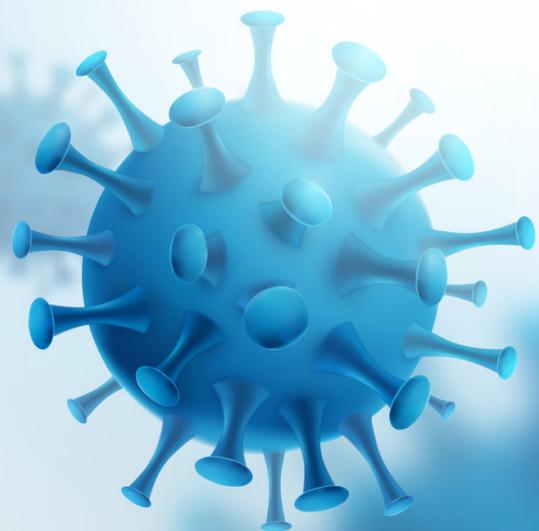


The Impact of the COVID-19 Pandemic on Future Financial Planning for People with Disabilities



A Supplemental Report
to the National Study of
Future Financial Planning
For People with Disabilities

*Prepared by the
National Leadership
Consortium*



The National Leadership
Consortium | on Developmental
Disabilities

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Organizational Mission

The National Leadership Consortium provides quality, values-based training, technical assistance, research, and evaluation aimed at developing the skills, knowledge, resources, and networks of leaders so that organizations and systems can best support people with disabilities to direct their services and lives and fully belong in their chosen communities.

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INTRODUCTION

People with disabilities and their family members have historically experienced financial exclusion which has affected their ability to engage in future financial planning.¹ People with disabilities and their families experience more financial hardships to earning and maintaining money, making financial planning even more important for this population. Despite great strides in recent years to support people with disabilities in gaining independence, choice, and control in their lives, the current financial status of this population remains bleak. People with disabilities are twice as likely as people without disabilities to have an annual income of less than \$35,000.² Similarly, nearly one-third of respondents of a recent study had an annual income of less than \$25,000, which is well below the estimated living wage needed for a single adult in most states across the U.S.³

Economic exclusion⁴ affects family members of people with disabilities too, as the financial demands of caring for a person with a disability can make saving and financial planning nearly impossible. For example, the cost of raising a person with an intellectual disability like autism over their lifetime has been estimated at 1.4 million dollars in the United States.⁵ A recent survey revealed that 45% of family member respondents claimed they or another family member provided monetary support for their family member with a disability, and almost 25% of family members said they were not prepared to handle the needs of the family member with a disability in an emergency.⁶

The COVID-19 pandemic has exacerbated the financial hardship and exclusion of people with disabilities and their families. Underemployment or lack of competitive employment is a well-documented problem among people with disabilities and their families.⁷ However, the pandemic has made it even more difficult for people with disabilities to find meaningful employment, and many who were employed have experienced changes in their work hours or duties, causing anxiety and frustration.⁸ The pandemic has also limited access to necessary services and supports that were already traditionally difficult for people with disabilities to acquire, particularly those from minority and underserved populations.⁹ These negative financial impacts, and many others, create an even more financially unstable environment for people with disabilities to plan for their futures

- 1 For more information about future financial planning, review our white paper at www.natleadership.org/publications.html
- 2 National Disability Institute. (2018). The Financial Challenges of Disability. <https://www.nationaldisabilityinstitute.org/lwp-content/uploads/2018/12/finra-infographic.pdf>
- 3 National Core Indicators (2021). NCI At-a-glance, 2019-2020 Final Report. Cambridge, MA: Human Services Research Institute. Retrieved from https://www.nationalcoreindicators.org/upload/core-indicators/NCI_201920_AAGreport_Final.pdf; Glasmeier, Amy K. Living Wage Calculator. 2020. Massachusetts Institute of Technology. livingwage.mit.edu
- 4 Economic exclusion is defined by processes and structures that prevent people from fully participating in the economy and limit access to benefits of economic involvement and inclusion. According to Greene and colleagues (2016, p. 2) “[Economic exclusion] occurs when people experience acute economic disadvantage over an extended time and results in an inability to improve one’s economic circumstances...”
- 5 Saunders, B. S., Tilford, J. M., Fussell, J. J., Schulz, E. G., Casey, P. H., & Kuo, D. Z. (2015). Financial and employment impact of intellectual disability on families of children with autism. *Families, Systems, & Health*, 33(1), 36-45. <http://dx.doi.org/udel.idm.oclc.org/10.1037/fsh0000102>
- 6 National Core Indicators (2019). *NCI At-a-glance, 2017-2018 Final Report*. Cambridge, MA: Human Services Research Institute. Retrieved from https://www.nationalcoreindicators.org/upload/core-indicators/NCI_AtAGlanceReport_1718_Final_May2019.pdf
- 7 Gildea, C., Bailey, C., Eidelman, S., & Sticinski, V. (2021). *Future financial planning for people with disabilities: What’s working and what’s not*. National Leadership Consortium on Developmental Disabilities. www.natleadership.org/publications.htm
- 8 Maroto, M. L., Pettinichio, D., & Lukk, M. (2021). *Working differently or not at all: COVID-19’s effects on employment among people with disabilities and chronic health conditions*. Center for Open Science. <https://10.31235/osf.io/yjfs>
- 9 Jesus, T., Bhattacharjya, S., Papadimitriou, C., Bogdanova, Y., Bentley, J., Arango-Lasprilla, J., Kamalakannan, S., et al. (2021). Lock-down-related disparities experienced by people with disabilities during the first wave of the COVID-19 pandemic: Scoping review with thematic analysis. *International Journal of Environmental Research and Public Health*, 18(12), 6178. MDPI AG. Retrieved from <http://dx.doi.org/10.3390/ijerph18126178>; Pineda, V. S., & Corburn, J. (2020). Disability, urban health equity, and the Coronavirus pandemic: Promoting cities for all. *Journal of Urban Health*, 97(3), 336-341. <https://10.1007/s11524-020-00437-7>

To further investigate the impact of the COVID-19 pandemic on future financial planning for people with disabilities the National Leadership Consortium on Developmental Disabilities was funded by the May and Stanley Smith Charitable Trust to study current experiences of people with disabilities and family members of people with disabilities and develop recommendations for the field. The project began by interviewing people with disabilities and family members of people with disabilities across the nation to learn about their experiences and perspectives related to future financial planning. Then, experts across the disabilities, financial, and legal fields, along with people with disabilities and family members of people with disabilities were invited to review the findings of the interviews and contribute recommendations to improve the process of future financial planning for people with disabilities. Gathering first-hand accounts from this population about the financial impact of the pandemic guides policymakers and professionals in the financial, legal, and disabilities fields on how to better reach, assist, and design programs for people with disabilities during natural disasters and beyond.

The current project is an extension of a comprehensive mixed-methods study of future financial planning for people with disabilities, funded by the May and Stanley Smith Charitable Trust. The original study began in June 2020 and consisted of three phases of data collection: 1) Interviews, 2) a National Survey, and 3) Expert Workshops. Interviews took place throughout the summer of 2020 and were used to inform the development of a national web-based survey that was disseminated in February and March of 2021. Experts across disabilities, financial, and legal fields, along with people with disabilities and family members of people with disabilities then met online in May of 2021 to discuss the current state of future financial planning for people with disabilities and suggest the direction for the next steps. To read more about the procedures and results of the initial study, visit www.natleadership.org/publications.

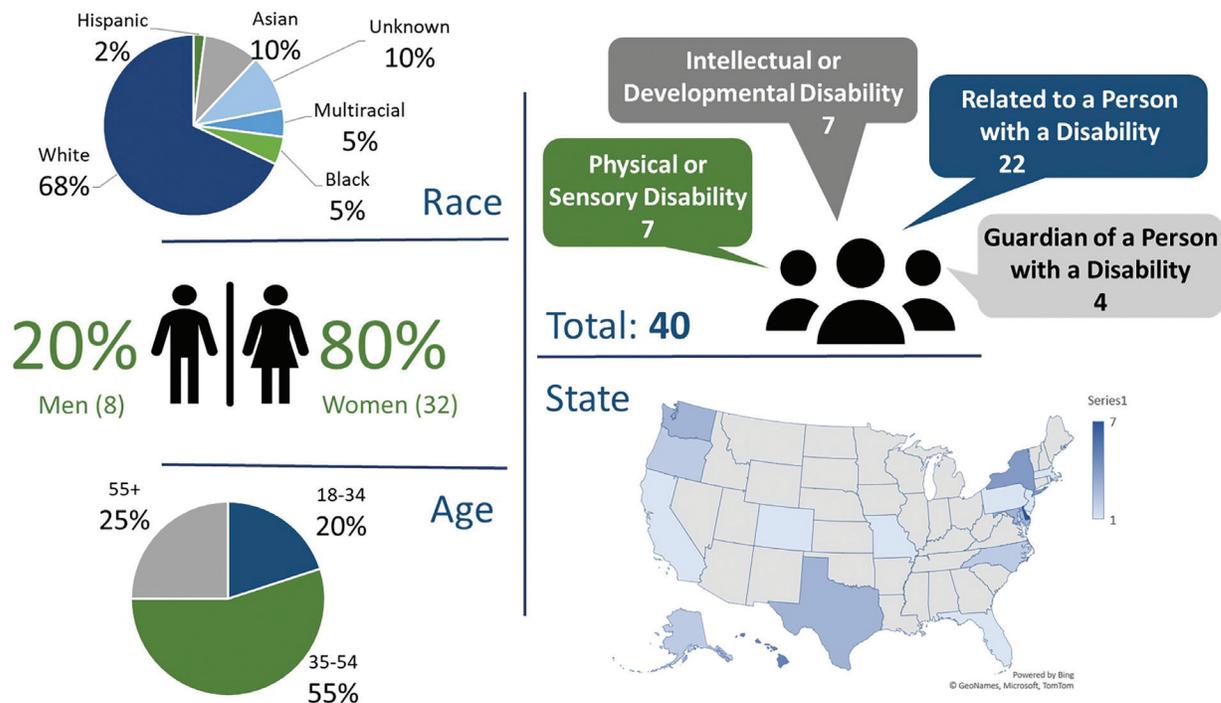
The Current Project

The first phase of the current project was conducted in the fall of 2021 and consisted of semi-structured interviews with 40 people: adults with disabilities (14), family members of people with disabilities (22), and guardians of people with disabilities (4). This exploratory qualitative study investigated the experiences and perspectives of people with disabilities and families of people with disabilities by asking open-ended questions related to the impact of the pandemic on their income, daily spending, overall spending and saving activities, future financial planning, mindset related to spending and saving, and any training or professional support they've received related to future financial planning. Participants were also asked to offer recommendations about how to improve future financial planning for people with disabilities both during the pandemic and beyond (see Appendix A for interview questions).

