

**Mid-Atlantic ADA Center
Podcast: ADA Today - Episode 3
Supported Decision Making**

Speakers:

Caleb Berkemeier, Host

Jonathan Martinis, Featured Guest

(Music)

>> CALEB BERKEMEIER: Welcome to ADA Today, a podcast of the Mid-Atlantic ADA Center. My name is Caleb. I'm your host and coming to you from the recording studio here at TransCen, Inc. in Rockville, Maryland.

Our episode today is on supported decision-making and my guest is Johnathan Martinis. Jonathan, welcome to the podcast.

>> JOHNATHAN MARTINIS: Hi. Thank you so much for having me.

>> CALEB BERKEMEIER: So, before we get into what supported decision-making is, I figured that we'd start with a little background on you in case anyone doesn't know who you are and what got you into this line of work.

>> JOHNATHAN MARTINIS: I can't imagine anyone not knowing who I am. For the 99.9% of the audience that doesn't know who I am, my name is Johnathan Martinis. I'm the Senior Director for Law and Policy at the Burton Blatt Institute at Syracuse University.

I'm an attorney. I've been working with people with disabilities for, well, my entire career, but more importantly than that, from a very young age, I was exposed to civil rights or as I call them, human rights, or as we all should call them, life.

I had an uncle who had cerebral palsy and he was at the dinner table with all of us. He had a life like all of us. And he was born in the 1950's and my grandfather made sure that he had the same chances to have the same life as everyone else.

So, here we are in 2019, or when I was in law school, a little bit before that, and people with disabilities weren't at the table either literally or metaphorically. This field – these things that we do, it's a chance for us as a country and as a human race to finally live up to what was said in the Declaration of Independence. All people are created equal. It's just taken way too long for people with disabilities to be considered people who are created equal.

>> CALEB BERKEMEIER: Yeah. Thanks. I think our topic for today, you know, is a great way for us to move in that direction. So, why don't we start by talking about supported decision-making. Can you give us an overview of what that is?

>> JOHNATHAN MARTINIS: Sure. Well, you just did it. Whenever I'm asked what supported decision-making is, I just say you just did it because supported decision-making is getting the information you need to understand what you need to understand to do what you have to do and to make the decisions you have to make.

It is what everyone, people with and without disabilities, do every day. People listening to this podcast, you've probably used supported decision-making more than once today because we all do it. Every one of us. In fact, we're encouraged to do it.

Think about the number of times that you were told not to go off half-cocked or not to make a snap decision or to consult with your coworkers or to talk to people before you did something.

Whenever you do that, whenever you're getting help, whenever you're getting advice, whenever you're asking for and using information from friends or family or professionals, every time you ever ask the doctor to explain something in plain English, you are using supported decision-making because you are asking someone else who has information you need to help you understand your situation so you can decide what to do.

That's all it is. It is something that is very common, that everyone has always done. The difference is that people with disabilities have been looked at differently. When a person without disabilities, or as I call it, a temporarily able-bodied person, asks for help, everyone says you're being smart. Everyone says you're doing what you should do. You're getting what

you need to do. You're making an informed choice. It's a virtue to use supported decision-making. In fact, you don't call it that if you don't have a disability. You just call it decision-making.

So, it's a good thing. But forever, people with disabilities have been looked at differently. If you have a limitation and you ask for help, everyone is going to assume that that means you can't do things. That means that if you ask for help doing something, it means you can't do it. It means someone else has to do it for you. And that is what has led for, well, fifteen hundred years of law, of things like guardianship where we assume that people who need help doing something aren't able to do anything and therefore really, really often, lose the right to do everything.

So, when I'm asked, again, to wrap up a very short question with a very long answer, what supported decision-making is, I say think about the way you make decisions. In fact, it really shouldn't even be called the supported decision-making. It should be called decision-making or life because we all do it every single day.

>> CALEB BERKEMEIER: Yeah. I really like the way that you approach that. We kind of do the same thing here. You know, when we're asked to do presentations on something like customer service or how to interact with people with disabilities, you know, sometimes there's an assumption that there is kind of a different set of things that you have to do in order to have that interaction. What we have to keep reminding people is that it's actually not different. Most of what we're trying to do is get people to stop doing things that are different for disabled people.

