

The Right Questions, Better Support

Hey there. Glad you joined me. I'm Stacy Nonnemacher, and this is A Supporters Toolbox.

I learned so much from the people in my life who have lived experience as someone who has a disability, probably more than I have learned in all the years of reading textbooks and research, I feel like I'm a better supporter from the time I take to sit and talk and listen to people share their experiences. In this episode, I sat down with Perri Spencer, someone I met through The Link Center Steering Committee, if you don't know about the link Center and our mission to increase mental health access for people with disabilities. I suggest you click on the link in the transcript. <https://acl.gov/TheLinkCenter>

Perri has a way of articulating his experiences and what works and doesn't work in his life. More recently, he made a comment during one of our conversations about asking the right questions to get the right information, to give the right support. So I asked him if he would sit down with me and share his thoughts with you all as well, just as an FYI Perri wanted me to share that he is an AAC user, so we took some time to edit this down a bit. Thanks so much and have a listen.

Stacy: So I'm really excited to have someone join me on the podcast today. Recently, I was talking with people on a steering committee for a national grant project called the link center, and I was struck by some powerful yet simple advice that was shared by Perri Spencer. Perri talked about the importance of supporters having the right information to provide the right supports, and that sometimes that requires asking the right questions. Hey, Perri, I am so grateful that you were willing and able to talk some more with me about this. So do you want to say hello and introduce yourself?

Perri: My name is Perri, and my pronouns are he him? I'm an autistic self advocate and AAC user. I'm a link center steering committee member as well as a member of the Kansas Council on Developmental Disabilities. Happy to be here. Awesome.

Stacy: Thanks, Perri, so I'm just going to jump right in and Perri, you shared with me times when people have not asked the right questions to get the information they need to best support you. And frankly, that's really stuck with me. I recall one example where you said that you went to the doctor and thought that it would be helpful to have your medications adjusted, but he ended up keeping everything the same because the questions that he asked you about feeling suicidal and the way that he asked them weren't helpful. So can you talk a little bit more about that and share that story or your experience with that?

Perri: So I went to see my med provider, he's an APR, and he asked if I was feeling suicidal right now. I said, not really. I was having a better day than normal right at that specific moment. I asked if he literally meant right now, and he said, Yes. So I thought he was asking about this specific moment, but I had been having a very hard time overall, and he didn't ask about that. So he thought I was doing better, and kept my medications the same instead of adjusting anything. I think when he said right now, he really meant it as an overall state instead of a tiny, specific moment in time. But he didn't ask the question right now, so I don't feel like I provided all the information that he needed to make decisions about my mental health medications. If he had asked, Have you been suicidal since the last time I saw you, I feel like I would have been able to give him a much better picture of my overall functioning.

Stacy: So what I'm hearing you say, Perri is the words that we use as supporters is really important.

Perri: I'm not good at reading between the lines of things that aren't specifically asked.

Stacy: That brings me to another point that you brought up you've you've talked about rating scales, and, you know, rating scales are used to get an indication of how people are doing and how people are feeling. How do you feel about rating scales and what are your experience in supporters using them to get information from you?

Perri: I have trouble with rating scales that don't have explicit information about what each rating would look like, and I never select boxes that say always on rating scales, because even if something happens 95% of the time, there are small amounts of time that it doesn't happen. So always would be inaccurate, but then the scale may be under reported by me if always actually just means most of the time or almost always. Are over 90% of the time. I really like the rating scale for depression because it's divided by how many days of the week do you experience certain symptoms, and that's a lot more concrete for me, because what vague ratings like almost always means different things to different people. And I don't want to exaggerate my symptoms, and I want to be honest as possible.

Stacy: So I think for me, Perri, the two things that are sticking out is that things need to be concrete. For you...

Perri: yes, and I feel like, if they're not, if they're not, if there's like, if they don't ask me the exact question they want the answer to, I'll answer what they actually asked for, especially in medical settings. Not because I can't, because there are medical appointments are already really, really stressful for me. So I don't, I can't, I don't really, just a lot of times I'll go to a medical appointment, I'll answer the question, exactly what they're asking, answer exactly what they're asking, and then after the appointment, and it's lower stress, I realized, oh, maybe they weren't actually asking the question I answered. But for me, with autism, like I I'm very literal, so I want the questions that I'm being asked to be concrete and, like, easily measurable. Like, because asking, Does this symptom occur almost every day, all the days? Like, oh, this symptom does occur every single day. But then if I get the same question formed, like, does the symptom occur none of the time. Like, from, you know, one of the ones that goes from three to five, like, none of the time is a one, one or zero, and then five is all the time. I will never get I won't hit that five because, like, even if it happens every day, I'm like, there's certain periods of day, like, there's this hour period that I was watching Steven Universe, and I didn't feel that feeling. So it can't be always, so I would only click a four.

Stacy: And you know, the other thing in listening to you explain that Perri is for you, it has to be concrete. But it's occurring to me that, and you touched upon this, it probably also should be individualized to the person, so knowing the person's important and how to ask the questions for that person, yeah. Perri, would it be helpful if, in the case of the rating scale or the Doctor Who asked you about feeling suicidal, if they gave you the questions or the rating scale ahead of time for you to think about them,

Perri: I think if I got questions ahead of time, I may stress about what the right answer is, and it might make me more anxious. It's hard to say so.

