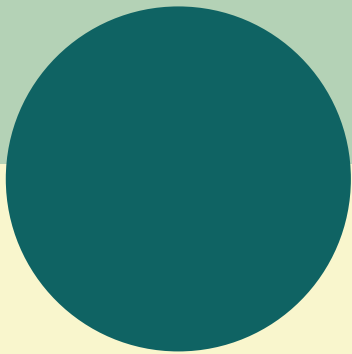


EXCEPTIONAL INDIVIDUALS



AUTISM DIAGNOSIS E-GUIDE USA

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Self-Advocacy

UNDERSTANDING YOUR AUTISM QUIZ SCORE

Our quizzes are an indication that you might exhibit neurodiverse traits.

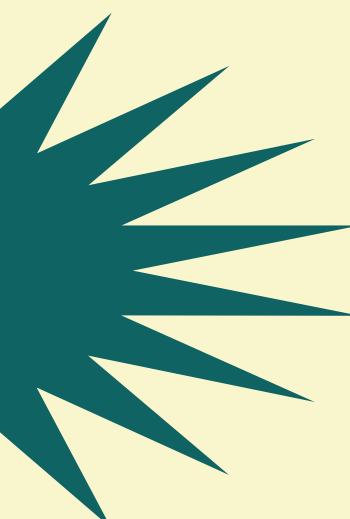
- **Source:** Our quiz is drafted based on and includes statements from the Autism Spectrum Quotient (AQ) questionnaire. The AQ is a self-administered questionnaire developed by researchers to assess the extent of autistic traits in adults. It consists of 50 statements, and individuals are asked to rate their level of agreement or disagreement with each statement on a scale.
- **Scoring:** For each question, a score of 0, 1, or 2 will be assigned based on the following criteria:
 - 0 - Strongly Disagree or Never
 - 1 - Somewhat Agree or Occasionally
 - 2 - Strongly Agree or Often
- The total score is calculated by summing up the individual scores from questions 1 to 28. You will be directed to an outcome based on the score bracket your total score sits within.

INTERPRETATION OF THE TOTAL SCORE:

- Total score of 0-24: It is less likely that you have significant autistic traits based on the provided questions.
- Total score of 25-40: You may have some mild autistic traits or tendencies based on the provided questions. However, it is important to consult with a healthcare professional for a comprehensive evaluation and interpretation.
- Total score of 41-50: There is a higher likelihood that you have significant autistic traits or tendencies based on the provided questions. It is recommended to seek a professional assessment for a more accurate diagnosis.
- It is important to emphasize that our Autism quiz has a simplified scoring system and interpretation and should only be utilized in conjunction with a professional evaluation by a qualified healthcare provider. They can assist in identifying potential symptoms, but a comprehensive assessment by a healthcare professional is necessary for an accurate diagnosis.

IF YOU BELIEVE YOU MAY HAVE AUTISM, WE RECOMMEND CONSULTING WITH A HEALTHCARE PROFESSIONAL, SUCH AS A PSYCHIATRIST OR PSYCHOLOGIST, WHO CAN PROVIDE YOU WITH APPROPRIATE GUIDANCE AND UTILIZE VALIDATED ASSESSMENT TOOLS TO EVALUATE YOUR SYMPTOMS.

1. WHAT TO DO NOW



If you have recently taken a characteristics test and received strong indicators of autism spectrum disorder (ASD), you may be feeling overwhelmed and unsure of what to do next. This is a normal reaction. Receiving a diagnosis of ASD can be a life-changing event, and it takes time to process all of the information and implications.

This e-guide is designed to help you take the next steps after receiving a diagnosis of ASD. It will provide you with information about ASD, including its symptoms, causes, and treatment options. It will also help you to understand your rights and options under the law.

