

Eric Neal:

Welcome to the State Support Team 11 podcast. I'm your host, Eric Neal. Today, we are joined by Jonathan Martinis. Jonathan is the Senior Director for Law and Policy for the Burton Blatt Institute at Syracuse University, leading its efforts to ensure that older adults and people with disabilities have access to the services and supports they need to lead independent, inclusive lives. Welcome, Jonathan. How are you?

Jonathan Martinis:

Hi. Doing great. Thanks so much for having me.

Eric Neal:

Yeah, it's a pleasure. I got to know you a little bit when we were planning this. I'm really looking forward to our conversation today. You're one of the leading voices in the movement for supportive decision-making. Can you tell us a little bit about what that is and how you became involved in the movement?

Jonathan Martinis:

Well, first, there's no way I'm going to live up to the leading voice comment, but I'll do my best. Supported decision-making is exactly what you just did. All supported decision-making is getting the information that you need to do the things you need to do in a way that you can understand them and get them done. We all use supported decision-making every day. Every time you ever ask a doctor to explain something in plain language, every time you ask a buddy for advice, every time you look something up, you're using supported decision-making because you're getting support to make the decisions you need to make.

Jonathan Martinis:

Where it comes in with people with disabilities is, unfortunately, people with disabilities way too often are thought of that they can't make their own decisions or that, when they need help, it's a sign of weakness instead of, for every single one of us, it is what it is. A sign of strength. A sign of getting what you need. I mean, think about the cliches we all use. Don't go off half-cocked. Make an informed judgment. My dad used to say, "If you measure twice, you only have to cut once." It all means get help before you do something. So, what supported decision-making really is all about is making sure that people with disabilities have the same opportunities to get the same help to do the same things as everyone else. It fits in so many areas of life. It's part of education. It's part of employment. It's part of healthcare. And that's a lot of what I do.

Jonathan Martinis:

I was involved in a case some years with a young woman who was... Her parents were trying to put her in guardianship. And she didn't want to be in guardianship. She wanted to live with her friends. They wanted her to live in a group home. She wanted to work in the job she had. They wanted her not to work. What we showed with this young woman... her name's Jenny... is that Jenny had support. Yes, Jenny had disabilities, but there were people in Jenny's life who she could go to to get support to do things. And we showed... We talked about them. We talked about what they did. In the end, Jenny became the first person to go to trial and to beat a guardianship in favor of having the right to use supported decision-making to lead her own life.

Jonathan Martinis:

From there, it's... The last eight years have been a whirlwind of talking to people and going around the country and having people I work with, I represent, all of whom are saying the same thing, which is this. If you give me a chance, if you give me support, if you give me an opportunity to exercise the freedom of choice we all have, maybe I can do something really amazing. And so many people have. I've been through Ohio and worked with several school districts in Ohio on setting up supported decision-making and other support plans for people with disabilities. I've been so many places and what we've seen time and time again is what we already know as human beings. When you get what you need, you can do what you have to do.

Eric Neal:

Yeah, it's really interesting how new lots of different parts of working with people with disabilities are compared to other civil rights kind of movements that have been out there. You had the right for women to vote is a hundred years old. You have the civil rights movement to give people from all different backgrounds and races the same rights as citizens in this country. There's all these different things. But when you think about people with disabilities, it didn't really start to creep up until the '60s or '70s and there's still lots of things that are kind of breaking ground and happening today.

Jonathan Martinis:

History has not been kind to people with disabilities. Quick history lesson. I'm sorry for being a giant geek here. But the first time in the Western world, in the Roman Empire, that they got all the laws in one place was an emperor named Justinian. I'm such a geek. One of my son's name is Justin and we did that on purpose. But the Justinian Code put all the laws in the empire in one place. That's 1500 years ago. One of those laws said, if you are feeble-minded... and that's what they called people with disabilities... you had to have a curator, someone over you, to make decisions for you. So, the first time all the laws were in one place, the first time all the rights were in one place, we started taking them away from people with disabilities. That's created an culture and expectation.

