



# CommunicationFIRST

Because communication is a human right.

## Guardianships for AAC Users?

Zoom Webinar (Part 2)

August 19, 2021; 3:00-4:30 pm ET

TRANSCRIPT

**GUARDIANSHIPS FOR AAC USERS?**  
Part 2: Continuing the Conversation  
By Popular Demand!

Tim Jin      John McCarty      Dana Lloyd      Joan McCarty      Jordyn Zimmerman

Clarissa Kripke      August 19, 2021      Morgan Whitlatch

12-1:30 PT / 3-4:30 ET

CommunicationFIRST  
Because communication is a human right.

**Tauna Szymanski:** Welcome to Part Two of CommunicationFIRST's panel discussion on guardianships and AAC users. My name is Tauna Szymanski and I'm the Executive Director and Legal Director of CommunicationFIRST. I'm a white woman with brown, shoulder-length, wavy hair. I'm wearing glasses and I have a wonky left eye. My pronouns are she and her.

To ensure access for attendees who cannot see the screen, I will ask our panelists to also provide a visual description of themselves, to introduce themselves, and to say their names before they speak.

First, some housekeeping details. We are recording this session. This is a Zoom webinar and not a Zoom meeting, which means we won't be able to hear or see you unless you are a panelist. Attendee names will not be visible on the recording or to anyone else except the hosts of the webinar unless you post a question in the Q and A box.

We are providing ASL interpretation and live captioning. If the live captioning does not appear automatically, please go to the bottom of your screen and click on the Closed Captions or Show Subtitles buttons. If you prefer the captions to show up in a separate window, rather than on the video screen, you can select “pop out” to make it into a separate screen. You should feel free to ask questions during the discussion by clicking on the Q and A button on the bottom of your screen. The questions will only be visible to the panelists until we type a formal answer and post it.

Like last time, we will not have any PowerPoint slides today. We do hope to make the recording available in the future. The recording for Part One of this discussion will be posted on our website soon at the link I’m going to ask Clarissa to paste into the chat right now.

Today we’ll be moving into a more advanced discussion of issues around guardianship and conservatorship of people who rely on augmentative and alternative communication or AAC to be heard and understood. But to recap the first part of this discussion, which took place on July 13th, I will start by reviewing the key takeaways.

**First, we learned last time that guardianships and conservatorships don’t really accomplish what people think or are told they are going to accomplish. We learned that these tools aren’t what they are chalked up to be. That they don’t, in fact, do anything to protect people with disabilities from abuse or from being taken advantage of, or from being arrested, accused, or convicted of a crime.**

**We also learned that people who are subjected to guardianships have fewer rights than convicted felons, and that they may lose the right to vote.**

**They may not believe -- be believed if they try to report a crime or to testify on their own behalf in court.**

**We learned that parents who seek guardianship over their children have to swear under oath that their child is incompetent and otherwise lacks the capacity to make decisions, even with support.**

**We also learned that guardianships and conservatorships are not actually necessary if parents want to remain on a student’s IEP team after they turn 18, or if parents want to remain involved in health care decision-making.**

**We learned that guardianships and conservatorships are not actually necessary for people who cannot speak or who need support with their daily lives, even on a 24/7 basis, like John McCarty does, for instance.**

**We learned from John that it is possible for people who cannot speak to terminate their guard -- their guardianships, and to become their own decision-makers. We believe that John McCarty is the first AAC user in the United States to have successfully terminated a guardianship.**

**We learned that the best thing that parents can do to protect their children from abuse and other dangers is to support them in learning how to make decisions from an early age -- to choose their caregivers and their services, to set boundaries, to develop self-advocacy skills. And of course, to provide them with access to robust, language-based AAC, and to ensure that they are always supported with it.**

And we started to learn about alternative and less restrictive legal documents that can be put in place to help achieve some of the protections that parents often seek with more restrictive guardianship arrangements.

As Tim Jin said last time, “There are so many different options to maintain the safety of your loved ones.”

After the last webinar, we circulated a [handout](#) with definitions on some key terms. We won’t repeat those definitions, and you can access that handout at the link we are posting in the chat.

So today we are going to answer your questions in the following categories and roughly in this order. First, two key terms that we didn’t really go over last time and that aren’t in the handout, but that come up a lot in these discussions, are the terms “capacity” and “competence.” We’ll spend a minute discussing what these terms mean and the differences between them.

Then, we’ll ask a few more questions about the risks and dangers of guardianships and conservatorships.

Third, we’ll spend some time talking about the less restrictive tools that can be put in place to support someone, to maintain their rights, and to be their own decision-maker and their own guardian. Tools like supported decision-making, and the various legal agreements that can achieve a lot of the same protections that parents often look for.

Then, we’ll discuss some best practices in preparing someone with significant communication support and other disability-related needs to live without a guardianship.

We’ll then ask whether it is possible to make an existing guardianship or conservatorship less restrictive. And then we’ll go over the steps involved in terminating a guardianship like John did.

We’ll talk specifically about people who haven’t been given access to robust, language-based AAC, which is most of our population, or who have significant intellectual disabilities.

Then we’ll cover some advocacy tips and we’ll answer some other practical questions that people have submitted if we have the time.

We aren’t going to have all the answers today, but we hope that this discussion gives you more tools to think carefully about whether it’s necessary or even desirable to terminate your own rights or the rights of your loved one who relies on communication tools and supports to be understood.

And we hope you'll leave today more familiar with some of the less restrictive tools that may provide greater protection and still preserve an AAC user's rights.

Okay, to kick us off, should we spend a few minutes just very briefly talking about the differences between capacity and competency? And, I think, Clarissa, do you want to kick us off with that?

**Clarissa Kripke:** I'd be happy to. So --

**Tauna Szymanski:** First, do you want to introduce yourself and do your image description?

**Clarissa Kripke:** Thank you. I'm Clarissa Kripke. I'm a family physician and on the clinical faculty at the University of California, San Francisco, I'm a white woman with brown hair that's pulled back a little bit and I have a blue sweater on and glasses that are reflecting too much in the light, and earphones on.

I go by she/hers pronouns. And I -- my clinical practice focuses on care for people with complex developmental disabilities, people who need skilled nursing, or who have complex behaviors such as self-injury and aggression. So I -- and I treat -- my patient population are people who are transition-age youth and adults.

So, I have a lot of experience with people with different arrangements. And I am speaking from San Francisco, California, and I have a California perspective because a lot of these issues are partially based on state law.

So, one term to understand is the difference between capacity and competence.

**When we talk about capacity, we're talking about a specific decision at a specific moment in time. And for somebody to have the mental capacity to make a decision, they need to understand the different options, to understand the risks and benefits of each option, to be able to weigh them against each other, rationally, and to communicate a choice.**

So that's what we mean by having the capacity. And you can get tripped up at any point in that. For example, you might understand your options and the risks and benefits, but not have the communication support to be able to communicate your choice. You may understand something like I don't like needles and I don't want to do needles, but I don't want to get the flu and understand those -- but not be able to weigh those two very different things against each other to say, I'm going to put up with getting a shot in order to prevent the illness.

So weighing -- weighing the ideas against each other can -- can be a challenge for some, especially when you're talking about very dissimilar things. Not all decisions are equally complex, like a decision where I have a lot of experience. Like when I take this Tylenol, my headache goes away, for example, and I know that this pill helps me, and I've -- and I've done this many times before. That -- that's a pretty simple decision.

Whereas a decision that maybe is very abstract, like I'm going to, I'm -- I'm going to take momentary pain to prevent an illness that I've never heard of before, that I've never had. And I don't know anybody who's ever had like -- like a childhood immunization for polio, for example. That -- that's a very different kind of decision that may be more challenging for some to make.

**So legal capacity is the -- the capacity to enter into contracts, and it requires understanding the terms and their implications. And, for all of us, we usually retain our legal capacity, even if our mental capacity fluctuates, and all of us have a fluctuating mental capacity at times.**

So at times, for example, if -- if I'm about -- if I've just taken a powerful medication for my migraine, I may not be able to make good decisions. Or if I've just been under anesthesia or if somebody bopped me on the head, they're -- they're -- or if I'm very overwhelmed, emotionally.

