

Financial and Future Planning for Siblings with Special Needs and Disabilities

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Introduction

This report describes the findings from two focus groups and other research on how families address financial and future planning for adult family members with special needs or disabilities. Findings focus on families' experiences with future and financial planning for a sibling's long-term needs; options for guardianships; understanding Social Security benefits, estate planning, and special needs trusts; and impacts on other family members. The report also includes program descriptions and contact information for organizations and agencies that provide support and information for families with adult siblings with special needs or disabilities.

Focus Group Findings

Abt Associates Inc., under subcontract with the University of Wisconsin's Financial Literacy Research Consortium, conducted two focus groups with individuals who had a sibling with special needs or disabilities. Focus groups were held at the Seattle location of The Arc of King County, Washington, one of the oldest community-based organizations in the United States providing support and resources for individuals with disabilities and their families. The Family Support Program at The Arc of King County facilitates individual support groups that target fathers and multi-cultural population groups, such as East African families, Southeast Asian families, and Hispanic families. The Arc of King County helped recruit participants through flyers and information on its website. Information was also sent to case managers at state and local agencies that work with families of adults with disabilities and two sibling support groups, the Sibling Support Project and LifeSPAN.

Although there was a low turn-out for the focus groups, it did provide the time to gather more in-depth information about how families are addressing

financial and future planning in very different family settings. Focus group discussions addressed three primary topics:

1. how families gather information about financial and future planning,
2. how families make decisions about future needs, and
3. how well families understand the rules and regulations governing benefits.

Overall, focus group participants were well versed about where to gather information about financial and future planning; if their families had not yet begun to work with attorneys or financial planners, they had a fairly good sense of where to locate information.

Future and Financial Planning.

Overall, the focus group participants were well versed about where to gather information about financial and future planning; if their families had not yet begun to work with attorneys or financial planners, they had a fairly good sense of where to locate information. Most participants were aware of the resources available through the Social Security website (www.ssa.gov), but appeared to be less aware of services available through the State of Washington or King County. The website for the Special Needs Alliance, a group of attorneys experienced in disability and elderly law, was frequently referenced (www.specialneedsalliance.org). Participants also mentioned the local Arc website (www.arcofkingcounty.org) as a good source with helpful links.

With regard to future planning, immediate and long-term housing needs for the sibling with

disabilities appeared to be one of the biggest concerns. One participant had a clear understanding of her parents' financial planning intentions for her sibling and future housing needs; however, she noted that her parents made these decisions on behalf of her sibling and did not seek any input from their children about their decisions. A second participant indicated that his parents had informed all the siblings that they planned to will their estate to a special needs trust or pool trust to care for their child with disabilities.

Decision Making.

The focus group discussion revealed differences in the decision-making process between families who were recent immigrants to the United States and the other participants. Those from immigrant families indicated that because of cultural norms, all family members were expected to help the sibling with disabilities.

The focus group discussion revealed differences in the decision-making process between families who were recent immigrants to the United States and non-immigrant families.

Non-immigrant participants indicated that although they were aware of the decisions that needed to be made, they were uncomfortable approaching their parents about provisions in their will or other estate planning matters, or talking about money in their families. One participant suggested that it would be helpful to have an "uninterested third party" available to initiate and facilitate discussions. Respondents also noted that written materials about how to engage their parents in planning discussions would be helpful.

Rules and Regulations.

The majority of participants indicated that they understood the rules and regulations related to SSI benefits and eligibility; however, there was some confusion about what items were not included in countable resources and what type of cash assistance could be considered as exceeding SSI's limit for countable resources. Despite this confusion, participants were familiar with the SSA website and did not mention any issues with navigating the website to get the information needed.

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Participants also seemed to understand how special needs trusts could be established for the care of an individual with disabilities, but there was less clarity about the potential impact of inheritance taxes on a sibling if all the resources were left to one sibling with the expectation that they would be a long-term caregiver. The participants referenced the websites for the Special Needs Alliance and Lolo Publishing (www.lolo.com) as good sources of information about legal issues related to disabilities. The participants also appeared knowledgeable about the legal process to establish guardianships and were complimentary about local programs that provided extensive training and certifications for potential guardians. The majority were also knowledgeable about "powers of attorney" and "designate payees" as future options to handle their sibling's finances.

