Disability Deep Dive Episode 103: Out Loud and Unapologetic: Squirmy & Grubs Take on Stigma and Storytelling

Jodi Beckstine (00:00:14):

What does it mean to live out loud when the internet feels entitled to your body, your relationship, and your mental health? How do you tell your story honestly without letting the loudest or cruelest voices take control of it? And what does it look like to set boundaries while still choosing visibility? That's what we're talking about today on out loud and unapologetic Squirmy and Grubs take on stigma and storytelling. This is Disability Deep Dive.

Keith Casebonne (00:00:38):

Welcome to Disability Deep Dive. I'm Keith.

Jodi Beckstine (00:00:41):

And I'm Jodi.

Keith Casebonne (00:00:42):

Today's conversation is about storytelling, mental health, and what it really takes to show up online as your full self, while also protecting your wellbeing.

Jodi Beckstine (00:00:51):

Our guests are Shane and Hannah, the creators behind Squirmy and Grubs. Through their videos, they challenge assumptions about disability, relationships, and intimacy, while also being honest about the realities behind the camera.

Keith Casebonne (00:01:04):

In this episode, we talk about navigating mental health challenges, responding to harmful commentary, setting boundaries as partners and creators, and deciding what to share and what to hold close.

Jodi Beckstine (00:01:15):

Let's get into it with Shane and Hannah.

Keith Casebonne (00:01:19):

Hi, Shane and Hannah. Thank you so much for joining us. Welcome to Disability Deep Dive. To start, can you introduce yourself for listeners who may be meeting you for the first time?

Shane Burcaw (00:01:28):

Yes. Thank you so much for having us. I am Shane.

Hannah Burcaw (00:01:33):

I'm Hannah.

Shane Burcaw (00:01:33):

And we are YouTubers and writers and disability advocates. And we're also married, just celebrated our five-year wedding anniversary.

Jodi Beckstine (00:01:48):

Nice.

Keith Casebonne (00:01:48):

Oh, congrats.

Shane Burcaw (00:01:51):

Thank you. For the last eight or so years, Hannah and I have been documenting our relationship journey and the ways that my physical disability colors that situation, and trying to improve the way that society understands disability. So again, really happy to be here.

Jodi Beckstine (00:02:14):

We're so glad to have you. You recently shared a pretty honest video about Shane's mental health challenges that you've had this summer. What led you to talk about that experience publicly, and what did that time period look like for each of you?

Shane Burcaw (00:02:33):

That's a good question. Oh, what led us to sharing that publicly? A lot of conversations. Hannah and I, over the years, have become very careful about what we've shared with the world, both for mental health reasons, wanting to protect our privacy and our state of mind, and then also safety and business reasons. I just wanted to never be inappropriate or anything like that. And so I felt like my journey with my mental health has been such a big part of my life, but I didn't want to share too early before I fully understood myself and what I was going through. I didn't want to speak from a place of ignorance or a lack of understanding with people, the wrong ideas while I was still figuring my own brain out.

(00:03:44):

So after starting therapy and doing a lot of self-reflection and conversations with Hannah, once I felt like I was making significant progress towards healing some of my mental health problems, or at least beginning on that path, it felt appropriate to finally share it, because ultimately, we hope that people who might be going through similar things or who know people going through similar things, can find our content about it helpful, and make people feel less alone because that is one of the big staples of depression and anxiety is feeling like you're very alone in that battle, but it doesn't need to be that way.

Hannah Burcaw (00:04:42):

Yeah, I think we always want to share both the good things and the bad things in our life. But for bad things, we found that it's better to share once we're at least partially through it. I feel like for a couple of things now, we've sometimes filmed during it, but just waited to release it till we're in a place where we can read comments that we might not like about it, stuff like that.

Keith Casebonne (00:05:04):

Don't read the comments, you know that.

Hannah Burcaw (00:05:07):

I know, right? I don't read comments, but if Shane has been posting all along and people were saying, "You're faking it," or whatever, that stuff can be hard to see when you're really in the moment. So I think just delaying it a little bit has been helpful.

Shane Burcaw (00:05:19):

Yeah. Part of the process was getting [inaudible 00:05:24], and that in and of itself is a huge undertaking. And I could not have done it if, like Hannah said, I was also reading comments from people that might not be helpful. So that's why we ultimately shared it.

Jodi Beckstine (00:05:43):

Yeah. I think it's very powerful, and I'm so thankful that you guys did that because I think it reaches many people. Mental health is something that we don't talk about a lot, and I think everyone can understand it. They either have issues themselves with dealing with mental health or they know someone that is, and I think it's really important to just put that out there. And I applaud you for that.

Shane Burcaw (00:06:09):

Thank you.

Keith Casebonne (00:06:10):

Yeah, I agree. And for all the haters and trolls out there with their nasty comments, the thing you always remember is that there's 10 times more people who are quiet, but really getting something out of it and hopefully improving their lives by hearing your story. So sometimes it's hard to remember that with the vocal haters.

Shane Burcaw (00:06:37):

Yeah. Thank you for saying that. Yeah, when we do public speaking engagements, we often get to meet many of the people that attend those events. And that's one of our favorite thing almost ever because we remember every time how much love and support there is out there.

Hannah Burcaw (00:06:56):

And that there are real people watching our videos.

Shane Burcaw (00:06:58):

Yeah, yeah. It makes it very human and not just these numbers and nasty comments that we see. So it's always a fun time.

Jodi Beckstine (00:07:07):

Yeah.

Keith Casebonne (00:07:08):

That's excellent. That's excellent. Well, when life gets heavy behind the scenes, as it often does, how do you set care and boundaries for yourselves and each other, both as partners and as creators?

Hannah Burcaw (00:07:23):

I think it's evolved over the years, for sure. We've been doing this for, like Shane said, eight years now. So I think we've adjusted how much we share and when we're filming, when things are just for us. I think that it's just taken a while to figure out the right balance.

Shane Burcaw (00:07:41):

Yeah.

Hannah Burcaw (00:07:42):

What do you think?

