



## **NCAPPS Webinar Transcript: “Pathways to Person-Centered Decision-Making and Alternatives to Guardianship”**

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### **SPEAKERS**

Nora Brahe, Michael Kendrick, Bevin Croft, Fil Clissa, Alixe Bonardi, Lori Thompson, Jordan Anderson, Dana Lloyd

#### **Alixe Bonardi 00:00**

Okay, well let us get started. I would like to welcome everyone. My name is welcome to this webinar, pathways to Person Centered decision making and alternatives to guardianship. My name is Alixe Bonardi, next slide, please.

#### **Alixe Bonardi 00:26**

And I would like to welcome you along with my colleague, Bevin Croft, to this webinar. For a brief visual description. I am a white woman with shoulder length light brown hair, I am sitting in an office with a blue wall and color bright, brightly colored art behind me. Thank you for joining us to learn about how disability systems are expanding alternatives to guardianship. And we wanted to note that this webinar series is sponsored by the National Center on Advancing Person-Centered Practices and Systems funded by the Administration for Community Living, and set up Centers for Medicare Medicaid Services, all in NCAPPS, webinars are free and open to the public. Next slide, please.

#### **Alixe Bonardi 01:17**

Briefly, I'd like to say that the goal of NCAPPS, is to promote systems change that makes person centered principles not just an aspiration, but a reality in the lives of people across the lifespan. And all of this work is aiming to support that goal. I will be going through a few logistics and then we'll launch right into the meat of this webinar. So next slide, please.

#### **Alixe Bonardi 01:44**

So, getting started, please note the participants will be muted during this webinar. The chat feature is open, and we see that there are people already starting to make their comments make comments in chat. Terrific. We really love the engaged comments that happen throughout webinars in chat. Towards the end of the webinar, our speakers will have an opportunity to respond to questions that have been entered into chat, so please do not hesitate to enter comments and questions as the conversation moves along. My colleague Bevin Croft will be facilitating Q&A, Question and Answer at the very end. This webinar is captioned in English and Spanish. My colleagues have been dropping into the chat the link for English captions and two for Spanish captioning. This live webinar also includes polls and evaluation questions. So, to the extent you can please be prepared to interact during the polling times and there will be a poll coming up soon. Next slide please.



# National Center on Advancing Person-Centered Practices and Systems

**Alixé Bonardi** 02:55

After this webinar, you can send follow up questions and feedback about this webinar to our website, and [NCAPPS@hsri.org](mailto:NCAPPS@hsri.org). Please note that this email address is not monitored during the webinar. This recorded webinar, along with a PDF version of slides and the plain language summary will be available within a few weeks on the NCAPPS website at [NCAPPS.acl.gov](http://NCAPPS.acl.gov). We will also can at that time include questions and responses in the materials that are posted following the webinar. Next slide, please.

**Alixé Bonardi** 03:45

So, here's the poll. In a minute, we will be bringing up a poll, and we ask that you please respond to this poll to how you self-identify. You can select one or more of the options. And please note that for many people in the poll, there's a little gray bar on the side that allows you to screen to scroll down to view all of the options there are eight options to choose from. So, we'll give people another few seconds to enter into the poll how you identify, there are still answers streaming in. So, I will add a few more seconds. Thanks for everybody's engagement, and this is this bodes well for the conversation. The panelists and presenters are always excited when there are lots of people who are presenting and engaged in this webinar. Okay, so here we have, let's take a look we have with about 85% participating 84%, we can see that almost half identify as social worker or counselor or care manager. About a third of you here identify as a government employee. We have people with this people who identify as a person with a disability, family member or loved one of someone who uses long term supports, and self-advocates. So, we've got a pretty broad range of peer specialists, self-advocates, family members, terrific. We have researchers and community of faith or faith-based organization. People who work with community or faith-based provider organizations as well. We're glad that you all are here, and this will bring us into a great conversation. So, with that I would like to thank you all for joining and introduce our panelists today. Next slide, please.

**Alixé Bonardi** 06:23

We have six panelists today. And to get started, we have Michael Kendrick, who has worked in many roles including assistant commissioner for the Massachusetts Department of Developmental Services Director of Kendrick Consulting international for over three decades director of supported decision making for the Center for Public representation. We also have Dana Lloyd, who currently serves as the developmental disabilities. That's director of the Developmental Disabilities Program at Georgia's protection and advocacy agency and leaves Georgia supported decision making coalition. Dana is a state team lead for the administration for community living center on youth voice youth choice, and national youth led supported decision-making project. Fil Clissa is a senior program policy analyst at the Wisconsin board for people with developmental disabilities, and also the project manager for the statewide self-advocacy organization and works with their leadership team to strengthen Wisconsin's self-advocacy voice. Jordan Anderson is a strong advocate for supportive decision making and CO leads the Center for Youth Voice youth choice project for the Wisconsin board for people with developmental disabilities and serves in dual roles as a co-lead and a youth ambassador for the project. Nora Bray has more than 30 years' experience working with healthcare delivery for people with disabilities and is currently a member of the Colorado Office of Community Living at the Department of Health Care Policy and Financing. And finally, Laurie Thompson has held multiple roles in the disability field in the last 16 years, she has been responsible for Medicaid long term services and supports



program policy development in her work with the Colorado Department of Health Care Policy and Financing. We have such a range of experts and great wisdom here together on this call, and we really look forward to getting into conversation with you all. With that I would like to turn the conversation over to Michael Kendrick to lay some of the groundwork regarding supported decision making and alternatives to guardianship. Over to you Michael.

