



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

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

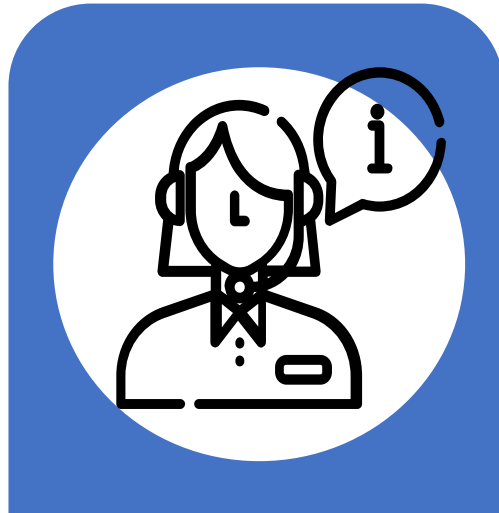
What helps or hinders people with disabilities and families with future financial planning

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

Summer 2020



Interviews

With 40 people who have experience and expertise related to future financial planning

Fall 2020



Survey Development

Informed by interviews and nationally disseminated

Winter 2021



Survey

Pilot survey with 30 experts before sending out to national organizations

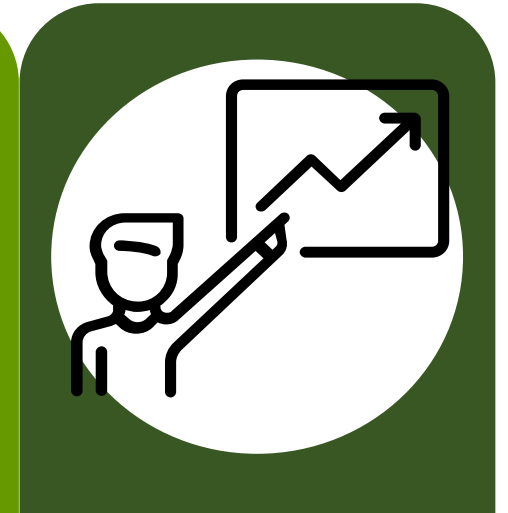
Spring 2021



Expert Meetings

