

Unsung Stewards



ReThink
Health
A RIPPEL INITIATIVE

PODCAST

Colin Killick
Executive Director,
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Hosted by Katy Evans



[00:00:00] **Katy:** In 2020 FORESIGHT, an initiative of The Rippel Foundation set out to hear from thousands of people across the country about how they envision a more sustainable and equitable future, and to begin to chart pathways toward achieving that. I'm your host, Katy Evans, and in this series of the Unsung Stewards podcast, we talk with people who are doing the hard work of imagining and building a new future in this moment. At Rippel, we call these people stewards. Stewards are people or organizations who take responsibility for working with others to create conditions that all people need to thrive.

[00:00:44] Today, we are so excited to welcome Colin Killick to the podcast. Colin is the Executive Director of the Disability Policy Consortium based in Massachusetts and a leader in the disability rights community.

[00:00:56] Colin, thank you so much for being here.

[00:00:58] **Colin:** Thank you so much for having me. I'm tremendously excited for this.

[00:01:01] **Katy:** Well, I would love to have you start just by telling us a bit about yourself, how you came to the Disability Rights Movement and the work of Disability Policy Consortium.

[00:01:10] **Colin:** I sort of stumbled into this by accident and then discovered it was what I'd always wanted to do with my life. So growing up, you know, my parents are progressive, right? My mother marched against the Vietnam War, a teenager. My dad was involved in student protests against the Apartheid in South Africa. You know, I've been going to marches and political volunteering since I was maybe, you know, 10 years old. And separately from that, I have a couple of disabilities.

[00:01:33] Most relevant. I have a neurological disorder called Motor Dysgraphia, which the short version makes. Fine motor skills. It didn't develop properly, which means I can't really tie shoes, I can't eat with chopsticks, and it's extremely difficult for me to write by hand and through the first part of my education that was this massive stumbling block.

[00:01:54] Writing was painful. It was difficult. I was so focused on how I was writing and they couldn't really focus on what I was writing. Some classes would let me use a laptop, but it would come with penalties. Some places, you know, they would be someone like literally standing over my shoulder to make sure I wasn't cheating.

[00:02:09] Or I went to one school where they gave me an automatic C minus every quarter for refusing to hand write. And then in seventh grade I had finally, you know, a special education person at the school who, who knew what they were doing, and said, Oh, you have a disability, you can get this thing called a 504 plan.

[00:02:28] And that will mean that you will have a civil right to get accommodations for your disability, to use a laptop in class. And it changed my life essentially overnight. I went from, you know, getting C's in some of my classes to getting A's. I discovered, once I didn't have to physically write that I loved writing and I, I married my, my interest in, in education with my, my passion for, for advocacy.

[00:02:55] I went to, to college, got my degree in political economy, and I did a year of AmeriCorps. And while I was in that, got recruited to join this disability commission here in, in Summerville, Massachusetts, where I lived. And then I started meeting. Disabled people, meeting activists in our community who had been involved in the fight to pass to the Section 504 regulations that had given me my plan, and I learned that this law that had transformed my life was not some.

[00:03:25] Gift from a benevolent government on high that had literally come about because disabled protestors had taken over a federal building in San Francisco and occupied it until the federal governments agreed to enact disability rights laws. And I also started seeing how profound the oppression of our community was in the present day.

[00:03:51] You know, the, the fact that we are more than twice as likely to be homeless than people without disabilities, that we are the least employed lowest income community in, you know, in this country. The fact that we make up half of all people killed by police. And I wish, like this is my cause. And initially I think I had a lot of fear that I know I wasn't disabled enough, but I, I've never been treated with anything but open arms by this community. And it's been a privilege to get to work every day on an issue that's so close to my heart and to feel like I get to pay forward, you know, the work that was done for me for the next generation of people with disabilities.

[00:04:27] **Katy:** Colin, can you share about the work that you're doing through the Disability Policy Consortium, your work there?

[00:04:34] **Colin:** We are a statewide civil rights advocacy and research organization based in the greater Boston area, around 25 staff, more than 75% of whom are people with disabilities. I mean, even disability rights organizations aren't always necessarily run by people with disabilities. You know, with us, every single member of our senior leadership team has a disability and we have people with, you know, every kind of disability, you know, across the organization from autism and mental health diagnosis.

