

## NRC-SDM Webinar Part II 05/14/15

Voice 1: Meera, you can start whenever you're ready.

**Meera Adya:** Okay, great, thank you. Hello, everyone, and welcome to our webinar. My name is Meera Adya, and I'm the director of research at the Burton Blatt Institute. And I will be facilitating today's webinar for part of the time. Our executive director will join us towards the end and be able to moderate some of the questions that we're going to be holding until the end.

Before we get started I did want to share information and answer some of the frequently asked questions. Today's webinar is being conducted using Blackboard Collaborate. It's system makes it possible for us to conduct workshops over the internet from just about any computer with an internet connection and web browser. Unfortunately, there may be computer issues inherent in your systems that are beyond our control, which is why it is important for you to check your systems prior to our session, but our IT staff is available upon request to work with you either in advance of the session, or once the webinar begins we might be unable to troubleshoot technical issues. Do email us, though, as this is going on and we will see what we can do. The session is being captioned, to turn on captioning please collect the CC icon, it is in the upper toolbar and will open a separate window with captioning.

Today's session is also being recorded and archived for future use so you will be able to view it again.

A link to the recording and presentation will be posted on the National Resource Center for Supported Decision-Making website at [supporteddecisionmaking.org](http://supporteddecisionmaking.org). All one word. Please share this with colleagues who may have missed the opportunity to participate in today's session. Also, all participants' microphones and phone lines are currently muted. If you have a question, please do type it in the chat area and we will be monitoring this. At this time we are advising you to close all other applications you may have running on your computer because they may interfere with your successful experience today.

Okay, so those are all the technical messages that we have to get out of the way. Our presenters today are Barbara Brent, the director of state policy at the National Association of State Directors of Developmental Disability Services. Samantha Crane, the director of public policy at the Autistic Self Advocacy Network. And Jonathan Martinis, the legal director for quality trust for individuals with disabilities.

Barbara is a director of state policy for NASDDDS. She has more than 34 years of experience in publicly-funded systems for children and adults with intellectual and developmental disabilities. She has worked in state and county government as well in the private sector. Before joining NASDDDS in 2012, Barbara spent six years as a state director for the Arizona division of Developmental Disability Services, supporting more than 30,000 children and adults with developmental disability as long with their families.

Samantha is the director of public policy at ASAN's national office. She's a graduate of Harvard Law School and has previously served as staff attorney at the Bazelon Center of Mental Health Law. Focusing on enforcing the right to community integration as established by the Supreme Court in Olmstead v. LC, and as an associate at the litigation firm Quinn, Emanuel, Urquhart, & Sullivan, where she focused on patent and securities litigation. From 2009 to 2010, Samantha served as law clerk for the honorable judge William H. Yohn at U.S. District Court for Eastern District Court of Pennsylvania.

And we have Jonathan, who has over 20 years of experience representing people with disabilities in cases under the ADA, the Rehabilitation Act, the Social Security Act, and other civil rights laws. In 2013, he represented Margaret Jenny Hatch in the "justice for Jenny" case which held that Miss Hatch has a right to use supported decision-making instead of being subjected to a permanent, plenary guardianship. He also represented the plaintiffs in Brinn v. Tidewater Regional Transportation, the first case to hold that people with disabilities have a right to paratransit transportation on a next-day basis, and Winborne v. Virginia Lottery, which held that the lottery must ensure that premises selling lottery tickets, including private businesses, are accessible to people with disabilities. With those introductions, I will now turn today's session over to Jonathan.

**Jonathan Martinis:** Good afternoon, thank you so much, Meera, my name is Jonathan Martinis, one quick note, we recently moved offices and therefore our tech may be still a little sketchy, if you're having trouble hearing me please write a comment and I will speak up. Today's presentation is about moving supported decision-making from theory to practice. I am the project director of the National Resource Center for Supported Decision-Making. We're a federally funded organization funded by the Association for the Administration for Community Living in the Department of Health and Human Services, designed to help people and organizations change policy and practice to make sure that people have the greatest amount of independence and self-determination as possible, and one of our areas of emphasis, in fact our major area of emphasis, is making sure that people have the options to live independently without being subjected to overbroad or undue guardianships. That is, guardianships on people who are able to make their own decisions without the need for a guardian.

So that is what I think the backdrop should be of today's entire presentation. You're going to hear about ways to make decisions in the healthcare and Medicaid arena and I'd like to focus those in my presentation on ways to avoid guardianship. As we do that, I want to focus on several articles of faith, the first of which is this, every person with a disability, and in that I include older adults who may have or are considered to have cognitive impairments, have a right to participate in every facet of society. That has been accepted law since the Americans with Disabilities Act in 1990. The second article of faith is that people who have more control over their lives, who have more what's called self-determination have better lives. That is not opinion; that is fact from over 40 years of studies. People with more self-determination are healthier, they're better employed, they're more independent, they have greater community integration. Third article of faith is that guardianship by definition, especially guardianship on people who are, who don't

need it, are able to make their own decisions, has a negative impact on people's lives. You are less healthy, less independent, less well employed. The fourth article of faith is that supported decision-making is an alternative to guardianship. It's a method of making decisions without disabilities, where people-- without guardianship, pardon me-- where people with disabilities make use of trusted family, friends, professionals, to understand the choices they have to make so they can make their own decisions without the need for a guardian. And lastly, that supported decision-making when used as I just described it increases self-determination. That people who use that have access to those benefits of having more life control.

So with those in mind, let's talk about what happens to people with disabilities. Is that in the healthcare field the studies have shown from the U.S. Surgeon General that as a general rule, people with disabilities have more medical conditions but are usually either over or undertreated so they don't get appropriate healthcare. And when we look in the guardianship arena, the studies have shown that a large percentage of people are referred for guardianship by medical professionals. So people aren't getting appropriate treatment and medical professionals are a major source of referrals for guardianship. I mean, think about it, think about why a medical professional would do that. Think about the obvious questions that would come that maybe you've heard from your friends or family members who've gone to the doctor. And the doctor says things like "well, this person may not be able to consent to this treatment, so who's going to sign the consent form?" Or, "who am I going to make sure pays for this treatment?" And all of that is about informed consent. I'm sure everyone has heard that phrase. Well, I liken informed consent in the medical field to capacity in the guardianship field. And it's the lynchpin, a person should not receive medical care unless they give informed consent. Unless they receive and understand information about the treatment, they understand the treatment they will be receiving, and unless they are able to exercise choice to receive that treatment. And from that you can see why a doctor, who is uninformed about things like supported decision-making may over-rely upon guardianship. May recommend guardianship because they are concerned a person can't give informed consent. Well what we need to know, what people need to understand is that supported decision-making can be used in every decision, and especially in the medical field. I mean, think about it, if you've ever gone to a doctor and heard a whole bunch of medical jargon about your diagnosis and you ever said "explain that to me in English, please," you ever said, you know, "I don't understand, I need some more information," you've engaged in supported decision-making. The difference is that people without disabilities when they do that, when they ask for more information so that they can get the information they need to give informed consent, people without disabilities are considered wise or showing good judgment to make sure they understand. A person with disabilities though, when they ask for more information, then by and large from what we've seen from the numbers are considered weak or dumb or in need of guardianship. Not wise like people without disabilities.