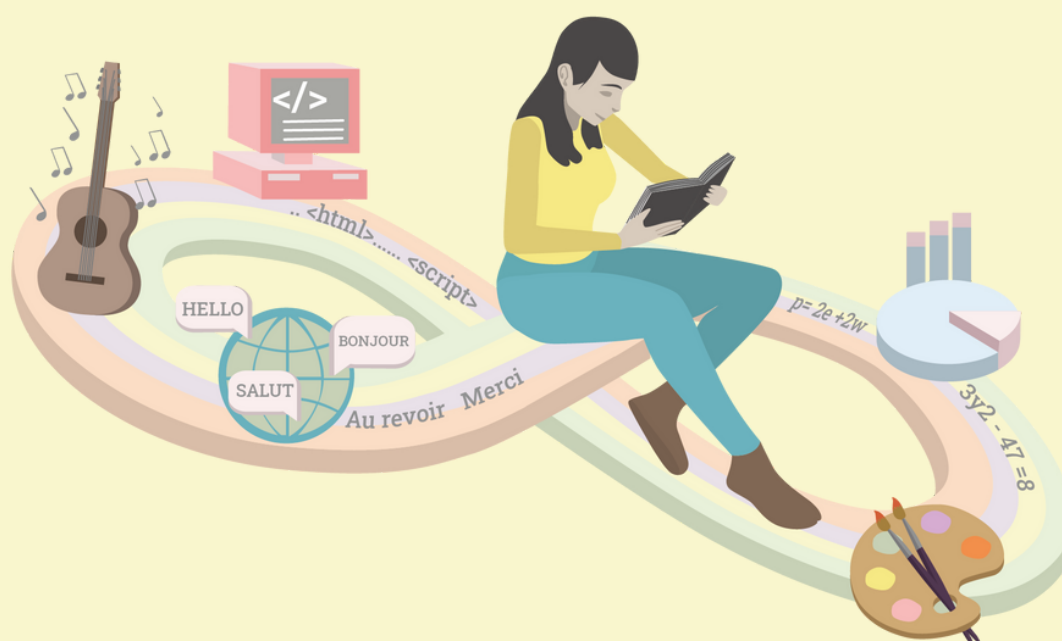
Whether you are an adult or a child, receiving a diagnosis of ASD can be a challenging experience. However, it is important to remember that you are not alone. There are many resources available to help you and your family navigate the journey ahead.

This e-guide is just one of those resources. It is designed to provide you with the information and support you need to move forward with confidence.



2. AUTISM DIAGNOSIS IN THE USA

Autism spectrum disorder (ASD) is a complex developmental condition that affects approximately 1 in 68 children in the United States. ASD is characterized by challenges in social communication and interaction, as well as repetitive and restricted behaviors and interests.



There is no single medical test to diagnose ASD. Diagnosis is typically made by a team of professionals, including a developmental pediatrician, psychologist, or speech-language pathologist. The team will consider the individual's developmental history, behavior, and observations of their interactions with others.

In the USA, there are two main diagnostic tools used to assess ASD: the Autism Diagnostic Interview-Revised (ADI-R) and the Autism Diagnostic Observation Schedule-Generic (ADOS-G). The ADI-R is a parent interview that asks about the individual's developmental history, while the ADOS-G is a structured observation that assesses the individual's communication, social interaction, and play behaviors.

The diagnostic process can vary depending on the individual's age and abilities. In some cases, a diagnosis may be made as early as 18 months of age. However, it is more common for a diagnosis to be made between the ages of 2 and 5.

Early diagnosis of ASD is important so that individuals can receive the appropriate interventions and support services. These interventions can help improve the individual's communication, social, and behavioral skills.

3. HOW TO AVOID BEING SCAMMED

pt. 1

By following these guidelines, you can increase your chances of receiving a reliable and trustworthy autism spectrum disorder assessment and make informed decisions about your care.

VERIFY THE ASSESSOR'S CREDENTIALS:

1. Check the assessor's qualifications: Ensure the assessor has the appropriate credentials and expertise to conduct ASD assessments for adults. Look for board certifications in relevant fields, such as psychology, psychiatry, or neuropsychology [See page 10].
2. Seek recommendations: Ask your primary care physician or mental health provider for referrals to qualified professionals with a proven track record of conducting ASD assessments for adults.
3. Review the assessor's professional affiliations: Check if the assessor is affiliated with reputable professional organizations or societies related to ASD, such as the Autism Society of America or the American Psychological Association.

