OPEN SOCIETY
FOUNDATIONS

TRANSCRIPT

The Story Of The First Two Nations To Pass Landmark Disability Rights Law

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MODERATOR:
TIRZA LEIBOWITZ

INTRODUCTION:
NICOLE WILETT

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ANNOUNCER:

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NICOLE WILETT:

Hi, my name is Nicole Wilett. I'm the chief of staff here at the Open Society Foundation, and I am standing in today for Patrick Gaspard, our president, who sends his regrets. He very, very much wanted to be here today. As soon as Emily Martinez and I talked to him about this event, he was immediately on board and very excited.

And he is a far more eloquent speaker than I am, so please bear with me-- as I try and do him and this incredibly important work justice. But I'll give it my best. Patrick was pulled away-- unexpectedly, and-- has sent me in his stead. And I will be sure to tell him all about this event. And, again, welcome: We're so pleased that everyone came, despite the winter snowstorm and state of emergency we seem to be having. So, thank you for your dedication to being here.

It is an honor to be here today with a group of advocates who have helped bring about true breakthrough in disability rights. As many of you know, in Peru at the end of 2018, and then in Colombia just a few months later-- these two countries were the first to recognize the full legal capacity of all citizens.

This is an enormous win for the disability rights movement, a movement which we at OSF are deeply committed to. Recognizing this right has been a key goal of the movement since the adoption of the Convention on the Rights of Persons with Disabilities in 2008. And we are pleased to be joined to talk about this today.

(OFF-MIC CONVERSATION)

NICOLE WILETT:

We're pleased to be joined-- by activists to speak about this groundbreaking legis-- legislation. I will try not to butcher names, but-- it is-- it is a special talent of mine, unfortunately. But Claudia Zapata-- great-- a self-advocate from Colombia and a facilitator for supportive decision making.

Karin Liza Gutierrez from the Peruvian Down Syndrome Society; Patricia Andrade, who heads the pilot work with the Peruvian Down Syndrome Society and is supporting Karin today; and Pamela Smith, the executive director of SODIS, an organization that was deeply involve in the adoption of this law in Peru. It is an honor to have you all here with us today. Thank you.

We are excited to hear your stories and hear your insights, and we hope that in the years to come, this stage will be filled with far more self-advocates from many countries telling their stories about how this right is now protected all around the world.

This is not a new issue for us at OSF. In 2011, our president emeritus, Aryeh Neier-- wrote about Maria Alejandra-- Villanueva, a young woman with Down Syndrome from Lima, Peru. At that time, the Peruvian Government had taken a step that took away the voting rights of people with intellectual disabilities.

And Ms. Villanueva was stripped of this right when she went to get an appointment to get a national ID card. I suspect that many of you are very familiar with this story. The government official processing the ID would not speak to her, addressing only her mother, who accompanied her.

Eventually, Ms. Villanueva's mother complained that her daughter was perfectly capable of answering the clerk's questions directly. "She votes," her mother told the clerk. "Not anymore," the clerk responded. And initiated proceedings to have her struck from the voting rolls.

All of this began an extraordinary campaign, led by Ms. Villanueva and supported by the Open Society Foundations, to help restore voting rights to thousands of Peruvians whose voting rights were denied because of their disability. Much of the campaign featured Ms. Villanueva speaking passionately for herself, for her own rights, embodying a reason to overturn Peru's discriminatory law.

She addressed the U.N., and Mr. Neier hosted her at an event in OSF. Eventually, the Peruvian Government relented, issuing a new rule saying that all persons with disabilities not under guardianship would be reinstated in the voting registry.

I tell this story for a few reasons: First because it shows the incredible impact that even one person can have to stand up to injustice. That is the kind of work that we are so honored to support here at OSF. Second, it stood out as important, but a partial, victory for people with disabilities in Peru, and is setting precedent all around the world.

At the time Peru failed to unequivocally acknowledge that all persons with disabilities have the right to political participation. And it maintained a system in which people with disabilities' voices and choices are restricted or denied in many other ways.

We are here today to tell the rest of the story, to listen to the rest of the story. We are here to understand why this story is so important: That it's not just about voting rights. It is about safeguarding the right to dignity for millions around the world.

Ms. Villanueva's story about the restrictions people with disabilities face on the right to vote was not an outlier, as you all well know. People with intellectual and psychosocial debil-- disabilities rarely enjoy equal recognition under the law.

For most people, this right is so familiar that we take it for granted. But for people with disabilities, it is often tossed aside by courts, doctors, bankers, and others. All over the world, once labeled with a disability one can lose one's voice and power to control one's own life through guardianship, or interdiction, or other ways of sidelining by family, guardians, and other members of the community.

In the United States, for example, 1.5 million people face some source of-- some sort of restriction to their legal capacity. In Peru and Colombia, each, tens of thousands, if not more, are restricted. Too often, these restrictions are based on a lack of faith in the judgment of people with disabilities and the desire to protect them from harm.

Or, like the case of the Peruvian Voting Registry, society applies its own notion of what is "in the best interests" of people with disabilities, rather than tr-- rather than remove what restricts people from disabilities for speaking or deciding for themselves. That is often the root of the problem. We call this "the soft bigotry of low expectations."

