Ellen Spannagel 0:02

Hello, and welcome to Enabling Commons, a podcast at the McGill Centre for Human Rights & 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.

My name is Ellen Spannagel. And today I'm joined by Sebastian Jodoin, director of the Disability Inclusive Climate Action Research Program, or DICARP. So Sebastian is a law professor at McGill University, where he holds the Canada Research Chair in human rights, health and environment. And before I ask you some more questions about disability, climate justice, your work there. I'm wondering if you can actually tell me a little bit about mn the podcast itself. And specifically, I'm really curious about the name. Why Enabling Commons?

Sébastien Jodoin 0:34

Well, so this podcast is really something, an initiative that we are hoping to use to be able to tell compelling stories about the challenges faced by people with disabilities, but also the roles that they're playing in dismantling the barriers that they confront, in terms of achieving quality and ensuring protection for their human rights. And so Enabling Commons in one part sort of references the importance of having a space that's empowering for people with disabilities. But also, we as a podcast itself is looking to create that space, and to feature and center the voices of people disability community, that are at the frontlines of remaking our world to to be more accessible and disability inclusive. So comments here also has this reference to to the environment, as this season and the future season of the podcast will also address intersections between disability rights, and the environment or also other spaces as well.

Ellen Spannagel 1:40

That's a really helpful and important explanation of enabling comments think that clarifies a lot of what it means for me. And since the season is about disability and climate justice, I'm wondering if you can explain a little bit more about DICARP itself. So the research program, how you got involved in starting it, what the goal of the research program is and what you're hoping to accomplish.

Sébastien Jodoin 2:08

So let me start with the program. The program is something that I'm leading with colleagues and students at McGill, as well as in collaboration with scholars and activists in the field of disability and climate change from all over the world. And we've brought everyone together with the objective of generating, co-producing, disseminating, and translating information, knowledge at the intersections of disability and climate change. So when I talk about co-production, I'm talking really about the importance of developing knowledge with people who are experts about the challenges that they confront in a changing climate and potential solutions that could be adopted, to empower them in that context. When I talk about translation, what I mean there also is the importance of ensuring that in our research, that we produce materials that are accessible in various formats to people in the disability community, but also to policymakers. So the word climate action is intentional, because we are really actively trying to promote the importance of rights based approaches to climate policy, climate decision making climate action for persons with disabilities.

Ellen Spannagel 3:26

I think this really helps give me a bigger picture of what DICARP is, and what you and the research program are trying to accomplish. I just want to know a little bit more about your own experience working in climate change and in human rights. And I'm wondering if you can talk about some of the work you've been involved in in the past and how it led into what you're doing now.

Sébastien Jodoin 3:51

So I've been working on the relationship between human rights and climate change for about 15 years. I've done this as an activist, as a lawyer and as a scholar, I've worked on a range of things from the role that human rights can play in obliging governments to reduce their emissions to the role that human rights would play in ensuring that solutions to climate change don't harm or disempower different segments in society. So most of my work had been looking at specifically the relationship between the rights of Indigenous peoples and climate justice. And I was due to go to Paris in 2015, which was kind of going to be the culmination of my many years of going to the climate negotiations. And I was going to go there to once again discuss and present work on human rights and climate change along with other lawyers and legal scholars and activists. And a few a few weeks before I was due to be in Paris for those negotiations, my life've changed. So basically, I, overnight developed a range of symptoms, which, which were pretty severe. And so were quickly diagnosed as relapsing Multiple Sclerosis in the emergency room. And so I did not go to Paris, I had someone else go in my place. And during this time, this period, I focused on rehabilitation. And at the time, I remember thinking that I was going to obviously end up working on on health care, this is just a disability rights, this is just the way my personality goes, I just focus on things that, you know, come up in my life. But and so my thought was, well, I'm going to, I'm going to finish up my work on human rights and climate change. And then I'll start working on this other other stuff. And then so this is where, you know, in November, December 2015, then in the summer of 2016, summer comes along. And I suddenly realized, you know, I live in Montreal, where it's hot and humid in summer. And I realized that like most people with MS and most people who have neurological illnesses, I'm very sensitive to heat. So I find that if I'm stepping outside, I get this, this symptom, which in fact, they used to use to diagnose ms, which is called Lhermitte's sign. So it's like you have these like tiny electric shocks that run through the back of your head and down your spinal cord. Very uncomfortable and unnerving. So we're in the summer of 2016. And suddenly, I realized that this problem that I've been working on for all of my adult life, that I'm suddenly a part of a group that's disproportionately affected by climate change, right. So we know climate change leads to a gradual increase in temperatures, we've just had 10 of the hottest years on record in the last decade. And we know also that leads to an increase in in the frequency and severity of heat waves. So as I'm realizing this, I'm also starting to think about, you know, how has anyone actually looked at the relationship between disability disability rights and climate change, and I and I realized a little bit to my own sort of shame that no, no one had really looked into this. I had recently, at the time, I was in the process of co-editing a handbook on human rights and climate governance, with other leading scholars and human rights lawyers and activists from around the world. And we had a chapter on women's rights and children's rights and of course, on Indigenous rights, and no chapter on disability rights. So that's basically how I started working on this topic. And, and saw that there was a huge gap and basically felt that I had a responsibility to help fill that gap in terms of research, and, and also in working with members of the disability community and advancing disability inclusive climate action.