**Michael Kendrick** 08:54

Okay. Hello, everyone, and welcome to our session. Supporting decision making probably isn't a term we would have heard much of, until really maybe the last decade or two. But its roots go back to the issue of the rights of people with disabilities to be in charge of their own life and to make their own decisions. And that have had of course, been taken away from many people with disabilities, as well as other people by the institution of guardianship, guardianship being a legal deprivation of people's rights, and guardianships have existed for a variety of people, not just for people with disabilities, now through the centuries, including women in many cases, as well as all sorts of other people that were thought to be in need of protection. And so guardianship goes back several times. Since of yours, and it has taken somewhat different forms, but it all guardianship shares that someone will make the decisions for the person, and the person is not allowed to make their own decisions. Now, the premise being that they aren't competent to make your own decisions. Now that has been changed, the thinking behind it has changed dramatically in the last generation and a half. And sort of a trigger for some of that change was the United Nations Convention on the Rights of Persons with Disabilities, which was a major international convention, that essentially said guardianship is very problematic, it's potentially harmful to people as opposed to a protection, and that people's rights should be restored. And when that declaration was made by the United Nations, it was quite a shock to people because they'd never heard that kind of criticism before. Now, in the North American context where we are, and there were many movements that contributed to an interest in supported decision making. One of them, of course, is the movement for people to have person centered life options, life options that are shaped around who the person is. And that movement was also influenced by what might be called the self-determination, rights movement. And that is the movement to restore to people their rights and their ability to determine their own life make their own decisions. And an aspect of that would be what we might call the self-advocacy movement, which started again, about a half a century back. And really, it was a movement to give people with disabilities, a voice in all kinds of matters. And eventually a movement to, for people to find their voice. When others have made decisions for you, you aren't necessarily all that practiced in thinking for yourself and expressing your own opinions, developing them over time, and so on. So, finding of one's voice isn't something that you do on day one, it's kind of a journey towards self-determination, which has many steps and many phases to it. Now, the sort of the significant development then, was the idea that there would be alternatives to guardianship that you could create alternatives to guardianship. And, in that's exactly what has happened. And not just in the United States, but in many countries, there have been efforts, first of all, to eliminate guardianship to really put it out of business. And some countries have done at wholesale. In others, they've opened up the option of support decision making, and as a pathway to, you know, to having guardianship withdrawn. And so, we would see people that have already had their rights restored. In other words, they, the guardianship has been legally lifted.



**Michael Kendrick** 13:44

But there's others that are practicing support decision making, that are hoping that that will happen for them sometime in the future. And then there would be people for whom either the person or the people around them is uncertain about whether they want to come out from under guardianship. And so there's still questioning and testing the idea, is it possible that a person could be their own decision maker, as many people have said. So that process is underway and not just in the United States, as I indicated, but also even within the United States, it's different from one person to another in to some extent, one state to another. But we already see here, in a relatively short time that 14 states in the United States have passed in the state legislatures, a recognition of supportive decision making as an alternative to guardianship. It does not necessarily mean even with those statutes being passed, that people are coming out from under guardianship, but it does reckon Nice, the validity of support decision making as a different way to support people, then is guardianship. And of course, this is those aren't the only states that are working on this, there are many states that have statutes that are almost past they've been in second or third reading. So, we'll see, I think, a very rapid increase in the number of states to well over the 50% mark, probably in a few years. So, what that means is that were beforehand, people hadn't heard of supported decision making. Now it's much more common that people at least had heard something about it, even if they couldn't quite readily explain what it is. And that's pretty good for a relatively short period of time. And, of course, we now have people that used to be under guardianship who are now doing public speaking about their experience of coming out from under guardianship and sort of how that happened, and what the benefits of it were for them, including the very people that put them under guardianship, such as their families, and the courts may also have come out in favor of individuals having their rights restored to them. So, some of this is in the works. And the data is variable, from one state to the other way as to what is collected or not collected. But there is certainly more activity, even if people aren't being very good at collecting the data. Now, the alternatives to guardianship don't exist in a vacuum, they're really raised the question of, is there some other way to support people with their decisions without taking away their rights. And that is, of course, a very similar question to other person-centered questions, which is, what would be the way for this individual to shape the life that would be best for them. And so all of that is happening as we speak. And with many of these kinds of changes, there are what might be called front runners, people that have started this process early, and then others that haven't started at all or may not even know about supported decision making. So, in the various states, in the United States, we have all mix of people from one end of the spectrum to the other. And this would apply not just for people with disabilities, but also to their families, to service providers, to advocates, to politicians, lawyers, and so on. So, we are not certainly on the same page that everybody is thinking similarly, but that's what you get, when you introduce change, you get some that aren't interested in the change immediately, others that are immediately interested in the change. So, we're somewhere along that process of introducing a change and having it be adopted by other people.

**Michael Kendrick** 18:27

A very good question is, if you practice support decision making, does it mean that you're a great decision maker? And the answer is probably not. Because many of you probably have been making your own decisions all your life. And if you're being honest, you'll have to say you've got a few board decisions in your background that you might regret and whatnot. So, support decision making isn't a



guarantee that people will make good decisions, it is rather that they have access to support. And people with support are more likely to make better decisions and people making decisions without support. And so just to say a few things about the support, the support can be as little as one person that support you or a small network of people that support you with your decisions. It's up to the individual to kind of lean one way or the other. But typically, most people rely on the advice of various people as they make their decisions. And so, the supporters of people aren't always the same person. They can be a variety of people that you turn to depending on the nature of the decision that you want some help with. And so, in this sense, you could think of supportive decision makers as having a small network of people that they are turning to from time to time for decisions and assistance with those decisions. And of course, most of us discriminate as to who we talk to about specific decisions, we tend to have people in mind that we want advice from and people that we certainly don't want advice from. And that's the same with people that practice support decision making. So, as I said, even if you aren't getting supported with your decisions, it doesn't mean you will always make great decisions. And it also doesn't mean that the advice you're getting is always going to be great. Because if people can give us advice in life, you know, often misguide us at times. So, there's always that risk present, that as people look around for support, they might not get optimal support. So, it's good to think of support decision making as a, an evolving practice in the United States and other countries. And that, over time, we can anticipate that the practices will improve, as people get more experienced with the both the supporting of people and the people making their own decisions. So, my task today was sort of to introduce us a little bit to support decision making. If you Google supported decision making, you're sure to find all kinds of resources online, about it. At the Center for Public Representation, where I was the director of support decision making, we've a website on supported decision making, and there'll be many websites around the country now on support decision making directed to often to particular groups. So, it's good to know that they're there. As such as the others have talked about the Center for Youth Voice use choice, and so on. So there, there are resources, you may not immediately know where to look for them, but they're there, and you will find them. So, I think I'll just stop there, having introduced us to a little bit about support decision making. Thank you.

