

Transcript

Shawn Ullman:

Good afternoon, everyone. And welcome to the Arc's Center for Future Planning webinar, entitled Future Financial Planning for People with Disabilities, a national study on what's working and what's not. And now I'm going to turn it over to our presenter, Caitlin Bailey, who's going to introduce herself and our other presenter.

Caitlin Bailey:

Wonderful. Thank you so much, Shawn.

Shawn Ullman:

Cory, do you want to move to the next slide?

Caitlin Bailey:

We are very happy to be a part of this webinar today, and we really appreciate the invitation to be with you. So I'll start by saying, in general, we have a weak culture of savings in the United... Or actually I'll start by introducing myself first. My name is Caitlin Bailey, I'm the Co-Director of the National Leadership Consortium. And with Cory Gilden, who will introduce herself, we have conducted this study and we're really excited to share the results of our work with you. Now I'll jump in. So in general, we have a weak culture of saving in the United States. In fact, it's estimated from recent studies that only about 30% of Americans have long-term, or have a long-term financial plan. And these trends related to lack of savings get even worse when we focus on the experiences of people with disabilities, who have traditionally been excluded from participating as contributors to the economy, or even contributors to their own financial futures.

Caitlin Bailey:

Often their finances are capped by outdated laws and regulations and their money is handled for them rather than by them. So in order for these trends to change, there needs to be better understanding about these issues.

Over the last year and a half. We've been very fortunate to receive support from the May & Stanley Smith Charitable Trust to examine the current state of future financial planning for people with disabilities and their families, and to make some recommendations to address barriers that people face throughout the future financial planning and savings process. We conducted a mixed methods research study, that involves interviews, surveys and focus groups of experts in financial, legal and disabilities fields. And we also included people with disabilities and their families in every stage of their research as essential experts as well.

Caitlin Bailey:

Then based on our research, we partnered with experts in all of those fields or in all of those categories that I mentioned to make recommendations to support future efforts, to help ensure that people with disabilities, their families and the professionals that work with them have the supports that they need to create sustainable financial futures. Before we jump into our study or jump more into our study, I want to give you a little bit of background about our organization. The National Leadership Consortium was founded in 2006 to support leaders in our field so that they have the skills, the knowledge and the resources that they need to improve services and to improve the lives of people with disabilities. Generally, our work is focused on providing training and development opportunities for leaders in our field. And we also conduct research and evaluation projects that can inform the work and the practices of leaders such as the topic of future financial planning.

Caitlin Bailey:

So we took on this project related to future financial planning as complete outsiders. Many of you on this webinar probably know more details and specifics about the topic of future financial planning than we do. But our perspectives as outsiders is really useful because we don't actually have direct experience in the topic coming in, and we don't really plan on continuing in this topic too heavily beyond this year. So we provide a really unbiased reflection of what's going on. We were able to come in and learn and to share what we found without a whole lot of our own biases coming in.

Caitlin Bailey:

As we share the results of the research with you, many of you might probably say to yourselves, "Well, yeah, I've been experiencing that thing that they just said for years in my own life," in my family members' lives, or in the work that I do. And we think that's really great because to date, mostly, we only have people's stories about future financial planning and their experiences related to it. But doing this national study that we did captures this kind of information. So now what we can do is say empirically, we know that this is a national issue that needs more funding support, and a lot more effort to improve people's lives and improve people's future financial wellbeing. Now I'm going to turn it over to Cory, who will tell us more about the study that we conducted.

Cory Gilden:

Hi everyone. So we set out on this project, we really wanted to know the, who, what, when, where, how of future financial planning and where at the current state of future financial planning for people with disabilities is. So we want to find out who is, or is not engaging in the process, how people

are engaging. So what kind of accounts do they have, or how are they saving now or planning to save for their future, things that help or hinder people with disabilities and their families in the financial planning process. And then also like when people start, and the entry points, how they kind of get started on their journey to setting up their future financial accounts. And then also what people feel about the abilities of people with disabilities with their finances and in the whole a financial planning process. So some values questions as well.

Cory Gilden:

Now, we certainly don't have enough time to cover all of this here, but just kind of wanted to give you a big scope of this study. More of this is covered in our white paper, which we're going to share a link with you at the end. And if you guys want to dive into that 50 page document yourselves and look for more details, that would be amazing. Even that white paper though, does not cover everything that we learned. So we are also working on publishing some articles in academic journals and in other venues and doing presentations like this, just to kind of get the word about little snippets and key findings extracted from the research we found, because we did get a lot of data from this study.

Cory Gilden:

So as Caitlin mentioned, we've been working on this for the past year and a half. We started with interviewing people who have expertise and experience related to future financial planning, including people with disabilities and their families. And based on those interviews, we developed a web-based national survey. So then we sent out the survey to people and we got it back. And we got a lot of data from that survey, we had more than 5,000 people answer it and I'll get into that in a minute. And then after we had the survey, we had these expert meetings where we discussed with

experts, we shared the results with them from the previous phases of the study. And we asked them to help us formulate some recommendations based on the results. And then we have now the final product.