The result is people with disabilities can be barred from: voting, getting married, being a witness, opening a bank account, signing a contract or a lease, appointing an attorney, organizing and registering as an organization, giving consent or refusing consent to medical treatment, and the list goes on. For some people with disabilities, decisions as basic as what to eat are made by others. This is wrong.

Upholding legal capacity is not about kindness. It is not about support. It is about assuming for everyone that the basic dignity of agency and choice is not taking shortcuts to enabling everyone to access that. The individual decisions we make day to day and cumulatively over the course of our lives are a fundamental expression of who we are.

Taking away a person's ability to make these choices is akin to taking away their voice and trying to take away their power. An Open Society does not wall off certain groups of people, saying that they do not have the capacity to make decisions about their own lives. An Open Society does not paint a portrait of the ideal decision maker against which all other people are judged.

And that is why this is such a fundamental issue for the Open Society

Foundations. And that is why for the past five years, OSF has funded efforts in Columbia and Peru and ten other countries to pr-- promote sociolegal r-- reforms on legal capacity. And this is why I turn to other human rights and development donors to consider the area of legal capacity as a crucial aspect of rights and development. We all know that this is an underfunded and critically important space. So we do hope to see the sector come together and support.

At the same time as we support efforts around the world, I would like for those of us from OSF to ask ourselves some tough questions. The pernicious biases that have led us to lead this struggle from behind are so ingrained into our societies, I think we need to ask ourselves honestly if they have bled, in some ways, into our work, as biases do.

Are there ways that we act that overlook people with disabilities, in effect rendering them invisible to us? Where do we need to change our assumptions and modify how we operate so we can fully include everyone? Are we working in a way that fully recognizes and respects the agencies of all of the communities that we serve? These are the really wrestling-- wrestled challenge within philanthropy.

Fundamentally, are we as individuals, members of our communities, and funders part of the change people with disabilities are seeking, are demanding from society? How do we keep ourselves from being the problem? From Brazil to Georgia to Zambia, governments are finding ways to allow people with disabilities to maintain more control over their lives and decisions. Systems and services are designs that people wishing to access greater control of their lives can do so.

At the end of 2018, Peru became the first country in the world to fully recognize the right of every person to exercise their legal capacity. Just three months ago, in August 2019, Colombia became the second country to do so. Both victories were led-- this is so critically important, by people with disabilities, many of whom themselves had been declared incompetent under the law.

We are lucky to be joined by three people who have helped win this tremendous victory, and are in a position to tell us why it is so important, and how we can better support their work. And then, just on a personal note, for me it's a real honor to be here.

My brother-- my dear brother, who I grew up with, has cerebral palsy, non-verbal-- paraplegic. And-- many of these struggles are known, deeply and inherently, to our family as we attempted to-- support him in telling the world that he has a voice, even if his words are not the same as many of us understand. So it is-- it is a real honor for me to be here amongst you, as well, association all of you who support this work. So thank you. (APPLAUSE)

TIRZA LEIBOWITZ:

Thank you very much, Nicole, and welcome, everyone, welcome to our panelists. And we will now just watch just very short clips that will bring you into the world of Colombia and Peru. I'll just say a word about the first clip that we'll see. I remember the day when we got notice-- from-- our colleagues in Peru that the law had passed. And w-- we could not believe it because we'd been struggling with many countries around the world to create this change.

And I think that what made us actually believe it was watching this short clip done shortly after the law was passed, very amateurishly. But really passes-- the message. And then we'll watch a v-- another short clip from Colombia-- which I-- we find interesting because it's a-- it comes from the media. This is a news item, and how they portrayed the victory in-- Colombia. And then I'll introduce myself and the panelists. So let's watch.

(VIDEO NOT TRANSCRIBED)

TIRZA LEIBOWITZ:

Thank you very much. So a quick introduction: I'm Tirza Leibowitz from the Human Rights Initiative here at Open Society. And we have our panelists-- with us. So starting from the end: Pamela Smith, who is the director of the SODIS. Claudia Zapata, who-- is a self-advocate and trained as a facilitator on supported decision making. And we'll learn through this panel what that means. And we have Karin Liza Gutierrez, a self-advocate with Peruvian Down Syndrome Society. And we have-- Patricia Andrade, who's here as a support person for Karin.

And so I'd like to begin with-- asking each of the panelists a question. And begin with you, Karin, maybe just to say we're going to be working across languages, styles of communication. And so we're going to-- make sure everyone has a chance to communicate the way they feel comfortable. And so, Karin, the-- the question to you is if you can tell us your story: When did you learn that you don't have legal capacity? What did that mean for you? And what did you do about it?

(FOREIGN LANGUAGE NOT TRANSCRIBED)

KARIN GUTIERREZ VIA INTERPRETER:

My name is Karin Liza Gutierrez. I'm 35 years old.

(FOREIGN LANGUAGE NOT TRANSCRIBED)

KARIN GUTIERREZ VIA INTERPRETER:

My name is Karin Liza Gutierrez, and I am 35 years old. I was born in Lima, Peru.

(FOREIGN LANGUAGE NOT TRANSCRIBED)

KARIN GUTIERREZ VIA INTERPRETER:

Thank you for inviting me to tell my story.

(FOREIGN LANGUAGE NOT TRANSCRIBED)

KARIN GUTIERREZ VIA INTERPRETER:

My mother banned me from collecting-- my father's pension.

