

Aging and Disability: An Exploration of Barriers and Facilitators to Community Living

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Demographic data projections for the United States indicate a significant increase in the population of older persons with disabilities. The Americans with Disabilities Act (ADA) mandates community access for individuals with disabilities, including older individuals who are aging with or aging into disabilities. However, there is limited research regarding the knowledge and the use of the ADA among this population specific to their perceptions and experiences regarding barriers and facilitators to community access and participation as mandated under the Act. The purpose of this qualitative focus group study was to explore the perceptions and experiences of a sample of older adults with disabilities regarding their community access, and their knowledge and utilization of the provisions of the ADA to facilitate community participation. Analysis of results identified three predominant themes within this sample of older adults: experiences with structural and attitudinal barriers to community access leading; fear of loss of autonomy and independence in the community, and how they deploy; coping and advocacy strategies to address barriers. Recommendations for improving ADA knowledge, access, and utilization among the population, as well as senior service providers, are also addressed.

Keywords: disability; aging; Americans with Disabilities Act; qualitative

The Americans with Disabilities Act of 1990 (ADA), and its amendments, were enacted to protect the rights of eligible individuals with disabilities to enjoy the full benefits of citizenship, including the access to and utilization of public and private accommodations and services, such as government, transportation, technology, retail, and hospitality (Bezyak et al., 2017). One U.S. population that has and can benefit from the ADA mandates is the rapidly growing older demographic, which includes both those with lifelong disabilities, and those who experience or acquire health conditions or impairments as a result of the aging process (Bachelder & Hilton, 1994). By 2034, adults over the age of 65 will comprise 21% of the population, up from 15% in 2018. This demographic shift is proposed to grow even larger in subsequent decades (Vespa et al., 2018), as a result of medical and technological advances, which

have significantly increased the lifespan (Cagney & Cornwell, 2018). For example, over the past 40 years, the life expectancies of men and women with disabilities have increased 4.7 and 3.9 years, respectively (Crimmins et al., 2016).

Age remains a risk factor for disability, while 11% of people ages 18–54 report having a disability, more than one in four people aged 65–79, or 26%, do so (Mehta et al., 2017). Given these data on existing and projected population statistics, it is safe to assume a significant expansion in the proportion of older Americans living with a disability into the twenty-first century. In order to realize

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the full benefits of citizenship—such as access to public accommodations, transportation, technology, commercial services, and employment, it is also safe to assume that many of these citizens will need the protections of the ADA.

Within its five titles, which refer to the broad subject or section headings under which a law is classified, the ADA prohibits discrimination on the basis of disability in employment, state and local government, public accommodations, commercial facilities, transportation, and telecommunications. Under the ADA, a person with a disability is defined as one who has a physical or mental impairment that substantially limits one or more life activities. For example, under Title II, state and local governments are required to follow specific architectural standards to ensure public access to all state and local services, such as education, courts, health care, social services, and town meetings. Under Title III, private and commercial facilities such as restaurants, stores, hotels, doctor's offices, and recreational facilities must provide equal access and opportunity to people with disabilities. The combined effect of the rights under Titles II and III is to improve meaningful community participation for people with disabilities.

Despite the ADA's mandates regarding removing barriers to education, housing, and public and private entities, studies show that people living with disabilities remain isolated in their communities (Emerson et al., 2021). Some of the most frequently identified barriers that restrict community participation include accessible transportation (Bezyak et al., 2017), accessible, affordable housing (Leslie, 2020; Serafini, 2018), and public attitudes (Dovidio et al., 2011). Lack of community participation has been associated with social isolation and loneliness (Emerson et al., 2021) and poor health and mental health among people living with disabilities (Andrews et al., 2015; Tough et al., 2017), as well as among the aging population (Wicki, 2021). These negative outcomes have been exacerbated by the recent global COVID-19 pandemic (Lebrasseur et al., 2021).

However, the extent to which older persons with disabilities, whether aging into or aging with a disability, know and invoke their rights regarding access to public and private goods and services in order to sustain or improve the quality

of their lives, remains a key question and an overlooked area of exploration. This gap in the research has been attributed to a number of systemic and research-related factors. Molton and Ordway (2019), for example, point to the explicit exclusion of individuals with early onset disabilities in medical studies evaluating therapeutic interventions for the aging population. Coyle and Mutchler (2017) point to the challenges associated with negotiating multiple systems and cultures of support for those aging with early onset conditions, where services accessed at earlier ages are no longer relevant to current desires and needs. Putnam et al. (2016) highlight the academic disciplinary differences in aging and rehabilitation research and discourse, where, for example, aging is viewed as a successful marker in disability studies, but disability is viewed as a deficit in studies on aging populations. All of these issues contribute to the relative lack of research on the intersection of age and disability in the literature.

