

Financial Planning and Utilization among Parents of Children with Intellectual and Developmental Disabilities: An Exploratory Study

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**Rumi Agarwal
Mentor: Dr. Shanna L. Burke
Florida International University**

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Abstract

Background: Families of children with intellectual and developmental disabilities (IDD) experience significant levels of financial hardship which has implications on outcomes for the child, family, and parental mental health. Participating in financial planning activities and utilization of financial tools such as the Achieving a Better Life Experience (ABLE) program have the potential to alleviate poverty and improve life outcomes. Unfortunately, current rates of banking and usage of ABLE accounts are low among individuals with disabilities, and no existing study has examined this phenomenon specifically among families of children with IDD.

Method: Parents of children with IDD (n=176) residing in the United States completed an online survey to explore rates of financial planning and utilization, in addition to the barriers, facilitators, and impact parents experience in the process of opening and managing ABLE checking, savings and trust accounts.

Results: Parents of children with IDD worry about their child's financial future, however, paradoxically, are not engaging in financial planning. Findings revealed that rates of banking and utilization of all financial tools are low among this population. Only 29.5% of children had an ABLE account, 26% had a checking account, 35% had a savings account, and only 13.6% had an established special needs trust. Several programmatic and personal barriers were identified which hindered financial planning and utilization. These findings can help inform immediate programmatic changes and long-term policy considerations.

Conclusions: This novel study offers insight into the financial planning experience of families with children with IDD. It is imperative to enhance the utilization of financial tools among these families, to decrease levels of poverty, improve parental mental health, and enhance outcomes for families and their children with IDD across the lifespan.

Background

Families of children with intellectual and developmental disabilities (IDD) experience significantly high levels of financial distress (Emerson & Brigham, 2015; Meppelder et al., 2015; Parish et al., 2004) which is exacerbated by having to provide care and cover expenses for adult children living at home, who largely remain unemployed (Piazza et al., 2014; Pryce et al., 2017; Vincent et al., 2020). According to the American Community Survey, the percentage of working-age adults with disabilities who live in poverty is more than double that of individuals without disabilities (26% compared to 10%; Goodman & Morris, 2017). This financial hardship impacts parental mental health (Lee et al., 2019; Patton et al., 2018), which can adversely influence the treatments parents choose for their child (Dardas & Ahmad, 2014; Wilson et al., 2018). Moreover, financial strain limits the ability of individuals with IDD to access necessary services such as housing, transportation, education, and healthcare, which consequently impacts opportunities for competitive employment (Brucker & Nord, 2016; Caniglia & Michali, 2018; Laser, 2018; Lauer & McCallion, 2015; Morris et al., 2016; Parish et al., 2010; Salvador-Carulla et al., 2015), and the overall life trajectory for both parents and children.

With an increasing prevalence of developmental disabilities, affecting almost one in every six children in the United States as of 2017 (Zablotsky et al., 2019), and life expectancy continuing to rise into the early 70s (Patja et al., 2000), the urgency to support families in financial distress across the lifespan is crucial. Through participation in planning activities, there are opportunities to enhance quality of life (Hewitt et al., 2013), which includes the creation and utilization of financial plans and tools. Unfortunately, financial planning specifically related to banking activities remains low among individuals with disabilities. In 2011, 18.9% of individuals

with a disability (compared to 7.4% for people without disabilities) were unbanked, referring to having a checking or savings account, which only decreased slightly to 18.1% in 2017 (compared to 5.7% for people without disabilities). Furthermore, less than 40% of families with disabilities were found to save for emergencies of which 18% were more likely to save at home or with family or friends rather than use a bank account (Goodman & Morris, 2017).

A few studies have attempted to understand long-term planning behaviors among families of children with IDD. In one study, long-term planning was found to involve largely “aspirational” discussions, rather than definitive actions (Burke et al., 2018, p. 96) while another study found family planning efforts lacked specificity (Bowey & McGlaughlin, 2007). Among individuals with disabilities, studies have reported that the ability to make financial decisions and access services is impeded by limitations in knowledge and skills (Caniglia & Michali, 2018), while reasons for being unbanked included fear of losing social security benefits, insufficient funds to keep in an account, and high account fees (Goodman & Morris, 2017).

The introduction of the Achieving a Better Life Experience (ABLE) Act in 2014 allowed individuals with disabilities (with an onset prior to age 26) to open an ABLE account (Social Security Administration, 2019). This account is designed to encourage savings for disability-related expenses which can enhance vocational achievements, financial independence, economic growth, and quality of life (Laser, 2018; Morris et al., 2016). The ABLE program has been considered a “down payment on freedom” as it allows individuals with disabilities to break through poverty by contributing to saving goals and investment without losing government benefits up to a certain threshold (Laser, 2018, p. 810). Unfortunately, the adoption of the ABLE program has been slow since its enactment seven years ago. Despite the ability of almost 8 million Americans with disabilities to access tax-free income (Morris, 2019), only 56,632 accounts have been opened as of December 2019 (Curley, 2020). It is not evident from existing literature if this slow rate of adoption is a result of the many pitfalls critics have associated with the ABLE program such as limits on age and yearly contributions (Hershey et al., 2017a; Rephan & Groshek, 2016), or myths which surround the program such as the loss of Medicaid, Supplemental Security Income (SSI) and Social Security Disability Insurance (SSDI) benefits if the account exceeds \$2,000 (Ulisky, 2019).

Given that individuals with intellectual disability comprise almost 14% of the 13 million working-age SSI and SSDI beneficiaries (Livermore, Bardos, & Katz, 2017), and that rates of banking and utilization of ABLE accounts among individuals with disabilities remains low, it is necessary to explore parental experiences related to financial planning. No studies to the best of our knowledge has explored the reasons which could explain the low rates of utilization, nor examined the rates of banking and ABLE accounts specifically among families of children with IDD. Moreover, no study has examined the impact financial planning and utilization, can have on employment, education, and independent living outcomes for children with IDD, and parental mental health. An understanding of parent’s perceptions is especially important to identify any gaps in disseminated information and within policies and programs. Bridging these gaps could improve utilization of financial accounts which can be seen as protective factors, and fulfill their intended purpose of improving life outcomes, and diminish the risk of financial distress.

As such, the present study sought to understand the financial planning experience among families of children with IDD, with an additional focus on the ABLE program. Specifically, the following research questions were examined: 1) What kind of financial planning options are families of children with IDD aware of? 2) Where do families obtain information regarding financial planning options, such as the ABLE program? 3) What barriers or facilitators do

families foresee or have experienced in efforts to establish financial stability? 4) What, if any, impact has the ABLE program, other financial accounts or Social Security Administration programs such as PASS had on the child's plans for employment, education, and independent living, and on the mental health of parents? 5) What is the association between demographic attributes and the utilization of an ABLE account?

Methods

Sample

Parents of children with IDD were recruited to participate in an online study from October 2020 through December 2020. A total of 176 surveys were collected, which is an acceptable sample size given the exploratory nature of this study (Jones et al., 2003). The eligibility criteria for participation included parents who 1) could read and write English or Spanish, 2) have a child (0 to 26 years old) with IDD, 3) live in the USA, and 4) consent to the study. The age of the child with IDD was limited to the range of 0 to 26 years old to help identify barriers among families with children and young adults, which if addressed could encourage financial planning to begin earlier, thereby allowing the family to benefit from its use longer. The upper age limit was also set at 26 to capture the experiences of families as they approached the maximum age for disability onset for ABLE accounts.

Procedure

An exploratory cross-sectional study design using an online survey was utilized. Parents were recruited via a two-prong sampling approach. First, using convenience sampling, a recruitment email (in English and Spanish) with study details and a survey link was distributed widely to disability service providers and organizations with whom the study team had prior contacts. In addition, parents of children who were currently/previously enrolled in an inclusive postsecondary program designed for students with IDD (18 to 26 years old), located in the University of the first author were sent an email to request participation in the survey. Second, using snowball sampling, parents, service providers, and organizations were requested to share the study details and survey link *via email* with all of their own contacts and networks. The recruitment email specifically requested that the survey link not be posted on any social media site to prevent bots and spam respondents from accessing the link, which is likely given the monetary incentive associated with participation. Flyers for the study were also translated in both English and Spanish which included a QR code and were attached to all recruitment emails.

Participants who clicked on the survey link were directed to REDCap, a Health Insurance Portability and Accountability (HIPAA) compliant platform where the survey was developed, and where data was securely stored. The survey link was enabled with the reCAPTCHA feature which attempts to distinguish between humans and bots, thereby protecting websites from abuse. A \$10 Amazon e-gift card was emailed to all participants who completed the survey and who chose to provide an email address, which was the only identifiable information collected. Approval for all materials and procedures was received from the University's Institutional Review Board.

Measures

A consent form and three surveys were designed in English and professionally translated into Spanish using a certified translation service company, to allow respondents the option to choose their language of preference. All surveys utilized multiple-choice, Likert scale, and open-

ended questions and aligned with the research questions. Participants were first directed to choose their preferred language, followed by the consent page. This page provided study details and required parents to check boxes confirming that they met the eligibility criteria and consented to the study. If they were eligible, they proceeded to survey one which asked demographic questions about the parent and child (for example, “what is your current marital status” and “how old is your child”). If the parents selected that their child’s age was 27+ the parent was exited out of the survey. Eligible parents were automatically directed to survey two which asked a few general financial questions, followed by specific questions related to the ABLE program (for example, “have you heard of the ABLE program”). Upon completion of survey two, parents proceeded to survey three which asked about the utilization of other financial tools such as checking, savings, and trust accounts (for example, “how easy or difficult was it to create a checking/savings account?”), and Social Security programs their child may have used. At the end of survey three, parents were given the option to provide an email address (please see Appendix for the complete list of questions from surveys 1, 2, and 3).

A significant amount of skip-logic was incorporated into survey two, to capture the perspectives of three different groups in regards to the ABLE program. The three groups categorized participants based on responses to two questions: “Have you *heard* of the ABLE program?” with two response options “yes or no” and “Does your child *have* an ABLE account?” with three response options “yes, no, and not sure.” Please see Figure 1 for an overview of these groups.

Analytic Plan

Data was downloaded from REDCap into the Statistical Package for Social Sciences (SPSS Version 26.0; IBM Corp., 2019) for analysis. The data were checked for normality and both the parent's age and the child’s age were found to not be normally distributed (Kolmogorov-Smirnov value $p = 0.048$ and $p = 0.00$ respectively). In addition, a review for outliers identified one record where the parent’s age was listed as ‘4’, and as such, this was set as missing. Descriptive analyses were conducted to describe the attributes of the population and analyze responses to the survey questions. Chi-square tests were conducted to identify associations between demographic variables and the utilization of ABLE accounts. Fisher’s exact tests were conducted and reported when the cell size was less than five.

Qualitative data from the open-ended questions were analyzed using reflexive thematic analysis to understand the participants' experiences. This methodology identifies codes and themes guided by the explicit content of the data through an iterative process (Braun & Clarke, 2019). Eleven surveys had short open-ended responses in Spanish, which were translated into English by a Spanish-speaking team member. Two reviewers followed the six-step process outlined for thematic analysis which included familiarization with the data, generation of initial codes, identifying and defining themes, and writing up of the results. Any discrepancies in the themes were discussed until a consensus was reached.

