



## COULD I HAVE GONE THROUGH MY ENTIRE CHILDHOOD WITH ASD? PURSUING AN ASD DIAGNOSIS AS AN ADULT

It's true: most diagnoses of Autism Spectrum Disorder (ASD) are given to children. However, there are likely many adults living with ASD who do not have an official diagnosis. This may be because these adults were misdiagnosed as children or simply found ways to "get by." Depending on how old you are, when you were younger, autism may have been a diagnosis only given to children who had little or no language abilities and who had severe disabling behaviors.

Perhaps you've done enough research to know that the diagnosis of ASD is now a broad one, which is given to individuals with a wide range of ability as well as disability. Nobel Prize winners, famous writers, actors, and musicians, as well as loads of everyday people with their own special talents, now openly declare they are "on the spectrum."

If you feel you may have ASD, and you are successful, have a good job or career, and are content and happy with your life, you may not feel compelled to get a diagnosis. On the other hand, if you are struggling to understand why you seem to be different from your friends and colleagues, and/or why you react differently to everyday things, you may be curious to know if ASD may help explain some of the difficulties you are experiencing. Additionally, you may hope that obtaining a diagnosis will help you get the support that you need to succeed at work or to find a social niche that feels right to you.

### *What are the Signs?*

All individuals with ASD have two things in common, which get in the way of their every day lives:

- Difficulty with social communication
- Repetitive or stereotyped interests and/or behaviors

Below are some common indications of ASD in adults; however, just because you have one or even several of these symptoms does not mean that you have ASD. The only way to know for sure is to be evaluated by a trained professional.

- Maybe you don't get some jokes. You take the comedian's language literally and don't understand what the others find funny.
- Maybe you don't like meeting new people and making "small talk." A cocktail party is simply boring.
- Maybe crowded spaces make you feel like you cannot breathe. You would rather take the stairs than squeeze into a crowded elevator.
- Maybe loud noises or bright lights actually cause pain. You walk into the florescent lit conference room, and it actually hurts your head.
- Maybe you have a special interest that overwhelms and dominates your conversation and thoughts. Your colleague just can't listen to your talk about outer space any longer and walks away when he sees you coming.
- Maybe you maintain a strict adherence to routines or rituals. If the train you take regularly is unexpectedly late, it is extremely upsetting and disturbing, so much so it ruins your day.

Every individual with ASD is different from every other individual with ASD. Maybe your particular set of symptoms, feelings, and behaviors will lead to a diagnosis - or maybe not.

If you are interested in pursuing a diagnosis, you may first consider trying a free, on-line self-assessment. Noted psychologist and autism researcher, Simon Baron-Cohen and his colleagues at Cambridge University developed the Autism-Spectrum Quotient for just this purpose. It is not a diagnostic tool, but it can help you decide if you are on the right track.

- [The Autism-Spectrum Quotient](#)
- [Signs of ASD in Older Children and Adults](#)

### *Getting a Diagnosis*

To pursue a definitive diagnosis of ASD, you will need to see an experienced clinician. It is important to note that not every clinician has the experience and the knowledge to evaluate adults who may have ASD. Diagnosing adults is a relatively new area, so make sure to ask about experience diagnosing adults with ASD before you make an appointment for an evaluation. Additionally, many insurance

companies do not cover the costs of evaluations for adults, and the charges can be in the thousands of dollars to complete a diagnostic protocol. Be sure to ask about charges and payment plans ahead of time.

Another option for those with access to autism research centers is to enroll in a research study for adults with ASD. By enrolling in research, you can contribute to the community, as well as save the costs of the evaluation. Be aware, however, that research studies usually don't enroll all people who are interested in participating; there may be certain inclusionary or exclusionary factors, such as age, an existing diagnosis, or specific symptoms.

