FINANCIAL HEALTH:

Living at the Intersection of Disability, Race and Poverty

Listening Session Research Report

March 28, 2023
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Project Overview

National Disability Institute (NDI) conducted listening sessions with Pittsburgh residents with disabilities and local providers serving persons with disabilities on March 1, 2023. The listening sessions discussed the financial inclusion needs and associated challenges faced by individuals living with disabilities and those at the intersection of race/ethnicity, poverty and disability.

The sessions were convened by the Pittsburg Coalition on the Intersection of Disability Race, Ethnicity, and Poverty, in partnership with JPMorgan Chase. This report details qualitative insights and findings for the research exercises conducted.

Methodology

Mixed methods surveys were administered to all participants. Providers completed a registration survey, whereas individuals and family participants completed both a registration and a pre-listening session survey. Participant responses were analyzed using Excel data analysis tools. Fourteen (14) providers and 17 individuals with disabilities completed the registration surveys. To get additional data not provided by the registration survey, an additional pre-listening session survey was sent to all registered participants. Eleven (11) individuals completed the pre-listening session survey.

A total of four separate focus group discussions were conducted with 12 service providers (2 groups) and 12 individuals (2 groups) with disabilities. Sessions ranged from 60 to 90 minutes in length, with groups of up to 8 participants each. Group discussions were audio recorded and transcribed. The data were then coded and analyzed using NVivo qualitative analysis software.

All participants either: 1) identified as an individual with disability or lived in a household with disabilities, or 2) were community service providers currently serving individuals and families with disabilities who identify as Black, Indigenous and Person of Color (BIPOC) and/or are part of the LGBTQIA+ community.
Overview of Participants

Providers represented a cross-section of disability and minority-serving organizations in the Pittsburgh area, ranging in services from serving children with emotional and mental health needs, adults living with mental illness, children with disabilities in the foster care system, adolescent female empowerment, support for parents of children with long-term medical conditions, basic resource supports for families, legal advocacy and referral partnership network coordination. Populations served by providers include, American Indian or Alaskan Native, Asian, Black or African American, Latinx of Hispanic American and Native Hawaiian or Pacific Islander persons with disabilities. Majority of the providers surveyed serve between 50 to 100 percent clients of color from several zip codes across Allegheny County, Northern Allegheny and the City of Pittsburgh. Four (4) of the 14 participating providers reported living in a household with disability.

Table 1. Provider demographics

<table>
<thead>
<tr>
<th>Survey/Group</th>
<th>Gender</th>
<th>Race/ethnicity</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Registration</td>
<td>1 Male, 13 Females</td>
<td>1 American Indian or Alaska Native, 4 Black, 1 Latinx, 8 White</td>
<td>14</td>
</tr>
<tr>
<td>Focus Group</td>
<td>2 Male, 10 Female</td>
<td>1 American Indian or Alaska Native, 4 Black, 1 Latinx, 6 White</td>
<td>12</td>
</tr>
</tbody>
</table>

Individuals and families participating in the research exercise represented a cross section of individuals with various disabilities, ages and ages of disability onset. A total of 17 respondents completed the pre-listening session surveys, and 12 individuals participated in the focus group sessions. The participants were majority female for both the pre-session survey and the focus group discussions. Individuals with disabilities participating were Black (9), Mixed race Latinx (1), and White (7). Participants’ primary income were form multiple sources including employment and public benefits.
Table 2. Individual and family demographics

<table>
<thead>
<tr>
<th>Survey/Group</th>
<th>Gender</th>
<th>Race/ethnicity</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Registration</td>
<td>3 Male, 13 Female, 1 Non-binary</td>
<td>9 Black, 7 White, 1 Mixed race – Black, Latinx, White</td>
<td>17</td>
</tr>
<tr>
<td>Survey</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Focus Group</td>
<td>3 Male, 8 Female, 1 Non-binary</td>
<td>8 Black, 3 White, 1 Mixed race – Black, Latinx, White</td>
<td>12</td>
</tr>
</tbody>
</table>

Mental or emotional conditions (59%) percent) was the most frequently noted disability and was experienced by more than half of the sample, whereas percent cognitive (41%) and physical (35%) percent disabilities were experienced by more than a third of the sample.

Table 3. Disabilities of individual and family participants.

<table>
<thead>
<tr>
<th>Disability</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mental or Emotional</td>
<td>59%</td>
</tr>
<tr>
<td>Cognitive</td>
<td>41%</td>
</tr>
<tr>
<td>Physical</td>
<td>35%</td>
</tr>
<tr>
<td>Visual</td>
<td>24%</td>
</tr>
<tr>
<td>Self-care</td>
<td>24%</td>
</tr>
<tr>
<td>Hearing</td>
<td>18%</td>
</tr>
</tbody>
</table>
Survey Findings

Providers

Half of participating providers noted that between 30 to 100 percent of the clients served were individuals with disabilities.

*Table 4. Percentage of clients with disabilities served by participating provider representatives.*

<table>
<thead>
<tr>
<th>Number of Organizations</th>
<th>Percentage of clients with disabilities</th>
</tr>
</thead>
<tbody>
<tr>
<td>5</td>
<td>90% to 100%</td>
</tr>
<tr>
<td>1</td>
<td>60% to 89%</td>
</tr>
<tr>
<td>2</td>
<td>30% to 59%</td>
</tr>
<tr>
<td>1</td>
<td>6 to 29%</td>
</tr>
<tr>
<td>2</td>
<td>5% or less</td>
</tr>
<tr>
<td>3</td>
<td>Do not track number of persons with disabilities served or unsure</td>
</tr>
</tbody>
</table>

Providers served individuals with disabilities of various races/ethnicities, including people of color. One 12 of the 15 (or 86%) of the providers who participated in the research activities serve Black and Latinx individuals with disabilities, whereas 71 percent serve Asian and White individuals with disabilities.
Providers listed several **systemic challenges** experienced in meeting the needs of individuals with disabilities, which were corroborated by insights from the focus group discussions. Challenges expressed include a range of issues associated with addressing the widespread and compounding needs related to access to care, transportation, socioeconomic challenges, time constraints and living with chronic medical conditions. Some of the challenges underscored by providers included:

- Difficulty locating available resources and supports, particularly for men of color.
- Challenges supporting clients with invisible and undiagnosed disabilities.
- Dealing with the challenge of discrimination in various settings, including employment and healthcare.
- A lack of success reaching and convincing clients of the advantages of working with a provider.
- A lack of accessibility and inclusion measures, including those that attend to the needs of invisible and other disabilities which are traditionally overlooked, and non-English-speaking clients.
- A lack of consistent communication and viable communication channels needed to support individuals and families with disabilities.
- A lack of long-term partnerships and funding to sustain programs.
Several barriers to providing services for clients with disabilities were enumerated including a lack of training, marketing costs to reach clients in rural areas and to educate families and connect them to care, resources and services.

Providers expressed that some of the greatest barriers to financial health faced by their clients included a lack of fixed income and funding resources, a lack of education, too little community support and a lack of personal stability and access to resources overall. Asset and resource limits for public benefits programs, a lack of available and accessible transportation, a lack of affordable housing, fear of losing benefits, stigma and a lack of education on benefits were also listed as significant barriers to establishing and maintaining financial health for persons with disabilities. A lack of access to technology and language barriers also featured as important barriers to financial health. For youth, in particular, a lack of soft skills, including communication and personal expression, were regarded as a barrier for developing the necessary competences to be successful in life in general.