Results

Quantitative Findings

Sample Demographics

A total of 176 parents participated in the survey of which the majority resided in Florida. Most participants were mothers, white and ranged between the ages of 24 and 68 years old. The majority were employed at the time of the survey, however, among those who were not

employed, approximately 35% stated that their job was affected by COVID-19. In response to a question about the parents current financial situation, about 32% reported that they lived comfortably, followed by about 31% sharing that they met their basic expenses and had a little leftover, almost 27% stated that they were just meeting their basic living expenses, while 5% shared that they did not have enough money to meet basic living expenses. Another 5% chose not to answer this question.

The average age of the child as reported by parents was 12.44 (SD = 7.78) and the four most frequently reported IDD diagnosis among children in the survey included: Down syndrome, autism spectrum disorder, intellectual disability, and developmental delay. Approximately 28% of these children received SSI benefits, 9% received SSDI benefits, and 44% received Medicaid. Please see Table 1 for complete demographic details. Parents were also asked if they had heard and used the Plans to Achieve Self Support (PASS) program offered by the Social Security Administration (SSA). PASS is designed to help individuals with disabilities pursue or return to employment (Social Security Administration, 2019), and as such, questions related to this program aimed to assess its impact on employment outcomes. Unfortunately, almost 88% of parents reported that they had not heard of PASS. However, when asked if they would be interested to learn more about the program given that it helps set money aside for specific work goals, almost 61% of parents who had not heard of PASS shared they would be interested to learn more. Utilization of this program was low in this sample, with only one participant who identified their child having used PASS. Over 14% responded that they had not used PASS as their child's disability limits this.

Knowledge, Awareness, and Source of Information Regarding Financial Options

Participants in the survey were asked about their awareness regarding various financial tools. In regards to the ABLE program specifically, 57.4% responded that they had heard about it. Among these parents, however, knowledge about the specific aspects of the ABLE program was low. Almost 30% were not sure or did not know (referred to as 'did not know' hereafter) what the ABLE program was about, 20.8% did not know who is eligible for the program, almost 48% did not know what expenses it could cover, and almost 37% did not know what the advantages of having an ABLE account are. Parents who had heard of the ABLE program reported that the source of their information included: a disability service provider or organization (41.6%) such as The Arc and the Down Syndrome Foundation of Florida, followed by a parent who had a child with a disability (24.8%), and a disability event (20.8%) such as the Family Café (an annual event in Orlando, Florida) and Buddy Walk. Almost 15% of parents also heard about the ABLE program from family and friends, the ABLE National Resource Center, and the internet. None of the participants stated that their source of ABLE information was the SSA.

Over 80% of parents in the survey were aware of a checking and savings account (84.1% and 82.4% respectively), followed by stock investments (59.7%) and a special needs trust (50.6%). Very few participants were aware of a pooled-income trust (10.8%) while almost 7% stated that they were not aware of any of these financial options. The source of information for these financial tools was most frequently reported to come from banks (55%), family and friends (40.2%), and financial advisors (28.7%). Around 20% of parents heard about these options from another parent who had a child with a disability, disability service providers, the internet, and their legal advisor. Approximately 7% heard of them from their child's school, while only a handful of parents had heard of these from the SSA (5.5%).

Utilization, Barriers and Facilitators for Financial Planning and Accounts

A parent's attitude, self-efficacy, and ability to make financial decisions and plans were assessed, as these factors could facilitate or hinder the utilization of financial tools. About 60% of parents were very confident or fairly confident that they were making the best choices to manage their money, savings, and investments. Conversely, almost 40% were only slightly confident or not at all confident. Almost all the parents (94.9%) stated that it was very or fairly important for them to secure their child's financial future, and approximately 80% of parents had thought about what they could do to secure their child's financial needs since their diagnosis. However, only half of the parents (51.1%) had a specific financial plan or schedule to save or invest for their child's future. This is interesting, given that most parents (70.7%) reported that they began to actively think about their child's financial future between the time their child was born till when the child was around five years old.

Similarly, the child's attitude and interest in personal finances and related competence were also assessed. Only about 16% of children were reported to show an interest in being involved in planning or managing their own accounts. Approximately 19% were not interested, 41% were too young, while 24% were reportedly not showing interest as a result of disability limitations. Parents also shared how confident they felt about their child's ability to manage money. Almost 22% of parents indicated that they were not confident at all, 23% indicated that they felt slightly or fairly confident, while only about 2% were very confident. The remaining 54% of parents reported that either their child was too young or their disability limits this.

The following sections highlight the findings of the study in respect to the utilization, barriers, and facilitators for the following financial accounts: 1) ABLÉ accounts, and 2) Checking, savings, special needs trust, and pooled income trusts (referred to as trusts hereafter). The first three sections relate to the ABLÉ program (Groups 1, 2, and 3 as seen in Figure 1), and the last section presents the findings for other financial options. A small percentage (1.7%, n=3) of the participants stated that they had heard of the ABLÉ program but were not sure if their child had an account. These participants were directed to survey three on other financial accounts and did not complete any further questions related to the ABLÉ program.

ABLE Group 1: Of the 176 survey respondents, only 52 parents (29.5%) had heard of the ABLÉ program and had an account for their child. The top three concerns and questions parents most frequently had prior to opening the ABLÉ account included: what the money in the account could be used for (almost 56%), what would happen to the money in the account in the event of death (42.3%), and would the account affect the child's SSI/SSDI benefits (almost 33%). The top three personal concerns that parents had before opening an ABLÉ account included: uncertain that they would have sufficient money left over to contribute to the account (42.3%), concerns that no one else in the family or friends would make contributions to the account, and concerns about their own or their child's ability to make financial decisions such as choosing investment options (almost 31% each respectively). Most parents took it upon themselves to research the answers to their questions and concerns (almost 86%). Some contacted the state ABLÉ office (23.1%) or asked a trusted friend or family member for help to answer their concerns (17.3%).

All of these parents took the initiative to set up the ABLÉ account themselves, and only six of these parents consulted with their adult child when opening it. In most cases, parents did not consult with their child as the child was either too young (55.8%) or the child's disability limited this option (25%). Most frequently, parents in this group did not use any help to *open* the ABLÉ account (80.8%). If they did, it was most frequently received from the state ABLÉ

program (9.4%) or a financial planner (3.8%). In line with these findings, almost 85% of parents shared that it was easy or very easy to open an ABLE account, while only 5.8% said it was difficult or very difficult. Approximately 10% stated that the experience was neutral. Almost all parents (98.1%) were responsible for managing the account, with only one parent who reported that the parent and child managed the account together. A little over 69% of parents shared that it was easy or very easy to manage an ABLE account, while about 2% said it was very difficult. Approximately 30% stated that the experience was neutral.

ABLE Group 2: Among the survey respondents, 46 parents (26.1%) had heard of the ABLE program but did not have an account for their child. Parents shared their top three reasons for why they chose to not open an account which included: uncertainty about the real benefit of having an ABLE account (32.6%), not being sure what the money in the account could be used for, and if the child would be eligible for an ABLE account (26.1% each). The top three personal concerns which kept parents from opening an account included not having the time to find out more about the program (54.3%), not sure that there would be enough money to contribute to the account (41.3%) and concerns that no family or friends would contribute to the account (21.7%).

Despite these concerns, almost all the parents believed that an ABLE account could be useful to support their child. Parents reported that they believed the account could be somewhat helpful or very helpful to pay for educational expenses (84.8%), employment expenses (89.1%), building an emergency fund (93.4%), independent living expenses (93.5%), health expenses (95.7%), and building long-term savings for the child (97.8%). As such, almost 72% of parents stated that they would be interested in learning more about the ABLE program. These parents most frequently reported that they would prefer to hear about the ABLE program from their state ABLE program or representative (33.3%), a disability service provider/organization, or their financial planner (18.2% each respectively). In respect to the communication method they would prefer, most parents stated that email (45.5%), a recorded webinar (24.2%), or a live webinar with opportunities for questions and answers (15.2%) would be the most desirable.

ABLE Group 3: There were 75 parents (42.6%) among all survey participants who reported that they had not heard of the ABLE program. Upon selection of this response, the survey directed them to a short description of the ABLE program which also briefly explained the eligibility criteria. This was followed by additional survey questions. After reading the description, 61.3% (n=46) of parents stated that they would be interested in learning more about the program, 21.3% said they were not interested at this time, while 17.3% said they were not interested. Almost 85% of the parents who expressed an interest reported that based on the description they read, they felt their child may be eligible for an account. Parents selected their top three concerns or questions that came to mind after reading the ABLE description. Most frequently, parents wanted to know how much the monthly fees were for an ABLE account (37%), if their child would meet eligibility requirements (28.3%), and what would happen to the money in the account in the event of death (26.1%). The top three personal concerns included that they had not heard more about the program from other people, agencies, and service providers (52.2%), were concerned about their own or their child's ability to make financial decisions (50%), and they were unsure if there would be enough money left over to contribute into an ABLE account (47.8%). An overwhelming 91.3% stated that they were somewhat likely or very likely to make an effort to find answers to the concerns and questions they had. When these parents were asked what their top three uses of an ABLE account would be if their child had one, similar to parents

in group 2, about 76% stated they would use it to build long-term savings for the child's future. They would also use it for independent living expenses (54.3%) followed by building an emergency fund (47.8%). Parents shared that their top three preferred sources to learn more about the ABLÉ program would be from a state ABLÉ program/representative (32.6%), disability service providers/organizations (26.1%), and/or families who have an ABLÉ account (21.7%). Exactly half of the parents (50%) stated they would like to receive more information via email, a one-on-one meeting (19.6%), and/or regular mail (10.9%).

Other Financial Accounts: To assess utilization of financial accounts other than ABLÉ, parents who were aware of other financial accounts (n=164) were asked if their child currently had, or had access to any of the following: checking, savings, special needs, and pooled income trusts, and stock investments. The majority of parents within this group stated that their child did not have any of these financial accounts (38.4%). However, almost 30% of children had a checking account (28%), and close to 40% had a savings account (37.8%). About 15% had a special needs trust (14.6%) and 6% had stock investments (6.1%). Almost 8% stated that their child had another account such as a 529 prepaid college plan, while no parent stated that their child had a pooled income trust.

The experience of opening a checking and savings account was explored among those who responded that their child had either of these accounts (n=87). Most accounts were opened as a result of parents taking the initiative to set up this account for their child, and only 23% of parents said that their adult child was consulted in the process. Almost half of these parents noted that their child was too young to permit this involvement (49.4%) or their disability limited this (21.8%). Parents shared their top three concerns and questions they had before opening the checking/savings account. Most frequently, parents were concerned if the account would affect SSI/SSDI benefits (36.8%), if it would affect Medicaid benefits (33.3%), and how much the monthly fees for the account would be (28.7%). Concerns of a personal nature which parents most frequently reported included: the ability of the parent or child to make financial decisions (54%), uncertainty that there would be enough money to contribute to the account (36.8%), and not being sure they could find someone to help answer questions (21.8%). Most parents researched the answers to their programmatic questions on their own (67.8%), spoke to someone from the financial institution (32.2%), or asked a trusted friend or family member (27.6%). Opening the checking/savings account was reported as being easy or very easy by almost 83% of the parents, with almost 53% sharing that they received help to open the account from someone at the financial institution. Parents were also largely responsible for managing the checking/savings account (88.5%) with about 87% reporting that managing the account is easy or very easy. Among parents who reported that their child had a special needs trust, 25% stated that the process to open it was difficult or very difficult, 50% stated this was neutral while only 25% stated the process was easy. Interestingly, the experience with managing trusts was different, with 25% reporting it is difficult, 29.2% stating it is neutral, while 45.8% sharing that it is easy or very easy.

