

# “I will die lonely”

## Aging, Disability and the ADA

### Abstract

**Aim:** Despite the enactment of laws such as the Americans with Disabilities Act (ADA), people with disabilities encounter barriers to full participation in their communities. This qualitative study explored the experiences and perceptions of older persons with disabilities regarding their access to community resources and services, the barriers encountered, and their knowledge and utilization of the ADA to address barriers.

**Methods:** Six focus groups were conducted across three states in the Mid-Atlantic region, including a total of 42 participants, with the majority being female and white.

**Results:** Older persons with disabilities encountered significant attitudinal and structural barriers to community participation, exacerbated by the COVID-19 pandemic. While knowledge of the ADA mitigated some of these barriers, their anxieties regarding their future dependency on senior services were heightened by their lack of knowledge regarding availability, and perceived fears regarding their accessibility.

**Conclusions:** The American ideal of successful aging does not adequately account for the lives and experiences of older persons who are aging with or aging into a disability. In order to improve community participation for this population, more collaboration and communication between aging and disability services and resources are required through research and training.

### Implications for Rehabilitation

- Older persons with disabilities encounter multiple barriers to community participation.
- Limited accessibility to public and private goods and services restrict community participation for older persons with disabilities, including structural access, communication, and negative attitudes.
- COVID-19 further exacerbated social isolation and anxiety.
- Efforts should be made to provide better access and services to seniors with disabilities, and provide more integrated aging and disability services.

Key words: seniors, disabilities, focus group, qualitative, community participation, barriers, ADA

## **“I will die lonely” Aging, Disability and the ADA**

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 access to and utilization of public and private accommodations and services,<sup>1</sup> such as services provided by state and local governments, and the goods and services derived from private non-profit and commercial entities, including transportation.<sup>2</sup> One U.S. population that has and can benefit from the ADA mandates are the rapidly growing older population, which includes both those with lifelong disabilities, and those who experience or acquire health conditions or impairments as a result of the aging process.<sup>3</sup> By 2034, adults over the age of 65 will comprise 21% of the population, up from 15% in 2018, and the huge demographic shift is proposed to grow even larger in subsequent decades.<sup>4</sup> Medical and social advances have extended the lives of persons with impairments acquired early in life, such as spinal cord injuries<sup>5</sup> or multiple sclerosis,<sup>6</sup> as well as increased life expectancies over time. These trends are also dramatically increasing the lifespans of individuals with life-long disabilities; for example, over the past 40 years, the life expectancies of men and women with disabilities has increased 4.7 and 3.9 years respectively.<sup>7</sup>

Age is a risk factor for disability; about 11% of people ages 18–54 and 26% of people ages 65–79 reported having a disability.<sup>8</sup> The U.S. can anticipate an increase in the number of individuals who acquire impairments as a result of the aging process, as well as those who are aging with disabilities acquired earlier in life. 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 disabilities into the 21<sup>st</sup> century. In order to realize the full benefits of citizenship – such as access to public accommodations, transportation, and services, it is also safe to assume that many of these citizens will need the protections of the Americans with Disabilities Act.

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 broadly defined as one who has a physical or mental impairment that substantially limits one, or more than one, major life activity. For example, under Title II, state and local governments are required to follow specific architectural standards and take other measures to ensure public access to all state and local programs, 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 of people with disabilities.

Despite the ADA’s requirements regarding removing barriers to education, housing, and public and private entities, studies show that people with disabilities remain isolated in their communities.<sup>9</sup> Some of the most frequently identified barriers that restrict community participation include inaccessible transportation,<sup>2</sup> inadequate housing,<sup>10, 11</sup> and negative public

attitudes.<sup>12</sup> Lack of community participation has been associated with social isolation and loneliness<sup>9</sup> and poor health and mental health among people with disabilities,<sup>13, 14</sup> as well as among the aging population,<sup>15</sup> particularly exacerbated by the COVID-19 pandemic.<sup>16</sup>

However, the extent to which older persons with disabilities, whether aging into or aging with a disability, know and invoke their rights under the ADA in order to sustain or improve the quality of their lives remains a key question. As “successful aging” in America is synonymous with health and vitality,<sup>17</sup> aging with impairments tends to be viewed as a failure to achieve the healthy, active aging ideal, and the subsequent negative stereotypes can play out in terms of exclusion from community participation or activities that can be both real and perceived.<sup>18</sup> Raymond and Grenier<sup>19</sup> conducted a qualitative study exploring social participation barriers and attitudes of older persons with disabilities residing in Quebec, finding a disparity between individuals’ desires for social participation, and social and physical barriers that restricted them. A related study also conducted in Quebec<sup>20</sup> explored the association between perceived proximity to neighborhood resources and its effect on social participation among older adults with disabilities, finding that stronger perceptions of proximity to neighborhood resources heightened social participation for women but not men. Using a cross-sectional research design, Siette et al.<sup>21</sup> profiled social participation of a large sample of older Australians with disabilities, concluding that urban residents were significantly less likely to engage than were those residing in more rural areas.

