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| TIM FUCHS: Okay. Welcome. Hello, everyone. I'm Tim Fuchs with the National Council on Independent Living. I want to welcome all of you to our latest IL-NET webinar, Preventing Guardianship: How CILs can be the front line to advocate for less restrictive alternatives. CIL-NET is operated through a partnership among ILRU, NCIL, Utah state University's center for persons with disabilities, and APRIL, with support for the project provided by the administration for community living. So, we are recording today's call as we always do so that we can archive it on ILRU's website. That archived version will be available within 48 hours, usually sooner. And we're currently in presentation mode, but we do want to encourage you all to ask questions today. There's a couple ways you could do that. I want to steer you all to the menu at the bottom of the Zoom platform. I know we're still a little bit new to Zoom, but I hope you all are finding it easy to use. In that menu in the middle is an option called Q&A, and if you ask a question elsewhere, we will still see it, but I'd like to point you all to that Q&A tab, and you can type your question in the text box and then hit enter there. You can enter those questions any time during the call, but we are going to wait for our Q&A breaks to address them. There's also the chat feature, which you may still want to use to offer a comment. You can also use the chat feature if you're having technical issues as opposed to a content question for today's call. If you're having technical issues, let us know, and we'll do our best too help you out. Since we're also hosting a call, if you're having really serious technical issues, you can also call us here at NCIL and let us know and we'll try to help you troubleshoot that. Of course, we have captioning today. You can click closed caption in that same menu and you should see. If you're only seeing a single line, please know that box is -- what's the word? You can zoom in. So if you're only seeing a single line, you can click the up arrow, and it will increase the size of that captioning box. If you still prefer to see more of the captioning, don't forget we always have a full screen captioning option. That link is a little too long to read out, but it was sent to you in the confirmation email. Not only is it full screen captioning, but there's also a chat feature, so you can log into the chat feature and you can enter your questions there. We'll monitor that as well, and we'll make sure to respond to those questions during our Q&A breaks as well. And finally, the last thing I want to mention is just our evaluation form. We really value your feedback on all these presentations, and when you close the webinar today, a window will open on your screen with that evaluation form. It only takes a minute to fill out, and I do hope you'll do that. I know some of you are participating in small groups and that's great, but I hope you'll each fill out the evaluation. If you're using your coworker's computer, say, for the live webinar, you can still click on the evaluation link that was in that confirmation email and we'll get your comments as well. So I do hope you'll share your thoughts with us. So, those are the housekeeping instructions I wanted to make. I'm really excited for today's presentation. I want to get us started here. I want to welcome Jerri Davison and Charlie Walters from ABLE South Carolina to the call. Charlie and Jerri, thank you so much for being with us today and for putting together this presentation. ABLE South Carolina has really established itself as a leader in this work. And Jerri Davison is assistant director of ABLE South Carolina. In 2016, Jerri spearheaded the South Carolina decision-making project. Jerri also has a law degree from University of South Carolina and spent six years as a disability rights attorney at the state P&A. And then Charlie Walters is Director of Transition Programs at ABLE South Carolina, and Charlie was previously in special education and came to the center. We've enjoyed getting to know Charlie with some of the on-site trainings we've done, and it's fun to do a webinar with him. Really glad that all of you are with us today and happy to be able to share this presentation with you. I'm going to go ahead -- before I turn it over to Charlie, here on slide 3, Charlie and Jerri have been nice enough to offer their contact information. I'm going to go to slide 4. I just want to run through these learning objectives quickly before I turn it over to Charlie today. So, first, you're going to learn the basic tenets of the Independent Living philosophy and their connection to self-determination and consumer control in decision making. What guardianship is and how it creates barriers to independence and consumer direction. Next, strategies for raising awareness of the dangers of guardianship. Then alternatives to and the importance of preserving civil rights for young adults with disabilities. And then finally, guardianship as an advocacy issue that can support or strengthen advocacy activities and support for youth in transition. Next, I'm going to go to slide 5 and turn it over to Charlie to continue. Charlie? >> CHARLIE WALTERS: Hey, everyone. Good afternoon. It's a pleasure to be here with you all this afternoon. We were doing a training on this, Jerri and I, earlier today with service providers here in South Carolina, and we were talking about it just being a breath of fresh air to be able to present this content with friends and folks in our community that have as an issue the access points we have as folks in IL, it's just a really readily accessible conversation for us. We talk a lot in our center about guardianship and supported decision making and this constellation of issues, and for us at our center, we recognize this rise, this uptick in folks whose families are pursuing guardianship and removing their rights from them as one of the most pressing issues in disability rights and the Independent Living movement today. And we believe that as a center, you know, for those of us that are at centers, our movement, everything about our movement, its very fabric speaks really, really intimately to the issue of the right of people with disabilities to direct their own lives. Speaks really, really intimately to just this whole idea of guardianship and promoting -- or the promotion of less restrictive alternatives to guardianship for the people we work with and building capacity towards that in our communities. We also recognize that on the other hand that centers might be unaware of some of these issues at hand. We were doing an IL-NET on-site training in Denver in 2017. For those of you that were there, it was a packed house. It came up in a conversation that we were having as a large group, and only a couple of hands in the entire audience were raised when we asked how many folks were familiar with supported decision making or alternatives to guardianship. And then we started hearing just kind of story after story from there, from, you know, some centers that were considering or maybe already fully established in providing guardianship as a fee for service, to other issues of, you know, a little bit less minor, or a little bit less major, that is, and just not really understanding it. And so we were happy to jump at the opportunity to give some support to our community in navigating some of these issues. A note on accessibility from this slide on. What we're going to do, some of the slides are a little bit word-heavy. They're a bit dense. Rather than cover each slide verbatim, we're going to go ahead, and most slides we will cover verbatim. But for those that we don't, for each slide, we're going to ask Tim to advance the slide and give the slide number. So if we're on an area that is something that we gloss over, and you want to note that slide, that would be great. Okay. On to slide 6, please. So, Able South Carolina is a Center for Independent Living. Like other centers, we are run by and for individuals with disabilities. In terms of the federal dollars we receive as a center, we serve 23 counties. A number of our grant-funded initiatives allow us to work with folks across the entire state. We are a non-profit, both federally and grant funded, and we are, like other centers, cross-disability as well. On to slide 7. Okay. So, this is an interesting couple of slides here. This is how we talk to folks. What we wanted to do in some of this content was just model for y'all how we talk to other people in the community about supported decision making and alternatives to guardianship. These are some rhetorical questions. It kind of falls flat because we're doing a webinar. But we talk with people, we ask them, can you independently make decisions about complex medical procedures? Can you independently make decisions about major car or home repair, contracts for major purchases, contracts for minor purchases, complicated situations in relationships, financial planning, taxes. We could go on and on and on with this list of things that point us to this idea that's central to all of this, that most of us make decisions with support. Some of us use Yelp when we go out of town to find a restaurant. Some of us have a go-to person that we ask for relationship advice when things are getting a little bit tricky in intimate relationships. However we do it. And it looks different for everyone, just like we constantly talk about in our movement. Making decisions is to different. It looks different for everyone. But making decisions with support is just as common as could be. Slide 8, please. And further, since you were 18, for the folks that are on the webinar today, who's made a terrible relationship decision? Who in this webinar has found themselves in an absolutely miserable relationship, or bought something without understanding the terms, or mismanaged a checking account or credit card. And we don't have our video on on this end, but both Jerri and I would probably be