

Welcome!

Future Financial Planning for People with Disabilities

Participants are currently in **listen-only mode** and will remain in listen-only mode throughout the webinar.

You can turn on **closed captions** by clicking on the live transcript button, and then select show subtitles.

Please use the Chat Box to seek technical assistance and communicate with the host.

Please use Q&A to ask the presenter questions. We have reserved time at the end of the webinar for the presenter to answer questions. We will not be monitoring the Chat Box for questions, so please do not put your questions in the Chat Box.

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







Cory Gilden, PhD
Research and Evaluation Manager
National Leadership Consortium
on Developmental Disabilities
University of Delaware

Caitlin Bailey, PhD
Co-Director
National Leadership Consortium
on Developmental Disabilities
University of Delaware



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



Summer 2020

Fall 2020

Winter 2021

Spring 2021

Summer 2021











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

benefits complications

proof of disability

need time and cultural shift mindset for people with disabilities general U.S. population No training facing mortality Misinformation · legacy of disability scared no saving culture no follow up Poverty Mindset economy in crisis overwhelmed specialty area choice/control/ self- uncomfortableto expectation of limited direction movement Societal talk about government professionals Issues support struggle to reach people values with disabilities & lack the · who should be in knowledge to serve them **Family** Professional control · how to use funds Issues Issues · vision for future legal and financial about saving about the best No vision/future planning beyond finances way to save **Barriers** lack of training/involvement of person with disability or family context to Future Financial variation in members lack of trust No knowledge mindset. · misunderstanding of disability between Planning for no time benefits values, and families and · business vs. individual interests no money context of People with the system & individual capacity for use of jargon family professionals • cost of process understanding members who Disabilities diversity of disabilities Vulnerable population are involved population starting too late can lead to no access to family conflict professionals or help · no family to help disabilities Systemic · vision/future planning does Issues not include finances · outdated, limiting or · no financial literacy training In the Field Government confusing policy · no financial planning training too long to change policy avoidance of uncomfortable · professionals lack conversations knowledge of disability · stay in lane thinking Diversity of disabilities benefits/eliaibility population · employment complications

no consensus about whose responsibility it is to start

the process or when it should be initiated

not enough coordination between the systems

The National Leaders
Consortium

· not enough outreach or

sharing of resources

"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



is taking steps to make sure you have the money and services you need in the future

ABLE Accounts

First Party Trust

Third Party Trust

Pooled Trust

Other savings accounts or plans

People with disabilities

Family members

Financial experts

Legal experts

Other experts

People who work supporting people with disabilities

With or without experience with financial planning

With or without experience with financial planning

Financial planners, people who manage trusts, etc.

Attorneys, judges, etc.

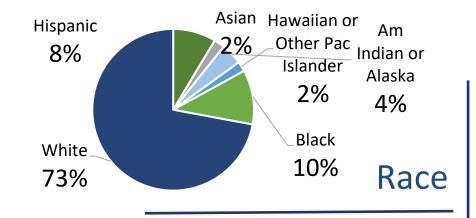
Scholars, advocates, benefits counselors, etc.

DSPs, case managers, agency leaders, transition coordinators, etc.



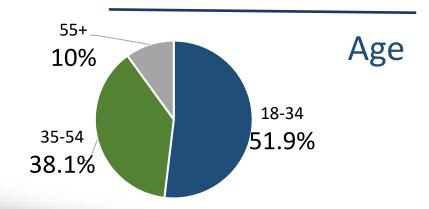
The National Leadership
Consortium

Developmental
Disabilities





Nonbinary, other, or prefer not to answer: 1.3%



Types of Accounts

ABLE Account	954	28%
First Party Trust	903	26%
Third Party Trust	557	16%
Other Savings in Person's Name	500	14%
Pooled Trust	302	9%
Other Savings Not in Person's Name	230	7%

BarriersTo Future Financial Planning

People with Disabilities

Don't Have Enough 97 Money Too Expensive 84 Afraid to Lose 70 **Benefits** Afraid Rules will 70 Change Don't Know Enough 63

About Them

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

Barriers

anning	People with	Disabilities
To Future Financial Planning		Families
To Fut		ofessionals

Professionals

Families	241	Families of people with disabilities do not plan and save money for themselves	
Societal	141	Many people believe that people with disabilities can't understand, manage, and save money	
Legal	138	Rules and laws don't let people with disabilities spend their money how they want	
Legal	140	Rules and laws don't let people with disabilities save a lot of money and keep their services	
People with Disabilities	123	People with disabilities do not have the help they need to plan and save their money	
Societal	117	Many people believe that people with disabilities can't direct their own lives	
Legal	128	Rules and laws make it too hard for people to save their money in savings accounts (ABLE, Special Needs Trusts, etc.)	
Families	127	Families who don't have a lot of money do not think they can save their money	
Societal	102	Many people believe that people with disabilities can't understand, manage and save money The National Leadersh Consortium on Develo Disabilities On Develo Disabiliti	

"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."

