

Brain Club®: The Podcast - S1E18- Reimagining the Clinician-Patient Relationship

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. 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, an invitation to think differently about health, connection and how we build systems that include everyone. Each episode features community panelists, sharing perspectives and lived experiences.

These conversations are for education purposes only and are not medical advice.

Before we get started, our book is here, A Failure of Imagination: How the Healthcare System Fails [00:01:00] Neurodivergent People, and What We're Doing Instead. Visit allbrainsbelong.org/book to get your copy

Today we have a special conversation, a joint panel of our staff here at All Brains Belong and our community moderators for the Brain Club program. Thank you to Mkazas, Sarah Knutson, Amy Noyes, and Liz Carney, as well as our staff, Lizzy Perrett, Sierra Miller, and Olivia Tyler as we talk about the doctor-patient relationship and how we have reimagined this together in this community

Mel Houser: Okay, team.

It's hard to believe we have never done a Brain Club moderator staff combined Brain Club panel before, but here we are. so we wanted to talk about clinician-patient relationships. I was wondering if anybody wanted to share what your experience has been of clinician-patient relationships, at [00:02:00] ABB

Amy Noyes: I wrote a few things down, but, the words that came to mind was consent-based, unconditional positive regard, and mutual respect. and I think my overall sense of the client-provider space is one that I get to exist in. That's a ... It's a

collaborative effort to understand what's happening, and so there's a lot of educational component to that to make a connection.

For the way my brain works, it's really important to make the connection to be able to do the thing, so that I feel like I'm involved in the decision-making

Mel Houser: I love that. It's, it's so interesting that that doesn't happen everywhere, like that experience of being involved in the decision-making. And it- and I think that, you know, because of the model we have here, Amy, I, I wonder, [00:03:00] you know, it's like decision-making for your own care, but it's also decision-making around like the direction of the community and the direction of the programs and like that kind of decision-making.

I mean, how could that not then spill over into an individual relationship?

Elizabeth Carney: Yeah, I, I was just thinking as you were talking that, w- I was thinking back to when I was first becoming a patient and I was just learning about, access needs and thinking like, "Oh my God, I don't even know how that fits into my life." But it came very quickly. Like, the, the autonomy that this model allows for gave me the space to adapt to this model really quickly, and it felt really good to come into appointments, and it felt really good to...

There were times, especially early on, when I was [00:04:00] thinking like, "Oh, I don't think I have this, I don't think I have this, disease or disorder," and Sierra gave me the space to honor the no. And of course, later on when I had space in my heart for it, I was able to say, "Yes, actually, I do have that thing and I'm ready for that information now."

And I really, and I, and you don't get that in the regular health model. Like, they don't let you have the no. They, they want to shove the information at you, and then if you say no, they're kind of like, "Well, I can't help you." You know? And that, it, it, it couldn't have been more different at ABB, and I was so ready for that and so willing to accept that.

and I think that really says something about the people, the model, the, that, that phrase of unconditional [00:05:00] positive regard came up. I didn't even know what that was, but I was feeling the benefits from it immediately

Mel Houser: I love that. and it's interesting, Liz, that you're talking about, like, what it was like to come into this.

Like, you've all been part of the community for a while now. I don't know, like, is there anything that comes to mind to anyone of, like, how, how this has changed over time? Like, are there things that have endured and things that actually are different now compared with, like, how, how we navigated all this, you know, three, four years ago?

Mkazas: I think, from what Amy and Liz both said, there's a piece of the, the collaboration takes give and take and practice on both sides. So the unconditional positive regard has to come from us as clients and patients, and it comes from you as practitioners. but that is practiced over time. And [00:06:00] I think about, you know, in counseling y- you take a lot of ethics classes, and with medicine you take a lot of ethics classes, and there's that question of, like, what if you live in a rural community and the person who, like, bags your groceries is the person you see every time you go to the store, but they're your patient, you know?