However, it is important to note that intersectionality studies that address aging with a disability have been produced, and these can offer theoretical and practical guidance. Raymond and Grenier (2015) conducted a qualitative study exploring attitudes and barriers to social participation among older persons with early onset cognitive disabilities, finding significant disparities between an individual's desire for social participation, and the social and physical barriers that restricted their participation. Other studies have looked at the frequency of use of various community services among the population of age and disability, and report similar findings. For example, DiGennaro Reed et al. (2014) compared barriers to independent living between younger individuals with disabilities and those who are aging, finding that the latter group identified health-related conditions (i.e., mobility difficulties) more frequently. Raymond et al. (2014) conducted case studies of a sample of older adults with early onset disabilities to explore their community participation, finding that integration of disability into identity was among the key variables facilitating meaningful involvement. Pardasani and Berkman (2021) studied reasons for nonparticipation among a sample of members of New York Center Senior Centers and found infrequent utilization was due, in part,

to members perceiving frequent users as more “disabled” than themselves.

Some researchers have examined the intersection of age and disability by investigating factors that may facilitate or hinder social participation among this population. For example, Levasseur et al., 2011 conducted a quantitative study to understand the association between perceived proximity to neighborhood resources and community participation among older adults with disabilities. They found that greater perceived proximity to resources and lower level of functional impairments were significantly related to greater social participation. Similarly, in a qualitative study with older adults with osteoarthritis, Martin et al. (2012) found several factors such as having a social network of friends, medical providers, community transportation, religious organizations, as well as environmental characteristics (e.g., sidewalks, walking surfaces, access ramps, handicap parking) affected community participation. Similarly, a review paper on aging adults with a disability found that perceived social support was a facilitator, while an inaccessible environment was a barrier to social participation for this group (Molton & Ordway, 2019).

However, few studies have explored aging and disability as they relate to invoking rights under the ADA. Here, for example, Dong et al. (2020) surveyed older workers regarding their requests for job accommodations under the ADA, finding that those who reported more knowledge of the ADA were more likely to request accommodations, as were those who reported higher levels of workplace supports. Interestingly, employees over the age of 61 were less likely to request accommodations, compared to those a decade younger.

Across these theoretical and empirical studies, it is clear that the intersection of older age and disability can adversely impact social and community participation; a circumstance that may have been exacerbated during the COVID-19 pandemic, where evidence shows the disparate impact on persons living with disabilities across the age span (Sabatello et al., 2020; United Nations, 2020a, 2020b). But how older adults living with disability in the United States view their access to the community, and whether and how they advocate for their rights under the ADA, such as by conveying information regarding the law, by initiating lawsuits, or by contacting the U.S. Department of

Justice to file a complaint, remain unclear. The purpose of this qualitative focus group study was to explore the lived experiences of a purposeful sample of older persons living with disabilities regarding community access and participation, as well as their knowledge and use of the ADA to facilitate accommodations and mitigate barriers. Research questions guiding the study were:

1. How do older adults living with disabilities view their opportunities for community access and participation?
2. To what extent do older adults living with disabilities understand and invoke their rights under the ADA to facilitate their community participation?

METHODS

Recruitment and Participants

Subsequent to securing study approval from the University’s Institutional Review Board, the author(s) used a purposive sampling method to recruit eligible study participants, largely drawing from state and local independent living centers, senior centers, and, in some cases, personal connections with target population groups with the purpose of reaching and including participants in both urban and rural areas. Eligibility criteria for participation were: (a) age 50 or older, (b) have a disability, and (c) have access to a device/internet connection for the virtual focus group interviews. Given that we used a focus group approach (elaborated upon in the following), we made efforts to ensure full inclusion/participation notwithstanding disability (e.g., using a sign-language interpreter for participants who were deaf/had hearing issues).

The sample consisted of 42 participants. Demographic information on participant’s age range, gender, race, age at which the disability was acquired, education, employment status, living situation, geographic location, and type of disability were collected. Participants ranged in age from 50 to over 70, with 44% of them being between the ages 55 and 59. The majority of participants were female (73.8%), and White (82.9%).

Participants also ranged in their educational attainment: the majority had a bachelor degree

(26.2%), followed by a master degree (21.4%). About 17% of participants had a high school diploma. About 43% of the participants were married/in a domestic relationship. With regard to their employment status, 41% were employed for wages, and about 12% reported being retired. Most of the participants (73.8%) lived independently by themselves or with their spouses at home, and the majority described their geographic location as suburban (50%). With regard to their disability status, a majority reported having a physical disability (45.2%), followed by a sensory disability (40.5%). An overwhelming majority of the participants (90.48%) had acquired the disability before the age of 35. See Table 1 for more information on demographic breakdown.

Procedures

Focus Group Description

Given the exploratory nature of the current study, we used a qualitative focus group approach. In addition, a focus group approach allows the participants to openly engage in conversations about their own experiences and has been found to be effective in research with older adults living with disabilities (e.g., Martin et al., 2012). Thus, this approach was adopted in order to encourage communication and participation among the older participants in the study and to maximize the opportunity to understand similarities and differences across the sample. Focus groups were also chosen as a “friendly research method” that is accessible to marginalized groups (Martin et al., 2012).

