Ellen Spannagel ([00:01](https://www.rev.com/transcript-editor/Edit?token=7HFPaKqrKoEvfWXfDN1QlVlu7MZYmIBFPp02q_eI5eaAkEGv_XzGdl9mF2aaGCyxH8K85k2sOFFiWKdvgWmuZBO0CwQ&loadFrom=DocumentDeeplink&ts=1.71)):

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.

Hello, my name is Ellen Spannagel and this is Enabling Commons. Today, we are very lucky to have Marcie Roth, as our guest. Marcie is the CEO of the World Institute on disability and has served in senior leadership roles for both national and global disability advocacy and public policy organizations for over 25 years. So Marcie, thank you so much for joining me today.

Marcie Roth ([00:24](https://www.rev.com/transcript-editor/Edit?token=PDqEOL8eJc7EujI2oD3ua2CV5YTPrcet3SyuDSMs-okkHX6rwmOMRjcgaopfQeiaATfucuG3bnmW0NhVCMihcKeNOss&loadFrom=DocumentDeeplink&ts=24.02)):

Thank you so much for having me. I'm excited about this opportunity to speak with you.

Ellen Spannagel ([00:28](https://www.rev.com/transcript-editor/Edit?token=LF8fAlM_T5ahVtr2iJaOmBVlXK2mjejPOczwkDM76RNI9GjD9l3xCL_bsPaOaAVP2PML5qBSqUAvS8wPncv71yu9cXM&loadFrom=DocumentDeeplink&ts=28.59)):

Yes, I am also very excited. Before I get into some of the more meat and bones questions, I'm just wondering if you could just tell me a little bit about yourself.

Marcie Roth ([00:38](https://www.rev.com/transcript-editor/Edit?token=yRwpjZa8b2YtOQN5CyV0zTi0dltBWcp8m5Dvfb1G5jseq-7rG7bUebYscsaPEW2AbFC5_xyTHBiGbOt_OvC1lxfDlQg&loadFrom=DocumentDeeplink&ts=38.15)):

Sure. I have been working in disability rights, my whole career. I'm a person with a disability, myself, both of my children have disabilities. Most other members of my family have disabilities. And so I've always worked in disability rights, but just about 20 years ago in the immediate days, following the September 11th terrorist attacks, I found myself taking a leadership role in the U S because lots of people with disabilities were in the area around ground zero and were suddenly cut off from a lot of the supports and services that they need in order to maintain their health, their safety, their independence. And so that began a 20 year journey for me in which my focus on disability rights took a much more laser view of what happens for people with disabilities before, during and after disasters. I've been with the world Institute on disability for just a little over a year. I had previously spent almost eight years leading a US government initiative around the federal emergency management agencies, commitment to disability inclusion. I've spent many years now working globally on disability, inclusive disaster risk reduction. Very involved with the development and implementation of the Sendai framework, and currently very involved with the United nations around the humanitarian action initiatives for persons with disabilities and as well, the implementation of the UN disability inclusion strategy. And that's a short version of them of what I've been working

Ellen Spannagel ([02:51](https://www.rev.com/transcript-editor/Edit?token=mkKK7o3ZcIhSVzo1C-g_3l9xEApZA9-xbnMCbEIvSk_Wt-4uXXXjnmR5hpSpvHIc2JZQJMCkI6yWAceDVlQpULqPD_0&loadFrom=DocumentDeeplink&ts=171.77)):

Short, but definitely very hefty, there's a lot there. You have a lot of experience in different areas of disability rights, for sure. But I'm wondering given, I mean, your twenty-five experience, when exactly did you start to include climate change and your work to advance the rights of persons with disabilities? I know you mentioned the Sendai framework, but I'm wondering if you could elaborate a little bit on when you became involved with the intersection of disability and climate change.

