



## Adult Autism Diagnosis Tool Kit



*A guide for identifying autism in adults  
and figuring out what comes next*



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# About This Tool Kit

This Tool Kit is designed to assist adults who have been recently diagnosed with autism, are going through an evaluation or suspect they may have autism. The original version was released in 2015 with a comprehensive review and update in 2023 led by a team of autistic adults, including outside contributors and Autism Speaks staff members.

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## INTRODUCTION

Society is much more aware of autism than it has ever been thanks to improved public health outreach, increased screening, advocacy, awareness efforts and media attention. While this has been great news for kids, there are likely many adults with autism who never received a diagnosis or were misdiagnosed.

Over the last few years Autism Speaks Autism Response Team (ART) has heard from an increasing number of autistic adults who are seeking information, tools and resources. Autistic adults now make up over 10% of constituents who reach out to us. In response, we developed this Tool Kit to address what comes next if:

- You are an adult currently seeking a diagnosis or were recently diagnosed with autism.
- You are an adult who recognizes you have autistic traits but are unsure what to do.
- You were seeking counseling or support for something else as an adult, and the clinician brought up autism.
- You recently found out that you were diagnosed with autism in childhood, but your parents/guardians did not disclose that to you.
- Your child was diagnosed and/or is being evaluated and you wonder about yourself.
- You are someone who loves or supports someone who fits one of the above.

While we will explain the clinical definition, signs and diagnosis of autism, we will also provide a glimpse into adult life on the spectrum, supported by testimonials from autistic adults. Among them are Autism Speaks staff, contributors and board and advisory members. You will also hear from a sample of autistic adults who participated in a 25-question survey we hosted online in March 2023. Respondents were solicited through Autism Speaks and personal social media accounts. We received 150 completed responses from adults who self-selected as being over 18 years old and either diagnosed with autism or seeking diagnosis. The average age of the respondents was 40 years old and

the average age of diagnosis among those who knew was 28. Self-described gender breakdown was: 54% female or cisgender female, 33% male or cisgender male, 6% non-binary, and 2% transgender. Another 5% of respondents didn't provide an answer about their gender. More about the survey responses can be found in the Autistic Perspectives section at the end of this guide.

This Tool Kit will also walk you through services and supports, disclosure, accommodations and critical information about your rights and protections. If you have any additional questions or need more specific resources, the Autism Speaks Autism Response Team (ART) is here to help. ART coordinators are specially trained to support the autistic community by answering calls, chat and emails and by providing guidance and information. ART can be reached at:

**In English:** [help@autismspeaks.org](mailto:help@autismspeaks.org) | 888-288-4762

**En Español:** [ayuda@autismspeaks.org](mailto:ayuda@autismspeaks.org) | 888-772-9050

*In advance, this revision was initiated and made possible through the work of the autistic community. Many work for Autism Speaks in various capacities; others volunteered their experiences. We know there is still more work to be done and look forward to continuing the conversation. This is just the beginning of what's next.*

# What is Autism?

## Definition

Autism, or autism spectrum disorder (ASD), refers to a broad range of conditions characterized by challenges with social skills, speech and nonverbal communication and repetitive behaviors. It is a lifelong condition.

The American Psychiatric Association's fifth edition of its [Diagnostic and Statistical Manual of Mental Disorders](#) (DSM-5), released in 2013, is the standard reference that health care providers use to diagnose autism.

Under the DSM-5, four distinct autism diagnoses were merged into one umbrella diagnosis of autism spectrum disorder (ASD). They included autistic disorder, childhood disintegrative disorder, pervasive developmental disorder-not otherwise specified (PDD-NOS) and Asperger syndrome. Individuals with well-established diagnoses of these disorders prior to the publication of the DSM-5 are clinically referred to as having the diagnosis of autism spectrum disorder now. Some people who were diagnosed prior to the DSM-5 prefer these older terms and continue to use them.

Per the current DSM-5, people with ASD "must show persistent deficits" in social communication and social interaction, and restricted and repetitive patterns of behavior, interests or activities.

More specifically, the DSM-5 states that people with ASD must demonstrate difficulty (either in the past or in the present) in social-emotional reciprocity, nonverbal communicative behaviors used for social interaction, as well as issues in developing, maintaining and understanding relationships. In addition, they must show at least two types of repetitive patterns of behavior including:

- stereotyped or repetitive motor movements
- insistence on sameness or inflexible adherence to routines
- highly restricted, fixated interests
- hyper- or hypo-reactivity to sensory input or unusual interest in sensory aspects of the environment

To read the whole DSM-5 criteria, including severity labels which we will not discuss in this Tool Kit, please visit [Autism Diagnosis Criteria: DSM-5](#).

*Note: This Tool Kit will not use labels to define types of autism like: Asperger syndrome, high-functioning, low-functioning, mild autism, moderate autism and severe autism. Rather, we will address autism broadly across the spectrum and supply information for a range of support needs.*

## Statistics and Facts

According to the [Centers for Disease Control](#), about 1 in 36 children has autism in the United States, with boys diagnosed four times more often than girls. Prevalence has increased markedly over the last 20 years since the first study in 2000 when 1 in 150 children met the diagnosis criteria. Autism affects all ethnic and socioeconomic groups.

It wasn't until 2020 that the CDC released its first [adult-focused data](#), reporting that an estimated 2.21% of adults in the U.S. have ASD. It is now estimated that over 5.4 million adults in the United States have ASD. Due to inadequate services and old workplace paradigms, more than half of adults with autism remain unemployed and unenrolled in higher education in the two years after high school. Nearly half of 25-year-olds with autism have never held a paying job.

## Causes of Autism

We know that there's no one cause of autism. Instead, research suggests that autism develops from a combination of genetic and nongenetic, or environmental, influences. For instance, autism tends to run in families. But certain environmental influences may further increase – or reduce – autism risk in people who are genetically predisposed to it.

Some factors have been identified that increase the risk of autism including parental age, pregnancy and birth complications, like extreme prematurity and low birth weight, multiple pregnancies (twins, triplets) and pregnancies spaced less than one year apart. Prenatal vitamins containing folic acid are thought to decrease the risk.

Scientists have conducted extensive research over the last two decades to determine whether there is any link between childhood vaccinations and autism. The results of this research are clear: [Vaccines do not cause autism](#).

## Signs of Autism in Adults

You may have spent your entire life not recognizing the signs of autism or not realizing that some of the issues and feelings you have dealt with were related to autism. But as described in the definition above, the hallmarks of autism occur mainly in social interactions, verbal and nonverbal communication and repetitive behaviors. However, individual presentation varies widely across these three core areas. Additionally, a major life change, including transition in and out of college, job switches or change in family status (marriage/divorce, birth of children, loss of parent), can result in a change in degree of one's challenges.

It is important to note that autism also often looks different in women and men. Health care providers have made strides in recognizing this. Still, autistic girls are diagnosed at substantially lower rates than boys, leading to a high rate of women seeking diagnosis late in life. One reason for this is that girls and women appear to better at masking, or camouflaging, their autism to fit in.

*"I think the gap in diagnosis comes down to the fact that girls mask better. We're trying so hard just to manage and not look incompetent. In our society, women are often seen to be less capable – whether they're on the spectrum or not. Add to it that autistic women have a different way of interacting with the world, and you set us up to constantly feel like we should be doing more."*

*– Dr. Elisheva Levin, Ph.D, senior research scientist at the Center for Development and Disability in the University of New Mexico School of Medicine, diagnosed with autism at age 45*

### Social interactions

*"It feels like I am an observer looking in on a conversation, occasionally interjecting, instead of an active participant. I am trying to learn how to connect with people more easily, but it is not intuitive for me."*

*– Victoria, 21-year-old working professional diagnosed by her therapist*

Social disconnection is a common theme among the autistic adults who helped develop this Tool Kit. Respondents to our survey reported both wanting to isolate from others and feeling isolated.

Common social issues that led to this response were:

- Feeling left out of social circles or not fitting in.
- Difficulty in interpreting what others are thinking and feeling.
- Inability to pick up on or misunderstanding non-verbal cues including: eye rolls, shoulder shrugs, grimaces and other facial expressions used to convey emotion.
- Inability to see things from another person's perspective.

### Communication differences

*"People often tell me that I talk too loud or too quiet, that I move my hands too much, and that I don't think enough before I say things. That really impacts my self-esteem and makes it hard to want to talk at all sometimes."*

*– Finn R, 24-year-old actor and student*

*"I am frequently misunderstood by neurotypical people. Info dumping is often seen as correction when I feel like I'm just adding useful facts. Sharing information, especially in my areas of special interests, is a love language that is frequently misrepresented and disrespected."*

*– Cynthia, 53-year-old autistic parent of an autistic child*

Social and communication skills are interrelated. For many autistic people, the ordinary give-and-take of conversation can be difficult and even exhausting, resulting in unsatisfying or even missed social connections. For instance, some autistic adults carry on monologues on a favorite subject, giving others little chance to comment.



Many respondents to our survey reported needing a high level of directness and honesty in conversation. A common strategy among them was to revert to text or email in order to most effectively communicate.

### *Repetitive behaviors*

***"I get hyper-focused and detail-oriented in my interests. It often presents as over-sharing or info-dumping and spending disproportionate time on my interests. This is often an asset professionally (so long as I don't miss deadlines) but can be obnoxious in personal interests."***

*– Kaitlynn, 36-year-old, married, cisgender woman diagnosed two years ago*

Repetitive behaviors are a core characteristic of autism. Some people with autism need to keep household or other objects in a fixed order or place. It can prove extremely upsetting if something or someone disrupts the order. Many require strict consistency in their environment and daily routine. Slight changes can be exceedingly stressful and lead to anger and frustration.

Repetitive behaviors can also take the form of intense preoccupations or obsessions. These extreme interests can seem unusual to others either for their content (e.g. machines, certain collectibles) or depth of knowledge (e.g. knowing and repeating astonishingly detailed information about astronomy). But these interests can have an incredible positive impact on quality of life. Sometimes they can even be harnessed into opportunities for employment.

## Strengths and Challenges

*by Dr. Stephen Shore, Ed.D., self advocate, author and assistant professor at Adelphi University*

While some signs of autism may present challenges, others can be great strengths and advantages for people on the spectrum. Consider this general list of strengths and challenges for those with autism. For every strength and challenge, you will often find examples in people that prove the opposite. For example, clumsiness is a common challenge. However, some with autism have significant strengths in movement and balance, perhaps as a dancer.