Two meetings with 25 experts to discuss findings and give recommendations

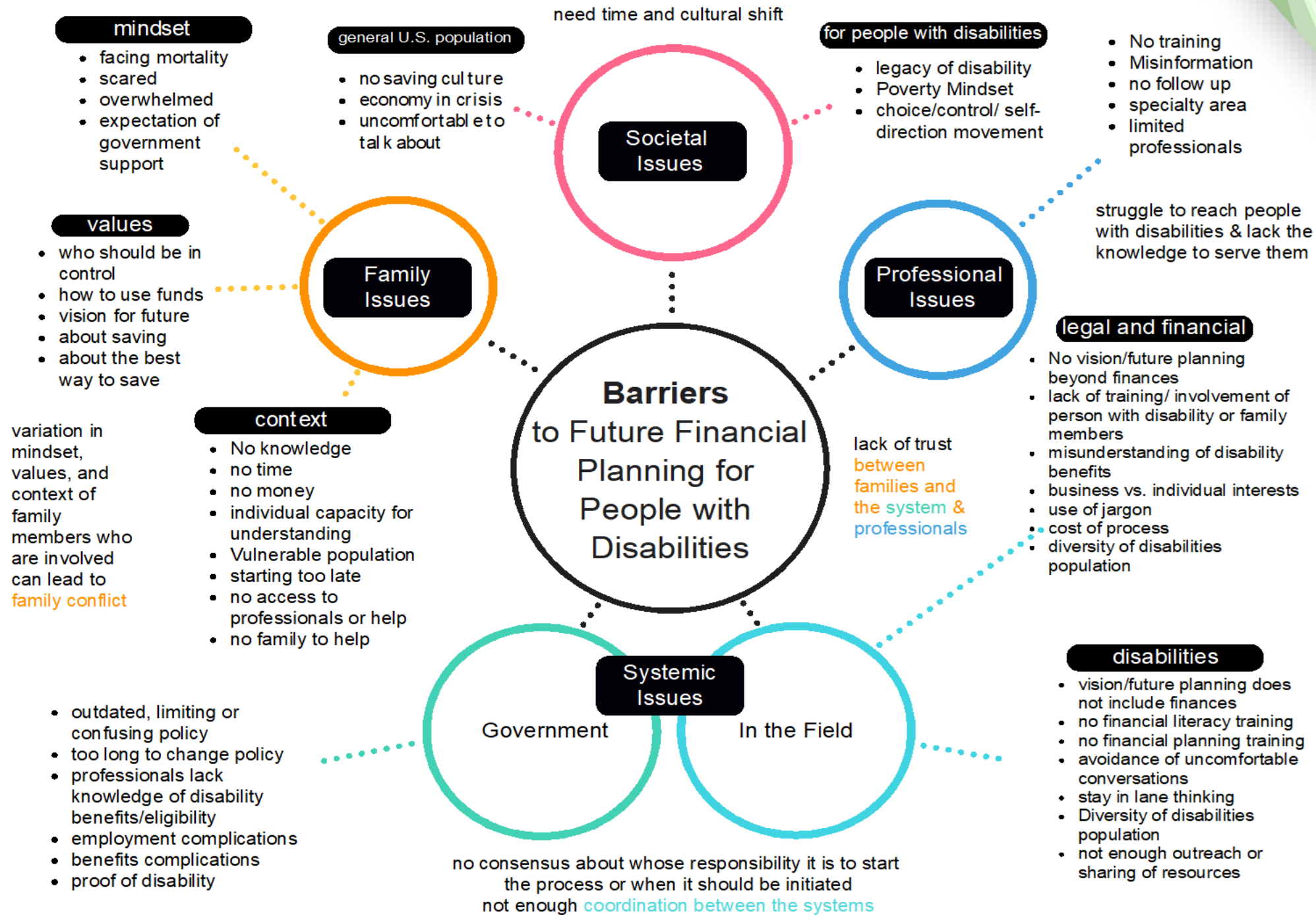
Summer 2021



Final Analysis

Data from 5,252 survey respondents analyzed

Interview Results



“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

Future financial planning
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

Participants

People with disabilities

With or without experience with financial planning

Family members

With or without experience with financial planning

Financial experts

Financial planners, people who manage trusts, etc.

Legal experts

Attorneys, judges, etc.

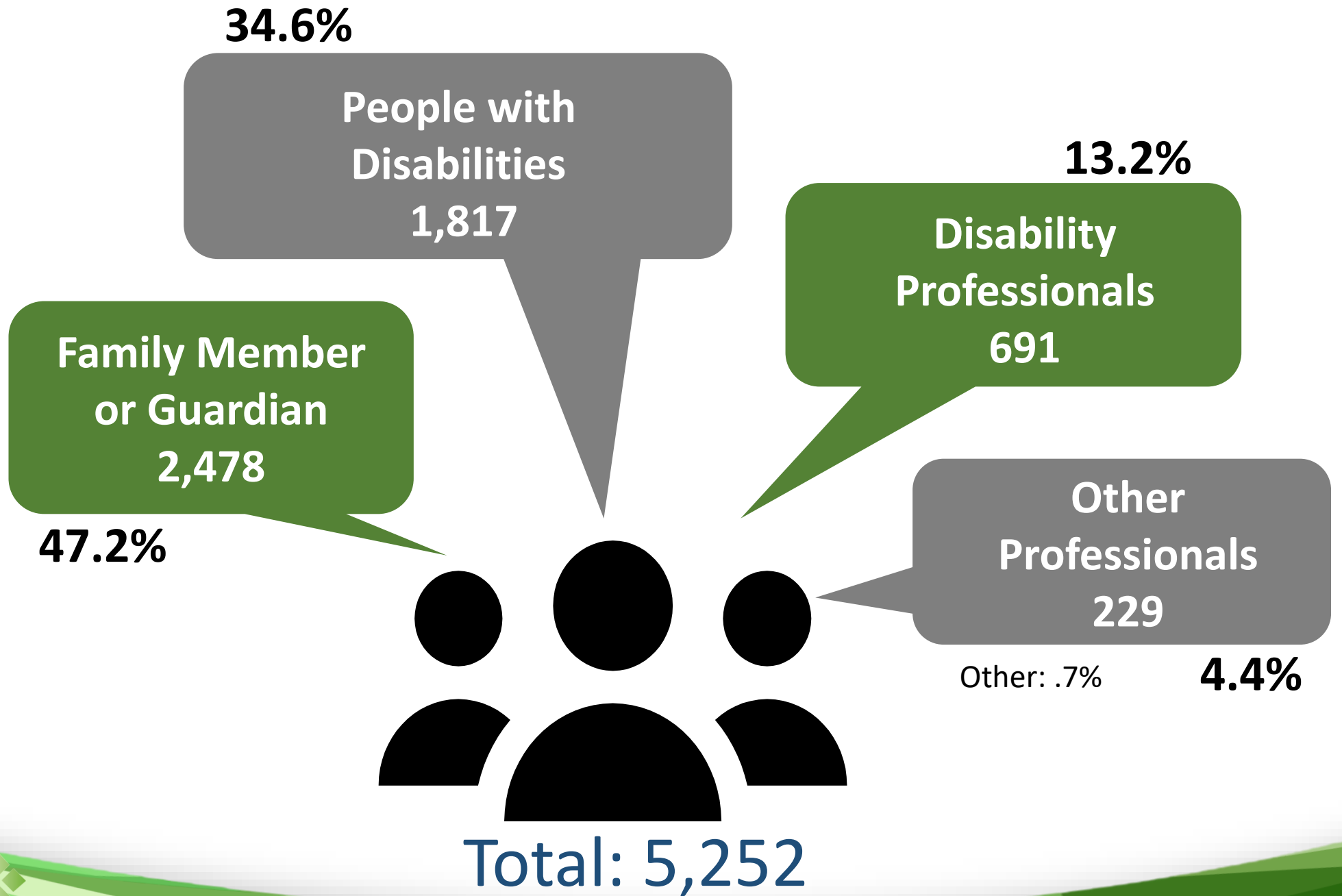
Other experts

Scholars, advocates, benefits counselors, etc.

