

BoggsCast Episode 5: Emily Shea Tanis

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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, a Training and Consultation Specialist at The Boggs Center. I'm joined by my colleague, Steve Gruzlovic, advocate and consultant. In this episode, we'll be discussing technology for community living with Emily Shea Tanis, PhD.

Dr. Tanis is the Principal Investigator for the State of the States in Intellectual and Developmental Disabilities longitudinal data project, which investigates the detriments of public spending for intellectual and developmental disability services across the United States at the University of Kansas Lifespan Institute.

She is the past Director at the Coleman Institute for Cognitive Disabilities. She is nationally recognized for her expertise in cognitive accessibility, inclusive research, and advancing the rights of people with cognitive disabilities to technology and information access. Welcome, Dr. Tanis and Steve.

I'm so glad that you're able to join us for this conversation today, Dr. Tanis, one that I hope is being had across the country and actually across the globe. I think that a really great place to start this conversation would be in establishing what brought us all here. I think, oftentimes, that personal connection is how any of us arrive at our careers and do it well. So, Dr. Tanis--

EMILY SHEA TANIS: Sure. Well, thanks for having me back. It's a pleasure to be with Boggs Center again, and be able to share some information, and speak with both of you today. Well, what brought me to the field?

Well, like many, I'm a family member of an individual with a traumatic brain injury. And that has colored my perspective on the world we live in and how we interact in that world. And so my brother, Coley, who is six years older than I am-- lives five blocks from me-- has definitely influenced my perspective.

And, I think, not only my perspective but my vision for what I hope for others, the ability to have that self direction. My background is in self-determination, and family professional partnerships, and special education.

And so, obviously, that self-determination, that knowledge of being able to give my brother the opportunities that this environment and our world doesn't provide him, has really been the primary focus of what I do in my work, making sure that he, and his friends, and others have those opportunities and that the environments we create aren't ones that are more restrictive for them.

JAIME ZAHID: Thank you for sharing that. Steve, we don't want to forget about making sure that you share your personal connection. What brought you here?

STEVE GRUZLOVIC: So I'm an individual and advocate with a disability. I have cerebral palsy. And I use a wheelchair full-time. I am an advocate for individuals with disabilities and I help families. I serve on councils. And I'm board president for my local independent living center. So my whole goal is to make sure that individuals with disabilities have a more fulfilling and most independent life.

JAIME ZAHID: Thanks for sharing, Steve. That's actually how Steve and I met at the-- actually, it's still both of our local, independent living center.

EMILY SHEA TANIS: Oh, nice. That's great.

JAIME ZAHID: So there's so many things that we can talk about. Of course, we've got limited time. Steve, I think you had prepared one of the first questions we wanted to ask Dr. Tanis and go over.

STEVE GRUZLOVIC: How has COVID impacted assistive technology? What lessons did we learn? And how do you think these lessons could shape the landscape moving forward?

EMILY SHEA TANIS: Yeah, that's a big question and has multiple vectors to look at. I think, through COVID, we really realized the penetration and reliance on information and communication technologies. You know, it accelerated what was digital transformation that had already begun. But it also exacerbated what were those digital technology barriers and the digital divide or the technology divide. It made it really tangible.

When you look at even just telemedicine and how it grew alone over 4000% in April of 2020. Having access to just the information about COVID-- knowing prevention, knowing treatment, knowing local statistics as to whether you're going to have a mask mandate-- these were all things that much was communicated through information and communication technologies to people.

For those with disabilities-- with intellectual and developmental disabilities, who may not have had access-- they were left in the dark. So it really became this tangible and even life-threatening recognition that the lack of access really can impact not only your life, your health, your well-being and

communication with others.

We learned some really hard lessons, I think, through COVID. I think we learned that we have not built in the skills and knowledge to allow folks to interact with technology. So for example, when we saw folks who were really launching e-commerce, doing shopping online to stay safe, to stay at home, those were not skills we had built around or supported people with intellectual and developmental disabilities to have. We hadn't taught digital communications, things like using Zoom. We hadn't taught the accessibility features or nor were they built-in early on because we hadn't been at the conversation. We hadn't been at that table to ensure that the technologies were built inclusively.

