Bringing an International Lens to Domestic Disability Work

Host: Rebecca Martin

Featured speaker: Luhan Gable

- [Rebecca] Good morning, everyone. Thank you for being with us today. It's lovely to have you here. I'm going to take a moment just to spotlight our interpreter, Amanda. Thank you for being here.

And also our special guest, Luhan Gable, who's here to talk about disability rights in an international context, particularly focusing on some projects in Taiwan and Mexico. I'm very excited to have her here today. My name is Rebecca Martin and I'm with the grant facilitation team here at Rutgers University, Edward J.

Bloustein School of Planning and Public Policy. And we're really excited for this conversation with Luhan today. And I think she's going to give us some enlightening perspectives that will help us bring an international lens to our domestic work and expand our perspectives today. Before we begin, I have a few housekeeping notes. I just want to let you know that we will be recording today's training.

We have enabled captions for the event and the ASL interpreter has been spotlighted for all users as well. There'll be time for questions and answers towards the end, but also throughout the conversation today. If you have any questions that you would like to ask, feel free to use the raise hand function or to put any questions in the chat and we will bring them up for you.

And then at the end, you can also unmute to ask questions yourself as well. And then finally, before we get started, I just want to take a moment to express our deep appreciation to Peri Nearon and her team at the New Jersey Division of Disability Services for making this training series and the IHC grant program possible. So without further ado, we'll get started.

I'm excited to start this conversation with Luhan Gable. Luhan, thank you for being here today. Would you mind by starting us off by telling us a little bit about yourself and the work that you do?

- [Luhan] Thanks, Becca. And hi, everyone. So I'm Luhan. I am an associate director with Open Society Foundation's Ideas and Fellowship Collaborative. Prior to my current role, I worked for OSF for over six years as a grantmaker. So for a long time, I was working on disability rights in a global context.

And I can tell you guys a little bit more later. And I've also worked on supporting democratic movements in general in China, Hong Kong, and Taiwan prior to the disability work. But more importantly, I actually worked as an OSF grantee in Beijing for about nine years at a disabled persons organization.

And I started in 2008 as a young person, really just kind of interested in radio and interested in podcasts. And I found a group of young people around my age, people with disability, but they run their own radio show.

And so I started working with them on editorial meetings and really trying to kind of figure out what shows that we want to put out. And then started from there to kind of develop a fuller programming and organization as a disabled persons organization and supporting other people's other organizations across China and also working with parents and service organizations in China.

And I think that's how I started getting to know the disability world. And, Becca, do you want me to maybe say a little bit more about what I did with OSF on disability?

- Sure.

- Okay. So a lot of OSF disability portfolio, we no longer have it, sadly. The years that I was working on it, we separate different work into different concepts. So there's one concept around working on inclusive education. And I've had work in Nepal and in Georgia, Georgia, the country.

To work on inclusive education, to promote inclusive education in those contexts. And there's also a huge part of work that's on legal capacity. So making sure that people with disabilities have the equal right in front of law with similar to other people.

And so that we have worked on legal capacity law reform in a range of different countries, and particularly in Latin America. So Peru, Colombia, and Mexico in the past few years, all passed legislations to guarantee legal capacity for people with disabilities. And that's kind of the outcome of a long-term support and a whole range of movements in those countries to advocate for that.

Obviously, there's still a lot of shortcomings and where does law meet practice. Those are kind of a separate piece of question that I can address later. We've also supported practices of peer support in different spaces. Trying to figure out what contacts people would find peer support particularly useful. And to support people with disability develop their own models of peer support, whether it's in medical context, or it's between students at school or universities, or in terms of practical support in the community.

I've had the privilege of working very briefly on kind of initial stage of investment in some of the organizations in the U.S. that work on alternative communications and work that support the rights of AAC users. And I really I still believe that that's a really important piece of work and it tells us a lot more more than just how do we provide good services for people with disabilities, but more about challenging our kind of traditional way of thinking about communication and respect.

So that's something I'm personally very passionate about and interested in. We also have a huge pot of work on criminal justice. In particular, we've basically pulled together some over 30 different organizations across the world. Some are justice reform organizations.

So for example, organizations that work on death penalty litigations or organizations that work on general criminal justice reform, and there are also other groups that we supported that work on disability. And we found that a lot of these groups have common interests and common challenges. So we figured we'd put them together to form a hub and then they can co-create a lot of knowledge together and we'll all benefit.

And I can say more on that later when I talk about Mexico in particular, because Mexico is one of the kind of the more involved countries within that hub. And lastly, really just kind of general support for the disability movement in different contexts and globally. And I think that there are a lot of lessons, a lot of lessons learned for sure what it means to support a global movement that's made up of country-specific movements and contexts.

But I can say a little more about that later. And much of that movement support is on supporting the most marginalized within the disability community. So that would be organizations run by people with intellectual disabilities, people with psychosocial disabilities or user survivors or psychiatry, depends on how people identify in different contexts.

