

Episode 2.2: Culture and Disability with Dayrin Lovan

Mike Hoenig: Well, hey everybody. It's Mike Hoenig from the Iowa University Center for Excellence in Developmental Disabilities, the Iowa UCEDD. And we are here with another episode of Disability Exchange. Disability Exchange, for those of you who have not listened before, is a podcast dedicated to elevating and centering the voices of people with disabilities and their families through meaningful conversation, which will also be very casual. We are very pleased to be partnering with the Midwestern Public Health Training Center, UI College of Public Health to produce these podcasts. We have a great episode on tap for you all today and we'll be introducing our guest very soon. But before we do that, I would like to turn it over to our co-host for today, Laury, for her to have the chance to introduce herself. Laury?

Laury Scheidler: Thank you, Mike. My name is Laury Scheidler and I am a student at the University of Iowa in the School of Social Work doing my practicum here at the UCEDD. So, I'm very excited to join you, Mike, and Dayrin.

Mike Hoenig: Great. All right. Well, as I said, we've got a very, very, very wonderful guest today. I first met Dayrin a couple of years ago through our LEND program, and we'll be talking a little bit more about that over the next half hour or so. I will just say, because I want her to tell her story, you don't need to hear more from me, but she has taught me a tremendous amount, not only about having a son with a disability, but also some of the cultural implications that I'm still not the best at. I'm learning though, hopefully, and Dayrin has been one of my best teachers. So, with that I'd like to introduce Dayrin Lovan to the program. And Dayrin, please introduce yourself, tell us a little bit about who you are.

Dayrin Lovan: Thank you, Mike. My name is Dayrin Lovan. I'm an immigrant. I am originally from Guatemala, where is beautiful country, but now I'm living here in Iowa City, Iowa, which has been a place I call my second home because I've been living here for the past 28 years. So, how many children I have? I have two children. My oldest, he's 25 and my youngest is 19, and he is a child. Well, as a mom I always say a child but he's a young adult with disabilities, with autism and all different other, the combo of having other diagnosis because of autism. He's nonverbal at this point still. And what I do? Well, right now I work at LEND here at CDD with three different places with UCEDD and different projects. My work has been doing through IC Compassion. It's a non-profit organization here at the east side of Iowa where we do a lot of work with the immigrants and refugees working in different things that they need or resources when they arrive to Iowa.

Laury Scheidler: Dayrin, I'm curious. Is your 19-year-old with autism, is he still in school or what does his life look like right now?

Dayrin Lovan: Yes, he's still in school. He's in a program right now called Transition, which when a young adult with disabilities has the opportunity to stay in school until they're 21. And so I was presented to the opportunity for him to continue, and so after the 18 he finished it up with the academics and now he's doing a transitional program, which mean they help him with cold skills for job training and outside and trying to be more independent.

Laury Scheidler: Oh, wonderful. And how is he doing in the program?

Dayrin Lovan: He's doing well. J.B., that's how we call him. Actually J.B. Shore his name. He's doing really well. I believe it helps him a lot because he was a person that cannot be around a lot of people or going to the store without doing situations that will be hard for us to take him. But to the Transition program, he being able to go to do some shopping for himself or riding the city bus. And that's really big for him because he never was able to do it before. And he's been participating in two different agencies where he go and volunteers.

Mike Hoenig: Oh wow. So, those of you that have been listening to this podcast for a while will remember that Judy Warth was one of our co-hosts from last year and I believe that J.B. has worked some with Judy. Are they still working together?

Dayrin Lovan: Yes, she always trying to oversee how he's doing with the work that he do. Yes.

Mike Hoenig: That's great. It's always good to have somebody like that on our side.

Dayrin Lovan: Yes, for sure.

Mike Hoenig: Yeah. So, it sounds like he's making some really good progress.

Dayrin Lovan: Yes, really. He really does.

