Brain Club®: The Podcast - Neurodivergent Healthcare Experiences

Neurodivergent Healthcare Experiences

Mel Houser: [00:00:00] Hello! Welcome to Brain Club: The Podcast, a space for learning, unlearning, and reimagining new ways of being together in neuro inclusive community. I'm Dr. Mel Houser, Executive Director of All Brains Belong Vermont. Welcome to our brand new podcast.

Brain Club is All Brains Belong's weekly community education program where we demonstrate our approach to neuro inclusive culture through community panels, guest speakers, and book chats. It's a place where we shift broader community awareness about the issues of concern and importance to neurodivergent people in our community and promote new ways of thinking and being in community together.

It's a place where we transform culture by modeling what's possible, with the idea that then you go out into the rest of your lives and carry it forward.

You can already access all the recordings from our website, allbrainsbelong.org, but our community asked us to turn it into a podcast. So here we are. These conversations are not medical advice and they're not support groups.

They're an invitation to [00:01:00] think differently about health, connection and how we build systems that include everyone. Each episode features community panelists, sharing perspectives and lived experiences. We hope you'll listen with curiosity and reflect on what it brings up for your own life.

This is part two of our conversation about autistic life experiences in part one. Back in episode 10, we heard from Rey's belong community members about their experiences discovering that they were autistic for the first time in adulthood. We return now for part two to double click on specific experiences receiving or trying to receive healthcare as a late identified autistic person.

In this episode, we hear from community members at all. Brains belong sharing their healthcare experiences before they joined our community. Unfortunately, the topics you'll hear are heavy, systemic, ableism, discrimination, medical trauma, gaslighting, invalidation. Please take care of yourself while listening.

Unfortunately, these are not rare [00:02:00] stories. Neurodivergent people are commonly misdiagnosed, dismissed, blamed, and harmed by a system that wasn't built with us in mind. This conversation names the patterns so many of us recognize and make space for others to feel less alone. This conversation names the patterns so many of us recognize and make space for others to feel less alone.

Thank you to our panelists, Sarah Knutson, Matthew LeFluer Amy Noyes, Linda Riddle, and Zeph Thank you for sharing your stories. Let's get started.

Sara Wilkins: When you think about your experiences trying to access healthcare, what comes to mind?

Linda Riddle: It's very hard to access health, healthcare. I think it's hard in general. I think our system is broken, for pretty [00:03:00] much everyone, but. The amount of additional layers that come when you have, you know, and in, in a way any type of disability.

Just it, it makes it truly a monumental problem.

Sara Wilkins: When you think about your experience trying to access healthcare, what comes to mind?

Zeph: Um, this is gonna be kind of a bummer of a conversation. So here's a content warning because I don't have a whole lot of really great healthcare experiences. I have medical PTSD.

When I think of the healthcare experiences that I've had, a lot of them have been. Very challenging, particularly from communications perspectives, trying to make myself understood to the doctor and being understood.

Matthew LeFluer: What [00:04:00] comes to mind is, is a doctor or a physician or the nurse, you know, uh, willing to, uh, understand that this individual is different than all the others.

How can he or she adapt to that individual needs? But with me it's more about, you know, will this doctor, nurse, physician accept me for who I am, not what I am.

Amy Noyes: I've obviously been autistic my whole life, but I didn't know I was autistic. So I didn't ever knew what the challenge was. I, when I think about myself, even as like a little child and someone had to put attention on me or, had to touch me in any way.

I think I had a real fear response that I'm just starting to really start recognizing. And I didn't always felt like I was asked permission and that I realized in retrospect is huge. So I kind of didn't access [00:05:00] healthcare or accessed it very, very minimally

Zeph: even in emergency rooms, like not being able to tolerate the environment and being, you know, potentially written down as an uncooperative patient because I had to leave before they were done with their stuff because I just couldn't tolerate it.

Sara Wilkins: What are some challenges that you've faced in accessing healthcare?

Matthew LeFluer: The challenges that I face accessing healthcare is accessibility formats, documentations that they give you new patients or existing patients, you know, forms that you had to fill out per meeting when you get there for your doctor appointment that day.

Just, you know, it's not accessible.

Amy Noyes: It was very anxiety producing for me. The thing I think is like what I've recognized, even in like a basic wellness exam, there wasn't a connection. I didn't have a connection to my [00:06:00] body and I didn't have a connection to understanding why the question was being asked.

So if I went to a wellness exam and they're like, tell me about your teeth. And I would just be like, I don't know. I don't know how. And I, because I'd be so anxious, I don't think I had access, like to my fully functioning, like speaking. I just wouldn't know what to say.

