

Peter Fremlin 2025 – podcast

In this episode of Inclusion Europe Radio, we welcome Peter Fremlin, known for his newsletter, [Disability Debrief](#).

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Milan: Welcome again to Inclusion Europe Radio. These have been interesting weeks and months for our podcast. We received a lot of feedback, and our episodes have been welcomed with interest. So, if you didn't listen to them already, don't miss them. But without any further delay, our guest of today: Peter Fremlin. Plenty of you will know him from his newsletter *Disability debrief*, but those who don't, I will ask Peter to introduce himself to the audience. With him we will, maybe tour the world again in this podcast as this is what Peter does in his newsletter. So, Peter, happy to talk to you and having you in our podcast. I kindly ask you to introduce yourself to our listeners.

Peter: Really nice to be here. Thanks. Thanks for having me. And hi to everyone. I'm Peter. I'm from the UK, where I grew up and from there, I started touring the world. First, I travelled a bit as a kid with my parents, but then I started touring the world to get as far away as possible from the UK. So, I started working in Bangladesh focusing on disability issues in international development. After the 10 years of doing that in different places, I accidentally started this newsletter called *Disability Debrief* as a side project just to keep colleagues up to date. But now that's my main job. *Disability Debrief* is a weekly newsletter sharing disability news around the world. I hope people can check it out if they don't know it yet. Now I'm back in the UK and I travel the world digitally.

Milan: I like how the newsletter started accidentally as I think that a lot of good things start by an accident. So, thanks for the brief introduction. I recommend people to check it. I read it every week. It's always full of information and interesting takes and insights. We'll talk about some of those things, later. But what does a Disability debrief do?

Peter: It's a type of a media platform with news on disability from around the world. One sort of motto I have is: *Putting a disability lens on World News*. So, it does different things. The accidental start was like I'm working on disability policy and development and there's a lot of resources coming out. We felt a bit overwhelmed by that. So, I thought, let's just help my colleagues in keeping track. Now there's a kind of really specialist audience at its heart, and it's still read by policymakers and disability specialists or activists within the community around the world. It shares the news and the changes on disability and how people were trying to make countries and policies better for disabled people. The newsletter got into the other components, which was more analysis. The biggest accident of this project was that during its development I

became a journalist. People pointed out that I was asking questions, doing research and then sharing it with people. This was journalism and I was like: ok let's continue in this way and that's where we are now. So, there's really kind of exclusive reporting on stories that you won't read elsewhere. And now in particular, one of the things that I'm most proud of is having created a space where other people can share their stories and insights. For example, stories like the one of Rachel Litchman writing about being stuck at home in the US and explaining how stories of disability online weren't representing her. Another example, Kate Ero writing about the situation of people with albinism around the world. She also tried to change the situation within the United Nations system based on her own experience. So, you can kind of see it's really bringing out lived experience and hearing from these amazing people that you have met through disability work. Their own experiences then become a fire with which they try to change the world. And there are so many amazing stories, and I really try to bring out those that are kind of creative and different. I try each week to make a little bit of a surprise. Late this week, I wrote about Pope Francis and how he was using a wheelchair for the last few years of his life.

The week before I wrote about the Global disability Summit, where we both met, I tried to keep it different for new readers. I write at the top, *what's in this edition* so the readers can decide if it is interesting for them or waiting the next week. And obviously I expect you to read every word, but I try to make it navigable and there is no compulsion to read everything. It's divided into sections, and I like sharing a lot of information creatively.

Milan I'm not, entirely sure if I fulfil your expectation one hundred percent. I'm shocked. So, you put a lot of words into the newsletters. It's, a lot of work to get through it. But I want to go back to what you were saying. I think there were these two kinds of key elements that you were describing. First there are so many things happening, so many policy developments, news and disability space, especially as you are looking at it from the global perspective. So, there is always something happening and it comes to the issue all of us face: *how do we first make sense of all these things?* And all of us, I think, have kind of tried to deal with this in our own way. For example, I've read this, I've seen this news, I read this report, would it be useful to make it available to others? Etc. And I think we are all sorts of trying to figure this out in different ways, across organizations, across individuals in those organizations etc. So, I like that it has emerged. That was one of the reasons why you started the newsletter, and the other one is the focus on people. To me another very strong and personal strong element of this is what I always talk about when we have some workshops on how advocacy should be on and how should communication be about people. We need to make it about people, and I think a lot of times the disability conversation becomes too policy heavy instead. So, I just wanted to say that I really like it. I like the perspective of that. You bring all the different voices, and you have people contributing to the newsletter. That, of course, opens to all sorts of different perspectives. But would you also just go back a little bit to the first element of it, the one-off *making the news and the*