Ellen Spannagel 8:09

So thank you so much for sharing, for sharing that and telling me, you know, like about that very, like personal journey. I'm wondering a little bit about how the disability community or like other disabled scholars and activists, were people who you started to learn from and started to draw on some of their knowledge. And a sense, I'm wondering if you could tell me about, like, how you got connected to the disability community.

Sébastien Jodoin 8:41

So I began looking at this relationship between disability rights and climate change and engaging with people in the disability community. I began to do this with a lot of modesty. Because, first of all, I knew that I was coming into this movement, which has been around for decades, and that I was a newcomer, that I had a lot to learn. And I also knew that I was coming into this with a lot of privilege. So as a as a white, straight man with relative job security, and you know, lots of socio economic privilege. I knew that my experience, my perspectives, the challenges and barriers I would encounter in society that I've encountered as someone who has multiple sclerosis, or not at all the same as people with disabilities, even within Canada and not to mention other parts of the world. In fact, that aspect of realizing how advantaged I was by my privilege in terms of managing my MS and is also sort of the one of the things that led me to really insist on having an intersectional approach to this work and every timeI present in public on climate change and disability, I always self identify as a person with disability. But I'm always very, very quick to also point out that, you know, I have this privilege that that I, therefore my perspectives don't, of course reflect the entire disability community, which is also really diverse. So that's, I guess, another thing to realize is that the disability community is really diverse. There's, there's really different experiences in terms of types of impairments, types of forms of oppression, especially that are intersecting. But what I've noticed, and coming again, coming from the sort of really the climate field and human rights, I was, I've been really, really sort of encouraged and heartened by how open people have been in the disability community. So my experience of you know, now 15 years of collaborating with people on climate change is that people are really busy. There's the NGO sector can be kind of competitive, everyone's competing for attention, resources that are far and few between and, and this community is also is confronted by similar challenges. But honestly, everyone, almost everyone that I've spoken to, when I've said, "Hey, I'm a legal scholar at McGill, I tried to launch a new program, or do new research on disability and climate change, would you like to work with me," pretty much every one except basically one or two, basically come back to me and said, "This is awesome. We'd love to work with you." And so that's been really encouraging. And what's been interesting is from from speaking with people in the disability community, there's this realization of, "Oh, we need to work on this. But we don't know how, right like, we know, climate change is a you know, a major threat to, to the world and obviously a threat to us. But we're new to the space, we don't have the resources or the know how to engage on these issues. " And so and there's not much of an evidence base to deal with these issues. So people have been very happy to collaborate with me. And on my end, I sort of have approached it as I'm new to this field of disability rights. I'm a climate expert, and I'm willing to learn and collaborate with you and see how we can work together. And so yeah, that's been very,very enriching and gratifying.

