

Episode 2.1: Challenging Stereotypes with James and Laury

Mike Hoenig: Well, hey everybody, it's Mike Hoenig from UCEDD, the Iowa University Center for Excellence and Developmental Disabilities, and we are so excited to welcome you back to year two of our podcast entitled Disability Exchange.

Disability Exchange is a podcast which gives individuals with disabilities, family members and those who support people with disabilities in their families a chance to share their stories and to elevate their voices, to talk about inclusion and how we can live just as normal a life as everybody else.

The podcast is a joint project of the UCEDD and of the Midwest[ern] Public Health Training Center within the University of Iowa College of Public Health.

We have some great guests, which we'll be introducing shortly. But first, I would like to turn this over to my co-host for this episode of Disability Exchange, Caitlin Owens.

Caitlin Owens: Wonderful intro, Mike. It's good to be back with you for season two of the podcast. Like Mike said, my name is Caitlin Owens and I also work at the UCEDD. We are so excited today to kick off our season with two guests who I will let introduce themselves in a second. But today, we have Laury Scheidler and James Lee with us. Would the two of you want to introduce yourselves?

James Lee: Hello, my name is James Lee and I have autism, and my mom is right next to me.

Laury Scheidler: Hi, I am Laury Scheidler. I'm the mother of James.

Caitlin Owens: Laury, do you want to talk really quickly about kind of your connection to the IUCED and how we came to know you and James?

Laury: My connection with the IUCED started last year when I was in the ILNRS program. And I enjoyed it very much, and so this year, I am doing my advanced practicum as a social worker student and working under the supervision of Caitlin.

Caitlin Owens: Wonderful. And for those who might be new to the podcast, ILNRS stands for the Iowa Leadership in Neurodevelopmental and Related Disabilities.

James: Basically anything working with your brain.

Caitlin Owens: Yes, exactly. Exactly. Well, so James, do you want to start off by telling us about yourself and your interest?

James: It's kind of strange having autism since ... When I found out I was at first confused about what it meant, and later on, I figured it out a little by little.

You can think of autism as running on a different program than everyone else, like every computer just being standardized, but then there's a few that have an abnormal program.

And as unfortunate as it is, I just feel like sometimes autism is stereotyped as someone just not being smart when the reality can be so many different things.

Like in my case, I'm intelligent, it's just ... Well, sometimes our system has capacity issues and this can cause my brain to overload really.

Laury: Hmm-mm.

James: Autism can sometimes mean having higher intelligence, but having some sort of weakness, such as breaking down easily.

Laury: Totally.

James: Or another factor. That's kind of weird.

Mike Hoenig: That is an amazing description. Yeah. And James, your mom shared the other day that she often, instead of using the term disability, that oftentimes you've started to talk about ... Or maybe not started, that you talk about autism as a gift. Would either of you be comfortable talking a little bit about that?

Laury: Well, we talk about it being a gift because it oftentimes, and our experience with individuals with autism, they have extra intelligence in a certain area or specialties that maybe your atypical don't. And with James, his gift is his memory with history information. Like you can ask him about anything and he'll know a date of the history, especially World War II.

James: It's weird since ... I've heard a lot of history documentaries before, but the World War II ones were almost always the one that stuck. In particular about the weapons and equipment. For example, the MG-42 can fire 1200 rounds per a minute. That's 20 rounds every second it's firing.

Laury: Hmm. Yeah.

Mike Hoenig: That's a lot of firing.

James: It was called Hitler's Buzz Saw for a reason.

Mike Hoenig: Absolutely.

Laury: And speaking of, he also has an incredible memory for details visually. So for example, one time, he saw a clock, he goes, "That looks just like the Big Ben." I go, "Well, what do you mean?" And he was able to list the very intricate details of what that meant.

James: I can't remember exactly where that's from. I'm pretty sure if I saw a photo or something, my memory would click then.

