



AutismUnited.org

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What is Autism?

Around 1 percent of children aged 3-17 in the US are diagnosed as having an autism spectrum disorder (ASD) each year and around 1-1.5 million Americans live with the diagnosis. As a parent of someone who has been diagnosed, or someone with the disorder, it is important to understand what autism is and how a person lives with it.

The [autism spectrum disorder](#) varies widely in how it affects each individual who is diagnosed with it, and the symptoms also differ depending on the age of diagnosis. Autism is a lifelong disability that can affect many aspects of life; those with autism often have difficulty communicating with others, as well as understanding the world around them. While some individuals are able to live with autism independently, many require additional support throughout their day-to-day lives and others will have to receive support for the learning difficulties associated with ASD.

To a person with ASD, the world is a confusing place. Daily living involves battling against the struggle that is making sense of social interactions, places, and events. While some will know intuitively how to communicate, many will find that understanding their friends and family is hard. At the same time, some people with ASD will also experience frustration in making themselves understood. The autism spectrum also covers Asperger's syndrome, which is a form of autism where the person has above average intelligence, but struggles with communication and social situations.

As far as communication and social interactions are concerned, those who have autism will struggle to interpret both verbal and non-verbal communication. Many will find understanding things like tone of voice, jokes, sarcasm, and common phrases such as "that's cool," to be difficult. This means that they will take everything that is said to them as being

literal. In some cases, those with autism may struggle to achieve basic communication on a verbal level, and their speech will either be very limited or non-existent. They do understand what people are saying to them, but they prefer to respond with visual signals, such as sign language.

As interpreting social situations is hard for those with autism, their behavior may seem inappropriate or insensitive. The majority of people without ASD are able to interpret the unwritten social rules that we all adhere to throughout our daily interactions with others, but those with ASD may either struggle to do this or fail to do so entirely. This means that their responses to what we perceive as normal social cues may seem 'strange'; this can include not recognizing how someone is feeling, starting an inappropriate conversation, or failing to observe when someone is in need of personal space.

An individual who has autism may also lack a 'social imagination.' This does not mean that they have no imagination at all, it simply means that they fail to develop the cognitive responses that are required to respond 'normally' to every day events. This means that they will be unable to form predictions about what will happen next, cope well in unfamiliar situations, perceive imminent danger (i.e. when a car is heading down a road at speed) and form plans for the future.

Those with ASD who do struggle with the social aspects of life tend to have a love for routines. To someone with autism, a consistent routine allows them to make sense of the confusing world that will otherwise cause them to feel a sense of anxiety. Such routines can be as simple as always taking the same journey to school or always eating the same thing for dinner. Although someone with autism may not like to make a change to their usual routine, they will often respond well to changes if they have been prepared for them in advance.

Along with routines, those who have autism will also gain therapeutic benefits from having special interests. They may become fixated on certain hobbies, such as collecting certain items, painting, or getting involved in a certain sport. Many parents whose children have autism, and individuals

on the spectrum, find that channeling each interest into something consistent and positive is beneficial.

Although it is common for a person who has autism to experience some form of learning difficulty, this tends to vary between each person. While one may need lifetime support for basic activities such as washing and dressing, others may just need more support in the classroom. It is important to remember that each person with autism can develop at their own pace, provided that they have the right form of support available to them.

Finally, some people who have autism experience hypersensitivity or hypo-sensitivity. This means that one of their five senses -- sight, sound, smell, touch and taste -- will be over or under-sensitive. Some find that background noises are amplified to the point that they become uncomfortable, while others experience sensations such as a high pain threshold.

Facts and Statistics About Autism

- The prevalence for autism in the US is around 1 in every 110 live births.
- Autism is the fastest growing disability in the US. There is around a 10-17% annual growth.
- It costs around \$60 billion a year to care for all of those who have autism in the US and 60% of those costs are from adult care.
- Around 56% of children who are diagnosed with autism complete their high school education.
- Around 20-30% of children who are diagnosed with autism also develop epilepsy.
- Life expectancy is normal.
- Boys are four times more likely to have autism than girls.
- An early diagnosis means that the lifelong costs of care can be reduced by around two-thirds.

All About Autism Diagnosis

If you are a parent who is seeking a diagnosis, it will be important to first ensure that your child does not have another disability. Many of the characteristics that are typical of autism are also associated with other conditions, and as such your family physician will want to observe your

child in more than one setting. In addition to a medical diagnosis, your child's school will be asked to form an educational assessment, and other bodies may be involved. A multidisciplinary approach is the best way to diagnose autism, and it will allow you as a parent to move on to living alongside your child with the condition.

It is also possible for adults who have not been diagnosed during childhood to receive a diagnosis. Again, this will involve a multidisciplinary approach that aims to set autism aside from other disabilities. Several things will be assessed, including communication, social interactions, and social imagination. Getting an autism diagnosis as an adult can help you, or someone you love, make sense of the world.

Living With Autism and Gaining Support

Those who receive a formal diagnosis for themselves and parents of children who have just been diagnosed will find living with autism is easier when you receive the right type of support. Online communities such as [Autism United](#) provide an outlet for learning from others who are involved with the autism spectrum (on a personal and professional level), as well as sharing emotions and stories. Although there is now a wealth of advice out there in a medical and educational context, the autism spectrum is so varied that it is often the case that a more personal support system is just as beneficial, if not more.

Following a diagnosis, one of the best steps that you can take is to become involved with an autism community like [Autism United](#). Autism communities exist in both an online and offline context, and by seeking strength from other parents you will find that adjusting to living with ASD is easier than if you go it alone. A sympathetic ear, tips that professionals may not think to give, reading blogs, and taking part in events are just some of the benefits that you can gain from becoming involved with a support network. As the advice and strength you gain from others who have personal involvement with ASD is endless and free, you can be involved as much or as little as you like.

Health professionals and those who work in the education sector will undoubtedly be able to offer a lot of great advice, but when it comes to the

more specific issues, being able to receive tips from others who are involved with autism on a personal level is invaluable. Whether it is a hard day at school, a tantrum in public, or adjusting to an unexpected change in routine, receiving advice on the issues associated with autism that suddenly creep up on you from multiple people can be reassuring and empowering.

The next step you should take is to focus on how you will gain respite as a carer for someone who has autism. Wanting to seek help when it comes to caring for someone with autism is natural; you may crave more time with your partner or more time for yourself. Either way, by having additional support you will find that caring for someone with autism is easier and places less strain on your relationship with others. As well as turning to your friends and family, see what resources are available in your state and how you can access them. The resources that are available may include someone coming to your home to offer help, your dependent going away for the day, or even a summer camp. Again, talking to people online or in person who have experience with seeking respite is a great way to find resources.

In addition to establishing support, you should also focus on how you can access financial resources. Some carers find that they have to stop working, while others may want to seek extra funds to access additional care services. There are some small grants available from autism charities that can provide extra funds, and those adults who have autism may be able to receive social security payments to help with their day-to-day expenses. Alongside this, you should check to see if your health insurance policy covers autism related treatments and how you can have it adjusted if not.

Finally, if you are a parent who has received an autism diagnosis for your child, it is vital that you liaise with his or her school or career as soon as you can. As autism is a disability that is not very well understood, it may take a little coercion when it comes to implementing the exact type of support you need when it comes to your child's school. However, with great lines of communication between yourself and your child's teachers, you will get there eventually. It is important to remember that life with ASD



is a great learning curve for all involved, and cooperation is the key to success and harmony.