

**Lessons Learned from the Canadian Experience: Supported Decision-Making Models**  
**March 26, 2014**

**Myhill:** We are ready to begin. Our moderator today is Tina Campanella the executive director of Quality Trust for Individuals with Disabilities.

**Campanella:** Thank you William. Welcome all and good afternoon. I am pleased to be serving as your moderator for today's webinar. The session with supported decision-making: Lessons Learned from the Canadian Experience supported decision-making models. This series is supported through a collaboration between Quality Trust for Individuals with Disabilities, the Burton Blatt Institute, and the Autistic Self Advocacy Network.

All three of these organizations care deeply about advancing the use of supported decision-making practices in support of people with significant disabilities retaining their rights as full citizens and exercising self-direction in life. The experience of our Canadian neighbors provides useful lessons for us about the principles and approach to make supported decision-making work as an alternative to guardianship and other substituted decision-making methods. We have asked them to share what they have learned from their efforts to operationalize supported decision-making in Canada.

Our presenters today are Michael Bach, who is Executive Vice President of the Canadian Association for Community Living, the national association of over 300 local associations and 13 provincial, territorial associations working to build a more inclusive Canada for people with intellectual disabilities and their families. He is also managing director of IRIS the institute for research and development [inaudible] and society. For the past 25 years he has undertaken research and development in Canada and internationally on ways to advance the full inclusion and Human Rights of persons with intellectual disabilities. His publications cover disability theory, policy and practice in a range of areas, including legal capacity, education, employment and funding and delivery of community-based services. He holds a Ph.D. in sociology and equity Studies

from the Ontario Institute for the Studies in Education of the University of Toronto.

Our second speaker is Peter Park born in small town in Ontario where he lived for the first 20 years of his life. For next 18 years he was incarcerated at the Oxford institution in Woodstock an institution in Ontario. When Peter reentered the community he dedicated his life for advocating for people labeled with disability. Whether it be at the Supreme Court of Canada, or small role setting, Peter continues to advocate and educate on the realities of living in an institution, the barriers he faced, and the violation of rights that occurred while he was there. Peter has delivered presentations in Canada and internationally. He spends much of his time and everything across Canada helping to organize other people first groups and advocate on behalf of Canadians who have been labeled with an intellectual disability. Peter currently lives in Toronto area. With his wife Ria of 24 years.

Our final speaker today is Lana Kerzner a lawyer in Toronto, Canada who has dedicated her legal career to disability law and policy work. She works often in collaboration with disability organizations to advance the rights of people with disabilities through law, reform and education. She teaches disability and the law at Ryerson University and at the Law Society of Upper Canada. Her work currently focuses on capacity, decision-making and the international law implications of the United Nations Convention on the Rights of Persons with Disabilities. And she speaks at conferences both in Canada and internationally on the topic. Lana works in private practice and previously worked in Ontario's legal aid clinic system both at ARCH Disability Law Center and the Advocacy Center for the Elderly. She obtained her LLB from the University of Toronto in 1992 and was called to the Ontario Bar in 1994. She is also a graduate of the Maytree Public Policy Training Institute.

We also asked Samantha Crane director of policy at the Autistic Self Advocacy Network to serve as reactor to the panel presentations we hear today. Samantha works out of ASAN's national office. She is a graduate of Harvard law school, and previously served as staff attorney at the Bazelon Center of Mental Health Law. Focusing on enforcing the right to community integration as established by Olmsted Decision and as an associate at the litigation law firm where

she focused on patent and securities litigation. Thank you to Samantha and to all of our Panelists today.

We are going to start with asking Michael Bach to give us a brief overview of the concept of the supported decision-making, including what we mean by supported decision-making, and why it's important. We will then move on to Peter Park who will go next and share a little bit about where this began for him and why it's important to self-advocates. And we will wrap up with Lana Kerzner who will talk about legislative provisions and lessons learned from the Canada experience. With that I want to William said at the beginning we will be taking our questions through the chat room so please type in anything you would like to have addressed by our distinguished panelists. We also are recognizing we may not get to all the questions during our allotted webinar time, so we will do our best to address any unanswered questions in a written follow-up to this session.

**Bach:**

Okay. Thank you very much, Tina and our thanks to the Quality Trust and Burton Blatt Institute and others who have made this webinar Series happen. And we are honored to be participating in this webinar series as part of the Jenny Hatch case, which provides, I think, much inspiration for all of us.

As Tina said we wanted to provide an overview of our experience in the Canadian context and really the evolution of this idea of supported decision-making. I wanted to start with a short, couple of minutes of a video we actually were just able to get it uploaded to YouTube today. By one of the leading founders and thinkers of this concept of supported decision-making. A mom named Audrey Cole a senior leader in our movement for almost four decades and she really inspired this notion on the experience of her son Ian. Very clearly that this idea of supported decision-making grew out of the experience of people who had the label of intellectual disability as well as their families who were really confronted by the challenges of guardianship and the idea that it took the authority away from people to be recognized as a person who is able to make decisions in their own life and director their own life.

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And I wanted to provide a brief outline of what I wanted to cover today. What's the right to decide and why does no matter so much to Audrey Cole and self-advocates and people First in our country? How we worked on that and were able to get with Civil Society and get recognition of this idea of support in decision-making into the UN Convention. And look at some of the main ideas behind this notion. Which I will review, that is that legal capacity is not the same as mental capacity, that the Convention on the Rights of Persons with Disabilities really gives us a new formula for thinking about legal capacity, and to outline the ways in which we understand legal capacity can be recognized. We will talk a little bit about supported decision-making how it works and then the beginnings of a law reform agenda the outline of a law reform agenda that Lana will pick up in her comments.

