

BoggsCast Episode 8: Season 1 Highlights

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JAIME ZAHID: Welcome to the 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, Training and Consultation Specialist.

In this episode, we're featuring a recap of some of our favorite moments from our first seven episodes. Throughout this episode, you'll hear our favorite clips. We hope that this inspires you to take a second listen to reinforce information and themes from our inaugural year of the podcast. Perhaps if you've missed an episode, this recap will spark some interest in checking out that missed episode.

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Disability Allyship and Storytelling to Connect About Disability with Emily Ladau, Disability Rights Activist, Writer, and Digital Communications Consultant. A clip that stands out to me is Charlotte Borgersen, co-host and New Jersey Partners and Policymaking graduate, asking Emily about her long-term goals as an advocate. Emily's response was a rallying cry for all of us.

She takes ownership of her own personal responsibility to continue advocating across her lifespan, and to also know when to pass the torch and lift up other advocates so that they, too, can be lifelong advocates along with her. Additionally, she speaks of using her experiences to extend support to marginalized populations within the disability space.

CHARLOTTE BORGENSEN: What are your long-term goals related to advocacy?

EMILY LADAU: For me, advocacy is really kind of cyclical. So, if I have achieved a goal in one area, there's a good chance that my work is not done. And I don't mean that to sound overwhelming, but it's the reality. There are so many people in this world that it's simply impossible to reach all of them. And so, my goal is to reach as many people as I can in ways that feel good and in ways that feel right. And so, my long-term goal is really to be doing exactly what I'm doing now, but just to continue to grow and to continue to advocate on a broader scale, and also to focus on really knowing when it's not my turn to speak and when I need to pass the mic to other people, and recognize that the best long-term goal that you can have for advocacy is giving the spotlight to other people whose voices may not necessarily be

heard in the conversation.

So, my goal is not so much to amplify my own words forever, but rather to provide jumping off points for other activists, especially people who are multi-marginalized, to have a platform, to have the spotlight on them to really give them the support that they need to share their stories. And I'm lucky to say that I do a lot of that already, especially through my work as Editor in Chief of Rooted in Rights because I support disabled writers of all different types of identities to share their story. And so that's an incredible privilege that I have to be able to do that. And longer-term, I just hope to do more of that and to spread that even more broadly.

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JAIME ZAHID: Episode two, Mental Health Needs Among Individuals with Intellectual and Developmental Disabilities with Andrea Witwer, Associate Professor at the Ohio State University and Director of Training and LEND Associate Director at the Nisonger Center. Andrea's commentary on lessons learned from the pandemic, experiences of people with intellectual and developmental disabilities and mental health needs truly highlights the utility and promise of telehealth as a strategy for continuing to reduce barriers to accessing services, even as things begin to open up.

STEPHANIE MICHAEL: Do you think there's any major lessons that we've learned from this experience with the pandemic? Are there any things that stand out to you that you don't want to kind of get lost as we go back and open up?

ANDREA WITWER: Right. Yeah, so I think there's a few things that I think for me personally stand out. One of them is telehealth. And I think that hopefully for years, people have recognized that there was so much potential, but insurance companies weren't paying for it, which meant that people just couldn't feasibly do it. And I'm hoping, and I know there's a lot of work and advocacy being done to really help with that because I think that has so many ways to break down barriers.

We spend so much time talking about folks that are in Ohio, we have lots of rural areas, where there's not only not DD experts, there's no mental health experts at all. It's a desert of all. And so, these mental health provider shortage areas that we have in the state. And so, using telehealth is such a great way to reduce those barriers for adults and anyone, that transportation aspect. And so, I think telehealth has some really great great ways to do it.

But I think the other piece of that is I think we realize that sometimes telehealth and that technology leaves some people behind. And so, I think hopefully that's the other lesson that we learned. I know we did some focus groups with adults with ID, and we were asking about just different aspects of mental health. But we were doing it in the midst of the lockdown. Virtual focus groups, of course. And they were sharing their different experiences with therapists.

