

Things to understand about autism

It can refer to a range of many conditions

Lauren Peace

Rochester Democrat and Chronicle USA TODAY NETWORK

What is autism?

According to Autism Speaks, a national autism advocacy organization, “Autism, or autism spectrum disorder, refers to a range of conditions characterized by challenges with social skills, repetitive behaviors, speech and nonverbal communication, as well as by unique strengths and differences. We now know that there is not one autism but many types, caused by different combinations of genetic and environmental influences.” In 2013, Autism Spectrum Disorder became an umbrella diagnosis for what were formerly distinct diagnoses, including autistic disorder, childhood disintegrative disorder, pervasive developmental disorder-not otherwise specified (PDD-NOS) and Asperger syndrome.

While some adults still identify as having the above diagnoses, medical professionals no longer diagnose patients as having Asperger syndrome, for example, instead assigning a diagnosis of ASD.

Understanding the spectrum

For years, when classifying people as autistic, the language would group them into one of two categories: low functioning and high functioning.

The reality is that an autism diagnosis isn't that black and white.

“A lot of people think of a spectrum as a line, but that's just wrong,” said Rachel Rosner, director of education and support for AutismUp, a Rochester-based autism support organization. “A spectrum is a circle. There's no top, there's no bottom, there's no low-functioning, there's no high-functioning. You're just somewhere on there. And as the circle turns, maybe you're up on the top, maybe you're down on the bottom. It might depend on the day, the moment.”

In simplified terms, autism is incredibly diverse in the way it impacts those diagnosed.

A person with autism could be nonverbal ... but have a PhD in astrophysics. Another person might have trouble with sensory regulation or social skills, and depending on the environment these difficulties may be prominent to a greater or lesser degree.

What language should you use?

Being politically correct with your language can be a challenge if you lack familiarity with the subject matter.

When talking about Autism Spectrum Disorder, a common question that comes up is “how should I refer to somebody with autism?” The answer varies.

“You're going to want to try to interchange using the phrase ‘people with autism’ with ‘autistic people,” said Rosner. “They don't typically like person first language, because you really can't separate somebody's autism from them as a person. It's a part of their neurology and who they are, so it's not like having cancer.”

People without autism should be referred to as neurotypical, *not* “normal.” People with autism and other umbrella disorders are neurodivergent.

At the end of the day, finding out the individual preference of the person you're communicating with may be best, as it may vary from person to person. There is no universal rule.

What's special about Rochester?

A combination of advanced medical research and care, state-funded programs and community partnerships make the greater Rochester area a magnet community for families with autistic children.

The Autism Treatment Network comprises 13 sites across North America, including the University of Rochester Medical Center with the Levine Autism Clinic at the Golisano Children's Hospital. These sites serve as leaders in clinical research and treatment specific to the needs of families of children with autism.

New York state offers free early intervention therapies for infants showing early signs of need, as well as greater support programs for people with developmental delays than most other states, while community partnerships in greater Rochester provide a unique emphasis on supporting the needs of the whole family, not just the child.

The opening of the Golisano Autism Center in 2019 will further define Rochester as a leader in autism-specific care. The revolutionary center is expected to include shared a sensory gymnasium, classrooms and therapy rooms and more, all in a location central to Monroe County to make the services accessible to more families.

It takes more than awareness.

April was National Autism Awareness Month, but members of the autism community say that awareness is insignificant without advocacy and acceptance.

"It's one thing to know that autism exists. It's another thing to accept that autistic people are in your community and school," said Rosner.

"It's another thing to really understand and respect their right to be in the same places that you are, and not just to understand that and let them be over there doing their own thing, but to welcome them in."

LPEACE@Gannett.com



Rosner