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So one the places to start is to really distinguish this notion of legal capacity from mental capacity because the two have been so connected in both philosophy and in law. In developing the UN Convention, the Office of the High Commissioner on Human Rights for the U.N. undertook a background paper to look at the definition of legal capacity in both common law countries and civil code countries around the world and came up with a very clear definition that having one's legal capacity respected means having the capacity and power to enter legal relationships to make them, change them, and terminate them. The definition focuses very helpfully we think on this idea that it's about having the power and the recognition that you can make those decisions. The definition doesn't speak to having any particular decision-making abilities. It's about having being recognized to have the power.

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So what kinds of decisions matter to us? In capacity law, and if you look at the UN Convention, if we look at our own lives, the decisions that matter to us fall into three main areas.

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We can talk about healthcare decisions. And whether or not we choose to give consent to treatments that are proposed to us. Financial and property decisions about our assets, about where and how we're going to spend our money, about opening a bank account, about closing a bank account and opening another one. Financial decisions. And then thirdly, personal life decisions. Where I am going to live, personal relationships I am going to have, my participation in society, employment, my sexuality, the supports I am going to use. So the law tends to identify those three main types of decisions.

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So the problem with the law of guardianship is that it requires the courts in many cases and professionals, to make a determination that some people have -- are incapable to decide on their own. And guardianship is the procedure that's been instituted to address that issue. And that prevents people from being able to exercise power in their lives. How does the law do that? It's really based on this usual formula that our legal capacity is equal to our mental capacity.

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And so what is mental capacity and how is legal capacity distinguished? Much of capacity law defines "capacity" as in mental and decisional abilities terms. So usually we see in the law that capacity, which is really mental capacity, is the idea that on my own, independently, I can understand the information that's needed to make a decision, I can retain the information, and I can appreciate the consequences of that information and then communicate the decision in ways that others understand.

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One the problems is that when people don't meet that test, that criterion, they can end up with another label. And so we have this cartoon up that just shows you know, come along now, one more

label and you are ready to face the world. And incapacity is really just one more of those labels.

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In working on the UN Convention, we worked to get as I said, a number of key provisions into the UN Convention that would give us foundation in international law that would really reflect the growing experience that we had in Canada about the right to decide and supported decision-making. So a key piece of the Convention is Article 12 (2) which says that we have the right to make our own decision is basically what it says in Article 12-2.

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Article 12 (3) says that government, states parties to the convention have an obligation to ensure that people can access those supports they need to make decisions, where that's needed. And that can include someone to help include legal capacity.

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The third piece in the Convention is that it provides some safeguard both in Article 12 (4) and in Article 16, that while people have a right to make decisions in their own lives, people also have a right to be protected against exploitation, violence and abuse. And governments have a responsibility to make sure such safeguards are in place.

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Another piece, a key piece of the Convention, is found in Article 5 (3) which recognizes that both governments and other sectors in society have a duty to accommodate people in the decision-making process. As a way of recognizing that people may need different kinds of supports, I may need a friend, or a brother or sister to come in the doctor's office or to the bank with me to help me make decisions, but the fact I may need that help shouldn't be a trigger for the bank or the doctor that I am incapable of making a decision. The duty to accommodate that's recognized in the Convention

means that doctor or the bank needs to recognize and include my brother or sister if I so choose in the decision-making process.

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There are different ways -- so if this idea that the only way I can have my legal capacity recognized is if I can make decisions all by myself and communicate those and demonstrate that I have the mental decisional abilities to communicate on my own. If we equate that with having full legal capacity and that's meant that certain people don't happen to have those abilities on their own are left out of the picture or that's the basis on which substitute decision-making can be imposed, what are some other ways the law and supported decision-making begins to recognize -- what are the different ways in which it recognizes that people can make decisions? One is the basis of the decision is simply that I can express my will and preferences to others. That I want to do something or that I don't want to something and if I have around me people who know and understand me and are committed to me, as Ian does in the video. Ian doesn't communicate in most ways other people understand, but he has got around him a network of people who know him really well and they know what he likes and doesn't like and the idea of supported decision-making is if Ian had those people around them, their interpretation of his will and preferences should be the basis on which his legal capacity or his power to make legal relationships should be respected.

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And this notion that -- I can do it myself. This notion that really at the core the core ability to have legal capacity should be simply that I have -- I can be known by others as a full person, by people who trust me and who are committed to me. That's what we are suggesting is the basic minimum for having my legal capacity recognized and Lana will share some examples of legislation in the Canadian context which respect that.

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So what does the Convention then provide us such as a new formula for legal capacity. If the formula used to be based on the idea my legal capacity depends on having certain decision-making abilities, what's the new formula the Convention provides? If you look at those bits that I identified of the Convention, those pieces of the Convention and you put them all together what it says, really, is my unique will and preferences plus my unique decision-making ability to there's things I want to do I have a will and preferences to do certain things, I have my own unique decision-making abilities - - maybe my ability is simply to be known by others as a full person. Maybe my ability is to think through what I want to do, but I have my own unique form of communication. Maybe my ability is I need some -- I have a sense of what I want to do, but I need some help in understanding what the consequences of doing this surgery or not mean. I may need that help, but I still have enough ability to know that when I have the information I can decide or not. We add that to the supports that I might need which might be my brother or sister coming to the doctor's office -- plus we add to that an equal legal recognition in the law that requires these different actors to respect my right to make my own decisions and supports I bring to the table you put all pieces together and that gives me capability to make decisions. So in the formula we've got now there's only one piece -- I have to meet that one piece around decision-making abilities. Most of our capacity law doesn't fully recognize these other pieces that go into the formula. That's what we're trying to do with supported decision-making.

