

BoggsCast Episode 22: Alixé Bonardi & Kate Brady

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JAIME ZAHID: 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 Jaime Zahid, a Training and Consultation Specialist here at The Boggs Center. In this episode, we'll be discussing how we can move towards an authentically person-centered system of supports and services for people with disabilities. I'm joined by Alixé Bonardi and Kate Brady, both of whom are from the Human Services Research Institute, HSRI for short.

Alixé Bonardi has over 30 years of experience with home and community-based services for people with disabilities. She is the IDD team lead at HSRI and has grown the National Core Indicators work, elevating participant voice and experience in state-level, quality monitoring of HCBS for people with IDD.

Kate Brady is project manager for NCAPPS and HCBS Setting Rule engagement and is particularly excited to grow community response to publicly-funded systems of support, such that they better fulfill with HSRI's goal of seeing all people live healthy, fulfilling lives as powerful, respected members of society. Kate and Alixé, welcome. Thank you so much for joining us today-- well, me.

I know I gave you both a brief introduction. I feel like people, for the most part, typically introduce themselves a little bit better than a third party can. I'm hoping that you guys can just take a few minutes to introduce yourself. And for myself, I'm particularly interested in what brought you both to this type of work.

ALIXÉ BONARDI: I can take that question, I guess, to start. This is Alixé. I came into this field-- actually, I'm trained as an occupational therapist and did my training as an OT in New York and worked for several years in New York City. That training and working with people had me both really grounded in identifying really person-centered solutions for people. I was working directly with kids and adults with disabilities and both in the public school system and then in people's homes.

And I loved that work, and I was constantly wondering about what factors led to people having really different experiences of just access to services. And so that kind of got me -- turned in on a different path, and I've been working, really, on the policy side of disability supports for a couple decades, I guess. So I

mean, that's really my background, and that's where my passion comes from, too, is that I'm really interested in making sure that everybody's got the access that they should.

JAIME ZAHID: Awesome. Thank you so much for that. Kate, can we go to you?

KATE BRADY: Sure. So this is Kate, and I think my passion has always been rooted in justice and equity anchor. I think I came by that as a kid, maybe just in my personality but also just as a kid using a wheelchair and being in a public school system that, in a variety of ways, was responsive and in other ways was not and also growing up in a pretty diverse neighborhood-- I grew up in Philadelphia, and racial inequity was not lost on me, even as a little kid.

So I think that's a through thread in my career. I'm trained as a organizational and community psychologist. I think I'm always thinking about systems. And most of my work, for the past 20 years, has been rooted in systems change as it relates to disability service systems. So I'm really interested in the interplay between policy and funding and values.

And in NCAPPS, we are really working exactly in the nexus of those things, recognizing that person-centeredness is a value that is necessary but not sufficient and that we have to align how we support people, how we fund those supports, and how we regulate and oversee. And so I've been putting a lot of work just recently into thinking about the Home and Community-Based Settings Rule and the coming Access Rule and recognizing there's always a gap, too, between our intent at the federal level and the ground capacity in local communities.

So I think that's another through thread of my passion is just recognizing that we need to hear from people about their discrete, hyper-local experiences to really understand what needs to happen in communities.

JAIME ZAHID: Excellent. Thank you, Kate. You're speaking to so many things right there, with that one answer, some topics we can have a conversation all day about, for sure. You mentioned capacity at the ground level, where people live. And that actually is one of the questions that I have prepared for both of you is, what about capacity? What to do when that capacity is not there? But we'll get to that shortly.

I try not to use acronyms, and I introduced the two of you using the NCAPPS acronym, N-C-A-P-P-S. So I'm hoping that we can start with that. Can we talk a little bit about what is NCAPPS? What does it stand for? What is the mission and purpose of NCAPPS?

ALIXE BONARDI: This is Alixe. Sure, I can take that. And like you, Jaime, I try not to use acronyms, but when I say all these words, hopefully, you'll forgive us for using the acronym NCAPPS. NCAPPS stands for the National Center on Advancing Person-Centered Practices and Systems.

And over the last five-plus years, we've come to affectionately know it as NCAPPS. And I know it's not exactly a household word, but it has come to roll off our tongues, I guess, pretty easily. The purpose, as

the center was designed, was-- I mean, we've got a lofty goal. And that is to promote systems change that makes person-centered principles not just an aspiration but a reality in the lives of people across the lifespan. Super broad, right?

