



AASPIRE

# Healthcare Toolkit

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## 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.