Transcript: #FreeBritney: Lessons for People with IDD and Their Families

Transcript

Shawn Ullman:

Good afternoon, everyone, and welcome to The Arc's Center for Future Planning webinar entitled FreeBritney: Lessons for People with IDD and Their Families. Before we begin, I'm just going to go over a few housekeeping rules. Everyone is in a listen-only mode. If you need assistance or if you have questions, please type them in the chat box at any time. This webinar will be closed captioned. To turn on the closed captions, get to the meeting controls at the bottom of your screen and click on live transcript, then select show subtitle, and the caption should appear right above your meeting controls. If your captions are too small or too large, you can resize them by clicking on live transcript again, and then selecting subtitle settings. If you join the webinar using your phone or tablet, you can turn on closed captions by going to more, then meeting settings, and there you will find the toggle to turn on closed captions.

Shawn Ullman:

We will have time at the end of the presentation to answer some of your questions. This webinar is being recorded. The link to the recording, the PowerPoint slides, and any handouts we mentioned during the presentation will be emailed to all attendees within a few days of the webinar. You will also receive a survey to evaluate this webinar as soon as it ends. Your feedback is very important and it helps us make sure that this webinar and future webinars are meaningful for our participants. So please take a couple of minutes to complete the survey.

Shawn Ullman:

Our webinar today will discuss Britney Spears' conservatorship. Her public battle over her conservatorship is shining a very helpful light on some of the broader challenges that people with disabilities face when under guardianship, which is another term that some states use for that kind of court involvement. This webinar will describe some of the issues being highlighted in the media from Ms. Spear's case, how they might apply to people with IDD, and alternative approaches that individuals with IDD and their families might consider.

Shawn Ullman:

My name is Shawn Ullman. I am the senior director of National Initiatives that The Arc of the US, and I lead our individual and family support initiatives, which seek to provide reliable information and assistance on topics such as navigating special education and disability services, healthy aging, housing, decision-making, and financial planning. Prior to joining The Arc, I was a staff attorney with Disability Rights DC for 11 years, where I advocated for children and adults with developmental disabilities to receive the services and supports they needed to live, learn, and work in the community.

Shawn Ullman:

Morgan Whitlatch is our other presenter today. She is the legal director of Quality Trust for Individuals with Disabilities, a nonprofit advocacy organization that has advanced the interests of people with developmental disabilities since 2002. She is also the lead project director for the National Resource Center for Supported Decision-Making. I just realized I didn't move the slides forward. Sorry, guys. Morgan has devoted her legal career to working with and on behalf of people with disabilities in matters involving capacity, guardianship and alternatives, and the right to self-determination, community integration, and living free from abuse and neglect. Prior to joining the Quality Trust in 2009, Morgan was an attorney with Disability Rights Rhode Island, the state's Protection and Advocacy program. And Morgan and I both proudly graduated from Georgetown University Law Center. Morgan, I'll turn it over to you.

Morgan Whitlatch:

Thank you so much, Shawn. So, first of all, we ask ourselves: What is guardianship? And each state creates its own rules for guardianship, including how to get a guardian and what kinds of guardianships are available. Generally speaking, guardianship is a formal process of going to court to determine whether someone is incapacitated or unable to make their own decisions and whether that person needs a judge to appoint someone else, called a guardian, to make some or all decisions for the person. When guardianship is ordered, it means the court is removing some or all of a person's rights to make their own decisions. And that's something we all value so it's a big step to take, and it should only be pursued or ordered if less restrictive options like the ones we're going to be talking about today won't work for the person. Next slide.

Morgan Whitlatch:

So, as Shawn was saying, Britney Spears's story really has shined a national and very public spotlight on guardianship, or conservatorship as it's called in California. It's important to keep in mind that overbroad, undue, or overly restrictive guardianship can really harm people. And Ms. Spears is not alone. Guardianship and conservatorship are regularly imposed upon and impacted those of all ages with different diagnoses, life experiences, and socioeconomic backgrounds. Guardianship can authorize third parties to make decisions about the most personal and important choices in a person's life, including what kind of medical, psychiatric or psychological treatment a person receives, how a person's owned money is spent, where a person can go, and even with whom they can associate. The popular press has focused on Ms. Spears description of how guardianship made her feel. She said, "I don't feel I can live a full life. We can sit here all day and say, conservatorships are here to help people, but there are thousands of conservatorships that are abusive as well." And speaking from Quality Trust perspective, we've heard some of that same reframe from other people with intellectual and developmental disabilities impacted by overbroad or undue guardianship.

Morgan Whitlatch:

There was a recent congressional hearing on this topic during which a video of Jenny Hatch was shown. And Jenny is a woman with down syndrome who Quality Trust represented in voiding a permanent and plenary guardianship. And she talked about how her guardians put her in a group home, took away her cell phone and computer, and stopped her from working in the community. She said, "I felt like a prisoner, but I didn't do anything wrong." Ryan King, who was the first DC resident to have his guardianship terminated in favor of making his own decisions with the support of his family and people he trusted, was interviewed for a New York Times article that was spurred by Ms. Spear's story. And he said, "I should never have been under guardianship, because I was always independent. Don't judge me before you get to know me. Everyone needs help sometimes."

Morgan Whitlatch:

It really comes down to self-determination or life control the ability of a person to be a causal agent in their own lives, to be an actor in their life rather than being acted upon. And decades of studies have shown that people with disabilities who are supported to have greater self-determination in their own lives, they are more independent, they're more integrated into their communities, they're healthier, not only psychologically but also physically, and they're better able to recognize and resist abuse. Studies have also shown that people who are denied self-determination can feel helpless, hopeless and self-critical, and experience low self-esteem and feelings of inadequacy and competency, decreasing their ability to function. So the quotes that we've been seeing and are highlighting on this slide really encourage us to look to options that promote self-determination and self-actualization. Next slide.

Morgan Whitlatch:

Another aspect of Ms. Spears's story highlights that once established, guardianships and conservatorships can be very difficult to limit or terminate. It's not until recently that Ms. Spears, even with all of her wealth and fame, was able to be truly heard by the court and have her position zealously represented. And I've heard this from people with disabilities and families as well, as part of the guardianship process. The New York Times said that she expressed serious opposition to the conservatorship earlier and more often than had been previously known. The article also described how it restricted everything from whom she dated to the color of her kitchen cabinets. And the articles have further emphasized this and noted that she really did assign some harsh blame to the California legal system and saying that she had tried to complain to the court but felt ignored. She said, "It made me feel like I was dead, like I didn't matter."

Morgan Whitlatch:

Core systems can be hard for people to navigate, and it can be hard to get certain kinds of problems with a guardianship addressed by the court. So, I think that's also a big, important piece of her story, that guardianship is not always the most flexible of tools because it does involve the court system. Another concern that happens when guardians misunderstand the role that they're supposed to play in people's lives. So for example, in The New Yorker, Jacqueline Butcher, a formal family friend said that when Ms. Spear's father became her conservator, he proclaimed, "I am Britney Spears." And that's not the case. In becoming her conservator, one should not see oneself as being able to take the place of the person entirely and not include her in conversations and decisions about her own life.

