

Ep. 20 Christine y Libby DD Councils_AS Final

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SPEAKERS

Christine Pisani, Matthew Wappett, Libby Oseguera

Matthew Wappett 00:23

You welcome to the Developmental Disabilities Network Journal, Author Insights Podcast. I'm Dr Matthew Wappett, the DDNJ editor in chief and executive director of the Utah State University, UCEDD, the Institute for Disability Research, Policy & Practice, and it's my privilege to host this podcast, as I've said in past episodes, this podcast is one of my favorite things that I get to do, because it gives me a chance to talk to so many different researchers and disability professionals who are out in the world making a difference. In fact, many of the people we have on this podcast are literally changing the world in their own quiet way, in their communities and in their programs. Now this podcast, I think, if you've listened in the past and you know that this is part of our ongoing commitment to increase the accessibility of DDNJ for a wider readership, not everyone has time to sit down and read an article these days, let alone an entire issue. In fact, now there's apps out there that take academic articles and read them to you, because it has become so popular to access information through audio. So, we are trying to put out the information in the journal in an audio format. We're not going to read the articles to you, though. Really, what we're trying to do is have conversations with the authors, give them a chance to explore their work. Help you get to know the author, some of the researchers and the folks that we're hosting here, so that you get to meet more folks and get to find new collaborations and hopefully new opportunities, new ideas to really improve all of the work that we're doing in the Developmental Disabilities Network. So, this podcast, though, means that you can access DDNJs content on the go wherever you are, and you can share it more readily across social media and other platforms. So, we're really grateful that you are listening, and we appreciate your support and your interest in the work that we do. So just a reminder before I jump into today's episode, please be sure to subscribe to our podcast feed on Apple. Podcast, Spotify, Stitcher, Overcast, Podbean, wherever you get your podcasts, and please leave us a rating and review that helps us get up in the podcast rankings. And please share this podcast with your friends and colleagues. Sharing this podcast helps this information reach a wider audience. And as I think most of you probably know, if you're listening, we are living in a time in our world where it is more important than ever to share the important work of the Developmental Disabilities Network. So, our upcoming issue is focused on the importance of the DD network, and today's podcast is specifically focused on the important role and impact of DD councils. Now our last episode, we had an interview with Talley Wells from the North Carolina DD Council. In today's episode, we're going to

talk to two DD Council directors from out west here. So, I had the opportunity for this podcast to visit with Christine Pisani from the Idaho DD Council and Libby Oseguera from the Utah DD Council, I've worked with Christine and Libby for many, many years. They are good friends, colleagues. They do incredible work, and I don't think they get the recognition that they deserve. So let me give you a quick intro to Christine and Libby before we jump in, so you kind of know who they are and a little bit about their background. So, as you go into this, you can really appreciate where they're coming from. So, Christine Pisani has multiple family members with disabilities, and she began working for people with disabilities as a college student at the University of Idaho in 1986, she's worked in many direct support roles, supporting people with intellectual and developmental disabilities, people with mental health issues and people with dementia. She is a caregiver to her mother, who has dementia. So, Christine has a wealth of lived experience. Christine started at the Idaho Council on Developmental Disabilities in 1996 as the council planner and then served as a Program Specialist. And it was during that time that I got to meet Christine, when I was working at the Idaho used and Christine really turned out to be one of my favorite people in the whole world. She's just so positive, just really an incredible advocate and person who is dedicated to making the world a better place. She has served. The executive director of the DD Council in Idaho since 2013 and her work at the council presents opportunities to work directly with people with intellectual and developmental disabilities, family members and policy makers statewide. Her work includes leadership, developments, service system redesign, voting rights advocacy and education and federal and state legislative policy. Christine holds a Master of Education degree in special ed with an emphasis in public policy. And she is also a graduate of the state of Idaho, Certified Public Management Program. In her spare time, she enjoys spending time with her two adult daughters, her golden retriever, Hazel gardening and backpacking. And as I said, I think you're going to find that Christine's dedication and really her passion for this work comes out in this interview. Now Libby I met after Christine, Libby has nearly 30 years of dedicated public service encompassing adaptive recreation, job, coaching and extensive advocacy, programming, policy development and active engagement and systems change for individuals with intellectual and developmental disabilities. She worked for the Utah DD Council for a while and then came back is the executive director. Libby earned her Bachelor of Science in recreation from the University of Nevada, Las Vegas, followed by a Master of Public Administration from California State University, Dominguez Hills. She's, as I mentioned, she's currently the Executive Director of the Utah DD Council, and she is committed to supporting and empowering people with intellectual and developmental disabilities to lead inclusive, meaningful and self-determined lives within their communities. So, I hope that you enjoy our conversation today. I hope that the passion that Libby and Christine bring to this work really shines through and again, they're just a remarkable pair of powerful, strong women who are truly making a difference. So, here's my conversation with Christine and Libby. So, let's jump in. So, thank you Christine and Libby for joining me this morning. It's exciting to sit down and have a conversation with both of you. We've worked together, all of us, for many years, and so yeah, thank you for carving out a bit of time. So why don't we start with you? Christine, tell us a little bit about your background and the path that brought you to the DD Council Network.

