



ADA Live!

EPISODE 31: SUPPORTED DECISION-MAKING: CONTINUING THE CONVERSATION

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Presenter: Jonathan Martinis, Senior Director for Law and Policy at the Burton Blatt Institute, and Project Director for the National Resource Center for Supported Decision Making

Host: Celestia Ohrazda, Burton Blatt Institute at Syracuse University

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

CELESTIA OHRAZDA: Good afternoon, and welcome to WADA ADA Live. On behalf of the Southeast ADA Center, the Burton Blatt Institute at Syracuse University and the ADA National Network, welcome to the 31st episode of ADA Live. My name is Celestia Ohrazda. I am the Information Technology Consultant for the Southeast ADA Center and also today's host. The topic of today's show is "Supported Decision-Making: Continuing the Conversation"

With us today we have invited back Jonathan Martinis, Senior Director for Law and Policy at the Burton Blatt Institute and also the Project Director for the National Resource Center for Supported Decision Making. Jonathan has over 20 years' experience representing people with disabilities in cases under the Americans with

Disabilities Act. In 2013, he represented Margaret, otherwise known as Jenny Hatch, in the Justice for Jenny case, which held that Ms. Hatch has a right to use supported decision making, instead of being subjected to a permanent guardianship. Last October Jonathan was our guest, talking about alternatives to guardianship. As a result of the show we received many questions so we invited Jonathan back to answer some of those questions. I encourage all of you who may have missed episode 25 to listen to the archive on our ADALive website at adalive.org. Jonathan, welcome back to our show.

JONATHAN MARTINIS: Thanks so much, Celestia. I usually shoot for not boring. I guess I was a success last time. See if I can do it again.

CELESTIA OHRAZDA: One of our most popular episodes, definitely. It gets listened to over and over again. I'm glad you came back to discuss Supported Decision-making in a little bit more depth. The first question I have for you to get us started is what is Supported Decision-Making?

JONATHAN MARTINIS: Supported decision making is a lot of words. It's a fancy way of saying, to quote a law school professor friend of mine, Supported decision-Making is a lot of words, it's a fancy way of saying what we do every day. I guess if you want a real formal decision. It's when people use trusted friends, family members, and professionals to help them understand the situations and choices they face so they can make their own decisions. Like I said, that's a lot of words. Now think about it. Think about the way you make decisions when you go to the doctor and the doctor talks in jargon. Talking about Cervical Spondylotic Myelopathy, or medication regimens. And you say can you explain that in English? And the doctor says oh, Cervical Spondylotic means you have a crick in your neck and this medication regimens means that if you take this it is going to help you in this way. What you're doing is you're getting support, you're getting help to understand the decision you have to make. The decision you have to make when you go to the doctor is what kind of treatment do you want, or do you even want treatment? The doctor's job is to help you understand your medical situation so you can make your decision. That's supported decision making. And supported decision making, you do it all the time. I got support this morning in figuring out what shirt to wear, because I have horrible taste in clothing. My wife said that one doesn't work, you

should wear that one that one. I got support. I go to the auto mechanic, and the auto mechanic has to explain in English what happened to my car instead of talking about head gaskets and timing chains. When that happens I am getting support. So we all get supported decision-making every day and that's what it is. It's just how we make decisions.

CELESTIA OHRAZDA: Thank you Jonathan for that nice, clear, plain English overview with an example we can all relate to. What's is the audience we are looking at? Who is the most appropriate candidate for supported decision-making?

JONATHAN MARTINIS: There's two ways of looking at it. First of all, We all do it all the time. We're all using supported decision making. So we're all the perfect candidate. But the fact of the matter is we all know that. We know that in our hearts. We know that we're using supported decision making. We're already expected to use supported decision making. That's what we do. When you ask me who the audience is, how I read that is who is out there who we don't expect to be making their own decisions. Or who society has never come around to understanding has the same rights to make the same decisions as everyone else. At the National Resource Center for Supported decision-Making we focus on older adults and people with intellectual and developmental disabilities. For 2,000 years, going back to the Roman Empire, we have taken people who we think have challenges in making decisions or who say I need a little help in making decisions and we have assumed they can't make decisions. We have taken away their right to make decisions through things like guardianship. So what we do is we work with older adults and people with intellectual and developmental disabilities to help them to set up supported decision-making. To help them to say that I can do just what you do. And to help organizations to develop policies and practices that encourage supported decision making, that expect people, that lead to the expectation that people will exercise their own choices. I call that the right to make choices. Because think about it. The right to make choices, the right to make choices in our life is the one that makes all the other rights useful. The right to free speech is the right to choose what to say. So when people who are older adults, and people with disabilities, when we assume they can't make choices and we take away their right to make choices, we're essentially telling them that you are less than everyone else. Supported decision making says you're the same as everyone else. With the same right to make choices as everyone else.

