



## Our Vision

A world where all people with autism can reach their full potential.

## Our Impact

Autism Speaks is enhancing lives today and accelerating a spectrum of solutions for tomorrow.

## Our Mission

Autism Speaks is dedicated to promoting solutions, across the spectrum and throughout the life span for the needs of individuals with autism and their families. We do this through advocacy and support; increasing understanding and acceptance of people with autism; and advancing research into causes and better interventions for autism spectrum disorder and related conditions.

*Through partnerships and collaboration, we are committed to:*

**Increasing global understanding and acceptance of people with autism**

**Being a catalyst for life enhancing research breakthroughs**

**Increasing early childhood screening and timely interventions**

**Improving the transition to adulthood**

**Ensuring access to reliable information and services throughout the life span**

## What is autism?

Autism, or autism spectrum disorder (ASD), refers to a broad range of conditions characterized by challenges with social skills, repetitive behaviors, speech and nonverbal communication. We know that there is not one autism but many subtypes, most influenced by a combination of genetic and environmental factors. Because autism is a spectrum disorder, each person with autism has a distinct set of strengths and challenges. The ways in which people with autism learn, think and problem-solve can range from highly skilled to severely challenged. Some people with ASD may require significant support in their daily lives, while others may need less support and, in some cases, live entirely independently.

## About Autism Speaks

Founded in 2005 and built on collaborations with other autism organizations, Autism Speaks has:

**Helped lead the genomic discovery of the biology of autisms**

**Invested in evidence-based research to decrease time to intervention and increase personalized care**

**Drove profound global increases in awareness, understanding and acceptance of people with autism**

**Championed multi-billion dollar increase in authorized federal research funding for autism**

**Led efforts to reduce the average age of diagnosis to enable earlier access to services and supports**

**Advocated for statewide autism health care coverage in all 50 states, affecting millions of people**

**Developed and distributed vital information and resources from diagnosis through adulthood**

## We're here to help.

(888) AUTISM2 | En Español (888) 772-9050 | [help@autismspeaks.org](mailto:help@autismspeaks.org)

To find resources, find ways to fundraise or make a donation, go to [autismspeaks.org](https://autismspeaks.org)

or connect with us on social [@autismspeaks](https://twitter.com/autismspeaks).

## 2020 Advocacy Priorities

---

Autism Speaks is enhancing lives today and accelerating a spectrum of solutions for tomorrow.

The Autism Speaks Advocacy Team works across the country to achieve this mission focusing on the following priorities:

### **Increase global understanding and acceptance of autism**

Educate legislators and regulators on autism spectrum disorder to ensure policymaking benefits individuals across the spectrum.

### **Be a catalyst for life enhancing research breakthroughs**

Increase funding for autism research at federal agencies, including the National Institutes of Health and the Department of Education.

### **Increase early-childhood screening and timely intervention**

Ensure that individuals with autism have access to the healthcare they need, irrespective of payer (Medicaid, private insurance, etc.).

### **Improve outcomes for transition to adulthood across the spectrum**

Increase access to housing and community-based services (HCBS) for individuals and increasing HCBS capacity to provide meaningful services for people with autism and their families.

Improve the quality and accessibility of employment-focused training systems for individuals with autism as well as advocating for increased employment opportunities.

Increase equitable access to high-quality postsecondary education opportunities for students with autism.

Expand support for resources and practices that keep our community safe, including Kevin and Avonte's Law.

Make ABLE accounts widely available.

Ensure staff across settings have appropriate training, particularly related to challenging behaviors, safety, sensory needs, and augmentative and alternative communication.

FOR MORE INFORMATION  
Contact [advocacy@autismspeaks.org](mailto:advocacy@autismspeaks.org)







## Education

---

**We support core principles of access, quality and enforcement of legal safeguards. In support of these principles, we work to increase the investment in educational research and encourage states and school districts to begin official transition planning by age 14.**

We work to ensure meaningful access to quality education services for all students with autism. We advocate on initiatives based not only in the classroom or school building, but also in local communities, and at all ages. These initiatives range from Early and Periodic Screening, Diagnostic and Treatment benefits to PreK-12 special education, postsecondary transition, career and technical education and higher education.

We believe all students with autism must be safe, supported and ready to learn - no matter the specifics of their race, gender, socioeconomic status or disability. All students with autism are unique individuals and deserve individualized supports.

**Our advocacy on education is undergirded by 3 core principles:**

**Access** Increasing access to educational services is a critical piece of our advocacy work. We strive to make sure that all students with autism can avail themselves of a spectrum of supports and receive the guidance to choose the most suitable services for them.

**Quality** Increasing the number of students who access services does not truly help anyone if those services are not appropriate for the specific individual in the specific situation, or if those services are not of high quality. We work to promote quality in education in several ways:

**Improve the professional educator pipeline** so that the next generation of educators is well-versed in ways to support students with autism;

**Ensure that services are consistently individualized** to the student, accounting for their wishes, strengths and needs. While the process to ensure delivery of services can and should be standardized, the services themselves must never be born from a cookie-cutter process;

**Increase the continuity of educational services over time.** Over the course of a student's life, they will encounter many different school personnel and systems, especially during times of transition. We work to improve continuity of services from the student's and family's perspective.

**Enforcement** The legal rights of all students are laid out in a large number of federal laws. Their respective regulations and their analogues at the state level. Students with disabilities share in these rights and protections but also benefit from a separate body of law designed to ensure they do not face discrimination based on disability and that their special education rights are protected. We work to ensure that students with autism can learn, supported by the full panoply of legal safeguards available to them, and to improve those legal safeguards.