Jonathan Martinis:

You said it didn't start bubbling up until the '60s and '70s and that's true, but people with disabilities didn't have the same legal rights as everyone else until 1990. It's only then, 31 years, that people with disabilities have been considered in a legal sense to be people. In the educational context, it wasn't until 1973 that people with disabilities even had a right to go to school. There was testimony in Congress that there were schools that simply would say, "You can't come here." I hesitate to say this is a new movement because people with disabilities have always wanted their rights, but I think it's only been recently that the rest of us have started paying attention.

Eric Neal:

Definitely. You wrote a book about your experience with Jenny called Supported Decision-Making: From Justice for Jenny to Justice for All. Sharing her story helped bring to light a problem that a lot of people didn't even really know existed. Do you think sharing that experience not only educated people but also got them to care? Because a lot of times, it doesn't affect them and they don't even know a person with a disability.

Jonathan Martinis:

I hope so. I truly hope so. Jenny got a lot of attention for her case. She was in People Magazine. She was in the Times. She was on TV. But what I always say is, if we're just telling Jenny's story, it's just a good story and who cares? I mean, at the end of the day, it's one person's story. What we need to do is show people that there are millions of Jenny Hatches out there. There are millions of people who, if they were just given the opportunities, given support, if they were given that initial respect instead of the expectation that they can't do things... I mean, think of it this way. I stink at math. Confession. I'm terrible at math. But no one says, "Because you're bad at math, you can't do anything else." What they do is say, "You should find a career where you don't do a lot of math." And I did. I used my strengths to get around my limitations. For people with disabilities, it's always been the opposite. It's that people look at their limitations and decide they have no strengths.

Jonathan Martinis:

So, for someone like Jenny, and more importantly, for everyone else, what we want to do is build on abilities. Don't judge on limitations first. Look at what people can do and use that to help them get around what they can't. Just like everyone else. The whole point of the book was not just to tell Jenny's story. The first part of the book does tell her story. But the majority of the book is about supported decision-making. About ways to incorporate it in all of the things that people use every day. There is a chapter on using supported decision-making in special education. A chapter on using it in employment. A chapter on money management. A chapter on healthcare. Because, if you think about it, decision-making is something we have to do every day. So, what we should be doing is finding the best possible way to do it and the best possible way to empower people to do it.

Jonathan Martinis:

In fact... here I'm going to be a geek again... what I can tell you is we have 40 years of studies that say, when people with disabilities make more decisions, when they have what's called more self-determination, they have better lives. Study after study after study says that, when people with disabilities have more choice in their life, they're more likely to be independent, employed, healthier, happier, safer, more involved in their communities. So, with that, what we should be doing, if we want the people in our lives to have the best possible life, is to empower them, again, to use their strengths to get around their limitations rather than use their limitations as a reason to take away opportunities.

Eric Neal:

That's interesting to me. You wonder sometimes about what's the motivation for people making these decisions for people with disabilities? I think that's part of why the awareness and talking about this is so important. Because there's kind of two aspects, right? There's the aspect of people that are in these industries... education, social work, different things like that... that are really interested in helping people. They think, well, I'm going to do what's best for this person. Even though they may not really be thinking about it from the person's perspective. They're looking at their education or what they've been trained on or taught. I think, a lot of times, they genuinely feel like, oh, I'm really... I'm doing this person a favor by taking away some of this. I'm making sure that they're safe. There's also the aspect of people that are out to take advantage of people that are elderly or have disabilities. You hear stories all the time about people getting rights taken away and then they come in and can take away their resources or whatever wealth they have. It's important, I think, to build that awareness and to make people conscious and knowledgeable about, like you said, the research behind that and why this is actually... not just better for them, but better for everybody.

Jonathan Martinis:

You're 100% correct. I will tell you this. There are people out to take advantage of people. They are the vast minority. There's bad people out there and they ought to be stopped. I have been involved in cases against legitimately bad people. But here's something I've discovered. I've been around the country, talking to people and working. 99% of people who are seeking guardianship over someone are family members. They're friends. They're loved ones who have the best of intentions. They want to do what's best for the person. The problem is it's cultural. It's kind of expected. They think that's their only option. No one's ever talking to them about other options. But what you said is so true. They mean well and they think what they're doing is the best or only option.

