What Happens After? Life Beyond the Film – with Patrice Jetter & Garry Wickham

Disability Deep Dive – Episode 113

[00:00:00] **Patrice Jetter:** "There's no reason that I can't be a movie star and your crossing guard."

[00:00:05] **Jodi Beckstine:** So what happens when the documentary ends, the cameras stop rolling, and life goes on?

[00:00:11] **Keith Casebonne:** Sometimes what comes next is just as interesting as what made it into the film.

[00:00:19] Welcome to Season Four of Disability Deep Dive. I'm Keith.

[00:00:22] **Jodi Beckstine:** And I'm Jodi. Today we're catching up with Patrice and Garry from Patrice Jetter: The Movie to talk about what life has been like since the documentary.

[00:00:29] **Keith Casebonne:** In our new segment, The Reef, Kelly and Avery from Wheel Talk discuss the power of friendship and shared experiences. Plus, our Deep Cut explores adulthood and independence through The Ride Ahead.

[00:00:39] **Jodi Beckstine:** We've got a lot to talk about, so let's dive in.

[00:00:43] **Keith Casebonne:**

[00:00:43] **Keith Casebonne:** Before we begin, we'll provide visual descriptions for listeners who may benefit from that. I'll start. Uh, again, I'm Keith. I'm a white man with brown hair and eyes, a graying beard, and I'm wearing a green shirt.

[00:00:54] **Jodi Beckstine:** And I'm Jodi, a white woman with blue eyes, glasses, and blonde hair, and I'm wearing a green sweatshirt.

[00:01:00] **Keith Casebonne:** Patrice and Garry, would you each like to give us a brief visual description of yourselves?

[00:01:05] **Patrice Jetter:** Um, I'm Patrice. I'm African American female with short hair, and I'm wearing a pink MTV shirt.

[00:01:14] **Garry Wickham:** Nice. Yeah. And I'm Garry, a white male with pepper... uh, salt and pepper hair, wearing a red, uh, U- uh, two, thou- uh, 250 year anniversary shirt for the, uh, the country.

[00:01:37] **Keith Casebonne:** Cool.

[00:01:38] **Jodi Beckstine:** Very nice.

[00:01:39] **Keith Casebonne:** All right.

[00:01:40] **Jodi Beckstine:** All right. Well, to start, could you guys introduce yourselves and tell us a little bit of what life has been like for you guys since filming Patrice Jetter: The Movie?

[00:01:49] **Patrice Jetter:** Well, the one thing that I'll say is e- ever since we, um, ha- did the movie, we're, we're well-recognized by folks now. People will walk up to us, "I saw your movie. I was very touched by it. I didn't know. I, I learned a lot. Is there anything I can do to help?"

[00:02:12] **Garry Wickham:** And as for, as for me, I get, I get the same thing. Uh, people come up and they, uh, say, "You were really something in the movie," and, "I like the jokes that you made during the movie," and everything.

[00:02:27] And being recognized, being somewhat of a celebrity like this, people seem to, if you speak, they seem to listen more.

[00:02:39] **Keith Casebonne:** Hmm.

[00:02:40] **Patrice Jetter:** We can do more... to help

[00:02:42] **Garry Wickham:** people.

[00:02:44] **Jodi Beckstine:** Yeah, definitely.

[00:02:45] **Keith Casebonne:** Yeah. No, that's awesome. Well, and you know, so a lot of people came to know you two through the movie, Patrice Jetter: The Movie, and so let's go back to the beginning of that experience.

[00:02:55] Um, when you were first asked to, to share your lives, uh, w- why did you decide to say yes? What, what made you want people to know your story?

[00:03:06] **Patrice Jetter:** I, I felt like when I got to be a certain age, that I had a lot of interesting things that happened in my life, and those stories needed to be told, especially because if I'm not here tomorrow, those stories will, um, become legendary, and I wanted to make an impact.

[00:03:32] Hmm. So I started off by taking the stories of my life, and I'm trying to make them into a graphic novel be- because without the pictures, the stories would never be believable. But depending on the type of humor you have, you might laugh at it, you might not, but I still think it was a great story to tell.

[00:03:59] And what was great was that when we decided to do the movie, we were able to incorporate some of the stories into the movie itself.

[00:04:11] **Jodi Beckstine:** Yeah, that was great Nice. Yeah.

[00:04:14] **Garry Wickham:** A- and as for me, when the, when they started first filming, uh, the, the movie itself was to be about Trish's, uh, life and everything else, and I was just gonna be like, you know, part of the movie, but you know, like a, uh, fill-in or whatever type thing.

[00:04:37] But then right in the middle of the filming, right a- pretty much right after we started filming, that was when I asked Trish to marry me, and- Mm ... that's when we found out that if we did get legally married, we'd lose our benefits. So we mentioned this to Ted, the director, and all of a sudden the light bulb went on, and he said, "He, this is something that we have to incorporate in the movie."

[00:05:10] He basically- Yeah ... fell off the chair when we told him. He couldn't believe it either. But, uh- Yeah ... he said, "This is something we have to incorporate in the movie," and it took off from, took off from there, and the movie's turned into something that I don't think anybody expected it to.

[00:05:29] Yeah. Yeah, I definitely didn't expect that the movie was gonna blow up to become as big as it had.

[00:05:38] **Patrice Jetter:** I, I thought in the beginning that I didn't really think that too many people would watch . Totally. Mm-hmm. I, I thought it was gonna be more like an, um, a revival of the, uh, ABC After School Special. Um, but it, it took on a life of its own, and it was... it's really been great.

[00:06:03] **Keith Casebonne:** As someone who's seen it several times, it... Uh, every time I see it, I think of more people that I, I have to tell about the movie and, and- Mm ... tell them, "You've got, you've got to watch it." Um, so you know, this, the movie was about your real life and your real relationship. What helped you both feel that you still had a say in how your story was being told?

[00:06:25] **Garry Wickham:** Because Ted was very open and he was very understanding about how if the story was gonna be told, it had to be told the right way. And he would ask us all, all kinds of questions, and if we said, "Well, well, we're not sure about this," or, "We don't feel comfortable about this," he's fine with working around it or changing it to fit how we felt about it.

[00:06:55] Because he himself thought that if we're gonna do this, it has to be as genuine and as real as can, can be, and he also wanted us to feel comfortable about it.

[00:07:10] **Jodi Beckstine:** Mm.

[00:07:12] **Keith Casebonne:** Oh, that's great. He made it so comfortable. Um, you know, and, and even with all that trust, you know, I'm sure it was still a little strange at times, uh, trying to live your normal life when there's a, a camera recording it. Um- Yeah ... what surprised you the... Yeah. What surprised you the most about making the movie?

[00:07:30] **Patrice Jetter:** Well, what, what surprised me the most was I wasn't expecting, um, I know that when they film that it's a lot of work- Mm-hmm ... but I, I wasn't expecting the cameras to be in the house at 9:30, 10:00 at night when it's almost- ... bedtime, and- Yeah ... sometimes- Yeah ... we had to remind him very politely- Yeah, like- ... it's time for you to go.

[00:07:56] **Garry Wickham:** Ted, it's 11:00.

[00:07:56] **Patrice Jetter:** Can you, can you- Yeah ... please

[00:07:58] **Garry Wickham:** leave? Because he, he- ... he's very good in what he does, very nice guy. He'd give you the shirt off his back if he, if it would help. Mm-hmm. But he gets so wrapped up in what he's doing- Yeah ... he forgets all track of time and everything else, and he's like-

[00:08:16] **Keith Casebonne:** Yeah ...

[00:08:17] **Garry Wickham:** the one night I said, "Ted, it's 11 o'clock, 11:00.

[00:08:21] We'd like to go to bed." And he's like, "Oh, crap." And he just grabbed his stuff and ran out of here like his pants were on fire. And, uh, no, but he was very nice about everything, and he was very understanding, and he always made sure that we were okay with everything, and that we had time to shoot and stuff.