**All of us have a fluctuating mental capacity and at times cannot make our own decisions. But that doesn't mean that we take away everybody's legal capacity.** I retain my legal capacity, even if my mental capacity to make a specific decision at a specific moment in time might -- might fluctuate. And people's capacity can get worse as we age. It can improve as we learn skills or have -- have issues treated, or gain access to communication.

Competency is a different thing. **Competency and capacity are often confused, but [in]competency is a legal determination by a judge that says that you don't have the capacity to make your decisions indefinitely.**

And that -- if -- if you're -- if you have that determination made by a judge to say -- to say that you don't have capacity for all types of decisions ever, then it doesn't give you the opportunity to use the capacity that you do have or to gain capacity or -- or -- and often it means that people don't have -- don't have the opportunity to participate in decision-making, even if they're getting a lot of support for that decision -- for those decisions from other people, from trusted supporters.

**So communication support should not be mistaken for incapacity or incompetence. So if somebody is receiving support to understand their communication, that does not mean that they're not able to understand their options, the risks and benefits, weigh them against each other and communicate a choice. That --**

**Tauna Szymanski:** Very helpful. That helped me a lot. Okay. Next topic is -- we had a few questions that sort of fell into the risks and dangers of guardianships. So Tim last time asked a very key question, which is, "Most children will outlive their parents' lives and what will happen to them then?" So, what happens if the person's guardian dies or themselves becomes incapacitated? What happens then?

**Morgan Whitlatch:** I -- I can weigh in. I -- or, Clarissa, I know you also have some comments to make on this point. You know, you have to remember if somebody is under guardianship and has been adjudicated incapacitated that the guardianship doesn't automatically terminate if their guardian become -- guardian dies or becomes incapacitated in some way.

And that there are some systems that the design would be kind of court oversight would identify that problem and try to find a replacement guardian. However, in practice, at least in my experience -- I'm sorry, I didn't introduce myself. My name's Morgan Whitlatch. I'm the Legal Director at Quality Trust for Individuals with Disabilities.

I go by she/hers. I'm a white woman with red curly hair with a little more grey in it than I would like. I wear glasses and I have a red shirt on and earrings. So from a legal perspective here, what you're seeing is that you sometimes see situations in which people do not have a guardian who's available to act for them.

They've been adjudicated incapacitated and they're kind of in this limbo land. **So it is important when you have a guardian to be thinking about successor guardianships or moving towards that** because of that kind of circumstance that I've seen. Unfortunately, I've gotten several cases recently that have kind of brought that to the fore. Dr. Kripke?

**Clarissa Kripke:** Yes. I want to -- to echo that -- that I see that happening, too. That sometimes because it -- you have to go before a judge to change a conservatorship it often doesn't happen even if -- I'm sorry, guardian -- another terminology, **guardianship and conservatorship are the same thing**. In California, we call it conservatorship. Elsewhere in the country, they use the term guardianship. But we're talking about the same thing and I may slip into California-speak. I'll try not to.

But -- but that often happens. I have many patients in my practice who do not use speech to communicate, who have very little expressive communication skills. Who have intellectual disabilities that limit their ability to make decisions without support, or sometimes for us even to determine their will and preference.

But most of them are unconserved. I have very few patients who have guardians or conservators in my practice. And -- and so I see what happens. And over time, people who thought it was a good idea at age -- when someone became an adult to become a guardian or conservator find that they no longer want that responsibility, or no longer have the capacity for that responsibility.

I have 90-year-old parents living in nursing homes who are -- who have advanced dementia, who are still the conservator. Or people who -- who are not really able to serve in that role. Conservators who have moved on with their lives 20 or 30 or 40 years later, and who are no longer contactable. But, when -- when they're needed ...

So, being a guardian, taking responsibility for all of someone else's decisions is a huge responsibility that you're taking on until a judge relieves you from it. I've had guardians who wanted to retire and wanted to pass on their responsibility. And the judge said, I still think you're the best person and I won't allow you to do this. I've had family disputes where the judge just says, I'm sick of your bickering, and I'm going to assign a public guardian and no family member can serve in this role.

There are immigration issues with being a guardian. Guardians often are deeply uncomfortable making decisions on behalf of another person and do what they can to avoid it.

And then -- then you're kind of stuck, because they're the person who is supposed to be making the decision. Being -- being **in supported decision-making models, if someone no longer wants or can serve, it's a pretty simple process to replace them with somebody who -- who wants to, or can. You can split the responsibilities among multiple people. It doesn't have to be just one person forever. And I think that that's healthy.**

We -- we -- who wants a single person making all of their decisions forever? And if -- if you want to -- if you, as a guardian or conservator need -- want to take a couple months' vacation, or you have to have surgery or you -- but want to resume your role later in the supported decision-making agreement, you could -- you could be replaced temporarily and then come -- come back into that role, without it being a whole legal procedure.

You can just -- just change that up very easily or have a backup plan. And so -- so it's a problem. And a problem that's much more fluidly -- it's a problem when children outlive their parents' capacity to do this job, or their willingness to do the job. And -- and so I'll -- I know Tim has some -- some comments on this too, but **in supported decision-making you have a lot more flexibility and a lot more control.**

**People think conservatorship is what gives them the flexibility and control, but it's actually -- but it actually takes the control away from you and puts it in the hands of a judge that -- that you know, may or may not share your values.**

**Tauna Szymanski:** Tim, and then Dana.

**Tim Jin:** Hi, my name is Tim. I'm in a brown shirt in a wheelchair and Korean. I have cerebral palsy and can type with my toes. I'm using a device to communicate.

My doctors never asked my parents if they want guardianship over me. It was never an option at all. My brothers never wants guardianship whatsoever over me because I am my own person, let alone live on the same street, ha ha.

**Tauna Szymanski:** Dana?

**Dana Lloyd:** Yeah. So my name is Dana Lloyd. I work for the Georgia Advocacy Office, which is Georgia's protection and advocacy system. I'm an African-American woman with short-ish, curly, black hair. I'm wearing glasses and a blue sweater today, too. And my pronouns are she and her. And I was really just going to add what -- the very end of what Clarissa said. Which is, **in a guardianship procedure, what you're actually doing is inviting in court oversight.**

**So you might have ideas about how this should all go. But really what you're putting forth to the court is that there's an issue and you want the court to make a decision on how to solve it. The**

**court may listen to your opinion or may not.** There may be solutions that work now, but that don't work in the future.

So, we spend a lot of time trying to help families understand that that's what you're inviting in is that **you're really removing decision-making from perhaps being a family or community decision to this being a decision that the court now makes about how decisions get supported.**

**Tauna Szymanski:** Okay. The -- someone submitted a question. Which is, can a school, hospital, Medicaid, or an adult living facility force someone into a guardianship without a parent's consent? And if that's true, what -- under what circumstances could that be possible? And are there steps that can be put in place to protect against that? Morgan?

**Morgan Whitlatch:** So, yes, the -- you know, it -- any -- in a lot of states, anybody can petition for -- for there to be a guardianship or conservatorship that's put in place. I've seen circumstances, for example, in which nursing facilities or other facilities that are serving a person, have filed for guardian -- guardianship -- for a guardian to be appointed in certain circumstances without the consent of family members.

And so that is a reality one needs to be aware of. I think planning is critical in cases like this. And I think it can be done in -- through -- through **responsible safety planning for people from trying to build people's support networks so that there are people to be called upon in the event certain circumstances happen.**

And to make sure that you're informing the -- the third parties. In other words, like, you know, the -- the schools, the healthcare professionals, et cetera, of that system of support and the backup people that are out there to be able to support someone. So that would be my perspective for you. For me, it really speaks to the need for thoughtful, advanced planning.

It is also, you know, the reality that there are certain things that are beyond your control. You can't control, necessarily, someone petitioning a court. Once that happens, a ball will start rolling that you will not have necessarily control over. So why not try to do some advanced planning so you don't get to that space?

