

Self-Diagnosis-Friendly Resources and Communities

This handout has been created to help you consider whether a formal autism evaluation is right for you. You will learn about the limitations of an official autism diagnosis, the validity of self-diagnosis, situations in which an official diagnosis is important, and ways to get help without one.

Often people seek an autism evaluation in hopes that it will open the door to the support that they need. Unfortunately, many find that the official diagnosis did little to change their practical circumstances. Autism-specific services for adults are severely limited. And if people around you are intolerant of your differences and difficulties, they will not necessarily become more accommodating after an official diagnosis. For many, the best part of learning they're autistic is understanding themselves better and finding a like-minded community. This can be pursued without a formal diagnosis.

In our experience at the University of Washington Autism Center, many professionals are not informed about the variety of ways that autism can appear, and often doubt an autistic person's accurate self-diagnosis. In contrast, inaccurate self-diagnosis of autism appears to be uncommon. We believe that if you have carefully researched the topic and strongly resonate with the experience of the autistic community, you are probably autistic.

Situations in which a formal diagnosis can be important:

- People who have the opportunity to participate in a particular program, such as an autismspecific support at their college or Microsoft's autism employment initiative.
- People who will probably qualify for services through the Developmental Disabilities Administration, which usually require an IQ score below 85. People who have lived independently generally do not qualify for this program.
- People who feel they need official confirmation in order to feel comfortable embracing their autistic identity.

Outside of these situations, people often find that an autism evaluation is expensive and timeconsuming without offering many practical benefits. It may be more helpful to pursue the following strategies:

- Seeking services and accommodations based on an already established diagnosis, such as anxiety or ADHD. (See https://askjan.org/ for suggested accommodations.)
- Finding therapists, doctors, employers, and others who respect your needs and preferences regardless of label.
- Receiving evaluation from a non-autism-focused psychologist in order to test for cognitive strengths and weaknesses, learning disabilities, ADHD, and/or mental health conditions.
- Connecting with other autistic people who will provide a supportive community.
- Encouraging supportive loved ones to learn about autism.



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The autistic community is very accepting of self-diagnosis, in large part because of the issues discussed here. They are likely to know of other strategies that may be helpful to you. Resources for connecting with this community are provided below.

We at the University of Washington Autism Center regret that resources for autistic adults are so limited. We will continue offering what supports we can, and continue speaking up about the need for more and better services in the community. We hope that the following resources are helpful.

The University of Washington Autism Center does not necessarily agree with all of the information or opinions shared in these resources. Please use independent judgement when determining whether the information is applicable and helpful to your experience and needs.

Crisis resources (not autism-specific)

- WA Recovery Help Line for crisis support and resource referrals in Washington State (866-7891511)
- Other Washington resources (https://www.crisisconnections.org/get-help/)
- Crisis Text Line (<u>https://www.crisistextline.org/</u>, Text "HOME" to 741741)
- National Suicide Prevention Lifeline (<u>https://suicidepreventionlifeline.org/</u>, 1-800-273-8255)
- Trans Lifeline (<u>https://translifeline.org/</u>, 877-565-8860)

General autism resources

- Welcome to the Autistic Community (<u>https://autismacceptance.com/</u>)
- Autistic Self-Advocacy Network (<u>https://autisticadvocacy.org/resources/</u>)
- Autistic Women and Nonbinary Network (https://awnnetwork.org/)
- Autism and Race, including the Autistic People of Color Fund (<u>https://autismandrace.com/</u>)

Local Seattle resources

- Square Pegs meetup groups, including a group for autistic parents (<u>https://www.meetup.com/Squarepegs/</u>)
 - The Square Pegs meetup Group is a place for those of us who are on any part of the spectrum, diagnosed or self-diagnosed, to get to know one another and make new friends without having to explain our eccentricities. If you are otherwise neurodivergent, you are welcome to join us as well.
- Arc of King County (<u>https://arcofkingcounty.org/</u>)
 - The ARC of King County serves all people with intellectual and developmental disabilities across the lifespan. Programs include information and family supports for parents, supported living services for adults living in the community, representative payee for



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individuals needing financial management assistance, homelessness prevention, and advocacy for people with developmental disabilities and their families.

- Email: <u>Ask@arcofkingcounty.org</u>
- Disability Empowerment Center (<u>www.disabilityempowerment.org</u>)
- Disability Rights Washington (<u>https://www.disabilityrightswa.org/</u>)

Autistic community:

- Square Pegs local support groups (<u>https://www.meetup.com/Squarepegs/</u>)
- Autastic (<u>https://www.autastic.com/</u>)
- Autism Late Diagnosis Support and Education Facebook group
- Autistic Families of Color (WA) Facebook group

Daily living resources

- Autistifying My Habitat (http://timetolisten.blogspot.com/2012/08/autistifying-myhabitat.html)
- Using Visual Supports as an Autistic Adult: A Review (<u>https://anotherqueerautistic.wordpress.com/2020/05/20/using-visual-supports-as-an-autisticadult-a-review/</u>)
- AASPIRE Health Toolkit (<u>https://www.autismandhealth.org</u>)
- Living Well on the Spectrum by Valerie L. Gaus

Employment services

- DVR: Department of Vocational Rehabilitation (<u>https://www.dshs.wa.gov/dvr</u>)
- JAN: Job Accommodation Network (<u>https://askjan.org/</u>) You may be able to receive accommodations through another appropriate diagnosis, such as ADHD or anxiety.
- NW ADA Center: (<u>http://nwadacenter.org/</u>) Support for any employment discrimination or ADA related questions

Resources for supporters:

- Understanding Autism: An Employer's Guide (<u>https://researchautism.org/resources/understanding-autism-an-employers-guide/</u>) – This may be informative for your workplace if they accept your self-diagnosis
- Understanding the Autistic Mind (<u>https://neuroclastic.com/2020/04/02/guide/</u>)
- Ask Me, I'm Autistic and Autism Inclusivity Facebook groups



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Self-help/self-reflection resources

- ASAN description of autism at https://autisticadvocacy.org/about-asan/about-autism/
- Neuroclastic description of autism at https://neuroclastic.com/2019/10/11/a-communaldefinition-of-autism/
- <u>The Dialectical Behavior Therapy Skills Workbook</u> by Brantley, Wood, & McKay (not autismspecific)
- <u>The Gifts of Imperfection</u> by Brené Brown (not autism-specific)
- DSM-5 diagnostic criteria with examples at https://tinyurl.com/dsmdetails
- Autism Quotient (AQ) and Ritvo (RAADS-R), available at www.aspietests.org
- Efforts to capture a "female profile" at <u>https://tinyurl.com/samcraftchecklist</u> and <u>https://tinyurl.com/TaniaMarshallChecklist</u> (overlap with a variety of characteristics, including trauma and ADHD)
- An Autism Self-Diagnosis Masterpost at <u>https://tinyurl.com/selfdiagnosispost</u>