

Episode 25: Part One of an Interview with James Steed

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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 week Matt Wappett interviews James Steed, who is a member of the advisory board for the Mental Health and Developmental Disabilities National Training Center. James is a longtime advocate of self-determination, and he has cerebral palsy and bipolar disorder. In part one of this two part interview, James talks about his upbringing, how he got involved in advocating for self-determination, and how diagnostic overshadowing impacted him in his journey of getting an appropriate diagnosis for his mental health concerns. Watch for part two of this interview with James Steed in the next month. We hope you enjoy this episode. Thanks. *Music*

Matt Wappett 00:53

Today our guest is James Steed. James is a self-advocate with whom I have a long history.
Laughter

James Steed 01:04

Very long history.

Matt Wappett 01:05

Very long history.

James Steed 01:07

Almost 20 years, right?

Matt Wappett 01:08

I know.

James Steed 01:10

We're pushing on 20 years.

Matt Wappett 01:12

Pretty close. I met James many, many years ago when I moved to Idaho. He was involved with self-advocacy there and was part of the Developmental Disabilities Council. We just kind of kept in touch over time. After I moved to Utah, James followed me *laughter* and moved to Utah and now he's part of the Community Advisory Council for our University Center for Excellence on Developmental Disabilities. He also serves on the National Advisory Board for the Mental Health and Developmental Disabilities National Training Center. So thank you, James, for taking a few minutes to visit with me today.

James Steed 01:55

Thank you. Thank you for having me.

Matt Wappett 01:58

Yeah. Tell me a little bit about yourself, where you grew up, your family, and some of your experiences.

James Steed 02:09

If we're going to go back to experiences, I will tell you number one, that I was born two months premature back in 1961. And just by happenstance, I survived. I don't know how it was possible. I did suffer brain damage from the lack of oxygen. Hence, why I have cerebral palsy. Probably a mild to moderate case, they would say. But it affects my hip, and my right side, and my ears and my vision. As I grew up, my family were very supportive. My mother, actually, my sister told me this story, which I did not realize. My mother actually went to the school board to make sure that I was mainstreamed into regular school, rather than sent to a special school for people with intellectual disabilities. That was back in like, I don't know, '67, '68. I had no clue that she did that until my sister told me this year. I had no clue. My mother, God rest her soul, passed away in 1976 from cancer, breast cancer. Then my dad was left with five kids, including one with a development disability. He remarried, of course at the time that he married I was very much a teenager and had been spoiled, of course. The young man with a developmental disability, they got to spoil him and boy did I take advantage of that. Anyway, as a teenager, as soon as I turned 18 I moved out on my own. I hated my stepmother at the time because she pushed me to, believe it or not, get a job. I got a job. And [she] pushed me to be actually more self-reliant. She is actually the first person that probably dragged me into self-determination and being more self-reliant on me, instead of someone else. I can attest to the fact that that lady, even though I did not get along with her for 35 plus years because I basically hated her when I was younger, was the one who probably changed my life for the best. And I can never repay her for that. Now we've got a really close relationship.

Matt Wappett 05:32

That's great. Was this in- were you born in Idaho?

James Steed 05:36

Yes, I was born in Idaho. Yes.

Matt Wappett 05:38

Where in Idaho?

James Steed 05:39

In Pocatello, Idaho.

Matt Wappett 05:42

Okay. So you grew up, you went to school, and when you moved out did you stay there in Pocatello?

James Steed 05:50

Yes, probably until like 1984. Then they moved to Washington with a family that, I guess, we became very close [with] so I moved up there to Washington with them. I was probably 23, 24 at the time. In fact, I became a godfather to their youngest daughter.

Matt Wappett 06:18

Huh, so you mentioned that your stepmother was the one who sort of pushed you to be more self-reliant, to exercise self-determination. Outside of your stepmother, how did you start to get into self-advocacy? You were born and raised in an era when self-advocacy organizations and even the term advocacy didn't really exist. What helped you develop your self-advocacy skills?

