Intellectual and Developmental Disabilities

Financial Planning among Parents of Children with Intellectual and Developmental Disabilities

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Abstract:	Families of children with intellectual and developmental disabilities (IDD) experience significant financial hardship, which could improve through financial planning and utilization of accounts such as the Achieving a Better Life Experience (ABLE). Unfortunately, current rates of banking are low among individuals with disabilities, and no study has examined this phenomenon specifically among families of children with IDD. In this cross-sectional study, 176 parents shared their financial planning and utilization experience. Findings indicate that parents worry about their child's financial future, however, paradoxically, are not engaging in financial planning. Utilization of ABLE, checking, and savings accounts, and special needs trusts are also low. Parents reported several programmatic and personal barriers which could inform immediate programmatic changes and long-term policy considerations.

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Abstract

Families of children with intellectual and developmental disabilities (IDD) experience significant financial hardship, which could improve through financial planning and utilization of accounts such as the Achieving a Better Life Experience (ABLE). Unfortunately, current rates of banking are low among individuals with disabilities, and no study has examined this phenomenon specifically among families of children with IDD. In this cross-sectional study, 176 parents shared their financial planning and utilization experience. Findings indicate that parents worry about their child's financial future, however, paradoxically, are not engaging in financial planning. Utilization of ABLE, checking, and savings accounts, and special needs trusts are also low. Parents reported several programmatic and personal barriers which could inform immediate programmatic changes and long-term policy considerations.

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Financial Planning among Parents of Children with Intellectual and Developmental Disabilities

Parents of children with intellectual and developmental disabilities (IDD) experience significantly high levels of financial distress (Emerson & Brigham, 2015; Meppelder et al., 2015) as they need to provide care to children who remain largely unemployed and living at home through adulthood (Piazza et al., 2014; Pryce et al., 2017; Vincent et al., 2020). Financial strain can limit the access of individuals with IDD to necessary services such as housing, education, and healthcare, which negatively impacts their quality of life (Caniglia & Michali, 2018; Laser, 2018; Morris et al., 2016). Given that one in six children are diagnosed with IDD in the United States (Zablotsky et al., 2019) and that their life expectancy continues to rise (Patja et al., 2000), the urgency to support families in financial distress is crucial.

One way to decrease financial distress, and improve well-being is to participate in financial planning and utilize financial services (Irving, 2012), such as checking and savings accounts (Goodman & Morris, 2017), special needs, and pooled-income trust accounts (Lacey, 2010), and disability-specific financial tools such as the Achieving a Better Life Experience account (ABLE; Laser, 2018; Morris et al., 2016). These financial tools allow families to plan for their unique life circumstances and achieve their financial goals (Irving, 2012).

Enacted in 2014, ABLE allows individuals with disabilities (with onset before age 26) to open a tax-advantaged savings account that can be used for a broad range of disability-related expenses, such as education, employment, and healthcare (Social Security Administration, 2019). ABLE allows individuals with disabilities to break through the cycle of poverty by contributing to saving and investment goals without losing government benefits up to a certain threshold (Laser, 2018).

Unfortunately, the adoption of the ABLE program has been slow since its enactment. Despite the ability of almost 8 million Americans with disabilities to access tax-free income (Morris, 2019), only 56,632 accounts have opened as of December 2019 (Curley, 2020). It is not evident if this slow rate of adoption is a result of some pitfalls critics have associated with the program such as limits on age and yearly contributions (Hershey et al., 2017; Rephan & Groshek, 2016), or myths 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).

Similarly, the utilization of other banking accounts by individuals with disabilities is just as bleak. In a report by the National Disability Institute, 18.9% of individuals with a disability in 2011 were unbanked, which only decreased slightly to 18.1% in 2017 (compared to 7.4% and 5.7% for people without disabilities, respectively). Furthermore, less than 40% of families with disabilities saved 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).

Unfortunately, these rates of utilization are reported for a heterogeneous group of individuals with disabilities, and no *utilization data* specific to individuals with IDD has been found. A few studies, however, that have examined financial *planning* in this population found that long-term planning is largely "aspirational" (Burke et al., 2018, p. 96) discussions, rather than definitive actions, and lacks specificity (Bowey & McGlaughlin, 2007). Additional barriers to planning and utilization by families and individuals with disabilities include limitations in financial literacy (Caniglia & Michali, 2018), high account fees, and insufficient funds to maintain an account (Goodman & Morris, 2017).

