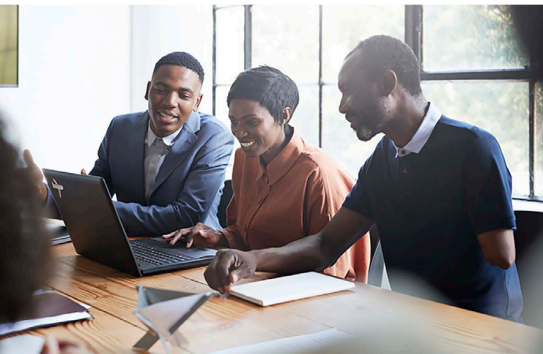
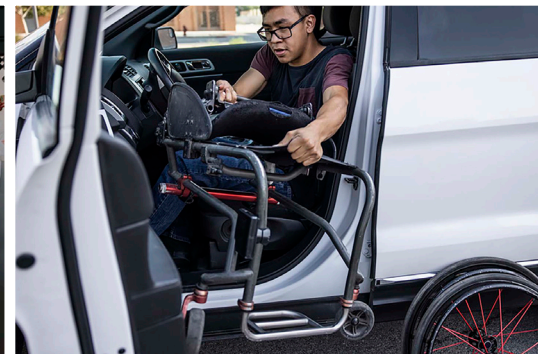


# Structurally Disabled: A Qualitative Study of Structural Contributors to Disability\*



Securing today  
and tomorrow



\* Disclaimer: Any published findings and conclusions are those of the authors and do not necessarily represent the official position of the Social Security Administration or the United States Government. Any remaining errors are our own.

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# Accessibility Info

**As part of the collaborative study process with people with lived experiences of disability, this report has been created with the intent to be accessible to many people. For example, this written report uses color schemes to make the content accessible to people with low vision and/or are color-blind; people using screen readers will find the alternative text for images under the images, rather than imbedded.**

**For Deaf people who use American Sign Language and deaf people who use closed captioning, a report summary video was created. For people who do not read, a report summary video was created. These videos are available here:**

***<https://www.ssa.gov/disabilityresearch/index.html>***

**All versions of the report have been reviewed and revised by people with relevant lived experiences with impairment to improve the accessibility of the content.**

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# Executive Summary

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# Executive Summary

This research aimed to understand the experiences and needs of potential and actual Social Security Administration (SSA) disability benefit recipients. Additionally, this work aimed to develop a conceptual model to frame internal stakeholders' future data generation about equitable Supplemental Security Income (SSI) and Social Security Disability Insurance (SSDI) service delivery. We anticipated that findings would also be relevant to other government infrastructure and service agencies.

With a Technical Working Group (TWG) of 13 people with lived experiences of disability, we designed an interview guide to explore the structures (systems, laws, policies, regulations, customs, practices, and cultures) that may socially, economically, and politically exclude people whose minds and/or bodies have been devalued. We conducted 44 90-minute interviews with people from 19 states and the District of Columbia who self-identified as experiencing disability in the U.S.; 66% of the participants had experience applying for or receiving disability benefits from SSA.

*“...I think it’s important to not hide that away, like if some people say, like, ‘oh, I don’t see disability,’ I think that’s problematic because, you need to see disability to see the needs that aren’t necessarily being met”*  
*(Participant 7).*

The interview questions focused on disabled living generally and SSA specifically, and data generated from these interviews demonstrated eight main structures that contribute to disablement in the United States: healthcare, technology, transportation, employment, representation, Social Security Administration, culture, and education.



Figure 1: The social, economic, and political results of these structures that, done wrong, are disabling



Below are summaries of the social, economic, and political implications of what participants shared about each structure. It is important to note that the summaries are specific to what participants shared and are not necessarily inclusive of all the ways that structural disablement manifests.

# 1. Healthcare (system):

*The organized provision of health care to individuals or communities*

For people living with an impairment that benefits from healthcare intervention, where they live matters. Insurance coverage is state dependent; access to specialists is also dependent on proximity to particular healthcare facilities.



**A young Black woman with long braids has her blood pressure checked by a clinician wearing a white coat.**

**People's ability to access specialized care depends upon where they live.**

For those whose health care is tied to their freedom from incarceration, there can be a coercive element to accessing the care they need. The present healthcare system enables or disables people, depending upon where they live and/or incarceration history, to receive needed health care, affecting their ability to participate as a worker in the economy (and thus a consumer). Those disabled or excluded from working in the U.S. experience the economic precarity of poverty, which further endangers their health,\* minimizing their capacity for social and political engagement.

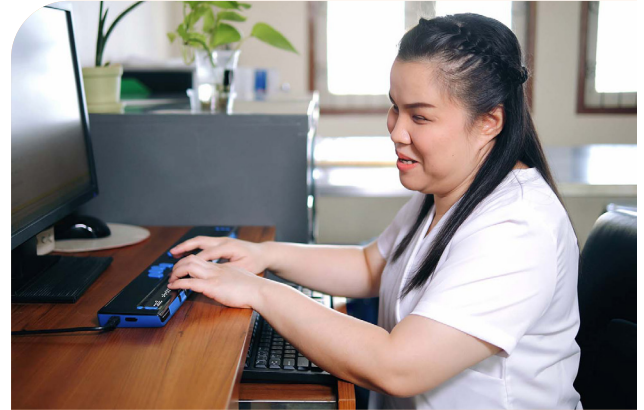
*“The amount of time I spent with doctors and nurses,...medical assistants. The amount of time I spent with insurance companies fighting over a bill. I just am like, I don’t think this is a world that I would wish on my worst enemy” (P43).*

\* The National Institutes for Health (NIH) recently recognized disabled people as a population experiencing health disparities stating “...exclusionary structural practices, programs and policies inhibit access to timely and comprehensive health care, which further results in poorer health outcomes.” <https://www.nih.gov/news-events/news-releases/nih-designates-people-disabilities-population-health-disparities>

## 2. Technology (practices, relational):

*The use of tools to ease or facilitate an activity*

Technology has the capacity to connect people with impairments to the rest of the world and others with impairments, and can make environments accessible. There is not a one-size-fits all approach, rather the technology needs to meet the need of a person and should be used appropriately. But the logistics of standardized and universal accessibility have been insufficiently implemented and support is inadequately resourced meaning some people miss out on social activities and job opportunities. Government use of accessibility technology may increase people's ability to access services and participate in political action.



**A smiling East Asian woman with a visual impairment uses assistive technology on her computer.**

**People need more access to appropriate assistive technology.**

## 3. Transportation (system):

*How people get around a geographic area, including movement under one's own power, use of a vehicle, forms of public transportation (e.g., bus), airplane, or railway*



**A middle aged White man in a suit using a wheelchair exits a public transportation bus using a lift.**

**Availability of accessible transportation is essential to people's ability to participate in society.**

Transportation offers opportunities for socialization, economic participation (working and consuming), and political action. While technology is improving to facilitate virtual interactions, in-person interactions still have value for individual wellbeing. The inability to be present in person limits prospects for social networking, and increases economic precarity and political exclusion.



## 4. Employment (laws, policies, practices):

*Hiring practices of employers, and worker experiences seeking and maintaining a job or promotion*

*“...the whole notion of accommodations needing to be ‘reasonable’ poses barriers and like people needing to have diagnoses in order to get school accommodations or work accommodations umm, is like, you know...makes it so that people who have additional...marginalized identities find it even harder to get those accommodations because of medical racism and you know medical gaslighting and, and other forms of oppression” (P39).*

There are laws to protect the rights of people with impairments in workplaces, but there are a lot of loopholes too. Accommodations can cost money and take time and/or effort, and not all employers are able or willing to make those investments if they are not required by law. Consequently, well-qualified people with impairments that require accommodations may be underpaid, underemployed, or unemployed, and reliant upon disability benefits, kinship networks, and/or gig work. As discussed below, disability benefits are insufficient to facilitate thriving (economic and otherwise); kinship networks may or may not be fiscally capable and financial reliance can complicate those relationships; and gig work offers fewer legal protections than traditional work arrangements and minimal fiscal future planning options. All of these realities coalesce to place people with impairments in socially and economically precarious situations, with diminished political capacity.



**A middle aged White woman with contracted hands is sorting pottery in a studio.**

**People with impairments are often underpaid or underemployed.**

## 5. Representation (laws, culture):

*Visibility in media (e.g., television, movies, books) and in community settings*



**A young White woman in a motorized wheelchair sits in a dark room, watching a movie.**

**Media representation is one way people learn about others and people like them.**

Media and community representation of various populations is how many people learn about those who are dissimilar, in some way, to them. Representation contributes to empathy and humanization, which builds individual capacity to accept difference and recognize overarching similarity. Limited accurate representation can facilitate harmful narratives about those who are unfamiliar and contributes to poor self-perception among those invisibilized,\* who may consume the same media. Inaccessibility yields isolation of people with impairments from the ordinary, public view. This isolation

contributes to the misconception that accommodations and accessibility adaptations are not needed. Study participants shared that invisibilizing people with impairments limits their socialization and employment opportunities, and their ability to equitably engage in political activity; and it means that accommodations are seen as unnecessary or of minimal value because people with impairments are deemed to be rare, when in fact 1 in 4 people have at least one impairment.<sup>1</sup>

---

\* To “invisibilize” is to make invisible or marginalize. This term is a powerful and apt descriptor of how historically excluded groups’ contributions and presence are erased from mainstream culture. Invisibilization is more than not being represented, as its impact has harmful social, economic, and political implications for the affected group(s). Interested parties can begin to learn more: Borderon M, Best KB, Bailey K, et al. “The risks of Invisibilization of populations and places in environment-migration research. *Humanit Soc Sci Commun* 8, 314 (2021); and Herzog B. “Invisibilization and Silencing as an Ethical and Sociological Challenge.” *Social Epistemology*, 32:1, 13-23 (2018).

## 6. The Social Security Administration (laws, policies, regulations, operations):



**An empty Social Security Disability application form is clipped to a clipboard.**

**Receipt of SSA disability benefits is what allows some people access to healthcare insurance.**

*U.S. federal agency that provides people with financial protection via various benefit programs*

Many of SSA's policies are determined by legislation and the implementing regulation or related decisions, like the amount of cash benefits. SSA determination of disability is important for allowing many people to access basic needs, including health care. In the current healthcare system, there is a resources gap between meeting non-disability eligibility or entitlement criteria for public healthcare

insurance and either being able to afford insurance coverage independently or having a job that provides health insurance. Consequently, many people with an impairment are not able to afford much needed health insurance without being approved for disability programs, or they cannot afford the full range of care that they need to be healthy without receiving disability cash benefits.\*

Further threatening people's economic security are the SSI limits on income and resources, and SSDI limits on earnings that recipients can have; recipients often live below and at poverty. For recipients who have kin that save money (besides disability benefit payments) for them, they have no legal guarantee the funds will not be used without their permissions. Moreover, they are at the whim of such friends and family, potentially complicating the kinship relationship and leaving them open to abuse or exploitation. Participants also noted difficulties communicating with SSA, making it frustrating and emotionally painful to access the necessary but often insufficient benefits of survival. With heightened economic precarity, SS(D)I benefit recipients can experience co-occurring social and political marginalization.

\* While this may technically be more of a healthcare system issue, it arose in participants' comments about SSA and why receiving SSA disability benefits is important for them.



## 7. Culture

### *What we learn from communities and systems*

*“...I’m getting a combination of messages of things like it’s a tragedy to become disabled because you aren’t as -- the implication there is that your body and/or mind are not as good as they were before” (P42)*

As described by study participants, researchers, and historians, racism has been a part of U.S. culture<sup>2,3,4</sup> and interacts with disability, complicating how people of color experience disability in comparison to how White people experience disability. Some people of color seek out support networks of color to feel understood, be protected, and avoid traumatization. Due to disability stigma within their racial or ethnic in-group, other people of color may only be able to access community according to (what others may call) an impairment rather than also within their racial or ethnic group. Similarly, data from

this study and others demonstrate that sexism has been a part of U.S. culture<sup>5,6</sup> and interacts with disability, complicating how women and genderqueer people experience disability in comparison to men.

The cultural value of independence, regardless of immigration history, permeates various U.S. communities and families, with social and economic implications. Independence is tied to the ability to work for pay and the ability to participate in compensated work confers economic value to the individual (the worker). The consequent economic power from working can translate into political power, but those who cannot work, or who cannot survive without additional financial support, experience diminished political power.



**An Asian woman walks with a Black woman using a wheelchair; they are carrying shopping bags and in conversation.**

**Experiences of disability interact with other marginalized experiences and identities.**

## 8. Education (system)

*The process of providing or receiving systematic instruction*

Children with impairments who are mainstream educated may experience social isolation, potentially because the other students do not know how to communicate with them or because the other students ostracize the mainstreamed children. School (including higher education) is where many people begin to develop a social-professional network of connections that contribute to employment opportunities;<sup>7,8,9</sup> it is also where many practice getting involved in their communities. Children who experience social isolation, and child and adult learners who do not receive necessary accommodations, are disadvantaged in their capacity to be economically self-sufficient and/or navigate participation in local communities.

*“...I love my country, but I don’t feel like my country loves me” (P28).*



**A multiracial group of young students walk together, smiling; one student uses a prosthetic leg.**

**School is important for more than curricular achievement and students build relationships that can support them later.**

Each participant also shared specific suggested policy and operational changes to structures that currently contribute to their experience of disability. Their advice drives home the idea that the 8 major structures described above are not immutable. Leaning on the insights from these participants, others with lived experience, and existing evidence, revisions to U.S. structures can facilitate a more socially, economically, and politically inclusive nation.





# Introduction

**Understanding SSI and SSDI ..... 13**

# Introduction

According to the Centers for Disease Control and Prevention (CDC), disability affects 1 in 4 people living in the United States (U.S.).<sup>1</sup> In December 2021 alone, the Social Security Administration (SSA) provided support to 12.6 million people determined to experience disability, either in the form of Supplemental Security Income (SSI) or Social Security Disability Insurance (SSDI); this does not even include people 65 years and older receiving a benefit based on their disability.<sup>10,11</sup> SSA's purpose is to offer financial protection to the nation's people;<sup>12</sup> additionally, SSA aims to ensure equity and accessibility in service delivery.<sup>13</sup> This study furthers those aims by a) exploring the self-identified needs of people living with impairments; b) investigating ways to serve more people who might be/are eligible for or are actively receiving disability benefits; and c) identifying targeted quantitative research and programming opportunities to improve SSA's distribution of disability services and benefits.

Moreover, the study question of *“What are the structural contributors to disability?”* allows SSA to learn more about the reasons people end up needing to access disability benefits in the first place. This research aimed to understand the experiences and needs of potential and actual SSA benefit recipients. This research also aimed to develop an ethically informed conceptual model to frame internal stakeholders' future data collection about equitable SS(D)I service delivery. In other words, we sought to understand upstream, structural factors and to illuminate potential SSA operational, regulatory,



Disability affects  
**1 in 4**  
**PEOPLE**  
living in the U.S.

In one month, the  
Social Security  
Administration provided  
support to more than

**12.6**  
**MILLION**  
**PEOPLE**

determined to  
experience disability



**A worried-looking older White woman sits on a couch, leaning on a cane.**

**“What are the structural contributors to disability?”**



and policy changes that can improve SS(D)I service provision to better the wellbeing of people disabled in the U.S.

## Understanding SSI and SSDI



**A blind Black man and a South Asian woman laugh while walking together.**

**SSI provides benefits to a diversity of people who have little to no income or resources.**

It is outside the scope of this report to fully describe SSA's disability programs, but it is important to contextualize the study findings. SSI provides financial support to people who are 65 or older, blind, or have other impairments and have little to no income or resources; people who may be eligible for SSI include children (under the age of 18 years). Those who live in American Samoa, Guam, Puerto Rico, and the U.S. Virgin Islands are not presently eligible to receive SSI. SSI funds come from general tax revenues; some states supplement

federal SSI payments.<sup>16</sup> SSDI provides financial support to workers who have worked long and recently enough, paid Social Security taxes on those earnings, and who have subsequently acquired an impairment that meets the SSDI program's definition of disability. SSDI benefit amount received is based on a worker's earnings. Some people are eligible for SSI and SSDI.

Benefit recipients can become eligible for Medicaid (SSI) or Medicare (SSDI).<sup>\*</sup> For SSI recipients in some states, Medicaid eligibility is automatic; in other states, Medicaid must be applied for separately. People are entitled to Medicare 24 months after the date of disability benefit entitlement, which can occur before SSI approval occurs. The hyperlinked websites offer more in-depth information about [SSI](#)<sup>14</sup> and [SSDI](#).<sup>15</sup>



**A multiracial group of people talk in a workplace, surrounded by plants. One man has one arm.**

**SSDI provides benefits to people based upon their work history.**

<sup>\*</sup> A brief primer on Medicaid and Medicare is available here: <https://www.hhs.gov/answers/medicare-and-medicaid/what-is-the-difference-between-medicare-medicaid/index.html>

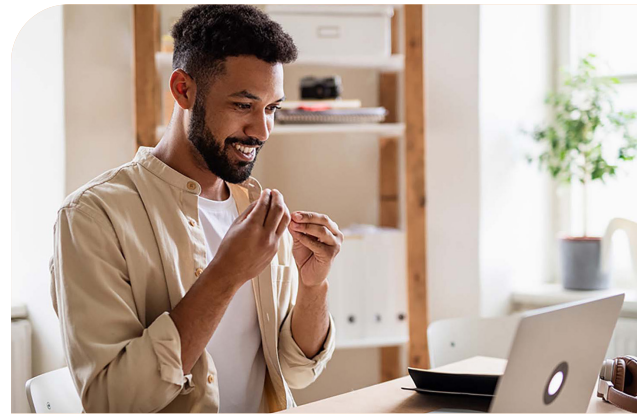


# Methods

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# Methods

Understanding Experiences is a grounded theory qualitative investigation. “Grounded theory” means the interviews, which generate the data, are used to develop a theory that answers the study question. The study design and methods were reviewed by SSA’s Office of General Counsel and the White House’s Office of Management and Budget. It was deemed exempt from review (45 CFR 46.104(d) category 5) by an external institutional review board (IRB), [Pearl IRB](https://www.pearlirb.com/)\*



**A Deaf Black man signs while having a virtual conversation using his laptop.**

**When people share their experiences, their stories are the data.**

## Study Team

The study team was comprised of 3 SSA research employees and 13 technical working group (TWG) members. The SSA research employees each had at least 10 years of qualitative research experience and all identify as women; two identify as women of color. Makini Chisolm-Straker is an MD MPH and she started working at SSA in 2022. Sika Koudou is a PhD MA (both in Sociology) and she started working at SSA in 2009. Katherine Bent is an RN PhD (Nursing) CNS and she started working at SSA in 2017.

An important part of this study was the collaboration with paid lived experience experts.<sup>†</sup> Technical working group (TWG) members were recruited from a variety of sources, including from community events, national media reports, service on a prior government technical working group, and recommendations from disability rights attorneys and advocates, members of the military, and appointed government employees. People with various impairments (physical and mental, visible and invisible); from various parts of the country; living in cities, reservations, and suburban and rural areas; of various employment statuses; of various genders (including transgender and nonbinary); of various races and ethnicities (including

---

\* <https://www.pearlirb.com/>

† Two members of the TWG declined payment.



Native, Black, Latiné, Asian, and White); of various military statuses; and of various relationships with SSA disability programs (including actively receiving benefits and in the application process) were sought. Diversity was important to this TWG



**Multiple headshots of people of various races, ethnicities, genders, and ages.**

**This research relied upon the lived experience of the TWG members to help guide the study.**

because the people who experience disability in this nation are diverse, and we wanted to create the best opportunity to develop a seminal, broad-based theory and comprehensive understanding of the structural contributors to disability in the United States. The TWG was created to provide a diversity of lived experience perspectives, not to reach consensus.

The TWG partnered with the SSA researchers in nearly every step of the research process and were paid for every completed activity

(see [Figure 1](#)). The TWG helped revise the interview guide so that the questions and prompts were approachable and accessible to the study participants, and would garner responses that help answer the main study question. The members recruited participants through their social and professional networks. They reviewed a sample of transcripts and member-checked the preliminary interpretation of the data to ensure the final report reflected what participants shared and the reality of disability experiences in the U.S. The TWG informed the graphic depiction of the conceptual framework and the report, as well as the dissemination plan. The only activity TWG members did not engage in was conducting the 90-minute interviews.



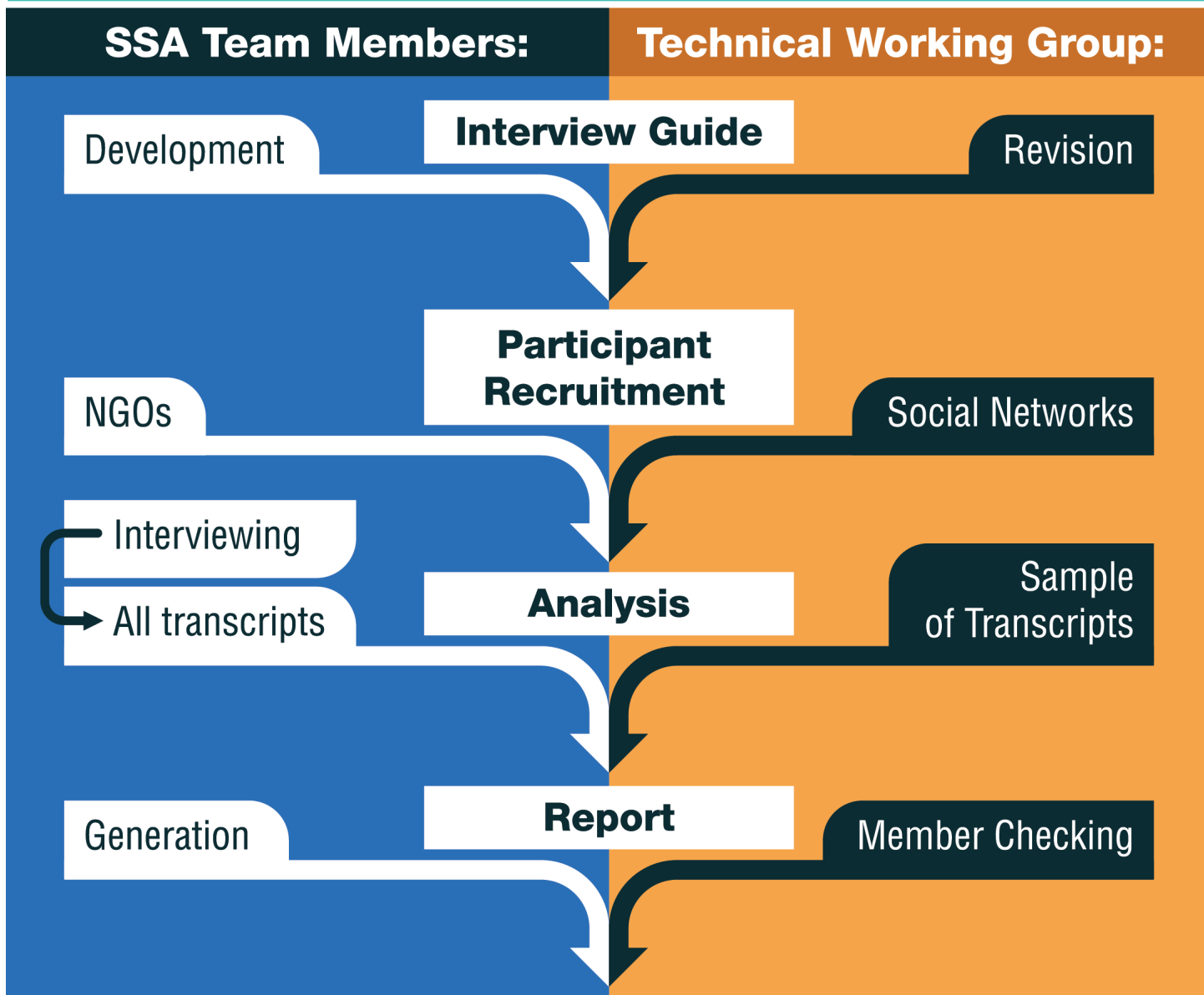
**An older Black man smiles while talking with multiple people in a virtual meeting platform, using his desktop.**

**The TWG met virtually, so that people from around the U.S. could participate.**



# Study Team Structure

Figure 2



## Dissemination Planning



# Interview Guide

The semi-structured interview guide was developed by the SSA team members based on the extant literature and expertise. It was then revised by the TWG. As the data was collected and, according to qualitative research standards, the guide was revised based on in-parallel analysis of the data and with the input of the SSA and TWG members, to probe gaps in the developing theory (see [Appendix: Interview Guides](#)). This means that in this study three iterations of the interview guide were used, as the theory developed.

Consent and interviews were conducted and recorded over Microsoft Teams. Participants who did not have access to the internet could either call into the interview by telephone or be called in via Teams. Teams auto-transcribed the interviews which were then reviewed and corrected by the SSA team that manages transcriptions for hearings. The transcription team blinded the transcripts (removed identifying information) before providing the final versions of the transcripts for the study team to analyze.

## Population

Participants (the people interviewed) were eligible if they were at least 18 years old and self-identified as experiencing disability in the U.S. Participants with cognitive impairments (e.g., intellectual developmental disorder) were invited but not required to have a legally authorized representative (LAR) or supportive adult present for the verbal consent process and interview. For those that did not have a LAR or supportive adult present, when relevant, probing questions were asked to confirm comprehension and capacity to consent or decline to participate.

Potential participants were recruited via convenience, snowball, and purposive sampling. This means that TWG members shared information about the study with their social and professional networks, and SSA team members asked national



**A multiracial trio of laughing young women with cognitive impairment pose for the camera. Some study participants heard about the study from their friends.**



**A Southeast Asian woman wearing a hijab laughs while using headphones and her laptop. Participants were interviewed using a virtual meeting platform.**

disability advocacy organizations to share information about the study with their networks (convenience sampling). Study participants also shared information about the study with people they know (snowball sampling). Toward the end of the recruitment and interview period, to fill in gaps in the developing theory, TWG members encouraged people they thought would have relevant experiences to participate (purposive sampling). Participants who completed the interview received a \$100 Visa gift card. Study

documents were translated, and interpreters were used when the participant did not read and/or speak English. Language support was provided at no cost to the study participant.

## Protocol

Potential participants reached out to the study team via email to indicate interest. They were provided with a personalized invitation letter and an information document (informed consent) to review (see [Appendix: Informed Consent](#) and [Appendix: Invitation Letter](#)). If still interested, they scheduled a 90-minute interview based upon their availability and the availability of one of the interviewers (SK, MCS). After verbal review of the informed consent document and if consent was given, the recorded interview ensued. After auto-transcripts were reviewed and corrected, the study team analyzed the data. Codes, or labels applied to text with similar or related content, were developed in vivo (based on the data) in MAXQDA.<sup>17</sup> The SSA team collaboratively developed, reconciled, and applied the codebook (a guide on how to use the codes) to all transcripts analyzed for the study (see [Appendix: Abridged Codebook](#)). Codes were arranged categorically in relation to each other, analyzed and compared; we repeated these steps iteratively to reveal the structures that contribute to disablement of people with impairments.\* Once theoretical saturation (i.e., a robust theory is determined and successfully probed) was achieved, interviews ceased.

---

\* For more on grounded theory analysis, interested people can read a brief instructive summary: [www.delvetool.com/groundedtheory](http://www.delvetool.com/groundedtheory)



# Results

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# Participant Demographics

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# Participant Demographics

From February to June 2023, 44 90-minute interviews were conducted and analyzed. The demographics describing the participants are shared in the table and charts below, and help to contextualize the experiences and insights shared. With respect to gender, 29 (66%) participants identified as women with one being a trans woman,

14 (32%) as men, and 1 (2%) identified their gender as queer ([Figure 3](#)). With respect to race and ethnicity, 18 (41%) identified as White ([Figure 4](#)) and some people identified as more than one racial/ethnic category. Of the 44 participants, 5 (11%) were immigrants, 6 (14%) were parents of minors, 4 (9%) were caretakers of others (e.g., of elders or children they did not consider their own), 2 (5%) were veterans, and 4 (9%) had service animals.

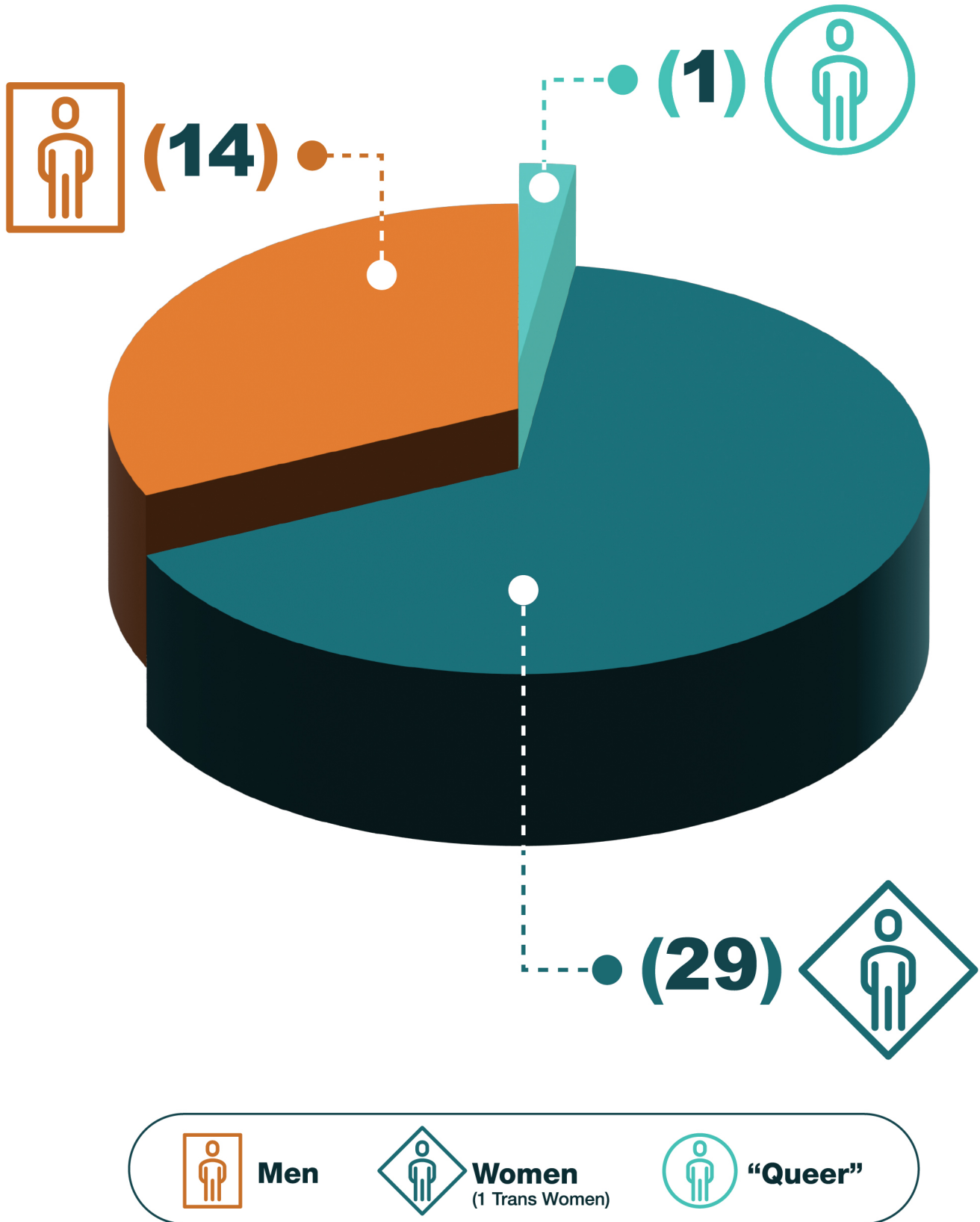
*“...they asked for like what is your current work status. And it was like ‘fully employed,’ ‘underemployed,’ ‘seeking work,’ ‘disabled.’ And it was like, you know, some people are disabled and also work” (P42).*

Participants were from multiple states in the continental United States ([Figure 5](#)), and were from cities, and suburban and rural areas ([Figure 6](#)). Participants ranged in age from 24

to 69 ([Figure 7](#)). [Table 1](#) shows a list of all the impairments participants reported; some participants reported experiencing more than one impairment. A little less than half (20; 45%) were born with or acquired their impairment in early childhood (less than 2 years old), and a little more than half (24; 55%) acquired their impairment in late adolescence or adulthood ([Figure 8](#)). [Figures 9](#) and [10](#) describe participants’ employment status and SSA disability benefit receipt status at the time of the interview; 8 (28%) of the women and 6 (43%) of the men were unemployed at the time of the interview; 2 (10%) of the participants who were “born with” their impairment were unemployed and 12 (50%) of those who acquired their impairment were unemployed at the time of the interview. A little less than half (10; 48%) of those who were receiving disability benefits at the time of the interview were also working in some capacity (e.g., full-time, part-time, self-employed).

# Participants' Gender

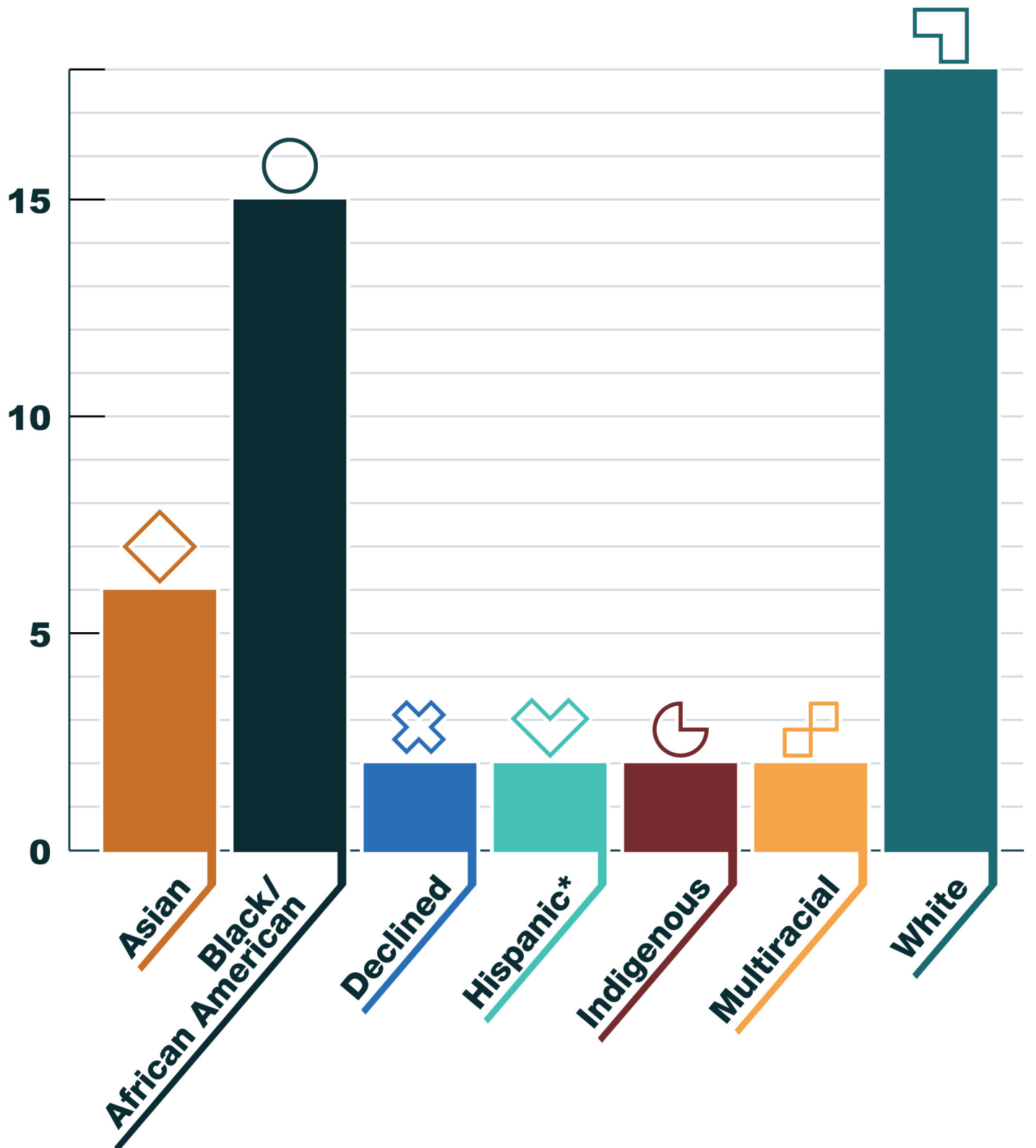
Figure 3



# Race and Ethnicity

(some people had more than one category)