James Steed 06:48

Well, see, I didn't realize what those skills were. But I must have had to practice them sometime throughout my life, and until like 20 years ago, or 22 years ago I think, that the Council on Developmental Disabilities was looking around for, now I know the word to be, self-advocates in Idaho to become a part of this program that promoted this self-determination program in Medicaid. Where people with developmental disabilities got choice, control, and responsibility of the care that they received. We would go throughout the state and talk to people with developmental disabilities or self-advocates, if you will, about these programs and how to become a part of them. That's how I really learned about self-advocacy, to be totally honest, and what it was and how important it was in my life.

Matt Wappett 07:56

So you were kind of just doing it and then... Yeah.

James Steed 08:01

Yeah. Before self-advocacy, believe it or not, I was part of what was called at the time and it still is the Cooperative Wilderness Handicapped Outdoor Group, basically the godfather of Common Ground, if you will. Someone in Logan got the idea from the Cooperative Wilderness Handicapped Outdoor Group. And that group, I became a part of doing biking and hand cycling and things like that. Now, the one thing that I noticed when doing that was, here's these

volunteers and they would just show up to tether people in skiing, to help them in waterskiing, to help them bike or whatever they wanted to do. They were there helping them. And some of these things were quite dangerous. And I told the director at the time, I said, we should start something that would encourage people, because they used to have what they called Hog Nights. But it was just showing films about 'Okay, these are amazing things that you need to be a part of, these amazing outdoor group activities.' I kind of got it to where it started to change. Basically, I told the director at the time that, here's these people, these self-advocates, and you're asking them to put their lives or their bodies, if you will. They're basically giving over their own physical ability to do things, to someone else to help them accomplish water skiing or snow skiing. You got someone tethering your back there. You're controlling it of course in some ways with a ski. What do they call those? When you're skiing, the poles. It's a ski pole, but they're behind you, slowing you down when you're on a biski or something like that. They're there to slow you down. And I said, here's these dangerous things and these people, these volunteers, just on the hill. I said, that doesn't cut it. You're asking people to give up- not knowing who these people were. So I started this thing called Hog *inaudible*. And what it was, we'd bring people together, they'd go bowling, they'd have dinners and it was bringing the volunteers and the participants together so they got to know each other. Then they became friends.

Matt Wappett 10:58

Oh, so it was a way for the participants to meet the people who were volunteering to take them outdoors.

James Steed 11:06

Yes, exactly. And to create that bond before they got out there and did these wild crazy things. So they were more apt to do these wild crazy things with a level of comfort zone. You know what I mean?

Matt Wappett 11:24

Yeah. That's interesting. I remember Christine showing pictures on Facebook of the activities that you guys would do. There were some pretty crazy things. I think I remember seeing one, it was Larry Freeze. Do you remember Larry?

James Steed 11:48

Yes, uh-huh.

Matt Wappett 11:49

I remember seeing Larry going like parasailing or something. You guys did some pretty amazing activities.

James Steed 11:57

Yeah, I mean, Larry was a gentleman or a self-advocate with profound cerebral palsy. He had no control over his body at all. The only thing that he had control of was his voice.

Matt Wappett 12:12

Yeah.

James Steed 12:13

And he really wanted to go parasailing. So they took him parasailing. And when they got back from Mexico, which this happened in Mexico, I pointed out to David that it's a good thing that nothing happened to Larry, because his parents were his guardian.

Matt Wappett 12:32

Laughter

James Steed 12:32

And I said, you did this without checking with his parents! *Laughter* And at the time, he was only like 19 or 20. And I'm saying, 'Oh my Lord, could we have gotten a lot of trouble.' So here's this boy, he convinced them, and I call him a boy because I'm so old. *Laughter* But here is this young man and he's conning David, who was the director, into letting him go up in this parasail, and they're duct taping him in. That's what they used, it was duct taping him in. There was no restraint free here. They duct taped him into the parasail and took off.

Matt Wappett 13:18

When he told that story... I don't think he was more proud than that moment he got to go parasailing. And I think the thing that he liked the best about it was the fact that it really made everybody worried. *Laughter*

Matt Wappett 13:18

Laughter I remember Larry telling the story. That was really one of the highlights of his life.

James Steed 13:24

It really was.

James Steed 13:38

Yeah, yeah, exactly.

Matt Wappett 13:40

Laughter Oh.

James Steed 13:44

And there was finally somebody that was really listening to what he wanted to do.

