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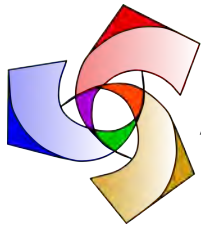
Healthcare Toolkit

Autism Information

Mostly for adults new to an autism diagnosis, information about autism spectrum disorder, adult diagnosis, therapy and assistive technology, disability rights laws, and Autistic culture and meeting others on the spectrum.

Contents

- About ASD
- Adult ASD Diagnosis
- Therapy and Assistive Technology
- Disability Rights Laws
- Meeting Others on the Spectrum



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Healthcare Toolkit

Autism Information: About ASD

Contents

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- What are the diagnostic criteria for autism spectrum disorder (ASD)?
- What's the difference between autism, Asperger's, PDD-NOS, and ASD?
- What might ASD look like in adults?
- I was just told about the possibility of ASD and I am having mixed feelings.

Autism Information: About ASD

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www.aaspire.org

Last Updated September 29, 2015

1 What is this topic about?

This topic gives very basic information about autism spectrum disorder (ASD). It is meant for people who are first learning about ASD. This topic focuses on ASD in adults.

2 What are the diagnostic criteria for ASD and what might they look like in adults?

Autism spectrum disorder (ASD) is a condition described in the Diagnostic and Statistical Manual of Mental Disorders: DSM 5.¹ It is diagnosed based on observation by a diagnostician or team of diagnosticians (e.g. neuropsychologist, psychologist, psychiatrist, licensed clinical social worker, etc.). If you're interested in learning more about diagnosis, see the topic Adult ASD Diagnosis .

The table below lists the current diagnostic criteria for ASD, along with examples of what they may look like in adults.²

DSM5 broken down by criteria and examples	DSM5 Criteria for ASD	Examples of how criteria may manifest in adults

A. Persistent deficits in social communication and social interaction across multiple contexts. (Diagnosis requires person meets all three criteria.)

1. Deficits in social-emotional reciprocity
2. Difficulty initiating or sustaining back and forth conversation; tendency to monologue without attending to listener cues; unusual response to greetings or other social conventions.
3. Deficits in nonverbal communicative behaviors used for social interaction
4. Lack of eye contact; difficulty understanding non-verbal communication; unusual tone of voice or body language.

B. Restricted, repetitive patterns of behavior, interests, or activities. (Diagnosis requires person meets at least two of four criteria.)

1. Stereotyped or repetitive motor movements, use of objects, or speech
2. Repetitive movements or "stimming" (e.g., rocking, flapping, pacing, or spinning for enjoyment or as a coping mechanism); arranging objects in a very precise manner; echolalia; continuously repeating sounds, words, or phrases.
3. Insistence on sameness, inflexible adherence to routines, or ritualized patterns of verbal or nonverbal behavior
4. Greater than expected degree of distress with changes in routines or expectations; difficulty transitioning between activities; need to do the same thing in the same way each time; greater than usual reliance on rituals for accomplishing daily tasks.
5. Highly restricted, fixated interests that are abnormal in intensity or focus
6. Intense special interests (e.g., looking at spinning objects for hours, learning the detailed schedules of an entire public transportation system, or becoming an expert in seventeenth century art) while having significant difficulty attending to topics outside of one's areas of special interest.
7. Hyper- or hyporeactivity to sensory input or unusual interest in sensory aspects of the environment
8. Being hyper- or hypo-sensitive to sounds, lights, smells, or textures; having an abnormally

high or low pain threshold; difficulty processing more than one sense at a time (e.g., not being able to understand spoken language while looking at someone's face); tendency to become confused or overwhelmed by sensory stimuli; challenges with body awareness or separating different types of sensations.

C. Symptoms must be present in the early developmental period (but may not become fully manifest until social demands exceed limited capacities, or may be masked by learned strategies in later life)

Though characteristics should have been present throughout one's lifetime, a change in circumstances can disrupt coping strategies and make characteristics more pronounced; alternatively, environmental facilitators, supports, and coping strategies may make characteristics less noticeable.

D. Symptoms cause clinically significant impairment in social, occupational, or other important areas of current functioning.

Characteristics lead to difficulty obtaining or sustaining employment, doing basic or instrumental activities of daily living, maintaining social life, or integrating with community. For example, there may be significant mismatch between educational attainment and occupational history.

E. These disturbances are not better explained by intellectual disability or global developmental delay. Intellectual disability and autism spectrum disorder frequently co-occur; to make comorbid diagnoses of autism spectrum disorder and intellectual disability, social communication should be below that expected for general developmental level.

N/A

Though the DSM-5 conceptualizes ASD primarily as a social-communication disorder, there is a growing literature supporting the hypothesis that ASD is primarily characterized by differences in information processing.³ See, for example, the [intense world theory](#) of ASD.

Adults on the autism spectrum may display autistic traits very differently from children. Most people, whether or not they are on the autism spectrum, mature and behave differently as they get older. As such, adults on the spectrum may not fit society's images of autistic children. Also, adults often find coping strategies that help them function in the world, but that may make autistic traits harder to recognize.

Among adults who meet the diagnostic criteria for ASD, autistic traits may look very different. While anyone on the spectrum would be expected to have challenges with social communication, these challenges can show up in many different ways. For example, a person may not be able to speak, may misunderstand facial expressions and body language, or may take language too literally. A person may have difficulty starting a conversation, may need more time alone than most people, or may feel uncomfortable socializing with others without a planned activity.

Likewise, anyone on the spectrum would be expected to have restricted or repetitive patterns of behaviors, interests, or activities, but that can be different for each person. For example, a person may look at spinning objects for hours, learn the detailed schedules of an entire public transportation system, or be an expert in seventeenth century art. Many people on the spectrum appreciate structure and can find routines very helpful in understanding or coping with the world. For example, they may always need to take the same route to get somewhere or may use a very complex organizational system to function at work or remember to eat. Unplanned events or changes in routines may cause anxiety for people on the autism spectrum.

