

ROUGH EDITED COPY

WVU-CED  
MEETING  
FEBRUARY 11, 2020

CAPTIONING PROVIDED BY:  
ALTERNATIVE COMMUNICATION SERVICES, LLC  
[www.CaptionFamily.com](http://www.CaptionFamily.com)

\* \* \* \* \*

This is being provided in a rough-draft format. Communication Access Realtime Translation (CART) is provided in order to facilitate communication accessibility and may not be a totally verbatim record of the proceedings.

\* \* \* \* \*

>> Live in their communities, healthier and safer. That's a problem too. For 1500 years, we have made cultural assumptions about people with disabilities.

I am a lawyer, please don't hate me. I am a bit of a legal geek. So I can tell you that the first time we put laws together in the western world. The eastern world has us beaten by thousands of years. In the western world an emperor named Justinian created the Justinian code. One of the things was if you were "feeble" you had to have a curator over you.

We created a culture that people with disabilities who are limited in any way, need people to do things for them. We got most of our laws from Great Britain. They said if you're an idiot or a lunatic you have to have people decide how to run your life. Just like that, we made that decision that limitations equal inability. I am not here to say there should never be guardianships. What I am concerned about are what are overbroad and undue guardianships. Guardianships that take away more rights than people need. They work this way in West Virginia and every other state, a judge decides whether or not a person can exercise his or her rights. And what that judge is supposed to do is decide which rights if any, the person is unable to exercise. And only those rights should be transferred to that person's guardian or conservator, demanding how you want to -- depending how you want to refer to it.

The vast majority of guardianships take away most rights. Second thing we know, healthcare professionals are one of the most common referral sources for guardianship. I have talked to plenty of doctors and healthcare professionals, and what they tell me in general is yes, we think a person might not be able to make decisions about their healthcare. And they recommend maybe a guardian for that.

But what happens inevitably, is a person can lose all of their rights. What I tell people is, be careful. Guardianship is not wrong or evil, but if we recommend it, likely, a person is going to lose all their rights. We know from studies, like ones on your screen, that guardians have control over people's lives. In the most intimate areas of their lives. Who they can see, whether they can date, whether they can work, whether they can get

healthcare? There are horrific stories.

So we need to be careful. I never say guardianship is bad. I always say think about it. Because we know from going on 50 years of studies that when people with disabilities lose their self-determination, their lives get worse. A 1975 study, people with disabilities who had their self-determination, their exercising of choices removed. Felt helpless, hopeless and self-critical. We know from the last couple decades, they function less well, in some cases live less long.

So I want to say be careful with what we recommend. Think first about ways to empower or to help people, because here's something else we know that's scary. We live in a time here in 2020, where I think it is fair to say that we have more ways to make more people more independent than ever before. We have supports and services. We have advances in healthcare. We have assistive technology. We have apps. All of you are carrying in your pocket, a computer that is anything more powerful than anything that was on a desk two decades ago. They can help us manage our money, manage our time. They can help people help us through scheduling.

I have one client I worked with who has a traumatic brain injury and diabetes, and he's exactly the type of person who would have been in an institution before the ADA. Because sometimes she doesn't take care of her blood sugar or she forgets to. You know what she has now? A free app. Free app connected to the glucose monitor. When her sugar gets low, it texts her. If it gets lows it texts her doctor, mother and sister, so they can intervene. Just like that, for free, she's able to live independently and manage her life.

But the scary thing is at a time when we have more ways to make more people more independent, as it says on your screen, the number of people under guardianship has tripled just since 1995.

In just 25 years. A million more people have gone into guardianship, and we know from studies that 90% of them have lost all of their rights. And some of you may be thinking well, of course, that makes sense. We're getting older as a country.

And that is true, but the study says this: just released by the national council on disability. The fastest growing population of people going into guardianship are 18-year-olds with intellectual and developmental disability. 18-year-olds, with people following that culture, this person has a limitation and you should get a guardian.

Number 3 is probably a healthcare professional for that, No. 1 are teachers.

So people who have a unique place in society to help build people up, are with the best of intentions mind you, in some cases causing them to lose all of their rights. Because the research is scary.

