

Ep. 15 Mary Beth Bruder and Tara Lutz

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SPEAKERS

Mary Beth Bruder, Matt Wappett, Tara Lutz

Matt Wappett 00:15

Welcome everybody to the Developmental Disabilities Network Journal, Author Insights podcast. It's my privilege to be here with you. I'm Dr Matthew Wappett. I'm the Developmental Disabilities Network Journal editor in chief and the executive director of the Utah State University Institute for Disability Research, Policy & Practice. And it's my privilege as always, to host this podcast. This is actually one of the fun things that I get to do, and I get to meet so many cool people and have so many great conversations, and I'm really excited to share our conversation today. In fact, today kind of kicks off a series of a couple of podcasts from our most recent issue of the journal that came out in the fall of 2024 that's focused on medical education for doctors and other healthcare professionals related to working with people with disabilities. So this is a up and coming topic. It is an important topic, and it's something that there's quite a bit of work going on around in the world today, and we're excited to have an interview today, kind of about a health assessment related to doctors, sort of competence to work with individuals with disabilities. And then in a couple of weeks here, we'll have an interview with a group of researchers who actually piloted a curriculum in a medical school to help prepare doctors to work with people with disabilities. So this is really kind of exciting to see this happening, and hopefully these conversations over the next couple of episodes of the podcast will be helpful for you. So just in terms of background, and I know I do this kind of at the beginning, but I never know who's listening and who, who is kind of tuning in for the first time. But you know, the reason we started this podcast was part of our commitment to making the journal more accessible. Not everybody reads these days. Not everybody wants to read an academic article, and in fact, there's lots of barriers to actually doing that. Even though the Developmental Disabilities Network journal is open access, it's free to submit to and it's free to read. Not everyone wants to do that. We're busy, we're on the go, and more and more people like to consume their information through video and audio. Again, I said, I've said this on many podcasts, but I listen to more books than I read these days because I'm moving and I can listen to a book while I'm walking, driving, whatever the case may be. In the same with podcasts, I listen to podcasts every morning as I'm getting ready to go get on with my day, so it becomes an important way for me to kind of keep up with things. So we created this podcast so that you can access the content in the journal without having to sit down and read an article, and our hope is that that increases the accessibility of the information. It makes it more, yeah, more open for you to share on social media

platforms. It's easier for folks you know, who maybe don't read at all, to access this information and the podcasts tend to be in more plain language than in a lot of the writing that comes out in most academic journals. And so we're excited to do this, and we hope it provides another alternative to access the information within the Developmental Disabilities Network Journal. So with that said, please be sure to subscribe to our podcast on Apple podcast, Spotify, Stitcher, Overcast, Podbean, wherever you listen to your podcast, leave us a rating and a review that's helpful, and please share the podcast with your friends and colleagues. Those ratings, reviews and shares really help us get this important work out and really ensure that these researchers that their efforts and their findings and write the important work that they're doing gets out and can make a difference. So the other thing is that we like to do the podcast because it gives us a chance to get to know some of the people behind the names on the page. A journal article is a name on a page and then usually an institutional affiliation. And people are complex organisms, right? We all kind of know this, and it's sometimes fun to get to know who are the researchers working in the field today, what drives them, what? Why are they doing this work? And so we really try to use the podcast as a chance to flesh out, as it were, some of the folks who are working in the field, and kind of put a voice at least to the work, and hopefully give you a better sense of who they are. And our hope is always that right these conversations will result in new collaborations, new opportunities and new directions in research in the developmental disabilities field. So anyway, with that said, we want to kind of do an intro for our podcast today. Our podcast today are with the authors of, as I mentioned, a journal article that came out in our most recent issue fall 2024 the journal article is called Barriers to Healthcare Among Adults with Disabilities in Connecticut. And the authors were Mary Beth, Bruder, Tara Lutz and Kelly E. Ferreira, all at the University of Connecticut UCEDD. Unfortunately, Kelly wasn't able to join us today, but we do have Mary Beth and Tara. Let me give you a little background on Mary Beth. I know that many of you probably know Mary Beth. She's been around in the field for a very long time. Dr Mary Beth Bruder is a professor in the University of Connecticut, School of Medicine and the neigh School of Education. She began her career as an Early Childhood Special Education public school teacher in 1976 where she also provided consultation to inclusive child care and Head Start programs. She went on to get her PhD from the University of Oregon in early childhood intervention and developmental disabilities in 1983 one of many people who came through that University of Oregon program, and since that time, Dr Bruder has been a project director and PI on over 100 competitively awarded grants, demonstration projects, centers, research projects. Anyway, Mary Beth has been extremely prolific. She's currently the director of the University of Connecticut Center for Excellence in Developmental Disabilities and their LEND program, and they'll talk a bit about that today. And she's also involved with the National Early Childhood Intervention Personnel Center for Equity with I believe, Dr Tawara Good, who is also working on that. Dr Bruder is also the editor of the Infants and Young of Infants and Young Children, an Interdisciplinary Journal in early childhood intervention. And she chairs the International Society of Early Childhood Intervention. And she was the recipient of the 2024, Lifetime Achievement Award from the Council for Exceptional Children. So we are really excited to have Mary Beth here today, and it's a privilege to have her on and to really benefit from her experience, her long experience, and her impact in the field. We're also joined by Dr Tara Lutz, who is the Associate Director for training at the University of Connecticut Center for Excellence in Developmental Disabilities the UCEDD out there, and she's an Assistant Professor of Public Health Sciences at the UConn School of Medicine. Dr Lutz coordinates and teaches the certificate of interdisciplinary disability studies in public health. And she received her PhD in public health and Master's in public health from the University of Connecticut. She earned her bachelor's degree in

