



ADA Live!

EPISODE 25: THE INTERPLAY BETWEEN GUARDIANSHIP AND THE ADA

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Presenter: Jonathan Martinis, the Legal Director for Quality Trust for Individuals with Disabilities and also the Project Director for the National Resource Center for Supported Decision Making

Host: Celestia Ohrazda, Burton Blatt Institute at Syracuse University

VOICE-OVER ANNOUNCER: (Music) Welcome to WADA ADA Live! Talk radio. Brought to you by the Southeast ADA Center, your leader for information, training and guidance on the Americans with Disabilities Act. And here's your host.

CELESTIA OHRAZDA: Good afternoon, and welcome to WADA ADA Live. On behalf of the Southeast ADA Center, the Burton Blatt Institute at Syracuse University and the ADA National Network, welcome to the 25th episode of ADA Live. My name is Celestia Ohrazda. I am the Information Technology Consultant for the Southeast ADA Center and today's host. The topic of today's show is "The Interplay Between Guardianship and the ADA."

I would like to introduce today our speaker, Jonathan Martinis, the Legal Director for Quality Trust for Individuals with Disabilities and also the Project Director for the National Resource Center for Supported Decision Making. Jonathan has over 20 years experience representing people with disabilities in cases under the Americans with Disabilities Act. In 2013, he represented Margaret, otherwise known as Jenny Hatch, in the Justice for Jenny case, which held that Ms. Hatch has a right to use supported decision making, instead of being subjected to a permanent guardianship. ADA listening audience, you can submit your questions about guardianship and supported decision making at any time on ADAlive.org. Jonathan, welcome to our show.

JONATHAN MARTINIS: Thank you, Celestia. Good afternoon. I'm honored to be here.

CELESTIA OHRAZDA: The first question I have for you is what is guardianship?

JONATHAN MARTINIS: Easiest and simplest way I can put it is, it's a legal process. It's about 2,000 years old, starting in ancient Rome, where one person's rights to make choices, their decisions, their most basic rights are taken away and given to someone else. That sounds over simplified, but it's actually true. Guardianship began about 2,000 years ago in the Roman Empire, where if you were –their words – “feeble minded,” they would put you under control of what they called a “curator “to make decisions for you or instead of you. That went on in Britain in the Middle Ages. If you were an “idiot” or a “lunatic” – again, their words - they would take away your rights and put you under the control of a committee. Here in America, we adopted that system, essentially, and we just call it guardianship, where if a judge finds that you have limitations in making decisions, they will take away some or all of your rights to make decisions and give them to someone else called a guardian.

Studies have shown that the vast majority of guardianships, as many as 90 percent, are full guardianships, where all the rights are taken away. So, imagine that all of the rights you have to make choices is given to someone else. One law professor I know says that when you're under a full guardianship, you're an un-person, because you have no legal rights, you can't interact with society except through your guardian. So, what is guardianship? It's a process where your rights are taken away and given to someone else.

CELESTIA OHRAZDA: Wow, Jonathan. What rights does a person with disabilities have under guardianship?

JONATHAN MARTINIS: You have the rights that someone else gives you. Remember, you're going before a judge, and even though the law says that the judge is only supposed to take away those specific rights where you need the most help, 90 percent of the time, that's all of them, whether that's what you need or not. I tell people all the time, when you seek a guardianship, you are inviting the judge into your life for the rest of your life. The judge will be the one who decides what rights the person with disabilities has or what they retain. Under a full guardianship, you can lose the right to vote, the right to work, the right to live where you want to live and do what you want to do. So, again, simply put, starkly put, you have the rights you are given, which is pretty shocking, given that, in America, we're used to saying that all of us have the rights to life, liberty and the pursuit of happiness. I tell people under a guardianship, a lot of times, the right you have is the right someone else gives you. So imagine that, if you had the right to life but someone says, you'll live the way I tell you to. You have

the right to liberty, but you're only going to do what I let you do. And, the happiness you pursue may not be yours.

