

THE BOGGS CENTER ON DEVELOPMENTAL DISABILITIES

New Jersey's University Center for Excellence in Developmental Disabilities Education, Research, and Service New Jersey's Leadership Education in Neurodevelopmental and Related Disabilities Program

BoggsCast Episode 14: Brian Tallant

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MELISSA CHEPLIC: Welcome to BoggsCast, where faculty and staff at The Boggs Center on Developmental Disabilities explore best practice, showcase success stories, and help listeners envision possibilities for innovation through interviews with state and national experts. Part of Rutgers Robert Wood Johnson Medical School, The Boggs Center is New Jersey's University Center for Excellence in Developmental Disabilities and Leadership Education in Neurodevelopmental Disabilities Program. I'm Melissa Cheplic, Senior Training and Consultation Specialist.

In this episode, we will be discussing supporting people with IDD who have experienced trauma. Our guest today is Brian Tallant. Brian is a Licensed Professional Counselor and Associate Director at Rocky Mountain Human Services in Denver. He is also the owner of Neurodiverse Communities, where he provides training and consultation to a variety of professional and academic organizations. Brian is a contributing member of the National Child Traumatic Stress Network, and he serves on the Board of Directors of NADD, an association for individuals with developmental disabilities and mental health needs.

We're so excited to have Brian as our guest today and share his expertise. Welcome, Brian. Thank you so much for making time for us today.

BRIAN TALLANT: Thank you, Melissa. Thanks for having me. I really appreciate being here.

MELISSA CHEPLIC: Can you talk a little bit about what drew you to this specific focus of trauma treatment and support?

BRIAN TALLANT: Yeah, absolutely. I would say that my professional career started back in the early 90s when I graduated from Illinois State University with my degree in psychology. I did an internship working as a vocational evaluator-- my first experience working with people who have disabilities. And soon after that became an applied behavior analyst. That was back in the days before there was such thing as BCBAs, but I worked for an agency in Central Illinois doing applied behavior analysis. I'd say that's the beginning of my professional career.

Although I do have to say that probably, actually my career began when I was probably about 14, 15 years old and I babysat for my neighbor who had a child with Down syndrome. I think that's where my cultural competency around this population started actually many years ago.

But I completed my master's degree in counseling at Illinois State and moved to Denver, Colorado, where I was really fortunate to work with a community mental health organization that was creating a specialized program for youth with intellectual and developmental disabilities and providing outpatient as well as day treatment. And I worked at the Aurora Mental Health Center there running that program as an administrator and a professional counselor for about 25 years before coming over to Rocky Mountain Human Services, where I started to create a center for START services program. For your listeners who are familiar with START, it is a mental health crisis prevention and intervention program for people with IDD. So that's what I'm doing today.

But, yeah, along the way I was, again, really fortunate to work with the National Child Traumatic Stress Network, specifically focusing on how we support people with IDD who have experienced trauma. And through that work with NCTSN as well as NADD, that has been an area of focus that I've been particularly interested in and have seen huge strides in the last 10, 15 years. So been excited to be a part of it.

MELISSA CHEPLIC: You touch on the experience of so many people with disabilities and also so many people who are in that support position, which is the intersectionality of trauma and mental health and crisis support services. So, we often see that people's needs intersect across those different types of support systems. And we see that also that statistics reveal higher incidence of abuse for people with disabilities, which is unfortunately not surprising to many of us who work across those fields of disability supports and mental health supports and trauma informed care.

Tell us a little bit about what you see about why people with disabilities are more vulnerable to trauma experiences.

BRIAN TALLANT: Absolutely. There's characteristics and also just life experiences that people with disabilities go through that make them vulnerable. And one obvious reason is because people with disabilities often have a higher-- they require higher level of assistance from caregivers for longer periods of time. And a lot of times for very invasive daily living functions such as toileting, or dressing, or bathing. And so that puts a high level of stress on family members, on caregivers. So that's one of the reasons that we understand youth may be not meeting developmental expectations for parents.

