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Abstract

The University of Wisconsin's Center for Financial Security and Abt Associates, Inc., conducted eight focus groups, four with adults with disabilities receiving SSDI or SSI benefits who work or want to work, and four with parents of children receiving SSI benefits and Medicaid coverage who are aging out of the school system The purpose was to gather information about how people with disabilities and their families address financial planning, understand SSA regulations, address employment, and interact with school systems. Findings suggest that information about financial planning, benefit rules, employment practices, and effective special-education models is vital to people with disabilities and caregivers to help them address financial and care needs.

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Attitudes to Savings and Financial Education Among Disability-Related Population Groups: Findings from the Financial Literacy Focus Groups

In July and September 2010, the University of Wisconsin's Financial Literacy Research Consortium (UW-FLRC) and Abt Associates, Inc., conducted eight disability-related focus groups that included four focus groups with adults with disabilities who receive Social Security Disability Insurance (SSDI) or Supplemental Security Income (SSI) who are working or want to work, and four focus groups with parents or guardians of children receiving SSI and/or Medicaid who were aging out of the school system (primarily children between the ages of 16 and 22 years old). UW-FLRC and Abt Associates, Inc. partnered with the Waisman Center in Madison, Wisconsin, and the State of Iowa's Work Incentive Planning and Assistance (Iowa WIPA) initiative to host these focus groups. The goal of the focus groups was to identify more effective ways of providing information on financial planning and disability-related benefits to people with disabilities and parents or guardians of young people with disabilities in order to promote financial planning and savings. The research questions the study intended to answer are provided in Table 1.

Table 1.
Core Research Questions

- What have individuals and families done to plan for their financial future?
- What are people's attitudes about employment?
- How do people interact with their local school district to address their children's special needs?
- How well do people understand the rules governing eligibility for Medicaid, Medicare, SSI, and SSDI?
- What sources of financial information do people find most useful?
- What lessons have individuals and families learned from their experiences in trying to

obtain information about financial planning and disability-related benefits?

This report has three main sections. Part 1 summarizes the key literature on benefit eligibility and financial and estate-planning behavior and describes the study's methodology and the composition of the focus groups. Part 2 separates the findings of the focus groups into two subsections: (a) the findings from the adults with disabilities focus groups, and (b) the findings from the focus groups with parents and guardians of children with disabilities who are aging out of the school system. Part 3 provides a discussion of lessons learned and the implications for individuals, families, community-based organizations, and government agencies interested in sharing more information about financial and estate planning, the impact of rules and regulations on employment and educational programs, and parental advocacy.

Study Background

Literature on Social Security Disability Income and Eligibility

SSI and SSDI. The Social Security Administration (SSA) administers disability benefits under two programs: Supplemental Security Income (SSI) and Social Security Disability Insurance (SSDI). SSI is an income supplement program funded by federal tax revenues and is designed to help low-income aged or blind individuals and individuals with disabilities by providing monthly cash stipends to meet basic food, clothing, and shelter needs (SSA 2010). SSDI provides benefits to individuals and certain family members based on years worked and contributions paid through social security taxes. To become eligible for SSDI or SSI, an individual must be unable to engage in *substantial gainful activity* (SGA) due to an impairment(s) that has either lasted 12 months, is expected to last 12 months, or is expected to result in death. If an SSDI beneficiary engages in SGA before 12 months have elapsed, the finding of disability may be reversed. This does not apply to SSI beneficiaries.

Children with disabilities can receive SSI benefits if they meet the basic eligibility requirements: they are disabled (according to SSA's definition of disability for children) and their income and resources fall within the eligibility limits (SSA 2010). For the SSI program, until a child who lives with a parent turns 18, a portion of the parent's income and assets are deemed available to the child. Parental income and assets, therefore, may preclude eligibility for SSI even if the child's impairment(s) meet SSA's disability criteria. Parental income and assets cease being a factor when the child turns 18 years of age. The eligibility limit for countable resources is $2,000 for an individual and $3,000 for a couple. This rate has not changed since 1990. For 2010, the federal SSI monthly benefit rate is $674. A beneficiary's countable income is subtracted from the benefit rate to yield the individual's SSI benefit. However, the amount of the SSI benefit can vary from state to state because some states add funds to the SSI payment. The eligibility requirements for SSI are further defined in Chapter 21 *Supplemental Security Income* in the Social Security Handbook available on the SSA website (http://www.socialsecurity.gov/OP_Home/handbook/handbook.21).

In 1996, the Personal Responsibility and Work Opportunity Reconciliation Act changed the definition of disability for children to require a medically determinable impairment or combination of impairments that results in marked and severe functional limitations (American Academy of Pediatrics 2009). In 2005, the Family Opportunity Act gave states the right to provide Medicaid coverage to children who meet the SSI disability standard but whose family income exceeds current eligibility levels. States were allowed to provide Medicaid coverage for families with income up to 300% of the federal poverty level (American Academy of Pediatrics 2009).

Medicare and Medicaid. Medicare is a health insurance program for (1) people 65 years or older; (2) people under age 65 with certain disabilities, and (3) people of all ages with permanent kidney failure requiring dialysis or a kidney transplant. The majority of SSDI beneficiaries receive Medicare. Information about the Medicare program is available on the U.S. Department of Health and Human Services/Centers for Medicare and Medicaid (CMS) website at http://www.cms.gov/MedicareGenInfo).

SSI beneficiaries typically receive Medicaid. The Medicaid program has become the largest single source of health insurance and long-term care and the largest source of public financial support for people with disabilities (Rowland 2008). Medicaid is available only to specific low-income individuals and families who meet eligibility criteria established by federal and state law. Low-income is only one test for eligibility; assets and resources are also tested against specific thresholds. Medicaid is a state-administered program and each state sets its own guidelines regarding eligibility and services. Eligibility for children is based on the child's status, not the parents'. Information about eligibility guidelines for the Medicaid program is available on the U.S. Department of Health and Human Services/Centers for Medicare and Medicaid Services (CMS) website at http://www.cms.gov/MedicaidGenInfo/.

During the focus group discussions, participants frequently mentioned that their medical coverage is as important to the beneficiary/family as social security cash benefits.

According to 2004 data (the most recent comparison data found), Medicaid's average per-person cost of caring for persons with disabilities was $12,364 a year, compared to Medicaid's costs of $1,474 for children without disabilities and $1,942 for adults without disabilities. (Rowland

2008). In 2007, individuals with disabilities made up 15 percent of the Medicaid population, but comprised more than 40 percent of program spending (Rowland 2008). Medicaid spending for people with disabilities was over $126 billion in 2007. (Rowland 2008).

The population with disabilities is diverse, with a wide range of conditions and variation in severity. Individuals with disabilities have a range of needs for acute care as well as long-term services and supports (Rowland 2008). The Family Opportunity Act gave states the flexibility to expand Medicaid eligibility beyond federal minimum standards to cover additional ‘optional’ groups, including the elderly, people with disabilities with incomes up to 300% of the federal poverty level, and the medically needy. Raising the income standard for people with disabilities has allowed children and adults to receive services and remain at home or in the community as an alternative to institutional care. These policies, however, vary widely across states.

The State of Iowa is an example of a state that has used this flexibility to create a Medicaid Buy-In called Medicaid for Employed People with Disabilities (MEPD) Program to serve people with disabilities who are under age 65. SSDI beneficiaries in Iowa who have earned income from employment or self-employment can qualify for this program until their Medicare coverage begins. The intent of the MEPD program is to allow persons with disabilities to work and continue to have access to medical assistance. MEPD recipients are required to pay a monthly premium when their monthly gross income is above 150% of the federal poverty level (currently $1,300 a month). Monthly net family income must be less than 250% of the federal poverty level for applicable family size (currently $2,167 per month for a family size of one). Additional information about eligibility requirements and benefits for the MEPD program is located on the Iowa Department of Human Services website at http://www.ime.state.ia.us/HCBS/MEDPIndex.html. (Many of the Iowa participants in the adults with disabilities focus groups were receiving benefits through the MEPD program).

Income Eligibility Requirements. The Fair Labor Standards Act requires employees to be paid a minimum hourly wage of $7.52; some states have minimum-wage laws specifying higher amounts (Miller 2010). At that wage, a full-time employee's monthly salary, based on approximately 40 hours per week, could exceed the income eligibility limit for specific social security benefits and other types of government assistance. When faced with eligibility requirements, an employee may be forced to choose between reducing work hours, reducing salary, or losing benefits (Miller 2010). Concerns over income eligibility may cause beneficiaries or family members to change their work patterns and create perverse incentives to work less or save less in order to maintain government benefits. Based on the literature review and focus group discussions, it is of critical importance that beneficiaries and their families have up-to-date information related to income eligibility requirements.

While earnings may reduce a SSI benefit, they increase the household's net income, with one exception. If someone receives SSI, SNAP (food stamps) and housing assistance, the simultaneous reduction of all three benefits will offset increases in earnings until the earnings zero out the SSI. At that point, net income will begin to exceed the value of the three benefits alone. If SSI stops because of earnings, Medicaid can continue under section 1619(b) of the Social Security Act until the beneficiary/family can afford to replace the coverage. If an individual has to stop working while eligible for Medicaid While Working, SSI will simply resume.

Employment affects SSDI benefits differently than SSI. There is no scaled reduction of benefits as earnings increase; a person receives full benefits – or no benefits – generally depending on whether earnings exceed an amount that reflects substantial gainful activity (SGA), which is currently $1,000 a month. For SSDI beneficiaries, to determine whether working is a good financial decision, depends on two factors: (1) whether the individual will earn enough income to cause their benefits to stop (following a nine-month trial work period and a three-month grace period; and, if they will, (2) whether the individual will earn enough to replace the value of the benefits they stand to lose. Earning enough income to cause SSDI benefits to stop, but not enough to replace their value, would reduce rather than increase net income.

The protections for SSDI beneficiaries are similar to those for SSI beneficiaries. If SSDI benefits stop because of earnings: (1) Medicare coverage continues for at least 93 months following the nine-month trial work period; (2) for the three years following the trial work period, SSDI benefits will be paid for any month in which the beneficiary's earnings fall below the SGA threshold; and (3) for five years following the trial work period, benefits can be reinstated quickly without a new application. Additional information on how income impacts eligibility and benefit retention is available on the SSA website at http://www.socialsecurity.gov/.

Financial Planning for Families with Children with Disabilities. Surprisingly little has been published regarding state policies on financial and estate planning for families with children with disabilities. There is no centralized source organizing state policies on financial planning into a comprehensive resource, and within individual states this information is not easily found. One reason may be that most states appear to regulate financial planning through administrative code rather than state statute, and this information is not easily accessible.

The most comprehensive public resource on financial planning for families with children with disabilities is the SSA website (http://www.socialsecurity.gov). This site provides resources on financial planning for families (http://www.socialsecurity.gov/kids/parent8.htm), benefits for children with disabilities (http://www.socialsecurity.gov/kids/parent6.htm), and resources and contact information for finding more information. An easily accessible but less relevant resource is the HealthCare.gov website. This site has a tab specifically for 'People with Disabilities' that provides broad information on the impacts of the Affordable Health Care Act on people with disabilities and timelines for implementation (http://www.healthcare.gov/foryou/disabilities/top5/index.html).

However, the majority of information on financial planning for families with children with disabilities comes from private attorneys, for-profit financial firms, and similar organizations advertising their planning services.

The findings of this literature review reinforce the findings from the focus groups, namely that the information and public resources available to families on navigating disability benefits systems and financial and estate planning are very limited.

Study Methodology

The study primarily used focus groups to identify more effective ways of providing information on financial planning and benefits to people with disabilities and the parents and guardians of young people with disabilities, to gather information about understanding among these groups of eligibility rules for disability-related benefits, to identify opportunities and impediments regarding employment and special-needs education, and to provide an opportunity to share lessons learned based on personal experiences. Preliminary findings from the focus groups were then vetted through interviews with staff from the host organizations and other key informants on specific topics.

Focus groups are group interviews designed to explore ideas, attitudes, and experiences among people who share some common characteristics. They can foster a richer exploration of a subject than individual interviews and capture more nuance than a survey on topics regarding behaviors. They also give participants an opportunity to explain their beliefs and experiences in their own words and provide useful insight into how and why they think and act the way they do (Kitzinger 1995).

Focus groups are also a useful methodology for initial explorations of a topic, and findings can help inform future larger-scale quantitative studies (Krueger and Casey 2000). In the case of financial education for people with disabilities and the parents and guardians of young people with disabilities, where little research exists, findings could be used to design more systematic data collection in two areas: (1) the role of school districts interacting with parents and guardians to address special education and other needs such as eligibility information, transition needs, and financial, estate, and guardianship planning; and (2) to further explore impediments to employment and greater self-sufficiency for SSI and SSDI recipients who are working or interested in working.

