

DDNJ Ep.21 LEND

MW: Hey everybody, welcome to the Developmental Disabilities Network Journal's Author Insights Podcast. I am the host, Dr. Matthew Wappett. I am the Editor-in-Chief of DDNJ and the Executive Director of the Utah State University UCEDD and it's my privilege to host this podcast.

It's just, again, one of my favorite things to do. I love visiting with our guests. I love learning. I love just seeing the tremendous diversity that there is within our network. So(...) thank you for tuning in. We appreciate you listening. We appreciate you sharing.(...) Please be sure to subscribe and to share these podcasts. It's how we get the word out and it's also how we raise awareness of the work that we do here in the DD Network.

Today is an ongoing episode in our series about DD Network programs. We've done DD councils, UCEDDs, P&As. We've had an episode on collaboration between the three agencies in the state of West Virginia. And today we're going to talk about LEND programs. So we've got several LEND directors on with us. And you're going to notice that these LEND directors are coming from Western rural states, which was intentional. I really wanted to focus on the importance of LEND programs in building rural capacity. Part of that is completely personal. I've grown up in the rural West and it is something that I am passionate about. But it's also, I think, just a great illustration of how important these LEND programs are to building capacity in our rural and frontier communities.

So today we get to visit with Marcia Moriarta from the UCEDD and LEND program in New Mexico. We're visiting with Rachel White, the LEND director in Alaska, and then Jenny Miller, who is a LEND faculty in Alaska. So by way of background, Dr. White in Alaska has been the project director for the Alaska LEND Without Walls since 2024. So relatively new, but she has over 20 years of experience working in and with community agencies that provide services for children, youth, and adults with autism spectrum disorders and other developmental disabilities. She's been the PI on multiple state and federal grants and systems change projects. She's also a BCBA and has done a lot of work in homes, schools, communities, around supporting the needs of children and adults with autism spectrum disorders and other developmental disabilities. So Jenny Miller is a faculty member in the LEND program in Alaska. She also has a faculty appointment in the Division of Population Health Sciences at the University of Alaska Anchorage. She teaches courses in their Masters of Public Health program on research tools and methods, health services administration, and policy. And as you'll learn, I think through our episode today, she brings a lot to the Alaska LEND program and has a tremendous amount of experience in helping

that program make the impact that it does in many of the frontier communities up there, way up north.

So finally, we're joined by my colleague and friend, Marcia Moriarta. And Marsha is a child family psychologist who is also the executive director of the University of New Mexico Center for Development and Disability, the UCEDD down there in New Mexico. She's done that for the last 12 years, and she's also had the privilege of serving as the LEND program, which, again, as a UCEDD director myself, I don't know how she balances those two, but Marsha is incredibly on the ball, organized, competent, and it's just great to have her on to visit with her today about her experience in the LEND programs. I think she's also important on this episode because she herself is a proud graduate of the LEND program at the Children's Hospital Los Angeles, where she was a trainee during her psychology internship almost 30 years ago. So it's a great example of some of the long-lasting impacts that these LEND programs have. So with that said, let's jump into our conversation with Rachel, Jenny, and Marsha.

MW: Well, thank you for joining me today for this conversation about LEND programs. So we're going to kind of go around the horn here and get a little ground on our guests today, Rachel, Marsha, and Jenny. So why don't we start with you, Marsha? Tell us a little bit about your background and the path that brought you into the LEND programs in New Mexico there.

MM: Okay, thanks, Matt. Well, you know, what brought me actually to LEND was my psychology internship 30 years ago. In 1996, I graduated from the LEND program at Children's Hospital in Los Angeles. And that is what set in motion my whole career with the entire network. And eventually, 10 years later here in New Mexico, where I came to work, not at the LEND program, but in our Children's Mental Health Services here at the University of New Mexico, and eventually made my way to the UCEDD where I became, had many hats here. In the past two years, I've actually served as the LEND director(...) after our long standing LEND director retired. And I did it initially, quite frankly, interim, thinking we would recruit and hire a new LEND director. And I fell in love all over again. And have found my participation in LEND as the director not only kind of brings me back to the regular interface with people who are living with disability, those who are serving them, those who are learning how to serve them in ways that are really real and kind of grassroots, in a way that my role as the director, executive director for the whole center does not. And so I'm going to retain this role. Because I think the synergy between my leadership role as the UCEDD director and the reality of what we're doing in LEND that really is(...) just, and we'll talk more about this, a forum for really just continuing to flip the prism on what does life look like for people with autism and other neurodevelopmental disabilities in our

communities will also inform the work of our center. So in some, I started as a trainee, I would not, quite frankly, have been in this field without having been a LEND trainee 30 years ago, I fell into it, was told I was going to be part of the LEND training program as part of my psychology internship, thought I was going to be a child family therapist. I was that, but I became a child family therapist for kids, youth, families dealing with neurodevelopmental disabilities, which was not on my radar until I was a LEND trainee.

MW: Wow, a long history there. That's amazing. How many people are in the LEND program there in New Mexico, just out of curiosity?

MM: Yeah, we have 11 faculty plus myself. And right this year, we have 24 trainees, which we are a LEND program that tends to shoot for a minimum of 20. And this year, we just had such a great candidate pool. We kind of went over that mark.