Laury: Hmm-mm. Or even the number of stacks on the Titanic of different ships. You'll know the number of stacks.

James: You mean smoke stacks? There was four.

Laury: Yeah.

Mike Hoenig: I see a Jeopardy contestant in the making. You know, there was a James that won a lot of money on Jeopardy, so maybe you'll have to follow that up.

James: Jeopardy number two right here.

Mike Hoenig: Do you watch Jeopardy?

James: No, but I know my grandma and grandpa do.

Mike Hoenig: Yeah, it's pretty fun. Yeah, that James, he didn't have to work again after he won all that money. So ...

Caitlin Owens: I like the sound of that.

Laury: Yeah.

James: I guess Jeopardy became his retirement plan.

Mike Hoenig: It certainly did.

Caitlin Owens: So James, what grade are you in in school?

James: Ninth currently.

Laury: Ninth grade.

Caitlin Owens: Are there particular, I would guess ... ? I was going to ask, are there particular subjects that you enjoy in school? My guess would be history's one of them.

James: Well, it is, but math and science have just been two main ones, because it may seem strange, but being a history buff, I'm actually interested in the technology that's rapidly advancing all around us since ... Well, that technology could be what sends us through space and possibly through multiple galaxies at the same time.

Mike Hoenig: Wow.

James: So technology in general has just caught my interest, but I don't mind sharing a couple of history facts.

Caitlin Owens: That's very impressive. A lot of different interests and strengths, it sounds like. That's really cool.

Mike Hoenig: I know that you said sometimes people have stereotypes about autism and things like that. How does that work for you in school? Are you able to connect with some people that you have shared interests with? Or what's the typical ... ? Well, I shouldn't ask that because there's no typical day in school. Every day is different, but ...

James: Every day is anarchy.

Mike Hoenig: Anarchy. Oh no.

James: I'm joking, of course.

Mike Hoenig: Is it good sometimes and bad sometimes, or ... ?

James: Oh, that brings me to one of the difficulties I run into, and that's different interests. A lot of my friends are into sports and all that and just your average teenage stuff. But due to my system operating very differently, it just sometimes makes connecting difficult since ...

Mike Hoenig: Hmm-mm.

James: I have a lot of interests with sci-fi or history that a lot of the kids just don't have. And while they're just interested in a lot of things like, well, for example, sports, because teenage boys will do those things.

Mike Hoenig: That's true.

James: Well, most of them. Not every single one does, but you get the idea.

Mike Hoenig: Now, are you a chess player by any chance? You strike me as somebody that might like to play chess.

James: I've played chess before. It's not one of my favorite things. One of the main things I do is just gaming stuff, since-

Mike Hoenig: Oh, okay.

James: The major thing about board games is, as well, they just get boring after a while. I mean, that was the past time back in the day, so ...

Mike Hoenig: Absolutely.

James: There's no harm in liking or disliking it. It really just comes down to opinion.

Mike Hoenig: Yep. And you have to find what works for you.

James: Yeah.

Caitlin Owens: So what kind of games do you like to play?

James: Typically sci-fi related with realtime strategy. Because here's another weird part which kind of goes back to the World War II thing; my mind thinks very systematically and strategically because ...

And Minecraft, what Levi saw as just a bunch of building up and just murdering random mobs, anytime we are in a PVP conflict, that Minecraft world suddenly turns into basically a battlefield where I was just constantly making tactics and strategies to overcome larger opponents since my friend Levi and I ... Well, let's just say we used to get into a lot of fights in Minecraft. I'll just put it at that.

I was always coming up with contingency ideas to try to figure out how to handle the fact that my equipment wasn't as good. The most famous example I can think of was using harming potions, which bypass basically every armor.

Caitlin Owens: Nice.

There are a lot of people in my life who are really into Minecraft and I'm kind of starting to understand it. So I understand.

James: It's extremely popular.

