Video Transcript

Inclusion of People with Multiple Disabilities and Chronic Illnesses from an Intersectional Perspective

Speaker: Kris McElroy

Rebecca Martin: Hello, everyone. Welcome.

We're thrilled to have you here today to join us for our rescheduled training on multiple disabilities and chronic illnesses from an intersectional perspective. My name is Rebecca Martin, and I'm a graduate assistant with the grant facilitation team at the Rutgers University Edward J. Bloustein School of Policy and Planning working to coordinate the New Jersey Inclusive Healthy Communities training series and IHC academies trainings. We are very excited to have you today here today for our talk with Kris McElroy, a self-advocate, artist, activist, and human services professional who will be talking about his lived experiences as a person with multiple disabilities and chronic illnesses, which he'll be discussing through an intersectional lens. Before we start, I'd like to make you aware of a few things. We'll be recording today's training, which will be made publicly available. We have enabled captions for today's event and are thrilled to have Tatiana with us as our ASL interpreter. If you would like to pin her to your screen, locate her in the gallery and click on the menu that appears in the top right corner when you hover over her image with your mouse. While Kris won't be using slides during the talk today, he has created accessible slides that summarize many of his discussion points and has provided those along with a few resources. In a few moments, I'll place a link to these documents in the chat. And you also should have received a link to them yesterday in the reminder email. There will also be time for questions and answers toward the end of the conversation today. Please feel free to add any questions that come up in the chat or hold them until the end when you'll be free to unmute …

Okay, one second here. Lost my notes. Okay, where were we? Okay, so please feel free at the end you'll be able to unmute and um ask any questions you have directly or you can put them in the chat. Also, given your interest in today's training, we'd like to send you updates about future IHC training opportunities. And if you would like to opt out of those and opt out of receiving information about the IHC program as well, you can indicate this in the chat or you can email me. And I'll place my email in the chat in a moment as well. And then finally, before we start, I'd like to take a moment to express our deep appreciation to Peri Nearon and her team at the New Jersey Division of Disability Services for making this training series and the IHC grant program possible. And now I'm excited to begin the discussion with Kris McElroy. Kris, welcome. It's nice to have you here today. Would you mind starting us off by telling us a little bit about yourself?

Kris McElroy: Yeah, thank you for having me. I'm Kris McElroy. I am a 38-year-old autistic, biracial, black transgender man with multiple disabilities and chronic illnesses including rheumatoid arthritis and complex hereditary spastic paraplegia. That's a mouthful. I'm also a trauma survivor. my professional experiences include being an educator, a camp counselor, an Instacart shopper, working for the National Alliance on Mental Illness as the coordinator of recovery programs, being an activity leader for an assisted living facility, and an advocate reviewer. I'm also an artist, a self-published author, and I received my Bachelor of Science in Psychology and my Master of Science in Multi-Disciplinary Human Services. I also have a wife and 8-year-old daughter. Rebecca Martin: Thank you so much. It's so lovely to have you here today. I've been excited about this for a long time. So thank you. Can you start us off by telling us a little bit about your personal journey to diagnosis and understanding of your disabilities?

Kris McElroy: Yes. So it's been a lifelong process. It started when I was five with developmental delay. And then my doctor noticed that the muscle tone was not developing in my legs the way it was supposed to, which started a series of testing. And at first they diagnosed cerebral palsy, but unspecified. And then it was spastic diplegia, spastic quadriplegia, an unknown neuromuscular disorder, spastic triplegia. And then

in my young adulthood, I was diagnosed with depression and anxiety and then bipolar disorder, which ended up involving numerous amount of psychotropic medications which had significant adverse effects on my physical health, which led to more neurological testing At that time between that and my family history, they switched the diagnosis from CP to hereditary spastic paraplegia or spinal cerebellar ataxia. So far all of those genetic tests have come back negative, so they have finalized it, so far, as complex hereditary spastic paraplegia with an unknown gene that has yet to be discovered. It does run on my dad's side of the family. However, my dad will not get tested nor will his brother. So … it's … they're not able to figure out the gene. It impacts my speech, my swallowing, my walking, my ADLs. It impacts my mental health and impacts my everyday functioning basically. I have learned a lot of ways to adapt, and I also have learned how to manage my mental health. It has been a really long roller coaster of a journey with unclear answers and a lot of different emotions. The rheumatoid arthritis journey began also on top of it in 2015. So I'm what a lot of doctors have called a complex case where a lot of things interact with each other and a lot of treatments will help in one way but have adverse effects on one of my other conditions. So it's been, it's been quite a ride.