MW: Wow, that's awesome. That's not a bad problem to have.

MM: No.

MW: At all. Cool. Well, so going from New Mexico, the bottom of the United States, all the way up to the top, we're going to go to Alaska. So Jenny and Rachel up there in Alaska, tell us a little bit about your background and the path that brought you to the LEND programs. And maybe we'll start with you, Rachel, if that's okay.

RW: Sure. So I'm a behavior analyst and I've worked with children with autism and developmental disabilities since around 2005. I was hired on to the University of Alaska Anchorage Center for Human Development, which is our UCEDD in like 2017, I think.

Yeah, that sounds about right. And I had been presenting in the LEND program, just when they would cover applied behavior analysis, because they didn't have a faculty for that. So I would come in as a guest speaker when they covered the ABA section.

And I had colleagues in the field who had been through the LEND program and had told me a little bit about it here and there. And then when our director was retiring, I was asked to join and come on as the applied behavior analysis faculty and then as LEND director.

And been really happy in that role. I think one thing that I see as a benefit is that applied behavior analysis is often, we often work very siloed and we need more interdisciplinary collaboration and training. So I look at this as a opportunity to start doing that a little bit more in Alaska.

MW: All right, Jenny. So what about you? What brought you to the LEND program up there in Alaska?

JM: So my trajectory just adds to the diversity of our backgrounds. I started my career as a public health nurse. And so I was so lucky to visit families in their homes. I was referring families to the Nisonger Center in Madison, Wisconsin. So I had an orientation to referral and management. And when I was doing a master's program in maternal and child health at the University of Minnesota, my mentor was all about disability studies and she herself was a practitioner. So kind of had a seed planted there. I then directed the State of Ohio genetics program in maternal and child health.

And when I went on to do my doctoral work, my dissertation was all about family issues among families who had infants that were technology dependent and really learning about psychosocial issues, economic costs, that sort of thing. So in Michigan, I was on faculty and spent some time doing research at the developmental disability institute. And then my family moved to Alaska and Karen Ward was interested in the research that I was doing related to access to preventative health services for women that experience disabilities. And then I don't know, I think we're talking 2011 or so. There was an idea that maybe Alaska could have a LEND program. And I have been a part of it ever since.

MW: You were involved in writing the application and everything?

JM: I was.

We had a planning grant 100 years ago, I think. I'm joking, a long time ago. And then after the planning grant, of course, we turned around a full proposal.

MW: It's been good to see that grow up there for sure. So thank you for sharing a little bit about your backgrounds. And it's probably good. I'm assuming that folks who listen to this, we're a pretty niche community and we assume that people kind of know what they're about. But it might be helpful if we give people sort of a short overview of what LEND programs are and what role they play within their state.

Maybe I'll come back full circle to you, Marsha, and start with you. And then we'll kind of go back around if that's okay.

MM: Yeah, it's actually timely because we've been doing LEND interviews for next year and I have my spiel kind of down. And actually I'm kind of struck, New Mexico always feels like we're sort of three steps ahead in some things and 11 in others. But we've been a LEND program for 25 years. This is our 25th year. So it's a very long standing LEND program. And I think LEND is really a leadership opportunity for a truly interdisciplinary group of people that includes people who are students, professionals, and people living with disability, both as family members and individuals with disabilities. And it's sort of this profound space to bring together the knowledge, the learning needs, and the community of people living in different vantage points around the same set of issues. And so one of the things I think

about with LEND is for professionals, it's a profound opportunity to hear from real live people that they will be, are, or will be if they're trainees, serving, and how to really understand some of the ways in which professionals don't always meet the mark. And or how they can really enhance and be more sensitive and thoughtful. The other thing that when you're in a clinical mind, like clinical psych, you learn about psychopathology, you learn how to diagnose, you know, the negative attributes that are, you know, accounted for when you diagnose autism, you don't actually learn as much about systems and how people actually access them or what it's like to sit for nine months waiting for a diagnosis in a family where you're grappling with, is it even the right diagnosis, let alone how do we start to get supports.

So I feel like LEND creates this opportunity and space for conversation and mutual learning and really influence that, you know, those voices of people living with disability can have over professionals, sometimes really early in their career. And then often we have mid-career professionals as well, who are kind of moving into the disability space, often nutritionists or others who are like, "We're seeing a lot of kids with autism in my practice and I'm not sure what to do," you know, that kind of thing.

But to me, the real kind of profound thing about LEND and I'm, like having flashbacks to being this really green trainee hearing people talk about dentistry, like it would never have occurred to me to think about what going to the dentist is like for a child with a disability until this was brought to my attention, right? So you have this ability to just have these very profound, sticky experiences that change practice, change relationships on both sides of the fence. And I could go on, but I would also say that one of the things we talk about on our LEND as well is we learn, the faculty learns, as much from our trainees every year as we provide them.

So I just think it's this very profoundly impactful space that is lasting over time. The other piece that's so important to LEND, and then I'll let my colleagues talk, is we're really teaching leadership and advocacy. Like it's not just about learning from each other. It's like, what are you going to do with it that's going to matter? And so we do a lot of work in storytelling and how you sort of tell stories effectively, even when they hold a lot of emotional cadence for you. You know, you're talking about your own child, you're talking about your own self, but how do you do this effectively? How do you talk to a legislator? How do you talk to a provider who's not hearing you? How do you do it effectively and from a relationship-building standpoint? And, you know, I know we'll get to the question of how does, do LENDs impact people in the community, you know? And I think it's in these sort of indirect, but really profound ways of influencing practice and relationship. So I'll pause there, but...