Interviews were conducted via Zoom teleconferencing and ranged from approximately 15 to 68 minutes in length. Participants were recruited through the listservs, websites, social media, known connections, and direct emails of the National Leadership Consortium and its partners of 18 national disability organizations.¹⁰ Snowball sampling was also employed; each interviewee was asked to share names and contact information for others they felt would be interested in participating in the study.

¹⁰ The American Academy of Developmental Medicine and Dentistry (AADMD), The American Association on Intellectual and Developmental Disabilities, The Alliance, The American Network of Community Options and Resources Foundation, Association of People Supporting Employment First, The Arc of the United States, The Autistic Self Advocacy Network, The Council on Quality and Leadership, Human Services Research Institute, The Learning Community for Person Centered Practices, National Association of Councils on Developmental Disabilities, NADD, National Alliance for Direct Support Professionals, The National Association of QIDPs, National Association of State Directors of Developmental Disabilities Services, Research and Training Center on Community Living, Institute on Community Living at the University of Minnesota, Self Advocates Becoming Empowered, and TASH

Figure 1 Phase 1 Participant Demographics



Potential participants completed a pre-screening questionnaire that collected demographic information and ensured that they met criteria to participate in the study (see Appendix B for pre-screening questionnaire). To be included in the study, participants had to identify as having a physical, intellectual, or developmental disability, or be a family member or a guardian of a person with a disability, as well as be 21 years old or older. Participants also had to be U.S. residents and speak English or Spanish. Data collection for phase one of the project was completed in October 2021.

Most of the 40 people interviewed were White (68%) and related to a person with a disability (22) (usually a parent). Of the 14 adults with disabilities who participated in the project, half (7) identified as having an intellectual or developmental disability, such as autism spectrum disorder or spina bifida, and half (7) identified as having a physical or sensory disability, such as blindness or muscular dystrophy. The majority of participants were women (80%), and between the ages of 35 and 54 years old (55%). Participants resided in states across the country, with Delaware and Hawaii being more represented than other states (see Figure 1 and Appendix C for participant demographics).

The second phase of the project invited experts across disabilities, financial, and legal fields, along with people with disabilities and family members of people with disabilities (who did not participate in phase one) to review the findings of the interviews and contribute suggested recommendations to improve the process of future financial planning for people with disabilities. Links to a pre-recorded 23-minute video presentation and an online feedback survey were sent via email to 51 expert participants and posted on the National Leadership Consortium online Community of Practice for other disability field professionals to respond. Experts were invited to review the presentation and offer additional recommendations via an online feedback survey. The online feedback survey asked demographic information and open-ended questions to elicit recommendations on how to advance future financial planning processes for people with disabilities (see Appendix D for expert feedback survey). Data collection for this part of the project was completed in mid-February 2022. Findings from the interviews and expert feedback were combined and thematic analyses that grouped related concepts of interest into themes was conducted with the data in January and February of 2022.

FINDINGS

To establish a foundational understanding of how the COVID-19 pandemic has affected future financial planning for people with disabilities, we first asked open-ended questions to elicit experiences and perspectives related to planning before the pandemic. While some participants shared positive experiences related to accounts for people with disabilities such as protection from theft or manipulation, enabling purchases that suit personalized needs beyond what Medicaid will pay for, the ease of setting up ABLÉ accounts, and the relief of having a place to put a sudden influx of funds, such as federal stimulus checks due to the pandemic, participants overwhelmingly spoke about the obstacles they faced in the process. Accordingly, this report focuses on the barriers to future financial planning in an effort to highlight areas of concern and best orient recommendations for the field.

The responses related to the impact of the COVID-19 pandemic specifically were more complex, revealing both positive and negative outcomes for participants, as well as direct and indirect influences on their finances. The pandemic slowed the pace of daily life for some people, giving them more time to investigate future financial planning and save money, while it flung other people into a state of financial crisis, sending them scrambling to pay for unexpected expenses, detracting from their already strained savings. The pandemic seemed to depress an already overwhelmed and understaffed system of public services, but also triggered supportive funding and expanded virtual services and resources that were previously unthought of. These key findings and more are presented in the following section of the paper in thematic maps, with significant themes in central circles and subsequent sub-themes with related concepts in linked circles.

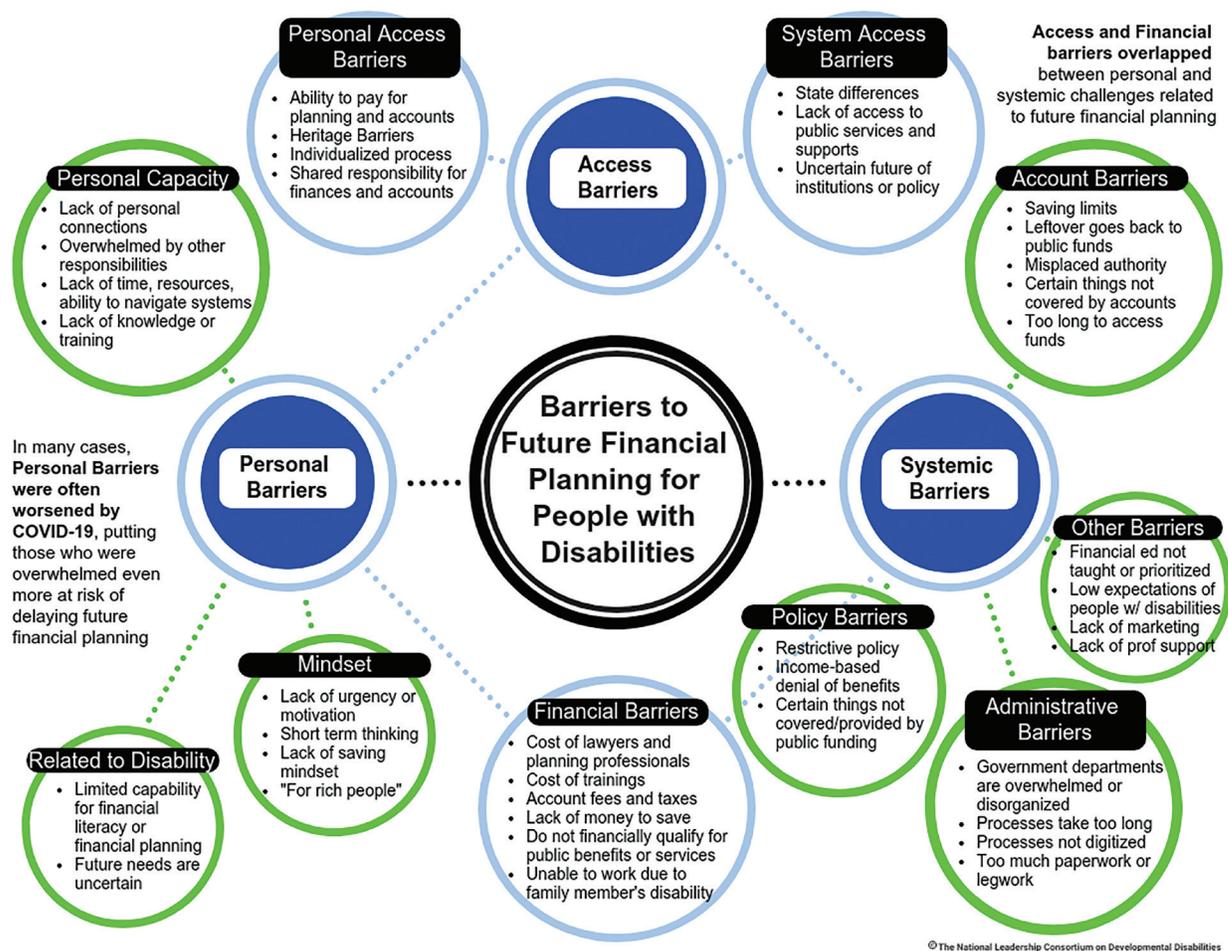
General Barriers to Future Financial Planning

Participants were asked to describe the general barriers to future financial planning for people with disabilities they had experienced before COVID-19. Barriers were organized into three major themes: personal barriers, systemic barriers, and access barriers, which spanned across both personal and systemic issues mentioned in the interviews. Similarly, financial barriers mentioned during the interviews served as a bridge between personal and systemic issues discussed (see [Figure 2](#)).

• Personal Barriers

Personal barriers were categorized into themes of personal capacity, mindset, and disability-related challenges. Many family members of people with disabilities felt they lacked the personal contacts that would help facilitate or carry out future financial plans, including family members, or networks of other families like theirs that they could turn to for help. They were also lacking a person they could appoint as a trustee or future caretaker for their loved one with a disability. Additionally, most family members were overwhelmed with other existing responsibilities such as their jobs, the day to day finances of the family, being the primary caretaker for their family member with disabilities, and the medical and behavioral attention that was required while managing everything else going on in their personal lives and the lives of their other children.

Figure 2 Barriers to Future Financial Planning for People with Disabilities Thematic Map



For example, one parent of an adult with autism said they worried about their child’s future and often thought about future financial planning, but had the more immediate financial needs of paying for their other child’s college tuition to complete first. Another parent of an adult with an intellectual or developmental disability said, *“It just seems like with mental illness rearing its ugly head on a regular basis, it’s like you just don’t even have the energy to say, ‘Oh, I’m going to go research financial planning.’ You’re just trying to get through the day. With your job and with the illness of your son, there’s not a whole lot left.”* A few people that were interviewed said that caretaking responsibilities had even led to downgrading their employment.