Whatever the setting, 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 with disabilities across the age span.<sup>22, 23, 24</sup> But it is unclear how and to what extent older persons with disabilities perceive community participation barriers, and whether knowledge of their rights under the ADA, and their access to other resources and supports, can mitigate these barriers. The purpose of this qualitative focus group study was to explore the lived experiences of a purposeful sample of older persons with disabilities regarding community access and participation, as well as their knowledge and use of the ADA. Research questions guiding the study were:

- 1) What are the experiences and perceptions of older persons with disabilities regarding their access to and use of public and private goods and services under Titles II and III of the ADA?
- 2) What resources, such as the ADA or senior services, were utilized and were they effective in improving community participation and access?

## **Methods**

### **Procedures**

This study used a qualitative focus group approach to address the research questions. A focus group 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.<sup>25</sup>

Subsequent to securing study approval from the University’s IRB, 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. Where possible, recruitment was undertaken with the assistance of several key organizations in the region, such as the Roads to Freedom Center for Independent Living, or local senior centers.

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 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 about 60-90 minutes. All participants completed a brief demographic survey prior to the focus group, and were compensated with a \$25.00 gift card at the conclusion. Eligibility criteria for participation were: 1) age 50 or older; 2) have a disability; and 3) have access to a device/internet connection for the virtual focus group interviews. The number of participants in focus groups ranged from 2-10.

A semi-structured focus group interview guide was developed by research team members working collaboratively with expert staff from the ADA Center. 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: 1) Access to public and commercial/private goods and services as required under Titles II and III of the ADA; 2) knowledge and utilization of the ADA; and 3) 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.

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.

## Sample

The sample consisted of 42 participants. Demographic information was collected on participant’s age range, gender, race, age at which disability was acquired, education, employment status, living situation, geographic location, and type of disability. Participants ranged in age from 50 to over 70, with 44% of the participants 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: 26.2% had a bachelor’s degree, and 21.4% had a master’s degree. 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% were retired. Most of the participants (73.8%) lived independently by themselves or with their spouses at home, and half described their geographic location as suburban (50%). With regard to their disability status, 45.2% reported having a physical disability, and 40.5% a sensory disability. An overwhelming majority of the participants (90.48%) had acquired their disabilities before the age of 35. See the [Appendix](#) for more information on demographic breakdown.

## Data Analysis

Data analysis was conducted using procedures outlined in a modified grounded theory approach.<sup>26</sup> Our data analytic approach was also very similar to the content analysis approach,<sup>27</sup> which is a popular and widely utilized approach for analyzing focus group data in the field of disabilities research.<sup>28, 29</sup> 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 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 on thematic categories were discussed until agreement was reached with regard to discrepancies. The final analysis included five major themes.

## Results

Five major themes emerged as a result of the analyses of the six focus groups, which included the addition of the consequences of the COVID-19 pandemic on the lives of participants. These themes and sub-themes are described in the following paragraphs.

### Theme I: COVID-19 Exacerbated Social Isolation, Loneliness, and Anxiety of Older People with Disabilities

Participants across all four of the focus groups conducted during the COVID-19 pandemic mentioned that COVID-19 had affected them due to the lack of socialization, which is well captured by this participant:

“In terms of what I miss most is the socialization factor with friends being able - not that I'm not able to talk with them on the phone or Zoom, but we used to enjoy getting together for game nights and you can't play Rummy Cube or Dominoes or other things via Zoom.”

Another participant from a different group expressed something similar:

“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.”

In addition, responses of participants across all groups were reflective of heightened fear and anxiety. Moreover, age and disability were additional factors contributing to these high levels of fear and anxiety. For example, a participant explained how the pandemic had limited their ability to go out due to their disability and the fear of getting sick:

“I have anxiety disorder also. It makes my anxiety so high that I don't want to go to the store. I don't want to go out ... I have a doctor's appointment tomorrow with an infectious disease doctor and I am now canceling that appointment because I am now afraid because the numbers are rising here in Philadelphia to actually go.”