[00:08:45] And he knew, like with her, she had the cross- she has the crossing guard job, and there are certain- ... hours that she has to- ... keep. So he was more than willing to work around that. And as for me, right now I'm not, um, I like to consider myself kind of retired, you know? And I, I have more time than she does, but he was more than willing to accommodate working around us.

[00:09:15] **Jodi Beckstine:** Mm.

[00:09:16] **Keith Casebonne:** Yeah. That's awesome, though. That's- That's great ...

[00:09:18] **Jodi Beckstine:** that's great. So when people finish watching Patrice Jetter: The Movie, what do you hope that they understand about the two of you that m- they may not have understood or even known before?

[00:09:31] **Patrice Jetter:** Well, they have a better understanding of what life really is like, especially when it comes to the finances.

[00:09:41] That as much as sometimes I would love to, like, go out and get a full-time job and make more money, it's just that at the same time, if I did do that, I would, I would lose my benefits. Because they don't know that there's requi- um, that there's, um, limits as to what you can do. A- and trust me, if I was able to do this stuff, I would have already done it years ago. It's just that- ... I need, as much as I like to work, I need my benefits more.

[00:10:18] **Jodi Beckstine:** Yeah.

[00:10:19] **Keith Casebonne:** Yeah, yeah.

[00:10:21] **Patrice Jetter:** And as for me, I,

[00:10:25] **Garry Wickham:** I have pretty good idea, you know, to learn how to do things. It might take me a little longer than the average person to do, do things, but my disability is not pretty much from the neck up.

[00:10:42] But you ask her, she might say otherwise. But but anyway, uh, my disability doesn't allow me to be quick about things. Like if you- ... need something done, it's gonna be done tomorrow or possibly the next day. And the more I try to speed up physically to do something, the slower I am. So for me to have- ... a full-time job- It's hard because there aren't too many jobs out there that will accommodate y- accommodate the fact that I can't move as fast as- you can and stuff. So I've spent most of my, the times that I have worked, I either volunteered or I worked in workshops. And workshops, if you know anything about workshops, they pay very, very little money, and I do mean very little money. You cannot, you cannot live on them. And again, it comes down to if it make too much money, then the benefits are cut, are cut off completely.

[00:11:55] **Patrice Jetter:** Yeah, just like in, in the movie, the s- ... the scene with the sheltered workshop.

[00:12:01] **Jodi Beckstine:** Mm.

[00:12:03] **Patrice Jetter:** Gluing f- uh, tips on flag poles.

[00:12:08] **Jodi Beckstine:** Right.

[00:12:08] **Patrice Jetter:** Yeah. That was, that job was the worst job ever in my life. I, I, I was having nightmares of being attacked by flags. And it was like, it was, it was like all these holidays required flags, so it was just back to back to back.

[00:12:27] Just from the, from the time you got to that place at 9:00 AM- ... in the morning until 4:00 PM, just putting that dot on the top, and just putting that tip on that flag.

[00:12:40] **Garry Wickham:** And I didn't re- I didn't realize until I started working in workshops that there's such a thing as less than a penny.

[00:12:49] **Keith Casebonne:** Yeah. Yeah, right.

[00:12:50] **Garry Wickham:** I mean it- Yeah.

[00:12:51] **Jodi Beckstine:** Hmm ...

[00:12:51] **Patrice Jetter:** it's

[00:12:52] **Garry Wickham:** imp- I- I'm like, "It's impossible. Why should there be le- less than

[00:12:57] **Patrice Jetter:** a penny?" I mean, the... Yeah. We, we framed, um, the paycheck and we put it in a scrapbook. Our friend Mike, who's also in the movie, brought home- ... a paycheck from the workshop for 13 cents. Oh

[00:13:13] **Keith Casebonne:** my gosh.

[00:13:14] **Patrice Jetter:** Geez. And, and you, you try going to the bank with some of these checks for less than a dollar. They're actually- ... like looking at it like going And then the other person goes,

[00:13:27] **Jodi Beckstine:** Yeah. And,

[00:13:27] **Patrice Jetter:** and it was just like some of those checks were bouncing.

[00:13:33] **Jodi Beckstine:** Oh, my goodness.

[00:13:34] **Keith Casebonne:** We've ... Oh, my gosh. I mean- P- pennies would bounce, wow. ... the

[00:13:37] **Garry Wickham:** most I've ever ... The workshops I've worked in, the most I've ever brought home in one week is $30, and that is- a big thing for me if it was $30 a week.

[00:13:51] **Jodi Beckstine:** Yeah.

[00:13:51] **Garry Wickham:** Luckily, at the time, most of the time when I was in the workshop, I was wor- living at home with my parents. I lived home with my parents until, uh, they both passed away. So I was able to put that little bit of money away and use it for whatever I wanted to use it for because- my parents basically helped with everything else and helped with the Social Security check and everything. It wasn't until I moved out on my own or I, after they passed away, I got a very quick lesson on how to take care of things. And luckily for me, the one thing that my parents did give me is I'm very good with money and hand- and handling my mon- money, even though I'm still a little short, but I'm a lot better than a lot of our friends and a lot of people that, uh, we know that are disabled, and I'm able to handle my own finances.

[00:14:59] **Jodi Beckstine:** Thank goodness for that.

[00:15:00] **Keith Casebonne:** Yeah. I, I, I have to tell you, not long after I saw the movie the first time, I, I came across one of those little, like, small, like, toy flags, and I just... I, I... As soon as I saw it, I remembered the scene from the movie, and I was like, I, I, I, I couldn't appreciate... I mean, like, seeing it just made me think, "This is awful-"

[00:15:18] "that, like, that this is... I, I know how this is made now, and it's, you know, for less than a penny, you know, a piece." Yeah. It's just... Yeah, it was just like you don't, you don't see them the same anymore after that. Um, but you know, I think also that's one of the great things about the movie is that you guys touched on so many subjects, but it really didn't become, like, overwhelming or, or- hard to follow. But, you know, you did. You talked about, you know, the supported workshops, and you talked about, uh, the marriage penalty, and you talked about, you know, the financial issues with losing your benefits, and you talked about transportation with the van. Like, all these different things. You know, this one movie really did, like, shed a lot of information on what the life of a person with a disability is really like.

[00:16:01] Um- Yes ... you know? And it's just, it's just fabulous. I can't think of any other movie that, like, has covered so many as- Usually they focus on one or two things and, you know- ... really dive in deep maybe. But y- y'all covered so much that I think it really gives people such a good picture, and I think it's... that's one of the unique things about the film. Um-

[00:16:19] **Jodi Beckstine:** Yeah, def- definitely.

[00:16:21] **Keith Casebonne:** For, for sure. Um, well, so, you know, it came out a couple years ago, right? Went on and, and received a, a lot of recognition, where you mentioned the Emmy. Um, what's life been like since? Uh, what has changed for, for you guys? And, and maybe even more interestingly, what hasn't changed? What's stayed the same?

[00:16:41] **Patrice Jetter:** Well, the one thing that I, I like is despite having a celebrity s-status, that I was still able to come back home and have a somewhat normal life. I'm still able to, um, go outside and get a ice cream without being mobbed by hundreds of fans. I, I can, I can, um, still maintain my apartment. I'm still able to go to my job And, and have the friends and, and still be me.

[00:17:15] **Garry Wickham:** Yeah. Biggest thing for me- ... I tease her all the time because we're very close. We've known each other for 35 years. We've only been together for the last, almost eight years now. But the thing is, we're always forever teasing each other, and there's been a couple places we've gone to a couple of schools to talk about the movie and to talk about to the other disabled community and the ki-kids.

[00:17:46] And for me, it's funny, uh, I've had, like, young girls in wheelchairs and teenage girls, they're following me around when I'm at the, where we're having the interview and the stuff and everything. They're following me, following me around, and she's, like, telling them, "Any time you wanna borrow him, I'll just drop him off and you can have him for the day."

[00:18:10] I'm like, "Thanks a lot," you know.

[00:18:13] **Keith Casebonne:** Thanks.