**Tauna Szymanski:** Thank you. So --

**Dana Lloyd:** This is Dana.

**Tauna Szymanski:** Sorry. Oh, go ahead.

**Dana Lloyd :** This is Dana. And I'll just add briefly to that. That advanced planning can be the answer to that petition, right? So you may not have control over someone filing a petition because a person was hospitalized. But being able to show up and have a clearly articulated plan over, "No, we don't need a guardian in this situation because XYZ there's this supporter and this supporter, and this is how John makes his decisions. And this is the support that we have." Helps to be a



defense against the petition. So I -- I agree a hundred percent that the planning, to me, that's the key -- one of the key differences about supported decision-making right? Is that we're -- we're being thoughtful and we're taking these steps. And then we have a platform and a foundation to work for when things change, because things will change even with supported decision-making, right?

Supporters might need to come and go or help changes, but you have the platform to begin working from -- from, versus just kind of being really responsive and reactive to a crisis.

**Tauna Szymanski:** Joan, were you going to add to that?

**Joan McCarty:** No, I was just still -- I'll introduce myself very briefly. I don't really have a comment. I'm Joan McCarty. I'm a -- I'm a further-than-middle-aged white woman with brown hair, shoulder-length. I'm wearing a purple shirt. And I'm sitting in my dining room, so you can see my dishes behind me. I don't -- I was just in total agreement with Dana and it all -- and -- and Morgan. It all has to do with thinking through it ahead of time and having conversation. And that's what we found with John. And that's what we found was most helpful. So I was just like shaking my head in agreement.

**Tauna Szymanski:** And I neglected to comment at the beginning that John is still ill and unfortunately can't join us live, but we're going to try to work in a lot of his work into today as well.

So last time we established and today we've already established that a guardianship isn't necessarily going to protect anyone from being taken advantage of. But we did get an explicit question even after last time about how do you protect an adult living in their own home with support from an aide from taking advantage of them. Morgan?

**Morgan Whitlatch:** So I think that -- You know, I think that also comes to safety planning. You know, when people need support in the home, that can place people at risk of a variety of different kinds of things. I've seen situations of identity theft and situations of other kinds of stuff like that. And so I think it's about trying to develop that, **trying to plan when you're planning a supported decision-making arrangement, what are going to be your safeguards? Your checks and balances? Are you going to support a person to regularly be looking at their bank account? To regularly be checking their credit report?**

I've also seen people who are -- when we think about guardianship -- **guardianship doesn't stop people from having caretakers steal from them either.** So those, you know -- you're going to be using those same kind of tools, I think, regardless of what decision-making method you all -- you know, families turn to. So, I think that's all part of safety planning and thinking through that. How do you -- how do you protect personal identifying information about the person? How do you protect the access to bank cards and you know, social security numbers? All those kinds of issues. And that's really the piece when we're talking about trying to be protected from abuse in that context.

**Tauna Szymanski:** Thank you. Most of the questions we received are really want -- people wanting more information about all those alternatives, all those less restrictive tools. And you know, we learned last time that **there are a whole bunch of AAC users, including folks on this call and on the last call who have never been subject to guardianship. So that it is absolutely possible to live a life as someone who needs significant, full time, 24/7 supports, including communication supports, to retain their rights and to make their own decisions.**

So, I wanted to invite another one of CommunicationFIRST's Board members, Jordyn Zimmerman, to say a few words about her and her family's experiences with guardianship and less restrictive alternatives.

Jordyn didn't receive access to robust AAC until after she turned 18. But she's really made up for lost time. And she's actually in her last semester of graduate school getting a master's degree in special education at Boston College. So, Jordyn, do you want to tell us a little bit about your experiences and your family's experiences with guardianship and school?

**Jordyn Zimmerman:** I'm Jordyn Zimmerman. My pronouns are she/her. I am a white woman with brown curly hair past my shoulder. I am wearing a brightly colored tie-dye shirt and sitting in front of a white wall. I am from Ohio, but I am currently a graduate student at Boston College and student-teaching in Boston Public Schools.

So, prior to my 18th birthday, the school district I was in told my parents they needed to obtain guardianship over me. I was in a small town. So the Director of Special Education was always in my meetings and she really pressured my parents, saying the school could file reverse due process, which is when the school sues parents, or even scarier, not let my parents advocate on my behalf.

This was a really hard idea to fathom for them, because I had never gone to an IEP meeting, I didn't communicate that I wanted to be there, and I really didn't have an effective form of communication yet. My parents were divorced. So, they met with an attorney who gave them a few options.

Rather than guardianship, they ultimately did something called an extended duty of support where the judge essentially said I needed support making educational and medical decisions. I am based in Ohio. So, I don't know if this is offered everywhere, but it has worked well for my situation. It gave my parents the ability to still file due process against the schools on my behalf but I was still an integral part of those proceedings.

It gave my mom the ability to advocate on my behalf when I went to college three hours away from home and needed additional accommodations. It allowed my mom to come into the ICU quicker when I recently had a procedure and started having seizures. **For me, this has been helpful while also allowing me to have autonomy with my bank account, where I live, the doctors I see, what I do every day, where I go, how I vote, et cetera. Having this level of independence and support is really important to me and has allowed me to grow, explore the world, and advocate for myself.**

**Tauna Szymanski:** Thank you so much, Jordyn. Morgan, do you -- are you familiar with the -- the option that they put in place -- that Jordyn's family put in place in Ohio? Is that common in other -- ?

**Morgan Whitlatch:** You know, some -- some states do have what Jordyn is describing and they're called various terms. I would say that is typically a minority of states. There -- there are, I would say though, a lot of states do recognize concepts of limited guardianship. In other words, only over certain kinds of things. Like, be it medical decisions, be it educational decisions. And so I -- I have -- that is a kind of common notion that, you know, might be alluded to in Ohio.

I don't practice law in Ohio -- Ohio, so I haven't heard that specific kind of terminology before.

**Tauna Szymanski:** Okay. Thank you. So in one of the videos that are part of John's supported decision-making toolkit, he said, quote, "The thing that will protect a person with a disability is teaching decision-making as a skill, as well as teaching self-advocacy as a skill." He also said self -- quote, "A self-advocate needs a supporter who will be the champion of his process, who will get it going, and keep it going. And without that champion, the likelihood that the self-advocate will have success with the supported decision-making process is minimal." I'm going to put in the chat or maybe ask Clarissa to, if she can, a link to that supported decision-making toolkit that John created.

So, we used this term a lot last time. And I think people might also be confused about whether supported decision-making is like this thing -- like a legal thing, or is it a generic term to describe all these sorts of things that you can put in place instead of guardianship? We've heard about supported decision-making agreements, and there are some states that have formally recognized it and some that haven't.

So, I guess the first question is, do you have to live in a state that has formally adopted or recognized supported decision-making to pursue alternatives to guardianship if you want to do that?

**Dana Lloyd:** I can chime in here. And I'm sure Morgan will fill in the gaps. So this is Dana again, and I think my favorite definition of supported decision-making is the set of arrangements, agreements, practices, and, you know, supports and services, right? That empowers and allows an adult with a disability to make their own decisions and whatever that looks like for them. So, yeah. It is a very broad umbrella term. I tell people all the time that I think people can use some of these legal tools in the context of supported decision-making. So in -- you know, in general, we're working on supported decision-making as the way that -- I'll keep using John as an example -- John makes his decisions.

But in the process of that, maybe there is a trust and maybe there is a power of attorney and -- and these other things, right? And so I try to think about, as much as possible: How are we arranging things so that people have the same tools at their disposal that you and I might have, right?

So, I've got some legal tools that protect some stuff, that give some people authority to make decisions for me, if I can't or in certain circumstances. And so there's the option to do that. I also have people that I just chat with when I'm confused about things. So what does that look like? Yes, I believe you can practice supported decision-making in states that haven't formally recognized it. There are ways to work on what Morgan talks about as third-party recognition, right? How do you get other people on board, even if your state hasn't done that? So, maybe that's a good point for her to jump in.

