

On Deck with PECC Ep. 1 – Mia Ives-Rublee, Disability Justice

Interviewer [00:00:06] So welcome to On Deck with PECC. PECC stands for pediatric emergency care coordinators who work to improve pediatric emergency services throughout North Carolina. On Deck with PECC is a platform that can be used as an educational tool for EMS providers, EMS administrators, EMS physicians and pediatric physicians that will impact pediatric families and their patients. Today's episode will be centered around disability justice, and language and equity. I'm very excited to welcome our special guest, Mia Ives-Rublee, who will be joining me today. Mia, she is the director of the Disability Justice Initiative at the Center for American Progress and Commissioner on the President's Advisory Commission on American Asians, Native Hawaiians and Pacific Islanders. Mia obtained her Master's degree in social work at the University of North Carolina at Chapel Hill and currently advises on disability in Asian American issues. Mia uses she/her pronouns and uses identity first person language, so Mia identifies as a disabled person again. Welcome.

Mia [00:01:23] Thank you so much. I'm so glad to be here.

Interviewer [00:01:26] So how do you define disability?

Mia [00:01:29] Yeah, so the definition of disability has sort of changed throughout history, but I really wanted to focus on the definition that the Americans with Disabilities Act defines how it defines disability and that a physical or mental impairment that substantially limits one or major one or more major life activities, a person who has a history or record of such impairment, or a person who is perceived by others as having such impairment. And the reason why that I emphasize this definition is because it's the definition that is utilized for much of the major civil rights protections for it for individuals. And so it's it's a fairly broad definition, but it's not as broad as some other definitions of disability that looks more at society and it's sort of structures and how it can impair individuals more structurally or more systematically.

Interviewer [00:02:42] So what would you say are some of the common misconceptions about disabilities?

Mia [00:02:47] Yeah, so I think the big common mis perception on disability is often that individuals assume that an individual is quote unquote impaired for, you know, individual quote unquote deficits, right? And I think what I like to sort of help people re organize how they think about disability is thinking about how often structures are the reasons why an individual has a disability in the first place. So an example of that would be I, as an individual, can pretty much do everything that I need to do at my home. But when I am in the community and dealing with community issues or at work, that's when my disability becomes much more of a hindrance because much of society is structured around individuals without disabilities. So, you know, understanding that providing supports, providing, you know, more universally designed environments actually helps cut down on a lot of the systematic ways that we tend to oppress or discriminate disabled people. So it's not to say that disability is going to be automatically fixed if we fixed every single, you know, inaccessible part of the world. But it does cut down on a lot of the discrimination and oppression and barriers that individuals with disabilities face within the current environment.

Interviewer [00:04:40] Yeah, I really like that. It sounds like you're saying that we tend to look at disabilities as, like you said, individuals like a person center versus looking at them.

They're considered disabilities because of the structure and the environment around us. Mm-Hmm. I think that's a common misconception, too, and I think he clearly stated that what does disability justice look like because you do a lot of work around disability justice as the director? So what does that look like?

Mia [00:05:17] Well, so one thing that I want to emphasize is that disability justice is actually a framework, right? So it is much like reproductive justice work. It was actually created by a group of black, brown, queer and trans individuals who developed a group called the Disability Justice Collective Collective and included people like Patty Byrne, Me Menés, Stacey M. Brown, Leroy Moore, Eli Claire and Sebastian Margaret. And these individuals decided that. Despite the disability rights movement was excluding multi marginalized individuals and that it was coming from a very white led framework, and so these individuals decided to create their own film framework that looks at disability and and ableism as it relates to other forms of oppression. So disability can't be defined through the lens of white, male or straight individuals. It must. Acknowledge that Ableism, you know, helps make racism, Christian supremacy, sexism and queer and transphobia possible. Now it's air twined with all of these other systems to create an environment that is structurally toxic for multi marginalized individuals. So Disability Justice actually looks at all of these different oppressions and and utilizes an intersectional framework which was written by Kimberly Crenshaw and and develops a way to to see how a community can come together to fight against all of these different oppressions and and work towards a collective liberation.

Interviewer [00:07:23] Can you speak about disability activism? Because I think sometimes we think about those disability, justice and disability activism of being the same thing?

Mia [00:07:35] Yeah. So I think we have to understand that that disability has, as I said earlier, morphed throughout history. And so we look at things like from from the 1860s on, you know, where slavery was rampant and it sort of idealized a specific type of body and skin type and and then, you know, morphed into things like eugenics and and sort of a morality of the ability to work. It wasn't until really the 1940s that we saw a real shift in understanding of what disability looked like. And that was partially because during World War Two, more veterans were coming home who were surviving massive injuries, right? So they were losing limbs. They were becoming paralyzed. And these individuals were surviving and saying, What about us? You know, we don't want to be shut up in these massive congregate settings that were extremely oppressive and extremely toxic. And, you know, seen and becoming infantilized, et cetera. And so, you know, the the disability rights movement actually corresponded much similarly to the civil rights movement. And a lot of there was a lot of crossover work, right? So we know that a lot of black civil rights activists were actually working with disability rights activists towards towards equity and equality for for the groups that they were fighting for. And so, you know, I think there's been this continual sort of seeing disability rise that the activists coming in to their own to to decide that they want to control their own fate. We're kind of seeing another renaissance within the disability movement in terms of, you know, black, brown, queer individual disabled individuals who are saying, well, the first civil rights movement for the disability community didn't really include us. So we want to actually be active and we want to make sure that our voices are heard. And that's where we've seen sort of it morph into what it is today, which is much more inclusive and and, you know, continues to push towards that understanding of collective liberation.

