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INTRO

Welcome to Partners for Advancing Health Equity, a podcast bringing together people working on the forefront of addressing issues of health justice. Here we create a space for in-depth conversations about what it will take to create the conditions that allow all people to live their healthiest life possible.

Karen Bell

Hello, and welcome to the Partners for Advancing Health Equity podcast. I'm your host, Karen Bell, an Associate Director for Partners for Advancing Health Equity, and an Assistant Professor at the Tulane University School of Public Health and Tropical Medicine. I'm excited to introduce today's guest, Colin Killick, who is the Executive Director of Disability Policy Consortium, a Boston-based civil rights advocacy organization run by and for people with disabilities. Colin holds a Master's of Public Policy from Harvard's Kennedy School and won their RFK Award for Public Service. He serves on several national boards and commissions, and he is also a published poet and voice actor. Colin, thanks so much for hanging with us today. Why don't we start with you telling us a little bit about your work?

0:01:19

Colin Killick

Well, thank you so much. It's a pleasure being here. Yeah, so this organization, it's a really special place.

I came here as a community organizer initially in 2014. It was kind of my first real job. And DPC has grown hugely. It was about six employees back then. It's 26 today. But the big thing about us is 75% of our employees are people with disabilities. And that really runs the gamut. If I have dyspraxia, which is a living disability, a neurological disorder, but we have folks who are blind, who are deaf, who are paralyzed, who have significant mental health diagnoses, you name it, really. And across the domains of our work, which are sort of grassroots organizing and policy analysis, research, and healthcare casework, what unites all of those is our mission of making Massachusetts and increasingly, you know, the nation as a whole, more accessible and inclusive for people with disabilities, as well as the belief that having people with disabilities take the lead in doing this work is important for our community and actually makes us more, not less, able to succeed at doing these kinds of things.

2:42

Karen Bell

Well, thank you for that introduction of sorts, because we're obviously going to get into a lot more. But thank you for that introduction and that explanation. Also, I think explaining that there's a range of disability. And I think we're going to talk about that in a minute. But really, we invited you because you recently participated in a webinar that we hosted titled Setting Health Equity Visions for Success. there is a link to the video recording in the summary description for this podcast. In that webinar, we covered a range of topics, including your work, Colin, around policy change on COVID standards of care and housing for the benefit of the communities that you serve. And since that was such a rich conversation, we are happy you are here with us to delve deeper. So, one of the things that you talked about in our webinar is how the disability community has largely been left out of the health equity conversation that we've been having. What do you mean by that? And can you maybe give us an example?

0:03:51

Colin Killick

Yeah, absolutely. So, I mean, I think the conversation around health equity as a core component of health policy and health practices is long overdue. But I think the disability community has been left out of these discussions because we're not necessarily seen as a community. We're often seen as a failed health outcome, right? So the existence of disability and the disparate existence of disability, and people of color, people who are low income, poor immigrants, etc., being more likely to have certain kinds of disabilities is treated as a sign of health inequity, which it is. But there's not a consideration of oh do people with disabilities have worse health outcomes because of structural bias because of bad policy design because of discrimination because, It's kind of a natural assumption well of course people with disabilities have worse health outcomes, that's you know it comes to the territory of being disabled we're not thought of as a distinct community or the really really important and potent distinct history of people with disabilities, the culture of disability really comes back out of the conversation. And this manifests in a variety of ways, you know, from inaccessibility in the way that health systems are designed, to quality measures often really leaving our community out. You know, there's this push to sort of pay for success, right, in healthcare making, you know, things like accountable care organizations, right, that have specific goals. But those metrics are all geared around healthy people, right? Someone is healthy, they get sick, they recover, right? That doesn't really apply to our community. And so there's kind of this presumption that because the typical standards for what high-quality health care are don't really apply to us, that means that no one really considers the quality health quality is for us. Nobody asks us. What would high-quality care mean for you and as a result? People with disabilities get poor care get discriminated against and wind up more likely to be homeless, more likely to be institutionalized, less likely to work, and more subjected to all kinds of violence and social isolation and you name it.

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Karen Bell

What you just said. I've been thinking about this concept of community. A lot of people say the black community or the gay community, whichever description that people might use, but I'm thinking about how we talk about community. Do you think it's an empowering thing to identify disability as a disability community, or excuse me, people with disabilities as a disability community, or is it something that kind of regulates people to another? And that's how I feel sometimes when we talk about other demographic and social groups. So I guess I'm asking about that.

0:06:54

Colin Killick

Yeah, that's a really good question.

I think overall, absolutely, it's positive. There's actually data that people with disabilities who have access to the disability community can report a sense of disability pride, which is something that comes along with that, you know, tend to live longer, tend to experience better health, etcetera. But certainly just to speak about my own experience, I was actually just discussing this earlier today with someone. So, you know, growing up with my disability, very fortunate in some respects, right? You know, my parents, you know, I grew up middle class. My parents were fairly educated. My father's a college professor. But they didn't know there was such a thing in the disability community, and no one kind of briefed them on what it would mean to have a disabled kid. Right? So, although they eventually, you know, worked to get me accommodations. I got a 504 plan to let me use a laptop in a class because my motor skills never developed. And so handwriting was a major struggle for me. But I did not feel great about myself. I felt like there was this thing about me that was kind of broken.

