Future Financial Planning for People with Disabilities

What's Working and What's Not

The National Leadership Consortium | on Developmental Disabilities

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The National Leadership Consortium on Developmental Disabilities

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MAY & STANLEY SMITH CHARITABLE TRUST

National Leadership Consortium on Developmental Disabilities

Leadership, Values and Vision: Transforming Lives and Organizations

The goal of the National Leadership Consortium is to assure the quality and commitment of the next generation of leaders for government and nonprofit organizations serving people with developmental disabilities. The Consortium is dedicated to building a corps of qualified and capable leaders and to the promotion of sound, values-based leadership practices.

Contents

Introduction

Planning for one's financial future is integral for the wellbeing and security of people with disabilities. Today, many people with disabilities are living longer and striving to enjoy productive, self-directed lives, making the need for future financial planning more critical than ever before. However, most adults with disabilities do not have a plan in place to secure their future financial wellbeing due to numerous personal, systemic, and societal barriers. To address this discrepancy, the National Leadership Consortium on Developmental Disabilities received funding from the May and Stanley Smith Charitable Trust to investigate the current state of future financial planning by:

1. Exploring the literature and services available; and
2. Conducting a research study to reveal challenges, facilitators, and perspectives of people with disabilities, their families, and experts in the disabilities, legal, and financial planning fields.

This paper begins with a brief background of future financial planning, describing what is known about the barriers that stakeholders face in the process. The paper then summarizes results of a mixed methods study that incorporates one-on-one interviews, a national survey, and expert workshops. The paper concludes by outlining recommendations to improve future financial planning processes for people with disabilities and their families, professionals associated with planning, and recommendations related to advocacy, systems, policy, and regulations.

Key recommendations include:

- Expanding training and education for people with disabilities, family members, disability service sector professionals, and financial planning professionals about various aspects of financial management, future financial planning, and the needs of people with disabilities and their families
- Creating online resources, networks, and communities of practice that connect people involved in future financial planning with vetted and reliable information and experts who can answer questions and address issues that people face in real time
- Facilitating widespread communication and outreach to people impacted by future financial planning, focusing on the need to start planning early in a person with disabilities' life and the dissemination of helpful resources and information
- Including future financial planning in the Person-Centered Planning process for people with disabilities
- Increasing the number of benefits counselors and financial coordinators who can help people understand their savings limits, accounts options, and help people with disabilities make financial decisions
- Increasing or requiring training and credentialing, certification, or another type of standard for financial planning professionals who work with people with disabilities and their families

Ultimately, this paper is intended to describe the findings of a research study and expert recommendations. It is not intended to inform a future financial plan as it does not account for variances in state rules and regulations or situational differences. Please consult a benefits counselor and/or financial planning professional if you have questions about your or your family member's benefits, savings, or future financial accounts.

Background

Planning for the future is a priority for people with disabilities and their families. Future planning helps people with disabilities and their families arrange the resources and support necessary to acquire and maintain needed services, sustain public benefits, and assure continued meaningful quality of life across the lifetime of those with disabilities. Future planning is particularly important when family members are aging and need to secure finances, living arrangements, services, and supports for their loved ones with disabilities once they are gone.

For people with disabilities and their families, planning for and securing a person's financial future is an essential yet complicated process, particularly for families of modest financial means. Publicly funded benefits and services are necessary for many people with disabilities to meet their basic daily living and health needs; however, additional funds are also needed to buy material things or procure ancillary services that public benefits do not or cannot fund. Additionally, current policies and eligibility requirements for many benefits and services limit the amount of income and assets that people with disabilities can have and save, making it difficult to earn and save needed money while maintaining their benefits. The uniqueness of each person's level of need for financial support, degree of public services, and financial assets means there is no one-size-fits all solution, further complicating an already difficult process to navigate.

This paper focuses on the experiences, challenges, and possible solutions related to future financial planning for people with disabilities and their families. The paper begins by offering definitions and background information about the current state of future financial planning. The second section focuses on the findings of a national research project of people with disabilities, families, guardians, and professionals who are involved in future financial planning. The paper ends with expert recommendations to improve future financial planning processes and experiences for people with disabilities and their families.

What is Future Financial Planning?

Future financial planning combines elements of future planning and financial planning. There are several definitions of financial planning and future planning (see the info box below). Both future planning and future financial planning focus on the anticipated services and supports of a person with disabilities. However, financial planning concentrates on the financial needs of the individual while future planning has a broader focus, considering things like lifestyle, living situation, career, and more. For the purposes of this project, future financial planning is broadly defined as: "taking steps to make sure you have the money and services you need in the future." Because future financial planning for people with disabilities is a complex undertaking, the study incorporates elements of future planning to consider factors that can lead to ideal outcomes for people with disabilities.

Future Planning

The Arc's Center for Future Planning describes future planning as "creating a guide for a person with an intellectual or developmental disability (I/DD) to lead a good life as independently as possible."[1] The Arc (2020) includes the individual's daily routines, needs, and supports; their living arrangements; their finances (including the family and the person's public benefits, assets, incomes, trusts, and insurance policies); their medical history and doctors' contact information; decision-making support; employment; education history; as well as details about the person's employment, leisure activities, religious beliefs, behaviors, interests, friendships, and other important relationships. Scholars add that planning should also respond to issues of inclusion, citizenship, and self-determination.[2]

Future Financial Planning

Financial planning is a part of future planning and has been defined as a "process that takes into account the client's personality, financial status and the socio-economic and legal environments and leads to the adoption of strategies and use of financial tools that are expected to aid in achieving the client's financial goals."[3] Personal financial planning can incorporate things like tax planning, cash flow planning, investments, risk management, retirement planning, and estate planning.[4] For people with disabilities, Lauderdale and Huston (2012)[5] divide financial planning into the two main areas of support: one focused on the person's future and continuity of their care, and one to on providing necessary and ongoing social and emotional support.

Future Financial Planning Options

There are many financial planning options available to people with disabilities and their families. Highlighted in this report are some of the most frequently used vehicles, including ABLE accounts and Special Needs Trusts, which typically allow people with disabilities to preserve their eligibility for Medicaid and other public benefits such as Supplemental Security Income (SSI) while saving money. Other savings mechanisms, such as retirement funds, stocks, and bonds, may also be used by people with disabilities, though many of these options were not designed to address the unique needs of people with disabilities and their families, particularly related to the protection of public benefits. For a more detailed description of different types of accounts, including rules and savings limits, see Appendix A.

Who is Involved?

Many people are involved in the future financial planning process for people with disabilities and their families, and they often have overlapping roles. First, and consistent with principles and practices of personal choice, autonomy and person-centered support, the person with the disability should be regarded as the primary decision maker. For many people with disabilities, family members are a primary financial contributor to future accounts; they often have a key role in the planning and decision-making process. Family members, guardians, direct support professionals, attorneys, financial advisors, financial planners, fiduciaries, conservators, benefits counselors, attorneys, accountants, trustees, and other professionals may all contribute critical financial, educational, and legal resources.

To support people with disabilities in securing their financial future, family members or guardians (i.e., any person expected to make decisions to the benefit of the person with the disability) assume numerous and varied roles. For example, family members or guardians generally offer the first introduction to the "financial culture" — the set of traditions, norms, and ideas that reflect the level of financial literacy, skills, and behavior of people in relation to finances[6] — and set the tone for long-term saving and spending. In addition, family members and guardians may be the first to develop a savings plan and assist in creating a financial planning team for people with disabilities. Family members may also take on the responsibility of appointing a trustee to act as an advocate and make unbiased decisions with and for the person with the disability regarding their finances and spending. Moreover, family members may assume the role of trust protector or co-trustee, so they have the authority to appoint, remove, and replace the trustee as necessary.[7, 8] Regardless of the role assumed by members of the future financial team, the ultimate goal is to promote future and financial security while maintaining the autonomy and dignity of those they support.

The Current State of Future Financial Planning for People with Disabilities

Growing Numbers

Due to medical advances, increased access to healthcare, and improved living conditions, people with disabilities are living substantially longer than ever before.[9] Generally, people with disabilities in the United States now have an improved average lifespan into their mid-60s and beyond. The number of adults with intellectual or developmental disabilities aged 60 years and older is also anticipated to almost double from 641,860 in 2000 to 1.2 million by 2030.[10] The growing number of aging people with disabilities makes the need for future financial planning more urgent than ever. However, many aging people with disabilities and their families may not have knowledge of savings habits that will support them in old age. Moreover, many face external barriers that also frustrate the future financial planning process; the following section outlines the barriers that people experience.

Barriers to Future Financial Planning for People with Disabilities

Future financial planning is one of the most important actions that people with disabilities and their families can take. However, a 2017 study of more than 25,000 people found that only 44% of respondents with disabilities had long-term financial plans compared to 61% of respondents without disabilities.[11] An earlier study of siblings of people with disabilities aligned with these results, showing that only 44% of families had made decisions about or opened a future financial account for their loved one.[12] There are several individual and systemic factors that make future financial planning a significant challenge, resulting in a substantial proportion of people with disabilities and their families delaying securing their finances long-term, including the lack of long-term planning, complexity of long-term planning, poverty, economic exclusion, lack of thinking beyond the system, intersection of race, poverty, and disability, and other systemic issues.

Lack of Long-Term Planning

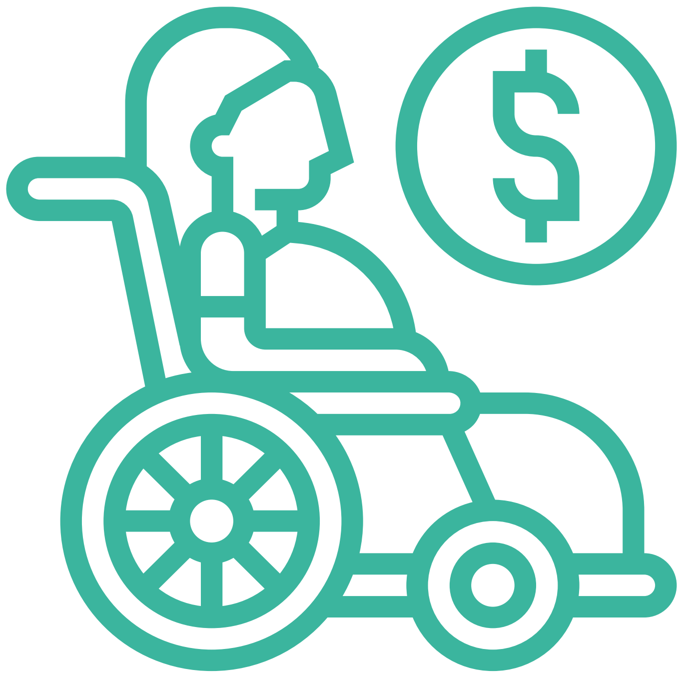
While most people with disabilities and their families are concerned about their financial futures, many struggle to engage in formal future planning. A 2010 study found that parents of people with disabilities delayed future planning for their loved ones because they lacked needed information, they had anxiety about finding and paying for the services and supports needed, and they feared facing their own mortality.[13] A more recent study supported these results, noting that families struggled to navigate complex processes and systems related to future financial planning, including finding trusted professionals and understanding regulations related to saving and maintaining public benefits.[14]

Hewitt and colleagues (2010)[13] also found that when parents of people with disabilities did plan, they often focused on short-term planning and avoided making future financial and legal arrangements needed to secure their loved one's finances after they were gone. However, their results also showed that 81% of families shared that they would be interested in receiving assistance with financial planning in the future. Although many families of people with disabilities delay future planning, increased support to navigate a complicated process may encourage more people to begin.

Complexity of Long-Term Planning

Long term financial planning is a complicated process that involves many components and systems of support. Studies of families of people with disabilities have demonstrated this complexity by asking families to describe elements of future planning that they have or plan to address. Results showed that families focused on future planning related to several aspects of their loved one's life, including day to day support, such as transportation, daily services, and medical management; long term decisions, such as where people will live, guardianship or supported decision making, and assigning a primary caregiver, or supporter (often while weighing concerns about putting the burden on siblings), and financial and legal planning.[13, 14]

From interviews with parents and siblings of people with disabilities, Lindahl et al. (2019) found that less than half of participants (44%) had discussed future financial and legal planning, including setting up and maintaining future financial accounts, selecting life insurance, writing a will, and seeking or maintaining public benefits and services. Of those, some families had begun planning, while others had not. Additional studies that focus on the planning actions of people with disabilities themselves are needed to understand concerns and issues they face in the future planning process.



Poverty

People with disabilities and their families experience higher rates of poverty and/or often struggle to make ends meet.[15, 16] Poverty or living with low income significantly limits people's opportunities to save and secure their financial futures, resulting in people with disabilities and their families being less likely to engage in short- or long-term financial planning. This is demonstrated in a 2017 National Disability Institute study that showed 55% of people with disabilities reported that they would not be able to raise $2,000 in a month (compared to 32% of respondents without disabilities) and 63% had concerns they will run out of money before or during retirement.[15]

The existing wage gaps or unemployment for people with disabilities, as well as eligibility restrictions on public benefits based on financial resources often relegate people with disabilities to a life of poverty and inhibit their ability to save money. People with disabilities are less likely to be employed and if they do have a job, are more likely to have low incomes. In 2019, only 38.8% of individuals with disabilities in the U.S. aged 18-64 living in the community were employed, while 78.6% of similar age adults without disabilities were employed. The median earnings of non-institutionalized people with disabilities aged 18-64 is about $23,848, which is well below the median U.S. individual income of $31,133.[17, 18] The median earnings of full-time, full-year people with disabilities with competitive employment in the community is $39,297, which is still more than over $7,000 less than their non-disabled counterparts[19] (see Figure 1). Additionally, asset limits for public assistance programs, such as having to keep resources below the threshold to qualify for Medicaid and means-tested programs where people have to have low incomes to qualify, obstruct and disincentivize saving.[20] As a result, the poverty rates of non-institutionalized working-age (21-64) people with disabilities in the U.S. is 26%, compared to 10% of people in the same age group without disabilities.[21] Further, the recent pandemic is sure to have negatively impacted these historically disparate numbers.[20]

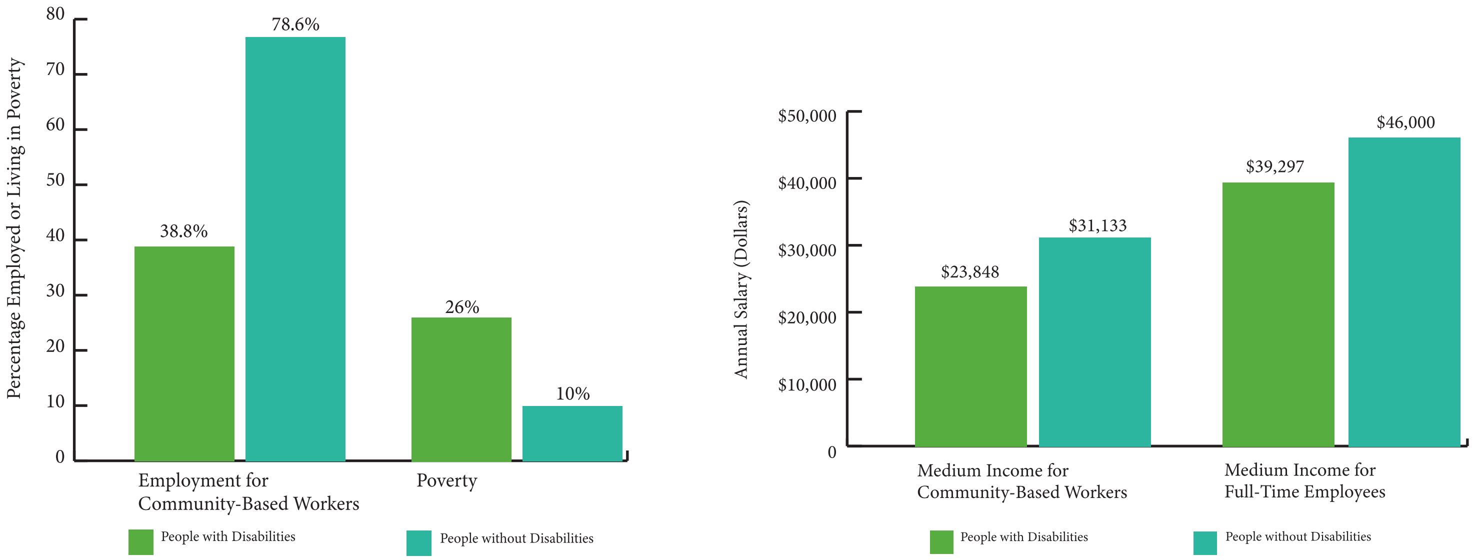


Figure 1. Employment, Income, and Poverty Differences Between People with Disabilities and People without Disabilities

Economic Exclusion

People with disabilities overwhelmingly experience economic exclusion,[22, i] which perpetuates poverty and dependence on insufficient services and public benefits. Several factors contribute to economic exclusion of people with disabilities, including underemployment,[23, 18] lack of access to and use of banks and accessible banking services,[15] under-enrollment and completion of degrees of higher education,[24] and fewer educational opportunities or support to manage day to day and long-term financial decisions.[15] This exclusion results in people with disabilities having less financial knowledge and support to make sound decisions about their money.[15]

A study by the Federal Deposit Insurance Corporation (FDIC) in 2015,[24] demonstrated the day-to-day impact that economic exclusion has on people with disabilities. Specifically, they examined the inclusiveness of the banking system and found that households having a person with a disability were less likely than other households to have an account at an insured institution or more likely to use alternative financial services (e.g., money orders, or check cashing services) even if they did have an account.[24] Households of people with disabilities were also less likely to have a savings account, more likely to have no credit, more likely to keep savings at home or with family or friends rather than in savings accounts, and less likely to save for unexpected expenses.[15]

Thinking Beyond the System

People with disabilities often become dependent on social services, and since many resources are not accessible through government support, they are at risk for getting trapped in a cycle of poverty that may impact their wellbeing or quality of life. About 65% of working-age people with disabilities receive some public benefits, such as housing, health care, or childcare support, compared to only 17% people without disabilities.[25] Although government agencies can supply financial support for critical services such as health insurance, disability insurance, housing, and social security income and insurance, as well as services like employment training, emotional support animals, and respite care,[26] public benefits may not provide resources for activities like vacations and hobbies in retirement.