>> JOHNATHAN MARTINIS: Right. The only difference – the only difference is in what each person needs. And again, that has nothing to do with disabilities. You and I, we just met, sir, but I will guarantee you there are things that you can do that I can't. And I guarantee you there are things I can do that you can't. I will guarantee you, you use different help than I use to get things done. Some things that you do without getting help, I need help to do.

So, the difference in supported decision-making or decision-making, is just what each person needs when they need it and how they need it. And that doesn't matter whether they have a disability or not. We all have characteristics and abilities. We all have things we do well and don't well.

What supported decision-making does is it helps each person, again, whether they have a disability or not, maximize their strengths and minimize their weaknesses and get the support they need to do what they have to do.

>> CALEB BERKEMEIER: So, let's talk a little bit more about the alternative which is guardianship. Can you describe what guardianship is?

>> JOHNATHAN MARTINIS: Sure. Guardianship is a legal process. I mentioned 1,500 years. I say that because the first time we ever wrote the laws down in the western world – the eastern world has us beat by thousands of years – but in the western world, first time we ever got all of the laws together was in the Roman Empire. An emperor named Justinian. I know this because I'm a geek. I named one of my children Justin.

But the Emperor Justinian, for the first time, gets all the laws together, puts them in a book called the Justinian Code. One of those laws said if you are feeble-minded – that's their word – you had to have a curator put over you to make decisions for you. So, by having a disability, you lost your rights.

And that was the first time that was put down in law and we have followed that for 1,500 years. It has – it has moved forward. So, what it says now essentially – every state has its own laws. Where you are in Maryland, the laws are slightly different from where I am in Virginia.

But essentially, guardianship says that if a judge decides that you, sir, are unable to make some or all of the decisions in your life because of your disability or any other reason, you simply cannot do it, then that judge takes away the rights that you truly cannot exercise and gives them to someone else, say me.

In that situation, I become your guardian. Some states call that a conservator, California, for example. In Louisiana, they have their own terminology called interdiction. But the way it works is pretty much the same. You lose rights. I get them and I exercise them for you.

And you know what? If it worked that way, there would be no problem. I have no problem with guardianship. Some people definitely need to have guardians for some things in their lives.

But unfortunately, even though the laws – my state in Virginia, your state in Maryland, and just about every other one – say that you should only take away the rights that you truly can't exercise, we know from study after study that 90% or more of guardianships take away all rights, regardless of what you can do.

So, in other words, if you have a limitation in doing something, you truly can't do something, or it's assumed you can't do something, what's going to happen 90% of the time is you are going to lose all of your rights, including the things you can do.

And I call that overbroad or undue guardianship because like I said, there is nothing wrong with guardianship when it's needed and appropriate. The problem is when we've got a person who is able to exercise his or her rights, either with or without help, and then loses them anyway just because we assume 1,500 years of cultural assumptions that a person cannot do it just because they have a disability.

When that happens, you know, you lose all of your rights. And I know one law professor who calls that civil death because in the eyes of society, you cease to exist. You have no rights to do anything unless I'm okay with it.

I mean, the guardian can decide where you go, who you see, what you do, whether you work, where you live, whether you get healthcare. As one congressman put it, sometimes when you die. When it's that way, it can be, again, in a congressman's words, the most severe civil penalty that can happen to an American citizen.

>> CALEB BERKEMEIER: Yeah. As I was doing the research for this episode, I didn't really know much about the full scope of guardianship and I was kind of surprised at the – the full range of things that can be taken away from a person with a disability, including who you're able to speak to. That was kind of surprising.

Hey, can you talk a little more about like, why – why that right? Why does that need to be restricted in some peoples' eyes?

>> JOHNATHAN MARTINIS: You know, the way I look at it is this. As a society, we mean well. It's that we're incorrect so often but we mean well.

Society sees a person with disabilities, sees a quote, unquote, “vulnerable person” and wants to protect that person. And the way that’s translated in guardianship and with people with disabilities is they are looked at for I guess good motivations, as less able to do things, and therefore to keep them safe, to keep them protected, we need to take away the thing that we think that they can’t do as opposed to build up the ability, but we take it away.