We know from studies that people who lose their self-determination, people in overboard or undue guardianship. That being in that position can have a significantly negative impact on people's mental health, they function less well, in some cases they live less long. On the other hand we know that people with disabilities with more self-determination make more choices, have a better quality of life. Study after study says they're more independent, more likely to be employed, more likely to be integrated into their communities.

Now the number one reason I ever hear why a person needs a guardianship is safety. And I never question that. It is every parent, every healthcare professional, every

person's obligation to look after people they care about, to make sure people don't get hurt.

I hear it all the time. If my son, my daughter, my patient, my student, doesn't have a guardian, something bad might happen. They might get abused.

I point them towards a series of studies by a professor from New York and she studies frequently, the interplay between self-determination and safety.

And one of the studies is on your screen. Classic study, control group, experimental group. The control group was called "go live your life." The experimental group "who was a group of people who were similarly situated to the control group." They had similar abilities and limitations, and they were given access to a curriculum designed about self-determination, to teach them about choices, responsibilities.

After that curriculum was completed, they brought the group back together and gave them a recognized study designed to measure a person's ability to recognize abusive situations and avoid abuse. You know what they found? It's on your screen.

People who were more self-determined were better able to recognize abuse and better able to avoid it. They were safer. I've told judges across this country, and judges and lawyers and doctors and teachers, if you want to keep people safe -- and we should! We shouldn't be taking away rights; we should be building abilities.

Think about it. This is not rocket science. Aren't you more protective of what you know is yours? If you know something belongs to you, a right, your body, your personal freedom and space. Aren't you more likely to protect it?

What we're telling people with disabilities, from a young age, the exact opposite of what we tell everyone else. We tell everyone else stranger danger, don't let people touch you. Don't let a stranger come and take you. Resist. People with disabilities, kids with disabilities, are told all the time, comply. They're actually graded sometimes or judged in their healthcare fields on how compliant they are. They're poked and prodded all the time and told not to question. Aren't we setting them up in some cases to be abused? So not to say that people don't need protection. Of course, they do.

But there are ways to do that that are scientifically more valid than others, because we know self-determination is directly correlated with safety.

Here's my favorite study. The national core indicators study, it was done twice in the last decade. It was a study on quality of life of people with disabilities.

And again, it was what I call an apples to apples study. Non-scientists. It measured the people of similar abilities and limitations. Even the old nomenclature, mild to mild, moderate to moderate, severe to severe. The whole point of the study was to see the impact that certain variables had on people's quality of life.

Just one of the variables they looked at was whether or not people had a guardian. And this is what was found across the country and in West Virginia, that across the country and in your state, people of similar abilities and limitations. Those that did not have guardians, were more likely to work, live independently, have friends, go on dates and socialize, have their rights respected and be more involved in their communities. Isn't this exactly what we want for people?

If you are a parent, isn't that exactly what you want for your child? If you're a doctor or healthcare professional, isn't that exactly what you want for your patient? To have the highest possible quality of life. If that's true, what I'm saying is think before we follow

1500 years of culture and say a person MUST have a guardian just because they have a disability.

Or assuming that just because a person has a disability, they cannot play an active role in their healthcare.

So where do we go from here? Well, this is what I suggest. If we know, and we do, from 40 years of studies, that people who have more self-determination have a better quality of life.

If we know the converse is true and that people who have less self-determination have a lesser quality of life, then what we have to do is take a next step.

Because self-determination is not just saying to people, you're on your own. Go be self-determined. It's not just saying, I'm going to leave you to your own devices.

That's not true. Because people with disabilities, older adults, sometimes need help. Think about it. We all need help. I can't imagine, I can't tell you how much difficulty I had logging on to this webinar. I needed help.

So what we need to do is recognize that help is a part of life. And then when it comes to the science, we need to make this conclusion. I hope you agree with me. We need to find ways to maximize people's self-determination, because that is directly correlated with quality of life and quality of health.

While at the same time, making sure that people have access to the supports and services, the help, they need to exercise effectively, safely, and appropriately that self-determination. And that's where I can get to the point of today's presentation.