So realize that, that every decision can be done with support. Things can be explained to people. And that capacity to give informed consent, it's along a spectrum. We all have different levels of capacity. But all of us, if we understand and are given the opportunity to understand the treatment in front of us, can engage in informed consent. The

shorthand for that is a person can have capacity to consent to a flu shot while not having capacity to complete a credit default swap or to change a transmission in a car. Or to perform surgery. The difference is for medical decisions, you need to understand them.

So what we need to do, I think, and I think this webinar is going to do is, I hope what it's going to do, is galvanize support for making sure that supporting decision-making is used in the medical field. That medical personnel realize that supported decision-making is a legitimate option so that people with disabilities can make their own decision in the medical field. So that they don't have to be asked the question, well, who is signing your papers for you? Or who is, who are we going to make sure is responsible for this? The person is and should be responsible for decisions in their own medical care.

Well, how do you do that? You know, how can a person with disabilities who doctors have for years have thought aren't able to understand, how can they understand? How can we use supported decision-making in medical field? Well, think about a HIPAA release. Every time you go to the doctor, each and every time, you have to sign a release saying what information the doctor can share with other people. You are giving the doctor permission to discuss your medical care with another person. Well, what is supported decision-making? Supported decision-making is just involving another person or people in the decision-making process so that you, the person, can understand the situation and the choice you have to make, so you can give informed consent.

So why not use the traditional HIPAA release, the one you're already signing? And why not make a small change to it? To say that not only can the doctor give information to a third party, but can include giving that information for decision-making. And just like that, when the doctor gives someone else-- when you give, pardon me-- when the person gives the doctor permission to share information about your healthcare with that person for decision-making, you've taken a HIPAA release and you've created a supported decision-making release. You have created a permission to bring someone else into the decision-making process that you designate. The person who you want to help you. You can make your own form or you can use models that are out there. On your screen is link to one that Samantha's organization, the Autistic Self-Advocacy Network, has developed. You can simply bring that to the doctor and just like that, you create a supported decision-making form.

And you're going to hear, and I've heard this, so I'm sure anyone who does this will hear it too, a doctor or healthcare person will say bringing a third party in, doesn't that violate doctor-patient confidentiality? The answer is of course not, because there's no violation of confidentiality if the person gives permission for the other person to get that information. If I give the doctor permission to share information with my friend, there's no violation of confidentiality because I've okayed it. Another way of looking at it is it's the exact same thing as when a person who is Deaf or hard of hearing uses a sign language interpreter or uses real time captioning. The interpreter is not violating confidentiality, the interpreter is seen as an accommodation for the patient, the same should be seen in the supported decision-making field. There are other options, you don't have to just go with supported decision-making, I think sometimes doctors are more comfortable with that which they're familiar with, like advanced directives or powers of

attorney. But ten years ago they weren't as popular. It's my hope that eventually supported decision-making becomes as commonplace as the advanced directive or power of attorney. Both of these are legal forms where a person voluntarily designates someone else to either make decisions for him or her or to help make decisions with him or her. And with those forms, once again, you can go to the doctor and you can say, here, here is my permission to involve this person in the decision-making process.

Well, it doesn't just have to be giving up rights, the person doesn't have to say I want my mother or my brother or my friend or my professional colleague to make decisions for me, you can create an advanced directive with language like you see on your screen right now that creates a supported decision-making relationship within the advanced directive. I mean, think about it, what you're doing is giving permission to have a third person be part of the process. So language saying my agent will work with me to help me understand the choices I have to make, so that I can be the final decision-maker and I can make health decisions to the maximum of my ability. The same document can include language that says if you're unable because of a medical situation or God forbid an accident to make decisions yourself, that person can become the decision maker, but in all other situations that person is your assistant or your supporter, and just like that you've created a legally-recognized supported decision-making agreement.

Another way is through the person-centered planning process. It's always been my position that person-centered planning is the same thing as supported decision-making, we are just talking about different shades of the same color. Person-centered planning has been a popular phrase for a number of years. It just involves planning with a person's medical care. We see it in the Medicaid field and the Medicaid waiver field, I'm sure Ms. Brent is going to talk a lot about this, but think of it this way: Instead of having a person surrounded by professionals telling him or her what's going to be done to him or her, in person-centered planning the professional are working with the person to help the person understand the choices he or she has to make in his healthcare. What types of services and supports does this person want, where is the person going to get them from, who is going to provide them? So the person can understand, and the person can make that decision.

What we do there is we see a change from what used to be a directive process-- I will tell you what you need-- to a participatory process where the person can say, "this is what's important to me. This is what I want." And the others can say, "here are some options about how to get there." And the person can make the decision about how to get there. Doesn't that sound like supported decision-making like we described it? Doesn't it sound like other examples of supported decision-making like you've heard about it, especially if you were on the last webinar, and if not I recommend you go checking out the archive of that. Because that sounds just like a student-led IEP or that sounds just like informed choice in vocational rehabilitation, where instead of decisions being made for or instead of a person in the critical areas like education or employment, decisions are made with the person, with the intent of letting the person make the final decision and chart his or her own path.

It's an awful good things it sounds like that that, because as Ms. Brent is going to tell you this is now required under Medicaid waiver programs. Medicaid waiver programs being designed to help people live in the community rather than in institutions, to live independently. It makes sense if a person is going to live independently to, that person be the final decision maker of what type of services that person will need. The driver, the causal agent.

And we know getting back to guardianship, getting back to ways that guardianship can be avoided, is that guardianship happens when society feels people can't take care of themselves in a manner that society deems is appropriate. If society thinks that a person cannot make his or her own medical care decisions or needs someone else to see to his other her own medical care then society thinks a guardianship is appropriate. So I hope you can see why this is so important to combat the overuse of guardianship. Think about it this way: If you heard of the Olmstead decision, I bet all of you have, we've known for years that unjustified institutional isolation or unjustified isolation is a form of discrimination. Well, what is more isolating than guardianship when guardianship is not appropriate? When a person isn't able to make even the most basic decisions in his or her life, who to be around, where to live, whether to work, what type of medical care to get or even whether that person will get medical care. As one professor has said, when you don't have an opportunity to exercise decision-making powers, you generally lose interest in those powers because you're isolated from them. So it becomes a self fulfilling prophesy or vicious cycle where the less opportunities you have to direct your own life, the less you're even going to be interested in directing your own life. And then we have 40 years of studies that says when you lose that ability, that interest, your life gets worse. Your health even gets worse.

In other words, decision-making is a skill. It should be exercised. People should have opportunities to exercise. And every person has a different decision-making voice and should be given an opportunity to use that voice. And that's what supported decision-making can do. It lets people develop and exercise their voices. Think about the challenges we face. Right here where I'm standing in Washington, D.C. there are about 2,000 people with disabilities served by a district agency. 70% of them are identified as either having a guardian or having some other legally-authorized substitute decision maker. Only 13% are identified as being able to make their own decision. Nationally, we know that over half of people with disabilities surveyed are exercising any kind of useful control, any kind of functional control over the most basic things like where they live or where they work.