And we came to the center through an opportunity that we had. This center was funded by the Administration on Community Living and Centers for Medicare and Medicaid Services, so that's ACL and CMS, if you want those acronyms. But this was put together as a concept, really-- gosh-- well, our funding started in 2018 at our organization to really launch the center.

And what's kind of neat about it is that it is very broad in its conception in that it is focused on advancing person-centered approaches that support people with disabilities in their lives. It is a cross-disability center, so we work to advance person-centered practices in aging and Alzheimer's and dementia supports.

And also, we've done efforts that have really focused on children and youth and families and developmental disabilities and people with brain injuries and physical disabilities. And so it's actually been a pretty far-reaching center. So that's really what our purpose is.

Our main area where we do our work, we start with focusing in on supporting states, tribes, and territories to accomplish that work for systems change. And then, at the same time, we've put a lot of effort over the last years in putting together publicly-available materials and resources, which are on our web page and also, then, providing learning communities that are topic specific.

So we're kind of broad but always driven by moving systems in the direction of being more person-centered. Some of our priorities, just to hit on those quickly, is as we were starting to talk about, is to be dismantling structural inequities that exist so that people with disabilities experience access and are able to access the lives of their choosing in their community and that structural inequities are actually addressed so that people don't experience some of the marginalization that exists across our society.

We're also very much about cross-system collaboration. So when I say "cross-system," a lot of states have very siloed systems delivery, depending on how people come to the system. And we really believe that cross-system collaboration works well. We're really very much about making sure that lived experience is centered in the work that we're doing.

So we work hard to make sure that, for example, when we do webinars, that people with lived experience of disability are in the presentation, in many cases leading the presentation as well. And so I mean, that's where our work lies. And after having a five-year cycle of the center, we're in a one-year bridge, which we hope and intend will lead us to another cycle, funded cycle, in coming years.

JAIME ZAHID: Excellent. Thank you for that very informative response. I actually had the privilege of being part of one of the most recent learning collaboratives and really enjoyed the opportunity not only to work with a team of people from New Jersey and people that I've interacted with before but didn't

necessarily have the chance to really sit down and say, hey, what's going on here? How can we fix this? And come up with a plan, and some of those plans that we came up with are in action now, which is exciting to see.

And I hope that the long-term effects of that are going to, hopefully, cover some of those inequities that you speak of because, for sure, access to the system is sometimes difficult for people to navigate. And you mentioned inequities, and it does boil down to that, for sure, sometimes, that there's just limited information or misinformation or whatever that makes it difficult for people.

So thank you for that. This was not one of our prepared questions. And it's a question I definitely-- I'd like to think I know the answer to it myself, but I'm hoping that one of you ladies wouldn't mind, just for our listeners, who keep hearing us talking about person-centered, so person-centered planning, what does that mean? What does that mean functionally for people that might be listening, who might be family members, might be service providers?

KATE BRADY: Right. Well, I think it can mean a number of things. In the context of publicly-funded social services, those services that you might be getting from a provider or from a Medicaid waiver to help you do your day or help you live in the community or find a job or go to social things that you want to go to, the person-centered plan is a tool that lets you figure out and identify and then document what you want from your life, what's important to you, and what's important for you, and how those services can happen and with whom-- who you want helping you and when and where.

And it, as a process, should be a process that you control and that you have a right to in concert with the services that you get, and you have a right to that every single year and to involve whomever you want in that process. And that plan ultimately drives how the services happen.

Outside of the context of funded services, we recognize person-centered planning can just be a great tool to think about who you are and what's important to you and where you want your life to go. And it might be happening not in the context of getting help. It might just be happening in the context of, what do you want to do after you graduate from high school? And where do you want to live? And what kinds of things might you need to help that go really well? And so it's both a tool for the public system and a right that you have as a recipient of supports and a really neat way to think about your life.

ALIXE BONARDI: Yeah, yeah. You've captured it, Kate. And the couple other concepts that are really related to person-centered planning, and I think are important to bring into the conversation, is person-centered thinking, which is really just the foundational principle that the person and their loved ones are the experts in their own lives and that all things should flow from that expertise and what comes from that. So that really is person-centered thinking.

And as you mentioned, Kate, the person-centered plan really is a process or a method for coming around to identifying and getting some clarity on what really is important and how people want to live and then drive their services. And then "person-centered practice" is the other term that we use. And person-

centered practice is really aligning services and supports so that people can live the life that they've identified.