developments, around the world? This must be a lot of work, just getting your head around everything that's happening.

Peter: I think there's another component that's important for me as well, which is, not just the news from what's being produced on disability, but how the news in the world affects disabled people. Yeah. Right. So, for instance, when the US makes big aid cuts that really affects, disabled people directly. A couple of years ago we did a series, led by Costello on climate change and disability because whether that was on our radars or not is going to affect us. So, I kind of really think like how our societies are changing and how are disabled people, according on that. Like I was proud to do a coverage of disabled people in Sudan when the war broke out. And that was one sort of exclusive pieces I had in terms of keeping up.

A friend of mine told me: look what disability debrief shows is like, keeping up with the literature in your field. You don't have to make it your job to do so. Right. That's partly the shift. At first it was like, I'm not reading these reports I'm seeing them but I'm going to share it with colleagues, and this will make me less stressed as I am putting it on someone else's plate. And now that I can read it a bit more because this is my job now, it also allowed me to build up a process. I just gather links from the social media of the newsletter. People send it to me like everywhere. And I like to have a file literally of 500 links and then once a month I'm like, well, let's go. And then I go through them, and they go into database on the debrief website. There's now a library of over 6,000 items and I do it all by hand. I think that's important to stress now that it's human curated. It's not an AI picking this out. It's me looking at it. Is this novel, is this interesting? Does this put a new light on something? Will readers find it interesting? Asking those questions and then sharing the news based on those answers. And then it's this kind of alchemy of like I've worked in disability staff for over 10 years, so like I'm a bit sort of some things I've heard before and less likely to share them. But if it's something that comes from a country that I get very little news from, I'm like, let's share from there. And so, there is like a couple of days per month where you won't hear from me on email. Because I'm like loading those 500 links and going through it. And then turning that out. It is really a project built in community, so people send me information and new connections come from it. I think our connection comes out of the debrief as well, if I'm not mistaken. like you are interacting and responding, and then conversations come out of that. And so, it's an important conversation starter. And I would say, it's the community infrastructure element as well. Like, what keeps us together? What are we reading, where are we getting news from? Sometimes organizations get a little bit focused on their own activities on just producing a report but not thinking about how you share it and get it out. Yeah. Sometimes it's important to get your report out. Sometimes it's important to get someone else's report out. Like taking an independent view.

Milan: Our first interaction happened because I came across your newsletter and started reading and then started interacting by when Twitter was useful. What I want to say with this is that I think that part of the job for you, for us at Inclusion, for everybody essentially, has become much

harder now in the sense that social media platforms are getting into more and more fragmentation.

Peter: You're totally right social media is a bit more fragmented, but it's also not just that, it has become very clear. Social media does not have their interests at heart. They will not. Like even if you click on Instagram, you want to follow someone, Instagram will decide whether you see that post or not, not you. Right? So, we really must be proactive about our media consumption. This is one of the reasons for doing a newsletter, is that it's like a kind of more direct communication. If you put in the email. If you put in you emerges, you'll get it and then you decide whether you read it. I think that we've got a lot of digital tools and possibilities to stay in touch with each other, but just posting on social media has made us a bit blasé. I think we need to think about how we as consumers are, how we're proactive about what we follow. And, as kind of creators of the disability community, we need to be creative like finding spaces and ways to be in touch and I mean, sometimes just the right WhatsApp group can change the world. Right. It's kind of a challenge, on how we do that in terms of dissemination, I kind of really noticed that pattern of putting a lot of effort into making the report doesn't mean putting effort into sharing that. Are you putting effort into like, telling that story in different ways for different audiences? Are you doing podcasts about it? Are you going to do webinars about it? Are you getting to people in different ways? And it's difficult because you've got to get out from the research mentality you are in when you're doing the report. And you need to be thinking like, well, what does different audience want to hear? And you chuck out a bunch of what you had. And there isn't enough investment in like developing trust with an audience so that they know how to listen. I think even on the social medias in other fields, you get a little bit more specialists saying, oh, here's this report, here's why I think it's interesting, and here's the highlight. And that's just useful thinking out loud in public. This sector never had so much of that online. Like the threads on Twitter, I think you are one of the few that use social media that way, and I really appreciate it, like sharing your thoughts. Thank you.

