

Brain Club®: The Podcast - S1E10 - The Best Way to Support My Health is to Believe Me - Part 2 TRANSCRIPT

Laura Lewis autistic healthcare research S1E10 PART 2

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.

Okay. This is part two of our conversation with Dr. Laura Lewis from the University of Vermont and her research team about a new study looking at the healthcare experiences of autistic adults with multiple chronic conditions. In part one, we shared reflections from the research team about what they found in their study.

they learned from stories from patients whose health was made worse by how they were treated during healthcare encounters, including being dismissed, disbelieved,

misunderstood, of course, not by, intention of the clinician, I'm sure. But if you haven't listened to that, we encourage you to go back, and listen before you begin listening here.

In this episode, we pick up where we left off. Looking at the relationship between the clinician and [00:02:00] the patient and some of the patterns we fall into, the communication patterns and the resulting impact on the relationship and ultimately health outcomes. what we hear is that when someone does believe you, there's something that shifts in that relationship. Something that shifts in the nervous system. It is not a fairytale ending. It's still complicated and often still painful, but being believed can open the door to something different, and I invite you to listen on.

Laura Lewis: And almost this questioning of what you're reporting as being the problem is the way you are doing the treatment plan. Not that the treatment plan doesn't work for you. or, that we're looking in the wrong direction. And I think that we saw a lot of that in our interviews too, that people really felt like the continual questioning of whether you were following things in the correct way.

And it comes back to Sarah, that blame piece, that it ultimately is on you, the way that you were following the plan is the problem instead of the plan is the [00:03:00] problem.

Sarah Knutson: They're assuming if I comply, that the problem is, one thing, and if I comply with this certain part of the treatment plan, all my problems get rosy and better.

My life experience is saying no. The treatment plan is like what you've named the treatment plan is, inadequate or at least. I'm not buying into it because I, don't understand why, it would work for me. It doesn't make sense to me in terms of what I perceive to be going on in my body, and you are not helping me make the links.

The person who could possibly help me make the links as to why these two things would fit together and why, these unanswered questions would get answered in this mental health treatment plan.

Laura Lewis: Sarah, I think one of the things that we also kept hearing and that we talked a lot about is that when people became more resistant to that treatment plan because it wasn't working for them, because it was painful for them, or worsened symptoms or was, you know, expensive and didn't meet their needs or whatever that looked like.

Participants often felt coerced into [00:04:00] doing that plan and comments like, well, if you really wanted to get better, this is what you would do. Yeah. And so then it became this like bad patient for not following a plan that really people knew in their guts, wasn't helpful for them, and in many ways was harmful for them. Yeah. and, then sort of this cycle happening of becoming more resistant, becoming frustrated, becoming angry, feeling more resistant, feeling more skeptical, and then being perceived by the provider as being like uncompliant, uncooperative, and all those difficult words.

Sarah Knutson: Yeah. Yeah.

Mel Houser: When someone is viewing you through a lens. That deficit based lens that you are difficult, you are doing it wrong, there's something wrong with you that is perceived by the person's nervous system. I think that professionals don't realize that when you're not viewing another human in [00:05:00] with unconditional positive regard, the interaction is different.

Sarah Knutson: Yeah.

Mel Houser: Plus you layer on that. We are talking about, a population that has experienced significant trauma physiology, right? So as a neurodivergent person growing up in a world that is not designed with you in mind, let alone that maybe you didn't, you know, have any framework for understanding what was happening.

You have these chronic health conditions and the lived experience of being dismissed and invalidated. Told, you're too much. You are worrying about the wrong things. The thing you think's important doesn't matter. Like that's been, that's the lived experience of a lot of people. So you come in and it, the, provider doesn't even need to say anything if they think that energetically the patient feels it.[00:06:00]

Laura Lewis: Mel, our ultimate takeaway from this study, I would say, is that. People went into a provider to seek help for something going on, and they left feeling like they now had two problems. The first being the same problem they went in with to begin with. And the second being, the added stress and burden of being invalidated and dismissed and gaslit.

And, it seemed like in many ways the healthcare experience for a lot of folks that we talk to. Only added to their poor health that they were already experiencing and to the burden of the, problems that they initially were seeking help for. I can tell you what I have at the bottom of this. Like, I have here that the transformative flipped script is feeling like my experiences are heard and understood.

And even if you can't help me understanding my experiences holistically and believing my lived experience of my body can support my health by at least removing the [00:07:00] psychological burden of feeling like my experiences are invalid and defy logic. I don't know if that's a helpful way to end. It is like that positive note of that there is.

A different version of this that's possible when people are believed and understood for what they're bringing to the table. that even if we don't have the medical tools to make the problems better, that we can alleviate some of the suffering and the burden of what people are experiencing.