And what that means is that we have experienced a lost generation. Everyone on the phone, think back to 1995, what you were doing, where you were. And I would point out if in 1995 you were a toddler in grade school, I hate you. You could actually be lawyers by now. But if you remember 1995, you remember how far backwards that was, it was four years before the Olmstead decision, institutionalization was still the rule of the day for people with disabilities. We were, we didn't have the technology we have now, we didn't have the services or supports programs we have now.

Fast forward 20 years. 2015, we have vastly superior technology that can enhance people's lives. We have services, supports and programs like Medicaid waivers, like advances in vocational technology and rehabilitation, like advancements in aging in place services and supports. So that people can be more independent. Yet in those 20 years, the number of people under guardianship has tripled. Why, at a time of miracles and wonders like we have now, are a million people more under guardianship today than in 1995? And I submit that's our challenge. That is our challenge, is to overcome the perception that older adults and people with disabilities somehow need guardianship because they cannot make their own decision. And as we saw, 10% of referrals to guardianship in one study are coming from medical professionals.

Our challenge is to turn that around so that we don't have a million more people under guardianship 20 years from now. I submit we need to cut down the number of people under guardianship right now. Identifying people who can make their own decisions right now using methods like supported decision-making. I've been looking at several state laws because guardianship is a state law process, and just about the every one I've seen always said that guardianship is designed or should be to maximize a person's independence. And that if a person is under guardianship, that person can ask to be released from guardianship if there's been some significant change in circumstances in that person's ability to make decisions.

Doesn't that mean that a guardian has an obligation to help a person learn new ways or to master new ways of making decisions? Doesn't that mean that it's the guardian's job to assist the person if the person can't already do it to make his or her own decisions, especially the medical field? Doesn't that mean that the guardian's job is eventually to lose his or her job? Because if a person with disabilities can use supported decision-making instead of guardianship, that person should be empowered to do so. That person should either have his or her guardianship terminated or modified so it is, it has less restrictive as possible so that the person makes his or her own decision using supported decision-making or other methods. If we do that, then that first article of faith I said, that people have an equal right to have equal access to all facets of society, if we focus on making sure that people have the opportunity to do that, then article of faith number 1 becomes the genuine article. It becomes article of fact number 1. People do have access. People can fully participate.

Thank you so much.

**Meera Adya:** Thank you, Jonathan. I see we do have a question that's added. We do have time for questions at the end, Jonathan, I don't know if you wanted to hold this until then. It says if parents already have guardianship how would this be reversed?

**Jonathan Martinis:** I think it makes sense to hold it until the end, Ms. Brent and Ms. Crane can go and then we can all address questions like that together.

**Meera Adya:** All right, great!

**Barbara Brent:** Good morning. This is Barbara Brent, and the director state policy for the National Association of State Directors of DD Services [audio unclear] remind me if I can move a slide here.

And so it's always fun to go, you know, to go right after a civil rights lawyer and say, hi, I'm from the state agency. So, but I hope to provide some information that will help people think a bit about information within the context of state IDD agencies that pose some of the challenges and opportunities within the new regulations, as well as what can be done that can increase the opportunities for supported decision-making. And one of those things where I sat on both sides of the fence, I've been the state director or commissioner in two states, but came from the advocacy world. And it is a dichotomy and often wanted to put on my business card when I worked for the state agencies at the card I wanted to put I mean well and on the back of the business card that I'm sorry.

So sometimes people wanted to understand in the realm of what is a waiver, it's too bad that people have to know vernacular, like I need a waiver, without knowing what in the world is being waived. To see where we've come from and unfortunately it came from an institutional bias. And forgive me for those that know this inside out and backwards, but it just meant that people were waiving an institutional bias in 1981. So as Jonathan talked about where we've been and where we are now is that there was a bias that people had, could get pretty much complete services, not maybe of their choosing or certainly not what we see as best practice today, but if they went to the institution as so many families were told was a great option for their loved ones, so no wonder as you look at people that are a little bit older for families that were told, hey, come on and send your loved one to the institution, not only is that the best place, it may be the only place you can get services, and now we're saying not only that come to the community, you can get services and people can experience all kinds of self-determination, that's confusing to some family members as they grow older.

But the bias was you couldn't get services in the community. So what that really meant is that in the role of the Social Security Act there was a waiver, hence you were waiving having to go to the institution and receive Medicaid money for people to live in the community and get supports. Hence was born the waiver. And for those of you that maybe didn't know that, that's the vernacular about how we got there. So there's been confusion even from the beginning for people about, no, you don't have to go to the institution. No, you don't have to go to, want to go to the institution, it's just that you met the level of care to be eligible, that you were at risk for, a person is at risk for or could be eligible.

So let's just move forward to think about our past, and it's unfortunate that there's a link, right? You have to be thought of as a person that has such significant support needs and maybe isn't very competent to qualify for so many of our Medicaid programs to get services and supports in the community. And I think that is put up a little bit of the problem that we see today that Jonathan and Sam are so articulate about and will share more about as we get into the questions.

So it puts you in a rough place to start, right? You presume the person's at risk and to qualify for the community and so now we're going to really move forward about people can make their own decisions. And so where you stand depends on where you sit. And for a lot of families that's created a little bit of confusion. And so there are some things, also within state system, that create a little bit of further tension for a state system that is getting this Medicaid money in order to support people while in the community. And states, happily we are moving the 13 states that have no state-operated institutions whatsoever, and there are few states now that have neither public nor private ICFs. And if you look at the trend lines, that's dropping. So people are moving from facilities to the community, but as Jonathan articulated, there are a lot of people that are still under guardianship, sometimes limited, but still even the limited guardianships may [audio unclear] basic civil rights like voting.

So, one finds as a state if you're going to take the federal money that you have to have state oversight and so the good news is that there is an obligation to get information about people about how they like their services. There's a challenge, so who are we asking as state agencies? So if we are asking the waiver participant and the person has been deemed not competent, so are we asking family members; are we asking guardians? Is there a better way to ask the person themselves about, and how we're asking about satisfaction. And are ways and mechanisms that we can think of together that better ask the person that is receiving supports and services about what's working and what's not. Are there ways at the person-centered planning level, national court indicators, which I'll talk about briefly. There is a way that does not allow for proxies in some cases. So it's what the person says by word or deed. There has to be a formal system to prevent report and resolve instances of abuse and neglect. There have been fines, there have been waivers frozen if those instances and systems are not robust enough. So you've got a dichotomy there as well. And I have, I'm working out of my house today, and if you hear it, I have a chihuahua that's very upset about the notion of abuse and neglect and he's now quieted down. Sorry.

So given these, there are some things that really do make a difference in terms of what is a state is being obligated to make all these assurances to the federal government, at the same time it's trying to increase opportunities for self-determination. And within that state agencies need your help in terms of how to improve that.