There is a really interesting Supreme Court case from about ninety years ago but it’s still legitimate. It’s actually called *Olmstead* and in the listing, known as the *Olmstead Decision*, this is not that one.

But what the Supreme Court said is that when we mean the most well, we have to be the most careful because when we act with the best of intentions but don’t understand the consequences, really bad things can happen. I think the quote is the greatest dangers to liberty lurk in men of zeal acting with good motivations but without understanding.

Think about it. If we have the good intentions of protecting someone and really think that taking away their right to choose who to talk to because if they talk to the wrong person, they can get hurt, we think that’s the right thing to do. But here’s the problem with that. We have got forty years of studies, study after study after study, that say that when people with disabilities make more choices, when they have more rights – the phrase is self-determination – when they can do more things, when they have more control over their lives, their lives are better. People with disabilities – I’m talking about compared to other people with disabilities who have similar abilities and limitations – we know that those that have more control of their lives have been found time and time again to be more independent, more likely to be employed, more likely to live in the community, healthier, happier, and yes, safer.

In fact, there was just a study called the National Core Indicator Study that came out last year where they looked at people with disabilities, people with intellectual and developmental disabilities, and they compared them to other people with intellectual and development disabilities of similar abilities. So, they used the old phrases, mild, moderate, and severe. So, they compared people with mild disabilities to people with mild disabilities, et cetera, apples to apples is my lack of scientific phrase.

Well, what they looked at was their quality of life across a whole bunch of variables. One of the things they looked at was whether or not people had a guardian. And across the country, in Maryland, in Virginia where I sit, in every state they did this study. What they found is that people of similar abilities, mind you, who did not have guardians, were more likely to be independent, employed, live in the community, have friends, go to the church of their choice, date and socialize, have better understanding of their rights than people who did have guardians.

There's another study that says people who were more self-determined, specifically women with intellectual and developmental disabilities who are most likely unfortunately to be abused and neglected, those that have more self-determination are safer because they're better able to recognize and avoid abuse.

So, all of those old cultural assumptions that result in rights being taken away, all of those well meaning assumptions, mind you, where we say we want to keep this person safe so we'd better not let them talk to someone else, we want to keep this person safe, so we'd better not let them choose where to live or choose where to work or date or do anything that they choose to do.

All of those old assumptions, they're actually wrong because forty years of science says that people with more self-determination who make more choices, who have more options, have better lives.

So, again, a long answer to a short question. The reason why guardianship so often takes away basic rights like who you can see and what – who you can hang out with and where you live and what you do is because society doesn't realize, and they're meaning well, that they could actually be making the situation worse, making people less safe by taking away their right to make choices.

>> CALEB BERKEMEIER: So, how do people end up with guardians? I suppose one way is when the person turns eighteen but what's the full range of ways that someone can get a guardian?

>> JOHNATHAN MARTINIS: The only way to get a guardian is to go to court. Someone has got to ask a court to appoint a guardian. And people come to me asking about that all the time. What I think people don't realize

is actually when you go to court to request a guardian, what you're doing is you're inviting the court into your life for the rest of your life because ultimately the court is the guardian.

The court reviews the person's job as a guardian. The court is ultimately on top of – you have to report to the court, et cetera.

So, the only way to become a guardian once a person is an adult, and you said turning eighteen, is to go to a local court and ask the court to appoint you the guardian. To do so, and remember, all state laws vary but they're generally the same, to do so, you're supposed to go to the court and the court is supposed to hear your evidence and it's supposed to be reviewing to see if you, the person with disabilities, is able to make decisions for yourself with or without help.

Unfortunately, again, what we know from studies is the vast majority of court cases take away all rights even though state statutes say they shouldn't. But the answer to your question is they get a guardian by going to court and you can go at any age. The fastest growing number of people going into guardianships are eighteen-year-olds with disabilities which is a whole other terrifying development. But there is no age limit. You can request a guardianship for anyone over eighteen.

>> CALEB BERKEMEIER: And what does – what role does IQ play in these decisions?

>> JOHNATHAN MARTINIS: Way too much in my opinion. This is a whole other tangent I often go on but often courts, because again, courts aren't well schooled in this because society isn't. They look at a person's IQ and they say whether IQ or your IQ should determine whether or not you can make decisions. Like, your score on a test can determine whether or not you're able to make choices.