Another person mentioned specific challenges with the pandemic and disability:

“Being a deaf person, a lot of us have a hard time with a drive-thru. We have to order our food and just tell them open up the window. But we have the mask on and we tell them to write it down, but they are not writing stuff down on paper. It's kind of hard for the deaf community.”

Another participant expressed his fears more vehemently:

“I'm scared like heck, I don't want to get on there [the bus] because other people may give the germs and you may end up coming down with the COVID-19. You may have to go to the hospital. I don't want to end up going to the hospital.”

Finally, one participant reflecting on the difficulties with social isolation during the pandemic said:

“... All of these people are like I can't take it, I can't take it ... It is a small taste of what people with disabilities are going through every day in their entire lives. They have a little short window where they aren't allowed to [go out] and I often think about that kind of thing.”

On the other hand, participants acknowledged a few surprising positive consequences of the pandemic for people with disabilities. For example, several noted the ease of tele-health, including virtual mental health counseling, as a convenience:

“... if it's just needed to talk to a doctor for an update on symptoms or whatever, the tele-health has been great for me.”

## **Theme II: Poor Accessibility**

Whether aging into or aging with disabilities, older persons encounter significant barriers to accessing public and private goods and services. Title II of the ADA protects qualified individuals with disabilities from discrimination in services, programs, and activities provided by state and local government entities, and Title III mandates similar protections within public accommodations such as restaurants, movie theaters, day care centers, recreation facilities, and doctors' offices.

Participants across all six focus groups vehemently shared how accessibility to goods and services had been a major factor that limited their community participation. Issues ranged widely: poor and expensive transportation services, inadequate parking, lack of physical access features such as elevators in buildings, lack of disability-friendly amenities, and narrow grocery store aisles. In addition, they mentioned how their independence had been severely limited by a lack of ADA compliant facilities in places such as restaurants, parks, and hotels, and lack of specific accessible features such as check-out counters and ATM machines. Disability and age further exacerbated these issues as the subthemes below illustrate.

### ***Subtheme 1: Structural and Attitudinal Barriers***

Almost every participant mentioned how physical access had been extremely challenging, and their age and disability intensified this. For example, one participant stated:

“I find I have such a hard time with stairs these days, more and more, so I find it very inaccessible. Trying to get out to go somewhere, I have to know how to navigate getting to the subway and down two flights of stairs and all of that. Then I have to think about where I'm getting off because I'm not sure - at that point in time, I'm already sore because I have psoriatic arthritis - that I have to think about where I'm going to get off because do I have it in me to be able to climb two flights of stairs to be able to - and that's just to get to where I want to go. That's not being able to actually do what I want to do. I find that extremely frustrating. And city hall is a nightmare.”

Many participants noted structural barriers to accessing goods and services in stores, restaurants and bars. One participant explained that “happy hour [in bars] was off limits to people with disabilities,” as restaurants required guests to sit at bar tables to qualify for discounts, and these types of tables cannot be used by most people who use wheelchairs. Participants noted similar structural barriers still existed in hotels, where as one noted, “they still have counters up to here, and if they have a low counter, it's at the very end, and then they have flowers or brochures on it” which interfere with access and usability.

While accessing stores and goods had been problematic, participants also mentioned how accessing health care and health-related services was even more challenging. For instance, one participant shared:

“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.”

Participants across all groups also mentioned that they often encountered attitudinal barriers to accessing services. For example, one participant 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.”

Another participant described her experiences with vocational rehabilitation in this way:

“When it comes to an older adult, they're much less likely to want to take your case...they told me, you really shouldn't be thinking about trying to get back to work now.”

A West Virginia participant described the attitudes of public officials in their town this way:

“... if you asked [someone in the town] about reaching the ADA coordinator, they would think what you needed was the American Dental Association.”

The attitudinal barriers among public officials could result in severe consequences for individuals with disabilities. For example, one of the participants who was deaf raised issues about the lack of training that police are given to deal with deaf people, as well as general attitudinal problems:

“I was in New York City recently, two weeks ago. One of my friends pulled me into the next room where she introduced me to a group of policemen who were being trained by an American sign language teacher explaining about deaf - how to explain [things] to deaf people if they arrest them. It's really important because deaf people have been killed by the police because they couldn't hear. Like in Florida, I remember a few years ago a man walked with a dog, a dark man, hooded, and shot him. If I happened to be walking in a dark place, I [wouldn't] know that someone is behind me and calling me. I couldn't hear. They could shoot me. Are they trained to



be aware of deaf people? It's possible that people couldn't hear the person. I'm being more careful now than before because more people have guns.”