The Present Study

More research is needed to understand the extent to which families of individuals with IDD are utilizing financial accounts, and what barriers they may be facing. As such, the present exploratory study examined the following regarding ABLE, checking and savings accounts, and special needs and pooled-income trusts: Are families aware of these financial tools? Where do they obtain information regarding financial tools and whom/how would they like to receive information in the future? What are the rates of utilization and primary purpose of using these financial tools? What barriers or facilitators do families foresee or have experienced in efforts to establish financial stability? And finally, what impact have financial accounts had on the parent or child?

Methods

Participants

Parents of children with IDD were recruited to participate in an online study using both convenience and snowball sampling. A recruitment email translated into English and Spanish (including study details, a survey link, and a flyer attached with a QR code) was sent by the research team to 10 disability service providers, organizations, and inclusive postsecondary education programs who were then asked to forward the email to families they served as well as their professional network. The eligibility criteria for participation included parents who 1) could read and write in English or Spanish, 2) had a child (0 to 26 years old) with IDD, and 3) lived in the USA. The age of the child was limited to between 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 and to capture experiences as families approached the maximum age for disability onset for ABLE accounts. A total of 176 parents completed the survey (165 in English and 11 in Spanish) of which the majority resided in Florida (see Table 1 for complete demographic details).

Procedure

The present study followed an exploratory cross-sectional design, using an online survey developed on REDCap, which is a Health Insurance Portability and Accountability (HIPAA) compliant platform. Participants who provided their email addresses at the end of the survey were compensated with a $10 Amazon e-gift card. This study was approved by the University's Institutional Review Board (IRB-20-0367-AM01).

Materials

A survey was designed by the study team and professionally transcribed into Spanish so participants could select their preferred language before consenting to participate. Participants then answered a series of demographic questions including, for example, the age of their child. After demographics, parents were asked a few general financial questions, followed by specific questions related to the ABLE program. Finally, parents were asked about their awareness and utilization of other financial tools (specifically, checking, savings, and trust accounts).

The survey captured the perspectives of three different groups regarding the ABLE program: Group 1 ($n = 52$) were parents who had an ABLE account; Group 2 ($n = 46$) were parents who had heard of an ABLE account but did not have one for their child, and Group 3 ($n = 75$) were parents who had not heard of ABLE (See Figure 1).

Data Analysis

Descriptive analyses were conducted using SPSS Version 26.0 (IBM Corp., 2019) and frequencies were reported. Qualitative data from the open-ended survey questions (11 surveys had short responses in Spanish, which were translated into English by a Spanish-speaking team member) were analyzed using reflexive thematic analysis (RTA) which is a suitable method for examining experiences and perceptions. This methodology identifies codes and themes guided by the explicit content of the data through an iterative but flexible process (Braun & Clarke, 2019). In this study, two reviewers followed the six-step process outlined for RTA. In step 1, both reviewers read through the open-ended responses from the survey and familiarized themselves with the data. In step 2, each reviewer separately identified initial codes and met for step 3, to group similar codes together into themes. Any discrepancies between the reviewers were discussed until consensus was reached. In step 4, all codes and themes were reviewed by the third author to ensure agreement. In step 5, the themes were refined by the first two reviewers, and in step 6 the themes and findings were written out.

Results

Quantitative Findings

When parents were asked to rate their current financial situation, approximately 32% reported that they lived comfortably, 31% shared that they met their basic expenses and had a little money left over, almost 27% stated that they were just meeting their basic expenses, and 5% shared that they did not have enough money to meet basic expenses (5% chose not to answer this question). Almost 95% of parents stated that it was important for them to secure their child's financial future, and approximately 80% had thought about what they could do to secure their child's financial needs since their diagnosis. Despite this, only about 50% had a specific financial plan or schedule to save for their child's future. Finally, 50% of all parents reported feeling worried, stressed, or anxious when thinking about their child's financial future.

