

**Is it Autism
and if so
What Next?
A Guide for
Adults**

About This Kit

Is It Autism and If So, What Next? A Guide for Adults is a tool designed to help assist adults who suspect they may have autism, as well as those who have been recently diagnosed with the disorder.

This tool kit was released in the spring of 2015. It was created by the Autism Speaks Family Services staff, in conjunction with a group of contributors made up of adults with autism and other professionals, as well as the Family Services Committee.

Acknowledgements

Autism Speaks would like to extend special thanks to those who contributed to the kit for their time and effort:

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It's time to listen.

A tool kit for adults who suspect they may have autism, as well as those who have been recently diagnosed with the disorder.

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Introduction

You have downloaded or ordered this tool kit because you suspect you may have autism or you've received a new diagnosis as an adult. You have come to the right place!

As autism awareness has grown dramatically in recent years, many young adults and adults have learned the signs and felt there may be a connection between their feelings and behaviors and the symptoms of autism. For some, it can come as a relief as questions they've had for many years may finally have an answer. Many have been misdiagnosed with other conditions or were never able to get a formal diagnosis of a condition or disorder that explains their symptoms.

This kit will provide an overview of autism to help you better understand the disorder and will hopefully clarify whether you should seek out a professional for a thorough evaluation. If/When you are in fact diagnosed with autism, the kit will also walk you through next steps in terms of accessing services and provide you with critical information about your rights and entitlements as an adult on the spectrum. There is also a list of helpful resources for you to find more information about next steps for the days and months following your diagnosis.

If you have any additional questions or are looking for resources, the **Autism Speaks Autism Response Team** (ART) is here to help! ART coordinators are specially trained to help support the autism community by answering calls and emails and by providing guidance and information. The Autism Response Team can be reached by email at familyservices@autismspeaks.org or by phone at 888-288-4762 (en Español at 888-772-9050).

Let's get started!

What is Autism?

Autism spectrum disorder (ASD) and *autism* are both general terms for a group of complex disorders of brain development characterized, in varying degrees, by difficulties in social interaction, verbal and nonverbal communication and repetitive behaviors. Though there are strengths and unique abilities associated with the disorder, autism is most often defined based on “deficits” and “symptoms” because the definition from the **American Psychiatric Association’s Diagnostic and Statistical Manual of Mental Disorders** (DSM) is science-based and the manual is used to describe disorders for diagnosis. With the May 2013 publication of the fifth edition of the DSM (commonly referred to as the DSM-5), all autism disorders were merged under one umbrella diagnosis of ASD. Previously, they were recognized as distinct subtypes, including 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 should now be given the diagnosis of autism spectrum disorder.

Under the current DSM-5, there are two domains where people with ASD must show persistent deficits. They include:

- 1. *persistent social communication and social interaction***
- 2. *restricted and repetitive patterns of behavior***

More specifically, people with ASD must demonstrate deficits (either in the past or in the present) in social-emotional reciprocity, nonverbal communicative behaviors used for social interaction, as well as deficits 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***

The DSM-5 also added an additional category called **Social Communication Disorder (SCD)**. This allows for a diagnosis of disabilities in social communication, without the presence of repetitive behavior. SCD is a new diagnosis and much more research and information is needed to better understand it. There are currently few guidelines for the treatment of SCD. Until such guidelines become available, treatments that target social-communication, including many autism-specific interventions, should be provided to individuals with SCD.

To read the whole DSM-5 criteria, please visit autismspeaks.org/dsm-5.

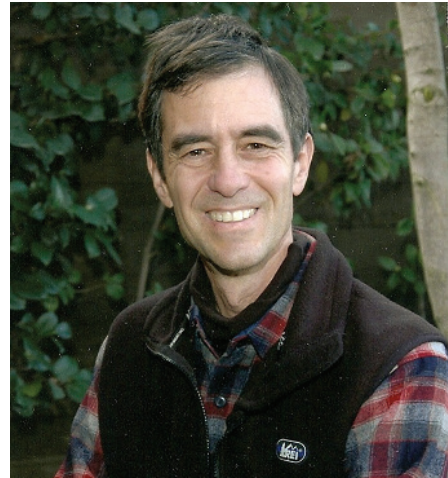
How Common is Autism?

While no studies have been able to confirm the prevalence rate for adults and more research is needed, autism statistics from the **U.S. Centers for Disease Control and Prevention** (CDC) released in March 2014 identify around 1 in 68 American children as on the autism spectrum – a ten-fold increase in prevalence in 40 years. Careful research shows that this increase is only partly explained by improved diagnosis and awareness. Studies also show that autism is four to five times more common among boys than girls. An estimated 1 out of 42 boys and 1 in 189 girls are diagnosed with autism in the United States.

ASD affects over 2 million individuals in the U.S. and tens of millions worldwide. Government autism statistics suggest that prevalence rates have increased 10 to 17% annually in recent years. There is no established explanation for this continuing increase, although improved diagnosis and environmental influences are two reasons often considered.

What Causes Autism?

