

BoggsCast Episode 25: Laura Vegas & Lindsay DuBois

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

I'm Colleen McLaughlin, the Associate Director at The Boggs Center. And in this episode, we'll be discussing National Core Indicators and Quality with Laura Vegas and Lindsay DuBois. Laura Vegas is the Director of Quality Initiatives and Supporting Families at the National Association of State Directors of Developmental Disabilities Services, or NASDDDS.

NASDDDS's mission is to assist member state developmental disabilities agencies in building person-centered and culturally and linguistically appropriate systems of services and supports for people with intellectual and developmental disabilities and their families. In her role, Laura directs NCI-IDD from the NASDDDS side and works with the Community of Practice for Supporting Families, as well as providing technical assistance and support to NASDDDS's members.

Lindsay DuBois is a Research Associate at the Human Services Research Institute, or HSRI. HSRI works collaboratively with local communities, state leaders, and federal agencies to collect information, evaluate programs, and generate reports that inform policies and infrastructure to support person-centered practices and inclusive communities. Together with NASDDDS and advancing states, HSRI develops and maintains National Core Indicators, a research and quality monitoring enterprise that collects data on performance and quality of life indicators directly from the human service systems users. In her role at HSRI, Lindsay provides strategic guidance on developing resources to share findings from National Core Indicators in accessible and meaningful ways to different audiences, with the ultimate goal of promoting equity in disability service systems and supporting people to thrive in their communities.

Welcome to Laura and Lindsay. We're really glad that you're here to join us to have a little conversation about quality services and developmental disabilities and the National Core Indicators. So I always like to start with the history. The history is really important in understanding the lives of people with disabilities and how we went from the past to where we are today. And quality and quality measures play a really important role in that. So can you share a little bit about why you think it's so important for us to measure the quality of disability services?

LAURA VEGAS: Yeah, sure can. Thanks. Thanks, Colleen. So disability services are typically administered through federal, state, or local government agencies. And because of that, there are a lot of policies and rules around how to promote access and quality of these services. And once you get past all the federal jargon, most of these rules and policies are focused on making sure people who need services can get services and making sure that those services are of high quality.

For example, CMS just released their proposed Access NPRN rule in 2023, that focused on improving access to long-term services and supports, including services for people with intellectual and developmental disabilities. We know measuring quality is essential to know the strengths of these systems and where there are opportunities to make systems changes and improvements. National Core Indicators, for example, has been working closely with states since 1997 to do just this.

Historically, quality was actually just measuring compliance with the rules and regulations, and it looked to make sure that people were safe and healthy. But the state DD directors back at that time really wanted to think about how the services and supports that they provided impacted the lives of people in their service delivery system and their families. And they wanted to make sure those services and supports were good and getting people to the outcomes and the lives that they wanted.

The objective of services is to support people to thrive. So we need to look at quality from that lens and whether people are doing the things they want to do and having the lives that they want to have. As you can imagine, that's a little more of a challenge to measure. But that's actually what NCI has been doing for the last 25 years.

LINDSAY DUBOIS: This is Lindsay. And I would just add, over the past 25 years, we've had a lot of conversations with people who use services and people who oversee the delivery of services, to figure out, What are these areas that we should really be taking a closer look at if we want to understand quality? And so we consistently see interest in a number of areas, such as, are people able to control their lives? Are they able to make choices? Are they engaged in their communities? Do they have meaningful relationships and activities that they're pursuing? And so, so many more areas.

And at the same time, we see policies and priorities change. So when we look back over the history of National Core Indicators, we're regularly testing our questions. We're trying to make improvements to our tools. But we need to do that in a standard, reliable way.

So we have a revisions process, and that involves gathering feedback from people who use services, the directors of developmental disability systems, other community members. We test these changes. And then we can update the training on our survey tools. So we have a formal process in order to make the tool-- to keep it standardized while also reflecting the fact that we have to be able to evolve, and we have to be agile.

And so the first tool that we developed was 25 years ago, more than 25 years ago. That was the NCI-IDD In-person Survey. But over time, we recognize that there's a need to hear from other individuals who use

services and supports and people who use those services, as well as those who support people who use services. And so that's when we added our family surveys. And we have three family surveys.