[00:18:13] **Garry Wickham:** But, uh, like she said, our lives have been basically normal. It's just, you know, once in a while it, uh, they'll notice, notice us and they'll start to talk to us, like you said, and say, "I didn't know exactly what you guys are going through. How do you, how do you manage it?"

[00:18:37] **Patrice Jetter:** My, my favorite was when, um, we won the Emmy, and I came back to work two days later, and one of the parents says to me, "You're back." and I'm like, "Well, yeah, why wouldn't I be?" "Well, we thought that when you got the Emmy that you were gonna move to Hollywood, and you weren't coming back and being our crossing guard anymore."

[00:19:02] Oh,

[00:19:02] **Garry Wickham:** wow. Aw.

[00:19:03] **Patrice Jetter:** And I was like, "No." I, I, I said, I just went... When the Emmy came home, I said, "One, they won't let me put the whole school on a trailer and move you guys to Hollywood with me." And, and, and so I said, "It was just easier for me to get on the plane and come back home and be with you guys." No. So I said, "The best part about it is that there's no reason that I can't be a movie star and your crossing guard."

[00:19:33] That's right. Yeah. So then they gave me the nickname Movie Star Crossing Guard.

[00:19:38] **Keith Casebonne:** All right.

[00:19:39] **Garry Wickham:** And w-

[00:19:40] **Keith Casebonne:** You don't hear that every day.

[00:19:41] **Garry Wickham:** Yeah. Like we, like we said, it's nice to talk about something and actually ha- because of our upper status now, people actually take the time and listen and- hear what we have, hear what we have to say

[00:20:01] **Jodi Beckstine:** Yeah.

[00:20:02] **Keith Casebonne:** Yeah, yeah.

[00:20:03] **Jodi Beckstine:** Otherwise, if we were anybody else, it'd be like, "Yeah, yeah, okay, get out of my face."

[00:20:08] Yeah.

[00:20:09] **Keith Casebonne:** Right. Well, you certainly travel a lot more. That's something that's probably changed, I

[00:20:13] **Garry Wickham:** guess.

[00:20:13] Yeah, that's more than I ever did in my whole entire life with my family. My, my thing was, my, uh, dad traveling when I was a ki- kid with the family, my family thought their vacation time was sitting on the couch watching TV, and I'd go to camp for two weeks.

[00:20:32] **Jodi Beckstine:** Yeah.

[00:20:32] **Garry Wickham:** That would be the extent of it. Oh, got it. Wow. And so all this traveling is new to me, and I'm completely amazed.

[00:20:41] And I didn't... Me, myself, being in a w- a wheelchair and not being able to really walk anymore, uh, it's like I didn't realize at times it's difficult to do some traveling. Especially when you go to the airport with the plane and everything else. But to come out on the other end, it's worth the hassle.

[00:21:06] **Jodi Beckstine:** Yeah.

[00:21:06] **Keith Casebonne:** Mm. Nice, yeah.

[00:21:08] **Garry Wickham:** And

[00:21:08] **Patrice Jetter:** No matter where we go, everybody is so nice.

[00:21:13] **Garry Wickham:** Yeah.

[00:21:13] **Jodi Beckstine:** Did you guys have a good time at Family Cafe when you came to Orlando this past summer?

[00:21:18] **Patrice Jetter:** Yeah. We, we had a really nice time. It was funny, when we almost got thrown out of our own, um, our own- Yeah ... screening, and then they realized who we were.

[00:21:28] **Garry Wickham:** Yeah, because they, they wanted people-

[00:21:30] **Patrice Jetter:** Oh, my

[00:21:30] **Garry Wickham:** gosh ... to wait until, like, a certain time before we came into the room that they were gonna have- Ah ... the screening and the- Q&A. And then we walked in, and they were getting ready to throw us out, and they're like, "Oh, geez. This is who- Oh, my God ... you know, it's supposed to be."

[00:21:49] Ah. And then afterwards, what really got to us was after the screening was over, the Q&A, they set us up outside in the hallway. And we were signing autographs and taking selfies and asking questions for an hour and a half. We couldn't believe it. Wow. The line, the line was unbelievable.

[00:22:13] **Patrice Jetter:** And, and we made sure that everybody who was in that line-

[00:22:18] **Garry Wickham:** Oh, yeah

[00:22:18] **Patrice Jetter:** got, got a selfie and a autograph. The security, um, guy was asking, "Uh, you just let us know when you want us to cut the line off." And we're like, "No, these people came here." "No, these people

[00:22:30] **Garry Wickham:** came here, and

[00:22:31] **Patrice Jetter:** we're gonna

[00:22:31] **Garry Wickham:** finish every last

[00:22:32] **Patrice Jetter:** one." "We- we're gonna see them." Nice. I, I even told people if they had to use the bathroom while they were waiting in line, I assured them that they wouldn't miss their spot.

[00:22:41] Aw.

[00:22:42] **Jodi Beckstine:** Aw. That's fantastic.

[00:22:44] **Garry Wickham:** Yeah.

[00:22:44] **Jodi Beckstine:** That's great. So now that everyone knows your story through the movie, um, what do you think your futures are like? What do you want for your futures?

[00:22:56] **Patrice Jetter:** We're ju- we're just gonna continue to keep doing what we're doing, getting the word out. We, we have folks that were asking if there was gonna be a s- a sequel- to the movie.

[00:23:08] **Garry Wickham:** Yeah.

[00:23:08] **Patrice Jetter:** I don't know if there's gonna be a sequel, but if there is, we'll cross that bridge when we get to it. And the funniest thing was that we did have a few friends that were trying to subtly submit their resumes that if we did- ... that they wanted to audition for a part in it.

[00:23:27] **Garry Wickham:** Yeah.

[00:23:28] **Keith Casebonne:** Oh, wow.

[00:23:29] **Garry Wickham:** And what we loved most where the movie debuted in the Toronto Film Festival-

[00:23:36] **Jodi Beckstine:** Mm-hmm

[00:23:36] **Keith Casebonne:** Hmm ...

[00:23:36] **Garry Wickham:** Uh, after it was over and we went to the reception afterwards, they had told us if we ever, if the laws ever do change and we're allowed to get legally married without losing our benefits, Canada will throw us the biggest party or the biggest thing you had ever seen.

[00:23:56] And we teased about wanting to have our wedding ceremony in the Toronto Blue Jays baseball field, because that's how- ... many people are gonna show up, we're gonna need the room. Oh, wow.

[00:24:08] **Patrice Jetter:** Yeah. We're gonna need to make that, we're gonna need to make the wedding an international tour because- Yeah ... with all the fans we have around the world, I don't think you're gonna be able to fit everybody in that one stadium.

[00:24:20] **Keith Casebonne:** Yeah,

[00:24:21] **Garry Wickham:** I

[00:24:21] **Keith Casebonne:** know. Wow. Right? God. Wow.

[00:24:23] **Jodi Beckstine:** Well, I'll keep my fingers crossed for a, for a, a sequel to the movie. I would love that.

[00:24:28] **Keith Casebonne:** Yes, indeed. Yeah. And I wanna go, I wanna go to Toronto for the wedding. Um.

[00:24:32] **Jodi Beckstine:** Yes, me too.

[00:24:35] **Keith Casebonne:** Yeah. Yeah. Well, so we, we wrap up our interviews with something a little different. Uh, we call it the Deep Cut, and it gives our guests a chance to tell us, uh, something that has influenced them, like a, a film, a book, uh, could be a TV show, a song, anything like that.

[00:24:51] Um, is there anything like that that's influenced your life or, or stands out to you recently or even just makes you happy when you see or hear it?

[00:25:02] **Garry Wickham:** Go ahead. I gotta think about that one. You put it on me. Nobody's ever asked me that.

[00:25:09] **Patrice Jetter:** The, the one thing that I, I do, and I teach it to the kids that I cross every day, that if you spend your life doing positive things, you won't have time to get caught up in negative things. Because there's a lot of negative things out here that c- you, that's very easily for us to get caught up in.

