

Introduction to Supported Decision-Making

April 30, 2014

Operator: Recording started. Good afternoon. And welcome to the Supported Decision-Making Webinar Series. This is Part 2 in our three-part series, "Introduction to Supported Decision-Making". I have a few announcements for the audience before beginning. We are using Blackboard Collaborate for the webinar. This system makes it possible for us to conduct workshops, webinars and virtual meetings over the Internet from just about any computer using a web connection and a web browser. It's also available for iPads, iPhones, and Androids. It allows us to provide real-time closed captioning and creates an audiovisual recording of the webinar. This recording will be available through the Jenny Hatch Justice Project Web site later this week in both a text transcript and audio recording will be made available in the coming weeks. If you're having difficulty connecting with audio or settings you may wish to switch to the toll free number provided it's 1-877-826-6967. The access code is 1188194.

During today's webinar your microphones and phone lines will be muted. If you wish to comment or ask a question, please use the chat box. The moderator will work these into the discussion as appropriate. At this time we are advising you to close all other applications you may have running on your computer because they may interfere with your successful experience. If your computer's network- it may shut down if idled too long. Periodically tap the space bar just to let the system know you're there.

We are ready to begin and I have Tina Campanella, the Chief Executive Officer for Quality Trust for Individuals with Disabilities, as the moderator. Tina, I'm going to turn it over to you.

Campanella: Thank you so much. Good afternoon, all, my name is Tina Campanella and I am indeed the Executive Director and CEO of Quality Trust for Individuals with Disabilities in Washington D.C. I

am very pleased to be serving as your moderator for today's webinar session on Supported Decision-Making, titled "Introduction to Supported Decision-Making".

This series is being supported through a collaboration between Quality Trust, the Burton Blatt Institute, and the Autistic Self Advocacy Network. All three organizations care deeply about advancing the use of supported practices in support of people with significant disabilities, retaining their full rights as citizens, and exercising self-direction in life. Jenny Hatch and her attorney today will discuss Supported Decision-Making using the context of the Justice for Jenny case. Discussion will focus on the differences between Supported Decision-Making and guardianship and how Supported Decision-Making has worked for Jenny.

The presentation will contrast Jenny's quality of life now as opposed to when she was under a guardianship, and include and address the practical and precedential importance of Jenny's case for others who wish to avoid or be freed from over broad or under guardianship. Our presenters today then are, first of all, Margaret Jenny Hatch who is a leader, advocate, and inspiration to people across the country. Jenny lives and works independently and is active in politics and counts among her friends, local, national, and state leaders.

However, because she has Down syndrome, Jenny spent a long, lonely year living in a group home, against her will, cut off from her friends and access to the life she built in her community. Like far too many people with disabilities, Jenny faced a guardianship petition challenging her right to make decisions and choices she always made for herself, like where to live, what to do, and who to see. After six days of trial, Jenny won the right to make her own decisions using Supported Decision-Making. The Justice for Jenny trial court was the first to order the use of Supported Decision-Making instead of a guardianship for a person with a disability. Jenny now lives and works where she wants, has the friends she chooses, and has the inspiration and face of the Jenny Hatch Justice Project and encourages others to do the same.

Jonathan Martinis is our second speaker and he is also the legal

Director for Quality Trust for Individuals with Disabilities. He has over 20-years experience representing people with disabilities in cases under the ADA, Section 504 of the Rehabilitation Act, the Individuals with Disabilities Education Act, and the Constitution of the United States. In 2013 he represented Ms. Hatch in the Justice for Jenny case. Again as we said, the first trial to hold a person with a disability- hold that a person with a disability has a right to engage in Supported Decision-Making instead of being subjected to a guardianship.

Prior to joining Quality Trust in October of 2012, Jonathan was the managing attorney for the Virginia Office for Protection and Advocacy, the Virginia state agency dedicated to protecting and advocating for the rights of people with disabilities.

We also have Ari Ne'eman as a reactor. Ari is the president and co-founder of the Autistic Self Advocacy Network, an advocacy organization run by and for autistic adults seeking to increase the representation of autistic people across society. And he will serve as a reactor to the panel presentation. Ari is an autistic adult and a leading advocate in the neurodiversity and Self Advocacy Movement. In 2009 President Obama nominated Ari to the National Council on Disability where he still serves today. He worked to shut down the New York University Child Study Center "Ransom Notes" campaign and also led other successful disability community responses to offensive advertisements, including the response to the Autism Speaks "I Am Autism" fundraising video. Ari serves as a member of the Institute of Medicine's Forum on Aging, Disability, and Independence, and as a Board Member of TASH. He was the first ever Patricia Morrissey Disability Policy Fellow at the Institute for Educational Leadership. Ari has received the HSC Foundation's Advocate and Disability Award and the Expanding Horizon's Award from United Cerebral Palsy. In his policy work, Ari has worked on a wide variety of disability rights related to legislation, related to education, transition, employment, rights' protection, and other areas.

Also on the call today is Kelly Morris. Kelly is a committed and passionate advocate and parent strongly supporting people with disabilities to exercise their right to live their lives in places and

ways they choose. When Jenny Hatch, Kelly's employee, was injured in an automobile accident and had nowhere to go, Kelly and her fiancé Jim Talbert took her in and became one of her greatest supporters. When Jenny faced a guardianship petition seeking to put her in a group home and took away her right to make her own decisions, Kelly and Jim fought together for Jenny, spending a year of their lives and thousands of dollars to defend their friend. Thanks to Kelly and Jim's commitment, compassion, and advocacy, Jenny won her trial and now lives with them using Supported Decision-Making to make her own decisions about her life.