[i] 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…"

This is critical, as such activities empower individual freedom, creativity, and enhance one's quality of life. Moreover, if someone is limited to government support, their investment options, such as stocks, bonds or homeownership, are also limited, keeping them from investing in things that increase in value over time, including investments that could benefit future generations. empower individual freedom, creativity, and enhance one's quality of life. Moreover, if someone is limited to government support, their investment options, such as stocks, bonds or homeownership, are also limited, keeping them from investing in things that increase in value over time, including investments that could benefit future generations.

Intersection of Race, Poverty, and Disability

Systemic inequality, particularly ableism, racism, and classism also contribute to increased disparity for people who have intersecting identities.[16] In general, people of color, especially Black people with and without disabilities, have poorer health outcomes and lower incomes than white people.[27, 28] The intersection of race and disability compounds poverty, particularly for Hispanic and Black people. Further, Hispanic and Black people with disabilities are also much less likely to participate in higher education[29] and are more likely to be underbanked.[24] These compounding factors lead to people with intersecting marginalized identities experiencing even higher rates of economic exclusion and decreased support and opportunity to plan for their financial futures.

Systemic Issues

To address their financial planning needs, people with disabilities and their families must navigate social and disability sector systems related to public benefits, services and supports as well as financial and legal systems that will help them plan for their financial futures. Many people with disabilities and their families struggle to navigate the process, fearing they will end up losing their needed benefits and services.[14, 30] Their concerns are valid. There is little coordination between the disability service sector and financial planning sector. Further, there are limited requirements for professionals who provide financial planning and legal services for people with disabilities and their families, meaning that professionals can (and sometimes do) advise people to make decisions that threaten their eligibility for benefits and services.

There are several organizations that are working to address these issues, such as The Arc's Center for Future Planning, the National Disability Institute, The National Academy of Elder Law Attorneys, various local programs, and service providers. These organizations help people with disabilities and their families by providing tools, resources, and training to help them begin the process of future planning, including future financial planning. Additionally, there are training and education opportunities for professionals who support people with disabilities and their families in the future financial planning process as well as organizations that conduct research, advocate, and provide resources and guidance to people who are involved in future financial planning.[ii] More research is needed to understand the impact that these entities have on mitigating challenges that people with disabilities and their families face as they engage in future financial planning.

[ii] Many national organizations that are dedicated to improving future financial planning for people with disabilities were repeatedly mentioned in the interviews and expert meetings, including: The Arc, the National Academy of Elder Lay Attorneys (NAELA), the National Disability Institute (NDI), the Special Needs Alliance (SNA), the Academy of Special Needs Planners, the Society of Settlement Planners, and Stetson University College of Law. Additionally, banking and Insurance institutions that have programs designed to assist in future financial planning such as Mass Mutual's SpecialCare, Merrill Lynch's Special Needs Services and MetLife's Center for Special Needs Planning were noted as beneficial resources. Many participating experts also praised the professional training programs of Virginia Commonwealth University and Cornell University that results in benefits practitioner certifications (e.g., Work Incentives Specialist Advocate (WISA), Community Work Incentives Coordinator (CWIC), Community Partner Work Incentives Counseling (CPWIC)). These courses educate professionals about how work government assistance programs such as social security disability benefits, Medicaid, work incentives, and employment support programs work in conjunction with future financial planning to help support employment and financial independence for people with disabilities. Please visit www.vcu-ntdc.org and www.ytionline.org for more information about these training programs.

It is essential to understand the issues that people with disabilities and their families experience related future financial planning, as well as the solutions that can begin to address them. Financial health is a critical factor in the wellbeing of people with disabilities and is listed as one of the five Social Determinants of Health, among access to quality education, access to quality health care, neighborhood and built environment, and social and community context, by the Office of Disease Prevention and Health Promotion (2020).[31] The issues outlined here demonstrate the impact of long term economic and employment exclusion and the complexity of navigating the financial planning process while complying with rules and regulations related to earnings, assets, and maintaining public benefits.

Future Financial Planning Project

Overview

The National Leadership Consortium on Developmental Disabilities at the University of Delaware was funded by the May and Stanley Smith Charitable Trust to study future financial planning for people with disabilities and develop a framework of best practices and recommendations to the field. The mixed methods study was launched in June of 2020 and consisted of three phases of data collection: 1) Interviews; 2) National Survey; and 3) Expert Workshops. Interviews took place throughout the summer of 2020, which 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[iii] and family members of people with disabilities then met in May of 2021 to discuss the current state of future financial planning for people with disabilities and suggest the direction for next steps. Data collection for the project was completed at the end of May 2021.

Phase 1 — Interviews

Phase 1 of the study was conducted in summer 2020 and consisted of open-ended interviews with key stakeholders of future financial planning for people with disabilities. Forty people were interviewed, including: people with physical, intellectual, or developmental disabilities (4); family members of people with disabilities (9), financial and legal experts, including financial planners, people who manage trusts, and attorneys specializing in disability law (10); people working to support people with disabilities, such as direct support professionals, case managers, agency leaders, transition coordinators, etc. (10); and other experts on the topic, including scholars, authors, and advocates (7). For a more in-depth description of the interview process, see Appendix B.

Barriers to Future Financial Planning

Barriers to future financial planning for people with disabilities discussed during interviews were sorted into four central themes: societal issues, systemic issues, professional issues, and family issues. Societal issues divided into challenges related to society as a whole (e.g., lack of a savings culture and the cultural norm of not talking openly about finances) and then challenges related to how society views and treats people with disabilities (e.g., the legacy of oppression and marginalization experienced by people with disabilities and the view that people with disabilities cannot or should not be in control of their finances). Systemic issues referred to government-related shortcomings (e.g., lack of knowledge by government employees and judges about disabilities benefits and eligibility and outdated, limiting, or confusing policy related to future financial planning), as well as issues with processes in the legal, financial, and disabilities fields (e.g., the legal and financial fields being focused on money and not quality of life or other considerations beyond finances, and the disability field being short-sighted and focused on daily expenses instead of long-term financial standing).

Professional issues were problems noted for professionals across all fields in relation to future financial planning, including not enough training, misinformation, little or no follow up, and that it is a specialized area with a limited number of professionals who have the necessary expertise. Family issues discussed during interviews broke down into subthemes having to do with family (e.g., how much time, resources, money, knowledge, and family involvement people have), mindset (e.g., feelings of overwhelm and fear), values (e.g., how to use the money and who should be in control of decision making), and context for the person with disabilities, which greatly influences how they go about future financial planning (see Figure 2).

[iii] For this study, "disability" was self-identified and categorized as one of the following: intellectual or cognitive disability, developmental disability, physical disability, autism or ASD, mental illness or psychiatric diagnosis, deaf or hard of hearing, blind or low vision related disability, brain injury, learning disability (e.g., ADHD, dyslexia, etc.), sensory disability, or chronic illness. Participants were also able to select "other" and write in their own disability. This survey did not distinguish between developmental and acquired disabilities. The definition of disability and opportunity to self-identify align with definitions and methods of the American Community Survey.

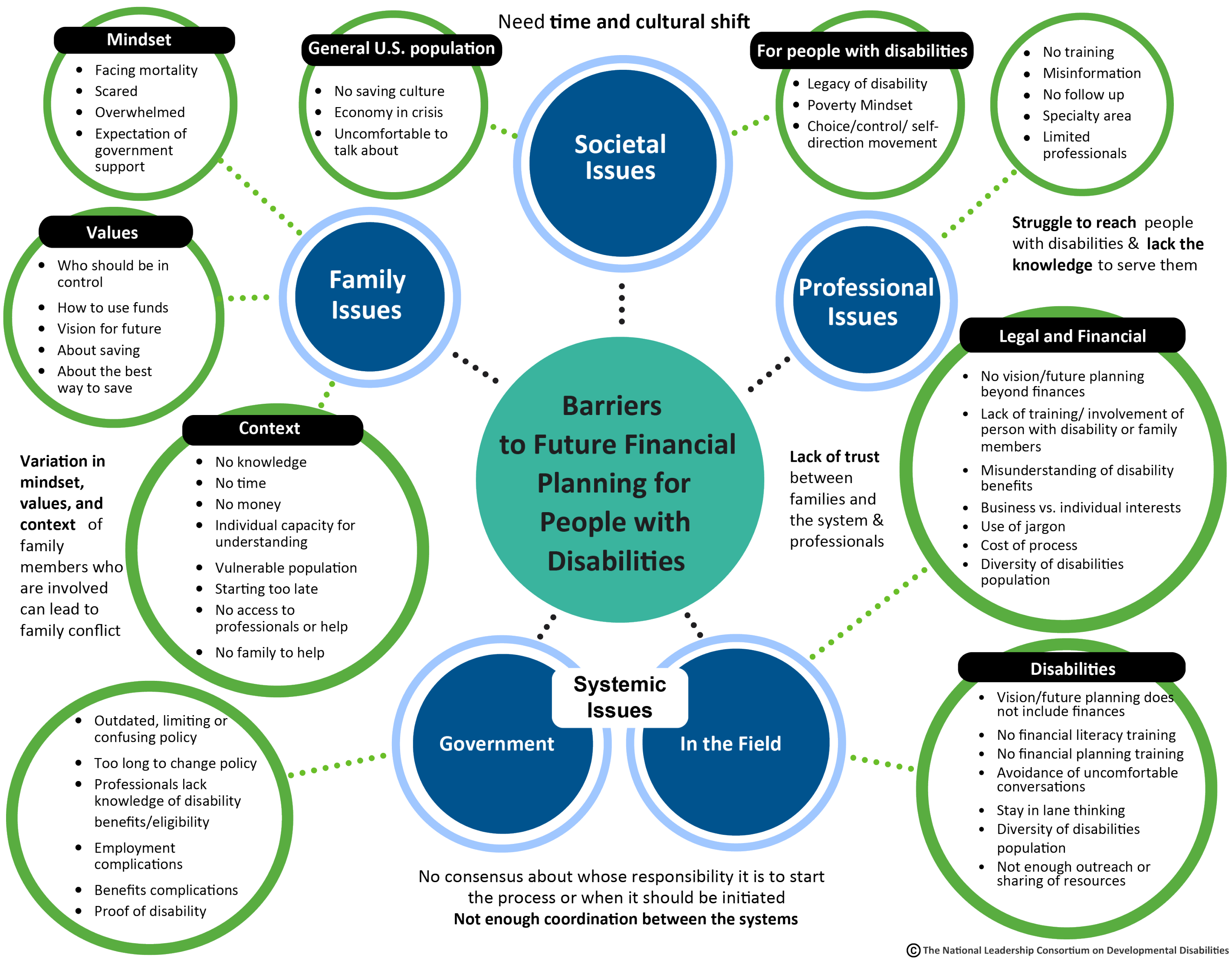


Figure 2. Barriers to Future Financial Planning for People with Disabilities

There were many additional themes among these barriers that repeatedly surfaced across different stakeholder groups. Interviewees often mentioned the siloed nature of future financial planning, with each type of expert knowing about their specific area, but not how it relates to the complexities of everything in the person's life. For example, interviewees shared that an attorney may be an expert in legal issues but may not know how to set up accounts that do not conflict with public benefits. Also, there was no consensus about who the first point of contact should be for a person or family entering the planning process. Family members and professionals alike spoke frequently about not knowing who to trust and not knowing the right questions to ask to properly vet experts. Most professionals agreed that there was a lot of information about future financial planning on the Internet and there were organizations and professionals doing work devoted to helping people with future financial planning, but that communication efforts were not sufficient to connect people to the appropriate resources.

Facilitators to Future Financial Planning

Facilitators to future financial planning for people with disabilities discussed during interviews were also sorted into four central themes: family facilitators, societal facilitators, government facilitators, and professional facilitators. Family facilitators divided into themes related to mindset/values (e.g., starting early and facing the sensitive issue of what happens after the family is gone), skills (e.g., the ability to research independently and have good financial literacy skills themselves), and context (e.g., having a family that is involved and having other family members who have gone through similar processes of setting up accounts). Some key societal facilitators included people having high expectations for people with disabilities as well as having a greater vision for the futures of people with disabilities. On the topic of government facilitators, interviewees expressed that more benefits counselors to assist families in navigating the systems would be integral to improve future financial planning. They also discussed policy changes that would support people with disabilities in saving without losing their benefits. Professional facilitators broke down into facilitators related to the disabilities field (e.g., disabilities staff serving as a connection to experts in future financial planning and helping to advocate for policy change to better future financial planning prospects for people with disabilities) and facilitators related to the legal and financial fields (e.g., having guiding principles that were aligned with self-direction and having a broader vision for the person with disabilities beyond financial concerns, such as social and emotional wellbeing) (see Figure 3).