Though the financial health barriers experienced by disability clients were glaring, some providers cited public funding, specifically Social Security Disability Income (SSDI) and Supplemental Security Income (SSI) as effective forms of financial support. Financial counselling or financial education, employment training and career development supports were suggested as effective resource support. From a provider standpoint, grassroots efforts to secure funding for program participants, training and support for staff, community partnerships and referral coordination and free or low-cost interpretation services were noted as additional resources.

**Intersection of Disability, Race/Ethnicity, and Poverty**

For individuals and families living at the intersectionality of disability race/ethnicity, and poverty, providers stated that there was vast inequity in available resources across communities of color. For example, one provider noted that mental health disparities are significantly high among Black female youth. Communities of color also often find it challenging to get to local providers who are outside of the city limits.
The suggested response to these dilemmas faced by undeserved communities of color includes recommendations for mandatory services in all communities and innovations in social media outreach to communities of color, in addition to transportation assistance to reach people within geographies where public transportation is inaccessible.

**Individuals and Families with Disabilities**

*Additional Demographic Data*¹

Nine (9) individuals reported having a bachelor’s degree or higher educational qualifications. Sixty-four percent (64%) of the sample earned $35,000 or higher, with over a third earning between $50,000 and $74,999 annually.

While most noted that they have not received or participated in employment support programs (91%), most had benefitted from financial support services (74%). These financial support services included free and paid tax preparation, free financial planning, and financial counselling or coaching. The remaining 36% of participants who had not benefited from financial support services indicated that they were not aware of listed or other programs.

Most the participants had not engaged in any type of financial education for asset building, with only two indicating they had participated in homebuying (Catapult Pittsburgh Homebuying Program) and savings programs. It follows that the 100 percent of the participants had either did not have an Achieving a Better Life Experience (ABLE) account (36%) or had never heard about ABLE accounts (64%).

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¹ Demographic data (education, income, use of support services, ABLE accounts and use of financial services) is based on responses to the pre-listening survey to which 11 participants responded.
Sixty-five percent (65%) of participants reported having access to other resources available to individuals with disabilities, such as the Equal Education Access (IDEA) program provisions, and Water, energy and/or heat assistance.

Participants also reported high use of financial services. However, the rate of use varies across products. One hundred percent of the participants used a checking account in the last 12 months; only 55 percent reported using a savings account. On the low end, two individuals had investment accounts (retirement), and only one individual had a home mortgage.
Participants noted several resources that have been helpful for them as they navigate living with a disability along with their various intersecting identities. These resources include having access to public benefits, having gainful employment, access to affordable housing, having the support of a financial empowerment counselor, having opportunities to contribute to employer-matched retirement savings plans and access to subsidized medicine and medical assistance. A summary of the responses is listed below:

**Table 5. Most helpful resources for individuals living with disabilities.**

<table>
<thead>
<tr>
<th>Most helpful resources:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Public benefits such as SSI and Medicaid</td>
</tr>
<tr>
<td>Employment</td>
</tr>
<tr>
<td>Affordable housing - Section 8 voucher</td>
</tr>
<tr>
<td>Financial counselor via FEC who has taught budgeting skills</td>
</tr>
<tr>
<td>Federal Employee Thrift Savings plan for more than 20 years at 0.5 contribution match</td>
</tr>
<tr>
<td>LIS (Low Income Subsidy for Prescription Drugs)/ &quot;Extra Help&quot;</td>
</tr>
<tr>
<td>Medical Assistance Benefits for Workers with Disabilities (MAWD)</td>
</tr>
</tbody>
</table>

Participants’ ages of disability onset varied and ranged from birth to age 45 years. A total of 11 (65%) participants first experienced disability between birth and age 17 years. Three (18%) participants first experienced disability between age 18 and 25 years and three (18%) individuals had disability onset between 26 and 45 years.
Table 6. Participant age of disability onset, by current age.

<table>
<thead>
<tr>
<th>Age of Disability Onset</th>
<th>Current Age</th>
<th>Number of Participants</th>
</tr>
</thead>
<tbody>
<tr>
<td>Birth to age 17</td>
<td>26 - 45</td>
<td>9</td>
</tr>
<tr>
<td>Birth to age 17</td>
<td>46 - 64</td>
<td>1</td>
</tr>
<tr>
<td>Birth to age 17</td>
<td>Age 65 or older</td>
<td>1</td>
</tr>
</tbody>
</table>

Total Age of Onset Birth to 17 Years Old: 11 participants

<table>
<thead>
<tr>
<th>Age of Disability Onset</th>
<th>Current Age</th>
<th>Number of Participants</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age 18 - 25</td>
<td>26 - 45</td>
<td>1</td>
</tr>
<tr>
<td>Age 18 - 25</td>
<td>46 - 64</td>
<td>1</td>
</tr>
<tr>
<td>Age 18 - 25</td>
<td>Age 65 or older</td>
<td>1</td>
</tr>
</tbody>
</table>

Total Age of Onset 18-25 Years Old: 3 Participants

<table>
<thead>
<tr>
<th>Age of Disability Onset</th>
<th>Current Age</th>
<th>Number of Participants</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age 26 - 45</td>
<td>26 - 45</td>
<td>1</td>
</tr>
<tr>
<td>Age 26 - 45</td>
<td>46 - 64</td>
<td>1</td>
</tr>
<tr>
<td>Age 26 - 45</td>
<td>Age 65 or older</td>
<td>1</td>
</tr>
</tbody>
</table>

Total Age of Onset 26-45 Years Old: 3 Participants

The majority of the participants’ reported their primary source of income as part-time or full-time employment, whereas the remaining participants’ incomes were SSDI, SSI or other public benefits. Several participants noted a combination of employment and public benefits as the way they meet their costs for daily living. One participant reported being self-employed/being a small-business owner.
Table 7. Primary source of income

<table>
<thead>
<tr>
<th>Income Source</th>
<th>Number of participants</th>
</tr>
</thead>
<tbody>
<tr>
<td>Part-time employment</td>
<td>6</td>
</tr>
<tr>
<td>Full time employment</td>
<td>6</td>
</tr>
<tr>
<td>SSDI/ SSI</td>
<td>8</td>
</tr>
<tr>
<td>Other public benefits</td>
<td>3</td>
</tr>
<tr>
<td>Combination of employment and public benefits</td>
<td>5</td>
</tr>
<tr>
<td>Self-employed</td>
<td>1</td>
</tr>
</tbody>
</table>

Several challenges to maintaining financial stability were noted by the survey respondents, some of which included:

- Being able to save and anxieties around running out of money before they die.
- Being able to work in their dream occupation, or finding and maintaining employment and receiving adequate wages, and anxiety about their disability affecting their ability to maintain long-term employment.
- Opportunities to access affordable housing.
- Unmanageable debt.
- Having to divest their retirement savings to a Special Needs Trust (SNT) to receive medical insurance and other medical assistance.
- Lack of educational qualifications needed to secure a better or higher paying job.

Finding and maintaining employment is one way in which individuals with disabilities have an opportunity to establish financial stability and maintain financial health. While many note the challenges associated with finding employment, several individuals also reported that maintaining employment came with particular challenges for those living with disability.
For the most part, the challenges enumerated relate to workplace practices that do not accommodate individuals with invisible disabilities and include being paid lower wages, technological challenges that are incompatible with assistive technology, a lack of opportunities for non-neurotypical individuals and inflexible work schedules.