Figure 4

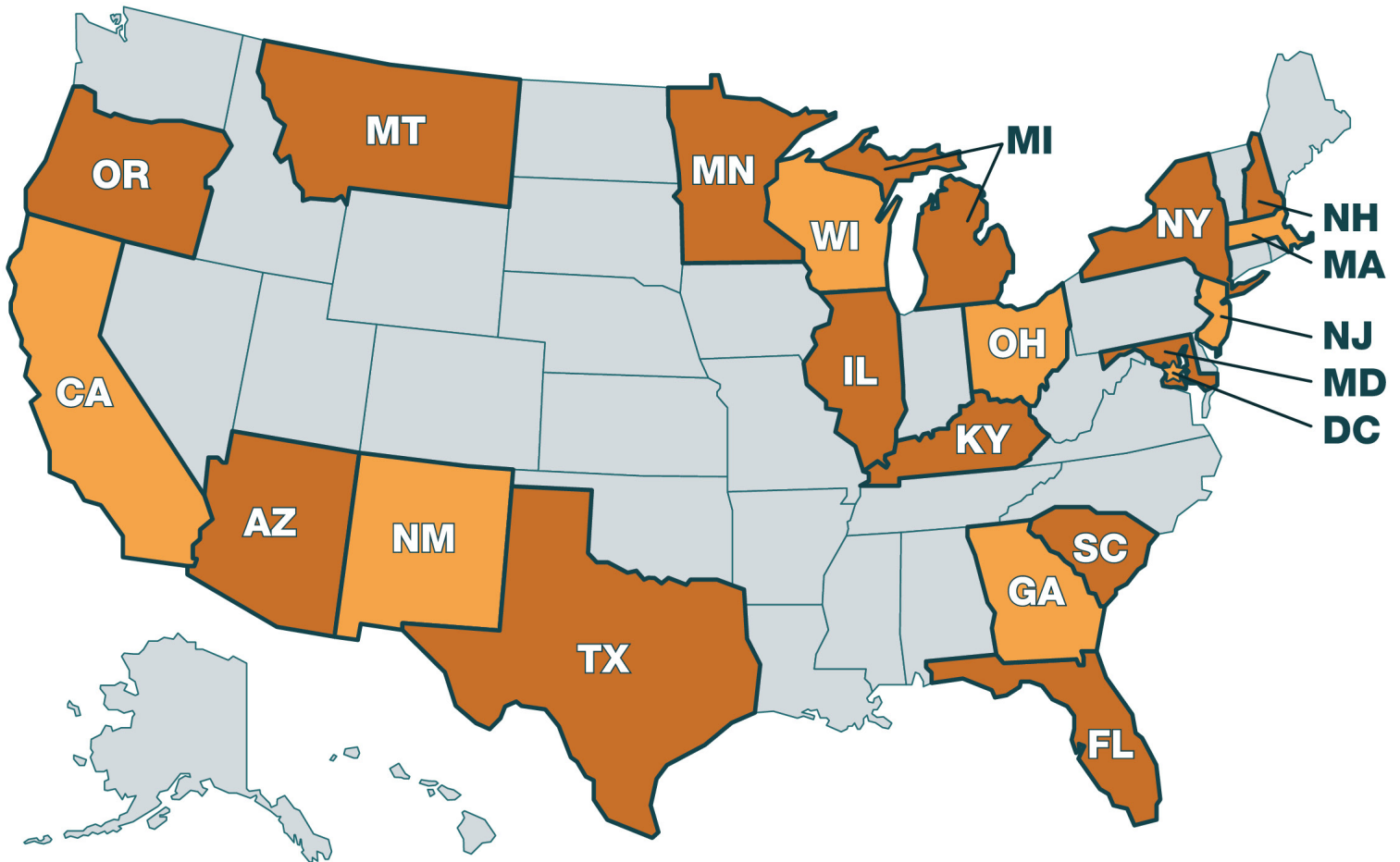




# Participants' States

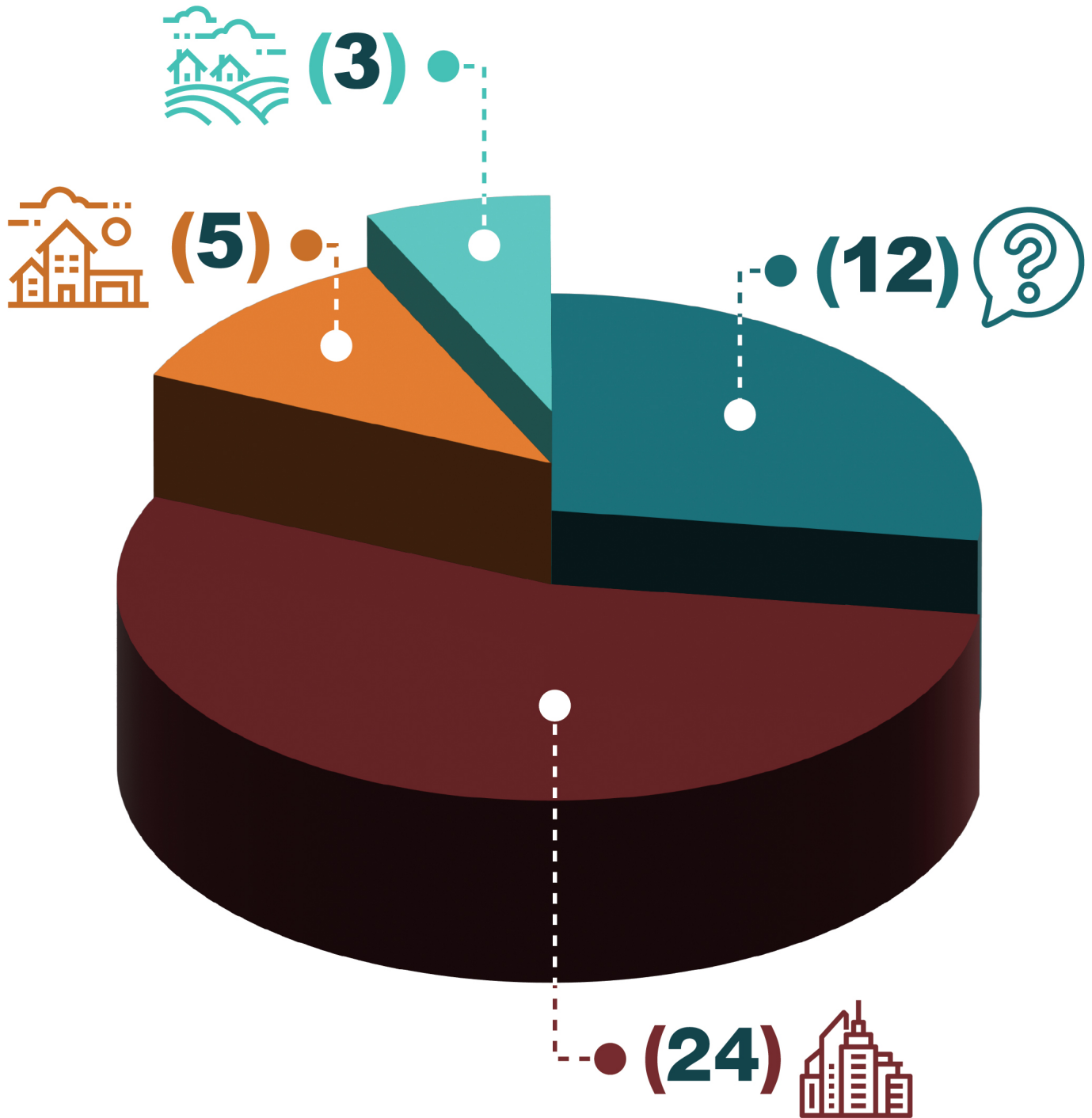
Arizona, California, Florida, Georgia, Illinois, Kentucky, Maryland, Massachusetts, Michigan, Minnesota, Montana, New Hampshire, New Jersey, New Mexico, New York, Ohio, Oregon, South Carolina, Texas, Washington D.C., Wisconsin

**Figure 5**



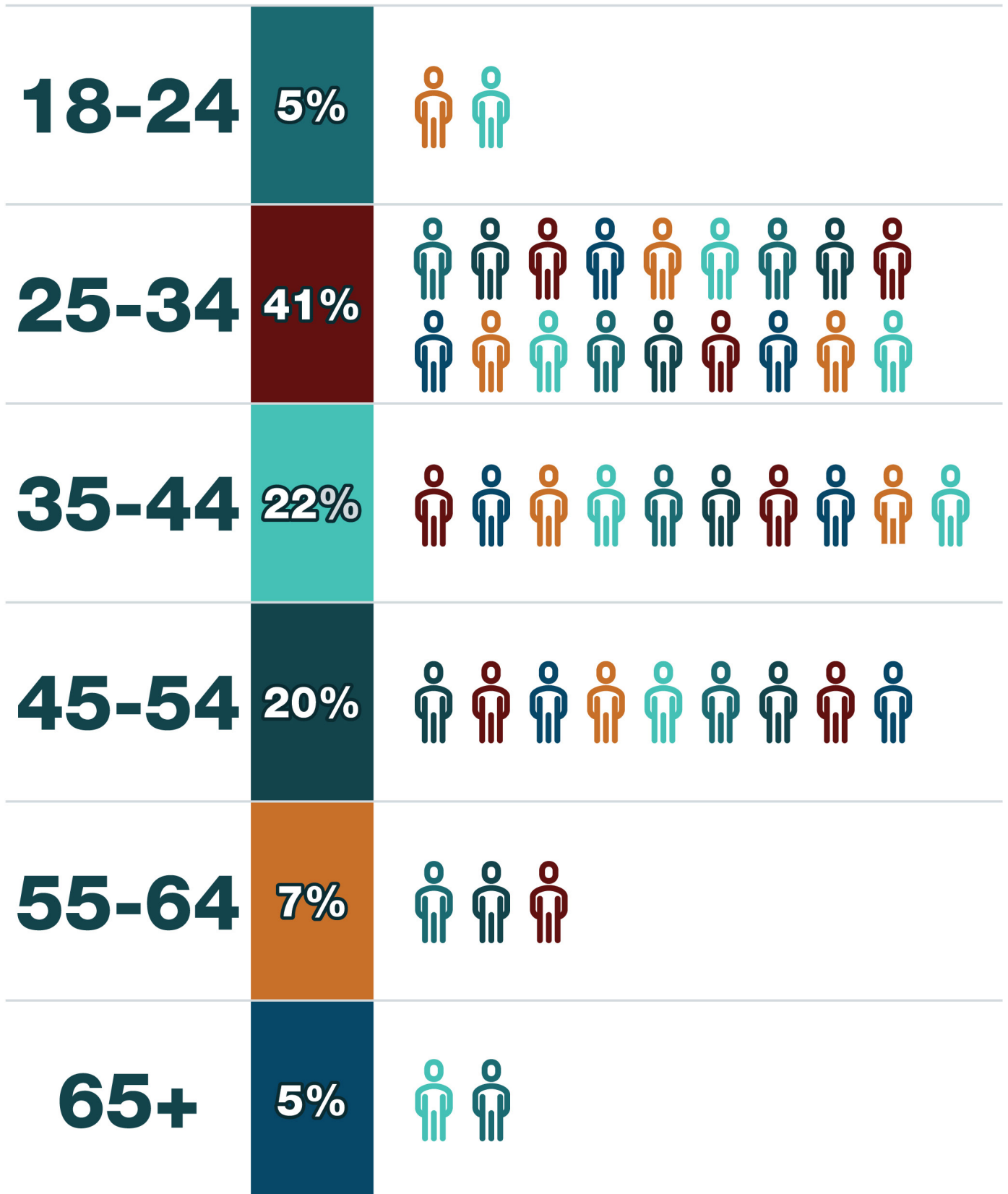
# Location Types

Figure 6



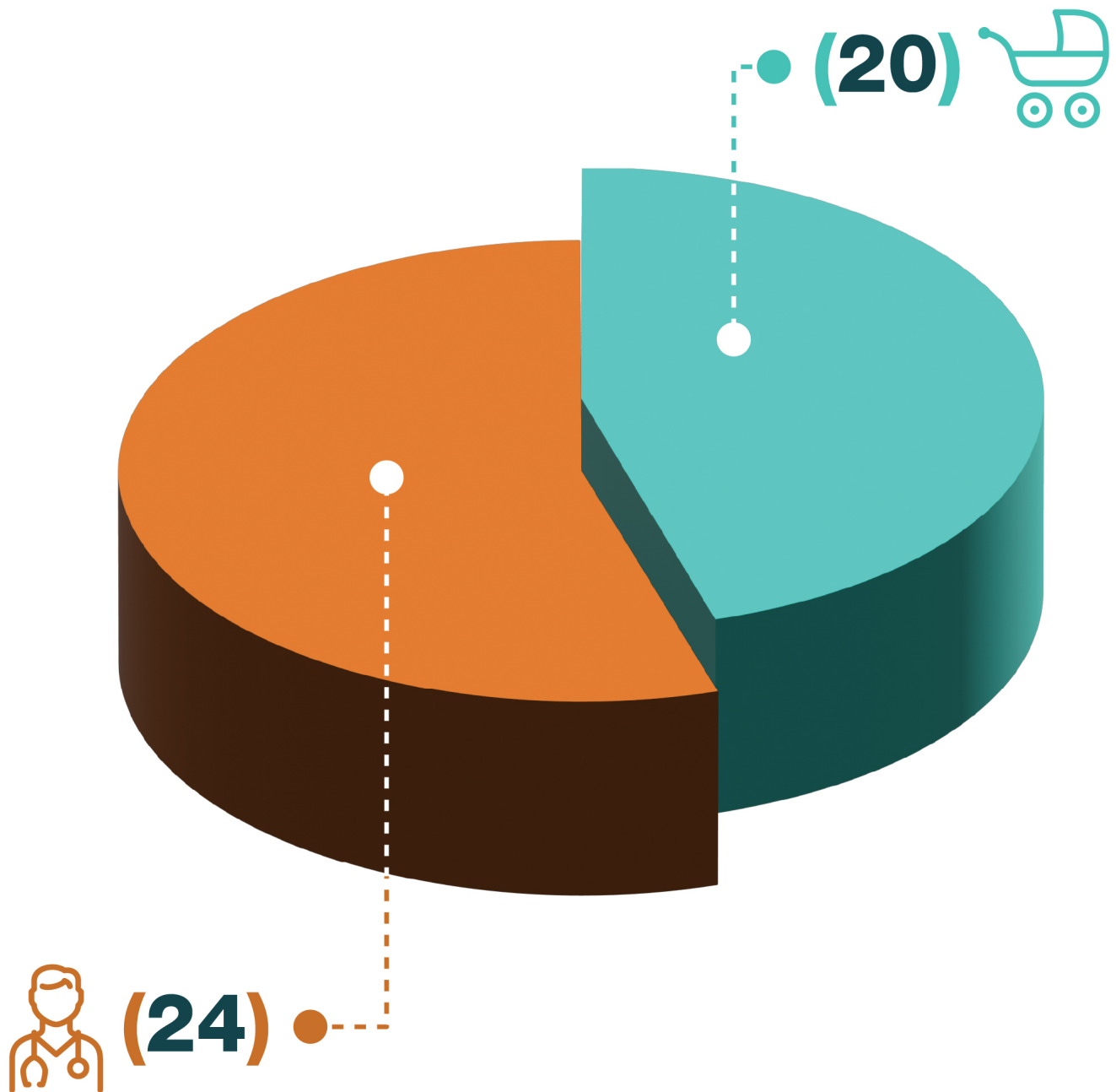
# Participants' Ages

Figure 7



# Participants' Impairment Recognition

Figure 8

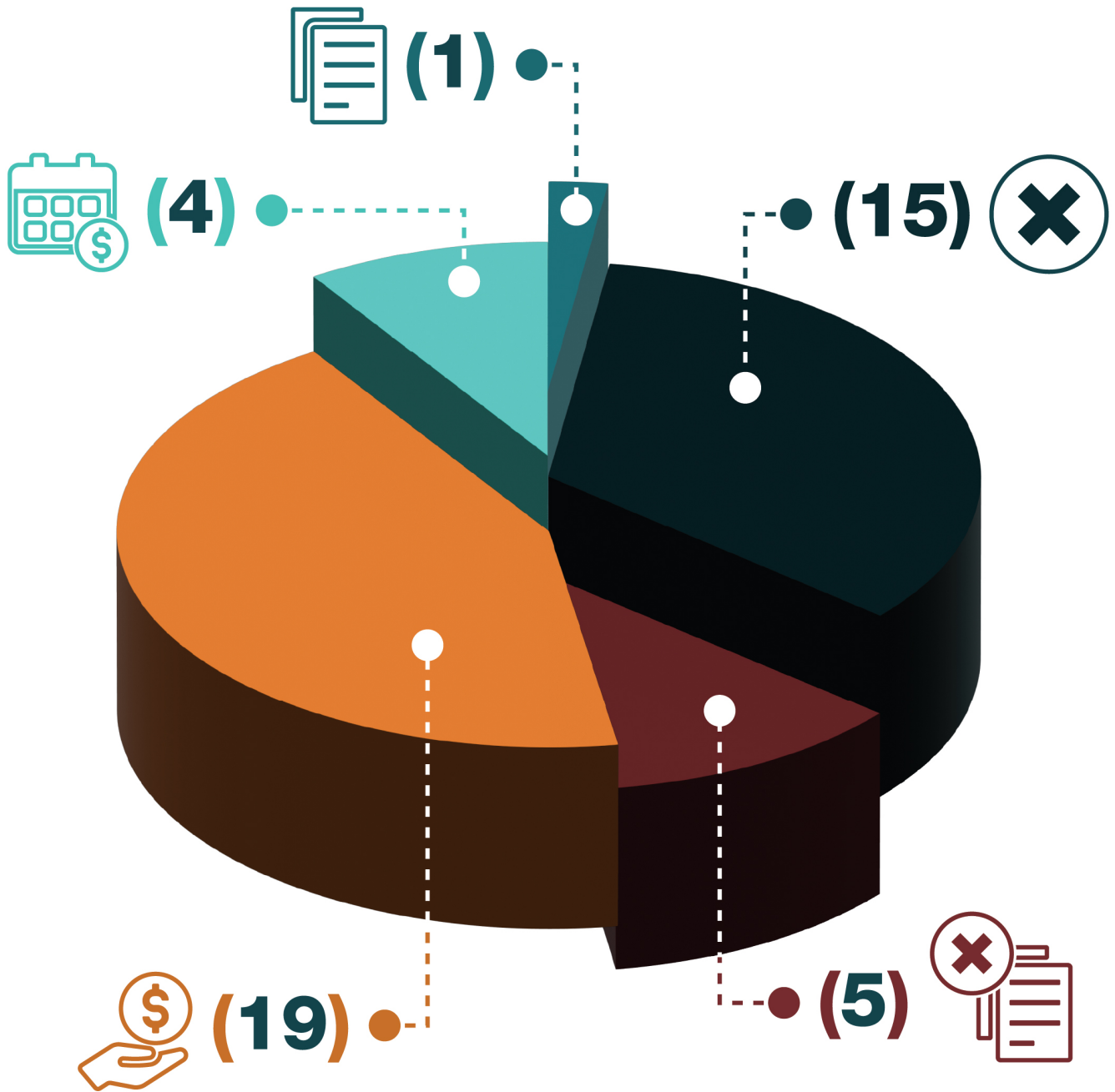


 **Acquired**       **Born With**



# Participants' SSA Disability Benefit Status

Figure 9



**Never Applied**



**Denied**  
(2 Reapplying)



**Currently Receiving**



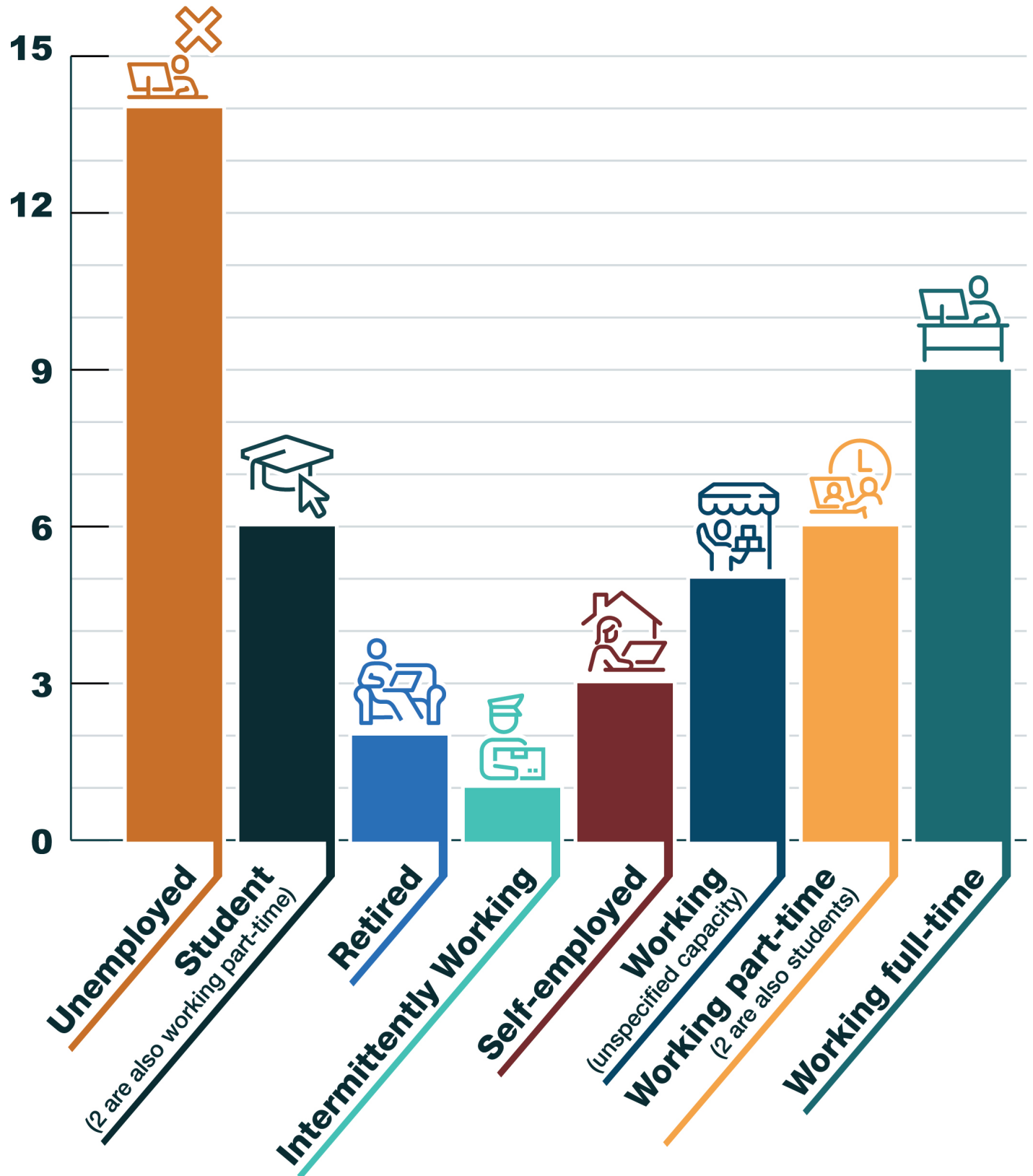
**Previously Received**



**Applying**

# Participants' Employment Status

Figure 10



# Impairment Types

*(some people had more than one impairment)*

**Table 1**

<b>“Leg defect”</b>	<b>Fibromyalgia</b>
<b>“problem with hand”</b>	<b>Hashimoto’s disease</b>
<b>“Use a wheelchair”</b>	<b>Immunodeficiency</b>
<b>Anemia</b>	<b>Intellectual developmental disorder</b>
<b>Anxiety</b>	<b>Learning impairment</b>
<b>Arthritis</b>	<b>Long COVID</b>
<b>Attention deficit disorder</b>	<b>Memory loss</b>
<b>Autism</b>	<b>Migraines</b>
<b>Bipolar disorder</b>	<b>Military sexual trauma</b>
<b>Borderline personality disorder</b>	<b>Nerve damage</b>
<b>Cancer</b>	<b>Neuromuscular degeneration</b>
<b>Cerebral palsy</b>	<b>Obesity</b>
<b>Chronic pain</b>	<b>Obsessive compulsive disorder</b>
<b>Deaf</b>	<b>Post-traumatic stress disorder</b>
<b>deaf</b>	<b>Premature birth</b>
<b>Depression</b>	<b>Sciatica</b>
<b>Diabetes</b>	<b>Seizure disorder</b>
<b>Digestive disorder</b>	<b>Spinal cord injury</b>
<b>Dystonia</b>	<b>Spinal disease</b>
<b>Endometriosis</b>	<b>Substance use disorder</b>
<b>Fatigue</b>	<b>Visually impaired/blind</b>



## On Language



# On Language

*Study question: “What are the structural contributors to disability in the U.S.?”*

The question this study explores conceptualizes disability according to the social model of disability (SMD), defining disability as being about disablement.<sup>18</sup> That is to say, disability is not inherent or internal to a person but rather it is imposed upon a diverse group of people who are presumed incapable or less capable based upon seen or unseen impairment(s), which are internal to the person. This understanding of disability from the root word “disable” aligns with the word’s origin in Middle English, “*disablen*,” which means “to deprive of legal rights.”<sup>19</sup> In the SMD model, lack of capacity materializes because structures create diminished ability to contribute or participate. This contrasts with other models, for example the medical model of disability (MMD), which conceptualizes the impairment as an essential limitation of an individual.<sup>20</sup> In MMD, disability is inherent to the person.

*“I may be disabled but I still have my pride and dignity intact...” (P31).*

*“I say visually impaired, disabled, blind...I don’t really use things like differently abled or like anything that’s sort of like softens it like, yeah, I’m disabled. Like it’s fine. It’s, it’s not a bad thing. It just is what it is” (P8),*

While this investigation is, by the very study question, clearly rooted in the social model of disability, we recruited participants who self-identified as experiencing disability based on their use or understanding of the term. SSA sought to hear from “people who live with disability” (see [Appendix: Study Recruitment Information](#)). Some people explained that they felt the term “disabled” applied to them because they are unable to do a particular thing (e.g., walk, see, be in a crowded room without having a panic attack), as described by the MMD. One participant who had a spinal cord injury and consequent paralysis

said, “I don’t mind the word ‘disability.’ I think it’s fine. I think it’s a good descriptive word because you know, an ability was taken away from me that I had previously...” (Participant 6).

*“...I was medically defined as disabled...Social Security, for example, does not currently define me as disabled due to their...economic concepts of disability... But by in large, I identify with identity-based language or identity first based language disabled person...and largely see my disability as a social construct that has particular body-mind experiences that are associated with them” (P41).*

Others defined disability in ways congruent with the social model of disability, sharing that they are disabled by structures that deny them accessibility or accommodation. One participant said, *“I identify as disabled and I believe that reclaiming language and using identity-first language like ‘disabled people’ rather than just ‘people with disabilities’ is important because it...kind of reminds us that disability is not within us or our body. It is a form of oppression that comes from society” (P39).* Some within this

group of people described code-switching: they use “disabled” as per the MMD to access government supports and other accommodations but do not believe or feel anything about themselves is incomplete or deficient, as the MMD implies. One participant said, *“...during my youth... when I identified as disabled...I was living with my parents. My, my parents sort of identified*

*me as disabled and put that in the paperwork, so that I had disability benefits until I got my own work” (P29).* Later she said, *“I don’t look at being Deaf as a disability, but society does. The federal government does. So, I label myself that way, but I think it’s a bit antiquated...I don’t say ‘hearing impaired.’ I don’t say I have an impairment. I don’t say anything like that. I just call myself Deaf” (P29).*

*“A lot of disability activists...find words like ‘special needs,’ infantilizing or cutesifying. And while on the one hand I, I understand why we still use terms like ‘special education,’ for example. I agree with the idea that continuing to call a person ‘special needs’ reduces the idea that accommodations should be universally available to an exception” (P42).*

*“I either say ‘I have disabilities’ or ‘as a disabled person,’ or ‘handicapped’... Something like that, because...it’s not important what I call it. It’s how somebody I’m speaking with understands that I have special needs...I don’t need to retrain them to use a different word...I’m just trying to alert them that they have to make some changes” (P35).*

For this report, “people experiencing disability” and “disabled people” will be used interchangeably, except when quoting participants.

Both MMD and SMD conceptualizations of disability center independence as a goal for the affected individual. But that is not necessarily the goal of all disabled people, or even a realistic option. Disability justice is a framework that centers the priorities and approaches of other historically excluded groups like people of color, 2S+LGBTQIA\* folks, and women. Further, disability justice de-centers the goal of achieving independence and centers the reality that interdependence is essential for all people.<sup>21</sup>

While this study did not specifically focus on other historically excluded groups (as described above), we did explore the goal of independence. Did participants value and work toward a goal of independence? Was this an achievable goal? Was this goal culturally resonant and relevant? The implication of the SMD and study question is that independence is achievable for all if supportive structures are in place. The reality is that this is not true for some people. Some people are wholly unable to independently perform activities of daily living (ADLs) and will remain so. One participant recognized this group of people though they are personally seeking complete independence, *“I think that’s the end goal for sure...to do most things by yourself. Some people are literally not capable of doing it, but if you still feel that your life is fulfilled with aid, with assistance, then that, that can be...fulfillment too. Now, if you’re -- speaking for me, yeah, I would like to do most things on my own for myself. I feel like that’s kind of me being an adult, you know, like adulting?” (P37).*

---

\* People who are Two-Spirit, Lesbian, Gay, Bisexual, Transgender, Queer, Asexual, and have other (non-heterosexual) sexualities and (non-cis) genders.

Some people are, to the best of medical knowledge, unable even with assistance to understand and answer the interview questions. Such individuals will rely on others for survival and, barring financial ability of kin, continue to need government support. This study was not designed to reflect their experiences or voices. Their voices, not heard here, reflect a counter-narrative to the mythology of complete independence being a realistic goal for all.





# Interpreting the Data

<b>Figure 1:</b> .....	<b>38</b>
<b>Healthcare (system):</b> .....	<b>39</b>
<b>Technology (practices, relational):</b> .....	<b>42</b>
<b>Transportation (system):</b> .....	<b>48</b>
<b>Employment (laws, policies, practices):</b> .....	<b>50</b>
<b>Representation (laws, culture):</b> .....	<b>56</b>
<b>The Social Security Administration (laws, regulations, policies, procedures):</b> .....	<b>63</b>
<b>Culture</b> .....	<b>72</b>
<b>Education (system)</b> .....	<b>81</b>

# Interpreting the Data

Based on the experiences and insights of the study participants, 8 structures were identified as *the structural contributors to disability in the United States* (**Figure 1**). The social model of disability defines disability as the social, economic, and political control of people whose minds and/or bodies are devalued, particularly in an independence-valued, economic system that relies on workers. Structures are systems, laws, policies, regulations, practices, customs, cultures, and norms, and the relationships and arrangements among them. According to the social model of disability, “impairment” is “the state of being mentally or physically challenged, and that is how the term is used in this report.”<sup>22</sup> Data generated from “Understanding Experiences” interviews yielded appreciation of 8 structures that are disabling of (social, economic, and political) participation and independence of people who have impairment(s).

Figure 1: The social, economic, and political results of these structures that, done wrong, are disabling



To make the findings more accessible to non-researchers, we present each structure’s results with interpretations about the present social, economic, and political impacts. It is important to remember that the content shared here is not exhaustive of all the ways that structural disablement may occur in the U.S.; the interpretations reflect on the data collected from this study’s participants.

## 1. Healthcare (system):

*The organized provision of health care to individuals or communities*

- a.** For people who have an impairment that benefits from healthcare intervention, geography affects access to equipment, and qualified clinicians, including specialists and high-quality specialized care. This affects whether individuals receive the highest quality of care or the basic clinical standard related to their impairment. *“I know there are other centers in the country that are specialized in spinal cord injury, but for me personally, I was kind of just at a care facility that didn’t specialize in spinal cord injury, it*



**A Black woman points to a part of her lower back while a clinician in a white coat examines her.**

**Access to health care was essential for many of the people interviewed.**

*was just a rehab center...So, I kind of -- I wish that I had been given more information about how to care for my body afterwards. I think they did the best they could, of course, the people that worked with me in...physical therapy and occupational therapy did the best that they could. But a lot of it, I just had to kind of learn on my own over the years...” (P6).* Although the Affordable Care Act allowed Medicaid expansion, geography also affects the rules of and access to health insurance for many disabled people,

as Medicaid coverages vary by state. *“...In my state...the health insurance benefits are really good. So, I think I was very lucky. I know it’s different in every state” (P9).*



Some participants relayed moving so that they could access such care; others commuted, even across country, to meet their needs.

- b.** Health care in the United States is expensive, especially for people with impairments, many of whom rely on Social Security disability programs, Medicare/Medicaid, or all of the above. These, and other public benefit programs, have complex regulations that govern eligibility, including limits on income and



**A masked clinician holds out a prescription bottle to masked Black woman; they are seated in the patient's home.**

**Some people need care that is not covered or that is insufficiently covered by insurance.**

resources. This puts people in the position of needing to “spend-down” the very resources that they would otherwise use, to stay healthy, prevent complications, and live autonomously, in order to ensure those benefits remain available. *“So, basically, you’re making people wipe out their funds intentionally in order to qualify for Medicaid”* (P35). Many impairments (e.g., neurological disease or injuries) result in sequelae that require specialty supplies and equipment that are not covered by insurance, either at all or as often as they need to be replaced, or perhaps only in a version that is merely functional rather than the

best-known version (e.g., urinary catheters, pressure relief cushions). People must pay (in part or in whole) for these items of necessity out of pocket; those that cannot afford these items experience complications (more frequently and with more severity) and/or isolation, making it impossible to work many types of jobs. *“My old cushion that I had was...giving me trouble. And that’s why I got, how I got the pressure sore. And I wasn’t able to get another one until that one was at least five years old. Because of the regulations and stuff like that, so. I had to suffer on it until I was eligible for a new one. And as soon as I got my new cushion, my sores were healed within a few weeks”* (P13). A recent study demonstrated that people who experience disability must earn 28% more than others to achieve the same standard of living.<sup>23</sup>



**C.** For people with a history of incarceration (for example) the state may mandate mental health therapy. But the patient is aware that there is no doctor-patient privacy: their personal health information is shared back with the state. Further, their probation or parole is contingent upon the therapy's "outcome." *"I'm ordered to do a mandated therapy through the state or city or what. They have a program that they have therapists that you know, report to my probation officer of how I'm doing and, you know, yadda yadda yadda. So, it's full disclosure. I had to sign a release consent form so they can read what's going on, which I don't have a, I don't have -- I don't get doctor-client privilege, confidentiality...the one from -- that, that's provided with -- by the feds or paid for by the feds, I don't really call that therapy. It's more of a, we're-keeping-an-eye-on-you-and-whatever-you-say-we're, we're-gonna-report-to-the, to-the-feds... yeah, they're licensed, but they're working for the feds. So, I mean they're -- at any moment, whatever they tell them can send me back to prison...until I find a job is when my therapist will release me. He was supposed to release me in January, but that was when I lost my job and they said, 'Oh, because you're not stable, we're gonna have to continue this'" (P33).*



**A young White man wearing business casual attire holds a box of personal items outside a metal gate with barbed wire.**

**Incarceration history can affect the privacy of mental health care.**

The court-ordered outpatient psychotherapy paradigm is not how therapy works for many people, does not align with most medical ethical codes, and may incentivize patient lies and penalize patient honesty in health care.<sup>24,25,26</sup> For the meaningful healing work and health care to ensue, this participant said he needed access to a non-state monitored practitioner. He shared, *"I went and got an actual therapist so I have my own peace of mind...because my probation doesn't know nothing about that"* (P33). But this requires resources many with an incarceration history may not have.

*“I think that the support you need in life is different when you don’t have a disability, like the amount of time I’ve spent with lawyers for SSDI, SNAP, like government benefits. The amount of time I spent with doctors and nurses,... medical assistants. The amount of time I spent with insurance companies fighting over a bill. I just am like, I don’t think this is a world that I would wish on my worst enemy” (P43).*

## Social, economic, and political domain impacts:

For people living with an impairment that benefits from healthcare intervention, where they live matters. Insurance coverage is state dependent; access to specialists is also dependent on proximity to particular healthcare facilities. For those whose health care is tied to their freedom from incarceration, there can be a coercive element to accessing the care they need. The present healthcare system enables or disables people, depending upon where they live and/or incarceration history, to receive needed health care, affecting their ability to participate as a worker in the economy (and thus a consumer). Those disabled or excluded from working in the U.S. experience the economic precarity of poverty, which further endangers their health,\* minimizing capacity for social and political engagement.

## 2. Technology (practices, relational):

*The use of tools to ease or facilitate an activity*

- a.** Accessibility technology which facilitates safety and inclusion is neither uniform nor pervasive, and is often lacking or incomplete. For example, for blind or visually impaired folks, the crosswalk indicator may sound off, but the audible indicator is not present at every crosswalk and the ding meaning is not standardized.  
*“...With specifically the sidewalk thing. I don’t think the beeping, you know, the audible sounds, are, are good enough ‘cause they,*

---

\* The National Institutes for Health (NIH) recently recognized disabled people as a population experiencing health disparities stating “...exclusionary structural practices, programs and policies inhibit access to timely and comprehensive health care, which further results in poorer health outcomes.” <https://www.nih.gov/news-events/news-releases/nih-designates-people-disabilities-population-health-disparities>



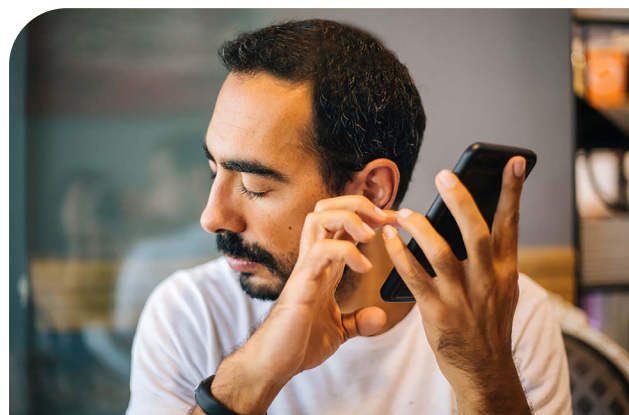
**A blind White woman wearing a plaid button down shirt stands with her guide dog at an intersection.**

**Assistive technology at crosswalks are not yet standardized across the U.S.**

*they chirp, or they cuckoo. But then how do you know when to cross? Like the ones that actually count you down and say are better than the ones that just chirp. ‘Cause like what, what does that even mean? You know?’* (P15). This participant also discussed assistive scene readers that help blind and visually impaired people independently navigate outside the home (especially) though they require having a smartphone with service, and while the

application is currently free, it is still experimental. Maximum safety for some blind and visually impaired folks navigating outside the home may require a sighted escort or a guide dog (difficult to obtain due to stringent standards and limited resources in comparison to need). This participant was only able to do some of her work as a teacher because she used a teaching assistant to compensate for the lack of accessible electronic communication. *“Sometimes I would get an email [about work] that was not accessible like a, a link...and I had a full-time teaching assistant. So, [I’d have to ask her] ‘Can you click this for me?’ or, ‘What, what does this say?’”* (P15)

- b.** Participants had a lot of suggestions about how communication technology could be better used by institutions; depending on the impairment various adaptations or accommodations are needed. One participant said that because they have low vision and a seizure disorder, braille documents and/or audio communication are most appropriate for them. Multiple participants said electronic, visual communication would be most effective for them. *“I need that on email, but then they [SSA] keep saying, that’s too insecure and you know, whatever. But you know, there’s people*



**A blind Latino uses assistive technology on a smartphone.**

**Communication technology can improve how institutions communicate with the public.**



*that can, there's technology out there that they're not using. So, make it quicker and more -- because I will respond to an email much faster, or even a text message saying, you have a new message on your SSA account and so then you log into that and you know, yeah. Like employ the same technology that a telehealth might...employ.”* (P15). A blind participant that also wanted email communications said assistive reading technology would allow them to read their notices.

Universal video relay to facilitate telephonic communication between hearing and Deaf people is free in the U.S., paid for by funds from the Telecommunications Relay Service (TRS) Fund. One participant described how a city government has made itself accessible to Deaf community members using this kind of technology, *“...I know [city] Mayor's Office of People with Disability, there, they have a dedicated line called Direct ASL. Anybody who called that number will have a signing person on the screen. So, I really think that's what every government agency should have”* (P22).

- C.** Participants noted that virtual communication platforms have improved their ability to interact with others, especially if they live in areas where transportation is not accessible. *“If I would have had to get transportation to go do this interview...I would have had to schedule it [paratransit] the day before. If it doesn't show up on time, or it doesn't show up at all sometimes”* (P10). Participants also noted that virtual communication platforms can make education and jobs more accessible, especially if they do not have access to reliable transportation. One participant is seeking *“...a fully remote position so that I don't have to worry about getting someplace on time...”* (P15). Importantly, while virtual communication platforms can increase accessibility, they depend on a strong internet connection which is not universally available across U.S. geographic areas or economic strata. *“I did offer the option of video, video remote interpreting, VRI. And the drawback of that was that the Internet connection was pretty lousy”* (P29). And a few participants noted that not all virtual platforms are “created equal.” One participant said the platform he prefers *“...of all things is Zoom, because honestly, right there, Teams is more glitchy”* (P7). Not during



interviews but in the study team’s efforts to provide informed consent and study documentation prior to interviews, some blind participants and those with low vision requested to call in or be called for the interview. They found the approved interview platform (Microsoft Teams) inaccessible when trying to use certain features or Teams was not compatible with their screen readers; they reported preferring another platform (Zoom) that did not require downloading to function and that worked well on various devices.

- d.** One participant’s story highlighted the importance of institutions appropriately using technology instead of as a substitute for real accessibility. For example, many hearing people incorrectly assume that written English is a sufficient form of communication with a Deaf\* person, and while not all deaf or hard-of-hearing people sign, American Sign Language (ASL) is a different language than English. *“...I have to depend on captioning or a transcript if that was available, and that’s not the same as having sign language...it’s not really equal access for me”* (P25).
  
- e.** Participants provided multiple examples of how appropriate use of technology increases accessibility and their ability to function. *“I use a, a, a big monitor to help me see things and so that’s how I work. That’s how I adapt at work”* (P23). A participant with autism and intellectual developmental disability (IDD) was interviewed with the support of a parent. He reported needing to use headphones sometimes, and being allowed to use them supported his ability to attend school and learn. Participants that had the means or outside support could use technology to facilitate independent movement outside of the home: *“...so, I got -- like went through that part of drivers’ training again and passed that and then I got a minivan, and [state service] paid for me to get*



**A masked woman with cerebral palsy uses a lift chair to get into her minivan. Technology can help people become more independent.**

---

\* “Deaf” with a capital D refers to the Deaf community, which has its own culture and sense of identity; “deaf” with a lowercase d refers to anyone who has a severe hearing problem or is severely hard of hearing.