Jonathan Martinis:

About 100 years ago, the United States Supreme Court had a quote that I always use. It doesn't have to do with guardianship, but it's so on the nose when it comes to exactly what you're talking about. It goes like this. I hope your audience just enjoyed my dog howling in the background. I'm going to have to let her out in a moment if she doesn't stop. But what the court said was this. "The greatest dangers to liberty lie in the insidious encroachment by people of zeal, well meaning but without understanding." What that means to me is that, when we mean the most well, we have to be the most careful. We can't assume that we know. Because here, when people have been told their only option is guardianship and they think they're doing the right thing and they rush right to it, they do it what I call reflexively. They don't mean any ill will. Sometimes they're not even really thinking about it because a teacher told them you have to do it. A friend. You have to do this. And they rush in and do it. They think they're doing the right thing. The problem is, when we rush in and do things that we think are right without considering or thinking about consequences, bad things can happen.

Jonathan Martinis:

Just like we have 40 years of science that say, when people with disabilities make more decisions, have more power, they have better lives, we've got study after study after study on the other side of that, too. What we know is that, when we take away rights, lives get worse. Here's just one example. Here's a study that's been done three times in the last 10 years called the National Core Indicator Study. What the National Core Indicator Study looked at was the quality of life of people with disabilities. They looked specifically at people with disabilities in what I call an apples to apples measurement. Meaning they compared people with mild disabilities to mild disabilities, moderate to moderate, severe, severe. The old phrases. What they looked at was the impact of certain things on their quality of life. Across the country and across the board and apples to apples, what they found is that people with disabilities who did not have guardians were more likely to live in their own home, to have a job, to have friends, to go around and socialize in their community, to get married and date, to practice the religion of their choice, than people with similar abilities and limitations that had guardians.

Jonathan Martinis:

Does that mean you should never seek guardianship? No! Absolutely not. My sister is my godson's guardian. Thank God for it. I never tell people what to do. What I do say is this. Don't rush. Guardianship will always be there as an option. If it's possible, try to empower. Try to give people more opportunities. Maybe that might work. And, if it does, what we know is that quality of life can get better. If it doesn't, guardianship is fine. That's really where Jenny's story comes out. Not that guardianship is evil or that guardians are bad, but that people should have the best opportunities to live their best lives with the most support they can get and that they need to help them achieve.

Eric Neal:

What's interesting is... It just popped in my head while you were talking. A certain case with guardianship has been all over the news lately. It made me think about... Here's someone who doesn't have a disability... talking about Britney Spears at this point... but has been locked in the guardianship for a very long time and looks to be having an incredibly difficult time getting out. Is that a common experience for people who get into guardianship? Is it one of those things where... It's like the Hotel California, right? You can check in, but you can never leave.

Jonathan Martinis:

I've used that analogy. I've been interviewed a few times on Britney's case and that's exactly what I said. That when people ask me, "What's the easiest way out of guardianship," I always say, "Not going in." Because while state laws... including Ohio's... say that you can ask the court to let you out of a guardianship, traditionally, it is very hard. Because, again, culturally what people have said is... They call getting out guardianship restoration or restoration of competency or returning to competency. It's looked at as being healed. People with disabilities... people with Down's syndrome, people with intellectual disabilities, people with mental illness... don't get healed. They learn skills. They gain abilities. But so often it's just looked at... what I call... as a life sentence.

Jonathan Martinis:

Really, what the laws say... including Ohio, by the way... is that people should have the opportunity to ask the court to get out when they have regained or gained skills. It should be a way station. It should be an opportunity. I had a case in Vermont years ago, where we made the guardianship for two years. With the idea that, in those two years, the guardian would help the person learn the skills that she needed so that she could then get out. If you looked at guardianship, I'd be a huge fan. Because sometimes people do need a little extra time. But far too often, it's exactly what you pointed out in that the Eagles analogy works. It's looked at just... This is what happens.

Jonathan Martinis:

I'll give you an even scarier concept. The fastest growing segment of people going into guardianship are 18 year olds. Young adults going in at 18. Meaning, [inaudible 00:17:49] speaking, they lose all their rights for the rest of their lives. 60 years of dependency. Of having the court involved in a person's live. Of having someone else having to do everything. Instead of the possibility of gaining skills and gaining independence and being the meaningful, productive citizen that so many can be if given the chance. That's why I say don't rush. Maybe we can help a person get to the place where he or she can be independent rather than the expectation that they're going to be in the rest of their lives.

