Ellen Spannagel 0:01

Hello, and welcome to Enabling Commons, a podcast at the McGill Center for Human Rights and Legal Pluralism. Enabling Commons is a space for dialogue among persons with disabilities and their allies to explore strategies that will transform our environments, our Commons to be meaningfully enabling for all. Hello, my name is Ellen Spannagel. And this is enabling commons. Today, we are very lucky to have Carlos Kaiser as our guest. Carlos is the executive director of Inclusiva NGO in Chile and has extensive experience representing people with disabilities and work related to disaster risk reduction. Carlos, thank you so much for joining me today. To start. I was just wondering if you could tell me a little bit about yourself.

Carlos Kaiser 0:50

Thanks a lot, Ellen. First of all, I'm just so happy to be here. Well, as you already said, I'm Carlos Kaiser, a Chilean guy here from Peñaflor. Peñaflor is, as the name suggests, is a town located near to Santiago, the capital city of Chile. The thing is that I has been born as a person with disabilities, I lack part of my upper and lower limbs due to a syndrome called Mira Melia. I have been working a lot in disaster risk reduction. First of all, because Chile is a country of disasters, we have everything but Godzilla. For instance, the other day was just watching TV with my wife on, she said, it seems its trembling. It was a 6.4. But it for us was it, it seems it was trembling. It's so common here. So I started taking this as my main focus because of the big earthquake of 2010 that was an 8.8, with a great tsunami, that happened in Chile. And that's why I committed myself to disasters, and disabilities. What has been incredible during those years is that I could combine a background that's kind of eclectic. And that's why I believe that my institution has been kind of innovative, because we have a nontraditional approach to things that happened.

Ellen Spannagel 2:29

Thanks for that, Carlos. So what has your organization learned about addressing the needs of persons with disabilities in relation to emergency preparedness, but also building back better?

Carlos Kaiser 2:42

The thing is, that first we have to address what are we talking when we're talking about people with disabilities? Because there are a lot of different concepts circulating globally, about what we are. We have to cope with real reality check. And this reality check called COVID-19 says what the world really think about this, not what they want to say, as some "nice" thing. Do you remember when even in the UK, they start saying that they are going to Yes, help people that have the real opportunity to survive. And they say that people with disabilities were not among those. So even some physicians, they told that people with disabilities were unethical because we were so attached to life.

Unknown Speaker 3:34

So

Unknown Speaker 3:35

So it depends on the approach. The social approach said that it's a complex mix of different variables that are all together. That's why we the we are thinking that disability is not a simple issue. It has also biophysical things. Of course, for instance, in my case, I was born lacking some part of the limbs. That's something that you can measure, but it doesn't define the person I am. I'm defining my own personality. I'm defining myself what we said first, its disability is going to be whatever the person with disability want this to be. It's like gender, you define it. I'm not going to say any person, the way they have to leave the way they have to love the way they have to behave in certain patterns. The only patterns of behavior that I really cares about how can we establish a world that we can share together.

