Autism FAQ for Seneca Staff

Table of Contents

- 1. What is neurodiversity?
- 2. What is Autism?
- 3. Is Autism a disability?
- 4. Is Autism an intellectual disability?
- 5. Who should I trust when it comes to information about Autism?
- 6. What is the proper way to refer to someone Autistic?
- 7. Can Autism be cured?
- 8. Is Autism more common now than it used to be?
- 9. Which types of therapy are harmful and which types are helpful for Autistic people?
- 10. What are good ways for co-workers and supervisors to support Autistic staff?
- 11. What is "mental age" and is it accurate?
- 12. Are functioning labels appropriate?
- 13. Is Autism more common in boys and men?
- 14. Is Autism more common in white people?
- 15. How do Autistic people communicate?
- 16. Do vaccines cause Autism?
- 17. <u>Does Tylenol cause Autism?</u>
- 18. Why is the puzzle piece sometimes used to represent Autism and why is it problematic?

Additional Resources

1. What is neurodiversity?

"Neurodiversity means that no two brains are exactly the same. Every person has things they are good at and things they need help with, and there is no such thing as a "normal" brain." However, society is generally designed to accommodate only some types of brains, which often makes navigating the world difficult for people whose brains diverge from the imaginary norm. Many folks whose brains diverge from the norm that people expect identify as "neurodivergent" and often experience their neurodivergence as a disability. Those with typically developing brains are often referred to as "neurotypical."

"The neurodiversity movement says that people with brain-based disabilities (like Autism, intellectual disabilities, learning disabilities, or mental health disabilities) should be accepted and included in society just like neurotypical people (people without brain-based disabilities)." ¹

A foundational belief of the Disability Justice Movement is that people with disabilities should not have to change to fit within society, but rather, society should change to be more inclusive of all different types of abilities and brains.

Terminology note: a single individual may be "neurodivergent" and a group of people may be "neurodiverse."

¹ Autistic Self Advocacy Network

2. What is Autism?

Autism is a neurodevelopmental disability that impacts an individual's nervous system, which includes the brain. "It affects many things about the way we learn, move, communicate, and experience the world. Disability is a natural part of human diversity."

While everyone experiences Autism differently, here are some common themes as described by the Autistic Self Advocacy Network (ASAN):

a) We think differently. We may have very strong interests in things other people don't understand or seem to care about. We might be great problem-solvers or pay close attention to detail. It might take us longer to think about things. We might have trouble with executive functioning, like figuring out how to start and finish a task, moving on to a new task, or making decisions.

Routines are important for many Autistic people. It can be hard for us to deal with surprises or unexpected changes. When we get overwhelmed, we might not be able to process our thoughts, feelings, and surroundings, which can make us lose control of our body.

- b) We process our senses differently. We might be extra sensitive to things like bright lights or loud sounds. We might have trouble understanding what we hear or what our senses tell us. We might not notice if we are in pain or hungry. We might do the same movement over and over again. This is called "stimming," and it helps us regulate our senses. For example, we might rock back and forth, play with our hands, or hum.
- c) We move differently. We might have trouble with fine motor skills or coordination. It can feel like our minds and bodies are disconnected. It can be hard for us to start or stop moving. Speech can be extra hard because it requires a lot of coordination. We might not be able to control how loud our voices are, or we might not be able to speak at all-even though we can understand what other people say.
- d) We communicate differently. We might talk using echolalia (repeating things we have heard before), or by scripting out what we want to say. Some Autistic people use Augmentative and Alternative Communication (AAC) to communicate. For example, we may communicate by typing on a computer, spelling on a letter board, or pointing to pictures on an iPad. Some people may also communicate with behavior or the way we act. Not every Autistic person can talk, but we all have important things to say.
- e) We socialize differently. Some of us might not understand or follow social rules that non-Autistic people made up. We might be more direct than other people. Eye contact might make us uncomfortable. We might have a hard time controlling our body language or facial expressions, which can confuse non-Autistic people or make it hard to socialize.
 - Some of us might not be able to guess how people feel. This doesn't mean we don't care how people feel! We just need people to tell us how they feel so we don't have to guess. Some Autistic people are extra sensitive to other people's feelings.
- f) We might need help with daily living. It can take a lot of energy to live in a society built for non-Autistic people. We may not have the energy to do some things in our daily lives. Or, parts of being Autistic can make doing those things too hard. We may need help with things like cooking, doing our jobs, or going out. We might be able to

do things on our own sometimes, but need help other times. We might need to take more breaks so we can recover our energy.