Another participant summed it up:

“... once you have a disability and once you're older, they all stereotype you big time.”

### ***Subtheme 2: Transportation Barriers - Public and Personal Use (Parking)***

Several participants across all groups were limited in their community participation due to transportation problems. For example, one person talked about how they have been dependent on others or public transport:

“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 ten 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.”

Another person's response from a different group exemplified struggles with transport:

“I have autoimmune issues, so I am terrified - actually terrified to go out. I do not drive. I live in [just outside of] Philadelphia. For me to get to most of the places that I need to go to, I have to get on the bus, or I have to get on the subway, which I haven't done since the pandemic. And trying to get a Lyft or a taxi has been an absolute nightmare because they're either not available because of the pandemic or their pricing has just been exorbitant to try and get - for me to go down for a doctor's appointment down to Center City from where I live, which is not that far, which usually would cost me \$1 with my subway card costs me \$17 one way.”

Participants also described their struggles with parking, including limited parking, parking spots not being close to stores, people blocking the access aisles adjacent to accessible parking spaces, very narrow parking spots, parking garages not being code compliant, people abusing accessible parking spots, and police officers not enforcing laws. This participant's response summarizes most 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 [parked in an accessible space]. 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. As far as accessible parking I don't need to park closer. I need the extra space to get my wheelchair out. I don't care if you want to be in the first spot. Distance doesn't bother me unless it is the dead of winter because of where we live, it gets very cold and icy and snowing.”

### ***Subtheme 3: Access to 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 Charleston - 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 and organized, which made it hard for them to find information, as stated by this participant:

“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 labelled wrong. It's always been that way.”

### **Theme III: Knowing the ADA and Disability Rights Mitigates Barriers**

Most of the participants in our focus groups were very familiar or moderately familiar with the ADA and their rights under the ADA. They stated that they felt comfortable asking for accommodations and for help. It is important to note here that an overwhelming majority of

the participants had aged with a disability. Thus, it is likely that over time, they may have become more comfortable requesting accommodations and advocating for themselves. For example, one participant said:

“I'm not afraid to ask for help when I need it, and I generally get it. When I go to Target, they all know me by name now and they just see me come through the door and I hear them ‘anybody available to help [name] shop?’ Same thing when I go into CVS.”

However, focus group participants also stated that they encountered several obstacles in order to receive accommodations. This participant’s response highlights this point, but also sheds light on the negative attitudes often encountered by people with disabilities:

“If you go to Social Security, sometimes they give you any answer just to get rid of you. Don't take no for an answer; if you have to go as high as the Regional Director of an office [go]. They treat everyone like they're second-class citizens, like you are below the wheels of [your] chair.”

Similar sentiments were expressed by another participant:

“Most often, you have to reinvent the wheel, you have to scream, every time you go [to a public service office] because, because if nobody has done that, they were inaccessible, their offices are inaccessible. They know they don't know anything about providing accessible formats. In most places, getting accessible formats right up front is very hard, especially because now everybody says, ‘oh, it's on the web.’ And, and, and their websites may or may not be accessible.”

Some participants also mentioned how they had to take it upon themselves to advocate for people with disabilities to get accommodations and services. For instance, this participant mentioned how they had to fight to get accessible parking services:

“The chronic problem that I find is, in the garages, again it's code compliance. It just took me two years to bring the Boston Metro parking garage into compliance with power doors for interior because they were way more than five pounds pull pressure, but there were 450 parking spaces, and there were four handicap spots or one van spot. Took me two years, and I had to use the Equal Rights Center, to get it.”

However, it is important to note that although many of the participants in our study were very/moderately familiar with their rights under the ADA and had advocated for themselves or others, they mentioned that there is still a vast majority of people who are unaware of ADA and disability rights, as this participant stated:

“One of the most significant issues that I’ve seen is still the ongoing issue of even 30 years, the amount of people who don’t know about the ADA, and yes, then there are people who say ‘I don’t care.’”

Another focus group participant offered:

“... we have to be the enforcers...there are no ADA police, there is no ADA sheriff’s office. It’s up to us to see that it’s enforced.”

#### **Theme IV: The Intersection of Age and Disability**

Several participants across all groups talked about how their disability, combined with their age, had led to financial and physical dependence, as well as the fear of becoming even more dependent. Participants also acknowledged the differences between aging with and aging into a disability. For example, a member of a focus group comprised primarily of deaf participants, referring to older persons who acquired hearing loss as a result of the aging process noted:

“That’s a different group that acquired disabilities after age 50 ... many of us, myself included, have faced a lot of discrimination issues because we are deaf, not necessarily because of the age.”

