

Episode 26: Interview with James Steed, Part 2

Summary Keywords: mental health, developmental disabilities, intellectual disabilities, people, behavior, Idaho, misdiagnosed, person, manic, support, struggles, community

Speakers: Alex Schiwal, James Steed, Matt Wappett

Alex Schiwal 00:00

Music Hello, and welcome to the Mental Health Crossroads podcast where we explore the intersection of mental health and developmental disabilities. This is part two of our interview with self-advocate James Steed. If you haven't listened to part one, stop right now, and go to the show notes where we've linked that episode. You can also find it wherever you've been getting your podcasts if you're ready for part two. Thank you for joining us. *Music*

Matt Wappett 00:35

This is a little bit of a curveball question. How many of these struggles with getting appropriate care, mental health supports, do you think was related to just the state of Idaho? Idaho is a rural state with a less developed mental health infrastructure. I don't know if you're prepared to answer that question but...

James Steed 01:00

It's not just Idaho. *Laughter* It's not just Idaho. Remember, I told you I spent actually eight years in Washington, and when I went to get mental health counselors there they misdiagnosed me there also. And yes, sure. I wasn't as confident as I am now, or even 10 years ago, but they misdiagnosed me there too. They thought it was my self-esteem. My low self-worth. They didn't recognize it as any type of mental health disorder at all. Just because Idaho is a rural state, does not mean it wasn't misdiagnosed just in Idaho. It was in Spokane, Washington also.

Matt Wappett 01:51

Yeah. That's interesting. Well, eastern Washington is very similar to Idaho, right? *Laughter* Don't tell people from Spokane that.

James Steed 02:02

Okay, I'll keep it to myself. And whoever listens to the podcast. *Laughter*

Matt Wappett 02:09

Exactly.

James Steed 02:11

But our hope is it's not somebody from Washington.

Matt Wappett 02:13

Laughter I know. You mentioned that you finally were able to get a diagnosis and get right the supports that you needed for your mental health about 10 to 15 years ago. What are some of the strategies that you found are effective in supporting your mental health?

James Steed 02:35

Getting up and doing things. Basically, doing things like this. Feeling like I've got something going on. That I'm not bored.

Matt Wappett 02:49

Okay.

James Steed 02:50

Boredom, for me, is a trigger. And in a facility, believe it or not, there's always something going on. So you're not bored. There's always something going on. I cruise around in my power chair, all over the place. And there's always something going on. Always somebody to- I don't want to say BS with (meaning to talk nonsense with), but to talk with and hear a joke or ask them how their day is, whether it be a resident or a staff member, or even a resident's guest. There's always someone that I can interact with or whatever. Yeah, there are times that I am with myself and I play games or watch TV. I'll be honest with y'all, I'll spend maybe 30 minutes watching a show and then I pause it, leave for 10 or 15 minutes, and cruise around. It's basically keeping my mind busy. That part of my body, I have to keep my mind busy.

Matt Wappett 04:04

It seems like part of that, to me, is it's also social. That need to connect.

James Steed 04:09

Oh, yeah. It's a big social thing. It really is. It really is. I'll be totally honest. It is. I love being around people. People once said- I've had somebody say, 'you're good for this person' or 'you're good for that person, you being in their lives'. And what they don't realize is it's a symbiotic relationship. They have done wonders, for them being in my life. So for them to say that to me, it's like you guys don't get it. *Laughter* This is not something wow, and amazing, and oh, look how this person's come out of their shell. This is going like 'Dude, this is a symbiotic relationship here.' What I have done for them they have done for me.

Matt Wappett 05:02

Yeah. I know there's lots of self-advocates in Idaho. You were a tremendous mentor to many of the younger folks. I know that you had a tremendous impact on their ability to speak up and to really take control. Although I know that it is a symbiotic relationship, I don't want to downplay the fact that your confidence and your voice has been really important to building self-advocacy in Idaho and now in Utah.

James Steed 05:42

I thank you for that and I really appreciate that. But as I help their self-advocacy, they help mine.

Matt Wappett 05:51

Yeah and that's an important aspect of resilience. We know from the research that that social support, feeling needed, feeling like someone's there to listen to you, that there's somebody to talk to who gets it is really important to supporting our own mental health and making us be able to handle challenging things.