We know instinctively that's not true. Think about the IQ tests you've taken, whether formally or on the internet. What an IQ test does is it asks a person – a person with disabilities in general, they go to a doctor's office – they're asking a person with disabilities to sit in front of a person they've never met before, in a place they've never been before, and do tests they've never done before like if the train is leaving Newark going one

direction at some miles an hour and another train is leaving California, when do they meet?

Questions like that are what we see on IQ tests or build a pyramid or reproduce a shape. How in the world is that related to a person's ability to make decisions?

I'll tell you about the young woman I worked with named Jenny Hatch and what her IQ test showed, but isn't it better to look at how a person actually makes decisions to decide if they can?

I mean, isn't decision-making something that we learn throughout life and that we can actually review? How a person reacts to certain situations, what a person does when presented with a certain situation. Couldn't we just observe a person to see what their decision-making methods and skills are?

So, to be very honest with you all, I'm not going to say that IQ should never play a role in anything. I think it's really unsuited for the vast majority of guardianship cases because it simply has nothing to do with how we make decisions.

>> CALEB BERKEMEIER: Yeah. You mentioned Jenny Hatch. Why don't we go there and talk a little bit about that to kind of demonstrate how the system works.

So, who is Jenny Hatch?

>> JOHNATHAN MARTINIS: Jenny is a young woman with Down syndrome. And Jenny, when I met her, was twenty-nine years old. She had graduated high school. She had her own job. And by job, I mean not a supported job, not a special job. She had her own job. She had been working at a job for five years, paying regular taxes, making regular wages.

Jenny had her own apartment, not a group home, not a supported apartment, her own place with a roommate.

Jenny was a political volunteer. Jenny had a church she went to. Jenny had friends she liked. Jenny had a life. Jenny, in fact, had a life like you and me and it's all she wanted.

Whenever anyone asks me about Jenny, that's what I say. She had a life like you and me. She didn't set out to be the patron saint of supported decision-making. She just wanted to live her life and was living her life really well actually, until one day when she was riding a bike, she got hit by a car and had to have surgery.

Now, mind you, that accident had no impact on her ability – her cognitive ability, her decision-making, her thought process. It was raining. The car hit her.

But she found herself on the receiving end of a petition for guardianship filed by her mother and stepfather and the court, like many courts, didn't really consider a lot of evidence. In fact, Jenny walked into a courtroom in Newport News, Virginia, a very tiny courtroom, mind you, with all of her rights, with the right to do everything that you and I do and that she had been doing her entire life. It only took three hours and she walked out of that courtroom; she was under guardianship. She had lost all of her rights.

In fact, a preprinted order, they walked into court with an order already written, said that the guardians who were appointed after those three hours, and it was called a temporary guardianship because she still had the right to a full trial, but you know, it wasn't going to be any time soon.

The guardians then had the right to decide where she lived, who she saw, what she did, what kind of medical care she got, if any, including whether to deny medical care.

Let's see. What kind of education she got, therapy she got, what kind of services she got, and who she could see during the day.

I'm not kidding when I tell you this. In fact, people always look at me like I'm exaggerating. I put all of this online. There's a website called the Jenny Hatch – it's called Jenny Hatch Justice Project dot org. Jenny Hatch Justice Project dot org. There's a section on Jenny; a dropdown menu says the Justice for Jenny Trial. You'll actually see some of the stuff from the trial because it's mind blowing, because Jenny, who had her own place, was then put in a group home where she wasn't allowed to see her friends unless her friends filled out a permission slip.

Yes, if you wanted to see Jenny, you had to fill out a permission slip where you said when you were going to – what you were going to do with her, for how long, when you'd have her back, where you were going to go. And on this permission slip, you had to agree to the rules of seeing Jenny. Rule number one, you're not allowed to talk about the guardianship because it would upset her to do so. It upset her because she didn't want to be under guardianship.

But think about it. Jenny said I want to see my friends and she was told, get used to your new life. You'll make new friends.

She wanted to go to her church. She was told, get used to your new life. We go to this other church.

She wanted to go back to work and then work wanted to have her back and she was told, get used to your new life. You now work here and here was a sheltered workshop where she made less than minimum wage. In fact, I think she made less than \$1,000 over eight months working pretty much fulltime.