MW: Yeah, no, I think I appreciate that. That's a very comprehensive answer. Is your LEND program largely in person there in New Mexico?

MM: It is, but we really make it hybrid because we are rural, right? We want representation. So what we have done is we've built budget to ensure we can fund the travel of trainees who are more remote so that they can come for key times, our orientation. We do a leadership academy that we do in person. We will pay for their hotels. We pay for their travel. And we make that really clear when we're interviewing so that we can create some of that in-person community. It matters. We also work really hard to make the remote participation as equitable and inclusive as possible. And I will tell you, some of our younger trainees are so much better at this than some of the old guard. They're so good about using the microphones and so good about saying their names and forging relationships. So we are, and any suggestions any other LEND programs have, but we're finding some pretty good success and continually refining how we really make participation through multiple methodologies work.

MW: So moving to Alaska then, and I'm going to tweak this question just a little bit. What does your LEND program look like? And what role does it play up there in Alaska? And is your program largely rural? Is it in person? So give us an overview. We kind of got a picture there of New Mexico. What does yours look like?

RW: So we are remote. We do all of our weekly seminars on Zoom. And then three times a year, we do pay for travel for trainees to come in person and do some in-person activities.

We are smaller this year, I think we had 12 long-term trainees and two medium-term trainees, advanced medium-term trainees that began the year with us.

And so we're usually around 14 or 15 people total for our trainee cohorts.

We do have 10 faculty this next year. We're actually going to be able to add on an additional one. So I think we'll be at 11 faculty for next year.

MW: Are most of your trainees coming from the more urban areas? Are you getting them from the remote villages? I mean, what does that look like in terms of your trainee population up there?

RW: Yeah, we definitely try to recruit from rural and remote locations. I think going off of this year's numbers, maybe half were within driving distance, which is basically Anchorage or the Matsu Valley, and half were flying in from elsewhere.

So that's, I don't know historically how those numbers have played out, but just this last year, that's about where it was. And this year, we are also in the middle of our interviews for next year's participants. And we do have a lot of applicants from all over the state. We do

get quite a few special ed teachers from remote villages, which is really good, that they have sort of an ongoing collaborative that they keep referring more and more people to LEND through that. So we do get quite a few people off the road system as it is in Alaska.

MW: Yeah, no, that's great. And those special ed teachers play an important role in those small communities. It's much more than just a teacher. It's a resource connector in many ways. I don't know, just the system up there in Alaska looks different. That's all there is to it.

So Jenny, I'm going to move to the next question for you. I would like your perspective on what makes LENDs a unique and important part of the DD network.

JM: Wonderful. If I can make one little comment about the last question, and I expect you to tell me if that's not okay.

MW: No, that's totally fine.

JM: Alaska always does things differently. You probably all know that. And we at one time were the only LEND that did not have an association with a university based medical school. So we look very different, not only in that our fellows all are not in training but also many are practicing professionals. And among those practicing, excuse me, professionals, many are also family members. So they kind of have a dual role that really enhances the perspective that they bring to the program. Really feeling that that has been wonderfully infused with family perspectives, as well as those from self advocates. So in terms of uniqueness, that's my next question. Right?

MW: Yeah. Yeah.

JM: Okay. So I think I think one of the really good things is that LEND programs bring a interdisciplinary lens to addressing challenges for families and family seeking services. We have an opportunity, not only in our certainly in our own practices, but during LEND to really model good interdisciplinary teaming. And in my mind, that underscores the leadership component of LEND that I think is, I think they're kind of on an equal platform of interdisciplinary work and leadership. In Alaska, we're building interdisciplinary networks and those networks are long standing. It's a big state, but it's a small town in terms of the number of professionals and specialty professionals. And when we have our LEND alum come and present to our new cohort, they universally, and we don't tell them what to say, but one of their long lasting values is their networking capabilities. They know who to call if they need a service in a remote village or a particular save family situation. I think that that's a large contribution to the network.

MW: Yeah.

MM: You know, I'll be back on that, Matt. I just, we're very similar in New Mexico. I mean, it's warmer and sunnier, but we're a big small town. And so the networks that are created through lend have huge impact on our state. For example, the current executive director for our DD council is a lend graduate from a couple of years ago. Like this is, we are building leaders that actually wind up taking on leadership positions clinically, as family advocates, in our state government.

You know, our DDS lead or Department of Development or Disability Services lead, you know, this is just a big small town. And so I think in these rural Western states, it really does build the leadership in the disability community that's going to continue the work. And I would just piggyback on what Jenny's saying is increasingly, although we are affiliated with an academic medical center in our lens started off being quite academic and clinical, we still hold that, you know, we're training clinical psychologists and SLPs and psychiatrists, but increasingly, like this year, more than half of our training group are people who are training to be professionals, but also identify as individuals with disability, which one of the things we're really looking to do consciously is build disabled professionals in the field. So I just would really that rural urban mix and the impact statewide is a really important piece for lens in states like ours.