Morgan Whitlatch:

First of all, that's not consistent with best practices for guardians. The National Guardianship Association has indicated that supported decision-making should not only be considered before guardianship, but its principles should be incorporated into guardianship when it is ordered, that guardian should make efforts to encourage every person under guardianship to exercise their individual rights, to the maximum extent of their abilities and include them in decisions that impact them, so that they can develop or regain capacities to the maximum extent possible.

Morgan Whitlatch:

Second, in saying that, "I am Britney Spears," one needs to take a step back and realize that no guardianship should imagine taking away every single decision from the person. Being a guardian means that the guardian is able to make certain legal actions or transactions on behalf of the person, like opening a bank account or signing a medical consent form. But it should not mean getting to decide mundane every decisions, like when a person wakes up in the morning, or what they eat for breakfast, or what clothes they do or do not wear. So we really do try to encourage guardians to take a really close look at how they're behaving within the guardianship to really be promoting supported decision-making principles within that arrangement as well.

Shawn Ullman:

So it's estimated that about 40% of people with intellectual and developmental disabilities also have mental health challenges. And when someone is having a mental health crisis, we might know that they have a harder time understanding and making decisions in that moment about their health, housing, their family, and matters related to their money. Many family members of people with IDD might be concerned about who will make sure that their loved one is safe, that their bills are paid, that their children are taken care of if they have children, and that they aren't taken advantage of during a mental health crisis. Recent articles describe, and I'm sure many people may remember from news coverage at the time, that Britney Spears appeared to be having some struggles after getting married and having children. So what can people in their families do when a person is facing a mental health crisis?

Shawn Ullman:

For someone with known mental health challenges, it's important for them to plan for what they want should they experience a mental health crisis. And one way to plan this is by signing, what's called, a power of attorney or POA. A power of attorney is a legal document that any person can sign that allows another person to make some or all decisions for them. Powers of attorney can be as broad or as specific as the person wants. They're signed voluntarily and typically in front of either a notary of public or witnesses, or sometimes both. And they don't have to go to court for the document to be legal. Powers of attorney allow individuals to choose who they want, instead of having someone choose for them. It also allows them the flexibility to change their mind, because you can cancel a power of attorney at any time.

Shawn Ullman:

When a person signs a power of attorney, they are not giving away their right to make decisions when they can and want to make decisions. They're appointing someone to be available to make decisions for them when they can't or when they don't want to. And it's especially important for people with intellectual and developmental disabilities, because a power of attorney does not require a person to understand the underlying decision that they're allowing someone else to make. So for example, they don't have to understand a complicated medical procedure or the language in a contract or the goals and objectives in their IEP, but they do need to understand that they're giving someone else the legal authority to make those kinds of decisions for them.

Shawn Ullman:

Another way to plan an advance for someone who has new mental health issues is to sign, what's called, a psychiatric advance directive or a PAD. Well, not all states have a law that specifically recognizes a PAD... Sorry, I keep hitting my space. They work just like a living will. They're also legal documents. And they allow a person with mental health challenges to describe their choices for the mental health treatment that they want, and importantly, the mental health treatment that they don't want to receive when they're in a mental health crisis. That information can include things like the preferred medications and treatments that they want or don't want, a consent for hospital admission if they need to be admitted to an inpatient hospital facility, and it can even include practical life directions, like how to handle their job or their house or their children should they have a mental health crisis.

Shawn Ullman:

PADs also allow a person to choose the person that they want to make decisions for them if they have been determined unable to make their own decisions. Like powers of attorney, the psychiatric advance directives are voluntary. You can sign them without going to court. They allow a person the flexibility to change their mind, and they don't give away a person's right to make their own decisions when they can and they want to.

Shawn Ullman:

But what about those who don't have a power of attorney or haven't signed an advance psychiatric directive and who have been found unable to make their own decisions because of a mental health crisis? In those instances, families should seek, if they need to, a temporary guardianship, which will expire after a certain period of time. And then once the crisis has ended and the person has regained their ability to make their own decisions, they don't have to go to court to remove the guardianship. Families should also seek limited guardianships, meaning guardianships on only the issues that a person needs help with during their mental health crisis.

Shawn Ullman:

So it could be issues like financial help, controlling their money, or medical help, making decisions about the treatment they're going to receive, or other aspects of important major life decisions that require an ability to understand those decisions. And then, after a mental health crisis, it's really important at that point to talk with the person about making a plan should a mental health crisis happen again in the future. And again, that's where you should work with a person to sign a power of attorney or a psychiatric advance directive.

Shawn Ullman:

According to the news articles, Britney Spears' family did seek a temporary guardian ship during her first inpatient hospitalization. And as Ms. Butcher said the whole process took maybe 10 minutes, which is pretty typical for certainly temporary guardianships, but unfortunately can sometimes also be the case for full term and permanent guardianships. But when Ms. Spears left her inpatient stay, no longer appeared to be in a mental health crisis, and was even able to return working, her family still saw a permanent guardianship for fear that she was being taken advantage of, particularly financially, which is something that we'll talk about in a moment. If her family had worked with her at that point to understand the risks of future mental health crises and the need to plan, Ms. Spears might've been able to work with an attorney to create a power of attorney and a psychiatric advance directive that reflected for voluntary choices, and she might not have needed a permanent guardianship to ensure that her interests were protected if she had to have future inpatient stays.

Shawn Ullman:

Now, while Ms. Spears has significantly more money than the average person and certainly then a lot of people with disabilities who rely entirely on Supplemental Security Income or SSI benefits, it is incredibly common for families of people with IDD to name fear of financial abuse as a reason for need of a guardianship. Many people with IDD don't have a lot of money, sometimes relying entirely on public benefits or working very minimum hours so that they don't lose their eligibility for services like Medicaid. So given what few funds people with disabilities do have, giving those funds to people who may not be trustworthy or have their best interests at heart is certainly a legitimate fear. So what can people in their families do to ensure that the funds of their loved ones are protected if they struggle to understand and manage their own money?

Shawn Ullman:

Well, one way, which Morgan and I are certainly big proponents of, is a supported decision-making. Supported decision-making involves people making their own decisions by using friends and family members, professionals, and other people that they trust to understand the issues and situations and choices that they're facing by asking questions and getting explanations in language that they can understand. Supported decision-making is something that all people, whether people with and without disabilities, use throughout their lives. Nobody makes important decisions in a vacuum. All people use support networks to weigh their choices, ask questions, and reach the decisions that work best for them. Many people contact lawyers to understand legal documents and legal situations and problems they find themselves in. Many asks doctors or trusted nurses or other health professionals to explain complicated medical procedures or things that come up at a doctor's appointment they don't understand. And a lot of people rely on their friends and family to get advice about their relationships and where to live and what kind of jobs to take or leave.

Shawn Ullman:

Before resorting to a guardianship, to protect people from fears of financial abuse, it's important to help them utilize friends and family, to manage their money and make important decisions about their money. And while these options may not have been appropriate for Ms. Spears given her financial wealth, other options to help people manage their money, include things like setting up a joint bank account, or setting up direct deposit for income from job, setting up automatic billing to make sure that bills are paid on time, and to ensure that family members and other supporters know where the money is going and how it's being spent. These are the kinds of things that everybody uses in their day, such as managing an account with their spouse or with a parent or with a child who doesn't have a disability. They're readily available to anyone.

