



# CommunicationFIRST

Because communication is a human right.

## Guardianships for AAC Users?

Zoom Webinar (Part 1)

July 13, 2021; 3:00-4:30 pm ET

### TRANSCRIPT



[TAUNA SZYMANSKI] Welcome, everyone, to CommunicationFIRST's panel discussion on the question of guardianships and AAC users. My name is Tauna Szymanski and I am 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.

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

Before I introduce our panelists and kick things off, I want to go over some housekeeping details. We are recording this session. This is a Zoom webinar, not a Zoom meeting, so unless you are a panelist, we won't be able to see or hear you. Attendee names and images will not be visible on the recording or to anyone except the hosts of the webinar unless you post a question in the Q&A box.

We are also providing ASL interpretation and live captioning for anyone who can benefit.

If the live captioning does not appear automatically, please go to the bottom of your screen and click on the Closed Captions button. If you prefer the captions to show up in a separate window, rather than on the video screen, you can select “pop out” and separate the screen to make it into a separate screen.

Many of you submitted questions in advance when you registered. We will try to get to all those questions and more. If any other questions about guardianship and conservatorship and their alternatives occur to you, you can submit them by clicking on the Q&A button on the bottom of your screen and then typing them in. The questions will only be visible to the panelists until we type a formal answer and post it. If you prefer to keep your question anonymous, please let us know when you type your question. There will not be any PowerPoint slides today, but we will be sending a handout with resource links to all who registered after the webinar.

So now to provide some background and to set the stage for today’s discussion on this important topic.

Guardianships and conservatorships are legal tools that are frequently used in the name of protecting people who cannot rely on speech to be heard and understood.

Britney Spears’ recent advocacy to end her conservatorship has brought to the public’s attention the downsides of conservatorships and guardianships. But parents of people who cannot speak are regularly told guardianship is necessary. Why is that? And is it? Are there any benefits to guardianships for AAC users -- for people who rely on augmentative and alternative communication? What are the harms? What are the alternatives?

CommunicationFIRST is the only disability-led nonprofit organization dedicated to protecting the rights and advancing the interests of the estimated 5 million people in the United States who cannot rely on speech to be heard and understood. More so than any other population in the United States, we believe that people who cannot rely on speech to be heard and understood are subjected to guardianships and conservatorships. We’ve been meaning to host a webinar like this for a long time, to feature the first full-time AAC user we are aware of who successfully terminated a guardianship, John McCarty. The attention Britney Spears has brought to this issue in recent months finally prompted us to get moving on this.

And this is very timely as it turns out, because just yesterday, CommunicationFIRST joined 25 other disability and civil rights groups in filing an amicus brief led by the ACLU in Ms. Spears’ case in California court. In the brief, we urge the court to allow Ms. Spears to choose her own attorney to represent her in her conservatorship proceedings. Choosing your own attorney is such a basic fundamental right, and it’s one of the rights you can lose if you become subject to a guardianship or conservatorship, as Britney was. We hope to spend a few minutes during today’s discussion discussing the similarities and differences between this case and what most AAC users experience in relation to guardianship.

I want to remind our panelists and attendees that CommunicationFIRST is a cross-disability organization. We represent anyone who cannot rely on speech to be heard and understood, including people who are born without the ability as well as those who acquire speech loss later in life due to stroke, Parkinson's, ALS, or other conditions. It is a diverse population in terms of life experience, but virtually everyone who cannot rely on speech to be understood faces low expectations and diminished opportunities and discrimination. We do not have data on this, but we would not be surprised to learn that most of the people subject to guardianships and conservatorships in this country are people who cannot rely on speech to be understood, or AAC users.

This webinar will be just an initial discussion. I will serve as a moderator and will ask all the questions that we regularly hear about guardianships, typically from family members. This will be a casual conversation, and none of the presenters are using slides. After the webinar, we will email a short handout with some definitions and resources and panelist contact information to everyone who registered.

So now we are pleased to be joined by an amazing panel of discussants today. We have CommunicationFIRST Board Member and resident of southern California, Tim Jin. We have Dana Lloyd, Program Director with the Georgia Advocacy Office in Atlanta. We have Joan McCarty, the mother and former guardian of John McCarty, based in Atlanta. We have Morgan Whitlatch, Legal Director, Quality Trust for Individuals with Disabilities and also the Lead Project Director for the National Resource Center for Supported Decision-Making. And I am hoping that my colleague Bob Williams, CommunicationFIRST's Policy Director, will chime in, along with the Vice Chair of our Board, Clarissa Kripke, who is a medical doctor and Clinical Professor of Family and Community Medicine at the University of California, San Francisco.

John McCarty as I noted was the inspiration for this program. Unfortunately, John cannot be here today because he is ill, but we fortunately have his permission to share some video clips of him presenting on this topic in the past.

We have a very good mix of attendees today: full-time AAC users, family members of full-time AAC users, educators, professional service providers, attorneys, advocates, professional guardians and conservators, and friends. And many of the attendees identify with several of those categories.

**Our goals for this session are for our audience to take away a better sense of what guardianships and conservatorships really mean for AAC users, to learn under what circumstances they may be desirable or necessary, to learn what the alternatives to guardianship might be and what that looks like for someone who needs extensive communication supports, and to hear real world examples of AAC users with different types of disabilities who have successfully experienced life without a guardianship.**

Finally, we know this can be a painful and uncomfortable topic and we want everyone to know that there is the risk that some of what we hear today might be challenging. We

want people to feel brave in asking honest questions and we will try to keep a welcoming tone for folks to speak their truths. This will also be a casual discussion for a very diverse audience and we will try as much as possible to avoid legal terminology.

I am going to turn it over now to CommunicationFIRST Board member Tim Jin to make some introductory remarks. Tim is a full-time AAC user in his 40s who lives in southern California. He has never been subject to a conservatorship.

And just a quick reminder to all of our panelists: Please say your name so people with vision impairments will be able to associate the name with the voice, identify your pronouns, and give the audience a visual description of yourself the first time you speak. Tim?

**[TIM JIN]** Thank you, Tauna, for the introduction. As you already heard, my name is Tim and I live in California and I have cerebral palsy. I've been using an augmentative and alternative communication device for my entire life and I'm somewhere in the middle of my fourth decade.

Here is the best way to describe myself: I'm a mid-40s-year-old Korean-American man who has cerebral palsy. I am using a communication device at the base of my wheelchair, by typing with my toes. My pronouns are he and him, but if you ask my friends, they have other pronouns for me that are not so appropriate to mention in this session.

I'm 46, if anybody is wondering, and I'm not using a 4K camera, because I want to hide away my sun spots.

I would like to give you a very quick overview of my AAC needs, and how I always make sure to get my voice heard in a medical setting, like at doctor's appointments.

It will take me too long to go through all of the communication devices that I've had in the past. Not to go into great detail of my communication needs, but I first learned how to type with my toes on a manual typewriter when I was in elementary school. After that, I have had numerous devices that I've used to communicate.

I don't use supported decision-making. **My parents never thought about conserving me.** They have always questioned who I'm currently dating at the time and I need better decision-making in that portion of my life, but I've always liked having variety. In some ways, this is not a joke within my family circle, but I'm laughing with you now.

My doctors always know that I communicate through an AAC device. They are fully aware that I am capable of communicating with them in person, email, or on the phone through TTY Relay and even texts. They understand that I only have cerebral palsy and many of my doctors have gotten to know me so well that we have become friends outside of their offices.

There are times when their staff reminds them that they have other patients waiting, but regardless of who is waiting in the next room, my doctors have always given me as much time as I need to let them know what is going on and why I am seeing them.

Before I go to my appointment, I always type out what is bothering me and print it out and hand it to my doctors so that they will know why I'm seeing them. Also, they keep a copy in my file for their records to make sure that I'm getting the proper medication and not coming back with the same illness every time. My doctor wishes that all of their patients would do this because there wouldn't be any communication barriers at properly diagnosing someone.

When I need to get a referral, my doctor always lets their colleagues know that I am fully capable of understanding and conversing with them and they need to give me time. This is a huge benefit for all.

