

Kelly Bron Johnson ([00:00](#)):

Welcome to episode seven of intersections on the spectrum. The intersections on the spectrum podcast is the brain child of Doug Blecher and Kelly Bron Johnson created to discuss intersectional issues within the autistic community and give visibility to commonly marginalized, repressed, underrepresented, or erased identities and issues. We aim to introduce you to the people and stories didn't know about, but needed to hear and hope that by seeing yourself represented in the community, allows you to feel seen

Doug Blecher ([00:32](#)):

Today I'm excited to have the creator of the Nigh functioning autism, Instagram account. One of my favorite follows on Instagram. Tiffany. Well welcome. We wanted to start out you know, we, we all have more than one identity. What would you say are the identities that, uh, best describe you?

Tiffany Joseph ([01:00](#)):

I would say disabled black American Latinex, uh, gender nonconforming, parent and advocate.

Kelly Bron Johnson ([01:14](#)):

Well, thank you. That's fantastic. So we also know that you're epileptic, right. Are there some common misconceptions about epileptics that people have that you wish would just go away?

Tiffany Joseph ([01:27](#)):

Oh yes. The most common and harmful one, I think is the, uh, people who have seizures are on drugs. That's, that's very harmful. Um, it keeps people from getting help or, um, keeps people from recognizing actual, um, epileptic seizures when they're happening. Another thing is after or before a seizure is somebody may act a little different and they may be seen as drunk or as on drugs or acting out of a, like a psychotic break. And that can actually be very dangerous if you're around like say police, for instance. So, yeah, I think that would be, um, one of them also, um, not all seizures are convulsive, so not like the ones you always see on TV or movies.

Tiffany Joseph ([02:27](#)):

Like I have seizures that I would have to tell you that I'm having one for you to even notice. Also I have seizures that make me like throw stuff on the ground. So I have broken a few things in stores and at home. Um, so those are, there are several different types of seizures, not just the convulsive ones.

Kelly Bron Johnson ([02:49](#)):

I just want to really touch on that point that you made, how dangerous it can be for certain people, especially black and indigenous people that is often a common fear, you know, or people will say we're on drugs or we're alcoholics, um, happens a lot, a lot with, uh, indigenous people, especially when they try and go help for help and hospitals. Uh, I'm speaking about in Canada, but it's, it's often that anytime anybody's acting a little bit different, uh, the first conclusion that somebody wants to jump to is that it must be drugs or alcohol and that they're not getting the help that they need. And that's, that is a very serious, uh, problem that our societies have.

Doug Blecher ([03:31](#)):

You mentioned on your, um, Instagram account that you support the keto diet and cannabis for epileptics. Can you, can you talk a little bit about those in terms of, of the benefits of, of keto diet and cannabis?

Tiffany Joseph ([03:48](#)):

Okay. So as far as keto is short for ketogenic diet, um, it was started for children who had epilepsy in the early 19 hundreds, and it was found to be the only way of keeping their seizures down or preventing them altogether. So it's, it's been, you know, over a hundred years, then people have found out that it's good for other things. And even for adult epileptics and for me, um, it's probably been my biggest help for preventing my seizures and not having to take as much medicine. It has been hard to stick with independent independence, um, but I definitely need to get back to it. Not having carbs or sugar allows fat to re replace as an energy source energy source in the brain. And for some reason that makes a difference in, in brain health and the way the brain uses it signaling. So for cannabis, I ha I, I really don't know if that has made a difference in preventing my seizures on in cannabis.

Tiffany Joseph ([05:01](#)):

I mean, as in THC and CBD alike, but I use both of those for getting help with my anxiety and my sleep. And two of my biggest theater triggers are stress and a lack of sleep. So that right there indirectly helps my seizures, but more directly, it actually helps me recover much faster after I've had a seizure. So after a seizure, I feel very groggy out of it. I can't speak, I can't think really. Um, and I usually need to sleep for hours and hours, sometimes 24 hours after a seizure. So having cannabis right after I have a seizure, um, means I can either use a fast-acting method or a long acting method in that helps me not have to sleep as much. And it kind of gives that groggy feeling like my brain is out of sorts. It helps my brain feel like it's coming back together.