[00:05:03] To paraplegia. We have multiple deaf employees and we do not succeed in spite of our disabilities. We succeed because of our disability. We have user expertise, We have lived experience in these systems and lets us know better how to modify them, how to dismantle them, where necessary, and our work. You know, it really wants the gamut, but we do participatory research on both a local and national level, you know, with partners including.

[00:05:28] The Lurie Institute for disability policy. At Brandeis, we run a program called May Ombudsman, which is the only Medicaid ombudsman program in the country, run by people with disabilities. Over the last eight years, we've helped thousands of people with disabilities negotiate. With their Medicaid plans to get services that they need to, to live and to thrive, whether that's power wheelchairs or personal care attendance services, or even basic things like oxygen.

[00:05:57] But the, the core of our work is community organizing and policy development. Our credo is about us by us. So there's, there's a phrase, nothing about us without us, right? This idea of if a decisions being made about our community, because people with disabilities are constantly infantilized, constantly have sort of, Well meaning people talk over us.

[00:06:21] Tell us what we need. My late predecessor and mentor John Winsky coined this phrase about us by us to say people with disabilities don't just need to have a seat at the table. They need to be at the head of the table where decisions affecting us are concerned. So we don't just consult on research projects to make sure that they're sensitive to disability.

[00:06:40] We lead them. We don't just serve on existing, you know, bodies to bring a disability perspective, and we create new forums. We do grassroots organizing within our communities to determine what problems they're facing, and then we develop and introduce and work, do our best to pass legislation to actually address those subjects.

[00:07:01] **Katy:** We have all been living in a pandemic for more than two years now, and I'm curious if you can tell us what the impact of covid and the events of the last few years, what the impact of those has been on the disability community and what the last several years have revealed about the way we as a society or community think about the lives of people with disabilities.

[00:07:25] **Colin:** It's been horrifying. There's a phrase that I've come to use in some of these contexts, which is I've never been more upset to be right because people with disabilities have been saying for years. Our healthcare system was failing us, that we were the victims of life threatening discrimination, that institutions like nursing homes were not only harmful to people's dignity and independence, but that they were actively unsafe and that.

[00:07:52] The healthcare system and the broader policy system as a whole quite literally valued our lives less than the lives of people without disabilities. We were told over and over again before covid that we were way off base on all of those things. Every single one of those has been made just starkly obvious by Covid.

[00:08:10] Data is hard to come by here in Massachusetts, for instance, the Department of Public Health did not collect any data on disability in any of their survey instruments. We don't know how many of disabled people in Massachusetts died of COVID in total, but other states national data data from other countries would seem to suggest that on the order of two thirds of people killed by Covid 19 have had disabilities.\

[00:08:33] We make up 20% of the population. And the last thing I would say is the devaluing of our lives. I did a lot of work on the use of cost effectiveness metrics in healthcare used in cost effectiveness analysis. Typically a prescription drugs, although it could be used for any healthcare treatment, it analyzes two aspects of the value that the treatment could provide, how it affects life extension and how it affects quality of life.

[00:08:59] But it measures quality of life by presuming that life with a disability is inherently less valuable than life without disability, that you can put in numerical values. That's the percentage of a healthy life that the life of someone with a specific disability is worth. So if a drug would keep you alive into current health state, if it wouldn't cure you, but it would keep you alive for 10 years.

[00:09:26] But your condition has a disability weight of, or let's say it's 20% right? A drug would keep you alive for 10 more years. It gets credit for two quality adjusted life years because 10 years of your life is just to be as valuable as two years of a non-disabled person's life. Which means the more disabled you are, the less it is worth spending to keep you alive.

[00:09:51] So we argued, this is discriminatory. This is taking away our civil rights. But we were told these metrics were just there for use in price negotiations. They were there to bring down the price of prescription drugs, which we support. We were told by a lot of liberal organizations, progressive organizations, that no one would ever use this kind of approach to deny lifesaving care to people with disabilities.