Focus Group Questions

A semi-structured focus group interview guide was developed by research team members working collaboratively with expert staff from the Mid-Atlantic ADA Center, one of 10 regional Technical Assistance Centers funded by the U.S. Department of Health and Human Services (<https://adata.org>). The draft protocol was reviewed by selected members of the ADA Center’s advisory board, who made recommendations regarding clarity and comprehension. The final structured interview protocol consisted of seven questions, which addressed three broad areas: (a) access to public and commercial/private goods and services as required under Titles II and III of the ADA;

(b) knowledge and utilization of the ADA; and (c) knowledge and utilization of services and resources targeted at aging populations. As the study was conducted during the pandemic, we added a fourth area to explore—the participants’ experiences with COVID-19. Appendix A contains the Focus Group Protocol.

A total of six focus groups were conducted between November 2019 and November 2020. Two of the groups were conducted in person, and four were conducted virtually, in accordance with the University’s Institutional Review Board regulations related to the COVID-19 pandemic restrictions. The two in-person focus groups were conducted in Maryland and Virginia, respectively; the four virtual groups were conducted with residents of West Virginia (2) and Pennsylvania (2). The focus groups followed a structured protocol, included two facilitators from the research team, and lasted between 75–90 minutes. The format for the focus groups that took place in person and virtually was identical, in that the same questions were asked and the sessions were recorded. Only minor differences were noted: the in-person focus groups were recorded using an audio recording device, while those conducted virtually were recorded using the Zoom recording function. Also, for the in-person focus groups, informed consents were obtained in person and physically signed. Virtual focus group participants were either mailed the hard-copy consent forms which they could sign and return via mail or email, or they could provide electronic consent via a secure link. Similarly, demographic information from participants in the in-person groups was obtained via hard-copy sheets, while those who participated virtually were provided with a secure Qualtrics link to enter their demographic data.

Since we were able to obtain a diverse sample in terms of participants’ demographic and individual characteristics (e.g., disability type and education) as well as diversity in terms of geographic location (recruiting individuals from rural, as well as suburban areas), data saturation was achieved after the sixth focus group when researchers noted that little new information was obtained, and therefore decided to terminate recruitment and data collection. All participants were compensated with a \$25.00 gift card at the conclusion. The number of participants in focus

TABLE 1. Summary of Participant Demographic Information

Demographic information	Number of participants	Percentage of participants	Demographic information	Number of participants	Percentage of participants
Gender			Employment status (<i>continued</i>)		
Male	11	26.2	Out of work but not looking for work	1	2.4
Female	31	73.8	Homemaker	3	7.1
Race			Retired	5	11.9
White	34	82.9	Unable to work	5	11.9
African American/Black	3	7.3	Marital status		
Hispanic	2	4.9	Single, never married	12	28.6
Asian	1	2.4	Married/domestic relationship	18	42.9
Other	1	2.4	Widowed	2	4.8
Age range			Divorced	9	21.4
50–54 years	7	16.7	Separated	1	2.4
55–59 years	18	42.9	Type of disability		
60–64 years	6	14.3	Intellectual disability/developmental disability	1	2.4
65–69 years	7	16.7	Physical disability	19	45.2
70 + years	4	9.5	Sensory disability	17	40.5
Education level			Mental health disability	1	2.4
Some high school, no diploma	1	2.4	Learning disability	2	4.8
High school graduate, diploma, or equivalent	7	16.7	Other	2	4.8
Some college credit, no degree	9	21.4	Living situation		
Trade/technical/vocational training	1	2.4	Living independently	31	73.8
Associate degree	1	2.4	Having roommates	2	4.8
Bachelor degree	11	26.2	Living with parents	6	14.3
Master degree	9	21.4	Group home/residential program	1	2.4
Professional degree	2	4.8	Other	2	4.8
Doctorate degree	1	2.4	Living area		
Employment status			Rural	2	4.8
Employed for wages	17	40.5	Small town	7	16.7
Self-employed	4	9.5	Suburban	21	50
Out of work and looking for work	7	16.7	Urban	12	28.6

groups ranged from 2 to 10. All six focus group sessions were audio-taped to make sure that no

information was missed, and audio tapes were transcribed by a professional service.

Data Analysis

The focus group data were analyzed using thematic analysis methods as highlighted by Braun and Clarke (2006). According to this approach, an iterative process was conducted. First, two research team members independently reviewed the verbatim transcripts to familiarize themselves with the content. Next, they independently coded each transcript, during which they identified broad themes and subcategories. They met weekly to discuss the themes and subcategories and identified similarities and differences in their coding. Discrepancies were handled via discussion and consensus was achieved. Next, a third research team member reviewed all the transcripts and generated themes in the initial analyses, noting any discrepancies between the two original raters. A document comprising of all verbatim quotes corresponding to each theme and subcategory was generated by each rater. A final meeting was held with all three raters during which coding differences in thematic categories were discussed until an agreement was reached with regard to discrepancies. Using this framework, the researchers captured several main categories: barriers related to structure/environment, barriers related to attitudes of others toward people living with disabilities, fear of losing autonomy and independence, and those related to coping and advocacy. Similarly, subthemes that fell under each of these categories were identified (e.g., public transportation issues falling under the broad theme of structural barriers). These themes and subthemes were retained for the final analysis as described in the study results. To protect the confidentiality and anonymity of participants, all identifying information from the transcripts were removed, and pseudonyms were used to refer to participants when needed.