Jenny's cell phone was taken away. Her laptop was taken away. Her pass – her Facebook password was changed.

Again, you'll see all of this if you go to Jenny Hatch Justice Project.

So, this young woman who had every right you and I had, who had a life just like you and I had, in the space of three hours, simply because she had Down syndrome, lost all of those rights.

And going back to your last question, one of the main pieces of evidence against her was that her IQ was low. In fact, my doctor, the expert that I had hired – I got involved in the case after that hearing – the doctor I had work with Jenny said her IQ is 49. She can't make decisions.

I'm like, shouldn't you guys talk a bit more? Why don't you go to lunch? The doctor came back and said oh, she makes her own decisions. She looked both ways before she crossed the street. She ordered her food. She paid for her food. She gave the right amount of money to pay for her food. She counted her change. She took care of her hygiene. She had pleasant conversation with me. She didn't talk to strangers. She, you know, kept her

napkin on her lap. She ate politely. We talked well. We came back. She acted safely.

That's what decision-making is, isn't it? It's how we live our lives. That's not dependent upon a number on an IQ test. But it took, you know, upwards of a year and six days of trial because what we demonstrated was that Jenny uses supported decision-making like you and me.

And it, frankly, shouldn't have been very hard to do that because there were so many examples. Like, even the doctor who examined her for the other side, who examined her while she was on Percocet, mind you, said things like Jenny needs assistance to make decisions. She needs someone to guide her and make – give her assistance so she can make decisions. About legal stuff, she would need assistance to understand legal documents. She would need assistance to work her bank account. She needs assistance to make healthcare decisions.

Think about it. Doesn't that describe all of us? There's no one listening to this podcast or in this world or you know who makes every single decision in his or her life without ever getting assistance.

So, the fact that we're all saying she needs help is we're all saying the same thing. She's like all the rest of us. Now, the help she needs is a little different, just like everyone else's. It might be more intense than some. It might be longer-term than others. But the fact remains, like you and me, Jenny needed help to make decisions sometimes.

And we had evidence that when she got that help, she made decisions just fine, just like you and me.

Just one example. It turned out that when Jenny was eighteen, so eleven years before all of this happened, her parents had her sign a power of attorney. So, we asked, if you think Jenny can't understand and make decisions, how could she sign a power of attorney? I mean, it was one of those internet power of attorneys with all of the long words that even I as a lawyer don't understand. And they answered that Jenny could understand the power of attorney because the lawyer explained it to her. The lawyer went through it page by page, line by line, let her ask questions, got to know her, understood the way Jenny communicated and communicated with Jenny. And they said in writing and under oath, that based upon these

series of consultations, the lawyer decided and we concurred that Jenny could understand that document.

At trial, they also said they ran it past their doctor and their doctor agreed that with that kind of assistance, Jenny could understand it.

Isn't that the perfect definition of supported decision-making? And we heard it time and again that when Jenny's case manager said she went over Jenny's person-centered plan with her, page by page and line by line and let her ask questions, Jenny understood it.

So, just like everyone else, when Jenny got help, she could do it. So, we wouldn't be judging Jenny by her diagnosis, by her IQ, by anything other than what she is actually able to do. And we were able to show that Jenny actually does make decisions when she uses support, good decisions.

And after a year, six days of trial, the judge in that small courtroom in that small town in Virginia held that Jenny should not be in a permanent guardianship, that she should be empowered to use supported decision-making, and that she should have the right to live with her friends who did support her.

Technically speaking, the judge kept Jenny in a limited guardianship for one year. She made the guardians the people Jenny wanted to live with. Their names are Jim Talbert and Kelly Morris and I can't say enough things about them. And it was limited only to health decisions and safety decisions. But the judge said your job, guardians, and every guardian's job, is not to make decisions instead of Jenny or instead of a person under guardianship. The guardian's job is to empower the person to make decisions him or herself using supported decision-making. That was the first time a trial judge ever used those words in an American courtroom.

So, just like that, Jenny walked into a courtroom, three hours later lost all her rights. It took a year but she walked out of the same courtroom with her rights back and with additional protections that empower her to keep making decisions. And yes, she is still living with her friends six years later. She is making – she is not under guardianship. That guardianship ended in a year. So, she has been living free for five years, working, having a life. She wrote the foreword to a book that I wrote and she's a frequent speaker.