And then in 2015, we launched the National Core Indicators Aging and Disabilities Adult Consumer Survey. And that gathers information from older adults and people with physical disabilities. And in addition to those, we have two tools that we use to gather information from provider agencies-- the State of the Workforce IDD and the State of the Workforce Aging and Disabilities. And those are to learn more about how agencies are supporting direct care workers and direct support professionals.

So as of 2024, we have, I think-- is it 48 states, Laura, participating in one or more of the NCI surveys? And we hear from more than 25,000 people who use long-term services and supports, living in a variety of settings. We hear from more than 25,000 family members, and we hear from more than 3,500 provider agencies that employ more than 250,000 DSPs every year. So we're getting just a wealth of information to understand the systems.

COLLEEN MCLAUGHLIN: That's such a huge amount of data over a quarter of a century. Really adding all of that up, it's wonderful to see what HSRI and NASDDS has really been doing to hear the voice of people and those that support them. I'd really like to hear more about that. I know that National Core Indicators has a really intentional focus on capturing the voice of people with lived experience. Can you share with us how valuable that really is and maybe provide some suggestions for how states and organizations can really continue those conversations on an ongoing basis?

LAURA VEGAS: I'll take that, Colleen. This is Laura. Quality is often really a really subjective concept. And we take a person-centered approach to understanding quality. So to me, to us, that means that each person may define what quality in their life is a little bit differently. So in order to understand quality from their perspective, we have to hear directly from the people who use our services to understand if the services they receive are of high quality to them and helping them live the life they desire.

Over time, expectations of what services should provide and how they should be delivered have changed, especially over the last 25 years. People's needs have changed. People's expectations have changed. And the only way to make sure that we're staying current and to learn about these important things is to hear directly from people who use services. For example, 40 years ago, professionals referred families to put their children in institutions under the premise that they would get the support that they needed there, and they would be safe and healthy, and that was the best place for them.

But over time, we learned. And there was recognition that there are better ways to help people get support. And if we don't talk to people about their experiences, we don't learn about how to make the services better.

LINDSAY DUBOIS: Yeah. And this is Lindsay, and I would just pick up on some of the ways that states can continue the conversation and enhance those opportunities to hear directly from people who use

services. So there's a lot of different ways, honestly. But I'll highlight a few that I think are the most powerful.

So first, I think we need to make more deliberate efforts to share our findings back with the community in accessible ways. This is a struggle, right? For all of us, it's a struggle. We collect a lot of information from a lot of people. And then we have to try to make sense of it.

But no matter what we do, we should always tell people what we learn. We're taking the time to figure it out. And we need to take the time to communicate that in accessible ways. And this can help create a shared understanding of this is an opportunity to improve. So how should we do that?

And those very same service users, they're really the experts in, this would work better for me, or this is not the way to go, like, please do not make these changes, because these are my concerns. So they can help to provide those recommendations about how we should change our services to improve quality. So those conversations should be ongoing. They should be bidirectional. And they can help us to figure out not only what's not working, but how to change that.

Further, people with disabilities should have meaningful roles in all of the work we're doing. So this is including designing research, so really, from the beginning, designing how we're collecting the information. So we're trying to do a lot of that at NCI.

But it also goes into the service delivery as well. So the more we can create leadership roles at service provider organizations and consumer direction within provider agencies, I think the better we're going to make these services. So that could be a position on the board of directors that has an advisory committee of people who provide oversight to the DD system. So it could be a number of ways. But ultimately, the goal should be for people with disabilities to have equitable and meaningful opportunities to help us design and monitor our systems.

COLLEEN MCLAUGHLIN: It's funny. It makes me think back. I started out in the field doing work in another state on their National Core Indicators project. And it was actually one of the states that has a pretty robust peer interview process. And I think that for those of us that were mentored and grew up in the field with that mindset, that the voice of people with lived experience is the end all, be all, when it really comes down to it, is so essential.

And I don't know if everybody has had that same opportunity. So I appreciate that you guys are sharing really the value in that. And Laura, I'm thinking of some of the work that you do, too, with the community of practice and the importance of family systems and understanding that everybody lives within the context of their family. And you all just talked about how the voice of people with disabilities is so important. But I don't know. Laura, do you have any thoughts on, too, the family perspective and how all of that ties together with quality and the information that you gather?