So I think we learned a lot. I think we also learned that our field is vulnerable and ready for disruption. I think technology is one of the tools that we can use in that disruption.

So I think if we've learned anything through the pandemic, it's that we've got to reimagine our services and supports and how people use technologies that drive our society. So I think there's a lot of lessons learned.

JAIME ZAHID: Absolutely. In your response, one of the first things we're talking about was how access to technology became a barrier for a lot of people with disabilities during the peak of COVID. And I actually-- oh, I forgot to cover my own personal connection. I have two siblings with disabilities. And, of course, have worked in the field my professional life.

And I saw personally and professionally people with disabilities who had smartphones, who had laptops or tablets but maybe didn't know how to utilize them to access the proper information, that had no idea about, let's say, mask mandates, that had no idea about travel restrictions.

And you've used the phrase cognitive accessibility. And in past-- actually, close to two years-- we've had a lot of talk about equity, diversity, and inclusion. And something that I think that has sort of been brought to the forefront is that disability fits into that conversation.

And often I've been in conversations speaking about accessibility where people will assume that I'm talking about barrier free entrances or ramps. Can you talk a little bit about cognitive accessibility and how that plays into people with disabilities being able to successfully use technology?

EMILY SHEA TANIS: Sure thing. So we've been working-- the Coleman Institute and a lot of the work we've done over the past decade has really been on looking at some of these features of accessibility. You look at screen readers as text to speech, speech to text, those as features for sensory disabilities.

And many of those have transitioned into mainstream. Well, cognitive accessibility features are less well-known simply because the heterogeneity or the diversity of the folks that we work with, and love, and are part of our community. The challenge is that there's no one item, right?

There's no one thing that works for everybody, which makes it difficult for technology developers to say, "OK, you know, I just want this list. If you give me these features, it's going to be accessible for people who are blind and low vision." Or "If I just check these list things off, it's going to work for those deaf and hard of hearing."

Well, for cognitive disability, there is no checklist. We are so diversified that there has to be a menu option that can be customized. And so we're starting to figure out what those menu items look like. The W3C, or the World Wide Web Consortium, COGA is the acronym.

And I'm not going to know the name of the COGA, cognitive and learning disabilities group, that really put forth some strategies or recommendations for just web accessibility, things like no timing out on web pages.

So that's a cognitive feature that helps with memory, that helps with processing, that helps with cognitive functioning. Things like linear or navigation being similar on every page-- that's a cognitive association feature. So we're starting to figure out what those features are, but we need to know more.

We need to have more people with cognitive disabilities talking about things that make the technologies, the solutions that they use-- and you'll hear me talk a lot about technology solutions versus assistive technologies or other terms-- we need people at the table because there is such a diversity of things that work.

But until we have these conversations with tech developers or have people with disabilities who are the tech developers, we are not going to get to the point where we have a diversified number of things that use cognitive access to engage in technologies. You'll notice we are starting to see them on your iPhones, on your smartphones, on your technologies.

You're starting to see an area under accessibility that says cognitive. And those generally focus on memory, representation of materials, et cetera. But we need more. We, frankly, need more and we need them more in everything that you see. So changing those environments to allow for people with multiple perspectives to come and engage. So cognitive accessibility is huge.

And I have to say, I am so excited, after all the time we have spent with big, large tech companies and tech innovators, that they are now seeing it. They see it. They just don't know how, frankly. They need the people. They need the workers who have cognitive disabilities to work with them and work for them to be able to guide some of this instruction.

JAIME ZAHID: Excellent. Sounds like a second career for Steve.

EMILY SHEA TANIS: Yeah.

JAIME ZAHID: And actually you just gave me something to check out on my phone. I just did an update on my phone recently. It has all these new features. I hope our listeners will check that out as well. And speaking of accessibility of technology, Steve, I know you were sharing with Shea and I earlier about using different platforms and how some of the accessibility features that are implemented don't always work. What are your thoughts on that?

STEVE GRUZLOVIC: So I'd like to say that before the pandemic, right, 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 features.