STRENGTHS	CHALLENGES
Attention to detail	Grasping the big picture
Often highly skilled in a particular area	Uneven set of skills
Deep study resulting in encyclopedic knowledge on areas of interest	Difficulty developing motivation to study areas of non-interest
Tendency to be logical (helpful in decision-making where emotions may interfere)	Difficulty perceiving emotional state of others
Less concern for what others may think of them (can be a strength and a challenge), also known as independent thinking. Often results in novel “big picture” insights due to different ways of looking at things, ideas and concepts.	Difficulty perceiving unwritten rules of social interaction, but can learn these rules through direct instruction and social narratives such as Power Cards (Gagnon, 2004)
Usually visual processing (thinking in pictures or video)	Difficulty processing in non-favorite modalities such as aural, kinesthetic, etc.
Often very verbal (propensity for giving detailed descriptions may be useful in providing directions to lost persons)	Difficulty parsing out and summarizing important information for a conversation
Direct communication	Sensory integration problems where input may register unevenly, distorted and difficulty in screening out background noise
Loyalty	Generalization of skills and concepts
Honesty	Difficulty in expressing empathy in ways that others expect or understand
Non-judgmental listening	Executive functioning resulting in difficulties planning long-term tasks

## DIAGNOSIS

### Seeking a Diagnosis

The only way to know for sure if you are autistic is to get a formal diagnosis. The gold standard to obtain one is by a psychologist, psychiatrist or similar trained clinician (example: neurologist or neurological psychologist) who specializes in ASD and makes an evaluation based on the DSM-5 criteria.

“Currently, there are relatively few clinicians who specialize in evaluating and treating adults with autism. Nor do we have established criteria to objectively judge such qualifications,” per David Beversdorf, Ph.D. and neurologist at the University of Missouri’s Thompson Center for Autism and Neurodevelopmental Disabilities.

While these specialists will take self-referrals, a referral from your primary care physician could help speed up the process. So, it could be beneficial to start by making an appointment with their office. You should expect your doctor will want to rule out other conditions or uncover conditions that commonly co-occur with autism. More in the Co-occurring Conditions section below. But know that this is a sign of a thorough evaluation.

An added benefit to starting with a primary care physician is that they can give you a recommendation for a specialist to conduct an evaluation.

Otherwise, Dr. Beversdorf suggests contacting a clinician who typically evaluates children for autism, like a developmental pediatrician, child psychiatrist or pediatric neurologist and asking if they are open to seeing older patients. If not, they might be able to recommend a colleague who is qualified to evaluate an adult. You can also check with a respected autism center in your area, like those you can find in [Autism Speaks Autism Care Network](#), search by your zip code in [Autism Speaks Resource Guide](#), reach out to the Autism Speaks Autism Response Team or ask your insurance provider.

### Evaluation Process

An autism evaluation typically consists of multiple appointments with a clinician. Unlike many healthcare visits, you won’t be asked to change into a gown or go through any scans or blood draws. Instead, you will talk with the clinician, do activities and be asked to fill out a couple of questionnaires. A few common: Autism Diagnostic Observation Schedule-2 (ADOS), Autism Diagnostic Interview-Revised (ADI-R), and Social Communication Questionnaire, among others.

Over one or more visits the clinician will ask questions to learn about your childhood and present-day life. For perspective, they may also want to interview a parent/guardian or partner who knows you well. You might be asked to attend multiple visits over multiple days in order for the clinician to really get to know you. This process can seem like a lot, but it is important for an accurate diagnosis. If you’re nervous, you can ask to have a support person come to the appointments with you.

Beyond conversational interviews, clinicians will do activity-based testing involving questions and puzzles to examine your behavior and communication. These may be done in a different room than where you first met, to see you in a different setting. The goal is to get a better understanding of your social and communication skills, sensory awareness and any repetitive behaviors. During these activities clinicians will also assess things like your attention, memory, processing speed, reasoning, problem-solving and personality. Like a primary care physician, they will be ruling out other conditions and checking for common co-occurring conditions.

## Provider Perspective: What the diagnostic process looks like for adults

*By Dr. Catherine Lord, Ph.D., clinical psychologist, George Tarjan distinguished professor of psychiatry in the David Geffen School of Medicine at UCLA and [Autism Speaks Medical and Science Advisory Committee](#) member*

Typically, we begin the process by meeting the adult virtually and talking to them about what they are looking for and why they want the assessment. Then, if the adult is comfortable with it, we get information from someone who knew them when they were a child. That is very useful because autism is a developmental disorder, so we are looking for something that has always been there but may not have caused difficulty until later in life.

Then, we do a 3-hour assessment face-to-face. With kids, we're often looking at language delays and intellectual disability, but that's less the case with adults. For adults, we do some standard cognitive tasks to see the person in action, because so many of the issues that come up for autistic adults are related to executive functioning and making judgments. For example, we recently saw a 30-year-old young man who has a degree in physics. We did a test where we asked him to define certain words and he was incredibly good, but he had a hard time knowing when to stop. He'd get started on a definition and go on for 10 minutes, not realizing that what we really needed is one sentence.

Then, we do an Autism Diagnostic Observation Schedule (ADOS) assessment. The ADOS isn't perfect – certainly, it can miss people. The smarter you are, the more likely you are to get missed, whether you're 14 or 40. But it allows us to do a series of tasks designed to create contexts in which many people with autism have some difficulty.

Lastly, we do a social-emotional functioning interview. It's nothing fancy – we ask simple questions like where you work, how you got your job, what you like, what's challenging for you, how you met your friends, what you look for in a friend, etc. We also do an adaptive behavior scale to measure independent living skills: Do you do laundry? Do you go to the grocery store? Who takes care of ordinary functions in life for you? We also may screen for depression, anxiety and ADHD – the most common co-occurring conditions that accompany autism.

A formal diagnosis will come with a written evaluation that will include which autism criteria you meet, perhaps even a level of diagnosis as defined in the DSM-5, other diagnosis and suggested supports. This is an important medical document which you should store in a safe place. You should also make copies for your primary care physician, other medical providers, and if necessary, your school or employer. You may also need these documents if you seek benefits or services from state, federal and other public agencies.

*Note: Some states require health care providers who provide a diagnosis to report it to their state Department of Health. It is typically for gathering statistics and funding reasons. Your provider must tell you if this is the case.*

## Barriers to Diagnosis

Not everyone is able or ready to pursue an autism diagnosis. Among the top barriers is cost. Evaluations can be expensive. For perspective, at Dr. Lord's clinic at UCLA, an assessment costs around \$5,000 to \$6,000 which is on the high side. Constituents have reported to us that an evaluation can run around \$2,000. Though Dr. Lord accepts insurance, many psychologists and psychiatrists with independent practices do not. It is always best to call your insurance company in advance and work with them to maximize your coverage. To help with cost, many clinicians and/or their related practice will offer sliding scale payments. You should always ask.

Another major barrier is time. The process often requires several long appointments, as Dr. Lord explains above. Waits for an appointment can be long, too. Also, since there are still too few clinicians experienced at diagnosing adults, distance can prove an issue for many.

If it seems impossible to get an evaluation with a qualified clinician, there may be other options. Check with your primary care doctor or a qualified mental health provider to see if they can provide a diagnosis based on their knowledge of you and your history.

## Do You Need a Formal Diagnosis?

You may be wondering if you need a formal autism diagnosis, especially if you have lived without one for many years.

One reason to pursue one is that an adult with a formal diagnosis could be eligible for supports, services and protection under the [Americans with Disabilities Act \(ADA\)](#). The act spells out specific rights, including the right to reasonable accommodations at work and school and protection against discrimination based on difficulties associated with autism. A diagnosis could also lead to state-provided vocational support services. This can include vocational rehabilitation programs that provide counseling and job placement services for people with disabilities, including autism.

***"You're still the same person, but a diagnosis might make it easier to be gentle and more understanding with yourself."***

*- Lisa C., 34-year-old working professional with autism*

An official diagnosis can also help answer questions you may have had about yourself and your behavior for many years. For some, it is simply a relief to know that these behaviors can now be explained with the diagnosis. It can help you focus on your strengths and work around your challenges.

Ultimately it is up to you to determine if you need a formal diagnosis. Even if a therapist or your primary care physician brings up autism as a possibility, you are under no obligation to pursue one. But you should evaluate your life circumstances and your support needs. Here are some things to consider.

### **You may want a formal diagnosis if:**

- You need a specific type of therapy or other service that is only offered to those with a current autism diagnosis.
- You want to access disability services and legal protections offered through the federal government or your state and are without another diagnosis that allows you to access them.
- Your source of funding for services – health insurance, grants or government programs – is limited to people with autism.

**You may not need a diagnosis at this time if:**

- You are already receiving or able to access the support you need, such as mental health counseling or Social Security Disability, based on another mental health or medical diagnosis.
- You have a strong network of natural supports, like a good social group.
- You are mainly interested in connecting with other autistic people.
- You wonder if a diagnosis may not be helpful. For example, if you plan to enlist in the military, a formal diagnosis could result in increased hurdles to join. If you are divorcing or ending a relationship with the parent of your children, a new diagnosis could complicate custody issues.

## What Does a Diagnosis Mean?

*"It's always good to know what you're made up of. It helps guide and understand how you react and interact."*

*– Simon, 46-year-old working professional  
diagnosed 2 years ago*

Because every autistic person is different, a diagnosis can mean many different things. For instance, it could come as a life-changing revelation. You might feel relieved to know why you always felt different from your peers or validated that your challenges are not personal failures. You might feel like there are other people who understand you for the first time in your life. You might even feel a sense of freedom, like you can finally unmask and live as your authentic self.

Or, you could feel angry for all the years you were misunderstood and unsupported. Perhaps you fear losing your identity and being treated as a label instead of an individual. You could also feel overwhelmed as you try to figure out what kind of support you need and how to get it.

You might feel a combination of positive and negative emotions, either all at the same or in waves. Over time, these settle down, and you will find that your diagnosis serves a purpose. It is like an arrow, pointing you toward information, resources and services that are designed for the unique strengths and challenges of autistic people.