I right now have a two-year-old. If you ever spend a significant amount of time with a two-year-old you understand human dysregulation. Right? I know that that's developmentally appropriate and I know that it's temporary. For some of our families that are supporting people with IDD, those developmental periods, or those types of behaviors and things, can last for years and years and years, which can put-Again, it can make people with disabilities very vulnerable within their own home.

There's also other factors too, however, that not only make them vulnerable at home but also in the community because one of the other things we know is a cognitive disability can interfere with your ability to predict high risk situations. Many of us rely on — we call it our Spidey-senses — you know, that sixth sense that helps you recognize when maybe there's a dangerous situation evolving around you or developing around you. We always talk about safety being related to being aware of your surroundings.

Well, we understand that a disability sometimes can interfere with our ability to predict those high risk — or recognize – those high risk situations and even, in some cases, understand what is happening is an abusive situation. So that's one of the things that we – that's sort of a reoccurring theme when we're working with people with IDDs. We have to start from the very beginning to help support people to understand what is an abusive situation and what isn't.

And of course, one of the other vulnerabilities is the barriers to reporting. One in five instances of sexual abuse are reported in the general population. When you specifically look at people with IDD, that drops to 1 in 30 instances of sexual abuse against the person with IDD are successfully reported. So those are really – I mean, the reports of reporting for the general population are staggering. When you look at specifically people with IDD, it becomes even more alarming.

And, yeah, I think that the underreporting obviously happens because of mobility challenges. People can't get away in order to be able to physically get to a place where they can report – the restricted ability to communicate.

And then finally, one of the things we have to acknowledge and also actively work against is that people with IDD are perceived as not being credible reporters. And, again, that has to do with another reoccurring theme we'll probably talk about a lot, which is the cultural competency, not only in the mental health field but other areas too in our communities, such as criminal justice.

MELISSA CHEPLIC: One thing that we do see across our field in mental health is – whether it's assessment or treatment – so much relies on self-report. Right? – people's need to or their ability to self-report their symptoms and self-report these experiences. And that's always been a barrier for people who have intellectual and developmental disabilities. So, we tend to recognize that needs change when there's a behavior change.

Since trauma experiences are so common, what kinds of behavior changes or what are some other indicators that we should be looking for to indicate that treatment is needed, or people are really struggling and they need more support?

BRIAN TALLANT: When we start to take a look at what are the keys to recognizing when people need help, I think that it's important to understand a little bit about what does trauma symptomology look like? What do typical people who experience trauma – what do they experience? And I think it's very important that the normal responses not be attributed to a person's developmental disability or pre-existing mental illness.

I mean, that's one of the things that we have talked about in organizations like NADD for years, which is this concept of diagnostic overshadowing. And having conversations with leadership at NADD, we talked about how diagnostic overshadowing originally was defined as a phenomenon that happens in the clinical assessment. Right? That that's a clinical term. That a clinician will over-attribute this mental health symptomology to a person's disability, and we know that does happen.

But I make the argument that, actually, diagnostic overshadowing happens well before a clinical assessment. I think that parents, caregivers, educators, loved ones, support people, and people with IDD-they do the same thing. Well-intentioned people, beautiful advocates still will sometimes-- out of lack of knowledge of mental health symptomology – will over-attribute those mental health symptoms to a person's disability.

So we, first of all, have to start by addressing the diagnostic overshadowing.

So what are some of the signs of trauma that any person will experience after a traumatic event? And of course, I want to normalize this and start off by appreciating the fact that people spontaneously recover from trauma. You know what I mean? Like even without support facilitation, people will experience these symptoms and often they will fade over time. It's when those symptoms don't fade. Things like feelings of loss of control during the event – That's the number one variable for people experiencing prolonged traumatic stress is not being in control of the situation.