Rebecca Martin: It sounds like it's been a long time for diagnosis that you've been going through. Can you tell us, because I think some of these different conditions might not be familiar to everyone, could you just give us a little bit of an idea of how it affects your daily life, what you experience?

Kris McElroy: Yes, so my neuromuscular condition is the complex hereditary spastic paraplegia falls under the motor neuron disease umbrella, which, the ones people are most familiar with are ALS. So it's not ALS, but it falls under the same umbrella, and it does impact, it impacts my, I'm like I said my swallowing. I do have to use thicken liquids. My speech is impacted. Even if it's cold my muscles will get tight and that impacts my speech. If I'm sick or even if I'm excited or upset my speech is impacted, because I don't have full control over my muscles and the signals get mixed up. That also impacts going to the bathroom as well, basically anything that involves signals from the brain to the body and my muscles. It impacts that which … the amount of things that occur every day from getting up out of the bed to carrying my daughter to making a meal to go into the bathroom. It's all impacted, and for me it does vary depending on the day. And then the rheumatoid arthritis, because of the joint pain and inflammation, it adds an extra component and stressor on my body. So it has further impacted all of those things as well. Sometimes I use the cane, sometimes I use a walker, and sometimes I use a wheelchair depending on the day.

Rebecca Martin: Thank you for sharing that with us. What has your experience been like in disability spaces as someone with multiple disabilities and chronic conditions?

Kris McElroy: My experience has been a mixed bag. Growing up with multiple disabilities, I was in mainstream education aside from being pulled out for physical therapy and speech therapy. And so it was a lot of not interacting with the disability community. I actually didn't know I had a disability. In my household my dad just told me we just walk a little different. It is what it is. And the message I got from my mom was if you just picked up your feet and slowed down, people would understand you and you wouldn't fall. So those messages … I didn't … even though I grew up with multiple disabilities, I didn't comprehend what that meant or knew what that meant. I thought it was just things that I was doing that were causing the disability that I didn't know I had. Even with the testing and the CP diagnosis at the time it was described to me as you're really tight and someone with your degree of tightness shouldn't be mobile and be able to walk. So the fact that you can keep going … my … It was challenging in school because not being identified as someone … It was a really weird experience because it's like visually you could see I had disabilities, and I did struggle in school, but I didn't receive any services outside of speech therapy, and special education wasn't offered to me.

My parents decided not to pursue that route. So by the time I got to graduate and then it was always instilled in me go to college, we went to college, you're going to go to college.
My freshman year was a mess to put it lightly. I didn't know about a disability services department. I didn't know about accommodations. I didn't know about any of it.
And I felt very isolated. And then I had trouble interacting with those spaces, because they were unfamiliar to me. They were new to me. I didn't know how to answer the questions, and I didn't find out my medical history, which still has a lot of gaps due to the way it was handled when I was growing up. So I didn't know how to relay the information and the questions being asked, and how to relate to others in the community in young adulthood. So it's … that that took a toll on my mental health as well. I felt very isolated and alone, and I didn't know how to ask for help, how to interact with others. And it was a challenge. And even now it's still I struggle to interact both inside and outside of the disability community.

Rebecca Martin: Thank you for sharing that with us. Have you … at what point did you come to identify more with the disability community in this journey? Was that in college?

Kris McElroy: It was part of my college. I ended up going to seven different colleges before I figured out what accommodations I needed in order to be successful. So my interaction first started from a mental health standpoint and perspective in 2009, so like my mid-20s. And that was a good connection, because I was able to meet others. And it wasn't …

I didn't experience that many barriers except with my physical disabilities. Sometimes places were not accessible to me where meetings were being held. But I was definitely able to connect from a
mental health perspective and challenges in recovery as well. My physical disabilities and being on the spectrum,

I'm gonna say 30. It wasn't until 30 where I was in … that was after two years into therapy where I was actually able to start … not … I was able to start the process of figuring out what it meant to me to be autistic and to have physical disabilities and how that connected to my life up to that point.