Christine Pisani 07:29

Thank you, Matt, thanks for having me on I appreciate this opportunity. My path, really, my life, has been filled with people with disabilities. I have family members with disabilities. I was exposed at an early age to people with developmental disabilities through some volunteer work that my mom did

through her company at Ore-Ida foods here in Idaho, because they did a lot of service work, and for whatever reason, one of their populations was people with developmental disabilities, and I always got drug along to help with those. But then it was in college that, because I needed to work, during college that I worked with people with developmental disabilities who were living in group homes in Moscow, and that just seemed to start me on the path. It was never my intention to work with people with developmental disabilities. I was going to school for a therapeutic recreation degree, and I just ended up staying in the field. During summers, I would work with people with developmental disabilities to raise money to go back to college, and I just seemed to keep landing in those positions. And I loved the work. I loved working with people with developmental disabilities. I worked with people who were the first people to leave our one publicly funded state institution, and that was when I was a direct care worker in group homes that made a significant impact on my life. And I started with the DD Council in 1996 and here I am, and I started as the council planner, then moved to a program specialist position and became the director in 2013 and what an opportunity to meet people and families and be a part of helping to create improved service systems and just work with people with developmental disabilities, which is my favorite part. I think there's so much to learn and to support their leadership in forging a better service system and life. That's my background in a nutshell.

Matthew Wappett 09:30

Yeah, no, that's so has all your work been in Idaho, out here in the West?

Christine Pisani 09:35

I did spend about six years in the State of Washington, and in that role, I was working with people who had Alzheimer's, I found that to be a pretty complementary set of work, given the fact that there's a lot of similarities just the way you support people with disabilities, and I would think of that group of folks as also marginalized. I think that it gave me a certain set of skills. Skills that I brought to the work that I do with people with developmental disabilities, and there's so much overlap in working with people with developmental disabilities, as there is with seniors, and we find that we're working across populations, because there's so many systems that serve those cross populations, and we're stronger together in doing that advocacy work. And people with developmental disabilities are living longer, so we now have seniors with developmental disabilities, some who experience dementia and Alzheimer's. So, I think it all relates and gave me the skill set I have today.

Matthew Wappett 10:33

Yep. No, I totally agree. I mean, most of us are going to age into disability, whether we want to or not, correct. So, all right, Libby, what about you? Give us a little bit about your background in the path that brought you to the DD Council Network.

Libby Oseguera 10:48

Thank you, Matt, yeah, it's funny. I've known and worked with Christine for many, many years, and never knew that we had a very similar beginning. I, I too have a background in therapeutic recreation, and my very first job in high school was at an adaptive recreation program. And my bachelor's degree is in recreation, which, for a number of years, my dad thought was fake, by the way, that you can't really study that, but it's, it's a real degree. But anyway, in college, I was a substitute teacher in the Clark County School District in Southern Nevada, and mostly I worked in special education classrooms

like Christine. I had family members and friends growing up that had developmental disabilities, and just that was just part of my life, and I really loved the community of people and just most of the some of the most fun memories I've ever had and the coolest people I've ever known. And then when I graduated college and moved from Southern Nevada to Utah, I had planned to work in in recreation. That was my hope. It was a little bit difficult to find a living wage job in that field. And I started working as a job coach, which I really, really enjoyed. And then an opportunity came available at the council. So, in 2012 I started working here at the DD Council as an administrative assistant role, and then I moved into programming and currently serving as the Director. So, it's been a long, weird path that I didn't expect, but it's been wonderful and fulfilling. And I really love my work.

Matthew Wappett 12:38

I think it's I think it's interesting with both of you, and I think this is common among folks who work specifically within the DD network, is it wasn't ever intentionally this is going to be my career path, but you kind of fall into it and get pulled in, and the work so engaging that it keeps over time. But that's funny, that you both have the same background. No wonder you get along so well.

Libby Oseguera 13:03

well, because she's awesome. That's true. Yep, I think very little people know about the immense amount of opportunities to serve people with developmental disabilities. Like I had no idea all the ways that you could serve people with developmental disabilities, whether it's through, you know, early intervention, like I didn't have any idea when I was going to college. I had no idea.

Matthew Wappett 13:28

Yep. Well, it's one of the things that we don't teach, and it's one of those things' disability intersects with every field, right? And regardless of where you're going to go, whatever workplace you're going to be in, there's going to be people with disabilities there. It's not just service-oriented programs. It's all just a normal employer down the street who's running the factory making Fat Boys, right, just up the road from us, right? You're going to have employees with disabilities, and it's you're going to need to figure out, right? How do I support these people and make them part of the part of the team? Yeah, so kind of just going back here. What I think most people who listen to the podcast know that what we typically do is interview authors who published within the Developmental Disabilities Network journal. But given this past year and some of the issues facing the Developmental Disabilities Network, we've chosen to shift our focus a little bit and focus on the different aspects of the network and the work that we do to really raise awareness of the network itself, not just write the research and the work that's happening within it. And both of you are in the DD councils, but I'm not sure that everybody understands the DD councils. So, Libby, I'm going to go to you, what makes DD Councils a unique and important part of the DD network?