Cory Gilden:

Just to give you a glimpse into the phase, one of the study of what informed, I know you guys, this is way too much for you to read and take in right now. You will be given in slides later if you want to dive in, but I just wanted to show you, this was that first round of interviews that kind of informed the creation of the survey. So one of the main things we were trying to discover is what were the main barriers to future financial planning with people with disabilities. So from that, we came up with this whole concept map and then went on to develop questions based on things that we heard about in the interviews.

Cory Gilden:

We have some great quotes throughout this presentation that I wanted to share with you from our interviews that really capture some of the key things that we're going to be sharing with you. So here's a quote from the manager of a pool trust, who said that, "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's a complicated system to manage. There are so many financial implications as it relates to healthcare for Medicaid, healthcare for Medicare, access to housing vouchers, employment, and disability benefits. It's 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 disability makes about one set of systems and rules are going to impact all the others." And this kind of spoke to the main crux of what we

saw was the big problem, right? All these kind of different silos and how they work together or not work together in many cases.

Cory Gilden:

So we developed this big survey and based on the survey track, you could get up to 57 questions and they were all different types of questions, mostly multiple choice, but we did have some ratings on a scale of zero 10 and some short answer questions in there as well. The questions asked about demographics, future financial planning, accounts and activities, financial literacy, point of entry into financial planning process, challenges and facilitators, and values related to disabilities. And we distributed very widely, we cast a wide net and got it out to all of our national partners. And then some of the organizations that we worked with in the past. And we said, "Hey, send this out to your networks as well." So a lot of people sent it on and put it on their social media and their websites as well, and got the word out.

Cory Gilden:

So we broadly define future financial planning in the survey as taking steps to make sure you have the money and services you need in the future. It's a very broad definition, in doing this research, one of the things we found is that people don't really have a clear understanding of a definition of future financial planning or what it really means. So this is one we crafted based on some of the government definitions and some other things. And we focused mainly on these main accounts that we kept repeatedly hearing about. So ABLE Accounts, first party trust, third party, trust, pool trusts, and other savings accounts or plans were kind of grouped together. So when we asked people questions about certain accounts, specific accounts, these are the ones we asked about, but we know of course there are more saving mechanisms.

Cory Gilden:

So people we were hoping to hear from in the survey were people with disabilities, family members, financial experts, legal experts, other experts, such as scholars, advocates, benefits, counselors, these types of people, and then people who work supporting people with disabilities, which was also kind of a wide group of people. We also wanted people who had experience with financial planning and people who didn't necessarily have experience with financial planning to ask them, "Why don't you have an account?" Because we thought that was important information as well.

Cory Gilden:

So here are the respondents that we had to the survey. As you can see the majority of the people who responded were family members or guardians of people with disabilities, 47.2%. And then the next group of people who responded were people with disabilities, had about 35% of those, and then disability professionals and other professionals made up that other 17, 18%. So we had more than 5,000 people ultimately. So when I share responses, it's from that pool of more than 5,000 people. Okay. And here's some more demographic information, again, they're is a lot of stuff on this slide. You don't necessarily have to take it in or understand it all, but just wanted to give you a glimpse of it.

Cory Gilden:

So we have the racial breakdown here in the upper left hand corner. Unfortunately, I mean, because we were hoping to break it down in terms of just race and some other factors. But we did have the majority of people who completed the survey are white. It was about evenly split between men and women, 57 to 42%. And also the majority of people who responded to this survey were between the ages of 18 and 34. Here are the most popular

accounts that people said that they had were the ABLE Accounts and the first party trust, and the third party trust were the top three. Again, all of that is listed in the white paper as well in more detail and you can read that later.

Cory Gilden:

So one of the central questions that we wanted to ask in the survey were, what are the barriers to future financial planning? So we asked people who said that they didn't have a future financial account, we asked them, "Why don't you have a future financial account, please click the top three reasons." So the top three reasons and these are the top five out of those selections. So we gave them based on the interviews that we had done before we gave them about 16 possible things that they could check off and then also allowed them, gave them space to write in a response if they wanted to. So these are the top ones that we saw from people with disabilities and from family members of people with disabilities.

Cory Gilden:

So for people with disabilities here on the left, most of them said, "I don't have enough money to have an account." And they said, "It's too expensive." So those are kind of in the same vein. And then third, they said, "I'm afraid to lose my benefits," which is a big thing I'm sure, that there's any families out there that's always on the forefront of their minds when they're talking about financial issues. A group of people said, they're afraid the rules will change, because the rules are changing sometimes, and sometimes they become more restrictive. And then a group of people said, "I just don't know enough about them." And then for family members, their top concern was they were afraid they would lose their benefits. And then also it takes too much time.

