

BoggsCast Episode 12: Katherine McLaughlin

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BETHANY CHASE: 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 and Neurodevelopmental Disabilities program. I'm Bethany Chase, Training and Consultation Specialist at The Boggs Center on Developmental Disabilities. In this episode, we'll be discussing sexuality and developmental disabilities with Katherine McLaughlin.

Katherine McLaughlin has a Master's in Education and is a Certified Sexuality Educator under the American Association of Sexuality Educators, Counselors, and Therapists. She is also the Founder, CEO, and Lead Trainer for Elevatus Training. As a national expert on sexuality and IDD, she trains professionals, parents, and individuals with disabilities to become sexual self-advocates and peer sexuality educators. She has spent her 25-plus year career committed to elevating the status of all people, which is why the name of her growing company is Elevatus Training.

Katherine, thank you so much for being with us today.

KATHERINE MCLAUGHLIN: Oh, I'm happy to be here.

BETHANY CHASE: So why don't we first just get started by having you tell us the story of your professional history. How did sexuality and developmental disabilities become your primary focus?

KATHERINE MCLAUGHLIN: Yeah, sure. Well, I really started my work with Planned Parenthood of Northern New England. And I was doing-- I was working in the health center and then presenting workshops on sexuality, and that was in my early 20s. And right around the beginning of that career, I experienced a spinal cord injury and started using a wheelchair.

So before, I was able-bodied and walking around in the world. And then all of a sudden, I was this wheelchair user. And I started to realize that people were treating me very differently based on that change in my life. And so I just sort of became more interested in just disability awareness and some of the beliefs people have about people with disabilities just in general.

And kind of at that same time, special educators and developmental disability agencies were reaching out to me for help addressing sexuality. So it kind of all came together. And I think, also, in particular, with

developmental disability, there's a little more of an openness because there are some issues that kind of come up a lot around this, and so people are really looking for help, which is nice. But it's also just kind of in this idea of as we are as a culture much more focused on problems versus being more positive about sexuality and healthy relationships. So I think because of those reasons, this topic really came to be my specialty.

BETHANY CHASE: Why do you think in general this topic is so hard, thinking about sexuality, and specifically with intellectual and developmental disabilities? Why is this topic so hard, particularly for people without disabilities, to talk about?

KATHERINE MCLAUGHLIN: Mm-hmm. Yeah. Yeah, I mean, I think there's lots of reasons. I think as a culture in general, we're not very good at talking about it, period, whether it's a person with a disability or not. I think there's that.

And then I think for a lot of people, those myths about people with disabilities around that they're not interested in being in a sexual relationship or they're oversexed, that's all they can think about, all these myths, if we talk about it, they'll do it, we'll give them ideas. So I think in general, people without disabilities might feel those same things, like, ooh. And sort of treating them like children, I think, is a piece of it. So if you see someone as a child, then you're not going to talk about certain things.

BETHANY CHASE: Absolutely. Yeah, if you never say anything, they'll never know, right?

KATHERINE MCLAUGHLIN: Right, exactly. They won't ever have any of their own ideas. Yeah.

BETHANY CHASE: No, no.

KATHERINE MCLAUGHLIN: Right. So I think that's part of it is viewing people with disabilities as children and all these myths. But I think also, there isn't a lot of representation in our culture, although that's changing now, seeing people as sexual beings or in relationships. We now have Love on the Spectrum and different kinds of videos and things that are really bringing this up more, and people are seeing it more. But I think before this time period, there were just no images of people with disabilities.

BETHANY CHASE: Yeah, not even examples or your day-to-day life something to stop and make you question, oh, I hadn't thought about that before, right?

KATHERINE MCLAUGHLIN: Yeah, exactly.

BETHANY CHASE: People have more access to it. Yeah.

KATHERINE MCLAUGHLIN: Yeah, yeah. And I think-- I remember someone who used a wheelchair talking about she happened to have a partner in a wheelchair and they would go out and people thought it was a field trip from the institution, not that they were together, that they were a couple.