*my adaptive equipment installed in my car” (P14). Another participant shared, “...my tablet is made by a company in Canada that...created an Android tablet specifically for blind people. And so, it’s great because it has all the functionality.” (P15) However, when the tablet needs to be repaired the participant said, “...I’m without it for, six weeks to three months ‘cause the...state’s rehab department will pay for it, but they drag their feet. You know, there’s a lot, all kinds of red tape. So, the time that it takes to ship it out, get it...figure out what needs to be repaired, get it paid for, and then repair it and ship it back is quite a bit of time. And that -- it would be like you, as a sighted person, being without your phone and your car” (P15).*

**f.** Participants also noted that technology increased their capacity to reach other people with their impairment or that experienced disability. These connections were helpful in learning to navigate a changed life if they acquired their impairment and/or develop a sense of belonging in a community of people with like-experiences and struggles. One participant finds community in an online group, *“...our lifestyles are all about adapting on a daily, hourly basis. Conversations are different. Talking about accessibility, lack of PCA’s\* like, wheelchair equipment, different stuff like that” (P10).* Others noted that online disability communities challenged them to push beyond presumed limitations and can function as a resource repository. Another participant said, *“...we exchange tips and tricks and all types of things anytime we get together and so that’s really nice to have that community and we all keep in touch throughout the year on social media and whatnot” (P6).* One participant finds the online community groups overwhelming and specifically only uses them

*“That’s one thing I really don’t quite understand. I’d like to get a conversation someday with people with four or five, six disabilities and speak about the day-to-day because I don’t really understand or know what they go through, you know. Don’t know” (P10).*

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\* PCA: personal care assistant/aide

for logistical purposes: “...I tend to go on those groups when I need something. Like, when I’m looking up, like...as a resource” (P44).

- g.** Some Deaf participants discussed the use of cochlear implants. One participant empathized with hearing parents who are unfamiliar with the richness of Deaf culture and have a desire to give their child every opportunity to succeed and be happy in an inaccessible society. Still, he thought having the implant should not supplant learning ASL and building community with Deaf folks, and thinks of the implant more like being bilingual. *“I see other Deaf kids who have cochlear implant[s]. You know, they have the best of both worlds”* (P22). Another Deaf participant recognized the implant technology as a tool but declined the surgery, *“...my decision was, no, I’m just going to be a signer and, you know, speak for myself, you know? And I decided not to use the tool”* (P29).



**An older North African man signs in conversation using a virtual meeting platform on his computer.**

**Some Deaf people choose to use video technology and sign language instead of a cochlear implant.**

## Social, economic, political domain impacts:

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Technology has the capacity to connect people with impairments to the rest of the world and others with impairments, and can make environments accessible. There is not a one-size-fits all approach, rather the technology needs to meet the need of a person and should be used appropriately. But the logistics of standardized and universal accessibility have been insufficiently implemented and there is inadequate resourced support, meaning some people miss out on social activities and job opportunities. Government use of accessibility technology may increase people’s ability to access services and participate in political action.

### 3. Transportation (system):

*How people get around a geographic area, including movement under one's own power, use of a vehicle, forms of public transportation (e.g, bus), airplane, or railway*

- a.** A few participants living in cities with reliable public transportation reported getting around independently this way. Many living in rural and suburban settings rely on private transportation (i.e., having and operating a car, or having access to kin who can chauffeur) or paratransit, a ride service for people with impairments. One participant said, “...I will always live in a city, because if I was out in the suburbs or in a rural area, I would be trapped” (P8). The Americans with Disabilities Act (ADA) only requires public agencies that provide fixed-route service to provide corresponding paratransit services. On demand paratransit services may be offered in addition to or instead of complementary paratransit. But what about people who do not live in a jurisdiction that has a public fixed-route service?



**A young White woman using a wheelchair looks around a city at night.**

**In a city, it can be easier for people with impairments to get around independently.**

*“...I have to like, think about where I’m going, whether or not it’s accessible” (P6).*

How can they maintain a job that requires in-person appearance? How do they engage with social networks, which also maintain wellbeing? How do they participate in political actions, including voting, especially in states that limit mail-in voting? This was particularly relevant for participants who lived in rural or suburban areas, “...I do feel limited in some ways, especially living out in a, a rural area because there’s a lot of woods around and that’s not easy to get around” (P6).

And even locations with seemingly good public transportation have deficits in their accessibility. One participant spoke about living in a city with one of the



nation's oldest subway systems, *"...if you're along several subway lines in the boroughs, they still have elevated tracks with...only staircases, and the elevators are constantly broken and nobody—it's just, it's, it's appalling at how low a priority it is..."* (P35).

Additionally, paratransit services are often insufficient and unreliable for workers, for example. One participant shared that the ride is scheduled to arrive during a

1-3 hour window but if it is late, the negative reflection is on her: *"...if they get me there to my school or work or whatever late then it's not my fault, but I am looked at as incompetent"* (P15). Once, she got to her drop off location so early the site was not open; she had to wait on the street. Or, the rides can arrive late when users need to leave a location, and they are stranded away from home. *"...then I could, we could be done with the interview. I might have to sit there for an hour or two because once again the ride's not there, didn't show up..."* (P10).



**A young White woman waits at a bus stop while looking at her phone.**

**Paratransit services need to be improved to be more reliable.**

- b.** Additionally, a participant noted that on multiple occasions she has had to educate public transportation and taxi drivers, and airlines\* about her rights under the law to travel with a service animal. *"And I had a situation with a cab that wouldn't take myself and another person. And unfortunately, you know, because he wouldn't, he got fired from his job and I feel bad about that, but...you know, people have to know what's, what's what. I mean, they have to know what our rights are. And if we don't show them, then they're not gonna know. So, every day I'm always out there educating people"* (P9).

*"Having a service dog is really, has really opened my world a lot. I, I feel more confident"* (P23).

\* The participant also mentioned this problem occurs in restaurants.

## Social, economic, political domain impacts:

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Transportation offers opportunities for socialization, economic participation (working and consuming), and political action. While technology is improving to facilitate virtual interactions, in-person interactions still have value for individual wellbeing. The inability to be present in person limits prospects for social networking, and increases economic precarity and political exclusion.

### 4. Employment (laws, policies, practices):

*Hiring practices of employers, and worker experiences seeking and maintaining a job or promotion*

- a.** Jobs for at least some people with impairments can be hard to come by and one participant noted that sometimes the physical infrastructure tells him that he should not even apply: *“You know, I can’t guarantee I would have gotten the job anyway, but I mean, some jobs I never even applied because I’d look at the building and say, ‘Yeah, that ain’t gonna work’”* (P13). Another participant noted that achieving a promotion is also harder for people with impairments; for her, promotion requires an interpreter commensurate with her skill level, so that her capacity is demonstrable. *“I feel limited. Even though I’m satisfied with my job. And it, but if I want to change to a different job, or move to a different job, it’s not that simple...There aren’t that many jobs available, specifically, for Deaf people...I have to work harder to prove my ability to do the job, so that has to be exhibited...The recognition, if I want a promotion or a different job...just takes more. You know, I’m thinking...like interpreter’s skills, and interpreter availability. And I have to have an interpreter that, to*



**A young White man looks concerned during a job interview.**

**Participants thought that employers' biases against people who use accommodations contribute to underemployment of disabled people.**

*match my communication needs, and the level of communication that I do, to have any type of promotion” (P25).*

*“...let’s face it, as much as they want to be diverse, if hiring you is going to present problems, financially, or otherwise, for the company, or if other people have to work harder so that you can be successful, they’re not gonna hire you” (P15).*

Participants expressed why they think employers, including small business owners (who are not required to make workplaces accessible), may not hire people with impairments: concerns about liability for accidents, and the expense to obtain and retain physical infrastructure and technological assistive devices.

*“...Because sighted people don’t understand blindness. And so, they’ll -- either they don’t, they don’t understand, they think that we’re a liability ‘cause if ‘Oh, if you walk around you’re going to trip and fall.’ Or, or, they can’t afford the accommodations, or just don’t*

*want to put up with the accommodations” (P15).* Participants said some employers think it is cheaper and more profitable to hire workers who do not require accommodations that cost money. *“...A lot of hearing... employers, like ‘Ahhh, what do I do with the Deaf person,’ you know, ‘How do I communicate?’ Even though you have the laws there, but they’re like, oh it’s gonna cost them money to provide interpreters or accommodation. So, it’s, you know -- well, in government, I think government, you know, especially in the federal government they’re the...highest employment agency to hire people with disabilities and Deaf people” (P22).* Some participants also described that potential employers presume disabled people are inherently less capable than nondisabled people.



**An older East Asian woman on a computer screen signs to another woman who isn't facing the camera.**

**Some accommodations cost employers money to provide.**



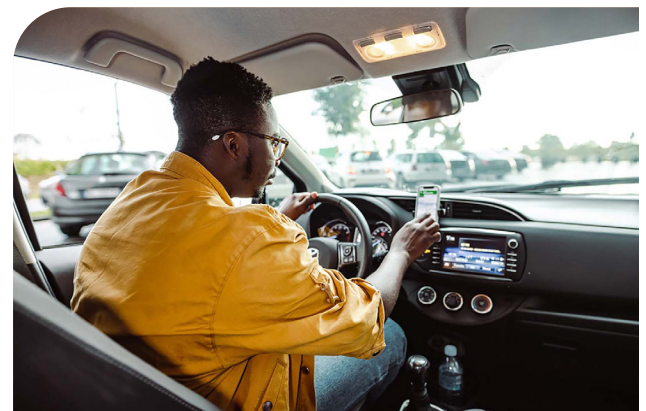
This participant shared, *“...being labeled as a disability has a negative consequence too, ‘cause people don’t think that you’re alive or you can’t do anything...people can think that you don’t have the -- you’re not capable of doing the work that needs to be done...So, a good example for me it would be when I applied for [company], they had never heard of a disabled, visually, legally blind person working in brokerage... So, I didn’t get offered the job and I had to go through the Americans with Disability Act for it, to get it”* (P23).

*“...you have to disclose your disabilities so you can get accommodations at work, and some people make assumptions. They have low expectations”* (P38)

- b.** When employers do not provide the necessary accommodations, besides harming worker productivity, participants also felt excluded.

*“[I] did depend on the [ASL] interpreters for meetings and sometimes my boss wouldn’t give me that access. So, I would have to rely on...my team members to write notes on the meeting or write out what was being said, and that didn’t feel very inclusive. I didn’t feel like I was part of that. I felt like it was just a hearing team meeting. And it happened often because the boss didn’t think I needed the interpreting”* (P29).

- c.** Participants were asked about gig work resulting in diverse insights. One person pointed out that gig work does not afford as many legal protections against discrimination. *“...As a gig worker, you can’t prove you’re being discriminated against. All you know is nobody’ll call you for work...but you cannot prove [it], it’s because they know that they’re gonna have to provide some sort*



**A young Black man sets his GPS' navigation before driving.**

**Gig work has some benefits but can be difficult to navigate while receiving disability payments.**



*of accommodation to make it possible for me to do my work” (P28). Another participant describing gig work and navigating the Social Security Administration (SSA) earnings reporting system and its slow response time said, “I wasn’t working full-time, but I was making money, you know, like, very brief gigs. You know that weren’t gonna last that long. But I, I didn’t wanna not report it. You know, and so I – there were times that I just didn’t, you know ‘cause, yeah...because, it would just take too long, once they started deducting. But then okay, you – now, that job is done. Or that show is done and to reinstate benefits would be quite a bit more time” (P15). A few participants pointed out that gig work is not reliable enough to pay enough to support survival but “...it helps me fill in gaps every month...” (P3).*

- d.** Accommodating schedules are essential for some people with impairments to be able to work. Some reported needing flexibility to allow for inherent complications related to their impairments (e.g., needing more time for morning hygiene, exacerbations of symptoms, tardy/unreliable paratransit services). *“...That happens about once a month, I would say, like, where I’m just really, totally inactive and like, pretty much in bed for at least five days...Which affects, you know...work and everything. But...my work has been, like, very, very understanding about stuff like that. And they’ve been really, really accommodating...” (P14).* For others, a fixed schedule is important so they can plan care needs or avoid mental/emotional stressors of surprise work. *“...I need to have a schedule. Like I, I can’t just, I can’t just be like called in at whatever like point in the day where my employer happens to think that they need one more person. That, that doesn’t, that doesn’t work with me” (P1).* Of note, the above quoted participant’s story highlighted the capricious nature of accommodations at some jobs. She described losing her job after a supportive supervisor was replaced by one who refused to make schedule accommodations. While the worker believes her rights were violated, she does

*“...so having those accommodations like are the only reason I’ve been able to get as far as I have” (P3).*

not have the finances to engage with the legal system to win back her job.

- e. Equal pay remains elusive for at least some people who have impairments, either due to employer bias or limitations on how much they can earn and still maintain benefits (see [SSA](#) below). They are often paid less and participants suspect it is because employers sense they can “get away with it.”

*“Employers...they think, well, if I give you, this person, a lower rate of pay to do the same set of skills, you know, they could get away with that because the, because the person’s Deaf. And I’ve noticed that, that’s what I’ve seen, that Deaf people tend to make less than their hearing counterparts” (P29).* Some participants expressed that employers think workers with impairments should be grateful they are hired at all. One participant described a time she was hired but the company refused to pay her rate from before she acquired her cognitive



**A Black woman with braids looks skeptically at another person who is not facing the camera.**

**Some participants were frustrated with how they are treated by employers.**

*impairment, “The amount they gave was one quarter of my quote five years ago, one quarter. I said, ‘Excuse me, I did not do one quarter of the job. I did 100% of the job. What the hell is this?’ And they’re like, ‘Well, we told you it was scaled back this year.’ I said, ‘Yeah, it was scaled back in other areas, in like, catering. I don’t work in catering. The show was not scaled back. I didn’t have fewer speakers. I didn’t have lower client expectations. I’m sure you didn’t pay the union stage manager on that gala one quarter of their fee. So, how is it okay that you pay me one quarter of that?’ I was only able to get them up to 50%” (P28).*



**A young White woman using a wheelchair gestures to a projected slide during a presentation.**

**Inclusion and accommodation in the workplace needs supportive leadership.**

*f.* Jobs where people with an impairment lead may be more inclusive because inclusivity is at the fore for the organization. One participant shared, *“If we brought in a hearing person to join our meeting, we provided an interpreter for that person. So, the Deaf-led organization just felt a little more accessible”* (P29).

*“...the whole notion of accommodations needing to be ‘reasonable’ poses barriers and like people needing to have diagnoses in order to get school accommodations or work accommodations umm, is like, you know...makes it so that people who have additional...marginalized identities find it even harder to get those accommodations because of medical racism and you know medical gaslighting and, and other forms of oppression”* (P39).

## Social, economic, and political domain impacts:

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There are laws to protect the rights of people with impairments in workplaces, but there are a lot of loopholes too. Accommodations can cost money and take time and/or effort, and not all employers are able or willing to make those investments if they are not required by law. Consequently, well-qualified people with impairments that require accommodations may be underpaid, underemployed, or unemployed, and reliant upon disability benefits, kinship networks, and/or gig work. As discussed below, disability benefits are insufficient to facilitate thriving (economic and otherwise); kinship networks may or may not be fiscally capable and financial reliance can complicate those relationships; and gig work offers fewer legal protections than traditional work arrangements and minimal fiscal future planning options. All of these realities coalesce to place people with impairments in socially and economically precarious situations, with diminished political capacity.

## 5. Representation (laws, culture):

*Visibility in media (e.g., television, movies, books) and in community settings*

- a.** People who experience disability are not meaningfully, consistently, realistically portrayed in media. One participant said, *“There’s so many like movies and TV shows that are portraying people with BPD\* and bipolar in ways that are just like ridiculous and over the top and so inaccurate”* (P1).

*“...if you don’t share the stories and then we are constantly silenced and we don’t motivate and lift each other up, and we only care about ourselves. How can we become a community? And if you don’t show different examples of other disabled women, how they overcame the obstacles, how can you help the next person get off the system? Don’t you wanna help people get off of disability?”* (P38).

Actors and models without disability experience portray people with impairments, while lived experience actors and models are not afforded the opportunity to represent themselves for work. Overall, people with impairments do not see themselves represented accurately or positively in movies, TV shows, ad-campaigns, etc, even when the merchandise is being marketed to them. One participant, who has had a few opportunities to model in ads shared, *“...you’ll see a lot in advertising that companies will use these stock photos of people in like these big, oversized hospital wheelchairs and you can tell like the person is not actually disabled...Cause anybody who actually uses a wheelchair is going to see that those images of people in this big hospital wheelchair and know that like that’s not genuine”* (P6). This participant said that the new trend to hire people with lived experience is important to normalizing the visibility of people who experience disability. *“So, I think*

*that’s really important to like use real people with real disabilities in advertising. So that’s part of the reason why I, you know, I was*

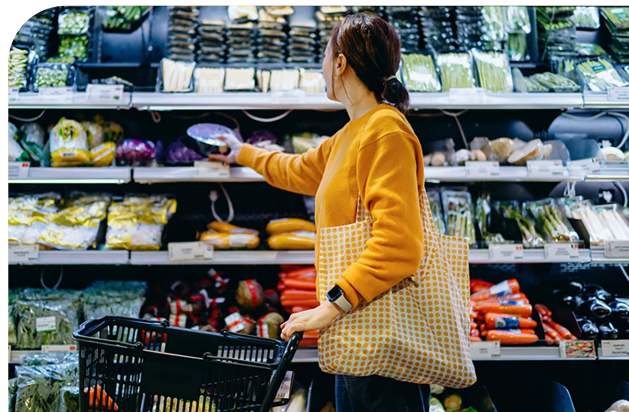
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\* BPD means "bipolar personality disorder;" the formal psychiatric term is "bipolar disorder."



*very happy to participate in that because I, I have seen a shift over the last few years in commercials, advertising, and like websites, clothing websites, using people with genuine disabilities. I think that's important because it helps us to be seen" (P6).*

- b.** Likewise, lack of visibility of people with impairments in their community (e.g., grocery stores) contributes to some people feeling shame or embarrassment. *"...In a case where you wanna go pick up something and then that place...has a, a large number of people you might...like I would feel embarrassed...[as] peoples' attention...shifts for me to pass through..." (P18).* Another participant described that children recoiled in horror at the sight of him in his wheelchair because people who use wheelchairs were not a common sight in the area. *"We went to go see a movie in town or and I was in a chair. It was one of the first times I had ever been in a wheelchair in public like that. And I just remember these, these two kids were horrified by me. And their parent like grabbed 'em and pulled 'em out of the way like I was gonna run 'em over and I was traumatized. Like, I love kids and all of a sudden now I'm a monster. And like, I, I was, that was the first major reality check. So, I was in the movie, I, I didn't, I just remember I was just crying to myself and really realizing, 'Oh my God, this is real now. Like, I'm a freakin' – I'm looked at like that now? Like, are you kidding me?' And I don't remember any part, I don't think I watched the movie. I think I was just sitting there and just devastated. So, yeah, that was the first reality check" (P10).* Similar to some other participants, this participant also described having to move to meet more people with impairments and feel more confident: *"After I finally moved here, it was like there's no looking back*



**A young woman, facing away from the camera, is picking a product from a grocery store shelf. People also learn about others by seeing them, in every day activities, in the community.**

*like, everything was good. I know a lot of people that have spinal cord injuries struggling like myself and...I didn't feel like an alien anymore. I didn't feel like...there was no one around me like me” (P10).*

Part of the lack of visibility in communities is due to the lack of normalized accessibility. For example, one participant described that she does not attend local town hall meetings because no ASL interpretation is provided, so she cannot participate in the conversations. Her political voice is silenced. *“I don't get involved in city politics...because they don't request interpreters and they don't provide them” (P29).* Another participant said that because his neighborhood streets and buildings are insufficiently wheelchair accessible, he usually does not go out alone, if at all. Further, he does not go out if it is not necessary, *“I don't really see the need...let's just say going out for fun because I feel I would...be inconveniencing you [family member]” (P18).*

Multiple participants described that they cannot participate in fun activities in their communities because the spaces are not accessible or accommodating: restaurants and bars often have tables and seats too closely spaced for wheelchairs to fit; menus are often not available in braille and their online menus are not compatible with assistive readers; some sporting venues provide terrible seats for people who use wheelchairs to view the event. Participants provided example after example of how lack of universal accessibility is socially isolating. *“I personally can't go to all the locations or go out to as much as fun places as I want to go. We can only meet in a particular place” (P34).* Just going out in public or traveling can be difficult if someone needs assistance toileting. *“...Let's say you need someone else to let you, help you go to the bathroom with you. Those things [airplane restrooms], there's not enough space*



**Two people out of frame lift a middle aged White woman using a wheelchair up three steps.**

**Many socializing spaces are not accessible to people with impairments.**

for two people in there” (P12). When some participants do try to use inaccessible buildings, for example, they risk bad outcomes.

One participant said, “Or, you can’t use the bathroom and like people have an accident” (P10).

*“We see somebody coming toward us who’s clearly ill, and they’re thinking, ‘Oh, I just got a cold. It’s no big deal.’ Well, a cold for them ends up being something much more serious for us if we catch it” (P28).*

A few participants described “MacGyvering” or jury-rigging accessibility when it was not present. But one participant described the potentially disastrous impact this can have. He was an event presenter but the stage was not wheelchair-accessible so he asked for some volunteers to carry him, in his wheelchair, up the stage steps: “...they asked me if I wanted to do it from the floor and I, and I looked up and I just see there’s no way all those people are

*gonna see me. So, I actually asked people to lift me on the stage... And, and the guy on the front right of my wheelchair, he, he fell, and I almost went down” (P10).*

- c. “Invisible”<sup>\*</sup> impairments (e.g., having autism, cancer, an auto-immune disorder, mental illness, low vision) are minimally and inaccurately portrayed in the media and are not necessarily obvious to others, so others do not believe or even conceive of the needs of this diverse population. One participant said, “I think the only place, area where venues, organizations, businesses have been held to account has to do with wheelchair access. And they think that if they’ve got wheelchair access down,



**A middle aged White woman wearing a mask, winter coat, and scarf sits on a public bus. Decreased masking in public spaces increases the danger for some people to work and play.**

<sup>\*</sup> In this report, we use the language of participants, which varied and included “invisible” and “hidden.” Language evolves and some people may use “non-apparent” instead of “invisible” or “hidden.”



*and they've got one wheelchair accessible bathroom, oh they've done it, their job is done, 'Whoo, that's it. Okay, we hit the mark.' And that's like – the idea of disability is so limited to the wheelchair, you know...so I've missed out on everything. Like, I don't know a thing I haven't missed out on" (P28). This participant has an invisible impairment and described that relaxation of COVID-related mask mandates confined her to limited spaces, "The drop of the mask mandates has just, you know... eliminated...spaces and activities for my community and me" (P28). About the dropping of mask mandates and its impact on her safety to be in public she said, "It's crazy that there's, that there's these policies of forgetting. And these policies of erasure. It's like we don't exist as valuable enough to take care of. We are disposable. That's how it feels in terms of our government...it's an utter failure in public health policy to, to treat the vulnerable as disposable" (P28).*

- d.** People with hidden impairments are made to live isolated lives or to disclose and educate, and then fight for accommodations and accessibility. This may be even more difficult for people with some invisible impairments (e.g., mental illness, IDD, traumatic brain injury) that inherently make it difficult for a person to disclose, educate, and self-advocate. One participant noted that fighting for accommodations for a hidden impairment is complicated by lack of support, even after disclosure. *"I don't like relying on people too much because*

*sometimes people are not supportive when you have a hidden disability. I think they're more of supportive when you have a physical disability. When they see somebody in a wheelchair, they're more easily to help. But I have to constantly prove myself because you can't see my disability" (P38).*



**A young woman covers her face with her hands while standing in a busy crowd.**

**Not all impairments are visible and having to explain can be burdensome.**

For those that are out or outed about their invisible impairment, they may also experience discrimination in the employment sector:



*“...it took me two and a half years to air quotes come out as disabled to you know, include that on, say, my, my Instagram profile in the, in the About Me section...partly because I was concerned about as a gig worker, as a freelance artist, I was really concerned about hiring bias which, as it turns out...I have experienced to an extreme” (P28).* Another participant described that people “talk down” to her when they learn she has a cognitive impairment, *“I’m not stupid. I might have a disability and that’s what happens with a lot of people. They think just because you have a disability, you don’t understand things” (P25).*

- e.** In traditional sports, people with impairments are often excluded. The Paralympics exemplifies adaptive sporting that welcomes and celebrates athletes with various bodies and minds. Adaptive sports have proven empowering for some participants with impairments. Of the participants who described involvement with adaptive sports, many were already engaged in outdoor activities and/or sports before acquiring their impairment, or were blind for most/all of their life. But all who participated in adaptive sports reported developing important connection with other community members who do and do not experience disability.

*“So, I was connected with the adaptive sports world. There’s an organization called the Kelly Brush Foundation. And they—I applied for a grant through them. They give out grants for adaptive sports equipment...After I received my hand cycle through the Kelly Brush Foundation, they do a really good job of connecting people in the adaptive sports world. So, they have like a huge fundraiser—the big bike ride fundraiser every fall. So, I think doing that I’ve met like tons and tons of people...” (P6).*



**A Native man smiles while seated on a three-wheeled hand cycle.**

**Adaptive sporting activities can be empowering.**

“...so I like that a lot of people just like, you know, your family doesn’t really treat you any different than like other family members. Like...you know these guides, they don’t really like, see you as less than. Like they, you know, treat you as a peer. Not as like, ‘Oh, this like poor disabled person I’m volunteering to help for an hour’” (P8).

## Social, economic, and political domain impacts:

Media and community representation of various populations is how many people learn about those who are dissimilar, in some way, to them. Representation contributes to empathy and humanization, which builds individual capacity to accept difference and recognize overarching similarity. Limited accurate representation can facilitate harmful narratives about those who are unfamiliar and contributes to poor self-perception among those invisibilized,\* who may consume the same media. Inaccessibility yields isolation of people with impairments from the ordinary, public view. This limits communities’ organic representation of people with impairments, feeding the misconception that accommodations and accessibility adaptations are not needed. Study participants shared that invisibilizing people with impairments limits their socialization and employment opportunities, and their ability to equitably engage in political activity (e.g., the Deaf participant who is excluded from her local town hall meetings); and it means that accommodations are seen as unnecessary or of minimal value because people with impairments are deemed to be rare, when in fact 1 in 4 people have at least one impairment.<sup>1</sup>

\* To “invisibilize” is to make invisible or marginalize. This term is a powerful and apt descriptor of how historically excluded groups’ contributions and presence are erased from mainstream culture. Invisibilization is more than not being represented, as its impact has harmful social, economic, and political implications for the affected group(s). Interested parties can begin to learn more: Borderon M, Best KB, Bailey K, *et al.* “The risks of Invisibilization of populations and places in environment-migration research. *Humanit Soc Sci Commun* 8, 314 (2021); and Herzog B. “Invisibilization and Silencing as an Ethical and Sociological Challenge.” *Social Epistemology*, 32:1, 13-23 (2018).

## 6. The Social Security Administration (laws, regulations, policies, procedures):

*U.S. federal agency that provides people with financial protection via various benefit programs*

- a.** A common concern for participants was the SSA “benefits cliff” which was cited as a disincentive to work. The ***Ticket-to-Work program***<sup>27</sup> was not commonly familiar to participants\* and may not adequately address their concerns anyway.

*“...you have to be poor to be disabled or you have to stay poor to be disabled. And that’s a very jarring experience when you have done so much work to not be poor” (P43).*

Participants were afraid to lose eligibility for Medicaid and/or Medicare,<sup>†</sup> particularly given they were already struggling to pay for out-of-pocket costs of essential equipment and services not covered by Medicaid and/or Medicare:

*“...if I work and earn, earn more than \$1000 a month, then you lose your disability. You lose your disability, then you lose Medicaid. Then I end up right where I started. [I] can’t get in that position” (P13).*

This participant also said, *“I think it would be nice if you could work and still get the care that you need. You know, and not have to have a disability payment to be able to get the care you need. You know, I have to be on disability to get Medicaid, but in order to stay on disability, I can’t be working. And that would have been helpful, you know, ten years ago. I might have even stayed healthier if I was still able to work and get out of the house...” (P13).*

Further, participants expressed concern about stability of work or ability to work. For some, the waxing-waning natures of their chronic impairment (e.g., long COVID, mental illness) means there are and will continue to be periods

\* Some expressed a desire for such a program, not realizing it existed; others denied knowledge of it when explicitly asked.

† For more on disability benefit recipients maintaining Medicaid or Medicare while working: <https://www.ssa.gov/disabilityresearch/wi/1619b.htm> and <https://www.ssa.gov/disabilityresearch/wi/medicare.htm>

*“...not only does Social Security put disabled people in poverty by enforcing these arbitrary and archaic...asset limits and, and, and, and monthly income limits, but also in the fact that when you die, if for any chance you have managed to somehow accrue any wealth whatsoever, it ain’t going to go to your next generation, right” (P41).*

of high- and low-capacity to work. *“...If they lose [the] job...you know, and then they need money. It’s they can’t always get the Social Security benefits back quickly” (P25).* This is compounded by the need to keep up with advancements in their field; such trainings may take time, cost money, and/or are difficult (sometimes due to the nature of their impairment.) One participant said he did not return to his field because the skills needed had substantially advanced over the period in which he was out of work. *“...I tried learning some of the new programming languages [coding], you know, doing a little bit of web design and stuff like that on my own. And the, it was really hard compared to what I was used to” (P13).*

- b.** The limited income and resources requirements of SSI and low substantial gainful activity (SGA) earnings limit of SSDI make it difficult, if not impossible, for people receiving benefits to achieve economic security, much less upward mobility. One participant succinctly put it, *“...being on disability, is just signing up to live in, in poverty...” (P14).* Some participants reported they avoid equal payment—despite working

*“...I just struggle with that a lot with that because it’s, like, I try, I try and work at it, you know, it’s like, I’m just -- I can, I can only work so much and then I’m just kind of stuck, you know, and can’t make any more money, and I mean, and then everything’s going up and everything costs more it I mean, I’m going to be just pushed out of my, I don’t know, everything really, living situation and things just keep on going up and I’m not allowed to make any more money...” (P14).*



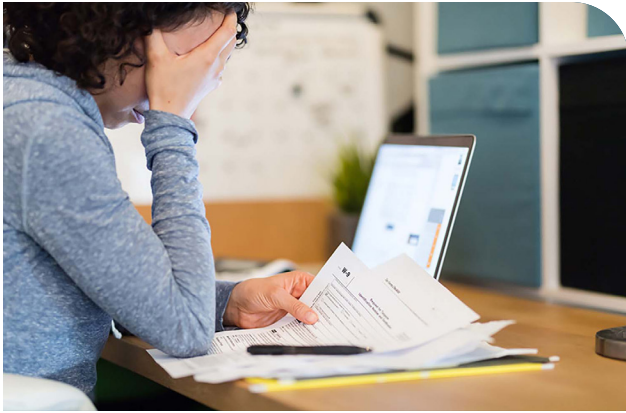
the same or more hours as other workers—to avoid overpayments from SSA and risking their non-cash benefit eligibility. *“...I had to be really cognizant of how much I made each month. And did I go over? I had to explain that to my employers because sometimes they wanted to pay me more than...I could make”* (P9).

- c.** While some participants expressed gratitude for their disability benefits, nearly all stated that the cash benefit\* is insufficient: *“...living on SSI disability like, you’re, you’re scraping two dimes together, you know”* (P10). Another participant expounded, *“It’s not enough money to survive on. But that threshold is so low, that God forbid, we made \$20,000 in a year, we lose our benefits as if we don’t need those anymore. That is bull. That is just not taking into account, cost of living at all”* (P28).
  
- d.** The “marriage restriction” (P4) has prevented some SSI participants from getting married, which denies them other benefits the U.S. system and society affords married people. If separate parties are receiving disability cash benefits and wed, they receive less disability-related cash benefits, than they would as two unmarried individuals. The marriage penalty increases financial precarity of benefit recipients or avoiding it obstructs people from other marriage benefits as they evade this specific negative economic consequence. This participant with IDD wants to marry her partner but financially they recognize it would be an unwise decision, as they are both receiving necessary disability benefits: *“I got a promise ring. And the problem, I want maybe to marry him. But with they don’t have the law to, for people with disabilities to get married. ‘Cause we lose our benefits”* (P4). The “marriage restriction” limits disability benefits recipients (if they decline to marry) or forces them into further economic precarity (if they elect to marry each other).

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\* For more on the maximum federal SSI payment amount and/or the average SSDI benefit payment: <https://www.ssa.gov/ssi/amount> and <https://www.ssa.gov/OACT/FACTS/index.html>

- e. The disability application process was considered “easy” by those who had a college degree before applying\* and/or worked with a particularly good SSA



**A curly-haired woman holds her face in her hand while trying to complete a paper form.**

**Completing a disability benefits application is difficult for some people, especially if they do not have help.**

officer or agent: *“I had a good...person at the Social Security Office, that person was very skilled and knowledgeable and was able to understand my disability and, and do what you know do their, their paperwork appropriately...so that I could receive Social Security benefits”* (P9). One participant said the process was technically easy but cumbersome; his parents had to drive him 40 minutes from their home to the SSA office multiple times: *“...we had to print out a lot of papers, and we had to, we had to go back to that federal*

*building maybe four, four maybe six times in like three weeks”* (P12).

The other group that found the process “easy” did not do the application themselves. Someone else (e.g., a family member) did the application for them as a child, or while they were hospitalized; and then they lived in a nursing home and rehabilitation facilities post-hospitalization, so they did not struggle to make ends meet during the determination (and/or appeals) process and until first benefit payment.

For those who had to do the application themselves, many reported experiencing difficulties. Some lamented having to submit to additional clinical evaluations besides what their own care team had performed. Others shared that the application required a level of concentration and complicated thinking

*“...if somebody told me like they were gonna apply for SSDI, I would tell them to have a plan for mental health coping and financial health, financial health coping, umm, at least three to five years. ‘Cause I, I don’t, it’s, it’s been tight”* (P43).

\* While we did not explicitly ask each participant about their highest level of education attained, most SSA disability program applicants do not have a college degree.

their impairment prevented or made difficult (e.g., traumatic brain injury, long COVID); or the application's demands (e.g., records of employment for 10 years, in-person appearance) were burdensome to meet and sometimes resulted in delayed application completion. Without funds to support survival during the application preparation and determination one participant described crowdsourcing funds to pay bills and buy food. *"And I don't know what other folks are living on during that time. I don't know how they're getting by. There, but for the grace of God and loans from friends, go I"* (P28). What happens to people without a fiscally-capable support network? *"I'm below poverty, just surviving, trying to survive. And though I've gotten the letter that I am officially approved for disability benefits, they haven't gotten me the first payment yet...so I still don't even have that to live on"* (P28).



**Faces out of view, two people's hands are visible while they are seated at a table with a gavel and the scales of justice.**

**Some participants reported getting legal help to apply for disability benefits.**

Some who knew about the complicated nuance of the application process and who had the resources used a lawyer to prepare and submit their application. A Deaf participant explained that when judges are unfamiliar with the variations and nuances of deafness, and the applicant does not know (how) to explain it, a lawyer is particularly important. *"...My attorney, I mean, he knew my family well and he knew the struggle that I had at growing up and he brought other testimonies as well, from other family friends, members, and friends who, you know, showed that I had a disability. You know, that even though I speak and hear, well, I still, I, I'm not hearing, you know, I still struggled. I didn't have the same access as they, you know, others"* (P22). Further he noted that he had to move jurisdictions and get a different judge (presented the same information) to have a positive determination, *"But in that area, [city A] is in [state], the judge was like, "No." And then when I moved to [city B], we got transferred,*

so. Yeah, it's just very – it's, it's like every judge has, maybe has their own opinions.” (P22).

**f.** Most participants were unfamiliar with **ABLE accounts** (Achieving a Better Life Experience)<sup>28</sup> which allow for eligible people to save for future needs (some expressed a desire for such a program, not realizing it existed; others denied knowledge of it when explicitly asked). When asked about savings mechanisms, many participants answered that they were focused on surviving month-



Two people review documents while sitting at a dining table.

**Focused on present-day survival, many participants were not thinking about future financial planning.**

to-month, had not started thinking about retirement, or found savings plans complicated to understand. Many participants who were receiving disability benefits, like this participant, were unfamiliar with the option: *“Like some sort of savings?...No, I mean, no. I don't know of any way that you're allowed to”* (P14).

Importantly, ABLE accounts are for certain benefit recipients who have acquired their impairment before attaining 26 years of age, so this does not help people whose impairments

develop or occur at the age of 26 or after, as was the case for the person quoted above.\* Given the risk of complications or exacerbations of their impairment, emergency needs that have high cost (e.g., disasters affecting their home, car repairs), and the high cost of uncovered medical equipment, supplies, and care, the low resource/earnings allowances place people receiving disability benefits in even more precarious living situations. Some participants reported needing to have kin who would keep funds aside for them to address these costs, so they can maintain their benefits. *“...How are you supposed to save? So, to do that, my parents had to open another bank account in their name, where my savings went”* (P15). Most of the few participants who reported saving for the future were not receiving disability benefits and had jobs;

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\* The Secure 2.0 Act raises the ABLE account eligibility age, to onset before 46 years, effective 1 January 2026: [https://www.help.senate.gov/imo/media/doc/secure\\_20sectionbysection.pdf](https://www.help.senate.gov/imo/media/doc/secure_20sectionbysection.pdf) and <https://blog.ssa.gov/able-programs-prepare-for-expanded-eligibility/>



importantly one participant pointed out that gig work was not as conducive (as traditional jobs) to pension development. *“I still do gig work within them, so the [company] and used to be the [company]...were where my two pensions are. The trouble with...both of those places is that, in order to get pension and health benefits and...funds in those pension accounts, you have to work. You have to have make X amount of money per year under those, under those union contracts in order to continue to qualify for pension later”* (P28).

- g.** Some participants noted difficulties in communication with SSA. A Deaf participant described struggling to use video relay service (VRS) to speak with SSA representatives because the representatives do not consistently understand VRS use: *“...if I didn’t understand something and I would call, they wouldn’t always take the VRS call, the video relay service call. So, I would have to emphasize, ‘No, no, no, you’re speaking to an interpreter who’s following the code of professional conduct, who has the right to interpret [for me].’ But it seemed like they didn’t know, and then they sometimes would hang up, which was rude”* (P29). Another participant described wanting to use virtual video platforms because he has a high voice and is often misgendered and consequently misidentified by SSA representatives who insist they need to speak with him as the benefit recipient. This is frustrating and emotionally upsetting for him. He shared he usually has to call back to speak with a different representative but thinks using a video platform might alleviate that problem for him.



**A White woman looks stressed while talking on her cell phone.**

**Some participants shared about various communication difficulties experienced when reaching SSA.**

Some people receiving disability benefits are assigned a representative payee if they cannot manage their benefits independently. One participant finds it

exasperating that she does not have a consistent representative payee,\* so she spends a lot of time providing context to new ones. *“But, you know, they change over your worker every six months...so you end up with a new worker”* (P25). This quoted participant found rep payee changes (by whom is unknown) particularly frustrating and difficult as a person with a cognitive impairment; she also said having a representative payee (who was not a family member or friend) obstructed her ability to pay her bills on time and she would rather manage her own money.

**h.** For reasons like those above, some participants reported not applying for disability benefits, or that others in their social network declined to apply or re-apply. Hearing how in-depth the application process is, some suspected they would not be considered “disabled enough.” Another person felt it was “not worth it” to hire a lawyer to successfully navigate the process, only to then have to pay the lawyer from the benefits awarded. Many participants or people in their network felt the low monthly amount of money was not worth the emotional trauma they learned that others experienced.

One participant described their own application process as *“demoralizing”* (P28). Similarly, another participant, whose application had been denied, said the language some SSA representatives use, when applying agency policy, negates the real-world experiences of disabled people. *“...I’ll never forget when I first got denied my disability benefits from Social Security...and I was talking on the phone with someone and they were like ‘Oh, you’re no longer qualified as disabled’ and I’m like, ‘Well, at what point did my cerebral palsy just get up and walk away?’ Right...And then the, the, the SSA rep had really no clear answer for me. And then when I insisted that their economic model of disability identify that exact period of time which my cerebral palsy suddenly had been cured, they were speechless”* (P41).

*“...if I have to, I will, but if I don’t have to, I’m not going to [apply]”* (P20).

\*

Not all benefit recipients have a representative payee, and often rep payees are a family member or friend. Read more about rep payees here: <https://www.ssa.gov/payee/>

Some participants described simply not needing disability benefits, either because they could work or otherwise had the financial means (e.g., family money) to support themselves. One participant reported that someone in her network continued to work, to the detriment of their health, to avoid using disability benefits. A few people reported that people in their network did not apply due to pride, or to avoid the stigma associated with not working or benefits receipt; no one said this about themselves though. Disability benefits were often described as an option of last resort: “...I want nothing to do with Social Security until I absolutely have to where [sic] I retire” (P41).