Shane Burcaw (00:07:43):

Yeah, it's funny, we talk about this a lot. In the beginning, we were ripping our camera out every minute of the day to film every tiny thing that we were doing. And that was great. In a way, now we're trying to do that more the way that we used to.

Hannah Burcaw (00:08:02):

It was so easy.

Shane Burcaw (00:08:07):

I know. Over the years, because of many, many reasons, we pulled back and we were more darted about our privacy and just living our life in the moment and not always filming it. And I think now, we're in a process of striking a balance between those two, literally setting up those boundaries that you speak about, trying to figure out what to film, when to film. So we're figuring it out, it's ever evolving. In our personal life, how do we set boundaries for caregiving and stuff? We really don't. Yeah.

Hannah Burcaw (00:08:51):

I feel like I really can't think of any problems or examples that we have.

Shane Burcaw (00:08:55):

I think we really love our nighttime routine of 7:00, 8:00, 9:00 PM watching TV together or a movie, or playing video games together, or doing separate hobbies, but in the same room, just having that quiet alone time at the end of the day.

Hannah Burcaw (00:09:21):

Yeah, we certainly protect that because it's very important to us.

Shane Burcaw (00:09:24):

Yeah, when we get invites at night, we're like, "Oh, are we giving up our Netflix time?"

Jodi Beckstine (00:09:34):

Yeah.

Shane Burcaw (00:09:36):

And then [inaudible 00:09:36], that really just goes hand in hand for us in our relationship, but we don't separate the two. This morning when Hannah was helping me get ready for the day, that was technically [inaudible 00:09:53], but we were also chatting about our dreams that we had, we had weird dreams, and chatting about what we were going to make for dinner tonight, just relationship stuff. And that was happening simultaneously without any kind of boundary that we set.

Jodi Beckstine (00:10:17):

Well, I've been a long time viewer of your channel, and one thing that I absolutely love about your channel is that you guys address very directly, and we had touched on this a moment ago, you address very directly ableist and cruel comments. You guys don't take any slack and any crap from that. So what goes into that decision for you guys to actually call those out publicly and the impact of those interactions, both on your mental health and your audience's mental health?

Hannah Burcaw (00:10:52):

Yeah.

Jodi Beckstine (00:10:53):

Deep question.

Hannah Burcaw (00:10:56):

I feel like the reason we initially began publicly talking about it is because it's in all of our comment sections probably. I stopped reading our YouTube comments years ago and I tend to only read Instagram comments right after I post. And if something goes viral, I will not read the comments, because that's when they get bad. So I feel like we initially talked about them because it was like, would we just all pretend at the same time that this isn't happening? Our supporters would be fighting with them in the comments, and it was just a

public thing. And then I think the only time that we take down comments is when they are aimed at other people, like our people, the viewers in the comments section, stuff like that. I feel like that's when we're like, if it's not specifically about us and you're just saying things about disabled people in general, we try to remove that. And obviously there's a lot and that would be a full-time job, but that's our boundary, is like, are you making this like a broad statement or are you saying something about us?

Shane Burcaw (00:11:58):

Yeah. And then when we usually respond, that's usually just like an accumulation of anger. We can take so much and then finally one puts us over the edge and we get really fired up and just spout off a sarcastic or snide reply. And that always feels really good [inaudible 00:12:24]. That's the other thing was like so many of the awful hummus we get can be so easily debunked or countered with either logic or just human empathy. And if they don't have either of those, then we win. So yeah, it's usually pretty easy to respond in a way that feels like we're putting them in their place.

Jodi Beckstine (00:12:57):

Yeah. Yeah, I'm usually watching and like cheering you on because I monitor ours for the channel and stuff, and it's hard to not take it personal. And you know that they're not necessarily... We hear the term keyboard warriors. They would never say some of these things to someone's face, they just feel very empowered.

Keith Casebonne (00:13:26):

Anonymity.

Jodi Beckstine (00:13:26):

It can take a toll and I'm glad you guys stick up for that and empower other people to not take that treatment either.

Shane Burcaw (00:13:35):

It's funny, you say about people hiding behind the keyboard on anonymity [inaudible 00:13:42].

Hannah Burcaw (00:13:42):

Anonymity.

Shane Burcaw (00:13:47):

Anonymity. Don't edit that out, make sure you leave that in there.

Keith Casebonne (00:13:49):

Absolutely. Got it.

Shane Burcaw (00:13:55):

When we go to speaking engagements and stuff or when we're out in public, people all the time come up and say that they recognize us from our channel and our videos. And we've never once had someone come up and say that they know us and that they don't support us. And by math, we've encountered them over the years. And I think it's funny that no one's ever felt the bravery to say, "I don't support you."

Hannah Burcaw (00:14:27):

Yeah, I think you're faking it to our faces.

Jodi Beckstine (00:14:30):

Yeah.

Keith Casebonne (00:14:31):

Right.

Jodi Beckstine (00:14:32):

I think the key word there, the bravery is that that's the key. They don't have that bravery.

Keith Casebonne (00:14:37):

Yeah, exactly. They're powers, really, yeah. Well, your videos often challenge assumptions about interabled relationships. How do you decide what myths or stereotypes to take on in your content, and has that approach changed since you started the channel?

Hannah Burcaw (00:14:56):

I think when we started our channel, it was more just us showing fun moments from our life. And we weren't fully aware of the stereotypes and myths around interabled relationships. We had had people come up to us and assume that I was Shane's sister. We had had a woman cry when she found out that we were a couple because she thought it was so amazing. Those were the kinds of things that were happening in person to us when we were out in the world, but it wasn't until we started sharing videos and then we would

get comments that we realized how hateful people could be, and that some people just straight up didn't believe that we could be a couple.

Shane Burcaw (00:15:35):

Yeah.

Hannah Burcaw (00:15:36):

So I think it definitely changed from there where we had a huge realization of like how badly people thought about relationships like ours.

