

## **Disability Exchange Season 3, Episode 1 The Intersection of Queer and Disability**

**Mike Hoenig:** We have a very exciting episode of Disability Exchange tonight. My name is Mike Hoenig. I am a program coordinator with the University of Iowa Center for Disabilities and Developments, UCEDD. And UCEDD is an acronym, which stands for University Center for Excellence in Developmental Disabilities. The purpose of Disability Exchange is to center and elevate the voices of people with disabilities and those who support them by engaging in conversation, which we hope will be casual, entertaining, and of course, provide some learning opportunities for everyone. We think it'll be a great learning experience for everyone who listens, and I certainly am looking forward to learning things as well. Before we introduce our guests, I would like to turn things over to my cohost Judy Warth.

**Judy Warth:** Mike, that was so formal. I hardly know what to do with myself. As Mike said we're excited about our conversations tonight. We have two guests who I've work with in the past.

Cassie Olmstead is a PhD student here at the University of Iowa. She'll share some of her story, and Kaleb Cook who is the director of Cook Inclusive, So welcome, you two.

**Kaleb Cook:** Thank you for having us today. We're really excited to talk about queer and disability.

**Cassie Olmstead:** Yeah, it's great to be here.

**Judy Warth:** Great. Would you guys mind sharing with our listeners a little bit about yourselves? Cassie, you want to start first?

**Cassie Olmstead:** Yeah. Like you said already, I am a PhD student in the learning sciences and educational psychology program at the University of Iowa and I do a lot of research that looks at the ways we can support inclusive education. I'm also a neurodivergent individual, I have autism and ADHD, and I have three children who are all varying levels of neurodivergent and disabled. my oldest is 22 and he is bipolar, and my middle child is 16 and has autism with a PDA profile.

And then my youngest, Ash, was actually born with a brain malformation that caused cognitive and physical difficulties, and a seizure disorder. She had a

brain surgery in 2020 to control her seizures, which has worked really well, but they removed the left half of her brain. She is also transgender.

**Judy Warth:** Awesome. You said ADHD with PDA. Could you tell our listeners what that might mean?

**Cassie Olmstead:** Autism with PDA.

**Judy Warth:** Oh, there we go. Awesome.

**Cassie Olmstead:** Autism with a PDA profile is persistent demand avoidance. So these are people who, anytime that they're asked to do something or given some kind of definitive instruction it can trigger their fight or flight system and they go into a complete anxious overload and this can sometimes be seen as aggression or sometimes be seen as just a shutdown or a meltdown.

**Judy Warth:** Excellent. Thank you, Caleb.

**Kaleb Cook:** Hello, everyone. My name is Kaleb Cook. I use he/they pronouns. I'm a past LEND trainee. I live currently in Colorado in Glenwood Springs I am the executive director for Cook Inclusive Company, which is a local nonprofit that provides Vocational and Therapeutic Recreation Services to the local Roaring Fork Valley, queer, disabled, deaf, and neurodivergent communities.

I, much like Cassie, am also someone referred to it as "neuro-spicy". I love that word. I'm autistic ADHD, anxiety, you name it, I got it. But really excited to talk more about lived experience. I'm also queer and non-binary so I intersect all those fun little areas in addition to the neuro-spiciness.

But really excited to join this conversation today. my hyper focus is intersectionality and how disability intersects with so many different communities, specifically the queer community. So excited to spend some time really highlighting how that works and how it impacts the disability community.

**Mike Hoenig:** Kaleb both of you are certainly welcome to, to answer this question and jump in, but Kaleb, since you use the term queer, I'm hoping that you can define it. I'm of an older generation and so when I was growing up that term was very much of an insult to someone. I think for years and years, it's carried a stigma with it. So I'm hoping that you can help clarify that terminology for us.

**Kaleb Cook:** Yeah, for sure. And I have this question come up a lot. I do a lot of business meetings and DEI trainings and we, I have every single person in the room, if they feel comfortable, say the word queer. it's not a bad word.