Rebecca Martin: Thank you. You mentioned that there were some spaces that you couldn't physically get to where you could have found support in other ways. Do you feel like you've been able to bring all of yourself to any of the disability spaces that you've been in? Or have you had to leave parts of you at the door to participate?

Kris McElroy: I … my experience up to this point is I have always had to leave at least one part at the door. The disability spaces I've participated in usually have a focus So if it's being autistic, then it's an autistic space, and that's the focus. If it's having an autoimmune condition, that's the focus. It really … where I'm able to bring all of me is usually one-on-ones where I'm having it's a smaller more open-ended interaction.

That's usually more where I'm able to bring all of me rather than the specific disability spaces. Even when I was participating with the Special Olympics and even that was very specific .
And even with that the county I was in some of the … some of the practice spaces were not physically accessible to me, so I would have to sit and go down the stairs while someone else carried my walker down. That … I count those as barriers of having to leave one part or multiple parts of me at the door because to me that means I have to adjust my needs and they're not included in that space.

Rebecca Martin: What types of stereotypes have you experienced

Kris McElroy: The stereotypes I've experienced … one is the assumption that I didn't graduate high school or go to college. That stereotype especially when I'm in a space and they're going around the table or asking people that are younger than I am, and I'm just … it's assumed that I can't participate in that because I haven't achieved it. A stereotype that I am not an athlete even though I am one with multiple medals. The assumption that I don't eat healthy or that I don't like to cook. The assumption that if I have an intellectual disability then that means I am unable to be a parent. That has been a huge stereotype that I've had to navigate. The stereotype that I'm not aware or cannot be a part of making decisions.

The stereotype that I have nothing to contribute or that I don't want to. The stereotype that I'm deaf because I use an AAC device to support my communication.

The stereotype that I don't have a spouse and that my wife is my caregiver and we are interacted in that way when we go out in public.

The stereotype that I automatically do not drive or cook or clean. Even if it it looks different, it's the assumption that I don't participate in any of those things.

So those have been stereotypes. Even in terms of my accessing confirming care for my hormone therapy for being trans, I've had to fight to access that because it was assumed because of me being autistic that I was unable to decipher that and make that decision for myself even though I was told in signed paperwork that it was based on informed consent and care. No one told me that being autistic was a barrier to that even though it shouldn't be.

Rebecca Martin: And how do you confront these barriers whenever they come up? Like, what do you do in terms of self-advocacy or, I don't know, challenging people's stereotypes?

Kris McElroy: One challenge was … I have tried to verbally in different ways address it and challenge it. Sometimes it is has worked. Other times my voice has been silenced, and

I have gone to a different provider or location. That access that … that for example was the case with accessing the hormones for my gender affirming care. It was not gonna happen there, and it didn't matter what I said. What they were requiring of me I was not going to do because it didn't say that was part of the process, and I counted that as discrimination. Now what I wish I would have done was — I know that now, I didn't know that then, and I was very emotional, rightfully so — but I wish I would have known how to report it and interact with it for the discrimination that it was. That I did not know back then, and I didn't have the skill. When conversations are happening around high school or college, I will just insert myself into the conversation and let people know because even if it's silence it makes me feel like I broke through that barrier. When I'm out with my wife, we have actually had a conversation around how to approach it, and she will actually step back. And if they're trying to hand her the money even if I'm the one that gave it to them, or someone says oh do you need help with your client … it's … I'll say, I'm her husband. And usually those interactions or those responses in my experience have caused a step back even if there's no other interaction. And I like to believe that at least it caused a pause. I I will advocate for access needs as a more normalized perspective instead of these accommodations being needed, because sometimes speaking in terms of accommodations especially in a work setting where accommodations are viewed as separate — over here — access needs apply to everyone and people's access needs differ on depending on the day or time. So that opens up more of a conversation and dialogue rather than something occurring on the side that creates this separation between, well, you're over here with your disabilities and that involves this, and we're over here, and there's no bridge. So I kind of view it as the challenging and the advocacy is creating bridges.

Rebecca Martin: Thank you. It's great that you brought up workplace, because I also wanted to ask you about … you've worked for NAMI and also as an advocate reviewer and an activity assistant at an assisted living day center. So what has it been like for you working as a human service provider as a person with mental health conditions and disabilities?