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Colin Killick

And, you know, I was delighted to learn that there was a federal law that meant that I no longer had to, like, beg and plead in every class to be able to use a laptop, it shouldn't have changed my life, but it still felt like, oh, there is this thing about that's wrong with me, but luckily there is this benevolent law firm on high that provides with this accommodation. And then after college, and I moved to Boston area, and I started doing some civil rights work by happenstance really, I met some of the local civility rights activists, and I learned that there was a community. And I learned that far from being some benevolent gift, the law under which I got my accommodations, Section 504 of the Rehabilitation Act, existed

because in 1977, a bunch of disabled activists took over a federal building in San Francisco and occupied it for a month and didn't leave until that law was implemented.

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Colin Killick

And that was the law that then paved the way for the ADA, which also succeeded because of disabled people protested. It was the famous Capitol Crawl, where folks literally got out of their wheelchairs and dragged themselves up the steps of Congress by their fingernails. And really, the history of the disability movement is one of successful protests.

In 2017, I was there for the protest in D.C. that saved Medicaid, and those were led by people with disabilities. And so I think being part of this community, I stopped feeling bad about myself when I started, when I found the disability community, when I was embraced by other people with disabilities. And when I started to see what this community could accomplish, because I saw what we were capable of, you know, society constantly tells people with disabilities that we're hopeless, that we're worthless, that our capacities are inherently diminished. But in fact, you know, disabled people are forced to be creative because we live in a society that does not accommodate our needs. And that creativity actually in some cases makes us really good at systems transformation, at finding ways of shifting things, at building alternative systems when the primary systems are inaccessible.

10:05

Colin Killick

And so that to me, like, finding this community, it gave me a way of understanding both the world around me and myself that was very different from this dominant narrative of, you know, normal and abnormal, right? Of, you know, that is so prevalent in terms of how society thinks about disability.

I do want to speak to the other side of your question of, you know, is there a downside? And yeah, I think there is. I think there are a lot of stereotypes. I mean, I think when people say, are you going on disability, right? That phrase, right? The single synecdoche, meaning, you know, oh, are you refusing to work and instead taking these cash benefits as though it were, as though that was something that was available to all people with disabilities, as though that was a simple thing to do. As though that was a position that a lot of people wanted to be in rather than one that they were stuck in. So I think that, yeah, our community definitely gets painted with a broad brush.

11:13

Colin Killick

And there's a lot of stigma against us. It shows up in healthcare, it shows up in employment, it shows up in all manner of things. So I think that's really the downside is and what keeps people from identifying proudly as disabled is you take on a lot of these stereotypes when you do.

Karen Bell

I really appreciate you responding to that in general because I think that some people don't want to have these conversations, they're difficult, right? So even you pointing out the potential disadvantages or the, you know, negative aspects of identifying as a community. I think that that's critical to moving not just our conversations forward, but really humanizing people. And I think that for the spaces that we're in, this health equity space, this equity space, whichever one it is, we tend not to talk about some of the negatives that come along with how people are identified, how people experience this identity and social communities. So I really appreciate you responding in that way and just being open to responding at all. My next question though is also based on what you just said, this concept of creativity due to your experiences and how that's used for advocacy. Yeah, I'm taking actually a leap in our conversation. We'll come back to some of the other stuff. Yeah, absolutely. Yeah, I'm taking a bit of a leap because we, again, in this equity, health equity, health whatever, public health community can get so bogged down in the details of definitions, of identifying causes, all of this type of stuff without actually talking about what is necessary to get to the goals that we want. So actually I am supposed to be asking you about what is the health equity goal for people with disabilities, but I think I'm gonna add on to that.

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Collin Killick

Yeah, we'll circle back to it.

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Karen Bell

Yeah, what do we need to do to get there? What do people with disabilities need to do to get there? I'll tack that on to my original question of what does health equity look like?

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Colin Killick

Well, let me start with this question about creativity, because I've needed a couple of concrete examples that what is really like. One is, I mentioned that 504, the 504 sit-in is the name of the protest. It was led by Judy Heumann, who passed away earlier this year. It was

this giant in our community. She was quite young at the time. And so this group of disabled protesters, they occupy the San Francisco offices of the Department of Health, Education and Welfare, as it was known at the time. And in an effort to end the protest, I'm not entirely sure if it was the people who the agency was building it was or the police or both, but they cut the cellulose. People inside the building couldn't communicate with people outside the building.

