Center for Financial Security Family Financial Security Webinar Series

November 13, 2012

Financial and Future Planning for Siblings with Special Needs and Disabilities

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Financial and Future Planning for Siblings with Special Needs and Disabilities

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Prepared for: Center for Financial Security

Family Financial Security Webinar Series
November 13, 2012
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The opinions and conclusions expressed are solely those of the author(s) and do not represent the opinions or policy of SSA or any agency of the Federal Government or of the University of Wisconsin System, including the Center for Financial Security.
• Abt Associates is a mission-driven, global leader in research and program implementation in the fields of health, social and environmental policy, and international development. Known for its rigorous approach to solving complex challenges, Abt Associates was ranked as one of the top 20 global research firms in 2011 and also named one of the top 40 international development innovators. The company has multiple offices in the U.S. and program offices in nearly 40 countries.
Research Focus Groups

• Focus groups held in 2010 with parents of children, 16-21 years old, who were receiving Child SSI/Medicaid (Wisconsin and Iowa)

• Focus Groups held in 2012 about financial and future planning for siblings with special needs and disabilities (Washington)
2010 Focus Group Findings

• Parents were frequently unaware of what their long-term financial or legal options were.

• Parents did not know how or where to access financial planning or legal services in their community.

• Parents were concerned about the costs of financial planning and legal services.

• Parents were very concerned about the impact on other children in the family and what their role would be caring for their sibling when the parents were no longer able to do so.
Sibling-Related Research

• Interviews with non-profit organizations, advocacy groups, sibling support groups, individuals with disabilities, financial/legal planners
• Literature review
• Focus groups in Seattle, Washington held at The Arc of King County
Planning for the Future

• The Team: financial planners, attorneys
• The Trust: special needs trust, pool trust
• The Estate Plan: responsibilities for care and money
• The Benefits: eligibility, maintain

“Assuring Care of a Family Members with Special Needs”
by Ron Lieber
The New York Times
October 5, 2012
Planning for the Future

“Proper planning can be the difference between children becoming homeless or thriving once their parents are gone.”

“Making Sure the Kids Are All Right”
by Veronica Dagher
The Wall Street Journal
March 14, 2011
Planning for the Future

• Future and Financial Planning by the Family
  – Interests and abilities of family member with disabilities/special needs; guardianships; payees; wills/estate planning; special needs and pool trusts; care (future) plan; housing; support networks; changing circumstances

• Qualifying for and Maintaining Government Benefits
  – SSI, Medicaid, state-funded programs, subsidized housing
Core Research Questions

1. How do families gather and analyze information about financial and future planning?
2. How do families make decisions about future needs? How are siblings involved in these decisions?
3. How well do siblings understand rules and regulations governing benefits?
4. What are some of the obstacles to future and financial planning?
General Findings

• Siblings gathered information from a variety of sources – workshops, support groups, community-based organizations, Internet. People indicated they spent a lot of time on research.

• Financial and future planning decisions had primarily been made by the parents with limited input from other family members.

• Siblings demonstrated a good understanding about SSA rules and regulations and indicated they were able to easily access information on SSA’s website – www.ssa.gov.

• Siblings had more difficulty understanding where to get information from state agencies that oversee Medicaid and other state-funded supportive services. Concern about getting accurate information on asset limits for Medicaid and other services available.

• Major frustration: Engagement with parents!
Overarching Themes

1. Information about Financial and Future Planning
   - Available through multiple sources – government agencies, service providers, advocacy groups, websites, publications, parent and sibling support groups, trainings, workshops, professional groups (e.g., Academy of Special Needs Planners, Special Needs Alliance).
   - For Medicaid, important to look at individual state rules and regulations. In some states, receiving Medicaid also made an individual eligible for other services such as transportation, job training, recreational programs.
   - Question: how to take the information available and apply it to their needs.
     “I have all the information; I’m just not sure how to use it.”
     Washington focus group participant
Overarching Themes