Shane Burcaw (00:15:45):

And I think that the center of all of it is usually like our personal experiences. So the most effective way that we can make people, strangers care about an issue is if it directly affects us or we're directly experiencing it because people tune into our channel because when they see Shane and Hannah's lives... Oh, I'm speaking the third person that's never a good sign. My dog's barking.

Jodi Beckstine (00:16:23):

The dog agrees.

Shane Burcaw (00:16:25):

You can edit this out. What was I saying? I lost my train of thought.

Jodi Beckstine (00:16:32):

What were we talking about?

Keith Casebonne (00:16:37):

You were speaking in the third person.

Hannah Burcaw (00:16:39):

Oh, they come to our channel to see [inaudible 00:16:42].

Shane Burcaw (00:16:45):

Oh, yeah, yeah, yeah. And so they don't come to have us yell at them about disability issues, they come for the fun and the humor and the entertainment. And so we don't want our advocacy content to feel preachy or we're, again, yelling at people. And that means

that the best advocacy that we can do is simply [inaudible 00:17:14] about our lives. And when we experience ableism or inaccessibility or structural disability issues, we can show the world how they're affecting us, and explain how they might be affecting others. And it just feels very natural and organic and can even be entertaining at the same time.

Hannah Burcaw (00:17:35):

Yeah, it's best if it's a funny story. And there are some exceptions to that, like things that are very important, but don't affect us just because we have a level of privilege to not have it affect us. So we make videos about marriage inequality and disabled people not being able to be married, and use our love story as like a, "You guys know that we're married and that's a great thing, and look at what's happening to other people." So I think that there's ways to bring in other issues, even if it's not like this happened to us. But yeah, I think in general, stories that can make people laugh while we're also telling them something horrible is always the best.

Shane Burcaw (00:18:14):

It's a nice silver lining to be a YouTuber is that whenever anything awful happens, we get to realize in the moment, "Oh, this will make a good video though."

Keith Casebonne (00:18:28):

The built-in silver lining.

Shane Burcaw (00:18:30):

Yeah.

Keith Casebonne (00:18:30):

Nice.

Jodi Beckstine (00:18:32):

So sharing your personal stories with the world is very powerful, but there's a vulnerability to it. When you decide what you're sharing and what you're keeping private, how do you protect your safety and dignity when you open up about these subjects, not only online, but out in the real world when you're at these events and stuff and people are seeing you face-to-face?

Shane Burcaw (00:19:03):

Well, again, I think Hannah over the years has adapted to not reading the comments as often. I still read them every day, and I try to give Hannah a high level overview of them. I was like, "People love your posts." That's just what I say every day. And I handle taking down the horrible comments when they need to be taken down, things like that, because I've developed a very strong sense of apathy over the years for people doing that and I can handle it without getting too upset about it. When we're in person though, again, we don't really feel that we need to protect our dignity or our safety or anything like that.

(00:19:56):

We've always had great experiences meeting people that support our channel. And often, we wish we had more time to give them. They'd come up and share their story, and it'd be so great if we had more time to get to know everyone, but there's only so much time in the day. So we love doing live streams, which we haven't done in a while, that's on our resolutions for this year. But livestream events online allow us to connect with our online followers a little bit differently than just uploading a video.

Keith Casebonne (00:20:44):

For sure. Wow. Well, so what's coming up next for you, whether it's your channel, advocacy, or other projects?

Shane Burcaw (00:20:57):

What's coming up next for us?

Hannah Burcaw (00:20:58):

What's coming up next?

Shane Burcaw (00:20:58):

I have a book to write.

Jodi Beckstine (00:21:00):

Oh, nice.

Keith Casebonne (00:21:01):

Oh.

Shane Burcaw (00:21:02):

Yeah. I am writing my first fiction novel, which I've only ever written nonfiction, so I'm really excited about the project. And I've been saying that for over five years. But now that our latest nonfiction book, Interabled, is out there in the world, I can finally devote all of my mental energy virtually on my novels. So I have that actually on my list of goals for the year is to get my novel done and then get it ready for the world.

Hannah Burcaw (00:21:42):

Yeah.

Jodi Beckstine (00:21:43):

That's exciting.

Shane Burcaw (00:21:48):

Thank you. We're going back to LA.

Hannah Burcaw (00:21:49):

Yep. In a couple of weeks, we'll be back in LA.

Shane Burcaw (00:21:51):

Yep.

Hannah Burcaw (00:21:52):

Should be nice because it's cold here in Minnesota.

Shane Burcaw (00:21:56):

Yeah, but we're just lining up speaking [inaudible 00:22:01] and stuff for the year and thinking about our own personal travel that we want to do.

Hannah Burcaw (00:22:08):

Yeah.

Shane Burcaw (00:22:12):

Taking it day by day.

Jodi Beckstine (00:22:14):

Any plans to be back in Florida?

Hannah Burcaw (00:22:19):

Maybe for the QRSMA conference. We're not sure if we can go to that yet, but that's in June. And it's at Disney World, which is always a fun one to go to.

Shane Burcaw (00:22:26):

Yeah.

Hannah Burcaw (00:22:27):

So hopefully then, but otherwise we'll see.

Shane Burcaw (00:22:30):

Yeah, our best friends live in Tampa, so we're always looking for any excuse to get down there.

Hannah Burcaw (00:22:35):

Yeah.

Jodi Beckstine (00:22:35):

Yeah?

Keith Casebonne (00:22:36):

Oh, cool, cool.

Shane Burcaw (00:22:37):

Yeah.

Keith Casebonne (00:22:38):

Well, we'll definitely be following your journey along the way.

Jodi Beckstine (00:22:41):

Absolutely.

Keith Casebonne (00:22:41):

Yeah, yeah.

Jodi Beckstine (00:22:43):

Well, speaking of books, before we wrap up, we do a second segment called Our Deep Cut where we talk about media in disabled spaces. So we always ask our guests if there's a book, TV or film or even music that has resonated with you lately that you'd like to maybe share with our listeners.

Shane Burcaw (00:23:05):

That's a great question.