But I do recognize that through generational changes and experiences that queer can be a very sensitive word for people. But now this is a term that we use to really identify the whole community. I have heard the term Alphabet Mafia multiple times by queer people where we just keep adding more letters to the little acronym that we're expecting people to remember. I, as a person advocating in the queer community, have a hard time spitting that out every single time. And I think my generation, like the people in their 20s, 30s, and teens, really have transformed and took the word queer back instead of using it as a word of hate and as a slur we took it and we're going to use it to empower ourselves.

And so when I refer to myself as queer historically, like people would probably say, oh, he's gay. But queer is almost like a little rainbow umbrella of all the amazing, beautiful sexuality and gender spectrums that we do have. And it's just a way to really address people in a very inclusive way.

A lot of times, I think people really get stuck on the gay community and the gay community or the lesbian community or the bisexual community. But we're hurting ourselves by not acknowledging trans and non-binary people. And so by using the word queer, you're actually including everyone. All the people regardless of your gender, pronouns, sexuality, anything like that. You're just queer. But it has been a big shift in terminology.

**Judy Warth:** Caleb I'm going to jump in here as somebody who's lived in the fringe of that world. I swear I have a mild case of dyslexia. I turn all the letters around. So queer is actually much easier for people like me to use. I too am older and identify as a lesbian in our world, the word gay, lesbian, queer, they were all merged. We asked the question the same way that we've always asked about disability. How do you want me to refer to you? Because we are people first too.

**Cassie Olmstead:** Yeah, I was just going to add that I think one of the things that's happened with this shift in terminology is also the idea that someone may be in multiple categories in the LGBTQ world. And so by just referring to people as queer, you don't make assumptions about what their gender or their sexuality may be. I'm a bisexual woman and I've spent my entire life feeling like I didn't actually fit in the queer community because there was so much focus on being lesbian or gay in so much of my younger years. So I didn't ever talk about

it. I didn't ever acknowledge it to most people. just being able to say queer removes that question. People don't ask.

**Kaleb Cook:** As a like historically marginalized community, we have so much culture that's pushing on us to really define who we are and make it easy and palatable for people to be able to understand us. And so I think it almost shifted that culture where we were putting ourselves in these boxes and this younger generation came in and said, 'no, I'm not getting put in a box. I'm going to be whoever I want to be and really embrace that.' And so that's why I think that word queer really caught on. It was because it was like, I don't have to identify as gay or lesbian or bisexual or transgender. I can identify as just, I'm part of this queer community.

I think unconsciously, LGBTQI+ is going away, if you're in a business training or something like that term is used quite often. But as you see those younger generations take those leadership positions and take over these organizations, queer is going to be used the same way that slang and language and culture shift.

**Cassie Olmstead:** Originally it was actually GLBT and after time that changed to LGBT, and then we started adding all these letters on to identify other groups of people, and I don't think anybody is ever going to completely do away with the types of identifying categories that allow someone to express themselves. I think as a whole society will eventually end up at a point where they use queer rather than the acronym because it's just simpler and more inclusive.

**Judy Warth:** Cassie one of the things that you mentioned was about Ash. Would you mind sharing with our listeners that journey?

**Cassie Olmstead:** Yeah. Ash started telling me that she was a girl when she was about two years old and at the time, I was actually really resistant to it not because I had a problem with the idea of her being trans, but because she was cognitively delayed, and at that point she was functioning more at a year and a half, somewhere in there. And I just didn't feel like she understood what she was saying. Initially I would tell her. 'Boys have penises. Do you have a penis? You're a boy.' And she would argue with me and she would get mad at me. And over a couple years, she was more and more insistent. And she was going to school at the same school as her brother and in a district that required them to wear uniforms. Every day it was a fight to get her to put the boy's uniform on. She was always so cranky and so miserable. And we thought it was because of all the medication she was on. We thought it was side effects.

And then, before she was going to start kindergarten, we had gone to therapy a bunch to see if we could help with some of the mood stuff and the fact that she was just so unhappy. And they were like let her wear whatever she wants at home. And at that point we were still using male pronouns.