Cory Gilden:

We know that this is a very taxing, complicated process, and we know that this is a population who, they have enough on their minds. They're already trying to juggle all their other service, that to add something else to it, they just don't have the time for it. Some people thought they wouldn't think their money would be safe, maybe because they just don't know enough about them. And also because, a lot of the research we collected, people were talking about kind of, they don't know who to trust. So trust was a big issue in this process too. And then finally, some people said, it's too hard to set up. It's too hard to do on your own, you need a professional to walk you through it. And then when you add a professional in, you add those trust barriers, you add cost issues and financial barriers to it. So it makes things way more complicated.

Cory Gilden:

So we asked these three groups, people with disabilities, families, and then professionals. We asked them, "Did you experience challenges during the future financial planning process?" And the vast majority of all three of these groups said, yes, yes. So then we asked them further. We said, okay, so those who experienced challenges, we went on to ask them, "Which would you rate as your biggest challenge?" And we gave them six major categories that challenges seem to fall into, societal, legal, organizational, family and people with disabilities. So down this left side of the page, you can see the top three choices for each of these participant groups. So people with disabilities thought that one of the biggest barriers was families. Families thought that there were legal barriers was the number one issue, just like professionals also thought legal barriers was the number one issue.

Cory Gilden:

And then we went on to ask them further, and we said, "Okay, so you said families was the number one issue for you specifically, what challenges do you experience?" And many of them said, "Families of people with disabilities do not plan and save money for themselves." And as Caitlin referred to in the introduction, we just don't have a big savings culture in this country, we don't talk about money a lot. And a lot of people don't know how to save. So that's a big financial barrier because obviously you can't plan a financial future or open financial accounts if you have no money saved in the first place, right? So for families and professionals, they both said that their number one barrier was legal. And for families, they said, "Rules and laws don't let people with disabilities save a lot of money and keep their services." And for professionals down at the bottom, they said, "Rules and laws make it too hard for people to save their money in savings accounts." So like ABLE Special Needs Trust. So lots of regulatory barriers and policy barriers are being seen in this data.

Cory Gilden:

Okay. Here are some quotes that kind of capture other things that we heard, "In our society, we always find it easier to do everything for people with disabilities rather than doing it with." And that was a person with IDD who said that. "There's not a lot of people, people who are talking about financial health and financial literacy directly to people with disabilities." And that was from a leader of a service provider agency. And then, "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." And that was the mother of a person with IDD. So these quotes of encapsulate the whole, just some of the process barriers that we heard a lot over and over again in the research.

Cory Gilden:

Okay. But it wasn't all doom and gloom. We also asked about, "What helps you in the future financial planning process?" So for people who had future financial accounts we asked them, "What, if anything, made it easier for you or your family member with disabilities to have a future financial account?" And we gave them 24 different options based on what we heard frequently in the interviews. And we also gave them a write in option to write in their own answers. And here's what they come up with. So basically they said, "Having a family member set it up," oh, these are the reasons why, sorry, these are the reasons why people had an account. So having a family member set it up was the main impetus for were most people, a professional recommended it, and then the third reason was people just wanted to keep money safe.

Cory Gilden:

So having a family member set it up is the number one reason people listed as having a future financial plan. But what about all these people who don't have family members at all, or don't have family members who savvy enough or have the time, or the resources to do that, then that can be a huge barrier. And also this second reason, "A professional recommended it." Well, what if you're coming across professionals that are not recommending that people start looking into and planning for their financial futures, right? And that's another thing that we found is that, in the disabilities field, a lot of disabilities professionals that helps to support people with disabilities either didn't see that it was their place to kind of talk about money with them or didn't know enough about themselves to feel comfortable to make recommendations. So I had a feeling that a lot of these people that say a professional recommended it, those professionals

might have been sought out by the individual disabilities or the families themselves to initiate that process. So a lot of barriers there.

Cory Gilden:

I'm sorry. Those were facilitators. Yeah. And now I'm talking about and facilitators at the same time, sorry, I don't mean to confuse you. All right. So here are some more facilitators. So here's where we asked them, "What made it easier for your family member with disabilities to have a future financial account?" And they have the 24 choices and they clicked on one, and here are the top three facilitators. So for people with abilities, if you look up here at number one, their number one facilitator was, "I had a clear vision for myself," and the families gave the same answer. "I had a clear vision for my family member," and this is the kind of stuff that the Arc has been really putting a big effort into is the whole future planning in general is to create that vision for the future, right? And then future financial planning is a sub of that, of something that has to be looked at in part of a bigger future plan.

Cory Gilden:

But if you don't have that bigger future plan, then it makes it harder to kind of think about the financial stuff separately. So having a clear vision for yourself was a big facilitator to people and a big step to kind of helping to design their future financial plan. All right. And then number two, people with disability said they had strong family support really helped out. And family said, "We went to a training or class." So what we know about training or classes is, they're few and far between, and it's a very kind of arbitrary process in terms of what's available to families. So that's definitely a need that I think Caitlin is going to talk about later.