Milan: That's exactly what I like. I essentially stopped doing it because I don't see any platform where it would work anymore. Right. Because, as you said, you can put things out and it doesn't mean that anybody will see them anyway because the algorithm completely overrides anything. So even people who choose to follow you for some reason will not necessarily be able to see what you post. So, an important, part is just sharing and cultivating a conversation about these things. I mean it's like: we've seen this, we've read this, let's put out some highlights. Either just as a highlight, this is what matters to us, or we add some additional thoughts and reflections. This is what I think, let's talk about stuff like that.

Peter: For sure. I think that this would be valuable because most people aren't going to read most reports, but you can get thoughts like that. I know it's a big challenge for the debrief and I see it as I've got this unique access to people on email. A wide range of people, they trust it, and they give time to what I'm putting out. It's sort of bit beyond my capacity now, but I'm wondering

how I then like connecting and making more discussions. Sometimes they have discord or slack channels for subscribers. How we like, help connecting people in that community and what terms they want to connect, which might be a bit different from, from what our interests are. So that's kind always an interesting thing. But yeah, it is essential for all of us to be thinking this through because it is the connections that are going to save us.

Milan: I think I'll also go back to, another thing that you mentioned, and I speak obviously as one that works for one organization of many that produces reports and does projects and whatever. And you are saying that there is a lot of times, when most of the energy goes into producing those reports, and much less goes into, making sure that somebody sees the reports and reads them and understands the points that we are trying to make. And I think that is an important message that you're bringing here. It, it's one of the topics that I spend a lot of time talking about, both within the team and with our members across Europe with inclusion Europe. The communication on the work we do is not something that comes after we've done the work. Right.

Because when that usually happens, it can be because we have no more time for it. For example, we are moving to some other report or something else. We try to make sure that people can understand the points we are making, can see the reports, can take some lessons from them. It's an integral part to what we do. It's, and it should be for all advocacy organizations or disability? I think so. I just wanted to go back to that.

Peter: Yeah, there's a big gap here if you're going to think about it more in terms of the social view of the results. When I am doing a debrief, I always struggle. When you say policy, it can sound boring, but what policy is about is looking at how we make social change. Right. And social change is interesting. Right. So, policy is boring. Social change is interesting and it's something, here there is this huge gap. When I was growing up as a disabled person in the UK when I was nine years old, the Disability Discrimination Act passed. Right. This was passed because of disabled people protesting and campaigning. Right? That was an act that made sure that I had equal chances growing up as a disabled person, that I could go to mainstream schools, I could sort of pursue what I wanted to pursue etc. By then, did I know about that? Right? No. I was told that this is like, this is happening because there are disabled people. Literally, I can get on a bus today because disabled people chained themselves in front of buses. Yeah. I was not aware of that and it's something obviously I feel very strongly as a disabled person, but I mean obviously it'd be great for everyone to be more aware of this. On the policy side I think that it's really in our interest to make people more aware. Maybe a wider number of disabled people won't like some of what we're doing and that's important to hear them, but maybe they'll be helpful. Most people covered by disability policy legislation don't even know that they are covered by it. They are not thinking of themselves in those terms. So, we've got that real challenge. The other side of this (that you were kind of mentioning), is that people centred thing, that's an important part of what I do now on the debrief. And this also comes out from my lived