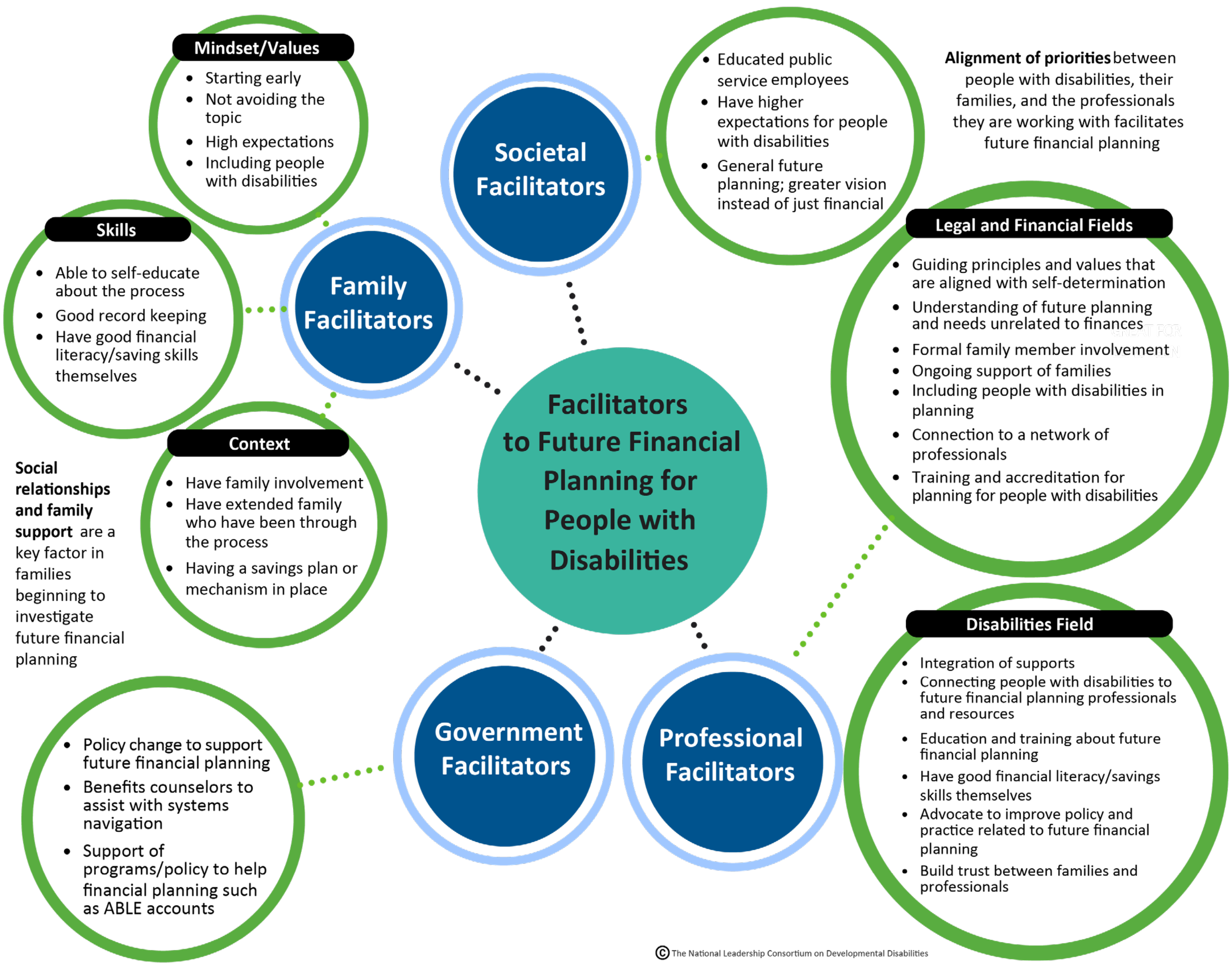


Figure 3. Facilitators to Future Financial Planning for People with Disabilities

Interconnecting themes across facilitators included the person with disabilities, the family, and professionals having a shared vision and aligned values when creating and maintaining accounts, and social relationships (e.g., the encouragement and experience of family and friends). Interviewees consistently identified these as key factors that influenced whether people began or continued the process of future financial planning.

The themes from the interviews in Phase 1 of the project informed survey development in Phase 2 of the study, which was designed to reach a wider population of similar stakeholders.

Phase 2 — Survey

Survey Description

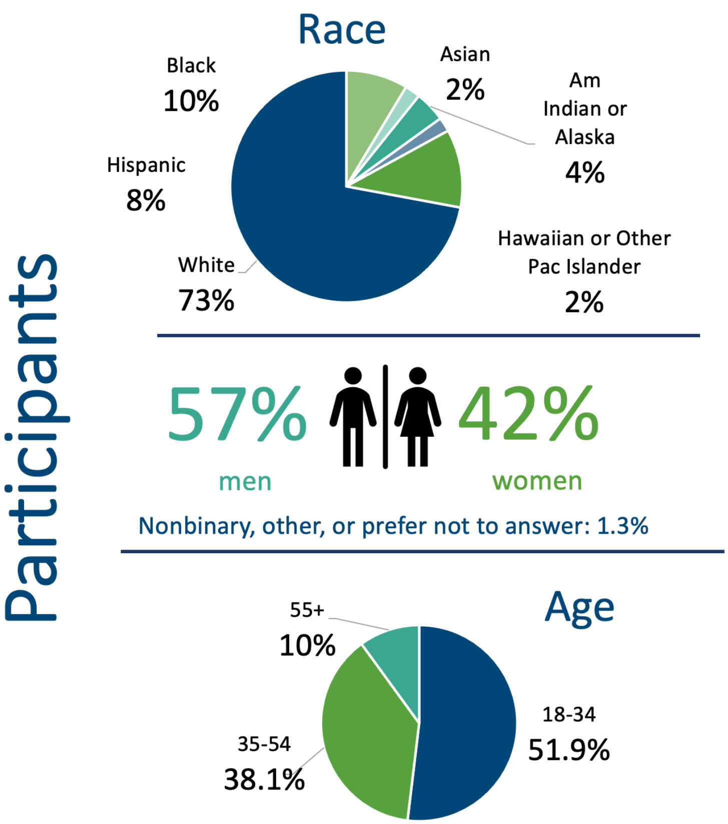
A national web-based survey was developed in the Winter of 2020-2021 with the intent of capturing the perspectives of people with disabilities, family members of people with disabilities, and professionals and experts in the financial, legal, and disabilities fields. The survey had six different tracks that steered participants to different questions related to how they identified, including:

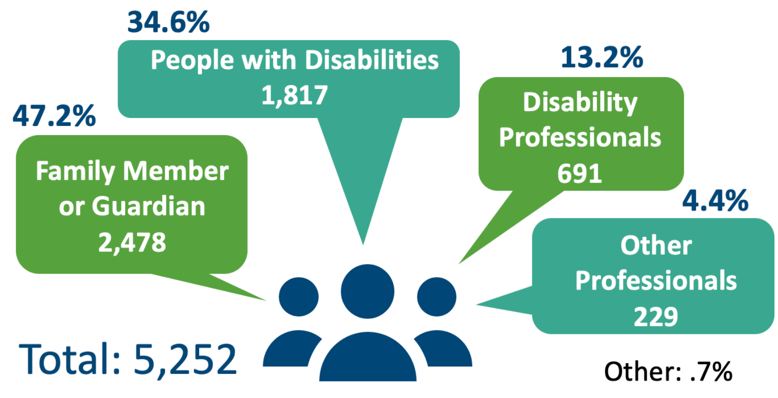
- Person with a disability[iv]
- Family member of a person with a disability
- Guardian of a person with a disability (no relation)
- Someone who directly and primarily works with people with disabilities (e.g., service providers, caseworkers, and special education professionals),
- Someone who works in a field focused on disabilities but does not directly work with people with disabilities (e.g., state agency professionals or compliance officers)
- Someone who primarily works in a field not focused on disability but has people with disabilities as clients (including attorneys and financial planners)
- The survey asked participants about various aspects of their experience and expertise related to future financial planning, including information about accounts, financial literacy, training, and barriers and facilitators that impact the future financial planning process. For the purposes of the survey, future financial planning was defined as "taking steps to make sure you have the money and services you need in the future."

Participants

Ultimately, 5,252 people completed the survey and met the requirements for participation. Most survey respondents were family members of people with disabilities (39.4%), followed by people with disabilities themselves (34.6%), professionals working in a disabilities-related field (13.2%), guardians of people with disabilities (7.8%), and professionals working in a non-disabilities related field (4.4%). Respondents were slightly more male (57.2%), mostly White (72.8%), largely from the southern U.S. (49.6%), and predominantly ages 25-34 (43.1%). Half of the survey participants were employed full-time, with another 12% having a part-time job in addition to a full-time job, 11.5% having just one part-time job, and 6.3% being on disability benefits and unemployed. Half of respondents (50.4%) were middle income, earning $40,000-$100,000 annually while 30.7% were low-income ($0-$40,000) and 17% were high income ($100,001+) (see Figure 4 and Appendix C).

[iv] For this study, "disability" was self-identified and categorized as one of the following: intellectual or cognitive disability, developmental disability, physical disability, autism or ASD, mental illness or psychiatric diagnosis, deaf or hard of hearing, blind or low vision related disability, brain injury, learning disability (e.g., ADHD, dyslexia, etc.), sensory disability, or chronic illness. Participants were also able to select "other" and write in their own disability. The definition of disability and opportunity to self-identify align with definitions and methods of the American Community Survey.





Types of Accounts

ABLE Account	954	28%
First Party Trust	903	26%
Third Party Trust	557	16%
Other Savings in Person's Name	500	14%
Pooled Trust	302	9%
Other Savings Not in Person's Name	230	7%

Figure 4. Survey Participant Demographics

Survey Analysis

Demographic information was used frequently in analyses to distinguish differences between groups of respondents. Specifically, differences among the perspectives of respondents of various incomes, ages, employment status, disability types, and belonging to different survey respondent groups (e.g., family member, professional) were of particular interest. Some of these data were collapsed into new groups to facilitate analyses. For example, the original survey question asked participants which state they lived in, and those responses were collapsed into four U.S. regions. Some demographic data was too imbalanced to perform analyses that showed differences between groups. For example, having nearly 73% of the respondents identifying as white did not allow for powerful analyses between different racial groups.

Key Survey Findings

Plan and Account Indicators

To establish a basic understanding of the perspectives of different groups of respondents related to future financial planning in general, we asked participants to rate on a scale of 0 (not important at all) to 10 (very important), "How important is it for a person with disabilities to have a future financial account or saving plan?" The average responses for people with disabilities (6.82) were very similar to the average responses of family members and professionals in the disabilities' fields (6.9) and professionals working in non-disability fields (7.0). Guardians gave a statistically significant lower average rating than other groups of respondents (5.7) for the importance of future financial planning for people with disabilities. While most ratings given were 5 or above, a total average rating of about 7 out of 10 shows that many people consider future financial planning for people with disabilities relatively important, but not very important (see Figure 5). For a more detailed description of results related to plan and account indicators, see Appendix D.

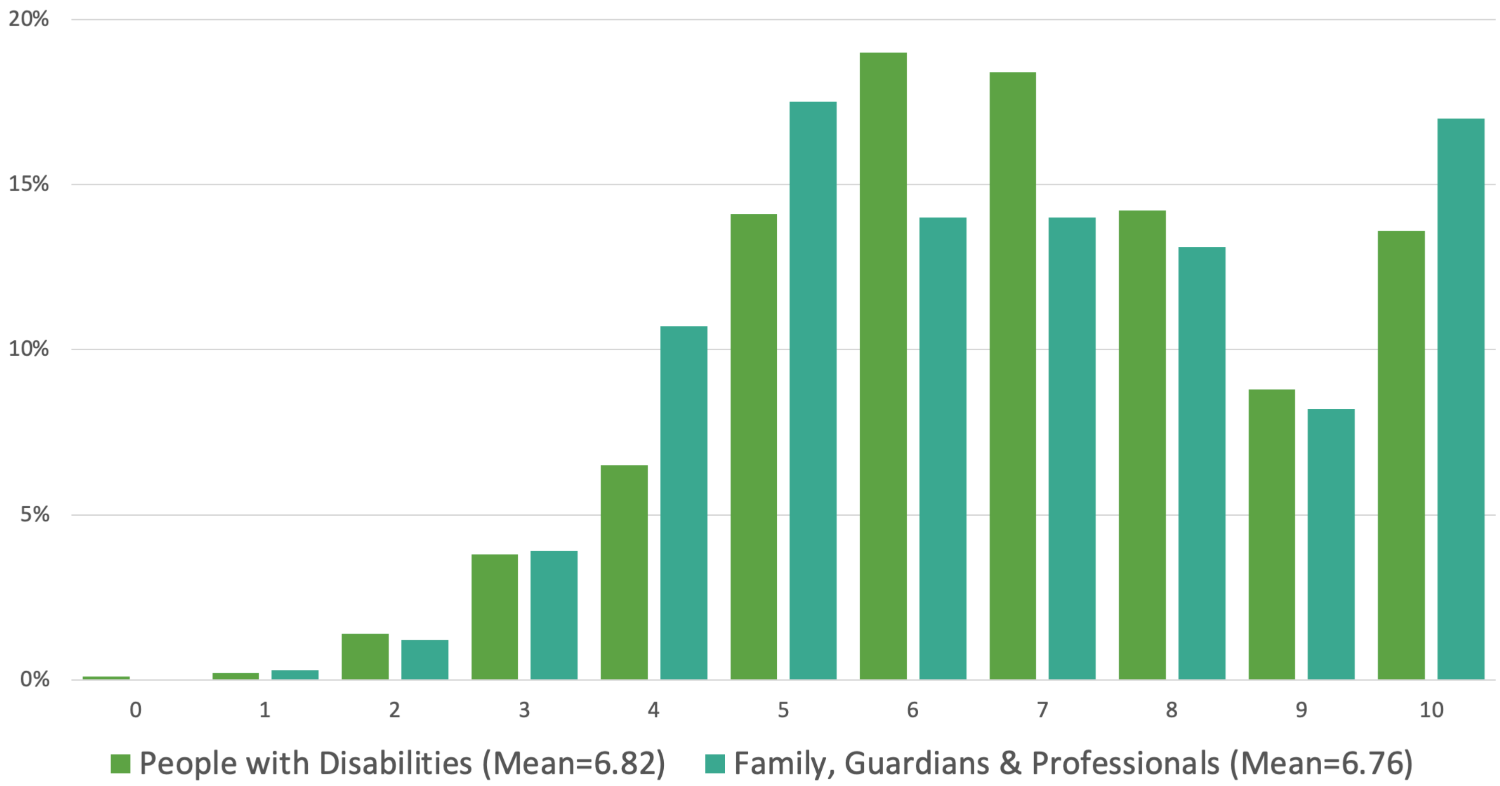


Figure 5. Importance of Future Financial Planning for People with Disabilities (n=4,776)

We also asked groups other than people with disabilities if they had a plan for their financial future that was anticipated to sustain them during retirement. The majority of families, guardians, and professionals (79.3%) said they did have a financial plan in place for themselves, while 16.5% said they did not and 4.2% said they were not sure.

In this survey, questions related to accounts focused on the most popular types of savings mechanisms mentioned by respondents in Phase 1, including ABLE accounts, first party trusts, third party trusts, pooled trusts, and other savings accounts or plans either in the name of the person with disabilities or in a family member's name. People with disabilities and their families were asked in the survey to indicate if they had an account and which specific accounts they had. Their responses were evaluated to assess if income and disability-type were associated with having certain types of accounts.

Results of the survey show that, overall, about 65% of people with disabilities and family members of people with disabilities had a future financial account; this percentage was fairly consistent across income levels. Differences were noted in disability type. People with intellectual disabilities were more likely to have an account (42%) than people with developmental, physical, sensory, or "other" disabilities (including psychiatric). Specific types of accounts were then analyzed across income and disability categories to assess if income and disability type are associated with having a certain account. This information can support a better understanding of the individual factors that impact the accounts people select or access. Figure 6 shows the amount, the household incomes, and the disability types most likely to be associated with specific accounts. For more detailed information about participants their accounts, please see Appendix C.

The results showed that people and families with higher incomes (more than $100,000) were more likely to use first and third party trusts and other types of savings accounts that are in a third party's name. However, people with lower incomes (below $100,000) were more likely to use pooled trusts, ABLE Accounts, or savings accounts in their own name. These findings are not surprising as some financial institutions require families and people with disabilities to maintain a substantial minimum balance in these types of trusts. Similarly, these trusts can be taxed at higher rates, making them cost more for people with disabilities and their families. However, first and third party trusts may also offer more control over how funds are spent by people with disabilities over time.

