Brain Club®: The Podcast - S1E10 - What Autistic People Want You to Know

S1E10 What Autistic People Want You to Know

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.

In this episode, All Brains Belong community members share what it has been like to move through decades of life without knowing they were autistic, and what finally changed once they learned, diagnosed in their twenties through sixties. Our community members' stories reflect how much energy went into surviving, masking, and making sense of things without a name.

This is about unlearning re-narrating and finding language that makes life make more sense. Thank you to our panelists, Kelle Bourdeau, Amy Noyes, Sarah Knutson, Matthew LeFluer and Zeph.

Five autistic adults who were [00:02:00] identified to be autistic as adults, we would like the conversation around autism to be about de-stigmatizing the autism narrative.

Sara Wilkins: When did you learn that you were autistic and what has it been like to get to know your brain?

Kelle Bourdeau: I only recently like, had somebody else say, Hey, you're right, you're autistic. , So it, I don't even think it's been like six months that I've like comfortably said it to other people, like, and feeling confident, like, no, I got someone backing me on this.

Sara Wilkins: Right.

Kelle Bourdeau: But I have always questioned my neurology because, because of the things. Because people do the things so easily and it always befuddled me. Like how? I mean just in school, how do you. Just walk in on the first day of school and, and just do the things [00:03:00] and not, and not be freaking out like, you know, how does that happen?

Matthew LeFluer: When I knew I was autistic, I was late diagnosed in, January after my physical, which is age 23. Okay. And that was, you know, when, you know, the SSI and SSDI program wants to make sure that, you know, to continue, I had to go through a psychiatric to continue my benefits. And that was, you know, through the healthcare provider and that was by law.

Sara Wilkins: Mm-hmm.

Matthew LeFluer: And that experience, and I found out that I was autistic then. But like I said, I've also had multiple disabilities that, you know, ADHD when I was young.

Sara Wilkins: Mm-hmm.

Matthew LeFluer: then, you know, dyslexia within that [00:04:00] ADHD form. And then, you know, cognitive speech issues, stuttering of my own words.

Sara Wilkins: Mm-hmm.

Matthew LeFluer: that is when I knew I was different, you know, thinking differently and my brain was working very differently and it sees the world in a different, you know. spectrum, but I sees it in a different place, you know, of its own, you know, its own reality and its own kind.

Sara Wilkins: Mm-hmm.

Matthew LeFluer: And my brain, you know, I actually love my brain the way it thinks because I can see the world around me, but also I can see the world in me through other people and see their experiences, discussions, difficulties and, you know, conversations [00:05:00] through a whole different set of lens.

Amy Noyes: I first heard the idea, or, someone asked me specifically, like, autism was not on my radar at all for myself. And, I had gone to see one of my spouse's college friends who I didn't, I had never met before.

I wasn't a person who like shared a lot about myself, but I found through the weekend of hanging out that I was sharing a lot. I was in a really challenging time in my life. And, it turns out that two years prior they had been diagnosed with autism. And so, the last day we were hanging out, we were in this really, really large restaurant in New York City and it was really, really loud and tons of people.

, But we had gotten to know each other enough that it was like there was this comfortability. And in that conversation that's when they had said like, had you ever considered autism? And ne I had never, and I don't, I like, it didn't even cross my mind. [00:06:00] I had very like, stereotypical ideas of what it meant to be autistic.

But they did this thing that like really changed my life. They put noise canceling headphones on my ear, on my head. Wow. And they did it like they put it on. And so there was something in the act of this connection with this person. And when they put them on, I think that they could see a shift in me.

, It was so palpable to have. All of the stimulus and in that connection with them in that moment, it was like the whole world, like went away for a moment. And I think it was like really in that moment I knew, and even though I didn't know know, but I got excited and I got really curious.

Zeph: I had come into contact with a blog or something that was written about the alien on the playground, and it was about an adult diagnosed, assigned female at birth person who. [00:07:00] Felt very alienated throughout their childhood, and I read this, blog and recognized myself in it.

Sara Wilkins: Mm-hmm.

Zeph: At the time I was partnered with somebody who had been diagnosed with Asperger's, which is a part of the spectrum, but that's what they were calling it when he got diagnosed and I found the RAADS Ritvo Scale online, which is a clinically validated assessment tool. It's correlated between people who have autism and people who don't. And I took it and he took it. And my results wound up being even farther off the charts than his were.