biology from the College of the Holy Cross, and she is also a master certified health education specialist, and she's a family member of a person with a disability. So both Mary Beth and Tara bring a wealth of experience and some really important perspectives to our conversation today, and so we're excited to visit with them. So welcome. Thanks for joining us today, Dr Lutz and Dr Bruder from the University of Connecticut. Thanks for being on the podcast. So to start off with, tell us a little bit about your background and the path that brought you to the article in the Developmental Disabilities Network journal. And why don't we start with you? Dr Lutz

Tara Lutz 09:14

purple Tara, please. Yep. Thank you for having us on to talk about this article and really this much bigger systems level issue, health and healthcare access for persons with disabilities has been a problem for a long time. It's not something that we happened upon or discovered, and that was really the impetus behind us completing this survey. It was to add to the growing body of literature, especially the the new sets of publications out at the national level of the. The systems pervasive challenges that exist. And we chose to look specifically within the state of Connecticut because thought that quote, unquote, new and state level data that would tell a similar story to what was happening at the national level would be compelling to support state level policy here in the state,

Mary Beth Bruder 10:24

I think I would only add that both Tara and I have lived experience within our families of watching healthcare delivery, everything from early childhood through projects that we've had, including projects that included populations such as teenage moms who had babies who had complications from NICU and watching the struggle they had, all the way to family members who we were both confronted in throughout our lives with physical accessibility issues, as well as the way providers talked to the family members we have, you know, somewhat condescending and also, like my elderly Parents, all of a sudden people were talking to me instead of them. So yeah, I think it just brought us into this space, as well as the work we've done about UCEDD from way back when, trying to establish medical goals in this state in the early 90s for parents of kids with medical complexities,

Matt Wappett 11:40

yeah, yeah, no, absolutely. And I really want to dig into some of those, some of those details here, as we get on with the conversation. But for maybe our hope is that people have read it, but if they haven't read it. Tara, could you give us a quick summary of your article? I would love to, and I'd also like to explain how we even developed our survey instrument, because that was a critical piece of living, the values that our center is founded upon. So in order to start to measure what healthcare experiences looked like for people with disabilities across the state. Our graduate students in our LEND program actually took the lead in doing the literature search and then also conducted what we called informant, informal informant interviews, supposed to have conversations with self-advocates, people with the lived experience to find out not just what questions we should be asking, but how to approach asking those sorts of questions. And throughout that entire process, we worked very closely with members of our state, Independent Living Council, self-advocates, parents, leaders, and they were really at the forefront of our decision making and helped us, not only in my words, plain language, if I our questions, but also expand on some of the disability data standard questions in ways that their original language was missing, so it's actually in the article. We took the six standard disability questions and working