[00:25:36] **Jodi Beckstine:** Mm. Yeah.

[00:25:37] **Keith Casebonne:** So true.

[00:25:39] **Jodi Beckstine:** That's

[00:25:39] **Garry Wickham:** great.

[00:25:39] **Keith Casebonne:** I- yeah.

[00:25:40] **Garry Wickham:** I just keep telling people, "We gotta just keep, keep fighting," because I'm in... I know there's times when, uh, it feels like you're not get- you're not getting anywhere or anything like that, and you just gotta ke- keep going because God knows, as my witness, I've had my moments more than once, "Why am I doing this and why am I here?"

[00:26:06] But I've learned after doing the movie and everything else, and doing what I'm doing now, I'd like to think that God put me here just for this, for one of, this is one of the purposes he put me here, for to do this, because this law and all this stuff has to change.

[00:26:28] **Keith Casebonne:** Yeah.

[00:26:28] **Jodi Beckstine:** Yes, it does. Yes, it does.

[00:26:31] **Keith Casebonne:** For sure.

[00:26:32] Well, Patrice and Garry, thank you both for joining us, uh, and for trusting us to share another piece of your story.

[00:26:40] **Garry Wickham:** You're welcome. Yeah, you're welcome anytime. J- just let us know.

[00:26:47] **Keith Casebonne:** Awesome.

[00:26:48] **Jodi Beckstine:** Well, one of the things I keep thinking about from this conversation is that a movie can capture a chapter of someone's life, but can never capture the whole person.

[00:26:56] The two of you had a life together before Patrice Jetter: The Movie, and your wonderful story keeps going after the credits have ended.

[00:27:02] **Keith Casebonne:** To learn more about Patrice Jetter: The Movie, visit PatriceTheMovie.com. The film is also available to stream on Hulu.

[00:27:10] **Jodi Beckstine:** You can find more episodes of Disability Deep Dive at DisabilityRightsFlorida.org/podcast or wherever you get your podcasts.

[00:27:18] **Keith Casebonne:** And if you enjoyed this conversation, please like and subscribe to Disability Deep Dive on your favorite podcast platform, and share this episode with someone who might enjoy it too.

[00:27:29] **Jodi Beckstine:** Hi, this is The Reef, our brand new short segment from Disability Deep Dive, where we bring in more voices from the disability community for focused conversations about the ideas, experiences, and issues that matter to our community.

[00:27:43] **Keith Casebonne:** The Reef gives us a chance to dive into one specific topic with guests who bring their own experiences and perspectives to the conversation. Today, we're joined by two very special guests, Kelly and Avery from the Wheel Talk podcast. Kelly and Avery, welcome to The Reef. We are so glad to have you here.

[00:27:59] **Avery Roberts:** Thank you for having us.

[00:28:01] **Kelly Berger:** Yeah, we're excited to chat.

[00:28:03] **Keith Casebonne:** We are too. So real quick before we get started, we'll each give a brief visual description for our listeners. I'm Keith, a white man with brown hair and eyes, a graying beard, and I'm wearing a green shirt.

[00:28:14] **Jodi Beckstine:** And I'm Jodi, a white woman with blue eyes, glasses, and blonde hair, and I'm wearing a green sweatshirt.

[00:28:21] **Kelly Berger:** And I'm Kelly. I am a white woman with, uh, shoulder-length brown hair, um, brown eyes, and I'm wearing a white tee with a brown sweater.

[00:28:31] **Avery Roberts:** I'm Avery. I'm a white woman. I have brown eyes, brown long hair, um, and I'm wearing a blue top.

[00:28:40] **Jodi Beckstine:** Great. So Kelly and Avery, to start us off, could you each introduce yourselves to our listeners and tell us a little about the work you do on your podcast?

[00:28:50] **Kelly Berger:** Sure, I'll go first. Um, I'm Kelly. I am a rare disease and disability advocate, um, and I live with a rare form of congenital muscular dystrophy. I'm a power wheelchair user. And yeah, me and Avery host our own podcast called Wheel Talk where we dive into, um, topics about disability that often aren't overlooked or not discussed.

[00:29:11] And, um, yeah, we're ... just love to talk about, uh, anything rare disease or disability related, so..

[00:29:17] **Jodi Beckstine:** Great

[00:29:18] **Avery Roberts:** I'm Avery Roberts. I'm a rare disease and disability advocate. Um, and I do a lot of focus on disability inclusion and disability inclusion done right and what that means, just 'cause, um, I think a lot of people probably have a different interpretation of it, um, which, you know, is understandable, and I do as well. Um, but I'm really passionate about that and bringing just conversations to the forefront, um, that, you know, are often overlooked or misunderstood or just are very much at the forefront of the minds of those living with these rare conditions. But also kinda something that I'm also passionate about is just allyship.

[00:29:58] Um, and I think that's a huge part of the podcast as well. And so Kelly and I have a lot of different passions ourselves as advocates, and we're able to kinda work that into the podcast, um, at large as well. Hmm.

[00:30:13] **Keith Casebonne:** Awesome. Well, as you just mentioned, you both share the same rare disability. Uh, and I imagine that there are parts of your lives you understand about each other without even having to explain it very much. What's it like to have a friend who shares that experience, and how has that friendship shaped the podcast that you created together?

[00:30:30] **Avery Roberts:** It's honestly, I would say, probably hard to put into words how meaningful it is to have someone who just truly gets it, um, on a whole other level. Um, and I think, like, when you share a rare disease or a rare disability with someone, there are so many different experiences you don't have to explain. Um, and you can talk about something that, that happened, and instead having-- instead of having to give,

you know, the whole backstory, um, you know, of what happened, they already understand what, um, was difficult, why it was difficult, why it was possibly funny.

[00:31:14] Kelly and I are always, you know, laughing about God knows what, um, or why it really, you know, mattered to, to you. Um, and I think that kind of friendship has really been freeing for me. Um, and there's just a comfort in knowing that someone, you know, understands the things that other people may not see or notice or overlook. Um, and just, you know, the day-to-day challenges, the, emotions, the you know, maybe awkward or uncomfortable moments, but also, again, the humor behind it all and the really good parts of life. And so, I think that's really just shaped the podcast in a huge way, and we don't have to really approach conversations from, like, an outsider's perspective looking inward. And so we're able to have, more conversations from a place of just lived experience, and that really create a different kind of honesty and authenticity, um, and we can laugh, we can disagree, we can be vulnerable. That's a huge thing that Kelly and I have had to really get comfortable with, vulnerability with the podcast, um, and really talk about, talking about things that might otherwise be difficult to, to say out loud or to bring to the forefront.

[00:32:40] And so, ultimately, I think the podcast really grew out of that friendship, but also helped us grow as well as human beings. And it's not just about having the same diagnosis, but it's really realizing that when you find someone who understands part of your world, it's truly-- there's truly nothing like it, for sure.

[00:33:04] **Keith Casebonne:** Hmm. Yeah, for sure

[00:33:06] **Jodi Beckstine:** How about you, Kelly?

[00:33:08] **Kelly Berger:** Yeah, adding on to that, I would just say it's really just about, like, feeling seen when the rest of the world just overlooks disability as a whole. Just having someone that's like, "I see you, I hear you, I get you." Um, that really ... That's just really what it's all about. And, um, and you know, just someone that j- just doesn't just understand disability, but they, they live it every day with you so they can, um, you know, celebrate the little victories or, you know, all, all the things that come with living life with a disability.

[00:33:37] So it's ... Yeah.

[00:33:39] **Jodi Beckstine:** I love that so much. I think there's really something deeply meaningful about having someone in your life who can understand the experiences that, you know, you would otherwise have to explain to someone else. Uh, I, I wanna thank you both, uh, very much for sharing just a little bit of that friendship and, and your podcast, and for joining us on our very first episode of The Reef.

[00:34:01] **Kelly Berger:** Yeah thank you for having us.

[00:34:03] Thank you.