Shawn Ullman:

In addition, several organizations offer money management tips and classes for people with intellectual and developmental disabilities, so we strongly encourage you to search the internet for help and see if there are local organizations or programs near you that offer these kinds of classes to help people with IDD better learn how to manage their money. I found that the National Disability Institute, and there's a link here at the bottom of this slide, is a good place to start. And finally, people with disabilities, as many of you may know, now have an opportunity to open an ABLE account if they qualify, and then they can deposit up to $15,000 a year of their income. And those funds can only be used for what are called qualified disability expenses. And of course, if the person isn't able to open or manage their own account, then they can utilize supported decision-making and receive guidance from their trusted supporters.

Shawn Ullman:

Finally, if Ms. Spears... Nope, not finally. If Ms. Spears wasn't able to manage her own funds by relying on advice from her trusted family and friends, and they knew there's some question about whether she could rely on family and friends, another option that they could have tried other than guardianship would have been to set up a special needs trusts to protect some or all of her income from others. Now, most people with disabilities set up special needs trusts because they want to protect the person's public benefits such as SSI and Medicaid. Obviously, Britney Spears is probably not qualifying for public benefits considering how much money she makes each year, but she could still benefit from setting up a special needs trust so that a financial professional who is subject to ethical rules and some licensing requirements, rather than a family member or friend, could have been appointed to manage her funds and make sure that they were well-invested and will last the rest of her life and can't be used by other people who might be interested in taking advantage of her wealth.

Shawn Ullman:

And finally, another action, which certainly probably didn't apply to Ms. Spears, is representative payees appointed through the Social Security Administration. And I would remind everyone that the Social Security Administration does not recognize guardians... Sorry, my computer just keeps wanting to jump one slide ahead. They don't recognize guardians as decision makers for benefits that you receive through Social Security, including Supplemental Security Income, Social Security Disability Insurance or SSDI, as well as Disabled Adult Children benefits. To manage those benefit, if anyone other than the person themselves wants to manage those benefits, the only way is to use Social Security's process for appointing a representative payee, and parents or other support persons can ask the Social Security Administration. They have a form, they have a process, it's all right there on their website.

Shawn Ullman:

Yes, there's some documents you have to provide to show that they don't have the ability to make their own decisions, and guardianship paperwork, maybe some of those documents, but then a family member could be appointed as a representative payee without meeting to get a guardianship. And you can get that kind of information from the person's healthcare providers, or maybe... I don't know, Morgan, what are some other good people who could provide that kind of documentation? I don't know, schools, IEPs maybe, evaluations that you've received through that process. You can use those documents in support of a request to become someone's representative payee.

Morgan Whitlatch:

Another element about guardianship that's been highlighted in Britney Spears's story is the impact it can have on a person's ability to marry or choose to have children. These are really important topics, and I hear them coming up a lot in conversations I have with people with intellectual and developmental disabilities and their families. The legal ramifications of whether people under guardianship can marry or have a baby without court approval is dependent on state law there. Many state laws have certain protections built into them in those kinds of circumstances, but it really does depend upon the state. But really, from a human rights perspective, when we think about guardianship's impact in this area, it's important to acknowledge that our country has a disturbing history of eugenics, where people with disabilities have been sterilized and denied reproductive rights for a very long time. And that's not okay.

Morgan Whitlatch:

These kinds of conversations can be really hard, but instead of focusing on removing legal rights, we should be focusing on education, on how to exercise choices about sexual expression and social relationships about individualized education and information to encourage informed decision-making, including education about issues such as reproduction, marriage, and family life. They're critical conversations to have. And The Arc has a position statement on sexuality that specifically states that people with intellectual or developmental disabilities have the right to make their own decisions relating to having and raising children with support as necessary.

Morgan Whitlatch:

Quality Trust supported a woman with an intellectual disability who had a professional guardian, and she really wanted to marry her long-term boyfriend. And her guardian and team were not initially supportive of that particular decision. It seemed to be initially kind of out of the realm of possibility of what they thought would ever be able to happen for her. The Quality Trust wanted to support her, and we encouraged and convened conversations with her, her fiance, her support team, and other people she trusted to talk about what it would mean to be married and what it would look like for her and what her values were and what her fiance's values were. And ultimately, her team supported her to get married and live with her husband like any other married couple. And it just took facilitation and time and a respect for her as a person.

Morgan Whitlatch:

Something else that I've found families are not aware of in the context of guardianship is that, depending on the state in which you live, guardianship can impact a person's right to vote. Some states have laws that say people under guardianship can't vote. Now those laws probably violate the American with Disabilities Act. I have to put my lawyer hat on here. But, they are on the books. And I recall a mother in Arizona, for example, talking to me about this. She had gotten guardianship over his son when he turned 18 and only learned afterwards that the adjudication of incapacity meant he could not vote in the upcoming election, and both he and she were devastated by that. And now, we're trying to find an attorney to help them terminate the guardianship. So it's really important to know what you're getting into, so you can make informed decisions and support people to make informed decisions.

Morgan Whitlatch:

Guardianship can have a big impact on people's lives that should not be taken lightly, and people can experience it as a real restriction. Michael Lincoln-McCreight, he's a resident of Florida, shared his story with Vice when they were covering Britney Spears' story. And he's quoted there saying, his full rights were taken away: the right to vote, the right to get married, "the right to choose where I wanted to live, the right to choose my socialized environment. I was not able to go to church. I was not able to do any volunteer work at all." He was ultimately able to get his guardianship terminated in favor of supported decision-making, but he spoke really powerfully about the impact it had on his life. And his experience is not alone. Next slide.

Shawn Ullman:

So, Britney Spears conservatorship has been largely linked to her mental health and not her physical health. But, many people with intellectual and development disabilities also face challenges when doctors and hospitals are concerned about their capacity to understand and make decisions about their health, such as having a particular dental or medical procedure. When I was working for the Protection and Advocacy organization, for example, I even had medical professionals refuse to provide care unless the family went and sought a guardianship, because they wanted confidence that the person making the decision knew what they were doing. It's an especially a big problem for individuals who have a difficult time communicating, and obviously and especially hard challenge for individuals who are nonverbal.

Shawn Ullman:

Many people with IDD can use supported decision-making to make important medical decisions too. And it's important that medical providers take the time to explain health risks and treatments in ways that the people that they're treating can actually understand, including people with intellectual and development disabilities. It's also important that medical providers allow a person's supporters to be present and to allow them to help explain information and help communicate a person's wishes if they're having a hard time in communicating themselves. And of course, it's also important that individuals have access to the technology that they need so that they can communicate their wants and needs in the way that they can communicate.

Shawn Ullman:

Health care is another area where, in addition to supported decision-making, people can also use a healthcare power of attorney to identify the people that they want to make medical decisions for them if a medical provider decides at any point that they aren't able to understand the medical decision themselves. And again, the standard for signing that healthcare power of attorney isn't that the person understands the underlying health condition or the treatment for it, but that they understand they're allowing someone else to make those kinds of health decisions for them. And for individuals who can understand end of life choices, healthcare powers of attorney and living wills are also ways that people can describe the kinds of medical care that they do and don't want to receive in lifesaving emergencies.

Morgan Whitlatch:

Well, not directly impacting Britney Spears, her case has brought to light some of the pipelines to guardianship that exists out there. One of those pipelines that got some press coverage was the school-to-guardianship pipeline, and it was highlighted in a National Council on Disability report in 2019. And that report found that among those with intellectual and developmental disabilities who received publicly funded developmental disability services, 18 to 22-year-olds are the age group that are most likely to be under guardianship. Studies have also found that schools and educators are the number one source of guardianship referrals for people with intellectual and developmental disabilities.