RESULTS

The majority of the participants in this study had experienced disabilities early in life and were “aging with a disability,” rather than aging into one. While the lived experience of disability, therefore, was more familiar to this sample of focus group participants, it was clear that the aging process affected this experience in primarily

negative, but in some positive ways, as these findings demonstrate. Overall, we identified three interrelated themes in our analyses of barriers and facilitators to community participation at the intersection of aging and disability: (a) perceived structural and attitudinal barriers to community access leading to (b) fear of loss of autonomy and independence in the community; and (c) coping and advocacy strategies deployed to address barriers (see Table 2). Each of these themes is elaborated in this section.

Theme I: Perceived Structural and Attitudinal Barriers to Community Participation

All of the participants noted that access to public and private goods and services was key to their overall successful functioning in society. Most participants described the numerous barriers that prevented full community inclusion. The barriers ranged widely: poor and expensive transport facilities, poor parking services, lack of disability-friendly physical access in buildings/lack of elevators, lack of disability-friendly amenities, and narrow grocery store aisles. In addition, participants mentioned how the lack of ADA-compliant facilities/physical access in several places such as restaurants, parks, hotels, check-out counters, and ATM machines had severely impacted community participation. It is important to note that these barriers are likely experienced by individuals with disabilities across the lifespan but were certainly exacerbated by aging.

Subtheme 1: Structural Barriers

We defined structural barriers as physical barriers that several participants noted in accessing places, goods and services in stores, restaurants and bars, as well as health care and public information.

Accessing Public Transportation. Ann, whose arthritis was gradually decreasing her mobility described her experiences with accessing public transportation this way: “Now that I’m older, and can’t climb stairs, every time I get on the subway I need to think about which station I can exit that doesn’t involve too much climbing.”

TABLE 2. Summary of Themes

Theme	Subthemes
Barriers to community participation/inclusion	<p>Structural barriers</p> <ul style="list-style-type: none"> • Accessing public transportation • Accessing health care and related services (e.g., medical equipment not suitable) • Accessing parking (e.g., limited handicap parking spots) • Accessing public information (e.g., poorly made websites) <p>Attitudinal barriers</p> <ul style="list-style-type: none"> • People's negative attitudes toward seniors with disabilities • Lack of trained people <p>COVID-19 exacerbated social and community barriers to community inclusion</p> <ul style="list-style-type: none"> • Social isolation • Lack of access to goods and services
Fear of losing autonomy	<p>Intersectionality of older age and disability threatens autonomy</p> <ul style="list-style-type: none"> • Feeling fear of losing independence due to being disabled and aging • Feeling fear of lacking money to pay for services or accommodation due to retirement <p>Dependency</p> <ul style="list-style-type: none"> • Depending on families or other people to preserve autonomy <p>Under intersectionality: lack of integration of aging and disabilities services and resources</p> <ul style="list-style-type: none"> • Having difficulties getting services in a senior center • "Aging community seems clueless about disability issues"
Coping and advocacy strategies	<p>Coping with inaccessible formats</p> <ul style="list-style-type: none"> • Asking for services or accommodation • Not afraid of asking for help <p>Advocating for compliance with ADA</p> <ul style="list-style-type: none"> • Taking initiative and involving effort • Relying on local disability rights groups <p>Dealing with ongoing ignorance</p> <ul style="list-style-type: none"> • Removing barriers by being "the ADA enforcers"

Note. ADA= Americans with Disabilities Act.

Another participant with arthritis shared similar issues:

If you have to wait 10 or 20 minutes on a public transportation to pick you up and mostly if it is raining or snowing and it is really hard for me because I have bad knees, bad back and everything. Old age creeping up on me. I'm 55 and it is rough when you're trying to catch a bus and you have to stand out in the cold and with arthritis and stuff, it's hard to do.

Accessing Health Care and Related Services.

Participants noted structural barriers still existed in the hospitality industry, where one participant who was a wheelchair user noted, "They still have counters up to here, and if they have a lower counter, it's at the very end, and then they have flowers or brochures on it," which exacerbates access and useability. Mark described issues he faced while accessing health care and health-related services:

I had the occasion to go to the hospital and have an MRI, and experience some of the problems accessing medical services for people with disabilities including people with sensory disabilities. For example, when you go into an MRI machine, you have to take out everything... I don't know what deaf people do. And of course, the equipment is often virtually inaccessible to people with mobility impairments.

Another participant pointed to the long-standing struggles he experienced regarding accessing services and resources that would enable him to remain in his home as he aged, "Everyone here is aging because we are still alive...we will wind up in an institution because every time we claw back some benefits to remain in our communities, it's gone with the next election." It is evident that experiencing these long-standing barriers generated a great deal of frustration among the participants.

