

BoggsCast Episode 26: Kelly Nye-Lengerman

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ROB KIMMEL: 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, also referred to as a UCEDD, and Leadership Education in Neurodevelopmental Disabilities program. So that is also called the LEND program.

My name is Rob Kimmel. I'm a Training and Consultation Specialist at The Boggs Center. And I serve on the employment and transition team. In this episode, I have the pleasure of speaking with Dr. Kelly Nye-Lengerman the Director of the Institute on Disability, out of the University of New Hampshire.

Her work supports the full inclusion of individuals living with disability in all aspects of community life. And Dr. Nye-Lengerman's portfolio includes research, policy, and service work focused on inclusive employment practices and policy, Social Security, Medicaid, long-term services and supports, organizational transformation, person-centered practices, and poverty remediation.

Kelly, thank you so much for being with us here today. We have a lot of great things that I want to talk about with you. But first and foremost for everybody that happens to tune in to our conversation today, I'd love to learn a little bit more about you and your journey to being the Director of the Institute on Disability.

KELLY NYE-LENGERMAN: Thanks, Rob. I'm very excited to be here today. And I'm excited to share bits and pieces of my own sort of personal and professional journey, but also to converse with you about the opportunities and challenges that are part of the everyday work that we do as UCEDDs.

So to share a little bit about myself is my background and professional training is as a social worker. I have my undergraduate, my master's, and my PhD in social work through and through, with some additional training in psychology. And how I really started and found myself on this professional journey was I started as a direct support professional. And I-- and at the time, when I was younger, you actually could make more money as a direct support professional than you could working at the mall, or at a restaurant, if that gives you any indication of the time frame we're talking about.

And so at the time as an 18-year-old, I'm like, I can make more at the-- working in residential services. And what I really learned and reflected on in that time was I was introduced to sort of a community of people that I came to deeply care about, want to know more about, and figure out ways to support them

to have the best lives that they wanted to have and in the simplest terms. And what that really led me on a journey in my social work training when I went off to college was, what are the things that we can do as community members, as allies, as family members to support people with disabilities to have a good life?

And as I learned more about disability history and the history of institutionalization, I came to better understand, sometimes some of the emotions, behaviors, experiences that people I was supporting were having, because they had come from such institutionalized settings. And it really actually made me more curious to be like, well, if we care about and are wanting to support people with disabilities, why do we have these sort of rules, structures, and systems that sometimes prevent or get in the way of people leading the lives that they want to choose for themselves?

So kind of a heady question. But it really kept me connected to the field of disability during my undergraduate degree. And in college, I worked at an employment program in the state of Iowa for a number of years as my work study. And so I worked as a job coach, I worked as a shift supervisor, and supported and trained people with disabilities.

But in my college years, and sort of post-college, I went on to work in more social-work-specific positions. I worked as a professional conservator and guardian, where we were court appointed to provide those legal supports to people with all types of disabilities. And I also spent a number of years working in day and employment services. And those were also incredibly informative to me because I had the opportunity to work in spaces where people were of their community. They were working, they were living in their own places, they were driving, and taking transportation in the ways that they wanted to.

And then I also worked in parts of program services where people lived in segregated spaces, worked in segregated or sheltered workshops, and had a lot of aspects of their life and their choices decided for them. And so it really helped me as a young professional see the kind of vast differences in people's experiences, sometimes because of labels, sometimes because of IQ, sometimes because of history, how they could have very different lives.

Yet, I was always challenged by, if we are the sort of services and supports that are supposed to be lifting up people, why are we the ones who are sort of constantly getting in the way of that? Does that make sense?

ROB KIMMEL: Absolutely. I think so. I think it's very valuable that over the course of your exposure to a population that you want to support, the underlying reason, the reason to be, you see coming into direct conflict with many of the systems that are intended to support. I believe that's something that we continue to see today in a lot of different ways. And now, we call it systemic dysfunctions. There's just things that are baked into systems. And it could be-- they were put there for good reason at one point, or someone with good intention.

But as times change, so should we. And a lot of the things that we continue to use continue to be from the past. And I think it's awesome that you have this-- the liberatory mindset from the beginning, and seeing it in this contrast over and over again throughout your professional career.

