



ADA Live!

Episode 75: Supported Decision-Making: From Justice for Jenny to Justice for All!

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

Host: Barry Whaley, Project Director Southeast ADA Center

Jonathan Martinis: Hi, this is Jonathan Martinis. You're listening to ADA live.

[Music]

Barry Whaley: Good afternoon everybody. On behalf of the Southeast ADA Center, the Burton Blatt Institute at Syracuse University, and the ADA National Network, I want to welcome you to episode 75 of ADA Live. I'm Barry Wayley I'm the project director for the Southeast ADA Center. And before we move on, listening audience, I want to remind you, you can submit your questions about the ADA at any time to ADA Live.

Barry Whaley: So recently there was a Washington Post article written by Teresa Vargas and it featured both Jenny Hatch and Jonathan Martinis discussing Jenny's struggle to win back her civil rights with Jonathan's help, by utilizing supported decision making. So with us today, one of the authors of a new book, Supported Decision Making: From Justice for Jenny to Justice for All, it's my pleasure to introduce somebody I'm proud to

consider a coworker and colleague, Jonathan Martinis. Jonathan, welcome. We're so happy you could be on the show today.

Jonathan Martinis: Thank you so much for having me, Barry.

Barry Whaley: Let's start with the discussion about Jenny, could you tell us a little bit about her and how you came to meet her?

Jonathan Martinis: Sure. Jenny's my friend. That is the most important thing I can say about her and the best thing, because I am really lucky to have her as my friend. But when I met her, it was about six years ago. Jenny had a life like everyone else, and that's another important thing to talk about her, is that there was nothing special about Jenny. She wanted to have a life like everyone else, and she did. She had a job. She had an apartment, she had a church she went to, she had friends she saw. Jenny had a life like everyone else. But the "problem," quote unquote, is that Jenny has Down syndrome so that when she was 29 years old, after living independently all this time, she was in an accident. She was hit by a car while riding a bicycle. And shortly thereafter her mother and stepfather filed a petition to put her in guardianship, to say that because Jenny has Down syndrome, she can't do all of the things that she had been doing all her life.

Jonathan Martinis: So Jenny walked into a courtroom in Newport News, Virginia in August of 2012 with every single right that you and I have. She had the right to vote, the right to speak, the right to go places, the right to choose who she saw, what she did. She had the same life as everyone else. Three hours later, literally three hours later, she walked out of that court room under guardianship, where she had lost all of her rights. And by all of her rights, I mean specifically all of her rights. The court order said that her guardians had the right to decide who she saw, what she did, what kind, if any, medical care she got, what kind, if any, education, support and therapy she got, and where she lived. So in those three hours, imagine that. In three hours she went from having all the rights you and I have; almost immediately thereafter she was put into a group home against her will.

Jonathan Martinis: She was not allowed to go back to her job because she had to work at the sheltered workshop attached to the group home. She wasn't allowed to go to her church. She wasn't allowed to see her friends. In fact, every time she asked to see her friends or go to church or go to work, what she was told was, get used to your new life.

Jonathan Martinis: So I met Jenny because her friends and her attorney asked me to go meet her, and I didn't know it at the time. But if you wanted to see Jenny, you had to fill out a permission slip. You literally had to tell the guardian when you were going to see her, what you were going to talk about, where you were going to go, what you were going to do.

Jonathan Martinis: And you had to agree to the rules of the guardianship, which are on the back of the form. One of which was, you weren't allowed to talk to her about her guardianship, because it upset her. Do you know why it upset her, Barry? Because she didn't want to be under guardianship. So technically, the first time I met her I broke and entered. I just walked into the group home. If you talk loud and carry a briefcase, I guess people let you go where you want. And I met Jenny, along with her attorney at the time and said, I'd like to help, can I be your attorney? And that's how I met her, because she asked me to help her.

Barry Whaley: What an extreme result of a bicycle accident.

