Future Financial Planning for People with Disabilities

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A recording of the webinar and slides will be provided by email after the webinar.
Results of a National Study about Future Financial Planning for People with Disabilities

What’s Working and What’s Not

Generously supported by the May and Stanley Smith Charitable Trust
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University of Delaware

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Co-Director
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University of Delaware
Research Aim

Who **is or is not engaging** in future financial planning, if there are differences related to demographic, individual, or regional characteristics

How people are **saving (or planning to save)** for their futures

What **helps or hinders** people with disabilities and families with future financial planning

Why people **do or do not engage** in future financial planning

When people with disabilities do and should **start** future financial planning

What people feel about **the abilities of people with disabilities to engage** in their finances and the financial planning process
### Interviews
With 40 people who have experience and expertise related to future financial planning.

### Survey Development
Informed by interviews and nationally disseminated.

### Survey
Pilot survey with 30 experts before sending out to national organizations.

### Expert Meetings
Two meetings with 25 experts to discuss findings and give recommendations.

### Final Analysis
Data from 5,252 survey respondents analyzed.

<table>
<thead>
<tr>
<th>Summer 2020</th>
<th>Fall 2020</th>
<th>Winter 2021</th>
<th>Spring 2021</th>
<th>Summer 2021</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Interviews</strong></td>
<td><strong>Survey Development</strong></td>
<td><strong>Survey</strong></td>
<td><strong>Expert Meetings</strong></td>
<td><strong>Final Analysis</strong></td>
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<td>With 40 people who have experience and expertise related to future financial planning</td>
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<td>Data from 5,252 survey respondents analyzed</td>
</tr>
</tbody>
</table>
Interview Results

Barriers to Future Financial Planning for People with Disabilities

Societal Issues
- Need time and cultural shift
- Legacy of disability
- Poverty mindset
- Choice/control/self-direction movement
- No training
- Misinformation
- No follow up
- Specialty area
- Limited professionals

Family Issues
- Values
  - Who should be in control
  - How to use funds
  - Vision for future
  - About saving
  - About the best way to save
- Context
  - No knowledge
  - No time
  - No money
  - Individual capacity for understanding
  - Vulnerable population
  - Starting too late
  - No access to professionals or help
  - No family to help
- Variation in mindset, values, and context of family members who are involved can lead to family conflict

Professional Issues
- Legal and financial
  - No vision/future planning beyond finances
  - Lack of training/involvement of person with disability or family members
  - Misunderstanding of disability benefits
  - Business vs. individual interests
  - Use of jargon
  - Cost of process
  - Diversity of disabilities population
- Systemic Issues
  - Outdated, limiting or confusing policy
  - Too long to change policy
  - Professionals lack knowledge of disability benefits/eligibility
  - Employment complications
  - Benefits complications
  - Proof of disability
- Government
  - No consensus about whose responsibility it is to start the process or when it should be initiated
  - Not enough coordination between the systems
- In the Field
  - Diversity of disabilities population
  - Not enough outreach or sharing of resources

The National Leaders Consortium
“People with intellectual and developmental disabilities are generally 90 to 98% dependent on some form of subsidy or services from the state and federal government and it is a complicated system to manage. There are so many financial implications as it relates to health care for Medicaid, health care for Medicare, access to housing vouchers, employment, and disability benefits. It is a complex myriad of financial, social services, and benefit planning questions that have to be coordinated because a decision a parent makes or a decision a person with a disability makes about one set of systems and rules are going to impact all the others.”

– Manager of a Pooled Trust
Web Based Survey
Up to 57 questions
• Multiple choice
• Rate on a scale of 0-10
• 3 Short Answer

Survey Themes
• Demographics (Survey Track)
• Future financial planning accounts and activity
• Financial literacy
• Point of Entry
• Challenges and Facilitators
• Values related to disabilities

Distributed Widely
• National Leadership Consortium Network; 19 partners; 50 DD Councils
### Research Focus