Before pursuing a diagnosis, it may be a good idea to consider finding a therapist who can help you talk through your feelings about obtaining a diagnosis. Look through the Mental/Behavioral Health section of the CAR Resource Directory™ to find someone who can help. If you decide you want to proceed, you can also find clinicians with experience making ASD diagnoses in the Resource Directory by searching for Diagnosticians. The same therapist may or may not be able to provide you with both services. If you are ready to move forward with a diagnosis, the following resources and articles in the CAR Autism Roadmap™ may be of interest to you:

- [CAR Resource Directory™](#)
- [How to Choose a Clinician to Evaluate for ASD](#)
- [Elements of an Evaluation for Autism Spectrum Disorder](#)
- [Getting an Evaluation for Autism Spectrum Disorder](#)
- [Who is Able to Diagnose Autism Spectrum Disorder?](#)
- [Autism Spectrum Disorder Measures](#)
- [Diagnostic Criteria for Autism Spectrum Disorder in the DSM-5](#)

*I Think I Have Asperger Syndrome. What's That?*

Asperger Syndrome used to be one of three named conditions that made up the broader category of ASD. (Pervasive Development Disorder Not Otherwise Specified and Autistic Disorder were the other two.) In May 2013, the American Psychiatric Association revised the manual which contains many diagnoses of adults and children (the Diagnostic and Statistical Manual of Mental Disorders) and combined these three diagnoses into one singular diagnosis of "Autism Spectrum Disorder" in the latest edition, the DSM-5. While there is no longer an "official"

diagnosis of Asperger Syndrome, it is a term which many adults relate to still, and you may hear it used both in the autism community and perhaps even by some professionals.

- [Diagnostic and Statistical Manual](#)
- [DSM-5 Impact on Services](#)

### *Why Might I Want to Pursue an Official Diagnosis At My Age?*

You may have heard that there are not nearly as many services and supports available to adults with ASD as there are for children. This is true. Nonetheless, if you do end up getting a formal diagnosis of ASD, the diagnosis may help you to cope with those things in life you find difficult and may in and of itself provide you with peace of mind.

Another reason many adults seek out a diagnosis is that having one may qualify you for vocational training or, if you have a job, enable you to request accommodations at work to make life on the job a bit easier.

Maybe you are having a difficult time finding work: you have skills, but other things get in the way of allowing you to be successful. With a diagnosis, you may qualify for vocational programs that may help you to refine your interests, develop skills, or even find a job. Additionally, if you receive a diagnosis of ASD, and if you choose to share it with your employer, you may receive workplace accommodations, such as a preferred or reduced schedule or organizational supports, to help you on the job.

Read the following articles from the CAR Autism Roadmap™ to learn more about accommodations and other employment issues that may be relevant to your situation:

- [CAR Resource Directory \(search for Vocational Programs\)](#)
- [What to Expect from OVR](#)
- [Workplace Accommodations and Supports for Individuals with ASD](#)
- [To Tell or Not to Tell: Issues of Disclosure in the Workplace](#)
- [Finding a Job: Measuring Your Interests and Aptitude](#)
- [The Role of a Job Coach](#)
- [Building Experiences and Developing a Resume](#)
- [Preparing for a Job Interview](#)

- [Protections Against Employment Discrimination](#)
- [Time Management and Other Executive Functioning Issues in the Workplace](#)

Having a diagnosis also makes you part of a larger community of adults with ASD. Adults with ASD, particularly those who are not diagnosed until adulthood, often find that they have much in common. Even if you are not someone who typically joins or seeks out social groups, you may benefit from reaching out to other adults who also have ASD. There are a number of organizations that offer support, resources, and connection to other adults who are also diagnosed with ASD. Three that you may want to investigate are:

- [WrongPlanet.net Online Community](#)
- [The Global and Regional Asperger Syndrome Partnership \(GRASP\)](#)
- [The Autistic Self-Advocacy Network](#)

There are also other more localized groups listed in the CAR Resource Directory. In the Directory, choose “Support Groups – Adults.”

- [CAR Resource Directory™](#)

The Center for Autism Research and The Children's Hospital of Philadelphia do not endorse or recommend any specific person or organization or form of treatment . The information included within the CAR Autism Roadmap & trade; and CAR Resource Directory & trade; should not be considered medical advice and should serve only as a guide to resources publicly and privately available . Choosing a treatment, course of action, and/or a resource is a personal decision, which should take into account each individual's and family's particular circumstances .