But also women with disabilities. And that's something that we paid extra attention to as well. So that's really me and my past work on disability. I don't know if people have any clarifying questions or Becca, do you want to move on to something else more specific?

- Does anybody have any clarifying questions that they want to ask before we go on? I feel like there are so many things I'd like to ask you about with what you've brought up already. But I'll let you get into some of your specific topics and then we'll circle back to some of these things if you don't touch on them, okay?

So I guess before we go too deep into the conversation, I'd like to orient us because I think that a lot of the people on the call today are focused primarily on more domestic work on disability. And so I would like to talk a little bit about sort of an international context. I don't know how much background people have in terms of how laws may be different or similar or kind of orientation internationally.

But what do you see as the benefits of sort of taking an international lens to the work that we're doing here?

- Yeah, I mean, I think if I go back to the beginning of how I got into the work on disability many, many years ago. Like for all of us working for a disabled person's organization, it was quite a challenge to figure out what that really means.

And I think for most disabled people's organizations, you start with people who are interested in something, same thing. And then you start, sometimes it's arts, sometimes it's theater, sometimes it's radio programs. But you start working together and you start to kind of develop an identity. But it's really difficult to make the leap from a self-help group or a mutual support group or an interest group to an advocacy group.

And I think in that process, it was really key to have an understanding of what others are doing outside of our own context. I remember, you know, sitting down together with my friends working at the radio station and taking a look at the UN Convention on the Rights of Persons with Disabilities.

It was a really kind of enlightening experience. And people all of a sudden will feel like, okay, we've talked about all these things in kind of ordinary terms or randomly, but we've never theorized. And this is a document that kind of speaks to people's personal experiences and their the kind of situations and discriminations that they face in their daily context.

And so having the document, the content itself was really, really kind of valid. It shows that our feelings, our experiences are valid. And it's not just about the

special context about China, that China's not doing great. But there's something about our understanding as a society about disability, the awareness is not there, and therefore people are experiencing challenges.

And that was really helpful. And on a practical level, I think obviously this is not incredibly relevant to the U.S. because the U.S. has had a hard time ratifying the CRPD, the Convention on the Rights of Persons with Disabilities at the UN. I think I want to say it was President Obama tried and almost got it.

And that eventually didn't go anywhere. But in China, because the Chinese government in back in 2008, about the time when I joined this work was really eager to host the Olympics in 2008 in Beijing. And the condition at the time was that they would have to host the Paralympics right after in order to host the Paralympics.

The condition is that China has to ratify the Convention on the Rights of Persons with Disabilities, which the Chinese government gladly did without actually reviewing any of the articles. So no reservation on the CRPD, which is quite remarkable. And we were able to, because China is a member state of the treaty, we as civil society were able to use the Convention to advocate for our cases.

This is both as kind of the review process in terms of for the civil society, for ourselves to learn about how you negotiate with the government. And sometimes it will be things that we will negotiate with the government outside of the review process, but then we'll feed information to the review committee so that they will ask the question that we want to ask the government.

So there's a really interesting process that we were able to utilize. And the concluding observation that the committee would eventually give to the government will be somewhat in line with what we're trying to advocate for. So in that sense, having the international community is helpful. And China, although has ratified the Convention, did not ratify the optional protocol, which is an additional piece that allows individuals in that particular member

country to bring a case to the CRPD committee, which I can talk about later in the Mexico contact, and they were able to utilize that.

So these are more kind of legalistic benefits, I guess, and kind of having the international community having the UN backing you as civil society in a country that civil society is not always not respected most of the time and face great danger in terms of operating most of the time.

And that was really helpful for us. And I think in general, it is helpful to be in touch with other practitioners and movements in different places and different contexts just to exchange and compare and contrast to kind of understand because I think a lot of the challenges within the disability world are very, very common.

And, I think Harvard Professor Michael Stein once said at an early stage, when it comes to disability, every country is a third world country. Nobody is really doing that great. And obviously, some countries have better practices, some countries are improving a little faster, but we're starting from a very, very kind of low place in general everywhere.

So it's useful to compare strategy, it's useful to compare what are the manifestation of disability based discrimination look like in different contexts, and how do we deal with them in different places. I think that's kind of what I think is important. I'd like to hear from you guys really because you're here.

So you must think hearing something about Taiwan and Mexico would be useful for you, much rather to kind of speak to those specific substantive engagements.

- We do have a comment from Barbara Coppens, and she says that we need to have the CRPD in the United States, and she's been advocating that for a long time. And I agree also, I think what you were saying, Luhan, the first time that I read the document of the CRPD and got exposed to it when I was living in Hong Kong, I think coming from a U.S.

context, we often think that we're sort of the leaders of human rights kind of things in the world. And it was really eye opening to me to see that in an international context, maybe the ADA inspired a lot of what happened with the CRPD, but the CRPD took it to a different level that I think has influenced the trajectory of things in an international context.