So there's sometimes, a colleague, Michael Smull, I think he uses the term a person-centered plan that is not implemented in a full way actually does harm because it's like making promises that may not be kept. And the person-centered practice part is really what's so critical.

And the little example that I have in mind from someone I know, where as part of the plan, they had identified that they really wanted to be more active and that swimming was something that they wanted to be doing. And as part of that, alright, we have a swimming pool that has been identified. People are going to line up to get support, to help somebody get to a swimming pool.

But the pool hours of that particular pool were like crack of dawn morning. This person is not a morning person. And in that experience, the practice-- there were actually other options, but it was mostly the service provider that found this most convenient to get someone there early. And that was the opposite of a person-centered practice.

So little things like that just, keeping going with an emphasis on making sure that the person, the person's needs and whether they're a morning person, is all part of the decision about how things get set up to support someone.

JAIME ZAHID: Excellent. Thank you so much for that illustration, Alixe. I appreciate that. And Kate, I really appreciated how you captured the fact that person-centered planning can be within the context of receiving services and also not. I'm always, when I'm training professionals and people and families, I like to drive home the fact that-- and I've only had this realization in the past few years-- that this is not disability specific. It's really not.

This is about people just having lives. And of course, within the context of the work we do, it's disability specific and important to recognize the importance of making sure that we're applying it to people's lives who are receiving services, but, truly, person-centered planning is-- I think I'm paraphrasing. Kate, you said just about living the life that you want for yourself.

So in New Jersey, we've done a lot to promote person-centered planning and practice. What do you think a person-centered system looks like, and how might we get there? I know that's a really big question.

ALIXE BONARDI: It's a big question, Jaime, and we've got some ideas. I don't think we've got all of the ideas because if we did, boy—

KATE BRADY: We could just snap our fingers.

ALIXE BONARDI: Exactly.

KATE BRADY: Right? [LAUGHS]

ALIXE BONARDI: Exactly. So in answer to the first part of your question, Jaime, I would say a person-centered system starts with person-centered thinking and the recognition, like I said, that the person and their loved ones are the experts in their own lives and that they are the ones who are identifying the life of their choosing, and the supports should flow from there, when we're talking about a system of supports. So that would be the first step.

It needs to include person-centered planning, which follows along with the person-centered thinking. And the one thing we haven't mentioned yet is that person-centered planning is an opportunity to-- people can be really supported in person-centered planning by people who are skilled facilitators to help with that plan.

And that was one thing we've learned early on when we got into this work. We were getting a lot of questions from systems saying, well, who should be doing that planning? Who should be doing that support? And in the work that we've done-- and again, this is across disability support systems-- the answer to that is, it can be any number of people who are facilitators. In many cases, it might be called a case manager or a service coordinator, but it doesn't have to be. But there are core competencies of the facilitator that really should be in place.

And I do think that is one of the cornerstones of a person-centered system. There are competencies that are understood for facilitating and supporting people to describe what makes sense to them, from a person-centered perspective. That's another resource that we developed through NCAPPS, and we don't need to spend a lot of time on it because it's on the NCAPPS website.

But I do think that we really need to turn back to making sure that the supports and the facilitators are absolutely aligned with core competencies. I'm going to turn it to you, Kate, because, of course, to the point of having a plan that doesn't get you there entirely. But I just wanted to see if there are other thoughts you've got, Kate, about that.

KATE BRADY: Well, thanks, Alixe. I think you've covered the foundational requirements, having those person-centered thinking values, recognizing how critical it is to have skilled facilitators. And we do have the competency domains for person-centered plan facilitators that, I think, are so critical to implement across the system.

And I guess the only other thing I'd add that I think we see in practice in our technical assistance work is that the system has to devote the energy to changing and aligning person-centered services.

So when we say person-centered thinking, planning, and practice, it's those funded services and lifting-up options, like self-direction and individualized, community-based services that are nimble and allow someone to go to whatever swimming pool is open in the afternoon and have someone that is equally

excited to be at that pool, in that neighborhood, at 2 o'clock in the afternoon, is really critical for the system to sustain itself as truly person-centered.

JAIME ZAHID: Excellent. Thank you, Kate. And Alixe, I just wanted to touch back on, real quick, you mentioned that the core competencies for facilitators of person-centered planning can be found on the NCAPPS website. Was that correct?

ALIXE BONARDI: That is right, Jaime, yeah. And just a few breadcrumbs there, the NCAPPS website has a tab called Resources. It's right in there, along with a bunch of other resources that we've developed or resources from our partners.