Awareness and Source of Information

When asked about their awareness of and source of information for various financial tools, over 57% of parents responded that they had heard about the ABLE program, most parents reported being aware of checking (84.1%) and savings accounts (82.4%), while fewer were aware of special needs trusts (50.6%) and pooled-income trusts (10.8%). Parents frequently cited that their source for ABLE information included a disability service provider, organization or event, or a parent who also had a child with a disability. The source of information for the other financial tools was most frequently reported to come from banks, family and friends, and financial advisors.

Despite being aware of the ABLE program, almost 30% of parents were not sure or did not know (referred to as 'did not know' hereafter) what the ABLE program was about, almost 21% did not know the eligibility criteria, about 48% did not know what expenses it could cover, and almost 37% did not know what the advantages of an ABLE account were. Parents wanting to learn more about the ABLE program stated that they would prefer to seek information from their state ABLE program or representative, a disability service provider/organization, their financial planner, and/or families who have an account via email, a one-on-one meeting, regular mail, or via a recorded/live webinar.

Utilization Rates, Purpose, and Impact of Accounts

Regarding the utilization of financial accounts, 29.5% of parents had heard of the ABLE program and had an account for their child (Group 1), 26.1% had heard of the ABLE program but chose to *not open* an account for their child (Group 2), and 42.6% reported that they had not heard of the ABLE program (Group 3). When parents in Group 3 were shown a short description of the ABLE program, 61.3% stated that they would be interested in learning more, 21.3% said they were not interested *at this time*, and 17.3% said they were not interested at all.

Of the parents who reported being aware of other financial accounts (n = 164), 28% had a checking account for their child, almost 38% had a savings account, about 15% had a special needs trust, no one had a pooled income trust, and over 38% reported that their child *did not have* any of these financial accounts (see Figure 1). Among children who accessed their checking/savings account using a debit card, parents reported that they were more confident and motivated to learn and grow.

Parents shared that the primary purpose for getting an account (checking/savings or ABLE) was to build long-term savings for their child's future, set money aside for emergencies, and support their child's independent living expenses. Parents responded that the ABLE account would *not* be primarily used for educational, employment, or health care expenses.

Programmatic and Personal Barriers to Opening Accounts

Figures 2 and 3 illustrate the six most frequently reported programmatic and personal concerns parents had regarding opening a financial account and highlight the differences and similarities between groups. Some examples of commonly cited barriers to financial planning included uncertainty about what the money in the account could be used for, if the account would affect the child's SSI/SSDI benefits, worries about having sufficient money to contribute to an account, and concerns about their own or their child's ability to make financial decisions.

Facilitators & Experience with Opening and Managing Accounts

Many parents who had an ABLE account for their child reported that they did not need any help to *open* the ABLE account (80.8%). If they did, it was most frequently received from the state ABLE program or a financial planner. Further, almost 85% of parents shared that it was easy or very easy to *open* an ABLE account, while about 69% shared that it was easy or very easy to *manage* an ABLE account.

Parents with a checking/savings account for their child shared that it was easy or very easy (83%) to open the account, and approximately 53% reported that they received help from someone at the financial institution. Most parents were also responsible for managing the checking/savings account and most stated it was easy or very easy to do so (about 87%).

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 in contrast to the above, only 25% stated the process was easy. Further, 25% reported that *managing* the trust was difficult, almost 30% stated that it was neutral, while about 42% shared that it was easy or very easy.

Qualitative Findings

Six themes were identified from the qualitative data: 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.

Theme 1: Barriers to Opening Financial Accounts

This theme describes the concerns and questions that parents had when considering or opening an ABLE, checking, savings, or trust account and has two sub-themes: 1) program barriers, which highlight the concerns that stem from the characteristics of the account itself, and 2) personal barriers, which emphasize the barriers that arise from personal circumstances.

Program Barriers. Parents from all three ABLE groups shared concerns related to the specific components of the ABLE program. Some parents questioned the advantage of opening the account when the child was younger, and others stated that they would open it when the child was older as it would be more relevant for their needs at that time. Parents were also worried about the level of risk associated with an ABLE account given that investments could lose value, that the political landscape could lead to changes in the rules of the program, and if an ABLE account was a safe option overall. Other concerns included what would happen to the funds in the ABLE account if something happened to the child, costs and fees, and challenges with finding trained representatives to answer questions related to a 529 rollover plan. Parents who had not heard of the ABLE program shared that they needed more information about the eligibility criteria (e.g., if attention deficit hyperactivity disorder was eligible, or if you had to be an SSI beneficiary to qualify).

