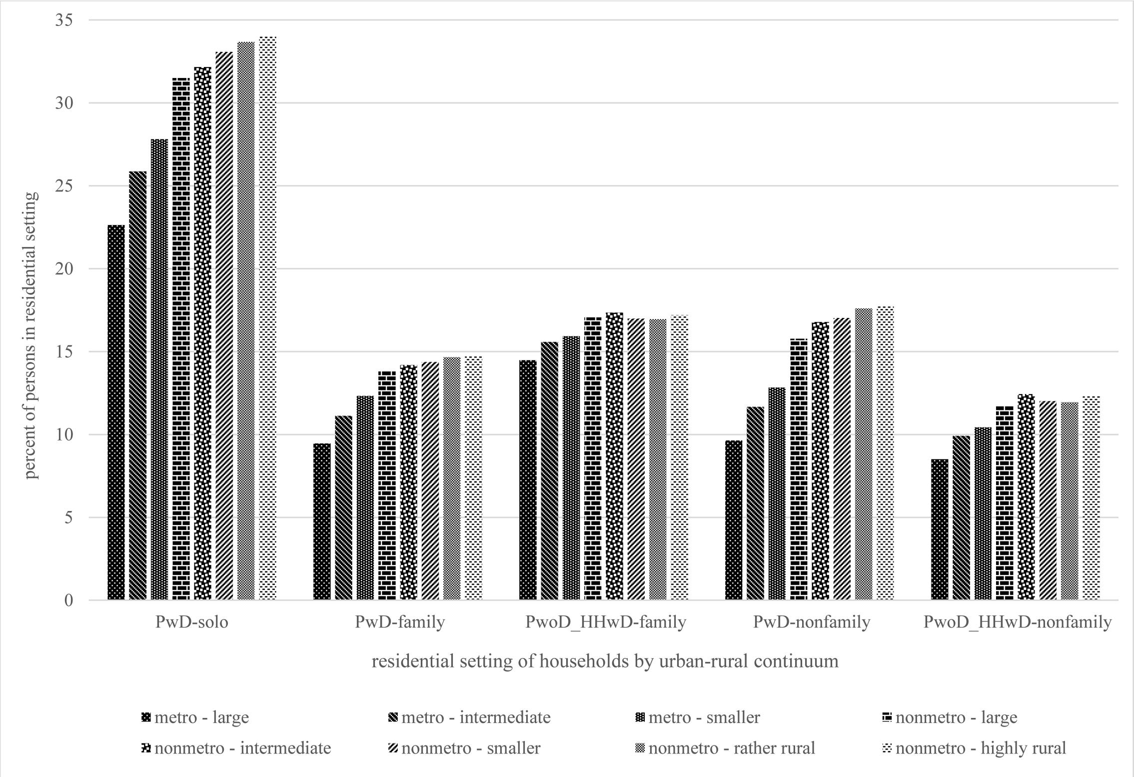
As it stands, while data from the ACS cannot explain the phenomenon, they clearly state that PwD and PwoD_HHwD make for a larger share of rural than urban populations. Conversely, PwoD_HHwoDs make for a smaller share of rural than urban populations, indicating that disability is experienced less in urban than rural areas.

The three-way (vs. two-way) classification of disability is therefore particularly relevant for rural areas. It highlights the even greater extent and impacts of rural disability than the binary disability classification, as disability is more widely felt

TABLE 1 Residential settings of the U.S. population, persons with disability (PwD), and persons without disability in households with disability (PwoD_HHwD).

	U.S. population	Persons with disability		Persons without disability in households with disability	
Residential settings	Persons[a] (%)[b]	Persons[a] (%)[b]	Rate[c]	Persons[a] (%)[2]	Rate[d]
Non-institution. GQ[e]	4.2 (1.3)	0.7 (1.7)	17.7		
Institutional GQ[f]	3.9 (1.2)	2.1 (4.9)	53.6		
Single-person HH[g]	33.6 (10.4)	8.7 (20.4)	25.8		
Family HH[g]	262.8 (80.9)	28.8 (67.6)	10.9	40.3 (95.4)	15.3
Non-family HH[g,h]	20.2 (6.2)	2.3 (5.5)	11.5	1.9 (4.6)	9.6
All settings in the U.S.	324.7 (100.0)	42.6 (100.0)	13.1	42.2 (100.0)	13.0

[a] Persons in million.
[b] Percent of U.S. population.
[c] Rate of PwD (disability rate) for residential setting.
[d] Rate of PwoD_HHwD for residential setting.
[e] Group quarters including dorms, military barracks, and group homes.
[f] Group quarters including nursing homes, correctional facilities, and mental hospitals.
[g] HH households.
[h] with two or more persons.
Source: Christiane von Reichert, derived from the 2015-2019 American Community Survey Public Use Microdata Sample (ACS PUMS).

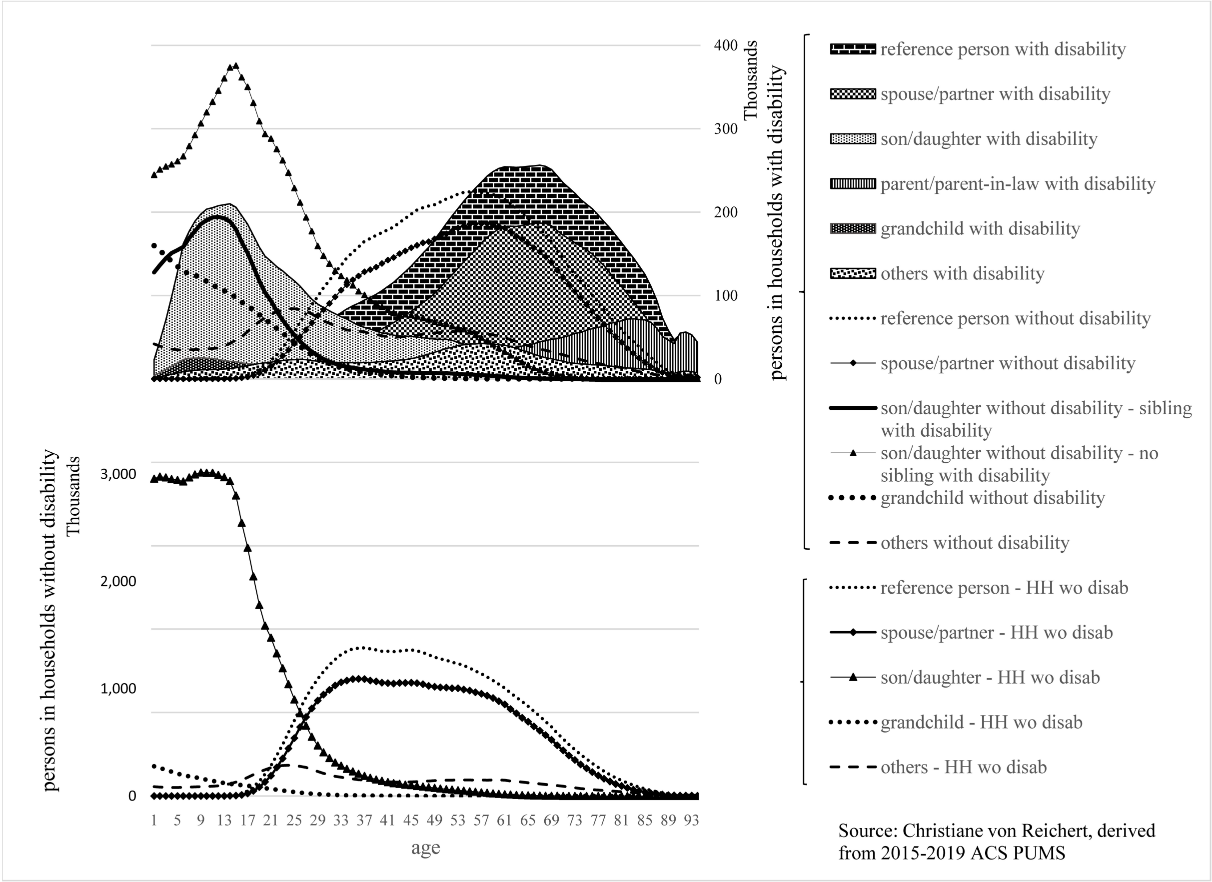


Source: Christiane von Reichert, derived from the 2015-2019 ACS PUMS with adaption of the ERS 2013 Rural-Urban Continuum Code

FIGURE 1
Persons with or without disability in single-person, family, and non-family households by urban–rural continuum.

by PwoD_HHwD in rural than urban areas, especially affecting rural family households.

The following segment focuses on family households and their composition.



Source: Christiane von Reichert, derived from 2015-2019 ACS PUMS

FIGURE 2
Persons in family households with and without disability: composition by relationship to reference person, disability, and age.

Differences in the composition of family households with or without disability

Family households with disability differ in important ways from family households without disability. The composition of families with disabilities is much more complex, partly as a result of including persons with and without disabilities, but also due to the different types of relationships to the reference person, and differences in age distributions.