James Steed 06:16

I've *inaudible* a program community/community center for Life Incorporated. I actually got paid for this job. What it did was it brought people with mental health, physical disabilities, developmental disabilities, intellectual disabilities together. My hope was, number one, that we'd all get together, we'd realized that we have a support system in ourselves. Then, taking that support system and not only having fun together, like bingo, bowling and all kinds of stuff, but also giving back to the community. We did a number of fundraisers for breast cancer awareness, carwashes for people that were injured, we did chili feeds and chicken noodle soup things. This one gentleman had to have a major surgery in Seattle for his brain because he kept having seizures. And we had a big chicken noodle soup fundraiser and we call it Chicken Noodle for Kenny's Noodle. *Laughter* We gave back to the community, because of the fact we wanted to show that people with disabilities, all types of disabilities, whatever the gambit was, could give back to the community also.

Matt Wappett 07:53

That is so incredibly important. There's this perception I think out there that, and unfortunately it still persists in some communities, that people with disabilities are always taking. And I like how you turn that on its head and really tried to subvert those expectations by giving back. I would expect nothing less James. *Laughter*

James Steed 08:20

I don't know about that.

Matt Wappett 08:23

So what has been your biggest mental health challenge during the COVID pandemic? You've been locked up and isolated so some of that social stuff hasn't been available. What has been your biggest struggle over the last year and a half?

James Steed 08:41

More than likely the depression, and some things that I did that were... And I don't want to go into detail with this, but I got addicted to something that I shouldn't have. It actually almost got me in trouble with all kinds of things. I needed to get away from that. And it was kind of hard to

do being in here. And being in here precipitated that. I don't know whether that's the correct word. It was kind of tough. I got really depressed, and they moved around my medications. For example, I'm finally on a good medication that has kind of really balanced me out and I feel great. But the only problem is, I'm hungry or **inaudible**. I gained back 40 pounds of the weight that I lost.

Matt Wappett 09:46

Oh.

James Steed 09:48

Yeah, that's the problem. It's like, 'Oh, dude, come on.' **Laughter** But, so it's kind of balancing things. I almost want to see if there's a possibility of going somewhere and getting my meds adjusted or something like that. Or maybe even looking into... Because I'm a big guy. I would be considered, and I'll say it right here, I would be considered someone who is morbidly obese. Okay, let's be honest. So I may end up going and getting the lap band or something like that. But we got to do something about the weight thing. Now that I'm more conscious of it, because I didn't even know. I mean, you're just hungry and you don't even think about it. And now that I know, I'm more conscious of it, and so is my doctor.

Matt Wappett 10:51

Yeah. That's always the hard part with some of those medications, is they can have side effects that impact-

James Steed 10:59

What's weird is even when some of the aids here or some of the nurses find out that I have a mental health disorder, they treat me differently. Isn't that weird? I'd never seen that before in my life. And it's kinda like, wait a minute.

Matt Wappett 11:20

What do you mean by treat you differently? What does that look like?

James Steed 11:24

They're more guarded.

Matt Wappett 11:25

Ah, okay.

James Steed 11:26

Yeah, they're more guarded. A lot of that is because when they have these shootings, and things like that, the first thing they go to, 'oh, gun control, and we need better mental health because this person had a mental health disorder.' And that's correct but that doesn't mean everyone that has a mental health disorder is going to do something like that. There is no way.

We're not all killers. We're not all on edge and ready to hit somebody or hurt somebody. And that's the one thing that has really heightened my senses, since I've found out that I have a mental health disorder. The stigma of they could be dangerous, they could go off at any time or being very standoffish, because, 'oh, they have a mental health disorder.'

Matt Wappett 12:29

Yeah. It's interesting that you bring that up, because right before COVID I was on a panel with the police department and with several community advocacy organizations about gun control. And they wanted me there to talk about mental health and gun control. We got in a huge debate around the fact that you have a mental health disorder or a mental health diagnosis doesn't necessarily mean that you're going to be violent. I got in trouble. I actually got quoted in the newspaper. *Laughter* It made it in the article in the newspaper I said, just because you're an asshole doesn't mean that you have a mental health disorder. *Laughter*

James Steed 13:19

Exactly, exactly.

Matt Wappett 13:24

There's that assumption, right? If you're violent, if you're angry, or whatever, that there must be something wrong with you. And it does reflect I think, on the way that people perceive things like depression and bipolar, anxiety, things like that. They assume you're going to snap and be violent and that is a complete false understanding of what mental health issues are.

James Steed 13:52

Exactly, exactly. My manic is just not sleeping and believe it or not cleaning and things like that. I don't get mad. There have been times when I've gotten angry, when I was younger and stuff like that, but now it's more just being fidgety. I even had my doctor, the first three or four months she started working with me, she goes, 'Well, you're not manic.' And I said 'Yeah, I kind of am right now and I need some help.' Because she was looking at manic as something big is gonna happen. Big anger or whatever it is, or going out and doing this major shopping spree or whatever it is. It wasn't like that. It wasn't like that at all. I mean, other things happened. Of course, like I said, the addiction that got me into trouble or the behavior that got me into trouble, that was a manic behavior.