Marcie Roth ([03:25](https://www.rev.com/transcript-editor/Edit?token=WUMKQIiRvCd76u0Hn5qFJ5Mlw2VMrSEASFs9FdC4Ei_gKBztqIvMm7eP9Cnrukgk58vA2n7HZ66LwatUREsJRUIU-_k&loadFrom=DocumentDeeplink&ts=205.23)):

Well, you know, it's interesting because my very earliest involvement in disability rights, I was a high school student and the first earth day was in 1969, 1970. And I found myself working at a glass recycling center. And that was really sort of the first time that I began to think about our global home mother earth and the climate that we are so affected by even something that came into my awareness. Over the years, as more of my focus was on extreme weather and on the issues of migration for people with disabilities who are so often left behind issues around building better after disasters and universal design and the many opportunities to not just meet legal requirements or building standards, but in fact, to create living environments that are equitable, that are, accessible for everyone, that community resilience is really only possible when people with disabilities and everybody else are able to access the environment.

Marcie Roth ([04:54](https://www.rev.com/transcript-editor/Edit?token=gWGa9uu3Ugq_MJ7E363_N7QRIJKEWPOF1CmmkTkOXogQdlJO9J_nlc43ZrdP_-xxBjdAhtEgam25-G_V1BDufrkOwjc&loadFrom=DocumentDeeplink&ts=294.75)):

So it's always been just sort of a natural part of what I do, but it wasn't until climate change, and I'm making air quotes, as I say, this climate change and the sustainable development goals, and the beginning to be aware of both the intersections and the silos between so much of the work going on around me, that I started to really think about where the climate justice work overlays the work in all of these other key areas. And quite honestly I have been alarmed and remain pretty concerned about the fact that everything is still so siloed. And so, as we talk about disabilities, it's especially important that we make sure that we're busting through any of those silos. You know, we have a saying in the disability community, nothing about us without us, and while disability organizations may not contribute massively to reducing the carbon footprint. We certainly, whether it's transportation or, you know, I mean, we could, we'll probably get into more of this in our discussion, but people with disabilities, disability led organizations, local community justice work are all very interwoven and intersectional if we allow them to be.

Ellen Spannagel ([06:34](https://www.rev.com/transcript-editor/Edit?token=l72BQinQ8Mp5d2sLeUeyFPhd1Im6fbHnooK4XEWf4kcIzcD3VEA5qN7zJ5miX4sHDlaLOMOOgS32RiCKtYHnmJynq9A&loadFrom=DocumentDeeplink&ts=394)):

Thank you. Thank you so much for elaborating a little bit on that. You brought up the idea of like community resilience and relying on the knowledge of local disability led organizations. I'm wondering if you could tell me a little bit more about that in relation to what you have learned about disaster preparedness and emergency response over the year. So this could be in relation to you know, like the area around grounds zero but also just in general, what have you learned about disaster preparedness and like community resilience among like disability led organizations, but also just persons with disabilities themselves and their communities and what are some of those takeaways that we could apply in the same way to responses to the climate crisis, but even just generally, you know, like in the context of COVID too.

Marcie Roth ([07:27](https://www.rev.com/transcript-editor/Edit?token=Jo_ZMhYlPNedf3Dajw7-JK_LXwsn2O-ISOj_T5wc9R7jeFoq4ArsV54X4zd92hGRkApE3cJ9Y0gaGo3yAHmj6BF0KX4&loadFrom=DocumentDeeplink&ts=447.97)):

Good. Yeah. So, you know, having worked for the us federal government throughout the Obama administration and having worked globally with government for many, many years, I have seen a tremendous amount of money invested in what's referred to as preparedness. And we could talk about lots and lots of recent disasters, whether, you know, we're talking about hurricanes or wildfires or tornadoes or cyclones or mudslides, floods, you know, I could go through that whole list of the things that are sort of described as natural disasters. But if you look at what's been happening with all of those, and then you look at COVID all that investment in preparedness hasn't much helped anybody. You know, I said for years that the preparedness initiatives, which, you know, would sort of typically tell people three days of food and water, and you need seven days of your medication and sort of have this whole list and you need a flashlight and you need duct tape and you, you know, and those lists would typically start with something like you need seven days of your medication, or sometimes it would even be more, and at least here in the US, that's not possible for most people.