Jonathan Martinis:

Again, Britney Spears is a perfect example. When I was interviewed about her case, she had just won the right to hire her own attorney. I said, "Imagine. She's been in guardianship for 13 years. She went in 13 years ago. What we're celebrating today is that she can hire her own attorney. If, 13 years ago Britney Spears had killed someone with an ax, if she was an ax murderer, she would've had the right to hire her own attorney then. So, what we're celebrating, what we're watching in Britney Spears, is that, after 13 years, she finally has the same rights as an ax murderer. Is that what we want for the people in our lives? Or do we want to empower and provide opportunities for people to have their own rights?"

Eric Neal:

Right. I'm a big systems thinker. I do a lot of my work in complex systems in education. It's crazy to me because, usually, there's not a simple solution for a complex problem. But this almost sounds like there's a very easy, simple thing you could do by changing the guardianship laws to make it a maximum amount of time with an automatic review or something like that to where it shifted the thinking into that kind of way. That you could legally set it up to avoid a lot of the pitfalls maybe. Maybe not all of them. Is that something that people are working on right now?

Jonathan Martinis:

Yes. In fact, Jenny's case was 2013. In just the eight years since then, we now have 13 states and the District of Columbia that have overhauled their laws. 13 states... New Hampshire, just about two years ago, signed their new law... have recognized supported decision-making as something the court has to consider before putting someone in guardianship. Your concept was done in Washington, DC as well, where every, I think it is, three years, someone called a court visitor checks up on the person under guardianship and issues a report including whether this person still needs guardianship.

Jonathan Martinis:

So, there are certainly movements afoot, but the first thing I tell people all around is look at your own laws. Ohio's law is very good. Ohio's law doesn't use the phrase supported decision-making, but Ohio's law comes out and says the court should be looking at less restrictive alternatives. The court should be looking at ways to empower the person. If a guardianship comes into place, the guardian should be empowering the person to make his or her own decisions. So, if in Ohio, you just looked at the law and followed it as its written, you'd be getting a long way toward accomplishing exactly what you said.

Jonathan Martinis:

Again, I call it a cultural expectation. We have to get past the culture that says this is the only option. No one is free from that culture. I've heard judges across the country say, "Oh, I just sign these. It's what's best." I've heard parents say, "The teacher told me I have to do it, so what else can I do?" Or lawyers say, "This is just what we recommend for everyone." We're locked into a mindset from 1500 years ago. To be real honest with you, 1500 years of saying people with disability can't do things is way too long. We can do a lot better.

Eric Neal:

Oh, definitely. That's why I think these conversations, the book... I saw a great documentary called Crip Camp this summer about a summer camp for people with disabilities run by hippies that was, for a lot of people, the first time that they'd ever been out of their home or apartment where they lived. Just getting people to experience on a human level, I think really goes a long way towards opening their mind to the possibility that there could be a different way. So, I appreciate this conversation for doing that.

Jonathan Martinis:

Well, if you watch Crip Camp... I know you have. Anyone else listening to this should watch it. It's an amazing documentary. One of the amazing things that came out of that was several people who went to that camp became leaders in the disability rights movement, which just proves that... Give people an opportunity. If you watch, you'll see people interviewed. I never knew that I had this ability. I never knew that I could do these things. These are people who, later, became national leaders. You said there's not often a simple solution. In that documentary and in so much of what we're talking about,

they found the simple solution, which is this. Assume abilities. We all do assume that we're all created equal. That's our Declaration of Independence, isn't it? That we all have inalienable rights to life, liberty, and the pursuit of happiness. If we start there for everyone and we say instead of how do I protect this person, with the best intentions, and instead say how do I enhance or empower this person, then amazing things can happen.

Eric Neal:

I'm already thinking about just if they... At the point where these cases come up, I think if they just looked at it through a different lens instead of what this person can't do, it would be... If they looked at it through the lens of what does this person need to be able to do these things that they can't do and what supports are available as the first step rather than jumping all the way to the end, the nuclear option of we're putting them in guardianship, just a simple thing like that could make a huge difference.