Not long ago, the answer to this question would have been, “we have no idea.” Research is now starting to deliver the answers. First and foremost, we now know that there is no one cause of autism, just as there is no one type of autism. Over the last five years, scientists have identified a number of rare gene changes or mutations associated with autism. Research has identified more than 100 autism risk genes. In around 15% of cases, a specific genetic cause of a person’s autism can be identified. However, most cases involve a complex and variable combination of genetic risk and environmental factors that influence early brain development. In other words, in the presence of genetic predisposition to autism, a number of non-genetic or environmental influences further increase an individual’s risk.



“Half my life was a long hard struggle where ‘I was not playing with a full deck’ in terms of negotiating the world before my diagnosis. After my diagnosis, ‘the light bulb went on’ and I found a huge population just like me with the same struggles. At this point, my life started falling into place and over time, after my diagnosis, I gained a much better understanding of myself and the world around me.”

- Paul Nussbaum

Some factors that have been identified to increase the risk of autism include parental age, extreme prematurity, difficulties during birth, mothers exposed to high levels of pesticides and air pollution. It is important to keep in mind that these factors, by themselves, do not cause autism. Rather, in combination with genetic risk factors, they appear to modestly increase risk.

What are the Symptoms of Autism?

Autism affects the way an individual perceives the world and makes communication and social interaction different from those without autism, often leading to significant difficulties. ASD is characterized by social-interaction challenges, communication difficulties and a tendency to engage in repetitive behaviors. However, symptoms and their severity vary widely across these three core areas.

“It is sometimes said that if you know one person with autism, you know one person with autism.”

- Stephen Shore

Social Symptoms

Individuals with autism tend to have difficulty interpreting what others are thinking and feeling. Subtle social cues such as eye rolling, shoulder shrugging or a grimace may convey little meaning to some people on the spectrum. Without this ability to accurately interpret gestures and facial expressions, or **nonverbal communication**, the social world can seem bewildering.

Many people with autism have similar difficulty seeing things from another person’s perspective. This, in turn, can interfere with the ability to predict or understand another person’s actions. It is also common – but not universal – for those with autism to have difficulty regulating emotions.

Communication Difficulties

At an early age, many children with autism experience significant language delays. However, some exhibit only slight delays or even develop precocious language and unusually large vocabularies – yet have difficulty sustaining conversations. Some children and adults with autism tend to carry on monologues on a favorite subject, giving others little chance to comment. In other words, the ordinary “give-and-take” of conversation proves difficult.



Repetitive Behaviors

Unusual repetitive behaviors and/or a tendency to engage in a restricted range of activities are another core symptom of autism. Some repetitive behaviors include arranging and rearranging objects or hand-flapping. Some people with autism are preoccupied with having household or other objects in a fixed order or place. It can prove extremely upsetting if something or someone disrupts the order. Many need and demand strict consistency in their environment and daily routine. Slight changes can be exceedingly stressful and lead to outbursts.

Repetitive behaviors can also take the form of intense preoccupations or obsessions. These extreme interests can prove all the more unusual for their content (e.g. machines, certain collectibles) or depth of knowledge (e.g. knowing and repeating astonishingly detailed information about astronomy). Adults with autism may develop tremendous interest in numbers, symbols, dates or science topics. Some of these interests can be a great asset in some circumstances, like employment, when harnessed in a productive way.

Executive Functioning and Theory of Mind

Individuals with autism often face challenges related to their ability to interpret certain social cues and skills. They may have difficulty processing large amounts of information and relating to others. Two core terms relating to these challenges are executive functioning and theory of mind.

Executive functioning includes skills such as organizing, planning, sustaining attention and inhibiting inappropriate responses. Difficulties in this area can manifest themselves in many different ways. Some may pay attention to minor details, but in turn struggle with seeing how these details fit into a 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**.

Theory of mind can be summed up as a person's ability to understand and identify the thoughts, feelings and intentions of others. Individuals with autism can encounter degrees of difficulty recognizing and processing the feelings of others, which is sometimes referred to as "mind-blindness." As a result, people with autism may not realize if another person's behaviors are intentional or unintentional. This challenge often leads others to falsely believe that the individual does not show empathy or understand them, which can create great difficulty in social situations.



"I'm proud to say I have autism, as it has helped shape the man I am today. I have genuine confidence in myself and I know that others out there like me can achieve anything they set their minds to. I truly believe that people on the spectrum are some of the brightest individuals in our society and can offer so much in the workforce and in life."

- Eric Kirschner

Strengths and Challenges

***by Dr. Stephen Shore, Ed.D., Self Advocate, Author
and Assistant Professor at Adelphi University***

While some symptoms of autism discussed above may present challenges, others can be great strengths and advantages for people on the spectrum.

In the piece below, self-advocate and university professor Dr. Stephen Shore shares a list of strengths and challenges for those with autism. It is important to note that this is a general list. 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
Nonjudgemental listening	Executive functioning resulting in difficulties planning long-term tasks

Medical and Psychiatric Issues that May Accompany Autism

Many children and adults diagnosed with autism have additional medical issues, including epilepsy, sleep dysfunction, gastrointestinal disorders or genetic disorders like Fragile X syndrome. As an adult, you may not have experienced these conditions that often arise at a very young age. But in addition to these disorders, many individuals with autism also have a variety of psychiatric and mental health challenges. Some research suggests that autism shares a genetic basis with several major psychiatric disorders, including attention deficit and hyperactivity disorder (ADHD), depression, bipolar disorder, anxiety and schizophrenia.