Or the person who, you know, whatever. Y- there's a lot of overlap in rural communities, and that ethics, which is supposed to be, like, separate and can't happen. But I also think in this community we haven't tried to make it happen, because it's not about the rigid rule. It's about practicing this relationship in a respectful way across the board, which also then allows for everybody to get their access needs met.

and for us to talk about our conflicting access needs, not in a, "Well, me first, then you," or a you first, then, or you're the boss, or you're the hierarchy, or, you know, all of that stuff happens. And so there's a way to find the balance in between, [00:07:00] and talk about it when that's hard. So I think that's incredible, and I think that has shifted over time, as we've figured out how best to do Brain Club, and we've figured out how to navigate, some of the other programs.

and we've shifted direction, and we've shifted, you know, timing and, and things like that in order to accommodate the evolving group of all of us, including you guys as practitioners

Mel Houser: I love that. and I think about, there was a time, I don't remember which Brain Club it was, but Sarah, you were on a panel, No, no, I remember what this was. You were an audience member talking, like it's when we had like discussion after a panel.

It was a panel with me, Gabe, and Sierra. Like, it's the one we play all the time, like the one we're talking about the, you know, the doctor-patient relationship and how the healthcare system is the villain and all that. Sarah [00:08:00] chimed in at the end

being like, and, like, no one else I think would know this, 'cause I never play the discussion at the end.

So anyway, but what, what, in 2023, what Sarah talked about, like, it seems to me like we're really just talking about having relationships as human beings. Like, yes, that is what we're talking about here.

Amy Noyes: That's what came to mind was that it's about humanity, and that it's not about authority and power over.

That it's really about, um, co- like we're saying, collaboration, but that we have deep respect for the knowledge that you have. But in turn, like I feel like every single person on staff has deep respect for me, and the, that relationship building feels like I get to be more included. And, and again, like I said before, I get to exist in the space where if I typically go to a doctor, like I, a lot of times I'm thinking, "Do they even know my name?

Do they even remember what I look like?" Where we have such, Yeah, it, it feels more, I don't wanna use the word intimate, but that's kind of [00:09:00] what I wanna use, of like the shared experience of we know you and you know us. And so whether we're giving feedback, I feel respected and I feel honored. Whether there's a miscommunication, we were t- thinking about double empathy problem and things like that, it's like I feel safe enough in my nervous system to say, "I know this person's gonna want to know what was my experience was."

And then I'm left feeling cared for, listened to, and a deeper connection, when it could be like I'm holding onto that resenting. So it is, it is a relationship, and it does bring in our humanity

Sierra Miller: I know we've talked about this in a bunch of brain clubs before, but like, I, I think, like, y- coming back to how key, like, the transparency aspect is in this and, and how that I can imagine how difficult that is in a [00:10:00] practice where you're only seeing somebody one or two times, especially like specialist practices.

I think the, like, longitudinal aspect of care that we do, whether we're somebody's primary care provider or not, but just, like, that longitudinal aspect is such an important part of, of this and of, like, being able to have that understanding and transparency of, like, you know, yeah, no, I, I can't fill this request or whatever, and this is exactly why, or, that transparency and that, like, longitudinal aspect is I think how we get that, like, we're just working together as humans, um, rather than these very specific kind of power dynamics.

Mel Houser: And Sierra, I think that we also try to carry ourself as humans. Like, we're not trying to be, like, the expert.

And I think that, you know, if you don't act like that role, it's, like, not that hard when you're [00:11:00] like, "You know, actually I, I can't do that thing right now. You know, I do need to, you know, save this for your next appointment," or I do ... Like, it's, it's, like, if you get to be a human being with finite capacities as all human beings are, like, then you get to h- you get to actually say that as opposed to, you know- It's like, it's, it's like more than being given the benefit of the doubt.