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Colin Killick

And they thought, well, that'll end the protest because they had to coordinate with them to bring in food and medical supplies, etcetera. And this was the 1970s. Cell phones wouldn't have come along for a couple decades, except that there were deaf people in the building and there were sign language interpreters outside the building. And so they just signed messages back and forth from the windows. And that was how they communicated with the outside world. You know, in the fight to pass the ADA, a bunch of wheelchair users from an organization called the DAP, they requested a tour of the Capitol. And when they got into the Capitol Rotonda, they turned off their wheelchairs, they put on the emergency brakes, and were like, cool, just try to arrest us, right? You don't know how to operate a power wheelchair, and we're certainly not going to help you. So it's using that ingenuity. And this also leads to the idea of universal design, where if there are people with disabilities, in the effort to push social systems to be accessible to meet our needs, we end up creating things that benefit everybody. Curb ramps are the canonical example of this, right? Where, you know, on a corner, you have a ramp, go down to street level so that someone in a wheelchair can go through it. Well, turns out, if you're pulling a suitcase, if you're pushing a baby stroller, what have you, right? Everybody benefits from these things, right? Actioning on TV shows was pushed for initially by deaf people is now, you know, incredibly widespread, has all kinds of benefits. So that's just a few examples of this. Just people with disabilities using their ingenuity. We approach the world in a different way. We have this kind of level of lived experience, right, in navigating these systems, which is absolutely a kind of expertise in them.

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Karen Bell

Yeah. Well, the second part was, what does this idea of health equity look like for people with disabilities? And also, not just for people with disabilities, but primarily for people with disabilities, but also for those of us who advocate or might be allies, which, you know, we can talk about whether or not you want to use that term or not, but for people who are advocates for people with disabilities, what does health equity look like?

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Colin Killick

So I think the main thing that it looks like is not so much a single indicator or a single measure, but rather people getting to define for themselves what a successful health care outcome would be. Because for our community, all kinds of services are wrapped up in health care that are critical for really participating in the rest of society writ large. I think during the webinar, we got into that discussion about, you know, that there are social determinants of health, but for our community, there's also health-determined socialization, right? And one big example of this is personal care attendance, right?

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Colin Killick

Most of these sort of things, the universe of long-term services and supports, things like personal care attendance, things like durable medical equipment like power wheelchairs, etc. All of these are legally defined in the U.S. to some extent as an accident of history as health care services, which means that they are provided through health care, through health insurance. When private insurance covers it, it usually doesn't, which means people have to be on Medicaid. But as a result, I think for our community, health care goals, right? Because I think you can say that, you know, health equity is, I think, when, you know, people receive the kind of health care that they need, you know, receive health care that improves their quality of life, right?

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Colin Killick

People receive health care that meets their needs, that helps them achieve what they want to achieve with the rest of their lives, makes sure that their health is not an impediment to, you know, fully, you know, you know, to living a happy, independent life, right? And so for those people with disabilities, often, you know, can I live independently is a healthcare outcome, right? Can I work is a healthcare outcome, right? Can I see my family or go to religious services or travel? These are healthcare outcomes because they are things that we need responsive, high-quality healthcare to achieve.

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Colin Killick

And so we played a significant role, for instance, in the creation of a demonstration program here in Massachusetts called OneCare, which is for people, also called dual eligibles. Those are people who are, because of their disabilities and their income, are eligible for both Medicare and Medicaid. So this was an innovative program to try and create, you know, unified plans pulling from both funding sources. And one thing we fought really hard for, and we have to continue to fight to preserve with mixed success, is the idea that every

member should have a care plan outlining their goals, that they take a lead role in writing, and a care coordinator whose job it is to hold their team, their providers, accountable to helping the member meet those goals. Right. And so I think that's an entirely different approach to health care quality than the standard discussion, but it's the one that I think makes sense for our community. And I think if that became the standard, that would go a long way towards achieving equity. I mean, I think even for people who aren't disabled, that kind of broader thinking, a somewhat less clinical approach to defining, is someone getting good health care or not, might be beneficial.

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Karen Bell

Yeah, definitely. I hear that for a project that I'm working on, I've been thinking about like medical visit companions and people who help the person or the patient. And so that makes a lot of sense. And the idea of making that the standard for everyone with disabilities, that makes even more sense. But I have a question about defining disability. And this is something that you mentioned and talked about. One of the things that I've become more familiar with recently is the social model of disability, which from what I understand defines disability not as the impairment or the functional limitation, but as when our society doesn't facilitate full participation in society. So you work in policy, right? How do you communicate that definition or that understanding of disability when people might have a more reductive or simple understanding of disability where they might just define it as the impairment or the functional limitation.

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Colin Killick

Yeah, it's, thank you for bringing that up. And this is a really interesting one. And it's one that kind of surprised people when I talk about disability being socially constructed. And what do you mean by that? Right?

Like, you know, but like it is right. Specific medical conditions exist. Right?

Um, but the notion of disability, um, is, you know, both a, that all of these fall into a certain categorization. And also, that's constructed. And also, disability is often constructed, you know, in relation to work, right? We talk about disability as an inability to work.