Family households without disabilities reflect the nuclear or core family made up of a reference person with a spouse/partner or single parent along with their sons and daughters. These three groups account for the overwhelming majority, roughly 92%, of family members. The share of extended family members (elderly parents/parents-in-laws, grandchildren, or other families) is small with only 7%, plus a very small share of unrelated household members.

Family households with disability deviate considerably from the core family model: Reference person, spouse/partner, and sons/daughters account for just over 80%, while elderly parents/parents-in-laws of the reference person show up among persons with disability. Persons without disability in these households include a good number of grandchildren. There are others, consisting mostly of relatives such as brothers/sisters of the reference person, a small number of sons-in-law/daughters-in-law, other relatives, and a few nonrelatives.

The multigenerational makeup stands out as a feature of family households with disability. Extended and multigeneration households have been seen as ways of lessening economic and personal hardship (12, 36). The disability of one or several family members could be contributing to challenges that a multigenerational household can address through reciprocity of family members giving and receiving mutual support and thereby increasing collective capabilities.

The composition by age and relationships of family households with and without disability is shown in Figure 2. The top segment of Figure 2 shows the composition of family households with disability, and the bottom segment represents families without disability (using five-year moving averages for a visually less distracting, smoother display). PwDs are presented as areas with patterns and PwoD as lines. The Y-axis shows the number of household members in each relationship category and disability group by single year of age (X-axis). To account for big differences in the number of persons in family household with disability and without disability, the information is displayed using two Y-axes. Differences in the complexity in the composition of households with disability *vis-à-vis* the core family composition of households without disability are pronounced.

As a note: Figure 2 shows cross-sectional ACS data and therefore a snapshot in time. Changes by age point toward life course transitions and household dynamics. Transitions taking place as people pass into higher age groups have relevance in disability analysis, as argued in the following.

In families with disability, the age of reference person and spouse/partner with disability peaks in the 60 s and for reference person and spouse/partner without disability in the 50 s. In families without disability, reference person's and spouse's/partner's age tends to peak between the mid-30 s and mid-40 s. The younger age of a reference person and spouse/partner in households without disability translates into the younger age of their sons/daughters vis-à-vis those in families with disability. For families with disability, sons/daughters of the reference person are disaggregated into two groups to account for noteworthy differences: those who have siblings with disability and those who do not. Children and adolescents without disability who grow up alongside siblings with disability may be among the most under-studied group in disability research. Yet, the impacts on their lives are profound (37), and their connection to siblings with disability may stretch over decades, longer than that of the parents (38).

In families with disability, nearly one-fourth of the reference persons' young and adolescent sons/daughters (ages 0–19) experience disability. There is a near equal number of their siblings without disability in the corresponding age groups. This means on average, children and adolescents with disability grow up with siblings without disability, and these siblings without disability encounter disability by coming of age alongside siblings with disability. A rapid drop in the number of sons/daughters without disability (with siblings with disability) in early adulthood (ages 20 to 25) suggests they leave the parental home in their early to mid-20 s, as do their counterparts in households without disability. For sons/daughters with disability, there is a decline in their number in early adulthood as well. However, that decline is much more gradual suggesting their departure from the parental home stretches into their mid-30 s. There are also sons/daughters with disability beyond age 30, indicating they live in the parental home well into adulthood, suggesting they may be staying with, not leaving, the family.

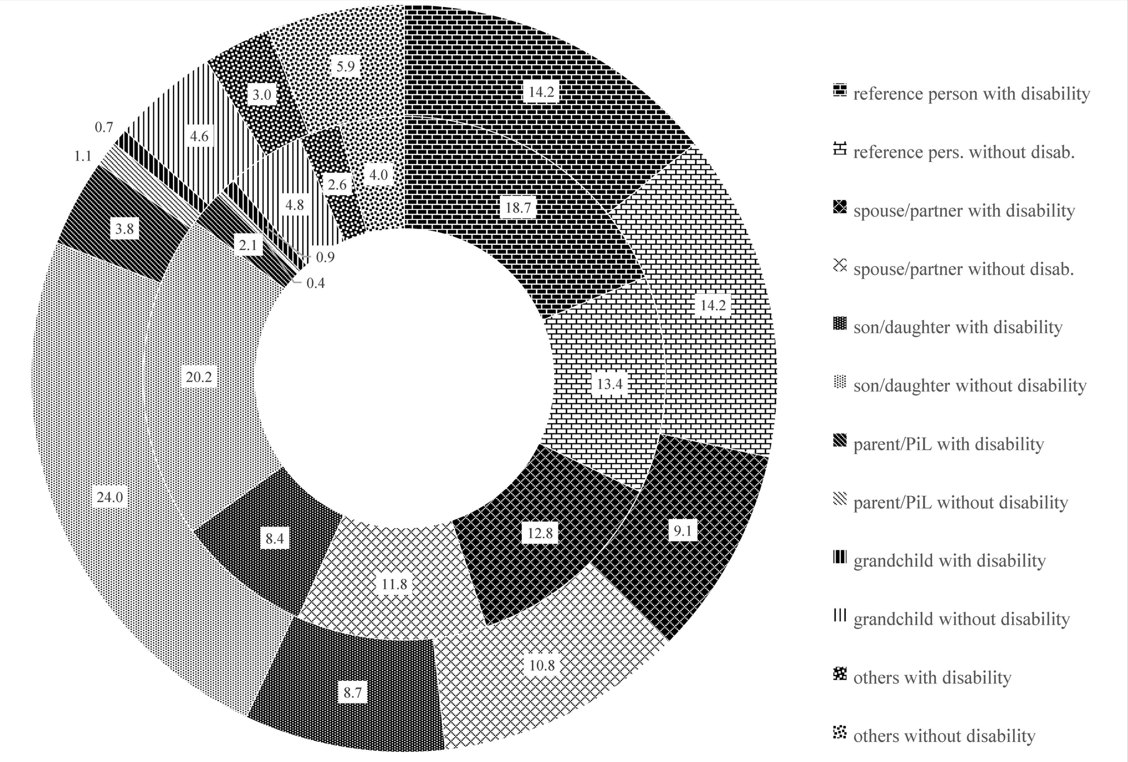
The great majority of sons and daughters without disability in family households with disability live with a reference person or the reference person's spouse/partner with disability (These are their parents/parent). In this household constellation, the number of sons/daughters without disability declines gradually in young adulthood, suggesting they leave the parental home at a relatively slow pace (or possibly returning to that home) compared to those with disabled siblings. From their mid-30 s to well into their 50 s, that group (sons and daughters without disability) account for a small but noteworthy and near constant number of household members. This suggests a certain number of adult sons/daughters without disability continue to reside into their 50, even 60 s with reference person and spouse (their parent/s with disability). A majority of those over 30 never married, and a quarter are divorced. Their choice of residence suggests support relationships between adult sons/daughters without disability and their parent/s with disability exist that may explain the much higher shares in households with than without disability. There is a sharp drop in shares around age 60. Concluding that sons/daughters without disability, who spent their adult life residing with parent/s with disability, would depart from the family home and leave aging, disabled parent/s at this stage of their life is not that plausible. More likely, the mature adult son/daughter becomes the reference person, and the previous reference person with disability shows up as a parent with disability. If this interpretation stands up, people who make up the family remain unchanged, even if relationship classifications change. The presence of the previous generation of adult sons/daughters turning into the reference person allows elderly parents with disability to continue living in the family household and age in place.

There is another angle on adult sons/daughters in their 30 s to 50 s living with an older reference person with disability. Of sons/daughters without disability over 30, over a one-fourth live in the parental home as subfamilies, some as a couple with or without children but most as a single parent with children. The children in the subfamilies of adult sons/daughters show up as grandchildren of the reference person, and two-thirds of grandchildren are children in subfamilies.

In essence, the complexity and intergenerational makeup of households with disability can be partly explained by adult sons/daughters without disability living in the family household well beyond adolescence.

Elderly parents contribute to the multigenerational mix of family households with disability. In these households, the number of elderly parents/parents-in-law with disability increases with age, as expected. This could partly be, as pointed out above, the result of previous reference persons transitioning into the parent/parent-in-law relationship class. It also could stem from the onset of disability of aging parents who have lived with the family for some time. In addition, elderly parents may move to join the family household.

Other family and a few non-family are also present in families with disability, accounting for under 8% of the members in the family household, for a one-to-two split of PwD vs. PwoD_HHwD.



Source: Christiane von Reichert, derived from the 2015-2019 ACS PUMS with adaption of the ERS 2013 Rural-urban Contiuum Code

FIGURE 3
Composition of family households with disability in large metropolitan and nonmetropolitan areas.

Urban–rural composition of family household with disability

Differences in urban and rural rates of disability and a higher share of PwoD_HHwD in rural than urban areas raise the question of whether or not urban–rural differences also show up in the composition of families with disability. It turns out that ACS microdata show relatively modest differences in the composition of family households with disability in urban (metropolitan or metro) vis-à-vis rural (nonmetropolitan or nonmetro) areas (Figure 3).