It's like more than, that's not really what I mean. It's, it's more like, oh, well, like of course you would have a finite capacity 'cause you're acting like a human, and humans have finite capacity

Mkazas: I have a question to hop in on if- Yeah ... because I think we're talking about it right now. But for you and, m- Sierra, Mel, how, how do you think between the clinician and, and patient relationship, how has that, how have that, how has [00:12:00] that been dynamically rediscovered over time?

and how have you had to sort of reinvent your own ideas coming out of the medical education industry of mayhem, and how you've been told to do things a certain way? How did you, how did you invent this, and then how have you been able to re- reinvent it and re-relation and outside of that sort of power holding?

you know, a- as the practice has gotten bigger and bigger, as, you know, so many of us are so different from each other, from the world at large, you know, we all hold and carry what we hold and carry, and we all have our experiences out in the world that has made carrying those things hard. And therefore, our finite capacities are waffley.

Sometimes we have more, sometimes we have less. So how have you rolled with that and, and reinvented it over time in your hearts and minds in practice?

Mel Houser: I [00:13:00] love this question so much. I'm thinking. Does anyone else on our team wanna speak to that?

Sierra Miller: The initial thing I think is, like- Being in a place where it's safe to unmask and talk about access needs, and that's both w- within the organization and with patients.

Like, I'm in a place where in a group visit I feel comfortable unmasking, and that makes it so I'm actually able to, like, do multiple visits today and not, not get kinda too, too

burnt out. Another thing I was ... I, I wrote this down. I was trying to figure out, like, how to, how to weave it in. But somebody was asking me the other day about, like, what if there was, like, a big difference I saw between, like, nursing and medical education. And, like, one of the things I really appreciate about having a background in nursing education is the focus on educating people. Because especially at, like, an RN level, you're often not [00:14:00] doing the evaluation and diagnosis part of it, but you're doing the, "Okay, you have this.

Let's do the education. The doctor came in and talked for five minutes. Okay, I'm gonna sit down with you for 20 minutes and talk through this and what this actually means." And I think having that as a background and where my personal, like, health education started was a really, really helpful place to kind of, like, come at it initiating from, and something I definitely saw really lost in, like, as I got higher in education, and definitely in the NP-level education.

so I don't know. I think, I think partly kinda coming, coming back to that. The other thing I'd say is I think when we're ... especially when we're focusing on the complex chronic diseases that we focus on, it's ... When it's a condition where we're, like, learning about it together as a patient-provider team, that feels like it makes it a lot easier to be in that, like, reducing that power [00:15:00] dynamic, because we're learning about it at the same time together, versus somebody coming in with me pretending or thinking that I have all the knowledge

Mel Houser: I never thought about that, how important your previous experience before you became a nurse practitioner, how that invariably impacts your experience.

Like that- that's really interesting to think about. I'd say for me, it's, it's like any other relationship. Like when a relationship has not gone well, like that's when you learn what your access needs are, right? And so, you know, like having the opportunity to, to start a practice, and like when Sierra and I first wrote the patient pr- clinician shared agreement that we start with, like when you're first applying, like we wrote that together.

And it was based [00:16:00] on, at least from my point of view, my contribution to that, were based on relationships that did not work. Like so in being in situations where, you know, someone will send, you know, a bunch of, you know, call, call on the phone and think you're gonna be on the phone with them. Like when- I'm not on the phone with anybody.

Like anybody. Like 'cause the phone's not how I communicate. It's too hard. So, you know, okay, we don't use the phone here. And so yeah, is that universal design? No. But it's transparency. This is a practice where we don't have anyone who has the ability to be on the phone. That's not how any of our brains work.

So like naming that up front, you know, yeah, that's gonna, you know, alienate some people. That's gonna make some people think, "Well, this is not the, this is not the practice," meaning this is not the relationship for me because I need something different, and I think that's okay. It's the transparency of knowing what to expect.

So I think, I think for me, and I've never had any [00:17:00] relationships like this, where actually being fully transparent about how we're gonna do things and asking y- a patient, a new patient, "What are your expectations? What are your needs?" And some people can't answer that, but some people can. And so, you know, related to the previous example, if somebody's like, "My expectations are being able to call up and talk to a nurse on the phone," and okay, we don't have that here.