**Morgan Whitlatch:** This is Morgan. I get a lot of questions about, well, if we don't have a supported decision-making law, how do you enforce anything, right? How do you enforce these kinds of arrangements?

I think Dana is absolutely correct that current legal tools that are voluntary kinds of tools, like powers of attorney, really -- it's really about the person choosing what is the tool set that they want to use to be advancing their rights and having a choice and voice in it.

So you're incorporating the idea of supported decision-making principles into existing tools. So, for example, I have seen durable powers of attorney for healthcare that spring into effect and authorize an agent to act for a person when the person is determined they can't act for themselves. And that person picks -- picks the person who's going to act -- The agent is picked by the person who's signing the durable power of attorney. And incorporated within those durable power of attorney are all sorts of supported decision-making principles. How that decision is going to be made, how the person is going to be consulted. All of those pieces are incorporated in.

And so there is a way to use existing tools to be able to support -- do supported decision-making. The other piece I will say to you is that, you know, if you're really looking for enforceability, the Americans with Disabilities Act celebrated its 31st year. And it says that those very third parties we're talking about have to reasonably accommodate a person's disability.

And I say what that includes is decision-making. That's part of our lives and that there's a responsibility for the doctor, for the bank, to really support the person in making their own decisions and making accommodations if that person identifies supporters. **So I think there are many legal tools out there that can advance supported decision-making and no, your state doesn't have to pass a law for you to be able to use that.**

The last thing I'll say is that, you know, there have been more and more case law. I'm a lawyer. So of course I focus on court decisions, right? But there's case law that's out there. And many of the very, you know -- the case law that recognizes formally supported decision-making occurs in states that don't have a statute on books.

**And so you don't need to have that kind of statutory change to be advancing supported decision-making.**

**Tauna Szymanski:** Okay. I did post in the chat, though, a [link](#) to something I think you probably put together, which is the states that have passed -- that have passed legislation referring specifically to supported decision-making.

But you're saying, no, we don't -- you don't need to live in a state that has recognized it formally. These are all things that you can just put into place as a human being in the United States. Tim and then Joan.

**Tim Jin:** I would like to go back on abuse. About 20 years ago, I had a staff that took my credit card and went on a shopping spree. This could happen to anyone. It really doesn't matter if you are disabled or not. Luckily, I was checking my credit card statement and saw that I got charged for motorcycle parts and we let go the staff.

**Tauna Szymanski:** That's a really good point. Excellent. Joan?

**Joan McCarty:** Okay. So I wanted to talk about, you know, the question, do I -- **do I go ahead and start with supported decision-making even though my state doesn't have a statute? And the answer is, yes.** And John says, in his presentations while he and Dana are out on the road, is that the most important thing for him, and I'm going to totally agree with him as his parent, was the discussion.

Like the -- with the supported decision-making -- and John had to write a supportive decision-making agreement because he was terminating his guardianship. And so he has a written plan, but probably the last time we looked at that written plan was when he was getting his guardianship terminated.

I mean, you start to live this organic kind of life where he doesn't have -- Like, we don't have to look at the agreement that says, we're going to talk now today, about how much money you owe me for the groceries. Like, we don't do that. It's just a more, this is how we live kind of a thing. Although John makes his own decisions about things.

So you don't -- you start a supported decision-making discussion and it has to do with the supporters you want, et cetera, et cetera. And I think when you go back to the -- John said -- and thank you for pointing this out, Tauna: "A self advocate needs a supporter who will be the champion of his process." And the bottom line is he needs people who will work with him to ensure that his decisions are always being followed. Because, a lot of times, people with disabilities can't do that.

So I'm going to give you an example. John goes to the doctor. I was in there with them. He has -- he's spelling. He has a computer and the nurse is talking to me and John typed, you know, I can hear you just fine. And I'll answer the question. He stepped in. He support -- he -- and I wasn't like -- I was like, oh, he's saying this to you.

And so I could have taken over or I could have stood behind John. And that's what I did. And that's what -- that's what John's point is. We need champ -- They need -- People with disabilities need champions. They need someone who's going to stand behind them and help, kind of, through the process. So there isn't a way to quote unquote enforce it. I think you're right, Tauna. It's what we do as human beings.

**Tauna Szymanski:** Right. I thought it might make sense to get really concrete. We've gotten pretty concrete already, but I thought it might make sense to spend the next little bit talking about -- like going through a laundry list of all the potential tools and -- and legal documents and other things that -- that can be put in place.

And I've sort of organized my notes in terms of sort of general things for someone's life. Then like something for the educational context, then specifically in the healthcare context, and then specifically on financial. So, I guess what I might do is I could just read through my notes here and you guys can sort of weigh in if like -- yeah --

So, one is a general durable power of attorney. I mean, when -- when my husband and I were getting our estate stuff in order, our wills done after we had our child, like our lawyer said, this is part of the regular packet of things that spouses should always have with each other and -- and our durable power of attorney with each other, allows us to sign documents for each other.

And we've actually used it on occasion when one person couldn't physically be there. So that's something that's used by, you know, anyone in society really to just get things done, I guess. And that, you know -- so that's one thing. Is that a sort of something that you all recommend in general or is that -- is that part of this SDM, sort of, toolkit of things that you recommend or is that ...? Anyone can weigh in on this.

**Clarissa Kripke:** I want to say a little bit about -- a power of attorney is handing decision-making to a third party. It's someone that you chose, as opposed to someone who a judge chose. So it's -- you're more in control and it can also be changed much more easily. You can withdraw that authorization at any -- at any moment and change who you've authorized at any moment or the terms of it at any moment with, with just a -- a notary public. So, so it's -- yeah.

**Tauna Szymanski:** And it can be very specific to certain things like you're only going to -- you're only allowed to do X, Y, Z specific things, and only in the circumstance where the other person isn't whatever, available or whatever.

**Clarissa Kripke:** Right.

**Tauna Szymanski:** Right. Dana?

**Dana Lloyd:** This is Dana and I'll just add to that. But I think Clarissa's point is well made though that in the context of supported decision-making, what we are striving for, kind of the gold standard, would be people making their own decisions, right?

Getting the support they need to do that. So, you know. I have an uncle who's a doctor. We have a pretty good relationship. But you know, really when I'm confused about something medical, I talk to him. I don't really talk to him about my relationship stuff. He's a bachelor, right? Like he doesn't have a ton of -- a ton of experience that I really want to draw on for that, right?

So, that's the context of supported decision-making that people are getting the support they need, whether that's someone to explain things or things in plain language, or access to things in a variety of formats, or an opportunity to visit things and try things.

In -- under that umbrella, if there are decisions that people are uncomfortable making, don't feel like they have the skills and practice yet to -- to fully understand those things, then yeah. We can lean on a durable power of attorney so that people can do exactly what Dr. Kripke was saying and choose the person and the circumstance and give the limitations, right?

That that's-- that that's better. It doesn't remove any decision-making rights. It doesn't say, well, you can never again make a decision. But I, I, I don't want to equate them. And I think that's what Clarissa was saying. I don't want them to -- they're not the same, right? It's better than guardianship, but you're still giving away a bit of that power. It's a limited time period. And we all use it, but it's not the same as supported decision-making. And I think that's a point that's well made.

And the only -- I was going to chime in at the end of something Joan said because a parent said this to me once and I -- I've held onto it as I think a really good thought. Yeah, I did this training and she came up to me afterwards and she was like, **I think supported decision-making is like yoga.** I thought, I -- I'm not sure that I follow. And she said, well, I mean, you can go to yoga. You can go to yoga and you can do yoga and **yoga can be an activity, but after a while it becomes a practice,** right?

**The things that you're learning in yoga, the principles that you're learning become a way of life,** your breathing and your posture and mindfulness, and it becomes this -- this different shift. And so she said, I think, I think we've been kind of living in a space of supported decision-making. We may go back and do it, right? We may go back and put something in place, but that's always been a helpful thing for me to hold on to people. And it's exactly what John was talking about.