Figure 3 is a two-ring donut chart showing the composition of family households. The inner ring represents rural/nonmetropolitan areas, and the outer ring shows the most urban/large metropolitan areas. Rural/nonmetropolitan areas, from large nonmetro to highly rural, are combined due to near identical household compositions (The household composition of intermediate and smaller metro areas fall between large metro and nonmetro and are excluded in the chart for not showing much additional information).

The shares of reference persons and spouses with disability are higher in nonmetro areas than in large metro areas, and the higher nonmetro shares contribute to the higher rural disability rate. In metro and nonmetro areas alike, there are fewer spouses or partners than reference persons pointing toward families not including a spouse/partner and made up of the reference person and other related persons (son/daughter, parent/parent-in-law, and other relatives) and a very small number of nonrelatives.

The share of reference persons and spouses in metro areas is somewhat smaller than in nonmetro areas, partly a result of the greater presence of sons and daughters without disability. Factors potentially associated with their higher shares of sons/daughters are the younger age of metropolitan reference persons (with fewer empty-nesters), the greater presence of single-parent households, along with greater racial and ethnic diversity in highly urbanized areas.

Parents/parents-in-law represent a small share of household with disability. There is, however, a greater presence of parents/parents-in-law with disability in larger metro areas than in nonmetro areas. The higher shares in metro households could be the flipside of less solo living in urban than rural locales. The lower share of parents/parents-in-laws with disability in rural households may indicate that the option of living with close family is perhaps less available if adult children and their families left rural for urban areas, as part of a long-term population trend. The larger share of PwD living solo in more rural areas lends support to that argument.

For grandchildren, there are near equal shares in nonmetro and metro family households with disability. The small share of other family household members (brothers–sisters of reference person, some other relatives, and very few nonrelatives) without disability is somewhat larger in more urban than more rural areas, which also contributes to the somewhat larger metro family size.

Analyzing the composition of a family household with disability shows that nonmetro and metro areas alike have highly complex household relationships which much deviate from the core family model of families without disabilities. Across the nonmetropolitan categories, differences appear to be minimal. However, in larger cities, the complexity is greater than for nonmetro households. Additional queries for racial groups (not shown here) reveal that the greater ethnic and racial diversity in larger metropolitan areas contributes to that complexity presumably due to a larger role of extended family and multiple generations, especially for families with disability. The multigeneration household appears to be a strategy to cope with higher costs and greater resource needs associated with disabilities. Additional household members sharing incomes and assets, such as housing, add to household resources or “commodities.” The “collective capabilities” may receive a boost in these multigeneration households.

Discussion

Using microdata from the 2015–2019 American Community Survey, this research builds on information about relationships in households and the residential setting of persons with and without disabilities. Leaving group quarters mostly aside, residential settings are separated into single-person (solo) households and two-plus person family households or non-family households.

For two-plus person households, most of which are family households, this research draws attention to a group often unrecognized in disability research and policy: persons without disability in households with disability. This common oversight stands in stark contrast to the major role many PwoD_HHwDs play in the lives of persons with disability. Based on the ACS, this research shows that in addition to 13% of persons with disability, there is another 13% of the population without disability in households with disability. Data from the ACS therefore suggest that over one-fourth of the U.S. population is impacted by disability, either of their own or a household member. However, disability estimates from the ACS, a general population survey, are deemed to be relatively conservative compared to surveys specific to health and disability (39) such as the Behavioral Risk Factor Surveillance System BFRSS of the Center for Disease Control CDC (30) or the National Health Interview Survey NHIS (40). The combined share of PwD and PwoD_HHwD is most likely much higher than one quarter. In addition, as the ACS is a cross-sectional survey giving a snapshot in time, an even higher share of the U.S. population may experience household-level disability over a lifetime. In contrast to the widespread impacts of disability in a household, disability does not receive all that much attention in public discourse. Even though disability is experienced by a sizeable share of the population, the perception that disability only involves a relatively small minority stems perhaps from limited visibility of persons with disability and their household members. Barriers limiting activities and constraining community participation could be contributing to this low visibility.

This research capitalizes on ACS microdata showing relationships within households and therefore information on household compositions. Importantly, it reveals the greater complexity of households with disability than those without disability, with the reference persons' sons/daughters without disability playing an important role in these households. The multigenerational makeup stands out as a feature of family households with disability. While there is a stark difference in disability rates between the most urban and most rural areas, ranging from 11 to 18%, urban–rural differences in the composition of households with disability are more modest. There are, however, some noteworthy differences for larger metro areas, with higher shares of multigeneration households. Greater ethnic diversity and the benefits of resource sharing in high-cost large cities may contribute to the larger share of multigenerational households.

Theories providing a background for this work address household decision-making (3–6), solidarity (10–12), and the capability-functioning nexus (15, 18–20, 22, 41). Solidarity-driven decisions of persons without disability contribute to a boost in household resources or commodities and favorably affect the practical opportunities or capabilities of persons with disability. A broader set of choices makes for increased functioning and reduced limitations on activities leading to broader opportunities to participate in the community outside the home. Persons with disability likely benefit from the presence of household members without disability who act to facilitate greater community participation. Concurrently, the desire for and benefits of community participation may be diminished as some of the social, emotional, and other needs may be met in the household due to the presence and support of other household members.

This raises the question, of course, of how community participation is or is not facilitated for the large number of solo persons with disability. Solo persons with disability may have a greater need but fewer opportunities for community participation. Are their needs met and if so how? This is especially relevant in rural areas where a third of persons in solo households experience disability.

Numeric results from the ACS provide a detailed picture of residential settings, disability, and household composition. Findings align with the literature on household decision-making, solidarity, and capabilities. However, the ACS is not designed to and does not provide explicit motivational and behavioral information. Qualitative research would be needed to specifically explore the nature of decision-making and support relationships and the linkages to capabilities, functioning, and community participation of persons with disability and members of their households. A qualitative research approach could also reveal how this plays out similarly or differently for persons with disability and their household members without disability. Does the presence of PwoD_HHwD raise the collective capabilities of the entire household, or is this more of a zero-sum game based on trade-offs between PwoD_HHwD and PwD? Such insight could have important implications, especially for policy recognizing and addressing the role of persons without disability in households with disability.

Data availability statement

Publicly available datasets were analyzed in this study. This data can be found here: https://www2.census.gov/programs-surveys/acs/data/pums/2019/5-Year/.

Author contributions

The author conceptualized and designed the study, conducted the data analysis, and wrote the manuscript.

Funding

The content of this research was developed under grants from the National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR Grant Numbers #90RT5023 and 90RTCP0002). NIDILRR is a Center within the Administration for Community Living (ACL), Department of Health and Human Services (HHS).

Acknowledgments

I want to express my appreciation to the leadership and research group of RTC: Rural at the Rural Institute for Inclusive Communities at the University of Montana for inviting me to their team and welcoming my research contributions to the work of RTC: Rural.

Conflict of interest

The author 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

Author disclaimer

The findings and conclusions are those of the author and do not necessarily reflect the view or policy of NIDILRR, ACL, or HHS. Endorsement by the U.S. Federal Government should not be assumed.

Supplementary material

The Supplementary Material for this article can be found online at: https://www.frontiersin.org/articles/10.3389/fresc.2022.875966/full#supplementary-material

References

1. von Reichert C, Greiman L, Myers A. *The Geography of Disability in America: On Rural-Urban Differences in Impairment Rates.* Independent Living and Community Participation 7 (2014). Available online at: https://scholarworks.umt.edu/ruralinst_independent_living_community_participation/7/ (accessed December 28, 2021).

2. U.S. Census Bureau. *2015-2019 American Community Survey Public Use Microdata Samples.* (2021). Available online at: https://www2.census.gov/programs-surveys/acs/data/pums/2019/5-Year/ (accessed November 27, 2021).

3. Becker GS. A theory of the allocation of time. *Econ J.* (1965) 75:493–517. doi: 10.2307/2228949

4. Becker GS. A treatise on the family. *2nd ed.* Cambridge, Mass: Harvard University Press. (1991).

5. Mincer J. Labor force participation of married women: a study of labor supply. In: Lewis HG, editor. *Aspects of Labor Economics.* NJ: Princeton University Press. (1962). p. 1–35.

6. Mincer J. Family migration decisions. *J Polit Econ.* (1978) 86:749–73. doi: 10.1086/260710

7. von Reichert C, Berry EH. Rural–urban patterns of disability: the role of migration. *Popul Space Place.* (2020) 26:e2271. doi: 10.1002/psp.2271

8. Day C. Young adult carers: a literature review informing the re-conceptualisation of young adult caregiving in Australia. *J Youth Stud.* (2015) 18:855–66. doi: 10.1080/13676261.2014.1001826

9. Rossi AS, Rossi PH. *Of Human Bonding: Parent-Child Relations Across the life Course*. New York: Adine de Gruyter. (1990).