Kris McElroy: I love it. I absolutely love interacting with people in general, which is a surprise to a lot of people that's also a stereotype and assumption that I challenge daily. NAMI … working for NAMI I love creating programs and connecting others to support and being able to share my story and also hear other people's stories and know that like at the beginning and end of the day people are people. No matter what they're living with or dealing with, people are people, and I love being able to create space for voice and validation and to be seen and heard. That's something that drew me to the field, because it's something that I didn't receive and that was often taken away or silenced or minimized.

The other side to that experience is getting through the … getting through the interview process and getting through the stereotypes and discrimination that can be oftentimes a part of the jobs I worked for, so especially being an activity leader it's really hard in general. One, going through the door and not being told, because it still happens in 2022, that the position has been filled, and the position actually hasn't been filled. But it's assumed that I'm not going to be able to do the job because what they've seen when I come through the door.
Now virtual has somewhat helped with that, but yet I encountered other barriers because of my speech or using my communication device. It's still assumed that I'm unable to do the job, so I'm not … I'm not able to continue … to continue with the interview process because that is no longer offered to me. I remember, too, because having multiple disabilities and being an adult finding employment is still a huge barrier and challenge, I do part-time work and contract work. But I have … it's really hard to find positions.

And I remember going through extra parts of an interview process for one of those positions and being told, I know we're … I know we weren't supposed to do that, but we just had to make sure you could do the job. And I knew that wasn't fair or right, and that that was also discrimination, but I also really needed the job at that time. And I encountered those same …

I encountered that same treatment while on the job in different ways. So even though I enjoy the work, and I enjoy helping people, I enjoy advocating, it's a both/and, because while I enjoy that I'm also actively experiencing and trying to deal with discrimination practices. Because even though it's against the law, it's really hard to break it down the individual people that are also a part of work spaces and break through the way biases and stereotypes come out in interactions while in the workplace as well.

Rebecca Martin: Can you talk a little bit about your experience with that within the workplace and also what your experience has been receiving accommodations in the workplace.

Kris McElroy: So what I have received … it was easier for me to receive accommodations actually working in the mental health field. As a human services professional, I was able to get documentation from my therapist, and I was able to bring that documentation and have those accommodations implemented at work. The physical disability accommodations have been much more challenging to implement because I have to go through a process on my end with the documentation and having it covered. But if the expenses are more than what is covered through my position, then I have to figure out how to cover them on my own such as an adaptive mouse, an adaptive computer, a desk, a chair that worked for my condition, because everyone needs something different. It's not an automatic across the board, and that takes time. It really takes a lot of time, and I have found on that end that the job started before I was able to have those accommodations in place. But I've also run into is that sometimes I don't know what accommodations I'm gonna need until I get a feel for the job and what the position calls for and how that impacts my condition. Even for me, like, I get significant migraines, and the blue light works at times, but also having larger font works, spacing out the interviews, and the amount of virtual meetings, but sometimes that's not always available to do. And trying to have appointments with the rehabilitative specialists that helped me figure out how to adapt and occupational therapist, it's a long process. And I have found that to be a barrier so I'm spending a lot of time off the clock trying to adapt on my own and makeshift my own seating and figure out my own system for what will help and what won't until I can get those things in place. It's … it's a system of trying to work through multiple areas. But it doesn't … I found even though it's a lot, it's much easier when the workplace or providers are supportive and patient and understanding of the process rather than this is taking too long, we're gonna … we can no longer offer you the position, or this is impacting this so we have to let you go, or anything like that. So it's the patience and understanding and collaboration has also been helpful. I have had some workplaces where they actually have collaborated with me on what can we do in the meantime while we're waiting for this to get creative and see what can be done. So those settings have been really helpful in the workplace.

Rebecca Martin: Thank you. So from an intersectional perspective, what do you … what have your experiences been inside and outside of the disability community?

Kris McElroy: My experiences have been … it has … in my view it has made me a chameleon with many different colors and experiences and connections and vantage points, and has also allowed me and it has allowed me to connect with a variety of different people within the larger disability community and outside. It's always a joy to me to be able to sit down one-on-one with someone and find out different things about their life journey or a loved one's life journey that connects with mine just because we're sharing.