LAURA VEGAS: Absolutely. As you said, Colleen, we do have a-- NASDDS is in partnership with UMKC in a national project called Supporting Families Across the Lifespan. It's a community of practice. And we're really learning that families need support to be able to better support their loved one. They need quality support as well.

It is about the person, but it's also about, what kind of systems and supports can be designed to support families in a quality way, so that they're able to continue their day, they're able to continue their job, they're able to continue to support their loved one in the way that they want to. And if the person isn't happy, then it's hard for the family to be happy.

And we talk to families about their experience of the service delivery system. So we're trying to get at, Are these quality services for the person? But also, are these services that are being provided to your loved one, are they quality from your experience? What things might we need to change or do better?

And then looking at what we do, what the system does to actually support the family directly, and making sure those things are of quality, too-- so there's two ways of coming at that. But they're both equally important. And the intersect I think is where we really get quality.

LINDSAY DUBOIS: This is Lindsay. I was just going to add to that, too. I think we're hearing more and more that sometimes, the term "person-centered" actually doesn't resonate with certain individuals and from certain backgrounds and that family-centered is really how they want their services to be designed. So that's been really, I think, an interesting journey, is from a policy perspective, with the 2014 HCBS Settings Final Rule, person-centered was put into law. That is how services need to be designed.

And I think there's been some recognition recently that in certain communities, different cultures, it's really family-centered. And person-centered can be off-putting. So the words we use, that's important. But also, the way we set up systems and trying to think through those cultural considerations is a challenge for the system as it moves forward.

LAURA VEGAS: And Lindsay mentioned that the people with lived experience are actually the experts about their lives, of course. And one of the biggest ahas and humbling moments I've had in my career-- there's many of them-- was back when I worked for a state agency, and we had our kickoff for the Supporting Families Community of Practice. And we intentionally invited several family members, family members of people who weren't receiving services, family members of people who were receiving our services, and brought them to the table and started having real conversations with them.

And I remember sitting back and thinking, wow, these people have the answers to a lot of the quality issues that we're dealing with. And it took a little bit of a load off to think they can help us figure this out. But then it was very humbling thinking, the professionals don't know everything. And it's that teamwork that-- it's that working together and partnership that's key. So I'll never forget that moment. It was very powerful in my career.

COLLEEN MCLAUGHLIN: But Laura, that's so insightful. And I know that we often hear people struggling with that collaboration. And you're thinking of it-- you're talking of it at the state level. When we think of service providers and that very same context of working in collaboration with the people they serve, as well as their families, would you have any recommendations for how providers can do this better?

LAURA VEGAS: Well, as Lindsay mentioned, first of all, when you're looking to have a person and their family member in a leadership role at your organization, there are certain supports and things that they may need that are different, that you need to pay attention to, so that they can be an active participant in the role that you've given them. Sometimes, I'm afraid, we have people in positions on the boards of directors and on quality advisory committees with the best of intentions.

But sometimes, it feels more like a token position, and it's not real. It's not giving value to anyone. A lot of providers have quality oversight councils, like advisory groups. Those are excellent places to invite families in and people with lived experiences who are receiving services to get started as providing a leadership role in your agency. It's a good place because you're going to be in a quality oversight committee. You're going to be looking at real data, performance measures. And so that's I think that's always a good place to start, is to find a place where families and people can have a real role in leadership at the organization.

LINDSAY DUBOIS: Yeah, this is Lindsay. I would just add to that, as well, that I think self-direction, obviously, is one of the areas that there's huge growth recently. And obviously, there's waivers that there's more opportunity to have self-directed services on. But even in spite of that, I think there's opportunities to build in consumer direction throughout all waivers.

And some of the things we've seen over the years are, if you have people with lived experience and family members who are part of the hiring committee when you need to bring in a new staff member, wow, that actually pays huge dividends in terms of-- you have a better fit. There's some anecdotal information. And hopefully, eventually, there will be more empirical information.

But for now, we're seeing stories of those fits being more optimal. And so people are staying in those positions for longer. And that makes a lot of good sense. I mean, all of us know that, when people join our teams, we've had those experiences when people are not a great fit. And no one wants to show up to work when there's conflict. So the more we can build in innovative opportunities for people with lived experience and families to be part of all of the key decisions, I think that's going to make a big difference in terms of turnover and all sorts of things that we know are pressures on the system presently.

