MATT BRANDENBURG:
You're listening to everyday evidence presented by the American Occupational Therapy Association, helping the occupational therapy practitioner apply evidence to practice. Here's your host, Matt Brandenburg. Alright. Today we are joined by Kristie Patten, Kavitha Murthy and Stephen Shore. Thank you so much for sharing your knowledge and expertise with us today.

KRISTIE PATTEN:
Well, thank you for having us.

KAVITHA MURTHY:
Yeah. Thank you.

STEPHEN SHORE:
It's a pleasure and honor to be here.

MATT BRANDENBURG:
I have been so excited for this interview and really looking forward to speaking with you three. You each contributed to the Occupational Therapy Practice guidelines for autistic individuals across the lifespan. And I just want to jump right into it. Can you quickly define what a practice guideline is, and how this publication can be used by students, practitioners, and educators alike?

KRISTIE PATTEN:
And again, thanks for having us, Matt. Practice guidelines really are about organizing information. And organizing information for use by practitioners, by educators, by students that are based on evidence and the evidence that's organized from the systematic reviews that are done. And in my mind, I think the most effective use of practice guidelines... Because what practice guidelines do is, they do the work for you to scan the evidence and really look at what's out there as far as an evidence-based practice. And I think you can look at that evidence as part of the practice guideline, but it also gives you an opportunity to see the lack of evidence in areas and look at recommendations to really help practitioners and educators, I think when we teach in this area, as well as students, when they're learning about autism, to really make good decisions and effective decisions. And one of the things that I think we'll get into that I'm really excited about this practice guideline. We had authentic autistic input and authorship so that it really does not only look at the evidence that's out there, but also really grounds it in a perspective that is very centered in those that we are working with to support attitudes and thoughts and contributions about the evidence and our interventions that we are doing.

So that, I think, is how it's used in general. I think this one is a little special in that we have been very intentional about the inclusion of authentic autistic representation.

MATT BRANDENBURG:
I love that I think that's so important to developing a practice guideline. I love how you compare it to being used to help people make better decisions. I think that's where my passion for evidence-based practice really started is with a desire to make the best possible decision for people I'm working with. For intervention, planning and practice guidelines are really meant to encourage that and...

KRISTIE PATTEN:
Can I just add to that, Matt, too.

MATT BRANDENBURG:
Of course. Yes, please.

KRISTIE PATTEN:
Not just about us making decisions, right? We can make decisions. We can look at something and make a decision. But unless you have that reciprocity with those that you are supporting with lived experience and you have their input as to these decisions, you're going in a in a unidirectional way that is can be harmful. And can be neutral, can be positive, but can also be harmful. So, I think this idea of really partnering with autistic authors and scholars for this practice guideline is key.

MATT BRANDENBURG:
Absolutely, absolutely. What motivated each of you to focus your efforts and scholarship on autistic individuals? And can you kind of introduce us to a little bit of your background and role in developing these practice guidelines?

KRISTIE PATTEN:
Well, what motivated me, I have as a practitioner, way back in 1987, I started working with autistic individuals in a way that was very much a grounded in how many of us were trained, and that was very deficit based, and that our job was to go in and look at interventions and use interventions to really impact the presentation that autistic individuals had. Back then we used different language, which I think we'll talk about later. But it was really this mindset that you were there to kind of make these students look less autistic so they could have been more included. And that through my work has totally shifted. It's now about include autistic individuals. Do not make them make them look less autistic in order to be included, which is a very, very ableist mindset, which we try to counter in many aspects of this practice guideline. So, I had a history as far as working with autistic individuals, my motivation to work on this guideline and really center this guideline in authentic artistic representation has been the paradigm shift that I've had in my own work over the years.

MATT BRANDENBURG:
I love that. Thank you, Kristie for giving us a peek into that background and experience. Stephen and Kavitha, how about for you?

STEPHEN SHORE:
Well-being an autistic person, I guess that's where it starts. Where after 18 months of typical development, I was struck with what I call the regressive autism bomb. Where I lost like, what 30% of us. I lost functional communication, had meltdowns, withdrew from the environment, and in brief, became a very autistic little kid. Fortunately, my parents refuted the professionals recommendations for institutionalization in favor of what we would today refer to as an intensive, home-based early intervention program emphasizing music, movement, sensory integration, narration, and imitation. If we look at it from today with today's lens, it would probably look like one of the more developmental approaches that we have today. Such as the Miller method or Floortime or RDI. And with the work my parents did, speech began to return. I entered regular school kindergarten at age six, where I was an academic and social catastrophe. But fortunately, my parents were there to step in and provide what I needed.