Supported decision-making. Supported decision-making in my mind is the largest advance for civil rights for people with disabilities. And you can see a screenshot on your screen of the recognized definition of supported decision-making. If you look at one of the supported decision-making textbooks, you'll find this definition. This definition appears in articles. I can do it from memory. You can read it on your screen, you can screenshot it if you want. I did write it. So you're speaking to the author of that definition.

And I hope that as you read it and as you take it in, you will now forget about it, because I believe this definition is crap. I do.

I think this is overwrought, overwritten pseudo-intellectual crap that I am guilty of writing. I had a case, I work would Dr. Blank, the primary author for a young lady named Jenny Hatch. It was the first time we showed that supported decision-making should be recognized as an alternative to guardianship. I want you to look at the definition and forget it. Because this is what supported decision-making is. It's on the screen now. You ask yourself, how do you make decisions. If you're a doctor, what do you when you're not sure of a diagnosis or when you're not sure how to communicate well with a patient; things outside your comfort zone; your taxes? What do you do when you don't know what to do? What you do is you talk to someone you know. I call them, those people in your life, I call them go-to people. The people you go to who know things. My sister is superintendent of schools, I called Jan for advice when my kid got in trouble at school. I have another sister who is a gerontologist. When we're worried about my mom, we talk to Judy first. There are people in my life I talk to about relationship issues because frankly I get too close to them to make a decision.

When my car has trouble, I call a buddy that knows about cars. That's what supported

decision-making. Supported decision-making is nothing more or less than getting the help you need to do the things you have to do. And we do it every day.

The last time I testified in court, a judge asked me what is supported decision-making. I said you just did it. You just did it. Because you asked something you didn't know.

So when you think supported decision-making, think your screen right now. It's getting help when you need it. And we do it every day, but there's a critical, critical difference.

If you're a professional. You're a person without disabilities. If you are someone that society respects when you do it, you're being wise. You're being smart. You're being judicious. You're being a good professional. You're being a good doctor. You're exercising informed choice because you're getting the information you need. You're not going off half-cocked, making a snap decision.

When you use supported decision-making, you're smart. But there's a problem. For 1500 years, and before that as well, when a person with a disability says I don't understand; help me. Or can you explain that to me, or can you give that to me in plain English or I don't know what you're talking about, society has assumed that they don't know. And they can't know.

And that I submit to you, has led to the surge in guardianship. Because we assume that limitation equals inability. We assume that the need for help equals the need for substitute. And I submit only people with disabilities and older adults are subjected to that.

When you as doctors and healthcare professionals ask advice, you're doing the smart thing. And here's what we know about self-determination. There's an emerging body of research, including studies going on right now that is saying exactly what's on your screen. When people with disabilities use self-determination to make their own decisions, to have more self-determination, they have a better quality of life. They make more decisions and they do more things. Again, I submit to you, that's not rocket signs. Because if we know that self-determination leaps to quality of life, and we -- leads to quality of life, and we do, then supported decision-making is going to lead to quality of life enhancements.

Think of doctors and healthcare professionals, I present to them often. And the number one thing I hear from them is something along the lines of well, people with disabilities or worse, "they," cannot give informed consent. And we cannot perform a procedure or provide medical care to someone who cannot give informed consent. By the way, I agree.

If a person truly is incapable of giving informed consent, that person should not be making medical decisions. That's why I tell you there is nothing wrong with guardianship when it's appropriate.

But we have to think about what on means. Because I think people with disabilities are subjected to a different --

The heart of informed consent is this. Healthcare professional gives information to the person and the person has to understand it. The person has to consider that information and make a decision. And communicate that decision to the doctor. Who has to understand that? That's all informed consent is. Informed consent isn't necessarily understanding every word or everything. It's understanding enough to make an informed decision and communicate it.

You want an example of what I mean? When I go to the doctor and I'm not feeling well and I kiss the doctor's ring and say please make me feel better and the doctor writes me a prescription and I say thank you and I take it, I have informed consent. I have no idea what is in a Z pack, and I have no idea between different medications and I'm not going to read the tiny words telling me what the possible side effects are.

So if you have to understand every last thing to give informed consent, none of us do. So think about it this way. Every step in the informed consent process is an opportunity for supported decision-making.