Mike Hoenig: So, I'm curious to find out a little bit about when you first found out that he had autism. I didn't realize that you had lived in Iowa City for quite a few years. So, I assume you were in Iowa City when he was diagnosed. Is that right?

Dayrin Lovan: Yes. He born here in Iowa. It was really hard at the time. I guess I take him to the doctor to doctor visit and the doctors are just saying, "We can do some testing." Because things was like he was not pointing. The eye contact was not there. So, I knew something was different from my first child. But his birthday is in November. I take him for his two-year physical and she say, "Something is not right, I need to refer you to the CDD." And I was like, "CDD? What is that?" And she say, "Well, they're going to help you." But I was so frightened, now. I was like, don't have even in mind that this is going to be a place for me to go. And so she did that referral in November and I remember I say, "No, I think she don't know. Maybe I just going to wait and so I don't need the appointment." And then J.B. get a ear infection in May, six months later. And she like, "How went the appointment in the CDD?" I say, "I'm sorry but I still don't go yet." So, as a mom I knew something was wrong but I was so frightened to confront it.

Mike Hoenig: So, then after that did you go to CDD?

Dayrin Lovan: Yes, finally they did the appointment for me and I came to the CDD. It was a long day for us from the morning until the afternoon. I feel I remember was yesterday when I was here.

Mike Hoenig: Oh, wow.

Dayrin Lovan: And that was when they say, "Yeah, he has autism and he have..." At that moment we call it a little bit of mild retardation. And he was nonverbal at the time so he was almost two years and eight months when he get diagnosis with that.

Laury Scheidler: I know you mentioned something about not wanting to really face the fact that there was something. You knew there was something. So, when you did find out, what was that experience like?

Dayrin Lovan: I will say that, I don't know, everyone experience pain in a different level. So, process a loss. It was like I always describe as having this crystal ball of dreams and hopes and he's going to go to school, he's going to graduate, he's going to get married, he's going to do a professional, he's going to be a doctor when he become a grown up. And so I just don't want nobody to take that crystal ball away from me of hopes and dreams. And for my personal no experience, it was devastating. It was like someone took that crystal ball and crush it in front of me. And after I was in front of those professionals and I say, "Did he ever going to talk?" And they say, "We don't know." Did he ever going to be independent?" "We don't know." And I was like, "What do you can tell me?"

"Well, we have a diagnosis about what he had." And now I feel like they just give me those pieces of my crystal ball. And it was so painful and it was really frightened at that moment because as I mentioned before, I'm an immigrant. I don't have any parents. I don't have a standing families. At that moment I

even don't have sisters. Nobody here. It was me, my two boys and my husband. Which I don't mention to you guys, but he's Asia so he's from another country, other culture. So, culture always been part of me. And fronting with this situation, it was devastating. I confess here today, I never confessed, but even to tell my mother that I have a special needs child took me a year to tell her that he has autism because of the stigma of our culture.

I always believe as growing up, if those kid is only going to be for those people, they did something bad or God cursed them or they did something wrong. Hence so, my first question. I get all the diagnosis about autism. I didn't know what it was, autism, at that moment. We talking about 20 years ago. I was younger and don't know about disabilities. And even the word disability, it was huge for me. And so now I confronted with this diagnosis that I didn't know what's happening or what's going to be the life will be turned for him. And so tell my mom that I have a child with autism was devastating. It was a shame, blaming myself. And I think during through the years I've been find out more and more that a lot of our parents that we experience, especially with immigrants and refugee, having a child with special need, it was compared to we did something wrong.

And so now it was the blame on me and it was those years of asking, "Maybe I did something wrong. What I did eat?" Or "What happened? Why, why, why, why, why?" The question of a million dollar question, "Why me?" And no answers. And I think, I don't know, but then my culture is really hard and we always feel blamed by something or afraid. I think more than ashamed it was afraid to confronting the world of autism. But through the years I've been learning that I enter to a new world and a new culture. It's disability culture, and which it teach you a lot. I don't say it's easy because there was times where I just finding myself locking in a bathroom and crying and say, "I cannot do this anymore." But consider as an immigrant, we really faith root-based. So, our faith, my faith, it was like what make a huge difference. And I can come out and say, "I need to do it and this child need me."