Please see Figures 2 and 3 for an overview of the six most frequently reported programmatic and personal concerns parents had about ABLÉ accounts (separated by Groups 1, 2, and 3) and checking/savings accounts to illustrate differences and similarities among groups.

Impact of Financial Accounts on Families and Children

The majority of parents with an ABLE account for their child (Group 1; n=52) reported that their top three reasons for opening an ABLE account was to build long-term savings for their child's future (almost 83%), followed by supporting their child's independent living expenses such as rent and groceries (51.9%), and setting money aside for emergencies (almost 33%). Almost 62% of the participants found the account very helpful for building a long-term savings account for the future of the child, followed by almost 52% reporting that it was very helpful for building an emergency fund. Interestingly, the ABLE account was not used for educational, employment, independent living, or health care expenses by the majority of these account holders (94.2%, 94.2%, 90.4%, and 82.7% respectively). Overall, almost 80% of parents agreed that the ABLE account served the purpose they expected it to, while 17% were not sure. Only about 4% of parents reported that the ABLE account did not serve the purpose they expected.

Parents were also asked if they noticed any changes in their child if the child was using the ABLE account. Only two parents stated that their child was taking more initiative and was motivated to learn and grow. Most respondents stated that their child was too young at this time to notice any changes in them (approximately 44%), while others stated that their child's disability limits the ability to identify changes (almost 38%). All other parents shared no changes were apparent in their child. Of the parents who reported that their child had a checking or savings account, the majority shared that the account was very or somewhat helpful in providing the child independence through the use of a debit card for daily living expenses (71.4%). Using these accounts was also helpful to build long-term savings for the child's future (56.3%), building an emergency fund (49.4%), and paying for independent living expenses (48.2%). Children who used their checking/savings account were reported to be more self-confident (8%), more motivated, and taking the initiative to learn and grow (12.5%).

To assess the impact of financial concerns on parental mental health, parents responded to the question "Do you worry, feel stressed or anxious thinking about your child's financial future?" Approximately 11% of the parents stated never or rarely, about 39% reported sometimes, while 50% of parents shared that they were often or always worried, stressed, or anxious.

Associations Between Demographic Variables and Utilization of ABLE Accounts

To examine any statistically significant associations exist between demographic variables and the utilization of ABLE accounts, cross-tabulations and chi-square tests of independence were conducted. Please see Table 2 for all cross-tabulation results.

Race and the age of the child both approached marginal significance, $p = .057$ and $p = .054$ respectively. Ethnicity was statistically significant, $p = .011$ with cross-tabulated findings indicating that families who were not Hispanic or Latino had a higher proportion of ABLE accounts (59%) compared to Hispanic or Latino families. There was no statistically significant association between the utilization of an ABLE account and the parent's gender, household income, level of education, marital status, and living situation of the child.

Qualitative Findings

Analyses of open-ended questions led to the identification of six themes: 1) Barriers to *opening* financial accounts, 2) Facilitators to *opening* financial accounts, 3) Barriers to *managing* financial accounts, 4) Facilitators to *managing* financial accounts, 5) Recommended changes to ABLE programs, and 6) The impact of financial accounts. Themes related to opening and

managing accounts were separated as they are two distinct stages in respect to financial planning and utilization.

Theme 1: Barriers to Opening Financial Accounts

This theme describes the concerns and questions that parents had during their experience with opening or considering to open an ABLÉ checking, savings, or trust account. This theme has two sub-themes: 1) Program barriers highlight the concerns that stem from the characteristics of the financial account itself, and 2) Personal barriers which highlight concerns arising from personal circumstances and characteristics of parents.

Program Barriers: Several concerns related to the actual components of the ABLÉ program were raised by parents from all three groups. Parents appeared to be unclear on what the correct age to open an ABLÉ program should be. Some stated that they would open it when the child was older as it would be more relevant for their needs at that time, while others questioned what the advantage of opening the account when the child was younger would be. Parents were also worried about the level of risk associated with an ABLÉ account arising from the fact that investments could lose value, that the political landscape could lead to changes in the rules of the program, and, overall if an ABLÉ account was a safe option. Other programmatic concerns parents shared included: what would happen to the funds in the ABLÉ account if something happened to the child (for example, could claims be made for Medicaid repayment), what the program fees are, can child support be deposited into the account after the child turns 18, why ABLÉ is not able to issue a debit card if there are two guardians for the child, and challenges with finding trained representatives to answer questions related to a 529 rollover plan. Questions related to eligibility for an ABLÉ account were a common concern among parents who had not heard of the ABLÉ program. Specifically, parents were not sure if attention deficit hyperactivity disorder (ADHD) was an eligible disability, or if you had to be an SSI beneficiary to qualify. Parents shared that they needed more information about the eligibility criteria. An additional programmatic concern voiced by parents from all three ABLÉ groups was related to what the advantage of having an ABLÉ account was compared to any other account. Specifically, parents questioned what the benefits of an ABLÉ account were if the rate of return was the same as other savings accounts, or how the ABLÉ account was different from the Florida 529 prepaid account. A few quotes from parents which capture some of these concerns are presented below:

[My] child is young now and I don't see much benefit [to opening an ABLÉ account]. It might be tax free [sic] but if the interest is a typical savings rate of less than 1%, it wouldn't make much difference anyway. *Parent from Group 3*

We opened the account and have not added funds except what we put in to open the account. I'm still not sure this is the best vehicle for my daughter to save. I don't like all the rules that apply. *Parent from Group 1*

Opening the account itself was easy. However, I had a direct FL-Prepaid-to-ABLE account rollover, and no one could help me with that. It was like the ABLÉ reps [representative's] had never heard of a 529 rollover, and it is a tax sensitive [sic] thing, so I had to know the facts. Ultimately, I contacted [blinded name], the director [of ABLÉ Florida], for help. He connected me with a [representative]

who could help, which was great, but the lack of educated [representatives] was unfortunate. *Parent from Group 1*

Parents also expressed programmatic concerns related to opening checking and savings accounts. Similar to the concerns expressed above, parents were not sure about banking fees, and who would have control of the account if something happened to the parent. In addition, parents shared they were worried about the process to transfer the account to the child when they turned 18 years old, and the ability of their child to make financial decisions. It was also evident that parents were concerned if funds in the account would affect their child's eligibility for benefits. This latter concern was shared by almost all parents who also had a trust account. Among parents who had an established trust, it was clear that a lot of detailed information was required such as what they were, the benefits of having a trust, the costs to set them up, and who would manage the trust.

Personal Barriers: At a personal level, parents expressed that opening an ABLE account was challenging given the lack of sufficient funds and worries about how to make the best investment decisions. There was also a clear need among parents for easily accessible information about the ABLE program, and the opportunity to receive ABLE advice and assistance.

We hope to get ourselves to a point where we can open and grow an ABLE [account] but our financial situation is such that we don't have the money to do so. *Parent from Group 2*

[I would like] better [and] easier to understand information that is accessible. I asked at my bank [about the ABLE program] and they had no idea what I was talking about. *Parent from Group 2*

Parents also reported that opening an ABLE account required time and money which was a significant personal barrier. Many parents stated that they did not currently have the time to think about the ABLE program or time to set it up. Moreover, they shared that they needed someone to explain how the ABLE program fits with other financial options available and eligibility for benefits, which would add to the costs of opening an ABLE account.

[I need] someone to help with the process that can provide advice regarding the workings of the ABLE account, in conjunction with a trust, social security benefits, Medicaid, etc., so that I can be fully informed to utilize resources effectively. *Parent from Group 2*

Similarly, time and costs were also reported barriers for opening trust accounts. Parents shared that trusts were expensive to open as they required an attorney, which they had to spend time finding, and that a significant amount of paperwork was involved in the establishment of a trust.

It took us years to save for this expense [creating a trust]. It's very expensive. It also took much effort to assign all of [the] assets to the trust and to set up the life insurance to fund the trust upon our death.

[Challenges with setting up a trust included:] Gathering all info [information], getting an attorney, [and] getting all parties together.

Theme 2: Facilitators to Opening Financial Accounts

This theme describes the factors that supported parents with opening an ABLE, checking, savings, or trust accounts. This theme has two sub-themes. First, program facilitators highlight the factors that stem from the characteristics of the account itself. The second sub-theme, personal facilitators highlights personal attributes which support the opening of financial accounts.

Program Facilitators: Parents reported that the website for the ABLE program was quite easy to use and understand, and representatives on the phone and via email were helpful. In addition, the ABLE program was easier to understand compared to some other financial programs. Moreover, parents expressed that the limited options available for investment choices in the ABLE program was desirable, as it made decision-making easier.

The Florida website and hard copy information [for the ABLE program] was well written. More importantly, it is an easy program to understand. It is not like an IRA or other tax advantage [sic] savings plan that uses pre-taxes dollars and has age base[d] withdrawal rules. I have not made any withdrawals. I have not had to call customer service.

It is very easy to open an ABLE account. The website is very straightforward, contributions are made automatically each month and the options for investing are spelled out well so they are easily understood.

Similarly, parents who reported that their child had a checking or savings account shared that opening an account online was easy to do. Checking and savings accounts could also easily be transferred to a child when they turned 18, which parents shared made it easy for their child to have access to an account. Moreover, staff at the bank were very helpful and worked with the SSA to set up the account appropriately.

[I] went to the bank and customer service was very helpful.

SSI [SSA] provided paperwork so setup at the bank was easy.

Personal Facilitators: At a personal level, parents shared that talking with someone who had experience with ABLE accounts was very helpful in opening one.

I had an experienced friend help with the process.

Having someone walk us through the process made it easy.

In respect to opening a checking or savings account, many parents shared that since they already had an existing account and relationship with a bank, opening this account for their child

was exceptionally easy. It was evident that parents with established trust accounts for their child had made the necessary effort to secure their child's financial future and benefits, especially for when parents would pass away. These parents took the initiative to research their questions themselves, and sought the help of lawyers and financial advisors to establish trusts.

[A trust was created] to provide [a] financial future for [my] child while preserving benefits.

I created the Special Needs Trust for my son in the case of my death.

We used a lawyer who specializes in special needs trusts who walked us through it.

Theme 3: Barriers to Managing Financial Accounts

This theme describes the concerns parents had arising from their experience with managing their financial accounts. In respect to the ABLE account, parents had concerns regarding the lack of control over where and how the money was invested and the limitations in respect to the amount of money that could be deposited. Although some parents stated that setting up the gift-giving option (the ABLE program allows the account holder to invite other friends and family to contribute directly into the account) was relatively easy, some parents expressed that this was difficult. In addition, some parents were unclear about how withdrawals from the account should be handled, and how tax forms should be prepared. It was also shared by one parent, that they did not know how to ensure that their child's expenses could be kept separate and withdrawn from the ABLE account when the family shopped together.

It is currently easy to manage the account since my son is 7 and does not need to routinely access the account. It [if] we were to need it frequently, the hardest part would be keeping his expenses separate from the rest of the family's expenses. We buy things for him at the same places and times that we buy for the rest of the family.