Whenever I am seeing a new doctor, there is always a misunderstanding about how to communicate with me no matter how much my primary care physician instructs their office.

There is always a communication barrier no matter how much forethought we do prior to the first visit. There are times where I get dismissed and mistreated, but I always get my point across.

My family never thought about conserving me and why should they, because I'm fully capable of handling things on my own and I have excellent credit too. Just because I'm disabled, it doesn't mean that I can't function on my own.

**My parents don't have power of attorney on anything, surely not my bank account. I'm going through the process of setting up a Durable Health Care Power of Attorney with my brothers, letting them know my wishes.**

The thought about conserving me never crossed my parents' mind because they saw me no differently than my able-bodied brothers. My parents gave me free will and I learned from my mistakes. My mom and dad understood that they didn't want control of my life or nor the court system.

**I understand that guardianship is something that most families have to face because who doesn't want your adult child to be safe. When a person is being conserved, they have fewer rights than somebody that is in prison.**

**I've been living on my own with the assistance from my staff for over 20 years. I have the ability to pay my bills, plan my vacations, and whatever else. No one has control over me.**

**I know many people who are in the similar situation like myself, but they have a developmental disability and they get help from others in their circle to live their lives how they want to and they don't need guardianship whatsoever.**

This afternoon, you will hear from parents, legal experts, and other professionals that are far better than me, but as a person with a pronounced disability, guardianship is not the answer. **There are so many different options to maintain the safety of your loved ones.**

I only call my mom and dad to ask them what I should bring to family dinners and like a typical mom, she always tells me to wear something nice because everyone is going to be at the house.

People tend to look at the disabled community as if we were plants in small pots that just need water to grow. But we also need the sun to shine, and space to spread out our branches. And we also need to prune every so often to grow our best.

Thank you for listening to me this afternoon.

[TAUNA SZYMANSKI] Thank you, Tim, so much. Before we open it up for a bit of discussion with the other panelists, I thought it might make sense for us to make sure we are all on the same page with some key terms.

I don't know who the best person is for this, maybe either Dana or Morgan maybe? First, can we **start by defining these terms, "guardianship" and "conservatorship"**? And what's the difference between those two terms, those two things, for instance? Morgan?

[MORGAN WHITLATCH] Sure. So, you know, states have different laws and procedures regarding guardianship and conservatorship. Some states use the term "guardian," others use "conservator," and still others have other state-specific kinds of terms to refer to these concepts. Some states separate guardianship into two categories, one for the person's finances, typically called like a "guardian of the property," "guardian of the estate" or a conservator, and one for everything else like personal decisions, "guardian of the person." I think we've heard a lot about Britney Spears' case recently. California uses conservatorship to refer to a lot -- all the different kinds of, kinds of arrangements.

But really what we're talking about here is it's a court involvement. So the court believes the person cannot make certain choices for themselves, and they appoint somebody -- they are called a guardian or conservator -- to make those decisions for the person. And with your resource -- resources you're going to get after the webinar, you'll get some definitions. But right now we're really, when we talk about guardianship and conservatorship, we're talking about that kind of court intervention.

Dana, did you want to add anything?

[DANA LLOYD] No, I think that was a good summary.

[TAUNA SZYMANSKI] So we also hear two terms a lot that have the initials S and D. And I know sometimes my head when I'm not focused very well, I'll just mix them up in my head, but we'll be using probably both of these terms today. **And so one is "supported decision-making" and one is "self-determination." What do those mean? What are the differences?**

[MORGAN WHITLATCH] Well -- go ahead, Dana.

[DANA LLOYD] I think I can take a stab at that. I'll do my visual description now as well. So, I'm Dana Lloyd. I'm an African-American woman, got short black hair, it's kind of like curly wavy. I'm wearing some glasses and a blue and orange top.

So, I think the way I try to remember these things, is that **self-determination is the goal -- self-determination being the ability to direct your own life.**

We often use the analogy of being in the driver's seat of your own life.

Self-determination is what, you know, we all want to experience, being able to make choices, have those choices be acknowledged by other people. Have other people kind of you know, support us to accomplish those sorts of things. **But self-determination is the goal and supported decision-making might be one of the ways that you get there, one of the things that you might do to support your self-determination.**

And so, as a definition, we kind of use the -- it's a mashup of lots of people's work, right? But this idea that **supported decision-making is kind of the arrangements and agreements and services and supports that you might use to understand the options that are available to you, get information in a way that works for you, communicate those wishes to others.**

**And you might use a variety of people to do that: family, friends, other professionals.**

This is, this is a phrase I steal from Morgan all the time, right? **It's human decision-making.** The way that if I'm going to buy a house, I'm probably going to do a little bit of my own research. I'm going to consult with a realtor. I'm going to talk to my friends and family.

But ultimately, I'm the person that's going to decide which house it is that I'm buying and what town I'm going to live in. And so, yeah, those are, those are how I define those terms. I'm happy to have colleagues jump in.

[MORGAN WHITLATCH] This is Morgan Whitlatch. I'm a white woman with red, brownish hair, a little too much gray than I would like, curly hair, wearing a black blouse and a suit jacket and earrings and glasses.

I think that was the perfect definition. I kind of call it the curse of too many SDMs, because there are, in addition to supported decision-making being called SDM, and self-determination, which is you know, the SD, you also have other concepts I think that sometimes get confused with supported decision-making because they also have the acronym SDM and I thought this would be a good opportunity just to kind of clear that up too.

Sometimes you might hear the phrase "substitute decision-making," and that is different than supported decision-making. **Substitute decision-making means that someone else is**

**making a decision for a person. While supported decision-making is the person using their support network but making their own decision for themselves.**

I also heard terms with another SDM called “**shared decision-making.**” I hear this a lot in the medical context and it’s very different as well. It’s really about reaching consensus to reach a decision, rather than, in supported decision-making, a person could disagree with their supporters and make their decisions themselves, **shared decision-making is more of a consensus-based model.**

So, I also wanted to kind of clear that up too, because I do know there is a curse of too many SDMs.

**[TAUNA SZYMANSKI]** Thank you. That’s helpful. And I don’t want to get too far in the weeds here but, the whole idea I guess with these -- with guardianships and conservatorships -- is that they are put in place when the person with the disability is assumed to lack “capacity” in some way. That’s the term that’s often used. They are “incapacitated” or they “lack capacity.” Just in a -- to make that just simplified, plain language, what does “capacity” mean? And what does “incapacitated” mean? Is there a shorthand way to talk about that?

**[MORGAN WHITLATCH]** This is Morgan. So, you know, capacity or incapacity is going to be defined specifically by whatever state law that is in there, but usually what you’re talking about is the ability to perform a certain kind of task.

So, the legal ability, for example, to perform an act like signing a contract is a form of capacity. **Capacity, though, must be seen as a kind of fluid kind of concept that ebbs and flows and can grow over time. And when we talk about legal capacity, I think too frequently, we think about capacity as being a static thing: You either have it, or you don’t. And that’s not really how capacity works.**

We also are seeing within the kind of, you know, civil rights movement, **a desire to move away from terms like capacity or incapacitated,** because it is becoming more of a kind of controversial term and we’re seeing model laws in the guardianship context, the most recent model law doesn’t even use the word capacity in it, even though it’s referring to guardianship.

Now, states haven’t gone that route. We only have two states that have passed that model law. So, you’re going to hear terms like “incapacity” and “capacity” within this context. But I think **the goal really is to move towards a more kind of functional model to look at what people can do with supports as opposed to basing capacity on things like diagnosis or IQ scores.**

**[DANA LLOYD]** I think the only thing I’ll add there -- I feel like I have this conversation with folks often -- is that, within the context of your, your state or your state law, you need to be clear on who can make this determination of incapacity, right? So, we’ll sometimes



get, you know, family members or even support coordinators or case managers calling us and saying, well, the doctor says they can't make decisions.

**Well, a doctor or a hospital system in and of themselves isn't the, isn't the mechanism by which, at least in Georgia, a person is declared to lack capacity. Or the school system said they don't think they can make decisions.** And so, I think there are times that, family members or people themselves are kind of facing this, you know, **unjust way of people kind of determining their capacity. It's clearly a legal process and it may differ from state to state.** But it's a legal process that has to happen that someone's capacity is being judged.