She and I spoke with the Department of Education in Nevada about the best ways to empower people with disabilities.

If you want to know more about Jenny and Jenny's case, again, Jenny Hatch Justice Project dot org. And like I said, Jenny wrote a book with me. She wrote the foreword. The book is called "Supported Decision-Making: From Justice for Jenny to Justice for All." And we have it on Amazon as a guidebook to help people use supported decision-making in their lives.

>> CALEB BERKEMEIER: It's definitely a great story and I recommend it to everybody. So, under that restrictive level of guardianship that she had, did that cause any problems for her ability to get legal representation?

>> JOHNATHAN MARTINIS: Well, I tell the story this way, is that given that you were not allowed to talk to Jenny about her legal case and you weren't allowed to see her without a permission slip, the first time I met Jenny, technically I guess I broke and entered because I walked into the group home with her other attorney and said I want to go see Jenny. Talk fast, carry a briefcase, that lets you go places.

So, that's how I met Jenny. Technically she wasn't allowed to see me. I guess I broke and entered and worse, think about that permission slip that said you're not allowed to talk to her about the guardianship case. And again, I had to put this online. But one of the first things I did was contact the attorney for the guardians and say, the permission slip thing can't possibly apply to me. I mean, you can't tell me I can't talk to Jenny about her own case. I'm her lawyer.

And essentially I was told, yes, it does apply to you. You can't talk to Jenny.

So, we had to go to court for the right just to talk to Jenny about her case. I hadn't even seen her file. I had to go to court to ask the judge to let me talk to my client. Now, think about that for a second. When we talk about rights and you talk about restrictions, think about it this way.

Imagine if Jenny was an axe murderer caught with an axe and a head, saying how she did it and laughing evilly. She'd have a right to talk to an attorney. She'd have a right to have that attorney take her side.

So, we literally had to go to court to ask a judge to give Jenny Hatch, a young woman with Down syndrome, the same rights as an axe murderer because apparently she wasn't lucky enough to be an axe murderer. She was too unlucky in that she was a person with disabilities under guardianship and apparently they don't have the rights that axe murderers do.

Thank God the judge agreed because if you can imagine how scary that is to be Jenny Hatch, to want your rights back, to want a lawyer, to have a trial coming up, and to apparently have no right to talk to your lawyer about that case. That's the danger when we mean well. Bad, bad things can happen.

>> CALEB BERKEMEIER: Yeah. I would say that's probably one of the most disturbing things that I discovered when I was reading about this case, the fact that you know, she would have to go to court. Someone would have to go to court in order to actually be able to represent her in court.

>> JOHNATHAN MARTINIS: Yes. It was a contested matter. We had to file briefs and have an argument. The attorney for the guardians argued that I shouldn't be allowed to be Jenny's attorney because she already had an attorney. So, apparently, if you have a right to a lawyer, you only have the right to one lawyer. Or you know, your lawyer shouldn't be allowed to speak to the person about a case.

It's just, you know, it's scary. It's an example of we go too far. It starts with meaning well. 99.9% of people who seek guardianship are well meaning parents or friends or children who love this person and want to see that person protected.

Like the Supreme Court said, the greatest dangers to liberty lie in people of zeal, well-meaning but without understanding. Bad things can happen. We have to be very careful.

I never say people should never be under guardianship. I just say we need to think about it first and that's actually not even my position. That's the position of the National Guardianship Association. That's a national organization made up of guardians by guardians and for guardians. Their website is guardianship dot org.

Their official position is before you seek guardianship, try something else first. Try something like supported decision-making. See if you can empower the person to be able to make his or her own decisions before asking for a guardian because it might work. And we know from the science that people who make more choices and have more rights have better lives.

You know what? If it doesn't work, guardianship will always be there. It will be and should always be a backstop. But we shouldn't go running to it first. The rights at stake are just too precious.

>> CALEB BERKEMEIER: One of the things that I didn't really understand from the case is that it wasn't until she was twenty-nine that she entered into guardianship. So, I mean, I guess that means that she had been living quite some time you know, without a guardian. She was making her own decisions.