And so we start the journey of seeking the treatment. But took me after I had the diagnosis to reach for resources because remember I have a lot of professionals, I don't know nothing about the autism, and then they give me a package. I remember it like yesterday. A big package of, "You can apply for this, for a waiver. You can get social security. You can have a speech pathologist, OT, all these other resources." But they are in English. I don't read English at that time. I don't know. And everything it was through English language and that was devastating. It was like I bring a child and now I living with that diagnosis, but it was like I'm in my own and it was devastating at that time.

Mike Hoenig: Were you able to find an organization or a family or somebody else to help you through that at some point?

Dayrin Lovan: At some point, yes. I believe Grant Wood get involved and they call me and say, "Could we help you?" And then it was like the moment was, I believe it was another organization, some of the parents maybe remember at that moment it was like Children's Center for Therapy.

Mike Hoenig: Oh yeah.

Dayrin Lovan: Some other parent tell me about it. So, I went and get treatment for J.B. And that was when, like I say, entered to a different world because my world changed. It was never be the same because it was like now I have this three-year-old boy and I have to find where to take him. And it was a lot of therapies. At time it was from 8:00 AM from maybe the whole day. And the thing at that time I was living in North Liberty, which 20 years ago they still don't have that much resources over there.

So, I have to travel to Iowa City all the time and to be here a lot of my day to be looking for treatment for my son, which that was how I end up to living in Iowa City. Because he went to preschool or kindergarten. They say, "We cannot have your son here. He have to go to Iowa City District because we don't have any resources of how to handle your son here in North Liberty." So, that's why I need to move to Iowa City because I had to bring this boy to Iowa City and go back to North Liberty. It was really tough at that time. But eventually we moved to Iowa City and since then I live here in Iowa City.

Laury Scheidler: It sounds like you've come quite a long way from that first feeling of the world crashing down, the new diagnosis, the new culture and the stigmas that came along with that. What was the turning point for you? What resource helped you turn that around into more seeking out more resources and strengths to help your son?

Dayrin Lovan: I think at the time I was continued to looking for ways of how to help him. Because I knew that was confronting to a big challenge in my life and I was determined that, yeah, it was a time where I just closed the bathroom door and just crashed down in tears myself for a moment, but then I just, like I say, go back to my faith and say, "I'm a strong believer and I know that God was having a purpose for me." So, I believe it's with any situation that you confront in life, call it a diagnosis in life, like a medical diagnosis, time you know nothing, you just have to continue to keep walking and looking and searching. And so it built me up. I think at that moment I was thinking that I don't have the strength, but learning as a mother I become more stronger with this different situation that was confronted.

Mike Hoenig: So, you mentioned a little bit ago that Grant Wood, the Area Education Agency, reached out to you. First, I assume that he went to the public school system in Iowa City. And if so then did Grant Wood, have they helped you with different therapies and special ed teachers and so forth during his time at school?

Dayrin Lovan: Yes. Grant Wood are the ones who get me in the house and from that they did the transition to school. And through his whole life, Grant Wood, they sending him a speech pathologist and people to help him with. Even now that he's growing up through his teenager years, he had a lot of anger issues and aggression. So, Grant Wood has to send in the specialist and helping with him. So, I believe that his whole life and being in school, Grant Wood being part of that-

Mike Hoenig: That's great.

Dayrin Lovan: ... treatment. Yeah.

Mike Hoenig: You've mentioned communication a couple of times. Does he have some words or does he use mostly sign language and other things to communicate with you?