[00:34:05] **Keith Casebonne:** And, and thank you everyone for listening. You can hear more from Kelly and Avery on the Wheel Talk podcast. Uh, this has been The Reef from Disability Deep Dive.

[00:34:13] Stay tuned. This week's deep cut is coming up.

[00:34:22] **Keith Casebonne:** For today's Deep Cut, we're talking about The Ride Ahead, a documentary co-directed by Samuel Habib and his father, Dan Habib. The film follows Samuel as he enters adulthood and begins figuring out what he wants his future to look like.

[00:34:36] **Jodi Beckstine:** Samuel wants many of the same things young adults want. He wants to go to college, find meaningful work, build relationships, and eventually live on his own. But getting there comes with challenges that many of his peers may never have to consider.

[00:34:49] **Keith Casebonne:** So Samuel sets out to get advice from people who have navigated some of those challenges themselves. He connects with disability advocates, performers, and activists, including Judy Heumann, Ali Stroker, Maysoon Zayid, and Bob Williams to ask them about their experiences and what they've learned along the way.

[00:35:06] **Jodi Beckstine:** What's especially interesting is that Samuel is asking the questions, exploring his own goals and giving viewers a chance to experience the world from his perspective. Today, we're talking about The Ride Ahead and what it tells us about growing up with a disability and what it means to have the freedom and support to build the life you want.

[00:35:24] So at the beginning of the film, Samuel's trying to figure out how to, uh, navigate, uh, adulthood. And one of the first things he asks the mentors he's talking to is about the biggest risks that they've taken in their lives. I really just love that question.

[00:35:41] **Keith Casebonne:** Me too.

[00:35:42] **Jodi Beckstine:** Why do you think it's such an interesting way to approach, you know, this conversation about growing up and becoming independent?

[00:35:50] **Keith Casebonne:** Yeah. Yeah, I love the question too. I thought that was really, uh, an interesting one, and, and some of the interviewees thought like, you know, "Oh, that's an, it's an interesting question."

[00:35:57] **Jodi Beckstine:** Yeah.

[00:35:59] **Keith Casebonne:** So, you know, when y- when you're independent, you're older, there's more opportunities, right? And sometimes those opportunities come with risk. And so you have to figure out, you have to be able to make that decision, you know, is that, is this a worthwhile risk or not? And so, um, sometimes it is. Sometimes, you know, you need to risk a little bit to, to, to, to get the gains you want, and I think that's a really interesting way he's looking at it. Like it's very-- To me, that's very mature and adult of him already that he's aware of that, um, and asking people, you know, "What was like the biggest risk you took?" I think that was a really, you know, interesting, thoughtful question.

[00:36:35] **Jodi Beckstine:** Yeah, it made me think about, you know, my life in adulthood and any risks that I have taken. You know, for him, h- his required brain surgery, I mean, talk about a risk. You

[00:36:47] **Keith Casebonne:** Yeah,

[00:36:48] **Jodi Beckstine:** knows what can happen with that, you know? And then he talked to, uh, to Allie, who's a performer, and hers was, you know, moving away from home and attending college.

[00:36:56] **Keith Casebonne:** Yeah

[00:36:57] **Jodi Beckstine:** her, that's a, a, a very big risk. So there's such a, a spectrum, um, to life in general in

[00:37:04] **Keith Casebonne:** Yeah

[00:37:04] **Jodi Beckstine:** what people consider to be risky.

[00:37:07] **Keith Casebonne:** Yeah, yeah, yeah. No, I, I agree. And I, I think it was great for him to learn and, you know, uh, like you said, different, different activists had different answers. Um, and I think he discovers that, you know, even people who have been very successful, uh, have faced uncertainty and fear, and that's important.

[00:37:23] **Jodi Beckstine:** Absolutely. Yeah

[00:37:26] **Keith Casebonne:** Well, Samuel, as we mentioned, is also the co-director of the film alongside with his father. Um, so we're experiencing his journey through his own questions, concerns, and ambitions. How does that change the way we connect with Samuel and understand his story versus someone else telling his story a- and, you know, he's just participating in the telling?

[00:37:45] **Jodi Beckstine:** Y- y- you know, we've talked about this so much. It, it really challenges, um, how we traditionally tell, uh, the disability story. Normally, it's someone else telling the story, and we're viewing as an outsider. And with Samuel being front and center, asking the questions, doing some of the camera work, we really get

not only his perspective, but just, um, to get to know him, you know, as a person and how he lives in the world and deals with things that are going on around him.

[00:38:23] It ... We're, we're starting to see that more, especially as we're interviewing different people, uh, about things, and I, I love that. I love that, that the, the person who's the center of the story is the storyteller, uh, which is so important.

[00:38:38] **Keith Casebonne:** Yeah, absolutely. I mean, we totally experience, you know, things from his perspective. Um, and, uh, you know, he does the dual camera thing on his, on his chair so he can... You know, we, we see, we see what he sees, and then we also can sometimes see him and his expressions, um, how he, how he responds to things. Um, and I think that's great.

[00:38:56] And I think, you know, honestly, the only reason he probably was co-director is because I think maybe this was his first attempt at a documentary. His, his dad's a filmmaker and can help him along the way, so they sort of did it together. Um, I wouldn't be surprised if he does future projects, if we see him, you know, as the sole, you know, director g- getting this experience, and that'd be great. I hope he does more, more stuff.

[00:39:14] **Jodi Beckstine:** Yeah. It made me think about when I, when I sit on my mobility scooter and when I stand, I'm about the same height. Um, so I, I was thinking what Judy had said something about , um, you know, when she's around she's staring at butts all the time. And I have the same experience. Like, if I'm in a crowd of people, it's just a sea of, of butts everywhere.

[00:39:37] So I was thinking about maybe I should put a camera, um, on my, on my mobility scooter and just have it at my sight line just to give people an idea,

[00:39:47] **Keith Casebonne:** Yeah,

[00:39:47] **Jodi Beckstine:** what it's like to roll up to the counter, you know, at a fast food place or at a bank and, you know, you're, you're barely seeing over it. And here you're trying to, like, conduct business. And, you know, all they can see is your, the top of your nose and your eyes, you know, glaring at them. So I just thought that was a, a great, a great POV for him to have.

[00:40:08] **Keith Casebonne:** I think so. And coming soon, Jodi's documentary, A Sea of Butts

[00:40:12] Uh,

[00:40:12] **Jodi Beckstine:** A Sea of Butts!

[00:40:14] **Keith Casebonne:** That's right, yes. K- keep your eyes open for that. Or don't. I don't, uh,

[00:40:18] **Jodi Beckstine:** or don't. So Samuel talks with Judy Heumann about, the very different experiences that they had in school.

[00:40:28] **Keith Casebonne:** Hmm. Yeah

[00:40:29] **Jodi Beckstine:** Samuel attended general education classes and participated in school activities, while Judy spent much of her education, you know, before, uh, segregated, you know, she was in segregated classrooms.

[00:40:41] So what do you think that contrast tells us about, um, how educational experiences can shape someone's expectations about adulthood and, and what to expect?

[00:40:53] **Keith Casebonne:** Yeah. No, that's interesting. School experience certainly shapes what, you know, all young people believe is possible. Um, you know, people who have good school experiences generally do come out, like, more, uh, hopeful and positive, uh, about their, their chances to succeed. Um, uh, I think that's, I think that's huge.

[00:41:11] I mean, like you said, Samuel grew up alongside students without disabilities and was able to join, you know, uh, activities and clubs and whatnot that, that Judy wasn't able to, to, um, to, to do as well. And I think that, you know, that in- that being included, uh, you know, helps develop independence and, and confidence.

[00:41:32] **Jodi Beckstine:** Uh, and on, you know, the, the opposite side of that, I, I went to school before the ADA and after. Um, so grow- you know, as my younger years, I was very lucky in the fact that I was included in everything. It was a, a non-issue. But then by the time the ADA c- came about and things could have changed and I could have had accommodations, I didn't know to ask for them.