Parents also questioned how the ABLE account was different from the Florida 529 prepaid account, and what the benefits of the ABLE account were if the rate of return was the same as other savings accounts, as evidenced by the following quotes:

> [My] child is young now and I don't see much benefit [to opening an ABLE 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*

Regarding concerns related to opening checking and savings accounts, parents were unclear about banking fees, who would have control of the account if something happened to the parent, and were worried about the process to transfer the account to the child when they turned 18 years old. It was also evident that parents were concerned if funds in the account would affect their child's eligibility for government benefits – a concern also shared by almost all parents who had a trust account.

Personal Barriers. Parents expressed that opening an ABLE account was challenging given the lack of sufficient funds, limited time and money to learn about the program and to set it up, and worries about their own and their child's ability to make financial decisions. For example, one parent from Group 2 shared "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." There was also a clear need for easily accessible information about the ABLE program, and the opportunity to receive ABLE advice and assistance. Moreover, parents wanted someone to explain how the ABLE program fit with other financial tools and eligibility for benefits. One parent stated, **"**[I would like] better [and] easier to understand information that is accessible. I asked at my bank [about ABLE] and they had no idea what I was talking about" while another shared:

> [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 as an attorney would have to be identified and hired, followed by the need to complete significant amounts of paperwork.

> 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.

Theme 2: Facilitators to Opening Financial Accounts

This theme describes the factors that encouraged parents to open accounts and have two sub-themes: 1) program facilitators, and 2) personal facilitators.

Program Facilitators. Parents reported that the website for the ABLE program was quite easy to use and understand, and representatives were helpful. In addition, the ABLE program was easier to understand compared to some other financial programs. Interestingly, the limited investment choices in the ABLE program was desirable, as it made decision-making easier. One parent said:

> 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.

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

Personal Facilitators. Parents shared that talking with someone who had experience with ABLE accounts was very helpful in opening one. In respect to opening a checking or savings account, many parents stated that since they already had an existing relationship with a bank, opening this account for their child was exceptionally easy. Regarding trusts, it was evident that these parents had taken the necessary effort and initiative to seek the help of lawyers and financial advisors to secure their child’s financial future, especially when parents would pass away.

Theme 3: Barriers to Managing Financial Accounts

This theme describes the concerns parents had based on their experience with managing their financial accounts. Regarding 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. Parents had differing experiences about setting up the gift-giving option, which allows the ABLE account holder to invite friends and family to contribute directly to the account. Some parents found this easy, while some faced difficulties. In addition, some parents were unclear about how withdrawals from the account and tax forms should be handled and prepared. For example, one parent shared: “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.” One parent also mentioned 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.

Parents who managed a trust account shared that it 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 with 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.

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. 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. Depositing and withdrawing money is straightforward. I have [not] had to fill out tax forms yet” and “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.”

Regarding 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. Many parents shared the sentiment that “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. Parents reported the need for more information about the ABLE program, such as the uses and limitations of the account. In addition, they expressed the need for more support to help manage and answer questions as they arose and resolve account issues. In addition, parents wanted to see an increase in the contribution and lifetime limits imposed on ABLE accounts, desired more control over investment decisions, and wanted to have an option for prepaid spending cards (with ABLE funds) to give to their children.

> [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.

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. Two sub-themes reflect two distinct areas of impact: 1) emotional wellbeing, and 2) independent living skills.

Emotional Wellbeing. Many parents with an ABLE account for their child 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 parents to know that these funds would not impact their child's eligibility for Medicaid and SSI benefits. Many parents, however, remained concerned that they did not have enough saved in the account. One parent shared: "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!" Many parents had yet to use the ABLE account, and thus could not comment on its impact on their lives: "We haven't used the account yet. We contribute monthly and hope it will be utilized with discretion and that it will be helpful" and, "[I feel] happier knowing that we are saving for his future without him losing Medicaid or SSI [benefits] as he becomes an adult." One parent shared an example of how the ABLE account created a sense of relief:

> 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.

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 and parents who had a trust account felt more secure, less anxious, and relieved about their child's financial future, especially for when they would no longer be around.