[TAUNA SZYMANSKI] Tim?

[CLARISSA KRIPKE] We have a question for you in the chat. Are you aware of any statutory supported decision-making --

[TIM JIN] Let's talk about the five principles of self-determination. The first one is always my favorite and should be for everyone. Freedom, freedom to do whatever you want and when you want. Freedom to live on your own if you choose to, or have a roommate, if you feel lonely. The freedom of who you want to support you in your life and who you want to be your friends and family. Everyone has the same rights like everyone else.

For example, let's say I don't like any of my caregivers and my next-door neighbor is a better choice for me. I could hire my neighbor to help me with no problem. If they passed a background check, I am no longer bound to an agency. That was my comment.

[TAUNA SZYMANSKI] Thank you, Tim. Clarissa, on the comment you were about to read, I think let's save that for when we get to that section of the discussion, if that's alright.

Before we move away from defining terms, I want to define a concept, I guess, related to the topic, which is -- we called this webinar "Guardianships for AAC Users?" With a question mark.

And I guess one question that might have arisen in people's minds is, what do we mean by AAC users in this context? So, CommunicationFIRST represents anyone who cannot rely on speech to be heard and understood. And that includes people who have not yet been given access to robust, language-based AAC, but may communicate with their gestures or eye gaze or shoulders or whatever, and we include that in the definition of -- the broad definition of -- AAC.

So, I guess just a sort of threshold question is, is there any practical difference when you're trying to determine, you know, capacity or whether someone can make a decision? **Is there any difference between the ability to make a decision and the ability to communicate the decision that you've made?**

And we don't have to answer that right now. But, I guess, is there a simple way to answer that? And because I think that probably folks in our audience are wondering, does this

apply to my cousin who has never been given access to the alphabet to communicate? Or is this only for people like Tim and Bob and John who have been given access to robust language-based AAC?

[DANA LLOYD] So this is Dana and I'll, I'll make it quick and say practically, I think it happens, but I don't think that it should, right? **I think people are judged all the time on their ability to communicate, which has little to do with whether or not you're actually able to make a decision. But for sure, it's a barrier, for sure, we, it's a, it's a harder fight when we're standing beside someone who doesn't have access to good communication.**

And there may be people around them who, you know, are really clear on how they communicate and how we know, you know, what Sally likes or what works for Johnny. But when we get into a legal context, having the proof of that can be problematic. But on its face, like when I'm standing beside people, that's not what I'm looking for, right? **I believe that we all have the ability to communicate. We all have capacity to make and express decisions. And -- and when -- and as a professional, I feel like the burden's on me to figure that out, right? Not -- not on the person with the disability, but it's -- it's on me to figure it out.**

And so, when we don't figure it out, as professionals, that's a challenge for people. **But I don't think it has to be a prerequisite, but it can be a barrier for sure.**

[TAUNA SZYMANSKI] Okay, excellent. So, we thought it might make sense to spend just a couple of minutes on sort of the historic, **the history, I guess of guardianships and conservatorships.** It's -- I don't know if this is true, but it seems at least in the public eye that the use of these mechanisms has really increased a lot in the last couple of decades. If that's true, why? Why is that? Morgan, do you want to spend a couple minutes on that, or - ?

[MORGAN WHITLATCH] Sure. So, you know, Dana can share some of the statistics, but it's right that there has been a dramatic increase in guardianships. The first thing is that we don't have great guardianship data nationally, in part because it's dependent upon separate state systems that some states don't even know how many guardianships even exist within their states. But there have been some estimates that Dana can talk a little bit about that really do show a dramatic increase in guardianship.

**In 2018, the National Council on Disability published a report called "[Beyond Guardianship](#)" that kind of put the guardianship context within a civil rights framework, really looking at it historically within the civil rights movement of disability rights. And I really encourage people to look at that particular resource too in thinking through how guardianship can impact people, because it really provided this overview and context for what guardianship means to people by looking at like beginning in the eugenics movement and people not having certain rights over their own bodies, depending upon what they were, quote-unquote, classified as, to institutionalization and then**

**deinstitutionalization, and then looking at the emergence of certain kinds of federal civil rights laws, like the Rehabilitation Act and the Americans with Disabilities Act.**

And they looked at guardianship and you know, guardianship has been the game in town, for centuries, basically. I mean, noting, it goes back all the way to ancient roots, like Roman law and then British common law. And it's how entrenched and constant it's been within our legal traditions, really steeped in a kind of a paternalism and ableism type of approach. And guardianship laws remained unchanged for -- for centuries.

And it really wasn't until you saw a real first wave of significant guardianship reform at the state level occurring in the late 1980s and early 1990s. So that's not that long ago where you actually saw people looking at due process rights, you saw states reforming their laws. And -- and so when you think about what we're talking about in terms of a culture shift in trying to incorporate notions of self-determination within this, in terms of due process rights, in terms of promoting ideas like supported decision-making, **no wonder it's so hard, no wonder it takes so much work, because we're really dealing with this kind of entrenched history of relying on guardianship.**

**I think we're seeing an increase in the number of guardianships for a variety of different reasons.** I think it's been linked to things like deinstitutionalization. It's been linked to aging populations and the way in which people are supported and a reliance on what has always been known, namely, going to court and getting guardianship to support people, rather than recognizing more -- kind of a movement towards community integration, aging in place, supporting people in the community.

Dana, can you add?

**[DANA LLOYD]** Yeah, I think, you know, the -- the two kind of factoids that stick out to me are that **since the late eighties, early nineties around the signing of the ADA, the number of guardianships in this country have tripled**, right? Even -- even given what Morgan is saying, that we don't have good data, the data that we have is showing this kind of trend towards guardianship.

And then one of the things that's been especially important to our work is that, in that, in that trending -- and so let me, let me even put it into more of a perspective. **We think it was about 500,000, so we're up to like 1.5 million**, right?

So -- and that number continues to grow. But within that trend, within that subset of people, we're also seeing **the fastest changing rate of new guardianships are for young adults with developmental disabilities between the ages of 18 and 24**. So the fastest number of new petitions that are being filed.

And so there seems to be this kind of correlation between, you know, developmental disability and guardianship, that wasn't always as prevalent, right? That we saw a guardianship -- adult guardianship -- show up more, you know, as folks had changes in their life where they -- their decision-making capacity was impacted.

But there seems to be this roteness to it now, around folks kind of reaching the age of majority and people seeking out guardianship. And so, we've just, you know -- I think we're at the point where, where we're noticing trends, right? We haven't been able to answer all those questions around why this is, but we can definitely highlight the trends.

[TAUNA SZYMANSKI] Yeah, Tim?

[TIM JIN] Also, I know that guardianship is a hot topic for most families, but **most children will outlive their parents' lives and what will happen then to them?** I would like Joan to join into a story about her son and how he got out of guardianship.

[TAUNA SZYMANSKI] Oh, are you asking ... sorry. Are you asking Joan to start her story? Yeah. Yeah. We're going to get to that in a second before we, and that's next. The first thing I want to just cover though, is like to just push both Dana and Morgan a little bit on the rationales, right? So we're seeing these trends of vastly increased rates of guardianship, particularly among folks with developmental disabilities.

**What are, I mean, the, what are those rationales and then are there any benefits?** So, we get questions all the time, or assumptions. **Do you need to have a guardianship to review your child's records, right? Your adult child's records. Do you need them, do you need a guardianship to be in an IEP meeting or other planning meetings and medical appointments?**

**Can guardianships be used to protect your child from abuse? Can they be used to protect your child from being taken advantage of, like from signing a contract or a lease that cheats them or takes away their money, for instance? Can guardianships be used to prevent your adult child from being arrested or charged with a crime?**

So, I think the perception among families is that the answer to these questions is "yes." And -- and maybe even among schools, my understanding is that **schools do a lot of this pressuring -- and maybe even medical doctors -- telling families that this is all you need to have a guardianship in place because, for all these reasons.** So, are -- is that -- are there other reasons?