## From denial to acceptance: Getting diagnosed with autism at 24

*John Taylor, Autism Speaks database coordinator*

One day my father showed my mother a magazine feature he read about Asperger syndrome and said something like, "Doesn't this remind you of John?" She agreed and talked to me about it. Together we went to Seaver Autism Center at Mt. Sinai Hospital in New York. After a series of tests, they diagnosed me with autism at the age of 24.

My autistic traits have been front and center all my life. Growing up I struggled socially. But three things really define me: splinter skills; special interests; and literal interpretation of language.

**Splinter skills:** From 4th to 6th grade, I was the geography bee champion at school. However, my knowledge of geography was quite lopsided towards the large scale. My small-scale geographical knowledge, like with counties and US states, was lacking. I wouldn't have been able to tell you much about my local area or where my town was in relation to other towns. Some call this lopsidedness a "splinter skill."

**Special interests:** When I get interested in something, my life centers around it and I want to learn everything about it. Trains were one of them.

I got into trains and model railroads in lower elementary school. If I had a choice of a present at those ages, I wanted something like a new train car, track or other feature for my model railroad. When I went to the library, I would check out books about trains. Little 3rd grade me didn't care if the books were for college students. They were about trains and that's all that mattered. While I watched plenty of shows and movies targeted towards little kids, I also enjoyed watching documentaries on trains and railroads. I wanted to learn all about trains, from old steam locomotives to modern electric trains. I started to lose my interest in trains some time in upper elementary school. I brought it up to demonstrate how intense special interests have been a part of my life since a young age.

From high school until now, I've been interested in linguistics. Linguistics is the scientific study of language as a whole, not about learning specific languages. Linguistics is descriptive, not prescriptive. That is, it aims to describe how language actually is, rather than to prescribe how it should be, or how some people think it should be. Among other things, linguists study speech sounds (phonetics), how sounds apply to different spoken languages (phonology), how words are structured (morphology), and how sentences are structured with those words (syntax).

In college, I majored in and earned a BA in linguistics. Since graduating, I haven't done any postgraduate studies in it, let alone pursued any related professional work. These days, I engage in it mainly through participating in Facebook groups, listening to podcasts, watching YouTube videos, and reading Reddit posts. I find this very beneficial to my mental health. There are times when I've been feeling depressed and eventually realize that I haven't looked at any good linguistics content in a while. After I remedy the situation, I get back into a good mood.

I'm not sure if I can explain why I've been so interested in linguistics, but I think it's just that language is a part of life. I am using language right now to tell you my story and you are using language to understand it, and possibly apply it to your own life. Isn't that fascinating? Well, if it's still not fascinating, that's OK. I don't think different special interests would be called such if everyone was into them.



**Literal interpretation of language:** Speaking about language, another thing many people with autism are known for is literal interpretation of language. This was definitely the case for me when I was younger. If the instructions were “color the fire truck red” and the crayon said something like “brick red” instead of simply “red”, I wouldn’t use it. Nowadays, I have a pretty good grasp on non-literal use of language, as long as I’m not overtired, and use it elsewhere in this story. Also, I can probably out-sarcasm even non-autistic people. *(Editor’s Note: This last sentence could not be fact-checked.)*

Remember, it was my parents who thought I might be autistic and it was my mom who brought me in to be tested? Well, the whole time during my evaluation and even afterwards, I was skeptical of any notion that I might have autism. That was because I barely had an idea of what autism was. When I thought about an autistic person, the image that popped up in my mind was that of a savant, which I am not. Now I know that only a minority of autistics are savants.

Even after I began to research autism, it still didn’t look like the criteria applied to me. I remember watching some YouTube video where they first interviewed an autistic guy who said something like “Before I was 24, I didn’t know people had emotions.” They probably interviewed other autistic people in that video, but I didn’t bother to watch the rest of it. Also, the stereotype about loving math isn’t true for me. I find it boring, except for geometry, and impersonal. Nor is the stereotype about not having a sense of humor.

Even though the first YouTube videos on autism that I saw were not relatable, I eventually found ones that were, mainly from autistic content creators. I also started to attend social skills groups for autistic people. I began to see the diversity of autistic life. Some of their experiences matched my own and so I slowly began to accept that I am autistic as well. There’s a saying that’s commonly attributed to Dr. Stephen Shore, whose “Strengths and Challenges” article appears in this guide as well: “If you’ve met one person with autism, you’ve met one person with autism.” Each one of us is so unique. This obviously also applies to non-autistic people as well, but people are less likely to try to fit them in a box.

Maybe you are reading this Tool Kit because someone suggested to you that you might have autism and you’re skeptical. Maybe you’ve even been diagnosed and you’re still not so sure. Maybe you think “Aren’t all autistic people like such and such or so and so?”. Maybe you’ve never come across autistic people who match your own demographic information. Trust me, there are autistic people who match your own demographic information. I would suggest learning from as many perspectives on autism as possible: from autistic people; from their family members; from their friends; and from professionals.



## When to Seek a Second Opinion

As previously stated, there are still too few clinicians with experience evaluating autistic adults. So what do you do if you think you are autistic but did not receive a diagnosis after seeking an evaluation?

First, it's important to remember that clinicians use a clearly defined set of criteria explained in the DSM-5 and used by their peers, to ensure there is uniformity across their professions in evaluating autism. Like other conditions in the DSM-5, a diagnosis of autism is based on your behaviors a clinician observes.

Many autistic people who are seeking a diagnosis in adulthood have mastered the art of masking their autistic traits. It can be very difficult to take off the mask, particularly in front of a clinician you just met and going through a process that can be anxiety-inducing. As such, a clinician may miss your autistic traits and your diagnosis. If you feel this applies to you, you may want to seek a second opinion or the help of a therapist to pursue another avenue for evaluation.

Otherwise, a good clinician should be able to explain their thinking, including which criteria you do and do not meet for any diagnosis they make or rule out. Here are some red flags about your clinician that should prompt you to seek another opinion:

- Dismisses the possibility of autism rather than asking questions to understand your reason for bringing it up.
- Denies that autism affects a specific group, like women.
- Eliminates the possibility of autism based on an achievement, i.e., you're a parent, a college student, a professional in a demanding field.
- Points out masking behaviors as reasons you cannot be autistic, such as making eye contact or appearing very social, rather than recognizing them as your coping mechanism.
- Suggests that your intelligence or verbal ability means you cannot be autistic.
- Says that you would have been diagnosed as a child if you were autistic.
- Believes that there are no supports or services available for autistic adults, so discredits the need for a diagnosis.

## The Role of Self-Identification

The rise in availability and ease of accessibility to information about autism has resulted in an increase in the number of people identifying with autistic traits. Given the barriers to getting a diagnosis, some people opt to self-identify as autistic after exhaustive research and careful self-reflection. Some may even identify as "self-diagnosed." However, a diagnosis can only be done by a qualified professional. Importantly, a major limit to self-identification is that it prevents you from accessing autism services and legal protections.

But for those who have established natural supports in place or who do not require autism-specific services available to those with a diagnosis, self-identification may suffice. For many, simply gaining a better understanding of their brain is what matters. The semantics around their label does not.

Additionally, the autistic community tends to be welcoming to anyone who feels like they belong there. Many autistic-run organizations and support networks are open to those who recognize certain autistic traits in themselves and who make use of many of the strategies, tools and resources designed for autistic people. It is in this space where progress towards full autism acceptance and awareness can be made.

But there are also reasons to be cautious about self-identification. One is the risk of missing another key diagnosis. Clinical evaluations include assessments for other conditions in addition to autism, such as a learning disability, anxiety or ADHD, which we will cover in the next section. These conditions can be just as important as autism when it comes to finding support and strategies that work for you.

Another risk is that misinformation is abundant online, particularly on social media. Sometimes, as in the case of many personal experience videos, incomplete information is presented and unfounded solutions are presented. It is important to note that a shared experience with another who is autistic does not automatically mean that common experience is specific to autism.

## CO-OCCURRING CONDITIONS AND OTHER COMMON RELATED ISSUES

Most autistic people are diagnosed with one or more other physical or mental health conditions. These generally fall into one of four groups: general medical problems, such as epilepsy, gastrointestinal issues or sleep disorders; mental-health conditions, such as attention-deficit/hyperactivity disorder (ADHD) or depression; developmental diagnoses, such as intellectual disability or language delay; and genetic conditions, including fragile X syndrome, which is typically diagnosed in early childhood.

Some research suggests that autism shares a genetic basis with several other psychiatric conditions, including ADHD, anxiety, depression, bipolar disorder and schizophrenia. Research also shows that some of these conditions, especially mood and anxiety disorders, are even more common in late-diagnosed autistic people than those diagnosed in childhood.

### Attention-deficit/hyperactivity disorder (ADHD)

ADHD is a developmental disorder that affects an estimated 50 to 70% of people with autism, according to the National Institute of Health (NIH). It affects the prefrontal cortex of the brain, which controls executive functions (more on those below) and other self-regulatory processes. One sign of ADHD is chronic difficulties with organizing and carrying out actions across time, especially when there is no recognizable or immediate reward for doing so.

The key traits associated with ADHD are inattention, hyperactivity and impulsivity.

- Inattention may include difficulty with focusing or staying on task, staying organized, listening and following directions.
- Hyperactivity may involve fidgeting and squirming, difficulty with quiet tasks and excessive talking.
- Impulsivity can cause an individual to act without considering the consequences, interrupt others when talking and have difficulty managing their emotions.

Signs of ADHD often overlap with those of autism. As a result, ADHD can be difficult to distinguish in someone on the spectrum. If you suspect you may have ADHD, look for a specialist familiar with both conditions. They can evaluate you and discuss strategies, therapy methods and medications.

### Anxiety

Studies show that up to 50% of autistic adults have an anxiety disorder – over twice that of neurotypical adults. Anxiety disorders can include generalized anxiety, panic attacks, obsessive compulsive disorder and fears or phobias. Social anxiety – or extreme fear of people, crowds and social situations – is especially common among autistic people. Anxiety can be triggered at different points in time and by different activities, including experiences that used to be enjoyable.

Anxiety can result in a racing heart, sweating, muscle tightness and stomachaches including nausea and vomiting. Some people may try to escape the situation, others freeze in place. Many people with autism have difficulty controlling anxiety once something triggers it.