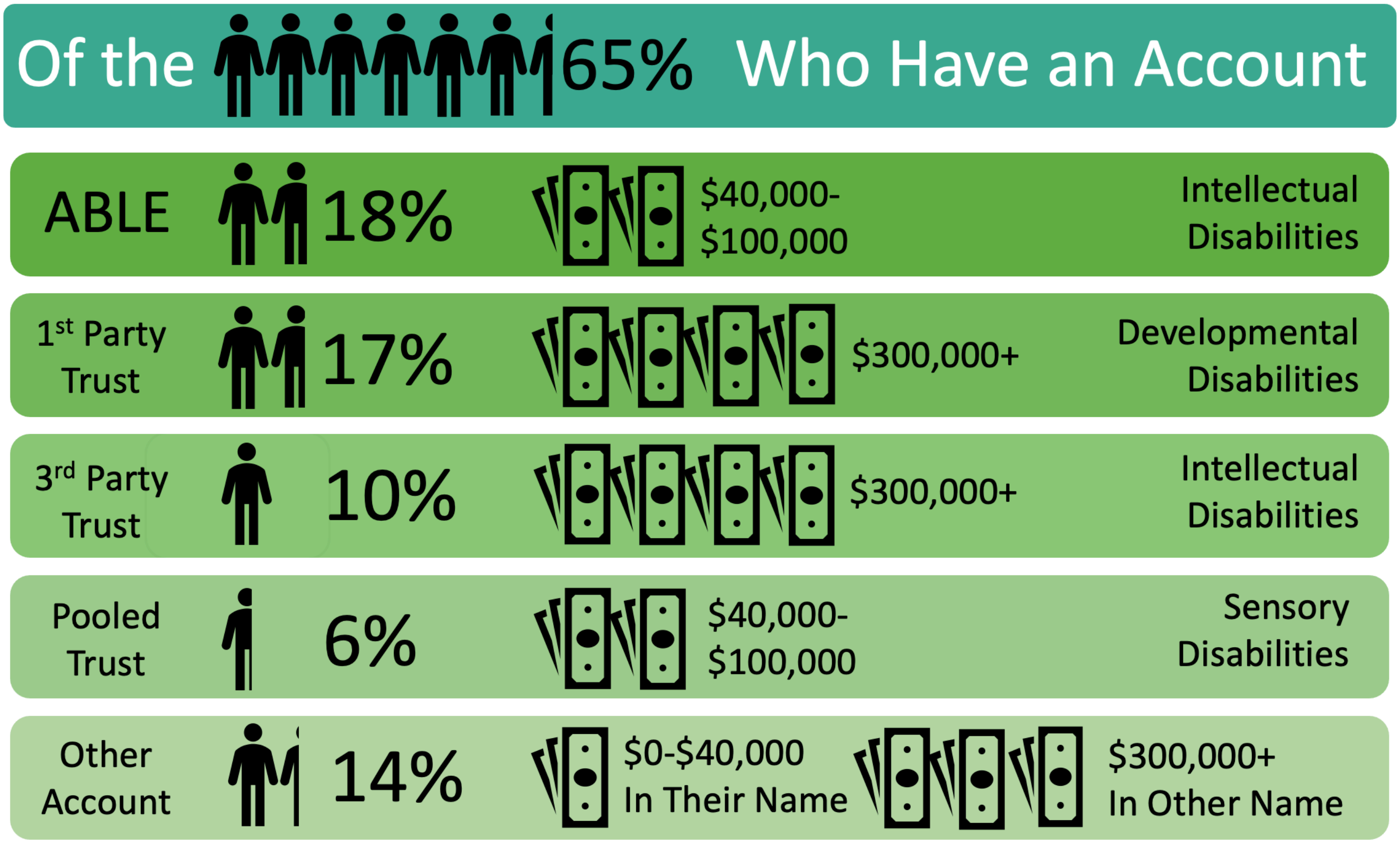


Figure 6. Percentage of Participants, Household Incomes, and Majority Disability Types for Types of Accounts

In addition to income and disability-type, financial literacy and support were strongly correlated with having an account. People with disabilities and their families were asked if they had training or help with saving or spending money. A bivariate correlation revealed an association between having at least some help or financial training and having an account. People with disabilities who received ongoing help with their finances were most likely to have an account (93%), while those who have never received training were least likely to have an account (30%). These findings suggest that people who have at least some help or financial training were more likely to have a financial planning account than people who have not had help or financial training, indicating that increasing access to help or financial training for both people with disabilities and their families may support improved financial outcomes. These findings demonstrate that financial training may be an effective strategy to increasing the access and utilization of future financial accounts.

Barriers

A primary focus of this project was to collect information about the barriers to future financial planning experienced by people with disabilities, their families, and professionals. Knowing the reasons why people do not have accounts, the challenges professionals and families face during the process of setting up or maintaining accounts, and the aspects of the process they believe to be most troublesome can help target prospective efforts to alleviate these issues and encourage people with disabilities to plan for their future.

The survey asked people with disabilities and family members of people with disabilities who indicated that they or the person in their life with disabilities did not have a future financial account to select the top five reasons for not having an account. They chose from 17 suggestions that were commonly heard in Phase 1 of the study. Participants were also given the option of writing in a reason. The top five reasons selected by people with disabilities and families of people with disabilities are included in Figure 7. The results reveal that both people with disabilities and their family members have fears related to losing public benefits and that neither group knew enough about future accounts to feel comfortable having one.

People with Disabilities	Family Members
Don't have enough money (97)	Afraid to lose benefits (320)
Too expensive (84)	Takes too much time (282)
Afraid to lose benefits (70)	Didn't think their money would be safe (227)
Afraid rules will change (70)	Don't know enough about them (211)
Don't know enough about them (63)	Too hard to set up (199)

Figure 7. Top 5 Reasons for Not Having a Future Financial Account

Overall, when asked to rate their experience with future financial accounts on a scale from 0 (very negative) to 10 (very positive), ratings tended to be slightly positive, with people with disabilities giving an average rating of 6.2, family members of people with disabilities giving a rating of 6.2, and guardians giving an average rating of 5.5. At the same time, the majority of respondents had experienced challenges during the future financial planning process, including 73% of people with disabilities, 54% of family members, and 71% of professionals (see Figure 8).

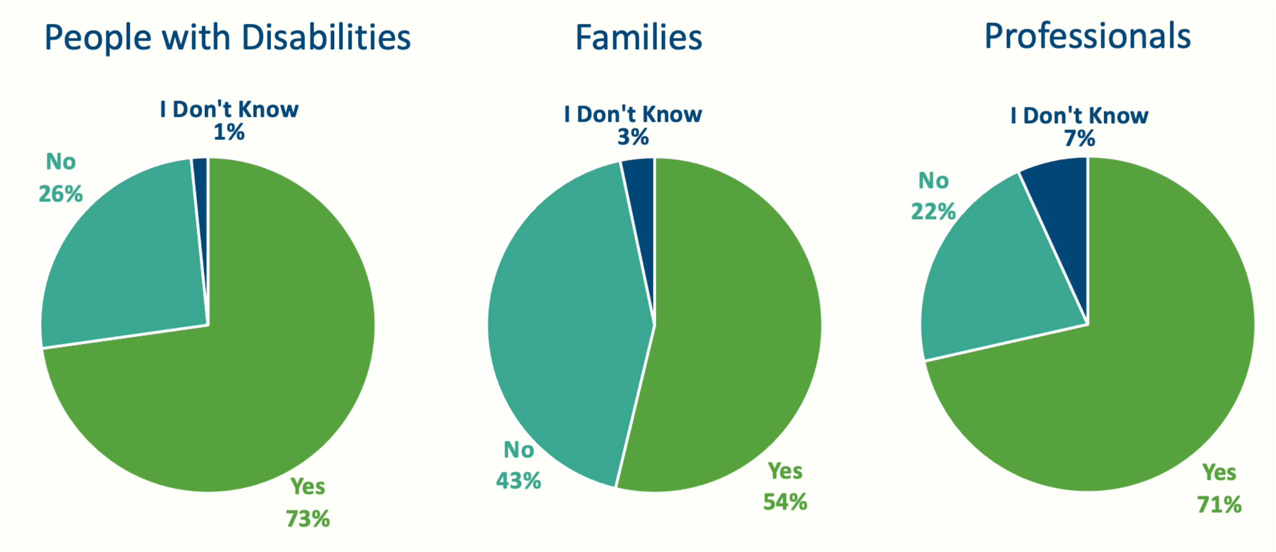


Figure 8. Percentage of Participants Who Experienced Challenges During Future Financial Planning Process

Survey participants were given six categories (i.e., societal, legal, organizational, professional, family, people with disabilities) and asked to choose which category was related to their biggest challenge related to future financial planning. Respondents in all three participant groups identified challenges in the "legal" and "societal" categories as the most impactful. Specifically, the "legal" category was the second most selected by families and professionals taking the survey and the third most selected category by people with disabilities. The "societal" category was the second most selected category by people with disabilities and the third most selected category by families and professionals.

Participants were then asked to select a more specific challenge that described what they experienced within the top barriers category they selected. Although the categories selected were sometimes different, the top challenges selected all centered around saving practices (see Figure 9). The top selected response from people with disabilities was in the families category: "Families of people with disabilities do not plan and save money for themselves." The top selected response from family members of people with disabilities was in the legal category: "Rules and laws don't let people with disabilities save a lot of money and keep their services." The top selected response from professionals was also in the legal category: "Rules and laws make it too hard for people to save their money in savings accounts (e.g., ABLE Accounts or Special Needs Trusts)."

Examining the top three responses for each group reveals potential areas for targeted development in the future. Findings indicate that saving practices of people with disabilities and their families could benefit from training and support. All groups surveyed also pointed to future financial planning rules and laws that were limiting and put saving for the future at odds with keeping disability services or benefits, indicating the need for a closer examination of how policies and regulations in the financial sector relate to those in the disability sector. Finally, all groups indicated the need for a better societal understanding of the rights and abilities of people with disabilities to have control of their financial future.

Group	Barrier Category	Barrier
People with Disabilities	Families (241)	Families of people with disabilities do not plan and save money for themselves
	Societal (141)	Many people believe that people with disabilities can't understand, manage, and save money
	Legal (138)	Rules and laws don't let people with disabilities spend their money how they want
Families	Legal (140)	Rules and laws don't let people with disabilities save a lot of money and keep their services
	People with Disabilities (123)	People with disabilities do not have the help they need to plan and save their money
	Societal (117)	Many people believe that people with disabilities can't direct their own lives
Professionals	Legal (128)	Rules and laws make it too hard for people to save their money in savings accounts (ABLE, Special Needs Trusts, etc.)
	Families (127)	Families who don't have a lot of money do no think they can save their money
	Societal (102)	Many people believe that people with disabilities can't understand, manage, and save money

Figure 9. Top Three Barriers to Future Financial Planning Selected by People with Disabilities, Family Members, and Professionals

Examining the top three responses for each group reveals potential areas for targeted development in the future. Findings indicate that saving practices of people with disabilities and their families could benefit from training and support. All groups surveyed also pointed to future financial planning rules and laws that were limiting and put saving for the future at odds with keeping disability services or benefits, indicating the need for a closer examination of how policies and regulations in the financial sector relate to those in the disability sector. Finally, all groups indicated the need for a better societal understanding of the rights and abilities of people with disabilities to have control of their financial future.

Additionally, the survey asked respondents to rate their confidence related to four different aspects of future financial planning on a scale from 0 (not sure at all) to 10 (very sure about it). There were no significant differences between families and professionals in ratings of confidence in "the rules and laws about future financial accounts staying the same," "professionals knowing what they need to know to set up and manage future financial accounts," and their confidence in "professionals who work on future financial accounts to do what is best for the person with disabilities." There was, however, a statistically significant difference in the average score related to confidence in "family members or guardians to do what is best for people with disabilities," with professionals giving an average rating of 5.9 and families giving a higher average rating of 6.3. Average ratings by family members for all four aspects ranged from 5.1 to 6.3 and scores for professionals ranged from 5.3 to 5.9. High ratings capping at about 6 out of 10 from both groups show that there is not total confidence in the capacities and intentions of family members, future financial planning professionals, and in the stability of the policies governing financial planning for people with disabilities.

Facilitators

People with disabilities and family members of people with disabilities who reported having a future financial account were asked what they thought helped make it easier for them to have an account. Knowing what facilitates future financial planning could reveal areas that should be emphasized or scaled up by professionals to help people create and maintain accounts. The same facilitator related to having a clear vision for the person with disabilities was selected by most people with disabilities and family members (see Figure 10). These results further reinforce

People with Disabilities	1 (341)	I have a clear vision for myself
	2 (267)	I have strong familiy support/involvement
	3 (232)	I have friends who support me
Families	1 (198)	I have a clear vision for my family member with disabilities
	2 (197)	I went to a class about future financial planning
	3 (179)	I have strong family support/involvement

Figure 10. Top Three Facilitators to Future Financial Planning Given by People with Disabilities and Family Members

a common theme from families and professionals in Phase 1 of the study, that future financial planning should be considered in relation to future planning, which takes into consideration the goals and desires of all areas of a person's life throughout the lifespan.

People with disabilities also found strong social support from their families and friends to be helpful in future financial planning, which may indicate an area of concern for people with disabilities who are more socially isolated or have less involved family members. Family members named going to a training or class about future financial planning as a key facilitator to their future financial planning, indicating that training could be a strategy that should be scaled up to reach more families. Family members also indicated that strong family support or involvement helped them in the future financial planning process, again emphasizing the important role of social relationships in future financial planning.

Point of Entry

Knowing how, when, and where people began the future financial planning process can help inform intervention and training strategies to promote service access and financial planning outcomes. The survey asked all respondents (i.e., people with disabilities, families, guardians, and professionals) to consider questions related to point of entry, or how and when they begin planning for a person's financial future. Specifically, survey participants were asked to share the ideal age that people should begin future financial planning, as well as the age that they actually did begin future financial planning. They were also asked to share who should begin the process of future financial planning, as well as who, in their experience, did begin the process.

Interviews with experts during Phase 1 of the project revealed that many people with disabilities and families delay future financial planning until they are aging or in crisis, which can put them in the difficult position to need to quickly make important decisions about their futures without the support and information needed. However, people with disabilities and their families are not alone in this challenge; recent research shows that many Americans, including millennials and those in older age groups, are not on track to meet their retirement savings goals,[32,33] and 34% of American adults have not engaged in any form of financial planning or saving.[34]

Results showed that most respondents believed that people with disabilities and their families should begin future financial planning in young adulthood or earlier. A Kruskal-Wallis one-way ANOVA further showed that families members and disability service sector professionals generally responded that people with disabilities and families should begin future financial planning a bit earlier than time frames indicated by participants with disabilities, guardians, and non-disability sector professionals (see Figure 11).

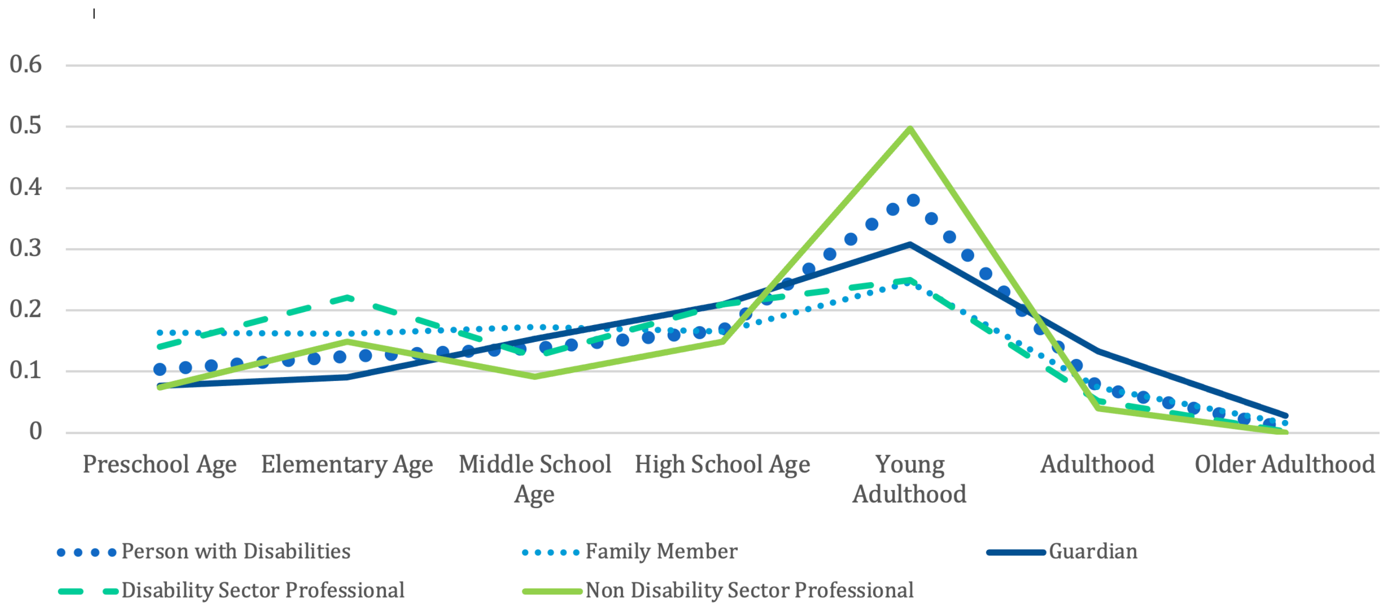


Figure 11. The Ideal Age to Start Future Financial Planning for a Person with Disabilities (n=2,790)

The survey also asked people to indicate who should and who did begin the process of future financial planning. Results showed that there was consistent alignment between these questions, in that participants felt that it is the responsibility of people with disabilities and families to begin, and in practice, those are the people who primarily started future financial planning. For more information about these findings, see Appendix E.