The participants noted several resources and strategies that have been helpful for finding and keeping a job as follows:

- Opportunities to network, volunteer and engage in leadership and skills-building activities.
- Access to mental health therapy and resources.
- Hybrid, remote/work-from-home, virtual and flexible work opportunities.
- Accessible workplaces and information sources.
- Access to grants, including education grants.
- Access to resources via the Family and Medical Leave ACT (FMLA).

While a few noted that their path to financial stability has included further education, all noted myriad challenges navigating the education system. While money was the primary challenge, a lack of accommodations, of disability-focused educational supports (including flexible attendance policies) and disability-informed education staff, were cited as major hurdles.

Conversely, loan forgiveness programs for individuals employed in public sector or nonprofit organizations were denoted as a major resource. Other resources delineated as helpful for achieving an education as an individual with a disability included: access to online, asynchronous education, including the availability of e-textbook resources; having a strong social support network, including education faculty and staff; and access to public benefits and programs.

Of note, the Office of Vocational Rehabilitation (VR) was credited by more than half of the participants as a helpful source for several of the resources listed for both educational and employment supports, including funding and mental health services.
Major Qualitative Themes and Insights

Several themes emerged from the focus group discussions that corroborated and expanded several findings of the pre-listening session survey. Whereas providers spoke to the challenges they faced in serving individuals and families with disabilities, and provided recommendations for addressing some of these issues, the sessions with individuals and families offered important insight into the lived experiences and current realities for individuals living in the city of Pittsburgh and its immediate environs. A range of challenges and solutions were discussed across both groups, with both providers and individuals with disabilities describing converging experiences and ideas around the reality of living at the intersection of disability, race/ethnicity and poverty.

When asked to define economic independence, income and employment, ability to manage everyday obligations and plan for the future, generational differences in financial health behaviors and access to financial education supports emerged as the most salient considerations for participants.

The employment factors that were deemed necessary to achieve and maintain financial stability were noted as the ability to acquire resources while on public benefits, the freedom to work without losing public benefits, equitable opportunities for promotion, greater access to diverse jobs and job supports and employment that offers enough remuneration to meet current standards of living overall.

One interesting finding was related to generational differences in financial and health behaviors. For example, participants expressed that the current generation believes in having multiple streams of income or participating in “hustle culture.” This may mean that younger individuals with disabilities are more likely to be employed, less dependent on public benefits and more likely to have retirement savings.
“Multiple sources of income has been how I've done in the past. So, I'm also an artist. So, anytime that I've been struggling through my nine to five, I've usually had that as a second source of support, which has been nice. I mean, I have loans from school, I have a credit card. But yeah, usually it's having additional strings of income, which I feel, going back to the generation question, that's been a thing, especially this generation is having those multiple streams of income. Everyone's like the hustle culture, growing culture thing, which is not good. But I mean, it's kind of like, what are you going to do?” – Participant 13

Younger people with disabilities were also regarded as more trusting of banks, more apt to use financial technology and more likely to experiment with new tools and ideas. Despite this, younger individuals with disabilities feel that certain financial stability markers, such as homeownership, are out of reach for their generation.

“I feel like older people do not trust banks as much as young people do. We have Cash app and PayPal and Venmo as so many mechanisms. My grandma's like, what are you talking about? Girl, go to the ATM, get my money out. That type of thing. It's more of a cash exchange. Do I think... It's of equal importance for folks to get on the same page about it. But I do think times have definitely changed.” – Participant 15

“I have college debt. My credit card's still active, but they're pretty much maxed. Yeah, I know this is, I feel like generations and economic independence kind of keep swirling, but I kind of just feel like generationally we're all in a boat where we're just, those things are out of reach. Because even though essentially what it would cost to have a mortgage is basically at this point sometimes even cheaper than what it costs to make rent, is how do we even get to that point where it's like we're dumping all this money into properties that we don't own? That even just to get by we need these multiple streams of income. We need credit cards, we need loans, and it just feels like everything is going out and there's nothing coming back in. And so yeah, at this point it feels like, a lot of those things just feel out of reach. And it feels like it would be a literal miracle to be able to own property at this point.” – Participant 15
There are several intersections expressed in the data across themes and insights, provider and individual and family participants, and across sessions. Some of the more poignant relationships that are less frequently explored, related to financial inclusion, disability representation and disability access, via the following themes:

1. Financial Inclusion and Financial Health:
   A. There is a relationship between financial exclusion and financial health.
   B. There is a relationship between financial fragility in old age and being Black with disability.
   C. There is a relationship between financial inclusion and immigration status, cultural beliefs and being Latinx with disability.

2. Disability Representation:
   A. There is a relationship between disability representation and the high turnover in direct service providers (DSPs).
   B. There is a relationship between a lack of equitable employment practices and lack of access to benefits and long-term financial stability for people with disabilities.

3. Disability Access:
   A. There is a relationship between a lack of access to transportation and technology.
   B. There is a relationship between a lack of access to disability resources and being a person of color with disability.
   C. There is a relationship between language barriers and the language around access and a lack of successful policy reform.
   D. There is a need to redefine what “access” to disability resources means.

Financial Exclusion and Financial Health

Financial inclusion and financial health are invariably connected. It follows that a lack of financial inclusion has significant ramifications for individuals living with disabilities. An interesting finding that emerged from these discussions concerns the intersection of being disabled, elderly and a person of color with a lack of savings and retirement income.
“I’m currently working with seniors right now and just really saying, wow... I didn’t realize and seeing what the barriers are for them as well. There is that assumption that as people get older, "Oh, you've saved enough money to live on." Through all the reality instance and what I'm seeing, it doesn't matter if you're Black or white, but in particular with a lot of the Black seniors that I've seen so far, they don't have the means. – Participant 2

“You can't afford to get older.” – Participant 6

“This is where, I don’t know, I think it’s overwhelming for us... we were talking about with hyper localism and kind of getting that stuff done and then you’re talking about the federal level and it's like, isn’t this stuff bifurcated on purpose? Again, the social justice piece comes in. That's so important because it's done on purpose... I mean it's dealing with legacies here. You brought too about people that went through all these civil rights and now they're 80 years old and you're like, well why don't they have money? Well, what the heck? They were left out for 40 years.” – Participant 3

Access to financial technology is another barrier for individuals with disabilities. Advances in financial technology means that individuals with disabilities need to be able to navigate government, financial services and other business platforms in order to successfully participate in modern society. In failing to legislate requirements and/or make their own platforms accessible, participants felt that government was culpable in perpetuating this barrier:

“And the government has refused to force both state and federal government and businesses to make their websites more accessible to people with vision loss or with any disability. Whether it's a system timing out before a person can actually get more things done because it's so complicated or whether there are strobe things going on that would affect somebody with disabilities that can be affected by those flashing lights on the website or whatever. They just don’t pay attention. And the government has been way behind on that.” – Participant 2
While several participants noted having positive experiences with financial technologies, such as Rocket Money for budget tracking, and tout the benefits of being able to manage their own finances via various applications, some also find the technologies stressful for different reasons:

“I'll say it's mixed because it helps you but then also, you'll go on and they'll be, oh apply for this credit card or apply for this. So, I also find it’s theirs and taxing in different places.” – Participant 12

In a broader sense, many persons with disabilities are excluded from participating in the financial economy in ways that are vital to achieving and maintaining financial stability. Participants noted that a lack of access to credit, and mortgages in particular, a lack of understanding and trust of financial technology and a lack of access to a bank account, particularly for undocumented households with disability, are detrimental.