Tiffany Joseph ([06:10](#)):

So for me, it's more of a, uh, recovery tool, um, that really helps and impacts my epilepsy. And both of those together allow me to use a lot less pharmaceutical anti-seizure meds, which are, are extremely important in preventing seizures. However, they have huge side effects. So people who are on anti-seizure meds, they can have dental problems, like drowsiness throughout the day, memory problems, weight loss, or weight gain. It just makes you feel like kind of in a daze, which is what seizures also do. So both of those together have helped me kind of replace some of that and I can use Keto and cannabis. So, um, kind of keep a good balance.

Kelly Bron Johnson ([07:05](#)):

It's always amazing to me how the pharmaceutical companies, um, often just kind of, I I'm, I'm not speaking from a place of it necessarily like knowledge or education here, but it just seems as sometimes they settle on certain drugs and then people are living with side effects, like really serious side effects of those drugs.

Kelly Bron Johnson ([07:26](#)):

And nothing has changed in like twenty-five years to develop something that, you know, would improve the quality of life for people. So it's, it's always so interesting thing that I noticed when it comes to certain, uh, certain conditions and especially those things that affect certain people or types of people I find

Tiffany Joseph ([07:46](#)):

um, yeah, the anti-seizure drugs pretty much all have a base of these certain side effects that you just like, if you have epilepsy, you have to deal with the side effects of these medicines, no matter what. So that it's pretty much all the drugs in that class are kind of heavy on the side effects and less ways and more ways your right. And just also touching on the keto diet. I mean, that's kind of, I knew people who were on it before for legitimate reasons and, and were trying to control their, their epilepsy, but it seems to have become a bit more of a fad diet, uh, and very popular popularized.

Kelly Bron Johnson ([08:26](#)):

So I'm wondering if you want to maybe comment on that. Do you feel that that has had an impact on let's say your access to the foods that you would need?

Tiffany Joseph ([08:35](#)):

Oh, yes.

Kelly Bron Johnson ([08:36](#)):

Thought down change prices in terms of things like that. Um, because it's been so, uh, mainstream.

Tiffany Joseph ([08:43](#)):

Yes. So, um, this happened, I'm also gluten free because I have celiac. So this happened, um, back when gluten-free was a fad and it's now happening keto. And I love the fact that I have a lot more options. I can go into the regular grocery stores now and get gluten-free keto products. It's really made it very beneficial impact in my life for it to become mainstream, just like the gluten free. And everything's a lot cheaper now, not only accessible, but it's accessible by price as well. I can just go order from anywhere and spend almost the same amount I would, you know, for their regular food. So yeah, it's, it's, it's been great.

Kelly Bron Johnson ([09:30](#)):

Okay. Good to know. Good to know. I know for me, like I was, I started going gluten free when I was in my twenties. So that's almost 20 years now. Um, and the food was just crap. It was terrible. It was nasty. It just, yeah, it was like cardboard and you know, it's, it's expanded a lot. There's so many more choices now. It's so much easier. But at the same time, I find that like, especially restaurants, they don't necessarily take it seriously.

Kelly Bron Johnson ([09:56](#)):

I'm not celiac, so I don't have to worry that much, but it's still like, uh, it's still, I find that food restrictions or food allergies, they need to be taken very seriously by people. It's not just a fad. It's, there's a real medical reason. A lot of the times.

Tiffany Joseph ([10:09](#)):

So, yeah. And th that is a part of an, another opposite issue is the, that it has become a fad. People think of it as a fad. And think like, when I say I can't, I can't be exposed to gluten and I can't have these carbs, people would think, Oh yes, you can. You just don't want to. And that's the other side of it, but I I've, I think there's a lot more positives and that these things have become mainstream the negatives.

Kelly Bron Johnson ([10:38](#)):

So now you sometimes use spoken words, but you're also an AAC user. Can you talk about some of the, not so obvious ways that AAC helps autistic people that can speak?

Tiffany Joseph ([10:52](#)):

So, yeah. So a lot of people who are autistic, um, also have epilepsy like I do. And I know for me after seizures, sometimes in the days leading up to seizures, it is very hard to speak, make words, find words. So, um, anybody who has like intermittent speech problems and for real, that's the most autistic people as well. I find that I am a lot more confident in conversations knowing that I have a source of communication other than speech that I can use if I need it. So before I would not try to involve myself in conversations or even do interviews like this, because I wouldn't know how long my speech would last and, you know, not to be embarrassed or to get extra frustrated I had just really stopped.