Jonathan Martinis:

Amen. Absolutely amen, Eric. That is exactly where we should start. Again, some people are going to need guardianship. But it ought to be, as you said, the nuclear option. When there's nothing else. I always say this. Before guardianship, we have to ask a question. What else have you tried? Because if we can't answer that question, 98% of the time... Yes, a person in a coma absolutely needs a guardian. I get it. But so often, if we don't ask that question, what else have we tried to empower this person, we are missing opportunities and, scientifically speaking, very likely causing that person to have a lesser quality of life. There is no parent that wants their child to have a lesser quality of life. When parents come to me, I always say, "What do you want for your child?" And they always say the same three things. Independent as possible, happy as possible, safe as possible. I say, "Okay, let's talk about that. Let's talk about ways to make exactly that happen."

Jonathan Martinis:

Do know? There's a study that says that people with disabilities... specifically women with intellectual development disabilities, but it's extrapolated out... who have more self-determination and make more choices are better able to recognize and avoid abuse. Safer. So, I tell judges across the country, if we want to make people safe, don't take away rights. Build awareness and build opportunities. That's not rocket science. Aren't you more protective of things that you know are yours? If I'm telling you it's your body, it's your life, it's your choice, you get to make it, you're going to be protective of that. If someone tries to take it away, you're going to fight. Those are things that we can do if we start exactly where you said. With abilities and with rights instead of jumping to taking them away.

Eric Neal:

It's so frustrating sometimes that you even think... That we have to talk about, "Hey, people have rights." It should be, like you said, it's in the Constitution. It's what were founded on. You're doing a series for State Support Team 11 called Education, Employment, and Independent Living Through Supported Decision-Making. Can you give us a preview of what will be covered during that?

Jonathan Martinis:

Absolutely. We're going to have multiple parts of the series for multiple audiences. The first thing we're going to do is for anyone. It's for anyone who wants to come. Parents, professionals, educators, whoever. It's introducing the concept of supported decision-making. It's going to be called From Justice for Jenny to Justice for All. The ideas behind supported decision-making and how we can make it

happen. All that stuff I talked about. Hopefully not boring. I try not to be boring. About the science about it. But I'll tell you about Jenny. I'll tell you about Jenny's story and I'll tell you about how Jenny's story probably fits in with a lot of people's lives. And exactly what we've been talking about. Why we shouldn't leap to take away rights.

Jonathan Martinis:

The second part of the series, we're going to divide up into one for educators and professionals and to one for parents. That lesson is going to be about using supported decision-making in education and in employment. The reason why we're dividing it is because it's a little different focus if we're talking to a teacher about incorporating supported decision-making, for example, into the student-led IEP or into transition planning or into interfacing with OOD, which is your vocation rehabilitation agency. There's a little different focus than talking to a parent about ways to advocate for your child to get the best possible supports and services. So, part two of the series is going to be about incorporating the supported decision-making theory we talked about in part one into the context of education and employment. And as I said, there'll be one session for professionals and one for parents.

Jonathan Martinis:

We're then going to have a part three that we're also going to divide up for professionals and parents. Part three is going to be about what I call, broadly speaking, life planning. Ways to use supported decision-making in things like healthcare and money management and benefits planning. Language you can use, if you wanted, for a power of attorney or an advanced directive. Again, we'll have one geared towards professionals about how you can work with the system and meet your responsibilities and one geared toward parents about how you can advocate. By the way, if you miss one, you can catch the other. The information I'm going to give you is the same in each. It's just going to be a little different focused, I think, for particular audiences.

Jonathan Martinis:

Part four, we're going to bring everyone back together again for what I call a sum up. Ways to bring everything together. Because one thing I really hope you learn from this series is that this supported decision-making concept goes all the way through life. Getting help to do what you have to do is part of everything we do in life. If there's a teacher, a parent, listening who's ever advocating for the student-led IEP, what you're really talking about is supported decision-making. Because the IEP team works with the student to identify supports and services and goals and objectives with the student providing input and the student, as the student gets older, having more and more responsibility so that, by the end, they're truly working as a team, so the student can lead the team and sign off on the IEP. In other words, the team supports, the student decides. Supported decision-making. That goes through into informed choice in vocation rehabilitation. It goes through to person-centered planning in healthcare. It goes through to able accounts in money management or special needs trusts. And then we'll talk in that last one about a way to change that culture that I told you about. The culture of people can't do it. To create a more coordinated culture where programs and projects work together to get the best possible results the most efficiently.