And that started me trying to get attention from my medical care professionals that I suspected that I had autism because it says on the RAADS Ritvo, [00:08:00] if you score in this range, take this into your doctor to be assessed. I worked for about a year and then wound up in a space for about four to six weeks where I just couldn't do anything and.

Amy Noyes: And around this time I was, I would consider myself an autistic burnout. And I, I couldn't really leave the house and I was having, you know, up to 10 panic attacks a day. Like it was just, my nervous system was just, everything was shutting down and, that was right when the lockdown happened. And so, it was like, it saved my life it felt like in a lot of ways because now all of a sudden there's no social interactions. I don't have to hug anyone. I don't have to set any boundaries for myself. I don't have to be anything for anyone. And it was, it's when I came out of, I realized I had been an autistic burnout.

Zeph: Fundamentally, it took me. It took me another couple [00:09:00] years to actually get diagnosed with the autism, but reading that article that enabled me to self-diagnose and really started asking the questions was kind of like this kaleidoscope twisting into focus where everything that never made sense about my life finally started making sense.

Sarah Knutson: Yeah, I've been suspecting that I was autistic for a long time. Or, you know, 10 or at least 10 years maybe. and I'm 60, a little over 60. So, so I guess they, it's what it's, I think the thing that's been the most important to me is really sort of finding a community of people.

Amy Noyes: Right about a year after that, I found ABB going into the Fox Market, a little market, and,

East Montpelier and they were donating tips to All Brains Belong for that month. And when I saw that, this is the place for me, [00:10:00] this is like, this is where I get, I'll start being able to exist in the outside world. 'cause that still wasn't part of my experience and. A B, B to me has been a way to have community, have social connections, to understand my body, to reframe mental illness into, you know, autism, to, take medicines that, you know, simple medicines that have been able to make my mobility and my ability to be in the world different. And, so I would say like the, my therapy gave me a space to, be myself in a way to myself. And ABB has given me a way to be myself and in community with others, that hadn't had in so long.

Sara Wilkins: What does being autistic mean to you?

Zeph: Honestly, the first thing that comes to mind is trauma.

you know, I don't want to be a downer or anything, but being an [00:11:00] undiagnosed autistic for most of my life, I've had a really hard time with social trauma. I've had death threats as a result of me not understanding either social cues or what people are saying and, I have cPTSD that my psychiatrist has identified is as a side effect of having autism.

Other than that, it basically means that my brain has. Differences in the way that it works and processes information. There are some things that it does really well. There are some things that it really sucks at. but fundamentally, I don't look at my autism is anything that needs to be cured. I look at it as a part of the natural standard deviation in terms of what is normal.

Sarah Knutson: If I [00:12:00] had to guess, I would say, you know, from an evolutionary standpoint that most of us are probably really, really wired to be incredibly sensitive to social context and social cues and what the rest of society, wants and needs and what other people are doing. And in a large way that's great, it helps us to all get along, but if a whole society is off base. then, or going in a direction that isn't so good. Evolutionarily, there probably needs to be at least a healthy minority of people that are able to not be so wired, cued into what the social world thinks. I think that's healthy for society to have that minority, and I think it's really hard to be in that minority because that difference is not at all appreciated in the mainstream.

Sara Wilkins: can you talk a little bit about the strengths and the challenges that you feel like go along with being autistic?

Matthew LeFluer: My biggest, you know, brain strength is insight [00:13:00] and knowledge, you know, a world around me plus the environment if it's to, or welcoming. And, you know, for me, that's my, that's my biggest strength is, you know, my brain is thinking fast on its feet and.

And the way it sees the world's perspective view, my brain's weakness is trying to comprehend or doing, doing too much overwriting, comprehending the situation.

Sara Wilkins: Mm-hmm.

Matthew LeFluer: And trying to analyze it in, in its own way, but there's too much, you know, background, brain status, noises. That it makes it hard for my brain to comprehend on what to focus on.

Zeph: I'm really, really good at things like pattern recognition. I rely upon pattern recognition for survival. I'm [00:14:00] also really good at working with things that are really complex. I have an ability to see both the forest and the trees. At the same time.

Sarah Knutson: Guess what it means to me to be autistic is like, to sort of be the moral, a moral conscience or a sort of an outlier to the rest of society saying, or outlaw, an outlier or an outlaw to the society I'm living in. Saying, I just don't see it the same way you do, and it doesn't make sense to me, and I think you're going in the wrong direction in this way and that way and this other way, and that you could be doing it. And so it's, and so I'm often on the, on the outs of it, and yet, you know, 20 years later, I'm often not wrong.