Matt Wappett 13:49

Yup. *Laughter* I mean that's the ultimate self-determination right there, right? Larry wanted to go parasailing, he figured out a way to make it happen. That's real self-advocacy right there.

James Steed 14:04

Right. Exactly. *Laughter*

Matt Wappett 14:06

Yeah. *Laughter*

James Steed 14:07

I would have been panicking. This is before we got involved in the self-advocacy movement in Idaho, and if I would have been in Mexico then I would've been like, we can't do this, David. His guardian would have a cow. *Laughter* We would be dead. We could be sued. But luckily, I wasn't there. *Laughter*

Matt Wappett 14:33

Yeah. You always have been the voice of reason, James.

James Steed 14:38

Laughter I don't know about that.

Matt Wappett 14:40

Laughter What is it about... Just thinking about this and this group you were involved with there in Pocatello making sure that people with disabilities can get outdoors. I know this isn't really one of the questions that I sent you, but I'm curious on your thoughts about the importance of allowing people with disabilities to take risks, and to do dangerous things. You brought that up several times. These are dangerous things that people are going out to do. Do you see that as an important element of helping people develop confidence and self-determination?

James Steed 15:22

I do in some ways. People have dangerous things they're doing at all times, you know what I mean? Whether it's living on their own, choosing to live on their own versus a facility or versus with mom and dad, or whatever it is. So when people with developmental disabilities who pretty much have to have at least some care during the day, if not 24 hours a day, they're taking risks every day. It's not necessarily doing something wild like you do in an outdoor program. But you said a word that doesn't belong in self-advocacy. And that word is, allowing. Allowing people to do this. Would somebody say that about Matt Wappett? We're gonna allow you to do this.

Matt Wappett 16:19

Yeah.

James Steed 16:20

Right.

Matt Wappett 16:21

Yeah.

James Steed 16:21

So I'm allowing myself to live where I choose to live.

Matt Wappett 16:26

Yup, I think that's a really important distinction. Yeah, you're right. The language that we use around that isn't always as accurate as it could be.

James Steed 16:37

Right, exactly. It's kind of like, for example, me, and I'm maybe jumping the gun here. But it's like where I live. I will be honest, I live in a facility. Number one, because I'm considered medically fragile, if you will, or whatever it is. But I also have mental health issues, that if I'm alone and my depression, part of my bipolar is kicking up, I could end up doing real harm to myself. Where if I'm depressed and I get up there's always somebody awake. And they come in just like, if you want to get up, just like you want to get up [at] whatever time you want to get up, it's the same *inaudible*. If I want to get up at three o'clock in the morning if I'm having a rough time, they'll get me up and there's somebody always to talk to.

Matt Wappett 17:39

Yeah. That's actually a really good point. It's a choice, right? It's a choice that you've made.

James Steed 17:48

Right. It's a choice that I made. Whatever it is, you want to live... Okay, when you say independence for everyone. They want to have the freedom to choose wherever they live. I choose to live here, because I feel safer mentally and that may be the biggest part of why I'm here. They give probably, at least get me 13 hours a day and I don't know whether they possibly give me 24. I don't know. But if they could get me 24, I'd probably go for it. But a major part of that is the mental health thing. But you never know when that's gonna kick up is the problem.

Matt Wappett 18:38

Yeah, that is true. I think it's interesting, I think there's a lot of people within the self-determination movement who would find it interesting that you were involved with the self-determination waiver in Idaho and advocating for people to live in the community on their own, and to hire and fire their own service providers, and everything else and yet, you've chosen to live within a facility for your own purposes. There are some people who might see that as contradictory.

James Steed 19:15

And it's not contradictory, and that's the thing. I really feel that it's not contradicting, because I'm making that choice. I'm making that freedom of choice. It's always, what is it? Freedom, control, choice, and responsibility.

Matt Wappett 19:33

Yup.

James Steed 19:34

I have freedom. I have control. I have choice. And hey, I'm responsible for my actions here just like anyone else.

Matt Wappett 19:42

Yup.

James Steed 19:43

I'm responsible for me. So if something happens, it happens.

Matt Wappett 19:52

That's great, I appreciate you bringing up those sort of pillars of self-advocacy. You're exactly right. Yeah. I think a lot of times we overlook that, we assume that self-advocacy means living in the community independently on your own, but that neglects choice, in some cases, right?