**Future financial planning** is taking steps to make sure you have the money and services you need in the future.

<table>
<thead>
<tr>
<th>Type</th>
</tr>
</thead>
<tbody>
<tr>
<td>ABLE Accounts</td>
</tr>
<tr>
<td>First Party Trust</td>
</tr>
<tr>
<td>Third Party Trust</td>
</tr>
<tr>
<td>Pooled Trust</td>
</tr>
<tr>
<td>Other savings accounts or plans</td>
</tr>
<tr>
<td>Participants</td>
</tr>
<tr>
<td>--------------------------------------------------</td>
</tr>
<tr>
<td>People with disabilities</td>
</tr>
<tr>
<td>Family members</td>
</tr>
<tr>
<td>Financial experts</td>
</tr>
<tr>
<td>Legal experts</td>
</tr>
<tr>
<td>Other experts</td>
</tr>
<tr>
<td>People who work supporting people with disabilities</td>
</tr>
</tbody>
</table>
Participants

- People with Disabilities: 1,817 (34.6%)
- Family Member or Guardian: 2,478 (47.2%)
- Disability Professionals: 691 (13.2%)
- Other Professionals: 229 (4.4%)
- Other: 0.7%

Total: 5,252
### Types of Accounts

<table>
<thead>
<tr>
<th>Type</th>
<th>Participants</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>ABLE Account</td>
<td>954</td>
<td>28%</td>
</tr>
<tr>
<td>First Party Trust</td>
<td>903</td>
<td>26%</td>
</tr>
<tr>
<td>Third Party Trust</td>
<td>557</td>
<td>16%</td>
</tr>
<tr>
<td>Other Savings in Person’s Name</td>
<td>500</td>
<td>14%</td>
</tr>
<tr>
<td>Pooled Trust</td>
<td>302</td>
<td>9%</td>
</tr>
<tr>
<td>Other Savings Not in Person’s Name</td>
<td>230</td>
<td>7%</td>
</tr>
</tbody>
</table>

### Race

- White: 73%
- Black: 10%
- Hispanic: 8%
- Asian: 2%
- Hawaiian or Other Pac Islander: 2%
- Am Indian or Alaska: 4%
- Nonbinary, other, or prefer not to answer: 1.3%

### Participants

- Man: 57%
- Woman: 42%
- Nonbinary, other, or prefer not to answer: 1.3%

### Age

- 18-34: 51.9%
- 35-54: 38.1%
- 55+: 10%
**Barriers To Future Financial Planning**

### People with Disabilities
- Don't Have Enough Money: 97
- Too Expensive: 84
- Afraid to Lose Benefits: 70
- Afraid Rules will Change: 70
- Don't Know Enough About Them: 63

### Family Members
- Afraid they would lose their benefits: 320
- Takes too much time: 282
- Don't think my money would be safe: 227
- Don't know enough about them: 211
- Too hard to set up: 199
<table>
<thead>
<tr>
<th>Barriers</th>
<th>Families</th>
<th>People with Disabilities</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>Families of people with disabilities do not plan and save money for themselves</td>
</tr>
<tr>
<td>Societal</td>
<td>141</td>
<td>Many people believe that people with disabilities can’t understand, manage, and save money</td>
</tr>
<tr>
<td>Legal</td>
<td>138</td>
<td>Rules and laws don’t let people with disabilities spend their money how they want</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Rules and laws don’t let people with disabilities save a lot of money and keep their services</td>
</tr>
<tr>
<td>People with Disabilities</td>
<td>123</td>
<td>People with disabilities do not have the help they need to plan and save their money</td>
</tr>
<tr>
<td>Societal</td>
<td>117</td>
<td>Many people believe that people with disabilities can’t direct their own lives</td>
</tr>
<tr>
<td>Legal</td>
<td>128</td>
<td>Rules and laws make it too hard for people to save their money in savings accounts (ABLE, Special Needs Trusts, etc.)</td>
</tr>
<tr>
<td>Families</td>
<td>127</td>
<td>Families who don’t have a lot of money do not think they can save their money</td>
</tr>
<tr>
<td>Societal</td>
<td>102</td>
<td>Many people believe that people with disabilities can’t understand, manage, and save money</td>
</tr>
</tbody>
</table>
“In our society we always find it easier to do everything *for* people with disabilities rather than doing it *with*.

– Person with IDD

“There’s not a lot of people who are talking about financial health and financial literacy directly to people with disabilities.”

– Leader of Service Provider Agency

“I have attorneys that I’ve worked with on my estate planning and I’m never sure I’ve gotten the right information. I keep wondering because I never know for sure.”