Hannah Burcaw (00:23:06):

Yeah.

Shane Burcaw (00:23:08):

Oh, I should have thought about it. We're both really bad at picking favorites like this.

Jodi Beckstine (00:23:14):

You can tell us more about your book.

Hannah Burcaw (00:23:17):

Does it involve disability?

Jodi Beckstine (00:23:18):

No, no, it could be anything that resonates with you and you'd like to tell the world about.

Hannah Burcaw (00:23:24):

What have we watched recently? We've watched some things. This is ridiculous, but I watched Freakier Friday and I loved it. I love that movie, which I don't really know why, I wasn't even a huge Freaky Friday fan. I liked it. But I really thought that Freakier Friday was so cute. We saw it twice.

Shane Burcaw (00:23:45):

Hannah said to me, "I think that Freakier Friday might be one of my favorite all time movies."

Hannah Burcaw (00:23:55):

Yeah, I don't know why. I just love it.

Jodi Beckstine (00:23:55):

Awesome.

Hannah Burcaw (00:23:55):

It was so nice.

Shane Burcaw (00:23:56):

Let's see. I am reading a very long book by, I can't remember his last name. It's okay. The book is called Tom's Crossing, and it's written by the author that wrote House of Leaves.

Hannah Burcaw (00:24:10):

Mark Danielewski?

Shane Burcaw (00:24:10):

Mark Danielewski, yeah.

Keith Casebonne (00:24:10):

Okay.

Shane Burcaw (00:24:19):

And it's one of the most immersive books that I've ever read, like the world that he created, which is like a parallel to our own world type thing. And the writing is just beautiful, it's very funny and very real, and it's taken me months to read it because of how long it is. But I talk about it all the time, and Hannah's like, "Oh my God, shut up and all this stuff."

Hannah Burcaw (00:24:46):

Or just finish the book.

Keith Casebonne (00:24:47):

Finish it already.

Shane Burcaw (00:24:51):

Yeah, that's what I [inaudible 00:24:53].

Jodi Beckstine (00:24:52):

Nice. Both of those are great recommendations.

Keith Casebonne (00:24:55):

Very cool.

Shane Burcaw (00:24:55):

Thank you.

Keith Casebonne (00:24:56):

Yeah, for sure. Well, it's been a real honor and privilege to have you guys on our show. Thank you so much for joining us. And as we said, we'll be continuing to follow you guys, and best of luck with everything coming up in this new year.

Shane Burcaw (00:25:12):

Thank you so much.

Hannah Burcaw (00:25:13):

Thank you. Thank you for having us.

Shane Burcaw (00:25:14):

Yeah, great to be here, thanks again.

Jodi Beckstine (00:25:16):

Keep warm.

Shane Burcaw (00:25:16):

Yes.

Keith Casebonne (00:25:16):

Keep warm.

Jodi Beckstine (00:25:21):

Stay with us, we're about to dive even deeper with this week's deep cut. Hi, for this week's deep cut, we're talking about the documentary, I Didn't See You There, directed by Reid Davenport. What's striking is how Davenport films it. It's quiet, observant, and intentionally uncomfortable in a way that makes you think about who's looking, who's being looked at, and who gets to control the frame. This film opens with a circus tent going up outside the filmmaker's apartment. It's such a simple image, but it carries so much weight. What did that moment set up for you, Keith?

Keith Casebonne (00:25:59):

Yeah, that was really interesting and apparently very unplanned when he was filming this. So the idea, that was really interesting, the idea of the historical background of the circus being the, "Freak show." And a lot of people that were in those shows were really just people with maybe rare disabilities, not even necessarily so rare disabilities, but just again, were framed as something for our entertainment. And the circus today is different, but yet I can see it still being a symbol for a lot of people of what it meant and just the historical challenges that a lot of people with disabilities have faced just being accepted.

Jodi Beckstine (00:26:52):

Yeah. Yeah, I started thinking about it. I didn't, of course, grow up during the heyday of the circus nor the freak shows, but I do remember going to the circus as a kid and not understanding the history whatsoever. I was there for the elephants. And so it makes me think about if I would've known then the history, how it would've affected me, and would I have noticed the stares and the things that happened to me as a child, would I have thought of it any differently having known that history, and would my parents have even felt different? I know my parents knew about it, but maybe in their minds too, society had changed, but really hadn't because they weren't disabled. So they weren't living through that lens either. But it brought me back to my childhood and thinking about that and the difference, knowing and not knowing what that means.

Keith Casebonne (00:28:06):

Yeah. Yeah, that makes a lot of sense. And just thinking through that lens, it was poetic in a sense that that went up as he's filming of, all things. It probably helped him guide the direction of the film, honestly.

Jodi Beckstine (00:28:26):

Yeah.

Keith Casebonne (00:28:28):

I'd be interested to see if he ever talked about that, what his intention was for the film versus what it became, because that circus tent suddenly popped up as he's filming.

Jodi Beckstine (00:28:38):

Yeah, even that comment, like, "I can't go out and film anymore without it being in the background." It's like there, it's just this ever present thing.

Keith Casebonne (00:28:44):

Haunting. Yeah, the past there, haunting him, the legacy of that thing. Wow, yeah.

Jodi Beckstine (00:28:53):

Which gives that overarching, he can't go out without being viewed for his disability. That metaphor was there and he was able to use it.

Keith Casebonne (00:29:04):

Yeah, for sure. Well, another thing that was noticeable pretty early on in the movie was one thing the film really refuses to do, which is that Reid doesn't really explain himself, he doesn't introduce his body, he doesn't center his face. How did that refusal land for you?

Jodi Beckstine (00:29:26):

It really let me see how in control he was, because he wasn't declaring, "Here I am, please understand me. This is the body I live in. This is my reality," he's saying, "I live here, this is me, but I'm watching you now. And you don't get access to me automatically." And that's powerful because so often, disabled people are open for interpretation in the world, or have to explain ourselves. There was scenes where he was on a plane. And he's just trying to get off the plane, get to the place where the transportation's going to pick him up. And they're asking him all these questions. "Where's your ID? Where's this? Where's that? Where's your boarding pass?"