Tiffany Joseph ([11:55](#)):

You know, I, I would never say yes to an interview, uh, long conversation. Um, anything like that, I would, I know I'd be frustrated at times. So this has helped me to even be involved in, in these kinds of things, because I know I have a source of communication to, to, to use if I need it other ways as I touched on word finding or memory problems, or for people with like alexithymia who have, you know, problems being in touch or having the words for emotions or feelings, I normally use my AAC device as a, I would text and then use the device for, uh, speech generation. But on these AAC devices or apps, you can also pre-program in words, phrases, or things or feelings that you wouldn't have access to any other time. And I always know I have a backup when, when that happens as well. So for me, it's just made me a lot more confident in therapy is really how I started this because, um, me and my therapist, even being in the same room would, you know, I'd have to rely on texting her through the phone. And eventually she was like, you know, you should start using this a lot more. And that's when I found AAC as, as a way of communication.

Doug Blecher ([13:30](#)):

That that's really interesting. One thing that you just mentioned that, um, really resonated with me was that, um, you know, I, I support a autistic person on a weekly basis who is also epileptic, and there's certainly days where we'll meet where this person doesn't necessarily have a lot of words. And I'm like, all right, well, we'll use your AAC. No problem. But I never made the potential connection that they had a heavy seizure and then that was affecting their verbal ability. So I was wondering, when did you initially, like, how did you initially make that connection?

Tiffany Joseph ([14:08](#)):

It took me being rediagnosed with both autism spectrum and epilepsy as an adults. Um, so these were things that I hadn't even thought about that happened in my life before. But as an adult, I was, um, diagnosed as autistic and epileptic again, and having several EEG over the past few years, which is where they put the electrodes on your brain. And you have to, um, go into the hospital for a certain amount of time and they take a video and you have to write down everything you feel. And I began to make the connection between what the EEG was telling my neurologist and I was having seizures and how I would feel after a while. So then I got to notice when she would say, well, you had a seizure here and he had a seizure here. And I, um, I noticed my, the seizures, how they made me feel. And I, I finally understood cause when you're having a seizure, I mean, if it's not like a convulsive obvious seizure, even to oneself, you might not understand that that's a seizure. So being connected with EEG helped me understand,

okay, this is how I feel when this type of seizure happens. And this is how I feel this way. So just several, several times in the hospital in the last couple of years. So it's helped me make that connection.

Doug Blecher ([15:43](#)):

I think one of the frustrating things is with AAC is that sometimes, um, insurance, um, denies, um, coverage for, for AAC. So if, if that is the case for some people out there, are there any resources or maybe work arounds that you can recommend to them?

Tiffany Joseph ([16:04](#)):

So for me, I started off with the smartphone that I had, the tablet that I had and some free apps. So on my Android phone, there's an app called speech assistant. It's free to use, but even, you know, even if you want to pay for it, it's only like \$6 for life. So just having my phone and that was the first step, usually in every region technology, lending library, there are organizations that provide them more grants to do so there are even programs have used to recycle them after a person changes devices.

Kelly Bron Johnson ([16:51](#)):

I know for me, I have an app, uh, as a free app called the emergency chat app was created by an autistic teenager actually. Um, but I don't think it reads out loud. I think the only text back and forth, but at least it's there. And for me, I put it with a warning like, uh, so that if I'm having a panic attack or something to explain what's happening and what to do with me, um, so I just hand them a phone.

Kelly Bron Johnson ([17:16](#)):

So, you know, stop asking me questions and just take me to a quiet place and then we can chat back and forth.

Tiffany Joseph ([17:24](#)):

Um, that's, that's pretty convenient because, um, most AAC isn't that like a one touch when you have a panic. So th that actually is a pretty good, um, thing for emergencies.

Kelly Bron Johnson ([17:37](#)):

Yeah. It's cool. So, yeah, it's free emergency chat app, autistic made. What kind of stories would you like to hear as we move forward with this, uh, podcast? Like we said, at the beginning, you're you are, uh, interview number seven. Um, and we're always looking for more people that we need to amplify their voices. So who would you love to hear more about or what kind of stories?