If a person so chooses, the doctor can explain things to the person, and a person's supporter, a trusted friend, family member, someone else they trust, can help that person understand by maybe breaking it down into component parts. A person who is a great descriptive of this is a supporter of his sister who has intellectual disabilities. When the doctor says we want to give you an electrocardiogram, she didn't understand. He said last year, you remember when they did a test for you last year and put electrodes and measured how well your heart was beating? Remember that? She said yes. They would like to do that again, is that OK with you? She said yes. Her supporter, Bob, her chosen supporter, explained the doctor's recommendation. Helped her understand. And then helped her understand the parameters of her decision. What the pros and what the cons were. What it was, what it meant. So that she could make her decision, and then she could communicate it to the doctor. And the doctor could understand it.

So together, the three of them formed the supported decision-making team. At her choice. Each step in the informed consent process being supported decision-making. Think about the impact of that!

If you use supported decision-making with people who want to use it and can use it, then people who you might otherwise think can't provide informed consent may well be able to. Then they will be the primary drivers of their healthcare, and they will manage their healthcare. They will communicate with you better than doctors who might otherwise not have good communication with their patients. Who might otherwise recommend guardianship or treatment and they're worried -- can know that informed consent was given. Family members and friends who would normally be concerned about the person's healthcare can be part of the person's healthcare... with the consent and permission of the person.

I use this great article from AMA Wire all the time. It refers to studies and discussions that say this.

When we have improved doctor-patient communication, including through supported decision-making. It doesn't say that in the article, but you can extrapolate out, when doctors and patients communicate better. We know from studies that leads to better outcomes for the patient. They're healthier. It leads to better medication and planned compliance from the patient. Your recommendations are accepted and put into practice. And! It leads to greater job satisfaction and less burnout.

So by using supported decision-making. By helping people be part of their own healthcare process, not only are you improving their lives, you're improving your job satisfaction as a healthcare professional. Why? Because it's what you got into this field for in the first place.

No one became a doctor to take people's rights away. No one become a nurse or professional or certified nurse's assistance or anyone providing healthcare. No one got into this field because they didn't want people to be healthier and happier.

This is a way to make that happen, and maybe that's why it's been endorsed through the country by the U.S. Department of Health and Human Services. I am fortunate to be the project director for the center on supported decision-making. They have supported supported decision-making projects across the country including two I am leading in Kansas and Missouri. The American Bar Association has said that lawyers and professionals need to look at laws to make sure that people aren't unduly being put into guardianship. The national guardianship association. A group made up of and by and for guardians.

No one is more invested in guardianship than the NGA. Guardianship.org. Their position. Try supported decision-making before guardianship. The Autistic Self-Advocacy Network, the Arc, all say, empower people, because it leads to better results. Here is the good news. If you're asking how do I make this happen. What's step 1, what's step 2, what's step 3, where's a book, where's an app? I have good news for you.

I am someone who has written two books. There is no one way to do it, and there shouldn't be! You already know this because every person I'm talking to right now makes decisions-touchily than any other person -- differently than every other person. There are types of help that you use that are different from everyone else. The same is true of supported decision-making. It is highly individualized. If anyone ever tells you there's only one way to do it, run away. They're wrong.

Supported decision-making can be everything from a listening ear, from you as a healthcare professional being able to explain clearly what a person's options are and what's going on.

Every time I go to the doctor, I use some version of, can you explain that in plain English.

And -- I want specifically this person to help me in this area, and I'm authorizing Jonathan to do so. To help me understand my medical care. I want Wendy to help me with my finances. I want Justin to help me with my interpersonal relationships, or we can have things even called micro boards and circles of support. Which are personal boards of directors or education teams and get together and I, as a persons with disabilities talk with them about my life, and I receive their input and advice, to help me make the best decisions I can.

All of these, all you see on your screen is supported decision-making, because all of them involve me as a person with disabilities, talking to you, as someone I trust, to help me understand my situations and choices so that I can consider them and I can make my decision.

What we know about supported decision-making is this:

I always call them the three commandments of supported decision-making. There's no one way to do it, but they all lead to these three things.

They are, I call, the paradigms. It goes like this. If we start with the assumption that everyone has the right to make choices to the maximum of their abilities, and that's easy. That again is the Declaration of Independence. We all have the right to make

choices. If we start there, the next step is even easier, because the next step goes like this.