So I think the more we see people with disabilities as just like everyone else, and some people are interested in sexual relationships, some aren't, just like everybody else. And I think the more we do that, I think a lot of these myths will go away. And they really started-- they have in a lot of ways, too.

BETHANY CHASE: I think also some folks haven't been able to uncouple perhaps that someone has some challenges around social emotional development, where they do need support, or if they have an intellectual disability, where they do need support, they have a difficult time uncoupling that from the idea that someone's sexuality is delayed or that it is somehow that their hormones are somehow affected, right? Can you help just kind of dispel that or explain that a little bit, if some of our listeners are scratching their heads?

KATHERINE MCLAUGHLIN: Yeah, I mean, I think one of the things that-- one of the messages I like to get out there is that we want to think of people based on their biological age and not how we see them, like you're saying, as having some kind of weakness and therefore younger in some way.

BETHANY CHASE: Right.

KATHERINE MCLAUGHLIN: To really think about every 18-year-old, whether they have an intellectual developmental disability or not, need the same information. How we teach might be a little bit different, but not what we're teaching. So I think that kind of helps people because oftentimes they'll think more about their ability as the age we want to teach to versus their biological age.

BETHANY CHASE: Yeah. You hear people say things like, oh, you don't understand, she's got the emotional capacity of a seven-year-old. Besides the fact that that's very ableist language in and of itself, it's also just scientifically irrelevant, right?

KATHERINE MCLAUGHLIN: Right, exactly.

BETHANY CHASE: Like, to someone's sexual development.

KATHERINE MCLAUGHLIN: Right, right, right. Yeah, so if we think of people as seven-year-olds, then yeah, we're not going to talk about puberty with them. And so we have to get away from that idea and really look at biology, or sometimes people call it chronological age.

BETHANY CHASE: When I think about sexuality education, I think that besides just the explanation of 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, these 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, 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 like, oh, we could think about this in a positive way, and so 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, I mean, 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 talking about-- 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, 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.

So I think that, that's a piece, just sort of an example of not having the tools to protect yourself or report something. But I think, too, there's, as you know, high rates of sexual abuse, high rates of perpetrating abuse on another, higher rates of sex crimes, unplanned pregnancy, sexually transmitted infections among this population, and a lot of loneliness, too, and I think mental health challenges when you're feeling really isolated.

So I think there's so much around sexuality and relationship education that's really about fitting in and being part of the society. And if you don't understand social norms and rules, then people don't want to be around you because they feel uncomfortable, and then therefore they pull away from you. And so there's so much that you lose when you don't have this kind of education. And then there's all the negative consequences, as well.

BETHANY CHASE: Yeah, and that becomes like a snowball effect, right? If you are behaving in such a way that you're making other people uncomfortable and people pull away, then you have less opportunity to continue to work on your people skills, which makes more people pull away, which gives you less opportunity, right?

KATHERINE MCLAUGHLIN: Exactly.

BETHANY CHASE: And it's just-- it just continues and continues. And we talk a lot with job coaches and just general supports that I always joke, like, if you say, well, they're not ready now, they're not able to be in community now because of their behavior, then I guess they're not ready. We're going to pull them out of community, out of relationships.

But that's like saying like well we should probably have them go to France to work on their Spanish, right? It makes no sense. But if people are making missteps around more social, sexual issues, then the stakes are higher, right? The consequences are higher.

KATHERINE MCLAUGHLIN: Absolutely.

BETHANY CHASE: Some of these consequences, of course, are very serious. And you mentioned just now rates of sexual assaults, sexual abuse. Can you talk a little bit about that?

KATHERINE MCLAUGHLIN: Yeah. You may have heard the National Public Radio series that came out probably three years ago at this point, maybe four, and they talked about the rates of sexual abuse. And from that project, they said that people with intellectual developmental disabilities were 7 times more likely to be abused than someone without. And if we look at females with intellectual developmental disabilities, they're 12 times more likely to be abused, so really high rates.