experience when I was as a policy head talking about disabled people, passengers with disabilities or whatever. I was just saying, *I wouldn't like you to talk about my life like this*. You know, you generalize and get into the vulnerabilities, all the barriers and everything that's going wrong. And it's like: I know my life has magic in it as it's not just barriers. Disability also brought me a vocation, a community, a way to connect with people, a way to express myself and my physicality. It's also much more than that. But you wouldn't know that from what I was writing professionally. So it was that collision, the real search for that in a philosophical sense to kind put that clash. Like there's a truth in lived experience for me and we need to bring that out, but also in a communication sense, right? That is just much more interesting for a listener, right? To hear about a person involved. So, there's, I think there's that as well as all these technicalities about how we do. There are the deeper questions underneath it for me. Yeah.

Milan: And I think this is hearing about people and people essentially understand the world through stories. It's like we as human beings, we are interested in other human beings. We are not interested in whatever big numbers and abstract policies or any of that stuff. And I think, for a lot of understandable reasons, there's been a sort of big move away from telling people's stories because a lot of what is labelled as telling a story in the intellectual disability space is very cheesy. Tokenistic, however we want to look at it, it is a branded approach to picking people with intellectual disabilities, forcing them to say very private things somewhere at a conference and then sign of moving them away and you continue with your conversation. There are of course elements also of the patient inspiration. Yeah, the inspiration, right? Like, a person does the most basic stuff in life and people go all theory, right? And what is crazy about it is how amazing this is. So inspiring. So, all of this to say that it is understandable that a lot of the work has moved away from telling the stories of people because there's been a lot of bad stuff with that. But I think in the process as well, we've lost the, the humanity of it, right? It's become about a policy and as you say, policy sounds very boring. How it is done is very boring. I think we all need to try to bring back the humanity, the human element. It's about people and it's for people.

Peter: Yeah. Exactly. This is important. I also got some criticism from a reader that was like: *you're making it too individual; you are losing track of the social things*. You can demonstrate that there is another factor here. How do we tell stories to mainstream audiences? Yeah. How do we tell our own stories? Yeah. And I think there's an important difference, and something I'm doing on the debrief is *let's do it our way*. This isn't a mainstream publication. I'm not trying to get the general population on side. If the general population comes and is interested, they can, but it's in our terms. This is done by a disabled editor with majority writers and illustrators. Let's do it our way and tell our story without letting go. Like what we need to prove it to the mainstream community. Because otherwise you just get into all the same old discussions of needing. Why is this an important subject? Why proving it every time from square one that I am a human that has worth? Like, oh look, I can work. Let me show you how I can work. And you just must get into that proof. Like so many of these discussions with the mainstream are like that. You see a lot of disability memoirs then come out in this way like no, look, this is like trying to

figure out these bad ideas. You have these X, Y, and Z, and what I'm doing on the debrief, that is absolutely needed. I kind of see myself in different part of the puzzle. I'm telling my story on my own terms and when I invite contributors, I invite them to do the same. When I highlight different voices, that's what I'm looking for, to highlight our stories on our own terms because our community needs that. Right? Yeah. What we then tell the wider world is a separate issue. And there are many different versions of that, but we can't be silent about our own stories, on our own terms because the outer world isn't ready for it. We need to do it anyway.

Milan: And I think what you just said, I find very important the change from where you start the conversation. This is something that we try to do similarly on some of the topics. For example, like on institutionalization for people with intellectual disabilities, one of the ways we try to approach it is: we are not justifying it anymore, right? It's settled. We take it as a given. And that, I think, really changes the conversation, right? A lot of advocacy works. So, I can say more about what you mean by taking it as a given. We've settled the argument that the institutions are bad. Right. And we now investigate, okay, let's get on with the work. And that's, I'm just saying it as an example of why what you said resonates me. Because I think it's a similar dynamic of where you start the conversation and how a lot of the advocacy communication works. Oftentimes it starts from: *let's justify everything, every time again*. And that undermines the argument and takes away the attention.

Peter: So, I think that's important to (I love what you just said) start the conversation on our terms. I think that's important.