CELESTIA OHRAZDA: Thank you Jonathan. Sort of tagging off that question, at what age should we consider supported decision making? Is there a minimum age for someone to have a team? Or can it happen at any point?

JONATHAN MARTINIS: For me, supported decision making happens throughout the life course. I think a perfect example is what the District of Columbia Public Schools is doing. It's a group we worked with. D.C. Public Schools said they introduce supported decision making concepts in pre-K, three-year-olds. It sounds funny having people help you to choose milk or juice. But think about it. If I'm three years old and I know that that's my choice to make and I can get help in making that choice if I need to, then look at what happens. You set up the expectation that the 3-year-old makes that choice, has the right to make that choice. As the decisions get harder, as the child gets older, then that expectation remains. And the use of supported decision-making matures with the child. So it goes through the life course. We like to say it's a birth until end of life event.

CELESTIA OHRAZDA: Excellent. Excellent. Because I know a lot of people when they turn 18 they say I can make my own decisions now, but if you teach them to make decisions throughout their life, we can only anticipate that they'll make smart choices when they get to be at that age.

JONATHAN MARTINIS: We say to 18-year-olds all the time, you make bad decisions, now learn from your mistakes. Think of some of the decisions you made when you were 18. I see pictures of me and think "What was I thinking?" But I learned from that. I learned from my bad choices. So if we empower people to make their own choices. They're going to have experience, they're going to get better at it. They will make bad decisions, just like you and I did. But with support, they will grow just like you and I have.

CELESTIA OHRAZDA: That's wonderful Jonathan. Are there any requirements of what a person receiving support decision making should do? For example, is there a mental health evaluation or some type of assessment that must take place first?

JONATHAN MARTINIS: Here's how I view supported decision making. I think it's the best way to look at it. It's that we should assume that everyone has the right to make choices.

And we should assume that everyone uses support to make those choices. And therefore we should assume that everyone can use supported decision making unless and until it is proven that they cannot. So rather than having to show that you have the ability to use supported decision making, we should do for people what you and I do, which is assume that they can. If there are difficulties in making it work, then we can look at what additional supports and services are needed to make it work. And if at the end of the day we have exhausted everything we have and it simply doesn't work, then you consider other options. But you start with the assumption that everyone has the right to make choices.

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

ANNOUNCER: The National Resource Center for Supported Decision-Making builds on and extends the work of Quality Trust's Jenny Hatch Justice Project by bringing together vast and varied partners to ensure that input is obtained from all relevant stakeholder groups including older adults, people with intellectual and developmental disabilities, family members, advocates, professionals and providers. The National Resource Center's website includes information, resources, news, events, and stories about the Right to Make Choices. We believe that everyone has the Right to Make Choices and that Supported Decision-Making is a way people can make their own decisions and stay in charge of their lives, while receiving any help they need to do so. To learn more visit their website at supporteddecisionmaking.org.

CELESTIA OHRAZDA: Welcome back to our show. We're talking with Jonathan Martinis. Let's switch gears here. We were talking about the person. Now let's talk about the team. So who is involved in the process of supported decision making? And what are some of the roles?

JONATHAN MARTINIS: Well first and foremost the center of every supported decision making team is the person. And if we start there, like we start with assuming that people can make their own decisions, we start with the assumption that the person is the focal point of the team. And then the team is built essentially by the person using people that person knows and

works with and trusts. Friends, family members, professionals. Now some people sadly don't have people in their lives. One of the technical terms is the unbefriended. And people like that, we can work with them to help them understand their interests. To help them identify people who they might want to work with. But to me, there is very little, if any limits on who can be on a person's team, because it's the person who is choosing who he or she wants to work with. Who that person wants to receive support from. But it could be, you know, it could be case managers. It could be family members. It could be friends. It could be attorneys. It could be teachers. Essentially the supported decision making team brings to the table that which the person wants them to bring to the table. Oh, my sister is a nurse. I want to work with her on medical matters. My brother is an accountant. I want to work with him on financial matters. My niece is a lawyer. I want to work with her on legal matters. Et cetera, et cetera.