Accessing Parking. Participants also described their struggles with parking, which ranged from limited parking, parking spots not being close to stores, parking spots/parking garages not being code compliant, to people abusing the

disability-friendly parking spot, and police officers not enforcing laws. This participant's response summarizes some of these struggles very well:

A lot of times when I go out, there is very little accessible parking. And I will see somebody in the car [parking in a disability-friendly lane]. And I know because I'm from a very small community, I know that that's the person without a disability. And I just want to go up and say to them that the spot is reserved for you to get out. It is illegal for the other person to get out and take advantage of the situation. Just—people don't get it. I need the extra space to get my wheelchair out.

Accessing Public Information. Title II of the ADA also mandates the provision of effective communication, requiring that all covered entities provide aids and services when needed to communicate effectively with people who have communication disabilities. Several participants mentioned how accessing public information was often a problem. Some of them had trouble finding the right person to ask for help as mentioned by a participant, "It is difficult for us to find [on public websites] even an individual who would be helpful to give us that information about what's available to the public." In response to that, another person said:

Well, I agree with you because I've tried to, you know, find the ADA coordinator for different [places] online, especially West Virginia—if you google Charleston West Virginia ADA coordinator, you won't find anything. I still don't know who the ADA coordinator is for Charleston. I can call and ask, sure. But that's something you should be able to Google and find. It should be, you know, up front and center.

Along similar lines, several participants mentioned that the websites were very poorly designed, which made it hard for them to find information, as stated by this participant who was blind, "Both Philadelphia and Pennsylvania's websites, for starters, they are behind, okay, and, yeah, their navigation, that's the problem. Their navigation is always skewed. So many times, they

have their links either broken or labeled wrong. It's always been that way."

Subtheme 2: Attitudinal Barriers

Attitudinal barriers were defined as laypeople's negative attitude or stigma held toward seniors living with disabilities. Several participants described how they encountered attitudinal barriers that impacted their access to goods and services, and their community participation. For example, characterizing the difficulties in finding housing, participant Ruth spoke about her experiences with local housing authorities, stating:

I try to talk to them about the needs of housing for seniors who are deaf...and they just ignore us. I'm scared to death that the moment I get too blind and too deaf to live in my own house, I will end up in a nursing home.

Another participant identified the barrier in public services regarding attitudes toward aging persons living with disabilities this way, "Every time I try to get vocational rehabilitation services, they're much less likely to want to take your case. They told me, you really shouldn't be thinking about trying to get to work now." Another participant while describing her experience at a public service office said, "Every time I go through there [a public service office], they are so inconsiderate and rude. They automatically label everybody as a problem that comes through their doors." Participant Nelly described the staff at her local municipal office on aging: "They get social workers there that don't know about disability! They may have gotten out of college and trained, but they still don't know." Another participant summed up the attitudinal barriers to community inclusion encountered by aging persons living with disabilities in service settings this way, "Once you have a disability and once you're older they all stereotype you big time."

COVID-19 Pandemic. As four of the six focus groups were conducted virtually during the COVID-19 pandemic, it is important to note how that global experience exacerbated the social and community barriers encountered by all individuals with disabilities, but perhaps particularly those aging with disabilities, who felt

uniquely vulnerable to the public health crisis both in terms of their own safety, as well as the exacerbation of barriers to inclusion. For example, Ruth noted:

The second biggest problem [of COVID] is socialization, the lack of it. I live in [exact location], Philadelphia, but I used to live in the suburbs where I still have many, many friends, and I am just not game for getting on the train to go out there and they don't want to come into [name of location] even though they can drive. Socially, it's been difficult.

Others expressed frustration at the additional burdens imposed by the pandemic on accessing goods and services:

I am from a small town, and we only really have one major store—Walmart. Of course, we have a couple of other grocery stores but there has been a shortage of main things—still, even now, there is shortage of toilet paper.

Another participant described how he had to wait in line for a long time to get his state ID renewed because of the shortage of staff during the pandemic, and how the wait was frustrating for him given his age and disability issues.

A final note on barriers to community access for the aging population is reflected in this participants' frustration:

You know, it's been 30 years or more [since the ADA], and people are still, "oh well, I didn't realize that applied to me" or "I didn't know we were supposed to do that." You see these problems, but there's really no police that go around and tell these companies you're not meeting the requirements!

Theme 2: Fear of Losing Autonomy and Independence

These participants, at the intersection of aging and disability, expressed their fears regarding the

loss of autonomy that arose from the physical and symbolic barriers cited earlier and were a major factor in shaping their current experiences, and their fears regarding the future.

For example, one focus group participant who was approaching retirement age expressed her fear of losing the financial independence she currently enjoys to pay for those additional disability services or accommodations that enhance her lifestyle. She explained:

I'm getting older...I'm still working and I love my job. But the reason I preface everything by saying that I'm running scared is because I'm scared of retiring because if I do, I won't be able to pay for the services that are so important to maintain myself in the community.

