NRC SDM Webinar Series III June 17, 2015

Supported Decision-Making and the ABLE Act, Achieving Better Life Experience

Michael Morris: Welcome, everyone, this is Michael Morris, and I will be the moderator today for the third of a three part series in understanding more about supportive decision-making and moving from theory to practice. We have people joining us from all across the country. We're very pleased you're going to be with us for the next 90 minutes. This, as I said, is, is the third of a three part series. The first two covered issues around supportive decision-making and the education system, the second part of the series looked at supported decision-making as it relates to Medicaid, home and community-based service waivers, and this one, today is looking at supported decision-making and the ABLE Act, the Achieving a Better Life Experince. It was signed into law just this past December by President Obama.

We have three outstanding speakers with us today. You will hear first from Jonathan Martinis, Legal Director, Quality Trust for Individuals with Disabilities. Jonathan will be followed by Allison Wohl, the Executive Director for APSE on a national level. And third, you'll be hearing from Lisa Mills, who is the Public Policy Chair for TASH.

We will first hear from each of our presenters. We then have some pre-prepared questions, but you are also welcome to submit questions and we will add those as well. And we hopefully can, in the time allocated both get to the predetermined questions and also the questions that come in from you across the country.

So, let me turn first to Jonathan Martinis, who will start us off with achieving a better life experience, supported decision-making and the ABLE Act.

Jonathan Martinis: Good afternoon, thank you Michael. My name is Jonathan Martinis, I want to thank all of you for joining us today, especially for those who have been to all three of the webinars. I'm sure you're getting tired of hearing my voice, but I'm pleased and proud to present this today, about supported decision-making and the ABLE Act. Our goal at the National Resource Center for Supported Decision-making is to make supported decision-making, which you'll learn about today, a true tangible practice to improve people's lives rather than a fuzzy concept.

The point of this webinar, this being the third, if you have not been able to join us for the other two, they are archived on our website at supporteddecisionmaking.org. The point of this one is to show how, through financial planning, using supported decision-making can improve people's lives, outcomes and independence.

So as we begin that, I want to start with a simple question, what is your favorite right? What is it that makes it, what is important to you? What is it that makes us fully functional citizens and Americans and human beings? Is it the free speech? The freedom of association? Independence? Community integration? What do all of those have in come? Choice. The freedom of speech is

the right to choose what to say and not say. The freedom of life, liberty and the pursuit of happiness are all bound up in the choices we make. As Jean Paul Sartre said, we are our choices, we are the end result of things we've chosen to do, both good and bad. So, as I say that, choice, clinically speaking, is what is known as self-determination or the control you have over your own life. As professor Michael Wehmeyer says a person exhibits self-determination when he or she is a causal agent in his or her life. The one who does things, rather than have things done to him or her.

And we've known for decades that when people exercise more self-determination, they have better lives. Study after study has shown that people with disabilities and older adults, when they exercise more control over their lives, when they make more choices, they are more independent, they are more integrated into their communities, they have better health, they are better able to recognize potentially abusive situations and avoid abuse and they are better employed at higher paying jobs.

And by the same token, we've learned the opposite, that when you have less self-determination, you have a less well-rounded life.

Now think about this. When we talked about community integration, which is one of those rights that we all hold dear, what is it that really makes us part of our community? How do we not just have community integration, but have community integration into our communities? Where do you meet your neighbors? Where do you talk about things? You do that when you interact in the life of the community. At the store, at your job. At the bank. When you are part of your community. When you are taking part in the financial life of your community. That's why I say community integration isn't just based on where you live, but how you live. Are you truly part of your community? And you cannot truly be part of your community unless you are a participant in the financial sphere. Unless you can buy things and sell things and take part in the financial and active lives of the community in which you live. We know this. We already know, becauwse the studies have shown, people in like Forbes Magazine have said, people with disabilities cannot have a decent quality of life. They cannot be truly integrated into their community with just the financial resources and modest government support that the typical person has. And for that reason, the ABLE Act has come into being.

Many of you have 529 accounts for children or grandchildren, or friends, or relatives for college. Think of an ABLE account like a 529 account. You'll learn about it from people who know much more about it than I do. But as I understand the ABLE Act, it allows people to create accounts for people with disabilities, where money can grow tax free, not count against their Social Security or Medicaid eligibility, and be available for the types of withdrawals to pay for the things we need in our every day lives. Those things that give us the opportunity to integrate into our community. Housing and transportation, where we can get out and actually live and be part of our community are the very point of the ABLE Act.

So here's my question. Who decides? Who decides how the money is spent? How does that work? Who is going to ultimately make the decision of how a person interacts with his or her community? Because if this money is for that purpose, shouldn't the person, being a part of his or her community make that decision as well? I mean, think about it, the ABLE Act, its

preamble says the whole point of the act was to support people with disabilities so they can maintain health, independence and quality of life.

And if we already know that if you have more self-determination, if you make your own life choices, you are healthier, more independent, and have a better quality of life, shouldn't the ABLE Act empower that? Given the point of the ABLE Act to increase independence of the quality of life, should not ABLE accounts then also increase self-determination? Increase quality of life? Increase life choices?

To do that, though, we have to overcome 2,000 years of history, because for 2,000 years, we have been taking people who have some limitations in their ability to make decisions and taking away their right to make decisions. Whether we call that a curator, as the ancient Romans did, for people who are, quote, "feeble-minded" or do what they did in the middle ages in Britain and create committees for idiots and lunatics. Or today, whether we use guardianship to take away rights. Is that what we should be doing? Because the statistics are damning. The vast majority of guardianships take away every, all rights. Every single right a person can exercise is taken away by a plenary guardianship.

Studies have shown that upwards of 90% of guardianships entered are plenary. So the person who would benefit from an ABLE account, an account that's supposed to increase their independence, increase their community integration and quality of life, actually has no ability to do that because he or she doesn't have the right to make decisions about how he or she will spend that money. And that leads to a problem. A problem we've known about for decades.