Not every Autistic person will relate to all of these things. There are lots of different ways to be Autistic. That is okay!² It is important to understand that whatever Autistic traits a person exhibits, they arise from an attempt to navigate the world and relate to others in ways that feel safe, comfortable, and accessible, just like we all do. An Autistic person who is not behaving in neurotypical ways is not being defiant or lacking an understanding of how to behave. Autistic behaviors often help to soothe the nervous system, make sense of a confusing world, and process overwhelming information. Unless their behaviors are dangerous to themselves or others, Autistic people should be accommodated and accepted how they naturally behave, not bribed, punished, or incentivized to behave in neurotypical ways, which can lead to long-term physical and mental health problems.

3. Is Autism a disability?

Autism is considered a developmental disability. However, not every Autistic person identifies as disabled. This speaks to the wide range of ways people experience Autism and how "disability" itself is defined.

Here is just one way of thinking about disability from neuroscientist Dr. Debra Bercovici who identifies as AuDHD (co-occurring Autism and ADHD) and disabled:

"I view being disabled/disability through the lens of the social model of disability. This means that I view disability as something that is largely dependent on society and the systems that are in place. To me, we are disabled if our needs are not being met in the current system. If society were more inclusive and accessible, then our needs would be met and many of the challenges we face would be supported. This does not make us any less Autistic, or a deaf person suddenly able to hear, but it means that we would be able to more easily navigate in society. Would disability be a thing if society were truly inclusive and accessible? If it really is the social construct I believe it to be, then I am tempted to think it would not!" 3

When working with an Autistic client and their family, you can use the word "disability" to help them understand the need for access to supports. However, because of social

¹ Autistic Self Advocacy Network

² <u>Autistic Self Advocacy Network</u>

stigma, some families may reject the use of this word. Ultimately you should allow space for the youth and family to use whatever terminology they want to use, whether "disability," "neurodivergence," "condition," "special need," or something else.

4. Is Autism an intellectual disability?

"Autism and intellectual disability are not the same thing. Intellectual disabilities affect how you learn and think. People with intellectual disabilities might learn more slowly, and they might need more help with everyday life. People with intellectual disabilities do learn and think, just differently.

Some Autistic people also have intellectual disabilities, but most Autistic people don't. There are a lot of different ways to be Autistic!" ⁴

5. Who should I trust when it comes to information about Autism?

"As Autistic people, we know more about Autism than anyone else. We know the problems that Autistic people face and have lots of ideas about how to solve them. Some non-Autistic people say they are "Autism experts," and try to make policies about Autism without talking to Autistic people ourselves. These policies usually don't help us, and sometimes even make things worse for us. That is why Autistic people have to be involved in making policy." ¹

Additional trusted resources are listed at the end of this document.

6. What is the proper way to refer to someone Autistic?

"In the Autism community, many self-advocates and their allies prefer terminology such as "Autistic," "Autistic person," or "Autistic individual" because we understand Autism as an inherent part of an individual's identity — the same way one refers to "Muslims," "African-Americans," "Lesbian/Gay/Bisexual/Transgender/Queer," "Chinese," "gifted," "athletic," or "Jewish."

³ Embrace Autism

⁴The Autistic Community

¹ Autistic Self Advocacy Network

You would think we would support the use of person-first language, because we want to be seen as people with equal rights, value, and worth to non-Autistic people. But we don't. Because when people say "person with Autism," it *does* have an attitudinal nuance. It suggests that the person can be *separated* from Autism, which simply isn't true. It is impossible to separate a person from Autism, just as it is impossible to separate a person from the color of his or her skin." ⁵

You should attempt to use appropriate clinical terminology and *avoid* euphemisms such as "person on the spectrum," "your superpower," or "highly sensitive child." Again, individual clients and their families may have other preferred ways to refer to themselves, which is OK.