And I think you also see that people who have more severe disabilities are definitely more vulnerable. They're depending on people for care. Maybe they are nonspeaking and don't have knowledge around what's a healthy relationship versus a not-- an abusive relationship.

BETHANY CHASE: So you mentioned the rates of sexual assault, sexual abuse. And then thinking about the fact that so many individuals lack access to education, I always think how incredibly unfair that is on so many levels, because the lack of education just only exacerbates the problem. And it's not saying that this is the victim's responsibility to stop abuse from happening, but if someone doesn't have a context for what's normal behavior, what is normal private behavior, what's normal public behavior, people who are taking care of my personal care needs, what do I set-- I mean, those kinds of complicated interactions between people with disabilities and a caregiver are so complex.

And then we're asking folks who already sometimes struggle with social cues to just suddenly know what to do and what to say. Like, it seems so unfair. Do you ever hear feedback about well, that's blaming-- people just shouldn't be doing that, let's not blame the people, let's not blame the individuals?

KATHERINE MCLAUGHLIN: Right. Yeah, I mean, I always start off with people with disabilities might be more vulnerable to abuse, but it doesn't mean that they're more at fault, and that the reason abuse happens is because someone is abusing. But what can we do, knowing that people might be more at risk?

We know the statistics. We know lack of sexuality education is a risk factor, but also just this idea of teaching someone to comply, that we want people with intellectual developmental disabilities to comply and do what they're supposed to do and please others. And that just-- if you talk about being unfair, that really sets people up. So how do we teach non-compliance? How do we teach it's your body, and you get to decide what's right for you? And it takes weeks and weeks for me when I'm working with a group of people and teaching for them to actually say no to something that I'm telling them they need to do.

So we use this name tag game that was developed by a Planned Parenthood in California. And each week you put your name tag on the right or the left, and you get to decide. It's your body. And then a week or two in, I might say, I'm the teacher. I think you need to move it to the other side. And they immediately start to move it.

And so-- and I say, wait, hold on. Who gets to decide? And they'll say things like yeah, but we're always told we're supposed to listen to the teacher. I said, yes, you are. You're right. When you're at school and it's time to go to the cafeteria or you have to bring out your assignment, yes. But no one can touch your body. No one can touch your body unless you want them to.

So I think that little bit of difference, and also just in the classes I'll say, and in this class, you get to decide whether you want to be here and whether you want to leave, and where you want to put your name tag.

And it's so exciting when they say no, finally, but it takes a long time. And if we started much younger with young people with disabilities and taught them about bodily autonomy, we wouldn't have adults struggling with saying no to an authority. So we just-- we don't do any of it.

And a lot of this, too, is kind of general society things, as well. I mean, you may have heard of like how we ask young kids to hug so-and-so goodbye, and not even with a disability. And it feels uncomfortable, but they're not allowed to. And they're not allowed to not do what they're told. And so we're teaching young kids in general, your feelings don't matter. You have to take care of Aunt Bethany, you know? And I think-- so that happens just in general. And then for children with disabilities, there's a lot-- there's even less permission. And as we view them as young children, even when they're not, then we just keep perpetuating that sort of lack of bodily autonomy or that right to bodily autonomy.

BETHANY CHASE: Yeah, absolutely. And we use words like noncompliant, right? Or if someone immediately removes themselves from a situation, we characterize that as elopement, right? We have all these systems terms to describe people who aren't doing what we want them to do, and then somehow magically expect them to know that they have a right to refuse unwanted touch. It's completely unfair. Yeah.

And I also just want to echo what you said about the people just complying, that we're teaching people to comply with directives and not asking permission. And I think that's something across the board when we speak with folks that work in day programs and employment providers and residential and just asking them how many times have you specifically asked the person you're supporting for permission to touch them, it doesn't happen very often, right? We're in a rush, we're like, oh, you need your help with the coat. Let's put your coat on, right? You start grabbing.