(00:30:24):

And they're not asking anyone else these questions. And they need it for their documentation or whatever, but even the simple task of getting off a plane and getting to transportation has all these extra barriers to it and explanations to it. "Why do you need this? Why are you going here? Why are you doing that?" And so I think by him having such control over what we got to see of him and how he saw the world, I love that. It was so unique, and I thought it was great.

Keith Casebonne (00:30:57):

Yeah, and almost every other documentary that I've seen, the person with disability is on camera and we see that. But again, we're seeing it from the same lens that we see the rest of the world, which is our own viewpoint. And this was now a way of seeing things from Reid's viewpoint, and what it's really like as he's in his power chair zipping down the sidewalk and there's a curb cut and there's a couple standing there just talking seemingly

oblivious to the fact that he's a foot away from them. And if I remember correctly, I think he had to say something like, "Excuse me," or something like that.

(00:31:37):

And then they like, "Oh," and they seem to almost reluctantly move, which maybe I'm reading too much into that. I'll be fair and say maybe that's just, again, I don't want to say what these people were thinking. But it's like, boy, I get why you named the film I didn't see you there, because that was wild to me that he was that close and they're just oblivious to the fact that this individual needs to use that curb cut to continue moving forward. And I don't know. So that perspective was really fabulous, I thought. I was very happy to see that, and it did make the film very unique, as you said.

Jodi Beckstine (00:32:21):

Yeah, that made me so angry because the [inaudible 00:32:23], I'm sorry, but I'm not going to speed up and I'm not going to correct myself, just sorry and keep doing what I'm doing. I was just like [inaudible 00:32:32], because that's happened so many times. I'm sorry I'm in your way, but I'm not going to do anything about it.

Keith Casebonne (00:32:36):

Right. It's so degrading and depersonalizing.

Jodi Beckstine (00:32:42):

Yeah.

Keith Casebonne (00:32:42):

Yeah.

Jodi Beckstine (00:32:43):

Yeah, absolutely. So with the camera pointed outward, and at his wheelchair height, moving through the streets and the crowds, for me, it was honestly a strange perspective because of my height, because I'm an ambulatory wheelchair user, it was my perspective of the world. Some of the things that I saw, it's like that's how I view it. To me, it wasn't a look at this unique way to view it, it was like, oh, this is where I am in the world. And it changed the trajectory of the film for me because to me, it wasn't like a choice or a cinematic view, it was a view of the world like I see it. So did that perspective change the way that you experienced the film?

Keith Casebonne (00:33:32):

Yeah, absolutely. And I think that choice that he made of filming it that way, I think it benefits everyone. It sounds like this is how you feel about it, but the idea that filming from that perspective for someone who lives their life at that perspective, it's embolding and it's reality. It's like, you can see this is who I am and this is me getting around. And for those individuals who don't use a mobile device for getting around, chair scooter, whatever, it puts them in that position to see what that might be really like in a way that they're not going to have experienced, as I was saying before, seeing the barriers that he was having to get through. So I feel like it's a bold choice, and I think it works for whether you view the world that way or not. So it's not like you disenfranchise one group to make another group have a better perspective, I think it works for everyone. And yeah, made the movie just so much more, again, unique compared to others that I've seen.

Jodi Beckstine (00:34:51):

And I think it made some of the scenes a little bit more intimate because you weren't looking down at what was happening or to the side, you were in it. And I don't know, I just really appreciated it so much.

Keith Casebonne (00:35:05):

Absolutely. Absolutely. Yeah, yeah. Well, we're so used to disabled people being asked to show themselves, explain themselves, to justify themselves. And as we've stated, this film flips that dynamic. So instead of being looked at, Davenport looks back. Why does that matter?

Jodi Beckstine (00:35:25):

Well, I think it flips the power dynamic. We've touched on it before, disabled people are used to being watched and measured and commented on. And this documentary said, "No, you're not observing me, I'm observing you." And I think that can make people uncomfortable. Right at the end, there was something that summed it up for me. He was filming and there was a man sitting on a ledge, a little high wall or a short wall, and looked at him, looked at Reid, and then looked away, and then Reid moved and he looked back again and saw that Reid was still facing him and he looked away, and then Reed moved more.

(00:36:11):

And so the fact that the guy just kept looking, kept looking and kept looking, like he just was waiting for Reid to stop observing him so he could feel comfortable enough to observe

Reed unencumbered. And I've had those experiences. A lot of times, I just brush it off because it'd be exhausting. But every once in a while, I get a bee in my bonnet and I will just watch someone who's watching me, and then watch them look at me three, four, five more times. And every time they look and they see me still staring, they're just like startled. Almost like how dare I continue to look at them, just let me look at you in peace. So I just think it totally flipped that power dynamic, and I love that. I love that.

Keith Casebonne (00:36:55):

Yeah. I'm sorry, that example of what you just said is just so wild to me. The idea that it's almost like saying, "Hey," and again, I'm going to go back to the circus term, and of course, I don't mean this seriously, but it's almost like they're saying to you, "Hey, hey, I'm not the freak. You're the freak. I should be looking at you. Why are you looking at me?" Which is complete BS. That's just ridiculous.

Jodi Beckstine (00:37:25):

Absolutely.

Keith Casebonne (00:37:25):

But that mindset, that's what it seems like it would be to me. That's what they're thinking, whether I'm not sure they're thinking the word freak or anything. Again, I'm being dramatic, but the idea being that you're the one that should be examined, not the person doing the examining is ridiculous.

Jodi Beckstine (00:37:52):

Yeah. It's almost like, "Just let me look. What's your problem? Just let me look. I'm curious." Yeah, you could be curious. Everyone's curious. Everyone's curious.

Keith Casebonne (00:38:01):

Sure, sure.

