

Episode 2.9 - Navigating Challenging Situations and Advocating as a Parent with Falcia Beck

Mike Hoenig: Well, hi everybody. It's Mike Hoenig from the Iowa UCEDD, the University Center for Excellence in Developmental Disabilities. We're coming to you with another episode of Disability Exchange. Disability Exchange is a podcast designed to center and elevate the voices of people with disabilities and their families. And we do this through a very casual conversational style in which we really invite and encourage our guests to share their stories. And we're very excited in just a minute or so to introduce you to a great guest that I'm really looking forward to getting to know. We partner with the Midwestern Public Health Training Center with the Iowa College of Public Health. They do our production and really provide the backbone of our support to make this podcast happen. So without further ado, I'm going to introduce now our co-host for this episode of Disability Exchange, Laury Scheidler.

Laury Scheidler: Thank you, Mike. Yes, I am here with Mike as a co-host. I'm a social work practicum student with the UCEDD. And we have the pleasure today to introduce you to our wonderful guest, Falcia Beck, who has lived experience. Falcia, if you'd like to tell us a little bit more about you and how you're affiliated with the UCEDD.

Falcia Beck: Thank you, Laury. Yeah, so right now I'm a social work student as well, finishing up my last semester with the University of Iowa. So I'm doing my practicum with LEND, the UCEDD, and CDD kind of splitting up my time there. But I'm also a parent of four kids. All of my kiddos have had one thing or another. So yeah, just kind of going through that. I don't know if you want to know more about my kids. Obviously, we'll get there, but...

Mike Hoenig: Well, we sure do. We probably should go back a step and just make sure, because we never know exactly who's in our audience, to clarify what LEND and CDD are. We already talked about what the UCEDD is, and don't want to put you on the spot, Falcia, but if you could describe a little bit about LEND and CDD, that would be great.

Falcia Beck: Absolutely. So LEND is... It stands for Leadership Education in Neurodevelopmental and Related Disabilities. It's very comprehensive. It's difficult to explain unless you experience, but it's kind of like coursework meets hands-on work. So doing anything from talking with legislators and policy work to research to working with other families with disabilities. It's an interdisciplinary program. So we work with other social workers, other public health. There's psychologists, self-advocates, family advocates, community supports, and lots of others that I know that I'm missing. So that's really awesome with LEND. And then the CDD is the Centers for Disabilities and Development, and it's onsite there with UIHC and it's just a center for kiddos to go to either get diagnoses or to have further supports.

Laury Scheidler: Falcia, you fit the program on two ends, one being someone with lived experience and as a social work student. So I imagine you bring quite a bit to the table for the others in the class. Would you mind telling us a little bit about your lived experience, like how old your kiddos are, and the lived experience you have with their disabilities?

Falcia Beck: Absolutely. So I've got my oldest, he's 15. Actually, just on Friday, I took him to the CDD and we had a day-long psychology appointment and found that they confirmed his ADHD, but then he was also additionally diagnosed with autism spectrum disorder, also major depressive disorder, and generalized anxiety disorder. So he's got the four. Been working with him for years. So he's in 10th grade

right now. Been trying to figure things out since he was in second grade. And then my second oldest is my angel. He would be 13, almost 14. He passed away almost 10 years ago. He had a condition called lissencephaly and his was actually List-3. It's a brain malformation, and he was actually the only known case with his particular malformation or genetic mutation in the world. Lissencephaly is basically smooth brain, and then he was missing one part of his brain, the corpus callosum, the part that connects your right and left hemispheres.

And then he also had a hole in his cerebellum. So he had a lot of struggles. And I was told he'll have a month to live, three months, a year, two years. And then he was almost four when he died. So I felt really blessed to have whatever time I had with him. And he's taught me a lot through life. And then my next oldest, she is four, almost five. She's my spitfire. She's my only girl. And I tell the world that they have to look out for her because she's going to be fierce, but she currently just has more issues with gastrointestinal, so trying to figure out all of that. So she's also my picky eater. So she's an OT and PT. For that occupational therapy and physical therapy to try to help her with some of those things to get her to eat more, so that way she can use the bathroom and I'm sure she'll appreciate this being out there one day.

And then my youngest, he is 15 months, almost 16 months old, and had a scare after he was born, or actually while I was pregnant with him that we were hearing galloping in his heartbeat. And so after he was born, we checked that and found that he had actually three little pin size holes in his heart. Luckily they said that that's actually fairly common that they did a study in India and they saw that almost all kids have these after they're born. It's just that you don't usually look for them. And within a week they're usually healed up. As our muscles grow, they kind of heal up those holes. So after a week, we had another appointment with a pediatric cardiologist, and we got the clear that two of the holes were completely filled. And the third, he had no doubts would be over time, but he also gave me a scare of seizures as well. But that cleared up and was okay. So.