Since the Justice for Jenny case, Kelly has continued to advocate for people's rights appearing at national conferences and becoming a founding supporter of the Jenny Hatch Justice Project. Kelly is here today in the role as supporter and does not have a formal presentation. We have invited her, however, to chime in if she has anything important to share from her experience.

So for today's presentation we are going to start by asking Ms. Hatch to share her perspective on her personal experience before, during, and after her guardianship. We'll follow that up by Jonathan Martinis then talking about Supported Decision-Making: what it is, how it was applied in the Jenny Hatch case, and why it is important to advocate for the implementation of Supported Decision-Making with more people in every day practice. I'll manage the questions so you should type them in. We'll try and work as many as possible into the presentation. And then we'll finish with Ari and he'll kind of wrap up with his final thoughts and I'm sure his challenges to us as advocates to advance the notion of Supported Decision-Making.

So, again, the reminder is that the questions are typed into the chat room. So please type anything you would like. I will promise to pay attention. And you know do my best to make sure that our presenters are alerted to the things you're most interested in hearing about.

So Jenny, I think we're going to start with you. Are you ready to go?

Hatch:

Yes.

Campanella: All right, you can go ahead, Jenny.

Hatch: Okay. My name is, sorry- My name is Jenny Hatch. I have Down syndrome. I have always been very independent. I volunteer on many republican campaigns. I worked in High School and I graduated in 2004. I was a Global major and was involved with the smart ones. I applied for my job at my thrift store and I loved it. I rode by bike to work, to visit friends, and even to my church. I did this by myself. I was very proud of my independence. I worked for almost 7 years at my thrift store. In March of 2012 I had an accident. I was hit by a car and was in the hospital. I had an operation on my back. It was scary. And I had to wear a brace. No one wanted me when I was getting out of the hospital. I had nowhere to go. I was so happy when Jim and Kelly let me come and stay with them.

Kelly and Jim helped me get services. But I could not get a waiver if I lived with them. I had to leave them in order to get a waiver. I did not want to leave. I was moved from one group house to another. I did not feel safe there. I was treated like a child. No one listened, no one cared. I tell my case worker I didn't like it. And I wanted to go back to live with Jim and Kelly. But she told me I couldn't. And I should just get used to living in group homes. I told her no. In a group home you wouldn't let me talk to my friends. Or let them come to visit me. They do not let me work at my job. I kept telling them that I love my job. But they didn't let me. They took my pictures away. I felt like a prisoner. But I didn't do anything wrong.

I was given a temporary guardian by the court -- I didn't want it. They took me to another group home where I did not feel safe. The case workers yelled at me and they would hit me. They would not let me talk to my friends or work at my friend's store. They told me I had to work at other things. And I put snaps together... It was boring. I did not like it. I wanted my life back. But they told me to forget about Jim and Kelly. Sorry. I wanted my life back but they told me to forget about Jim and Kelly. Move on with my new life. I cried every night at the group home. I was taught I had rights at the group homes but it wasn't true.

The CSB and JFR took them away. They took away all my rights,

my sources, and my opinions. I was kept away from my friends, my job, my charts, and my community. I lost a year of my life being forced to stay in group homes. And forced to work at a job I did not want.

How do we make sure that a person's rights are not taken away like my rights were? Who will make sure that no one has to go through what I went through? Who will make sure that the CSB and JFR will do the right thing? Just because a person has a disability does not mean they need a guardian. Many times they just need support and need help.

Living with a disability can be very hard sometimes. We don't need people to take away our rights and force us to work in a sheltered workshop -- they may not want to.

My life is much different now. I go to work and help my friends there. I go to the mall and to the park with my friends. I have my cell phone Jim and Kelly got me. They support me. They taught me to make good decisions. I am very happy for Jim and Kelly. I love them very much.

I want to thank Jonathan and Quality Trust for all they have done. Because of their hard work I got my freedom and my rights back. I get my life back. This system has to change. And this group home has been shut down. End of discussion. Thank you.

Campanella: Thank you very much Jenny we're going to hold questions --.

Hatch: Thank you.

Campanella: Let's go to Jonathan. Okay.

Martinis: Thank you and thank you, Jenny. Jenny, you should know that even from 300 miles away you can still make me cry every time.

And every time I've met Jenny and every time I've been around her I'm struck by her story because the first time I ever met Jenny she was already put in a group home, her case had already begun, and she had already had an order saying that she should be under a

guardianship. At that time I had to actually break and enter to meet Jenny, because then the court said that the guardians could control whoever got to see Jenny. You actually had to file a permission slip to ask someone for the right to see somebody who her entire life had chosen for herself who she could see, what she could do, or where she could go.

So the first thing I did was ask Jenny if she wanted help and she said yes, so I went to the attorney for the other side and I said, "I'm going to be representing Jenny, I don't have to fill out a permission slip to talk to my own client, do I?" And he said yes, so the very first thing I did in Jenny's case, I had to ask the court to tell the other side that I was allowed to see Jenny and talk to Jenny without fearing being arrested.