– Mother of a Person with IDD
To Keep Money Safe

- Family Member Set it Up: 603
- Professional Recommended: 419
- To Keep Money Safe: 386

Facilitators

To Future Financial Planning

- People with Disabilities
- Families
<table>
<thead>
<tr>
<th>Facilitators</th>
<th>Category</th>
<th>Description</th>
<th>Value</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>People with Disabilities</td>
<td>Clear Vision for Myself</td>
<td>341</td>
</tr>
<tr>
<td></td>
<td>Families</td>
<td>Clear Vision for My Family Member</td>
<td>198</td>
</tr>
<tr>
<td>2</td>
<td>People with Disabilities</td>
<td>Strong Family Support</td>
<td>267</td>
</tr>
<tr>
<td></td>
<td>Families</td>
<td>Went to a Training or Class</td>
<td>197</td>
</tr>
<tr>
<td>3</td>
<td>People with Disabilities</td>
<td>Support from Friends</td>
<td>232</td>
</tr>
<tr>
<td></td>
<td>Families</td>
<td>Strong Family Support</td>
<td>179</td>
</tr>
</tbody>
</table>
“A big thing is getting family advocacy groups, state agencies, and case managers to help families and individuals think about their lifespan and what their role in it is ... People have to keep active allies and advocates with a person all throughout their life so when somebody disappears, there are other people who know the case managers, who know all the people, and who can stay involved, otherwise things get lost in the chasm.”

– Leader of Disability Service Provider Agency
Recommendations

Education, Training, and Certification
Communication
Advocacy
A Guidance Organization
Resources
Ongoing Support and Services
Research
Recommendations

Overarching Recommendations

Communication and Advocacy
• Change policies that limit peoples’ ability to save
• Shift in perceptions and mindset

Resources
• Live and continually adapting virtual listserv, network, or community of practice
• Static one-stop virtual platform

An Organization or Structure for Oversight and Guidance
• Collect, vet, offer updated tools and resources
• Advocacy, policy recommendation, training, etc.
Recommendations

To Support People with Disabilities and Families

Education, Training, and Certification

- For people with disabilities and families: accessible financial literacy training, planning opportunities
- For disability service sector professionals: introducing people to financial literacy and planning, supporting people to control and manage their finances
- Included in person-centered planning, supported decision making, early education

Communication

- Targeted communication and campaigns: from many sources and media focused on the need for future financial planning, the rights of people with disabilities, and opportunities that exist
<table>
<thead>
<tr>
<th>Recommended Requirements</th>
<th>Professionals</th>
<th>Guardians</th>
<th>Families</th>
<th>People with Disabilities</th>
</tr>
</thead>
<tbody>
<tr>
<td>Complete One Training</td>
<td>85%</td>
<td>87%</td>
<td>87%</td>
<td>85%</td>
</tr>
<tr>
<td>Earn a Certificate, License, or Credential</td>
<td>70%</td>
<td>72%</td>
<td>69%</td>
<td>73%</td>
</tr>
<tr>
<td>Belong to a National Group</td>
<td>70%</td>
<td>73%</td>
<td>54%</td>
<td>73%</td>
</tr>
<tr>
<td>Complete Ongoing Training</td>
<td>76%</td>
<td>74%</td>
<td>51%</td>
<td>70%</td>
</tr>
</tbody>
</table>

The National Leadership Consortium
“Self-determination and the ability to have input and control over how your assets are allocated is something that is important to you, it's important to me, and there's no reason why it's also not important to a person with a disability. The major problem is we haven't given them the tools to help them be successful. If we're ever going to break the cycle of poverty that is rampant through the population of people with disabilities, there needs to be much bigger focus on financial planning. It's just combating the misinformation, making sure that they have the resources to access the services and supports, and dispelling the myth that it's going to ruin your services.”

-Legal director for a disability rights organization
Want More?

Look for more information in the White Paper
https://nlcdd.org/publications.html

Future work:
Impact of Covid-19 Pandemic on Future
Financial Planning for People with Disabilities
For Questions about the Project
Caitlin Bailey (cebailey@udel.edu)

For Questions about the Research
Cory Gilden (cgilden@udel.edu)
The Arc’s Videos on Financial Planning

- An Overview of Special Needs Trusts
- An Overview of ABLE Accounts
- Special Needs Trusts and ABLE Accounts: How Are They Different?
- Pooled Special Needs Trusts
- How Death Affects the Money Left in ABLE Accounts and Special Needs Trusts

[English Playlist] [Spanish Playlist]
Questions?