Libby Oseguera 14:50

I'm going to get to that, but before I do, I just want to say that when people with developmental disabilities have access to education, employment, recreation, right, all of these things that lead to fully participating. They enrich local communities and with appropriate supports and services, they become dynamic contributors to the communities that they choose to be a part of, and everybody wants the same opportunities to direct their lives and have autonomy and choice, and DD Councils help facilitate

that right we, as councils identify what the most pressing needs are within each state and territory, because there are councils that exist within all of states and territories throughout the United States, and then what we do is we work with individuals with developmental disabilities and their family members, alongside policymakers and leaders at the local, state and national levels to try to advance policies and systems to promote integration and self-determination and empower individuals so that they can gain greater control over lives and choices. And I think that that's really the power and the uniqueness that DD Councils hold it is helping to facilitate and empower individuals to really have that opportunity.

Matthew Wappett 16:17

So, I know that when, so my background is in the UCEDD network. And I know that when you look at one UCEDD it can be very, very different from another UCEDD in a different state, is that same rule sort of apply to DD councils? Do DD Councils look different depending on the state they're at and the issues they work on? And I guess we could have you address that.

Libby Oseguera 16:37

Christine, well, we all have the same federal charge, which is we are required to support leadership development of people with developmental disabilities. We are also required to work on public policy and systems change and create capacity where it doesn't exist, where there are gaps. We're supposed to figure out how to fill those gaps, and I would say, depending on the culture of the state, whether or not you are a minimum allotment state, which I know that Utah is not a minimum allotment state, but they might as well be, because of the amount of funding that goes to our state, and that's all based on population and poverty within our states. So there's different abilities of councils to do things based on the funding, but I would say that we all have sort of a uniqueness to us based on essentially what we learn through all the public input that we gather to create our five year plans, which we're about ready to implement our next five year plan and that's really driven by what Libby said, which is addressing the pressing needs of the state, and that is only learned by talking to people within our states who are impacted by the services, by what our communities look like, and really, I would say, amplifying the voices of people with intellectual and developmental disabilities and their families. I think that that's our that's where we get our marching orders for from. And I've always thought of DD Councils as having this beautiful, little sort of relationship between developing leaders, and then those leaders help us inform public policy, which also inform systems change and also informs capacity development, filling those gaps where they exist. So, it's a beautiful relationship between the work we're required to do and if you're able to do all of that well, it's quite a relationship to watching how leaders, people with developmental disabilities and families create all of that wonderful change through the mandates that DD Councils are required to do. So sometimes it's difficult because we're not funded at a level that allows us to really do what I would I would love to be able to support more people with intellectual and developmental disabilities and families to experience opportunities to learn about leadership, and then to lead and to support them, to lead in spaces where we need leadership, but we have to. We have to do a lot of things as a council, and we have to make decisions about how to meet all the mandate

Matthew Wappett 19:15

so going to that funding issue. So, DD Councils are primarily federally funded. And you brought up a term earlier that folks may not be familiar with this notion of a minimum allotment state. What does that mean?

Libby Oseguera 19:28

A minimum allotment state is a state that receives less funding than, say, larger states like the state of Texas or California or Massachusetts or Florida, and it's a minimum amount of funding based on the federal formula that is essentially devised by what does the poverty look like in your state? What does the population look like in your state? And then they use a formula that calculates how many people with developmental disabilities are. Living in your state, and that's how they generate the federal allocation for every council across the country and in the territories, and for those states who do not meet a certain population, we receive what's called the minimum amount of federal funding to do the work that all councils are required to do.

Matthew Wappett 20:24

So, so Idaho is a minimum allotment state, but Utah is not.

Libby Oseguera 20:30

no but our budgets are pretty similar because Idaho gets some state funding and Utah does not,

Matthew Wappett 20:38

right, right? So, so the funding of DD Councils really depends on a lot of factors, right, population, poverty, whether a state's invested or not, right? Some states will put some money towards it. Some states won't, and that all dictates, really, the capacity the council has to do the work that they're federally mandated to do. That's correct, yeah. So, what, what sort of issues do your respective DD Councils focus on? And then how have you arrived at these areas of focus? So, you've talked about the overall intents, to build leadership, to build capacity, but Libby, let's, let's deal with Utah here first. What sort of issues does the Utah DD Council focus on, and how did you come to those areas of focus.

Libby Oseguera 21:21

Well, earlier, Christine mentioned developing this state plan. So currently we have a state plan that's a five-year period, and 2022, to 2026 is the project period for this plan. And within that we've got goals that are focused on improving access to transportation, physical and behavioral health services and community supports, along with our federal mandates that were mentioned, the leadership development for people with IDD and their family members, and some of the things that we've accomplished within those goals area. Goal areas, for example, we worked with the Department of Transportation here in Utah to enhance transportation safety and accessibility for people with disabilities. We also funded a feasibility study for the Utah Transit Authority. They wanted to explore whether or not micro transit would be effective in serving Utahns. When I say micro transit, I mean something like Uber or Lyft, that kind of on demand model. And so we explored that, like I said, we we funded the study, and that resulted in the rollout of a micro transit model that is now providing low cost on demand and safe transportation to residents in I think currently, three counties through the UTA Utah Transit Authority service area and throughout their 10 year long term strategic plan will be rolled out in more communities to replace some of their fixed route service, And we're really excited about the