with our health advocates, we actually added three additional measures in which someone could indicate that one of those was a way that they lived their life, and that was how we helped to operationalize disability. From there, we structured questions on number of times an individual attended a health care appointment, not using those exact terms, asked, how individuals got to those appointments? What kind of transportation did they use? How were those appointments made? What did our participants need for it to be a good visit for them, but that is where we brought in all of the aspects of the built environment. Do you need access to an office with ramps and elevators? Do you need an office that has an accessible exam table that moves up and down, accessible scales. Do you need access to literature in large print or in plain language? Do you so? We approached asking about those systems barriers in a way that was understandable to our audience, to try and capture the true experiences so that we could report that back out across the state. So on that, on that note. So how did you how did you recruit participants for this, and how did you find folks to respond to the survey?

Tara Lutz 15:42

I will say that here in Connecticut, we are very, very fortunate to have Developmental Disabilities Network that works very close together. Our partners in those spaces agreed to share it out for us. It was out on our social media, and it was shared with other disability and advocacy organizations and agencies across the state, and we let it snowball from there.

Matt Wappett 16:12

That's awesome. It's incredible just how important those connections and the DD network, just in general, can be and right in doing a lot of this work. So kind of on that note, we you started to bring some of these up, but through the work that you've done on this survey and through other work that you're doing, what are some of the major barriers that you found to healthcare for individuals with disabilities?

Mary Beth Bruder 16:37

I can start with this, and I think you need to put the context in that this is a self-select survey, so it does not represent the whole state. The majority of the respondents are over 45 so there are some age-related issues, I'm assuming. And the majority, you know, slightly more than half report motor disabilities or motor challenges, and a might, very small minority using the indicators had issues in regard to everyday focusing or using devices. So, it's a fairly functional sample of the population who was able to navigate themselves, which also is reflected in some of their responses, in terms of the number of times they're visiting a doctor, or the number of are they doing it independently. But within those categories of the people who are responding, they still had that, you know, related to attitudes and beliefs of providers and communication strategies as an example, many of them felt that their provider, and it could be the wide range of providers and office staff did not necessarily understand disability as a normal piece of the lifespan that we all have, and instead, again, did not communicate very openly, directly to the patient, or suggested in their communications that they did not understand the disability and their everyday life.

Tara Lutz 18:24

So in addition to the attitudes, the communication barriers, our respondents did also report out needing that accessible medical diagnostic equipment and in instances that it was needed, they they didn't have

it, so they might need it, but the office, the facility they were going to or wanted to go to, could not serve them, could not meet their needs, or could only meet their needs. Some of the time when they went for an appointment,

Mary Beth Bruder 19:03

going along with that, with what Tara had said is transportation was a challenge as a structural barrier, along with the MD equipment and the MD equipment, findings were similar to national studies that have just been conducted over the past less than five years. And you know, they suggest everything from patients, and we call them persons, obviously not having a full physical done if they're in a wheelchair, that they were left in their wheelchair because people did not want to move them, to the fact that staff did not understand how to even use so if they had something that was accessible, how to use it. And we're talking things such as exam table that would go up and down low, or even from mammograms that the mammogram machine would go down low. So. So there's some real barriers that impact quality of life and health care over a period of life that are still in existence,

Matt Wappett 20:11

yeah, well, we're well into the 21st Century here, right? We started addressing these issues, you know, initially, right, the disability rights movement in the 70s and 80s and the social model of disability, right, challenging that medical perspective has been around for almost 40 years, right? But why hasn't the medical field still fully embraced this or address these issues of accessibility. It's almost mind boggling. I mean, I will tell you just personally, Alex and I are working with our Department of Health here in Utah, and we've had similar findings as we've gone around to do local surveys. And it's kind of mind boggling that we're here in 2024 and the medical field still has issues with basic accessibility. So why do you think that is?