Jodi Beckstine (00:38:02):

I like that shirt. Everyone's curious. You take a look and then you move on with your life. You don't need the series of looks. And you know when you're making someone uncomfortable by whatever you're doing. And the people that could tell and just don't stop... And it's exhausting because it's not one person a day when you're out in large groups, it's one person this and then 20 feet later, another person and then 50 feet later, another person. It gets tiring.

Keith Casebonne (00:38:31):

It does, yeah. Wow.

Jodi Beckstine (00:38:33):

The film explicitly connects this modern circus to the history of the freak show. So it's not so much a metaphor, but like lineage. What does the film suggest about how much really has changed?

Keith Casebonne (00:38:48):

Yeah. It's an interesting juxtaposition of past and present. Sure, the modern circus is different, but again, just in his daily interactions, and as we're talking about, the way he's observed and whatnot, that doesn't feel all that different than the way people used to look at the people in the circus back in the day. So maybe they're not all under one tent presented to you for an admission fee per se, but people still sometimes have that perspective of something's wrong or something that needs to be examined or is a spectacle out there for my pleasure to just check you out, what's going on here? So yeah, things have changed, but things have also stayed the same.

Jodi Beckstine (00:39:47):

Yeah. I think it goes back to what we were just saying about the stairs and stuff, but it bleeds into comments that people feel they're able to say to your face or online jokes that are made in shows and movies, and just the entitlement to your life and your access. We talked about a curb cut, and the people are just like, "Well, yes, they're doing something and they're doing a task, but did they have to do it right there?"

Keith Casebonne (00:40:21):

Right.

Jodi Beckstine (00:40:21):

"No."

Keith Casebonne (00:40:21):

Right.

Jodi Beckstine (00:40:23):

"People who are blocking the ramp with different equipment or whatever, yes, they're doing a job, they're trying to get it done, they're trying to be as quick as possible, but did they have to block the ramp with theirself? No."

Keith Casebonne (00:40:34):

Right.

Jodi Beckstine (00:40:35):

So they're deciding what he has access to. And then when he tells them, "You're blocking this or I need..." They get real like, "Well, I only need five more mutes, or I only need two minutes to get into my apartment." Why is your access more important than mine? So I think that leads to that. We don't, like you said, pay admission to see this or to judge this, but it's just now in the everyday life.

Keith Casebonne (00:41:07):

Yeah, yeah. It's still the same curiosity, the same to some people, I don't know, almost like entertainment or something. Whether it's under a tent or not, yeah, some people still see it that way.

Jodi Beckstine (00:41:22):

Kind of like with celebrities. You chose to be a celebrity, so you should get to be talked about. Well, you're disabled and you chose to be on public, so you deserve to be looked at and judged. It's that same mindset in my opinion.

Keith Casebonne (00:41:33):

That's interesting. Yeah. It's an interesting way of looking at it. Well, something else I found unsettling, there's a lot of unsettling things about this, but something else I found unsettling is that the film doesn't let the viewer feel safely distanced from that history we've been discussing here. It suggests that we're still participating in it. So we talked about this, but do you feel implicated as a viewer?

Jodi Beckstine (00:42:02):

Yes, and it brought back to me a little bit about what we're doing here on the podcast, because we have moved from audio podcast to video podcast. So in doing so, it's more than just a technical shift for me. I'm putting myself out there now for people. They don't just hear my voice, they get to see my face, they get to see my mannerisms, they get to see how I physically react to what we're talking about. And now, my body can become part of

the conversation should they choose it to be. So it's there, I'm putting this out for the public gaze.

(00:42:47):

And I don't think the film necessarily gives you a clean answer to what people are entitled to, but I do feel like anytime a disabled person puts themselves out there, and I wish more people were able to because I think the voices are so important, but the more we put ourselves out there, especially in the beginning, that judgment, that gaze is going to be more critical. And eventually, it will, for lack of a better term, become normalized and it will ease. But I think even now, it's still, again, you put yourself out there, you should be prepared to be judged and gazed upon and looked at.

Keith Casebonne (00:43:38):

Wow. That's an incredible answer in response to that. Honestly, I'm not even sure what else to add. It's a very interesting point. Yeah. I don't know, it's almost like there's an ethical question there of the observation of the watching, critically looking at these individuals. And I don't know. Again, I think a lot of us to do with the filming perspective. And seeing it from Reid's eyes, it hopefully makes the audience think about their choices and how they might react if they encounter someone themselves in public maybe differently.

Jodi Beckstine (00:44:26):

Yeah. Absolutely.

Keith Casebonne (00:44:28):

Yeah.

Jodi Beckstine (00:44:29):

Absolutely.

Keith Casebonne (00:44:29):

Yeah.

Jodi Beckstine (00:44:31):

So there's a lot of restraint in this film, but there is some anger in it, it's not always loud. And it can be political and not very explanatory. So why do you think Reid chose to use that tone to let this anger come out every once in a while?

Keith Casebonne (00:44:52):

Yeah, I think it was interesting. There were some times that I was expecting that he was going to get a little more angry than he did. And then honestly, there's a point where he gets so angry just for one moment that because the tone was that softer tone, that moment of anger, it made me sit up and almost feel like, I don't want to say uncomfortable, but everything changed. Everything just changed at that moment. And I was just like, "Oh my God. Okay, I get it. I get it." It's almost like he's holding it in, and just trying to just be, "Okay, I'm trying to get through my day. I'm trying to choose my battles. I'm trying to decide what to react to, what not to react to."

(00:45:46):

And then at a point, there's like the last straw. And again, his anger is private. So I don't want to go into the scene too much in case people watch this later, but he's still not showing that anger really to that extreme in front of anyone, but you can feel just how much everything has been really getting to him. And everything just flipped at that point. And I was just like, "Wow, what a moment. What a moment." I was not expecting it, and I'm sure that was the point. It was interesting. So yeah, that's something I got from it, just the saving it up and showing how it... It's like a slow burn.

Jodi Beckstine (00:46:42):

Yeah. And once the dam breaks, it's there.

Keith Casebonne (00:46:46):

Yeah.