So, what my goal is, is to, you might say, return the favor that my parents gave to me in providing me for what I needed, even though the terminology didn't even exist, or what we call today providing support for autistic individuals.

MATT BRANDENBURG:
And that's amazing. I love how you're so open and sharing your lived experience and the lessons that you've learned to encourage and help others establish and maintain the support that we all need to thrive. So, thank you so much for your work on this as well. And Kavitha as well we'd like to hear from you.

KAVITHA MURTHY:
Absolutely. And thank you again, Matt, for having me here. This is like an absolute dream to just be with Kristie and Stephen. They're like absolute superstars in the OT sort of field and pushing the paradigm and boundaries. So, for me personally I started my practice in India, which is a very sort of like patriarchal and hierarchical society. And when it came to working with children on the autism spectrum, the outcomes were very limited. Right? So, outcomes were just like, you participate in schools. Many of the schools where like when I started practicing in 2011, it was all separated, there was not even the concept of inclusive education in mainstream cities like Mumbai. And I was practicing in Mumbai, which was one of the biggest cities in India. And that sort of led me to move to a different context where I wanted to understand and explore what different outcomes could look like. Because I was educated on books that were from the US, where from the UK and I wanted to see how the society and the perception of disability looked in different contexts.

And for that purpose, I went to the UK to do my master's and when I was working... So, when I was studying, I also had the opportunity to work for a bit. And I remember for the first interview I walked in. I had a non-speaking autistic individual on the panel interviewing me. And for me, it was at that point, like a huge, I don't know, like a light bulb or a bomb. And I was like, oh my God, I've been doing this like differently. I did not sort of understand what expertise they bring to this whole therapeutic dynamics. And the questions they asked. I still feel one of the most thought-provoking questions for me, because I had to really think and answer in a way that I never thought and answered before. And it was at that point I felt like I need to go back. I need to collect my thoughts and see if I could do a PhD or do something where I immerse myself in the research process. And that's where Kristie comes in. And when I was like, looking out for like different programs, I was reading everyone's profile, like who could be my potential mentor.

And when I read Kristie's, I'll never Forget she was the dean of the OT department at that time at NYU. And I read it and she mentioned about strength-based practices. And for me, that was just like, that was it. That was the light bulb. That's the lightning strike moment where I'm like, I need to learn what that is. And yep, that's how I'm here. And I've been learning and growing every single day with these wonderful sort of mentors in my life.

MATT BRANDENBURG:
Those light bulb moments truly are wonderful, and I think most people within the field of occupational therapy have felt a moment like that. And I want to thank you three for contributing to what I see as really a gold standard of inclusivity, of quality research, and of improving the impact that we can make as OT practitioners. With your work on these guidelines, it's so important to approach these with the correct perspective, I think. Some people, though, are gonna notice the first thing when they look at these new practice guidelines, maybe the language change and the title. Can you kind of talk to us about how the language changed from people first, for example, people with autism to the language now of autistic people?

STEPHEN SHORE:
Yeah, I certainly can do that. And there's been some recent research by (UNKNOWN) that was released a couple of years ago. However, let's go into a time machine and go way back to 2003, about 20 years ago. As I was getting involved in the autism community. The autistic community, I noticed that there was a community of people on the spectrum referring to themselves as autistic individuals. And very much like Kristie. All I heard of from my school was person first. Person with recognized the person who happens to have something. So that piqued my curiosity. And as a result at a large autism conference, I got about a hundred autistic people in a room to hash this out. Should we be referring to autistic individuals with person first language and the term identity first language didn't exist, or at least I didn't know about it then. So, I called it Condition first language. Or should we be using autistic person? And there was some very interesting discussion that came about. One person said that autism affects everything they do is not all they are, but it does affect everything they do and thus they considered themselves as an autistic person.