Milan: We can't always do it, but of course it is always possible. And as I say, we try to do it with the institutionalisation. It doesn't mean that it always works or it's always succeeding or anything. It is just that we can get rid of pulling ourselves backwards. A lot of the advocacy work and a lot of the communication essentially puts us on the back foot already. And then we must justify, renegotiate everything all over again. And that's what you were saying, right? Like this is your space. You are telling it you don't need to justify in every single piece that. Like the things that, you don't feel like you need to justify. And I, really think that's important for the audience.

Peter: I just wanted to never try to justify like people with disabilities have worth as humans on an equal base with us. That's what we're starting from, not justifying, because when you justify it, there's no end to it. Yeah. Like I used to work on kind of employment issues, and they would say, are you sure the disabled person can do the job? And you end up with a 20-pages scientific paper, proving that this person can do the job safely. With other candidates you ask, like you meet another candidate, you have a chat with them, you check a reference, you hire them. Like maybe it works out, maybe you don't. But like on the disabled candidate you're scared about it, you're like, oh, like tell me, like prove to me from like every scientific angle that this is okay. And like you can never prove everything's going to be okay. So, it's unending. Yeah. There's this social construction of disabilities such in terms of risks, such in terms of can't do, and then the

own nurses proving it will all be okay. And then, and then it's a very self-defeating thing because as soon as you prove, like an example of someone who is living in the community and living in their own house and making decisions in their own life and look how beautiful it is, then they'll be like, well, that's the exception.

And you're like, well, of course it's the exception. Like if you've created the scenario, so no one else gets that chance. Yeah. But then it's kind of, the exception then that proves the fact that everyone else shouldn't be there. It's something I was really thinking ahead of this interview I did with Raul K Enson on segregation in Germany. He was kind of arguing the way you break the segregation. He was like : I can't promise everything will be okay in a mainstream environment, but like we need pioneers, to do it. And that's the only way. He was kind of arguing, it's through encounter that it changes because in Germany the segregation is like very locked in, like from school to work to living places. Then in the incentives of all those organizations, to keep people in those spaces and to get out of this you just must do it. If something goes wrong, there are people on hand to support and help making it better.

Milan: I just do it like there is no other way. Like there is no laboratory environment in which these things can be made perfect for every individual with disabilities. And then you can apply that perfection to people, right? Like you need to do things with all kinds of considerations and measure based on the individual needs. But it's not possible to create inclusion while keeping people segregated and preparing them for being included. Right.

Peter: So how do you balance that? Because some forms of institutionalization are quite reckless and they're just closing thing overnight and turfing people out on the streets and there's quite a few examples of it going wrong or into models that aren't necessarily better. How do you balance this need to just do it with the real knowledge. You might not put the concerns and at the same time in the same way as people are blocking the process, but you also have concerns about the process.

Milan: Yeah but just doing doesn't mean just do anything. We know what the institutionalization means. We know what it could support. For people, it looks like this is not. We talk about this, posting, it's not rocket science. It's not a wheel that needs to be invented like we all know this. So yeah, when I say just do it, I mean do it in the right way and let's discuss and have a conversation.

It doesn't mean do anything. And as long as you use the word deinstitutionalisation, it's fine. Right.

Peter: It is tough. And I mean, it brings us to next part of the conversation as well: governments and disability policies. Giving one hand and taking the other is so often the theme.

Milan: And exactly as you said, it brings us to the other topic. So, let's go into it. I wanted to ask about, a theme, if I can call it that. Wherever I go nowadays, whoever I talk to across Europe, there is one thing that we hear to all the time. There might be some good stuff happening, but for most countries it seems that we are going backwards. Right? There are cuts to visibility and the budgets of organizations that support people with disabilities. I was at Malta last week to talk about inclusive education and the conclusion from that meeting was that we have no inclusive education in Malta anymore. We used to have it, like we don't have it anymore. I've heard people from Nordic countries talking about things that are really getting worse. Did you know? Do you hear similar things, globally? What are your thoughts about, this development?