It is important to note that while some research suggests that just over two-thirds of children with autism have been diagnosed with one or more psychiatric disorders, healthcare professionals not familiar with autism tend to over-diagnose psychiatric problems in this group. This may be due to overlap between autism symptoms and those associated with psychiatric disorders. It is critical to receive accurate diagnoses of these conditions because medication or therapy to treat them may significantly improve autism symptoms and quality of life.

This section contains more information about some of these challenges faced by individuals on the autism spectrum.



“My anxiety can be so profound because of the fear of social expectations, sensory violations and unexpected changes. These are all so unbearable that I can feel frozen and unable to move forward. A simple request of me can sometimes be the core trigger of a meltdown.”

- Sondra Williams

Anxiety

Recent studies suggest that 30% of individuals with autism struggle with an **anxiety disorder** such as **social phobia, separation anxiety, panic disorder** and specific phobias. Some experts suspect that outward symptoms of anxiety – such as swearing and acting out – may be especially prominent among people on the spectrum. Even in the absence of an anxiety disorder, many individuals with autism have difficulty controlling anxiety when something triggers it. Anxiety can range from occasional, mild and completely understandable to unremitting, severe and irrational.

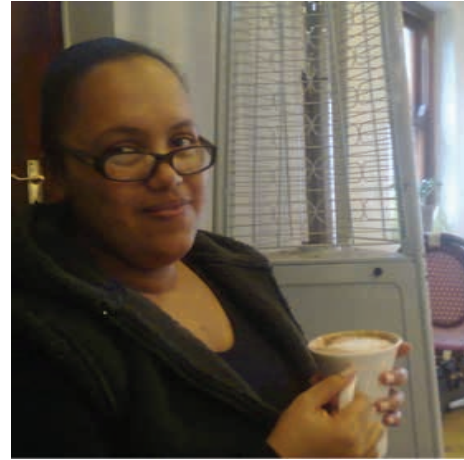
The Food and Drug Administration (FDA) has not approved any medication expressly for the treatment of anxiety in persons with autism, however some drugs approved to treat anxiety disorders in the general population are commonly used to help individuals with autism, such as Prozac and Zoloft. Medicines for relieving anxiety are best used in combination with counseling or other behavioral interventions. Individuals with autism may respond best to tailored treatments specific to those with both diagnoses.

If you suspect you may have an anxiety disorder, ask your doctor for recommendations for mental health professionals who may specialize in treating anxiety.

Attention Deficit Hyperactivity Disorder (ADHD)

According to the **National Institute of Mental Health** (NIMH), ADHD affects about 4.1% of American adults age 18 and older and 9.0% of American children age 13 to 18. Those rates are estimated to be much higher among the autism population as many children and adults with autism struggle with **ADHD**. While there has not been a study on ADHD specifically among adults, recent studies suggest that 1 in 5 children on the spectrum also has ADHD. Another study found that just 1 in 10 children diagnosed with both autism and ADHD was receiving medication to relieve the ADHD symptoms, as many symptoms can likewise result from autism.

According to NIMH, inattention, hyperactivity and impulsivity are the key behaviors of ADHD. Inattention can result in individuals being easily distracted and having difficulty focusing on one thing, processing information, listening and following directions. Sometimes ADHD can go undiagnosed if symptoms are viewed as emotional problems, challenging behaviors or difficulties at school and in the workplace. Symptoms of hyperactivity may include fidgeting and squirming, difficulty with quiet tasks or activities and trouble sitting still during



“I suffer from anxiety and depression, so for a long time my ‘strangeness’ was attributed to these conditions. Since my diagnosis, I feel more in control now. I am in charge of my life and destiny. I feel that even though autism has its challenges, I have been more blessed than anything else.”

- G.W.

meals, class or other activities. Impulsivity, a third hallmark of ADHD, can cause an individual to be very impatient, blurt out inappropriate comments, act without regard to consequences and have difficulty showing his or her emotions without restraint.

If you suspect you may have ADHD, it is important to be evaluated by a licensed mental health professional because treatment of the disorder, which often involves medication, can be very helpful in correcting these symptoms. To be diagnosed with ADHD as an adult, you must have symptoms that began in childhood and continued throughout adulthood. For some adults, a diagnosis can bring a sense of relief as it can help explain behaviors that have been present for most of their lives.

Depression/Bipolar Disorder

Individuals with autism may be particularly prone to **depression**, another disorder of the brain, in adolescence and adulthood. It can be difficult to diagnose, however, because many people on the spectrum are less likely to communicate the feelings used to diagnose depression. Seeing a mental health professional who has experience with autism is very important when seeking a depression diagnosis. Many people with depression never seek treatment, but when diagnosed properly, both cognitive behavioral therapy and medications can significantly improve the individual's feelings. If you feel you may be depressed, learn more about the signs and symptoms from the National Institute of Mental Health and ask your doctor for a referral to a mental health professional.