And after the event, often people will experience this intrusion of material from the event in their minds and their memories. This perseveration. Can't stop reliving it. Numbing. Emotional constriction. These intense efforts to control experiences that might elicit memories of the events. This dissociative splitting off of aspects of the experience. And in a lot of times, people will talk about leaving their body, which is a normal protective mechanism that happens during trauma.

But ultimately people start to experience hypervigilance, an enhanced startle response, sleep disturbance, night terrors, and then all of these other self-identity – or this shattered sense of safety, disruption of a person's self-identity. And those are the things, again, that are really, really normal. And they are normal for people with IDD and they're normal for people without IDD.

I think that these are the things we really need to focus on when we're talking about trauma and traumatic stress. And keep in mind that those trauma responses represent a significant change from a person's normal global level of functioning. So, these are changes. It's the way it is with lots of other mental health symptomology is that we understand, especially as we get to know an individual and the aspects of their disability, we don't want to confuse that with what we know is not related, which are some of these typical trauma reactions.

MELISSA CHEPLIC: So I'm just thinking about the great point you made about diagnostic overshadowing.

It's often a family member, a caretaker, a direct support professional, who sees these kinds of behavior changes like hypervigilance, or sleep disturbance, or even the individual themselves recognizing these changes that are happening in their body or in their mental health.

How can we help people make those differentiations between what are trauma responses that may be temporary and may resolve as opposed to an anxiety disorder, or a feature of autism, or obsessive

compulsive disorder, especially earlier in the process than at a clinical assessment? How can we help make those distinctions?

BRIAN TALLANT: Yeah, great question. This is what I hold in my mind as I – whenever I do – And, again, this is not necessarily related to a clinical assessment. But as I get to know an individual and I understand what we understand about developmental disabilities, which is these are skill deficits. These are typically areas where people require training and assistance.

But if you look at, for example, like the DSM-5 diagnosis for intellectual disability or if you look at the DSM-5 for an autism spectrum disorder, there's not anything in there about those disabilities that are inherent to emotional behavioral dysregulation. There's not anything about hypervigilance, or startle response, or night terrors, or inability to regulate your emotional behavioral state that are indicative to those disabilities.

Now you have to keep that in mind because as you get to an individual you have to trust your gut when you recognize – Again, this is also about cultural competency for people in the helping professions. Like, the more you understand and the more people that you meet with intellectual and developmental disabilities, the more that you understand that has to do with skill deficits and the need for supports because of the lack of executive functioning. There is nothing about that behavioral and emotional dysregulation that is indicative, and we always have to keep that in mind.

Now, with that being said, it's a challenge sometimes because what we do know about executive functioning is that when you have executive functioning deficits and you have a hard time anticipating consequences – when you have a hard time with forethought and planning – what that means is that you kind of walk around reacting to things emotionally because you have a difficult time anticipating them.

So, things like perseverative anxiety are highly correlated with people who have executive functioning problems. And I like to make that comparison because actually, I sort of believe – and, again, this is another area where I think we need more research – because those of us that are working specifically in the dual diagnosis area know that there's a lot of parallels between that generalized, floating, perseverative anxiety that comes with living with problems of executive functioning that often look like, or are related to, in some ways post-traumatic stress.

So, one could argue that simply by taking a look at these statistics that we discussed earlier and also the experience of living with an executive functioning difficulty, yeah, there's a high correlation between – There's a lot of traumatic events, and a lot of stress, and a lot of anxiety that's simply paired with having a disability.

But I also want to point out like for an example, I've had a parent say to me, I think that my child is experiencing depressive symptoms. And I said, oh? Yeah, well withdraw. And even in an assessment, I had a child who went into their closet and closed the door. And the parents said, see, this is what I'm talking about. And then we have a discussion about an autism spectrum disorder and what's typical with

an autism spectrum disorder. And sometimes sensory deprivation when you're getting overwhelmed is a pretty normal experience and a characteristic of people on the autism spectrum. So I always am working with people who know the individual to constantly be assessing is this indicative to their disability or is this something that we would not expect as a result of dealing with executive functioning problems or having an autism spectrum disorder? And so that's always an ongoing process.