Financial Choice and Control

Values related to people with disabilities' short- and long-term financial choice and control were assessed among families, guardians, and professionals working either directly or indirectly with people with disabilities. They were evaluated for differences across income, age, and disability-type categories. Participants were asked if they believed people with disabilities should have choice and control in their short-term financial decisions (e.g., meals, clothing, etc.), and choice and control in their long-term financial decisions (e.g., larger purchases like a car or house, future financial accounts, etc.). Financial choice and control support individual autonomy and are aligned with the fundamental principles of person-centered practices and self-determination; consequently, assessing these values offers insight into the reception and application of self-direction among families, guardians, and support professionals.

Choice

In general, participants agreed that people with disabilities should have choice in their short-term and long-term financial decisions, and there were no significant differences regarding short- and long-term choice among participants with different annual household incomes. However, there were significant differences in the age groups of families, guardians, and professionals regarding their beliefs that people with disabilities should have choice in their short-term and long-term financial decisions. People aged 55-64 agreed most strongly that people with disabilities should have short-term choices regarding their finances, and people aged 18-34 reported the lowest level of agreement. People aged 45-54 agreed most strongly that people with disabilities should have long-term financial choice, and people 65 and over agreed the least.

Finally, there were statistically significant differences across family-reported disability types in family, guardian, and professional beliefs that people with disabilities should have choice in their short-term financial decisions, with families of people with intellectual disabilities reporting the highest level of agreement, and families of people with disabilities that include brain injury, learning disability, chronic illness, and mental illness reporting the lowest level of agreement. There were no significant differences related to long-term choice among disability groups.

Control

In general, participants agreed people with disabilities should have control over short-term and long-term financial decisions, but statistically significant differences were found among different income, age, and disability-type categories. For example, there were significant income differences regarding beliefs that people with disabilities should have control over their short-term financial decisions, with people earning $100,000 to 300,000 per year reporting the highest level of agreement, and people in the lowest income group (earning $0-$40,000 per year) reporting the lowest level of agreement. There were no significant differences between how participants in different income groups thought about long-term control. There were also significant age differences in family, guardian, and professional beliefs that people with disabilities should have control over short-term and long-term financial decisions, with people aged 45-54 reporting the highest level of agreement to short-term control, and people aged 18-34 reporting the lowest level of agreement. Moreover, results revealed people aged 45-54 had the highest score of agreement that people with disabilities should have control over their long-term financial decisions, while people 65 and over reported the lowest level of agreement.

Finally, though there were no significant differences noted between family, guardian, and professional beliefs that people with disabilities should have control over short-term financial decisions, there were significant differences across disability types and family, guardian, and professional beliefs that people with disabilities should have control in their long-term financial decisions, with families of people with sensory disabilities reporting the highest level of agreement in long-term financial control, and family members of people with intellectual disabilities reporting the lowest level of agreement.

Though there were no significant differences in beliefs about long-term financial choice and short-term financial control, families, guardians, and professionals reported differences in their beliefs about short-term choice and long-term control among people with intellectual disabilities. Specifically, though participants strongly agreed people with intellectual disabilities should have short-term choice in their financial decisions, they were less likely to agree they should have long-term financial control. This may imply differences in beliefs about short-term choice and long-term control may be related to the severity of the disability presentation.

Professional Confidence/Knowledge

The survey asked professionals to rate their confidence levels in guiding people with disabilities and their families through the future financial process, as well as their knowledge of ABLE accounts, Special Needs first and third-party trusts, and pooled accounts. Professionals were divided into two categories: those who work in a disabilities-related field (e.g., state professional, compliance officer, direct support professional, supervisor/administrator, etc.) and those who work in a field not focused on disabilities (e.g., attorney, financial planner, etc.). Ratings were on a scale of 0 (no confidence at all) to 10 (expert). Survey results showed that professionals who work in a disabilities-related field have significantly less confidence in guiding people through the future financial planning process and less knowledge of ABLE accounts, special needs first and third-party trusts, and pooled accounts than professionals who work in a field not focused on disabilities. These findings indicate that more training and commensurate credentialing is needed to increase the confidence and financial account knowledge of professionals working in disabilities-related fields. Training of professionals on the ground who spend a lot of time with people with disabilities may be especially critical because of their day-to-day influence on spending.

Oversight

A recurring theme that emerged in Phase 1 of the project was the lack of professional responsibility and oversight of the future financial planning process. Many people noted that where oversight exists (e.g., court appeals), it is limited in its capacity to protect people with disabilities or their families from mistakes or wrongdoing. To explore the idea of oversight further, participants were asked if there should be oversight of the future financial planning process, and the majority of people with disabilities (92%), family members (94%), guardians (84%), and professionals (77%) responded "yes" (see Figure 12).

However, there was more variance between respondent groups about when oversight should happen and who should be responsible for oversight. Results showed that the highest number of people with disabilities (38%) thought that oversight should occur while the account is open, while the majority of family members and guardians (37%) believed that oversight should happen before an account is created, and the highest number of professionals (31%) thought that oversight should be ongoing and continuous. Responses also varied related to which type of entity should be in charge of oversight for future financial accounts, with the largest number of people with disabilities (26%) naming the "federal government" and families (43%) naming "banks" and "associations devoted to disability support or advocacy" as the most popular choice among guardians and professionals alike (see Figure 13).

While most participants agreed there should be additional oversight of the future financial planning process, there were varying opinions among participant groups about when the oversight should happen and who should administer the oversight. The varied responses indicated that further consideration about

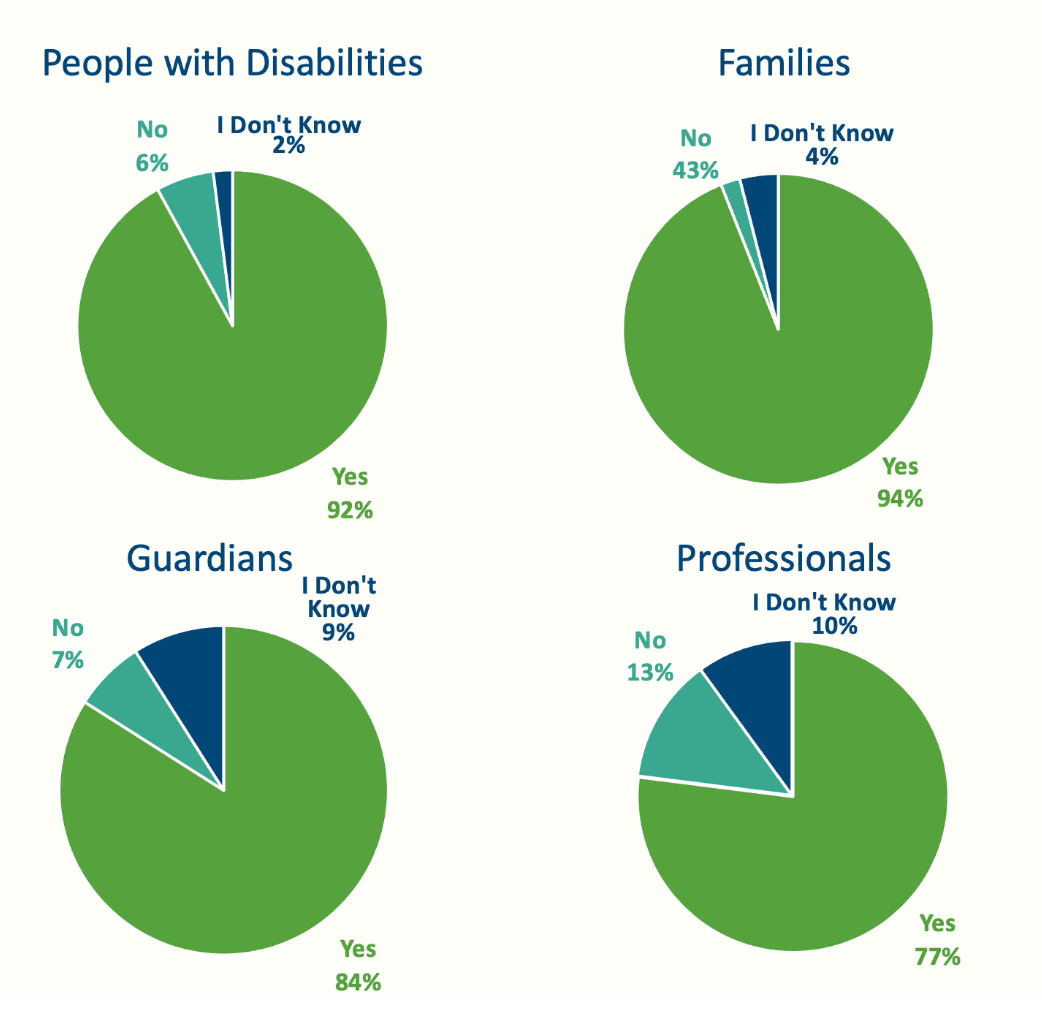


Figure 12. Percentage of Participants Who Believe There Should Be Oversight of the Future Financial Planning Process

People with Disabilities	1 (26%)	Federal Government
	2 (19%)	Banks
	3 (17%)	State Governement
Families	1 (43%)	Banks
	2 (24%)	Courts/Legal System
	3 (11%)	Federal Laws/Regulations
Guardians	1 (20%)	Associations Devoted to Disability Support or Advocacy
	2 (19%)	Banks
	3 (18%)	State Governement
Professionals	1 (19%)	Associations Devoted to Disability Support or Advocacy
	2 (18%)	Courts/Legal System
	3 (17%)	Banks

Figure 13. Top Three Entities Identified by Participants That Should be Responsible for Oversight of Future Financial Planning

the vision of oversight for future financial planning is needed. The topic was added to the agenda for discussion during expert workshops in Phase 3 of the project.

In summary, participant interview and survey responses revealed significant challenges in the future financial planning process. Specifically, the complex nature of future financial planning, including inconsistencies in point of entry, limited professional oversight, low confidence among people working in the disabilities field regarding knowledge of future financial planning, poor marketing and communication, and lack of training opportunities impede financial planning efforts and perpetuate the economic exclusion of this population. The personal, familial, systemic, and societal issues people with disabilities and their families face continue to deter and confuse even highly educated family members with access to resources and support from pursuing future financial planning before they are forced by external circumstances to do so. In order for people with disabilities and their families to fully engage in the future financial planning process and have a chance at securing their future wellbeing, the siloed financial, legal, and disability worlds need to be connected and more joint outreach, encouragement, and guidance from these sectors is needed. To address these challenges, expert recommendations were solicited to inform targeted interventions and concrete solutions.

Phase 3 — Expert Workshops

Experts and professionals in the financial, legal, and disabilities fields gathered virtually via Zoom teleconferencing on May 18th and May 27th, 2021, to discuss recommendations for next steps for future financial planning for people with disabilities. Experts participating in the workshops included people who have dedicated their careers or significant time to improving the future financial planning process for people with disabilities and their families. They represented people with disabilities, family members, disability service sector professionals, financial planning professionals, legal professionals, and academics. Many experts identified with two or more of these groups.

The data collected from Phases 1 and 2 of this project mainly focused on the current state of future financial planning for people with disabilities and indicate several areas of need for potential intervention. The expert workshops were two, three-hour sessions to discuss those areas of need in further detail and advise next steps for the field.

The recommendations made by experts during the workshops were grouped thematically and reviewed with recommendations that emerged from the initial interviews, as well as qualitative responses to six survey questions[i] that focused on potential solutions to improve future financial planning.

[i] Survey Questions: What advice would you give to other people starting the future financial planning process? (Question for people with disabilities only). What advice would you give to other family members starting the future financial planning process? (Question for families only). What advice would you give to other guardians of people with disabilities starting the future financial planning process? (Question for guardians only). What could help fix these problems? (Question for all respondents, referring to the barriers to future financial planning identified). Do you have other suggestions about what additional oversight of the future financial process might look like? (Question for all respondents). Is there anything else that you would like to add to help us understand future financial planning for people with disabilities? (Question for all respondents).

Recommendations

Recommendations to improve future financial planning processes and services for people with disabilities fell into several categories. These categories are listed below:

- **Education, Training, and Certification:** recommendations focus on educational opportunities and/or required training or criteria that could help people become more informed about and skilled in their role in the future financial planning process
- **Communication:** recommendations focus on extending communication and messages that will engage and notify people about future financial planning, the rights of people with disabilities to control their finances, and available helpful resources
- **Advocacy:** recommendations focus on efforts needed to expand opportunities to champion or change legislation, policies, rules, regulations, and/or systems that impact future financial planning for people with disabilities
- **An Organization or Structure for Oversight and Guidance:** recommendations focus on creating an entity that would offer information, resources, and work to ensure that people with disabilities and their families can access professionals and services that will effectively support them to plan and secure their financial futures
- **Resources:** recommendations focus on developing tangible and virtual resources that will help stakeholders successfully fulfill their roles and responsibilities related to the future financial planning process
- **Ongoing Support and Services:** recommendations focus on services that are available or could be created to improve the future financial planning process
- **Research:** recommendations focus on conducting systematic and empirical research about topics related to the future financial process that would enhance knowledge about the experience and needs of stakeholders who are invested in future financial planning for people with disabilities

Some recommendations included new ideas that experts have developed based on their experiences and understanding of the challenges people with disabilities and their families face in future financial planning. However, many of the recommendations that emerged either currently exist or are in development; they focus on opportunities to scale up or replicate existing practices that work. Some recommendations are overarching or can be implemented to impact all people who are invested in future financial planning for people with disabilities. Most recommendations are specific to different groups including people with disabilities and their families and professionals, or they are recommendations that impact policies, regulations, and systems. While recommendations are categorized here, many of the recommendations coincide with one another. The recommendations have been organized by the people who will be most impacted or supported and then by category.

Overarching Recommendations

Overarching recommendations focus on ideas and solutions that can impact several groups of stakeholders who are invested in the future financial planning process for people with disabilities and their families. These recommendations fall into three categories: Communication and Advocacy,[i] Resources, and an Organization Structure for Oversight and Governance.

[i] These categories have been combined because many of the recommendations for advocacy incorporate communication strategies

Communication and Advocacy

At every stage of this study, experts and participants noted that there are two major changes needed to improve the future financial planning process and experience for people with disabilities: First, there is a need to use intentional language for future financial planning by establishing a common definition of what future financial planning is and eliminate ableist[ii] terminology, and second, there is a need to support a fundamental shift in perceptions and overall mindset about people with disabilities and their involvement in managing their finances and savings.

Use Intentional Language for Future Financial Planning

Several experts recognized that a major barrier for people with disabilities, families, and professionals is that there is no one definition of future financial planning. They shared that lack of a cohesive definition and understanding makes the process, including how and when to start planning, confusing for many people. Further, without a cohesive understanding, people who are involved in future financial planning do not use the same language or provide consistent recommendations for services and strategies that help people plan. Experts recommended the development of a common definition of future financial planning that is shared broadly and adopted by all stakeholders who are invested in the financial wellbeing of people with disabilities.

Additionally, language that is used to describe financial services for people with disabilities must be evaluated. While services, products, and supports labeled as "special" have been used to differentiate them as specifically for people with disabilities, terms like 'Special Needs Trust' are outdated because they emphasize the 'otherness' of people with disabilities in the financial system. Language begets practice; reducing the economic exclusion of people with disabilities may be facilitated by reducing exclusive language.