So, Joan, maybe you're a good person to sort of talk about -- about what families sort of experience when their kids are approaching 18. And whether what they're told is necessary or is the best thing to do to protect their adult children.

[JOAN MCCARTY] All right. So yeah, certainly I can talk about that and thanks, Tim, for making sure that Tauna didn't forget I was here. [Laughter.]

I'm Joan McCarty and I'm a white, aging woman with a thin face. And I have brown hair and I'm wearing a blue shirt, and I think that's all I'm supposed to say. Oh, my pronouns are she and her.

You know, the first thing that you just touched on, Tauna, is what my husband and I experienced. And I think my experience knowing a lot of other families who have people

with disabilities is that as our kids -- 'cause they are kids at the time -- start to hit the age of 18, everyone starts to talk about it. Now, my son John wasn't in school, but certainly we knew people in school **and the school systems were pushing for that.**

**And schools will say to parents, well, when he's 18, you won't be able to come into his IEP meeting if you don't have -- people -- that -- that's what they hear. So that's not true of course, but that is what families hear. John's pediatrician was very much a proponent of and pushing the fact that he thought John needed guardianship.**

You know, I think -- **I think a lot of it comes down to the low expectations, particularly for people with developmental disabilities, that's prevalent in the school systems.** No one in the school systems -- I shouldn't say no one because there probably are some educators on here who are trying to educate themselves. And there are probably some very good educators out there, but schools seem to focus most on what our people with disabilities cannot do. And they don't focus on what our people with disabilities can do and so what they miss is all the hidden talents and skills.

And so, it has become rote, Dana, and it's become rote because -- hey, he's -- he's not going to be able to -- it's an assumption that's made, and it's made from the time that kid gets into quote-unquote special education when he's in kindergarten.

So, you know, my story begins where maybe the parents who are on this call, you know, maybe your story begins the same way. But we, you know, we didn't know if John should be under guardianship. We really didn't know after all the stuff we were hearing from people that we knew who had their kids under guardianship and the pediatrician.

And so, we were worried. We did not think -- because John needs a lot of physical support day-to-day, he needs 24/7 -- we did not think that anyone would force him into marriage, or take what little money he had, you know, with benefits or, you know, we -- **we were afraid that there would be a medical emergency and we get to an emergency room and we wouldn't be able to make decisions about his care.**

And -- and we were afraid of that. And so, we thought, well, we're going to hire -- we're going to go to an attorney and ask him. And, the attorney that we used for our will and John's special needs trust said, yeah, I don't do that kind of work, but here's the guy who does. He's very prominent here in Atlanta.

He does -- that's his -- that's his thing. So, we met with him, and we asked him the question about how, you know, using the scenario about John and the medical situation, how would that work? **And what he told us was that if John could not communicate broadly to everyone, he had to be under guardianship.**

**Now I'm going to interject right now that that's not true.** And I found that out when my son started working with Dana at the Georgia Advocacy Office. That there's a statute here in Georgia that is called the Medical Consent Statute. And it doesn't matter why you can't

communicate, but if you get to the hospital and you can't communicate, someone can communicate for you.

And it goes -- there's like hierarchy. We didn't know this. We were ignorant. We were totally ignorant. **And, we didn't do the research we should have done so kudos to everyone who's out there as a parent who's actually listening to me.** I don't mean to ramble on, but [clearing throat] yeah.

**I'm ashamed to say -- I'm ashamed to say that without considering the broader implications of what guardianship might mean to my young adult, we became his guardians.**

And I say, I am ashamed because I have always believed in full integration. My son is going to be fully integrated in his community. He is going to be fully included in his community. **I don't have any idea how, in my mind, I reconciled the fact that you could be under guardianship and fully included and fully integrated, because that's simply not true.**

**If you are under guardianship, you don't have your rights and you can't be part of your community if you don't have all your civil and human rights.** You're not part of your community. I mean, that is, that's a, that's a fact. So, I hadn't considered all of those -- those implications.

And, you know, I'm going to say that people who -- only a self-determined people or people with disabilities fully integrated in their communities and only -- and self-determined people make their decisions and decision-making is a process. And the thing that underlies all of self-determination for that person is that you have to presume that they are competent.

You have to know whether they have a developmental disability or not, whether they can communicate or not, you know, that they're there. And you know, that they have hopes and dreams and they have hopes and dreams just like everyone else.

They're not "special needs." There's no -- no such thing as that. All people need the same things and that, you know, you could start with Maslov's hierarchy of needs, but we all need friendship. We all need -- we need more than just food, clothing, shelter, safety. And so, people with disabilities, people with developmental disabilities, also, they have hopes and dreams. So, you make your decisions about what your dreams are when you're making your decision.

You fully define what that potential is. You define your potential based on your own dream. **I don't define my son's potential. My son can't speak, but he's a, but he makes a living presenting,** you know? He's a consultant. So, But, you know, that's not what I would have gone with first. Right? It would have been something else probably.

**So, he defines his dream and you can only do that if you were the person who makes your decisions.** And so that's, you know, I don't want to beat a dead horse. I know a lot of

people have questions. But I think, truly, once I understood -- so, I had John -- John was under guardianship before he could communicate effectively.

And when he started communicating effectively, he made it very clear that he wanted to be out from under guardianship. He was involved with the supported decision-making council through the Georgia Advocacy Office. And --

[TAUNA SZYMANSKI] So -- we can -- let's -- should we hold that process for --

[JOAN MCCARTY] OK.

[TAUNA SZYMANSKI] I also -- I had planned to actually play a short clip of John making this point. The quote verbatim is, **"I learned that many parents believe that guardianship will protect their children from harm like a magic shield and the truth is the opposite."**

Unfortunately, I'm just now realizing that because that is from a video that's a Zoom video, Zoom will not let me actually play another Zoom video while we're having a Zoom webinar. So, fortunately, some of the other videos are not on Zoom and we'll be able to see some of John, but -- but I -- I really liked that quote about the magic shield, because I think that's -- that seems to ring true.

There's also a couple of comments in the Q&A. One is: "My daughter is 16. I am being pressured into guardianship by the age of 18. They tell me I need it for medical support and decisions."

And then someone else wrote: "It is so true that there is so much pressure to get guardianship or conservatorship for your child. I did not even think it was an option. I did not get one because we were moving to a different state and postponed the process. I still -- I've still not done one, but up to now, it was felt I was doing something wrong. Thank you so much for clarifying this such important topic."

So -- so it sounds like there's a lot of pressure on this.

Tim?

[TIM JIN] I have a question for Dana and Morgan. Can someone get guardianship over someone that is my age, when they don't want it at all? **Is guardianship something we need to fear no matter how old we are or is there an age limit?**

[MORGAN WHITLATCH] This is Morgan. There's no age limit to getting guardianship. **A guardianship, a guardianship petition can be filed over any age of an adult.**

We're here talking about adult guardianship and conservatorship. So, and -- and when -- when you -- when you kind of discuss -- is there an age that I don't have to worry about it anymore? Someone doesn't have to worry about it more? That -- it's just not true. **And unfortunately, I've seen, kind of, practices in the community that can be, kind of -- that can be coercive to people with disabilities.**

Like if you don't go along with this plan, we'll get you a guardian. And so, **I think we all have to really challenge ourselves to make sure that people do not feel that kind of duress. It's -- it's coercive. It -- it goes against people's human rights to do -- to do it with that approach.**

Dana?

[DANA LLOYD] Yeah. This is -- I just wanted to kind of add. I think -- we were chatting about this in the pre-session. As Dr. Kripke said, you know, **one of the problems seems to be that people don't realize you can do something different. You can make something else work.** 'Cause they've never seen anything else work. And I still find that, right?

I mean, you know, we've been doing this work for what feels like a long time now. I think Joan is absolutely right about the -- the assumptions that people have about folks with disabilities and kind of that societal devaluation of -- you know, people aren't capable.

But then there's just a lot of ignorance, right? And so, we will help, kind of, propose alternatives to people. And then they're like, oh! **A release of information can keep me in my kid's IEP meeting? That's all I need?**

Yeah. That's all you need.