**Alixé Bonardi** 22:20

Thank you, Michael. And I know that the conversation will continue in their questions, a few have popped up. At this point, I would like to turn it over to Dana Lloyd, to who to continue this conversation with a little bit of the basics, and how systems need to think about the work that they're doing in terms of supporting people. Over to you, Dana.

**Dana Lloyd** 22:47

Thanks, Alixé.

**Dana Lloyd** 22:49

And thanks, Michael, for getting us started. My name is Dana Lloyd, I'm an African American woman with short, curly, dark hair, I'm wearing glasses and, in the background, like a yellow painting of flowers. Emily, it's really great to be with you today. If we could get the slides up, that'd be wonderful. Thanks. So, we can go to the next slide? So, I just want to be really clear and give some attributions, that, you know, the quote says if I've seen further, it's by standing on the shoulders of giants. And so, the work



on person centeredness in this country and around the world is deep and rich. And so, these are things that I've learned from people I see as kind of experts in this field. And the things that have particularly resonated with me from their teachings, but most of this is my reflection on other people's work, we can get to the next slide. And when I think about person centeredness, I think about this quote a lot, right? And it says that institutionalization is administrative control over people's lives, from either novice Smith with a disability civil rights advocate. And I think about that, especially when thinking about person centeredness. Because in many ways, person centeredness is the opposite of that right, the opposite of administrative control over people's lives. And that when we are thinking about person centeredness, we're working really hard to kind of move away those administrative barriers.

**Dana Lloyd 24:23**

So, people that we're supporting, have access and control in their own lives. It also reminds me that the challenges with institutional realization aren't relegated to places, right? That if we think about institutionalization as administrative control, which can exist anywhere, and that should really be what we're looking to kind of root out and offer alternatives to we can move to the next slide. And I really think there One question that I have found so helpful when trying to determine how I can help myself my team, places that asked me to come in and help their teams think about getting more person centered. And the question is, who is the person? And what do they need? I want to break those kinds of two questions that have been smushed into one down. When we ask who is the person? We're not thinking about a diagnosis or a label. But who is this person as a human being? What are their human needs? As mom or brother, a cousin, a community member? Who is this person? What do we know about them their likes, and wants and desires? These are the things that would be that when we introduce ourselves to people we might highlight about us in our lives, who is the person as a human? And then when we ask the question about what do people need, that we would shift away from thinking about service needs? Right? Not what's on our menu to offer people, but what are their fundamental human needs? Is it about connection? Is it about relationship? Is it activity? Is it purpose? And when we think about these questions, the answer should be things that would be true for anyone, that anyone who was this isolated in their life might be withdrawn, that anyone who lack of control had this much might be seeking out to get more control in their life in a variety of ways, right, that these questions should really focus on our shared humanity, when we're thinking about them. And so, I've just found that question to be kind of uniquely and centrally helpful in thinking about person centeredness. And so, it's one thing that I wanted to share with you all today, as you're thinking about these things, that that we have to dive into that curiosity about really who people are, and what are their human needs. Next slide.

**Dana Lloyd 27:15**

And so, because we have such a limited time today, I thought that I would let you hear from some folks I think of as experts in this field, who can give you some really quick snapshots of their definition of person centeredness for us to build on as we go through, and you can play the video now.



# National Center on Advancing Person-Centered Practices and Systems

## **Citizen-Centered Leadership Community of Practice Course Trailer, Beth Mount 27:56**

Person Centered work is so many different things, it's not a plan. It's not a couple of things. It's a very complex interaction of social dynamics, investments, and commitments that we make to the process that leads to real change.

## **Citizen-Centered Leadership Community of Practice Course Trailer, Jack Pearpoint 28:13**

Person centered planning is about being acutely focused on the capacities of a person, anybody, anywhere, anytime.

## **Citizen-Centered Leadership Community of Practice Course Trailer, Beth Mount 28:23**

So, to be person centered, is to start with getting to know a person and their family and the people in their lives first and grow and understanding of the vision and the hopes for that person. And then to take direction for our work from that wisdom from that knowledge from that information.

## **Citizen-Centered Leadership Community of Practice Course Trailer , Michael Smull 28:44**

This is not about having a brilliant plan. It's about having pervasive Person-Centered practices that then eventually get reflected in plants. When we were attending to Person centered planning, we paid attention to different ways to plan. And we chose an approach about that, that builds on the notion of what's called idealized design. So instead of trying to think about what you want to get away from, you think about what it is that you want to create. And those are two fundamentally different orientations to the approach to things and more people pay attention to what they have, rather than what they do.

## **Dana Lloyd 29:27**

Thanks for that. So, I hope that those, those 90 seconds were really helpful. And you're thinking about person centeredness, and what the essential factors are, and we can go to the next slide. Something that John O'Brien says there at the end, is that, you know, we really want to shift our focus and thinking to what we are building towards, and I find that to be very, very helpful. But I also think that we want we do want to be clear, right? about the past that we are moving away from, as Michael kind of ran through that history. And when we think about the changes that we've seen, in the work of supporting people with disabilities, it's important to remember what that past was characterized by. And be aware when those things show up, even if it's in different ways, right? So, isolation and seclusion might not look like institutions. But it might look like a separate time at the gym, designed for people with disabilities to work out. Right, that might still be leading us towards isolation and seclusion and separation, and rejection and loneliness, I think it's important for us to be mindful as we're supporting people about the relationships that they're in. And what might show up as rejection might be what we call staff turnover. Right? What might show up as loneliness might be, you know, people seeming to have gained skills, so they need less support. But that means their life has gotten a bit emptier. Right. And these negative reputations and old stories that can sometimes follow people forever, it's documented that I threw the plate across the room once. And that story lives on forever and ever. And I'm kind of relegated to being that person, without folks realizing that I've really learned and grown from that moment. And we're being curious about what happened in that moment. That might help people see differently than just that old story. So, I just wanted to highlight some of the ways in which these things show up in our work. And we have the ability to ask ourselves the question of whether or not our choices really



reinforced these old patterns or help us move towards something different. And someone asked a question in the chat that I'll try to hit a little bit about how to staff turnover, to loneliness or, or isolation, and that people might just not feel known. I think there's, I've heard from folks with disabilities before, using long term supports that, you know, if you kind of extrapolate out the number of people that have been in their lives, over a given period of time, this might be training hundreds of new people, and just basic getting to know your things, and that can feel isolating and lonely. So that's kind of where I was going with that. But the idea of, of keeping, keeping these things in mind, and paying attention to how our choices are connected to what we're building for people, we can go to the next slide.