We don't have that capacity here. And so but again, you know up front, and so both parties can make a decision. Somebody saying, "I need this," and we saying, you know, "I'm concerned that we don't have the capacity or the scope to meet your needs." I think just that is a radical experiment of like could you begin with complete transparency about ways of working and ways of being, without pretending you don't have them

Elizabeth Carney: I'm thinking about right now how systems don't tolerate disclosure, [00:18:00] and they don't, they don't, they don't tolerate, just all the layers of, of things. Like, very quickly you bump up against like, you know, well, that's, you know, that's exposure. That's exposing you, you know? And that's meant negatively in systems, you know?

And what ABB is doing is exposure, but for the purpose of authenticity and expanding capacity and working with folks who have a, who have very specific chronic illness needs that need a lot of kind of incremental care. And I, I can't think about how you could do this another way for all those patients who need, that kind of [00:19:00] incremental, well, let's try it.

Let's change this, and then wait, and then evaluate, and then if that doesn't work, we'll try this and this. You know, systems don't work that way at all.

Mel Houser: Yeah, and what comes up for me about that is that I think as a staff we are very intentional about protecting not just individual, protecting the organization's capacity to

do what you just said. And that looks like, so every week at staff meeting we look at where are, if somebody calls up with an acute need, where are they gonna go in the schedule? So, like, we have that game plan. It's like that happens every week. And if we find that the person's gonna have to wait too long, we shut the practice down.

No new patients. and when we see that, oh, look, there's, you know, [00:20:00] we could see this number of acute visits this week, okay, we can take a couple people off the waiting list this week. Okay. and I think we talk about sometimes, like, these dynamic tensions, like the dynamic tension between wanting to provide deep, comprehensive, thorough, frequent enough care to the people who are here in tension with serving the community and all the other people who don't have care, including the people in the community who want us to see their friends and family, right?

So, like, all of that has to be balanced, and if we have to choose, we will choose meeting the needs of current patients even over serving more people. But it's all in flux, and we make those decisions every week. Can people come off the waiting list this week? No, they cannot. Can they come off this week?

Yeah, I think we can take s- we can take one person. Okay, we'll let them know.

Sierra Miller: I think that's a hard part with, like, dual relationships added in there of we are also living in the community, not only that our patients are involved, so the people that [00:21:00] wanna become patients or are trying to access other parts of our services.

And I think that can make it a, that can make it a difficult part as, like, a broader community, especially, like, advocacy organization, even though I don't think we necessarily are that. But, as that broader community organization, that can be hard with that dual relationships, too

Amy Noyes: I'm just curious about, as providers, how your health and wellbeing, has shifted or changed based on the quality of relationship you have with your patients. and specifically, how does it feel to have deep connection with your patients, which I, you know, I personally feel with, with all of you.

I just was curious for all of you as staff

Mel Houser: Anybody else wanna take this one first?

Sierra Miller: I'd say for me it feels very much like when I used [00:22:00] to do home care. There's a, like, building a, like, long-term relationship with somebody and helping them become an expert and, like, you becoming an expert in their bodies and their health conditions, that's, that's what I get the dopamine from. That's what I like doing this type of care for. And so I think being able to, being able to really focus on that is definitely continuing to get dopamine and self-actualization part of burnout prevention, which I think is really, really important and helpful.

and, and I'd also say having an organization and team that is supportive of taking time off, including having, like, patients who are supportive of taking time off. Like, that's something that, has been a huge game changer that I've never seen in any other organization I've worked in

Mel Houser: Yeah, and I also think I'm coming back to Liz's [00:23:00] observation around authenticity and the conditions that, like, afford authenticity.

Sarah Knutson: Mm-hmm.

Mel Houser: And so it would really never happen that I would feel like I needed these really rigid self-protective boundaries, because no one would be asking me to not have them.

Mm. When I think about, like, what drains my battery now, it never comes from patient care. It's like, "Oh, I'm on my computer too much," or, "Oh, I'm getting too much email," or, "Oh, I'm doing too many projects at once." It's more like losing my, like almost like in the way that I describe, like the organization has these practices that help us understand our [00:24:00] capacity and like what we can do.

