



Autism Society
Greater Akron

NEW TO AUTISM GUIDE

For Adults



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ABOUT ASGA

The Autism Society of Greater Akron (ASGA) developed this guide for adults who are newly diagnosed with Autism Spectrum Disorder (ASD) to connect individuals living in Northeast Ohio local to supports and services. It is not intended – nor could it feasibly cover – every possible service; however, we hope it is a helpful starting point.

Of note is that one of the most frequent questions we receive through our HelpLine is from people over the age of 18 requesting information about being evaluated for a diagnosis of Autism. Their stories are similar of growing up feeling different and misunderstood, but the differences eventually became barriers to employment, relationships, housing, and friends. Their challenges made them seek a diagnosis to better understand themselves in the hopes it would help remove or better manage the barriers they were experiencing.

We put this information together to help you on this new journey. ASGA provides an array of programs and services, including an Adult Social Club that may be of interest to you. ASGA is an affiliate of the Autism Society of America, the largest and oldest grassroots Autism organization in the country. Founded in 1987, ASGA's service area is Summit, Stark, Medina, Portage and Wayne Counties. ASGA provides:

- **Support** with support groups and social clubs.
- **Education** with webinars and speakers.
- **Community**-based programs that connect people.
- **Information and referral** to local services.

ASGA is a proud member of the [Ohio Family Network](#) (OFN), a state-wide collaboration funded by the Ohio Department of Developmental Disabilities that connects people with disabilities and their families to local information and resources within their communities.

Please join our mailing list to receive weekly emails about upcoming events, programs and other community-based opportunities that may be of interest to you. Contact our Helpline at 330-940-1441, ext.1, or email info@autismakron.org if you need assistance or to be connected to community support services. You can also learn more about ASGA on our website at www.autismakron.org.

The Autism Society of Greater Akron is your partner on this journey.

Give us a call...we're right here!



MISSION, VISION, AND MANIFESTO

Our Mission.

We create connections, empowering everyone in the Autism community with the resources needed to live fully.

Our Vision.

Creating a world where everyone in the Autism community is connected to the support they need, when they need it.

Our Manifesto.

Because the experience of Autism is not one thing. Because it is many things. And because the connection between those experiences is you.

Because we see you. The way you think. The dreams you hold. The talents you bring. Because you can't be categorized into neat little diagnostic boxes. Because you break the mold.

Because sometimes you're quiet. Because sometimes you need help reaching for where you belong.

Because sometimes what happens is not always right or fair or just. Because there are keys to every door that looks locked.

Because no matter how you were born, the person you are is infinite—and you are the only you there is.

Because Autism is not going away, neither are we.

The connection is you.™

INTRODUCTION

Being diagnosed with Autism Spectrum Disorder (ASD) as an adult might come as a huge relief. It may answer several childhood questions, perhaps like why didn't I fit in? Why was it so hard for me to make friends? Why did I feel different? For others, the diagnosis may make sense of the struggles that surfaced as an adult, such as becoming upset if someone gets too close or having rigid routines, schedules, and daily patterns that must be maintained no matter what. Or, maybe you have been misdiagnosed throughout the years.

No matter the path that led you to seek a diagnosis, a clinical evaluation or suspicion of Autism is the start of a journey that leads to countless new opportunities.

WHAT IS AUTISM?

Autism spectrum disorder (ASD) is a developmental disability that can cause significant social, communication and behavioral challenges. ASD is a spectrum disorder, meaning symptoms can range from mild to severe. The effects of ASD and the severity of symptoms are different in each person.

There is no known cause of Autism, and there is no blood test to diagnose it. Autism occurs across all economic, ethnic, cultural, and educational environments. A 2020 study by the Center for Disease Control (CDC) reported that 2.2% of American adults have an Autism spectrum condition. That adds up to 5.4 million people aged 18 and older, or about 1 in 45 adults (Fox, 2020).

Often, profound forms of Autism are diagnosed in the first two years of a child's life based upon missed developmental milestones, but for individuals who achieved the traditional walking, talking, and intellectual ability milestones – especially those born before the year 2000 – Autism may not be diagnosed until much later in life.