(FOREIGN LANGUAGE NOT TRANSCRIBED)

KARIN GUTIERREZ VIA INTERPRETER:

We went to the bank, and when-- they were supposed to pay me, they didn't call me. They-- told my mother that she should sign, and they gave her the money.

(FOREIGN LANGUAGE NOT TRANSCRIBED)

KARIN GUTIERREZ VIA INTERPRETER:

They didn't take me into account.

(FOREIGN LANGUAGE NOT TRANSCRIBED)

KARIN GUTIERREZ VIA INTERPRETER:

I went several times to the bank, and it was always the same, until I quit going because I realized that there was no use in going.

(FOREIGN LANGUAGE NOT TRANSCRIBED)

KARIN GUTIERREZ VIA INTERPRETER:

And neither my mother understood. When I arrived at the-- Down Syndrome Peruvian Society, I learned to-- about my rights. I knew that some people are banned and that is why they cannot make their own decisions.

(FOREIGN LANGUAGE NOT TRANSCRIBED)

KARIN GUTIERREZ VIA INTERPRETER:

At that moment, I didn't know that I was also banned.

(FOREIGN LANGUAGE NOT TRANSCRIBED)

KARIN GUTIERREZ VIA INTERPRETER:

And when I started to work, that was the second time that they were treating me differently, as if I was a little girl.

(FOREIGN LANGUAGE NOT TRANSCRIBED)

KARIN GUTIERREZ VIA INTERPRETER:

They gave me my contract so that I could start working, and I signed it. But they told me I had to call my mother for her to sign because my signature was not valid.

(FOREIGN LANGUAGE NOT TRANSCRIBED)

KARIN GUTIERREZ VIA INTERPRETER:

I told my mother, "Why do you have to sign if I'm the one who's working?"

(FOREIGN LANGUAGE NOT TRANSCRIBED)

KARIN GUTIERREZ VIA INTERPRETER:

Other times, I had to sign contract, and every time, the same thing happened.

(FOREIGN LANGUAGE NOT TRANSCRIBED)

KARIN GUTIERREZ VIA INTERPRETER:

She explained to me that that happened because I was banned. I didn't like it. I wanted to sign on my own by myself.

(FOREIGN LANGUAGE NOT TRANSCRIBED)

KARIN GUTIERREZ VIA INTERPRETER:

There I realized that I did not want to be banned. Seven years ago, it's been, since I work. I pay my own bills, but my mother has to sign so that I can get my bank-- card, collect my salary, and buy my things.

(FOREIGN LANGUAGE NOT TRANSCRIBED)

KARIN GUTIERREZ VIA INTERPRETER:

Even my cell phone had her name. I didn't feel well. It didn't feel right. It was always my mom, my mom. I felt discriminated against. That's when I learned that I was banned, and I didn't want to.

(FOREIGN LANGUAGE NOT TRANSCRIBED)

KARIN GUTIERREZ VIA INTERPRETER:

The third time was when I was not allowed to vote. I had to go vote and they told me that I-- I could not vote because I was not on the list. Once again, I felt discriminated against and I went to the bathroom to cry. I was enraged.

TIRZA LEIBOWITZ:

Karin, we want-- we would like to hear from you what you did with this in-- with this situation. But I do want to stop for a second because something may have got lost in translation. People may be asking, "How is it that, Karin, you become-- became banned? Like, how did that actually happened?"

And I just wanted to fill in the-- the term "interdiction" that we keep on referring to. It is a situation where someone can go on behalf of a person to the court and to ask for an-- an order that legally puts that person aside and appoints someone else to make decisions in their place. So that's folded into the word "interdiction" that appears here in the translation.

And I just want to add one thing. In conversation with Karin before this event, what happened here was-- and I'm saying this because it con-- connects to the point that, Nicole, you made beforehand. Sometimes the motivation is the protective one, right? In this case, the authorities apparently asked-- and Karin, tell-- tell me if that was the case. They suggested to the family, "Why don't you go ahead and sign these papers? It will be easier for Karin to receive a-- the-- the pension that she's entitled to."

And, Nicole, in-- in your-- when you were recounting what happened-- in-- in Peru around the voting rights, this was the-- the government saying, "P-- voting in Peru is mandatory. Why have people with disabilities go through the hassle of it? Let's strike them off," right?

So that motivation of protection, which we're saying-- this is a very, very political s-- protected space. So-- Karin, why don't-- let's-- let's hear: What did you do, after crying? 'Cause we know you became active on this. Please give the-- tell us what you did with this.

(FOREIGN LANGUAGE NOT TRANSCRIBED)

KARIN GUTIERREZ VIA INTERPRETER:

I went with a judge and-- protested. I asked the judge to remove the interdiction.

TIRZA LEIBOWITZ:

Can I-- can I ask a question, Karin, about this? I know that you ha-- the-- the law had to be changed in Peru. And I wanted to ask if you participated in the work to change the law in Peru?

(FOREIGN LANGUAGE NOT TRANSCRIBED)

KARIN GUTIERREZ VIA INTERPRETER:

I was in conversation with the Congresspeople so that they would eliminate this interdiction.

TIRZA LEIBOWITZ:

And just cur-- out-- out of curiosity, you are a-- colleague and a friend of-- Maria Alejandra? Was that something that you did together with other self-advocates?

KARIN GUTIERREZ VIA INTERPRETER:

Si. Yes.