So, And it's a long time to wait. And by the time everybody else is caught up, I'm usually on to finding something else that I don't like. So.

Kelle Bourdeau: Or just people understood things that I just didn't seem to understand and I didn't know where they were getting the information. You know, like [00:15:00] had Google existed as, as if I was a child. Like I would've been Googling that all day long. Like, why is it so easy for people to do this stuff? Like, yeah. You know, all throughout school I was a solid like. I loved the middle of the school year. Like you're in your groove. You got your notebook that's already half filled in. You got the rest to go.

There's no beginning of the year icebreakers. There's no end of the year zigzags. You're just, whew. On your path, and I've always said that about myself, and now I can kind of like look back and be like, well, duh. Yeah. Like of course, of course. That makes sense. Like it was comfortable. I knew the rules. I knew the expectations.

Amy Noyes: That's when I tended to be more engaged in class because I just, I understood the expectations, but beginning and end of anything is just so challenging for me. I can feel like I'm nervous, to talk. And that's part of it is like the [00:16:00] excitement. It can cue on safety in my system. and and so I just wanna like name that for myself, all of the ways that I had felt different, or been made to feel different around, like, pickiness being overly sensitive, controlling, highly anxious.

even though I, those were all kind of separate points or relationships in my life, all of a sudden it came into this clear view under this one umbrella of, of this, you know, neurobiology or this difference. I think of it differently now, but, and so in that exploration of that, So I had always was, you know, very sensitive.

I was always, shy. it was really hard for me, but mainly what I was discovering was I had an inside world and I had an outside world. So I would go into the world and I would try the best I would study. Human behavior was very adept of understanding and really sensitive to energetics [00:17:00] within how people were leading, which was often very confusing because I could tell if someone was dysregulated, even though they were acting like everything was fine.

But in my social environment with my peers, it was really difficult because I could sense when someone was. Was challenged, but if I a pointed that out or I was direct around it, it would often get turned around like something wrong with me or that

Sarah Knutson: I, I've had to work really, really, really hard to actually care about other people.

Sara Wilkins: Mm-hmm.

Sarah Knutson: And to actually, to connect with other human beings and to. So the challenges are I, I often get in the way sometimes of good things and maybe many times of good things that other people are trying to make happen.

Sara Wilkins: Mm-hmm.

Sarah Knutson: Just because it doesn't work for me.

Sara Wilkins: Mm-hmm. Sure.

Sarah Knutson: And just because I don't understand why it works for other people. Yeah. So it's sometimes hard to know when it's really important to take a stand. When it's [00:18:00] just like I'm being stubborn and I don't like being left out and I wanna do it my way,

Kelle Bourdeau: I'm exhausted all the time of all of the thought and all of the effort that I have to do in advance to be successful in the future.

Sara Wilkins: Mm-hmm.

Kelle Bourdeau: And I didn't see other people doing that. Like my husband can get up out of bed 10 minutes before he is gotta leave the house. And he's just, and I'm like, are you kidding me? I get up at like 5:00 AM even if I'm not leaving the house, just to like prepare myself. For the day, I need a, I need an ease into my day. I can't just get up and go

Sarah Knutson: painful. It's like, oh, I'm always, you know, and, and it just, it's the reality of being autistic. It's like, like I'm always, I, that's just how my brain works. It does, it works differently than the culture that most of the people in the culture I am in. And I believe evolution designed it that way.

And what I, a thing that I think I would love to see our culture change is the way that we deal with outliers, because I don't think [00:19:00] outliers are mistakes. I think outliers are necessary for a society that needs to be self-reflective and that the best of humanity is kind of self-reflective. So, I think outliers are a good thing. Not a mistake of nature, even though, you know they slow down corporate production. How is your life different since learning that you're autistic? All of a sudden, like by saying, by sort of saying I'm autistic and learning about the autism community, all of a sudden there's this whole group of people that's like, oh my god, instant sort of social connection that, otherwise I would sort of find piecemeal, case by case.

and you know, I mean, you still have to make friends, but at least it feels like you're, it's. It's like the community itself is, has the feel of human community, the kind of human community I've been looking for an awful long time. I'm glad to know because it gave me more grace with [00:20:00] myself.

Sara Wilkins: Mm-hmm.

Kelle Bourdeau: And it also just connected my son and I a little bit more, you know, and I told him. He was like, well, of course mom, that makes so much sense. You know me so much more than anybody else.

Sara Wilkins: Mm-hmm.