Daily obligations left many family members struggling to maintain daily life, limiting the time to gain needed resources, and knowledge to try to figure out future financial planning. Many participants said they did not even know where to begin or what to ask about future planning. They wished they knew more about different accounts, such as general savings accounts, trusts, and ABL Accounts, and how they impacted public benefits. They also did not know how to start finding trustworthy professionals and training to help them navigate the process. A parent of an adult with mental illness said, *“I hate to think about parents who are not as educated as I am and don’t have the money to pay. I hate to think of it. If you do not have the education and training, I can’t imagine how difficult this must be for people.”*

Many people lacked the motivation to start planning for the future because they were overwhelmed with their daily duties. They also struggled to gain the motivation to begin to navigate the complex future financial planning process; financial planning was often viewed as something they would get to eventually. A parent of an adult with autism said, *“It’s the type of thing that people postpone until they absolutely have to take care of it. Because they don’t want to have to deal with it because it’s a pain in the butt to take care of.”*

Many families also believed they were not in the financial position to save because they were already struggling to pay their bills and put food on the table. A few people said they thought financial planning was *“only for rich people.”* One adult with a physical disability noted, *“I still have this block where I think that financial planning is for people with money. The reality is all of us could benefit from basic financial education.”* People relayed that financial planning was for those who had money to set aside and save as opposed to families who were living paycheck to paycheck.

Finally, some people said that while they would like for their loved one with a disability to help with their finances and future planning, they felt that financial matters were too complex. Family members also mentioned that financial planning was challenging because they did not know what the needs or desires of the person with a disability would be down the road, making it difficult to plan for an uncertain future.

• Systemic Barriers

Systemic barriers were grouped into four categories: policy barriers, administrative barriers, account barriers, and other barriers. Those interviewed repeatedly mentioned that they wished that policy related to the finances of people with disabilities was not so restrictive. For example, the \$2,000 ceiling that limits the amount that people with disabilities can save and maintain their public benefits, such as Medicaid and Supplemental Security Income, complicated how people worked and saved. As one adult with an intellectual disability explained:

“ If you’re on SSI, your maximum is \$2,000. Let’s be real, \$2,000 can’t do squat. I mean, it sounds nice to have in the bank account. But if you have that, you have to do a spend down. That’s crazy. It makes no economic sense. You cannot plan for safety if you only have \$2,000 ... We’ve made a poverty system that says we’re gonna keep you in poverty. ”

Understanding and utilizing changing rules to best take advantage of available services and supports were mentioned as a confusing process for many. For example, some people who were interviewed said they were able and willing to work full time, but only worked part-time so they could remain eligible for public benefits. One adult with cerebral palsy said, *“If you’re willing to work, you should be able to do it on your own terms!”* Income and saving restrictions discourage people with disabilities from working and earning money they could save for their futures. One parent of an adult with intellectual disabilities said:

“ Our government has hogtied people; you’re strangling them that they will always stay in this perpetual circle. Whether they are low income, whether they are elderly, or whether they are a person with an intellectual disability, whoever receives these [government supports] because she can’t work what might be her full potential. She and millions of others make money and are taxed and pay into the system that supports her. But then they decide she’s making too much money. I mean, I realize if someday she should make \$100,000, then fine. But while we’re still just making, you know, \$10,000 I don’t think we’re like breaking the bank. Now you don’t even have this population paying into the system that’s helping to support them. Multiply that by millions of people—that’s a lot of money! ”

Family members of people with disabilities also spoke negatively about other restrictive policies that hindered their incomes and saving habits, such as parents not being paid as caregivers. Family members mentioned having to limit or forgo their employment outside of the home to provide unpaid support for their loved ones, which dramatically decreased their household income and their ability to save for the future.

Many also shared that they were denied participation in public benefits or denied benefits or reimbursement for things they needed, forcing them to pay out of pocket for disability-related expenses instead of being able to save for their futures. Participants also noted their frustration with the lack of choice and agency they perceived concerning their financial control. For example, one adult with mobility needs that was interviewed said that he needed a non-motorized wheelchair that folded to fit in the trunk of his car, but because Medicaid would only pay for a motorized wheelchair he had to buy the wheelchair he needed with his own money.

Many people we interviewed also complained about the administrative barriers they encountered while trying to contact government agencies about public benefits, saying that many forms are not digitized or available online so things had to be physically mailed in and often would get lost before they were processed. They also shared that government employees were difficult to reach by phone and that it was difficult to make an appointment to see them. *“You can’t get anybody on the phone. But why? Why can’t they just transfer all of this to home and get it done at home? Why is it so hard for the government organizations to get this all done at home when it is working for the private sector?”* said one parent of an adult with mental illness. Overall, families were deterred by the massive amounts of paperwork and legwork involved in getting information, applying for benefits, or appealing benefit denials.

Participants also noted that accounts designed to provide for the future needs of people with disabilities, such as ABLÉ accounts and special needs trusts, had many limitations; in addition to how much a person can save each year, people were limited by what their saved funds could pay for, and the time it takes to withdraw one’s own money from the accounts. There were also some issues related to who had the authority to create an account or make transactions on accounts. For example, one participant who was a guardian discussed the ongoing communication needed between the rep payee, direct service providers, and herself to make financial decisions for her aunt with an intellectual disability who lived in another state. Many people we spoke with were also hesitant to open accounts because the remaining money in certain accounts rolls back over into public funds after the person with disabilities passes away.

Other systemic barriers mentioned in the interviews included people with disabilities not receiving financial education in school and the low expectations of school and other disability professionals about people with disabilities and their ability or right to have control over their finances. Most participants agreed that financial literacy should be taught early at home and in schools to all students, not just those with disabilities. A professional in the disabilities field who serves as a guardian for multiple people said, *“I don’t know how you change that narrative on a national scale within people’s homes. Money and budget are something to talk about. And if you ignore it, it’s not just going to happen.”* Many people we interviewed also had the sense that there was information about future financial planning, accounts, and professionals out there, but they had not heard about it and would not know where to look, so the marketing of resources to people with disabilities and their families about future financial planning is not reaching them.

• Access and Financial Barriers

Participants spoke about barriers that limited their access to future financial planning in two ways: personal access issues and systemic access issues. Personal access barriers discussed included: the ability to pay for planning services and account fees; barriers such as language differences and obstacles due to citizenship status; the need for individualized financial planning and support, making it difficult to find professionals who could respond to specific situations, accounts, or goals; and coordination between professionals, families, and people with disabilities when there is shared responsibility for finances and accounts, such as when a rep payee is involved. System access barriers included: differences in accounts designed for people with disabilities, public policy, and waiting lists across states; the lack of access to public services and supports due to geographic location, approved funding, service provider availability, or waiting lists; and the perceived uncertain future of public and business institutions, such as banks closing, public benefits programs ending, and changing policy related to future financial planning. Participants receiving government benefits noted that government agencies often limited their access to resources, including much-needed medical equipment, as agency officials decide what can be purchased. A participant with cerebral palsy noted, *“If you’re financially dependent on the state or government funding, you just get what you get.”* Another participant adds, *“I want independence. I want [my wife] and me to make decisions, not the government telling us, ‘Oh we can only have this wheelchair because this is the one we’ll buy you.’”* Some participants claimed the quality of resources accessible through government agencies was substandard, and many showed an inherent distrust of agency service providers as they felt their ultimate goal was to decrease agency spending.

Though many people with disabilities would like to plan for their financial stability, participants spoke about various financial barriers that inhibited their ability to participate in the future financial planning process. Most participants noted the costs of services related to future financial planning, such as an attorney and planning professional fees for appointments and services, the cost of training or materials such as books to learn about future financial planning, and the fees associated with accounts that are specialized for people with disabilities, such as special needs trusts and ABLE accounts. Low and middle-income participants we spoke with said that they did not have extra money to save for the future. Some noted that they fell into a financial position where they did not financially qualify for public benefits because they made too much money, but then struggled to pay for the medical and therapeutic needs of their loved one with a disability. Additional financial strain was experienced by families that were dependent on one income or part-time work because their family member’s disability required one parent to be a full-time caretaker. As one parent of an adult with autism and bipolar disorder explained, *“I think that there are just so many families out there, it’s so hard to get services. You work so hard at all this stuff. I mean really, it’s like a full-time job, as a parent, trying to organize all these things and find the resources and get the resources. And so, it leaves you without being able to work consistently to have that income.”*

COVID-19 Pandemic Barriers to Future Financial Planning

Multiple personal, systemic, financial, and access barriers to future financial planning existed long before the COVID-19 pandemic, however, the ongoing nature of the pandemic has heightened the difficulty and complexity of saving for many people with disabilities and their families. An adult with autism who coaches college students with disabilities said, *“I don’t hear a lot about in the world of disabilities folks talking about finances. And I think it’s also maybe an illustration of realizing that, at least in the nature of my work, that kids become adults who often or sometimes become independent, and, maybe thinking about their lives outside of that point in time. So consequently, I think the pandemic is a watershed moment that is enabling individuals to realize what are their life priorities? Quality of life is so vital and often tied inextricably to that is, what is your financial situation.”*

The COVID-19 pandemic has had direct and indirect impacts on people’s spending and saving habits and lifestyles, as well as prompted changes in the ways they think about their finances (see [Figure 3](#)). These major themes that emerged from the interviews greatly influenced the future financial planning processes of people with disabilities and their families.