Mary Beth Bruder 21:07

Well, I'll jump in and let Tara expound on it. It's really education, training, and building of confidence and competence among the healthcare It is an area that it's not provided during medical school training. But then we're also expanding to office if there is no expectation that people with disabilities are independent and they can inform it's not expected because people haven't had that attitude about people with disabilities being equal members of society.

Matt Wappett 21:47

I could not agree more that these attitudes and assumptions of our decision makers and our leaders is really where we could make the most impact. Unfortunately, our healthcare provider training programs do not yet require this sort of content. Yet it's not part of any licensing or accrediting requirements, and that sort of mandate would not only require that training for future professionals, it would say to the world that this is important. I think that kind of attitude adjustment, frame shifting is what's needed, and often what we hear as the barrier to some of this happening is the cost behind it. Like, oh, we don't have the money to do that. But if you don't understand the greater picture, well, of course, there are limited resources for everything, but that doesn't get to be the excuse, and until we can kind of raise the consciousness of everyone, but particularly those who have the influence to make these changes, we're going to see, I'll call them pockets of really great work and great evidence based practices and all people receiving quality health care. But it's not the standard. So, it's if I'm living in a certain place and

have a certain type of insurance and lucky enough to have a certain provider on that day, I might have a great experience, and that's not fair. Yeah, absolutely so. So, this isn't a question that I sent you ahead of time, but it does, as you're talking about, this kind of come up for me. So, if these issues of accessibility and inclusive care are still significant challenges, what are the implications of that for people with disabilities in the community? What does it what are sort of the long-term outcomes of this lack of access?

Mary Beth Bruder 24:18

I'm going to just tap into what Tara had said about cost. On the front end, we hear from, you know, hospital associations to individual physicians that it would be too costly to swap out their machinery. But we also have some physicians in Connecticut that did a cost out, and it really wouldn't be if we did replacements and were able to just upgrade equipment that way. And then also our hospitals, where we assume things like accessible scales for wheelchair users are there, you know, they can tell you what's on the fifth floor. People don't have that attitude to but in regard to what's the implications, it is long term possible for society, because if people are not having well care checks, let alone able to access diagnostic equipment, if there is something that needs to be examined or they're not being examined comprehensively, we are going to have people who have healthcare implications and are going to need more intensive health care support.

Matt Wappett 25:29

So it's going to cost more somewhere down the line. It's just a question of, where do you deal with that cost? But also, you know, it's also a quality-of-life thing, I think, right? You know, waiting for people to get worse is not helpful for anybody,

Tara Lutz 25:47

and that's exactly what public health is. It is prevention, right? So, to your point, if, if folks cannot access no routine exams, we're not going to catch things at early stages or when we can easily make adjustments. And people are sicker, unfortunately, and that tends to disproportionately happen to some communities within the disability community,

Mary Beth Bruder 26:23

and to tap into that. One of our findings in regard to the communication with healthcare providers is our insurance structure, persons with disabilities may need a longer visit because right, what we had people write in is they felt that the doctor didn't have time to listen to them. And we know that that's the best diagnostic tool, is having open communication, feeling like you can share, and especially people who have communication challenges, we have seen that, and I'm sure you have to anecdotally, where physicians or nurses or even medical students don't do the wait time that's needed for a person to gather the communication they're trying to say, whether it's through a speech mechanism or through an augmentative system. Yeah.

Matt Wappett 27:16

Well, and this, we were excited to actually publish this article on this issue, because there was another article in it about preservice curriculum for doctors that was, hopefully, you know, they were piloting it and gathering some initial data to address some of those preservice issues and the training, right? How

do you communicate, right with somebody who maybe doesn't have typical communications, and how do you right? How do you make sure that your clinic's accessible and is inclusive and can meet the needs of a wide variety of individuals? So, but, um,

Mary Beth Bruder 27:51

I was just gonna say, so I did. You just gave me a vision. I don't know if people remember way back when, from early childhood, we might have done things that's called Kids on the Block and then kind of to open up little kids and elementary school and high school kids awareness, put them in a wheelchair for a day, or give them blindfolds. I almost think our medical teams have to do that in one of our residency programs, we used to have a resident need a family at the parking garage, and then just go through the whole hospital experience, not open their mouth as a not health care professional but put the shoes on of the tail. So, it's like sensitivity training, you know, put yourself in a wheelchair and, you know, feel what it's like to be restricted.