Some of them had very favorable experiences. Some of them, because of the needs they needed related to adaptive technology or not being able to have access to high-speed internet, they didn't feel like they were able to access their treatment during that period. And so, I think there's a lot we can do, but I also think hopefully we've learned we need to do some educating of providers to make sure they're doing it in a way that's inclusive of everyone.

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JAIME ZAHID: Episode three, Disability Inclusion in Public Health Programs, Training and Leadership with Adriane Griffen, who served as the Senior Director of Public Health and Leadership at the Association of University Centers on Disabilities at the time. Adriane's explanation of public health as a blend of science and communication art, the need for plain language, and of course the concept of same time access to everyone, or STATE, are so key to really ensuring that messaging is accessible, timely, and successful in reaching people with disabilities.

MELISSA CHEPLIC: And when we talk about serving the community, we talk about serving everyone in that community. And certainly, that includes people with disabilities, and intellectual and developmental disabilities included. Of course, one important area of focus at the National Center on Disability and Public Health has been vaccine confidence efforts. What have been some really critical considerations about messaging, specifically around vaccines, for people with disabilities?

ADRIANE GRIFFEN: Yeah, it's been really very important to make sure that we're building out vaccine confidence and sharing information in plain language, really getting at the heart of the messaging, breaking it down, making it as simple as possible. I really like to remind people that public health is a blend of science, but it's also a communication art. And it's so important when you're working with the general community, and then also including people with disabilities in your outreach, that the information is plain language, that it is simple so people know what to do, just one, two, three. Make it as simple as possible.

So with our vaccine confidence messaging, that's what we've really tried to do. And we also have made sure that we are including self-advocates every step of the way. So that goes from design, material creation, reviewing it, critiquing it, taking that feedback and making it better, and then showcasing it back to people with disabilities to make sure we're on track. So all of those pieces, plain language, and then really testing it with people who have different types of communication needs, making sure that it's on track.

MELISSA CHEPLIC: That's so important. You talk about the blending of art and science and including advocates and testing and plain language messaging. And what are some other important public health issues that impact people with disabilities that those principles of the vaccine confidence protocol can really be applied to to increase dialogue and discussion in the same way, with the same success?

ADRIANE GRIFFEN: Yeah, I would say that it's really critical to make sure that people with disabilities get the same access at the same time as everyone else in the community, no matter how that individual might communicate. So, we call that same time access to everyone, or STATE, S-T-A-T-E, same time access to everyone, for just an acronym to remember it so that, as you're doing these campaigns, ask yourself, is this same time access to everyone? And that is something that would be applicable across no matter what you're doing-- a heart health clinic, a diabetes prevention program, a cancer screening, you name it.

Is that campaign same time access to everyone? Are you using plain language materials? Are you including closed captions? Are you including ASL? Are you including those interpreters from the beginning, not as an afterthought, not weeks and weeks later, but when you're launching the materials, are you having it available all at the same time to everybody in the community, no matter how that individual might communicate? So, I would say those principles really transcend-- they're lessons learned from the vaccine confidence work, but they really factor into any kind of outreach you're doing for public health.

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JAIME ZAHID: Episode four, Transition with Julie Lounds Taylor, Associate Professor of Pediatrics at Vanderbilt University Medical Center and Investigator at the Vanderbilt Kennedy Center. The discussion between co-host Tara Palamarik, parent advocate, Partners in Policymaking and New Jersey LEND alumni, and Julie Lounds Taylor about the importance of timing when providing and receiving information and their thoughts on getting information to families when they can really use it to the maximum extent possible was beyond enlightening. I also love Tara's suggestions around parents partnering with other parents whose child is slightly older to serve as a resource for navigating complex experiences and systems.

