

The Next Level of Policy Development

May 22, 2014

Ohrazda: Good afternoon and welcome to the Supportive Decision Making Webinar Series presented by Quality Trust for Individuals with Disabilities, the Burton Blatt Institute at Syracuse University, and the Autistic Self Advocacy Network. Today's session, Supported Decision Making: "The Next Level of Policy Development," is the third in this series. My name is Celestia Ohrazda and I will be facilitating today's webinar.

Before we get started I wanted to share some information and answer some of the Frequently Asked Questions. Today's webinar is being conducted using Blackboard Collaborate. The system makes it possible for us to conduct workshops over the Internet from just about any computer with an Internet connection and web browser. Unfortunately there may be computer issues inherent in your systems that are beyond our control. Which is why it's important for you to check your systems prior to the session. Our I.T. staff is available upon request to work with you in advance of the session. Once the webinar begins, we are unable to troubleshoot technical issues. This session is being captioned. To turn on the captioning please select the CC icon in the upper toolbar to open a separate window with captioning.

Today's session is also being recorded and archived for future use, a link to the recording will be posted on the Jenny Hatch Project Web site. Please share this freely with colleagues who may have missed the opportunity to participate in today's session. Also, all participant's microphones and phone lines are muted. If you have a question either for our presenter or technical in nature please type them in the chat area. 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. And at this point I think we're about ready to begin. Jonathan, I'm going to turn it over to you to introduce yourself and today's session.

Martinis:

Thank you Celestia. Good afternoon, I'm Jonathan Martinis I'm the legal director for Quality Trust for Individuals with Disabilities and on behalf of Quality Trust, the Burton Blatt Institute, and the Autistic Self Advocacy Network, I want to welcome you to the third in our three-part Webinar Series on supported decision making.

This series came about as the result of the courage and fight of one young woman. In the summer of 2013 Jenny Hatch, who has Down Syndrome, faced life in a group home, cut off from her friends, her work, and her life in the community. Like far too many people with disabilities Jenny faced a guardianship petition challenging her right to make decisions. Jenny's parents asked the court to make them her guardians so they could decide where she lived, where she worked, and who she saw. Jenny fought for her rights. I was honored to represent her. And after a long trial, Jenny won her freedom and her right to make her own decisions using supported decision-making.

Supported decision-making is an alternative to guardianship where people with disabilities use trusted friends and family members to get the help they need and want to understand the situations they face and the choices they have to make so they can make their own decisions. Supported decision making is already in use in parts of Canada and Europe and it is growing in acceptance in this country. It holds great promise as a way to ensure that people with disabilities have the right to choose their own paths in life without the quote-unquote "need" for a guardian to make decisions for them. To learn more about Jenny, her fight, guardianship, and supported decision making here and abroad, please visit www.Jennyhatchjusticeproject.org. If you missed our first two webinars, which focused on supported decision making in legislation and in practice, tapes and transcripts are available at www.BBI.Syr.Edu.

Today's webinar focuses on ways to develop policies and procedures at the local, state, and Federal levels to advance the use of supported decision making. And we have an All Star panel of presenters today. In fact I've taken the liberty of shortening their bios so they'll have more time to talk to us.

With us today, and we are very honored to have them, are Sharon Lewis, who was the Principle Deputy Administrator for the Administration on Community Living and Senior Advisor to the Health and Human Services Secretary on Disability Policy. Prior to that, she was the Commissioner of the Administration on Intellectual and Developmental Disabilities. Miss Lewis has received more awards and honors than we have time to mention, including the 2010 Distinguished Leadership in National Disability Policy Award.

We also have Allison Wohl, who is the Executive Director of the Collaboration to Promote Self Determination, an organization that's had great success at changing public policy affecting people with disabilities, with a focus on modernizing systems that are out of date, inefficient, and harmful to people with disabilities. CPSD has led the fight against Sheltered Workshops and to ensure that people with disabilities benefit from the recent increase in minimum wage for Federal contractors.

We also have Barbara Brent, who is the Director of State Policy for the National Association of State Directors of Developmental Disabilities Services. Prior to that she was the State Director for the Arizona Division of Developmental Disabilities Services, supporting more than 30,000 children and adults with developmental disabilities. Her reforms resulted in over 87% of all people with intellectual and developmental disabilities in Arizona living in their family home or their own homes instead of institutional settings.

We have Sue Swenson who was the Deputy Assistant Secretary for the Office of Special Education and Rehabilitative Services in the U.S. Department of Education. She served two presidents as Commissioner for Developmental Disabilities, and along with her son Charlie, she delivered testimony on legal capacity of people with disabilities to the caucus that drafted the UN Convention on Rights of Persons with Disabilities, and as a side note we really need to ratify that.

We also have Ari Ne'eman who is the president of the Autistic Self

Advocacy Network. He was nominated, and recently re-nominated, by President Obama to the National Council on Disabilities. Ari's worked on a wide variety of disability rights issues legislation relating to education, transition, employment, rights protection, and other areas. I've personally had the honor of working with Ari and presenting alongside of him on a number of issues, and I can say that he is my only friend who can get a meeting at the White House with one telephone call.

Now we have a lot of ground to cover in an hour and a half today, so the first thing I'm going to do is ask each of our panelists to spend about two to three minutes telling us about their offices and specifically their offices' interest in supported decision making. Then we'll engage in a discussion with the panelists and audience using questions submitted before and during this webinar, so please use your chat box to submit questions and we'll get to as many as we can. First Ms. Lewis, would you please tell us about your office and briefly tell us about its interest in supported decision making.

Lewis:

Certainly. Thank you Jonathan, and thank you all for being with us today. I am currently, as Jonathan mentioned, with the Administration for Community Living here at the Department of Health and Human Services and our component of HHS is really focused on individuals with disabilities and older adults and ensuring that all individuals, regardless of age or disability, have the opportunity to live with dignity, make their own choices, and participate fully in society. We do that through a whole host of programs and services. But this arena of supported decision making is really a little bit unique in that we think it filters through everything that needs to be imparted in terms of policy and programs for people with disabilities and older adults and ensuring their right to live self determined lives and make their own decisions.

This issue, long before the Jenny Hatch case came up, was something that actually came to our attention and was a focus of some conversations with the National Guardianship Association and the American Bar Association back in 2011 in talking about guardianship reform and the needs of these -- the disparate needs

of these populations. Out of those collaborations, we convened a roundtable in 2012 looking at supported decision making as a model as well as supporting other recent events. We think there are tremendous opportunities at this point in time around moving our conversations from an older and out dated notion of guardianship towards Supported Decision-Making and there are several elements that are coming together to create that opportunity.