“So, if you don't have a status, you don't have the chance to go to any work. If you try to show to the government that you are going to the school, like the Dreamers for example, DACA status, you are trying to do everything in the right way, but it doesn't mean anything to the government. So, they don't have the right to go to open account in a bank. So, what happens is, for example, if you work for me, I don't have a status. I will take advantage that you don't have. I will open an account and you will make money lesser than I am doing because you are under my name account. I will take off the money, I will withdraw the money, and I will give you whatever I want. Because you don't have the right to open an account because you don't have ID.” – Participant 14

“You have a kid over there with autism diagnosis. You think in the future you want to buy a house maybe. Because what is going to happen when you pass away? Who is going to take care of your kid? So, you want them to be safe, at least economic, in some way. Like if they can’t have access later to some kind of benefits. But if you can’t buy a house, what is going to happen with the kid? Now he’s a kid, but later, he could be 30 years old. Who’s going to take care of a guy 30 years old?” – Participant 12
In addition, many participants personally related to having gaps in their financial knowledge, especially around investments and retirement savings. In tandem, existing financial literacy programs often do not target or cater to the needs of people with disabilities. A lack of financial literacy means individuals find alternative ways to save that do not offer them the benefits of being banked. These alternatives include participation in “personal lending circles” and results in the use of alternative and predatory lending services at higher fees and interest rates.

“But another way to save money that I am not, I don't even look at it, I don't even understand it. Let's be real, I don't even understand it. With work I have a retired, I have a 401k and I'm taking money out savings that way, and I'm maxing it out because some older person told me once, "Look, however much you could take out, you need to do that because life be, life is after. When you retire it's really important." However, I could assure you I know nothing. I don't know, I don't know. I know it is a deduction out of my paycheck. I know who like the company. But I don't really understand again, the financial terms, the long term, short term. If you pull in the percentages and I was a math tutor, I don't understand it at all.” - Participant 16

“Well, I was just going to say on that where I see that there are barriers in reference to yes, as I continue to see and know, there are so many programs that are popping up around financial literacy, but they're not, in my opinion. I mean, you don't want to just say, Hey, make sure you include people with disabilities. But at the same time, there could be some kind of language that would say all are welcome. But they would also have to be staffed to be able to meet some of those needs, not knowing what the needs are going to be. And I see those as being barriers. There could be, in my opinion, there could be more ways for people to be able to learn about financial literacy, what services are available out there if it was promoted differently.” – Participant 12

“I know in particular for my son and my brother and some of the families that I work with who have cognitive disabilities themselves, if they felt the spaces were more welcoming and there were people there that could help them, they would welcome accessing that information. Who doesn't want to say there’s so many people who have never been on a vacation? You know what? Because first of all, they don't know how to say it. If they can say, and there's not that welcoming door
Public benefits are often an important resource for individuals with disability and is a primary source of income for many. However, many participants noted that many people with disabilities face insurmountable challenges to accessing public benefits, ranging from an inability to prove their need for support, having too high income or working too many hours, as well as a general lack of education around benefits and public resources.

“I'm able to write, I'm able to speak, that be misinterpreted as me not needing assistance where they're like, you seem like someone who has it all together. What could you possibly need? And it's like, well, excuse me, because I'm able to do what you’re able to do means that I don’t qualify or I don’t need these services. And so that's always been an argument or a disagreement or a place of debate whenever it comes to what I'm needing because I know me, yes, I'm able to participate in class. Yes, I'm able to speak, yes, I'm able to advocate for myself, but here's the things that I need…” - Participant 15

“Actually, if we can go back to finances, I have sometimes a hard time... I can't qualify, I make too much quotations. I make too much money to qualify for any assistance with any of my bills. And I say quotations because just because I make the amount that I make doesn’t mean that that's taking care of all of my experiences and I still need assistance, so there's that.” - Participant 12

“I think that needs to be more education too and educating people about what their benefits are and what resources are out there. Because we deal so often with families who, they’ll call us about their loved one with a disability and honestly they're not sure whether it's SSI or SSDI. They don't understand how someone 30 could be receiving Medicare. There's these ideas that Medicare's only for old people” – Participant 13

“Or Medicaid is only for poor people... We do benefits counseling and really letting people know, okay, well you don't qualify for this benefit, but maybe this service can help you out. So if one resource doesn't provide for them, maybe there's another, but I think we need more organizations that can tie or more if ever, just more organizations that can guide people because one or two organizations out there can't help everyone.” – Participant 16
Many individuals struggle to acknowledge their own disabilities. In communities of color, however, disability is often not accepted, particularly invisible and mental health disabilities.

“[As a Black woman]... I think, for me, it's... I know I struggle with even acknowledging my disability at times because you feel like you have to push through. And I don't know the way that our society trains us to see disability as a weakness is like a personal failing.” Participant 18

“For example, I remember many times when my sister say to my mom, "I feel depressed." She say, "No, you don't feel depressed, you just need to do something else. Go to clean the rug room, go to do this. You have a lot of time. You are losing your time." I don't think we consider them as people with disability. No. We consider them people with difficulties. Like, for him, it's hard to do this. We will help him. But I have to say it in Spanish... It's nothing to do with you, your disability. No, we don't do that.” – Participant 14

Another interesting finding pertains to the relationship between financial inclusion and immigration status, cultural beliefs and being a Latínx with disability. This particular finding notes significant barriers related to accessing health insurance and public benefits, a lack of employment opportunities and a lack of educational opportunities, in addition to a language barrier. While these challenges are not unique to the undocumented Latínx community, these barriers are compounded by culturally embedded stigma and negative beliefs about disability and the risk of incarceration and/or deportation as directly related to being undocumented.

Undocumented Latínx families with disability often subscribe to negative beliefs about disability that are compounded by the negative stigma attached with being Latínx and considered “illegal.” In addition, the stigma in the wider Pittsburgh community that associates being Latínx or Hispanic American with being “illegal” immigrants, also impacts how disability services are performed. According to some providers:
“He’s going to be curing someday. It was my fault. It was like punishment because I did something wrong when I was a kid or something coming from my family. Or is my husband.” – Participant 11

“You were talking about the employment stuff too. I know they’ve talked about some of the credentialing and trying to make sure, again, if you are coming into Pittsburgh, that we help kind of build on those credentials or get you re-credentialed. Because again, it’s hard to do that. But yeah, it’s weird that we still go back to like, oh, I’m Polish, I’m Italian, I’m German, whatever, here. But you’re right. When it comes to Hispanic, it’s automatically like, "Oh, you're illegal."”
– Participant 12

“So as soon they seen you are Hispanic American, that means you are illegal.”
– Participant 14

Having a **language barrier** makes it challenging to receive services, even for children who are born in the U.S. to undocumented families and are legal citizens and entitled to those benefits.