impact that that's had to support and improve transportation access for our community. We've, we've done some other things in the area of community supports around employment, which is, is very important. Work brings a lot of value to people's lives in a number of ways. In the past couple of years, we've provided quite a few mini grants to different organizations who support people with disabilities to expand job opportunities, as far as improving employment supports, so that people can learn different job skills and practice whatever supports they would need to gain and maintain employment. And then I guess the last and one of the things that I'm most proud of are some of the partner activities that we've done with our Parent Training Center and our colleagues and friends here at the IDRPP, and that is that we're actively working to reduce abuse by helping individuals with intellectual and developmental disabilities and their support networks better understand how to form and maintain healthy relationships. You know, there are a number of other projects that we have done over the past several years to support these goals, but those are just some of the accomplishments I wanted to highlight. There's a really cool program that we've all worked on together, but I want Christine to talk about that.

Matthew Wappett 24:32

Yep, well, I'm glad that you I'm glad that you made that transition, because that is an important one that I think is worth addressing. But yeah, so transportation, employment, healthy relationships. I know that we've worked on that healthy relationships project. It's been really great. Some of the capacity we've been able to build, but also some of the challenges that we struggle with, especially but Christine, what about you? What sort of issues does the Idaho DD Council focus on it? I'm assuming you've arrived. Arrived at those areas of focus the same way through a five-year planning process. But kind of, what does it look like in Idaho?

Christine Pisani 25:07

Well, similar to Utah, we have in this current five-year plan, worked on abuse and neglect and exploitation. We were a recipient of a federal grant, a five-year federal grant called a living well grant that really gave us the funding to do a lot of deep work that we wouldn't have been able to do without it, because it gave us the funds to really explore abuse and neglect in our state. The DD Council funded five studies that were done by a department at Boise State University, and they created some really exceptional data for us to use to help us be informed about what are the things that are the gaps, opportunities for capacity development in our state around abuse, neglect and exploitation when it comes to people with disabilities? We use those five studies we worked with people with developmental disabilities and families, and we worked with all of the various agencies that touch on abuse, neglect and exploitation in our state, whether it's investigation or adult protection, all those different systems the protection and advocacy organization, we created recommendations to create a more effective service system to meet the needs of people with disabilities when it comes to abuse, neglect and exploitation, and those recommendations touched on the need for better education for adults with developmental disabilities, starting at a much younger age, also education for parents. Parents often don't you know, they're afraid to have that education, but education informs the ability to try to prevent some of these. Same can be said for adults with developmental disabilities, and they're starving for this information. So I'm really interested now in learning about this healthy relationships training that you're talking about, because we could benefit from the work you've already done in that area, but it also provided recommendations about how we might be there a way to consolidate these agencies so that they could better collaborate, that maybe they share resources when it comes to training, or would this help them

to better collaborate when it comes to investigations and all the things that they need to do in order to stay informed about the latest trends and education and opportunities available. We recommended a one phone number to call instead of all, like in Idaho, there's like 10 different places you can call, and none of them are coordinated. So, all these recommendations were put into a report have been shared with the governor's office, and just this week, I was asked to send that report again to the governor's office because of the state of Idaho's looking at consolidating agencies. So could this be an opportunity to create some efficiencies but also improve the service system so that people with developmental disabilities have better access to getting their needs met, getting education and honestly seeing some justice when they have been a victim of abuse and neglect. So that's something that I'm really proud of. The work of leadership development has been a consistent theme for the Idaho Council since I've been here, and so one of the things that we really targeted was an unserved population in our state, is the Spanish speaking community, and that's about 13% of the state of Idaho. And what we learned in doing a lot of talking to Spanish speaking families and individuals is that there's very few people who speak Spanish who can help coordinate services. There's a real lack of education for families to understand what options are available. What are the services? What does that mean? How do I access the service? So we hosted a conference in 2023 that was in Spanish in a rural community, and identified some leaders from that community, while at the same time working with our wonderful partners in the state of Utah, both duty Council in Utah as well as the UCEDD in Utah, because I knew I had allies there, and you also had a high population of Spanish speaking families and individuals in the state. So, we work together to create curriculum and recruit from our own states to host six sessions that were two days over, I think, about an eight-month timeframe. And we collaborated, collaborated on resources. We collaborated on everything. And it was, it was really a wonderful partnership that allowed us to provide some really excellent, culturally competent leadership development for Spanish speaking parents. It was one of the most meaningful pieces of work I've ever done in my entire career, and I couldn't have done it without the commitment and collaboration from my two partners in the state of Utah. So. Think that demonstrates a uniqueness that we have to go across borders and work with our states to do something really great, to serve two states where we wouldn't necessarily have the resources to do it on our own. That opportunity to develop that leadership led us to have those six leaders that we identified early on who participated in this leadership development program. They have now planned the next conference that we are hosting in Burley that will be a bilingual conference in November. They've planned the entire conference, and we just supported them along the way. And so, they are. We refer to them as the Burley leaders, I'm just immensely proud of the work that they have done in leading a rural community to provide this two day conference, and I think it's a model that I want to apply to different parts of the state, because it requires tenacity and time to be able to work with the plan to develop the type of leaders that you want to see take on issues in your state. All we did is support them. I mean, we just said, okay, tell us what you want, and we'll pay for it. It's just, it's been really beautiful, and so out of this, I'm really hoping that we attract some new leaders that we can now invest some leadership development into, just like the model we just got done doing. So anyway, I'm just particularly proud of that, of that work that we did together, because I couldn't Idaho, couldn't have done that alone, and we benefited greatly from the expertise we got from both organizations in Utah, as well as the resources that we would have never been able to pull that off alone.