I'll give an example of what my former state, and I still am using "they" and "my" because it hasn't been that long since I was in that state. We put in mandatory voter registrations in every single one of our offices. And people had to either -- when people came in to apply for services but in a good person centered system, right, you go to people's homes, you don't make people come to your office. It's intimidating, it's not, it really takes away some of the self-determination, right, if people have to come into a formal state office. So people had to take the voter registrations to people's homes or wherever they lived in most states and we'll talk about that in a moment. People live in their family home or on their own.

And they were, and people were trained about how to have people fill out that form. And so that increased the number of people that were able to sign up to vote. Now, does your state for those of you on the line, prevent all voting rights if someone is under guardianship? Or do you have limited guardianship and do you know this? Have you researched this? If somebody has different kinds of levels of guardianship can the person still vote? So that's something a state agency can do is have somebody who is the point trainer, to train the trainer in your state systems or your support case managers, whatever they're called, to be trained in helping people fill out the registration, how to get those turned in, and make sure that people know those rights, increasing self-determination and supported decision-making, right? So if that person doesn't want to do that on the spot can you help somebody in their family know about that right, know what their state legislation is on that, on whether a person can vote or not, and to learn.

But those are hard things, right? We've spent a lot of time working on advanced directives and as Jonathan so aptly pointed out, there is a lot of discussion about what it is people can't do, like who's going to sign the informed consent. And what's the liability about that if certain medications or procedures are given, are suggested and a physician is saying, whoa, can this person really consent? At the same time as we're telling people and their families, by the way, they should be able to vote. And then think about even to apply for services, what it is like to fill out those assessments? And we frankly in some of our systems and some of the advocacy systems tell people to fill out as much of what a person cannot do in order to qualify so they can get on the system themselves, you know, pass whatever the pre-admission screening is, pass the pass, and then turn around in a person-centered plan and say tell us all the gifts, strengths, wonderful things you can do and I think the best thing we might be able to do is be honest about that. Hey, we're going to maybe have some thing that we ask that are a little bit unkind and then we are going to be asking the opposite in this plan.

So the what's the big deal stuff in these new HCBS rules? I know I'm talking fast, that's a family gift from a large family about he who talks the fastest wins. So not new to you, the new rules really talks about what is community, what's likely not. It codifies person-centered planning. So these requirements have been in place a while except for a few components. And what was in guidance in conflict-free case management now in blue and red. And why is this important? So if it's not community and it's [audio unclear], sure, we know these things, I won't read them to you, are not HCBS, but do, once you're in the community, are you making some of your own decisions, are you supported in that?

So the bottom bullet on this one, how about that settings with the effect of isolating individuals from the broader community? So you can live in a group home, you can live in or work in a place that may only have a few people if it, but you really have to get to that person-centered plan level to think about are you isolating people? So decisions are made for people, think about the studies of isolation that Jonathan mentioned. And what is the power of the true person-centered plan that increases the decision-making about how a person goes about their day, how a person spends their time, with whom, and how

that can be built into that person-centered plan. And there is some new wording in the person-centered planning process that can help.

So there are some things that, about settings that isolate, and so a few there to point out without leaving the slide. So if you live in a setting that, or work, because it's not just about the how somebody is, spends their, you know, where you hang your hat at night, but what it's primarily exclusively for people with disabilities and most of the people are staff if they don't have disabilities, and even for certain type of disability and what if it's mainly for housing, day, medical, behavioral and therapeutic. And rather than people being out in the community and making choices about that, and if the support coordinator is not the only person that can make those suggestions about what's important for and to, who else can you bring to the table? Sometimes that's a trusted family member; sometimes it can be somebody else that come with them. And there are a few states, even though general fund is very hard to come by, state-only fund, non-waiver funds, that have even come up with money for some self-advocacy groups to help people learn more about decision-making and can make available someone, a peer, to come to some of the person-centered planning meetings. Good idea, hard to fund. And think about the settings that isolate, what about the restrictions that are used in institutional settings.

Think about for a moment about how people might be secluded and whether that is not a time out room of days of yore, but those things where everybody is making the decision about the rhythm of the day, who you're with, what doctors you go to, what happens in terms of your medical supports that every decision is being made for you and to you without some level of supported decision-making. While the setting, which is a physical place, is there are many people talking within the new HCBS regs and the person-centered planning, that provide the opportunity after you get that past the personal settings of really getting under the hood into those individual plans. That's the opportunity that is not something the state system can do alone. A state system can't get into hundreds of thousands or really in fact millions of plans around those qualities of the individual plans. And we need all of your help to make some of that happen.

So how about that one in red? Hey, the one before it, I got excited, provides opportunities to seek employment, that's new, and work in competitive integrated settings. That actually has to be discussed in the plan. Some states do that so well already. Engage in community lives and control personal resources. That has not been codified, although best practice, although in some planning, so it's an opportunity to think about what can be done within waivers and person-centered planning tools, templates, training about what can be done to help somebody; what are the questions to ask that aren't currently in there about controlling personal resources without immediately jumping to who has the power without appointing somebody that is going to take control of all the financial decision-making. Who's got the power to, and ability to, every decision-making without full guardianship. Again, need your help. Wanted to point that one out specifically without leaving the slides.

So there's also that ensuring individual's right of privacy, dignity, and freedom from coercion. Freedom from coercion is another big statement here about along with the next

one about optimizing individual initiative, autonomy, and independence in making life choices. It has to be in the plan, it has to be in the setting requirements. So help us think through what would be in the person-centered planning process and what would be in the safeguards. Remember that besides our institutional bias that when people turn 18, that our schools -- one time states only serve adults by the way, so by the time they get to the waiver there is -- there are 37 states right now that serve adults -- excuse me, serve children, but for the others, look at the transition planning is composed of in many states before the IDD system even sometimes touches a person. What's transition planning? It's the realization that there's no entitlement to services in the IDD system. It's maybe learning about jobs. Isn't it the, oh, my gosh, I'm no longer guardian for families. So how do we help people intervene early about finding out about autonomy and supported decision-making before that, those workshops take place around you better get guardianship. And again, it's not just residential. It applies for everything.

One thing I wanted to point out here as we move along quickly, I will move quickly, is that we don't serve everybody, you know. So there's about -- incident prevalence about 4.7 million people with IDD in our country. And we serve about 2 million within our formal systems. So who's the biggest provider of the day to day support for people that need it with IDD? Families. So 89% of people with IDD are supported by family. And of that group about 13% live out of home, and most people live at home. And what does that mean for supported decision-making? Let's get into another set of data, again, you have these slides, I will not read them to you.

So for those receiving services, we're at 56.5% of all people receiving supports and services through IDD state agencies living in the family home. With some states topping well over that, they're highlighted. My home state being the highest. What does that mean? We got inherent tension. We've got to look at -- state agencies have to look at both, right? Families have to be supported in ways that maximize their capacity, their strengths and abilities, so they can best support, nurture, love, and facilitate the individual with a disability. And their achievement of self-determination, interdependence, productivity, integration, inclusion in all facets of community life. Right? So what do a lot of families learn throughout the years? They learn protect, they learn nurture, they love, and they facilitate. At the same time they're learning that people with disabilities want their own lives. Now, if you raised teenagers, that line is really a tough one. Even in adulthood that line is a tough one, and I don't know how many of you had to bounce back while your adult child moves back home and then that line is really pretty tough. But if people live with their families kind of technically because of lack of services or because of economic factors, we need to come up with ways to help families and people with disabilities learn about supported decision-making and state agencies can help do that through education, through our person-centered planning templates, and through even the kinds of services and supports that are offered to families and offered to people with disabilities. I contend this is one of our biggest challenges.

