

BoggsCast Episode 16: Kara Ayers

[MUSIC PLAYING]

CARRIE COFFIELD: Welcome to BoggsCast where faculty and staff at The Boggs Center on Developmental Disabilities explore best practice, showcase success stories, and help listeners envision possibilities for innovation through interviews with state and national experts. Part of Rutgers Robert Wood Johnson Medical School, The Boggs Center is New Jersey's University Center for Excellence in Developmental Disabilities and Leadership Education in Neurodevelopmental Disabilities Program, the LEND program.

I'm Carrie Coffield, Assistant Professor of Pediatrics and Training Director for the LEND program.

In this episode, I'm going to be discussing disability and health equity with Dr. Kara Ayers. Dr. Kara Ayers is the Associate Director of the University of Cincinnati Center for Excellence in Developmental Disabilities at Cincinnati Children's Hospital Medical Center. She's trained as a psychologist and leads the National Center for Disability, Equity, and Intersectionality.

Dr. Ayers' research interests include health equity, disability ethics, and parenting with a disability. She enjoys applying what she learns through research by educating policymakers about ways we can improve outcomes through better policies for all.

So welcome, Dr. Ayers. Thank you so much for being with us today.

KARA AYERS: Yeah, thank you for having me. I'm looking forward to this conversation.

CARRIE COFFIELD: So as a way to start, can you tell us a little bit about your leadership journey and kind of what brought you to the work that you're doing now?

KARA AYERS: Yeah, as I was going through my many years of graduate programs, I definitely didn't envision that I would land here. But I'm really glad that I did.

I pursued a PhD in clinical psychology and really envisioned that I would have a more traditional kind of clinical role in terms of seeing clients or patients. And I enjoyed that work when I did it. But I was also just completely unaware of this whole field, really, related to disability work. I, at the time, was involved in disability advocacy. I'm a disabled person myself. And I think I viewed that work as extra or almost a hobby.

So, I often spent a lot of my evenings and weekends learning about disability policy, advocating around it. I didn't see it as a way that I could integrate it into my profession. And really, what altered that dramatically was I had my first daughter. I have three kids now. But when I had my first daughter, it was pretty immediate that I was like, "Oh, I can't [LAUGHS] have this weekend, evening second job that I do."

CARRIE COFFIELD: Sure.

KARA AYERS: So, I really started looking for ways that I could integrate the two. And I'm really grateful that I found UCEDDs, which both of us are part of in some way, and LENDs, and really the AUCD network, the Association of University Centers on Disability. So, I found that network about 12 years ago now.

And that's where my leadership journey to where I am now began in terms of getting my role as the Associate Director of our UCEDD. And then as UCEDDs do, we look for other grants that-- I see it like under an umbrella. And so, I think we're going to talk about the Center for Dignity grant that you and I worked together on. And then when that grant concluded, the new center that we have is the National Center for Disability, Equity, and Intersectionality.

And so that leadership opportunity gives me the chance to work with people from across the country and really just having these shared goals of improving outcomes for people with disabilities. And so, that is a taste of how my leadership journey got me to where I am today.

CARRIE COFFIELD: I think it's always so interesting to hear people's journeys and how they got to where they are. And I think it's so important to share that because I work with so many students who really feel called to this work. And so, knowing there's a way to make it something that they can get paid to do and just not their hobby, second job I think is really important.

KARA AYERS: Yeah.

CARRIE COFFIELD: Yeah, so thank you for sharing that. So, you mentioned that you have a daughter-- actually, you have more than one daughter. You have--

KARA AYERS: Yeah. I have three kids, yep.

CARRIE COFFIELD: So, you've done some work about parenting with a disability. So, can you talk a little bit about that work and kind of what you think are the next steps for this field of study?

KARA AYERS: Yeah, my work in researching parenting with a disability and also the policies around that began actually before I had my first child. So, I began to have the pretty upsetting realization, that many people who study this do, that the vast majority of states at that time had laws in place that state that children can be removed from the custody of parents with disabilities on the basis of disability alone. So, no evidence of abuse or neglect just because the person has a disability.