Ellen Spannagel 12:26

So you've explained to me that the disability community has like a lot of expertise and knowledge that often is pushed to the wayside, especially when it comes to climate justice. And from what I understand DICARP is really about bridging that gap. It's about bringing, like evidence and like scientific knowledge into disability communities, and like disability NGOs, but then also elevating the voices of people with disabilities in climate justice. You have people in this research program from all over the world representing all kinds of disability organizations and movements. So I'm wondering how, like, how you're bringing everybody together, what kinds of what kinds of projects you're doing in relation to the to the rights issues, but also some of some of the other missions that you were explaining to me a little bit earlier in our conversation.

Sébastien Jodoin 13:20

So we have been working together to engage the disability community. Basically, we started by building an advisory panel, we're bringing together disability activists and scholars and some climate activists, all from all over the world, representing together a global network of people who are interested in these issues are already working in unrelated issues. And together, we're moving forward an agenda that has sort of three big prongs. So one prong is basically using the disability rights framework to understand the impacts of climate change for persons with disabilities, and the opportunities and challenges that they face in terms of adapting or coping with climate change. And so there's a component to that research, which is legal research, but also empirical research. So we have funding to do a project in India that will allow us to to conduct the first empirical assessment of the capacity of people with disabilities to cope with different climate impacts. We have then a second prong, which is really looking at influencing public policy, climate policies at the domestic and multilateral levels. So we're working closely with the International Disability Alliance, and which is a sort of large umbrella group that represents disabled persons organizations from all over the world, and something called the thematic group of persons with disabilities on Disaster Risk Reduction and climate action. And so we're going to support them on their efforts to establish a constituency for the disability community under the climate negotiations. And here in Canada, we are working right now on a review of all of Canada's climate policies to look at whether they consider the rights of persons with disabilities and will have recommendations on, on what should be done. So those are the kinds of things that we're doing. And then the third thing is really, actually really closely connected to this podcast. And in our website, which is to position, to center the voices and expertise of people with disabilities in relation to climate change.

Ellen Spannagel 15:39

Something that has really stuck out to me. And opportunities I've had to speak and like, look at some of your work is that you talk about people with disabilities, as no worries makers, and doers of climate action. And I think that's like, very powerful. But I'm wondering if you can explain to me like what that means for yourself, but also in general.