⁵ Lydia Brown

7. Can Autism be cured?

No, Autism is not a disease that can be cured. It is simply a part of neurodiversity. Even if it could be cured, "most self-advocates agree that Autism doesn't need to be cured. Instead of wasting time and money on something that isn't possible and that Autistic people don't want, we should focus on supporting Autistic people to live good lives." ¹

"The goal of a cure is to 'fix' something, and Autistic people don't need to be fixed." 4

8. Is Autism more common now than it used to be?

No, Autism is not becoming more common than it used to be, we are just learning more about Autism and how to properly identify it.

"Autistic people have always been in the world. People say that there are more Autistic people now than there used to be, but this is not true. Doctors are just getting better at finding us.

In the year 2000, doctors said that about 1 in 150 people were Autistic. Right now, they think 1 in 59 people are Autistic. This isn't because more Autistic people are being born. It's because doctors are getting better.

¹ Autistic Self Advocacy Network

⁴The Autistic Community

Doctors still aren't perfect. They miss some Autistic people, like girls and people of color. Doctors are trying to get better at figuring out who is Autistic. That means the number of diagnosed Autistic people might keep going up. This is a good thing, since it means more Autistic people can get the help we need." ⁴

9. Which types of therapy are helpful and which are harmful for Autistic people?

"Many therapies can be helpful for Autistic people, like physical therapy, speech therapy, occupational therapy, and AAC" (Augmentative and Alternative Communication).

"But there are some therapies that focus on making Autistic people seem "normal" or appear "less Autistic". The most common type of this therapy is Applied Behavioral Analysis (ABA). ABA uses rewards and punishments to train Autistic people to act non-Autistic. ABA and other therapies with the same goals can hurt Autistic people, and they don't teach us the skills we actually need to navigate the world with our disabilities. Sometimes people say they use ABA to work on other skills, like communication. There are better ways to teach those skills.

ASAN does not support any one kind of therapy for Autistic people. Different things will work better for different Autistic people. The most important thing is that any therapy should help Autistic people get what we want and need, not what other people think we need. Good therapies focus on helping us figure out our goals, and work with us to achieve them." 1

In general, behaviorally-based interventions are not helpful for Autistic clients, for the reasons described above. Attempting to get Autistic clients to change their natural behaviors is likely to cause greater nervous system dysregulation. Further, many fears and anxieties experienced by Autistics are actually factual and based in reality and should not be treated as cognitive distortions as is common in many kinds of talk therapy. Therapies that some Autistic people have identified as helpful include animal-assisted therapy, art therapy, somatic therapy, Acceptance and Commitment Therapy, and play therapy. The goal should be to help Autistic clients experience a greater understanding and alignment with their inner selves, soothe their activated nervous systems, and achieve their goals, not to change them into someone they are not.

⁴ The Autistic Community

¹ <u>Autistic Self Advocacy Network</u>

10. What are good ways for co-workers and supervisors to support Autistic staff?

Having a workplace, supervisor, and co-workers who understand and account for the needs of Autistic staff makes life easier for everyone on the team! Since every Autistic person's experience is different, it can be helpful to ask the person directly how you can best support them in the workplace. However, here are some common practices to create a more neuro-inclusive workplace ⁶:

- Address varying sensory experiences by accounting for lighting, noise, and other sensory input. Things like bright fluorescent lights, distracting sounds in the work environment, or uncomfortable seating can contribute to overstimulation.
- Another way to avoid overstimulation is to allow for decompression breaks before and/or after meetings, and throughout the day.
- Sending agendas or talking points ahead of meetings can be helpful.
- As a supervisor or collaborator on a project, you can ask the Autistic staff member how they want to tackle a task in a way that complements their working style.
- As a supervisor, providing step-by-step, written instructions can be helpful.
- As a co-worker or supervisor, be open to different communication styles. To avoid miscommunications, be direct, don't expect Autistic staff to read between the lines, and check for understanding. Be open to the possibility that you may have incorrectly interpreted a staff member's communication, and ask for clarification or confirmation when necessary.
- Be open to learning about Autism and neurodiversity, challenging your negative and positive assumptions.