>> JOHNATHAN MARTINIS: All true.

>> CALEB BERKEMEIER: So, that surprised me. Like, I mean, I can kind of understand the logic at least of you know, when someone turns eighteen and the parents want to go become guardians. I can at least understand the logic of it even though we might disagree if it's necessary. For someone who is twenty-nine, it's like, she should have been – she had demonstrated already that she didn't really need a guardian just by the very fact that she was twenty-nine when they tried to get her into that system.

>> JOHNATHAN MARTINIS: Yeah. It's not for me to say Jenny's mother and stepfather's motivations. They filed the guardianship petition when she was twenty-nine. One of the things they said was that the accident that she was in proved to them that she needed a guardian, that she couldn't live safely.

The irony of that is after the case was over, the insurance company for the person who hit her gave a settlement and actually gave up every penny in the insurance policy. Meaning not only did Jenny not cause the accident, it wasn't even partially her fault. So, you know, whatever their motivations were, if it was because she got into an accident, it was an accident that

wasn't her fault. And if everyone who has ever gotten rear ended needed a guardian, we'd probably all need guardians.

So, as to why they did it, it's not something I can answer. But you're right. She was twenty-nine. She had the same job for five years. She was a political volunteer. She knew people in the House of Representatives and the Virginia General Assembly quite well.

She – people from the community came out to support her. She had witnesses. One person sat in that courtroom for days until he got a chance to talk because he wanted to tell the judge that Jenny was helping him create an anti-bullying curriculum, to help people, you know, be better parts of their community.

Another person testified that she had been volunteering with Jenny for years and years over things like breast cancer research and had never seen Jenny act unsafely or inappropriately.

A doctor who Jenny knew well testified, she was also a council member for the town of Virginia Beach, I believe, testified how Jenny was very active in politics and very – very well-suited to living in the community.

Someone else testified how much he missed her because he used to come by her office every now and then because he worked for the republican party.

So, yeah. She had a life. That is the biggest thing I stress when I talk to Jenny. There is nothing special or angelic. We shouldn't make the mistake of making anybody a symbol. Jenny just had a life like you, like me. And the scariest thing when you have a life like you and me, is the thought that you could lose it all in three hours. And that's what happened to her.

>> CALEB BERKEMEIER: So, let me wrap up on this. Is there anything practical that we can do to move guardianship more in the direction of only used when necessary and supported decision-making is the norm?

>> JOHNATHAN MARTINIS: Yeah. Plan. Plan and act in advance. The thing is, supported decision-making should not be just seen as an option or as an alternative to guardianship. If we look at supported decision-making just as an alternative to guardianship, that means that if you've got a child

with disabilities, when that child turns eighteen, you have a choice to make. Guardianship or supported decision-making.

That's kind of where we are now or just, really, people see it as no choice. You have to go to guardianship. People know about guardianship. They've been told about guardianship. Guardianship has been around like I said, for 1,500 years.

So, if we just present something like supported decision-making as an alternative at that moment, despite all the science, despite stories like Jenny Hatch's, and despite what we know from studies showing that people who use supported decision-making are more self-determined, they're still going to pick guardianship because it's what they know.

So, the way to minimize the use of overbroad and undue guardianship, and remember, guardianship when it's appropriate is a good thing so I'm not talking about never guardianship. It's to start infusing decision-making all through life.

So many of the supports and services, in fact, I think all of them, that people with disabilities use and people take part in every day have at their core, supported decision-making even though we don't call it that.

A couple of brief examples. When we are in school, which is the first place we learn to make decisions outside of the home, if you're a person with disabilities and have the right to special education, you have a right to an individual education plan. It's a meeting where you decide the person's education goals and objectives.

Well, the Department of Education, US, says that the best way to do that is what's called the student led IEP where, as the student gets older – and by the way, if you're listening to this and have a child in education, get your child to the IEP meeting even for a couple of minutes. The best thing we can do is teach the child that this is his or her team and start to work with that team.

The idea of a student led IEP is that as the student gets older, the student takes more responsibilities at the IEP meeting. You know, a three-year-old, by and large, could say his or her name. A five-year-old could say what they want. A seven-year-old can pick a favorite subject. A nine-year-old can

say what they want to do that summer or how they want to do in school and what they want to do.