Matt Wappett 28:40

Yep, yeah, absolutely. I mean it's, it's kind of out of sight, out of mind, unless somebody has that lived experience, unfortunately and that goes to not just people with disabilities, but other right, diverse populations who also struggle. So, this really happens across the board when we're thinking about the healthcare system. So, the intent in your article isn't necessary. It's to kind of highlight these issues, and you do provide some suggestions. So, what are some easy suggestions that clinics or hospitals could implement that would help increase access to healthcare for individuals with disabilities? One of the first things that needs to happen, if it isn't already, is that we need to be inviting and welcoming people with disabilities and lived experience to the conversation. We need to hear from our community members what they need and how best to meet those needs. And that's not a one-time listening session. It is an intentional throughout the decision-making process and then throughout managing an office, a unit of full system, because we, as researchers, as members of the community, should not be speaking on behalf of and making decisions without input from those who are most impacted.

Mary Beth Bruder 30:20

Tara is finishing up a study with local health departments trying to get information from the other side. And I think, you know, one of an easy things to do that we're learning is that people have never really even thought about issues around disability access and also understood that it is their responsibilities to be welcoming for a person with a disability and to provide those accommodations and modifications from the get go, even putting in an electronic medical record, which everybody's using now, the accommodations that should be provided from the time a person who has specific needs comes into that door, everything from parking transportation into you know how the front facing staff interacts. So there's lots of again, it's kind of etiquette, but it's also etiquette with an understanding and awareness that you know this population is part of our population. We are all human, and we need to address everybody's individual needs.

Matt Wappett 31:32

Yeah, no, absolutely. I was shocked. Years ago, we were working on an NIH project, where we were working with individuals with disabilities who were pregnant, right? Women who are pregnant. And I was shocked to find out that in these medical records, right, it doesn't know what somebody's disability

is or what accommodations they need, or anything else. So, it was really hard to identify, right? Some of these women who are coming into clinics because the doctors are not. There's nothing in there to indicate that this person may need right an accessible exam room, or any one of a number of other accommodations, which kind of mind boggling in this day and age,

Mary Beth Bruder 32:12

and especially because so many different providers see somebody you may not see the same provider, you know. So yeah, the lack of communication among providers is astounding. And again, that's not just for people with disabilities. It's just plenty of us in the medical field. We are still carved up by specialties.

Matt Wappett 32:33

Yep, absolutely. So, I wanted to go back to something you said, Tara, about the importance of that the voice of people with disabilities and lived experience. How, how would a clinic or a hospital or a medical group right, formally engage right? We're in a process where they're getting that feedback and listening to those to those voices and that experience. That is a great question, and one that has been coming up a lot in our work in in the community space. So, a couple of couple of ideas, there is at least one UCEDD so University Center for Excellence Developmental Disabilities in every state. So, encourage anyone listening to find out who that is. In a similar note, every state also has a State Council on Developmental Disabilities and a protection and advocacy unit so that that exists in every state, reach out to independent living centers. We work very closely with Connecticut SILC and other disability advocacy organizations. So, there are national and then within each state kind of networks of this work going on. So, if those places and spaces are not the best fit, they're also going to know who might be better suited to join a group answer a question, something like that. Yeah, absolutely. So yeah, and every and I'll just re-emphasize that the Developmental Disabilities Network exists across the country, and there's a lot of organized, advocacy minded individuals who are involved in those systems, for sure. So, one of the other things that we like to do on the podcast is kind of look under the hood and behind the scenes. When an article comes out, it's very focused on, kind of the outcomes. But as you're going through a project, and any project, there's things that happen, there's experiences, right? That aren't reflected in the work. And so, we like to ask authors who are on the podcast to share a memorable story or event that occurred as you worked on this article, and you know, maybe something that's not reflected in what ended up being published. So, it's hard to choose 1, one in particular. But I think what made this project uniquely rewarding us was that we had students involved, also from the beginning, so learners who have self-selected to become leaders in the disability space, and at the time in their training, didn't know a whole lot yet, but wanted to learn. So when our students were conducting their informal informant interviews or conversations and hearing firsthand from someone with lived experience, like, Yes, I had a provider turned away from me and to x person in the room, their responses, talking to us about how they felt, hearing that, to hear like their genuine anger and frustration and want to change this was really powerful, and those students have now graduated and moved on, but to be part of their journey in becoming change maker in this space and going through a research process that was so intentional to bring in the lived experience as the driver and motivator. I think is something that I very much take away from this project. Yeah,