Dayrin Lovan: No. For years and years, I cannot tell you how many years now, it's like looking back, I'm like, "How many years that we went through these long days?" But he improved because he was really bad in his communication. Now he has a device. He was able to maybe talk one or two words, but those who are in autism world, it's like we gain some progress and then regression and gain and regression. And eventually those two words that he had, he lose them. And no matter what I did, it was like he never can talk. He's nonverbal. But he communicate to visual cues and body language and through a device. We have an iPad now through the years-

Mike Hoenig: That's great.

Dayrin Lovan: ... and are advancing with a communication app.

Laury Scheidler: Does he seem to do well with the communication device in general?

Dayrin Lovan: Oh, overall, yeah. We can say and sometime we use picture changing. Yes.

Mike Hoenig: Technology has come so far. It's amazing.

Dayrin Lovan: Yes. And especially with J.B. being one of those cases of severe autism, I think it make a huge impact.

Laury Scheidler: Did you notice a difference in his behaviors once he started having that communication device and that method of communicating?

Dayrin Lovan: Yeah, it helps. Even though it's still really frustrating for him. Especially, he cannot tell us that he hurt or something happens to him or he don't know how to express. Because the device only help him to like, "I want to go. I want to play. I want to pray." But he don't have those other expressions or how he feel that day. And we have language and we can express how we feel, like the emotions. With him is everything internal. So, at times it was the aggression, it was how he can say more how he was that day.

Mike Hoenig: I know that you said that there's a stigma at least from your parents or your mother in Guatemala, and just I think in many, many cultures there is a stigma around disability. And have they come to accept J.B. as a part of the family? And if you'd prefer not to answer that I totally understand, but I'm just very curious about that.

Dayrin Lovan: Yeah, I believe that eventually they become accepting him and knowing that he was different, that his appearance look like any typical, but after you have five minutes or three minutes with him, you're going to notice some things that are different. And yeah, become more accepting of him. But I know that what you say is really hard with our society or our culture. I remember they always giving suggestions. "Maybe you should do this or that may be improving." And I become really helping other parents. And I remember also Grant Wood called me one time and say, "I have another parent like you. They having hard times with her son that has autism." And at that time I already start talking English and I went in and know this young mother, and she say the same thing.

"I am struggling with the same situation like you about my parents, but they say that I can give birdseeds to my child. That way he can talk." And I believe as all humans, always looking for treatments to improve the health of your child. And so it was like I never will forget about that. And I have to sit with her and say, and through professionals too, Grant Wood help her and say, "No, this is not going to be doing the change. But therapy has been improving. They improved language and independence." But a lot of stigma. Until today we have a lot of stigma about disabilities back home.

Mike Hoenig: And I will say that there is still stigma in the United States to some level. I being blind, I experience it in different ways, but not to the extent I think that there are in some other countries. And I don't know what changes it. But I know that you mentioned, Dayrin, that you help families from different cultures.

Dayrin Lovan: Yeah.

Mike Hoenig: And I'm sure that that support you give them is super helpful. I'm sure they just are glad to have a compassionate ear.

Dayrin Lovan: Yeah. Like you say, maybe still stigma here in United States, but it's not compared to my country. I believe if my son born in my country, he will be tryingng into or put him into... Young adults over there, they suffering a lot. Still now they insolate them or put them in a place and they cannot go to public school or they cannot be part of the society. So, they be insulating. Until now, it's still rough. And I believe talking with refugees, you cannot imagine, Mike, the stories, they will broke my heart to here now still. Until now how the stigma is in our back home in refugee countries, which violate a lot of the rights of people with disabilities.

Mike Hoenig: Yeah. I can't even imagine what that must be like. I know that there are things that just need to change and I know that I've learned so much from you and I'm just so grateful that you are making others aware of it and making life better for immigrants in this country.

Dayrin Lovan: Yeah. We have so much to do. And like you say, maybe we see things there are stigmas here in United States, but to hear stories. Even six months ago devastating my heart of where a neighbor just has autism, her son. And it was so violent that they have to put him and lock him and don't let him go nowhere. And so his whole life it was locking him in a small room because he was not able to go out. So, those are still my heart, it's saying that it's more to do for young adults or adults with disabilities.