• Spending Changes

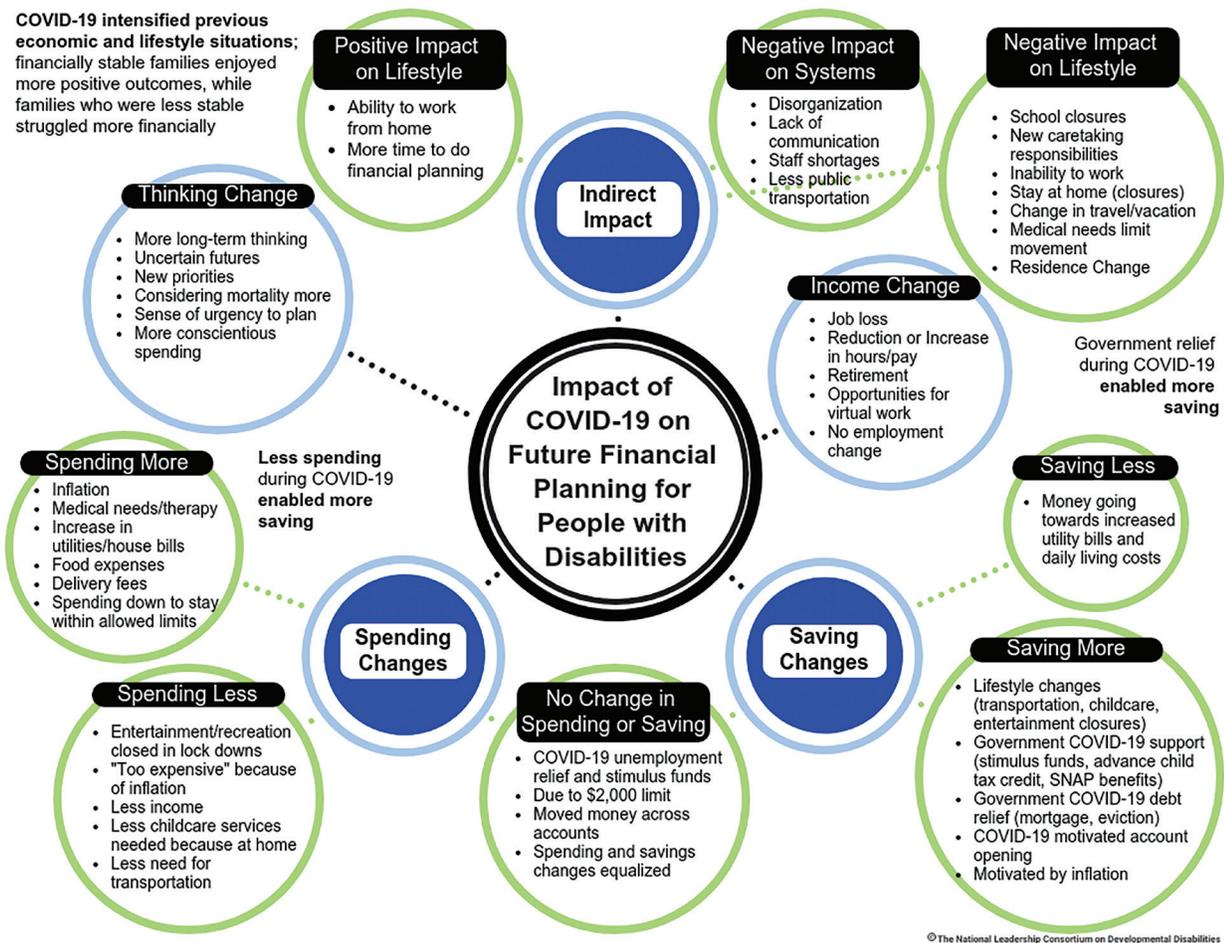
Direct impacts of COVID-19 on future financial planning for people with disabilities were categorized by changes in saving and spending. Participants noted that increases in spending were due to the inflation brought on by the pandemic on items such as food, utilities, and transportation bills. An adult with a physical disability spoke about transportation costs, *“I don’t know what happened with Uber and Lyft, but it’s so frustrating how much more expensive it is now. Like I used to live like four miles in the theater. Now, I’m like two miles from the theater. And somehow it’s more expensive now.”* Another participant noted that increased transportation costs made him reconsider his spending, *“It used to be, like, 16 bucks round trip, which wasn’t bad, but now it’s like \$20-25 round trip. So, it’s kind of like, how much do I want to go? Should I wait and see if I can go with someone so they can drive?”*

Several participants also discussed increases in food-related expenses such as inflated prices or food delivery fees. One adult with a physical disability said, *“It changed up spending a lot ... One night specifically, I ordered Chinese food for myself, I ordered like a combination thing. And it turned out to be \$17. That’s a lot of money just for one dish.”* A parent of an adult with mosaic trisomy-9 also felt the financial strain associated with increasing food costs, saying *“...when online food shopping became a thing, I signed up for it. So probably with the delivery fees, based on that I probably spent more money on groceries and just shipping costs.”*

Utility bill increases were mentioned as a result of inflation as well as a consequence of being home more often than before due to pandemic-related closures and environmental restrictions. A parent of a child with autism said *“Well, you know, the groceries and the utilities, that definitely went up. Because otherwise, my college kids would have been running up the water and the electric bill at school.”*

Many participants also discussed spending increases due to medical needs brought on by the pandemic such as increasing therapeutic services to combat accentuated mental health challenges, utilizing telehealth as opposed to in-person services, purchasing large quantities of essential medical supplies to avoid delays caused by backorders, and purchasing assistive technology to work from home. A parent of an adult with autism said, *“The normal things that we could do, we couldn’t do, and so that I just think it hurt our mental health, which added more money that we had to pay out because then we had to see therapists. So, you know, it’s just kind of snowballed.”* Another parent of an adult with autism and bipolar disorder said *“It*

Figure 3 Impact of COVID-19 on Future Financial Planning for People with Disabilities Thematic Map



just brought to light that there are huge medical needs. There are, you know, doctor's visits and things. And then what happens if he gets hospitalized and, you know, how are all these things going to get paid?"

Several participants noted that they had to increase their spending to stay within the limits to continue receiving benefits. Many participants described balancing their income and savings with regulations put in place that manage who can access public services or benefits. One parent of an adult with autism described this process, saying *"It's a lot of moving parts. And so, you really have to sit down and figure out, 'what is the goal?' And the goal is to keep all the benefits as secure as possible, but also provide for an extra stream of income to augment that."* The COVID-19 pandemic triggered new governmental funding, aid, and relief programs. As a result, several participants described experiencing increases in their income and thus their savings. At the same time, these participants mentioned challenges with balancing their savings to continue receiving benefits regardless of their income change. A guardian of an adult with a physical disability said, *"I think she has too much money now ... so I tried to spend more money."*

Decreases in spending were noted in areas of entertainment and recreation, as the pandemic led to business closures that limited social interactions and activities. A parent of a child with mosaic trisomy-9 said, *"Nobody was going to movies or amusement parks or to the beach or whatever the case may be. So, we thought well, we will spend our money in other ways."* Additionally, some participants discussed feeling uncomfortable using public transportation services during the pandemic which decreased their spending.

Simultaneously, closures kept people inside their homes, decreasing the need for transportation services and therefore decreasing expenses in this category. Many participants also discussed inflated transportation prices as a motivator to decrease the use of transportation services. One parent of the child with a developmental disability said, *“Everything is super, super, super expensive. So definitely, we were not spending money when we didn’t have to.”*

Several participants with younger children described decreases in childcare expenses as they began to work or stay at home and provide care for the children themselves. A mother of young triplets with autism said, *“The positive was because I work from home most of the time, my childcare expense has reduced.”* On the other hand, a few participants mentioned needing additional childcare services during times when they needed to work from home, because they could not provide supervision to the children while working. A parent of a child with autism said, *“Since they were home and not at school, I had to figure out childcare. So that’s an extra cost that would not have been needed if they were in school.”*

Changes in income were also identified as a factor in spending less for several families. For example, a guardian of an adult with a physical disability experienced a decrease in her income during the pandemic. As a result, she explained, *“Normally, we would, you know, travel in the summer. But we couldn’t travel because we didn’t have the money.”* Another parent of a child with autism whose income decreased during the pandemic said, *“We didn’t have any really any money to go do anything, we had to go out and exercise, go for walks and hikes. And we didn’t have money. You know, we were pretty limited on funds for everything except food and paying bills.”*

• Saving Changes

Oftentimes, less spending enabled people’s capacity to save; in fact, many participants noted increases in their saving habits. Many participants shared that government COVID-19 support and debt relief programs aided in increased savings. An adult with a physical or sensory disability said, *“I also have a lot of student loan debt. So having the government put a hold on those payments, you know, in the end, they’ll get paid. But in the short term, it was a helpful way to save some money.”* Several participants mentioned receiving stimulus checks aided in their savings. For example, one parent of a child with down syndrome said *“With the [stimulus] checks, that has helped our family, like our savings has increased because we’ve sort of been mindful with our spending.”* A participant who works supporting adults with intellectual disabilities said, *“Financially, most of the folks we support through guardianship are better off than they ever have been because of the stimulus payments. They’ve never had that much money handed to them.”* Conversely, some participants mentioned that the increased income as the result of the stimulus checks created new challenges for money management across accounts to ensure staying under account limits and continuing to be eligible for necessary benefits. A professional guardian of several individuals with disabilities said, *“Because of the stimulus payments, they’ve never had that much money handed to them. The problem or panic is, many of them don’t have a ton of expenses, because one, they’re going nowhere. Now, they can’t do anything. The money is just sitting there.”*

Some participants also noted the pandemic and the associated inflation as motivating factors for saving more. For example, a parent of an adult with a speech delay said, *“We had to start saving money because everything was just so expensive. You know, and the extra things that you buy, that’s not in your budget, so you have to save money.”* Lifestyle changes aided in increasing saving habits for many participants. These changes include areas of entertainment, transportation, and childcare. One adult with a sensory disability said, *“I think between all of those things changing and like not commuting and not getting my clothes dry clean. I think that there’s been a real cost savings to being able to work from home.”* A parent of an

adult with a learning disability also noted, *“We ended up saving money early during the pandemic. I didn’t have to pay for parking. We had to pay downtown parking prices monthly and that was a huge, you know, 200 plus dollars a month. So that was, you know, over \$1,000 just like in not parking.”*

A handful of participants credited the pandemic with motivating them to open an account to plan for their future finances. For example, a parent of an adult with autism described experiencing an increase in income that motivated opening a savings account for their child; *“So I actually have had all this extra money, because I haven’t been going out I’m not spending it. And I know there’s people who are struggling. So I kind of feel a little bit bad about that. We’ve been very fortunate. And that’s allowed me to, you know, save and open the account.”* A parent of an adult with a physical disability also mentioned having an increased capacity to save as the result of decreased spending, saying *“Because I feel like, you know, she’s spending less. And, you know, I worry about her future and her financial wellbeing and so we’re saving now. We’re putting direct money from her SSI into that [account].”*

Conversely, decreases in savings were mentioned by a few participants. These participants noted having increased spending on daily living expenses and bills that resulted in having the inability to add money to savings or needing to take money out of savings accounts. For example, an adult with an intellectual disability mentioned taking money out of his savings account to pay for bills heightened by the pandemic.

Some participants experienced no changes in their saving or spending habits. Those individuals noted that government support, such as unemployment benefits and the stimulus checks, equalized some of the impacts of the pandemic thus balancing out expenses and resulting in no changes in saving or spending. Additionally, some participants mentioned moving money across accounts. As a result, they changed their saving habits but not the amount of money saved. In most cases in which money was moved, the identified goal was to ensure that account requirements and limits were met to avoid loss of benefits. One participant identified as a professional guardian of more than 50 adults with intellectual disabilities stated, *“We used to have to move money maybe once or twice a year to keep their account from, you know, going into the review phase. Now we’re up to like, three to four times of having to move funds to keep them from losing their [benefits].”*

• Indirect Impact of COVID-19

Indirect impacts of the COVID-19 pandemic on future financial planning for people with disabilities were described by participants as being both positive and negative. The following themes were identified as the most influential indirect impacts of the COVID-19 pandemic: positive impact on lifestyle changes, negative impact on lifestyles changes, and negative impact on systems.