Independent Living Skills. Parents of children who had access to an ABLE, checking, or savings account reported that their child was learning to be independent by using a debit card (for checking and savings accounts only) and having access to funds. Parents were also happy that these accounts allowed their child to learn basic financial skills such as budgeting, saving, 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” and **“**[My] 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 because of poor money management skills or limitations arising from their disability.

> I opened the checking account before the ABLE 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.

Discussion

This novel study set out to examine the awareness, utilization, facilitators, barriers, and impact parents of children with IDD report regarding their experience with various financial tools, including the ABLE, checking, savings, and trust accounts. It was evident that almost all parents were aware of checking and savings accounts, and about 60% were aware of the ABLE program. Encouragingly, findings from both quantitative and qualitative analyses demonstrated that parents who were utilizing these accounts did so to build long-term savings and an emergency fund for their children. This is an extremely important finding given the high costs of disability-related expenses which span across the lifetime (Lunsky et al., 2019). Further, it was evident that having an account was important and beneficial for parental emotional health knowing that their child's future was more secure. Finally, children with IDD who used their accounts exhibited increased independence and improvements in money management skills, allowing them to experience and align with the societal expectations of adulthood.

Despite these encouraging findings, the present study also draws attention to the gaps which need to be bridged to enhance financial security. Most parents had contemplated their child's financial future and believed that securing it was important. Despite this desirable intention towards financial planning, only half of the parents in this study had enacted a specific plan for their child. This is concerning as the absence of financial planning has been associated with poor self-rated health and depression (Weida et al., 2020) which could explain why almost 90% of parents in this study expressed worry, stress, and anxiety thinking about their child's financial future.

Even though most parents reported that opening accounts (except for trusts) were easy, utilization of all financial tools in this study was low. This can be attributed to many of the programmatic and personal barriers reported by parents in this study and others, such as the lack of confidence with managing money and making financial decisions, and 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

Over 120,000 children with intellectual disability receive SSI benefits, with even more qualifying based on an additional developmental disability (The Arc, n.d). Although SSA benefits were designed to protect Americans from extreme poverty in the event of certain life circumstances, such as disability (Social Security Administration, n.d.) two out of five SSI recipients live in poverty, and three out of five live under the 150% poverty line (The Arc, n.d.).

It is evident that financial distress persists among SSA beneficiaries, which could be a result of the low $794 monthly maximum SSI benefit (Social Security Administration, n.d.). Given that families of children with IDD reported not having sufficient funds to put aside for their child's future needs, the SSA may consider policies and programs that support opportunities for planning and savings such as increasing this monthly amount to break the cycle of poverty (Parish et al., 2010).

The SSA may also want to provide financial planning and consultations as an automatic benefit to families to improve financial literacy and confidence. This will ensure that parents participate in specific, goal-oriented financial planning efforts (Lee et al., 2019) which can begin soon after diagnosis. In addition, the SSA could prioritize money management training among individuals with IDD themselves, so they can gain the skills needed to become more financially independent.

Recommendations for the ABLE Program

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 are easy to open, access, and manage for disability-related expenses (Rephan & Groshek, 2016). To ensure that these benefits are realized, ABLE programs must address the programmatic barriers reported by parents. For example, parents from all three ABLE groups were not sure what the real benefit of an ABLE account was, and some were concerned about how funds in the ABLE and other accounts could impact eligibility for SSI, SSDI, and Medicaid benefits. It was also interesting to find that over 50% of the parents who had an ABLE account were *initially* unclear what the money in the account could be used for. These barriers can be quickly resolved through clear messaging, enhanced awareness, and wider distribution of information (Lee & Burke, 2020). ABLE programs should develop easy-to-understand informational material which explicitly explains the unique benefit of an ABLE account versus other accounts, eligibility criteria, impact on government benefits, fees, the right age to open an account, expenses the account can cover (which emphasizes its use beyond a savings account such as education and employment expenses), how to complete withdrawals and tax forms, and risks of having an account. In the longer-term, ABLE programs should consider advocating for the need to increase contribution limits given that costs for healthcare continue to rise and offer prepaid debit cards to account holders.