Mary Beth Bruder 36:56

I can expand on that, because this was a three year long project each year a different group of students, starting with the first year listening to informants to find out what the issues were, and then to start thinking about what else we needed to know. The second-year group then helped format the survey and formalize the questions and pilot the survey, and then the third-year group got to see their fruition, because we actually had a public hearing at the legislature on healthcare barriers for people with disabilities through a coalition of groups that we had been working with, our DD network, SILC. A number of local organizations, we brought in national experts who came in on Zoom to do the testimony, and we got the attention as a community. And what was great is that the students happened to be doing their legislative day, all serendipitously, the day there was a hearing, so they got to sit in at the second part of the hearing. The first part we brought a lot of people to testify. The second part was when they talked about it in committee. So, it was just a really good example, as Tara says, of helping people, students, graduate students, understand that number one, change can happen. but number two, it's not magic. It is hard work. It is more time than you think it should take. And most importantly, it's collaborations and coalitions, finding your allies, and, you know, building momentum. And of course, our persons with disabilities, who really had the compelling testimony, and were the ones who got the attention of the legislators?

Matt Wappett 38:45

Yeah, absolutely, there's so many students who I've talked to, and I know others who have talked to that those one-on-one individual experiences, right, hearing these stories are just so life changing in terms of their career and their focus and recognizing right the issues that actually need to be addressed out there in the community. So, with that said, as we're kind of wrapping up here, what, what is the take home message from your article? If you know, if you wanted readers to remember one thing, what's one thing you want them to take away from it throughout the article, and that's not necessarily specific to our findings, but I will echo words that have been instilled in me for a long time. It's nothing about us without us that we need to continue to center the experience and expertise of people with disabilities and demonstrate to others how we can support and advocate with but not advocate on behalf of how we we do all of this together. Yeah, yeah, that's a powerful it's a powerful thing to take and especially, it's a powerful statement, really, when we think about the medical field, right? You think about the medical field here in the United States, they're kind of at the top of the food chain in terms of being viewed as experts and having status. And, you know, there's that nothing about us without us. Philosophy, um, requires some humility sometimes to implement, which I think is tricky in some of these areas.

Mary Beth Bruder 40:35

You know, the only thing I would add to that perfect ending is that we need to keep educating people to keep their eyes open and put on the shoes of somebody has less ability, whether it's motoric abilities, or whether it's cognitive, than they have, because just like you, Matt, I can't believe it's 2024 almost 25 and we still have a portion of our population who cannot access minimum care, let alone good medical care. It's unconscionable.

Matt Wappett 41:07

Yeah, no, I totally agree. It's it really is mind boggling, as we started to also get into doing some of this work. It's just, you're like, what? How is this even happening? But it is, and it's a lot more common, I

think, as you pointed out, than most people want to admit. So here at the end, we end the podcast the same way with all of our guests. And again, a lot of times when you read an article, we're focused on the content, and the authors are just a name, and we like to put a bit of a face on the authors who publish in the Developmental Disabilities Network journal. So, I've got two personal questions here, and I'll have both you, Tara and Mary Beth, answer these. But what motivates you to do this work? Why do you do what you do?