Quoted by Congressman Claude Pepper in 1987, when he said the typical person under guardianship has fewer rights than the typical convicted felon. As we've known now for years that people under guardianship have a negative impact on their health, their longevity, their independence and their ability to function. Doesn't this mean that guardianship, plenary guardianship, especially when it's not necessary, when it's overbroad or undue, actually works against the letter and the spirit of the ABLE Act?

Think about it. Typically, again, what is the main financial method for providing for a person with a disability? A special needs trust. How does that work? Who decides how the money gets spent in speciail needs trust? It's the trustee. It's someone else. The person can make a request for money to be dispersed from the trust. That does not have to be approved. It removes self-determination, removes control, causality, and life choices. It's antithetical to the purposes of the ABLE Act and it goes against all the studies we just talked about.

So how can we make ABLE able? How can we fulfill purpose and the aim of the ABLE Act, and I say through supported decision-making. People with ABLE accounts may in fact have limitations in their abilities to make decisions. Don't we all? Everyone on this phone call has limitations in their abilities to make decisions because there are things you don't understand. And when we don't understand something, when we have questions about what a doctor tells us, or an accountant, we go and we get information. We ask people for advice. We do research. That's what supported decision-making is. It's where people with disabilities, older adults, people with limitations, use friends, family members, and professionals to help them understand

the choices that they have to make. To help them understand the situations they face. So that they can make their own decisions without the need for a guardian. Doesn't that serve the purpose of the ABLE Act, to increase independence? Rather than taking away the right to make decisions, empowering it. Enhancing it. Giving people what they need to make their own financial decisions so they can be a part, truly, of their own communities, just like you and me.

Everything I've just said describes the same way you and I make decisions. There isn't a person listening to this call who didn't use supported decision-making this week, who didn't ask someone for advice or do some research, or go to a doctor and say, can you please explain that in English? And if you can do it, if you get help especially in financial decisions from an accountant or an investment professional, or something online, then a person with a disability can do the exact same thing through an ABLE account.

And what we know about supported decision-making from the publications, is that it can increase self-determination. So if supported decision-making increases self-determination, and we know conclusively that self-determination increases quality of life, do we not have an obligation to use supported decision-making in order to reach the goals set by the ABLE Act and so many other laws? Of course we do. Because through that, we can increase self-determination.

What we know about supported decision-making is one size doesn't fit all. Just like you and I make decisions in different ways, people with disabilities can use supported decision-making to make their own decisions. Everything from informal support when you ask for advice to people helping you out in written decisions to powers of attorney and advanced directives to even very formal microboards and circles of support. All of these are forms of supported decision-making. If you think about the way you use supported decision-making, you individualize how you use it for the situation you face.

So can people with disabilities. Let me give you an example. You can use a power of attorney to incorporate supported decision-making into financial planning. Everyone recognizes powers of attorney these days. Look at your screen. What if you put in a written decision that people would work together, I will work together with the person who is the agent under the power of attorney form to make sure I can make my own decisions, that we're going to have an accepted method of supported decision-making, a formal method that says precisely how we will implement this method and that could even go so far as to making a cooperative spending agreement, not much different, by the way, from a joint bank account that requires two signatures on a check. I can say, you know what? I feel I have some limitations in decision-making, so I'm going to deputize you to be my supporter. And if I want to spend more than $1,000, I'm going to need to consult with you first. And we're both going to have to agree before that check gets cut. Everything up to that I can do on my own. And it's your job, supporter, to help me understand these choices so that I can make my own decisions and putting that in a power of attorney, lets the whole world know, lets the banks know, lets the merchants know, lets the professionals know that we use supported decision-making as our method of making decisions. It tells the whole world that I am an equal participant in this process, that I have the right to make choices on an equal level as everyone else. And out there are opportunities to exercise the right to make choices again and again and again from an early age through adulthood all the way through end of life.

There's all these opportunities to develop supported decision-making and decision-making skills. From the IEPs, where students at a young age can be talking about independent living skills like financial management, to vocational rehabilitation, where you can exercise informed choice to ensure you have the ability to work in integrated settings, to individualized service plans in Medicaid, where you exercise person-centered planning where others help you make the best decisions possible to live as independently as possible. All of these are opportunities to develop the decision-making skills inherent in supported decision-making, so that when you have an ABLE account, you are in the best possible situation to make your own decisions about how you will be integrated into your own community.

And if we do that, then we reach the goal of ABLE. We maximize independence, we maximize quality of life by giving each person an opportunity to be his or her own causal agent. Where each person has an opportunity to be the driving force in his or her life. Getting the help to make decisions that we all already have. We all already need. Accessing the support we all already use. People with disabilities may need help making decisions, but don't we all? We all have the same rights to make choices.

And as I leave you, I, I invite you to join the National Resource Center for Supported Decision-Making, you'll be able to find these slides and everything else you'll hear today, as well as our prior two webinars. here you'll see resources and research about supported decision-making and have the opportunity to access supported decision-making interactive, a dedicated Listserv where I invite you to ask questions. Questiion this method. Make us hone this method. Make this method better so that we can truly reach the goals of ABLE and federal laws and state laws and all of the studies saying that self-determination equals a better life. Thank you so much.

Michael Morris: Thank you, Jonathan, and this is just part one of a three member panel today that you're going to hear about supported decision-making and the ABLE Act. I do, before calling on our next panelist, want to express our support and appreciation for the funding for the National Resource Center for Supported Decision-Making, is funded by the U.S. Administration for Community Living within the Department of Health and Human Services. This is year one of a multi-year project and as Jonathan mentioned, I do hope you will take the time and if you haven't already, visit the website which is www.supporteddecisionmaking.org, where you will find this and the prior two parts of this webinar series archived and wonderful other information and resources to learn more about supported decision-making.

Let me turn next to Allison Wohl. Allison is the Executive Director of APSE National. And Allison, maybe just for some of the people who are joining us from across the country, do a short infomercial for APSE. You've got lots of things going on next week and all year long. I appreciate you taking time out of your schedule to be with us, but do a little brief introduction to APSE and then we can turn to your PowerPoint.