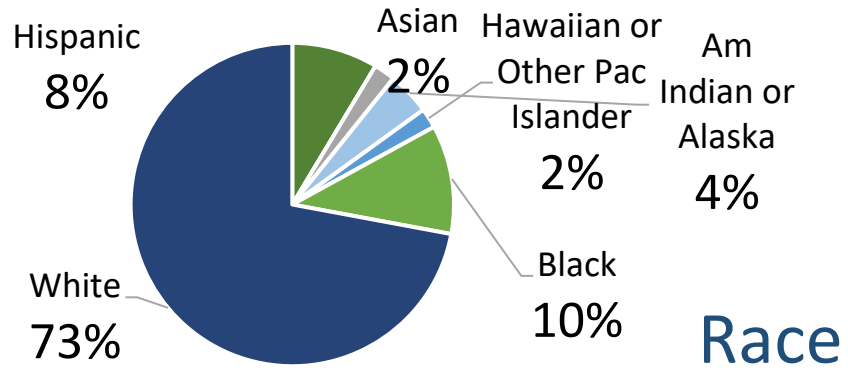
**People who work supporting
people with disabilities**

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

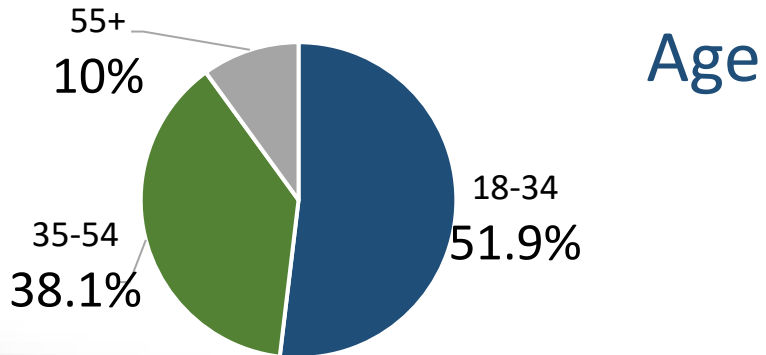
Participants



Participants



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



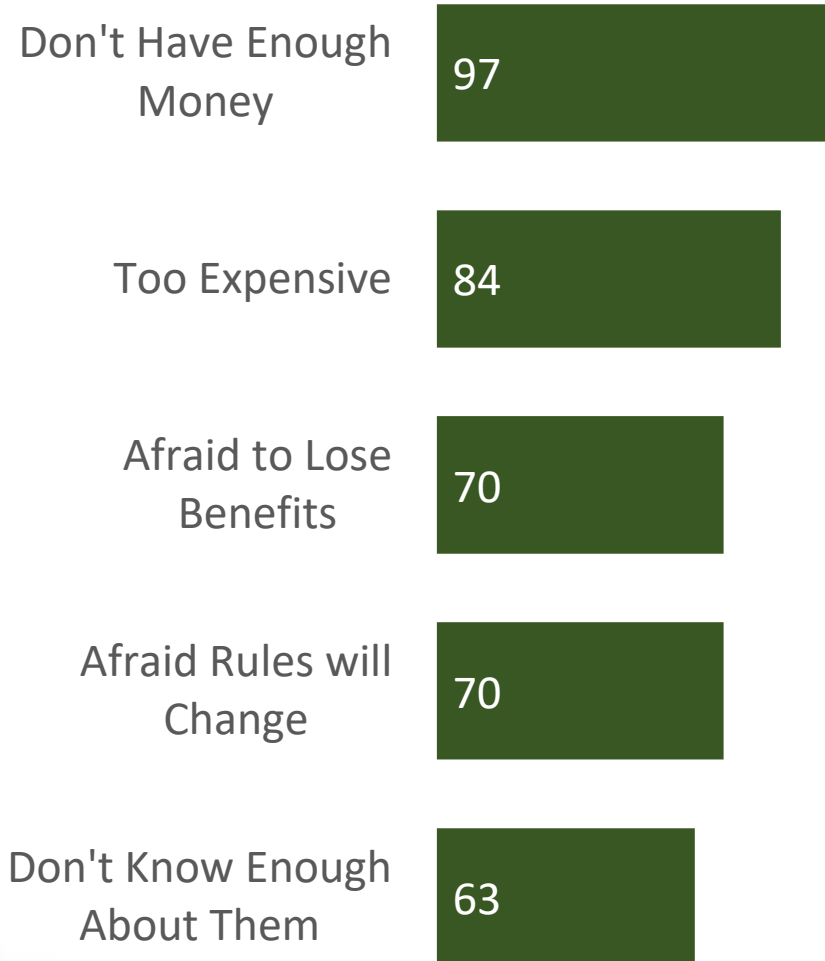
Types of Accounts

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%