It's been very easy to deposit and change the investment option. I am somewhat intimidated on how to withdraw the money, so I haven't even attempted it. I have not applied for the debit card option yet...if it's available.

Easy online platform. Finding where to allow others to make contributions is challenging.

[I have] concerns about tax consequences but withdrawals and deposits are easy.

Some parents shared that managing a trust account was challenging as they always had to be alert about changes in their lives that would require updating their trust, and the laws and rules associated them. Although most families had hired a lawyer or financial planner to open and manage the trust, concerns related to taxes and laws were evident.

[Need to be aware of] accounting rules, fiduciary rules, and disbursement rules (to maintain public benefits).

We have to continually think about the trust to insure [sic] all of our accounts and assets are included in the trust.

Theme 4: Facilitators to Managing Financial Accounts

This theme describes what facilitated the management of financial accounts. Overall, parents stated that managing an ABLE account was relatively easy as the website was clear and navigating it was simple. As such, parents were able to access the accounts readily. Contrary to the experience of some parents, a few noted that depositing and withdrawing funds was straightforward while setting up gift-giving was also easy.

I have only recently begun withdrawing money from the account each money. Depositing and withdrawing money is straightforward. I have [not] had to fill out tax forms yet.

The website is easy to navigate, and all the info needed to maintain the account is laid out in an easy to read [sic] format.

Interestingly, in respect to the management of a trust account, most parents stated that they did not need to spend any time managing it after the initial set-up, as the trust would become active upon their passing. The following quote captures the sentiments of parents:

All the work to form the trust is done, now it is just waiting to be used.

Theme 5: Recommendations for ABLE Programs

This theme describes the suggestions parents made regarding the ABLE program to increase awareness and to make them easier to open and manage. Findings were categorized under two sub-themes: 1) Program components, which highlights recommendations regarding features of the ABLE program itself, and 2) Information and support, which describes the type of support parents need.

Program components: It was evident that parents would like to see an increase in the contribution and lifetime limits imposed on ABLE accounts. Many parents also commented on the need for more control over investment decisions, and that having the option of prepaid spending cards (with ABLE funds) would be useful to give to their child for spending. It was also suggested to allow the gifting link to be more customizable, with perhaps a personal photo a parent could use.

[A] prepaid card for withdrawals sounds interesting, as I would like my child to have access to SOME of the money, so he can practice buying things, like a Slurpee or a t-shirt he wants, but NOT have access to the whole account. If I could somehow remotely program him to have \$25 week [sic] credited to his card, that would be awesome.

My account is already linked and I can transfer money with just a click and entering the amount to contribute. The links for gifting are easy to share with family and others who may want to contribute, but I'd like to be able to customize the gift link with a picture.

Information and Support: Parents reported the need for more information about the ABLE program, such as the uses and limitations of the account. In addition, they wanted more support to help manage and answer questions as they arose, and resolve account issues. One parent suggested the following in regards to more information and support:

Have a recorded webinar on how an individual is managing their account for monthly living.

Theme 6: Impact of Financial Accounts

The final theme discusses the impact that having a financial account such as an ABLE, checking, savings, or a trust account had on families. Findings reflected two distinct areas of impact, which have been presented as sub-themes: 1) Emotional wellbeing, and 2) Independent living skills.

Emotional Wellbeing: Having an ABLE account had an impact on how parents felt. Many parents reported feeling good and more secure knowing that they had money set aside for their child which could be used in the event of an emergency or after their death. It was also important for the parents that these funds would not impact their child's eligibility for Medicaid and SSI benefits. One parent shared an example of how the ABLE account created a sense of relief, as the funds were able to support a health care expense. However, many parents remained concerned that they did not have enough saved in the account. Interestingly, many parents shared that they could not comment on the impact of the ABLE account on their lives yet, as they had not used the account.

We haven't used the account yet. We contribute monthly and hope it will be utilized with discretion and that it will be helpful.

[I feel] happier knowing that we are saving for his future without him losing Medicaid or SSI [benefits] as he becomes an adult.

I feel a little more secure [knowing] that she has an account that no one can use for any other purposes than for her personal needs. I worry that there isn't enough money in it!

I feel as a mom [I am] more relieved that this [ABLE account] can help with my sons [sic] life. He needed a hearing aid that insurance or even agencies won't help [acquire]. [Because he has] the ABLE United [account, he was able] to save [and] buy his own hearing aid which made us all happier. Thank you.

The impact on families from having a child that had a checking, savings, or trust account mirrored the findings from above. Parents with checking/savings accounts were happy that their child had funds for emergencies. Among parents who had an established trust account for their child, parents felt more secure, less anxious, and relieved about their child's financial future especially for when they would no longer be around. One parent was concerned that it was not fully funded, while another expressed worry regarding the management of multiple trusts especially when parents were divorced. The following quotes capture the sentiments of parents with established trusts for their child:

It takes away financial worry, or worry that my child will be left open to fraud or huge tax bill after my passing.

[I feel] better than before we had it, but anxious because it is not fully funded.

Independent Living Skills: This sub-theme describes the impact of financial accounts on the child's independent living skills. Specifically, it describes the growth and concerns parents shared in regards to money management skills among their children. Parents of children with access to an ABLÉ, checking, or savings account shared that their child was learning to be independent by using a debit card and having access to funds. They were also happy that these accounts allowed their child to learn basic financial skills such as budgeting and savings, and managing their accounts.

[I am] confident that my child is learning to use a debit card and [the] responsibility of managing the account. That is, knowing what is on the account and how much is available for spending.

I am happy he can use the ATM card and shop for food and other small items he likes. He does need supervision on how much to spend.

The child is depositing his own money into the account from birthday gifts from grandparents. He is building the habit of growing savings.

However, some parents were concerned about their child's ability to use the checking/savings account, or make sound financial decisions as a result of poor money management skills or limitations arising from their disability.

I opened the checking account before the ABLÉ account, hoping I could teach my child how to use a debit card, but I feel it is too difficult for him, so the account sits dormant with about \$200 of his Christmas money in it.

I am happy he has an account, but it makes me scared that he knows about money and could take money out he does not have, even after he has been instructed and educated about it.

I'm worried about the future and if they can safely handle their finances.

Discussion

This novel study set out to examine the awareness, utilization, facilitators, barriers, and impact parents of children with IDD report in regards to their experience with financial tools. Specifically, this study focused on the ABLÉ program and other financial accounts such as checking, savings, and trusts. It was apparent that most parents were aware of checking and savings accounts, while only about 60% were aware of the ABLÉ program. Among parents who had these accounts, overlap in many qualitative and quantitative findings reinforced some encouraging findings. First, parents shared that accounts were most commonly being used to

build a long-term savings and an emergency fund for the child. This is an extremely important finding given the high costs of disability-related expenses which span across the lifetime (Lunsky et al., 2019). Second, the impact of having an account was also desirable, as parents reported better emotional health knowing that their child's future was more secure after they had passed away. Third, parents reported that their child exhibited increased independence, and improvements in money management skills if their child used their account, allowing the child to experience and align with the societal expectations of young adulthood.

Despite these encouraging findings, the study draws attention to the glaring gaps which need to be bridged if financial security and trajectories across the lifespan among families and their children with IDD are to be improved. Utilization of all financial tools relative to the overall study sample (n=176) was low. Only 29.5% of children had an ABLÉ account, 26% of children had a checking account, 35% had a savings account, and only 13.6% had a special needs trust. Given that the majority of parents with financial accounts reported that opening them (except for trusts) was easy and straightforward in both qualitative and quantitative responses, it is clear that programmatic and personal barriers hinder more families from participating in financial planning for their child.

Clearly, the majority of parents in this study had contemplated their child's financial future and believed that securing it was important. Despite this desirable attitude and intention towards financial planning, only half of the parents in this study had enacted a specific plan for their child. This is concerning given that financial planning has been associated with self-rated health and depression (Weida et al., 2020). It is not surprising then, that almost 90% of parents in this study expressed worry, stress, and anxiety thinking about their child's financial future. This lack of planning may be attributed to the lack of confidence in respect to managing money and the ability to make financial decisions (their own and their child's), as reported in the qualitative findings and illustrated in the quantitative results in Figure 4. Another reason, common to all groups in this study, and also aligned between quantitative and qualitative findings and previous literature, was the concern that there would be insufficient funds to contribute towards an account (Burke et al., 2018; Goodman & Morris, 2017).

Recommendations for the Social Security Administration and the ARDRAW program

President Franklin Delano Roosevelt, created the SSA in 1935 to ensure that American's were protected from extreme poverty in the event of certain life circumstances, such as disability (Social Security Administration, n.d.). Currently, the monthly maximum SSI payment for an eligible individual is \$794 (Social Security Administration, n.d.). In 2015, the monthly maximum was only slightly lower at \$733 per month, and findings from that period indicate that two out of five SSI recipients lived in poverty, while three out five lived under 150% levels of poverty (The Arc, n.d.). It is evident that financial distress persists among SSA beneficiaries, and as such, it is recommended that the SSA encourage programs and activities that support opportunities for education, employment, and savings. This would align with advocating for enrollment in programs such as the PASS and the ABLÉ program. The SSA should consider, in this regard, prioritizing individuals with intellectual disability (who commonly have other co-occurring developmental disabilities), given that this population is more likely to seek employment or be employed compared to those with other impairments (Livermore, Bardos, & Katz, 2017).

Findings from both the quantitative and qualitative findings highlighted that families do not have sufficient funds to put aside for their child's future needs. This may be a reflection of the monthly maximum SSA benefits individuals receive, and as such, the SSA may want to

support policies that allow families who live in financial hardship to break past the cycle of poverty (Parish et al., 2010) such as increasing the monthly maximum amounts. Findings from the study also brought to light the lack of confidence among families to make financial decisions. As such, it is essential that the SSA “build people’s capacities to improve their financial situation” (Weida et al., 2020, p. 11), which should include training and workshops on financial planning and management. The SSA may want to include regular financial planning and consultations as an automatic benefit to these families at critical junctures, such as within two years of diagnosis. This will ensure that parents participate in specific, goal-oriented financial planning efforts (Lee et al., 2019) which begins when their child is young, and that parents who need support and assistance (such as those without financial literacy) are not left behind. Similar to providing financial training to parents, it may be necessary to prioritize money management training among individuals with IDD. To promote these independent living skills, the SSA could embed such training within employment programs like the PASS. In addition, to increase awareness and encourage utilization of financial tools, the SSA should collaborate with banks, disability organizations and state ABLER representatives to disseminate up-to-date and thorough information.

Finally, most parents in this study used their ABLER account for building a savings and emergency fund, and did not utilize it significantly for employment, education, and independent living goals. In the event that programmatic barriers are addressed in the future (by the ABLER program as suggested below), the ARDRAW program may want to consider supporting a longitudinal study which examines the impact of the ABLER program on life outcomes among individuals with IDD.

