

BoggsCast Episode 10: Jonathan Martinis

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JAIME ZAHID: Welcome to the BoggsCast where faculty and staff at The Boggs Center on Developmental Disabilities explore best practice, showcase success stories, and help listeners envision possibilities for innovation through interviews with state and national experts. Part of Rutgers Robert Wood Johnson Medical School, The Boggs Center is New Jersey's University Center for Excellence in Developmental Disabilities and Leadership Education in Neurodevelopmental Disabilities program. I'm Jaime Zahid, Training and Consultation Specialist. I'm joined by my colleague Steven Gruzlovic, who is a former Partners in Policymaking graduate and current LEND faculty advisor. In this episode, we'll be discussing supported decision-making with 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.

In 2013, Jonathan represented Margaret Jenny Hatch in the Justice for Jenny case, the first trial to hold that a person has the right to use supported decision-making to make her own life choices instead of being subjected to a permanent plenary guardianship. Since then, Jonathan has led supported decision-making projects in New York, Nebraska, Ohio, California, Virginia, Vermont, Missouri, and Kansas. He has also educated and trained tens of thousands of older adults, people with disabilities, families, and professionals across the country on supported decision-making theory and practice. I'm going to hand it over to my co-host Steve to get us started on the conversation and elaborate on any introductions that I might have missed.

STEVEN GRUZLOVIC: Hi, Jonathan. I just recently got introduced to you earlier. But I watched you a lot on YouTube and I've read your website. And I really admire what you do because I use supported decision-making, and I also help families as well guide them towards this method. And it's been really successful for a lot of people, including myself.

So, the first question that we had that we would like to ask is, how do you define supported decision-making?

JONATHAN MARTINIS: Well, you just did it, actually. You absolutely just used supported decision-making just now because you didn't know something and you asked someone who you thought did know it about it. You asked, I didn't know what supported decision-making is. You think I have information to give you so you ask me to give it to you. That's what supported decision-making is. We all do it every day.

Whenever we need information, whenever we need to make a decision and we don't know what we need to know to do it. What everyone does is we go talk to someone. We get advice. We get information. We go find someone who has the information we need.

That's what supported decision-making is. And I know it sounds like this big fancy thing, but every time you go to the doctor-- every time I go to the doctor anyway, and the doctor speaks jargon, I say, can you please explain that in plain language? That's supported decision-making because I didn't know what the doctor was talking about.

And the last way I'll define it is by all the cliches we use. Don't make a snap judgment. Get a second opinion. Make an informed choice. Don't go off half-cocked. My dad always used to say, if you measure twice, you only have to cut once.

They all mean the same thing. Get information. Get help. Ask for advice. That's all supported decision-making is. It's getting what you need to do what you have to do.

JAIME ZAHID: Thank you for that definition. I always love your definition-- not the first time I've heard it, Jonathan, as you know. And every time I think about it, I think about all of the things in life that I make decisions on that part of me feels like I'm-- actually, I know I'm not equipped to make that decision. For instance, we bought a new house a year and a half ago. Most of the paperwork I really didn't understand. If I had to sign something and wasn't sure about it, I looked at my husband like a deer in the headlights.

JONATHAN MARTINIS: Oh, my God. It's so true. I mean, all of us who do that-- lots of us on the job, we are evaluated how good an employee we are by how well we operate in a team setting. So we're judged on how well we use supported decision-making. Here's the difference, is that for people without disabilities, people I call temporarily able-bodied because we're all like one second away, one accident, one diagnosis, one heart attack from having a disability.

So for temporarily able-bodied people, if you use supported decision-making, and I know no one out there calls it that. We just call it living life. If we use supported decision-making, we're being smart, right? We're making an informed choice. We're getting a second opinion. But forever if a person with disabilities says, I don't understand. Explain it to me or I don't know what you're talking about. Society automatically thinks they're dumb. Automatically thinks they can't do things.

So that's the huge difference. Temporarily able-bodied people have the luxury of using supported decision-making every day without having to call it that. People with disabilities have to say I'm using supported decision-making. Otherwise, the rest of the world thinks they're just not very smart, and that's not fair. We need to do better than that.

JAIME ZAHID: Absolutely. So I'm hoping for our listeners, Jonathan, could you tell us what do you feel like-- if you had to sort of write it down, and I know you've written a lot of publications. What would you

say the difference between supported decision-making and guardianship really is functionally for a case manager or a parent or a support coordinator looking to find out?