However, another participant in the same group warned:

“We try to talk to them about the needs of housing of seniors who are deaf – and they just ignored us. I’m scared to death that the moment I get too blind and too deaf, that I will end up in a nursing home.”

In response to this statement, another participant said:

“You see, that’s on everybody’s mind. Everybody here that’s aging – we’re all aging because we are 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 home and community health 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, to be able to stay in our communities and age in our communities – we know it’s cheaper and healthier to age in your community. We’ve got to beat the big dogs ... and have more laws that support us. So, you can see it’s universal: the basic fear of aging with a disability and holding on to our independence.”

Another participant from another group also shared very similar worries:

“I’m getting older... I’m still working, and I love my job. But the reason I preface everything by saying that I feel like 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 important to me."

### **Theme V: Categorical Service Systems for Aging and Disability**

Even though aging and disability services tend to be offered by the same state or local offices, focus group participants who were aging with a disability noted the lack of integration of these services, particularly how senior services and organizations were not prepared to address disability and accessibility issues. For example, participants who were Deaf expressed dismay at the inadequate accessible communication available to assisted living residents. As one participant said:

"It is my fear when 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. That will happen if we do nothing about it. That's my fear. We'd better do something about it."

Another participant expanded on this issue, stating:

"There are many, many programs designed for aging, but they are decentralized programs because it's a large population. They're limited to certain areas – if you live in that area, you get services there. But Deaf people are scattered all over. We need centralized programs, not decentralized ones. Hearing people use decentralized programs. Deaf need centralized programs."

In another group, a participant described her experiences with local aging offices, noting that "sometimes they get girls in there that don't know [about disability]. They may have gotten out of college, but they still don't know."

An example of efforts to strengthen connections between disability and aging resources was described by one participant:

"A group called 'Deaf Seniors of America'. It's the same thing with AARP (American Association of Retired People). It's about people and access for deaf seniors and retired people as well. They're developing a partnership with AARP."

As one focus group participant stated regarding aging resources, "I need to educate myself more about what is available."

### **Discussion**

This qualitative focus group study explored the experiences and perceptions of older adults at the intersection of age and disability regarding community participation and the ADA. Perhaps

the least surprising finding of this study was that despite the enactment of the ADA, older adults 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 the age of 35; 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 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.<sup>30</sup> Molton and Ordway<sup>31</sup> refer to these disparate views of the intersection of age and disability as the difference between gerontologists, who may think of disability “as problems in doing”, whereas disability researchers view it as a problem of identity and access. This divide was neatly summed up by a focus group participant who was deaf from an early age, saying, “That’s a different group that acquired disabilities after age 50.”

Another factor contributing to persistent barriers to community participation may be the concept of successful aging in America, which emphasizes health and functionality, absence of disease and disability, and active engagement.<sup>31</sup> Media tends to depict old people as active, energetic, and able-bodied – dancing, exercising, caring for children, and even bungee jumping. Disability and rehabilitation are markedly absent from the successful aging image.<sup>17</sup> Older people with disabilities are categorized as “unsuccessful agers.”<sup>32, 33</sup> The juxtaposition of aging with a disability and the aging ideal in America can exacerbate anxiety and depression among this group.<sup>19</sup> In the current study, several participants indicated significant worries about disability and aging, particularly around their fears of increasing dependence. Of course, fear of losing independence or autonomy is a concern of many older persons,<sup>34</sup> but perhaps exacerbated for these participants at the intersection of age and disability where, as one participant who was Deaf from birth put it, “I worry about being isolated in an assisted living facility where there would be no captions, no interpreter, no one who can sign. I will be back in isolation. I will die lonely.”

The COVID-19 pandemic had severe consequences for both older persons and those with disabilities, and the virtual focus groups conducted during the pandemic demonstrated these devastating impacts, with participants remarking on their own anxieties about the virus, as well as the heightened anxiety of their family members for their own safety. As one participant complained, “the way my family treats me, I feel like a dog on a leash.” National studies have shown the consequences of the pandemic on people living with disabilities, who experienced more social isolation, greater fears and anxieties, and expressed hesitation to seek medical or other services for ongoing health issues.<sup>16</sup> One participant summarized the reactions toward medical services and disability during the pandemic in this way, “I literally walk around with electrostatic cloths, disinfectant spray ... in the doctor’s office, I literally spray the entire section that I’m sitting down in.”