[00:41:57] I didn't know that, you know, those were my rights anymore. Um, and so you go from just doing it all yourself and, and learning how to problem solve and, and, and, you know, you could be anything you want to be and to then you graduate high school, and everyone's all like, "Bye," you know?

[00:42:16] **Keith Casebonne:** Yeah.

[00:42:17] **Jodi Beckstine:** "Go do those things." And you're kind of like, uh, you know, how do I make that, how do I make that leap?

[00:42:22] So I think, um, I think education for people with disabilities is so different. Um, for y- not only just generationally, but just by where you grew up, um, and, you know, what was available to you. Uh, and I think that's a, a big contrast.

[00:42:42] **Keith Casebonne:** Yeah, for sure. But, you know, let's not forget, even though it's improved, there's still plenty of barriers and, and there's still, you know,

students that are facing segregation and low expectations, limited opportunities, things like that. Um, you know, being physically present in the classroom is good, um, but unfortunately it doesn't automatically mean having, uh, you know, meaningful opportunities.

[00:43:02] **Jodi Beckstine:** It's true. Very, very true.

[00:43:03] **Keith Casebonne:** Yeah. Well, the trid-- the transition out of high school can be overwhelming for anyone. But for young adults with disabilities, there's often an additional challenge of figuring out college accommodations, employment opportunities, services that may change or, or maybe even disappear after graduation. Um, so what stood out for you about the challenges Samuel faces as he starts planning his future?

[00:43:27] **Jodi Beckstine:** Yeah, we touched on it just a little bit. You know, like you said, a lot of the services and support can disappear. Um, and you're left with, you know, what do I do now? And two things can happen. Y- you know, a lot of times the family steps in, uh, to, to bolster that support, and it can lead to either a kind of a takeover, um, or a problem-solving situation.

[00:43:54] And I don't think, um, I don't think parents do that in the, in the way of wanting to, to control. I think it's just out of fear of what's available, fear in general. All, all parents have fear when their, when their children start, um, to transition from childhood to adulthood. Um, so I think it just, you know, it doesn't eliminate uncertainty.

[00:44:21] Um, people with disabilities attend college, you know, build these wonderful careers. Um, but like anyone making that transition, you know, he's anxious about his future.

[00:44:35] **Keith Casebonne:** Sure, sure.

[00:44:36] **Jodi Beckstine:** He doesn't have a clear path forward. And, you know, when you're talking about accessibility and support and services that you need that aren't, are no longer, you know, necessarily guaranteed, that could be a frightening, uh, thing to think about and, and to y- find hope in. Uh, so I think it was an interesting topic that he covered.

[00:44:59] **Keith Casebonne:** Yeah. Yeah, for sure. And, and, and it turned out there was a community college that I think was just minutes away from him that turned out to be accessible and, you know, uh, he-- that's where he att- started to attend.

[00:45:09] **Jodi Beckstine:** Yeah

[00:45:10] **Keith Casebonne:** but you know, it, it's, it's, it's amazing how like there can be a school down the street and yet, you know, still don't know, uh, is, is it accessible?

[00:45:20] Is it, is it friendly to people with disabilities? Those things aren't like, you know, sitting on the website or in the, you know, the brochure you know, or whatever. And so I, I, I, know, I, I noticed that when they were talking about, you know, the, the challenges of trying to find out what schools are the best ones to go to, and it turned out that, you know, there was one around the corner essentially.

[00:45:41] So,

[00:45:41] **Jodi Beckstine:** Yeah. And he's so lucky. He's so lucky because, you know, even though it's accessible, what if they didn't have anything he was interested in? So,

[00:45:50] **Keith Casebonne:** Absolutely.

[00:45:51] **Jodi Beckstine:** is that now, "Well, you have to settle because this is the closest one"? And, you know,

[00:45:56] **Keith Casebonne:** Right

[00:45:56] right.

[00:45:56] **Jodi Beckstine:** know, he went through and she was like, "You wanna be a nurse? You wanna be the..."

[00:46:00] You know, all the things that she was, his, you know, assistant was kind of joking with him about. But that could've very easily been the only thing available to him. Um,

[00:46:09] **Keith Casebonne:** That's right

[00:46:10] **Jodi Beckstine:** i- i- the, the big focus needs to be what are their goals and how, how can we make this happen? Um, and that needs to be the driving force of, uh, you don't have to necessarily settle.

[00:46:24] **Keith Casebonne:** Yeah, agree. Yeah.

[00:46:26] **Jodi Beckstine:** So one of his major goals was to eventually live on his own, even though he, he understood that he was gonna still need support from, you know, direct support professionals and, you know, even his family. So why often do we associate, um, independence with doing everything ourselves rather than just having control of the decisions, um, that shape our own lives?

[00:46:50] **Keith Casebonne:** Yeah. You know, that's-- I, feel like that's the... I, I don't know if this is a, global thing or in some respects more of a sort of an American culture thing, but I feel like sometimes we, we, we're, we're raised to, quote, "pull ourselves up

from our bootstraps" or whatever, you know? Like, you know, there's honor in, in doing it yourself,

[00:47:12] **Jodi Beckstine:** Yeah

[00:47:13] **Keith Casebonne:** uh, I mean, that's, that's ridiculous.

[00:47:15] Um, you know, a- again, there's a big difference between being independent and not having any control over anything. Um, and there's a spectrum, of course. But, having all the control that you should have over your life, um, is, is really what we're talking about with independence. Having help along the way is not a problem. I mean, I, I, I have-- I mean, we've all, know, lived on our own for a little bit and still probably it's like, you know, called our parents when something broke down and, you know, needed to borrow money or something or... I mean, you know, it's, it's-- uh, there's nothing, there's nothing wrong with that.

[00:47:53] Um, you know, we're all there to help each other and, you know, I mean, it's a cliché, but the whole it takes a village kind of thing. I, I, I mean, I think that's really true. You-- nobody, nobody is alone. Independence does not mean alone, and, uh, that's an unfortunate, like, thing that I think we, we, we equate it with, and someone seems weak if they aren't literally doing it all by themselves.

[00:48:16] And that's, that's, that's an absurd, uh, thing. And again, I think it's, I think it's just cultural, uh, uh, maybe even not even worldwide, uh, cultural, but, but here, at least, you know, North America.

[00:48:28] **Jodi Beckstine:** Yeah

[00:48:29] You know, people like to think that if you're disabled you don't have ableist, um, thoughts and ideas. And that's one of

[00:48:36] **Keith Casebonne:** Interesting.

[00:48:37] **Jodi Beckstine:** Definitely ableist things I had to kind of work through is, is that independence doesn't mean you're doing it alone. It, it's, it's so different than just that thought of if I can't do this by myself, that means I, I'm no longer independent.

[00:48:53] **Keith Casebonne:** Yeah, that's interesting. And again, you know, transportation, there's technology, and there's... I mean, there's all these things that like... I mean, none of us do anything alone. I mean, we all have help of some kind, you know? It, it's just, yeah, it's silly Well, and speaking of not being alone, Samuel's family, you know, plays a very important role in his life, particularly his parents, uh, and his brother Isaiah. Uh, but as Samuel becomes an adult, you know, those relationships are naturally changing. How can families and support professionals strike that balance

between providing the assistance someone needs and giving them the freedom to make their own decisions?

[00:49:30] **Jodi Beckstine:** I think one of the big keys is that things are always evolving and changing,

[00:49:35] **Keith Casebonne:** Hmm

[00:49:36] **Jodi Beckstine:** as you, make that transition into adulthood and as you live your life as an adult. You know, things that I needed and wanted and, and was doing when I was in, you know, my early 20s is way different now. You know, my whole life has evolved, you know?

[00:49:52] And so I think that is, I think, one of the big keys is, um, you know, shift from making all the decisions as, like, a parent would to, I know, helping them, you know, explore options and make, make their own choices. Uh, you know, we talked about independence and risk-taking. That is part of it. Um, y- you know, as a parent you may see, oh well, um, I see that as a big risk. I don't want him to do that. But, you know, unless t here's a, a major danger, you have to let some of those mistakes happen. Um, so a learning process and a, for both parties can happen as well.