And part of why I'm so interested in the work that's being done around the world, and bringing that back to reflect on the United States, like in the work we're doing here, is because I think that this kind of cross-cultural movement that is happening, oriented to the same guiding principle document, really allows for innovation that we're kind of secluding ourselves from here.

And that sometimes getting that exposure can really help us to break out of the boxes that we put ourselves in, and kind of our perspectives on how we look at these problems and the solutions to these problems.

- Yeah, I think just another word on the CRPD, I think the ADA in the U.S. is quite good. But like you said, Becca, I think CRPD really takes it to the next level. I was just thinking about it yesterday. R.A. Nyer, former president at OSF, had an event last night where he kind of talked about his, he has an oral history project that's going on with Columbia University.

That's what the event was about. But during the Q&A session, one of the audience members asked him a question, what are kind of the biggest failure that he think that he has encountered during his lifetime? And he actually brought up the rights of people with psychosocial disabilities.

He felt like he wasn't, he didn't do a very good job, or he didn't do it enough. I think it's interesting because in the end, the conversation goes into the limitation of a rights process. And we can talk about that a little bit more. But he was talking about when it comes to disability, just having the rights process is not enough.

The human rights process maybe is not enough. And there has to be a lot of kind of extended thinking about what it means to have economic and social

rights and what it means for people to actually live together. What is the new kind of social relations we have to build?

And that is a lot of that is in the essence of the CRPD, and is waiting to be further interpreted and mined and talked about. So I think it's an incredibly radical document. It talks about agency with support, right? It talks about what it means to meaningfully engage and live in the community, and to communicate meaningfully and have respect.

And a lot of these things are, I think it's in a very basic sense, it's different from the approach of the ADA.

- Thank you. So Octavio has asked for the opportunity to ask a question. Amanda, would you be able to assist with that, please?

- I just have to find him.

- Will it help for me to spotlight him for you?

- Yes.

- Or spotlight him? Okay.

- [Octavio] Hello, my name is Octavio. I'm president of the National Hispanic Latino Organization for the Deaf. And I wanted to discuss a little bit about contact with the Native, the World Federation of the Deaf. Are you familiar with that?

I've met a lot of Latin American centers that struggle with interpreters, getting for deaf and hard of hearing people, also setting up programs for them, teaching babies, zero to five ASLs, exposing infants to sign language, everything internationally. And most of the countries are very behind.

And maybe the higher-ups are ignoring these kinds of situations. So then it kind of spirals from there. How can we apply that specifically to deaf and hard of hearing or other disability groups? And do you have any resources for that?

- I don't have a kind of official affiliation or a relationship with the World Federation of the Deaf, but I do know some of the people who work there. I'm happy to connect you afterwards if that's useful. And I work much more closely in terms of the deaf communities in different specific contexts. For example, in Nepal and in China, those are the two places I've personally have connected with deaf communities and funded their work.

And I'm happy to, and in Taiwan as well, and I'm happy to connect you with people if you're interested. I think one thing, my experience about working with the deaf community is, especially from my OSF capacity as a grantmaker working for a human rights organization, is that the deaf organizations often ask for very kind of social, with a social orientation, those kind of projects.

People ask for kind of very early on reaching out to families with deaf children and talking about early education and talking about communication. And I think a lot of times, other than... For a human rights organization, we don't usually touch on that unless it's a technical problem when it comes to inclusive education or it's a problem when it comes to criminal justice procedures.

And I think we, in my mind, we need to kind of start way earlier to think about how to build awareness in communities and even to kind of start, to really start thinking about broad-based education for sign language, for children who are deaf and children who are not deaf, and to build community base for just, as a second language, right, for people to have it and to be able to communicate with other kids of their age.

So that's something I feel like there should be much more work on, rather than kind of limited work on just in the classroom or just in the courtroom. So that's... Happy to communicate a little bit more, but that's my learning from my own experience.

- Yes, I have been learning about international and what they have availability and support for that and doing events.

And I hope to have future collaboration with the Latin American Center in the future. Thank you.

- Yeah, I can help you find out if there are other people to connect with, because the ones in Taiwan and in China, definitely, and Nepal, they definitely have their own international partners. I'm not sure if it's in Latin America, but definitely is throughout, say, Southeast Asia. So it will be an interesting, let me look into it and maybe I can connect you with some people or some organizations.

- Great, thank you.

- Thank you. Okay. All right, Luhan, I think we will move to, I guess, our next question was going to be, this might be a little bit of a shift, but in terms of strategy, how had your views changed throughout the years working in the fields of disability?

Did you want to talk about that?

- Yeah, I mean, I can share that kind of in general throughout the conversation. But I think if there is one thing that I have learned is really trying to figure out how to translate disability rights from laws and conventions and principles into practice. And I think that's the biggest challenge the disability movement face everywhere, right?

And there's rights on paper and the rights that's pronounced in law, but it's not really happening in everyday lives of people with disabilities. And they're like, rather than spending a lot of time to focus on rights processes, I think more time needs to be spent on really changing practices and changing community attitudes and changing minds and hearts.