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 complete 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 say 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 design process. We're starting to see what is inclusive research design where folks with disabilities come at the beginning of the solution, problem identification, go throughout the whole process, even to dissemination. And we just have to keep hammering that approach in until people are-- 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.

JAIME ZAHID: Absolutely. I talk about that often when I talk about community inclusion. It's not just about having people in the community. It's part of the community that makes it truly effective for everybody, not just for the person with a disability.

So we had started to sort of talk about this concept-- and I'm hoping you can talk a little bit more about it-- the digital divide. We had touched on how people might have access to the physical technology and not know how to utilize it. So what are some ways that you think, Shea, we can work towards eliminating that digital divide?

EMILY SHEA TANIS: Sure. And this is just, as I mentioned, gotten exacerbated or grown since COVID. I mean, we're seeing more and more-- because of the reliance on technology-- we're seeing more of the

challenges. And it's technology, overall. It's not just digital. It's everything from digital to hardware to actually what's going on in our homes, smart homes.

So you have to look at this multi-pronged and diversified approach, I think, to eliminate what is really a systemic, societal, and culturally embedded problem. We have not empowered people with disabilities to use technology.

Now we're rolling back. We're running backwards trying to say, "Oh, no. Now we need technology. Now we need people to have the skill sets." When we haven't started from early intervention and early years to have that expectation that technology is part of their life.

So I think we need a couple of things. And it needs to be a bigger systems perspective. It needs to be a cultural change issue. We need system change efforts, like Technology First, to really be supported and reinforced across states, across parties, to be able to know that systems change is needed and to use a model that is systems change oriented.

So that means it has multiple components built in. I think we also need to focus on person-directed, not just person-centered but person-directed approaches to technology. Meaning that it's not just an assessment that is done, that there's a new method for identifying what technology is.

I mean, I always kind of joke. I do it cheekily, but it's real. I don't know how many people without disabilities have to go through an evaluation to have a phone. I don't know how many people without disabilities have to go through an assessment and an evaluation to get a computer.

And there are reasons. It's funding and you have to go through it. But the reality is many people are not doing that. And we need to have person-directed approaches to identify things not just as to mitigate the impairment, but to be part of their environment, to be part of their whole practices. A computer could do a whole bunch of things besides just mediate an impairment.

And I know a lot of people are not just using a computer or not just using a phone to mediate their impairments. They're using it for joy. They're using it for pleasure. They're using it for communication. But yet our policies and procedures don't demonstrate that. And so we need to do that modernization and harmonization that happens through systems change.

So we need to take that person-directed approach. I think we also need to reinvent what are our professions in this field, that align with what are contemporary skills and technology utilization and break that dependency model of care.

So using the technology-- so people can use it to engage in their environment-- but using professionals to not only support the technology utilization, try different things, but be innovative in operations and engaging. So we have DSPs who can provide opportunities. They should be opportunity makers.

And they should be able to get compensated appropriately for doing that work rather than just this caretaking model. So I think we need to reinvent our professions to deal with that. I think we absolutely need to look at investing and advancing what is technology-- not only technology literacy, so how you use the technology, but technology agility and resilience. And those are different things.

And it needs to be not only for just the user-- but it should be focused there-- but also for professionals, family members, and caretakers, and caregivers. That holistic approach to using technology, to using what everyone else is using every day, and just making sure people have access to it needs to happen, but also breaking that cycle of reliance, breaking that cycle of needing others by empowering people through education on how to use their own technologies.

I mean the big joke I always say is, how many of us have called our IT people to have their first response be, did you turn it on and off? That's the big joke.

STEVE GRUZLOVIC: Guilty! Guilty!

EMILY SHEA TANIS: Yeah, exactly. Their first response is, well, that's great you're having a problem. But did you first try to turn it on and off?

Well, we're kind of now getting well versed in that. But we don't teach that. We don't teach people, hey, guess what? Turn it on and off first. So that they can direct their own problem solving.