Yeah, so and I think there are other contributions also to the network lens make but maybe let Rachel chime in. Yeah, sure.

MW: Yeah, Rachel, do you want to weigh in on that one?

RW: I was gonna just echo what Jenny had said that that interdisciplinary piece, I think is something that I didn't get in my own professional training until I started working in, you know, settings where that was prioritized and having all of those different perspectives come together and also hearing from families and individuals with lived experience and disability helps to kind of make a more well rounded perspective on how you should approach things as opposed to often the disciplines are very much focused on just like one aspect and don't necessarily in your professional training, you don't necessarily hear all of those perspectives and maybe have some uncomfortable conversations where those perspectives differ significantly and figure out how to work together because really we are all working towards the same end goal.

But we don't often get a chance to practice that interdisciplinary collaboration. So

MW: yeah, yeah, for sure. And that's I think that's a real challenge often in rural states where a community may have one provider, right? And they don't have that chance to do interdisciplinary teaming unless there is a network of professionals that they're connected to that they can reach out and leverage. So yeah. Yeah. Well, thank you all for answering that one. So we've kind of intimated this one, but I do want to kind of go touch on the rural piece because again, I think it's the way that your respective LENDs work is really focused on building a lot of that rural capacity and building again, those networks that make, right, services to people who live in rural remote communities more feasible.

So you've kind of addressed this, but I thought we'd go maybe dig into it a little more. I mean, outside of what you've said, I mean, what role do your respective LENDs play in building capacity in those rural communities? Say outside of just that networking connecting people, are there other ways that your LENDs are actually making an impact in rural and remote regions of your state? Jenny, do you want to start on that one?

JM: I'd be happy to.

MW: Okay, let's do it.

JM: Because I can then take the opportunity to brag that at one point we had the most, a LEND fellow from the most northern part of the country. She was in Venn Barrow and she was just turning her community on its head by really looking at what services families may need and how she could make it happen. So she did a wonderful job cross discipline. I think that probably the primary care provider who I think was a physician assistant in her community started thinking about families and primary care in a very different way. And I think and I'm not suggesting Marcia, I have good information on this, but really Alaska has difficulties with workforce development, recruitment and retention are huge problems. So the whole idea of taking expertise out to communities and giving someone some added tools to their toolkit can really go a long way in not only services to families, but also really growing more professionals that are interested in this kind of interdisciplinary work.

MW: Yeah, yeah. Marcia, what about New Mexico? I actually, and this is really embarrassing for me to say, I knew that New Mexico was remote, but until I went down there in November this year and spent time on the Navajo reservation, everything, I had no idea you could drive for like, it felt like Alaska. You could drive for like three or four hours and not see anybody. It was way more remote than I thought it would be.

MM: Yeah, I mean, you know, so we yeah, we have all that frontier country and then we have our urban centers, right? And in more than, you know, most of the state lives in the Albuquerque metro area, or down in the Las Cruces area. So I'm thinking about how to answer this question, because there is, we are, we are certainly pulling largely, you know,

we pull a lot from the metro area, because that is where our providers are, and I'm thinking the way our LEND program really does this is we actively try to recruit from the rural areas, including, and I was just going to talk about our native communities, our Pueblos and our, the Navajo Nation, because we're part of the Four Corners area there. And, you know, we're more or less successful with direct recruitment, but we have multiple partnerships with other state and university entities that actually support this. And let me see if I can say this concisely.

So our state is really invested in methods to encourage people to go to work in rural communities, whether it's loan repayment, or extra payments for physicians or for allied health or other kind of professionals to go into rural communities and work for a period of time as part of an incentivizing. And so those are trainees that are sometimes coming through LEND. So we work in partnership with some of those programs.

But the other piece that comes to mind, and this is maybe an example, is we have a program through our Speech and Hearing Department called MESA, which is really designed to encourage Spanish speaking and native students to study speech and hearing, and then go back into their communities to serve. And we have a direct line where those, part of the MESA program is that those trainees spend a year in LEND. So this past year, we have 4 MESA trainees who are SLPs in training, who will then go out and serve in these rural areas and/or have the linguistic skills to serve, you know, because we have a high Spanish speaking population here. So I think we're really doing a lot of partnership in that just to sort of like, so they have sort of like designated spots in our LEND program.

And then actually, they have a new director who was actually going to do LEND this year, because she's like, I need to understand what these students are doing. So, and with that, the other piece that is lined with what Jenny said is we do LEND in collaboration with some of our other UCEDD programs. So as the University Center for Excellence in Developmental Disabilities in a high need state, we're actually, as you know, Matt, a pretty large UCEDD in a small community, because we're like this forum to do a lot of innovative practice that can't happen in a traditional medical center. And we're the only one like UNM is the only medical center in this state. So I think that the LEND program partners with a number of our other clinical programs. And we're implementing START, which is this sort of systems based mental health, you know, START, but mental health intervention for people with IDD and ASD who also have challenging behaviors to bring people into other parts of the state by basically, you know, giving them jobs in those programs when they finish LEND. And so it's a little less direct.

And I'm not sure I'm making full sense with this. But I feel like it's like LEND is like these tentacles that infiltrate and we're constantly looking like how do we pair this with this and

make more impact in this rural community, or get that provider over there where the need is. The family voices are also really important too. We have had a lot of LEND trainees who are either parents, family members who are living in rural communities that participate in LEND and really demonstrate the challenges to our trainees and kind of motivate them, I think, to want to work more in those spaces.