And you're like, oh, but we got to get out. We got places to go. And folks don't get the sense that they're allowed to refuse physical touch, because we haven't taught them how and we certainly don't model it. Yeah.

KATHERINE MCLAUGHLIN: Yeah, and that's the piece, if we could do that, starting younger. But we want people to act a certain way and behave a certain way, and we don't want people to be empowered.

BETHANY CHASE: Right. Right, that's going to make us late.

KATHERINE MCLAUGHLIN: Exactly.

BETHANY CHASE: Yeah, yeah.

KATHERINE MCLAUGHLIN: Yes.

BETHANY CHASE: The other thing that what you were just saying that just touched off for me thinking about some of the work that we do at Boggs Center, I teach a course for job coaches on understanding how sexual harassment policies affect individuals at their workplace, and both that individuals can be perpetrators or victims of sexual harassment at the workplace. So we talk through these strategies of how to be more proactive and, again, how to assist individuals to know what's normal work behavior.

And I feel like a lot of what you're saying, whether it's teaching kids their proper anatomy, teaching children body autonomy, self-advocacy skills, it's what we see in society, but with higher stakes and more a very vulnerable population. But just so often, as you mentioned, folks with disabilities have higher rates of sexual abuse, sexual assault, sexual harassment. And thinking to the recent MeToo movement of how many women felt uncomfortable at work and nobody knows what to do or what to say, and we have individual with disabilities in the same exact positions with even less resources and less information to advocate for themselves.

KATHERINE MCLAUGHLIN: Yeah, absolutely. I've done some work with Project SEARCH, too. And they wanted a curriculum written because they felt like people were losing their jobs, not because they couldn't do the job, but because of the relationships.

So when we're talking about being at a worksite, sometimes it's not just-- it's not Project SEARCH. They're doing all these great trainings and helping people become great employees. It's the place that the person is working and these views of people with disabilities where they hug the person every morning...

BETHANY CHASE: Yes, yes, yes.

KATHERINE MCLAUGHLIN: And just really thinking, just that idea of do you do this with every employee every morning? Nope. That's right, then you don't do it with this person, too.

So there's, yeah, just being thought of as a child all the time. And so we can do things like we do with children that just-- it just doesn't make sense. And it sets them up.

BETHANY CHASE: With all this work, I feel like sometimes it's easy to get a little outraged, right, and be like, why is everybody hugging? Haven't they ever met some with a disability before? But it's always, a reminder that as a society, we're just still learning. And for a lot of people, especially in employment settings, this might be the first time they've ever had a legitimate work relationship with someone with a disability before and so they're doing what society is showing them they're supposed to do, which is going in for the hug.

But I mean, you ask people like do you go and hug and high five your coworkers every morning? And then they start to laugh. And I'm like, because it's ridiculous.

KATHERINE MCLAUGHLIN: Exactly. Right, right.

BETHANY CHASE: For someone if they do struggle, especially if they struggle with understanding the social expectations of the workplace and everyone's coming in and touching them all the time and hugging them all the time, and it is so unfair. It's sending such mixed messages, and it puts people's jobs at risk.

And again, do they feel like they can say, please don't touch me to their new boss? I mean, there's a lot of problematic things that are happening at work. And the stakes are particularly high when you're talking about someone's job and their livelihood.

KATHERINE MCLAUGHLIN: Absolutely.

BETHANY CHASE: So I once heard someone say that an individual that they were supporting in their day program couldn't possibly be transgender, and that this individual was wearing clothes of the quote, "opposite sex" because this was attention seeking behavior, and so they were reaching out to us for an appropriate behavior plan. So I had to breathe deeply, right? But can you please talk about issues around sexual identity and gender identity in folks with disabilities?

KATHERINE MCLAUGHLIN: Yeah, sure. Well, I think there's this myth there, as well, that if a person with a disability is sexual, then they're heterosexual, and that they're cisgender, meaning their gender identity matches the gender they're assigned at birth, and that there's a variety of gender identities and sexual orientations in everyone.