The pandemic influenced people’s work and leisure in ways that impacted their future financial planning both positively and negatively. The opportunity to work from home due to the pandemic had a positive impact on lifestyle because it added free time that would typically be taken by commuting to and from work, saved money on gas and parking, and afforded some people the ability to work in an environment that was more accessible to them. For example, one adult with a developmental disability said, *“I think that the pandemic really opened up a lot of opportunities for people with disabilities, especially when it comes to employment, being able to telework and work from home, and like the accommodations for me to be able to do some meetings in bed sometimes. I mean, it makes a huge difference.”* Conversely, the pandemic interrupted the workplace for many, leaving them unemployed or with reduced working hours, slashing their income.

A professional guardian of a caseload of adults with intellectual disabilities described one man's situation: *"He had to stop working because of the pandemic, and the restrictions because he's in a facility and yet he had this job that he can't go to. And it was such a long restriction, I'm still not sure he's even back to work. You know, he more or less lost his job just because of the pandemic."* A mother of an adult with autism told a similar story: *"He had a job before COVID hit. And he had been working just fine, and then all of a sudden they had to start cutting people and they just kind of took him off the schedule and never really told them anything."*

Additionally, some participants mentioned being affected by the decreased availability of public transportation services. Lack of transportation limited movement and ability to work outside of the home thus negatively impacting income. Reduced incomes had a dramatic impact on some families, as one mother of a child with a disability described: *"We're now in the process of filing bankruptcy because we just have too many medical bills, and those just piled up during COVID with lack of income."*

A few participants also mentioned how the pandemic changed how they travel and vacation. Of those participants, some mentioned increased travel as a result of increased savings during the COVID-19 pandemic, for example, a parent of an adult with autism said, *"My salary went, you know, into my savings account. And then with all the stimulus checks, I actually went on vacation this year for the first time in 15 years."* Others mentioned decreasing travel due to health and medical concerns for the individual with a disability resulting in changes in spending and saving:

“ I think a lot of folks have been, you know, if folks have been saving money on gas, for instance, or other things through working from home, I think, and not being able to travel. And if you have the privilege to be able to save toward that, and you've had additional time to accrue through not traveling during the pandemic, then there's a greater sense of motivation. And I also say that recognizing that many folks have been traveling over this period. And that's not a diss at all to them, it just kind of recognizing what we're all individually comfortable with, and where we want to utilize our money if we have discretionary income. ”

–Adult with autism

As the pandemic paused traditional work and travel for many, it gave them more time to investigate or take action toward future financial planning for some families. One father of an adult with a visual impairment said that the pandemic gave their daughter extra income that enabled them to start an ABLE account. *"She had a pretty active life before this and went out often. She had a boyfriend, you know, she did her thing. So now she's not going out. [We're not putting in] a whole lot, but it's a start. And I think it's something that we will continue to do if life changes."* A guardian of a person with intellectual disabilities also used the pandemic as an opportunity to save:

“ I've worked and my salary hasn't been impacted. I've been very fortunate. So I actually have had all this extra money and I haven't been going out, so I'm not spending it ... That's allowed me to save and open an account. And I know that it's something that I will continue to do after; it's now part of the budget. ”

Participants also mentioned negative impacts on their future financial planning due to systemic challenges because of the pandemic. Several participants noted frustration as a result of communication difficulties with the systems that are meant to aid in the future financial planning process. Staffing shortages also disrupted communication pathways and systemic processes thus making it further difficult to access resources and services that aid in future financial planning. As one guardian of an adult with cerebral palsy explained:

“ So when COVID happened, of course, it’s hard to keep the distance, you know, everything gets shut down. But then once stuff started trying to reopen, a lot of staff either didn’t come back or the state just couldn’t fund it. So they wound up, like shutting down, basically. ”

• Income and Thinking Changes

Changes in income and how people thought about their finances were major themes noted by the participants that influenced changes in both spending and saving behaviors. Income changes affected both increases and decreases in saving and spending. Closures and health-motivated restrictions disrupted employment that thus affected income. Some participants noted reduced hours from job loss or decreasing one’s hours to work from home and provide new caretaking responsibilities as a result of school closures. For example, a participant with spina bifida said, *“I was planning on going back to work eventually, once my son went to school ... So if they ended up not going to school or doing hybrid or something like that, which is crazy for kindergarteners, that actually would probably affect me, because then I really couldn’t really think about going back to work.”* Another adult with a physical disability who lost their job said, *“So I’d say that affected me mostly, like probably a month or two into it because I had a little bit of savings, like \$2,000. And then after that, when you’re making unemployment is like a lot less than when I was making on the job...so yeah, so that’s like work with a lot less and savings is dwindling pretty quickly.”*

On the other hand, some individuals described an increase in their working hours due to being an essential worker or increased employment availability as a result of new opportunities for virtual work. Some participants mentioned that working from home allowed them to work more hours, increase available time, and save on caretaking expenses. A few participants mentioned stressful aspects of the pandemic motivated and accelerated their retirement plans regardless of the negative impact on their income. A parent of an adult with a physical disability said the pandemic caused her husband to reevaluate his career:

“ The more you work, the better your pay. But COVID was just so stressful for everybody, not only just for him ... and so we looked, we looked at everything. And we just said, you know, now is the time to retire. And so he actually did retire. I think the pandemic really helped him... ”

Several participants experienced no change in their employment or income during the pandemic, thus preventing major changes in spending or saving. Thinking changes were identified in most participants as an important reason for changing saving and spending habits. Thinking changes entail new prioritization of money allocation or changed perspectives about what is considered essential in one’s life in terms of spending on or saving for.

The pandemic shifted people’s priorities in terms of saving and spending, increasing their urgency to save. Many participants noted spending more conscientiously. Additionally, they said the pandemic caused them to take a more long-term approach to thinking about their finances. An adult with a physical disability described his thought process,

“ So before I was looking into mostly spending stuff, ‘I want to save to spend this, buy this, buy this’ but now it’s more of saving to make sure as we plan for later on, so maybe a property down the road by house, etc. Instead of just focusing on purchases for consumption or for purchases for investments. ”

The pandemic caught a lot of people off guard, so it emphasized the uncertainty of the future and therefore the need to start planning for it. Consideration of mortality was commonly mentioned as an influencing factor on future financial planning as the pandemic shined a light on the inevitability of death and the need to plan for the future. One parent of an adult with autism noted, *“I mean, we’re all gonna live, we’re all gonna die. We’re all gonna have to worry about our kids when they get older and we’re not here anymore.”* Another parent of an adult with autism said:

“It just makes me more aware that I need to keep things updated. Because I am 72. Although I do not have comorbidities like a lot of people who are in ICU, or who are unvaccinated. But still, it just makes you very aware of your own mortality.”

RECOMMENDATIONS

The diverse experiences of the participants in this study illustrate the barriers that impede future financial planning for people with disabilities and their families. Further, these findings exemplify a deepening divide in socioeconomic inequities. People who lost their jobs due to the pandemic, or who were underemployed and living in poverty before the pandemic struggled to save or plan for their financial futures. Ultimately, participants’ and some financial planning experts who reviewed the study findings offered recommendations for government agencies, professionals, disability support agencies, and people with disabilities and their families to help address these barriers. Recommendations are organized by area of influence, starting with macro-level recommendations for government agencies, and shifting to increasingly micro-level recommendations for financial and legal professionals, disability support agencies, and people with disabilities and their families. The recommendations listed in the tables at the beginning of each section are presented in order of frequency of response.

Recommendations for Government Agencies

Recommendations for Government Agencies	
Teach People with Disabilities How to Navigate the Future Financial Planning Process	<i>Offer targeted information sessions and workshops for people with disabilities on how to navigate the future financial planning process.</i>
Teach Families How to Navigate the Future Financial Process	<i>Provide education and train families of people with disabilities on how to navigate the future financial planning process.</i>
Increase Awareness About the Need for Future Financial Planning	<i>Increase awareness of the urgency and importance of future financial planning.</i>
Provide Direct Outreach to People with Disabilities and Families about Future Financial Planning	<i>Design marketing strategies and increase direct outreach to people with disabilities and their families.</i>
Change Saving Policy	<i>Remove or increase saving and spending caps; streamline the financial planning process.</i>
Provide Accessible Educational Resources	<i>Offer resources and begin educating people with disabilities and their families about the benefits of future financial planning.</i>
Invest in Future Research	<i>Fund research to explore the short and long-term impact of the COVID-19 pandemic on economic health and future financial planning of people with disabilities and their families.</i>



Participants offered suggestions for government agencies to support the future financial planning of people with disabilities and families, including the need for local, state, and federal agencies to teach people with disabilities and their families how to navigate the future financial process, increase awareness about the need for future financial planning, provide direct outreach to people with disabilities and their families about future financial planning, change saving policy, provide educational resources, and invest in future research.

The most frequent recommendation for government agencies offered by participants was to teach people with disabilities and their family members how to navigate the future financial planning process, either directly or by funding the effort. For example, participants noted that targeted information sessions and workshops for people with disabilities, as well as education and training for their family members, would help them to navigate the complexities of future financial planning and to understand the various financial planning options. Online seminars and workshops were thought to be particularly helpful, as members of this population have caretaking and time restrictions which make it difficult for them to attend in-person meetings.

Another frequent suggestion among participants involved the need for government officials to make people with disabilities and their family members aware of the urgency for future financial planning. For example, many family members participating in this study noted that, though the pandemic underscored the need to save money for their family member with a disability, they had not given future financial planning much thought before the pandemic. In other words, it took a global crisis like the pandemic to create a sense of urgency about the need for future financial planning; this suggests a strong need for government-supported interventions so people with disabilities and their families will be better prepared for future crises.

Though participants noted the need for government agencies to increase awareness about the importance of future financial planning, many felt that government agencies at the local, state, and federal levels could better provide direct outreach about the future financial planning process. Specifically, they noted more direct marketing and outreach strategies by state Developmental Disabilities Councils would increase awareness of future financial planning. They also suggested that government-sponsored public service announcements, as well as mass media campaigns, could draw attention to the need for future financial planning for this population.