Allison Wohl: Sure, I'd be happy to. Thanks, Michael and thanks, Johnathan. So, APSE actually stands for the Association of People Supporting Employment First. We're a national membership organization. We have 38 chapters, 38 state chapters and about 3,300 members and we do have our national conference next week in Philadelphia and APSE has stood for the rights for individuals with disabilities to have real employment and real wages in their communities since

its inception in 1988. And it actually really grew out of a supported employment grant that came out of the Department of Education. And so our membership is families and individuals with disabilities and also providers who support employment services and a lot of state, Voc. Rehab., and mental health agencies personnel. So it's a coalition of people who believe very strongly in, in supported employment for individuals with disabilities. And I became the national director in January, so I'm pretty new. But I'm also the parent of a 5-year-old son with Down Syndrome, so if you're wondering why I'm on this webinar, that's why [audio unclear]. Do you want me to keep going, Michael?

Michael Morris: Yes, take it away.

Allison Wohl: Okay, great. As I said, I do have a young child with Down Syndrome. And there are a lot of reasons why decision-making and the ABLE act are really important to me. Personally to me, my family and this generation of families, people with disabilities and, and I say that because this is the relatively, it's not relatively, it's a fairly new concept in the sense that it's a generational concept. You know, the families who fought hard in the 60s and 70s to close these institutions, the institutions for the "mentally retarded." For them, you know, guardianship was a really, was, seemed like the only way to have sort control of resources of their loved ones who were no longer in institutions. And what we know now is that's not the case, and in most cases, guardianship is a real problem in terms of making decisions, in terms of having standing in a court of law, in terms of having basic rights of citizenship, like voting, for instance, in many states.

But for us, personally, so, I was introduced to this when my son was very young because my father happens to be a tax and estate attorney. And so this was when my son was a newborn, and shortly after this my dad said to us, have you set up a special needs trust, or a supplemental needs trust, as it's called in some states? And I said "I don't know what that is." And he said, "you have to write him out of your will or else he will accumulate assets and he will be ineligible for services when he's an adult." So let me repeat that. We had to disinherit our son. My mother-in-law had to disinherit him and obviously it's extremely emotional for us. My mother-in-law is Jewish and for us to say, well, you know, Julian's bar mitzvah invitation, it had to say no cash gifts, it was just emotionally devastating. But luckily, I was in Washington, and got involved with the National [audio unclear] Society.

Because when I realized we had actually set our child up for a life of poverty, I realized that something had to be done. So shortly after that Christmas, and we celebrate both in our house, we celebrate Christmas and Hanukkah, I attended, actually Julian and I attended together the first national society capitol hill day. And as you know, the national [audio unclear] society speaks for the groups that really [audio unclear] ABLE Act. And so Julian and I went and we learned about ABLE. We learned about what ABLE could do and for our family and for our children. And how it would really change the paradigm of economic self-sufficiency. It wouldn't do everything that we wanted it to do, but it really went a long way towards righting a wrong that is in the Social Security Act.

So we were also working to be able to witness the house vote in December, after we'd been through five years of NDSS Hill Days, advocating for the ABLE Act. Meeting so many other

families, and meeting so many members of Congress who, one by one by one by one, really began to understand why this was so important.

And along that way, we also learned that our system of support and services for individuals with disabilities in this country is deeply flawed. I'm either lucky or [audio unclear], I can't decide, because I learned so much of this when my son was so little. For most of us parents, we only realize that our system has these problems after our children age out of IDEA. And then all of a sudden, they are facing what we call the cliff. And so now you have to transition into the adult system. And in most cases, during the transition system, the transition years, 18-22, school personnel tell families you need to do two things. You need to get guardianship and you need to get your child on SSI. And that's because in many states there are waiting lists for Medicaid waivers. So you have to get SSI and that's how you qualify for Medicaid. And it's simply not true. Some schools tell families, you can no loner participate in IEP meetings unless, if you don't get guardianship. Again, that's not true.

So, when I first met Jonathan, a couple years ago, one of the first things I said to him, we have to get the schools out of the business of advising guardianship and SSI and working with the Department of Education to try to have them put new guidance on that. I don't know whether it will happen, but we'll keep going to visit them until they do. So when you apply for SSI, you have to declare yourself unable to work in order to be deemed eligible for SSI. And for those of you who don't know, that's Supplemental—sorry, I'm drawing a blank here. Supplemental Security Insurance?

Michael Morris: Supplemental Security Income.

Allison Wohl: Thank you, Michael. We have a conference next week, and my brain is full. But basically, you know, you have to say I am not able to work and that's why I must be on SSI. And then, we get really confusing messages from the Social Security Administration. Because in order to get your support and those long-term supports of services, one of those services is employment services, you have to say that you're ineligible. You're unable to work. What happens though, once you get on SSI, you're subject to the Security Administration's artificially low asset income limitation.

We think that's essentially confining to a life of poverty. So that asset limitation is $2,000 over a lifetime, which means the individual cannot accumulate, over a lifetime, more than $2,000 in assets. And there are also income limitations that are decided by the state. So the system sends really confusing messages. It effectively incentivizes work, and discourages work at the same time. It says, the system says, you can work and there are work incentives, but if you make too much money to qualify for SSI, you can get Medicaid, you can do Ticket to Work or all these other programs you can take advantage of. However, you're entitled to the benefits because you're unable to get to [audio unclear]. Really, this was designed for another time. It was designed for a time when people with disabilities were never assumed to do anything but really live in an institution and probably die young, and certainly not work. So clearly our system is really, really outdated.

And that's why it was really necessary that the ABLE Act be passed. Because what the ABLE Act effectively does, is it raises the SSI asset limitation to $100,000. So let me be clear. It doesn't do anything in the Social Security statute, in the Social Security Act statute. What it does is kind if goes around the statute and says, but you may, through the ABLE Act, open an account, which ew mentioned earlier is a subsection of the 529 code. One limitation of the ABLE Act is that it doesn't address state income limitations; however, the Act does encourage [audio unclear] savings, by allowing income to be deposited into ABLE accounts up to $14,000 per year. So if I have someone who's keeping my income artificially low, so I don't disqualify myself for benefits, now I can actually save and I can go ahead and work more hours if I want and get that raise if I want. Because I can now my income in an ABLE account and it won't disqualify me for that.