James Steed 20:11

Exactly. And who's to say I can't be involved in the community, not only here but in a broader sense in Clearfield, where I'm living now, or in the state of Utah, or at the national level. Like I'm doing on the two different boards that I'm on.

Matt Wappett 20:30

Right. Right. You mentioned earlier, your struggles with mental health and that's a big reason why you have chosen to live where you live. When did you start to recognize your challenges with mental health?

James Steed 20:41

Well, as I go back, as I look back, because this is more of a looking back, I see where I would get manic, early. I would call it manic, early in my mind, where things would be just out of control. My mind, my brain would be just totally out of control. And I didn't know why everybody else said oh because he's spoiled or because whatever the reasons. Mainly people would say it had something to do with my self-esteem or whatever because I have a developmental disability. But when I'm talking wild, I'm talking wild. I was 15, 15 or 16, and I got so mad at my sister, this was one of those times where I didn't have control. I really truly didn't have control of what was going on, with my brain or in my life and stuff. I mean I'd get so mad at my oldest sister, that I

went to the utensil drawer and tried to pull out a knife and I ended up pulling out a butter knife. Now the family laughs about that story now. But as I look back on it, how manic I was and I don't know whether you'd call it sprung out, stressed out or whatever it was, but I couldn't sleep. I was up. It was a pretty wild time. I guess that's back when, as I look back, that's when those things started happening. When I started to notice it, it's probably about only 15 years ago, I realized what it was going on. About 15 years ago, I started on my first mental health med (medication). Then about 10 years ago, it started to where the depression got so bad. I ended up in a number of facilities, while they tried to figure out what meds would be best for me.

Matt Wappett 22:44

Right.

James Steed 22:45

And as I got older, it has gotten... I don't know whether it's my brain or what it is, but it has gotten worse. Because in the last year and a half, I spent six weeks in a mental health facility, two weeks at a time. So it has affected my life in a lot of ways. 15 years ago was probably when I knew I had a problem.

Matt Wappett 23:18

Yeah. You're currently, as I mentioned earlier, on the Mental Health and Developmental Disabilities National Training Center's advisory board and one of the reasons that we selected you to be on that board was a presentation that you gave, that somebody sent. I think it was Christine from the DD Council in Idaho who sent the recording with your application to sit on that board. And it was you, talking very candidly about the struggles that you face with dealing with your mental health, but also accessing mental health supports.

James Steed 24:01

Well, yeah. I mean, they were there but they always went back to my- the problem was with my developmental disability, my cerebral palsy.

Matt Wappett 24:10

Right.

James Steed 24:10

They never looked at the fact, and this is even 10 years ago, they never looked at the fact that it could be something like bipolar disorder. They always looked at the fact that it had something to do with my self-esteem, my lack of self-worth, whatever it was, even 10 years ago, Matt. To be honest with you, I was not diagnosed with bipolar disorder until 10 years ago. The stuff was going on and everything, but it wasn't until one counselor and one doctor, at a facility that they sent me to, figured out that, 'hey, he's got he's bipolar.' And that's when they diagnosed me with bipolar disorder. As I look back through my life, they hit it dead center.

Matt Wappett 25:19

That's really interesting and yet, unfortunately, I don't think it's uncommon. We call it, in the technical term, it's called diagnostic overshadowing. Where the disability, the physical aspect of the disability overshadows.

James Steed 25:38

Exactly.

Matt Wappett 25:40

-And other issues. And yet, it's unfortunate, that you had to go for so long not getting the supports and the recognition that you needed because everybody assumed it was because of the cerebral palsy.

James Steed 25:56

And the lack of self-worth because of that.

Matt Wappett 25:59

Because of that, right. You just weren't confident enough. *Laughter*

James Steed 26:05

And you and I both know that that wasn't the case.

Matt Wappett 26:08

Yeah.

James Steed 26:09

Because think about it, I was speaking up for myself, way back there. To say that it was my self-worth or my self-esteem, as I look back, it was kind of laughable. It's kind of laughable now, because I know how I was 10 years ago. There would have been no way or 12, 13, 14 years ago, there would have been no way that that was the case. That it was my cerebral palsy or my physical disabilities.

Alex Schiwal 26:42

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