“So when we start to receive people with kids with autism, they assume that something wrong has happened with the kids because they don’t make eye contact or they start to flip or they have some kind of behavior that doesn’t match with the age. So they came to Casa San Jose and say, "Is something going on with my kid?" But the problem, if you have a kid, even in your language, I bring your kid to the doctor or psychology or pediatrician and they say, "Okay, now he’s autistic." What that mean, autistic?” – Participant 12

“So it’s not easy. And as I say, we try to find the best way to help our family, but it’s too sad when I am calling every week the same 30 or 40 agency and no one is speaking Spanish. So they say, "No, we help someone who speak English." I don’t want just the kid learn. I need the mother, the parents, the siblings to learn how they communicate with the kid.” – Participant 12
The **fear of incarceration** brings with it a distinct disadvantage when interacting with law enforcement personnel, who often do not have foreign language interpreters on hand. In tandem, though often in dire need of public assistance, many fail to apply for benefits due to fears of being deported.

“But they are not easy. The problem is sometimes the parent, they don't want to apply for the benefits because they don't want to put the name, the address and everything. They don't want to take the risk. Because many times ICE say they won't look for that information, but that happened. It's the same system. It's a federal system. So they don't want to take the risks because again, if they catch the some day they are asking for asylum, and they are afraid if they appear in some paperwork, they lose a chance to have the status. So if you are open case in immigration and that is still not clear if that can play against you or that doesn't really matter when you ask for a status. So you don't want to take the risk.” – Participant 12

No legal employment, no bank account and no access to public assistance means these families are not able to achieve any measure of financial stability. These families also often fall prey to predatory or underground lending services that charge exorbitant fees to conduct financial transactions on their behalf. These factors together make it difficult for undocumented Latinx persons living with disabilities to meet eligibility requirements for residency or qualify for an adjustment in their status.

It follows that many families with disabilities are **negatively financially interdependent**. Participants indicated that this interdependence makes saving difficult, prevents them building credit and launches un(der)resourced biological families into untenable financial positions resulting from needing to foster their relatives.

“I feel like my family is more in the negative way, economically interdependent. Usually if one of us is doing well, someone else is needing some extra cash here and there, and so it's really hard, one, to make savings, but also to have money month to month that you can count on that's going to be there, because sometimes someone's going to have an emergency that's going to take away from that. I think the only strategies that have worked for me in the past is having things
on an auto draw. So, if I make the time to set it up to where everything's on autopay, I don't have to think about it. That's been the only way that's been effective in terms of saving money. But again, recently I haven't been able to do that to make sure that I can support my family.” – Participant 13

Providers described the lack of financial autonomy experienced by their clients who control their finances:

“And sometimes that has to do with their family situation. I've had clients who's, this is a foster child with eight other siblings and their family is really involved, but at times too involved where they really don't have a lot of autonomy in the choices. Or on the other side, maybe their parent is a little bit more absent, but still has a lot of the say in the situation. Or maybe they take control over the financial situation. And so as young people who are just entering the work force who are some trying to make their own income, it's really difficult.” – Participant 14

One participant noted that she is unable to build credit as her cards are in her sister's name, which also leaves her with unexpected liabilities:

“I have a debit card and I have a credit card, and they're both in my sister's name. So when I decide to spend my credit card, they automatically know just by the spite of it, and then they'll notify me before my next payment. I had to get another credit card because all the bills that were transpired, I called them and I said, "I didn't purchase this, that, and the other." They didn't know what to say. And I said, "You and I could fix this, because if you want me to be a loyal customer, and an honest customer, you're going to have to fix this," which they did. They sent me a new credit card. I use a little bit, but then I just save it for a rainy day.” – Participant 11

Another described the challenges associated with families having to take on added responsibilities to foster relatives with disabilities:

“I would say where we're seeing the most financial challenges is for kinship families, which are, research is shown that additional layer of trauma where when a child is taken and put in a stranger's house. So there's a huge push to put them in a kinship situation, which is either a relative or a known family friend. Something that is more familiar. But where we see those differences is that foster
families make a decision to foster. They spend time under training, they prepare for this. Kinship families receive a call that says, ‘If you can’t take your grandchildren today, they’re going into the system.’ And so we have an 80-year-old grandmother who comes in with three kids under five who’s just doing her best to keep her family together, but does not have the resources to provide for them. And we’ve had to develop a food pantry because our families needed food so badly. And so those families who are just trying to do their best for another family member that might be in crisis are really unprepared to take on the financial addition that that is.” – Participant 14

Disability Representation

Disability representation is a multifaceted issue that is often characterized by underrepresentation across several spheres, including employment, research, service provider personnel and Black, Indigenous and other people of color (BIPOC) issues. Two areas emerged as particularly interesting in this study: the high rate of turnover among DSPs and the relationship between inequitable employment practices and long-term financial fragility for individuals with disabilities.

Individuals and families with disabilities often relay heavily on DSPs to assist them in navigating a world that is not designed to accommodate them. Unfortunately, low wages result in a high rate of turnover for DSPs who support individuals with disabilities. This further complicates the issue of a lack of representation among DSPs, which is a deterrent to individuals accessing these supports, particularly for people of color.

“What I will say is I’m just going to be straight up. One thing that can’t happen that should happen is people have to be hired that look like the people you serve and that’s one thing that, that’s one thing that we talk about. We don’t walk it unless somebody pulls you to the carpet to say... and you wonder why people don’t come. You don’t hire people that look like them. They are the best people that can talk you into sometimes that you need. We don’t walk it unless somebody pulls you to the carpet to say... and you wonder why people don’t come. You don’t hire people that look like them. They are the best people that can talk you into sometimes that you need.” – Participant 12
Inequitable employment practices extend beyond DSPs to the individuals they serve, and this has perpetuated long-term financial fragility for all involved. **Discrimination in employment** takes many forms, all of which negatively affect the financial and emotional stability of people with disabilities. Many individuals choose not to self-identify as a person with disability due to fears of discrimination.

“But it's not something that I've made them aware of and I don’t even know if I put it on my paperwork because you’re just wary about... even when you’re applying for a job, I don’t want to be nobody's check box, right? Sometimes I may decide not to even put that I'm Black or I may not decide to put it with disability because sometimes that's just life with the job because they don't have that in their space sometimes.” – Participant 18

“I think it comes down to education because I know if my mom works in the medical field and she was the first person who would say, don't check you're disabled on any documentation because that will give people a reason to fire you and not hire. I’m going to hire you because even if they can't ignore you because you're Black, once they find out you're disabled, that will be the ease and so I think a lot of education has to be done.” - Participant 16

A wage gap also remains between workers with disability and workers without disability. Access to employer benefits, and equitable opportunities for promotion and tenure, are also a challenge for many workers with disability.

“I would say, for my job, I make under 60 and I have two graduate degrees and it is very hard to get a livable wage, and so that is something that happens, and then also to have a job that covers medical benefits is difficult, because some places will give you a wage, but not the health insurance or health benefits.” – Participant 15

“You purposely keep people from achieving raises. And then once... Because if you stay under a certain, I guess a salary cap so to speak, in employment pool, you're automatically exempt from paying out X, Y, and Z in terms of benefits and all these other superfluous things that come attached to your paycheck.” – Participant 3
Individuals with disabilities also encounter additional system issues that affect their ability to fully participate in employment and/or earn enough to be financially stable. Many make employment decisions based on their ability to maintain benefits. People with disabilities are also disproportionately affected by COVID-19 and long-COVID and some regard the COVID vaccine mandate as a barrier to employment. The participants noted that Black individuals specifically suffer this fallout due to pervasive mistrust of vaccines.