People on the autism spectrum may experience sensory input differently from other people. For example, a person might have very sensitive hearing whereas another might have an extremely high pain threshold. Often people may have a very hard time coping with certain sensations, such as fluorescent lights, loud sounds, light touch, or particular textures or smells. They may not be able to process more than one sense at a time; for example, they may not be able to understand spoken language while looking at someone's face. They may also get overwhelmed when there are a lot of sensory stimuli happening all at once.

Some people on the spectrum may have difficulty with motor skills. Examples may include difficulty with handwriting, catching a ball, or planning out complex, multi-step actions like learning a dance sequence.

Autistic traits can potentially be strengths or challenges, or sometimes both.

Not all people on the autism spectrum have stereotypical positive traits such as being good at memorizing things or using computers. Similarly, people on the autism spectrum do not all shy away from social interactions, and many can maintain strong friendships or relationships.

3 What's the difference between autism, Asperger's, PDD-NOS, and ASD?

The Diagnostic and Statistical Manual (DSM) is the book that defines these terms. Different versions of the book define different terms. The DSM-IV has a category called Pervasive Developmental Disorders (PDD) with different sets of criteria for autistic disorder, Asperger's disorder, and pervasive developmental disorder - not otherwise specified (PDD-NOS). The Centers for Disease Control (CDC) has posted the [DSM-IV criteria](#). The differences between these three terms have not always been very clear to people, including the people who need to diagnose them. Sometimes the same person would be given different labels from different clinicians. To try to get rid of some of this confusion, the most recent version of the DSM, the DSM-V, has defined only one set of criteria and term which is autism spectrum disorder (ASD).

4 I was just told about the possibility of ASD and I am having mixed feelings.

It is normal to feel a wide range of emotions when you are told about possibly having a medical label, especially if you are not familiar with the condition. Many individuals who have received an Autism Spectrum Disorder (ASD) diagnosis have reported feelings such as anger, confusion, embarrassment, but also relief, validation, and belonging. For some Autistic adults, finding out why they have always felt different from others provides them with a sense of relief and direction. Other newly diagnosed Autistic individuals might feel

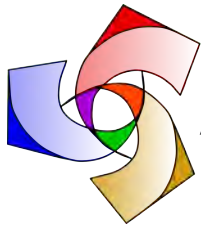
angry about the diagnosis, especially if they do not have support from their parents, friends, or other relatives. A lot of people become very interested and focused on learning about autism when they first find out; it can become a temporary or permanent special interest. Some people find it helpful to work through their doubts and feelings with others who have had a similar experience. See the section Meeting Others on the Spectrum for more information about how to find peers and support groups. Some people can find therapy helpful. Whatever your feelings, it is OK to feel them. Over time most people find a balance. Working through all the feelings is a natural process and it takes time.

5 References

¹American Psychiatric Association. Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM-5). Washington, DC: American Psychiatric Association; 2013.

²Nicolaidis, C., Kripke, C.C., Raymaker, D.M. (2014) Primary Care for Adults on the Autism Spectrum Medical Clinics of North America. 98;1169-1191.

³Kapp, SK (2013). Empathizing with sensory and movement differences: Moving toward sensitive understanding of autism. *Frontiers in Integrative Neuroscience*. 7(38)



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Healthcare Toolkit

Autism Information: Adult ASD Diagnosis

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Autism Information: Adult ASD Diagnosis

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1 What is this topic about?

This topic is about getting evaluated for an autism spectrum diagnosis as an adult. It covers reasons for being evaluated, how to get evaluated, and a little bit about telling friends, family, and other people you know about your diagnosis if you get one.

2 Why might I think about being evaluated for a formal diagnosis?

Getting a diagnosis as an adult has been helpful to many people, though it can sometimes be a mixed or negative experience. Not everyone may need a formal diagnosis. Many things that are helpful to people with a formal diagnosis, like the information in this toolkit, are also available to people who are self-diagnosed. Also, being evaluated for a diagnosis does not mean you will get one.

2.1 Ways a formal diagnosis may benefit you:

- You would have legal rights to accommodations in school, at work, in healthcare, or in other settings.

- You may get a better understanding of yourself.
- Your healthcare providers, including mental health professionals like counselors and therapists, may be able to provide better service to you.
- You may get peace of mind from a professional confirmation of your experiences.
- You may get new ideas for how to make better use of your strengths to handle your challenges.
- It may help your family members, friends, and other people you know to understand and support you better.
- You may qualify for benefits and services for people who have an ASD diagnosis.
- You may qualify for special programs for people with disabilities, such as scholarships or incentives to increase workplace diversity.

2.2 Common risks associated with being evaluated for, or getting, an ASD diagnosis:

- The evaluation process may be stressful or may make you feel bad about yourself.
- You may have a negative experience with an evaluator who does not treat you well.
- You may not get a diagnosis, even if you meet criteria. Different evaluators may interpret criteria in different ways.
- Other people may not believe you or be supportive, even if your diagnosis is official.
- Some people might assume problems you are having are because of autism, rather than for other reasons that need attention in your life.
- Simply having a diagnosis may not be enough for you to qualify for services.

3 How can I get evaluated for a diagnosis?

Typically the first step is to find someone who can make the diagnosis in adults. Here's a list of kinds of professionals who can diagnose individuals on the autistic spectrum.

- Psychiatrists or other medical doctors (MDs) with expertise in ASD
- Psychologists and neuropsychologists
- Licensed clinical social workers

If you need help finding someone who can make a diagnosis, here are some ideas:

- Ask your primary care physician
- Ask someone you know and trust
- Contact a local autism related group (for example, your local Autism Society of America branch)
- Search the Internet (for example, if you live in Portland, you might type into a search engine: autism adult diagnosis Portland)
- Contact your student health services department if you're a student
- Contact your state's Department of Vocational Rehabilitation to help you with getting evaluated for a diagnosis, especially if you are having trouble finding or keeping employment
- Check if there is an autism clinic or autism center in your area. If so, call or check their web site to find out if it has services for adults.