Bipolar disorder, once commonly called manic-depression, involves episodes of abnormally high energy alternating with depression over a period of time. Among individuals with autism, the symptoms of bipolar disorder commonly include abrupt increases in "pressured speech", pacing, impulsivity, irritability and insomnia. Some studies have found that as many as 27% of those with autism may have **bipolar disorder**, compared to its prevalence in the general population of around 4%. Psychiatrists often prescribe psychoactive medications to treat bipolar disorder. Studies suggest that mood-stabilizing medications may be safer treatments for those with autism.



Obsessive-Compulsive Disorder

Doctors or therapists unfamiliar with autism often mistake some of autism's core symptoms like repetitive behaviors and restricted interests with those of **obsessive-compulsive disorder** (OCD). But it is important to distinguish between the two. A distinguishing hallmark of OCD is that the compulsive thoughts or behavior cause anxiety. By contrast, persons with autism 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

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. **Sensory Integration Dysfunction** (SID), the clinical term for this characteristic, can involve hypersensitivity, such as an inability to tolerate being touched, or hyposensitivity, such as an increased tolerance for pain or constant need for sensory stimulation. Treatment is usually addressed with sensory integration therapy, which is provided by certified occupational and physical therapists.

This Sounds Familiar . . . Now How Do I Get a Diagnosis?

If you feel you might have autism, it is important to find a mental health professional with experience diagnosing the disorder, preferably in other adults. Bring your concerns to your general practitioner and ask for recommendations for a psychiatrist, psychologist or social worker who can help you. It may help to bring a list of the symptoms of autism you feel you may have, including examples of some of the behaviors and feelings that trigger your concerns. You can also try searching the **Autism Speaks Resource Guide** for mental health professionals in your area at autismspeaks.org/resource-guide. While some may only diagnose children, they may be able to point you in the right direction.



"Autistic people like me have many sensory processing issues that stand in the way of being flexible. People with autism can be extremely sensitive to noise, lights, smells and many times touch. I need direct instruction about what the rules of expected behavior are in the different environments. Kind are those who are truly patient."

- Jeremy Sicile-Kira

How Do I Get Evaluated as an Adult If I Suspect I Have Autism?

by David Beversdorf, Ph.D., neurologist at the University of Missouri's Thompson Center for Autism and Neurodevelopmental Disabilities

With awareness of autism so high today, it's no longer as common for an autism diagnosis to be overlooked in childhood. However, this wasn't always the case. As a result, it's not infrequent that I see teens and adults seeking a diagnosis.

Evaluating autism in a previously undiagnosed adult can be challenging. And yes, it's true that the standardized diagnostic checklists we commonly use are designed for children. There are no established diagnostic tests for ASD in adults. However, I'm glad to report that they are currently in development.

Conducting an Adult Evaluation

Because of these limitations, the evaluation of an adult has to lean heavily on direct observation. This will be in the context of a discussion between the clinician and the patient about current challenges in the areas of social interaction and communication, sensory issues and restricted interests or repetitive behaviors.

However, some higher functioning adults on the autism spectrum become very resourceful in developing strategies to compensate for their disabilities. Clearly, this makes a diagnosis based on observation much more difficult. But diagnosis remains important even when for those who have learned to hide their symptoms because they may still struggle in their everyday lives and interactions.

In these cases, it's important to explore the lifelong presence of related developmental issues. In particular, it's critical to get detailed information about early childhood. Sometimes this clearly reveals an early development that fits with a diagnosis of ASD.

While our diagnostic checklists are designed for children, I find that they can be useful as we explore an adult's childhood development. In particular, I sometimes interview older relatives – such as parents – who can recall the patient's early childhood in some detail. Often they can answer questions from diagnostic checklists and, so, inform a possible



diagnosis. Clearly, this is not possible when there isn't an older relative available for a reliable report.

Sometimes, a person's early development did not have any features suggestive of autism. Instead, they began struggling with social withdrawal and related issues in their teens or adulthood. This suggests a cognitive or mental health issue other than ASD.

Finding Someone Qualified to Evaluate Adults with ASD

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.

In my opinion, your best bet may be a developmental pediatrician, child psychiatrist or pediatric neurologist who is both experienced in evaluating autism in children and open to seeing older patients. If she or he does not feel qualified to evaluate an adult, he or she may have a respected colleague who would be.

Otherwise I would recommend contacting an established and respected autism center in your area. Examples include the centers in the ***Autism Speaks Autism Treatment Network***. To locate an AS-ATN near you, visit autismspeaks.org/ATN. This will provide you with the assurance that the clinician has agreed to adhere to the center's high standards for care for patients with autism, regardless of age.

Why Do I Need a Diagnosis?

You may be wondering why you need an autism diagnosis, especially if you have lived without one for many years in adulthood. Many young adults and adults who suspect they may have autism are afraid or unwilling to seek an official diagnosis because of the stigma they may feel is associated with the disorder. However, as autism awareness increases rapidly around the world, many are beginning to see the strengths and unique abilities of individuals on the spectrum.

An official diagnosis can help answer questions you may have had about yourself and your behavior for many years. For some, it can be a relief to know that these behaviors can now be explained with the diagnosis. It can also help you access the treatment and services that will help improve your symptoms and help you overcome the challenges you may have faced during the years before a diagnosis, as a diagnosis is often required to access services. A diagnosis can also lead you to seek out autism-specific supports that can help you along your journey with autism, such as support groups and social skills training. Getting a diagnosis can also increase self-awareness which can help you focus on your strengths and work around areas of challenge.