**Dana Lloyd** 32:46

So, this is another piece of gold, I think I came across from other people who've studied and done this work for a long time that I found immensely helpful. So, if you're not aware of John O'Brien, five valued experiences, I again find them really direction giving in my work. But John talks about those experiencing being those experiences, being sharing places with people, making choices, making contributions, growing in relationships, and experiencing respect. And then this visual overlays them on the eight sectors of community life, the places where we have opportunities to share these experiences. And they show up and things like creative expression and work and learning at home and neighborhood. But I liked this tool, because for me, and maybe it's not a tool, but a graphic, because it gave me an idea of how to see people's lives, right. And I can pick any one of these sectors, and kind of ask myself is, is a person having an experience to share space? When it comes to say, a spiritual or religious practice? Are people at the religious events that are happening? Are they making choices about what to participate in? And what not to participate in? And are they making contributions? Do they serve on a board or helping a class? What are the opportunities for that? Are the relationships growing and deepening there? Have there been any connections that have been made in this religious institution?

**Dana Lloyd** 34:25

And are people experiencing respect here, but I can kind of see this all laid out? And then gauge what might be true about people's lives? And where are their opportunities for more growth and development? And where are places that are really strong and robust for this person? And where are the places that there might be some more, you know, opportunities for me to think about helping to nurture that. So, I just found that as a really helpful visual to think about those two things, the value of experiences and the sectors of community life. Next slide. And so, I think sometimes curiosity is a really underutilized tool in our work. And so, I focus on asking a lot of questions and what I am sharing with people and hopefully giving you questions to continue to think about. So, the question here is, how do we support people to have to create a good life and a life well lived? What does that look like? And I think these are some really essential proponents of, of person centeredness, right. But real choice has to exist for people, not constrained choices, not just choices between the things that we've always done. But if we go back to that first question about who are people, and what do they need? That gives us some guidance into what choices might be available for people? How do we get to know what those choices are? But really, thinking about what choices are we offering to people? What choices are we not offering to people in our work is super important. And then making sure that people are treated with dignity and respect, right? And I think of dignity as about humanity. Right? What interactions are we





having with people that just value folks as humans? What are we doing to support their natural friendships and relationships, because those are central to who we are as humans? Communication is deeply important. So, another little video, we'll watch about that in a second. But if folks don't have access to real meaningful communication, it's difficult for us to really be thinking about anything. Person Centered, right? And so, what does that look like? And how do we dive deeply into that, and then these opportunities for community involvement, thinking about us together as humans, right, that people are more alike than different, and opportunities to just experience life to be out in the world and figure out what I do like and what I don't like and what things I might want to pursue more, that doesn't happen in my living room for the most part. And we all can remember how challenged we were to do those things during the pandemic, right, when we had to figure out how to live our life from the living room. That's not what most of us thought of is real life. How do we create those opportunities? And for life to be joyful and productive? Those are really essential questions that I think are just kind of guiding principles, we can move to the next slide. And so, when we think about supported decision making, in the context of person centeredness, I find those two things to really go hand in hand. And when we think about supported decision making, I kind of have to start with thinking about choices.

**Dana Lloyd** 37:56

And for me, it's important that when we're thinking about that those choices, and especially the choice around supported decision making, we ask a different question, right? So, there's 717 of you on this call right now. And if I asked you a question, and I asked you, if you would like strawberry ice cream or chocolate ice cream, you have two choices. I'm going to get two answers. We put up the poll, and it's going to split however, it splits. But next slide. If I asked you a different question, if I asked you what's your favorite flavor of ice cream? We could have 717 different answers, we get different solutions, based on the question that we ask. And so, when it comes to supported decision making, I often hear people kind of stuck in this binary around. Well, can people make decisions? or can people make decisions? Do people need a guardian to make decisions for them? Or do they not need a guardian to make decisions for them? And I say we back away from all those questions and asked, what support do people need to make decisions? What support? Do people need to get better at making their decisions? What would it take for someone to make a decision around their healthcare or their finances? But we have to start with the right question. Because if we get stuck in those binaries, we only get stuck with two options. And there's way more options to the ways in which people can get support for their decision, then guardian or not. And so, I hope that that's a helpful way to think about that. And I think it's hot most places in the country. So, who doesn't want to think a little about ice cream? Next slide. So, then I really began to see supported decision making as both a result of and a tool to promote greater person centeredness. Right. So, we spent time getting to know people and the folks around them. And we lean into that deep curiosity. And we, we think about what it would take for a person. Jack your points at any person, right? And that leads us to getting the information we need to know, to answer that question around, what would it take leads us to support a decision making. And as we dig into that process and figuring out what it would take and figuring out how to help people communicate more effectively, figuring out what's important in their life, that they want to take the lead on a place where they want more choice and control. Well, that leads us back to more person centeredness, right. And then we find ourselves in kind of this endless and in my imagination, exciting feedback loop, where these two things are constantly kind of supporting each other. Next slide.