**And so, there is this -- there's this messaging, there's this kind of branding around guardianship that it is, to John's point, you know, this magic shield.** Or -- or that it's the -- it's the fast pass, right? That like, I can just do guardianship and all the questions are answered. And that's not true either.

And so, I think, I would encourage, you know, folks who are kind of struggling under that pressure to ask people why, right? **Ask the question, start putting it out there. Is there another way we can meet this need?**

**Because the schools might not tell you that, you know, a release, a FERPA release, will get you the information that you need. But they're on the hook to tell you if you ask them, right? Your -- your doctor may not say, oh, well, yeah, we could use a HIPAA authorization to keep you involved in this process. Or, there's a medical consent statute in your [state].**

You may not get those answers right away. But I think the -- the very first thing people can do is just kind of reject the premise of the question. Right? And just -- you know --

[MORGAN WHITLATCH] And I would just -- this is Morgan. I would just echo: **most, if not all states have some form of medical surrogate statute like Joan described.** They have different kinds of specificity in what they look like and how they're triggered, but, almost, I think most, if not all states have that.

The other thing I will say: there's some myths associated with, you know, access to educational records, actually. **And one of the exceptions to FERPA, which is the**



educational privacy law, is that if a child is a dependent of their parents, their parent can continue to get access to information. So that's not a frequently told people, that's not frequently told of people.

And then the final thing is, yes, I think **HIPAA is frequently used as a weapon -- HIPAA being the health privacy law -- against concepts like supported decision-making. And it's very easily overcome through -- through a release of information form.** That said, there has to be a -- be able to be a communication of that kind of release piece of this, absent medical consent law.

**[TAUNA SZYMANSKI]** Can we be a little more specific for a few minutes now, I guess, about **what rights are taken away from folks who are subject to guardianship?** Joan touched a little bit on this, but could we be a little more specific? Like, voting, financial control of your bank account, you know? All these. Like, where you live, deciding educational stuff, going to college, reporting crimes, you know, like --

**[MORGAN WHITLATCH]** Well, so **it's going to vary by state.** So, some states are impacted -- the vote -- right to vote is impacted as to whether or not you're under guardianship. Okay. That's not all states, but that is some states have that right. **I've had families come back to me and say, oh, I had no idea that in my state, that if I got guardianship, my -- my -- my adult son could not vote. And now I have to tell him he can't vote and he wants to vote.**

So that can be impacted. There's a really great [guide](#) by the Autistic Self Advocacy Network on the -- that goes through each of the laws -- that talks about which states have these kinds of rules and which don't. And I encourage people to go to that website to find that information.

But if we think about common ideas about -- like, if you think about a general or plenary guardianship, the bank account, where you live, who you associate with could be covered. It could be, you know, your reproductive health, your control over your own body. All of these issues that I think have come to kind of sharp relief with Britney's story, that's now in the popular press. Really, it can be an extraordinarily restrictive kind of environment.

And I want to go back to what Tim said in his statement that, you know, there -- there have been, you know, there was a Congressional hearing back in the 1980s that said, you know, you don't -- **when you're under guardianship, you have less rights than a convicted felon.** I mean, there can be -- it has -- **can have serious impact on people's ability to exercise self-determination and control over their own lives.**

**[TAUNA SZYMANSKI]** So, could you report a crime like -- that you witnessed, or were a victim of, for instance? I mean, there's this whole notion that -- that if you're subject to guardianship, you don't have the capacity, or you're incompetent to --

**[MORGAN WHITLATCH]** You can report a crime. **Your credibility may be called into question as a consequence of adjudication of incapacity.**

[TAUNA SZYMANSKI] Can you not testify? Like, how could you --

[MORGAN WHITLATCH] Right, with -- **with guardianship, it means you've been adjudicated incapacitated and that can, of course, impact your credibility when it comes to testimony, when it comes to, um, witness statements, all those kinds of issues.**

[TAUNA SZYMANSKI] And what about, sort of, going to college?

I know that there are AAC users who would like to go to college and their parents are thinking, let's establish a guardianship over them. I mean, it's sort of an indirect way, but, but -- you know. Could you, like, take the SAT, for instance, if you were subject to a guardianship? I mean, there are sort of things that people might not think -- that maybe that maybe you can, but it calls into question your credibility, I guess, right? If you're subject to a guardianship.

[MORGAN WHITLATCH] I don't know of any pro-, this is Morgan. I don't know of any prohibition of taking the SAT for guardianship, but I also haven't looked into that particular issue. **I do know that some colleges' admittance programs have certain restrictions based on whether or not you are under guardianship or not.**

Arguably those are discriminatory against people with disabilities. But I do know they exist out there and so that you can be impacted that way. That said, I have worked with people who've gone to college and under guardianship. It's just -- it all -- you have to think about from the legal capacity perspective. **The person has been adjudicated incapacitated and that has legal consequences and, at a minimum, certain perceptions by society at large.**

[TAUNA SZYMANSKI] So, one example I've heard of just as recently as this week from a parent was: they believe that guardianship made sense for their adult child because they thought it would protect them from criminal liability -- so, being convicted of a crime, for instance, or maybe even arrested. Is that true? Does it protect you against that?

[MORGAN WHITLATCH] **Guardianship does not stop you from being arrested and the process by which you are adjudicated is a separate process from guardianship.**

[TAUNA SZYMANSKI] So it won't -- it won't necessarily protect you from those things.

[MORGAN WHITLATCH] **No it doesn't. I unfortunately get calls all the time from people saying I'm terrified my child will be arrested by the police. And I say, let's engage in some safety planning because guardianship is not going to be the tool that is going to prevent that fear from occurring.**

[DANA LLOYD] Yep. This is Dana. And I think that's the most important point, right? To ask these questions, to **realize that pursuing guardianship for someone isn't a one and done thing.** It kind of sets off this cascading list of questions that you have to consider for maybe situations you're not thinking about considering in the moment, right? It doesn't, it

doesn't answer all the questions. And what I've found a lot is that people treat guardianship like it precludes that safety planning, but it doesn't.

**People still wind up in situations where they need, they need the skills to keep themselves safe and they don't have them because someone has been in that role of making decisions for them and they haven't learned that skill.**

So, that's one of the, you know -- in one of the -- some of the reporting, some of the literature on supported decision-making, it actually talks about **when people have greater access to self-determination, they're, they're safer, right? They're better able to recognize and resist abuse.**

And there's a, you know, trainer in the field of disability and he doesn't talk about this in the concept of supported decision-making; but -- his name's Dave Hingsburger -- and he talks about safety. And he says, you know, if we, if a person's never had an option to say no to peas for dinner, what makes you think they're going to say no about anything else, right?

**And so, when we create these protective arrangements that keep people from being able to say no and have their no recognized -- you -- it's easy to believe that you kind of lose the -- you lose the belief in your own ability to direct your life. Right?**

And so if someone is trying to encroach and take advantage of you, well, you might not believe that there's anything you can do about it because you haven't ever been able to say no to peas for dinner or what shirt to wear.

**And so, I think sometimes it's about just kind of reorganizing those questions and to think about what is it that really keeps us safe? What are the protections that we all have and how might guardianship get in the way of that? And what are the other things we can do to support people having the autonomy to be able to protect themselves?**

[TAUNA SZYMANSKI] So, I want to tie this back just briefly to Britney in a second, but before we do that, let me -- let's hear from John. Here we go -- video. All right. Hopefully everyone can hear this.

*[Begin screen-share of recorded video stream]*

[JOHN MCCARTY] -- supported decision-making process. I say "process" because a supported decision-making plan is part of an overall process. Having a supported decision-making process can help a person with a disability avoid being under guardianship.

[JULIE KEGLEY] And about ten years ago, I started getting phone calls from people with disabilities who were under a guardianship and they wanted to have the guardian removed. So, as I began representing them in court, to have the guardian removed, I realized that there was a common theme or thread across all of those cases. And that was, in order for them to live their life without a guardian, they all relied upon the support of

others to do things in all of their daily activities, whether it be managing money, reminders to take medication, how they were going to go to get around for transportation.