Cory Gilden:

And then the third reason people with disability said, support from friends and family said strong family support. So again, we keep seeing these kind of social supports and impetus to starting a future financial account. So a lot of people who started them it's because they had the support from their family and friends, or even a professional to get started down that path. Here's another quote for you. "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 is in it. The role in it is people have to keep active allies and advocates with a person all throughout their life. So when someone disappears, there are other people who know the case managers who know all the people and who can stay involved, otherwise things just get lost in the chasm." And it was from a leader of a disability service provider agency.

Cory Gilden:

Again, emphasizing the role of social relationships in people of disabilities lives, so that even to help facilitate the future financial planning process. I'm going to pass it back over to Caitlin. So [inaudible 00:22:09] some of the findings that we just went through and some of the other phases of the project, we came up with pages of recommendations, oriented towards different groups of people, toward people with disabilities, towards their family members, towards professionals in the legal, financial and disabilities fields. And so we detailed different recommendations, and Caitlin's going to highlight a few for you right now.

Caitlin Bailey:

Thank you so much, Cory. So like Cory said, we developed these recommendations and arranged them around themes that are shared on

this slide. And those themes include education training and certification, communication, advocacy, developing and guidance, organization, resources, ongoing support and services and research. These themes came up consistently during the interviews, the surveys and the expert meeting phases of the project. And like Cory said in the white paper that we came mentioning, we organized these recommendations according to the groups that were most impacted by them so that we could offer targeted direction for supports or for opportunities to improve future financial planning for people with disabilities. For example, if you read the white paper, you'll see that there's a section focused on recommendations that impact families and people with disabilities most, there's also a section that focuses on recommendations that impact professionals including financial planners and attorneys most and more sections like that.

Caitlin Bailey:

For this presentation, we're going to focus on some of the overarching recommendations and particularly recommendations that most impacts people disabilities and their families. So the overarching recommendations that we want to share with you focus on ideas and solutions that can impact several groups of stakeholders, or several groups of people that Cory talked about as participants in our research, who are invested in the future financial planning process for people with disabilities and their families. These recommendations fell into three categories, which were communication and advocacy, resources and an organization or structure for oversight and governance.

Caitlin Bailey:

So when it came to communication and advocacy, we really heard consistently that to improve future financial planning, first and foremost, we needed to address the discriminatory beliefs and practices that limit the

control that people with disabilities have over their finances. Our history and our field of, and our long standing traditions and services, supports and practices that regulate several or all aspects of the lives of people with disabilities really limit people's rights to autonomy, choice, and control. And we heard over and over again that this extends to people's finances. We also heard that many of the regulations and the rules that limit opportunities for people with disabilities to earn and save money, leave many people in cycles of poverty and they lead to economic exclusion. So these two core issues inspired recommendations related to communication and advocacy.

Caitlin Bailey:

First to begin the shift in perspectives and practices, experts discuss strategies, including public messaging or wide reaching campaigns that could be done at a state level, at a national or federal level, or that could be done locally in people's communities. And they suggested that these different communication efforts provide education about the rights of people with disabilities to control their finances and to achieve financial wellness. So really to focus on financial wellbeing as right, that people with disabilities have. They also suggested communication that would promote the economic inclusion of people with disabilities, or that would focus on how people with disabilities already contribute to the economy and how people with disabilities can contribute more to the economy when they have opportunities to save their money and to be financially well.

Caitlin Bailey:

They made recommendations related to communication and advocacy so that we could increase national understanding about the barriers that people with disabilities and their families experience related to financial health and wellbeing. Cory talked about some of those barriers, and I just mentioned those cycles of poverty and things like that, making sure that

more and more people understand those barriers that people face, and more and more people are engaged and try to advocate for change for that. And finally, they suggested communication to share potential solutions to more meaningfully involve people with disabilities day-to-day in their long-term financial decisions. And I'll go a little bit more into that. Some of the recommendations that were specifically made that impact people with disabilities and their families.

Caitlin Bailey:

Recommendations related to resources. We also heard that the creation or communication about existing resources that would help people with disabilities, family members and professionals have the information and tools that they need to successfully engage in financial planning and saving are really essential. Two of the specific recommendations that we heard and that particularly the experts that we engage with kind of parsed them out, were first alive or continually adapting something like over virtual list serve or a network or a community of practice that can help professionals, families of people with disabilities. People with disabilities, all connect around topics related to future financial planning. So this resource would provide a space to share resources, post questions, and also to receive reliable inform. Ultimately this live network would be ongoing, it would be kept up to date and it would provide in time support.