Finally, the siloed nature of disability and aging services was evident in this study. The majority of these participants, who were aging with a disability, 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. As one participant said, “aging services are either very medically oriented or social work oriented ... they don’t think in terms of accessibility.” Molton and Ordway<sup>31</sup> 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. 4s). Based on our focus group findings, we would add that the disparate views also have their roots in the ideal of American aging described earlier, as well as the predominant focus on children, youth and working-age adults in the disability literature.<sup>19</sup> These factors further marginalize the population from the dominant discourses in both of these relevant disciplines.

### **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, gender, and race. Second, participants who had consented for one of the virtual focus groups were unable to access the platform due to technology and broadband barriers. Thus, the focus group was conducted with only two people although several others had indicated interest. Researchers in the field working with older adults with disabilities may learn from this experience by making sure in advance that the participants have the access and technology to participate in virtual activities. Third, a majority of the participants in our study had acquired their disabilities before the age of 35, thus, they had aged with a disability. While not the focus of the current study, it is likely that experiences may differ for seniors who age with disabilities compared to those who age into disabilities. 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. Lastly, although we were able to obtain rich information from the participants using the focus group method, it is likely that we may have failed to capture all participants’ experiences with community participation. Thus, the findings may be strengthened by utilizing a mixed method approach (e.g., using individual interviews, and/or surveys/questionnaires in addition to conducting focus groups), as it may help capture any information that we may have missed.

### **Implications**

This qualitative study of the experiences and perceptions of older persons with disabilities regarding community participation and the ADA highlighted several of the challenges, as well as the solutions participants used to mitigate or resolve them. Since the majority of the study participants had been living with a disability for decades, it was not surprising that they were knowledgeable about the ADA and used disability resources, such as centers on independent

living, but their lack of knowledge and/or anxieties around the accessibility of senior resources was surprising. This finding highlights the siloed nature of disability and aging services and resources, and suggests a need for better communication among researchers, policy makers, and advocates in order to devise solutions to serving this growing population of older adults who are aging into and aging with disabilities. For example, training senior living facility staff on effective communication requirements of the ADA in order to enhance participation is critical in order to comply with the ADA and proactively address isolation of people with communication disabilities. Understanding and addressing attitudes regarding disability and impairment among aging researchers and service providers can also initiate a different and more diverse perspective on successful aging, that doesn't include stereotyping disability as a negative attribute of aging. Many resources developed under research grants sponsored by the U.S. National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR) that study aging and disability can be more widely disseminated, and embedded into standardized training programs for nursing home staff, so that no human being who is Deaf has to fear "dying lonely" in a nursing home because there is no one who is able to effectively communicate.

Molton and Ordway<sup>31</sup> characterize the intersection of aging and disability research as being "in its infancy," but the growing population of older individuals with disabilities creates an urgent need to align these disciplines, and so align the policies and services that are generated by them. Successful aging for adults with disabilities exists in a unique context. Older adults with long-term disabilities may be excluded from the prevailing successful aging paradigm. However, our study showed that older people with disabilities offer valuable and unique perspectives on aging, and their viewpoints should not be ignored.

Moreover, the geriatric community should promote and protect the rights and dignity of older persons with disabilities and also facilitate their full community participation. To ensure environmental inclusion and accessibility, the intersections between aging and disability need to be considered in the design, development, and implementation of policies and programs related to aging.

## **Conclusion**

In summary, this study makes several important contributions by identifying barriers, both attitudinal and structural, that seniors with disabilities face and which restrict their community participation. The COVID-19 pandemic exacerbated those challenges. Knowledge of their rights under the ADA helped them advocate for themselves and others with disabilities, yet in many cases they had to overcome daunting obstacles to do so. Given these findings, efforts should be targeted towards increasing awareness of disability issues in the general population, improving community participation for this population, and increasing collaboration and communication between disability and aging services.

**Declaration of interest statement:** The authors have no conflicts of interest to declare.



## Appendix: Summary of Participant Demographic Information

Gender	Number of Participants	Percentage of Participants
Male	11	26.2
Female	31	73.8

Race/Ethnicity	Number of Participants	Percentage of Participants
White	34	82.9
African American/Black	3	7.3
Hispanic	2	4.9
Asian	1	2.4
Other	1	2.4

Age Range	Number of Participants	Percentage of Participants
50 - 54	7	16.7
55 - 59	18	42.9
60 - 64	6	14.3
65 - 69	7	16.7
70+	4	9.5

Education Level	Number of Participants	Percentage of Participants
Some high school, no diploma	1	2.4
High school graduate, diploma or equivalent	7	16.7
Some college credit, no degree	9	21.4
Trade/technical/vocational training	1	2.4
Associate degree	1	2.4

