**Episode 6: What does it mean to be nonverbal?**

**HOST**: This is Autism Points of View by Autism Speaks. I’m Felipe Maya. In this episode we’ll talk about our understanding of nonverbal people with autism. Through research, we know that about 30 percent of people with autism are nonverbal, but the term “nonverbal” can mean something different for each person. Professor Connie Kasari, of the UCLA Center for Autism Research and Treatment.

**CONNIE**: One of the things we’ve learned over the past decade or so is that individuals really aren’t nonverbal, there are very few individuals who can make absolutely no sounds or have no communicative intent.

There’s a range of ways that people communicate. Sometimes with actually long scripts that they’ve learned from TV or from other situations. Most individuals can say some words. But they will also communicate in other ways, through gesture use and so on. So it’s probably not the case that people who are minimally verbal can’t say any words at all.

**HOST**: Some people on the autism spectrum who communicate using scripts or gestures still may have trouble finding a way to express complex ideas. But some do find a way

Tell me your name and a little more about you.

**PAUL**: My name is Paul Kotler and I go to Widener University. I am majoring in psychology.

**HOST**: As a child, Paul Kotler was nonverbal and some medical professionals even told his mom he was “intellectually disabled.” Then he began typing at 14 years old. His first words to his mom were, “I love you” and “trust me.”

**PAUL**: Yes. Sometimes people speak to me like I’m a child. Most nonspeaking autistics are mislabeled as cognitively impaired and referred to as “low functioning.” Low functioning is a common fallacy. It makes people reduced to failures. It allows people to assess and really dismiss people without any true understanding including the insights the person has and the obstacles that prevent the person from being able to participate.

**HOST**: Kristie Patton Kaenig, Chair and associate professor in the department of occupational therapy at NYU Steinhart.

**Kristie**: I think as educators and as professionals, when we hear the term nonverbal we assume a profile. I think what I've learned talking to a lot of individuals that have found a way to communicate that are non-speaking and now for example type independently, many of my assumptions were wrong. You know what if I could go back and say, “I'm sorry.” You know I get it now. I would do that you know. But as I grow as a professional and in my research and in my career that I think is to me a fundamental “do no harm” proposition. Talking to you as if you can understand as a medical professional or as a healthcare professional, even if you’re not responding versus “I’m talking about you in front of you,” which we do all the time right? Which one should I choose? And I think that choice can be very powerful for that individual whether or not you feel like they’re getting it.

**PAUL**: Treat nonverbal people as totally intact in every way. Show patience and understanding without patronizing. Talk to us like peers. Everyone deserves dignity. No matter what a person acts like outside, they may just be unable to share their inner thoughts with you. I’m a living example; the behaviors I demonstrate outwardly have nothing to do with my intellect. In reality, there are full, complex people trapped within until they find a way to communicate.

**HOST**: Professor Koenig has worked with Paul for years. I could tell he was excited to see her again – every so often during our interview, he would smile and say her first name – Kristie.

**KRISTIE**: Oh Paul, Paul I met when he was 14 and I think that's right when he started typing independently so he’s someone that really when I met him he was communicating and he was communicating a lot.

**PAUL**: I have apraxia. It is slow getting each correct sound very clear because my mouth muscles can’t move fluently. I cannot naturally always get the right vocabulary when I talk. Typing allows me to always say exactly the same thing I’m thinking. Being autistic makes connecting with others more challenging because I can’t very naturally have a very normal conversation.

**HOST**: When I met Paul, he didn’t shake my hand or wave at me, he just walked right past me to look out the window at the busy NYC street.

He really loves being in the city because of the sensory input he gets from the traffic and crowded sidewalks.

**PAUL**: It seems like Greenwich Village, in New York City, would be an overwhelming sensory experience but lands me in a sensory calm place. So much traffic and many vehicles to look at. Cabs sound different than trucks. Sometimes I can even hear a bike coming. Lots of mechanical noises to keep me focused. I don’t care about the crowds because of it. I can find that I get lost in the crowd and no one notices that I move differently or act differently because there are so many around.

**KRISTIE**: I remember going in one day we got out a big piece of paper like “what do you want in your life like what.” He can clearly communicate, non-speaking types to communicate. And we just started mapping out what he wanted and what strengths he had in order to get there. And you know I think for so many young adults, adolescents/young adults and adults that are autistic, the way the system is designed, and I'm going to say special education and therapy related services, the way the system is designed is to work on your remediated weaknesses. Right? And no one builds their lives on remediated weaknesses. You don't. I don't. We don't build our lives on our remediated weaknesses. Yet systems are set up to really just focus on that and that alone and not that weaknesses and challenges shouldn’t be addressed they absolutely should. But there's got to be a parallel process deeply integrated I would say deeply embedded about the strengths and abilities and talents. You know because I think it's a crime if someone gets to the age of 21 and they have no idea what they're good at.

**PAUL**: For me shifting an emphasis to strengths saved me in better accepting myself. It was very powerful and motivating having confidence I could accomplish meaningful, heartfelt goals, and I could get supports instead of focusing on my deficiencies.

**CONNIE**: I think this term, this kind of coined term, “optimal outcome,” referred to individuals that really didn’t look like they had autism. So an optimal outcome was an individual with IQ in the typical range, going to a regular school, acting like every other child in the classroom and not showing any symptoms of autism. And of course, that happens, our kids fit in and can do well in a general educational program. Optimal outcome, however, is broader than that. So I think optimal outcome really has to do with where you start. Our interventions need to be so much more personalized and diversified.

**HOST**: There is a popular saying in the autism community by Autism Speaks board member and Adelphi University Professor Stephen Shore, “If you’ve met one person with autism, you’ve met one person with autism,” meaning no two people on the autism spectrum are the same – each has a unique combination of strengths and challenges.

**PAUL**: Learning to type has allowed me to communicate, share ideas, go to college, and teach people about autism. Before I developed my typing skills I could listen but not express myself in a complex way. That is why even though typing is exhausting and makes me anxious, I do not take it for granted. Without writing, my life wouldn’t be as exciting and would be much more limited. Writing is a powerful tool for anyone who wants to express themselves.

**HOST**: Paul is one of the most interesting people I’ve ever met. He works hard on his challenges every day and he has this invaluable insight into the world around us that needs to be heard.

**PAUL**: Overall, I want people to know that I am a normal guy who just happens to communicate differently than the vast majority of people, a guy who has different ways of dealing with the great amount of sensory input that is found naturally in the environment and a guy who has lots to say if people take the time to listen.

**HOST**: All the answers you’ve heard from Paul so far were typed ahead of our interview. Paul types one letter at a time so it takes him a little while to compose a full answer. But I was able to ask him some follow up questions in person, then, waited for him to type his replies.

The final question I asked him was “What advice do you have for parents of nonverbal or nonspeaking children with autism?”

**PAUL**: Know that your children hear you, treat them as you would your other children. Talk about everything and know that even though they may not appear to understand, they do.

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