And right about that same time, the concept of supported decision-making became more prevalent within the disability community. And we started, within the office, started really using supported decision-making when we were looking at the cases of people who wanted to have their rights restored.

**[JOHN MCCARTY]** Studies show that supported decision-making increases a person's self-determination. Meaning, they have more control over their lives. Without a guardian, they are more independent, more integrated into their communities, healthier, and better able to recognize and resist abuse. Additionally, they are more likely to have paid jobs, live independently, have friends other than staff or family, go on dates, socialize in the community, and practice the religion of their choice.

**[End recorded video stream]**

**[TAUNA SZYMANSKI]** One more brief clip here.

**[Begin screen-share of recorded video stream]**

**[JOHN MCCARTY]** ... a process and it should be flexible. People making decisions get support regardless of whether or not they have a disability. The idea of supported decision-making for people with disabilities is to formalize that process we all go through.

**[End recorded video stream]**

**[TAUNA SZYMANSKI]** Ok. So, that, Julie -- is it? -- Kegley, is that how it's pronounced? She was John's attorney, right, through this process. So, I just wanted to get John in there.

Morgan, do you want to talk a little just very briefly about the [inaudible]? Oops, sorry Tim, go ahead.

**[TIM JIN]** Why couldn't they go to college? I went to college and also took many tests with accommodations. **I really don't understand why they want power over someone else. We learned from our mistake like everyone else.**

For example, my mom taught me to look both ways when I crossed the street. I learned from her example to make sure to look both ways. **If my parents had guardianship over me, they still can't force me to be safe and healthy when crossing the street.** It's my choice to look both ways.

I think guardianship is a broken umbrella. When it's raining outside, you still need to deal with the flooding.

**[TAUNA SZYMANSKI]** Thanks, Tim.

Morgan, what -- what's -- what can we learn from the Britney experience here? Is there any connection to our AAC community? Or, is this just --

[MORGAN WHITLATCH] I think there absolutely is. The first thing was just how restrictive guardianship -- in this case they call it conservatorship in California to cover a lot of different things -- can be and we saw it in her case. We talked a little bit about that just a moment ago.

I think the other thing that really highlights for me is -- is somebody with so many different kinds of resources -- so, you know, so much fame. And she's -- after 13 years -- still can't get her guardianship terminated or limited in some way. **That just speaks to how difficult it can be to get your rights restored and why it's really worthwhile in thinking, before establishing a guardianship, is this really the least restrictive option for people? What have I tried that could work this differently? Could I have, if I, if a guardianship is necessary, could it be temporary? Have I really looked at the kind of financial planning that could provide protections to assets that wouldn't necessitate the removal of someone's ability to act for themselves?**

And, so, I think that's a really core piece of this. Another piece is the -- it really, I think, highlights due process protections and problems, I would say, within guardianship and conservatorship systems. Like, she's fighting for her right to retain an attorney of her own choice. **She didn't know, she says, how to restore her rights, that she could petition the court to seek that kind of restoration.**

All of these really speak to the problems within the system of people who are within them, who are under conservatorship or guardianship, not knowing what their options are or how to meaningfully access those kinds of less restrictive options and seek court review. You know, so I, I think this brings to light a lot of different kinds of issues.

And really also thinking why does conservatorship or guardianship have to last forever? If it was -- if it was there to kind of serve in an emergency circumstance, why are we viewing it as the end result rather than a waystation to really assess things? You know, **guardianships can be established sometimes in times of crisis and when the crises are -- are -- are overcome, and systems are set in place, networks are -- become more robust.** Services get delivered. I think all of those are things that are really highlighted in Britney's case.

[TAUNA SZYMANSKI] So, right. I guess, another -- another question that I wonder -- Once you have a -- or are in the process of obtaining a guardianship over your child, for instance, if you're a parent, **does the parent have to sort of swear under oath or sign something that agrees with the fact that their child is incapacitated incompetent and incapable of making decisions?**

[JOAN MCCARTY] All right. So, I can answer that. **And the answer is yes. Definitely.**

[TAUNA SZYMANSKI] Okay, then. **So, what does that then potentially mean about the child -- adult child's ability to access AAC and get, you know, enforce communication rights in the future?**

[JOAN MCCARTY] So, I don't know the answer to that question because, you know, when I -- when I got guardianship, I was one of those parents who thought it was like the magic shield, right? And I never considered the implications of it. So, when John said to me, I want to vote. I thought, oh, huh. Now, in Georgia, they have to specifically take away the right to vote. So, John -- it took me a while to figure that out. But once I did, John registered to vote and started voting. But, I don't -- when John got access to the alternative communication that worked for him and, you know, in terms of his ability to communicate in, you know, a seamless and robust way, I, I provided that. How could he have accessed that under guardianship without my help? I don't know.

So, he'd had my help with or without guardianship. So, I don't know the answer to your question. **But I do know that I did have to say he's incompetent. I did have to do that. And I'm ashamed to say I did it.**

[TAUNA SZYMANSKI] And, I guess, Morgan or Dana, I guess D--, could you imagine a scenario where that declaration -- and -- which is like certified in a court document, could interfere with the person -- the disabled person's ability to gain communication access at some point in the future?

[DANA LLOYD] This is Dana. And I'll say this briefly, and then kind of let Morgan wrap it up. I think that, you know, this kind of goes back to the question we had earlier about, does access to communication impact guardianship?

And so, I think there's the practice, what we see happening, you know, over and over, and what might be legal, which may not, they're often not the same thing, right? And so, I think that -- I think the presumption of incapacity is this cloud that hangs over people. Especially once it's been adjudicated in some way, shape, or form. So, does it have to? No, it doesn't have to. Can it? Yes. Does it? Yes.

And so, **I think that that's just another thing to consider is that you're taking, oftentimes, you're taking what might be a presumption about a person, right? And you are solidifying that -- and -- through a court process.** And so, you know, so -- And another way I see this show up in practice is that, even without guardianship, there are times when, and I'm sure parents and folks who are AAC users on this call recognize this, that **people are fighting so hard just to get the -- to get access, but like, you wouldn't want to interject another barrier.** Right?

I will -- I will read through, you know, 12 years of education records where it's just the box check that said, no, this person doesn't have any reliable communication. I can't find an evaluation. I can't find where they've done anything else, but just, nope. This kid showed up and we don't think that's true and so we've just been checking that box for 12 years.

And so, I definitely don't think that adding a layer of, you know, having been adjudicated incompetent is going to help that process. I don't think it has to get in the way, but I'm sure Morgan can talk about the legal ramifications.

[TAUNA SZYMANSKI] Briefly. Morgan, any --

[MORGAN WHITLATCH] This is Morgan. No, Dana, you said it very beautifully. I think, when we think about what courts typically are looking for, when they're looking at assessments of capacity, they're typically looking for some kind of certification from a medical or psychological provider. And those certifications can have an impact on people -- can over, you know, overhang, the person's head in a lot of ways and you said it beautifully, Dana.

[TAUNA SZYMANSKI] All right, so let's -- so, there's the decision that a parent or a family member would have before the adult child or sibling reaches 18. But then what happens if -- if you're in a situation where someone has already been subject to guardianship? I mean, **John, to our knowledge is the first AAC user in the United States who has successfully terminated a guardianship.**

Should we hear a little bit more about that? And let me -- we've got a little clip from that same video, I think, of John talking a little bit about starting that process. So, let me see about sharing my screen again.

Alright. Okay. Oops, that can't be it.

Alright. Joan, do you want to talk a little bit about how that process began while I tee up the video?

[JOAN MCCARTY] Okay. So, are you -- so when John -- Are you talking about the process of having it removed?

[TAUNA SZYMANSKI] Yeah.

[JOAN MCCARTY] So, when John decided he wanted to have his guardianship removed -- because John has vast support needs -- for a long time I didn't do anything about it, because I thought; he's already making his own decisions. What difference does it make?

So, once he convinced me that it did make a difference -- and I thought, okay. Great. So, you know, he had already had someone suggest he talk to Julie Kegley. And, so, he connected with Julie Kegley. Julie's first thing was, first of all, we've got to go through this whole thing, go pick up your records and then let's go through them and let's see why they put you under guardianship.