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Colin Killick

But yeah, how we typically break it down for people is, and this is, you know, this is drawn on all kinds of disability scholarship, which other people, you know, frankly know more about than I do. I'm not an academic, but the very basic way is what most of us are typically

learn is what disability scholars refer to as the medical model of disability. And there are a lot of ways of describing it, but the way I tend to is it starts from the presumption that there is such a thing as a normal body and a normal mind. And if you believe that, then it logically follows that when the institutions of society are designed, whether it's a literal physical institution like a school, or whether it's a social institution like work or voting or what have you, that those institutions are constructed around the properties of normal bodies and normal minds.

And therefore, if someone cannot access those institutions because the way their body functions or their mind functions is quote-unquote "abnormal", then logically the solution is to fix them, right? To make their body or mind normal so that they can have access to those institutions.

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Colin Killick

And we often don't hear it phrased in those terms, but that's generally the way society, you know, approaches disability. The social model of disability, on the other hand, starts from the presumption that bodies and minds naturally vary. And if you start from there, then that means that when society constructs its institutions, it decides implicitly which bodies and minds will be included and which will be excluded, right? When you're putting up a building, you decide, is there going to be a ramp going up or just a flight of stairs, right? When you are, you know, putting or sending out a mailing about a health care service, right? You decide, are we only going to do this, you know, on standard letters? Or, you know, are we going to do it electronically? Are we going to have Braille available, right? You decide, are you going to have sign language interpreted on the back, right? And so, if under this model of thinking, if someone cannot access one of those institutions because of the way their body or mind works, the solution is to fix the institution, not to fix them.

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Colin Killick

And that's a really powerful way of looking at it. It positions disability as a policy problem, right? You know, we as individuals have impairments, but we are disabled when society fails to construct its institutions in a way that facilitates, you know, access despite those impairments. And to give something, a very concrete example. So because of my dyspraxia, I cannot write by hand, as I mentioned, or at least writing by hand is very cumbersome, very slow, very painful for me. When I go to the doctor's office, about half the time I can check in online or check in on an iPad. And my inability to hand and write is completely irrelevant to whether I receive high-quality health care. The other half of the time when I go in as a new patient, I am handed a stack of paper forms and a pen and told to fill them out. And I have to grapple with, if I don't finish filling in this form, or if they can't read my writing, then the wrong information may go into my chart, and I could be harmed as a result. And in either instance, I am the same, but in one instance, my impairment is utterly irrelevant to whether

I get good health care. And in the other instance, my impairment is extremely relevant to whether I get health care. So that's really the long and short of it. And usually when I explain it that way to policymakers, it clicks.

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Karen Bell

Yeah, it makes a lot of sense, and that's not just a simple example, it's a real-life example. And I think that having that example helps all of us understand what you're talking about and hopefully helps all of us change the way that we think. So it's not just understanding what you're saying, but like literally changing how we are not just thinking, but fashioning our society, fashioning policy, fashioning how we interact with each other also I think matters, right? So thinking about how I as a professor interact with students who might have some disability, whatever it is, if I can change the institution that I'm a part of, in this case, the classroom, right? Then I'm doing what I'm supposed to do to get to equity, to get to this goal of equity. So I really appreciate that explanation. You said that policymakers understand it. Do you feel like they change their thinking or change their actions rather than just like understanding and acknowledging what you're saying?

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Colin Killick

Sometimes. I think it's, you know, there's understanding and then there's being able to act on that understanding. And some people don't, even sometimes people who, you know, vote the right way don't get it. I did once have an interaction with a former member of Congress who had been in Congress in the 90s, was a centrist Republican of the kind that don't seem to exist much anymore but I, I thanked him for co-sponsoring the ADA and started to try to explain the work that I do and he stopped by interrogating me about whether my disability meant I could throw a baseball and then patted me on the chest and walked away.

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Colin Killick

But yeah, I think that you know, doing this work is, it's grueling. And on a day-to-day basis, it can seem like nothing is changing. But when you step back and take a wide view, we can really accomplish a lot. When I was just starting out as an organizer in 2014, my dear friend, Allegra Stout, now Keith Stout, who was then an organizer at Boston for Independent Living, we were looking at housing as a major issue that affects people with disabilities. We're more than twice as likely to be homeless as people who do not have disabilities. And so we started a little organizing project that was just focused on taking currently or formerly housing insecure or homeless people with disabilities up to the Statehouse over and over again, to

advocate for increased funding for this one little state-funded housing voucher program for low-income disabled people. And in 2014, that program had \$3.5 million in funding, which was less than it got in 1996, and it only housed about 350 people. And over the years, this program, you know, this group going up there year after year, pushing for this in the budget, making sure every legislator on Beacon Hill, which is where our capital is here in Boston, knows about the program. And multiple generations of organizers since leading it after Allegra and I handed it off. Last year, we got to \$19.1 million, more than a five-fold increase. And the program now houses over 1,000 people. And actually, it's grown sufficiently fast that we're now pursuing legislation to make more housing authorities eligible to get the vouchers and to allow some of the vouchers to be project-based to make sure that all of the funding actually gets used. So, you know, much is on a day-to-day basis profoundly frustrating. And once we have to deal with some really pretty gross discrimination that, you know, questions the value of our lives, on a long enough timescale, we can't absolutely have a real impact.

