



Toolkit for Adults with Autism
Or Suspect They
May Be Autistic



Many people who suspect they may be on the Autism spectrum believe the first place to start is getting a professional diagnosis. However, getting an Autism diagnosis can run several thousand dollars and some insurances may only cover part of the expense.

Few services are offered to adults diagnosed later in life, especially for individuals who may have flown under the radar all these years. Most professional services provided to adults are for those "less" impacted by Autism. A professional diagnosis may do little to give additional support to someone less impacted. The good news is that there are resources that don't require a professional diagnosis, such as some of the support groups.

To learn more about the role Autism may play in your life, we recommend joining some of the groups listed in this guide, reading some of the recommended books, and watching other Autistic adults discuss their experiences and viewpoints on YouTube or TikTok.

This toolkit was designed for individuals in Riverside and San Bernardino County in Southern California, although there are plenty of online resources no matter where you live. At the Autism Society Inland Empire, we are here for you. We have our peer mentor Resource Specialist to answer questions and support you through this journey. Reach out to us at info@ieautism.org or ieautism.org, or call us at (951) 220-6922. Welcome to our community!

TOOLKIT FOR ADULTS WITH AUTISM OR SUSPECT THEY MAY BE AUTISTIC





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You may have seen autism portrayed in such movies and shows as Atypical, The Good Doctor, Love on the Spectrum, or The Accountant. Autism is very diverse, and no one show represents what autism is. Autism is a spectrum and affects people to various degrees. Autism Spectrum Disorder, or Autism for short, is first and foremost a social communication disorder accompanied by other behaviors.

The diagnostic criteria have changed over the years. In 1994 Autism, Asperger's Syndrome, and Pervasive Developmental Disorder- Not Otherwise Specified (PDD-NOS) were all combined into Autism Spectrum Disorder. Currently, in the US, the criteria for an Autism diagnosis follow the DSM-V criteria. To learn more about the diagnosis criteria, visit the CDC website. www.cdc.gov/ncbddd/autism/hcp-dsm.html

What common characteristics may you have if you are on the Autism Spectrum? Please note that under the DSM-V criteria, you don't need to have every characteristic to be on the Autism Spectrum.

- You may have a hard time making and keeping friends.
- Eye contact may be a challenge.
- You may repeat things you say or have little inflection in your voice.
- You may take things such as sarcasm and jokes literally.
- You may have difficulty reading body language and expressing yourself through body language.
- Being overly interested in something beyond what most society considers "normal,"
- Needing a routine to get by and not being flexible or having your entire day ruined if something changes your routine,
- Flapping your hands when you get excited or rocking back and forth to calm yourself,
- Getting overwhelmed by outside stimuli (loud noises, bright rooms, too many people, perfumes, the feeling of certain fabrics, etc).







Most people who realize they are on the autism spectrum later may identify as having Asperger's Syndrome or High Functioning Autism (HFA). In some communities, these terms are taboo for various reasons. The word "High Functioning Autism" can be offensive to some people as there is technically no such thing as low functioning and high functioning autism, and such language can be seen as discriminatory.

So, what is the difference between "high functioning" and "low functioning" Autism? Even though such terminology is controversial in some circles, both terms are still often used. The term "low-functioning" or "severe Autism is often used to mean someone who also has an intellectual disability and is on the Autism Spectrum.

"High functioning"Autism usually means someone that passes off as "normal" at first glance. If you are reading this toolkit and believe you are on the Autism Spectrum, chances are you will fall into this category.

The term "Asperger's Syndrome" is still used in some communities but is not recognized as an official diagnosis in the United States. Asperger's Syndrome is often used synonymously with high functioning Autism. Some people, including doctors and other professionals, sometimes use these terms when discussing Autism.

At the end of the day, whatever labels you choose to use for yourself are your decision.







According to the CDC, in 2018, 1 in 27 boys had an Autism diagnosis, and 1 in 116 girls had Autism. Boys are four times more likely to get an autism diagnosis than girls.

Many women don't receive an Autism diagnosis as a child but later in life. One of the leading theories of this is that girls whose symptoms are subtle, or whose intelligence allows them, are able to "mask" or camouflage their autistic traits to fit into social situations. Furthermore, our culture expects girls to behave in quieter and less assertive ways than boys. Therefore a girl who seems shy, withdrawn, or unengaged may be seen as "feminine," while a boy who has the same behaviors is noticed as different in a way that gets addressed.







As you learn more about Autism, you will come across commonly used terminology online or through interactions with different people. The following articles dive into some of the more common terms you may encounter.