10. Hogan DP, Eggebeen DJ, Clogg CC. The structure of intergenerational exchange in American families. *Am J Sociol.* (1993) 98:1428–58. doi: 10.1086/230194

11. Silverstein M, Bengtson VL. Intergenerational solidarity and the structure of adult child & parent relationships in American families. *Am J Sociol.* (1997) 103:429–60. doi: 10.1086/231213

12. Bengtson VL. Beyond the nuclear family: the increasing importance of multigenerational bonds. *J Marriage Fam.* (2001) 63:1–16. doi: 10.1111/j.1741-3737.2001.00001.x

13. National Alliance of Caregiving and American Association of Retired Persons. *Caregiving in the U.S.* (2020). Available online at: https://www.caregiving.org/wp-content/uploads/2021/01/full-report-caregiving-in-the-united-states-01-21.pdf (accessed March 1, 2022).

14. Sevak P, O'Neill J, Houtenville A, Brucker D. State and local determinants of employment outcomes among individuals with disabilities. *J Disabil Policy Stud.* (2018) 29:119–28. doi: 10.1177/1044207318782676

15. Mitra S. The capability approach and disability. *J Disabil Policy Stud.* (2006) 16:236–47. doi: 10.1177/10442073060160040501

16. Walls RT, Dowler DL. Disability and income. *Rehabil Couns Bull.* (2015) 58:146–53. doi: 10.1177/0034355214530788

17. Sage R, Greiman L. *National Disability Institute Blog*. Missoula, MT: Rural Institute for Inclusive Communities. (2018).

18. Sen A. *Commodities and Capabilities. Amsterdam North-Holland.* (1985).

19. Nussbaum MC. *Frontiers of Justice: Disability, Nationality, Species Membership*. Cambridge, Mass: The Belknap Press, Harvard University Press. (2006).

20. Trani J-F, Dubois JL. Capability and disability: approaches for a better understanding of disability issues. In: Trani JF, Dubois JL, Mahieu FR, editors. *Development Efforts in Afghanistan : Is there a will and a way : The case of Disability and Vulnerability*. Paris: L'Harmattan (2011). p. 25–45.

21. Dubois JL, Trani JF. Extending the capability paradigm to address the complexity of disability. *Alter.* (2009) 3:192–218. doi: 10.1016/j.alter.2009.04.003

22. Trani J-F, Bakhshi P, Bellanca N, Biggeri M, Marchetta F. Disabilities through the capability approach lens: Implications for public policies. *Alter.* (2011) 5:143–57. doi: 10.1016/j.alter.2011.04.001

23. Ibrahim S. From individual to collective capabilities: The capability approach as a conceptual framework for self-help. *J Hum Dev Capabil.* (2006) 7:397–416. doi: 10.1080/14649880600815982

24. Greiman L, Sage R, Bates T, Lissau A, Wagner L, Chapman S. Personal Care Assistance in Rural America. *Rural Institute for Inclusive Communities, University of Montana and Health Workforce Research Center, University of California San Francisco.* (2021).

25. Washington Group on Disability Statistics. *The Washington Group Short Set on Functioning (WGSS)*. (2020). Available online at: https://www.washingtongroup-disability.com/fileadmin/uploads/wg/Documents/Questions/Washington_Group_Questionnaire__1_-_WG_Short_Set_on_Functioning.pdf (accessed June 14, 2022).

26. National Center for Health Statistics. *Washington Group on Disability Statistics*. Rationale for the short set. (2015). Available online at: https://www.cdc.gov/nchs/washington_group/wg_rationale.htm

27. World Health Organization. *World report on disability 2011 Geneva, Switzerland: World Health Organization*. (2011). Available online at: https://www.who.int/publications-detail-redirect/9789241564182 (accessed December 6, 2022).

28. Altman BM. Definitions of disability and their operationalization, and measurement in survey data: An update. In: Barnartt SN, Altman BM, editors. *Exploring Theories and Expanding Methodologies: Where We Are and Where We Need To Go. Research in Social Science and Disability*, Vol. 2. Bingley: Emerald Group Publishing Limited (2001). p. 77-100.

29. Altman BMP. Definitions, concepts, and measures of disability. *Ann Epidemiol.* (2014) 24:2–7. doi: 10.1016/j.annepidem.2013.05.018

30. Center for Disease Control and Prevention CDC. *Behavioral Risk Factor Surveillance System BFRSS*. Available online at: https://www.cdc.gov/brfss/index.html (accessed December 6, 2022).

31. U.S. Census Bureau. *2015-2019 ACS 5-year PUMS Data Dictionary*. Washington, DC2021. Available online at: https://www2.census.gov/programs-surveys/acs/tech_docs/pums/data_dict/PUMS_Data_Dictionary_2015-2019.pdf (accessed date December 1, 2022).

32. U.S. Census Bureau. Understanding and using the American Community Survey Public Use Microdata Sample files. *What Data Users Need to Know*. (2021). Available online at: https://www.census.gov/content/dam/Census/library/publications/2021/acs/acs_pums_handbook_2021.pdf (accessed December 1, 2022).

33. Office of Management and Budget. *2010 Standards for Delineating Metropolitan and Micropolitan Statistical Areas Washington, DC: Office of the Federal Register*. (2010). Available online at: https://www.whitehouse.gov/wp-content/uploads/legacy_drupal_files/omb/federal_register/FR2010/06282010_metro_standards.pdf (accessed 19 June 2022).

34. Economic Research Service. *2013 Rural-Urban Continuum Codes*. US Department of Agriculture. (2020). Available online at: https://www.ers.usda.gov/webdocs/DataFiles/53251/ruralurbancodes2013.xls?v=41404 (accessed September 1, 2022).

35. U.S. Census Bureau. Table S1810. Disability characteristics. *2015-2019 American Community Survey*. (2021). Available online at: https://data.census.gov/ (accessed November 29, 2021).

36. Lofquist D. Multigenerational Households. *Families and Households Working Papers*. Washington, DC: US Census Bureau (2013).

37. Mayer DJ. *Views From Our Shoes: Growing up with a Brother Or Sister With Special Needs*. Seattle, WA: Sibling Support Project (siblingsupportorg). (1997).

38. Braaten E. *Growing Up With Siblings With a Disability: The Clay Center for Young Healthy Minds*. Available online at: https://www.mghclaycenter.org/parenting-concerns/growing-up-with-a-sibling-with-a-disability/ (accessed June 26, 2022).

39. Altman BM, Bernstein A. *Disability and Health in the United States, 2001-2015 Hyattsville, MD: National Center for Health Statistics*. (2008). Available online at: https://www.cdc.gov/nchs/data/misc/disability2001-2005.pdf (accessed July 1, 2022).

40. Center for Disease Control and Prevention CDC. *National Health Interview Survey NHIS*. Available online at: https://www.cdc.gov/nchs/nhis/ (accessed June 26, 2022).

41. Mitra S. *Disability, Health and Human Development*. New York: Palgrave MacMillan. (2018).

Frontiers in Rehabilitation Sciences

TYPE Brief Research Report
PUBLISHED 05 September 2022
DOI 10.3389/fresc.2022.876099

"Sympathy" vs."Empathy": Comparing experiences of I2Audits and disability simulations

Emily C. Hicks[1]*, Meg A. Traci[1] and Karin Korb[2]

[1]Rural Institute for Inclusive Communities, University of Montana, Missoula, MT, United States, [2]Karin Korb LLC, Ft. Lauderdale, FL, United States

OPEN ACCESS

EDITED BY
Jean P. Hall,
University of Kansas, United States

REVIEWED BY
Delphine Labbe,
University of British Columbia, Canada
Zhuoying QIU,
China Rehabilitation Research Center/WHO Collaborating Center for Family International Classifications, China

*CORRESPONDENCE
Emily C. Hicks
emily1.hicks@umontana.edu

SPECIALTY SECTION
This article was submitted to Disability, Rehabilitation, and Inclusion, a section of the journal Frontiers in Rehabilitation Sciences

RECEIVED 15 February 2022
ACCEPTED 16 August 2022
PUBLISHED 05 September 2022

CITATION
Hicks EC, Traci MA and Korb K (2022) "Sympathy" vs."Empathy": Comparing experiences of I2Audits and disability simulations.
Front. Rehabilit. Sci. 3:876099.
doi: 10.3389/fresc.2022.876099

People with disability often experience stigma and discrimination, and people with disability in rural areas may experience these at higher rates. Additionally, people with disability in rural areas may have fewer opportunities for physical and social participation due to barriers in the built environment. Activities such as disability simulations and inclusive, interdisciplinary community planning workshops (i.e., I2Audits) seek to draw awareness to and address these problematic experiences. The present study used thematic analysis from qualitative research to examine the advantages and disadvantages of using disability simulations and I2Audits in rural communities. Findings suggest that disability simulations increase stigmatization, lead to feelings of embarrassment and discomfort, and do not capture the experiences of people with disability. On the other hand, I2Audits lead to meaningful environmental changes, create feelings of empowerment, and center the lived experiences of people with disability within a bio-psycho-social model of disability. Results suggest that not only can I2Audits be a powerful tool to draw attention to physical barriers that people with disability face, but they also draw attention to the multi-level changes needed to increase opportunities for participation and address sources of stigma and discrimination in rural areas.