Can we take new people? Can where we put the people? like I don't necessarily always have those objective parameters for myself, which is why I overshoot and overspend. but that's on me, not because I feel like my relationships with our patients are really contributing to that at all. I don't know if that makes sense.

Olivia Tyler: Ultimately I think, there's the space that's provided for us all to get to know each other ultimately creates, overall better health. So I think that's very apparent. because there's more space and it feels like more time than, but ultimately it's a faster return on feeling better.

And I think, you know, in a work environment where you can, [00:25:00] you're allowed there's more time to do your work than, you're less likely to be, sick. So, yeah.

Lizzy Pieratt: And I personally don't know any other system besides ABB This was my first, job in the medical field. And so, I can't really, since I don't have a background to compare it to, but I, I just don't know how anything else could work, 'cause we're all in community together, and we heal in community together, and we take care of each other and our nervous systems in community together.

And it's a beautiful thing to be a part of this journey and welcomed in.

Mel Houser: I love that. I'm curious 'cause boundaries and the power dynamics of boundaries has come up. [00:26:00] Like, in this example of like, oh, I am short on capacity, I need something else, I need a boundary, like, what is your experience of that?

I'm sure over the years you've seen me do that to you, right? 'Cause I do that to everyone when I need to. So, what is your experience of that?

Amy Noyes: I could just say that, well, one, I think a boundary, a good boundary is one that you can keep, not one that you're expecting other people to keep. And I think that, All Brains Belong has really taught me, because it's one of the first spaces that I was able to be myself in without feeling like I had to earn, be worthy or do something or, um...

And I do give a lot to, to All Brains [00:27:00] Belong, and I do care so deeply about it. But in this last year, I've had other things. I'm building a business. I've had other things, so I haven't been able to show up as much, but it doesn't feel like that would diminish my care or my connection or my worth. And so I think that this community has helped me set boundaries to know where I wanna spend my energy and those relationships that I want to focus on. There's so much mutuality. that is really one of my biggest values, is to be able to be of service, but also to be cared for. All of my primary relationships are people in the comm- withi- within the community.

And so I think that's, particularly you, Mel, like modeling so many different things. So sometimes if I'm in a struggle or something, your voice will come in, not in a sense of you're telling me something, but in the sense of things you've said [00:28:00] about yourself that you're doing. So it's really modeling, you, you, you all walk the talk.

You all, like, things you say, and because we're in relationship, we're in community together, and see each other in a lot of different dynamics, whether that's Brain Club or
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the community, Friday nights or, And the, the services you're providing, like I've seen so many people come out for the lightning talks to share their special interests that I haven't seen other ways.

And so we, um, so I guess that's what I would say is like, it's easier to set a boundary 'cause I know what my priorities are, but I also feel like I can do that safely in my primary community, and it's being modeled for me

Mel Houser: That's amazing

Olivia Tyler: what I'm thinking about, on this topic of boundaries, I think ultimately, you know, because we have more space to explore, [00:29:00] that we're less likely to be in burnout and maybe coming at each other as a community or coworkers from a space that, you know- I can't think of the right word right now, but we're less likely to come at each other from a place of, being stressed, right?

Well, whether we're not feeling well, or just coworkers, or community members. And because we have more space to have our needs met, I think it's easier to hold a boundary because you're not needing to overpower or from, you know, like on fire to each other. so I think that that's, you know, and that creates more power within ourselves.

You know, we feel stronger, you know. And then if there is something going on in our lives, we know we can notice it within our patients, like, because, oh, so and so's, you know, having a hard time, and it's clearly ... We can see it more clearly because [00:30:00] they're coming from a place that they normally wouldn't come from.

You know, in the traditional healthcare it seems like people are always on fire. Everything's always on fire. And I think at ABB, we notice a quick, we notice it immediately if something's on fire because most people are not coming from those places. so that's probably the long way of saying our nervous systems are more, are less likely to be on fire, which creates better boundaries just naturally.