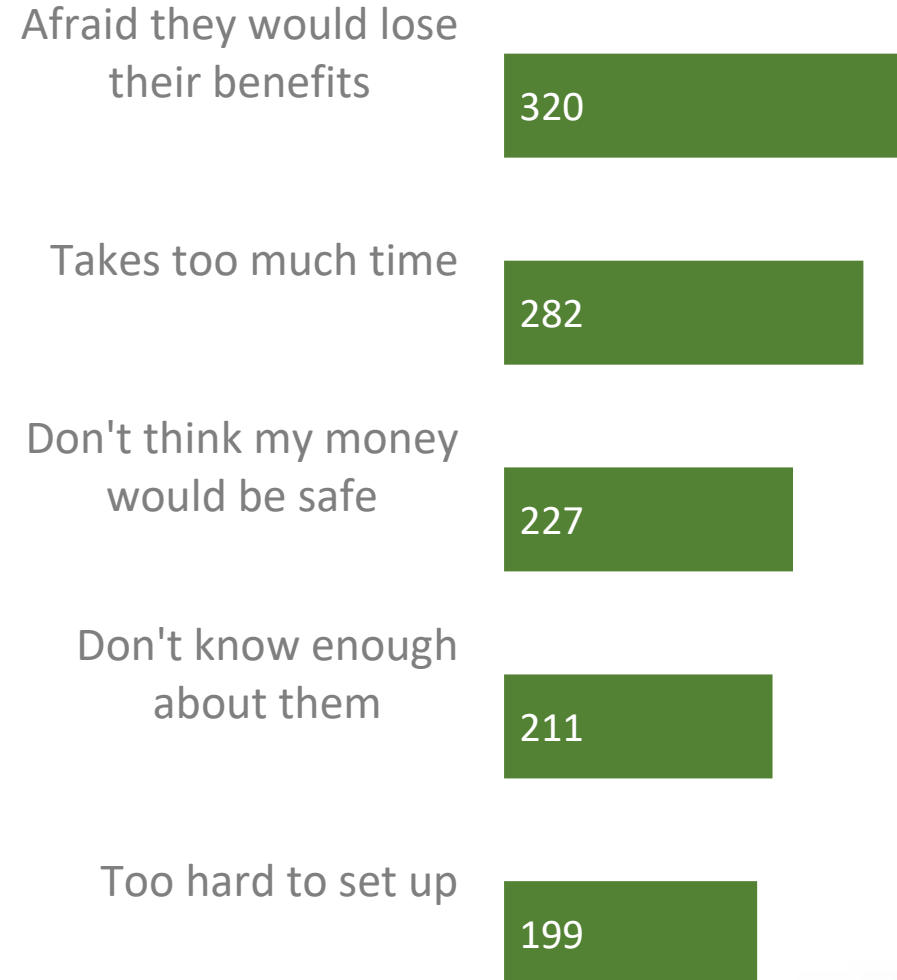
Barriers

To Future Financial Planning

People with Disabilities



Family Members

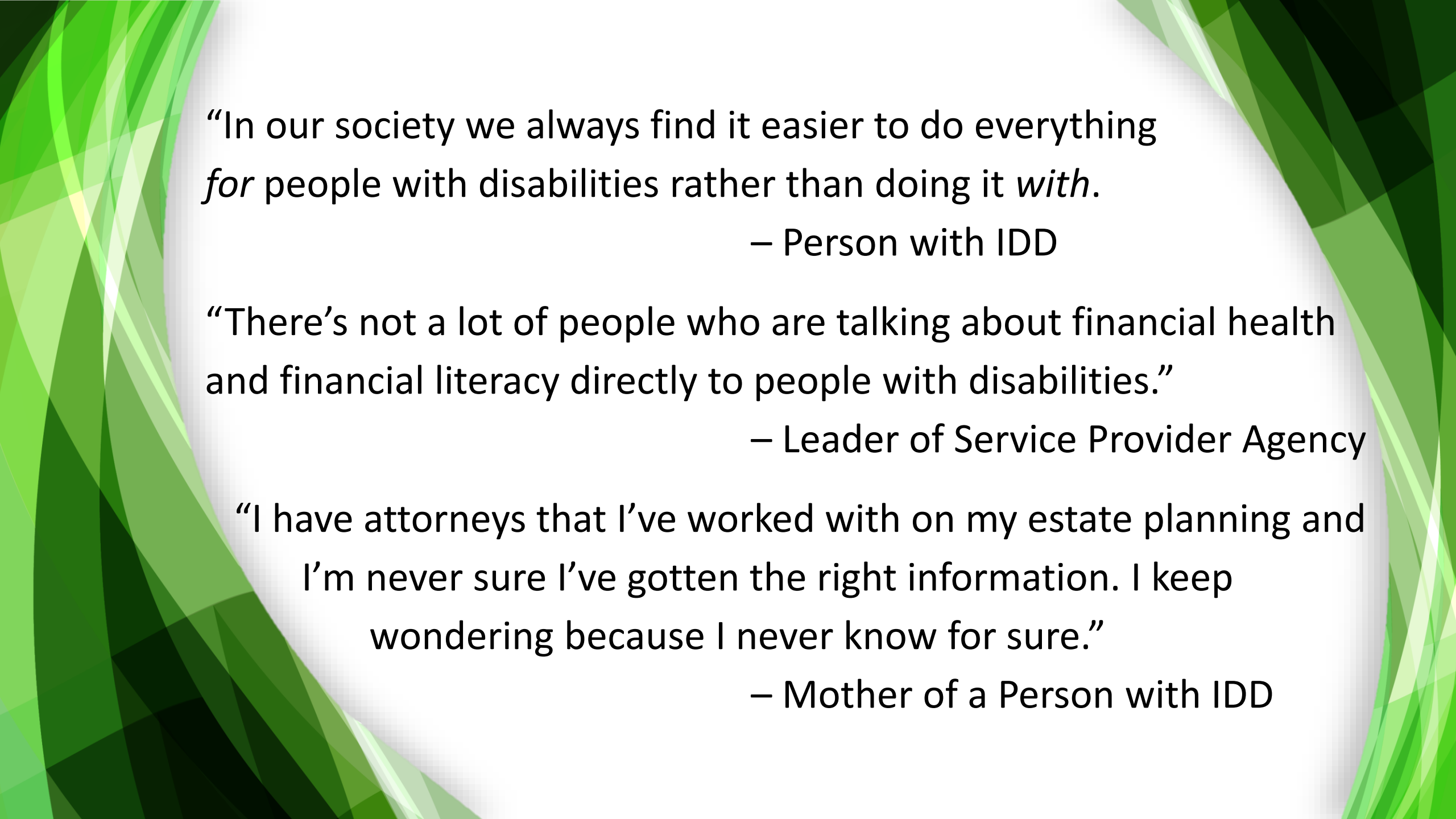


Barriers

To Future Financial Planning

People with Disabilities
Families
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



“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.”