Matt Wappett 15:13

Yup, you're right. It looks different for everybody else, that swing. Yeah, you can't generalize, it's an individual sort of phenomenon. What advice would you give other self-advocates who are maybe trying to figure out how to support their own mental health?

James Steed 15:43

I would tell them to get involved in programs, or maybe even start a program with other self-advocates and other people with developmental disabilities and those with mental health.

Because the big thing is finding someone that understands what you're going through. It's interesting to realize that you have a dual diagnosis. Because at times you feel alone, but then you look around, and there have been a number of my friends that have been misdiagnosed. They figure it's their disability, especially those with intellectual disabilities. 'Oh, it's a behavior.' Well, excuse me, why are they having that behavior? It has nothing to do with a neurological disability. My buddy's not doing that, because he scored poorly on some *inaudible* tests that you had 20 years ago. *Laughter* His behavior is coming from something else. Maybe he's missing his brother, whatever it is, it may not be from an intellectual disability.

James Steed 17:12

And that's the screwy thing for me is, I watched from that community center, and whatnot - and as I began to realize my own mental health issues- when they would say, 'Oh, that's Charlie's behavior. It's just a behavior.' Here's a young man who happened to have autism. And it's a pretty severe case. I don't know if they have certain degrees, like he had profound autism, let's say, and some intellectual disabilities. And his family had some intellectual disabilities, but they were ashamed of Charlie. And so they would, and this is awful, but they would lock him in the room with the dogs. And when he finally got out and free of that, and thank God, and I very seldom would say this- in fact, this is the only time I've ever said this, and I've said it in the past, thank God for sheltered workshops. *Laughter* Because they noticed what was going on and they helped to get him out of that situation. But when they sit there and say, to me, that what he does like throwing away his coat or whatever it was, that it's just a behavior. I'm kind of going, 'Wait a minute, there's something else going on here.' What do they say? Behavior is communication or something like that? Is that the correct words?

Matt Wappett 17:13

That is, yup.

James Steed 19:05

Behavior is communication. Now, my buddy, he's basically nonverbal. You have to figure out what that behavior is saying. And not just address the fact of, 'oh, we're not going to give them another coat. He's gonna have to freeze for a few days.' No, you're gonna have to figure out why he's throwing away his coats.

Matt Wappett 19:34

Right. Or even saying, 'Oh, it's just the autism.'

James Steed 19:39

Exactly. Exactly.

Matt Wappett 19:41

That's not always... Just because somebody has an autism spectrum disorder doesn't mean they don't feel anxiety, they don't deal with depression. They can experience exactly the same range of emotions-

James Steed 19:54

And mental health disorders. Because who would not have developed some type of mental health disorder being treated like that when they were younger?

Matt Wappett 20:04

Yeah.

James Steed 20:05

Not only do you have this profound autism, but now you've developed mental health disorders, due to the way you were treated. And if you do not address the behavior as 'What is he trying to communicate?' Then he's going to continue to have those problems *inaudible*.

Matt Wappett 20:34

It's interesting that you bring that up, because we know that instances of physical and sexual abuse are the highest among the population of people with intellectual and developmental disabilities. And the one mental health issue we don't talk about a whole lot with this population also is post traumatic stress disorder.

James Steed 20:36

Exactly.

Matt Wappett 20:37

And that person, Charlie, that you mentioned, being locked up with the dogs and stuff. How can he not be struggling with something like post traumatic stress disorder? And just like anybody else who goes through a traumatic experience, he needs the supports, and the structure to really process those experiences and get on with his life. That's an amazing story. Was that in Pocatello too?

James Steed 21:32

Yes, it was. If they would have had somebody that was not only *inaudible* a person with a developmental disability, but also had experience in treating somebody with mental health? If they were to have somebody there, maybe he wouldn't be doing this type of behavior, or at least they would have figured out why he's doing the behavior. I'm here now, for all I know, he may be still experiencing or doing those behaviors and they may have gotten worse, because they don't have anybody looking into the fact of why he's doing the behaviors. They're not looking at behavior as a communication. He's communicating something.

Matt Wappett 22:30

Right. Right. That is such a good point. I'm so glad that you brought that up, because I think we overlook that so frequently, that behavior is communication. Behavior is one of the primary ways that we communicate that we're not feeling well. *Laughter*

James Steed 22:52

Exactly. And people just assume that- Especially my brothers and sisters, who I call my brothers and sisters because of the fact that they share kind of the same experiences that I have. So I say, especially my brothers and sisters who experience and have to deal with each and every day, and there's no *inaudible* disability, they automatically assume it has something to do with that disability. They don't look at the fact that maybe ten years ago, they were sexually abused by one of their aides. Even if they know about it, they don't look at that fact. They don't look at the fact that maybe it's post traumatic stress, we need to look at this.