Morgan Whitlatch:

For the NCD report, qualitative interviews were done of stakeholders around the country, including people with disabilities, family members and professionals. And the school-to-guardianship pipeline was a common thing. One family member said, "Too often schools have told family members that a student with IDD must have guardianship if they want a family member or friend to assist with one's IEP when the student turns 18." Now that information from schools is not accurate, and we'll talk about that more in a minute. But that's the message that a lot of schools are giving to families. One formal educator talked about the dearth of information that is given about alternatives to guardianship. She said, "Students are not informed. Parents are uninformed. Educators are uninformed. It's a triple whammy." So we want to inform you about those options within the special education context so that families can make informed decisions with their family members, to find the right fit for them. Next slide.

Morgan Whitlatch:

So, there are three main options for less restrictive means for decision-making within the educational context. Now, the first is supported decision-making, which Shawn provided a very great definition of. In this case, it would be when adult students make their own educational decisions with the supportive people they know and trust. Parents do not need to have guardianship in order to participate in IEP team meetings. To facilitate the flow of information to supporters, the adult student can sign an educational release of information form, known as the FERPA form. The adult student can invite their parents to be part of the IEP team so that they can get help in understanding the choices and decisions they face.

Morgan Whitlatch:

Another option in the school realm for adult students with disabilities are educational powers of attorney. So just as we were talking about financial powers of attorney and healthcare powers of attorney, an educational power of attorney is a legal document that allows the adult student, called the principal, to appoint a representative, called an agent or attorney-in-fact, to act on the adult student's behalf in educational matters. It's different from a supported decision-making agreement because the agent, unlike the supporter, can actually make educational decisions for the adult student. And despite the terminology, the attorney-in-fact doesn't need to be an attorney or a lawyer. It can be a parent or a trusted friend.

Morgan Whitlatch:

Some states have a third option, depending on state law. In DC, for example, adult students who can't make their own educational decisions even with support and can't knowingly and voluntarily sign a power of attorney, parents can apply to the Office of State Superintendent of

Education to be appointed as the adult student's educational representative without having to get guardianship, provided they supply certain kinds of professional certifications from doctors and other professionals on the appropriate forms. And there are some other states that have similar processes like Virginia and others.

Morgan Whitlatch:

So, you shouldn't assume that guardianship is necessary to be involved in adult student's education. There are less restrictive options that are available that I don't think that families and people with disabilities know enough about, and I also don't think schools know enough about them either. And so really, we're trying to help spread the word about these different options so that families can make the right decision for them and know what they're getting into when they're thinking about pursuing guardianship. Next slide.

Morgan Whitlatch:

So now we're going to open things up for questions. Right, Shawn?

Shawn Ullman:

Yes. And there are a lot of them in the chat so I'm going to do my best to start from the beginning. Just as a reminder to everyone, as I said in the housekeeping section at the beginning, we are recording this. We will share the recording out with all of you by email afterward. We will also share a copy of the slides, and you are free to share that recording and the slides with anyone you want to share them with. We highly encourage you to share them with anyone you want.

Shawn Ullman:

Okay. Give me a minute, Morgan, to get through all the hellos. A couple of people asked about getting a certificate for the course. We can provide a certificate of attendance. We do not provide that to everyone. As you can see, we have over 500 people participating, so that's a very difficult logistical challenge. But if you need one for education credits, for any reason, please email us. My email is on the next slide. And you can also email the Center for Future Planning at futureplanning@thearc.org, and we'll get you a certificate of attendance.

Shawn Ullman:

Thank you for your patience, everyone. I'm just scrolling through the chat. I know you guys have seen it's been very busy.

Morgan Whitlatch:

Well, one question I saw was, "How do you revoke a power of attorney?" You should revoke when you want to revoke. You can revoke powers of attorney. If you have the ability to make a power of attorney, you have the ability to break power of attorney. And so, you can do that depending upon the terms of your state laws. Usually it takes the form of a writing of some kind, indicating that you're revoking the power of attorney, and you would need to give that notice to everybody who received a copy of it, of the original. So, it is possible to revoke a power of attorney.

Shawn Ullman:

So someone asked, "There's legislation that has been proposed for reforming the guardianship process, which bills does The Arc support?" I am not a member of our policy team, so I can't tell you specifically names of bills or what's in them. But as Morgan referenced earlier, The Arc does have a position statement on this topic. So, we support legislation that is in line with our positions. And that is something that I will make sure I share a link out to with everyone, in addition to the recording and the slides.

Shawn Ullman:

Morgan, just FYI, someone pointed out that one of the quotes in the beginning, we dated it wrong. We've dated it 2001 instead of 2021. That's our bad, everyone. Sorry about that. Just a typo.

Morgan Whitlatch:

Whatever goals with this presentation was to really highlight the most recent dialogue around Britney Spears and really kind of try to demonstrate its relevance to the sphere in which we all work in and support people in. So, I'm sorry for that typo.

Shawn Ullman:

And I can try to fix it before we send out the final slides. So, this isn't exactly a question, it's a comment, but I think that it's something we can comment on, Morgan. "I knew family members who have had their role as caregivers taken away, and even their contact with their loved one not allowed when there was no reason for guardianship." Do we have some suggestions on what a family member might do if their access to their loved one is being limited, unless they go get a guardianship and sort of force the issue? What might their options be to make sure that they're able to see and have contact with their family member?

Morgan Whitlatch:

I've seen it kind of both ways. I've seen situations in which visitors are limited by guardians, so guardians have limited family involvement in a person's life. And I've seen situations in with, but for guardianship, parents are somehow being cut out of the process. And I really think that when you're thinking about different kinds of options to support those circumstances, guardianship is not going to solve complicated family dynamics. And if you're dealing with service providers that are limiting you, limiting access to people that the person wants to see, I think you're dealing with some straight-out rights issues that can be enforced through other kinds of means like through complaints systems within that service provider arrangement. Those are some of the suggestions I've seen people use short of guardianship. What about you, Shawn?

Shawn Ullman:

Yeah, I mean, that's what I would say is, if your access is being limited, maybe even getting guardianship may not solve that problem. And so, the better way is probably... I mean, that does... Again, if the person doesn't want to see you, there's maybe nothing you can do about that. But if it's a situation where they want to see you and somewhat, a third party is getting in the way, then there are complaint systems available and your state's Protection and Advocacy program is probably your best starting point for figuring out what your remedy options are.

Shawn Ullman:

Another question we have, Morgan, is, "Can a power of attorney appoint someone to make decisions on behalf of their children, i.e., medical care, if you are the person that is not able to, or not available, or does not want to do so?"

Morgan Whitlatch:

So, that's going to depend upon state law. I'm going to say that first of all, because some states have specific custodial power of attorney forms like in DC, for example, where it's a separate form that would have to be completed by the biological parent to be able to authorize someone to care for minor children. So, if I'm understanding the question correctly, it can vary depending on state law, what the rules are for how an agent can manage the affairs of minor children.