We hear a lot of pushback, I hear these all the time from a lot people, say they don't want change. They're driven by fear and as a parent, I do understand that, but I don't think we need to be you know, having fear as our guiding principle. Because we know that, as John mentioned, we do have other opportunities from sole guardianship. So if your loved one does need support in different areas there, are plenty of people out there to help them.

Here's what I hear all the time: My adult child doesn't understand money. So therefore, they should have financial guardianship. [Audio unclear] you have too much income. That's a really qualified statement; the system is extremely complex. But by and large, that is a myth. Up to a certain level of income. Which a lot of people, people, not just people with disabilities, are not going to reach.

Another myth is, she needs a trustee to make financial decisions for her, on behalf of herself. Well, so do I. We have an accountant, we have an investment advisor, and those people can be put in place also to help anybody make a financial decision. Another myth, his assets will count against him in determining eligibility for benefits. Well, true, but with an ABLE account, that person can save up to as I said, $100,000 without losing benefits. And what's interesting and what's key to the ABLE Act is that an individual can save up to $100,000, actually $102,000 at which point the benefits are suspended. So everyone's biggest fear is, I waited five years for that Medicaid waiver and I don't want to get back in line. So what the ABLE Act does is, your benefits will be suspended but you will not lose them.

Another thing we hear is she's vulnerable to scam artists, so she needs guardianship. Well, guess what? So are a lot of people. I have my father now who actually has Alzheimer's Disease and guess what? He doesn't have a guardian. We know that many people, many older Americans, just many people in general are vulnerable. But again, that doesn't mean they need all of their rights as Americans taken away because they need help making decisions. What we do know is the truth is that the majority of people with intellectual and/or developmental disabilities can manage their own affairs with informal assistance and guidance from family, friends and others. What's really important to think about in terms of supported decision-making, is most guardians are appointed by the state. They are not, in most cases, people who are family and friends and who will help make decisions on behalf of the individual who is under the guardianship. So what happens is, there is an enormous amount of fraud and abuse in the system.

So, sort of like institutions, we think that somehow, restricting people's rights is making them safer. When actually we know that people are much safer, their decisions, their assets, their persons, are much safer when they have people around them to help.

Jonathan touched a little bit on this, but you know there are many alternatives to guardianship. Power of attorney, [audio unclear] money management advisors, Social Security representatives of payment programs, and trusts. And I will say that the ABLE Act wasn't meant to supplant needs trusts, they were meant to supplement them. So a person can have both a trust and an ABLE account. So I'll end by saying individuals may communicate wishes, decisions, likes and dislikes in nontraditional ways, which can include actions, rather than language. Friends, family members, and others who are trusted by that individual can help interpret those decisions. Just because someone doesn't communicate in a way that is traditional doesn't mean they shouldn't have likes and wishes and desires that should be addressed.

So, I will go to the next slide. If you have any questions, please feel free to contact me and I know that you will have these slides, so here is my contact information. Thank you for your time.

Michael Morris: Thank you, Allison. And now let me go to our third panelist, Lisa Mills. Lisa is the Public Policy Chair at TASH. She also is an expert advisor to many states across the country, working on cross-system collaboration, working with typically state IDD agencies, as well as Vocational Rehabilitation, the workforce development system, educational agencies, looking at ways we can kind of pull things together, integrate resources, blend and braid resources, to achieve better outcomes in terms of employment and economic self-sufficiency. Lisa, I'm glad, in your travels, we were able to capture you today and you're going to share your perspective on the ABLE Act and a new path to self-determination.

Lisa Mills: Thank you, Michael, I appreciate the introduction. Yes, I'm going to talk about the ABLE Act as another and new path to self-determination and think about it from the perspective of someone who is also receiving Medicaid, home and community-based services through an individualized budget. It's often the case of self-determination and the way we have tried to make self-determination happen for people has been through the creation of individualized funding in the long term care system. And so I think the ABLE Act presents a new opportunity for people to have even greater self-determination. So could we please go to the next slide? I'm on slide 39.

ABLE accounts beyond supplemental needs trust. As Allison mentioned, ABLE accounts are meant to be complimentary to supplemental needs trusts, not to eliminate those trusts, but the reality is that ABLE accounts do something distinctly different from a supplemental needs trust. So trusts have been in existence for a long time and have allowed people with disabilities and their families to set aside funds for a person with a disability without impacting their eligibility for Medicaid. Not all people can afford the cost of setting up and maintaining a supplemental needs trust. Although, numbers of states have established cool trust options that have lower costs for setting up an account and for maintaining that account over time.

But the biggest thing I think the ABLE Act brings that a supplemental needs trust did not is that it allows you to purchase things that can enhance Medicaid. A supplemental needs trust has always been for things that Medicaid can't pay for. Hence, it was called supplemental. But that

didn't have a lot of utility for people whose real primary need was to have more of what Medicaid pays for. Because a supplemental needs trust didn't allow you to use the funds for that. The ABLE accounts, do do this, and I want to talk about why and how that could be beneficial for people. Next slide please.

I'm on slide 40, what ABLE can pay for? This is from summaries of the ABLE Act. As Jonathan mentioned at the beginning, any qualified disability expense, meaning any expenses related to living a life with a disability and so...this is far broader than what a supplemental needs trust can pay for and includes things like education, housing, transportation, employment training and support, assistive technology and personal support services and then things like health prevention, wellness, financial management and administrative services, legal fees and then expenses for oversight and monitoring and last but not least, funeral and burial expenses. There may be additional expenses defined in the regulations, I highlighted in red on this slide, the things that really lend themselves well to people achieving economic self-sufficiency and true self-determination.

And so, being able to use an ABLE account for education, for transportation, for employment, training and support, to ensure that you can get a regular job, as Allison spoke about, a real job at real wages in the community, to use assistive technology and personal support services as well to help with employment, opens up a tremendous option for people in terms of building their assets through work.

Next slide, please, I'm on slide 41, access to Medicaid preserved. I think we will need to repeat over and over in many different ways, the protections for Medicaid eligibility that come with having an ABLE account. So ABLE accounts are disregarded for the purposes of determining if people are qualified for Medicaid, in terms of their asset limits.