Marcie Roth ([09:05](https://www.rev.com/transcript-editor/Edit?token=d9BVTqByB4UDmoPbnmE65mUeseAnELBuVTuzpyaKB7bPW4j2bZ7G7ZjV2mePKyFlcmG0DXJ674zZORr3xPFwjPqukNA&loadFrom=DocumentDeeplink&ts=545.25)):

If you try to get an extra supply of your medication, your insurance provider, or the federal government, if they are providing your medical insurance, you're not going to get an extra seven days of medication. Right out of the gate, we tell people things that are really not achievable. And then, you know, beyond that, it's hard to imagine that people are going to pay attention to anything else. And then with regard to community preparedness, so very often communities prepare for people with disabilities and not with us. And even more often, in fact, we are not considered at all, whether it's the, including us in exercises, simulations, drills, whatever you call them, you know, they often will use actors or stuffed animals, or people will hang a sign around their neck saying, you know, "I'm deaf," but they're not using real people with real life experiences. Alerts and warnings fail miserably in providing equal access to effective communication that is actionable in a disaster. Information has to be accessible to be actionable.

Marcie Roth ([10:27](https://www.rev.com/transcript-editor/Edit?token=_vudh1-BxvYPX2x-ZC8nwG-KhwVlb8P3OrIlAGqufiFmuCDagTAIlXG12K-AulpzNTELMgMQoIcNDa3Z8W0gbYX45zQ&loadFrom=DocumentDeeplink&ts=627.18)):

And then, you know, whether it's building evacuation or whether it's moving to a safer area, whether it's across town, out of state, what have you, very little is in included in the emergency planning processes and having spent years and years and years trying to embed disability inclusion throughout those practices. I unfortunately know all too well, how ill-prepared local communities are to accommodate people with disabilities in their preparedness. Sheltering is a huge issue. Local shelters are very frequently not accessible to people with disabilities. So you have simply getting in the doors is an issue issue moving around using the bathroom showers meals, you know, I could go on and on. And so for all of that preparedness and all that money spent, our communities are really ill prepared for disasters. Then to take it one step farther in a pandemic in a public health emergency, think about all of those preparedness actions, and none of those really apply. Shutting down the whole world within a very brief period of time, had such a devastating impact on so many people with disabilities. And then, and let me add, you know, there are lots of people who say, "well, you know, COVID-19, who could have seen that coming," well, for those of us who've been working in emergency management, we've been seeing that coming for a very long time. And in fact, I have participated in many projects, programs, initiatives in which we exercised some of those circumstances. And it's very obvious that all that planning has done us no good. To make matters, even more complicated, you know, now you add a concurrent disaster to a public health emergency, and we are here in the U S we've had several catastrophic hurricanes floods, wildfires tornadoes this year that have really forced some very difficult circumstances around how to safely evacuate, how to safely shelter.

Marcie Roth ([13:05](https://www.rev.com/transcript-editor/Edit?token=r1Gv8djTJhSFFHF9orC6UKWLN_vqK51cTqKECAxeMZAuv-WYMj1BhKgfsH11Lb8zz3ct3yo46aMiyAob6spfsMRuZtc&loadFrom=DocumentDeeplink&ts=785.14)):

And so to me, much of what has gone into emergency preparedness has really failed to consider the reality for people. And then you take the devastating impact of that on people who have been living in congregate facilities. Here we are 40% of all of the deaths have been in long-term care facilities. Really, even they're being described as nursing homes and long-term care facilities. I don't even think we're counting the people who are in carceral facilities, you know, jails, prisons, criminal justice facilities. We're not counting people in group homes. We're not considering people in other sorts of facilities, such as, you know, detention centers and people in psychiatric hospitals or mental health facilities. You know, I could go on and on. But even if we just stick with that 40% of all of the deaths here in the us, just over the past week, there have been people dying in congregate facilities at a rate of about 300 every hour, which is just a shocking number and going up.

Marcie Roth ([14:32](https://www.rev.com/transcript-editor/Edit?token=yBsSaOirlG9weiLQSTpE6CjN7EH8R3Uutf2vfIrMWpOK_cMtBxNVUyKP70agau7rOR5qE4DTr31qLRHNLXkhPzU1Njg&loadFrom=DocumentDeeplink&ts=872.65)):

And unfortunately, people are still being admitted to these congregate facilities to relieve overcrowding in the hospitals because the hospitals are beyond a hundred percent capacity. And then one of the facts that is overlooked is that all of the debt in these congregate facilities globally, the people who are dying in the congregate facilities are virtually 100% people with disabilities. And people have often, they'll sort of look surprised when I say that. And it's like, "Oh no, you know, they're, they're older people. They're fragile people. They're people who have underlying conditions" and they use all these other words, but those are all words for people with disabilities and nursing homes are not for old people. You don't go to a nursing home because you're old. You go to a nursing home because you have a disability and your community doesn't have the supports and services in place for you to maintain your health, your safety and your independence.