*“...when my doctor read the ALJ’s decision, his, his term was ‘gaslighting.’ And I was so deeply triggered from the ALJ that I thought I was going to have to go back inpatient and I had to stop reading it. Like, I could not read the document any further...” (P43).*

## Social, economic, and political domain impacts:

Many of SSA’s policies are determined by legislation and the implementing regulation or related decisions, like the amount of cash benefits. SSA determination of disability is important for allowing many people to access basic needs, including health care. In the current healthcare system, there is a gap between meeting non-disability eligibility or entitlement criteria for public healthcare insurance and either being able to afford insurance coverage independently or having a job that provides health insurance. Consequently, many people with an impairment are not able to afford much needed health insurance without being approved for disability programs, or they cannot afford the full range of care that they need to be healthy without receiving disability cash benefits.\*

Further threatening people’s economic security are the SSI limits on income and resources and SSDI limits on earnings that recipients can have; recipients often live below and at poverty. For recipients who have kin that save money (besides disability benefit payments) for them, they have no legal guarantee the funds will not be used

\* While this may technically be more of a healthcare system issue, it arose in participants’ comments about SSA and why receiving SSA disability benefits is important for them.

without their permissions. Moreover, they are at the whim of such friends and family, potentially complicating the kinship relationship and leaving them open to abuse or exploitation. Participants also noted difficulties communicating with SSA, making it frustrating and emotionally painful to access the necessary but often insufficient benefits of survival. With heightened economic precarity, SS(D)I benefit recipients can experience co-occurring social and political marginalization.

## 7. Culture

### *What we learn from communities and systems*

- a.** Multiple participants commented about the difficulties of being disabled while holding other marginalized identities. Of those who discussed how racism

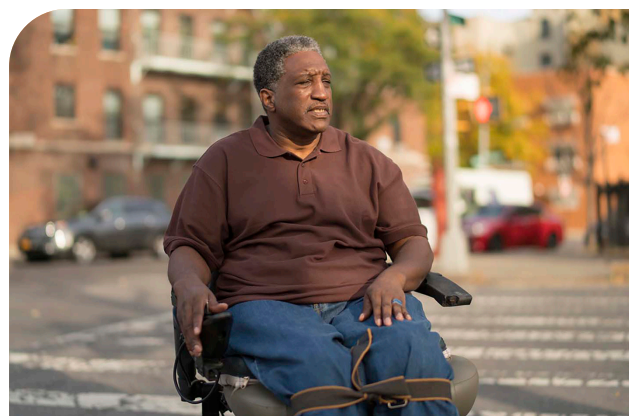
*“The person who’s Black and disabled has two different forms of baggages, right?” (P11).*

interacts with disability, most participants shared about the interaction in being diagnosed, people’s perceptions of their character, accessing care, or their ability and willingness to access services. For example, one South Asian participant noted that she experienced negative interactions with White clinicians that she attributes to their biases about her race and her accompanying mother’s foreign

accent. *“My mom, you know, she has a little bit of an accent. You know what I mean? So, I think because of that, you get like brushed off”* (P44). Multiple participants described

that Black men using wheelchairs are assumed, and even directly asked, if they are paralyzed due to gun violence. One participant said about his experience, *“...I think people perceive you different and like, yeah, so they’re like...‘Maybe you got – because you’re Black, you got the injury while trying to rob or something’”* (P36).

One participant said that concerns about negative stereotypes being attributed to



**An older Black man using a wheelchair is outside in a city; he looks sad.**

**Racist stereotypes affect how some disabled people are perceived.**



racialized people may keep some from accessing benefits they need: *“...for Black, the Black American side is like you don’t, you don’t want, you don’t want White people talking about you. You don’t want...your name in their mouth. So, I think both sides keeps us away from actually getting the help that we need if it’s there”* (P19).

- b.** Multiple women of color described the effect of racism on their efforts to obtain mental health care. A Black participant described wanting the best care possible for herself and knowing that care in her area was less likely to be of high quality. She said, *“...I found out, at least in this [city] area, where are, the, the complex PTSD disorder where, where are the rich White women going? I knew that this was the place to be for my care. And it had limitations because like I said, it was designed with them in mind”* (P43). Some described seeking mental health providers of their race to avoid further traumatization during the receipt of care, and even paying out of pocket to access these licensed practitioners who were out of their insurance network. One participant said she and her children use an Indigenous therapist, *“Because I’m not sending my [Indigenous] kids to a White therapist. Like that just is not happening because they don’t understand...they don’t get it. And I don’t mean to be like that, but at the end of the day, that’s factual in a lot of things, you know, because they have this false, they have this sense of security that a lot of other communities do not have”* (P20). Another participant further notes that having fellow Black women as her therapists protected her career while seeking treatment: *“They didn’t want those things attached to me, ‘cause they’re also Black women. I guess they were trying to protect me too, you know, by being very vague in general about the diagnosis. So it won’t hinder me in professional and career pursuits, and I’m very thankful for that as well”* (P19).



**A younger Black woman sitting on a couch leans forward talking while another Black woman not facing the camera takes notes.**

**Some participants of color sought mental health providers of the same race to protect their emotional or work safety.**

White participants also noted that their race was protective when perceptions about their impairment would have contributed to a bad outcome. One participant described kicking in the door to an apartment at the landlord's instruction, because the lock was broken. A nearby witness called the police; he said, *"...two uniformed PD\* officers and a detective came into the apartment with their guns drawn. And in the moment of putting me under, I wasn't technically under arrest, but whatever it was -- because they...thought I was breaking and entering, they almost shot me because I kept moving because of my balance. And I repetitively told them like, 'I'm not moving voluntarily, like, this is my, my disability'...And in that moment, I realized the only reason I walked out of that, out of that apartment was because the color of my skin"* (P41).

- c.** Some participants from immigrant communities shared the about stigma they experience in their racial or ethnic group as a disabled person. One participant described knowing of other Asian deaf folks but minimally interacting with them; her understanding is that their families hid them away in shame of their deafness. Consequently, she learned Deaf culture from her White Deaf friends. *"...The Asian community members, often they don't, they look down on me...There's a lot of judgment. And I grew up with that, a lot of that judgment. So, I have pushed that part away and I'm not very involved in that part. And I mostly am involved in Deaf events or communities. But you know, the majority of my friends are White. And very, very few Asian Deaf people within that community, it's a very small number"* (P29). This stigma extended to accessing benefits, other participants noted. In this context, one participant said the elders from her immigrant community accessing disability benefits do not openly discuss how they support themselves. *"...They're being supported by some sort of benefits. However, it's like not a thing to talk about how, how you're making that happen, or helping each other and figuring those out, unless you're very, very close"* (P3).

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\* PD: police department

**d.** Other participants described pressure from their immigrant parents to avoid association with “disability.” One participant described her father’s reaction to learning she had applied for disability benefits: *“My dad was not happy. He*



**A White woman looks sad and leans against a window pane.**

**Some participants reported experiencing stigma from their family or community for seeking disability benefits.**

*said, ‘You are not an American child.’ And he says that sometimes when I may do, like, what he considers...like, lazy things or easy-way out things” (P37). Another participant described that people raised in her family’s home country felt that even as a disabled person one should not seek government assistance: “...I think the [country] part has this larger belief that you just work hard and hard work will help you figure it out. And for the very religious ones of us, hard work and prayer will help you get over your*

*disability, so there’s no need, I think sometimes they think it’s a cop-out. It’s just long arms begging for something, instead of it -- and it should be a point of shame that you go into the government for assistance...That’s how I think culturally it is” (P19). Another participant shared that neither of her parents supported her seeking a diagnosis for her mental illness struggles. “They didn’t like that I was trying to get diagnosed. They didn’t believe that there was anything wrong with me. They thought that, just like everyone else thought like that, I was just disrespectful...but that wasn’t true...And then also like you know, my mom is from [one country] and...like mental illness there is, is not really like legitimized. And then my dad is from [another country] and you know, like over there, they really don’t, you know, have much developed around mental health and especially so for when they*

*“...disability is something you...do or do not claim and a lot of that is based off of who your family or your social cultural background is” (P41).*



were growing up...So you know, a lot of different cultural stigmas...” (P39).

- e. The stigma attached to an impairment diagnosis or disability benefit receipt is not unique to immigrant communities. U.S.-born participants, with U.S.-born parental figures, of color and White, also reported being shamed by their families or feeling socioculturally stigmatized for identifying as disabled or accessing services. One White participant from a low-income, “hard-working” family in rural USA said, “...when I was growing up rural [state], I never claimed myself as disabled, right?...It was how do I run away from this? How do I not have to claim this and, and...you know, I, I would like pine for my friends to be like ‘Oh, I don’t see you as disabled’...”

*“...just feeling like you’re contributing, you know. I don’t think anyone really wants to just get everything for free...” (P10).*

(P41). A Black participant who had experienced poverty and middle-class in childhood said, “...in terms of my family unit and their identity around work and employment and...rank in society -- disability is, you might as well be sitting right beside Satan in hell because there’s no value and no worth in you, [and] you’re like ‘Damn’...” (P43). For this participant, mental illness diagnosis was two sided, “...having the diagnosis it was... holding two things. A relief that, that I was getting a diagnosis that was really, I think, addressing what my lived experience was, but then also the shame of not wanting people to know that this was my diagnosis and the full impact that it was having on my life, my career, everything.” (P43).



**A White woman with is outside petting her service dog. A Southwest Asian man who is blind and wearing sunglasses uses a cane while waiting in the subway. Multiple participants, of various ethnic and racial identities, shared about the cultural value of independence.**



- f.** Exploring the reasons underlying the stigma around impairment diagnosis or accessing disability benefits, participants grappled with the cultural value or concept of independence. Many described coming from communities and families that valued independence, as it related to positive judgments about individual character and an ability to work and therefore offer fiscal value. One participant noted that independence is so valued it was taught to her by teachers in her public school, in a cluster for deaf children. *“...I had teachers in elementary school, middle school, who were very supportive of me, to make my own decisions, to encourage me, who taught me a lot about becoming and being independent and being adventurous and to get to know the world. So...and not to rely on others as well and to really make my own in the world”* (P29). Some immigrant participants said their communities’ associate independence with a “hardworking” character whereas accessing disability benefits meant dependence, which showed weakness and was associated with being a “freeloader.” Interestingly, though it is (as mentioned above) considered by some immigrants to be an “Americanism” to access benefits, participants with U.S.-born communities and families also value independence for similar reasons. *“...My family sees working as synonymous with identity. And...as synonymous with value in society”* (P43). Another participant agreed, saying, *“...if we don’t have...financial power, as an economic sector then we don’t have a voice”* (P28).
- g.** Other participants highlighted practical concerns around independence. One participant expressed that her parents were additionally concerned about her collecting disability benefits because they thought she would consequently be relegated to a life of poverty. *“They was happy when I got that check, but...I think they also thought it meant that I can’t work. All I’m gonna do is get this little check, and you know, I’m not gonna be...successful or fulfilled in life because I’m gonna be struggling with this little bit of money every month”* (P37). Other participants noted that dependence diminished their capacity for privacy, with respect to government officials evaluating their continued need for benefits or having someone help with activities of daily living (ADL). Others pointed out that relying on other people meant they were at another’s whim and mercy; if that person was unable or

unwilling to help them, they would be stuck. *“I don’t necessarily like having to rely on other people for accessibility because it just makes me feel like -- I don’t know, it’s just like a very confining feeling. And I don’t like feeling stuck or feeling like I can’t move around freely”* (P6). Many participants who acquired their impairment after living a nondisabled life described grieving loss of independence. *“...It took me a long time to*



**Two people sitting across from each other holding hands.**

**Some participants pointed out that needing help or support is a normal part of life.**

*really accept being disabled because I was so independent. And I remember I can -- I [said] to my doctor well, ‘When can I go back to work?’ And he said ‘[participant’s name], I don’t know’”* (P2).

Still, some participants shared examples of exception in which independence was not prized above needs. *“...My grandma had a, a career and hobbies and was very independent. And so strangely, her independence in most of her life has made her much more willing to give*

*up certain kinds of independence as she gets older”* (P42). Here the grandmother considers her dependence earned and embraced it. She moved into an assisted living home and the participant said, *“...she talks about, like, other people who live there, saying that they hate that they can’t cook and clean for themselves, whereas my grandma’s response is like, ‘Why? I love that I don’t have to cook or clean anymore’”* (P42). A younger, working-age participant described creating a personal “counter-culture” of interdependence. *“And another time it may be good to be interdependent, you know what I mean?...I don’t think the goal is to be so independent, hyper-independent, where you can’t do -- you have to do everything by yourself, ‘cause I think that’s more of a trauma response, to say that I can’t rely on anybody...I’ll be*

*“I also didn’t see it as a stigma. When you need help, you need help”* (P37).

*lying, I'll be trying to perform to say I can do it all...So, I spend a lot of time...creating my own culture, counterculture, to what I feel is an overconsuming...Black female culture that requires us to be the mules of the world” (P19).*

**h.** Another participant pointed out that independence may not be a realistic goal in disabled living, which requires varying degrees of accessibility, accommodation, and/or support. One participant described working at a business where the culture was a combination of hard work and support, as needed. Not a Black woman herself, she attributed this culture to the racial and gender make up of her boss and colleagues, who were mostly Black women: *“Just if you felt like the makeup of the group...in a sense, influenced it being a more supportive environment in regards to one’s health. I mean, I think like the other aspect of it, like being mostly Black women, I think that’s probably what made it feel like that” (P44).*

**i.** Some participants who identified as women or genderqueer noted that their (perceived) gender complicates their disability experiences. One participant described delay in accurate diagnoses receipt because of their gender: *“...doctors in [city] and [state] never considered a sleep disorder probably because I’m not male and over 50...And similarly, doctors were very quick to diagnose me with depression and anxiety, but didn’t consider that there -- they -- it could be related to not just the sleep disorder, but something like autism, which I now have” (P42).*

Others described that having a racialized gender impacted their mental healthcare, as described above ([Culture, section a](#)).

Another participant shared how her community and school’s protection of men who sexually harass and assault women, in a state that does not protect her right to



**A young trans Afrolatina points to her throat while talking to a clinician who is wearing scrubs and isn't facing the camera.**

**Some people reported that their perceived/ gender affects their disability experiences.**

an abortion, affected her health decisions. She said, “...I got my birth control implant for a lot of [impairment-related] health reasons. Also, because I live in [state] and our reproductive justice and reproductive health laws like aren’t great. And there was just like, a large pattern of sexual assault at my school...I know first and foremost I wanted to be taking care of myself and my mental health...” (P3).

## Social, economic, political domain impacts:

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As described by study participants, researchers, and historians, racism has been a part of U.S. culture<sup>2,3,4</sup> and interacts with disability, complicating how people of color experience disability in comparison to how White people experience disability. Some people of color seek out support networks of color to feel understood, be protected,

and avoid traumatization. Due to disability stigma within their racial or ethnic in-group, other people of color may only be able to access community according to (what others may call) an impairment rather than also within their racial or ethnic group. Similarly, data from this study and others demonstrate that sexism has been a part of U.S. culture<sup>5,6</sup> and interacts with disability, complicating how women and genderqueer people experience disability in comparison to men.

*“...I’m getting a combination of messages of things like it’s a tragedy to become disabled because you aren’t as -- the implication there is that your body and/or mind are not as good as they were before” (P42)*

The cultural value of independence, regardless of origin country, permeates various U.S. communities and families, with social and

economic implications. Independence is tied to the ability to work for pay and the ability to participate in compensated work confers economic value to the individual (the worker). The consequent economic power from working can translate into political power, but those who cannot work, or who cannot survive without additional financial support, experience diminished political power.



## 8. Education (system)

*The process of providing or receiving systematic instruction*

- a.** “Mainstreaming” is when children with impairments are schooled with children who do not experience disability. Some participants suggested that this choice adults make for children is logical but does not necessarily or inherently have the intended effect of helping the child. *“...I remember when I was in, taught in the other [mainstream] classes, I excelled in the other classes, but I still remember being isolated because I was different than the other students”* (P23). In some ways, it may marginalize the mainstreamed child while learning in a school dedicated to teaching with their needs in mind may better develop their sense of self and community, as well as their education. One Deaf participant was initially mainstreamed and he said *“...I learned a lot, but with all like memorizing it because I was trying to understand what people were saying, so I really learned where I tried to anticipate what the hearing person or teacher would say and then when I went to the Deaf school I...mean no guessing game, no filling in the blank. So, I went from a 2nd grade reading level, by the time I graduated high school, I was up to 8th or 9th grade. So that’s where I was learning everything visually”* (P22).

But as mentioned earlier ([“Technology,” section g](#)), while invisibilizing a part of the person, mainstreaming may offer the future worker more employment options: *“...a lot of them are mainstream, so they’re not necessarily capital D Deaf, they’re oral like me. They’re, they’re able to, you know, be able to communicate with the employers, but those who don’t speak at all, it’s really...or don’t have the... understanding or capacity to really educate the employers, on how to make it work”* (P22). Additionally,

*“...as I’ve gotten more educated...and I have more or less, assimilated in like non-disabled society”* (P41).

“mainstreaming” may allow people who do not experience disability a chance to learn about a diverse group from whom they are otherwise isolated during education years. One participant shared, “...I strive to change the face of disability and fight stigma by showcasing my abilities and the abilities of others. I once disclosed that I have a disability to a fellow classmate who I asked to be my volunteer notetaker. When it came time to working on a group project together, he did not expect anything of me...He would just add my name to the project, and I didn’t have to worry about it. Right before we presented, right, right before we presented, I edited the presentation drastically. When it came time to present, I rocked it. That next semester the student came up to me on campus. He thanked me for showing him what students with disabilities can do. He is in charge of hiring...at his company. He said that in the past he would not even give people [with] a disability half a chance, but now he knows he can place people with disabilities where their talents lay” (P39).

“I mean, I remember, you know, my parents having to advocate every single step of the way, just for me to get education, right” (P41).

**b.** For disabled children whose families chose to mainstream, entering or



**Two young people have a conversation, using sign language, on campus.**

**Some participants reported that going to Deaf schools provides more work and community opportunities to Deaf people.**

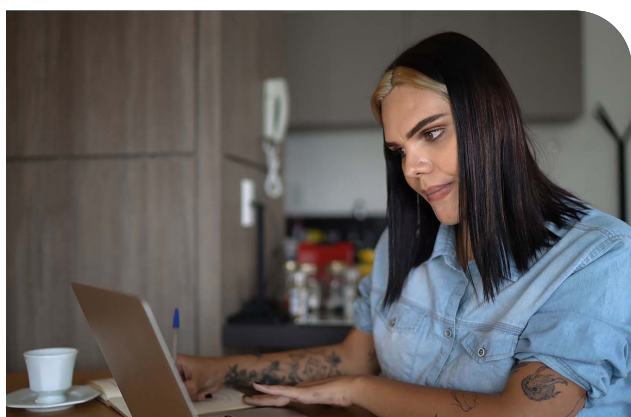
participating in public mainstream education and associated benefits was not always easy. One participant’s mother tried to enroll her in elementary school and was initially blocked by the principal: “*The principal literally greeted us at the door...She literally said to our faces, ‘We don’t take those children here. She’s not allowed to come to our school’*” (P4). Others report not having the option to go to a specialized school because of their location and consequently having fewer job opportunities and diminished

community involvement: *“So, if you have a good network of people and a good network of Deaf people in the Deaf community, I think that becomes a real benefit. And then if you have a Deaf person who has a connection to a hearing family, that gives you, that’s a good benefit too. If you’re connected to a Deaf school, I think you have a lot more benefit being Deaf in that way. But we don’t have a Deaf school here. I mean, I didn’t graduate from Deaf school myself, so the mainstream schools provide less opportunity. I, I, I’m less involved in my community than I think I would be...”* (P29).

- c.** Accommodations seemed to improve at the post-secondary (college or university) level, but still many participants reported difficulty with accessibility and getting necessary accommodations. One participant with obesity reported that she could not fit into the school’s auditorium chairs, *“I tried my freshman year of undergrad to just be like everybody else and sit in the auditorium, and that’s when I got the bruised thighs, and I was like, ‘I wish they had ones without arms.’ I seen one. I’ve been to one at a community college, that the back row or a few seats at the very back row, the arms did go up so someone in a wheelchair [could] slide over”* (P37). Another participant noted that some of her peers had to switch majors because relevant university buildings were inaccessible, *“At [school], there are students with physical disabilities that can’t get into...some buildings for classes and have had to change degree plans and majors because of that”* (P3).

A few participants felt that post-secondary academic expectations are unreasonably high for nondisabled people and worse for disabled students. *“...People are expected to be very abled and very...like almost, like overly capable to like a unrealistic degree...Which I think makes being a disabled person even harder because you know, I know I am like not even up to par with functioning on...like a [sic] even reasonable level, like the way I used to, and so being expected to do like even more than that, is, is even more overwhelming...”* (P1). Further, another participant noted that accommodations in academia are slow

to be approved and the proving process places a high burden on the person, even as faculty: *“I know that it would take probably several hours total of emails and meetings and documentation and additional physician appointments. So, that’s just hours taken up, but it also adds additional stress and cognitive load of, of having to plan that out and make it happen. And then there’s also the concern that I wouldn’t be able to get it sorted in time, or that I’d have to re-qualify at a regular basis. Scholars of disability in academia have found that -- like they have documented that it takes time to do this and that people get forced out of academic jobs because of the work it takes to secure accommodations”* (P42).



**A young Latina works on her laptop at home. Some higher-education students used online degrees to avoid inaccessible campuses.**

A few people reported avoiding difficulties with accessibility and accommodations. One participant said he was grateful his parents had the money to pay for an accessible primary and secondary education for him: *“I was very lucky. I was very fortunate. Our parents who could afford private school back then, very fortunate. And that’s one of the things that differentiates me from many other people, is that I’ve been given economic means and other means*

*to be able to do well”* (P11). Others opted for online higher education when in-person college did not meet their needs: *“...I like it because you can basically take everything at your own pace. You can take multiple classes at once, or you can just do one class and then sign up for another one”* (P1).

- d.** Early identification of impairment or accommodation needs is important to the education and development of a child, and it has lasting impacts on the adult as well. All the Deaf and deaf participants in this study were deaf since early childhood; they do not have a memory of hearing without technological support, if they ever heard. Still, one Deaf participant did not have a formal language until



the age of 7 years. She describes Deaf privilege as “...Deaf people from Deaf families, so they have the heritage of being Deaf and have been in it for several generations. In some cases, that ASL would be their first language, ‘cause they had it from birth, exposure to the language. I had seven years with no language, nobody signed to me. So, seven years of life before I started learning, so that kind of messed up my life, from there and out, really. And, so, the ones that had language from birth tend to be smarter” (P5). Participants diagnosed with mental illness or fibromyalgia (for example) later in life felt validated once able to name what was negatively affecting their primary school performance.

## Social, economic, and political impacts

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Children with impairments who are mainstream educated may experience social isolation, potentially because the other students do not know how to communicate with

*“...I love my country, but I don’t feel like my country loves me” (P28).*

them or because the other students ostracize the mainstreamed children. School (including higher education) is where many people begin to develop a social-professional network of connections that contribute to employment opportunities;<sup>7 8 9</sup> it is also where many practice getting involved in their communities. Children who experience social

isolation, and child and adult learners who do not receive necessary accommodations, are disadvantaged in their capacity to be economically self-sufficient and/or navigate participation in local communities.



# Participants' Concerns and Advice

**Table 2. Abridged Concerns & Advice for SSA ..... 87**

# Participants' Concerns and Advice

In addition to what the participants' shared above, all had advice about structural changes, either in the form of policy or operational changes. Participants' advised changes that would increase social, economic, and/or political capacity and security for people who experience disability in the U.S. To be clear, these suggestions are not necessarily reflections of SSA's beliefs or ideas; participants' made appeals for what they believe would function as solutions to problems they experience with structures as they currently exist.

**Table 2** shares some participants' advice for changes to some SSA operations and policies; the complete table of their advice for SSA is found in the **Appendix**.

**Table 4, also found in the Appendix**, shares participants' advice for changes to other structures' operations and policies. Importantly, many if not all, operational changes cost money; policy changes for SSA and other governmental bodies would require new laws or amendments to existing laws. These tables reflect what participants said, not necessarily SSA's agreement.

## Table 2. Abridged Concerns & Advice for SSA

### Policy Concerns and Advice

**Participants' advice:** Raise the income and resource limits for SS(D)I so that people who are able to do some work can better supplement their disability check and afford necessary costs (legislative change).

**Rationale:** "...like if you have more than so much money in your account, then they penalize you. Umm, so much of what we spend our money on is medical stuff that our insurance doesn't pay for. So, when all of a sudden some, more than \$2,000 in your account, that very well could be going to some medical device could penalize you and take your benefits away" (P10).

"I'd like if I could earn more money. I mean, the -- what they cap at, I can't remember the exact number, but what they cap at, it's still hard to live, especially on your own, you know, it's, it's hard..." (P37).

**Participants' advice:** Eliminate the disparity between blind people and others receiving disability cash benefits (legislative change).

**Rationale:** “So when blind people, they tend to get a lot more, when they fight, they tend to win their cases and get an increase in their benefits. Whereas in the Deaf community that’s not the same experience” (P5).

“There should be no differentiating, you know, that a person that is blind to be able to get paid more if they work, if they’re on disability, more than another person. You are creating segregation within segregation” (P38).



**Two older adults and their daughter smile for the camera while signing their marriage certificate.**

**Eliminate the “disability marriage penalty.”**

**Participants' advice:** Eliminate the “disability marriage penalty” such that two recipients can marry and still receive their full benefit allotment (legislative change).

**Rationale:** “...he and my mom were talking about maybe getting married before he had his stroke, but now they can’t because it would mean that his, um, the disability insurance would get cut. So, that’s a major life experience that is not available to them simply because of the structure...” (P42).

“And the problem, I want maybe to marry him. But with they don’t have the law to, for people with disabilities to get married. ‘Cause we lose our benefits” (P4).

**Concern:** People who acquire a disability with limited work experience may not initially receive the same allotment as others but their cost-of-living is not inherently less (regulatory change).

**Data:** “...it’s hard, harder for me because I have to manage, you know, money on a tight, tight budget. Because I didn’t have enough years in to work to get a large social security check” (P38).

**Participants' advice:** Allow SSI benefit recipients the ability to save or receive money to use as they need, without restrictions (legislative change).

**Rationale:** “...the only thing that’s protecting us from this is the ABLE accounts. Why does it have to be an ABLE account? Why can’t you just be a checking account or a savings account?” (P7).



**Concern:** Despite applicants having their own clinical assessment and care teams, SSA sometimes requires an independent clinical evaluation for disability determination. (regulatory or sub-regulatory change)

**Data:** “...they’ve shared how a, a doctor had to see them and how they, their own doctor gave documentation” (P24).

## Operational Concerns and Advice

**Concern:** Benefit recipients need, in simple language, the rules of disability benefit participation, return-to-work flexibilities, and reporting (e.g income). (regulatory change)

**Data:** “I have to go to court. I have to go see an ALJ, an Administrative Law Judge. Uh, for a four-thousand-dollar overpayment that occurred because I was receiving fellowship money while on my scholarship. And nowhere in Social Security’s notion of gainful, substantial employment is scholarships, grants, or fellowships listed” (P41).

“...I’ve just noticed that there’s a real inconsistency in information and gig work, um, I’m not really sure what kind of payment they provide or ask, what kind of proof they ask for when someone is doing gig work.” (P29)

“...like, if you go on the website, it says you can make this much money per month, but like, that’s actually not true. Like, that’s if you’re doing, like, the ticket to work” (P14).

**Concern:** Multiple rounds of applying to finally be awarded disability benefits delay access to benefits and needed fiscal support. (legislative change to give benefits before adjudication)

**Data:** “They denied him three times until they actually gave him his disability. And I guess that’s the thing here in [state] is they deny you three times before you get qualified or, you know, even if -- that even if you have this much paperwork from your doctor they’re still gonna deny you...of course you do get the back pay, but, I mean, why would somebody have to wait so long?” (P33).



**A young Black man is concerned while looking at financial documents.**

**Delayed access to benefits can cause financial hardship.**

**Concern:** As a whole, SSA staff’s understanding of the nuanced needs and realities of Deaf and deaf people is not consistent or sufficient.



**A Deaf man with a cochlear implant communicates with someone else using sign language.**

**Staff at SSA need to have a better understanding of the needs of Deaf and deaf people.**

**Data:** *“I’ve known deaf people who have applied for SSA’s programs and been turned down...The reason given was, is because they were talking about getting cochlear implants. And if they had cochlear implants, they were perceived a hearing people, which is just not the case at all. Whether a Deaf person has an implant or not, they are still not a hearing person and they still need that support” (P5).*

*“...with kids or even adults who have that range of hearing loss, that really affects each individual differently...So again it’s like, maybe somebody applying for Social Security disability income, they have an implant. Wow, they can hear a lot, but once they turn it off,*

*they can’t hear a thing. Where if I have a hearing aid and, but, oh, I can hear a lot but maybe they don’t qualify. I don’t know. It’s just like it’s kinda, it’s not like, it’s not consistent across the board” (P22).*

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**Participants’ advice:** Update communication methods to reflect modern modes of Deaf communication and reinforce interpretation standards with SSA staff. (possibly regulatory change)

**Rationale:** *“...remove the idea of TTY from any of the marketing literature? Because nobody uses a TTY anymore. We all use video phones, so TTY access is obsolete. Um, I mean or, you know, maybe leave it, I don’t know, maybe you should leave it on there because there’s some elderly deaf people that still might use it. A very, very low percentage. But most Deaf people are using the video phone...” (P5).*

*“So, if I didn’t understand something and I would call, they wouldn’t always take the VRS call, the video relay service call. So, I would have to emphasize, ‘No, no, no, you’re speaking to an interpreter who’s following the code of professional conduct, who has the right to interpret.’ But it seemed like they didn’t know, and then they sometimes would hang up, which was rude” (P29).*



**A young Central Asian woman smiles while signing to another person not facing the camera.**

**ASL is not English and some Deaf people do not read English.**

**Participants' advice:** As ASL is a different language than English, and as SSA provides translation for read languages, use ASL videos to communicate SSA information to Deaf people.

**Rationale:** "...it would be nice to see some of the information translated into ASL and provided that way, instead of just in written text, like if there would, if there would be, if there could be videos of the same information provided in ASL" (P5).

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**Participants' advice:** Ensure that ASL interpreters are available for in-person appointments. (possibly regulatory change)

**Rationale:** "Even if we show up in person for an in-person appointment, there isn't an interpreter present, even if we've requested it. So, the, the federal government that set the law is in violation of the law and violates our access to communication" (P29).

"...they need a better interpreter request system. My understanding is that SSA doesn't have an interpreter, they just use their own local office. So, they'll just like, you know, request anybody at the last minute" (P29).

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**A middle aged White man, wearing scrubs and a lab coat, talks on a phone at his desk.**

**It may be easier for an applicant's primary care practitioner to provide information than the applicant.**

**Participant recommendation:** Allow a listed clinician to be the point of contact for healthcare documentation. (regulatory change)

**Rationale:** "They should even like have the application and say who's the primary care doctor and who's the contact person. That's all they need" (P7).

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**Participants' advice:** SSA should educate people about available benefits by meeting people in their communities.



**A multiracial, multigenerational trio stand outside chatting, and holding chickens and eggs; the young man has Down syndrome.**

**SSA should visit people in their communities to share about benefit options.**

**Rationale:** “...there should be people that that are from Social Security that are going into the schools and, you know, these places where people go every day and educate people. ‘Cause there’s a lot of people that don’t know about Social Security and don’t understand about it” (P9).

**Concern:** There is insufficient education of disability benefit recipients on the practicalities of the transition from Medicaid to Medicare.

**Data:** “...while I’ve been on Social Security disability like, I had Medicaid for two years and then it kind of transitioned to Medicare.

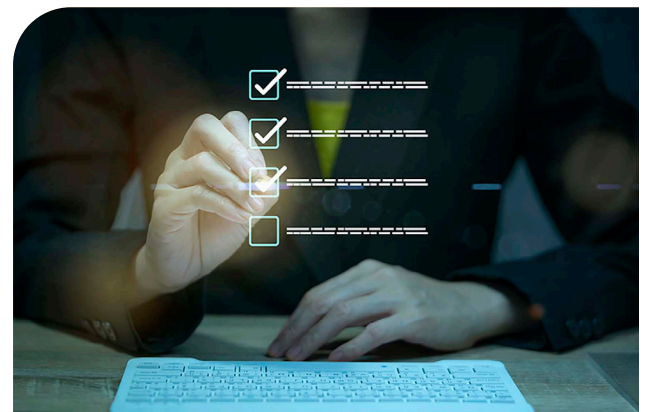
*And that’s like a whole different system and I wasn’t really provided much like, education on how it’s different. You know, I, I just kind of received a letter saying like, ‘Oh, you know, you have Medicare and you’re going to be like responsible for, like, more out of pocket costs or whatever’” (P8).*

**Participants' recommendation:** Use email to communicate with benefit recipients. (regulatory change)

**Rationale:** “So make it quicker and more -- because I will respond to an email much faster, or even a text message saying, you have a new message on your SSA account and so then you log into that...” (P15).

**Participants' advice:** Provide applicants with a comprehensive application checklist.

**Rationale:** “I would just say, when we do apply, to give us a little checklist of the documents we do need to bring. So, that process, when we hand the case worker with the papers, that it makes it a lot easier” (P12).



**A hand holding a stylus checks off a box on a virtual reality checklist.**

**A comprehensive checklist would help ensure the applicant has all of the required documents.**



**Concern:** People who have been previous disability benefit recipients and are again without a financial safety net are not presently prioritized for paperwork processing.

**Data:** “...I see through my clients, you know like, if they lose job, um, you know, and then they need money. It’s they can’t always get the Social Security benefits back quickly...if they had some emergency funding, or emergency system was stronger to help them out more quickly until they return to work, that would be something that would be helpful” (P25).

“I wasn’t working full-time, but I was making money, you know, like, very brief gigs. You know that weren’t gonna last that long. But I, I didn’t wanna not report it. You know, and so I -- there were times that I just didn’t, you know ‘cause, yeah. Because once, yeah, because, it would just take too long, once they started deducting. But then okay, you -- now, that job is done. Or that show is done and to reinstate benefits would be quite a bit more time” (P15).



**A middle aged Southwest Asian man using a wheelchair waits in line with others. Being previously approved for disability benefits does not presently speed re-approval.**

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**Concern:** Ensure that benefit applicants can and know how to designate who can complete the application on their behalf. (possibly regulatory change)

**Data:** “...the application process was difficult, but mostly because of the questions of who was allowed to help him with it in that because he and my mom had not gotten married and had not, like, filed a power of attorney, she was the person who was caring for him, but all of the paperwork had to go through his parents, who are, fortunately, in this case, able to or were at the time, but there they’re -- they were old enough that they’re very easily could not have been, in which case it would have been his teenage and early 20s children who were not living in the same city as him. And so that was probably the main difficulty with the process and just the delay in getting that support because he didn’t have a lot of money sitting in savings” (P42).

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# Discussion

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# Discussion

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This study starts from a social model of disability's explanation of disablement as imposed upon people and presumes more independence and thriving is possible depending upon structural design. As discussed above, functional independence is not necessarily the goal or even possible for all disabled people. That said, this study, like the work of others, demonstrates that like race, disability is socially constructed. In this study and based on participants' words and/or lived experiences, we identified 8 structures that presently function in disabling ways. Many of these structures also appear (sometimes with synonyms) in the World Health Organization's (WHO) ICF Model of Disability (International Classification of Functioning, Disability, and Health), which combines the medical and social models of disability. The ICF focuses on health, health outcomes, health information systems, and data comparisons, and thus includes many other individual-specific factors.<sup>29</sup>

The model developed in our study is grounded in the lived experiences of disabled people and is focused on how external structures presently limit or disable people with impairments. This model specifically offers lived experience insights on structural improvements to decrease social, economic, and political disability in the U.S. Moreover, these structures are often complexly situated and co-mingled in U.S. society. In this section we first dig into some areas that participants highlighted about non-SSA structures. Then we delve into the structure of SSA and focus on how SSA can better serve people who may be/are eligible for disability benefits or who are actively receiving them. We also point out some areas for further research for non-SSA and SSA structures. It is important to remember that these issues are not meant to be exhaustive of the ways in which structural disability manifests in the U.S.; rather, they are areas of saliency raised by the lived experiences of this study's participants.



**A close up image of multiple Social Security cards.**

**SSA wants to provide great service to the U.S. people.**

*“And also the fact that [state] doesn’t offer the same pay rate as they do for these type of jobs [home health care] in [state], and where I live right on the border it’s better pay for them to go down to [state]. They make, you know, \$4 or \$5 more an hour than what they get paid up here in [state]. So given that, it’s hard for me to find someone to do this” (P13).*

## Structure Highlights

With respect to ***Healthcare Structure***, multiple participants discussed relying upon home healthcare workers (HHCW) (e.g., personal care attendants) to assist with ADLs, like bathing or cooking or performing bowel regimens. Participants reported struggling, even with Medicaid, to get and retain HHCWs. The pay for these workers is low and state-dependent; most rely on some type of public assistance with the median annual salary for HHCWs being less than \$30,000.<sup>30</sup> Participant 13 shared that he lost an HHCW because she moved to another state that paid \$4-5 more per hour (***Participant Concerns and Advice table for SSA***; in ***Appendix***). Some work is being done to improve the compensation of HHCWs but the efforts focus more on work hours than pay.<sup>31</sup> Ironically, the long hours some HHCWs work contributes to or causes their own need for home care.<sup>32</sup> It is concerning that the people relied upon to provide essential health care at home are paid below the federal poverty line and that people who rely on HHCWs cannot always get that care in a timely fashion. Furthermore, participants also noted that HHCW support is only paid for by Medicaid. Some participants recommended that Medicare and private insurance should also pay for HHCWs to ensure that all people who need home care can get it. In the current system, participant 13

*“I had to quit working and go on disability in order to get the care in my home that I needed. I tried several different private insurance companies, and they all told me the same thing. ‘We don’t cover that kind of thing. Go on Medicaid’...And I ended up just filing bankruptcy, giving up my house, and moving here [an assisted living complex] with a disability, just to get the care that I needed” (P13)*



reported having to “go on disability” to get the needed care at home; to meet the resources requirements he gave up his home and filed for bankruptcy (*[Participant Concerns and Advice table 3](#)*; in *[Appendix](#)*).

Under the *[Technology Structure](#)*, one blind participant discussed the intersection between technology and transportation. She noted that the audible indicator at some crosswalks is not standardized, so the sound’s meaning is not consistent across U.S. geography (P15). For example, the sound could mean “cross now,” or “time to cross is ending;” this makes it difficult for blind pedestrians to navigate public streets with the ease and safety that sighted people do. She said that the signals that count down are the clearest, as these explicitly tell the commuter how much time they have left to cross the street. On 8 August 2023, a Rule by the Architectural and Transportation Barriers Compliance Board was posted to the Federal Register requiring new and altered pedestrian crosswalk signal heads to have audible and vibrotactile features. The goal is to help people who are blind or who have low vision know when it is safe to cross the street. The Rule, Accessibility Guidelines for Pedestrian Facilities in the Public Right-of-Way, also includes other



**An older Black woman presses a button in front of the wheelchair accessible entrance to a public transportation bus.**

**Transportation is important to participation in daily life, including socialization.**

accessibility requirements but this requirement had the most public support.<sup>33</sup> As audible and vibrotactile features become universally available at crosswalks and based upon participant feedback, it is important that *what* they communicate is also universally consistent.

Under the *[Transportation Structure](#)*, many participants discussed how lack of public transportation or reliable paratransit makes it difficult to work outside of the home. But many also discussed that lack of or insufficient transportation hinders their ability to socialize.