“*I got an Autism diagnosis as an adult. I lived in a rural community growing up with no supports or Autism programs. Getting diagnosed with Autism was a life-changing diagnosis because I had so many communication challenges and terrible meltdowns, and no one ever linked them to Autism. I always loved art growing up, and now, I make all kinds of pieces. I never realized art could help me communicate. Now, I use art to communicate my goals.*”
AH, age 34

WHAT IS NEURODIVERSITY?

The **Cleveland Clinic** describes *neurodiversity* as the differences in the way people's brains work. Everyone's brain function is unique, and there is a wide range of ways that people perceive and respond to the world. All differences are to be embraced and encouraged.

Neurodiversity is a movement to support people outside of the mainstream in the way their brains work and to focus on developing their strengths and talents. This movement acknowledges that Autism, ADHD, and Learning Disabilities (LDs) do cause impairment; they can create obstacles that get in the way of neurodiverse people doing the things they want to do. Treatment should help

individuals reduce symptoms that interfere with their goals and allow them to be included in activities of everyday life.

IS IT “PERSON WITH AUTISM” OR “AUTISTIC”?

Words and language are powerful tools by which an individual can express ideas, whether abstract, actionable, or concrete. Words also help us to describe who we are. Language, however, continues to shift to reflect new knowledge.

“People First Language” puts the person *before* the disability and describes what a person has, not who a person is. The goal of person-first language is to avoid language that dehumanizes or stigmatizes people. Person First Language uses phrases such as “person with a disability,” “individuals with disabilities” and “children with disabilities”.

In today’s world, it is important to note that while person-first language is still used in formal writing or public settings, many people with disabilities, particularly younger people, are choosing to use identity-first language. How a person chooses to self-identify is up to them, and they should not be corrected or admonished if they choose not to use person-first language. Self-advocates are proud to announce that they are “autistic.” It is a way to celebrate their unique neuro-type.

However, out of courtesy, the best approach when speaking to someone with autism is to ask how he/she prefers to be addressed.

THE SIGNS AND SYMPTOMS OF AUTISM IN ADULTS.

Common signs and symptoms of ASD in adults can include (NHS, 2019):

- difficulty making conversation
- difficulty making or maintaining close friendships
- discomfort with eye contact
- challenges with regulating emotions
- extreme interest in one particular topic
- frequent monologues on the same subject
- hypersensitivity to sounds or smells that do not seem to bother others
- involuntary noises, such as repetitive throat clearing
- difficulty understanding sarcasm or idioms
- lack of inflection when speaking
- limited interest in only a few activities
- preference for solitary activities
- problems reading the emotions of others
- trouble understanding facial expressions and body language
- reliance on daily routines and difficulty dealing with change
- repetitive behaviors
- social anxiety
- superior abilities in a particular field, such as mathematics or other disciplines
- the need to arrange items in a specific order

HOW ARE MEN AND WOMEN WITH AUTISM DIFFERENT?

For every one woman with Autism, there are four men with Autism. Autism can manifest itself differently in women and men.

Autistic women are generally able to “hide” or mask their symptoms better than men because women are often more socially adaptive. For instance, a woman can often maintain better eye contact, be more involved in conversations and have better self-care because they observe and learn to pick up habits that will mask the symptoms of ASD. Scientists call this *camouflaging*; women camouflage three to four times more than men do. This means it can be harder to diagnose a woman with Autism (OAR, 2018).

AUTISM AND RELATED HEALTH ISSUES

It is important to note that there are often co-occurring medical and psychiatric conditions associated with Autism, such as:

- Anxiety
- Attention-Deficit/Hyperactivity Disorder (ADD/ADHD)
- Autoimmune Dysfunction
- Bipolar Disorder
- Depression
- Epilepsy
- Gastrointestinal problems
- Gender confusion
- Learning disabilities
- Mood Disorders
- Obsessive Compulsive Disorder (OCD)
- Poor coordination
- Schizophrenia
- Sensory issues
- Sleep Disorders



One reason it is important to be aware of co-occurring medical and psychiatric conditions is that many conditions have treatment avenues that may be helpful to your overall quality of life. Routine screenings should be part of an annual physical exam.

HOW IS AUTISM TREATED?

While there is no known cure for Autism, effective treatments do exist. Effective interventions may reduce symptoms, improve cognitive ability and daily living skills, and maximize the ability of an individual to function and participate in the community. Remember, Autism is a spectrum disorder. Some people may need little to no treatment, while others may require intensive therapy. Treatments can be behavioral therapies, medications, and alternative therapies (Gaus, 2007).