Jonathan Martinis: It's not extreme at all. I wish it was. There are studies showing that more than 90% of guardianships are just like Jenny's was, they take away all rights. Almost every state, and I recently just wrote a paper on this, so I looked at the laws of every state, all say that a guardianship should be limited. They should only take away the rights that people truly can't exercise. And you know what? If that's how guardianship worked, I'd have no problem with it, because some people do need guardians sometimes. In extreme situations, people need a guardian. Jenny didn't, but some people do.

Jonathan Martinis: But what we know from studies is that more than 90% take away all rights, whether or not people can exercise them. It's cultural in a way. We just make an assumption that because a person has a disability, they can't do anything. Now again,

imagine that. Because there are things you and I can't do, Barry. I'm pretty bad at math, but no one says because you can't do math you're not allowed to balance your checkbook, you're not allowed to have money. I don't know, understand medicine, but no one says I can't manage my healthcare. But if you have a disability, for Jenny Hatch, and you don't know something, we all assume, society assumes you can't do anything, and that's how that extreme situation comes about. Society makes assumptions.

Barry Whaley: Real bias against people with disabilities, simply on the basis of disability.

Jonathan Martinis: And it goes back about 1500 years, actually. The first time we wrote the laws down, and I am a huge legal geek, the first time in the Western world we wrote the laws down; Eastern world has us beat by thousands of years, but in the Western world it was a thing called the code of Justinian, in the ancient Roman empire. I'm such a geek. I named one of my sons Justin. But in this code of Justinian, when they put all the laws together for the first time, one of them was the guardianship law. It said if you're feeble-minded, their words, you had to have a curator over you to make decisions for you.

Jonathan Martinis: So the very first time we wrote the laws down, we were taking away rights from people with disabilities, and it's all just flowed from there. It's become part of our culture. In the middle ages, Britain updated that law to say if you were an idiot or a lunatic, their words for people with disabilities, you had to have a committee over you. So it's been a culture that's happened where the society again assumes that if you have a limitation in doing something, it must mean you can't do anything.

Barry Whaley: Jenny, as far as I know, she was the first person to use supported decision making as a way to get her rights restored.

Jonathan Martinis: You know it's funny, I always say that Jenny was the first person who defeated a guardianship at trial, because she uses supported decision making, but she sure as hell isn't the first person to use supported decision making, 'cause you and I do it. Everyone uses supported decision making every day because all supported decision making is, is it's getting help to understand the things you have to do so you can do them. I mean think about the number of times that you are told, get some input, get some

advice. Don't go off half cocked, make an informed decision. When one of my interns asks me a question about something, the first question I asked is who did you talk to and what kind of research did you do to look for the answer? So we all use supported decision making because we all have things we don't do well.

Jonathan Martinis: Again, I don't do math well. I have a calculator. That just really dated me, by the way. I understand my taxes. I have TurboTax. My doctor speaks jargon, I ask my doctor to explain things in plain English. We are all using supported decision making every day. That's the cultural problem, is that we assume people with disabilities can't do the things we do every day. So at trial, yes; we had to show that Jenny, just like everyone else, gets help and makes her own decisions. And there were example after example, like her case manager who thought that Jenny needed the guardian. We asked her if she can't understand things, how did she sign her person centered plan? And she went off on this whole thing about how they explained it to her. They went page by page and line by line to make sure she understood it.

Jonathan Martinis: And then when she understood the page, she initialed the bottom. And when they were sure she understood every page, she signed the last page. So I said, do you feel confident then that the way you explained it to her by going through page by page and line by line, by giving her the chance to ask questions, are you sure that that helped her understand it? She said yes. I said, thank you. That's what supported decision making is.