JONATHAN MARTINIS: At its most basic level, when I use supported decision-making I am making decisions for myself with your help or with someone's help. In a guardianship, someone else makes decisions for me. That's the biggest difference. In a guardianship, someone else has the final say. For everyone else who's not in the guardianship, they have the final say.

Now, that's the easy part. In my personal opinion, supported decision-making can be used in guardianship too and should because it's every guardian's responsibility not just to say what's going to happen, but to work with the person. So a good guardian-- and I never say bad things about guardians. My sister is my godson's guardian. Thank God for it because she helps him. A good guardian empowers the person, talks with the person, uses supported decision-making with the person to give that person as much opportunity and as much power in their own lives as possible.

So at a base level, SDM, I have final say. Guardianship, you have final say. But really, supported decision-making should happen in a guardianship as well as much as possible.

JAIME ZAHID: Thank you for that. And Jonathan, I mentioned before we hit record today, I've always admired your passion in this work. And I do love to find out from people what got you started in this work. I often find that the passion comes from wherever you got started. What was the spark, the person, the whatever that got you started in working with people with disabilities?

JONATHAN MARTINIS: So I had an uncle, my uncle Bob. And I have to warn-- I tell this there's no aha moment here. There's no single moment where I said, this is what I want to be because as I hope you're going to hear it's the way it's always been. So my uncle Bob was born with cerebral palsy in, I think, the early 1950s. And this is the story I heard from my mom, and it's still pretty fresh all the details with me. So it still weirds me out a little.

So my mom tells me that the nurse went to my grandfather and said, he's never going to walk. He's never going to talk. We can leave him by a window if you want and nature will take its course. So my uncle-- my grandfather runs and gets a doctor and the doctor takes care of Uncle Bob.

And at some point later says to my grandfather, he's never going to walk. He's never going to talk. There are places, a place we can take care of him. You never have to see him. He'll be fed, all that. And someday, nature will take its course. Don't worry.

And my grandfather went and put an addition on his house, and put a ramp on his house in the 1950s, a ramp on his house. So I was a kid in the 80s. Uncle Bob was at the dinner table. My grandfather had fought to get him an education well before the Individuals with Disabilities Education Act said that was right.

So uncle Bob couldn't talk. He communicated. He could spell. He could tell jokes. He was funny. And there he was at the dinner table with everyone else. And I was in law school in the 90s when the Americans with Disabilities Act was passed and people with disabilities still weren't at the dinner table, still not equally at the dinner table or the legislative table or the table of power or the employment table. And to be honest, it just pissed me off, and I'm sorry for the language but that's just bullying. If my grandfather could do it in the 50s, put a ramp on a house, businesses can put ramps into their business doorway in 2022. If my uncle Bob can get a good education in the 50s and 60s, then people with disabilities should be able to get good education now. And if-- it's not just an equal rights thing. It's a morality thing that people with disabilities still are far too often excluded. It's just a sin, and that's how I've always felt.

STEVEN GRUZLOVIC: I agree with you. We're still fighting for some of the same things that we had to fight for 30 years ago. And I think part of it is we still have to combat and change the current narratives and the mindset, in some ways. Members of the general public and also those in legislative and political positions as well. I often find that if it doesn't personally affect them in some sort of way, they don't know. And it's not for lack of caring because once they find out they typically do care.

But I think we've done a much better job as a society with the exposure of real people with disabilities on TV nowadays. It's gotten much better. It's still not where it needs to be, but we're getting there slowly.

JONATHAN MARTINIS: You make such a great point about changing the narrative, and that's a phrase I'm probably going to steal from you. What I use is I say that there's a culture. I think people care. They don't think because they never had to.

The first time in the Western world's tradition, 1,500 years ago that we had laws in one place was the Roman Empire. This emperor named Justinian gets all the laws from the provinces into one book called The Justinian Code. So it's the first time in the European tradition there was law. The Eastern world with the Code of Hammurabi has it beat by thousands of years. But in the Western tradition, the Justinian Code was the first time all the laws were in one place.

And one of those laws said if you're feeble-minded-- and that's how they describe people with disabilities. You had to have a curator. Someone over you to make decisions. So this culture started 1,500 years ago. This expectation that people with disabilities need someone over them. That they can't do things. That any kind of limitation equals an inability.

And like I said, that's a sin because we've been telling people forever, people who have so much to contribute who could be educated and employed and living independently and doing everything everyone else does. They've been told they can't and laws have stopped them from doing that. And now we have laws, but we still have the culture expecting that people can't do things, and that's what we have to change.