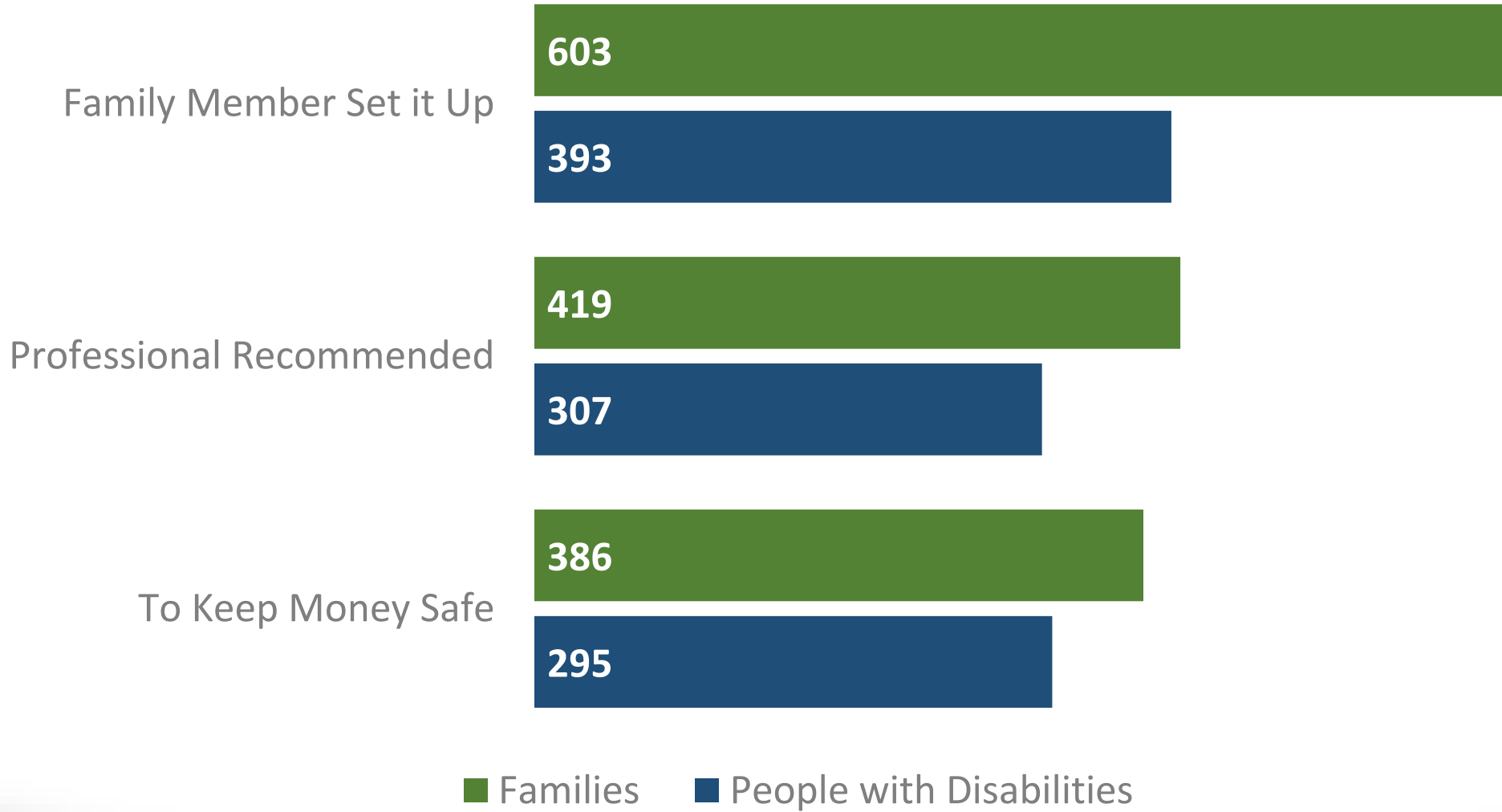
– Leader of Service Provider Agency

“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

Facilitators

To Future Financial Planning