Another participant who had been deaf since birth said that:

Now I have access. I have an accessible internet. Everything is accessible. But it is my fear that as I get older, going to nursing homes, no captions, no interpreter, no one can sign. I will be back to isolation. I will die lonely.

In response to this statement, another participant said:

You see, that's what's on everyone's mind. Everybody here is aging. We're all aging because we're all still alive! We will wind up in an institution because the nursing home lobby, as you know, is so strong, and we claw back some benefit for community-based home services, and it's gone with the next election. It's a battle that goes to the soul, the core of who we are as human beings, able to stay in our communities and age in our communities...we know it's cheaper and healthier to age in your community. So you see, it's universal: the basic fear of aging with a disability and holding onto our independence.

John, who was born with cerebral palsy (CP) viewed losing independence this way:

I was born with CP, and you know up until 50, the only problem I had was I couldn't walk, you know I can do anything else but walk independently, but now I'm 63, and the loss of function and loss of independence is present...I wouldn't say I need total care, but you know, it's gonna be a whole new set of problems.

Several participants talked about how they have been dependent on family members or other people to preserve autonomy. For example, many of them depended on their family for transportation. One participant shared:

I don't drive. So I use the public transportation or my sister or my mom or my brother takes me wherever I need to go. And it is rough when you are on [your own], if you have to wait 10 or 20 minutes on a public transportation to pick you up and mostly if it is raining or snowing and it is really hard for me because I have bad knees, bad back and everything.

Increasing dependence on family members also raised attitudinal issues for participants, as Eleanor described, "I know a lot about disability...but age has a lot to do with how people treat us...even our children feel that maybe we've kind of lost our abilities, we lost our brightness, that we're just kind of lost."

The intersection of age and disability also presented barriers in terms of having access to those services, such as housing or senior centers, that might enhance or prolong independence and autonomy. For example, Rose, who was blind since birth put it this way:

In the aging community, there is resistance to even wanting to recognize the disability community...every time I go to my local senior center [to access activities] I ask about compliance with accessibility standards of the ADA, and they argue that 'we've created senior facilities that are universal design!' But they don't necessarily comply with accessibility standards—it just drives me insane.

Another individual who was deaf since birth agreed that “the aging community seems clueless about disability issues,” an attitude that impeded her opportunity to access services that foster independence. One participant summed it up this way, “that’s a whole different group...those that acquire their disabilities after age 50.”

Accessible, affordable housing for all persons living with disabilities was a key element in sustaining autonomy and independence in the community, and many of the focus group participants identified this inadequacy in their local communities. For example, George, a wheelchair user, explained that access to a senior housing community could sustain his community independence, but noted:

You would think they (senior housing organizations) would understand people with disabilities when it comes to housing, if you are of a certain age. But I find...like so many things, you are either a senior *or* a person with disabilities, even if you are a senior *and* a person with a disability.

This sentiment was captured by Ella, who described the “siloeed” nature of aging and disability services in her community, and the difficulty of navigating complex systems to optimize her opportunities for independent living.

Theme 3: Coping and Advocacy Strategies Deployed to Address Barriers

Despite the protections of the ADA for eliminating barriers to accessing public and private goods and services, it was clear that the participants in this study encountered numerous barriers that restricted or limited their access, with a significantly negative impact on their community participation. However, these participants, who were primarily aging with rather than aging into disability, described how their prolonged struggles with access and opportunity had enabled them to develop coping and self-advocacy strategies to address them. Many of these participants described how their familiarity with the ADA facilitated their efforts. For example, Elaine, who was blind since birth described

how she assertively managed a barrier frequently encountered by individuals with visual impairments in restaurants this way:

Of course, if there is no accessible format for a restaurant menu, the ADA says they [restaurant wait staff] can read it [the menu] to me... and what happens 30 years after the ADA, they hand you a menu and *you* have to say, can you read it to me? And they try to say, “Well, what is it you think you’d like to have?”... But I’m real particular, and I make them read the whole thing!

Another participant, Rosemary also blind, gave another example of coping with inaccessible formats:

As a blind person, I find going through the State of Pennsylvania’s website is just awful...But I just call my state representative and tell them I need to know what’s there right now. Like I said before, I’m not afraid to ask, and I tell people with disabilities all the time...if you don’t ask for what you need, you won’t get.

One focus group participant who was deaf since birth offered her example of advocating for interpreter services when enrolling in a knitting program sponsored by her county this way:

When I asked for an interpreter, the event organizer told me that I could get an interpreter for only one hour; not the full four hour event. I told them about the law [ADA], and I had to work so hard to acquire an interpreter for this event, for two or three weeks in advance. I told them: that’s not full accessibility. That’s just one example. You shouldn’t have to work that hard to get an interpreter...these are typical life situations that we’re talking about.

Another participant described an airline experience in which she and her husband used humor to cope:

We were traveling to Colorado. When we got on the plane, we usually tell the flight attendant that we are Deaf, and ask that if

there is an important PA announcement, to please come and let us know. Other than that, we'll be fine. The flight attendant says great. She asked us where we sit. OK, a minute later the same flight attendant comes over to our seats and hands us an instruction card to use in case of emergency—in Braille! Attitude or ignorance, I don't know, but we tried to tell her the difference!