And so what about that person-centered planning? So, yeah, that CMS plan puts us in that unique position of, we've got to talk both about the personal preference and ensure health and welfare. And, yeah, we're talking about the strengths, preference, and needs of

clinical support and the outcomes of the person. And we get to now say what services are self-directed, hooray. So states are now scrambling to realign what they're doing with the person-centered planning process in, look for the sweet spots here, there are some. Hey, the settings chosen by the individual. And it is integrated in and support full access to the greater community. Employment, it's in there for the first time. And engage, control personal resources, I just have to emphasize that, again, not been in there before.

And I'm not going to read this one, but I do want to say there are -- there's an out, and that out is that if you do want to restrict somebody's right, so what if it says something like you're going to limit somebody's access to food? Or you're going to remove furnishings, or you somehow else modify somebody's plan that has a number of rights in it and freedoms. There are happily not many, but some providers that are immediately jumping to that portion of the rule and regulation saying oh, good, there's an opt-out. Because what if we don't want to have, you know, food out because somebody might just get in there. What if we want to restrict access to certain parts of the home? Or what if we are going to limit that person's desire to be out in the community as much because they might be a danger to self or others. We need to collectively as state agencies, and those in the advocacy community to ensure that's the default. That's at the bottom. We need those of you working in the realm of supported decision-making to ensure, buddy up with people to make sure that is the default, that is the last resort. And what can be done with supported decision-making to ensure that does not pop into plans as that just has to happen for people. Because they can't make those decisions.

And then conflict of interest, you know, we with just have to make sure that there's a lot of protections. That there is a good firewall between case management and the person who develops a plan and providers. So that that case manager, support coordinator, whatever it's called in your state, is really a true advocate, if you will, although people get nervous about that word, to help that person be as self-determined as possible without the worry of real or perceived, and perception once perceived can become reality in some eyes, that you a provider that might work for the same agency may have those worries about all those freedoms and may want to subtly want to restrict some of those rights.

And so I think I am borrowing from Jonathan without knowing that. What's important to, what's important for. And here is a challenge for state agencies. Is the person happy? And how do state agencies measure that? I'm not going to repeat because Jonathan talked about the person-centered planning. Let's talk about one example about what a state agency can truly do, national core indicators, most of you are familiar with. What we've found, here's one little research example. In the national core indicators, which is a project of our association and HSRI, we interview a number of people in each state on a variety of measures, including health measures, by the way. But this is about jobs. We looked at people who were interviewed and 45% of people who were interviewed who reported not to have a paid job in the community said they want to have one. Of them, 13% of those who, without a community job, had an employment goal identified in their support plan, in the person-centered plan. So again, 45% said they wanted a job. 13%, only 13% had that in their goal in their plan.

So, so we've got a big dichotomy on supported decision-making of, that's a easy place to fill the gap, right? I want it, it's my choice, and it can even get into my goals. And then NCI is the number of assisted performance measures about choice and control and health and welfare that we see as a way to help us.

So the role gives us a lot to think about and a lot to do, and maybe we can get closer to let people want and what we aspire to in our vision and value statements. So thank you.

**Samantha Crane:** Hi, everyone. I'm Samantha. So I just jump right in?

**Michael Morris:** Yes, Samantha, it's Michael has joined, please go ahead.

**Samantha Crane:** I was going say, I'm going to interpret your silence as consent. So hi, everyone, I'm Samantha Crane, I am the policy director of public policy at the Autistic Self-Advocacy Network. And we've been doing a lot of work this year both on the new home and community-based services rule and on supported decision-making and how we can facilitate that kind of process. Before jumping into my slides I wanted to get to some things Barb was saying, because I think she covered a lot of things I would be saying about community-based services, but I wanted to add onto that, that we've been seeing a lot of concerns that, for example, when someone is going through the person-centered planning process and the exceptions processes that are being mandated by the new home and community-based services rule, we want to make sure that guardianship doesn't simply form a way to get around those meaningful protections. So for example, let's say a person is living in a provider-owned residential setting, and the provider wants to limit the number of visitors or the amount of visitors, et cetera, that this person has. We want to make sure that the provider doesn't, for example, either approach the person's guardian and simply ask them to consent to that limitation, or even recommend the person into the guardianship system. And Jonathan and I have actually seen cases where this will happen, where a person will either object to a setting placement that's provided by a waiver and as a response to that objection instead of meaningfully working with that person to find a place that is appropriate for them, they'll get referred into the guardianship system. And as an explicit attempt to circumvent these kinds of person-centered planning protections.

We want to make sure that when we're looking at home and community-based services systems we include an examination of how often do people receiving these services get referred into guardianship. Because that's a meaningful measurement of whether or not the system is actually supporting the person's right to self-determination. We also want to make sure that we're not just focusing on whether or not a setting restricts someone's ability to exercise choice, but also on whether or not they're actively facilitating a person's right to exercise choice.

Many people, as both Jonathan and Barb already said, and as I'm about to get into a little bit more, many people really need a lot of help in order to be able to make the choices that they should be making and that they want to make. Both in healthcare contexts, financial contexts, job searching contexts, they really are going to be set up for failure

unless or, or set up for referral into the guardianship system unless they're getting these supports, these decision-making supports that they need.

I am going to skip through a few slides because they've already more or less been covered. But I wanted to specifically focus on these issues of transition that we've noted.

We've noted that about 40% of youth with special health needs actually got transition planning services to plan for their transition toward adult-focused healthcare. And taking control of their own healthcare once they reach the age of majority. Compared to other youth with special health needs, people with autistic spectrum diagnoses, developmental or psychiatric disabilities are actually even less likely to be encouraged to take responsibility for their own healthcare when they become adults. That's a really major challenge for people once they're transitioning onto these ID/DD or other waivers of the and a lot of this is due to negative assumptions about people with disabilities, especially in terms of their capacity to make their own decisions.

When we're also not building skills and encouraging people to take on additional responsibility, this can be a self-perpetuating phenomenon. Where a person starts checking out of their own healthcare, they never really develop a sense of what needs to be done because it's all being done for them and people are not really engaging them in these decisions. So people are not going to simply magically become capable of making decisions for themselves after a while of having decisions made for them. You can't wait until they're, a lot of people will say, oh well, we'll just get guardianship until they become competent to make their own medical decisions. If you're not doing supported decision-making, they're not going to achieve that competence.