2. Engaging Families in Planning Discussions

• The most challenging issues
  • Sibling is not receiving any eligible benefits (SSI, Medicaid) because parents have been paying all expenses
  • Parents do not have a will, have not made any financial decisions, or received inadequate financial/legal advice
  • Parents have not shared their intentions with family members
  • Decisions were made without involving the family member with disabilities/special needs
  • Decisions were made without consulting siblings impacted – e.g., guardianship, trustee, living arrangements
  • Decisions were made many years ago and have not been revisited when siblings became adults or when parents’ own health and care needs changed
2. Engaging Families in Planning Discussions

• Support Needed
  • Groups such as The Arc, parent advocacy groups, are helpful to start planning efforts
  • Interest in “facilitators” who are not selling a product/service to bring families together to start the planning process in a neutral environment
  • Interest in seeing a check list developed for financial and future planning that would be distributed by Social Security, schools, community organizations, sibling groups, professional groups
  • Encourage parents to be motivated and start planning early
Overarching Themes

3. Importance of Cultural Traditions and Beliefs
   - Cultural traditions may lead families to take differing approaches to financial and future planning
   - The Arc of King County’s (Washington) Family Support Program facilitates multi-cultural support groups for East African families, Southeast Asian families, and Hispanic families
Implications

• Abilities, needs, and interests of the sibling with disabilities/special needs must be taken into consideration. A person-centered planning approach focusing on the person rather than the systems that impact his/her life.

• A desire for the entire family to be involved in planning and implementation of the care and estate plans.
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Director of Asset Opportunities Unit
Sargent Shriver National Center on Poverty Law
Assets Building and the Disability Community
Shriver Center

The Sargent Shriver National Center on Poverty Law
A national law and policy center that provides national leadership in identifying, developing and supporting innovative and collaborative approaches to achieve social and economic justice for low-income people.

Community Investment Unit
Takes action against poverty by advocating for policies that expand asset-building opportunities for all.

www.povertylaw.org
Income Poverty

Official U.S. Poverty Level in 2010

46.2 Million
15.1%
52 years

Supplemental Poverty Level in 2010

49.1 Million
16%
Households with a disability make on average $25,550 per year versus an average of $58,736 per year for households without a disability.
Income Poverty v. Asset Poverty

Asset poverty focuses on total household wealth, rather than just income.

“Asset poor” household does not have enough assets to meet its expenses for 3 months if no outside sources of income.

1 in 6 U.S. families are income poor.

1 in 5 U.S. families are asset poor.

1/3 of U.S. households have zero or negative assets.

80% of households with a disability have zero or negative assets.
“The relevance of disability in the understanding of deprivation in the world is often underestimated ....”

Amartya Sen, Winner of 1998 Nobel Prize in Economics, former honorary president of Oxfam
Existing Barriers

General lack of banking experience and knowledge of the financial industry

Lack of access to banking locations and/or banking facilities

Policy barriers
Asset Limit Rules

AABD - $2,000 per individual, $3,000 per couple

GA - $2,000 per individual, $3,000 per couple

SSI - $2,000 per individual, $3,000 per couple

TANF - $2,000 per individual, $3,000 per couple

SNAP – NO asset limits for categorically eligible households

SSDI – NONE
Asset Limit Reforms

States have authority, whether by legislation or administrative rule, to eliminate asset tests and/or increase the amount allowed in TANF and Medicaid and, with USDA approval, SNAP
# Asset Limit Reforms

<table>
<thead>
<tr>
<th>Asset Limit</th>
<th>TANF</th>
<th>Medicaid</th>
<th>SNAP</th>
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<tbody>
<tr>
<td>$2,000 to $3,000 in most states</td>
<td>$1,000-$30,000 in states that have limits</td>
<td>$2,000 ($3,250 if disabled or elderly household member) - $25,000 in states that have limits</td>
<td></td>
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## What States Have Done