CELESTIA OHRAZDA: This sounds a lot like circles of support. How is it different than a circle of support?

JONATHAN MARTINIS: It's not. It's not. I always like to say that supported decision making is a paradigm, not a process. It's an umbrella with lots and lots of things that fit under it. One of the things, the classic circle of support, or microboard we sometimes hear it called is almost like a personal board of directors. A group up of people who get together regularly and talk with the person and help the person work through his or her life and come up with plans, that's a form of supported decision making. Think about it. It's the person working with several people to help the person understand what the person is facing and what the person should do. That's a form of supported decision making, but so are so many other things. Just talking with a friend around your options is supported decision making. Working with an IEP team in special ed is supported decision making. It's a paradigm.

CELESTIA OHRAZDA: Once we have this team in place, does it change over time? Or is it set in stone? Oh, this is the person who is going to help you with financial matters. This is the person you're going to go to for medical questions. Or does it evolve over time?

JONATHAN MARTINIS: It should evolve over time. Because the person is at the center. The person chooses who he or she wants on the team. The person may say, oh It didn't work out

with my niece the lawyer as the legal person, I want to work with my other niece the lawyer as the legal person. I want to work with my brother, the nurse for medical et cetera. It should evolve, as our choices evolve, as our life evolves, the people we work with changes. You have to understand that the person is at the center. Therefore the person chooses the team members, and sometimes we evolve to wanting to work with different people.

CELESTIA OHRAZDA: What kind of decision do supporters help an individual make? Is it a laundry list of decisions? Or how does that all work?

JONATHAN MARTINIS: It really is whatever the person wants help with. You know, I have seen supported decision making work on very basic human choices like, you know, what kind of job should I look for? Where should I live? I've seen it work with complex choices where whether or not I should get surgery, whether I should sign this power of attorney. The beauty of it is to think of it as a decision making model that follows the way you do it. Think about the way you make decisions and some of the decisions you get help with. I mean I ask my friends for advice all the time. And it could be something as simple as, you know, what do I do when my kid decides to paint the walls. That is a choice I have to make. (Laughter). I get help with it. So a supported decision making team or a person or a supporter can work on any decision that we need to have made. And I don't think there's a limit.

CELESTIA OHRAZDA: Does this team have to reach consensus. Because reaching consensus can be very difficult. So is there some sort of mechanism that they all need to decide on what's right? How does this work? How do we manage these conflicts?

JONATHAN MARTINIS: You know there shouldn't be conflicts. The team doesn't make the decisions. The person does. The person may get different advice or different supports from the team. Of course people have different opinions, but ultimately it's the person who makes the call. If I have got five team members, and they all want me to do X, and I say I heard you, but I'm still going to do Y. The supported decision making team worked because they helped the person understand his or her options and helped the person make a choice. It is not a democracy. Absolutely not. It is at best an advisory board. The person makes the call. I would hope there would be conflicts, because that means the person is getting lots of different types of advice and lots of different types of information. No one wants any, a horribly

functioning board of directors is one where everyone has consensus all the time. Think of it that way. The person makes the decision receiving the input and support from other people. But other people don't have to agree. Other people don't have to reach a consensus. There does not have to be a vote. It is the person who makes the decision.

CELESTIA OHRAZDA: How can we ensure that the team is acting in the best interest of the person? To say, they're not going to influence a person? They're not going to be biased? What sort of mechanisms are in place to ensure this doesn't happen?

JONATHAN MARTINIS: You know, it's a tough thing to talk about. Because we want to protect people. We want especially people who we see as vulnerable to only have option to good people and only have access to good decisions and only make the best decision. That's not the way life works. In fact, I will guarantee you right now that people using supported decision making are getting bad advice. That people are trying to influence them because that's what happens in life. If you're going to condition my right to make decisions in my life on my friends not being bad influences, then I've got to stop playing poker. Because my friends get me to do all kinds of stupid things. I got to stop going out at night with my friends, because they get me to say stupid things. That is just life. But the point is this. That when we empower people, and this is not Jonathan talking. This is 40 years of studies talking. That when we give people better options in life, when we empower them to make their own decisions, we are increasing what's called their self-determination. Their control over their lives. And 40 + years of studies have said that when people have more control over their lives, they've got better lives. They're more likely to be employed, more likely to be independent, more likely to live in the community, less likely to be abused. So if my choice is between a process that is going to increase my self-determination and give me access to all of those good things or one that doesn't, then I'm every day and twice on Sunday going to pick that one, even though we know there is the risk of undue influence. Because a person with more self-determination is going to be better able to recognize that undue influence and avoid it.

