

2024 KT Online Conference

Listening to Autistic Voices: What Participatory Research Reveals about Prioritizing Good Mental Health for Autistic Individuals

Presenter:

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<https://ktdrr.org/conference2024/index.html>

Transcript for audio/video file on YouTube:

<https://youtu.be/D3EPgyMikjk>

Stephen Shore: To present at this AIR Knowledge Translation Conference, spreading knowledge, useful knowledge that can be implemented tomorrow or at least in a very short timeframe for making fulfilling and productive lives for autistic and other neurodivergent individuals the rule, rather than the exception. The physical description, I am a white male with a gray beard wearing a black hat that says Adelphi University. I'm wearing a blue shirt short sleeve shirt, and my background is an old school chalk blackboard. Alright, so we continue on to the next slide. This is funded by PCORI and the whole focus is meaningfully including and engaging autistic stakeholders in identifying health priorities to support patient-centered outcomes, research and collaboration, meaningful collaboration with autistic individuals. So we flip over to the next slide and the way it started is that I had just participated on a panel on autistic intelligence after that panel,

I was accosted by this OT who started talking about the need to research into healthcare issues facing autistic individuals, Teal Benevides to be specific. And she was talking about how we need to ask the question, what is the most challenging healthcare issue facing autistic individuals? And oh gee, why would I want to do that? My focus is on comparative approaches for supporting autistic individuals. But it seemed interesting, especially when the discussion turned towards how we would conduct this research. And the research would involve, in addition to asking autistic people themselves what the most challenging healthcare issue is,

This research was going to be done with equal participation of autistic individuals. Okay, in that case, I'm in. And what we did is we proposed to Patient Care Outcome Research Institute the following, one, to establish a paid community council of autistic adults and other stakeholders such as what was then called the Asperger's Association of New England now called autism...I don't even remember, it's changed twice. But anyways, neurodiversity is involved in their grasp, the Autism Society of America, Autism Speaks, and also research organizations such as the AJ Drexel Autism Institute with Paul Shattuck when he was there and AASPIRE, Christina Nicoletti and Dora Rainmaker, et cetera. So we had these 18 paid community council members, mostly autistic individuals and it was them that we would go to

ask key questions as to what is important to ask, how are we going to ask and how are we going to set up the research? And just to show that autistic individuals can also be inclusive, we made sure that the lead team was half autistic and half non-autistic. Flipping over to the next slide, how do we engage?

How do we promote authentic autistic engagement in research? And this can be summarized in the next slide, which shows the engagement guide that we published presenting how we promoted authentic and meaningful engagement and compensation for autistic researchers. We focused on what we call the four Cs of authentic engagement: competence, communication, compensation, and consideration. So on the next slide we will look at enhancing engagement. And here we focused on eliminating the myth in our society that individuals, autistic individuals and others who don't speak are less intelligent than those who do. We use a positive approach and presume competence that the individual, the autistic individual, does understand what is being communicated. And it's up to us to figure out a way to develop a reliable means of communication. We modified our language instead of using the medical model of disability disorder and deficit and you need to be fixed, the focus now is on what can we do to recognize these differences and make environmental modifications to address them.

So for example, instead of talking about sensory dysfunction, we talk about sensory differences. The focus is to communicate with the autistic person whatever age they are getting away from talking about the individual as if they're not listening, even though they're there in the room. And including that person in the discussion with a recognition that deficit based language attending a meeting full of deficit based language about yourself is going to be detrimental to that individual person's health. So as we go onto the next slide, as we look at our communication, we found that our emails had a very low response rate and it was a typical email, essentially a wall of text and you'd have to read through the whole thing to figure out what you really wanted. So borrowing from the work of Elesia Ashkenazy from AASPIRE, we minimize verbiage and emails are written in this outline form.

And in that way you can very quickly understand what needs to be done, if anything, as a result of this email. Now what you see on the top, what is good for the goose is good for the gander. And what that idiom means is that although we often make modifications initially for autistic individuals or others with disabilities, we often find out that these modifications, such as this way of writing emails, tends to be good for everybody else as well. Those who are not autistic, I believe also appreciate receiving emails and messages like this. So on the next slide, compensation and what we noted is that autistic people tended not to be compensated at all, or at least not as well as others who are not autistic. Autistic people have important and valuable contributions to make, and we should be compensated for such, especially in view of the fact that according to the National Autistic Society in England, the combined under an unemployment rate for autistic individuals is at about 88%, which means only 12% of US autistics are working to our capacities.

So, all the community council members were hired at \$50 an hour, which we were later able to raise to a hundred dollars an hour. A barrier we face is that payments

can interfere with disability benefits, where commonly a person has to spend down to almost poverty level before they can receive benefits and they get penalized for earning money. So, we need to take a look at how to best compensate. One possibility are gift cards, many organizations are not set up to provide gift cards as compensation. So that's something we need to work on. Let's continue, on the next slide we look at consideration, building trust, respect, and support. The ability to trust each other, to bring up differing ideas and concerns, all contributions are valued, and everybody has an equal voice. So for example, we were going to, initial plan was to capture priorities using Facebook, but there were many community council members concerned about the security of private information on Facebook. So as a result, we had to change our methods. And that's an example of respect, the community council members said, we don't want this, we need to do it another way and thus we followed them. And likewise, we provide opportunities to author and co-author materials and are supported in being able to do so. As we flip to the next slide,

Kathleen Murphy: And as we do that, Steven, we can't run this conference late because of the ASL interpretation. So, I did want to let you know you have about 5 minutes.

Stephen Shore: Okay, Yeah, I think I can pull that off.

Kathleen Murphy: Awesome, thanks.

Stephen Shore: Thanks for the warning. Alright, so here we go. As we look at considerations, more considerations, you see a number of points, seven points to be specific, which I'll let you review on your own time as you look at this handout. And it's with these seven points that are necessary that are vital for autistic individuals to be authentically and meaningfully included in our research efforts. So moving on to the next slide, we look at methods. Where did we get this information? Well, we had two large stakeholder meetings, a number of online surveys, face-to-face focus groups, and now what we found is if we flip over to the next slide, looking at the results in doing so, what are the results we move, We see that what bubble to the top, to the great surprise of some people, but not to others, is that mental health interventions and outcomes bubble to the top.

That is what is most on the minds of autistic individuals. Access to mental health interventions and supports followed closely behind by gender inequalities and diagnosis, treatment, and sexual wellbeing. The work continues this project ended a few years ago and in the same community council, a few more members, some dropped out, some others joined. We're now working on a 5-year, \$9.2 million suicide prevention grant, where we're going to compare two suicide prevention strategies for autistic individuals. Since mental health is the priority and suicide is the leading cause of death in autistic individuals, it was decided that we need to turn our energies to this area. So we're involved in this \$9.2 million grant. That's another three point something, maybe \$1 million grant that focuses on comparing CBT with MBT, MBT being mindfulness based training. So if you flip over to the next slide, you'll see some references to articles that were written as a result of our research. The work continues and this presentation just gives you a taste, a mere

taste of what went into making sure that autistic individuals are meaningfully and authentically involved and included in all aspects of research. Thank you very much.