It is also evident that parents need support to answer questions, make financial decisions and manage accounts. Although the ABLE program is intended to allow individuals to open and manage their accounts, there is an inherent risk of penalties and loss of government benefits if the owner is not knowledgeable about dynamic tax laws (Hershey et. al, 2017). As such, while ABLE programs already offer access to representatives and parent volunteers to help answer questions, it may be necessary to increase this presence and the level of expert guidance offered.

Unlike the recommendation by Goodman et. al (2017) to disseminate information via the SSA (Goodman & Morris, 2017), findings from this study indicate that awareness efforts and distribution of information would be more impactful if undertaken by state ABLE programs, disability organizations, financial planners, and families with an existing ABLE account. Information should be made available via email, regular mail, recorded and live webinars, and one-on-one meetings. However, given that many parents shared that their current financial situation limited the funding of an ABLE account, and they did not have the time to learn more about the program, parents should receive up-to-date information periodically so that the lack of information and the effort to access it does not impede or delay action when families are ready.

Limitations

A few limitations should be noted. First, generalizability is limited as the sample size was small, and most participants resided in Florida. In addition, the cross-sectional design is unable to infer causality and future research should consider two-wave designs. Moreover, the sampling design, incentive, and personal nature of the questions may have increased the likelihood of volunteer and social desirability bias.

Conclusion

This exploratory study identified the utilization rates of financial tools and factors that facilitate and hinder financial planning among families of children with IDD. Clearly, utilization has a positive impact on both parents and their children. Perhaps with policies that address poverty, better financial self-efficacy, and improved support with readily accessible information, utilization rates will improve, and positive effects for families will be seen.

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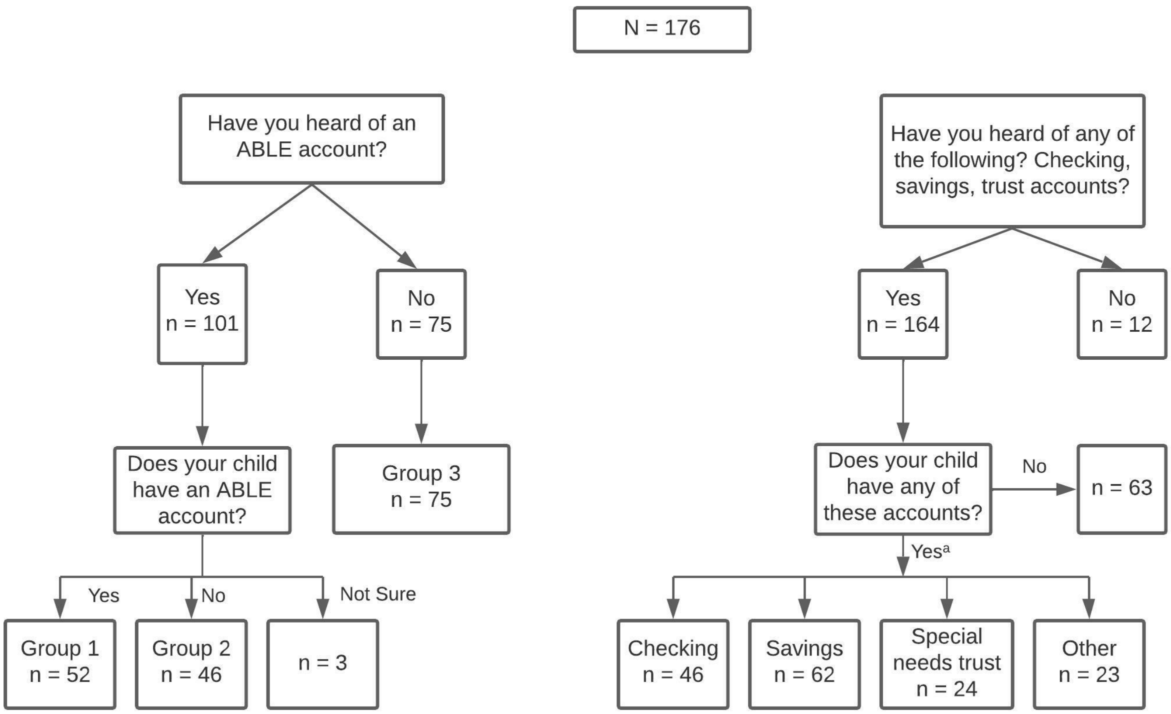
Figure 1