Recommendations for the ABLER program

To increase planning efforts and utilization of financial accounts, it is essential that ABLER programs address the programmatic barriers reported by parents. For example, parents from all three ABLER groups were not sure what the real benefit of an ABLER account was, while parents from Group 1 and the checking/savings group were concerned about how funds in the account could impact eligibility for SSI, SSDI, and Medicaid benefits. It is also interesting to find that over 50% of the parents who have an ABLER account (Group 1) were *initially* unclear what the money in the account could be used for. These barriers and others can be quickly and largely resolved through clear messaging, enhancing awareness, and distributing information widely (Lee & Burke, 2020). ABLER programs should develop easy-to-understand informational material which explicitly explains the unique benefit of an ABLER account versus other accounts, eligibility criteria, impact on government benefits, fees, the right age to open an account, what expenses the account can cover (which emphasizes its use beyond a savings account), and risks of having an account. For example, in regards to risks, one parent in this study shared that the changing political climate and its impact on program policies can deter families from participating in programs such as the ABLER account. Similar worries were reported in a previous study where families worried how changes in the state’s budget would affect the availability of disability services (Burke et al., 2018). This is a concern that should be addressed by ABLER programs. If this risk exists, it should be clearly communicated.

In the longer-term, ABLER programs should consider advocating for the need to increase contribution limits given that costs for healthcare continue to rise. Additional considerations for ABLER programs include offering prepaid debit cards to account holders and a more customizable gifting experience.

It is also evident from both qualitative and quantitative findings that parents need help to answer questions, and support when making financial decisions. Although the ABLE program is intended to allow individuals even without a financial planning background to open and manage their own accounts, there is an inherent risk associated with this. As suggested by Hershey et. al (2017a), “A key pitfall of ABLE account DIY management is that an unsophisticated owner who is not knowledgeable about tax law dynamics could inadvertently create investment results that exceed account limitations and open the beneficiary to penalties and the loss or suspension of certain public benefits” (Hershey et al., 2017a, p.73). Although ABLE programs already offer access to ABLE representatives and parent volunteers to help answer questions, it may be necessary to increase this presence and the level of guidance offered.

Unlike the recommendation from the report by Goodman et. al (2017) to disseminate financial curriculum and planning information via the SSA (Goodman & Morris, 2017), this study finds that awareness efforts and distribution of information would be more impactful if undertaken by state ABLE programs. In addition, support from disability organizations, financial planners, and families with an existing ABLE account should be harnessed. Information should be made available via email, regular mail, recorded and live webinars, and one-on-one meetings. Particular attention should be paid to ensuring that families from underrepresented groups, including Hispanic and Latino families are reached through this effort. Given that many parents in the study began to think about their child’s financial future between the ages of birth and five years old, this may be an opportune time to intervene. However, given that many parents in this study shared that their current financial situation limits funding of an ABLE account, and that they also lack the time to learn about the ABLE program (as suggested by both quantitative and qualitative findings), it is imperative that parents receive updated information periodically so that the lack of information and the effort to access it, does not impede or delay action when families are ready.

Among parents with an existing ABLE account, parents shared that they opened the account with the intent that it could be useful for building savings, emergency funds, and independent living expenses. However, most parents used the account primarily for building a savings account, but not for independent living, employment, educational, or other disability-related expenses. This could be due to the concerns regarding withdrawals and completing tax forms, which have led to many families not actively using the account. ABLE programs should ensure greater clarity on the various expenses the account can be used for to maximize the benefits from an ABLE account and offer step-by-step support to enhance account management.

Ultimately, a key benefit of the ABLE program is its intent to provide individuals with disabilities greater autonomy in their lives, by offering an account with tax benefits that is easy to open, access, and manage for disability-related expenses (Rephan & Groshek, 2016). To ensure that these benefits are realized, it is imperative that the above barriers and suggestions are considered. Improved planning efforts and utilization of financial tools such as an ABLE account have the potential to improve the mental health of parents. Moreover, it can ensure that individuals with disabilities, such as those with IDD, benefit from financial services which allow savings, enhance employment opportunities, and improve economic inclusion (Goodman & Morris, 2017).

Limitations

This study has a few limitations which should be noted when interpreting the findings. First, the sample size is small, and most participants resided in the state of Florida. As a result,

the generalizability of the findings is limited. In addition, the small groups within demographic variables limited the ability to undertake a regression analysis. As such, future studies should aim for a larger sample size ideally with national representation across race and ethnicity groups. Given the cross-sectional design, the study is unable to infer causality, while the sampling design and gift card incentive, creates the likelihood of volunteer bias. Also, there is the possibility of social desirability bias given the personal nature of the financial questions. Despite these limitations, however, this study offers a unique insight into the financial experience of families with children with IDD, especially in regards to the different groups within the ABLE program, and checking, savings, and trust accounts. These findings may allow a more targeted approach in addressing the needs of each group.

Conclusion

This exploratory study helps to increase our understanding of what factors facilitate and hinder the utilization of financial tools among families of children with IDD. It is clear that utilization has a positive impact on the life trajectory of both parents and their children. Perhaps with clearer and readily accessible information, better financial self-efficacy, and improved support utilization rates will improve, and positive effects of financial planning on education, employment, health, and independent living outcomes will be seen.

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Appendix

Table 1. Demographic attributes of study sample

	<u>Overall sample (N=176)</u>	
	<u>N</u>	<u>%</u>
Parent's age* - Range, <i>M (SD)</i>	24 – 68, 45.92 (10.37)	
Child's age - Range, <i>M (SD)</i>	0 – 26, 12.44 (7.78)	
State of residence		
Florida	148	84.1%
Tennessee	7	4%
Oregon	5	2.8%
Other states	16	9.1%
Parent Gender		
Female	146	83%
Race		
White	142	80.7%
Black or African American	20	11.4%
Other	9	5.1%
Prefer not to answer	5	2.8%
Ethnicity		
Hispanic or Latino	43	24.4%
Not Hispanic or Latino	128	72.7%
Prefer not to answer	5	2.8%
Currently employed		
Yes	108	61.4%
No	68	38.6%
If not employed, was job affected by COVID-19?		
Yes	24	35.3%
No	44	64.7%
Household Income		
<49,999	54	30.7%
50,000 – 74,999	59	33.5%
>100,000	53	30.1%
Prefer not to answer	10	5.7%
Highest level of education		
Two-year associate degree or less	65	36.9%
Bachelor's degree	60	34.1%
Master's/Doctoral/Professional degree	51	29%
Current marital status		
Married	122	69.3%
Widowed/Divorced/Separated	36	20.5%
Never married	18	10.2%
Child's living situation		
With one parent	48	27.3%
With both parents	110	62.5%
In an extended family	12	6.8%
Other	6	3.4%
Child's IDD diagnosis**		

ADHD	41	23.3%
ASD	62	35.2%
Behavioral Disorders	22	12.5%
Cerebral Palsy	15	8.5%
Developmental Delay	49	27.8%
Down Syndrome	69	39.2%
Fetal Alcohol Spectrum Disorders	1	0.6%
Hearing Impairment	11	6.3%
Intellectual Disability	49	27.8%
Language & Speech Disorders	42	23.9%
Learning Disorder	28	15.9%
Tourette Syndrome	1	0.6%
Vision Impairment	12	6.8%
Other	14	8%
Government programs/services child receives**		
SSI	49	27.8%
SSDI	16	9.1%
Medicaid	78	44.3%
VR agency funds	10	5.7%
HUD housing	5	2.8%
SNAP	22	12.5%
529 Prepaid college plans	10	5.7%
FAFSA	4	2.3%
Social Security programs	1	0.6%
Other	8	4.5%
None of the above	62	35.2%

* One missing value

** Does not add to 176 or 100% as participants could select multiple responses

ADHD: Attention-Deficit/Hyperactivity Disorder; ASD: Autism Spectrum Disorder; SSI: Supplemental Security Income; SSDI: Social Security Disability Insurance; VR: Vocational Rehabilitation; HUD: Housing and Urban Development; SNAP: Supplemental Nutrition Assistance Program; FAFSA: Free Application for Federal Student Aid

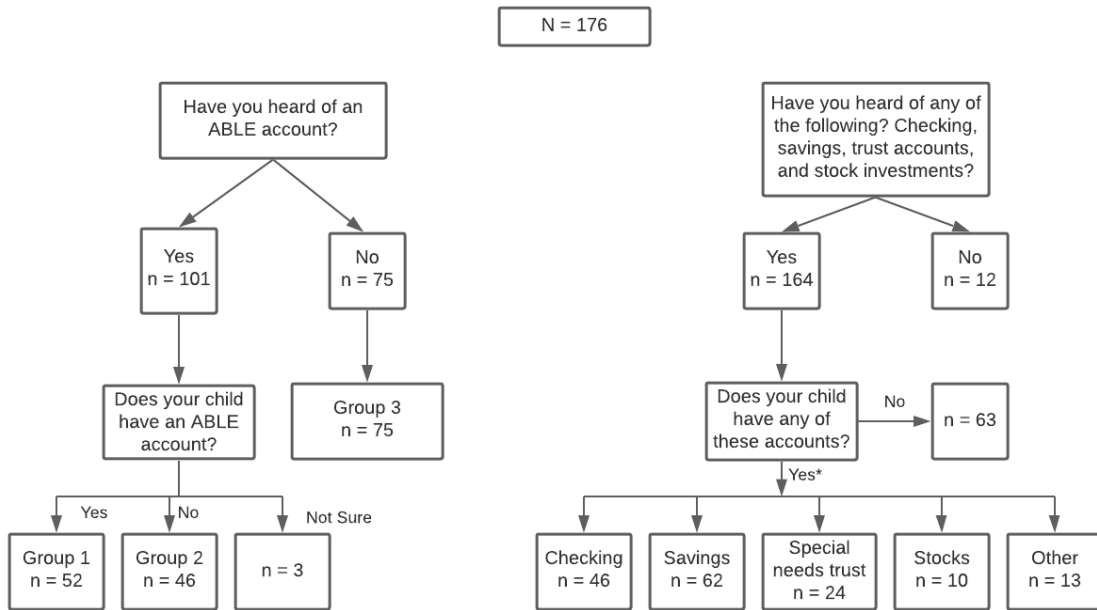
Table 2. Cross-tabulations of demographic variables and status of having an ABLÉ account

	Does your child have an ABLÉ account?				<i>p</i> -value
	No/Not Sure		Yes		
	Count	(%)	Count	(%)	
Race					.057*
White	40	46%	47	54%	
Black or African American	3	37.5%	5	62.5%	
Other	2	100%	0	-	
Prefer not to answer	4	100%	0	-	
Ethnicity					.011*
Hispanic or Latino	16	72.7%	6	27.3%	
Not Hispanic or Latino	32	41%	46	59%	
Prefer not to answer	1	100%	0	-	
Household Income					.431
<49,999	15	62.5%	9	37.5%	
50,000 – 74,999	13	44.8%	16	55.2%	
>100,000	18	46.2%	21	53.8%	
Prefer not to answer	3	33.3%	6	66.7%	
Highest level of education					
Two-year associate degree or less	19	61.3%	12	38.7%	.210
Bachelor's degree	16	47.1%	18	52.9%	
Master's/Doctoral/Professional degree	14	38.9%	22	61.1%	
Current marital status					.732
Married	35	47.3%	39	52.7%	
Widowed/Divorced/Separated	10	47.6%	11	52.4%	
Never married	4	66.7%	2	33.3%	
Child's living situation					.934
With one parent	13	50%	13	50%	
With both parents	31	47%	35	53%	
In an extended family	3	50%	3	50%	
Other	2	66.7%	1	33.3%	
Child's Age					.054*
0 to 5	9	42.9%	12	57.1%	
6 to 10	10	50%	10	50%	
11 to 15	11	78.6%	3	21.4%	
16 to 20	12	54.5%	10	45.5%	
21 to 26	7	29.2%	17	70.8%	