JAIME ZAHID: Absolutely. And thank you for sharing that story about your uncle, Jonathan. Of course, I anticipated your response as I've heard it from you before, but it always-- it does make me think about saw that from a young age that was your point of reference probably-- I'm going to assume your first point of reference of people with disabilities. And for you and any of us that grew up with that point of reference of people with disabilities just being part of the family, I'm sure that, whether we realize it or not, that influenced how we approached disability.

JONATHAN MARTINIS: Oh, totally. Totally. One of the miracles of inclusion is it's inclusive, is that when you're just around people with disabilities you see people. My children grew up in an inclusive daycare and there were children with disabilities there. And no one-- not once did one of my sons say, oh there's AJ. He's got this, that, and the other wrong with them. They would say that's AJ. He doesn't talk, but he's really funny and this is what he does and it was just natural. It was like being blonde. It was a characteristic. And we can learn a lot from kids.

JAIME ZAHID: Yeah. Oh, absolutely. Absolutely. I have a three-year-old myself, and I've been putting a lot of thought into the fact that it's going to be so important for her and for her peers, disabled or not, to be an inclusive environment so that she grows up with the expectation that people with disabilities will do everything and want to do everything that she hopefully will and will want to do.

JONATHAN MARTINIS: That's what I mean by culture. I make-- it's a kind of sort of joke, but it's really true that people without disabilities are not judged on what they can't do but people with disabilities are. And the example is this. I am terrible at math, and I mean terrible at math. You know what I did? I picked a career I don't have to do math. I have strengths that allow me to overcome my terrible math skills. But people with disabilities are judged on what they can't do and we assume they can't do anything else. This person can't do this so he has to lose the right to do everything else. It's so backward. Everything is skills and strength-based unless you have a disability. At which point, it's limitation-based.

JAIME ZAHID: Right.

STEVEN GRUZLOVIC: I know you talked a little bit about history and some of the policies that have changed times. Where did supported decision-making as a practice come from?

JONATHAN MARTINIS: It's-- the concept, of course, has been around forever. We just haven't called it supported decision-making. But really, it started coming and being talked about more with the UN Charter on the Rights of People with Disabilities. The Convention-- pardon me, on the Rights of People with Disabilities. That said-- it didn't use the term supported decision-making, but it said that everyone has the right to make decisions. They have the capacity to the maximum of their ability and everyone deserves the support they need to exercise their capacity.

That's in the earlier 2000s, I'm going to say. There have been papers written about self-determination forever. Self-determination, making choices for yourself. We've known for 40-plus years in studies that when you have more power in your life when you make more choices, your life's better. Not exactly rocket

science, but we studied it. And there are studies showing that people with disabilities who make more decisions instead of having others make decisions for them have a better quality of life.

So the idea of supported decision-making came from those two things. One, that we know that self-determination, making choices, is a better life. And two, the idea that people should have the right to do that. So there was some papers written. There was some academic arguments.

I was very fortunate enough to have a case for a young woman named Jenny Hatch, which was the first trial to hold that a person had a right to use supported decision-making instead of being in guardianship. Since then-- that's only 2013, by the way. It's only been nine years since Jenny's case. But since then, I believe 16 states the number is, either have or will soon, have laws recognizing supported decision-making specifically as an alternative to guardianship in those words. In my opinion, any law in New Jersey's law has language like this that says you should have the least restrictive alternative encompasses supported decision-making, but these other states actually use the words.

STEVEN GRUZLOVIC: I noticed from reading your website that New Jersey really doesn't have a specific statute when it comes to supported decision-making.

JONATHAN MARTINIS: No, they don't.

STEVEN GRUZLOVIC: So what can we do to change this and what would be the first piece of legislation that-- what would it look like and what would you like to see?

JONATHAN MARTINIS: Please understand when I answer your question I'm only speaking for myself. This is Jonathan's point of view because Jonathan's point of view isn't the same as everyone else's. So I just want to say there are people out there who are going to disagree with everything I'm about to say. Laws and legislation are great. We should want laws and legislation.

But you said this earlier, Steve, it's about the implementation not the law. You can have-- there are laws right now that say you have to drive 55 on the highways. Go tell me how many people are driving 55 on the highways. So it's not about the existence of a law, it's what we do with it.

So my opinion is this, what we need is education and more education, even before legislation. We need to have people understand that guardianship isn't the only option. When I talk to people in New Jersey and elsewhere, lots of them have never heard of anything but guardianship. Their teacher told them they have to get guardianship, a lawyer said it, an accountant, or a doctor said it.