MW: Yeah, yeah, no, that's, that's incredible. And that MESA program sounds really cool.

MM: It's very cool.

MW: Having that partnership.

MM: They just did their capstones, the four of them. And I oh my god, these guys, like they can run the center someday. Like it was awesome. So that's what I want to say about the contribution to the you said our network, our DD network is, we're building the leaders for the future. Yeah, they like, I would not be in this role without a LEND program. And, and they also get exposure to this larger network that we all represent that they don't know about. They don't know that this larger national community exists until LEND is part of their repertoire. And it's like profoundly changing. And it's, it's very motivating, right? People like to be part of communities.

MW: Yeah, absolutely. So Rachel, do you see something similar in Alaska, where you see these LEND trainees taking on leadership roles in their community, you know, maybe within universities, research settings, whatever the case may be, and, you know, how is that influencing maybe the dynamics there in the state of Alaska? And I know I didn't give you that question ahead of time. So I'm just making it up.

RW: You know, when we reach out for partnerships with different community partners, right, our infant learning programs and stuff, in almost every community partnership, there's like somebody that was part of LEND.

Even in the rural areas, it's like, oh, well, one of the features of LEND is pairing people with like a host family, if they haven't had any experience with families of individuals with disabilities, that they get a chance to talk with that family, maybe join them on some outings or things like that, and just kind of see what their lives are like. And we pretty much never really have a challenge of finding somebody in a community that we can partner with, right? Because somebody's heard of LEND or somebody was a former LEND fellow. And I think we just finished year 16. So, you know, it's been around for a while. And so I think that we do have, and I'm sure Jenny would have specifics, but we do have former LEND fellows in various leadership roles in, you know, government connections and different organizations. And that really helps us to continue to build that LEND program. So hopefully Jenny can fill in some of those gaps.

MW: You want to weigh in on that, Jenny?

JM: So I was so lucky in one of our re-applications to put together a listing of where our LEND alum were currently working. So like you, Marcia, the director of our senior and disability services, a mid-career professional went through LEND. And it wasn't that there was a direct recruitment, she was just interested in learning more. And in a leadership position, she wanted to know how that happened. So you might imagine there are several program managers in senior and disability services that have also gone through LEND. And I can think of three alum in our governor's council that are certainly, they're proud alumni from my perspective of LEND. And also, Stone Soup Group, the executive director there, after she had been in that role for some time, went through LEND. In fact, I was lucky enough to be her mentor. And it's really kind of this nice dance of different professional backgrounds, but really focused on what LEND all means in terms of interdisciplinary work. So we work pretty closely with our Title V organization. And certainly they have several program people that are LEND graduates as well. Another special thing is that we've been lucky enough to have fellows that are professionals at the Alaska Native Medical Center. And that's really infused naturally. Certainly by intention, we work on that in our seminars and our didactics, but that's infused some really natural collaborations that might not have easily happened otherwise. So I can send you the list because I'm like a loud, clucking hen about where our LEND alumni are, but they're everywhere.

MW: Yeah, no, it is interesting. It makes me feel a little bit on the outs. I did not go through a LEND program, but I know a lot of you said directors have, and it has created this tremendous capacity across the network. So yeah, one of the dangers of the work that we do, I think, is we talk in broad generalities, because we're always talking about systems level things and everything else. So one of the things I like to do is really get down to practical stories, right? What does it look like? So I was hoping that each of you would maybe be able to share concrete example or a story of how your LEND programs have made a difference in the lives of people with disabilities in your state. So Rachel, I'm going to start with you this time. So I'm going to put you on the spot.

RW: All right. So Jenny has a good one too, but I did think of another one after she and I kind of talked this morning.

So a couple of years ago, we had a LEND trainee who was a special education teacher in a remote village that had moved here from another country. So one, I don't know if it's unique to other states, but one thing that Alaska struggles with is recruiting and retaining teachers in many of those remote communities. So Alaska has developed some systems to recruit teachers from international locations. So this LEND trainee, as part of his leadership project, formed a collaborative online group for international teachers that were in remote

Alaska. And through that group, he's helping them to learn the details of U.S. special education law and connects them with resources and strategies to help support their students.

And sometimes those are special ed teachers. Sometimes they're more gen ed teachers. Some of our remote communities don't have special ed teachers. And so they have, there's a SESA, and I'm not going to remember what it stands for, but they send out special education teachers to remote communities to help consult and write FBA's and things like that, and then go around to other communities as well. But so the LEND fellow is helping to connect those teachers with those resources and those supports. And as a result, all those teachers are better able to support the needs of their students in those remote villages.

MW: Yeah, no, that's really, that's an incredible resource. And I'm sure I had no idea there were that many international teachers in those remote villages now. It didn't used to be that way. But wow, that's really cool. And that would be a steep learning curve to learn special ed law and everything.

But you do bring up something interesting. Sorry, I got to editorialize here just for a minute. Alaska is unique because SESA is a unique agency. I think it stands for the Special Ed Service Agency, right? And for villages that don't have teachers or resources, right? SESA sends personnel out to provide those services, which I think other states could really learn from that model. Because I know we have rural communities here in Utah that don't have those resources, but we do not have an agency like that that sends out the professionals. So anyway, I always think Alaska does some really interesting things. So I'm not biased at all, Marsha. So Jenny, let's hear you. What is a practical example of how you've seen LEND make a difference in the lives of people with disabilities?