And I would have never known that they were a part of that community within the larger community. I absolutely love that because it reminds me that everyone has a story and a journey and it all intersects in many different ways. We just have to take time to interact and communicate and share with each other and in many different ways. And it doesn't always look one way.

And it's also been eye-opening to me to know like within the disability community like I'm meeting more people who are a part of the LGBT community and the autistic community than

I did when I was first starting out on my journey um with my transition. And that's exciting to me because it means that different communities are starting to connect with each other. And it means that more parts — because we're all made of many different parts, make up who we are — so it means that we're we're getting further along with being able to share different parts of ourselves in these settings in communities. And that has not always been my experience as I talked about earlier, but it's becoming more and more now. Even being able to see someone that from a program I took, a day program, and yet we're doing adaptive tennis together in a different community, and then we're both running into each other at the grocery store.

Like to me it all … it all interacts because it's not isolating. We're not all isolated in our own spaces. And I know there are people that still are. And it's my hope and part of the advocacy work that through opening up more of intersectionality and that many people are made up of many different parts. And that you can be a part of this, those parts make you a part of this community and that community and that community. Instead of it being isolated, it's all together

Rebecca Martin: Thank you. What would you want somebody working on disability including service providers to consider and put into practice when working with people with multiple disabilities and chronic illnesses and as well as people who've been historically marginalized by their intersectional identities?

Kris McElroy: I wish that one of the biggest things is make space for all the different parts that make up who I am or who someone else is rather than splitting them up. Or sometimes I found with providers is they would decide for me which part of me or which need was more important even. And I see them all as important and intersecting with each other. So having space and awareness and getting to know what all of those different parts of who I am and my experiences how they make me is one of the biggest things. Because the better you know me, the deeper the relationship and the better I'm able to be served. And that applies across the board whether it's I'm interacting in the community whether it's a health care provider, a service provider, a family member. And it's taking the time to get to know all of me and giving space for my voice. So it's asking me what my pronouns are and respecting and using those pronouns. It's asking me what I like to eat, as basic as that may sound, that's not an automatic. It's asking me my input and my services, what I like to do, how I want to spend my time, what I don't like and creating space for my voice or helping … and helping me figure out how to make space for my voice if that's not present and advocating for that. It's giving me different options to interact and participate and grow. It's not requiring me to do something a certain way but also knowing that if there's something I want to do but I can't do it that specific way it may require getting creative to figure out, okay, how can we do this and supporting that or helping me figure out what supports are needed to do that. It's understanding intersectionality and marginalization and equity while also keeping aware … keeping an awareness of how all of those three things are and are not at play. Sometimes it is easier to read about it than … or pick up on the big things and we miss the little micro things that are present and those have an impact as well. It's being authentic and transparent and adaptable and flexible, because having multiple disabilities and multiple parts of my identity not everything — most things — don't fit into a neat box.

And having that awareness and support in general is supportive of my holistic being, my whole well-being. And just like mental health impacts physical health, impacts social health, it all matters. And being able to also partner with historically marginalized communities, individuals, and self-advocacy organizations help the growth and the awareness and also show that this is a value and priority as well. And just also treat it as more than a diversity checkbox and instead as an evolving practice to grow a culture that values all people and is grounded in equity and inclusion. And the last thing I'm going to say connected to that is be aware of integration versus inclusion. It's not the same thing. And sometimes that integration versus inclusion can unintentionally have a detrimental impact.

Rebecca Martin: And just for anyone who doesn't understand the difference between integration and inclusion, can you expand on that just a little?

Kris McElroy: So integration is … take this Zoom meeting, for example. We're all in the same space. That's integration. It's we are all put in the same place. Inclusion is that care was taken in that space to make that environment in a way that everyone's needs can be met or accessed and included in that space. So it's … I have what I need to fully participate and interact. So does everyone else in that space. And everyone in that space is equally valued as well.

Rebecca Martin: Thank you.

Kris McElroy: You're welcome.

Rebecca Martin: We have about 10 minutes left, and I want to make sure that I allow time for questions, but before we do that is there anything else you'd like to share with the New Jersey disability community before we move on to questions?

Kris McElroy: The last thing I would like to share is that if you are a part of the disability community you are valued and your voice matters. And if you are serving that community you are also valued and your voice matters. And together we can continue to grow and make a difference.