EVALUATE THE ASSESSMENT SETTING:

1. Choose a reputable clinic or practice: Opt for a well-established clinic or practice with a positive reputation for providing high-quality ASD assessments.
2. Confirm the clinic's accreditation: Check if the clinic or practice is accredited by a reputable organization, such as the Joint Commission on Accreditation of Healthcare Organizations (JCAHO).
3. Ensure a comfortable and private environment: The assessment should be conducted in a quiet, private, and comfortable setting to minimize distractions and allow for focused evaluation.

3. HOW TO AVOID BEING SCAMMED

pt. 2

SCRUTINIZE THE ASSESSMENT PROCESS:

1. Review the assessment tools: Ask about the specific assessment tools and procedures the assessor plans to use. Reputable assessors typically use standardized tools validated for adult ASD evaluations.
2. Inquire about the assessment duration: Assessments should be comprehensive and thorough, but not excessively long or demanding. Ask about the expected duration of the assessment process.
3. Seek transparency in communication: Ensure the assessor clearly explains the assessment process, including the purpose of each component and the criteria used for evaluation.
4. Request written documentation: Ask for a written report summarizing the assessment findings, including the diagnosis (if applicable), strengths, challenges, and recommendations for support or intervention.

PROTECT YOUR PERSONAL INFORMATION:

1. Verify confidentiality: Ensure the assessor adheres to strict confidentiality guidelines and obtains informed consent before collecting or sharing any personal information.
2. Be mindful of data handling: Ask about the clinic's data security protocols and how your personal information will be stored and protected.
3. Resist unnecessary requests: Be wary of assessors who request personal information or financial data beyond what is necessary for the assessment.
4. Seek clarification on fees: Ask about the assessment fees and payment arrangements upfront to avoid any surprises or hidden costs.
5. Maintain control over your information: You have the right to access and review your assessment records. If you have any concerns about the assessment or the handling of your information, don't hesitate to ask questions or seek clarification.

4. WHAT QUALIFICATIONS DOES AN ASSESSOR NEED? PT.1

EDUCATIONAL QUALIFICATIONS

01.

- Master's degree (or higher) in psychology, psychiatry, social work, or a related field
- Specific coursework or training in autism spectrum disorder (ASD) assessment and diagnosis

CLINICAL EXPERIENCE

02.

- At least two years of supervised clinical experience working with adults with ASD
- Experience conducting comprehensive ASD assessments using standardized tools



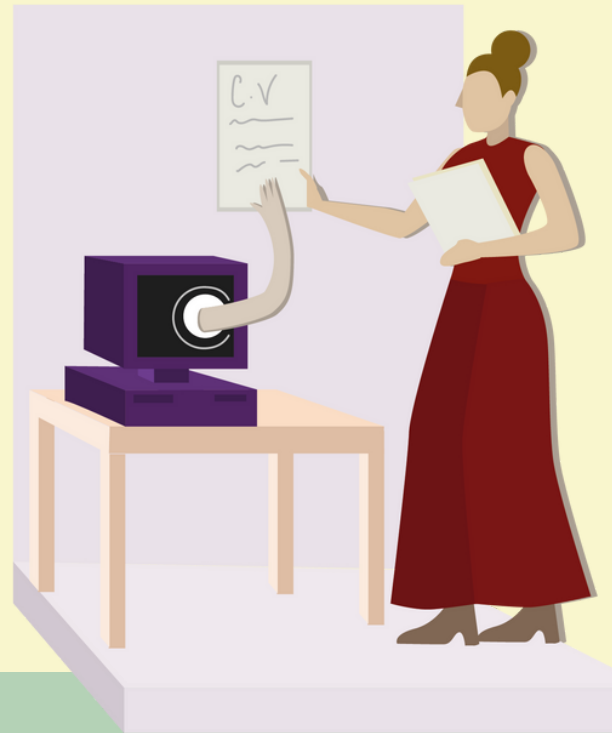
PROFESSIONAL CERTIFICATIONS

03.