I can ask you for help, I can ask my doctor for advice, I can ask my nurse to explain something to me, ask my direct care professional to help me interface with my doctor, without you saying the fact that you need help means that you can't do it.

And that's even easier, because we do that every day. You talk to your colleagues for advice every day doesn't mean that you're not a qualified professional. The third step is the easiest. There are as many ways to give and get help as there are people. Maybe the first time doesn't work, maybe not the second, but we can keep trying. Something might work.

And if nothing works, guardianship is appropriate, but we shouldn't jump to it.

What are some ways some strategies we can use? Like I said, there's no one way, but there are guidelines.

The first thing we should think about is deciding where people need help. We should not assume because a person has a particular condition or a particular diagnosis, or even a particular IQ, and I am not a fan of IQ -- but we ask questions, like where do people need help. There's a great link on your screen called the Missouri stoplight tool. That's just a list of everyday situations, managing my money, my healthcare, remembering to take medication, interpersonal relationships, work transportation. And it asks three questions.

Can this person do this on his or her own? Does a person need help to do this? Can a person not even do this with help? That is a way for us to zero in on where people truly need assistance. Or where people might be able to do things with support. If with a person's family member or supporter, or a professional, we can triangulate where the areas are need are, which can take us to the next step. Figure out for those areas where people need support, what kind of support they want.

There is a very high probability that person is using supported decision-making, not calling it that of course. Because no one calls it supported decision-making. You don't. When you use supported decision-making, you just call it life. But they don't realize, we don't realize, that we're using that phrase.

But there is a way to figure out how we're implementing it in our lives. So the odds are if we're using it in one area of our lives, we are using it in others or could use it in others.

So on your screen, the supported decision-making brainstorming guide. A guided conversation to help us figure out where we're already using support and how we can either use that type of support or adapt it in other areas of life.

Because the next step then is to figure out who can provide that support. And there are organizations across West Virginia and every community. If a person doesn't have people in their lives, and some people don't. The ABA calls them the unbefriended. We can help them link to organizations. If they're young adults, special education. If they're older, Medicaid waiver, centers for independent living. Specific organizations like the Autistic Self-Advocacy Network, et cetera, et cetera. In West Virginia, you have the VD council. You have disability rights, West Virginia. You have the Center for Excellence in Disabilities. All of these are organizations that are either able to provide support or provide information or maybe even link you to people who can provide support.

Because the next step is when you know what kind of support a person wants, when

you know where they need help, when you know what kind of help they use, and when you know who can help it, the next step is just to put it together. To put together a plan. How they do it, when they do it and how they're going to do it.

Resource on your screen called the setting the wheels in motion guide. Cowritten by me, and a good friend of mine who is an advocate. A law student. And a mom of three children with disabilities. And she talks about the way that she implements the supported decision-making with her children, but at the end of this guide, there are great worksheets that can help you think through these issues.

Think through what kind of support the person is getting now. Think through who is or could be in their lives. Where the person wants support.

To help you create that individualized plan of action. Just like miles away, avenue healthcare professional does create an individualized care plan. Shouldn't this be part of an individualized care plan given that we know that self-determination is a better quality of life. Given that we know that communication and healthcare leads to better quality care.

Lastly, if you want, it's not specifically required, but you can put it in writing. There's all kinds of plans out there you can use. There's all kinds of forms. There's all kinds of places that can fit at the resource center site. Supporteddecisionmaking.org, there are lots and lots of forms. I'll pause for a second, because often I hear from doctors, you can't do this because of HIPAA. The second objection after informed consent is HIPAA. We can't have a supporter in the room because of HIPAA. It would violate the patient's privacy rights.

To which I always say. Think about a HIPAA release. Every time I go to the doctor, I have to sign a HIPAA release, and what a HIPAA release says is you, doctor, may not share my information. I am not letting you share my information.

Except with this person I name at the bottom of the form. Well, after everything I've told you about supported decision-making, isn't supported decision-making at its essence sharing information? I can create, then, a supported decision-making agreement with my doctor, by taking that form and writing on it for the purpose of helping me make decisions, as I add that person's name.