Glossary of Autism Terms:

This article from Dictionary.com discusses some of the common terminology you may come across such as Asperger's Syndrome and neurotypical.

https://www.dictionary.com/e/autismterms/#:~:text=Clinically%2C%20the%20term%20ASD%20has,term s%20are%20still%20sometimes%20used.

Understanding Autism - Terminology:

Another article that discusses common terminology used in the autism community.

http://www.autismtoolbox.co.uk/understanding-autismterminology





Diagnosing Autism

"Being diagnosed later in life is like watching a TV show with a huge plot twist revealed at the end of the season, and then rewatching it with this new knowledge, picking up on all the foreshadowing, and getting upset that you didn't see it all before."

- Unknown

Do I Need A Medical Diagnosis?

Many people believe that getting an official Autism diagnosis will mean they will receive help and services. For adults, there are generally fewer services available than for children. In addition, getting a diagnosis often costs a few thousand dollars out of pocket depending on your insurance. Also, a diagnosis does not mean you will get access to all the services out there. For instance, the Regional Center may still deny services despite having a diagnosis, if for instance you did not receive any services or therapy as a child while in school.

Luckily, there are various support groups (often free or low cost) which do not require an official diagnosis to attend. You may find answers and reassurances meeting other people on the Autism spectrum like yourself. Please check the section on support groups to learn more about these groups. With that said, you may still want an official Autism diagnosis. Most insurance providers will cover some services and therapies if you have an official Autism diagnosis. Often a psychologist or primary care provider provides a referral to get an Autism diagnosis.





Do I Need A Medical Diagnosis?

Receiving a medical diagnosis is a personal decision and is based on different factors such as your financial resources and if you will be pursuing government services such as employment, social security, etc. To learn more about getting diagnosed as an adult, read this helpful article and scroll below to the section on getting diagnosed as an adult: Getting an Autism Spectrum Diagnosis / The Diagnostic Process. Another helpful article to read is AASPIRE Toolkit on Getting an Autism Evaluation.







Listed below are professionals and organizations that offer diagnostic services:

AB Psych Consulting - Dr. Anthony Benigno Psychologist

(909) 244-9593

10165 Foothill Blvd STE 3 Rancho Cucamonga, CA

Comprehensive Diagnostic Evaluation CDE-ages 2.5 to adults.

Wait time: few weeks

Accepts: IEHP, BLUE SHIELD, AETNA, CASH PAY

Dr. Laurie Montes, PhD

805-746-7136

290 Maple Court, Suite 112, Ventura

Experienced diagnostician that specializes in diagnosing adults regardless of age.

Autism Heroes

www.myautismheroes.com

(909) 312-3070

420 Brookside Ave, Redlands CA

Psych Diagnostic evaluation. Offers several services including Diagnosis by a medical doctor for children, behavioral feeding therapy, and sexuality training. Cash pay.







Casa Colina Children's Services

www.casacolina.org

(909) 596-7733 or 1 (866) 724-4127

255 East Bonita Ave, Pomona

Medical Diagnostic evaluation. Dr. Margaret Bauman M.D. visits Casa Colina (home is Mass General Hospital) to provide neurologic assessments and services once every 3 months. Cash pay

Desert Care Network Neurology - Dr. Muhammd Salim

https://desertcaredocs.com/bios/muhammad-salim-md/

760-771-6166

La Quinta

Yucca Valley

Adults and Children Autism and Epilepsy

Accepts a variety of insurances.

Gunn Psychological

www.gunnpsych.com

909-989-4055

8300 Utica Ave Unit 245 Rancho Cucamonga CA

Psych Diagnostic evaluation. Evaluations for children 12 months and up. Commercial insurance (each doctor is paneled with different insurance companies)







Dr. Tanya Mesirow- Licensed Clinical Psychologist https://drtanyamesirow.com

28991 Old Town Front STE 102 Temecula CA 951-775-4057

Specializes in psychological and neuropsychological assessment with children, adolescents and adults demonstrating a variety of neurological issues including

head injuries, dementias, stroke, learning disabilities, ADHD, and Autism spectrum disorders. Dr. Mesirow also sees adults for individual psychotherapy treatment.

Pinnacle Counseling- Murrieta and San Diego www.pinnaclecounselingca.com

41197 Golden Gate Circle Suite 206 Murrieta, CA 92562 951-396-5701

Offers a Psychological Diagnostic evaluation for ages 2.5 years through adults.

Cash pay only.