But I tell people that when you're working with individuals, trust your gut. Know what the general effects are of disability for people across the people that you've met and understand what's the difference in terms of the emotional behavioral dysregulation that you see in people, especially as you start to recognize patterns. Because when we talk about post-traumatic stress, we're often talking about people's reactions to triggers, and memories, and situations that elicit that intrusive material that comes from traumatic events.

MELISSA CHEPLIC: And I think what's so great is that we learn more through assessment that helps inform our treatment. Right? We tend to talk about assessment and then treatment in a linear way, but, really, assessment continues even as we're providing treatment. It keeps informing that treatment and finding better ways to help people. So, sort of keeping and finding out more about that information I think is a really important key piece that you highlighted.

Let's talk a little bit about treatment. Let's talk about how once we've recognized the need to provide that treatment and find supports for people, what are some treatment models that you've found to be helpful – some therapy, some adaptations – and where do those models come from in your work?

BRIAN TALLANT: Yeah. As a result of the 9/11 tragedy in 2001, the federal government recognized that we did not have a lot of evidence-based practices in child trauma treatment. And so that actually – The funding that was put forth by the federal government created the National Child Traumatic Stress Network, which is based out of Duke University and UCLA, where they started to take a look at what are the evidence-based practices and how do we train communities and practitioners across the country in being more competent around evidence-based practice and in trauma treatment for children?

And of course, the model that was selected by NCTSN was trauma-focused cognitive behavioral therapy. It's a strength-based approach. It's focus is on development of competency skills, which we know is exactly what the needs are of kids with IDD. It uses CBT techniques, which are relatively easy to adapt for people at varying developmental levels. That's the reason that NCTSN selected it for treating children is because obviously children come at varying developmental levels. And so, it's inherently a model that's designed to be adapted for varying developmental levels. And it's already been structured for a use across a wide range of chronological ages.

It's phase-oriented trauma treatment. And it really does involve multiple stages that are relatively commonsensical.

We first start off with – And some of these phases also sort of happen simultaneously. But we start off with a good assessment. And when we do assessments, we talk – we're going to take a look at what are the traumatic experiences that this person has experienced in their lifetime. And then we're going to take a look at trauma symptom severity, and traumatic stress severity, frequency and severity, in what ways does the post-traumatic stress manifest itself with this individual. And we're going to do that while also simultaneously doing psychoeducation.

And the assessment and psychoeducation happen simultaneously because psychoeducation is really, really important, especially for this population because not only are we going to talk about the normal reactions to traumatic events – because a lot of times people come into trauma treatment saying, I think I'm going crazy. I'm losing my mind. And our responsibility is to normalize their experience and say, no, you're not crazy. You're experiencing exactly what any normal individual would experience when they go through these kind of events.

So, educating about disability and educating about developmental disability along with normal trauma responses is a big piece of the psychoeducation phase.

And one of the most important things that we always want to do with this population is include all of the caregivers and all of the significant relationships in that person's life. If you're doing trauma-focused CBT with a person in your office and you're not including all of the caregivers, you're doing treatment in a vacuum. The caregivers and the people in the lives of people with IDD are the therapeutic change agents. And so when we're talking about trauma, you also have to talk about the caregivers' reaction to the individual's trauma. What are their trauma histories like? And so working with caregivers is an exceptional part of this. And sometimes we lose track of who those people are. You may be talking to a teacher and a special educator but the person who really has the relationship and the knowledge of the child is the therapeutic aide in the classroom. You follow me?