KELLY NYE-LENGERMAN: And I don't think I would have been able to reflect on it if I hadn't worked as a DSP, and if I hadn't worked in a variety of kind of different direct practice settings. And how it sort of motivated me to go on to get my master's in social work and eventually my PhD was sort of every time you got a little bit more education or experience, you're like, there's the way that I can make it better. There's the way I can fix it. It's through policy. It's through research. It's through other types of things. And that's actually really what drove me was figuring out some of the policy angles.

So if I want to maximize the number of people that can benefit, or be helped, or supported, if we change policy, or if we change some of these rules, that'll help. At the same time, no matter how much training or education you get, you can see the problems and the challenges at different angles. But if I go back and then reflect on the early parts of my career, and using the experiences of people with disabilities, my role as a direct support professional, the other professionals that I worked with, it's like, well, people with disabilities and their families aren't included at some of these tables where decisions are getting made.

And I think-- and I think too, it's also one of the things I've really reflected on. And kind of these different roles and jobs I've had in disability policy and services is that I think now more than ever, representation matters. And that I talked about sort of being able to get-- and sit in different places because of the privileged roles, or titles, or job I have.

At the same time, as a person who doesn't-- who isn't a parent, who doesn't identify as having an intellectual or developmental disability, sometimes, it can be hard to say, well, now, actually we don't want to listen to you, or your experiences, or your leadership because you're actually not representing us, or you're not representing this group.

And so I do think it's an interesting tension. And I think it will continue to be an important part of the dialogue. Because from my professional reflection is that we really need all kinds of advocates, allies, professionals, everyday people, citizens, to be involved in building inclusive, accessible communities, and that whether you're inhabiting this label, or this label, or you're playing this role or that role, if we are all really striving for meaningful inclusion, and belonging in people with disabilities, there are many perspectives that can advance that.

ROB KIMMEL: When you talk about representation and having space at the table, how do we get people to recognize, as you've recognized in your career, that it's not a false duality of, we need to take the professionals completely out of the picture and then feature individuals with disabilities because of their relevant lived experience, which is important, but not throwing the baby out with the bathwater, as it might be-- as it's sometimes called? And maybe I shouldn't be using those kind of colloquial sayings.

But yeah. More so that these things can both exist at the same time, that professionals have done this and spent their time dedicated to working with and for individuals. And there are systemic things that may occlude their vision when it comes to looking at the whole picture that others can supplement in or show based off their lived experience, but that it shouldn't be one versus the other. That's something that I think I hear a lot. And I would love to know your perspective on it as somebody that clears the way.

KELLY NYE-LENGERMAN: Well, I certainly try to clear the way. I'm not always successful at it. I will say, again, it's such a slippery slope. Because the thing is because I sit and come from a place of privilege, I recognize that I can't see things sometimes in the same way. So I think always trying to approach it with a perspective of curiosity, and humility, and being able to genuinely listen to other people's perspectives. So it's like, well, if I invite somebody to come to a meeting with me, or I make sure that I add this group of people to an email-- an opportunity that was provided via email, are we all going to see it the same way?

Because I think I'm being inclusive that way, when actually, other people might not interpret it that way. So I think coming with that humility, the curiosity, and then the willingness to listen, and at the same time, be open to sharing your perspectives and your ideas. And one of the more successful ways that I do try to do that is that helping my colleagues, our teams, our groups that we work with are like, where are the common things that we agree on? What are the things that we want to stand for?

We might not always agree about how these things show up in some of the finer details. But how do you build from a place of, we share these same values around inclusion, participation, belonging, representation? Finding those things to build off of rather than really focusing too much time and effort on all the ways that we're different, or all the ways you should or you shouldn't be a part of the group.

Now, that is not a hard-and-fast way to operate groups and have partnerships. But I have found that to really be a successful way that, for me, in trying to unpack some of that structural bureaucracy and oppression that is inherently built into a lot of our social services, and a lot of our higher ed systems, and at the same time, be able to still hear if people are frustrated, angry, disappointed, confused, that I'm responsive to that as well.

So again, not a hard-and-fast way. But I will say it's tricky. And I think in the next two, five, 10 years of my career, it's probably only going to get more challenging. Because I think in post-COVID environments, and-- well, we're not really post-COVID. But in whatever environment we are with COVID now, in our different and changing political landscape, those differences seem to be getting a lot of attention and become huge wedges, when really trying to find the commonalities is sort of the way to advance that.