And just like that, you have a legally viable and acceptable supported decision-making form that resolves any concerns about HIPAA.

We can do that through powers of attorney too. I have done powers of attorney or advised on them in several states. Power of attorney says, as you all know, if I can't do something, I want you to do it for me. We can create a power of attorney that has supported decision-making in it. On the screen, for example, we can say I'm giving you the power to do things, but here's how you're going to do them. You're going to consult with me first and you're going to talk with me and get my input, and you won't make a decision, for example, that I don't want you to make. We can put specific decisions. I have written power of attorney that say you can never consent to electroconvulsive therapy; I never consent to forced treatment.

So we can create supported decision-making and patient self-determination as a part of powers of attorney. We can do that in advanced directives. Advanced directive, power of attorney for healthcare. Where we say, if something happens to me, I just you to make my healthcare decision -- I want you to make my healthcare decisions for me.

But we can also say in advance, as I'm signing this, I don't need someone to make decisions for me. So I'm designating you, the person who will make decisions for me, if I can't, to be my supporter during the times that I can.

It says on your screen, when you don't have the power to make decisions for me, you're going to come to the doctor with me, provide support to me to help me understand so I can understand and help make my own healthcare decisions.

If we add a HIPAA waiver in that, "and I authorize my doctor to share information with you pursuant to HIPAA ..." we just created a legally enforceable, legally appropriate supported decision-making form that every doctor can use.

Last couple of thoughts. I always hear this. What about safety?

Safety should be our first concern. I never question anybody who's looking out for safety. But I'll tell you this.

Nothing is safe. Ever. There has never been one study, not a single one, that has ever found that people are inherently safer or better off in guardianship.

In fact, there have been some terrifying stories on guardianship abuse in the last year, Richmond Times dispatch ran a series. There have been stories in the New Yorker, in the New York Times the last couple years. That's not to say guardians or guardianships are bad. I'll also guarantee you that people with and without disabilities are being taken advantage of by people that they trust. So what we know is nothing is inherently safe, and we know that people are going to be bad at times. So we can't assume that everything is inherently safe. But here's what we can assume, backed by studies.

If we know as we do, that self-determination is correlated with increased safety, then shouldn't we at least try an option that is associated and correlated with self-determination? That's the position of the National Guardianship association. At least try. And if we can do that, we can change everything!

I'm going to leave you with a cliché about changing the doctor. That's what every doctor gets in this field to do. To change one patient's world. To change the culture. To change our health. Well, that's what we do when we use supported decision-making. When we empower someone who would ordinarily have his or her rights taken away, or who would not be listened to.

When we empower them to be the center causal agent in their life, and receive the associated benefits that come from that, then we change the world for that person. And for every person that comes after that person, because let me tell you, it gets easier after you did it first.

The case I mentioned for Jenny Hatch. It took a year of litigation, a week at trial at multiple hours to get her case won. The first one I did in D.C. took a day.

There was a case in Indiana that took a hearing with one memo. And it was a case in Kentucky, where we just talked about it, and the other side said you know what? This is what we want to do.

Because when we know something is appropriate, that it's an option and that it works and can work, that's how we change 1500 years of culture. One person at a time. One doctor, one healthcare professional, one nurse, one DSP, one CNA, saying, we can do this differently.

We can empower people. We can make people the central part of their healthcare. We can improve their healthcare. We can improve our job satisfaction.

And doing that is the way we change the world. And I would be thrilled to do it with you. On your screen you see my contact information. You can reach me at that e-mail address anytime. If you're looking for resources, there is a free journal called the impact journal on supported decision-making that just came out. It discusses some reasonable work on supported decision-making. Some studies is -- recent work on supported decision-making. Some studies, some issues.

And there is a book on Amazon I have written. So supported decision-making as an alternative to guardianship, but also using it in education and healthcare and money management, in all areas of life. The most important thing that you can do if you have any questions, is e-mail. We need to chat. We need to compare notes.

We need to talk about what works and what doesn't. What strategies are effective. And we need to talk about your successes, and yes, we need to talk about your failures and horror stories. Because they're going to happen too.

Working together, we'll maximize people's authority, maximize people's quality of life.