So yeah, I mean I think-- I do some work with a woman in Massachusetts who's a trans woman with intellectual developmental disabilities. She does some of our trainings for us. And you know, I think it's-- again, it's kind of that treating like children. How would they know that they're transgender?

Maybe it's true. And what's important is to believe people, believe them when they say they're transgender and believe them when they say somebody touching their vulva, and believe-- like, there's this-- we just don't believe them. We don't see them as credible humans. And so I just think you have to believe. It doesn't even matter if it's true, you know? I mean, just go with it and then it'll unfold and things

will get sorted out. So I think there are many people with intellectual developmental disabilities that are LGBTQ. And that's a fact.

BETHANY CHASE: Yeah. I like that use of the word, credible. It's like we just don't think that people with disabilities are credible narrators of their own truth, right? Right, we just don't-- yeah. Yeah, it's like how could they possibly know what that is or what that means, or--

KATHERINE MCLAUGHLIN: Right.

BETHANY CHASE: Yeah, yeah.

KATHERINE MCLAUGHLIN: Yeah, and I get that, sort of on some level. Like, it's kind of, wow, it's a pretty big deal, right? And I know when I taught a group about pronouns and what are the different pronouns, I had a brief moment where I thought, I don't know, is this too abstract? And I just sort of taught what a pronoun was and then they went around and said what their pronouns were and totally got it, you know?

So I get that you can think that, but just, I think, we need to stop thinking that, right? Yeah, and right, just start believing and going forward.

BETHANY CHASE: Yeah. So the last big topic that I wanted to chat about with you was around parents. I feel like a lot of professionals are interested and feel ready to start talking about these topics and teaching classes and getting certified. The one question that I think is most terrifying to a lot of these professionals is how do you manage the parent anxiety, the parent concerns, sometimes the parent outright refusal. Talk to us about working with parents.

KATHERINE MCLAUGHLIN: Yeah. Well, I think first-- you know, when I've done some trainings and I've had staff people frustrated, maybe, frustrated with parents and you start to feel a little bit of an adversarial relationship. So I ended up doing this, a fishbowl where I had the parents in the middle talking to each other and then staff listening.

And I think that's important, just to hear that perspective. And I remember someone saying, the parent in this fishbowl saying, every time I interview someone who's going to be a personal care attendant for my son, I think, are you the person that's going to abuse my child? And so living with that, right, living with that.

Parents have also said, parents of children with very severe disabilities feel like it's not if my child will be abused, but when will my child be abused. So living life like that is-- I feel like we need to be empathetic.

BETHANY CHASE: Absolutely, yeah. To have that on your mind every time you interview a staff member, that's—

KATHERINE MCLAUGHLIN: Frightening, right? So there's a lot of fear, and I think a lot of empathy is very helpful.

And then I also try to explore with parents what worries them about certain things, what worries you about your child learning about this or what worries you about your child being in a relationship, because that helps me understand where it's coming from, too. And is it they're worried that they'll get in trouble because they'll do some sort of behavior or they will never leave their room because they've discovered their own body? What is the worry, so that I can be reassuring?

So I think that just sort of working on that, but also-- and many parents talk about when they heard their child had a disability, they felt like they had to do some grieving, and that there are different points where they have to do some grieving. And this is one of them, as well. And many parents with kids without disabilities feel grieving when their child grows up. And so I think just being sensitive and kind about their perspective and their position, and so I think that helps.

And then sometimes-- and I don't like to focus on sexual abuse as the main message around sexuality, but it does speak to parents, that sexuality education is sexual abuse prevention, and that there's these myths that parents have, that sexuality education means you're going to teach my kid to have sex and we're going to give them all these ideas and then they're going to have sex with everyone. And that's just not the case.

So I think that's a piece of it, too, is just making that connection to sexuality education as being protective, having the language to say when something happens, having the bodily autonomy to speak up when someone wants to touch you and you don't want it. So I think that making that connection for parents often is helpful.