The Convention on the Rights of Persons with Disabilities and its approach to acknowledging that everyone has capacity is a critical public policy vehicle that has really set the highest bar around how we might think about these decisions.

We have a generation of individuals who have grown up with higher expectations under the Americans With Disabilities Act. We have the Olmstead decision which is ensuring that individuals have the opportunity to fully participate in community, and we have an aging population for whom issues of dementia and traumatic brain injury are going to bring this to the forefront not only for persons with intellectual disabilities and mental health disabilities, but for a broader population. So we are looking at it through all of those lenses.

Martinis: Thank you so much Ms. Lewis. Ms. Wohl - Allison, are you there?

Wohl: Yes, thank you. So the Collaboration to Promote Self Determination, and we just call ourselves CPSD because that's a really long name. We're an advocacy network of national groups, 22 and counting, which advocate for the full inclusion of Americans with disabilities. And particularly those with the most significant disabilities in every aspect of life including learning, earning, saving, and living in their communities. Our Executive Community- our Executive Committee and those who created CPSD, are made up of six family consumer led organizations that provide for families who want a modernization, as Sharon talked about, of an outdated and fragmented system of public support: National Down Syndrome Society, National Down Syndrome Congress, Autistic Self Advocacy Network, the Autistic -- Society, CASH, and the National Friend Elect Foundation. We're also really lucky to have the

National Disability Institute and Quality Trust as partner organizations.

Starting in 2007 we started to have a very different conversation about disability policy around the principles of self-determination. CPSD came together and what this means, what self-determination means for CPSD is that a modern system would include up to date assumptions about what we know about people with disabilities rather than relying on an out dated model which was built on an institutional assumption. One of our core values is a fundamental commitment of providing support to discover and honor individual choice. However, options that foster a separate but equal scenario, or that promote exclusion in mainstream society, are not options that foster true individual choice or empowerment. The issue of guardianship is really inextricable from any of the issues that we cover and the pervasiveness of the practice is -- to creating a system that's built on a presumption of competence and high expectations.

As a parent of a four year old son with Down Syndrome, I can safely say that I don't know another parent of my generation with a child with a significant disability who would wish for the kind of life that being progressive when I was my son's age in the 1970s. But emerging from the age of institutionalization, guardianship must have seemed like a good choice, but by today's standards it's not. And I would like to see my own child live in a very different paradigm. And I'd like to quote one of my favorite advocates, Don Hoyle of the Arc of Michigan: "Supporting an economy of individuals rather than caring for them changes how we view and deal with people with disabilities. Accommodating an individual with a disability and ensuring the supports they want and need to live, learn, work, play and participate in their community projects a different image that is incompatible with guardianship."

Martinis: Thank you so much, Allison. Ms. Brent.

Brent: Hi, and hello everyone, and thank you very much for your participation and interest in this topic today. I am with, it's got a lot of initials, but it's the National Association of State Directors with Developmental Disabilities Services, or NASDDDS. And we are a

membership association of all of the state directors and the District of Columbia that provide public services and supports to people with intellectual and developmental disabilities across the country. And what we do is work together to improve services and supports in communities across the U.S. in every state, and look at policy, practice, and best practices across the country. And we've done things around Supported Decision-Making at looking at what makes a good life for a person in the community. We've done publications, we've hosted webinars, and most recently we've been really putting thought into how do we support families and support adults at the same time and find that good balance. The fact of the matter is most people and more people are living with their families into adulthood. Given that, what is it that we can do as state policymakers to ensure that people have their rights and still live with, and in parts of their communities, and their families as they've grown up over the years? We hosted a conference last year around supporting families, and this is an offshoot of a grant that we received from AIDD around supporting families.

And in that conversation, we have to have people with IDD at the table expressing their wants and interests about being independent, being in the world, making their own decisions, and getting support. Support when they need it. But not support over them.

And to give an anecdote about that, when I was a State Director in Arizona, we had to work a lot even on vernacular, the support coordinators would sometimes ask each other: is that person under guardianship or are they their own person? Certainly those aren't the two choices, to be under something or their own person. So we are working very hard at finding ways for states to honor the relationships that people have with their families and finding ways to get support when you need it but not be over or under. Thank you.

Martinis: Thank you so much Ms. Brent. Ms. Swenson. Sue, are you there?

Swenson: Here I am, here I am. Sorry. I'm very glad to be part of such an illustrious panel today, thank you very much. OSERS, as you know does special education and vocational rehabilitation also the national institute for disability and rehabilitation research and

independent living and assistive technology. Now, I think our focus on the topic of Supported Decision-Making cuts across all of those pieces and also other pieces of that like the Office of Elementary and Secondary Education, the Office of Career and Technical and Adult Education, the Office of Post Secondary Education and particularly I think we should start thinking about how Supported Decision-Making cuts into Federal student aid as well.

I think it's really important for us to think about how Supported Decision-Making is a part of a generalized approach to preserve the legal capacity of people with disabilities and that this can start when the child is very, very young. I think when we are doing early intervention and trying to reach families with the right kinds of supports and a message about how to help their child grow up and thrive with a disability, part of that thriving is having the ability to make decisions. So really excellent early intervention will be helping families understand that reaching out to a child and helping them decide what they are going to wear to school that day is a beginning of a process of Supported Decision-Making that becomes an organic part of someone's life. We think the individual education plan with its team approach also gives us tremendous opportunities to begin to understand how Supported Decision-Making is really about the individual and it's about their wants and needs but it's also about bringing supports in that are recognized by systems and frankly we hope some day legally. So I think there are plenty of opportunities in the educational process and also of course in the VR process as we work with people to determine what kind of work they want to prepare for, what kind of job skills they actually have already, how they are going to move forward.

These are really exciting times to be working on these things. And I think I would like to remind myself and everyone else who is a Fed on the line is that, there's a lot that we can do right now without changing the law. Yes we do want to change the law. But that may take some time. And we need to figure out what are the best ways to make sure that people understand their actual power to preserve legal capacity whether you're a parent or a sibling or someone who works in the system. You do have power to bring that forward. So that's where I'm coming from. Maybe one more thing. Because of NIDDR I think I'm a little bit more aware of the importance of

informed decision making in a medical process as being an important place for the exercise of Supported Decision-Making and I just wanted to put that on the table. Although it's not really our bailiwick, we do run into, you know, all of the issues of participating in research grants, and what does that mean, and how do you get informed decision making, informed consent for people. So just wanted be to put that on the table, too.

Martinis: Thank you Miss Swenson. Mr. Ne'eman.

