

## **BoggsCast Episode 18: Season 2 Highlights**

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ASHLÉ LAIDLAW: 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 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 Ashlé Laidlaw, Training and Consultation Specialist.

SEAN CUDDIHY: And I'm Sean Cuddihy, Multimedia Specialist.

ASHLÉ LAIDLAW: In this episode, we're featuring a recap of some of our favorite moments from our second season. We hope this inspires you to check out any episodes you've missed, or take a second to listen and discover some highlights of your own.

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On episode 9 of BoggsCast, we're joined with Bethany Chase, who's interviewing Keith Diaz, a husband, father of two, including his five-year-old son, who has Down syndrome, and a health scientist living in New Jersey. He's also a co-founder of a disability hiring program at his employer, Columbia University Medical Center.

The topic was employment advocacy. And Keith's goals were to inspire others to advocate in their everyday spaces to include individuals with disabilities.

KEITH DIAZ: Our first hire was the most frustrating experience. So we had identified a candidate, thought they were a really great match and took it to HR and said, "here's our person. We want to hire her. And by the way, they have a job coach."

And the response was, "Whoa, whoa, whoa. If this person needs a job coach, then they must not be the most qualified person for the job." And they put a halt to that.

And we were livid because that's a clear violation of ADA. The job coach is an accommodation. It doesn't disqualify you or make you any less capable. And so, that for us, to use the phrase, we want to go

scorched Earth and be like, “Alright. We're getting lawyers involved. That's it. You guys are discriminating.”

And we had to step back and say, “Well, hold on. What do we really want to achieve here? What's the purpose of this? And is it really that they're trying to discriminate, or they just don't know?”

BETHANY CHASE: Right.

KEITH DIAZ: And in our experience, that's been more so the case, is that people just don't know. That disability is just foreign to them. You and I in the disability community world, we understand. But to most people, they don't understand or have any clue of what the day in and day out issues that people with disabilities face. And to me, my sense is it's a lack of awareness or lack of knowledge, not a true intent to discriminate.

That's not always the case, but it tends to be, in my experience, what is usually what's going on.

BETHANY CHASE: Yeah. And that's why I think these efforts are so important. Because it is brand new to a lot of folks. And so it takes persistence and patience and understanding to move the needle forward in this area.

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ASHLÉ LAIDLAW: On episode 10 of BoggsCast, we're joined by Jaime Zahid and Steven Gruzlovic with Jonathan Martinis, the Senior Director for Law and Policy for the Burton Blatt Institute at Syracuse University. He also represented Margaret Jenny Hatch in the Justice for Jenny case, the first trial to hold that a person has the right to choose supported decision-making to make their own life choices instead of being subjected to a permanent full guardianship. Let's take a listen.

JONATHAN MARTINIS: So there's a specific study I always talk about-- please forgive me for being geeky-- but a study by a professor named Dr. Khemka out of Long Island University. She did a series of studies looking at safety and self-determination. One of them is the one I always talk about.

She worked with a group of women with intellectual and developmental disabilities. Women with IDD are way more likely to be abused and neglected than any other segment of the population, so awfully high levels of abuse and neglect. What she did-- I'm not a scientist-- it was an apples to apples study. They compared people of similar abilities and limitations to people of similar abilities and limitations and did the classic move, divided them up, had a control group who she said, go live your life, and then had an experimental group, where she gave them access to a curriculum designed to increase their self-determination, how to make more choices, why you should make more choices, getting support.

After the study is done, she brings both groups back together and she gives them both a test, a recognized test, designed to examine how well people recognize potential abuse and avoid it. Guess

what she found? Apples to apples, those with more self-determination were safer. They were better able to recognize abuse.

And I always say that's not rocket science. Because aren't you more protective of what is yours? If you know it's your life, your choice, your body, your stuff, you're going to fight like hell if someone tries to take them away.

One more geeky study for you—because this one was done in New Jersey. It was called the National Corps Indicators Study. It was done in a whole bunch of states, including New Jersey. The National Core Indicators Study looked at the quality of life of people with intellectual developmental disabilities. And again, apples to apples, they compared people of similar abilities and limitations.

The whole idea of the study was to see what impact certain things had on quality of life. One of the things they looked at was guardianship. And this is amazing. In Jersey and in every other state, people who did not have guardians were more likely to be independent, employed, have friends, date and get married, practice the religion of their choice, be respected, and be more involved in their community than people of similar abilities and limitations who did have guardians.

