

Title: How we talk about autism

Felipe Maya:

This is Autism Points of View by Autism Speaks. I'm Felipe Maya

There are always topics in any community that aren't universally agreed upon and the autism community is no different. Because autism is considered a "spectrum disorder," that means that each person on the spectrum largely has an experience uniquely their own.

Some have incredible intelligence and talents that they can turn into a career, while others struggle to find ways to express their wants and needs. Some are able live fulfilling independent lives while others require round-the-clock life-long care.

When I speak about a person's strengths, I just want to make clear that even though someone with autism may have many talents, that doesn't mean they don't have challenges as well. The same goes for those with profound challenges, it doesn't mean they don't also have great strengths.

Then there are the family members and friends who see autism through their loved ones' experience. The autism community also involves a large network of professionals like educators, therapists and researchers.

I could go on about the diversity of the autism community but the point is, all experiences should be respected.

One topic that often quickly turns into a debate is how we talk about autism. There are two ways we typically do this, they're called "person-first language" and "identity-first language."

Person-first language does just that, it separates the person from their diagnosis, so you would say "I have autism" or "my son or daughter has autism." Identity-first language makes the diagnosis a part of the person's identity, so you would say "I am autistic" or "My son or daughter is autistic."

In this episode you'll hear from a variety of perspectives throughout the autism community, from autistic adults to parents and professionals.

Let's start by breaking this topic down a bit more with Adelphi University professor and Autism Speaks Board Member, Dr. Stephen Shore.

Stephen Shore:

There are some factions in the autism community. One of those areas of division is actually person versus identity-first language. So for example, I consider myself as an autistic individual that's identity-first language. So those of us who do use

identity-first language. We feel that autism colors every aspect of our lives. But at the same time it's not all who we are in considering that autism isn't a bad thing. It just kind of is. Then why not just be autistic as opposed to person-first? Now getting to person-first language, there's a number of reasons that people prefer a person first language and that is to honor the person's humanity first, recognize that individual as a person who happens to have something.

Originally people did use identity-first language but you might say for the wrong reasons and we'd hear medical profession and educators talk about the retardate in room 201 for example which was a very disrespectful way of talking about people who we now term as having intellectual disabilities. The R-word is disappearing otherwise known as retardation because it has gained so much stigma that it's really not usable anymore.

Felipe Maya:

In 1974, the first self-advocacy conference was held in the US. During the conference, a man spoke about being labeled as mentally retarded, the diagnosis at the time for anyone with an intellectual disability, his words sparked a movement. He said, "I want to be known as a person first."

Robert Naseef is a Clinical Psychologist and author and he experienced this cultural shift first-hand. His son Tariq was diagnosed with autism and intellectual disability in 1984 when he was 5 years old.

Robert Naseef:

I'd say when my son was born person-first language was just kind of coming in I Think, and it was a relief to me because of how stigmatizing the identity language was because since he had cognitive disability he was called retarded. So that kind of horrified me and the person first-language which celebrated his humanity was a relief.

Felipe Maya:

Tariq is now 39 and nonverbal, meaning he doesn't speak but he's able to communicate his needs and wants in other ways.

And while growing up he was never able to let his dad know how he would like to identify, Robert formed his opinion from his involvement in the autism community.

Robert Naseef:

Things started changing and I started understanding him better and the world of autism and special needs better. I've come to prefer identity-first language and i've learned a lot of that and I've been influenced by the self-advocates. We don't talk about people as being a person with Italianism or a person Arab Americanism such as myself. We talk about how we can't really separate ourselves from our identity questions. Autism isn't really separable from the person and yet not every person

with autism prefers identity-first language and I think that's fine. I think we need to respect everyone and that's really the main thing. Language does play a role in societal attitudes. What I've come to see is that people in groups such as the autistic, the blind, and deaf tend to prefer identity-first, whereas people in the parent and professional groups tend to the person-first although that's changing over, you know, probably right as we speak.

Felipe Maya:

Many autistic advocates in the neurodiversity movement prefer identity-first language. The concept of neurodiversity was first introduced in the late 90s. It views autism not as a disorder but as a natural genetic variation.

But just like Robert's son, Tariq, not all people with autism are able to express how they would like to identify. Amy Kelly is a family and community services Director and mom to 17-year-old Annie, who has autism and intellectual and developmental disabilities.

Amy Kelly:

I prefer a person-centered language or person-first language. As a mother, I prefer that, so my daughter is profoundly affected by autism and has limited language and verbal skills, but she communicates well with her iPad but I'm essentially her outward voice. I noticed years ago after her diagnosis, people didn't really know how to talk about autism around her or even ask the questions. I just found I was getting almost offended when they would say, well she's autistic. And I thought, gosh you know Annie is so much more than her autism. And that's sort of what started me as a parent understanding that. And then in my professional role I had to learn much more about language around disabilities. And I have found that I'm much more comfortable and prefer and model person-centered language.

Amy Kelly:

Just like autism is very different in every person. I think every person has their own opinion about this especially if they are someone that can speak about having autism and self-advocate. It's totally their right to call themselves autistic.

Felipe Maya:

A 2015 UK study published in the journal, Autism, of nearly 35-hundred people with autism, their family members and friends, as well as professionals showed that autistic people and their loved ones largely preferred identity-first language.

Here's Brigid Rankowski, autistic educator and circus performer.