Behavioral Therapies

- **Cognitive Behavioral Therapy (CBT)** - Useful in helping people with Autism manage anxiety. CBT is a type of talk therapy between a client and a trained psychologist where individuals learn about the connections between feelings, thoughts, and behaviors.
- **Sensory Integration Therapy (SIT)** - People with Autism are sometimes unusually affected by sensory input, such as sight, sound, or smell. SIT is based on the theory that heightened senses make it hard to learn and display positive behaviors. With the help of an occupational therapist, SIT attempts to even out a person's response to sensory stimulation.
- **Social Skills Training (SST)** – A type of behavioral therapy used to improve social skills in individuals with developmental disabilities. For some people with Autism, interacting with others is very difficult, which can lead to many challenges over time.

SST may be used by teachers, therapists, or other professionals to help individuals with anxiety disorders, mood disorders, personality disorders and other diagnoses. Someone undergoing SST learns fundamental social skills, including how to carry on a conversation, understand humor, and read emotional cues. Clinical psychologists and occupational therapists often administer social skills training.

Medication

There are no medications specifically developed to treat Autism. However, several medications used for other conditions that may occur with Autism might help with certain symptoms. Before taking any medication, speak with your physician about your symptoms.

Medications used to help manage the symptoms of Autism fall into several categories:

- **Antipsychotics.** Some newer antipsychotic medications may help with aggression, self-harm, and behavioral problems in both children and adults with Autism.
- **Antidepressants.** While many people with Autism take antidepressants, researchers are not sure whether they help with Autism symptoms. Still, they may be useful for treating obsessive-compulsive disorder, depression, and anxiety.
- **Stimulants.** Stimulants, generally used to treat ADHD, may also help with overlapping Autism symptoms, including inattention and hyperactivity.
- **Anticonvulsants.** Some people with Autism also have epilepsy, so anti-seizure medications are sometimes prescribed (Osborn, 2020).

Complementary and Alternative Therapies

To help relieve the symptoms of Autism that interfere with daily life, some healthcare professionals use treatments that are outside of what is typically recommended by family practitioners. Complementary and Alternative Therapy treatments refer to products or services that are used in addition to, or instead of, traditional medicine. They might include special diets, dietary supplements, biologicals (for example, secretin), or mind-body medicine, i.e., yoga, mindfulness meditation, craniosacral manipulation, acupuncture/acupressure, and reiki (Rudy, 2020).

There is also a range of Autism-specific food supplements that are often used to treat Autism. Outside of a regular multivitamin (as is generally recommended by doctors), the most popular include vitamins A, C, B6, zinc, and folic acid.

Complementary and alternative treatments have an important place in supporting some traits of Autism, though neither they nor any mainstream treatment is likely to lead to a “cure” for those seeking it. When selecting treatments, however, it is important to ask these questions:

- What is the desired positive outcome?
- Are there risks associated with the treatment?
- What do researchers, my family physician, and other trusted sources say about the treatment?
- Can I afford the treatment if it is not paid for by my insurance?

THE DIAGNOSIS

Currently, there are no standard testing tools for adults with suspected ASD, but they are in development. In the meantime, clinicians primarily diagnose adults with ASD through a series of in-person observations and interactions. They also take into consideration any symptoms the person reports experiencing. The clinician will want to talk with you about any issues you have regarding communication, emotions, behavioral patterns, range of interests and more. You might answer questions about your childhood, and your clinician might request to speak with your parents or other older family members to gain their perspectives about your lifelong behavior patterns (MedicalNews Today, 2021).

“*I received my Autism diagnosis at age 30. I always knew I was different from other people, but I couldn't define why. I started asking questions and doing my own research. Eventually, I took those questions to a professional and received an official diagnosis of Autism. I don't consider it an illness, disorder, disease, or disability, but the official diagnosis gives me an answer to the question of why I'm so different.*” JR, age 35

If you are interested in being evaluated for ASD, begin with your family doctor, who will evaluate you to be certain that there isn't an underlying physical illness to be considered. Your doctor may then refer you to a psychiatrist or psychologist for in-depth assessment.

If you are looking for locations in your area that offer adult ASD testing, call the ASGA Helpline at (330) 940-1441, ext. 1.

IS THE DIAGNOSIS REALLY THAT IMPORTANT?