raising our hands for every single one of these. Who's made a decision only have to make another decision because you went in the wrong direction? Who's acted impulsively without understanding the consequences? Further, one of the things that we recognize when we start talking about these issues and the rush that a lot of families make towards guardianship when their son or daughter or family member is reaching the age of maturity, we still haven't gotten to a place where it's okay for people with disabilities to be human and make mistakes and make terrible decisions and learn from those decisions. And so when we're talking with our broader community here, when we put it in terms of, you know, the ability that we should all have, our right to make terrible decisions, it's usually a place that we find some real clear common ground with folks, and it's a pretty easy point for people to access this conversation in terms of all of the wealth of things that they've learned, from making their own terrible decisions. Okay. On to slide 9. And further, you know, if we believe that it's healthy to make decisions, minor and complicated decisions alike, if it's healthy to make those decisions with support and it's okay to make bad decisions and learn from mistakes and these things are just part of being human, is there -- is the threat of bad decisions or someone's need for support in making decisions, is that cause to remove somebody's right to make their own decisions? Is that reason enough to take someone's decision-making authority from them and transfer it to another person? In most of our states, and Jerri will get into it in a minute, these issues vary greatly state to state, but in most of our states, that is enough. That is plenty for a court to make a decision to remove someone's decision-making authority and transfer it to another person in the form of guardianship. On to slide 10. So in terms of the model, a lot of the complication with understanding decision-making and understanding guardianship, a lot of it results from the fact that we need to pull back and just explore what we -- the forms that decision-making takes. I think for a lot of us, it's difficult to pinpoint that place where we learn to make and communicate responsible decisions. It's kind of complicated to think about what some of these differences are in decision-making authority. And so guardianship falls into an area that we refer to as surrogate, or substitute decision making, and there's a lot of other forums that fall into surrogate decision making as well. But on this slide, there's a graphic with surrogate, and an arrow pointing to another text box that says provider. And the individual is off to the side. In essence, surrogate decision making simply means that your surrogate, someone's responsible for making and communicating decisions on your behalf to any number of providers, from a bank teller to your general practitioner, and you are not necessarily needed to be included in that process. On to slide 11. So the chief form of surrogate decision making that we'll be talking about today is, of course, guardianship. We pulled the definition from the Uniform Probate Code. This is the probate code that nationally states look to shape their own guardianship laws, their own probate court policy. And so we recognize that in most states, there's a pretty high degree of relation between your own state's probate code in terms of guardianship and this uniform probate code. And it really all centers on this idea of what it is to be incapacitated. Incapacitated in South Carolina, like this Uniform Probate Code, really just means that it's a person impaired by reason of mental illness, mental deficiency, physical illness or disability, chronic use of drugs, chronic intoxication, or other cause to the extent -- and this is the important part here -- to the extent of lacking sufficient understanding or capacity to make or communicate responsible decisions. And that's a quote there from the law. And so this is -- it's really, really interesting language to use. It assumes that the person is living in a bubble. It doesn't take into account any other -- any support means that they might utilize to make decisions. It looks at someone and assesses rather coolly, can they make and communicate responsible decisions. In South Carolina, we go on to say responsible decisions about their person or their property, and that's pretty common as well. If someone is deemed to be incapacitated, their rights can be transferred to a guardian, and that guardian can be a full guardian, they can have a limited guardianship. Full guardianship, what we found -- and what a major study in 2015 found that kind of woke all of us up to this issue of guardianship is that 90% of guardianships in the United States are full guardianships. It's a full transfer of rights from your right to sign hiring paperwork with an employer to your right to sign a marriage license and everything in between. It's a full transfer of rights. Some states have gotten a little bit more progressive and they will require really substantial evidence in each area of decision making before awarding or granting or transferring those rights to a guardian. Guardianship isn't the only form of surrogate decision making. If this is still kind of fuzzy, it might make a little bit more sense in line with other forms of surrogate decision making. Most of us are probably familiar with a power of attorney, where in advance, we grant decision making authority or authority to another person through a power of attorney. Conservatorship is another way that we do this, typically with financial matters. Nearly all of us are probably familiar with Social Security Administration and the Representative Payee Program, and how the Social Security Administration recognizes a surrogate decision maker in terms of -- in regard to someone's Social Security benefits. On to slide 12, please. And like so much else with our movement, I think it's important to understand where we are by taking a quick look at where we've come. And the history surrounding guardianship is really as atrocious as the history surrounding every other issue in disability rights. It was 2,500 years ago that we first see the public law on record that makes a reference to a guardian. When someone can't take care of themselves in Rome, that in order to protect that person and his goods, then someone would be designated to be responsible for them. By the end of the millennium, so right at the turn of the millennium there, they were referring to those folks as curators, and they were appointed to handle the affairs of the "feeble-minded." And by the Middle Ages, that's a pretty rapid fast forward, but by the Middle Ages, we see the British appointing actual committees to make decisions for folks that have been deemed to be "idiots" or "lunatics" in quotation there. That's the terminology that they used. And we're no strangers to "best interest" decision making. It is one of the things that Independent Living as a movement, we stand in stark contrast to throw our belief and our practice in consumer control. We recognize the evil, the danger that's inherent in what happens when decisions are made in the best interest of a person with a disability. Here in Columbia, we drive by the facility where we forcibly sterilized over 3,000 people. The estimates are between 3,000 and 4,000 people. Right up until 1979. Facility placements was a big push. A lot of the proponents of institutionalizing people claimed that that was the most loving and caring thing that you could do, is put your loved ones in an institution where they can be properly cared for. A quick note on sterilization, too. Someone that's considered a ward, someone that's placed under guardianship, their guardian can still have them sterilized. In 2018, someone can still be forcibly sterilized. A lower court just recently ruled that as long as the court approves of them being sterilized, their guardian can move to have that court make that approval so that they can have a doctor forcibly sterilize them. This is 2018. These are still the issues that we're coming in contact with, all in the name of best interest decision making. On to slide 13, please. Okay. So, for those folks that are in Alabama and Nebraska, those are the only two states in the country where the age of majority is 19. Everywhere else it's 18. This is a really simple concept, and I'm sure most of us on the webinar today have probably lived it ourselves. Quite simply, at the age of majority, the rights and the responsibles of the parent -- or before the age of majority, the rights and responsibilities of the parent are emphasized. Once you reach the age of majority, 18, or 19 in Alabama and Nebraska, those rights automatically transfer. For youth without disabilities that are hitting that age of majority, no one puts them under a microscope and says -- and asks whether or not they are fit to receive those rights. This just isn't something that happens. For youth with disabilities, however, that microscope comes out, and families and professionals alike ask the question, what's going to happen? What's going to happen when they are, in the eyes of the law, seen as an adult with all the rights and responsibilities that transfer in kind. And so we have to ask what the difference is for young adults that are turning 18 with disabilities. And this is something that I wish we could have an extended conversation about to hear from y'all what you're seeing. Here in South Carolina, we see an IEP process, and this is, of course, how it's mandated federally. But we see an IEP process for youth with disabilities that is by and large at regular intervals a systematic detailing of a person's every weakness. So at least annually, young adults find themselves in a room full of professionals talking about all of the things that they're terrible at doing. Very rarely do we emphasize strengths in that process. And so, you know, family -- the message that that sends to families