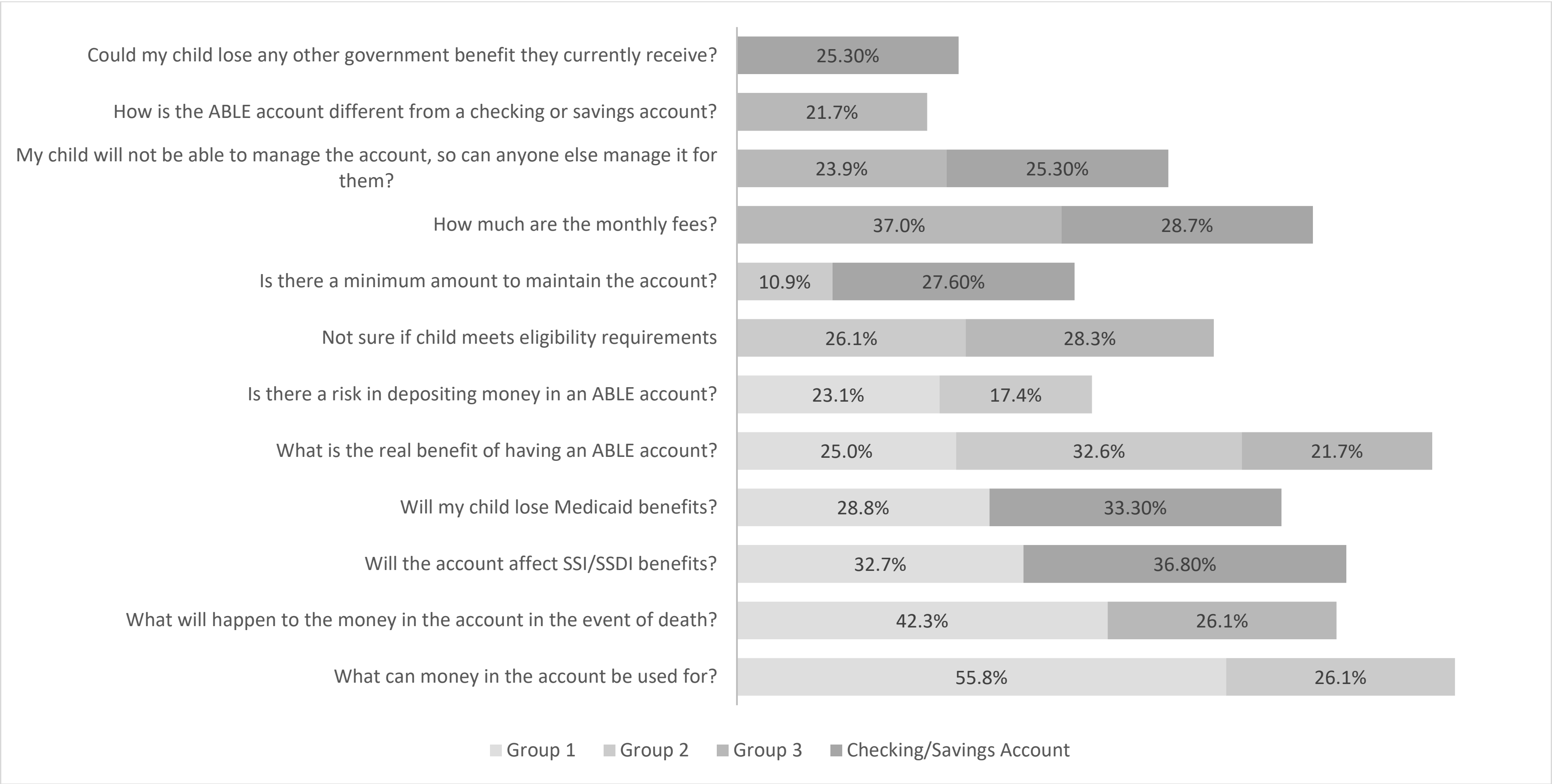
Awareness and Utilization of ABLE Accounts and Other Financial Tools