Linda Riddle: Nobody believes you. And then there are different levels of that in, you know, well, you look at it wrong, or you couldn't possibly know yourself because you're this subgroup or that subgroup.

And then they're the ones where, well, they, everybody looks fine, so it has to be fine. And I found that a lot as a parent that. I would know something was wrong, but my kids didn't look disabled. Oh, they looked cute and perfect and just the right amount of chubby, [00:07:00] but no, no. I'm just one of those moms.

Matthew LeFluer: Yes. The difficulty healthcare system for me was the physicians of trying to understand my complexity. Of my learning knowledge and how I learn and how can they adapt to my learning. For me, it's more about, you know, not only speaking to them on that same level, which is very, very tricky, but also complexity of the healthcare system in in itself, because they're running on the medical terminology of the healthcare college insight and when they use those, or explain those to patients, sometimes patients like myself with disabilities, cannot get it because it's, you know, it's like you're teaching [00:08:00] a seminar at a university, but you're doing it with her patient.

Linda Riddle: Well, she has staring spells. She can walk a straight line and touch her nose. So there couldn't possibly be any neurological difficulties and it's coming from otherwise knowledgeable people.

You start to wonder where is the problem.

I have spent a lot of time not getting a lot of things, and part of it was, well, maybe this is just something I'm not, maybe I'm wrong. You know, maybe there's this big cosmic thing that 95% of the populace gets and I don't get because I'm me and I don't get it. And I didn't know why I didn't [00:09:00] get it then, but I just knew I didn't get it right. But no. It wasn't me this time.

Zeph: Seeing a lot of different symptoms show up in the different symptom systems of the body that were fundamentally neurologically related.

Matthew LeFluer: Long COVID, you know, and other, you know, uh, medical issues like asthma. It's, you know, it's very common, but as also seeing sex should never be ignored in a medical profession field. Because those could complicate, you know, the lifespan of an autistic adult or child.

Zeph: Even though I talked with them about the other symptoms of the autism, my symptoms were brushed off as PTSD.

Amy Noyes: And I can just feel when I walk in, I don't know if it's a safe space for me, and I know, I don't know that it's like a safe space for me, like. Uh, being neurodivergent, but I also don't know if it's a safe space because of the way that I'm gonna be [00:10:00] treated and, and disregarded in terms of like, just go lose weight.

I'm terrified to go. I, I think there's a lot of assumptions being a fat person and, so like if I go get my blood pressure checked or something like that, there's this like quality of. Oh, I can't believe that you have normal blood pressure like the, just like the things that people are saying to me, you know, I just recently had a routine mammogram and like what was said to me during that appointment was incredibly inappropriate.

Linda Riddle: When I came to Vermont and you know, I moved here so you had to get a new medical home.

This old country doctor. Nice man, otherwise. Took a look at me, weighed me, and signed me up for like the entire list of every health test you could possibly have. And I'm like, I don't really wanna pay for all these, but okay. And then I was like, no, we don't need to do the cholesterol. At least I know that one is fine because I'd had [00:11:00] it done recently and I inherited low cholesterol from my dad.

And he wouldn't believe me. So we ran the test and my cholesterol actually had gone up and I said, well, should we worry? Because it's gone up six points and a year. That's the most it's ever gone up. And he told me to be quiet and I was like, okay. And. I couldn't really voice anything back for me because we're trained not to do that.

Well, how is your menstrual cycle? And I was like, fine. Great. Well when was your last cycle? Or whatever. And it was like, I have no idea. And I immediately like was yelled at. And what they said to me was, and I started crying, and they said to me that it's my job. Like I always think it's a good sign when people are crying 'cause it's my job to [00:12:00] make sure and if I have to yell at people to make sure that they're taking care of their health.

Zeph: Going through that time period was super frustrating. Trying to get attention and going to like all these different specialists and not getting a whole lot of answers.

So many of these experiences are me advocating for what I need. It took me five years to get a diagnosis for my autism.

Amy Noyes: My healthcare provider said, well, we can't say you're autistic. Or like, you know, like, my chiropractic care was like, um, no. There's just no way. Like, just like not asking me, not. Not curious at all, like not saying why, what makes you think that you're autistic or how could we find you an autistic specialist to figure out or...

Zeph: to give you some idea how powerful it was. Number one, learning that I was stuck with learning that I was autistic was like a kaleidoscope coming into. [00:13:00] Focus for my entire life. That made everything make sense. And I was also diabetic at the time. My blood sugars literally dropped 20 points overnight and stayed down with a self-diagnosis of autism.

