ATTITUDES TO SAVINGS AND FINANCIAL EDUCATION AMONG DISABILITY-RELATED POPULATION GROUPS: FINDINGS FROM THE FINANCIAL LITERACY FOCUS GROUPS

By Katherine Anne Dahlem

The University of Wisconsin’s Center for Financial Security and Abt Associates Inc. conducted four focus groups with adults with disabilities who are working or interested in working, and four focus groups with parents or guardians of children with disabilities who are aging out of the school system. The purpose of these eight focus groups was to gather information on how people with disabilities and their families address financial and estate planning, understand eligibility rules and regulations, seek and maintain employment, interact with local school systems, and share lessons learned. Study findings suggest that the dissemination of information about financial and estate planning, benefit rules and regulations, employment opportunities, and effective special education models is vital to people with disabilities and their caregivers in order to help them address long-term financial and care needs.

Between July and September 2010, eight disability-related focus groups were conducted, including four groups with adults with disabilities who receive Social Security Disability Insurance (SSDI) and are working or want to work, and four groups with parents/guardians of children who receive Supplemental Security Income (SSI) and/or Medicaid who are aging out of the school system. The groups were conducted in four Midwestern cities: Milwaukee, Wisconsin; Madison, Wisconsin; Mason City, Iowa; and Des Moines, Iowa. While focus groups varied in terms of age and gender, participants were primarily white. The Waisman Center in Madison, Wisconsin and the State of Iowa’s Work Incentive Planning and Assistance (Iowa WIPA) initiative served as partners in the administration of the focus groups.

The goal of the focus groups was to gather data that will enhance the provision of information on financial planning and savings. The focus groups explored attitudes and behaviors concerning financial and estate planning, employment, special education needs, the understanding of rules and regulations, and lessons learned from personal experiences.

Adults with Disabilities

Financial Education and Planning. The majority of participants perceived significant obstacles to saving and financial planning. Respondents indicated that they have barely enough money to cover basic expenses, and have no extra funds for amenities or savings.

*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.*

Some individuals were concerned about using credit to pay for monthly expenses or emergency needs, while others were worried about having no credit record.
I have credit cards and loans in part to pay [for] expenses from having owned a home and being less and less able to take care of it as my disability got worse.

Participants were very focused on not engaging in any financial activities that would jeopardize their eligibility for SSDI or Medicare. Respondents preferred one-on-one guidance to address financial issues, and most relied on benefit counselors or community agency staff to help them better understand which financial options would allow them to maintain eligibility.

Employment. Overall, focus group participants wanted to be able to work, be productive on the job, and earn more income. They reported a desire to see income caps raised, and to be able to benefit from good job performance by accepting raises, bonuses, and other cash incentives without losing medical coverage.

I was recently offered a bonus...I had to deny the bonus. I have to deny the raise coming up in October because...I am allowed to make a certain amount of money per month and keep my disability. And I can’t live on what I am making part time.

While many participants thought they had the potential to work more hours, they minimized their work schedules because they could not afford to lose medical coverage.

The lack of vocational training opportunities was an important concern. Barriers to vocational training included multi-year waits, training programs that do not match the skills required for available jobs, and funding cutbacks. Participants appreciated employers such as Wells Fargo and Wal-Mart that actively recruit and hire people with disabilities and have human resource staff who are knowledgeable about Social Security Administration (SSA) program rules and regulations.

Understanding Rules and Regulations. Participants in all four focus groups depended on local community resources to provide reliable, accurate information about SSA and Medicare programs. While respondents voiced very few complaints about contacting SSA staff by phone with questions, some were afraid if they called SSA with a question that their files would be ‘red-flagged’ even if they did nothing wrong. Participants stressed that they wanted to have a personal relationship with the individual helping them navigate the federal system and advocating on their behalf. Most were aware of the SSA website, but no one indicated it was their final source for information.

Parents/Guardians of Children Aging out of the School System

Financial Education and Planning. Financial and estate planning, wills, and guardianship issues impact both immediate and extended families of children with disabilities. Families were seeking access to experienced financial planners and attorneys to help address long-term financial and guardianship issues. In rural areas, families had very limited access to these types of services. Respondents were also concerned about the costs of legal and financial planning services.

Parents noted that they must be aware not only of SSA policies, but also of state administrative codes when setting up 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. Respondents reported that as their families
engage in financial planning, there is an overwhelming concern that no financial instruments or gifts jeopardize a child’s social security benefits or Medicaid coverage; parents discouraged family members from gifting money to their children for this reason, unless it could be done without affecting asset limits.

My father-in-law has a sizable portfolio. 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 non-touchable.