(FOREIGN LANGUAGE NOT TRANSCRIBED)

KARIN GUTIERREZ VIA INTERPRETER:

And I'm also a friend of Sandra Selis (PH).

(FOREIGN LANGUAGE NOT TRANSCRIBED)

KARIN GUTIERREZ VIA INTERPRETER:

Sandra Selis is also a person that is a-- self-advocate.

TIRZA LEIBOWITZ:

I think our translator has learned a new word-- for this event: (LAUGHTER) "self-advocate," a very important word. (LAUGH) And maybe just the last question, Karin, for this round: You approached the judge after the law was changed. If you can just tell us how you felt? Or what-- first of all, what did the judge decide and how you felt?

(FOREIGN LANGUAGE NOT TRANSCRIBED)

KARIN GUTIERREZ VIA INTERPRETER:

I was given some letters by an attorney to bring to the judge--

(FOREIGN LANGUAGE NOT TRANSCRIBED)

KARIN GUTIERREZ VIA INTERPRETER:

--to remove the interdiction. But it's something very hard. But this is how we learned.

(FOREIGN LANGUAGE NOT TRANSCRIBED)

KARIN GUTIERREZ VIA INTERPRETER:

I noticed that this was impeding me from voting or to sign the contract at work.

(FOREIGN LANGUAGE NOT TRANSCRIBED)

KARIN GUTIERREZ VIA INTERPRETER:

I didn't like this legislation.

TIRZA LEIBOWITZ:

I just want to add that-- Karin sent us the-- the note-- the notice of the revoking of the interdiction. And I have to say that I had mixed feelings: on the one hand, participating in-- in Karin's sense of liberation, and on the other hand, you know, the bittersweet feeling that people actually have to fight for this very, very basic right.

(FOREIGN LANGUAGE NOT TRANSCRIBED)

KARIN GUTIERREZ VIA INTERPRETER:

I felt liberated by the fact that the judge removed the interdiction.

TIRZA LEIBOWITZ:

Thanks. And I g-- I guess I borrowed-- having conversations with Karin, I borrowed the word "liberation" from-- from your story. Thank you, Karin. We'll move on to-- Claudia. We threw out the word "supportive decision making." If you could say a word about what that is, and then I'll ask you a follow-up question.

(FOREIGN LANGUAGE NOT TRANSCRIBED)

CLAUDIA ZAPATA VIA INTERPRETER:

First of all, thank you for inviting us, and thank you for listening to us.

(FOREIGN LANGUAGE NOT TRANSCRIBED)

CLAUDIA ZAPATA VIA INTERPRETER:

I would like to thank you, and then I will speak more about this pilot for the decision taking and for the support, and-- and speak that not too long ago, I was also-- I found out that I was also-- disabled, 'cause I was diagnosed with bipolar syndrome (?).

(FOREIGN LANGUAGE NOT TRANSCRIBED)

CLAUDIA ZAPATA VIA INTERPRETER:

Thank you for the-- thanks to this project, I was able to become a facilitator--

(FOREIGN LANGUAGE NOT TRANSCRIBED)

CLAUDIA ZAPATA VIA INTERPRETER:

--the training to become a facilitator for this person who was 35 years, from my organization-- was 35 years old.

(FOREIGN LANGUAGE NOT TRANSCRIBED)

CLAUDIA ZAPATA VIA INTERPRETER:

So this is like a-- it's-- the support for decision making is a kind of tool to help people kind of exercise their legal capacity so they could make their own decisions.

(FOREIGN LANGUAGE NOT TRANSCRIBED)

CLAUDIA ZAPATA VIA INTERPRETER:

To c-- to explain to them other options so that the person can make their own decision after being informed.

TIRZA LEIBOWITZ:

And-- and just a follow-up question, something that we also-- we discussed before, and, Nicole, you also mentioned it. Is this kind-- is the kind-- I could see people thinking, "Ah, okay, this is help. This is help, this is kindness, this is compassion." What-- how would you des-- descr-- is it-- it that the essence of the support-- supportive cis-- decision making or upholding legal capacity? Or how would you describe the essence to someone who doesn't know what it is. Like, what is this-- what is decision--

(FOREIGN LANGUAGE NOT TRANSCRIBED)

CLAUDIA ZAPATA VIA INTERPRETER:

It turns out we're all human beings. And as human beings, we have dignity, we want dignity--

(FOREIGN LANGUAGE NOT TRANSCRIBED)

CLAUDIA ZAPATA VIA INTERPRETER:

--values, and legal capacity.

(FOREIGN LANGUAGE NOT TRANSCRIBED)

CLAUDIA ZAPATA VIA INTERPRETER:

And this is true. The-- it's mentioned in the Convention of Human Rights.

(FOREIGN LANGUAGE NOT TRANSCRIBED)

CLAUDIA ZAPATA VIA INTERPRETER:

When someone like myself is diagnosed and is considered to be someone disabled--

(FOREIGN LANGUAGE NOT TRANSCRIBED)

CLAUDIA ZAPATA VIA INTERPRETER:

--automatically, as a person, for the community and to their family, you lose all legal capacity.

(FOREIGN LANGUAGE NOT TRANSCRIBED)

CLAUDIA ZAPATA VIA INTERPRETER:

And with this new law that has been approved in Colombia, we are reestablishing that cap-- legal capacity.

