

Quality of Life

The Autism Society believes that adults on the spectrum have the right to lives that are self-directed, taking into account their talents and desires. Indicators of progress should be measured by impact on basic human rights such as...

- Respect and Dignity
- Inclusion
- Communication
- Health/Wellbeing
- Safety
- Academic Success
- Friendship/Support Network/Social Connection
- Independent Living (to the maximum extent possible)
- Meaningful Employment with Fair Wages
- Financial Stability
- Recreation/Leisure
- Subjective Wellbeing
- Self Identity & Acceptance
- Autonomy & Self-Sufficiency
- Pursuit of Dreams



AUTISM SOCIETY

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United Way/CFC #11808



WHAT IS AUTISM?

HOPE

Now is the Time...

- 1 to 1.5 million Americans live with an autism spectrum disorder¹; this represents 1 percent of the population of children in the U.S. ages 3-17.²
- Despite evidence that ASDs can often be identified at around 18 months, many children do not receive final diagnoses until they are much older.³
- 56% of students with autism finish high school.⁴
- The unemployment rates for people with autism are estimated to be 90%, compared with 9% for people without a disability.
- The cost of autism over the lifespan is 3.2 million dollars per person.⁵ 60% of those costs occur in adulthood.



To Change the Discussion...

- ... Autism should be accepted as a whole life, whole body condition that affects all aspects of well-being.
- ... All children, regardless of economic level or ethnicity, should be screened for autism prior to age three. Early diagnosis and intervention can reduce the cost of lifelong care by two-thirds.
- ... Well-trained professionals must prepare adolescents leaving school for employment, advanced education, and independent living so they are well positioned to be successful adults.

¹ *Pediatrics*, October 5, 2009, based on a National Children's Health Survey done with 78,000 parents in 2007.

² Based on the autism prevalence rate of 1 in 110 (Centers for Disease Control and Prevention, 2009) and 2000 U.S. Census figure of 250 million Americans.

³ *Arch Gen Psychiatry*, 2006;63:1094-1091.

⁴ Wagner, M., et al. An Overview of Findings from Wave 2 of the National Transition Study. SRI International, Menlo Park, CA.

⁵ *Arch Pediatric Adolescent Medicine* 2007;161:343-349.

⁶ Prevalence of Autism Spectrum Disorders — Autism and Developmental Disabilities Monitoring Network, 14 Sites, United States, 2001.

You are not alone.

The Autism Society advocates for effective services and supports, offers reliable information, and provides a nationwide network of chapters so that parents, professionals, and those on the autism spectrum can meet, share resources and experiences, attend conferences, and receive the latest information.

The Autism Society can't do it alone.

We need those on the autism spectrum, their families, and the professionals who work with them to join our efforts to change the discussion and ensure that those with autism are treated with dignity and have the opportunity to lead independent and productive lives.

Become a member or donate today! www.autism-society.org/get-involved

AUTISM SOCIETY

empower

What is Autism?

Autism is a specific diagnosis that falls under the umbrella term Pervasive Developmental Disorders (PDD) in the Diagnostic and Statistical Manual. Autism is a complex developmental disability that typically appears during the first three years of life and affects the normal functioning of the brain.

Currently, no medical tests can be performed to indicate the presence of autism or any other PDD, the diagnosis is based upon the presence or absence of specific behaviors.

The key defining symptoms in both children and adults with autism are typically difficulty with verbal and non-verbal communication and social interaction.

Autism is a spectrum disorder, meaning two individuals, both with the same diagnosis, can be completely different from one another and have varying capabilities. Diagnostic labels indicate commonalities among individuals but do not define them or provide a complete picture of who they are and what they are able to achieve.

It is important to understand that people with autism can learn and progress with appropriate treatment and education.

Autism is Treatable

The causes of autism are not well understood and no cure currently exists. Early intervention can significantly improve the quality of life for individuals with autism. However, the majority of individuals on the autism spectrum will continue to exhibit some symptoms in varying degrees throughout their lives and may require lifelong care and supervision.