While the “necessities” of life, like food, shelter, education, health care, and work (for those who can) hold advocacy currency when disabled people are fighting for access, the ability to socialize freely may be considered secondary or less important. It is not. Besides supporting health and being an organic means of networking and resource-finding, socializing is inherently good. Disabled people

*“Well, I can’t work full time, to earn a full-time income, so I can’t do a lot of things that I would like to do. You know, I have to save for four or five years before I have enough money to do what I need to do. I remember one time going on vacation -- I hadn’t been on vacation for seven years, because I couldn’t afford it, and I was saving, you know, you have -- an emergency comes up, then I’d have to use that vacation money to pay for it. And then you have to start saving over again and that type of thing” (P5).*



**A young Native woman using a prosthetic leg and two canes smiles at the camera; she is standing in a park.**

**Everyone should be able to enjoy the community in which they live.**

have as much right to participate in socializing and luxury activities as nondisabled people. In fact, in the IDEA Act (Individuals with Disabilities Education Act), Congress states, “Disability is a natural part of the human experience and in no way diminishes the right of individuals to participate in or contribute to society.”<sup>34</sup>

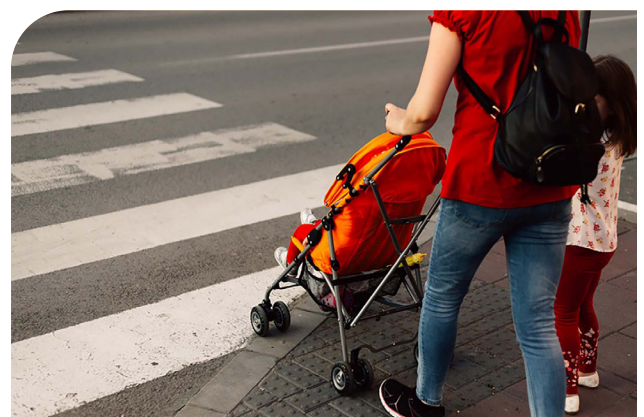
Under the ***Employment Structure***, participants described difficulties in being hired or staying on at their job for a variety of reasons

external to themselves. The obstacles included the physical inaccessibility of the intended work building, the work schedule, or employers’ reluctance to invest in accommodations, for example. One participant suggested that a national effort focused on hiring disabled people is needed to overcome the underemployment of this population (***Participant Concerns and Advice table for Other Structures; P28***). The participant highlighted that among the many assets disabled people can bring to the workplace is adaptability (P28). This necessitated skill can prove useful in solving difficult or chronic problems a company is facing. On 11 August 2023, the Department of Labor (DOL) announced it expects to use over \$69 million to fund 4 Tribal and/or state governments that develop scalable strategies to support marginalized young people’s participation in the labor force, including disabled young people.<sup>35</sup>

More and dedicated efforts to encourage the hiring of people who experience structural disability may prove crucial to increasing the disabled workforce. For

instance, following federal example, more jurisdictions are adopting fair-chance policies for people with histories of incarceration. In 2019, the “Fair Chance to Compete for Jobs Act of 2019” prohibited most federal agencies and contractors from asking about arrest and conviction history on job applications; they must wait until conditionally offering the applicant the job. By 2021, 37 states and 150 cities and counties have adopted “ban the box” and 15 states and 22 cities have extended their fair-chance laws to private employment.<sup>36</sup> Many jurisdictions go further than “banning the box” and follow the best practices of the 2012 U.S. Equal Employment Opportunity Commission’s guidance.<sup>36</sup> Employers that hire people with arrest and incarceration histories have reported these employees are more productive and their companies experience less turnover.<sup>37,38,39,40,41</sup> The 2019 federal law and subsequent local laws can affect the more than 70 million people in the U.S. that have a criminal record.<sup>42</sup> A similar concerted effort to improve the hiring of disabled people in the U.S. could affect more than 83 million people (i.e., 1 in 4 people in the U.S.).

Under the ***Representation Structure*** multiple participants shared that inaccessible transportation limits visibility of disabled people in their communities. One participant shared that he enjoys international travel for fun but noted that airplane lavatories are not accessible, even with grab bars. Specifically, this participant commented on the small size of the airplane lavatories not allowing for people using the lavatory to receive help (***Participant Concerns and Advice table***; P12). This means that some disabled people loathe to fly because they risk their health, comfort, and/or dignity when they cannot use a lavatory while commuting by plane. On 29 July 2023, the Department of Transportation announced regulatory action to increase the accessibility of lavatories on single-aisle airplanes with more than 125 seats. The language of the final rule requires that single-aisle aircraft (which are more commonly being used for long-haul flights) have, among other accessibility features, accessible faucets, controls, call buttons, door locks, and space for an attendant.<sup>43</sup>



**A parent pushing a stroller getting is ready to cross the street at a crosswalk.**

**The "curb-cut effect" highlights that accommodations for one group can have effects that help many.**



Such improvements are likely to benefit more than those for whom they are initially anticipated to serve. This is commonly referred to as the “curb-cut effect,” and refers to the reality that supporting one group ultimately improves wellbeing for many other groups.<sup>44</sup> Curb-cuts first appeared in 1945 in Kalamazoo, Michigan but thanks to disability activists, in 1972 the curb-cut created at one Berkeley, California street corner started a national wave of inclusive curb-cutting. The curb-cuts made commuting easier for all sorts of people, including people pushing strollers, workers pushing carts, people traveling with luggage, and so on. Similarly, improving accessibility for airplane restrooms will likely improve the experience for others, including people traveling with children for example. Sometimes the additional community members who will benefit are not always apparent until after the improvement is implemented. Importantly though, improvements do not need to benefit more than the groups for which they are initially intended to merit implementation. Accessibility is valuable even when it only benefits disabled people.

In the ***Culture Structure***, participants of various races shared personal experiences of how racism is intertwined with their disability experience. A White, male participant shared about an experience in which his Whiteness likely protected him against police violence (***Section 7a***). Disabled people of color are less likely to get the benefit of the doubt or moment of police pause that the participant received, and their impairment (e.g., gait imbalance, autism, deafness) may be interpreted as threatening by law enforcement agents.<sup>45</sup> Of note, the impairment is specifically threatening because of the disabled person’s (perceived) race and the racism still present in U.S. culture.<sup>46</sup> The disproportionate arrest and killing of people of color by police is often complicated by impairments and structural disability.<sup>47,48</sup> According to analysis of data from a National Longitudinal Survey of Youth, disabled people are more likely to be arrested by police and more so if the

*“...being disabled in America, in my opinion, is a dehumanizing experience. And if I say being a Black female in America, for me can be a dehumanizing experience. And then if I linked the two, then I would say hey, being Black female is almost like I already had a disability, ‘cause I was already being dehumanized, and now I’m being layered another dehumanizing experience on top of that...” (P43).*



person is of color; among disabled people of color, Black disabled people had the highest risk of being arrested by police.<sup>49</sup> It is not that people of color are inherently more criminal than Whites, but rather that these populations are more likely to be criminalized.<sup>45,47,50</sup>

Importantly, racism is not subordinate to the experience of disability (nor vice versa). Disability justice scholars would caution against such a characterization of intersectionality. Rather, race and disability are inextricably linked as social constructions; one scholar posits that the concept of Blackness was constructed to be disabling *a la* the Middle English definition: people racialized as Black were classified as inferior, worthy of enslavement, and deprived of the basic rights of personhood.<sup>51</sup> In this study we scratched the surface of racism-disability intersectionality, and to a lesser degree, sexism-disability intersectionality. More in



**A lecture hall has many students taking an exam.**

**An accessible higher education is not currently guaranteed by the IDEA Act.**

depth interviews focused on the experiences of racism-disability, sexism-disability, and racism-sexism-disability intersectionality could offer more insights into how these structures interrelate to affect various peoples' experiences of disability.

Under the *Education Structure*, multiple participants addressed “mainstreaming” as well as accessibility and accommodations in higher education settings. The IDEA Act makes an appropriate public education freely available to children with impairments and requires

that special education and “related services” are also available. This law provided recourse for at least one study participant who was initially denied entry into her local public, or “mainstream,” school. But in higher education, some participants reported struggling with accessibility and to get the accommodations needed to succeed. The IDEA Act focuses on childhood education and provides discretionary grant opportunities to institutions of higher education (and others) for activities such as research, technical assistance, technology development, personnel development, and parental figure-training centers.<sup>52</sup> The IDEA Act does not guarantee a college or university education for learners with impairments.

While Section 504 (of the Rehabilitation Act of 1973) and Title II (of the Americans with Disabilities Act of 1990) prohibit discrimination based on disability, college and university education is not guaranteed to disabled learners in the same way that Section 504 protects certain disabled learners' right to a free, appropriate public education (FAPE).<sup>53</sup> U.S. colleges and universities are required to provide “appropriate academic adjustments” to prevent disability discrimination but there are limitations to this requirement. For example, the adjustments cannot cause an “undue financial or administrative burden” to the school, and institutions of higher education do not have to provide personal attendants, readers, or individually prescribed devices.<sup>53</sup> As one participant pointed out, the determination of what accommodations are appropriate is open to interpretation (P39). Students that disagree with a negative determination need the financial and legal resources to dispute the decision. These limitations pose significant obstacles to many disabled learners, as study participants shared. A postsecondary education is a way out of poverty for many people in the U.S. and increases individual wellbeing and life expectancy.<sup>54,55</sup> That some disabled learners cannot meaningfully access postsecondary education may pose a structural barrier to their economic self-sufficiency and improved health.

While some participants reported wanting or having to attend mainstream schools, others expressed that they did not benefit from mainstream education as much as they did or would have from schooling dedicated to students like them. This was specifically reported by participants who were Deaf. One participant called out the networking available to Deaf learners who attended Deaf schools. Study findings reported in 2007 seem to bear this out, at least for Deaf students. Weathers, et al reported that analysis of SSI data demonstrated that Deaf students who graduated from the National Technical Institute for the Deaf (NTID) were more likely to stop using SSI benefits than other d/Deaf SSI recipients.<sup>56</sup> As study participants pointed out, the Deaf community has a strong network and decades of culture development (P5); attending a Deaf school provides access to that network that mainstreaming cannot offer (P29). This may in turn

*“...I mean [as a Deaf person] I was always learning things by memorizing, never really understanding the English language in, in the private and public schools up to 8th grade” (P22).*

expose Deaf school graduates to employment opportunities not as easily accessible for mainstreamed learners. More work is needed to explore how not/mainstreaming impacts the wellbeing and economic self-sufficiency of other disabled populations.<sup>57</sup>

In the SSA Structure, participants shared about many areas in which their experiences with the agency are disabling. Below, we dig into some findings of note and areas ripe for more exploration and intervention.

## Structural Ableism

While disability justice and disability scholars have been having these conversations for decades, the federal government’s understanding of disability has historically been less complex and nuanced. For example, based on the Social Security Act, the Social Security Administration’s definition and operationalization of disability has essentially been binary: either a person can work and therefore is not disabled, or a person cannot work because they are disabled. The latter group may be qualified to receive SS(D)I and the former group is not. As one participant commented, this is an economic determination of disability, and it is incomplete.

*“...we aren’t feeding capitalism in the way that the capitalists want us to, which is as simply as possible. ‘Please have no needs’” (P28).*

Someone may not qualify as disabled by SSA standards, for example, if they can work sufficiently to support themselves, but they would still experience structural disability in U.S. society. Associated with the economic determination of disability is structural ableism. Public health specialists Sheth Valdez and Swenor define the U.S. manifestation of structural ableism as “...the experience of disability [that] is shaped by a political economy rooted in capitalism, a system that treats the disabled body as disposable and prioritizes the right to wealth over the right to inclusion.”<sup>58</sup> Multiple participants in this study describe their



**A young Black man sits in a row with others, who are out of focus.**

**Even if someone can work, they may still be structurally disabled.**

experiences in these terms, including one small business owner who understands and even makes profit-based choices over those that would further inclusion. He explained that in a capitalist economy, these are choices of business survival.

## Working And Saving While Disabled

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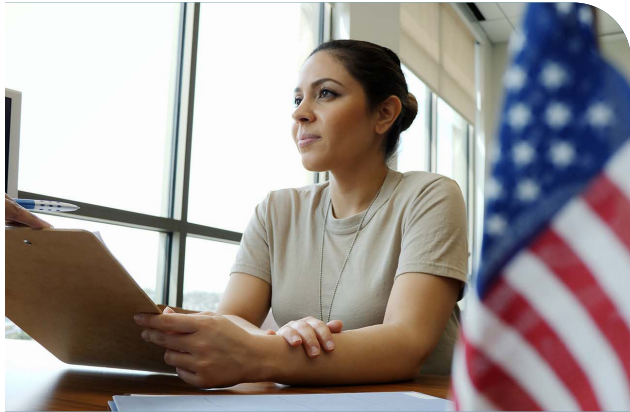
Despite the Social Security Act, the reality of disability is more complex than “can” versus “cannot work.” At the time of the interview, more than half of the study participants (25; 57%) were working in some capacity; less than half (21; 48%) were receiving SS(D)I, and there was some overlap between the two. In fact, almost half (10; 48%) of the people interviewed who were receiving SS(D)I were also working in some capacity. SSA’s Ticket to Work and other work incentive programs indicate a governmental understanding that not all disabled people will/always need governmental economic support for survival, and that some disabled people will be able to work to some capacity. In 2019 SSA convened a Technical Expert Panel to consider what mechanisms or actions might promote or encourage SSDI recipients to engage, to some degree, in the labor force.<sup>59</sup> One recommendation was to eliminate the binary conceptualization of disability and incorporate concepts of partial, temporary, and waxing-waning disability. While this may complicate SSA’s workload it more accurately reflects how impairment and disability manifest in the U.S. Multiple participants in this study expressed concern about intermittently working after being deemed “disabled” by SSA because it imperiled their access to needed healthcare (via Medicaid or Medicare, by way of SSI or SSDI, respectively) or economic support when they were not able to obtain substantial gainful activity (SGA) earnings.

*“...if you’re fully honest, like about the things that you are capable of, it feels like they will so quickly, like latch on to the things that you are capable of and, and basically just use the fact that you said you were capable of something as a reason to deny you when there’s, when there’s so many, when there’s -- you’ve been like, open with describing like, you know I don’t function on this, on this level of and you know and here’s why and, and it just, and it just feels like if you, if you don’t...really like drive home the fact that like I do not function with this specific thing, then, then they’re just gonna be like, ‘yeah, you’ll be fine’” (P1).*



Moreover, the binary determination process is so burdensome to the applicant and so long, and is “...predicated on establishing inability to perform SGA [that it] discourages work and diminishes residual work capacity.”<sup>59</sup> That is to say, in the present binary SSA system, recipients put so much effort and time into proving they cannot work—because that is their only option for getting survival support—that it is counterintuitive and counterproductive for some to then attempt to work. This is magnified by the complexity of successfully navigating the current SSA work incentives and savings options programming<sup>60</sup> (e.g., *Plan to Achieve Self-*

*Support*,<sup>61</sup> *continued payment under Section 301*,<sup>62</sup> *Trial Work Period*,<sup>63</sup> *Individual Development Accounts*<sup>64</sup>).



**A young Latina sits holding a clipboard.**

**There are a variety of work and savings options for disability benefit recipients.**

Some participants suggested policy or operational options that already exist (like those listed above) including an expedited return of cash payments or a grace period of continued Medicare or Medicaid coverage while working.<sup>65</sup> More work is needed to quantitatively explore if and what percentage of disabled people are unaware of the various work and savings

options or if the options are just too difficult to navigate. In one survey well less than half (6.2% - 34.6% depending on the program/option) of eligible disability benefit recipients were aware of the SSA work and savings options and programs available to them.<sup>66</sup>

Another investigation was conducted about ABLÉ accounts; the team found that people are unaware of ABLÉ accounts and experience barriers related to how the program is administered and having limited finances. Researchers found that ABLÉ accounts are more likely to be taken up by wealthy families, who are more likely to be White and connected to service organizations that inform them about ABLÉ accounts. Additionally, there were a lot of misconceptions about the program, survey respondents said the program’s informational language was not approachable, and 30% of those surveyed said they did not open an ABLÉ account because they did not have enough money to save.<sup>67</sup> In this example, the option to save (for a select group of people) has low awareness and is poorly navigated without support.

Still, if SSA's binary determination of "disabled or not" was eliminated, SSA's various work and saving incentives may seem more like the rule than the exception. These programs could, with resourced support, be more accessible to people like many of our study participants who state a desire to participate in the labor force and/or save money.

## Marriage Penalty

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A few participants raised the marriage penalty as an SSA policy that should be changed and it directly impacted one participant. That participant cannot afford to marry her fiancé because of this penalty that lowers the monthly payment of married SSI recipients. Balkus and Wilschke (2003) examined potential resolutions to the problem that SSI couples face.<sup>68</sup> The policy of lowering the monthly payments of married SSI recipients was based on an "economies of scale" theory that a shared household would, with shared expenses, have less cash need. This theory is not applied to other people sharing a household (e.g., SSI recipients who are not married but live together) and it is not used by Temporary Assistance for Needy Families (TANF) or the Food Stamp program (now called Supplemental Nutrition Assistance Program or SNAP).<sup>68</sup>

The application of this theory impoverishes married SSI couples, doing the opposite of what SSA aims to do. According to Koenig and Rupp (2002), the poverty rate for two unmarried SSI recipients is 9.8% but for wed SSI recipients it is 45.1%;<sup>69</sup> in 2008, an analysis by Balkus et al found the wed SSI recipient poverty rate was 52% (the specific poverty rate for two unmarried SSI recipients was not shared).<sup>70</sup> Furthermore, the economies of scale theory is particularly inapplicable to people experiencing disability. An SSI recipient couple cannot share a singular wheelchair cushion or supply of catheters, for example. Other work has demonstrated that disabled people need 28% more income than nondisabled people to reach the same standard of living.<sup>23</sup> Multiple participants



**Two wedding bands rest against each other on a table.**

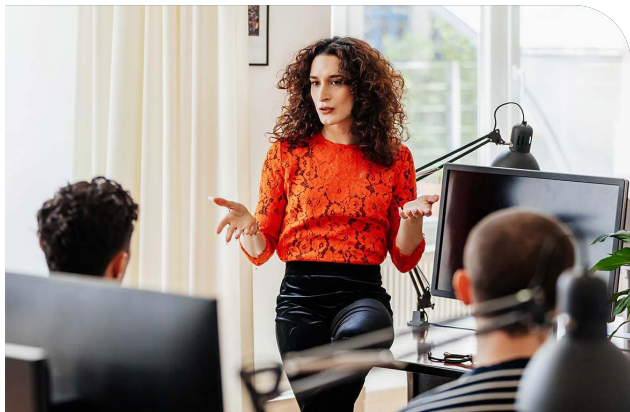
**Multiple studies, including this one, have examined the impact of the marriage penalty.**

in this study described needing to pay for medical or assistive devices out-of-pocket because Medicare or Medicaid, does not provide the requisite support. The legislative SSI marriage penalty either hinders people from exercising free will and experiencing the social and economic benefits a marriage affords people in the U.S.; or it further imperils their economic survival by decreasing, what participants have described as, “below poverty” monthly supports.

## Gender

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This work did not explicitly explore gender, perceived gender, and their interactions with disability. Still, some participants raised gender and gender perception in discussing how disability manifests in their lives ([Culture, section d](#)). In this qualitative study, 28% of women were unemployed at the time of their interview; in comparison, 43% of men were unemployed at the time of their interview. This study



**A Southwest Asian woman is leading a team meeting.**

**In this qualitative study, more disabled women were employed than men, but quantitative data shows the opposite.**

was not designed to allow for examination of statistical significance, and in fact, a 2021 Department of Labor report demonstrates that disabled women are *less* likely to be employed than disabled men. Still, the gendered experience of disabled unemployment reminds us to consider the literature that identified that women, with “a severe, work-related, permanent impairment” are more likely to be denied disability benefits than men.<sup>71</sup> Qualified but denied disabled women are not (re-)entering the work force,<sup>71</sup> so more work should explore if and how women inappropriately denied disability benefits

achieve economic security. More work is also needed to explore why women are inappropriately denied disability benefits more than men, and how to effectively and systematically resolve this.

## Impairment Early Vs. Later

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More work is also needed to explore the phenomenon in this study in which only 10% of people born with their impairment (or acquired very early in childhood) were unemployed at the time of interview; in contrast, 50% of those who acquired their impairment later in life were unemployed. Again, because this is a qualitative study, it is not known if this finding is generalizable or a chance occurrence. Quantitative data is first needed to determine how unemployment occurs in “born with” versus “acquired” populations. If a disparity remains, additional investigation should explore the reasons for this. One possible explanation is that people who have lived nearly/all of their lives navigating a structurally disabling society may have developed more capacity for adapting to an inhospitable work-world. Another possible explanation is that, when someone has developed a particular skillset over many years if they acquire an impairment that interferes with their ability to do their previous work, they are less likely to find SGA employment.

## Disability Determination Process

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SSA has a standing list of impairments that may be recognized in applicants’ disability evaluations. Long COVID is a relatively new phenomenon and does not



**A young South Asian woman using a wheelchair answers a landline phone in an office.**

**SSA evaluates each disability application individually.**

fit into just one of the existing categories; its symptoms and ramifications are diverse and may affect multiple organ systems in a variety of combinations.<sup>72</sup> SSA’s guidance to clinicians explains that SSA’s determination considers the “impact of the illness on each affected body system,” not the diagnosis of Long COVID itself.<sup>73</sup> One participant with Long COVID felt it was not the applicant’s job to educate SSA on how Long COVID affects someone’s ability to “participate in society” and thus how it affects eligibility for disability benefits (P28). Rather, she suggests it is SSA’s

responsibility to communicate with the National Institutes for Health (NIH) and do



that “self-education.”\* This concern about the burden on applicants to convey how an impairment affects their functioning and ability to work is noteworthy because this is SSA’s disability determination process for all disability benefit applicants.

SSA’s disability evaluation is specific to the individual because the same impairment may affect different people differently.† For example, an office manager and a construction worker may both experience a traumatic spinal cord injury at the same level resulting in the same limited lower extremity use. Based on the nature of the work, the office manager may be able to return to their job while the construction worker may not. Still, another participant expressed a similar sentiment and stated that applicants should not have to submit to an additional series of tests to prove their impairment (P7). Others felt that the SSA reassessment for continued disability was unnecessary for certain impairments like IDD. This group of participants expressed that SSA’s evaluations and requirements for clinical examinations outside of the applicants’ care teams are intrusive and onerous.

They offered a range of suggestions about SSA rules‡ to address this including SSA simply believing applicants when they say they are disabled; relying on existing clinical evaluation data to make determinations; and clarifying why some benefit recipients require impairment reassessment and not others. In SSA’s July 2023 Quarterly Roundtable with Disability Advocates, a panelist similarly raised concerns about the individualized evaluation process.<sup>74</sup> Among the issues raised were that the personalized nature of the evaluation is time intensive and thus costly (including for SSA), many adjudicators are not fluent in the clinical language of the healthcare documents provided, and that reliance on whether applicants can independently perform ADLs does not comport to their ability to sustain a full-time job. The panelist suggested that, similar to how food benefits for children were allocated during the COVID pandemic, SSA should use data to identify who is most likely to qualify for disability benefits and automatically enroll them.

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\* Of note, SSA has engaged in work with the National Academies of Science to understand more about the impacts of Long COVID: <https://nap.nationalacademies.org/catalog/26619/long-covid-examining-long-term-health-effects-of-covid-19>

† Read more about SSA’s disability determination process here: <https://www.ssa.gov/disability/professionals/bluebook/index.htm>

‡ Regulatory changes are different from legislative changes, which require a change in law. Regulatory changes may be made by the agency.

## Poverty-Level Payments And Earnings Allowed

While some participants expressed appreciation for their monthly disability monthly cash benefits, nearly all the recipient participants lamented the small monthly

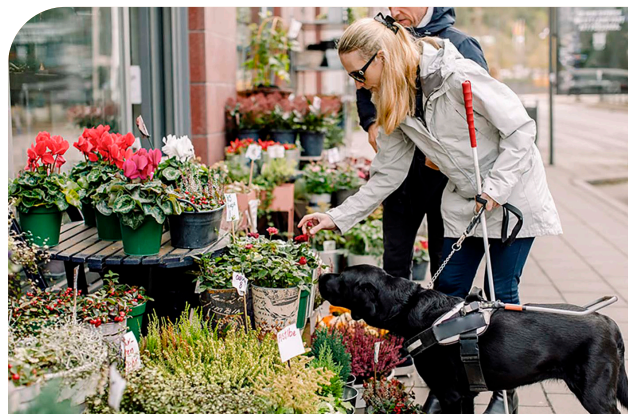
*“...America has enough money to support its people...But it’s only wealth for certain people, only supports for certain people” (P19).*

amount. Recipient participants and applicant participants described the monthly allotment as “poverty level” or below. This is not surprising or new information. Without additional support (e.g., housing voucher, SNAP), an SS(D)I payment cannot support independent living for many people, especially when disabled people need 28% more income than nondisabled people to achieve the same standard of living.<sup>23</sup>

Participants also raised concerns that the monthly incomes allowed are lower for non-blind recipients than blind disability benefit recipients according to present law. This means that disabled people who are not blind are not allowed to earn as much income and remain eligible for disability benefits, in comparison to blind people.<sup>75</sup>

While nearly all the blind study participants were working (one was retired) and some were also receiving disability benefits, 36% (14) of those who are not blind were unemployed at the time of interview; further study is needed to determine if this is a chance finding or reflects a disparity in employment between blind people and other, not blind, disabled people.\*

SSA raises disability benefit monthly payments using cost-of-living adjustments (COLA) as required by law.<sup>76</sup> These adjustments are meant to account for inflation and prevent erosion of the purchasing power of benefits. Annually, SSA reviews the Consumer Price Index (CPI) to



**A blind White woman is shopping for plants outside a store with her service dog.**

**Blind people are currently allowed to earn more money than other disabled people and still receive disability benefit payments.**

\* Much of the work examining employment rates among the blind use non-disabled people or disabled people collectively (which may include blind people) as the comparator. See examples: McDonnall M. “Beyond Employment Rates: Summary of Findings and Conclusions From the Series” Journal of Visual Impairment & Blindness. 2022; 116: 5, pp 593-595. And, Paul, S., Rogers, S., Bach, S., & Houtenville, A.J. (2023). Annual Disability Statistics Compendium: 2023. Durham, NH: University of New Hampshire, Institute on Disability.

calculate COLA. Specifically, SSA uses the CPI for Urban Wage Earners and Clerical Workers (CPI-W), which is determined by the Bureau of Labor Statistics in the Department of Labor.<sup>77</sup> CPI is based on the cost of goods and services in 8 major categories: housing, clothing, transportation, education/communication, recreation, medical care, food/beverages, and other goods/services. The categories are then weighted for use in the CPI calculation. CPI existed before SSA started using it for COLA computation in 1972 and is used to gauge inflation and measure changes in people's ability to make purchases. Given years of feedback and this study's participant reports about the inadequacy of SS(D)I payments, and given COLA-



**A middle aged Black man selects items from a food pantry.**

**Disabled people need 28% more income to have the same quality of life as nondisabled people.<sup>23</sup>**

determination was not CPI's originally intended purpose, perhaps CPI is no longer the best measure for increasing monthly benefits from one year to the next.

The Official Poverty Measure (OPM) was developed over 50 years ago and was originally determined by calculating the cost of food for a household and multiplying by three; that is no longer an accurate way to evaluate for poverty.<sup>78</sup> The current OPM calculation still does not center on what people and families need to live.<sup>79</sup> States use the Self-Sufficiency Standard (SSS), which is based on the major

budget items of 18–64-year-old working adults: housing, childcare, food, health care, transportation, and taxes. While OPM is the same for all the continental U.S. the SSS is location-specific and usually calculated by local county. It also varies by age and number of children in a household. The SSS in New York, for example, demonstrates that many incomes above the OPM, or federal poverty thresholds, are still inadequate to meet household needs,<sup>78</sup> and in 2022, New York State voters elected to recalculate the SSS. At the time of this writing, a bill is in Committee Assembly for the 2023-2024 Legislative Session requiring the New York Department of Labor to contract with a third party to study how to update the SSS.<sup>80</sup> This information will allow New York to more accurately determine what households need to survive. This revision, among other improvements, would help New York better determine how much financial support in-need households should receive. More work is needed to



determine what other, more accurate measures SSA might use to support people receiving disability benefits more effectively and comprehensively; changes to the computation measures would require a change in law.

As required by law, SSA annually determines SGA based upon the national average wage index. In 2024, the monthly SGA amount for blind people is \$2,590; for other disabled people the SGA amount is \$1,550.<sup>75</sup> This means that non-blind disabled people must earn less than blind people to remain eligible for disability benefits. The national average wage index for a year is calculated by multiplying the previous year's national average wage by the percentage in wage change between the previous and current year.<sup>81</sup> Because SGA is based on national data, it may not reflect the average wage of local geographic areas. For example, in the second quarter of 2021 people in Santa Clara, California were paid (\$3,516) a weekly wage over 3 times (or \$2,788) more than people in Hidalgo, Texas (\$728).<sup>82</sup> Using a national wage may benefit the people in Hidalgo but be insufficient for people living in Santa Clara. As with the SSS, more work is needed to determine what other, more locally relevant measures SSA might use—instead of the national wage index—to determine appropriate SGA levels for benefit recipients. The geographic SGA allowance disparity may be further deepened by the blind-not blind SGA allowance difference, disadvantaging disabled people who are not blind and living in more expensive U.S. counties. Removal of the SGA allowance difference based upon blindness requires legislative change.

## Benefits Delay

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A few participants raised concerns about how long the disability application and review process takes; one participant specifically noted that while she is waiting for her benefit payments to begin she is crowd-sourcing fiscal support for survival. For people approved, benefit payments are due to the recipient 5-months from the date of disability onset; because the determination process can take longer than 5-months, recipients approved more than 5 months after disability onset



**Someone holds a receipt while reviewing a pile of receipts and using a calculator.**

**Making ends meet while waiting for disability benefit payments can be hard.**



receive retroactive payments. Some people can be or are approved faster (e.g., they have an impairment on the Compassionate Allowances list or their application is identified by the Quick Disability Determinations process)<sup>83,84</sup> but the 5-month waiting period is burdensome. Many people do not have a resource network that can, even temporarily, provide financial aid while they wait for disability benefit payments to start. A bill called “Stop the Wait” proposes to simply eliminate the 5-month waiting period.<sup>85</sup>

In addition to the current 5-month waiting period for disability payments, SSDI recipients must wait 2 years (after disability entitlement) before they are entitled to Medicare. In those two years, beneficiary recipients may or may not be eligible for healthcare through their former employer. If they are not eligible and cannot afford to purchase health insurance in the Marketplace, what do they do? This waiting period may also disproportionately harm people of color and/or women, for example, as these groups disproportionately have to work jobs that do not offer comprehensive/health insurance.<sup>86,87,88,89</sup> Regardless of race, gender, or any other social demographic, people need access to health care which is often too costly, in the U.S., to afford without insurance. In addition to eliminating the cash-payment waiting period, the SSDI Medicare eligibility waiting period could also be abolished.

## No Wrong Door

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**A young Native American woman stands in her backyard with a toddler on her hip.**

**Being eligible for one type of support often means needing support in other ways too.**

Multiple participants shared interest in disability programming being related to other supports, including housing, energy assistance, food assistance, and broadband/internet connection, in addition to Medicare and Medicaid. Of note, participants suggested that if receipt of disability benefits made them eligible for those non-cash services, even if people started working/again, they should remain eligible for those non-cash benefits for some period of time (see [\*Participant Concerns and Advice for SSA\*](#) P24, P38 in [\*Appendix\*](#)). One participant also suggested that there be some sort of

checklist, so that members of the public could simply check off areas of need, be assessed, and get services in those areas ([Participant Concerns and Advice for Other Structures](#), P19; in [Appendix](#)).

On 13 December 2021, President Biden issued Executive Order (EO) 14058. In it, SSA was tasked with supporting applicants and benefit recipients in identifying other benefits for which they might be eligible. Of all the federal agencies, SSA has contact with more of the public, and more frequently. SSA is uniquely positioned to connect members of the public with needed resources. In fact, SSA already does in a number of areas including Medicaid, interim assistance pending SSI approval, housing assistance, energy assistance, the Affordable Connectivity Program (ACP) for SSI-eligible folks, and SNAP. In certain cases, SSA must help a person complete the SNAP application rather than make a referral. This last example lowers the burden of governmental bureaucratic navigation for the person in need.

One model to consider that is working well is in California. In Los Angeles County, systems and agencies share hundreds of data points into one platform, via privacy-enhancing technology, to identify community members at imminent risk of housing insecurity. Community members' data is protected and their need is identified regardless of whether they went to an emergency department, signed up for benefits, experienced an arrest, or presented to some other system or agency.<sup>90</sup> In LA County, there is “no wrong door” for someone approaching housing insecurity to be recognized. Aligning with the spirit of EO 14058, “Transforming Federal Customer Experience and Service Delivery to Rebuild Trust in Government,” more work is needed to determine the best way(s) for the federal government to efficiently meet the needs of the public so that there is “no wrong door” for a person to access survival services.

*“I think there should be like a card where it says, ‘here are all the things, check off what you need,’ and then maybe you can have like, you know, quarterly conversations and then you can actually look at their data” (P19).*



## Limitations and Future Work



# Limitations and Future Work

As a qualitative study this work was not intended to be representative of the diversity of experiences of disabled people in the U.S. Rather, “Understanding Experiences” sought to develop a foundational theory—grounded in the experiences of disabled peoples—of the structural contributors to disablement. While the study participants were diverse in a variety of ways, notably missing from those voices were people who cannot communicate for themselves; people without access to the internet or broadband to initiate study contact; people without access to phone use; people living on reservations or outside of the continental U.S.; people experiencing housing insecurity or unsheltered living. The study also may not have recruited people whose primary language does not use or have the word “disability,” as in the Northern Arapaho or Hmong languages, for example. One scholar said, “...most Indigenous languages have no word for disabled or impaired...as there is no ‘ideal’ person or way of existing, no human body or mind is necessarily preferential.”<sup>91</sup> Some who used a spoken, non-English language or who lived in a U.S. territory reached out but were unable to join or reschedule their interviews for unknown reasons. The voices of people from these groups are not necessarily reflected in this study and they may have offered insights that generated data about other structures or other ways that the identified structures contribute to disability. Future work should purposefully seek out members of these groups to add to or revise the grounded theory of disability developed here.

Additionally, this study did not explicitly or sufficiently explore the interaction of perceived/gender, class, and other marginalized identities and experiences, with disability. And while participants were asked about whether they had their impairment for all of their living memory or they acquired it, more work is needed to explore how structures support or exclude people with respect to this differentiation.



**A young Native woman in a fencing uniform sits in a wheelchair, gazing off camera.**

**Some communities do not have a word for "disability."**



Highest level of education attainment was not explicitly asked of each participant, and this information may have offered more insight into how different structures impacted study participants.

Although the study explored some aspects of culture, study participants were not explicitly asked, nor did they share about disability culture. According to Steve Brown, disability culture is a group identity formed around “a common history of oppression and a common bond of resilience...we are proud of ourselves as people with disabilities. We claim our disabilities with pride as part of our identity. We are who we are: we are people with disabilities.”<sup>92</sup> While elements of this definition appear in the stories, opinions, and insights shared by participants, further exploration of how culture affects disability experiences could specifically explore disability culture.



# Conclusion

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**Figure 11:**..... **120**

# Conclusion

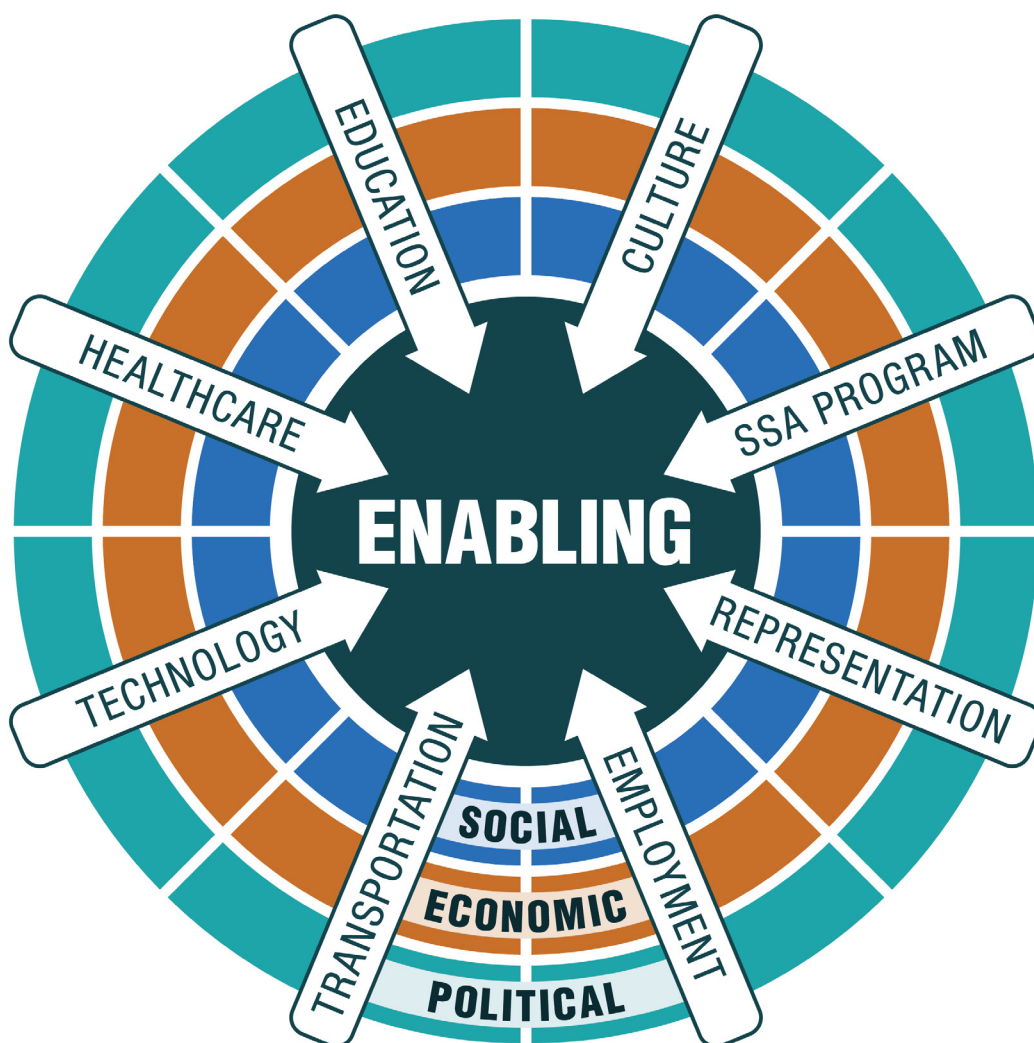
Disability is often portrayed and operationalized as inherent to the individual by practitioners of Western medicine, scholars, and many U.S. government agencies, including SSA. This study, by its very question, challenges that understanding. This study leans into the social model of disability that defines disability as societally created social, economic, and/or political exclusion of people whose minds and/or bodies are devalued. Based on the lived experience and insights of 44 disabled people living in the U.S., this study names 8 major structures that currently disable people socially, economically, and/or politically.

Figure 1: The social, economic, and political results of these structures that, done wrong, are disabling



The manifestations of these structures are not fixed; that is to say, the structures themselves are not inherently disabling and can be changed to promote social, economic, and political participation. The structures must be redesigned to become enabling. For example, improvements of some SSA policies, programming, and regulations can improve SS(D)I service provision to people with impairments and consequently increase participation in the workforce. Furthermore, the “curb-cut effect” demonstrates that investment in purposefully inclusive structural design and implementation will improve the lives of everyone living in the U.S. This study, grounded in lived experience expertise, is a step toward a socially, economically, and politically inclusive nation.