and young adults alike is that those weaknesses need to take the fore in the conversation for what makes that person a person. Interestingly, I think that in our movement -- and please feel free to comment if your experience has been different. I think in our movement, there's also been a large degree of ableism that's existed and still exists in how we relate to people with intellectual disabilities. And a lot of that comes from just a blatant misunderstanding of things like IQ scores and developmental ages and assessments that are provided for youth in special education of adaptive functioning or, you know, any other academic area. These things are -- these assessments are oftentimes overextended to the point of absurdity. IQ scores were never intended to sum up a person. They were never even intended to sum up a person's intelligence, let alone what a person is capable of in terms of their range of motion as an adult. A lot of us have kind of taken those things to the bank. While John has an IQ score of 40, and the psychologist says that he functions like a 5-year-old. That couldn't be a worse representation of what that IQ test was able to say about John. It's a real sad state of affairs. I think there's been an awakening recently to that whole range of issues. I think day in and day out, one of the things that probably draws a lot of us to the jobs that we're in is that we see across the board lower expectations for people with disabilities. We see that folks don't necessarily -- folks don't necessarily see people with disabilities turning 18 as a completely normal thing, as those mistakes that they could make as a completely normal thing. They'd have an expectation that, you know, they're going to need a whole lot more, and they're going to be capable of a whole lot less. And so those expectations are just really debilitating for folks from the outset of all of this. And the belief of parents with youth with disabilities. We recognize that parents can be incredible allies. Parents and their attitudes can be incredible barriers as well. You know, I think about a lot of the parents that I have met, in talking with them about that process of their child being diagnosed with a disability, and the things that they say about what they began believing on that very day, you know, whether it was a disability that was diagnosed at birth or later. A lot of parents described this mourning process where they began thinking about what it would look like for their son or daughter to live with them for the rest of their lives and take care of them for the rest of their lives, and a lot of those expectations, a lot of those beliefs that parents have, they don't just disappear. They persist well into the adult years of those folks. And so it's really important to kind of note that as something that really contributes to this process of what makes turning 18 a bit different for young adults with disabilities. On to slide 14, please. Okay. So the Truth About Guardianship is the title of this slide. The truth about guardianship is real simple. For the folks on the webinar today, or viewing it at a later date that consume research out there yarding people with disabilities, there's not a single study out there that's shown guardianship to improve lives. Not a single study showing guardianship as a sound practice. But we have hundreds and hundreds of pieces of research that show the positive effects of empowering people and of self-direction and self-determination. We'll talk a little bit more about that. As I mentioned earlier, over 90% of guardianships awarded in the U.S. are full. Sometimes referred to as plenary guardianships. Guardianship referrals come from a number of sources. Teachers, often in the IEP process, recommend guardianship to families without having any idea of what alternatives exist. Service providers were also found in a research study to be fairly notorious for recommending guardianship. For service providers, a lot of times this just simplifies things for them. If they inform, for example, for rehabilitation counselor, informed consent might be tricky if you actually need to give some forethought to how you explain services to someone. It's a whole lot easier if their mom is their guardian and you can just get informed consent from her before providing services. Medical providers as well. This is a bit more insidious because medical providers oftentimes seem like they should be a whole lot more credible or trustworthy, but they're at the fore for providing recommendations that guardianship be obtained. And they use the language of Independent Living skills as the reason oftentimes for recommending guardianship. Well, does your son or daughter, do they understand financial decisions? Are they brushing their own teeth? Et cetera, et cetera. A lot of them have their own assessments that they do for folks that are turning 18. And a lot of them actually give families what looks like data, or, you know, underscoring the need for why guardianship is appropriate. Since 1995, between 1995 and 2015, that same study found that the rate of guardianships triple. More than a million new people were put under a guardianship in just 20 years. We're talking post-ADA. We're talking post Olmstead decision. We're talking post-HCBS Final Rule, even though we know the implementation of Final Rule has been pushed back here recently. We're talking about a time in disability rights where we've never had more protection, more credibility, more arrows pointing us in the direction of full community integration, integrity as people. We saw an incredible uptick in the rate of guardianship. And I think it caught a lot of us in IL, in the field of disability service provision kind of at large really off guard. It was kind of happening under our noses. Most of us -- this wasn't on our radar three or four years ago. And so for those that are just now becoming aware of some of these issues as we talk about them today, you're not alone. This is something that's just coming to light here recently within the last couple of years. A lot of states don't require that people try less restrictive options first. Some of them do. A lot of states don't require any evidence that someone attempts to use less restrictive options before awarding a guardianship, which is kind of scary in that guardianships are really hard to reverse. You essentially need to go back to a judge to get them to admit that they were wrong, or give them compelling evidence for why things have changed between the time they awarded guardianship and the time that you realize that it wasn't a real good fit for the person that's now in your care. That's a real hard pill to swallow, real difficult to do. Especially on the part of the person who's under the guardianship, the ward. That's a really, really tough sell, because they have been declared by a court to be incapacitated. If they then say that they don't want a guardianship, that's coming from the mouth of someone who has been declared not competent to make decisions about their person or property, so it's kind of a scary set of affairs. On to slide 15. So on and on and on, when Jerri and I do this presentation, the surveys almost invariably say, well, you did a really good job of scaring us about guardianship, to which we usually say, good. You know, there's not enough content out there, just like sheltered workshops. If you were to Google Search sheltered workshops right now, you would see more than employment first or anything else talking about the detriment of sheltered workshops or sub minimum wage to people with disabilities. You'd see people applauding them and desperate to keep them in motion. The same with guardianship. A lot of folks applaud it, recognize it as absolutely necessary. It's really easier now, but still difficult to find people that are actually speaking out about what it really means for a person with a disability to be under a guardianship. Loss of autonomy and self-determination we know to be associated with higher incidents of abuse, neglect, and exploitation. People under guardianship have been shown, whereas we don't have data showing the benefits of guardianship, we have data showing that people under guardianship are less likely to be employed, practice the religion of their choice, or have friends other than their service providers. The process is expensive. It involves attorneys, hearings, evaluations, and what I always tell folks is follow the money. If you follow the money back, you see how this has become a service that's really been advanced by attorneys that don't necessarily truly have the best interest of their clients at heart. Very difficult to modify or terminate a guardianship. For folks that are considering pursuing guardianship, parents, you know, we always remind them -- and it's typically parents. And note here, too, guardianship doesn't necessarily always come in as someone's turning 18, or as they're in those young adult years. This is where we're seeing most of it happen. A lot of our conversation hinges on that. But this issue extends across the life span of folks. But what we always tell folks that are considering pursuing guardianship as parents is you've just now signed on to be a parent with all those rights and responsibilities intact until you die. That's a tremendous responsibility. And for folks that don't fully understand the process, it's highly -- it can be highly damaging to relationships. We've seen some folks that didn't know what it meant to be a ward. They didn't know what it meant for their mom or dad to be their guardian. When that all unfolds, it's not real pretty for a family. And lastly, you know, guardianship hinges on this idea of somebody's incapacity, somebody being incapacitated. If you've been declared incapacitated, whether it's a limited guardianship or a full guardianship, what does that mean for you? What does that look like? You've been publicly declared incapacitated. What kind of range of motion do you have? Are you employable? Are you marriable? Could