Shawn Ullman:

Yeah. I think quite a few... I mean, it's an alternative to the foster care system, right? If a parents need someone to make decisions that they would typically make for their children and they need someone else to make those decisions, there are usually options in states. I don't know if it's necessarily through the power of attorney process or if it's from a surrogate parent type process, but there are usually processes in most states for a parent to designate someone else to make their parental decisions for them because they, for whatever reason, are not able to, whether that's because of a health condition, a mental health condition, or possibly they're going to jail, or something along those lines. So, it might be a power of attorney, it might be called something else, but that is typically available in most states.

Shawn Ullman:

I'm sorry, I'm reading kind of a long question and I'm trying to get a grasp on exactly what it's asking.

Morgan Whitlatch:

Well, while you're doing that, is the guardianship transferable when the principal guardian dies? Okay. So, guardianship is a creature that's governed by the courts. Okay? So the court is going to decide what happens when a guardian dies. The guardianship doesn't go away because the court has ruled that the guardian is in place. The court decides who will be appointed as the successor guardian and what will happen under the guardianship. And I have noticed families don't always realize that. They think that they might be able to pick who's next. Some courts have certain processes for standby guardians, but not all do. So, it really is going to depend upon the court rules.

Shawn Ullman:

Right. And it's something that if there is a particular person that the current guardian wants to be the next guardian, they're going to need to go to the court and ask for that permission, and get the court to order that as part of the current guardianship order.

Shawn Ullman:

Someone asked a really good question, which I'm not sure I have a great answer to, "Under the psychiatric advance directive option, who and how is the end of the mental health crisis determined?" And I think the answer is that the mental health professionals have to decide. They're the ones who decide that there is a mental health crisis and that the person doesn't currently have capacities, so they're going to be the ones to decide that the crisis has ended and the person does now have capacity. You have to rely on the mental health professionals in that regard. Do you agree, Morgan?

Morgan Whitlatch:

Yes. I think that the law defaults to the professionals in these kinds of circumstances, when you have questions about incapacity. I also think it's really important within those kinds of documents to be spelling out exactly when they get triggered and when they don't get triggered. So in other words, working with a really good form that spells that out, so that everybody's on the same page about when it springs into effect and when it is not an effect, is really important. And so, it can benefit if you talk to an attorney about that.

Shawn Ullman:

Right. And I would also point out that, like any medical opinion, you're always capable and able to go get a second one. So if the mental health professional that originally said you don't have capacity, still says you don't have capacity, but you believe that you do or you believe that your family member does, then you can always seek a second opinion from another mental health professional.

Shawn Ullman:

I think Morgan sort of already talked about this in the ability to revoke a power of attorney, but another question is, "What can a person do when the person they gave their power of attorney to was their long-term attorney, and the attorney did not allow that person any say in their decisions?" I mean, the answer is, revoke that power of attorney and write a new one, assigning a different power of attorney.

Shawn Ullman:

Morgan, what would you say to the situation where they wrote the power of attorney, giving it to one person, they now no longer have capacity, but they're unhappy with the person they gave the power of attorney to, but they don't have capacity anymore. What can they do in that situation?

Morgan Whitlatch:

It's a complicated circumstance. I do think when we think about what is the capacity to revoke a power of attorney, the traditional wisdom is that you have to have the capacity to make it in the first place. But I've seen people who have revoked powers of attorney while they've been in a delirium state. So, you can still try to revoke the power of attorney. You just might not be left with an alternate power of attorney if, for some reason, the thought is that you do not have the capacity to execute a new one.

Shawn Ullman:

Right. So you might be allowed to revoke it, but not write a new one, which could be a problem.

Morgan Whitlatch:

I have seen that circumstance come up, but sometimes that is the right move to make if you really feel as though you are in an abusive agent kind of relationship.

Shawn Ullman:

And I will say that there are... Again, the Protection and Advocacy programs are available to help people who feel that they're being abused or neglected by the people who are supposed to be responsible for taking care of them. And so, even if someone lacks capacity, the Protection and Advocacy program might be able to assist them in identifying an abusive situation with a power of attorney and getting that person removed. Unfortunately, if they don't have capacity to execute a new power of attorney, they might be in a situation of them being appointed a guardian that is not someone of their choice. So, it is the pros and cons to weigh.

Shawn Ullman:

Morgan, someone asks you to explain the guardianship renewal process, whether it's done annually. And, of course, that's a pretty big guardianship reform issue that I was hoping you would address.

Morgan Whitlatch:

So, I think that's going to depend upon state law. There are some states that you don't have a kind of renewal process. You're the guardian, unless there's some change in the courts. But there's now a movement towards regularly reviewing guardianship, and we're seeing more states kind of introduce that kind of protection to realize that guardianship isn't necessarily a state that should exactly exist forever, that they should be reviewed periodically. DC, for example, has a review every three years to determine if the guardianship is still necessary for certain guardianships happening after 2015. In some states, there's guardianships that automatically terminate after three years, and you have to renew them if you want to continue to do them. So, it really does vary depending upon the state that you're in, so I can't offer you legal advice with respect to your question.

Shawn Ullman:

Right. You've got to talk to somebody in your state about what the rules are in your state. As a larger matter of systemic reform, most disability advocates believe it's important that there be regular review in the guardianship process, because people's capacity really changes over a lifetime from year to year and from decade to decade, and someone who may not have been viewed as having capacity before may have gained life experience and be viewed as better able to make their own decisions, and someone who may have been using the supported decision-making may, as they get older, like all people with and without disabilities, experience signs of aging and have more issues with capacity in making decisions. And so, from a reform perspective, we think it's important to be regularly reviewing all guardianships to ensure they're still appropriate.

Shawn Ullman:

Someone asked to provide more information about ABLE accounts and what they are. We have a whole webinar on that topic, which I think would do a better job of explaining it to you. But, just very, very briefly, ABLE stands for Achieving a Better... Oh, I forgot what the E stands for. Achieving a Better Life Enrichment? Ugh, I'm sorry, I can't remember what it stands for. Now, ABLE is an acronym that stands for something, and ABLE accounts are available to people who became disabled before the age of 26 and who either are currently eligible for Social Security benefits, or who have documentation from a medical professional that their disability significantly disables them. And it is an account that is set up very much like a savings account, which allows people with disabilities to save money. There's a lot of rules about how much and how often. That, our webinar goes into more detail about, so I would direct you to the Center for Future Planning's website. But-

Morgan Whitlatch:

ABLE is Achieving a Better Life Experience.

Shawn Ullman:

Experience. Of course, as soon as you found it, I remembered it, Achieving a Better Life Experience. Those accounts allow people to save without impacting their eligibility for public benefits. So, as many people may know, you can't have more than $2,000 to qualify for SSI currently, and you are allowed to save up to a hundred thousand dollars in an ABLE account without losing your eligibility for public benefits. So that is the advantage to having an ABLE account.

Shawn Ullman:

I also saw a comment that someone said that ABLE accounts were very expensive and would eat up the amount of money if they use one. I am not an expert on each state's ABLE account, and each program is different so you have to look up what the ABLE accounts rules are for the ABLE program you want to sign up for. The ABLE National Resource Center has all of the information you could ever want to know about each state's ABLE program. But my understanding is that most of the fees are actually quite low, significantly lower than, for example, special needs trust, so I'm surprised to hear that someone felt they were an expensive option. Again, I encourage you to go to the ABLE National Resource Center site and get more information about ABLE accounts.