Facilitators

1

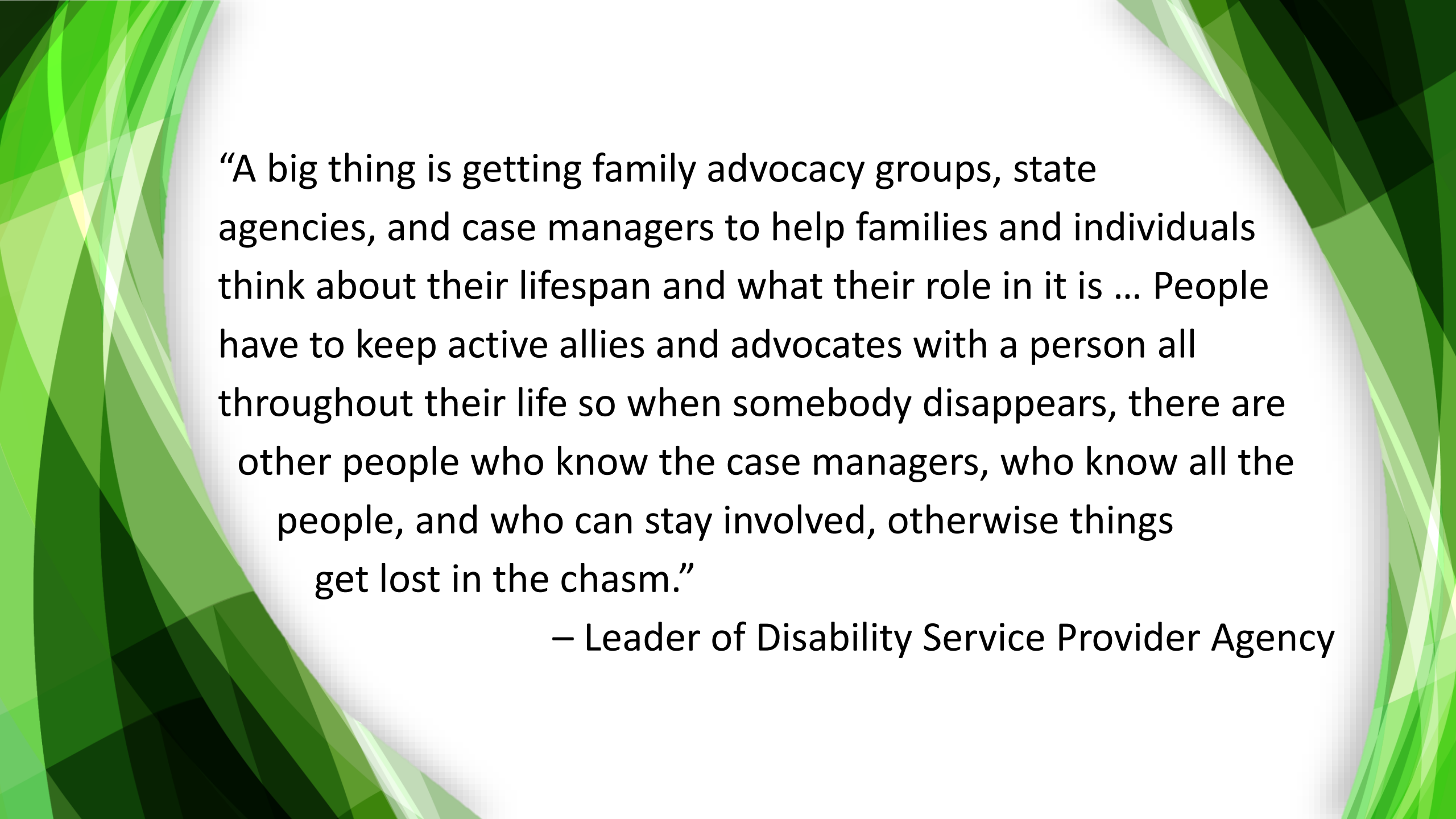
People with Disabilities	Clear Vision for Myself	341
Families	Clear Vision for My Family Member	198