COLLEEN MCLAUGHLIN: Yeah, no, I appreciate everything that you all are saying. That's such a positive culture change, when we think of the evolution of self-directed services and people hiring and managing their own staff that are getting paid through a fiscal intermediary. It's wonderful to see the growth in that.

And then in addition to that, I think some of the things that we're seeing are even provider organizations that are structuring their organizations in that way, where people do have a voice in who their staff are. It's so great to see when that starts from the very beginning. So when a person selects their service provider, that culture of collaboration with the individual and family is there and communicated well, and people are kept in the loop. And I think both people with disabilities and families can really appreciate that teamwork. So thanks for you all sharing the value of that and how it impacts quality, too.

So 25 years is quite a long time. We think of things-- change is incremental. And I think 25 years in the DD service system seems like almost 100 years in other realms. So you've heard from the voices of people with disabilities, families, providers, for quite some time. Knowing what you've heard, where do you see systems heading? And what do you appreciate most about how the systems have really evolved over time?

LINDSAY DUBOIS: Well, let me just pull out my crystal ball here. I honestly really like this question because as I was hinting at earlier, I feel like so often, we just talk about gaps, and we're like, oh, so much of it's not going well, headache after headache after headache. But I really do believe that it is so important to celebrate those successes. And sometimes, those successes, they're small, little milestones. They're little checkpoints. It's not necessarily like a complete 180.

But even moving the needle 5% is a tremendous achievement. And so one of the great things about NCI is we have benchmarks. And we can look year over year over year, and say, Are we seeing the needle trend forward? Do we have signals of progress? And so I think that's so important to look at.

And the one that really sticks out to me-- and we talked about this a little bit already. But it's that shift from system-centered to person-centered or system-centered systems to person-centered systems. We're seeing this in the reflection of how policies are created. At CMS, the Center for Medicaid and Medicare Services, we're seeing that first in the Settings Final Rule.

Now we've got this Access proposed rule. And person-centered systems are really informing and influencing those policies. So I think that's a phenomenal sign of progress and evolution and gives us a hint as to where the systems are heading.

Of course, there's room for improvement in how policies are implemented, how they're monitored. But advocates fought so tirelessly for those changes. And so I think that's a success that we should continue to celebrate for a long time, that emphasis on person-centered supports in policy.

I do think the system is going to continue to head in that direction. And as we've already talked about a little bit, I'm anticipating that in the coming years, we're just going to see a ton of demand for consumer direction, for self-direction. And I'm excited to see how the system adapts to provide supply to meet that demand. Because I think it's coming. And we're seeing signs of it now.

LAURA VEGAS: I agree with all that, Lindsay. And I would add that I've seen systems evolve a bit over time to embrace flexibility a bit more. It used to be, if a person began to use waiver services, their choices were so limited to what the system offered. So oftentimes, if you needed support at home, a person and the family was forced to choose between this 18-person group home and this 18-person group home. And that's not really choice.

And so as people with lived experience and families have learned and understood informed consent, I think the expectations are really different now. When you come into the service delivery system, now it's more of, how do you want to live? Where do you want to live? What does your ideal home look like? Who do you want to live with? Instead of the opposite.

And although, as Lindsay says, we still have some more work on that, I think that's a huge change in the conversation for people. And it's really causing our system to be more flexible. And when COVID hit, systems were forced to really adopt some flexibilities. I always say we made 15 years of progress in those two years. Some things that would have taken the system years to make happen happened because it had to under COVID.

And some examples of that are increasing self-direction and using remote supports and paying family members to be support providers to people with lived experience. And the majority of these changes to the system worked remarkably well. We absolutely need more resources and more flexibility to support people with unique needs and intersecting identities. But the system has come a long way in a short time.

Some of the more immediate changes on the horizon that we're really excited to see getting traction are efforts to address the long-standing workforce crisis among direct support professionals. The key to quality is to have a well-trained and stable workforce. So that's an important aspect of quality, and that's something that NCI is really helping states examine.

Some of the efforts, including increasing wages, developing career ladders, and an occupational code for those direct support professionals to a more professionalized role-- and I'm really hopeful that these change will be the tipping point to fix some of these challenges. And finally, I think we saw the rise of technology supports in the last decade. And that really took off during COVID. And I think systems are going to continue in that direction, looking for ways to leverage assistive technology and remote supports, to continue to support people to be as independent as they'd like to be as well.