If you have any family, friends, or acquaintances (people who you know a little bit) whom you trust, you might ask them if they can recommend a psychologist or other professional who can diagnose autism. Many people find it helpful to

mention that they are especially interested in seeing a professional who has a good reputation for working with adults on the autism spectrum.

You can ask, *"I am wondering if you know of any professionals who diagnose autism and have a good reputation for working with adults?"*

4 What if I don't have health insurance that covers diagnostic testing for ASD?

Being uninsured or unable to afford a diagnosis can be distressing. If you're in this position, here are some possible resources:

- Check with your state's Department of Vocational Rehabilitation (VR), to see if it can be of assistance, especially if you are unemployed or are searching for a job.
- Check with your local Department of Human Services (DHS), to see if it offers medical assistance.
- Check with your student health department if you attend a college to see what options it has for students who need to be evaluated for a diagnosis.
- Check out university psychology clinics to see if your local university offers a clinic, and ask if they evaluate for ASD diagnoses. If so, find out the cost of evaluation, and ask if they have a sliding scale fee. A sliding scale fee means that the cost goes down the less able you are to be able to afford it.
- Check if your state offers low-cost health insurance options for people who do not have access to insurance plans via employment, or other means. For example, if you live in Columbus, Ohio, you might type into an Internet search engine such as Google: low-cost insurance plans Columbus Ohio.

- Check with your parent(s), if you have a good relationship, and see if they might be willing to help fund part or all of the cost of evaluation.
- Explain your situation directly to the diagnostician or provider, and ask whether he or she offers a sliding-scale fee.

5 What usually happens during a diagnostic evaluation?

Your provider's evaluation of you might take anywhere from two days to two or more months, depending on the method your provider uses, and how busy he or she is. The provider doing your assessment may do the following:

- Ask you questions;
- Ask you to take a series of tests (tests often include an IQ test, adaptive skills tests, and the Autism Diagnostic Observation Schedule);
- Ask you to complete questionnaires about your autistic traits such as sensory issues, or other things that may relate to autism;
- After getting your permission and if possible, interview your parents, other family members, or close friends who know you well or can give information about your childhood development (for example, using the Autism Diagnostic Interview-Revised);
- Explore other possible diagnoses, for example, ADHD, social anxiety, obsessive compulsive disorder, or learning disabilities.

6 How might I prepare for an evaluation?

Spend some time listing your autistic traits before your appointment. For example, list the types of difficulties you have with social interactions, what your special interests are, and any of your sensory sensitivities. A list can help you

a great deal if you get overwhelmed or anxious and forget what you want to share with a provider. Lists are also a helpful way to open and direct the conversation with the evaluator. If possible, talk with the people you would want your provider to interview about your life or childhood development. Make sure that they know that you are considering an evaluation for diagnosis of ASD, and that they are comfortable talking with a provider about you. Note that you can still get an evaluation even if there is no one who can report on your early childhood.

7 Should I tell my friends, family, and acquaintances that I have a diagnosis of ASD?

Disclosure is very personal. When it comes to sharing an ASD diagnosis, each person will have different boundaries and needs that they must consider. Disclosing your diagnosis can strengthen relationships with people. It can also cause tension, especially when you disclose to people who do not understand autism or are not interested in learning about it. While there is always a risk when you choose to disclose, there is also the possibility of reassurance, better communication, and new understanding. Keep in mind that negative attitudes and perceptions, as well as misunderstandings, are at the root of most unsuccessful disclosure scenarios. In any situation where you need to disclose your diagnosis, try to maintain a sense of confidence and strength.

7.1 Questions to ask yourself before you disclose:

- What might be good for this person to know about my diagnosis?
- Will disclosure improve communication and understanding between this person and me?
- Could my disclosure bring about any negative effects?

- Is this the best time for me to disclose my diagnosis?
- How might this person react to my disclosure, and will I be able to cope with the reaction?

7.2 Reasons some people choose to disclose their diagnosis:

- A friend or family member is confused by a certain need or request, and mentioning an ASD diagnosis might help resolve the confusion (For example, perhaps holiday gatherings are very hard for you. You want your family and friends to know that you care about them, but need to limit the number or length of gatherings you attend.);
- A person who mentions he or she is seeking an evaluation for ASD might benefit from your support, guidance, and commonality;
- People might be more likely to understand you and stop misinterpreting your behaviors.

7.3 Ideas to help disclosure go smoothly:

- Be precise and specific.
- Share your strengths.
- Share your challenges and some solutions you are working on.
- Remind family and friends that you are still the same you and that the only thing that has changed is that you now have an official diagnosis.
- Stay strong if people do not respond in a way that you had hoped for. People often come to understand things better after they have some time to think. Try to be patient and persevere in educating others about yourself and your needs, even if you only do so a little bit at a time.

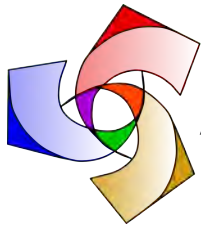
8 What can I do if people who are important to me react badly to my diagnosis?

Some people may react with disbelief, hostility, or other negative feelings when someone discloses either their plans to pursue evaluation, or when they disclose their diagnosis. This can be hurtful or even traumatizing for the person who has disclosed. There's not always an easy way to get through the tough situation of having a negative response to disclosing. That makes it especially important to find sources of encouragement and strength. Ideas:

- Seek counseling from a trusted counselor or therapist.
- Seek support from a trusted friend or family member.
- Seek guidance from a trusted pastor, priest, rabbi, or other religious or spiritual figure.
- Seek support from other people who have had experiences similar to yours. You might wish to join an autism listserv or forum where you can meet other autistic adults, or you might look for a support group for autistic adults in your area.
- Seek out other members of the Autistic community.
- Seek books written by autistic adults or self-help books that focus on helping people get through hard times.
- Keep a journal or blog of your daily feelings so that you can have a safe way to vent your hurts or frustrations.
- Offer to give the person more information about ASD.
- Write a letter to, or have a conversation with, the person about your experiences and why you think you are on the autism spectrum.
- Give the person time to think about it. Disclosure may take others by surprise.