Mike Hoenig: That's quite a list, and yet you have so many positive, I can just tell by your voice the positive attitude that you have. And I have questions about each of your experiences. So I guess I'll start with one, and then Laury, we can kick back and forth. But I'm curious about your 10th grader, your son, and with those diagnoses, how school has worked for him and what maybe some of the challenges have been, and what some of the adaptations have been for him to be able to be successful.

Falicia Beck: That one has been the most challenging, I think. So was approached by his second-grade teacher. That was kind of a really negative experience for me. I would go into school and try to observe when teachers would tell me that he's having some troubles or things like that. And so I'd go in and observe. And he didn't really seem that much different than the other kids with his attention. And in particular, she was talking about his respect. So that's back when I was first looking at that. And then was told he's for sure got ADHD, you need to put him on medication. And was told by another that he had a seizure disorder, and that's why he wasn't focusing.

So needless to say, got him out of that school and moved into a different one that was a little bit more open to him. And working with him, I've been pushing since he was in middle school for a 504 Plan, the school, so said that he doesn't meet the criteria, which is not really the case for a 504 Plan. So just have been waiting for a diagnosis to really get the supports that he needs. So this was an exciting first step on Friday, even though it's been years in the making, and I've been advocating for years to just get some simple adaptations for him, but hopefully, this will be the thing that gets him there.

Laury Scheidler: Would you mind telling us what type of adaptations you've been trying to achieve for him?

Falicia Beck: Oh, yeah. So for an assignment, when they have the explanations for what you need to do for the assignments, instead of having it in a paragraph form, I've wanted it to be in bullets. And then the other one is check-in, check-out policy. So just in study hall, checking in with the assignments that he has and then checking out if he's completed them.

Laury Scheidler: It sounds like they're pretty simple accommodations that you're requesting.

Falicia Beck: Yeah. The teachers have been wonderful. When I bring this up to the teachers, they usually are more than willing to work with Damon and understand the situation. It's the administration that has made this a lot more challenging.

Mike Hoenig: We recently had a guest on Disability Exchange who experiences autism, is very open about it, and talked about some of the challenges that he had with socialization throughout school, and that making friends was difficult for him for a good period of time. So how has that been for Damon and has he gotten some support to try to make that a little easier?

Falicia Beck: So he's always been this outgoing kid almost to a degree. That was to a strange point, but luckily he was able to make friends, and I've always been a supporter of trying to reach out to the friends that he's made, their parents, and getting play dates together. Right now, he actually has a girlfriend. So I think it's helpful that he's stayed in the same school district and that friends have followed him. I think he would struggle more now to make friends than he would have in elementary school. So that's why I think he has a small friend group at this point because I think some of the friends he was making in elementary school see him as a little eccentric maybe, and he has a different sense of humor. He's a gamer. But I don't know. I think that the people that he has around him are wonderful kids that I am grateful that he has for friends and he can be himself with, and I think that's what is really amazing.

Mike Hoenig: He sounds like a future guest for Disability Exchange.

Laury Scheidler: Especially if he is outgoing, I bet he'd have some wonderful insight to offer others.

Falicia Beck: Yes. Yeah, I think he would love that because yeah, I asked him first how he felt about me talking about him and things, "Are you comfortable with me sharing this information?" And he's like, "Yeah, when is it going to be? Can I listen?" And it's like, "Well, it'll be edited. I'll let you know when it's done." But yeah, he was very excited.

Laury Scheidler: Falicia, I could certainly relate with the whole social thing. James is my son, who's also 15 years old, and we have similar challenges with that end where the friends he had in elementary school and now are fewer but fortunate to have that tight-knit close friends that they do have.

Falicia Beck: Yes. Yeah, I'm grateful for them. And yeah, Damon's girlfriend is a very wonderful girl that is very patient with them.

Mike Hoening: That's great.

Falicia Beck: Yeah.

Mike Hoening: And there's a lot to be said for having kind of a smaller, close-knit group of friends. I think when we think about it, we probably all fit into that category in some way or other.

Falicia Beck: Yeah.

Laury Scheidler: Absolutely.

Falicia Beck: Yeah, I think I'd rather have a fewer, more reliable friends than a whole bunch of people that barely know.

Mike Hoening: Absolutely. So one thing you shared with us, Falicia, is that your second son was the kiddo who brought you into social work?

Falicia Beck: Yeah.

Mike Hoening: So could you expand on that a little bit about how that connection happened for you?