Sarah Knutson: It's really rare as an autistic person to be viewed as a person, to be seen and treated as a person, period in our society, even among peers. But then when you add to that, people who, who have power to say whether something exists or doesn't exist, [00:08:00] it's, even probably. It's even probably rarer. And, so probably the most, the, most healthful thing.

Laura Lewis: and, to the extent that so much of what perhaps goes on with me is the reflection of like. The trauma of living in a culture that, dismisses and undermines my humanity at every turn. The fact that there's someone that, there's a clinician who has a. Someone who has a incredible amount of power, who treats me as a human being and who takes what I'm saying seriously and who's willing to try to align with me, to get, to support me, to get answers to, questions that I, don't understand.

I mean that in and of itself. Is, E even, if that in and of itself is, potentially [00:09:00] curative. I mean that in and of itself is potentially changing, helping to reverse the, and this is probably gonna sound woo woo, but sort of the energy dynamics that have gone on in my body between me and the culture.

I mean, if you just, if you just think of the stress of living in a culture and what your body has to do to adjust to living in a culture where that wants to throw you out at every turn, and that wants to throw out your personhood to stamp over it, and. To, and to have somebody who's a power, who's powerful, who's succeeding in the culture, who has a voice in the culture, actually say that they're your ally and they're gonna help you to get to the bottom of what's going on in your body, and, not throw you out in the way that, that you expect to be thrown out.

That in and of itself is the beginning of healing. It's the human relationship is where the healing starts. And doctors think it, that the healing starts at the medical relationship, but with [00:10:00] autistic people who have been and, other people who are generally

seen as powerless in the culture, the place where the healing relationship starts is not with the good, is not with what you consider good medicine, it's with what you consider, it's with what people would consider like respectful personhood. It's like seeing another person as a person and, that's where the healing starts. And until that starts, there is no health. It's like until, until I, start to be seen and feel about myself as a person vis-a-vis other people in the culture that I'm living in.

And as a medical doctor, you're a symbol of that. Until I start to see myself as that, there is no healing. That is healing is not, my body doesn't, isn't resourced to heal. There's just too much stress and too many factors against me.

Mel Houser: Thank you for naming

that.

part of healing. Is, taking a look [00:11:00] at that power dynamic. So I, think Sarah, I mean, everything you just said was so powerful and,

found like everything you said. but, the, power dynamic part, I think we should include that in this, right? Because if

a doctor patient, a clinician, patient interaction with inherent power imbalance. I think that is something that really bears further reflection. Right? So I, think that if the clinician has the mindset that I am the expert in the thing you have, how does that not impact the [00:12:00] interaction if. Instead, a clinician would recognize that the patient is the expert in what's going on in their body, the whatever they're experiencing and whatever is communicated.

That's what it is. Like that's what it is. If that is acknowledged, then it's about like, yeah, I have some skills, I have some tools, let me share 'em with you and see if any of 'em are a fit for you. But like the, this business of I am expert. I am here to fix and change and cure. I, think that's not helpful.

I think we also saw a lot of gatekeeping happening with that power dynamic where if exactly what you're saying doesn't fit exactly what this textbook says, this condition looks like, then I'm gonna withhold that diagnosis from you. And what a lot of people talked about was the power of a diagnosis. [00:13:00] both in like social validation of their experience when they can go into.

Other people if they choose to, that I have X and, that sort of takes away the need to explain and give a list of symptoms and a reason why they don't have a diagnosis and

all these other pieces. and it also in many cases, gave some direction to a plan. like just having a name for what I'm living felt so powerful to a lot of people.

And Mel, you had said, I wrote this down in a previous meeting, that doctors are trained in shared decision making, but not in shared diagnosis making. And I think that was something that stood out to me because for so many people, they wanted to be a part of naming what was going on with them and giving that information that they had as the expert of what it was.

and, they were left out of that and ignored in that process.

And, I think that part of shared diagnosis making. involves like [00:14:00] an awareness and a, transparency around the limitations of the diagnostic tools, right? So, if I were evaluating someone for mast cell dis, activation disorder, I, have this awareness that the tests. Or bad tests that, you know, you have to be in a big flare, you have to have the lab test drawn in the middle of a big flare.

it, the, the specimen has to be collected and spun in a cold centrifuge and like, it can't be on out in room temperature for more than a few minutes 'cause it disintegrates like, and so mostly labs are not following that. Right. So I have to know all that. In order to know that your pattern is telling me that you have mass cell dysfunction, I can tell you that like probably those tests are gonna come back normal, but that doesn't mean you don't have this.

and so while I might not, you know, if I like wanna be consistent and follow the documentation of what the medical gatekeeping thing is. [00:15:00] Fine, I'm, I'm gonna say you have mast cell dysfunction and not mast cell activation disorder. but I'm gonna like be transparent about that. Like it's not 'cause you don't have this or it's the idea that, you know, if you meet criteria for hypermobile Ehlers-Danlos syndrome.

there's not actually a difference in how we approach that as peer to if you don't meet criteria and you have hypermobility spectrum disorder, like, we're still gonna approach this the same. but, people don't know and professionals don't know enough about these conditions.