Stacy: You also talked to me about people asking you the question, are you okay? Or how are you feeling? I think specifically you asked about or specifically you talked about a conversation that you had with your case manager when they called to check in and just simply asked if you were doing okay.

Perri: It's hard because I deal with such a high level of mental illness that even when I'm having a good day, I'm still struggling a lot. I have chronic suicidal ideation, and my depression is severe. Not just saying the word severe to mean bad, but specifically the diagnostic term severe in the DSM for depression. So me always being mentally unwell in some capacity, even on good days, when added to my black and white thinking and rigidity from Autism means that unless I'm actively in a mental health crisis that may need a higher level of care, that I think I'm okay. My brain basically believes I'm okay, no matter how bad I feel if I currently don't need outside support to not hurt myself, and that's very different from a person without disabilities definition of okay, because if I used a non disabled person's definition of okay, I'd literally never be okay by that definition. When my case manager asked if I was okay, I needed lots of help. But I thought that since I didn't need the hospital, I was okay. If she asked if I needed help, I would have said yes, even though I said I was okay.

Stacy: That's such an excellent point Perri. And it comes back again to what I said earlier. It's important to know the person that you're supporting. It's important to know how they define the words that you're going to use if you're going to use those words. So I So, I think, I think the message here for supporters who may be listening is that we need to know how people define the words that we're going to use, right?

Perri: Right, yeah. Like, I didn't even think that.

Perri: I didn't even think, oh, other people might not have the same definition as me, because I have, you know, it's an autism thing. I have weak theory of mind, so I assume my definition is everyone's definition. Like, not even like, Oh, I'm right and you're wrong. It's just subconscious. I forget other people think differently from me, yeah, and that can sometimes lead to frustration between when communicating with people about, like, my status, like, because usually I have, not always, but usually there's some level of, like, suicidal thoughts, even on a good day, it's just on the good days, it's easier to, like, distract myself or focus on different things. So like, even if I was having a good day, like, I would probably still be at least some level of suicidal. And like, for most people, if you're suicidal, you're not okay at all. You know, no matter what the level is, right?

Stacy: And one thing Perri, as I'm listening to you talk, is I know another person on the steering committee has offered that she sat down and she made her own rating scale and defined each of the pieces of The rating scale based upon herself and how she shows up, and she has shared that with her supporters. So for her, that's really helpful, because it's individualized, it's concrete and just specific to how she's defining words that are vague, like, how are you feeling?

Stacy: Yeah, okay, so just sort of to wrap it up a little bit, we've said a lot about things that supporters could do, or people can do to help their supporters ask better questions or the right questions. But is there anything that you can add to give general advice when asking questions, to get information that would be helpful...

Perri: especially if you if you're working with a person, like with IDD like, especially if you know they have a developmental disability? Like, if you're a medical professional and it's in their chart, or, like, be very clear and very specific. So like, in as long and like, speak in a way the person can understand. So maybe instead of how are you feeling right now, if say you're asking about depression, and you want to know like information from the last two weeks, because that's usually how depression is diagnosed, maybe instead of asking how are you feeling right now, and maybe the person's feeling okay right now. And I

think you mean right this minute they and they say, Oh, I'm okay right now. But what you when you really want to know about the last two weeks, you could ask, Oh, how have you been feeling the last two weeks? Have you been feeling any of these symptoms? And then if they report any of that, you can do, like the PHQ nine, or something like that, if you don't, because I really liked it, because it's very I think that PHQ nine, the reason it's such a great screener is that it's very specific, like it asks none of the days, a few days, more than half the days, nearly every day. So you can so it specifically asks about frequency in a way that's like, very concrete, and you don't really have to decide, Oh, what is this question really asking? Because it says exactly what it's asking. And I just think we need to like, this is harder than just what specific people can do, but just to generally like, make screening processes very specific, instead of having hitting meetings and also when you're specifically asking questions about a person's medical history, like if you if you're not sure if a person understood the question. And like, you can always like, ask, like, reframe the question and ask it again. And if you have a person that has, like, an intellectual disability, you can might, you might need to amend the question to fit their level of understanding, like, of course, ask the question first and see if they can understand the question. But then, if you think there's something, they're not extend understanding. You can explain more or ask a different question.

Stacy: I think you're emphasizing, again, how important it is to know the person, yeah, to keep things individualized based upon...

Perri: maybe sometimes, if you ask, Oh, am I depressed? The person may not know exactly what that means, but maybe if you ask, do you feel sad a lot of the time and not feel like doing anything, they might say yes to that question, but not know what depressed really means.

Stacy: Great example.

Stacy: All all really, really good information, Perri, and I think that we've given people a lot to think about, that's great. So thank you for always showing up and being willing to share your stories and experiences. I learn a lot, and I am so glad that you were willing to share this conversation with others, because I think it can be food for thought and how we talk with people we support. So thanks so much, Perri. I appreciate you giving us your time.

Perri: Yeah

Stacy: I am so incredibly grateful that Perri took the time to share his thoughts and his experiences with us. Thanks again for joining me. I'll leave you with the simple words of Dr Atul Gawande. Do what is right and do it now.