JM: Sure. I do want to underscore that at least two of SESA professionals went through LEND. So that's a good example of how everything kind of gets all, everything's connected in one way or another. I love this story because I know the person that was involved. We had a family-disciplined LEND fellow who's from Ketchikan. And Marsha, you can't get to Ketchikan in a car. You just can't get there. So it's off the road system. You're either in a boat or on a plane. And the individual seemed at first a little bit intimidated at our seminar environment. And that's not necessarily uncommon among family discipline fellows or self advocates. However, she had an adopted daughter, she still does, that experiences FASD, had been to Seattle Children's for a comprehensive workup. But in her home and school, Mel U faced a lot of behavioral challenges.

So while the leadership project, I've heard Marsha mention this already, really offered her an opportunity to dig deep into something she was very interested in, and as a parent, in

trying to manage behavioral issues, she had really read a bit about the value of service dogs. And that can really help a child stay focused and be in a safe environment so that they can optimize their growth and development. Well, it turns out, this wonderful fellow became so interested in it, that she explored how she might secure that kind of service dog for her daughter. And it turns out she just went really over the top in terms of fundraising and advocacy. And after a lot of hard work, her daughter does have a dirt service dog now. And she's taken that advocacy more over another step where she is doing public speaking organizations that want to know more about this and what it entails and tells her story to not only community groups, but professional groups. And we're really proud of her. She's making a difference for sure. And her daughter's doing fabulously well.

MW: That's awesome. It's amazing what dogs can do. We had service dogs come in here a couple of weeks ago to meet with our students. And I'm just blown away. One of the service dogs actually was indicating that one of our students with diabetes had low blood sugar. A dog can tell that. I'm like, "Holy cow, how do you do that?"

But that's really cool. That's awesome. And I'm sure it was quite a challenge working from Ketchikan to get that dog and find that opportunity to get it out there. Cool. Marsha, what about you? What's a practical story there in New Mexico?

MM: Yeah, I've got a couple, but I just want to articulate that it's rare for me to feel like I'm the urban person in the group. So only Alaska could make me feel that way. It's like, "Oh, we do have roads. They might be dirt, but you can get to the Navajo Nation. You can." So this is really interesting. I have a couple, and I also want to say we actually had a service dog do LEND year. We have a trainee that has multiple disabilities, also a public health masters in public health. We actually brought our LEND trainee and their dog to the disability policy seminar. It was phenomenal. And I think one of the things that we're really committing to is we're going to do what it takes to get the right voices at the table. But yeah, the service that we were commenting was relatively new at the start of the lend year. And every time anybody would applaud, bark, freak out, but now he is perfectly fine with applause. And so learning too. But actually, I'm going to share a really recent story because our lend group this year is kind of phenomenal. And really, like almost all of them have an intersecting experience personally with disability, either their own or as a family member and are also in a professional discipline. But one is a mom who actually has a history of being an actress, but she has a daughter with Down syndrome who's a middle schooler. And it's been very interesting to experience middle school, which is, you know, let's face it, not the easiest time of life for parents or children. But with all that transition that happens for a youth with Down syndrome who is also a performer, you know, this girl loves to dance and perform. So this mom has hit a lot of barriers trying to have her have accessibility access to the

performing arts, performing arts school here, which is a charter school, it's a public school. So that's part of what is going on. But the bigger piece is this mom has had a vision for creating what she's calling a Down syndrome office or a Down syndrome family resource support space. And through the course of the LEND year, just having the interface with her and kind of dialoguing with me, with some of our other leaders here at the center, you know, we have a very robust family resource team related to autism, but not other developmental and neurodevelopmental disabilities. She got very inspired. And through the course of being in LEND, visiting our state legislature and then going to the disability policy seminar, we are looking at funding to start this office, where her vision would be to really be a lived experience resource for families who are struggling with the school districts, transitions, IEPs, health issues. It's also coinciding with a pediatrician here who is really starting a more targeted clinic for youth, children and youth with Down syndrome. So we're going to partner and really kind of start to create an interdisciplinary clinic and also host this Down syndrome family support resource center, bring her in to staff it and actually deploy. So we would not that would not have happened with this level of kind of (...) exponential trajectory if she hadn't walked through the door of LEND.

MW: Yeah. It sounds like it created the connections and...

MM: The connections and like the mentoring, like you know, what can a parent do versus, you know, obviously I, as a university employee, I can't like lobby, but I can certainly coach a parent on how to go talk to why this is important. You know, she and her daughter wound up on the legislative floor. We have a Down syndrome day, New Mexico Down syndrome day that she got created that created the impetus for the potential next year for a state allocation to support this work.

MW: Wow. Wow. You know, the theme that keeps coming up as you're all talking about this is, and part of this is probably just, you know, I've been tangentially involved with LEND, not directly. You know, and I always thought, you know, the impact of LEND was, right, the curriculum, the training that people went through, but from listening to all of you talk, that isn't not what the impact is, the impact connection and the network and, right, and the opportunity that people have to create these interdisciplinary opportunity is to work together, which is just, which is just incredible. I mean, it's really cool.