CARRIE COFFIELD: One of the things we hear repeatedly about the transition process is how overwhelming it really is. And oftentimes, families are challenged by sort of the abundance of information and how to sort of cut through it and find the right information that they need at the right time. And I know, Tara, does that resonate with your experience?

TARA PALAMARIK: Absolutely. I know that from attending many, many lectures and no matter how useful the advice is, sometimes all those acronyms, all those SSS's and PPP's go right over your head. And it takes a few times and it turns into-- it only gets absorbed when it's most needed. So, a lot of times, somebody will go into a beautiful explanation of SSI and Medicaid, and the most that I can absorb at a certain age is that's something I'm going to look at in more detail in two years. But at least I know it's something I need to look at.

And for some parents, you're bombarded with all of that information, with confusion between what comes from the state, what comes from the federal government. And if you get it all at once, it's really hard to

distill what do I need to do today. I've heard many parents ask me questions about this.

And my most useful advice that I've received and given to many parents is get to be the best friend of somebody whose child is about two years older than yours. And I think that becomes your best resource. And then you pay it forward to someone whose child is a little bit younger, to know the tips and tricks.

JULIE LOUNDS TAYLOR: I love that advice. And this issue of when information like this is the most helpful, I think, is a really, really important question. And I don't think the answer to that is easy. We're actually going to test that, to some extent, in the research project, in the ASSIST research project right now.

So, in our pilot work, the grant that funded that pilot work that allowed us to first develop the program was very specifically aimed at youth on the autism spectrum who were exiting high school in the next two years. And they were very specific about the age range there to prepare them to leave high school. So that was who you recruited for that study.

And I think sort of conventional wisdom would be that getting people information early is better. The earlier you can get people information, they can plan. And I think there's some truth to that. But I also feel what you're saying here, Tara, and we've seen this in our work, where you can give families a lot of information early, but it's hard to know what to attend to, especially when there's a lot. It's hard to know what services and supports your son or daughter is going to need after they leave high school or what's going to be the most beneficial.

And also, service systems change. And so, you can give families information five years out, and the Medicaid waiver may completely change between then and when-- that actually happened in our pilot work. We ran the intervention twice. We had our sort of intervention group who took it right away, then we had a group that got to take it after a year. And in between those two sessions, our Medicaid waiver completely changed. And so, we had to redo that whole entire session.

And so, we had some families in our pilot work whose sons and daughters were in high school. They were leaving and going to college. And they kind of told us at the time, I don't think a lot of these services and supports are going to be relevant in our situation, but we're going to be sort of good citizens and research participants, and we're going to kind of help you out with your program and your intervention, even though I don't know that we're going to really use this.

And we had more than one case where, once they left high school, in one case a son and in one case a daughter, encountered some pretty significant challenges, both times in post-secondary education, a couple of circumstances where people actually dropped out of college pretty quickly. And the services and supports start to take on a different meaning than they had before their son or daughter had these experiences. So, there may be something to be said for having some experience in the adult world and seeing where the challenges are and what to attend to and what might be the most helpful.

So, we're actually for this-- it's not answering all the questions that you talked about, Tara, because I do think sort of ultimately staggering some of this information may end up being the most effective, but we will be testing. We have some people who are still in high school. They can be as young as 16 up through 26. And we're going to at least run some statistical analyses to see if getting this information at a certain age, before high school, after high school, right after high school, a little ways after high school, seems to be more beneficial to families. But I think it's a tricky question, and I think it's really important because you want to get this information to families at a time when they can really maximally use it, right?

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JAIME ZAHID: Episode five, Technology for Community Living with Emily Shea Tanis, PhD, Associate Research Professor at the University of Kansas Life Span Institute. Co-host Steve Gruzlovic, New Jersey Partners in Policymaking graduate, speaks with Dr. Tanis about the importance of keeping people with disabilities as part of the development process in making technology, and really all things, accessible, and not including people with disabilities simply as a tokenized member of the team. Dr. Tanis' response gives some specific direction on how this can be done in a meaningful way across the entire development process.