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So in the formula, legal capacity is not equal to mental capacity. What a person wants, their hopes, and plans, is at the center of the decision-making process; the focus is on supports and accommodation and when people have different ideas about what I might want or Ian might want, for example, they talk to figure out what's the best interpretation of Ian's will and preferences as it applies to the decision about whether he's going to move into this house or this support person will work with him, as opposed to that support person? It's our best interpretation of his will and preferences as it applies to this decision not what we happen to think are his best interests, because the usual best interest test is

what's been used to create a pretty paternalistic system of support and services that people with disabilities around the world are wanting to challenge.

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So what does this mean about the different ways to exercise legal capacity that we want to see recognized in law and the place of supported decision-making? So we have on the right side of this picture, me anyone one of us trying to decide which way we will go in making a decision and we have the State in the little pictures at the top that represents the government recognizes my right to make own decisions. The State also recognizes on the left-hand side of the picture the doctor or the dentist, the bank, the landlord or the employer, the other third parties, if you will, in the decision-making process, they have obligations to support and include and accommodate me. And really the question is how will I make my way to the community? The doctor the bank the lawyer, the landlord they represent the community and what we are trying to figure out how can people with disabilities make their way into the community in ways that most respect their rights to make decisions. One way is independent way I will make decisions by myself and communicate with others and I will be respected, but if I can't make decisions by myself, or I need some support, or like Ian I need some assistance of people who can interpret me to the world, then we need a process to recognize supported decision-making, really, which is really a network of people that help bridge me to the community to make those decisions.

The third way is what we would call representative decision-making. So I may decide to -- I am just getting an email here. I am wondering if -- yes, I see that there's a request to post the slides. We will certainly be posted on the Burton Blatt Institute site.

So if we look at that third way, the representative decision-making, that's me appointing a Power of Attorney or an agent who will make decisions as an advanced directive. If I have a psychosocial disability or a mental health issue and I want to appoint someone who will guide decision-making if I end up in a crisis, I appoint someone who will make decisions, but I define the decisions that

person is going to make, the medications I will accept or those that I will refuse. And then we feel that we provide in our model what we call facilitative decision-making. At the end of the day there may be people who have no one around them and no one who can understand their wills and preferences, its critical to get some decisions made -- we would call that facilitative decision-making and their the state has a responsibly to get a facilitator in place to get the decisions made that need to be made, but also to help that person develop relationships so they can be known as someone to make decisions in their own lives. Eventually.

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So the supported decision-making as we have evolved it and Audrey from her experience helped to evolve it with other members of people, first self-advocates, parents across Canada -- is really recognizing a group of trusted others to assist me in expressing my will and preferences and to making and acting on my decisions.

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It means I appoint supporters by myself, I may support Lana sitting next to me to be my supporter, but there may be people and this might be the case for Ian where no one could be fully sure he's appointing his brother or sister or mother or somebody else. And so in that case, our model would provide that others would apply to be my supporters on the basis of trust, personal trust and a commitment and knowledge about me.

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The types of support that need to be available in a supported decision-making process are decision-making supporters, so we are talking primarily about people who are not paid people in my life, but people who I care about and who are appointed to support me. It may be peer support, which is often a support for people with psychosocial disabilities. It may mean that we need communication assistance so the physician can understand my unique form of communication. Provision of information about surgery in plain language and alternate formats. And we also may

need independent advocates. It may be I am a self-advocate and I don't actually want someone -- my brother or sister or mother to be formally recognized to be my supporter -- I want to make my decisions by myself and I might need an advocate to help convince the doctor that I can make decisions by myself. With some help I can understand and appreciate on my own, because we want to make sure that we don't impose support on people, legal sense where it's not required.

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The types of accommodation that we are asking third parties to provide are more time by a doctor, the duty to provide information in plain language, including supporters in the decision-making process.

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In this new approach we are trying to shift the framework from this idea of a presumption of capacity -- because that's really the test by which so many people with intellectual disabilities lose the recognition of their legal capacity. It's not about having a presumption of capacity, really, it's a presumption I can act independently. So we all have legal capacity the presumption should be is that I can make decisions by myself, if I can't, then we may need some support. Which means shifting from capacity assessment of my mental capacity or mental abilities to assessing the supports that I need for an alternate arrangement. It means shifting from detention in a psychiatric facility to an exploration of alternatives, from a finding of incapacity to a finding of needs for support. From substitute decision-making to supported decision-making. And from the best interest test to the best interpretation of will and preference.

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So what are we calling for in the work that we have done in the Canadian Association for the last 20 years? Recognize right to supports in decision-making and the government's duty to help establish those support. Prohibitions on findings of incapacity and

substitute decision-making and detention where alternatives exist. The legal obligation to explore alternatives on the part of third parties, the doctors, banks. Ensuring that we have rights advisors and the duties of government to establish supports.