Caitlin Bailey:

On the other hand, there was also several recommendations to create a more static virtual, like a one stop shop or platform that would be used, or that could provide up to date resources, materials and maybe state specific information about legislation, regulation, available services and issues related to the future financial planning process. The experts recommended that this platform could focus on educating different stakeholders and

getting materials and resources out to people who need them at every stage of the future financial planning and maintenance process. So essentially the resources that were recommended, one was like an ongoing networking thing. And then another was like a get information out to people thing.

Caitlin Bailey:

The third recommendation that came pretty consistently was this organization, or structure to provide oversight and guidance. We learned that it might be helpful to create this organization or this collaborative that could be responsible for collecting and vetting regularly updating and offering information tools and resources that can be useful to people, again, at each stage of the financial planning process. The entity could, or this organization, or this group of organizations could also assume other really important roles, they could do advocacy, they could make policy recommendations, they could provide training and develop best practice guidelines for professionals or share existing best practice guidelines for professionals that were vetted, and that they gave their stamp of approval on. Experts who were part of our meetings acknowledged that this entity could be modeled from existing groups and could be a collaborative, like I said, that could be modeled off of organizations like the American Association of People with Disabilities, the disability planning and policy center that's at Eastern Michigan University or the Arc's Center for Future Planning, that's hosting this webinar, or that is part of hosting this webinar.

Caitlin Bailey:

It's also important to note that many of the experts that we learn from, shared that some of the recommendations were already happening. For example, they shared, or they acknowledged that there are a ton of resources that are focused on future financial planning. And so the issue

can really be more of an outreach one, or getting things into the hands of the people who need the most. And so those recommendations kind of always came back to that importance of communication and advocacy, or making sure that people understand and are aware of and have access to the things that would help them most throughout the future financial planning process.

Caitlin Bailey:

Today, we also wanted to share some of the recommendations that came up consistently that might be most useful or impactful for people with disabilities and their families. First, we heard from so many people with disabilities and their families that training and education are essential. Like Cory shared, our results even show that people who, or I don't know if Cory shared this, but our results even show that people who participated in training and education and opportunities, were more likely to engage in future financial planning, more likely to have savings accounts or mechanisms that help them save. So some of the trainings and the education opportunities that were recommended are listed on this slide. So like I shared on the last slide, the ongoing practices of excluding people with disabilities from managing their finances really puts them at a disadvantage to begin saving.

Caitlin Bailey:

So one of the first recommendations related to training and education focused on training that helps people understand how to manage their finances both in the day to day. And then in the long-term, and also to learn about opportunities for planning and accounts that really could help them overcome some of these longstanding barriers. The second recommendation really focused on a suggestion to introduce disability service sector professionals, like direct support professionals, which we call

DSPs earlier, or people who directly support people with disabilities. Also, leaders of disabilities service sector organizations, or leaders of organizations that provide services directly to people with disabilities to educate them on the basics of future financial planning, and to train them on strategies to support people who their organizations support, to control and manage their finances, and to start engaging in future financial planning.

Caitlin Bailey:

Like Cory talked about that question we had, or the focus that we had on point of entry, or when people start, and how people start future financial planning, we heard from a lot of people that their first engagement into any kind of services is through the disability service sector or through agencies that directly provide support to people with disabilities. And so training and education for those professionals might be a really effective tool. Along those same lines, many experts suggested that organizations start to embed future financial planning into services and supports that people with disabilities already receive. For example, it could be embedded into person-centered planning or an aspect of person-centered planning for people. It could be an aspect of supported decision making, it could be a resource that's shared in school before people graduate from high school, or it could be a part of supporting people throughout a transition process to adult services. The thought is that if we make future financial planning a part of people's everyday life, then they're more likely to plan and more likely to be supported to control their finances.

Caitlin Bailey:

And then finally, we also heard from people with disabilities and their families that a huge barrier to future financial planning is that many current financial planning professionals don't understand the disability service

system rules and regulations. Actually, I'm sorry, I just skipped over an entire section. So finally, the next recommendation or the other recommendation on this slide was related to communication. So we talked about some of those targeted communication campaigns, but again, really a lot of the people with disabilities and families that we talked to said that they felt isolated, or they felt like they didn't know who to go to, to get the resources and the information that they need related to future financial planning. So one of the recommendations was to really focus on opportunities for communicate with people with disabilities and their families, and to meet them where they're at.

Caitlin Bailey:

We heard from one organization that actually started walking door to door, in neighborhoods where they knew that people with disabilities lived and handing resources to people with disabilities and their families, so that they knew more about future financial planning. And so those recommendations related to communication or related to targeted communication happened both at the very, very local level. And then up to the state and the national level as well. Now, lastly, we heard from people with disabilities in their families, that one of the biggest barriers to future financial planning is that lack of understanding that future planning professionals have about the disability service system about rules and regulations that impact people with disabilities, things like that. We heard some really, really tough stories about people receiving bad about how to save their money, which led to them losing their benefits or their services, because they had too much money in their accounts at one point in time.