Tara Lutz 41:58

Reading this question before getting on today, I did take pause, though I feel like it's second nature at this point why I do what I do, but I wanted to frame this correctly. It's personal to me, as was shared a little bit earlier. I have a very close family connection to disability, and it's really shaped my life as a family member, and then also my professional life and this work aligns with my own personal core values about respecting and upholding the dignity and personhood of other people. I think that's both of those together has what's brought me to this, this space and to work in a UCEDD within this network to try and change systems.

Matt Wappett 43:03

Yeah, yeah, thanks for sharing that. Tara Mary Beth, what motivates you? Why do you do what you do?

Mary Beth Bruder 43:10

You know, I There isn't an easy answer. I think those of us who've been in the field for a long time, and I have been in the field for a long time, it was something I wanted to do from the time in high school when I was a daycare counselor for a new day camp. Day camp counselor for new day camp for children with disabilities, I've been a regular town day camp counselor, and they've got to start this. And everybody has a story. My father played golf for recreation director, and the recreation director said, I don't know how we're going to staff it again somebody who didn't have the right attitudes. And my dad said, well, my daughter will be there. And I just found my calling, and I had a wonderful undergraduate program in a very small, all women's school, catholic, who felt very I was instilled with social justice, and the, you know, this is an extension of social justice, because this was before 94- 142, right And I just found my passion, not just with disabilities, but little children with disabilities and their families and then spend a lifespan seeing what happened. So, it's something that I can say was not a conscious decision. I was lucky to find something early on, and I always say I've always been at the right place at the right time and take advantage of opportunities to kind of enhance quality of life issues. It's a human rights issue, but more importantly, it's a human being, we are all here to help each other. And yeah, but I will tell you that during this podcast, if anybody is looking for a career path and haven't decided disability is really a wonderful career path, because, like Tara said, we learn from things. Yeah, so listening to the human experience helps us be better all together. So, I really would love to see shortages we're facing, the quality challenges we have really be taken upon by this next generation who will help advance.

Matt Wappett 45:20

Yep, I would totally agree with what you both said, for sure. And I love how both of you focus on that lived experience, that experience and exposure and is just so important to the passion that drives a lot of us to do this work. It is. It's a very personal work and people take it right seriously, because it is so

personal and it is so important. So, the last question here is, again, one of the things that we try to do with the journal is, make things more accessible and inclusive, and we like to kind of get people to think about what they're doing to make their day-to-day work more inclusive and accessible. So again, going back, we'll start with you, Tara, what's one thing you've been doing to try to make your work more inclusive and accessible?

Tara Lutz 46:18

I will answer that after hearing Mary, that's what brings her to this space. I do want to add a little bit to mine. So, my undergrad was in biology. I was pre-med, but I was going to become a physician, and it was about time to graduate. I realized that I didn't want to make an impact one person at a time, but I did not yet have the language of public health, so I applied to grad school. I actually applied to public health programs and special ed programs, given my background, my family background, and I chose public health, and was still interested in that disability aspect of it, and was introduced to Mary Beth here at the center, and that is how I came to be in the disability public health space focused my masters and my doctorate here and now, faculty continuing to help educate and make change. To answer the question about what we're doing to make work more inclusive and accessible. Following this publication or kind of parallel to it, we continue to work with the Coalition of individuals who were advocating for accessible medical diagnostic equipment, and together, we just published a checklist, a checklist of best practices to provide healthcare to adults with disabilities. And it was a really big undertaking. There were a lot of voices that deserved to be heard, and then creating a product that that made sense. So, it's not necessarily focused on meeting needs of persons with specific types of disabilities, but more, how do you address different functional, or communication needs more broadly. So that is now up on our website. Our State Department of Public Health actually sent out annual communication to almost 30 individuals. So, health care organizations and providers at links to our checklist. So again, kind of staying in that space of changing our systems. One thing that I do personally in the public health courses that I teach is I walk students through how to create accessible Word documents in PowerPoint presentations, and then I start to grade them on it. So not only do I grade their work on the content that they present, but how they present it. That's my small contribution to how I'm trying to change the world.