So, you, as, as others have said, you can have up to $100,000 in an ABLE account and not impact Medicaid eligibility. This is incredibly important and people will need to hear it many times because they will probably doubt, doubt it the first few times they hear this. And most importantly, I think, ABLE is intended to supplement, not to supplant Medicaid benefits, so, to enhance people's supports that are available to them, in addition to what Medicaid would pay for. And I think if you are a person with a disability who is involved in a home and community-based waiver or you are a family member of someone who is likely to be eligible at some point, you will probably know already that Medicaid doesn't meet all needs.

Next slide, please? So rhere are opportunities to use assets in an ABLE account when Medicaid doesn't provide everything that people need. And there are a variety of reasons that Medicaid will not provide things. First, they have a requirement that what they pay for must be deemed medically necessary. And so depending on the state's policy and interpretations, they may deem something you as an individual with disability needs as not medically necessary.

And they also say what you'd like in terms of services and supports may not be, in their view, the most cost effective way to meet your needs and so, they may deny certain types of supports to you on that basis. Sometimes though, I think what happens typically, is they'll give you a certain amount of service, a certain allocation of service to meet what they deemed to be your assessed

need, but they will not necessarily give you the level of service that you, you believe that you need to have a full life.

The last thing that can happen in Medicaid is they can tell you in Medicaid that you don't meet the eligibility criteria for a particular type of service or support. So even though you are eligible to be part of a home and community-based waiver, you may not meet the criteria for certain types of services and supports. All of these situations are situations in which an ABLE account can be useful.

Next slide, please? I put this slide together to show you a couple of different ways that you could use an ABLE account to get out of poverty. And frankly, a lot of things that people with disabilities deal with on a day-to-day basis are not necessarily because of their disability. It's often because they are living in poverty. So for families of young people, with children, the star on the left side of the slide is where you may start, with opening an ABLE account at a very young age. And beginning to save into that account for a young person with a disability. That, then, can contribute to that person getting the kind of access to education and the educational supports to progress out of secondary school and to get to employment training and supports and to get a job.

We now know that secondary education is a critical part of what youth with disabilities need to succeed in adulthood. And that, followed by good employment training, supports, help with transportation, and assistive technology, can help people achieve a decent job. And when they have earned income, then, that can go into the ABLE account, and that can build up in that account. And it offers things. One of the main things that we think of when we think of American Dream is owning our own home, and the security that that gives people, to have their own home where they choose who their providers of service will be, who their roommates or housemates will be, where they will live.

A tremendous part of self-determination is not having to live in a home that’s owned by a provider service or owned by someone else who at any point could terminate your lease. So the star to the right of the job circle would be where an adult who had acquired their disability at an age below 26 to be eligible for an ABLE account who could open an account now and use that ABLE account to hold earned income. Again, to help them potentially pursue homeownership, pursue additional education and training to get an even better job, or to pay for the things that Medicaid is not paying for.

Next slide? So, I want to talk a bit about self-directed support under a Medicaid waiver and when people have an individualized budget. This is becoming a popular option in many states to go this direction with Medicaid waiver services. So these happen, these occur, when people choose an alternative to an institution or a nursing home. They want to live in the community, they want community supports, and the state will allocate an individualized budget to them, through capitated funding model. That budget, that Medicaid budget, is attached to the individual and can be used to purchase any waiver services, any services that the state offers for community support under its waiver program. Many people like individualized budgets and want to be part of that, if it's available through their Medicaid program because they can choose the services, then, that they wish to have, the types of services that will meet their needs and help them achieve their

goals They can also choose and hire their own service providers and they can select from a broader range of providers. In terms of who they want to deliver those services. So there are a lot of things about individualized budgets that are very attractive and that really do promote self-determination. People can also decide how much to pay for the services to a varying degree. There are some states where there are certain safeguards in place, very broad, just to prevent really significant overpayment for a service. But some states dictate rates and you don't have as much choice, and I think there's still an issue with whether or not people can pay for outcomes. So, instead of me paying you for hours of effort, I'd like to pay you when you get me a job. Those kinds of things are things I still think we need to work on, but overall, individualized budget gives people a lot of control that the old, the traditional system, did not.

Next slide? Slide 45, the, continuing with the discussion of self-directed supports under a waiver. The downside of the individualized budget is you still only have the resources that Medicaid would otherwise allocate to you. So it doesn't create additional Medicaid resources for your use, it simply puts them in a budget and allows you to choose the services and the providers of service that you wish to have. So it's a fixed amount of money and it, in many cases, may not feel like enough resource to really meet all your needs. The other issue is that even though we have a principle responsibility built into self-directed support and self-determination, it's often not emphasized and mostly the emphasis is on choice and control. And in a reality, an individualized budget doesn't create any new incentives for work. We still have a Medicaid, the same disincentives for working and saving money.

In some cases, and this has been touched on before, people who have an individualized budget, but who also have a legal guardian find that they don't really experience any greater self-determination. That the guardian is in full control of the budget. And this has been an issue and it's been talked about, we have not found a way, at least not on a broad scale, to actually utilize supported decision-making, rather than defaulting to the substitute decision-making models where we essentially take over choice making for people.

Next slide? So the ABLE Act and the ABLE accounts are a great extension of self-determination and supported decision-making. So, if you are a person, or will be a person in the future, who has an individual budget under a Medicaid waiver, you will have, typically have a support broker which is a person that's paid for through Medicaid, that assists you with making a plan for how you're going to use the budget. You must use the budget to meet your needs and achieve goals that you have and the support broker is really there to help you do that. They are not case managers in the traditional sense and the good thing about that, they're not gatekeepers of the resources. Models that don't involve individualized budgets, you often have a case manager assisting you, and they are, in some sense, a gatekeeper of public funds. When you have an individualized budget, the funds have been allocated to you. It's not a question of gatekeeping those, it's a question of how do you use them best? And your support broker plays that role and you typically have the choice of who you look to hire as your support broker. So, ABLE account are very similar in a lot of ways to an individualized budget under Medicaid. And when you put them together, I think people can have tremendous opportunity that they don't currently have.