And I'm like, I guess it does kind make sense. Again, I'm the tree. You're my little apple, you know? But not being diagnosed as a child.

Amy Noyes: Like I had to go back through my life and in the grief of that and realizing like, oh, I always cut paper. Like I would just cut paper all the time. I realized, oh, this where's my stems.

Sara Wilkins: Mm-hmm.

Amy Noyes: You know, I watched ton of tv. It's where I got all my social understanding. I was often like, really? Like physically my face would change.

Like if I was hanging out with somebody, I would start speaking like them. I would start, I would take up their interest. and, but then I would go home and just be very, able to be in my own world listening to songs over and over [00:21:00] again. so what I was taking the quizzes, it felt like someone was entering into my world.

Like, how do they know that about me? How do they know that I have a fascination with running water? How do they know that? Like it was like someone was peering into my soul and I felt known for the first time in my life just from reading the questions. So, at the time I was in tremendous amount of, internal struggle.

And so. I think what happened for me was I, I entered into that world and so I became very quiet and very curious about myself for the first time. 'cause I realized there was this quality of dissociation when I was going out into the world. and I was really doing a lot of work to try and undo that and to, but I didn't have any awareness of my body.

I didn't have any like ability to like self-reflect in the sense of like, I could self-reflected, like how did my behavior affect the other person? But I had no ability to reflect how am I actually being affected by what's happening? And there's a really big [00:22:00] difference in that for me. and so I think that was the first time all of a sudden sounds were coming in.

And so I wasn't just getting unconscious pain from it. I was actually getting very conscious pain. In fact, my husband one time said, are you getting, is this getting worse or is this getting better? And I realized for me internally it was getting better. But how I was living or how was acting that out was getting worse for the world.

Kelle Bourdeau: So much of what they're saying is wrong with my kid are ways that I am, are ways of my being. And so I bring that up. I'm like, you know, I think he actually does that because I do that. You know, like that would make sense to me. You know, I, I'm a stay-at-home mom. He's with me all the time. Yeah, of course he's gonna do that.

Yeah. And they're like, well, that isn't a thing that, you know, neurotypical people do. And I'm like, oh. That's fascinating, isn't it? Yeah. and you know, then I met Mel and things just went from [00:23:00] there. And, you know, me receiving my diagnosis was such a difference from when my child received his, we were, and I mean it when I say we were literally handed a box of tissues.

Sara Wilkins: When they said he's autistic, well, he's on the autism spectrum. Oh, here's your box of tissues. And like my husband, we are both like, great, thanks for the answer. Like, next step, you know, what do we do? Right? And when Mel told me, she was just like, congratulations, your autistic. what do you wish parents of autistic children or the broader community knew?

Matthew LeFluer: Oh, what do I wish parents in a older autistic community brought or knew about me? One, I wish they knew that we're all in this together as individuals that, you know, that see things differently here, sees differently and moves things differently.

Sara Wilkins: Mm-hmm.[00:24:00]

Matthew LeFluer: To me, the broader public. That are, you know, parents and autistic individuals that knew about me, that I'm very, very compassionate, supportive, and I do take a leadership role when necessary to support those individuals that may not have a voice.

They may not even know how to speak, you know, with their voices, or they may not understand what we're talking about because that's not, that's not the way. Our brains act in reality work, you know, everybody's brain is, thinks differently and acts differently. And for the autistic community, it's about, you know, understanding other people's brains works and how to connect with that brain in a me and having a meaningful conversation and [00:25:00] discussion.

Within that brain pattern of an autistic individual, whether it's parents or children, it just, having that conversation with them makes 'em feel like they're welcome and a bigger part of the, not only a bigger part of the picture, but a bigger part of the family together. And that I would like to see more of is that value.

And welcoming sense of we're all in this together. We all help each other. Let's move forward together so we can, you know, be the best we can be to educate others about, you know, our special strengths.

Sara Wilkins: What do you wish parents of autistic children or the broader community would know about what it's like to be autistic?

Sarah Knutson: I think I touched on that also. I just think it's like, change the perspective on [00:26:00] outliers we're necessary. We're let's embrace the, let's as a humankind, let's embrace the outlier perspective for what we can learn from it and for what we can learn from seeing life through the eyes of the outlier per the, of, through the eyes of outliers that we would never see because that we, that we would never see because of the na, the natural bias of the majority.

And, and, and, and the natural and the perspective of the majority and how the majority is going to is, is wired, literally wired to see things differently. And so as a culture, if we sort of embrace the idea of the, of the, that the value, the social value that people bring is broader than economics and we need to bear the burden or, or, or the be, we need to gain the benefits and bear the burden of a diverse culture Then.