STEVE GRUZLOVIC: I'd like to say that, before the pandemic, accessibility was thought about, but it was kind of like towards the bottom of the list. And now that we've had the pandemic, people are starting to pay more attention to accessibility and accessibility leaders. And we don't have it perfect yet, but they're trying. But there still needs to be a lot of improvement.

And I think it's important that we bring individuals with disabilities to the table without making them a token. I think that's also really, really important. And we need to hear from a variety of different disabilities, from the full spectrum. So, I think, overall, the pandemic has led to a major push to make things more accessible.

EMILY SHEA TANIS: I love that you talk about the tokenism, Steve. I mean, the number one thing when we have developers or tech engineers coming to us to ask about cognitive disability, our response is talk to people with disabilities, and not only talk to them, but hire them so they're part of the development process from the very beginning, identifying where the issues are until the very end so we're not engaged in what is this tech ableism or using technology to be the solution to disability.

We're starting to see this user-designed process. We're starting to see what is inclusive research design, where folks with disabilities come at the beginning of the problem identification and go throughout the whole process, even to dissemination. And we just have to keep hammering that approach in until the folks with disabilities are the ones driving the research, are the ones driving the design, are the ones driving the engineering. But the tokenism and just having someone present, we've done that. We've been present. It's time to be really engaged.

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JAIME ZAHID: Episode six, Self-Determination with Karrie Shogren, PhD, Director of the Kansas University Center on Developmental Disabilities, Senior Scientist at the Schiefelbusch Life Span Institute, and Professor in the Department of Special Education at the University of Kansas. This episode of the podcast was so incredibly valuable to people with disabilities and their families.

One clip that really stood out to me was Dr. Shogren's response to co-host Steve Gruzlovic's question about why self-determination matters. Dr. Shogren tells us that people who are self-determined, even those who don't have disabilities, are more likely to have the outcomes that make them happy and fulfilled in life, versus those who are not self-determined. I see her statements on the topic to be a promise to all of us that positive outcomes are possible, but they must be organically grown within the individual.

STEVE GRUZLOVIC: Looking towards the future, why does self-determination matter for future generations of individuals with disabilities?

KARRIE SHOGREN: Yeah, I think it's really a very simple answer, in some ways, but very complex in terms of how that plays out throughout all parts of society. But think about it for anyone. For anyone that's listening, if you're involved in identifying the things that are important to you, in choosing where you live, in identifying kind of the future that you want, that's personally meaningful. We're going to be more motivated to do things, to take action. And we all have the right to do that. Everyone has the fundamental right to be a part of decision-making about their lives.

And so, we know from a lot of research that when people are more self-determined, when they're supported to grow in these abilities, to make decisions, to set and go after goals, to advocate, that it actually predicts better outcomes. Like for example, when young people leave high school with higher levels of self-determination because they've gotten good teaching, good supports, they're more likely to have integrated employment, participate in their community, and other things. We still need to build the supports in the community that allow that to happen, but self-determination is really critical for the person to have those skills and abilities to really take advantage of opportunities to make things happen in their life, in partnership with their families, with other supporters, that they want to happen.

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JAIME ZAHID: Episode seven, Equity, Diversity, and Inclusion with Regina Rodriguez Sisneros, Director of Equity Initiatives and Systems Innovations for the National Association of State Directors of Developmental Disability Services, co-hosted by Raneta Anderson, Boggs Center Interdisciplinary Trainee and New Jersey Partners in Policymaking graduate.

Regina's commentary on how to infuse conversations about equity, diversity, and inclusion into person-centered approaches within the everyday work of those who do direct work with people with disabilities and families is a wonderfully specific instruction on how to be available to learn about the people that a professional is serving. She instructs us not to leave the responsibility fully on the person that we are

supporting to inform us on every aspect of their cultural norms, but rather take a more proactive approach and seek out information on your own, while also taking the time to check in with the person on how what we learned may or may not actually apply to them.