- Board certification in a relevant field, such as:
 - Psychology:
 - American Board of Professional Psychology (ABPP)
 - National Association of School Psychologists (NASP)
 - Association for Psychological Science (APS)
 - Psychiatry:
 - American Board of Psychiatry and Neurology (ABPN)
 - American Board of Child and Adolescent Psychiatry (ABCAP)
 - American Psychiatric Association (APA)
- Certification in a specific ASD assessment tool, such as:
 - Autism Diagnostic Interview-Revised (ADI-R)
 - Autism Diagnostic Observation Schedule (ADOS)
 - Autism Diagnostic Interview (ADI-R) and Autism Diagnostic Observation Schedule (ADOS) Second Edition (ADOS-2)

4. WHAT QUALIFICATIONS DOES AN ASSESSOR NEED? PT.2

CHOOSING AN ASD ASSESSOR WITH THESE QUALIFICATIONS CAN HELP ENSURE THAT YOU RECEIVE A COMPREHENSIVE, RELIABLE, AND CULTURALLY SENSITIVE ASSESSMENT THAT MEETS YOUR INDIVIDUAL NEEDS.



PERSONAL QUALITIES

04.

- Strong communication and interpersonal skills
- Empathy and understanding of the challenges faced by adults with ASD
- Cultural sensitivity and awareness of diversity
- Ability to provide clear, concise, and easy-to-understand feedback
- Commitment to ethical and professional practice

ADDITIONAL CONSIDERATIONS

05.

- Membership in professional organizations related to ASD, such as the Autism Society of America (ASA) or the American Academy of Child and Adolescent Psychiatry (AACAP)
- Ongoing professional development and training in ASD assessment and intervention

5. WHERE CAN I GET DIAGNOSED?

Here are some resources to help you find a qualified professional to diagnose autism spectrum disorder (ASD) in the USA:

- The Centers for Disease Control and Prevention (CDC) has a website with information on ASD, including a list of healthcare providers who can diagnose ASD. You can find the list here: <https://www.cdc.gov/ncbddd/autism/index.html>
- The National Institute of Child Health and Human Development (NICHD) also has a website with information on ASD, including a list of healthcare providers who specialize in ASD diagnosis. You can find the list here: <https://www.nichd.nih.gov/health/topics/autism>
- The Autism Society of America has a directory of autism-friendly healthcare providers, including those who can diagnose ASD. You can find the directory here: <https://autismsociety.org/>
- Autism Speaks also has a directory of autism-friendly healthcare providers, including those who can diagnose ASD. You can find the directory here: <https://www.autismspeaks.org/>

IN ADDITION TO THESE RESOURCES, YOU CAN ALSO ASK YOUR CHILD'S PEDIATRICIAN FOR A REFERRAL TO A QUALIFIED PROFESSIONAL TO DIAGNOSE ASD.

6. CHECKLIST BEFORE A DIAGNOSIS

CHECKLIST OF THINGS TO DO BEFORE AN AUTISM SPECTRUM DISORDER (ASD) DIAGNOSIS FOR ADULTS:



GATHER INFORMATION

01.

1. Review your own developmental history: Reflect on your childhood and early adulthood, including information about your motor skills, language development, social interactions, and play skills. Talk to your parents, siblings, and other close friends or acquaintances to gather as much information as possible from their perspectives.
2. Document your current behaviors and experiences: Keep a journal or notes to track your current behaviors and experiences, including any concerns you have about your social interactions, communication patterns, and repetitive or restricted behaviors.
3. Consider seeking input from others: Talk to trusted friends, family members, or colleagues to get their honest feedback on your social interactions and behaviors. Their observations can provide valuable insights.

PREPARE FOR THE EVALUATION

02.

1. Choose a qualified professional: Seek recommendations from your primary care physician or mental health provider for referrals to qualified professionals who specialize in ASD assessments for adults. Look for professionals with board certifications in relevant fields, such as psychology, psychiatry, or neuropsychology.
2. Schedule an appointment: Make arrangements with a qualified professional as soon as possible as there can be a wait list.
3. Gather any relevant medical records: Collect copies of your medical records, including any assessments, evaluations, or diagnoses related to your development, mental health, or learning.
4. Prepare questions: Make a list of questions you have for the professional. This will help you ensure that you have all the information you need to make informed decisions about the assessment process.

DURING THE EVALUATION

03.