So, I started working on that before I became a parent, which was pretty eye-opening. And I was able to participate in some interviews with other people who already were parents with disabilities. And it really just continued my work. But along the way, I've had three children now of my own. So, we have two daughters that we had biologically. And then we adopted my son, in the middle of those two daughters, from China.

So, we've had a wealth of our own personal experiences as well. And I think what I'm really motivated-- while it's sometimes frustrating to work in this space because the systems and the policies are so unfairly against families like mine, I'm definitely motivated by the families that I meet because people just want what I think many people want, which is to be able to have families of their own and raise children. And they're doing a great job at that despite a lot of stigma in society.

And we are starting to see some improvement. So, in Ohio, took us I think about seven years, but just this last January, we finally got a bill passed that prohibits discrimination on the basis of disability in parenting. So, it's not perfect, but it's a start. What it does is it removes that really outdated-- there was a piece in our Ohio code that said that on the basis of disability alone, a child could be removed from custody. So, it's a good starting place because it allows us to have the same footing that other families do.

So, a lot of times when I teach people about this issue, one of their first questions is, "Well, what about if a parent's disability really means they can't parent?" And so, what I think it's important to point out is that all we're asking for as parents with disabilities is to be along the same footing and in the same system as everyone else. So of course, if any parent indicates that they're abusing or neglecting their children, then we have a system for that, whether it's perfect or not, I think we could have lots of thoughts around.

But, parents with disabilities are still held to the same standards. What we really try to advocate against is that we are held to a different standard. And that often that different standard is just by having a disability alone, it's assumed that you are not capable of parenting. And that's what we actively advocate against because it's not accurate.

CARRIE COFFIELD: I've heard you talk a little bit about ableism. Can you-- I mean, I guess this is really a form of ableism or an impact of ableism may be a better way to say that. And so, can you just talk a little bit about what ableism is?

KARA AYERS: So, ableism is a devaluing of the lives of people with disabilities. And sometimes it comes in very explicit ways. Other times it comes-- and what I mean by explicit is very much like, you can't parent because you have a disability. Other times it comes implicit where sometimes when it's happening, people who are perpetuating ableism aren't even aware of it.

So maybe it's that they ask more questions of a parent with a disability in their office than they do of others or that they hold these doubts or assumptions about what a person can or can't do. Or sometimes in parenting, it's how certain things should be done in their opinion.

Interestingly, our society has this really strong held conviction that babies, when they're newborns, you should carry them around in their car seats if you're going from car to car. Whereas when we think about it developmentally, there's no need or purpose for that. There's lots of ways to carry or transport a baby. But it's interesting that a lot of parents who use wheelchairs, like myself, we face that question over and over and over again of like, how are you going to carry the baby in the car seat?

And it's kind of funny in a way because it's like, you do know you don't need to carry babies in car seats? That's not part of their development.

[LAUGHTER]

So, for whatever reason, that gets really stuck in because I think that's an example of our society has gotten used to the way most people do things. And so, when somebody we presume can't do it that way, we wonder, well, are they going to be able to do the other things they need to do? That is, I think, one funny example because it's very clear that there are lots of ways to carry a baby. And there are other options other than lugging the heavy, cumbersome car seat. But people really like that method, I guess.

CARRIE COFFIELD: It applies to parenting, but ableism is really a very broad -ism. What do you see as things that we can all do to help eliminate this type of bias?

KARA AYERS: Yeah, I think the first step is starting to recognize it and identify it. And sometimes that takes some lowering of our defenses. So, when I teach my students about ableism, I use an image of a factory smokestack and smog coming out because smog, up close, is really easy to see and not something that we'd want to breathe. But far away, it's harder to know that we're breathing it, but still bad for us.

And that's kind of the way ableism is in that it's all around us in our messaging. It's in the way that we're-- that I was trained as a psychologist-- in that I was taught lists of symptoms. And then I was taught with the assumption that people would want to eliminate these symptoms. And that is a really overly simplified way of explaining somebody's lived experience, which brings us to why, when we have discussions about curing disability, it can be very controversial. And views of ableism can dominate those discussions when we assume that all or most people want a cure for their disability.