CELESTIA OHRAZDA: Does everyone with a disability need a guardian?

JONATHAN MARTINIS: No. Every person with a disability is, first and foremost, a person, and every person has individual abilities and limitations. I've never said that no one needs a guardian, but I will tell you that everyone does not need a guardian. You look at an individual person, what they can, what they can't do, where they might need help, where they can do things on their own, and you decide, or the judge decides. A judge is supposed to decide, based upon those specific areas where you may be so disabled that you are unable to make those types of decisions, even with somebody helping you out.

I would say, without a doubt, a person in a coma needs a guardian. A person in the very last stages of dementia, who is unable to communicate or understand may need a guardian for some or for all things. Some people who show no interest in making decisions for themselves or want to surrender their rights may need a guardian, but the vast majority of people are able to play a primary part in their decision making, even if they get a little help to do it, and those folks, they don't need a guardian.

CELESTIA OHRAZDA: Are there different types of guardianships to suit these individuals?

JONATHAN MARTINIS: Yes, there are different types of guardianships. The most basic separation is the difference between a full guardianship and a limited guardianship. Like I told you, a full guardianship is over everything, every single right you have given to someone else, and that's the one that's used in the vast majority of situations, according to studies. What it's supposed to be is what's called a limited guardianship, where the judge looks at your specific situation and only puts you under guardianship if you have an inability to make certain decisions and then only in the areas where you are unable to make those decisions. So, let's say you can do everything fine, but you have, you just can't handle money, your disability stops you from being able to understand the concept of money, you're paying rent or something like that, then you might need a limited guardianship over monetary issues. That's sometimes called a conservatorship, in some states.

CELESTIA OHRAZDA: Is guardianship covered by state law or federal law? How can I find information on the laws in my state?

JONATHAN MARTINIS: Guardianship is covered by state law, and every state has its own guardianship law and its own process. We have a website where you can see the guardianship laws in every state. That's www.supporteddecisionmaking.org, and you

can click on your state, and you'll see things, like the statute on guardianship in each state, whether the person has a right to an attorney in guardianship proceedings in that state. Another option is to contact your state organization called the Protection and Advocacy System, and you can find them by going to the National Disability Rights Network's website, or NDRN.org, and you can contact an organization in your state that specifically addresses disability rights, and they would be able to point you in the right direction.

CELESTIA OHRAZDA: That sounds like a wonderful resource, Jonathan. That was www.supporteddecisionmaking.org?

JONATHAN MARTINIS: Yes, and thank you for saying it's a wonderful resource. We have worked pretty hard to make it that way.

CELESTIA OHRAZDA: How do I find an expert in my state who can help me decide whether guardianship or something else is the right choice for me and my family member?

JONATHAN MARTINIS: That's a hard choice, and it's an individual choice, and that's what I tell families all the time, is that only you can make that decision, and by you, I mean including, and I think primarily driven by the person with disabilities, the person for whom guardianship is considered. Please, if you're listening to this and you're considering guardianship for a loved one, you know, incorporate the loved one into the process, but if you're looking for someone to talk to, I think a decent place to start is us. Again, you can go to the www.supporteddecisionmaking.org website, and there's a contact us or request assistance. We try to serve as a kind of information hub, where we can then reach out to various organizations in your state and see if there's someone we can refer you to. Another option, again, is the National Disability Rights Network, the Protection and Advocacy assistance, they might be a good resource, but please feel free to check us out and try our website.

CELESTIA OHRAZDA: I definitely will do that. ADA Live listening audience, if you have a question about guardianship or supported decision making, please submit it at any time at our online forum at ADALive.org. Now a word from our sponsors.