Education Level	Number of Participants	Percentage of Participants
Bachelor's degree	11	26.2
Master's degree	9	21.4
Professional degree	2	4.6
Doctoral degree	1	2.4

Employment Status	Number of Participants	Percentage of Participants
Employed for wages	17	40.5
Self-employed	4	9.5
Out of work and looking for work	7	16.7
Out of work but not looking for work	1	2.4
Homemaker	3	7.1
Retired	5	11.9
Unable to work	5	11.9

Marital Status	Number of Participants	Percentage of Participants
Single, never married	12	28.6
Married/domestic relationship	18	42.9
Widowed	2	4.8
Divorced	9	21.4
Separated	1	2.4

Type of Disability	Number of Participants	Percentage of Participants
Intellectual or developmental disability	1	2.4
Physical disability	19	45.2

Type of Disability	Number of Participants	Percentage of Participants
Sensory disability	17	40.5
Mental health disability	1	2.4
Learning disability	2	4.8
Other	2	4.8

Living Situation	Number of Participants	Percentage of Participants
Living independently	31	73.8
Having roommates	2	4.8
Living with parents	6	14.3
Group home/residential program	1	2.4
Other	2	4.8

Living Area	Number of Participants	Percentage of Participants
Rural	2	4.8
Small town	7	16.7
Suburban	21	50.0
Urban	12	28.6

## References

---

- <sup>1</sup> Scotch RK. Models of disability and the Americans with Disabilities Act. *Berkeley Journal of Employment and Labor Law*. 2000; 21:213.
- <sup>2</sup> Bezyak JL, Sabella SA, Gattis RH. Public transportation: an investigation of barriers for people with disabilities. *Journal of Disability Policy Studies*. 2017 Jun; 28(1):52-60.
- <sup>3</sup> Bachelder JM, Hilton CL. Implications of the Americans with Disabilities Act of 1990 for elderly persons. *American Journal of Occupational Therapy*. 1994 Jan 1; 48(1):73-81.
- <sup>4</sup> Vespa J, Armstrong DM, Medina L. Demographic turning points for the United States: Population projections for 2020 to 2060. Washington, DC: US Department of Commerce, Economics and Statistics Administration, US Census Bureau; 2018 Mar.
- <sup>5</sup> Halvorsen A, Pettersen AL, Nilsen SM, Halle KK, Schaanning EE, Rekand T. Epidemiology of traumatic spinal cord injury in Norway in 2012–2016: a registry-based cross-sectional study. *Spinal cord*. 2019 Apr; 57(4):331-8.
- <sup>6</sup> Foulon C, Cerliani L, Kinkingnehun S, Levy R, Rosso C, Urbanski M, Volle E, Thiebaut de Schotten M. Advanced lesion symptom mapping analyses and implementation as BCBtoolkit. *Gigascience*. 2018 Mar; 7(3):giy004.
- <sup>7</sup> Crimmins EM, Zhang Y, Saito Y. Trends over 4 decades in disability-free life expectancy in the United States. *American Journal of Public Health*. 2016 Jul; 106(7):1287-93.
- <sup>8</sup> Mehta NK, Patel SA, Ali MK, Venkat Narayan KM. Preventing disability: the influence of modifiable risk factors on state and national disability prevalence. *Health Affairs*. 2017 Apr 1; 36(4):626-35.
- <sup>9</sup> Emerson E, Fortune N, Llewellyn G, Stancliffe R. Loneliness, social support, social isolation and wellbeing among working age adults with and without disability: Cross-sectional study. *Disability and health journal*. 2021 Jan 1; 14(1):100965.
- <sup>10</sup> Leslie E. *The Impact of Mixed Population Public Housing on the Quality of Life of Both Elders and People with Disabilities* (Doctoral dissertation, Southern Connecticut State University).
- <sup>11</sup> Serafini MW. For people with disabilities, a fight for access to housing. 2018; 37(3): 346-348.
- <sup>12</sup> Dovidio JF, Pagotto L, Hebl MR. Implicit attitudes and discrimination against people with physical disabilities. In *Disability and aging discrimination 2011* (pp. 157-183). Springer, New York, NY.
- <sup>13</sup> Andrews J, Falkmer M, Girdler S. Community participation interventions for children and adolescents with a neurodevelopmental intellectual disability: A systematic review. *Disability and rehabilitation*. 2015 May 8; 37(10):825-33.
- <sup>14</sup> Tough H, Siegrist J, Fekete C. Social relationships, mental health and wellbeing in physical disability: a systematic review. *BMC public health*. 2017 Dec; 17(1):1-8.
- <sup>15</sup> Wicki MT. Physical and mental health of older people with disabilities in residential homes in Switzerland. *SAGE open medicine*. 2021 Mar; 9:20503121211000530.