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



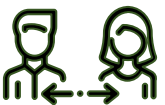
Advocacy



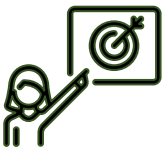
A Guidance Organization



Resources



Ongoing Support and Services



Research

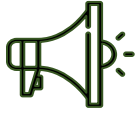
Recommendations

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

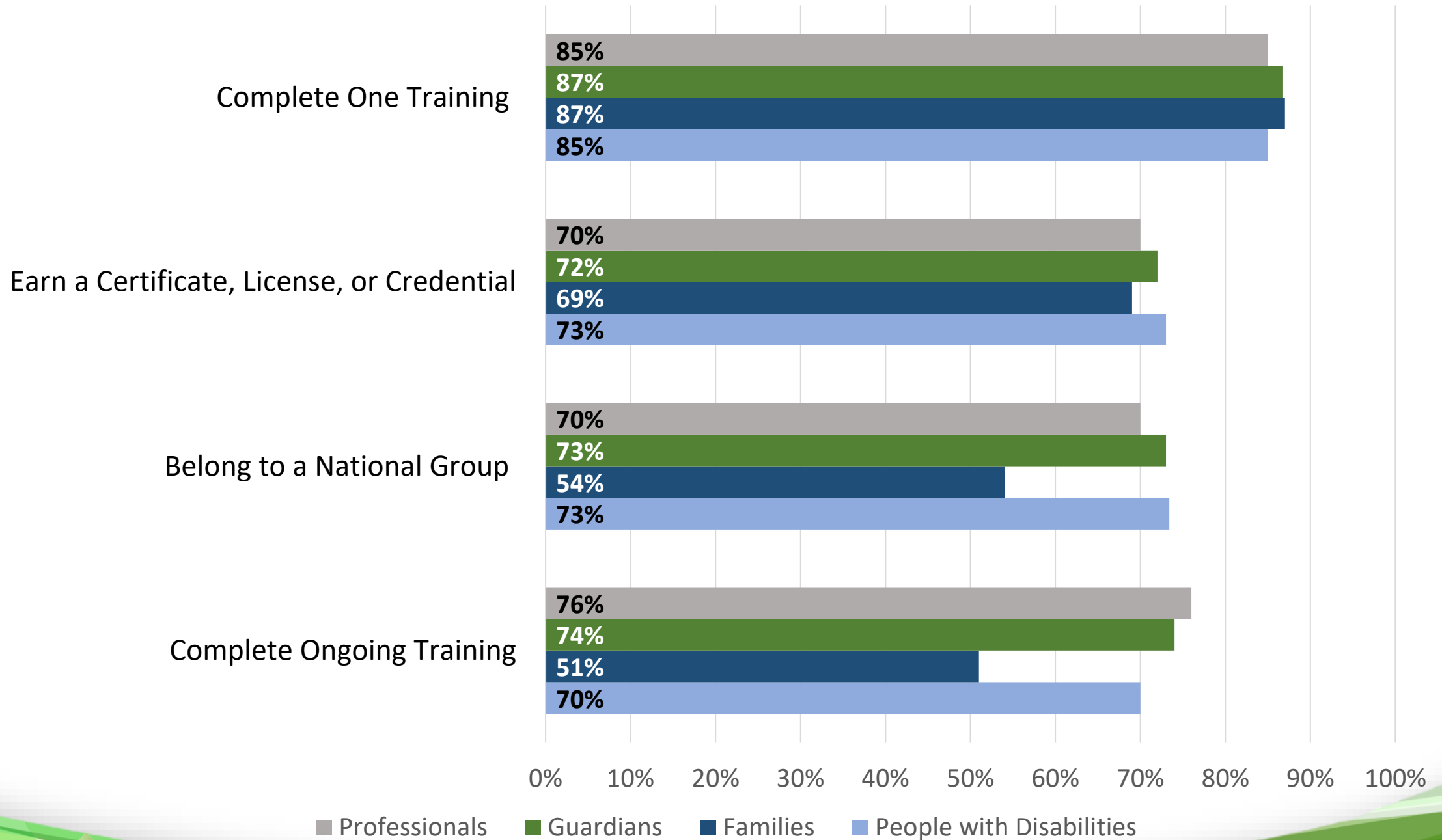
- **For people with disabilities and families:** accessible financial literacy training, planning opportunities
- **For disability service sector professionals:** introducing people to financial literacy and planning, supporting people to control and manage their finances
- **Included in** person-centered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