you be a friend to people? Could you be responsible to even have a dog? This is a really, really serious thing that a lot of people pass over with kind of a minimal amount of concern. So we really want to stress from the outset what it actually means to be declared incapacitated via guardianship. >> JERRI DAVISON: One other note with that is that sometimes people may not realize that it could have a real effect on that person's relationship with their employer and who signs employment paperwork. We find here that the inclusive higher ed programs are -- some of them are not accepting folks with guardianship because it complicates their teaching of Independent Living skills to those folks if they have to call the parents in. So those are two just concrete ways that people may not even realize that the guardianship options. >> CHARLIE WALTERS: We don't have a tremendous amount of case law out there about guardianship, but there's so many questions that arise. If you were under a guardianship and decide to get married, and now you work it so that your guardian approves, and you figure out a way to get that marriage license signed, can you consent to have sex? If you've been declared incapacitated, can you consent to a romantic relationship with someone? It gets really, really tricky and it raises a whole lot of questions that need to be asked in advance of someone pursuing guardianship for a family member. On to slide 16. This is a 20, almost 30-year-old quote now from U.S. representative Claude Pepper that's really important here. I'm going to go ahead and read this now. Representative Pepper stated before this was an issue on anyone's radar, it came across his desk. This is what he said about guardianship. The typical ward has fewer rights than the typical convicted felon. They no longer receive money or pay their bills. They cannot marry or divorce. It is, in one short sentence, the most punitive civil penalty that can be levied against an American citizen, with the exception of the death penalty. And then another quote from Jenny Hatch. Jenny is a young lady with an intellectual disability who chose to challenge the guardianship that she was under and really kind of blew the doors off of this whole conversation. Her case was a huge, huge victory for the disability community. It was a huge victory in terms of bringing attention to these issues at hand. And Jenny has since become a really outspoken advocate about these issues. And in her own words on this slide is a handwritten note that she wrote. It says, just because people have a disability does not mean they need a guardianship. Many times, they may need just a little help. Thank you. Jenny Hatch. On to slide 17, please. All right. So we are at our first question and answer break. What questions are popping up for y'all? >> TIM FUCHS: Great. Thank you so much, Charlie and Jerri. So, again, I'll point you all to the Q&A feature in the menu at the bottom of the screen. You can type your questions there. We'll give a second for those to come in. Any questions from this first section? Okay. If you're using the full screen captioning, you can type your questions in that chat feature as well. Whatever works best for you. Okay. We'll give it about 15 more seconds. We've got plenty of time for Q&A today, folks, so I hope you'll take advantage. Always tough being the first person to ask a question, but don't be shy. While we've got some down time here, I know that some folks had some problems with the audio during the first section. Did my best to help. I'm a little bit limited because I was sharing my screen, but just so you know, for everyone, under the menu, there's an option called "more," and then audio options. And you can test your speakers and audio settings there. That might help. And let us know if you have any more problems. Beth asks if we will receive a copy of these handouts. You will, Beth. In fact, you already have. It may have gone to a colleague, whoever's name and email were on the actual registration, they should have received the confirmation email with the connection instructions late last week, and these PowerPoint -- or this PowerPoint, I should say, was included in that. So check with them. If you don't have that for any reason, you might want to check your junk folder on your email, and if you still don't see it there, please let me know and I'll forward a copy to you. I'll be happy to do that. Okay. Next question is from Tiffany. Tiffany asks, guardianship is presented so pervasively in schools and medical communities. What is being done to present this information in those environments? Charlie, can you respond? >> CHARLIE WALTERS: Yeah. This is a really complicated one. I'll let Jerri chime in here, too. So this is a really small project for us in South Carolina. I think one of the biggest issues and one of the reasons that we were so happy to oblige with doing this webinar is the disability community isn't at the fore of these conversations. We're not building capacity across the board. These are supported decision making and alternatives to guardianship is really being championed by groups that are not traditionally staffed by people with disabilities, like UCEDs in higher ed and folks that don't necessarily have skin in the game, if you will. And so we're working on getting resources to professionals. We actually did a training for I think around 60 folks here in South Carolina today. We put videos together. We'll talk a little bit more about the resources we've put together here in South Carolina. But we also wanted to make kind of an open call to all of you as centers, as a community, we really have to link arms on this. That's a huge question. I think the best answer is that we still need to -- we have a long way to go in linking arms to addressing it collectively. >> JERRI DAVISON: And some of the strategies that we've used as we partner with our Department of Ed to get funding to go out and provide technical assistance to school staff. So Charlie and I have both gone out and done some staff trainings at local school districts, and we also have leaned on other -- we have a DB council grant, which we'll talk about a little bit later. We've also leaned on other grant funding sources as well to educate the community. We've been building up a website, which I'll also talk about later. But trying to get those resources out there so that they're readily accessible to anybody who wants to pass them on. And sounds like we need to take this issue to our legislators. Yes. Currently, five states have supported decision-making legislation, which we'll talk some about. South Carolina just revised their guardianship statute, and it's going to be changing to be a little more strict and have to jump through some more hoops. But that will happen in 2019. But, yes, we will be trying to introduce legislation next session in our state, and we encourage you all to find out what your legislation is like and kind of do the same. Because I think that's kind of the heart of the issue, is the law making room for alternatives to guardianship. Our state court actually has a great alternatives to guardianship resource on their site. We are working to get supported decision making included in on that. But it does try to divert away from guardianship. And then, Tim, I guess I'll jump in on the institutionalization one, if you're okay with that. The question that Melissa is asking, is why is there an increase in guardianship in the mid '90s, is it related to deinstitutionalization? I don't think there's any studies to show the link with that, but that's kind of our feeling, is that everything has been headed on the right course for disability rights. We're seeing more integration, more inclusion in the classroom. None of it's going as fast as we want it to, but we are seeing everything trending in the right direction except guardianship seems to be that outlier there, and we think it is because people are being given more access to the community, and so they're keeping tighter tabs on people, which is kind of sad that that kind of backfired. >> CHARLIE WALTERS: Yeah. Funny enough, we just had someone in the training that is an administrator for our state DD agency that serves a local area. She was just saying she came as a service provider to the training today, but pulled us aside afterwards to tell us why she was not really a fan of the content we were providing. It's because of her fears about final rule, and HCBS final rule getting more -- a little bit more authority or more autonomy to the individual receiving services, and in her mind, final rule was a reason -- is more of a reason now for her as a parent to pursue guardianship because she doesn't believe in this kind of legislative push that we've had to give people more autonomy, that paternalistic mindset still runs very, very, very deep. >> TIM FUCHS: Okay, thanks. All right. Next question also comes from Melissa. She says, what are your thoughts on Centers for Independent Living running a guardianship program? >> JERRI DAVISON: And that's a tough question, because obviously, we know Centers for Independent Living are doing some amazing things as far as disability rights. Personally, the stance from our Center for Independent Living is that we have a hard time seeing how that is consumer-driven, and that's at the heart of the services that we're supposed to provide. So if we are assisting family members with taking those rights away, then are we truly being Independent Living and consumer driven as far as our philosophy is concerned. So, obviously, there are going to be people who disagree with us on this, but we think in all of our services we provide, we try to think about whether it's consistent with the mission and philosophy for Centers for Independent Living and what our legislation says about what we're supposed to do. And so that's kind of a contradiction for us. In most cases, we are -- well, in all cases, we are trying to get families to think through less restrictive options. If they still