Peter: Yeah. That's really striking to hear about something as a fundamental as inclusive education. Which maybe just listening to your question that puts some of the issues more starkly than I'd realized. I think there are a few dimensions to this. Like one dimension is many of us got in the idea. That progress was unidirectional. Yeah. Right. And I think that idea doesn't serve us in, in many ways. Right? Like, I think it was never very helpful to understand the differences between countries because it was always a whole. US and UK are ahead or whatever, but the others not. And sometimes there was the mentality (in other places you'd go) that you'd put off progress until you got into their ways. And from the US and UK there was a bit mentality of: *we don't just need to listen to other people because we're ahead*. And both of those were, false. Like we'd assumed we'd won more battles than we'd won. I think it's more shifting. Right? I think in terms of kind of two specific points, one is kind of like how this can be. I've seen it in the UK in the past 10, 20 years becoming undermined and we've gone backwards in that sense. And then the other is the current moment that we're in, right? The last few years. Right. The UK is quite an interesting example in going backwards because we used to be going forward, right. And we were like brewing up social models here and there and sort of coming up with this great thinking, being proud of ourselves with this vibrant disability movement that secured legislation that made my life as disabled better. And they're still doing it. Those recently built train line in London, the reason I can use it as a wheelchair user is not because people were following standards automatically, but because of campaigners were like: *what the hell, how are you making a new train line without thinking about this?* And then accessibility was more built in. Absolutely, love it. But over the past 10, 20 years, like particularly in terms of austerity brought policies, there is, as you say, less funding to disability organizations. There is now cutting of the benefits to disabled people, deliberate scapegoating by government of disabled people as being quote unquote benefit frauds. Even though they are benefit fraud is a tiny, factor in disability benefits. And that one has really gone backwards. And it puts, again, in terms of like conversations in our own terms, the conversation entirely on the back foot and it has turned disability campaigning into like: oh, we really need these benefits, otherwise we'd be so helpless. Right? That's not the bold social model liberational agenda that we'd wanted, to go on about. That is a very much on the back foot, desperately trying to scramble onto something and explaining how we're so much in need, which isn't like the nice story to tell. We are in another kind of slightly confusing aspect that makes it hard to tell the direction of travel, because now so

many more people are saying the right thing. So, there's a piece, and I'll send it to you so we can put it in the episode. It is *Turning the tide* by Fazilet Hadi on disability. And she points out that, like in the good old days, people would just tell you if the old days were away. So, you knew where you stood. Right. Now people say like, oh, we are respecting the riots etc. And then like, they'll screw you anyway. So, it's now much harder to tell where you stand. Yeah. In terms of really going backwards unfortunately the prospect is opening now. Like in terms of the current political and economic moment, the economic prospect in Europe looks a bit tough. And look, it's not exactly that. We have been unlawful for years now. Like we haven't necessarily had that growth. I think the new political reconfiguration, the need to be investing more in military staff, takes away from these investments and social issues in a more progressive social policy. So that is a real challenge. We also see this attack being led in the states that explicitly attack diversity, equality and inclusion issues. That is kind of presenting people that get social benefits from the states as entirely fraudulent, or just a scheme for illegal immigrants. I think one of the disgusting things Elon Musk has said, that to me is really worrying. As I kind of said at the beginning, a lot of my career was international corporation. International Corporation budgets are being cut nearly everywhere. The biggest supporter was the US and this is something. Like in debt. I mean, it ties in some European countries because many European countries were benefiting from international corporation, particularly maybe in Eastern and sort of outer edges of Europe, and distributed organizations were getting small amounts of money. But those were the amounts of money that let them run do things to challenge the governments etc. A lot of that money is now gone. Maybe they also got funding from the European Commission that now is also doable. What happens is that now *we need to buy tanks* or whatever we are doing. So that's really challenging. Both in the US but also around the world, you see real threat to civil society. Right. And we really need civil society because we want that independent organizations represent our voice in a way, independently of government, part of the whole point of disability organization. We can say to government, look, what you're doing isn't working right. But you can only do that in an environment where government is happy to have an organization that says to you what they are doing. Seeing NGOs as suspicious, as foreign agents, as agents of woke is a troubling threat to our work, to these possibilities for us to come together. We were kind of like going, like all saying deinstitutionalization is the right direction. Even the UK is like allegedly, like according to some stories of deinstitutionalization, but we still have people living in residential facilities that they can't go to hospitals and we're still making new ones. And we have young people in these situations. How would you do it? And I'm like, oh, I mean, we don't have the numbers or the information on it. So, I think that's been like under the radar. So, is it going like forwards or backwards? It's unclear.