And that actually means really engaging with people in other spaces and people in other movement and people in the community. And that to me, how do you translate these principles? I think is the hardest piece. And I can talk a little bit about that in the two examples in Taiwan and in Mexico.

- Okay, so let's do that. Because I'm... Our grant project is very much about policy systems and environmental change. And we see that as a way of also shifting culture and making changes that impact people's perspectives, culturally as well.

So I'd like to hear about these different projects that you're talking about in these different contexts. So should we start with Taiwan or Mexico?

- Either one, it's up to you.

- Whichever you like.

- We can do Taiwan first.

- Okay. So can you tell me about the context of this? This is about independent living, correct?

- So the organization that I had in mind to talk about is an independent living center called the new vitality. So the new vitality is one of the, I think, nine different independent living centers across Asia. So there is this really helpful foundation in Japan, the Sasaki Foundation, that they have set up together with independent living center in Japan, these kind of mentor programs.

So they would have these kind of mentor programs in Japan, and with fellows coming from different parts of Asia. And these fellows will stay for, I think, two, three months at a time in Japan, and do really in-depth work with the independent living in Japan.

And then they will be going back to their own country with a little bit of seed funding to set up their own independent living center. And it has been really successful in quite a few countries across Asia, and Taiwan being one of them. Yes?

- Can I just have you tell a little bit about what independent living looks like in Asia? Because I'm not sure if it looks the same as it does, the movement would look the same as it does in the U.S. And I just want to make sure that we're kind of all thinking of it in the same way.

- Yeah, it's interesting, because there might be, you should tell me what you think independent living movement look like in the U.S. There might be some differences. And I think in Asia, it's interesting, because a lot of these independent living centers starts with kind of the concept of living with support inside of the community.

And they're very, very adamant about people shouldn't be living in institutions, however much support that they might need. So it comes from a very kind of abolitionist perspective in terms of people shouldn't be in institutions.

But and then if we say people shouldn't be living in institutions, and they should be living in the community, then how do we provide adequate support for people to be living in community, not to just function on a daily basis, but really to participate in society in a meaningful way. So the Taiwan Center, for example, I think this is true for a lot of the independent living center across Asia, that they started with really trying to legislate specifically for personal assistant and practical support.

So in Taiwan, those are separate. So daily support in terms of having people help you dress, or help you get out of bed or to take a bus, right, these are the daily necessity of support. And there's a separate piece that's about personal assistance.

And those are the people who would be hired by mostly by the government, their independent and private business out there in Taiwan as well. But mostly it's, it's guaranteed after 10 years of advocacy of the independent living center in Taiwan, guaranteed hours by the government to provide personal assistance.

And so this service is for you to be able to access social activities, whether you're going to work, someone can help you prepare your PowerPoint, to make formats accessible if you're attending a meeting. So all of these things that relating to your engagement with the society and with the community. I think it's, I mean, that's kind of the basic demands of the independent living center across Asia.

And in the Taiwan case in particular, you know, they had a, it's interesting because Taiwan also has a really strong and vibrant human rights community and with a group of human rights lawyers who are very interested in disability rights issues.

I mean, in the U.S., there are lawyers and human rights groups who are interested in disability topics as well. And so they started with putting personal assistant and practical support into law and to have the government guarantee certain hours.

And I think it was maybe two years ago when they had a case of women with, with support needs that the, I think the 60 hours per week of support, including practical support and personal assistance, couldn't meet their, her demand. And so the independent living center, New Vitality, brought the case together with the plaintiff to the new Taipei government and to kind of argue for more hours.

And eventually they were working with lawyers, they're working with the press, and eventually won the case. And it was really interesting for me to see that whole process, because they didn't stop there, right? And then they go in to arrange for a whole series of sit down meetings together with the government official who were just been taken down in the courtroom and service organizations that the government contract with, and to try to figure out what is preventing the government from saying, agreeing to more hours, because they have their reasons, right?

That they're saying, this is going to bankrupt us. We don't have that much money to support if someone asks for 120 hours a week, how do we deal with that? It's not possible. But since they're struck down in the courtroom, they had to come to the negotiating table with independent living movement.

At the time I was visiting Taiwan, this was earlier this year, and they invited me to some of these meetings, which is fascinating, just to see people with disabilities and their representative groups, service organizations who are contracted by government and government officials sitting down together to

talk about specific cases and use them as an example to say, how do we set the standard for how these kind of services would be provided?

And what are the ideal situations? And it's not necessarily have to be, okay, we're searching for consensus, and each side would have to take compromise. A lot of times, what I found, what was discussed in those meetings, were what are the kind of inherent flaws of the social service structure, right? For example, if a social worker has to kind of visit, does her round in different households, and each household is kind of billing for one hour, but in reality, they might just need a 10 minutes visit.

And that makes it really difficult for the social worker to budget, and she can't budget for just 10 minutes, because it's not worth her time, right? So there are a lot of these kind of contradictions within the service industry, and the service arrangement that the government is providing, and they were able to work out really creative solutions.