Falicia Beck: Yeah. So after... His name was Trayton. Was born... We knew right away that something more was going on because I knew when I was pregnant with him that he had cerebellar hypoplasia, which is the hole in his cerebellum. So after he was born, he had some troubles breathing, and so they did an MRI and CT scan to find the rest of those issues in his brain. And I was kind of left alone to deal with a lot of this thing. The things that were being thrown at me were diagnoses, and "What does this mean? Here's a surgery that he's going to have to do." And so the social worker at the NICU was not only somebody who helped me end up getting resources for when it was time to leave the hospital, but she was a person who was there for me who helped me to understand some of my feelings because I kept crying and I was like, "I should just be happy. I should be happy that he's alive, that we're doing these things."

And she was the one who ended up telling me, "It's okay to mourn the child that you were expecting. That you can still love the child that you have in front of you, but you had this whole life planned out for this other child who would be healthy." And that was really something that changed my whole mindset when it came to Trayton, that I could be both sad and grateful that he was there. So that was a motivator for me to want to help other families in that same situation, to help give them hope, I guess, and to just be graceful with themselves. But it's okay to be both.

Mike Hoening: I think families need permission to be able to do that. I know that it's a little bit controversial, but I know there's a... I guess it'd be sort of an essay, and I don't know if you've... It's called Welcome to Holland, and it's about a family that was flying and they thought they were going to go to par... It was either Paris or Rome, and to see all these sites and everything, and they ended up landing in Holland, and it was still a wonderful experience, but just a very different experience than what they were expecting. And so they used that as kind of a metaphor, I guess, I'd say.

Falicia Beck: Yeah, I love that. Yeah, that's exactly what it felt like. Yes.

Laury Scheidler: It was just very wise of the social worker to point that out, because oftentimes we don't recognize even our own feelings that it was okay, so what a blessing.

Falicia Beck: Yeah, it really was. I don't know. It just empowered me to keep being this mom that I didn't feel inadequate then, that I was not worthy of being his mom because I was having these feelings of almost grief. Especially, I was being told every day constantly that he's probably not going to live very long, that you may have a year at the most, but probably more like a month or two. So I was constantly grieving that I would not have my son, that I was going to have to plan his funeral before I died. And so I had those feelings. And so after being empowered like that, then it helped me to focus on what I could do, that I can't control his life where it'll lead, but I can control right now his next steps, the next hour. How can he thrive right now? And it's me being present with him. It's me making these decisions that can help him feel comfortable, at least right now. So it just empowered me to be that mom that advocate for him.

Laury Scheidler: I guess looking back at that situation, you're talking about what you were told, I'm assuming from doctors and other professionals, how did those messages come across to you? Would you have any advice to offer other professionals in the future as far as how they said it? Was it helpful at the time? Could it have been done in a different way that you feel would've been more effective for you as a parent? Can you tell us a little bit about that?

Falicia Beck: Yeah. So I feel like the doctor was doing the best that he could. I kept thinking at the time, I think he's doing this because he's just trying to make sure that I understand the reality that I'm not living in this fantasy world, that he wants me to understand this is the real situation. He was having to reach out to John Hopkins because this was such a rare brain malformation. Literally, he was the only known case with his particular mutation. So it's just so rare. There were only 30 known cases in the world with List-3 to begin with. So it was just a learning curve for him. He was present too. So I think overall, I think he did the best he could with what he had. I think it was more so doctors later on that I was actually told by a world-renowned specialist who specialized in brain malformations that Trayton would literally be a blob that he wouldn't...

He literally used the word blob and that he would never know people around him, that he would just never be able to do anything purposefully, that it was more he would live and then he would die, and there would really be no in-between for him. That I feel could have been more tactful because at that time, Trayton was already a little bit older to where I knew he was doing things. I knew he knew who I was at that time. He was already saying, "Mum." Like the British mom. "Mum, mum." A call for me. And when I came, he would stop because he got what he wanted.

So he was able to communicate with me. He communicated with me through grunts and groans. So I think when you're a specialist and you're supposed to be the world-renowned and you're wanting to learn more, I think the idea is to listen to the patients, listen to the patient's families because they are the experts in themselves and their children. And if they are in this falsehood, is it really important to knock them down, or is it really okay for them to see something that even might not be there because it's caring and loving to that individual? So I guess it's just trying to reevaluate why you're sharing the information, why you find it so important to push something unless it's really helpful for the individual and the family.

Mike Hoenig: Well, and in this case, he was providing false information.

Falicia Beck: Yep.

Mike Hoenig: And not learning from you, which I guess somebody maybe when you become world-renowned, you think you know everything, but clearly, he wasn't listening to you or Trayton. And I think it's shameful.