Caitlin Owens: I know, I've heard. So James, I was wondering, you know, you've talked about the strengths that come with having autism. What might you share with somebody younger than you, or their parents, who are just getting a diagnosis? What might you want them to know about autism?

James: Well, for starters, there can be many advantages. Some have photographic memory, some have audio graphic memory. Some of them can remember various events from the past very well.

Well, in me and Mike's case, we can remember a bunch of stuff about World War II. In fact, one of the thoughts I had is there was a chance that me and Mike might turn this podcast into a history documentary.

Mike Hoenig: Well, I'm sure you know way more history. I just love the time period. I don't know why. But I could study up.

James: Yeah.

Mike Hoenig: I could study history,

James: Both Jingle Jangle Jingle and In the Mood were both songs made in the forties, which just happened to be the time when Hitler was crotch shotting Western Europe.

Mike Hoenig: Yeah. The music and World War II are so closely intertwined, and the comedy. You know, they had to have things going on to try to take their minds off of what was some really, really difficult stuff going on.

James: Yeah, since overseas there was a lot of bad stuff going on, which I won't go into if it causes people to be very sensitive about these topics.

So I'll just go into the general stuff; none of the really bad events, I'll just not go into for the sake of not ... Well, just for the sake of not sparking anything sensitive.

Mike Hoenig: Yeah. Hopefully we learn some lessons. Sometimes I wonder.

James: Yeah. There's a famous quote, I can't remember who said it, but, "Those that don't learn from history are just doomed to repeat it." It kind of reflects on how the modern world's going.

Mike Hoenig: Yeah. There's a lot going on. So on a little lighter subject maybe, I understand that you are in marching band.

James: Yeah.

Mike Hoenig: And you're a drummer. Is that what I hear?

James: Playing bass.

Mike Hoenig: Playing bass. That's good.

James: There wouldn't really be much of a rhythm without us.

Mike Hoenig: That's true.

Caitlin Owens: The heartbeat of the marching band.

Mike Hoenig: Absolutely.

James: Yeah. That's why we get along.

Mike Hoenig: That's a good description of it. Caitlin, were you in marching band?

Caitlin Owens: You know, I wasn't. I played clarinet briefly, but I just didn't have the chops.

Mike Hoenig: Maybe you should have been a percussionist.

Caitlin Owens: I know. I think that would've been ... My dad really tried to get me to do that actually, but...

Mike Hoenig: You had other interests.

Caitlin Owens: I insisted on clarinet and wasn't very good at it.

Mike Hoenig: Yeah.

James: So the main thing I ran into with band and the reason why I play by ear is just counting efficiency. The problem I had with reading notes is I could never count effectively while being able to hit the drum simultaneously. If I tried moving for drum efficiency, I just couldn't read the notes or count fast enough and I'd just get lost. If I move for counting, then beat efficiency would decrease and it would sound like the bass drum was having a heart attack.

Mike Hoenig: So how did the band director ... ? Did you have to convince the band director that you could do it by ear?

James: I still use a music sheet, but the thing I do is I listen for sound cues instead of counting all the time.

Mike Hoenig: Okay.

James: The primary time I use counting is a part where I'm just waiting to start playing again. The sound cues can be very useful for knowing which parts to play.

This is why certain pieces like Bigfoot Stomp are easy, because there's a number of sound cues that are easy to pick up, and [inaudible 00:14:03] Colliding Visions had some difficulties at first because it had sound cues, they were just harder to detect.

Mike Hoenig: That's very interesting. I played in band when I was in high school and college and it's so much fun. It's really a ...

Caitlin Owens: What did you play, Mike?

Mike Hoenig: I played the euphonium, or the baritone, it's often called.

Caitlin Owens: I don't even know what that is.

Mike Hoenig: It's like a-

Caitlin Owens: I'll have to Google it.

Mike Hoenig: It's kind of ... It's shaped similar to a tuba, but it's smaller, so it plays an octave up from the tuba. And you can hold it on your knee, and ...