1. Be honest and open: Communicate honestly with the professional about your concerns and experiences. Provide them with all the information you have gathered about your development, behaviors, and experiences.
2. Ask questions: Do not hesitate to ask questions. The professional is there to help you understand your experiences and provide you with information about ASD.
3. Take notes: Take notes during the evaluation so that you can remember and revisit the information that is discussed.

AFTER THE EVALUATION

04.

1. Review the assessment results: If you receive an ASD diagnosis, take some time to review the results and ask the professional any questions you have.
2. Learn about ASD: There are many resources available to help you learn about ASD in adulthood. Talk to your healthcare provider, join a support group for adults with ASD, or read books and articles about the condition.
3. Consider seeking support: Explore various support services available for adults with ASD, such as individual therapy, group therapy, or social skills training programs.
4. Develop a self-care plan: Create a personalized self-care plan that includes strategies to manage stress, promote emotional well-being, and maintain overall health.



REMEMBER, SEEKING AN ASD DIAGNOSIS AS AN ADULT CAN BE A SIGNIFICANT STEP TOWARDS GAINING A BETTER UNDERSTANDING OF YOURSELF, IDENTIFYING YOUR STRENGTHS AND CHALLENGES, AND ACCESSING APPROPRIATE SUPPORT SERVICES.

7. HOW MUCH DOES A DIAGNOSIS COST

The cost of an autism spectrum disorder (ASD) assessment can vary depending on several factors, including the location, the qualifications of the assessor, and the complexity of the assessment. However, you can expect to pay between \$1,000 and \$3,000 for a comprehensive ASD assessment.

Here is a breakdown of the factors that can affect the cost of an ASD assessment:

- **Location:** The cost of living in the area where you live can affect the cost of an ASD assessment. Assessors in higher-cost-of-living areas may charge more than assessors in lower-cost-of-living areas.
- **Qualifications of the assessor:** The more qualified the assessor, the more they may charge for their services. Assessors with board certifications or specialized training in ASD assessment may charge higher fees.
- **Complexity of the assessment:** The complexity of the assessment can also affect the cost. Assessments that require more time or involve more specialized tools may be more expensive.

Here are some tips for saving money on an ASD assessment:

- **Shop around:** Get quotes from several different assessors before you make a decision.
- **Consider group assessments:** Some clinics offer group assessments, which can be less expensive than individual assessments.
- **Ask about insurance:** Some insurance companies cover ASD assessments. Check with your insurance company to see if they cover any of the cost of the assessment.
- **Look for scholarships or grants:** There are a number of scholarships and grants available to help people with ASD pay for assessments and other services.

Region	Northeast	Mid-Atlantic	Midwest	South	West
Average cost	\$1,500 - \$2,500	\$1,200 - \$2,000	\$1,000 - \$1,800	\$900 - \$1,700	\$1,300 - \$2,300

These are just averages, and the actual cost of an ASD assessment can vary depending on the factors mentioned above. If finances are a factor then it is always best to get quotes from several different assessors before you make a decision.

8. WHY IS DIAGNOSIS IMPORTANT?

A diagnosis of autism spectrum disorder (ASD) can be important for several reasons. Here are a few of the most important:

01.

Access to services and support: A diagnosis of ASD can help you access important services and support, such as early intervention programs, special education services, and vocational rehabilitation. These services can make a significant difference in the lives of people with ASD, helping them to develop their skills and reach their full potential.

02.

Understanding and self-awareness: A diagnosis of ASD can help you to better understand yourself and your strengths and challenges. This can lead to increased self-awareness and self-acceptance, which can be very empowering.

03.

Improved communication and relationships: A diagnosis of ASD can help others to better understand you and your needs. This can lead to improved communication and relationships with family, friends, and colleagues.

04.

Access to accommodations: A diagnosis of ASD can give you access to accommodations in school, work, and other settings. These accommodations can help you to participate more fully in activities and events.

05.

Peace of mind: For some people, a diagnosis of ASD can provide peace of mind. It can help them to understand why they may have experienced challenges in the past and give them a better sense of their identity.

In general, a diagnosis of ASD can be a valuable tool for helping people with ASD to live fulfilling and productive lives. If you are concerned that you or your child may have ASD, it is important to seek a professional evaluation.