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Linda Riddle: find that hypocrisy bothers me a great deal in general. And, you know, we're supposedly a society where we're supposed to take care of ourselves and be informed and make decisions and be self-actualized and everything. And even if you're all those things. And in many ways, if you are those things, healthcare isn't designed to work for you.

You know, it's sort of designed for, you show up and they send you places and. Put you in little cubbies and folders and if you actually are like, no, uh, this, that, that doesn't [00:14:00] actually affect me. This over here affects me. Nobody quite knows what to do with you.

Zeph: Doctors I don't think are really taught how to work with patients who don't fit the expectations of, you know, what the profile is, they're trained to make decisions in a very specific way. They need to, in order to be really good with their time because nobody else lives in your body but you. So you think after a certain amount of time you would become an expert in it?

Sara Wilkins: Yeah.

Linda Riddle: I mean, that's kind of how I look at mine. Yeah, thanks.

Zeph: Knowing that just because somebody shows up in front of you and may appear normal-ish enough, but there needs to be given some amount of space or grace to allow for the fact that maybe this person has [00:15:00] other things going on that you don't know about.

Linda Riddle: I try very hard to communicate, but then when I get frustrated, I become very. Blunt and the new doctor I have, he at least can deal with that. But a lot of people in healthcare are still sort of trained in that, you know, I am in charge and you are here at my whim sort of thing. And you know, we must be respectful.

There's so many different layers of those nuances that I'm like, no, I had to wait 45 minutes for you.

Amy Noyes: I could never go back. So in that one moment, and I like, I went to therapy and like we had, we're starting to get all these strategies of how do I go back? And that's when I found ABB.

Sarah Knutson: Really, I basically, I was going through another round of low mood and fatigue [00:16:00] and sort of growing hopelessness about the possibility of having a future.

I had pretty much exhausted mainstream healthcare options, or at least the mainstream healthcare options I was willing to try. I was sitting with this friend Over coffee who was the director of the Vermont Disability Council, and she was raving about this new doctor in Montpelier who was out as autistic and starting a medical practice.

Sara Wilkins: So, what do you wish healthcare providers knew about neurodiversity and neurodivergence?

Amy Noyes: It's really like, I want them to know about ABB. I want them to know what Mel has figured out. I want them to know this connection between all of the things, that I wasn't waking up in the middle of the night with panic attacks.

I was waking up because I wasn't breathing because I needed a sleep study. I was waking up because I have dysautonomia because my autonomic nervous system doesn't work correctly. Everyone was putting this on me that like my thoughts were causing these panic attacks. Like, I don't know who has panic attacks.

I wasn't having a thought in the middle of the night. [00:17:00] And the way in which Mel has reframed that it's my fault that I am not doing something correctly, that I am broken, which is I feel like what the healthcare would say, like, you are not doing enough. And what I hear Mel saying is, no, the medical system isn't doing enough for you.

And so that's what I would love to say is that if the medical care system didn't blame people who have, um, difference. That instead was curious about that.

Linda Riddle: And we have made some, not enough, but some progress over the last 40 years. Learning to accept people a little bit, to give people a little bit more grace, a little bit more space to be themselves when we can tell they need it, but if you look like you [00:18:00] should fit and then you don't, people get cranky. And if the cranky people are the people that we're relying on to give us the referral. To actually listen, to think about what we're saying and try and put the pieces together in the areas that we aren't knowledge about.

'cause nobody can know all of this stuff.

Sara Wilkins: Mm-hmm.

Linda Riddle: And if they're just grumpy because we don't fit what they think. No.

Matthew LeFluer: For me. I see that, you know, process of the healthcare industry is starting to come around and understand neurodivergent, individuals and neurodiversity,

Amy Noyes: having curiosity around my experience, like [00:19:00] asking me do I understand where the question is coming from?

Providing a space that I can feel comfortable in and safe in. Um. Helping me make connections back to myself. Not making presumptions about my body, but asking me if like, that makes sense. Finding a b, B is just like,

you know, I've said this to Mel, I've said this to a lot of other people, but it's like, I just know I'm gonna live longer.

I can't imagine being yelled at. I can't imagine not being cared for. I think the whole first wellness visit that I had with Sierra, I think I bled the entire, like, I just remember like my shirt being all wet because I was just couldn't believe the care that I was getting and I couldn't believe the access and I didn't even know what I needed.

I had zero idea and the, that there was all these different options and so it's just so radically different for me.[00:20:00]

Linda Riddle: The idea that we can just say, this is my access need. And if we can take that step to say, okay, we're gonna actually look at this problem, what is the actual problem with access?