<table>
<thead>
<tr>
<th>TANF</th>
<th>Medicaid</th>
<th>SNAP</th>
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<tbody>
<tr>
<td><strong>Eliminate limits entirely</strong>, as 6 states have done</td>
<td><strong>Eliminate limits entirely</strong>, as 24 states have done and all states must do by 2014</td>
<td><strong>Eliminate limits entirely</strong>, as 36 states have done</td>
</tr>
<tr>
<td><strong>Substantially increase limits</strong> so they do not affect most recipients</td>
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<td><strong>Exclude classes of assets</strong>, such as individual development, retirement or college savings accounts</td>
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Asset Limit Reform

• H.R. 3172: Freedom To Save Act of 2007
  – Eliminates asset tests for SSI, SHIP, and TANF; raises Food Stamp asset limit to $6,000 and exempts all vehicles.

• H.R. 4937: SSI Savers Act of 2011
  – Increase limits on countable resources to $5,000 for individuals and $7,500 for couples and index these limits to inflation.
  – Exclude any assets (up to $10,000 for individuals and $15,000 for couples) included in a qualified retirement plan, trust, education savings account, savings bond, or individual.
Federal Legislative Initiatives

H.R. 3423 & S. 1872: Achieving a Better Life Experience Act (ABLE Act)

- One tax exempt account per SSI beneficiary up to $500,000
- Allowable expenses include:
  - Preschool & postsecondary education, including tutoring, special education services and training;
  - Employment supports;
  - Personal assistance and community-based supports;
  - Respite care;
  - Assistive technology, home modifications and transportation vehicle purchases or modifications;
  - Out-of-pocket medical, vision, or dental expenses and insurance premiums; and
  - Habilitation and rehabilitation services.
ABLE Accounts vs. Special Needs Trust Funds

- Beneficiary can be trustee (also family members, financial institutions, and other qualified 3rd parties)
- Contributions up to $2,000 per year per individual are tax deductible (similar to 529 College Savings Accounts - not refundable)
- Contributions can be made by anyone - including the beneficiary (does not count as ‘earned income’ by SSI)
- No contributions can be made after beneficiary turns 65
- Can pay for Housing - including rent & mortgage
Programs and Initiatives

Presentations and Trainings

City of Chicago’s Mayor’s Office on Disabilities
Disability Rights Consortium
Washington State Treasurer’s Office

Free Financial Planning Sessions
Resources

• **Shriver Center Webinars**
  – Asset Building in the Disability Community

• **Shriver Center Presentations**
  – Disability Rights Consortium Presentation
    http://www.illinoisprobono.org/index.cfm?fuseaction=home.dsp_content&contentID=7142

• **Clearinghouse Review Law Review Article**
  – *Accessible Assets: Bringing Together the Disability and Asset-Building Communities*

• **Join SSI Savers Act Coalition**
  – CFED Advocacy
Questions

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Discussant

Johnette T. Hartnett, Ed.D.
Director Strategic Partnerships & Research
National Disability Institute
MAKE DISABILITY THINKING, AWARENESS AND INCLUSION A NATURAL PART OF THE FINANCIAL INDEPENDENCE CONVERSATION

DR. JOHNNETTE HARTNETT
WASHINGTON, DC
NOVEMBER 13, 2012
The Nation’s proper goals regarding individuals with disabilities are to assure equality of opportunity, full participation, independent living, and economic self-sufficiency for individuals with disabilities.

National Disability Institute

MISSION

Build a better economic future for Americans with disabilities

Founded 2002
Non-Profit Status 2006

OBJECTIVES

Increase economic and employment opportunities for people with disabilities through education and training as national technical assistance lead with Department of Labor nationwide.

Expand access to economic mainstream (tax and financial education) for low- to moderate-income people with disabilities through the Real Economic Impact Tour in 100 cities touching over 500,000 annually.

Modernize disability public policy through congressional education, briefings and national advocacy.