[00:10:13] And then covid hit and there were shortages of ventilators and hospital beds, you know, And you know, our healthcare system was being pummed and policymakers across the country immediately started putting policies in place. To deny people lifesaving care cause of their disability. You know, in some it was blatant like Alabama, where they put together standards saying that intellectually disabled people would not even be admitted to the ICU because their lives were just to be less worth saving.

[00:10:43] Or you saw it play out in individual cases, like in Texas where a black paraplegic college professor was removed from life support by a judge and his doctor over the objections of his wife because they judged his life was not worth living. But even here in Massachusetts, right, Deep blue, progressive Massachusetts.

[00:11:02] The state adopted crisis standards of care, which said that the goal should not be to save the most lives, but to save the most life years, which meant if you had any condition unrelated to covid that would shorten your life expectancy. If you had cancer or heart disease or diabetes or asthma, you go to the back of the line for life saving treatment.

[00:11:25] If you have one of you know many, many disabilities, you go to the back of the line for life saving treatment. So we led the fight against those standards. We got them repealed, interview the second set of standards that were slightly better, but still really bad. We got those repealed. Finally, they got sick enough of me shouting at them that they put me on the committee that wrote the third set of standards.

[00:11:46] And I am proud of who we ended up. We, we put in some really important safeguards for people with disabilities, but I had to have those conversations with doctors, medical, smart people where had to, you know, make a logical case. For why it wasn't a good idea to let members of our community die. Why, You know, we shouldn't go with the popular moral intuition hearing, you know, things like, how do you expect a doctor to explain to a family why they didn't save their, you know, younger, healthier kid.

[00:12:20] Instead of an older, more disabled person, I'm having to say back, because our commonwealth should not be in the position of deciding that some people's lives are more valuable than other people's lives. So that's where I am, you know, And that's what we're still doing because you know, that is going on and the problem is still incredibly severe. Our community was put on the chopping block deliberately during this pandemic.

[00:12:43] **Katy:** You have been leading the charge a new non-discrimination legislation in Massachusetts through your work with the Disability Policy Consortium, and I think building on what you've described as the conditions that you saw and fought against during covid, can you tell us about that legislation and the future you are trying to build through it? The new legacy if you're trying to create through that work.

[00:13:06] **Colin:** Yeah. Actually we're at kinda a pivotal moment in the Massachusetts state legislature. It's an act relative to preventing discrimination against persons with disabilities in the provision of healthcare. One is, it would prevent the state, but also just as importantly, individual hospitals, medical providers, right, from denying someone treatment because of a disability or from rationing treatment on the basis of disability.

[00:13:31] So you couldn't say, you know, We're going to give these drugs to, you know, to these people first, or we're gonna deny this person to hospital bed because they'll consume too many resources. The other thing this legislation would do is around the issue of do not resuscitate. Now we've heard a lot of discussion, but why?

[00:13:51] DNRs, you know, can be a good thing when they reflect people's wishes. You know, people worrying that, you know, if they don't have one in place, that that more steps will be taken to keep them alive than they would want. But with people with disabilities, it's actually been somewhat the opposite. There's been real abuse of DNRs.

[00:14:08] People with disabilities being pressured to sign DNRs, especially during the pandemic, saying that they don't want to be kept alive when they do want to be kept alive because of this perception that our lives are less worth living. Oregon actually passed a law, putting important guardrails. In place in this process making it illegal to pressure disabled people preferentially to sign DNRs or to condition receiving any treatment on having a DNR.

[00:14:36] And we heard a couple of really powerful pieces of testimony. One from a woman who's a wheelchair user herself who had her medical providers. When she was hospitalized during the pandemic, repeatedly push her to sign a DNR that she did not want to sign because they told her flat out, they believed that she had a low quality of life and that given her low quality of life, it would be inappropriate to keep her alive. But that really shows you what our community is dealing with. So this bill was incredibly, important.

[00:15:04] **Katy:** So you and I have known each other for several years. We met through FORESIGHT the Rippel initiative designed to equitably envision a new future for health and wellbeing, and you are an advisor on that effort. So I'm curious, as you look to the future, which is part of what we were doing together in FORESIGHT, and thinking about the challenges and the opportunities that are on the horizon, what vision you hold for the world that we need to achieve and,

and how we get there, the kinds of conversations we need to be having and the kinds of legacies we need to build, like the legacies that were created for you that have put you on this path.