09. WHAT IS THE HISTORY OF AUTISM IN THE USA?

Autism spectrum disorder (ASD) has been recognized as a distinct condition in the United States since the early 20th century. However, the history of ASD in the USA is complex and marked by periods of both progress and setbacks.



Early Recognition

The first recorded instance of what is now known as ASD in the USA appeared in a 1938 paper published by Leo Kanner, an Austrian-American child psychiatrist. Kanner described 11 children who exhibited a constellation of behaviors that he termed "early infantile autism." These behaviors included:

- Impaired social interaction and communication
- Repetitive and restricted behaviors
- A lack of empathy

Kanner's paper helped to raise awareness of ASD among the medical community and the public. However, it was not until the 1960s that ASD began to be widely accepted as a legitimate diagnosis.

The Myth of the "Refrigerator Mother"

In the 1950s and 1960s, a controversial theory emerged that blamed the mothers of children with ASD for their children's condition. This theory, known as the "refrigerator mother" theory, suggested that cold and unloving mothers caused their children to withdraw from social interaction and develop repetitive behaviors.

The "refrigerator mother" theory was largely based on anecdotal evidence and lacked scientific support. However, it had a significant impact on the way that families of children with ASD were perceived and treated.



The rise of behavioral interventions

In the 1960s and 1970s, a new approach to treating ASD emerged, known as behavioral intervention. Behavioral interventions are based on the principle of operant conditioning, which states that behaviors that are rewarded are more likely to be repeated, while behaviors that are punished are less likely to be repeated.

Behavioral interventions have been shown to be effective in improving the social, communication, and behavioral skills of people with ASD. However, they can be time-consuming and require intensive training for parents and therapists.

The development of diagnostic criteria

In the 1980s, the American Psychiatric Association (APA) developed diagnostic criteria for ASD, which were published in the third edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-III). The DSM-III criteria helped to standardize the diagnosis of ASD and made it easier for clinicians to identify individuals with the disorder.

The DSM-III criteria was later revised in the DSM-IV (1994) and DSM-5 (2013). The DSM-5 criteria is more comprehensive and include a broader range of symptoms than the previous editions.

Increased awareness and acceptance

In recent years, there has been a growing awareness of ASD among the general public. This is due in part to media coverage of the disorder, as well as the efforts of advocacy groups.

As awareness of ASD has increased, so has acceptance. People with ASD are now more likely to be included in schools, workplaces, and communities. However, there is still much work to be done to ensure that people with ASD have equal opportunities and are treated with respect.



Looking to the future

Researchers are continuing to learn more about ASD, including its causes and potential treatments. They are also developing new diagnostic tools and interventions.

In the future, we can expect to see even greater progress in the understanding and treatment of ASD. This will lead to improved quality of life for people with ASD and their families.



10. WHAT SUPPORT CAN I GET AFTER A DIAGNOSIS IN THE USA?

Here is a list of support services available to individuals with autism spectrum disorder (ASD) in the United States:

Individualized Family Service Plans (IFSPs):

For children under the age of 21, IFSPs are developed through the Individuals with Disabilities Education Act (IDEA) to provide special education services and related services. These services may include speech-language pathology, occupational therapy, physical therapy, behavioral interventions, and counseling.

Vocational Rehabilitation Services:

The Vocational Rehabilitation (VR) program provides services to help individuals with disabilities prepare for and obtain employment. These services may include vocational counseling, job training, and on-the-job support.

Social Security Disability Insurance (SSDI):

SSDI provides benefits to individuals who are unable to work due to a medical condition. To qualify for SSDI, individuals must meet certain requirements, including having a work history and a disabling condition.

Supplemental Security Income (SSI):

SSI provides benefits to low-income individuals who are disabled, blind, or elderly. To qualify for SSI, individuals must meet certain income and asset requirements.

Housing Assistance:

There are several housing assistance programs available to individuals with disabilities, including Section 8 housing and the Housing Choice Voucher program. These programs can help individuals with ASD find affordable housing.

Mental Health Services:

Mental health services are important for individuals with ASD, who may experience anxiety, depression, or other mental health challenges. These services may include individual therapy, group therapy, and medication.