They didn't see it as something bad. It just kind of was something that was there. Another person taking things very literally said, "Well, autism isn't something that you put into a bag and then hopefully you don't forget your bag of autism before you leave. Another person indicated that they prefer to be recognized for their humanity first, who happens to have something. And then another autistic person responded with, "Well, if we consider autism as an extension of the diversity of the human gene pool, then I'm just as human as the next person". And it went back and forth in a similar way. We voted and the vote came down to about 80% in favor of what we call now call identity first language. And most adults and people who are able to communicate with about this, is that we identify with being autistic. We don't see it as something bad, it's just a different way of being as opposed to a disordered way of being. Now, that said, there certainly can be plenty of challenges that come with being autistic.

And those do need to be addressed. And that's why we have occupational therapists working on these very things. And that was the beginning of what I saw the change or at least my recognition of the change from person first to identity first language.

MATT BRANDENBURG:
Thank you so much for sharing your experience with that and that 80%... That's a really high percentage of people who were in favor of using identity first language in this community example. It's also a wonderful example of starting a discussion and including individuals who are impacted most and part of this community to really come to a consensus that segways really. Well, to our next question, I wanted to ask about the importance that Kristie's already mentioned for OT professionals to partner with autistic individuals when it comes to generating, synthesizing, and applying evidence related to interventions for this population.

KRISTIE PATTEN:
I just want to give a quick example. And I know Kavitha probably has some thoughts on this based on her research as well. But I think if you look at the absence of this partnership that has been the hallmark of research related to autism and autism interventions. We gonna be going down roads that we shouldn't be going when we don't partner. So, for example, I can look back on studies about eye contact, many studies about eye contact. Eye contact with robots, eye contact with reinforcement, eye contact... You name it. In the previous decades of autism research, there are tons of studies about how to get better eye contact that were absent any and all autistic participation and looking at generating this research or applying this evidence to what they feel is important in interventions and supports. Because if we would have had autistic representation from the beginning, they would tell us, as they're telling us now. Eye contact does not equal comprehension. You know, the neuro normative standard of if you look at me, then you're paying attention does not hold true for the lived experience, for many individuals with autism.

Some, but definitely not all. And I'm sure Steven has an opinion on this as well. So, by putting all this research evidence about something that the autistic community says, this isn't even relevant. Your assumption about this is wrong from the beginning. And then we do all these interventions to gain more eye contact when our fundamental assumptions about what eye contact means for that autistic individual is flawed. So, it really is about really changing how we look at who are we partnering with to really understand in a fundamental way to ask better research questions. And I'll let Kavitha add some things as well.

KAVITHA MURTHY:
Thank you so much, Kristie. That's such a wonderful example. What I wanted to like and what I encountered in my sort of, like, dissertation research that I'm doing at this point is the sort of fundamental and bidirectional sort of lack of understanding between autistic and non-autistic people. Right? And that's called the double empathy problem. It's an excellent read if people have not heard about this theory. It was coined by Doctor Damian Milton. And this sort of and my research is in the area of problem solving. Right? I'm trying to understand problem solving from a perspective from autistic adolescents. And what KristIE mentioned about the questions that you ask are gonna be more meaningful if you ask with the help of people with lived experiences. And when I like workshop, my questions, what I did was took my research questions that came out of my curiosity and from the literature and went and workshopped those questions with autistic researchers who were researching autism. And I found like such a beautiful, insightful sort of... The workshop experience itself was so wonderful because I got so much knowledge, just based on their perspectives of how the question should be asked, how the questions could be tweaked, how the questions could be presented, what we could use to as methodology to understand the answers to these questions.

And using that in environments which are more like supportive and safe, help me go through with understanding the perspectives of autistic adolescents when it comes to problem solving. And there are a lot of differences in the way that I would look at a problem and problem in the most simplest term is something that I encounter that I don't know the answer to right at that point. And when it comes to a child on the autism spectrum, they had a very different way of going about it. And as Kristie mentioned, instead of looking at it from the neuro normative way, just bringing in those differences sort of helped me understand what I could do differently in those situations. And all this was in the context of after school programs where children were working on projects independently. And many of the challenges that they faced in those projects were very logistical. And answers to many of them where things that I didn't know at that point, and I learned how to collaborate and work with and find solutions to the problems.

So just by giving that ownership and democratizing the process of research in itself is a wonderful way to provide. And I think the whole point for OTS is to build more meaningful evidence. Right? And this could be done when we sort of partner up and democratize that process.