Figure 11: The social, economic, and political results of these structures that, done right, are enabling





# References

- 1] Centers for Disease Control and Prevention. “Disability Impacts ALL of US.” 2023. Available from [Cdc.gov/ncbddd/disabilityandhealth/infographic-disability-impacts-all.html](https://www.cdc.gov/ncbddd/disabilityandhealth/infographic-disability-impacts-all.html)
- 2] Reséndez A. *The Other Slavery: The Uncovered Story of Indian Enslavement in America*. Mariner Books; 2016.
- 3] Morris T. *Southern Slavery and the Law, 1619-1860*. University of North Carolina Press; 1996.
- 4] Kendi I. *Stamped from the Beginning: The Definitive History of Racist Ideas in America*. Nation Books; 2016.
- 5] Tankersley J. 19 August 2018. “From Cradle to the Workplace.” *The New York Times*.
- 6] Edwards M, Schaffner B. (2020). *Sexism Among American Adults*. *Contexts*, 19 (4), 72-74.
- 7] Carnevale AP, Strohl J. “Separate & unequal: How higher education reinforces the intergenerational reproduction of White racial privilege.” Georgetown University, Center on Education and Workforce. 2013. <http://cew.georgetown.edu/wp-content/uploads/SeparateUnequal.FR.pdf>
- 8] Coe DL, Davidson JD. “The origins of legacy admissions: a sociological explanation.” *Rev Relig Res* 2011; 52(3): 233-47.
- 9] Synnott MG. *The Half-Opened Door: Discrimination and Admission at Harvard, Yale, and Princeton, 1900-1970*. Westport, CT: Greenwood Press; 1979. P. 190.
- 10] Social Security Administration. Annual Statistical Report on the Social Security Disability Insurance Program, 2021. Table 66. Available from: [https://www.ssa.gov/policy/docs/statcomps/di\\_asr/2021/sect05.html#table66](https://www.ssa.gov/policy/docs/statcomps/di_asr/2021/sect05.html#table66)
- 11] Social Security Administration. SSI Monthly Statistics, December 2021. Table 1. Available from: [https://www.ssa.gov/policy/docs/statcomps/ssi\\_monthly/2021-12/table01.html](https://www.ssa.gov/policy/docs/statcomps/ssi_monthly/2021-12/table01.html)
- 12] Social Security Administration. About us [Internet]. Available from: <https://www.ssa.gov/agency/>
- 13] Social Security Administration. “Agency Strategic Plan. Fiscal Years 2022-2026” Available from: [https://www.ssa.gov/agency/asp/materials/pdfs/SSA\\_Agency\\_Strategic\\_Plan\\_Fiscal\\_Years\\_2022-2026.pdf](https://www.ssa.gov/agency/asp/materials/pdfs/SSA_Agency_Strategic_Plan_Fiscal_Years_2022-2026.pdf)
- 14] Social Security Administration. “Supplemental Security Income (SSI).” Available from: <https://www.ssa.gov/pubs/EN-05-11000.pdf>
- 15] Social Security. “Disability Benefits.” Available from: <https://www.ssa.gov/pubs/EN-05-10029.pdf>
- 16] Social Security Administration. Understanding Supplemental Security Income SSI Benefits—2023 Edition. Available at: <https://www.ssa.gov/ssi/text-benefits-ussi.htm>
- 17] VERBI Software. (2021). MAXQDA 2022 [computer software]. Berlin, Germany: VERBI Software. Available from [maxqda.com](http://maxqda.com).
- 18] University of California, San Francisco. 2018. “Medical and Social Models of Disability.” Available from: <https://odpc.ucsf.edu/clinical/patient-centered-care/medical-and-social-models-of-disability>
- 19] Merriam-Webster. “disable” Available from: <https://www.merriam-webster.com/dictionary/disable>
- 20] University of California, San Francisco. 2018. *Medical and Social Models of Disability*. Available from: <https://odpc.ucsf.edu/clinical/patient-centered-care/medical-and-social-models-of-disability>
- 21] Mingus, M. November 2010. “Changing the Framework: Disability Justice. How our communities can move beyond access to wholeness.” Available from: <https://leavingevidence.wordpress.com/2011/02/12/changing-the-framework-disability-justice/>
- 22] Taylor S. (2004). “The Right Not to Work: Power and Disability.” *Monthly Review*. Available from: [Monthlyreview.org/2004/03/01/the-right-not-to-work-power-and-disability/](http://Monthlyreview.org/2004/03/01/the-right-not-to-work-power-and-disability/)

- 23] Goodman N, Morris M, Morris Z, McGarity S. (2020). “The Extra Costs of Living with a Disability in the U.S.—Resetting the Policy Table.” National Disability Institute. Available from: <https://www.nationaldisabilityinstitute.org/wp-content/uploads/2020/10/extra-costs-living-with-disability-brief.pdf>
- 24] Shearer RA. (2003). “Court ordered counseling: an ethical minefield for psychotherapists.” *Annals of the American Psychotherapy Association*. Vol 3, no. 3, pp8+.
- 25] Honea Boles P, Griffin JE. (2001). “The court-mandated client: Does limiting confidentiality preclude a therapeutic encounter?” *TCA Journal*, 29(2), 149-160
- 26] Corey G. (2010). *Theory and Practice of Counseling and Psychotherapy* (6<sup>th</sup> Edition). Belmont, CA: Brooks/Cole.
- 27] Social Security Administration. “Ticket to Work: Access to Employment Support Services for Social Security Disability Beneficiaries Who Want to Work.” Available from: <https://choosework.ssa.gov/about/how-it-works/>
- 28] Social Security Administration. “Spotlight on Achieving a Better life Experience (ABLE) Accounts—2023 Edition.” Available from <https://www.ssa.gov/ssi/spotlights/spot-able.html>
- 29] “The ICF: An Overview.” Available from [https://www.cdc.gov/nchs/data/icd/icfoverview\\_finalforwho10sept.pdf](https://www.cdc.gov/nchs/data/icd/icfoverview_finalforwho10sept.pdf)
- 30] U.S. Bureau of Labor Statistics. “Home health and personal care aids.” Washington, DC: U.S. Bureau of labor Statistics, 2022. Available from <https://www.bls.gov/ooh/healthcare/home-health-aides-and-personal-care-aides.htm>
- 31] Lee DA. “The nonprofit war on workers.” New York, NY: New York State Assembly, 2021. Available from <https://assembly.state.ny.us/mem/Ron-Kim/story/100283>
- 32] Ain’t I a Woman. Fall 2019 Newsletter. New York, NY: Ain’t I a Woman, 2019. Available from <https://static1.squarespace.com/static/5c79891fc46f6d31b8a8a4c0/t/5da4cef1f8bca22404064a28/1571081972204/2019+Fall+Newsletter.pdf>
- 33] National Archives. 8 August 2023. “Accessibility Guidelines for Pedestrian Facilities in the Public Right-of-Way.” *Federal Register*. Available from <https://www.federalregister.gov/documents/2023/08/08/2023-16149/accessibility-guidelines-for-pedestrian-facilities-in-the-public-right-of-w>
- 34] “Chapter 33—Education of Individuals with Disabilities.” Available from <https://uscode.house.gov/view.xhtml?path=/prelim@title20/chapter33&edition=prelim>
- 35] Grants.gov. 10 August 2023. “FOA-OEDP-23-12 Equitable Transition Models Demonstration Grants (ETM) project.” Department of Labor, Office of Disability Employment Policy. Available from <https://www.grants.gov/web/grants/view-opportunity.html?oppld=349833>
- 36] Avery B, Lu H. 1 October 2021. “Ban the box: U.S. Cities, counties, and states adopt fair hiring policies.” National Employment Law Project. Available from <https://www.nelp.org/publication/ban-the-box-fair-chance-hiring-state-and-local-guide/>
- 37] Eric Kresll, “Consider the risks—and rewards—of hiring ex-offenders,” *HR Magazine*, 57(2), 2012.
- 38] Brad Friedlander, “Give criminals another employment shot,” *Crain’s Cleveland Business*, May 21, 2012
- 39] Suzy Khimm, “States push to provide some ex-felons a second chance,” *MSNBC*, July 21, 2013.
- 40] Shelley Kofler, “In Tarrant County, Program Helps Turn Former Prisoners into Eager Employees,” *KERA News*, January 4, 2014.
- 41] Iowa Civil Rights Commission. (2009). “Ex-Offenders in Employment: Issues Surrounding Ex-Offender Hiring Practices in Iowa.” Iowa Government. Available from <http://publications.iowa.gov/13669/1/ExOffendersinEmployment2009.pdf>
- 42] Wendy Sawyer, Peter Wagner. 14 March 2023. *Mass Incarceration: The Whole Pie 2023*. Prison Policy Initiative. Available from: <https://www.prisonpolicy.org/reports/pie2023.html>

- 43] Department of Transportation. 1 August 2023. Available from “Accessible Lavatories on Single-Aisle Aircraft.” Federal Register. <https://www.transportation.gov/sites/dot.gov/files/2023-08/Final%20Rule%20Accessible%20Lavatories%20Single%20Aisle%20Aircraft%20-%2088%20FR%2050020.pdf>
- 44] Angela Glover Blackwell. 2017. “The Curb-Cut Effect.” Stanford Social Innovation Review. Available from [https://ssir.org/articles/entry/the\\_curb\\_cut\\_effect](https://ssir.org/articles/entry/the_curb_cut_effect)
- 45] Abigail Abrams. 25 June 2020. “Black, Disabled and at Risk: The Overlooked Problem of Police Violence Against Americans with Disabilities.” *Time*. Available from <https://time.com/5857438/police-violence-black-disabled/>
- 46] Robin L, McCoy EF. 15 November 2021. “Policing is Killing Black Disabled People. Centering Intersectionality is Critical to Reducing Harm.” Urban Institute. Available from <https://www.urban.org/urban-wire/policing-killing-black-disabled-people-centering-intersectionality-critical-reducing-harm>
- 47] James Doubek. 21 September 2017. “Oklahoma City Police Fatally Shoot Deaf Man Despite Yells of ‘He Can’t Hear.’” NPR. Available from <https://www.npr.org/sections/thetwo-way/2017/09/21/552527929/oklahoma-city-police-fatally-shoot-deaf-man-despite-yells-of-he-cant-hear-you>
- 48] Vilissa Thompson. 10 February 2021. “Understanding the Policing of Black, Disabled Bodies.” CAP. Available from <https://www.americanprogress.org/article/understanding-policing-black-disabled-bodies/>
- 49] McCauley EJ. “The Cumulative Probability of Arrest by Age 28 Years in the United States by Disability Status, Race/Ethnicity, and Gender.” *American Journal of Public Health* 107, No 12 (1 December 2017): pp 1977-1981
- 50] Nembhard S, Robin L. 2021. Racial and Ethnic Disparities throughout the Criminal Legal System. Available at: <https://www.urban.org/sites/default/files/publication/104687/racial-and-ethnic-disparities-throughout-the-criminal-legal-system.pdf>
- 51] Harris JE. Reckoning with Race and Disability. *The Yale Law Journal Forum*. 30 June 2021. Pp 916 -958.
- 52] Department of Education. “About IDEA.” Available from <https://sites.ed.gov/idea/about-idea/>
- 53] Office for Civil Rights. September 2011. “Students with Disabilities Preparing for Postsecondary Education: Know Your Rights and Responsibilities.” Department of Education. Available from <https://www2.ed.gov/about/offices/list/ocr/transition.html>
- 54] Aron L, Loprest P. 2012. “Disability and the Education System.” *The Future of Children*, Spring 2012, Vol. 22, No. 1, *Children With Disabilities* (Spring 2012), pp. 97-122
- 55] National Center for Health Statistics (US). “Health, United States, 2011: With Special Feature on Socioeconomic Status and Health.” Hyattsville (MD): National Center for Health Statistics (US); 2012.
- 56] Weathers RR II, Walter G, Schley S, Hennessey J, Hemmeter J, Berkhauser RV. (2007). “PERSPECTIVES: How Postsecondary Education Improves Adult Outcomes for Supplemental Security Income Children with Severe Hearing Impairments.” *Social Security Bulletin*, Vol 67, No. 2. Available from <https://www.ssa.gov/policy/docs/ssb/v67n2/v67n2p101.html>
- 57] Gilmour, A.F. (2018). *Has Inclusion Gone Too Far? Weighing its effects on students with disabilities, their peers, and teachers*. *Education Next*, 18(4), 8-16.
- 58] Sheth Valdez R, Swenor BK. (2023). “Structural Ableism—Essential Steps for Abolishing Disability Injustice.” *The New England Journal of Medicine*, 388; 20. Pp1827-1829.
- 59] Gubits D, Gibson S, Wood M, Sierks C, Epstein Z. 2019. “Post-Entitlement Earnings Simplification Demonstration Technical Experts Panel Meeting, Final Report.”
- 60] Social Security Administration. “Red Book. A Guide to Work Incentives and Employment Supports for People Who Have a Disability Under the Social Security Disability Insurance (SSDI) and Supplement Security Income (SSI) Programs.” Available from <https://www.ssa.gov/pubs/EN-64-030.pdf>
- 61] Social Security Administration. “Plan to Achieve Self-Support (PASS).” Available from <https://www.ssa.gov/disabilityresearch/wi/pass.htm#:~:text=Plan%20to%20Achieve%20Self-Support%20%28PASS%29%201%20We%20base,that%20reduces%20or%20eliminates%20SSI%20or%20SSDI%20benefits3>

- 62] Social Security Administration. “Qualifying for Benefit Continuation After You Turn 18.” Available from: <https://www.ssa.gov/pubs/EN-64-118.pdf>
- 63] Social Security Administration. “Trial Work Period.” Available from <https://www.ssa.gov/OACT/cola/twp.html>
- 64] Social Security Administration. “Spotlight on Individual Development Accounts—2023 Edition.” <https://www.ssa.gov/ssi/spotlights/spot-individual-development.htm>
- 65] Social Security Administration. “Continued Medicaid Eligibility (Section 1619(B)).” Available from <https://www.ssa.gov/disabilityresearch/wi/1619b.htm>
- 66] Social Security Administration. (2018) “National Beneficiary Survey: Disability Statistics, 2015.” Table 35. Available at: <https://www.ssa.gov/policy/docs/statcomps/nbs/2015/nbs-statistics-2015.pdf>
- 67] Briscese G, Levere M, Pollack. 4 August 2023. “Improving Financial Security for People with Disabilities through ABLE Accounts.” Annual Retirement and Disability Research Consortium (virtual).
- 68] Balkus R, Wilshcke S. 2003. “Treatment of Married Couples in the SSI Program.” Social Security Issue Paper
- 69] Koenig M, Rupp K. 2002. “The Poverty Status of Different Types of Multirecipient Households: Is SSI Fair to Married Couples?” Paper presented at the 2002 Annual Meeting of the Population Association of America, Atlanta Georgia.
- 70] Balkus R, Sears J, Wilschke S, Wixon B. “Simplifying the Supplemental Security Income Program: Option for Eliminating the Counting of In-kind Support and Maintenance.” *Social Security Bulletin*. Vol 68, No 4. 2008
- 71] Low H, Pistaferri L. (August 2020). “Disability Insurance: error Rates and Gender Differences.” NBER Working Paper No. 26513, JEL No. H55J1671 (p. 36)
- 72] Centers for Disease Control and Prevention. (11 August 2023). “Long COVID and Significant Activity Limitation Among Adults, by Age—United States, June 1-13, 2022 to June 7-19, 2023.” *Morbidity and Mortality Weekly Report.*, 72(32); 866-870.
- 73] Social Security Administration. “Long COVID: A Guide for Health Professionals on Providing Medical Evidence for Social Security Disability Claims.” Available from <https://www.ssa.gov/disability/professionals/documents/EN-64-128.pdf>
- 74] Social Security Administration. July 2023. Quarterly Roundtable with Disability Advocates, virtual.
- 75] Social Security Administration. “Substantial Gainful Activity.” Available from <https://www.ssa.gov/oact/cola/sga.html>
- 76] Social Security Administration. “Compilation of the Social Security Laws.” Section 215(i) of the Social Security Act. Available at: [https://www.ssa.gov/OP\\_Home/ssact/title02/0215.htm#act-215-i](https://www.ssa.gov/OP_Home/ssact/title02/0215.htm#act-215-i)
- 77] Social Security Administration. “Cost-of-Living Adjustment (COLA) Information.” Available from <https://www.ssa.gov/cola/>
- 78] Kucklick A, Manzer L. 2021. “Overlooked and Undercounted 2021: Struggling to Make Ends Meet in New York City.” The Women’s Center for Education and Career Advancement.
- 79] The United States Census Bureau. “How the Census Bureau Measures Poverty.” Available from: <https://www.census.gov/topics/income-poverty/poverty/guidance/poverty-measures.html>
- 80] The New York State Senate. Assembly Bill A1539A. <https://nysenate.gov/legislation/bills/2023/A1539/amendment/A>
- 81] Social Security Administration. “National Average Wage Index.” Available from <https://www.ssa.gov/oact/cola/AWI.html>
- 82] Bureau of Labor Statistics. “County Employment and Wages in Arizona—Second Quarter 2021.” Available from [https://www.bls.gov/regions/west/news-release/2022/countyemploymentandwages\\_arizona\\_20220111.htm#:~:text=Among%20the%20largest%20U.S.%20counties%2C%2090%20reported%20average,the%20national%20average%20in%20the%20remaining%20253%20counties.](https://www.bls.gov/regions/west/news-release/2022/countyemploymentandwages_arizona_20220111.htm#:~:text=Among%20the%20largest%20U.S.%20counties%2C%2090%20reported%20average,the%20national%20average%20in%20the%20remaining%20253%20counties.)



- 83] Social Security Administration. “Compassionate Allowances.” Available from: <https://www.ssa.gov/compassionateallowances/>
- 84] Social Security Administration. “Quick Disability Determinations.” Available from: <https://www.ssa.gov/disabilityresearch/qdd.htm>
- 85] Govtrack. “H.R. 883: Stop the Wait Act of 2023.” Available from <https://www.govtrack.us/congress/bills/118/hr883/text>
- 86] Hodges, L. (2020). “Do Female Occupations Pay Less but Offer More Benefits?” *Gender & Society*, 34(3), 381–412. <https://doi.org/10.1177/0891243220913527>
- 87] Kristal, Tali, Yinon Cohen, and Edo Navot. 2018. “Benefit Inequality among American Workers by Gender, Race, and Ethnicity, 1982–2015.” *Sociological Science* 5: 461–88.
- 88] Hersch, Joni, and Shelley White-Means. 1993. “Employer-Sponsored Health and Pension Benefits and the Gender/Race Wage Gap.” *Social Science Quarterly* 74 (4): 851–66.
- 89] Hemyonov, Moshe, Noah Lewin-Epstein, and William P. Bridges. 2011. “Explaining Racial Disparities in Access to Employment Benefits.” *Ethnic and Racial Studies* 34 (12): 2069–95.
- 90] Von Wachter T, Bertrand M, Pollack H, Rountree J, Blackwell B. (2019). “Predicting and Preventing Homelessness in Los Angeles.” p. 8. Available from [https://www.capolicylab.org/wp-content/uploads/2019/12/Predicting\\_and\\_Preventing\\_Homelessness\\_in\\_Los\\_Angeles.pdf](https://www.capolicylab.org/wp-content/uploads/2019/12/Predicting_and_Preventing_Homelessness_in_Los_Angeles.pdf)
- 91] Lovern LL. (2021). “Indigenous Concepts of Difference: an alternative to Western disability labeling.” *Disability Studies Quarterly*. Vol 41. No 4.
- 92] University of Illinois Chicago. “Definitions of Disability Culture.” Available from <https://www.dcc.uic.edu/about/definitions-of-disability-culture/>



# Appendix

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## SOCIAL SECURITY

### **Understanding Experiences of Living with Impairments in the United States, Customer Research Study**

is a national study conducted by the Social Security Administration (SSA).

SSA wants to hear about the experiences and opinions of  
people who live with disability in the United States.

Virtual interviews are about 90-minutes.

People who complete the interview will receive a \$100 Visa card.

If you don't use English, that's ok!  
We'll send you information in the language you read  
and use an interpreter for the interview.

The study started in February 2023 and you're still welcome to participate!

If you are interested in learning more about the study or want to participate,  
please email [ Researcher ] @ssa.gov.



*QR Code  
no longer used*





## SOCIAL SECURITY

### Invitation Letter

Date 2023

Dear [Potential Participant's Preferred Name],

You have expressed interest in participating in the Understanding Experiences of Living with Impairments in the United States Customer Research Study, a national study conducted by the Social Security Administration (SSA). During this customer research study, researchers will collect information about the experiences and opinions of adults who live or have lived with mental and/or physical impairments. We want to learn about your experience and the structural contributors, if any, that diminish your participation in your community. This study will help the SSA better understand the needs of people who live with various impairments; identify ways to serve more people who might be eligible for disability benefit programs; and design targeted quantitative research and programming to improve the distribution of service and benefits. Participation in this study is voluntary and SSA will protect your information in accordance with the Privacy Act and other Federal laws. Your name or other identifying information will not be included in any published report. Participation in this study will not affect your eligibility for benefits now or in the future.

We invite you to participate in a 90-minute, in-depth interview about your experiences and opinions about living with impairment and disability and accessing disability-related benefits from SSA. The interview will be conducted virtually (online) or by phone and scheduled at your convenience sometime between Mondays through Fridays, 8a – 4p EST. Once you have completed the interview, we will send you a \$100 Visa gift card. You can stop the interview at any time without penalty. You can choose not to answer one or more of the questions.

By participating in this study, you will help SSA understand what things might be helpful to people who live with impairments. For questions about the study, you can call the investigator at [PI's phone number] or email [PI's email address].

I hope you will agree to participate in this very important interview. Your participation may help SSA to improve their programs.

Sincerely,

Makini Chisolm-Straker



## **Privacy Act Statement**

### **Collection and Use of Personal Information**

The Social Security Act, as amended, allows us to collect this information, which we will use to conduct research and improve Social Security Administration (SSA) services. Providing the information is voluntary. Failing to provide all or part of the information will not affect you. As law permits, we may use and share the information you submit, including with other Federal agencies, our contractors, student volunteers, and others as outlined in the routine uses within System of Records Notice (SORN) 60-0218, Disability Insurance and Supplemental Security Income Demonstration Projects and Experiments System; available at [www.ssa.gov/privacy](http://www.ssa.gov/privacy). The information you submit may also be used in computer matching programs to establish or verify eligibility for Federal benefit programs and to recoup debts under these programs.



## SOCIAL SECURITY

### **Informed Consent**

#### **Who is conducting the study?**

The Social Security Administration (SSA) is conducting the Understanding Experiences of Living with Impairments in the United States Customer Research Study.

#### **What is the study about?**

This study will collect information about the experiences and opinions of people who live or have lived with mental and/or physical impairments. The study population includes people regardless of whether they:

- Are currently receiving disability-related payments from SSA, or
- Have previously received disability-related payments from SSA, or
- Never received disability-related payments from SSA.

This study will help SSA better understand the needs of people who live with various impairments; identify ways to serve more people who might be eligible for disability benefit programs; and design targeted research and programming to continue to improve the distribution of service and benefits.

#### **What do you want me to do?**

By consenting to participate in this study, you agree to take part in:

- A video or telephone call that will take about 90 minutes. A member of the research team will ask you questions about your experiences with impairment and disability in your community, and your experiences with SSA.

After completing the video or telephone call, you will receive a \$100 Visa Gift Card. This will be sent to you either by mail or e-mail.

## **How was I selected to be in the study?**

SSA has compiled a group of consultants who are assisting us in identifying participants for this study. These consultants have been asked to reach out to those they know who may be eligible to participate and share information about how to contact SSA about participation. Those who learn about the study are also invited to further share information about it with others. SSA did not receive your information from our group of consultants, only from you when you reached out to the agency about participation.

## **Do I have to be in the study?**

No, your participation in this study is voluntary. Your decision to take part in the study, or not, will not affect any decision SSA makes about your current or future disability benefits or payments.

You can stop the interview at any time without penalty. You can choose not to answer one or more of the questions. If you choose to stop participating in this study, that decision will not affect any decision SSA makes about your current or future disability benefits or payments.

## **How will you protect my privacy?**

SSA will protect your information in accordance with the Privacy Act and other Federal laws. SSA has strict information security and privacy practices to ensure that information is protected from the time we collect it to the time we dispose of the information, consistent with federal requirements.

Your name or other identifying information will not be included in any published report. To participate, you must agree to have your interview audio-recorded and transcribed. If you do not want the entire interview to be audio-recorded, we suggest that you do not participate in the study. If you decide to participate, you can pause audio recording of some parts of the interview and still participate in the study.

Your name will also be removed from the transcription of your interview. The transcripts will then be shared with the SSA consultants working on this study. These consultants are responsible for safeguarding the information you shared in your interview.

## **What are the benefits?**

By participating in this study, you will contribute to:

- SSA's understanding of policies and programs that might be helpful to people who experience disability in the United States;
- Helping SSA improve its programs.

There is no direct benefit to you.

## What are the risks?

Although it is not likely, it is possible that some of the interview questions may make you feel uncomfortable. If this happens, you can take a break, skip any section, or stop the interview. If you get upset during the interview, you may be offered a referral to crisis management services. It is your decision to use this referral if you wish.

Because the same SSA consultants who will help us review your interview transcripts may be who reached out to you to recommend your participation in this study, by participating you risk your interview information being shared with an SSA consultant who personally knows you and who may, even without association of your name, be able to identify you. All consultants will be required to safeguard your personal information and to use information learned for study purposes only.

## Who do I contact with questions?

For questions about the study, you can call the principal investigator at XXX.XXX.XXXX. For questions about your rights and welfare as a research participant, you can call the Pearl IRB Human Subjects Protections office at XXX.XXX.XXXX. Leave a message with your full name, the name of the research study (Understanding Experiences of Living with Impairments in the United States Customer Research Study) and a call-back phone number beginning with the area code. Someone will return your call as soon as possible.

## Consent to Participate

I \_\_[ name, Date of Birth]\_\_ have reviewed the above Informed Consent to Participate in the Understanding Experiences of Living with Impairments in the United States Customer Research Study and had an opportunity to ask questions about the study. I represent that I consent to participate in the study and that:

- I understand that this study is voluntary and being conducted for research purposes.
- I understand the risks involved in participation and how SSA intends to protect my information.
- I consent to SSA audio recording and transcribing my interview, and SSA maintaining all information that I disclose during my interview.
- I understand that I will receive a gift card only after completing the study interview.



### Understanding Experiences of Living with Impairments in the United States

#### Semi-Structured Interview Guide/Prompts

In this first set of questions, I'd like to learn more about you to better understand the experiences and opinions you share later on in this interview.

1. Please describe how you identify yourself.  
(prompts: race, ethnicity, religion, gender, caretaker/parent, immigrant, sexuality, career, hobbies, US region, personality trait, etc)
2. The term “disabled” is used by some people but not others. Some people say “people with disabilities,” or “people with challenges.” Some people use the word “impairment” or “difference” to describe their individual diagnosis, disability, or issue. How would you describe why you identify as a part of this larger group? [or, What word do you use to describe this group?]
  - a. Do you think the word “disabled” applies to you? Why or why not?
  - b. Is your [use the word the person uses] currently recognized by the Social Security Administration?
3. With whom do you live and how do you help or support each other?
4. How do you describe your community?/Who is in your community?  
(prompts: the people you spend your free time with, share meals with, lean on for emotional or tangible help, where you live, who comes to you for help)
  - a. Do you have an [impairment or disability or use the word they use] community? In what ways are they dis/similar to the first community you described [if not the first community described]?

Thank you. Now I'd like to learn a bit about your experiences living with [use their word].

5. As someone who experiences [use their word] how would you describe your typical day? How does [use their word] affect your daily life? [Please, tell me more]

6. In what ways have you seen that your experiences are different from or similar to people who don't have [use their word]?
  - a. As you may know, the United States has some laws that require certain accommodations or arrangements for people with [use their word]. For example, in schools, workplaces, on sidewalks, and things like that. But there are still many people who have to fight for things to be accessible to them/to work for them. What kinds of things have you, or someone you know, missed out on because they were not accessible?
  - b. Sometimes there are other traditions or rules [regulations/customs/policies/practices] that exclude people with [use their word]. What kinds of traditions or rules have you noticed that affect your ability to participate?  
  
(prompts: to function at work, in the local community, in performing self-care, in caretaking, in education, in hobby-making, in romantic relationships)
    - i. What tradition or rule changes could improve your financial security?  
  
(financial security [if needed]: e.g., income, job opportunities, health insurance access)
  - c. What changes, if any, would increase your participation in your community? (prompts: changes that help you to function at work, changes that help you in the local community, changes that would help you in performing self-care, in caretaking, in education, in hobby-making, in romantic relationships)
  - d. Sometimes challenges can present special opportunities too. What kinds of things have you, or someone you know, had because of [use their word]?

Thank you. Now I have some questions specific to the Social Security Administration, known as SSA. Some of them may not be relevant to you, and that's ok! We can skip those, just let me know.

7. Do you know anyone who has applied for SSA's disability programs? What did they share about their experiences with you?
8. Have you ever applied for SSA's disability programs?
  - a. [If no] Oh, can you share more about that? Can you say more about why you chose not to apply?
  - b. [If "yes"] What was the process like for you?
    - i. What went well? What would you change?

9. “Gig work” has become more common in the past decade or so. By this I mean task-oriented jobs, like making deliveries, driving Uber or Lyft, housecleaning, dog walking, and so on. SSA’s policies may impact people who use gig work, especially if they can’t meet all their needs with the money from this kind of work. What are the benefits/attractions and drawbacks/concerns of “gig work” for you?
  - a. Have you ever used gig work?
    - i. [If “yes”] How well does it support your needs? Does it give you enough money to live?
    - ii. [If “yes”] How are you building a “nest egg” for when you need to retire/stop working? [Does this include both disability insurance and retirement benefits? Do they know they would be eligible but only if they pay in via taxes?]

The goal is to examine the structural contributors to disability in the United States. **What are the policies, practices, customs, and laws that socially, politically, and/or economically exclude people whose minds and/or bodies are outside the “norm?”**

This information will be used to inform future Social Security Administration research, potentially suggest reasons for **why SSA applications have continued to decline**, and offer lived experience insights to inform future **federal programming**.

### Interview Protocol

## LIVING WITH IMPAIRMENT IN THE UNITED STATES SOCIAL SECURITY ADMINISTRATION

Thank you for agreeing to participate in this interview. My name is [NAME] [if have someone else there, introduce them as well]. [I/we] work for the Social Security Administration, or SSA, to conduct the Understanding Experiences of Living with Impairments in the United States Customer Research Study (or Understanding Experiences Study, for short).

During the Understanding Experiences Study, we collect information about the experiences of adults across the country who live with impairment or experience disability. We will use what we learn to identify ways to improve the disability-related benefits process and disability-related research. The study also gives SSA information that may improve the agency's disability-related programs and policies.

Today, we'd like to hear about your experience living with mental and/or physical impairments and accessing disability-related benefits from SSA.

We previously sent you an informed consent sheet, explaining your rights in participating in this study. Did you have any questions about that information? [ANSWER QUESTIONS]

I just want to remind you of some of the key points about your rights. This is a customer research study. Your participation in this interview is voluntary. Taking part in the study, or choosing not to take part, will not affect any decision SSA makes about your disability benefits or payments now or in the future.

You can stop the interview at any time without penalty. You can choose not to answer any question. If you get frustrated or anxious at any point, we can take a break, skip a section, or stop the interview. If you get upset during the interview, we can offer you a referral to crisis management services that you can use if you want.

At the end of the study, SSA will create a report summarizing the needs of people who live with a disability. We may use quotes from you or others in our reports but no one's name will be linked to those quotes.

We have planned for this interview to last about 90 minutes. At the end, you will receive a \$100 Visa gift card to thank you for your participation.



Please note that a Federal agency may not conduct or sponsor, and a person is not required to respond to, nor shall a person be subject to a penalty for failure to comply with an information collection subject to the requirements of the Paperwork Reduction Act of 1995 unless the information collection has a currently valid OMB Control Number. The approved OMB Control Number for this information collection is 0960-0818. Without this approval, we could not conduct this interview. Public reporting for this information collection is estimated to be approximately 90 minutes per response, including the time for listening to these instructions, understanding the questions, and answering the questions. All responses to this interview are voluntary. Send comments regarding this burden estimate or any other aspect of this information collection, including suggestions for reducing this burden to the Social Security Administration.

Do you have any other questions? [ANSWER ALL QUESTIONS]

Finally, with your permission, I would like to record this interview to help [me/us] recall what was said. Are you okay with me recording? [PAUSE FOR RESPONSE]

[IF DECLINES RECORDING]

That's fine, thank you for your time and consideration. [DO NOT INTERVIEW]

[IF AGREES TO RECORDING]

I'd like to start the audio recording now. [TURN ON THE RECORDER.]

Have you done this interview before? [if "yes," DO NOT INTERVIEW]

You \_\_[name, date of birth]\_\_ have reviewed the Informed Consent to Participate in the Understanding Experiences of Living with Impairments in the United States Customer Research Study and had an opportunity to ask questions about the study.

- Do you agree to participate in this study?
- Do you understand that this study is voluntary and being conducted for research purposes?
- Do you understand the risks involved in participation and how SSA intends to protect your information?
- Do you consent to SSA audio recording and transcribing your interview, and SSA maintaining all information that you disclose during your interview?
- Do you understand that you will receive a gift card only after completing the study interview?

[ALL ANSWERS MUST BE AFFIRMATIVE. FOR EXAMPLE: "YES" OR "I DO."]

Is it all right if I take notes?  
[PAUSE FOR RESPONSE.]

OK let's begin.

### **Understanding Experiences of Living with Impairments in the United States, Semi-Structured Interview Guide/Prompts**

In this first set of questions, I'd like to learn more about you to better understand the experiences and opinions you share later on in this interview.

1. Please describe yourself.

(prompts: race, ethnicity, religion, gender, caretaker/parent, immigrant, sexuality, career, hobbies, US region, personality trait, etc) \*for immigrant probe: "knowing that we're trying to learn about people living in the US experiencing disability but we're not collecting information about documentation status, can you share about where you were raised and where you live now, please?"

2. The term "disabled" is used by some people but not others. Some people say "people with disabilities," or "people with challenges." Some people use the word "impairment" or "difference" to describe their individual diagnosis, disability, or issue. How would you describe why you identify as a part of this larger group? [or, What word do you use to describe this group?]

- a. Do you think the word "disabled" applies to you? Why or why not?

3. With whom do you live and how do you help or support each other?

4. How do you describe your community?/Who is in your community?

(prompts: the people you spend your free time with, share meals with, lean on for emotional or tangible help, where you live, who comes to you for help)

- a. Do you have an [impairment or disability or use the word they use] community? In what ways are they dis/similar to the first community you described [if not the first community described]?

5. What are your thoughts regarding growth or independence? Is it okay to rely on others to do most things for you or is the goal to gain functional independence (do most things by yourself)?

Thank you. Now I'd like to learn a bit about your experiences living with [use their word].

6. As someone who experiences [use their word] how would you describe your typical day? How does [use their word] affect your daily life? [Please, tell me more]
7. In what ways have you seen that your experiences are different from or similar to people who don't have [use their word]?
  - a. As you may know, the United States has some laws that require certain accommodations or arrangements for people with [use their word]. For example, in schools, workplaces, on sidewalks, and things like that. But there are still many people who have to fight for things to be accessible to them/to work for them. What kinds of things have you, or someone you know, missed out on because they were not accessible?
  - b. Sometimes there are other traditions or rules [regulations/customs/policies/practices] that exclude people with [use their word]. What kinds of traditions or rules have you noticed that affect your ability to participate?  
  
(prompts: to function at work, in the local community, in performing self-care, in caretaking, in education, in hobby-making, in romantic relationships)
    - i. What tradition or rule changes could improve your financial security?  
  
(financial security [if needed]: e.g., income, job opportunities, health insurance access)
  - c. What changes, if any, would increase your participation in your community? (prompts: changes that help you to function at work, changes that help you in the local community, changes that would help you in performing self-care, in caretaking, in education, in hobby-making, in romantic relationships)
8. How does it affect you when you do or don't see yourself in movies, in books, on TV, or at the grocery store, at school, or at the bus stop?
9. In what ways do you think your life would be different if you were [blind, etc] but were [White/of color]?

Thank you. Now I have some questions specific to the Social Security Administration, known as SSA. Some of them may not be relevant to you, and that's ok! We can skip those, just let me know.

10. Do you know anyone who has applied for SSA's disability programs? What did they share about their experiences with you?
11. Do you know anyone who has decided NOT to apply for SSA's disability programs? What did they share about why they chose not to apply?

12. Is your [use the word the person uses] currently recognized by the Social Security Administration? Have you ever applied for SSA's disability programs?
- a. [If no] Oh, can you share more about that? Can you say more about why you chose not to apply?
  - b. [If "yes"] What was the process like for you?
    - i. What went well? What would you change?
    - ii. How does your upbringing or cultural background affect your experience with the disability application process? Disability program? DEFINE CULTURE. DO YOU THINK HAS ANY IMPACT ON HOW YOU ACTIVATED A SUPPORT NETWORK, WHAT YOU WANTED...
    - iii. If you could go back to work, what other non-cash benefits (besides Medicaid or Medicare) would you like to keep (remain eligible for)? (e.g., SNAP, energy assistance programs, housing assistance programs, Affordable Connectivity Program)
    - iv. If SSA's disability programs meaningfully allowed you to work and save, what's an acceptable limit to say someone doesn't need more cash-benefits from SSA?

Thank you for taking the time to share about your experiences and your thoughts. We really appreciate it. As a token of thanks, SSA will provide you a \$100 Visa gift card. To what email address can we send your gift card?

Great; thank you! And as a head's up, when the electronic card is sent to you, you will be provided the option to have a physical card mailed to you instead. If you chose the option the cost of shipping will diminish the card's value to \$95.

[If they do not want it sent via email,] Ok. We can mail it to you, but SSA will not be able to track it via mail. To what mailing address should we send the gift card, and to whose attention (what name should the card be addressed to)? [confirm the address on GoogleMaps BEFORE hanging up; we cannot reach out to them after.]

[TO KEEP IN MIND, NOT TO READ] The goal is to examine the structural contributors to disability in the United States. **What are the policies, practices, customs, and laws that socially, politically, and/or economically exclude people whose minds and/or bodies are outside the "norm?"**

This information will be used to inform future Social Security Administration research, potentially suggest reasons for **why SSA applications have continued to decline** and offer lived experience insights to inform future **federal programming.**



### Interview Protocol

# UNDERSTANDING EXPERIENCES OF LIVING WITH IMPAIRMENT IN THE UNITED STATES SOCIAL SECURITY ADMINISTRATION

Thank you for agreeing to participate in this interview. My name is [NAME] [if have someone else there, introduce them as well]. [I/we] work for the Social Security Administration, or SSA, to conduct the Understanding Experiences of Living with Impairments in the United States Customer Research Study (or Understanding Experiences Study, for short).

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Today, we'd like to hear about your experience living with mental and/or physical impairments and accessing disability-related benefits from SSA.

We previously sent you an informed consent sheet, explaining your rights in participating in this study. Did you have any questions about that information? [ANSWER QUESTIONS]

I just want to remind you of some of the key points about your rights. This is a customer research study. Your participation in this interview is voluntary. Taking part in the study, or choosing not to take part, will not affect any decision SSA makes about your disability benefits or payments now or in the future.

You can stop the interview at any time without penalty. You can choose not to answer any question. If you get frustrated or anxious at any point, we can take a break, skip a section, or stop the interview. If you get upset during the interview, we can offer you a referral to crisis management services that you can use if you want.

At the end of the study, SSA will create a report summarizing the needs of people who live with a disability. We may use quotes from you or others in our reports but no one's name will be linked to those quotes.

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Do you have any other questions? [ANSWER ALL QUESTIONS]

Finally, with your permission, I would like to record this interview to help [me/us] recall what was said. Are you okay with me recording? [PAUSE FOR RESPONSE]

[IF DECLINES RECORDING]

That's fine, thank you for your time and consideration. [DO NOT INTERVIEW]

[IF AGREES TO RECORDING]

I'd like to start the audio recording now. [TURN ON THE RECORDER.]

Have you done this interview before? [if "yes," DO NOT INTERVIEW]

You \_\_[name, date of birth]\_\_ have reviewed the Informed Consent to Participate in the Understanding Experiences of Living with Impairments in the United States Customer Research Study and had an opportunity to ask questions about the study.

- Do you agree to participate in this study?
- Do you understand that this study is voluntary and being conducted for research purposes?
- Do you understand the risks involved in participation and how SSA intends to protect your information?
- Do you consent to SSA audio recording and transcribing your interview, and SSA maintaining all information that you disclose during your interview?
- Do you understand that you will receive a gift card only after completing the study interview?