Next slide? Slide 47, ABLE as an extension of supported decision-making and self-determination. I believe that a support broker who is working with you on an individualized

budget can help you grade the ABLE resources that you would have in your account with a Medicaid individual service plan that is funded by your individual budget. So ABLE can help when a Medicaid budget and plan are limited, either because, as I've mentioned before, something is deemed not medically necessary, so you can't spend your individual budget on that. You could use your ABLE resources at that point to purchase whatever that is. In some cases, you will be able to spend your individual budget on a type of service or support that you need, but you won't be able to get as much service or as much support as you think you need. Your budget will be fixed, it will only go so far. In that case, you can use the ABLE account to supplement for particular types of services and supports.

And then, the third thing is where an individualized budget under Medicaid cannot be used for a certain type of expense. It is not permissible, it's not covered and if you need that kind of support, you could then use your ABLE account for that kind of support. So there are a number of ways where an ABLE account can enhance an individual budget under Medicaid and get at some of the gaps that that budget won't address.

Next slide. So, in terms of advice as we go forward, this is all very new, but support brokers, I see as a critical assistance. They will be helping you spend your Medicaid budget and come up with a service plan to use that budget and they will be a very important ally in terms of thinking when does it make sense and how does it make sense to use ABLE resources to supplement a Medicaid individual budget. But people also need trusted families, trusted friends, a circle of support, whatever you want to call it, people need people who are in their life, not paid to be there. And to help them, again, to see what are their goals and what are the pieces of support that they need that are missing from what they might get through Medicaid.

I believe a Financial Advisor is also important. Support brokers are not financial advisors. They're trained to help you spend a Medicaid budget and an a service plan. They are not trained to help you know, to help you figure out when to contribute and how much to contribute to an ABLE account and how much to withdraw over time to keep your account going for as long as it can go. You really need somebody with different type of expertise for that. So, I wanted to point that out. And my last point is really, I want us all to remember that the goal of life really is not to be able to buy all the supports that you need. We often find people with disabilities are isolated and segregated from the mainstream of life and what I see mostly is that's because they live in poverty. And because our service system hasn't really focused on community benefits. But if we can use our public resources and ABLE resources to help people be full participants in community and in society, that is when you get the opportunity to have natural supports in your life, the people that you can rely on who are not paid. Who we do not have to pay to provide support to us.

So, I want to keep that in mind as we're building assets and financial funds for people, that what we want, ultimately, is for them to have access to a good network of family, friends and people who can support them. Thank you. I think the last slide is my contact information. Slide 49.

Meera Adya: Thank you very much. Can everyone hear me?

Lisa Mills: Yes, Meera, we can hear you, want to go ahead with the questions for discussion?

Meera Adya: Sure, thank you. This is Meera Adya and I'm the Director of Research at the Burton Blatt Institute. Michael had to step away momentarily, he will be returning, but in the meantime, I'd like to moderate the questions. So we have some prepared questions and of course if folks have questions, they can type them into the chat box, and we might be able to get to them today in the meeting or if not we can gather responses and post them alongside the rest of the materials from today's conference that we'll be hosting.

The first question that we have in hand is financial decision-making is a set of knowledge and skills that should be learned based on educational experience over the course of the life from children to adults to older adults. Should these skills be part of IEPs, IPEs and individual support plans? And I'll just throw this out there and you guys can respond to it in turn.

Jonathan Martinis: This is Jonathan. The answer is absolutely. And those requirements are already, in my opinion, in the law. For example, an IEP, an Individualized Education plan is supposed to include supports and services to help people make the transfer from school to post school activities, including independent living skills. Specifically including independent living skills. Transition planning required to started at the latest at age 16 is supposed to include supports and services to help people acquire daily living skills. In today's world, financial decision-making is a critical part of independent and daily living skills. So absolutely in Special Education.

In Vocational Rehabilitation, the ability to manage money is a crucial part of gaining and keeping and maximizing your employment capacity. If you're unable to budget, how can you keep a job? Would you hire somebody who isn't able to be organized enough to do the most basic financial planning requirements? And the same in the Medicaid world. How can a person live independently, which is the point of a Medicaid waiver plan, if he or she cannot make basic financial decisions? So it is both implicit and explicit in all of these service systems that there should be financial decision-making built in. If you don't demand it, you're not getting everything you can out of those services.

Lisa Mills: This is Lisa Mills. I'll just add on to that, of course the answer is yes here, but I think it's really important that, that we recognize that people learn by experience. And from a very young age, when we give children spending money or we have them do things that they then earn money they save to purchase something they want, we're helping build those skills for adulthood and I think when you, if we look at some of the research that is going on, we see that youth with disabilities are often excluded from those fundamental opportunities that we often provide to all other children. That they have not had an allowance or spending money from a very young age. They have not been given chores like other children in the family where they can learn the relationship between completing a task and receiving remuneration for that. And I think waiting until IEPs, IPEs, and individual support plans, which frankly started, if we're lucky, IEPs start at age 14 and the rest occurs after, it's too late. I think we need to start thinking about opportunities that start much younger, where we go forward, assuming that youth with disabilities will grow into adults who control their own finances with support from others.

Michael Morris: Okay.

Meera Adya: I think Michael is back.

Michael Morris: I'm back, and I'll take over and go to question number two, and I guess this one is, is to Allison, and as you described, you're a parent with a younger child with disabilities. What do you think parents, responsibilities of parents to advance financial decision-making skills, even with young children?

Allison Wohl: Well, I, you know, Lisa just talked about that. I think, for instance, you know, just, giving your child some responsibilities with his or her own money, doing things around the house, giving allowance, just like you would with any other child. And then, just you know, this can be part of the IEP process, financial management skills are being taught more and more in high school and personally, I think it's a great thing for, for any you know, any teenager to learn. No different than you would teach any of your other kids. I guess that's, we've developed this whole system that is, the idea that people with disabilities need some others, some other system, program, set of skills. They often need additional supports, but not necessarily a completely different program that any of your other kids. So I would say whatever you'd do with your other children.