I think it's fair to say that at that time that was literally the threat that was made for Jenny at the time she was working in the Sheltered Workshop you can see on the screen she made less than \$1,000 for working five days a week for eight months, she had no computer or cell phone. She wasn't allowed to talk to her friends. She wasn't allowed to go to her job. That was the situation that she found herself in. And why did she find herself in that situation? Well, because, we reviewed the evidence in the case, somebody got on it. And their expert, their psychologist, had reviewed Jenny and said over and over and over again that Jenny needs help doing things. The position was actually that Jenny needs a guardian because she needs some help. Jenny could manage a bank account if she got some help, Jenny could understand a contract if she got some help, she could live independently if she got some help. Then the expert said this beautiful sentence that you see on your screen right now. She said, "I believe that what would be beneficial to Jenny is that she be afforded the opportunity to have individuals around her who support and love her, who give her the assistance she needs." That was the reason why, in their opinion, she needed a guardian because she needed some help.

Look at other things. It turned out Jenny had done a power of attorney in 2001 at her parents request, and we asked the parents: if you think Jenny can't make decisions, if you think she made a - needs a guardian, how exactly did Jenny fill out a 40 page power of

attorney that talked about things like stock market transactions, that talked about complicated health care issues? And this is what they said, they said she can fill that out because we explained it to her. That the attorney talked to her about it, so she understood it. And based upon explaining it to her over several visits and letting Jenny ask questions, the attorney concluded and we agreed that Jenny was capable of understanding this gigantic one inch thick document.

And there was still more. JFS, who Jenny mentioned, was her temporary guardian had records that showed with their assistance Jenny could fill out applications for services, Jenny could fill out an application for power transit and Medicaid and assign a representative payee. So all of these things said to us that Jenny could do things but she needs help and to them because Jenny needed help it meant she needed a guardian. To us, what it meant was thanks, because all that evidence made our case for us. All of their evidence made our case for us. Because think about what their evidence said. It said that Jenny is a person who needs help, needs support to understand legal issues, and medical issues and monetary issues. In other words, Jenny is a person. Just like you and me.

We all need support on medical and legal and like day-to-day issues. Think about the way you make decisions in your life. Think about the things that you do every day. If you have a big decision that you have to make, do you just make it with your gut all the time? No, you do research. You ask people for information. You go out and you get the support and the information that you need to make the best decision that you can. And when you do that, people tell you that you're smart. People tell you that you are making an informed and intelligent decision.

When Jenny Hatch says: I need a little help; everyone assumes that she can't make any decisions. Why is that? Why is it that when Jenny Hatch needs a little help, when a person with a disability needs a little help, they are called weak or unintelligent or needy? Let's have a little exercise. I can't see you where you are but I want you to play along with me. Everybody out there who has ever closed on a mortgage raise your hand. Did you read every

document that was in front of you at that closing or did you just assume it said what it was supposed to say. I already know the answer. And it's a bad decision that you made, where is your guardian? Everyone out there who has ever agreed to have surgery, raise your hand. Did you read all of those informed consent forms they put in front of you or did you just assume that they meant what they said they were going to mean? I know the answer. You made a bad decision. Where is your guardian? Now everyone who just like me has ever bought a pasta maker at 2 in the morning on an infomercial, raise your hand. That's a bad decision, where's our guardians? No, we made bad decisions, we're allowed to make bad decisions because we call them learning experiences. We say that we get better by trial and error. We say that when we learn, we grow. Unless you are a person with a disability. Unless you are Jenny Hatch. Because, as the as the court talked about in Jenny's case, he said he had a first cousin who had the same disabilities as Ms. Hatch and he'd want someone to take care of her, not to help her make decisions or learn or grow, but take care of her. All of this coming from a theory that we call guardianship for your own good, where people with disabilities get under guardianship to protect them, to protect them from making bad decisions and bad choices, to protect them from making mistakes. Or as I put it, to protect them from growing and learning and from being people with rights the same as every other person is. So in Jenny's case, we had to give the judge some more education. We had to come up with an alternative to guardianship to talk to the court to show that there doesn't need to be guardianship, she doesn't need to be taken care of, because Jenny already exercises something called Supported Decision-Making. In fact we all do, Supported Decision-Making is a very fancy phrase, what it means something that you and I do every day, it means decision making. A quick digression: my nephew is graduating from college next week and he had to choose between jobs, I know it's a tough problem to have in this day and age, but he couldn't decide and he was agonizing over it and he finally told me, "Uncle John I talked to my dad, I did research, I talked to friends and after all that, I decided that this job was better than the other one, so I took it." And I said, Mark, congratulations you've just done what people with disabilities call Supported Decision-Making, or as everyone else calls it: decision making. And the evidence in Jenny's case is that

Jenny already does it too. Think about all of the things she had done: a 40 page power of attorney, a document applying for Medicaid, applying for services. She had already consented to surgery at one time. So Jenny does it already, and we had experts to come on and tell the court that Supported Decision-Making will increase Jenny's independence. That studies show that people with disabilities who are more independent are less likely to be abused. And that there are services, supports available through Medicaid that could help her learn and grow and become even more independent while dealing with things that the court seems to think she needs protection from.

So we put these people on, and the judge wasn't very friendly at first. We had a psychologist say that in his opinion, without a doubt, Jenny could do Supported Decision-Making now and it would give her a better life and make her more independent. And the judge said: Well why don't we start her out in a group home, and give her a little bit of independence now and then see what happens after that?

So we put on an expert in independence. An expert in independence told the judge that independence is a right. It's not something one earns. It's something we are born with. And the independence that Jenny was seeking, that she could already exercise and had exercised her whole life, was going to make her even more independent and able to achieve even more and he quoted studies talking about it. And the judge said: I don't know about that. Because if I was here in a guardianship you can always come to me with a problem, you can file another motion and I don't know what's going to happen if we give individuals with disabilities more freedom. We just don't know.