MM: And I'll just say, I think a lot about building community and trying to find language that is more accessible to people who aren't in our network. Cause even interdisciplinary training is a jargony thing to say. So I've, it just builds community and builds relationships that are trustworthy(...) and based on real knowledge of disability, whether it's your professional and or your knowledge living with it coming together. Like I think it's as simple as that, but as profound as that.

MW: Yeah. Yeah. Well, and the fact that it does value that lived experience, right? And it welcomes people with lived experience into that community, I think is so incredibly important.

So let's address the elephant in the room here. So the reason that we started doing series was because there's been some challenges to keeping disability related programs funded, especially over the last year and a half.

And so we wanted to just kind of raise awareness about what these programs are, why they're important, what difference are they making in their communities? And maybe this is a rhetorical question, but from your experience and from your perspective, what do you see as the greatest existential threat to lend programs?

MM: You know, I think that the real threat is to kind of erode the fabric of this long standing community building and kind of weaving we've done.(...) You know, it's actually really paying off. Like, you know, I'm going to share this, like we have a trainee applying this year who actually runs a nonprofit where she wants, she's called Three Sisters Kitchen and they do a lot of food training and teaching and building entrepreneurs in the community. It's a very innovative space.(...) And the woman who runs this has acquired blindness in the past three years and would really like to make it a space where she can be inclusive of people with disability and understand the nutritional needs and how food, which is so basic to all of us, is a part of disability. Like, and so like to me, I'm sorry, like, if we're thinking about what is MAHA about, like MAHA is about this kind of thing. And we are the really important place to try innovative things or to think about how we support the well being of people with disabilities. So the threat is not understanding that. Like what the federal government has built in the Autism Cares Act has built in the history of these programs has built is this really deep community based network that's ready to move in whatever direction we need to support the well being of people with disabilities. And if you erode this or you see us as frivolous or not doing our jobs, it's not true, first of all. And it actually creates, like it actually will kind of harm a platform that's actually really ready to move into new innovative directions to do more. Like I would say, we could be doing even more, right? So I don't know if others would agree with that, but I think the threat is really devaluing something you don't fully understand and almost disinvesting in something that has had such a long standing investment. We're really a great platform to deploy.

MW: Yeah.

MM: Do it.

MW: Yep. Absolutely. Absolutely. And I'm in, and Lend is one of those things that a lot of people don't understand. It's probably one of the least aspects, I think, of the DD network.

MM: So I'll go back to what I said before is also, I do think we could challenge ourselves to use different language and move away, really challenge ourselves to use really plain direct language about what we do and why it's important. And like I made the comment about interdisciplinary practice, even that once you get out one circle away from me, people don't know what I'm talking about.

MW: Yeah. Yep. For sure. So Rachel, Jenny, what are your thoughts on the existential threats to Lend programs? What would happen if they went away?

JM: So I'll share Rachel, and I'll expect you to correct me if needed. Our colleague in Nevada has coined the term LEND never ends. And we really collectively embrace that because we have certainly from, Oh, years ago, we still have LEND alumni that are in the community and doing innovative work in their practice spaces. It just continues. We have early on in our LEND history, we had two, one speech language, one occupational therapist that were so keen to start in interior Alaska, a summer came up for children that experienced autism. And we were like, Oh, how are you going to do that? How are you going to get a business plan? How are you going to get buy in from the community? What about liability? There's all kinds of, and they did this great job of first doing a need. I mean, they just showed us how wonderful they were. It was a needs assessment. Even did an IRB protocol to make sure families knew what they were asking about. Long story short, in 18 months, in spite of us, they had a summer camp outside of Fairbanks for families who have kiddos that experienced autism. So for me in Alaska, I would make the point I'm not endorsing anything. And, but I think that some of what we do continues through our alums, not necessarily. And I, I, in Alaska, the support that we offer to individuals that are going through clinical programs is really informative and valuable as well as they face their own clinical practices. Yeah. So I didn't answer the question because I don't really know the answer.

MW: No, but I think you brought up some important points to consider as we think about, right? What would happen, right? What would we be losing? But at the end, I like to ask everybody on the podcast the same two questions, partially so we get to know you a little bit better and partially just to understand how people are trying to make their little corner of the world better. So the two questions are what motivates you to do this work? Why do you do what you do? And then what is one you've been doing to make your work more active and or accessible? So Rachel, I'm going to start with you. I know you didn't answer that last one. So we're going to start with you on this one. So what motivates you to do this work? And what's one thing you're doing to make it more inclusive and accessible?

RW: So my mom was a speech language pathologist and a special ed teacher. So I grew up watching her and hearing about her helping children with disabilities to develop skills that allowed them to better advocate for themselves. And that was always a priority. Even she worked with medically fragile children who couldn't go into the school. So she was a special ed teacher on site at a nursing facility.

And a lot of the stuff that they worked on was really helping the kids build skills so that they could control more in their environment. So pushing the Big Mac button to turn the fan off or on, smiling at their caregivers so that they can receive better services, better care, be more enjoyable to care for, for their life because they're going to need supports for their entire life.

And all of that just led me to wanting to work with kids with disabilities. And that's how I ended up in applied behavior analysis.