Build strategic partnerships that leverage opportunities that empower community inclusion, employment and promote disability inclusive practices and services with over 900 community-based partners and 40 national organizations in the private and public sectors and corporate affinity groups.

Contribute to growing awareness of the economic and employment needs of people with disabilities through research and public policy.
New Reality for People with Disabilities

Growing Poverty Not Prosperity

- 54 million Americans report disability
- 18 million children in poverty
- 2 to 5 times more likely to experience poverty (She & Livermore, 2009)
- 28% or nearly one in three live in poverty nearly double the national poverty rate (U.S. Census, 2010)
- Over half people that report income poverty report disability (Fermstad, 2009)
- Pay higher out of pocket health expenditures $795 vs $256 (Livermore & Hill, 2002)
- 18 million taxpayers said they would use free tax services if they were available (IRS 2011)

Growing Poverty Not Prosperity

- 58% report struggling to get by, going into debt each month, living paycheck to paycheck compared to 34% of people without disabilities (Harris Poll 2010)
- 61% increase homelessness since December 2007
- 50 million people on Medicaid in any given month
- 80 million taxpayers $57,000 AGI or less
- 46 million on food stamps
- 40% of people accessing food pantries, shelters and kitchens report receiving SSI, SSA, or SSDI (Feed America, 2011)
PROFILE AND GAPS
Taxpayers with Disabilities

FINANCES

- 54% earn < $20,000 compared to 35% without disabilities (AGI Adjusted Gross Income)*
- 22% earn > $40,000 compared to 42% without disabilities*
- 35% employed full time compared to 66% without disabilities*
- 46% unemployed or on disability compared to 13% without disabilities*
- 30% of taxpayers with disabilities using free tax preparation reported using a checking account compared to 66% without disabilities (Ford Study 2006)

*IRS Benchmark Study: 2007/2010

DISABILITY PROFILES

- Rates vary with age and ethnicity – 52% of people over 65 have a disability
- 6% use wheelchair or ambulatory aid
- 6.5 % sensory disabilities
- 7% difficulty with cognitive, mental, or emotional functioning.
- 11% of individuals enrolled in higher education
- Many disabilities non-visible

State Disability Profiles:
www.cornelldisabilitystatistics.org
U.S. Disability Demographics

Demographics
- 54 million people
- 22 million families

Employment
- 22.0 million working age
- 7.6 million employed
- 15.8% unemployed

Geography
- 15% in the Northeast
- 31% in the South
- 28% Midwest
- 16% West

Profiles

Ethnicity
- 12.7% White
- 17.5% Black/AA
- 21.7% Native American
- 6.3% Asian/Pacific Rim
- 11.9% Other - 10.2%

U.S. Census 2009 Data

Voting Numbers

<table>
<thead>
<tr>
<th>% of Population</th>
<th>% Voting</th>
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<tbody>
<tr>
<td>Seniors 8 – 9%</td>
<td>80%</td>
</tr>
<tr>
<td>Labor Unions 8-9%</td>
<td>85%</td>
</tr>
<tr>
<td>African Americans 12.14%</td>
<td>70%</td>
</tr>
<tr>
<td>Latino 14%</td>
<td>70%</td>
</tr>
<tr>
<td>Veterans 10%</td>
<td>70%</td>
</tr>
<tr>
<td>Disability 20%</td>
<td>35%</td>
</tr>
</tbody>
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2012 NISH Conference Data
Financial Wellness Survey 2012*

Financial Wellness Survey of 3,011 People Living with Multiple Sclerosis (MS)*

Accounts and Investments
- 94% checking account
- Four in ten no savings account, money market account or CD
- Less than half invest in a 401(k) or IRS
- 26% investments in stocks, bonds, mutual funds or other securities

Use/Knowledge Financial Stability Programs
- 25.9% aware/or used Earned Income Tax Credit
- 0.9% aware/or used IDA
- 0.5% family Self-Sufficiency Program
- 1.2% Plan for Achieving Self Support
- 73.7% not of aware/or used any of these programs