Jonathan Martinis: We do it in different ways. Everyone is different. Just like we all have different needs. And people with disabilities might need more support sometimes, or different kinds of support. But the principle is exactly the same. Everybody uses help when they need it. But when you and I do it, Barry, when you and I say, I'm not sure I get this, so let me get some more information, everyone thinks we're smart, 'cause we're making an informed choice. We're not going off half cocked. We're getting what we need to make a decision. But when a person with disabilities like Jenny Hatch says, I don't understand this, can you explain it to me? Society assumes she's dumb.

Jonathan Martinis: So that's what that trial was all about, showing that Jenny Hatch is just as capable as all of the rest of us, as almost everyone else in the planet is, of getting the help she needs to do the things she has to do.

Barry Whaley: So I'm curious, was there one defining moment in the courtroom? You got to convince the judge at the end of the day; was there one defining thing that you felt that this was going to lead to a victory for Jenny?

Jonathan Martinis: I thought we were going to lose. In fact, we expected to lose and expected to win on appeal. But I will tell you some moments that really were important, and this is going to sound like I'm sucking up, but I always said that the turning point of the case was the testimony of Peter Blank, who is now our boss. 'Cause Peter got on the stand to talk about what supported decision making is, and how it can impact people's independence. And the judge, who'd been super hostile and wasn't exactly always friendly throughout the year this case was in litigation, listened. And they were talking back and forth like having a conversation, talking about studies that showed that people with disabilities have better lives. We know this, there's 40 years of studies that say people with disabilities have better lives when they have more control over their lives.

Jonathan Martinis: The fancy term is self-determination. When people have more control over their lives, their lives are better. It's not rocket science. Your life is better when you have more control over it. You feel better. But we have all these studies that say when people with disabilities have more self determination, when they make more choices, they're more likely to be employed, safer, healthier, happier, more integrated into their communities. And I sensed that the judge became more receptive, because Peter was on the stand for a few hours, and the judge was, by the end, engaging him in conversation rather than having testimony. With all that said, no, we never thought that we were going to win that one. The story I always tell is that after closing argument, after I paced around the courtroom for 45 minutes waving my arms and hoping for the best, the judge said he'd be back in 15 minutes, and came back in an hour, and started reading his decision.

Jonathan Martinis: The first several pages of that decision are all why Jenny needs a guardian. And because this story sometimes sounds unbelievable, I always tell people, we put it online. You can go to JennyHatchJusticeProject.org and you can go to a section called the Justice for Jenny Trial. You can see the permission slip people had to print out. You can see the closing argument, you can see the order. And if you look at the order, you'll see the first several pages say that Jenny should have a guardian, but by later, he said, however, the guardians aren't going to be Jenny's parents. The guardian is going to be the people Jenny wanted to live with. See, Jenny wanted to live with her friends, Tim Talbert and Kelly Morris, who took her in after she got out of the hospital. I have no problem saying this.

Jonathan Martinis: It's in the court record. When Jenny had to get out of the hospital, she could not go back to her apartment. She needed rehab. Her parents, who were seeking guardianship, remember, would not take her in. So who takes her in? Her employers, Jim and Kelly. And that's who Jenny wanted to live with. So the judge said the guardians will not be your parents. It's going to be Mr. Talbert and Ms. Morris. And then the judge says, that guardianship ends in one year because, Mr. Talbert and Ms. Morris, your job as guardians is to help Jenny make decisions for herself, to use supported decision making. That guardianship ended in August of 2014. Jenny has been living independently, her own citizen like everyone else, using supported decision making, using the help of people like Mr. Talbert and Ms. Morris, and I'm honored to say, me.

Barry Whaley: Thinking about Jenny's life now, obviously it's improved. You've made the case for, when we make decisions, when we have empowerment, we lead a better life. What's Jenny doing now as far as work and her living arrangement?

Jonathan Martinis: She's living her life. Again, I always am very careful to say she's a human being, like the rest of us. She has her ups and downs, like the rest of us. She's no angel, like the rest of us, but what she has is a life. She's got friends, she's working, where she wants to work. She's doing the things she wants to do. She's living where she wants to live. It hasn't always been easy for her, just like it's not easy for all of us. She's

the first one to tell you that she is happy with her life, because she makes her own decisions. People aren't telling her what to do.