So that's the interesting thing about trauma treatment is trauma treatment is not an investigation, first of all. It's one of the ones things I have to point out also is that I've had too many people refer an individual for trauma treatment saying I'm not sure exactly what happened, but I'm hoping that therapy will get to the bottom of it. That's not – As a matter of fact, engaging in trauma therapy can confound what's needed, which is an investigation, because trauma treatment is about a person's perceptions of what happened. It's not about what actually happened. So it's very important we let the individual – It has to be a personcentered process where they guide the treatment as to what is most significant.

And so the assessment, the psychoeducation are happening simultaneously until we get to the skill development stage, which is typically teaching self-soothing and self-regulation skills. And how do we adapt that? This is an oversimplification for time here, but it's a lot like working with younger children. We teach these skills to preschool age and children that are as young ages five, six. We're teaching how to – doing mindfulness exercises, teaching deep breathing.

Sometimes we make it playful. We make it fun. We take straws and we blow cotton balls across the desk. Sometimes we're teaching how to take slow deep breaths. So can you make the pinwheel spin as slowly as possible? I mean, it's only limited by yours and your client's creativity in terms of how you adapt some of these skill development sessions to be developmentally appropriate.

And then the real, I think, meat of trauma-focused CBT is developing a trauma narrative, which is basically – a trauma narrative – is a verbal or visual representation of the person's experience in their trauma stories. Now you can work with people who have discrete episodes of trauma where that is really the focus of the trauma narrative. It's not unusual that the people that I'm working with have multiple chapters. And so we'll continue to develop chapters as the person explains their experience. And they're allowed to practice their self-regulatory emotional regulation skills while they're disclosing and getting in touch with that trauma material and facilitating that into some representation – tangible representation that they can keep.

And how do we adapt that for people with IDD? Again, it's only limited by your creativity. Most people with IDD are in the mild range. So what we're doing is we're listening to people's narrative and we're transcribing into a computer. And we allow them to illustrate it or sometimes we find illustrations on the internet that we put in. And that's typical.

But then as people have more limited intellectual capacity than we might, or verbal expressive and receptive language skills, we've done all kinds of play therapy adaptations, such as sand tray, where people will play out their traumas in sand tray, for example. And then we take still photographs, or maybe video, of the sand tray process. And we turn it into a tangible representation for that person.

The last two phases I can touch on briefly is the trauma processing is really important. So when the narrative is completed, what we'll do is go through it with the individual to start to identify distortions. We'll start to identify cognitive distortions especially around things like perception of responsibility in the events. We will take a look at exaggerations and places where – because really what we want to get to is a place where the person recognizes that this is simply what happened. It's not me. It's not who I am. It's simply what I went through.

And a key important part of that is getting to the place where the person talks about their recovery. And they start talking about how they are survivor, not a victim, of these events.

And ultimately, we want to get to the reintegration phase where we take all of these lessons learned in treatment and we say, how can you apply these concepts that you've learned to other stressful events in your life? And that's a lot on trauma-focused CBT.

I do want to bring up one other thing real quick which is there are individuals that I work with who TF-CBT is an exposure therapy. In other words, you're going to be working with people to utilize their emotional regulation skills while they access the trauma material. For some people, either because of the level of disability, the severity of how they're impacted by their disability, or how severely they're impacted by their

PTSD, where they don't have the ability to safely access that trauma information – I'm a big fan of Trauma Systems Therapy.

And I can't go in too much because the time about Trauma Systems Therapy, but basically it's a model that uses very accessible, concrete language for caregivers to provide a very trauma sensitive, and informed, and supportive environment around the individual. Exceptional in use in cases that involve Child Protective Services or Adult Protective Services because it creates a level playing field across caregivers with language and conceptualization of this person's experience and their symptomology.

So, if you're not familiar with Trauma Systems Therapy and you work with people who have complex trauma, where they've got early onset of an abuse and neglect and lots and lots of trauma material aversion, look into Trauma Systems Therapy because I think it's ideal for this population when they have really experienced severe, complex PTSD.