So that's what I felt like was really interesting. So it's not just these independent living centers won a case, and we just kind of demand something from the government, but really come to the table and become the solution provider, and to improve on the service sector, and improve on government planning as well. And that eventually will benefit whole other sector of the population in Taiwan.

Taiwan, as many other East Asian countries are, massively, quickly aging. So there's public demand to figure out what it means to have long term care in the community for the elderly, rather than sending people to nursing homes in Taiwan.

I think right now we're still looking at 93% of people with disability, that's including elderly, still are supported in the community. So it's not a common practice to send people to institutions, but you would always want to guard against that, unless governments start to think this is the easier solution.

So to me, that the independent living center and how it works in Taipei is a really, really, really interesting example of people with disability and their organizations can be involved in advocacy to improve their own lives and improve on general government processes.

- Can I ask a quick clarifying question and then a follow up question for this? So the clarifying question would be in New Jersey, we have kind of a legacy of group home kind of living situations for a lot of people with disabilities that we tend to kind of see as being community dwelling or independent living in a lot of ways, right?

Because it's not institutionalized and people are free to exist in community and they have more agency within community. But I just want to know whether there's, if there's something that is equivalent to that in this independent living in Taiwan, or if you're saying that all of the people living in community in Taiwan are living like, not within these kinds of group home situations to consolidate care.

- Yeah, group homes definitely exist, but it's not a kind of institutionalized way of dealing with the challenges to living in community. And group homes shouldn't be a solution for people to genuinely having a life in the community. And I think the independent living center, at least the ones that I've come across in Asia are very, very serious about their commitments to what it means to be included in community and what it means to really engage meaningfully with others in society.

And I think people, sometimes some people would say, it doesn't matter if you call it a group home or institution, or a psych ward. I want to know, can I have a bowl of ramen noodle at 2pm, if I wanted to. And if I can't do that, then maybe, maybe I'm living in an institution.

It doesn't matter what you call it. So all of it kind of comes from the idea of agency of individuals, right? I think this is also a conundrum when people talk about getting people out of institutions, it doesn't matter whether it's officially called a group home or an institution.

There's always, people always talk about the process of getting people out of institution, but there's never really enough attention paid to what do people want? Where do they want to go? And do they want to go anywhere? And so that kind of consultation, and that process of communication and figure out what are the options and what do people want, usually just never happens.

We just have this kind of arbitrary kind of from outside, of definition of what institutions are look like, and we should get rid of them. But rather than asking people whether this is the living condition that they want, or whether these are the people they want to live with, right?

And also present multiple options for people to be able to choose from. And I think another thing maybe is a little bit special about Asia in general, is that the sense of family responsibility is very strong. So a lot of the care burden is on families.

And it depends on where you live and what your kind of social status is, right? And I think in a place like Taiwan, you could easily, for someone who's more well off, or the family is more well off, you can hire a migrant caretaker.

And that's something that people have been utilized to supplement the kind of the gaps in what needs to be provided in the community as well.

- Thank you. I want to be cognizant of time, because we also want to talk about Mexico. Does anybody have any questions they want to ask about this before we move on though? Barbara says we need the home based community service, get the waiting list down to the curb. And Joy had asked, what have you found to be the primary obstacles to changing hearts and minds in Mexico and Taiwan?

- Yeah, I think that there are always things that are easier to change hearts and minds are inclusive education is usually the kind of easier one, especially in any society, when you're talking about what do we do with children, people feel like, of course, we should utilize all resources for children and their education, although there's still a lot of shortcomings on that.

But I think, probably similar here in the U.S. and in many places, once you become an adult, that kind of social acceptance and willingness to use government resources or community resources for people with disability to provide support for people to engage drops dramatically.

I also feel like this is just me thinking back on my role in the disability movement myself, a lot of times we spend a lot of time to doing kind of legal advocacy, doing kind of government related advocacy, but haven't done enough on really engaging with practitioners with other minority groups and with others in the community.

For example, what Octavio asked the question about the deaf community, I think that there's one thing that I learned from the deaf community is that they want to do language trainings, right, like sign language trainings for everyone.

And, and that should be something that we pay a lot more attention on, rather than kind of thinking, I mean, of course, you have to pay attention to specific human rights abuses, for sure. But I think as long as we see that as the only way to work, we kind of ignore the wider society and having people being able to interpret the world and understand the world from the perspective of people with disabilities.

And that's usually the hardest. And to have people, especially kids, to be together in an inclusive environment and build those kind of real connection and real relationship is definitely harder. I think when it comes to, I can talk about it in the Mexico case, I think there's an added layer of difficulties in changing hearts and minds when you're working in the criminal justice system.

And especially when it comes to people with psychosocial disabilities who the general public has this perception of fear and a lot of time that is imposed on people from media, from social media portrayal of people with psychosocial disabilities and how, essentially the government is trying to use a very militarized approach to deal with, say, people who are on the streets or people who are struggling with their personal crisis, "mental health crisis."