Matthew Wappett 31:45

Yeah, and I know that that training had a huge impact here in this state. It sounds like some of the folks in Burley are continuing that work in Idaho. I know that down here, Eduardo, who works here at the UCEDD, has built his multicultural Disability Network, and many of the folks who are involved in the training here in Utah are involved in that work really trying to build out some of the some of the and give people leadership opportunities right to reach out to their communities and to raise awareness of these issues. So, Libby, you were involved in that training, and this kind of leads to the next question, which is a specific project you've worked on over your career that's made a measurable impact. And it sounds like you know, from Christine, this joint leadership training for Spanish speaking families was a big one, I know. And anyway, I'm going to editorialize here just for a minute, because I know I worked in Idaho before I came here to Utah. I know more than I should, so I can talk more about it, but I mean, the Idaho DD Council has done a remarkable amount of work around leadership development. When I was there, you helped build the self-advocates Leadership Network and really build a cohort of self-advocate leaders in the state, many of whom are still involved, and again, some of whom have moved here to Utah and are involved here in Utah. So, there is a long tradition of that leadership development in Idaho that continues to make a difference and an impact regionally. So, thank you for that work. Christine, yeah, so Libby, what about you? What's a specific project that you've worked on over your career that's made a measurable impact on the disability community here in Utah or regionally.

Libby Oseguera 33:27

Thank you, Matt. I just want to thank you, both you and Christine. She spoke beautifully about the project that we work on together to support Spanish Utahns and Idahoans, and that really was impactful and very, very meaningful. But the other project that I want to talk about is another wonderful partner opportunity that we have had, and that is our Advocates as Leaders, Speakers Network, which educates various community members on disability issues. And just to give you some context about that program, it began, I believe, in 2015 and it was a DD Council funded project that was operated through the UCEDD IDRPP. At the end of that plan period in 2021. Came underneath the DD Council as part of our in-house programming, and it's currently supported by the Council and the speakers' network. The intention is to educate self-advocates, family members, siblings, professionals and other community members about various issues that impact people with intellectual and developmental disabilities in everyday life and the network itself, the speakers who are providing this training are people with lived experience. So, all of the speakers of the network identify as having a developmental or intellectual disability, and then we as. Staff help to support them, by helping them to be professional speakers and to develop their training content and to learn to present on these different issues in various formats, and to tailor their content to the audiences that they present to. And so, their presentations that are designed by self-advocates, then they cover all these diverse subjects that significantly impact people with disabilities. And it's had, you know, pretty big impact on the state, but it's been, it's been a very good tool that several other councils have been interested in and have asked to use some of the presentations so that they can implement the format in their own states. So other states have adopted the model, and since its inception, the speakers as a network have trained over 10,000 people throughout the nation. So, it's been a pretty good program, and they've shared a lot of really valuable information about the most important issues to them. So, it's, it's been a very meaningful and impactful project.

Matthew Wappett 36:10

well, and it's belt leaders too. I mean, many of the folks who are participating in that speakers network right serve on the council, or serve on the Community Advisory Council for the UCEDD or there some have been involved with the P&A here in Utah, it's really built capacity, not just to raise awareness, but to get people involved in some of these systems. Yeah, thank you. Thank you both for sharing those i i have a personal investment in sharing the work that you do, primarily because we're out here in the West, but I think it's made I mean being here and seeing it and hearing about it has helped me recognize just how important the work of DD Councils are in building that capacity and really providing the support that people with disabilities need to get involved and to make a difference in in this, in these systems. So, transitioning to more depressing subject's life for DD Councils has been troublesome over the last few years, and not just within the current administration, but even in the past, right, there have been existential threats to DD councils. There have been proposals to get rid of DD councils. What do you see as the greatest existential threat to DD councils, and what happens in our states if DD Councils go away? We'll start with you, Christine, because we were just with Libby.