Mel Houser: That's really interesting. What comes up for me about what you said, I think there's, there's two other layers. Like, one is the interdependence, right? So, like, if there is something that is draining my battery, I pretty quickly bring it to our staff team. I'm practiced in that way. Like, oh, that always helps. I'm gonna do that. So, like, you know, there's a breakdown at Bring Club, or there's a, you know, whatever. You know, "Hey, can we talk about this 'cause I wanna do this differently," or, "What do you

[00:31:00] think I should say?" Or whatever, like that team-based, like the co-regulation aspect I think is really different.

And I think that in traditional healthcare, the amount of, like, dedicated time that, you know, not even just our staff, but even, like, you know, our other, like our different circles of leadership, like even this Brain Club moderator team, like we're kind of constantly reflecting with each other about things, right?

Like the dedicated look back, like the processing of things, like that doesn't happen in traditional healthcare, and I think it really helps, at least for me

Elizabeth Carney: I'm thinking about all the work that the Brain Club moderating team put into kind of like all of those slides that you go over every meeting, and those really evolved out of like what do we need [00:32:00] to prioritize the group safety? And we, I mean, I can't even remember how many iterations those slides have, have gone through, and they'll go through more because we'll always be evolving and looking at, you know, the, the group needed this today and we didn't deliver for them, so how can we change the, the, how can we change the explanations?

How can we norm better? How can we invite people in? How can we lower shame? And that's all very dynamic

Sarah Knutson: You know, I think that's a really, you're making me think of something that I think is really important about ABB, Liz, which is that, that part about the, like the idea that the slides will change again.

And, and, and the reason they'll change again will be in response to something that came up, [00:33:00] and it will be this question of how do we, how do we not only, this balance between how do we create a space where... It's really about, it's about how do we create a space where everybody can be there?

And so, and we just keep go- and we find out that somebody can't be there. There's conflicting access needs. Somebody can't be there because of this or that. And, and so like ABB is just this continuous sort of iterative process of negotiating conflicting access needs. And, you know, round one will be, "We can't do that right now because we don't have the energy to do it," but, you know, six months later ABB has the energy to do it, and then that access needs get negotiated.

And so it's just this continually, continual kind of iterative process of sort of how, how can All Brains B- It's, you know, the question, it's really faithful to the name and the mission, you know, how can all brains belong? And the question just keeps being

asked over, and over, and over again, at increasingly nuanced and [00:34:00] deeper levels.

Which is, is different from the tr- Like the system that ABB has is really put the priority of how can we make all brains belong. So that's the question that ABB keeps asking and, and seems to ask first. and, and I think the other, other organizations I think are like, "We can't do this because we have to go through this long process, and we have to go through this huge hierarchy, and we have to go through..."

So there's, there's all these ways, these things that get in the way of traditional organizations that want to, sincerely want to be responsive. But they, but, but the s- the systems and the ways the systems are set up, something else, and I'm not sure what, but something else is getting prioritized - some kind of systemic need is getting in the way of asking, how can we serve our patients in, in as responsive a way as possible?

I just think All Brains Belong has really has really [00:35:00] nailed that as an, as, as like a, a priority , and something that continually the organization is striving to do .

Mel Houser: I love that, and I think that, it's also been really helpful to, like, build a predictable system for what feedback is here-

Sarah Knutson: Mm-hmm

Mel Houser: so that when someone makes a suggestion, you know, there's like, oh, well, because it's in the context of ongoing relationship. Like, I'm not even really sure we take feedback from people we don't have relationships with. I don't think we're open to it, right? But, like, when we're in relationship with people and people make a suggestion and we say, "Oh, you know, that's actually a really good idea. I really love that idea," and we're beyond capacity, like, that's just taken at its word. And then to your point, like, if capacity shifts, and it often does, we'll reach from the parking lot and say, "You know that thing that... we really liked that idea. We just didn't have capacity." But, like, I think that the person who gives the feedback knows that there's that structure.