Milan: I think it's an important part, like how do we figure out a way of talking about issues that matter to people with disabilities so that the non-disabled part of the society can hear all those things and be informed about them?

Peter: Yeah, I think there's a couple of things like, first a lot of disabled people don't know about what we are doing. So, it's also to reach them and lots of disabled people who we might identify as disabled people wouldn't necessarily use that term about themselves. So, it's showing the broader society not plugged in on these issues. Like the relevance. I think that's important. I don't take it as criticism at all because they both are needed. I kind of see like my own role now is a bit more curious for community and disability. I'm glad you're thinking of that because I think it's one of the important roles of an organization like Inclusion Europe. And I think that one of the challenges of this kind of going backwards moment is like, oh, so what messages are to double down or what messages are to change? Now we've got a kind of, both governments and societies are more sceptical about the idea of an organization going on about like social issues and riots and like all this kind of woke stuff. How do you show it a wider audience? No, it is important to have a disability led organization, the use of the reasons for it. How do you show them that, to get them interested in this use of funds? Because now if governments aren't going to give us money, we must figure out how to get money from other people. So, we must figure out how to sell this right story to two different audiences to have both their commitment and new sources of money. And that's really, I would say a kind of increasingly question of survival. And I worry that established disability organizations are not necessarily pivoting to the new circumstances and be able to embrace the challenge of: *okay, as well as what we've been doing, we need to explore many new approaches and see how to make new partnerships and talk about these issues in different ways to different audiences, and yet find, different funders of the work.* I'm bit concerned about the consequences of going backwards haven't been taken on board by people that need to address it. It's that some people insist there should be a purity on the activist organization versus the organization that's more like giving direct assistance or services. But I'm less of a purist about that. And I kind of think *you've got to find a way to make a sustainable organization and keep onto your mission.* And I really wish people developed more guidance about that one. One example I've been giving quite a lot recently is, as someone writing a newsletter, I have 20 different resources on the internet of other people making newsletters saying how to make a newsletter, right? This is how you make the business side of it, this is how you do the content, just like down to microscopic detail, but there aren't similar resources if you want to make a disability led organization, like affecting policy in your country, right? There aren't those resources on like, well how are you going to fund this?

How are you going to do the policy work? How, what works? What doesn't, what failed for me? What is working for other organizations? And I think like, I would really see an organization like Inclusion Europe and many others as, in part responsible for helping, to do that and helping in bringing people together in a network, but also helping them in developing connections independently on their own terms because now we can no longer bring people to the centre and promise them that like a good flow of money is going to be coming because like, well, we don't know. Like we must help people make the tools. I see this a bit more like the responsibility of people like yourself than my own. But I think your question is valuable and an important thing for my reporting. One thing that I am reporting on, or I'm sort of commissioning pieces is on

how people have worked on disability in environments where civil society is closing. Right? So, I'm kind of exploring that, like the pros and cons. Established organizations will have to cozy up to government bodies and from the outside, it will look disgusting. But you kind of have to do it. And I think it will also be good for disabled people if there are some people still on the inside as well as all of us, like dissatisfied, and complaining on the outside. And that will be a complicated balance as well. Saying how to do things, how we are doing things. I think it's important and interesting in a few different ways. One is this whole project of these organizations is quite interesting, right? Like how do you speak for disabled people as an organization? What are those processes of representation like how are you finding the different views of people? How are you putting them together? We talk a lot about representative organizations of disabled people, but I very rarely see like organizations saying, look, well these are the processes and like the challenges of it and here's what we were able to represent and here what we weren't personally. I would find their positions more convincing if they shared that. Right. And I think that I would say to others. Right. I think it's interesting from another point of view, because basically we're trying to do a lot with small budgets, right? Like we're just a tiny organization and we're like our ambition is roughly to change all of society and we've got three people in the office and well, let's go. Exactly. It's really, like David and Goliath Tale, like it's just brilliant. How are you doing this? And the best disability advocacy you just look at and it's like; how did you do that? Yeah. There's just like an amazing sort of story.