And I find that true kind of holistically in disability work is that if we look at other communities in need, oppressed communities, underrepresented groups and communities, many of the things that we want, and desire, and demand, and are entitled to as citizens and humans, are pretty universal of high-quality health care access, safe shelter, transportation, childcare, food security. Those are very universal human needs. And some of those needs are not being well attended to to a variety of communities, including people with disabilities.

And so finding, again, those places where we can share shared strength and look for shared solutions that, again, maximize the benefit to the most amount of people, to me, are the winning strategies that I really have tried to elevate both in my research, and in my practice, and in my leadership.

ROB KIMMEL: And I think that's wonderful that you are incorporating that in your day-to-day work and recognizing that the greater sphere of the world, that there is kind of competition for time and attention, and thereby money, and supports, and resources. I think that we feel that rub in a lot of different ways. And in our field, and working with individuals with disabilities within the structures that we exist in.

And you've mentioned a few of these things on your professional journey. What are some of those big questions, those big challenges, that you're currently focusing on, or that you believe need to be at the forefront of the work that you do, and maybe the work that the field does as well?

KELLY NYE-LENGERMAN: I think one of the things that we have seen within the work that we do at the Institute on Disability, and not just specifically for our state, because UCEDDs touch and work with all kinds of states and communities, and all kinds of federal and state agencies, are a number of the setbacks that we had during the active COVID pandemic.

And what I mean by that is that when we had to go remote, when we had to learn how to quickly do virtual services, when we had to figure out, well, what are the reimbursement rates for a virtual voc. rehab appointment, things like that, out of necessity for safety and well being because a lot of things we didn't at the time, we walked back some of those protections that really need to be in place under IDEA, under WIOA, and under HCBS.

So to spell those out, the Individuals with Disabilities Education Act, WIOA, the Workforce Innovation and Opportunities Act, and HCBS, Home and Community-Based Services. So those acronyms. And again, we did that out of safety and protection, I think, because there were so many things about COVID that we didn't know.

And while, in some cases, it created some new opportunities, because now we're doing telehealth, and virtual services, and all sorts of different things differently, that's really helpful. But some of the protections that were there, people sort of forgot about. And so when individuals and families are like, hey, what about my IEP? Hey, what about my-- updating my individual plan for employment? Hey, what about these things that we focused on in my person-centered plan? Because there are so many pressures at-- for providers, and vendors, it's easy to swat away.

Well, we've got too many-- there's too many things. There's too many questions. We don't do that anymore. And that because we've also had an incredible amount of turnover in many professional positions, whether they're DSPs, paraeducators, educators in schools, voc. rehab counselors, county social workers, we've also lost some of that knowledge of yeah, yeah. No, we can't push that away, like that it's actually a requirement that we have student-led IEPs or just as an example.

And so that is a really big challenge, a sign of clawing back where we were at pre-COVID. And believe me. Pre-COVID, things weren't awesome, and sunny, and shiny either. But we were making, I think, some measured progress on advancing inclusive home and community-based services, increasing competitive integrated employment, and lifting up fully-inclusive educational opportunities in the least restrictive environment for students with disabilities. We were making a fair-- we were making progress. Slow, but progress.

And in a post-COVID environment, we've just seen so many walk backs. And reminding people of, what are those-- what are those requirements? What is under the law? Empowering people with disabilities and their families to know and understand what their rights are, and from a research perspective, how do we study why did it happen this way? What are the results of that when we roll back in-person requirements for-- and again, I'm just making this part up, an IEP meeting per se? Because we can do IEP meetings virtually.

What do we lose by having to change sort of the rules during COVID? So I think that's one big, big thing that we will be tackling, and navigating for the next, I don't know, five, 10, 20 years, and figuring that out. And how do we get back to where we were pre-COVID?

ROB KIMMEL: It almost seems like a Maslow's hierarchy of needs on kind of a global scale right now. That we're worried about health and survival, all things related to preference, all things related to kind of the higher ideals of existence, and these things are baked into our-- the laws that we work with, and how we support individuals with disabilities. Those things get brushed aside.

And so I think from-- on the surface of it, it almost seems like now, in the post-COVID era, they might not even seem as important. And I think that that's a very interesting insight in to how we continue forward. Because I think a lot of people know-- people are really, again, saying the new normal. People don't know if they should be dropping COVID or not from the things that they say. But it was a catalyst for a lot of change, good, bad, and otherwise.

I think-- what I'd like to ask you is some things have fundamentally changed. And people are comfortable with some of those changes. And they're baking them in. How do you think that's going to affect our work and the challenge that you had spoke to previously?