Jonathan Martinis:

Right now, I'm talking right to teachers and counselors. You didn't get into this field, a teacher, to do employment counseling. You didn't get into this field to do independent living counseling. But you're required to do it under the transition regulations. What we're going to talk about is ways for

professionals to work with other professionals. With counselors from OOD who didn't get into their field to do education, but they're required to do it. Or case managers from your local board of developmental disabilities who didn't get in their field to do employment, but they're required to do it. Well, if you've got these three entities that have to do similar responsibilities, shouldn't they work together so that specialists can specialize? Teachers teach. Employment counselors focus on employment. Independent living specialists focus on that. We call that the culture of coordinated support model. We did a pilot project in Pickaway County in Ohio and we've got one going in Perry County. What it's showing is that teachers and counselors and parents and students can gather together, do joint plans and work together, to have better results with less work. Isn't that the golden goose? To be more effective and more efficient? And that's what that last one's going to be about. Ways we can all work together to create a new and better and more effective culture.

Eric Neal:

I'm excited for the whole thing. I think it's timely. I think it's going to be something that people are hungry for. It's really going to be a big help. If you're interested in signing up, check out our website at sst11.org and you'll be able to find the information on how to register for that. For those that may not be able to make the series, what do you think... If you had to think of one strategy for a student with a disability to self-advocate so that they're treated equitably, what do you think is a thing that a student could do?

Jonathan Martinis:

Take direct responsibility. For students... I'm told all across the country and I'm sure it's the case in Ohio too... they feel like they're getting talked at, not talked with or talked to. It's hard when everyone in your life is telling you what you should do or what you can and can't do. I think from as young an age as possible, you should be saying, "This is who I am. This is what I want. Let's work together to make it happen." I'm talking directly to students right now. Every teacher you work with got into this field to make a difference in the lives of their student. They didn't get into this field to say no. They didn't get in this field to tell you that you can't do things. They got into this field to work with you and give you the best, most effective education.

Jonathan Martinis:

Amazing things happen when students lead. I did a project in Mansfield, Ohio that they wrote up in their journal, where students took the lead in their IEPs. They took the lead in communicating what they wanted. What their goals were. What their dreams were. What they wanted to be in their future. We had teachers saying they had tears in their eyes because that's what they wanted more than anything else was the student leading. Was the student saying, "This is what I want. This is who I am. How can I get there?" We had one student... Just one of the examples in Mansfield. Someone said they wanted to be a fashion designer. The school changed the student's IEP all around. Not just about fashion design, but all the things that would go into having your own business. I mean, if you want to be a fashion designer, that's a business. You got to be ready to do your taxes. That means we have to have specialized math to help you go through that. You've got to learn about advertising, so they had creative writing. All of the things that teachers want you to do anyway, they did with a focus on what the student wanted to be. It all happened because the student took the lead.

Jonathan Martinis:

There's a fancy phrase called self-determination that just means taking charge. What I can tell you is that, when you take charge, great things can happen. I don't mean be a dictator and say, "My way or the highway," but I do mean say, "This is who I am. These are the things that I want. This is where I want to get to. How can you help me get there?" That is my biggest and most basic piece of advice. That idea flows through everything through life. Scientifically speaking, it is the key to a good life for people with disabilities. It's the key to a good life for everyone.

Eric Neal:

You think about also... We're always trying to promote student engagement in the education profession. What's more engaging than supporting someone in what they really care about?

Jonathan Martinis:

Absolutely. One of the things we're going to talk about, actually... spoiler alert... in that last session is a thing called making a dream board. It's a way to communicate. A way to have direct student engagement. Something a student can take to a meeting and say, "This is who I am and this is what I want." That is what we did in Mansfield that led to teachers having tears and counselors and one parent who was written up saying she never knew her daughter wanted to work at Starbucks. Now, her daughter's working at Starbucks. It happened from direct engagement.

Eric Neal:

It's funny because my next question was going to be how can teachers and caregivers and others be an ally when it comes to supported decision making? It sounds like we kind of just answered it. It's really about finding out what they are interested in and what they care about and helping them make that happen.