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**Dana Lloyd 40:55**

So, in Georgia, we use this framework, the I decide framework, decide is an acronym for direct and list, choose and form, determine and experience. That phrase I decide right helps us kind of get right to the heart of the matter that this is person centered. And then we think that those words help to highlight some of the most important parts, kind of the essential thought products or practices that you need for supported decision making. And then when people are really engaged in this way, when we're asking the question, what does it take? And what does it look like? And what do you need, these are really kind of person centered by nature, right? When we're spending the time to center the person with a disability that I and I decide, then it helps us to move in that way. So we spend a lot of time with both folks with disabilities and their families introducing this framework, thinking with teams who are supporting people about this. But it's really been kind of arisen as a crucial part of our supported decision-making work. This framework and so that's a way in which we try to kind of get everything we've spent the past 10 minutes really kind of talking about out into the world. Next slide.

**Dana Lloyd 42:18**

So, this is a quick video that I want to show you from some folks in Washington, who have been using, they're talking about in a different context. But I think it just highlights some of the things that we've gone over today. And Elayne, I think I forgot to tell you this, but this video starts at 1:30 minute mark. And we'll play till the end thanks.

**PASRR Communication Toolkit Video 42:18**

In the community, pastor is all about being person centered. And that's a word that you hear in any conversation when you're talking about the disability community and service planning around that we need to get to that individual, the one who's driving the process, it needs to be about what makes them happy and fulfilled, and what are their goals for their life? What does self-sufficiency look like to them, but our assessors have brought so much energy to this. And really, they caused it to happen in the beginning. It's our team because we started talking to them about person centered principles. And they said, what do we do with people who don't use words? How do we do that? And we now have an answer for them then. So that's when we knew we had to find an answer. And so, we consulted with a speech language pathologist Brittany Asher, who's been fantastic. She's worked a lot with people who have disabilities, especially intellectual disabilities. And so, she totally got what our vision was. And she has helped us to develop a toolkit that we can use, whenever we go out to do an interview. When we're meeting people initially, we don't really know how they communicate, we can have some tools in our bag that can help us get more information from them and have to rely less on the other people in the room, what we really hope is that we'll be able to change some people's lives, that maybe this will be the start of something bigger, maybe other agencies will want to jump on board. And maybe this will become the new standard of what access looks like for people with disabilities. So, we could overtime add new tools for the kid decide, maybe some of the tools aren't as useful or some are more useful. We'll keep moving with that and we're very excited to see where that takes us.

**PASRR Communication Toolkit Video 42:18**

The thing I like to do right off the bat is the iPad and that shows can he look at the target does he know to push it and can he physically push it and then the go to talk that I used with Scott he was able to



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recognize the yes and no, but he couldn't push it hard enough for it to actually verbalize yes or no, which, again, is why the iPad was a better option for him because he didn't have to push it as hard.

### **PASRR Communication Toolkit Video 42:18**

Scott, the whole time we were there, he was communicating nonverbal facial gestures with nodding his head shaking his head, tapping on his brother's hand when something interested him. Lots of indicators that came from Scott that he's got a lot to say. But he doesn't have the words to say them. And it really is our responsibility as an agency to say to Scott, how can I help you tell me what it is, you really need to tell me, access is not just about being able to get in the door, if you use a wheelchair access is also about being able to make your thoughts known if you don't use verbal language. And there's a lot of people who have intellectual disabilities. For them. That's the case, we are advocates every single day for our clients, very little of our assessment actually talks about their care, most of it is about what makes them happy, what are their goals and what they enjoy doing. We want to see what this person is capable of. And that's what's exciting about our program is that we really push the boundaries to give the individuals choices and see what they can do, and it opens the doors for them.

### **Dana Lloyd 46:14**

So, I just wanted to highlight that right because this is a program. This is a program that's assessing people's needs based on the past bar, which you may or may not be familiar with. But they really took a deeper dive and ask some of those questions about how that process was working and what it was leading to, for the people that they were supporting. And I just thought it was a great example of putting Person Centered practices into play. And then that focus on communication, which I really, you know, I mentioned earlier, but starting with that, to get to that point, we can go to the next slide.

### **Dana Lloyd 47:00**

So, this is an these are there's just two slides left, just to kind of highlight why we're doing any of this. And so, this was a group that I worked with some folks on, we asked the question, right, what did folks with disabilities wish was different in their lives. Most of these folks were either living in long term, home, and community-based service settings, or receiving some of those supports, maybe at home with parents. And I obviously can't read all of this, but that one in the center always stands out to me right to tear the roof off of my sheltered life. There are things that you might see there, like I want to open my own mail, I want to connect with other people, I don't want to be segregated. I want to learn things like how to use the computer, or maybe go to college or learn about budgeting. These are such simple but powerful, everyday things that many of us take for granted. Many of us probably have policies and procedures that say people should get to do all these things. But it's not what people experience. But we have the power to make changes to our services. So, this is what people experience if we focus on thinking about who people are, what they're asking us for, and what we can do to get closer to those. I think the process of supportive decision making of just turning to someone and saying, what's important in your life? Where do you want more choice and control? How can I help you get there is a part of how we get to some of these answers, and gets us moving in that direction? And then last slide is this quote that I love. I included in in almost all of my trainings from Gerard Quinn, who says that self-determination opens up zones of personal freedom. It facilitates uncoerced interactions. So, we're right to focus on things mundane things like opening bank accounts and going to



the doctor. Because this is how we positively express our freedom. And that idea that the work that we're doing is helping people with disabilities who've been denied that freedom move closer to it, I think it's central to both Person-Centered thinking, as well as supported decision making. So, I hope I was able to help you kind of see how those two things connect to each other and give you some ideas about jump starting the work within your systems.

**Alixé Bonardi** 49:47

Dana, thank you so much for covering so much good ground there. I really appreciated all the slides that you shared. And I know there was a lot of comments too on that in chat. Like to turn it over now to Jordan Anderson and Fil Clarissa, who will be taking another perspective and I think also answering some of the questions people have been asking in chat as well. So, with that, I'd like to turn it over to you Fil and to Jordan.