What makes identification tricky is that traits that characterize autism, including social differences, can mimic symptoms of anxiety. Compounding the problem is that diagnostics to screen for anxiety were developed for neurotypical people, leaving many autistic people misunderstood and/or under- or misdiagnosed. The risk: untreated and poorly treated anxiety in autistic adults is known to lead to depression, aggression and even self-harm.

Recently neuroscientists discovered structural differences in autistic people's amygdala, the brain's emotion and fear center, that indicate anxiety is different for those with ASD than it is for everyone else. It only makes sense then that management would be different for autistic people.

Autism-specific anxiety management is still being researched. But there are treatment options, including cognitive behavioral therapy adapted to autistic people and sensory diets. The same medications approved to treat anxiety disorders in the general population are commonly used to help autistic people. These medications may be best used in combination with counseling or other behavioral interventions. Read more about what has worked for other autistic adults [here](#).

## Disrupted Sleep

Many adults on the spectrum have difficulty falling asleep and staying asleep through the night. Over time, sleep problems can impact physical health, thinking and learning and mood. If you have disrupted sleep, start with good sleep hygiene, like limiting screen time before bed, sticking to a routine and limiting caffeine later in the day. You can also talk to your primary care doctor or psychiatrist if these strategies are not effective.

## Eating and Feeding Disorders

Autistic people frequently experience sensory aversions to tastes, odors and textures and a strong need for sameness in the foods they eat. If these issues are significant, the person may be diagnosed with an eating disorder.

Anorexia nervosa is more common among autistic people, especially late-diagnosed women. It appears that up to 20-35% of women with anorexia nervosa meet the diagnostic criteria for autism. Treatment often involves a team of professionals, including primary care doctors, registered dietitians, therapists and sometimes psychiatrists.

Avoidant/restrictive food intake disorder (ARFID) applies to those who eat such a limited diet, they are at risk of malnutrition and medical complications. ARFID is different from anorexia nervosa in that it does not involve concerns about body weight or shape. While extreme food selectivity is more common in children, symptoms can carry over into adulthood. Because ARFID is a newer diagnosis, it may be harder to find a qualified clinician who also has experience with autism.

## Epilepsy

While epilepsy (seizures disorder) affects only 1 to 2 percent of the general population, it affects up to one third of people with autism. Seizures almost always develop before adulthood, with symptoms most likely to develop during adolescence.

## Executive Dysfunction

Executive dysfunction is not a medical diagnosis but a common behavioral experience that disrupts a person's ability to manage their own thoughts, emotions and actions. Executive functioning includes skills such as organizing, planning, sustaining attention and inhibiting inappropriate responses. Difficulties in this area can manifest themselves in many ways. Some may pay attention to minor details, but in turn struggle with seeing how these details fit into the bigger picture. Others have difficulty with complex thinking that requires holding more than one train of thought simultaneously. Others have difficulty maintaining their attention or organizing their thoughts and actions. Individuals with autism often face challenges using skills related to executive functioning like planning, sequencing and self-regulation.

## Gastrointestinal Issues (GI)

GI issues, such as chronic constipation or diarrhea, abdominal pain and gastroesophageal reflux are even more common in autistic people than the general population. The reasons are not fully understood, but it is thought that extreme food selectivity and high levels of stress common in autistic people might be related. Because GI discomfort can negatively affect sleep, mood and behavior, it is important to address these issues with a doctor.

## Mood Disorders

Autistic people are prone to depression. About one-quarter of autistic people will be diagnosed with depression, a rate four times higher than non-autistic peers. Many people never seek treatment for depression, but when diagnosed properly, therapy and medications can significantly improve symptoms.

Sometimes, autistic traits can mask symptoms of depression. Many autistic people experience alexithymia, which is characterized by difficulty identifying, expressing and describing one's emotions. This can make it harder to notice when a mood disorder is creeping in and harder to let others know when you need help. Common behavioral signs of depression might be easier to recognize in yourself, like loss of interest in favorite hobbies, changes in sleep or appetite, low energy levels or frequent headaches and stomachaches without a physical cause.

Bipolar disorder, also known to be more common among autistic people and known to develop in the later teens and twenties, involves episodes of abnormally high energy, or mania, alternating with episodes of depression. Among autistic people, symptoms of mania commonly include abrupt increases in pressured or rapid speech, pacing, impulsivity, irritability and insomnia. Psychiatrists often prescribe mood-stabilizing medications to treat bipolar disorder.

## Obsessive-Compulsive Disorder (OCD)

Doctors or therapists unfamiliar with autism often mistake some of autism's core signs like repetitive behaviors and restricted interests with those of OCD. But it is important to distinguish between the two. A distinguishing hallmark of OCD is that compulsive thoughts or behavior cause anxiety. By contrast, autistic people are not generally bothered by their repetitive behaviors and restricted interests, which tend to bring them comfort and enjoyment. The estimated prevalence of OCD in those with ASD ranges from 8 to 33% depending on the study, compared to the general population prevalence of 2%. For an OCD diagnosis, it is important that the mental health professional has knowledge of autism and its symptoms. As is the case with other disorders, a combination of medication and cognitive behavioral therapy can significantly improve the symptoms of OCD.

## Sensory Integration Dysfunction (SID)

Many individuals with autism experience unusual responses to sensory stimuli or input due to difficulty in processing and integrating sensory information. Vision, hearing, touch, smell, taste, the sense of movement and the sense of position can all be affected, meaning while information is sensed normally, it may be perceived much differently. Stimuli that seem "normal" to others can be experienced as painful, unpleasant or confusing by an individual with autism.

SID can involve hypersensitivity, such as an ability to tolerate being touched, or hyposensitivity, such as an increased tolerance for pain or constant need for sensory stimulation. These issues are usually addressed with sensory integration therapy, which is provided by certified occupational and physical therapists.

## Autistic burnout: When navigating a neurotypical world becomes too much

*by Brigid Rankowski and Lydia Wayman, self-advocates and Autism Speaks contributors*

Navigating a world designed for neurotypical minds can present some unique challenges when your brain works differently than most. You might find yourself struggling with things that come easily to those around you. Over time, this can lead to what many people in the autism community refer to as autistic burnout — a state of intense mental and sometimes physical exhaustion and loss of skills needed to manage daily life.

**“I was masking and doing a lot of customer service work. I had someone yell at me and felt like I couldn’t talk anymore (a recurring theme I didn’t understand) but became so tired of trying that I quit my job and stayed in my dark bedroom for a week. I didn’t eat unless it was already made even if I was hungry.”**

**– Jessica, 27-year-old working professional with autism and single parent to an autistic child**

Although autistic burnout is not a clearly defined medical term or formal diagnosis, it is a common and widely discussed experience, especially in those who have learned to mask their autistic traits to the point that their true support needs are not recognized.

Neurotypical people can experience burnout, too, often in relation to high-stress jobs or long-term caregiving. Autistic burnout is similar, but the causes and consequences may look different.

Autistic people may experience burnout at points in life when expectations increase and new, more complex skills are required for you to keep up. This could be a major life transition, such as a new job or moving, or a shift into a new stage of life, such as the transition to early adulthood,

Burnout can also creep in slowly. You may feel more worn down without any way to feel like you are fully recharging yourself. These feelings can gradually affect your home, work and social life in ways you aren't aware of because you are unable to see the bigger picture.

It's important to keep in mind that burnout is not a personal failure but the result of trying to keep up with demands that take too much energy and are unsustainable for long periods of time.

Autistic burnout might look like:

- Difficulty with skills such as speech and language, executive function, self-regulation
- Heightened sensory sensitivity or need for more sensory input
- Increase in mental health issues like anxiety and depression
- Withdrawing from your usual social activities or relationships
- Difficulty with executive functioning, such as completing tasks and making decisions Increase in repetitive behaviors, like stimming
- Difficulty with activities of daily living like cooking, cleaning or personal hygiene
- More frequent meltdowns

- Sleeping more or having trouble sleeping
- Spending more time alone than usual

Preventing or recovering from burnout involves a combination of reducing demands and increasing supports. It may take some trial and error to find strategies that work for you.

- If you feel overwhelmed by social interaction at work, you might decide to spend your lunch break by yourself instead of socializing.
- If you experience sensory overload in crowded indoor places, you might do errands during off hours or try wearing earplugs at the grocery store.
- If you struggle with executive function demands like keeping appointments or managing finances, you could use a visual chart or checklist to help you keep track.
- If you are experiencing symptoms of depression or anxiety, consider seeing a mental health clinician. Look for a therapist who is familiar with autism in adults.
- If you are someone who frequently masks your autistic traits, consider who or where you might be comfortable enough to let down your guard. You might find it less draining if you don't force yourself to make eye contact or avoid self-soothing repetitive movements.

## SERVICES AND SUPPORTS

Autistic adults are often eligible for services to support them in various aspects of their lives. Services vary from state to state, but most involve a team component comprised of the individual, family members, friends, and coordinators from any agency or organization where you may qualify for services. The following is not exhaustive but provides some basic information to help you begin to navigate programs and options. An official diagnosis is required for all federal and state services.

### Supplemental Security Income (SSI)

SSI is a Federal Social Security cash benefit that is available to disabled individuals who demonstrate financial need. If you are aged 18 or over, your financial need is based on your ability to earn income. Receiving SSI does not prohibit you from working. SSI operates on a sliding scale. The amount of cash received monthly is adjusted according to your current income.

Applying for SSI can take several months and involves providing detailed medical or other documentation, as well as undergoing evaluation(s) by qualified SSI medical professionals. It is never too late to apply for SSI. The process can be initiated by you, a family member or support person at any time. For more information on SSI, visit [ssa.gov](https://www.ssa.gov) or call or visit your local Social Security Administration office.

### State Vocational Rehabilitation Services (VR)

The State Vocational Rehabilitation (VR) Services Program, authorized by the Rehabilitation Act of 1973, provides grants to states to assist in VR programs in providing services for individuals with disabilities so that they may prepare for and maintain employment and achieve economic self-sufficiency.

To qualify, you must demonstrate that autism or another disability currently presents obstacles to employment that can be remediated through vocational rehabilitation services. A VR counselor will review your medical and educational history, as well as employment experience. This is a significant arena where community and personal advocacy play an important role.