Support groups have been found to be very helpful for adults diagnosed with autism. Search the **Autism Speaks Online Resource Guide** for Support Groups near you at autismspeaks.org/resource-guide.



The National Alliance on Mental Illness (NAMI) helps explain how an autism diagnosis can help you as an adult:

“Diagnosis as an adult can lead to a variety of benefits. You can gain a better understanding of yourself. Many people have suffered from mental health problems and/or have been misdiagnosed as having mental health problems such as schizophrenia. A firm diagnosis can be a relief because it allows you to learn about your condition and understand where and why you have difficulties for the first time. Others will also gain a better understanding as it will be easier for them to empathize with your position once they learn there is a reason for your difficulties. It is also helpful to meet others within the community with ASDs by learning about their experiences and sharing your own. Support is a good step in seeking treatment and relieving anxieties, helping to maintain a healthier lifestyle while dealing with this disorder.”

My Story: Diagnosed with Autism at 34

by *Samantha Ranaghan*

My whole life I thought there was something wrong with me. My diagnosis changed those thoughts. When I learned about my diagnosis, I knew nothing was wrong with me...I knew that I had something very special about me and my life was about to change.

It was two weeks after my 34th birthday when I heard the words: "you're on the spectrum." As soon as I heard those four words, my body collapsed into my mom's arms. My mom and my stepdad were both in the room with me and you could feel the relief that went out the window. I remember walking out of work two days after my official diagnosis after a long day and stopping in my steps in the middle of the parking lot thinking to myself, "I feel normal." Why, after all these years, did I finally feel "normal"?

I'm still trying to figure out what this all means. All I know for sure is that I finally feel whole and as strange as this might sound, my life makes sense now. I don't feel out of place and awkward. I guess the greatest thing that came out of this is how I've been feeling my whole life has finally been validated.

When I tell people I am a high functioning autistic, their reactions are mostly, "Wow, I would never have guessed that. You don't act like you have autism." I want to say back to them, "How am I supposed to act?" You can't tell a person is on the spectrum by just looking at them. As I try to explain what being on the spectrum means, I can see them start to get an interest in what I'm saying and they start asking me questions. I answer them as best as I can by using examples of my own life.

While I'm glad that I finally know I'm autistic, I sometimes wonder what my life would have been if I had been diagnosed as a child instead of in my early thirties. I wonder in my own thoughts if I was a child now with the same course, would I be diagnosed? I didn't speak until I was four years old and spent many of my early years in speech therapy. I've been sensitive to loud noises and I now understand my over sensory issues. No one suspected autism. In 7th grade, I was diagnosed with Dyslexia and in my early twenties, it was ADHD. The funny thing is I never really felt as though I had either of those. Throughout my twenties, I saw many therapists that never thought of the idea of autism. It was so frustrating for me not knowing why I was and felt so different. No one seemed to know.



While I was going to my last therapist, it was my mom who brought up the idea of me having Asperger's Syndrome. She had been reading about it and she saw some of the traits that she saw in me...especially the social aspect of it. As my mom brought this to my attention, I started to do some research on my own. The more I read about Asperger's/autism, the more I saw myself in those words. Could this be the answer that I had been looking for all my life?

I think I had two things working against me growing up. The first was that autism wasn't as well-known as it is today. Second, it was and still is in a small way considered to be a boys thing. While boys on the spectrum tend to become rowdy, girls on the spectrum tend to introvert and are labeled shy and quiet. That's all I heard growing up...that I was shy and quiet. It annoyed the heck out of me.

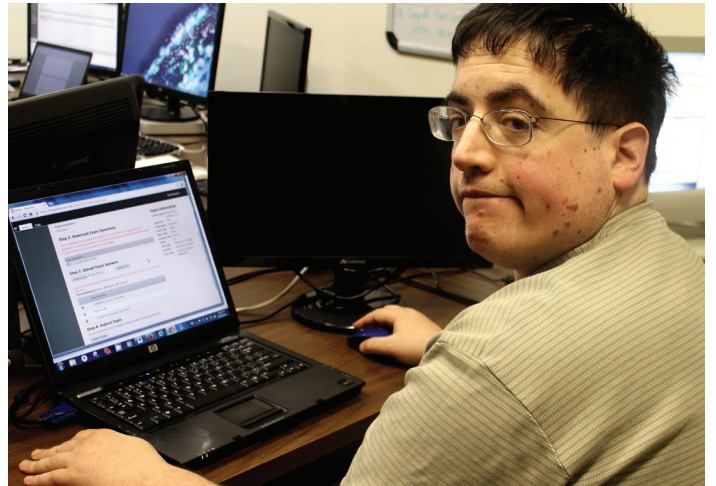
I now feel that I am understood much better by the people in my life. It's a struggle everyday trying to figure out this thing called life as someone who is on the spectrum, but with the support of my family and friends, I know I can become a better person. Just the other day, someone very close to me mentioned how far I have come in such a short time. I still get frustrated about little things I feel I shouldn't do and my sensory sensitivity, but I am learning how to live as a female on the autism spectrum.