9 Summary

- Adult diagnosis is possible, and seeking evaluation for it has both potential benefits (for example, increased understanding, access to services, legal rights) and potential risks (for example, stress, not receiving the diagnosis).
- Diagnosis is typically done by psychiatrists or other medical doctors (MDs) with expertise in ASD, psychologists, neuropsychologists, and licensed clinical social workers. You can search for them, or ask others to find them.
- If you don't have health insurance that covers diagnostic testing for ASD, there are free or low-cost options such as Vocational Rehabilitation, universities, and providers with sliding scale fees.
- A diagnostic assessment typically includes interviews of you and people who know you well, a series of tests (like IQ tests), questionnaires about your autistic traits, and looking at other possible diagnoses.
- To prepare for an evaluation, it can be helpful to list your autism-related experiences and to talk with the people you would like the evaluator to interview.
- Disclosing an adult diagnosis to friends, family, and acquaintances is a personal choice, with both possible risks (like not being believed) and possible benefits (like being better understood).
- If someone does react badly to your disclosure of an adult diagnosis, you can discuss it with someone else, offer the person more information about autism to help better understand, or give the person time to think about it.



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Healthcare Toolkit

Autism Information: Therapy and Assistive Technology

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Autism Information: Therapy and Assistive Technology

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1 What is this topic about?

This topic is about therapy and assistive technology. Therapy includes things like speech and language therapy, occupational therapy, and mental health counseling. Assistive technology helps people do things they could not do without the technology. Speech devices, wheel chairs, and electronic reminder programs are examples of assistive technology. Whether or not to have therapy should always be your choice. Therapies and assistive technologies are not always perfect solutions to address disability-related challenges. The therapies and assistive technologies discussed on this page are not meant to cure or stop someone from being autistic. They are instead meant to provide ideas for ways to accommodate or relieve challenges that are common among individuals on the autism spectrum.

2 Why might I be interested in therapy or assistive technology?

Therapy or assistive technology might help with certain autism-related challenges. Examples of reasons someone on the autism spectrum may choose to explore therapy or assistive technology include:

- Sensory integration or sensory sensitivity

- Motor skills and motor planning
- Communication difficulties
- Challenges with typical social interaction
- Difficulty with sequencing or planning activities
- Assistance with self improvement and achieving personal goals

3 Mental Health Therapy

Life can be challenging and stressful for anyone, and especially so for many individuals on the autism spectrum. Mental health is a person's emotional and mental well-being. Mental health therapy is used when a person is having difficulty with emotional or mental well-being, or when a person wants to feel more satisfied with life but doesn't know how. A person might seek mental health therapy for a mental health problem, like anxiety, depression, pervasive fears (for example, fear of leaving the house), obsessive compulsive disorder, eating disorders, post-traumatic stress disorder, or a personality disorder.

A person might also seek mental health therapy for help with changing unwanted behaviors, meeting goals, or finding strategies to improve life. Mental health therapists may be able to offer strategies, scripts (things you can memorize and say in specific social situations), or ideas for accommodations to help with communication, organization, or sensory sensitivities. Some mental health therapists assist with learning ways to understand and manage social situations. People may find therapy helpful in finding ways to understand and respond to negative emotions or to help prevent melt-downs. They may also use therapy to identify behaviors they wish to change and find ways to change them (for example, ways to stop smoking, change rituals that are interfering with life, or have more productive reactions in negative situations). Different mental health therapists may have different approaches to therapy, resources, or tools available to help address their clients' specific needs. It's important

to find a mental health therapist whose ideas about therapy fit well with your own goals.

To find a mental health therapist in your area, ask your doctor or healthcare provider for a referral, or search the Internet for professionals in your area. Also, many of the tips in Finding a Healthcare Provider also apply to finding a mental health therapist.

4 Occupational Therapy

All people need skills for the "job of living." Occupational therapy (OT) helps people do things that they need and want to do. Occupational therapy is used to develop, recover, or maintain the daily living and work skills of individuals with physical, mental, or developmental conditions.¹ Occupational therapy also can help with adapting environments, modifying tasks, teaching new skills, and educating clients and their families.

People might seek occupational therapy if they are having difficulty with personal care tasks, motor movements, staying organized, or sensory processing. A person might also see an occupational therapist if they have difficulty with eating or drinking, balance and coordination, or with skills that are needed to do a job. Occupational therapists have a big-picture perspective and often focus on changing the environment to fit the client. Occupational therapists consider the client an important part of the therapy team.

Different occupational therapists will have various approaches, resources, and tools available to help address their clients' specific needs. It's important to find an occupational therapist whose ideas about therapy fit well with your own goals. Occupational therapy services often include:

- An individualized evaluation, during which the client and occupational therapist determine the client's goals,
- A customized plan to improve the client's ability to reach their goals,

- An outcomes evaluation to make sure the goals are being met and/or to make changes to the plan,
- Possible evaluations of the client's home and other environments (for example, the client's workplace),
- Recommendations for assistive technology and training in its use,
- Guidance and education for the client's family members and/or caregivers.

To find an occupational therapist in your area, ask your doctor or health care provider for a referral, or search the Internet for professionals in your area. Another resource is the America Occupational Therapy Association ([AOTA](#)). Also, many of the tips in Finding a Healthcare Provider may also apply to finding an occupational therapist.

5 Speech and Language Therapy

Most people find useful speech and language skills important for standing up for their rights and having a good life. Speech language pathologists (SLPs) can help autistic adults with a variety of speech and language related difficulties. Speech language therapy is used to develop, recover, or maintain speech and language and social communication skills. Speech language pathologists also work with people who have trouble swallowing.

An autistic person might seek speech and language therapy for speech difficulties and difficulties with using language in a social context. Speech production refers to the ability to make sounds, voice quality, and fluency. Some people have a hard time making specific sounds or combinations of sounds, difficulty modulating vocal quality or intonation (such as use of a "monotone" voice), and stuttering.

Language refers to one's understanding and communication of thoughts, ideas, feelings, wants, and needs. Understanding and using words and grammar are

part of language. Trouble with language can lead to communication breakdowns.