KELLY NYE-LENGERMAN: So a couple of different things. And I think about it kind of from two, I would say, equally-important parallel positions. And that is, what are people with disabilities and their families telling us about their experiences? What is working and not working for them? The other piece is using data to make informed decisions as providers, as policy makers, as legislators, as leaders? And it's sort of like the notion, and we talk about this all the time in our UCEDD work of, you need both and. You don't just need people's stories to make change.

That's a huge part of it. And you don't just need research and data to make change. It is actually the integration of people's lived-in personal experience and personal stories with the data that-- and the

research that also helps us tell those stories about impact. Because again, in the case of talking to policymakers, sometimes, an individual's story will absolutely resonate with the policymaker, or a legislator, or a commissioner. And they're like, I'm going to make sure that this gets fixed right now.

However, if you can give somebody a really beautiful report that says, well, gosh, when we don't do these things, this many young people are missing their participation in early childhood special education. And so like, we need data to talk to us about where are we missing the mark, or where are our successes. And we should be doing more of that thing over there because we're getting access to more families who are eligible for and are requesting early childhood special ed.

So it's sort of both and. You need-- you need the stories and individual experiences of people with disabilities and their families, but you also need good research and data to make data-informed decisions, particularly around policy and a broad array of services.

ROB KIMMEL: You're speaking my language. You know that I-- anytime anyone talks about data, I'm just like, yes. Please. More of that. I do agree with you.

KELLY NYE-LENGERMAN: And they're not opposing, like again-- and it's one of the things that I so love about working within a UCEDD, and working within our AUCD network is like, those are both important. And like I said, one isn't necessarily more important than the other. I actually think they're both equally, but differently important, and that when we can make them come together and sing, that's the sweet spot.

ROB KIMMEL: I subscribe to everything involving bringing individuals with disabilities to the table.

KELLY NYE-LENGERMAN: Can I reflect on one other thing I wanted to share about sort of challenges that you kind of inquired about? And some of this is related to, I think, the walk backs and the set asides we had to experience during COVID. Is that I don't even know exactly how to even phrase it now today. The DSP crisis, the workforce crisis, the workforce shortage, whatever you want to call it. And again, I think there's a number of our colleagues in the field who would say, this-- is it really a crisis because we knew it was coming?

And the thing is it's been bad for a really long time. COVID just highlighted even how much worse it can get. And that is the-- what we are up against is that for-- to ensure and to maximize the full participation and inclusion of people with disabilities, there is a workforce that goes alongside of that.

And whether that is paraeducators working in school settings, whether that is job coaches who are supporting people in employment, whether that's direct support professionals supporting people to live in their own homes, or shared homes, or whatever model, or it's paid family caregivers who are supporting their family member or a relative.

The lack of a high-quality, well-compensated, competency trained workforce is abysmal at the moment. There are millions of amazing and wonderful direct support professionals in this country today that are

virtually and continue to be invisible. Yet, they are the backbone, and in some cases, the hope of some of our public policies in the United States.

And so I think that that is a bell that many of us have been ringing for many, many, many years to say, we need integrated policy solutions at the federal, state, and local level to ensure that we have a high quality, compensated, well care-- well-supported and well-respected direct support workforce in this country in schools, in housing, in transportation, in health care.

And we will never, or will be virtually impossible from my perspective, to really achieve many of the goals and visions under the Americans with Disabilities Act, under the Olmsted decision, if we don't invest in and prioritize the direct support workforce.

ROB KIMMEL: Absolutely. The DSP crisis, whether it was inevitable to one degree or another, it's something that, I think, amongst other things that COVID highlighted in sharp contrast, that was one of them. How do you think knowing that this is one of the big challenges, how do we address it? How do we start?

KELLY NYE-LENGERMAN: Well, first and foremost, I would direct many anyone listening to my former and wonderful colleagues at the University of Minnesota's Institute on Community Integration, who I think have been national leaders in the UCEDD network, of both identifying, strategizing, and building solutions for holistic workforce investment.

And it is not easy. Because as I said, it takes multiple layers of both policy, practice, and an individual touch and leadership to make some of these changes. So I think training is a big part of that. I think being able to use data and research to help, say, at an individual state, or even at as a provider level about what's going on. What is your turnover rate? What is your vacancy rate? What are your wages and benefits compared to other people in your local community or other jobs in your state?