What is the actual problem with communication? What is the actual problem with coverage? Oh, then maybe we can fix some of this shit. So I think that's what we need.

Matthew LeFluer: What I want providers to do across Vermont, statewide is to understand the individual needs. If we can understand your needs, we need to be re respected in the same way.

And for me it's more about, you know, having that work individual participant relationship, basically you [00:21:00] want the doctor to know, get to know you better. Vice versa. The patient should get to know the doctor better, helps move things along quicker and make the process more easy for both parties, the doctor, the nurse, and the physician at large.

Plus the individual patient would feel that ease of, you know, coming back to those services.

Sarah Knutson: So, , I did the intake, which invited me to share like among other things what I care about. And also also offered to have a provider spend ti time discussing things I cared about, which really Im, which I really impressed.

And, among other things, like the possibility of sort of like, how do you structure an appointment in a way that it's comfortable to you, when you feel comfortable. And I thought, and, you know, things I had never thought about as even possibilities of sitting in a doctor's chair, you know, chair with, [00:22:00] you know, a comfortable blanket or, you know, pillows or, you know, something like that, you know?

So. That was like, oh, I could, you know, and, and so that, it was just nice that people thought about things like that. Mm-hmm. Um, and then I when I was sitting in the waiting room for my first appointment, there was this a short, a really short book written for kids. It basically told my life story of losing it.

I mean, I remember reading it, waiting for my first appointment, so sort of losing it and having these public meltdowns that I was so ashamed of, and it explained those things in terms of the flight, the fight flight response, which I was. Totally on board with already. So, and then there was also something on the wall in the office about polyvagal theory, which I was also totally on board with already and thought and was impressed that, that ABB knew about.

Sara Wilkins: Mm-hmm.

Sarah Knutson: And was thinking about, and I, so at that point I thought, wow, it looks like these people speak my language.

Matthew LeFluer: And what I wanna see forward is, you know, that sense of [00:23:00] belonging within the healthcare field industry, but also. Understand everybody's access needs is different. We're all different. We're not the same.

And for me it's more about trying to connect, have that universal connection between each industry or each systems, and try to make it a collaborative system where it's cost effective and more efficient. Because everybody wins that way. And it's more collective than having these barriers or what you call silos that are preventing us from providing those services in the first place.

Sarah Knutson: A really sincere attempt, the most sincerest attempt I've ever seen in a medical practice to meet people where they are at. To serve everybody well and to leave nobody behind. It's an incredible effort to make groups and meetings and medical care [00:24:00] accessible and interpersonally, practically financially.

And I love that the practice is really developed in consultation with patients and like we're in these advisory groups and invited to join them and that what happens in the practice after that, how the practice develops is informed and driven by what we say in those meetings and basically informed and driven by patient needs.

Amy Noyes: I just didn't know, that I would make it. And so when I say like. I know I'll live a longer life. It's not only do I live a longer life because I have the healthcare, but now I have community. I'm making friends. I feel understood. I feel like all of the things that seem so isolated in the issues with my health are now under understood with very simple medications.

It just changed my relationship to being able to get up in the morning, like limited my limbic response so that I actually can be here right now speaking to you. All of these things that ABB are [00:25:00] providing for me. And then it's like the other patients are just, I learned so much.

Sarah Knutson: This, this is just like so amazing to me. There, there are these amazing group medical visits where. Mel and Sierra offered this cutting edge information, and, but they, and they also allow lots of time for questions and in-depth discussion around , the areas that concern us. And there's and beyond that, you know, and, and there's more because there's also an opportunity to meet others in the community who are going through the same or similar things, which then gives, you know, us the opportunity to learn from each other's experiences. And to really value and feel valued by each other and feel a lot less alone and a lot more hopeful.

For many of us, healthcare isn't just ineffective. It's traumatic. But being in a space where your access needs are expected, where your patterns make sense, and where you are believed, that can [00:26:00] start to shift something. We're so grateful to Sarah, Matthew Z and Amy for sharing your experiences.

Thank you for sharing what you've, thank you for sharing what you've been through and what has become possible.

Thank you again to our panelists, Amy, Sarah, Linda, Matthew, and Zeph

Mel Houser: If you wanna keep exploring with us, you can join our Live Brain Club events most Tuesdays at 6:00 PM Eastern. You can also dig into our free digital resource library with all [00:27:00] the recordings from the past four years at allbrainsbelong.org.

You're not alone, and we're glad you're here. See you next time.