To learn more about applying, visit your local VR office or find your state VR website [here](#) where you can find and connect with your [state liaison](#) for further information.

## Medicaid Waivers

Most states have a program for individuals with developmental disabilities called a Medicaid Waiver (also known as 1915(c) Home and Community Based Services (HCBS)). A Medicaid Waiver is designed to provide support services and care to allow an individual to remain at home or in the community, rather than in an institution, nursing home or hospital. The benefits provided by these waiver programs vary by state, but most generally provide coverage for medical treatments, respite care, transportation, in-home support and more. Waiver criteria and availability varies from state to state.

You should also note that waivers may have different names in your state. Some common names for them are: Autism waiver, Person Directed Support waiver, Developmental Disabilities waiver or Individual and Family Support waiver.

To learn more about HCBS visit <https://www.medicaid.gov/>. Find out the waivers available in your state here: [www.medicaid.gov/medicaid/section-1115-demo/demonstration-and-waiver-list/index.html](http://www.medicaid.gov/medicaid/section-1115-demo/demonstration-and-waiver-list/index.html)

## ABLE Accounts

A new type of savings option was made available for individuals with disabilities through the Achieving a Better Life Experience (ABLE) Act of 2014. The law helps ease financial strains faced by individuals with disabilities by making tax-free saving accounts available to cover qualified disability expenses. It allows you to save for long-term expenses without sacrificing eligibility for public benefits such as Medicaid and Supplemental Security Income (SSI).

Once an account is established, account contributions will accumulate tax-deferred and any earnings will be tax-free at the federal level if the money is used for qualified expenses. Typically, contributions for an ABLE account may not exceed the annual gift tax exemption. Distributions are only to or for the benefit of the designated beneficiary for qualified expenses including those related to education, housing, transportation, employment, and health and wellness among others.

You can open an ABLE account by going directly to an ABLE program's website or by calling their customer service. Some state programs may offer paper enrollment. Find your state's ABLE programs and website here: [www.abletoday.org/able-programs](http://www.abletoday.org/able-programs)

## THERAPY

Autism is a lifelong condition, but supports for adults are often approached differently than in those for children. Though far more research has gone into effective therapies for children, as the population of adults on the spectrum continues to rise and more adults are seeking diagnosis, more studies are beginning to focus on the best ways to help autistic adults.

It is important to remember that each person with autism is unique, and as a result, a therapy approach that works for one autistic adult may not work for another. You should choose a therapy based on an area or skill set you are trying to improve or better manage. The upside to most therapy for autistic adults is that the insights and skills you can gain can help with other co-occurring conditions.

Some common therapies are as follows:

**Applied Behavior Analysis (ABA)** involves techniques for understanding how behavior works with a focus on positive reinforcement. It is one of the more common therapies associated with autism. It also worth mentioning that it has been criticized by some autistic adults who contend it is an attempt to make them fit neurotypical standards.

**Cognitive Behavioral Therapy (CBT)** is a common type of talk psychotherapy. Working with a therapist you work to identify negative thinking so you can view situations differently and respond to them more effectively. CBT is not adapted for autism though many autistic people try it.

**Occupational Therapy (OT)** helps build daily living skills such as cooking, cleaning and personal care that become a challenge due to overload. A therapist will focus on addressing any sensory processing issues or sensory sensitivities that interfere with your ability to participate in daily activities.

**Social Skills Groups** are therapeutic groups for learning and practicing ways to interact with others and build fulfilling relationships. Some autistic adults who participate report long-term improvement in social communication, social engagement and empathy.



## Beyond autism-specific therapy: Finding the help you need

*by Megan Farley, Ph.D., psychologist at the Waisman Center at the University of Wisconsin*

### **General Guidelines for Finding the Help You Need**

Beyond autism-specific programs and therapies, I can offer you some general recommendations based on my clinical experience, that of my colleagues and that of the many adults with autism with whom I've had the privilege to work. First, it's important to consider what type of help you need. Every individual with autism is unique in terms of their challenges and strengths.

Typically adults with autism come to a mental health clinic because they're struggling with one or more issues. Common autism-related challenges include social isolation, finding and keeping a job or a romantic partner, anxiety or mood problems or an inability to organize one's life.

For mood or anxiety problems, I recommend seeing a psychiatrist for a medical consultation and a psychologist or social worker for individual therapy or group counseling. Ideally you want someone experienced in helping adults who have autism. So ask for such expertise when you contact a therapist or mental health clinic.

### **Beyond Autism-Specific Therapy**

Unfortunately, not every community has adult autism specialists. If yours does not, I recommend finding a counselor who seems sincerely interested in learning more about autism in general and your experience in particular. In addition, it's important to understand that both psychologists and social workers can vary widely in the approach they use in counseling. In my experience, most individuals with autism do best with therapy that takes a concrete, skill-building approach. Cognitive behavioral therapy (CBT) is a good example of this type of therapy.

I also suggest that you consider bringing along someone who knows and cares about you for at least part of the therapy session. In my experience, many adults with autism have difficulty explaining their challenges. Someone who knows you well may be able to help you and the therapist zero in on the behaviors that are creating problems and develop strategies to address them.

You might also want to consider group therapy or classes for those who have difficulty with social interactions. Learning social skills in a group can be particularly helpful because participants can share observations and suggestions. Your therapist or social worker may be able to recommend such a group in your community.

Finally, I recommend you look to the community of adults with autism. There are several good websites that provide information and forums for adults with ASD.

## RIGHTS

With an official diagnosis you are awarded certain protections under various laws. Below is an explanation of some of these and the rights they give you as a person with a disability.

### Americans with Disabilities Act (ADA)

The ADA prohibits discrimination and ensures equal opportunity for persons with disabilities in employment, state and local government services, public accommodations, commercial facilities and transportation. In terms of employment, Title I of the ADA applies to public and private employers with 15 or more employees and prohibits discrimination based on disability when it comes to any aspect of employment, including hiring, firing, pay, job assignments, promotions, layoffs, training, fringe benefits and more.

The law also requires an employer to provide reasonable accommodation to an employee or applicant with a disability, unless doing so would cause significant difficulty or expense for the employer. More on reasonable accommodations below. If you do receive an official diagnosis, it is important to read about your rights under the ADA, especially if you feel you have been treated unfairly or even discriminated against in the workplace. If there is a “reasonable” accommodation related to challenges you face as an autistic person that could be put into place that may help better support you in your job, a diagnosis may help you secure that accommodation. You can learn more at [ada.gov](http://ada.gov).

### Section 503 of the Rehabilitation Act of 1973

Section 503 prohibits discrimination and requires employers with federal contracts or subcontracts that exceed \$10,000 to take affirmative action to hire, retain and promote qualified individuals with disabilities. This law is enforced by the Employment Standards Administration’s Office of Federal Contract Compliance Programs (OFCCP) within the U.S. Department of Labor.

### Section 504 of the Rehabilitation Act of 1973

Section 504 is a national law that protects qualified individuals from discrimination based on their disability. It applies to employers, public colleges and universities and other organizations that receive financial assistance from any federal department or agency. For purposes of employment, qualified individuals with disabilities are persons who, with reasonable accommodation, can perform the essential functions of the job for which they have applied or have been hired to perform.

Under Section 504, a recipient of federal financial assistance may not, on the basis of a disability, deny qualified individuals the opportunity to participate in or benefit from federally funded programs, services or other benefits or deny employment opportunities for which they are otherwise entitled or qualified. Section 504 is also the law that requires school districts to provide a “free appropriate public education” to each student with a disability, regardless of the nature or severity. While ADA also protects individuals with disabilities against discrimination, Section 504 goes a step further by requiring organizations receiving federal funds to make their programs accessible to these individuals. If you have an official diagnosis of autism, you are able to seek protection and accommodations in all federally funded programs – employment, housing, community living, etc. – under this law.

### Enforcing Employment Law

The Equal Employment Opportunity Commission (EEOC), found at [www.eeoc.gov](http://www.eeoc.gov), enforces laws against workplace discrimination on the basis of an individual’s race, color, national origin, religion, sex, disability and age. The law also protects people from discrimination based on their relationship with a person with a disability (even if they do not themselves have a disability). For example, it is illegal to discriminate against an employee because her husband has a disability. It is illegal to harass an applicant or employee because they have a disability, had a disability in the past, or is believed to have a physical or mental impairment that is not transitory (lasting or expected to last six months or less) and minor (even if they do not have such an impairment). Harassment can include, for example, offensive remarks about a person’s

disability. Although the law does not prohibit simple teasing, off-hand comments, or isolated incidents that aren't very serious, harassment is illegal when it is so frequent or severe that it creates a hostile or offensive work environment or when it results in an adverse employment decision (such as the victim being fired or demoted).

## Voting Rights

It is critical to exercise your right to vote. To access accommodations, understand the process or learn about candidates in local, state and national level elections, as well as register to vote, visit the [National Disabilities Rights Network](#).

# SELF-ADVOCACY

## Communication Basics

*“Because I was diagnosed later in life, I don’t really have a great barometer for my support needs. That said I now speak up when I am feeling overwhelmed, and people have become more supportive when I do so.”*

– Tahitia, 49-year-old Black cisgendered, queer, autistic woman diagnosed at age 45

Self-advocacy can take many different forms, but it comes down to the same thing – speaking up for your needs and rights. How can you do this when, as an autistic person, communication itself is a challenge?

Here are some strategies you can try in situations where communication is limiting your ability to advocate for yourself:

- Create a script for yourself before making phone calls, attending meetings, or any other situations where you want to feel prepared.
- Use a checklist, bulleted list, or visual cues to help you organize your thoughts.
- Use emails or messages to communicate ideas that are hard to verbalize.

- Practice conversations with someone before initiating the real one. You can also ask someone to read over a script, email or typed message for you before sending it.
- If you are struggling in the moment, try pausing to write out or even type out your thoughts on your phone.
- Find creative ways to express yourself, like art, music or writing.
- Carry pre-printed cards in your wallet, pocket, attached to the back of your phone or even as saved pictures on your phone for high-stakes situations, such as an emergency contact card or a medical information card.
- Some autistic adults who have limited speech find using some form of alternative and augmentative communication (AAC) device, such as an iPad, is beneficial.