A common recommendation seen in the current literature on financial disparities experienced among people with disabilities and their families addresses the effects of government saving and spending caps on the ability of this population to save. Several participants in this study recommended government agencies change or eliminate spending and savings caps and create saving-friendly policies to support their financial planning options. Moreover, many participants felt that the government should provide more educational resources specific to the impact future financial planning could have on public benefits. This could be accomplished by integrating financial planning into the transition curriculum for youth, offering resources about future financial planning at transition fairs, or through the creation of a neutral government entity to support families as they navigate the planning process. Participants and experts also emphasized that the written resources should be as accessible as possible, using plain language and websites that are easy to navigate.

Finally, the findings of this study point to the need for more studies that explore the short and long-term financial impact of the COVID-19 pandemic on people with disabilities and their families. While not explicitly noted in participant recommendations, the results of this study align with recent research that shows the disproportionate impact of the pandemic on people who were economically vulnerable and/or disadvantaged before the spring of 2020.¹¹ Further research is needed to understand how the pandemic has impacted the economic wellbeing of people with disabilities and their families differently, specifically to explore factors that limit or facilitate saving behaviors and engaging in future financial planning. Funding for research projects from federal government agencies, such as the Administration for Community Living, the National Institute on Disability, Independent Living, and Rehabilitation Research, and state programs, such as developmental disabilities councils or state developmental disabilities agencies, would support needed research and evidence-based solutions to improve future financial planning for people with disabilities, particularly those who are underemployed or poor.

Recommendations for Financial and Legal Professionals

Recommendations for Financial and Legal Professionals	
Connect with Disability Organizations	<i>Connect with disability organizations to facilitate frequent presentations and workshops about future financial planning.</i>
Reduce Fees	<i>Offer reduced rates, packaged deals, or other ways to minimize costs for people with disabilities and their families.</i>
Improve Access to More Training and Resources	<i>Expand education and training options for people with disabilities and their families.</i>
Market Available Accounts to People with Disabilities	<i>Advertise more widely about benefits of and differences between accounts that are designed for people with disabilities.</i>

Participants identified many recommendations relevant to professionals in the financial and legal fields, including connecting with disability organizations to provide more direct support related to future financial planning, reducing fees for their services, improving access to professionals and their resources, and wider marketing of accounts for people with disabilities. A number of participants recommended that professionals offer people with disabilities and families more direct future financial planning support and that this support be more consistently available. While some participants had seen or participated in workshops or presentations offered through their direct service providers, schools, or other local organizations, the presentations were few and far between. Financial and legal advisors have an opportunity to grow their client base by building relationships with organizations that have frequent contact with people with disabilities and their families by offering support and resources directly to the target populations.

Many people we interviewed pointed to attorney and financial planner fees as the reason they have not begun future financial planning. Because people with disabilities and their families' finances are often constrained, lowering the fees associated with future financial planning or offering one-time payments on package deals would help make planning more accessible to all families. Package deals that cover consultations and updating documents over time would be particularly helpful to middle and lower-class families who have been delaying planning to avoid not only initiation costs but also maintenance costs over the length of the accounts.

¹¹ Perry, B., Aronson, B., & Pescosolido, B. (2021). Pandemic precarity: COVID-19 is exposing and exacerbating inequalities in the American heartland. *Proceedings of the National Academy of Sciences*, 118(8). <https://doi.org/10.1073/pnas.2020685118>

Because legal and financial professionals have the opportunity to benefit financially from people with disabilities and their families, offering free education and training for families could be viewed as an investment in potential new clients. Participants suggested that professionals facilitate training focused on general financial management and planning for the future, how to teach financial literacy to children and youth, how public benefits and services are impacted by different accounts, clarifying legal jargon and interpretation of policy, and about the various account options that are available to people with disabilities to plan for their futures. Moreover, participants suggested that professionals improve resource access by offering more virtual training, tools (e.g., checklists, information in layman’s terms, and other useful documents), services, language interpreters, and more localized support. Additionally, experts thought that collaboration between professionals could assist in helping families understand how everything worked together.

In addition to expanding training and resources for people with disabilities and their families, increased marketing and outreach efforts by professionals associated with banks, law firms, and other entities that assist people with disabilities with future financial planning are needed to raise awareness about future financial planning and available options. There was a consensus among participants that they had to find the information on their own and that many people do not know special accounts such as ABLE exist or why they could be beneficial. Participants suggested that marketing target aging caregivers and that multimedia campaigns utilizing the internet, radio, television, and other outlets be created to spread information more widely about the different types of accounts that are available.

Recommendations for Disability Support Agencies

Recommendations for Disability Support Agencies	
Increase Outreach	<i>Increase opportunities to reach out to people with disabilities and their families about the importance of financial planning and connect them with services to navigate the process.</i>
Offer More Local Resources	<i>Connect with other trusted and frequented local organizations like churches and schools.</i>
Increase Technology-Based Resources	<i>Increase access to online communication systems, worksheets, and virtual training.</i>
Target Aging Caregivers	<i>Future financial planning is particularly urgent for older caregivers.</i>

Many participants made recommendations for agencies that directly support people with disabilities. They viewed disabilities service agencies as a primary source for families to gain relevant information. Many participants shared frustrations with these types of agencies not sharing more guidance and information about future financial planning. Participants recommended increased outreach from disability support agencies to members of the community that could provide opportunities to spread awareness and connect people with disabilities to helpful financial planning resources.

Some participants believe disability service agencies should coordinate with other trusted local organizations, such as churches and schools, to offer more local resources for future financial planning. Creating systems of networks between local agencies promotes financial planning awareness by reaching people where they are already connected to their communities. Additionally, it increases access points for financial planning resources and services as information should be more easily shared once relationships are established.

As the pandemic caused a shift into a virtual world, several participants recommended creating computer-based resources to increase access opportunities. Participants suggested that virtual resources should include training opportunities, financial planning guides, and online communication pathways to speak with professionals in the future financial planning field. Creating virtual resources allows for access to the information within the comfort of one's home. It also provides alternative formats for disseminating information.

Numerous participants discussed giving more consideration to death as the pandemic emphasized the uncertainty of life. As a result, many participants suggested having disability support agencies reach out to aging caregivers of the people their agency supports. Targeting these individuals can help to inform them about the need to plan for the future of their loved ones. It will ensure that the person with a disability will have a plan put in place to clarify financial responsibilities and that they will be taken care of when the caregiver is gone.

Recommendations for People with Disabilities and Their Families

Recommendations for People with Disabilities and Their Families	
Engage in Life Course Planning	<i>Begin life course planning as a channel for future financial planning.</i>
Start Planning Early	<i>Engage in future financial planning research and activities as early within the life course as possible.</i>
Research Future Financial Planning	<i>Investigate steps involved and resources available for future financial planning.</i>
Research Public Benefits Early	<i>Learn about available public benefits through independent research or consultation with a professional early on in the planning process.</i>
Live Within Your Means	<i>Be aware of your financial position to best tailor the future financial planning process to your individual experience.</i>
Consider Caregivers	<i>Consider the need for current and future caregiving.</i>
Consider Residential Location	<i>Examine available resources within your geographic location to be aware of what options may be feasible.</i>
Stay Current in Planning	<i>Consistently examine and update future financial planning documents to stay up to date.</i>

Several recommendations for people with disabilities and their families were identified by participants and experts. The most common recommendations were to engage in life course planning as a segue into future financial planning; creating a vision for the future and goals for other areas of life makes it easier to develop financial goals to support that vision. Frequently mentioned recommendations were to start planning early and to expand planning as needed across the lifespan. Planning early gives people with disabilities and their families time to navigate the complex future financial planning process. One financial planner suggested starting with the easiest steps and building off of them to avoid becoming overwhelmed by looking too far into the future. One strategy could be to create a list of what needs to be done and prioritize the steps that are considered most essential.

Many participants suggested that individuals with disabilities engage in their own future financial planning research. Participants suggested research could be conducted independently or with the help of professionals. Researching future financial planning options and resources should involve identifying the next steps for future financial planning. Many participants suggested researching how different

savings accounts impact various public benefits. Participants noted that having this knowledge aids the decision-making process and prioritization of future financial planning. Additionally, the research process can create opportunities for identifying trustworthy and knowledgeable support professionals or agencies that suit that person's needs.

Participants recommended that it is best to live within one's means, which entails being aware of one's financial standing and capacity. This knowledge allows one to tailor the future financial planning process to the individual situation. Additionally, participants emphasized the impact of geographic residence on access to services and professionals. Available services or agencies differ by location. Many participants recommend knowing what is available before moving and considering relocation if the current location does not provide access to what is needed. Participants also thought that it was important for people with disabilities to stay current in their planning. Habits such as updating financial goals and accounts frequently should be exercised. A few participants noted updating documents such as wills ensures these documents reflect the family member's future wants and needs. In addition, yearly revisions of financial plans ensure that rule changes and lifestyle events are being considered and integrated into future financial planning documents.

“ I think having someone assigned to us that can help us navigate everything [would be beneficial]. You know, because we talk to one agency, and they send us to another agency. My son has mental health issues, as well. So he's bipolar, he has autism, he has a heart condition, he has intellectual, and developmental delays. So because of all these things, everybody wants to point a finger somewhere else: go talk to them, and go talk to them and go talk to them. And nobody wants to really help us. ”

–Mother of an adult with autism

“ You know, in some cases some things are good for some people, but not for [my son]. You know, some people, Oh, they'll get closer with their family. Or they spend more time outdoors. That has not happened with [my son] at all, because for a while we couldn't even see him and I understand... Well, he was supposed to have little jobs through the vocational program, but that all went, you know, by the wayside too. ”

–Parent of twins with autism

“ Data tells us that people with disabilities are often unemployed and underemployed much more than their counterparts who don't have any disability...It's scary how little attention there is to this, and how much of an opportunity there is, with just proper education and obtaining the right support, and complemented by that notion of finding avenues for individual agency. ”

–Adult with an intellectual disability

CONCLUSION

People with disabilities and their families face unique financial challenges that traditionally put them at an economic disadvantage, even before the COVID-19 pandemic. Income restrictions necessary to maintain public benefits, denial or lack of access to needed resources and services, and substantial expenses not covered by public benefits for supports such as medical and behavioral services all contribute to less-than-ideal economic standing. Because people with disabilities and their families face more obstacles to earning and maintaining money, there is even a greater need for this population to focus on financial planning to secure their futures.