So we need to stop, to change the culture because if we just get a law that says supported decision-making and no one pays attention, what's the difference? So I believe the first step is educating stakeholders. People with disabilities to say I want this. Family members to say I don't want to do guardianship if there's something else. Teachers and doctors and lawyers to understand there are other options available.

Because until you have that-- I'm going to call it constituency, people who want and believe in this, that number one, the law might not get passed anyway because there are people who don't believe in supported decision-making. And number two, if it is passed, whose is it?

So that's step one, step two, step three, step four, step five in my opinion. Educate people. Talk to people. Get out there and tell people that they can do other things. That they should do other things. Why? Because everyone does this.

So with that information, then when you've got what I would call a groundswell or constituency, sure, go for legislation. But to think that legislation alone is going to change culture doesn't-- never has.

STEVEN GRUZLOVIC: And schools especially, I've found, need to stop using guardianship as a scare tactic. You know, it's—

JONATHAN MARTINIS: Absolutely true. Schools are the-- schools are the number one referral source for guardianship. We found that in a study. I was part of that study. We asked parents and guardians what their first prompt was to seek guardianship, and I thought they were going to say lawyers. Maybe I'm just being egotistical. I thought they were going to say family members or friends, but nope. Number one with a bullet was teachers and educational personnel saying things like your child is going to turn 18 next year. If you don't get guardianship, you can't come to an IEP meeting. Which by the way, is not true.

STEVEN GRUZLOVIC: Thank you.

JONATHAN MARTINIS: If you hear that it's not true. The top of every IEP form says you can bring whoever you want. So yes, at 18 a child with disabilities becomes an adult. You know who else became an adult at 18? Me. Nobody told my mom that I was going to become an adult. She had to become my guardian. So it was just about the disability issue.

Any person, any young adult who turns 18 and becomes a legal adult can say I want mom, I want dad, I want whoever to come to my IEP meeting. So of course they can. So that one actually I hear it across the country, and frankly, it upsets me because you're correct. Schools are, maybe with good intentions, pushing people into guardianship. And we know statistically speaking that over 90% of people in guardianship lose all their rights, all of them. Imagine being 18 and not having any rights and possibly not having them for the rest of your life. You can do better than that.

STEVEN GRUZLOVIC: Yeah.

JAIME ZAHID: Absolutely. That's so scary. And Jonathan, forgive me for putting you on the spot here. I referenced it though in your introduction and you referenced it yourself a few minutes ago. The Justice for Jenny case, would you mind-- I know that it can be a long story, but would you mind telling our listeners what happened with Jenny. Why were you involved with Jenny? Go, sorry.

JONATHAN MARTINIS: First, any story I tell is a long story. I'm sure you haven't noticed that yet. So Jenny, Jenny Hatch was-- is—she's thankfully still here. But Jenny, when I met her, was 29 years old, has Down syndrome. She had graduated high school. She'd had the same job for five years, not a supported job, not a sheltered workshop job, not a special job, a regular job making regular pay, paying regular taxes. Jenny had her own apartment, not a group home not a supported apartment, an apartment. That by all accounts was kept spotless.

So Jenny had a life. She had a church she went to. She had friends. She was politically active. 29 years old. And she got into an accident when she was riding her bike, got hit by a car. That accident did not diminish her cognitive abilities at all. She hurt her back.

So at 29, though, her parents filed a petition for guardianship. And when Jenny turned 29-- she's 29 years old. Remember, 29. She'd been living 11 years without a guardianship. But when I met her, she had already been placed in guardianship, so-called temporary guardianship, where she was living in a group home. She didn't want to live there, but she was living in a group home.

She wasn't allowed to go back to her job. She was welcome to go back to her job. She wasn't allowed to. She was put to work in the sheltered workshop run by the group home where she made significantly less than minimum wage. She wasn't allowed to use her cell phone. Her laptop was taken away. Her Facebook password was changed.

And if you wanted to see or speak with Jenny, you had to fill out a permission slip. Hand to God, a permission slip. You had to tell the guardians when you wanted to talk to her, what you would talk to her about, if you're going to go somewhere, where you were going, and when you're going to come back. And you had to agree to the conditions of visitation, which were on the back. Rule number one, you're not allowed to talk to her about the guardianship because allegedly it upset her. It upset her because she didn't want to be in guardianship.

She wanted to live with friends where she was welcome to live. Was told nope, get used to your new life. You live in the group home. Want to go back to work, where she was free to return. Nope, get used to your new life. You work here. Wanted to go to her church. Get used to your new life, we go to this church, et cetera, et cetera, et cetera.