But let her wear whatever she wants at home. And do your best with the situation with the school. And so that summer, between pre K and kindergarten, they decided they wanted to move her to a different school because they needed her at a school with a nurse full time.

And so we were presented with this opportunity that she was suddenly going to be at a separate school from her siblings, And no one was going to know her there. So we talked with her therapist and we talked with our family and we sat down and we went, 'all right, Ash, you can be a boy all the time. You can be a girl all the time. You can be a boy who wears girls clothes. You can be a boy sometimes and a girl sometimes. What do you want to do?' And she was like, 'I am a girl.' And we went, okay. And so we bought her a whole new wardrobe and we let her socially transition and start using female pronouns.

She told us then that Asheron was a boy's name, but Ash was a girl's name. So she was okay with Ash. But so it meant we didn't necessarily have to worry about trying to get everybody in the family to change the name they were calling her just to change the pronouns they were using. And so that took work and time. It was like this overnight change in her personality because she went from being miserable to this happy bouncy kid that nothing gets her down. She had a brain surgery and they removed half of her brain and she spent two months in the hospital and this child was laughing and smiling the day after she woke up and never complained about anything.

She just does what she does. Everybody who meets her their reaction if they find out that she's transgender is 'wait, she wants to be a boy' and I'm like. 'No. Other way around. She was born biologically male.' But we have run into issues here in Iowa with the changes in underage care. Ash is currently on a puberty blocker. She'll be 13 in November. And she was originally put on a puberty blocker four years ago because she went into precocious puberty and it was too early for a male body to start puberty. We initially started the puberty blockers because of that, but then also it was beneficial in helping some of the dysmorphia. Her endocrinologist was able to convince the insurance to approve the puberty blocker replacement one last time this year. But as soon as she turns 13, it can no longer be for precocious puberty. The only reason to continue it is for gender affirming care. So, if we have not moved out of Iowa by the time it needs to be replaced again next year, we will have to let them take it out and she

will have to start dealing with male puberty until we can get someplace where they'll provide the care.

**Judy Warth:** I appreciate you sharing that. I think it's important for people to know that people may leave places that their loved ones can't get the care they need during this time.

**Cassie Olmstead:** Yeah, currently I'm almost done with my dissertation. I'm on track to graduate in May. And I am applying to jobs as we speak. And I am only considering places that have transgender supports and care.

**Kaleb Cook:** Cassie, I'm sorry that you're having to go through that. And it's so frustrating to hear this same story from so many families that I work with in Iowa. I also empower you, go to a state that is going to affirm your family and affirm what you need and the services you need because that will seriously save lives.

I personally left Iowa as soon as I turned 18. I moved out. I'm living in Colorado now where it's like a protected state. It's not that Iowa is a horrible place. It's just the legislation that's horrible. And that makes it really hard for queer people to live. And I think a lot of times we spend so much resources and energy in Iowa thinking we want to make this a place for people to stay, but we leave queer people to the sidelines and say 'it's going to be a great place if you're straight' and not so much on 'Hey, these kids need medically necessary services and we're not giving it to them.' And I have many friends and family members driving like eight hours for care that should just be something you can go to 30 minutes away at the home state.

**Judy Warth:** I want to believe that our legislators created laws that they thought made sense, but perhaps without the absence of the perspective of people who are living with lived experience. If you were going to speak to them directly, what would you say?

**Cassie Olmstead:** I would come at it from two sides. I would talk about all the research that supports the idea that being LGBTQ and specifically being transgender is a brain and biology difference. We have lots of research now that shows that it's actually differences in hormone levels during certain parts of the pregnancy that lead to brain differences and mismatches between body and brain.

And then I would talk about the research that shows that providing gender affirming care and gender supports, which are not permanent changes, up until

the child turns 18 and is old enough to make permanent decisions for themselves is important. Not only acceptable, but is best practice. And then I would talk about our experience with Ash and the fact that she was asking to remove body parts before we put her on a puberty blocker and stopped all these hormones from going through her, because she was trying to figure out how she could remove the parts of her body that made her so upset.