So then we put on another expert to say that if he was worried about someone being there for Jenny, this expert identified nine different places that you could file a complaint, anyone of which could deal with the problem within 30 days. And the judge talked about his grandma and how his grandma always said, you can't have the best possible life. That's not what you wish for, it's what you live.

So that's what we faced going into the end of Jenny's case. And Jenny kept telling me: He's going to send me home. I know he is going to send me home and I kept preparing Jenny that Jenny you're strong. You can handle anything. And if the decision doesn't come out the right way, you can handle it. She kept saying he's going to send me home. So at the end, the judge made his decision and the first four pages he read, and this was a guy who read slowly, all talked about why Jenny needed a guardian and I just kept rubbing her shoulder and saying, Jenny you can handle this, you're strong, she kept saying he's sending me home. And then the judge said "however". And as any lawyers out there, you know you don't want to be on the wrong side of however, the wrong place to be. On our case, we loved to be on the right side of however, and I looked up, I met my co-counsel Morgan's eyes and we said, "However"? And the judge then proceeded to make Jenny free. He said yes, she's going to have a guardian for one year and then it ends. And it will only be over two things, everything else Jenny gets to make the decisions. And the guardian was ordered to let Jenny live where she wanted to live, and do what she wanted to do, and the guardian was who Jenny wanted it to be. Kelly Morris and Jim Talbert.

And Kelly Morris is with us on the phone today, and let me just say what I always say to Kelly and I don't think she understands fully yet: that Kelly, you are an incredibly special person, you and Jim both. I can't imagine a person who would take in an employee and fight for them the way that you fought for Jenny and support them the way that you support Jenny. You have made Jenny free. And I thank you for that and I hope everyone on the phone does the same, because Jenny gets to live where she wants and what that means, is that even while she's under a guardianship, even while that time the judge said: Guardians, you are going to use Supported Decision-Making. You are going to help Jenny make her own decisions, even on the things under which you have control, because a guardian's job is not to make decisions for the person. It's to make decisions with the person. The decision the person would make. Not what you think is best. But the person would make. And I have had the greater honor to be with Jim and Kelly and Jenny a number of times and I can tell you that's exactly what they do. They are not guardians. They are supporters. And on

August 2nd their guardianship ends and they are still going to be supporters, and Jenny is still going to live the life she wants, and what that means is that Jenny got justice. Jenny got justice. She got to go home. She got to live the life that she wants.

Why did Jenny get justice? I'll tell you, because one, Jenny is awesome. She's strong and she's smart and she doesn't take no for an answer. But there's another reason why Jenny got justice. She had friends. First and foremost she had Jim and Kelly. She had national organizations that would support her. The HCLU supported her. The Bazelon Center for Mental Health Law supported her. The ARC of Virginia and National supported her. Ari Ne'eman and ASAN supported her, both tangibly and intangibly, she had so many people in her corner, I can't imagine how anyone could have stood against them. And she had a judge that was going to listen and learn, and lastly but not leastly, she had media. She had a reporter who followed her around and had her story and wanted everyone to know that Jenny had rights and Jenny's rights should be protected, and all that means is that Jenny got really, really lucky. Because if you take away any of those things, you take away Jim Talbert and Kelly Morris, you take away that judge, you take away that media, and I'm afraid that Jenny is still in that group home. And that somebody as powerful and intelligent and giving as Jenny Hatch would be locked behind cinder block walls putting snaps together and stuffing envelopes is something that should make us all terrified. Jenny got lucky, and what we cannot let happen is for people to have to depend upon luck for their civil rights to be respected.

And I tell you this: This is the issue, this is the defining civil rights issue of our time. Because supported decision-making isn't just another process. It's not just another concept. It is a paradigm. Everything that is important to us in disability rights is captured in Supported Decision-Making because what is more important than the right to make a decision? How can a person have community integration if they can't make the decision of where they want to live? How can they have inclusive employment outside of a Sheltered Work shop if no one will respect their choice to work where they want to live? How can they have freedom of association and speech if no one will respect their choice of who to talk to?

How can we have life, liberty, and the pursuit of happiness if the life you are living is what you're only allowed to live? If the liberty you exercise is what someone lets you exercise? And if the happiness you pursue isn't yours? You can't. This is the issue that will capture all of those.

And we have the chance to make it real. But here is the problem: In this age, in 2014, at a time when we've got Medicaid waivers and iPads and more services and supports than we have ever had to help people be independent, to empower them, to respect them, to let them be the people they want to be, the number of people under guardianship has tripled in a generation. How is that possible? How is it that as we have gotten more independent, as we have gotten more programs, we have gotten more restricted in guardianship?

It's because typically when someone is turning 18, there's still tons of voices in their parents ears saying get guardianship. I did a lecture for the Special Needs Alliance which is probably the largest group of attorneys doing cases for people with disabilities. And I had a whole presentation set to go, I was ready to talk to them about important things. I was waiting to be introduced and I saw they have a pamphlet, and the pamphlet is called, "What Happens When I Turn 18?" It's about a millimeter thick because when you open it, what it says is two things: When your child with a disability turns 18, One: get guardianship. Two: get SSDI. End of list. So I scrapped my speech and I said if this is your advice, you're committing malpractice. There are so many more things that need to be done that you need to think about for a person with a disability. There are so many more supports and services available that could make people independent. That could give them the types of life that we enjoy if we are lucky enough to enjoy them, if we are not unlucky enough to have a disability and be under guardianship. And yet no one is pursuing them because of two pieces of advice, get guardianship, get SSDI. I can't tell you the number of people I've had come into my office saying, my school just called and they told me if I want to be involved in my child's IEP after he turns 18, I have to be the guardian. That's wrong. The number of people who have said, my social worker said if I want to be involved in planning services after they are 18, I have to be the

guardian. That's wrong. The number of times I've had people say, I want to live outside of this institution but my guardian won't let me. So I can't live where I want to live. And that's wrong.