⁶ Association for Autism and Neurodiversity

11. What is "mental age" and is it accurate?

"People use mental age when they talk about developmental disabilities. Adults with developmental disabilities need help with a lot of things. Some of those are things that most kids can do by themselves, so people say that in our minds, we are like kids.

Some Autistic people have interests that usually only kids have. We might also talk like kids do, or play in the same ways that kids play. People might say we are like kids, but these people are wrong.

For example:

Beth is 36 and has an intellectual disability. She does not know left from right, and she really likes Blue's Clues. A doctor says that Beth is like a 5-year-old, and says she is "mentally 5." This doesn't make sense, since Beth has been alive for 36 years. Her brain is not like a 5-year-old's brain, and it is rude to say that she is like a child.

Being a kid isn't about what you can and can't do, or about how you talk or play. Neither is being an adult. You learn and grow every year you are alive. People are the age they are, and mental ages aren't real. Autistic adults don't have the minds of kids. We have the minds of Autistic adults, and Autistic adults with intellectual disabilities are still adults.

Autistic people can do anything that any other adult can do. Autistic people can have sex, get married, have kids, make our own choices, and live our lives. We might do things differently than non-Autistic people, and we might need more help. But we are still adults." ⁴

⁴ The Autistic Community

12. Are functioning labels appropriate?

"ASAN doesn't use labels like "high-functioning" and "low-functioning". Functioning labels aren't a good way to think about Autism. We all have things we are good at and things we need help with. Using functioning labels makes it harder for us to get the help we need, and for us to make the choices we want. Instead, we should talk about people as individuals. Talk about what someone is good at, and what they need help with. This makes sure we can get what we need." ¹

While some Autistic people may appear better able to "function" within the unspoken neurotypical rules of society, this typically means they are just trying harder to hide their

traits and behaviors from you. "Masking" is a common trait among Autistic people because they have been punished and bullied for being themselves. They may have learned to blend in and look "functional" but this does not mean they are not experiencing internal distress. In fact, while the rate of suicide among Autistic people is 7x that of neurotypical people, it is highest among people who may be labeled "high-functioning" because they are often receiving the least amount of support. A better way to conceptualize differences among Autistic people may be "high-support needs," and "low-support needs."

¹ Autistic Self Advocacy Network

13. Is Autism more common in boys and men?

"Right now, more boys and men get diagnosed with Autism than girls and women. Boys are diagnosed with Autism about 3 times as much as girls, but that doesn't mean that there are more Autistic boys than Autistic girls.

The tests doctors use to diagnose Autism were made just by looking at boys. Doctors decided what Autism means by looking at boys, so a lot of Autistic women and girls get left out. They are Autistic, but doctors don't notice.

Plus, Autistic people are lots of different genders. There are more genders than just boys and girls, but nobody is counting people who aren't boys or girls.

Since we are missing so many people, the Autism diagnosis numbers are wrong. We don't know what the real numbers are, but we do know that people of all genders can be Autistic." ⁴

⁴ The Autistic Community

14. Is Autism more common in white people?

"Anyone of any race can be Autistic. Because of racism, white people get diagnosed with Autism more than people of color. But people of color are Autistic just as often as white people.

The tests doctors use to diagnose Autism were made just by looking at white boys. Doctors decided what Autism means by looking at white boys, and they didn't think about Autistic people who aren't white boys. That's why people of color get diagnosed with Autism a lot less. They are Autistic, but doctors don't notice. Now, doctors are

starting to notice more, but people of color still don't get diagnosed as often as white people.