VOICE-OVER ANNOUNCER: Quality Trust is an independent, non-profit advocacy organization focused on improving the lives of children and adults with disabilities and their families. Quality Trust works with individuals and family members to solve problems, identify opportunities and find ways to make the most of each person's abilities. Their vision is for a community where everyone is respected, belongs, contributes, is valued and shapes his or her own present and future. Their mission is to be an independent catalyst for the change in the lives of people of all ages with developmental disabilities. They partner with people and their families so they can

succeed, thrive and experience full membership in the communities they choose. To learn more about Quality Trust, visit their website at www.DCqualitytrust.org.

CELESTIA OHRAZDA: Welcome back to our show. Jonathan, we're talking a little bit about guardianship and supported decision making, so what are some of the alternatives to guardianship, if I think it's too restrictive?

JONATHAN MARTINIS: There are lots of alternatives. One that I really am in favor of is called supported decision making. It sounds like a big phrase, like a lot of words. I call supported decision making a fancy way of saying what you and I do every day, because everyone needs a little help in making decisions. Think about when you go to the doctor and the doctor throws a whole lot of jargon at you, and you say, can you please explain that in English? The doctor helps you understand precisely what the situation is, and you've engaged in supported decision making, because you've gotten help in understanding what you need to understand so you can make choices you have to make. We do this every day, when we go to the auto mechanic and we have to breakdown things into simple steps so we understand it, when we go to an accountant to ask difficult tax questions, when we ask a lawyer about legal questions, that's all supported decision making.

The clinical definition is an alternative to guardianship where people work with trusted friends, family members and professionals to help them understand the situations they face and choices they make so they can make their own decisions without the need for a guardian. See, it's what you do every day. When you say help me out here, when you say help me understand my options, you're engaging in supported decision making, but there's one critical difference. When you do that, Celestia, you're seen as smart, you are checking out your options, you're doing research, you are checking out your opportunities and making good, informed choices.

Historically, when people with disabilities say I don't understand, can you help me, can you please help me make this decision, they're seen as weak or unable to make decisions, and as we've seen for 2,000 years, that leads to guardianship, where their power to make decisions, their right to make choices is taken away. So, when I talk about supported decision making, I want you to think about the way you get help to make decisions and then realize everyone has that ability, everyone has that right, everyone can play a part in decision making with a little bit of help, just like you get a little bit of help. People with disabilities may need a little more help, different type of help, they may rely upon people to help them understand their choices or communicate their choices or to weigh their options, just like you do, so that when they do it, they're operating just like you do, the only difference is in degree, and supported decision making can be put together in ways for people with disabilities, either informally, where they just rely upon certain people, or through more formal methods,

like through powers of attorney or medical advance directives that include language about supported decision making.

Let me give an example. When we do a medical advanced directive, and everyone is advised to have one, where if you're incapacitated, there's someone you choose to make decisions for you. Why couldn't a person with disabilities have that form, but also have it say if I'm not incapacitated, I want you to help me understand and make decisions? I'm the final decision maker, but I am appointing you as my helper to help me understand, and when I go to the doctor, I can present the doctor with that form, and that would allow you to be part of my supported decision making team, just like you might be if you were going with your mom or a friend or another family member, helping out, and we've all done that for our friends.

So, that's supported decision making. It sounds like a lot of words, it sounds like a lot of concepts, but, really, it's only one concept, it's the way you make decisions and the way that we implement that can be a number of ways. Like I said, there are other alternatives to guardianship, like powers of attorney and advanced directives or representative payees that can incorporate supported decision making methodologies.

I think it's got a lot of potential to finally put people with disabilities on the same plane as people without disabilities, as showing that we all have the right to make choices. And if we assume that we all have the right to make choices, and I think every person listening to this would assume that we're all born with equal rights, including the right to make choices, then the only question should be - how do I make that happen? Supported decision making is about that how.

CELESTIA OHRAZDA: Well, I definitely appreciate having supports in place, that's for sure. I have a question from our listening audience, and that's if guardianship is already in place and I want to modify it or remove it, how could I go about doing that?