Caitlin Bailey:

We also heard stories about professionals, mismanaging people savings, and spending them on things like really expensive and unneeded attorneys

fees, or things like that, that drain people's savings. And didn't help people use their money on things that would really actually benefit them throughout their lives. Because of those stories, we asked people to share whether they thought there should be some requirements for professionals to ensure that they have the knowledge and the skills that they need to guide people through the future financial planning process. And so we thought these results were really interesting because we heard that most people who completed the survey, or most people who completed the survey shared that they thought the professionals should have some requirements, including completing at least one training, completing an ongoing training, earning a certificate, license, or credential or belonging to a national group.

Caitlin Bailey:

However, on the flip side, when we asked experts about these recommendations, we heard some differing opinions. We heard that there's already a lot of requirements on financial planners, we heard that there's not enough future financial planners that do this work with families and people with disabilities well, and that adding more requirements for credentials or training, or things like that would lessen the pool of available professionals who are really good at the work that they do. So since that's the case, we wanted to share that there was a lot of recommendation to do it, but also that those kind of results are mixed. So we're not really sure where to sit with that.

Caitlin Bailey:

Finally, we wanted to end this presentation with a quote that we heard from a leader in our field when we conducted the interviews early on, because we really felt that this quote captured our approach and then importance of future financial planning for people with disabilities and their families. So

this leader of the legal director for a disability rights organization said that, "Self-determination and the ability to have input and control over how your assets are allocated is something that's 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 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 a 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."

Caitlin Bailey:

With that, we are happy to answer any questions that you might have about our work or about the results of what we found. Oh, and we mentioned it so many times, if you'd like to read the white paper, if you'd like to just download it so that you have access to it, please click on this link here. Well, you'll have these slides I think, or just go to nlcdd.org/publications, and you can have access to the white paper that we created. And also some recommendations frameworks that came from this study as well. We also wanted to mention some of the work that we're currently doing. We have the opportunity also to do a small follow up study, or have the opportunity to do a small follow up study with people with disabilities and their families to ask about the impact of COVID-19 on future financial planning for people with disabilities.

Caitlin Bailey:

And so what we'll do is we will create another shorter, smaller report that shows some of this impact, because we know that during the time that we were doing these initial interviews in this study, we learned that a lot of people were impacted by COVID-19. And so we wanted to be able to dig a

little bit deeper to understand what that means for people related to future financial planning. So we'll share that as soon as we are available to, or as soon as it's done and it's available to share. With that, I can actually say, we'd love to take questions if you have them. And I see that there's a lot in the Q&A.

Shawn Ullman:

Cory, could you go to the slide after your contact information for one moment?

Caitlin Bailey:

Yeah, for sure.

Shawn Ullman:

So we'll make sure we come back here so that you guys will have Caitlin and Cory's emails, you will also be getting copies of these slides. So you'll have them in your emails within a few days as well. But Cory, can you go to the next slide. Before we get to the questions and answers, we did want to share some new resources that are available from the Arc Center for Future Planning. We hope that most of you participating in this webinar know that the Arc through center for future planning is one of the organizations that's working to implement many of the recommendations that Caitlin and Cory referenced in their study. Including providing education, and creating resources and communicating to people with intellectual developmental disabilities and their family members about the importance of future planning, including future financial planning.

Shawn Ullman:

And our most recent efforts include five new videos that answer some of the most common questions that people have. And I've seen some of them

in the Q&A and in the chat about Special Needs Trust and ABLE Accounts, including why to consider one or both of them, how they work, how they're different, and how to get started. These videos are free and they're readily available to anybody on YouTube. We have them available in both English and Spanish here on the slide when you get it, those blue underlines are links to the playlists. And when you receive the materials, we hope you'll take a few of minutes to watch the videos and share them widely with anyone you think might benefit. So let's switch over to the questions. One question that folks have is when you talked about people with disabilities and you talked about family members, did families include people with disabilities or were those two different subsets?

Cory Gilden:

Great question. They were two different subsets. So when people clicked onto the survey, they had to answer some demographic questions first. And then the last demographic question was asking them, which best describes you? And they had to select one of the groups. So person with disabilities, a person with intellectual developmental disabilities person with physical disabilities, and then family members was a separate one from there. And then from there, they were launched into a unique track of questions. So yep. Some of the questions they were asked were the same, which is why you saw on some of the slides, we said, this is what family members said, and this is what people with disabilities said. So we were able to combine, not combine the responses, but display both of their responses side by side.

Shawn Ullman:

We had a question about whether a first party trust and a Special Needs Trust are the same. And I would encourage you all to take a look at those videos that I just shared to very quickly answer that question. A first party

trust is a kind of Special Needs Trust, there's also a third party trust and the differences where the money come from, but please take a look at those videos for more information.