BETHANY CHASE: Yeah, so it's like using safety to kind of get them in the conversation and get them in the door. And then when they realize that it's going to give them a lot of help rather than cause harm, then the conversation continues. Yeah, that makes sense, just to invite them in with conversations around safety first.

KATHERINE MCLAUGHLIN: Yeah, yeah. And it's not-- I don't feel like it's manipulating or being tricky. It's speaking what they want to know about. That's number one on their list. So let's talk about how sexuality education helps people be safer.

BETHANY CHASE: Right. And I think it's-- I really appreciate what you said, too, about the grieving, that milestones often kick up some stuff for all of us, that big milestones, and linking that. The young adult transition's difficult for the whole family. And that's a really interesting perspective, that the sexual development is another thing that can really kind of kick that stuff up. So it's good to be empathetic and compassionate.

KATHERINE MCLAUGHLIN: Yeah. Yes, absolutely.

BETHANY CHASE: My last question for you is, what have you learned from the self-advocates that you teach with?

KATHERINE MCLAUGHLIN: Well, I know when I first started working with self-advocates and I said, oh, I'm going to create this curriculum. And they said, hold on, nothing about us without us, excuse me, which was wonderful, right? Like, oh wait. I don't—

BETHANY CHASE: Like, I knew that, right?

KATHERINE MCLAUGHLIN: So you know, nothing about us without us. I think many of them talk about wanting to be seen as human and having the same needs and desires, and all these, but also really wanting to be able to make mistakes, as well. And they're often saying, let me make mistakes to their parents, to staff. Like, that's how I learn and grow and become an adult in some ways, too. So I think that's a lot of what I've learned.

And then I've also learned not only did they say nothing about us without us, but they have a unique perspective, too. And so they reviewed all the lessons. And I just remember I was using the term sexual behaviors, and they said we hate the word behavior.

BETHANY CHASE: Oh, yeah. Right, of course.

KATHERINE MCLAUGHLIN: Inappropriate behavior, right, those words. So we changed it to sexual acts. It didn't have those negative feelings around it. So I think they have that unique perspective.

And then they also said, oh yeah, we want to be one of the teachers of the curriculum, as well. And so that was a really big aha moment for me, that I had never really thought of them as part of the solution or being the leader in this, because I was viewing them differently. So that was a really good-- I've learned a lot from them around right, yes, you're adults.

BETHANY CHASE: Yeah. Yes.

KATHERINE MCLAUGHLIN: You want to be in charge you want to lead this movement. And so the curriculum was designed to be team taught.

And as I work with more and more self-advocates, training them to be sexuality educators, I'm taking a much more of a back seat. It used to be more sort of co-training, and now I'm like, this is yours and I'm back here and I can-- if you need me for anything kind of thing. And so that's been great.

BETHANY CHASE: Absolutely. Yeah. It's a good reminder that those of us in the field who think we've got it all figured out, every now and then it's a reminder of like, wait, nope, I'm doing the thing, too. Thank you for the call out.

KATHERINE MCLAUGHLIN: Yes, exactly.

BETHANY CHASE: Right, yeah. It's a great reminder for all of us that we always have to stay aware, no matter how much we think we're on the ball.

KATHERINE MCLAUGHLIN: Right, right.

BETHANY CHASE: Well, thank you so much for your time. I know that this is a very hot topic, and it's something that a lot of folks are always looking for more information on, so we really appreciate you being with us today.

KATHERINE MCLAUGHLIN: Thank you so much. I really enjoyed it.

BETHANY CHASE: Thanks for listening to this episode of BoggsCast, a podcast by The Boggs Center on Developmental Disabilities. A full transcript of this episode can be found at theboggscenter.podbean.com. Be sure to subscribe to this podcast on your favorite streaming service to stay up to date with the newest episodes. To learn more about The Boggs Center, visit our website at boggscenter.rwjms.rutgers.edu and follow us on Facebook at [TheBoggsCenteronDevelopmentalDisabilities](https://www.facebook.com/TheBoggsCenteronDevelopmentalDisabilities).