KEYWORDS
i2Audit, disability simulation, disability, rural, stigma, built environment

Introduction

According to the Centers for Disease Control and Prevention (CDC), one in four (61 million) adults in America report having a disability [as cited in (1)]. The World Health Organization and World Bank reported that 15% of the world's population, or one billion people, experience some form of disability (2). Further, approximately 60 million Americans live in rural areas (3), and of adults in rural areas, one-third report a disability (4). Of note, these numbers may be underestimated due to lack of disability disclosure due to disability stereotypes and discrimination, as people with disability[1] experience noteworthy challenges, including inaccessible environments, stigma, and negative attitudes (5).

---

[1] The term people with disability (person first language) is used to reflect the current preferences of the disability community members with whom we engage on this work. Identity-first language is used in the positionality statements.

Stigma first began to be looked at in modern times by Erving Goffman, and he defined stigma as an "attribute that is deeply discrediting" (6, *p.*3). It has since been defined in other ways, such as "the process by which a society bestows its own negative meaning on the behaviors, signs, or attributes of an individual" (7, p. 39), and "social devaluation or the potential for negative treatment" (8, p. 3). Although these definitions may seem abstract, they have real-world implications for millions of people. For example, a recent field study found that fictional applicants with disabilities received 26% fewer statements of interest from employers compared with fictional applicants without disabilities, with little difference between applicants other than disability status (9). Additionally, the Royal Mencap Society reported that children with special education needs (SEN) are twice as likely to be bullied as children without any SEN (10). Furthermore, only 6% of adults with a learning disability were in paid employment that was reported to local authorities in 2017/2018 in England, compared with 76% of the general population ages 16 to 64 (10). Studies have found that experiencing stigmatization is related to more depressive symptoms and decreased emotional well-being in persons who self-identify as having a disability (11, 12). Additionally, greater depression severity was found to be a statistically significant predictor of perceived stigma (13). So, the relationship between stigma and depression may be circular, creating negative cycles of poor social experiences and mental health outcomes in persons with disabilities and chronic illnesses.

People with disability in rural areas may face increased stigmatization and discrimination (14). Qualitative research examining the lived experiences of people with disabilities in rural areas indicates that individuals experience increased isolation, violence, and social exclusion (14). Further, people with disability in rural areas experience barriers to healthcare due to accessibility concerns. There are significant differences in healthcare access for those in rural vs. urban areas, with individuals in rural areas facing a lack of public transportation, fewer health services, and cultural and financial concerns (15). For example, in rural areas, healthcare professionals may also be friends and neighbors, which may hamper a person's level of comfort with seeking services and sharing personal, medical information (15). Additionally, finances may prohibit treatment-seeking, as research has noted an inequality in health care coverage between urban and rural areas such that rural areas tend to have higher numbers of uninsured individuals than urban areas (16). This factor combined with higher rates of poverty in rural areas (17) leads to multiple financial barriers in accessing care. For people with disability living in rural areas, the financial concerns of living in a rural place may be compounded by disability status, as research has found statistically positive relationships between disability and poverty (18). Thus, access to services in rural areas may be hindered on multiple levels, which contributes to people in rural areas experiencing poorer physical and mental health (19). For example, people residing in rural areas are more likely to experience chronic conditions, activity limitations, and are 1.5 times more likely than those in urban areas to rate their physical health as "fair to poor" (19).

Social participation and perceived isolation have also been linked to the health of people with disability (20). Research suggests that decreased social participation and increased isolation is related to poorer health and less satisfaction for people with disability (20). Objective measurements have indicated that rural areas tend to be less accessible than urban areas (21). This is significant as community environments with poor accessibility lead to less opportunities for social participation.

Barriers to social participation for people with disability in rural areas may also be attributed to lack of transportation. Data from the Rehabilitation Services Administration (RSA) suggests that people with disability in rural areas receive less transportation services than people with disability in urban areas (22). Previous research has cited inadequate public transportation to be a barrier to social participation, especially for those in rural communities and those with mobility issues (23). Transport systems not only include the availability of public transportation, but also the physical characteristics of environments, planning processes, design, and policies that allow people to move from place to place (24). The Association of Programs for Rural Independent Living (APRIL) describes transportation as the "systems, services, vehicles, routes, stops, programs, and all other aspects of transportation" (25). Accessible transport systems have been linked to well-being (24). Thus, it is important to consider the relationships between transport systems, social participation, isolation and exclusion, accessibility of the environment, and health and well-being for people with disability in rural areas.

The recognition that people with disability in rural areas experience barriers to health services (15), social participation (20), and transportation (22) due to physical, sociocultural, and sociopolitical obstacles has led to a variety of efforts aimed at drawing attention to these critical issues. One effort that has frequently been used is a disability simulation. Disability simulations are "interactive role-playing experiences to improve disability attitudes and increase understanding" (26, p. 324). These simulations may ask participants to wear blindfolds or glasses to mimic low vision, earplugs to approximate hearing loss, or go through their day in a wheelchair to imitate the day of someone with paraplegia. While these exercises are likely engaging for the participants, little research has examined the effectiveness of these traditional disability simulations to improve attitudes and increase understanding (27). A meta-analysis examining the effectiveness of disability simulations suggests that there is a lack of research regarding effectiveness, as much of the research surrounding simulations describes steps to hosting a disability simulation (27). A recent study examined this issue and found that across two experiments, students who completed low vision, hearing impairment, dyslexia, or mobility impairment simulations felt more confused, embarrassed, helpless, and susceptible to becoming disabled after the simulation compared to baseline (26). Additionally, the study found that while empathetic concern increased in both studies, participants ultimately expressed greater discomfort about interacting with persons with disabilities following the simulation (26). Therefore, there is some evidence that traditional disability simulations do not fulfill their stated goals of improving attitudes and increasing understanding. This idea was supported by a meta-analysis examining ten disability simulations that suggested, based on effect sizes, that there was little evidence to suggest that disability simulations effectively improve attitudes towards people with disability (27). In fact, some researchers have noted that disability simulations not only fail to show the reality of disabilities, but they also actually perpetuate the stereotypes of incompetence and dependency (26). These simulations have been critiqued as misleading participants to think that the source of disadvantages is the person with the disability, while ignoring environmental barriers and government policies that are discriminatory and stigmatizing towards some people (26), leading to harmful effects. Other critiques of disability simulations suggest that the simulations may ultimately lead to discrimination due to reinforced stereotypes (28). It should be noted that while some studies have suggested that disability simulations lead to harmful outcomes (26), others have demonstrated that while disability simulations are ineffective, they are not harmful (27). Still other studies have found mixed results of disability simulations, with one study noting both positive attitude changes and no attitude changes following a simulation (29).

Notably, a meta-analysis of disability simulations explored the factors that may lead to improved attitudes towards people with disability. Results indicated that interaction with people with disability was most effective (27). In fact, this interaction was described as “an essential component of attempts to change attitudes or behaviors related to people with disabilities” (27, p. 76). This suggestion is supported by empirical research, which has indicated that students who interact with children with disability in classroom environments were more accepting of their peers with disability than children in classrooms without disability representation (30). In another study, nursing students engaged in a disability simulation in pairs, with one student acting as a “patient” and simulating hemiparesis, and the other student acting as a “rehabilitation nurse” (31). Results of the study indicate that while all students had increased empathy scores after the simulation, the students acting as rehabilitation nurses had higher empathy scores post-simulation (31). Although disability was simulated in this study, the results suggest that higher empathic changes can occur when engaging with people with disability rather than pretending to have a disability. Ultimately, it has been suggested that interacting with people with disability may lead to greater acceptance and understanding than disability simulations (27, 28).

As an alternative approach to disability simulations, an inclusive, interdisciplinary model may be better suited to truly increase understanding, improve disability attitudes, and instigate institutional and government policy changes. Interdisciplinary systems are “teams or individuals that integrate information, data, techniques, tools, perspectives, concepts, and/or theories from two or more disciplines or bodies of specialized knowledge to advance fundamental understanding or to solve problems whose solutions are beyond the scope of a single discipline or area of research practice” (32, p. 2). Inclusive, interdisciplinary models have been found to have benefits for students in both primary (33) and secondary education (34), enhance professional growth and trust among colleagues (35), and improve patient outcomes in healthcare settings (36). Due to the promising findings from inclusive, interdisciplinary models found across community settings, the Rural Institute at the University of Montana developed the Inclusive Interdisciplinary Audit Toolkit (I2Audit) in 2018.