Jonathan Martinis: One of the worst things that happened to Jenny because of the guardianship was she wound up losing her right to vote. In Virginia, you automatically lose your right to vote when you're in guardianship, unless the court specifically protects it, and no one protected it. Jenny was a volunteer on campaigns. She called herself a door knocker. She knew her local representatives, and just like that in three hours, she lost her right to vote. So getting that back was huge to her. And in fact, she and I just spoke after election day about the results, and what she liked and didn't like.

Jonathan Martinis: So it's those things we have to think about. I never say that guardianship's evil, or if you're a guardian, you're bad. There are times when it's appropriate, but we have to think about the consequences of it and what we think we're doing with it. I'm not willing to say that Jenny's parents had bad motives. I'm just saying that we often don't think about the consequences. And with Jenny, losing the right to vote was huge. And losing the right to say where she lived and what she did and where she worshiped. These are things that make us who we are. And before we take that away, we should be really careful and think about it.

Barry Whaley: So thinking back to that Washington Post article, which was a great article, incidentally. You're quoted as saying that the number of people who are under court-appointed guardianship has tripled in the last 25 years, which I was just amazed to hear that. Why do you think that is, Jonathan?

Jonathan Martinis: Well, that's a study. We have three different studies. As a preface, one of the things that we don't have with guardianship is a lot of data, but there were three studies done and there were three years, beginning November, beginning in 1994 and going until, I think it was 2009 or 10 that did estimates of the number of people under guardianship, and those studies showed that the estimated number of people under guardianship went from 500,000 to 1.5 million. So yes, it tripled. We basically lost a generation of people.

Jonathan Martinis: And people always say, well of course we're getting older. Alzheimer's is more prevalent. Not true. We are getting older, but that's not the driver. The National Council on Disability just found that the majority of people going under guardianships are 18 year olds with intellectual and developmental disabilities, and the reasons are pretty clear.

Jonathan Martinis: The number one referral source for guardianship are schools and teachers. I was part of a study on that. We were surprised. We asked guardians, we asked parents, we asked people under guardianship, what was the first thing that nudged you to seeking guardianship? What was the inspiration for guardianship? Frankly we expected to hear lawyers or family members; number one with a bullet, educational professionals. And I talk with a lot of people, and that's not surprising anymore, 'cause we hear it all the time, is that a school says, your child is going to be 18 next year. If you don't get guardianship, you can't come to an IEP meeting. Or, in a year, your child is going to have all the rights of an adult. Have you thought about guardianship? They treat guardianship like a stepping stone or a rite of passage. And there were studies showing that too.

Jonathan Martinis: So again, we're assuming what people can and can't do. I mean, think about yourself at 18, Barry. If you were anything like me, were you ready to run your whole life?

Barry Whaley: [inaudible 00:00:17:20].

Jonathan Martinis: I certainly wasn't, and nobody went to my mom and said that when Jonathan turns 18 he gets all the rights of an adult even though it's the same thing as people with disabilities. Someone had told my mom that I'd have been under guardianship 'cause I drove a blue Datsun and dressed in really weird clothing and had long hair. So we all have to look in a mirror.

Jonathan Martinis: And then I can boil it down to fear. Parents of people with disabilities, man, I'm a parent. I have two children, I love them dearly, but they run me ragged. When you are a parent of a person with disabilities, you got to be more than a parent. You are

the advocate, the educational advocate, the attorney, the healthcare advocate. And when someone you trust, like a teacher or a doctor says, get guardianship, what would you do? What's a parent to do? There's a lot of fear and a lot of misinformation because news flash, if a teacher tells you you can't come to an IEP meeting if your student is 18 unless you're a guardian, they're wrong. Student can bring whoever he or she wants to an IEP meeting. In the District of Columbia, they let you say it in advance. I want mom, dad, brother, sister, whoever to come in advance. So there's a million different ways to make this work, and it's just unfortunate that fear keeps winning the day.