And so, every point, like, point by point. This, you said this, how is it different? You said this, how is it different? And so, Julie and John started working together in order to -- and Dana, you can chime in if I start missing something, 'cause sometimes it's just all a blur in my head.

They worked, they worked for months, actually. And one of the things that Julie said to him is, you know, I need a plan. And I need a plan that's pretty specific on how you're going to live your life, considering your finances, your safety, how are you -- how are you going

to live without a guardian? She asked him very specific questions. And so John was interested in a supported decision-making plan because he's part of the supported decision-making advisory process and John and I started working on that.

It took us months and months, and John defined his -- the areas where he thought he needed support. And that included financial, and it included his -- his -- his professional life. It included his volunteer -- he called a volunteering and leadership. It included his socializing.

So, he has all these various categories. And then he started by just trying to figure out what he knew. Like, what do I think I know? And then he started after he figured out what he knew, he got to what he needed to know.

And through those series of questions -- and he -- his working with Julie, they came up with a plan and it was a way to show the judge in court that he could communicate now, and he was very effective in communicating what he needed. And he was also very effective at making the decisions about that.

So, we had to have a little bit of a history of decision-making. So, John, and then the court said, okay, once he filed the petition, they said, okay, we're going to have an evaluation.

And, you know, we'll go back to the, you know, presumptions that people make about people with disabilities and that person showed up at our home and -- anyone who knows John -- has seen John -- thinks: Oh yeah, there's nothing much there. And so, she had that tone of voice and she was asking John what he did every day.

She was focused very, very much on activities of daily living and he wouldn't answer it. He's like, I'm not answering that question. And she, they kind of had it out a little bit. **And he said, here's the deal: Stephen Hawking needs more support with his activities of daily living than I do and no one has ever questioned his competence.**

**And so, she backed down.**

He went through -- went through his day. He never once said the kind of physical support he gets from me. Good for him. And he -- he made his case with this person. He also -- he had a list of -- he had a resume, all the work that he had done. He had contact information for his supporters. He has about twenty supporters. Which includes Dana. Actually, he -- he -- he -- I gave her all this information and said, I want you to contact all these people. And before she left, she said, I don't need to. 'Cause he somehow convinced her. And I think it was the whole Stephen Hawking thing.

But then they went to court. He and Julie practiced very specifically about the questions he was going to answer. She said, I'm going to ask you these questions just so that he would, you know, he gets pretty nervous and he, she wanted him to be eloquent enough in front of the judge and that's how it worked.



And then, then she, she asked me some questions. I am the guardian. I was also at that -- in that procedure, I was his communication partner and she asked me some questions, which I answered. And then she gave him his rights back. And -- and so, you know, John has a plan and in his supported decision-making plan, he makes the decisions, but he does need a lot of support. **But physical support is very different than making a decision about what needs to be done. I can do the banking, but he has to tell me what to do with the banking.**

[TAUNA SZYMANSKI] Yeah. I see that Bob has joined us. I want to give him a second if he has something to say. He turned on his camera. But I also want to apologize that the videos that I had intended to show of John just aren't teeing up. But in the [thing we're going to circulate by email](#), we will have links to them. And they're amazing and very good. And so I encourage everyone to just watch them in full. There are a couple of very long ones, but also like five-minute ones that are excellent. So, Bob, did you have something that you wanted to add? Bob Williams is our Policy Director.

[BOB WILLIAMS] I am Bob Williams, the Policy Director of CommunicationFIRST. I am a 64-year-old white man with cerebral palsy. My pronouns are he, him, and his. I have lived and worked in Washington, D.C. since I was 21. Before joining CommunicationFIRST, my career included working on the passage of the Americans with Disabilities Act, helping to close and move people out of an institution, and overseeing several disability programs at HHS and the Social Security Administration.

I have been extremely lucky to be able to access and effectively use multiple modes of AAC throughout my life. What I am wondering about is whether and what is happening to challenge some of these practices and the blatant prejudice they are based on under the ADA, especially in the schools?

**We say these are civil rights issues. How are we using disability civil rights laws to challenge them?**

[TAUNA SZYMANSKI] Maybe that's a good segue to -- to just providing a little bit more guidance. I'm looking at the time. This was a very ambitious agenda. We had a lot of questions. But trying to give our attendees some practical tools to -- to either resist that pressure, to try to, you know, adopt that magic -- quote-unquote magic shield, which isn't a magic shield at all, and/or trying to terminate. Like, how easy is it?

I mean, it sounds like John's experience terminating his guardianship has been vastly easier than Britney Spears's, which is completely counterintuitive given all the resources and speech that Britney Spears has. So, is that realistic? **I mean, is John's experience realistic for folks?**

And, I guess, the other question I have is, you know -- other, sort of, you know, the questions I get are does -- **does someone with a disability sort of need to have a threshold level of like privilege** in the sense that they're surrounded by people who have the resources, not financial resources, but educational resources and ability to advocate and support the person with a disability to not become subject to one of these things.

I mean, is this a sort of, you know, is this only for really privileged people with disabilities? I guess I just want to ask that -- that question. And -- and where do -- where do people go also for -- for more information or resources about this? And, to challenge this sort of nationally. So, Morgan, I don't know if you're the right person for that question or Dana.

[MORGAN WHITLATCH] This is Morgan. **Getting your rights restored is -- is possible. It is very resource-intensive. And that means you need to find the right kinds of connections like John -- you know, John's family did.** He had -- he had Joan's support. He had the protection and advocacy system in Georgia to support him and provide him with free legal services. He had access to evaluations. An evaluation means that psycho- -- that usually courts want to see. So, it is very resource intensive.

**A lot of people aren't aware of what their rights are to seek that kind of restoration. And a lot of people have difficulty finding attorneys who are willing to provide that kind of representation.**

I think one resource that's in every state and territory to approach is [the protection and advocacy system](#), which is a federally funded organization in every -- that -- that's available. Not all of them do this type of contestation work. Some do. So those are avenues by which to go to. **It can be very difficult to restore guardianship -- restore rights.**

I will say, you know, when you say John's story versus Britney's story, I think we have to kind of think it a little differently. We don't know if Britney sought to petition the court to end her conservatorship until only really recently when she said that, right? She was seeking to change her conservator, which is a different kind of approach.

I know that her record is sealed and a lot of it isn't public. But I think when I hear, when I hear Joan and John's story, I think to myself, they actually had to put a lot of resources and planning and to trying to show the evidence necessary to convince the court of this. I have known processes where it's taken years to get one's rights restored and certain kinds of zealous representation.

[JOAN MCCARTY] I want to say one thing. I'm just going to interrupt you just for a second.

[MORGAN WHITLATCH] Go ahead.

[JOAN MCCARTY] This is Joan. **The biggest difference for John was the communication. The fact that before he was 18, he could not communicate effectively and -- except through mostly gestures. And then when he sought to end the guardianship, he could communicate fluently through typing. That's the difference.**

And so, we did put a lot of resources into it, but Julie's thing was -- this is like, it's almost like night and day. See? We didn't know what he knew. Oh, now we know what he knows.

[DANA LLOYD] Yeah. I, and I think this is Dana and I think to add to that point -- When there hasn't been a material change in circumstance, it is much more difficult for people to make the case that -- to terminate their guardianship. And so, I think that's often, you know, the people that I've stood beside for a long time that have been working towards restoring their rights, that is when it's most challenging.

Well, yeah, like I, you know, I've experienced a traumatic brain injury. I still have a traumatic brain injury. These are the ways that I support myself. That was kind of true when people petitioned guardianship for me. But I -- I -- I don't think I want this anymore. This isn't working for me anymore.

Those are much harder cases to make, when there's not this -- this change.

And I think that is something that made things a bit more difficult, or a bit more -- a bit less difficult for John. But to Morgan's point, it still wasn't easy peasy, right? This wasn't, **it was the exact same process of getting a guardianship, but filing the petition and making those payments and having, you know, an evaluate- -- it was the same process.**

So just that in and of itself meant that it wasn't quick. And that doesn't -- that doesn't account for all the years where they weren't necessarily planning to petition for guardianship restoration, but were doing the work of John having that history of decision-making process and all those sorts of things.