And once we got her on the puberty blocker, no change had to be made to her body. Her body is still the same as it was then, but now that all those hormones aren't rushing through her body, she's able to be okay with it with the support of just some therapy until she's at an age where she can make a more permanent decisions for herself.

**Kaleb Cook:** Cassie, I think that brings into the conversation of gender dysphoria. And I think a lot of people really get confused on what that truly means, but that is literal pain and distress that young people are feeling because they are not in the bodies that they need to be in.

And when you talk about sustaining gender dysphoria in an unaffirming environment the complications on mental health that it brings, suicide rates are so much higher for LGBTQ and queer kids. In my valley right now, I have had to go to two services for two queer young high schoolers who were not affirmed and they were denied access for gender affirming care and as a result, committed suicide and that's the sad truth. Kids are dying because we are we're trying these laws and regulations on these kids in reality, we're just hurting these kids more and putting them farther away from true happiness. I don't know if that's similar to your experience Cassie, but it's just sad. It hurts me

**Cassie Olmstead:** Yeah, Ash is lucky that everyone in her life loves and supports and affirms her for who she is and that we have been able, up until this point, to provide the things that she needed and hopefully, we'll be able to continue it because we'll be able to get someplace that will allow it.

**Mike Hoenig:** Many of the issues, although they may manifest differently, are the disabilities experience. They have not been affirmed and I'll put myself in that category, there have certainly been times that people really haven't understood either my needs or my capabilities. We have a medical student training program where we match small groups of medical students with adults with disabilities.

And we've had more than one person with a disability say that the patient encounter is the first time that anybody in the medical profession has

acknowledged their sexuality. And I recognize that those circumstances may be different for people who have disabilities and people who identify as LGBTQ or queer that a lot of the lack of affirmation is present.

Maybe if you feel comfortable sharing your own personal experiences or those of others when you identify in more than one marginalized community. And if so, how are the impacts multiplied?

**Kaleb Cook:** I love that you have that question and that focus on intersectionality. I would love to touch a little bit more on what it feels like to be othered. And I think this is something that brings the disability and queer community so close together.

As a person who came out as queer first, you know the process of coming out is... all the emotions at one time. And it's like rebranding yourself and having to come out as your true authentic self. It's a hard process. But you went through that process of identifying that you are different and that you identify as something different.

And so what I've seen is that a lot of people with disabilities and a lot of people that are queer intersect both of those communities because they already understand what it means to be othered and how it feels to be maybe from a different community.

And then when I realized I had ADHD and autism, that wasn't as hard of a come out because I've already felt what it's like to be othered. The people that affirm and love me, I know they're going to still affirm and love me, regardless of my disability, regardless of my queer identity.

I feel like my unique perspective of being othered in the queerness made me really love and embrace my identity as a disabled person.

**Judy Warth:** Just to keep walking down this path a little bit differently, sexual relationships and individuals with disabilities are often cast to the wayside, that as a individual who lives with a disability, often times society holds you out and holds you off and says you shouldn't be a sexual being. Do you think this further confounds things?

**Kaleb Cook:** we've put on so many different ableist mindsets on thoughts that disabled people are not sexual. it's the fact that like people with disabilities do have sex and medical providers didn't really think that perspective. If you have not seen the movie Crip Camp, you should watch it. It's free on Netflix. And

that talks about one of our leaders in the disability rights movement, went to a doctor because she was sick and they took out her appendix because they that's the only thing that they could really dictate it to and she, with the brightest smile, says that she has gonorrhea and the doctor didn't even assume that they would test her for sexually transmitted diseases or infections.

But again, we're all human and we all do human things and whether you have a disability or whether you're queer, you still probably have sex and it's still it's part of life and because someone might be disabled or in another group doesn't mean that they don't have a sexual identity.