The high costs of care for persons with long-COVID, in addition to the lack of uniformity around practices for diagnosing the condition, are especially challenging for people who can no longer work or are forced to work reduced hours, yet are not able to access benefits without a medical diagnosis.

“COVID has shifted so much and people still fighting with long COVID. That is a conversation I don’t think that enough attention gets paid to it. And I always talk about the one lady who worked for Netflix, she was the executive Netflix who killed herself over long COCID. She had... Because of insomnia and her... Yeah, she couldn’t sleep for three weeks or something like that. And her senses never came back. They never came back. But yeah.” – Participant 12

“I don’t know if this is completely relevant or even a major issue, but one of the other barriers that I think is relevant now what hasn’t been is most employers are mandating the COVID vaccine. And a lot of people within the population that I serve, whether it be Black people, old people, it doesn’t matter, don’t want to be forced to get it. And that’s a big issue of getting employment and having your own income is being required to get the vaccine. Now I always say it’s not my place what to do with your body in the state of the world. I do think that my opinion aside, people aren’t choosing to get jobs that require the vaccine and that has been an issue for them getting hired.” – Participant 13

“The Black community like mistrust for the...[vaccine] 100%. But it’s very complicated now that employers are requiring it, that that’s an added barrier that wasn’t there pre-pandemic.” – Participant 10
Redefining Disability Access

The relationship between accessibility and financial health is well established. As such, a major recommendation from the discussions entailed reframe the strategies and language around ‘access.’ A lack of access to transportation has ramifications across opportunities for employment, education, medical care and community engagement, which are all important to establishing and maintaining financial health and wellness for individuals with disabilities.

Access to transportation remains a major area of challenge for individuals with disability living in Pittsburgh:

“It is true because Pittsburghers ride the bus three times higher than the national average. People say, I have to go two bus stops up. So there’s a spot.”
– Participant 5

“We know resources exist, but people in the community specifically the disabled, [live in parts of] Pittsburgh ...that is [not] public transportation friendly. There's really not a culture of public transportation here. And as it's always the first thing cut from Department of Transportation, their budgets [are] always cut. Bus routes have been reduced. I've been in Pittsburgh now 11 years and I think that the bus has run less and less and less over the years that I've been here.”
– Participant – 7

By extension, individuals living at the intersection of disability, race/ethnicity and poverty experience even greater challenges accessing public transportation. Participants spoke to the disparities in access in poor communities of color versus affluent suburbs. The discussion also explored the impact of gentrification and the plight of those who are forced to relocate to new areas that are inaccessible to public transportation and how this negatively impacts their ability to navigate new physical spaces, as well as new social space, including an unknown and often insulated job market.
“... And it is the inequality of access, again in Pittsburgh. It's not obviously by my accent, I'm not from here, but it's very difficult to get from one end of the city to the next. Extremely difficult... that makes the location of those resources infinitely more difficult to identify. It's no longer in areas that Black people are familiar with.” – Participant 4

“And specifically the gentrification has been this theme of Pittsburgh. What areas provide access at what rate and to which demographic of people. And there's a staunch difference. If you go to the affluent suburbs, everything is accessible. There's resources. And this is an aspect of safety. People think of safety as policing and all these different things or whatever it looks like. The communities that are the safest of the communities are the most resources. Whether this means mental health, whether this means disability access, whatever this means, access to grocery stores, Pittsburgh's food desert problem is wild. And that can be related to a whole bunch of different things. I don't want get into that rabbit hole, but so safety, disability and racial identity tend to become these very violent, but unfortunately compatible bedfellows when it comes to making this perfect storm of inequality in Pittsburgh. – Participant 8

“You have people who, because of how gentrification works, and I'll spare you all the socioeconomic lesson, but if you're in Pittsburgh for your whole life and you, the area you were living in was bought down ... and you're relocated 45 minutes outside the city, what are you going to do? Ready? It's a whole new world. Most people were taken to Jeanette. I don't even know the hell Jeanette is. I just know it's far. I just know you can't take, even if you could take Pat bus, you're not taken prior from there though. I do. That's what I know about Jeanette is a phenomenal athlete. The rest of it is just like that's, you have all these recent Black people that were placed in the middle of nowhere with no access to anything. No familiarity with the landscape, no familiarity with the job market. Cause in our community you get job cause you know somebody... It's communal. When you describe the communal aspect, and again, that's cultural competency, right? That's not factored into it, but again, it's that overarching aspect of it. You know what I mean? There's a divisiveness that is very well strategized and placed into it and it's like this really terrible system that we all kind of navigate through." – Participant 6
There are ongoing efforts to alleviate the transportation challenges, including the Carnegie Mellon University Metro21 Smart Cities Institute demonstration project that is assisting low-income, single mothers with special mobility needs living in Allegheny County to access Uber and Lyft rides. However, participants note that these efforts, though they may point to addressing a larger policy issue in future, are inadequate for meeting the needs of the broader disability population and is only one area of transportation access.

In addition, transportation access is a broader issue that entails considerations for access to technology, as well as access to driver’s licenses and other unique challenges faced by individuals with invisible disabilities:

“And the places where those resources were once made available no longer exist. And if they do exist, they moved to some places even more than difficult to find. So that’s one thing. Like ride-sharing can be expensive... And then the means of if you are taking public transportation downtown being your junction point, but that doesn’t work like that in the city.. That makes things very difficult if you’re a disabled or differently abled person. Even mental health access, there’s a lot of things here that just don’t take into accountability that people with invisible illnesses or just things that you can’t see aren’t properly attended to because of the lack of the financial support of these resources or the, I guess the overinflation of them.” – Participant 2

Participants noted that access to transportation is often predicated on access to technology:

“Because access to transportation is a huge, huge issue. And it’s not just as simple as monthly is a $100 or so, it’s just how do you find where to get a connect card, and how to reload it if you don’t have access to transportation or Wi-Fi. Buying one every time, do you have the money to pay for a weekly, and that’s extra money if you don’t have a card to reload? Where are the bus stops?” – Participant 3

“I’m thinking about one kid in particular that I’m working with who his main barriers are access to housing, access to transportation, access to Wi-Fi. And when he’s trying to access his bank information, he is kind of stuck because if he can’t leave his house, he lives in Duquesne, PA, which you’re not going anywhere. I mean your buses are so limited.” – Participant 3
“If you don’t have technology, if you don’t have your own phone, or have service and it can only work on Wi-Fi, you cannot track your bus. And it’s a lot of the times inconsistent. And to being out there by yourself alone on a bus stop, maybe you’re downtown, that could be potentially very unsafe for you, and anxiety inducing for sure. And so there are programs through OVR that I think are very beneficial, but then there’s that added layer of the service fatigue, and service providers not even knowing what they can and can’t do.” – Participant 2

The discussion pointed to some of the challenges involved with accessing public transportation, including being welcoming to service animals and emotional support animals.