Michael Morris: Okay, let go to question number three. The beneficiary is the ABLE account owner, some families are concerned their son or daughter doesn't have the skill or experience to manage their own account. Allison, I think all three of the panelists spoke about this, what options for support do you suggest as alternatives to guardianship? And maybe I'll start with Jonathan?

Jonathan Martinis: I think Lisa had an excellent description of the navigator or supporter through the ABLE account. So I would just echo that myself. I think the same support options, formal and informal that we all have to make decisions. My family is probably concerned, as I speak, that I don't make solid financial decisions. So what we have to do is the same thing I do. I do the best possible research and get the best possible advice. Understanding, and this is something I cannot state enough, is that we cannot condition the right to make choices on someone sitting here right now having the skill or experience to make good choices, because we all learn to make our own choices, often through making mistakes. People with disabilities and older adults are the only people who are held to the Mr. Spock standard. That if you can't make a perfect logical decision right now, then you're not allows to make any decisions. People have to be given the opportunity, with support, with guidance, that we all need to make our own decisions as we go along. If we give that kind of individualized assistance, you'll see that the decision-making skill, and it is a skill, will advance as well.

Michael Morris: Okay, I'm going to take one of the questions that came in on the chat room. It is, can you use ABLE account funds to enhance the pitiful wages paid to direct support staff by Medicaid? Lisa, do you want to answer that?

Lisa Mills: I'm trying to think creatively, because there are some issues with supplementing what staff are paid through their employment arrangement. I'm going to say, at this point, that I do not think that that kind of direct supplementation would be permissible, but I do know that families sometimes want to give gift cards and things and get into issues with that. So, I do not

believe that for the hours of service that a person is providing supports that are funded by Medicaid, that you can supplement that. If ABLE is being used to purchase additional services that are not funded by Medicaid, there may be ways that those services can be more fairly paid. And I think that'd be one thing I would suggest that this resource center take a close look at, because it is such a critical issue that the folks doing the work, the folks that you rely on the most are oftentimes so poorly paid for what they do.

Michael Morris: I would add to that, that the regulations or the proposed regulations to implement the ABLE Act are expected this summer. They're being drafted by Treasury and the IRS. And it will probably have additional explanation and guidance that helps qualify disbursements that are qualified as disability expenses. And so, there probably is more to come about that. I think that you could structure payments in a way that might meet one of the many focused areas that are clearly allowable in the statute to be covered from transportation to helping with employment to just overall, improving quality of life and independence. But it probably will be something worth looking at further.

There was also a question in the chat box: Can the trustee of a special needs trust transfer funds to an ABLE account? And here again, the answer would be yes, they could. That would be, again, a matter of an individual decision, depending on a person's circumstances, depending on the trust that the funds are in, and who is making decisions about the transfer of funds. But here again, the transfer of funds from different types of accounts to an ABLE account is probable something that will have further guidance in the proposed regulations I expect to come out later this summer.

Allison Wohl: Michael, this is Allison. Just a follow-up on that. But I assume if someone transferred funds from a trust to an ABLE account, they would have to pay the tax. The income tax: 39% to take the funds out of the trust? Is that true?

Michael Morris: Depending on the type of trust it was.

Allison Wohl: Because I know you cannot, I just had this conversation last week—you were there—we had this conversation about transferring money, the inability to transfer money from one 529 to an able account.

Michael Morris: Right, right. That's why it is an area that is not clear enough in the statute. And again, they may not touch it in the proposed rules, but what you would like to see is a transfer from a 529 college savings plan into an ABLE, a transfer from other types of retirement accounts or from a trust without consequences from a tax standpoint. Whether that would be allowable or not is unknown.

Allison Wohl: Okay, thank you.

Michael Morris: I'll go back to one of our questions. Question number four, how would you recommend states support the development of skills to be an account owner? And I think all of you have touched on this. But knowing the beneficiary of an ABLE account is also the account owner raises the point, Allison, you talked about it. I think all three of you talked about, is that

means there is a responsibility that could come within and Individual Education Plan, a plan for employment, individual support plan. That making the decision of the support plan is a skill set that could be a part of one of those individual programs and plans. Any of our panelists want to comment further?

Jonathan Martinis: No, except to amplify what you said, Michael, which is that these are already obligations that the state has. The state does not have to do anything more than what is already required to do. I hear from parents every day how the million things they have to do and to ask a parent or family member to be aware of the state's responsibilities, this to me seems cruel. So the most important thing the state can do is meet it's already existing obligations to special education, to take the step to ensure decision-making authority.

For example, I was just part of a study that just came out that said that the number one referral source to guardianship or school personnel. The school, teachers, guidance counselors are telling parents to go get guardianship. And I always asked the same question when I hear that. If a school had a concern that a student might have difficulty making decisions, where was decision-making skill in the child's transition plan? Because if you're advocating for guardianship at age18, what were you doing when that student was 15 or 16 and you had reason to believe the student had limitations in making decisions? IDEA requires that the school enhance that decision-making if they feel it's limiting the students independent living skills. The same is true of the Vocation Rehabilitation Act. It requires informed consent, which requires decision-making skills. So the most important thing states can do is do what they're already required to do.

Michael Morris: Alright. Let's go… can we go to question number five, if someone can move the slides and go to the next one? There we go. From a legal perspective, what are ways to formalize supported decision-making for an ABLE account owner? Jonathan, you're the attorney in the group. I guess there are a couple ways you could do that, what do you suggest?

Jonathan Martinis: I'm a fan of formalizing supported decision-making, although there is nothing requiring that you do that. One of my slides talked about placing supported decision-making methodology into a power of attorney or advanced directive. I've done that for people I've worked with. So that you have a piece of paper that people can see and respond to and respect. People tend to respect powers of attorney; they understand what it is. So if I go to a bank, or I go to a trust or attorney and say here's my power of attorney and it says how we're going to make decisions with regard to this ABLE Act and everything else, I think you're much more likely to get acceptance of it. So I'm a big fan of putting that in writing, and you'll be able to see for example the language I use on the slide, if you access our website.

Michael Morris: Okay, let's go to question number six. Can you envision an individual having an ABLE account and a special needs trust? If so, why and how would an individual utilize a trust versus an ABLE account? Well, I think we talked about this, but Allison, do you have thoughts?