So what I say to parents is this. Guardianship might be right for your child. It might be. But given all of the science and all of the things at stake, doesn't it make sense, except in the most extreme situation, to at least try something else first?

That's what I ask, what else have you tried? Because you can't know, except in the most extreme circumstances. And those circumstances do exist. But 98% of the time, until you try something, how can you know? And we're talking about quality of life for the rest of your life at stake.

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ASHLÉ LAIDLAW: On episode 11 of BoggsCast, we're joined with Jaime Zahid and Melanie Ayers in interviewing Jennifer Turner, who is the Assistant Director at the LifeCourse Nexus Training and Technical Assistance Center and Research Associate at the University of Missouri at Kansas City Institute for Human Development.

Melanie Ayers is a mom of a 24-year-old daughter with Down syndrome. She's also a nursing professor who is currently completing her Ambassador training for Charting the LifeCourse training tools. Let's take a listen.

MELANIE AYERS: So I want to go back to something that you were talking about earlier. When you're doing these trajectories and what the person's idea of their best life and maybe their parent or family or their provider, whoever is with them, don't necessarily agree with that. What advice can you give to help them get the expectations and their desires to align a little better with the person who has a disability?

JENNIFER TURNER: Yeah, it's a great question. And I think that this is one of those natural parts of life. I think about as I have gotten older, my parents having to kind of let go. And that was gradual over time. I think one of the things that we don't do well in the disability field is that gradual letting go. It's very much like, "OK, well, you're 18. So now you need to be able to make your own decisions. And now you have self-determination because you're 18."

And it's like well, hang on a second. Decision making is a skill set that's learned over time. And that comes from making mistakes and learning from those mistakes.

And so the first thing I would say is start early, as early as you possibly can, with small decisions, with small risks. That's something that has to be developed over time. I didn't learn how to make good decisions because I turned 18. In fact, I made terrible decisions when I was 18.

So I think there's an element of first of all, just allowing that dignity of risk, the right to risk, the right to make some poor choices. But I think where I find Charting the LifeCourse to be really helpful in navigating that is everybody, again, having an opportunity to share their perspectives, their thoughts, whether it's everybody doing their own trajectory and talking about what's my vision? What don't I want?

What I tend to do is start with that, what don't I want. So I think that oftentimes, when there's a difference of opinion, it's because there's some fear.

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ASHLÉ LAIDLAW: In episode 12 of BoggsCast, we're joined by Bethany Chase, who's interviewing Katherine McLaughlin, a certified sexuality educator. She's also the founder, CEO, and lead trainer for Elevatus Training that trains professionals, parents, and individuals with disabilities to become sexual self-aware advocates and peer sexuality educators. The topic of the episode was sexuality and developmental disabilities.

BETHANY CHASE: When I think about sexual education, I think that besides just the biological explanation of what's going on with bodies, that sexuality education can do a lot of normalizing of feelings, of reactions, of emotions. And when I think about people with disabilities who have not had access to this kind of education or information, they not only lose the ability to have these feelings normalized, they also don't have the language to describe it.

And I'm wondering if you can just talk a little bit about what the risks are to a person who doesn't have these human responses, this natural human reactions and longing. What happens to someone who doesn't have these things normalized?

KATHERINE MCLAUGHLIN: I think we can all relate to it on some level, that we all receive messages like, very shameful messages about sexuality and sex. And so I think there's a lot of unlearning that we all have to do. But I think for people with disabilities, they're not even exposed necessarily to something else,

too, to say, "Oh, we could think about this in a positive way," and not even knowing that there's something to unlearn too.

So I think that's part of it. And I think when you talk about consequences, there's so many negative consequences of the lack of information. And in particular, when you talked about language, you may have heard similar stories like this.

But someone shared with me that a woman was saying that "he keeps touching my purse." And they thought it meant her pocketbook, or her purse. And so for a couple of weeks, they were putting her purse in the locker and doing all these things and then all of a sudden, realized that it was a slang word for her vulva.

And so just that took three weeks for them to realize what was happening because she didn't have the language to describe it. So just something like that, things are going to take longer maybe to discover. And just that language and knowledge is powerful.

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SEAN CUDDIHY: So episode 13 focused on how to support a meaningful life through community engagement. It was hosted by Jessica Short. And she sat down with Abby George, who's an expert in customized employment at SEEK. SEEK is a progressive non-profit agency providing a wide range of community supports to help people with intellectual and developmental disabilities live lives of their choosing.