Brigid Rankowski:

Well I know a few people who are people living with autism because they've decided to name their cat autism, so they are living with autism. But as someone who jumps in the professional, personal spheres and stuff, I'm very well versed in this topic and

I am autistic. It's part of my identity. I view the world through the autism lens and what other people have sometimes brought up is look at the number of words people sometimes place between the word person and autism and think about that distance and understanding that yes we are all people but some of us are autistic and there is nothing wrong with it. I think I've seen a lot of parents and professionals who even fight me for how I refer to myself. And that goes along with the gender lines of...OK but this is how a person is choosing to identify and it's important to respect that. I choose to use identity-first language because that's how I identify. It's part of my identity. When I do presentations and speeches I'll sometimes switch between the two purely because that's how my brain works and it's a jumble. But I see a lot of parents and professionals advocating for a person-first language and although that has been on the textbooks for a while, again with the advocacy movement in some ways starting with the parents and professionals. That was awesome. And now it's time to hand the torch over to the self-advocates and say, "All right how do you want to be referred to? Who are you?" And I still think with the best of intentions sometimes people place the onus on what this is how I want to view you and understanding, especially in the autism world, that autistic people are stepping up now and saying we want to live our lives this way. We are in control of our lives. We can live independently and let us identify as autistic. I think I've seen both sides of the topic. I'm taking classes on it. I've gotten my papers written on because I refer to autistic people instead of people with autism. I will take those points off and submit articles in response by my peers because again it's a community perspective.

Felipe Maya:

According to Kristie Patten Koenig, Chair and associate professor in the department of occupational therapy at NYU Steinhart, students are being penalized for using identity-first language and are taught to solely use person-first language but she says she would like that to change.

Kristie Patten Koenig:

We've had situations where whether it's a journal or professional conferences have wholesale rejected things because the professional used identity-first language.

Well my take is as a professional right. I grew up in my profession which is occupational therapy learning person first-language. Right? It's more respectful and you can see why that was important.

But as I've grown as a researcher and an educator, my feeling is that you ask the person, you ask the person and you really don't assume that one is going to be better than the other. You know and I think that as professionals we're trained person-first, person-first, person-first you know but I think identity-first language is really important because who is the first language coming from, autistic individuals, you know. They don't feel like autism is something they can put aside. They're not

someone with autism just like a person isn't someone with deafness, they're a deaf person, they're an autistic individual.

If you're a professional body and you're saying no we're going to decide what you're going to call yourself, you should be called person-first. You know, that doesn't show respect and doesn't show kind of the evolution of what's happening in the disability community.

Felipe Maya:

Since its founding in 2005, Autism Speaks has had a policy of using person-first language following the recommendation of medical professionals and educators. But last month, we decided to survey our community on social media.

We conducted a poll of our Facebook, Twitter and Instagram followers. In just 24 hours, it received more 21 thousand votes. It was clear... this topic is important to the community. The results were that 69 percent of voters said they preferred identity-first language and 31 percent said they prefer person-first language.

As a result of this feedback, moving forward, Autism Speaks will be using both person-first and identity-first language. Of course, first and foremost we recommend asking the person what they prefer and to respect that.

So if you're subscribed to this podcast, following Autism Speaks on social media or see a future press release about an upcoming campaign, you may see us talk about children with autism or autistic adults.

There are so many important issues facing the autism community that need attention and support but perhaps this topic will become less of a divisive one. Here's Valerie Paradiz, Autism Speaks Vice President of Services and Supports.

Valerie Paradiz:

I find it a distraction. For me and all the years I've been involved in this and it's just when you can't agree to disagree which I don't think anyone ever will, and that's okay. That to at least allow anyone to choose what they wish is probably again the best one can do. For me personally, I use everything interchangeably because for me I care more about acknowledging others than I do about how I represent myself. But that's because I work in this field so I care that people are passionate about it. I understand that people have different wishes. I also like to ask how do you want to be referred to. How does your child want to be referred to as, have you ever asked your child, have you ever informed your child or loved one that there are options. You know I think acknowledging that it's a big question and important is critical. But I feel that the time and space that used to tell others that they're wrong or you know expect others to change in an environment well even that mirrors our own political environment in the country right now. People aren't going to agree to disagree. So

let's turn our focus on something else that can you know move us forward and other in other ways within our community because so much work needs to be done still.

Stephen Shore:

So, getting back to the history. So, we started with inadvertently I would think identity first language and then people were being identified by their conditions whatever they were and it seemed to be kind of a rude way of referring to a person, which is why we then saw the rise of Person first language and it made a lot of sense because we needed to respect people as individuals. We needed to respect their humanity. However, I think we have evolved to a point where we can see autism as a part of humanity. Autism is a part of the diversity of the human gene pool. Now that said, as we talk about the abilities of autistic individuals we do have to keep in mind that there are significant challenges that come with being on the autism spectrum. If those challenges didn't exist, we wouldn't have Autism Speaks and we'd all be doing something else. So we do have to address those challenges. We have to lower barriers so that the abilities of autistic individuals can shine through.

Felipe Maya:

I want to leave you with Paul Kotler's take on this topic. Paul is the non-speaking college student we featured in Episode 6 who doctors thought was intellectually disabled until he learned to type. I asked him how he wants to be referred to and his answer was short and sweet.

Paul Kotler:

I prefer Identity-first language. I agree that each individual should be asked. I have used both.

Felipe Maya:

Thank you for listening to this episode of Autism Points of View. Make sure to subscribe wherever you listen to podcasts to get future episodes as soon as they're released. If you have a topic you would like us to cover, email us at connectwithus@autismspeaks.org.

Visit our website at autismspeaks.org/podcast for past episodes and resources. This episode was written and produced by me and edited by Dax Schaffer with original theme music by Dustin Gledhill. I'm Felipe Maya, thanks for listening.