So I think that is a longer process of changing hearts and minds. I don't think you can discount the fear as irrational. So many things are irrational, but how do we work with that, I think is really, really important. And that is something that I've seen really challenging in a place like Taiwan as well. In Taiwan, we're really seeing the possibilities of government starting to say, oh, we should just build medical prisons for people with psychosocial disabilities or other types of disabilities that they deem are not capable of being involved in the criminal justice procedures.

And that's a really worrying trend that happens everywhere.

- And Luhan, when you're seeing psychosocial disabilities, these are what we've previously called mental health conditions or okay, I just want to make sure that we're understanding what Taiwan deems as psychosocial condition.

- Yeah, I mean, the thing about terminology is maybe a whole other conversation. I've worked with people who self identify as or groups self identify with people with psychosocial disabilities, because people really want to be part of the disability kind of narrative and the rights paradigm.

And there are also people who are rejecting mental health labels altogether, and would call...would consider themselves survivors of psychiatry, right, and to see psychiatry as a very oppressive system, which it is, and there will also be people who accepting their own psychiatric labels and would prefer the words mental health challengers or mental health disabilities.

It really depends on where you are. And in Taiwan, there's a term that the mad community would use for themselves is people who lost water. So, there's a normality that we presume about water and sanity.

And so they're kind of rejecting about that water. So I thought that was interesting, but in different places, people have different interpretations.

- Thank you. I think it's sometimes very difficult when we have these different words in different contexts, because it's hard to know exactly who we're talking about, or what we're envisioning to try to understand the context of

what it is we're talking about exactly, and I just wanted to make sure we were all on the same page about that.

So what do you think regarding Mexico is like, the most important pieces of the movement there and what you have seen that we should know about and think about with our work?

- Yeah, I think our big chunk of our work in Mexico is on criminal justice reform. So with them working, our close partner in Mexico is an organization called Documenta, and they're essentially a human rights organization, but they have really in-depth expertise on disability.

And they have people with disability leading parts of the work in their organization that's related to disability. So their idea around working on criminal justice and disability is twofold, right? One is, this is the first desire is similar with all the other disabled people's groups and human rights groups that we work with across the world is like, people, disability rights groups and parents groups often have the trouble of someone they know or someone from the community has an encounter with the law.

And quickly they realize, either as a victim or a perpetrator. And so that they quickly realize that whatever or a witness and whatever role they play may play in that criminal justice system, their legal capacity is being dismissed by the authorities.

So first of all, there's one case that Documenta worked on in 2019 that they appealed through the optional protocol, a part of the CRPD appeal to the CRPD committee. So it's a man called Arturo Medina Vera. You can probably find his information.

I can send more stuff later if people want to read up on it. So basically he is a man with intellectual disabilities and he was allegedly was stealing a vehicle back in 2011. And the thing about that is that then once he was arrested, he didn't, he wasn't given a chance to testify or to refute what the police said happened.

And there's no summons for him to attend any of his own hearings. And there's no kind of court documents that's made available for him throughout the whole case. He wasn't allowed to appoint his own lawyers either. So it was a really kind of serious problem that many people with intellectual disabilities and sometimes with mental health labels would face is that they will be deemed not capable to stand trial.

This is a big problem, I think in the U.S. as well. And then as a result, there will be a case about them, but they're not even part of that. And so in 2019, Documenta brought this to the CRPD community. And eventually in 2021, after a lot of the reviews and the CRPD community basically criticizing the Mexican government for a lack of support and lack of involvement of people with disabilities in their own cases, and the Mexican government actually came out in 2021 to issue a formal apology to Arturo.

So that was a really interesting moment for the disability community in Mexico to say, okay, the government actually acknowledged that they violated Article 12, which is on legal capacity, respecting people's equal rights before the law, and Article 13, which demands access to justice for people with disability, people to be meaningfully participating in criminal justice procedures.

So that was a really kind of interesting case. And that's another thing about international collaboration, that we set up this criminal justice and disability hub for he past few years. And the Mexican participants from Documenta was able to consult with others from the hub and from other their peers in Kenya, in Europe and UK or in other places, and to talk about how do we deal with this case and how do we strategize?

Can different organizations from different parts of the world write amicus brief for us? How do we do this in TV interviews? So a lot of these things are really useful for the Mexican activists who are working on this case. So I, in the end, I do feel like, obviously, apology is kind of useless, but it's a starting point for the Mexican government to really look into not only their legal regime when it

comes to legal capacity, respecting people's legal capacity, which did get changed a year later.

So Mexico is the latest, one of the few countries in the world that actually have laws recognizing legal capacity for people with disabilities. And also to kind of figure out, that's the second part of what Documenta wanted to do is how do we look at disability and from the perspective of people with disability in a way to reform the criminal justice system, right?

The criminal justice system is very, very problematic and very flawed in many countries. And if we look at the cases and the struggles of people who are most vulnerable in that system, and there's a chance that we have creative solutions and demands for how that system can change. So that's the kind of the flip side.