JAIME ZAHID: Excellent. Thank you. And I hope that listeners check that out because it sounds like it could be a really helpful tool for doing person-centered planning and for holding people accountable for doing person-centered planning well, which leads me to my next question for you both. How can families and people with disabilities be more informed of what a person-centered life looks like for them? And how can they hold the system accountable for ensuring that's what they're getting from services and supports?

ALIXE BONARDI: Jaime, I love this question. Kate-- both of us are probably are brimming with things to talk about.

KATE BRADY: Yeah, you go first. Yeah, it's a great question.

ALIXE BONARDI: It's such a great question. Well, one of the things I wanted to say is that you've hit on, really, one of the core tenets of NCAPPS, as we were developing this because we recognize that both if systems are really going to change, there needs to be pressure from what we call sometimes the top-down, so that could be policy changes and restructuring of how services are delivered or funded or authorized.

And there also needs to be the bottom-up demand coming from people and expectations about a service delivery system that is truly person-centered. So we've been really interested in working on both fronts because that kind of pressure is what we think is really going to help drive systems change.

So, the quick answer, I just have one thing to suggest. And Kate, you might have other-- I'm sure you have others. I've mentioned the NCAPPS website already. One other resource, which we're pretty proud of. And this is an opportunity for families just to get a little bit more of a sense from multiple perspectives. We have a series of videos called NCAPPS Shorts. And they are short YouTube videos that were created by a whole range of people with lived experience of disability, talking about what person-centeredness means to them directly. And I feel like they're short. It's worth going back to. And I've been back to them several times.

And spending time directly, hearing from people who have put some thought into what person-centeredness means to them, I think, can be a real opportunity to get sparks of, oh, that would be the kind of thing we'd look for. That's one thing.

JAIME ZAHID: Excellent. Thank you, Alixe. Actually, I knew about the NCAPPS shorts. And I'm going to admit, I kind of forgot about them. So I'm glad you reminded me.

Kate, did you have anything to add to that?

KATE BRADY: Sure. Yeah, that culture and PCP short series is just phenomenal. I hope folks will take a look at that. I think the other thing I'd like to add is just to encourage listeners who might be people with disabilities or family members that this is something we're working at the system level because we know systems have drivers that interrupt an intent to be person-centered.

But for individual people, you may also have experienced interruptions. And you may also have been in a school system that cues an interruption to your instinct, that schooling ought to be person-centered for a young person with a disability and that you do instinctively know when you're being respected and listened to and when you're driving your own life.

And it's those external drivers that interrupt that experience. And so I would just call folks to trust those rooted feelings and know that you functionally do have those rights, I mean, that we have embedded these rights in the regulations around home and community-based services. We have embedded them in many developmental disabilities waivers, systems. And there are resources to support you. There are protection and advocacy resources. There are DD councils. There's NCAPPS.

I think you can carve out space within your own person-centered plan and within your own tiny, hopefully, provider network to experience this system in a person-centered way.

JAIME ZAHID: Excellent. And I think both of you-- forgive me if I'm mistaken-- I think both of you mentioned expectations. In college, I thought I was going to be a school teacher for a minute and took some classes on classroom management and whatnot. And what stuck with me from that and has carried throughout my work in the disability world is the idea of expectations and how expectations are going to be the driver of success.

And we talk about that with children in school. And I've realized it's the exact same for the people that we are supporting, who experience disability, that that expectation is going to make a world of difference. For somebody who grows up expecting to get a full-time job and go to college, they're going to actually realize that dream.

And if you grow up with limited expectations due to disability and the service system, then it's likely not to happen. So I'm glad that you touched on that. I hope that a takeaway for anybody listening is to have those-- I hesitate to say high expectations. I think they're just typical expectations of your own life.

ALIXE BONARDI: You've really hit the nail on the head there, Jaime. One of our colleagues who works with us on the NCAPPS project, Nicole LeBlanc, also talks about how-- she says, I don't experience autism in a negative way. I experience the low-expectation syndrome in a negative way.

And that has been really something that-- I mean, her voice is so powerful. And I think she'd be OK with me sharing this because it's something that-- it's a strong message. And the low expectations-- you're right-- is something that can really be a barrier.

JAIME ZAHID: Yeah, because without that high expectation, you're not asking for what you want and what's going to make your life a full, meaningful life.

ALIXE BONARDI: Yeah.

KATE BRADY: Yes. And I think it can be insidious, too. The impact of limiting expectations over time can interrupt our vision for how school might go, how transition might go, where one might live, what work might be, what relationships might look like. And so there's a sort of vigilance that is required.