The idea is as the student gets older, the student takes more responsibilities to the point where the hope is when the student is eighteen, the student is essentially leading the meeting. The student is working with the team to collaboratively develop that IEP, to come up with the information and create the goals and objectives and agree to the IEP.

In other words, the ultimate goal of the student led IEP is for the student and team to work together, for them each to give each other information, for the team to provide information, advice, and help develop those goals so that the person can then agree, yes, this is the IEP I want and then sign it.

In other words, the team provides information, advice, and support. The student decides. Doesn't that sound just like supported decision-making?

So, if we are infusing that from a young age – and the District of Columbia Public Schools starts that at age three, by the way, starts supported decision-making and encouraging people to work with others to help them understand decisions – we are teaching a practice. We are creating a habit.

So, if you've got someone who is making decisions and showing that ability all through their young years, guardianship isn't necessary. We've demonstrated that.

But you can go farther than that. If you're getting employment services through vocational rehabilitation, you have a right to an individualized plan for employment where they are supposed to provide you with informed choice which is defined in law as your counselor giving you information, telling you about resources, giving you advice, telling you about potential jobs and providers with the goal that based upon that advice, I can decide the job I want to get and the supports and services I want.

In other words, the counselor gives me information and support. I pick my job goal. I pick my supports and services. Doesn't that sound like supported decision-making?

Person-centered planning. If you're getting a Medicaid waiver, you're working with a Center for Independent Living, or any other federally funded healthcare provider or agency, they're required to provide person-centered planning. In person-centered planning, the counselor is required under law to find out what is important to the person and for the person, to help the person say and understand where they are now or where they want to be, and develop their goals and objectives so that the ultimate goal is that the counselor gives the person information and advice so the person can choose his or her goals, objectives, and supports. Doesn't that sound like supported decision-making?

And we can go all through life. End of life planning. Five wishes in the conversation. Or just guided charts or guided conversations about what we want for the end of our lives and what we want to do up to and including what kind of music we want at the service if we want a service.

Financial planning through an able account or a special needs trust or a power of attorney is all about supported decision-making because just in the example of an able account, you can name a person who can have access to your account, who you can work with as you decide what kind of money you want to put in, take out, how you want to save, spend, and budget.

So, supported decision-making isn't a separate thing. It's not a separate program. It's not just for people with disabilities. I can't stress that enough. What it is, is the way we live our lives and it is infused throughout the support systems that people with disabilities use.

So, if we do that, if we make sure that these support systems are using supported decision-making, are respecting the person's choices, protecting and empowering the person's choices, then what we're doing is not only scientifically proven to help the person have a better life, but we're also proving the person does and can make his or her own decisions and therefore there is no need for a guardianship.

And when a person does need a guardianship, because that exists, when people do need guardianships, and some do, just about every state law, Maryland's does, Virginia's does, so many others, require the guardian to do exactly what the judge in Jenny's case said, work with the person, help the person regain or learn the ability to make decisions.

So, the guardian's job is to use supported decision-making to empower the person to the maximum of that person's abilities. So, even in a guardianship, we should be using that type of support.

So, it goes all through our lives. So, we don't need to look at supported decision-making as a yes or no guardianship thing. We need to look at it as a yes life thing because that's what it is. We all use it every day in our lives. Every person does and people with disabilities are people with the same rights to make the same choices as everyone else.

>> CALEB BERKEMEIER: My guest today has been Jonathan Martinis. Jonathan, thank you for joining us.

>> JOHNATHAN MARTINIS: Thank you. I realize that we just ran through a whole bunch of concepts in about a half an hour but I am always available to talk about this. You can reach me at JG Martin at Law dot SYR dot EDU. And if you're interested in looking at some of the strategies for making these things happen, please, you can find the book that I wrote with Peter Blanck of the Burton Blatt Institute on Amazon.com, "Supported Decision-Making: From Justice for Jenny to Justice for All." Thank you so much for having me.

>> CALEB BERKEMEIER: ADA Today is produced by the Mid-Atlantic ADA Center and is part of the WADA Podcast Network. You can find our sister podcast, ADA Live, at ADA Live dot ORG.

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