Ne'eman: Thank you so much Jonathan, and it's an honor to be a part of such an illustrious panel. For us at the Autistic Self Advocacy Network, the topic of guardianship and more critically, alternatives to guardianship and building an infrastructure that really transcends and moves beyond guardianship towards Supported Decision-Making is absolutely critical. Virtually everything we conduct advocacy on from deinstitutionalization to integrated employment to fighting back against abusive bio medical interventions or the withholding of life sustaining treatment connects to the issue of legal capacity.

As was mentioned earlier, in the eyes of many people in the service provision and policy-making world, those who lack legal capacity are very frequently not even viewed as full human beings. In terms of how we move forward in this discussion, you know, there's been a lot of discussion about the problems with guardianship and the need for Supported Decision-Making. I think it's very important for us to start thinking about how we can build the legal infrastructure and policy infrastructure to make Supported Decision-Making possible. And we're hearing from a lot of people, well, that's all well and good, you're talking, you know, about some great principles here. But what does Supported Decision-Making actually look like in the day to day? How can we put in place the infrastructure so that if a person with a disability goes to their doctor or to their bank or to any number of the various places in which people very frequently with and without disabilities need help to understand complex concepts in high stake situations and they want to bring a supporter, that that support relationship will be recognized in a way that validates that person's autonomy and choice and does not require them to surrender their legal capacity, to surrender their

right to make decisions about their lives, in order to receive a little bit of assistance. In many ways, we're talking about a very similar process to moving from institutional placements to community supports and even within community supports from full time residential service provision to a supported living model. We're telling people just as we said: You shouldn't have to leave your home in order to get services. You shouldn't have to lose your legal capacity in order to get help in making decisions.

I think the deinstitutionalization model is in many ways a really valid one here because we don't necessarily know what the future of Supported Decision-Making is going to look like. Later this month, ASAN is going to be releasing model state legislation on Supported Decision-Making in health care so we hope we can help begin this dialogue, but we don't necessarily know what tomorrow's decision making support infrastructure will look like. But we can establish a basic principle that we can all work towards. Everyone should be able to retain their legal capacity just as we have previously stated that everyone should be able to live in the community and everyone should have the opportunity to access integrated employment and a good life within their broader communities. I think that's the principle we're working towards. I'm looking forward to a robust dialogue to figure out how we can get us there.

Martinis: Thank you Ari. To the audience members, please remember you can submit questions in the chat box in your lower left hand corner. I've heard almost all of the panel members talk about how Supported Decision-Making can cut across the life span, across so many areas of it. I would like to start with one that is - that addresses children. And Ms. Swenson, I wonder if you would talk to us about how Supported Decision-Making can be a part of special education planning.

Swenson: So, it's really interesting. There are several ways that it can be. And one is that the IEP team, the parent, is very much a central part of an IEP team. And can bring discussions of issues of concern and one of the things that could certainly be brought is: I want to make sure that my son or daughter is beginning to learn how to manage their own supports in decision making roles. You can also model a lot in an IEP by just showing the team, A) that you

always bring your child to the meeting, B) that when you are discussing something that's important, you address your child in a consultative way. I did this with my Charlie. Charlie didn't speak and didn't use a communication device but you could certainly tell what things he wanted and what things he didn't want if you were paying attention to him, and that was part of his IEP, you know starting when he was a little kid. The great thing about special ed planning is, it is flexible enough for parents to bring these topics of concern and bring these issues to an IEP team meeting. The bad thing about it is it's not really easy for us as feds to write a rule that says everyone shall do this. So it still remains a question of parent education and making sure that parents have the tools and understanding that they need to be able to do this. It's also - I think I would be remiss if I didn't say it's not just in the IEP team. I mean let's remember that decision making is an integral part of life. Many decisions are high stakes. And you do want legally recognized decision supports built in for someone. Many decisions are not that. And they turn out to be really important decisions. But they are not legal decisions. And those are things like: who is your boyfriend, who is your girlfriend, who do you want to play with. You know, how do you want to be spoken about by your teacher. How do you want to engage and play with your siblings? These are not something where you're going to have a contract or a legal arrangement. But having a way for the young person with a disability, even a child with a disability, to be put in a decision making role and begin to learn to think of themselves as the center of that decision is a really important organic process. I see the question that says, "What does IEP mean?" It's an Individualized Education Plan delivered under the Individuals with Disabilities Education Act in schools.

Martinis: And I have broken my own no acronym rule, from now on folks when we use acronyms, and I'm saying this to myself as much as anyone else, please spell out what they mean. Thank you Ms. Swanson. Ms. Wohl, as an advocate and a parent with a child with disabilities, can you tell us how you see Supported Decision-Making being incorporated into the practice.

Wohl: Sure, you know, I would really like to echo two comments there's really a lot of education to be done with parents and professionals

at the school level in IEP teams, administrators, transition counselors, and what we would really like to see is not just for the families to, you know, have their child who is the subject of the IEP meeting to, you know, be able to advocate for him or herself but also we would really like to see the schools and the school staff get out of the business of recommending guardianship and SSI. Which they often do. We hear about it all the time. And that as soon as a person is nearing the age of consent of 18, that they are told that, the families are often told, well you really ought to look into SSI and guardianship and in some- many cases told that they- the parents will not be able to be part of the IEP team meetings and of course that's scary to parents, it's scary to students. And it's simply, it's simply not true.

So we would love to see guidance become part of education that incorporates discussion of Supported Decision-Making in the IEP planning process.

Martinis: Thank you. To either of you or anyone else on the panel, we often hear about student led IEPs or student centered IEPs. In your mind, is that kind of a model of Supported Decision-Making where the student is the ultimate decision maker and other people are informing about information and options.

Ne'eman: This is Ari. I think it's a start for Supported Decision-Making. It's certainly something that can model the expectations that you are in charge of your own supports as quickly as possible. And I remember my own IEP meetings. And I remember times when I did have the opportunity to participate in them. And I also remember times when I knew they were going on and I had to wait until somebody decided they were going to invite me in to tell me what they had decided. And I'm afraid that too often students with disabilities are experiencing the latter, not the former. They are not being invited in to even attend their own IEP meetings regardless of, let alone being given the opportunity to actually lead them.

So I do think student led IEPs do give us a starting point for Supported Decision-Making. We can also build Supported Decision-Making priorities within the IEP goals.

(Audio lost).

Martinis: Hello?

Ne'eman: Sorry; where did I lose you?.

Martinis: The last thing I heard is we can build Supported Decision-Making priorities within the IEP I don't know if it was me or everyone else, as well.

Ne'eman: I think I accidentally toggled the button, so I think it was, I think it was everyone. Yeah, there are a lot of opportunities to do that within school settings ranging from supporting students to have more choice as to what classes they take to helping educate students about the implications of different accommodations and services. If we start students making their own decisions earlier and we acclimate, not only the students, but their families to that, we'll see much better outcomes.