Shift in Perceptions and Mindset

Next, experts recommended efforts to shift perceptions about people with disabilities as it relates to economic inclusion and financial autonomy. Specifically, they expressed a need to recognize that people with disabilities are capable and worthy of earning and saving money and making decisions about their finances. More broadly, there is a need to acknowledge the meaningful contribution that people with disabilities can make to the economy. These recommendations were supported by the study findings, as all participant groups named societal challenges related to beliefs about whether people with disabilities can understand, manage, and save their money, in the top three barriers to future financial planning.

Originally, service systems were set up with the assumption that people with disabilities could not work or meaningfully contribute to the economy or their communities. These assumptions led to a system of supports that require people with disabilities to live in poverty in order to maintain their benefits and services. These traditions and systems have perpetuated practices that prohibit people with disabilities from becoming financially self-sustaining by limiting their opportunities to work and earn meaningful income, excluding them from short- and long-term decisions about their finances, and withholding financial education and support that is available to many people without disabilities.

To begin the shift in perspectives and practices, experts discussed strategies including public messaging or a wide-reaching campaign to:

- Provide education about the rights of people with disabilities to control their finances and achieve financial wellness
- Promote the economic inclusion of people with disabilities
- Increase understanding about the barriers that people with disabilities experience related to financial health and wellbeing

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[ii] Ableism is discrimination against people with disabilities and is founded in discrimination in favor of 'able-bodied' people.

- Share potential solutions to more meaningfully involve people in day to day and long term financial decisions

Finally, experts recognized that many people with disabilities face overlapping systems of oppression, particularly people of color, and people and families that are poor. These identities impact access to future financial planning resources and services. Experts shared that efforts to support people with disabilities and their families should increase the availability of resources to people from families with modest or low income, and people of color. While experts did not identify specific programs, resources, or opportunities to meet this goal, several did indicate that these efforts extend across the recommendations listed below, including Training and Education, Communication, Resources, Advocacy, and Research.

Resources

Another recommendation that has far reaching potential is to create virtual resources that are available to help people who are invested in future financial planning, including people with disabilities, families of people with disabilities, disability sector professionals, and legal and financial professionals. These resources could include:

- A live and continually adapting virtual listserv, network, or community of practice that would facilitate connections between professionals, people with disabilities, and families around the topic of future financial planning: this resource would provide a space to share resources, post questions, and receive reliable information. Ultimately this live network would provide ongoing, up-to-date, and in-time support.
- A static virtual one-stop platform that would provide up to date resources, materials, and state specific information about legislation, regulations, available services, and issues related to the future financial planning process: this platform would focus on educating different stakeholders and offering materials and resources that could be helpful to people at every stage of the future financial planning and maintenance process.

Organization or Structure for Oversight and Guidance

A final overarching recommendation was to create an organization or a collaborative made up of several organizations that are invested in the economic wellbeing of and future financial planning for people with disabilities. This organization or collaborative would collect, vet, regularly update, and offer information, tools, materials, and resources that would be useful to people at each stage of the financial planning and maintenance process. This entity could also assume other integral roles such as advocacy, making policy recommendations, providing training, and developing best practices guidelines for professionals. Experts acknowledged that this entity could be modeled from existing groups, such as the American Association of People with Disabilities, the Disability Planning and Policy Center at Eastern Michigan University, and The Arc of the United States.

Recommendations that Support People with Disabilities and Families

Several of the recommendations focused specifically on services, strategies, and opportunities that directly impact people with disabilities and their families. These recommendations fell into the categories of Education, Training, and Certification, Communication, Resources, An Organization or Structure for Oversight and Guidance, and Ongoing Support and Services.

Education and Training

Some experts recommended training and education opportunities for people with disabilities and their families as an important place to begin to improve future financial planning. These included accessible resources and early intervention strategies that would engage people in future financial planning at younger ages.

Accessible Training Focused on Basic Financial Skills

Accessible training, available in plain language and focusing on building basic financial skills of people with disabilities and their families, was recommended as an initial step to enhance financial wellbeing and prepare people for long term planning. This type of training would include topics such as money management, principles of financial wellbeing, strategies and options for saving, and planning for one's financial future. Some experts believed that beginning with this type of education and training would offer a ground up approach to addressing issues related to the economic inclusion of people with disabilities.

Currently, there are resources and training opportunities available to people with disabilities and their families that could be scaled up or inform the development of future training and education materials. For example, financial planning experts have written books and produced resources to help people with disabilities and families avoid common mistakes related to future financial planning.[7, 35, 36] Similarly, many of the expert financial planners who participated in the study shared that they have provided training to people with disabilities and their families all over the country. Recognizing that there are resources available, this recommendation may be modified to create or promote a centralized and validated training that is widely accessible to people with disabilities and their families.

Early and Ongoing Intervention and Training

Experts recommended early intervention strategies, starting when the person with disabilities is a child or adolescent, that would be offered through the school or early intervention services. Such training and supports educate people about the need to begin future financial planning early in a person's life and would include information related to elements and stages of future financial planning, a realistic description of what the adult support system can and cannot offer, strategies for supported decision making in financial decision making, planning, and maintenance, and strategies that promote financial autonomy.

These recommendations align with several of the needs identified in the national survey. For example, results showed that 27% of people with disabilities who responded and 32% of families shared that their loved one with disabilities did not receive any financial education or training. Basic and accessible financial training and early intervention would begin to mitigate those issues.

Communication

While training and education were identified as effective strategies to improve the financial wellbeing and futures of people with disabilities, many experts acknowledged that there already exist several trainings and resources that are helpful to both people with disabilities and their families. However, there are significant barriers related to widespread sharing and communication of these resources that leave people with disabilities and families feeling isolated and frustrated when they start to engage in the future financial planning process. For example, several people noted that the underutilization of ABLE Accounts is, in part, because many people with disabilities and families do not know about them or how they could benefit from them. Existing interdisciplinary approaches (e.g., product life cycle, diffusion of innovation, and integrated marketing communication) could be applied to improve outreach practices. Experts recommended ideas to support widespread communication about options and resources related to future financial planning that may include:

- A state by state media and communication about the need for future financial planning and state-specific options and resources that are available to people with disabilities and their families
- Multidisciplinary approaches to marketing through different outlets should be applied to reach various audiences, such as working professionals, families with disabilities, academics, etc.
- An ongoing campaign focusing on economic inclusion of people with disabilities and basic needs to educate and support people with disabilities to manage their finances and plan for their financial futures
- Ongoing and regularly updated communication and marketing focused on available and existing

resources, services, training, and support that can help people with disabilities and their families manage their money, save, and plan for their financial futures

Resources

Experts also recommended several resources that could be created, replicated, or more widely utilized to help people with disabilities with day to day and future financial decisions and planning. Resources include:

- A trusted and vetted application (app) or website that can help people understand and manage their finances and plan for their short- and long-term financial futures while maintaining their benefits and services: Experts noted that several apps currently exist that are not geared toward people with disabilities or families who need to ensure that they maintain eligibility for public benefits. However, these apps provide models of financial management, decision making, and planning that could be replicated and tailored to be accessible and useful to people with disabilities and their families. Developing even more specialized opportunities to connect with peers and experienced advisors could also greatly improve outcomes. For example, the NextPhase Community offers a path for potential and actual claimants to learn from each other, from expert advisors, and from previous personal injury victims who've settled their cases and are willing to share what they've learned.
- Services and resources from banks and financial institutions that help people open and maintain accounts that also protect their benefits and services: A recent study from the National Disability Institute showed that 18% of people with disabilities are unbanked, compared to 5.1% of people without disabilities. Lack of access to bank accounts and mechanisms to save and maintain finances can perpetuate economic exclusion and limit people with disabilities from controlling their money and financial decisions.[10] Several experts recognized that there is an opportunity for banks to develop accessible resources and support for people with disabilities.
- Resources that include information, checklists, and decision trees that help people with disabilities and their families make informed decisions about financial planning services and professionals needed to set up and maintain their accounts: The current study demonstrated that on average families and guardians rated their confidence that financial professionals would act in the best interest of the person with disabilities at a 5.8 out of 10. Further, they rated their confidence that financial professionals have the knowledge and skills needed to help people make financially sound decisions and maintain their public benefits at a 5.57 out of 10, on average. Experts shared that the creation of these resources would help address issues that people with disabilities and their families face related to finding and selecting financial planning services. They also noted that these resources could build on existing tools such as the American Association of Retired Persons (AARP) Medicare Decision Tool[iii] that was designed to help people make decisions about their futures, service eligibly, and support needs.

An Organization or Structure for Support and Guidance

Some experts recommended an organization or structure that would provide guidance and support specifically to people with disabilities and their families. They merged several existing concepts in and out of the disability service sector including No Wrong Door Systems[iv] and AARP tools (mentioned above) that help people make decisions about their future support needs. This recommendation culminated in an organization, collaborative, or series of state specific organizations that would be created to help people with disabilities and their families understand the elements and processes of future financial planning and connect people with available and vetted professionals, services, and resources that could support them in every stage of financial planning and

[iii] https://www.aarp.org/health/medicare-qa-tool/

[iv] No Wrong Door Systems streamline access that people with disabilities have to needed services and supports by coordinating between different funding and service streams. Essentially, a No Wrong Door System is built to make it so that people with disabilities and their families are not solely responsible for navigating complex and siloed systems and processes to access needed long term

management. Several experts and study participants recognized that the siloed nature of the disability sector and financial planning services, as well as the complex coordination of services within each sector, make the financial planning process confusing and complicated. People with disabilities and families would benefit from a central organization that exists to help them navigate available options, make sound decisions about which services and professionals they select, and have confidence that they are being supported by professionals who have the knowledge and investment needed to act in the best interest of a person with disabilities.

Ongoing Support and Services

Experts identified opportunities to either create or scale up existing services and supports that would be helpful to people throughout the financial planning process. First, experts agreed that future financial planning should be included as an integral part of services that people with disabilities receive, such as Supported Decision Making,[v] Person Centered Planning,[vi] and Individual Support/ Service Planning (ISP) processes.[vii] They noted that the exclusion of future financial planning in these services is tied to the economic exclusion of people with disabilities; it ensures that people with disabilities will not have the support they need to be more in control of their short- and long-term financial decisions.

Experts also recommended expanding availability and knowledge about existing services that can help people plan for their financial futures and maintain their accounts. Specifically, experts noted that Benefits Counselors[viii] are an essential resource for many people with disabilities who receive SSI and their families. Although they provide an integral service, shortages of Benefits Counselors can make caseloads unmanageable, and decrease the amount and quality of support they are able to offer. Further, several experts expressed the need for more education about what Benefits Counselors can offer to increase their recognition, demand, and support.

In addition, there is a relatively underutilized profession that has knowledge and experience related to disability services and benefits eligibility as well as rights and supports needed to help people be in control of their lives, services, and finances. These professionals go by different titles in different state, but they act in a coordinator role to help people manage their finances and accounts and make decisions about spending. Experts identified two states where these services are currently available: California, and Ohio.[ix] Specifically, an organization in California (East Bay Innovations) provides coordination services and a group of financial planning attorneys in Ohio (Hickman & Lowder Co. L.P.A.) work with coordination professionals to help people manage their financial accounts. Experts noted that there is an opportunity to expand these services and increase understanding of their needs and benefit.

Finally, experts acknowledged that a first and important step in future financial planning is supporting people with disabilities and families to determine a vision for their futures and decide which types of services, accounts, and amount of savings are needed to achieve those visions. Some financial planners offer this service or connect families with consultants who have this expertise. Experts recommended that these services also expand or become more widely available to people with disabilities and their families.

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[v] Supported Decision Making is a process by which a trusted and appointed person helps a person with disabilities make informed choices about various aspects of their lives. Supported Decision Making recognizes the dignity and worth of people with disabilities by supporting them to be in control of their lives. Supported Decision Making is often a legal tool to help people with disabilities make major life decisions that involve risk, and has been used as an alternative to guardianship. For more information, visit http://www.supporteddecisionmaking.org/

[vi] Person Centered Planning is a process or tool that is used to determine and organize services and supports that a person with disabilities will receive. A Person Centered Plan should be directed by the person with disabilities and should focus on their goals, wants, and support needs.

[vii] An Individual Support or Service Plan (ISP) is a plan that is constructed by professionals and, ideally, with the person with disabilities, to determine the supports and services that will be provided to meet their goals, wants, and needs.

[viii] Benefits counselors are professionals who are available at no cost to people who receive Supplemental Security Income (SSI). They provide resources and information to people with disabilities who are working or want to work and maintain their public benefits.

[ix] We understand that there are likely more agencies that do this in other states.

Recommendations that Support Professionals

Many of the recommendations focused specifically on strategies, support, and criteria that directly impact the disability sector and financial and legal professionals. These recommendations fell into the categories of: Education, Training, and Certification; Communication; An Organization or Structure for Oversight and Guidance; and Ongoing Support and Services. It is important to note that experts did not unanimously agree with each of the recommendations listed below, particularly in the areas of Education, Training, and Certification and An Organization or Structure for Oversight and Governance. Differences are noted when applicable.

Education, Training, and Certification

Experts and study participants made several recommendations related to training and education that could be helpful to inform and improve the practices of professionals. Four trainings or educational opportunities shared include:

- Education and training for disability service sector professionals focused on future planning options and financial services for people with disabilities and families: several experts noted that the silos between systems may be improved by educating disability sector professionals about strategies and options available to people with disabilities and their families. They added that training could also include strategies to embed financial management and future financial planning into services and supports that people with disabilities already receive.
- Training for professionals who impact people with disabilities early in their lives: including early intervention specialists and Individualized Education Program (IEP) team personnel (educators, specialists, administrators, transition coordinators, etc.) focused on developing skills to help families begin to think about future financial planning. To build on the idea of education and training opportunities for families of young people with disabilities, experts recognized that early educators, school staff, etc. would need to receive adequate training to be able to effectively provide supports. Specifically, training would help professionals gain skills to begin conversations about financial wellbeing and provide basic education about the need to begin future financial planning early in a person's life. Training information would include the elements and stages of future financial planning, a realistic description of what the adult support system can and cannot offer, strategies for supporting people to make sound financial decisions, and strategies for financial planning that ensure people with disabilities can be in control of their money from an early age.
- State specific training and education opportunities available to both the disability service sector and financial and legal professionals: this training would provide professionals with the information needed to direct people with disabilities and families to resources and state specific rules that can inform their future financial planning.
- Education and training related to Person Centered Planning, Supported Decision Making, and Self-Directed lives for people with disabilities: disability sector professionals and financial and legal professionals would learn basic tenets of financial inclusion for people with disabilities and would gain resources and skills to help people with disabilities and families include financial planning in person centered planning, supported decision making. They would also learn how to apply principles of self-direction to the future financial planning process. Experts noted that these existing concepts and strategies are largely absent from financial planning but could be used to ensure that people with disabilities are at the center of their future financial plans, are supported to make sound financial decisions, and are encouraged to consider how they can save and use their money to increase autonomy and control.

Across the United States, there are several education and training opportunities and resources that exist to enhance the knowledge and skills of professionals who are involved in the future financial planning process, including university degrees and certificate programs. Many experts recognized that these programs effectively educate and prepare professionals to support people with disabilities and families as they engage in the financial planning process. To that end, several experts noted that there is not necessarily a need to create education, training, and certification programs, but instead to expand access to and utilization of these programs.

Similarly, experts and study participants differed in their recommendations to move beyond offering educational opportunities, to mandating that professionals complete training or meet specific criteria by earning a certification, license, or other credentials. Many experts felt that there are already enough criteria and a shortage of professionals who have the necessary knowledge and skills to effectively support people with disabilities and their families in financial planning. They argued that increasing or mandating criteria may limit professional's interest in supporting people with disabilities and their families to navigate the complex future financial planning process.