[00:15:39] **Colin:** What I wanna envision is a world. That breaks the link between disability and poverty, where having a disability is no more tied to the likelihood that you will succeed, that you'll be able to achieve your goals, the likelihood that you will be independent and self-directed and successful in whatever way you define it, than being left handed or having green eyes.

[00:16:01] In your, in your, a world in which people with disabilities will be valued for who they are and the perspective and the expertise and the insights that they can bring to society. And I think that that can happen and I think it's gonna require a lot of policy change, but it's also gonna require reframing.

[00:16:16] Right. And mental change. There's one thing I would love people to take away from this. It is this notion, it's one thing I could teach to everybody. It's the difference between the medical model of disability and the social model of disability. Because if folks understand this, it will reframe things. And I think once we understand the social model of disability, we can understand what might actually bring about this kind of future.

[00:16:38] So to the medical model of disability, it starts with the presumption that there is a normal body and the normal mind, right? That those are, those are real tangible things. And if you start from that presumption, then naturally the institutions of society, whether that's a physical institution like a school or a cultural institution like art.

[00:17:00] Those things are designed for people whose bodies and minds are normal, and therefore, if you cannot access those institutions because of the way your body or mind works, that the solution is to fix you. Right. And that's where we see so many of these things come from. Whether it's, you know, this building is inaccessible, let's make a super fancy wheelchair that can go upstairs, right?

[00:17:24] Nevermind how much it's gonna cost, nevermind how available it's gonna be. Nevermind how reliable it's gonna be. Right? Change the individual. Fix the individual. That's, that's the problem, because there is something wrong with the individual social model of disability, flips that on its head. It says start from the presumption that bodies and minds naturally vary.

[00:17:46] If you start there, then logically, when society constructs its institutions, it chooses which bodies and which minds along that spectrum will be included and which will be excluded based on how those institutions are designed. And therefore, if you find that you cannot access the institutions of society, the fault lies with those institutions and the way they were designed, and the solution is to fix them, to redesign them.

[00:18:17] So don't invent a wheelchair that can climb stairs. Put in a god damn ramp, put in an elevator, which has the added advantage of, is it a systemic solution that will help disable people? It will help everybody, right? That's this notion of universal design. You know, and we see this all the time, right? There's the wonderful 99% invisible episode about curb ramps, right?

[00:18:38] This thing that we're put in to help disable people to have wheelchair users that are now usable by you know, mothers with baby strollers and people pulling luggage, right? TVs have had chips in them for closed captioning cuz of the efforts of deaf people fighting tooth and nail against the efforts of the, the TV industry, the electronics industry to put them in.

[00:18:57] Now I feel like everyone watches things with captions, right? And in fact, you know, the first places to use those captions, word bars, right? You know, the sports bar arguably exists cause of ad, you know advocacy by deaf people. So I would say this is like, if we can start with that presumption, let's make things, build things from the ground up to be accessible, and let's be willing to tear up the things that aren't accessible and remake them.

[00:19:21] Then great. We can get technology and people who can access it and people who don't, don't have to. We can get medical advances and people who want them to get them, and those who don't, don't have to. But our community isn't being told to wait around until those things exist and we're not being told we have to change it ourselves just to participate in society. We get the same right as everybody else to fully participate today because that is more than possible.

[00:19:50] **Katy:** Colin Killick is the Executive Director of the Disability Policy Consortium. Colin, thank you so much for joining us today.

[00:19:56] **Colin:** Anytime. Love working with you folks.

[00:19:59] **Katy:** The Unsung Stewards podcast would not be possible without the talents of Maggie Cook. Molly Belsky, Teri Wade, Brad Girard, Rachel Gotbaum, and Amanda McIntosh. Deep gratitude to the thousands of people who shared their hopes and aspirations for the future through FORESIGHT, an initiative of The Rippel Foundation, and particular thanks to our guests. I'm your host, Katie Evans from The Rippel Foundation, and you are listening to Unsung Stewards.