The I2Audit can be utilized to assess environmental needs and “work together to find equitable policy, systems, and environmental (PSE) solutions” (37). Walk/move audits are facilitated group explorations of an area to examine its support of physical activity and active transportation. The I2Audit builds on traditional walk/move audits and is inclusive in that people with disability lead and are decision-makers in the planning, implementation, and evaluation of the audit. This model highlights that audit events should facilitate acts of shared discovery, and not simply showcase experts telling others what they should be experiencing. The I2Audit also differs from traditional walk/move audits in that it is interdisciplinary and encourages teams to consist of people with disability, and representatives from disability advocacy, public health, planning and land use, and engineering and infrastructure systems. The team evaluates an area’s sidewalks, bike lanes, curb ramps, and transit options for site design, safety, and accessibility. Since its inception, sixteen communities in a rural state have used the I2Audit and established 23 policies and plans for built environments focused on physical activity, including 11 inclusive complete streets policies (37). The I2Audit model presents a promising alternative to traditional disability simulations due to its focus on the people with disabilities, rather than the disability itself. This model may be particularly useful in rural communities, as research suggests that rural areas tend to have limited built environment features that promote active living and active transportation (38). These limitations lead to fewer opportunities for physical activity (38), less access to health care services (15), reduced social participation (20), and decreased well-being (23). Additionally, people with disabilities are often not included in rural development interventions, leading to social exclusion (5), despite research noting that people with disability are active, effective leaders and participants in projects aimed at developing accessible rural areas (39). I2Audits create opportunities for people with disability and other community members to work alongside each other to identify barriers and develop solutions to improve features of the built environment that limit healthy lifestyles for people with disability in rural areas. While the I2Audit is designed to address concerns regarding social participation, the I2Audit is also used to address concerns surrounding stigma and discrimination. Of importance, the I2Audit is purposeful in pairing people with and without disability to explore their community, and interaction with people with disability has been cited as a key factor in instigating greater acceptance of people with disability (27).

Methods

Given the relative lack of research regarding disability simulations, limited evidence noting the problematic outcomes of disability simulations, and the promising nature of inclusive, interdisciplinary models, the present study sought to gain insight into the advantages and disadvantages of disability simulations and I2Audits from community members who had participated in one or both activities in rural communities. Thus, a Participatory Action Research (PAR) modality was chosen, and the researchers sought insight from community members and stakeholders, including people with disability, state Department of Public Health and Human Services (DPHHS) representatives, and active community members. The researcher's original idea for the study was to conduct both a disability simulation and an I2Audit and obtain both objective and subjective data regarding the effectiveness of the interventions in improving attitudes toward people with disability. However, upon proposing the research design, group members strongly objected to the idea of conducting a disability simulation as part of the study. The group suggested that given the research that disability simulations may be harmful (i.e., 26), it would be unethical to conduct such a simulation. Thus, the research objective was altered. Rather than conducting both a disability simulation and an I2Audit to compare effectiveness, the researchers aimed to explicitly describe the concerns with disability simulations and how I2Audits may be similar or dissimilar to disability simulations. The PAR group members approved this approach and felt that this methodology may delineate between helpful and unhelpful practices that aim to improve attitudes toward people with disability.

As in all research, it is helpful to understand the positionality of the researchers as this influences the lens through which the study is conducted, and the results understood. The first author is a non-Disabled, American Indian, cisgender woman, and a U.S. scholar. She is a member of tribal communities and works within the local community with people with disability as a researcher and mental health clinician. The second author is non-Disabled, White, cisgender woman, and an academic researcher with decades of experience working with people with disability and advocacy organizations using a Disability-led participatory approach and methods. The third author is a Disabled, White, cisgender woman and Disability thought leader and Diversity, Equity and Inclusion advocate. Authors had discussions with each other, as well as with people with disability and community leaders, to ensure the study was guided by cultural knowledge and expertise.

Sample

The sample consisted of 12 participants residing in a large, rural state. Participants included community members, disability advocates, and university students who had participated in a disability simulation, I2Audit, or both. Convenience sampling was used, and a recruitment email was distributed by the PAR group. The email was sent to disability advocates, community members, and stakeholders who were known to have either participated in a disability simulation or I2Audit. Participants were excluded from the study if they were under 18-years-old or had not participated in either a disability simulation or an I2Audit.

Procedure

A targeted approach was used, and a qualitative survey was emailed to participants. Participants were asked to describe their previous experiences with disability simulations and I2Audits. Additionally, they were asked to note how they found the two experiences to be similar and/or different if they had participated in both activities. Finally, they were asked to list any policies, systems, or environmental changes that had occurred in their communities as a result of I2Audits. Specific questions included, but were not limited to: (1) Please describe your past experiences with I2Audits, (2) If you've participated in a disability simulation awareness training, what do you perceive as the major differences between disability simulation trainings and I2Audits, (3) Do you feel that disability simulation trainings or I2Audits are more effective for community understandings of the experiences of people with disabilities, and (4) Please describe any policy, systems, environmental or program changes that have occurred as a result of an I2Audit that you participated in. Participants were also given space to detail other information they would like to share about disability simulations and/or I2Audits and their effects.

The PAR group advised the recruitment, development, outcomes, and dissemination phases of the study. In order to honor the words of participants, a qualitative descriptive methodology was used rather than a method that forces categorical responses. Descriptive methodology is especially important when the research concerns underrepresented groups in research, including people with disability, as researchers have historically taken advantage of marginalized communities. Additionally, qualitative research is often useful in understudied research areas, including the topic of the present study. To best respect and understand participant's responses, a qualitative study protocol that uses verbatim responses was used. Authors had conversations with each other and members of the PAR group to determine overarching themes based on the participant's responses. While this innately requires a level of data interpretation, qualitative methodologies allow for this interpretation to occur while considering cultural, societal, and contextual factors. For example, some participants identified as having a disability, while others did not. Disability status may influence people's experiences of disability simulations and I2Audits – a contextual factor that is important for data interpretation.

Results

Participant demographics

The majority of the participants identified as White ($n = 11$), female ($n = 8$), and had some college education ($n = 12$). Five of the participants identified as having a disability ($n = 5$). All participants resided in a large, rural state at the time of the study. All participants had professional and personal experiences working with individuals and community organizations in rural counties in the state as well. The majority of participants had participated in both a disability simulation and an I2Audit ($n = 7$), with three participants having only participated in a disability simulation ($n = 3$), and two participants having only participated in an I2Audit ($n = 2$). Questions about the specific disability simulation or I2Audit the participant had participated in were not asked; however, several participants disclosed this information in their responses to other questions. Three participants described participating in a disability simulation meant to mimic speech impairment, and four participants stated the city of the I2Audit that they participated in. The disclosed cities had populations of 34 to 75 thousand people and were located in a rural state.

"It made me feel flawed": Disability simulations ignore environmental barriers

The first theme that emerged surrounded the idea that disability simulations ignore environmental barriers. One participant noted, "Instead of learning about the social and environmental barriers experienced by people with disability and having that community provide solutions, the simulations just have us learn that it is harder to move around the world." This participant highlights the stigma that people with disability face by people assuming that difficulties can be attributed to the individual, rather than access concerns. A second participant stated, "It [disability simulation] made me feel flawed. I just felt like I couldn't do anything right." Again, this participant draws attention to the individual stigma that one may experience, rather than considering broader, environmental barriers. A final participant described, "They [disability simulation] made it impossible to succeed. I think with time and practice I could learn to live with it [dyslexia], but it was so short that we all just felt annoyed." This participant highlights the idea that a person can live a full life with environmental support but managing discrimination can be difficult without this support.

"A different mindset": I2Audits provide a variety of perspectives

A second theme that emerged was that I2Audits offer a variety of perspectives. One participant noted, "[It is] very helpful to experience an area with a different mindset." This quote describes that the participant was able to listen to and learn from someone else's perspective on the built environment of a space. This idea was corroborated by another participant who stated, "It allows all participants to have a voice and not be overshadowed." In addition to highlighting shared perspectives, this quote underscores that each participant's knowledge is considered equally important. Another participant expressed, "I always learn a lot and gain a different perspective…It is good to hear a variety of perspectives." This participant appears to have engaged in multiple I2Audits and has gained different knowledge with each experience. Finally, a participant said, "Everyone had a chance for their voices to be heard." This quote draws attention to the idea that there is no expert in I2Audits, but rather, each perspective is considered valuable and meaningful.