Martinis: Thank you, Ms. Lewis looking from a Federal perspective can you tell us what you feel the role of the Federal policymakers and Federal Government is in educating parents and self advocates about the things that Ari just spoke of Supported Decision-Making both in and out of the educational context?

Lewis: Certainly. So I think I would echo other speakers comments that this is something that's inherently a component of decision making across a life span and we need to start with families early and this is a culture change we're talking about. And so I think that some of this change is going to come through policy. But some of it is also inherently culture, and policy can drive some of that cultural change. Here at the Department of Health and Human Services, a critical tool or component of this process we think is how we talk about and think about supports for people across the life span. And one of the important support mechanisms we have in this country around long-term services and supports are those that are provided through our Medicaid waivers or other formal systems of support, which creates an intersection and an opportunity around how do we ensure that Sue has, just as Sue has articulated that individuals are able to make critical and important life decisions for themselves

supported in the ways that they want to be supported. Person centered planning is an important tool that again we think is a vehicle for Supported Decision-Making. In that context in terms of looking across all aspects of life holistically towards the goals that an individual holds and thinking about how that needs to be supported through both formal services and supports and informal services and supports. So that is one mechanism.

I think this notion that we need to work with families and professionals and allies and supporters to really articulate that all individuals regardless of the severity of their disability, regardless of their communication style or mechanism, which may include behavior, can express volition and preferences and that those volitions and preferences need to be supported.

And again, from our perspective, person centered planning is a critical piece of that. I think that the Individualized Education Program can also be a very, very good tool in moving this conversation forward in a way that then allows us to get out of the legal construct that we're currently entangled in as it relates to guardianship and eliminating individuals' rights.

Martinis: Thank you so much. Ms. Brent based upon your current work and your work in Arizona what role can states play in educating parents and advocates about Supported Decision-Making?

Brent: Sure. And as Sharon has said in talking about the formal systems with the Medicaid waivers, person centered planning is critical because it can provide the opportunity through however definitions are done to do two things: One is the kinds of services that are formally paid for, that focus more on employment, community engagement those kinds of things that lend themselves to independence, and being in the community rather than in more segregated settings where there are less opportunities to learn about the community, be in the community, and be able to make more decisions in the first place. Person centered planning, there are processes that can be put into place and the association is working and working and keeping educating and informing communities of practice with state directors to do more of this. Is to move from the checklist that talk about solely what are the risk

assessments and those things that have dealt with protection from harm to really engaging in a conversation. Sure, there may be mandates about assessments or functional assessments but really what is the conversation about what a person wants, what are their aspirations and then what are those barriers and what are the services and supports both formal and informal that will get a person to reach those aspirations.

Sure it's easy to say around person centered planning, but it's harder to do in a formal system. So there's much that can be done in the formal system to educate, educate, educate. And a lot of ways in a state system it's teaching ourselves. It's changing what we've done with our forms. It's changing what we have done with our conversations. It's changing how we engage.

Another thing that states can do is to in a less formal way as far as not using the Medicaid waiver is engage early. You've heard it from everyone that's spoken so far. But if someone comes to the front door of a DD system when they are 18 and everything has already triggered to go into full guardianship, if you will, it's a little bit late to undo. So the extent to which a DD system can be welcomed into speaking to self advocates, to families and please, please, into the schools, to talk about what's out there in the adult world, particularly for those states that do not serve children it's a little bit harder. If you can get in there early and work together and talk about adult services because there are misconceptions that people are going to lose services if they don't have guardianship. They have to lose their, that families lose their rights and therefore people will go into an institution or their loved one will lose services to make sure that the myth busters are out there. And for people to develop relationships both formal and informal with the systems of support across the life span.

And another, semi informal in that it's not paid through the Medicaid waiver, is that, at least in Arizona and a few other states do this, there are actually other contracts that are not waiver funded with the Family to Family Information Network and with the self advocacy system. And in those contracts rather than the state saying, hey, don't worry, you don't have to do guardianship, there are other alternatives, because when the state says it, sometimes

it's suspect. Why not fund that families to talk to each other about alternatives to guardianship, to learn about the, what guardianship is in your state, because in some states there are different levels. And other states you really need to just look at possible, if somebody doesn't need anything legal. Sometimes somebody might want to do health care power of attorney, but to find out what it is locally, to have training sessions, families talking to families, self advocates talking to self advocates, not only to build the decision making skills but to find out what is relevant in their state. And also funding and PNAs to do legal options, manuals, training, and doing those together, we found that to be very effective.

Another thing besides engaging early is, engaging early I'll say that again, if there can be something done in person centered planning before a crisis to know beforehand what support somebody needs because there tends to be a reaction when there has been financial exploitation or the threat of such, you know, hopefully it's been averted or a medical crisis to immediately go into guardianship proceedings and in some states that means you lose, it depends on the state what you lose in terms of holding a bank account or any basic human adult right that we have in this country now. So knowing beforehand, so engaging early, and invite the DD system in early, and others to talk about what happens as an adult so there's not a crisis. And then alternately have a backstop. Know what you're going to do if there is a crisis. So that if there is a health emergency, that you've got supporters out there for you. And state systems can develop policies in the person centered planning practice to make sure that that is addressed in the event of an emergency. So those are some of the kinds of things that states can do in the policy arena, but states can't do it alone, so partnership is key, and working across other agencies, working with families, self advocates, the schools, and other allied partners is essential. Thank you.

Martinis:

Thanks so much Ms. Brent. I've heard all of you mention Supported Decision-Making as an alternative to guardianship and I think many people on the line know that guardianship is a creature of state law and nearly all state laws and the Uniform Guardianship Act require judges to consider less restrictive alternatives to guardianship before imposing a guardianship on a person.

Most mention a couple of examples like powers of attorney or advanced directives, but none mention Supported Decision-Making. So my question and I'd like Mr. Ne'eman to address it first is: should state guardianship laws be changed to specifically mention Supported Decision-Making as an alternative to guardianship?

Ne'eman: Hang on am I coming through?

Martinis: You are.

Ne'eman: I think so. And not just state guardianship laws but also other areas in state law or state policy, which are routing people with disabilities into guardianship. Barb talked about the role that state developmental disabilities service provision agencies can play in preventing people from entering guardianship but very frequently we see state DD agencies at times increase the likelihood of that occurring when eligibility for services assessments incorporate whether or not a person is under guardianship as a factor in whether or not they meet level of care requirements. And you know that's certainly a problem. You know, we should not be looking at the status of a person's legal capacity as a proxy for the level of severity of impairment. Certainly I think we all have enough experience to know that whether or not somebody ends up under guardianship is very frequently the result of social or cultural circumstances or something that happened in that person's life rather than necessarily the severity of their disability.