want to pursue guardianship, then we are referring out and not really handling those. But again, that's just kind of our philosophy as a center. >> TIM FUCHS: Good. Thank you, Jerri. >> CHARLIE WALTERS: Great questions. >> TIM FUCHS: Okay. I don't see any more questions. Let's give just ten seconds to make sure no more come through. And you can use the Q&A feature at the bottom of your screen. I just checked the chat. I didn't see any -- excuse me, the CART chat, to be clear. I didn't see any there. Okay, here's one more from Beth. Beth asks, if a person wants a voice and has no family to support, what is your feelings about guardianship? >> JERRI DAVISON: And I think every situation is so individualized. So, you know, trying to figure out where that person may need that support and what are the resources that are available in the community. So, are there providers who can be supporters and help that person make decisions, not make decisions for them, but help guide them in how to make sound decisions and help teach them those decision-making skills. I think centers can be a huge asset there. You know, case managers and neighbors and church families, and we can just get really creative on what that support network looks like. With guardianship, typically there's kind of a one-to-one relationship. That one person is responsible for the oversight. And if that one person abuses that power or if something happens to that one person, then that whole strand of support system breaks. If that person has not been taught those decision-making skills, then their world falls apart. So we'd like to look more toward a support network, where there are multiple supporters helping that individual, so that if one strain of that breaks, then there are other people who are going to step in and make sure that that person gets the support they need to make those decisions and live the life that they want and reach the goals that they want. So that's kind of another reason that we would sway someone who doesn't have family members toward supported decision making, because you can have that multiple supporter option. >> TIM FUCHS: Great. Thanks, Jerri. All right. And the last question I saw on the chat was, well, what are some of the alternatives to guardianship? What a great segue. We're going to talk about that in section 2. So, I'm going to go ahead to slide to 18 here and turn the mic back over to Charlie. >> CHARLIE WALTERS: Perfect. Thanks, Tim. Yeah, wonderful questions, y'all. Thank you very much for those. So, in Independent Living, we live by consumer control. Why? Just a refresher to make sure we're all on the same page, we believe in consumer control because we believe that we are ourselves are the best experts on our own lives. We know that the folks that we work with often come from environments where they're not trusted to direct their own lives, or they're often coming from places and upbringings where consumer control is not the practice that's in place for helping them and supporting them and being in community with them. Many understand decision making with support very intuitively, and I think that we all understand the value of self-direction. What we want to make sure of is that -- excuse me -- is that we understand that we're kind of on the same page there with folks. Guardianship is -- like Jerri was talking about, it's really hard to make a case for guardianship being consumer controlled. Even if you have a couple saying, I want someone to be my guardian, it falls into that really weird philosophical territory like physician-assisted suicide, where that might be someone's will, but it's very, very easy to see why that's in conflict with our movement as a whole. We know the value as anecdotally through our lived experience and through decades and decades of research what the value of self-determination. When we talk to other professionals in other fields, a lot of times bringing that language into the mix to help them understand the value of consumer control is helpful because there's not many things in the field of education or the field of working with people with disabilities generally speaking that are better supported that the value of self-determination. On to slide 19, please. So, like I mentioned earlier, ableism is alive and well, both within and outside of our own community. There's a pervasive idea out there that people with intellectual disabilities are like an alien life form. There's our movement, there's everything we believe the disability rights should extent to, and then there's people with intellectual disabilities, and it's hard to see sometimes I think for people how that fits in. A lot of people, you know, they'll say to tell you that they believe in consumer control or the value and importance of self-determination, but how does that -- they're not sure how that fits in with folks with intellectual disabilities. What we have is a BVCIL research that shows that IQ scores, in other words, intellectual disability is not predictive of someone's self-determination status. Science has shown us really clearly, where even though the popular conception is a little bit different, that just because someone has an intellectual disability doesn't they can't be self-determined. I think we know that as a community really, really well. We have, like I said, tons and tons and tons of research showing self-determination's predictive value, or predictive nature in terms of quality of life, in terms of outcomes, postsecondary outcomes, including employment, Independent Living, community inclusion. The more self-determination you have, the more likely you are to be living the kind of lives that we all want to live. On to slide 20. And on and on and on. People with greater self-determination are healthier, they're more independent, they're more well-adjusted. A big one for us is that we know that women with intellectual disabilities are the most likely population to be sexually abused or exploited. The one thing that's predictive of that population's ability to recognize and resist abuse is self-determination. And so on and on, there's just this -- what we hope to connect the dots for y'all on is just this wealth of resources that we have from both within and without our community on the value of self-direction and self-determination, and this complete absence that we have in terms of more restrictive means of surrogate decision making like guardianship. On to slide 21. >> JERRI DAVISON: And so now we want to talk a little bit about what we think is kind of the -- should be the foundation of any alternatives to guardianship that someone considers. This doesn't have to be solely the only option. This can be combined with other options. Some of them Charlie mentioned earlier like powers of attorney. In our state, we have some other laws out there, like the adult healthcare consent Act Or the Educational Rights Consent Act. Every state is different, but know there are other laws out there that protect people with disabilities, but also protect anybody that could be at any point in their life unable to make medical decisions or make -- if they're incapacitated in some way, even if it's just temporarily in a coma or unconscious, there are laws out there to protect people. And so I think a lot of the scenarios that parents and medical providers see are already covered under other laws, they may just be unfamiliar with those. So I do encourage folks to check out their local laws on those things and we can kind of guide you in the right direction if you want to follow it with us later for some ideas about where you might find those. But supported decision making we're hoping will be the foundation for all individuals on how things should go. This slide has the individual in a circle in the middle of the slide. If you'll recall, the surrogate decision making diagram that Charlie showed earlier, the individual was to the side. Supported decision making, the individual is to the center, and to the left a circle with information and a circle with supporters, and a plus sign with those two leading to the individual, and an arrow leading to the provider. And basically what that means is that you've got this complex information sometimes that needs to be communicated to the individual, and then you've got supporters who are responsible for making sure that information is communicated in a way that an individual can understand and that may be weighing out pros and cons and may be watching some videos. It may be role-playing. But making sure that information is communicated to that individual, and the individual wants that decision for their life and they communicate it to the provider, and they can communicate that with assistance and support, but ultimately, they're the ones -- the provider is coming to the individual to find out about how services should go. Slide 22, please. So, in text form, supported decision making is simply a process in which individuals with disabilities are assisted in making decisions for themselves. And, you know, it doesn't have to be individuals with disabilities, but since that's our specific topic today, but we all use supported decision making. An individual is the decision maker is provided support from one or more persons who explain issues to the individual in a manner that he or she can understand. There is no one model of supported decision making. It can be very informal. Most families are already practicing this in some way or another, but supported decision making happens all the time. Slide 23. So, there are formal agreements out there. There are templates. Several states have created those. I think Washington, D.C.'s education system uses a form of supported decision making in their schools. For our project, an attorney from protection advocacy created a supported decision making template that can be found on our website. And it typically can be a notarized one, or some folks like to have it even more formal and they outline that supported decision making in a power of attorney document. That