Rebecca Martin: Thank you so much. I see that we have a couple of questions in the chat. And also if anyone wants to unmute they can … you can ask questions as well. I guess, let's see, what we have here.

So I have a question: How did you learn to separate your sense of self from others' expectations of you?

Kris McElroy: The biggest way was therapy. I …it was therapy and also self-care. I engage in regular self-care practices including listening to meditations that helped me stay grounded within my own self, and that helps … that helps me discover who I am and stay connected to that.

Rebecca Martin: Thank you. Des anybody have any other questions they would like to ask?

John Gattuso: Rebecca, may I jump in? Because I had … I'm wondering about your experiences with the the medical profession and especially because as you describe yourself as a complex … your situation as being complex, did you have difficulties finding professionals who would treat you know treat your whole self as opposed to the various components of your situation?

Kris McElroy: Yes, I have. It's still a journey. Western medicine … I … it's been … I would have 12 different providers, and most of them did not actually communicate with one another either, so it was on me to bring my really thick packet of records to each appointment. And by the time they would go through those records there would only be five minutes left.
So I found that was a barrier especially – and also draining. I have had to go to the alternative route of medicine for some of my care and or private practice for the people that I have found that take Medicare, and that has allowed me to be able to spend more time with providers. And they are looking at the whole picture even the unknown parts or the parts that are not clear. It's been, well, we're unsure but let's take it one step at a time and see where we can go and how we can get you where you want to be. And that has been really helpful. And also healing from my negative experiences with medical providers. One key thing has also been more of the providers I have now will actually listen to me rather than requiring someone else to be there and speak for me.

Rebecca Martin: How did you find the providers who do treat you respectfully and give you the space to speak about what you need to and who look at you as a whole person?

Kris McElroy: One way has been asking others who they would recommend both within the disability community and the LGBT community for me. And trying out … what I'll actually do is ask for a consultation first and be able to gauge based on how they're interacting with me there is this something I wanna continue to pursue with that provider or do I want to try the next one? I used to stay with providers for a really long time. Now I interview them myself. That has been helpful. And then also asking for support finding different providers from my wife and also my case manager with telling them what I'm looking for. And they're also aware of my negative experiences and trying not to duplicate that. So it's been a process, but I have a few now that are much better than in the past.

Rebecca Martin: Thank you.

Kris McElroy: You're welcome.

Rebecca Martin: I think we have time for one more question if anyone has something they'd like to ask.

John Gattuso: I can jump in again if you like. I wanted to give anyone else a chance who wants to jump in or make a comment, but I don't see anything on the comment list. So, yeah, so Kris my question had to do with how you … you've said that you encounter people who very often have stereotypes or preconceived notions about you. How do you respond to that, you know, how do you correct those preconceived notions? Or do you, or do you simply let it go?

Kris McElroy: Sometimes I have let it go, especially if I'm out with my daughter At times I will let it go because I have to focus on her and it's usually a side comment rather than a direct interaction comment. When it comes to other ones, other interactions, I usually will actually say something so it's … whether it's saying that's not okay to say or that's harmful to me especially in terms of my gender identity or that I'm just as capable of paying for this as my wife is, can you please … I gave you the money to pay for this, can you give me back my change? Or thank you for your offer to help, but I'm able to hold the door open. You held the door open for me, I would like to hold the door open for you. I can. Thank you. Or even with doctors, like the question before, I have said, like, I have worked with my speech therapist. We have set up this template, and I have my notes. I'm able to communicate in this appointment. There's no need for you to call my family member to be in this appointment with me. And if you require that then I will need to find another provider, because that's not okay. And those are just a few examples. So it usually does depend on the situation as well.

John Gattuso: Right, great, thank you.

Rebecca Martin: Thank you so much, Kris. We've come right up to the end of the hour. I cannot thank you enough for sharing with us so openly about your experiences. I've really enjoyed the conversation today and just thank you so much for being here.

Kris McElroy: Thank you for having me.

Rebecca Martin: It was truly a delight. And I also, you know, at the end of our presentations I would like to also thank the New Jersey Division of Disability Services for allowing us to have this opportunity to meet with you today. But thank you again so much, Kris, and take care. Have a great day

Kris McElroy: You, too. Bye.