Unknown Speaker 4:44

So when they said that I'm this or that I said how, they don't have that much knowledge. They don't have that authority. People with disabilities. The approach we have is person that are entitled to rights but also are entitled to work in society not isolated. So disaster risk is possible only if you have a community. If you have no community, you can't establish the the links needed in order to face whatever may happen, not in the near future. Not in the far future, not now, not tomorrow. People with disabilities, what we said is that in order to have inclusive disaster risk reduction, first we need meaningful participation of people with disabilities themselves, not the damsel in distress waiting for the shining night, we're not going to break, we're we're just there and we endure a lot of hardships during all our lives. So sometimes we're kind of stronger, we can help, we must help. And they say to people with disabilities that we are not able to, we have to wait for a physician to say whatever we can say or do. So the thing is that if you are lacking that humankind power of all those abilities, we are lacking, for instance, this case more than 1 billion mines. And that's the thing we are doing with inclusive disaster risk reduction, the very first thing to say is, we need people on board, we need their skills, knowledge, experience, all those things on board. The second aspect is that we need applied knowledge and also ancient knowledge. For instance, in Chile, we have a tribe, it's more than a tribe, it's a culture. Mapuche. Mapuche means people of the land, Mapu is the land itself or herself. Che, people. They have a group that has inhabited, the seaside, and they have these marvelous legend to explain when you have an earthquake and tsunami. They say that there are two great separate Gods take a blue, three blue, also known as CaiCai and TenTen protects humankind is the land, the soil. Caicai hates us, and it's the sea monster. So every time you feel an earthquake, is Chi Chi fighting, with TenTen, protecting humankind. And that's why that he’s alerting you is not the problem, the earthquake itself. It's just an alert saying beware the waves are going to come. So it's an invite from the god, or all the goddesses because it has no clear gender, people to say, Come aboard me. You yes can get in my back, all the hills and mountains are the back of TenTen. So what happened now, two things first, Mapuche didn't build things that collapse with earthquakes. So there was no problem with the earthquake in the sense that no building was supposed to collapse. Also, they inhabit parts that were more secure in front of tsunami. But also, they knew which hill they have to claim, because of the structural integrity of this because they say that there was TenTen with five foot, four foot, three foot, two foot TenTen**.** That means the level and amount of security you have, and they also talk about the depth TenTen that are the hills that any person we all of us are called winkas, for them, all of winkas could never understand the difference among TenTen. Well, nowadays, some universities send the engineers, structural engineers, soil engineers to visit those places. And they have confirmed all of the legends are, in the sense that the structural points the most secure places are the ones that are described by Mapuche a tradition, we honor them. But also when we talk about environmental issues, and also human rights, Mapuche, they have a very good cosmology. They cannot understand individual rights without environmental rights, because people and the land are one and the same. How can you establish that something is good to be consumed when it's part of your own spirit. So we are not commanding people, we are understanding phenomenon for us together to solve the problem. And when I talk about inclusion, of course, I share my knowledge, but I mix with their knowledge and we create a new set of values, a new set of standards, a new set of indicators, whatever you want it. For instance, when I'm in my wheelchair, some people just believe that they can grab it and move my wheelchair without asking me. That's the equivalent of if I assault you, but in my case this because probably they consider the time I wheelchair and not a person that is using the wheelchair assistive device is not defining that I'm a person. What I'm saying here is that knowledge is something that you build up with people.

Carlos Kaiser 10:09

Knowledge is something that must be applied. Because why not one of the one of the problems we have is sometimes we have very good universities all around the world. We have a lot of very good teachers, professors, I mean, professional not teachers, we have a lot of good research that probably is not changing the world. And sometimes it happened to me that when I read some guidelines, or things that have been produced by different governments, I said they lack a lot of knowledge.

Ellen Spannagel 10:42

Thanks for that. Carlos. Could you tell me about challenges for including climate action in the Latin American context?

Carlos Kaiser 10:52

When you talk about Latin America, Latin America, for many, many people all around the world, they consider that we are the toilet cleaner crew, that we are just working in low paid jobs, that we have no brains, and that we all they are just sleeping, siesta, and dancing all day on like a sort of that we are always smiling, dancing, sleeping or having sex. That's the the cartoonish version that people sometimes refers to Latin American. So why I say this? Because in Latin America, of course, we have our issues. Of course, we have different things, but it's not this cartoonish thing that they talk about that. Also we have our great thinkers, a lot of them. And one of the problems of Latin America is that our brains are most of the time get into Germany, or Japan or the United States, or sometimes UK, and, or France, because sometimes they don't get open arms here. The other problem is that, we have a neo colonialism movement. You know that, for instance, I've been told once that all my ideas could be welcomed, because Inclusiva is very well known in the NGO community Disaster Risk Reduction because of our production. But they want our ideas to be executed by European NGOs. You would say to me from high official from one of the European agencies, international cooperation agencies, so you want the superior being to come here to tell me, you are inferior so we the Europeans know better what is going on during your history and country because read history books, you are a sub product of us, you are kind of imperfect Europeans mixed with Indigenous people, it's like that sentence they have. So sometimes when they get too into our land, they forget to say two things could I have permission to and thanks. When we visit their lands, sometimes they look at us like, well, they're the funny people. Let's hear what those taco eaters and dancing cumbia dancers are going to say, sometimes they're kind of rough. Imagine that I faced this in this creating an NGO in a small town, in Chile, in the bottom of the world, far away from all the economic powers. During those years, I have watched more than 50 projects that were copies of my intellectual production without any warning or without any saying thanks to Inclusiva and most of the time produced by colonial powers. So I remember that sometimes they ask us freelance work in order for them to hire a European or USA citizen as a consultant, very well paid to execute what I've been working on. I said it not with rage. No, believe me because I have been also having a lot of good experiences. I am not an isolationist, so I want the world to be a friendly place for everyone. I want to be your friend. I want to be friends with everyone. But I want to be friends. That mean equals. That means that we deserve the same behaviors. Did you know that once I faced that in an international activity, there was some behaviors from part of the organization or from the staff there, that in my culture are considered very offensive. And I complain, you're saying the, if something offends me because of my culture is my own problem, because I'm a Latino. So that's why I started in this part, because the way the society treats people with disabilities is very similar the way that Western powers treat everyone else.