Jodi Beckstine (00:46:46):

There was one scene that we had already talked about, so I'll bring that one back up about the getting off the plane and asking for all this information. At first, it shocked me because he was getting a little brisk with them, and like, "What do you want?"

Keith Casebonne (00:46:59):

"Why do you need this?"

Jodi Beckstine (00:47:01):

And asking them questions. And at first in me, I was like, "Why is he acting like that? " And I thought to myself, I would just comply. To make things easier for everyone, I would just get

out of the stuff and I would just comply and I would apologize for holding things up. And I started thinking to myself, but why? Why? Why is he doing that? And the reason is because no one else is being asked those questions. And even me had to think the scenario through because it's instinctive to just comply and apologize. I apologize for asking people to get away from the curb cut. "I'm sorry, but I need to get down this curb." Why am I apologizing?

Keith Casebonne (00:47:42):

Why are you sorry? Right, exactly, exactly.

Jodi Beckstine (00:47:43):

It's just instinctive. And I think him showing just the fed upness of, "I shouldn't have to apologize for being in this space, for living my life, and you shouldn't have to go out of your way to ask me things and require things from me that you don't require from anyone else. And I know the exact scene you're talking about, I think it's just all of those things accumulating because who knows how many times things like that happen throughout just leaving his house, going to the grocery store and coming home, how many things he had to deal with, and then the last straw.

Keith Casebonne (00:48:23):

Yeah. Yeah, absolutely. I keep thinking about how often disabled people are expected to just be grateful or inspiring or instructive. And the film doesn't do any of that, clearly, it does not do any of that. So what do you feel like it gives us instead?

Jodi Beckstine (00:48:42):

I think it shows you the cost of being disabled in the world right now. He touches a little bit on about where he came from versus where he's living now. There wasn't a lot of transportation and accessibility things for him where he was. He has those things now where he's living, but there's a cost to it. It doesn't just like, "I went from point A to point B and point B is so much better. Point B is better for certain things, but it's worse for others." And I think he's displaying the cost of what it is for a disabled person to just be, to just live. And for some, it's a huge cost. For some, it's not as much because everyone's lived experience is different. But I feel like there's always a cost, and he shows that, what it is for him.

Keith Casebonne (00:49:40):

Yeah. That's interesting. Yeah, yeah. Right, it's like a world of trade-offs. It's like no matter where you go, yeah, so where he lives now overall is better, but it's not like it's a utopia or

anything, it's still got its issues and trade-offs. Yeah, that's a really interesting perspective that I took to some degree, but until you said it, I didn't really fully think about those trade-offs, like how it compares. And it's really interesting, I almost want to go back and rewatch some of the scenes that illustrate that because I think to some degree, I didn't fully grasp that. So that's really interesting. Yeah. I feel like there's a lot of space for unresolved feeling in the film where, again, he's just living his life. He's not supposed to be inspiring, or he's not supposed to be educating people about his disability or whatever.

(00:50:51):

So it's left without telling you how you should feel or not feel, or feel how you want to feel, and it just leaves that up to you. It just leaves that up to the viewer, how they take it. It's not preachy. It's very subtle in a lot of ways. I'll be honest, the first 15, 20 minutes, I felt it was a little slow. I was like, "Okay." But it makes more sense then as you watch it further and things happen and things change that you suddenly get that first whatever, 15, 20 minutes and what that tone is about and the contrast later. I have to admit, I didn't even really quite get it at first. I'm just like, "Okay, what's going on?" Boy, then it hits.

Jodi Beckstine (00:51:48):

Yeah.

Keith Casebonne (00:51:48):

Yeah. Yeah.

Jodi Beckstine (00:51:50):

And I think that's because you live and work in this disability space.

Keith Casebonne (00:51:56):

Sure.

Jodi Beckstine (00:51:56):

So for you, it wasn't anything that you hadn't seen or heard before.

Keith Casebonne (00:52:00):

That's fair, yeah.

Jodi Beckstine (00:52:01):

And I agree that you're just like, "Yeah, this is it, this is the thing." And then it starts building up. But it doesn't tell you what to think.

Keith Casebonne (00:52:10):

Nope.

Jodi Beckstine (00:52:12):

I think it's asking you to notice how you look at people who are disabled and what you expect from them, and I think it tries to make you uncomfortable. So ultimately, what do you think it's asking the audience to take away from it?

Keith Casebonne (00:52:29):

I think ultimately, I think it questions how we view disability in general. Again, the whole perspective of how it's filmed, it's different, it's unique, and it gives viewers a different way of looking at things. I've seen a lot of documentaries about disability, films, fiction, nonfiction, and this might be the only one that I've seen fully filmed in the perspective it's filmed in. And I think it's probably, in a lot of respects, the most powerful one that I've seen, just because of that perspective and making you think differently. The whole thing's about visibility, right? It's called I Didn't See You There. And it's like he's invisible when he needs to be visible, and he's visible when he just wants to be invisible, if that makes sense.

Jodi Beckstine (00:53:30):

Yeah.

Keith Casebonne (00:53:31):

He's invisible when he's trying to get down the sidewalk and hits a curb cut and someone's there and they don't seem to notice him, but then when he just wants to sit and wait for his public transportation to pick him up, he's being examined and looked at, and it's like everything's flipped. Can he just be who he is and not be either visible or invisible, just be?

Jodi Beckstine (00:53:57):

Yeah. Yeah, if he's sitting alone by himself, that means something's wrong. "We must help him because why else would he be alone and sitting? He must need something." And it's good Samaritans and everything, but then when he's trying to get somewhere, let's just be in his way and not bother getting out of the way.

Keith Casebonne (00:54:15):

Right, right. It doesn't make any sense. It doesn't make any sense. Right, right, yeah.

Jodi Beckstine (00:54:20):

I think it talks about, there's another scene that I won't go into too much detail, but it's at the very beginning, where it shows how isolated disabled people can be and their experiences can be by those systems that are set up. And it has to do with a subway and how people get off a subway, they go up the stairs and they go out into the street and they live their lives, and the way that a disabled person, the hoops they have to jump through, no pun intended, to get out, and all these systems that, "You have to go here and do that," can be so isolating.