Several participants' coping efforts involved more intense efforts to advocate for compliance with the ADA that would allow them, and others, access to public and private goods and services, as required under the ADA.

For example, Evelyn, a wheelchair user, described her long struggle to force a large urban Metro transportation service to meet accessibility standards that would enable her, and others, to more easily use the metro parking garage. She said, "It took me two years to bring them [the metro board] into compliance with interior power doors because they were way more than five pounds of pull pressure, but I finally got them to do it." Vivian, who was blind, described a year-long effort to get her local election polling place to accommodate voters who were visually impaired and used audible ballot tablets to provide some type of stand so they didn't have to "balance the ballot in their hands while listening to the electoral options and voting their choice." She went on to proudly describe how during the 2020 election, when she entered her polling place, election officials greeted her, "We're so glad you're here...look what we designed for holding the audible ballot tablets," noting that a small lectern was such a simple accommodation for achieving full accessibility. Another participant described her experience in advocating for compliance under the law:

I constantly find that our county is NOT 508 compliant—I can't access internet information with a screen reader. Is that due to ignorance or attitude—it's due to attitude...I worked with the [local] lawyers committee, and told them, we're either going to do it the easy way or the hard way, but it's going to get done. It's been 30 years, to not be 508 compliant is absurd. They will come into compliance!

Other participants indicated that they relied on their affiliations with local disability rights groups, such as Disability Pride, or Centers for Independent Living (CIL) to collectively advocate for broader social change around accessibility and access. For example, Richard, long involved with his local CIL, described their struggle for accessible housing in his community this way:

We told him [the apartment developer] he had to make units accessible...heck, we told him, if we have to, we will take you to court or we will take you to the cleaners. Then they made the modification without even taking him to court...so eventually it all worked out.

Other comments across focus groups resonated with a social justice theme around advocating for change. One focus group participant, summarizing a group discussion around a discussion of barrier removal put it this way:

So we have a serious problem with code enforcement. Do you think that's due to lack of knowledge about the ADA [Americans with Disabilities Act] requirements or just a refusal to enforce—their attitudes. And you know, for these things, either we're gonna do it the easy way or the hard way, but it's gonna get done. It's been 30 years.

Group members' agreement with that statement is reflected in Tom's assertion, "Ignorance is still very widespread when it comes to the ADA. That's because we are the enforcers. There is no ADA police. There is no ADA sheriff's department. It's up to us to see that it's enforced."

These participants at the intersection of age and disability offered a unique perspective on the ongoing struggles for access and equity, both for the individual and the larger disability community. While participants asserted a commitment to continue to engage in advocacy efforts to remove barriers by being "the ADA enforcers," their frustration around entrenched barriers 30 or more years after the enactment of the ADA was evident, a circumstance they attributed to a combination of public ignorance and attitude. Perhaps Richard, a wheelchair user who had multiple disabilities since

birth, articulated the general frustration, but also suggested his motivation to advocate for change:

During the COVID-19 pandemic, everyone got a small taste of what people with disabilities are going through every day in their entire lives. They all had a little short window where they couldn't go out, go shopping, participate in stuff, and they say, "I just can't take it...I can't take it." From where I sit, I often think about that type of thing.

DISCUSSION

This qualitative focus group study explored the experiences and perceptions of older adults at the intersection of age and disability regarding community access, and knowledge and utilization of the ADA to invoke their rights. Perhaps the least surprising finding of this study was that despite the enactment of the ADA, older adults living with disabilities encounter significant barriers to effective participation in the community. The majority of the study participants were aging with a disability, that is, their disabilities were acquired prior to young adulthood, thus their experiences with structural, attitudinal, and communication barriers were not novel, and their knowledge of the ADA and its provisions possibly helped in their efforts to mitigate them, such as requesting accommodations, or asking for assistance to fully utilize public or commercial facilities and services. In this way, their views were aligned with a disability rights framework, in that the solution to improving community participation lies in addressing social and environmental barriers, rather than mitigating or improving individual capacities.

Perhaps another issue that inhibits the exploration of age and disability intersectionality and its impact on addressing barriers to community participation is the disparate academic disciplines that ground the fields of gerontology and rehabilitation. Some researchers have indicated that among those who study aging, disability is characterized as a loss and something to be avoided (Gibbons, 2016; Rubinstein & de Medeiros, 2015), while for rehabilitation

professionals, aging is perceived as an accomplishment to be appreciated. In this study, for example, the majority of participants appeared to view their disabilities as part of their identities, which probably contributed to their capacity to cope and self-advocate. Several were present at the original signing of the ADA, and many were active members of disability advocacy organizations, such as CIL or Deaf Pride. Still, and unfortunately, the examples and stories they recounted regarding the number of barriers they continued to encounter in accessing public and private services, and their mounting frustration, indicates, as several members suggested, that 30 plus years since the enactment of the ADA, and there is still a long way to go.