So, I really think that learning to identify ableism and just be more confident to discuss it is a really important first step. It is everywhere. It's in our doctor's offices. It is in our schools. And it's something that we can improve upon, but we can only do that if we're willing to talk about it and be honest and real about where ableism is impacting us.

CARRIE COFFIELD: I agree. I agree. And it's hard to acknowledge these things about ourselves and that we're not as open or accepting all the time as we would like to be.

KARA AYERS: I think some of the ways that I try to kind of like remove the blame or the guilt that people feel is that some of the ways that we've shaped our beliefs that we now want to unlearn are based on what we've been taught. We're not only taught by what we're told. But we're also taught by what we don't see or what we aren't told.

And so, there's a huge lack of representation of disability in basically everywhere. But if we just look at our media or our advertising, the fact that we grow up and we don't see kids with disabilities in the same ways that we see other kids portrayed or adults, or I can't think of very few roles-- and that's only because I've looked for them, as I know the few-- of people with disabilities in a parenting role in a TV show or a movie. So, the effect of never seeing these portrayals, or when we do, they can be very stereotypical, that teaches us something.

And so, our job is really to unlearn what we've been taught. It's not our fault that we've been taught this. But we do have this responsibility to unlearn it. So, it is hard. But yeah, lowering those defenses and trying to recognize that we're all-- another thing that motivates me is we're all made better by reducing ableism. So, ableism harms all of us.

So, I don't really like to dwell on the fact that if you're not disabled today, you could be disabled tomorrow because I think sometimes it inadvertently sends like a scare factor, a fear factor. But it is just a reality of changing health, and so with that in mind, there are just so many reasons that reducing ableism would help all of us, whether you have a disability or not.

CARRIE COFFIELD: Yeah. And I have a sister with some significant disabilities. And so, growing up, you always knew when people were curious and when they were looking and when they were watching. And you could even see the questions that they had and that they just didn't ask. I don't know if it was just discomfort or not wanting-- their own discomfort, not wanting to make our family uncomfortable.

But I feel like even just opening up some of those conversations in these very natural settings, just ask.

KARA AYERS: Yeah. I think sometimes it is best to just ask and have those conversations. And even better is to-- our households to have more of these conversations to prep kids.

Now, we are really fortunate now to have a growing number of-- there's some great kids' literature out there to talk about disability. There's increasing representation on shows. I was really thankful to be part of a-- there's a Disney cartoon that had a premiere episode of a kid who has a cleft palate. And so, there's increasing examples that are really varied disability-wise.

But yeah, having those conversations at home so that it is not entirely upon the family and that individual with a disability too to do the education is so helpful. But we've also had those moments where it's just natural to, like, let's just talk about it because it's obviously in the air among us.

And my younger kids sometimes have pulled that out of-- I have a six-year-old now who's very outspoken. And so, she will notice sometimes very loudly if people are staring.

It takes a toll on people to be the recipient of that too. I think that's another thing people don't realize is on the day that I-- if there's a day that I am more short with my answer or whatever, you are not the first or even the 500th person that-- and so the way that people ask matters too.

I often teach kids with visible disabilities you do not have to respond to a question like "what's wrong with you?" There's a problem with the way that question was asked. And so, I do not expect a kid with a disability to then launch into a very informative discussion of their diagnosis.

[LAUGHTER]

So, in some ways, we need to educate the kids without disabilities. I saw a great-- it was actually just a carousel on Instagram, which I like the idea of getting it out in different ways. Right? And it was saying we would never teach our kids to go up to a person who was bald and say, "where did your hair go?" or a person who was pregnant and say, "how'd the baby get in there?" We teach our kids to ask questions in socially appropriate ways.

And so, we can do the same with disability. We can teach them to talk with kids with disabilities-- even about disability-- but make sure that they do it in a way that's not dehumanizing. And starting off with what's wrong with you is not a good conversation starter.

CARRIE COFFIELD: No. No. It inherently circles back to that ableist mentality of something's wrong with you.

KARA AYERS: Right. It's that assumption.

CARRIE COFFIELD: Instead of your body just looks different than mine, works differently than mine.