When we, after we sort of came to that conclusion, we started wondering, all right, we know that supported decision-making is great, but what actually is it; what are the nuts and bolts of supports that people might actually need? And in the developmental disability context and also the intellectual disability context that's often going to be getting people communications supports, reminders, assistance with scheduling appointments, assistance with understanding health decisions, information in alternate formats. All sorts of things that are going to help people understand the information available to them and act on that understanding, but it's going to leave the person with a final right to make a decision about their healthcare.

The supporters, and this is crucial, have to be people that the person trusts. Right? If you are getting advice from someone that you don't know or you don't trust, or maybe it's a family member that you have a bad relationship with, it's just not going to work. But once we have that trust, it doesn't have to be family or a spouse. It could, for example, be the same direct care worker that the person has chosen to provide in-home supports and that they've developed a significant trusting relationship with. So these decision-making supports can actually be delivered through the waiver if it turns out that that is the best person to be delivering the supports.

Some people, especially when you look at the population of adults with disabilities living alone, you're going to see a lot of people who are what we call un-befriended or who don't have the particularly trusting relationships or supportive relationships with family members. Maybe the family member is not living with them, maybe the family member has some problems of their own, is just not capable of providing support or maybe the family member is just not someone that they like very much. So sometimes it might be best to have a home and community-based services funded worker doing some of these supports.

I already mentioned these. These are all examples of strategies to support decision-making. It can include assistance with monitoring health, reminders to make appointments, help making appointments. Some people aren't very good on the phone. Accompanying a person to doctor's office. Helping keep health records organized. Or even direct assistance with treatment routines, like helping a person measure out insulin. That obviously would take some training. But many people are able to be trained to support family members in taking insulin already. So that kind of support is something that people are already doing on a day-to-day basis.

It can be informal or formal. There should be an understanding that having a supporter involve, it's not just required by the home and community-based services rule, but it's also really required by the Americans with Disabilities Act. Because if a person needs a supporter to help them access a service, then that should be seen as a reasonable modification when accessing that service.

When we, and it's also an integration issue as both Jonathan and Barb were mentioning. I have, we went through a bunch of guardianship decisions and we saw a lot of really good examples of people who made this work. One decision in New York state was a woman named Dameris L. She was a person with an intellectual disability, and she was married to a man who also had disabilities. She had a child, and as a result the woman's mother petitioned for guardianship. The Court awarded co-guardianship to the mother and the husband in part because they were concerned about Dameris' ability to parent her child. The family then had to move to Pennsylvania, but because the person was under guardianship they couldn't do so without Court approval. The judge did give approval in part because she thought that she had jurisdiction over the issue once the family had moved to Pennsylvania. But she also issued a pretty ground-breaking opinion in which she analyzed the supportive relationship that Dameris had with her family. And really explained why this kind of supportive relationship was vastly preferable to guardianship and that when people had supports like this guardianship was in her opinion actually unconstitutional. She said that people should consider supported decision-making relationships as a less restrictive alternative to full guardianship. And whenever possible, these relationships should be fostered and developed.

The family really came together in that case to support Dameris, the woman who was under a guardianship, and she had a very robust network both with her husband, her mother, her father, and other people around her that were really helping her make the best parenting decisions and healthcare decisions for herself and her child.

Now, we ended up-- I'm sort of clicking through a lot of this because it was relevant to another topic that I ended up deciding not to talk about. But we ended up, when we were thinking about these nuts and bolts questions in terms of supported decision-making, we ended up distilling it into a piece of model legislation. And I'm discussing this model legislation not as a law that need to be passed, but as a sort of way of setting down a basic process for supported decision-making. So this process could be implemented through your home and community-based services waiver. It could be implemented through legislation. It could be implemented informally by families that simply want to do the best thing for their family members. There's some parts of this that are more legislative than informal, but it really gives it a sort of a sense of what we're looking for here.

We need a recognized support relationship, one that's written down in some way, and clearly delineated. We need to avoid costly and traumatic court proceedings or other kinds of adversarial interventions. And we need to really think about how we're protecting people from abuse or exploitation in part by empowering them to make their own decisions and go against the wishes of a support person. We focused on healthcare contexts. And so, for example, we wanted to make sure that supporters could access health information and communicate with health providers under HIPAA, the health privacy law. And we needed to make sure that people had access in simple language to a description of the relationship they had with their supporter. We also wanted to make sure that doctors were aware of this relationship and felt empowered to follow directions made through supported decision-making as long as they felt that in that particular context the person with support was making an informed choice.

Our legislation is available on our website. There is a URL here. If you can't read the URL, it's ABLÉ, searchable on our website for our model legislation on supported decision-making. Our website is [autisticadvocacy.org](http://autisticadvocacy.org). We designed the model legislation based on a review of guardianship cases and in particular a review of situations where a court awarded guardianship despite the fact that people felt that they should have a less restrictive alternative. Basically a contested case where a person wanted to use supported decision-making but it was considered not available. We also analyzed supported decision-making legislation in other countries, such as Sweden and the UK and Canada. Our goals were to make sure that people could access supported decision-making even without, you know, getting a lawyer and going through a complex or inaccessible process. Especially if they don't have a lawyer, because many people don't have legal representations. We wanted to support a decision-making system to be available to people with significant cognitive impairments. And we wanted to make sure that people maintain the right to make their own decisions even when they disagreed with the supporter or the supporter disagreed with them.

We didn't want to -- people to enter into a private agreement that involved potential relinquishment of rights. And this is a case where, for example, signing a broad power of attorney could actually be a less optimal solution than supported decision-making agreement, because a broad power of attorney for healthcare often will say that, you know, if at some point you aren't able to make a decision for your receive, you want a

person to make a decision on your behalf. And that could end result in a situation where if a person is sort of on a bad disability day they're having more difficulty communicating than other days, someone could step in and make a decision for them that they disagreed with. That might be actually what someone wants to be able to do, but we wanted it to be at least not mandatory. That there could be a standard form where a person says, no, your only goal here is to help me make my own decisions and I'm not giving you authority to make decisions for me.

We wanted to respect diversity and choice of supporter, and that's as I had just mentioned earlier, for example, a person might not want their next of kin to make, to be their supporter. They might instead want a friend or even a support worker if they don't have any such natural supports. We wanted to avoid conflict of interest. Prevent abuse and prevent fraud. So what we ended up recommending, and this is the type of thing that can be implemented with minor recommendations through home and community-based services, is we had a sort of a form agreement that a person with an intellectual or developmental disability could execute, it would name a supporter. The supporter acts as what's called the person's authorized representative under health insurance privacy, healthcare privacy laws. So that person is able to communicate with the doctor, facilitate communication with a doctor, help get medical records, help make appointments, help accompany a person to appointments and help in daily health routines. And all of these could be checked or not checked based on what a person individual wants help with or doesn't want help with. The person with a disability makes all final decisions, as I said, and a decision need with a supporter is explicitly set, acknowledged as potentially being informed consent, all right? We're recognizing that everyone needs support in order to make a decision and so the very mere fact that a supporter is helping a person make the decision doesn't mean that it can't be informed consent from a healthcare perspective.