So yeah, I think that's my motivation is that, you know, LEND is another way to continue to support individuals with disabilities throughout their lives.

And by improving the care and consideration that they receive from professionals.

And I really enjoy seeing the way that our trainees are able to expand their perspectives on disability and launch into their own projects. One thing that we've been doing is just improving on our accessibility, especially lately, as we have had more individuals with disabilities participate in the programs.

So I'll just highlight specifically, we've learned a lot more about like screen readers and how to make our documents more accessible for visual impairment. And we're continuing to improve upon that. We've also provided some feedback to the university that the course system that they use, Blackboard is not always as friendly to screen readers as we would like it to be. And that that is an accessibility that, that our trainees need. So yeah, I think that covers something.

MW: That's great. No, I think you, that was perfect. And those are, I'm partial to digital accessibility efforts since we do a lot of that here. And I can empathize on the Blackboard thing. I do not know why universities continue to use Blackboard, but Canvas is so much better. It has its issues, but it's so much more accessible. But anyway, this is not a promotion for Canvas or Adobe, but there we go. Jenny, what about you? What motivates you to do this work? And what's one thing you've been doing to make your work more inclusive and accessible?

JM: So I've already shared with you that I'm just so, so grateful for the kind of leadership that our alums have offered to the community. And I think part of that is really just a shared

system of values. And from a public health perspective, if it's all about access to services, having a group of individuals that know about the web of services and how to help families navigate it is really very valuable.

I would mention that I think we've already said we have terrific faculty, one of whom started out as family faculty. She happens to be the chief of her tribe. And Marcia mentioned that she learns as much from the LEND trainees as perhaps and teach them. This has taught all of us for a number of years about the importance of including cultural perspectives and not just assuming there's one way to look at it. And in some very important teaching us cultural humility, I think that we've all gained from that and certainly helps in terms of access to services, as well as how we approach the materials that we really that we present and they go a little deeper in our culture.

MW: Yeah, yeah. No, that's such an important point.

The Native American, yeah, Alaska Native approach to disability is often very, very different than, right, sort of what we think of as mainstream American culture. And I often think that's overlooked. So that cultural humility and being willing to learn and to recognize there are lots of different ways to look at this. And for families to be structured and for communities to support people is so incredibly important. So that's great. Thank you for sharing that Jenny.

Marsha, what about you? What motivates you and what are you doing to make your work more inclusive and accessible?

MM: You know, the question about what motivates me has evolved over time. And I have this huge privilege to be the director and have this leadership role. And today what really motivates me, there's lots of reasons why I'm in the space I'm in, including some family history with significant mental health disability and growing up in that environment. But today what really motivates me day to day is I really enjoy creating space for others to reach their fullest potential. Like I'm a developmentalist at heart with a true belief that any, you know, like disability does not mean there's no developmental trajectory. How do we support and grow people to feel their own confidence and skills. So like LEND is like this really amazing forum where you watch people start at point A and land sometimes at point, you know, Z, like they got to the end and they're like, I never thought of myself this way. And I find that incredibly motivating and really generative and really important. And certainly had people do that for me over my career and just life. And so I find kind of at core in this space where often you were talking with people who were like, you know, nobody ever identified me as the person to be the one mentored. I wasn't the straight A student. I

wasn't... I love that. I love being able to give people space to flourish when maybe it's not in their identity yet.

The other thing in terms of accessibility is, and this is a great privilege of my role is as the UCEDD director of being in LEND has really motivated me to ensure that I am capturing and providing resource, the resource that's actually needed to ensure we're being more inclusive. You know, ASL interpreters cost money.

It's not something that often gets budgeted for, it's sort of in the law, but not funded. So I find in a very concrete way, it has to fall to me to say I'm going to put resource towards this. Because if we don't, there's no way to do it. Right? It's not magic. There are concrete things that need to happen. So I've really made a commitment as we look at our you know, core budgets for the center or LEND grant and other sources of revenue we have to sort of make sure that we have a budget for this, quite frankly.

Matt: Yeah. Yeah, nope. Super important and continuing conversation. Even in our office here. Yeah, I'm always continually shocked that right, sign language translation, captioning, things like that are not put in budgets and yet we have to provide them.

MM: Right. And it's not okay to say we can't afford it, right?

MW: That's right. Yeah, right. That is not an excuse. For sure. Well, I am incredibly grateful, like I said, for all of you carving some time out of your day to have this conversation. I've learned a tremendous amount.

And I'm hoping that others are going to learn a tremendous amount from each of you. So thank you all for taking some time and yeah.

Okay, that's it for our conversation today with Marcia, Rachel, and Jenny. I would like to thank you all for joining me again, just so much to take away from this conversation. And I hope that you found it valuable. Here in the end, I just want to thank our managing editor and the DDNJ Author Insights podcast producer, Alex Schiwal, for her work on getting this out and keeping the journal moving.

We also want to thank the UCEDD here at Utah State University, that provides financial and in-kind support for the podcast in the journal, and for the USU Libraries and Digital Commons that help with the journal platform. So as I mentioned earlier, please make sure to subscribe, like, leave your ratings and reviews, share these podcasts. It's how we get the word out about the work that we do in the DD Network. So thanks again for listening today. Keep up the good work. You're making a difference and we want you to know that what you do matters.