James: So I'm assuming your playing method was also unique like mine.

Mike Hoenig: Yeah, it was unique, but it was ... So I had braille music, and so I had the music on my left hand and then I had the baritone in my right hand. Because I don't have photographic memory. We had some students where I went to school that did, but I definitely was not one of them.

And I remember one time we were at a concert on the road, I was in college, and I left my music in the bus. So I was like, "Oh." And I had a solo.

So I tried it, and I couldn't believe it, I actually could play it by memory. And I'm sure that's probably because we'd played it so long that I just ...

James: It's probably a good thing you did all that practice.

Mike Hoenig: Yeah. Man. Well, we had like two concerts a day when we were on the road, and I guess I had just gotten so used to it.

And the band director said, "Well, try it and see what happens." And luckily, I got through it, but ...

James: So how exactly does the baritone work when you're reading notes? Because I know that whole baritone thing exists, I just never really knew how it worked effectively.

Mike Hoenig: Well, it's just like playing any instrument with notes. I mean, the difference was ... I mean, you read the note and then you play it hopefully. It's in bass clef, and I was doing it in braille, so there's a whole different system.

Obviously in braille you can't present a staff. There's a particular symbol for each note, like a C or a D, and then there would be a dot at the bottom indicating whether it was a quarter note or a half note or an eighth or a 16th. And then there are signs for triplets and the whole nine yard slurs and dotted notes.

But I don't think I could do anymore of it. It was fun while it lasted.

You know, we haven't talked to you much, Laury. We should announce this though, that Laury is going to, in addition to being a guest today, she's going to be one of our podcast hosts moving forward.

So you're a mom and I know that you're a sub teacher, and you are now getting your degree in social, or your master's, right? Is it a master's in social work?

Laury: Yes. Correct.

Mike Hoenig: So it's interesting that you ... I don't know what your field was before James came along, but you seem to really do a great job of blending your role as a parent and then bringing that to the table as ...

I got to know you a little bit last year, but you really seem to ... You're not only getting your degree, but you did such a wonderful job last year educating all of us that were connected to.

So maybe you could talk a little bit about that and kind of bouncing those roles back and forth, and how you've been able to do such a good job of bringing them together.

Laury: That's a really good question, Mike, and thought process.

It really was back when I decided to make sure that my career life fit my home life. Because I'm like, "Why do I need to have two separate lives? Why can't I have a life of sole interest?" If that makes sense.

Mike Hoenig: Yep.

Laury: And James really sparked a lot of interest through his development and has really driven my passion.

When he was first diagnosed was at age two years, 10 months, and through that process was, I-

James: Scale? I don't know exactly where I was on that.

Laury: Oh, on the scale of autism?

James: Hmm-mm.

Laury: We haven't really ever talked about that, have we?

James: Yeah.

Laury: So-

James: I guess I'm learning things while we're doing the podcast.

Mike Hoenig: How about that?

Laury: So to answer your question, James was wondering where he was at on the autism spectrum.

Mike Hoenig: Hmm-mm.

Laury: We had two separate evaluations done at that time. One diagnosis was pervasive developmental disorder, not otherwise known. And what that meant at the time was that you fit most of the criteria of autism, but not completely.

James: But then the second one revealed I had autism?

Laury: And the second one, they diagnosed you with autism. And I remember the doctor saying that that would also help you receive services, having that diagnosis, because at the time we were living in Massachusetts.

James: And was this back in the early 2000's before autism awareness was a major thing, from what I understand?

Mike Hoenig: It's progressed so much in the last 15 years, 20.

Laury: It sure has.

James: It seems like the awareness has grown along with it, which makes me hopeful for all those kids that may be misconcepted as bad, but really just are struggling with their own things.

Laury: Yeah.

Mike Hoenig: Absolutely.