Quality Life Group - Dr. Kotomori

www.qualitylifegroup.com

6529 Riverside Ave Ste 133, Riverside (951) 684 2627

Board certified in Child and Adolescent Psychiatry and General Psychiatry. An expert in the diagnosis and treatment of Psychiatric Disorders and experienced with cultural issues and how they may affect the presentation, course, and treatment of psychiatric conditions.







Riverside Psychiatric Med Grp, Dr Antonius "Tony" Brandon www.rivpsych.com

5887 Brockton Ave Ste A Riverside, CA 951-275-8500

Can perform a psychological diagnostic evaluation for ages 5 years through adults. Accepts many insurances and cash pay.

San Diego Brainworks Temecula and San Diego www.sdbrainworks.com

858-914-1347

Offers psychological diagnostic evaluations, specializing in Comprehensive Psychoeducational/IEE, Learning Disorder, ADHD & Autism Evaluations, Neuropsychological Assessments, EHRMS Assessments, Psychological Testing, & Therapy. Accepts many insurances and cash pay.

Dr. Ta Tanisha Jones, PsyD
Psychological And Substance Abuse Services, Inc
21250 Box Springs Rd, Suite 203, Moreno Valley, CA
951-335-5858

Diagnosis and works on substance issues as well. Takes IEHP.







Dr. Terry Matteo

http://www.terrymatteophd.com/

74-710 HWY 111 Ste 102 Palm Desert CA (480) 382-4142

Psychological testing for ages 18 month to adults. Cash pay only.

Dr. Victor Cordova PsyD

9033 Baseline Rd Ste A Rancho Cucamonga, CA 909-922-2442 Diagnosis only - Bilingual (Spanish). Accepts only IEHP.

Willowbrooks Behavioral Health

https://willowbrooksbehavioralhealth.com

818-918-6429

Locations in the Inland Empire: Apple Valley, Murrieta, Riverside, and Upland They only do a 1-hour psych screening for ASD in adults. If needed they will submit a CDE to IEHP/MOLINA. Also provides mental health 1-1 counseling /family therapy. All females Psych D (1 bilingual LMFT) ZOOM only. Currently booking 30-45 days for screening. Takes IEHP, commercial insurance & cash pay.







There are also several free online tests you can take that may indicate whether you are on the Autism spectrum or not. Please note that these online tests do not take the place of a professional diagnosis and only indicate that you may be on the Autism spectrum.

RDOS—Aspie-Quiz:

https://rdos.net/eng/Aspie-quiz.php

According to the website, the purpose of this test is to check for broader Autism cluster (Aspie) and neurotypical traits in adults. Broader Autism clusters traits can give a reliable indication of Autism spectrum traits prior to an eventual diagnosis.

The Ritvo Autism Asperger Diagnostic Scale-Revised (RAADS-R): https://www.aspietests.org/raads/

According to the website, The RAADS-R is a modified version of the Ritvo Autism Asperger's Diagnostic Scale (Ritvo et al. 2008). The rationale for its development was the need for a clinical adjunct diagnostic tool. While several diagnostic scales for children and adolescents with ASD are available, only one peer-reviewed scale, The Autism-Spectrum Quotient (AQ) was designed specifically for adults. Its authors emphasize that it is useful in identifying Autistic traits and as a screening instrument but not as a diagnostic tool.

The Ultimate Autism Resource:

https://embrace-autism.com/

Provides additional Autism tests and assessments worth taking a look at.





Resources

"I want us all to live the kind of lives where, when it is all over, we can slide into home, dust ourselves off, and say: Dang, that was fun!"

- Jennifer Cook Author and speaker,



• "Pink on the Spectrum" www.autismempowerment.org/wp-content/uploads/2014/11/Pink-On-The-Spectrum-Jennifer-OToole.pdf

Autism Society Inland Empire

https://ieautism.org/adult-resources/

Talk to a Peer Resource Specialists, visit a support group, meet new friends in our social recreation opportunities or check out our resources on adult topics!

Thinking Person's Guide To Autism https://thinkingautismguide.com/

A one-stop source for carefully curated, evidence-based, neurodiversity-steeped information from Autistic people, parents, and Autism professionals. TPGA aims to help you fast-forward past society's rampant autism fabrications and negativity by providing clear, thoughtfully presented, balanced, and referenced information.