**Fil Clissa** 49:59

Good afternoon, everyone. I'm Fil Clissa with the Wisconsin board for people with developmental disabilities. And I'm a co-leader, along with Jordan, on the youth voice, youth choice Wisconsin team. I am an older woman with white hair pulled back and I am wearing a purple top. And I'm sitting in front of some bookcases in my office at home today. So, I just before I, I invite Jordan to introduce himself, I did want to mention that Wisconsin is one of those states that has passed supported decision making legislation. We've had an supported decision-making agreement legislation since 2018. So, Jordan, would you like to introduce yourself and then share your story?

**Jordan Anderson** 50:59

Okay, Fil, it's nice to see everybody today. And I'm just honored again to share my story. And then you fool for passing you on. My name is a brief description of myself. I am zooming in power wheelchair, I am a white male, sitting in my bedroom. And my story started off like this. Hello, my name is Jordan Anderson. And I am from Auburndale, Wisconsin. I have cerebral palsy. And my brother is a little bit more and more than I am. I went to Auburn to high school in 2021. And this past year, I completed a program called Project SEARCH after I was done with school, but some of my favorite subjects in school were journalism and government. The reason why I like some of those classes in school, where, because I really like sports. And I really like talking to different announcements and stuff. And the other reason is, I live in a small town. And I really like doing advocacy work for the state of Wisconsin, in my small community. So, I've talked to many different politicians and stuff like that. So the first time I have read about I'm gonna backtrack a little bit. So, I went to when I found out about Project SEARCH that was supposed to do not a year of education for me. And no, have you heard about Project Search, but it finds people with disabilities to get internships and to gain work experience. And with that, with going through my little clinic in hospital, I found a job in gastroenterology. And my number one goal was to find a job that I love. And as you see here, public speaking is what I'm I would say what I'm really good at. And I love talking to people and my number one goal is being a receptionist. So, I get to see about 50 to 75 people a day when they work through my doors. And I'm just so glad for that. And no, I found out supported decision making about in 2001. I attended our local self-determination conference in Wisconsin. We have it every year and overweight been up I'd have it for two years. But since the pandemic had happened, we've been having a virtual, but fingers crossed, we will be having



an interesting and virtual with those who don't feel comfortable. But I attended some of those sessions on because one of my former teachers in school, so passion in me the agency at first, and she really wanted me to attend. And I was always worried about missing schoolwork in stuff. So, she said, Oh, may get us to attend this conference. And one of the sessions that I attended with Gordon chip and supported decision making, and

**Jordan Anderson** 55:59

I learned a lot from that session. And when I turned 18, actually on that day, I got a call from my doctor, saying, "Can I talk to your parents? Because you're your own guardian." because we didn't have anything set up at the time, and I didn't know what it was about. And then I attended this conference, and then at home, told my parents what I learned, and they were so impressed, and it was a little too close for comfort. A few days later, my mom and dad had to go to court to retain my rights to vote, and to vote. And I really like having my voice heard, and my number one, like, I would say, right is to vote. And I like to say who is representing me, so it's very important to me. And they actually came and got me out of school that day, because the people in the court here said I was incompetent. Well, in the meantime, when they were getting me out of school, my lawyer that was assigned to me, said, I don't know what he really said, but we need to hire our own attorney, because he had some worldly, like, some more expertise, and thirty-minutes later we gathered back in the court, hearing and my attorney just started having small talk with me, like what your favorite thing to do, all the school stuff, and then a joke came, and then he asked me some questions. And then we basically never gathered into session because virtually the judge and my attorney, did some digging before they went to get me, but I just hope my story brings some light to other people's stories because like you claim, I never thought I would be a public speaking on this issue. But it's really helped me overcome my story. And for that I have my own power overturning for finances and healthcare and my parents are my supporters. I'm so I am honored to speak with you today. And I hope to answer any questions you guys might have. But Fil, I'm going to toss it back to you is leftover then details to cover?

**Fil Clissa** 59:53

Sure. Thanks, Jordan. I can quickly do a little recap as I'm going through some of the points It's I don't think I could have created or developed a script better than Jordans, true story. And it really illustrates a few things for me. First, Jordan was very lucky that he had parents that were willing to listen to him. You know, his parents were told through the school system, that they needed to get guardianship. And that's all that they heard they needed to get guardianship, they needed to get guardianship. And so that's what they pursued, you know, they were, they were, you know, taking, they were interesting people that they felt had their best interests at heart. And, you know, Wisconsin, we also are lucky to be you know, that it is required that the person with a disability or the potential Ward, attend those hearings for guardianship. And it was then when Jordan really realized that that was a possibility for him that guardianship was potentially eminent. And how fortunate it was for Jordan, to only days before that, be able to attend a conference that he normally would not have been able to attend to, except for the fact that it was virtual that year because of the pandemic. So, I guess one good thing came out of the pandemic, right, Jordan. And, you know, he learned about supportive decision making, and he was able to speak up for himself and tell his parents and the attorney and the judge what he wanted. And that was not to be under guardianship, he felt he could make his own decisions, and he did not want his



rights, to vote, or to hunt, be taken away from him. So, you know, those are really a lot of things really aligned in the right place for Jordan. And while you know, there was some conversation, probably in IEP meetings about supported decision or about guardianship. There was never any real conversations or discussion with Jordan, about, you know, what that meant, and whether or not he felt that that was the best thing for himself as well. And so, you know, this is where informed choice is really critical in being able to make decisions for yourself and also to be more self-determined. And, you know, had he not gone to the conference had he not had the opportunity to, to learn about this concept, this new concept about support decision making, he probably wouldn't have been advocating for himself during those IEP meetings. Anyway, so those are really important, important stories that are lessons that we've learned from, from Jordan. And, you know, Jordan is someone who, you know, has just really hit the ground running in the sense of, you know, he has a strong passion for advocacy. He's also Jordan, do you want to tell him a little bit about your project with SARTAC? Just real quick?