We have a chance now to make what's wrong right by using Supported Decision-Making -- by getting past the continuing public perception that people don't need rights, they need protection. Well I'm sure you all have heard about the Olmstead case of 1990, or 2000, pardon me, that said that people with disabilities have the right to live in the community if they can. Well I want to talk to you about a different Olmstead case from 1928, where the court said, "the greatest dangers to liberty lurk in insidious encroachment by men of zeal, well-meaning but without understanding." In plain English that means, we do the most harm when we try to do good without having any idea what it is we're doing. And when people say: Get guardianship over your 18, I'm not saying they're over your 18 year old. They are not being evil. They are just being wrong. And they don't get it. We need a massive change in understanding and a massive change in how we do things. And we have opportunities. Lawyers out there, challenge guardianships and promote Supported Decision-Making. Jenny Hatch went down to the Virginia General Assembly this year and testified multiple times in favor of a law to study Supported Decision-Making to see if it could be used instead of some of the other more restrictive methods. At the end of one of her testimony an old right wing state Senator said: Ma'am, you're not going to have any trouble getting this passed. Jenny Hatch went and did that.

There are people on this phone call, people on this webinar, who are able to do things like that. Who can promote appropriate laws and policies? There are lawyers and advocates on this call who can promote cases that say: Supported Decision-Making is the new paradigm. Not the new shiny toy. Not the new theory. But this is how we are going to provide rights going forward. We are going to give people the same rights everyone else has. Because all Supported Decision-Making says is that people with disabilities can make decisions the same way you and I do using the same methods you and I do. People with disabilities may need more support. They may need more in-depth explanation to understand the situations they face and choices they make. But that does not

mean that without that they cannot make decisions. We must start from the assumption that people with disabilities can make decisions and beyond that that they have a right to make decisions. And once we get there, we will be in a very special place because we won't have to talk about people with disabilities having rights anymore. We will talk about people with disabilities having choices. The same way everyone else does and when that happens, we won't be talking about Justice for Jenny. We will be talking about justice for everyone. And the Jenny Hatch Justice Project exists to make sure that day comes and I invite any of you to contact us and work with us to bring that day to this day. Thank you.

Campanella: Thank you, Jonathan. Okay. So please feel free to type in your questions here. But I'm just going to start it off by following up with a couple of things. You said an awful lot of stuff.

So please in the simplest way you can possibly do it, give me your basic definition of Supported Decision-Making.

Martinis: For everyone on this call, the person asking that question is my employer and she should know better than to ask a trial lawyer to make a simple description. However, I will say this: Supported Decision-Making is a very simple concept and when asked, I explain it this way: Supported Decision-Making is, Number 1, the assumption that everyone has the ability and right to make their own decisions. And Number 2, providing people with disabilities with the help that they need and they want so they can understand the choices they have to make so they can make their own decisions.

Campanella: Great, thanks, so the next is what does it look like in practice? What are the key elements you look for?

Martinis: Everyone is different. Everyone has different needs just like you and I do. We all have to figure out things different ways, we all have strengths and weaknesses; there are all some concepts that we get better than others, but essentially it's finding out how a person makes decisions and how they state their own preferences and working that way.

I promised not to put her on the spot, but Kelly Morris I know you're out there. If you would like, can you tell us how Supported Decision-Making works in your house?

Morris:

So, Jonathan of course I knew that you would do this, we had this discussion earlier and we agreed that you weren't going to put me on the spot, but once again, okay. No, it's just that to us it's just a simple, basic premise. I mean it's how we deal with, you know, our friends and our families. You know, we just support Jenny. We don't try to control her decisions. We try to- if she's having a problem with something, we just, you know, have a discussion and talk about it. And you know, let her make those decisions. She's grown. She's 30 years old. And she's very intelligent. So she just has us to kind of bounce things off, you know, just like a friend or a family member would do. That's about, you know, it's just a simple concept.

You know, watching Jenny go through the guardianship process and just how controlling so many things around her were, I mean it was just heartbreaking to witness and to think. You know, that any one of us is- we're not immune to this kind of stuff. This happens. It's rampant. You know, we can bonk our head tomorrow morning and to think that somebody can come along and make these decisions for us and not take into consideration how we would feel, it's scary.

You know, it's just we, you know, had witnessed Jenny for five years at the thrift store. And she pretty much rode her bike everywhere. She applied for the job on her own. She went to church every Sunday on her own. She joined different organizations all on her own. She did a very good job with the decisions that she made.

So I mean it was just normal for us. We just- you know, she knows how to make the right decisions. If she has- you know, if she's confused about something then we'll sit down and we'll discuss it.

But I hope I answered your question. That's all I've got.

Campanella:

That was perfect, Kelly. Jenny, do you have anything else to add in terms of why Supported Decision-Making is important? Not just for

you but for other people with disabilities? I think you probably know other people with disabilities.

Hatch: Yes.

(Dog barking).

Morris: Can you ask her the question again? I'm sorry we had someone knock on the door so she got distracted.