Sort of saying that we are superior to your inferiors, you learn from us, we are the ones that provide the money. We are the ones that say what's going to be done. The guidelines are us. Those things I tailor, for us, for our culture, the way we express is that way. So that's why we are kind of misfits, if you will, because we are saying that we need freedom. We need to respect, and we want to cooperate, but the thing is sharing. It's saying that whatever they base it on our house, treat us as the owner of the house. And the problem that is happening and is related with climate change is that that kind of abusive way of thinking and doing things, it's affecting Earth. We're saying to people with disabilities, and in my land what happened when you are a woman with disabilities, living in a country like my country, that everyone considered that you have trash? Because you are lacking? Because you are women? Because you have disability? Because you are from an indigenous group? Because you live in poverty? And probably because you have a religion that is not the predominant one. What are we saying to them, starve to death? We are going What are we giving them, we have an expression in Chile, we call them Sona, the sacrificial, that we can translate to the places that we have neglected. So apart from those things, we need people to be happy. We need to see our creatures there, all the animals to be happy to. We need tress to grow, happy, not polluted. And I believe that's kind of vibe that we have. So the vibe where that is we're having now is suffering. A lot of suffering there. You can smell it. You know, I remember when I was a kid, and to have friends was so easy. I remember my pa my mom, my dad, yes, with my sister in a park. Plenty of kids and saying, Do you want to play with me? And it was like those days like, yeah, playing. So happy. Now it’s that much difficult to be in front of a grown-up out and saying what do you want to be my friend? So that's why we are trying to face a word that probably is missing. Justice. It's very strong word, justice. So when we're talking about environmental, we need to talk about environmental justice.

Ellen Spannagel 18:38

So So what can people do? What is your message to persons with disabilities around the world to take action regarding climate change? What do they need to know? And how can they get meaningfully involved?

Carlos Kaiser 18:52

Well, first of all people with disabilities have to widen their interest. We had been so focused on the justice, that we suffer daily, that probably we are not seeing the whole picture probably as a group. Because we were complaining about things that are so needed for instance, ramps, accessibility, sign language interpreters, and so on. But the thing is, that of course, we need those things. If I am here, and I'm a deaf person, and there is no sign language interpreter. I'm not going to be part of this. If I have a blog or an internet website, with no accessibility, digital accessibility, we are just saying to different people with low sight or blind people that they are out. When we were without this COVID-19 pandemic and they organized meetings, accessibility was not always the top priority, so there were some issues. I remember in attending very high level meetings entering by the kitchen. That's not red carpet. It's very strange. It happened to me all the time that no matter how high the meeting, the meeting is, or the owner conceived, or whatever. They are always this path among the trash they have in the building, the backside of the building, not always from the from the front door. So the message is “you are not equal, or we don't want you here.” So what we need people with disabilities is to understand that part of this ecosystem that we need to build, the ecological part of inclusion, is not just about the physical environment made by humankind is about the whole system, because we are the most affected by climate change. All groups say that we are the most affected, but I have proved that mine is. Because we are part of all the other groups. When we said they said elderly people are the most affected. And I said yes, but you know that most of the other people you are talking about are people with disabilities. They say “okay, but women are the most affected.: Yeah, but women with disabilities, when they say migrants, yeah, but migrants with disabilities, you know that some of them, even their groups, forget them in the world. In order to get to the promised land. We need to get involved, not just because we're the most affected, we need to get involved because it's part of our mission in life, to be part of society, to improve what's not good to share our experiences. And believe me, we are experts on barriers and disasters, because we live them on a daily basis.