Christine Pisani 37:39

Well, I just came across our 1978 report. We were established in state law in 1978 even though law went into effect in 1971 for the DDM, and we were charged, originally as DD Councils to basically map the deinstitution, deinstitutionalization plan. And when I read, I've been reading this book. It's a book really. It really is amazing that it was DD councils that really charted the plan for our states around, what could our service system look like if we weren't warehousing people in public institutions? And we've been doing this work ever since then, when I came to the council in 1996 people with disabilities were not at the legislature. You never saw people with this disabilities at the legislature, and that really bothered me. So that's been a core function of what I wanted to change. We have been on this path, just like Libby has explained about the leadership work that people with developmental disabilities are doing through the speakers' bureau to inform and support people with intellectual and developmental disabilities and their families to be a part of the policy making table. And I don't know who else does that work. I don't I don't know that anyone else is investing the resources and time that it takes to both identify people in our states that want to come along and be a part of this, because it's not, you know, not everybody wants to do policy work, but who, but who do we have in our state that wants to get on board and create change? And it's not, it's scary work. But I think what I found is that once people are exposed to the work, they get hungry for it, and it's like a it becomes an addiction, like they want to just be a part of making change and speaking up and sharing their lived experience. And so, if we just open the door and provide a platform, they just take off, and I think that's the most exciting part of DD Council's work. And I, I honestly don't know who would do that if DD Councils went away, because that is, that is the unique function of DD Councils is to support people with intellectual developmental disabilities and their families, to lead, in creating better policy, better systems, inclusive lives, people working. I mean, we can touch every life area that there is on the planet. And I don't, I don't know who else would do that. I can't think of another organization in my state that has that very specific role and is so committed to making it happen.

Matthew Wappett 40:24

Yep, yep. I would totally agree. I would totally agree. I know, just here at the UCEDD in Utah, we have people who are on our community advisory council who came through the DD Council in Idaho and

Utah. We have staff here that have come through the Utah DD Council and gained experience and expertise. I mean, they really do serve a unique function in helping people with disabilities and their family members play an active role and open up opportunity for them to get involved in these systems that can be very difficult. So, Libby, let's turn that question to you, what do you see as the greatest existential threat to DD councils and what and what happens? Let's say here in Utah, if a DD Council goes away,

Libby Oseguera 41:08

well, I was just thinking about what Christine said and just reflecting on where she started with this 1970s map of deinstitutionalization and really just beyond councils. If the DD network disappeared right the absence of the network would lead to significant regression and Community Services and integration, and even more worrisome, people's civil rights, and even worse, human rights would be threatened. And it was a very dark period in American history prior to the shift towards the deinstitutionalization movement of the 1970s it was horrid, right? People were living in horrid conditions, and we can't go back there anyway. I digress. So, what, what I think is a really big threat, is we've talked a lot about how councils are charged with developing leaders, and how leaders then go and make improvements in Community Services and build capacity and make all these positive changes and influence policy and really have great lasting impacts on communities. But that's difficult to monitor and it's difficult to measure, especially when councils are often minimum allotment or I'm not saying that it's not possible. It's just difficult. We just don't have the capacity within our staff to do that kind of evaluation and monitoring of those long-term impacts. And decision makers who are deciding appropriations and how to fund programs like this really struggle to recognize the value, because we're planting an acorn and growing an oak, and that takes a really long time to show somebody that progress, and I think that, you know, the network and councils were having some really significant challenges, because our federal budget is increasingly constrained, and we are continuing to see rising needs. Our programs for people with disabilities, both at the state level and the federal level, are more and more at risk because of growing pressures to reduce federal spending. And councils rely on state and federal funding to fulfill our missions. And I really think that the biggest threat we have is helping decision makers to understand the value of the DD Act, the value of councils and DD network programs, and the value of people with IDD and their family members themselves. That's the biggest threat, demonstrating value of people.

Christine Pisani 44:04

we are in the we don't provide direct services. Our work is exactly what Libby has said, which is planning an acorn and growing an oak. Our work takes time to see results and working just working with adults with developmental disabilities, it can take I've watched people's development. It can take up to 10 years to really see a person gain the confidence overcome all of the messages that they've heard over their lifetimes that you know that's not for you. You can't do that. You know this is something you can do to overcome that, to sort of grow these mighty oaks where they are delivering their lived experience and how it impacts their lives when it comes to policy and service systems and how to improve those things and that's long-term work. This is why I love to iron, because I can iron and have a quick outcome from it. But out. Outcomes take councils in the DD network programs often a long time to see the results of our work. And it's worth it, because look at all these amazing people that we have in our states that are working and contributing and creating amazing systems change and leading and

helping to change the perspective of what people in the general public think about people with intellectual and developmental disabilities. Developmental disabilities, the fact that now we have people that are visible in the workplace, in integrated settings, in schools, and it's, it's become normal, whereas in my mother's generation, they didn't see people with developmental disabilities, they were all somewhere else. And I mean, that's amazing change, but we have so much more work to do, and the work takes the work takes time, the type of work that we do, and it's absolutely worth the investment of the money that we receive. We do a lot on a little, and we create significant change. And I'm afraid to think, and I believe that the seeds are starting to be planted already about re institutionalizing people. This is my biggest fear right now, is there's already these little undercurrents of misinformed ideas about, well, why don't we just re institutionalize that might be a cost savings mechanism for these rising Medicaid budgets. And that's a very uninformed thinking, because the people that are thinking those things have no idea about what those lives that were warehoused in these large public institutions look like. They don't know the cost that came with that policy decision.