[00:50:36] **Keith Casebonne:** Yeah. Yeah, no, for sure. Um, you know, I mean, making mistakes is also sort of a part of independence. You know, you have to, y- y- you have to, to sometimes screw up to learn how to fix that or what the right thing is to do.

[00:50:51] **Jodi Beckstine:** Yeah

[00:50:51] **Keith Casebonne:** and that's fine. Like, you know, no problem making mistakes. You know, good support, um, can respect that, including, like, personal boundaries and, and your, your own sort of self-determination. Um, it's-- The, the idea is, is, you know, respecting that you have authority over your own life, and then the support is in addition to-- It, it, it supports that, without repeating the word. Um, you know, that help is there to support your desires and your, you know, determination, your goals.

[00:51:24] **Jodi Beckstine:** We saw that a lot with his father. Like, his father kind of had a standoff approach when it came to, like, the interviews and situations that was happening, and only stepped in a- at certain times. It's like it, it wasn't he was there first. He, he allowed Samuel to handle the situation and then stepped in as needed, and I think that was, is a good, um, evolution for probably the relationship where the father always stepped in first when he was a child, I'm sure.

[00:51:54] Um, and then, you know, things slowly evolved to him being his own adult, which is, which is, was great, and was nice to see.

[00:52:02] **Keith Casebonne:** that's hard, for a parent. I, I,

[00:52:04] **Jodi Beckstine:** Yeah.

[00:52:04] **Keith Casebonne:** It doesn't matter who your child is, that, that's a hard thing for a parent to do, but that's, you know, it's, it's another... We're all, we're still learning, even as we're older adults, you know? You're, you're still learning those, those, you know, so many different things like that.

[00:52:15] **Jodi Beckstine:** Yeah

[00:52:16] That, that brings me to a moment in the film that actually enraged me. I could feel, um, the heat just rising up my body, was

[00:52:25] **Keith Casebonne:** I think I know what it is. Yep

[00:52:26] **Jodi Beckstine:** when Samuel, um, encountered, uh, this lady at the airport, and she spoke to him like a child. Um, you know, "How cute are you?" And, you know, just, ugh. It was so annoying. And you could see Samuel was just so annoyed.

[00:52:42] And then rightfully so angry because the father stepped in and was like, "You can talk to him. He's an adult," you know, trying to be nice but, uh, to let this woman know, and she just did not get the hint. So what do you think these experiences reveal about the difference between just providing accessibility and actually, you know, treating a person with, uh, respect?

[00:53:07] **Keith Casebonne:** Yeah ... That, scene really annoyed me too. I, as soon as you-- I knew exactly what you were gonna, what you were gonna ask, um, 'cause I had, I felt the same way. I could see it in his face. And, and like you said, the, I mean, the dad made repeated attempts to explain it, and sh-she just didn't get it. It just didn't...

[00:53:22] It, uh, yeah. Um, you know, and I think it boils down to, you know, things like accessibility and things like respect.

[00:53:30] **Jodi Beckstine:** Yeah

[00:53:31] **Keith Casebonne:** are-- they're two different things. Um, just because a service is accessible or, or, or a place is accessible doesn't guarantee that someone with a disability is gonna be treated with dignity, you know? Um, they often mistake disability as a lack of understanding or a lack of ability, um, and, uh, you know, uh, that's just a-- Don't, don't make those assumptions. You, you

[00:53:55] **Jodi Beckstine:** Yeah

[00:53:55] **Keith Casebonne:** You don't know, um, that that's the case with this individual.

[00:54:00] **Jodi Beckstine:** I think a lot of people are afraid to ask questions, um, and that's where the assumptions come in. Um, you know, s- speaking to the assistant as opposed to speaking to the person. Uh, just ask people questions about, you know, how, how would you like this interaction to be, and let them dictate, um, you know, the rules and the guidelines, and then respect that a- and stick with it.

[00:54:26] Uh, and I think just too many people are afraid maybe to just say, you know, "What, what can I do to help you? How can I handle this situation in the best way possible?" It's really simple

[00:54:39] **Keith Casebonne:** yeah

[00:54:39] Yeah.

[00:54:40] **Jodi Beckstine:** to ask.

[00:54:41] **Keith Casebonne:** It is, and I think we've talked about this in previous episodes where, like, I think people are raised to not ask. They're told that that's rude. Don't look, don't stare, don't ask, don't whatever. Um, and so yeah, you're tau- you're almost taught that from, like, a young age, and I just think it's that's a, that's a mistake 'cause that's how we learn.

[00:55:01] **Jodi Beckstine:** Yeah

[00:55:01] Yeah.

[00:55:02] **Keith Casebonne:** And, so ask the questions. I would much rather someone ask me about something than just assume and be totally wrong.

[00:55:08] **Jodi Beckstine:** Yes, absolutely.

[00:55:11] **Keith Casebonne:** Well, Samuel uses a communication device, and the film gives us a really interesting look at the time and preparation that's involved in conducting his interviews. Why do you think people so often underst- underestimate someone's intelligence or abilities based on how they communicate, and what can we learn from the way that Samuel conducts these interviews?

[00:55:31] **Jodi Beckstine:** Yeah, it's, it's, that's something that's really frustrating to me, how, how often people determine, uh, intelligence by how quickly or clearly someone speaks. I, I don't understand it. Um,

[00:55:46] **Keith Casebonne:** Yeah

[00:55:47] **Jodi Beckstine:** eh, eh, how, I don't I don't know how else to clearly d- define this thought, but it's just, uh, he had an idea for this film. It was his idea originally. He knew the questions he wanted to ask, so he took a, he had to take some time to, to

prepare it, you know? His dad didn't... I even noticed this when they were preparing the questions. You know, he's, he's speaking, it's taking him a few minutes to get out the full thing, but the dad's not filling in the blanks. You know, like, like Google fills in the words as you're typing. His dad was letting him s- say every word that he wanted to say to be intentional about his question, and I just, I really appreciated that, that he wasn't trying to step in. He was just allowing, the question is coming from Samuel 100%. And, um, and, and the follow-ups, and just, I don't know.

[00:56:41] I just, I don't, I don't understand it. I, I have a hard time with it. It, it comes back to, I guess, um, questions. You know, ask questions. You know, "What do you need from me for us to conduct this interview?" Um, and res- respect the boundaries, you know, that the person sets.

[00:57:01] **Keith Casebonne:** Yeah. Yeah. I, um, uh, I, I agree with you. It's really interesting that, like, there is that, uh, c- for some reason people equate the inability to speak with s- a lack of intelligence.

[00:57:15] **Jodi Beckstine:** Yeah

[00:57:15] **Keith Casebonne:** no, it just means they aren't able to speak the same as, as, as, as maybe you, you know? And, and that's why they have a device. That doesn't mean that they aren't of, of, of, know, forming their own thoughts or questions or goals or, or should be treated like a child in the airport or, you know... Um, I, I, yeah, I've never understood that either. Um, you know, and, and communication... you know, I think communication in general, you know, requires some patience and some res- and, and respect to the other person. Uh, a- and I don't care, that's, that's whether you have a disability or not. Um, people have different communication styles, and sometimes if you don't stop and think or listen, um, to what the person's saying, you might assume they're saying or meaning something different.

[00:58:00] **Jodi Beckstine:** Yeah

[00:58:01] **Keith Casebonne:** I, I mean, it's just sort of a basic tenet of psychology even. Like, you have to sometimes just, you know, really listen and, and maybe even reflect back what you think you heard to make sure you heard it right,

[00:58:12] **Jodi Beckstine:** Yeah

[00:58:12] **Keith Casebonne:** Because we're all different and we all have different styles of communication. This is just another style of communication in my mind, and maybe it takes a little longer. Okay. Again, patience, respect, give it time and, and, and give that person the, the, um, you know, the, the, the time and respect they deserve to, to get their thoughts out.