Many autistic people who are diagnosed as adults have been told for many years that because they speak fine in one situation, they should be capable of doing so in any situation. They are told to try harder, do better or get it together. Over time, you may internalize these messages, but it is important for you to know that your challenges are real, and they are not your fault. Some autistic people find that the right communication strategies are what finally allow them to share their true self with others. It starts with understanding how your brain works and what strategies work best for you. Learning to be patient with yourself will be key in becoming your best self-advocate.

## Disclosure

To tell or not to tell is a very personal decision and totally up to you. There is no law obligating you to disclose your diagnosis. While weighing the pros and cons of disclosure and who needs to be told, you should consider why they do and how much they need to know.

It could be helpful to share your diagnosis with your immediate family and close friends to help explain your behavior and experiences that may have been challenging. Just as your diagnosis may have helped answer questions you had about yourself, it may also help clarify questions others in your life may have had about

you. For example, telling your sibling you have been diagnosed with autism could help them understand why you like to use emojis rather than words when responding to their texts, or why you prefer to talk about your interests rather than the latest streaming shows that they might find interesting. Telling them can also help start a broader conversation about autism where you can learn about it together. More information on Relationships can be found below.

Some level of disclosure will be necessary at school or work if you want to be eligible for accommodations or exercise protections under the laws covering both as outlined above. In these two situations, note that once you do disclose, the information is considered confidential. You own it and are protected from it being shared or used against you. Neither institution has the right to disclose your diagnosis to anyone else.

As noted above under the Evaluation Process, some states require providers report your diagnosis to the state Department of Health. Also important to note is that if you use your health insurance to seek autism-related services, by default you are disclosing your diagnosis to your insurance provider. However, all your medical records are protected and considered confidential under federal and state laws, including the Health Insurance Portability and Accountability Act of 1996 (HIPAA). This law further protects you by giving you the right to tell providers and your health insurance company not to share your information with certain people, groups or companies. To find out if anyone other than your provider or health insurance company has accessed your medical record and been granted access to your diagnosis, visit [hhs.gov/ocr/privacy](https://hhs.gov/ocr/privacy).

## Accommodations

Thanks to an increase in awareness and acceptance of autism, public places have started to proactively offer accommodations for autistic people. Retailers have offered autism-friendly shopping days when the lights are dimmer, the store-wide speakers are silenced and the crowds limited. Sports stadiums have installed autism-friendly rooms which are sound-proof from outside noise and easily accessed through special entrances free from long lines and crowds. Cruise lines have offered autism-friendly tours and hair salons have adjusted their practices to make autistic customers more comfortable. The best thing about most of these is that you do not need to prove your autistic to enjoy these sensory-friendly events.

But when it comes to school and work, autistic adults still need to disclose their diagnosis in order to be eligible for accommodations. Here is how it commonly plays out at both.

### School

Under both the ADA and Section 504, colleges and universities are required to provide reasonable academic accommodations to students they admit who have disabilities. However, colleges and universities are not obligated to identify students with disabilities. It is up to you to let your school know you are autistic. It is completely voluntary to do so in your application process.

Whether you disclose your diagnosis on your application or not, if you require accommodations, your first step is to meet with your school's Disability Support Services office. Bring documentation of your diagnosis and the impact it has on your ability to function in school. It is a good idea to meet with your psychologist, psychiatrist or primary care physician beforehand to get a letter of their expert opinion of your functional limitations.

A counselor within Disability Support Services will help you write an accommodations letter which you will then be responsible to share with your professors. Some typical accommodations include:

- Wearing noise-canceling headphones in class
- Using augmentative and alternative communication (AAC) devices in class
- Preferred seating in the classroom
- A quiet testing space
- Additional time to take a test
- Living alone in a dormitory even though the rooms are meant to share

In speaking with Disability Support Services you may find out that there are specialized programs, clubs and activities available to autistic students. Some can assist the individual with some barriers they may face in college such as socialization, communication and organization.

## Employment

Employers have increasingly focused on expanding efforts to improve access to employment for job candidates on the autism spectrum to tap their diverse talents. Many have adjusted their recruitment, hiring and onboarding practices to increase access for this population.

Under Title I of the ADA described above, employers with 15 or more employees are required to provide reasonable accommodations for an individual with a disability. A “reasonable accommodation” is defined as a modification or adjustment to a job, the work environment, or the way things are usually done during the hiring process. These modifications are meant to enable an individual with a disability to have an equal opportunity not only to get a job, but successfully perform their job tasks to the same extent as people without disabilities.

But in order to ask for accommodations, it is up to you to disclose your diagnosis. You can do so at any time in your hiring or post-hiring process. A good place to start is with Human Resources. Be prepared to discuss how the accommodations will help you perform your job.

Some common and inexpensive accommodations include:

- Asking for a job coach to help with daily tasks and appropriate workplace behavior.
- Requesting bright distracting lights to be dimmed.
- Using noise-canceling headphones to focus as long as they do not impede your safety.
- Asking to respond to verbal requests in writing.
- Requesting advanced notice of meetings, particularly when you may be required to provide or present information.

The Job Accommodation Network (JAN), a service of the U.S. Department of Labor’s Office of Disability Employment Policy, offers accommodation ideas specific to autism and even sample accommodation request letters. JAN is free to access at [askjan.org](http://askjan.org).

## Person-First vs. Identity-First Language

A note on self-advocacy and language: There are so many different ways you can describe your autism diagnosis. Among them, you may say you have autism or ASD, are an autistic person, are on the spectrum, are diagnosed with autism, are autistic, or even refer to yourself as an autist, the noun form of autistic. What’s the difference?

Person-first language (“I am a person with autism”) puts the person before the diagnosis. In English, we tend to use person-first language for conditions that are temporary (“I am a patient with cancer but am receiving treatment”) or separate from a person’s identity (“I have allergies, but they do not define me”). Some think person-first language is a respectful way to talk about any disability.

Identity-first language (“I am an autistic adult”) puts the disability in your description. Those who use this say autism is part of what makes them the person they are, like their nationality (“I am an American citizen”) and gender (“I am a female employee, not an employee who is female”). Many who use identity-first prefer the permanence of it versus the temporary and perhaps negative connotation of person-first language. We found several studies that suggest identity-first language has become the preference of autistic people.

Neither person-first nor identity first seemed to matter among 150 autistic adults who responded to an online survey we hosted for this Tool Kit. When asked “Do you prefer to be called” and told to pick one of four selections, only 19% chose “Autistic person” and 17% chose “Person with autism.” The majority of respondents (57%) selected either “No preference” or “Neither.” (No answer was given by 7% of respondents).

The bottom line is the choice is yours, and others should respect your preferences.

Of note, an increasingly popular term used to describe autistic adults is self-advocate. Many autistic adults also refer to themselves as belonging to the “autistic community” to distinguish autistic people from the broader autism community which also includes parents, siblings, clinicians and allies.



## RELATIONSHIPS

*“Prior to getting my diagnosis, I believed that maybe being close to someone just was something not for me. However, the diagnosis and being kinder to myself and more open to sharing has helped me strengthen existing family relationships. It’s also helped me navigate romantic relationships better.”*

*– Tahitia, 49-year-old Black cisgendered, queer, autistic woman diagnosed at age 45*

When it comes to navigating any relationship with a new autism diagnosis it is important to remember that you have always been this person. You just didn’t have the language to explain how you interacted with the world at large.

Expanding on Disclosure addressed above, telling your immediate family and close friends can prove to be helpful in building a support system as you come to learn more about yourself. But you must be prepared that not everyone in your life will be receptive to your news. There may be people who have known you for years, like your parents, who don’t understand the ways your disability has affected you. They may think you had rough times but not fully grasp what that means – perhaps out of guilt, perhaps out of lack of awareness of what autism is or perhaps both. There may be others less receptive to your diagnosis and resulting personal growth because they liked or benefited from the person you were before your diagnosis.

Here we explore how you can move forward with different relationships, and the ways in which you can discuss how autism affects your life with these people.

## Families

The biggest thing a diagnosis can bring to families is the beginning of conversations around accommodations, supports and authenticity.

Some things to keep in mind when you discuss your diagnosis with family members:

- Try not to assign blame for things done, or not done, in the past.
- Assume your family doesn’t know anything about autism, especially the complicated psychology language, diagnosis criteria and related concepts.
- It is okay to end conversations or place some topics as “off limits.”
- Your family isn’t entitled to know anything about your medical information.
- People from older generations most likely have different experiences with disabilities.

A common question from family members will be “is this genetic?” As stated above under Causes of Autism, research suggests that autism does tend to run in families. Your diagnosis may result in your parents or other family members seeing examples of your autistic traits in themselves. Whether they pursue a diagnosis or not, this can spark conversations in your family about disabilities and better ways to support each other.

It is possible that as you work to discover more about yourself that you will come to realize that some choices you made in life weren’t to live life on your terms but choices you made out of obligation to or expectations from your family. But an added bonus to getting a diagnosis is that many autistic adults reveal it leads to greater authenticity. That is, you can now allow yourself to reflect on what you want in life.

It is worth mentioning that autism awareness has grown exponentially in the last three decades. Thirty, forty years ago, autism was largely misunderstood. The prevalence in 2000 was 1 in 150 had an autism diagnosis. Today it is 1 in 36. Disclosure was nearly non-existent, except for those whose disability was physically visible. In some cases, parents either hid an autism diagnosis from their child or refused to pursue one. If you are

such an adult whose parents withheld this information, it is understandable that you have a whole range of emotions now. The “what-if” questions that may arise as you come to grips with learning all of this information about you at once can be overwhelming. Family counseling with your parents may be in order. To find one near you, search by your zip code in [Autism Speaks Resource Guide](#).

## Parenting

Resources for parents who are autistic are few and far between. Fewer are those for autistic parents who also have autistic children, or children with any disabilities. There is no beating around the bush on this: Life can be difficult if you are an autistic parent. But it can get easier with a diagnosis, if you let it.

For starters, a diagnosis should serve to remind you that it is normal and healthy to prioritize your care in order to be there for your children. There should never have been debate about this pre-diagnosis. There is definitely no room for that now.