Cory Gilden:

Yes. And in the survey we separated the group's first party, third party, and Special Needs Trust because you ask certain people and they don't know, they just say, "Oh, I don't know, it's a Special Needs Trust." So we didn't want to exclude those people and their data. So we listed all of it and just hope that people were as specific as possible when answering those questions when they knew the answer.

Shawn Ullman:

There was also a question about life insurance and how to include it in financial planning. And I would encourage you to speak to a special needs planner where you live because in a national webinar like this, we can't provide questions about people's individual situations. You need to be able to have someone, a special needs planning attorney, or a special needs planner. You can take a look at all of your personal finances and your personal situation and what the rules and options are in the state, where you live and then help you figure out what's right for you. Do you guys have advice for family members who are wanting to get started in this, on who they should be talking to?

Cory Gilden:

That is an amazing question, because one thing, as we said, one thing we quickly discovered when we first started in this journey was that there are many people and many points of entry that you can go to, to start your future financial planning. Honestly, if it were me, I would start at the Arc and get that bigger vision going and get the future planning in general going,

because as you said, most people who had a better vision for their future... And that's the first thing, when you sit down with the financial planner, they're going to ask you, what do you want, what are your goals? Where do you see yourself? And if you don't have that vision, it makes it a lot harder to kind of develop a plan to work toward that vision.

Cory Gilden:

But technically you can start off with a lawyer or a financial planner, or even an advocate working in the disabilities related field that can kind of help guide you. You can start with the benefits counselor. So we had all these points of entry. And this is a question that we threw out to a lot of people, like who should be the person to be starting this conversation, or who should I go to first? And unfortunately there wasn't a really clear your answer in the data. And that's one of the major issues because no one's really taking responsibility for that role. We, I think in an ideal world, the people who have the most direct contact with the people with disabilities and their families. So people providing services and supports would kind of, of be knowledgeable about the best jump off point. So hopefully they would be able to guide families to different professionals based on their own individual situation, knowing that family.

Cory Gilden:

So, yeah, sorry, no clear answer to that. But there are many places you can go to get information. What I would recommend is that you definitely go to somebody who is familiar with, like an elder law attorney who's familiar with kind of estate planning in general, and then also somebody who not only just says, "Oh yeah, I think I do that with people with disabilities," but who is knowledgeable about how these accounts will influence different benefits, public benefits you might be receiving and also talk with the benefits counselor about that as well, somewhere in your journey, early on.

Shawn Ullman:

So I've seen several folks provide recommendations in the chat and just, I think there are two primary sources that we here at the Arc recommend, which is the Special Needs Alliance and the Academy of Special Needs Lawyers. I would add the National Academy of Elder Law Attorneys, and we can provide links to all of those organizations to you in the email that we send after this webinar. And the other thing I would add is, the Arc Center for Future Planning has a tip sheet on our website for questions to ask lawyers and financial planners, just to make sure you feel comfortable with their knowledge of special needs planning, someone who's created a trust for someone with a lot of money, who's trying to set it aside for a family member is very different from the information that they need to understand to set up a special trust for a person with a disability that legally and safely protects their SSI and their Medicaid, and their long-term services and supports.

Shawn Ullman:

So we have a tip sheet on our website, and again, I'll share the link with that in the email that you'll receive after the webinar to help you try to pick a lawyer or a financial planner, as you're looking to make individual decisions. One participant pointed out how you spoke, I don't remember which one of you talked about the complexity and how hard it is to follow everything, and wanted to know if there's any work you're aware of that's happening around advocating to simplify the process and make it a little easier to understand how to save and how it affects public benefits and make the rules a little easier for everybody to understand so that they can take advantage of saving options.

Caitlin Bailey:

[crosstalk 00:48:16]. Yes. I mean, we are aware of some of the work that's being done nationally, and then on local levels, Shawn, the work of that your organization is doing is one of those that we would definitely point to the National Disability Institute is also doing some work related to advocacy and then also education and research as well. That is, we think can be incredibly helpful. We did hear about a lot of more local, either training, or education opportunities that exist that can connect people with resources that can be helpful. But I think naming them here might not be the most useful thing because those were more local and state by state examples. Cory, do you want to share some and then Shawn, I'm sure you have some as well.

Cory Gilden:

Yeah. I mean the hard about being a researcher and swooping and saying, "Okay, we'll examine this one issue. We'll point out to you what's working, what's not. And then we'll swoop back out." It's like, we work with people for a short amount of time and then as we go around presenting about the work, people will approach us and say, "I'm working on that issue, and that recommendation that you just said, but it's in development." Or, "We're getting that group together, but it's in very early stages." So the good news is, is that we do know that there are a lot of different people, both locally and nationally realizing that this is a hardship for people and wanting to kind of streamline the process.