MATT BRANDENBURG:
I love that. Thank you so much for providing that framework and example of how meaningful and impactful research can and should be carried out. I think the process that you followed in all of your research, and specifically on these practice guidelines gives that foundation and framework to our listeners. We definitely want to encourage all of our listeners to read the practice guidelines, review the practice guidelines. We're gonna start discussing some of the recommendations and specifics covered in the guidelines but won't be able to cover it all. So please read it. Study it and use this as a supplement to learning about this important research. As way of introduction to the guidelines, how would you describe the occupational therapy process for autistic individuals?

STEPHEN SHORE:
Well, before we get to that, I want to underscore the importance of meaningful and authentic involvement of autistic individuals and research and basically anything that involves autistic people. For example, some years ago I was involved in some participatory research asking the question, what is the most challenging health care issue facing autistic individuals. And with Teal Benavides. She and I developed a study, that was funded by Patient Care Outcome Research Institute to study this very question. And while the two of us thought we could probably take a survey of various professionals, including OTS. What the most challenging health care issue facing autistic people was, wouldn't it be much better to ask the autistic community directly, just like Kavitha was talking about. And even beyond that, let's involve autistic people in all aspects of the research in a meaningful and authentic way. So, we immediately established a lead team. Half autistic and half non-autistic, just to show that us autistic people could be inclusive as well.

And we assembled a community council. A paid community council. Because autistic people should be compensated for what we contribute, just like everybody else. Mostly autistic people who answered critical questions as to how we would go about that research. Well, two conferences late a number of surveys, focus groups. What bubbled to the top was access to mental health supports. And this was coming directly from the autistic community. And we probably wouldn't have found that if we didn't ask autistic people directly. And if the study wasn't designed with authentic and meaningful input from autistic individuals. So that's just another example. Anyways Kavitha, You're on.

KAVITHA MURTHY:
OK. Thanks, Stephen. That's such a wonderful example. And I think we can later talk about how that also helped us answer in our practice guideline. One of our systematic review brief is on positive developing positive mental health outcomes. Right? So that just shows truth to power to that entire example and how useful and important authentic collaboration is. And Matt, to answer your question about the OT process, I'm directly quoting AOTA here. So, the process, the OT process is to basically achieve health, well-being and participation in life of the people that we work with through engagement in occupation. So deeply rooted in occupations, deeply rooted in the values and goals that are personally meaningful for an individual that you're gonna work with. For me, what stands out as an OT is to use myself therapeutically, because I feel like as a therapist, I'm not just this person of... As Kristie mentioned, like a person of expertise, but a person who is a change agent. Right? I want to be more intentional when I work with people and work with communities that I serve.

And by using the therapeutic and I think the power to that sort of the frame that therapeutic use of self. And I learned this not like when I was practicing in India because OT process was very prescriptive. But when I moved out and started like learning more about it and other contexts where the partnership goals are more relational and more intentional that way. I felt like there is tremendous power for the practitioner to use themselves as agents of change and also to change the mindsets of not just the society and the person, but to change the mindset of other therapists and other interdisciplinary professionals that we work with. So that is one thing that I'm gonna take from the OT process and that I feel is more important, but I would love to hear Kristie and Stephen.

KRISTIE PATTEN:
Yeah. I mean, I think... And this isn't in the practice guidelines because it just came out in 2024. And I will say practice guidelines are limited to and time bound for the literature that the systematic reviews include, because you can't just keep including. But I was struck by a by an article that speaks to, I think, the traditional OT process and it was on community priorities similar to what Stephen said with mental health. Community priorities for outcomes targeted during professional supports for autistic children and their families. So, this was looking at the professional supports that are given and what are the community's priorities for these outcomes. And I was struck it's by (UNKNOWN). I don't know if you're gonna do the resources here, Matt, but I was struck by ranking the outcomes because when you look at the outcomes, you think about, wow, this is fundamental to the OT process. And there was, I don't know, about 15 to 18 outcomes ranked. And this was a survey of 181 participants.

72 autistic adults, 85 parents and 69 professionals. And the things that were ranked the lowest for both children aged zero to five and children aged six to 12 were things like motor skills, knowing ways of being social, school skills, social skills training, play, focused interests, sensory behaviors. All things that are part of the OT process, right? That we intervene on and assess all the time. And they were the lowest. Right, above these kind of traditional OT skills and processes was participation, which was ranked again pretty low. And we were like, "Wow, how could that be? Participation is so important". And I'm struck and this could just be my on-the-spot analysis. The things that were at the top were like Steven said, mental well-being, physical well-being, behaviors that harm self and others were at the top. Self-Advocacy skills. Inclusivity and accessibility. Understanding yourself. Sensory tools, which is very different than sensory behaviors, right? Sensory and satisfaction with supports.