Language pragmatics refers to how language is used socially or in a social context. Issues with pragmatics are common in the autistic population. An individual with pragmatic difficulties might say atypical or unrelated things during conversations, or tell stories in a jumbled way, or take language very literally. Pragmatic disorders often coexist with other language-related issues, and they can interfere with social acceptance, as people might avoid conversation with someone who struggles with pragmatics.

Speech language therapy services often include:

- An individualized evaluation, during which the client and speech language pathologist determine the client's goals,
- A customized plan to improve the client's ability to reach his or her speech or language goals,
- An outcomes evaluation to make sure goals are being met and/or to make changes to the plan,
- Recommendations for assistive technology and training in its use,
- Guidance and education for family members and/or caregivers.

To find a speech language therapist in your area, ask your doctor or health care provider for a referral, or search the Internet for professionals in your area. The American Speech-Language Hearing Association ([ASHA](#)) provides many resources, as well a feature to help you find a qualified SLP in your area. Also, many of the tips in Finding a Healthcare Provider may also apply to finding an occupational therapist.

6 Assistive Technology for Communication

Everyone deserves access to communication that works for them. Alternative and Augmentative Communication (AAC) gives many people the ability to communicate in a way that works best for them. It involves communication methods that aid or replace speech and/or writing with other kinds of communication like pictures or sign language. AAC can be a temporary or a permanent feature in a person's life. Some individuals are full-time AAC users and others are part-time users. It is OK to only use AAC when you need it. Speech and Language Pathologists (SLPs) and Occupational Therapists are the kinds of therapists who usually help people get set up with AAC. Reasons why a person might seek AAC include challenges related to communicating with speech, either sometimes or all the time. There are a lot of different kinds of AAC. Which kind of AAC will work best for a person will have to do with his or her own personal strengths and motor, visual, cognitive, language, and communication styles. Some high-tech AAC solutions might include:

- Dedicated speech devices (for example, devices by [Dynavox](#))
- Multi-purpose devices such as a laptop computer or an iPhone that has an AAC program installed (for example, [Assistiveware's products](#))

Some low-tech or no-tech AAC solutions might include:

- American Sign Language (ASL), which is commonly used by Deaf people (Check your local community college or university for classes.)
- Communication boards or books with letters, words, phrases, and/or photos
- Notebooks or notepads

Some people will find a combination of AAC strategies useful. It is important for environments to support communication and foster interaction of AAC

users. Activities might need to be adapted in order to be inclusive of people who use AAC. Non-AAC users might need help understanding how to accommodate an AAC user in business, conversations, entertainment, schooling, and other settings. To find out more about AAC, ask your doctor or health care provider for resources or referrals, or search the Internet for AAC devices that are sold either online or in your area. Speech language pathologists and occupational therapists are both trained to recommend, provide, and teach people with disabilities about AAC.

7 Other Types of Assistive Technology that May Be Useful

Assistive technology helps people to do things they could not do without the technology. Some assistive technology is so common that most people don't even think of it as special, like eyeglasses. Other kinds of assistive technology might be more rare or highly specialized, like a machine that translates typed text into Braille. There are a lot of reasons why people on the autism spectrum might find assistive technology helpful. Here are some ideas:

- To help with sensory issues
 - Headphones and music players, ear muffs
 - Sunglasses, tinted glasses, and hats with brims
 - Chewing gum or other chewable items
 - Stress balls or other "fidgets"
- To help with motor skills
 - Mobility devices like wheel chairs or scooters
 - Computer keyboards or speech-to-text programs as alternatives to handwriting
 - Tools designed with large grips, often made for people who have arthritis

- To help with communication
 - Alternative and Augmentative Communication (AAC) strategies and devices (see Assistive Technology for Communication)
 - Speech to text programs for people who can express themselves with speech better than writing
 - Screen readers (text-to-speech) programs for people who have trouble reading
 - TTY (telecommunications device for the deaf) machines or relay services for telephone communication
- To help with organization and other learning disabilities
 - Smart phones, tablets, and computers with programs for organizing, managing calendars, setting reminders, and keeping instructions
 - Paper-based organizers, like day planners or visual schedules
 - Calculators
 - Egg timers, visual timers, programmable watches, and other kinds of clocks

Some assistive technology is easy to get, like day planners or sunglasses. For other equipment, a prescription from your doctor may be needed. For example, some mobility devices require a prescription. Talk to an occupational therapist, speech/language pathologist, disability services professional, other people on the autism spectrum who use assistive technology, or your health-care provider for more information or ideas.

8 Service Animals

Some individuals on the autism spectrum find that service animals help them to be more independent, or live safer or happier lives. Though service animals do not replace human reasoning and judgment, they can be trained to

help humans in many ways. Jim Sinclair, an autistic self-advocate, disability educator, rehabilitation counselor, and long-time private animal rescuer has worked with and written a lot about service animals, namely SSigDOGs (Sensory Signal Dogs or Social Signal Dogs). He notes [many reasons](#)¹ a person might want to use a service animal:

- Managing sensory and motor behavior; for example, a service dog can be trained to stop at all street corners, to lead its owner out of harm's way, or to pull its owner out of the path of obstructions.
- Orientation to social environments; for example, an office worker might have a good relationship with coworkers in the work environment, but might have trouble recognizing them outside of a work environment. A service dog can be trained to alert its owner to the presence of familiar people, or to people calling the owner's name.
- Help with routines and changes; for example, the dog's owner might struggle to remember necessary steps to get ready for work. A service dog can prompt the owner to dry off after a shower before getting dressed.

There are many types of service animals, including dogs, cats, birds, monkeys, and horses. The Americans with Disabilities Act (ADA) says that service animals must be allowed to accompany their owners in many settings, but it only recognizes specially trained dogs as service animals. So, for example, other animals may not necessarily be allowed in public buildings or at a job site. To find out more about service animals, ask your healthcare provider's staff or therapist for resources, or search the Internet for service animals near your area. For example you might search for "certified service dogs Portland Oregon" if you lived near Portland, Oregon.