However, many people with disabilities and families struggle to find a qualified professional who can help them understand requirements and make sound financial decisions that protect the rights and choices of the person with disabilities in the future. Some people shared that, without some type of standard or criteria, people with disabilities and families do not know who they can trust to act in their best interest. Therefore, some experts did recommend that professionals who provide financial or legal services to people with disabilities and their families should earn a certificate or other qualification that demonstrates their knowledge and credibility. This may be particularly important for people who are disabled by others' incompetence, negligence, or even intentional acts and become claimants in a personal injury suit, which can result in an award or settlement that needs the guidance of a professional with specialized expertise. Plaintiff experiences are complicated by the judicial system, as well as the financial and healthcare systems, and are particularly vulnerable to receive subpar advice that can dramatically reduce the value of their recovery. Several organizations offer regular educational training for advisors, including the Society of Settlement Planners, and the Academy of Special Needs Planners. The Society of Settlement Planners offers the Registered Settlement Planner Designation, fulfilled by courses in a variety of planning subjects including legal, financial, and settlement.

An Organization or Structure for Oversight and Guidance

Experts and study participants agreed that creating or scaling up an organization or collaborative of organizations that will bridge siloes between systems and provide useful and timely information to help professionals act in the best interests of people with disabilities and their families should be a priority. (This type of organization or collaborative was described above in the Overarching Recommendations section.) Some experts felt that an organization specifically for professionals is urgently needed to immediately address issues related to financial planning services that people with disabilities and families access. A few collaboratives exist that may be able to fulfill this role more broadly, including the Alliance of Pooled Trusts, the National Academy of Elder Law Attorneys, the Special Needs Alliance, and the Society of Settlement Planners.

There was no consensus about whether an organization should provide any kind of oversight or governance to ensure that professional practices adequately meet the needs and protect the public benefits of people with disabilities. Some experts felt that there are already several requirements and regulations that professionals need to meet and adding an organization for oversight or governance could deplete an already sparse field of professionals and services. However, some experts and study participants felt that, without oversight, professionals can take advantage of or fail to act in the best interest of people with disabilities with little or no consequences, leaving people with disabilities and families unprotected.

One solution that a few national organizations have tried, including the National Academy of Elder Law Attorneys, True Link Financial, Stetson Law School, and the Life Passages Pooled Special Needs Trust is to create standards of best practice that apply to the specific roles of financial and legal professionals. These standards include several domains that guide professional's approaches, values, and services for people with disabilities and their families. While these standards do not regulate practices, they do demonstrate a professionals' commitment to the best interests of people with disabilities and families when they are adopted.

Recommendations that Impact Systems, Policies, and Regulations

Some expert and study participant recommendations would need to be addressed at a systems or policy level. While many experts recognized the challenges to influencing policy or systems change, others contended that these changes were needed for long term and widespread improvement to future financial planning for people with disabilities and their families. Moreover, survey findings showed that legal barriers, such as rules, laws, and regulations, were in the top three barriers for all participating groups (it was the top barrier for families and professionals). Recommendations that were consistently offered fell into the categories of Education, Training, and Certification, Advocacy, and Research.

Education Training and Certification

Experts and study participants shared that a major barrier many people with disabilities and families face as they are managing and planning for their financial futures is when there are misunderstandings or misinformation provided about benefits eligibility and personal finances and savings. For example, some people with disabilities and families shared that they were told they did not have saving options or could not pursue work opportunities that offer meaningful employment and wages if they wanted to maintain their benefits. To address these issues, recommendations were made to provide education and training to professionals who work and make decisions related to benefits eligibility, including people who work for the Social Security Administration. Training and education would focus on helping administrators understand the need for future financial planning, options for saving, and how their role relates to or supports people to successfully plan for their financial futures. There was no agreement among experts as to whether this training or education should be mandatory. Some felt that it was necessary to ensure that these professionals have basic knowledge and information that will enable them to help people with disabilities and their families. However, some felt that these professionals already have too much on their plates, so adding additional requirements would not be beneficial.

Advocacy

Additionally, many experts believed that advocacy efforts to change rules and regulations that limit people with disabilities and their families from saving or setting up accounts that protect their benefits are a priority. They shared that rules and regulations that require people with disabilities to be poor in order to maintain needed services and benefits guarantee that people with disabilities will not be able to direct their lives and experience opportunities for inclusion and autonomy that are available to people who do not rely on public benefits. Further, for many people with disabilities, benefits and services are not designed to meet their full scope of needs, wants, and goals. People with disabilities need mechanisms that allow them to meaningfully earn and save money to pay for resources that are not funded by public benefits. This is particularly true as the number and lifespan of people with disabilities increases, while funding, available workforce, and resources for disability services remain limited. While strategies for advocacy efforts were not discussed, experts highlighted the following rules and regulation changes:

- Expand Social Security Income (SSI) benefits limitations: several experts shared that current SSI limitations on income prohibit people with disabilities from gaining meaningful employment and accruing savings that will help them have quality lives beyond the supports and services that come with public benefits. They recommended that limitations on the amount that people with disabilities can earn and keep in their bank accounts are raised to allow people to save and spend their money as they want and need. Currently, there is proposed legislation, the Supplemental Social Security Income Restoration Act of 2021, that addresses these recommendations.
- Increase eligibility for ABLE Accounts: currently, only people with disabilities who have an age of onset

of disability before age 26 are eligible to open ABLE Accounts. However, for many people who acquire disabilities later in life, or who are not diagnosed early enough to qualify for developmental disability services and benefits, these limitations disqualify the allowances and opportunities for saving associated with ABLE Accounts. Specifically, many experts recommended support and advocacy for proposed federal legislation, the ABLE Age Adjustment Act, to raise the eligibility age to 46. This change was not supported by all experts.

- Allow Medicaid funds and public benefits to pay for future financial planning: several experts recommended that people with disabilities should be able to allocate Medicaid and service dollars to pay for future financial planning support. Experts noted that there are states currently considering this option.
- Advocacy efforts could support regulations that require that financial planners who service people with disabilities be fiduciaries to ensure professionals are working in the best interest of people with disabilities and their families.

Research

Finally, several experts recognized that much of the information we have about the future financial planning for people with disabilities and their families is anecdotal. They noted the need for more systematic research to inform policy, training, education, and service delivery. This research should focus on:

- Understanding the population and needs of people with disabilities, particularly as it relates to their financial wellbeing
- Quantifying the financial contribution of people with disabilities to the economy
- Better understanding the experiences, challenges, and facilitators to financial planning that people with disabilities and families face (with the possibility to build off of or replicate the current study)
- Policy analysis to understand the limitations of current policies and regulations on the financial and future wellbeing of people with disabilities and their families

Experts also shared that research should focus on the needs of people who experience multiple levels of disenfranchisement, including people of color and people from families of modest and low income. Though limitations in this sample preclude a more rigorous investigation of these factors, future research should focus more specifically on the impact of intersecting identities and financial wellbeing of people with disabilities and their future financial planning processes.

Conclusion

Future financial planning is often complicated and difficult to navigate for people with disabilities and their families. Many people struggle to overcome discomfort and anxiety that is heightened by regulations and systems founded on outdated ideas and practices, lack of training and education about savings options, and limited access to essential resources. These challenges highlight the need for efforts that will maximize existing supports and create new initiatives in the areas of:

- *Education, and training* for people with disabilities, their families, and professionals who work with them
- *Training and certification for financial planning professionals*
- *Communication, and advocacy* for all stakeholders to ensure people with disabilities and their families understand their rights and have access to existing resources that will help them engage in the planning process, inform them of their rights to control their finances, and inform them of resources available
- *Advocacy* to advance policies, rules, and regulations that will increase access to future financial planning
- *Creation of a guiding entity* that will meet a critical need to guide best practices, facilitate future financial planning, and ease the complexities involved in the planning process
- *Creation and distribution* of resources and ongoing support, that will meet the needs of stakeholders throughout the lifespan
- *Research* efforts to increase information about future financial planning for people with disabilities and their families.

The recommendations featured in this report were guided by the latest research on the topic and feedback from experts in the field. They provide a strong framework to advance the future financial planning for people with disabilities and their families and to support their financial security through their lifetime.

APPENDIX A: Future Financial Savings Accounts

ABLE Accounts

ABLE accounts are the result of the Achieving A Better Life Experience Act that was signed into law on December 19, 2014.[37, 38] The ABLE Act allows people with disabilities who experienced the onset of their disability prior to age 26[i] and their families to save contributions of up to $15,000 per year in an ABLE savings account without compromising their Medicaid and Social Security benefits as long as the account combined with other resources does not exceed approximately $100,000. It also stipulates that income earned by the account is not taxed. It is important to note, however, that ABLE account funds must be used for qualifying disability expenses and that in most cases when the benefactor dies, the remaining funds in the ABLE account are subject to payback to Medicaid. Moreover, since ABLE accounts can differ by state, residential location may influence what someone can and cannot access. For more information regarding your home state and the potential availability, please visit the ABLE National Resource Center at www.ablenrc.org.

Special Needs Trusts

Like ABLE accounts, Special Needs Trusts (SNTs) allow people with disabilities to save money while preserving their eligibility for Medicaid and SSI.[39] SNTs are typically set up and owned by a family member for people who have a permanent or severe disabling condition.[35] Funds from SNTs can be used broadly on expenses such as education, recreation, and medical expenses. Special Needs Trusts may be more expensive and more complicated to set up than an ABLE account but may provide a solid financial foundation for people with disabilities, which they can supplement with an ABLE account if they choose.[38] There are many different types of trusts, the most popular of which (i.e., first-party trusts, third-party trusts, and pooled trusts) are highlighted in this report. More information about Special Needs Trusts can be found at the Special Needs Trust Alliance website at https://www.specialneedsalliance.org.

First-Party Special Needs Trusts

A first-party trust is also known as the self-settled trust or (d)(4)(a) trust.7 The trust is funded by the beneficiary's (i.e., the person with a disability) own assets which may come from sources such as personal injury settlement, inheritance, equitable distribution, alimony, or child support. This type of trust is for the "sole benefit" of the beneficiary and may lead to a loss of public benefits if used otherwise.[40] A first-party trust is used as a "payback" trust, so like the ABLE account, when the beneficiary dies any money remaining in the trust is subject to payback to Medicaid.[8]

Third-Party Special Needs Trusts

The main difference between a first- and third-party trust is that a third-party trust is funded by another person's assets other than the beneficiary.[7, 35] Often the third party is a parent or other family member. There is no limit to the number of assets in the trust and the funds can be used for most things the beneficiary needs (e.g., transportation, equipment, furniture, hobbies, etc.). The beneficiary does not own the property in the trust and does not have direct access to funds in the trust. Additionally, the government has no claim to a third-party trust, such as payback to Medicaid.[41]

[i] There is currently proposed legislation (the ABLE Age Adjustment Act; S.331 and H.R. 1219) to change the qualifying age of disability to 46 years old.

Pooled Trusts
Pooled trusts are used in cases where people with disabilities and their families do not have enough money or do not wish to open a trust on their own.[7] In a pooled trust, people "pool," or comingle, their funds to be used for certain living and medical expenses that are not covered by public benefits to secure better financial outcomes for the benefactors without affecting their Medicaid or SSI eligibility. Pooled trusts are run by non-profit organizations in individual states.[35]

Other Financial Planning Options
There are other non-structured options that people with disabilities and their families sometimes use, such as saving money or buying property in another family member's name. Families often save money and time with these measures because there are fewer fees and they do not have to have expenses approved. However, these approaches often put the will of the person with disabilities as secondary to whoever is in charge of the account or property. There are other structured savings mechanisms that some families use including retirement funds, stocks, bonds, etc. Although these options were not necessarily designed for people with disabilities and their families, they may offer flexible and affordable options for future financial planning. More information about saving options for people with disabilities can be found on the National Disability Institute website https://www.nationaldisabilityinstitute.org (click on the "Financial Wellness" tab).

APPENDIX B: Study Procedures

Phase One: Interviews

Phase 1 of the study was conducted in summer 2020 and consisted of open-ended interviews with key stakeholders of future financial planning for people with disabilities. Interviews sought to gain the perspectives of different stakeholders about the challenges faced during the process of future financial planning for people with disabilities, as well as what helped facilitate the process.

Recruitment

Participants were recruited by email invitation to targeted people from four subgroups: (1) families of people with intellectual and developmental disabilities and adults with intellectual and developmental disabilities; (2) service providers or support agencies for adults with intellectual and developmental disabilities and their families; (3) financial experts (financial planners, lawyers, bankers); (4) other experts in the field of future financial planning (researchers/scholars, judges, etc.). Participants were also sought from open recruitment through listservs of the National Leadership Consortium on Developmental Disabilities and through social media of various national groups. Potential participants receiving some sort of open recruitment (through a listserv or social media) were asked to complete a screener survey first, identifying themselves as one of the four sub-groups of participants. Researchers used the information from the screener survey to invite participants to the study in an effort to have balanced representation for each participant group. Snowball sampling was also employed, with researchers following up on potential participants recommended by people who were interviewed. People with intellectual and developmental disabilities that were interviewed were chosen based on recommendations from professionals who have worked with them to ensure that they will be capable of answering the survey questions. These participants were invited to have a support person with them during the interviews.

The research team interviewed 40 people from the four subgroups. Interviews averaged about an hour and took place via Zoom video conferencing. Interview recordings were transcribed, and transcriptions were analyzed.

Analysis

The data were analyzed using thematic analysis outlined by Braun and Clarke (2006).[42] First, the research team familiarized themselves with the data by reviewing transcripts and or video/audio recordings. Researchers then generated initial codes of interesting features of the data. Codes were then collated into potential themes, which were reviewed by the research team, and a thematic map of the analysis was generated. Themes were refined through the ongoing analysis of interviews, with a clear definition and names for themes emerging from the analysis process. The online qualitative platform Dedoose (www.dedoose.com) was used to facilitate analyses.

Phase Two: Survey

A national web-based survey was developed in the Winter of 2020-2021 with the intent of capturing the perspectives of people with disabilities, family members of people with disabilities, and professionals and experts in the financial, legal, and disabilities fields. The survey had six different tracks that steered participants to different questions related to how they identified, including:

- Person with a disability
- Family member of a person with a disability

- Guardian of a person with a disability (no relation)
- Someone who directly and primarily works with people with disabilities (e.g. service providers, caseworkers, and special education professionals),
- Someone who works in a field focused on disabilities but does not directly work with people with disabilities (e.g., state agency professionals or compliance officers)
- Someone who primarily works in a field not focused on disability but has people with disabilities as clients (including attorneys and financial planners)

Depending on the track chosen and the answers given, participants could be prompted to answer as many as 57 questions, but most answered far fewer. The survey contained mostly multiple-choice questions, but also several questions that asked participants to rate their experience on a scale of 0-10, as well as three short answer questions for participants to write in responses. The survey asked participants about demographic information, their experience with future financial planning accounts, financial literacy training, point of entry for future financial planning, challenges, and facilitators to obtaining and maintaining accounts, and their values related to people with disabilities regarding choice and control over planning and spending.

Recruitment

Purposive and snowball sampling was used to seek responses from as many potential participants of the target populations as possible. The survey was distributed nationally in February and March of 2021 to the 19 national organizations that are partners of the National Leadership Consortium, the listserv network of National Leadership Consortium (consisting of about 3,400 professionals), and about 50 state Developmental Disabilities Councils. Organizational leaders were encouraged to post the survey link on their websites and social media platforms, as well as distribute the survey widely to any additional contacts who were relevant. An incentive of $10 was offered in the first week of dissemination to respondents who were people with disabilities, a family member of a person with disabilities, or a guardian of a person with disabilities, as it is traditionally difficult to get participation from these populations.

A total of 6,191 potential participants opened the survey online. Ultimately, 5,252 participants who lived in the U.S., were at least 18 years old, and completed all the demographic questions at the beginning of the survey were included in analyses. To help ensure the authenticity of the data, respondent data that had a ReCAPTCHA score of less than 0.5, included a duplicate email, a suspicious email, or a duplicate response in the short answer questions were eliminated. Additionally, responses from participants who were younger than 18 years old or lived outside of the U.S. were eliminated.

Analysis

Initial analyses included descriptive statistics, which evaluated measures of central tendencies to investigate the types of participants in the study and how they responded to questions related to values about future financial planning. More advanced statistical analyses (including correlations, independent samples t-Test, Chi-square tests for independence, binomial logistic regressions, and one-way analyses of variance, or ANVOAs) were then performed to arrive at findings shared in this report. Particular attention was paid to responses about the difficulties experienced during future financial planning. These analyses revealed how, when, and where difficulties related to future financial planning are experienced and the specific barriers that stand in the way of successful experiences for people with disabilities, their families, and professionals associated with financial planning and/or people with disabilities. IBM SPSS Statistics 26 software was used to facilitate analyses.