So absolutely we need to modify state legislation. I think we want to be a little bit careful when we talk about modifying state guardianship laws in part because I don't wish to give the impression that we just need to tweak the system and guardianship will be fine. I think we need to be talking, recognizing, that this is a decades-long process about a future without guardianship and thinking creatively as to what a continuum of Supported Decision-Making acknowledging that there are perhaps limited exceptions for substituted decision making is required might look like. In, you know, future model that was not so dependent on court appointed guardianship.

Martinis: Thank you, Ari. Ms. Wohl, based upon your organization and you have done some marvelous advocacy work to get state and Federal policies changed. Can you give us some insight on how one would go about advocating for these types of changes that Ari spoke about?

Wohl: Sure, I mean from our perspective in both states and Federal level It's the a question of educating parents and having personal choice come from parents whether that means to the Federal or state agencies of jurisdiction or to their elected representative and that comes from groups like ours and groups like ASAN and all of the other groups that we work with to really make the message simple and clear, because I think to Ari's point there's an awful lot of people who end up in these circumstances because of circumstances out of their control, not just their parents, you know, choosing this because they think it's a good idea. But certainly this is only people with disabilities you know find it necessary to do this.

And I think what people don't understand, and this is something that we talked about last October at your symposium, but that you know it introduces sort of a third party into your relationship with your family between the family and then the person under the guardianship and then the courts. And I think what people don't understand that the courts who are often not, don't really understand guardianship laws and the whole, you know, guardian ad litem system, they have the most say once that happens. And I don't know that there's an awful lot of education to be done on the grassroots level to help parents understand what it means to have a guardianship situation and how difficult it is to undo and what that situation really looks like in terms that they understand.

Martinis: Thank you ma'am. I realize I said earlier that guardianship is a creature of state law but there are some very interesting articles out there that suggest and come out and say in their opinion, the authors feel, that over broad or undue guardianship can violate Title II of the ADA's integration mandate, the Olmstead decision. Ms. Lewis is there anything, any kind of Federal guidance that can come down, that can help families and advocates address that issue?

Lewis: At this juncture, I don't know that the Department of Justice or the Department of Health and Human Services has explicitly linked those two ideas. I think certainly again when we look --

(Audio lost).

Lewis: -- and the Americans with Disabilities Act, the Olmstead integration mandate is very, very clear. And we as an administration have been very assertive in ensuring individuals' rights under Olmstead and I think again that has assisted in this culture change and we are hopeful that under the new home and community based settings regulations that more states and provider systems will utilize the tools of person centered planning and acknowledging the individual right to community participation and community integration when those individuals are supported in formal service delivery systems which are often a challenge in terms of ensuring community integration, that that's the mechanism by which at this point the administration has expressed our approaches to Olmstead.

Martinis: Ms. Brent can you address this from a state perspective?

Brent: As far as anything formal around Olmstead I can't think of anything specific. But as Sharon pointed out, the new home and community based settings regulations provide a good opportunity to further discussions. And indeed, policy around people being in the community and part and parcel of that is the person centered planning conversations.

To Ari's point, even getting into the system I thought was brilliant and unfortunately true that a factor not necessarily in the DD system but it could be but for level of care determinations for waiver eligibility can be whether a person has guardianship. So that's something on the frontend. But as far as person centered planning itself, having good conversations early on so again intervening early around what the different options are for shared decision making, what the mechanisms are, and having those what can be uncomfortable discussions early, including with providers. Sometimes, whether a state DD system does it, with intention or without, around trying to figure out whether guardianship is

appropriate, some of those decisions are made out of fear. So we talk about family fears but there can be state DD agency fear of what will happen, what is the best way to make a decision. And there can be provider fear, whether a provider is fearful of not knowing what to do. The provider is fearful that they might go the wrong direction and get in trouble. How do you have those conversations? So we are looking forward to the implementation of the new rule and furthering person centered planning to actually formalize the best way to implement policy and practice and then have more informal conversations that lead to community and these discussions. They are hard to have and they are essential.

Martinis:

Thank you so much. I have a question from the audience: how can you coordinate Supported Decision-Making with HIPAA, the health, the privacy law that covers doctors? I would like to start real briefly by saying I addressed the medical convention last Saturday in Baltimore. And I had to tell them how comfortable I as a trial lawyer was talking to a room full of doctors but I said to them that Supported Decision-Making agreements, formal or informal are essentially the same thing as HIPAA releases. The, a doctor that receives an authorization allowing someone to see your medical records and talk to someone else about your medical care is very little different from the doctor receiving permission to discuss your medical decision making. In fact I think it is the same thing. As long as a doctor allows the third party in the room to discuss a person's care, that leads itself pretty directly to Supported Decision-Making .

And I would like to ask the panel if they feel that way or if, how they feel that Supported Decision-Making is part of the medical decision making context. Ari, I know that you're working on legislation; I've had the honor to work with you and Sam Crane on it. Can you address that first?

Ne'eman:

Sure. And you know, we're very grateful for your and Quality Trust's expertise on that. I apologize, Jonathan, I should have mentioned your role earlier. At the end of the day, you know, one of the challenges that we face in scaling the Supported Decision-Making context is that providers, whether we're talking about health care providers or banks in the finance world or any number of other

contexts are naturally liability sensitive. You know, they are worried about somebody coming to them later. And saying you performed this procedure. This person didn't really have the ability to consent to it. You know or you disclosed this information to this person's supporter. You know that's a violation of HIPAA. That's a violation of that person's privacy. And even if it's done within the context of empowering somebody, providers are understandably reluctant if they worry that this is potentially going to expose them to liability in the future. And so, you know, it's very interesting. Typically we in the advocacy community are all about provider liability. You know providers do something wrong, we want to make sure that an infrastructure exists to hold them accountable. And certainly we don't want that to go away. And yet at the same time part of the concept behind recognizing people's capacity and recognizing Supported Decision-Making is also recognizing that people may sometimes make decisions that others may not like. You know, there's this concept of the dignity of risk.

And so part of what we really need to do here and Jonathan I think the expertise that you and Quality Trust have brought has really been invaluable in that process is identify what are the fears faced by providers, health care, financial, otherwise, in working with people with significant disabilities who have retained their legal capacity and create a legal infrastructure that will alleviate those fears and allow folks to bring their supporters with them into the process without losing the ability to make the final call themselves.

Martinis: Thank you Ari. Would anyone else on the panel like to jump in and discuss the interplay between HIPAA and Supported Decision-Making?