Now as my 35th birthday and the one year anniversary of my diagnosis approaches, I could not be any happier with whom I am. The past year has been a roller coaster ride, but I can finally truly say that I am comfortable in my own skin. It's a great feeling!

How is Autism Treated?

Autism is often treated differently in adults than in children. **Applied Behavior Analysis (ABA)**, **Verbal Behavior therapy** and **Cognitive Behavior Therapy (CBT)** are just a few of the therapies out there that are used to treat children on the spectrum, and in some cases adults. These treatments involve focusing on the principles that explain how learning takes place and teaching children as young as two the basics of communication and social interaction. Far more research has gone into effective treatments for children with autism, but as the population of adults on the spectrum continues to rise, more studies are beginning to focus on the best ways to help young adults and adults diagnosed with autism.

When thinking about treatment for autism, it is important to remember that each individual with autism is very unique, and as a result, a treatment that works for one adult on the spectrum may not be helpful at all for another. When looking for treatment options, be sure you fully understand both your strengths and your challenges so you can build on those abilities and improve upon areas that may be difficult for you. The more you understand your needs, the better you and your health care provider can tailor treatment to these needs and the greater the strides you can make.



As an Adult with Autism, How Can I Access Appropriate and Effective Treatment?

by Megan Farley, Ph.D., psychologist at the Waisman Center for Developmental Disabilities at the University of Wisconsin

The question of what treatments can help adults with Autism is both a great question and a difficult one to answer. Currently we have far too little in the way of evidence-based treatments for adults with autism spectrum disorder (ASD).

We have a small handful of treatment strategies that have been clinically evaluated and found to be effective for helping adolescents and young adults with autism. At the University of Texas, for example, researchers have successfully used a virtual reality training program to improve social skills among young adults with autism. The PEERS program has likewise shown promise for teaching social skills to young adults with autism. Learn more about PEERS at semel.ucla.edu/peers.

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 his or her 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.

If you're seeking help finding and keeping a job, you can find additional help through your state's vocational rehabilitation (VR) agency. These agencies have the mission of helping adults with disabilities – including autism – prepare for and find appropriate employment. Also, the ***Autism Speaks Employment Tool Kit*** was designed to help you research, find and keep employment.

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. One such site is ***WrongPlanet***. Another is the ***Global & Regional Asperger Syndrome Partnership*** (GRASP).

Thanks for your question. I hope these tips prove helpful to you and other readers.



From Denial to Acceptance: I was Diagnosed with Autism at 24

by John Taylor
**Autism Speaks Family Services
Database Coordinator**



Sometime when I was in my early 20s, 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 took me to see some professionals at the 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.

Growing up, I often excelled in about every subject other than math and for a few years was reading well above my grade level. However, I also had an IEP which included being placed in a Special Ed class for 1 year in elementary school and extra time on tests until I graduated high school. Depending on what age, I had intense interests: trains, basketball, linguistics, etc. I also struggled to find a job even after graduating college. These are some of the reasons that my mother brought me in to be diagnosed.

I was in denial at first. To this day, I haven’t seen the movie Rain Man, but my perception of autism was mainly shaped by what others had told me about the movie. Basically autism made you some sort of socially inept mute (or almost mute) savant. I was intellectually gifted and often struggled socially (a nerd you could say), but certainly not like Dustin Hoffman’s character.

As they say, “If you’ve met one person with autism, you’ve met one person with autism”. I slowly came to accept my diagnosis by connecting with others on the spectrum. I started attending social skills and support groups. On the Internet, I discovered the autism blogosphere and YouTube videos by people with Autism. I found their personal experiences about life on the autism spectrum to be a lot more relatable than what someone off the spectrum, however educated about the facts, could tell me.

What are My Rights?

Another benefit to obtaining an official diagnosis is eligibility for supports, services, treatment and protection under various laws. Below is a list of just a few of these protections that can help you address some of the challenges you may be facing as an adult with autism at work, at home or in the community.

Americans with Disabilities Act

The ***Americans with Disabilities Act*** (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. 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 the challenges you face as an individual with autism that could be put into place that may help better support you in your job, a diagnosis may help you secure that accommodation.

Learn more at ada.gov. The ***Job Accommodation Network***, a service of the ***U.S. Department of Labor’s Office of Disability Employment Policy***, is another tool that offers accommodation ideas specific to autism at askjan.org.

Vocational Rehabilitation Services

With an autism diagnosis, you could also be eligible to receive services from vocational rehabilitation programs which coordinate and provide counseling, evaluation and job placement services for people with disabilities. Each state has a ***vocational rehabilitation*** (Voc Rehab or VR) agency that provides employment service supports to people with disabilities, including autism. VR agencies can give you vocational assessments that lead up to the development of an ***Individual Plan for Employment*** (IPE), under which a variety of employment-related services can be provided, including training, counseling, job placement and supported employment. You can find the contact information for your state VR office at www2.ed.gov/svr.

Medicaid Home and Community Based Services

You will also want to contact the developmental disability agency in your state to see if you are eligible for services through the ***Medicaid waiver*** in your state. State and local DD services operate under a variety of different names across the country. Frequently the funding for these services comes through the ***Home and Community Based Services*** (HCBS) waivers, which are made available through Medicaid. Medicaid can play a critical role providing both health care and long term services and supports that help meet ongoing needs of adults with autism. HCBS provide opportunities for individuals benefitting from Medicaid to receive services in their own home or community, such as case management, adult day health services, both day and residential habilitation, home health aides and more. The requirements for gaining access to these services vary from state to state. Contact your local or state agency to see if you may be eligible. For more information, visit www.medicaid.gov.