It's not just about disability and the rights of people with disabilities, but to utilize their perspective and their concept and demand on rights to change a broader system that will benefit more people. So that's kind of a quick summary about the work of in Mexico. I'm happy to answer more questions.

- Thank you. That was very interesting. And I think, does anyone have any questions off the bat that they would like to ask? I feel like I'm monopolizing all the questions. If not, I have one for you.

- Okay.

- All right. While you're thinking about your questions. So both of these projects, I have heard you talk about the important role or the prominent role of people with disabilities at the table or driving the conversation. And I would like you to talk about what role you think that might have on sort of the inroads to creating change that involvement might have.

Does that make sense as a question? Sorry, I feel like it's a little back... So what role do you think, if any, does having the people with disabilities at the table, both in the Taiwan conversations and in this work in Mexico have on the outcomes, do you think?

- Yeah, I think, I mean, I come into disability work from working for a disabled people's organization. So that definitely shapes how I think about disability and how change happens.

- I'm not sure that everybody knows, because that's a very, like, CRPD work. So can you describe what a disabled person's organization is?

- Yeah, so great... That's a good question actually. We at the very beginning, when we were kind of transitioning from just a fun radio station to what we consider ourselves as a disabled people's organization, there are numerous conversations and long conversations among us to think about what it means to be a disabled people's organization, even down to the organizational structure, right?

Who holds power, who makes decisions? And does it mean that we can't have people without disabilities in the organization? Of course not, but what does it mean to be holding that power and how to use that power? And what's the connection with the broader disability community? These are the questions that we were grappling with when we're trying to consider, are we a disabled people's organization?

And also, do we do advocacy on behalf of people with disabilities or certain sectors of people with disabilities? And if so, what kind of responsibility is that? And can we take on that responsibility? What does that really mean? So I think I don't want to give a definition because I think it would be useful for people to have those conversations and to really ask themselves these really important questions.

But that's kind of generally where I come from, a place that's, most major decisions made by people with disabilities. And I think in our organization at the time, there were maybe somewhere at any given time, anywhere between 15 to 20 people, maybe one or two would be people without disabilities and the rest would all be people with different kinds of disabilities.

So that's something we're very conscious about. And I think when it comes to, and New Vitality, the Taiwanese Independent Living Center is entirely run by and staffed by people with disabilities. And I think that they are very aware of their kind of own challenges in life, and they're constantly kind of trying to connect with broader communities and even with communities outside of the urban area in Taiwan and to figure out what are kind of rural people with disabilities, what kind of troubles that they would run into and what kind of support that they would need.

And for me, I guess that's... To be a disabled people's organization, there has to be a genuine way, a practical way to be connected with the broader community. It's not just 5 people, 10 people, 20 people in an organization and have no connection with the broader community, because in that way, then there's very little legitimacy that you can rely on when you're negotiating with the government, because the government can say, well, there's this other disability group that really is just asking for more pensions or whatever.

Nobody has monopoly on disability, but it's up to individual groups to figure out what they want to do and who they're connected with. I don't know if that answered your question about disabled people's organization, but maybe it is a very CRPD term.

- Well, I think so much of the work in the United States, we don't think, we often think of providers or advocates as separate from people with lived experience. And so I think it's important to kind of orient toward.

- Yeah, I see what you mean. I actually don't think that there has to be a separation between disabled people's groups and service providers. But that's something that we have debated a lot. And I know that the independent living center in Taiwan has talked about that a lot, right? Because people with disabilities know their needs.

And oftentimes, we're the first group to figure out how to provide a solution to something. And if we create a pilot project, and the oftentimes what happens

is we create a pilot project, the government is, and we do all these advocacy and the government is like, okay, this is a great project.

This is a great model. Let's implement it more widely. And then they give it to a service agency to do that. And I think sometimes some of the disabled people's organizations will feel a little sour about that. But I think oftentimes after kind of lengthy conversations, some of the disabled people's organization would come to terms to say we're advocacy organization, right?

Maybe we, because we have the lived experience, so we can come up with good models and good solutions, but doesn't mean that we have to run it ourselves. But that is a difficult transition to say, okay, this is a good model. But what are the actual assets and principles that is not just the form of the model, right?

What goes into it? What's the spirit of it? What we're trying to achieve eventually? What are the ultimate goals? It is something that's a lot harder to pass on to service organizations, especially ones that are not run by people with disabilities. Because I think like any government programs, the desire often is to manage people and their needs rather than involving people in society.

If your ultimate goal is to manage people, and then you always come in from a more paternalistic and managerial perspective, and that's not what people with disability want as a way to live in the community.

- Well, and I think to your point, with power sharing and in terms of securing power for people with disabilities and decision making and in informing the decisions that are made about their lives or the services that are provided. Something about the CRPD that always strikes me as really important, but I don't always hear in conversations, is the role of monitoring of laws and the way that services are provided and things within societies by disabled persons organizations and people with disabilities.