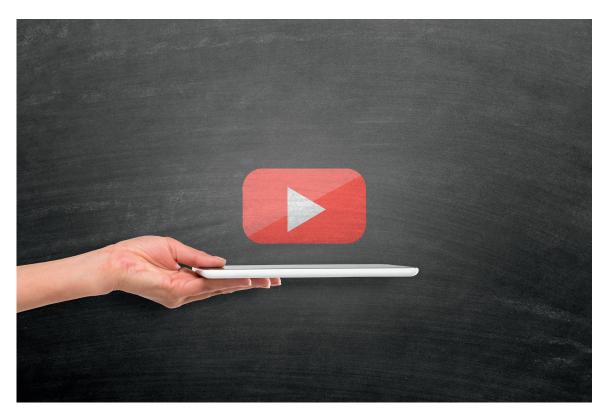




- Autism in Heels: The Untold Story of a Female Life on the Spectrum
 by Jennifer Cook O'Toole
- Autism and Girls
 by Tony Attwood and Temple Grandin
- The Complete Guide to Asperger's Syndrome by Tony Attwood
- I Think I Might Be Autistic: A Guide to Autism Spectrum Disorder Diagnosis and Self-Discovery for Adults by Cynthia Kim
- Preparing for Life: The Complete Guide for Transitioning to Adulthood for Those with Autism and Asperger's Syndrome by Jed Baker







- The Aspie World https://www.youtube.com/c/TheAspieWorld
- Purple Ella https://www.youtube.com/c/PurpleElla
- Agony Autie https://www.youtube.com/c/AgonyAutie
- Neurodivergent Rebel <u>https://www.youtube.com/c/NeurodivergentRebel</u>
- Dean Beadle
 <u>https://www.youtube.com/channel/UCHQvbcTMsMPZp5r2yaF1KKw</u>
- Aspergers from the Inside <u>https://www.youtube.com/c/AspergersfromtheInside</u>
- Yo Samdy Sam https://www.youtube.com/c/YoSamdySam
- Temple Grandin's Lecture "The Autistic Brain" <u>https://youtu.be/MWePrOuSeSY</u>







Autism Society Inland Empire

https://ieautism.org/events/

Please check the calendar of events to keep up to date on current groups and events. Has three online groups currently.

- Talk to Me Tuesday- meets every week (adults with ASD, family members, and professionals just hanging out virtually);
- Teen & Adult Support Group (a facilitated group that meets every other Thurs afternoon- Virtual)
- Rancho Adult Group (meets every other Friday for fun events Virtual & In-Person). Check out the calendar for the latest dates.
- CV
- Late Diagnosis Group

Autism & Asperger's Social Activities Group

http://meetup.com/empoweringautism

This group is for individuals on the autism/Asperger's spectrum who are 18 years or older. They meet on ZOOM and in person and their primary focus is to create a fun and engaging environment for individuals on the autism spectrum.

Autistic Women and Nonbinary Network (AWN) https://awnnetwork.org/

Provides community, support, and resources for Autistic women, girls, nonbinary people, and all others of marginalized genders.







GRASP

https://grasp.org/membershipsupportgroups/

Monthly and weekly chat groups are moderated by GRASP through their Zoom Chat Room and Patreon-only Facebook groups with Autistics, individuals on the Autism Spectrum, and Neurodivergent folk. These groups are an accessible way for fellow Autistic adults (age 18+) to get together to chat in a safe space. Please note to access some of their groups, you are required to have a Patreon membership with them.

Orange Country Asperger's Support Group https://ocaspergers.org/

OCASG is a nonprofit organization committed to improving the quality of life for individuals with Asperger's, High-Functioning Autism and PDD-NOS and their families.

Riverside Adults with Aspergers and Autism Meetup

www.meetup.com/Riverside-Aspergers-Meetup/

This meet-up is for high-functioning autistic adults who want to socialize and connect with other like-minded individuals. Any adult with high-functioning Autism is welcome to join this group. We will participate in various social activities to have fun and get to know each other. Game nights twice a month.







Women's Autism Spectrum Group

Claremont, CA

www.meetup.com/WomensASgroup

A group for women on the autism spectrum and between the ages of 18 and 35. monthly meetings in which we discuss pertinent and engaging topics and do fun activities. Moreover, we have fantastic outings such as going to play mini golf, go-kart racing or hanging out at the mall. This group is for women only.

Wrong Planet

https://wrongplanet.net

Wrong Planet is the web community designed for individuals (and parents/professionals of those) with Autism, Asperger's Syndrome, ADHD, PDDs, and other neurological differences. We provide a discussion forum, where members communicate with each other, an article section, with exclusive articles and how-to guides, a blogging feature, and more.



Questions? Contact us.

www.IEAutism.org info@IEAutism.org 951.220.6922





Your local Autism connection