The UW-FLRC and Abt Associates research team partnered with two organizations, the Waisman Center in Wisconsin and Iowa WIPA, to identify and recruit participants to the focus groups. The **Waisman Center**, located on the University of Wisconsin-Madison campus, is dedicated to the advancement of knowledge about human development, developmental disabilities, and neurodegeneratative diseases throughout the lifespan. The center is one of nine national facilities that include a Eunice Kennedy Shriver Intellectual and Developmental

Disabilities Research Center and a University Center for Excellence in Developmental Disabilities. The Waisman Center houses 60 laboratories for biomedical and behavioral research, a brain imaging center, a clinical biomanufacturing facility, ten specialty clinics for people with developmental disabilities and their families, numerous early intervention and outreach programs, and a model preschool with a developmentally diverse enrollment. The Waisman Center's website is www.waisman.wisc.edu.

Focus group participants in Wisconsin were either clients of the Waisman Center or referred to the Waisman Center through independent living programs in Madison (Access to Independence, Inc.) and Milwaukee (Independence First).

The Iowa Work Incentive and Planning Assistance Initiative (Iowa WIPA) is a state office designed to support all Iowa SSA beneficiaries in pursuing their career objectives and effectively managing their benefits and applicable work incentives at the same time. The State of Iowa supports two community work-incentive coordinators (CWICs), who coordinate a wide array of disability and employment professionals statewide in providing job seekers with information about benefits management and in connecting job seekers with professional assistance in benefits management. One coordinator is based in Mason City and serves northern Iowa; the other coordinator, based in Des Moines, serves central and southern Iowa. Iowa WIPA works in partnership with other state agencies, including Iowa Vocational Rehabilitation, Iowa Department for the Blind, Iowa Workforce Development Access, Iowa Department of Human Rights/Division for Persons with Disabilities, Iowa Department of Human Services, Iowa Department of Education, and Iowa Governor's Developmental Disabilities Council. Iowa WIPA's website is www.iowawipa.org.

Focus group participants in Iowa were clients accessing services at one of the regional Iowa WIPA offices.

The combination of partners provided an opportunity to gather information about peoples' experiences in different states, Wisconsin and Iowa, as well as to look at how attitudes and behaviors may differ in a large metropolitan area (Milwaukee), midsize cities (Des Moines and Madison), and rural areas (centered around Mason City). (Although the Iowa WIPA office in Des Moines serves both central and southern Iowa, the focus group participants in Des Moines were primarily from Des Moines and the surrounding suburbs.)

Eight focus groups were held as part of this study. Focus groups for adults with disabilities were held in Madison, Wisconsin (July 2010), Milwaukee, Wisconsin (July 2010), Des Moines, Iowa (September 2010), and Mason City, Iowa (September 2010). Focus groups for parents and guardians of children aging out of the school system were held in Madison, Wisconsin (July 2010), Milwaukee, Wisconsin (July 2010), Des Moines, Iowa (September 2010), and Mason City, Iowa (September 2010).

Due to issues of confidentiality, the partner organizations recruited all of the participants for the eight focus groups. Recruitment letters and emails were sent to specific pools of clients who fit the targeted participant groups, i.e., adults with disabilities receiving SSI or SSDI benefits who were either working or wanted to work, and parents or guardians of children receiving SSI benefits and/or Medicaid coverage who were aging out of the school system (primarily young people ages 16–22). People who were interested in participating in the focus groups then contacted Abt Associates to confirm their participation.

All focus group participants signed a written consent form and were compensated for their time. The compensation was $50 for each participant. For the focus groups with parents and guardians, if more than one parent participated in the focus group, the compensation was limited to $50 per household. In Iowa, focus group participants also had the option of being reimbursed by the State of Iowa for their transportation costs based on mileage. The focus groups lasted approximately two hours each. The Madison and Milwaukee focus groups were held at community-based independent living organizations (Access to Independence, Inc., and Independence First) that foster independent living services. The Des Moines and Mason City focus groups were held at the regional Iowa WIPA offices. The focus groups were recorded and transcribed, using participants' first names only. Participants' names have been masked in this report.

Table 2 presents the demographic profile of the eight focus groups. While the focus groups varied in terms of age and gender, participants were primarily white. All of the parents in the child-beneficiary focus groups were the parents of children receiving SSI benefits and/or Medicaid coverage. One participant in the Mason City focus group was the parent of a child in his early 20s who had also just stated receiving SSDI benefits. Nearly all of the parents in these focus groups were employed or their spouse was employed, and the majority mentioned having college degrees. For the adults with disabilities focus groups, the majority of the participants were receiving SSDI benefits. Only three of the participants (one in Wisconsin, two in Iowa) mentioned receiving SSI benefits. In the adult beneficiary focus groups, there was a mix of people who were previously employed full time but, due to disability or health issues as an adult, were now receiving SSDI benefits, and people who were born with disabilities or were disabled by an accident or illness at an early age (under 18 years of age). Three hearing-impaired and two visually impaired adults participated in the adults with disabilities focus groups. The Waisman

Center provided interpreters for the two hearing-impaired participants in Madison, and Iowa WIPA provided interpreters for the one hearing-impaired participant in Mason City.

Table 2.
Demographic Profile of Disability-Related Financial Literacy Focus Group Participants

	Waisman Center: Adults w/Disabilities (SSDI/SSI beneficiaries)*	Waisman Center: Parents/Guardians of Children w/ Disabilities (child SSI/Medicaid beneficiaries)	Iowa WIPA: Adults w/ Disabilities (SSDI/SSI beneficiaries)*	Iowa WIPA: Parents/Guardians of Children w/Disabilities (child SSI/Medicaid beneficiaries)**
No. of Groups	2	2	2	2
Total Participants	12	9	13 + 1 parent of an adult participant***	13 + 3 spouses****
Age	19 to late 50s	late 30s to early 60s	19 to 60s	40s to 60s
Race/Ethnicity	Majority white	Mixed race	Majority white	Majority white
Gender	Mixed gender	Majority female	Mixed gender	Mixed gender
Income	Primarily low-income	Ranges of income	Primarily low-income	Ranges of income

* One adult in Wisconsin, and two adults in Iowa were receiving SSI; the remaining 22 participants indicated that they were receiving SSDI.
** One child had just qualified for SSDI benefits in addition to his SSI coverage.
*** One adult with disabilities came to the focus group with his mother, who is also now his legal guardian. She participated in the discussion; however, compensation was provided only to her son.
**** Three participants in the parent and guardian focus groups brought their spouses to the focus groups. The spouses participated in the discussions; however, compensation was provided only to one parent.

All of the focus groups were moderated by the same moderator, using a structured guide with a core set of common questions and separate modules for each population group. (Copies of the moderator guides are provided in Appendix A.) Table 3 presents the main questions discussed in the focus groups for adults with disabilities who were either working or interested in working. Following the completion of each group, the focus group transcripts were coded thematically and analyzed using qualitative research software.

Table 3.
Questions Discussed in Financial Literacy Focus Groups for Adults with Disabilities who are SSDI or SSI Beneficiaries

- Where do participants get financial information?
  - Where do participants go to find financial information now?
  - What sources do they trust?
  - How they received any financial advice from counselors/benefit advisors? Case managers? Others?
- What are participants' current attitudes and behaviors toward financial planning and savings?
  - Are participants saving and planning for their financial future now? If so, how?
  - Are participants planning for retirement?
  - Do participants use credit cards or loans?
- How well do participants understand the rules and regulations of SSDI, SSI, Medicare, and Medicaid?
  - Do rules and regulations affect your employment decisions? financial decisions? personal decisions?
  - Where do participants get advice on eligibility and benefit rules and regulations?
- What lessons have participants learned based on personal experiences?
  - What kinds of information sources have been helpful? How did they learn about these sources?
  - Have they had any problems getting accurate information?

Focus Group Findings

Overall, the focus groups explored attitudes and behaviors with regard to financial and estate planning, employment, addressing special-education needs, understanding rules and regulations governing benefits, and sharing lessons learned from personal experiences. This section presents overall findings from the focus groups, with separate findings for the adults with disabilities (adult SSDI/SSI beneficiaries) focus groups and the parent and guardian of children who are SSI/Medicaid beneficiaries. focus groups.

One overarching finding from all eight groups was that ***beneficiaries and their families must navigate a complex network of programs and organizations that offer financial and other supports for people with disabilities***. Perhaps the most telling sign of this complexity is the sheer number of organizational and programmatic acronyms that arose in focus group discussions. Appendix B contains attachments prepared by the Waisman Center staff and the Iowa WIPA staff that list many of the agencies, programs, and services that impact the lives of people with disabilities and their caregivers; even more programs and services were referenced in the focus groups, and participants frequently mentioned that they were unaware of a program or service that was referenced by another participant. The ability to navigate the federal, state, local, and school-district networks for people with disabilities is crucial. Participants frequently referred to their reliance on community resources, such as the study's partner organizations and school districts, to navigate and advocate on their behalf and help them understand their benefits and rights. There was also significant concern that many of the programs that participants depend on for support services (e.g., transportation, vocational training), are facing significant budget cuts, primarily on the state and school-district levels.

Overall, the study findings suggest that the ***majority of the participants are under considerable stress, and in some cases, feel shame, in trying to address current and future financial needs, remain in compliance with Social Security, Medicaid and Medicare rules and regulations, and address other family and personal needs.*** A constant theme of focus group discussions was the need to obtain accurate, up-to-date information on benefits, regulations, and community resources. Participants shared their perceptions that programs such as SSI, SSDI, Medicare, Medicaid, and Ticket to Work (a federal employment program for people with disabilities) change their rules and regulations frequently. Monitoring these changes consumes a significant amount of time and is viewed as a constant job. Many participants, particularly parents, indicated that they are overtaxed as it is in dealing with medical needs, financial concerns, school-district issues, housing and transportation costs, and the emotional impact on family members; they often given up on trying to understand everything and only choose to fight eligibility and benefit battles when and if they arise.

The study findings from all of the focus groups also demonstrate the ***vital importance of Medicare and Medicaid coverage*** for eligible recipients. In nearly all of the groups, participants indicated that medical coverage was as vital as—if not more important than—their monthly social security cash benefits. Participants indicated that without government-funded medical coverage, individuals and families would be unable to access health care without facing financial ruin.

The study findings from the child beneficiary focus groups showed the importance of ***getting accurate information to SSI recipients and their families at as early an age as possible***. Parents in these focus groups expressed a strong interest in having their local school districts be a focal point for information on Social Security benefits, community resources, family support, and financial planning and legal information for beneficiaries and their families. Many parents indicated that before their children entered the school system, they had found it difficult to get information on topics such as community resources and financial and estate planning.

Overall, the study findings showed that the ***participants had mostly favorable experiences when they contacted SSA staff*** with questions; however, some participants indicated that they did not like to contact SSA because of fears that it would 'red flag' their files even if they had done nothing wrong. Participants did express their difficulties in navigating the SSA website and understanding printed materials, including letters, distributed by SSA. Participants in Milwaukee and Iowa also indicated that prior to and following most communication with SSA they also check in with their local support organizations (i.e., Independence First, Iowa WIPA) to verify the information they receive from SSA.

Focus Group Findings: Adults with Disabilities who are SSDI or SSI Beneficiaries

There were four focus groups for adults with disabilities who were SSDI or SSI beneficiaries and who were working or wanted to work. These focus groups explored participants' attitudes and behaviors toward financial planning and employment, understanding of rules and regulations, and lessons learned from personal experiences in these areas.

A number of adults arrived at the focus group sessions thinking that the group discussions were designed to provide them information on disability benefits, and their introductions implied that they were looking for a forum that would simplify the rules and regulations. They were also looking to learn from other people's experiences with financial planning, working with SSA and state agencies, and addressing other issues. Although it was not the intention of the focus groups to provide such a forum, the majority of focus group participants thanked the facilitator and partner organizations for the opportunity to participate in the focus groups and stated that they did learn about additional resources and programs in their community.

The findings for these focus groups are presented below in four sections, covering the following areas of inquiry:

- Financial Education
    - Current sources of financial information and advice
    - Opinions about forms of financial education
- Employment Attitudes and Behaviors
    - Attitudes about employment
    - Current employment status

    - Employment barriers
- Financial Planning
    - Current financial-planning motivations, impediments, and techniques
- Understanding of Rules and Regulations
    - Understanding of the rules and regulations governing SSI, SSDI, Medicaid, Medicare
    - Sources of information about benefits and eligibility

Overall, the study findings suggest that people with disabilities are anxious to go to work and earn more money; however, they are deeply concerned about jeopardizing their benefits, especially their medical coverage. The findings also suggest that there is an overall frustration with not being able to build assets or plan for the future due to their limited income.