“It is true because Pittsburghers ride the bus three times higher than the national average. People say, I have to go two bus stops up. So there’s a spot.”
– Participant 2

“I can’t speak onto that, but one thing I know a friend is dealing with specifically is ESAs the difficulty of obtaining an emotional support animal. And I know she lives in a building where she had to get additional paperwork. And again, I don’t know how this necessarily ties in, but I know not all public transportation welcomes ESAs. I know that for a fact.” – Participant 5

Some participants felt that there is an overemphasis on physical access to the neglect of other areas of accessibility that are equally important for financial inclusion. This observation is encapsulated in the following quotation:

“And I just wanted to, as you said, physical and it kind of nerves me sometimes, whether it’s a family member or working for a provider, oftentimes we’re so stuck on physical accessibility. And we’ve talked to the mayor about this. It has to be across disability that we’re talking about. We’re talking about across disability, how it affects people across disabilities. We can’t continue to get stuff all physical yes, that is important. But more and more we’re seeing people who have disabilities, whether it’s visible or invisible. So how do we continue to change the language when we talk about it.” – Participant 4
A broader discussion of access must necessarily include expanding opportunities and eliminating barriers. This may include meeting people where they are, including in their homes, as well as making resources available at times when individuals are free to use them.

“...And our community can recognize that resources exist, but they don't have the pathways or the resources that access... to access these resources. So our organization and a lot of the things we do is try to knock down those barriers. Try to find institutions and organizations who maybe can provide mobility towards the access for said resources. Whether that's, you know? We paying for ride-sharing, or we're paying for these resources to come to these individuals at their homes or whatever the place of residence is. Or having a localized place in conjunction with other community organizations. Be that ... in a way of a fair or something like that where we can make resources accessible to everybody at the same time and in a long window.” – Participant 3

Any lack of mobility, including not having a driver’s license, can perpetuate financial dependency on public supports as this often decreases the options to engage in full-time employment:

“I was just working with a woman today who's in her mid-fifties, has a stable job working for a local hospital, but... [is] looking for additional options, but she wants to become a CPS... Well, for that job you have to be full-time and you need a driver's license. Two of the biggest barriers for people with lived experience, and that's a job that she's literally unable to do as a Black woman in her mid-fifties who's grown up, lived on the hill and relies on her public transportation and is casual working 16 hours a week so that she can keep her disability benefits and only make about a $1,000 dollars every month or so, you know. She's been really struggling because she wants to do the work, be people with lived experience being in social work roles as a CPS. That's the point of CPS. You would need lived experience, but those are unattainable jobs for people with barriers who have lived experience [for whom] full-time employment, [is] not an option. [And] driver's license [is] very much different a barrier.” – Participant 3
Improving access for individuals with disabilities must also include **building advocacy and support and partnerships** around mitigating employment and other barriers. This must include incentivizing and increasing the DSP workforce and stemming the attrition that continues to negatively impact people with disabilities.

“All agree totally... direct support professional work, they’re not paid well. A lot of this stuff starts at the federal and it drills down at each and every level. And when we think in terms of a decent wage, people need to be paid a decent wage or they’re not going to be anybody to be able to support the people who really need it. And I said DSPs supports coordinators, service coordinators. As a family member, I deal with that as well as working with families or working with seniors. I continue to see the same thing. When people really need the help, people aren’t there. And people have said plenty of times they’re not paid well. So there needs to be policy change at all levels and also an increase in pay. There also needs to be policies in place.” – Participant 11

Building advocacy and support partnerships means allying with disability champions in the legislature and establishing a network of services and service organizations for people with disabilities.

“We’ve got to continue to build champions. We talked about our legislators. It’s not just people with disabilities. It’s not just advocacy organizations. I say that we got to start reaching out to the people we haven’t reached. Oftentimes, we so ourselves and we continue to preach to the choir, if you will. We can’t continue to do that. That’s got to be policy change at all levels and also an increase in pay. There also needs to be policies in place.” – Participant 11

“There has to be policies put in place or people will never do it. They’ll continue to say, well they won’t come. And it goes back to again, either building champions changing policy. And again, we can’t stop at one level. We got to turn to policy at all levels.” – Participant 8
“Resources are a lot shorter now. But we need to continue to figure out for agencies, organizations in general that help to support people. How do they continue to get that funding? And it may have to do around policy change, it may have to do around figuring out how we create more partnerships with legislators and getting those stories out.” – Participant 10

More specifically, participants felt that these advocacy efforts must influence policy changes toward ensuring **fair wages and increased hiring** of people with disabilities. Another recommendation was made to consider a **social workshops approach** to employing people with disabilities, where persons are paid for completing a project or item versus by the hour.

“[Implement a] we won't discriminate policy, if you will. There needs to be policies that clearly state that they will hire more people with disabilities. They will give them a good wage. That's another thing that I think really needs to happen. And again, it's not just, we think about federal all the time, but it always trickles down. Right... And then people were able to pass the buck. Well, it didn't happen at the federal level cause we're not, so we're not going to do it. We've got to hit every level.” – Participant 7

“This is, in my mind, should be illegal for an employer to have an entire pool of people who are not eligible because it should not be based off of casual pool. It should be like, I know it's super complicated, but that is one thing that has been such a major issue is that this is a career job at the largest employer in Pittsburgh and they are not eligible for benefits.” – Participant 8

“What I say about that, that is a policy thing. Just whoever the employer is, right? Right. Yeah. That should a casual pool or something like that be, right? It kind of goes back to social workshops, right? Yeah. It still exists in some places, which is where individuals with disabilities were paid by the piece versus the hour and so very sudden from each. So that is something that we might want to look into as well. When it comes to, I don't know if there's. That is something that we might want to look into as well when it comes to employment. I don't know if there's a lot of people with disabilities in there. Probably. - Participant 5
Change vs. Progress

Several policy recommendations were suggested by the groups to focus on making tangible progress that positively affects the lives of people living with disabilities versus simply ‘making changes’ that have no material impact. While participants gave credit to the disability resources available across Pittsburgh, Allegheny County and even the state of Pennsylvania as comparatively better that those offered in other states, most felt not enough was being done toward advancing financial opportunities for people with disabilities.

The following quotes offer a critique of current approaches being undertaken in the city of Pittsburgh as an example of how change does not equal progress, but instead hampers the lives of people with disabilities:

“Pittsburgh is a city that loves to masquerade as a progressive city. Pittsburgh likes change. They do not like progression. They love when things change…. Oh, they love that. They love gentrification. They love kicking [B]lack people out of places and putting Black Lives Matter signs up in place of the residents that used to live there. They like saying that we have a handicap route, but my building has handicapped parking, but no handicapped ramp. And actually the handicap ramp leads [to] the steps. And for a city, such as Pittsburgh, that say they’re stronger than hate don’t lie to me. Because that’s hatred right there. If you’re literally leading a handicapped person to steps, there’s nothing else but hatred right there.” – Participant 1

“That’s literally the issue with my building. It’s like you have handicapped ramps that lead to steps….And then you have to carry that person up. How dehumanizing is that? And that leads back to the things do you feel that you have worth as a human being in this city? Globally, of course. But we’re in Pittsburgh right now, so I’m talking about issues in Pittsburgh. Without this, what does that lead you to? And then that turns into a whole mental health discussion.” – Participant 3

“And again, I think that’s the thing that we’ve seen as a coalition, that people are just checking boxes and they’re saying things and it’s not... We listen to people and we’re not hearing this. This isn’t what people are saying. This is no lived reality.” – Participant 2
To mitigate ineffective providers underscored the importance of basing solutions for progress and bettering the lives of individuals with disabilities on actual lived experiences, as well as the importance of stakeholders coalescing around meeting real needs.