Note: Fisher's Exact Test reported when cell size is less than 5

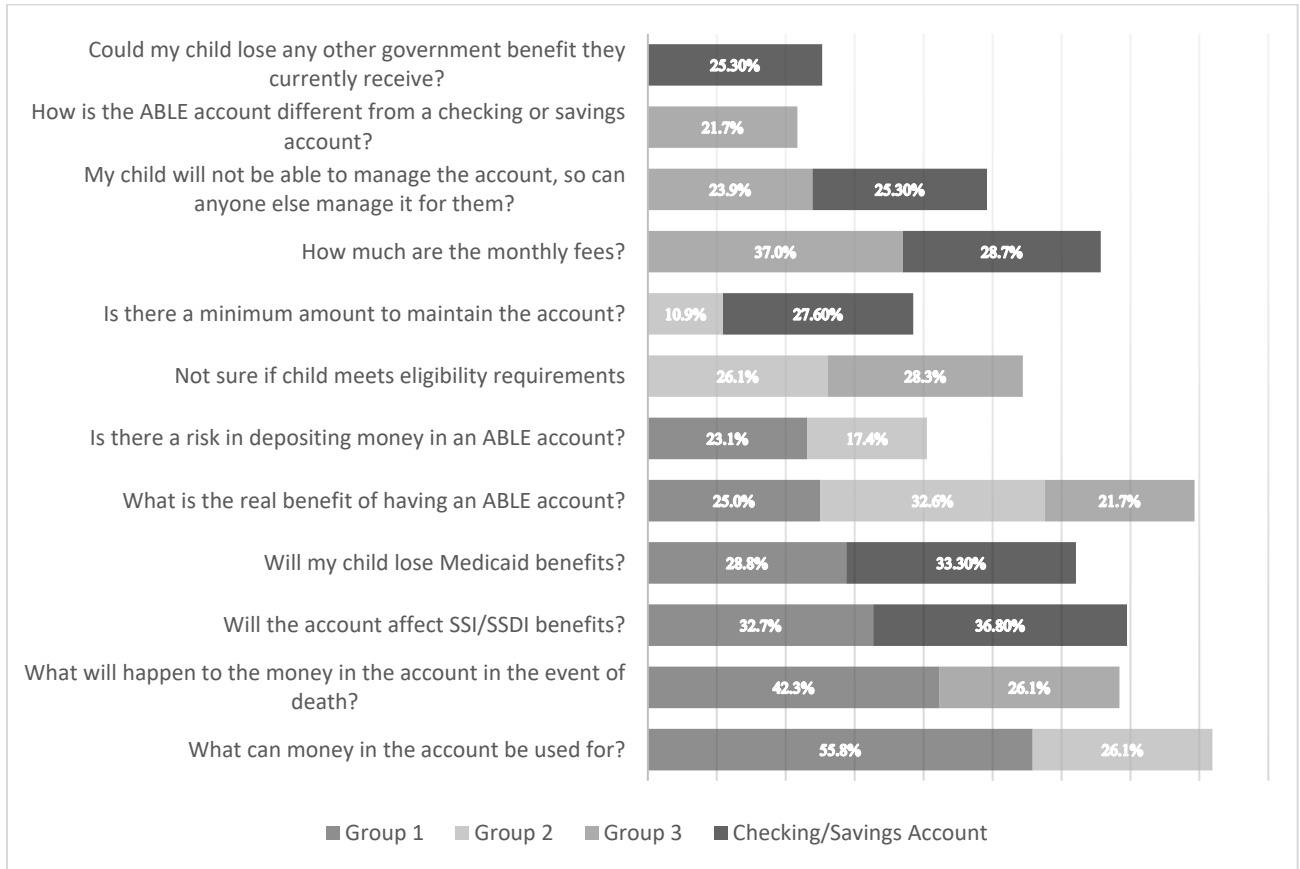
*Significant or marginally significant at the 0.05 level

Figure 1. Overview of awareness and utilization of ABLE accounts and other financial tools



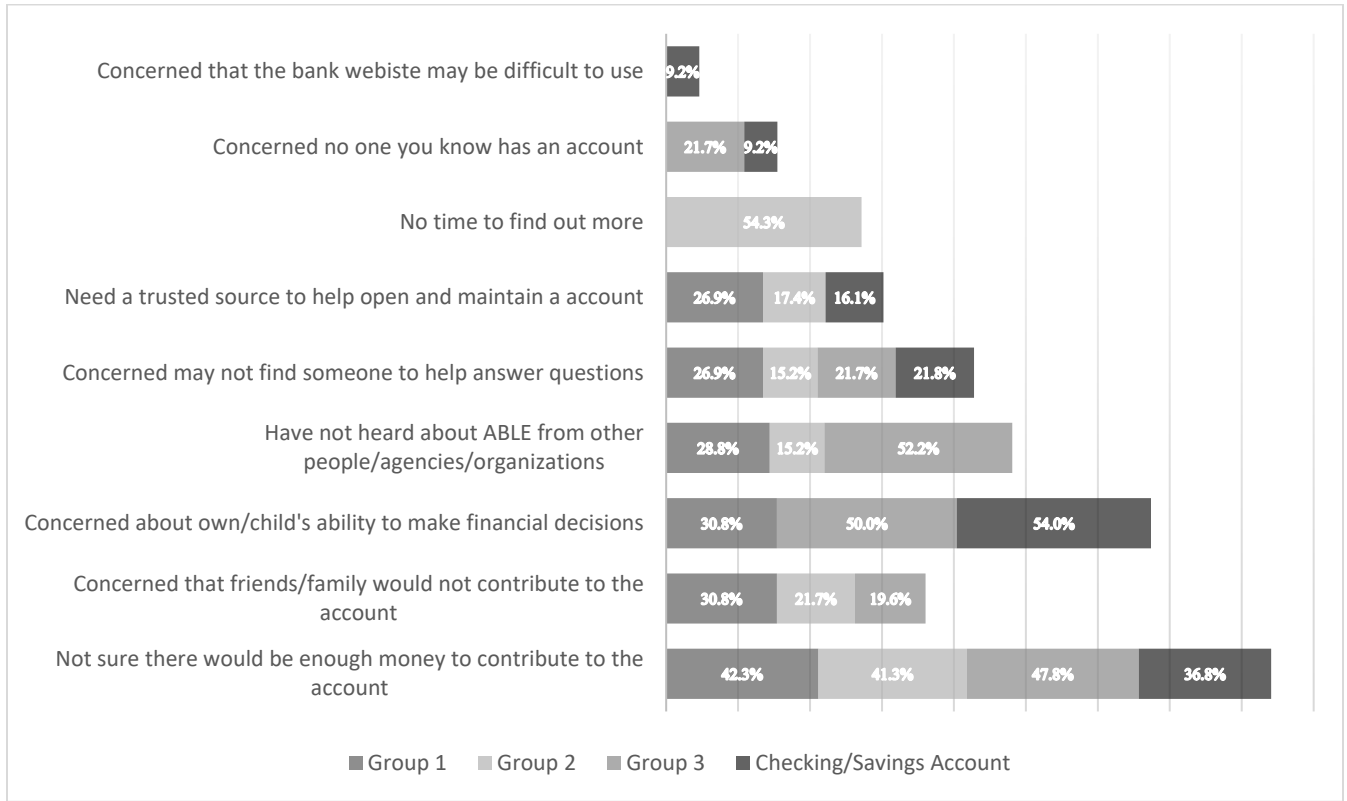
*Does not add to 164 as parents could select multiple responses

Figure 2. Top six programmatic concerns and questions of each group



Note: Does not add to 100% within groups as parents could select multiple responses.

Figure 3. Top six personal concerns of each group



Note: Does not add to 100% within groups as parents could select multiple responses.

Online Survey Questions

Survey 1 of 3

Please answer the following questions about yourself. Everything you share on this survey is anonymous. At the end of survey 3, you will have the option to provide an email address to which we will send you a \$10 Amazon e-gift card in appreciation of your time.

1. What is your age (must provide value): _____

2. Which state/territory do you live in:

- Alabama
- Alaska
- Arizona
- American Samoa
- Arkansas
- California
- Colorado
- Connecticut
- Delaware
- District of Columbia
- Florida
- Georgia
- Guam
- Hawaii
- Idaho
- Illinois
- Indiana
- Iowa
- Kansas
- Kentucky
- Louisiana
- Maine
- Maryland
- Massachusetts
- Michigan
- Minnesota
- Mississippi
- Missouri
- Montana
- Nebraska
- Nevada
- New Hampshire
- New Jersey
- New Mexico
- New York
- North Carolina
- North Dakota
- Northern Mariana Islands
- Ohio

- Oklahoma
- Oregon
- Pennsylvania
- Puerto Rico
- Rhode Island
- South Carolina
- South Dakota
- Tennessee
- Texas
- U.S. Virgin Islands
- Utah
- Vermont
- Virginia
- Washington
- West Virginia
- Wisconsin
- Wyoming

3. What is your sex:

- Female
- Male
- Non-binary
- Prefer not to answer

4. What is your race (Select ONLY one with which you MOST CLOSELY identify):

- American Indian or Alaska Native
- Asian
- Black or African American
- Native Hawaiian or Other Pacific Islander
- White
- More than one race
- Prefer not to answer

5. What is your ethnicity (Select ONLY one with which you MOST CLOSELY identify):

- Hispanic or Latino
- Not Hispanic or Latino
- Prefer not to answer

6. Are you currently employed?

- Yes
- No

Skip logic: YES to Employed: What is your occupation? _____

Skip logic: NO to Employed: Was your job affected by COVID-19? Yes / No

7. What was your total household income in **2019**. Please include all income earners residing in the household in which your child with intellectual/developmental disability lives in:

- < \$25,000
- \$25,000 - \$49,999
- \$50,000 - \$74,999

- \$75,000 - \$99,999
- \$100,000 - \$149,999
- \$150,000 - \$200,000
- >\$200,000
- Prefer not to answer

8. What is the highest level of education you have completed:

- Less than high school
- High school diploma or equivalent
- Some college, no degree
- Two year associate degree from a college or university
- Bachelor's degree
- Master's degree
- Doctoral or professional degree
- Prefer not to answer

9. What is your current marital status:

- Married
- Widowed
- Divorced
- Separated
- Never married

Please answer the following questions thinking about your **child** with an intellectual/developmental disability:

10. What type of intellectual/developmental disability does your child have? Check all that apply:

- Attention-Deficit/Hyperactivity Disorder (ADHD)
- Autism Spectrum Disorder
- Behavioral Disorders
- Cerebral Palsy
- Developmental Delay
- Down Syndrome
- Fetal Alcohol Spectrum Disorders
- Fragile X Syndrome
- Hearing Impairment
- Intellectual Disability
- Kernicterus
- Language & Speech Disorders
- Learning Disorder
- Muscular Dystrophy
- Tourette Syndrome
- Vision Impairment
- Other (please specify): _____

11. How old is your child?

- Less than 1 year old
- 1
- 2

- 3
- 4
- 5
- 6
- 7
- 8
- 9
- 10
- 11
- 12
- 13
- 14
- 15
- 16
- 17
- 18
- 19
- 20
- 21
- 22
- 23
- 24
- 25
- 26
- 27+

12. What is your child's current living situation:

- With one parent
- With both parents
- In an extended family setting (for example, with parents AND grandparents in the same house)
- With a legal guardian
- With a sibling
- With a roommate
- With paid supports, but not in a group home
- Supervised residential setting/group home
- Alone
- Other (Please specify):

13. Is your child currently receiving money, have an account, or using services from any of the following?

Select all that apply:

- SSI (Supplemental Security Income Program)
- SSDI (Social Security Disability Insurance Program)
- Medicaid
- State Vocational Rehabilitation (VR) agency funds
- HUD housing
- SNAP (The Supplemental Nutrition Assistance Program)
- 529 Prepaid college plans
- FAFSA (Free Application for Federal Student Aid)
- Social Security programs (such as Ticket to Work) (Please state which Social Security program(s) your child is using:)

- Other (please share what other government program your child is receiving money from/has an account/using services)
- None of the above

14. How did you hear about about this survey?

- FIU Embrace LIFE/Education
- Citrus Health Network, Embrace Medical Center
- Disability service provider/organization (please share the name of the service provider/organization from where you heard about the survey)
- ThinkCollege
- A friend or family member
- Other (please share where you heard about the survey from)

Survey 2 of 3

This section of the survey asks some general financial questions. Everything you share in this survey is anonymous.