Matt Wappett 49:46

No, that's so important. That's, um, that digital accessibility is a big part of what we do here in Utah. And, you know, it's amazing that, again, kind of like healthcare, we're here and, you know, well into the 21st Century, and most people don't know how to make a Word document basically accessible, or PowerPoint or pet peeve, right? Exactly? Yeah, PowerPoints are a big one too. So, Mary Beth, what's one thing that you're doing to make your work more inclusive and accessible?

Mary Beth Bruder 50:16

Well, I think it's just an ongoing mission, which I know you share, which is to employ as many people with a lived experience. And that starts with the fact that LEND now requires somebody with intellectual disabilities, and we've been very fortunate that we as a faculty, that we've always had good input. Tara mentioned the coalition. We have a coalition of disability groups across the disability alliance, and so we always tend to get people who want to come into lend and share their experience, and then they stay on in some way with us. But we have a number of family, parents of kids, and what we find in our

center is, again, it's their passion and their mission, and our work is elevated by having people who are living the experience of disabilities themselves or within their family. So, I think that's always something we have to keep striving.

Matt Wappett 51:16

Yeah, absolutely, well and thank so I want to thank both of you for Yeah, your time today and just being willing to share your experience, your research, your background. It's always fun for us to get to know write the authors who are who are publishing in the journal, and hopefully, right this this podcast is going to make some of this information more accessible, maybe for folks who don't want to read the journal, can still access the ideas. We will make sure to post the links to the tool, and I'm assuming Tara that it's okay to share that broadly, yes, please. Okay, we'll make sure we post that and we'll post a link to the article. But yeah, we just want to thank both of you for taking time to visit with us today, and best of luck on continuing to do this work and fighting the good fight.

Mary Beth Bruder 52:07

And you too.

Matt Wappett 52:10

Thank you. Thank you. So that's it for our conversation today with Dr Bruder and Dr Lutz, where we're just thrilled to have had them on and to have learned so much, I feel like, yeah, every one of these conversations that I have, I learned something, and the work that they're doing, especially around access and health equity, is so, so important. As I mentioned at the beginning, this is the first in a couple of episodes that we have coming up around health equity for people with disabilities. Our next one coming up will be with actually, some physicians who piloted a curriculum in medical school to help doctors or doctors in training to become more comfortable in working with people with disabilities. So anyway, stay tuned. Tune in for that one in another few weeks. But here at the end, I'd like to thank the Developmental Disabilities Network journal managing editor and the author insights podcast producer Alex Schiwal. She's the one who makes this sound good, and we appreciate her hard work to keep the journal moving and to get this podcast out. She does a lot of the heavy lifting, and so Alex is key to making sure that the Developmental Disabilities Network journal continues to grow and thrive. We'd also like to thank the Utah State University Institute for Disability Research, Policy & Practice for their financial and in-kind support for this podcast in the journal. And the journal also receives support from the Utah State University Libraries and Digital Commons, and we're grateful for their ongoing efforts to support our effort to get this information out there in an easy, accessible and affordable manner. So, as I mentioned earlier, please be sure to subscribe to the podcast on Apple podcast, Spotify, Stitcher, wherever you get your podcast, please leave us a rating and review, and please share this via email, via social media, whatever the case may be, share the important work that these people are doing. Your shares, your ratings, your reviews. They all help us share this important work that's being done in the field today. So, you can learn more about the Developmental Disabilities Network journal at our website, which is digitalcommons.usu.edu/ddnj/ and you can download podcast transcripts in English and Spanish and learn more about our podcast guests at idrpp.usu.edu. You go there, go to the drop-down menu for the about, and under that, you'll see Developmental Disabilities Network, journal, and the podcast is linked there. And yeah, you can access transcripts and links and lots of other information that was brought up today. So, thanks so much for listening. Keep up the great work. You're making a

difference, and we want to know that. What we want you to know that what you do matters. Stay tuned for the next episode. We'll see you in a few weeks.