Adults with Disabilities: Financial Education. Many participants in the focus groups for adult SSDI beneficiaries had been employed before becoming disabled as adults due to medical conditions (e.g., stroke, heart condition) or injuries. Participants mentioned having to cash in their 401(k) or other retirement accounts to pay living expenses or medical costs while waiting for their SSDI eligibility determination. Ongoing credit and debt problems were also a concern to many of the participants. They mentioned running into problems using credit cards to purchase goods and services beyond their means, which resulted in bad credit. One adult in Des Moines mentioned being ‘plastic happy’ years before, when she overspent and had to file for bankruptcy. An adult in the Madison group had struggled with the ease with which she could secure a new credit card. Earlier in her life, she had been able to buy a house, but that resulted in her using a credit card to pay for daily necessities and any unexpected costs:

> I have credit cards and loans in part to pay from expenses from having owned a home and being less and less able to take care of it as my disability got worse. Well, in hindsight, my biggest mistake was buying a house, taking out another credit card after I had a bankruptcy years ago, and misusing that credit card instead of trusting my judgment to say ‘No, I cannot spend it on this; I cannot use it.’ Lessons learned and no more credit cards. (Madison)

Other participants also cited instances of paying higher credit card fees because they did not understand that interest rates and annual credit card fees were negotiable. Another participant noted that she did not understand the fees associated with cash withdrawals using her credit card, which amount to $10 at her bank and caused her to exceed her credit limit which then generated additional fees. Another participant in Des Moines cited how she had been a victim of a telephone ‘scam’ that led to monthly charges on credit card for services or products that she did not understand. She cancelled the transaction after describing the call to her family, but the charges to her credit card were continuing. This woman was unclear where her next stop for help would be to stop the charges.

Some participants wanted to avoid credit cards all together, and a few said that they had been unable to establish credit or get a credit card. One participant mentioned his inability to get a loan as a catch-22, because in order to get a loan he had to have previously established credit, but as an adult without any established credit, he could not find a way to start building a good credit history:

> To be honest, I don’t even know what my credit [score] is, and I talked to my bank and I asked how do you get credit. Because of me not having credit, there is no credit number [credit score]. So, it is sort of like a catch-22 but they told me

> the only way that I can start receiving credit is to go to Target or Wal-Mart and get one of those secured $100 credit cards and then you can use it right away, pay it back, and that is how you can start your credit. So, that is what I am thinking about doing next month is to do that, so when I go to the bank they can see that I got [a credit card] so I can take out a loan, like a student loan, a house loan, or a car loan. (Madison)
>
> I don't know a lot about loans or credit cards. I don't have any credit and that's sad because I am 23 years old. I know how to pay my bills and cash my check. (Mason City)
>
> I don't have any credit cards. I don't have any credit. I don't want credit cards because I know I wouldn't be able to [manage it], but I want to build credit, and I'm still trying to figure out how I can build credit so that I can take out a loan if I need to because I don't have credit. And they said 'no credit' is worse than 'bad credit' so like I'm really bad off. (Mason City)

One Mason City participant said that she struggled so much financially that she ended up resorting to taking out payday loans and suffered when she could not pay them back:

> Falling into the trap of payday loans was a big lesson because it just made me cry. It was just such a demeaning feeling that I had to go back there and re-borrow and everything. But I learned that if you really take steps to try to just pay down those loans and just get rid of them, then you'll be fine. But [I will] never do it again. Borrowing from multiple loan places was really like a circus. I got caught; you know, like caught without money and had to pay bills. (Mason City)

Sources of Financial Information. Participants in the adults with disabilities focus groups were knowledgeable about sources of financial education, including financial planners, the Internet, and the media; however, they did not perceive information available through these resources as relevant to their current financial situation. Overall, people were very cautious about their sources of financial information for fear of taking actions that would exceed income caps and jeopardize their eligibility for SSDI and medical benefits. For financial education specific to their needs, participants looked more to their benefit counselors or community organizations such as the Association for Retarded Citizens (ARC), Access to Independence and Independence First (Wisconsin), Iowa WIPA, or GreenPath (which provides free debt counseling and other financial information).

Many of the participants also relied on their parents or other family members as trusted sources of information. This was particularly true of younger participants who were born with disabilities or became disabled during their youth (under the age of 18). For two participants, one aged 19 and another in his early 20s, parents continued to serve as their payee for social security benefits. One of these participants indicated that he would like to assume control of his finances but did not know where to go for basic financial information and was concerned it might be difficult to convince his mother to give up her role as his payee.

Although all focus group participants had access to the Internet on a regular basis either through a personal computer or at a local library or community organization, many of these participants were uncomfortable using the Internet as a resource for financial information. They cited fear and skepticism about the information available, or they had difficulty understanding the information on government sites such as the SSA and IRS websites.

> The Internet, I am afraid of that. (Milwaukee)

> There is always a risk [of] being taken advantage of. I don’t think the Internet is reliable. (Madison)
>
> I don’t want to give them [agencies or businesses] my e-mail. When they start asking personal information, especially when people starting wanting your social security number or anything like that. If it is even the social security office, I will not give them the information; no, I just refuse to give that kind of information out. To me, that is so personal. (Madison)

People who did use the Internet for financial and credit information reported using sources such as Yahoo, MSNBC, Fox, and Google to search for information on specific financial topics.

Participants in the adults with disabilities focus groups expressed their preference for getting financial information on a one-on-one basis rather than through a workshop or seminar. People did not want to share their information or circumstances in a group setting. They also thought that discussions about other people’s financial circumstances would not be relevant to them.

Adults with Disabilities: Employment. Focus group participants who were SSDI beneficiaries demonstrated some clarity about eligibility to work and the impacts that earning an income would have on their benefits. A Milwaukee participant who had experience with the Ticket to Work program relied on a benefits specialist at Independence First (an independent living community-based organization) to help him navigate the SSA system and ensure that he did not exceed income limits. This participant worked only 16 hours a week in order to keep his income below the SSDI income cap so that he could maintain his social security benefits, especially his medical coverage. He thought that he would be able to work and earn more if the SSDI income caps were increased. A participant in the Des Moines focus group had just completed her graduate coursework on vocational rehabilitation counseling and found that many of the people she interviewed did not work because they were afraid of losing their medical coverage. Participants who wanted to work said that they did not encounter any push back from SSA staff or benefit counselors trying to persuade them that it was easier to not work rather than risk exceeding the income cap and jeopardizing benefits.

In general, focus group participants who were physically able wanted to work; this was especially true with participants in the Iowa focus groups. People expressed that they felt a sense of self-worth and happiness from being able to earn their own income and wanted to become more financially self-sufficient. They also emphasized that they needed the additional income to supplement disability benefits, and they wished they were allowed to earn more without that income causing them to be 'kicked off the program.' Several participants noted that they wanted to earn more so that they could enjoy a more comfortable, less stressful life:

> There is a huge gap between the amount of money you can earn and the amount of money you need to have to survive. And I am talking like actually surviving with like food and shelter and not having any luxury whatsoever. That allowable amount of money needs to be increased before services and subsidies are taken away. And when they [legislators] do that, they may think it is kind of a bad idea at the time because, you know, everybody, including the state, is in the deficit. However, in the future this benefits society and the economy as a whole because we are making more money, and we can get off those subsidies and be a vital part of society and pay more taxes. (Des Moines)
>
> I'm proud to be able to work. I'm proud to be able; I mean it makes me feel I can't sit at home. I just can't. (Des Moines)

> All we want to do is to make our life a little bit more comfortable. You know, I am not out there trying to make $35 to $40 an hour. If I did that, I'd quit [SSDI]. I'd call up Social Security to stop sending me the checks because I am making some decent money. But there is no way [I can] because of the physical disability that I have. (Des Moines)
>
> I don't think that any of us want to be sitting here for the rest of our lives. I think all of us would be willing to go ahead and work if we could manage it. But it's like, right now, I have advanced my checking account, and I have to keep advancing it to pay my bills. And so the bank takes money out every month because I have to keep advancing it. And so if I could catch up [by working more], I mean, it just feels like I am never catching up. (Madison)
>
> DHS [Iowa Department of Human Services] should be able to work with a person, if they have different income guidelines, have it set up more like a support thing. They [SSA] should encourage us to work and be able to give us some reward because there's got to be a better way to survive on the income. (Mason City)

In the Mason City focus group, participants who were SSDI beneficiaries strongly agreed that they would like to see SSA raise the income limits for people with disabilities. One participant mentioned that she did not think the $1,000 a month limit had been raised in over three years. When asked how much of an income limit increase they would recommend, participants could not provide a definitive answer—just 'higher than it is now.' Two of the participants even suggested that they would be willing to forgo SSDI benefit checks if they could earn and save more, yet maintain their Medicare coverage. They did not envision a time when private insurance would both be affordable to them and provide adequate coverage for their medical needs. They thought that eventually they would be able to earn enough at their jobs to match the amount of their SSDI benefit checks; however, they were in no position to pay for their own medical coverage, especially for prescriptions. It appeared through the focus group discussions that some of the adult SSDI beneficiaries were unaware that they would be able to keep their Medicare coverage for an extended period of time if they exceeded the income limits.

> I guess medical is the main thing we want to keep. That is the biggest issue. But you have to be able to live as well. (Mason City)
>
> When I started all this with SSI and SSDI and Title 19, well, what I really wanted was Title 19. But they said you have to have SSDI or SSI to get Title 19, and so it was kind of a Catch-22. Why can't they just have one program without the other? (Mason City)

The majority of the employed participants who were SSDI beneficiaries said that their employers were well aware of the SSDI income caps for their wages and scheduled their time accordingly. Participants said they experienced no pressure to work off the clock or be paid 'under the table' for additional work. One participant cited Wells Fargo Bank as an example of a company that is active in working with people who receive SSDI, and said that the bank staff keep up to date on regulations regarding income caps. A significant concern for participants was that they were unable to accept promotional or merit raises or performance bonuses because they would then exceed the income cap. There was an overall feeling that it was 'unfair' that because of income restrictions they are unable to accept acknowledgment for doing a good job. Many employed participants indicated that they had made professional progress on the job, but they had to pass up opportunities for greater pay and responsibility because of income limits:

> I was recently offered a bonus on my job. I have been working there for over a year. I had to deny the bonus. I have to deny the raise coming up in October because of the fact that, yes, I am allowed to make a certain amount of money per month and keep my disability (benefits). Well, I am always under that quite a bit, but if I would have accepted the bonus, I would lose my social security benefits for a whole year. And I can't live on what I am making part time. So that is the rules. (Des Moines)

In both the Wisconsin and Iowa focus groups, both the adult SSDI and SSI beneficiaries expressed frustration with state and local vocational rehabilitation programs, mentioning long waiting lists and training that is not relevant to available jobs. This was one of the only areas where people mentioned dealing with rude and unhelpful staff. People noted that there were very limited employment opportunities or job training programs, especially in the rural areas. State funding for job training programs was also expected to be significantly reduced in both states in the coming year. A couple of the participants noted that they were no longer physically or mentally able to do the types of jobs that they previously did, but they did not have the training or skills to apply for other jobs that would pay more than minimum wage. There was also concern about accepting employment that would represent a significant reduction in stature and income compared to the jobs participants previously had (e.g., a former accountant was not interested in working at McDonalds or being a greeter at Wal-Mart). One participant in Mason City noted that without any type of work he was drinking and smoking more:

> I got my master's degree in May of 2009 and have not been able to find work. But I am still applying, and at some point, hope to get off of disability. That is my

> plan. However, I turned 65 in March, so I am having difficulty not only with the disability but also my age. (Des Moines)
>
> When I was let go from my 13-year job, I was making very nice money, and I had to start all over again, back at the bottom at what high schoolers make when they get out of school. And it's pretty much what forced me to have to work two jobs just to survive because I bought my home making a decent wage. And then all of a sudden, I am down to half. And when I was ill, that's where all of my savings went because my check didn't cover everything. So I had no savings left. (Des Moines)
>
> I've been starting to smoke and drink more that I'm not at work. You know, I just have nothing to do but pace and drink and go to bed. (Mason City)

Adults with Disabilities: Financial Planning. While the majority of participants indicated that they knew how to set up a budget plan, the overwhelming sentiment expressed is that they do not make enough money to save, build a nest egg, or even think about retirement planning. They indicated that they are living on a check-to-check basis with no room for extras, especially long-term retirement planning. The overall sentiment is that participants do not think of retirement as an option given their current financial situation.

When asked about the use of written budgets, participants said that having either a written budget or 'one in my head' was important because there was only a set amount of money coming in every month and they knew how long they had to live on those funds. Participants in all of the focus groups indicated that they kept close track of their income and spending. Some kept notebooks to jot down their expenses; others said they knew in their heads how much they had to draw on in a month and they would occasionally check it against their checkbook. Very rarely was there money left over at the end of a month for entertainment, dining out, or nonessential goods. Some participants indicated that they couldn't keep to a budget because food and gas were too expensive or because of impulsive buying habits:

> We don't have a written [budget], but we know pretty much what goes where. And that there is nothing left over at the end of the month. (Milwaukee)
>
> Well, at the beginning of the month I put down this is what I am getting in, or think I am getting in or hope I am, and these are the known expenses in terms of the bills I have and rent payment and loans and that sort of thing, and this is how much I have left to spend for the month for food. I don't have entertainment because there isn't enough. (Madison)
>
> There are times I have three days left in the month [and] I notice my penny jar is three quarters (75 percent) full, so I can take that [to the bank] and say, oh okay now I have $5.00 and I can, you know, buy a cup of coffee or something. (Madison)

One person noted that it was difficult to keep track of income and asset caps for different federal programs. He mentioned that he currently receives a Section 8 housing voucher (funded by the U.S. Department of Housing and Urban Development (HUD)) through a housing program in Iowa and there are asset cap rules for federal housing assistance which make it even harder for SSDI recipients to save. The participant said that he did not want to lose his housing assistance because he exceeded HUD's asset caps for Section 8 assistance. He said it would be helpful if there was coordination between federal programs so that people would not get confused with different regulations then find themselves getting penalized for not being in compliance with both programs.