So we have different perspectives that some of the people that are taking decision now, they lacked. So our vision is needed. You know that it happened to us all the time. Have you ever read the new dress of the Emperor, or the Emperor's New dress, it's a fairy tale about an emperor that he was so vain, and he was always looking in the mirror. And they gave him invisible suit. It was a hoax, you know that they were just giving his money away. But they said that people that are not up to their position, will now be able to see the dress. So everyone pretends that they see the Emperor's New cloth. And he was Yes, marching in front, the whole kingdom. And he was naked. So one kid say the Emperor is naked. Well, it happens all the time with the presence of people with disabilities. Every time we get into a conference, we with our very presence, we show that the Emperor is naked. Because nowadays, for instance, COVID, they said, or we need that we have a lot of people dying, but two thirds of people that have died because of COVID are people with disabilities. They is telling about now about the vaccines, but they're not even mentioning us. When we are talking about climate change. Do you know that some disabilities affect people with disabilities in a way that they cannot tolerate extreme weather patterns, extreme cold or extreme heat? For instance, have you ever tried to use prosthetics? That very hot to use, I know that firsthand, because I used to use them in hot weather, you are going to get the heat stroke soon. So we need people to with disabilities and we have started working this is something that we are constituting groups on this saying that we need to be there, but we need to demand accessibility of information, meaningful participation. Yeah, our knowledge to be present and accounted. We need also to have positions on this. For instance, I would love to see a person with disabilities in a high-level position in ministries in the in all the countries or UN, not just about disabilities, why cannot be a person that is entitled to work on for instance, on climate change. So the thing is that I need them to understand that we are not an appendix, you know that sometimes, “They said we have all those conversation about that topic, for instance, environmental aspects. And well, that's the workshop for people with disabilities.” Why can we be part of the main, the main thing? We are a sideshow. So we need to be the big show. But at the same time, I believe that's kind of our fault. You know that I have this very strange concept that sometimes if something is not fixed, it is my fault, because I was not part of the solution. It's not my fault alone. I mean, as a person, I'm not responsible for all evils in the world. When we are just complaining and doing nothing, when we just keyboard warriors, and sometimes even, not this, even whatever, there are people that are not even complaining. What are we doing? It’s like I'm saying something because I want someone else to fix it. Who's someone else. If for instance, if I am mistreated, of course, I'm not guilty of being mistreated. But I'm guilty of not. If I'm not working hard for this to never happen. To tolerate what's wrong, is like whether I cannot remember the exact phrase. But the idea that Martin Luther King said that the problem is not the amount of bad people doing bad things, it's the amount of good people doing nothing. One main idea: we need to make a very inclusive call for people to disabilities to get involved in environmental justice, we are now producing some materials to make this. I don't know how good they are going to be, I want them to be top quality. But the result is not the production is the outcome. So you know that you can have a very good video and produce nothing. And you can have a sort of meh, the not that good production video. But the thing that we need to measure is the impact. It’s the amount of people that move their bodies and said, I'm going to do this because this inspire me

Ellen Spannagel 27:10

the amount of people who move their bodies because it inspires them. What other topics should be brought to the forefront and conversations surrounding disability and climate action.

Carlos Kaiser 27:23

I believe that the lack of formal agreements about disabilities and climate change, because we need to reach some formal agreement. You know, the, you know, that we were part of the COP, the COP 25 in Chile, but was not able to be we work hard, advising our government, and then all the social things happen in Chile, and we couldn't, because it was interrupted. And we were there in order to have very specific agreements about disabilities. And that's the topic, we need formal agreements among countries, their governments, human rights, okay, environmental rights are okay, but we need inclusive environmental and human rights towards disability inclusive ones. So that's the thing, we need to emphasize them. It happened this discussion happened in a broader sense when we established the Convention on Human Rights of People with Disabilities. Because the very first thing was, well, are we establishing that we are an alien nation, different from the rest of humanity that we need a special right? And the answer was kind of, in the sense that we are entitled to the same human rights of all humans, because we are humans. But at the same time, we have some different needs that have not been addressed by society and in practice, our human rights have been denied because of our difference. So what I'm saying here is that we have the same rights and duties, environmental ones, but there's something special in certain conditions that are making almost impossible for us to meet those things. And that's what we need to establish.

Ellen Spannagel 29:23

Speaking of formal, inclusive agreements, you have worked with the United Nations on the Sendai framework for disaster risk reduction, and on other inclusive disaster risk management initiatives. Can you tell me about some of the barriers you faced or opportunities in establishing these?