KARA AYERS: Exactly. So, I do hope these conversations continue so it's not that I want people not to talk about it. It's just that let's have conversations even about how we talk about it. And yeah, not starting with the assumption that it's anything wrong.

And I get too, when I think about our work related to developmental disabilities, when I say, let's ask questions that are socially appropriate or something, when you think about intersecting disabilities, a young person with autism may word that question in a very blunt way.

I think we can still have conversations about ableism and assumptions about disability but also valuing that a kid without a visible disability may ask the question in a way that's influenced by their own disability.

So, it gets all sorts of interesting when you add in those elements.

CARRIE COFFIELD: I think this leads up to a topic that is somewhat controversial, I guess, in our field right now. But that's really around language and how we talk about disability. And do we use person-first language? Or do we use identity-first language? And what's the right way? And so how do you think about that and respond to those kinds of questions?

KARA AYERS: I think your listeners probably know that person-first language is putting the person first. So, my diagnosis is osteogenesis imperfecta. And because that's ridiculously long, we say OI for short. So, saying, a person with OI, or a person with a disability, person with autism.

And then identity first is really claiming the disability piece as central to one's identity or a central part. It doesn't have to be the center.

But when I introduce myself, personally, I feel most comfortable saying I'm a disabled woman. And that is because I definitely view disability as a central part of my culture, who I am. I'm proud of that piece of me.

I had a mentor a few years ago that when I was more in the habit of introducing myself as a person with a disability, she stopped me and said, well, you don't introduce yourself as a person who is a woman. You don't separate yourself from your gender in that way. And I'm wondering why that is?

And I said, well, first of all, people don't do that. But-- [LAUGHS] and so we talked about how, OK, well, our language choice is based on what other people do and what's typical. But as I have thought more about this in my personal space, I identify as a disabled woman. I bounce back and forth though when I speak about disability because I also validate that I have a lot of colleagues with intellectual disabilities who prefer person-first language. And I respect that.

I also have a lot of colleagues who are autistic who strongly prefer identity-first language. So, I wrote a little bit about this in a peer-reviewed article called "The Evolution of Language About Disability." And what my co-authors and I really tried to emphasize in that article was that both approaches are valid. We need to understand the origination of both approaches.

So, person-first language was started largely by Kathie Snow, who's a parent of a person with a disability, so it's a parent-led movement, whereas identity-first is usually accredited to the autistic self-advocacy movement, which is meaningful because it was started by autistic people who were and are very clear that autism is not a separate entity that they want to distance themselves from.

I find all this really interesting. And I try to maintain a stance of curiosity about the way that we use language.

I think that the reason people really appreciate person-first language is that it gave some clear guidance. People wanted to know, just tell me what the to do's and the to don'ts are. And some of those things remain true across all forms of language. We have more agreement that there are certain slurs-- the R word. In my household, my son and my husband and I are all little people. We have different forms of

dwarfism. And so the M word, or midget, is really hurtful in our household. And there's no acceptable place to use those words.

So, I think the guidance that burst onto the scene that person-first language had was really appreciated. And we just need to add some nuance and recognize that language is powerful. It shapes how we think about who we are, how we think about who other people are.

So, I always ask for some patience and grace from people who-- I get it when people are like, just tell me what to say. Or they'll say something like, "well, this used to be fine. And now this isn't." And that's OK. We're evolving over time. And so, I expect our language will change. If you and I had the opportunity to have this conversation even five years from now, there would be different trends and different-- and that's OK. That just means we're continuing the dialogue.

I mainly try not to correct people on their self-identity. So, if somebody has a disability themselves, they have a lot of individual freedom to define how they describe themselves. And then as we look at disability described in other ways, we can discuss as a community what's appropriate and what's not.

CARRIE COFFIELD: I appreciate that response. And it is very sort of open. And I think it is a continually evolving language just in general. And our use of language just continues to shift, I think, around the different trends or the different conversations that are happening around us.

I work with a colleague. She identifies as a disabled woman. And she gets really frustrated about the conversation about language as one that isn't necessarily helping to advance the real work, I think, to address ableism at its heart. And I'm just curious how you think about that. Language to her, it seems like a very superficial way to think about that and that we've been stuck there for a while-- that we can't get beyond the language.