"Instead of increasing my skill…it increased…fear": Embarrassing vs. empowering

Participants who had participated in both disability simulations and I2Audits tended to describe the disability simulations as uncomfortable or embarrassing, while describing the I2Audits as empowering and helpful. For example, one participant noted, "An I2Audit includes people with disability to share their lived experience and influence change through their perspective. The disability simulations I have been a part of do not involve people with disability…There is little context put to these simulations and therefore sympathy, instead of empathy and partnerships, is developed. The I2 audit fosters the latter and gives the participants a new perspective and skills to make change. Therefore, systems change is more likely to occur on that specific project and in future projects." This participant notes that disability simulations, while positive in their intentions, may lead to pity rather than empathy. A second participant described, "I used to think those [disability simulations] were good tools but since doing I2WALK [I2Audit] trainings where people with a variety of mobility, vision, or cognitive challenges are the actual leaders and can share their life experience and people can see how they need to navigate a flawed environment… I feel the I2WALK [I2Audit] audits are more powerful." Again, this participant draws attention to the idea that while both disability simulations and I2Audits attempt to bring positive change for the disability community, the I2Audits do so in a way that empowers the disability community. A final participant stated, "The other simulation I was a part of required me to wear earplugs for a day and not talk. I was embarrassed to do so. I don't think I was embarrassed to have a "disability" but rather that I had to pretend to do so… Instead of increasing my skill to support people with disability, it increased sympathy and fear. I have never forgotten these experiences. At the time I didn't know why they felt wrong, but I am now glad to have the skills to include people with disability, to amplify their voices, and promote audits that increase individual, social, and environmental change in our communities." This participant describes that disability simulations were uncomfortable, even if they were unsure why, and that learning how to be alongside people with disabilities, rather than in place of them, was an empowering experience.

"Tool for…community engagement": Engaging with people with disability leads to meaningful interactions and environmental changes

The fourth and final theme that emerged was that engaging with people with disability led to meaningful interactions and changes in the built environment. I2Audits were described by participants as a "change agent," and participants identified specific shifts in the infrastructure of their towns as a result of I2Audits. For example, one participant stated, "[City name's] wayfinding system was created from the I2Walk/Move audits [I2Audit], too. I use those signs weekly." Another participant remarked, "The uptown [City name] Master Plan is an extension of many years of work inspired by walk audits. Many new bus stops and curb extensions have come from walk audits [I2Audits]." Another city's downtown master plan was also described as being informed by I2Audits. Finally, a participant remarked, "I think they [I2Audits] are a great tool for general community engagement, educating policymakers and staff, and engaging people with disabilities and learning from their life experiences for the betterment of all of us." This final quote highlights that not only do I2Audits create awareness around disability, but they also lead to environmental changes and further the education of community members and leaders.

Discussion

People with disability experience stigmatization and decreased social participation that negatively impact both physical and mental health. Thus, efforts have been made to improve attitudes and understanding toward people with disability; however, some efforts that have been taken (e.g., disability simulations) have been found to be ineffective and possibly harmful. There is a need for interventions that improve attitudes toward people with disability, as well as interventions that may increase social participation and active community engagement. It has been suggested that interaction with people with disability may be more effective than disability simulations. Based on past research, Inclusive, Interdisciplinary Audits (I2Audits) sought to fill the gap in increasing interaction with people with disability in order to improve disability attitudes and understanding.

Overall, results suggested that participants found disability simulations to increase fear, frustration, and embarrassment. In contrast, participants found I2Audits to allow for sharing of perspectives, increased empathy, and learning from the experiences of people with disability. Participants identified multiple environmental changes that occurred as a result of I2Audits, including changes to bus stops, curb extensions, and wayfinding systems. Of importance, these changes occurred in rural communities. While previous research has documented the limited infrastructure changes of rural built environments (38), I2Audits led to meaningful improvements to the built environment in rural areas, increasing opportunities for physical and social engagement for people with disability in rural places.

It is common during I2Audit planning processes for new team members to suggest that traditional elements of disability simulations such as wheelchairs or blindfolds be added to the audit. It also is common for I2Audit participants to suggest adding disability simulations as follow up activities. These findings can support I2Audit teams to facilitate difficult conversations about negative experiences associated with traditional disability simulations, refocusing participants towards community changes that will better support people with disabilities.

Given the past research indicating ineffective and potentially problematic outcomes of disability simulations, combined with promising findings regarding I2Audits, communities should be encouraged to discontinue disability simulations and implement other interventions, such as I2Audits. A major difference between disability simulations and I2Audits is that I2Audits center the lived experiences of people with disability, while disability simulations mimic the experiences of people with disability; however, this mimicry does not lead to the desired outcomes of (1) increased recognition that there are layers of challenges in communities that limit and oppress people with disability; (2) increased engagement with people with disability and disability organizations; (3) prioritizing solutions developed in the disability community that, from a universal design perspective, can benefit all; and (4) valuing the lived experiences of people with disability and centering their subject matter expertise in community planning and decision-making. Allowing people with disability to lead the discussion on needed environmental and societal changes leads to improved outcomes and is in line with Participatory Action Research principles. Thus, interventions that prioritize having people with disability in leadership and decision-making roles will likely be more effective in meeting research and community goals.

Limitations, future research, and recommendations

The primary limitation of the present study was that this was a convenience sample and the use of online mechanisms to gather qualitative data. Though participants had information or direct experience with both interventions, participants varied in their exposures to the interventions. Additionally, while participants provided detailed responses, the researchers had many follow-up questions that could have been answered more fully through an interview process. Future studies using qualitative interviews would be useful to clarify the information obtained in the present study. Additional limitations of the study include the small sample size and the use of subjective data. Future research should use objective measures to assess for differences in empathy, stereotype beliefs, and attitudes towards people with disability when examining the effectiveness of I2Audits.

The present research can be used to inform future qualitative research measurement selection when comparing simulations and audits, where measures are appropriate and culturally sensitive. Future research could evaluate the short- and long-term impacts of disability simulations vs. I2Audits on rural community group composition and planning priorities. Findings suggest that disability simulations that do not center the lived experiences of people with disabilities are an outdated, and generally problematic, exercise. This observation needs to be taken into consideration for future applications of disability simulation models such as experiencing wheelchair basketball and adaptive sports. Educators and researchers should instead consider using alternative activities, such as I2Audits, that highlight listening to and learning from people with disabilities.

Contributions to the field

The present study seeks to fill a gap regarding the advantages and disadvantages of using disability simulations and Inclusive, Interdisciplinary Audits (I2Audits) in rural communities. While both aim to increase awareness towards barriers that people with disability face, findings suggest that disability simulations do not capture the experiences of people with disability and instead lead to embarrassment and discomfort and perpetuate stigmatization. On the other hand, I2Audits center the lived experiences of people with disability and lead to empowerment for people with disability and other community members. Additionally, I2Audits have led to positive built environment changes for people with disability in rural communities, creating additional opportunities for physical activity and social participation. These findings are particularly encouraging given past research noting the tendency to have limiting built environment features for people with disability in rural areas. Future research using objective data to compare outcomes between disability simulations and I2Audits in rural communities is needed.

Data availability statement

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

Ethics statement

The studies involving human participants were reviewed and approved by Institutional Review Board, University of Montana. Written informed consent for participation was not required for this study in accordance with the national legislation and the institutional requirements.

Author contributions

Data aggregation for the project was done by MT and EH. Data analysis was done by EH in collaboration with all authors, and the idea for the project was by KK. The writing was done by EH. All authors completed critical review and suggested edits. All authors contributed to the article and approved the submitted version.

Funding

This project was supported with funds from cooperative agreements between the CDC and the Montana DPHHS (DD16–1603; DD21-2103). This research was supported by the Research and Training Center on Disability in Rural Communities (RTC:Rural) under another NIDILRR grant (grant number 90RTCP0002). NIDILRR is a Center within the Administration for Community Living (ACL), Department of Health and Human Services (HHS). The research does not necessarily represent the policy of NIDILRR, ACL, or HHS and one should not assume endorsement by the federal government. Emily Hicks receives/received support from Montana INBRE – an Institutional Development Award from the National Institute of General Medical Sciences of the National Institutes of Health under Award Number P20GM103474.

Acknowledgments

The authors thank The Rural Institute for Inclusive Communities for their support on this project, and all participants for their time and contribution.

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. Okoro CA. Prevalence of disabilities and health care access by disability status and type among adults — United States. *MMWR Morb Mortal Wkly Rep*. (2018) 67:882–7. doi: 10.15585/mmwr.mm6732a3

2. World Health Organization. World report on disability. (2011). Available at: https://www.who.int/publications/i/item/9789241564182 (Accessed February 10, 2022).

3. United States Census Bureau. What is rural America? (2017). Available at: https://www.census.gov/library/stories/2017/08/rural-america.html (Accessed February 10, 2022).

4. Center for Disease Control and Prevention. Prevalence of disability and disability types by urban-rural county classification – United States, 2016. (2021). Available at: https://www.cdc.gov/ncbddd/disabilityandhealth/features/disability-prevalence-rural-urban.html (Accessed February 10, 2022).

5. International Fund for Agricultural Development. Disability in rural areas: A matter of perception. (2020). Available at: https://www.ifad.org/en/web/latest/-/blog/disability-in-rural-areas-a-matter-of-perception (Accessed February 10, 2022).