9 What qualities might I look for in a therapist?

If you are interested in therapy, it is highly recommended that you search for a therapist who has both a strong and positive history of working with autistic individuals. Not all therapists understand autism and the unique ways it can appear in individuals. Some therapists might have negative attitudes about autism, or might have been trained to communicate in ways that do not work well with autistic clients.

You may also want to think about the things in "How do I know if a healthcare provider is a good choice?"

10 How might I pay for therapy?

10.1 If you have insurance:

Not all insurance will pay for all kinds of therapy. Before you go to your first therapy appointment, consider doing the following.

- Find out if your insurance company will cover the kind of therapy you want.
- If the therapy is covered, find out if you need a referral to a therapist from your primary care provider, and try to get one if needed.
- Find out how much of the appointment will be covered by the insurance and how much you will need to pay "out of pocket" or "co-pay." Make sure you can afford this.
- Find out if there is any additional paperwork, communications, or forms that the insurance company needs in order to agree to pay for the therapy.

10.2 If you do not have insurance or insurance won't cover the type of therapy you want:

You still might be able to get the therapy you want even if you don't have insurance, or if the insurance won't cover the therapy. Some options to ask about:

- Ask the therapist or their office staff if they will see uninsured or self-pay patients.
- Ask the therapist or their office staff if they have a sliding scale or other low-cost option for self-pay patients.
- Find out how much it would cost for you to see the therapist, and consider if you can afford it.
- If there is a university in your area that trains therapists, find out if you can see a therapist in their program for a lower cost.

11 Consent and Self-Advocacy in Therapy

All people are worthy of inclusion and respect, regardless of what a person's support needs may be. Autistic individuals deserve helpful and respectful therapy. Self-advocacy is important in therapy. Many autistic people are concerned about scientifically unproven treatments. Others are concerned about therapists who care more about making an autistic person look "normal" than they do about that person's self worth and quality of life. Meaningful therapy works with an autistic person's natural way of being instead of trying to "intervene" against, change, or wipe out who they are. Respectful therapy plans do not make autistic people feel bad, guilty, or inferior. It is important that you know your rights and how to advocate for them. There are some situations where your rights may be limited. For example, if you have a conservator or guardian, that person may make decisions about your therapy that you do not

always agree with. Or if a professional is concerned that you might be suicidal or dangerous to others, he or she may have the right to take actions that you don't agree with to ensure your safety. However, in most circumstances, you should not be forced into a therapeutic situation without your permission. If you are uncomfortable with a healthcare provider, therapist, or mental health professional, then you have the right to say no to their services and to seek therapy from someone else. If a professional makes you feel uncomfortable or does something you feel is wrong, bring it up to him or her. Make it known that you are uncomfortable and that you would appreciate if they would respect your boundaries and concerns. Your therapist should always be able to explain to you why they are doing something and how it relates to what you want out of therapy. If your therapist cannot respect your wishes, you do not have to continue seeing them and you can look for another therapist. If you feel you have been treated wrongly by a therapist, three places to try asking for help are:

- your state's Protection and Advocacy ([P and A](#)) program.
- the therapist's professional licensing board in your state; for example, search for terms like "speech language pathology licensing board Arizona" or "occupational therapy licensing board Oregon".
- a primary care provider (a "regular doctor") who you trust, if you have one. Tell him or her what happened, and ask for advice.

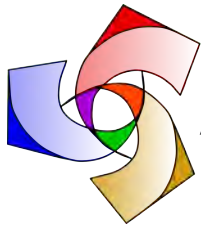
12 Links and Resources

- [American Occupational Therapy Association](#)
- [American Speech-Language-Hearing Association](#)
- [Augmentative and Alternative Communication Institute](#)
- [Autistic Self Advocacy Network](#) (Scroll down to Therapies and Health Care.)

- [State assistive technology programs](#)

13 References

¹Sinclair, Jim. "What Is A SSIG (Autism) Service Dog? by Jim Sinclair." *Http://www.inspire.com*. N.p., n.d. Web. 23 May 2013.



AASPIRE

Healthcare Toolkit

Autism Information: Disability Rights Laws

Contents

- What is this topic about?
- Are people on the autism spectrum protected by disability rights laws?
- What laws protect the rights of people with disabilities in the U.S.?
- Where can I get more information about these laws?
- Links

Autism Information: Disability Rights Laws

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www.aaspire.org

Last Updated September 29, 2015

1 What is this topic about?

There are laws in the United States that help prevent discrimination against people with disabilities. A person with a disability is discriminated against if they are treated unfairly just because they have a disability. People on the autism spectrum may be protected by these laws. This topic gives a brief summary of the major laws that protect the civil rights of people with disabilities in the U.S. For more information about these laws, please see the section "Where can I get more information about these laws?". These laws include civil rights protection in:

- Employment
- Public and private services and buildings
- Public Transportation
- Telecommunications (like telephones and pagers)
- Housing
- Air travel
- Voting
- Institutionalized settings

- Education

How these laws may apply specifically in healthcare is covered in more detail under Your Rights in Healthcare. These laws are a good start in helping to prevent discrimination. Unfortunately, in practice these laws are not always followed very well. Understanding your rights is just one part of a continuing fight for equal access to education, employment, and the community.

2 Are people on the autism spectrum protected by disability rights laws?

The U.S. government uses the following definition of disability for all of the laws listed here except IDEA. The IDEA definition of disability can be found on the [IDEA web site](#). "An individual is considered to have a 'disability' if s/he

- has a physical or mental impairment that substantially limits one or more major life activities,
- has a record of such an impairment,
- or is regarded as having such an impairment.

Persons discriminated against because they have a known association or relationship with an individual with a disability also are protected." (Source: Americans with Disabilities Act [Questions and Answers](#)). This means that if

1. a person has an autism spectrum diagnosis, and
2. being on the autism spectrum makes it hard for that person to do things like hold a job, use the telephone, or have relationships with others, or
3. others consider that person to be on the autism spectrum,

then that person would likely be protected by these laws. A person does not need to call themselves "disabled" to meet this definition. The definition covers the perception by others of disability.