“But it is really trying [to] bring in together this intersectionality of all of these things though. And again, even what you guys are talking about, I work a lot with banks, but it's also the healthcare providers investing alongside the banks on these things.” – Participant 2

Revisions to asset and resource limits is perhaps another area of progress that is necessary for individuals with disabilities to advance financially. One provider noted that, if the goal is to alleviate poverty, then the system must change. Another articulated the concern of outdated asset and resource limits this way:

“...it seems like one of the over overreaching or overarching problems is on some federal level, even with people get paid in social security or SSD each month, I don't think that amount has changed much in 50 or 60 years. So for now, for an individual who SSI is like, what, $800 a month, how can you live on it? Like we said, how are you going to pay your rent and have transportation? Right? So on a federal level, those numbers seem to need to go up.” – Participant 12

One other participant related this personal experience:

“Clearly if you need them you can't work sometimes. So I mean that’s the whole problem right there, is resources. Can I say my relationship? So my dad is, he was forced into early retirement for health reasons, like strokes and that. He came from working and every day the old school mentality of someone who’s born in that era has, my dad’s been on a fixed income now, almost half of my life now. And he can’t drive. He’s not allowed to have a driver’s license anymore, cause seizures and strokes. So he’s really just at the mercy of what he’s given monthly. My mom passed a couple years ago and she was also a disability. So it's like they were supporting each other with fixed income and it's not feasible. I think you said about the SSI not being the same or being the same 50 years. My father lived by himself, but can't live on $500 or $800 a month. – Participant 10
Disability as an “Other” Issue

Another key issue identified concerned how lawmakers view and respond to disability issues. Participants felt that disability access is regarded as secondary or an “other” issue that policymakers are sometimes reluctant to add to their list of causes:

“Lawmakers and policymakers look at disability access and look at these things, and they think of it as other. ‘Well, I’m already dealing with civil rights. I’m already dealing with trans rights. I’m already dealing with gay rights. I’m already dealing with this. The last thing I need to look at is people who are healthy,’ air quotes and that for the sake of recording, ‘Who are bitching and moaning about not having access to these things.’” – Participant 3

Providers noted that disability issues are often approached at a “hyper local” level, versus a broader policy level where action can be taken legislatively, as legislators are often not responsive to the plight of individuals with disabilities. The proposed recommendation is to continue to introduce disability issues on a human and local level first where it can be transformed into relevant action, then subsequently introduce these issues at the legislative level where broader impact can be initiated.

“So, when you make people aware of it, how it immediately impacts them, ‘Hey, this is a deaf voter. This is a blind voter.’ If politicians don’t care about anything else, they care about votes. They care about votes, and they care about where their campaign contribution is coming from. Making it relatable on that level, even if it’s not the most magnanimous gesture. Because all politicians are tragic. No matter how much you like them they’re going to let you down eventually. It’s the nature of politics. You can’t please everybody. Introducing something like that on a human level, hyper-local, making politics local, making it feasible, making it tangible, then you start to introduce legislation. Then after legislation happens, then you can take it to the next step.” – Participant 3
More Discussions Needed

At the risk of sounding cliché, the provider participants concluded that more discussions were needed, specifically for the purposes of bringing organizations together that serve underserved and minority groups to develop map disability resources, such as grants. The groups noted that these discussions must include individuals living with disabilities and their families who can give accounts of firsthand experiences with these systemic and pervasive issues.

“I’m thinking about that even from my perspective too, because I identify as a young social worker and within that identity, I also have to take a look that I’m a young, white, privileged woman and I even feel, I know the importance of asking about stigma, but I personally don’t even feel comfortable talking about that because I think it should come from the people. I think that if I’m going to describe the stigma, it’s not going to be as... It’s really meaningless coming from me. And my perception of lived experience. It has to come from that.” – Participant 5

These discussions should also deliberately target individuals who are not primary stakeholders in the disability experience and may not be aware of the issues faced by disabled individuals.

“And I think sometimes we even find in our organization, and [name redacted] said the same thing. Sometimes you are preaching to the choir. Sometimes we have webinars every month and it’s a lot of the same people, which is fantastic. So how do you reach... Because I'm not defending other people, but sometimes people don’t know what they don't know. So sometimes the people out in the suburbs don't even know that there's a crisis in the city of Pittsburgh because they go to work there, they go home, maybe.” – Participant 7

In tandem, the participants expressed the double-edged sword of needing to continue these discussions, but also being research-fatigued. As such, the groups noted the importance of researchers, funders and stakeholders hosting these discussions to be intentional in acting on findings.
“It’s a linear thought process. But if you’re having a conversation about inclusivity and the aspect of preaching to the choir becomes kind of like Occam’s Razor in a sense. Cut through the middle, how do you get to the solution around policy and all of that, having sessions like this, these listening sessions are extremely important. But they only become important when it depends on who’s listening. With our communities, we’re the most surveyed, we’re the most studied the most analyzed with the least progress or the least support around it. So people from our community stop coming up.” – Participant 1

“It's dehumanizing. I don't want to have to have a conversation every day with CMU or PIT or one of the universities that hits my emails, ‘Hey, we want to do a study.’ For what? Shit is [curse word redacted] up everywhere. The end. If you’re not going to give me a solution, just go ask somebody else. If you’re not going to break me off with some of that $30 million you just got, then what are we having a conversation about really? Is it about how you want to feel better about listening to people with access needs? Okay, I'll find someone that acquiesce you. But at the same time it's like, where's the intentionality of it? What are you going to do about it?” – Participant 3

Participants noted that the best way to communicate with individuals with disabilities involved the following:

- Meet people in social spaces where they converge.
- Ensure reciprocity.
- Utilize diverse media, including social media and culturally based outlets.
- Offer financial literacy as part of the school curriculum.
- Engage individuals through provider and community organizations, including the use of financial inclusion communications tools.
- Deliberately target and include people of color.
- Ensure accessible resources, including human resources.
- Provide information from the point of view of persons with disabilities versus from the provider point of view.
- Address the realities and challenges of living with intersecting identities throughout research, program design and program implantation processes.
Conclusion

The disability landscape remains a complex and nuanced space and one that continues to inadequately ensure that people with disabilities have equitable opportunities to establish and maintain financial stability. Despite the many challenges however, there are existing supports in the Pittsburgh, Allegheny County and offered by the State of Pennsylvania that stem the tide of all out financial ruin for many.

Participants agreed that a combination of supports are required to support people with disabilities including: access to a menu of curated services, people supports (family, colleagues, counselors and coaches of various sorts, social groups), access to grants and other financial support, access to therapists, social workers, and care coordinators; employer-provided benefits, community supports, including a culture of financial health, alternative public supports (such as state disability pension plans), communication supports, education supports (accommodation supports, financial education supports and technology access); financial education and inclusion (resources to build credit, access to credit, neurodiverse financial counseling and other assistance); deliberate outreach to underserved populations including responsive, wrap-around services for immigrants and their families; transportation access; and communication supports.

One poignant finding from this project involves the idea of building a culture of financial health from the community level. One provider described it this way:

“I'm one of those people who I want other people to be able to have access to it. Not necessarily my money, but to build a culture around it where it's like, If I can't give, you should be able to bring your friend or refer a friend to get in that same space. Who wants to be a part of a community where you're alone? I don't like sometimes being the only person at the table saying some of the stuff that I have experienced.... I think that I should be able to refer for somebody to get on the same path. Everyone has their own path, but have some of the same resources that I've had because there's always just certain qualifiers that really... I don't know, puts somebody in a different category.” – Participant 11