So that's an introduction to the idea of supported decision-making as I said it evolved starting over 20 years ago in the Canadian context, by self-advocates, by parents looking for a different way than having the right to decide removed from them and their authority vested in a guardian. One of the leaders that helped advance this cause in the Canadian context and help build the examples on which we could negotiate the UN Convention is Peter Park. Peter who's with us and going to speak next, Peter is known in Canada as the Godfather of the People First Movement. An independent movement of the people who have been labeled to make decisions for themselves. And Peter was instrumental in creating the National People First of Canada. And when it came together for its first annual meeting in 1989, its very first resolution at first annual general meeting of People First members from across the country was a call to end all Guardianship laws. And so I turn over to Peter to talk about why that was so important for People First and what this has meant to him personally. Peter?

**Park:**

Okay. I was going into the Guardianship first. Better not. Better go the way I planned it. Bit of my late history. I happen to be an epileptic since birth. As Michael said I went into an institution in 1960. There, Mom and Dad, and myself were told by two doctors who are the doctors at the institution that I could leave whenever I wished. Well, I tried leaving several times. I was brought back several times, thrown into a new ward, where you were locked up. Bare, the walls were bare, the floors were bare there was no mattress. This happened before I didn't know that they had made up rules. Someone that I didn't know had made them up. And having rules for any person with any disability didn't make any sense to me. I figure for 18 years, existing in an institution, I was locked up for nine, this gives you an idea of how much, nine years that is, of how much I abided the rules set up by the institution. One of these doctors, I figured well, this guy is getting old, old age caught up to him. I didn't mind. But my papers that I signed and all that jazz, they became -- lost for 18 years. I was about to vote for

the first time, or so I thought, so I asked the so-called counselor where was the town hall meeting? Who are the candidates? What was their stand on issues? He said, Peter, you are in an institution. You have no rights. And furthermore you are going to D Ward. Well this was my introduction to D Ward. Also, the second thing that I was saying about we definitely were used as human guinea pigs when it came to medications. I happened to have my grade 12 education, so I was lucky enough to be able to read and write. My father was a druggist or pharmacist or whatever they were called back in those days. And he gave me a manual and CPS. The side effects of any medication weren't in there I refused to take them. Needless to say I refused to take medication many times and was sent to D Ward for refusing to taking the medications many times. Social workers and doctors said I would never have a job. Well I did. I got married and have my own place, too. I was told I would never have my own place, by the way. And in those 18 years I made two what I call real friends. The ones you can talk to about every other thing and then still remain friends. You are actually afraid to make any friends at an institution, because one of the two people that I made a friend actually died in front of me and I was told he was having an epileptic seizure. It's completely different. You had no say in who your roommates were or if you were going to another cottage or Ward. Cottage A and B were males. And cottages 1 and 2 were female. This segregation was terrible. There were around 100 to 200 people in each of the cottages. I mentioned D Ward; here there were -- it could range anywhere from 50 people and 50 locked up and 50 just roaming around doing nothing. And 50 locked up at a time. First I was in a room with 13 other people, again, not of my choosing. And after 3 or 4 years, eight people, kept downsizing again to 6 and finally after 16 years I moved in with a roommate who happened to be one the only friends I had left. He got out about a month or so before I did. One of the things I remembered quite well is we visited each other and kept in touch until he passed on from cancer and then we kept in touch with his wife until she passed on. Everyone in this cottage B was supposed to have a shower between the hours of 4 and 4:45 or between 6:30 and 7:30, both p.m. Only on Thursday. If I work, and my boss at work put in a shower for the people that worked there and there were only three people that worked [inaudible] the Department handled all the food for the institution. Approximately

7,000 people. When I got out, I found that I was still under some kind of financial guardianship. When I went to make a purchase in the town that I was living in at the time, I was -- [Inaudible] let me go into a personal -- to a lawyer and finding out how come and why and all the rest of it. Basically that's how they -- that was a form of guardianship right in of itself. I was thinking how the guardianship seemed to -- Michael I am going to call on you here - - to tell about the -- case and because to me, that example of how the mother took over the person's right to be a person.

**Bach:**

So just to jump in here. This was a really important case for motivating the push for end to guardianship laws in Canada. This was a case about a young woman in the early '80s in Canada. Prince Edward Island who's mother was concerned about her. She had a boyfriend and her mother was concerned about her getting pregnant. So she went to the doctor and the doctor -- to make arrangements to have her daughter sterilized. And the doctor said I am not so sure that you can do this. Don't we need consents from your daughter? And the mother said she is not able to consent. I am effectively her guardian. The daughter was adults age. So this case made its way through the courts and eventually, to the Supreme Court of Canada. And there was a decision for our board at the time -- this goes back very early '80s -- around whether we would support the mother or the daughter at court. And Peter Park and a couple of other self-advocates people who would be labeled and the process of forming People First came to us to have this discussion and ultimately our Board couldn't decide, should we support the mother? Should we support the daughter? So the board agreed on a we should support what was called then the self-advocacy caucus to the Supreme Court of Canada and got lawyer and went to the Supreme Court to make a -- intervention so people couldn't be sterilized against their will and it's known as the Eve decision. Which came down from the Supreme Court. And the arguments of People First of Canada and their lawyers were instrumental in winning the case. And I think Peter, that really motivated helped to motivate people's -- the decision of People First to make the issue of guardianship such a priority.