In this clip, Abby George discusses how to build employment skills in everyday life, doing everyday activities that can help people when they are searching for jobs. Let's take a listen.

JESSICA SHORT: Since your area of expertise is customized employment, I would really like to discuss your thoughts about how community-based supports and services impact employment for people with intellectual and developmental disabilities.

ABBY GEORGE: Yeah, they go hand in hand, honestly. Employment is a part of a meaningful life, right? It's a part of being in our communities. We work and live and thrive in our communities. So I think the two go hand in hand.

There are so many employment skills that you can build during your day in the community that can be directly applied to a job search or discovery. So, I always like to use the example of even if a person isn't quote, unquote, "ready for work," if they're not interested in work, we can still build up skills just by doing everyday things.

So, if we take a swim lessons, the person goes swimming. That's their recreation during the day. They have to go in. They have to usually greet someone, maybe at the front desk. They have to pay their

money. They have to, at least at our swim center locally, it's multi-level. So you have to navigate. You have to get changed beforehand. So just in going swimming, we covered four or five skills, so...

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SEAN CUDDIHY: Moving on, episode 14, which was hosted by Melissa Cheplic, looked at how to support people with intellectual and developmental disabilities who have experienced trauma. She had Brian Tallant on, who's the Program Director at Denver START at Rocky Mountain Human Services. And he tells us a bit more on how direct support professionals, caregivers, and family can help identify trauma in people with intellectual and developmental disabilities.

MELISSA CHEPLIC: How can that DSP or caregiver really be empowered to play a role in supports and recovery?

BRIAN TALLANT: Yeah, a great question. I think probably the most important thing that direct service providers can do is educate themselves on the normal Post Traumatic Stress reactions, really have a good working knowledge of what PTSD looks like.

I would also want to make your listeners aware of a wonderful product that's available through NCTSN. It's the IDD Trauma Tool Kit that they have available. And you can download it for free.

If you go to the NCTSN website, [www.nctsn.org](http://www.nctsn.org), you register on their website. You can download this product and it's called *The Road to Recovery, Supporting Youth with Intellectual Developmental Disabilities Who Have Experienced Trauma*. First of all, I would say get your hands on that tool, number 1.

And then what you can do is really get in touch with what PTSD symptomology looks like. The more you learn about what's typical trauma response, and the more you use your familiarity and your cultural competence with people with disabilities, the more that you can differentiate these conditions. You will be able to understand what is pretty typical, in terms of global impairment, or even specific impairments that are related to a disability, versus the impact of trauma.

And again, be mindful. Record data. Because it is about advocacy. It's about educating other people about diagnostic overshadowing and educating the systems around an individual to know the difference between what are PTSD symptoms and what are typical impairments related to a disability? Because they're very different things.

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SEAN CUDDIHY: Episode 15 examined the Home and Community-Based Services Waiver with Alison Barkoff, who is currently serving as the Administration on Community Living's Acting Administrator and as the Acting Assistant Secretary for Aging.

This episode was co-hosted by Jaime Zahid and Amanda Chirelli, a disability advocate who was born with cerebral palsy.

In this clip, Alison Barkoff discusses the rights of those with disabilities guaranteed by the HCBS Settings Rule and some of the changes we should be seeing in the near future, if we haven't seen them already.

ALISON BARKOFF: You should start seeing-- you should have already seen some of these changes that really give you more control and more choice. And I want to mention, it's not just these basic things we're talking about, but things like people having control over their own financial resources, freedom from coercion or restraint, people being able to have a choice of what services they want and who provides them.

In addition, so many systems-- and again, it's really historical from where we started with disability services, which were mostly places for people with disabilities, things like group homes, or day programs. The rule requires that people have a choice to receive services in settings that are not disability specific.

So what does that mean? Instead of living in a group home, people need to be offered the option to live in their own apartment and get in-home support, being able to probably self-direct your services, and be able to hire a family member, or someone that you know.

On the day service side, traditionally, there have been either sheltered employment programs or day services. And this really is changing the options that are being offered in a state, so people being able to work in a typical workplace with employment supports, instead of going to a place that is only people with disabilities. So hopefully, people have seen over the last several years, as the state of New Jersey and states across the country have been implementing these changes in their life, the changes in what they're being offered.

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SEAN CUDDIHY: Episode 16 looked at disability and health equity. It was hosted by Dr. Carrie Coffield, who is an Assistant Professor at Robert Wood Johnson Medical School, Director of Pre-service Training at The Boggs Center, and the Training Director of NJLEND.