There's a period of time where you may be doing the activity, having the discussions, figuring out what works best for people, trying different things, working with certain organizations to get that kind of solid, but then it becomes a way of doing, and the principles really kind of flow in and out of a lot of people's lives and it's not something that's quite so formal. So we'll put that on a t-shirt at some point, right? Supporting decision-making is like yoga.

**Tauna Szymanski:** Morgan?

**Morgan Whitlatch:** You know, I -- I really wanted to just -- I'm going to not repeat what the excellent things that were just said before about supported decision-making. You notice I say

supported decision-making *principles* can be incorporated into any tool. But there is, when you think about supported decision-making, it's the person making the decision not someone else making it for them.

And I do -- so I do really want to underline that that is an important piece of this. The other thing I just want to say, you know, I think when -- just to go back to your discussion of durable powers of attorney for healthcare, Tauna. I think a lot of times when, you know, people with -- people with disabilities are kind of forgotten as part of -- do -- to do the kind of advanced planning that all of us should try to do when we're trying to plan for the future ourselves. I've seen a lot of assumptions that people with disabilities who may have, you know, communication support needs that somehow they can't sign those kinds of documents or they can't execute it.

**And there's a lot of myths associated with what the capacity is necessary to sign one of those kinds of documents or even what it means to sign one of those documents. So I would like to bust that myth out there. I've worked with many people with many different types of support needs who have been able to knowingly and voluntarily execute a power of attorney.**

**Tauna Szymanski:** So actually specifically on that question, we did get one or two questions about -- and they were phrases. What about people who cannot sign a document? And I had, I had interpreted that to mean *physically* sign, but maybe it was a broader question. If that person is present, maybe they can clarify in the Q and A. But -- but what if there is a -- like, what if someone physically can't hold a pencil and sign a document? What would you say to that?

**Morgan Whitlatch:** You know, I think that there are a variety of different best practices for -- This is Morgan. There are a variety of different kinds of best practices for doing that. Usually it requires some kind of voluntary act on part of the person. **So I've seen documents executed in front of a notary, in a variety of different kinds of creative ways -- be it holding a pen in the mouth, be it a stamp, be it some kind of way of doing that.**

**And when that occurs, you really want to make sure you're witnessing correctly and you're notarizing correctly according to the laws of your state, because power of attorney laws do vary across states. So you don't need to be able to sign your name perfectly. There are many different ways to sign by mark, it's called.**

**Tauna Szymanski:** So -- so we talked about durable powers of attorney -- pros and cons of those and ways to sort of limit them and ensure the person is making their own decisions. It seems like another thing that comes into play a lot, and you all have mentioned this, is that best practices are sort of to create a sort of team of support people who might help you in different areas of your life with making decisions.

So, is this like -- how technically does that work? Would you put that on paper somewhere? Would you create a formal structure for this? Would you share all the various legal documents in your life with all these people? Would you have their names and contact information, like on your wrist, if in case you had to go to hospital, I would, how, how does this work really?



Like, what do you have to do to get this set up? Like, do you pay? Like -- how does -- Like, what's the relationship here?

**Joan McCarty:** Alright so I want to answer that question because that's how John started. When we started the process, it's really -- there's lots and lots of stuff out there, and it can be very big and unwieldy. And so what he wanted to do was he wanted to start out with who would support him.

And he's a thinker and the way he decided he wanted to structure it was, kind of, with tiers of support. And so the -- his immediate family are his primary supporters. That's because we support him physically every day and we understand a lot of the kinds of things he needs. And we all have the ability to communicate with him.

He communicates through spelling and he needs a communication partner. And then he has, kind of, two tiers that are under that. And it's like friends and family, like his cousin is -- is -- he's close to. And -- and then he's very close actually to Dana Lloyd here. They're coworkers and friends. And so -- then he has a mentor through his fellowship and someone that he worked for here in the state. And that's like part of the other tier.

And what he did was he wrote, he just wrote a letter and that's actually on [his SARTAC webpage](#) and it was, hey, here's what I'm doing and I'm going to need some support. And would you be one of my supporters? And the thing about that is, is that, when he has needed or wanted to talk to one of his supporters about something specific, then he just kind of contacts them. And all it is is kind of reaffirming: Hey, you're very close to me. I feel very close to you. Can I rely on you when I need a little bit of extra help? And that's really what it is. It's not some really deep -- it's not -- it's not real formal. I mean, I don't know how to put it.

**Tauna Szymanski:** Not like an agreement that you would sign if you were a supporter?

**Joan McCarty:** No, we did not -- we didn't do that.

He has a list as part of his -- his written plan. He has a list of his supporters and he has them listed as, you know, professional, personal, family kind of a thing. But -- but that is how he did it. And then his plan, his written plan, it's formalized, but it's not really formal.

So that's John's. So, I don't know if Morgan and Dana, if you have experience with people who have done it differently or more formally. Maybe Tim could address this because Tim, you've got supporters.

**Tauna Szymanski:** Yeah. And I know Tim's typing. There -- there are templates too out there. Like you don't have to invent these from scratch, so. But you *can* invent them from scratch, right? These are just informal ones.

**Joan McCarty:** John decided just to write a letter and that's -- that's as part of his webpage. He welcomes anyone to take and use that and edit it as they -- as they see fit. But, yeah.

There's plenty of stuff out there where we saw on -- out there on the web, just for people who want to go Google around, you know. This person for this specific thing, this person for this specific thing. I mean, it's very, very granular. I'm John's primary supporter in a lot of things because I'm his primary supporter. But yeah, there's a lot of different ways to do it. There are templates out there. Sorry, Tim. I didn't mean to jump on what you were trying to say.

**Tauna Szymanski:** Tim's still typing. Morgan, do you want to ...

**Morgan Whitlatch:** I do because I do want to -- I just have to put one thing out there. Okay? Is that **there are some states that have passed laws that have specific forms you have to use for supported decision making. It's a minority of states.** Okay? And you-- I believe that, yes. Tauna posted the [Supported Decision-Making in Your States](#) from our National Resource Center for Supported Decision-Making.

And so, you know, I -- you do have to keep in mind what your state law is when it comes to this. Because some states say if you want to have a formal supported decision-making document in writing, it needs to look a certain way. Okay? And it needs to be signed a certain way. Like just -- just to like a power of attorney would need to be signed in a certain way. That said, you know, **supported decision-making is so much more than a piece of paper.**

**You know, it's a much more kind of organic process. And so you might have that form that you need. But then you're going to have the supplemental lists and these other things Joan is talking about even if you live in one of those states. Because supported decision-making and the support people need evolve over time.**

I really encourage people to think about supported decision-making as kind of a living and breathing approach to things that you might have to change. And then to also realize that it's going to be very individualized and it's going to, in practice, look very different for different people, depending upon their sort -- support networks, their wishes, and their support needs.

**Dana Lloyd:** This is Dana and if Tim's still typing then I'll -- I'll go on.

And just add to that to say a couple of places, easy places, to go get some of those sample documents, right? So the ACLU has the sample form. So if you Google [ACLU and supported decision-making or ACLU and alternative -- alternatives to guardianship](#). The [supporteddecisionmaking.org](#), right? The National Resource Center has a list of several samples that will work. The Arc US has several samples as well. And so there are tons of -- of documents out there that get -- you know, that are available for people. And then people often then kind of take a piece from this and maybe a piece from that and kind of put things together to answer questions about how they want to do it.

But I -- when sometimes parents will ask me that question, well, how do I get started? Two things I'd say there right? Number one, you're not getting started. So, you need to talk to the person that you're thinking about and this, and find out how *they* want to get started. And -- and what's the

area, right, where people really want support? Because that'll probably guide you a little bit, if we're really thinking about finances or something medical or going to college, right? Then some of the -- some of the ways that get supported will become a little bit more obvious to you when we -- we start there.

So, I think Tim's done now and I can stop talking.