[00:58:31] **Jodi Beckstine:** And if something's not clear, just ask, ask that to be repeated. You know?

[00:58:35] **Keith Casebonne:** Great.

[00:58:35] **Jodi Beckstine:** it's, I don't know. It, it always seems like basic understanding and basic, um, just to be nice and be a, a good person. But, you know, I think it co- again, it comes back down to, you know, no one wants to ask questions or be perceived perhaps like they don't understand.

[00:58:57] So it's just better to kind of like, you know, plow through it and assume and make these assumptions. Um, I don't know. It's just as absurd to me as like, you know, you know, judging my, uh, intel- intellect on how much I, how high I can reach, you know? It's, it ... To me,

[00:59:14] **Keith Casebonne:** Yeah,

[00:59:14] **Jodi Beckstine:** the same type of concept.

[00:59:17] **Keith Casebonne:** Yeah, that's a great analogy. Makes sense. That makes sense, yeah. Yeah

[00:59:20] **Jodi Beckstine:** So one of my favorite aspects of the film is his decision to seek out these mentors who have disabilities. You know, he talks to several people who've had years navigating barriers, challenging expectations, you know, and building these wonderful lives on their own terms. What do you think, um, makes mentorship from people with shared experiences so valuable?

[00:59:46] **Keith Casebonne:** Well, mean, I think there's nothing like it. Shared experiences, uh, are hugely important, especially for people with disabilities who may not feel like they've had individuals that understand or share what they go through. And so sh- finding others that, that can provide like, you know, real information, real assistance based on, again, like similar experiences, a shared understanding, um, that's important.

[01:00:18] And, and that builds, um, connection. It makes, uh, uh, again, like I, I, I-- if I don't have the same disability as you, I can maybe like, you know, think, "Oh, well, okay, perhaps this, perhaps that." but I, I'm not gonna really be able to help in the same way that someone that has a similar disability to you has,

[01:00:39] **Jodi Beckstine:** Yeah

[01:00:39] **Keith Casebonne:** because they've lived it.

[01:00:40] And that's, that's the whole point of lived experience. That's one of the whole reasons we talk with-- we, we, we have the people we have on this podcast is to share

lived experiences, um, because it's that, it's that important. It's, it's huge, you know? Um, and everyone needs mentors. Everyone needs, uh, you know, people to look up to and, and help guide them. And, uh, I think this was great that he had a whole set of, of mentors that he was able to go out and ask these questions to.

[01:01:05] **Jodi Beckstine:** Yeah, we, we have an episode coming up, um, with Julie Wyman where, uh, she has the same type of dwarfism with me, and I've never spoke to someone like that. It's, it's still sticking with me. It's been a few weeks since we spoke to her, and it's still something that resonates with me because, because of that shared experiences, because of that, um, ability to relate to someone on such a level that I ha- there's no other person I've ever been able to do that with.

[01:01:32] And I think it's just so important to, um, compare and contrast and learn. Um, I think not only did Samuel learn from them, I think their interviews with Samuel, um, you know, they learned from him a- as well.

[01:01:48] **Keith Casebonne:** Yeah Yeah

[01:01:49] And, and I like that his mentors, um, he, I can tell he put a lot of thought into who he wanted to talk to because he had mentors that were, you know, younger, closer to age, um, as him, and then others that were, you know, definitely older, you know, a different generation. Um, and, uh, I think getting those opinions from those diff- you know, different people, different generations who've lived through different experiences.

[01:02:10] Again, we go back to the Judy Heumann example. Uh, you know, uh, school life was very different than Samuel's, and I think it's great that they got to talk and could talk about those things. But yet there were a lot of things they talked about that were still much the same when it came to just interpersonal relationships and dating and things like that. That doesn't matter whether you did it in 1960 or 2020. It, you know, those things are just, that's relationship building and that's, you know, doesn't really change much. Um, and so, uh, I think it was really great to get all those different perspectives. Seeing that someone who's a lot older and experienced than you can relate on the same level f- on certain things has got... You know, that feels good. That, that feels, you know, like you're not out there in some space that makes no sense to anyone else, uh, or, or, you know, you're, you're, you're alone on an island. No, you're, you're, you're not, and I, I think that's really important that he got some great advice from a lot of really great, great people.

[01:03:07] **Jodi Beckstine:** And I think I, you know, I'm speaking for both of us, uh, correct me if I'm wrong, but I feel like that's what we're hoping kind of the podcast does, is that people that are listening or watching find someone else that they can connect

with, um, and then do more research and, you know, maybe reach out to them, et cetera, um, to, to make those connections.

[01:03:25] **Keith Casebonne:** Yeah. I mean, we, we learn from our guests as well, you know? Um, absolutely. So the film gives a very honest look at Samuel's life, including his ambitions, frustrations, uh, relationships, humor, and uncertainty about the future. For someone who watches The Ride Ahead, what do you hope they'll take away from, uh, Samuel's experience, especially when it comes those assumptions we make about what people with disabilities can do or, or, or want for their lives?

[01:03:55] **Jodi Beckstine:** Um, I think one of the big things is that a lot of barriers that people with disabilities face often come from society's expectations, uh, the systems that we built. Um, and I think his experience in this film encourages viewers to maybe question whether someone's, you know, opportunities in their life are being limited by their disability, which I don't think so.

[01:04:24] I think it's, but it's limited by barriers that could be addressed, um, through services or attitudes or just, you know, physical accessibility in general.

[01:04:38] **Keith Casebonne:** Yeah. Yeah. I mean, you know, everyone, i- including people with disabilities deserve the, the freedom to create their own futures. And, um, Samuel, you know, he doesn't have everything figured out yet, and that's fine. It's perfectly normal, y- you know, for someone entering adulthood. Independence and success will look different for everyone, and each person, you know, needs to have that meaningful say in defining them.

[01:04:59] And I'm, and I'm glad that he kinda shared that journey of, uh, you know, figuring out what that experience might look like for him, um, uh, in, you know, making this film 'cause it, it, it was, it was a really fascinating look and, uh, you know, I, I really appreciated it.

[01:05:18] **Jodi Beckstine:** Yeah, I'd like to see where he, where he is in five, 10 years from now.

[01:05:21] **Keith Casebonne:** Me too, for sure.

[01:05:23] **Jodi Beckstine:** So today we talked about The Ride Ahead, Samuel and Dan Habib's documentary about growing up, finding independence, and navigating the opportunities and challenges that come with adulthood.

[01:05:34] **Keith Casebonne:** Samuel's story reminds us that becoming an adult means figuring out who you are, what you want, and how you're gonna get there. For people with disabilities, that journey can come with additional barriers, but their goals and aspirations deserve the same consideration and support as anyone else's.

[01:05:49] **Jodi Beckstine:** I think one of the biggest takeaways from this film is the importance of asking people what they want for their own lives and respecting their answers. Whether it's going to a college, finding a job, building relationships, or living independently, people deserve the opportunity to make those decisions and access the support they need to pursue them

[01:06:08] **Keith Casebonne:** Thanks for joining us for this deep cut. To learn more about The Ride Ahead and explore the film's resources, visit RideAheadFilm.com.

[01:06:18] **Jodi Beckstine:** And that brings us to the end of our season four premiere. A big thank you to Patrice and Garry for catching us up on life after the movie, and to Kelly and Avery from Wheel Talk for helping us launch The Reef.

[01:06:28] **Keith Casebonne:** And our Deep Cut, The Ride Ahead, reminded us that everyone's path to independence looks different. But whether we're talking about love, friendship, or growing up, having choices and the support to pursue them matters.

[01:06:39] **Jodi Beckstine:** You can find more episodes of Disability Deep Dive at DisabilityRightsFlorida.org/podcast or wherever you get your podcasts. If you wanna share your thoughts about the show directly with us, you can use our new contact form on our website.

[01:06:53] **Keith Casebonne:** And if you enjoyed this conversation, please like and subscribe to Disability Deep Dive on your favorite podcast platform, leave a review, and share this episode with someone who might enjoy it too.

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