- 
- <sup>16</sup> Lebrasseur A, Fortin-Bédard N, Lettre J, Bussièrès EL, Best K, Boucher N, Hotton M, Beaulieu-Bonneau S, Mercier C, Lamontagne ME, Routhier F. Impact of COVID-19 on people with physical disabilities: a rapid review. *Disability and health journal*. 2020 Nov 1:101014.
- <sup>17</sup> Moody HR. From successful aging to conscious aging. *Successful aging through the life span: Intergenerational issues in health*. 2005:55-68.
- <sup>18</sup> Molton IR, Yorkston KM. Growing older with a physical disability: A special application of the successful aging paradigm. *The Journals of Gerontology: Series B*. 2017 Mar 1; 72(2):290-9.
- <sup>19</sup> Raymond É, Grenier A. Social participation at the intersection of old age and lifelong disability: Illustrations from a Photo-Novel Project. *Journal of aging studies*. 2015 Oct 2; 35:190-200.
- <sup>20</sup> Levasseur M, Gauvin L, Richard L, Kestens Y, Daniel M, Payette H, NuAge Study Group. Associations between perceived proximity to neighborhood resources, disability, and social participation among community-dwelling older adults: results from the VoisiNuAge study. *Archives of physical medicine and rehabilitation*. 2011 Dec 1; 92(12):1979-86.
- <sup>21</sup> Siette J, Berry H, Jorgensen M, Brett L, Georgiou A, McClean T, Westbrook J. Social participation among older adults receiving community care services. *Journal of Applied Gerontology*. 2020 Jul 29:0733464820938973.
- <sup>22</sup> Sabatello M, Landes SD, McDonald KE. People with disabilities in COVID-19: Fixing our priorities. *The American Journal of Bioethics*. 2020 Jul 2; 20(7):187-90.
- <sup>23</sup> United Nations (UN). Policy Brief: The Impact of COVID-19 on older persons. 2020
- <sup>24</sup> United Nations. Policy brief: a disability-inclusive response to COVID-19.
- <sup>25</sup> Adler K, Salanterä S, Zumstein-Shaha M. Focus group interviews in child, youth, and parent research: an integrative literature review. *International Journal of Qualitative Methods*. 2019 Nov 7; 18:1609406919887274.
- <sup>26</sup> Anderson CA, Leahy MJ, DelValle R, et al. Methodological application of multiple case study design using modified consensual qualitative research (CQR) analysis to identify best practices and organizational factors in the public rehabilitation program. *Journal of Voc Reh*. 2014; 41(2):87-98.
- <sup>27</sup> Miles MB, Huberman AM. *Qualitative data analysis: An expanded sourcebook*. sage; 1994 Jan 12.
- <sup>28</sup> Fabian E, Havewala M, Deschamps A, Owens L, Horton N. *The Road to Work: Youth with Disabilities and Their Views on Employment and the ADA*. Rehabilitation Research, Policy, and Education. 2021 May 5.
- <sup>29</sup> Hernandez B, McDonald K, Divilbiss M, et al. Reflections from employers on the disabled workforce: Focus groups with healthcare, hospitality and retail administrators. *Employee Responsibilities and Rights Journal*. 2008; 20(3):157-164.
- <sup>30</sup> Andrews EE, Forber-Pratt AJ, Mona LR, Lund EM, Pilarski CR, Balter R. # SaytheWord: A disability culture commentary on the erasure of “disability”. *Rehabilitation psychology*. 2019 May; 64(2):111.

---

<sup>31</sup> Molton IR, Ordway A. Aging with disability: populations, programs, and the new paradigm an introduction to the special issue. 2019 Nov 12; 31(10\_suppl): 3S-20S.

<sup>32</sup> Gibbons HM. Compulsory youthfulness: Intersections of ableism and ageism in “successful aging” discourses. *Review of disability studies: An international journal*. 2016 Sep 1; 12(2 & 3).

<sup>33</sup> Rubinstein RL, de Medeiros K. “Successful aging,” gerontological theory and neoliberalism: A qualitative critique. *The gerontologist*. 2015 Feb 1; 55(1):34-42.

<sup>34</sup> Stone AA, Schwartz JE, Broderick JE, Deaton A. A snapshot of the age distribution of psychological well-being in the United States. *Proceedings of the National Academy of sciences*. 2010 Jun 1; 107(22):9985-90.