**Part of this work is ensuring that students with autism are safe in schools.** Issues of school safety can take many forms, such as questions related to inclusive emergency preparedness, wandering prevention and response, seclusion and restraint, response to challenging behaviors and disproportionality. We strive to share evidence-based, practical responses to critical safety issues.

## Education

---

The legal rights of all students are laid out in a large number of federal laws. Consistent with these principles, we focus on increasing the investment in educational research. The U.S. Department of Education (ED) supports autism-related services, supports and research through programs administered primarily by the Institute of Education Sciences and the Office of Special Education and Rehabilitative Services. Growth in educational research supported by ED will redound to the benefit of the autism community.

We also focus on encouraging states and school districts to begin official transition planning through the creation of an individualized transition plan by age 14, as allowed but not required by federal law, which sets 16 as the age by which such services must begin. For many young people on the spectrum, the transition to adult life is complex and challenging, filled with potential but fraught with uncertainties. Early transition planning better enables students to access the services and supports needed for adult life.

## Employment

---

**We support employment initiatives that prepare, recruit, onboard, retain and advance individuals with autism, recognizing that everyone with autism has different strengths and aspirations.**

We work to ensure that all individuals with autism who seek employment can secure and retain it with appropriate, individualized supports.

**We take a holistic view of employment with a focus on sustainability.**

We believe the career path of an individual with autism should closely resemble that of any other person, so we advocate for government- and employer-level support for initiatives that include all the components of employment: preparation, recruiting, onboarding, retention and advancement.

**We support a systemic view of employment with a focus on community.**

We believe that to improve the status quo of employment for people with autism and other disabilities, many stakeholders need to adapt their daily practices. These groups include not just individuals and employers, but also families, schools and a web of interconnected community systems. We advocate across groups to improve employment outcomes.

**We recognize the heterogeneity of autisms and promote disaggregated results.**

The autism spectrum is extremely broad, encompassing innumerable combinations of different personality traits, including a vast array of both strengths and needs. Every person with autism is distinct from every other person with autism. As many employment initiatives are geared for people with disabilities generally rather than people with autism specifically, we promote accountability measures for programs that recognize disability type rather than those that aggregate all disabilities into a single category.

**We understand that employment offers benefits beyond income.**

Employment has impacts on quality of life beyond the dollar-value of a wage—health, wellbeing, community connection, sense of purpose and personal identity are all affected by working. This phenomenon is as true for people with autism as it is for those without. At the same time, just as in the non-disabled population, each individual with autism has unique priorities, some valuing their wage above the other considerations, some the opposite. Autism Speaks strives to improve access, promote equity and support self-determination. The whole community benefits when each individual fulfills personal goals for independence and self-reliance.

**We believe in raising expectations.**

One of the primary barriers to creating widespread access to employment for individuals with autism and other disabilities is the “tyranny of low expectations.” Those limitations - and the ability to overcome them - must come from the individual, supported by the community. Autism Speaks supports access to individualized optimal post-secondary outcomes - including competitive integrated employment for all who seek it. We work to build sustainable connections between government, individuals, families, employers and communities to empower people with autism and other disabilities so that everyone on the spectrum can achieve their goals and reach their potential.

## Lifelong supports

---

People with autism and the families that support them rely on a range of options throughout their life spans to live, remain safe and participate in their communities. This includes residential and day supports, respite, recreation, transportation and others.

### Support for caregivers

Family caregivers frequently play a significant role in providing support for people with autism. These unpaid caregivers require assistance to continue caring for people with autism – both children and adults – living in the community. Family caregivers provide supports for children and adults living with autism across their life span – 80% of adults with autism live at home and receive support from a family caregiver.

### Home and community-based services

The majority of these lifelong supports are funded by Medicaid Home and Community-Based Services (HCBS). Different HCBS may be available to people based on their age, where they live and level of functional impairment. Lengthy waiting lists exist around the country and the availability, scope and duration of supports varies widely by state. The result is a patchwork system that struggles to meet the demands of both families and adults with autism living in the community. Without HCBS families and individuals must provide these supports on their own.

### Policy priorities

Autism Speaks believes that lifelong services and supports must be sufficiently funded to ensure that every person with autism and their families receive the individualized services they need, when they need it. Furthermore, these supports must fundamentally respect the dignity and individual needs of each person receiving services. Access to HCBS must be increased, HCBS providers must be trained and paid adequately to ensure they have the capacity to provide high-quality services. Additionally, residential and day services options as well as affordable housing programs must be increased and improved ensuring that autistic people have access to supports across the spectrum. Finally, more must be done to ensure that families and people with autism have access to the appropriate resources and interventions to ensure their dignity and safety. Access to high-quality community supports must be significantly increased and a permanent financing solution must be created to address the lifelong support needs of individuals with autism and their families wherever they live.

### Financial planning

Many children and adults with disabilities, including autism, have significant current or anticipated expenses. Planning for those expenses has often proven difficult.

The lifetime cost of supporting one person with autism can range from \$1.4 to \$2.4 million.

The Achieving a Better Life Experience (ABLE) Act amended the federal tax code to allow families to set up tax-exempt 529A savings accounts for disability-related expenses. These accounts can be used by people with disabilities to save without losing their eligibility for Medicaid or Social Security.

As of September 2019, \$292.6 million in assets had been invested in over 51,119 ABLE accounts. Increasing the number of people who use ABLE accounts will help improve and sustain ABLE accounts overall.

### Resources:

Autism Speaks. 2013. National Housing and Residential Supports Survey: Executive Summary

Buescher AVS, Cidav Z, Knapp M, Mandell DS. Costs of Autism Spectrum Disorders in the United Kingdom and the United States. *JAMA Pediatr.* 2014;168(8):721-728. doi:10.1001/jamapediatrics.2014.210