You asked what can people with disabilities and family members do. And although it is unfair, I think there's a vigilance needed to anchoring and expectations that are rooted in what someone wants and loves, where their interests lie and really holding fast to those, despite interrupting or limiting notions that might—

JAIME ZAHID: I love that word interrupting, Kate. I'm going to steal that from you and use that.

KATE BRADY: No, steal it. I don't know where I got, it but you steal it freely.

JAIME ZAHID: Excellent. And a closing question, and keeping in mind-- the three of us know this-- that we can't put people's lives on hold while we wait for the system to catch up. So what suggestions do you have on navigating a system that, perhaps, doesn't quite have full capacity to do what people need, to have a meaningful, person-centered life?

ALIXE BONARDI: This is NCAPPS and beyond, just from my experience. I will say, I've experienced and learned so much from the creativity that people bring to their lives when they recognize that the service system is not really going to bring to me what I need. And often, in many cases, it seems like that creativity comes early or that realization comes early. And then the creativity is what brings people, in some cases, some success.

And by creativity, I mean just in terms of thinking about different ways to engage with people so that you can get support providers that are good and local to your community and work with you. And I hesitate to say, "just be more creative" when people are really struggling with this. I recognize that it doesn't come off right.

I'm just reflecting that in my experience, I've really observed that finding ways that are just kind of out of the box really seems like it brings people to life that they are most interested in.

The one other thing that I'll mention is, there are some ways of thinking about the effort and the impact that you're going to have, as you're trying to move systems and then, also, as you're trying to access things at an individual level. And the effort impact matrix is something that people can find online, but it is a way that I live my life. I think about how much work is going to take to try and get to something and have a really serious think with myself and others about whether I'm doing something that is, to use a metaphor, banging my head against a wall or whether I really see I'm going to be able to make some change.

Sometimes, it's hard when you're in it, and you're frustrated, and you need to step back. But that's been something that I find helpful. I mean, that's at a systems-change level but also, really, an individual level, too. It's just been a helpful way of thinking.

JAIME ZAHID: Excellent. Thank you for that perspective, Alixe. Kate, did you have anything to add?

KATE BRADY: Maybe just re-mentioning self-direction as a powerful path that probably is available to most folks in some form or another. And in the framework of effort to impact might be fruitful for getting folks out of the constraints of the system and into pathways that let you make your own choices about who provides support and when and how.

And I can offer, in my own life, I have found great success in hiring people to help me who are artists and who are creative folks and who are working on their own lives in creative ways because they show up in my life in a way that presumes nothing, and that is a powerful place to start. And so I'll offer that as a personal experience of how I've used self-direction.

JAIME ZAHID: Thank you so much for sharing. And Kate, I feel like you nearly-- I'm not exaggerating-- you nearly took my breath away there when you said that they presume nothing. I was expecting you to say something completely different. You said "nothing." And in that moment, I was like, wow, is really powerful because people do come into situations with so many preconceived notions. And sometimes, that can be the blinders to what's possible, for sure.

KATE BRADY: Yeah.

JAIME ZAHID: And thank you for that note about self-direction perhaps being part of the answer for people making their own way while the system tries to catch up. I know this is full circle in our conversation, then. The NCAPPS cohort, the team from New Jersey, we did all of our work around, how can we improve self-direction?

And a lot of the work, a lot of the stuff that we talked about was, how can we improve access to self-directed services in New Jersey? Because, unfortunately, there's been some systemic barriers there, for us, here in New Jersey.

And so improving that through our NCAPPS work is a sort of full-circle moment here on this conversation that I hope that people listening are utilizing self-direction and know that it's not an all or nothing when it comes to using self-direction. You can use self-direction in some facets of your supports and services and use provider-managed in other areas. And it can, for some people, really make that meaningful full life.

Did you ladies have anything else that you wanted to add to the conversation before we wrap up today?

KATE BRADY: Just a thank you for having us and letting us think about NCAPPS.

ALIXE BONARDI: Me, too. I've really enjoyed this conversation, Jaime and Kate. These kind of conversations really fuel a lot of energy to keep this work going.

JAIME ZAHID: Absolutely. My only frustration with doing podcasts is that I wish we could talk so much longer, I really do. I'm watching our time because, of course, our listeners are probably not looking to listen to us for five hours, but I definitely feel like I could have spoken to the two of you for a lot longer on all of this.

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