(FOREIGN LANGUAGE NOT TRANSCRIBED)

CLAUDIA ZAPATA VIA INTERPRETER:

And every-- and everybody who is considered disabled can now make decisions about their bank account--

(FOREIGN LANGUAGE NOT TRANSCRIBED)

CLAUDIA ZAPATA VIA INTERPRETER:

--and all legal levels: medical or any project in life.

TIRZA LEIBOWITZ:

Thank you, Claudia. We may get back on that, may-- maybe dig a bit further because it-- it's huge progress. But there are also challenges. So we'll-- we'll get to that further. Pamela, bring us into the political space. So this happened in Peru. It happened in Colombia. There are many other countries around the world who are working on this, but they have not succeeded in reaching this level of legislation. What made it work in-- I'm gonna say to you in this room, in Peru and Colombia, of all places?

PAMELA SMITH:

Hi, everyone. I'm very honored to be here-- sharing with-- the self-advocates. If I have to think about what was the process that led to this piece of legislation-- unfortunately, it wasn't an act of justice coming from government. It was an entire and articulated strategy we had to put in place-- in order to obtain-- this piece of legislation.

First of all-- we-- kind of-- assessed and-- yeah, as-- assess the political and legal situation of our countries. We were aware that-- the CRPD and the paradigm-- the paradigm shift brought by the CRPD, the Convention on the Rights of Persons with Disabilities, was quite challenging. And the Article XII was one of the most contested articles-- in the process of adoption.

So we have to think about a strategy that addresses-- all the-- the challenge that we would found on the way. So-- first of all-- we-- we went through-- this analysis. We tried to engage people into the conversation. And, actually-- one of the first steps was-- right after the-- Peru ratified the Convention, so when the new disability act was being negotiated, we kind of laid the ground and laid the foundations for this new legal reform-- the reform of legal capacity, back in 2012.

So it's been years of work. We've been id-- identifying allies during all this process. So a commission was formed at the Congress level. We also were aware that we need to, like, tackle the system and untangle the system at very different levels, not only legally but also practically.

So that's why we went through-- we went for the law. We tried to, like, to set out-- the paradigm-- the paradigm shift into this new-- bill-- regarding legal capacity. And in that particular space, like, we-- engage Congressmen, politicians, public officers. So they were now aware of what it meant to-- for someone-- to-- what the removal of legal capacity meant for persons with disabilities.

So we proved that the system didn't work. And that legal capac-- that interdiction and guardianship didn't protect anyone-- even though it was, like, created, or it was supposed to-- to protect people. So we work on legislation. We engage allies in this process at very different levels.

And we tried to move from legal and the policy side also to practice. So we are now introducing this new concept of "supports" rather than "legal representatives." So what do supports mean? We work then on projects, on pilot projects, regarding supports-- for decision making, and focus on persons with intellectual and psychosocial disabilities.

Raising awareness was quite important, and that's why the self-advocates were speaking up, sharing their stories of-- how a life without legal capacity looks like. So in that sense-- more people-- understood this issue, the importance of this issue-- at the very core of the-- the human rights. Many of us-- didn't struggle with that, so it was quite important for the self-advocates and the disability rights movement to-- to speak up, to share their stories, and to be involved in this entire process.

TIRZA LEIBOWITZ:

Thank you very much. I just want to complete the picture. I know that we have a couple people from the U.S. working on legal capacity. So we're hearing from Latin America. We're sitting here in New York City, in the United States, and it would be interesting to hear-- where is-- is Cathy (PH) here? Cathy? Cathy Costanza, can you just say a word? Wh-- what-- how-- you know, I was going up the elevator today with the-- director of-- of the Open Society U.S. And I mentioned the event and he said, "Oh, the U.S. is doing well on this, right?" (LAUGHTER) What would you say to him? Hello, Tony.

CATHY COSTANZA:

Hi. We-- I run an organization. We've-- had-- the experience of doing seven pilots-- six of them in Massachusetts, one in Georgia. We're working with a group of people in Georgia. As you all probably know-- the United States did not ratify the U.N. Convention. Article XII was a big factor. Why? Because there were very conservative parent groups who were, you know, very well organized, very well financed who absolutely-- fought it. And-- as a result, there--

(OFF-MIC CONVERSATION)

CATHY COSTANZA:

Article XII-- yeah. Well, it w-- it would recognize the rights of all individuals to have legal capacity. And that was something that they just could not tolerate because they thought that it would challenge their ability to continue as guardians for their own children.

So-- we've-- we've had-- w-- I would say that in our pilots-- we've had a lot of very positive, wonderful things happening. Not surprisingly-- when someone is no longer under guardianship and their full personhood is allowed to emerge-- you know, great things happen. And people really are full participants in their own lives and they feel very empowered and-- rightfully so.

So-- you know, we've really seen this metamorphosis of a number of the people that we've worked with. In the United States-- there are eight states and the District of Columbia that have-- legislation now where a law has been passed around supported decision making that recognizes it in the law. That's a good thing. Those laws are more or less good.

And, you know, where the rubber really hits the road is are they gonna be implemented? And what is it gonna look like? And is it going to, you know, just be like a fancy new version of guardianship dressed up to look a little differently?

So those are all the things that we really see as challenges here. One of the things we've done I remember-- you know, we see that there's this huge issue of trying to rule out the idea of supported decision making across the entire country, or even the entire State of Massachusetts, which is not even that big.