Interviewer [00:10:32] Yeah, I like the point that you just brought up about disability being overlooked in the civil rights movement. You know, like in the first part of the movement.

Why do you think that disability is often left out when it comes to intersectionality? I know you talked about we're kind of on this renaissance wave, but why do you think in general or in the past, it has been left out?

Mia [00:10:58] Part of that is because of the understanding of what disability is. The society is still very much stuck on what is a body worth right so that when the 1860s during slavery and the belief that a person was only worth what their body could produce, right? And that sort of morphed into eugenics and the ugly laws, et cetera. And Protestant work ethic where put morality and your ability to work. And so I think, you know, given the fact that our society is still sort of stuck within that that kind of framework in the framework of capitalism, for good or for bad, you know, it still believes that bodies and individuals are only worth what they are able to produce. And so when folks talk about disability, they still see disability as a deficit, right? And so with that understanding it, it results in things like making individuals inspirational, infantilizing individuals and believing that these individual. It was just they're never going to be whole human beings. When you dehumanize individuals like that. You don't see that they should have equal rights, right? So you think that, oh yeah, of course, it's OK to pay disabled people who are doing similar work less because, you know, they are less than human? Right? And so I think, you know, unfortunately and this is seen in communities of color as well as like, we bought into this belief that you know what you're able to produce. This is what you're worth. And so it's just allowed for the continual marginalization of disabled people and particularly black and brown individuals.

Interviewer [00:13:16] OK. And so. In your bio, I mentioned. You were being the commissioner on the Advisory Commission for Asian Americans, Native Hawaiians and Pacific Islanders. So can you talk a little bit about how intersectionality impacts people with physical disabilities when seeking emergency care specifically?

Mia [00:13:46] Yeah, I think that, you know, my experience is a little different from many individuals experiences, particularly because I'm a transracial adoptee. So my my parents are white. And so, you know, I didn't have to deal with some of the issues that many, particularly Asian American or black and brown communities have to face when dealing or interfacing with the with the health services. And so, you know, the things that I think about, particularly for disabled individuals who are people of color, is a number of factors. So cultural fluency that a lot of providers don't have an understanding of different cultural beliefs and sometimes those cultural beliefs. You know, doctors will be flippant about somebody's cultural beliefs. And so that creates a bunch of distrust between the the the communities of color and and the provider, right? And so I think that's really one of the biggest deficits is that that a lot of providers don't have cultural competency. And so they may become flippant about a person's individual or faith led beliefs and and different types of alternative medicine. And so dealing with that and resulting in and mistrust is not helpful and encouraging people to to seek treatment. So we know people of color, particularly black and brown and Asian Americans is they don't trust the providers. And so that means that they're not going to try and get receive treatment, that they are coming to get treatment much later, sometimes resulting in emergencies, right? So individuals aren't doing care there, so they're ending up in emergency rooms instead. And you know, you know, a lot of providers would scoff like, why are they using emergency services so often it's because they don't trust the other doctors. And so they don't go to the doctors until they're in emergency situations and they have to go to treatment. So I think that, you know, and for that, that's super unfortunate. Another thing that I will say is that people of color are often treated suspiciously thinking that they're they're seeking, they're seeking medications like opioids, right? Right. I've had that experience. Am I on my own account? I, whenever

I'm with my parents, my parents will advocate for me to deal with my pain and ensure that I have pain management throughout my treatment when I am alone. I am extremely wary of doing that because I've had providers who will act like I am seeking drugs out. And so that kind of treatment is as very detrimental to somebody receiving the care that they needed and they deserve. So I think there's a still we're dealing with a lot of medical racism as we're also dealing with the sort of medicalization of disability, which means, you know, the belief that we need to fix individuals, right?

Interviewer [00:17:40] Right.

Mia [00:17:42] We haven't really talked about that in this podcast, but there's a real like because we're looking through the medical lens and medical devices disability to the point of causing individuals with disabilities to see their disability as a detriment as something that needs to be fixed. And so you have, on the one hand, dealing with the medical racism part and then, on the other hand, being told that you you're not human, all human being because you have a disability, because they see it as a medical issue. So all of this combines into this very toxic relationship of disabled people of color trying to receive treatment.

Interviewer [00:18:42] This has been part one of our episode with Mia Ives-Rublee director of the Disability Justice Initiative at the Center for American Progress and commissioner on the President's Advisory Commission on Asian Americans, Native Hawaiians and Pacific Islanders. Please check out part two of this conversation, as well as the other episodes of On Deck with PECC. Thank you for listening.