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Karen Bell

Right, right. Yeah, I totally understand. I think also, broadly speaking, health equity can be slow, just like you're saying that we created this society and so making those changes can take a long time and it takes policymakers down to people in the community that the housing vouchers are being used for. You know, like it takes everyone.

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Colin Killick

It does. The line that I sometimes use is doing this work is it's like head-butting a brick wall, but on the good days, the wall moves.

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Karen Bell

Right. I like that. I think we all should be using that because some people can get really discouraged, you know, so I really appreciate those examples. I'm going to ask about, you know using, again, going back to different definitions, the medical model, the social model, I'm wondering if there are ways to, ways that a cultural definition of disability might come up and what that means, what can be done about that? Did you have any thoughts about that?

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Colin Killick

Yeah, absolutely. I think that is a real thing. I think, I mean, so one thing that for it to get fucked up is, is, which is a sort of shallow answer to the question, but it's revealing all by itself. I mean, there's a deeper answer. It's about culture, but there's this idea of the minority group model, which is complementary to the social model, but that says that it's not just the disability, it's a social phenomenon, but that we are a distinct group of people with that history and culture, and that we need to be in solidarity with other marginalized groups in society. And I think that, I think the disability rights movement, in ways that I think disability leaders have historically not done nearly enough to acknowledge, really, I mean, our playbook came straight from the civil rights movement. I mean, there is a great photo that I use sometimes when I teach trainings and whatnot of Judy Heumann and Justin Durden and others like disability leaders marching under a banner with the Endocritic Kings quote about, you know, injustice anywhere is a threat to justice everywhere. And, you know, the fact that, like, I mentioned the five of fours it is, right? You know, and the ingenuity of people who were communicating and who were leading as well. It's also true that they only succeeded because the Black Panthers were feeding everyone.

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Colin Killick

So, and I think that, you know, the push for intersectionality in advocacy, in policymaking, in all domains of society. Disability does sometimes get left out of that, and conversely disability organizations sometimes fail to be intersectional in thinking about showing up for other people. We're marginalized, but I think that at long last that is starting to shift, and I think we are seeing some really productive things, especially coming from organizations that are led by disabled people of color, by disabled queer people, by disabled immigrants, both documented and undocumented. I think that's only going to continue, and I think some really important things are going to come out of that.

But I think a step deeper into culture, I think that there is some of this. I think as the disability movement kind of comes of age, I think that there is more effort to tell our history. It's been wonderful seeing the impact of things like the movie Crip Camp, for instance, this Netflix documentary on the profile Judy and other folks in her orbit who were part of these protests. It was wonderful hearing people who see this and come talk to me about it and learn these stories that are incredibly precious to me. I mean, Judy was my hero. The first time I met her, I was completely starstruck. But, you know, learning disability history and ways it goes back, you know, things like there was an invalid brigade in the Civil War who actually wound up playing, he was supposed to only be ceremonial, but wound up playing a key role in the defense of DC. So, there's always history there.

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Colin Killick

And there is disability culture, right? There are, there is, you know, there's incredible disabled creators out there making art, making visual art and poetry and dance and music and theater that is informed by, I mean, is enriched by the disabilities of the people who make it. And I will say that the one part of our community that is, I think, really ahead on this is our deaf people. There is a very rich deaf culture, and people will talk about small d deaf, which is just meaning not being able to hear, versus big d deaf, which is speaking ASL, being part of deaf culture, etcetera. Now, if you talk to deaf people, you'll get different answers on whether they consider themselves disabled or not. Not being deaf is not for me to say. You'll see deaf and disabled as a group, you know, because certainly we are in solidarity with each other at the very least. But I think that for the rest of the community, there is that kind of growing awareness of the importance of that kind of cultural work and of preserving history, which is often not necessarily written down. As you know, the elders of the movement, the ones, most who did the work that led to 504, that led to the ADA, etcetera, start to pass away.

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Karen Bell

Yeah, I think that that is important to think about this idea of culture in multiple ways. And you actually, you talked about it like three or four ways, which I really appreciate. But thinking about the power of culture for people who experience some marginalization, whichever form it is, right? Whichever disability identity someone might have, or even if they don't identify as disabled, like you were mentioning, some people who are deaf, small D versus uppercase D, large D.

And so I'm thinking about how people can celebrate themselves and how that can impact things like, not just advocacy, but you talked about self-determination before and when we were preparing for this. And I'm wondering about celebrating being a part of whatever culture you are, how that might go into this.