Shawn Ullman:

I'm not sure I quite understand this question. Morgan, I'm going to see if you do, "What role does an authorized representative serve for adults with disabilities?"

Morgan Whitlatch:

An authorized representative is... Some states have authorized representatives for different kinds of programs. So, for example, I've heard authorized representative used within the context of a state's ABLE account, for example. I've seen authorized representatives used for the purposes of receiving home and community based waiver services. So I would need a little more context to know exactly what that means. I think that that terminology varies depending upon the program we're talking about. But I've heard of that phraseology too, and it can mean something very different depending upon the program you're talking about.

Shawn Ullman:

Yeah, I think that sounds right to me as well. I agree. I think that's something that's specific to whatever program you're talking about, and so what it means and what their authority is, is something you'd need to talk to the program and get more information about.

Shawn Ullman:

Someone asked, what if they can't afford a lawyer for supported decision-making? And that's where supported decision-making is so great, you don't need a lawyer.

Morgan Whitlatch:

You don't need a lawyer for supported decision-making. Supported decision-making can really vary in what it looks like depending on what the person's needs are and their support networks are. Some are very formal kind of arrangements and agreements between the different party. Most are very informal. Okay? Just as I seek advice when I am making a big medical decision, so to people with disabilities should be able to have that opportunity as well. There are some examples of supported decision-making forms and brainstorming guides on the supporteddecisionmaking.org website, which I see somebody has put into the chat that I can put into the chat too, for where you can see some examples for that, but you don't need a lawyer to use supported decision-making.

Shawn Ullman:

I think an important question, Morgan, for us to answer is, "When might guardianship be appropriate?"

Morgan Whitlatch:

I think there can be circumstances in which guardianship is appropriate. I've seen situations in which advance planning wasn't able to be accomplished or was not accomplished, and someone's in a medical crisis requiring some kind of immediate intervention, or financially abused. So there can be circumstances in which guardianship is appropriate. I would say it's a far over-utilized tool. And it just kind of teaches you that you need to really do some advance planning, and that includes people with intellectual and developmental disabilities. They should be able to have access to knowingly and voluntarily sign some of these voluntary documents we're talking about to do planning. But I would never say guardianship is never necessary. I think there can be certain circumstances in which it's an appropriate. If someone, for example, were in a coma or was in the middle of a mental health crisis that was not able to be resolved through some of these other less restrictive options that we're talking about.

Shawn Ullman:

Yeah. I do think one reason why Morgan and I, in our advocacy positions, think it's so important to consider alternatives, first, is that as Morgan was talking about in the education slides, we have seen and we believe families have experienced that the moment a person with an intellectual developmental disability turns 18, the conversation immediately goes to, "You need to get a guardianship because you won't be able to do X, Y, and Z." And there isn't any discussion about alternatives and what might work for that person in their particular situation.

Shawn Ullman:

So, it's not that guardianship is never appropriate because, of course, there are situations where it is, crisis situation certainly, and other situations where individuals genuinely don't have capacity to make legally binding decisions and need someone who can do that for them because they can't sign a power of attorney. They don't have that capacity. But we think that most people in their families, if provided information in a language and at a level they can understand, might be able to execute some of these voluntary, less restrictive documents that allow them to have a choice in what kinds of decisions are made for them and in decisions that they make for themselves.

Morgan Whitlatch:

I did note here, someone said, we seem to be using guardianship and conservatorship interchangeably, and they're different things. Different states call guardianship different things. For example, in California, conservatorship covers what we would consider guardianship in DC. And so, there's different terminology that's used across states as to what guardianship is called. Some places called the guardianship of the person and guardianship of the property like Maryland. Others use conservatorship broadly like California. Other people use guardians for being guardians of the person, and conservators for being guardians of the money. So it really does vary across states. I think we were using a kind of shorthand.

Shawn Ullman:

Yep. And we should've clarified that at the beginning that we were going to do that. So, thank you for asking that question, and thank you for clarifying, Morgan. It was something I had thought to say and then I forgot to say.

They do mean different things in different places. We were using them interchangeably to mean sort of the same thing.

Shawn Ullman:

Someone asked, Morgan, if supported decision-making is a term of art or more of a philosophy, or a little bit of both.

Morgan Whitlatch:

I would say it's both. I think that supported decision-making is a philosophy, but it's also a legal term. Some states have passed specific legislation recognizing the word supported decision-making. At least 40 states and DC have introduced some form of supported decision-making legislation or resolutions, and at least 19 states and DC have passed them. So I think we're seeing it becoming more and more of a considered official term. But it does also describe a philosophy, a philosophy of starting from a place of presuming people's capacity and their ability to make decisions on an equal basis to others, with the support that they need and want.

Shawn Ullman:

Morgan, if you have a guardianship in one state and move to another state, does the second state recognize the guardianship from the first state? Or do you have to go get a new guardianship in the new state?

Morgan Whitlatch:

So there's a uniform model law that talks about jurisdiction over guardianship, that many states have passed, that has mechanism by which you can record the guardianship of the other state. So it depends upon whether your state has passed this uniform law and what its rules are as to how you can get that guardianship recognized. I have also seen some states that in practice, you do have to reapply. So I think it really does vary depending upon state, which I know is not a very satisfying response, but it is the response that's accurate here.

Shawn Ullman:

Someone asked, "Is a supported decision-making agreement recognized by banks, doctors, and hospitals?" And of course, our answer is well, obviously, it should be. But in real life, what can people do if they're having a hard time getting a supported decision-making agreement perspective?

Morgan Whitlatch:

So one of the things to keep in mind about supported decision-making, and I get this question a lot about... We don't have a state law that recognizes supported decision-making. And I say, "Well, we have a federal law, the American with Disabilities Act and the Rehabilitation Act that says that third parties like banks, like healthcare providers have to reasonably accommodate people with disabilities." And I think a reasonable accommodation includes a reasonable accommodation for decision-making. So I consider supported decision-making to be an accommodation for a person's disability. And I've made that argument for enforceability of supported decision-making agreements, even before the states I've practiced in have passed supported decision-making legislation. So, there's ways in which to advocate for accommodations for people in the form of supported decision-making.

Shawn Ullman:

Someone had a comment that they found it difficult to find supported decision-making literature, and their local agencies also have little information about the process to offer. Obviously, the National Resource Center on Supported Decision-Making has lots and lots and lots of information about supported decision-making, and we'll make sure we send out that link to everyone in the email with the recording and slides. The Arc's Center for Future Planning has also created several documents related to decision-making that provides some more general guidance on supported decision-making and what it is, and we'll make sure we share links to those documents as well.

Morgan Whitlatch:

And I would also encourage people to visit there. If you're looking kind of for state specific information about supported decision-making, I'm finding that more Protection and Advocacy organizations are having things like this posted on their website, and that can be very helpful as well.

Shawn Ullman:

That's a good point. I will make sure that we also provide a link to the P&A, find your P&A site. A lot of them have good information about their state specifics. That's a good point.

Shawn Ullman:

How can guardianship in general impact parents with a disability? Can the person with the guardian raise their children and make legal decisions for them? Does it depend on state laws and how independent the person is? So if the person who has a guardian is a parent themselves like Ms. Spears.