Barry Whaley: So let's talk a little bit about the book, Jonathan. Supported Decision Making: From Justice for Jenny to Justice for All. Tell me a little bit about the book and why you chose to write it.

Jonathan Martinis: We chose to write the book, Peter Blank and I, for two reasons. The first we just talked about, fear, is that people are often feeling like they have no choice but to seek guardianship, and supported decision making has become a phrase we hear a lot in the disability field. So much of the material out there on supported decision making is one of two things; one, very, very academic. Like, written for college professors, and I was part of a textbook. I can tell you what that looks like. It's not the friendliest writing. And two, super expensive. That textbook costs about 90 bucks on Amazon. What Peter and I wanted to do was to help people get the information they need to address their loved ones, their children, themselves, their supporters. This book is aimed directly at people on what I call the front lines, people with disabilities, parents, and professionals like teachers and counselors, people who have to actually make things work.

Jonathan Martinis: Not professors, not administrators, not executives who have to tell people what to do, but the people who have to actually make things happen. We talk about Jenny and we talk about supported decision making, but the vast majority of the book is how to make supported decision making work for you, for your children, for the people you support in areas that people have to deal with every day. So we have an entire chapter on supported decision making and special education, how to get the best possible supports and services and special ed. There's model language. There's

suggestions for goals. There's an entire chapter on using supported decision making in vocational rehabilitation to get employment services, to get the best possible job, in health care, in person centered planning. And there's strategies for bringing it all together. The idea being that so many people are sent in so many different directions.

Jonathan Martinis: Again, I hear that from parents all the time. We are sent in so many different directions to get supports and services. It's hard to even get anything in place, and if we can't get anything in place, my kid who is perfectly capable doesn't get what he or she needs, and society looks at him as the failure or her as the failure, instead of the system as the failure.

Jonathan Martinis: This book is designed to get that information to people where they can use it in a way they can use it, and frankly at a price they can use it, because we wanted to make sure people could afford it. So yes, it's on Amazon. I feel tacky, saying like I'm making a commercial for it. But you got the title right. It's called Supported Decision Making: From Justice for Jenny to Justice for All, and it's \$19.99 for paperbacks and \$9.99 on Kindle. But I will tell you this, if anyone out there knows someone or is someone who can use this book and can't afford it, get in touch with me. That's JG Martin, jgmartin@law.syr.edu, and I'll make sure you get a copy.

Barry Whaley: That's great. Thanks Jonathan. We'll come back and talk more about the book in a second. We have to pause for a moment. ADA live listening audience. If you have questions about this month's topic or any other ADA live topic, you can submit your questions at (404) 541-9001 or through our website, which is www.adalive.org. So we're going to pause for a second to hear a word from our featured organization, our employer Burton Blatt Institute, [inaudible 00:00:22:17].

Voice over announcer: The Burton Blatt Institute at Syracuse University, also known as BBI, reaches around the globe in efforts to advance civic, economic, and social involvement of people with disabilities. BBI builds on the legacy of Burton Blatt, former Dean of Syracuse University School of Education, and a pioneering disability rights scholar. Burton Blatt was a pioneer in humanizing services for people with disabilities. He was an advocate of mainstreaming people with disabilities. In honor of Burton Blatt, BBI's

work focuses on two interconnected innovation areas, economic participation, and community participation. Through program development, research, and public policy guidance in these innovation areas, BBI continues to create innovative solutions to the challenges faced by people with disabilities. BBI has offices in Syracuse, New York, New York City, Washington, DC, Lexington, Kentucky, and Atlanta, Georgia. To learn more about the Burton Blatt Institute, visit their website at bbi.syr.edu.