So, Regina, how do we infuse conversations about equity, diversity, and inclusion into person-centered approaches within our everyday work? And so specifically, I'm thinking about those who might be listening and they spend their day doing the day-to-day case management work, who are direct care worker, teacher, job coach. How do we infuse this conversation into their work?

REGINA RODRIGUZ SISNEROS: Well, I would say that it's really important, first, to take on some responsibility, right? Don't put all the burden of learning about a new culture that you may be presented with of a new family that's on your caseload, don't put all that burden on them to tell you about the history of their state, the history of their community. Go learn. Go learn about them as much as you can. Then, recognize that their experience is not necessarily a mirror to what you just read. Right? Consider that there was some complexity and some diversity and some influences in their experience. And then start to ask some questions. Pull the culture wheel out and start to ask some questions and start to engage.

But the only way that you're going to be able to get to any of those things is if you create, first, before you even engage on your person-centered practice, your checklists and all those things, you have to create a safe environment for someone. People know, and I will challenge many people to recognize that especially individuals who are of the African American community, the Asian community, the Latino community, I believe that we even have a stronger muscle of recognizing when somebody is not genuine. And so, we will, as a survival of what we've endured in our surviving, we will put up a barrier that says I'm going to just tell you just a little bit about me. And that's part of the intersectionalities of the experiences of oppression and racism that we've gone through so that we're careful to protect ourselves, our family, and the community that we represent.

So, we have to come with humility. We have to come with genuine intent of really trying to support that person in front of us, and then get to know that person. Start asking questions, and know that if you want vulnerability from someone, you have to offer vulnerability to someone. It's human nature. Now, I'm not saying that we cross barriers, cross lines related to our profession. But I can tell you what my favorite foods are and why that's my favorite food without crossing any barriers related to my profession, and show you how I celebrate culture by modeling it and showing you some different dynamics of cultural characteristics. Introducing that starts to create a safe place for someone else.

The other thing I will say if you really want to be considerate and be your strongest form when you're executing DEI in person-centered services is to be considerate about the cultural norms you enter into. So, if you're entering into someone's family's home and they offer you food, it's OK to take that food because, first of all, there's many cultures who are giving you their last meal. There's many communities who are offering their last meal to you. And it's very disrespectful for you to not take something, to not accept water, to not sit down, if they're sitting on the floor, to not sit with them, to not remove your shoes

when you walk into their home.

Pay attention to what their cultural norms are and pay attention to how you can respect those and how you can enter it because a lot of the work that we do-- now, obviously we weren't doing it during COVID, but a lot of the work we do, we go into people's homes. And also ask people if they feel comfortable in their home having these types of conversations.

And for many communities, it's really important for us to live together. And we like to have-- I grew up on a block where all of my aunts and uncles lived on the same block in four houses. And that included my grandparents and my great grandparents. And so, we were all-- there was no privacy. Like, if I'm having a meeting, I'm going to be like, uh, can we meet at the library? Because everybody and their mama is coming to this meeting. So think about how people are representing to you, no, I don't really want to have this conversation there or whatever. You know?

JAIME ZAHID: Thanks for listening to this episode of BoggsCast, a podcast by The Boggs Center on Developmental Disabilities. A full transcript of this and every episode can be found at theboggscenter.podbean.com. We hope you've enjoyed listening to season one as much as we've enjoyed making it.

BoggsCast will be taking a break for the summer and will be back in October with new episodes. If you haven't yet, we hope you'll use this time to check out this past season and find your own highlights. Be sure to subscribe to BoggsCast on your favorite streaming service so you'll be among the first to know when we're back with season two. To learn more about The Boggs Center, visit our website at rwjms.rutgers.edu/boggscenter and follow us on Facebook at The Boggs Center on Developmental Disabilities.