3 What laws protect the rights of people with disabilities in the U.S.?

This is a summary of the more detailed list that can be found at A Guide to Disability Rights Laws published by the U.S. Department of Justice (DOJ). The detailed list can be found at www.ada.gov/cguide.htm.

3.1 Americans with Disabilities Act (ADA)

The ADA is a broad law that makes sure people with disabilities are not discriminated against and have equal access to

- employment,
- state and local government services, information, and buildings,
- public transportation,
- privately operated facilities that are open to the public (for example, restaurants, retail stores, hotels and movie theaters, to doctors' offices, homeless shelters, and recreation facilities),
- telephone service, including the requirement that telephone companies provide relay service.

For more detailed information, see the [Americans with Disabilities Act](#) on the DOJ site.

More information and resources can also be found on the [ADA Regulations and Technical Assistance Materials](#) page, as well as on the [ADA home page](#) www.ada.gov

3.2 Telecommunications Act

This law requires equipment like telephones, cell phones, and pagers to be accessible and usable by people with disabilities. The law also requires that telephone services like operator services, emergency calls, and directory assistance are accessible to and usable by persons with disabilities.

For more detailed information see the [Telecommunication Act](#) on the DOJ site.

3.3 Fair Housing Act

This law says people can not be discriminated against in housing based on their disability (as well as other things like race). This law covers both buying and renting homes. This law also requires that owners of housing facilities make changes to their policies to give people with disabilities equal access. For example, a landlord with a "no pets" policy may be required to let someone who has a service animal rent from them.

For more detailed information, see the [Fair Housing Act](#) on the DOJ site.

3.4 Air Carrier Access Act

This law says people with disabilities can not be discriminated against in air travel. It requires airlines to provide accommodations, such as early boarding, assisted boarding, or wheelchair access, to people with disabilities.

For more detailed information, see the [Air Carrier Access Act](#) on the DOJ site.

3.5 Voting Accessibility for the Elderly and Handicapped Act

This law requires polling places to be accessible to people with disabilities for federal elections. If it is not possible to make polling places accessible, then a

different way for people to cast their votes needs to be offered. This law also requires voter registration and information about voting to be accessible.

For more detailed information, see the [Voting Accessibility for the Elderly and Handicapped Act](#) on the DOJ site.

3.6 National Voter Registration Act

This law requires that all state-funded programs that provide services to persons with disabilities give the people they serve voter registration forms. It also requires the programs to offer assistance with registering to vote.

For more detailed information, see the [National Voter Registration Act](#) on the DOJ site.

3.7 The Civil Rights of Institutionalized Persons Act (CRIPA)

This law says the U.S. Attorney General can look into the conditions of institutions of confinement, such as jails, nursing homes, or institutions for people with developmental disabilities. Its purpose is to allow the Attorney General to find and correct problems that may harm the health and safety of residents.

For more detailed information, see the [CRIPA](#) section of the DOJ site.

3.8 Individuals with Disabilities Education Act (IDEA)

This law requires public schools to educate individuals with disabilities through age 21. This includes providing accommodations and services that meet the individual needs of each student.

Note: Colleges are covered under the ADA.

For more detailed information, see the [IDEA](#) section of the DOJ site.

3.9 Rehabilitation Act

This law says people with disabilities can not be discriminated against in any program that gets money from the government. This includes state-run colleges and higher education. It also protects people with disabilities who are government employees. Some of the things in this law are also covered by the Americans with Disabilities Act. Section 508 of the Rehabilitation act requires the government to have accessible technology, including accessible web sites.

For more detailed information, see the [Rehabilitation Act](#) on the DOJ site.

3.10 Architectural Barriers Act

This law requires that all new or re-built government buildings are made to be accessible to people with disabilities.

For more detailed information, see the [Architectural Barriers Act](#) on the DOJ site.

This is a summary of the more detailed list that can be found at A Guide to Disability Rights Laws published by the U.S. Department of Justice (DOJ). The detailed list can be found at www.ada.gov/cguide.htm.

4 Where can I get more information about these laws?

Online:

- Department of Justice summary of laws <http://www.ada.gov/cguide.htm>
- ADA Centers <http://adata.org>

Offline request for information:

- 800 - 514 - 0301 (voice)
- 800 - 514 - 0383 (TTY)
- U.S. Department of Justice

Civil Rights Division

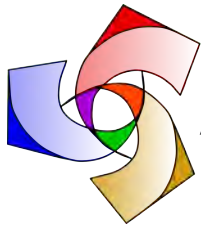
950 Pennsylvania Avenue, N.W.

Disability Rights Section - NYAV

Washington, D.C. 20530

5 Links

- <http://www.ada.gov/cguide.htm>
- [ADA Regulations and Technical Assistance Materials](#)
- [Telecommunication Act](#)
- [Fair Housing Act](#)
- [Air Carrier Access Act](#)
- [Voting Accessibility for the Elderly and Handicapped Act](#)
- [National Voter Registration Act](#)
- [CRIPA](#)
- [IDEA](#)
- [Rehabilitation Act](#)
- [Architectural Barriers Act](#)



AASPIRE

Healthcare Toolkit

Autism Information: Meeting Others on the Spectrum

Contents

- What is this topic about?
- Autistic Culture
- Meeting autistic people in person
- Meeting autistic people online or learning about the self-advocacy movement online
- Finding autistic people you like
- Reflections from autistic people
- Summary
- Links and Resources

Autism Information: Meeting Others On the Spectrum

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www.aaspire.org

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1 What is this topic about?

This topic is about Autistic culture, and how to find other people on the autism spectrum both in person and on the Internet. Meeting other people who are like you can be rewarding.