[ALL ANSWERS MUST BE AFFIRMATIVE. FOR EXAMPLE: “YES” OR “I DO.”]

Is it all right if I take notes?

[PAUSE FOR RESPONSE.]

OK let's begin.

### **Understanding Experiences of Living with Impairments in the United States, Semi-Structured Interview Guide/Prompts**

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(prompts : race, ethnicity, religion, gender, caretaker/parent, immigrant, sexuality, career, hobbies, US region, personality trait, etc) \*for immigrant probe: “knowing that we're trying to learn about people living in the US experiencing disability but we're not collecting information about documentation status, can you share about where you were raised and where you live now, please?”

2. The term “disabled” is used by some people but not others. Some people say “people with disabilities,” or “people with challenges.” Some people use the word “impairment” or “difference” to describe their individual diagnosis, disability, or issue. How would you describe why you identify as a part of this larger group? [or, What word do you use to describe this group?]
  - a. Do you think the word “disabled” applies to you? Why or why not?
3. With whom do you live and how do you help or support each other?
4. What are your thoughts regarding growth or independence? Is it okay to rely on others to do most things for you or is the goal to gain functional independence (do most things by yourself)? How do you think your family's culture influences your thoughts about this?

Thank you. Now I'd like to learn a bit about your experiences living with [use their word].

5. In what ways have you seen that your experiences are different from or similar to people who don't have [use their word]?
  - a. As you may know, the United States has some laws that require certain accommodations or arrangements for people with [use their word]. For example, in schools, workplaces, on sidewalks, and things like that. But there are still many people who have to fight for things to be accessible to them/to work for them. What kinds of things have you, or someone you know, missed out on because they were not accessible?

- b. Sometimes there are other traditions or rules [regulations/customs/policies/practices] that exclude people with [use their word]. What kinds of traditions or rules have you noticed that affect your ability to participate?

(prompts: to function at work, in the local community, in performing self-care, in caretaking, in education, in hobby-making, in romantic relationships)

- i. What tradition or rule changes could improve your financial security?

(financial security [if needed]: e.g., income, job opportunities, health insurance access)

- c. What changes, if any, would increase your participation in your community? (prompts: changes that help you to function at work, changes that help you in the local community, changes that would help you in performing self-care, in caretaking, in education, in hobby-making, in romantic relationships)

- 6. How does it affect you when you do or don't see yourself in movies, in books, on TV, or at the grocery store, at school, or at the bus stop?

- 7. In what ways do you think your life would be different if you were still [their word] but were [White/of color]? (Can you talk about what it's like to be [race] in the disability community? What is it like to be race w/[impairment] in the broader world?)

Thank you. Now I have some questions specific to the Social Security Administration, known as SSA. Some of them may not be relevant to you, and that's ok! We can skip those, just let me know.

- 8. Do you know anyone who has applied for SSA's disability programs? What did they share about their experiences with you?
- 9. Do you know anyone who has decided NOT to apply for SSA's disability programs? What did they share about why they chose not to apply?
- 10. Is your [use the word the person uses] currently recognized by the Social Security Administration? Have you ever applied for SSA's disability programs?
  - a. [If no] Oh, can you share more about that? Can you say more about why you chose not to apply?
  - b. [If "yes"] What was the process like for you?
    - i. What went well? What would you change?
    - ii. Defining culture as customs, practices, and ways of thinking, do you think your family's culture affects how you viewed the disability program or how you felt about applying?



- iii. If you could go back to work, what other non-cash benefits (besides Medicaid or Medicare) would you like to keep (remain eligible for)? (e.g., SNAP, energy assistance programs, housing assistance programs, Affordable Connectivity Program)
- iv. If SSA's disability programs meaningfully allowed you to work and save, what's an acceptable limit to say someone doesn't need more cash-benefits from SSA?

Thank you for taking the time to share about your experiences and your thoughts. We really appreciate it. As a token of thanks, SSA will provide you a \$100 Visa gift card. To what email address can we send your gift card?

Great; thank you! And as a head's up, when the electronic card is sent to you, you will be provided the option to have a physical card mailed to you instead. If you chose that option the cost of shipping will diminish the card's value to \$95.

[If they do not want it sent via email,] Ok. We can mail it to you, but SSA will not be able to track it via mail. To what mailing address should we send the gift card, and to whose attention (what name should the card be addressed to)? [confirm the address on GoogleMaps BEFORE hanging up; we cannot reach out to them after.]

[TO KEEP IN MIND, NOT TO READ] The goal is to examine the structural contributors to disability in the United States. **What are the policies, practices, customs, and laws that socially, politically, and/or economically exclude people whose minds and/or bodies are outside the "norm?"**

This information will be used to inform future Social Security Administration research, potentially suggest reasons for **why SSA applications have continued to decline** and offer lived experience insights to inform future **federal programming.**

# Abridged Codebook

(Codes are presented in the order in which they were created, *in vivo*).

Code	When to use	Example
<b>Medical cost</b>	When a participant discusses or laments the difficulty of paying for medical care or supplies.	<i>"...the income limits, as far as, being able to qualify for Medicaid, if I had, you know, less of an income, then I would qualify, but unfortunately, I don't. Uhm, so then it falls back on me to pay that co-pay anytime I need a new wheelchair or a cushion or catheters, which I get on a monthly basis." (P6)</i>
<b>Accessibility</b>	When the participant describes ways in which edifices, activities, jobs, etc are unavailable to them or people like them. Or, When a participant describes the ways in which things are or have been made to be accessible or accommodating.	<i>"If there's any sort of steps, any stairs with no ramp or elevator, or if the doorways aren't wide enough, I run into bathroom problems, like the doorway is not being wide enough..." (P6)</i>
<b>Plan</b>	When participant discusses the need to plan for common lack of accessibility or accommodation	<i>"...more planning goes into what I do like, if I'm going-- I have to like, think about where I'm going, whether or not it's accessible..." (P6)</i>
<b>Estimate</b>	When the participant discusses how/that others make assumptions about a limited/capacity without actual knowledge of an individual's ability/abilities. People may over- or underestimate capacity.	<i>"...sometimes people, you know might step in, and overstep and think that they're helping, but they're really not." (P6)</i>

Code	When to use	Example
<b>Connection</b>	<p>When a participant discusses feeling or being linked with or feeling comfortable with another or others.</p> <p>Also use when participant describes lack of community or connection.</p>	<p><i>“I mean my had, I had my whole family back in (state) obviously, but I wouldn't really say that I had a community. I mean, I mean, I had all of my friends too. I don't know why I feel that way, but I just don't...It's like -- they didn't know that, like the new me.” (P14)</i></p>
<b>Self-advocacy</b>	<p>When the participant talks about relying on themselves to learn and create a way where there wasn't one, or where they were told there wasn't one. Or, When the participant talks about choosing not to self-advocate.</p>	<p><i>“The more I read and the more I did my own research, I realized that, you know, it would probably be possible for me to have a natural birth. And that's what I aimed for...” (P6)</i></p>
<b>MacGyver</b>	<p>When a participant describes make-shift, on the spot, or non-systematic accommodation creation/ solutioning.</p>	<p><i>“...I've had a few instances where I've asked complete strangers to carry me up flights of stairs to get to my event, but most people wouldn't be crazy enough to do that.” (P10)</i></p>
<b>Confined</b>	<p>When participant discusses how/that a lack of accessibility or accommodation limits their ability to move or function (without assistance).</p> <p>Or, When a participant describes how an accommodation or accessibility jeopardizes something else important (e.g., safety, financial security)</p>	<p><i>“...there was a two-story house, so I could only be on the bottom floor. And it was. It just felt very-- it made me feel very like confined. And uhm, being able to move around independently is very important.” (P6)</i></p> <p><i>“...if I lived on my own, in central [city], in an apartment, then I would have to live in Section 8 housing.” (P15)</i></p>

Code	When to use	Example
<b>Identities</b>	When a participant describes (without prompting) how they identify and “disability” (or synonyms) aren’t it.	<i>“Identify as a woman of, woman of -- I'm a first generation American from [region]. Umm, identify as a mother, a wife. Umm, also identify as a womanist and not a feminist per se.” (P19)</i>
<b>Disability Identity</b>	When the participant mainly or primarily identifies as experiencing disability	<i>“I identify as a Black, African American individual with a disability status.” (P9)</i>
<b>Work</b>	When the participant describes that or the kind of work they do.	<i>“...not always, but my students like one-on-one. And they want me to focus just on them and their needs. I've noticed that older students like, um, 55 and up, they're like a half-an-hour sessions...” (P5)</i>
<b>Same same</b>	When the participant describes experiencing the same needs/activities/wants as people who do not experience disability.	<i>“I mean, typical day, I get up, I do my thing, I clean up, I check on my e-mail, I check my phone, I check with the people I need to contact. I go out for errands, um, I do shopping, I make breakfast or make the meals, I make lunch. Um, just typical day, hang out with my family, my kids.” (P29)</i>
<b>Entertainment</b>	When the participant describes not being able to engage in fun activities (e.g., movies, restaurants) simply because the activity has not been made accessible.	<i>“...there's certain like restaurants or shops in my area that aren't accessible that I either haven't been in or don't go in very often because it's just such a pain.” (P6)</i>



Code	When to use	Example
<b>Representation</b>	When a participant describes lack of or realistic/inclusive media or community (e.g., at grocery store) representation of people who experience disability. This can be in a negative or positive context.	<i>“I saw my first play about disability that happened to be also about cerebral palsy that was written by a disabled person and also performed by, uh, a person with CP and I wept with joy.” (P41)</i>
<b>SSA documents</b>	When a participant describes ease or difficulty of gathering documents for the SSA benefits application	<i>“...I think the hardest part was like gathering, uhm— gathering my income information and just sending it over...” (P6)</i>
<b>Application help</b>	When a participant describes getting or needing help applying for SSA or other benefits.	<p><i>“...I did have help in the beginning, navigating all that stuff.” (P6)</i></p> <p><i>“...he handed the lady that makes...the decision, about that many...pieces of paper [demonstrates with hands]. The lady goes, ‘I am not reading through all that. Put that in a spreadsheet and let me see.’ So, we went back again.” (P26)</i></p>
<b>SSA online</b>	When a participant describes applying or re-applying online rather than in-person. This can be in a negative or positive context.	<i>“...I found it to be pretty user-friendly, especially doing it online now instead of filling out the packet. You can just go online and reapply through website.” (P6)</i>

Code	When to use	Example
<b>Alienation</b>	When the participant describes being abandoned by friends/ family, or concern for/ being treated differently/ badly by people who don't know them (including bullying), because of their impairment/disability	<i>"...I once disclosed my disability to a professor who treated me differently afterward. He knew I had a disability because I was using accommodations, but he did not know what it was. When he found out what was he said 'No wonder you e-mail me so much.' He also seemed visibly afraid of me and would begin to step back when I approached him to ask a question." (P39)</i>
<b>Network</b>	When a participant describes having or needing a disability/ specific community they look to for advice, tips, etc	<i>"...it's just, like, a group or whatever, but it's actually a really good resource because you're, you know, you're able to ask you anything and just like pure responses and pure advice, you know, and what went wrong for them, or what went right for them and what they suggest and stuff. So, that's like a good resource to have." (P14)</i>

Code	When to use	Example
<b>SSA Operations and Policies</b>	<p>When a participant describes ways or a story that highlights that SSA itself or rules should be improved or explained/clarified/made consistent.</p> <p>Or</p> <p>When someone describes negative experiences with SSA.</p>	<p><i>"...in my 20s I, when I graduated high school, I applied for – I was living in [state) and going to school in [state], and I applied for SSI. I was turned down like one, two, three times. And then when I went to college in [city], I, somehow, I think I got accepted. Or I didn't, but then, you know, my dad got an attorney or something and I moved to [school] in [city] and and got a appeal, like three times. And then we finally went to the administrative judge and then he he agreed to us. But that's what I mean, those, who like can speak well, or hear a lot, but you're still missing so much that, you know, that's where it was tough to get the Social Security Income benefit back then, you know, with my parents..." (P22)</i></p>
<b>Insufficient</b>	<p>When a participant describes that accommodations are insufficient</p>	<p><i>"...often times the paratransit, like, the shared ride programs, are late." (P15)</i></p>
<b>Employer</b>	<p>When the participant describes potential/actual reasons employers don't hire ppl with impairments</p>	<p><i>"...they can't afford the accommodations..." (P15)</i></p>

Code	When to use	Example
<b>Application improvement</b>	When the participant describes ways in which the SSA application/ process can be improved	<i>“I would just say, when we do apply, to give us a little checklist of the documents we do need to bring. So, that process, when we hand the case worker with the papers, that it makes it a lot easier.” (P12)</i>
<b>Mainstreaming</b>	<p>When people who don't experience disability and are in power put ppl w/impairments into “mainstream,” regardless of intention. (e.g. education, getting medical procedures to “fix” the impairment)</p> <p>Or</p> <p>When the participant describes the benefits or drawbacks to not being mainstreamed.</p>	<i>“...the medical field, you know, pushing, you know, deaf kids to be able to function in their, you know, auditory world where, you know, now with the cochlear implants, you know, that started like in the 70s and 80s, but that really, that made it more, you know, that that changed the whole, you know, Deaf community because most, you know, deaf kids are born with hearing parents like mine...” (P22)</i>
<b>Takes care</b>	When a participant describes how/that someone takes care of them or needs someone to take care of them	<i>“My kid brother is my, um, primary supporter. He's one person that, um, that is always there to support me, um, help me with things and many other things. But my mom also, um, plays that role why because, um, my kid brother has, um, school to attend. And when he's away, um, my mom has to, um, act the role of a, a caregiver for me.” (P18)</i>



Code	When to use	Example
<b>Discrimination</b>	When a participant describes experiencing discrimination attributed to their impairment.	<i>"...so I get to the point where I'm like, "Alright, I need to, um, fill out my invoice, and send it to you guys. Which address do I use on that?" And they're like, 'Oh, yeah, um, send it to blah, blah, and for this amount.' The amount they gave was one quarter of my quote five years ago, one quarter." (P28)</i>
<b>Technology</b>	When a participant describes use of or need for assistive technology; how technology helps or hurts their capacity; or what tech they are developing	<i>"...I use different apps...to transcribe. So, I can go back 'cause I need to read it and see it and hear it." (P38)</i>
<b>Transportation</b>	When the participant describes using or needing any mode of transportation	<i>"I called mine my 'cocoon mobile'. It was not safe for a, an immunocompromised, less healthy person to be using anything other than their own private vehicle. You shouldn't even been in one of the little vans with other people." (P35)</i>
<b>ADLs</b>	When the participant describes being un/able to perform their ADLs or needing help to do them	<i>"I did find a neighbor who would go across the street to the supermarket for me." (P35)</i>
<b>Spontaneous</b>	When the participant describes NOT being able to be spontaneous because of lack of or insufficient accommodation or accessibility, or because of their impairment	<i>"...last minute plans, if I want to go to a certain event tomorrow, I can't if they don't have an interpreter scheduled for that for public events." (P25)</i>

Code	When to use	Example
<b>Standard</b>	When a participant describes that a standard is inappropriately high, regardless of dis/ability	<i>"...in like a lot of high stakes environments, academia umm, very high professional, I, uh, spaces I feel like there is very little room for understanding different experiences and needs, especially when you, it's so demanding of high performances." (P3)</i>
<b>Education</b>	When a participant describes their education	<i>"I didn't even know I had a learning disability at that time. But I noticed teachers just yelling at me rather than trying to figure out what's going on. I went to the math tutoring center every day, and I still failed courses." (P5)</i>
<b>In/dependence</b>	When the participant discusses the value, import, or difficulties of the concepts of independence, interdependence, or dependence.	<i>"I like the concept of interdependence. I like that concept. For example, I think a lot of American culture -- well, for me, American culture is very 'me, me, me, me, me.' And it's that encouraging...independence of everyone and people aren't, you know, they don't care, they get pissed off if they have to help too much and that kind of thing, so, you know. Even within families, you know, they say do it yourself, you know." (P5)</i>

Code	When to use	Example
<b>Intersection</b>	When the participant discusses the intersection of being a racialized, or otherwise oppressed, person and experiencing disability	<i>“...the whole notion of accommodations needing to be reasonable poses barriers and like people needing to have diagnoses in order to get school accommodations or work accommodations umm, is like, you know umm, makes it so that people who have additional umm, marginalized identities find it even harder to get those accommodations because of medical racism and you know medical gaslighting and, and other forms of oppression.” (P39)</i>
<b>Effect</b>	When the participant describes how their impairment or disability-related policy affects their life or an effect it has had	<i>“...there's a test you have to take, um, to become a licensed social worker, and that's really how people hire you, and I have test anxiety, so I just never took the test...” (P37)</i>
<b>Culture</b>	When a participant describes how their culture or family views disability or use of benefits, or how those ideas impact their interaction with benefits programming or disability	<i>“...I think the (country) part has this larger belief that you just work hard and hard work will help you figure it out. And for the very religious ones of us, hard work and prayer will help you get over your disability, so there's no need, I think sometimes they think it's a cop-out.” (P19)</i>

## Table 3. Participants' Concerns and Advice for SSA

### Policy Concerns and Advice



**Two women, one using a wheelchair, have a discussion in an office high-rise.**

**Income limits for SS(D)I make it hard to work while also receiving benefits.**

**Participants' advice:** Raise the income and resource limits for SS(D)I so that people who are able to do some work can better supplement their disability check and afford necessary costs (legislative change).

**Rationale:** "...like if you have more than so much money in your account, then they penalize you. Umm, so much of what we spend our money on is medical stuff that our insurance doesn't pay for. So, when all of a sudden some, more than \$2,000 in your account, that very well could be going to some medical device could penalize you and take your benefits away" (P10).

"I'd like if I could earn more money. I mean, the -- what they cap at, I can't remember the exact number, but what they cap at, it's still hard to live, especially on your own, you know, it's, it's hard..." (P37).

**Participants' advice:** Eliminate the disparity between blind people and others receiving disability cash benefits (legislative change).

**Rationale:** "So when blind people, they tend to get a lot more, when they fight, they tend to win their cases and get an increase in their benefits. Whereas in the Deaf community that's not the same experience" (P5).

"There should be no differentiating, you know, that a person that is blind to be able to get paid more if they work, if they're on disability, more than another person. You are creating segregation within segregation" (P38).

**Participants' advice:** Eliminate the "disability marriage penalty" such that two recipients can marry and still receive their full benefit allotment (legislative change).

**Rationale:** "...he and my mom were talking about maybe getting married before he had his stroke, but now they can't because it would mean that his, um, the disability insurance would get cut. So, that's a major life experience that is not available to them simply because of the structure..." (P42).

"And the problem, I want maybe to marry him. But with they don't have the law to, for people with disabilities to get married. 'Cause we lose our benefits" (P4).



**Participants' advice:** Allow people who return/begin to work a longer period of earning (regardless of income earned) to continue to collect disability benefits (including non-cash benefits) before discontinuing service. (legislative change)

**Rationale:** "And just say, 'okay, let's, let's see how you do for one whole year for working after you graduate'" (P38).

"If somebody was on a fixed income and if the government was to say, 'Okay, well, for two years, we're gonna let this person work. We're gonna let this person have a job, and we're gonna let this person pay out. And we're going to let them save all their money for two years before we start deducting their income'" (P24).

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**Concern:** People who acquire a disability with limited work experience may not initially receive the same allotment as others but their cost-of-living is not inherently less (regulatory change).

**Data:** "...it's hard, harder for me because I have to manage, you know, money on a tight, tight budget. Because I didn't have enough years in to work to get a large social security check" (P38).

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**Participants' advice:** ABLÉ accounts should be for all people receiving disability benefits, regardless of age of impairment onset/recognition. (legislative change)

**Rationale:** "...I know there's this ABLÉ-account thing, where if you're on disability, you can have a savings account, but it's only if your accident happened before you were [26] years old. And like, that doesn't make any sense to me. Like, why wouldn't we all be able to use this ABLÉ account?" (P14).

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**Participants' advice:** Allow SSI benefit recipients the ability to save or receive money to use as they need, without restrictions (legislative change).

**Rationale:** "...the only thing that's protecting us from this is the ABLÉ accounts. Why does it have to be an ABLÉ account? Why can't you just be a checking account or a savings account?" (P7).



**A senior couple view savings documents. Making it easier for people to save money would improve the lives of disabled people.**

**Concern:** Despite applicants having their own clinical assessment and care teams, SSA sometimes requires an independent clinical evaluation for disability determination. (possibly regulatory change)

**Data:** "...they've shared how a, a doctor had to see them and how they, their own doctor gave documentation" (P24).

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## Operational Concerns and Advice

**Concern:** Some applicants and benefit recipients do not feel they with are treated with decency and respect in the application process or by SSA staff.

**Data:** "I don't know what it is about SSDI process, but sometimes you really feel like you didn't pay into this. Like you really feel like they treat you like, we ain't gone give you this no matter what" (P43).

"...some of them just are very, very unaware of how to speak to people. How to ask people questions and how to -- and, and, and don't understand that somebody with different challenges might be, might not be capable of, of umm, filling out the form, or answering the questions or doing anything by themselves" (P9).

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**Concern:** SSA has a long time between appeals and hearings.

**Data:** "...it's been two years and I still haven't, I don't have my session with the ALJ scheduled" (P43).

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**Concern:** Benefit recipients need, in simple language, the rules of disability benefit participation, return-to-work flexibilities, and reporting (e.g income). (regulatory change)

**Data:** "I have to go to court. I have to go see an (ALJ), an Administrative Law Judge. Uh, for a four-thousand-dollar overpayment that occurred because I was receiving fellowship money while on my scholarship. And nowhere in Social Security's notion of gainful, substantial employment is scholarships, grants, or fellowships listed" (P41).

"...I've just noticed that there's a real inconsistency in information and gig work, um, I'm not really sure what kind of payment they provide or ask, what kind of proof they ask for when someone is doing gig work." (P29)

"...like, if you go on the website, it says you can make this much money per month, but like, that's actually not true. Like, that's if you're doing, like, the ticket to work" (P14).

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**Participants' advice:** Dedicate research efforts to how SSA employees interact with the public and why.

**Rationale:** "...this is kind of an issue within federal research to begin with. We tend to focus on the like, you know, the the, the, the, the, person who experiences it, right? Like a disabled person or the starving mother or whatever, right? But we don't actually spend a lot of time on the people who are working in these systems and the way that these systems are impacting them, right, because all I can think about it, what about that [SSA] woman that says, 'Well, I have my doctorate, and I think this is easy,' right? Who's interviewing her? Who's getting an idea of how she responds to clients, right?" (P41).

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**Concern:** Calling benefit recipients "customers" feels inappropriate to at least some recipients.

**Data:** "...the title of this is about customer experience. It's a federal organization, and if we're seen as customers, I think that tells me a lot of how the organization views me in the end of the line, right?" (P41).



**A young White woman holding her phone looks out the window.**

**Some people are denied multiple times before receiving their disability benefits.**

**Concern:** Multiple rounds of applying to finally be awarded disability benefits delay access to benefits and needed fiscal support. (legislative change to give benefits before adjudication)

**Data:** "They denied him three times until they actually gave him his disability. And I guess that's the thing here in [state] is they deny you three times before you get qualified or, you know, even if -- that even if you have this much paperwork from your doctor they're still gonna deny you...of course you do get the back pay, but, I mean, why would somebody have to wait so long?" (P33).

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**Participants' advice:** Offer support to disability applicants to help them understand the implications and consequences of accepting SSA cash benefits. (possibly regulatory change)

**Rationale:** "...Social Security is saying, 'Oh, hey, there's survivor benefits and you're entitled to it.'...in hindsight, I feel like I, I would have preferred having someone to actually like walk me through and understand what this meant because I would really have loved to be, you know, spared this headache" (P41).



**Concern:** The time between disability application submission and determination is too long, and people should be able to apply online. (possibly regulatory changes)

**Data:** "...It taking so long to get a decision" (P39).

"...increase uh, online, uh, registration and make it fast as possible" (P36).

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**Concern:** As a whole, SSA staff's understanding of the nuanced needs and realities of Deaf and deaf people is not consistent or sufficient.

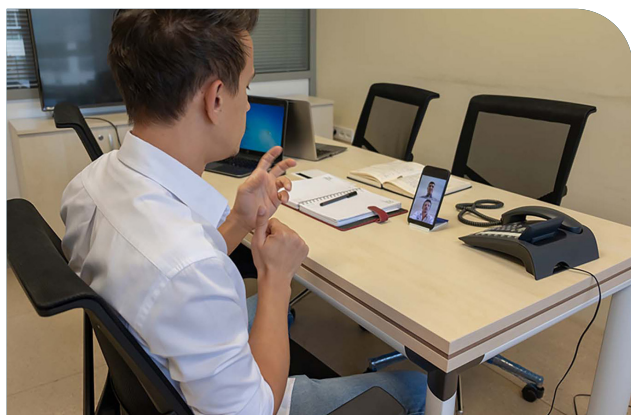
**Data:** "I've known deaf people who have applied for SSA's programs and been turned down...The reason given was, is because they were talking about getting cochlear implants. And if they had cochlear implants, they were perceived a hearing people, which is just not the case at all. Whether a Deaf person has an implant or not, they are still not a hearing person and they still need that support" (P5).

"...with kids or even adults who have that range of hearing loss, that really affects each individual differently...So again it's like, maybe somebody applying for Social Security disability income, they have an implant. Wow, they can hear a lot, but once they turn it off, they can't hear a thing. Where if I have a hearing aid and, but, oh, I can hear a lot but maybe they don't qualify. I don't know. It's just like it's kinda, it's not like, it's not consistent across the board" (P22).



**An older White man sits in a waiting room.**

**The disability application process can be too long and difficult.**



**A man facing away from the camera signs to someone on his smartphone.**

**In this study, many Deaf people reported communication difficulties with SSA.**

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**Participants' advice:** Improve SSA processes and interactions with Deaf applicants and recipients, including planning for more time for interpretation.

**Rationale:** "I think that all of the employees should be culturally Deaf aware. They should be aware of Deaf culture...the employees at SSA need to be more patient and also allow for more time for a meeting. If you figure an hour interview for a hearing person, it's gonna be two hours to interact with a Deaf person who comes in" (P5).

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**Participants' advice:** Update communication methods to reflect modern modes of Deaf communication and reinforce interpretation standards with SSA staff. (possibly regulatory change)

**Rationale:** "...remove the idea of TTY from any of the marketing literature? Because nobody uses a TTY anymore. We all use video phones, so TTY access is obsolete. Um, I mean or, you know, maybe leave it, I don't know, maybe you should leave it on there because there's some elderly deaf people that still might use it. A very, very low percentage. But most Deaf people are using the video phone..." (P5).

"So, if I didn't understand something and I would call, they wouldn't always take the VRS call, the video relay service call. So, I would have to emphasize, 'No, no, no, you're speaking to an interpreter who's following the code of professional conduct, who has the right to interpret.' But it seemed like they didn't know, and then they sometimes would hang up, which was rude" (P29).

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**Participants' advice:** As ASL is a different language than English, and as SSA provides translation for read languages, use ASL videos to communicate SSA information to Deaf people.

**Rationale:** "...it would be nice to see some of the information translated into ASL and provided that way, instead of just in written text, like if there would, if there would be, if there could be videos of the same information provided in ASL" (P5).

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**Participants' advice:** Ensure that ASL interpreters are available for in-person appointments. (possibly regulatory change)

**Rationale:** "Even if we show up in person for an in-person appointment, there isn't an interpreter present, even if we've requested it. So, the, the federal government that set the law is in violation of the law and violates our access to communication" (P29).

"...they need a better interpreter request system. My understanding is that SSA doesn't have an interpreter, they just use their own local office. So, they'll just like, you know, request anybody at the last minute" (P29).

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**Concern:** The SSA wait time from application approval to benefit disbursement makes it difficult for people in need to survive. (at minimum, regulatory change)

**Data:** "I'm below poverty wages. I mean, I'm below poverty, just surviving, trying to survive. And though I've gotten the letter that I am officially approved for disability benefits, they haven't gotten me the first payment yet, um, so I still don't even have that to live on" (P28).



**Workers sitting in a conference room for a training.**

**Some participants said that SSA staff should be better educated about the practical implications of applicants' impairments.**

**Participants' advice:** Increase the education of SSA staff on the real-world implications and consequences of SSA impairment categories.

**Rationale:** "...we shouldn't have to educate the system as to what the nature of our disabilities are, and how severe they are, and how much they've changed our lives" (P28).

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**Concern:** The application (including what historical information is needed) and gig work reporting processes are complicated and the rationales are not transparent.

**Data:** "It's very complicated process...and confusing. They don't know what to do, how to fill out the applications, how to report certain information" (P25).

"And I was working, so, and nobody explained to me how to report my earnings, even though I sent them in, they weren't caught up...So that continued for a, a long time, and resulted in overpayments" (P25).

"They expect you to know certain things that you're not necessarily gonna know. Like, I don't give a crap what my dad's job was when he was 22" (P24).

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**Participant recommendation:** Allow a listed clinician to be the point of contact for healthcare documentation. (regulatory change)

**Rationale:** "They should even like have the application and say who's the primary care doctor and who's the contact person. That's all they need" (P7).

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**Participants' advice:** Ensure that SSA staff are familiar with the regulations and provide consistent information to the public.

**Rationale:** "...the biggest thing I would say, is standardizing information, and, and the staff that works in the Social Security offices to know their stuff" (P25).

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**Participants' advice:** Simplify the automated phone process and provide a way to easily reach an SSA representative.

**Rationale:** "...why am I gonna press one if I wanna go to talk to an SSA representative? Why can't you just send me to an SSA representative?" (P24).

"...it is a labyrinth. Like, reaching a human being to give an answer to a question is insanely difficult, especially for people who have neurological issues, and we can't be on hold for an hour and expect to still be functional" (P28).

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**Participants' advice:** Assign benefit recipients a point of contact.

**Rationale:** "...if I had a set agent, maybe I'd feel more confident calling the Social Security Office" (P24).

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**Participants' advice:** Ensure that all SSA information is accessible to all applicants and benefit recipients.

**Rationale:** "...either there needs to be a braille version or an audio version" (P24).

"The SSA is supposed to call me to read me my letter when they send it. They haven't been" (P24).

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**Participants' advice:** Consider the mental health needs of the applicants or beneficiaries when making service appointments.

**Rationale:** "...the ones that do the interviews at the um, at the places, the um, the intake people for the all the paperwork that they get in. Like if you know a person has dealt with like MST [military sexual trauma] like my situation, don't put 'em in a room with a man. What is wrong with you? You know, like don't do that. That's to me, is just like you giving that person anxiety and you giving that person, you know a, a trigger possibly, you know, just be sensitive to the situation" (P20).

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**Participants' advice:** SSA should educate people about available benefits by meeting people in their communities.

**Rationale:** "...there should be people that that are from Social Security that are going into the schools and, you know, these places where people go every day and educate people. 'Cause there's a lot of people that don't know about Social Security and don't understand about it" (P9).

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**An older White man uses his wheelchair to enter his vehicle via a ramp.**

**Benefit recipients may need more explanation about the transition from Medicaid to Medicare.**

**Concern:** There is insufficient education of disability benefit recipients on the practicalities of the transition from Medicaid to Medicare.

**Data:** "...while I've been on Social Security disability like, I had Medicaid for two years and then it kind of transitioned to Medicare. And that's like a whole different system and I wasn't really provided much like, education on how it's different. You know, I, I just kind of received a letter saying like, 'Oh, you know, you have Medicare and you're going to be like responsible for, like, more out of pocket costs or whatever'" (P8).

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**Participants' recommendation:** Use email to communicate with benefit recipients. (possibly regulatory change)

**Rationale:** "So make it quicker and more -- because I will respond to an email much faster, or even a text message saying, you have a new message on your SSA account and so then you log into that..." (P15).

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**Participants' advice:** Provide applicants with a comprehensive application checklist.

**Rationale:** "I would just say, when we do apply, to give us a little checklist of the documents we do need to bring. So, that process, when we hand the case worker with the papers, that it makes it a lot easier" (P12).

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**Concern:** People who have been previous disability benefit recipients and are again without a financial safety net are not presently prioritized for paperwork processing.

**Data:** "...I see through my clients, you know like, if they lose job, um, you know, and then they need money. It's they can't always get the Social Security benefits back quickly...if they had some emergency funding, or emergency system was stronger to help them out more quickly until they return to work, that would be something that would be helpful" (P25).

"I wasn't working full-time, but I was making money, you know, like, very brief gigs. You know that weren't gonna last that long. But I, I didn't wanna not report it. You know, and so I -- there were times that I just didn't, you know 'cause, yeah. Because once, yeah, because, it would just take too long, once they started deducting. But then okay, you -- now, that job is done. Or that show is done and to reinstate benefits would be quite a bit more time" (P15).



**Concern:** Ensure that benefit applicants can and know how to designate who can complete the application on their behalf. (possibly regulatory change)

**Data:** "...the application process was difficult, but mostly because of the questions of who was allowed to help him with it in that because he and my mom had not gotten married and had not, like, filed a power of attorney, she was the person who was caring for him, but all of the paperwork had to go through his parents, who are, fortunately, in this case, able to or were at the time, but there they're -- they were old enough that they're very easily could not have been, in which case it would have been his teenage and early 20s children who were not living in the same city as him. And so that was probably the main difficulty with the process and just the delay in getting that support because he didn't have a lot of money sitting in savings" (P42).

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**Participants' advice:** Make the rationale behind continuing disability reviews transparent and logical. (possibly regulatory change)

**Rationale:** "Each year, while my blind friend is not evaluated because of her particular disability. Every year I have to do a medical evaluation. Why do I have to do one when she doesn't?" (P38).

"...like if it says, okay, this person has a developmental disability, like, - intellectual - like, we don't have to review them" (P7).

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## Table 4. Participants' Concerns and Advice for Other Structures

### Healthcare Concerns & Advice

#### Policy Concerns and Advice

**Participants' advice:** Increase the items and services that health insurance covers, and improve the reimbursement rates.

**Rationale:** *“But I think medical insurance and how it can just financially devastate people when they can’t afford just basic stuff for daily living and uh, you know, are they gonna eat or are they gonna, are they gonna buy their medical supplies that they need”* (P10).

*“When you, certain medical things that aren’t covered, I mean, what do you do?”* (P10).

*“...I just wish there was there was more financial aid for like, medical equipment like that”* (P12).



**A seated older Black man smiles as a careworker holds his hand.**

**Healthcare insurance should cover supplies and services that people need.**

**Concern:** Mental health professionals are not currently required to clearly indicate whether the therapy they provide is rooted in religious beliefs and practices.

**Data:** *“For therapists or counselors like licensed professional counselor -- well, first of all, it’s very hard to figure out if people here are licensed professional counselors because there are so many folks that are, billing themselves as counselors -- they’re not claiming to be LPCs, but they are practicing counseling as part of a ministry or as part -- like if you do some research on them, you find out they’re also a pastor...”* (P42).

**Concern:** All health insurances do not support home health care.

**Data:** *“I had to quit working and go on disability in order to get the care in my home that I needed. I tried several different private insurance companies, and they all told me the same thing. ‘We don’t cover that kind of thing. Go on Medicaid’... And I ended up just filing bankruptcy, giving up my house, and moving here [an assisted living complex] with a disability, just to get the care that I needed”* (P13).

**Concern:** People are pushed into poverty to become eligible for Medicaid.

**Data:** *“There is a clause in the Medicaid where -- with the lookback...they have a lookback rule that used to be three years. So, you could give money to your children, you know, or somebody else looking back three years, and they changed it to five years. So you basically have to become poor with -- can’t leave anything to anybody. Because it’s too late. And if you don’t, especially and now the long-term care policies are so expensive, if you weren’t smart enough to sign up a long time ago. Now I hear long-term care policies are like 2000 dollars a month. So, and when you’re talking about living to 80 to 100 years you know, forget it” (P35).*

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**Concern:** Improve the pay that tele-mental health practitioners earn.

**Data:** *“I also do not want to use one of the newer um, online services for counseling...Because from what I gather from like social media conversations about mental health care, those professionals are paid very poorly. And so, for all that, it’s a very affordable access point. I also don’t -- haven’t decided that I want to be a part of that” (P42).*

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**Concern:** Families lack confidence that Veterans Affairs will ensure long term care is provided to veterans who need it.

**Data:** *“...I would like to have more confidence in an institution like, like the Navy, like the Department of Defense to make sure that that long term care is, care is paid for because I don’t think he has any retirement saved up, because he hasn’t been able to hold down a consistent job probably, related to that PTSD from his deployments” (P42).*

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**Participants’ advice:** Access to high-quality, comprehensive (including non-Western healthcare interventions) health insurance should be available to all.

**Rationale:** *“...there are reasons why he had a stroke in his 50s. And it’s partly because he had terrible health insurance. He worked full time. He had a number of jobs in his career, but at the time of his stroke he had been a -- he worked for a car dealership, managing repairs, I believe. And so, he had a really decent full-time job, but it did not provide good insurance. And he did not pay the extra for the extra good insurance” (P42).*

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*“That is probably the, the most important policy change that would improve quality of life for people with disabilities and people who could have disabilities, which is all of us, is affordable and accessible and available care for both physical and mental health. I know that’s not in your power to change, but maybe the people who read the results of this survey could change it” (P42).*

*“And the fact that we have no dental. And everyone I know is spending 10 to 20,000 dollars minimum on teeth. Yet you need teeth to eat. So, why is that being forgotten, and the only people who get that again, are people on Medicaid?” (P35).*

*“...in [State 1], I utilize Eastern medicine for treatments that Medicaid doesn’t cover in [State 2] anyway...” (P28).*

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**Participants’ advice:** Home healthcare should be supported by Medicare as well.

**Rationale:** *“Now the one thing that I think would -- it -- A) is a phenomenal program, B) should be extended to Medicare and not just Medicaid, is home health care” (P35).*

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**Participants’ advice:** For the financially insecure, home healthcare should be provided regardless of ability to pay.

**Rationale:** *“...if the healthcare companies for patient assistance are saying, okay, we know you can’t pay for this medicine without our help, even though you’re on Medicare, we’ll, as long as you make under X percent over the poverty line, we will send you the medicine for free. That should be the same thing for home health care” (P35).*

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**Participants’ advice:** All adult emergency departments should have geriatric medicine specialists.

**Rationale:** *“Geriatric is fantastic. And all emergency rooms should have that” (P35).*

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**Concern:** Healthcare coverage does not fully support the individual anywhere they are, in the U.S.

**Data:** *“I’m on Medicaid and my health insurance is all based in [State], so once I cross state lines, I’m essentially uninsured” (P28).*



**Participants' advice:** Masks should be required of all people working, visiting, or receiving care in health facilities.

**Rationale:** “And I’m terrified in the freakin’ waiting room because there’s no more mask mandates in [State] in medical environments. How the F do you, how the F do you actually justify that in places where we’re trying to get care for the very thing that disabled us, you’re making masks an optional thing? Are you kidding me?” (P28).



**A masked White woman sits on a clinic gurney while listening to a masked clinician explain treatment options.**

**Masks should be required in healthcare facilities.**

**Participants' advice:** Healthcare should be available to people, regardless of whether they are receiving disability benefits.



**A multigenerational trio make a meal together. Everyone needs access to health care.**

**Rationale:** “Well, I think they should, I think it would be nice if you could work and still get the care that you need. You know, and not have to have a disability payment to be able to get the care you need” (P13).

**Concern:** Insurance companies do not cover what clinicians and patients/families deem necessary for healthcare.

**Data:** “...the doctor wrote a script for me and said we’ll see if the insurance company -- said most of the times they don’t cover it. Well,

she’s right. She even put an authorization explaining the situation. They wouldn’t budge for it. This is what I’m talking about” (P7).

**Concern:** Participants' advice: Home healthcare workers should be able to earn a living wage in any state.

**Data:** “And also the fact that [state] doesn’t offer the same pay rate as they do for these type of jobs [home healthcare] in [state], and where I live right on the border it’s better pay for them to go down to [state]. They make, you know, \$4 or \$5 more an hour than what they get paid up here in [state]. So given that, it’s hard for me to find someone to do this” (P13).