Carlos Kaiser 29:42

It ‘s kind of a sour experience for me? It’s 's going to sound more disappointed and sadder than other things. It is so hard to be in front of people that at the very beginning, they don't want you to be there and some of them They're because their bosses told them, but at the very beginning, they didn't believe in what we were doing there. And with all those microaggressions they have. All those small details that are Yes, showing that they don't want you there. They're laughing. There is a special poet in Chile, Pedro Lemebel. I don't know, if there is an English version of his poems, I recommend you have them especially his manifest of his difference. He wrote a manifest about his difference, his right to be different, because he was homosexual writer. And he said in a very poetical way in Spanish, that I'm not probably able to reproduce the whole meaning in English. But he said that he has plenty of scars because of their laughing. Could you imagine this? So you present, you're there, you're supposed to be an expert and educated person. In my case, I have had the opportunity of having a master's degree, from very good university. Also, I have my professional degree, I talk at least two language and a half. And also, I have written more than 30 books, I have been National Authority in my country, and I have had a lot of good positions, jobs, in universities, local governments, and so on. So I was supposed to be entitled to set this a little bit. And you know, they are laughing, because they don't consider you they're equal. Even if you have more knowledge, even if you even have have a higher position into governments, it doesn't matter. Because they are not looking directly into your eyes. And they are not looking with respect to your fellow companions there. And that's the very beginning of this. Then some of them converted hallelujah. So we start having allies into those governments. Some of them were just with us, because they have a daughter, or sister or a brother with a disability. So they start saying, well, that happened to my brothers/ sisters/ mother, or whatever. And then they just approach us in a more respected way. And what hurt me a lot is that in every movement, we create some sort of how can I say, elite, the ones that are always invited to the international platform seminars. The ones that get all the funding. And it could be kind of strange that I said this, because I'm part of the group that I've always invited to the platforms and regional platforms. I really hate this. I really hate this. I really hate when, you know that three days ago, I was in a high-level meeting of a group that we have about health with a very important institution. And we were discussing about everyone has the right to know whether a vaccine has some side effect that can affect them because of their disability. It sounds marvelous, but it's about privilege, because this is for rich countries. in poor countries, they're going to, Yes, with a lot of effort in one shot for you. And one shot alone.

And you are going to discern if you want it or not. Its such an elite thing. So we are here eating our caviar discussing about the fate of the poor people all around the world. Well, I have no caviar but I'm saying this in a metaphorical way. So We Are The thinkers, we are the big shots. We are the big brains. We know better, what's good for you. And I don't like this. So what we are proposing that the work of inclusive is what can we get more people involved. Now we have more technology to do so. So we can not reach everyone because poor people and among the poorest of the poorest in the world are people with disabilities, no surprise, but we have them with no internet connection. But we need to reach them. We need to reach them. But we need to reach them not to be the guy in the picture of mine. PowerPoint next time that I'm going to talk about them without them. That's the problem. The problem is that we are using people as assets. So now I'm going to show you how people with disabilities live in Chile and presented by Carlos Kaiser. So what I'm thinking is that we are reproducing the oppression we are against. But we are reproducing that oppressive system into the way we are presenting social issues. And that's the problem. The problem is that we are continue having elites so we have the elites of the outcasts. So we have the ones that talk with the government and the ones that cannot, we have the ones that are invited by the United Nations and the ones that are not. And it's so difficult, because we are supposed to have a lack of representativeness there. Because if you look, for instance, an expert about disability and disaster risk reduction, you're going to hit my name more than 100 times prior to get another one. And that's a problem not because I'm bad at what I'm doing. I love what I'm doing. But I'm not the only one. Why cannot women with disabilities be more present? Why cannot be non binary people with disabilities present? So that's why we start making more and more and more presence of people. We have been making international training course we are going to have and we are opening now one in English, and it's totally free. The thing that we need to do is to create community, if there is no link among us, there is no love among us, if there is no love, there is a void. And when there's void, hate. So we cannot talk about climate justice, we cannot talk about inclusion, if we are not above fear, fear itself is tearing us apart, we have a lot of fear for the future. So we are getting a lot of stuff, a lot of goods to be consumed. Because that way we feel safer. I don't know if next time that there is a natural event here like for instance, rain, heavy rain falls or dry. Like the one we are experiencing here. I almost forgot the sound of rainfall here because it's so dry now. That's what I want to say to you that what we need to address is, first to have an understanding, second meaningful participation of those that are not in the spotlight. And also we need to address direct to them. Less profits, more community. And also, we need to do it without fear. When you share you don't lose. I mean, that's the thing that people say, Oh, if I start sharing, I'm going to have less as part of the cake. Now we can bake any cakes we wanted. That's my two cents.

Ellen Spannagel 38:12

Thanks, Carlos. Is there anything else you feel is important? That was left unsaid or any message you would like to leave me or anybody else engaging in this conversation with.

Carlos Kaiser 38:24

But my final message for people is don't wait for anyone else to do the thing that we are entitled to do today. And we are getting left behind on this. For people with disabilities we need to work in a broader aspect, not just about the sign language, the ramp or other things because we are a very huge group, very diverse group. And this diversity could be a strength that they will need. So that's my final statement.

Ellen Spannagel 39:01

Well on that I just wanted to say thank you so much for taking the time to talk to me today, Carlos, you've helped shed a lot of light on a lot of really important issues surrounding disability and climate justice. And I just really appreciate you taking the time to speak with me today.

Carlos Kaiser 39:18

Thanks, Ellen. It's a pleasure to talk to you. Have a nice day.

Ellen Spannagel 39:25

Thank you for listening to enabling comments. Stay tuned for our next episode and take care.