Matt Wappett 23:45

You're exactly right. It's so important and it's so powerful coming from somebody who's lived that experience. I appreciate your perspective and your experience, James. I'm trying to see what other questions do we have. Any other thoughts? I'm trying to be mindful of your time, because I know you've got an appointment here at 1:15.

James Steed 24:07

I guess I would say that, please do not just look at the developmental disability. If you just look at that, my friends and I will never live a full life. And I don't want to end on a low note, if you will, but it is a problem, a systemic problem. Is that the word?

Matt Wappett 24:36

Yeah.

James Steed 24:36

A systemic problem that needs to be addressed. And I think that colleges that teach mental health and counseling need to start having classes on how to treat people with intellectual and developmental disabilities, to look past those and to look at behavior.

Matt Wappett 25:00

Yup.

James Steed 25:01

Because some of us cannot communicate. And some of us that do have no idea what's going on. And if you just treat it as something to do with our developmental disabilities, or intellectual disabilities, then we'll never live a full life.

Matt Wappett 25:19

I think you're exactly right in that point that we need to start training professionals. It's not just training professionals, it's also making sure that the tools that professionals use are accessible and meet the needs of a person with a disability.

James Steed 25:41

Exactly.

Matt Wappett 25:42

A lot of the diagnostic criteria, and the tests and everything else they do, aren't going to work for somebody who struggles with reading or somebody who doesn't communicate.

James Steed 25:57

I never thought about that. But that's more than likely the one of the reasons why they go right to our developmental disability or an intellectual disability, because a lot of us can't take those tests. So where's the starting point? Or where do we start? And they stop there, too. They don't look at the fact that, hey, this person may be bipolar. They may be schizophrenic or borderline personality disorder. They don't look at that fact. They look at what's going on when you're talking about intellectual developmental disabilities, because they have no way to gauge what it is because, like you said, no tools to really access for some of us.

Matt Wappett 26:52

Yep. It is an issue of accessibility, I think, really being able to create tools that are going to help with getting more accurate diagnosis. Let me ask you one last question here, because I'm curious. You kind of touched on it, but I want to go back to COVID. During the COVID pandemic, you were in the facility, were you allowed to go outside?

James Steed 27:18

Oh, no way. We weren't allowed to go outside. Believe it or not, the first time I was able to go outside was when I spent basically Christmas and the holiday season, I was diagnosed with COVID for the second time on Christmas Eve, and I was shipped to the the unit. And one of the administrators here, unit managers, I've developed a very close relationship with, he basically made me take my power chair. Because I don't want you just laying around. Because he'd known that I had been having some struggles. And so they let me outside, I mean, it was colder than hell, but they let me outside and let me kind of cruise around. I had to cruise around in a certain area. I couldn't run into people and whatnot. But I could cruise around. And up until it got really bad, I was able to cruise around outside, but when it got really bad I could not cruise around for like, what, two or three months.

Matt Wappett 28:35

That had to be hard. You mentioned earlier how important social interaction is for you and your mental health and not being able to go out and talk to people and get outside that had to be really challenging.

James Steed 28:51

I have a certain loop that I make, and it's into the rehab area and everything else like that and long term, *inaudible* I'll go over saying hi to people that are on the staff and whatnot, and when they cut off, they separated rehab and long term. That drove me crazy. When are they gonna open it? When are they gonna open it up?

Matt Wappett 29:23

Laughter Cut off half of your social support network.

James Steed 29:29

Exactly. Yeah, it's cutting it into half. It's like, wait a minute. *Laughter*

Matt Wappett 29:33

Yeah. I appreciate you taking time to visit with me, James. I know we've been trying to do this for a while. I appreciate your honesty and candor with sharing your experience today.

James Steed 29:48

Sure.

Matt Wappett 29:50

I know these are not always easy things to talk about, but I do think that hearing you talk about it hopefully is going to make others feel more comfortable speaking about their mental health challenges. Hopefully we'll encourage folks to go out and find the supports that they need to stay healthy.

James Steed 30:13

Thank you very much. I really appreciate it, being here.

Matt Wappett 30:16

You bet. You bet. Thank you. *Music*

Alex Schiwal 30:21

Thank you for listening to this episode of the Mental Health Crossroads podcast, visit our website at mhddcenter.org or follow us on social media @MHDDcenter for more. Thank you.
Music