Iowa WIPA produces two annual calendars that were described as being extremely helpful for SSA beneficiaries to track their income and expenses. One calendar is called the *Iowa Benefits Planning Calendar*. This six-by-nine-inch spiral bound calendar is designed to help SSI and SSDI recipients keep track of when they worked, how much they earned, what expenses they could deduct, when they reported to Social Security, and other important information. The calendar is also designed with pockets to keep important papers, pay stubs, work-related expenses, and information from SSA. There is a form in the calendar for people to record benefits, expenses, and other information for each month of the year. Iowa WIPA also produces a large monthly wall calendar to track similar information as the benefits calendar, and it also provides important contact information for individuals and community support programs. Both calendars also include resource information for government agencies and nonprofit organizations.[1]

In contrast to the other adult focus groups, participants in the Mason City focus group spoke in greater length about 401(k)s and the challenges they had in retirement planning. One participant indicated that his employer had a 401(k) plan, but the participant was not eligible to participate because he was only a part-time employee (in order to avoid exceeding the income cap). A couple of participants noted that they had 401(k)s or other retirement plans with previous employers (before going on SSDI), but had to cash out of these plans because they needed the money:

> I did have a 401(k), but I worry about the future because honestly, I can’t seem to save it. I have to keep accessing [the account] to keep up with the bills I owe. Everything costs so much, it’s depleting my funds so quickly. By the time I’m 60, it’s going to be gone. I’d like to be able to leave it there and not get into it, but

> you know everything costs so much. It takes $1,000 sometimes to even withdraw with the taxes and everything [penalty fees] you have to pay to even take money out. (Mason City)
>
> Well, if I had a job that offered a 401(k), I'd do that. Every 401(k) plan I was in I had to cash out before I got on SSDI to pay the bills. (Mason City)

Overall, the study findings indicate that participants are living month to month and do not see any opportunities to save or plan for retirement for two reasons: (1) they do not have extra funds to set aside, and (2) they believe that they will jeopardize their benefits by setting up savings or retirement accounts:

> Well, I certainly thought about it [retirement planning], but at this time I don't think that is going to be realistic, I think it is going to be impossible. I don't even think or foresee any retirement in the future. If it does happen, I certainly haven't planned for it. I will probably have to work for the rest of my life. I haven't put any money aside for retirement. (Milwaukee)
>
> No, I thought about it but . . . I mean, there is nothing left. When you are on a fixed income and you are really not allowed to have anything when you are getting any type of state assistance. I mean, you can't even have a decent car to get to and from the medical appointments. That is counted against you when you go for any kind of Medicaid. So how are you supposed to go? It just doesn't make a lot of sense. I don't know what is going to happen. (Milwaukee)

Iowa WIPA heavily promotes the Plan to Achieve Self-Support (PASS) exclusion, which allows a disabled or blind person receiving SSI to set aside income and/or resources for a work goal such as education, vocational training, or starting a business. Funds can even be set aside to purchase work-related equipment. Income and resources that are set aside through a PASS are excluded under the SSI income and resources tests. SSA has established four criteria for recognizing an individual's PASS: (1) you have a feasible work goal; (2) you have a specific savings/spending plan; (3) you provide for a clearly identifiable accounting for the funds set aside; and (4) you follow the plan and negotiate revisions as needed. (http://www.socialsecurity.gov/OP-Home/handbook /handbook.21/handbook-2177.html). The Iowa WIPA staff indicated that through the use of PASS been very successful in helping individualsSSI recipients have been able to purchase cars, which is an essential need in many parts of the state where there are extremely limited, if any, public transportation services available. The WIPA staff mentioned that they thought that it was unfortunate that the PASS program was not available to individuals who only receive SSDI benefits. However, SSA staff has noted that more than half of the people who use the PASS program are SSDI beneficiaries, some of whom had been receiving both SSDI and SSI benefits, and some of whom had been receiving only SSDI benefits but were able to establish eligibility for SSI through a PASS.

For financial-planning advice, participants rely on family members or local community staff (e.g., Iowa WIPA or the independent living programs in Wisconsin) to provide guidance. Some participants who had been employed full time before their disabilities indicated that they had worked with financial planners in the past, but no longer did so because they are living on very restricted budgets.

A participant in Milwaukee who is a parent of teenagers said that he was teaching his children to become self-sufficient in their late teens as soon as they started working because he would not necessarily be able to provide for them. He said that he stresses the importance of financial management, limited credit card use, and retirement saving to his children, and he expects them to start implementing good financial-planning practices as soon as they start earning their first paychecks.

One woman in the Des Moines group had a different point of view about saving. She thought that taxpayers should not be paying her disability income so that she could then set aside her own pot of savings:

> I am grateful for the fact that I am on disability (assistance) and that I can barely make it. I don't think taxpayers probably want to pay for me putting money on the side or any of us putting money aside when they probably can't themselves. So I guess I'm finding these questions moot, as far as I am concerned, because there is no way I can. I would feel guilty if I did. And I know there is a job out there for me, and I guess that is what I am feeling right now. (Des Moines)

Adults with Disabilities: Understanding the Rules and Regulations of SSI, SSDI, Medicare, and Medicaid. As mentioned in the general findings for this study, focus group participants shared their perceptions that Social Security, Medicaid, and Medicare programs frequently change their rules and regulations, and monitoring these changes takes a great deal of time. Most participants noted that they rely on local agencies or community-based organizations and support systems to keep them abreast of policy changes. There was an overwhelmingly positive response from participants regarding their local contacts with organizations such as ARC, the independent living centers in Wisconsin, and Iowa WIPA; participants said that these organizations were most helpful in clarifying questions about rules and regulations.

Participants noted that they had difficulty understanding printed materials and letters they received from SSA. It was generally noted that people were able to get their questions answered when they called SSA hotlines; however, some people thought that the people answering the phones were typically generalists and could not answer detailed questions about specific programs or address information in individual letters from SSA. Participants in Mason City suggested that additional effort was needed to get information to people in rural areas since they do not necessarily have resources in close proximity where they can go to get questions answered. They mentioned that is helpful to have an opportunity to meet people in person and not just deal with them over the phone. The Mason City participants noted that SSA's Benefit Team Services was helpful in getting them information about SSA rules and regulations; however, the team is located in Kansas City and people do not have the opportunity to meet with them in person.

People were aware of the SSA website, but noted that it was hard for them to navigate the website with their limited computer skills and they had trouble understanding the different links on the site. One participant noted that she could eventually find the information she needed, but it was hard going back and forth through different links. The participants who were hearing- and vision-impaired said that they have had difficulty getting information on SSA, Medicare, and Medicaid rules and regulations because the resources they needed to access information (such as transcription devices) were not always available. In Iowa, it was mentioned that state and local resources to provide interpretation services were becoming more limited due to budget cutbacks.

Focus group participants were also asked about the impact of the rules and regulations on life decisions, such as getting married, having children, and deciding where to live. Some of the participants (primarily in Madison) discussed their approaches to marriage, indicating that an unmarried status would result in more comprehensive or better disability benefits.

> Actually, when I got really, really sick I was told that I could get support through different agencies if I spend down my money and if I got divorced because my

> husband makes a lot [of] money so I couldn't get services. So, I never got the money. I thought it was sort of strange they were like encouraging me to get divorced. (Madison)
>
> My son's mother and I were together 13 years before she passed away, but we never got married. I know that is a sin, but it [marriage] affects benefits big time. (Madison)

The few participants who had children had them prior to their disabilities, and they expressed concern about not being able to provide for their children, for instance, for college tuition. They also did not want to become burdens to their children if their health conditions deteriorated. One participant expressed dismay and even shame at not being able to provide for his son because he does not have enough income and cannot save:

> My son is 23 now and he will be graduating from MATC [technical school] but now he is planning on going to UW Whitewater because he cannot afford to go to UW Madison. I just feel like a deadbeat dad. I have done so much for him but I can do so little for him now with the education. (Madison)

The only housing issue raised was the concern that the federal Section 8 housing assistance requirements have asset caps, so people who depend on federal housing assistance were forced to deplete their assets even lower if they wanted to qualify for HUD federal housing assistance.

Summary for Adults with Disabilities. It was apparent throughout the focus groups that the majority of the participants are managing their limited resources as best they can, but they believe that they have significant impediments to savings and financial planning. Focus group participants indicated that they barely have enough money to live on each month and there are no funds for 'extras' or to set aside into saving or retirement accounts. People overall were very concerned about not engaging in any financial activities that would jeopardize SSDI, SSI, or medical coverage. People preferred one-on-one guidance in how to address financial issues, and it was apparent that most people were looking to their benefit counselors or community agency staff to help them better understand their financial options to maintain eligibility. They are also concerned about using credit to pay for monthly expenses or emergency needs. If they are able, participants want to be able to work more and earn more income without giving up their medical coverage. Most people had developed a level of trust with their benefits counselors or Iowa WIPA coordinators so that they were comfortable sharing financial and personal information and felt they were working with people who understand 'the system.'

Employment. Overall, people participating in the focus groups want to be able to work, be productive on the job, and earn more income. They would like to see income caps raised, and they would like to be able to benefit from good job performance by being able to accept raises, bonuses, and other cash incentives. While many of the participants thought they would be able to work more hours if the work was available and their income cap was increased, they were very concerned about not losing their medical coverage. The lack of vocational training opportunities was an important concern. Barriers to vocational training included year-long waits for training programs; training programs that did not match the skills required for available jobs; and funding cutbacks for vocational programs. There were also expressions of appreciation for employers, such as Wells Fargo Bank and Wal-Mart, that actively recruit and hire people with disabilities and have staff knowledgeable about SSA program rules and regulations.

Rules and Regulations. It was clear from all four focus groups that participants depend on local community resources to provide reliable, accurate information about SSA programs and community resources. There were very few complaints about contacting SSA staff by phone with questions; however, some people were reluctant to bring attention to themselves by calling, for fear that their files would be get ‘red flagged’ even if they had done nothing wrong. It was also apparent that participants wanted to have a personal relationship with the person who was helping them navigate the federal system and would advocate on their behalf. Most people were aware of the SSA website, but no one indicated that it was their final source for information.

Focus Group Findings: Parents and Guardians of Children who are SSI/Medicaid Beneficiaries and are Aging Out of the School System

Four focus groups were held with parents or guardians of children who receive SSI and/or Medicaid benefits and are aging out of the school system. These focus groups explored attitudes and behaviors toward financial and estate planning, involvement of other family members in the planning process, and coordination with local school districts, as well as participants’ understanding of rules and regulations and lessons learned from personal experiences in these areas.

The findings from these focus groups are presented below in three sections, covering the following areas of inquiry:

- Financial and Estate Planning for the Family
    - Current sources of financial information about financial/estate planning
    - Current financial/estate-planning motivations, impediments, and techniques
    - Role of other family members in the planning process
    - Wills, special-needs trusts, and guardianships
- Involvement of Local School Districts in Addressing Family Needs
    - Point of contact
    - Resources for transitional planning, vocational rehabilitation

- Understanding Rules and Regulations
    - Understanding of the rules and regulations about SSI and Medicaid
    - Sources of information

There was only minimal discussion about basic financial education topics such as budgeting, savings, and debt and loan management, because the participants in these focus groups indicated that they understood these topics and were more concerned about financial and estate planning.

Overall, the study findings suggest that many parents of children with disabilities are scrambling for information about financial and estate planning and community resources to assist their family. Most parents rely heavily on informal community networks, primarily other parents of children with disabilities, to glean information. Throughout the focus group discussions in Milwaukee, Des Moines, and Mason City, there were frequent statements indicating that parents had never heard about a program, resource, or service that was being discussed, although the Madison focus group was very small and all of the participants were actively involved with the Waisman Center and were well aware of programs and services in their community.

Parents also shared their concerns about minimizing the financial and emotional burdens on other family members as they addressed financial and estate planning and guardianship issues. As an example, many parents expressed concern that they would not be able to assist with college tuition for other children in the family. There was also considerable discussion about the involvement of local school districts and how schools are, or could be, the front line of information for a wide variety of issues.

Parents/Guardians of Children with Disabilities: Financial and Estate Planning. As indicated by the study findings, financial and estate planning are major challenges that create considerable worry for parents and guardians of children with disabilities. Parents reported difficulty getting adequate information about planning tools and finding experienced attorneys to set up guardianships and special-needs trust, especially in rural communities.