Dr. Coffield, along with Dr. Kara Ayers, who is the Associate Director of the University of Cincinnati Center for Excellence in Developmental Disabilities at Cincinnati Children's Hospital and Medical Center, discuss what is ableism and how to work to identify it. Let's take a listen.

CARRIE COFFIELD: Ableism is really a very broad -ism. What do you see as things that we can all do to help eliminate this type of bias?

KARA AYERS: Yeah. I think the first step is starting to recognize it and identify it. And sometimes, that takes some lowering of our defenses.

So when I teach my students about ableism, I use an image of a factory smokestack and smog coming out. Because smog up close is really easy to see and not something that we'd want to breathe. But far away, it's harder to know that we're breathing it, but still bad for us.

And that's kind of the way ableism is, in that it's all around us in our messaging. It's in the way that I was trained, as a psychologist, in that I was taught lists of symptoms. And then I was taught with the assumption that people would want to eliminate these symptoms.

And that is a really overly-simplified way of explaining somebody's lived experience, which brings us to why when we have discussions about curing disability, it can be very controversial. And views of ableism can dominate those discussions, when we assume that all or most people want a cure for their disability.

So I really think that learning to identify ableism and just be more confident to discuss it is a really important first step.

It is everywhere. It's in our doctor's offices. It is in our schools. And it's something that we can improve upon, but we can only do that if we're willing to talk about it and be honest and real about where ableism is.

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SEAN CUDDIHY: Episode 17, which is our last episode this season, celebrated the life and legacy of Judy Heumann, who's widely regarded as the mother of the disability rights movement, who passed away in March of 2023. As described on her website, Judy Heumann was a leader in the historic Section 504 sit-in of 1977 and instrumental in the development and implementation of other disability rights legislation.

This episode was hosted by Jaime Zahid and features three advocates and activists-- Steffen Klenk, who was a recent graduate of the New Jersey Leadership Education in Neurodevelopmental Disabilities program, or NJLEND, and a Partners in Policymaking graduate. Jaime was also joined by Marlene Brockington, who is an advocate who graduated from the Partners in Policymaking program in 2020. Last but certainly not least, Steve Gruzlovic, an advocate and consultant for businesses and individuals with disabilities and their families.

STEFFEN KLENK: None of us would be sitting here today if it weren't for Judy Heumann. The mark that she has left on society has really made such an impact. And I know I've used that word quite a bit, but her persistence and drive to make the disability community, really the community in general, a better place is life changing.

And now is the time where we really need to start having conversations. People need to join in the fight for disability rights across the board, no matter what it is, whether that is joining a group, whether it is talking to individuals, politicians, whoever it might be. We need to have a voice. We need to be able to speak up. We need more people like Judy Heumann in our society.



STEVE GRUZLOVIC: To follow up on Steffen's point, I think another great part of Judy Heumann's legacy was that she was a connector of all people.

STEFFEN KLENK: Yes.

STEVE GRUZLOVIC: And I think part of the problem that we have, in this state especially, is a lot of the services and a lot of the organizations that deal with disability and disability-related services are so siloed. And they really don't get together to promote positive action amongst everyone.

And I think part of her movement and part of the movie and part of her book and her international exposure-- she was really a connector that connected all those people and organizations together to really promote positive change. And I think if we want to do that, we have to replicate that on a much, much larger scale, to serve and promote the most impact possible.

MARLENE BROCKINGTON: I would say to keep the legacy going is to know all you can know. Knowledge is power. It's important that people with disabilities, people in general, know their rights. There is a lack of people knowing their rights.

In order to fight for something, you have to know about it. So that's important. Judy was known for being feisty and fighting for what she wanted and helping other people do the same. So stay feisty.

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SEAN CUDDIHY: 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](http://theboggscenter.podbean.com).

We hope you've enjoyed listening to Season 2 as much as we've enjoyed making it. BoggsCast will be taking a break for the summer and we'll be back with new episodes in the fall.

If you haven't, we hope you'll use this time to check out the past two seasons 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 3.

To learn more about the Boggs Center, visit our website at [boggscenter.rwjms.rutgers.edu](http://boggscenter.rwjms.rutgers.edu) and follow us on Facebook at [TheBoggsCenteronDevelopmentalDisabilities](https://www.facebook.com/TheBoggsCenteronDevelopmentalDisabilities).