In addition to addressing the long-term financial needs of their children with disabilities, parents and guardians were also concerned about how, or if, they would be able to plan for the financial needs of their other children (for example, paying for college). It was important to parents that their other children not be financially penalized because of one child’s disabilities. Respondents were less focused on saving for their own retirement, because they felt doing so was simply not possible.

I don’t have a plan for me, I plan for her. I am going to live as long as I live and whatever I leave, she gets.

Involvement with School Districts. Many parents viewed their local school district as the place at which their children’s educational needs were addressed, they obtained information on community resources, and they had opportunities to interact with other parents in similar circumstances. Many participants considered school their children’s bridge to the outside world. The quality of special-needs education in specific districts even dictated where families chose to live—or not live.

We left [the previous] district and moved to a different district intentionally. [The new district] had a superintendent who was very proactive in working with children with special needs.

Parents expressed a desire for schools to play a significant role, not just in delivering special-education services, but also in serving as a community-based resource to provide education to families on a wide variety of topics.

There doesn’t seem to be any real centralized place where you can go to 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.

Parents also expressed an interest in having SSA and Medicaid staff members participate in school trainings.

Understanding Rules and Regulations. Most parents and guardians had a basic understanding of the rules and regulations governing SSA and Medicaid programs. However, uncertainty arose when policy changes were implemented or in regard to specific issues concerning individual benefits or coverage. Parents relied most heavily on local school districts and informal parent networks to decipher rules and regulations or understand policy changes.

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...or my son’s school case manager.

Participants were aware of the SSA website; however, it was not one of their primary sources of information. Parents looked more to local school districts to help clarify and validate information.

**Implications**

One overarching finding was that individuals and families must navigate a complex network of programs and organizations that offer financial and other types of support for people with disabilities. The ability to navigate federal, state, local, and school district networks is crucial.

_I would love to have...a Cliff Notes on special needs...just because I think all of us are spending so much time trying to make those connections._

Participants depended on community agency employees to navigate and advocate on their behalf. Respondents expressed significant concern that many of the programs they depend on for support services are facing significant budget cuts.

Findings reveal that the majority of participants are under considerable stress as a result of trying to address current and future financial needs, remain in compliance with Social Security rules and regulations, and address other family and personal needs. Respondents repeatedly emphasized the need to obtain accurate, up-to-date information. Medicare and Medicaid coverage was as vital as—if not more important than—monthly cash benefits. Participants indicated that without Medicare or Medicaid coverage, individuals and families would be unable to access health care without facing financial ruin.

_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 system._

In general, participants had favorable experiences when they contacted SSA staff; however some feared their files would be ‘red-flagged’ as a result of such contact. Participants did report difficulties navigating the SSA website and understanding printed materials, including letters, distributed by SSA.

**Acknowledgments**

The authors are grateful for feedback from discussants and participants at the CFS FLRC Workshop held on August 24, 2010, in Madison, Wisconsin. We also wish to acknowledge the review provided by Christopher Herbert of Harvard University. Hanif Nu’Man and Emily Ley of the University of Wisconsin-Madison helped in the development of the literature review and Elizabeth Copson of Abt Associates Inc. helped with the subject research. Katherine Anne Dahlem served as the facilitator for all focus groups. Finally, we thank the Waisman Center and the State of Iowa Work Incentive Planning and Assistance Office and the 48 focus group participants and their family members who so generously shared their time and insights.

The research reported herein was performed pursuant to a grant from the U.S. Social Security Administration (SSA) funded as part of the Financial Literacy Research Consortium. The
opinions and conclusions expressed are solely those of the author(s) and do not represent the opinions or policy of SSA, any agency of the Federal Government, or the Center for Financial Security at the University of Wisconsin-Madison.

The Financial Literacy Research Consortium
The Financial Literacy Research Consortium (FLRC) consists of three multidisciplinary research centers nationally supported by the Social Security Administration. The goal of this research is to develop innovative programs to help Americans plan for a secure retirement. The Center for Financial Security is one of three FLRC centers and focused on saving and credit management strategies at all stages of the life cycle, especially helping low and moderate income populations successfully plan and save for retirement and other life events, including the use of Social Security's programs.

The Center for Financial Security
The Center for Financial Security at the University of Wisconsin-Madison conducts applied research, develops programs and evaluates strategies that help policymakers and practitioners to engage vulnerable populations in efforts which build financial capacity. The CFS engages researchers and graduate students through inter-disciplinary partnerships with the goal of identifying the role of products, policies, advice and information on overcoming personal financial challenges.

For More Information:
Center for Financial Security
University of Wisconsin-Madison
Sterling Hall Mailroom B605
475 N Charter St.
Madison, WI 53706
(608) 262-6766
http://www.cfs.wisc.edu/

© CFS Research Brief, Center for Financial Security, copyright 2010 by the Regents of the University of Wisconsin. All rights reserved.