Autistic kids of color might not get diagnosed with Autism, or they might get diagnosed with other disabilities instead of Autism. For example, they might get diagnosed with an intellectual disability, or a mental health disability. A lot of times, the diagnosis is wrong! Doctors have wrong ideas about people of color, so they diagnose people of color with other disabilities instead of Autism. This isn't fair!

People of color should get the right diagnosis. Everyone should know that people of color can be Autistic, and that people of color are part of the Autistic community." ⁴

As service providers, it is important for us to understand that this historical misdiagnosis and under-diagnosis of girls and children of color often has a selfperpetuating effect. White boys who are Autistic tend to be over-represented in media and popular culture, leading to a stigma among families with children of other genders and cultural backgrounds who believe that their child couldn't be Autistic.

15. How do Autistic people communicate?

"Communication is a human right. Not every Autistic person can talk, but every Autistic person communicates in our own way. Some Autistic people need support to communicate, like Augmentative and Alternative Communication (AAC). AAC is a way to communicate without talking, like using picture cards, a letter board, or typing on an iPad. Autistic people need to get communication supports right away, no matter what other things we can or can't do. People should never have to "earn" the right to communication supports. We need to make sure AAC is available for all Autistic people, and that Autistic people are supported to communicate in the way that works best for them." ¹

Some Autistic people may be able to communicate verbally some days and unable to communicate verbally on other days. This does not mean they are faking or being defiant, merely that their brain and nervous system experiences different states of being overwhelmed and overloaded, which can shift depending on whether their needs are being supported on any given day.

⁴ The Autistic Community

¹ Autistic Self Advocacy Network

16. Do vaccines cause Autism?

Vaccines do not cause Autism.

"In 1997, a scientist named Andrew Wakefield lied and said that vaccines caused Autism. Lots of scientists proved him wrong, and showed that Autism is not caused by vaccines. But some people still believe vaccines cause Autism. They don't give their kids vaccines since they think it is better for their kids to get sick than to be Autistic. It hurts Autistic people to hear that other people are so scared of us.

It is safe to get vaccines, and vaccines keep people from getting sick. If people weren't so scared of Autism, they would be calm about vaccines. That would be better for everyone.

We don't always know what makes people Autistic, but we do know that Autism is mostly genetic.

In the end, what causes Autism doesn't matter very much. What matters is supporting Autistic people. We should be able to have good lives no matter what." ⁴

⁴ The Autistic Community

17. Does Tylenol cause Autism?

There is currently no proven casual link between Tylenol use in pregnancy and Autism. 7.8

In fact, Tylenol (Acetaminophen) is one of the few safe options to reduce fever during pregnancy, and "untreated fever in pregnancy can pose serious risks to the fetus and to the mother." ⁸

⁷ Jama

⁸ UC Davis

18. Why is the puzzle piece sometimes used to represent Autism and why is it problematic?

The puzzle piece was created in the 1960s as a symbol of Autism by neurotypical people who believed that Autism is a puzzling and tragic disease. It was popularized by the group Autism Speaks, an ableist organization that has called Autistic people

"burdens" and "tragedies," claiming that those afflicted with the "disease" of Autism "live behind a wall" and are "[robbed] of their dreams."

"[Most] Autistic people reject the puzzle piece symbol for multiple reasons, but the main reasons are that it is infantilizing, it promotes the mentality that Autistic people are incomplete or are missing puzzle pieces, and it treats Autism as a disease that needs to be "treated" or "cured."

Better symbols for Autism include the Neurodiversity rainbow infinity loop or the symbol for "Autism acceptance rather than awareness." ⁹

⁹ In the Loop About Neurodiversity

Additional Resources

Autistic Self Advocacy Network (ASAN): https://Autisticadvocacy.org/

Embrace Autism (information by Autistics for Autistics): https://embrace-autism.com/

Academic Autism Spectrum Partnership in Research and Education (ASAN is a part of): https://aaspire.org/

AANE (Autistic people on the staff and board): https://aane.org/

In The Loop About Neurodiversity (created by Autistic SPED teacher): https://intheloopaboutneurodiversity.wordpress.com/

ASAN's book for parents of Autistic children: https://Autisticadvocacy.org/book/start-here/