JONATHAN MARTINIS: It's not easy. Like I said, when you have a guardianship, you're inviting the court into your life, and if you want to modify or remove it, you have to go back to the court, and if you want to remove a guardianship, often, the legal phrase used for removing guardianship is called restoration, as in restoration to your rights, and most, again, every state has its own laws, but by and large, what those laws say is that if a person is able to make his or her own decisions or has overcome the limitation that led to him or her not being able to make decisions, they can be restored. Well, what if you're a person with an intellectual or developmental disability and that is what gives you difficulty in making decisions? You can never be cured of your intellectual or developmental disability, and too often, that's what's viewed by society as being the thing that's caused you to have a guardian. So, once a person with intellectual or developmental disabilities has a guardian, it's almost impossible to

get out, because they have to prove they were cured, or they have to prove that the judge was wrong to put them in the guardianship in the first place, and I can tell you from experiences, judges don't like being told they're wrong very often, so it's hard. The process exists, you can seek it, you can go back before the same judge and say, Judge, we'd like to modify this guardianship, we'd like to terminate this guardianship, and here's why, and some judges may do it. Others, and I've seen the situation happen, may not.

CELESTIA OHRAZDA: Interesting, and is the same true for supported decision making, if I have that in place, can it be taken away from me?

JONATHAN MARTINIS: Supported decision making is not, at this time, a legal concept, like guardianship, or even a power of attorney. Think of it more as a relationship that can be formalized into a power of attorney document. If I have a successful supported decision making team in place, that should be evidence that I don't need a guardianship, because I am able to make decisions with support from my team. If someone tries to seek guardianship over you and you say, Judge, I have a supported decision making team in place, look, I'm doing this, I don't need a guardianship, the judge could theoretically disagree and say I'm putting you under a guardianship by a stranger, and therefore, your team is no longer in place. So, the answer to your question is it could. It's another reason why I tell people to seek alternatives to guardianship rather than taking your chances in court. I think it's better for everyone to be involved in the process. I think a lot of judges would tell you the same.

CELESTIA OHRAZDA: Thanks a lot, Jonathan, for that valuable information. You've provided quite a bit of valuable information. Before we continue, here is a word from our sponsors.

VOICE-OVER ANNOUNCER: The Southeast ADA Center is your leader in providing information, training and guidance on the Americans with Disabilities Act and disability access tailored to the needs of business, government and individuals at local, state and regional levels. The Southeast ADA Center, located in Atlanta, Georgia, is a member of the ADA National Network and serves eight states in the Southeast region. For answers to your ADA questions, contact the ADA National Network at 1 800 949 4232.

CELESTIA OHRAZDA: Welcome back to our show. We're talking with Jonathan Martinis from Quality Trust, and we're discussing guardianship and supported decision making. Jonathan, how does the ADA, or the Americans with Disabilities Act, and the *Olmstead* court decision affect guardianship and related issues?

JONATHAN MARTINIS: I certainly think they do, and here's why. As I said before, guardianship is a state law issue. The states pass the guardianship laws, the state courts decide whether or not to put someone under guardianship. Lots of times, state agencies oversee the guardianship process, especially when it's a, what's called a public guardian or organizational guardian, so we can see the state is very heavily involved in guardianship.

Now, the Americans with Disabilities Act, in Title II, says that states must implement their programs in a way that allow people with disabilities to live in the most integrated setting, or take part in those activities in the most integrated setting. The most integrated setting is the one that gives people with disabilities the most freedom, the one that allows them to interact the most with people without disabilities. So, in 1999, the Supreme Court said in *Olmstead*, that that part of Title II, the most integrated setting language, which was also called the integration mandate, what that means is that a state can't warehouse people with disabilities in institutions. If a person with disabilities is able to live in the community, wants to live in the community and has the services and supports to live in the community, what the state cannot do is say, yeah, but you're going to live in an institution, whether you like it or not, because what the courts said is that "unjustified institutional isolation is a form of discrimination."