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Colin Killick

Yeah, absolutely. I think it's really important. And I think it changes people's mindset. In a world in which we are forced to feel shame about having disabilities, right, about how we show up and that, you know, that houses our lives that we're living. Like, it's kind of, well, people with disabilities are the one community, I think, who are, I mean, there's discrimination, there's horrible discrimination, there's all kinds of communities and, you know, especially we're seeing transphobia and homophobia, etcetera, racism. But what's

unique is that disability is still, the disability community is one of the only communities where people will still openly say, you know, oh, I'd rather be dead and disabled, right? Like, you know, we'll still say, you know, you know, there's still research. And actually, I won't go down a whole tangent, but there's some really good research out there by folks like Lisa Iazzoni, who's a professor, academic out of Harvard in the Mass General Hospital that shows that those predispositions are particularly common among doctors, which has some rather serious implications in health equity, right? Physicians are particularly likely to view life with a disability as inherently, people with disabilities having an inherently lower quality of life. And that leads to things like pressuring patients to sign de-barcelotators or deprioritizing people for organ donations, or it goes on a whole, all kinds of things. But in a world where you're bombarded with those messages, encountering not just disability community, but you know disability culture, right? Disability art. Getting to see people with disabilities doing amazing and beautiful things, right? Makes you feel differently about yourself. I think like gives you a way of relating to your body, to your mind, that isn't feeling negative. And like I'm not, I'm not sitting here saying, you know, they all be having disabilities is wonderful. You know, sometimes it sucks, you know, I would very happily do away with, you know, separately from my dyspraxia, I have an anxiety disorder. I would very happily do away with that.

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Karen Bell

Yeah.

0:37:44

Colin Killick

You know, and, you know, there are people with certain disabilities, you know, particularly like, you know, chronic conditions that shorten people's lives, that cause them pain, et cetera, who really want, you know, cures. There are other people, like a lot of deaf people, for instance, who emphatically don't want cures. But no matter how you feel about that, feel about that kind of question. I think having things about your body and about the way that you show up in the world that give you a sense of pride is an incredibly helpful thing. And I think, we know it prolongs people's lives. We know that it helps with depression. And we know also that it's, inspiration is a loaded word in our community because so many people who aren't disabled, you know, portray, oh, look at this inspiring disabled person. The term is inspiration porn that sometimes gets used. But to reclaim it a little bit, there is something genuinely inspiring as a person with a disability, seeing art and culture and, you know, and storytelling, etcetera, from other disabled people, and having a sense of community, and having a chance to then create such things yourself, that is dramatically transformative in terms of quality of life.

0:38:58

Karen Bell

Yeah, yeah. It makes a lot of sense, and it really resonates with me. I'm also thinking about what you said. We're actually kind of back into some of these topics. So I want to ask you about like racism and sexism. You mentioned transphobia stuff like, you know, all of the isms that we have in the world, but you sort of backed into it and talking about the solidarity and how the advocacy and social justice approaches have been you know, taken from the civil rights movement you mentioned the Black Panthers and that totally makes sense talking about the protests that happened in San Francisco that, you know, was Black Panther. Maybe not headquarters, depends on the time. But I'm wondering if you could just talk a little bit about racism. For example, we are understanding racism as a public health crisis or public health problem in more concrete and effective terms, I think, than we have in the past. And I'm wondering how you see racism sort of intersecting with ableism. And maybe you can talk about all of the other isms that could possibly happen.

0:40:14

Colin Killick

Yeah, absolutely. So there is, there's a deep connection between these and, you know, kind of a fraught history. And there's actually, there's a whole school of thought, the disability justice movement, which came about because of a, I think, a correct perception that, you know, on the one hand, the discussions of race and racial justice often didn't include disability. And on the other hand, the disability movement, which is still, you know, too white-led, present company included, but was even more so at the time, fails to address issues of race adequately.

And so folks like Patty Byrne and Mia Mingus and Stacey Milburn, Lee Warrymore, founded this idea of a disability justice movement, organizations like Sins Invalid also doing incredible work, you know, art and such around this. And it's the idea of sort of leadership of the most impacted, right, of that those who are closest to the pain, right, those who are multiply marginalized, experiencing both racism and ableism, need to, you know, their voices need to be prioritized, that they, and that finding solutions to these problems, you know, is not going to come from folks that are at that intersection.

00:41:36

Colin Killick

And I think for those of us who are disability leaders who don't experience racism, it's on us to make sure that folks have a seat at the table, that those ideas are uplifted, and to call out

our own, to both examine our own behavior and call out our colleagues when that, you know, they feel they live up to that. I won't get into the details and name names, but I definitely remember things years ago of somebody in the disability community saying about, oh, you elected official, whatever, you care more about illegal immigrants than you do your own disabled constituents. The rest of us were like, absolutely the hell not.