Why do I need a diagnosis now? So far, I've gotten through life without one!

Some adults question whether they need a diagnosis later in life; some people self-identify as Autistic without receiving an official diagnosis. Independent exploration can provide sufficient answers, and some individuals find that the presence of Autism answers the current and past challenges faced and talents possessed. Pursuing a diagnosis can be expensive, as most health plans will not cover the cost. Also, it can be difficult to find a professional who is adept at providing an adult diagnosis. Some

individuals find that getting an official diagnosis is unnecessary; self-diagnosis in the adult Autism community is widely accepted. In the end, it is a personal decision.

On the other hand, receiving an ASD diagnosis as an adult can mean a greater understanding of yourself and how you relate to the world. Knowing that you have ASD can help you gain a different perspective on your childhood. It can also help those around you to understand and empathize more with your unique characteristics.

Understanding your personal set of challenges can help you find new and inventive ways to work with or around those hurdles. And it can help you to better work with your strengths and to support areas of your life that are challenging.

Finally, a formal Autism diagnosis can allow an adult access to resources and services. Remember--it is okay to be different because there is a giant network of people with Autism (Bennie, 2020).

SERVICES AVAILABLE TO ADULTS WITH AUTISM (OVER 22)

With a formal Autism diagnosis comes several protections that can assist you in addressing some of your challenges. Whether it be in the workplace, post-secondary education or in the community, take advantage of these services and programs.

Social Security Income (SSI): The Social Security Administration (SSA) may provide financial assistance and Medicaid health coverage to adults with Autism. The SSI program is open to any individual with disabilities, of any age, regardless of work history, if they meet the medical eligibility and financial limitation requirements. SSI is a need-based program and as such means that an applicant must have *very limited income* and financial resources available to pay for everyday needs and ongoing care.

If you are applying for SSI for yourself, collect as many medical records as possible. The more thorough the medical documentation that accompanies your application, the more likely it is the argument for disability can be made. In 2023, the SSA has made available individuals who can help you apply for SSI benefits. Call 1-800-772-1213 to make an appointment to start the application process.

Additionally, statements from friends, family members, doctors, teachers, and caregivers can be instrumental in proving that Autism limits your ability to care for yourself or to participate in and appropriately respond to everyday situations, conversations, and activities.

Since there is a financial component to SSI, you will need financial records, too. These may include paystubs, statements from any other benefits received, bank account statements, and any other documentation related to income and other financial assets or resources.

Opportunities for Ohioans with Disabilities (OOD): OOD assists individuals with disabilities find and keep employment. OOD offers career exploration, resume and interview preparation, job development and placement, on-the-job support, work incentive planning, and assistance with workforce barriers.

Vocational rehabilitation counselors customize services for each individual beginning at age 14, who has physical, mental, and emotional disabilities by providing direct, personalized services to assist them in finding and retaining meaningful work and personal independence. To contact OOD, go to <https://ood.ohio.gov/wps/portal/gov/ood/individuals-with-disabilities/oodworks>.

The Americans with Disabilities Act (ADA): The *Americans with Disabilities Act (ADA)*, signed into law in 1990, is a civil rights law that prohibits discrimination against people with disabilities and guarantees equal opportunities for individuals with disabilities in employment, transportation, public accommodations, state and local government services and telecommunications. The purpose of the law is to ensure that people with disabilities have the same rights and opportunities as everyone else. In addition, Title I of the ADA states that employers must provide reasonable accommodations to qualified applicants or employees. A reasonable accommodation is any modification or adjustment to a job or the work environment that will enable an applicant or employee with a disability to participate in the application process or to perform essential job functions. You can find more specifics about the ADA at <https://adata.org/learn-about-ada>.