With your children, the important thing to remember is that you set the tone of how behaviors will be handled. They have been picking up all along on all your subtle and unspoken communications. That doesn't change because you have a diagnosis. What does is that you are now in a uniquely wonderful position through them to influence how future generations view disabilities as just another part of the human experience based on how you react to your own sensory, communication and healthcare needs.

One of the greatest things a parent can do is role model for their children healthy coping mechanisms and natural supports. Children may lack language to verbalize when they are stressed, struggling or dealing with things that don't 'feel right' in their bodies. But now that you know yourself better, you can role model language, supports, and strategies and normalize the concept of advocating for your needs instead of suffering in silence. In doing so, you will also let your children know that adults aren't perfect and that everyone needs support at different times to be their best self.

Another thing autistic parents can do is lean on their community for natural supports. Find babysitters, even if it is so you can have some alone time in your house. Sign up to be the recipient of a meal train. Don't feel you need to handle everything by yourself. “It takes a village” applies to all parents. Embrace this.

If you are co-parenting it may be wise to consult a counselor together to navigate what your diagnosis means. Many now do virtual visits to purposely observe you in your home element, with children present. If you are already seeing a therapist, ask if this is something you can pursue or for a recommendation of someone. Or look for one in [Autism Speaks Resource Guide](#).

## Romantic Relationships

Receiving or pursuing a diagnosis while already in a romantic relationship could provide clarity on difficulties that exist within it. But a diagnosis does not mean that relationship difficulties are on you. In fact, no one in a relationship can be held responsible for something they were completely unaware of. Instead, a diagnosis should help both partners begin to learn more about their differences; it should lead you to strategies for better communication, problem solving and acceptance.

The self-awareness your diagnosis brings could also result in you re-examining your reasons for entering the relationship and your needs for the relationship to continue. Your partner may also have questions. Be prepared for your relationship to change. As long as you fully accept and honor your authentic self, change will be for the better.

One of the bigger issues is: what if you are not in a romantic relationship, then what do you do after a diagnosis? First, you are armed with information to help you know yourself better. That is extremely helpful to any person in any relationship. Perhaps if you have had trouble finding or keeping a romantic relationship, your diagnosis will help provide some insight as to why.

Second, when you decide to disclose is when you feel the time is right. It is ok to wait a few dates. But you shouldn't spring it on anyone as the moving boxes from your apartment are going into your new shared home.

Third, autistic people can and do date non-autistic people. In his article for Autism Speaks 10 things to know about dating someone with autism. Dr. Kerry Magro, Ed.D., author of "Autism and Falling in Love" and autism consultant to the Netflix series Love on the Spectrum U.S., wrote, "Often a misconception is that people on the spectrum want to only date others who are on the spectrum. This couldn't be farther from the truth. We just want to find someone we connect with and can be ourselves with."

## Relationship Scripts

It is very common to have trouble communicating your diagnosis in any of your relationships. It isn't just that autism affects your communication, but maybe more so that the person on the other side of the conversation knows little about autism and will have many questions. This can be overwhelming for you. Below are some short scripts you should keep in mind. Some are stock answers that can be used for a variety of questions.

**"I wanted to talk to you about this, but I didn't know how to bring it up. I recently learned I was autistic and wanted to share it with you."**

**"I'm still the same person I always was, but now I have new language for some of the areas in my life I may struggle with."**

**"I knew there were things I viewed differently, but I didn't have the specific words for how I viewed the world."**

**"It's not that things didn't bother me before, but I pushed them down because I didn't know how much they bothered me or how to express them."**

## Autistic Community

***"I have found community with the parts of my family and friends who are also autistic or generally neurodivergent. I really appreciate the deep and meaningful conversations we have and being able to exist around people who get it."***

*- Kit V, 20-year-old Native American male currently undergoing evaluation for autism*

Wherever you are in your journey with an autism diagnosis, it's important to know that you are not alone. Whether you feel relieved or overwhelmed about a recent diagnosis or you're still figuring things out, there are people out there who have been in your situation.

Within the autistic community, people come together for many different reasons -- they might share specific interests, advocacy goals or challenges. There are groups with vastly different opinions, experiences and beliefs. It can take time, and some trial and error, but there are people out there who will welcome you and make you feel accepted as yourself.

Check out our [Finding Your Community](#) page for a list of online support groups including peer, recreation and religious groups, among others. Included is one of our Facebook groups "[Adulting on the Spectrum](https://www.facebook.com/groups/adultingonthespectrum)" ([facebook.com/groups/adultingonthespectrum](https://www.facebook.com/groups/adultingonthespectrum)). It is a space for autistic adults to cultivate friendships, find support and have fun. The moderators of the group, Andrew Komarow and Eileen Lamb, are autistic adults themselves, and all group members either have an autism diagnosis or identify as autistic.



## AUTISTIC PERSPECTIVES

Whether you have just been diagnosed or wondering if you should get a diagnosis, it is important to learn about what autism looks like first-hand from other autistic adults. As stated in the Introduction, in March 2023 we opened up a 25-question survey and solicited participation from autistic adults aged 18 or older across social media. All questions were optional, and the majority were open-ended. We also asked respondents for their permission to use their name, demographics and each of their answers in this Tool Kit.

**Our goal:** To present a diverse set of experiences across the life span. We received 150 completed responses from adults who said they were either diagnosed with autism or seeking diagnosis. Without their honesty and insight, we could not have revised this Tool Kit. Their candor is invaluable in promoting autism acceptance. We hope that you take comfort in seeing yourself in some of their responses or at the very least, can learn from their experiences.

**Here is a picture of who completed the survey:** The average age of the respondents was 40 years old and the average age of diagnosis among those who responded was 28. Self-described gender breakdown was: 54% female or cisgender female, 33% male or cisgender male, 6% non-binary and 2% transgender. Another 5% of respondents didn't answer. The breakdown of respondents by race skewed white (66%). Another 5% reported being Black or African American, while Asian, Hispanic and Native American were each reported by 3% of respondents. A full 20% of respondents did not disclose. In terms of intersectionality, 20% identified as being LGBTQIA+, 38% reported having multiple disabilities and 38% reported as being a single parent and/or a parent of an autistic child.

### Here is what we found in terms of their experiences:

We broadly wanted to know how autism impact adults and received an array of responses for each of the questions listed below.

*(Note: Responses were only lightly edited for grammar and spelling.)*

### *How has autism impacted your relationship with family members, romantic relationships and/or friendships?*

*"Not knowing my diagnosis as a young person, I tended to camouflage myself by mimicking the behavior of others, which over time wore me down and depressed me. In the present with the diagnosis, I put my needs ahead of the expectations of others. I have no more patience for the theater and hypocrisy of others. I don't believe in relationships just because of the title they carry. If in practice something is not true, I just walk away. As a result, I am quite lonely, but at the moment I prefer it that way."*

*- Yan, 31-year-old male considering being non-binary, diagnosed at age 30*

*"With family, I've always been the alien. I'm obviously very different from them. With potential friendships, I'm also pegged quickly as different, in a way the potential friend can't quite put their finger on. I am either avoided as weird or they try to be friends anyways, which ends one of two ways: They either realize the oddness is all encompassing and ghost me due to "being difficult" or "disinterested" or they completely understand my differences because they are also autistic and are thus not put off. It's important to note I've only had two long term adult friendships, both with autistic men. With romance, I was easily taken advantage of. With my marriage, I lucked out and randomly met a man who is definitely not neurotypical but also not autistic. I count him as my best friend. Even so, we still have VERY autistic miscommunications and have been in couples therapy to learn how to communicate with each other. No danger of divorce, but it is hard."*

*- Rachel, 32 years old, married, diagnosed at age 3*

### How does autism affect the way you communicate?

*"I have to constantly think about what I say versus what I mean. I hate small talk and prefer longer conversations that have a definitive beginning and end. I have a hard time dating [because of this] and tend to be too open about my feelings, wants and desires."*

– Jeremy W, 27 years old, diagnosed at age 5 with Asperger Syndrome

*"I find it difficult to understand people's intentions, communication makes me extremely anxious as I don't trust what people say as they often mean something else. I prefer text and email so that I have time to process the conversation. I avoid speaking to people on the telephone."*

– Anneke, non-binary, single 36-year-old recently diagnosed with autism

*"I do struggle to "read the room" and have to be told to "know your audience" because I frequently say exactly what I am thinking and feeling. I have a hard time if someone is displaying emotions, but they do not tell me exactly what is going on. I have very black and white thinking (I am also diagnosed with BPD)."*

– Anonymous, non-binary working professional with multiple disabilities including autism

*"I communicate very pedantically and love to teach others about things I've learned. But when it comes to casual conversation, I often don't know how to respond."*

– Victoria, 21-year-old working professional diagnosed by her therapist

### How does autism play a role in your interests and how you engage in them?

*"There are only so many things I am interested in, but content creation and gaming allowed me to communicate in a unique way. Not only did I get a kick out of making people laugh, but I also used this opportunity to fundraise for autism awareness for two and a half years. It's being able to give back with your interests that counts."*

– Colton Hurst, 18-year-old college student diagnosed at age 2

*"When I get interested in something, I get \*really\* interested in it. The term "gift" with regard to autism is very controversial. If there is a "gift" part of autism, I think this is it. I kind of feel bad for people who only half-\*ss their interests."*

– John Taylor, Autism Speaks database coordinator; read John's story on page 10.