James: Since it's weird, since, in a way, I can just swap language between age groups and all that since I still have a huge imagination like a kid, but at the same time, I also know when it's all right to fire those systems full cylinder and when it's a bad time.

Laury: Hmm-mm.

Mike Hoenig: Well, I hope you always keep your imagination.

James: Yeah, I hope so too, because ... Let's just say I just have a lot of fun doing it.

Mike Hoenig: Absolutely.

Laury: You've grown so much, James, over the years. I'm very proud of you.

And as you were starting to grow after ... Going back to your diagnosis, I wanted to understand as he was growing what they considered typical development and what would be related to the autism. And so I thought, "Well, the more I know about child development, the more I have a better understanding."

James: And then she decided to go, "Screw it, we'll just get something like that."

Laury: Well, it kind of led me in that direction. I took child development courses and received my bachelor's in psychology with the emphasis of child development.

James: I think she's getting her practorum this year or early next year.

Laury: My practicum.

James: Practicum, sorry.

Mike Hoenig: Practicum.

James: Latin nonsense.

Caitlin Owens: It's a weird word. I mean ...

Mike Hoenig: It is a weird word.

James: I feel like it's Latin and I don't want to offend any Latin speakers out here. It's just ... A lot of that stuff just seems very random.

Caitlin Owens: Yeah. Let's just call it an internship.

Mike Hoenig: Internship.

James: I know what ... Latin's a unique language and it's the basis of several languages today.

Caitlin Owens: Hmm-mm.

Mike Hoenig: Yeah. It is.

Caitlin Owens: I took Latin in school.

Laury: Oh, you did?

Caitlin Owens: I did, yeah.

Mike Hoenig: Did you go to a Catholic school, Caitlin?

Caitlin Owens: No, I just was like, "Let me pick the most useless language I could possibly think of. Though actually it does come in handy.

Mike Hoenig: I think it does. I wish I had taken it.

Caitlin Owens: Yeah, yeah. It ...

Laury: Does it help your understanding of words in general?

Caitlin Owens: Yeah, I think so. I mean, it's been a long time since I was in high school, and I wasn't the most studious of Latin pupils, but I definitely absorbed more than I thought I might have.

Well, so we'll wrap up here in a few minutes. So first, I wanted check, James, is there anything that we haven't talked about that you wanted to talk about before we wrap up?

James: Another thing I wanted to point at is, another thing that kind of drove me and my mom to try to just power through as well, another thing that occurred in the family ... I'm not going to say who the family member is for confidentiality reasons, but basically me and that person were in a number of verbal conflicts, mind games played, and I actually came out of that with PTSD.

Caitlin Owens: That sounds really hard.

James: Before coming on the podcast, I saw the word Massachusetts and I almost thought of that stuff, but well, defense initiative forces are thankfully able to respond before that occurred.

Caitlin Owens: That's hard. You know, I've heard ... You were talking about computer systems and all that, and I love that analogy. And I've also heard of PTSD as kind of being a code and a computer and that kind of stuff.

James: It's just like a giant system error.

Caitlin Owens: Yeah. It's just kind of stuck and keeps replaying, and I know that can be really hard.

James: I should probably introduce you guys to the System Defense Initiative, which is basically the mental defense force of my system. Their entire goal is basically to just keep the system and its assets secure while also keeping beliefs alive.

And this is just me going into war terms, since I do that quite a bit to process a lot of this stuff, because World War II knowledge, basically this is just an estimate from the war terms; according to estimates, 90% of all defense initiative units were wiped out during an event that I called the three defensive, where basically that person sent every combat unit they had and one Hail Mary to try to break the system.

And it almost worked. And were it not for a new [inaudible 00:24:28] system implementation that was shorter and had a small period in between, there was a high chance the system could have fallen.