Trusted Contacts for Financial Advice
- 11% Use a financial planner
- 7.9% Use an Accountant
- 29.4% Use a Family Member
- 1.8% Use a Clergy Person
- 4.3% Use a Doctor
- 13.5% Use Online Research
- 2.6% TV personalities (Suzie Orman)
- 26.7% No One

*National Disability Institute & Multiple Sclerosis Association of America Report on Findings from NDI & MSAA's Online Survey and Focus Groups (August 2012)
TECHNOLOGY USE AND DISABILITY

- 2% of people have a disability/illness that makes it harder or impossible to use the internet
- 39% of Americans without broadband access living with a disability
- 54% use the internet compared to 81% without a disability
- 10% use tax prep software compared to 20% with no disability
- IRS W & I Research recommended IRS and other agencies partner with tax prep software companies to ensure software is disability compatible and accessible

Pew Internet & American Life Project January 2011
Self-Sufficiency Investment Model*

Cyclical Dependency Model – The Past

- **Education** - Segregated; out-of-home district; not on diploma tract
- **Transition** – Lowest expectations; lack career counseling
- **Employment** – Presumption of not employable; subminimum wages; little skill development
- **Housing**; Institutional or congregate living; little choice allowed
- **Financial Planning** – Asset limits not revised since 1985 remains at $2000; few savings accounts that are tax advantaged or exempt from asset limits

**RESULTS:** Chronic impoverishment, cyclical dependency loss of human dignity across the lifespan.

Self-Sufficiency Model – 21st Century

- **Education** – Full inclusion; community integration; exposure to general education; access to same extracurricular activities
- **Transition** – Need presumption of employability; begin transition planning age 14 – begin financial planning much earlier
- **Employment** – presumed eligibility to employment supports via VR, American Job Centers and other programs; integrated employment; access to skills training
- **Housing** – in integrated setting; ongoing personal support; focus investment on individual - not programs
- **Financial Planning** – Individual budgets; increase asset limits; access to community programs

**RESULTS:** Optimal self-sufficiency, independent living, economic empowerment and full community participation across the lifespan.

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* Serena Lowe, September 2011, Federal Reserve Bank of Boston, REI Tour Mayor’s Academy
Disability Spending
Federal and State

TOTAL SPENDING
- $429 Billion spending on Federal/State disability programs
- 30% growth 2002 to 2008
- $71.19 Billion spending on State expenditures for working-age pwd 2008

EXPENDITURE CATEGORIES
- 40.8% Income Maintenance
- 54.9% Health Care
- 2.7% Housing and Food Assistance
- 1.2% Education, Training and Employment
- 0.6% Other Services

Mathematica Policy Research Center for Studying Disability Policy
September 2011, Number 11-03
Building a Roadmap Out of Poverty

GOAL

Collaborate with community groups, public entities and businesses to make disability thinking, awareness and inclusion a national part of the financial independence conversation.

www.realeconomicimpact.org
NDI’s Financial/Tax/Technology Work

- **DeafTAX**: Use Video Relay Services and Internet to provide deaf on deaf remote filing nationally.

- **Virtual VITA**: Piloted/tested remote filing in FL – rural taxpayers use remote intake site and talk over computer to preparer in another location.

- **TaxAccess**: Work with Southeast ADA Center (previously known as Disability Business Technical Assistance Centers DBTAC) to build online technical assistance to help community organizations serving taxpayers with disabilities receive real-time information on access issues.

- **Social Media/Communications**: Provided nine states with radio reading service ads specific to economic empowerment, tax filing. Re-purposed ads for YouTube with pictures and captioning. My Free Taxes/Walmart Campaign.