Parents of children with disabilities expressed concern that relatives who do not understand the rules and regulations around disability benefits would make monetary gifts or provide for their children in their wills, which can impact SSI benefits if allowable asset levels are exceeded. They indicated that extended family members assumed that any financial support would be welcome for children who may not be able to earn an income for themselves:

> My father-in-law has a sizable portfolio and there are six grandchildren. I have had the conversation directly with him: Do not give it to [my daughter]. It goes in the family trust and through the channels that make it nontouchable. You know, don't do the generous thing; do the correct thing. I have just said, you can start giving away anything you want to whomever you want, just don't do it in the same manner with [my daughter] that you do with the rest of the kids. (Milwaukee)
>
> When my son first became eligible for Medicaid he was three months old, and we learned what the asset (i.e., income and resource) restrictions were. I mean, one of the first things we did was tell all our family members not to will him any money because he would then become ineligible. So that is like the opposite of what you want to do; and, at that time we didn't know about special-needs trust and that kind of thing and we actually haven't given our family members any other message since we have learned about the trust. (Madison)
>
> [My husband's parents] don't get it. I have asked him to please make sure [our daughter] is not on anybody's paperwork for getting money, because if she is,

> then we will deal with it. But if we can avoid it, it would make sense. I don't think they get it. I don't know if they are going to get it. And I haven't really gotten an answer on that. So I have some concerns even about extended family members that they are now being benevolent and going to say we will shower this kid that is by herself with money. (Milwaukee)

One parent had set up a college fund for his daughter before realizing the child had disabilities, and those good intentions created challenges in securing disability benefits due to an assets test:

> That money for [my daughter] that I put away for college for her when she was six months old prevented her from getting anything until she was 18. No Katie Becket [services/benefits in Wisconsin], no SSI, no nothing because she had assets. So she missed all of Katie Becket and only through our fighting did she do the three- to five-year-old programs and everything else afterwards. Because when she was six months old, I was stupid and was planning like she was a 'normal child' to send her to college. I didn't know [it] was going to be a problem. (Milwaukee)

(The Katie Becket Program is a special eligibility process that allows certain children who are residents of Wisconsin with long-term disabilities or complex medical needs, living at home with their families, to obtain a Wisconsin Medicaid card. Katie Becket is available when children are not eligible for other Medicaid programs because the income or the assets of their parents are too high, as long as other eligibility criteria are met (http://www.dhs.wisconsin.gov/bdds/kbp/). Many other states have also established Katie Becket programs to provide state-funded Medicaid assistance for children.)

Similarly, a parent in Des Moines was considering dissolving a trust fund that she had set up for her daughter because disability benefits rules had changed since she started the fund and she perceived that the trust would count against her daughter’s benefits:

> It sounds weird, but in a sense, you have to hide the money so nobody knows where it's at. And it's not counted, because technically you don't have it, but you have it, quote, under the table, in a sense. (Mason City)

Throughout their discussions of financial planning, parents of children with disabilities expressed greater concern for the financial future and security of their children than for themselves. Though worried about their own financial security, many parents seemed to believe that they would be able to work out issues as they arose. They were worried about what would become of their children with disabilities when they were no longer there to provide for them:

> I don’t plan for me, I plan for her. I am going to live as long as I live and whatever I leave, she gets. I have a special-needs trust inside of a family trust. (Milwaukee)
>
> I think it has impacted us in a number of ways. I think it has definitely reduced what we are able to put away for savings. But at the same time, it has also made us feel incredibly more concerned about what happens when we are not working and we still need to provide support to [our son], if we don’t have enough retirement funds set up essentially to support three people, because we don’t. We are relying on public support now and in a state [Wisconsin] where systems are really pretty good and supportive of individuals. (Madison)

Across all focus groups, participants said that planning for retirement was nearly impossible because their budgets are already tight and they have more immediate priorities:

> Oh, no, I don’t have a retirement plan. We live day to day. I did purchase life insurance. I don’t have a will; it is divided equally among my surviving children. That is pretty much it. We do talk jokingly like, who is going to take care of [my daughter] and she will say, me, what about [her brother] because he is the youngest. (Madison)

The only participant to say that she had no doubt she would be able to retire said that she and her husband both worked for the State of Iowa, where they received good retirement benefits.

Parents of children with disabilities varied significantly in terms of their estate planning, including guardianship. The majority of parents knew about special-needs trusts, although it was through the focus group discussions that some of the participants were first learning about this type of trust. When asked how parents had learned about special-needs trusts, most responded that they heard about them through contacts at their local school districts or through other parents.

Two of the Madison parents discussed at length the conversations that they had had with their other children regarding the care of the sibling with disabilities. The parents tended to emphasize that they did not want their other children to feel burdened by their sibling and the prospect of caring for him or her after their parents were gone:

> We definitely talked with my younger daughter [that] while there is a formal system out there, in the end it is family who makes a difference so that when we are gone she is going to have that role. We have talked with her about this special-needs trust that we set up and he may need some help, both negotiating those things but also having someone who works as an advocate on his behalf. My son is his own guardian, so he will be making his own decisions but he needs to make

> those with support and assistance. So, we have tried to reassure [our daughter] that financially there is a plan and that she will not be responsible for him financially. I think that all of us want to try to insulate siblings to some extent from, you know, being caregivers and we have certainly tried to do that with [our daughter]. So, I think we have done less thinking about the money piece and more about the support and helping with decision making and the care giving pieces. (Madison)
>
> I have had [fewer] conversations with our other two boys about financial implications. But, we sought full guardianship for my son when he turned 18, so my husband and I are co-guardians. [We] talked with his brothers about how when they become 25 we are going to name them as successor guardians and we are very clear to say that they will not be sort of in a sense responsible for [son], but again will help him make decisions and will help him advocate for himself. They know about a special-needs trust that will be set up after we are gone. (Madison)
>
> We have a will, but the will splits everything in half between our other two children [without disabilities], with the oral agreement that the other two kids will make sure that [son with disabilities] is taken care of. And at this point, we do trust our other kids enough, you know, to do that. (Des Moines)

In Mason City, one parent had named in her will a financial institution to handle the child’s financial matters. And, instead of choosing family members to be the child’s guardian, the parents had chosen the child’s former babysitter, because they thought she was someone they could ’trust and were philosophically align[ed] with’ and would provide a higher level of care for the child than family members could. Several parents in Iowa had opted not to seek guardianship for their children when they turned 18:

> I've never secured guardianship of her, even though she's 22, and have not had any issues at all not being her guardian. And I'm choosing not to go that route, at least as long as I can. When she turned 18, I mean I knew it was available. I know who the attorneys are. I could tell you every resource available. But you know, I just kind of didn't do it when she was 18, and really no other issues have resolved, come up about that. So just it's kind of become now a nonissue. (Des Moines)

Many parents had not formalized financial plans for their children with disabilities and had not yet set up wills. They were worried about what would happen when they were gone but had not made decisions or put their intentions in writing:

> My concern in the future is for my kids. I have five children. Two of them, they have cerebral palsy and special needs. And my main concern is who is going to take care of my kids when my husband and I are not here to take care of them. And we have no plans yet about that. So that is scary. (Milwaukee)
>
> You know, if I was to pass away today, they probably would get $200 a month because I have never really been able to hold anything steady, between the doctors and the schools and constantly fighting and being a voice for the boys. It is very hard. No, there is no trust. We don’t have one. We have a life insurance policy. We have a small amount of savings and everything that we basically do is [earned and spent]. And that is our life. I have an older son who I really never addressed anything with. He knows that he would be the person in charge as far as making decisions along with both his Auntie and cousin. And we have not

> actually put anything in writing. I really feel in my heart that they would do the best that they possibly can because they know my heart and my desires. (Milwaukee)
>
> We don't have a special-needs trust. I guess I think that is something we should have. I mean, when we set up our will when [our daughter] was little and we didn't really know what was happening. So we just did the standard kind of thing. And that is bothering me and I think I need to address that along with other things like guardianship, et cetera. I don't think we have her as beneficiary. (Milwaukee)
>
> Yeah, I actually don't have a will yet. I am working on that. (Madison)

The barriers to establishing wills or special-needs trusts that focus group participants cited included: (1) lack of good financial, estate, and guardianship planning information; (2) difficulty in finding an experienced attorney with knowledge about wills, special-needs trusts, and guardianships for children with disabilities, especially in rural communities; and (3) the cost of ensuring that documents were set up correctly. In Iowa, parents also noted adult guardianship documents (for their children over 18 years of age) have to be renewed each year with the state of Iowa; this costs about $1,000 a year in legal fees. In smaller communities, there is less access to low-cost or *pro bono* legal assistance. One parent in Mason City said that his family was working with a local for-profit business that specializes in benefits and financial planning for people with disabilities. The individual who runs the business is neither an attorney nor an accountant, but has been very helpful in drawing up guardianship and estate plans, which the parent then takes to his family attorney for filing. He indicated that the costs for this business's services were considerably less than legal or accounting fees, and he has not encountered any problems to date. This parent indicated that in a small community (outside of Mason City), people do not have access to all of the resources that exist in larger communities.

It was also noted that most law schools do not include specific coursework on financial and estate planning for children with disabilities and their families; so while an attorney may understand general guardianship and trust issues, he or she may not be knowledgeable about federal regulations impacting social security beneficiaries and their families. As noted in the literature review, an attorney would also need to be knowledgeable about applicable revised code in the state where the special-needs trust or guardianship agreement was established.

> So the costs of making sure that you're doing things correctly and your children are cared for can be pretty exorbitant for families, I think. (Des Moines)
>
> We have not actually set up the special-needs trust. I think one of the problems is we don't know of an attorney that knows how to do it. (Des Moines)

One parent who had set up guardianship for her son and discussed with her other daughter the implications for his care should the parents pass away had not prepared a will. She said the discussion at the focus group was a good reminder to her that she and her husband needed to make a will.

In response to a question about when parents should begin financial and estate planning to address the needs of their children, most parents agreed that planning should begin as soon as the child is diagnosed; however, most parents said that it took a couple of years before they actually began the planning process. Two parents noted that for the first couple of years in their child’s life, they were overwhelmed with meeting the daily physical and social needs of their child. Both parents indicated that when their child entered the school system, they began to think more about the child's long-term needs and had access to additional information and resources about financial and estate planning.

Many parents suggested that it would be helpful to have a resource guide available that discusses financial and estate planning and guardianships. It would also be helpful, they suggested, to have a listing of attorneys who specialize in setting up financial and estate plans for families with children with disabilities. Since there are also individual state regulations regarding trusts and guardianships, it would be helpful for state agencies or bar associations to assemble this information and then make sure that it is updated on a regular basis so there would be no compliance issues if federal regulations changed. A couple of parents noted that it would be particularly helpful if this type of information could be disseminated through the local school district, since that is the only general point of contact that all parents of children with disabilities will have. It was also suggested that it would be helpful if the schools could facilitate planning sessions for parents so they could get more information about financial and estate planning, benefits, and local resources such as attorneys and financial planners.

Parents/Guardians of Children with Disabilities: Involvement with Local School Districts. The discussions about involvement with local school districts were different for each of the four focus groups. Obtaining educational services for their children was clearly a top priority for all participants; however, parents' satisfaction with their own district was varied. In Madison, there was little discussion about any issues with the local school district. In Milwaukee, the majority of parents had children in the local public school system, and they expressed frustration about a number of issues, including school choice (some individual schools were viewed as better much as others), pressure to complete the student's transition plan out of high school with no services available to support the transition plan, cutbacks in school transportation services, lack of opportunities for vocational training due to waiting lists that were years long, and unresponsive staff. Parents whose children were in suburban schools had more favorable responses to their interactions with their school district, although they also mentioned that they could not get their children enrolled in vocational training programs due to state cutbacks in funding. One parent said that his child had been on a waiting list for vocational training since she was 14 years old; she was now 20 years old and had already graduated high school. His daughter was working at a job requiring minimal skills because she could not get enrolled in any other training program. He was very concerned about her getting 'dead ended' in a minimal skill, minimum-wage job because training opportunities were not available.

In Des Moines, the majority of parents were actively involved with their children's schools and many served on parent advocacy committees. These parents had fairly positive opinions about the quality of services their children were receiving. A couple of parents mentioned that they had purchased a new home so their child could be in a specific school district that was known for the quality of its special-education programs. These parents noted that they were fortunate to be able to have the option of being able to relocate to a better school district and recognized that many other families (e.g., lower-income families) did not have this option.