**Cassie Olmstead:** I think that one of the things that I see where it's an intersection where it overlaps a lot is in whether or not Ash is considered competent enough to make choices and whether or not she will ever be considered competent enough to make choices about her gender treatments.

Currently we have an amazing endocrinologist who does a really good job of listening to Ash and hearing what she wants and needs. But she has trouble convincing the insurance to approve it, right? And it's not always the case that doctors assume Ash is competent. And then just in general, Anytime you are different in the ways that you experience life. Your descriptions, your explanations, your ways of interacting with people are going to be different. I personally have been through multiple experiences where just because of my differences, I don't describe pain the same way a neurotypical person would, right?

And my pain is ignored. I spent eight years going to doctors repeatedly saying there's something wrong with my hip and nobody would actually go in and do an MRI or a CT. And it turns out that the reason why is because what I was describing, they weren't hearing as hip pain. They were hearing it as just muscle pain, the way that I described it. And after eight years, I finally got to a doctor that did an MRI, and he went, 'Holy crap, you need hip surgery now.'

And I see that same thing when we start talking about the intersection and the care because the second somebody finds out that Ash is either transgender or that she's cognitively delayed, the assumption is that nothing that she says is going to be valid or true. And that can be very frustrating.

**Judy Warth:** I have another question for you guys. If we have family members who are listening who have a child who's identifying as a gender, then that's different than what they were born with or they've got some sexual preferences

that may feel unusual to the family what advice do you give to family members? What can they do and how, who should they reach out to? What's helped you?

**Cassie Olmstead:** I think for me as a parent, the big things were threefold. One that loving your child for who they are is something that we sign up for the second we decide to be a parent, because we don't know if they're going to be disabled.

We don't know if they're going to be typical in their functions. We don't know if they're going to be queer. We don't know anything about that when we decide to have a child. And we decide in that moment that we're going to love them for who they are. And so that's part of our job.

The second thing is that it's okay to grieve, maybe what you thought you were going to have, that's a normal process. And that just like when we grieve the loss of a family member, we don't necessarily share all that grief with our children. You can grieve. It is okay to do that. It is okay for it to take time for it all to feel normal. But, try and keep that grief more private when it comes to the child you're trying to support.

And then third, to reach out. There are support groups of parents who are all dealing with this in every community I've seen, and they're online. There are other people you can talk through all of this with, and they are more than willing to.

**Kaleb Cook:** Just to echo off the resources piece, my main job within the queer community here is that resource connector, and providing those support groups and therapeutic opportunities for families that might have queer kids that just came out.

I urge families to take... A moment to find their chosen family. I know a lot of people talk about chosen family and maybe that doesn't really make a lot of sense, but you have your family and that's the family you're born with. When you're queer, you have your chosen family. Your chosen family are the people that you surround yourself that might be queer, maybe they're not that love and affirm you for who you are, and regardless of your gender and sexuality, lean on those parents.

The same way we talk about disability, like we have so many families that go into autism support groups or they have others like the Down Syndrome programs. Do the same for queer kids. You are going through something that

will feel so isolating at times and can be one of the hardest challenges of parenting.

But the reality is, you're not doing it alone. There's other people that are going through the same thing and so take some time to find those groups. Just to name drop a couple that are available nationwide. PFLAG. With PFLAG I sit on their board of directors on our local chapter and we do a climbing program. So the kids get to climb and then the parents sit back and talk. And that hour of climbing is so fun for me because I get to go climb with the kids, but it's so meaningful for those parents because they have someone to listen to their struggles and understand.

Same with disability. You can talk about your autistic kid to parents of neurotypical kids for days and they won't truly understand it until you find that other parent that might have a kid with autism. It's that, idea that you just need to find people that are in that same group. And when you find those supports and when you go to those programs, you're going to find your chosen family.