Barry Whaley: Welcome back everybody. We're speaking with Jonathan Martinis. He is the senior director for law and policy at the Burton Blatt Institute at Syracuse University. He is also a co author of a recently released book, *Supported Decision Making: From Justice for Jenny to Justice for All*.

Barry Whaley: So as you were saying, Jonathan, the book not only supported decision making, it's so much more than that.

Jonathan Martinis: Thanks for saying that. I think that's because supported decision making is so much more than what traditionally it's looked at. Like I said, it's a phrase and a paradigm that's really gaining a lot of traction, but I think the way it's being talked about is limiting. People are looking at supported decision making as an alternative to guardianship or another option, something that can be used instead of guardianship, or to help people get out of guardianship, and that's all 100% true. But I also think just looking at it that way is limiting, because like I said, we all use supported decision making every day, so we should be empowering people with disabilities, and frankly everyone, to use it every day in everywhere that they are, because it just makes sense. Again, think about special education. If you work at all in special ed, you know that the gold standard, what they tell you to do is what's called the students led IEP, where the student works with the IEP team to give and get information. And as the student gets older, the student gets more responsibility.

Jonathan Martinis: The student leads the meeting. The student incorporates more information. The student might introduce people, or might ask for certain supports and services, might even be the leader of the team. That's the point of the student led IEP, with the end goal being that the student works with the team, giving and getting

information, to create an IEP with goals and objectives that match that student's abilities and needs, that the student can then say, yes, I want to sign. In other words, the student gets information from the team and the student decides to sign the IEP. That's supported decision making.

Jonathan Martinis: In person centered planning, the team is supposed to work with the person and find out what's important to the person, and what's important for the person, to help the person understand where he or she wants to go, what his or her goals are, and what supports he or she might need to get there, so that they can suggest things that the person might want to do, and the person makes the decision about whether or not to do them.

Jonathan Martinis: That's supported decision making. There's so much in life. Vocational rehabilitation, informed choices, just supported decision-making. Informed consent in healthcare is just another way of saying supported decision making. So supported decision making becomes a link. It becomes a common tongue between all of these supports and services.

Jonathan Martinis: So if we are empowering people to make their own decisions and get the support they need, just like we all do, then what we're actually doing is empowering people to live the exact kind of life that we all want to live, where we make the decisions, and we seek out the help, and we get the information that we need, so that we can make our own decisions and lead our best lives. Isn't that what we all want for ourselves? We want the life we want and the help we need. That's what supported decision making does, and that's what it can do if we look at it as what I call a paradigm, a way for us to live, rather than just a practice, a way for us to address this one thing, guardianship.

Barry Whaley: You mentioned in writing the book that it has a broad audience. How was the book written specifically for people with disabilities? What did they gain from the book?

Jonathan Martinis: Anyone gains, and people with disabilities are anyone. Information that they can use directly in the things that they do. The hope is that people with

disabilities are taking charge of their lives and doing the things they want to do. So anything that book talks about is usable by anyone reading it. For example, when we talk about money management and Able accounts as a way for people with disabilities to be as independent monetarily as possible, people with disabilities forever have been subject to what one writer, Michael Morris, calls a life sentence of poverty. Because if you are on social security or Medicaid, you can't have more than \$2,000 to your name or you lose that money, you lose your Medicaid, you lose your social security possibly. So what an Able account can do is help you save money, because money in an Able account doesn't count against that \$2,000. You can have up to \$100,000 in an Able account and you can put in about \$15,000 a year.

Jonathan Martinis: And here's where it gets really important. The person who has the Able account, the person with the disability, makes the decisions about how to use that Able account, budgets it, saves and spends. And we talked about how to use supported decision making to do that. To get assistance from people, to understand budgeting and to make decisions in spending and saving money; to again, do the things we all have to do. So people with disabilities are getting information that, I hate to say it this way, that society just doesn't give. 'Cause for too long, society has just assumed that people with disabilities can't manage money, or can't manage their healthcare, or have to have someone else do things for them. It's my hope that a person can read this book and go, yeah, I can do that, or I am doing that, and how dare you tell me I can't do that. It's an opportunity to say, these are the tools I need and you're not going to take them away from me.