**Jordan Anderson** 1:03:30

So, I was manning probably no, you guys are probably actually done this more than I have because I got selected to be a SARTAC fellow. And it's a national program just like you guys are today, that's being held on the webinar. And I was one of six people selected all across the country. And I do my project is based on making sure people have durable medical equipment, because it's so hard to get like, a total wheelchair, for instance, because I am going harder the one I have now, and with me putting in 36 hours a week at my job. When I get home. I am so sore. Then me doing advocacy work. I just decided to work with the people in my wheelchair company, and anybody that wants to listen to me. I actually have a survey out right now because I'm just trying to gather feedback, but I want to get the survey and my story into other people's hands, because my wheelchair has been denied. I think it's going on its fourth time right now. So, I've been doing a ton of advocacy work on making sure people have the right people to prepare their stuff they need. And that's just one of the many projects I'm doing reach as well, decision making. And right. So, I don't know if you want to, I don't know if we have time, but I don't know if you want to mention about the dying or the word.

**Fil Clissa** 1:05:48

Yeah. No, maybe that we can save for a different time. But I did want to, you know, circle back to the project, the Youth Voice Youth Choice project, and why it's so important for us here in Wisconsin, and why we're so passionate about making sure that youth have a voice in this process of supportive decision making guardianship, person centered planning, because we really do want, you know, we hear so many stories about youth who haven't been part of the process of discussion about, you know, what's going to be happening to them in their lives, in the future regarding guardianship, and this is such an important component of being able to, you know, have some form choice, have your voice and advocate for yourself. And it's just truly a missing piece to the, to the puzzle to the work that we're doing here in Wisconsin, on supported decision making. So, we're really thankful for that opportunity to be part of that project as well. And I think I will end there and happy to answer questions. I think we're going to do those later.



**Alixé Bonardi** 1:07:04

We will be and Jordan and Fil, thank you so much. I don't know if you've seen there's much, much appreciation coming through in chat for both of you, and particularly for you, Jordan, for your speaking about your own experience, your advocacy and self-advocacy. Much, much appreciation coming through for both of you and the work that you're doing in Wisconsin. We will have time hopefully for a few questions at the end. But before that, I would like to turn our conversation over to our colleagues from Colorado, Nora Bray, and Laura Laurie Thompson, who has some content about the experience in Colorado and the work that they've been doing for some really exciting work to try and drive alternatives to guardianship forward in Colorado particularly. So, with that, I'd like to invite Nora and Lori to join us there we go. There's Lori, and I think Nora will be joining us shortly, and we will get your slides up.

**Nora Brahe** 1:08:19

Hello. I'm Nora and I'm a white woman with brown hair and green eyes. I'm wearing glasses. I'm wearing a turquoise blouse is sweater and I'm sitting in front of a green wall with a painting of a young girl sitting in a country setting. Thank you so much for sharing Jordan and congratulations on your award and the work that you're doing. It's going to be so applicable for so many people. So, I'm going to talk a little bit about supported decision making, how we can use it just you know mechanics of supported decision making. So, there's no single best practice for supporting people with disabilities to reach decisions. Systemic factors and such as availability of support networks or person-centered service providers can impact the provisions have supported decision making training and opportunities. And then of course, individual factors such as the level of need accessibility to support networks and providers and capacity at the time of need will also impact how support might be provided to individuals. Consider the decisions that they need to make and then decide which of those decisions they can make on their own and which might require some support. And this may also lead to considering what types of support the person might want to make decisions. So, using SDM and personal life, it can be used to help decisions make choices about housing, about finances, about health care, leisure time, education, employment opportunities. And there are many areas of areas of life in which a person might need help with making decisions and including some that are not listed here. Next slide please. So, the SDM process centered around the individual who is designated the decision maker, that decision maker then decides who their supporter supporters will be. And this can be anyone from families, members, friends, service providers, just anyone that the decision maker would like to have included in the process, as long as the supporter agrees to be to serve in that role. And then the decision maker will work with the supporters to determine what types of decisions will be made. And but to go back to supporters for a minute, sometimes individuals don't have a strong network. So, in those circumstances, it will be important to look at other opportunities to build, create a support network. And that, again, that can be anything from maybe there's a family member, who could be a strong supporter, or seeking out organizations that match people with mentors, or look, looking at organizations where relationships develop, like schools or places of worship. So, the decision maker, then decides what types of decisions need to be made, and what they need help with. So, they can choose to have support in some areas, but not in other areas. And they can also decide what kind of help they would like in making certain decisions, for example, they might need help gathering information, or they might want assistance to understand information, or they may want help



communicating a decision to others. So, the possibilities are, are endless. The decision maker and supporters will determine which areas the person may need support and as well.

**Nora Brahe** 1:13:22

So are the different types of decisions that they'll need help with. Again, as Dana pointed out, it's so important to start with the person and asking them what do they want to happen in their life? How do they see the next stage in their life? Or how would they like to move forward in particular areas? So we always start with, what would it take to provide the support to this person, so that they can make the decisions they need to make or want to make, or to make decisions to address a presenting concern, or issue. It's always important to make room for change and to focus on the present and the future when you're involved in this process. And again, you know, the individual may want help specific help from certain individuals, but not others. So, they may want assistance from their brother to make decisions about housing but would prefer to have assistance from their sister about their finances. So again, that would always be the individuals This is the there's no one size that fits all for supportive decision making, it will look different for everyone. Sometimes there'll be a plan a supported decision-making agreement SDMA. And this is a plan that is a written plan that gives information about what the decisions, what decisions will be made, who will support those decisions. And specifically, what kind of support the individual is requesting. The plan can be followed as it's written, or it can be changed as the member moves forward or suits the needs of the decision maker. That that plan is not a legally binding document, it is more like a person-centered plan. So, again, the decision maker is always the central person in this whole process. Next slide, please.

**Nora Brahe** 1:16:20

So, supporters, the role of supporters, and supporters should be people that the decision maker knows and trust to provide the type of support they want for the types of decisions they want to make. They need to be individuals who will follow the plan set forth and will never substitute their own choices for those of the decision maker. They can be again, family members, friends, neighbors, service providers, members of worship communities, or maybe service providers, professional providers in the community. Actually, it can be anyone that the decision maker would like to have involved with the process. The decision maker can assign supporters to certain types of decisions and not others. For so again, for the example of an individual may want a friend to help him decide, make choices about education, but may not want that same friend to help them decide what type of you know activities they would be involved with. The decision maker can choose as many supporters as they want. And the decision maker can fire their supporters at any time and of course, supporters have the option of quitting.