> We used to live in the [NAME] school district when my daughter was born and part of the reason we moved is because at that time the [NAME] school district was not really committed to providing good services to children with disabilities. So we left that district and moved to a different district intentionally. [The new district] had a superintendent who was also very proactive in working with children with special needs. He worked well with ChildServe and he also worked

> with Youth Homes of Mid-America and those students who have special needs in educational areas. He was forward, very forward looking and forward thinking about that kind of stuff long before a lot of other people even realized it. (Des Moines)

In Mason City, most of the parents were fairly satisfied with the educational services that their children received. Parents noted that they were pleased with the special-education staff at their children's schools and thought that the school administrators were knowledgeable about special-education needs and SSA programs; however, it did not appear to the parents that mainstream teachers received much training or support for working with students with special needs. One focus group participant was also a school administrator who said that while he believed that all the teaching staff wanted to do a good job working with students with special needs, there was neither the funding nor the time available to provide training for all school staff. Only one parent in the study, from the Mason City group, homeschooled her children. She lives in a rural area and has three children with disabilities; she thought that it was best for both her children and the family that they be homeschooled. This mother was also working with other parents of homeschooled children with special needs to organize a group where parents and children could come together to participate in recreational and educational activities and meet other families. Families with children with special needs who attend school would also be invited to participate. The mother mentioned that there are few, if any, community-based programs for children with disabilities (e.g., Special Olympics, Very Special Arts) in small, rural communities.

The most urgent request from parents in the study is for their local schools to treat them as equal partners in addressing their children's educational needs. School experiences generated a wide variety of response, ranging from mostly positive to very frustrated, primarily depending on the local school district. Parents expressed a desire to view their local school districts not only as a place for their children to be educated, but also as a focal point to learn about other community resources and their rights as parents and as an opportunity to interact with other parents.

Overall, the study findings showed that most parents believe that their school districts meet the minimum federal and state requirements for providing special-education services. Parents typically had good feedback about the special-education staff at their school districts, but these positive interactions did not necessarily extend to their experiences with other school district personnel or ‘mainstream’ teachers. Some parents noted that the schools were not forthcoming with information regarding additional services for which their children were eligible. A number of parents cited the need to find out what their rights were in advocating for their children, and they were very concerned that their rights would be violated otherwise. One parent in Des Moines mentioned that when her son was younger (he had recently graduated) she had twice threatened to take her local school district to court for not providing mandated services for her child. She worked for the State of Iowa and was knowledgeable about mandated services, so she was able to present documentation to the school district about her child’s rights. This parent said that she feared that other parents who did not have access to the information she did through her job would have more difficulty getting mandated services for their children. It did not appear to many parents that there was any government entity monitoring how effectively school districts fulfill their mandate to provide special-education services, especially since there was considerable inconsistency among school districts. One parent noted that the Des Moines focus group included some of the area’s most active local parent advocates for special-education needs, and even they had difficulty navigating their local school systems on behalf of their children. She said she particularly worried about parents who were not involved in with school advocacy groups, especially low-income parents and parents with limited English-speaking skills, since they may not fully understand their children's rights or how to be an effective advocate.

Parents in the Des Moines focus group cited a local school district in suburban Des Moines as a model district for addressing special-education needs. In this district, the commitment to special-education needs starts at the top, with the district superintendent. He annually presents the district's top priorities for the upcoming school year, and special education is always included on the list. Most importantly, they said that this commitment is communicated to all school district personnel. Special education is addressed throughout all of the district's programs. At the end of each school year, the superintendent reports back to the board and the community on the district's progress in addressing the annual priorities, including special education. Parents also commended this superintendent for keeping up to date on SSA rules and regulations and other state programs and services that are available to families in his district. Other parents noted that in their school districts, special education is not even mentioned as a district priority. Parents in the Milwaukee and Iowa focus groups all expressed concern about state and school funding cutbacks and how these cutbacks will impact their children. One parent in Mason City noted that parents of children with special-education needs are not seen as a strong vocal advocacy group, so legislators may find it easier to make funding cutbacks in special-education programs and support services because there would be less negative feedback from their constituency.

For these parents, in addition to delivering educational services for their children, the schools also serve as a focal point for educating them about accessing programs and services for their children. Many parents noted that when their children entered the school system, it was the first opportunity they had to interact with other parents of children with disabilities. Some parents mentioned that they had been interacting with other parents whose children had disabilities similar to their children's (e.g., groups working with parents whose children had been diagnosed with Down Syndrome or autism), and it was helpful to broaden their network of parents. One parent noted that some parent support groups had greater access to information about programs and services in the community, so it was helpful to hear about the experiences of other parents and groups and learn more about the resources they are accessing. One parent stated that when her child entered school, it was the first time that she had accepted the fact that her child was different from other children and would need a different educational and support structure than her siblings.

The parents in the Milwaukee focus group expressed the most dissatisfaction in working with their local schools. One city high school was recognized as having good programs for children with special needs. One parent expressed deep frustration because she was finally able to get her child into this high school, but cuts in transportation services out of her neighborhood meant that she would now have to send her child to a 'lower-quality' neighborhood school. This parent could not afford to take time off from work every morning and afternoon to transport her child to and from school. She said that at some point she had to accept that she could only do so much for this child and had to also think about her other children, and she needed to work. Some other feedback from Milwaukee focus group included the following statements:

> I have never had a social worker, I have never had a case manager, and I have never had anyone but myself. My desire is to see what I want for my kid's future and try to fight for it. The more severe your kid's [needs] are the less help.

> Milwaukee public schools think the county is doing it [providing programs/services], and the county thinks Milwaukee public schools is supposedly doing it. And in the middle is the family. (Milwaukee)
>
> I have talked to Student Services who has said that you are an equal partner and I have told them point blank that I have not felt like an equal partner. Step up to the plate, you have to hire people, you have to educate the parents so that you can work as a team. Not fighting with each other. (Milwaukee)

Parents in the Milwaukee focus group did not mention participating in any school- or district-based advocacy programs like the parent groups that were referenced in the Des Moines focus group. One participant was starting her own grassroots advocacy and youth activity group for parents of children with disabilities. A father in the Milwaukee focus group said that his family had benefited from its involvement with Special Olympics. In addition to providing his daughter with recreational opportunities, Special Olympics was also a very good way to meet parents of children with disabilities and share information about community resources and financial and estate planning. The involvement of children from different age groups also helped his family learn how their daughter's physical and social needs would change as she got older. This parent also said that the reason he liked Special Olympics as a way to get information was that it was a 'neutral' meeting place; people weren't coming to a meeting with an agenda or trying to push a product or service. He said parents are typically in a celebratory mood when they attend Special Olympics events, as opposed to school district meetings, where most parents are very angry.

In the Milwaukee and Iowa focus groups, parents mentioned the need for a centralized resource for accurate, up-to-date information about programs and services for children with special needs. Parents noted that at the time their children enter the school system, they may have only been accessing medical services; once their children enter the school system, parents do not know what to expect or what their children's rights are:

> You're having to jump through all those hoops to figure out how to access those school programs. Nobody hands you a book. So you're hoping that there's some really good school person that's heard of these other things and gets you connected with somebody in the county who's also really good, and you get a social worker and you get connected. But then you have to get used to having a social worker, who gets to know everything about your life. You go from health insurance to school, and then there's this thing that happens, transitioning to high school, because high school and middle school, that's a huge jump, huge jump. Every time you jump a building, huge jump. And then the biggest is what we're going through now after he graduates, then what? And so we're just trying to keep this as long a transition as possible while we get all the pieces in place. (Mason City)

In Iowa, a parent mentioned a local group called Inclusion for All Kids (IFAK) that holds sessions to educate parents about the individualized education plan (IEP) process so that they understand how to work with their children's schools to develop a more comprehensive educational plan.

It was recommended that schools establish a point of contact (perhaps a guidance counselor) for a family while their child is young; that person would make sure that the family received the most accurate and up-to-date information throughout the time that their child was in school. It was also recommended that special-needs staff and other school district staff should receive training on addressing the needs of special-education students; it would be helpful if SSA could be part of this training. Again, many parents noted that they depend on the school staff to provide them with information on disability-related programs, services, and benefits; therefore, they thought that it was critical that these school personnel have the most up-to-date and correct information from SSA and state agencies. The Mason City parent who was a school district administrator said that he could not recall any time when anyone from SSA or a state agency participated in a teacher-training program. Although he expressed his support for the concept of having the school district staff be a focus point for information and support for families, he said that it also should be noted that school districts are facing significant budget pressures and funding and support would have to be found for this expanded role for district staff.

Parents/Guardians of Children with Disabilities: Understanding Rules and Regulations of SSI, SSDI, and Medicaid. As with the study findings from the focus groups with adults with disabilities, a predominant theme of the focus groups with parents and guardians is that they did not want to do anything that would jeopardize their child's eligibility for SSI benefits or Medicaid coverage. Most parents of children with disabilities appeared to rely primarily on their school districts or other parents to answer questions about the rules and regulations governing social security and Medicaid programs. Many participants noted that they were overwhelmed with the amount of information that they receive from SSA, Medicaid, schools, state programs, and other sources, and they relied on updates and word of mouth from other parents to decipher all of the materials:

> I think that Wisconsin is resource-rich in places that can help families. I think a lot of families still don't know how to access those resources and that information and that help. I am fortunate because I have a lot of friends who know stuff, so I

> go to them first. When they cannot help me, I would go [to] my son’s county case manager, who is pretty knowledgeable, or my son’s school case manager. Our experiences have ranged the gamut from horrible to incredibly creative, strong, knowledgeable people. (Madison)

Parents discussed various opportunities they had through their local school systems to learn more about SSA and Medicaid rules and regulations, along with information on other state disability-related programs. They mentioned meetings with school case managers, parent-night activities, workshops for parents of children with special needs, and an annual statewide special-needs education conference in Iowa. However, not all school districts offer these learning opportunities or have the funding or staff to support such activities.

There was a general perception by parents that the rules governing Medicaid change frequently, and parents struggle to remain informed and understand how changes could impact their children’s care. With regard to Medicaid coverage, parents appeared to be primarily concerned about specific instances when coverage was denied or questioned. Parents with private insurance said that many of the treatments that their children needed were either not covered by their insurance or exceeded the private insurance cap, and they were looking for guidance on how to use both private insurance and Medicaid coverage to cover the costs of their children’s health needs. A few people mentioned that they delayed signing up for SSI benefits and Medicaid coverage for their children because they thought that they could financially support their child and they were reluctant to sign up for ‘public assistance.’ However, due to rising medical costs, most of the parents who had been reluctant to sign up for SSI and Medicaid coverage said that the costs of multiple surgeries and treatments and costly prescriptions exceeded both their insurance coverage and their financial means. One mother did not immediately consider that her child might be able to qualify for public benefits because of her household income:

> I think what I would really want families to know [is] that there is help available. I mean it never occurred to me that we were eligible for public benefits. I think [that] is true for many families. Families really struggle until they find out, for example, that their child with a significant disability can be eligible for Medicaid and get that kind of help. (Madison Parents)

One parent in Des Moines said when she had a question about Medicaid, the local Medicaid office referred her to the agency's website, but she could not understand the website and did not know where to look for the information. The Milwaukee County Department of Social Services is responsible for facilitating Medicaid coverage for SSI recipients in the Milwaukee area, and many focus group participants expressed frustration at the difficulty of getting information from this department. People perceived that they were getting conflicting information about benefits and coverage, and it was very difficult to reach a 'live person.' One parent noted that there also appeared to be confusion about the roles and responsibilities of Milwaukee County versus county school districts for children with disabilities.

For SSI benefits, parents primarily expressed confusion in two areas: a) the benefits eligibility process, and b) benefit payments. Some parents said they could not figure out why their children were initially denied SSI benefits; however, once they finally were determined to be eligible, the parents said they were just happy to have the benefit and they did not pursue the question of why earlier eligibility applications were denied:

> I consider myself to be pretty well versed in the system in Wisconsin, and what was really tricky was navigating my son's enrollment into the SSI program. I find

> that I got a lot of conflicting information even when I went directly to the Bureau for Disability Determination, which was our first stop. I got a lot of conflicting information even from supervisory personnel about processes and policies. (Madison)
>
> When you hear you qualify . . . that is enough for me. (Milwaukee)

Two parents said they had difficulty getting responses about why their child's SSI benefit varied from month to month. One parent mentioned that she was afraid to cash a benefit check that had a different amount for fear that doing so would jeopardize future benefit payments. In Iowa, the regional Iowa WIPA staff were reported to be very helpful in talking to SSA to understand why there was a change and then reassure the parents that there was not a problem.

When parents did have questions about rules and regulations or printed materials sent to their home and needed to contact SSA, their interaction with the SSA staff was viewed favorably:

> One wonderful surprise is that I found people at our local social security office to be incredibly helpful, and that was a pleasant surprise because I had heard all these myths about how hard it is to crack through that bureaucracy. (Madison)

Many parents noted that they nearly always talked to a 'live person' when they contacted SSA and did not have to leave a message and wait for a call back, as is the case with many other government agencies. As mentioned in the section about school districts, Iowa parents also expressed a desire to have SSA staff participate in school training programs so that school administrators, case workers, and teachers could learn more about benefits and rules and regulations.