Campanella: Yeah, no, I heard the dog. Jenny, I was trying to think- say as an advocate for other people with disabilities about why Supported Decision-Making gave the same sorts of opportunities you have how -- why it's important for others.

Hatch: It's because I help with other disabilities and it will help those who have special needs. And just the decision-making is like, if you have good or is it a bad decision, it doesn't matter what you have, and it's very important and I like the word that Kelly said that they will help. Thank you so much, Kelly.

Morris: Oh, it's okay, Jenny.

Hatch: Don't cry, I still love you.

Campanella: No problem, Jenny, we got it. So thank you so much for that. Does Supported Decision-Making assume no one needs guardianship? And as a matter of law how do you draw the line between those who can manage with help and those who can't. Let me start with that. It's a two-part question here so let me throw that out to Jonathan.

Martinis: Opinions in the field differ on that. Speaking for myself, I don't think it does. I think every person is different. And I think there are people who have disabilities that are so acute that they are unable to make decisions and therefore could benefit from a guardianship. When I'm asked that question I always answer it the same way. A person in a coma needs a guardian, so you can't say you never can have a guardianship, and as a practical matter I don't think guardianship as a legal thing is going anywhere anyways, it's been in the law

forever. So, the way I view guardianship this way it's not a good thing or a bad thing. It's a tool. If you use the right tool in the right way, at the right time, you can fix things. Use it the wrong way, the wrong time, and you get hurt and people get hurt around you.

So the key is not that guardianship should never exist, not that it should never be a thing, but it should be the absolute last thing. Supported Decision-Making is a less restrictive alternative to guardianship and courts are required to examine those anyway. So I always say this: We're going to know that we've gotten some place with Supported Decision-Making when someday someone files a petition for guardianship that no one opposes because no one knows they can, and the court says, the judge says, well I know you want this, but what else have you tried? When we've gotten there, we'll know that guardianship is at last the last tool in the box, not the only tool and not the first tool. I'll say it this way, disability issues are all based upon the individual. Every person has a right to be judged as an individual as to their decision making capacity. Everyone's wants and preferences and needs have a right to be judged individually, so I'm not willing to say this IQ level and you need a guardian or this disability and you need a guardian with the exception perhaps of a coma. Otherwise you look at the person and you look at the person's abilities. And by the way, even when a person is under a guardianship, that is not an excuse not to use Supported Decision-Making. Remember what the judge said in Jenny's case. Even under a guardianship the guardian's job is to find out what the person wants and the decision the person would make.

So it's not guardianship or not. It's Supported Decision-Making whether or not there's a guardianship.

Ne'eman: Jonathan, this is Ari, I know I'm the respondent but can I speak to that question? Because I have a slightly different opinion.

Campanella: I was just going to go to you, this is -

Ne'eman: Tina, you went in and out there. What was that?

Campanella: - I was going to transition to you and give you an opportunity to do

the reactor now so please take the floor.

Ne'eman:

Great. So I think that the question of is there a future for guardianship that was asked is I think a really important one. And to me, I look at guardianship as in many respects very similar to institutionalization. We are on the verge of moving to a future without institutions for people with intellectual and developmental disabilities. We're really starting down a similar process around Sheltered Workshops. But, we've, you know, made a tremendous amount of progress in deinstitutionalization between 1960 to the present almost 200 institutions for people with developmental disabilities were closed. And people were supported to move into the community. Now we're starting to really challenge the idea that an institution is just a large state run facility, and are now looking at smaller group homes, smaller institutions, many that go by the name group homes. And I think we're really going to be embarking on a similar process when it comes to guardianship.

I do think we could envision a world in which guardianship is not necessary. And I do think we can be saying very credibly that with the right infrastructure for Supported Decision being put in place and when I talk about infrastructure, I mean putting in place legal arrangements that will be recognized by financial institutions and other settings that allow people to involve their supporters in a meaningful way and interacting with various forms of decision making, that we could be moving to a world in which guardianship is not really a tool in the toolbox.

I don't anticipate that that world is going to come tomorrow. But I really - I think about the way in which the deinstitutionalization movement which is a movement that's had extraordinary success but is still very much ongoing really was rooted in a compelling moral vision.

Everyone can live in the community. And I think we need a similar compelling moral vision when it comes to the fight against guardianship, and the fight for Supported Decision-Making, which is that everyone should be recognized as a human being with the right to make their own decisions, and the right to express through whatever mechanism they have the ability to do so preferences.

So you know, does that mean that we don't have any structure in which some form of substituted decision making is utilized at any time? Well, no, I mean Jonathan gave the example of somebody in a coma and clearly there's a need for a structure there. I would hazard a guess that you could come up with a much more effective structure than guardianship, which is very hard to reverse. And you know, it's very comprehensive and, you know, there are well established alternative structures for substituted decision making in the context of health care that are much less restrictive than guardianship, but I do think we can be moving into a world in which this construct, this tool called guardianship, is not something that we apply. Not only in the cases where it's very clear that it's inappropriate. But also in the cases where it's more difficult, and where we need to build the infrastructure, to meaningfully support people in other ways. I want to add one more thing. Because Jonathan mentioned that courts are required to look at less restrictive alternatives. And you know I just, I want to point out and Jonathan, I know you're 100% aware of this. But I want to point it out for the sake of our audience. The courts almost never do. And we've really, we're actually- ASAN is about to release a report on this that analyze case law from a wide array of different guardianship proceedings and found that even in states that have fairly robust protections that are supposed to suggest to the courts that they should really think twice before placing somebody under guardianship, they are very rarely utilized. One example that's featured in our report is a case in which a Department of Corrections was actually named the guardian over a prisoner within the- within a jail they were administering.