Mike Hoenig: Well, it's interesting that you use those. When you talk about the force and the defense, it sounds like that's kind of a strategy or a coping strategy or ... I don't know if that's quite the right word, but you've figured out ways to, when some thoughts come in that you'd rather not enter in, that you have come up with some ways to combat those. And I think that's great.

James: Well, the main thing about it was not only did it make it easier to process, but how my brain processes those is strange. It doesn't see it as an argument, it sees it as a war. Every one of those arguments was a battlefield to the system, and strategy [inaudible 00:25:15] going constantly to try to find ways to block enemy assaults and launch our own counter strikes to slow them down.

Mike Hoenig: That is amazing. It's hard to describe that into words how ... You know, you can kind of feel that connected. But I get it.

Caitlin Owens: James, we like to end all of our podcast episodes by asking guests the same question. And so we are wondering, could you tell us, what do you think your superpower is and what do you want people to know is your superpower?

James: Well, when I think of ... I don't typically think of it in that way. I mean, I know the whole superhero community exists, like MCU, the DCU, et cetera.

Mike Hoenig: This isn't so much about superheroes maybe as ... What's another word for superheroes?

Caitlin Owens: What's your greatest strength?

Mike Hoenig: There you go.

James: Probably the greatest strength is ... Well, right here.

Caitlin Owens: Can you-

James: Defensive initiatives, strategic systems capable of outmatching most it runs into.

Caitlin Owens: Yep. So James pointed at his brain. Since we're a podcast, I'll describe it.

James: Oh, right. They can only hear audio. Sorry

Mike Hoenig: That's right. I love it. That's awesome.

Caitlin Owens: Yes. Just in the brief time of knowing you, I would say that sounds totally accurate.

James: Typically when I have the knowhow of something, my system could come up with the various greatest strategies to try to overcome obstacles. Not just having to follow by the meta AKA what's most commonly used in certain scenarios, but also coming up with the greatest strategies to overcome issues.

Mike Hoenig: Well, and we should ask Laury too, what is your superpower? Yeah,

Laury: My superpower.

Mike Hoenig: Your superpower.

Laury: That's a tough question.

You know, my superpower I think is getting to know someone and how they learn, and just really paying attention to the behavior around it and kind of finding out how they're thinking and the way they're processing information, and teasing that all out, and finding creative ways to teach.

So even before going into social work, I worked in human resources, training people, and that was just one thing I like to do. Because I think everybody thinks differently and processes differently, just like you manage different people differently, because everyone has their own different motivations too.

Caitlin Owens: That is wonderful.

Mike Hoenig: Yeah.

Caitlin Owens: And based on the time I've known you, Laury, that sounds totally accurate.

Mike Hoenig: Well, it sounds like you're good at finding other people's superpowers and-

Caitlin Owens: Yes.

Mike Hoenig: ... Helping them work with that.

Laury: Yes. My sister actually has often said something similar to that. Yeah.

Mike Hoenig: Hey.

Laury: And just finding ways to encourage others to flourish. It's very rewarding.

Mike Hoenig: Well, as Caitlin said, I've learned a lot too. And we just want to take the time to thank both of you, James and Laury, for joining us today.

We certainly always want to acknowledge and thank our partners and friends at the Midwestern Public Health Training Center. And also want to thank you, our listeners, out there for joining us today.

So Caitlin, any final words from you?

Caitlin Owens: Nope. Just want to thank James and Laury again. And-

James: No problem.

Caitlin Owens: Thank you, Mike. Nice chatting with you.

Mike Hoenig: You too. And please, out there in podcast land, stay tuned. We have an awesome lineup already scheduled. So stay tuned for fun and exciting things to come.

Caitlin Owens: Thank you for joining us today on Disability Exchange. Disability Exchange is brought to you by the University Center for Excellence in Developmental Disabilities, which is housed at the Center for Disabilities and Development at the University of Iowa. We are produced by the fine folks at the Midwestern Public Health Training Center. Special thanks to Kyle Delveau for the music contribution.