Barry Whaley: I was just kind of thinking here, how do we get your book, and really the concepts of regular life, a typical life; how do we get this book in front of lawyers and judges and other people in the legal profession who have to address these issues of guardianship?

Jonathan Martinis: Well, you can certainly give it to them. You can buy it off Amazon and hand it off to them. But seriously though, I think what we need to do is, let's talk about the book and I'd love for people to use the book and buy the book and use it as a

resource. But really, what we need to do is just talk to people about things that we know in common sense.

Jonathan Martinis: See, all of those stereotypes about people with disabilities and what they can and can't do and why they need guardianship, they tend to fall apart when you think about them for 10 minutes. I've been in courts across the country talking about guardianship and I always hear the same things. I have to have a guardianship because if I don't, my kid might not take his meds. And it's like, do you think guardians can force people to take meds? Or, I have to have a guardianship or my kid might have sex. Is that what guardians can do? Or, they might get taken advantage of on the street. Is the guardian going to be there 24/7?

Jonathan Martinis: My shorthand is, guardianship is neither a suit of armor nor a chastity belt. But what we can tell people about are the decades of studies that show that when people with disabilities have more self-determination, they're better able to recognize and avoid abuse. That when people have more self determination, again, when they make more choices for themselves, they're more likely to work. They're more likely to be involved in their healthcare. So all the old arguments about what people can't do, they fall apart, not just with common sense, but with science. And that's what I try to tell judges and lawyers is, you are the keepers of the law. You are the people who are charged to enforce and interpret the law. And what the laws say across the country is that unless a person is, quote unquote "incapable" of making his or her own decisions, or "unable" is often used, or "incapacitated," they can't have a guardian.

Jonathan Martinis: So how can you know? Except in extreme situations, and there are extreme situations, but except in those extreme situations, how can you know that a person is incapable unless you have tried something to help them become capable? Unless you have tried to empower them to manage their affairs, to manage their medical care, to make decisions about their personal life.

Jonathan Martinis: And you know what, that's not my position only. The National Guardianship Association, which is an organization, guardianship.org by the way, made up of guardians by guardians for guardians. They have a code of ethics for guardians.

They train guardians. There is no one more invested in guardianship than the NGA. Their position is that before we do a guardianship, except in extreme situations, we should try something else first, like supported decision making. You know why? 'Cause it might work. It might not. If it doesn't work guardianship's fine, but given the science, shouldn't we try to empower people? Given the law, shouldn't we try to empower people? I always tell that to judges. That's my pipe dream.

Jonathan Martinis: In Jenny's case, remember she was in court for three hours and she lost all her rights, and they handed up an order they had preprinted with all of those rights that Jenny lost. Someday I want to see a judge get a case like Jenny's when she didn't have an attorney, when it was all rammed through, it would have taken like three hours. Or she didn't know she had an attorney. She didn't have the opportunity to prepare with her attorney 'cause it was very quick hearing. Where they get that order, and that order is preprinted, taking away all the rights. I want some judge to look at that and go, you know what, before I take away all these rights, tell me what else you've tried before resorting to guardianship. And if the person can't come up with something, they've tried, case dismissed. Because except in extreme situations, you can't know. And the rights at stake are precious.

Jonathan Martinis: Barry, imagine losing your right to vote, or your right to live where you want to live, or work where you want to work, or even to see your friends. If someone tried to take that away from you, wouldn't you fight? If someone tried to take away from a loved one, wouldn't you raise an absolute ruckus? Course you would.

Barry Whaley: Absolutely.

Jonathan Martinis: Unless people with disability, especially disabilities, because that's what society has been and we need to change that culture. It's one of the lines I say when I speak, if we change the culture, we can change the world. And changing the world for people with disabilities is, unfortunately, as simple as coming to the conclusion that they have the same rights as the rest of us.