**Park:**

Is why People First started and, I think, is why we made the guardianship so important to look at as a resolution so that perhaps

CHL and other like-minded organizations in Canada would take the issue and move with it, not just us, and support the principle -- guardianship. A very good friend -- friends, pardon me -- they both are -- one has a disability and his older brother is saying, well, if you do get married, I don't like that because then you can't get married because of -- I have my -- give him a chance to make a mistake if he wants to -- after all several people get married and then a year later they get divorced. They weren't told they need a guardian, but because he has a disability he was told -- no. That's wrong. He has rights that is my way of thinking and those rights overturn the guardianship. I don't care. That's my argument.

**Bach:**

Well, and that, thanks Peter and that was an argument that our association by 1991 or 1990 heard loud and clear from Peoples First of Canada. So our association launched a national task force on supported decision-making if People First was making that very clear political demand, what was the alternative? And it's through that task force process that CACL came up and created a framework of supported decision-making. And those ideas were beginning to trickle out through our Provincial associations and their own engagement with their provincial governments in developing what would come to be a legal framework for supported decision-making in the country.

So Peter, maybe we could turn it over to Lana to talk about the evolution, then, of those legal provisions. Over to you, Lana.

**Campanella:**

We have had a question that really is about, as this was evolving in your experience: Were there concerns that the people providing support as you moved away from guardianship that the people providing support might not act honestly and put the people being supported at risk of financial or other kinds of exploitation?

**Kezner:**

It's Lana here. And yes, there were and there are ongoing concerns about the potential for supporters abusing and exploiting the person who they are supporting. We don't see that as different as the potential for substitutes, guardians, attorneys, to also abuse or take advantage of the person for whom they are making decisions. But we don't see that as a reason to say that supported decision-making is not practical and should not be recognized in law. What

that does is drive us a legal and legislative framework that carries with it sufficient safeguards to prevent abuse and it would be -- and that the safeguards are comparable to the kind that we see in well-crafted guardianship and substitute decision-making legislation. That said, while there are fears of abuse in supported decision-making, one of the things that I have heard from people in British Columbia where supported decision-making is recognized in law, is that there have not been a lot of reports of abuse by supporters in the context of the use of supported decision-making as a legal instrument.

**Campanella:** Thank you, Lana. That is a perfect transition into your presentation so please continue.

**Kerzner:** Thank you. So I should start by thanking -- can you hear me okay? The audio okay?

**Park:** I also wanted to comment on that. What we have done and -- to get around that obstacle of different people overriding each other is developed what we called the is there of friends around us. My wife and I. And no one person -- we are at the middle and we drive -- that's the opinion -- take or reject it. We have a good discussion about it, whatever it might be. We found it's very helpful in all sorts of cases, especially financial.

**Campanella:** Thank you so much Peter. Yes, Lana we heard you fine. Continue.

**Kerzner:** I should start by saying that I am presenting today as a disability law lawyer who is being practicing disability law in Ontario, Canada, for several years. I noticed on the very beginning slide of the webinar that it identified me as associated with Ryerson University and the Law Society of Upper Canada. I do teach at both of those institutions, but I want to say that what I am saying today is in my role as an independent lawyer in Canada. And from my perspective in practicing in Ontario.

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So I am going to ground -- I am going to take what Peter and what Michael already presented in terms of how supported decision-making works, how it was evolved, how it was crafted on the Convention on the Rights of Persons with Disabilities and show how Canada's laws recognize supported decision-making and what the limits are to that legal recognition. And I am going to do that by using a simple scenario throughout my presentation. So I am going to be talking about Sam. Sam is an adult with an intellectual disability and he has a dream to go on a vacation and he knows that it's going to cost a bit of money for him to take that vacation.

So on the first slide, you will see I have identified four different players that Michael also referenced in a decision-making process. There's the individual decision-maker so that would be Sam. There's the supporters so who helps Sam to make the decisions that may be his mother, his father, his brother; it may be his best friend. And each of these people may support him differently in different circumstances. Third parties who Michael also mentioned are players in the decision-making process so whether Sam is making a decision about surgery and the doctors have to seek his consent; whether he wants to open a bank account or enter into a contract. So in Sam's situation, he's wanting to save money and he's wanting to open a bank account at a financial institution. In some circumstances there may be a role for the government to play in enhancing people's ability to make decisions to make supports and I will go into that a bit later in the presentation.

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So what is important in terms of a comprehensive legal framework for recognizing supported decision-making is that the laws must address the role of each of these four players. And when I described Canada's laws, we will see that Canada recognizes the roles of some of these players better than others.

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So Canada's laws give legal recognition to supporters in some context and they also give legal recognition to -- or recognize a role that third parties can play in enhancing people's ability and in

fact, right to make decisions with support. Canada's laws also in some circumstances allow people to avoid having a guardian appointed if they can demonstrate that there is an alternative course of action to meet their decision-making needs.

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So while the technicalities of Canada's laws aren't that interesting I want to go over a few of the basics so that it helps to understand how they work. Canada's laws as I said do not fully recognize supported decision-making, but Canada's decision-making laws are different in each of Canada's provinces and territories. What that means is that supports are recognized more fully in some jurisdictions than others. But that said, some jurisdictions essentially don't recognize supports at all.

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And so the jurisdiction that have the most clear recognitions of supports are Alberta, British Columbia, Manitoba, Saskatchewan and the Yukon and the last slide in my presentation has lists resources on supported decision-making. And so if people are interested in the details of these laws and the exact statutes that they are found in, they can see them in those resources.