Support Groups:

Support groups can provide individuals with ASD with a safe and supportive environment to connect with others who share similar experiences. Support groups can also provide information and resources about ASD.

Advocacy Services:

Advocacy services can help individuals with ASD protect their rights and access needed services. Advocacy organizations can also help individuals with ASD connect with other resources.

In addition to these formal support services, there are many other resources potentially available to individuals with ASD in the United States.

These resources may include:

- Autism-friendly businesses and organizations
- Online communities and forums
- Books and articles about ASD
- Self-advocacy training

It is important for individuals with ASD to seek support that meets their individual needs and preferences.

There is no one-size-fits-all approach to ASD support, and what works for one person may not work for another.

Here are some tips for finding support services in the USA:

- Contact your state's Developmental Disability Services Agency (DDSA): The DDSA can provide information about available services in your area.
- Search online directories of autism services: There are several online directories of autism services, such as the Autism Society of America's resource directory.
- Ask for recommendations from other individuals with ASD: Talk to other individuals with ASD, their family members, or their therapists for recommendations for support services.



With the right support, individuals with ASD can live fulfilling and productive lives.



11. SELF-ADVOCACY FOR ADULTS WITH ASD:

Self-advocacy is the ability to speak up for your own needs and rights. It is an important skill for people with ASD to develop, as they may face discrimination or challenges in accessing the services and support they need.

HERE ARE SOME TIPS FOR SELF-ADVOCACY FOR ADULTS WITH ASD:

- Educate yourself about your rights. Everyone has the right to access education, employment, healthcare, and other important services. Learn about your rights under the law and be prepared to advocate for yourself when needed.
- Develop self-awareness. The first step to self-advocacy is to understand your own needs and strengths. What are your goals? What are your challenges? What accommodations do you need to be successful?
- Communicate your needs clearly. Once you understand your own needs it can be easier to communicate them to others in a clear and concise way. This may involve writing down your needs or practicing communicating them with a trusted friend or family member.
- Build a support network. Having a support network of people who understand and support you is essential for self-advocacy. This network may include friends, family, therapists, and other people with ASD.

HERE ARE SOME EXAMPLES OF HOW YOU CAN SELF-ADVOCATE IN DIFFERENT SITUATIONS:

At work:

- If you need accommodations at work, such as a quiet workspace or extra time to complete tasks, talk to your supervisor.
- If you are not being treated fairly at work, such as if you are being harassed or discriminated against, report it to your supervisor or HR department.

At school:

- If you need accommodations in school, such as a note taker or extra time on tests, talk to your teacher or counselor.
- If you are struggling in a particular class, ask for help from your teacher or a tutor.

In healthcare:

- If you need accommodations at the doctor's office, such as a longer appointment or a quiet room to wait, let the staff know in advance.
- If you are not being treated fairly by a healthcare provider, such as if they are not listening to your concerns or are not providing you with the care you need, report it to the office manager or the state medical board.

Self-advocacy can be challenging, but it is an important skill for people with ASD to develop. By speaking up for your own needs and rights, you can ensure that you are treated fairly and have access to the services and support you need to live a fulfilling life.

Other terms for ASD:

In the past High-Functioning and Asperger were used in diagnosis to distinguish specific characteristics of the Autistic Spectrum but are not in common use today. Those that have already received a diagnosis in previous years however may have these terms referenced in their diagnostic reports.

MEET THE TEAM



MATT BOYD

Founder

Neurodiverse

I am a passionate advocate for neurodiversity in the workplace. I founded Exceptional Individuals to help neurodiverse individuals find work and thrive.



RUTH-ELLEN DANQUAH

Chief Innovation Officer

Neurodiverse

As Chief Innovation Officer for Exceptional Individuals, I deliver neuro-inclusive programs through training, mentoring and coaching. I have 10 years of experience working in the neurodiversity space and I am an author of The Rejection Sensitivity Journal for ADHD.



IZY WINTER

Marketing Specialist

Neurodiverse

I'm the Marketing & Sales Specialist at EI. My role involves spreading the word about the valuable service EI offers to the neurodiverse community in the workplace, via seminars and online content. My background involves creating videos and producing award-winning podcasts about accessibility.



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