- Please rate your current personal financial situation. Would you say you:
 - Don't even have enough to meet basic living expenses
 - Just meet your basic living expenses
 - Meet your basic expenses with a little leftover for extras
 - Live comfortably
 - Prefer not to answer
- How confident are you that you are making the best choices for how to manage your money, savings, and investments?
 - Not at all confident
 - Slightly confident
 - Fairly confident
 - Very confident
- Since your child's diagnosis, have you ever thought about what you could do to secure your child's financial needs?
 - Yes
 - No
 - **Skip logic: If YES to above:**
 - How old was your child when you actively began to think about securing their financial future? _____
 - Do you have a specific plan or schedule for how often, how much, and where to save or invest your money for your child's future? Yes/No/I don't know
- How important is securing your child's financial future for you?
 - Not at all important
 - Slightly important
 - Fairly important
 - Very important
- Do you worry, feel stressed or anxious thinking about your child's financial future?
 - Never
 - Rarely

Sometimes
Often
Always

- Has your child shown an interest in being involved in financial planning or managing their own financial accounts?
Yes
No
Not applicable - Child is too young
Not applicable - Child's disability limits this
- Do you feel confident in your child's ability to manage money?
Not at all confident
Slightly confident
Fairly confident
Very confident
Not applicable - Child is too young
Not applicable - Child's disability limits this

This section of the survey is about the ABLE (Achieving a Better Life Experience) program. Everything you share in this survey is anonymous.

- Have you heard of the ABLE (Achieving a Better Life Experience) program?
Yes
No
 - **Skip logic: If YES to above:**
 - Where did you hear about the ABLE program? Select all that apply:
A parent who also has a child with a disability
ABLE National Resource center
Banks
Blogs
Disability event (please share the name of the disability event)
Disability service provider, agencies, organizations, advocacy groups (please share the name of the organization/agency)
Family and friends
Financial advisor
Internet
Legal advisor
School
Social media
Social security administration
Vocational Rehabilitation (VR) office
Other (please share where you heard about the ABLE program from)
 - Thinking about the ABLE program, do you know:
 - What it is? Yes/ No / Not completely sure
 - Who is eligible? Yes/ No / Not completely sure
 - What expenses it can cover? Yes/ No / Not completely sure
 - What are the advantages of having an ABLE account? Yes/ No / Not completely sure
 - Does your child have an ABLE account?
Yes
No

Not sure

- **Skip logic: If YES to having an ABLE account:**
 - Who took the initiative/made the effort to set up the ABLE account?
 - Parent(s)
 - Child
 - Someone else (please share who made the effort to set up the ABLE account)
 - If your child is 18-26 years old, was the ABLE account opened in consultation with your child?
 - Yes
 - No
 - Not applicable - Child is too young
 - Not applicable - Child's disability limits this
 - Who manages the ABLE account?
 - Parent(s)
 - Child
 - Designated representative
 - Legal guardian
 - Other (Please share who manages the ABLE account)
 - What were your top 3 reason(s) to open an ABLE account? Select up to 3 responses:
 - For employment-related expenses (such as job training, transportation)
 - For health-related expenses
 - For education-related expenses (such as tuition, books)
 - For independent living related expenses (such as rent, groceries)
 - Build long-term savings for the child's future
 - Set money aside for emergencies
 - Set money aside for another reason
 - After you heard about the ABLE program, but before you opened an ABLE account, what top 3 concerns/questions did you have? Select up to 3 responses:
 - Does my child meet eligibility requirements?
 - Will my child lose Medicaid benefits?
 - Will the account affect SSI/SSDI benefits?
 - Could my child lose any other government benefit they currently receive?
 - What will happen to the money in the account, in the event of death?
 - What can the money in the account be used for?
 - How much are the monthly fees for an ABLE account?
 - Is there a risk in depositing money in an ABLE account?
 - Is this a government program?
 - My child will not be able to manage the account, so can anyone else manage it for them?
 - How is the ABLE account different from a checking or savings account from my bank?
 - What is the real benefit of having an ABLE account?
 - Who can withdraw money from the account?
 - Will my child be able to withdraw all the money when they become an adult (turn 18)?
 - Which ABLE account should I open, there are many choices?
 - Is there a minimum dollar amount that has to be kept in the account?
 - Other (please share any other questions or concerns you had before opening an ABLE account)
 - What were your top 3 personal concerns before you opened the ABLE account? Select up to 3 responses:
 - Not sure that there would be enough money left over to contribute into the account

Concerned that nobody else (family member, friends) would make contributions to the account

Concerned about not having a trusted source to help open and maintain the account

Concerned about your own/child's ability to make financial decisions (such as choose investment options)

Concerned about needing a reliable internet connection

Concerned that no one you knew had an ABLÉ account already

Concerned that the ABLÉ website may be difficult to use

Not sure if you would find someone to help answer questions you may have

Concerned that you had not heard more about the ABLÉ program from other people, agencies and service providers

Other (please share any other personal questions or concerns you had before opening an ABLÉ account)

- What did you do to find answers to these questions/concerns before opening the ABLÉ account? Select all that apply:
 - Researched it yourself
 - Asked a trusted friend/family member
 - Contacted the State ABLÉ agency
 - Asked a financial planner/legal advisor
 - Posted the questions on a blog/read blogs
 - Other (please share any other ways you found answers to your questions before opening an ABLÉ account)

- How easy or difficult was it to create an ABLÉ account?
 - Very difficult
 - Difficult
 - Neutral
 - Easy
 - Very easy

- Please state what made it easy and/or difficult for you to open the ABLÉ account. (For example, was the website easy to use, was the information difficult to understand, would you have liked for someone to help you through the process?) TEXT BOX

- Did anyone help you open the ABLÉ account?
 - Financial planner
 - Legal advisor
 - State ABLÉ program
 - Friend/family member
 - Other (please share who helped you open the ABLÉ account)
 - Not applicable

- How easy or difficult is it to manage the ABLÉ account?
 - Very difficult
 - Difficult
 - Neutral
 - Easy
 - Very easy

- Please state what makes it easy and/or difficult for you to manage the ABLÉ account. (For example, the online platform is easy, accessing customer service over the weekend is difficult, filling out tax forms for withdrawals is confusing) TEXT BOX

- How helpful has the ABLÉ account been to support your child in the following:

(Not at all helpful, Somewhat helpful, Very helpful, Have not used the account for this purpose)

Educational expenses (such as tuition, books)

Employment expenses (such as job training, transportation)

Independent living expenses (such as rent, groceries)

Health expenses

Building an emergency fund

Building long-term savings account for your child's future

- Does the ABLE account serve the purpose you expected it to?
 - Yes
 - No (please state the reason why the ABLE account does not serve the purpose you expected)
 - Not sure (please state the reason why you are not sure if the ABLE account serves the purpose you expected)
- If you could change anything about your child's ABLE account to make it more useful, what change would you make? (For example, change contribution limits, have prepaid cards for withdrawals) TEXT BOX
- How does it make you feel knowing that your child has an ABLE account? (For example, I feel happier knowing that my child has money for job training and education, I sleep better knowing that my child will be okay after I am gone, I worry that there is not enough money saved yet) TEXT BOX
- If your child has an ABLE account which they use, have you noticed any changes? Select all that apply:
 - Child is more self-confident
 - Child is taking more initiative and motivated to learn and grow
 - Not applicable - Child is too young at this time
 - Not applicable – Child's disability limits this
 - None of the above
 - Other (please share what changes you have noticed in your child)

- **Group 2 - Skip logic: If NO to having an ABLE account:**

You shared that you have heard about the ABLE program, but your child does not have an ABLE account:

- What were your top 3 concerns/reasons for not opening an ABLE account? Select up to 3 responses:
 - Not sure if child met eligibility requirements
 - Worried that child could lose Medicaid benefits
 - Worried that child could lose SSI/SSDI benefits
 - Concerned that child may lose other government benefits they currently receive
 - Not sure what would happen to the money in the account, in the event of death
 - Not sure what the money in the account could be used for
 - Concerned about monthly fees for an ABLE account
 - Unsure about the risk of depositing money in an ABLE account
 - Unsure if the ABLE account is a government program
 - Unsure if anyone else can manage the account, as your child will not be able to
 - Not sure how the ABLE account is different from a checking or savings account
 - Not sure about the real benefit of having an ABLE account
 - Concerned about who can withdraw money from the account
 - Concerned that child will want to withdraw all the money when they become an adult (turn 18)

Not sure which ABLE account to open given the various choices
 Not sure if there is there a minimum dollar amount which has to be kept in the account
 Other (please share any other questions or concerns which have kept you from opening an ABLE account)

- What were your top 3 personal reasons for not opening an ABLE account? Select up to 3 responses:
 - Did not have the time to find out more about the ABLE program to open an account
 - Not sure that there would be enough money left over to contribute into the account
 - Concerned that nobody else (family member, friends) would make contributions to the account
 - Concerned about not having a trusted source to help open and maintain the account
 - Concerned about your own/child's ability to make financial decisions (such as choose investment options)
 - Concerned about needing a reliable internet connection
 - Concerned that no one you knew had an ABLE account already
 - Concerned that the ABLE website may be difficult to use
 - Not sure if you would find someone to help answer questions you may have
 - Concerned that you had not heard more about the ABLE program from other people, agencies and service providers
 - Other (please share any other personal questions or concerns which have kept you from opening an ABLE account)
 - Do you think an ABLE account could be helpful to support your child in regards to: (Not at all helpful, Somewhat helpful, Very helpful)
 - Educational expenses (such as tuition, books)
 - Employment expenses (such as job training, transportation)
 - Independent living expenses (such as rent, groceries)
 - Health expenses
 - Building an emergency fund
 - Building long-term savings for child's future
 - If you could change anything about the ABLE program which would encourage you to open an account, what change would you make? (For example, change contribution limits, have prepaid cards for withdrawals, have someone who would help you through the process) TEXT BOX
 - Would you be interested in learning more about the ABLE program?
 - Yes
 - No
 - **Skip logic: If Yes to learning more**
 - Who would you prefer to hear more about the ABLE program from?
 - Disability service providers/organizations/agencies
 - Families who have an ABLE account
 - Financial planner
 - Legal advisor
 - School/education system
 - Social Security Administration
 - State ABLE program/Representative
 - Other (please share who you would like to hear about the ABLE program from)
 - How would you like to learn more about the ABLE program?
 - Email
 - Regular mail
 - Live webinar with opportunities for question and answer

A recorded webinar
 Live event you can attend
 One on one meeting

- **GROUP 3- Skip logic: If NO to have you heard about the ABLE account:**

You shared that you have not heard about the ABLE program. Here is a short description:

ABLE accounts are savings and investment accounts for individuals with significant disabilities. The account may grow tax-free and be used for qualified disability expenses such as housing, basic living, health-related expenses, education, transportation, and more. This flexibility in how the money can be used is very helpful since you may not know what your future holds.