Overarching Themes

The experiences of the members of this small but diverse focus group revealed three primary conclusions. First, information about financial and future planning for family members with disabilities and special needs is available through multiple resources, including government agencies, community-based organizations, support groups, websites, publications, workshops, trainings, and professional organizations. People either had the information they needed, or knew someone that could point them in the right direction. Their lingering questions concerned how to use the information they received within their families.

The experiences of focus group members led to three primary conclusions:

1. *information about financial and future planning is available from multiple sources;*
 2. *participants desired more guidance about how to engage families in discussions about planning; and*
 3. *cultural traditions and beliefs influence the planning needs of families.*
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Second, participants desired more guidance about how to engage families, especially parents, in discussions about financial and future planning. Siblings noted that they wanted to encourage their parents to revisit decisions that may have been made many years ago, and encourage their parents to consider the interests of their sibling as well as his/her abilities to make

decisions about the future.

The third theme was the importance of considering cultural traditions and beliefs when addressing the financial and future planning needs of family members of individuals with disabilities. Cultural traditions may lead families to take differing approaches to the planning process.

Implications and Resources

The focus group discussions showed that although the process of planning for siblings with disabilities or special needs varies from family to family, there are some common aspects. First, the abilities, needs, and interests of the sibling with special needs or disabilities need to be taken into consideration. Some advocacy groups encourage families to think of the process as

person-centered planning and therefore focus more on the person with disabilities than the systems that impact his/her life.

Families that have not begun to plan appear to need some motivation to initiate the process and keep all family members aware of decisions.

Second, there is a desire for the entire family to be involved in planning, and for siblings to have open discussions about their roles and responsibilities. Finally, families that have not begun the process of financial and future planning appear to need some motivation to initiate the planning process and keep all family members aware of decisions.

Sources of Information about Financial and Future Planning and SSI Benefits for Siblings with Special Needs and Disabilities

Federal Government:

U.S. Social Security Administration. Main website: <http://www.ssa.gov>

U.S. Social Security Administration. Social Security Handbook. Updated April 2012. http://www.socialsecurity.gov/OP_Home/handbook/. Chapter 21 of the handbook addresses Supplemental Security Income.

U.S. Social Security Administration. "Supplemental Security Income: Understanding Supplemental Security Income." 2012 Edition. Website: <http://www.ssa.gov/ssi/text-eligibility-ussi.htm>

U.S. Social Security Administration. *Social Security: Supplemental Security Income (SSI)*. www.ssa.gov/pubs/11000.pdf

U.S. Social Security Administration. *What You Need to Know When You Get Supplemental Security Income (SSI)*. Publication No.05-11011. <http://www.ssa.gov/pubs/11011.html>

Sibling Support:

The Arc of the United States – national organization: The ARC has more than 700 state and local chapters nationwide, as well as a National Sibling Council. The Arc's national website is: www.arc.org.

The Arc of King County, Washington: This chapter's website is: www.arcofkingcounty.org. There are special support groups for fathers and multi-cultural groups targeting Vietnamese, Hispanic, and East African families.

The Sibling Leadership Network: The Sibling Leadership Network has affiliate networks in many states. The network's website is: www.siblingleadership.org.

Sibling Support Project: The group's website is: <http://www.siblingwupport.org>.

SibNet. People can subscribe to SibNet on Yahoo at groups.yahoo.com or join the group on Facebook at <https://www.facebook.com/groups/SibNet/?fref=ts>

Legal Resources:

Special Needs Alliance: SNA currently has members in 47 states. Its website is <http://www.specialneedsalliance.org>

The Lolo Network: Main website: www.lolo.com. Lolo's website has a section dedicated to disability law at <http://www.nolo.com/legal-encyclopedia/disability-law>.

Guardianships:

National Guardianship Association, Inc. Website: <http://www.guardship.org>. Information on state affiliates is available at http://www.guardianship.org/state_affiliates.htm.

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