**Tim Jin:** I have three answers. I know exact how John feels when he goes to the doctor. I too have been in the same situation when staff learns to be my shadow and they follow my lead in the conversation. Sometimes I need their support to help me take the lead when my new doctor doesn't understand my capacity,

I have a stamp with my signature and it's been notarized. As soon as I was 18 years old and got a bank account, my parents went ahead and make a stamp for me and we went to a public notary.

As for John's comments about John's circle of support. I too have my circle of friends also in my person-centered plan. Right now I'm trying to transition over into self-determination. And, I recently had my team meeting with regarding staffing. And, my circle of support are helping me getting through the process.

**Tauna Szymanski:** And what Tim is referring to is a California-specific set-up about self-determination, right? In case anyone was wondering about that -- about self-determining I think, your own services and stuff.

Jordyn, go ahead.

**Jordyn Zimmerman:** I just wanted to add that I also had a list of people who agreed to support me while I was in undergrad and people who can now support me while I am in Boston. For me, this has been about asking people that I feel comfortable with, who are patient with my communication system, and who can help me advocate.

**Tauna Szymanski:** Nice.

**Clarissa Kripke:** I -- I wanna say a little bit about these alternatives to -- to -- **the legal processes of guardianship or even power of attorney is really about figuring out *who* can make a decision. Is it the person or someone else? Whereas supported decision-making is really about the *process* of making a decision. And -- and I think that's a really key -- key thing.**

**And a lot of people with communication disabilities may not be able to initiate a request for help when they need it, especially if they rely on someone else to communicate. And so, if you're in that situation that needs to be built in -- either regular check-in points, like, I'm going to meet with my -- my circle of support on a quarterly basis, regardless of what's going on, or a monthly basis. Or, I need someone to check in with me every day and just say, I'm okay, or I'm being mistreated and I need access to communication.**

Everybody needs a way to communicate that they're being mistreated. And if you are not someone who can ask for help necessarily when you need it, then you need to build in external oversight into your plan and people to be nosy and give them the permission to be nosy and tell them what you want them to do. If they notice that you've lost access to communication or that you suspect someone is not acting according to the agreement. And you can -- you can build formal oversight into your plan.

So some, especially for financial supported -- supporters, you -- you can build someone whose sole job it is to monitor the supported decision-making relationship and make sure that it is -- that it is still operating as it should. And -- and do some of those external controls. Like, getting your credit report and looking at your bank statements and looking specifically for fraud and abuse.

Somebody asked about whether you should freeze your credit. That's a really good way to -- to -- to protect yourself and add another layer of -- of support, but also assigning someone to order your -- your -- your credit files. And -- and maybe have -- like, banks will often send you any time there's a transaction they'll send you an email. You could -- that email could come to you, but you could also ask it to go to someone else as well. And so you can set up representative payees or authorized representatives for bank accounts and set up some of that oversight and -- and reach out to people who you want to intervene. If -- if -- if it's not going well and -- and create regular periods for that.

People tend to behave better when they think they're being observed. And liking and trusting someone does not mean that they won't abuse. Most abusers are friends and families and aides and people you know. They're not -- they're not -- they're not strangers. And, often there are people who are in positions of trust and -- and who are even trusted by the person who's being mistreated. So -- so creating those external monitoring systems, because people do behave better when they know they're being observed and when you have those -- that oversight.

**Tauna Szymanski:** So, Clarissa and others, I think, have talked about elements that might go into something called the safety plan. Is there some -- like, was that part of a supported decision-making plan or is that a separate thing? Can someone talk about safety plans? Is that a distinct thing, or I hear this, this --

**Morgan Whitlatch:** This is Morgan.

It's not like it's a legal term, like a power of attorney or something like that. There can be safety plans for a variety of different things. I think safety plans are very important. For example, someone calls me and they say, I'm worried my child will be arrested. We need to look at why you're worried about why your child will be arrested. And we need to talk through what are you going to do to try to -- to do that. And so it's like an informal kind of safety discussion.

Within contexts of like domestic violence and other kinds of concerns about like sexual violence, for example, there are best practices for the kind of safety plan to create. That's not necessarily

what I was talking about, but I think that's part of safety planning and best practices. So, there's not one way of doing it.

**I think when I say safety plan, I'm meaning having a discussion about what really is the cause of what's going on and helping to support a person in trying to create the kinds of safeguards that Dr. Kripke was talking about.** You know, any legal tool we're talking about, be it a guardianship, representative payees, be it powers of attorney, supported decision-making, all of those can be abused by bad actors -- by those actors that people trust, who -- who -- who hurt someone. So you have to -- **all of those tools have to have safeguards built into them.**

And I think when we think about safety planning, that's also another kind of safeguard to be thinking about.

**Tauna Szymanski:** Okay. We haven't talked about special needs trusts. I know that's something that people put into place. In general, we don't use the term special needs anymore, but I think this has become a term of art in the legal field for these kinds of trusts.

And these are generally put into place to protect the person's ability to continue to receive benefits essentially. Is there anything about those mechanisms that sort of comes into play here that will help protect someone in whatever way, or is that just sort of a separate thing?

**Dana Lloyd:** This is Dana, and I definitely think that you can use, you know, trust and estate planning under this umbrella, right? I think that it's another -- it's another one of those things, though, that takes away some power and control, right? **Anyone who is receiving funds via a trust is not making all their decisions about how that money gets dispersed or how they have access to it or all those sorts of things.**

So I want to, you know -- I just keep want to -- **I keep wanting us to come back to that point to make sure that we're not creating a different monster, right?** So that people don't -- people aren't subjected to guardianship. But there's still all these other power-over dynamics. And so I just encourage people to try to -- this -- this goes to Morgan's point about safety planning, right? To ask the question. We talked about this a little bit last time in the -- with the practical tool from ACLU. **Let's presume that people don't need these restrictive things. They don't need guardianship. They don't need power of attorneys. They don't need trusts, right? Let's -- let's assume that -- let's start with that presumption.**

**And then ask the reason why we're having these conversations and what are the paths that would be available to you and me that will keep people in control of their lives?** And -- and then to keep working through that acronym, right? So then if that's not true what else is available? And what could we find in the community?

And then we get to the point of trying to weed out these restrictive things instead of just turning to them. **I would say that almost all of them, right, especially trusts, the power of attorney, advanced directive -- those things are better than guardianship, better than someone else being**

**able to make all your decisions in all circumstances. But I don't think -- I don't think that we should reach for them as a matter of course. I think we should still be really kind of digging in and interrogating why are we seeking these things? And -- and what's the recourse that would be available?**

So there's a question in the Q and A about someone making an unwise or perhaps more than unwise decision that's tied them to some sort of financial commitment over time. What would you do if that was a son or daughter without a disability, right? How would you try to work with that company to say, okay, how do we get out of this? What -- what can we do? Can we make smaller -- can we end the contract and make smaller period payments over time, right?

There's -- I read this in the [National Council on Disability report around guardianship](#) a couple of years back, right? That it's often only parents -- parents of children with disabilities that are able to intervene in those circumstances. And my daughter's 13, right? There's lots of things that she's excited about doing that I'm nervous about, right? Is -- is she ready for that? You know, an overnight, away from us sleepover. I'm nervous about that. I'm nervous about her turning 18 and going to college. But the work that I do now, right, is the training and support and the opportunities for her to make good decisions, because I'm not going to have a tool.

And I guess I could petition for guardianship, right? But that -- that pathway isn't created or isn't offered often to parents of children without disabilities to say: well, you're worried about all these unwise decisions that your child may make, or that they're not ready for adulthood. So here's how you can circumvent that.