And w-- the-- you know, there's a limited utility of just doing pilots. We've worked very closely with self-advocates, with families. We now have the government very interested, the government agencies, in working with us to think about how to expand the idea of supported decision making.

But we've put a lot of our resources recently into developing a training and technical assistance center. And to-- we have a-- great website dedicated to supported decision making. I'll-- welcome you all to look at it and get feedback from you about it. But-- it talks a lot about the successes, what we've learned, what we need to learn, and the challenges ahead.

I think-- just one last thing to note: I think the political context of the U.S., like probably every country, has to be taken into consideration. And right now it's pretty ugly here. And the realities are, you know, that there's backlash against people with disabilities because we don't wanna do anything about gun control, so it's easier to blame people who have psychiatric-- labels attached to their names and to their lives.

And so-- the-- you know, I think those are the kinds of things that are now resulting in, you know, this move toward institutionalizing people more. And I'm sure if that's the case, it will be stripping them of rights in other ways. So that's probably enough.

TIRZA LEIBOWITZ:

Thanks, Cathy. I ju-- I just wanted-- thank you. I-- I know that we have some colleagues listening to the-- to this-- event. We heard Latin America. We heard United States. Just to say-- and also for some of you who are working in other countries from Open Society.

In some places, guardianship may not be the issue so much, although guardianship-- provisions exist almost all over the world. But in many places, it's-- it's the way community is arranged. It's-- sometimes it's informal arrangements. Sometimes it's just the ability to go to court and sideline a person with disability. And we have a colleague from OSISA-- from Open Society Initiative in Southern Africa, who is leading some work in that region around this category of "unsound mind" that exists in many countries. Under which people then cannot run for office and many other things.

So this-- this notion that a label brings about some form of taking away very, very basic rights is something that we're seeing around the world. And it may take different names or different forms in different countries, but it's something that we're-- we're-- we're trying to understand in ea-- in each context: What's-- what's the root there, and ad--advocates are trying to address.

I want to-- open up just for questions from-- from the audience. And I see already hands raised. I just want to say we'll collect a couple of questions, and I also invite colleagues that don't work on disability necessarily, either within Open Society or outside, but do-- are in the-- in the business of human rights: If you have any reflections, if this-- what you've heard and what you've learned-- does it connect in any way to your-- to your work? Does it-- does it, you know, resonate in-- in any way? Do you find it useful in any way for y-- for how you're thinking about your field of work? It would be great to hear th-- that, as well. So let's collect a few questions. Is that Tony back there? Yes, hi, Tony.

TONY:

I have a question. What is the (UNINTEL PHRASE)? Everybody here wears glasses. What is the difference? Is it that (UNINTEL PHRASE) at the person. I should have the same rights as everybody else, no matter what. Okay, I'll (UNINTEL PHRASE) taking decision making. Number one, I'm working on (UNINTEL). Number two, I am certain (UNINTEL PHRASE) an agency money making project. Decision making: I don't want it to be a money-making project for the agency. But I'm saying I don't want it to be used (?) as a goal (?).

TIRZA LEIBOWITZ:

So-- Tony, can-- can I-- I think I kn-- I underst-- I know what you're referring to, or I can say the concern that you're voicing is some-- is some-- is something that we also struggle with. If I understand you correctly, you're pointing at the risk of supported decision making projects to become a-- money-making mechanism? If I understand correctly some-- or if I may add, something that may be artificial, not reflect how people actually make decisions or be a way to do other things? Is that what you're referring to?

TONY:

Right. Right. Everything that we know is about money making. Even if we go to the bathroom, (LAUGHTER) they will make (UNINTEL PHRASE). (LAUGH) And I think it's ridiculous. If we are human beings, just like you, why do you use us to make money? Why can't we get a regular job like you? Why can't we get paid like you? When we go to the store, we don't get nothin' free. They ask us, "Do you have money?" (UNINTEL)-- come on.

TIRZA LEIBOWITZ:

Well, Tony, I want to keep your question in-- in this room. I want it to-- to hover. I-- I want to see-- people may want to address. If not, I can share some of our dilemmas around what you're raising. So let's-- let's collect one or two other questions an then get back to the--

QUESTION #2:

Good afternoon, I'm from the U.N. Partnership on the Rights of Persons with Disabilities. The Partnership basically supports U.N. country teams at the field level to implement the Convention on the Rights of Persons with Disabilities. And of the four (?) 39 countries that we're currently supporting projects in-- there's currently work going on in Serbia, and previously in Moldova, around legal capacity.

So I just wanted to share a little, because you asked earlier about what's happening elsewhere. But also really ask a (UNINTEL) colleagues-- in Latin America what their experience was, which hopefully we might be able to take back and share with our colleagues in the field.

So in Moldova, actually the work was very closely linked with the process of de-institutionali-- -lization. Which was basically moving people-- giving them the right to live in the community with their families-- like other persons in their family. And because of all of the abuses, the human rights violations that were happening in institutions, and because people in institutions did not really have the right, or the legal capacity-- they were not re-- really able to go to court or to make complaints.

So the processes were quite parallel. The advocacy that led to the de-institutionalization was also the advocacy that ensured that legal capacity began to be recognized-- as a result, of course, there was an independent monetary mechanism to, you know, over-- oversee the violations that were taking place. And people could go to court. Following the legal capacity reforms that happened.