KARA AYERS: Yeah, I can share in that frustration sometimes especially when a project really gets sidelined or stifled by the discussion. Some of my work is with-- I serve on the Board of Governors for PCORI which is Patient-Centered Outcomes Research Institute is what PCORI stands for. And the disability community has a long history of rightful frustration that we are sometimes called patients when we're not patients.

So, some of the older literature that I've read about my own disability type, the whole article will describe OI patients. And, I mean, they're talking about us in school and work like we're just permanent patients in the purview of the authors of this research. So, I understand the frustration of wrongfully being called patients. But when we're talking about in health care settings, I am a patient just as you are a patient.

And so for that, I'm able to recognize the hang up but move past it. And unfortunately, for a lot of people regarding my work with PCORI, sometimes we can't get over that. And that's what I feel really is unfortunate and in line with your colleague in that, let's have conversations about it. It merits that. But let's move on.

And I really don't think that we-- I personally don't think that we have to hard-line pick one camp or the other. There are ways to volley back and forth. But I know that's not the opinion embraced by everyone. You have very staunch identity first folks and very staunch person first folks. And I hear both sides. I just personally refuse to pick one. [LAUGHS]

CARRIE COFFIELD: Fair enough.

KARA AYERS: Yeah.

CARRIE COFFIELD: So, I was fortunate enough to be part of the work of the Center for Dignity in Healthcare for People with Disabilities. Can you introduce our listeners to the Center for Dignity and what the goals of our work together was?

KARA AYERS: Our center aimed to reduce healthcare inequities for people with disabilities. And the way that we define inequities is these gaps in outcomes. So, if you look at people without disabilities where their health outcomes are, and then if we look and we realize that people with disabilities, their outcomes are worse. We focused in on the part of that gap that is preventable and avoidable and is influenced by ableism, so by inaccurate beliefs and devaluing of disability.

And, our Center for Dignity was interesting too because we were handed four specific topic areas that the funders, which was the Administration for Community Living, wanted us to look into. And those included discrimination in organ transplantation, discrimination in end of life or aging care for people with disabilities, discrimination in mental health, and discrimination in prenatal testing.

And then because of our timing for starting, we very quickly realized that the response to COVID was an area where there were significant inequities faced by people with disabilities. So, we added that as a fifth area of focus.

And yeah, we worked together for three years. We produced recommendations for each of those areas about how to reduce these health inequities and a lot of other things along the way too-- toolkits and trainings and webinars. And so yeah, it was really fun to work together on that important work.

CARRIE COFFIELD: Our work together with the Center for Dignity has come to an end, but has your efforts in this area come to an end?

KARA AYERS: No, we've expanded. I'm always sad to see the nature of our work being grant funded is that grants often have a time end date. And that was the case for our Center for Dignity. But, we applied for another funding mechanism that was slightly different in that it expanded beyond just healthcare to also include community living and also the justice system. So, justice and justice.

So, this center also requires us to have different partners. And it is called the National Center for Disability, Equity, and Intersectionality. So, we're still found at the same handles in that it's

@thinkequitable on Twitter and Facebook you can find us. And then our website too is www.thinkequitable.org or .com. Either one gets you there.

Yeah, so we've just started that work this past fall. We do not have the same specific areas of health care focus. But I'm so grateful that we did that Center for Dignity work because it just informed me so in-depth about-- so I will continue to pull those threads along as the specific topic areas that we worked on together.

CARRIE COFFIELD: Yeah. And I think overall, there does seem to be this growing awareness and attention to the issues around access to equitable healthcare. And I want to in my next question just think about that COVID pandemic that definitely sort of impacted the way that our work with the Center for Dignity looked. But I know that there were a lot of impacts of COVID on people with disabilities. And so, can you talk a little bit about some of the work that you did in trying to really understand what some of those impacts were?

KARA AYERS: Yeah. On our early days, we looked at the crisis care standards that were coming out from each state, which were basically laying out plans for if the state ran out of ventilators or beds, how would this state triage, meaning how would hospitals decide who gets care first? And so, we began to realize that many of these plans had inaccurate assumptions that people with disabilities would already have a lower quality of life, so therefore, wouldn't benefit from literally saving their life.