Parents who did express feeling overwhelmed by the sheer amount of information they receive from SSA and other agencies said that they tried to monitor all the information in order to keep up with changes in regulations. The parents wished that there was a central resource—either a professional contact person or a published source—that they could go to for clarification. One mother indicated that she would appreciate having a counselor who could summarize everything and advise her on what would be worth the time to do. Most parents said that they would like to see this contact person stationed at the school district level:

> I really don't have the time to find [the information], to organize [it], to dig into it, and I found a lot of parents are probably the same, so busy working every day. It is just harder to get information organized for us to access and I wish there [were] people like a case manager for parents [who] can tell them what kind of resources they have and they can help [you] out. I wish parents had that kind of person [who has] all kind of knowledge in their head and they can just tell you what you need to do. (Madison)
>
> I would love to have just like a Cliff Notes on special needs. Like, we could just hit and say, try these parent groups, here is ARC, here is this or you know, birth to three, here are your contacts. You know, just because I think all of us are spending so much time trying to make those connections [for more information]. (Milwaukee)
>
> There doesn't seem to be any real centralized place where you can go get your questions answered or help even finding an attorney who deals with trusts and disability issues. It just is hard to get the resources that you need. (Des Moines)

Many parents of child SSI/Medicaid beneficiaries expressed an interest in participating in group seminars or workshops as a means to learn about benefits, rules and regulations, and programs specific to their children's needs. In Madison, the parents suggested that these sessions would ideally be free of charge, because most of the parents' budgets and time were strained anyway. Iowa parents expressed an interest in having the schools host these types of group meetings, with SSA participation. As opposed to one-on-one education and planning opportunities, parents expressed more interest in opportunities to talk with other parents about benefits, coverage, local services and resources, and financial and estate planning.

Parents also talked about the need to educate their children about social security benefits as they became adults. Parents were particularly concerned about managing their children's expectations of self-sufficiency with the SSA limitations on being able to work. Several parents said that they had raised their children to have a strong sense of self-worth within the context of SSA's programs:

> When my son was about 18 and we were thinking about beginning to talk about work and getting a job, he (incorrectly) said, "Well Medicaid will not let me work." I think that the need to understand the rules and pay attention to them and work within them, the message that my son got was he couldn't in any sense envision his life and move forward with it. I regret that message because he has in his mind now that there are these external forces that get to decide for him and that is absolutely the wrong the message. So, I think there is still a very strong sense that people with disabilities cannot work or they will lose benefits. (Madison)

This young man had apparently received inaccurate information about Medicaid coverage and earnings. In Wisconsin (his home state), residents whose earnings end up zeroing out their SSI benefits can keep their Medicaid coverage until their earnings exceed $32,284. (In Iowa, the earnings amount would be $30,477). The earnings amount could be higher if the person's actual medical expenses exceeded the state's average per capital Medicaid expenditures. This young man's comments demonstrate the vital need to get accurate information about benefits to beneficiaries and their families.

A parent in the Mason City group said that his son had been working and earning an income, and it turned out he enjoyed saving cash in a drawer in his room of which his parents were not aware. His son had saved $1,700 in cash for a car, which then had to be declared as assets. He said that the situation prompted him to talk to his son about his social security benefits and budgeting:

> The hardest part of this whole financial thing is to try to explain to a kid who likes to save that you can't save that much. It goes contrary to what you're trying to do. But in order for him to get through school, which may be the next, you know, five to seven years, he's going to have to follow a plan where he's limited on what he can actually own (cash). (Mason City)

This parent worked with Iowa WIPA to set up a PASS plan for his son so that he could set aside funds to purchase a car which he needed to get to work.

Summary of Parents and Guardians of Children with Disabilities: Financial and Estate Planning. The main themes emerging from the focus group discussions are that ***financial and estate planning***, ***wills***, and guardianship issues are topics that ***impact both immediate and extended families***. Families are looking for ***access to experienced financial planners and attorneys*** to help them address the long-term financial and guardianship issues. In rural areas, families have very limited access to these types of services. Families are also concerned about the ***costs of legal and financial-planning services***. As demonstrated by the literature review, there is limited state-specific information available about special-needs trusts. Parents must be aware not only of SSA policies, but also of state administrative codes regarding special-needs trusts and guardianships. Most parents who had already established a special-needs trust for their child learned about this option through other parents. As families engage in financial planning, there is an overwhelming concern that no financial instruments be set up that would put a child's social security benefits or Medicaid coverage in jeopardy.

In addition to addressing the long-term financial needs of their children with disabilities, parents and guardians are also concerned about how, or if, they are going to be able to ***plan for their own retirement or the financial needs of their other children***, for example, paying for college tuition. It was important to parents that their other children not be financially penalized because of one child's disabilities.

Involvement with School Districts. Many parents view their local school district as ***the focal point*** where their children's educational needs are addressed, where they get information on ***community resources***, and where they have opportunities to ***interact with other parents*** in similar circumstances. Many parents view their local school as their ***children's bridge to the outside world***. The quality of special-needs education in specific districts even dictated where families would choose to live—or not live! Apparently due to a comfort and trust level with the schools, parents expressed an interest in seeing schools play a significant role not just in providing special-education services, but also as a community-based resource to support parents and families and provide educational opportunities for families on a wide variety of topics from SSA rules and regulations to legal and financial planning. Parents also expressed an interest in having SSA and Medicaid staff participate in school trainings so that the school district staff has the most accurate information about programs. At least in the Iowa focus groups, it was also apparent that parents who are active in their children's schools appear to have more access to information about parenting a child with special needs. It would be interesting to have further discussions with school districts to see how they view their role beyond providing special-education programs.

Understanding Rules and Regulations. Most parents thought they had a basic understanding about the rules and regulations governing SSA and Medicaid programs; however, some of their comments suggested otherwise. Uncertainty arises when there are policy changes or in regard to specific issues around individual benefits or coverage. Parents appeared to rely more on their local school districts and informal parent networks to decipher rules and regulations or understand policy changes. People were aware of the SSA website; however, this was not a primary source of information for them. Parents were looking to their local school districts to also help them clarify and validate information that they receive from SSA.

Implications

This study examined attitudes to savings and financial education among two distinct groups: adults with disabilities who are SSDI/SSI beneficiaries and are either working or want to work, and parents and guardians of children with disabilities who are SSI/Medicaid beneficiaries and are aging out of the school system. While many of the findings are specific to each group, the overall findings show that people with disabilities and their families are constantly seeking accurate, up-to-date information about maintaining social security eligibility so that they do not jeopardize their benefits, especially their Medicaid coverage. Results further indicate that it is important to examine how and where people get information on topics ranging from rules and regulations to financial planning and to ensure that they have access to the resources they need to move forward.

Findings are presented in five topic areas: knowledge about financial education; attitudes and behaviors toward financial planning, including estate planning, retirement planning, and guardianships; understanding of social security and Medicaid/Medicare rules and regulations; issues around employment attitudes, behavior, and impediments; and interactions with local school districts in addressing special-education and other needs.

Knowledge about Financial Education. Overall, there was ***not a lack of financial education*** knowledge among focus group participants, particularly with participants from the parent and guardian focus groups. In both sets of groups, especially the groups for adults with disabilities, participants indicated that they are ***living on very tight budgets*** that cover essential living functions (i.e., shelter, food, utilities) with no additional funds available to be set aside for savings or 'extras,' such as a meal in a restaurant or recreational activities. Many participants indicated that they ***do not have a 'nest egg' of funds*** set aside for emergency or extraordinary expenses.

While some participants had experienced problems with credit cards or loan payments, others expressed their frustration at having no credit history and not being able to get any type of credit card or loan. Among both populations, people indicated that they knew how to save and they wanted to save, but they stated that they had ***no extra funds to save***. Some participants mentioned that even if they had extra money to set aside in savings, they feared that they would be penalized for exceeding asset caps for other federal programs, which could jeopardize their benefits or their eligibility for other public assistance programs, such as federal housing assistance.

Focus group findings also suggest that the calendar and budgeting materials distributed through the Iowa WIPA Initiative serve as a good model for helping SSA beneficiaries to manage their funds and benefits and save receipts and other documentation.

Financial and Estate Planning: Attitudes, Behaviors, and Impediments. For individuals and families impacted by disabilities, financial planning incorporates an array of activities ranging from estate planning, guardianships, retirement planning, and planning for individual or sibling long-term care. Financial planning—planning for the future—was an overall concern among all focus group participants. Adults with disabilities worried about who would take care of them when their conditions worsened; families of children with disabilities worried about who would take care of their children as they grew order and when they were deceased. A theme throughout the discussions is that participants did not want to create burdens for other family members.

For financial-planning needs, there appear to be four issues that need to be addressed: (1) dissemination of information about income eligibility so that people maintain eligibility and do not jeopardize current or future social security benefits or medical coverage; (2) access to experienced legal and financial-planning resources to help individuals and families plan for the future, especially in rural communities; (3) the cost of legal and financial-planning services, including the limited availability of *pro bono* or low-cost legal services; and (4) the involvement of other family members in the planning process. Financial planning to care for the individual or family member with disabilities appears to be the most important consideration, followed at a distance by retirement planning and other types of planning, including college tuition planning for other siblings.

It was critical to participants that they get ***financial-planning information*** based on relevant experience, and that they feel they are able to trust the information source. While adults with disabilities appeared most interested in receiving financial-planning information in one-on-one settings, parents and guardians of child SSI/Medicaid beneficiaries expressed an interest in getting this type of information in a ***group setting*** so they could learn from other participants. The context of how financial and estate-planning information, along with guardianship information, is disseminated is also vital, and participants looked to community-based organizations (e.g., independent living centers) or local school districts to facilitate the delivery of this information. Many parents indicated that they currently get financial and estate-planning information from other parents or contacts in their local schools. Participants expressed concern about individuals and ***parents and guardians who may be isolated*** through circumstances such as language skills and income not having ready access to information on how they can address long-term financial-planning needs.

While parents cited individual contacts at their school districts for helping them get information on topics such as special-needs trusts, there were no references to actual financial and estate-planning workshops held at local schools. Throughout the discussions, ***the role of school districts in facilitating financial-planning workshops*** was one example of how families were looking to expand the role of school districts to make them more of a community focus for children with disabilities. Concern was also expressed that as school districts are facing budget cutbacks, individual districts may ***not have the funding or capacity to expand their role*** beyond special education.

Understanding Rules and Regulations about Social Security, Medicaid and Medicare. Overall, participants in both focus groups conveyed that they had a ***basic understanding of the***

rules and regulations about social security benefits and Medicaid/Medicare coverage; however, some of the adults with disabilities in Iowa were unclear as to whether they were receiving federal Medicaid or Medicare coverage or the state Buy-in Medicaid program (MEPD). Concerns arose when policies changed or when there was a ***question about individual benefits or eligibility***. Participants were aware of the SSA website, along with other government websites; however, they frequently mentioned that they did not have the computer skills to navigate the website (including clicking on links and going back and forth between web pages). Even individuals who said that they had good computer skills indicated that they had problems with the website. It may be helpful to provide tutorials to community-based organizations (such as independent living agencies) so they can share website information, including using links for specific information, with their clients.

People also commended the SSA for having 'live people' answer the phones at their call centers, as opposed to having to leave messages and wait for someone to call back. Most questions to the SSA call centers appeared to be in ***reference to specific circumstances*** and not part of a search for general information.

Even when SSA staff responded to questions, participant indicated that they also went to their community-based organizations (e.g., Iowa WIPA or the independent living agencies) or school districts in order to ***validate the information*** they received from SSA. There was a tremendous amount of ***trust*** demonstrated toward interactions with community-based and school district staff, and participants wanted that final confirmation before accepting information they received from SSA. It is important to determine ***how people are getting their information 'validated'*** and make sure that validation sources have accurate, up-to-date information about eligibility, benefits, and coverage.

Employment: Attitudes, Behaviors, and Impediments. Overall, adults with disabilities expressed an ***interest in employment and increasing their ability to be self-sufficient***. However, their overwhelming concern appeared to be that they did not want to do anything that would jeopardize their social security benefits or medical coverage. Especially in the Iowa focus groups, there was an overwhelming interest in raising the income limit for adults with disabilities who are SSDI beneficiaries, as long as they can maintain their Medicare or state Medicaid coverage. Many of these individuals expressed a desire to become more self-sufficient.

Focus group participants who were adult SSDI beneficiaries had positive feedback about their employers—citing examples of Wal-Mart and Wells Fargo Bank—in providing a ***good working environment for people with disabilities***. They commended their employers for outreach and recruitment efforts, commitment to hiring people with disabilities, and company human resources staff knowledgeable about SSA compliance regulations (e.g., income caps). Participants recommended that these employers be used as ***employment models*** to encourage more employers to hire people with disabilities. Findings also suggest that people were demoralized by ***not being able to accept raises, bonuses, or other cash incentives*** offered by employers for good work performance because of income limits. It was recommended by the focus group participants that SSA review policies that cause people to turn down ‘rewards’ for good work performance.