Similar to the experiences of those documented in broader quantitative studies, the participants in this study shared that the financial hardships exacerbated by the pandemic impacted their ability to engage in future financial planning. For example, a recent study on the future financial planning of people with disabilities and their families reported that over 77% of respondents claimed their income was negatively affected by the pandemic.¹² Likewise, many participants in this study reported pandemic-related income losses, which often resulted from changes in employment or increases in household expenses like food and utilities. Moreover, mounting research suggests the pandemic intensified financial barriers caused by government regulations such as spending and savings caps.¹³ This sentiment was echoed by the participants in this study, as many who received pandemic-related aid felt compelled to “spend-down” or risk losing much-needed benefits.

Participant experiences in this study also reflected differences in pandemic-related socioeconomic disparities described in other research. Specifically, research suggests that lower-income families were more deeply affected by the pandemic than wealthier families. In this study, higher-income participants or those who enjoyed employment stability during the pandemic were more likely to report positive financial outcomes associated with the pandemic. For example, stimulus money and other forms of government relief were more likely to supplement the income and facilitate future financial planning among those with stable employment or higher qualifying incomes. On the other hand, families with lower incomes or those whose employment was compromised during the pandemic often reported they were unprepared to face extraneous pandemic-related financial demands like childcare expenses brought on by forced school closures. These added expenses make it more difficult for lower-income families to save or engage in future financial planning.

Finally, studies suggest lockdown-related closures forced during the pandemic disrupted a wide array of service and support networks for people with disabilities and their families—including those necessary to support future financial planning.¹⁴ Indeed, participants in this study claimed pandemic-related closures made it difficult to engage in future financial planning as lock-downs precluded access to needed support services.

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The findings of this study contribute meaningful and actionable recommendations that can inform state and federal government agencies, legal and financial planning professionals, professionals and agencies that support people with disabilities directly, family members of people with disabilities, and people with disabilities themselves. Communication efforts, training, and interventions that provide needed education, information, and resources to people with disabilities and families of people with disabilities can begin to mitigate some of the fear and uncertainty that people feel about the process of future financial planning. Further, the recommendations clearly show that there are multiple points of intervention that could be helpful to reach and support people with disabilities and family members to begin or continue through the future financial planning process, including schools, agencies that provide services to people with disabilities, community organizations (such as churches, community centers, etc.), online platforms (including resource hubs, communities of practice, and plain language websites), and financial experts themselves. Efforts to inform, educate, and support people before or during future financial planning may be particularly helpful for people who have experienced significant financial setbacks throughout the COVID-19 pandemic. Helping people understand options for planning and saving while living in poverty, or resources to help people gain employment and/or enhance their financial wellbeing could help people feel like they have the time or resources needed to engage in future financial planning.

Ultimately, future financial planning is a critical process to the overall wellbeing and quality of life for people with disabilities. However, it is a process that continues to confuse, overwhelm, or feel inaccessible to people with disabilities and their families. The findings of this study show that the COVID-19 pandemic had a mixed impact on the financial, saving, and planning experiences and behaviors of people with disabilities and family members of people with disabilities. Understanding this impact should inform the responses of government agencies, professionals, and experts to ensure that people have the resources and support they need to address the short and long-term challenges brought on by COVID-19.

APPENDIX A: Phase 1 Interview Schedules

Interview Schedule for Person with Disabilities

1. Do you currently work?
2. Have your work, pay, or finances changed during the COVID-19 pandemic? Can you tell me how?
3. Has the COVID-19 pandemic changed your daily spending? How?
4. Please describe any sort of financial planning you've done for your future, such as a special needs trust, ABLE account, life insurance, retirement fund etc.
5. Has the COVID-19 pandemic changed anything about the way you plan for your financial future? How?
6. Has the COVID-19 pandemic changed the way you think about planning for your financial future? How?
7. Have you received any training or support from a professional (including a financial planner, an attorney, or another professional) about future financial planning related to the impact of the COVID-19 your finances? If so, can you tell me about it?
8. What do you think was or is needed to help improve future financial planning during the pandemic?
9. How about after the pandemic?
10. Is there anything else you'd like to share about how your finances were affected during the pandemic?

Interview Schedule for Family Members

1. How are you related to your family member with a disability?
2. How old is your family member with a disability?
3. Does this family member work? (Please describe their work—type of job, hours worked)
4. Has their work, pay, or finances changed during the COVID-19 pandemic? Can you tell me how?
5. Has the COVID-19 pandemic changed your family member's daily spending? How?
6. Please describe any sort of financial planning you've done for the future of your family member with a disability, such as a special needs trust, ABLE account, life insurance, retirement fund etc.
7. Has the COVID-19 pandemic changed the way you or your family member with a disability plan for their financial future? How?
8. Has the COVID-19 pandemic changed the way you or your family member think about planning for their financial future? How?
9. Did you or your family member receive any training or support from a professional (including a financial planner, an attorney, or another professional) about future financial planning related to the impact of the COVID-19 pandemic on your family's or your family member's finances? If so, can you tell me about it?
10. What do you think was or is needed to help improve future financial planning during the pandemic?
11. How about after the pandemic?
12. Is there anything else you'd like to share about how your finances were affected during the pandemic?

APPENDIX B: Prescreening Questionnaire

#	Question	Response Choices
1	My first name is	Write in Response _____
2	My last name is	Write in Response _____
3	Which best describes you?	<input type="checkbox"/> I am a person with a physical or sensory disability <input type="checkbox"/> I am a person with an intellectual or developmental disability <input type="checkbox"/> I am relate to a person with a disability <input type="checkbox"/> I am the guardian of a person with a disability (not related)
4	What is your gender? - Selected Choice	<input type="checkbox"/> Man <input type="checkbox"/> Woman <input type="checkbox"/> Non-binary <input type="checkbox"/> Other (write in response) _____ <input type="checkbox"/> Prefer not to answer
5	Which state do you live in?	<input type="checkbox"/> <i>Write in Response</i> _____ _____
6	How old are you?	<input type="checkbox"/> 0-99
7	How old is the person with disabilities?	<input type="checkbox"/> 0-99
8	What is your race or origin? - Selected Choice	<input type="checkbox"/> White <input type="checkbox"/> Hispanic, Latino or Spanish Origin <input type="checkbox"/> Black or African American <input type="checkbox"/> Asian <input type="checkbox"/> American Indian or Alaska Native <input type="checkbox"/> Native Hawaiian or Other Pacific-Islander <input type="checkbox"/> Multiracial <input type="checkbox"/> Other (write in response) _____ <input type="checkbox"/> I prefer not to answer
9	Are you currently employed (person without disability)? Including self-employment - Selected Choice	<input type="checkbox"/> I work full-time <input type="checkbox"/> I work full-time and have an additional part-time job <input type="checkbox"/> I work one part-time job (not retired) <input type="checkbox"/> I work more than one part-time job <input type="checkbox"/> I am working age and unemployed <input type="checkbox"/> I am retired and unemployed <input type="checkbox"/> I am retired and working part-time <input type="checkbox"/> I am on disability and unemployed <input type="checkbox"/> I work part-time due to the COVID-19 pandemic <input type="checkbox"/> I am unemployed due to the COVID-19 pandemic <input type="checkbox"/> I am a full-time student <input type="checkbox"/> Other (write in response) _____ _____

APPENDIX B: Prescreening Questionnaire ...continued

#	Question	Response Choices
10	<p>Are you currently employed (person with disability)? Including self-employment - Selected Choice</p>	<ul style="list-style-type: none"> <input type="checkbox"/> I work full-time <input type="checkbox"/> I work full-time and have an additional part-time job <input type="checkbox"/> I work one part-time job (not retired) <input type="checkbox"/> I work more than one part-time job <input type="checkbox"/> I am working age and unemployed <input type="checkbox"/> I am retired and unemployed <input type="checkbox"/> I am retired and working part-time <input type="checkbox"/> I am on disability and unemployed <input type="checkbox"/> I work part-time due to the COVID-19 pandemic <input type="checkbox"/> I am unemployed due to the COVID-19 pandemic <input type="checkbox"/> I am a full-time student <input type="checkbox"/> Other (write in response) <hr/>
11	<p>Are you currently employed (person with disability)? Including self-employment - Other - Text</p>	<ul style="list-style-type: none"> <input type="checkbox"/> I work full-time <input type="checkbox"/> I work full-time and have an additional part-time job <input type="checkbox"/> I work one part-time job (not retired) <input type="checkbox"/> I work more than one part-time job <input type="checkbox"/> I am working age and unemployed <input type="checkbox"/> I am retired and unemployed <input type="checkbox"/> I am retired and working part-time <input type="checkbox"/> I am on disability and unemployed <input type="checkbox"/> I work part-time due to the COVID-19 pandemic <input type="checkbox"/> I am unemployed due to the COVID-19 pandemic <input type="checkbox"/> I am a full-time student <input type="checkbox"/> Other (write in response) <hr/>
12	<p>How much money do you make each year? If you are married or cohabiting, put your annual household income</p>	<ul style="list-style-type: none"> <input type="checkbox"/> \$ 0-\$10,000 <input type="checkbox"/> \$10,001-\$20,000 <input type="checkbox"/> \$20,001-\$30,000 <input type="checkbox"/> \$30,001-\$40,000 <input type="checkbox"/> \$40,001-\$50,000 <input type="checkbox"/> \$50,001-\$60,000 <input type="checkbox"/> \$60,001-\$70,000 <input type="checkbox"/> \$70,001-\$80,000 <input type="checkbox"/> \$80,001-\$90,000 <input type="checkbox"/> \$90,001-\$100,000 <input type="checkbox"/> \$100,001-\$200,000 <input type="checkbox"/> \$200,001-\$300,000 <input type="checkbox"/> \$300,001-\$500,000 <input type="checkbox"/> More than \$500,000 <input type="checkbox"/> I don't know <input type="checkbox"/> I prefer not to answer