Swenson: I just want to again put a really difficult issue on the table. And that is although Supported Decision-Making is better because it preserves legal capacity and we want to recognize that every person is fully and equitably a person before the law, there's nothing magic about it. That means that just because you have a Supported Decision-Making team that they don't still have their own interests at heart when they are pushing a particular decision.

And when you get into health care decisions, these are very

personal things where people make decisions based on their fear of pain or their understanding of death or many other questions. And we really need to be sure that when we build Supported Decision-Making, we have clear protections that preserve against the conflicts of interest that families might bring to the table.

The other thing I want to point out is just because, yes, I think we should start with children. Yes, I think we absolutely need Supported Decision-Making processes that are recognized legally in every state. The fact is there are a lot of people who are already under guardianship. And there are a couple of things there. Whether it's HIPAA or whether it's just ordinary legal capacity. We need a way for people to get out from under guardianship, which is to have their legal capacity restored to them. But we also need a much deeper understanding of how, what are the good ways to practice guardianship? So if currently the legal situation in a state doesn't allow you to have Supported Decision-Making recognized in a legal context or in a HIPAA context, then what are the ways that you as guardian could put a team in place? I mean, there's nothing in the guardianship law that stops you from having it been a person centered decision process. And one that is individualized and one that really depends on what we know about the person. So I think, I don't know. HIPAA is maybe a hard place to bring that up. But I think we sometimes forget that just because the parent is asking for the most aggressive thing, that doesn't necessarily mean that it's in the person's best interest or that it is in fact something where the parent does not have a conflict of interest.

And you know what? One more thing I'm going to put out there. And that is we've got to stop thinking about this as something that affects only people who we serve in formal systems. Most families don't have any formal systems of support. And yet their son or daughter is in the world. And has or doesn't have legal capacity. And it would really help if we had among the tools that we were developing some way to reach out to families who were in that situation. And help them understand how they could be supporting decision making by their son or daughter or brother or sister or nephew or niece or whoever it is they are working with, elderly parent for that matter, Sharon. I think it's, I think it would behoove us to think a little bit more clearly about that too.

Martinis:

Thank you so much Miss Swenson. I would like the panel to discuss a couple of the points that you just made. First with regard to Supported Decision-Making and the guardianship context, I think one of the less recognized but most important parts of the Jenny Hatch decision was when the judge said that even a person under guardianship has the right to engage in Supported Decision-Making. That the guardian should be making the decisions the person would make, not what the guardian thinks is in that person's best interest. And I think that gives us a real roadmap to follow, even if there is a guardian in place.

But secondly, with regard to the protection part, where there might be undue influence, that was raised in Jenny's case as well. Our psychologist was asked that question directly. Couldn't a supporter unduly influence a person making decisions? And our psychologist was honest. He said yes, that could happen. It happens to everyone - with or without disabilities.

And if we're going to say that our friends don't influence us to do things we wouldn't normally do, I need to cancel my Friday night poker game.

So I'd like to however, on a serious note, discuss where we can build protections through education in the system. Ms. Wohl, what do you think parents need to learn about to make sure that No. 1 that primary consideration is given to what the person wants. And No. 2, that there is protection from that type of undue influence that can come from friends and supporters.

Wohl:

Boy, that's a tough question, because if you only, you know if you rely on your IEP team or your only means of support is through your school and they are telling you to, that this is the right thing to do, that puts them in an untenable situation. So I just go back to, you know, any of the, and I think this kind of information could come through any of the agencies that they interact with, whether it's Medicaid agency, DD agency, if it's through education, you know, this kind of information can be disseminated through all different kinds of places wherever they receive support whether it's their local or state ARC. Whether it's a condition-specific group that

they belong to, I mean, I think there are just a lot of opportunities to disseminate this kind of information.

And I do think a lot of this is generational. I think that that was sort of continuing along the, you know, in the spirit of aid to permanently and totally dependent, I mean, this fits in a different paradigm. So I do think there's a tremendous opportunity now to educate and to have parents or families who are thinking about guardianship or think that's the only way to go about the next step, that's just sort of what you do along this path, there's a great opportunity now to consider a completely different model. You know, if it was a part of transition planning to consider what level of support and you know we are already talking about supports needed for transition it's a great opportunity to have that conversation then or certainly as they get in, you know apply in VR issues, I mean, there are a lot of entry points where this information could be expressed. By the time they get to, you know, a waiver they are past the age of, well past the age of 18. So certainly the earlier the better and the more people you bring to the IEP team meetings the better who can come around with this information, but I think there's an awful lot of opportunities to disseminate information. And also, you know, I don't know that people necessarily understand that once, the complications and difficulties of undoing guardianship once it's been granted.

Martinis:

Great. Ms. Brent earlier you said that one of the most important things we can do is engage early. If we engage early and get children involved in taking responsibility and making decisions for themselves, is that going to help guard against children becoming unduly influenced in their decision making as they get older?

Brent:

I think we'll know more about that later. But early indications are, yes. Because families will see that their sons, daughters, their family members, are making decisions, getting comfortable, and will know other people in the community besides just the family members, will see those interactions. The person with disabilities, him or herself will find out that people are reacting to them as peers rather than solely as a family member - as a loved one with some disabilities.

And so the more decisions someone makes, and the more somebody is out in the community like all of the rest of us - we can gain respect, we get relationships. And we get more standing in the community. Just think of our own lives, whether we do or don't have disabilities, how surprised our families are that we learn to get from Point A to Point B all by ourselves and this is -- we're 40 and our parents are 60, wow, you flew a plane by yourself and you went from this city to the other or you managed to get through college or gosh I didn't know you knew how to pay your bills. It's not much, sure it's different based on somebody's level of disability but everybody can learn about what their options are. Can learn to engage early. And be out in the community. Learn about decisions. And their families are likely to view them differently and as partners and growing up and becoming adults.

Martinis:

Thank you Ms. Brent. Ms. Lewis earlier you discussed the aging population, Ms. Swenson did, as well. Can you address how Supported Decision-Making can aid in end of life planning or other decisions that are more specific to people who are getting older.

Lewis:

Well, I think there are several elements here, right? So stepping back for just a second in terms of context, it's very interesting in our culture in the United States how much difficulty we have with over all with the conversations related to end of life. Whether those conversations be about retirement planning, planning for the need for long-term services and supports which the vast majority of individuals in this country don't do. And -- or for these decisions and processes. There are often decisions that are made in crisis instead of in a planful way. And when a decision in terms of supporting alternatives to the individual being able to consent to particular health decisions or other decisions, you know, where they might live.

Often, more often than not, families across the United States don't plan for these events and don't, or have not been engaged across our society around end of life planning and ensuring that people have advanced directives. This is not specific to disability. This is for all of us as individuals who have our own preferences and desires that we would like to see honored. And I think it's an important and broad conversation that needs to take place for

everyone.