To accommodate the diverse needs of individuals with autism, effective approaches should be flexible, evaluated regularly to ensure measurable progress and provide the person with opportunities for generalization. No single approach will be effective for all people with autism. Caregivers and individuals on the spectrum should investigate treatment options thoroughly before choosing the options that are most appropriate to their needs and unique circumstances.

Early Screening

Early identification and access to effective treatments before age 3 significantly improves outcomes in people with autism. Ideally, a multidisciplinary team of professionals should participate in an evaluation; a brief observation in a single setting cannot present a true picture of an individual's abilities and behaviors. Parental (caregiver) input and knowledge of developmental history are essential components of making an accurate diagnosis.

There are differences between a medical diagnosis and an educational determination, or school evaluation. A medical diagnosis is made by a physician based on an assessment of symptoms and diagnostic tests. An educational determination is made by a team comprised of various school professionals to determine whether a student qualifies for special education and related services.

The CDC states that the median age for an autism diagnosis is between 4.5 and 5.5 years, but for the majority of children with ASD developmental concerns were recorded before age 3.⁶ Parents and caregivers are encouraged to watch for the early signs of autism, which can include:

- Lack of or delay in spoken language
- Repetitive use of language and/or motor mannerisms (e.g., hand-flapping, twirling objects)
- Little or no eye contact
- Lack of interest in peer relationships
- Lack of spontaneous or make-believe play
- Persistent fixation on parts of objects

Strong Educational Foundation

Services provided through the school system are federally mandated by the Individuals with Disabilities Education Improvement Act (IDEA). A strong educational foundation prepares a student for the greatest degree of independence in employment, advanced education and living - all components of success in adulthood. Educational planning for students with autism must

address a wide range of skill development, including academics, communication and language, self-help, self-advocacy, leisure, behavioral issues and social skills. It is important to consult with professionals trained specifically in autism to help ensure the greatest benefit from school programs. Laws require that transition planning begin no later than age 16 and become a formal part of the student's Individualized Education Plan (IEP). Transition planning should include the student, parents and members of the IEP team that work together to support the individual make decisions about next steps. When entitlement to public education ends at age 21, the transition to the adult service system can be a challenge.

Adults on the Spectrum

In mainstream culture, autism is often associated with children. However, autism is a lifelong condition, and the availability of necessary supports and treatments change as people on the spectrum move through major life phases. Quality of life depends not only upon the foundation that is provided in childhood, but requires ongoing supports that are specific to the needs of a person.

The Autism Society works to ensure that every adult living with autism has opportunities to seek jobs of their choosing and have the chance (and support required) to achieve the highest possible quality of life and are able to pursue independence, fulfillment and productivity.

We identify gaps in services and societal issues that negatively impact adults living with autism and their family. Problems such as poverty are common and can result in dependence on government support as well as high rates of unemployment and violations of civil rights. The Autism Society is working for social services that encourage work, family and savings (all common American values). A lifespan approach is required for adults with autism to reach their greatest potential and be empowered, self-sufficient citizens who contribute to their community.

The Autism Society

Since 1965, the Autism Society's nationwide network of chapters has provided a place for the autism community to share resources and experiences, receive the latest information and join in advocacy efforts.

Our programs and services focus on the following:

- Proactive Advocacy in collaboration with the greater disability community that leads to systemic change via federal, state and local public policy that benefit of the autism community.
- Community outreach and education with accessible and accurate information that supports stakeholder ability to make informed choices.
- Encouraging and fostering a strong grassroots network that creates local connections and provides support as an integral part of a larger community.
- Building capacity within local communities for delivery of effective services to individuals and their families.
- Translating research results into applied practice that impacts everyday lives.

Now is the time...

- ... to join our efforts and advocate for improved services
- ... to change the discussion to one of hope
- ... to get involved in your local chapter
- ... to support the Autism Society's critical work with national and local impact.

Please consider membership for yourself or as a gift. Your generous donation is essential.

SUPPORT

For more information or to find your local chapter contact Autism Source™, the Autism Society's Information and Referral Contact Center. Call us at 1.800.3AUTISM seven days per week with your questions or visit us online at www.autismsource.org.