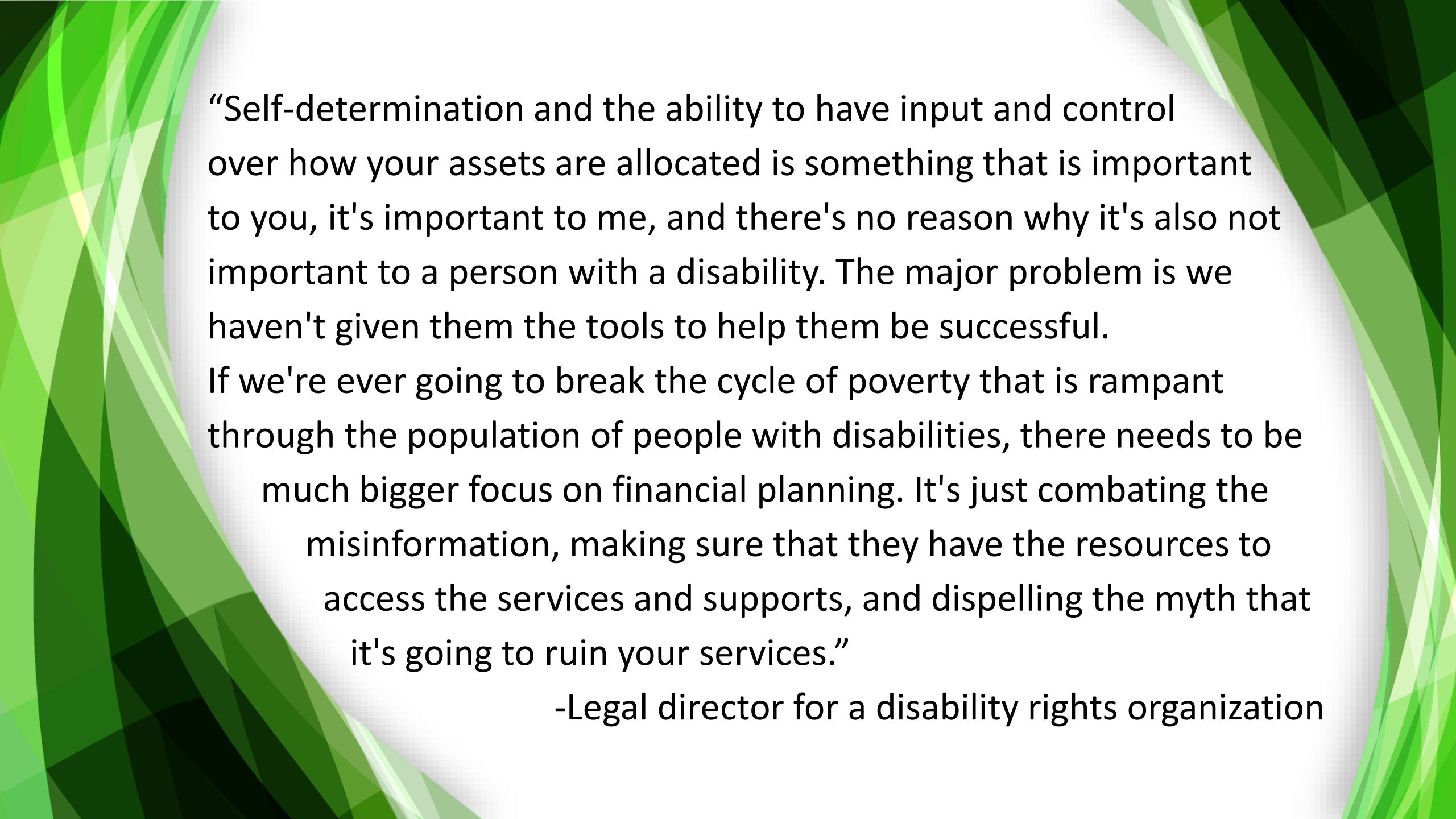


Communication

- **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

Recommended Requirements





“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

Contact Us

**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?