People should be writing down and acknowledging their own preferences early on in life. And for individuals who need support to sort through those decisions, again, I think relationship based decision making is ultimately going to serve people well. People keep people safe. And for the aging population, these conversations are very, very interesting. Because one of the things that we have had some robust conversations about here at the Administration for Community Living is that cultural difference and the need to not only support individuals' important personal decisions related to health and safety and welfare, but really in the aging population are often driven around assets and financial matters. And often those plans are put in place. But these other core life pieces are not. And I think there's opportunity for dialogue and education across the life span.

Martinis:

Thank you, Ms. Lewis. You know, you said something that I think is particularly apt when you said this is a broad area. When I speak on the subject, I always say that Supported Decision-Making isn't just a process. It's a paradigm. And by that I mean that all of these important rights we're discussing are captured within the Supported Decision-Making paradigm. By that I mean, what good is it to have the right to live in the community rather than an institution if there is someone who has the power to say even though you want to live in the community, I'm not going to let you.

So when we discuss Supported Decision-Making in that context, I would like to ask each of you: what are areas of policy or practice that need to incorporate Supported Decision-Making and how would you go about changing those? Ms. Wohl would you start us off? Allison are you there? Okay Ms. Brent would you please start us off. Hello?

Brent:

Yes, it worked. There. Sorry. As far as areas that need to be addressed in policy, there are probably many and some of them are state specific and some we can be talking about throughout our state policy making discussions. If there is an override so we can have the discussion, and everybody is at the table and there's good person centered planning and at the end of the day there are two

things that could happen. And one is that there's an override because somebody will say and you may honor a family's wishes or there is something with guardianship because you don't agree, it's a tough spot particularly if somebody does have the legal mechanism one can engage and engage and discuss and state agencies may not find themselves in a good place other than a conversation. There are some technical things that are really uncomfortable about whether you want to go into due process by delaying that decision and coming and saying why. And getting back at the table again in 10 or 14 days and providing support to the person and/or the family member that's trying to override. And then there's the practical application where if somebody makes a decision about where they would like to live and where they would like to be and the state or the system can't deliver. The services aren't there yet - the services are delayed. The system itself can't put itself together and there the state can and needs to make a change. Because if somebody puts the effort and people put the effort into having good collaborative care decision making and it should be a celebration because success breeds success in this area and there should be particular attention to "I would like to live in the community," then, boom, that a Transition Plan starts or somebody would like a job that there's great focus in delivering in those areas.

So the former in which somebody does trump decision making is not easy. People can come back to the table. There's ways to have conversations to bring in somebody neutral, to bring in again family-to-family groups or self-advocates to help in a conversation. That's harder. It's also harder for systems to be nimble. But when there is a victory, get out there and get the system to respond.

Martinis: Thank you, Mr. Ne'eman if there was one policy area that you could change to require greater support in decision making what would it be and how would you go about doing that?

Ne'eman: Oh, God. That's a difficult one. (Chuckles). Only one, huh?

Martinis: It did rather sound like a dating game question, I'm sorry (Chuckles).

Ne'eman: You know this is actually -- this is actually -- it's not really remotely related to the direction we've been going in up until now but just because I really do think that we have an obligation to not only be building a better system for the future, but to be there for the people who are currently stuck in today's system. I would really like to see a funding stream become available to the protection and advocacy system. And possibly to state and local self advocacy organizations specifically focused on supporting people now under guardianship who want to get out and helping to divert people who are heading into the guardianship system, perhaps do not want to be. And who need assistance either with navigating the legal proceedings or potentially with something as simple as communicating to their families and others in their lives that there are other options if they are willing to stop and consider them.

Martinis: Thank you. Ms. Swanson, Ms. Swenson, I'm sorry, are there specific areas of policy or practice that you think should be changed to incorporate this area?

Swenson: So on the practice side, I'd like to help us start thinking about more what is a network of people who do support. Because typically in a Supported Decision-Making model, at least for a person who has very high support needs or communication difficulties, or other things that don't allow them to ask for you know, ask for what they want in really clear-cut ways, typically you see the language that says you will have a network of people who express and articulate a decision based on the will and intent of the individual. And the knowledge they have of the individual as a result of a trusting relationship, that comes from Inclusion International's website, which their Right to Decide Project, I would put that out to anyone here as something that would be really worth looking at and worth understanding. But my point, the thing I'm trying to get at here is the role of Mom and Dad. I used to say to my son, and I really meant this with all of my heart, when people would say "Nothing About Us Without Us", I used to say to Charlie, and remember honey, not everything is about you. So we have to remember that Supported Decision-Making is not a candy store. It's not a cookie jar. It's not another way to put the person with the disability in a position above their family but rather to recognize their voice as a really strong part of the family.

And I think many of our policies are underdeveloped to take on the current efforts to have people live with the support of their family as adults if they have formal supports and certainly live with the support of their family as adults if they don't have formal supports. I just don't think that in the United States we have much family policy and therefore, there's not really a way for us to get in here and ask questions like, well when does the mother get self determination, or as Bob Williams used to say, how do we make sure that the family is not just indentured servants to what is best for the person with the disability.

And I think we are at risk of that in all kinds of systems. And it's the flip side of conflict of interest. You know, you have a conflict of interest perhaps. But you also have a life. And you have a right to self-determination in your life just as your son or daughter or loved one has a right to self-determination in their life.

And those sort of messy responsibilities are what families are made up of. And I just don't think we have a really good way to talk to people about this yet. That when we say Supported Decision-Making, it doesn't mean necessarily laying down your life to do what your kid thinks they want to do. And it doesn't also necessarily mean stopping your kid from doing what they want to do even if you think it's risky for them. And these are very difficult emotional decisions. So I think, I think there's a little bit of family policy work to do here that we might find in the United States there's not a lot for us to hang our hat on in terms of how do we make sure that families of persons with disabilities are treated equitably with all other families. There's not that much policy there.

So that's a big one for me. I also want to say I know we are not in a funding environment where we're funding new centers. But when in 2000 we wrote the Developmental Disability Act's reauthorization, it authorized ten new UCEDs and my thinking at the time was that some of them should be in law schools. And I do think it's something we have fallen down on because our funding has been so difficult in recent decades. I was never able to accomplish it. And I just wish we thought more clearly about how legal thinking is really part of our research infrastructure as well as being part of our

services infrastructure. Thank you.

Martinis:

Thank you. And I think you make an excellent point, when I'm asked to describe Supported Decision-Making and how it differs from guardianship, one way I say it is Supported Decision-Making is making decisions *with* a person with disabilities or a person with disabilities, better yet making decisions *with* their support team, guardianship decisions are made *for* somebody. Ms. Lewis the same question to you, what areas of policy do you think are uniquely qualified to address this issue?