And there are countless of other cases in there in which it's very clear that even in the very obvious cases the procedural safeguards within guardianship are not enough to address the problem.

So I think from our perspective, and from the perspective of the Self Advocacy Movement, we need to look at guardianship as a concept and as a tool that does not have a place in the future of disability policy. And that transition is going to take place over a long period of time. Just like with deinstitutionalization. We don't you know say good luck and God speed to everyone, go fend for yourself. But I

think we need that compelling moral vision. Everyone should have capacity. And we can create a world without guardianship just as we are in the process of creating a world without institutions and without sheltered workshops.

I have broader thoughts but I don't know if you wanted to go back to questions or if you wanted me to just speak to my thoughts on the broader discussion, Tina.

Campanella: Absolutely, Ari, this would be the time to share your broader thoughts.

Ne'eman: Well, I want to start by thanking Jenny in particular for sharing her story and for her bravery. You know, I know you know this, Jenny. But what you have done has had a tremendous impact not only at the individual level but at the systemic level and the broader society. For a long, long time those of us in the advocacy movement who were fighting against things like institutions and fighting against things like Sheltered Workshops and sub minimum wage and abuse in any number of different ways, we were always met by people who said: Well, you should maintain these things because it's a choice. It's a choice. You should maintain institutions because they are a choice that people can pick. You should maintain sub minimum wage because it's a choice that people can pick.

And the response that we've always had to give is: Whose choice? And really I think at the end of the day the conversations around getting people out of institutions or around supporting people out of Sheltered Workshops and into integrated employment or around fighting back against abusive forms of treatments like the Judge Rotenberg Center's contingent electric shock, in which people with disabilities are literally hooked up to devices that function like dog collars and shock people when they are deemed to misbehave. All of these things come down to disputes about guardianship.

You know, people do not choose to go into an institution. People do not choose to say: I want to spend my life living in a place I don't control with you know, a few dozen of my nearest and dearest perfect strangers. That's not a choice that people make for

themselves. It's a choice that family members or professional guardians are all too frequently making for people with disabilities.

And so if we're going to be making progress in the under lying conversations, if we're going to be making progress in the areas of advocacy in which the Disability Rights Movement have been engaged with for a very long time, we need to start addressing this root issue of whose choices are being respected. And you know whose agency is being acknowledged.

And I think one of the interesting challenges and opportunities that we have along that process is to recognize that this Supported Decision-Making movement, it's beginning with the easiest cases to prove that guardianship is unnecessary in.

And that's, I think, appropriate and it makes sense. We're establishing a principle. And then we're working to broaden it further. But the implications are far broader than that.

We have always maintained and you know my background is in the autistic community. And there are many autistic people who can talk like I can, and there are many autistic people who can't talk, and maybe communicate through augmentative communication or don't have any functional communication system and have to communicate really only through what's deemed behavior or what other people may deem acting out or having a meltdown. We need to start recognizing that even when people lack access to a functional communication system, there are ways of understanding people's preferences. There are ways of looking at what people are trying to communicate to you and what people are trying to communicate to the world, even if it's not in the typical fashion.

I remember a friend of mine. He has since passed away. He was a person- He was a person with a very significant intellectual disability and he had no speech, no access to functional communication. But he lived in the community. And every week, a few times a week, he had on the schedule of his - you know the activities he was supported to do during the day going to the pool at the local Community Center. And every week when he was out on the schedule to go to the pool at the local Community Center his

support staff would help him get to the front door of the Community Center and they would stop right in front of the front door right next to the button that you push in order to automatically open the door for wheelchair users and they would just stop and wait for a few moments they would stop and wait and see if he pushed the button. And when he did, it was his way of communicating I want to go swimming today. And when he didn't, it was his way of communicating, "look, I know this is on my schedule". But I really don't want to do it. I don't feel like going in the water. Let's do something else.

He had no functional communication system in any sense that would be traditionally understood by the general public. But my friend was still able to engage in Supported Decision-Making.

And I think the real promise of this movement is not only to liberate a tremendous amount of people who are now being imprisoned in horrifying conditions you know what happened to Jenny, if it had happened to a person without a disability, it would have been- it would have been you know considered kidnapping. In fact, you know, we really should think of it that way.

And it's only the law that needs to catch up so that we can understand that way in the minds of the general public and the minds of the law, as well.

But the other promise of Supported Decision-Making is to help us begin to understand not only at a legal level, but at a social and a cultural level, that everyone should have the opportunity to express agency. Everyone should have the opportunity to make their own decisions. And the concepts of self-advocacy and self-determination are not the province of those deemed sufficiently communicative or sufficiently high functioning, a term I despise by the way, in order to exercise them. But instead, they are fundamental birth rights of human beings. Self-advocacy and self-determination is something everyone should have access to.

And it's incumbent upon us, it's our responsibility, to help to build a world in which that is recognized.

Campanella: Thank you, Ari. That was wonderful. We certainly appreciate your moral vision here, and to really challenge us to embrace that and hear that as a challenge to us all going forward.