*"When I find something that I "like," for example, with TV shows, I can become obsessed and watch episodes repeatedly to the irritation of my husband and child. And it might be one or two shows at a time. So I could watch the same episode numerous times in a week and even in the same day. As for other interests outside of TV, it can take a lot for me to break away from the one or two things I'm currently obsessed with. I can put a lot of financial investment into that focus that could last for months or even years in some cases. The stuff I buy can pile up to the point that when my obsession is over, I've got tons of things on it that I may never use again, but I also can't make myself give them away "just in case." I could invest hundreds or thousands of dollars to get everything that has to do with whatever that focus is."*

– Anonymous, 42-year-old married autistic parent of an autistic child

### How does a routine or change in routine affect you?

***“Routine is important in my work life. Too much change or not following the rules leads to burn out.”***

*– Sally, 58-year-old single autistic parent of an autistic child*

***“I will often have a physical reaction of intense discomfort and sweating if there is a change in routine. I often become tense and irritable. If it can be explained in a logical and practical way why the routine is changing, then I am more likely able to adjust or at least accept the change. But I often find it hard to express my thoughts and feelings when routines are changed. This can make others perceive me as rude or unreasonable. I’m often left feeling frustrated, ashamed and misunderstood by my reaction and that of others towards me.”***

*– Kaelen, 47-year-old working professional diagnosed last year*

***“I require routine, or I dysregulate. Unexpected routine changes cause a disruption in my internal state, which in turn reduces my ability to function well and compromises my ability to process or relay information.”***

*– Anne, non-binary 44-year-old diagnosed at age 41*

### What sensory experiences do you find challenging?

***“I can’t shower the way most people do. I have to stand outside of the running water and wash my hair separate due to the feel of the water on me I feel like I’m drowning. My foods are limited due to sensory. Sometimes clothes I love and I want to wear feel like a thousand pins digging into me.”***

*– Grainne N., 35-year-old autistic parent of an autistic child*

***“I work every weekend to avoid having a lot of free time when most other people also do. I prefer weekdays when most people are at work.”***

*– Pat W., 65-year-old divorced autistic parent of an autistic child, diagnosed at age 46*

***“I’m sensitive to texture when I eat so I don’t usually like to try anything new. I tend to eat the same thing repeatedly until I change to the next repeat thing I like. When I was younger I couldn’t stand for my food to touch each other on my plate. And I would rotate my plate as I ate. Years later I found out my great-grandfather did that.”***

*– Amy, non-binary and married 57-year-old diagnosed at 45*

***“Hanging out at bars and clubs can help my sensory seeking needs.”***

*– Jeanna, working professional diagnosed at age 2*

## CONCLUSION

**In conclusion it is only fitting that we pass along this advice from a gracious autistic community member who participated in our survey:**

*"Utilize every resource that you can to get your diagnosis and to better understand your diagnosis. Also identify your sensory triggers so you can know what triggers your overstimulation and how you can calm yourself. The biggest advice though is this: Don't be ashamed to be on the spectrum. Autism is not a horrible thing, it's what makes you unique and your own person. You are a normal person, you're just wired to see the world differently."*

*– Ashleigh S., 28-year-old working professional diagnosed at age 3*

Wherever you are in your journey – whether you just received an autism diagnosis, are going through an evaluation or considering being evaluated – we hope this Tool Kit has been a valuable resource to help you better understand yourself and move forward.

If you receive an autism diagnosis, keep in mind that you are not alone. The adult autistic community is getting stronger every day and the list of resources, supports and adult providers is growing larger and smarter. Remember the autistic community is open to anyone who feels like they belong there and who make use of many of the strategies, tools and resources designed for autistic people.

If you have any questions or additional concerns, or are looking for more, please call or email the Autism Speaks Autism Response Team (ART):

**In English:** [help@autismspeaks.org](mailto:help@autismspeaks.org) | **888-288-4762**

**En Español:** [ayuda@autismspeaks.org](mailto:ayuda@autismspeaks.org) | **888-772-9050**

## GLOSSARY

**Americans with Disabilities Act (ADA)** is the US law that ensures rights of persons with disabilities with regard to employment and other issues.

**American Psychiatric Association's Diagnostic and Statistical Manual of Mental Disorders (DSM)** is the standard classification of mental disorders used by mental health professionals in the United States. The current edition, the DSM-5 that was released in May 2013, merged all autism disorders into one umbrella diagnosis of ASD.

**Anxiety disorder** is a disorder that affects an estimated 30% of individuals with autism and includes social phobia, separation anxiety, panic disorder and specific phobias. An individual suffering from anxiety may experience strong internal sensations of tension such as a racing heart, muscular tensions and stomachache.

**Applied Behavior Analysis (ABA)** is a style of teaching using series of trials to shape desired behavior or response. Skills are broken into small components and taught to child through a system of reinforcement.

**Asperger syndrome** is a developmental disorder on the autism spectrum defined by impairments in communication and social development and by repetitive interests and behaviors, without a significant delay in language and cognitive development. The diagnosis is no longer used in DSM-5, but instead indicates that individuals with a "well-established diagnosis" of these conditions "should be given the diagnosis of autism spectrum disorder."

**Attention-Deficit/Hyperactivity Disorder (ADHD)** is a disorder that affects approximately 1 in 5 children with autism (statistics are not currently available for the prevalence in adults with autism). Symptoms include chronic problems with inattention, impulsivity and hyperactivity.

**Augmentative and Alternative Communication (AAC)** refers to the systems and devices used by people who, some or all of the time, cannot rely on their speech. Typically, AAC includes unaided modes of communication, like sign language, and aided modes of communication, like communication boards or iPads.

**Autism community** is an umbrella term that includes autistic individuals, parents and family members of autistic people, providers, autism allies. Some autistic individuals prefer to be excluded from this term.

**Autistic community** refers to the community of autistic individuals.

**Bipolar disorder** is a psychiatric condition once commonly called manic-depression that involves episodes of abnormally high-energy alternating with depression over a period of time.

**Cognitive Behavioral Therapy (CBT)** is a form of treatment that focuses on examining the relationships between thoughts, feelings and behaviors and is used primarily to help individuals with autism regulate their emotions, develop impulse control and improve their behavior as a result.

**Depression** is a common but serious illness that involves sadness that interferes with daily life. People with depression may experience a lack of interest and pleasure in daily activities, lack of energy, feelings of worthlessness or excessive guilt and recurrent thoughts of death or suicide.

**Executive functioning** is a core term that relates to the challenges faced by individuals with autism, including skills such as organizing, planning, sustaining attention and inhibiting inappropriate responses.

**Fragile X Syndrome** is a genetic disorder that can cause intellectual disability, behavioral and learning challenges. There is no cure, but therapies, interventions, and medications are often prescribed to treat behavioral symptoms like anxiety, aggression, and ADHD.

**Home and Community Based Services (HCBS)** provide opportunities for Medicaid beneficiaries to receive services in their own home or community. These programs serve a variety of targeted populations groups, such as people with mental illnesses, intellectual or developmental disabilities, and/or physical disabilities.

**Job Accommodation Network (JAN)** is the leading source of free, expert and confidential guidance on workplace accommodations and disability employment issues. JAN helps people with disabilities enhance their employability and shows employers how to capitalize on the value and talent that people with disabilities add to the workplace.

**Medicaid waiver** is a program that states may choose to use to provide home and community-based services (HCBS), like respite and habilitation, to individuals with disabilities who need a certain level of care; all states operate Medicaid waivers to provide HCBS but the eligibility rules and services vary across waiver programs and most states have long waiting lists for these programs.

**Nonverbal communication** is the process of communicating by sending and receiving wordless (mostly visual) cues between people, including postures, facial expressions, gestures and eye gaze.

**Obsessive-compulsive disorder (OCD)** is a psychiatric disorder characterized by unreasonable thoughts and fears (obsessions) that lead individuals to do repetitive behaviors (compulsions).

**Panic disorder** is a psychiatric condition diagnosed in people who experience spontaneous seemingly out-of-the-blue panic attacks and are preoccupied with the fear of a recurring attack.

**Rehabilitation Act of 1973** is an act of Congress that prohibits discrimination on the basis of disability in programs conducted by federal agencies, in programs receiving federal financial assistance, in federal employment, and in the employment practices of federal contractors. Section 504 of the Act created and extended civil rights protections to people with disabilities.

**Schizophrenia** is a serious mental disorder in which people interpret reality abnormally. Symptoms can include delusions, hallucinations, disorganized speech, trouble with thinking and lack of motivation.

**Self-advocate** is a person who takes an active role in improving their own life by speaking up for themselves and communicate their own needs, wants and interests. Here it refers to autistic individuals.

**Self-advocacy** is representing oneself. Here it refers to autistic individuals.

**Self-regulation** refers to both conscious and unconscious processes that have an impact on self-control, but regulatory activities take place more or less constantly to allow us to participate in society, work and family life. Self-control is a conscious activity.

**Sensory Integration Dysfunction (SID)** is a neurological disorder causing difficulties processing information from the five classic senses (vision, hearing, touch, smell and taste), sense of movement (vestibular system) and positional sense (proprioception). Sensory information is sensed normally, but perceived abnormally. SID may be a disorder on its own or with other neurological conditions.

**Social Communication Disorder (SCD)** is a new diagnostic category established in the DSM-5 that applies to individuals who have deficits in the social use of language, but do not have the restricted interests or repetitive behavior you see in those with autism spectrum disorders.



**Social phobia** is a strong fear of being judged by others and of being embarrassed, that can be so strong that it gets in the way of going to work or school or doing other every day things.

**Social Security Disability Insurance (SSDI)** is a Social Security Administration program that provides benefits to people with disabilities (including those with visual impairments) who are “insured” by workers’ contributions to the Social Security trust fund, based on one’s wage earnings (or those of one’s spouse or parents) as required by the Federal Insurance Contributions Act (FICA).

**Supplemental Security Income (SSI)** is a program of the Social Security Administration that pays benefits to people with disabilities who have limited income and resources. It is designed to help aged, blind, and disabled people who have little or no income. And it provides cash to meet basic needs for food, clothing, and shelter.

**U.S. Centers for Disease Control and Prevention (CDC)** is the leading national public health institute of the United States. Its main goal is to protect public health and safety and is responsible for calculating the autism prevalence numbers, which as of 2023, stand at 1 in 36 children.

**U.S. Department of Labor’s Office of Disability Employment Policy (ODEP)** is a division of the U.S. Department of Labor dedicated to developing and influencing policies and practices that increase the number and quality of employment opportunities for people with disabilities.

**Vocational rehabilitation** (VR; sometimes shortened to “voc rehab” in conversation) is a federal and state-funded program providing services to help individuals with disabilities enter or return to employment. It is designed to assist individuals of work age with physical and/or mental disabilities compete successfully with others in earning a living.



**Have more questions or need assistance?  
Please contact the Autism Response Team for information, resources and tools.**

**TOLL FREE: 888-AUTISM2 (288-4762) | [help@autismspeaks.org](mailto:help@autismspeaks.org)**

**EN ESPAÑOL: 888-772-9050 | [ayuda@autismspeaks.org](mailto:ayuda@autismspeaks.org)**

**[autismspeaks.org](https://autismspeaks.org)**