Matthew Wappett 46:43

Well, it's a great example of if we don't study the past, we're doomed to repeat it, and we are at a point I know here in Utah, there are recommendations to expand institutional beds. I know that other states are looking at it. I know there's even a federal push to move towards greater institutionalization. And it is, yeah, it really just highlights the importance of what the DD Council in making sure that people can speak up and say, no, I want to live in my community. I want to be involved. I want to have a job. I don't want to be locked inside, you know, this institution for the rest of my life. Yeah, it is. It is a very scary time.

Christine Pisani 47:23

when I think about the denial of the rest of the community members to have access to the ideas, the talents, the humor, the great people that we all know within intellectual developmental disabilities that are contributing in a multitude of ways, and the general public would be completely denied access to these amazing folks that add such a rich fabric to every community.

Matthew Wappett 47:48

Yep, I couldn't agree more. Couldn't agree more. So how can people get involved with the work that you do at your respective DD councils? How can they learn more about what you do? And why don't we start with you? Libby, maybe I should clarify that question. Can somebody just call you and say, I want to be on the DD Council, or is there a process that people need to go through, right to get involved? And what does that what does that process look like?

Libby Oseguera 48:17

Thank you. That is a that is a great question. So there, there are a number of ways to be involved with the DD Council. So, we have a lot of different programs that we offer, like the speakers' network that I mentioned. We have a lot of different training and a number of different avenues for people to participate and learn and be educated with tools and resources. To actually be a formal governor appointed council member, we open applications every winter, and a person could apply if they are a family member of a child with a person with an intellectual or developmental disability, or of an adult with an intellectual or developmental disability who cannot advocate for themselves, or they are an

individual with an intellectual or developmental disability, there are a couple of other different membership types. But to learn more, you can find that information out on our website, or you can contact us directly by phone or email, and we'd be happy to discuss that with you as far as the other programs and offerings that we have to help support people, to learn how to advocate and gain leadership skills to make positive changes in Utah and other communities throughout our wonderful United States.

Matthew Wappett 49:41

Yeah, so I'm gonna ask a follow up question there. So, you mentioned this, and I'm sure folks who don't know DD councils will be interested. You said they're governor appointed if they want to be on the DD Council. That means that they submit an application and the governor's office actually looks at it and decides if they can be on the council. Or not. Is that how that works?

Libby Oseguera 50:01

That is correct. Yes, the governor reviews applications, and then we as the Council, and the process is a little different in every state. So, I will say that, but, but yes, they are governor appointed boards. So, we, in Utah, we make recommendations for appointments, but the governor, the governor decides who is actually appointed as a council member and makes those formal appointments. That's kind of a big deal. It is a very big deal. You get an official embossed letter, and it's very cool.

Matthew Wappett 50:35

Yeah, it is no and I think it brings weight and authority to the important role that, you know, members of the council play in shaping the work in the state. So, Christine, what does it look like in Idaho? People want to be on the council. Get involved with the council. What are how does that look there?

Christine Pisani 50:54

It's very similar the way Libby described it. We go through the process of accepting applications, and we have a membership committee that interviews all the applicants, they make recommendations to the governor's office, but it's ultimately up to the governor to decide who he appoints to serve on the council. And we have had times when we've made recommendations and the governor didn't go along with that recommendation, so he very much decides who serves on the council, but we have 23 positions on the council, and 60% of those are either people with intellectual and developmental disabilities or family members, and the rest are represented by various mandated representatives from either state agencies or protection and advocacy organization or our UCEDD and the other ways are exactly how Libby has described it. We have lots of opportunities for Person centered planning training that we're doing. We are in the middle of a lawsuit. This is we've been in the lawsuit around the Adult Developmental Disability Services. So now I think, going on our 14th year, and a council, the council initiated something called Community Now, which is people with intellectual and developmental disabilities in the adult DD service system and their family members who are leading the Settlement Agreement work. That's another opportunity for adults with developmental disabilities to be involved in the work of shaping how this lawsuit turns out. We're always looking for people who want to be involved in the Our Care Can't Wait work that we're doing this is all about trying to improve the way direct support workers in our home and community based services are being paid, the benefits, the training that they get, sick leave, and that is really led by people with disabilities and families, the council, other

advocacy organizations are involved, including the center and the protection and advocacy organization. So, we're always looking for the lived experience of people and families to be involved in that work, leadership, development, opportunity. I mean, it's just there's if you call us, we will and you tell us what you're interested in, we probably have something that we can offer to just get you involved. And then what's beautiful about that is it's building a relationship with a person and then seeing if maybe it's a good fit for being a member, because not everybody wants to commit the amount of time that's required to be a council member. It's not just to show up to a meeting like we expect you to lead and help inform the plan and decide what we're doing and it's a lot of time invested, but it's critical to the work of councils to have that be informed by people with developmental disabilities and family. So, there's just, there's a ton of opportunities for people.

Matthew Wappett 53:39

and we will be sure to share links to each council website and related projects on the show notes for this episode. So, if folks want more information, you're welcome to go check out those show notes. And yeah, go, go look at the various opportunities to get involved. So here at the end, we asked the same questions at the end of every show, because everybody has their own story. What motivates you to do this work? Why do you do what you do? And then the last one is really related to the focus of the journal, to make research and the information that we put out more inclusive and accessible. So, we'll start with the first question though, Libby, what motivates you to do this work? Why do what you do?