Barry Whaley: You know, Jonathan, we're about out of time, and I know that Jenny sent you a letter after you had asked her to write the forward to the book. And in that letter, she says, we all deserve to live a life that makes us happy. So maybe the way to end our show is maybe your thoughts on that comment.

Jonathan Martinis: As usual, I say things in a million words and she hits the nail on the head in about five. Isn't that right? Isn't that all we want in our lives? Self-determination, all those fancy phrases, supported decision making, all of them just come down to one thing. We want to live the lives we want to live, and we want to have the opportunities everyone has. I'll end it this way. In 1776, I'm in Virginia right now, so in 1776 a Virginian, Thomas Jefferson, writes the Declaration of Independence where he says, we hold these truths to be self evident, that all men, people, are created equal and are endowed by their Creator with inalienable rights and among these rights are life, liberty, and the pursuit of happiness. What do any of those rights mean if you're not allowed to choose the life you live, not allowed to exercise the liberty you have, and not allowed to decide what your happiness is?

Jonathan Martinis: For people with disabilities, it took until 1990 for the Americans with Disabilities Act to say that people with disabilities have the same rights as everyone else. So from 1776 to 1990, people with disabilities weren't included in people who had those inalienable rights. And here we are, it's 2019, it is 29 years after the ADA, and we're still talking about whether or not people with disabilities should have rights that were laid out in 1776.

Jonathan Martinis: It's long past time for us to stop assuming that people with disabilities can't do things, and start looking at people, with and without disabilities, people, by what they can do. And if we start looking at just people, then we're not going to use the phrase like supported decision making anymore, 'cause there's not going to be a need for it. Because we're just going to understand that people make decisions every day. People give and get the help we all need to lead our best lives. And that, in about a thousand words, is what Jenny said in five. We all deserve an opportunity to be happy, and I can't echo that enough. So just thank you so much for giving me an opportunity to talk about it.

Barry Whaley: Absolutely. Thank you Jonathan. As always, fascinating conversation with you. Again, thanks for being on the listening audience. If you have questions for Jonathan regarding this podcast, Supported Decision Making the book, please feel free to send those comments and questions to ADALive.org and we'll make sure that Jonathan gets them and we can respond to you.

Barry Whaley: So listeners, our guest today has been Jonathan Martinis, senior director for law and policy at the Burton Blatt Institute, Syracuse University, and along with Dr. Peter Blank, co-author of recently released book Supported Decision Making: From Justice for Jenny to Justice for All. I want to thank you listening audience as always for joining us for this episode of ADA Live. This episode and all previous ADA Live episodes are available on our website at adalive.org, as well as on our SoundCloud channel at soundcloud.com/ADALive. Every episode is archived in a variety of formats, streamed audio, accessible transcripts. You can also download ADA Live from your mobile device. Just go to the podcast icon and search for ADA Live.

Barry Whaley: Also listening audience, the 30th anniversary of the ADA will be here before you know it. You can check out the ADA anniversary toolkit from the Southeast ADA Center and the ADA National Network for celebration of the ADA anniversary on July 26 and year round. The tool kit features media kit, publications, and other resources to keep the celebration going at www.adaanniversary.org.

Barry Whaley: As a final reminder, if you have any questions about the Americans with Disabilities Act, you can submit those questions anytime, either at the website, ADALive.org, or you can contact your regional ADA center (800) 949-4232 and remember, all those calls are free and they're confidential. ADA Live is a program of the Southeast ADA Center. Our producer is Celestia Ohrazda with Beth Harrison, Mary Mortar, Emily Ruber, Marsha Shwanky. Our music is from Four Wheel City, Movement for Improvement. We'll see you next episode.

[Music]

[End of Transcript]

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Contact for More Information or Assistance:

Southeast ADA Center

Email: ADAsoutheast@law.syr.edu

Phone: 404-541-9001