I -- I'm not trying to discount that some of these things are real concerns. **Of course they're real concerns. But what are the tools that are available that don't -- that don't discriminate against people, right? What are the tools that we can use so that folks are able to learn the skills that they need? What are the opportunities we can create for safe failing?**

I -- I made some really unwise decisions, right? I probably could be -- my mom could be writing that in the chat about financial decisions I made at 18 or 19. I learned from them. That's -- that's what happens. **So, I think that we have to find that balance of what's learning, what's growing, and what's actual harm that we need to be working to prevent.**

**Tauna Szymanski:** Morgan put in the chat about considering ABLE accounts and those can make sense. And a lot of people have both, I think, but there are a lot of limitations to ABLE accounts, so they don't protect you, for instance, if you -- someone dies and it gives you a lot of money and then you're completely ineligible for any kind of benefits. So, I think that's one of the main reasons to do a trust, but it's true. It does take away control.

One --, I did want to talk a little bit more -- get into more detail of what Dana was getting into about how to prepare -- get -- you know, help someone develop some decision-making skills. But before we move on from the various agreements, I thought, in the educational context, several people have asked questions -- attendees -- about, you know -- here and in Jordyn's experience,

especially like parents being told: You -- you can't join this IEP team. You can't be part of the IEP process unless you have guardianship.

So -- so last session, Dana, I think you mentioned that a FERPA release is really all that a family might need. Someone else said, well, actually, if your -- your child is still your dependent, even after 18, you don't even need that. What's the answer here? Who wants to answer that?

**Dana Lloyd:** This is Dana and I can start and -- and toss to Morgan, if that makes sense. I mean the, oh, and I don't remember the acronym for FERPA but it's the federal education something private.

**Tauna Szymanski:** Yeah. Educational rights and privacy act, I think.

**Dana Lloyd:** Right. Which just gives people an opportunity to say, right? The same way we use HIPAA releases, that this is the person that I want to use -- for the school system to release information to.

And so, you know, I spend a lot of time encouraging parents that you don't have to be the experts on all these things. It's sometimes it's just a simple question of, well, school district, you are -- you are recommending "A" what else is there? Right? You're, you're recommending that we get guardianship to meet this need, but are there other alternatives to meet this need?

So starting again with that, just presumption that there's something else out there that would work. You know, I don't -- in-- in Georgia, when we run up against this, we do encourage people to talk to their school districts about getting that authorization. And, all the districts call it something a little bit different.

So, I'm not sure about the whole dependency thing and when that changes or if that changes in other states. But, I think the -- the blanket answer is know that there is an alternative. **Know that it isn't -- guardianship isn't the only way that you can continue to receive information and support children and students through their educational process after the age of 18.**

**Morgan Whitlatch:** This is Morgan. That was very well said, Dana. I think it's about knowing, you know, it's not -- it's not, it's about assuming that the information you're getting from schools or others that are saying somehow guardianship is the only answer, isn't the case. That there -- there are other options that may be available to facilitate access to information and to kind of de-weaponize what I frequently see used as a weapon against supported decision-making, namely HIPAA, which is the health privacy law, and FERPA, which is the educational privacy law. Those are very easy barriers to overcome, fairly -- you know, relatively easy barriers to overcome.

**Tauna Szymanski:** So that's -- that moves us into the health care context then. So HIPAA -- HIPAA release form. And is that something you would need with every provider or could you create like a blanket HIPAA release form that you just signed once that you can just carry with you?

I mean signing documents can be a huge barrier for people with, like, significant disabilities. So, I mean, just getting one in place, that would be really easy -- much preferable if you could set one that you could just bring around. I mean, is that possible? Clarissa?

**Clarissa Kripke:** Yeah. I mean, legally -- legally you can put this on any piece of paper.

You can say it verbally. You can -- HIPAA is actually very non-restrictive. But a lot of organizations -- health care organizations, medical centers, want stuff on their own forms and whatnot. But that isn't legally required. And -- and **I think you could make an ADA argument for -- for people to be able -- to be required to accept whatever form you've done it in.**

And -- and there isn't actually -- if -- if somebody is actively involved in the healthcare team, and the support team, and the care team, there -- there is no HIPAA -- HIPAA requirement. So, as a primary care doctor, I can call your specialist without HIPAA release. I can if -- if you're -- if you've -- if you're in the appointment with the patient and they haven't kicked you out -- nobody's kicked you out then -- that there's -- if you're actively engaged in it, there -- there isn't a -- a release. What you get into the biggest problems when you're working with low-level staff, who've been given -- given directives to be very rigid about -- about HIPAA because the institution, the medical center, the doctor's office doesn't want to get into trouble.

And so, often it's a matter of talking directly to your doctor or directly to someone with a little bit more authority than the person who answers the phone, who may not be authorized to make exceptions and -- and -- and work around the system. They want to make sure it's someone who really understands the law and their responsibilities and who isn't gonna mess it up.

**Tauna Szymanski:** Jordyn had a comment about financial stuff and bank accounts. Jordyn?

**Jordyn Zimmerman:** I personally have my own debit and credit card and I go over the payments almost monthly with my parents. Every time I purchase something, I am the one to get a text message. And I'm also the one to have access to my accounts. I have my own credit score that is probably better than my brother's. And, if you know me, that's good for our sibling rivalry.

**Tauna Szymanski:** Nice.

**Clarissa Kripke:** On that note, too, you can -- through CalABLE, at least -- there are credit cards that will allow you to -- and debit cards that will allow you to preload just a certain amount. So again, allowing people to make reasonable mistakes, so you can sort of put an allowance on their debit card without draining their entire account or, and the CalABLE one has the ability to restrict it to certain vendors or restrict certain vendors off of it.

So if there's -- if -- if you want the ability, you say, I have a problem with, you know, buying too many video games or something like that, and I need some help to -- to -- to manage that so I'm not making purchases that go over my budget because I really want to save up for something else. So, I want you to restrict how much I spend on, you know, any one thing. So that -- there are tools within



these things. Partly you can have an authorized representative, or a rep payee, or someone that helps you manage your finances, but you can also -- there -- there are a lot of digital tools now that will allow you to keep with your intentions around your money and protect you from spending too much on things that you didn't intend to spend them on.

So, and -- and I wanted to say you've emphasized special needs trusts too, Tauna. A special needs trust is -- is an important and a good tool. But it also gives a trustee control of your money instead of you. And -- and, in fact, you can't have any control of your money. And it also costs a fair amount of money to set up.

So it's own -- a full, special needs trust is -- only makes sense if you have probably half a million to a million, at least, in it. Otherwise it's -- it's gonna spend down your assets. But, there is something called a pooled trust, where -- for people who have fewer assets. Where they've set up a special needs trust -- a -- a general special needs trust where you can put a smaller amount of money into it that will be managed by a trustee who's managing that trust for a lot of different people.

So let's say you only have \$2,000 to put into the pooled trust. Then that money would be combined with other people's money. And -- and you could still access it. So you can get access to special needs trust through a pooled trust even if you don't have a lot of assets to -- to write your own document.

**Tauna Szymanski:** I'm going to go to Morgan next and I want to wrap up this section, cause I know there's a lot of interest. We got a lot of questions about terminating guardianships and I'm looking at the time. So, Morgan?

**Morgan Whitlatch:** I'm going to keep it really short. I just wanted to go back a little bit to the discussion about blanket HIPAA forms.

I think Dr. Kripke is absolutely correct. That accommodation -- accommodation requests can play into that, if people do have difficulty in submitting all those forms. That said there are restrictions within HIPAA about what -- about the bla -- about the blanketness of a HIPAA form. So you do want -- you may -- and you will see some pushback when it comes to that.

**Tauna Szymanski:** Okay. Good to know. So HIPAA forms, healthcare powers of attorney, healthcare decision-making agreements, asking for accommodations, and all that sort of thing. So, those are all tools that likely can accomplish all the same goals that someone might want to achieve in lieu of a more restrictive option like guardianship.

So -- so I think we had sort of set aside some time today to talk, really, about some of the steps -- to talk about how to support and set someone up to live without being subject to guardianship and all those best practices. And, you know, there was a comment that it seems like parental support matters a lot here.

And John talked about, in some of the stuff we shared last time, you know, and, Joan talked about spending months and months and months with John working on -- on getting practice in making major decisions and -- and going through, you know -- going through and setting up his plan for decision-making in the future.