Allison Wohl: Yes, when the ABLE Act is passed in Maryland, when we have our own, our own law here, we will definitely have both. And [audio unclear] trust for our son, and he will absolutely have an ABLE Act as well. Lisa touched on the fact that the ABLE accounts really

specifically pay for things that, that Medicaid does not. That's really the thinking behind the ABLE accounts. And sometimes the trust, you can put, you can use much more, you can put money in there. If my son wants to go to the movies or take a trip or take people out to dinner, you don't have to have a receipt and sort of proof of every expense the way that we do for a supplemental needs trust. The difference is that there is a trust, a trust custodian, and a trustee along with my son. So we will absolutely have both there for totally different purposes, but you know, as we mentioned a couple times, when you do withdraw funds from the special needs trust, it is taxed at the rate of about 39%. So you know, that's, you have much more, much more ability to choose what you use the funds for, but you do have to fund a tax from this.

Michael Morris: Okay, back to the chat box. Here's another question: As it currently stands, can an individual on SSI earn more than the maximum amount allowed per month and yet then save the additional amount in an ABLE account? I think there's a second part. I think we hear more about the ABLE Act as a parallel to the 529 savings plan, so this is a point of confusion. So, let's take both of these. In the first part, yes. A person could earn more, but thoughts about, could they put their money into an ABLE account? If they put their money into an ABLE account, and if they put their money into an ABLE account, would that reduce their SSI payments at all? Jonathan or Allison?

Allison Wohl: Can you say that one more time? The audio is a little bit dicey, so I want to make sure I answer correctly.

Michael Morris: Yeah. If you start earning more money to the point where for every dollar earned, your SSI is going to go down, instead, you're putting the money into an ABLE account, does that mean your SSI monthly payments will not be going down?

Allison Wohl: That is a really good question.

Lisa Mills: This is Lisa. I would say that think of the ABLE account as a way to disregard the asset limits associated with Social Security and Medicaid. It doesn't change the fact that you earned the money so you need to be able to use the work incentives and other things, your Social Security payments will go down if you're on SSI, you earn $2 and your payment goes down by $1, but there again, people can earn a pretty sizeable amount of money as compared to what they get in a monthly SSI check and still retain SSI eligibility. And the thing about it is that ABLE allows you to not have to waste that earned income just to get rid of it so you don't go over that $2,000 asset limit. So ABLE allows you to save earned income and only use it when you find that you have something legitimate that you want to use it on, up to $100,000. Which is a pretty sizeable account. But it doesn't change the fact that if it's earned, there will be the need to use work incentives.

Michael Morris: That's an excellent answer. The second part of the comment in the chat box is that so often we hear ABLE being talked about as a parallel to the 529 savings plan. And at times, this is confusing. And so, here, maybe, in shorthand, a summary of some of the points where it's the same, but many ways, it's different. Compared to the 529 college savings plan, because, in most states, as they begin to establish their ABLE program, it is going to be run by the same administering agency or office, often in the state treasurer's office. Second, it's similar

in the fact that for the money that comes out, income made on contributions come out tax free. So from that standpoint, it's also like a 529 savings plan. But in many ways, it's significantly different. There is no cap on an annual amount you can contribute to a 529 savings plan. There is a cap on annual contributions to an ABLE account of $14,000 a year whether it's one person contributing or multiple people contributing.

But also, on the other side, in terms of what you can use the money in an ABLE account for, it's not limited just to college tuition and housing and books. It has an array of needs which were shared in the slides that qualify as disability expenses for disbursement of money from an ABLE account that lasts over the course of a lifetime. And it is quite comprehensive in scope, education, housing, technology, health care, even financial advising. So, it has many more legitimate uses. It has raised the question for many, is that some people will create ABLE accounts for their son or daughter. Others, maybe adults with disability, who will be eligible to open an ABLE account and some people may use it for long-term, the idea of some day, going to buy an accessible vehicle. Or an apartment. And others may use it much more in a transactional way, daily or weekly. In the way the ABLE account, the ABLE Act was drafted, both uses would be legitimate as long as they qualified, it's a qualified disability expense. So there are some similarities, but there are a lot of differences.

Any of the panelists want to comment on that? Okay, I think we can get one more question here, also in the chat box, is what is the impact of ABLE not addressing state income limitations? And I think, Lisa, this is similar to the point you were making, maybe you can answer that?

Lisa Mills: I think I would defer to Allison on this question. Because I don't know that I'm the expert on this. Sorry.

Allison Wohl: Well I'm flattered that you we defer to me, but I don't know, we, actually talked about this last week at a meeting. It does not address the state income limitations. When you do have an ABLE account, at this point, you are still subject to state income limitations, which then, impact you know, your SSI eligibility. So it's both asset and income limitations and again, they're state by state. So, the ABLE Act gets specifically at the asset limitation if that makes sense, which is $2,000 and they are different depending on the state.

Michael Morris: And many people have raised the question, and in a few states they've tried to move this forward, is your ABLE account is not considered a resource or asset for means tested federal benefits. What about state or local benefits that have means or resource testing? And the answer there is it will depend on the state, a few states are actually looking at that they might follow and model the federal approach, but most probably will not. And that's, again, a related type of question. Well, I see, I believe, we're, we're just about out of time.

Give me enough time to thank our panelists, Jonathan Martinis, Legal Director with DT Quality Trust, Allison Wohl, Executive Director at APSE, and Lisa Mills, both independent consultant and also the Public Policy Chair at TASH. Thank you for your insight and I hope our audience has learned a great deal about not just ABLE Act, but also the relationship between supported decision-making and ABLE accounts. All of what you heard today will be archived on the website: www.supporteddecisionmaking.org. I want to thank, again, the Administration on

Community Living at HHS, Department of Health and Human Services for funding the National Resource Center for Supported Decision-Making. Everyone has the right to make choices, we hope we've given you better understanding and many things to think about in your work, whether it's individually or personally, in your family, or for yourself or it's in the work you do in support of people with disabilities to advance their community participation and independence.

So, thank you for joining us, we hope, again, you will visit the website and continue to learn more about supported decision-making. Thank you very much. Take care.