Marcie Roth ([15:43](https://www.rev.com/transcript-editor/Edit?token=eZs2V1jpC-37iAKq7m9oEDiSt4qep__Mlh6Hkq4w8fPG_p1-jGcM09hOMmJzr2Q7IVWS9fmhrCfEo7J3EoevGvZ3YTA&loadFrom=DocumentDeeplink&ts=943.46)):

And that is true globally. Whatever the number is on any particular day, I know that at least 40% of the people who died that day were people with disabilities, who are entitled to civil rights protections in some places. Human rights protections everywhere. And yet there have been absolutely no indications that the rights of people with disabilities have been protected. In fact, we've had to deal with rationing issues. Many people with disabilities have been denied access to people who they choose to provide care and assistance. People who are deaf have been denied sign language, interpreters, so many injustices, and many, many, many people with disabilities have died alone without any support in these congregate facilities. When in fact they had the right to be living in the community and not in these facilities. As the world Institute on disability has been focusing on all of these areas, emergency preparedness, disaster, risk reduction, climate resilience, one thing that we have very clearly learned, I've learned over the many years that I've been working in all of this is that the humanitarian relief that comes to communities in crisis, whether it's because of slow moving disasters, secondary to climate change or rapid onset disasters, maybe climate related, maybe not, in almost every case, local disability led organizations are completely left out of any of the more traditional humanitarian relief resources. And so earlier this year, we started , founded Global Alliance. It's called the Global Alliance for Disaster Resource Acceleration. And it is a collaboration between disability led organizations, corporate and foundation funders, allies, accomplices, who are working together to match the people who have resources like the corporations and the foundations to match them with those local disability led organizations to rapidly respond and support those local communities in their most challenging times. We've held a number of town hall meetings. We've had participants from now 69 countries. Our most recent event was a summit led by young people with disabilities, talking about their role in climate change, climate justice, disability rights, humanitarian action. And we're, we're very excited about the opportunity to match those local folks and the leaders from our communities who are taking all of this forward with corporate and foundation folks who typically don't see their support going directly to the folks on the ground.

Ellen Spannagel ([19:27](https://www.rev.com/transcript-editor/Edit?token=IuxnS4zj6ywD4nTjmPXg3TlSZkbLl-nLtVsnYPjqHcBQqmwxk7uBwjrdxVglAdlPHKrs_cJMNH5ZWwBVOTtREZisiIw&loadFrom=DocumentDeeplink&ts=1167.59)):

Yeah. First of all, thank you so much for providing like a really close to home explanation of everything that's happening right now in the United States, but also talking about how, like, this is not like exceptional to the U S like, this is just from my position, like the same things are happening in Canada and also in the world as well. So I really appreciate you just speaking to your experience and your knowledge about that, but I'm wondering a little bit more about involving like corporate stakeholders and funders. I'm wondering if you could tell me how people have responded to your work so far.

Marcie Roth ([20:02](https://www.rev.com/transcript-editor/Edit?token=_w8pFjz1Z-Hon1adgwCKerMqJ8ttp-vfDwFNTlDrXEADuJNwnEeAS0iW-CX-2lKahxpyRXg5dDyBvdsqAevvou5Ao9c&loadFrom=DocumentDeeplink&ts=1202)):

So for instance we have an amazing relationship with Bristol-Myers Squibb and they actually came to us last week. They are part of our founders circle. And they came to us last week because they operate globally and they operate in Columbia, which was very hard hit by hurricane iota last week. And so we are working together to identify immediate needs and rapidly directing support to those who have been most significantly impacted. So we're working with the organizations that we have relationships with in central America, and they are bringing to the table other corporate folks and foundation folks that they have relationships with. And as of yesterday, they have begun a fundraising initiative with their employees, that the company is matching two to one, all donations from their employees, and this will support the work that we're doing so that our GADRA team, which is, you know, led by the world Institute on disability, the Partnership for Inclusive Disaster Strategies and Inclusiva, we're all working together with each of the roles that we play to identify what are the disability related supplies and equipment that people in this hard hit area need?