Lewis:

Well I think, so I completely agree with Sue that the intersection with family policy is critically important. I think that one of the challenges that we have with guardianship or many of our, and whether it's limited powers of attorney or other elements of legal structures that are intended to protect individuals, is that they are not currently in most states and in most ways built in a way that acknowledges that needs change over the life course. Right? I mean, we think about what an individual needs and I've heard several speakers mention that transition point, might be a transition point from childhood to the age of majority at age 18 is a critical decision point in this process. Yet I like to joke that there are few among us who have raised children or experienced teenagers who would argue that all 19 year olds are equipped to make all life decisions absent any support. And that, that's less about disability and more about maturity.

And our current systems do not acknowledge in any way those changes over the life course that what we need around supports to make decisions at age 19 may be very different than what we need at age 40 versus what we age at age 70, and that there's context in all of this that needs to be thought about and carefully in determining how we're going to integrate Supported Decision-Making across our policies.

So I think that that's a critical piece. Because I think it's something that needs to be constantly revisited. I mean, we all have, we all change over the course of our lifetime and we learn different things and we may need supports around different elements of decision making at different points in our life.

And one of the challenges of building those protections into a legal structure in the way that we have so far is that it's very hard to be flexible in the way that individuals need. And so I think more thinking around that aspect of how we do this and how we think through building structures that balance the needs to ensure that we're protecting the rights of people and that we're making decisions with them and not for them, over that changing life course.

Martinis: Thank you, Ms. Wohl, are you back with us? Okay.

Wohl: Yes, I am.

Martinis: Ms. Wohl, what policy issue would you want to address, a specific one to improve Supported Decision-Making to improve the policy and practice?

Wohl: So I would go back to transition planning. And I know we have talked about that. You know as part of that - providing parents with information about alternatives to guardianship as a part of the long-term planning process. And, you know, having teachers and educators and administrators be informed and educated about not just telling families to make a decision but being able to work with them to make their own decisions and make sure to echo I don't know whose comments that this is person centered planning. Not on behalf of the person. But including. And you know, we often hear well this person doesn't speak so we don't know what they want and they can't possibly participate in this process, but, Jonathan, as you yourself had said, you know, people know what they want. And all you have to do is ask them. Whether or not they can speak, they can certainly communicate. And they can let you know what they want and don't want. Thanks.

Martinis: Thank you. I was recently interviewed on a television show and at the end the interviewer said, "I am sure there's something that you came into this interview wanting to say that you didn't get a chance to." So, given that we have five minutes left, I wonder if each of our panelists can take a minute and say if there's something important on this topic that we haven't hit, what that is or was something

important to them. Ms. Lewis, would you start us off?

Lewis: Sure, I mean, I think what's the promise of Supported Decision-Making is that it is really an asset based approach where we're thinking about the capacities of the individual and supporting the capacities of those individuals in a way that acknowledges the interdependence that we all experience instead of a deficit based model and that's consistent with disability policy writ large. And I think for all the reasons that have been articulated today it's an exciting time to pursue this as an agenda item and a component of public policy as it relates to both people with disabilities and older adults.

Martinis: Thank you, Ms. Brent?

Brent: I echo Sharon's comments that it is an exciting time. It does focus on people's strengths in ways that we've done in other parts of our systems of supports, but in a very specific way. And it's going to take more thinking. And I agree that it's going to take good conversations and good policy work that's maybe not even been done in the general community nonetheless in supporting people with disabilities. We have to put good thought across the life span because systems are driven to distraction. And we may have a tendency to put all of our efforts into youth in transition which I'm the one that keeps saying engage early but if we don't put equal thinking across the life span then we may have as many older adults or middle age adults end up in guardianship that may not need that either. And so we have to think about the pathways and keep that life span in consideration as we move into this exciting time.

Martinis: Thank you, Miss Swenson?

Swenson: So, I think today is a really good example of, first I never get to the end without having said everything I want to say, just so you know that about me. (Chuckles).

(Ari talking off mic.)

Swenson: Ari knows that.

Martinis: A person after my own heart. Thank you.

Swenson: But the process today has been extremely valuable to me and I think what it points out is that this is an ongoing conversation that we need to continue to have and to continue to have in very inclusive ways and that it's not a question of going to one person and saying here fix this. It's a question of what are we all going to bring to the party and what little pieces can we all do together in a concerted way, so thank you for that.

Martinis: Thank you, Ms. Wohl?

Wohl: Well, I'm relatively new to this work - I'm very new. So, I learn every single day and I'm grateful to be part of this panel to rub elbows with these folks because I learn so much and I have so much to learn. And when I came to work people used to say to me, this was a couple of years ago, people are radicals, these things are never going to happen, you're out of your minds, and, you know, I'm so happy to hear that there's, either things are, ideas are not so radical or they are, you know, the word is getting around, but I'm so happy to say so much thoughtful discussion and policy going into place to make the next generation you know their road a little bit easier.

Martinis: Thank you, Mr. Ne'eman?

Ne'eman: I think, the thing that I really, you know, would like to leave folks with is that this connects not only to everything we do with disabilities rights advocacy, but it connects to everything that people do period. I mean, this issue really got driven home to me a few years ago when I got a Facebook message from a young woman who is transgender and is under the guardianship of her family members and is having really significant difficulties because they don't recognize her gender identity. And I thought about how at the end of the day if we believe not only that people with disabilities should live in the community and shouldn't be in Sheltered Workshops and so on and such forth and such forth, but if we believe in basic civil and human rights for everyone, you know from the perspective of any advocacy movement not just the disability advocacy movement, then we have to fight to protect

people's decision making powers, we have to fight to protect peoples legal capacity. I'm really hopeful that this is an issue on which we may be able to rally the support of other movements. I know that's kind of been the holy grail on all of our issues in disability rights advocacy and we really haven't seen what we wanted to see there, but I'm hoping this is the issue that's going to finally let us do it because it does cut across everything that we want to do and I'm so glad that we had such a great turnout for this discussion. Thank you so much for calling us all together.

Martinis:

Thank you to you all, and I think Ari you said it perfectly I think this is the defining civil rights issue of our time. As I've said before and I'll say until I can't say it any more you cannot have life, liberty, and the pursuit of happiness if someone else decides the life you live, the liberty you exercise, and the happiness you pursue. To everyone on our panel thank you so much for joining us. If anyone would like to connect with me off line my e-mail is jmartinis@dcqualitytrust.org. And I hope Ari that you're correct and this is the issue we rally around because I can't think of a better one, thank you all so much for your time.

Group:

Thank you.