typically requires an attorney, and so you would have legal fees associated with that. We want supported decision making to be as accessible to everyone as possible, but that is another option. But there's also the informal way to do that. As long as the individual knows who they go to for what issues. And we all have that. We know who we go to to talk about automobile repairs, or who we go to to talk about if we have questions about financial management or things like that. We all have -- we all informally kind of know what our system is. Most states do not formally recognize supported decision making. I think we're up to five states. Three of those states just adopted legislation within the last few weeks. So we're seeing a huge trend right now. We're excited about that. South Carolina is not one of those states, but like I said, we're hoping to introduce legislation next session. We don't think that this is a barrier to using supported decision making because we believe it's an accommodation that can be requested under the Americans with Disabilities Act. There are lots of ways to justify that as a way for that person to understand the services that they're getting and make decisions about those services. And we don't really think there should be much pushback from service providers if it's phrased as an accommodation. We did have someone ask about those alternatives, and sometimes when parents are coming to us about their fears if they don't get guardianship, HIPAA releases are one of the most simple solutions. They're worried they're going to be locked out of those medical conversations, and HIPAA forms that we fill out are an easy solution that are already in place for that. Like I said, most states now have some sort of educational one as well so that parents can still have access to that information, even with decision-making after the student turns 18. I think our state was actually a little late to the game when they introduced that legislation, which is fairly recent. Slide 24. So some of the benefits of this, and you're probably getting the gist of this by now, but that individual is at the center of that decision making. They're not left out of those conversations. They get to decide who offers support, which in turn means they're most likely to trust that person and follow their advice. If someone else is deciding who's making the decisions, then you may not have as much reason to listen to that input and take it into account before they make their decisions. Individual retains their legal rights, which should always be an emphasis when we're working with individuals at Centers for Independent Living. There are no attorney fees or court fees. I did a parent training on this topic last night, and I had a family who had paid 1,500 for guardianship and they were asked for another thousand dollars for conservatorship, and they were coming up to me saying, it sounds like this may not even be necessary, and they wanted me to talk through that with them. So that's a huge financial burden. They were having to make payments on this. The biggest benefit is that it teaches individuals those decision making skills and how to learn about their affairs. It teaches them about their medications, about who to call in an emergency, about who they can trust to give them advice on education decisions or financial decisions. It's basically teaching them how to be an adult, just like a youth with a disability and that should be what we're thinking of. One thing we tell parents is that guardianship will always be an option. That's always going to be an option until the courts help -- you know, until legislators outlaw it or whatever. But, it's permanent. It's hard to modify. We try supported decision making first. If we need to fall back on something more restrictive, then we can look at other things. Guardianship would be the last resort, but can we look at some other things first. Slide 25. So, y'all kind of got ahead of us at the break and y'all were already thinking about how we can have a call to action for this. So I'm so excited to hear that. With all of our major disability rights legislation, the Rehabilitation Act, the ADA, the Olmstead Decision, all of those things, who were leading the charge? People with disabilities were at the heart of all of that system change, and it's brought about a huge change in the way our community works and how much people are included with disabilities. So I think we need to look at guardianship as an opportunity for the disability community and Center for Independent Living to unite on this as well. Next slide, please. Slide 26. So, in South Carolina we've kind of taken a grass roots advocacy approach. It started kind of with a partnership between our Center for Independent Living, Able South Carolina, and then our parent training and information center actually, Family Connection. They had a parent there there who was serving as a consultant to other families, and he was telling parents to get guardianship. He had a teen with down syndrome and he was planning to use guardianship for his son. He had interacted with us more and more, and at one point, Kimberly, you may know her, executive director, sat down with him and said do you want him to be special or capable, and that kind of triggered something for that parent. That parent said, you know, this is not what I want for my son. I do not want to take away his rights. We have a really good relationship. He consults me when he makes decisions. I feel like he listens to advice and makes sound decisions when he has that information. So they had chosen to go the supported decision making route. In turn, he's become an activist for supported decision making an warning against guardianship. He's featured in a video in our website, and you're going to see that. But from there, we kind of said, okay, we need to get the word out about this. And so we applied for a grant with the DD council and we had started doing trainings on a small scale about guardianship and that grant allowed us to bring in more partners. We brought in the ARC of South Carolina, and we started creating more resources, developing that website, and providing trainings. So we have a lot of resources. Families and individuals, we have one for attorneys. And then we have some national resources included on there, too. Our attorney from protection advocacy, that's a partner on this has worked to advocate for a change in our state guardianship to allow more protections. She did try to get supported decision making, included in that, and we had some judges who pushed back on that. But we are going to attempt to do legislation next session and try and push that through. So this is just kind of what -- a little version of what the resources tab of our website looks like. You'll see kind of at the top it's got the agreement template, so if families do want a formal supported decision making agreement, that option is there and they can fill that out. And then there are the three manuals that I was talking about. And then there are some videos. That first video is that parent that I was telling his story, he tells that story much better than I can. And his son is on there too talking about his goals when he becomes an adult and what he wants to do with his life. And then the second video features a family, but it also features an attorney and how an attorney came to realize that he would recommend guardianship when it wasn't always necessary. There's a third video, there's a medical professional talking about just the importance of including youth in the healthcare transition and making sure they understand their healthcare, that they are starting to prepare to make those decisions on their own, and just the importance of parents kind of taking a step back so that they're really making sure that youth is prepared for adulthood. Okay. Slide 28. So, what next? And that's what you all were asking about. So, try to see if there's some room in your state for supported decision making. Get connected to it. If there's nothing existing, try and find partners like we did. Look to your local ARC, because the national ARC has very clear language about supported decision making and being cautious about guardianship. Protection and advocacy system as well. The national bar association has come out cautioning against guardianship, so your state bar association may be a place to connect. The attorney that's on our -- that's in our partnership, she's on the elder law committee, so that may be where folks want to look first. But the key to that is that we need people with disabilities -- we need the IL community, we need Centers for Independent Living to be heard here and make sure that these laws that are getting made and changed have the disability voice in them, and that they are not necessarily restrictive when they promote individual rights. There's a link on here to show how you can research what your state's guardianship policy is. Don't stop there. Also, look at adult healthcare consent. Those states have a law on that. Educational rights consent. Look at those things, because those may be alternatives to guardianship that you can steer parents toward and professionals. Because a lot of professionals have not heard about these alternatives. Talk with families about what their fears are. Is the school the one pushing it because they're going to turn 18 and they're going to get control of the IEP process? Because there are lots of things out there to make sure parent stays a part of that. There are so many creative solutions out there. We just have to get to what the heart of those fears are and talk them through their individual situation. And just kind of remembering this is not a one size fits all approach in talking through that and making sure you're covering their specific fears for their young adult. But really, we started super small here in South Carolina. We are not a progressive state by any means, and so we just kind of found some likeminded organizations and got together