We were not able to go all the way. And this was from about a year and a half ago, which was when we have the last reports from. But they did reform the civil court. And each and every case of guardianship had to be reviewed and allowed by the courts. So it did open up the whole process for appeal.

But what we saw was, as a result of this, it wasn't just about legal capacity in a court, but about participation. The people went to court if they were not allowed admission in their neighborhood school, and received damage and received-- received-- decisions that helped them to participate in other areas of life. We're currently also supporting work in Serbia that's looking to revise the family law. Which is the basic-- the (UNINTEL) law that governs legal capacity issues in the country. And my question is related--

(OVERTALK)

TIRZA LEIBOWITZ:

Okay, go ahead.

QUESTION #2:

Yeah, and my question was related to colleagues-- who spoke earlier. And what we're finding is, of course, parallel to the whole legal process that the U.N. is supporting other partners to work on, is how do you build a robust movement of self-advocates?

Because we're talking about societies that have traditionally not had any participation or any legal capacity, where parents' groups are still very strong. So how did you-- what was the s-- what was the factor that enabled success in that regard?

TIRZA LEIBOWITZ:

Okay. Let's-- let's take one more question? Please, Amar.

AMAR:

I am-- Amar, I work at-- Open Society U.S. Just-- just want to say in terms of-- you know, you had asked, Tirza, how-- what we heard here might resonate with work for folks-- who don't necessarily work on disability rights. I just wanted to share that when I was an advocate-- an organization I worked with-- for created an app-- a ph-- a phone app to allow-- members of the Sikh community, the faith community in which I belong to, to file complaints-- that were accepted as official complaints by the Department of Homeland Security if they're accusing-- the Department of-- profiling.

And-- and what we found when the app was released, in addition to the Sikh community, the two populations that were using the app the most and filing the most complaints that the Department of Homeland Security then had to respond to officially, were-- 1) women complaining of-- gender discrimination, and then second was-- folks with disabilities.

And then when we released the second version of the app, we worked with-- advocates-- who focus on those-- both-- both those communities to adjust the questions the app would ask to take into account-- the rights of-- of women and the rights of folks with disabilities. And that's just my way of saying that as we sort of-- this week at OSF, think through-- our commitment to disability rights and inclusion-- you know, that it'd behoove all of us to make sure, as we do all our rights work, that we-- bring everyone along.

It was-- it was a real learning experience for me just creating the app-- to see that we hadn't accounted for-- the rights of every we could have accounted for in putting that out into the world. So thank you for this forum, and-- it's been a real great learning experience.

TIRZA LEIBOWITZ:

Thank you. So-- so, Chris, we'll hear you. And then I'm gonna appoint just a couple of people to give short answers. And we'll wrap up. So, Chris, please?

CHRIS:

Since you mentioned New York-- this is by way of information-- we have a very robust pilot project in New York. I think it's, to date, the largest project in the country. We've enrolled over 100 people in the last three and a half years. We are moving towards-- beginning to plan for legislation and also hoping that New York State will adopt this-- system that we developed for facilitating and enabling people to use support to make their own decisions in their own lives. Both to get out from under guardianship, but also to persuade parents and others who might be seeking guardianship for transition-age youth.

So if people are interested in what's going on in New York, we are SDMNY, s-- Supported Decision Making New York. We have a website. But what I also want to say is that when we started this five years ago-- and-- and began to try to think about what kind of a facilitation model we wanted to use-- we were emboldened and-- and enlightened and supported by the projects that OSF supports around the world, particularly the folks in Bulgaria, in Kenya, and in the Czech Republic.

And we have learned so much in the international-- communications and support and sharing of-- of-- experiences has really been incredible. And we are so excited and thrilled by Peru and by Colombia. Every time I go to an information session with parents or others now-- and especially with the young people who we call "decision makers," the people with intellectual disabilities: Knowing that they are part of a worldwide movement is an incredibly important thing for them as well. So I wanted to thank you for that, and let people know that we're here in New York. And if you want to talk to us and help us, that'd be great.

TIRZA LEIBOWITZ:

Thank you. And I'm-- I-- I want to s-- put, actually, Luhan on the spot-- to address some of the tougher issues here that we heard in the room. There is an inherent tension between finding a system of support and decision making, right? When we make decisions in our lives, we-- we just do it. We-- we go and we ask people for-- we all actually get support in decision making. But we just do it, and it's not written in law, and it doesn't have procedures. So that's on-- that's on the one hand.

And now we-- we're m-- trying to mimic that and to just enable equal rights for everyone. And it-- yes, there is a tension there. Because suddenly it's kind of quantified in law. And I just want to point out that in Peru and in Colombia-- contrary to the United States, the United States is not there yet. There-- there is progress, but the United States has not eliminated taking away legal capacity, which Peru and Colombia have pretty much eliminated.

But they went as far as kind-- of saying, "If you want support, you ask for it," right? Now, some people feel th-- at least their advocates feel left out. "What if I don't know how to ask for support?" So we have a-- we have a tension between full-- you know, full rights, and how does that look, and not leaving anyone behind. And I just want to ask Luhan if you have any thought about that-- the tension that Tony brought up f-- th--? Yeah.