MELISSA CHEPLIC: You talked about the role of the teacher's aide or the direct care staff and people who are really closest in those relationships to individuals really, really having that important information about their experiences. Sometimes the direct support professional, or some other frontline staff, is in a position to recognize behavior change or other symptoms. How can that DSP or caregiver really be empowered to play a role in supports and recovery?

BRIAN TALLANT: Yeah, 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 encourage – I want to make your listeners aware of a wonderful product that's available through NCTSN. It's the IDD trauma toolkit that they have available, and you can download it for free. If you go to the NCTSN website – 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 one. And then what you could do is really get in touch with what PTSD symptomology looks like. The more you learn about what's typical of a 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.

And so, I would say trust your gut, read up, record your data, and use your advocacy skills to educate systems and people around a person with a disability to know the difference. And work collaboratively.

MELISSA CHEPLIC: So, understanding behavior, using the IDD trauma toolkit, being a good advocate, collecting data-- These are great guidelines to working collaboratively because we know that people with IDD are often served through different service systems and across settings.

What are some other different ideas or frameworks that you can recommend to promote partnerships across systems and across settings where people's needs are being served?

BRIAN TALLANT: You know, I've found in my career that I've always had sort of a two-pronged approach to this.

I find it a little bit interesting and also unfortunate that the IDD community that I work in in a major metropolitan city is still relatively small. And so, I worked for many years in a mental health organization. I now work in an organization for people with IDD. And what I find is, is that both of those systems need cross training. And not just clinical information but cultural changes. So, I'm always trying to educate people in the IDD arena and that field about mental health, and about trauma symptomology, and about the normal effects of trauma, and helping people in the IDD world work against the diagnostic overshadowing of taking all these behaviors and overattributing them to a person's disability, or their, quote unquote, "those are their behavioral problems." And so really helping them understand what does trauma symptomology look like.

And in the mental health field, when I encounter people who are working in the mental health field, I have a very different advocacy and education responsibility, which is this is what it's like to work with somebody who has an intellectual and developmental disability. And really – because the way that I feel about it is that I always hear from the mental health field that we don't have people that are competent and trained to work with people who have IDD. And my response to that is this is a cultural competency, not a clinical expertise.

Really the barriers that exist in getting good mental health treatment for people with IDD has to do with clinician apprehension, fear, and all of those things that come with working with people that you're not culturally competent with. And so, helping clinicians and people in the mental health field recognize that working with people with IDD is more similar to working with the general population than it's different. You've got the clinical skills. You've got the intuition.

And a lot of times they'll say, well, I don't know how to do trauma treatment with somebody with an IDD. And I say, do you know how to do trauma treatment with a 7-year-old? And they go, yeah. And I say, well, if you've got a 25-year-old in there who's developmentally functioning in a lot of ways like a seven-year-old, then you know how to adapt treatment for that developmental level. And just really helping people in the mental health field recognize you have the capability, you have the skills. What you're grappling with is cultural competency. And it's the way that you would struggle with maybe working with an immigrant, or

a refugee, or maybe working with somebody with a racial, or religious, or ethnic background that you're just not familiar with. And that's what this is about.

That also is important to breaking down barriers systemically in the mental health field because we would never tell people, we don't have expertise in people that are LGBTQ, we don't have expertise in working with immigrants, so you have to go somewhere else. But because people with a developmental disability—their minority status is defined by a medical diagnosis, and that fact allows our health care systems to discriminate based on disability. And we have to actively work against that.

This is a cultural competency issue, and we have the capability. And those of us that are working in the IDD system, we have to stop doing the diagnostic overshadowing and just passively accepting the fact that this trauma symptomology is a manifestation of a person's disability because it's not.

MELISSA CHEPLIC: Breaking down those barriers to promote collaboration and coordination will definitely build capacity across service systems.

Brian, we're so grateful for your time. Thank you to our listeners out there.

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