Marcie Roth ([22:00](https://www.rev.com/transcript-editor/Edit?token=VwlhVrN5JUn126bvAb5L3RchoJJAyLidZZOFNtc8snCAIeRtv8ueROueU1QnwgumcBFwYBXf9wSNPeI-n7_9rWGV9oA&loadFrom=DocumentDeeplink&ts=1320.31)):

What are the things that the organizations that serve them need in order to either continue their operations or resume their operations? Because they're the local experts, they're the folks who know what the needs are in their community and what goes wrong so much of the time is that the generosity of humanitarian relief never really quite makes it to the local folks on the ground. And so right now, as we speak, we are shifting that paradigm to address the immediate housing needs, the immediate disability-related needs the healthcare, basic clean water and, and food and building supplies and transportation issues that people with disabilities and the organizations led by people with disabilities are left out of. And surely hurricane iota, and all of those that proceeded it this year, we're very much a result of climate change, but there has been very little justice in terms of the equitable focus on accessibility, on equal access for all of the people impacted by those climate-related disasters.

Marcie Roth ([23:39](https://www.rev.com/transcript-editor/Edit?token=_99w3GBIupWqmjwL8IKTHd4qlf-TrNVyc2tBPc_cGpeGr6DPMSEJloJoAsv8hqT2zWr4FetwGscUnkbdagEIs1wjrDM&loadFrom=DocumentDeeplink&ts=1419.13)):

Certainly in an atmosphere of COVID, as you can imagine, people with disabilities are in so much more jeopardy. And so whether it's providing the kinds of support that keeps people out of those dangerous congregate facilities, or whether it's just simply getting personal protective equipment, PPE to disaster, impacted people with disabilities and the organizations that are serving them, the wheels of relief move far too slowly. And they fall very far from those small organizations fighting to keep people alive. And so GADRA is a gap filler. That's what we're, that's what we're about. We're not replacing something we're filling the gaps with folks who want to do the next right thing and want to make sure that it's getting to the right people. And then we continue to work with those folks to be ready for the next disaster, the next climate related impact that that community is going to need to deal with.

Marcie Roth ([25:00](https://www.rev.com/transcript-editor/Edit?token=IhHl8VyuSq90Ri9kZM7IQu9OG-pbgyp1mDBxBAQ_F_t3AgwB0dzZyvYxzl29w4HusEMBb_u1YAW0PDNtOK74AiEZYgs&loadFrom=DocumentDeeplink&ts=1500.02)):

One of our sayings is that GADRA is disrupting exclusion and accelerating radical inclusion. It's a focus on eliminating the typical exclusion of those organizations and people with disabilities and accelerating their inclusion in ways that are radical, because we have typically failed miserably in accounting for making room, lifting up leaders to assume those important leadership roles. And it's especially important that as we're talking about all of this, that we both acknowledge and operate from the understanding that we must be centering black and Brown, Indigenous, people of color people who are multiply marginalized at the heart of all that we're doing. The disproportionate impact of all of this is so clearly felt by people with disabilities and especially people of color, multiple marginalized people who live in poverty. And if we don't center our work in disability justice, even the disability work is siloed. We need to center everything that we're doing around the people with lived experience who are so disproportionately excluded.

Ellen Spannagel ([26:45](https://www.rev.com/transcript-editor/Edit?token=Tm4Qj7XNP4nRQZfNkp4rPOgKIJe7dHoaNtUI-Fl4wn-_tLBGfUgrw0jYZppRRJAQxjlsfpcv-QQ-RVDgpZiYxmLaqqs&loadFrom=DocumentDeeplink&ts=1605.86)):

I really, I really like thinking about it that way. From something you just said, you you're talking about like prioritizing the needs of local communities and about how, like, that's, that's what you're trying to do is bridge that gap to make sure that those needs are prioritized and at the center, what is your message for people who are working in these organizations who are doing work like disability, justice work, climate justice, work, racial justice work as well in relation to the needs of persons with disabilities.