[a] Does not add to 164 as parents could select multiple responses

Figure 2

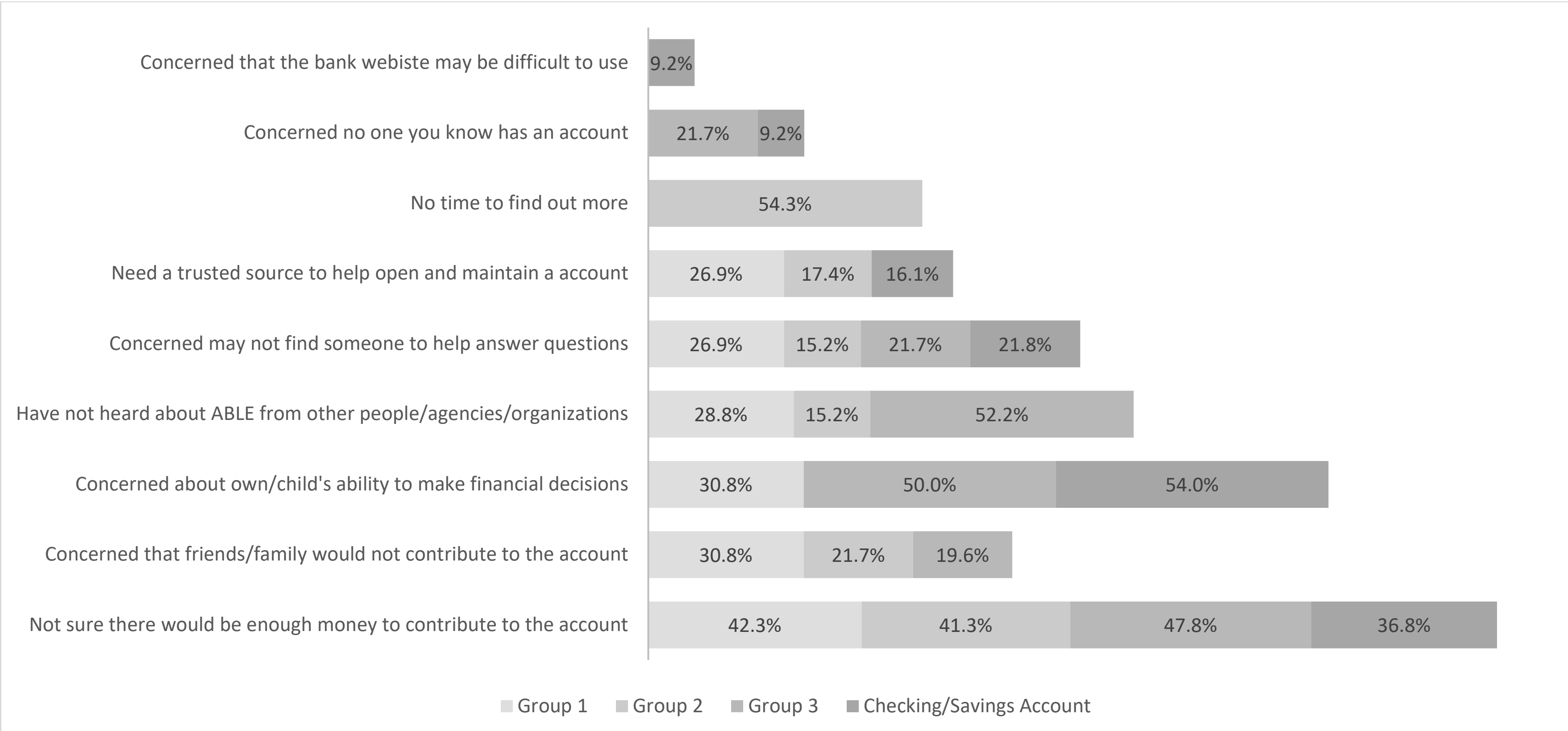
Top Six Programmatic of Concerns and Questions of Each Group



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.

Table 1

Demographic Attributes of Study Sample

	Overall sample (N=176)	
Parent's age[a] - Range, *M* (*SD*)	24 – 68, 45.92 (10.37)	
Child's age - Range, *M* (*SD*)	0 – 26, 12.44 (7.78)	
	N	%
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 (USD)		
<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 disability diagnosis[b]		
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[b]		
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%

Note: 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

[a] One missing value. [b] Does not add to 176 or 100% as participants could select multiple responses