We wanted to recommend a lot of oversight because people with decision-making, healthcare decision-making needs deserve protection from coercion or abuse. So for example, we bypassed the court involvement but instead we wanted to make sure that the agreement was signed, witnessed, and all above board so it couldn't be, we're sort of reducing the potential for fraud of someone just signing this on someone's behalf and then claiming that they have authority. We wanted to make sure that doctors knew the person with a disability had to actually make the final decision. So they can't simply rely on a decision made by a supporter. That means that a supporter can't be going behind the person's back and making decisions behind the person's back. And this helps prevent fraud or abuse.

We put in conflict of interest provisions. So for example, a treating physician or a staff in an institutional or quasi-institutional setting couldn't serve as supporters. We don't want people making, trying to coerce people into making decisions based on their own convenience or based on their own opinion of what's medically right if they're treating physicians. They can't be making the medical recommendations and also acting as a supported decision-maker.

The conflict of interest provisions, however, we didn't want to rule out the possibility that a spouse or a home support worker could provide services. So we didn't include a conflict of interest provision that said that a paid employee couldn't provide services. An employee might include home support worker. We wanted to include them. We wanted to make sure that this agreement was accessible and that it was recognized. Even for people who had significant communication impairments. Our goal was that if you could express a desire to have someone support you in healthcare then you could execute a valid agreement. That was our goal. We didn't want to set an incredibly high bar because otherwise we would be ruling out exactly the people who need supported decision-making the most.

We also wanted to preserve the role of doctors and other care workers who were already involved in this person's care. A doctor doesn't have to, for example, provide treatments that they think is medically contraindicated or medically wrong. They don't have to provide care that they think is harmful. They don't have to provide care if they believe that the person hasn't actually given consent, that the supporter is coercing the person, the supporter is withholding information from the individual, or if they think the supporter is committing abuse.

They have to report suspected abuse by a supporter to an adult protective services agency. And this is already something that home and community-based services providers should be doing. There should be a process to deal with suspected abuse. So this is fitting into what we already have in the system. And substantiate the complaints that would result in the removal of the supporter or failure to recognize the supporter as a healthcare decision-making supporter.

And that is the end of my particular presentation. And I will now let Michael bring up our questions. Michael, are you there?

**Michael Morris:** Yes, can you hear me?

**Jonathan Martinis:** We can now, Michael.

**Michael Morris:** Okay, sorry. Sorry about that. So wow, we've heard three wonderful presentations from Barb, Jonathan first, and then Sam, Samantha. There are a lot of questions that have been coming in. We don't have a lot of time. We have some questions we also had prepared in advance. And I'm going to quickly start in and maybe throw the first one to Jonathan is, we know under the HCBS waivers that there's a clear intent to promote self-determination. How can individual plans improve decision-making skills so that lives are more self-directed and really incorporate the concepts of supported decision-making?

**Jonathan Martinis:** Thanks, Michael, really quick before I start to answer that question, there was a person who asked while I was speaking how a person, how a parent could move to modify or minimize a guardianship. Every state has different rules. I'd be happy to speak with you off line to go over the rules in your state. My email is

jmartinis@dcqualitytrust.org. With regard to the question, Michael, I'm a big fan of what I call "I" statements in plans. It requires a person to take charge of his or her plan. So instead of a plan saying something will happen, like it will happen to a person, a person takes charge of the plan. In the special education world, for example, instead of saying things like reduce your tardiness, say I will come up with a plan where I will be on time to class 75% more of the time. So in an HCBS plan I think "I" statements are perfect. I will identify a community-based service or support that helps me identify a job goal. I will pursue in the medical field, I will engage in a supported decision-making plan with my doctor. I will consult with my supporters to do this. It creates a requirement for the person to take charge of his or her plan. Which is the very definition of self-determination. When we are causal agents in our lives, we are more self-determined. So I think every time a person is involved in a plan, any type of plan, that plan should not only be centered on the person, that plan should be driven by the person.

**Michael Morris:** Okay. I'm going to quickly jump to the second question and I'm going to shoot this one to Barb. Do states, from your perspective, have an affirmative obligation to identify and help individuals with guardians to restore their decision-making authority?

**Barbara Brent:** Um, I know of no such affirmative obligation that says anywhere, "thou must help restore the decision-making authority." With the new HCBS person-centered planning, there are I think some ways for states to begin to look at their person-centered planning and say if you have a guardian what are some ways to increase, are there alternatives to full guardianships and are you aware of the laws, but I do not have any awareness of thou shalt do that, an affirmative obligation. Now, because of the self-determination and -- that's part of that -- you know, the planning and to talk about to increase people's own autonomy and authority, I think there will be more attention focused on this, but there's no such question that says one will.

**Michael Morris:** Right. Okay --

**Jonathan Martinis:** Michael, can I jump in real quick.

**Michael Morris:** Please, Jonathan, go ahead.

**Jonathan Martinis:** I agree with Barb, there is no rule that says states must do this, but I think there's an Olmstead component here. If there is a person that cannot access the service or support because he or she has a guardian and the state knows the person can access that support but for the guardianship, I think the state has an Olmstead or ADA requirement to do that. Barb brought up voting before. If a person is cable of voting, if a person wants the vote, if the person has the capacity to vote and the person has lost the right to vote because of a guardianship, I think there's the argument that the state has an obligation to help that person gain access to voting, because the only thing keeping that person from voting is the guardianship, which is a result of his or her disability. So I think there's specific areas where a state might have that obligation, and secondly, if you look at your state laws, almost every state law says the point of guardianship is to

increase self-determination, to increase independence and self-reliance. If that's the case, and a person is under state guardianship like by a state's public guardianship, I think the state has an obligation to help that person become more independent, to access things like supported decision-making which could then lead to the guardianship being terminated.

**Samantha Crane:** I would also say-

**Michael Morris:** Okay.

**Barbara Brent:** I would add to that that there is some difference between how states address public guardianships that actually run by counties or by state than there is addressing those within family situations. With the latter being dicier.

**Jonathan Martinis:** Absolutely. I agree.

**Samantha Crane:** I think I would also say there's a real role for that in person-centered planning process for home and community-based services. If a person has a guardian, first of all, they have to still be participating in the person-centered planning, the guardian cannot just be participating for them. And if one of their goals is I want to take on more autonomy, I want to start managing my money, I want to start making my own decisions I would say that's something that should be addressed in the person-centered plan from the HCBS perspective, and they should be getting services that will facilitate that person going toward that goal, which could include supported decision-making or help getting to a point where they could then move out of guardianship.

**Barbara Brent:** And that's certainly an avenue to make sure that there are goals and outcomes that talk about managing my own funds, finding out about even the cost -- you know, one thing is finding out the cost of service and support, sometimes people are quite search surprised at how much fiscal effort is going into the cost of a person's services for that which, are those things I really want?

**Michael Morris:** Let me, I think it's a good discussion, I'm going to take it to a more practical level just skipping to question number five and turn to Samantha: For an individual with significant disabilities, who should they turn to for help in making informed decisions?