Because again, we can't really make informed decisions about the best strategies for solutions at a local or state level unless we sort of know what the landscape is. And there are many states and communities that still struggle even knowing exactly what the sort of depth or breadth of the problem is. And then the other piece is thinking about-- and this kind of goes back to just worker and employee care and concern is, what are the things that we as employers need to be doing to support healthy, productive employees?

And that means access to paid sick leave, access to health care benefits, other types of, I think, positive either benefits, relationships, training, investment, visibility, recognition of the roles that they play, whether you're at a provider level, whether you're at a state level. So I think there's a lot of things that we can do.

I think also, a big thing we certainly have tried to do at the institute on disability, again, learning from a number of our other national and UCEDD partners is also just the recognition of direct support workers as

a deeply-essential part of disability and community services, and not just for people with disabilities. Because as I said, it affects young children in schools. This affects older adults in long-term care.

And so again, giving and shedding light on the direct support workforce, and how critical they are for so many parts of our community, is actually something that we all can really do. Because I would venture to guess that most of us have known and worked with someone who's working as a home health aide, a CNA, an LPN, a DSP, a job coach, a paraeducator. And those are critical roles.

So even just acknowledging and recognizing to try to further lift up, and also remind folks that we want well-trained professionals in these jobs. These are some of the most critical essential jobs, I would argue, in the United States today. And we should pay them accordingly, and that we should certainly be able to recognize and understand the deep value that they-- that they provide as professionals.

ROB KIMMEL: Yeah, direct support professionals truly are the spine of everything, but oftentimes, through a variety of means are undervalued.

KELLY NYE-LENGERMAN: Yes. A couple years ago, the folks at the Institute on Community Integration in Minnesota, they did-- Jerry Smith did a film called Invisible about the invisible direct support workforce. I think-- I actually think it did happen pre-COVID. It's interesting how you forget the timeline. Like did COVID make time stop? Was that pre-2020? I actually can't remember offhand when that film was produced. But there are some great clips. There's a lot of access to materials related to that.

And there's a lot of data that came out about direct support workers driven by the folks at the Minnesota UCEDD to understand the experiences of DSPs during COVID. And even, they followed up with some of that with some additional research and survey work around the experiences of DSP, and kind of this post-COVID world.

ROB KIMMEL: I think that circles back to bringing people to the table to listen to their lived experience, and be reflective and responsive to that.

KELLY NYE-LENGERMAN: Absolutely. Absolutely.

ROB KIMMEL: Well, Kelly, this has been delightful. I find you, and speaking to you, to be delightful. I find you to be incredibly engaging. And I hope that everybody that's been listening to our podcast here today takes something from it. And also, if they have further questions, you can always reach out and learn a little bit more, just as I continue to learn from you.

KELLY NYE-LENGERMAN: And I would encourage folks to go to our website. You can Google us, Institute on Disability at the University of New Hampshire. I work with many amazing and smart colleagues.

And I think maybe where I would just want to close this at the end of the day, Rob, because I was actually thinking about this when I was sort of taking notes, is that I want to really express, again, in the most genuine way that I can on a podcast, the deep gratitude that I have for the people that have taught me from the experiences that I had and the people that I supported as a direct support professional, as a social worker, working in direct practice, have deeply touched and informed how I think about and move about the world.

And I also want to say that I'm deeply impacted and influenced by my colleagues around me. Both here at the University of Minnesota, I feel like that provided such an amazing place to continue to grow and learn as a professional that have really supported me and helped me to where I am to the place today, to my amazing colleagues here at the Institute on Disability, who teach me things all of the time and just being able to reflect on new ways to, again, maximize the inclusion and belonging of people with disabilities in genuine, meaningful ways.

So I'm a product today of all of the care and investment that other people have taken in me, and all of the other people in my life, personally and professionally, that have really challenged my thinking about what does inclusion and belonging really mean and feel like? And at the end of the day, there's no one right answer because that is a very individual and personal experience. But I'm honored to be on that journey with so many of my colleagues, my community members, and my partners.

So and Rob, you are one of them. You teach me things too because I've watched plenty of your data presentations and have challenged and made me think about things in a new way. So I appreciate the opportunity to share some of my story with you today.

ROB KIMMEL: Well, thank you so much, Kelly. That growth and gratitude goes both ways. And so thank you, once again, for joining us. And thanks for everyone that's listening to this episode of the 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.

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