And then came language, self-care, social emotional skills, all about participation and the ones I mentioned earlier. And I was struck by the fact that maybe what we're missing the boat on in our OT process is that we ground participation in all those things that were on the bottom of this list. When really, what if we grounded participation with our skills to work on all the things that are at the top of this list. And then then people maybe really would be looking at participation more meaningfully when we talk about participation in the OT process. So that is a armchair analysis of reading one study very recently. But I'm struck by it. I'm struck by going back to Stephen too. This community outcomes and what are important to the community. And then you pair that against the evidence that we have had to look at. And there's a real mismatch. There is a real... And we fundamentally have to come to grips with that as a profession.

MATT BRANDENBURG:
Absolutely. That in and of itself is a light bulb moment that the profession needs to have in order to move forward and progress the quality of care that OT professionals can provide and really emphasizing the input of the affected community. So, thank you so much for these insights this is a wonderful discussion. I want to ask now about some of the recommendations that are made in the practice guidelines. How can practitioners begin to implement this new perspective, a new way of hopefully approaching the OT process for autistic individuals? And let's start with one of the systematic review questions that's covered in the guide. What clinical recommendations would you give to practitioners about interventions that address participation in meaningful occupations for autistic people under the age of 18 years?

KRISTIE PATTEN:
Well, I think that one, right away we're recommending to really think about the use of the word interventions versus supports. I think that that is clear from the community that that intervention implies this idea of that medical model of fixing something with an intervention. So, I think that that is really important to just begin going back to Stephen's thing about language. Our language is so powerful, and our language is gonna be evolving. I also think that one of the recommendations, although there have not been a lot of studies on this, is using this idea of a strength based approach, which does not mean do not look at challenges. Or that someone's inherent worth is not just based on their strengths, but really have a more nuanced approach that is grounded in understanding individual strengths. Utilizing interests which can be powerful catalysts for some of these self-advocacies, feelings of worth, inclusion, mental health and wellbeing outcomes that we talked about. And then using those strengths to build skills in areas of challenges, but not solely to build skills in areas of challenges, but rather to fundamentally embrace that they have inherent worth just in and of themselves would be one of the recommendations that I know I would recommend for anyone under the age and over the age of 18, quite frankly.

So, that would be mine.

STEPHEN SHORE:
I think one good way to look at it, until now we have not been successful in transforming autistic people into non-autistic people. And the way I look at it is that we have a choice. Either have an autistic person be a poor imitation of a non-autistic person, or work with that and support the autistic person to be the best autistic person they can be with their character.

KAVITHA MURTHY:
I just want to quickly jump in on this and just bring the point that Kristie and Stephen have been talking about, just talking to the people that we work with and trying to bring their voices into this whole process because they're... Just like, as Kristie said, if you want to give support to someone, their voices should be what needs to be challenged, right? Like it's their voices in the center and our ideologies and our interventions or our practices at the sidelines. So, it's very important to just bring that. And that's something that I've probably learned through this doctoral journey that I've immersed myself and the research that I'm doing along with Kristie and Stephen.

MATT BRANDENBURG:
I love that, I love that, thank you so much. I think we all want to shout an agreement like yes, a strengths-based approach. An interest-based approach is so important for us to do and it's vital and I hope we can encourage clinicians to implement that. Because it can be tough to do in a clinical situation where maybe you're collaborating with a family and there's a young child and you're speaking with parents and they're unsure how to use a strengths-based approach or an interest-based approach for their own child. And it's important for clinicians to provide this education and ensure that the correct approach to the process begins from day one to really improve best outcomes. So, thank you for these recommendations and it can be really tricky to do. And I wanna ask if you could help to kind of summarize the current state of evidence for this population and explain how and why it's difficult for the current questions to identify strengths-based interventions for autistic individuals?