I'm not saying you have to stay at these programs forever. Go to that Wednesday night program, maybe once or twice, find the cool people and then go and have a beverage with them or a coffee later with them. Find those people and connect with them and stick with them because they are going to be the people that will be at the phone when you're having a crisis. Having a queer kid is the most beautiful experience ever but with that, it might be really hard to tackle. And so knowing your resources and knowing what's available is so important. The Trevor Project is one of the most outstanding programs and it is all about suicide prevention and affirming kids. The Human Rights Project is a great way to educate yourself just on queer etiquette and understanding on what it means to be queer.

They have a bunch of great resources on their website about parenting and parenting a queer person. But again, just keep those contacts bookmarked in your laptop, just so you have those resources in your back pocket. The people that are going to know the most are the people that might be a couple of years ahead of you on their child's come out and they will be a great guide for you.

**Mike Hoenig:** The commonalities of the importance of peer support or family support that shared experience is important. In fact, I worked for a number of years for Nonprofit Center for Independent Living where the majority of people that were hired were people with disabilities who really could identify. When we ran into a crisis or ran into people that just did not understand, there was a listening ear on the other end and then in turn, we attempted to be that listening

ear. Within the queer community it's great to know that type of support is out there and is being encouraged so strongly by both of you.

**Judy Warth:** For our audience who's queer, what advice do you give them? For the kids? For the adults? What are you going to tell us here today that maybe if one person hears it and gleans onto it, this whole time with us will have been worth it?

**Cassie Olmstead:** It gets better. It sucks sometimes, but it gets better. And there are so many people out there that want to love and support you. You just have to find them. So don't give up and don't be afraid to advocate for yourself and say, I get to be who I am and that's okay.

**Kaleb Cook:** I would say slay the day every day because you as a person is beautiful and there are people out there that want to love and support you and surround you. I struggled for so many years and now I have my queer community, my chosen family, and I am thriving. It's crazy what happens when you find those affirming environments. And yes, to echo it off, it does get better. It sucks for a while. But the reality is, you'll find your people. It takes time. Push yourself, push your boundaries a little bit, and really get you outside of your comfort zone, because welcome to the queer community. It's a great place to be.

**Judy Warth:** Any advice you'd give their physicians or professionals working with them?

**Cassie Olmstead:** Remember that they're human beings, and that just because your experience doesn't align with theirs doesn't mean it's not real. Afford them the same dignity you would want your own family afforded.

**Kaleb Cook:** That was beautiful. One thing I would add is, be knowledgeable of the resources out there. You might not know what you don't know, and you can only do with what you know, but when you know better, you'll do better. Just pushing yourself out of your boundary a little bit and like better understanding the community that you are going to be serving.

Even if you don't think you're going to be serving queer people, statistically, most likely you'll have queer clients. You'll have queer patients. And I tell everyone to do this to really throw yourself in the community and better understand what it is. Go to a drag show and just live it up, enjoy it, and take a moment inside this community that's so beautiful. Take a moment to learn be kind to yourself.

You're not going to know everything right away, but as long as you devote time and energy to learning more, you will do better for all of our queer community members.

**Judy Warth:** We appreciate you guys' open and honest candid dialogue with us today because I think this is new territory for so many people to openly discuss what it means to be queer, how we acknowledge the queer community and how we live together you know if you go with the Alphabet Mafia, you notice the A stands for allies, and I think in the perfect world, everyone will be queer. We can only dream, right?

**Mike Hoenig:** It's great that you have been willing to be so open and honest with this discussion. I think it's very educational for so many, including myself.

To learn more about your own experiences as well as the intersectionality of queer and disability. It's something that I think is a topic that we've certainly become a lot more open with over the past few years. And both of you are excellent examples of people that are leading the way in that effort. Appreciate both of you. for your honesty, for your openness and for spending time with us and our audience.

**Judy Warth:** This is Disability Exchange, a podcast from Iowa's University Center for Excellence in Developmental Disabilities. We're focused on centering and elevating the voices of people with disabilities through meaningful conversations and connections. We thank our listeners, and we thank Caleb and Cassie, and our producer, Joanna Sabha.

**Mike Hoenig:** Stay tuned for many more interesting episodes to come during this third season.