Jonathan Martinis:

Yeah. It's why you got to... I mean, I know being a teacher... Good god. I've talked to so many teachers and sometimes... like in all fields... it just feels like things are getting just ripped out of you. All the paperwork. All the time. All the meetings. You lose sight of why you got in in the first place. But my god. I have talked to so many teachers who did exactly what you just said. Support that idea. Engage in that idea. We're going to talk about this in the series, but create new ways of looking at IEPs. New ways of looking at supports and services that are exactly what's supposed to happen and consistent with science and studies and the Department of Education best practices but that make such a huge difference. I've had teachers tell me, "All that paperwork, all that time, all those regulations and the secret is what I've always known. It's why I got in. I wanted to work directly with students and parents. When we do that, great things can happen."

Eric Neal:

Definitely. So, if people would like to find out more about you, your book, the work you do, where should they go?

Jonathan Martinis:

The book is on Amazon. We did that intentionally. I'll make a confession. We originally submitted the book to a publisher who didn't want to publish it because we used contractions and we didn't have big, specific ways of citing scientific articles. I said, "People use contractions and people want analogies and

people want real lessons." It's self-published for a reason. So we could make it cheap. There's a textbook I co-wrote that's like 100 bucks and I recommend people don't buy it. It's for graduate-level students. People who need to know about supported decision-making are the people who use it every day. The people with disabilities. The parents. The teachers. The counselors. And so I wrote that thing, I put it on Kindle, and the whole idea was to give people access to information. In a very real sense, it's the most commonsensical thing we know. Empower people and good things happen. But the reason for the book isn't just to tell Jenny's story. It's for the rest of it. To give you practical, usable information about ways to incorporate this into IEP plans, into vocation rehabilitation, into person-centered planning, and ways that we can make happen what we've always wanted to happen for our children, for our students, for the people in our lives.

Eric Neal:

It's really the... Making the book about accessibility accessible. It's living your brand. I appreciate that about you.

Jonathan Martinis:

I say, right in the beginning, this book is not for academics. It's for you. It's for people who have... people on the front lines. People who come to me and they hear me speak and they go, "Great job. I'm all in. What do I do?" The theory is wonderful. I will warn you. That first session we're going to have is all about theory. You're going to say, "Great. What do I do with this?" That's the second, third, and fourth sessions. But if we can come to that agreement in the beginning that self-determination, that independence, that decision-making, are good things and lead to better lives... and Jenny's story is the perfect example of that. And you'll see yourself in her. I've actually got excerpts from testimony in the trial where you'll go, "Oh, yeah."

Jonathan Martinis:

Like when someone said that taking away rights is kind of like taking away, in the eyes of society, a person's existence. Because if I have a guardian that does everything for me, then everyone's looking to the guardian and not me. I'm like a ghost. You'll say to yourself, "Oh my god. I never thought of it that way," because culture told us that's the only thing we could do. Well, there are other options that can empower. I hope you'll see yourself in her story or your loved one. Your parent, your friend, your brother, your daughter, your son or your daughter. Your student. And then the rest of it is all about making it happen so that it's not just a concept that self-determination is a good thing. It is here's how we get there. And that's the important part.

Eric Neal:

Jonathan, I really appreciate you joining us today and sharing your story. I'm really looking forward to your series. So, thank you.

Jonathan Martinis:

It's been an absolute honor. I can't wait to work with the Support Team 11 and I'm looking forward to interacting with anyone. I'm going to tell you right now. If anyone has any questions, if you want to reach me, my email will be all over the presentation, but here it is right now. It's JG, as in Jonathan Gerald, Martinis, as in more than one martini, 15, at gmail. So, J-G-M-A-R-T-I-N-I-S-1-5 at gmail dot com. Email me anytime. Tell me I'm full of it or tell me I want to know more. Because the only way we do well is when we communicate more. I'd love to communicate with you.

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Eric Neal:

Well, that's your chance right there. Make sure you reach out if you have those questions. That wraps up this episode of the State Support Team 11 podcast. If you'd like to know more about who we are and what we do, check us out on our website, sst11.org, contact us by phone at 614-445-3750, or follow us on Twitter [@sstregion11](https://twitter.com/sstregion11). Until next time, I'm Eric Neal. Thanks for listening.