LUHAN:

Yes, I think it's broader than what Tony-- mentioned. Obviously, I think that there's a real danger of creating the supported decision making model to believe as that's the only way that we can guarantee people legal capacity. That becomes a-- threshold: For anybody to have legal capacity, you have to have support.

And I think that's a-- that's a real challenge for a lotta people. And, you know, for a lot of the deci make-- decision making that we're doin' in life, sometimes we need support, sometimes we don't need support. Sometimes, you know, support is welcome, sometimes it's part of the paternalistic environment that's confining people.

So I think, you know, there's a real tension there in terms of promoting supported decision making, how we explain what it is, and how we say that that's only one framework that we can-- we can use to look at decision making. And there's a broader-- concept of decision making.

And I think there is also-- I mean, I work in Asia around-- the subject of legal capacity. And there, I think, a lot of the emphasis is on perhaps developing more tools. If we have advanced directive written into our laws, perhaps we can make use of that.

Of course I think that's all very helpful. But I think it's also important for the disability movement to be able to come up with a narrative, and to talk about decision making, and talk about legal capacity beyond these tools, beyond the technical-- interventions. And to say what exactly it is, and how can these technical-- advancements help? And sometimes maybe they provide further limitations if we don't change the overall atmosphere.

TIRZA LEIBOWITZ:

Thanks. I'm reminded by-- Claudia what you said about-- something about being human and the dignity that comes with it, period. Right? That's--

CLAUDIA ZAPATA:

Si, si.

TIRZA LEIBOWITZ:

I just want to end just with the one question about-- which I think is an important one for all us-- about self-advocacy. Whomever-- whoever asked here about how do you-- how do you do more of that? So I don't know if there's one short intervention that one of you-- I see-- on-- on self-advocacy specifically: What does it take to get more-- of-- of that? Juliana, do you want-- very short.

JULIANA BUSTAMANTE:

Hell-- hello. Hullo?

(OFF-MIC CONVERSATION)

JULIANA BUSTAMANTE:

Maybe this? Hello? Yeah. Well, hello: I'm Juliana Bustamante from Pais in Colombia. And-- I just want to mention a quick-- thought about-- self-advocacy. What we find is that having organizations empowering people with disabilities, like in Colombia, was as (UNINTEL) and Pro Familia on legal-- on sexual and reproductive rights.

As long as-- these organizations I know (?) are experiences that seeing these organizations talking to persons-- to people with disability, teach them how their leg-- what means to have legal capacity, and-- teach them how to be-- empowered and how they can-- become agents of change and of decision making, they become multipliers of the message.

So I think it's a lot of work from the-- base, social base, from organizations, that have been. And that's the same case in-- in Peru-- being able to-- come together with the people with disability, talking directly to them and be-- and turning them into facilitators like Claudia and-- into multipliers of the message of legal capacity, empowerment, and human rights for people with disability. That's the key.

TIRZA LEIBOWITZ:

Thank you. An-- anything that-- I'm gonna actually-- we'll end by this. I'm gonna put you, Patricia, on the spot, if that's okay? Because you're now support for-- supporting Karin in this-- panel. But you also work with families. And if you can say one thing that is difficult for families to do that you work with them to do to-- ar-- around self-- ar-- around family members to take more autonomy, just-- maybe the biggest challenge?

PATRICIA ANDRADE:

Uh-huh (AFFIRM).

(FOREIGN LANGUAGE NOT TRANSCRIBED)

PATRICIA ANDRADE VIA INTERPRETER:

What we have done is-- like with-- Karina's mother, we have taught her that, yes, that Karina can make her own decisions, that she doesn't need someone else to make decisions for her.

(FOREIGN LANGUAGE NOT TRANSCRIBED)

PATRICIA ANDRADE VIA INTERPRETER:

(UNINTEL) with families, people-- professionals, they let 'em know, "You really don't know how it is to have this fear, or the-- the person you're guarding to-- for them to make their decisions, or not being able to."

(FOREIGN LANGUAGE NOT TRANSCRIBED)

PATRICIA ANDRADE VIA INTERPRETER:

The strategy's always been family speaking with family, judies speaking with-- judges, attorneys speaking to journ-- attorneys, so that everyone's more aware of this topic.

TIRZA LEIBOWITZ:

Thank you. So I think we're gonna wrap up. Just to-- and then to leave you with the complexity of the issue. One thing that we're also struggling with around the question of, let's say, "self-advocates": We often speak about us empowering self-advocates. And I think the real power will be when we-- we just-- we-- we don't do it for self-advocates. It's-- they, you know, people do what they do. Which is speak up for their rights.

I w-- want to thank-- all of you f-- and especially-- those of you who

(UNINTEL) a story that was your individual story, and you turned it into an issue that is relevant to many people. So thank you for joining us, and thank you. For everyone, I want to just end with a poem by Cavafy, the Egyptiate (SIC) Greek poet from this century, from the 20th century.

"Walls without consideration, without pity, without shame: They have built great and high walls around me. And now I sit here and despair. I think of nothing else. This fate gnaws at my mind, for I had many things to do outside. Ah, why did I not pay attention when they were building the walls? But I never heard any noise or sound of builders. Imperceptibly, they shut me from the outside world." It sounds pessimistic, but it's-- walls are built. They're not inherent, they're built. And we can take them apart. Thank you. (APPLAUSE)

* * *END OF TRANSCRIPT* * *