Interaction with Local School Districts: Addressing Special-Education Needs and Being a Community Focus. The questions about interactions with local school districts generated the liveliest discussions during the focus group sessions with parents and guardians. People reported relocating their families so they could live in specific districts that were known for the quality of their special-education programs and ***districtwide commitment to these programs***. At the same time, parents noted that the ***option for relocating to a 'better' school district*** was not available to all families. One concern expressed by parents was that there is a discernible difference in the quality of special-education programs, even though a district may be meeting the minimum requirements for providing mandated services, and no federal or state agency appears to have ***responsibility for monitoring the quality of special-education programs***.

Despite concerns parents may have about their school districts, they almost universally saw their ***local school districts as the front line for parents*** coming together and disseminating a variety of information related to issues beyond special education. Many people shared a vision for their local districts to serve as community resources that would not only be a source of information about community and educational resources, but that would also ***facilitate education and training programs for parents of children with disabilities***, such as financial and estate planning. It was noted that most school districts in this country are facing severe budget constraints, and this ***vision of the school district as a community focus for parents*** exceeded current educational mandates. It would be interesting to conduct further research to see if models for this type of school-based community resource do exist and how they are funded and staffed. Because families of children with disabilities count on their local schools for information, parents also expressed an ***interest in having SSA staff and staff from disability-related state agencies participate in teacher and staff trainings*** to ensure that all relevant staff have accurate information and can continue to serve as effective resources for families.

Acknowledgments

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Appendix A: Moderators Guide

Focus Group#1: Parents/Guardians of Children receiving SSI and/or Medicaid who are aging out of the school system (16-22 years)

Introduction

Hello, my name is (NAME) and I work for a company called Abt Associates. I am facilitating this group today as part of a project run by the Center for Financial Security at the University of Wisconsin-Madison. The Waisman Center is a partner in this project and our host here today.

Thank you for your time today. We want to hear from you about your financial planning for your child, and what might be helpful to you to learn more about financial matters. What you have to say is very important and will be used to help families address their financial needs.

At this stage we are planning on conducting three focus groups across Wisconsin with a total of about 24 to 30 people participating in these discussions. The information we get from you will help us develop research about what the financial educations needs of families like yours are and how they might be met.

I will be tape recording this session; however, none of our reports will identify anyone by full name and we will not be sharing your names. Your name cards have first names only and I will only know you and refer to you by your first names. If you happen to know people here, please do not use anyone's last name in our discussions.

Your participation is this discussion is voluntary. You do not have to answer any questions you would prefer not to answer. You can decide to leave the group at any time if you do not want to continue.

Also, please know your participation in this group will not affect any benefits your child may be receiving now or will in the future receive from any government agency, or with any relationship you may have with the University of Wisconsin-Madison. In the coming months, we will use the information from today and other focus groups we hold nationally to prepare a report.

You signed a consent form earlier and were given a copy. The consent form provides contact information for the study director should you have any questions after leaving today about the study. The consent form also includes contact information for (NAME) of the University of Wisconsin-Madison's Institutional Review Board should you have any questions about your rights as study participant.

My role as facilitator is to find out your views on some issues and to move the conversation forward from time to time.

Does anyone have any questions about today's focus group?

Does anyone have any questions about this study?

Before we start, can you introduce yourself and say a little about why you decided to come to the focus group.

Module 1: Planning for Your Child's Future

1. How are you planning for your child's financial future as they exit the school system? What kinds of issues are most important to consider? Which ones are the hardest to get good information to make decisions?
    a. Do you involve other family members (e.g., siblings) in the planning process?

2. Has planning for your child's future affected your own retirement planning? How?

3. Do you address financial plans for your child's future in your will? How?
    a. What type of conservations, if any, have you had with extended family members about bequests to the child with a disability?
    b. How do your financial decisions impact other family members?

4. When should a parent/guardian who has a child with a disability begin to plan for their child's financial future?

    a. What resources were available to you when you started planning your child's financial future? Were they adequate?
    b. If resources were available, were they free, minimal cost, or market rate services?

5. Where do savings and investments fit in for your child's financial future?

Module 2: Rules and Regulations

1. How well do you understand the rules and regulations of the school system regarding the services they should provide to your child? How about the rules of Medicaid? The rules of SSI or SSDI?
    a. If you had difficulty understanding any of the rules and regulations, who did you contact with your questions? Did you find assistance readily available to answer your questions?

2. Do the rules and regulations affect your financial decisions? How?

Module 3: Financial Information

1. What kinds of financial topics do you feel you know the most about? Least?

2. What more could schools do to help you make better choices for your child's future? What about other institutions?

3. How helpful have you found counselors/benefit advisors? Case workers? School professionals? Paid financial planner? Peers and other parents/guardians?
    a. Do you use any social networks (e.g., Facebook) to share information with peers and other parents/guardians?
    b. Who do you trust for financial advice regarding your own finances? Regarding your child's finances?

Module 4: Lessons Learned

1. Are there any cautions you would make to other parents about financial issues related to their child with disabilities?
    a. Scams or rip offs to avoid?

Conclusion

Thank you very much for your time today. It's been very useful to talk with you. (Tell them again what will happen; make sure they are comfortable with stories but no names, etc.

Focus Group #2: SSDI/SSI Beneficiaries who are Working or Want to Work

Introduction

Hello, my name is (NAME) and I work for a company called Abt Associates. I am facilitating this group today as part of a project run by the Center for Financial Security at the University of Wisconsin-Madison.

Thank you for your time today. We want to hear from you about financial literacy and your decision to return to work, and what might be helpful to you to learn more about financial matters. What you have to say is very important and will be used to help people address their financial education and planning needs.

We are planning on conducting three focus groups across the country with a total of about 24 people participating in these discussions. The information we get from you will help us develop research about what the financial educations needs of people like you are and how they might be met.

I will be tape recording this session; however, none of our reports will identify anyone by full name and we will not be sharing your names. Your name cards have first names only and I will only know you and refer to you by your first names. If you happen to know people here, please do not use anyone's last name in our discussions.

Your participation is this discussion is voluntary. You do not have to answer any questions you would prefer not to answer. You can decide to leave the group at any time if you do not want to continue.

Also, please know your participation in this group will not affect any benefits you may be receiving now or will in the future receive from any other government agency, or with any relationship you may have with the University of Wisconsin-Madison. In the coming months, we will use the information from today and other focus groups we hold nationally to prepare a report.

You signed a consent form earlier and were given a copy. The consent form provides contact information for the study director should you have any questions after leaving today about the study. The consent form also includes contact information for (NAME) of the University of Wisconsin-Madison's Institutional Review Board should you have any questions about your rights as study participant.

My role as facilitator is to find out your views on some issues and to move the conversation forward from time to time.

Does anyone have any questions about today's focus group?

Does anyone have any questions about this study?

Before we start, can you introduce yourself and say a little about why you decided to come to the focus group.

Module 1: Financial Planning

1. How are you planning for your financial future?
    a. Are you involving other people (e.g., other family members, financial advisors, etc.) in planning for your financial future?

2. Have you thought about or planned for retirement? If so, how?
    a. If you had questions about retirement planning, who would consult for more information?

3. Do you use a written budget? How does this work for you? What makes it hard?

4. Is it a good idea for you to try and build up a nest egg?
    a. If so, how do you save money? (e.g., payroll, savings account, CD, investments, etc.)
5. Do you use credit or loans? Is take on debt a bad idea? Do you find many lenders offering you credit cards or other kinds of loans? How and what do they offer?

Module 2: Rules and Regulations

1. How well do you understand the rules and regulations of Medicaid and Medicare? The rules of SSI or SSDI?

    a. Do the rules and regulations affect your financial decisions? What kinds of issues are most important to consider? Which ones are hardest to get good information on?

    b. Do SSA rules impact your estate planning? How?

    c. Would you save more if you did not have to worry about these program rules?

2. How do you view the Social Security survivor benefit? Do you see this as a form of life insurance?

3. Do SSI or SSDI rules impact decisions to marry? Cohabitation choices? Decisions to have children?

4. Do you think that eligibility is something people are aware of? Where do people get advice on how to work with these rules? Is that good advice?

Module 3: Financial Information

1. What kinds of financial topics to you feel you know the most about? Least?

2. Who do you trust for financial advice?
    a. What type of financial advice are you receiving?
    b. Are you paying for this financial advice?

3. How helpful have you found counselors/benefits advisors on financial topics? Case workers? Paid financial planners? Peers or family members?

Module 4: Lessons Learned

1. What kinds of information sources have you found useful? Workshops, newsletters, the Internet, etc.?
    a. How did you learn about these information sources?
    b. Have you had any problems with getting inaccurate information?
    c. Would you trust information you obtained online?

Conclusion

Thank you very much for your time today. It's been very useful to talk with you. (Tell them again what will happen; make sure they are comfortable with stories but no names, etc.

Appendix B: References for Disability-Related Agencies, Programs, and Services in Wisconsin and Iowa

Table B1.

Disability-Related Agencies, Programs, and Services in Wisconsin

FOCUS GROUPS: GENERAL	
ADRC	Aging and Disability Resource Center
SDS	Self-Directed Supports
SSI/SSDI	Supplemental Security Income/Disability
DDB	Disability Determination Bureau
Badger Care-Plus, Benchmark	Medicaid programs (Wisconsin)
MA	Medical Assistance, Medicaid, or Title 19 (all the same thing)
CSHCN	Children with Special Health Care Needs
DHS	Department of Health and Family Services
DPH	Division of Public Health
DPI	Department of Public Instruction
DVR	Department of Vocational Rehabilitation
HIRSP	Health Insurance Risk Sharing Plan
LPHD	Local Public Health Department
MCH	Maternal and Child Health
UCEDD	Center for Excellence in Developmental Disabilities
FOCUS GROUP: PARENTS OF CHILDREN WITH DISABILITIES	
FSP	Family Support Program
FSRC	Family Support and Resource Center – Madison, WI
KB	Katie Becket Program
CLTS	Children's Long-Term Support Waivers
CSP/CSS	Comprehensive Community Supports for people with mental illness; wraparound or Children Come First
B-3	Birth to Three (Wisconsin Early Intervention Program)
IDEA	Individuals with Disabilities Education Act
IEP	Individual Education Plan
WI FACETS	Wisconsin Family Assistance Center for Education, Training, and Support
CESA	Cooperative Educational Service Agency
CYSHCN	Children and Youth with Special Health Care Needs
FOCUS GROUP: ADULTS WITH DISABILITIES	
CIP	Community Integration Program
COP	Community Options Program

CSP/CSS	Comprehensive Community Supports for people with mental illness
Medicaid Managed Care Long-Term Supports	• Family Care • IRIS • Partnership (Madison) • MCO-CMO (case management organization)
ILC	Independent Living Center
PASS	Plan to Achieve Self-Support
IPE	Individual Plan for Employment

(Prepared by the Waisman Center)

Table B2.
Disability-Related Agencies, Programs, and Services in Iowa

ADA	Americans with Disabilities Act
ASL	American Sign Language
BLN	Business Leadership Network
CAP	Client Assistance Program
CILs	Centers for Independent Living
COOP	Cooperative Work Experience Program
CRC	Certified Rehabilitation Counselor
CRPs	Community Rehabilitation Programs
CSAVR	Council of State Administrators of Vocational Rehabilitation
CWIC	Community Work Incentive Coordinator
DDS	Disability Determination Services
DESE	Department of Elementary and Secondary Education
DHS	Department of Human Services
DMH	Department of Mental Health
DOLIR	Department of Labor and Industrial Relations
DSE	Division of Special Education
DSU	Designated State Unit (Voc Rehab)
DVR	Division of Vocational Rehabilitation
DWD	Division of Workforce Development
DYS	Division of Youth Services
EEOC	Equal Employment Opportunity Commission
IDEA	Individuals with Disabilities Education Act
IL	Independent Living
IPE	Individualized Plan of Employment
LCSW	Licensed Clinical Social Worker
LPC	Licensed Practical Counselor
LWIB	Labor and Workforce Investment Board

MC	Medical Consultant
MOUs	Memorandums of Understanding
MSD	Most Significantly Disabled
OSEP	Office of Special Education Programs
OSERS	Office of Special Education and Rehabilitation Services
RCEP	Rehabilitation Continuing Education Program
RSA	Rehabilitation Services Administration
SILC	State Independent Living Council
SD	Significantly Disabled
SE	Supported Employment
SRC	State Rehabilitation Council
SSA	Social Security Administration
STATUS 08	Case Closure after Referral for Services
STATUS 26	Successful Employment Case Closure
STATUS 28	Case Closure Not Rehabilitated after IPE
STATUS 30	Case Closure Not Rehabilitated before IPE
TAP	Transition Alliance Program

Prepared by the Iowa Work Incentive and Planning Assistance Initiative

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Notes

1. The Iowa WIPA calendar was made possible by a grant from the Center for Medicaid Services Medicaid Infrastructure in collaboration with Iowa WIPA and the Center for Disabilities and Development at the University of Iowa Children's Hospital. The calendar also acknowledges the Massachusetts Developmental Disabilities Council for sharing its Benefits Planning Calendar format.