Morgan Whitlatch:

Yeah. I think it's interesting that you asked that, because I do think it's dependent on state law. But at this committee hearing that I told you was happening or had happened last Tuesday before the subcommittee of the judiciary committee and the US Senate, a man from Indiana told his story of being under guardianship. He had experienced a traumatic brain injury.

He later got married and had children. And he describes being able to medically consent for his child's health care but not his own. I think it does vary, but that was just such a stark description to me, about how, as a parent, his ability was impacted by guardianship to consent for himself. So I think it does depend upon state law and how that would work. But his story certainly grabbed me when he said it that way.

Shawn Ullman:

Someone asked a question about having a personal representative under SSI. And I would point out that that is slightly different from a representative payee for SSI.

Shawn Ullman:

And what happens if you gain full employment and no longer qualify for SSI? Does the personal representative go away? What happens with the [inaudible 01:05:21]? Does it become moot? And I think the answer is, yeah, if you're not receiving Social Security benefits, then that person is no longer relevant.

Morgan Whitlatch:

That's right, because it's a personal representative for only the purpose of Social Security benefits. And if you're not receiving Social Security benefits or you're not somehow involved in some kind of battle about them, like in other words, say you are challenging an overpayment and you have a personal representative helping you with that, it's not going to be much help for you in terms of managing finances.

Shawn Ullman:

This is kind of a big question. I don't know if it'll be too hard to answer. But what needs to happen in order for the pipeline from school-to-guardianship to be broken? What kinds of systemic efforts would you recommend, Morgan?

Morgan Whitlatch:

I want to see a lot more education of educators in this area about the alternatives to guardianship pipeline. And I'm really trying to educate them about the full range and the full continuum of support that can be provided to people, because I think that school professionals only know what they know, and if they're not actually educated on what the full scope of alternatives to guardianship are, they won't necessarily know what the impact of recommending guardianship could be for someone who's just a young person at the cusp of adulthood. In interviewing some of the educators for the National Council on Disability report, one said to me, "I had no idea I was recommending removal of rights." I didn't know what the impact of guardianship truly was when I did that. So I think that's a really big step.

Morgan Whitlatch:

I also think that really thinking about special education planning as including building decision-making abilities over time, incorporating into the educational planning process an opportunity for young people to be engaging in self-advocacy and to not just be exposed to making decisions for themselves When they turn 18, or only have the conversation when they turned 16 or become transition age. I think that could go a huge way in terms of trying to be promoting on the decision-making rights of young people. So those are, I think, two really important ways in the school system to do that, that I actually think should be able to be accomplished. As long as we are giving kind of concrete tools to IEP teams and special education planning teams about how to be implementing some of these alternatives and that guardianship is not the only game in town, we could go a long way.

Shawn Ullman:

Yes, I agree. I think that incorporating self-determination and self-advocacy into the IEP process, making it a goal from year to year in students plans, and proactively providing students tools and opportunities to make decisions and screw up, make bad ones, and learn the consequences in a safe way with minor decisions that don't have lifelong consequences and do that just like all people do. And this is easier for me to say than for some people to feel comfortable implementing in practice, but allowing kids to fail is very hard for any parents. Allowing kids with disabilities to fail, it's like a wall for parents of kids with disabilities. So doing it and practicing it with very small decisions through the IEP process so that parents can be there to support their kids if they do fall, I think, is a really, really important skill to teach in the special education process and particularly in the transition years, but even sooner, really.

Shawn Ullman:

This question upsets me, Morgan. Do you have a sample of a FERPA form? And does it allow parents to participate in the education decision-making process of a young adult? They were told by a school that FERPA forms do not allow families to participate in the education process in that way. And I think that's the exact opposite.

Morgan Whitlatch:

I think that upsets me too.

Shawn Ullman:

That's the exact opposite purpose of the form. The whole purpose of the form is to allow the parents to come to the meetings, review the records, be a part of the decision. Now, the FERPA form is not a substitute decision-making form. It does not take away the decision-making authority of an adult student and give it to their parent. The student can do that through a power of attorney, an educational power of attorney. A FERPA form allows the parent to continue receiving educational information, which I would point out the parent doesn't actually need, because the IDEA requires that parents continue receiving all of the same notice that their children receive when rights transfer to the adult child.

Shawn Ullman:

So, invitations to IEP meetings, prior written notice of any changes they want to make to a student's plan, due process, rights, all of those things go to both the adult student and the parent. The IDEA requires that. The parent isn't cut off at 18, unlike what we often hear. And again, if someone's not respecting a form that an adult that has capacity to assign that form has signed, that's a civil rights violation, and it needs to be addressed through a civil rights process. And whether that's some sort of informal complaints system or whether it's formal litigation, we strongly encourage you to reach out to your state Protection and Advocacy program and talk about your particular situation if that's happening.

Shawn Ullman:

I don't think I know the answer to this question. I don't know if you do, Morgan. Do you need a guardianship to be able to get Social Security for an adult child with disabilities?

Morgan Whitlatch:

No.

Shawn Ullman:

Should you help an adult apply for disabled child benefits. Do you know if you-

Morgan Whitlatch:

No, you do not need [crosstalk 01:11:30] to seek guardianship to do that. Now what has to happen if you're helping an adult apply for benefits, it's going to be the adult who signs the paperwork, but you can assist and be their authorized representative. And then if they're not able to manage those benefits themselves, then you would become the representative payee upon the award of those benefits. But it is a separate application process from the authorized representative piece. But it's a good question. And I find that Social Security Administration field offices don't always provide the right information to people about guardianship. Always take what you hear, like with any system, any bureaucracy, take it with a grain of salt.

Shawn Ullman:

Exactly. Morgan, is there information on the National Resource Center site or anywhere that provides sort of some practical examples of how to use supported decision-making?

Morgan Whitlatch:

Okay. So we have some brainstorming guides on our website and a variety of different kinds of formats and some other resources. So yes, there are. I put into the chat the supporteddecisionmaking.org website, and I encourage you to take a look at that. There also are archived webinars that talk about supported decision-making within different kinds of contexts. So, we kind of went pretty quickly over medical, financial, and education. There are some that do a deep dive into each of those.

Shawn Ullman:

Morgan, did you talk about already the process for having a guardianship terminated if someone got one initially, for example, when the school recommended it, and you feel it's no longer appropriate and wish you hadn't gotten that?

Morgan Whitlatch:

So, every state has a restoration of rights process. And so, the way that process works is going to be dependent upon your state law. But in some practical tips for doing so is, I think it's really important to get some strong representation, an attorney that's going to be zealously advocating for the termination of the guardianship. I think, unfortunately, in the way in which guardianship systems operate, and this has also come up I think in the Britney Spears situation where she doesn't want to be evaluated again, courts tend to like to see proof of capacity. So you're going to have to try to show that the circumstances have changed in some way, and that is usually done through some kind of expert proof.

Morgan Whitlatch:

So you want to find the right kind of medical or psychological professional who's willing to be on your side with respect to getting that guardianship terminated or to show that less restrictive options will be available. Going in with that kind of evidence, I have found in my practice, is critically important. I've had circumstances where people have tried to go in without that kind of evidence and left with more guardians than when they first came in. So, you want to make sure you're really preparing your case, and that really needs to be done, I think, in consultation with an attorney.

Shawn Ullman:

Morgan, can you talk about your experience with guardians who identify who they want to be the next guardian in their will and how that goes over in court?