And I think also just on the fundraising thing now. The approach that I take on the debrief to fundraising is like: *I'm going to tell you exactly how I do this and why I am doing this and please help.* Yeah, this is why I need help and that's this very small scale that I've done that it's been quite effective. Sometimes it gets into then: oh, *like look at the starving child, please give him five pounds.* We give it directly to the starving child. We don't have any like salaries at all. Nothing like that's going on here. And I think that's a bit dishonest about how social change works. But I think there's a really sort of interesting and one that would get people in and from other sectors quite interested in it. Like I think the disability sector has just so many interesting stories that, I mean, if we told them, other people would be interested because they will be like: *How are you? Yeah. How are you tackling some of the hardest problems that you could imagine in some of the most rigid systems and attitudes against us?* And like changing also what people are imagining a human in this society can be. And you're just doing that with like four people in an office with some dreams. I mean it's kind of exciting. Let's not keep this to ourselves or hide it behind like processes or commissions or rights or whatever. It's kind of vivaciousness.

Milan: Yeah. And I was just now thinking that this was nice and optimistic. It would be almost ideal to finish the podcast here. And thank you very much. This is lovely but obviously I won't do that yet. There was another element. You said that people would trust in some organization if they could see and the organizations would also talk more openly about how they do, how the representation works and what are the challenges they face. And, it just really got my attention,

what you said about being honest. I think about how this is like, let's not pretend that we've solved everything.

Peter: I take all your points about the reasons why we don't do it and there's this big pressure to try and be perfect. And sometimes I'm wondering like, am I like undermining? Because I don't want to give arguments like our enemies, right? I think there's a real contribution to be made here because our democracies are struggling with ways and forms of representation, right? Like we don't feel represented by our political parties. Right. We don't feel like we have input in so many so-called democratic countries now, we don't feel we have input. Can we help resolve a pothole outside my house? Or like, I see a road outside my house that needs a zebra crossing. I don't have faith that the local government is close enough to me that they'll listen to something that's obviously needed. Right. On disability, we are making new forms of representation. We're saying, look, if you're going to make a policy about this community, you have to take on and listen to the voices of this community. And we are bringing people together and we're speaking about that, right. We are doing something innovative and socially important, something that could really be part of refreshing democracy. Right. Let's tell people about it. Yeah. Right. And tell people about how it's working, like no one. We have like everywhere sort of diminishing faith in how our society is on our side, if our governments are our side and what not. That's kind of uniting across us, across political persuasions. We've each got a different explanation for why that is the case and on disability we are finding like this way to bridge it. This concept of nothing about us without us is so powerful. Like showing people like how you put that into practice. How you say like you've got a policy. Then you're translating it into easy read. You're helping to workshop it. You're getting an opinion from this group of people. You know, this group of people is only like a subset, but you're trying to make it diverse in whatever ways. I'm kind of like projecting a bit on what you must be doing, but I mean that's just such an important thing and it is a real model for like how other policies could be made as well. So we are really like hiding our best thing. If we are not sharing that. And just like, I think it's no longer something people are buying to say we are representative, right? Because I mean, we don't buy that when the political party tells us why would we buy that when the social organization says it? But if we can show like what the means are, then that would be an important social contribution, not just in our field. Yeah.

Milan: Okay. Well, I didn't end it on the optimism side. I'll end it on this. Very at least to me interesting. And then as they like to say in Brussels thought provoking, element, Thank you, Peter. I really enjoyed talking to you. It was a lot of topics. We could go on for much longer. I'm sure we can maybe, revisit the conversation at some point in the future. I really enjoyed it. Thank you very much. I'll say to all listeners, obviously go, find the disability debrief newsletter and subscribe. Read Peter's description about how he makes it and why he needs the fundraising and decide for yourself what to do next.

Peter: It was a pleasure. Thank you so much. It's always a pleasure to speak with you and I really appreciate how we can get into these other topics and through stuff together. I really enjoyed that.