Falicia Beck: Yeah. It was really gut-red shame because I was so excited. I had packed this bag full of stuff to show what Trayton could do, and was so excited to learn from him and from him to learn from Trayton. And that just didn't happen. It was more of, "Here's these things. You probably should be preparing for a funeral because he is a little bit older." I think he was just under one at that time, so it was just gut-wrenching.

Mike Hoenig: I'm sure. I'm sorry, you had to go through that.

Falicia Beck: Thank you.

Mike Hoenig: Your four-year-old now... It sounds like she's had quite an interesting beginning. And is she in some sort of preschool at this point, or is she still trying to get some of the other, these things worked out before she's able to do that?

Falicia Beck: So she's in preschool right now. She loves it. She's the COVID kid. So wasn't sure how that would work out to go back into a social setting because she was less than one before COVID hit. But she's doing really well. We had talked about it when she was three but agreed that she seemed to be learning things. We were teaching her from home, and so waited till this year till we felt a little bit safer that she could be vaccinated and go be a little bit safer at school. So yeah, she's doing really well. The preschool teachers are amazing too, and her issues aren't so... They don't really take over too much of her life. It's more of we have to give her a mirror relax every morning type of thing.

Mike Hoenig: Well, I can empathize. It's not very fun.

Falicia Beck: No.

Mike Hoenig: Do they have flavored now for little ones so that they can...

Falicia Beck: I haven't found it. At least she actually likes it with her morning water, so.

Mike Hoenig: All right.

Falicia Beck: ... It doesn't. As long as it's cold water, we have to make sure that she is a little bit one of those where she has to have it her way, snap the fingers type.

Mike Hoenig: That's funny.

Laury Scheidler: That fierceness that you talked about.

Falicia Beck: Yes. Yep.

Mike Hoenig: And your little guy is learning from all of them, right?

Falicia Beck: Yes. Yeah. That's where... Well, my oldest son, he tends to hang out in the basement. We have given him his own little cave, I guess, for him to be able to go to be away from the littles if he chooses. But yeah, my youngest is very much in love with his older sister and loves to follow her all over the place. And sometimes to her dismay.

Laury Scheidler: I was wondering how she was dealing with that.

Falicia Beck: Well, sometimes it's one way or the other. Either, "Get away from me." Or, "Come here. I'm going to hold you so tightly that we're both going to fall to the floor." So one or the other, it's never in between.

Mike Hoenig: And he probably... Obviously, he's worth the reinforcement, are worth the disappointments, right?

Falicia Beck: Yeah. He knows to keep trying. He's a little bit different too. I think he's going to be more chill, introverted. The other two are pretty extroverted, actually.

Mike Hoenig: Pretty out there. Well, Falicia, we always kind of like to end our podcast with a question, and it's a little bit sort of an honor of our first year. One of our hosts was really into superheroes and superpowers, and we love to hear people share what their superpowers are. And I don't know you very well, but just within this half hour, I could probably come up with some, but we want to hear what you think your superpower or superpowers are.

Falicia Beck: I'm an outside-of-the-box thinker, so a lot of the times with the kids, I've had to come up with different ideas of how to help them either socialize or be able to do cause-effect type thing. So I've had to think outside of the box of what you traditionally would think, this is the way you do this. And I've had to come up with a different solution for that.

Mike Hoenig: That seems like a great superpower to me. And it's pretty obvious that you've had to do that for many years now.

Falicia Beck: Yeah. Thank you.

Laury Scheidler: And Falicia, I've had the pleasure of getting to know you. I don't think we've mentioned it earlier. We're in the same cohort class. And I'd like to add that you are an absolute wonderful inspiration to the people around you. And I think that comes with the other things you've talked about so far, being an advocate for your children, but you also do that for others. You really let your light shine. And if I could just add to your superpowers for you.

Falicia Beck: Thank you.

Laury Scheidler: That means a lot coming from you.

Falicia Beck: Thank you.

Laury Scheidler: You're welcome.

Mike Hoenig: Well, it's been a real treat, Falicia, to spend time with you to hear your story. So maybe if we do are fortunate to be able to continue these, we hopefully could have you back on and maybe bring Damon on too. I think that would be really super fun. So I'd like to thank you for your time. And I'd also like to thank all of our listeners out there in Podcast LEND who have taken the time to listen to us and

especially to Falcia and her story. And we again, want to thank the staff at the Midwestern Public Health Training Center for their excellent support throughout these podcasts. And we just invite all of you to stay tuned as more podcasts drop within the next few weeks. So Falcia, thank you once again.

Falcia Beck: Yeah, thank you.

Caitlin Owens: Thank you for joining us today on Disability Exchange. Disability Exchange is produced by the University Center for Excellence in Developmental Disabilities, which is housed at the Center for Disabilities and Development at the University of Iowa. Special thanks to Kyle Delve for the music contribution.