“I’m still trying to figure out what this all means. All I know for sure is that I finally feel whole and as strange as this might sound, my life makes sense now. I don’t feel out of place and awkward. I guess the greatest thing that came out of this is how I’ve been feeling my whole life has finally been validated.”

- Samantha Ranaghan

Social Security

If you require a certain amount of supports as a result of your autism diagnosis, you also may be eligible for social security benefits. Many individuals with disabilities who are unable to secure competitive employment rely on Social Security benefits for the majority of their income. **Social Security Disability Insurance (SSDI)** and **Supplemental Security Income (SSI)** disability programs are the largest federal programs providing assistance to people with disabilities, both of which are administered by the Social Security Administration. These programs are only available for individuals with disabilities who meet certain medical criteria. If you are eligible, SSDI pays benefits to you and certain members of your family if you are “insured,” meaning that you worked long enough and paid Social Security taxes. SSI pays benefits to individuals with disabilities who have limited income and resources to help them meet basic needs like food and shelter.

Once you have an official diagnosis, it is important to schedule a consultation with a Social Security disability representative in order to understand your specific needs and the benefits you are entitled to receive. You can also learn about benefits you may be able to get from Social Security by using the **Benefit Eligibility Screening Tool (BEST)**.

Social Security also offers some work incentives in order to allow you to work and keep your benefits, which may apply to you. These include a **Plan for Achieving Self Support (PASS)**, the **Impairment-Related Work Expense (IRWE)** and the **Ticket to Work** program. More information can be found in the benefits section of the [Autism Speaks Employment Tool Kit](#).

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.

Disclosure . . . To Tell or Not to Tell?

Many adults with autism find it difficult to share their diagnosis with others, even those closest to them. This can be partially due to the stigma many people feel is associated with autism. Whether or not to disclose your diagnosis is a very personal decision that is of course entirely up to you.

Some adults have found it helpful to share the new information with their families and friends because it may help explain their behaviors and past experiences that may have been challenging. Just like your diagnosis may have helped answer questions you may have had about yourself, it can also help clarify questions others in your life may have wondered about. For example, telling your sister you have been diagnosed with autism will likely help her understand why you haven't understood her sense of humor or why you would much prefer to talk about cars than the latest movies that she might find interesting. Telling her will also allow her to do her own research about autism so she can learn how to support you and help you on your journey after your diagnosis. You can even share this tool kit with her!

In terms of the workplace, the issue of disclosure can be complicated. You may feel that your employer or a prospective employer will judge you or label you if you tell them you have been diagnosed with autism. But as is the case with family members, disclosing your autism diagnosis can also help increase the supports available to you. For example, if there is an accommodation that could be helpful to you such as a desk in a quiet area or a couple additional breaks throughout the day, revealing your diagnosis to your boss can help you secure that accommodation, and as a result, allow you to be more successful at work. Your employer or human resources officer is required to keep your diagnosis confidential if you'd rather keep that information between the two of you rather than something your coworkers are also aware of.



“People do not fully understand the person I am, and therefore treat me like I am different. I had to find a way to help my social interactions with people without being scared to socialize. Then I found the solution, and it was simple. I spoke out about my autism, and told my friends, peers and professors about it. After I did that people accepted me for who I am, and I have lifted a heavy burden off my back.”

- David Powell

There are pros and cons to disclosing your autism and only you can decide what you feel is best for you. Try making a list of both sides to determine what will make you as happy and as supported as possible.

Conclusion

Whether or not you have received an autism diagnosis, we hope this kit has provided you with the tools and information you need to move forward. If after reading this, you feel your suspicions have been confirmed, be sure to seek out your health care professional for a referral and that when you do so, you are able to clearly explain why you feel this way. Bring this tool with you to share with your doctor or mental health professional or visit autismspeaks.org/what-autism and print out information that can help back up your thoughts.

If you do receive an autism diagnosis, keep in mind that you are not alone. There is help out there and the resources and supports available to adults with autism are growing every day. Visit the adult services page of the Autism Speaks website at autismspeaks.org/audience/adults to download our adult-specific resources and read news and blogs on topics related to adults on the spectrum. The **Autism Speaks Resource Guide**, which you can access at autismspeaks.org/resource-guide, is a great first step in looking for resources and supports in your area. While some of the resources may be children-focused, it is likely that local organizations and service providers will be able to refer you to other services that can meet your specific needs.

If you have any questions or additional concerns, or are looking for more information and resources, please feel free to call or email the **Autism Speaks Autism Response Team** for assistance at 888-288-4762 (en Español 888-772-9050) or familyservices@autismspeaks.org. This team of dedicated professionals is happy to help you as you take the next steps on your journey with autism.



“Everyone has challenges. But having autism has made my life amazing in so many ways. What I have is a part of who I am. Autism hasn’t defined me. I’ve defined autism. I’ve never seen myself labeled by my diagnosis.”