- **Used Twitter campaign** with 100 approved tweets for free and self-assisted tax preparation, food stamps, available for communities to download and use. Provide social media education to cities on how to use tools to push out information and work (Facebook, Twitter, Blogs, YouTube). MyFree Taxes/Walmart

- **Webinars**: Educational Webinars that are open and free to the country on issues of economic empowerment and disability. NDI 2013 series forthcoming. December 13, 2012 - 2 pm EST – Highlights of My Free Taxes playbook for 2013; First of 9 part series on the upcoming 2013 tax season –

- **Virtual Toolkits and Online Learning**: Holding virtual meetings nationally and distributing new tools.
NDI’s Economic Empowerment Strategies
2005 - Present

- **Created** a national movement of public/private partnerships with the IRS and DOL to build disability inclusive free and self-assisted tax preparation. Increased number of taxpayers with disabilities from 6 to 14%.
- **Established** relationships with mainstream antipoverty programs and public benefit information across government, states and private sector to build disability capacity and services. Not stand-alone programs but inclusive.
- **Accomplished** effective development of local cross/agency/non-disability community partners workgroups;
- **Pioneered** use of technology (Video Relay Services VRS), Virtual VITA and social media for people with disabilities.
- **Influenced** federal legislation and regulations to be more inclusive of people with disabilities (Congressional VITA grant; IRS Virtual Regulations, etc.)
- **Customized** existing financial education curriculum for people with disabilities.
- **Developed** new national federal partners for disability with IRS, Federal Reserve Bank, FDIC and 40 other national groups.
Path to Prosperity

**Path to Prosperity**
- Transition Planning
  - School to Work
  - Post High School Education
- Coaching/Education
  - Finances
  - Housing
  - Benefits Planning
  - Healthcare
  - Tax Filing
  - Savings
- Employment
  - Job Coach
  - Mentoring
  - Internships
  - Job Shadowing
- Community Involvement
  - Volunteer
  - Board Service
  - Advocacy
  - Social Integration
New Paradigm for State Prosperity Systems Change


Governor Led Economic Empowerment Initiative

Stand By Me Delaware

DIVERSE PARTNERS SHARE ONE MISSION

Non-Profits

National Partners

Faith Based

K-12

Employers

State/Local/County/Government

Higher Education

Veterans Disability Seniors

Coaching/Financial Inclusion:
Across the Lifespan – Free – Individual – Employer/Market Based
Together. No Matter. We're Here.
Moving Forward:
Financial Capability Strategies

- Forwarding Public Policy – Advocates for systems change at the federal, state and local level affecting economic self-sufficiency and independence of people with disabilities – ABLE Act
- Creating more synergies across diverse organizations public and private – 2013 Workforce Systems
- Financial Coaching and Education programs – Importance of budgets, credit counseling, savings and planning
- Teaching people to file their own taxes – MyFreeTaxes
- Research on the financial needs of Americans with disabilities ($1 billion in tax credits still unclaimed)
- Research on barriers to financial services and products - example assistive technology needs
- Creating more knowledge about use and availability of public benefits – Financial Wellness Survey
NDI Reports & Resources

- For more information, visit National Disability Institute’s website: [www.realeconomicimpact.org](http://www.realeconomicimpact.org)

- Under “Resources”, scroll down to “Document Library.”
  Under “Reports & Publications”, click ‘View More’
  - NDI’s Real Economic Impact (REI) Tour Reports
  - Financial Wellness Among Individuals Living with Multiple Sclerosis (MS) (2012)
  - 2010 Taxpayers with Disabilities Benchmark Study (IRS)
  - Characteristics of Disabled Taxpayers Ages 18 to 59 (2007) (IRS)
National Disability Institute

Become part of a national movement that is modernizing 21st century disability programs and policy with the singular goal of creating a better economic future for Americans with disabilities.

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Washington, DC 20006
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1-202-296-2043
Q&A
Save the Date:

December Webinar
Tuesday, December 11, 2012
1pm-2pm Central

Household Debt
Lonnie Berger
UW-Madison School of Social Work

cfs.wisc.edu/webinars