So that was our early work. Then we really worked on understanding, what is the experience of people in congregate care settings? We realized that they were not able to stay as safe from becoming infected from COVID, just the way that care works in terms of sharing caregivers and not being able to socially distance and sometimes not having access to PPE.

Yeah, and then really after that, we continue to look at the ways that COVID-- so unfortunately, COVID resulted in people being stuck longer in congregate care settings, which we know already has multiple negative outcomes. So, it really put up significant barriers to getting people out of those settings into the community, which was and is always a goal. And I'm still working around that area.

In November, a report that I authored came out from the National Council on Disability about what do we need to do to strengthen our home and community-based services from here? So, recognizing, OK, what did we learn from COVID? And then how do we integrate those lessons learned to improve things?

And so just one thing that stands out from that report that I'll share is hospital discharging. I learned a lot about that process and how that is such a dangerous situation when a person with a disability has been in the hospital, and they need to get out. And maybe they've had a decreased level of functioning because they've been sick or injured or had surgery. That, unfortunately, is a really common path that people with disabilities find themselves in a congregate setting like a nursing home, or sometimes they think they're going to a rehab facility where they think that they will pretty quickly get out. And they end up getting stuck in these settings.

So, I learned a lot about the importance of hospital discharge planning-- being aware of, how do we get supports for people so that they can return back to their home in the community? And we want them to rehab and recover, of course. But along the way, we don't want people to get stuck in settings that are not beneficial for their health.

CARRIE COFFIELD: Mm-hmm. Mm-hmm. And I think everything that you've described, I definitely see the theme of your work. And it bridges all areas of life, from parenting to health care, to community. But it really is about those opportunities for equitable access and just treatment or equitable living.

KARA AYERS: I'm glad you see it. Sometimes I feel like I'm running around doing 50 different things. But--

CARRIE COFFIELD: No. No.

KARA AYERS: They are related.

CARRIE COFFIELD: It's very clear. So just as we're wrapping up, what research areas or policy or focus areas are next on your list? What are the things that you really want to focus your attention on?

KARA AYERS: That policy piece is really interesting and exciting to me because I think that there's a lot of bad policy out there. But there's also a lot of good policy out there that we can learn from. And in our work as UCEDDs and LENDs, we don't lobby, but we educate policymakers. And I really appreciate that role because we're able to connect what our research tells us, which is what science tells us, which makes sense. And then we can really improve policies for all.

So yeah, I think my focus remains on that equity piece, whether it be for families led by parents with disabilities, some of my work related to increasing that accurate representation of disability that we talked about and why that matters. It's not just a feel-good thing to do. It actually has impressive opportunities to improve understanding of disability.

And yeah, from all levels, from kids learning about disability up to our policymakers who make important decisions about what our lives are like at least in the government space and then trickling down to all different sectors.

So, trying to educate about that spectrum of opportunities that you talk about and how we want people with disabilities to have that spectrum available to them and have that choice of what they want to do and where they want to go.

CARRIE COFFIELD: That's awesome. Well, I look forward to opportunities too to be involved in that work with you. I so admire your leadership in the field and all of the work that you've done and I'm sure will continue to do.

KARA AYERS: Yeah. We'll look for something. I really enjoy working with your center too. And we are geographically separated, but I think have very similar approaches to our work. So, we'll find something to do together again soon.

CARRIE COFFIELD: Yeah. I would absolutely agree and would love that. So thank you Dr. Kara Ayers.

KARA AYERS: Yeah, thank you.

CARRIE COFFIELD: And thank all of you for listening to this episode of BoggsCast, a podcast by The Boggs Center on Developmental Disabilities.

A full transcript of this episode can be found at theboggscenter.podbean.com.

Be sure to subscribe to this podcast on your favorite streaming service to stay up to date with the newest episodes. To learn more about The Boggs Center, visit our website at boggscenter.rwjms.rutgers.edu and follow us on Facebook at [TheBoggsCenteronDevelopmentalDisabilities](https://www.facebook.com/TheBoggsCenteronDevelopmentalDisabilities), all one word.