And then, lastly, well, I think we need to invest in what are future technologies. We are a very reactive community in terms of our practices. I think we need to be future driven. We need to be the ones creating the tech. And we need to be looking how the technologies that are supposed to come out tomorrow-- things like automated vehicles, things like haptics-- these technologies that seem in the future but really aren't. We have to be at that conversational table to engage.

And then, finally, our field, again, has been very siloed, in my opinion. And I think we need to start to take advantage of naturally occurring situations that are in our environment, things like remote work and the gig economy.

We've been building customized employment for people. Those naturally occurring phenomena now support every principle we have been engaged in for many years. And we just need to learn how to leverage and take advantage of it.

So I think if you look at a big multi-pronged approach, and at any point you can make those changes, it's got to be holistic in addressing what is a cultural and societal issue.

STEVE GRUZLOVIC: And, I think, it's also important to point out that we're not saying, "Oh, let's get rid of the relationship with the DSP."

EMILY SHEA TANIS: No.

STEVE GRUZLOVIC: We're saying, let's let the DSP have the opportunity to use technology but also still have more time to build that personal relationship as well. I also wanted to know, what do you say to people that are concerned or nervous about adopting technologies because of safety and privacy?

JAIME ZAHID: Oh, that's a great question.

EMILY SHEA TANIS: It is. It is a fantastic question. And it's one that comes up all the time. And in fact, for some time we had a project that we were funding-- we had providers telling us that we're violating HIPAA if we let people have access to social media, OK? So there is a fear. People have fears about technology. They have fears of the unknown.

Kevin Kelly, the editor for Wired magazine, talks about that we have to become comfortable with being newbies for the rest of our lives. We have to be comfortable with the discomfort that technology changes over time.

What I talk to people about is very much getting back to the dignity of risk, the very core principle of what we have used in our field for many years, that it's not so much the desire-- and we can show through our data. It has nothing to do with the desire of people with disabilities to use technology. They want to use it. It's not they don't want to use it.

It's that there are these other barriers around them, people concerned about competency, people concerned about risk, people taking over the concern of others and denying them access because of these fears. What I believe many times are, internally, their own fears and discomfort with technology. And so how do you combat that?

You empower people with disabilities to know about the risks and the benefits of technologies. You have to be able to understand the weighing of the risks and the benefits, and just as much online as you do in your everyday activities.

We just have ignored that and used the security and privacy as the crutch for denying access rather than-- instead of saying, we're going to empower you by teaching you about what the risks are for you to make your own decision. I have yet to see a program or practice that talks to how to educate people in an accessible way about their own risks and benefits of using different types of technologies.

And in my opinion, that's where we need to be, to empower people, instead of saying we're too scared about the security and privacy. Because when you drill down deeper into what they're really scared of, oftentimes, it's a provider being scared that they're going to get in trouble or they're going to get caught without educating people on how to interact appropriately.

STEVE GRUZLOVIC: And for families, you know, as far as dignity of risk goes, you can do it in steps.

EMILY SHEA TANIS: Absolutely.

STEVE GRUZLOVIC: You can take small chunks and do it in steps. We're definitely not saying, "Oh, just go out there and go do it." No, this has to be done in a systematic, step-by-step approach to figure out what the individual can handle.

JAIME ZAHID: Absolutely. Shea, you were talking about empowering people to know the risks and the benefits. And it got me to thinking that there's so many people with disabilities that don't even know that they have the right to access particular things, not just technology but including technology. And so, I think, it even needs to start with education and empowerment around what you have the right to access.

And, Steve, you made such a great point about it doesn't need to be all or nothing. And I think that a lot of us lose sight of the fact that for most of us-- I grew up in the 80s and 90s when a lot of this technology were utilizing-- most of this technology we're utilizing today didn't exist. And so I didn't go from having nothing to suddenly having a smartphone.

I went from having nothing to having a phone where if I wanted to do the letter J to text somebody, I think I had to press the number five, three times. And so there was those incremental learning opportunities for all of us. And we need to remember that and apply that concept-- that was a great point-- apply that concept to people with disabilities as well.

Steve, did you have any other additional questions for Shea before we wrap up?