Get this guy, whatever. We did not pit ourselves against other marginalized groups, like we're, you know, we, you know, their, their fights are our friends. And I think too, I mean, these things, like, we don't live single issue lives and, and these problems reinforce each other, right? I was just talking, you know, about an hour ago with some colleagues about, just like one example, the fact that, you know, highways, right, were put through black neighborhoods. As a result, right, respiratory issues, right, are more common in those communities. Also, you know, like sound pollution, right? Noise pollution causes, you know, has connections to mental health diagnosis, right? That means that people in those communities experience higher rates of disabilities. And when they try to get care for those disabilities, they encounter racism, which keeps them from getting that care.

00:43:13

Colin Killick

We actually have a study, which we're about a year into, with the Robert Wood Johnson Foundation, the Father to the Bride Robert Wood Johnson Foundation, based out of Springfield, Massachusetts, where we're examining whether disabled people of color and disabled Spanish speakers experience greater barriers getting access to personal care attendants and power wheelchairs and other such services, and whether that means that they are less likely to be employed, are less likely to live independently, and are more likely to wind up either in nursing homes or homeless.

So, too early yet to get data from that. I have a suspicion that we're going to find that in fact that they do. But yeah, and this is going to fall over the place, right? I believe trans people are, I think, more than twice as likely as cis people to report having a disability. And so, you know, trans rights and disability rights are tightly intertwined, even besides the fact that both our communities have to spend way too much time thinking about bathrooms. And, you know, immigration, so we are doing immigration work.

When the Trump administration tried to put in place its public charge rule, one of the major ramifications of that would have been that all immigrants with certain disabilities would have been disqualified from receiving U.S. permanent residency or citizenship because, you know, the idea of public charges, well, you know, we would be turning away people who would be likely to depend on government benefits.

00:44:41

Colin Killick

Well, a lot of these services, like personal care benefits, for instance, no private health insurance covers those. The only insurance that does is Medicaid. So if you have those disabilities, you have to be so wealthy that you can afford \$30,000, \$40,000, \$50,000 a year out of pocket for PCA costs, or you have to be on Medicaid. So right there, right? It's how all the things are just ranging. I could go on and on about this stuff. I know I'm rambling a little bit, but yeah, I think our communities have to work together.

The other big one I should mention is police violence. People with disabilities make up between a third and a half of people killed by police, depending on which data you use. And there are all kinds of issues of this, whether it's mental health, that deaf people are disproportionately killed by police, who don't recognize someone communicating in sign language, or that if you shout verbally at someone to put something down, and they're deaf, they're not going to be able to hear you. Autistic people, likewise, people with learning disabilities are hugely disproportionately represented in prisons.

00:45:46

Colin Killick

It really goes on and on. And I think that there is this kind of growing awareness that we all have to work together if we're going to solve these problems. Lydia Brown, a fantastic disability activist, trans activist, person of color, they talked a lot about ways in which ableism, right, which is fundamentally, when you boil it down, the idea that some bodies are worth more than other bodies has these deep links to racism, you know, going all the way back to the racist pseudoscience that we used to justify slavery, right, going back to, you know, just, right, this idea that like, oh, that you can, like, localizing worthiness, and, you know, sin, oh, that you can, like, localizing worthiness and, you know, sin and whatnot in the body, right? You know, like, misogyny, like, so much of, like, you know, bias against women is rooted in this assumption that, oh, there is something about women's bodies that makes them less, you know, institutions being, and similarly, institutions are designed to be inaccessible. People with disabilities, a lot of institutions are designed in ways that are inaccessible to women, right? Design of systems being accessible to non-binary people, to trans people, and they can identify themselves. It's just all over the place, especially in healthcare.

0:47:00

Karen Bell

Yeah. Yeah. I think this additionally goes back to the defining of disability and how we make it, we make disability. We don't necessarily make impairments or functional limitations, sometimes we do, but we make this concept of disability. I wanted to ask you in light of all of that you just said, talking about racism, transphobia, sexism, xenophobia, all of that, I

wanted to ask you about COVID because when we had the webinar, we talked about COVID and some of the work that you, or a lot of the work that you all have done around COVID, but I'm thinking about how, and a lot of people are thinking about how, COVID can be viewed as a mass disabling event. And I wanted to ask you what you think about that term and what you think about a large number of people becoming disabled, especially when we just talked about all of the ways that different identities can intersect with ableism, how we create this concept of disability. What do you think about COVID and people becoming disabled?

0:48:30

Colin Killick

Yeah, it's a really good question. And a lot of people have become disabled. There's an old kind of joke in the community, a slogan, that people with disabilities is the one minority group you could join at any time. Right? And I think when it comes to the pandemic, I've never been more angry to be right, because I think people with disabilities had been saying for generations a whole bunch of things. I think we had been warning that, you know, nursing homes were death traps, right? That herding together large numbers of immunocompromised people, disabled people, etcetera, was a bad idea, was constraining to their dignity, to their liberty, to their ability to lead full and independent lives, and also was unsafe.