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So the most well-known legal recognition of supported decision-making in Canada is -- I will refer to them broadly as supported decision-making planning documents. And some of the listeners to this webinar may be familiar with representation agreements that are in the representation agreement Act in British Columbia. So if we go back to Sam, and Sam wants to open a bank account and wants his father to assist him, to deal with the bank, what Sam might do is create a legally valid document and in the document he says he's appointing his father to assist him to make decisions. He then takes that document to the bank with him, his father comes along with him and then the bank has to include his father with him in opening the bank account and dealing with the bank. So that gives Sam control over who's going to support him; gives the

supporters legal recognition and requires the bank to include and legally recognize the Sam's for or supporters in opening a bank and other transactions. What happens, though, in British Columbia, for example, with that kind of document, you can't create it unless you have you meet a certain very minimal test -- they call it a test of incapability. So the question arises: What if Sam can't meet that Test of incapability? What if Sam doesn't understand what it means to be creating a document where he is appointing supports to assist him? There's another legal mechanism recognized in Canada to create, to recognize supported decision making that does not involve Sam creating a document to appoint supporters. That is sometimes referred to as co-decision-making and I should say that co-decision-making is not, even though it may be called the same thing in different jurisdictions it's slightly different. But the concept is same. The concept is where a court appoints supporters rather than Sam appointing his supporters. So in Sam's situation what might happen is the court might appoint the Sam's father to be Sam's legally recognized supporter. So it's a court process, where someone applies to the Court and says maybe Sam's father says I want to be Sam's legally recognized supporter and a court makes a determination as to whether or not that supporter -- that person should be Sam's legally recognized supporter. And to respond and concretize this process as safeguards, one safeguard for supported decision-making as recognized in law, is the actual creation of these legal mechanisms, which -- for example, the evidence that goes before the court, the court's assessment, the process that you have to go to create a supported decision-making planning document, that ensures some level of both accountability and certainty at the front-end that there's a trusting relationship between the supporter and Sam, for example. And that they have -- that the supporter is able to understand Sam's communication and his will and preference and communicate and interpret that to the outside world. So it's partly in the actual creation of these legal mechanisms; that's the first safeguard.

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So then the question arises as to what happens in jurisdictions that don't have co-decision-making, don't have supported decision-making planning documents where there's no opportunity to apply

to a court or for Sam to himself appoint a supporter through a planning document. There are jurisdictions like that in Canada and I understand most or all of the jurisdictions essentially in the United States although I don't practice law in the U.S. so I stand to be corrected, don't have legislative recognition of supports. Now what happens? Sam goes to bank to open a bank account to save money for vacation. He doesn't have a planning document there's no court order recognizing his supporters. His father goes with him to the bank to open the bank account, and the financial institution says, I am not going to deal with your father or allow your father to participate in your decision to open a bank account. If you don't understand the implications of opening a bank account and the paperwork on your own, we won't allow you to open this bank account. There are in Canada -- every jurisdiction in Canada has human rights law, human rights code. And part of our human rights laws in Canada are a prohibition against discrimination on the basis disability. And tightly connected to that prohibition is a duty to accommodate. A duty-to-accommodate simply is a requirement on third parties to take whatever steps are necessary to ensure that their services are equally accessible to people with disabilities as to people who don't have disabilities. And we see the same prohibition against discrimination and duty-to-accommodate in the Convention on the Rights of Persons with Disabilities and it applies most people think about this duty to accommodate in the context of the built environment or employment situation. For example, in the built environment, a ramp to get into a building that has stairs and most people understand that concept.

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But the duty-to-accommodate isn't limited to the kinds of circumstances that we're most familiar with. The duty to accommodate also applies to decision-making scenarios to any provision of services, such as health professionals, financial institutions and lawyers. So what that means is that if Sam goes to the bank with his father, the bank does not have a right to say I am not dealing with your father; the bank has a duty to include Sam's father as his supporter in the decision-making process. One of the fundamental principles of the duty-to-accommodate is that the duty has to be individualized and this is critical for supported

decision-making because people who make decisions with supports, everyone uses supports differently and relies on their supports differently.

So what if Sam -- Sam wants to go on the vacation and save money and wants to open a bank account, but he's afraid that no one in his life is going to approve of it so his supporters are not going to help him to open the bank account. This is their way of putting a roadblock in front of his dream vacation. Sam wants to go to the bank and open the bank account by himself. What he wants in this circumstantial is not that the bank recognize his father as a supporter, but the bank accommodate him by providing, perhaps plain language material or having someone at the bank sit down with him and spend some extra time explaining to him what it means to open a bank account and what the duties and obligations are and that would be the accommodation to allow Sam and right dignity to open the bank account on his own without supporters, but do it in a way he chooses and a way it maintains his privacy and confidentiality.

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There is one final mechanism in the laws in Canada that allows for recognition of supports. And I almost want to say through the back door, because often it's not necessarily laid out that explicitly. And we refer to that as the alternative course of action to guardianship provision. So there are many guardianship statutes in Canada in the different provinces and territories, that say -- that specify that a guardian -- that a court is prohibited from appointing a guardian if an alternative course of action exists and this provision is critical and I am going to illustrate, again, with Sam what makes it to critical. Let's say Sam's father knows that not only Sam wants to open a bank account to go on a vacation, but Sam's father knows there will be other important financial decisions that Sam will want to be making throughout his life father says the best thing is to go to court apply to be Sam's legal guardian and I will be able to make his financial decisions for him. So Sam's father goes to court and applies to be Sam's guardian. The alternative course of action provision allows Sam as a respondent in the court process to say to the court, no; you are prohibited from appointing my father as guardian, because there's an alternative course of this action that

exists and I have put evidence before the court that the alternative exists is I have three best friends who are going to support me to make decisions and so I don't need my father to act as guardian. Some of the alternative course of action provisions in Canada specify that supports are a legally recognized alternative course. That's not the case in Ontario, although we have a court decision in Ontario that has recognized supported decision-making as a valid alternative course of action.