Libby Oseguera 54:22

I think this will be short and sweet, and it's that I value people and perspectives and experiences that are different from my own. I believe that we all have gifts and talents to offer, and I believe that we are all entitled to dignity and respect.

Matthew Wappett 54:42

that is a very good, concise answer and comprehensive so. Christine, what about you?

Christine Pisani 54:47

I am a junkie for watching people who have never been given an opportunity to share their perspective and watch them lead. I'm an absolute junkie for watching people with intellectual and developmental disabilities be given a chance to be heard, and giving them some tools, and then watching them fly. I can't get enough of it. I get excited about it every time I watch the transformation happen, and I just wish that we could do more of it. I wish that we could reach more people. But that's what keeps me going because it's powerful. It's powerful to watch people with intellectual and developmental disabilities when they're given the chance to rise to the very high bar of expectations, and they never disappoint.

Matthew Wappett 55:36

And I can personally verify that that is true. I have never seen somebody get more excited than Christine about people actually getting involved and making a difference. It's, you know, yeah, it's been one of the fun things about working with you through the years. Christine, Thanks, Matt. You are legitimately excited about people, yeah, just doing this work, which is really, yeah, it's a really fun, infectious energy. So, thank you. Okay, last question, though, we're always trying to make things more

inclusive and accessible, and I know that this is an ongoing effort for everybody, but what's one thing you've been doing to make your work more inclusive and accessible? Why don't we start with you this time Christine?

Christine Pisani 56:19

I would say it would have to do with the lawsuit and the community now work that we've been doing, and we do everything at the council now in English and Spanish, and we create all the information in accessible formats, and we have council members who are Spanish speaking. So, I feel like because of the work we've done, we're serving more people better, and I'm really proud of although I feel like the work is not done of recruiting diverse lived experiences and perspectives and really the different barriers that different communities in our state face. So, I feel like I think the work of the DD Council here in Idaho has been significantly shaped by our intentional work with Spanish speaking communities to really become more inclusive.

Matthew Wappett 57:14

Libby, what's one thing you've been doing to make your work at the Utah DD Council more inclusive and accessible?

Libby Oseguera 57:20

our programs and content are designed with or AND and OR by people with intellectual and developmental disabilities. We do this to ensure that our content is relevant and impactful for our community. We also prioritize diverse voices and perspectives through all levels of planning and programming. And I would say that this approach has allowed us to consider a wide range of factors throughout every process, and it helps foster more accessibility and inclusion. You know, I mean, I said this at the beginning, and when everybody can participate, communities are stronger and better, and that's true at all facets, so we've been very careful and thoughtful about that. If you invite more voices to the table. I know that is something that people say a lot, but it really does make a difference. Right? Include people at every step of every process, and you're more likely to have a successful outcome. I would say another thing that has been very successful, and it's a very simple thing to do. When you discover that you're not doing something well, or you found a way to do it better, change what you're doing. It doesn't mean you have to do things perfectly or always be great at inclusion and accessibility. It means, when you know better, do better and try that. That's all you got to do,

Matthew Wappett 58:49

no and that's a great observation. That's why we asked this question, because that work of becoming inclusive and accessible is an ongoing work. It's not like you figure it out, right? There's always ways that you can improve and do better, and it requires, yeah, it requires ongoing, focused effort to do that. So, thank you for bringing that up, Libby, and thank you both for making time to visit. It's been a privilege to work with both of you over my career in the DD network, and can't explain how grateful I am to to know both of you, and to be able to sit down and have this conversation and have an opportunity to share the work that you both have done out here in the west.

Libby Oseguera & Christine Pisani 59:30

So, thank you. Thank you, man. Thank you.

Matthew Wappett 59:33

So that's it for our conversation. Today, I'd like to thank DDNJ Managing Editor and author insight Podcast Producer, Alex Schiwal for her hard work to get this podcast out. Alex is really the lifeblood behind DDNJ. She does a lot of the heavy lifting, and really, we couldn't do any of the work at DDNJ without Alex's leadership and support. We'd also like to thank the. USU Institute for Disability Research, Policy & Practice, for their financial and in-kind support for this podcast and for the journal, and the journal also receives support from the USU Libraries and Digital Commons, and we're grateful for their ongoing efforts and commitment to the work that we do. So, as I mentioned earlier, please be sure to subscribe to our podcast feed. Wherever you get your podcasts, please leave us a rating and review. Share the podcast with your friends and colleagues, your ratings, reviews, your shares, they all help us get this important work out and raise awareness of what's being done in the DD network today. So, you can learn more about DDNJ at the DDNJ website, at digitalcommons.usu.edu/ddnj, and you can download podcast transcripts in English and Spanish and learn more about our podcast guests at the IDRPP website, which is idrpp.usu.edu, it's under the about drop-down menu, and there you'll see DDNJpodcast link. So, thank you so much for listening today. Please keep up the good work. You're making a difference, and we want you to know that what you do matters and stay tuned for our next episode. Thanks. And have a great rest of your day.