and said, what can we do collectively, and that's kind of made all the difference for us and things have taken off. And the demand for the training that we offer in our state has just been really great, and we've loved seeing it blossom. I mean, there are at least three to four people who have said you've got to talk to the staff that I work with. So it just kind of keeps ballooning and mushrooming from there. Slide 29. So this is our contact information. The center's website is on there, but also, we did a separate website called SCsupporteddecisionmaking.org, because we wanted the partners to have an equal stake in this and not just feel that they were directing people back to our website. There's a national resource center. It's actually supporteddecisionmaking.org, so it's just like our state website but without the SC on there. So that's got some webinars that you can dive more into these alternatives to guardianship, you'll be more able to cover all of those since they're so state specific. And then the National Council on Disability recently released a report. It's got some great information there. There's some really good recommendations at the end for some things that we can do to try and make systemic changes to stem the rise of guardianship. Yeah. And then slide 30. >> TIM FUCHS: Great. Thank you, Jerri. So here we are at our final Q&A break. We've got 15 minutes for questions, so plenty of time. So please let us know what we can answer for you. We've got a lot to think through. We've got a good question from Alexa to start with. This is a tough one. So, Alexa says, as a center, we get a good number of people with adult on set disabilities, like brain injuries, MS, or mental health disabilities who are under guardianships, or about to be taken to court by local jurisdictions. Those under guardianship want it lifted but they need help and they need representation to prevent guardianship. How can we help them as a center, how can we help them to find a lawyer since these consumers may not have money? Jerri, what would you suggest in situations like that? >> JERRI DAVISON: Yeah, and we've been really lucky with this here. What we found, there's actually a large law firm, and part of their pro bono work is to get guardianships pro bono for parents, and we went to them and asked if they would do the reverse. And they've helped us out on a couple of cases and helped us undo some guardianships. So that's been really cool. We also made a partnership within our state and we found an ally who buys into that guardianship is unnecessarily restrictive and he's helped with cases, too. We've had some attorneys reach out to us and we've testified in some cases about how independence can look differently for everybody, and it doesn't necessarily mean a checklist of things that you can or can't do because it's not necessarily considering support. In that way, we've educated some attorneys. With our partner from protection advocacy, she's done some community legal education trainings, those continuing ed requirements for attorneys, and she's started to throw in some supported decision making into those that we can get our attorneys educated on on the alternatives that are out there. So I would try and make friends, maybe do some trainings for some attorneys or find an attorney partner who can get in and infiltrate that world. That's kind of how we've had some luck with that. >> TIM FUCHS: Okay. Good tips. All right. Alexa asks, is supported decision making a legal status or ordered by a court, or is it something we can help through with peer mentoring or Independent Living skills training? >> JERRI DAVISON: Yes, and that is the great thing about supported decision making. It is not formal. So you do not have to go through a court system. There's no cost to it. You don't need an attorney involved. It's really making a plan that's going to help. That's where CILs can be amazing, helping that person come up with a plan that's going to give them the support they need to make decisions for themselves. You can go on the website and look at the template and see how it works. Or you can create your own template. You don't have to have a formal agreement. You can kind of just jot some things down on a notebook paper and as long as that person understands the support system, then you've done supported decision making planning. And so just kind of practicing with them and making sure that they understand how to go to the right people for the questions that they have. >> CHARLIE WALTERS: Yeah, and that kind of is the somewhat slippery thing in all of this, too. I think one of the appeals about guardianship for folks is it kind of looks and feels like a silver bullet type of solution. TV your one stop shopping for everything you're worried about. And in reality, when you start -- when you look at supported decision making for an individual consumer, it's going to be entirely different person to person. The concerns, the networks of support. It's highly, highly individualized. And so one of the reasons we didn't jump in, when we talk to folks in the state here, we jump into all of the alternatives to and kind of the state law that applies here. We didn't do that here because it's even very different state to state for what kind of leverage a person has with this and their own rights in a given area as well. >> TIM FUCHS: Okay. All right. Thanks, Charlie. All right. We still have ten minutes, so I hope you guys will share some more questions. Let's give it a few more seconds for that. So you can use the Q&A feature or the chat on the CART screen. Okay. Susan asks -- Crystal asks. This is Crystal. Is supported decision making essential with e are lease of information forms? >> JERRI DAVISON: It would be in conjunction of release of information forms. If they are needed to help communicate that to that individual, they may need a release of information form. But supported decision making is more about how the decisions are going to be made, where the release is just about the sharing of information. Supported decision making makes it clear that the individual is still going to make the decision, but the release of information is just who am I going to share this information with so they can help me make decisions, so those two can definitely be used together. >> TIM FUCHS: Okay, great. All right. While we're waiting to see if there's any other questions -- ah, Crystal says thank you. While we're waiting to see if there are any other questions, you can see the link to the evaluation here. That's not a live link, although my cursor says it is. But it will come up automatically when we close the webinar. That evaluation link is also included in the confirmation email that you received as well as the PowerPoint from today in a couple different formats, and those resource pages on the slides that we just went through. You'll be able to visit those to get even more of the resources and documents that Jerri and Charlie have walked through, so please take advantage of those. All right. We've still got a few more minutes, but I'll give it about ten seconds more here to see if any questions come through. >> CHARLIE WALTERS: It's a great question too that was just asked, just to underscore what Jerri mentioned as well. I mean, Tim, it could be as simple right now if I was asking you to help me with medical decisions, and Tim, up in D.C. agrees to help me with medical decisions. I'm going to go to him to chat through things. That's not going to be recognized by my doctor when I say, hey, Dr. So and so, Tim might be coming with me through a video chat to appointments or Tim might call in to double-check my appointment times. You know, that doctor is still going to need a HIPAA release. And depending on my relationship with the doctor, they might not tell me that's the hoop I need to jump through. But I will need to jump through an additional hoop, and a lot of times what we hear from folks is doctors just outright say, oh, you know, you can't. Charlie's 18. There's no way you can be part of this process. You need to know where to assert your rights and kind of a little bit more as far as the details of that process, if that makes sense. >> TIM FUCHS: Right. Okay, good. Another question from Elizabeth on the chat. Elizabeth asks, what's the difference between Person Centered Planning and Supported Decision Making? >> CHARLIE WALTERS: That's a fantastic question. I think for all of the drawbacks that we have -- that I think we see with Person Centered Planning, I think there's a number of places where that kind of comes into conflict with consumer control for us at a center. It's a really cool model at the same time. It really takes that, at least most forms of Person Centered Planning take that community model or that community approach of rather than looking at a person by themselves, looking at someone in the context of their support in their community and making plans based on leveraging kind of their cultural capital, or their social capital. And supported decision making is really, really similar. We can't stress enough that supported decision making can be as simple as me just having asked Tim to help me with my medical decisions. It can also be as complicated as sitting down with a network of supporters like you might do in a person centered planning meeting and actually spelling out, Tim's going to help me with medical decisions, Jerri's going to help me with decisions in higher education, on and on and on, and exactly how you're going to help them. It can be just as formal as outlining every last detail of what that looks like, too. >> JERRI DAVISON: And typically, supported decision making would take that person centered planning just a bit further, just take it a step further. Still with person centered planning, and maybe this isn't the case where you live, but we see a thorough assessment of what the person is wanting and their goals and everything, but we're not necessarily seeing that person making the decision still. They're asking that