Sébastien Jodoin 16:04

So this expression actually comes from something called the Crip, Feminist Technoscience Manifesto, persons with disabilities, there's no words makers and doers.And the idea is, and so this is a put together by a scholar, who has studied design, and tells the stories of people in the disability community, remaking the world around them. So the famous example of this is, in the 70s, people with disabilities started just making their own curb cuts in the sidewalks in Berkeley, San Francisco. So today, you know, these curb cuts are a common feature of cities in the industrialized world. But this wasn't always the case. And in the 70s, in, in San Francisco, people with disabilities just took equipment and made their own curb cuts. And there's still examples of this today. In Toronto, for instance, there's an initiative where people are, basically there's there isn't a lot, there's going to be, it's going to be a legal requirement in Ontario, in about two years for all businesses to be physically accessible for wheelchair users. But that legal requirement hasn't come into effect. And in the meantime, there's members of the disability community there in Toronto, that have been putting the sort of makeshift little ramps that are A making those businesses accessible. But B they also actually are a political statement around the fact that there's still a gap that hasn't been has been addressed. So there's lots of examples of people with disabilities remaking the world around them. And what we want to do is we want to tell stories of people with disabilities as knowers, makers and doers, doers in the climate space. So whatever exists on climate change, and disability, for the most part, highlights the vulnerability of persons with disabilities. And you know, honestly, this is pretty much the case from a lot of research and a lot of mainstream accounts of disability is all about their vulnerability. And that's not to say that there aren't serious and significant and disproportionate ways in which climate impacts affect persons with disabilities. But for me, as someone who has a disability, it's really important to also talk about the contributions that people with disabilities can make in terms of enhancing their resilience to climate change, and how those efforts can also can also contribute to society at large. So I'll give like a very personal example, which is I think, I took this I already told you how I was more sensitive to heat.But you know, I have a nine year old and I guess, you know, she was younger back then. And we like to do a lot of hiking as a family. And for me, it was really important that I was able to spend time with my daughter outside in the summer. So I started thinking about what can I do to basically go outside, and I eventually, eventually found these cooling vests. So these are vests that are, that are, sometimes they have water, or the more advanced ones have like another type of liquid that freezes at a certain temperature and it can keep you cool if you wear them. You basically are wearing, like, ice packs on your chest in your back. And I found that basically, I could go outside, even if it was 40 degrees, and I would be fine. And I could do that for about three hours. And so, you know, one of the things that I used to walk around basically Montreal wearing this test in the summer, and I you know and i At first I was a little bit I guess shy about it or I thought if people would ask me questions about it or whatever. And then I realized Of course this was silly, because it was like myequivalent of using any type of device that ensures your mobility. Anyway, what I found also over time is when people would ask me about the vest, a lot of people were like, Oh, I need this. So menopausal women, were the ones who were like, "Oh my god, I need these, I need a vest like this." You know, I think there's people who work out in the summer, who are athletes who would need a vest like this, unfortunately, if there are parts of the world, and I think Montreal is one part of the world where there's an increase in temperatures, heat waves. I think if if we don't do more to combat climate change, unfortunately, I think we will find ourselves perhaps many of us needing these types of vests to walk around in 20 years in the summer. So this is sort of my little unique personal example of, of someone who had to figure out a solution for themselves. What we want to do for our research is find more of these examples in terms of climate resilience, and then more broadly, I really want to again, celebrate the agency and the contributions of the disability community to combating climate change. Now, it's true that there isn't a lot of expertise on climate change per se, in the disability community. However, there are lots of ways in which combating climate change intersects with things that people with disabilities do know a lot about. So for instance, I would argue, if you're someone who has been as as is the case in many parts of the world, advocating for your mass transit system to be accessible to you, as a person who has a impairment, whether sensory or in terms of physical mobility- Well, I think your climate activist, the climate activist, because we know that we need to reduce reliance on automobiles, and promoting mass transit making that more accessible not only to people with disabilities, but to anyone else who could also benefit from an accessible mass transit system, that's going to reduce carbon emissions. If you're an expert in disaster, risk reduction, then when those those risks are caused or fueled by climate change, then you are also an expert in climate adaptation and resilience. And there's so much that we can learn about the stories of people who are on the frontlines of fighting for their rights, in ways that intersect with the challenges that societies face in responding to climate change. Finally, if you're if you're a person with a disability, and you're confronted by a range of challenges on a daily basis, living in a world that's not been built with your needs and perspectives in mind, you must necessarily develop a whole set of skills and really practices of resilience. I like to think that many people with disabilities are experts in resilience. And even though we've seen in the pandemic that's still unfolding, that the majority of the victims in the world are, have a disability. I also know and have seen online commentary from people with disabilities who have also pointed out "okay, well, I was actually kind of ready for this, like, I faced challenges like this, in terms of accessing food or transportation," or, specifically, you know, as people have had to work remotely, it's been a huge psychological adjustment for people and very hard. But if you were someone who was already remote working remotely, because of your disability, then the learning curve was not the same. And, in fact, you may have found that you were, basically that that adjustment challenge wasn't the same. So I just think, in general, you know, if we look at long term trends around climate change, we're going to live in a more challenging world. And I think that we should look to the expertise of people who, because of disabling policies and environments have had to learn how to live and thrive even in really difficult circumstances.

Ellen Spannagel 24:17

So you've talked to me about how people with disabilities are makers, knowers and doers of climate action, and have lots of agency. But you've also talked about how people with disabilities are experiencing the effects of climate change in different ways worldwide, someone who is experiencing like, for example, a heatwave in Montreal is not going to feel the effects the same way as someone in Fiji. So I'm wondering maybe if you could explain how you think about the tension of people who have disabilities as agents and like who, who are enabled to do climate justice work and take part in climate action, but also like these systems of inequality.

Sébastien Jodoin 25:05

Yeah, well, thanks for asking. It's something that I, that I care a lot about, and think a lot about. And I want to start by saying, you know, that ice vest I mentioned, as something I had found to deal with heat. Well, now it's in, you know, it's in my basement. Even in the summer, I don't I don't use it anymore. I don't need to use it. So I've had this, this advanced treatment for multiple sclerosis, which has basically eliminated the symptom that I used to have heat sensitivity. And so why have I had this treatment? Well, I live in a wealthy country, this treatment has developed in specifically from my condition, and I'm sure that my gender has played some role in the treatment that I've received. And the education that I have has also played some role in the treatment that I've received. There's lots of research, showing that doctors take the pain of men more seriously than women. I'm also convinced and that, you know, my education has helped me sort of understand research and advocate for myself in different ways. And so this complicates the story of agency, at least as far as this story that I tell about the ice vest, right? So that's particular to, to my circumstances. It's relatively rare today that you'll find people who will say that change only occurs because of the actions of individuals. Usually, there's some recognition that there are structures at play that enable change, or make it less likely.