Cory Gilden:

So I feel like forces are gathering to do that, and hopefully a few years down the road, it'll be a little better. There will be more. And which is why one of our main recommendations is there needs to be, and this is a lot of

parents and families we talked to said, there's no central hub, really. All the information's out there, I know it's out there, but it's over here. It's over there. I don't know who to trust, I don't know where to go and what questions to ask. I don't know that I'm asking the right questions, which as Shawn mentioned, they developed some materials to kind of help guide families through that process.

Caitlin Bailey:

One more that I forgot to mention, the Society for Settlement Planners is also doing some work and they're creating an app. The Society for Settlement Planners focuses more on people who have acquired disabilities, maybe through accidents or are later in life and are going through maybe some of those settlement processes. But they also, when we got to talk to them about the app that they're creating, the resources that they're creating, and some of the advocacy that they're doing is to make it so that more people have access to the services and supports that they need throughout their lives, whether they have a disability for their entire lives or whether they have a disability that comes on later in life.

Caitlin Bailey:

One of the other things that they had mentioned that they're doing, and what we know is that there's some advocacy to change some of the policies and regulations that impact people with disabilities. So there are some suggestions to raise the age at which people can open up an ABLE Account to later in life, or can start accessing ABLE Accounts until later in life. So that it is for people who both have developmental disabilities that start earlier, and then also for some acquired disabilities that might start later in life. There are also some recommendations to be able to, or some talks to be able to use some Medicaid funds to access future financial planning services. But I know that those are very early on.

Shawn Ullman:

Can you share any of the organizations or people, the online websites that you came across in your research that in addition to the Arc Center for Future Planning, that do help provide information about financial planning and are able to provide legal advice and maybe who are doing some of the local and state level advocacy that people could connect with.

Caitlin Bailey:

Yeah. I think it might be helpful if we send you a list to include in the resources that go out.

Shawn Ullman:

That's good.

Caitlin Bailey:

Yeah. A couple that come to mind, there's an organization, Special Needs Navigators, and another one that are that's called Planning Across The Spectrum, both are really focused on supporting people with disabilities to access and to understand financial planning. And we had really just wonderful opportunities to engage with the leaders of those organizations.

Cory Gilden:

A lot of these organizations are also highlighted in the white paper, but we will pull them out and create a list so that's easier.

Shawn Ullman:

Yeah. I was going to say, I'm assuming that many of the experts, as you called them in the white paper that you pulled together for your interviews would be folks you would maybe want to share. We did actually have a

question and I accidentally clicked on answered it even though we hadn't yet. Which was that when you talked about the experts, as you were going through their presentation, do you list them, do you say who they are anywhere in the white paper? Is that something that people can understand who you mean when you used that term experts?

Caitlin Bailey:

That's a great question. Yeah. On an early page of the white paper, we have a list of people who contributed to this work and that is that list of experts. But if there's a way to highlight that, I think one of the things that we can send you obviously is the white paper to send out, but early on in that thank yous that we provide, that list of experts that was included.

Shawn Ullman:

Thank you. And I think we have time for one more question. So I'm just scrolling through a lot of them are kind of similar to see if there's a different one.

Cory Gilden:

And just to speak for a second to that term that we use experts. I mean, obviously I consider people with disabilities and families as the number one experts in this process, because they're experiencing it firsthand, they're getting the knowledge. But we had them labeled as what they were, people with disabilities or family members of people with disabilities. And then these experts, we labeled experts as kind of a catchall category, including people who have written books about it, people who have done research about it, scholars in the field, and then people in the financial and legal sectors who have been working on this work for 50 years and have devoted their lives to helping people with disabilities and their families kind of navigate this process. So, yeah.

Shawn Ullman:

Did you guys come across to any good resources that describe sort of what's happening at a more local or state level rather than at a national or federal level? I'm wondering if NALA or ASNP might have something like that?

Caitlin Bailey:

I think that's a really good suggestion. We did talk to some people who were, they were running trusts though. And so that creates those slight issues of maybe a little bit of conflict of interest, but they were also providing some resources. I'm trying to think of that, but I think that NALA is a good, an ASNP are good places to go to for that.

Shawn Ullman:

All right. There were lots of questions about where to go and how to get started. And we are out of time. So just to remind everyone, there's lots of resources and information that Caitlin and Cory and their team put together in the process of writing their white paper. A lot of it is reflected in the white paper, which you all have a link to in this presentation and that you will get within a few days, once we get the recording and everything put together for you. So a lot of your questions about where to get started and who you can talk to, and what's happening at the local and state level will be available after the fact in those resources.

Shawn Ullman:

Unless you guys have, have anything else. I just want to thank everyone for attending. Thank you both for your time today and sharing the results of your research. I do think for many of us in the field, it didn't come as a surprise, but it's good to know that it was confirmed in your survey of

talking to more than 4,000 people. And I think I saw someone post the chat, "Now we just need to get everyone to implement your recommendation." And I 100% agree with that.

Caitlin Bailey:

Thank you. So for us.

Cory Gilden:

Yes. Thank you.