person about their goals, and then they're tailoring a plan that's going to help them get their goals, but they're not necessarily checking in with that person every step of the way and saying is this what you want? And if it's done right, then yes, I think person centered planning should very much mirror supported decision making in that setting. But in our case, we're still seeing people having meetings without the individual present because they've done this person centered plan, they already know what the person wants. Whereas with supported decision making, every step of the way, that person is there. >> TIM FUCHS: Okay, great. A few more questions came in. And we've got time for them. Alexa asked, what can a consumer do if a guardian is abusive or makes decisions that restrict independence? Anything that that would allow or any suggestions? Jerri, do you want to start? >> JERRI DAVISON: Yeah. So with abuse of the guardian system, that is the court is responsible for making sure that system is working appropriately. So there can be some complaints made to the court if this is actual abuse. Now, a lot of times what we see is kind of borderline behavior, abuse behavior, and the court moves very slowly. And then more so, it's just in direct contradiction of what the person wants. And in those cases, then you're going to probably need to look at some of the things we talked about earlier, about getting the guardianship revoked. If that is not an option, if the court is not going to consider that, then we need to, you know, think about, even changing guardians as an alternative to that. There's a national case where parents got guardianship of a young adult, and then they found out about alternatives to guardianship and realized, we should have never done this. He makes decisions all the time. And so they tried to have it revoked and the judge refused to do so, because the judge was basically being asked to say, I made a mistake, this person was not incapacitated. And so they ended up having to get a national supported decision making attorney involved in the case, and fortunately, it was finally revoked. But that's one of the cautionary tales about guardianship, is even if the parents change their mind, even if the individual wants it revoked, it may not happen, and so changing the guardianship may be the only alternative to that if you can't. But there are legal experts out there, and if you've got a good case, we can probably connect you with national experts for consulting on that. So we're happy to help in any way we can. >> CHARLIE WALTERS: Yeah. But from sterilization to forced facility placements, like these are all kind of part and parcel with guardianship. It's one of the reasons we wanted to talk about it. It's kind of the wild west in terms of abuse and misuse of that system. >> JERRI DAVISON: And if you come from a state like we're in where probate judges don't necessarily have to have a legal degree, then you kind of get a random assortment of people who don't necessarily understand individual rights. >> TIM FUCHS: Okay. All right. Tiffany asks, many people who may not be aware of self-determination rights often are willing to agree with whoever is trying to persuade them. So how do you approach that subject without being just another person trying to dominate their viewpoint? >> CHARLIE WALTERS: Yeah. So in terms of talking to like actual prospective consumers or consumers, I think it's a bit different. We tailor a lot of this content to service providers and to family members because it's -- you know, those are the folks that are really creating and supporting this system of guardianship. For the consumers themselves, it's a little bit different. You know, we focus on empowerment. We do work with folks to better understand their particular circumstances, but we really focus on their own leadership skills, the empowerment of them really helping them to feel empowered, to self-direct their own future. It's rather unfortunate in terms of their -- what kind of say so they actually have in the process. And we haven't been in a situation where we've had -- we've been working directly with a young adult consumer or any consumer -- well, a couple that have been on the verge. Not any young adult consumers that I know of whose parents have been on the verge of obtaining guardianship and we've worked with them to change their viewpoint. That's a great question. I don't know that I answered it very thoroughly. Jerri? >> JERRI DAVISON: Yeah. I think what we see a lot of times is just that people with disabilities haven't been given those options to make those choices, and when they are, if it happens all of a sudden, they may not have that confidence level built up, and so you may at first feel like just another person who's trying to tell them what's appropriate. But I think if you can really focus on getting at what the heart of what they want is and building up that self-esteem and building up that confidence and making decisions, then you're able to separate yourself from everybody else who's saying this is what you should be doing. Because this is actually -- I mean, like we said, the evidence is behind this. This is the key to outcomes and this is in line with our philosophy, which is consumer control. So we're just merely teaching them how to take that control back. We're not making decisions for them. We're just trying to show them that this may be a world that they've never had access to, and there's lots of things that they may find exciting about it. >> CHARLIE WALTERS: Yeah. Over and over again, we hear someone's pursuing guardianship because their son doesn't know how to manage money. How many opportunities has he had to manage his own money? You know, or what does that look like with supports? There's no reason, even if you're not fully in line with the philosophy of self-direction and consumer control and self-determination, you can at least get with the philosophy that it's a real steep pendulum swing to the other side to jump from a potential barrier all the way to the most restrictive means for addressing that potential barrier. >> TIM FUCHS: Okay. Thanks, great. All right. We've got two minutes left and we've got two questions. So one minute each. Ashley asks, is there anything negative about power of attorney? It seems like a good alternative. How would you all respond to that? >> JERRI DAVISON: So, power of attorney can be a little complicated, because to sign a power of attorney, you have to have capacity. So, if you're trying to argue that the person doesn't have capacity, then a power of attorney option is not an option. Capacity to understand the power of attorney document is a little tricky, though, because we don't think that they have to understand the legalese behind the document or even be able to read it, but they have to understand that they're giving over some control to someone else to make decisions. And so they have to understand that they're appointing an agent. There are actually two types of two power of attorneys. I'm going to try to keep this quick, but there's the point that you appoint an agent, and that agent can start to work on your behalf right away. It doesn't take away any of your control. You can still make decisions, and your decisions actually trump your attorney in fact, but that one starts right away. There's also the other one, which is the more common one that most of us use, which is a springing power of attorney, and that is when we sign something, and then if something were to happen to us, and we were to be hit by a car or something like that, then there's -- we've appointed someone to make decisions on our behalf when that happens. So it's more of a future planning document. So these can be useful tools. You just have to make sure you understand it and that it really does what you think it does, and that the person understands what they're doing and what authority they may be giving up. And the person can revoke it at any time unless something has changed with their capacity in the meantime. >> TIM FUCHS: Okay. Great answer on the clock. Thank you, Jerri. One more with just a few seconds left. When a public entity initiates guardianship, what obligations do they have? >> JERRI DAVISON: So a public entity as the guardian? If that's kind of what you're thinking, then they would have the same obligations as a private individual. They're responsible for the safety and well-being of that individual, depending on what the guardianship entails for the sound financial management. It really depends on the wording of that document, and it's really important if you have someone who has guardianship, read that document, because it may not be a full guardianship and it may specify certain rights. But there shouldn't be a difference when a public entity is seeking guardianship from a private individual to respond to it. >> TIM FUCHS: Okay. All right. Well, fantastic job. Thank you so much, Charlie and Jerri. I really appreciate it. This is a really great introduction to the issue, and something that's really, really important to Independent Living Centers and to people with disabilities. Thanks so much for laying this out for us. Thanks so much to all of you for joining us. Almost 50 centers on the line. I really appreciate you-all taking time out of your day to join us. Please let us know if any questions come up. Jerri and Charlie have been kind enough to share their contact information. Please know you can always reach out to me as Welch my email is Tim@ncil.org. So whether it's later today or in two months, please do share any questions or comments that you have. Please fill out that evaluation before you leave today. We really appreciate your thoughts. And don't forget that for you or for your colleagues, the archive version of the webinar will be on ILRU's website within 48 hours, usually earlier. With that, we're going to go ahead and close the webinar. I hope you all have a wonderful afternoon. Bye-bye. |  |
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