Phase Three: Expert Workshops

The expert workshops were teleconferencing forums via Zoom for select people with expertise in future financial planning to discuss potential recommendations for the future of the field. Initial results from previous phases of the study were shared with workshop participants as a foundation for discussions. The two, three-hour workshops held on May 18th and May 27th, 2021, involved small and large group discussions centered around:

- The future vision for the future financial planning process, services, and resources
- Prioritizing areas of greatest importance or need
- Exploring challenges of prioritized areas of need and existing resources to address those challenges
- The needed components of oversight for future financial planning
- Potential training and credential requirements
- Expanding existing successful strategies or resources
- Prioritizing efforts to address barriers and enact solutions

The sessions and break out group discussions were recorded, and recommendations were documented by National Leadership Consortium researchers.

Recruitment

Targeted recruitment for the expert workshops involved emailing select people interviewed in Phase 1 and survey participants from Phase 2 of the study, as well as people recommended to the research team from other sources. Potential participants were also recruited broadly from the National Leadership Consortium listserv. Participants who were hand selected by the research team initially completed a screener questionnaire to ensure that people invited to participate in the workshops represented a diverse array of stakeholders, including people with disabilities and family members of people with disabilities, leadership from national disability, legal, and financial organizations, as well as authors, and scholars on the topic. Twenty-two experts participated in the workshops.

Analysis

Thematic analysis (see analysis for Phase 1 above) was performed to reveal and sort themes and concepts that emerged from the data. Results from the expert groups are outlined in the "Recommendations" section of this report.

All phases of this project received approval from the Institutional Review Board (IRB) of the University of Delaware.

APPENDIX C: Survey Participants

Participant Demographics for Future Financial Planning Survey (N=5,252)

Variable	N	%
U.S. Region		
Northeast	564	10.8
Midwest	682	13.0
South	2076	49.6
West	1921	36.6
Age		
18-24	463	8.8
25-34	2265	43.1
35-44	1569	29.9
45-54	431	8.2
55-64	297	5.7
65+	227	4.3
Gender		
Man	3002	57.2
Woman	2186	41.6
Non-Binary/Other	40	0.8
Prefer Not to Answer	24	0.5
Race/Origin		
White	3824	72.8
Hispanic, Latino or Spanish Origin	436	8.3
Black or African American	517	9.8
Asian	97	1.8
American Indian or Alaska Native	214	4.0
Native Hawaiian or Other Pacific-Islander	99	1.9
Multiracial	29	0.6
Other	8	0.2
Prefer Not to Answer	31	0.6

Variable	N	%
Employment		
Full-Time	2633	50.1
Full-Time and Part-time Job	630	12.0
One Part-Time Job (Not Retired)	603	11.5
More Than One Part-Time Job	299	5.7
Working Age and Unemployed	104	2.0
Retired and Unemployed	183	3.5
Retired and Working Part-Time	83	1.6
On Disability and Unemployed	331	6.3
Part-time due to Covid-19	177	3.4
Unemployed due to Covid-19	146	2.8
Full-Time Student	29	0.6
Attended day program/workshop	3	0.1
Other	31	0.6
Household Income		
$0-40,000	1613	30.7
$40,001-100,000	2626	50.0
$100,001-300,000	780	14.9
$300,001+	112	2.1
I Don't Know	17	0.3
Prefer Not to Answer	105	2.0
Participant Group (some participants identified as more than one)		
Person with a Disability (PWD)	1817	34.6
Family Member of PWD	2069	39.4
Guardian of PWD	409	7.8
Disabilities Field Professional	691	13.2
Non-Disabilities Field Professional	229	4.4
Other	37	0.7

APPENDIX D: Plan and Account Indicators

A cross-tabulation revealed that about 18% of people with disabilities and family members of people with disabilities had an ABLE account, with the highest percentage of respondents earning $40,000-$100,000 per year (19%). Additionally, those with intellectual disabilities were more likely to have an ABLE account (27%) than people with other disabilities.

Respondents with middle or high incomes and those with intellectual, developmental, or sensory disabilities were more likely to have a trust. About 17% of respondents have a first-person trust, with the highest percentage of people with this account earning $300,000 or more per year (23%). Moreover, people with developmental disabilities (including autism spectrum disorder) were more likely to have a first party trust than those with other disabilities (25%). Overall, about 10% of respondents have a third-party trust, with those earning $300,000 or more per year having the highest percentage (21%) over other income categories. Those with intellectual disabilities were more likely to have this account (19%) than people with other disabilities. About 6% of respondents have a pooled trust, with those earning $40,000-$100,000 per year most likely to have this type of account (7%). People with sensory disabilities (including hearing and vision impairments) were more likely to have a pooled trust (10%) than people in other disability categories.

Other accounts assessed included savings accounts or plans either in the name of the person with disabilities or in someone else's name (such as a family member). Overall, about 14% of respondents reported having another type of savings account, either in the person with disability's name or another person's name. People earning $0-$40,000 per year were more likely to have a savings account in the person with the disability's name (10%), while people earning $100,000-$300,000 per year were more likely to have savings account in another person's name (6%). Moreover, about 17% of people with sensory disabilities reported having a savings account in their name, while people who listed "other" as their disability category were more likely to have an account in another person's name.

APPENDIX E: Point of Entry

The survey also asked people to indicate who should and who did begin the process of future financial planning. Results showed that there was consistent alignment between these questions, in that participants felt that it is the responsibility of people with disabilities and families to begin, and in practice, those are the people who primarily started future financial planning. Differences between respondent groups for the question "Who should start the future conversation about future financial planning?" were also explored. Results from descriptive analyses show that respondents usually identified themselves as the ones who should be responsible for beginning the future financial planning process. For instance, many people with disabilities felt that the person with disabilities should start the future financial planning process, while many family members and guardians felt that family members should begin the process (see Table 1).

The survey asked people with disabilities and family members to name who actually did start the conversation about future financial planning in their experience and found that people with disabilities (21%) and families (34%) typically initiated the future financial planning process. These results demonstrate that the beliefs and practices related to who is responsible for beginning the future financial planning process align. Many participants felt that it is the responsibility of people with disabilities and families to begin, and in practice, those are the people who primarily started future financial planning. However, there may be more discrepancy in beliefs and practices related to when people should begin planning for their financial futures. While most respondents agreed that people should begin in young adulthood or earlier, we know from national data10 that many people with disabilities and families actually begin later. Results suggest additional resources and supports may help people begin the process earlier.

Table 1. Top 3 Groups Identified by Participants as Those Who Should Start the First Conversation about Future Financial Planning

	Person with Disabilities (N = 963)	Family Member (N = 1,078)	Guardian (N = 145)	Disability-Sector Professional (N=450)	Non-Disability-Sector Professional (N=183)
Top Group	Person with disabilities (274, 28%)	Family members of the person with disabilities (495, 46%)	Family members of the person with disabilities (42, 30%)	Supporting person with disabilities (119, 26%)	Person with disabilities (39, 21%)
2nd Group	Family members of person with disabilities (184, 19%)	Person with disabilities (167, 15%)	Person with disabilities (42, 30%)	Family members of the person with disabilities (94, 21%)	Legal Professional (35, 19%)
3rd Group	Professional supporting person with disabilities (155, 16%)	Professional supporting person with disabilities (161, 15%)	Professional supporting person with disabilities (20, 14%)	Person with disabilities (63, 14%)	Family members of the person with disabilities (35, 19%)

References

1 The Arc. (2020). *Future Planning*. Thearc.org. https://thearc.org/our-initiatives/future-planning/

2 Petriwskyj, A. (2018). Diversity, inclusion, and the voice of older people: Engagement and decision-making in seniors' organizations. *International Journal of Public Administration, 41*(9), 671-683. https://doi.org/10.1080/01900692.2017.1295463

3 Warschauer, T. (2002). The role of universities in the development of the personal financial planning profession. *Financial Services Review*, *11*(3), 201-216.

4 Altfest, L. (2004). Personal financial planning: Origins, developments and a plan for future direction. *The American Economist*, *48*, 53-60. https://doi.org/10.1177/056943450404800204

5 Lauderdale, M., & Huston, S. J. (2012). Financial therapy and planning for families with special needs children. *Journal of Financial Therapy*, *3*(1), 62-81.

6 Andreeva, G. B., Nikitina, O. A., Pavlova, L. V., & Sokolova, E. A. (2020). Managing the formation of the individual financial culture of university students. *SHS Web of Conferences, 79*, 1-5. https://doi.org/10.1051/shsconf/2020792002

7 Begley, T. D., & Hook, A. (2012). A dozen common mistakes with special needs planning. *Estate Planning, 39* (5), 44-47.

8 White, M. C. (2013). "Retirement planning for 3": For families with a special-needs child, advisors must employ a variety of tactics. *Financial Planning, 43*(7), 53.

9 Heller, T. (2010). People with intellectual and developmental disabilities growing old: An overview. *Impact: Feature Issue on Aging and People with Intellectual and Developmental Disabilities, 23*(1). https://publications.ici.umn.edu/impact/23-1/people-with-intellectual-and-developmental-disabilities-growing-old-an-overview

10 Heller, T., & Arnold, C. K. (2010). Siblings of adults with developmental disabilities: Psychosocial outcomes, relationships, and future planning. *Journal of Policy and Practice in Intellectual Disabilities, 7*(1), 16-25. https://doi.org/10.1111/j.1741-1130.2010.00243.x

11 Goodman, N., Morris, M., & Boston, K. (2017). *Financial inequality: Disability, race and poverty in America.* National Disability Institute. https://www.nationaldisabilityinstitute.org/wp-content/uploads/2019/02/disability-race-poverty-in-america.pdf

12 Heller, T., & Kramer, J. (2009). Involvement of adult siblings of persons with developmental disabilities in future planning. *Intellectual and Developmental Disabilities, 47*(3), 208-219. https://doi.org/10.1352/1934-9556-47.3.208

13 Hewitt, A., Lightfoot, E., Bogenschutz, M., McCormick, K., & Doljanac, R. (2010). Parental caregivers' desires for lifetime assistance planning for future supports for their children with intellectual and developmental disabilities. *Journal of Family Social Work, 13*, 420-434. https://doi.org/10.1080/10522158.2010.514678

14 Lindahl, J., Stollon, N., Wu, K., Liang, A., Changolkar, S., Steinway, C., Tractenberg, S., Coccia, A., Dvaney, M., & Jan, S. (2019). Domains of planning for future long-term care of adults with intellectual and developmental

disabilities: Parent and sibling perspectives. *Journal of Applied Research in Intellectual Disability, 32*, 1103-1115. https://doi.org/10.1111/jar.12600

15 Goodman, N., & Morris, M. (2017). *Banking status and financial behaviors of adults with disabilities: Findings from the 2015 FDIC National Survey of Unbanked and Underbanked Households.* National Disabilities Institute. https://www.nationaldisabilityinstitute.org/reports/

16 Goodman, N., Morris, M. Morris, Z., & McGarity, S. (2020). *The extra costs of living with a disability in the U.S.: Resetting the policy table.* National Disability Institute.org. https://www.nationaldisabilityinstitute.org/reports/extra-costs-living-with-disability/

17 U.S. Census Bureau. (2020, June 17). *Anniversary of Americans with Disabilities Act: July 26, 2020*. Census.gov. https://www.census.gov/newsroom/facts-for-features/2020/disabilities-act.html

18 Data Commons. (2019). *Median individual income in the United States of America.* Data Commons.org. https://datacommons.org/tools/timeline#&place=country/USA&statsVar=Median_Income_Person

19 Rafal, P. S., & Houtenville, A. (2020). *Annual disability statistics compendium: 2020* (Table 4.10). Durham, NH: University of New Hampshire, Institute on Disability.

20 Altiraifi, A. (2020, April 7). A deadly poverty trap: Asset limits in the time of coronavirus. *Center for American Progress*. https://www.americanprogress.org/issues/disability/news/2020/04/07/482736/deadly-poverty-trap-asset-limits-time-coronavirus/

21 Erickson, W., Less, C., & von Schrader, S. (2020). 2018 *Disability status report: United States*. Ithaca, NY: Cornell University Yang-Tan Institute on Employment and Disability.

22 Greene, S., Pendall, R., Scott, M., & Lei, S. (2016). Open cities: From economic exclusion to urban inclusion. *Urban Institute*.

23 U.S. Bureau of Labor Statistics. (2021, February 24). *Persons with a disability: Labor force characteristics summary.* Bls.gov. https://www.bls.gov/news.release/disabl.nr0.htm

24 Burhouse, S., Chu, K., Ernst, K., Goodstein, R., Lloro, A., Lyons, G., Northwood, J., Osaki, Y., Rhine, S., Sharma, D., & Weinstein, J. (2016). *2015 FDIC National Survey of Unbanked and Underbanked Households*. FDIC.gov. https://www.fdic.gov/analysis/household-survey/2015/index.html

25 Goodman, N., Canfield, N., & Morris, M. (2018). *Addressing the needs of Americans with disabilities in financial capabilities programs.* National Disability Institute. https://www.nationaldisabilityinstitute.org/reports/fin-found-fin-cap-brief/

26 USA.gov (n.d.). *Disability Services*. https://www.usa.gov/disability-services

27 Ndugga, N. (2021). *Disparities in health and health care: 5 Key questions and answers*. Kaiser Family Foundation. Kff.org. https://www.kff.org/racial-equity-and-health-policy/issue-brief/disparities-in-health-and-health-care-5-key-question-and-answers/

28 DeNavas-Walt, C., & Proctor, B. D. (2015). *Income and poverty in the United States: 2014.* United States Census Bureau. https://www.census.gov/library/publications/2015/demo/p60-252.html

29 National Center for Education Statistics. (2020). *The condition of education: College enrollment rates.* Nces.ed.gov. https://nces.ed.gov/programs/coe/pdf/coe_cpb.pdf

30 Livermore, G.A., Stapleton, D.C., & Claypool, H. (2010). Health care when workers need it most: before and after entry into the Social Security Disability Insurance Program. *Inquiry*, *47*(2), 135-49. www.doi.org/10.5034/inquiryjrnl_47.02.135

31 Office of Disease Prevention and Health Promotion. (2020). *Social determinants of health.* Healthypeople.gov. https://www.healthypeople.gov/2020/topics-objectives/topic/social-determinants-health/interventions-resources

32 Elkins, K. (2020, January 23). *Here's how much Americans have saved for retirement at different ages.* Cnbc.com. https://www.cnbc.com/2020/01/23/heres-how-much-americans-have-saved-for-retirement-at-different-ages.html

33 Ameritrade. (September, 2019). 2019 *Retirement pulse survey: Catching up on retirement savings.* https://s2.q4cdn.com/437609071/files/doc_news/research/2019/retirement-pulse-survey.pdf

34 Northwestern Mutual. (2019). 2019 C.A.R.E. Study. https://news.northwesternmutual.com/2019-care-study

35 Urbatsch, K., & Fuller-Urbatsch, M. (2019). *Special needs trusts: Protect your child's financial future.* NOLO.

36 Wrubel, R. (2017). *Financial freedom for special needs families: 9 Building blocks to reduce stress, preserve benefits, and create a fulfilling future.* Rosalibean Publishing LLC.

37 ABLE National Resource Center. (2021). *History of the ABLE Act.* Ablenrc.org. https://www.ablenrc.org/what-is-able/history-of-the-able-act/

38 Herzberg, P. (2015). ABLE Act considerations for estate planning. *Journal of Financial Planning*, *28*(8), 35-36.

39 Dussault, K., & Lauterbach, J. R. (2002). Special needs trusts: Powerful planning tools for disabled individuals. *Journal of Financial Planning, 15*(1), 70-78.

40 Urbatsch, K., & Fuller, M. P. (2013). Traps for the unwary during special needs trust administration. *Estate Planning*, *40*(6), 14-22.

41 Safier, I.J. (2005). Using special needs trusts: Comfort for parents, dignity for disabled children. *The CPA Journal*, *75*(11), 12-13.

42 Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, *3*(2), 77-101. http://dx.doi.org/10.1191/1478088706qp063oa