COLLEEN MCCLAUGHLIN: Thanks so much, Laura and Lindsay. You guys just gave a lot of really helpful information to our audience. And I always like our audiences to be able to leave with the information, but also, feel empowered and energized to take the information and move it forward. As we're wrapping things up today, do you have any thoughts to the advocacy community, both families, people with disabilities, and professionals, to say, there's a vision? There's a vision for quality, and there's a vision for social justice. What suggestions do you have for them to keep powering through and moving forward?

LAURA VEGAS: This is Laura. I would suggest that-- and not to put all the responsibility on them, but to continue to partner with their provider agencies, and their state organizations, and their state agencies as much as they can. And I know all families are not in the position to do this, but it's so important to talk to your lawmakers.

Occasionally, I think back when I worked for the state, we had a legislative day on the Hill, and it was specifically for people with disabilities and their families to come and make appointments with their legislators and talk about the things that are most important to them. And we need families to give us feedback on some of the new things that we're implementing.

If things aren't going well, we need to know it. And I know some families and people with lived experience are afraid to say anything if they're not exactly happy, for fear of losing their services that they've waited so long to get or fought so hard to get. So I just think it's important that as much as families are able, to stay connected, to get the most current information, and to keep advocating for their family and their loved ones.

LINDSAY DUBOIS: Yeah, this is Lindsay. I would add a couple things to that. I know that it's very-- from the family members I've talked to and the lived experience that I have, it's really tiring to always have to advocate. So I guess one plug I'll put in is to let NCI know if there are specific areas that you feel like you need resources to be able to advocate better. Because as we know, policymakers, as Laura was mentioning, yes, anecdotes, they want to hear those. But they also are very motivated by seeing some firm numbers that are like, and here's how this is going to help our bottom line.

So we have to be business minded, in a sense, and think about how we can best pair that data with those real-world examples that people have. And I can't read anyone's minds. So the only way that we know what people need is if they reach out to us, and they say, I'm looking at your reports. I see this you've got some data on this topic, but can you develop a brief that we can use when we go to Capitol Hill, and we want to lobby? So letting us know about those things, that gives us the information we need in order to better support advocacy efforts. So that's one thing.

And then I guess the other piece, too, is I know that intersectionality is becoming a very frequently discussed topic. And we didn't touch on it here too much. So I wanted to just mention, we recognize that people have so many different identities that they are bringing forward. And that can make the challenges accessing services even more profound for folks.

And so I think having those conversations and making sure not to-- just to bring that forward as you're advocating, to say, yes, this is something we all experience. But I just want to mention, also, there's this other lens that we need to make sure we're looking at things through. Because I want to make sure we continue to push forward with that.

And I know CMS is committed to trying to look at data and stratify, to be able to see if there's inequities between groups. And so I think we're going to continue to see a focus on intersectionality. And I know

advocates are usually the best people to talk about that. Because they're like, this is my lived experience. Here's all the different groups that I represent and I identify with. And that, I think, is really important to continue to center those conversations around the unique aspects that people have.

LAURA VEGAS: And saying all that, I just want to say, I also think it's incumbent on the system to make it easier for people to be heard and their families to be heard.

LINDSAY DUBOIS: 1,000%, yes, Laura. Thank you.

LAURA VEGAS: I think it's tough. It could be intimidating, whether you mean for it to or not. So the more we can learn about in supporting families, for example, how to make it easier for families and people with disabilities to interact with the system, I think we'd be better off for it.

COLLEEN MCLAUGHLIN: Thanks so much for sharing that. I mean, what a wonderful message to convey, is the importance of being listened to, being heard. And really, it's wonderful to have such great partners like the both of you to really help states and organizations take that and move it into action, so that people do get the quality supports that they're looking for and being able to live out their life visions. So it's so wonderful.

I can't thank you both enough for joining me today and sharing in this important conversation. I look forward to continuing the work in collaboration and seeing how far we can go to help the lives that people want to become a reality. So thank you, both.

LAURA VEGAS: Thank you, Colleen. We're very grateful for our partners like The Boggs Center and you. You really help us understand more about the impact of the work that we're doing for people with disabilities and to help us really understand what the NCI data is telling us.

COLLEEN MCLAUGHLIN: Thank you.

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