And I think to Liz's point just about, like, it's, it's [00:36:00] community agreement of Brain Club, there's a community agreement almost of feedback giving, right? Of like, if I know how this works, because it's been explained to me, and if it hasn't been, that's on us for not explaining it. I think one of the reasons, and going back to Brain Club, like, the reason we change that community agreement all the time is because when something goes wrong, like, it is very clearly... at least I can only speak for myself, my

go-to interpretation of almost every breakdown is we didn't prepare the people well enough. We didn't prepare the environment well enough. That's why there was a breakdown. And so of course the first thought is let's change the community agreement and not really anything else.

Sometimes it's like, "Dude, stop trying to change community agreement. We don't have to change it every five seconds." Like, yes, we do have to change it every five seconds because it failed

Sarah Knutson: I also wanna [00:37:00] get back to something I think Olivia said early on about when, I think when, Olivia, when you were talking about boundaries, and maybe, there's, what, what the huge difference I notice, and I notice it, I just notice there's all this anxiety I'm not carrying in my body because I am no longer anxious about my healthcare I mean, and that has an incredible effect on my health.

I don't think that other systems get that, like how much health is related to the way the system interacts with the people in it, including the patients. There's also this talk about safety and blah, blah. But I think what safety means to the ordinary organization is that we don't get sued by you. And that's a very different concept of safety that actually is like we actually care that you get your needs [00:38:00] met, and it goes beyond that. It's not just about getting needs met. It's not just about getting healthcare needs met because it's like I get this sense that ABB likes me as a human being. ABB appreciates, you know, sees and appreciates me as a human being and wants good things for me as a human being, and that's a very different ... that's the essence of a good relationship, a good mentor relationship, a good all kinds of different relationships and I get the sense of like, when you talk about your patients, Mel, it's like it's different than you talk about patients different than you talk about the rest of the world 'cause it's like there's something about that relationship happening and it becoming a relationship now, I get the sense that you believe in the patients at ABB. And that we're on this journey together and, and somehow we're on this journey together toward health and staff is on a journey toward health, their own journey toward health, and we get to see that too. There's this believing in each other and liking each other and caring about each other that all goes together in it that really, that kind of [00:39:00] somehow makes the secret sauce.

Mel Houser: Well, I think what you've just operationalized is unconditional positive regard.

Sarah Knutson: Okay.

Mel Houser: Right? What you just described to me, like, that's what comes up, is like-

Sarah Knutson: Okay ..

Mel Houser: . Yeah, when you truly have unconditional positive regard. It's, you know, I think sometimes we talk about that in terms of, like, ascribing good intentions, but it's so much more than that.

It's the I like you, I care about you, I'm in a relationship with you, I'm loyal to you, because I know also that that's how you interact with me.

Sarah Knutson: 'Cause it's really interesting, you get taught unconditional positive regard, like in therapy school or probably any healthcare profession.

You get taught that, but it's doesn't usually mean, it doesn't usually feel like that. It usually feels like I'm, you know, I'm not gonna dis what you say when you say it to me directly. That's ... And but that's as far as it goes, you know? It's like I'm gonna go, "Uh-huh, you get to have your beliefs," you [00:40:00] know?

I'm not gonna dis your beliefs, I'm gonna let you have, like, what your, what your beliefs are. But it's, that's very different than the positive feeling of I see you as a human being, I like you as a human being, you matter to me as a person, and I think you, and I think the planet is better for you being here.

That's a differ- that's, that, that feeling. I don't think anybody can live without that. I think that's a need that human, every human being has, or at least most human beings have. And I think there are very few places in this world where human beings actually get that. and including most families, you know? Especially if you grow up autistic.

Amy Noyes: There's this thing about, I don't know what it is, and it may be... But there's something about, children who are seen when, when they come into the room and your eyes light up to delight in them feel more safe. There's something about that feeling of, like, [00:41:00] when you come into the room, you feel known, you feel like, people are happy you're there. And that's whether that's a community event or I'm going in to, like, pick up something from the office. I mean, every time I see Olivia, you know, it's like I'm...