Marcie Roth ([27:36](https://www.rev.com/transcript-editor/Edit?token=_48KCdZZsGr9mHg2cG6WlVpgc-_OpG0PIpoG-5kxPz_foqaQFdhaGP_bUX_H2Od9Z0GNTaZL-aLTaJ5CD-WSifVwFk0&loadFrom=DocumentDeeplink&ts=1656.11)):

My overarching message is that we must find ways to support each other and to work collaboratively if we believe nothing about us without us, which we absolutely do, then we need to make sure that disability-led organizations are in a leadership role. You know, there's a lot of organizations that think they're disability-led organizations because they may have a staff leader who has a disability, but we operate from the convention for the rights of persons with disabilities definition which I'll, I'll take a moment and share. WID Defines disability led organizations or disabled persons organizations: "these are representative organizations or groups of persons with disabilities, where persons with disabilities constitute a majority of the overall staff board and volunteers in all levels of the organization and disability led organizations, DPOs , have an understanding of disability in accordance with the social model, which notes that barriers are caused by society rather than by a person's disability."

Marcie Roth ([29:09](https://www.rev.com/transcript-editor/Edit?token=aGc43EehoL6F7PS4aZ4Nq5TqG0eJ3uiMlH0EA1x2RW5TmGLuNUSoSO4A4qfLmSZCD7rlO4qoCN42rECflE_dNtVSK90&loadFrom=DocumentDeeplink&ts=1749.68)):

And it's particularly important to make that distinction because there are lots of organizations that serve people with disabilities, who many of whom approach disability from more of a medical model, but many organizations who are not intentionally disability-led intentionally governed by people with disabilities. That's one of the important messages from my perspective. If there aren't disability led organizations at your leadership table, and if we're not being accommodated with the accessibility accommodations that we required, then we're really not at your table until we're getting that part right, just like I said earlier about resilience, communities will never be resilient unless the whole community has the accessibility and the accommodations that they need in order to benefit from all of those resilience initiatives.

New Speaker ([30:23](https://www.rev.com/transcript-editor/Edit?token=RQ-L_sF5FkYAutCOdKz44gphl8nSikPzbt7e2XaKxAaKb2A30tYpA5X_r9J5COhOwuREjD71CuJNN23byv4ou4DDTvs&loadFrom=DocumentDeeplink&ts=1823.53)):

So my question is how are disability led organizations being held up? What is it that folks are doing to center, disability led organizations and the people in them. What's working? Supporting these organizations rather than funding organizations that are disability service organizations or organizations that have a very important mission, but that are not the organizations led by people with lived experience intentionally. If funders are really committed to bonafide inclusion of people with disabilities as leaders, not offering a place at the table or not being authentic about offering that place at the table, you know, sort of like, um, well, " I would very much like to participate, but, uh, I might be a person who needs a sign language interpreter in order to participate. Oh, well, we don't have a budget for that. Or maybe we can find somebody to donate those services." Those are examples of miserably failing to be authentic in wanting to include people with disabilities. Oftentimes we need some people with disabilities, but we're not really talking about people with intellectual disabilities or psychosocial disabilities. We're not really serious about people who don't speak English. Those are some of the things that really can't be afterthoughts. They can't be nice to have, they need to be legitimate elements of an organization's commitment to disability inclusion. And also with regard to, you know, siloing, we have so many people who are working in climate justice, environmental justice, and the sustainable development goals and the convention on the rights of persons with disabilities. I mean, I could go on and on public health emergencies versus, you know, extreme weather emergencies. I mean, there's all these silos with a very laser focus. And unfortunately for people with disabilities and disability led organizations, it's very hard to be at all of those tables and having to convince everyone that accessibility is an imperative. And yet if we're not at those tables, accessibility falls right off the priority list. I believe there needs to be sort of a core set of values, principles, standards, that are not just words but words into action without exceptions.

Ellen Spannagel ([30:25](https://www.rev.com/transcript-editor/Edit?token=cGHXy8QXenm5so1iL3Er7qgV0axBhzNYWTqTjbhlB8Z1cVNAv_bwFF9Xh046S89iDvYV45zDK60tdt0ccyaAzMprqlE&loadFrom=DocumentDeeplink&ts=1825.11)):

As you were saying, like, this has obviously been a trying a couple of months, I don't have the words. But I'm wondering just in terms of your own like self care and also like your own like vision for like moving forward and like keeping going, what is, what is something that is at the forefront of your mind during this period in relation to disability justice.