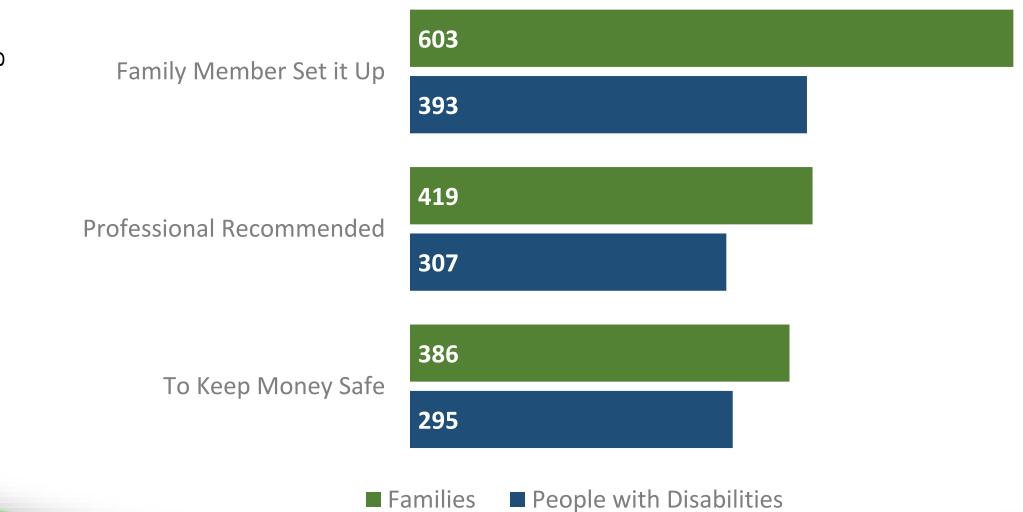
Leader of Service Provider Agency

"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







1

People with Disabilities	Clear Vision for Myself	341
Families	Clear Vision for My Family Member	198

2

People with Disabilities	Strong Family Support	267
Families	Went to a Training or Class	197

3

People with Disabilities	Support from Friends	232
Families	Strong Family Support	179

"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



景 Ongoing Support and Services



Research



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.



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



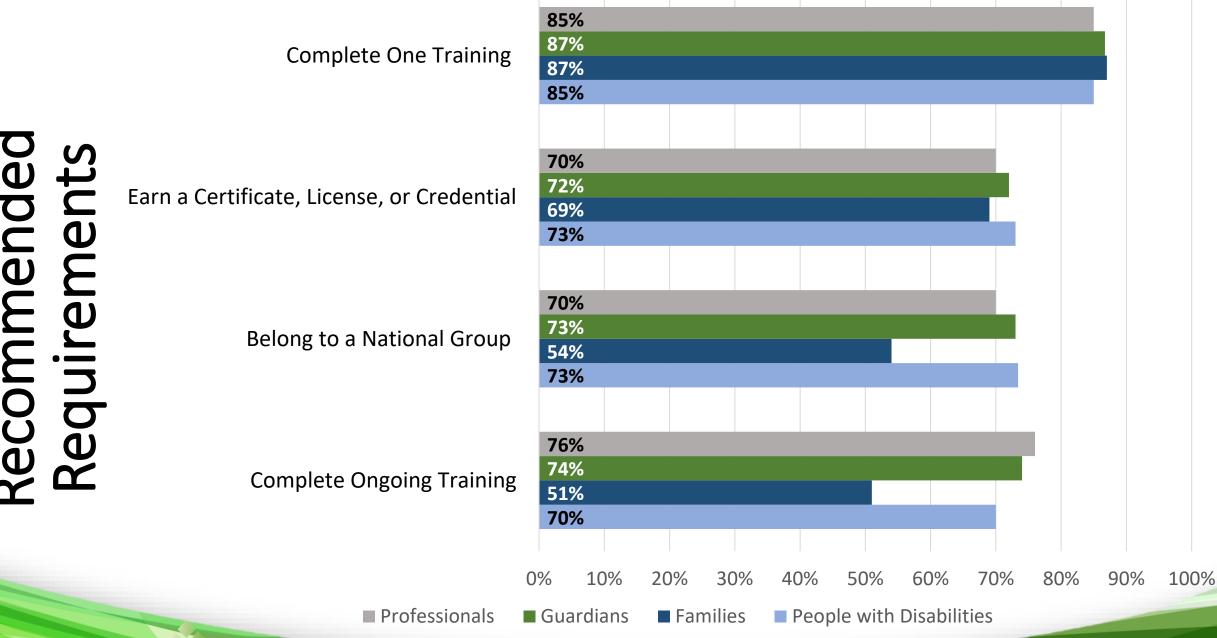
Communication

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 The National Leadership Consortium



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



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?