I think kind of to Bob's point and, Tauna, as you were wrapping that up to think about, like, how do we push back? This isn't a great answer, but it's push back, right? It's to say: No, no, I don't -- I don't understand this question. **I don't understand why you're making this suggestion. I -- isn't there something else? Is there another way we can do this? What about my child's IDEA rights? What about my child's ADA rights? Are you saying that I can't have an accommodation in this specific circumstance?** And I -- I -- it's not -- it's not fair.

It's not the system that I wish we had built, but it's the system that we have that I think oftentimes parents and supporters of people with disabilities have to be armed with a little bit more knowledge than the folks around them. Right?

And when, when that feels overwhelming to people, I tell them that oftentimes that can just be a question or two, right? Just to -- just to again -- reject the premise. Right? I don't believe that what you're telling me is true. Because oftentimes I think professionals are treading on the fact that you -- you're believing them because of their professional credentials.

And I think there are times where people are not necessarily have any ill will -- they're just not aware. They're not used to seeing it this way. They expect that people are going to have a guardianship. And so, I think, of course the -- our P & A and a lot of the network, does work to support people when things rise to the level of -- of needing legal support or advocacy support to help people exercise their rights.

**But I think there are itty bitty ways we can do that all day, every day by just, kind of, showing up and saying, no, I don't -- I -- I'm not accepting that answer.** You know, I -- I want, you know -- I need there to be a conversation about something else.

[TAUNA SZYMANSKI] I see that Bob is typing, but also I want to give -- highlight two other examples of CommunicationFIRST members who -- who are adults who have not, who are -- well, members who have not been subject to guardianship. One is -- some of you all may remember about a year ago at this time we worked with -- on behalf of a patient whose pseudonym -- we used "[Patient GS](#)." She was a 73-year-old woman with aphasia who -- she'd had aphasia for 11 years -- and she really needed communication support in the form of one of her two daughters -- who she could speak somewhat, but she really needed a lot of support with just communication and language.

And she ended up going to the hospital and, because of COVID no-visitor policies, was -- was prevented from having that communication support. Patient GS, whose real name is Joan Parsons, she's never -- I confirmed with her daughter this morning, 'cause I thought that that would have been the case. It never actually ever came up the whole time we were working on that -- on that complaint. She's never been subject to guardianship.

She did have a healthcare power of attorney with her husband, but it really was never, ever an issue in terms of advocating with her, getting her access to communication support she needed in the hospital, filing a federal complaint with the Office for Civil Rights. Never, never -- mediating it. I mean, it was never an issue. So, I just wanted to throw out that example, especially with someone with acquired communication disability.

And then I wanted to just read briefly from an email we got recently from -- from a young adult member, a full-time AAC user, who talks a little bit about the supports that -- that she has in her life.

She goes, "I plan to join the Self-Determination Program next month." This is someone based in California.

"It is a new program with the regional center that allows one to choose one's services and providers within a budget. And I'm ready to try it. I have most of my services through school right now, and I just signed my own IEP. I have a POA, power of attorney, for things that are too much to deal with, but I am running my own show. I write to my doctor through MyChart. I write to teachers. I have my own CalABLE account with authorized representative and a representative payee for my SSI, social security checks. I'm saving them in my CalABLE account to have money I control to solve problems. I have medical insurance, a credit card (with her mom), my RealID and passport, and my chosen name, disability placards, and local state and national parks memberships. This is all I can do to be independent."

And then -- and then she goes into some more detail, but I just love that example of all the things that -- that she's putting into place as she has entered adulthood that -- that, you know, that -- that are -- that don't involve guardianship.

So, Bob, did you have something to add? So just a sec. Okay.

**[DANA LLOYD]** While we're waiting on Bob. I'll just add, someone said it -- This is Dana -- and someone said it in the -- in the question and answer section, right? That, you know, **asking what other options are available, right? Asking what are you trying to accomplish with guardianship? What are, what, what are you suggesting this for can sometimes lead to the answer in and of itself, right?**

I'm worried about, you know, I'm worried about criminal liability. Well, this isn't the solution for you. I'm worried about, you know, financial decisions and protecting resources. Well, there's a whole ton of options for that, whether they're ABLE accounts or special needs trusts, or just having two signers on a checking account, right? If that's something that people will consent to, and provides a little bit of protection.

But I think when we ask the question: What would it take? What does this look like? How can we? Then sometimes those answers are embedded within. **And then just run screaming from anyone who says guardianship's your only option because they aren't a really informed source.**

**[TAUNA SZYMANSKI]** Okay. Wait for Bob to finish. I feel like we've just scratched the surface of this and we're getting so many amazing questions. I'm wondering if -- if it makes sense to see about scheduling, like a part two to this at some point. Sort of a 201, instead of the 101. We can talk about that and maybe we can convince you all to rejoin and if there's interest -- but there's so much more I wanted to cover that we didn't have time for.

We will be including a lot of resources in this [handout](#). So, look out for that in the next 24 hours or so.

**[MORGAN WHITLATCH]** I was looking through some of the questions, just as Bob's doing that. And -- and you know, there are a lot of good questions that we're not reaching here in the Q&A. **How does one establish a history of decision-making process?** Joan kind of touched upon that a bit when she spoke.

I think that's what you want to look at. **You want to give people an opportunity to be making decisions over time that kind of vary in complexity.** When I'm working with someone and they're only for the last, you know, five years -- it's been -- their decision-making choice has been picking what shirt to wear -- what color shirt to wear in the morning. That's not what I'm talking about. **I'm talking about kind of really giving people experiences and establishing decision-making,** so Joan might have some ideas for that.

**[JOAN MCCARTY]** Well, I think, you know, when we -- when we started -- when John -- John, John, more or less, like the young lady who wrote to Tauna, John started kind of asserting himself and indicating what he wanted. And then, you know, I would be like, yeah, okay. I had the good fortune of having other kids. And so John has other siblings.

And so, it wasn't as though I thought, oh, I'm going to have to control him for the rest of his life because, you know, there's this natural kind of a -- an ebb and a flow to -- as people,

you know, hit their teenage years or whatever, the things that they can and want to do and the way that they become independent.

Now, John has more of a difficult time with that because he needs 24/7 support, physical support. But, right, just what you just said, Morgan, about how you set up, the -- John decided in this area, I want to, I want to have control. And there are six areas he has, this is a different presentation that he has.

He goes through the six areas, and then he talks about the questions that he and I just kind of hashed out just to figure out what he knew. And then what he didn't know, you know, all of this -- part of the discovery -- it was his taking control, you know, answering the questions about his, for example, his public benefits.

[TAUNA SZYMANSKI] Okay. We've lost our captioner because the time is up, but Bob, do you want to have the final word here?

You're on mute. Bob, you're on mute.

[BOB WILLIAMS] ... set up to feel shame and blame. And what you did was ultimately freed your son --

Joan, this is what I want to say to you. Hope you take it to heart. It is completely understandable that you feel sorry for your initial decision. I want you and others to note that many times parents are set up to feel shame and blame. And what you did ultimately freed your son. The shame is not on you. The shame is not on you.

[JOAN MCCARTY] Yeah. Bob, thank you very much for -- for that. You know, the thing I was mostly -- **I just am embarrassed that I put him under guardianship. I don't know what happened to me. Like, I don't know how in my head I ever reconciled someone being fully integrated in their community and also under guardianship.** I did it. I don't know how I did it, but so it's more of my own failings that make think -- give me pause.

[TAUNA SZYMANSKI] Thank you, everyone, for joining us. It looks like we've got a lot of votes for another session. People loving this -- and it seems like there's a lot of need and desire for more information on guardianship and alternatives, specifically, for folks who have difficulty communicating and need supports to communicate.

So let's -- let's talk about that and hopefully we can convince you all to come back for part two. Thank you to all of the panelists and to our interpreters and captioner and to everyone who's joined and submitted such amazing questions, as well. And I apologize that we haven't been able to get to all of them, but hopefully we'll be able to do that in a part two.

So, thank you all again!

[END]