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So this is the last -- I am wrapping up -- this is my last slide and I am wrapping up with a question we have had supported decision-making laws in Canada for several years, and the question is: What have we learned from the Canadian experience? And what can people in the United States and other countries learn from Canada in crafting their own supported decision-making laws? One of the things that we have learned is that in general, supported decision-making laws in Canada are underutilized. In other words, while we have the ability in some provinces and territories to make supported decision-making planning documents, they are not used as much as they could be -- co-decision-making orders are not always granted very often. And one -- we suspect that the reason for this is that there isn't broad awareness in education around supported decision-making, what it is, and how the legal mechanisms work and how they can be used. So it's crucial that there be broad education awareness and assistance to people who want to create supported decision-making documents.

The other lesson we are learned in Canada is as I have illustrated in my talk Sam may choose to use supports differently depending on his circumstances and depending how he likes to make decisions. Any laws that recognize supported decision-making need to recognize the different ways in which people access supports. If Sam can create his own planning document, that a legally planning document would allow that to happen -- if Sam cannot create a planning document if it's more of a type of relationship between Audrey and Ian from the video clip at the beginning, it would be perhaps a court appointment. The other lesson we have learned in Canada is that while our laws are very -- can be very detailed about how supported decision-making arrangements are created, a set of

guiding principles, that are broad and firm at the beginning of a legislation is something that everyone can understand and people can use that to guide their lives in a more broad sense than just what the law laws for. And the last two points are that let's say Sam did not have any supports in his life or let's say Sam lived in New York, and then moved to California. He had supports in New York, but none in California. There needs to be a state government rule to assist someone like Sam to create facilitation of supports in his life. And this is addressed in Article 12 (b) of the Convention. And lastly as was raised in the question there needs to be safeguard to prevent abuse by supporters. And this can be in the form of being able to raise concerns to an administrative body or a court in legislative duties that I had mentioned earlier. And in legislatively-created rules for how supporters must act and they need to act in a fiduciary duty and not take advantage of the person they are supporting and be able to understand the person's will and preferences and so on.

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So on the last slide I have just chosen to put three resources with links. The first one is a paper written by Michael and myself. And in it, we set out a recommended paradigm for how the law can recognize supports. And there's also a section in there that covers supported decision-making laws in different jurisdictions. There's also a link to material from the mental Disability Advocacy centers' website on what supported decision-making is. And a link to the United Nations website with the Convention text and relevant materials relating to the Convention.

So I am going to finish my presentation at that. And we can take some I believe there's time for a response and questions?

**Campanella:**

This is Tina. Thank you very much Lana and thank you all three of you. This is very interesting. You have covered a lot of ground. There are a couple specific questions I think, we would like to get answered. And I will start with -- can you help us understand how a representation agreement is different or similar to a power of attorney?

**Kerzner:** Okay. So it's similar in that it's a legal document that I create myself that gets written out, where I say I am appointing someone to do something with certain instructions. So in that respect, it enhances my autonomy in that I am choosing the person, so in that respect it's the same. It's a planning document where I am choosing someone to do something. It differs in that a representation agreement or a supported decision-making agreement allows me to appoint someone to support me to make decisions and not to substitute decisions. So in Sam's case, if he's creating representation agreement he's appointing father not to make decisions on his behalf, but to assist him with decisions. Power of attorney would be Sam's father making substitute decisions.

**Campanella:** Got it. Go ahead.

**Kerzner:** And the last thing is that the threshold for creating -- for when you create a power of attorney you need to make a test of capacity. To do so the traditional cognitive test of capacity. Whereas to make a representation agreement, the test of -- it's a test of incapability and it's a lower standard of a trusting relationship and so it doesn't require the same high-level of cognitive understanding.

**Campanella:** Wonderful. Thank you. There's another clarification question. And it relates to your references on the co-decision-making where the court appoints a supporter. How exactly is this different from guardianship?

**Kerzner:** So it's different from guardianship in the same -- it's an analogy to the last question asked. In other words, the court is appointing someone to me not to make -- that's the fundamental difference - - co-decision-making and rep agreements are about people assisting making decisions not substitute decision-making.

**Campanella:** Thank you and we have had an additional question, asking and it could be any one of you to speak a bit more about what an individual would do if none of her supporters agree with her preferences? For example, if an individual wanted to buy a fancy sports car, but no supporters thought it was good idea. Would she still be able to do it?

**Bach:** It depends on the nature of the agreement. So if the supported decision-making agreement that she made with her supporters indicated they were legally recognized to support her in making financial decisions those kinds of purchases, then if -- this raises some other questions about how does that agreements get known and recognized and registered so third parties know it's in place or not? And we don't have mandatory registries in Canada now. In the legal framework that we are proposing, the third party -- if she decided without her supporters to proceed and was able to get the money and make the purchase that if the third party had not -- had any question about her capacity, and had not checked out to see if she had supporters, then that may not be a valid contract. So but this raises questions of law and mechanisms that have not been fully worked out.