KRISTIE PATTEN:
What I would say, because researchers are not doing the research needed. As far as part of it. I think that when you see research that includes a very neurodiversity affirming paradigm or mindset, you see good outcomes with autistic individuals. The problem is- and I do think this is changing, I will say, I absolutely think that this is changing. And we're being led by top researchers, especially in the UK, I would say, and Australia, that are challenging these deficit-based paradigms in research. But if I am applying for funding for my research, and I'm saying, OK, what is most important is looking at remediating a weakness, and that's how I get my funding and funding sources are still funding a lot of kind of remediation of weakness or, like Stephen said, making someone less autistic. That research is gonna get into the literature as evidence. I think we have an NSF grant right now where it is a very much a strength-based research project. And we have published many papers around this as well.

But that's not the norm. So, I think the I would call researchers to say, how can you fundamentally look at this a different way? We have a colleague in the UK that is doing research on flexible seating. It's not published yet, but in an inclusive environment. And they are bringing in all sorts of flexible seating and letting kids, whether they're autistic or non-autistic, just choose what seat works best for them. And then measuring the impact. That is very much a strength-based paradigm and inclusive paradigm. A paradigm that is about access to what you need to learn versus remediation and intervention to remediate kind of a weakness. So, I do think part of it falls on the researchers. I think the practitioners are doing the best they can with the information that's out there. So, I think part a big load of this is on researchers really looking at the paradigms and the models they're using to even ask their research questions about interventions.

MATT BRANDENBURG:
I love that I think that's so important and so well said. The process you're following for this research is a wonderful framework for how to apply that paradigm and hopefully we can continue to encourage it. How do you recommend practitioners use these practice guidelines, specifically to combine clinical recommendations with a strengths-based approach? How can they apply that in a clinical setting? Given the fact that research may not be following or providing as much concrete examples that they can use.

KAVITHA MURTHY:
So, the practice guidelines, specifically this one, as Kristie really underscored, was developed with autistic researchers who provided expertise in every single stage of not just the systematic review brief development, but also the questions right from questions that by mental. That is why we have mental health outcomes and positive mental health interventions at the top like we did that systematic review brief. And then we went into every single sort of avenue or aspect of an individual's life to see where we could bring in evidence to see how we could support an autistic individual. So, the way we develop the practice guideline was, we have the evidence and evidence tables, but we also have case studies and these case studies where of course, like we did not have a real case study, but we mimicked it very similar, very close to a real-life person. And also, when we provided solutions and our strategies that we would sort of like got it from the evidence, we had something called an epigraph.

So, the epigraph was like a visual sort of framework. And this framework acted as a guideline for us to provide a systematic process of how we can work with this person in this case study and find out like outcomes that are more meaningful and helpful for the person and that like in that specific case study. However, like I just also want to add that at every aspect, the epigraph is not like comprehensive. And so occupational therapy practitioners definitely need to sort of use that as a guideline. At the same time looking reflectively on what has happened in the setting, what works in the setting. And then use their reflexiveness of how this new information can help support or help push things a little bit further. And sometimes, as you said, it's tough in clinical settings. It's tough in resource constrained settings, right? So, at that point, what we could do is sort of change the way change our mindset. And that's why we have a lot of strategies in there, which is grounded in evidence and also supported by the perspectives and the evidence from autistic researchers.

So, we were very intentional in the way we created this. And so, this is the sort of recommendation I would give and sort of go through the epigraphs, but also create epigraphs in your practice that is very easy to adapt and very flexible to use and use them to guide your decisions.

MATT BRANDENBURG:
And as mentioned, the practice guidelines do provide these wonderful case studies and they always come with their disclaimer as well in every practice guideline. Very rarely will practitioners find an evidence-based intervention that perfectly fits their clinical setting and the client's specific needs. So, thank you, Kavitha, for encouraging us all to approach it in that way and take important examples from the case studies. And I want to ask what some of those recommendations and examples you would like to highlight for our practitioners? What are some of the key takeaways to approaching intervention design and interest based and strengths-based approaches? What would you recommend clinicians do more of in the clinic?

STEPHEN SHORE:
What it really begins with is getting to know the autistic person as an individual. What are their strengths? What is important to that individual? And then from there start assembling needed supports.

KAVITHA MURTHY:
And I actually want to coach Stephne on this like he's... Stephen and his colleagues have written like a wonderful article in Autism Spectrum, which is we are all on the same side. Unite the spectrum. Right? Stephen, I hope...

STEPHEN SHORE:
Yeah, that's right. Yeah.