We need to find a way to support everybody, emotionally, socially, economically, and make space for all of us. And truly, and be truly committed to [00:27:00] the guests that each person is trying. The person's spirit is trying to have them offer the world they live in.

Zeph: One. I wish people just understood that our brains were different, period. It's not something that we can control, but two, don't pathologize the differences and don't pathologize and or ostracize us because we are non-conforming.

Kelle Bourdeau: But less of a tragedy.

Sara Wilkins: Mm-hmm.

Kelle Bourdeau: You know, because it isn't like, yeah, I, I made it to 46 years old all the while questioning.

But you know, I experienced a very classic, you know, when I told certain family members, are you sure, you have like college degrees? I'm like, yeah.

Amy Noyes: The thing that I would love, like people to understand is that, First of all, what I'm speaking about today is like my own experience [00:28:00] and that I think it's really important to understand that everybody, gets to have their own experience and their own access needs.

And even though there may be like traits or characteristics that overlap, that is not actually the experience of being autistic. being autistic for me means. Being unto myself, being individual and allowing myself and whatever my needs are, whatever my sensitivities or whatever my extraordinary abilities be.

And it gets to be a collection of my human experience. And I think the other thing in terms of like what I would want, like the broader community to understand or what I would want my family to understand or parents of autistic people, family members of autistic people is that it's so important to allow difference, to be a wonder and allow. Yourself to be different within even your relationship to someone who knows [00:29:00] themselves to be different and to be curious and to ask questions and to, instead of presume, because I could be having a really sensitive, sensibility right now to a noise that's happening.

And if there's an assumption of what that noise is, that was not gonna help me. But if there's a curiosity around. What does that feel like in your body? Or could we identify what the sound is? It's such a radically different experience for me. And so I think, for me, like even like my, you know, my face is all red.

I'm really flush. I'm super nervous, I wanna be here. Part of that is that my excitement, but part of it is having the attention on me of like, how will I be perceived? You know, am I safe? But also just like, that's not an easy way for me to exist if the tension is directly on me, like I've gotta find another way or I get to observe the experience.

And so I think [00:30:00] it's just really important that folks know and understand that there's no one way, but more curiosity. You can have less presumption around what people's actually experiencing. It could be an opportunity for openness.

Mel Houser: How much I appreciate the vulnerability that all five of you should, and your willingness to share, to share really, really important aspects of your life narrative. because I think, you know what, what is just continues to just, I have no words to describe this really, but [00:31:00] like all of the pain that comes from feeling broken and alone and defective and that you're the only one who is so broken, I mean, we watched five different people who coming from all different perspectives and experiences who had so much in common. Just the five of you. And as you are talking in the chat, everyone's like, that resonates. Like, just, can you imagine what life could have been like if we all knew each other as little children, we were laying down the initial story of our lives and who we are and what our value is in society.

I will read in the chat many people sharing. thanking, thanking you all. your bravery and your stories brought me to tears. There's so much that resonates with me from everyone's stories. Thank you for sharing your amazing [00:32:00] thoughts and experiences.

Amy Noyes: I felt really touched by your. the way in which you put us all together and when at the very end I was just thinking like, oh yeah, wouldn't it be amazing if we were all together? And Sarah's like the idea of like, oh, outliers unite, you know, that we get to, to be able to share.

'cause even within the community, everyone has a lot of different experiences, but because it's allowed, we get to learn more and then start weaving together as a community. So I appreciate everyone listening and I'm really grateful and [00:33:00] honored to have been able to share, some things that I've never shared before. So, I look forward to having more access to that and to be able to share, continue to share.

Thank you, Amy. Kelle's saying something similar, in, in the chat. It's such a, you know, it's all been interviewed separately, but all speaking together, it's like weaving the fabric of the narrative.

And though of course there's every individual is going to have an individualized experience, I think we heard some real threads of commonality, that I think is really powerful.

Rediscovering yourself. Discovering how your brain works is a truly complex process. It's not all relief. It's grief, anger, resentment, confusion, clarity, all at once, [00:34:00] sometimes all at once. Discovering that you're autistic can open the door to understanding what you've always needed. It's not the end of the story.

It's the beginning. Keep learning. Come to Brain Club, read with us, talk with other autistic people. Find the words that help you make sense of your own experience. Thank you so much to Amy, Sarah, Kelly, Matthew, and Zeph for letting us be part of yours.

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 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.