So I met Jenny. I don't do permission slips. I kind of just walk in. And I said I want to help. She had a lawyer. The lawyer reached out to me. I said, can I be your lawyer? Jenny said Yes. And I know it's a long story, but it's worth hearing.

When I became Jenny's lawyer, I asked the lawyer for the guardians. This permission slip thing doesn't apply to me, does it? I was told, yeah, it does. And I said, I can't talk to my client about her case? And the answer was, yeah, that those are the rules.

Now bear with me. Consider that if Jenny wasn't a person with disabilities but was instead an ax murderer and she was found holding a head and holding an ax and saying, I did it. I did it. I did it. I did it. Ha, ha, ha. She'd have the right to talk to a lawyer.

But Jenny wasn't lucky enough to be an ax murderer. She was unlucky. She was a person with disabilities under guardianship who don't apparently have the same rights as ax murderers. So the first time I went to court I just had to argue that she has a right to talk to her lawyer. No one-- this sounds unbelievable. I know. If you're hearing this story for the first time, it sounds unbelievable so I put it online. Jennyhatchjusticeproject.org. You can go there. There's a section called Jenny, and it's called the Justice for Jenny trial. You can see the permission slip. You can see the emails between me and the attorney. You can see the motion I had to file just to talk to her.

So to make a long story only slightly longer, we spent a year going to court with Jenny, a year arguing. But it turned out that Jenny had been using supported decision-making her whole life. She didn't call it that because who calls it that?

But her case manager is on the stand. Case manager talking about how they go over her person-centered plan with her and make sure she understands it and take her opinions in, and she doesn't sign it until they're sure she understands it. Her parents had to do a power of attorney where we asked if you think she can't make decisions, how did she sign this? They said, oh no, the lawyer went over it with her and let her ask questions. And we know she understood it because she asked questions. And time and time again, we saw she was getting information and making decisions.

So at the end of the day, that was our argument. If she can make decisions with support, why does she need a guardian? So the judge did an amazing thing. A Virginia judge, at a time when no trial judge had ever used the words supported decision-making said, we can do better. Jenny is now 9 years in using supported decision-making, living her life, living where she wants, working where she wants, having the life she wants just like everyone else.

So in a way, going back to my story about my uncle, it just reminds me of it because she was doing all these things already. She's doing them now. She just lost a year of her life because people assumed she couldn't just because she had a disability. And that's a sin.

Nothing in Jenny's life really changed before guardianship and after guardianship. It was just when people decided for her that she couldn't do it, and that's what needs to change.

JAIME ZAHID: So thank you for sharing that story. Your storytelling, Jonathan, I always appreciate it. It's colorful and interesting and keeps the listener engaged for sure. And I think it's so valuable. I'm so sorry that Jenny had to experience that.

But that being said, it's so valuable for us to hear her story because it's a story that I'm sure is happening again and again in small-- probably in large pockets across the United States with disability.

JONATHAN MARTINIS: Of course. And the press called it the Justice for Jenny trial. But when I talk about it, I say that Jenny got justice, but lots and lots of other Jennys don't. There are people who are, quote unquote-- I hate the phrase but work with me. Quote unquote, higher functioning than Jenny who are in guardianship right now with no rights.

The difference is the press paid attention to Jenny. She got a lot of attention and experts came to help. It was amazing the help she had. And she had her friends who hired their own lawyer to fight for her well before I ever heard of Jenny's case. These people, Jim and Kelly, who became her supporters hired an attorney to fight for her. Who does that?

So take away all that support and Jenny's right back in guardianship just like untold numbers of other Jennys. So that's what we had to take out of this. If Jenny's case is just a great story, I've wasted your time. It's a waste of time because she's one person in a sea of people. But if Jenny is an example for others, if others say, wait a second, maybe we shouldn't be doing this, maybe we should think about it first, then it matters.

JAIME ZAHID: So Jonathan, what would you say to parents or even adult siblings or professionals or whomever, but typically parents, that hear about supported decision making versus guardianship and they're scared? They're scared of their loved one making a terrible decision. You know, fill in the blank. What would you say to those parents?

JONATHAN MARTINIS: The first thing I say is I never second guess a family member or a loved one who wants to protect someone they care about. The first job of any parent is to protect their children. But I do talk to parents about science because one of the amazing things in this field is we've got decades of studies. I gave you one example that people with disabilities who have more self-determination and make more choices, have better lives. And I'm talking study after study after study has found that. More likely to be independent, employed, healthier, happier, and safer. Safety is the number one reason I hear. So there's a specific study I always talk about. Please forgive me for being geeky. But a study by a professor named Dr. Khemka out of Long Island University. She did a series of studies looking at safety and self-determination. One of them is the one I always talk about.