Ideally what happens is that people recognize there's a conflict here, and work out -- work it out through discussion and have access to community agency that assists that network in mediating that conflict and addressing it. An alternative also would be that she could decide to change the supported decision-making agreements. She could terminate the agreement, and seek other supporters. But ideally they work it out together.

**Campanella:** Right and I want to get this question in because I think it's a good one. If you could keep your answer brief I want to make sure I get Sam our reactor a chance to speak. We have a question in the audience that talks about whether or not Canada has had any difficulty with guardianship becoming somewhat of an industry, where one person is guardian over dozens of people. And is that something that you have experienced and if so, how have you battled it?

**Bach:** No, it hasn't evolved in the Canadian context that way in the way that in some European -- central European countries they have large systems of state-paid guardians and guardian systems. Public guardian and trustee in different jurisdictions in Canada, to the extent they are engaged as the public guardian, may be involved in that, but that tends to be more of a minority of cases.

**Campanella:** Wonderful. Thank you very much. Now, Samantha, you have been listening to all this and you are our designated reactor. So you want to share some thoughts with us?

**Crane:** Yes, can you hear me.

**Campanella:** Yes.

**Crane:** Awesome. I was listening with a lot of interest to the presenter on the Canadian system, because the Autistic Self Advocacy Network has recently done some research into barriers to creating similar supported decision-making agreements in the U.S. And I would like to take a minute to compare and contrast the U.S. and Canadian systems. In the United States, with the exception of some state legislatures like Texas which are trying to create representation agreements like British Columbia's, we have some major obstacles to having supported decision-making arrangements recognized to the same extent they are in Canada. In particular, as someone has already noted, if someone with a disability is determined to lack mental capacity then that person will be also be determined to lack capacity to sign a power of attorney or other kinds of representation agreements, without special sort of legislative authorization. Which as I said, doesn't exist yet in the U.S. So these are people we see a lot of people who are able to form informal networks in order to support their decision. And those will work as long as the courts in that state are willing to recognize them. But a lot of people will not be able to get a recognized representation agreement. In many cases where there was a contested guardianship, the court will note that the person's power of attorney is not an adequate alternative to guardianship, because the person lacks the capacity to sign the power of attorney.

We also have an issue with pipelines if which, for example, the educate system once the student reaches the age of 18, educators will inform the parents that the parents can't take a role in the young adult special educate. And young adults are entitled to special education until age 21 and they will say the parent cannot be involved in the special education planning unless they have guardianship. So we will find that a lot of parents who wouldn't

otherwise even want to seek guardianship over their child feel as if they have no alternative.

And finally, there's a real issue with educating guardianship justice. In America there are a lot of specialize courts usually called probate courts or orphan courts and the judges in these courts have really internalized this sort of protectionist stance that guardianship is the only way to adequately protect people with disabilities. And these judges -- sometimes there will be an adequate alternative, but the judge will dismiss that alternative on the basis of the fact that it's not as restrictive as guardianship. We saw one case in which there was an elderly man; he was in a nursing facility. And some of this man's children were seeking guardianship and he objected and said, well, I have signed the power of attorney authorizing this one child of mine to act on my behalf. And I clearly had legal capacity to sign this power of attorney. And the judge actually determined that the power of attorney was not an adequate alternative to guardianship, because the man with the disability could revoke it. So the sense of if a person with a disability is in control, then it's not an adequate alternative. Which is exactly the opposite of what we would want to see.

And similarly, in the Jenny Hatch case, which was the seminal case that Quality Trust took on last year. They did an extremely good job of educating the judge in that case, but even then when the judge said we will try and let the supported decision-making process work -- he put the burden on Jenny and her supporters to prove it would work before guardianship would be removed. So he put guardianship in for one year and said we will let her try supported decision-making and then if it works, then we will revisit the guardianship decision. This is exactly the opposite of what we want. We don't want to put the burden on the person with disability to come up with alternatives because the person with a disability is often from not in a very good position to do that research on their own. Jenny Hatch, for example, if she hadn't had such competent counsel would never be able to provide a plan for decision-making given that she was forcibly placed in a group home with limited opportunities to communicate with her chosen support people. It would have been very onerous and difficult for her to provide a comprehensive plan given that the judge given his skepticism --

those are the kinds of concerns we are seeing in the U.S. and we would definitely need, in order to come in line with Canada, not only to create legislation like British Columbia, that would have representation agreements and allow people to enter into representation agreements even if they have significant support needs, but we would also need this general statement of human rights as a sort of a public education function. So that judges will understand that, in fact, our goal is to maximize autonomy and any intervention that minimizes autonomy is not acceptable in the name of the fact it's an established procedure and they feel it gives more protection.

**Campanella:**

Wonderful, Sam. Those are beautiful ending thoughts. So thank you very much. Thank you to all our presenters. This has been a wonderful inaugural session. We are so pleased that you have agreed to join with us on this. And begin the conversation. Obviously this is a large conversation that has -- that will continue on for some time. In ending I want to remind everybody this is the first in a three-part series. So be sure to join us for the next session on April 30<sup>th</sup>, when we will have Jenny Hatch and her attorney, Jonathan Martinez present to introduce us to supported decision-making and how it works in practice for Jenny and to talk about the decision and probably if Sam has noted for us to really begin to talk about what needs to change in the United States if we are going to see supported decision-making advance in practice as so many of us would like to see. So with that, again, I want to thank you, everybody who chose to join us. I think this is a wonderful beginning to the conversation. And I look forward to talking with you again in April. As we continue to think about how we can move this forward.