CELESTIA OHRAZDA: Thanks Jonathan. That's really valuable information and you speak with passion. Before we continue here is a word from our sponsors.

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

CELESTIA OHRAZDA: Welcome back to our show. We're talking with Jonathan Martinis from the Burton Blatt Institute and we're discussing supported decision making. We're going to switch gears here. Often questions come in about the legal process of getting supported decision making. Is there a formal process, a legal process that's put into place? Some sort of agreement? What are the official legalities behind it?

JONATHAN MARTINIS: The answer is there doesn't have to be a formal legal process. There doesn't have to be a supported decision making agreement in writing. But I think often it helps. Think about it this way. We're all taught as we get older that a power of attorney in advance directive is a good thing. My wife has got my advanced directive, because if God forbid something happens to me, I would want her to make decisions for me, because she knows me the best. She would know what I would want in that situation. We hear that again and again. Think of an advance directive. An advance directive says God forbid I become incapacitated, I want my mom, my dad, my wife, my brother to make decisions for me. Now, if we were to add another paragraph to that same agreement the one we've all seen, and that paragraph said even if I'm not incapacitated, I want mom, dad, brother, sister, to help me make decisions, to work with me as the final decision making, so I understand my choices and I give my healthcare providers the right to share my information with my mother, my brother, my sister, so they can help me make decision, then I have just created a legally binding document that gives my doctor permission to become part of my supported decision making team and there will never be a question, you'll never hear a doctor say I can't share that with you because it violates confidentiality, because you've got a written document saying that. Same thing with a power of attorney. They say God forbid I become incapacitated, I want you making my financial decisions, or you making medical decisions, or you making my living

decisions, add those extra paragraphs. Even if I'm not incapacitated, I want you to work with me on it. We have created a legally binding document with a plan in it that says who is going to be my supported and how. I happen to prefer that. Even one that is entitled supported decision making agreement and says the same thing. I prefer it because there's evidence and I think people like stuff. It's good to have stuff. You can show a doctor stuff.

CELESTIA OHRAZDA: Are there any legal responsibilities of the team members?

JONATHAN MARTINIS: You know, as such I don't know of any laws that say if you're part of a supported decision making team you must do this or you must not do that. There's really only one state that has a law that specifically authorizes supported decision making agreements in that term. And that's in Texas. But I think it's fair to say as a general rule, that every person has a legal obligation not to commit abuse and neglect and not to exploit people. And that's another answer to the question you asked earlier, how do we make sure people don't act opposite to someone's best interest. We all have an obligation to make sure people aren't getting abused and neglected. We all have a moral, ethical, and legal obligation where if we see abuse, neglect, or exploitation to report it to the police or adult protective services. That's one of the ways we do it. If we, other members of the team, or other members of society, if we see someone violating those legal obligations the ones we all have, we have an obligation to go to the police or to go to APS. That's one of the ways that we do that.

CELESTIA OHRAZDA: So other than life and trial and error, is there any sort of training for the team members and also the person?

JONATHAN MARTINIS: I think there is the training that happens all through life. But I think if you look at organizations that encourage self-determination. If you look at our website. www.supporteddecisionmaking.org, you'll see training packages on there, you'll see introduction to supported decision making if you haven't gotten already tired of my voice, you can see videos and audio recordings of trainings I've given that talk about these very topics that I think are useful. Because if nothing else they introduce the concept and show examples of how and when it can work. But I think Celestia you answered the question better than I do. Life and trial and error. It's the way we all learned to be responsible adults. We had to make

difficult choices. We had to make mistakes and learn from them. We had to have opportunities. Supported decision making is about giving people those opportunities.

CELESTIA OHRAZDA: What if somebody already has a guardian appointed to them. This question comes up all the time. They already have a guardian and they don't want to use that guardian, what are their options to sort of get onto this supported decision making track? You would think it would be an easy process to fire your guardian.

JONATHAN MARTINIS: I wish it was that easy.