**Samantha Crane:** Well, so it really sort of, I'm not sure whether we're assuming that the person's disabilities, you know, to what extent they're affecting communication. But first, many people even with significant disabilities can tell you who they like to help them, who they trust the most, who they want to spend time with. And that should really be the first person that we turn to. Unless there is a significant concern that person is abusive or is not willing to provide help making informed decisions, we should really be trusting people to say who they trust the most. When it's more difficult to ask someone, simply ask someone who do you trust the most, let's say a person has a harder time accessing language to express themselves, then you really start asking who is spending the most time with this person? Who is providing support with this person? Are, who is best at

communicating with this person? Sometimes there might be one or two people who really understand what that person is saying. A lot of other people do not understand what that person is saying. Especially if they have difficulty articulating speech or need specialized communication supports that only a few people can provide. And those are the people that you'd probably look to first when helping a person with significant communication needs in making informed decisions.

**Barbara Brent:** Well said.

**Michael Morris:** Let me quickly jump to another question, which is sort of the opposite end of the spectrum about supported decision-making is the question is, will support decision-making make more people more vulnerable to coercion or manipulation of what their true desires and needs are? And maybe I'll go to Jonathan first.

**Jonathan Martinis:** Let me preface this by saying that we should never make the measure of whether supported decision-making is a good or bad thing about whether people might be influenced. We're all influenced by things every day, as a psychologist who testified in a case of mine said, if the measure of whether we should have friends is whether they may influence us in the wrong way, I need to stop playing poker, because my friend gets me to do some really dumb things. So that's a long-winded way of saying, yes, it could happen. People could be influenced by their supporters, they could be. People may also be influenced by their guardians. In fact, there is no study showing that people under guardianship are any more or less likely to be abused than people not under guardianship. In fact, the studies say that people who have more self-determination are better able to recognize abusive situations and therefore better able to avoid abuse.

So maybe what needs to be done is from very early age help people recognize areas and times when they can be self-determined so they essentially selves are better able to recognize when people in their lives are trying to influence them and therefore are better able to avoid undue influence. But with regard to whether as an absolute a person might be unduly influenced by a supporter, a person might be. And a person might be unduly influenced by a guardian. All things being equal I'm always going to choose the thing that gives people the most rights and the most opportunity to exercise them.

**Michael Morris:** Yeah. I think we're just about out of time and I'm just going to go back through each of you quickly rather than continue on the questions and, Sam, you know, in general you've proposed some legislation that would further help states understand ways to move to less restrictive alternatives than guardianship. In this focus on HCBS waivers and Medicaid, any last comment in terms of advice to the listeners in further trying to develop the capacity within states and service providers and capacity of individuals with disabilities to benefit from supported decision-making?

**Samantha Crane:** Well, first I want to clarify, you know, that legislation that I brought up, it wasn't in, it wasn't saying you must pass this legislation.

**Michael Morris:** Right.

**Samantha Crane:** It was more saying this is an example of a system that we could implement on the HCBS side. I think it's really going to come down to common sense and a acute attention to what kinds of supports a person needs, both as expressed by that person and as indicated by the people who know them best. And we really just need to problem solve and make sure that whatever that person needs, whatever a guardianship would be doing for them, how can we provide that same service through supportive relationships.

**Michael Morris:** Okay. And Barb, any thoughts from the perspective of state agencies are going to be as you discussed, more challenged by certainly CMS and the direction and movement repeatedly towards self-determination which certainly is going to look at structures to achieve that of which supported decision-making would be a positive structure and process. Any last thoughts from where states are headed and some of the challenges and opportunities ahead related to supported decision-making?

**Barbara Brent:** I would say that it is good timing because states are looking at implementation, they've put in their transition plans, the statewide transition plans are in the process of equivalence, and they have been deluged, to be fair to CMS, they were given a number of waivers specific because there were individual waiver transition plans that had to be approved first because they were in that waiver cycle of, I don't know how many that had to be approved. And then there were the state-wides that were applicable to every single waiver and as some of you are aware there are states that have 11 or 12 waivers. And so they're a little bit backed up, but that is not stopping states from beginning to implement. So this is an opportunity for states to work together with people on the phone and other advocates and other agencies to begin to put into place the ideas that you've brought up. And then one suggestion in so doing is, and we've heard them today, are practical solutions.

When things come in as you need to do this or you should do that, that can be overwhelming. But if there is an opportunity to break bread, bring coffee and say here are five or six bulleted areas that we think would really augment the supported decision-making or increasing the control of people within these different components of the new regs, I think that it would be really helpful and digestible. So that would be a recommendation. And to also recognize the dichotomy and then your data about what happens when supported decision-making actually reduces the vulnerability is really powerful as states begin to answer to others, answer to their state governments, their legislators, their other funders. So all that is great data, share it.

**Michael Morris:** Okay, thanks, Barb. And Jonathan, I turn you to last, this is the 25th anniversary year of the ADA, Olmstead is probably the most significant case in interpreting the ADA. Where do you see the crossroads between Olmstead, where CMS is headed, and perhaps even a more affirmative view towards supported decision-making?

**Jonathan Martinis:** We're at a crossroads right now. Barb's right, the timing is perfect. There's never been such a confluence of opportunity and people and theory and practice.

We have a chance, perhaps the only chance, to make supported decision-making truly grounded in the way that we treat people with disabilities and older adults. We get this chance to turn around 2,000 years of history. Guardianship has been the rule, not the exception, for 2,000 plus years. Well, now we have the chance to create and to implement and enhance and empower and give people the opportunity to make their own decisions.

What I said before is true, it's 20 years and in 20 years, since 1995, we've had a million more people go under guardianship. I think in the next 20 years we should set a goal of getting more than a million people to be empowered, more than a million people to make their own decisions and to reap the benefits that come with self-determination. And that should be our goal. Because here when we talk about medical care decisions, medical planning decisions, that sets us up for the type of life we're going to live. That sets us up for the thing that we're going to do and the things that we're going to need and the things that we want. The crossroads is now. We're at it. And for everyone on the phone, we need your input. We need your questions, your comments, your successes, your failures, your challenges, please go to [supporteddecisionmaking.org](http://supporteddecisionmaking.org). Please join our listserv, supported decision-making interactive. And tell us what you're worried about. Tell us what's worked for you. Tell us what hasn't worked for you. So that together we can create a useful and lasting and recognized method so that people with disabilities and older adults can run their own lives. Thank you so much for having us today.

**Michael Morris:** Thank you, Jonathan. Thank you, Barb. Thank you, Sam. This, I think, could be a dialogue that could go for several more hours. I hope you will join us for part III of this series on supported decision-making and its application in current policy and practice. Our next webinar is on June 18th from 1 to 2:30 eastern standard time. Supported decision making and the ABLE act, Achieving a Better Life Experience Act, a new crossroads, again, and we will have it that time Lisa Mills, public policy chair from TASH, Allison Wohl executive director of APSE, and Jonathan Martinis again, legal director at Quality Trust for Individuals with Disabilities. Please do visit [www.supporteddecisionmaking.org](http://www.supporteddecisionmaking.org). Please do, as Jonathan said, send in your questions. We appreciate you being with us, and this dialogue will continue next month. Thank you so much for joining with us. Take care. Bye-bye.