Mike Hoenig: Absolutely.

Laury Scheidler: Dayrin, I am just impressed with the strength that you've shown all through the years of going through all these things that you've experienced. I know we are getting close to wrapping up where we're at this point. Is there one thing that maybe we didn't ask that you would like to share before we end?

Dayrin Lovan: I believe when you close to those who are from another language or culture, be sensitive to their culture. At times maybe they don't want to share or they don't want to reach for help, but they need the help. But just be sensitive of not judging them maybe because why they don't go and receive the help that they need. Well, you don't know the process that they going through. Or maybe they don't understand how the system work here in United States and that will prevent them from not reach the level. Or I've been having a lot of people saying, "Why the Latinos or refugee, they don't come to the school. They don't get involved?" Well, it's because of maybe they thinking the school know better and they don't know how to advocate for themselves or how to advocate. Because back home, and I believe other countries, everything we have to pay our pocket.

We don't have Medicaid. We don't have any help there. So, at times we say, "Maybe this is going to cost us money and how we going to pay?" So, be sensitive to the culture and not judging, but that we all together in this. And my goal and my hope is to continue bring awareness of disability. It's huge new

world because you have the wrong self culture. But you're going to have beauty too because you learn so much. I believe that I'm the person who I am right now, it's because of my son with disability.

Mike Hoenig: Wow.

Dayrin Lovan: And I cannot have a thousand words to say that because of him I respect, I honor the population with disability. And this is the best opportunity that God give me to have J.B. and just continue to advocating. And that's my passion, to be advocating for others with the special needs.

Laury Scheidler: That's wonderful, the disposition that you have, Dayrin.

Mike Hoenig: Yes, it is. I think we'll wrap up. Sometimes we do a final question, but what we were going to ask was... And go ahead and if you want to add anything to this, Dayrin, but I think you pretty much covered it. We usually close in honor of Judy because she was, last year, was one of our podcast hosts, and because also you know her. We know that she loves the word superpower. Yeah. So, what would you say, I think you kind of answered it about being a passionate advocate, but if you have anything to add about that for yourself. And also, what's J.B.'s superpower? I'll bet he has lots of them too.

Dayrin Lovan: He have a lots of them. But I think J.B.'s superpower is that he's very speed. He's faster. Before you know, he going get that candy. And you even don't going to notice when he just grab that candy. Or I going to enter to McDonald's and he see the french fries. And before you know I was like, "He has the french fries in his hand." And I'm like, "J.B., where you get that from?" He's very speed. And my superpower I believe is compassion and patience. He teach me patience. And I believe that a lot of parents and caregivers, we need a lot of patience.

Laury Scheidler: Yes.

Mike Hoenig: Yes.

Dayrin Lovan: Those are my superpowers.

Mike Hoenig: That's awesome.

Dayrin Lovan: Yes.

Mike Hoenig: Well, I would just like to thank you, Dayrin, and also thank all of our audience for tuning in today. I'd like to thank the Midwest Public Health Training Center for helping us and producing the shows. And I would just encourage all of you out there listening to stay tuned for more podcasts coming forward. And Laury, would you like to close us out?

Laury Scheidler: I would also like to thank everyone and especially Dayrin for sharing your vulnerable story, and what an amazing story you have, from the very beginning of feeling overwhelmed to pulling in some amazing strength and advocating for not only your own son, but also for other families too. And that is a true blessing for others.

Dayrin Lovan: Yes. Thank you. And I hope that we continue to give the opportunity to those who are minorities and refugees and immigrants. And I'm sure in the future I will like to have more stories about other people.

Mike Hoenig: We will bring you back.

Dayrin Lovan: Thank you.

Mike Hoenig: Thank you.

Outro Speaker: 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 DelBo for the music contribution.