Individuals who receive SSI/SSDI benefits are eligible for an ABLE account if their disability began before the age of 26. Money in the ABLE account does not affect the benefits the individual may be receiving such as SSI (to a certain limit) or Medicaid.

Individuals who do not receive SSI/SSDI are also eligible for an ABLE account if their disability can be certified by a physician as causing severe functional limitations and began before the age of 26. This could include a diagnosis of ADHD or autism spectrum disorders.

- After reading this description, would you be interested in learning more about the ABLE program?
 - Yes
 - No
 - Not at this time
- **Skip logic: If No/Not at this time interested in learning more about ABLE**
 - Please share why you are not interested in learning more about the ABLE program. This will help us understand what types of services may be more useful to you and other parents, and identify changes the ABLE program may need to consider. (TEXT BOX) *[survey continues to questions about other financial accounts]*
- **Skip logic: If Yes interested in learning more about ABLE**
 - After reading the short description of the ABLE program, do you think your child may be eligible for an ABLE account?
 - Yes
 - No
 - Not sure
 - **Skip logic: If No/Not sure about eligibility:**
 - Why do you think your child may not eligible for an ABLE account? (TEXT BOX)
- After reading the brief description of the ABLE program, what top 3 questions come to your mind that you would want answered? Select up to 3 responses:
 - Does my child meet eligibility requirements?
 - Will my child lose Medicaid benefits?
 - Will the account affect SSI/SSDI benefits?
 - Could my child lose any other government benefit they currently receive?
 - What will happen to the money in the account, in the event of death?
 - What can the money in the account be used for?

How much are the monthly fees for an ABLE account?
 Is there a risk in depositing money in an ABLE account?
 Is this a government program?
 My child will not be able to manage the account, so can anyone else manage it for them?
 How is the ABLE account different from a checking or savings account from my bank?
 What is the real benefit of having an ABLE account?
 Who can withdraw money from the account?
 Will my child be able to withdraw all the money when they become an adult (turn 18)?
 Is there a minimum dollar amount that has to be kept in the account?
 Other (please share any other questions or concerns you have about an ABLE account)

- What are your top 3 personal concerns about an ABLE account? Select up to 3 responses:
 - Not sure that there would be enough money left over to contribute into the account
 - Concerned that nobody else (family member, friends) would make contributions to the account
 - Concerned about not having a trusted source to help open and maintain the account
 - Concerned about your own/child's ability to make financial decisions (such as choose investment options)
 - Concerned about needing a reliable internet connection
 - Concerned that no one you know has an ABLE account already
 - Concerned that the ABLE website may be difficult to use
 - Not sure if you would find someone to help answer questions you may have
 - Concerned that you have not heard more about the ABLE program from other people, agencies and service providers
 - Other (please share any other personal questions or concerns you have about an ABLE account)

- How much of an effort are you likely to make to find answers to the questions you have about the ABLE program?
 - Not likely
 - Somewhat likely
 - Very likely

- An ABLE account could support your child in the following areas. If you had an ABLE account, which of these would you most likely use the account for? Select your top 3 uses:
 - Educational expenses (such as tuition, books)
 - Employment expenses (such as job training, transportation)
 - Independent living expenses (such as rent, groceries)
 - Health expenses
 - Building an emergency fund
 - Building long-term savings for child's future
 - Other (Please share what you would like to use the ABLE account for)

- Who would you prefer to hear more about the ABLE program from?
 - Disability service providers/organizations/agencies
 - Families who have an ABLE account
 - Financial planner
 - Legal advisor
 - School/education system
 - Social Security Administration
 - State ABLE program/Representative
 - Other (please share who you would like to hear about the ABLE program from)
- How would you like to learn more about the ABLE program?
 - Email
 - Regular mail
 - Live webinar with opportunities for question and answer
 - A recorded webinar
 - Live event you can attend

One on one meeting

Survey 3 of 3

This section of the survey is about other types of financial accounts. Everything you share on this survey is anonymous.

- Which of the following financial options have you heard of? Select all that apply:
 - Checking account
 - Savings account
 - Pooled-income trust
 - Specials needs trust
 - Stock investments
 - None of the above
 - **Skip logic: If checking/savings/pooled trust, special trust, stocks selected. Not “none of the above”:**
 - Where did you hear about these financial options? Select all that apply:
 - A parent who also has a child with a disability
 - Banks
 - Blogs
 - Disability event (please share the name of the disability event)
 - Disability service providers, agencies, organizations, advocacy groups (please share the name of the organization/agency)
 - Family and friends
 - Financial advisor
 - Internet
 - Legal advisor
 - School
 - Social media
 - Social security administration
 - Vocational Rehabilitation (VR) office
 - Other (please share where you heard about these financial options from)
- Which of the following financial account(s) does your child currently have, or have access to? Select all that apply:
 - Checking account
 - Savings account
 - Pooled income trust
 - Specials needs trust
 - Stock investments
 - None of the above
 - Other (please specify what other account(s) your child has)
 - **Skip logic: If checking/savings account is selected**
 - Who took the initiative/made the effort to set up the checking/savings account?
 - Parent(s)
 - Child
 - Someone else (please share who made the effort to set up the checking/savings account)
 - If your child is 18-26 years old, was the checking/savings account opened in consultation with your child?
 - Yes
 - No
 - Not applicable - Child is too young

Not applicable - Child's disability limits this

- Who manages the checking/savings account?
 Parent(s)
 Child
 Designated representative
 Legal guardian
 Other (Please share who manages the checking/savings account)
- What top 3 concerns or questions did you have before a checking/savings account was opened? Select up to 3 responses:
 Will the account affect my child's Medicaid benefits?
 Will the account affect SSI/SSDI benefits?
 Could my child lose any other government benefit they currently receive?
 What will happen to the money in the account, in the event of death?
 How much are the monthly fees for the account?
 Is there a risk in depositing money in the account?
 My child will not be able to manage the account, so can anyone else manage it for them?
 What is the real benefit of having a checking/savings account?
 Who can withdraw money from the account?
 Is there a minimum dollar amount that has to be kept in the account?
 Other (please share any other questions or concerns you had before opening a checking/savings account)
- What were your top 3 personal concerns before you opened the checking/savings accounts?
 Select up to 3 responses:
 Not sure that there would be enough money left over to contribute into the account
 Concerned about not having a trusted source to help open and maintain the account
 Concerned about your own/child's ability to make financial decisions and choices
 Concerned about needing a reliable internet connection to access accounts
 Concerned that no one you knew had a checking/savings account already
 Concerned that the bank website may be difficult to use
 Not sure if you would find someone to help answer questions you may have
 Other (please share any other personal questions or concerns you had before opening a checking/savings account)
- What did you do to find answers to these questions/concerns before opening a checking/savings account? Select all that apply:
 Researched it yourself
 Asked a trusted friend/family member
 Asked a financial planner/legal advisor
 Spoke to someone from the financial institution
 Posted the questions on a blog / Read blogs
 Other (please share any other ways you found answers to your questions before opening a checking/savings account)
- How easy or difficult was it to create a checking/savings account?
 Very difficult
 Difficult
 Neutral
 Easy
 Very easy
- Please state what made it easy and/or difficult for you to open the checking/savings account. (For example, someone from the bank helped me/my child, the website was easy to use, the information was simple to understand) TEXT BOX

- Did anyone help you open the checking/savings account?
 - Financial planner
 - Legal advisor
 - Someone from the financial institution (such as a bank)
 - Friend/family member
 - Other (please share who helped you open the checking/savings account)
 - Not applicable

- How easy or difficult is it to manage the checking/savings account?
 - Very difficult
 - Difficult
 - Neutral
 - Easy
 - Very easy

- How helpful has the checking/savings account been to support your child in the following: (Not at all helpful, Somewhat helpful, Very helpful, Have not used the account for this purpose)
 - Educational expenses (such as tuition, books)
 - Employment expenses (such as job training, transportation)
 - Independent living expenses (such as rent, groceries)
 - Allow the child to have independence using a debit card for daily living expenses
 - Health expenses
 - Building an emergency fund
 - Build long-term savings for child's future

- How does it make you feel knowing that your child has a checking/savings account? (For example, I feel happy my child is able to learn financial independence using a debit card and ATM, I worry that my child may make wrong choices about spending money, I'm glad I am able to save for my child) (TEXT BOX)

- If your child uses a checking/savings account, have you noticed any changes in the following? Select all that apply:
 - Child is more self-confident
 - Child is taking more initiative and motivated to learn and grow
 - Not applicable - Child is too young at this time
 - Not applicable - Child's disability limits this
 - None of the above
 - Other (please share what changes you have noticed in your child)

- **Skip logic: If pooled income trust/special needs trust is selected**
 - What was the reason(s) to open a pooled income trust/special needs trust? TEXT BOX

 - What concerns or questions did you have before a pooled income trust/special needs trust was opened? TEXT BOX

 - How easy or difficult was it to open a pooled income trust/special needs trust?
 - Very difficult
 - Difficult
 - Neutral
 - Easy
 - Very easy

 - Please state what made it easy and/or difficult for you to open the pooled income trust/special needs trust. TEXT BOX

- How easy or difficult is it to manage the pooled income trust/special needs trust?
Very difficult
Difficult
Neutral
Easy
Very easy
- Please state what makes it easy and/or difficult for you to manage the pooled income trust/special needs trust. TEXT BOX
- How does it make you feel knowing that your child has a pooled income trust/special needs trust? (TEXT BOX)

The Social Security Administration offers many services and programs to support individuals with disabilities.

Please type in the age of your child (for example, 24). (TEXT BOX)

Have you heard of the Plans to Achieve Self Support (PASS) program?

Yes

No

Skip logic: If no.

The PASS program allows individuals with disabilities to set aside money to pay for items or services needed to achieve a specific work goal.

- Would you be interested to learn more about the PASS program?

Yes

No

Skip logic: If yes.

- Have you used the PASS program?

Yes

No

Not applicable - Child is not old enough at this time

Not applicable - Child's disability limits this

Skip logic: If yes to USED PASS

- Has the PASS program helped your child reach their work goals? What has been your experience with this program? (TEXT BOX)

Thank you for completing the survey.

In appreciation of your time, we would like to send you a \$10 Amazon e-gift card. If you would like to receive the gift card, please provide a valid email address. Gifts cards will be sent out at the end of the month. Your email address will only be used for this purpose.

Email address: _____