Morgan Whitlatch:

So that varies depending upon court. There's some states that don't allow that at all, and there are other states that do allow it. For example, Maryland and DC have very different approaches to your ability to do that. So, you need to consider it. Even if a state allows it, you have to always remember, it's just a recommendation to the court. The court is the one who's going to have the ultimate decision about who will be the follow-up guardian.

Shawn Ullman:

We have a lot of sort of personal circumstances, and of course, Morgan and I can't provide any advice on personal situations. So I'm looking for sort of broader lessons that we can learn from some of the questions asked. If you're seeing any that I'm missing, Morgan, please go ahead and feel free to... Well, here's one. So, someone is describing a situation where an individual gave a power of attorney to someone, and one of the agencies providing supports believes that person is abusing the authority that they've been given, and the person is not interested in revoking the power of attorney that they executed. Is there advice we can give on what an agency's options are in that situation?

Morgan Whitlatch:

In those situations, frequently, agencies are mandatory reporters of suspected abuse under their state laws, and so contacting adult protective services may be an obligation that you have if you think an agent under a power of attorney is abusing that document. It sounds like a very difficult situation.

Shawn Ullman:

Someone asked about difficulty understanding state laws and maybe not being able to afford an attorney. And I would remind you that the Protection and Advocacy programs in states might be available to help you understand what your state's laws are regarding guardianship, powers of attorney, supported decision-making. And I don't know, are they a lot... Most of them do not charge for their services so you should reach out to them.

Morgan Whitlatch:

I see a question. "Do you have somewhere a list of terms with the definitions? It would be helpful to have to know what each term means." I know there's a lot of different terminology that we've used on this call today. I know that the National Council on Disability report has a section that just is about definitions. So I can put that into the chat. I don't know if The Arc also has resources on that.

Shawn Ullman:

Let me think about it. Nothing is coming to mind, but we might.

Morgan Whitlatch:

How can you have a family member added to a guardianship in case of... Oh, we answered that one as best we could. It really does depend upon state law.

Shawn Ullman:

Sorry. I was trying to make sure I understood this question before saying it out loud. So someone is raising a question about... If someone is using supported decision-making but they're being taken advantage of in sort of signing a document without anyone from their support network present, is supported decision-making really appropriate for that kind of person? How-

Morgan Whitlatch:

One of the things you want to think about with supported decision-making is, all of these legal tools we're talking about today, all of them can be subject to abuse by bad actors. There's no study that says guardianship is safer, and I think we've seen cases where there have been abusive guardianship arrangements. I've seen cases where representative payees have abused people or powers of attorney have abused people. And so, it's really about trying to provide education to the person with a disability to create safeguards and to be utilizing their supporters appropriately, to be saying, "Do you really want to sign a document if you don't have your supporter with you?" Trying to help that person kind of be educated in how to effectively use supported decision-making in a way that provides the kind of safeguard it's designed to do, I think is a key in that kind of situation.

Morgan Whitlatch:

Ultimately, in supported decision-making, it's the person with a disability, in this case, who's the one who's signing on the dotted line, and so they need to be educated as to what that means, and they need to be developed comfort in turning to their supporters to say whether they want help or not with certain kinds of decisions.

Shawn Ullman:

Yeah. I think educating them, training them, role playing, giving them opportunities to feel empowered, to say to someone, "No, I'm not signing that. I don't have a supporter." I mean, I actually talked a little bit with families about this and the IEP context when I advocated for students is, you can have the absolute, most beautiful, amazing, wonderful IEP document but you, parent, are not physically setting next to your child as they walk their day in school.

Shawn Ullman:

So, we need them to know what's in that document and what services and supports they're supposed to be getting, what accommodations they're supposed to have so that they have the ability to raise their hand and say, "Actually, I'm supposed to get more time to answer that." Or come home and say, "Hey, I was given a test today and they didn't give me the extra time I was supposed to take." And whatever language is appropriate for them, if what I'm saying is too high level, I think it's really important that we try to educate and empower the person as best we can. And I know that's not a perfect answer and that vulnerable people will still be taken advantage of. I would point out that happens to people without disabilities too. And they don't end up in guardianship because of it.

Shawn Ullman:

This is a good question, and I don't know that there's a great answer, but what resources are there to be able to use supported decision-making and other less restrictive options when people really don't have family or unpaid supports that are available to them?

Morgan Whitlatch:

It creates a challenge when people don't have the kinds of natural supports around them. I've had circumstances like that where, for example, I am working with someone who is older, in her 80s, and she doesn't have the same kind of natural support network that she perhaps once did. And I saw my role, as supporter, was to link her into additional kinds of supports and link her into additional kinds of social services, to be able to promote a different looking kind of supported decision-making that had at its forefront, more professionals. She had links to her church, let's also link her into an aging social service agency. Let's also link her into other kinds of community supports. It comes down to community integration. That takes time, and it is a gap. I think, right now, a lot of our legal system depends upon guardianship to serve that kind of role, rather than trying to think about, "Why don't we try to build up community networks to support people, to have checks and balances?" But there's no easy answer, like you said, Shawn, to that kind of question.

Shawn Ullman:

Yeah, when there aren't natural supports, I mean, I think the best thing you can do is try to build some natural supports. And in the meantime, more restrictive options may be the only thing available unfortunately.

Shawn Ullman:

I saw a comment, and we only have about five minutes left, and so I wanted to point this out. Someone identified that they run a guardianship program and they've incorporated supported decision-making throughout their guardianship network. And Morgan talked about this when she was talking about concerns about guardianship, and the National Guardianship Association actually has a position encouraging guardianship programs to incorporate supported decision-making enter the guardianship. And so, while some individuals may very, very much need appointment of guardian either when they become an adult or upon a crisis situation, there are guardianship programs out there using supported decision-making concepts, empowering people to make their own decisions and I hope, eventually when possible, helping restore their rights so that they no longer need a guardian. And thank you to all the guardians out there in the art network and outside of it who are doing that.

Shawn Ullman:

A lot of people find themselves in guardianships and don't even realize it, and then they need a lot of support and help to get out of them. And the guardians that help them do that, Ryan King's mother helped him do that. And it took her 10 years to get rid of her own guardianship. That is part of the guardianship reform process, is for guardians to absolutely exercise authority when needed and when appointed, but to use supported decision-making allow the person to make as many decisions on a day-to-day basis as they're able to make, and even allow them to fail in some ways so that they can learn just like people without disabilities learn through making mistakes, to be better at making better decisions.

Shawn Ullman:

I'm going to move the next slide forward so that everybody has our contact information. I'm going to just scroll through and maybe we can do one or two more questions. And then, I think our time together is up today.

Shawn Ullman:

I'm getting a lot of thank-you's, so I think I'm getting to the bottom of the questions, finally. All right. Well, I'm going to, I think, end us there. Thank you all so much for joining us today. We hope that the information we provided was useful. Again, one more reminder, we did record the webinar. Everyone who registered and attended will be receiving the link to the webinar recording as well as the copy of the slides with the updated 2021 dates. And Morgan and I mentioned a few other resources, the links to the National Resource Center, The Arc's position statement on decision-making as well as decision-making documents that we've created, and a link to find the Protection and Advocacy program in your state.

Shawn Ullman:

Morgan, thank you so much for sharing your wisdom. And everyone, enjoy the rest of your afternoon.