Thank you also to Jenny and Jonathan and to Kelly for being here and sharing from your personal perspective kind of what our challenges are going forward. I certainly want to remind everybody that this is the second in a three-part series. So we hope that you will join us for the next session on May 22nd when we will have Sharon Lewis from the Administration on Community Living, Allison Wall from the Collaboration To promote Self Determination, and I believe Barbara Brent from the National Association for State Directors of Developmental Disability Services. In order to address our next topic, which is "Supported Decision-Making, The Next Level of Policy Development". I believe as Ari has challenged us, we really need to think about envisioning a world in which things work very different. So again thank you to all of our presenters. Thank you to everyone who joined us. I know there are some additional folks that -- additional folks that -- additional folks that may have questions. And so please, bring them on now. We'll take some final questions.

Okay. Again, not seeing any, Jonathan, do you have any final thoughts?

Martinis: I do, there was one person who posted a question about what can be done to educate judges indicating that she had a brother who's in a situation much like Jenny's and if you're out there, number 1, I'm very, very sorry for what you're going through. I think Ari said it best, this is almost medieval in the way people have their rights taken away.

Circling back to Ari's comment real quick there's almost nothing he said that I disagree with.

When we look at guardianship, the old style of guardianship, what's also known as plenary guardianship where one person gets the final say over everyone's rights - that needs to go away. The way Ari put it, methods of substituted decision making, as he says there may always be a need for something like that. But the old, I decide

for you based upon what I think is best for you without getting input from you, that is an out dated and dead concept and it needs to stay away, so thank you for that information, Ari. As to the person who is asking what can be done to educate judges: lots. And the first thing that has to be done is judges need to understand in any case that there are options, as Ari said they don't know. The law says you must consider less restrictive alternatives. The first thing is to tell the judge these things exist. There are commonly considered alternatives like powers of attorney. No one talks about Supported Decision-Making perhaps because there are no laws that talk about them. So that's one thing -- Like Jenny Hatch you can advocate for passing laws that recognize Supported Decision-Making. I'm tangentially involved in drafting one as we speak, so that judges can say here is an existing thing. There is a Supported Decision-Making agreement that can be taken to a judge or to a doctor to say: Doctor, I know that usually you- you'll only deal with a patient or the patient's guardian or parent. Here is a piece of paper that says you can deal with the supporter, to lawyers who would normally say I can only talk to my client or the parent or guardian, here is a piece of paper, a thing that says you can deal with the supporter, too.

So that's how you eventually educate judges, you educate lawyers and you change laws.

If you are going before a judge soon, read everything you can on what Supported Decision-Making is. And bring in a big stack of paper and give it to the judge and say: Judge, here are study after study after study that talks about this as a less restrictive alternative. Please contact us. The Jenny Hatch Justice Project. We can at least give you information that you can use or that you can bring to someone else to use that can help people avoid this horrible, horrible almost medieval situation.

Campanella:

Thank you Jonathan and we had another question about whether or not there's a formal relationship between the assisters and the person needing assistance in the model of Supported Decision-Making.

I just would encourage people who missed our first presentation to

check back. There is an audio archived version on the Jenny Hatch Justice Project Web site because we started this series by inviting our neighbors to the north from Canada who have been utilizing this concept in some way to share with us their experience on how it got implemented. So again I'm going to ask either Ari or Jonathan to take this question specifically about kind of what the formal relationship might be and how they see kind of the relationship of being addressed. But I think that in short, the short answer, is that the folks to our north and in other places have much more experience with this concept than we do in the United States. And we can look to them to really help us sort of envision how these things will play out.

Martinis: The answer from my standpoint, and Ari please jump in if / when you have something to add, is that there doesn't have to be but there probably should be. Like I said, we have to make Supported Decision-Making a tangible thing so that people can touch it and know it and understand it rather than just being a concept. So I always recommend some kind of Supported Decision-Making relationship, even something as simple as a note saying: I want this person to support me. I want you to talk to this person. Every profession allows for what they call authorizations. But once you have a piece of paper or something that shows that you've made a choice, that you can take and hand to someone and I think the relationship gains more respect. I hope we don't have to get there. I hope, I'm sorry; I hope that we don't always be there. But I think for now it makes the most sense. I can tell you that again the draft legislation I'm working on includes a draft Supported Decision-Making agreement and I think it is something that is badly needed in this field.

Campanella: Would you add anything, Ari?

Ne'eman: Only that I have just the most profound appreciation for Jenny, Jim, Kelly, and Jonathan and all others who have been working on this issue. We have a long way to go. And I think we can do some great things. And help a lot of people.

Campanella: Okay any final thoughts Jonathan I know we're a little short on our time but I don't see any other questions. And so --.

Martinis: My final thought is this: Thank you. Jenny, I've known you for a year and a half. And every day I've known you, as I've known Kelly, as I've known Jim, has been a better day. Thank you for showing us the way and I always make the joke that I get to follow Jenny Hatch. But I feel pretty honored to do that and I think in a very real sense we're all following Jenny Hatch. Thank you, Jenny.

Hatch: - And (...) but I don't give up on my parents either, but I love you. You are a good lawyer. Don't cry.

Campanella: Thank you, Jenny, all right. So I'll just go back and once again thank everybody who has joined us. Again these webinars are- we would like to make them as interactive as possible. So hopefully people have joined us this time will think about joining us again on May 22nd when we do our next one. We've got some pretty heavy hitters joining us so this would be a great time to ask lots of questions and get the top policymakers at a national level really engaged at helping us think through where we go with Supported Decision-Making in the future. So again, thank everyone, certainly our partners from ASAN and Burton Blatt Institute and on behalf of Quality Trust and this entire partnership thank you all for joining us today. That's a wrap.