2 Autistic Culture

Culture brings people together to share everything from common beliefs and principles, to goals, identity, customs, and arts, to literature, history, shared experiences and communal achievements. Most people end up sharing their family's culture. For example, children of Latino parents often adopt a Latino culture. This is not always the case, though. Individuals from heterosexual families can adopt a LGBT culture; deaf people from hearing families can adopt the culture of the Deaf community, and autistic individuals from non-autistic families can adopt an Autistic culture. For cultures that are not always passed through family lines, culture and information are passed from established members to newer members in a cycle that continues to build on and create tradition. Examples of Autistic cultural events include [Autreat](#), [Autistic Pride Day](#), [Autism Acceptance Day](#), and [Autistics Speaking Day](#). There is an

Autistic community that many Autistic people enjoy being a part of. The Autistic community is similar to [the Deaf community](#) though it is much newer (the Deaf community has been around since the 1800s) and more often considers autism to be a disability. Like other minority communities, the Autistic community has its own support systems, leaders, values, social spaces, traditional events, and organizations. There is much to gain by meeting and befriending other autistic people. Interacting with autistic people can positively impact an autistic person's social life and well being. We have much to learn from each other and our individual experiences. The Autistic community generally champions [neurodiversity](#), including appropriate services and support¹.

3 Meeting autistic people in person

If you are interested in in-person social gatherings, advocacy groups, and support groups, here are some ideas for finding groups in your area:

- Check [Meetup.com](#) for local autism-focused groups in your area. Some groups will likely be for parents of autistic children, but others may be for autistic teens and/or adults. If your area has groups for teens and adults, you might find advocacy-focused groups, social groups such as gaming groups, or support groups.
- If you are a student, check out the student-run groups at your university to see if they have any established chapters for autistic students. If not, you might consider if you have the time to start a group at your university.
- Check out your favorite autism or disability rights organizations to see if they have chapters in your area. For example, you could check with Autism Society of America ([ASA](#)), Autistic Self Advocacy Network ([ASAN](#)), Self Advocates Becoming Empowered ([SABE](#)), or [ADAPT](#).
- Do an Internet search for groups with your city or town name included. For example, google "adult autistic social group Portland".

Groups may have different goals and areas of focus. When you come across a group that interests you, find out about their mission and goals to see if it fits what you're looking for. You might need to try a few groups before you find one that fits your needs.

If you're interested in self-advocacy, look for an advocacy-focused group where you can get involved with other autistic people who are interested in changing legislation (laws) that affects autistic people. Advocacy groups also educate the public about autism and work to combat fear, pity, and negative stereotypes.

4 Meeting autistic people online or learning about the self-advocacy movement online

If you're interested in meeting other autistic people, but you feel more comfortable doing it online, there are many listserves, forums, and web sites that you can visit. To find local groups and listserves, go to [Google Groups](#) and browse for autism-focused groups in your city or state.

The sites below can help you get started. They will have links and resources that might be of interest to you:

- [Association for Autistic Community \(AAC\)](#)
- [Autistics.org: The Real Voice of Autism](#)
- [Making Sense of Autism](#)
- [Shift Journal of Alternatives: Neurodiversity and social change](#)
- [The Autism Acceptance Project \(TAAP\)](#)
- [The Autistic Self Advocacy Network](#)
- [The Autism Society of America \(ASA\)](#)

- [The Thinking Person's Guide to Autism](#)
- [WrongPlanet.net](#)
- [Jim Sinclair's archive via the Way Back Machine](#)
- [Autism Women's Network \(AWN\)](#)

5 Finding autistic people you like

It's important to remember that autistic people are as unique, varied, and shaped by personal life experiences as anyone else in the world. If you run across an autistic person who does not treat you well (either online or in person), try not to take it personally. Just like everyone else, autistic people range in personality and interests. Keep on looking and exploring, and eventually you'll probably find an autistic person who shares some of your interests and views.

6 Reflections from autistic people

"I recently met a lot of autistic people at an advocacy group I attended last night. For the first time in my life, I felt like I could be myself and that people would understand me and not judge me for being autistic. I was in good company!" Ernie "Autistic people should reach out to each other for friendship and support. You never know who you will meet that you might end up having a lot in common with." Alice "I've been around autistic people all of my life. But I did not realize that I was autistic too until I was diagnosed in adulthood (shortly after my son received a diagnosis). I had always known there was something different about me, as I always felt that I was from another planet. I had joined an autism-focused listserve shortly before my diagnosis. And that is where I met one of my friends. Like me, she is autistic. Over the years we

have had many deep conversations about autism and about being autistic, from what it was like growing up to defining ourselves in the here and now. It brings happy tears to my eyes to admit that it is my autistic friend who helped me to find myself and who helped me to explore and understand myself, my needs, and my relationship to the world.” Jemma ”Autistic people ROCK!” Kramer

7 Summary

- Autistic culture has common beliefs, goals, customs, arts, literature, history, and community achievements.
- Some ways to meet autistic people in person are through meetup.com, through student-run groups, and through autism or disability rights organizations.
- There are many web sites, listserves, and forums for meeting autistic people online, or for learning more about the self-advocacy movement.
- Many autistic people enjoy meeting others like them and participating in Autistic culture. Just like any people though, not everyone will get along. When you do find people you do get along with it can be rewarding.

8 Links and Resources

General Autism Groups

- <http://autisticcommunity.org/> Association for Autistic Community (AAC)
- [The Autism Society of America \(ASA\)](#)
- [Autism Women’s Network \(AWN\)](#)

- [The Autism Acceptance Project \(TAAP\)](#)
- [WrongPlanet.net](#)

Disability Rights and Advocacy Focused Groups

- [The Autistic Self Advocacy Network](#)
- [Self Advocates Becoming Empowered \(SABE\)](#)
- [ADAPT](#)

Other Information and Resources

- [Autism Now](#)
- [Autistics.org: The Real Voice of Autism](#)
- [Making Sense of Autism](#)
- [Shift Journal of Alternatives: Neurodiversity and social change](#)
- [The Thinking Person's Guide to Autism](#)
- [Jim Sinclair's archive via the Way Back Machine](#)

9 References

¹Kapp, S. K., Gillespie-Lynch, K., Sherman, L. E., & Hutman, T. (2012, April 30). Deficit, Difference, or Both? Autism and Neurodiversity. *Developmental Psychology*. Advance online publication. doi: 10.1037/a0028353