(00:54:55):

And I think he also shows that for the fact that he is the cameraman, he is the narrator, he is the star, it's all alone, it's him, that's it. It's very isolating in the experience that he has. And I think it's just like the message of how the systems and how people treat people with disabilities, how isolating it can be. And I think that's what it's trying to show the audience, that it can be a very lonely place, but it doesn't have to be. It can be very isolating, but it doesn't have to be.

Keith Casebonne (00:55:35):

Well, and then I don't know if this is the same scene you're referring to or not, but to flip it the other way, there's a scene where he's getting on the train and they're helping him get in, and the way that they need to strap him in for whatever reason, he's needs to turn around. And he's like, "Why?" And they said, "You got to face the other way." And I don't know, maybe the car is designed that way. I don't know, they don't really explain it or anything. But he complies and he turns around, but then that view from the camera, everyone is just staring, just watching.

(00:56:08):

And I felt so uncomfortable inside. And it's like now I'm being put on display, because for some reason you designed this thing that I have to face the other way. And just getting in, I'm thinking to myself, well, what if you have a motion sickness issue or something? Some people can't be backwards, and they'll get sick. I don't know. Not the issue here, but just in my head, I'm like, why does anyone design things that way? But then when I just saw the perspective, and talk about, again, the filming perspective as a first person viewpoint, I thought to myself, I would hate this deeply, just the rest of the train is just looking that way.

Literally, my heart, I was truly, truly uncomfortable in living the moment there for a moment.

Jodi Beckstine (00:57:04):

Yeah.

Keith Casebonne (00:57:05):

Yeah.

Jodi Beckstine (00:57:06):

There's a theme park in Florida, which will remain nameless, that I rode the bus system for the first time when I first started using a mobility device, and they have a similar thing. And it becomes an event.

Keith Casebonne (00:57:24):

Yeah. Oh, wow.

Jodi Beckstine (00:57:24):

And the getting on, the whole bus has to stop, the driver has to get out, there has to be this whole big thing. And there is a moment of facing backwards. And you're in this bus that's just packed to the gills with children and adults, and everyone is just watching the whole process. And you're like the Lion King show all of a sudden, you're just part of the event. I rode it once and then I've never used that transportation again because it becomes such a big deal. I just want to roll on, sit down, get to my destination, get off. I don't need the whole rigmar roll.

Keith Casebonne (00:58:02):

Wow. Wow. Yeah. That's interesting. Well, all right, so to wrap up, who do you think this film is for, because it doesn't feel like it's trying to persuade everyone?

Jodi Beckstine (00:58:16):

This is just my take, it may be completely off, but I think it's for disabled audiences first and then for anyone who's willing to be challenged because it's not really even asking for understanding or to be liked, it's just saying, "This is my experience. This is how it is. What do you think?" And I think disabled people just get it. And they'll see moments of their experience in what he's talking about. There'll be moments like I had where it's like, "Oh, I didn't think about that," or, "I am doing that so much differently than how he's doing that."

And then the people who don't have those lived experiences but are willing to be open and challenge their thinking, I think it's for them. I think people who aren't willing to challenge themselves might actually be offended by some of it.

Keith Casebonne (00:59:14):

Or at least not get it at all.

Jodi Beckstine (00:59:16):

Yeah. Just be like [inaudible 00:59:18].

Keith Casebonne (00:59:17):

Not sure what the point is.

Jodi Beckstine (00:59:18):

I think they'll think he's mean. I think they'll think he's mean.

Keith Casebonne (00:59:21):

Wow.

Jodi Beckstine (00:59:22):

And his mom touches on that. I won't go into it, but his mom touches on that a little bit. He's having a conversation with her, and they discuss that a little bit. And I think most people would be like, "He didn't have to react like that." And they just won't understand. But hopefully if you're watching it, they might get a better insight.

Keith Casebonne (00:59:43):

I would hope so. Yeah, I would hope so. But yeah, it's really interesting. I do feel like everyone could potentially get something from it that's different, as I mentioned earlier, from most other documentaries or films regarding disability that I've seen before. I think the potential there is for something new for everyone. It's just there are those people that won't be willing to let that in and see it. And probably if this film doesn't do it, nothing would, unfortunately.

Jodi Beckstine (01:00:16):

Yeah.

Keith Casebonne (01:00:17):

Yeah. Well, I Didn't See You There isn't an easy watch, but it's not meant to be. It's a film that asks us to confront the legacy of spectacle, and to sit with the discomfort of being a witness rather than a consumer.

Jodi Beckstine (01:00:31):

It reminds us that representation isn't just about being seen, it's about who controls the frame, who benefits from the gaze, and who gets to look back.

Keith Casebonne (01:00:40):

Thanks for spending this time with us in this deep cut. These are the stories that don't wrap themselves up neatly, and that's often where the truth lives.

Jodi Beckstine (01:00:47):

That's right. See you next time.

Keith Casebonne (01:00:53):

That's a wrap on today's episode. We're grateful to Shane and Hannah for trusting us with their story, and for modeling what it looks like to lead with honesty while still protecting themselves.

Jodi Beckstine (01:01:02):

Yes, their work reminds us that visibility doesn't mean obligation, and sharing doesn't mean surrendering control. We have links to Squirmy and Grubs in their work in the show notes.

Keith Casebonne (01:01:12):

If this conversation made you reflect on how you engage with creators, with partners, or within your own boundaries, sit with that. These stories matter because people matter.

Jodi Beckstine (01:01:22):

Thanks for listening.

Keith Casebonne (01:01:24):

We'll see you next time on Disability Deep Dive.

Jodi Beckstine (01:01:26):

Disability Deep Dive is a podcast that is brought to you by Disability Rights Florida, where real conversations about life, culture, and ideas meet the lived disability experience. Follow us on YouTube, Spotify, and wherever you get your podcasts. You can also find us at disabilityrightsflorida.org/podcast.