And they're common, they're common everyday conditions. And in fact, like the things that. So clinicians do know are common, like diabetes, like in our practice of mostly autistic and A DHD adults. Every single human with diabetes and pre-diabetes has the constellation of neuro immune conditions, every single one.

So we have this thing that traditional medicine says is common, and yet it is [00:16:00] completely not known. This major big deal that contributes to that.

Laura Lewis: Mel, one of the things that we talked about early on in this project was this idea of like population health and sort of making judgements about the person in front of you based on a population. And we were sort of like coming at this like anti population health lens a little bit. And one of the things that you said that I thought was really powerful was that.

It's not that you can't use population health, it's that we're misidentifying the population that's in front of us. So we're making assumptions about a broader population and applying it to a subpopulation when there are separate assumptions we need to make about this. Subpopulation perhaps

Mel Houser: He said that? I don't remember saying anything, that's a pretty astute observation.

Zeph Lodestone: that's the reason why the diagnostics are so important.

Because even just getting a diagnosis of autism [00:17:00] puts you into that population because autism is so invisible otherwise. I mean, I saw doctors for 50 years and no one said anything to me about autism.

Mel Houser: Zeph, that's really important, right? Because, so 1, of the things that people who, like, you know, don't get their medical care here, you know, like people on social media, they'll reach out like, how do I get this?

I'm like, well, you, you know, print out the tool from the All of Things project and bring it into your doctor and you know, that whole thing. But if they don't know, if the doctor doesn't know that they are autistic or ADHD. The doctor won't know that this tool applies to them. Right. So it's like, it's like the gatekeeping entry into the subpopulation that maybe we have a chance for the professional to match.

'cause I think that a lot of professionals would say like, no, I don't actually know anything about autistic adults. Teach me. Sure, I'll learn. it's, lack of recognition about how many [00:18:00] autistic adults there are.

Zeph Lodestone: They may not even know it.

Mel Houser: Exactly. Exactly. So that's another thing that I think is really important because here we are, we have, a, subpopulation that the doctor doesn't know and the patient doesn't know, right?

They just are suffering. They just are suffering with multiple systems of the body. and you put 'em all together and then you like, like that. It also supposes that someone knows something about autism. you know, it, if, we're talking about, you know, anyone other than the stereotypical, you know, white, 4-year-old cis boy, you know, like there's all these layers for how we're not matching the pattern.

Even though the pattern is well established. We didn't make the pattern up

Sarah Knutson: I mean, I think there's another aspect of this also that I mean. If, I'm asking if I'm, if I'm going in as an [00:19:00] autistic person and I'm asking a doctor to stand with me, in my understanding of myself, and, in some ways I'm, what I'm asking the doctor to do is to.

There's the comfortable herd of the medical community that the doctor can stand with and, then it's like if, the doctor stands with like this weird patient who has this weird self understanding and actually takes it seriously, then the doctor is at risk.

Of, like, you know, the, rest of the medical communities, you know, looking at the doctor like, the rest of the world looks at me.

Mel Houser: The oblique angle to that, that I think would be a good one to wrap up on is what Zeph has in the chat right now. The best way to support my mental health and my physical [00:20:00] health is to believe me.

The oblique angle is that any doctor would tell you they wanna help their patient. Any doctor would tell you that. Of course. That's like why they did all this training and all the things, right? Like, so, Now we're saying what we found in this study is that like widespread finding of autistic patients are feeling that they are not believed.

And in fact, the best way to support help is to believe the patient. this is not controversial. It's not controversial at all. It's not taking a stand, getting quackified. even the most neuronormative constructs of the healthcare system. Like nobody's gonna like argue with that.

We should like, try to help the patients and make the patients feel good. You know, like, patients are feeling bad. It's the opposite. It's the opposite of what you think you're doing.

[00:21:00] Being believed doesn't erase the harm. It doesn't undo years of gaslighting. It doesn't fix a broken healthcare system, but sometimes it's the thing that makes the start of healing possible. This research and the reflections from Dr. Lewis's team show what shifts when someone listens, and how that moment of recognition can ripple outward.

We're so grateful to Laura, Sarah, and Zeph for holding space for both the damage and dignity of these truths.

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.