Thank you so much. I'm happy to answer any questions.

>> Thank you so much. That's a powerful presentation. We appreciate that. With that, let me go ahead and unmute everyone's lines. If you have a question, please let us know.

>> This is Lori Heginbotham speaking. Can you hear me?

>> I can.

>> Lori Heginbotham: I have a question, and this is mostly for Leslie, did we record this?

>> Yes, we did.

>> It will be archived somewhere we can access it. It will be on our website. We'll look at particularly with the contact information and some of the links that Jonathan had mentioned.

>> Excellent. Thank you.

>> How do you approach parents who already have the mindset that their children or adult children can't make decisions for themselves?

>> JONATHAN MARTINIS: Yeah. I get that a lot. When I talk to parents a lot, I do a lot of presentations to parents, and always asked the same question. I always ask the same question. What do you want for your child? Every parent answers the same way. Some variation of I want my child to be as happy, as safe, as independent as possible. And once I hear that, I can work with that. That's what every parent wants.

I never tell a parent what to do. I don't know their child. So I start there. I'm not telling you what to do with your child. You know best for your child. But let me give you some information that can help you have options.

Help you think through. Because if we're looking for our child to be independent, we can direct that entirely with self-determination, and we can look at options.

I also have [Inaudible] materials. The Missouri developmental disabilities council, which is MODDcouncil.org, I believe it is. Has some really good, really user-friendly material on supported decision-making. I'm not just saying that because I wrote it.

[Laughter]

They were designed to help communicate directly with parents. One of the guides, the very first one is called "do I have to get guardianship.?" Just as a thought exercise.

I think of all the parents I have ever spoken with some are right that their children need guardianship. I always say I never speak against it. My Godson is under guardianship and thank God my sister is there to be able for him when he needs it. But for those who don't need it, we can do better.

And materials like that provide the options that help people make the best decision.

>> This is Leslie. Katrina, are you on? You provided a very good question on chat, and I didn't know if you wanted to --

>> Yes, yes, I am. I fought very hard to get a local court to recognize supported decision-making. However, the guardian ad litem for the individual fought equally hard for full guardianship. The judge in that case, family ruled for a limited guardianship of the individual.

The individual wants to regain her rights back and she wants to become her own guardian. She does have a network of individuals that she relies on to help her make decisions.

But what will she need to do to convince the judge to let her have her rights back?

>> JONATHAN MARTINIS: So one, thank you for that. And two, I would be very happy to talk with you offline about strategies.

I remember my review of West Virginia law, it's pretty consistent with most others. That says any person may challenge the existence of a guardianship to show that either he or she has either gained capacity or that guardianship is no longer necessary.

The way I have helped people challenge guardianships is to do two things.

One, to argue that the use of supported decision-making. Either this person has been doing it all along and never lacked capacity, but we never fully considered it.

Or... has empowered a person to have the capacity he or she previously lacked, and the guardianship is no longer necessary. Two strategies that I think make this effective.

Like I said, please e-mail me, and I'll be happy to talk. I am a big fan of either a day in the life story or video.

Which you don't need an expert for necessarily. You just have to document how the person lives their life. What does he or she do, how do they work, who is in his or her life? And then create a chart. For this, the person does this. For this, this person does the other.

For Susie in Kentucky, we created for her, what's called the dream board. That showed her plan and her supporters. It was a beautiful piece of art actually, but it showed how she directed her supports and services and what she wanted in her life.

And with that, they were able to show that she did not need a guardian. In your particular case, what I'd like to do is remind judges about what the law says. Judges are part of our culture too.

And they fall prey to the protectionist attitude as well. But if you look at your law, I'm pretty sure West Virginia law says very clearly guardianship is only effective if there is no other alternative. Well, judge, here's the alternative. And you need clear and convincing evidence for this. Maybe you didn't have this before, but now you have it.

As the "guardian," so to speak, of the law. This is how we can move forward in compliance with the law. As to the GAL, I'm sorry. I wish that was a rare story.

We had six days of trial in Jenny's case. We had multiple experts. The other side had no experts. And the GAL still recommended full guardianship in a group home,

segregated group home, with the guardians controlling all access to her. Sometimes people just don't want to hear, and that's why we need good advocates to fight.