Now, with that in mind, think about what guardianship can do. Like I said before, if you have the right to life, liberty and the pursuit of happiness but there's someone out there with the power to say, I don't care, you're going to live where I tell you to, when I tell you and how I tell you, and you're going to do what I tell you to do, isn't that isolating just like institutional isolation? There's a legal scholar named Professor Leslie Salzman, who wrote an article that compared guardianship, or what I call overbroad or undue guardianship, to an *Olmstead* violation, because if I'm not able to live where I want or do what I want or see who I want, isn't the effect of that just as isolating as being told I must live in an institution?

Now, I have to warn people listening that there has been no case holding this, but I think it fits pretty clearly into the ADA and *Olmstead* rubric, that we cannot tell people you may not see who you want to see or do what you want to do, or live where you want to, if you are able to make those decisions by yourself or with support, and if we do that, if we take away those basic rights to make choices, aren't we dooming people to the same type of unjustified isolation that people suffer when they're placed in institutions against their will?

CELESTIA OHRAZDA: Most definitely. I understand that you represented Jenny Hatch in the Justice for Jenny case, which held that Jenny had the right to use supported decision making. Who is this Jenny Hatch woman and whatever happened to her?

JONATHAN MARTINIS: Jenny's a pretty awesome person, and I'm going to tell her about this so she can listen to the show, too. Jenny was an adult, like you are, like everyone else is, she just happened to have Down Syndrome. Jenny graduated high school, she worked in the community, regular job making regular wages, paying regular taxes, had her own apartment.

When she was 29, she was in an accident, and her parents moved for guardianship. They had their own reasons for doing so, and when I met Jenny, she had gone from her own apartment to a group home because the guardian said you must live in that group home. Remember, like I said, guardians often have the power to say where you live, whether you like it or not. Jenny was no longer working at her job, because the guardian said we don't want you to work there, even though she had successfully worked there for five years. She had went from her job, which she liked, where she made regular wages, paid regular taxes, to what's called a sheltered workshop, where she worked about eight hours a day, what she called snapping snaps together. Bored, but eight hours a day, roughly full time, made less than \$1,000 in eight months.

So, all these things, Jenny went from one to the other, and she was told, get used to your new life, and that's not something you tell Jenny. She wanted to be independent, she wanted her life back, she wanted to make choices, just like you and I make choices. And again, when I talk about things like this, I want you to think about how you would feel if you were placed in this situation, if you were told, Celestia, you can't do the job you love, because no other reason than I say so. You can't live in your house for no other reason than I say so. That's what she faced. Only people with disabilities, for 2,000 years, have been expected to accept that, and Jenny's not the type to accept things like that, and she fought. And I was very lucky to meet her, and I was even more lucky to represent her. And we went through the litigation for a year, six days of trial, a years' worth of litigation, and luckily for Jenny, and I do say luckily, her case caught some national attention, so she had some national experts come in to defend her.

Peter Blanck from the Burton Blatt Institute was one of our most effective witnesses. He came in to talk about all of the negative effects overbroad or undue guardianship can have on a person. We had a psychologist talk about how Jenny is able to make her own decisions using supported decision making. So we were able to say to the judge, you have to not just look at Jenny Hatch as a person with Down Syndrome and say all people with Down Syndrome need guardians, or because you have Down Syndrome, you need a guardian, or for your own good, you need a guardian. You have to look at what Jenny can and can't do, and what Jenny had been doing her entire life was making her own decisions with support.

One of the fascinating pieces of evidence in the case was that Jenny had signed a power of attorney form about ten years before the guardianship case. It was, like, 40 pages long, with all of this legal jargon in it -- talking about stock transactions and medical care and surgery. And I asked the petitioners, if you say that Jenny can't make her own decisions, how was she able to sign this document? And they said, we explained it to her. We went through it page by page and helped her understand what it meant, and our lawyer let her ask questions, and the lawyer went over it with her in real detail and gave her the time to understand it. And only when we decided that she completely understood it, did she sign it. And I said, thank you, isn't that supported decision making? Then we saw that she had filled out and been part of her Medicaid waiver plan, and I said to her case manager, how can she do this if she can't make her own decisions? And the person said, no, we made her part of the plan, we explained it to her, we helped her understand. She made her own decisions after it was explained to her what decisions she had to make, and I said, thank you, that's supported decision making.