- Kerry Magro

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 DSM5, but DSM5 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.

Autism Spectrum Disorder (ASD) and autism are both general terms for a group of complex disorders of brain development. These disorders are characterized, in varying degrees, by difficulties in social interaction, verbal and nonverbal communication and repetitive behaviors. With the May 2013 publication of the DSM-5 diagnostic manual, all autism disorders were merged into one umbrella diagnosis of ASD.

Benefit Eligibility Screening Tool (BEST) is a tool from the Social Security Administration that helps you find out if you can get benefits that Social Security administers based on answers to questions.

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. Fortunately, a combination of therapy and antidepressant medication can help ensure recovery.

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.

Food and Drug Administration (FDA) is a federal agency of the United States Department of Health and Human Services that is responsible for protecting the public health by ensuring the safety, efficacy and security of human and veterinary drugs, biological products, medical devices and the nation's food supply, among others.

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.

Impairment Related Work Expense (IRWE) is a Social Security work incentive that can be used to pay for items that are necessary to work and are incurred due to the individual's disability.

Individual Plan for Employment (IPE) is a written document developed and implemented in a manner that gives eligible individuals the opportunity to exercise informed choice consistent with selecting an employment outcome including the employment setting, specific Vocational Rehabilitation services needed to achieve the employment outcome, including the setting in which services will be provided, the entity or entities that will provide the services.

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.

National Institute of Mental Health (NIMH), part of the National Institutes of Health (NIH), is the primary agency of the U.S. government responsibly for biomedical and health-related research.

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.

Plan for Achieving Self Support (PASS) is a provision of the Supplemental Security Income (SSI) section of the Social Security Act that enables people with disabilities to return to work. PASS allows its users to set aside money and/or items in service of a particular work goal.

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.

Self-regulation and self-control are related but not the same. 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.

Separation anxiety is a psychological condition in which an individual experiences excessive anxiety regarding separation from home or from people to whom the individual has a strong emotional attachment.

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.

Theory of mind is another core term that relates to the challenges faced by individuals with autism and refers to one’s ability to perceive how others think and feel and how that relates to oneself.

Ticket to Work program is another program from the SSA a type of support program that allows a person with a disability to take a Ticket to purchase support from an approved employment provider as part of the Ticket to Work & Workforce Investment Act. Organizations that are selected to participate in the Ticket to Work program must provide people with disabilities the opportunity and support to prepare for, obtain and keep jobs that will realistically enable you to achieve independence.

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 2014, stand at 1 in 68 children, including 1 in 42 boys.

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.

Verbal Behavior therapy (VB) is a method of Applied Behavioral Analysis (ABA) for teaching individuals with autism, based on B.F. Skinner's description of the system of language.

Vocational rehabilitation (VR, voc rehab) 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.

Resources

AUTISM SPEAKS RESOURCES

Autism Speaks Employment Tool Kit

autismspeaks.org/family-services/tool-kits/employment

Autism in the Workplace Resources

autismspeaks.org/family-services/adult-services/autism-and-employment

Autism Speaks Housing and Residential Supports Tool Kit

autismspeaks.org/family-services/housing-and-community-living

Autism Speaks Postsecondary Educational Opportunities Guide

autismspeaks.org/family-services/tool-kits/postsecondary

Autism Speaks Adult Services

autismspeaks.org/audience/adults

Autism Speaks Resource Library – Books

autismspeaks.org/family-services/resource-library/books

WEBSITES

Autistic Global Initiative: A Project of the Autism Research Institute

autism.com/tests

Wrong Planet: Asperger & Autism Forum Community

wrongplanet.net

GRASP

grasp.org

Autism Hangout

youtube.com/user/autismhangout

Carly's Café: Experience Autism through Carly's Eyes

carlyscafe.com

BOOKS

Beyond the Wall: Personal Experiences with Autism and Asperger Syndrome

by Stephen M. Shore

Defining Autism from the Heart: From Nonverbal to National Speaker

by Kerry Magro

Life and Love: Positive Strategies for Autistic Adults

by Zosia Zaks

Thinking in Pictures: My Life with Autism

by Temple Grandin

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

TOLL FREE: 888-AUTISM2 (288-4762)

EN ESPAÑOL: 888-772-9050

Email: FAMILYSERVICES@AUTISMSPEAKS.ORG

WWW.AUTISMSPEAKS.ORG

Text ART to 30644



AUTISM SPEAKS®
It's time to listen.

www.AutismSpeaks.org

Autism Speaks is the world's leading autism science and advocacy organization. It is dedicated to funding research into the causes, prevention, treatments and a cure for autism; increasing awareness of autism spectrum disorders; and advocating for the needs of individuals with autism and their families. Autism Speaks was founded in February 2005 by Suzanne and Bob Wright, the grandparents of a child with autism. Mr. Wright is the former vice chairman of General Electric and chief executive officer of NBC and NBC Universal. Since its inception, Autism Speaks has committed more than \$500 million to its mission, the majority in science and medical research. Each year Walk Now for Autism Speaks events are held in more than 100 cities across North America. On the global front, Autism Speaks has established partnerships in more than 40 countries on five continents to foster international research, services and awareness.

To learn more about Autism Speaks, please visit AutismSpeaks.org.