**Nora Brahe** 1:18:05

Hmm, next slide please. Building a supportive relationship is essential. It's essential to the SDN process. And there's some key components for doing that, that need to be considered. You should always think about the individual wishes first. It's important to know the individual know who he is what they what they want in their life, you know? Yeah, provide the least restrictive form of support. Again, it's not guardianship or not guardianship, there's a whole range of types of support that can be very useful for an individual so provide the least restrictive form of support always. You're going to want to





allow for growth and maturity as a person experience, experiences, and practices new skills. This is so crucial you want as much as often to provide opportunities for the decision maker to make choices of their own. Again, informed choice, as I just mentioned, is so crucial, our supporter's objective one objective is to be sure to provide enough information so that the individual can indeed make an informed choice. You want to talk about respect and boundaries. Expect differences of opinion and worldview and then also have a discussion about how you might disagree. Make room for change. The relationship needs to be flexible; the process needs to be flexible. And then again, always focus on the present and future. And next slide please. So, supported decision making can be as formal or as informal as a decision maker would like it to be. All forms of SDM, however, do recognize a person's self-autonomy and right to make decisions on an equal basis with others, recognizes that individuals can take part in the decision-making process that individuals sometimes need assistance in decision making. So, people have the capacity to make some decisions but not others, or have capacity to make decisions sometimes, but not at other times. Or they may be able to make decision given if they get help understanding what the decision is and is provided that information that needs that allows for that informed choice. So, Laura is going to talk a little bit about Colorado's efforts to enhance SDM.

**Lori Thompson** 1:21:40

Hi, my name is Lori. And I am a white woman with long blonde hair. And I am in a green blouse with a blue curtain in the background and a couple of pieces of art. I just wanted to quickly we had don't have much time left, but quickly talk about four efforts in Colorado initiatives that build on what Nora was just saying. The first is that following the implementation of the federal final HCBS settings rule, the department really made a concerted effort to enhance the person centeredness of all of our programs and policy decisions. And so, we partnered with the University of Colorado, Colorado Springs, to develop a curriculum for people to learn how to lead their own person-centered support planning process. And that's called the Speak Up. And it's a course offered to all people seeking or receiving home and community-based services. It's really exciting new partnership that we have. We also we developed it in 2018, that we piloted it in 2019, than we had the pandemic. And so we needed to do that virtually. And now we've rolled it across all of Colorado we use. We have co facilitators, and one of the facilitators is always a person with disabilities with lived experience. So that's been just a really great effort that we have put forward and that people are really enjoying learning how to use their voice, to speak up about what their hopes and dreams are and identify things that matter the most to them, have self-advocacy in herself advocacy in advocating for themselves and activism in their own personal lives and in their communities to the degree that they want to. There's a workbook that goes with it group exercises, and a final presentation that people do to articulate what they're they want in their support plan in particular. We also have a group of trainers, person centered thinking trainers in Colorado, that we meet quarterly, and we work collaboratively to increase the access of Person-Centered thinking training across Colorado to folks that really want to access that type of training. And then an all of these I have the resources posted that NCAPPS will get to you all and we in Colorado, our Developmental Disabilities Council created a guide for self-determination supported decision making. It's just a wonderful guide that uses plain language and really articulates the supports that people could have in in supported decision making accessing that. And then finally, we did have the ARC in Colorado champion legislation Senate Bill 21-075, which initiated a process for supported decision-making agreements and then having a supportive community that people can use that folks



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have talked about already, but it just codifies it in our statute. So, it's just another avenue that we can pursue. We're just in the beginning stages of that. So, we'll use all of these tools to really implement that supported decision making more formally in Colorado. So that's just a brief snapshot of the efforts that we are using in Colorado to enhance supported decision making. And with that, I think we are about running out of time. So, I'll hand it over to the next slide.

**Nora Brahe** 1:25:21

So, this is Nora again, and very briefly, just some information about how we're moving forward in Colorado, in partnership within caps. So, what our focus has been that or continues to be is to support knowledgeable and or create knowledgeable and committed service providers. Because we know that that's essential to assist individuals to successfully actuate their right to have control in their life. So, to that end, the Office of Community Living in Colorado is developing resources that will guide providers towards the goal of moving away from traditional service model through integration of Person-Centered practices. And we're doing that through a number of objectives, developing an SDM framework across different Long Term Support populations. So that would include individuals with physical disabilities, those with brain injuries, those with behavioral health challenges, and certainly, the elderly who also have coexisting disabilities would be included in that. In that group, we will be creating opportunities to increase awareness and knowledge that promote self-determination skills. So as Laurie mentioned, we'll be providing PC peep training to all of our HCBS case managers. We're providing the same training to Transition Coordination training and supported by Michael Kendricks paper we are developing a an SDM initiative that will have provided the opportunity to create training and for members and providers and designing and implementing an exploratory project that will be conducted with a designated group of providers and members, giving them the opportunity to practice those SDM skills. So, with that, I'll turn it back over to Alixe.

**Bevin Croft** 1:28:02

Thank you, Nora, and to all of our speakers. This is Bevin Croft, co-director of NCAPPS with Alixe Bonardi. Like Alixe, I'm a white woman, but I am in a pink room with lots of art behind me. And I'm here to simply close this out. To thank our speakers and to tell you to please stay tuned, you will receive an email follow up from this webinar, and we will be posting written responses to your very excellent questions in chat, and compile all of the beautiful resources that have been shared today into a document or resource that you can take with you. And also, please do be sure to check out our new report that was created. You know, thanks to the work of Colorado, through uncaps technical assistance that provides some additional thoughts and ideas about how to promote supportive decision making in your system. So, thank you so much all of our speakers. And finally, before you hop off, we would greatly appreciate it. If you could take the six-question post webinar evaluation that is up on your screen now. We use your responses to help continuously improve NCAPPS webinars for future months. Thank you to all and we will see you next month.