KRISTIE PATTEN:
And I feel like in that what struck and will stay with me for a long time is the fact that the four A's that you were talking about like awareness, acceptance, appreciation. And I think the last one was action.

STEPHEN SHORE:
Yeah. Yeah. Exactly. Yes.

KRISTIE PATTEN:
Yeah. I feel like once we understand the person, then use this and as Kristie said, support the person. But in our practice guideline, very specifically, we went in, and we didn't use this same format, which could have looked way more savvier. But then we went in and looked at different aspects and sort of came to similar conclusions where we talk about being open to different languages and perspectives and trying to sort of use that and integrate that in our practice. And also keeping our focus very sort of like intentional when it comes to the subjective well-being. And Kristie beautifully laid out like how the different when it comes to outcomes looks different for us versus people from the autistic community. And I feel like this would happen when we bring in diverse voices into our research, into our practice, and also to appreciate like, different cultures. Right? Like we work with people from diverse. We are now in this globalized system where people from different cultures are gonnao be like researchers with us gonna be practitioners with us.

And I remember when I was about to start my PhD journey and, you know, like be with Kristie as her mentee, Kristie told me that we need as many diverse minds to solve this problem. And I feel like that still holds true. And I think it'll hold true in perpetuity that we need to appreciate that differences and in diversity when it comes to actually applying some of these guidelines and practice. And Matt, can I add something? We were very intentional when you read this practice guideline from all of us, we were very intentional about addressing and defining the problem of ableism in our own practice early in these guidelines. And I was struck. I was giving a lecture the other week, and I had asked the group, which was about, I don't know, 250 OTS, raise your hand if you got a lecture on ableism. There was hardly a hand that went up. And this is what we're fighting against. Saying so much of this research, so much of what we've done has been impacted by an ableist mindset. And it's OK. That's how we were all taught.

But I think we grounded this practice guideline in that because I know all of us feel the need that until you understand that you're gonna be looking at things and planning interventions and supports with a piece of the puzzle missing. And there were a bunch of authors Bottema Beutel. Again, this just came out in 2024 no assassin, Steven Capp, a bunch of people that did an article called Unpacking Ableist Language in Schools and Suggestions for school-based Practitioners. And it's a powerful article because many of the OTS out there that are working with autistic individuals are seeing them in schools. And they have an infographic that I just love that when we think about what your recommendation, where you should start. I think... And I'm gonna just be very biased here and say my bias. The most important piece of our practice guideline, it's all important that it's very much. But like reading the part about ableism and how that is plays out in a lot of these interventions and a lot of these, this research is incredibly important.

And these authors that were unpacking this ableist language gave a wonderful example of an IEP goal. That is where we are now and where we should be. And the IEP goal was in a general education, given a visual, a script and role play practice, the student will calmly implement a predetermined strategy to resolve a difficult interaction with a peer in 70% of the observed opportunities across three consecutive weeks. Meaning that that autistic individual has to come up with a strategy to resolve a difficult conversation or an interaction with a peer, placing the onus on them to get it better. Kavitha talked about the double empathy problem earlier. This is a very ableist goal as well because it really is saying you have to be. The onus is on you to make it better for everyone else in the environment. And they talk about what if the goal were in that same setting, following a whole class engagement in a neurodiversity awareness curriculum, the student will report more enjoyable and affirming interactions with peers in the classroom and on the playground as compared to prior to the implementation of a neurodiversity affirming curriculum.

There's a fundamental difference in those two goals, right? And until we see that, I think we're spinning our wheels a lot of the time. And bullying, we know is a huge long-term impact on mental health and well-being. And look at those two goals and what the difference would be around bullying in those two goals. And that's why this is so important to get right, and why I think we leaned into this idea of ableism at the start and really fundamentally understanding it and whether it's uniting the spectrum, going with strength based it fundamentally all revolves around getting that part.

STEPHEN SHORE:
Yeah. And a good example of that is you just mentioned bullying. Often, I hear people say, ignore the bully or you've got to work something out with the bully. And why would we be asking the person who has the least amount of social power in an interaction? To do most of the work?

KRISTIE PATTEN:
I have no idea. (LAUGHTER)

STEPHEN SHORE:
I don't either, but.... May I answer your question, Stephen? I know. I know it's like a rhetorical question we shouldn't be doing that.