You know, like, I feel known. And even though it's like I'm not necessarily in med visits all the time with Olivia, but I just feel like still Olivia probably knows me and knows what's going on. And that's the same with Sierra and Mel and and Lizzy. And so there's this thing of like, "Hey, we were thinking about you. This might be a thing that you

need." Or, and that's, feels like that's a regular thing. Like, I think I just got a text from Lizzy yesterday like, "Hey, do you wanna come to this med visit?" Or, you know. And so I was thinking about, like, the, I did prepare a little bit about soliciting feedback, and I was thinking, "Okay, we've had task force. We've had community advisory board. We have, different forms that go out, emails, meetings, Discord, [00:42:00] surveys. Like, what was the big project you did where you, it was like a long, like, three-year project or something?

Mel Houser: Yeah, the, the equity audit of all the barriers- all the things that aren't going well that we should solve for together.

Amy Noyes: The equity audit. I mean, and this is just, like, embedded in the practice. And I was thinking about even, like, the, the pre-visit forms. Like, every week, and so I could, like, share some personal information on those forms if, if I needed to or felt like I wanted you to know this other thing that was going on.

So there's so many ways, and then the new texting to make it easier access. Like, now we can text, and it's HIPAA. And so, and so there's just, like, an ongoing, so it's not even just the community agreement. It's like, "Hey, we wanna know you. Hey, we wanna know you. Hey, we wanna know you. We'll ask you this way, and we're gonna ask you that way."

I know I could, like, email or text or go to a community group and there's so many different ways to access, this community. And one thing I just wanna really say is that one [00:43:00] thing that you've all really taught me is that when you're asking people, particularly people who are disabled, for feedback to compensate them for their time.

'Cause there's so many surveys or research projects or- Some people are writing books, and I never see that. And I just want you to know I've implemented that into my practice, where any time we're asking for feedback, we're compensating. And, and so we also offer time where they could offer feedback that we're not asking for, but if they wanna give it, they have a way.

So I just feel like you've learned that. And then someone was saying, "Well, I can't really give you feedback because the way you ask questions doesn't really work for my brain." And then I was thinking about the pre-visit planning form and where it started and where it is now. And now I knew this, like, this last one I just got recently, like, had a prompting question, and I was like, "That's what this person in my practice was asking me for.

I need prom-" And I was like, "Oh, yeah, this is when you listen to your people, you can start providing," and that it's the fundamental value. [00:44:00] It's not performative. That's really so important. It's not like bureaucratic. It's not like Sarah saying like, "We forward, we're gonna get sued."

This is like the fundamental value of we wanna know you and we wanna care for you, and that is felt, like, so deeply.

Mel Houser: That's amazing. And I think, like, part of, and I think this, like what Sarah was saying around, you know, I see you, I appreciate you, I value you. Like, part of the reason we ask all the things is because the ideas that people have are better than the ideas we would come up with on our own.

Like, when you look at the pre-visit form questions, I think some of you wrote those questions, right? So, so y- yeah It is a community effort. Or like the new texting thing, you know? That was maybe a year ago. Sarah had that idea. We're like, "Whoa, that sounds expensive and hard, and ah, no new [00:45:00] things."

And then it was like, "All right, well, we have, we have a little bit of capacity. What are we gonna do with it? Oh, we should do that thing that's on the parking lot from a year ago that Sarah said." So yes.

Anything else anyone wants to share before we wrap up?

Elizabeth Carney: I just wanna say this has been a really cool conversation, and I've learned a lot about kind of some of your behind-the-scenes practices and how you think and how you discuss and how you resurrect ideas and how that's tied to your capacity. The, this is, I've learned a lot just in this conversation

Mel Houser: That is inadvertently giving me feedback that, like, maybe we could even be more transparent about some of those processes. Like, I thought it was well established that that's what we do. [00:46:00] But it turns out, no.

Thank you again to Mkazas, Amy, Sarah, Lizzy, Liz, Sierra, and Olivia. I think this conversation, I'm hoping, captures how healthcare as it exists right now is not a foregone conclusion. To think it has to be this way is a failure of imagination, and we are grateful for our community for co-creating this community health village of learning and healing together.

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.