And I think if I'm not mistaken, which I might be, but I think don't disabled people's organizations as defined by the CRPD have to be over 50% people with disabilities. I think technically with the so that then the monitoring bodies, right, are then at least there's an avenue to bringing up these problems and to making sure that if there's a service provider that doesn't feel like they're providing services in a way that aligns with what people with disabilities feel is right for them.

There's a way to call this to attention to bring this up and make it significant. So I thought, I guess that's why as you were talking about both of these projects, it really jumped out to me that in both of them, there were really significant roles in the conversations and where it sounded like there was power sharing among the people with disabilities so that they could influence the outcomes.

- Yeah, I would also caution the kind of...just simply identify disabled people's organization just based on, say, a percentage of people with disabilities, right? Because people with disabilities are a diverse group. People have different politics. People have different views about how society should work, function.

And I think a lot of times if you talk to, I mean, I know the spaces in Taiwan and in China the best, if you talk to people with disabilities and their kind of advocacy organizations that they would feel that a lot of the challenges actually come from the community itself.

And I think in Taiwan, in particular, the independent living center, New Vitality, felt like it was really, it's really difficult to be in the same movement a lot of times with kind of a little more old fashioned disability groups that are often really just lacking imagination and trying to kind of maybe just trying to improve their pension or really thinking very...not really thinking about changing society, but really thinking about, okay, the society that we've got is how it will always function, right?

There's no kind of mindset about social change, but only within this framework, what kind of benefit can we get, right? A lot of times it's what a disabled people's organization find themselves in. And that, it requires a lot of time to work with the community. So to me, having the CRPD, one of the most important thing is it provides a baseline and a piece of text for you to use and to kind of talk to other people with disability and other groups and to be able to say, because at the end of the day, you wouldn't agree on a lot of things, but if you don't have those conversations, it's not guaranteed that certain minority groups would always have the mindset to change the society, right?

That's not always a given. So there's definitely a challenge there.

- Thank you. I want to make sure that I give a few minutes for any final questions from our guests, because we're running out of time.

- Can I just say one thing about working with service providers or other professionals? I think that it's always a kind of a point of tension in my past experience, whether it's funding groups or working in disability groups myself. I feel like there's something for people with disabilities and their organizations to do better is to be able to be in conversation with professionals.

Obviously, right, I think work needs to be done on both sides, but, and there will be better if more people with disability become professionals themselves, and there will be more of a kind of a common base for a conversation. But what I sometimes, especially in criminal justice, I think lawyers or psychiatrists or people who work in that, in the judicial system professionally would question some of the more audacious demands that come from people with disability, especially in respect of respecting people's legal capacity.

And that makes the continuation of conversations and finding specific solutions really, really difficult. And I feel like if there's anything that I would want to kind of figure out how to do better is how to hold those kinds of spaces so people can actually sit down together, without offending each other, and come to creative solutions.

Especially if it's really, really difficult, in my opinion, to bring together, for example, using survivor psychiatry together with people from a psychiatric background, and the line of questioning can become just very, very challenging and disrespectful very quickly. So there's a lot of kind of communication to be done and public education to be done as well.

It's not just on people with disabilities for sure. I'd imagine in that space too that that requires very deliberate balancing of power and sort of moderating of that conversation to ensure that, because if the system has perpetrated harm toward people, and then people are trying to advocate for themselves, and some of the people are working within that system, then you're sort of starting off at an imbalance of power, right?

- Exactly. Yeah.

- Yeah. So...

- Yeah, I mean, small things to think about. How many people in the room and what is the power dynamic will be in the room? What is the power dynamic will be in that room? Right? These kind of things. And yeah, it's really tricky. And also the language, right?

Sometimes, if you say, invite a forensic psychiatrist to a conversation, and the person will start out with, oh, people with schizophrenia, this and that, right? And that becomes, it's just the general way of how we describe people with disabilities. There's a lot of problems there.

And oftentimes, you can't even pass the language barrier to be able to talk about substance.

- Thank you. All right. I think we're just about at time. Do you have any final thoughts you would like to share with us?

- I'm happy to send out more information about stuff that people are interested in. And if anyone has any questions, feel free to reach out. I think Rebecca will help facilitate that process.

- Louise had asked for materials from Taiwan and Mexico. So if you want to send anything you'd like to share out to me, and then I'll send it to everyone who registered for today.

- Sure. I'll put together a few things and I'll share with you guys.

- That would be fantastic.

- Thank you.

- All right. And then I just want to thank you very much, Luhan, for your time today. This has been wonderful. And I really appreciate your very interesting discussion. I think you've given us a lot to think about. I really appreciate it and you. And I want to thank Amanda for being here to support us in our conversation today.

Thank you for your interpreting. And once again, I want to thank the team from the Division of Disability Services for supporting IHC and our webinars and allowing us the opportunity to do this with you. Thank you, everybody. Thank you for being here and have a wonderful day.

- Thanks. Thanks, everyone.

- Thanks so much. Bye.