And we saw time after time, and example after example of Jenny making her own decisions, and at the end of the day, the judge came out to read his decision, and Jenny kept saying he's sending me home. I'm going to get to go home. And I kept saying, I don't want you to get your hopes too high up. We're going to fight this if you don't win this case. I want you to be ready. And she kept saying, he's sending me home. And the judge started reading his opinion, and the first several parts seemed to say that she needed a guardian. And I kept saying, Jenny, you know, you're strong. You can get through this. And she said, he's sending me home. And then the judge said, however -- and I can tell everyone listening that you never want to be on the wrong side of however -- but this was a good day, because we were on the right side of however, and the judge said that Jenny could make her own decisions using supported decision making. He sent her home that day.

Her friends, who she wanted to live with, were named her temporary guardians for one year, which expired a year ago, in August of 2014. Jenny has had no guardian since then. And they were instructed to help Jenny implement supported decision making, to work with her, to help her make the decisions that she wants to make in the way that she wants to make them. That was the first case where a judge ever, at trial, said a person is not going to be in the permanent guardianship because that person uses supported decision making. I have to tell you, I am recounting this only from having reviewed the transcripts and stuff, because once the judge made it clear he was sending her home, I was kind of busy sobbing into Jenny's shoulder. It was a remarkable day for a remarkable person, who now is the face and the name behind the Jenny Hatch Justice Project, which you can check out at www.jennyhatchjusticeproject.org, and she's out there, she's working at her job, she's

living independently and encouraging other people to do the same. I have done a number of presentations with her, and Jenny brings the house down every time.

CELESTIA OHRAZDA: What an inspiring story, Jonathan. We're almost out of time. One more question. What other issues do I need to think about that would enable a person with a disability to live more independently in the community?

JONATHAN MARTINIS: One overarching issue that addresses, I think, really, everything, and you say to yourself, this particular person has the right to make choices to the maximum of his or her ability, and if we start there, the only remaining question is what does this person need to do it? What does this person need? What is between this person and independence? What are the barriers? And then we work to break through them. There are many, many available supports and services in the community that can be used to help a person live more independently. For people with developmental disabilities, every state has an agency that works with people with developmental disabilities, every state has Medicaid waiver programs that can provide supports and services to increase or improve a person's independence, every state has a vocational rehabilitation agency that can provide supports and services to help a person work, every state has a department of health, every state has a protection of advocacy system. The key is knowing who to come to to ask these questions. Too often, and for too long, for 2,000 years, we have assumed that people with disabilities cannot do things, and that has led to rights being taken away, the most critical rights. Think about the rights that are most important to you in your life, and realize that for 2,000 years, we've been taking them away from people with disabilities. What I recommend is thinking about what we do to preserve, protect and respect those rights, and finding the supports and services needed to do so, and one place you can come is us, and we can serve as an informational hub. We can help you find people who can help you. We can help you, you know, connect with those services and support providers, and again, our website is www.supporteddecisionmaking.org. Please feel free to contact us.

CELESTIA OHRAZDA: Thank you, Jonathan. I would like to thank Jonathan Martinis, the Legal Director for Quality Trust for Individuals with Disabilities and also the Project Director of the National Resource Center for Supported Decision Making.

This show will be archived on our website, ADALive.org, and thank you also to our ADA Live listening audience. The Southeast ADA Center is grateful for your support and participation in this series of WADA ADA Live broadcasts. You may submit questions about any of our ADA Live topics by going to ADALive.org. Please join us again on November 4th, 2015 for another episode of WADA ADA Live.

If you have questions about the Americans with Disabilities Act, please contact your regional ADA center at 1-800-949-4232. Once again, that's 1-800-949-4232. All calls are free and confidential.

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