And Clarissa will post something else that her office has developed about helping -- [helping folks develop self-direction skills as another tool](#). And I guess one thought I had is -- is -- does it make sense for -- for parents of younger folks especially to think about integrating goals in IEPs, for instance, that are focused on building decision-making skills?

I mean, is that a tip that everyone really should be doing, even before the, you know, transition age of 14 when things start down that process? But really from the first pre-K IEP, really? Like, how do we make decisions and let's respect decisions and that sort of thing? I mean, is that -- does that -- is that best practice -- does that make a lot of sense to do -- to set someone up for this? And how do you say no? And how do you determine -- how do you consent to things and that sort of thing? So ...

**Morgan Whitlatch:** This is Morgan. Yes. That makes absolute sense. Well said, Tauna. You know, I think frequently we talk about decision-making rights when somebody's are approaching 18 or they hit what's considered transition age and that's -- you know, I really encourage people to -- **you need to be thinking about building decision making skills over time, as early as possible.**

And I think that -- that takes a lot -- that can take a lot of advocacy, **thinking creatively about how you kind of build a diverse diet of different kinds of decision-making skills.** Cause sometimes I see people have like a choice goal and an IEP that's something like -- you know -- or other plan like, you know, I'll pick what color shirt I wear today or, it'll -- and that'll be the same goal for years.

And that's not what I'm talking about here. I'm talking about kind of building the skills and incorporating it into a really -- a growing of the trajectory of the skillset of the person. And there's some good models on [supporteddecisionmaking.org](#) about how to do that.

**Tauna Szymanski:** And I think one thing I'd just counsel, folks to do is -- you know, **bring your child, if you're a parent, to their IEP meetings beginning as early as possible -- at age 10, you know? They should be making -- they should be part of this planning, right, for their IEPs and determining what the goals are. So that -- just get -- having some control as early as possible over just their education, I'd say, I think is invaluable.**

So let's move on to terminating guardianships and I guess one intermediate question is: is it possible to make -- so we have a lot of folks who are interested in these webinars who have already established guardianships over themselves or their children who are interested in seeing what can be done to make that less restrictive, to restore some of their rights.

Apart from terminating a guardianship and restoring full rights, I guess, is there a way to make existing guardianships and conservatorships less restrictive? Is that possible? Like, could you

convert a general guardianship to a limited one? Is that even worth it? Is it possible in all states, or -- like, what would you say to that?

**Morgan Whitlatch:** This is Morgan. So it is possible to seek partial restoration of rights. It's going to depend upon state law, how partial it is and the willingness to convince the judge why it needs to be so partial. So you're going to deal with some of the same barriers that you may deal with in trying to get a guardianship terminated completely. And I'm just being very kind of frank with that.

I think in terms of -- **if you think about the guardianship relationship itself, there are certainly ways to bring in certain kinds of supported decision-making principles into that, to try to help the person build the capacity over time, to be able to demonstrate to a judge that full guardianship or conservatorship is not needed.**

And I think, you know, there are -- there are solid stories about how to do that. But it -- you know, it's not like an all or nothing with guardianship, technically, under the law, in the sense that you can get it to be narrower rather than completely terminated, but it can be difficult. That's what I would say.

**Tauna Szymanski:** Okay. I want to share my screen here and show this video of John talking about starting the process of terminating his -- oh. Alright. Good. Can you all see that?

**John McCarty:** After petitioning probate court to terminate my guardianship an evaluator came to my home. The last phase was an appearance in court where I testified on my own behalf and it was determined I no longer needed a guardian. My rights were fully restored.

There is no way to describe the emotional effects of having my rights restored. If I could, I would scream it from the mountains. Getting out from under guardianship and having control over my life is a dream I've had since the first day in court.

**Tauna Szymanski:** Okay. So in that short clip, you heard John talk a little bit about, just at a high level, the process of terminating and of course, how it made him feel. And that video is available on his [website](#), which we shared earlier. So, I don't know, Dana or Joan or whoever, what -- I guess, one -- well, one question we got from an audience member was: Can the fact that a parent was coerced into getting a guardianship under like false pretenses, like they were told by the school or by someone else that they had to do this is -- could that make the process of terminating a guardianship easier?

**Joan McCarty:** So on this ...

**Dana Lloyd:** So this is Dana.

**Joan McCarty:** Go ahead, Dana.

**Dana Lloyd:** And I'll try to go quick so Joan can answer too. I think that having the current guardian support restoration is always helpful, right? Regardless of the reason why they're supporting

restoration, I think that's always helpful. So -- and then I think that in general, what I tell people when I have to do this quickly is that **the process for restoration -- and this is again, mostly -- this isn't -- this is my experience in Georgia and Virginia, the other state I've done this in, is the same as the process for petitioning to get guardianship.** Right? You file a petition, there's an evaluation. There's a hearing. It's -- it follows the same course. It's just, the question is different. That might also get to the question about finances, that, for most people, it was the same financial cost, right? Because you're going through those same processes.

**For most people it is difficult. You're asking a court to, in some ways reverse itself, right? And the burden of proof has shifted from someone making the case that a person needs a guardian to now that person being required to prove that they are -- and this is the Georgia statute -- able to make and communicate reasonable, safe decisions about themselves, right? The -- the -- the onus is on the person with a disability now.**

And so I've supported people like John who've been successful in that process and I've supported people who have petitioned every opportunity the law allows over several years and haven't -- several, maybe not quite decades, but 15, 16 years. **And haven't been able to make that -- to make that case, right? With tons of support that, you know, the -- the court just isn't willing to make that determination.**

**So, yes. It is difficult. And that -- that would be the thing to consider.**

**Tauna Szymanski:** And we've had several questions about what my child or someone I know has just recently gained access to AAC as an adult. They've already been conserved. So, that would be an instance where it seems like -- like in John's case and it might be easier to -- to terminate the -- the guardianship.

There was a specific question in the Q and A about being conserved by the state but now being able -- newly able to communicate with AAC. Any different advice in that instance? It could be --

**Dana Lloyd:** I think we hit on this really briefly last time that **anytime there's a material change in circumstances, right? That something has happened to show that life is really, really different, then that's helpful. It is not always a slam dunk, right? It's not always a home run. But those are things that help, right? Guardians being supportive, material change in circumstances, a plan to answer some of the questions.**

**So for some people there hasn't been a material change in circumstances, but we now have a plan for how all these things get addressed. And we can show that we've been successful with that without the support of a guardian or kind of with the guardian, maybe perhaps removing themselves a bit from this, right? So those are all things that help the case for people to be able to seek restoration and be successful.**

**Morgan Whitlatch:** And while -- excuse me, this is Morgan. While it's not fair, frequently expert evidence is required. Like, in the form of a psychologist or other kind of medical professional. A

person that's considered by the court to have the right credentials behind -- you know, by their name to actually be successful in making that case.

I would like to say that piece too. It can be, you know, resource-intensive to get restoration of rights in certain contexts.

**Joan McCarty:** Okay and I'm going to follow on what -- this is, Joan -- what Morgan just said and what Julie -- Julie Kegley, who is John's attorney over at GAO who helped him get his rights restored.

Julie's point is -- is that our expert has to have better credentials than their expert. And so when we were having -- John had a court-ordered evaluation for both, and it was a social worker. And so our expert was a psychiatrist because he had better credentials. And that's one of Julie's strategies. Like your -- your -- your expert ought to be better than their expert.

**Tauna Szymanski:** All right. I think we are nearing time and we still have so many other questions that weren't addressed. But I think what we may try to do is do a revised handout and address some of the questions in that, and add some of the additional resources that we -- that we mentioned today and included the chat.

We also will be circulating another [survey](#) to those of you who attended. Thank you so much for the amazing feedback last time. It was very helpful.

And thank you to all the amazing panelists today and for joining us again for this second event.

It looks like Dana's posted the survey in the chat but we'll also send a follow-up email probably within the next 24 hours with that and with the handout. Thank you, again, everyone for attending and for the interpreters and captioners.

We look forward to seeing you again in a future webinar. Thank you so much.