KAVITHA MURTHY:
And can I just quickly jump in? And this is such a powerful example because this also sort of like when we ask the person with the least amount of power to do most of the work, it impacts their mental health, right? Like so seriously and severely. And then there is no supports for that. So, I feel like just tying all those things in, it's such a dynamic sort of challenge that we have for us as like practitioners and researchers to solve.

MATT BRANDENBURG:
Yeah. It's a moment of reflection and realizing that maybe the incorrect approaches that have been used in the past have contributed to the increased need for mental health services now and until those approaches and ways of thinking begin to change, true impact and true increases in participation and well-being can't really happen. Thank you so much for emphasizing that point, I think it's really important for all practitioners to hear and reflect upon and be aware of in their own practice and their own approach and in their daily work. I just have two more questions for you three as we conclude our interview today. What additional resources related to best practice for autistic individuals across the lifespan would you like to recommend to our listeners?

KRISTIE PATTEN:
I would say the best. I mean, the practice guidelines are gonna be published in (UNKNOWN), right? So, they can be accessible and they're gonna be accessible on the AOTA website. But I think that you know, if I can give one recommendation to anyone, if you're thinking about, well, how do I change my practice? How do I do best practice for autistic individuals across the lifespan? Talk to autistic individuals. Best resource ever. And if you can't talk to autistic individuals, find information that they are putting out there. Whether it's their research, their lived experience, their narratives. Just start learning from them.

STEPHEN SHORE:
Yeah. That makes perfect sense. If you want to know more about a community, in this case the autistic community, what better resource is there then the autistic community.

KAVITHA MURTHY:
I couldn't agree more. That's perfect. And even there are lots of podcasts these days, so I don't have one at the top of my head, but I can share that with you later. Matt.

KRISTIE PATTEN:
I would just add one thing in INSAR, which is the International Autism Research Conference. We have a couple of PhD students going. Stephen, are you going? I think Stephen might be going.

STEPHEN SHORE:
Yeah, yeah. I'm going. I have a poster on participatory research. And also, I'm on the panel for the early career seminar.

KRISTIE PATTEN:
So, when you have this big international conference, the things I pay attention to a lot of the research, but I really pay attention to research that is grounded in this perspective. And that is grounded in autistic representation, whether as authorships or significant representation in many different ways. And those are the things I actually kind of use as guideposts. And not as I think more OTS could be doing this kind of research. We have some OTS that are very well involved in participatory research with autistic individuals like Teal Benavides that Stephen mentioned, and many others but really pay attention to what research is including autistic representation in these large symposiums that the proceedings come out and you can look at all the abstracts.

MATT BRANDENBURG:
I love that, I love that we're gonna have to do a follow up interview and review some of that research from the conference. I'd love to hear more from you, Stephen, about your presentations. To conclude, today we end every show with the Golden Nugget segment, and I want to ask if you could share one last piece of advice or one last recommendation with our listeners. What would you say?

STEPHEN SHORE:
well. I'll start. It's important to recognize the wide diversity that we see within the autistic spectrum. And so, what I often say is that when you've met one autistic person, you've met one autistic person.

KRISTIE PATTEN:
I would say that's the best nugget. And a lot of people quote that and don't quote Stephen. And he was the first person that said that. So, thank you. I'm glad you said that, Stephen. I would say that we have a professional bias, and we came by it honestly. But understand your professional bias and try to do differently. But you first have to understand, and it's OK. It's OK. And really learn about ableism from a different perspective.

KAVITHA MURTHY:
And for me it is just keep learning and be open to learning because learning happens in very different situations. It doesn't have to be like a formal degree or something. Learning happens from the environment, especially as Kristie and Stephen highlighted. Talking to autistic people can really change your perspective. I would credit most of my initial push and passion into this field was from the people that I worked with. From the kiddos that I used to work with and what they would bring in and how I wouldn't have answers to those things at that point that try to motivate me to learn more.

MATT BRANDENBURG:
Thank you so much. This has been a wonderful conversation. It's important, it's informative, and I think it deserves a lot more attention. So, thank you all so much for your contributions to the practice guidelines and for what you've shared today. I really appreciate your time.

KRISTIE PATTEN:
Thank you. Thanks for having us.

STEPHEN SHORE:
Thank you. (CROSSTALK)

MATT BRANDENBURG:
It's been my pleasure. Thanks for listening to Everyday Evidence. Tune in next time for more evidence-based practice, insights and applications. (MUSIC PLAYS)