6. Goffman E. *Stigma: notes on the management of spoiled identity*. New York, NY: Simon & Schuster, Inc (1986).

7. Joachim G, Acorn S. Living with chronic illness: the interface of stigma and normalization. *Can J Nurs Res*. (2000) 32(3):37–48. PMID: 11928132

8. 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

9. Ameri M, Schur L, Adya M, Bentley S, McKay P, Kruse D. The disability employment puzzle: a field experiment on employer hiring behavior. *ILR Review*. (2018) 71(2):329–64. doi: 10:1177/00197939177717474

10. Royal Mencap Society. Stigma and discrimination – research and statistics. (n.d.) Available at: https://www.mencap.org.uk/learning-disability-explained/research-and-statistics/stigma-and-discrimination-research-and (Accessed February 10, 2022).

11. Cadden MH, Arnett PA, Tyry TM, Cook JE. Judgment hurts: the psychological consequences of experiencing stigma in multiple sclerosis. *Ethics Sci Med*. (2018) 208:158–64. doi: 10.1016/j.socscimed.2018.01.015

12. Green S. Components of perceived stigma and perceptions of well-being among university students with and without disability experience. *Health Sociol Rev*. (2007) 16(3):328–40. doi: 10.5172/hesr.2007.16.3-4.328

13. Pyne JM, Kuc EJ, Schroeder PJ, Fortney JC, Edlund M, Sullivan G. Relationship between perceived stigma and depression severity. *J Nerv Ment Dis*. (2004) 192(4):278–83. doi: 10.1097/01.nmd.0000120886.39886.a3

14. Neille J, Penn C. Beyond physical access: a qualitative analysis into the barriers to policy implementation and service provision experienced by persons with disabilities living in a rural context. *Rural Remote Health*. (2015) 15(3):3332. doi: 10.22605/RRH3332

15. Douthit N, Kiv S, Dwolatzky T, Biswas S. Exposing some important barriers to health care access in the rural USA. *Public Health*. (2015) 129(6):611–20. doi: 10.1016/j.puhe.2015.04.001

16. Rust G, Baltrus P, Ye J, Daniels E, Quarshie A, Boumbulian P, et al. Presence of a community health center and uninsured emergency department visit rates in rural counties. *J Rural Health*. (2008) 25(1):8–16. doi: 10.1111/j.1748-0361.2009.00193.x

17. Brems C, Johnson M, Warner T, Roberts LW. Barriers to healthcare as reported by rural and urban interprofessional providers. *J Interprof Care*. (2009) 20(2):105–18. doi: 10.1080/13561820600622208

18. Banks LM, Kuper H, Polack S. Poverty and disability in low- and middle-income countries: a systematic review. *PLoS One*. (2017) 12(12):e0189996. doi: 10.1371/journal.pone.0189996

19. Health Policy Institute. Rural and Urban Health. (n.d.). Available at: https://hpi.georgetown.edu/rural/ (Accessed July 1, 2022).

20. Repke MA, Ipsen C. Differences in social connectedness and perceived isolation among rural and urban adults with disabilities. *Disabil Health J*. (2020) 13(1):100829. doi: 10.1016/j.dhjo.2019.100829

21. Seekins T, Arnold N, Ipsen C. Assessing and comparing the accessibility of community environments: a feasibility study. *Res Soc Sci Disabil*. (2014) 8:55–70. doi: 10.1108/S1479-354720140000008004

22. Ipsen C, Swicegood G. Rural and urban differences in vocational rehabilitation case mix, delivery practices, and employment outcomes. rehabilitation research. *Policy Educ*. (2015) 29(4):349–70. doi: 10.1891/2168-6653.29.4.349

23. Lamanna M, Klinger CA, Liu A, Mirza RM. The association between public transportation and social isolation in older adults: a scoping review of the literature. *Can J Aging*. (2020) 39(3):393–405. doi: 10.1017/S0714980819000345

24. Siren A. Beyond accessibility: transport systems as a societal structure supporting inclusion in late-life. In: K Walsh, T Scharf, S Van Regenmortel, A Wanka, editors. *Social exclusion in later life: interdisciplinary and policy perspectives*. Cham: Springer International Publishing (2021). p. 327–38. doi: 10.1007/978-3-030-51406-8_25

25. Association of Programs for Rural Independent Living. Accessible Rural Transportation. (n.d.). Available at: https://www.april-rural.org/index.php/advocacy/accessible-rural-transportation (Accessed February 10, 2022).

26. Nario-Redmond MR, Gospodinov D, Cobb A. Crip for a day: the unintended negative consequences of disability simulations. *Rehabil Psychol*. (2017) 62(3):324–33. doi: 10.1037/rep0000127

27. Flower A, Burns MK, Bottsford-Miller NA. Meta-analysis of disability simulation research. *Remedial Spec Educ*. (2007) 28(2):72–9. doi: 10.1177%2F07419325070280020601

28. Silverman AM. The perils of playing blind: problems with blindness simulation and a better way to teach about blindness. *J Blind Innov Res*. (2015) 5(2). Available at: https://nfb.org/images/nfb/publications/jbir/jbir15/jbir050201.html doi: 10.5241/5-81

29. McKenney A. Attitude changes following participation in disability simulation activities. *Ther Recreation J*. (2018) 52(3):215–36. doi: 10.18666/TRJ-2018-V52-I3-8543

30. Diamond KE, Carpenter ES. Participation in inclusive preschool programs and sensitivity to the needs of others. *J Early Interv*. (2000) 23(2):81–91. doi: 10.1177%2F105381510002300203

31. Levett-Jones T, Lapkin S, Govind N, Pich J, Hoffman K, Jeong SYS, et al. Measuring the impact of a ‘point of view’ disability simulation on nursing students’ empathy using the comprehensive state empathy scale. *Nurse Educ Today*. (2017) 59:75–81. doi: 10.1016/j.nedt.2017.09.007

32. Committee on Facilitating Interdisciplinary Research. *Committee on science, engineering, and public policy. Facilitating interdisciplinary research. National academies*. Washington: National Academy Press (2004).

33. Epstein JL, Dauber SL. Effects on students of an interdisciplinary program linking social studies, art, and family volunteers in the middle grades. *J Early Adolesc*. (1995) 15(1):114–44. doi: 10.1177/0272431695015001007

34. Weinstein J. Coming of age: recognizing the importance of interdisciplinary education in law practice. *Wash Law Rev*. (1999) 74(2):319.

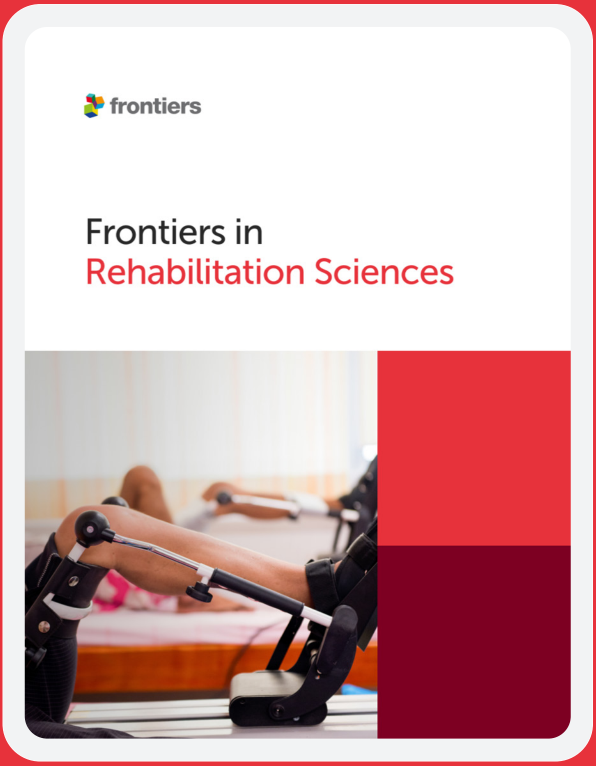
35. Miller PS, Stayton VD. Blended interdisciplinary teacher preparation in early education and intervention: a national study. *Top Early Child Spec Educ*. (1998) 18(1):49–58. doi: 10.1177/027112149801800108

36. Hirth V, Baskins J, Dever-Bumba M. Program of all-inclusive care (PACE): past, present, and future. *J Am Med Dir Assoc*. (2009) 10(3):155–60. doi: 10.1016/j.jamda.2008.12.002

37. Traci M, Costakis C. Walkable rural communities for all: Using inclusive, interdisciplinary walk audit workshops to achieve health equity. Presented at the American Public Health Association’s Annual Meeting and Expo (2018). Available at: https://apha.confex.com/apha/2018/meetingapp.cgi/Paper/421924.

38. Hansen AY, Umstattd Meyer MR, Lenardson JD, Hartley D. Built environments and active living in rural and remote areas: a review of the literature. *Curr Obes Rep*. (2015) 4(4):484–93. doi: 10.1007/s13679-015-0180-9

39. International Fund for Agricultural Development. Economic activities of persons with disabilities in rural areas: New evidence and opportunities for IFAD engagement. (2019). Available at: https://webapps.ifad.org/members/eb/128/docs/EB-2019-128-R-7.pdf?attach=1 (Accessed February 10, 2022).


frontiers
Frontiers in
Rehabilitation Sciences