Tiffany Joseph ([18:05](#)):

I think it's important to highlight that for black and Brown autistic people, there is a greater risk of being in trouble at school or by the police also not being able to answer questions for police not maintain steady eye contact or having to use sign language or AAC can all be extremely dangerous for any disabled person when interacting with police, but especially black and Brown autistic people. All of these things are a matter of life and death, and we don't have the time to wait for police culture to change as we can interact with them at any moment,

Kelly Bron Johnson ([18:46](#)):

a hundred percent. There's a, another organization that I got connected with called lives in the balance. I don't know if you've heard of them. Um, they might've talked, um, it's the same name, it's also called lives and balance. And, uh, it talks about that school to prison pipeline, and it talks about the, you know, over policing in schools, um, and especially how it affects what they call children with behaviors. Um, so anybody with any sort of diagnosis or even if they don't have, uh, you know, they might not have a diagnosis, but they're not behaving the way that, uh, teachers want them to comply in such a way that, uh, it's leading to over, uh, disciplinary action on children, children being suspended. They're not able to learn then, um, or to hold that's a whole other story and probably a whole other podcast. But,

Tiffany Joseph ([19:42](#)):

um, yeah, I actually had a, um, one of my best friends. Uh, he was a non-speaking autistic and, um, he was actually jailed after a meltdown in school, like jailed, like hard times in, in, um, juvenile detention for a meltdown. Like we did the whole system over that and that just sets up trauma and it's, and the thing is that what people don't realize it doesn't just traumatize the person going through it, it traumatizes all the other students who are seeing this. It actually, they know restraint actually even traumatized as the people who are doing it. So there's no, Oh, there's no good outcome for any of this. Yeah. That's a, that's another work that I'm trying to get into and trying to see if I could make changes.

Doug Blecher ([20:35](#)):

That's a, that's a whole nother podcast for sure. So I'm going to do my best to transition from, from that, but, um, and plug my cohost, uh, because she, uh, recently wrote a great book, uh, how to parent like an autistic. And I believe recently I saw that it is now an audio tape. Is that, is that correct?

Kelly Bron Johnson ([20:59](#)):

It finally made it to audio book and that it took three tries before it got approved. So, so it's a long journey.

Doug Blecher ([21:09](#)):

So, so Tiffany, I know you're a parent as well. Uh, what advice would you give to parents out there in terms of how to parent like an autistic?

Tiffany Joseph ([21:21](#)):

Um, so for me, I think the part about being an autistic child that is universal, um, maybe with all children, but especially autistic and disabled children is the consistent running theme of your actions and your words and your movements being constantly misrepresented and misunderstood and misinterpreted. And I remember that very much as a child. So one thing I always, well, I always try to give grace to my children is that maybe I'm misinterpreting their actions and maybe they need the benefit of the doubt, or they really don't know why they did something, you know? So I, I don't lead with anger or punishment. Again, I try, it's still human, but I, I try to hash out these so-called behaviors and, um, see what the intent was, where it came from. And we just kinda talk about what to do better versus, you know, just immediately getting angry, because I remember times that people have gotten angry for me, adults when there's something like either my, my body just did by itself or something, I, I didn't pick up that I was supposed to, or they just misinterpreted my intent behind the, the action.

Kelly Bron Johnson ([22:59](#)):

Yup. I feel that that affects you all through your life. It affects you for me, especially in the workplace because people just say, Oh yeah, we ascribed like the worst possible thing when it could be just like, I was focused on my work. I wasn't ignoring you. I don't hate you. But like for whatever reason, like they go for the worst thing, like, Oh, she must hate us. Or she's like stuck up or something like that. It's like, you don't have to assume that all especially children that I really truly don't believe that children are there to manipulate you, they have something better to do with their time. Honestly, like kids, they don't come out of you angry, you know? So they don't like they go and just do things just to make you angry. There's other, you know, I could go on and on about this. Yeah. But that's the thing I really, I really agree with you on that. And I really wish more people kind of understood that, but sometimes people just do weird things and sometimes they break things or whatever, but it's not like, Oh, it's not because they hate you or something. Yeah, definitely no ill intent behind the accident.

Doug Blecher ([24:08](#)):

And a lot of times they're just learning from the adults. I mean, you know, to Kelly's point.

Tiffany Joseph ([24:14](#)):

Yeah. Oh, the hip, the hypocritical nature of being an authority, um, that does not escape me now as a parent because I definitely remember it as a child.

Doug Blecher ([24:28](#)):

Well, Tiffany, thanks so much for joining us today. I always learn something from you and if you're not following Nigh functioning autism on Instagram, go and do that right now. Thanks so much.

Tiffany Joseph ([24:40](#)):

Thank you.