Even with their prolonged experience with disability, and their capacity to manage physical and symbolic barriers to participation, it is important to note the fears these participants expressed regarding the loss of autonomy or increasing dependence. Several of the studies of aging and disability cited earlier in this article found similar results. For example, a qualitative study of older individuals aging with cognitive impairments found that participants felt that organizational and social barriers to participation threatened their right to informed choice and autonomy (Raymond et al., 2014). In another qualitative study of factors associated with successful aging among people living with disabilities, Molton and Yorkston (2017) identified autonomy as a predominant factor, in the sense of having the ability to direct and participate in all of the areas that affect one's life. In our study, participants voiced concerns regarding how inadequate accessible housing options denied them their choice to remain in their homes and exacerbated their fears of ending up in institutional care, such as nursing homes.

Finally, the siloed nature of disability and aging services was evident in this study. The majority of these participants were aware of the ADA, their rights under the Act, and the availability of disability resources, such as independent living centers. On the other hand, their knowledge and use of senior services, whether for social activities or transportation was surprisingly limited. Molton and Ordway (2019) attribute siloed services, in part, to the separate research and service networks aligned with

aging and disability, stating that “lines defining research in aging and disability have historically been drawn based on when in life disability first emerges” (p. 4). Coyle and Mutchler (2017) called the phenomena as “living at the seam” of the aging and disability communities, pointing to the difference between those who aged with and those who aged into a disability and the challenges of negotiating multiple systems of support.

Limitations and Future Directions

While our study revealed several interesting findings, it had some limitations. We used a convenience sampling method, and our participants were recruited from four states on the East Coast. Also, a vast majority of our participants were White and female. Thus, it is likely that the findings of our study may not generalize to other populations. Future research should attempt to obtain a more diverse and representative sample with regard to geographic location and gender, as well as race. Secondly, one of our focus groups was conducted with participants who were deaf/had hearing loss. For that group, we used a sign-language interpreter. While the interpreter did their best to capture the participants’ views, it is likely that M. W. (2018). For people with some content may have been lost in the process. Thirdly, a majority of the participants in our study had acquired their disability before the age of 35, thus, they had aged with a disability. While not the focus of the current study, research suggests that experiences of seniors living with disabilities who age with it versus those who age into it may differ (Molton & Yorkston, 2017). Thus, future research may aim to add to the literature by attempting to recruit a fairly equal number of seniors who acquired their disability at different stages in life, and then compare how that affected their experiences. Fourth, this study was conducted during the global COVID-19 pandemic, forcing us to conduct four of the six focus groups virtually. Although the impact of the pandemic was not a focus of this study, it is reasonable to conclude that participants’ experiences during this period exerted an influence on their views

and feelings. Finally, the study included individuals with both static (i.e., deafness) and degenerative conditions (i.e., arthritis), which may have contributed to peoples’ perspectives.

Implications

The findings of the current study highlight how older individuals living with disabilities may feel more vulnerable regarding the barriers they encounter to community participation, compared to younger age groups, as the fear of social isolation and the loss of autonomy increase with age. First, despite legislation mandating community access and opportunity, older persons living with disabilities may have a difficult time meeting their basic needs (e.g., transportation, health care, and public services) to live independently in the community. While it is true that there are no “ADA enforcers,” informing individuals of their rights under the law and encouraging individual and collective action to assert them need to be encouraged by advocacy organizations, policymakers, families, and individuals.

Additionally, the results indicate that personnel who assist people living with disabilities need additional training to address the needs of older people (e.g., health concerns, inaccessible housing, senior centers, technology). The resolution of barriers is a challenging task; it cannot be accomplished through one action, but rather by continuing to educate and advocate for change. Multidimensional strategies are needed, such as creating training interventions for people who work with older people living with disabilities. This includes changing negative attitudes toward older people living with disabilities and training about how to provide information, communication, and social interaction skills (Chan et al., 2009).

Moreover, successful aging for adults living with disabilities exists in a unique context. Older adults with long-term disabilities may be excluded from the successful aging paradigm, which looks at disability as failure (Ansello, 2004). However, our study showed that older people living with disabilities offer valuable and unique perspectives on knowing and accessing disability rights, and their viewpoints should not be ignored. Therefore, future studies should focus on their lived experiences not only as people living with disabilities but also as older

adults. For example, there is a need to incorporate the intersection of age and disability in the successful aging paradigm (Gibbons, 2016).

CONCLUSION

The United States is poised to witness a significant demographic shift both regarding the proportion of the population that is aging, and the proportion of that group that is aging with, and into, disability. Although the ADA and its amendments were enacted to ensure access to the community in all of its aspects, studies continue to highlight the physical and symbolic barriers that mitigate or restrict access. This qualitative study, exploring how a sample of aging individuals living with disabilities managed their rights under Titles II and III of the ADA, offers a unique perspective on the challenges they still encounter, and the strategies that have been used to adapt or cope with them. It is clear that the needs of this growing population cannot be ignored, and the demand to design strategies that will improve their lives in the community is an imperative.

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