>> Thank you.

>> Any other questions?

>> Hi, this is Steve with the Developmental Disabilities Council. It was a great presentation. Very powerful. And had a lot of great resources attached. So I think everybody got a lot from this. I'm so glad you had this, Leslie.

In West Virginia, the law is not black and white. There is limited guardianship, and in fact, there's an inclination that you should be looking at limited guardianship, if you're going to look at guardianship at all.

But unfortunately, we learn from people's testimony that it's not applied universally. And as a matter of fact, even with families, it's not consistently, across the state.

We have an issue, and we have a wings group here, and I'm sure you're familiar with those. In West Virginia. And we're very concerned about it. We need to step up, ramp up the enforcement at least of that issue. And it would probably help a lot of people keep from falling down the abyss of full guardianship. Ideas?

>> JONATHAN MARTINIS: I completely agree. I believe you and I have met or spoken before. But what you said before is so true. WING is an acronym for workgroup on [Inaudible] network guardianship systems, I believe? It was by the judiciary to look at alternatives to guardianships.

In reviewing it, again, it's not unclear. It's actually pretty clear that guardianship should only be done as a last resort. The key is to get that information out. To make sure that judges understand it.

And frankly, some judges don't want to apply it. And you have to go after that frontally and say this is law.

And to a judge, that's the Bible. To say this is what we have to do to hold them to their case. To hold them to the truth. I told judges all the time is if all you've got is a person coming before you saying he's got Down syndrome, he's got intellectual disability.

That's not enough for a guardianship. You need clear and convincing evidence of what a person can and can't do.

So if all it is an IQ test and a diagnosis, that can't be enough. I've pushed across the country for functional evaluations. Jenny Hatch had a measured IQ of 49. And the expert said there's no way she can make decisions. I said she likes Chick-fil-a, go to lunch, see you in an hour. He came back and said oh she makes decisions. Looked both ways before crossing the street, ordered, paid, counted change, pleasant conversation, and she took care of her hygiene needs.

In other words, she did all of the things, functionally, that equal decision-making and directing your life.

She needed some support in some areas. So that's what we have to push to a judge and to the people who say that guardianship should be a blanket option. What else are we looking at? I always call that the critical question.

What else have you tried? You can't order a guardianship until you answer that question in 95% of the cases. Of course, there are people who need a guardian, a person who is so limited that they can't take part in decision-making, based upon

reviews, needs a garden.

But for the vast majority of us, the question is one of degree. What is that person's limitation, and what help is needed and can that help be provided. The person who said she fought on a guardianship; the person had a network. That's what we need, is to show the networks and show the impact and put it right there and make the argument. And it's not going to happen tomorrow. It's going to require a large amount of banging heads against walls. Sometimes that's the only way to let the fight through, and I know it's frustrating. 1500 years of culture pushes back.

But the only way to beat the darkness sometimes is to kick it until it bleeds daylight. And it's on us as advocates to do that. To keep pushing. So the BB council is uniquely situated to put together stakeholders.

I'm working in Ohio, Kansas, Missouri, on statewide supported decision-making projects that includes not only advocacy and implementation, but educational materials and training for parents and teachers and doctors and judges and attorneys. To say, this is what this means. And this is how we can make it happen.

I'm so sorry for soapboxing. I know I'm preaching to the choir. But this is how we can make the changes that need to be made.

>> Any other questions or comments?

>> Yes, I have a question. This is Regis with specialized family care. I totally love this concept of supported decision-making. But with some of our folks, most of the people who are in their lives are paid to be in their lives. And what happens -- a selfish motive or an agency wants to keep that person within their agency?

>> JONATHAN MARTINIS: Yeah. And I get this question a lot as well. I have to preface this by saying it's a controversial subject, and I am not always in the mainstream on it.

But here is my position. Supported decision-making is about self-determination. It's about choice. So if a person chooses, or a person has no choice because that person has no one in their life, and wants a paid professional to provide support, I believe that's appropriate.

I know that there are laws across the country, and some pending, that say a supporter cannot be someone who is paid. My answer to that is that would mean I could never support Jenny Hatch, because I'm on a salary. I'm her lawyer.