Marcie Roth ([30:47](https://www.rev.com/transcript-editor/Edit?token=Xpdqn88npwwqeRtcItqeJU4_DgyKDJEdODYwH5sa4LYNcTZs_aorMXC20AWAGCtaB9BCjHoFbIv4CgPi6Pafd1LIUF4&loadFrom=DocumentDeeplink&ts=1847.16)):

I'm happy to actually go personal because this has been an amazing time. It has been, you know the genocide of people with disabilities in congregate facilities somebody the other day called it heard eugenics, which I thought was another interesting way of using herd immunity. So first and foremost, I have been devastated by the lack of focus on our siblings in those congregate facilities. You know, even today as COVID is absolutely out of control, it's not too late for the people who have not yet been impacted by the failures of our systems. For me, the part of all of this that has absolutely been the hardest has been the lack of care, lack of attention, lack of importance, lack of humanity, towards people with disabilities in facilities. The failures to improve home and community based services, to keep people out of facilities, devastating.

Marcie Roth ([32:32](https://www.rev.com/transcript-editor/Edit?token=MSXnyLe7dgZG6hKYId8_xNKRKy6xPX3fwb-ZdGXaGBh5-B-RlVkbzGiC7iHZ2DOP8NW2hNNQmg60NzQB1JmnBGkT87I&loadFrom=DocumentDeeplink&ts=1952.82)):

The fact that we've had to argue about the rationing of care - that rationing of care should never be predicated on what someone's perception is of the value of someone else and denying people, the supports and services that they need. I mean, it's just, all of that has been incredibly disheartening. So self-care for me, you know, as a person who, you know, I have a lot of chronic pain and I also have a lot of stamina issues at times. And so for me, working from home and not being constantly on planes has actually been wonderful. It has made it possible for the World Institute on Disability to operate more broadly. And, you know, we were able, we're very fortunate. We were able to very seamlessly move our operations from a lot of in-person to totally remote operations. Many, many, many people are not fortunate in that way.

Marcie Roth ([34:00](https://www.rev.com/transcript-editor/Edit?token=xmg_X1MqNtqMhJm3_xMvsmcadQQdnA4XpgFpue4UpuFxjShKDEuSosIr2BuBHwCMxt9arDl59HxXdYDr0Nl3fv4zBAM&loadFrom=DocumentDeeplink&ts=2040.71)):

And while many people with disabilities have lost their jobs, we are confident that savvy companies are really in a position to hire lots more people with disabilities because of the accommodations that become more readily available. So we are very hopeful that multiply marginalized people with disabilities, rather than being excluded, in fact, this is a time when great opportunities lie ahead. So my parting statement to all of us is, you know, I appreciate the buzz around building back better. I would strongly encourage that we're building forward better. We do not want to go back. We want to move forward. So let's, let's build forward better from here.

Ellen Spannagel ([35:07](https://www.rev.com/transcript-editor/Edit?token=pcNqBz-sQihgCN7zl6DR3_xhaK3RFonkmXyHUgsjS_Fd-ZzbaKmUwAte0Af1pWsnUu3JDoW2l5-ZZ_0D8LSV5MN-ATc&loadFrom=DocumentDeeplink&ts=2107.9)):

Yeah. I really like that. Building forward together. So I just wanted to give you like a super heartfelt thank you from the bottom of my heart for taking the time to talk to me today and yeah, just for sharing all of your knowledge. It's yeah, you, you have such an interesting perspective as your position as CEO and then also your experience so...

Marcie Roth ([35:48](https://www.rev.com/transcript-editor/Edit?token=70GR-j_8aiZ02p9hJ2nB0yiOlgfJTCmdFbQGmG3OUN4TOCYOfdxZ2Qp2LfjyAS3oOC1oqGMtdSGxkvWNS1JTC9qdSFY&loadFrom=DocumentDeeplink&ts=2148.71)):

Yeah. Thank you. And, and I'd love to keep talking.

Ellen Spannagel

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