The Rehabilitation Act of 1973: Section 504 of The Rehabilitation Act, was the first piece of civil rights legislation to specifically address the rights of people with disabilities. The Act made it illegal for programs that receive federal funding, such as universities, to discriminate based on disability. In addition, the Act was the first legislation to address equal access for individuals with disabilities through the removal of architectural, employment, and transportation barriers. <https://www.ada.gov/cguide.htm#anchor65610>

The Olmstead Act of 1999: The Olmstead Act found that segregating people with disabilities is a form of unlawful discrimination under the Americans with Disabilities Act (ADA). The US Supreme Court ruled that states are required to provide community-based services for people with disabilities who would otherwise be entitled to institutional services when such placement is appropriate, the individual does not oppose such treatment and the placement can be reasonably accommodated, considering the resources available to the state and the needs of other individuals with disabilities. The result of the Olmstead Act is that many individuals are now integrated within their communities as opposed to institutions. Increased hours of personal care and assistance are being provided to individuals who require additional services to remain in the community. <https://www.hhs.gov/civil-rights/for-individuals/special-topics/community-living-and-olmstead/index.html>

DO I WANT ANYONE ELSE TO KNOW ABOUT MY NEW DIAGNOSIS?

It is important to consider when and if you will disclose your ASD diagnosis. Should your employer know? Your romantic interest? Friends? Remember, in all cases, disclosure is a personal choice, and there is no law obligating you to disclose your disability. However, to be eligible for the accommodations under the American Disabilities Act, OOD and Social Security, some level of disclosure is necessary. ***Once disclosed, though, that information legally must be kept confidential in the workplace, places of higher learning, housing options and medical environments.***

In her book *Cognitive Behavioral Therapy for Adult Asperger Syndrome* [http://rehabilitationpsychologist.org/resources/\[Valerie L. Gaus\] Cognitive-Behavioral Therapy for\(BookFi.org\)%20\(1\).pdf](http://rehabilitationpsychologist.org/resources/[Valerie L. Gaus] Cognitive-Behavioral Therapy for(BookFi.org)%20(1).pdf), Gaus (2007) discusses several additional factors people may want to consider when exploring the option of disclosing their ASD. The question is not

only whether to disclose, but *how much* to disclose. To arrive at a decision involves analyzing your goals for disclosure, as well as understanding the many possible outcomes -- positive and negative.

Gaus' book (2007) suggests that the individual explore the following questions:

- **Why do you want this person to know about your diagnosis?** Would disclosure possibly improve a professional relationship? Or could it deepen understanding and intimacy in a personal relationship?
- **How do you think disclosure will improve your interactions with this person?** Without thinking through this goal, the individual is less likely to achieve the desired effect.
- **Are you prepared to ask this person to support you differently because of this new information? If so, can you be specific with the person about what you need?** For example, if the individual hopes that an interpersonal problem will improve with the disclosure, it's important to be able to explain specifically how the person should use the new information. The other person may be unsure about the purpose of the disclosure or how he or she can help.
- **What are the risks of disclosing to this person?** If it's someone the client doesn't know well, such as a coworker or employer, anticipating the reaction can be difficult. Exploring this question can help the individual plan for the possibility of a negative or confusing reaction.

HELPFUL TIP

WHEN TO DISCLOSE A DIAGNOSIS

Disclosing a diagnosis of Autism to health providers, friends, and family is not required by law. It is a personal decision.

To get accommodations in employment under the Americans with Disabilities Act (ADA), some level of disclosure is necessary. Once disclosed the information must be kept confidential.

YOU ARE YOUR BEST ADVOCATE

This new identity may cause feelings of loss, resentment, or anger. It is okay to feel this way as this is a life-changing diagnosis, and it can be overwhelming. But knowledge is power and when you know something about yourself, you can seek the information and support you need to succeed.

An ASD diagnosis can provide access to support and services that may not be available without a diagnosis, such as an income support program that provides additional income if mental health issues prevent being able to work full-time. Maybe you need a job coach, a support person to check on you a couple of times a week, specialized mental health services, or support in the workplace.

Additionally, you can join a support group or get together with other Autistic adults without a formal diagnosis.

A FINAL THOUGHT

The path to an adult Autism diagnosis is not an easy one, and it can be challenging. However, awareness and information about receiving an adult ASD diagnosis is slowly improving.

There is a large community of adults who identify with the Autism population. ***You are not alone.*** There are countless ways to connect with others and to find support. Find a support group, a social club or an online community that has like interests. Everyone's experiences are unique, but we tend to be attracted to others with the same interests and/or challenges.

Most importantly, be honest with yourself, respect who you are as a person and celebrate your achievements. Autism does not have to define you any more than you want it to.

“
“I was diagnosed with Autism at the age of 21. Getting diagnosed helped me to understand why some settings were good for me and others weren't. And it forced me to place myself in situations that would help me grow.”
JB, age 26
”



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DISCLAIMER

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