0:49:17

Colin Killick

That was proven to be true, right? You know, the Trump administration fought against the infection control standards in nursing homes, kept Obama, the rules that the Obama administration proposed going into effect. Would that have prevented COVID in nursing homes entirely? No, of course not, but it certainly would have saved a lot of lives. And you know, but also some other things too, right? People with disabilities had been asking for things like remote work as accommodations for generations and for generations have been told that these things were impractical. Overnight, they became necessary, and society had to work out in real time how to do these things when it could instead have been providing them from the beginning and worked out how to do so deliberately if it cared about accommodating the needs of those disabled people.

0:50:02

Colin Killick

And in general, I think that the pandemic exposed a lot of the ways in which our broader social system in general, and health care system in particular, did not care about the lives of people with disabilities. I had been involved for years pre-COVID in activism around

discriminatory metrics in health care, things like quality adjusted life hear and all of these other approaches and methodology which have in common the presumption that the lives of people with disabilities are less valuable than the lives without disabilities. And the more disabled someone would be, the less it saving their life would be worth. And over and over again, we were at the risk of overusing a bit of millennial jargon. We were gaslit, right? We were told that, oh, no, no, no, these are only used in negotiations. You're being paranoid. No one would ever be denied care based on their disability.

0:50:01

Colin Killick And then COVID happened and people were immediately denied care based on their disabilities. And not even just informally. And we know of all kinds of cases of this happening informally. There was the tragic case of Michael Hickson in Texas, a black quadriplegic man who was in the hospital for COVID and was removed from life support over the objections of his wife, exclusively because of his paralysis was determined that his quality of life was too low to warrant him being kept alive. We heard all kinds of instances, we continue to hear all kinds of instances of people with disabilities being pressured into signing due to their social status orders. Even pre-COVID, we heard all kinds of instances and they've continued, people with disabilities being deprioritized for things like organ transplants on the grounds that they would get less use out of those organs that like, you know, extending their life would be, provide less utility to society than extending someone else's life.

0:51:54

Colin Killick

But even explicitly, like as a matter of policy, as a matter of law, all kinds of states, they developed these crisis standards of care. These were rationing documents, saying if we don't have enough ventilators, if we don't have enough ICU beds to serve everybody, somebody's going to have to not get care. How do we determine who gets care and who doesn't? And in state after state, not every state, but many states, people with disabilities in one way or another went to the back of the line to get that care. You know, the worst of it was Alabama, where they said that people with intellectual disabilities wouldn't even be admitted to the ICU. But even here in Massachusetts, right, you know, high-minded, liberal Massachusetts, the corrective standards of care initially said that the priority was not to save the most lives, but to save the most life years, which means if you were elderly or if you had any condition that would reduce your life expectancy, not in your eyes of surviving COVID, but your life expectancy, assuming a full recovery from COVID, you'd go to the back of the line. So diabetes, heart disease, cancer, asthma, you know, MS, what have you, back of the line.

0:53:06

Colin Killick

We strongly felt that that was discriminatory and we fought to overturn those. And fortunately we won. And even more fortunately, things here never got quite bad enough. Well, the crisis standards were activated, but they were never actually used. They were used in some states. Unfortunately, disability activists across the country fought to get these standards overturned, particularly want to shout out our good friends at Center for Public Representation, who filed a lot of those lawsuits and administrative complaints led in that fight. But discrimination is still happening. And so we've actually filed legislation here in Massachusetts to fight a lot of these forms of discrimination and to enshrine in state law the principle that it is unlawful, it would be unlawful to deny or deprioritize someone for medical care based on the presumption that they had a lower quality of life due to their disability.

0:53:53

Karen Bell

There's so much to think about, but technically there's not, right? I think your last statements are telling me that you have to protect the life, well-being, and self-determination of everyone, regardless of whatever we define as disability. So I just wanna thank you so much for this conversation, for your work. We really, really appreciate it. It was great. And of course, thanks to our listeners. We hope you found this engaging and we look forward to having you tune in for our next episode.

0:54:35

Colin Killick

Thank you so much for having me. And also, yeah, anyone who wants to learn more about our work, our website is dpcma.org and you can find us Disability Policy Consortium on Facebook, on LinkedIn, on Twitter, wherever you go online, we'd love to connect with you.

0:54:53

Karen Bell

Awesome. Thanks so much.

0:54:59

OUTRO

Thank you for joining us this episode of Partners for Advancing Health Equity. Be sure to visit our website and become a member of our collaborative at partnersfortheequity.org. That's Partners, the number four, theequity.org. Follow us on Facebook, LinkedIn, and Twitter. And be sure to subscribe wherever you enjoy your podcasts. Partners for Advancing Health Equity is led by Tulane University School of Public Health and Tropical Medicine, is part of the Tulane Institute for Innovation and Health Equity, and is supported by a grant from the Robert Wood Johnson Foundation. Until next time.