She worked with a group of women with intellectual and developmental disabilities. Women with IDD are way more likely to be abused and neglected than any other segment of the population. So awfully high levels of abuse and neglect. What she did-- and it was another scientist. It was an apples-to-apple study. They compared people of similar abilities and limitations to people of similar abilities and limitations and did the classic move, divide them up. Said had a control group who she said go live your life. And then had an experimental group where she gave them access to a curriculum designed to increase their self-determination-- how to make more choices, why you should make more choices, getting support. After the study is done, she brings both groups back together and she gives them both a test, a recognized test designed to examine how well people recognize potential abuse and avoid it. Guess what she found? Apples to apples. Those with more self-determination were safer. They were better able to recognize abuse. And I always say that's not rocket science because aren't you more protective of what is

yours? If you know it's your life, your choice, your body, your stuff, you're going to fight like hell if someone tries to take them away.

One more geeky study for you. This one was done in New Jersey. It was called the National Core Indicators Study. It was done in a whole bunch of states, including New Jersey. The National Core Indicators study looked at the quality of life of people with intellectual developmental disabilities. And again, apples to apples, they looked at-- they compared people of similar abilities and limitations. And the whole idea of the study was to see what impact certain things had on quality of life. One of the things they looked at was guardianship, and this is amazing. In Jersey and in every other state, people who did not have guardians were more likely to be independent, employed, have friends, date and get married, practice religion of their choice, be respected, and be more involved in their community than people of similar abilities and limitations who did have guardians.

So what I say to parents is this, guardianship might be right for your child. It might be. But given all of the science and all of the things at stake, doesn't it make sense, except in the most extreme situation, to at least try something else first? That's what I ask. What else have you tried? Because you can't know, except in the most extreme circumstances, and those circumstances do exist.

But 98% of the time, until you try something how can you know? And we're talking about quality of life for the rest of your life at stake. And to me, as a parent, as a family member of people with disabilities-- and I know that there are parents out there listening who feel the same way. I would do anything to give my child the best possible chance at the best possible life.

JAIME ZAHID: Absolutely. And I think that we-- I hope that a lot of young families, young parents, or young people with disabilities are listening to this because I think that this conversation needs to start early. For somebody such as myself who grew up not experiencing disability firsthand, I grew up with people empowering me and asking me what you want to be when you grow up, and teaching me how to make decisions. And I think a lot of that gets lost with people with disabilities, unfortunately. And then we end up with these situations where we're trying to maybe empower people to make decisions, but they don't have that experience or we just don't give them that opportunity at all.

JONATHAN MARTINIS: Yeah, it becomes a self-fulfilling prophecy. If we're not working with people from a young age and giving them opportunities. And if we say at 18, you're on your own, of course. they're not going to be equipped.

JAIME ZAHID: Right.

JONATHAN MARTINIS: When I talk to people about school, I say transition begins at age three. Any parent out there listening to me, any person who's in school right now listening to me who's getting special education services, they're supposed to be providing independent living supports and services from day one. Ask your school, what are you doing to help prepare my child for independent living. What are you doing about decision-making? What are you doing about self-determination? You might be

surprised at the answer you get. You have to be prepared to advocate for it because they may not know what you're talking about.

JAIME ZAHID: Right. Jonathan, unfortunately, I think we're nearing the end of our time. I wish that we could have this conversation for hours. I truly do. And also, for listeners, I know Jonathan mentioned a number of resources while he was speaking. And two that I just want to highlight is the UN United Nations Convention on the Rights of People with Disabilities, which has some great resources around supported decision-making. And then also the National Core Indicators study as well, which has, as Jonathan mentioned, statistics related to New Jersey and beyond. And so I would encourage you to look that up. Thanks for listening to this episode of BoggsCast, a podcast by The Center on Developmental Disabilities. A full transcript of this episode can be found at theboggscenter.podbean.com. Be sure to subscribe to this podcast on your favorite streaming service to stay up to date with the newest episodes. To learn more about The Boggs Center, visit our website at rwjms.rutgers.edu/boggscenter, and follow us on Facebook at [TheBoggsCenteronDevelopmentalDisabilities](https://www.facebook.com/TheBoggsCenteronDevelopmentalDisabilities).