So we also see from research on climate change, that the vulnerability of people to different climate impacts is something that's exacerbated, or the product of these existing inequalities. And that these inequalities will play a role also in the ability of different people to, to exert agency and transform the world around them. So in the research on climate resilience and disability rights that we are intending to do in India, we're explicitly going to look at the factors that make it possible for people with disabilities to be agents of climate resilience. So we are recognizing and interested in understanding and unpacking what are the conditions that make it possible for people with disabilities to be knowers, makers, and doers. So on the one hand, we want to recognize the agency of people with disabilities. And at the same time, we also want to look at what are the contextual factors that make someone's disability more or less likely to be able to act as an agent and then influence the world around them. And so we, we anticipate, of course, that other intersecting forms of oppression will play an important role in the ability of people with disabilities to act as agents. And here we'll be looking at, specifically children, women, queer individuals, and of course, looking also at the impact of socio-economic background and education, on on this role that people can play in enhancing their resilience and shaping the world around them.

Ellen Spannagel 28:29

It really helps me understand like how it's, it's an individual, like enabling individual people to take part in climate action, but also, these bigger systems of oppression. And I feel like that also helps relate to the idea of like enabling the commons. That's, that's what I'm thinking about right now, when you're explaining to me how to remove these barriers and make it easier for people in different contexts to be Makers, Knowers and Doers of clime action. This is a very humbling conversation for me, like I feel like I'm learning a lot. I'm really excited to learn more about some of the ways that people with disabilities are known as makers and doers of climate action and hear a little bit more about the stories that you're going to tell with the DICARP program. So I'm wondering if maybe just to know a little bit more and be a little bit excited about what's to come, if you can just tell me what is next for DICARP in the immediate future.

Sébastien Jodoin 29:23

So as soon as conditions allow, we'll initiate our research project looking at climate resilience of people with disabilities in India, we will continue to do legal and policy research and put together briefs and other types of capacity building materials with people in the disability community to not only reach people with disabilities and let them know about the importance of climate change for their rights and their struggles, but also to inform people in the climate movement about what disability is what rights people disabilities have what what accessibility means. How to organize an accessible climate activism initiative. And then finally, through the DICARP website, through webinars, through one day in person events, and through this podcast, we want people with disabilities to share their stories of how climate change is affecting them, how they are responding to climate change, and how they are playing an important role in the climate movement, and what needs to be done to further empower them in that context.

Ellen Spannagel 30:33

So thank you for answering all my questions. I know asked you a lot of questions today. I feel like in some ways, like I learned a lot, but in other ways, I feel like we barely scratched the surface as to some some of these points and like greater issues within disability in the climate movement. What would you like to say to just the way to think about?

Sébastien Jodoin 30:55

Well, I guess the last thing I would say is that, um, you know, we decided to start this series of interviews with me. Because that way, I could explain sort of the genesis of DICARP, and the broader sort of vision. But actually, you know, going back to what I said earlier, well, I'm this is still the perspective of a person who is an academic, who has lots of privilege. And what I want us to do in this podcast series, is really reflect and center other voices that have had different experiences of oppression, and have also, I'm thinking about all the people that you'll be interviewing, and they all have way more experience in the disability rights movement, across a variety of contexts than I do. And so I'm really excited to hear their stories. And I look forward to to the next series of interviews in this in this first season of this podcast.

Ellen Spannagel 31:53

Thank you so much Sebastien for giving me your time today. And yeah, I also look forwardto hearing about the experience and the knowledge and for the other people we're going to be speaking with. So thank you for giving me all your time today and sharing your knowledge.

Sébastien Jodoin 32:09

You're welcome.

Ellen Spannagel

Thank you for listening to Enabling Commons. Stay tuned for our next episode and take care.