CELESTIA OHRAZDA: What sort of suggestions or advice would you give someone or a parent who is already in that position, where they have signed the legal paper and have a guardian assigned to them? What sort of advice would you give them?

JONATHAN MARTINIS: I'm going to cheat a little bit first and say the best advice I can give to parents, especially parents of younger people with disabilities is the best way to get out of a guardianship is not to be in one in the first place. The vast majority of states have guardianship laws that say if there is a less restrictive option other than guardianship, the person doesn't need a guardian. So what I always say is before you make that decision. Whether or not to seek guardianship is an intensely personal decision. I'm not saying that you shouldn't get one, or that you're evil if you're a guardian. It's an incredibly personal and familial decision. But I do tell people this, think carefully about it. It's incredibly important decision. So I say, before you sign that paper, before you seek guardianship, ask yourself the most important question. What else have I tried? What other options have I attempted? Have I tried supported decision making? Have I tried to get a power of attorney? Have I tried to create a supported decision making team? Because if you can do that, you can avoid all the problems I'm about to tell you about and that's this. Once you're in a guardianship, it can be really, really hard to get out. And that's a scary thing. It can be really hard. Because most laws say that a person can get out of a guardianship if he or she has been restored to competency. Restored is often the word they use. Now restored I think means are you cured? Do you no longer have the problem that led to the guardianship? Well, for a person with intellectual disabilities, you're never cured. So it's sometimes really hard to get out. On the upside, lots of state laws also say that the guardian is supposed to maximize the person's

independence, maximize self-determination. So to me, that says you should be using supported decision making within the guardianship – right? You should be maximizing independence by incorporating supported decision making methods. And the second that you feel that that person is able to use supported decision making and no longer requires a guardian making decisions for him or her, you should go back to the judge and say judge, I have done my job. Fire me. Remove me as a guardian. Or the person can say the guardian has done his or her job. I can now handle this and here is the method through which I'm going to handle this. Fire the guardian with my thanks. The problem is that can be really hard. It can take time and it can cost money and there's no guarantee you're going to win. So my answer is where I started. The best way to get out is to avoid it. And once you're in, the best way to get out is to show that you no longer need it.

CELESTIA OHRAZDA: It's a lot harder to get out of things once you're in. That's for sure. Jonathan, we're just about out of time here. Before we close this session, is there one message that you want to deliver to our audience?

JONATHAN MARTINIS: Celestia, I'm a lawyer. Of course I always have another message I want to deliver.

CELESTIA OHRAZDA: Your closing arguments, Jonathan, please. (Laughing).

JONATHAN MARTINIS: What I want people to remember is if you take nothing else out of what you've heard today, and what you've heard before, take this. That we, every single one of us has the right to make choices. We're all human beings. We're all given that right at birth with the divine spark if you will. We are given the right to determine our life course, to chart our future. If we accept that, if we accept that each and every one of us has the right to make choices to the maximum of our ability, we have the right to be our own person. I can't imagine anyone disagreeing with that. If we agree with that, then there's really only one more question to ask. For each and every one of us. What do you need to make that right work? Some of us will say we don't need anything. We can make our own choices our self. Some of us will say I need a little help with this type of choice, or that type of choice. Some of us will say I need help with so many things. Some of us will say I need help with everything. For all of those answers, supported decision making works. Supported decision making says you have

the right to make to choices. It is on all of us to figure out what services and supports you need to make those rights effective. And that's what I think we need to keep in the front of our minds. We need to get away from 2,000 years of history that has said if you're a person with a disability, if you're an older adult, and you say I need help doing something, we're going to assume you can't do anything. We need to get past of that. Because all of us need help doing things. All of us get support throughout our lives. And if it's good enough for us, it's good enough for everyone. And if we do that, if we get in that head space that says everyone has the right to make choices, then the rights that make you feel the best as a person or a citizen. Whether it's free speech, or the right to live in the community. Or the right to choose where to work. Or the right to spend your life with whom you want. And the right to visit with who you want. The right to eat what you want. If we assume that everyone has the same right and the same right to make choices, then at long last, those rights that are important to you, they'll be equal rights. Thank you so much Celestia.

CELESTIA OHRAZDA: Thank you Jonathan. It's always a pleasure to have you on our show. I would like to thank Jonathan Martinis, Senior Director for Law and Policy at the Burton Blatt Institute and the Project Director, National Resource Center for Supported Decision-Making.

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