## Operational Concerns and Advice

**Concern:** Not all clinicians respectfully seek patient histories and perform respectful, gentle pelvic exams.

**Data:** “...a lot of the men in the [healthcare] industry are very inappropriate, rude. Even when they do the exams, you feel like you’re being raped because they’re very aggressive when they do the internal exams. Umm, so it’s very traumatic, like going to the surgeon consults...” (P44).

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**Participants’ advice:** Train clinicians on how to support disability applications of their patients.

**Rationale:** “I think my biggest issue that I can think of right now has been like because I, I don’t -- I can see where health professionals could probably grow in their understanding of disabilities” (P43).

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**Participants’ advice:** Develop a public education campaign to encourage people to seek health care when they recognize a problem or do not feel well.

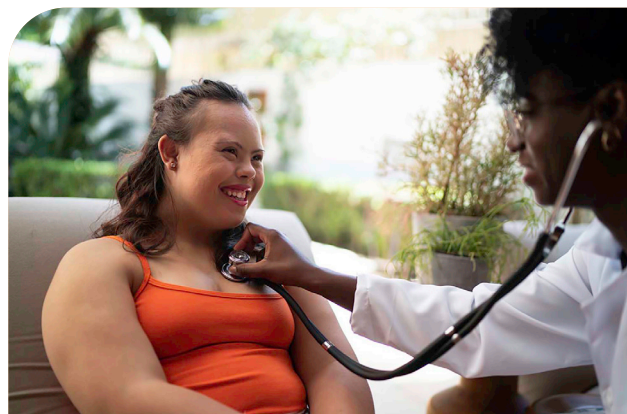
**Rationale:** “...so a public awareness campaign that medicine has changed so much, that you should not fear -- it’s not a weakness. It’s just the most immature thing you could possibly do, giving in to fear by not going to a doctor because God forbid something might be wrong, when the only thing you’re doing is reducing the chance of them fixing it ‘cause they can fix almost anything now... make it a thing where, it’s manly to go to a doctor would be a great public awareness campaign” (P35).

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**Concern:** The public has not been educated on the real-world implications and consequences of their health plan selection.

**Data:** “The Medicare Advantage plans. Most people don’t realize that that means they have no control over which doctor they see and what hospital or clinic they use” (P35).

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**A young White woman with Down syndrome smiles while a clinician listens to her heart with a stethoscope.**

**It would be helpful if clinicians also knew how to support patients' disability benefit applications.**

**Participant' recommendation:** The Department of Health and Human Services and SSA should work together to educate disabled people about Medicare.

**Rationale:** “There should be more, there should be more of a, a, link, since SSA is involved with people who are disabled. It would be nice if they and the Medicare and the [CMS] actually meet and talk together about educating people before they make decisions” (P30).

**Participants' advice:** Healthcare policy should be made by people with lived experience as well as non-lived experience policymakers.

**Rationale:** “...the task force that's needed -- is a meeting of the patients with the practitioners and the policymakers” (P35).

**Concern:** It takes too long for applicants to receive Medicaid support after approval.

**Data:** “It took me a while to get her [home health aide] paid, though. I was paying her out of pocket when I first moved in, because it took me about six months to get on Medicaid” (P13).



**A young Latina is being examined by a clinician wearing scrubs.**

**Medicaid takes too long to receive.**



**A Deaf White woman has a conversation using ASL with another person.**

**Healthcare facilities should have more ASL interpreters.**

**Concern:** Healthcare facilities do not consistently provide ASL in-person interpretation, as needed.

**Data:** “...another time here, in (State), um, the hospital, I had a seizure, oh, concussion and the hospital refused to provide an in-person interpreter. Um, they tried to force me to use the VRI [video remote interpretation] system, which is a remote interpreter and just a screen, and it was awful” (P5).



## Transportation Concerns & Advice

### Operational Concerns and Advice

**Participants' advice:** Public trains should have accessible restrooms.



**A middle aged South Asian woman using a wheelchair holds a hot drink while outside an apartment building.**

**Smooth streets and sidewalks increase accessibility for many people.**

**Rationale:** “...the trains, on their trains. [Train System] -- I don't know. I just think they should all have bathrooms” (P44).

**Participants' advice:** Repair crumbling and broken sidewalks, ensure cut-outs for all sidewalks, and eliminate cobblestone streets.

**Rationale:** “The sidewalks. Or sidewalks sometime are, sort of janky. Yeah, broken sidewalks I mean” (P4).

“...if they could just freaking even out those cobblestones, you know, I mean -- I'm, I'm like literally having a, you know, watch my step everywhere I go...” (P41).

**Concern:** Public transportation is underdeveloped or nonexistent in suburban areas.

**Data:** “...transportation is somewhat great in the, in the city. But once you get to the suburbs. You don't really have that transportation” (P24).

**Participants' advice:** Provide disabled people with discounted/subsidized access to use taxis and ride-sharing applications.

**Rationale:** “...let's say I wanted to take a cab someplace. A cab nowadays is \$60.00 just for a round trip for me to go to uh (City) to (City). Okay, that's a lot of money for somebody that's on a low income” (P24).

“...let's say, let's say if like, if you're on SSI, or at, or Social Security or whatever and you, as of, as of benefit of that, then I can also use Uber for free or like a reduced, extremely reduced amount, then, I'll just be able to say, 'hey, I'll meet you somewhere.' You know? And there's a lot more freedom, as far as me getting around and then less burden on other people” (P15).



**Participants' advice:** Paratransit services should provide single-passenger service.

**Rationale:** *"If dial-a-ride went back to one-on-one" (P15).*

*"It was not safe for a, an immunocompromised, less healthy person to be using anything other than their own private vehicle. You shouldn't even be in one of the little vans with other people" (P35).*

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**Participants' advice:** Ensure that public transportation methods are accessible to disabled people.

**Rationale:** *"...if you're along several subway lines in the boroughs, they still have elevated tracks with no staircase, with only staircases, and the elevators are constantly broken and nobody -- it's just, it's, it's appalling at how low a priority it is and if you're an old -- I mean the subway is, you know, well over 100 years old and if you're in one of the older stations that hasn't been refurbished, sometimes you're grandfathered to avoid having to comply with ADA" (P35).*

*"...the [foreign city] subway system in [foreign country] was really good and like much more accessible for at least people with mobility impairments. Uhm, like the doors were wider. Like there wasn't much of a gap in between the platform and the train. Like, it just seemed like more thought was put into it" (P8).*

*"But I think improvements could definitely be made to like, help blind people use their smartphones to like way-find in these [subway] stations" (P8).*

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**Participants' advice:** Clearly explain new transportation services dedicated to disabled people.

**Rationale:** *"...take, uh, disability transportation and they just -- I'll see how this new program works out 'cause they're really kind of horrible right now in [state] with [paratransit company]. So, they said they have a partnership with Link [sic] and Uber, but, um, they're not really even explaining that really good to people like me. They're just sending out, 'Oh, go apply.' And that's it. They're not, you know, given like a video explanation. Like I said, I need to see visually, how would I, you know, get this type of ride? And what is the difference between this ride and other rides?" (P38).*

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**Concern:** Railroad cars are not uniformly accessible without train conductors having added labor.

**Data:** “They just opened up the, the new, um, access for (railroad) and now there’s an east side (rail station) access, instead of going to the west side of (rail station). But they really didn’t ever -- but it turns out that...the conductors have to put in a special ramp for the wheelchairs to get access to those trains...there was a woman on the news yesterday, she said, by the time the conductor got the ramp to get the wheelchair in, it had closed the doors and left” (P35).

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**Participants’ recommendation:** Ensure that paratransit services support disabled people having the same flexibility and freedom of geographic movement as nondisabled people.

**Rationale:** “...you can’t do something last minute. You can’t say like, ‘Oh hey, [name], do you wanna get dinner in like 20 minutes?’ No, the ride only lets you book a day in advance” (P24).

“...you can’t like book multiple [paratransit] trips in a day, so” (P23).

“...having accessible transportation, uh, that actually runs on time and allows to have some flexibility, uh and gets me places” (P41).

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**Concern:** Airplane lavatories are too small to allow people who need assistance to fly comfortably or safely.

**Data:** “...it’s good that they [airplanes] have grab bars, at least, and they make everything accessible, and they have handholds for everything, but if there’s, if you need, let’s say you need someone else to let you, help you go to the bathroom with you. Those things, there’s not enough space for two people in there” (P12).



**Airplane wall with light-up bathroom sign.  
Airplane lavatories are not as accessible as they need to be.**

## Housing Concerns & Advice

### Policy Concerns and Advice

**Participant advice:** Make housing affordable for all.

**Rationale:** “...make rent cheaper” (P19).

**Participants’ advice:** Make affordable/subsidized housing available to more people with disabilities.

**Rationale:** “...with affordable housing, this is an example, umm typically they only provide priority to vision and mobility impairments. Uh, and, and sound, too. But I do believe they should offer a priority to other disabilities, not just those.” (P44)

**Participants’ advice:** Create housing vouchers for disabled people who need them, not spaces/units, and regardless of their impairment type.

**Rationale:** “...if I moved, this voucher doesn’t go with me. It’s for this unit.” (P7).

“...It’s umm, called Project Days Voucher. And she, they told me -- I talked to our mayor of [city], the, umm, his name is [local mayor]. He was very nice. He tried to help me as much as he could. The Housing Authority in [city], I’ve been on the list since 2019. And I asked him ‘Well, can you give me a voucher to find a place that could help me with my rent, cuz they’ll accept it here.’ And they told me when, no, that they couldn’t. And I asked him, ‘Well, how does other people that have social workers that have mental disabilities get theirs?’ And they said because their workers get it through them for them. So, I feel that that is wrong. I, I think that they need to change that...” (P2).



**In an apartment hallway, an older Latino using a motorized wheelchair and two prosthetic legs receives keys from a standing White woman.**

**Housing vouchers should be for people not housing units.**

## Operational Concerns and Advice

**Participants' advice:** Increase accessible housing.

**Rationale:** "...the apartment or certain buildings that don't have elevators or don't have accessible friendly things. Like that would be the most thing for me is I'm struggling to find an apartment that's on -- I'd prefer not to be on ground level." (P20)

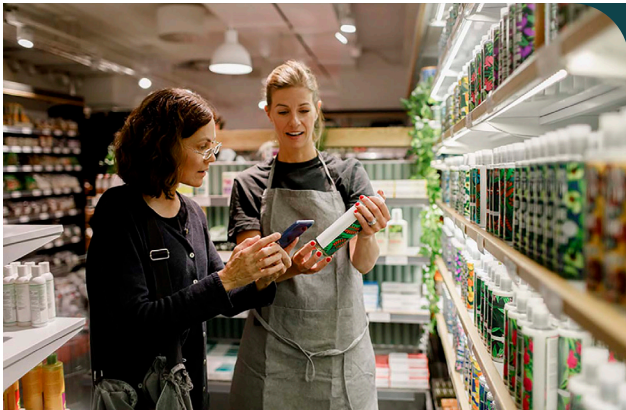
"I would have to say more buildings with elevators" (P20).

## Food Concerns & Advice

### Policy Concerns and Advice

**Concern:** Supplemental Nutrition Assistance Programming benefits do not currently increase according to the cost of food.

**Data:** "...if food stamps gives you \$280 to spend for a month of food, great. But a thing of beef at being \$10.68. That's one thing of beef for two days...So, they want us to eat nutritiously a thing of asparagus is \$8.00, and some change. A thing of strawberries is \$8.00 and some change" (P24).



**A middle aged White woman gets help from a younger White woman wearing an apron at a grocery store.**

**Grocery stores should have shopping support for disabled people.**

## Operational Concerns and Advice

**Participants' advice:** Grocery stores should offer in-store shopping support services for disabled people.

**Rationale:** "...like, the grocery store for example. It would be great if, like the co-op, we have a service where a volunteer will walk with you with the cart. And then take the cart back, you know? So, that's something that grocery stores could do, like not just co-ops..." (P43).

"And, um, I can't bend down to the bottom shelf [at the grocery store] and reach something and then stand back up and be sure I'm not gonna faint...people think of stuff that's up high that's not reachable. It's, like, actually down low is also not reachable for some of us" (P28).



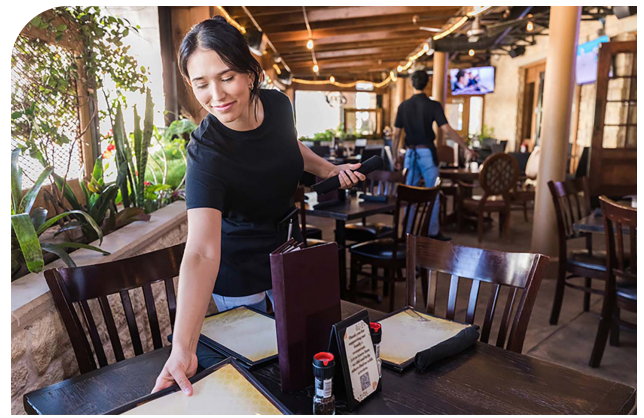
**Participants' advice:** Restaurants should offer braille, audio, and image-based menus.

**Rationale:** "...I know verbal menus will be expensive, but maybe little pictures or something like that. Or in the grocery store, maybe like, say, like, let's say, I don't know, my mom told me like, bread aisle or something like that, put a little bread, a picture of bread or something like that 'cause this simple... [Interviewer: Now, what do you mean by verbal menu?] Umm, like, it reads it to you. Like instead of like having it, like, a regular menu. Just have, like, someone say it..." (P4).

"If you were to go to a restaurant, how many restaurants do you know that have blind menus, for in braille?" (P24).

**Concern:** Restaurants do not have a private room for patrons who need it.

**Data:** "Umm, how many restaurants do you know that have a separate room for somebody that gets agitated? None" (P24).



**A young White woman sets a table at a restaurant with menus.**

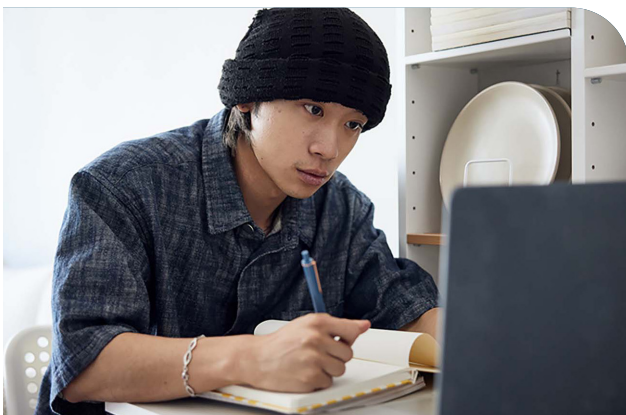
**Restaurant menus should be accessible to people who are blind or do not read written English.**

## Education Concerns & Advice

### Policy Concerns and Advice

**Participants' advice:** High school students should be taught "financial literacy."

**Rationale:** "...teach financial literacy to high, in high schools" (P35).



**A young Southeast Asian man studies with a notebook and a laptop.**

**College education should be more affordable.**

### Operational Concerns and Advice

**Participant recommendation:**

College/University education should be more affordable.

**Rationale:** "...the school fees should be reduced..." (P18).

## Congress Concerns & Advice

### Policy Concerns and Advice

**Participants' advice:** Elected officials should be required to demonstrate objective knowledge of U.S. history and government.

**Rationale:** *“I want a constitutional amendment that says you cannot run for state or federal elective office if you don't take and score at least a 90 on the citizenship test...in labor law, it's called the BFOQ, a bona fide occupational qualification. That should be BFOQ to run for state or federal elective office” (P35).*

**Concern:** Sufficient COVID-pandemic financial support for creative and art workers was and still is lacking.

**Data:** *“...the creative economy and arts workers took a massive hit during the pandemic that we still haven't recovered from, especially when the prior administration did not even acknowledge the value of arts workers, even though the creative economy is significantly larger than, say, the Department of Transportation in terms of GDP and, um, what we put into the economy. So, we were not provided, uh, rescue funds or support funds at a level commensurate to what we contribute, um, whether it's, um, employment taxes or ticket sales, or, um, you know, the, the ancillary services. All the, the economies of the creative sector um, have just been devastated, and there's a real delay on support of new work because venues are still trying to fulfill the contracts that had to be put on hold or cancelled because of COVID. So, we also have fewer opportunities we're competing for. And, um, you know, the UK put money into the arts sector within six months of COVID hitting. We never saw that for two years” (P28).*



**A middle aged Black man wearing a suit is sworn into office by another Black man who is facing away from the camera.**

**Citizenship knowledge should be a prerequisite for holding elected office.**

**Concern:** There is no memorial to acknowledge the collective harm experienced in the COVID pandemic.

**Data:** *“...we have not come up with an adequate ritual of grieving as a country. We have no memorials, really. We have no acknowledgment of the massive loss, not just of deaths but of who so many of us were before, and who we are now. And what we lost, whether it be physically, or in skills, economically, or just the way we used to move in the world” (P28).*

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**Participant advice:** COVID-related making mandates should be re-instated in public spaces and on airplanes.

**Rationale:** *“...Every public space that drops those mask mandates, in effect, excludes us from being able to go there. The ADA is supposed to protect accessibility. Well, those spaces are not accessible to us. If we’re [immunocompromised people] putting our lives at risk, they are not” (P28).*

*“If everybody masked on the plane” (P28).*

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**Concern:** The Americans with Disabilities Act has many loopholes that allow entities to avoid accessibility and accomodation compliance.

**Data:** *“...the law, the ADA law is very complicated and it’s not black and white and, you know, there’s loopholes and all sorts of things that people can get through, so. As a Deaf person, I, you know, I know that there’s so many details in that law, that it’s not like 100 percent guaranteed just because of the law that there’s access” (P29).*

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**Concern:** The minimum wage and sheltered workshop wages are not living wages.

**Data:** *“...the wages are not up to date” (P22).*

*“What I don’t wanna do is do what my father did, uh, who had ended up working for thirty cents an hour in a sheltered workshop until he died right? One of the reasons why he lived so long, it was stage four lung cancer was because when he hit hospice, he was finally getting three square meals a day. Poor guy could barely afford to pay, you know, rent. He literally ate Oscar Mayer hot dogs and Wheaties” (P41).*

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**Participants' advice:** Update the naturalization laws so that international adoptees are eligible for the benefits into which they have been paying.

**Rationale:** “...so when I, I was on state disability and when it ran out, I had to get on Social Security. It was a big issue -- umm, I had to go get a work permit to get just my SSA. Now, through the years that I worked at (employer) as an inspector I did pay into SSDI. They will not give it to me unless I had a residence card for, uh, um, naturalization. And, so, I don't, I don't get the full benefits that it -- other people get...in 2000, when Clinton was in office, he passed the bill from the age of 18 down, for international adoptees, to receive citizenship or naturalization. Well, he left out about six generations of adult international adoptees...So, we have international adoptees that's been deported or they can't get their benefits but they worked here. There was a bill last year [2022] that was passed to the Congress -- um, it was February the 4th. And it was our adoptee bill to revise the bill so, it would give us our, our naturalization. It went to the Senate and it didn't go nowhere else...So, a lot of international adoptees, adults, umm, that are still working -- they're not gonna find out until they try to retire. And some of them will not receive their benefit. Umm, and it's really sad to say this -- you know, even though we paid our taxes...” (P2).

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**Concern:** Federal marijuana laws prevent some people (including those with an incarceration history) access to health care.

**Data:** “...I would use marijuana, if it was medical marijuana because I had a medical card. But now because I'm on federal probation, I cannot use, which is funny because state probation and state jails and state prisons, they can use their medical marijuana, but because it's not federally legal, I cannot consume” (P33).

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**Concern:** Gun violence feels pervasive.

**Data:** “You know, and the way society is today with people shooting guns off everywhere. Does that make me really wanna go out? No” (P24).

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**Participants' advice:** Institute universal income.

**Rationale:** “I find it very difficult that people are working poor. These aren't people who, you know, and these are people actually get up every day and they work and they still come home with not enough money to meet their ends. I think things like that, shouldn't, there should, or there should be some type of, yeah, universal income” (P19).



**Concern:** There are not universal or federally required pay transparency laws.

**Data:** “...I think -- was it [state] that came up with pay transparency for certain corporate, there were like some stipulations about the size of the company, the stipulations around, you know, which companies could, that are expected now to be more transparent about compensation” (P19).

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**Concern:** Disabled people experience obstacles in efforts to adopt children.

**Data:** “I would like to adopt, but they, they don’t let many times people that have a disability adopt” (P38).

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**Concern:** Student loan forgiveness eligibility requirements are difficult to achieve without being impoverished.

**Data:** “...all these kinds of like student loan forgiveness, all these things right on one hand seem really useful but then when you get to the brass tacks of it, there’s so many loopholes, there’s so many different hoops that you have to go through in order for them, any of them, to come through, you have to be put into poverty” (P41).

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**A White student with Down Syndrome smiles at graduation with his family.**

**It is difficult to get student loan forgiveness without being in poverty.**

**Participants’ advice:** Increase accessibility to parks’ and trails.

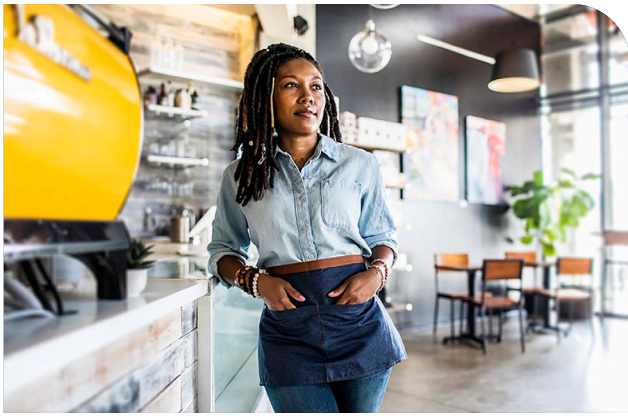
**Rationale:** “I do feel like it limits me a bit like. I wish there were more paths and parks that were, that had like nice walkways and stuff” (P6).

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**Participant recommendation:** Create and make available (to disabled people) a universal restroom key for accessible public restrooms in the U.S.

**Rationale:** “And by the way, this is something that you guys really should consider. England has this wonderful thing -- I’m not sure if it’s within the entire United Kingdom or just England itself. You go to their -- to an office there, at the time for four pounds, which is just a few bucks. You get a key. That key is the same key for every handicap bathroom in the country” (P35).

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**A Black woman leans against the counter at the coffee shop where she works.**

**People who can work may still not make enough money to independently support themselves and may still need benefits.**

**Participants' advice:** People who can work still may not make enough to fully support survival; allow non-cash benefits (including Medicare, Medicaid, SNAP, affordable housing, energy assistance, and funeral programming) to continue for those who can work.

**Rationale:** *"I would love to have kept some of those [non-cash benefits] just in case, like there's a chance that my health issues would come back again, you know?" (P44).*

*"...they have the funeral program where Medicaid would pay for your funeral" (P38).*

*"...I would hope that could remain [in affordable housing] for a small, small period of time. I see, say at least, uh, two years" (P38).*

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**Participants' advice:** Do not require disabled people move further into economic precarity to become eligible for Medicaid.

**Rationale:** *"...I own my apartment. But if I had to have -- but if I needed care then we really are going to be stuck. Because I'm not going to -- because now there's no one for me to transfer the money to, and it'll all be gone. So, basically, you're making people wipe out their funds intentionally in order to qualify for Medicaid. Now, I think that they should expand home healthcare for people who are like, income under 60,000" (P35).*

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**Concern:** When a benefit recipient dies their assets do not pass on to their beneficiaries.

**Data:** *"Social Security comes along and literally takes everything my father owned. So all the estate, all of t- money that I could have to have financial freedom went back to the state because...that's just the it's the nature of special needs trusts...cause of his Medicaid balance, uh, you once you die, you have a the you have a lien based on how much you know, whatever they estimate your care was for, and that goes away" (P41).*



**Mourners stand around a coffin in a cemetery at a burial.**

**Benefit recipient assets do not pass to their beneficiaries when they die.**

## Operational Concerns and Advice

**Concern:** Sentate building access is not accessible to disabled people to the same degree as it is for nondisabled people.

**Data:** “...I think about my time I worked as an intern for the United States Senate. Okay, now this was during COVID. If I worked there now, where do I get in, right? I’d have to go through the basement” (P41).

**Participants’ advice:** Lived experience experts should be included in policymaking.

**Rationale:** “People who are not, don’t understand the system, should not be making policy. Because they don’t understand the reality of how it’s used. It’s got to be more inclusive of the actual community” (P35).

**Participants’ advice:** Enforce equal pay for equal work laws.

**Rationale:** “...equal pay with hearing people, obviously. We, from my experience, I, well, I can’t speak for others. I can’t speak for all Deaf people. But I’ve noticed that Deaf people get a lower rate of pay compared to a hearing person. Even though I have the same skill set, I’ve got the same experience, the same knowledge, but I get a lower rate of pay. If that law were to change, it would affect all of people who are labeled as disabled, it wouldn’t be, there wouldn’t be pay dependent on ability, in that way” (P29).



Two young women chat and laugh while speed walking. One woman has one arm.

Lived experience experts should be included in policymaking.

## Private Sector Concerns & Advice

### Policy Concerns and Advice

**Concern:** Life insurance is not available to all people.

**Data:** “I don’t have a life insurance because guess what, I’ve been denied by every life insurance person because of a disability” (P38).



**Participants' advice:** Employers should meaningfully consider disabled candidates for jobs.

**Rationale:** "...I think there's a lot of remote jobs and some jobs that I think we may qualify, but we don't have the opportunity to do it. Cause the government should come up with a, with a way to give this, uh, us this first opportunity before, uh, giving them to others..." (P36).

"I think there needs to be a publicly articulated push to hire more of us...Right now, it's framed in a way that's, like, oh do the disabled person a favor, instead of, actually there's a disabled person is value added. They are bringing something unique in their skills, or in their knowledge of how it is to work in the world, navigate the world, or, um, in their neurodiversity, and the way they see things differently, and may approach problems differently. I mean, we have to be, we have to be highly adaptable" (P28).

## Operational Concerns and Advice

**Participants' advice:** Employees should be better paid and have equity in the companies in which they work.

**Rationale:** "...I just don't think that there should be billionaires in this society when they don't have -- or those people should have access to getting equity in the company that they are somehow making bigger" (P19).

**Concern:** Accessibility isn't universally incorporated into products and services.

**Data:** "...so another thing that kind of came to mind was like, now everything is touch screen based. And that can really be inaccessible for a lot of people with visual impairments, or like -- uhm people with like, uh, motor disabilities, like if they can't really use their hands in a certain way. So yeah, if there is a screen and there's not, like a headphone jack, or umm, like any sort of setting that you can enable that will read the text out to you, then you can't really interact with that terminal. And you'd have to seek sighted help, which you know, can be annoying if it's like sensitive information" (P8).



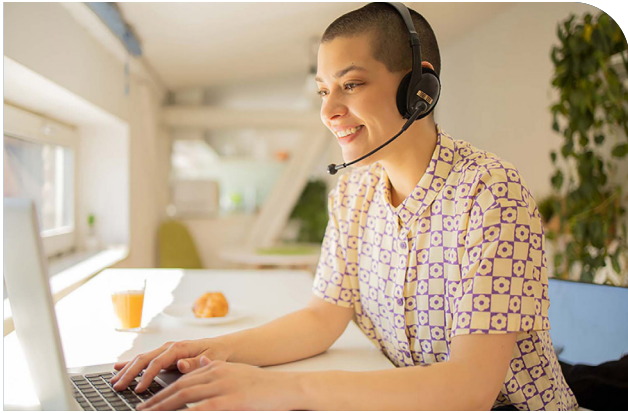
**A Black worker stands in a factory in a hard hat and ear protection.**

**Compensation for workers should be expanded to better reflect their contributions to the company.**



**Concern:** Some museums do not allow patrons to bring in liquids which excludes people who need frequent hydration.

**Data:** “...some museums don’t allow you to bring in a bottle of liquids. And I’ve had to say like, look, I’m missing most of my colon. I have to drink. Like, if I don’t have sips throughout the day, like, I’ll literally pass out...” (P44).



**A White woman wearing a headset smiles while typing on her laptop.**

**People with lived experiences should be included in the creation of products to increase accessibility.**

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**Participants’ advice:** Have lived experience experts create accessibility in products and services.

**Rationale:** “There’s a lot of blind people that know how to write the script, so that your website can be, so that that screen reader knows what it’s talking about with your website. So, employ more blind people to do that” (P15).

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**Participants’ advice:** Embed accessibility into theatrical performances.

**Rationale:** “...what I’m pushing for, is for, dialogue, or the, the show to be designed, so that there is no need for audio description. That you, you can, you a blind person, would be able to enjoy that show with the written dialogue, the, and music, and sound effects narration. So, like the, use the, the theatrical elements to embed accessibility within everything” (P15).



**Silhouette of an audience watching a play. Theatrical performances could be designed with accessibility in mind.**

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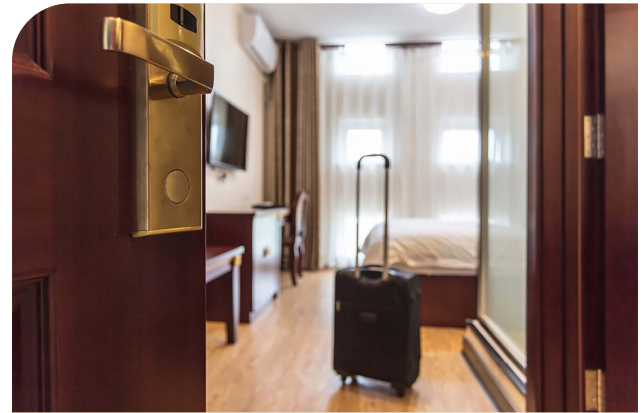
**Concern:** All gyms are not accessible so many disabled people cannot use them.

**Data:** “There’s accessible gyms and, and so on, but that’s not the case in the majority of the country...” (P10).

**Concern:** Hotels that claim to be accessible do not always have functioning accessibility amenities and room components.

**Data:** “...you reserve a handicapped room, and then honestly, like, there’s probably been one time out of maybe, um, I don’t know, a dozen, a dozen to a dozen and a half times, that um, I actually got an accessible room, that, like actually, like actually had, like, what they said it was gonna have. And then, actually had, like, a pool lift that was, like, working because, like, 99% of the time - they have those pool lifts, but they’re never working, like, they’re never, never functional... there’s always something wrong with them.

Um, and then, even like the accessible bathroom or bedrooms, like, they’ll, they’ll say that they’re accessible, and then, but there’s always something, like, usually, like, they don’t have, actually, like, a shower chair or any way for you. And then if they do you, you can’t reach the handles to like turn on the water then, like, the, the beds are always, like, always super high. So, I mean, unless you have really good upper body strength...the doors are really, really heavy in some hotels. And I mean, that’s just hard to try and get open on your own...” (P14).



**A wheeled luggage case stands in an empty hotel room.**

**Hotels claim to be accessible but often are not.**

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**Concern:** Amusement parks have limited wheelchair-accessible rides, excluding this group of people from equal access to park entertainment opportunities.

**Data:** “...some of the amusement parks here in (State) had a few wheelchair-accessible rides. But I mean very few of them” (P13).

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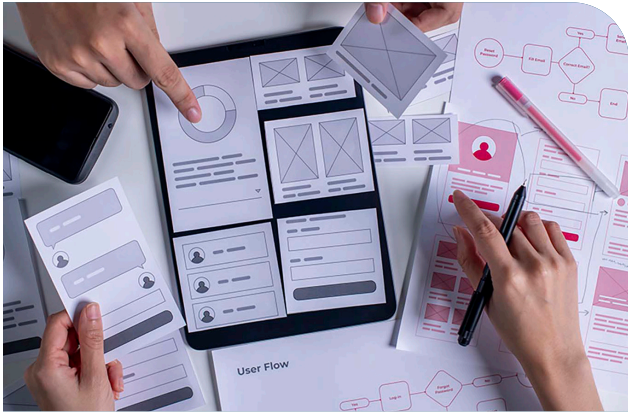
**Concern:** Wheelchair-accessible portable restrooms are often too small to allow for assistance and independent use.

**Data:** “They had these little wheelchair porta potties. That you would go into and, yeah, you could do it, but it was difficult. And you needed, you needed someone to help you. It wasn’t something that you could do freely on your own” (P13).

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**Participants' advice:** Websites should be accessibly designed and functional.

**Rationale:** "...website literacy and accessibility is still very much an issue for people with visual impairments...Like using different apps on your phone, like some developers don't really have accessibility as like, a priority, so when you're trying to use it with your screen reader and like, find out what the different buttons are like, it's just labeled as a button. So you know, you're trying to scroll through it and it's just like button, button, button, and that's not helpful at all. Like, you can't really navigate through the app that way" (P8).



**Two people using cards to design different sections of a website.**

**Too many websites are not accessible.**

"...having like, a text only option for the websites would be great...so it would basically just have like, an overlay, and like have a like, a different version of the website where, like the images are removed and then you can use the screen reader that's either on your phone or on your computer to read it out" (P8).

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**Concern:** ASL interpreter agencies' processes do not allow for equal and flexible participation of Deaf people.

**Data:** "...the [ASL] interpreting agency's requirements were that you needed to get an interpreter a couple of weeks out because interpreters would be booked" (P29).

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**Participant recommendation:** Hire human resources staff who are familiar with the diversity of accommodations available for the workplace.

**Rationale:** "...like they'll say that they provide reasonable accommodations, but they might not, like, know what those are. So having HR people like, educated in the different types of reasonable accommodations would be great" (P8).



**A biracial woman interviews someone, who is facing away from camera, for a job.**

**HR staff should be trained on the accommodations that can be provided to people with impairments.**





Four golden coated dogs sit in a field looking away from the screen wearing guide dog jackets; the two in the middle are puppies.

More training classes for service dogs are needed.

**Participant recommendation:** Increase the number of service animal training schools.

**Rationale:** “I think that they need to supply, you know, supply classes for dogs that can be trained and pay, you know, pay for it or supply it or however they wanna do it. Where we could come with our dogs to, you know, smaller dogs and get them certified, you know? And I think that that would be a benefit because waiting on a community, on a place to supply dogs, train the dog. They bring you in to train the dog or to train with the dog. You know what I’m saying? Like, I think it would be easier to have a central place” (P20).

---

**Concern:** ASL interpretation agencies do not uniformly employ high-quality interpreters; some companies block video interpretation services on their secure network.

**Data:** “Well, certain places have their own, um, policy or regulars that they have to use an [ASL] interpreter from a contract agency ‘cause that’s what’s been approved. Um, maybe that specific agency doesn’t provide great interpreting services, um, or they don’t have great interpreters working with them. Some places will have, um, a strict internet firewall so, um, they can’t attach a video phone, uh, to that, uh, computer system, because of the firewalls. And so that makes it harder in terms of time, to communicate on a timely basis” (P25).

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**Concern:** Businesses do not uniformly consider the neurodiverse needs of workers and patrons.

**Data:** “...they’re blaring music, and they’ve got fluorescent lights and it’s, like, it’s really incredibly taxing, energetically, to be in those spaces” (P28).

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**Participant recommendation:** Make captions a standard part of screen media (including movies and television).

**Rationale:** “...to get not just closed caption, but open caption on the screen, [!] mean just on there all the time” (P22).

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**Participants' advice:** Include “accessibility” in hiring and retention diversity, equity, and inclusion actions.

**Rationale:** “...when I would go on job interviews, they would ask about EDI. And I would always talk about, like, you know, don't forget, you know, disability, as well” (P44).

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**Participant recommendation:** As much as is technologically and practically possible, make accessibility the default such that it is available to employees without requiring disclosure.

**Rationale:** “...everything should be universally designed for all employees. I shouldn't have to, you know, be forced to disclose anything” (P38).

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## Internal Revenue Service Concerns & Advice

### Operational Concerns and Advice

**Concern:** Plain language is not used in tax filing forms.

**Data:** “...I have a family friend that helps me with taxes. I'm gonna be honest. They help me a lot with it...a big barrier is like not understanding that system in general or not understanding these pieces of information, umm, to be able to make a very informed decision” (P3).

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## Federal Service Agencies Concerns & Advice

### Operational Concerns and Advice

**Participant recommendation:** Do not eliminate in-person and paper processes.

**Rationale:** “...a lot of people who are disabled or elderly can't use the computer, and so much has switched to computer only. Which is just wrong. Um, the exact people who need it are the people who, they can't get access to find out these things” (P35).

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**A Latina using her laptop holds a kitten while viewing benefit websites.**

**Access to benefits and government websites should be streamlined and user friendly.**

**Participant recommendation:** Streamline and simplify how people access benefits.

**Rationale:** “I think there should be like a card where it says, here are all the things, check off what you need, and then maybe you can have like, you know, quarterly conversations and then you can actually look at their data. (P19).

---

**Concern:** Many government websites are not user friendly.

**Data:** “...lot of the, a lot of the government related, uh, websites, whether you’re reporting that you had a little income, um, that particular week, or they just are, they are designed in ways that are not instinctual at all” (P28).

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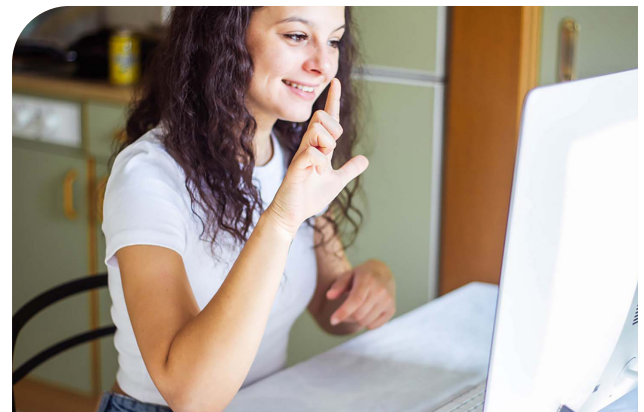
**Concern:** Building accessibility does not uniformly include restroom accessibility.

**Data:** “...schools, buildings, like government buildings, and all that, those are generally accessible but even then, can you like, you may not be able to open the door to get in the bathroom, it might be super impossible to open...” (P10).

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**Participants’ advice:** Government agencies should have a dedicated number for Deaf people to use.

**Rationale:** “I know [city] Mayor’s Office of People with Disability, there, they have a dedicated line called Direct ASL. Anybody who called that number will have a signing person on the screen. So, I really think that’s what every government agency should have. Um, because, um, Deaf people, when they go through the phone tree system, they they don’t -- a lot of them might not they, they don’t even -- understand the phone culture” (P22).



**A curly haired White woman signs while smiling to someone on a virtual meeting platform.**

**A dedicated line for Deaf people would be useful at government agencies.**

## Local Jurisdictions Concerns & Advice

### Operational Concerns and Advice

**Participant recommendation:** Make portable restrooms available at community events.

**Rationale:** “There’s a lot of, in [city], there’s a lot of, like, street fairs and festivals, things like that. Umm, I definitely think they need to put Port-a-Potties out” (P44).

**Concern:** Some voters who use accommodations to engage in their civic duty experience feel embarrassed or humiliated by the way election officials interact with them.

**Data:** “And voting, too. ‘Cause like, I always have to tell them, hey, I have a reading disability. Oh, can you prove it?...[Interviewer: Oh. So, what happens when they say, oh, can you prove it? How do you move forward from there?] I have to show ‘em my ID. And then, I have to go tell ‘em, hey, this is my aide. And then, we always had to sign a piece of paper to prove it...I don’t cry now, but I get angry” (P4).



**A shorter, masked White woman holds a clipboard and takes notes while talking to a taller, masked Black man. They are at a polling station.**

**Election officials are not always respectful of voters with impairments.**

**Concern:** Train law enforcement agents to check multiple areas of the vehicle for accessible parking designation.

**Data:** “...a lot of cops don’t even look at the license plate, and they’ll give you a ticket, if you don’t have the tag...” (P35).

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**National Organization on Disability  
Access Living**

**American Association of People  
with Disabilities**

**TASH**

**Access Alaska**

**Hope Alaska**

**The Arc of Anchorage**

**Disability Rights Hawaii**

**United Hmong with Disabilities**

**Hmong with Special Needs**

**Supporting All Abilities, Welcoming  
All Voices (SAWV)**

**African American Advocacy Center  
for Persons with Disabilities**

**National Caucus and Center  
on Black Aging**

**National Indian Council on Aging**

**National Association  
for Hispanic Elderly**

**Disability Rights California**

**Arc of the United States**