#	Question	Response Choices
13	Where do you live?	<input type="checkbox"/> I own my own home <input type="checkbox"/> I rent my own home <input type="checkbox"/> I live in a home my family owns <input type="checkbox"/> I live in my family's home with my family <input type="checkbox"/> I live in a group home owned by an agency that supports me <input type="checkbox"/> I live in a nursing home <input type="checkbox"/> I live in an Intermediate Care Facility (ICF) for people with disabilities <input type="checkbox"/> I live in another type of institutional care facility <input type="checkbox"/> I live in another type of situation
14	Who do you live with?	<input type="checkbox"/> I live alone <input type="checkbox"/> I live with my spouse <input type="checkbox"/> I live with 1 other person (not my family) <input type="checkbox"/> I live with 2-5 people (not my family) <input type="checkbox"/> I live with more than 5 people (not my family) <input type="checkbox"/> I live with a friend. We are not in a program <input type="checkbox"/> I live with someone who supports me (not my family) <input type="checkbox"/> I live with my family
15	Where do you live?	<input type="checkbox"/> I own my own home <input type="checkbox"/> I rent my own home <input type="checkbox"/> I live in a home my family owns <input type="checkbox"/> I live in my family's home with my family <input type="checkbox"/> I live in a group home owned by the agency that supports me <input type="checkbox"/> I live in a nursing home <input type="checkbox"/> I live in an Intermediate Care Facility (ICF) for people with disabilities <input type="checkbox"/> I live in another type of institutional care facility <input type="checkbox"/> I live in another type of situation
16	Disability Type	<input type="checkbox"/> Intellectual or Cognitive Disability <input type="checkbox"/> Developmental Disability <input type="checkbox"/> Physical Disability <input type="checkbox"/> Autism or Autism Spectrum Disorder <input type="checkbox"/> Mental Illness or Psychiatric Diagnosis <input type="checkbox"/> Deaf or Hard of Hearing <input type="checkbox"/> Blind or Low Vision/Vision Related Disability <input type="checkbox"/> Brain Injury <input type="checkbox"/> Learning Disability (ADHD, dyslexia, etc.) <input type="checkbox"/> Sensory Disability <input type="checkbox"/> Chronic Illness <input type="checkbox"/> Other (write in response) <hr/> <hr/>
17	Please rate the degree of financial independence of the person with disabilities	0-10 _____

APPENDIX B: Prescreening Questionnaire ...continued

#	Question	Response Choices
18	The person with disabilities receives the following benefits from the government	<input type="checkbox"/> Food and cash assistance from the state (TANF, SNAP, etc.) <input type="checkbox"/> Food and cash assistance from a local area agency on aging <input type="checkbox"/> Social Security benefits <input type="checkbox"/> Medicaid benefits <input type="checkbox"/> Medicare benefits <input type="checkbox"/> Other (write in response) <hr/> <hr/>
19	The person with disabilities has the following health insurance coverage	<input type="checkbox"/> Employer-sponsored health insurance <input type="checkbox"/> Medicaid <input type="checkbox"/> Medicare <input type="checkbox"/> Both Medicaid and Medicare <input type="checkbox"/> Health insurance out of pocket (paid by me) <input type="checkbox"/> Other (write in response) <hr/> <hr/>
20	<p>Since March 2020, I have paid the following amount for medical costs (including products and services) related to my/my ward's disability that my insurance does not cover</p> <p>Including money from personal funds, from family, from friends</p>	<input type="checkbox"/> 0\$ I have not paid anything <input type="checkbox"/> \$500 or less <input type="checkbox"/> \$1,000 or less <input type="checkbox"/> \$5,000 or less <input type="checkbox"/> \$10,000 or less <input type="checkbox"/> \$15,000 or less <input type="checkbox"/> More than \$15,000 <input type="checkbox"/> I don't know
21	<p>Since March 2020, I have found it hard to save money for the following:</p> <p>Pick all that apply</p>	<input type="checkbox"/> My/My ward's food <input type="checkbox"/> My/My ward's housing <input type="checkbox"/> My/My ward's transportation <input type="checkbox"/> My/My ward's education <input type="checkbox"/> My/My ward's employment training and support <input type="checkbox"/> Help for me/my ward in my home <input type="checkbox"/> My/My ward's medical expenses (medication, therapies, appointments, etc.) <input type="checkbox"/> My/My ward's assistive technology <input type="checkbox"/> My/My ward's medical devices (including wheelchair, scooter, etc.) <input type="checkbox"/> My/My ward's financial management <input type="checkbox"/> My/My ward's legal fees <input type="checkbox"/> My/My ward's funeral and burial expenses <input type="checkbox"/> Other expenses related to my/my ward's daily living (write in response) <hr/> <p>This question does not apply to me</p>

#	Question	Response Choices
22	<p>Right now, I find it hard to save money for the following:</p> <p>Pick all that apply</p>	<ul style="list-style-type: none"> <input type="checkbox"/> My/My ward's food <input type="checkbox"/> My/My ward's housing <input type="checkbox"/> My/My ward's transportation <input type="checkbox"/> My/My ward's education <input type="checkbox"/> My/My ward's employment training and support <input type="checkbox"/> Help for me/my ward in my home <input type="checkbox"/> My/My ward's medical expenses (medication, therapies, appointments, etc.) <input type="checkbox"/> My/My ward's assistive technology <input type="checkbox"/> My/My ward's medical devices (including wheelchair, scooter, etc.) <input type="checkbox"/> My/My ward's financial management <input type="checkbox"/> My/My ward's legal fees <input type="checkbox"/> My/My ward's funeral and burial expenses <input type="checkbox"/> Other expenses related to my/my ward's daily living (write in response) <hr/> <ul style="list-style-type: none"> <input type="checkbox"/> This question does not apply to me
23	<p>During the next five years, I think it will be hard to save money for the following:</p> <p>Pick all that apply</p>	<ul style="list-style-type: none"> <input type="checkbox"/> My/My ward's food <input type="checkbox"/> My/My ward's housing <input type="checkbox"/> My/My ward's transportation <input type="checkbox"/> My/My ward's education <input type="checkbox"/> My/My ward's employment training and support <input type="checkbox"/> Help for me/my ward in my home <input type="checkbox"/> My/My ward's medical expenses (medication, therapies, appointments, etc.) <input type="checkbox"/> My/My ward's assistive technology <input type="checkbox"/> My/My ward's medical devices (including wheelchair, scooter, etc.) <input type="checkbox"/> My/My ward's financial management <input type="checkbox"/> My/My ward's legal fees <input type="checkbox"/> My/My ward's funeral and burial expenses <input type="checkbox"/> Other expenses related to my/my ward's daily living (write in response) <hr/> <ul style="list-style-type: none"> <input type="checkbox"/> This question does not apply to me

APPENDIX C: Phase 1 Participant Demographics

Variable	N	%
Participant Type		
Person with an Intellectual or Developmental Disability	7	17.5
Person with a Physical Disability	7	17.5
Family Member of Person with a Disability	22	55.0
Guardian of a Person with a Disability	5	12.5
State		
Alaska	2	5.0
California	1	2.5
Colorado	2	5.0
Delaware	7	17.5
Florida	1	2.5
Hawaii	5	12.5
Maryland	3	7.5
Massachusetts	1	2.5
Missouri	1	2.5
New Jersey	1	2.5
New York	4	1.0
North Carolina	2	5.0
Oregon	2	5.0
Pennsylvania	1	2.5
Texas	3	7.5
Washington	1	2.5
Prefer Not to Answer	3	7.5
Age		
18-34	8	20.0
35-54	22	55.0
55+	10	25.0
Sex		
Man	8	20.0
Woman	32	80.0
Race		
White	27	67.5
Hispanic, Latino or Spanish Origin	1	2.5
Black or African American	2	5.0
Asian	4	10.0
Unknown/Prefer Not to Answer	4	10.0

Variable	N	%
Household Income		
\$0-\$10,000	2	5.0
\$10,001-\$20,000	1	2.5
\$20,001-\$30,000	2	5.0
\$30,001-\$40,000	2	5.0
\$40,001-\$50,000	3	7.5
\$50,001-\$60,000	6	15.0
\$60,001-\$70,000	4	10.0
\$70,001-\$80,000	0	0
\$80,001-\$90,000	0	0
\$90,001-\$100,000	4	10.0
\$100,0001+	6	15.0
Prefer Not to Answer	9	22.5
Don't Know	1	2.5

Employment*

Person with Disability

(these reflect the employment status of people with disabilities who were discussed in the study, both self reported from people with disabilities interviewed directly or reported about people with disabilities by family members and guardians interviewed)

Full-time	7	17.5
Full-time and Part Time	1	2.5
One Part-Time Job (Not Retired)	4	10.0
More Than One Part-Time Job	3	7.5
Retired	1	2.5
Unemployed (Not Retired/Disability)	2	5.0
Unemployed (Student)	4	10.0
Unemployed (Disability)	6	15.0
Unemployed (Pandemic)	2	5.0
Unemployed (Child)	3	7.5
Prefer not to Answer	7	17.5

Person without Disability

(These figures reflect the employment status of people without disabilities who participated in the studies, family members and guardians)

Full-time	16	59.2
Full-time and Part Time	1	3.70
One Part-Time Job (Not Retired)	1	3.70
More Than One Part-Time Job	1	3.70
Retired	1	3.70
Unemployed (Not Retired/Disability)	1	3.70
Unemployed (Student)	0	0
Unemployed (Disability)	0	0
Unemployed (Pandemic)	1	3.70
Unemployed (Child)	0	0
Other	2	7.41
Prefer not to Answer	3	11.1

APPENDIX D: Phase 2 Expert Feedback Survey

1	<p>What is your first and last name? (Your name will be kept confidential and is only for record keeping purposes)</p>	<p><i>Write in Response</i></p> <hr/> <hr/>
2	<p>What is your title or role in your work?</p>	<p><i>Write in Response</i></p> <hr/> <hr/>
3	<p>Which state do you live in?</p>	<p><i>Select State</i> _____</p>
4	<p>How old are you?</p>	<p>0-99 _____</p>
5	<p>What is your race or origin?</p>	<ul style="list-style-type: none"> <input type="checkbox"/> White <input type="checkbox"/> Hispanic, Latino or Spanish Origin <input type="checkbox"/> Black or African American <input type="checkbox"/> Asian <input type="checkbox"/> American Indian or Alaska Native <input type="checkbox"/> Native Hawaiian or Other Pacific-Islander <input type="checkbox"/> Multiracial <input type="checkbox"/> Other <hr/> <p><input type="checkbox"/> I prefer not to answer</p>
6	<p>Which describes you? (select all that apply)</p>	<ul style="list-style-type: none"> <input type="checkbox"/> Person with disability <input type="checkbox"/> Family member of someone with a disability <input type="checkbox"/> Guardian of someone with a disability (no family relation) <input type="checkbox"/> Directly and primarily works with people who have disabilities (e.g., service provider, case workers, special education professional, etc.) <input type="checkbox"/> Someone who works in a field focused on disabilities, but I do not work directly with people with disabilities (e.g., state professional, compliance officer, supervisor/administrator, etc.) <input type="checkbox"/> Someone who primarily works in a field not focused on disabilities, but I have people with disabilities as clients (e.g., lawyer, financial planner, etc.) <input type="checkbox"/> Other <hr/>

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