STEVE GRUZLOVIC: So what other sources can people look to as far as to learn about technology? I know, myself, I attend a trade show every year called the Abilities Expo. It's right here in Edison. But they have companies from around the world. So I get a good world view of how the world is developing, in addition to America. But are there additional solutions that people should look to learn information about what's coming out?

EMILY SHEA TANIS: Yeah. Absolutely. Because I'm a family member, the number one resource I use are other families and other peers with disabilities. So just like I would if I wanted to try a new technology, I'm going to call friends and family and say, "Hey, have you tried this? What does it look like? How does it work?"

So I think we don't take advantage, again, of some of our naturally occurring resources, those natural supports around us. We're so prescriptive about how you have to search for something. We always want a catalog, right? We always want that catalog of technology that we can say "I have a hearing impairment. Show me all the tech that works for me."

Well, the reality is we've been trying to do that for years and it doesn't work. And I'm going to tell why it doesn't work. A, the technology advances so quickly, the only way those programs work-- those catalogs really work-- are if they have the tech developers contributing to that catalog.

A lot of catalogs, there are a bunch out of there-- AbleData. One of my favorites I will say for apps is BridgingApps. They're out of Texas. But they are driven by families. They are family members, professionals, and advocates identifying the apps that work for them and just putting them online for others to view, and rate, and see.

But the other place that I go-- I don't want to skip out, certainly, in your state, which is the ATAP programs, the Assistive Technology Act programs. They are federally charged to be able to share resources, funding in particular, through training and information about technologies, assistive technologies.

And, as I've said, I have this love of assistive technology but want to look at the terminology a little bit broadly. But I do think they are an immediate resource in your own backyard. And then just using word of mouth and people around you to say what works for you, what doesn't? That has been huge.

In states where Technology First has really taken off, they have built systems where they have ambassadors. They have folks who are going around and sharing the technologies that work. We funded a program here in Colorado that was family members training direct service professionals around the technology they use. And then letting them have the time to play with it. And saying, "OK, what's your technology in your back pocket? How do you use it? And how can you apply it to others?"

So I cannot say enough about using the people around you, rather than systems, to identify things that will work.

JAIME ZAHID: Excellent. Thank you. And I can't help but just sort of recapture your thoughts about where to find out about assistive technology and what works for people. And you echoed the sentiments twice in your response about just asking other people.

I think that very often-- in this whole field of disability-- we often overthink things. We always want to resource. And we always want it documented somewhere, which is valid. But, oftentimes, just asking people with similar needs and similar experiences is probably, very often, the best source of information for people.

So, Shea, I know that your time is precious, and so we want to let you go. But before we let you go, do you have any closing remarks, thoughts, words of wisdom for the people of New Jersey and beyond. Because it's a podcast after all and who knows who's listening.

EMILY SHEA TANIS: Oh, you put me in a position to have some very wise words. And I don't know if I have them besides just coming behind the passion that we are at a really critical place in time where we

are about to create new boundaries and barriers for people if we are not paying attention, if we are not part of the conversation.

And where we had taken down those physical institutional walls, we're now creating what I believe our digital walls of exclusion by not engaging in the conversation. So as long as the deinstitutionalization movement took us, and is still really taking us, to devolve those systems, we don't want to create new ones by not being part of the conversation in technology.

And I think we are at that really dire point. I think COVID was the kind of event that demonstrated two different paths. We can go down a path where we continue to ignore the utilization of technology for people with disabilities and create new barriers, and boundaries, and environments where they cannot engage.

Or we take the alternative path and drive the discussion and have people with disabilities who are the designers and creators to have inclusive environments. So I challenge people to look at what the future can be and not wait.

JAIME ZAHID: Thank you for those closing thoughts. We really appreciate them, Shea. So I think that brings us to the end of today's conversation. I know that the three of us could probably chat for hours on this topic and many offshoot topics. I actually took a few notes of ideas for future podcasts. But we don't want to keep you from the important work that you're doing, Shea. So with that, I'm going to thank you so much for joining Steve and myself. Steve, thanks for co-hosting this podcast with me. It's been a pleasure.

STEVE GRUZLOVIC: An absolute pleasure.

JAIME ZAHID: Thank you.

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.