Autism Speaks is enhancing lives today and accelerating a spectrum of solutions for tomorrow.
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. According to the Centers for Disease Control, autism affects an estimated 1 in 44 children in the United States today.

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.

A common saying in the autism community:

“If you've met one person with autism, you've met one person with autism.”
### Describing autism

Autism Speaks utilizes both person-first (person with autism) and identity-first language (autistic person). In 2019 we polled our community about their preference and heard that there’s no “one-size-fits-all” approach. For that reason, we always recommend respecting individual preferences and using the language that feels most comfortable to the person on the spectrum.

<table>
<thead>
<tr>
<th>INSTEAD OF:</th>
<th>USE:</th>
<th>WHY:</th>
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<tbody>
<tr>
<td>high-functioning / low-functioning</td>
<td>less affected or impacted / more significantly affected or impacted</td>
<td>Autism encompasses a broad, diverse spectrum of behaviors and abilities. A person who struggles in one area may be highly capable in another.</td>
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<tr>
<td>living with autism</td>
<td>has autism / is on the autism spectrum / is autistic</td>
<td>Many people on the spectrum embrace autism as an intrinsic part of who they are.</td>
</tr>
<tr>
<td>Autism / Autism Spectrum Disorder</td>
<td>autism / autism spectrum disorder</td>
<td>Both autism and autism spectrum disorder should be lowercase, except at the start of a sentence.</td>
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Interview tips

When interviewing an autistic person, ask for personal preferences on person-first or identity-first language. Make sure to interview the person with autism, not just their family or friends, to ensure you capture their story from their perspective.

Clearly set expectations for interviews by providing step-by-step details and even a visual schedule, depending on the person, prior to the day of the interview. Many people on the spectrum rely on a routine, so it’s helpful to avoid potential disruptions or shifts in schedule.

It is important to know if there are any “triggers” to keep in mind. The interviewer or crew should be made aware of any words, phrases, actions or other things the person with autism may find upsetting.

If conducting a video interview, it is important to ask the person and/or their family if they have concerns about camera lights, flash photography, specific sounds or volumes, or any other sensory-related issues.
About Autism Speaks

Our mission

Autism Speaks is dedicated to promoting solutions, across the spectrum and throughout the life span, for the needs of people 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 and related conditions.

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

Our vision is a world where all people with autism can reach their full potential.
Our work

Across research, advocacy, programs and services, Autism Speaks is committed to creating a brighter life on the spectrum. Following are just a few of our key propellants to accomplish this.

**Services and Supports**
The Autism Response Team connects individuals and families to information, free tools and resources for every stage of life.

**In English:** (888) AUTISM2  |  **In Spanish:** (888) 772-9050  |  **Monday - Friday,** 9 a.m.-5:00 p.m. (all time zones)

**Email:** help@autismspeaks.org

**Live chat** is also available between 9:00 a.m. and 2:00 p.m. ET

**Adult Services**

*Autism Speaks offers free online resources for transition, employment, education and housing and community living.* We recently launched Workplace Inclusion Now, an initiative to build and support inclusive, welcoming workplace culture through resources for autistic job seekers, employers and community leaders. We’re already seeing a great response from job seekers on the spectrum who have been among the early users of the program.

Through the Delivering Jobs campaign, we’ve reached nearly 1 billion people with messages of employment and inclusion through radio and TV for which is dedicated to creating 1 million pathways to employment and leadership opportunities for people with autism and other disabilities by 2025.

**Science**

*Autism Speaks is helping to lead faster implementation of best practices and more informed autism research for personalized care and treatments through health networks, advancements in virtual learning and strategic advocacy.* We administer the world’s largest open access autism genomic databases; have invested $234 million in scientific grants resulting in an additional $1 billion in public sourced funding focused specifically on autism; and advocated with and for our community, resulting in $3.9 billion increase in federal research funding for autism to date. With your support, we remain steadfast in our mission to promote solutions, across the spectrum and throughout the life span, for the needs of people with autism.
Our work

Advocacy

*Autism Speaks successfully advocated autism benefits coverage for an additional 3.4 million Americans,* bringing the total number of covered individuals to 207 million or an estimated 65 percent of the U.S. population.

Awareness

*One of the most powerful ways to foster understanding is to highlight the diversity of experiences within the autism community.*

Through our social platforms, website and email, Autism Speaks shares thousands of stories to represent just how broad and diverse the spectrum is. You can find some of these stories at AutismSpeaks.org/Profile, and anyone who would like to share their story can send an email to ConnectWithUs@autismspeaks.org.

We are also proud to share that Autism Speaks public service campaigns with the Ad Council have increased autism awareness by more than 50% - helping to create a more understanding, inclusive world for all.
April is World Autism Month

This year, we invite people around the world to take the pledge to help create a world where all people with autism can reach their full potential.

Along with pledging to support people with autism that need it, there are other ways to be involved:

**Pledge:** Take the pledge to create a world where all people with autism can reach their full potential.

**Share:** Submit your story for our social media pages here: https://www.surveymonkey.com/r/AutismSpeaksShareYourStory.

**Engage:** Invite your colleagues, classroom and friends to join our Kindness Campaign.

**Give:** Make a meaningful, lasting impact for people with autism with your gift.

**Fundraise:** Learn about all the ways you can fundraise on social media.

Together, we can build a world where all people with autism can achieve their full potential. We’re as committed as ever to this vision, but we can’t achieve it without you.
### How we help

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<thead>
<tr>
<th>Impact Area</th>
<th>Specific Achievement</th>
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<tbody>
<tr>
<td>Advocacy for Autism Insurance Coverage</td>
<td>Successfully advocated for autism insurance benefits covering 207M people in all 50 states</td>
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<tr>
<td>Investment</td>
<td>Invested $234M in scientific grants, resulting in additional $1B public sourced funding focused on autism</td>
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<tr>
<td>Research Funding</td>
<td>Championed $3.9B in federal funding for autism since 2007</td>
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<tr>
<td>Genomic Discovery</td>
<td>Helped lead the world's largest genomic discovery about biology of autisms</td>
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<tr>
<td>Tool Kits for Families</td>
<td>Provided tool kits offering critical information and support to over 1.5M families and professionals</td>
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<tr>
<td>Lowering the Age of Diagnosis</td>
<td>Funded research to lower the age of diagnosis, driving earlier screening and interventions</td>
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<tr>
<td>Healthcare Services</td>
<td>Aided over 24.1M people through funded services and supports</td>
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<tr>
<td>Financial Support</td>
<td>Funded nearly $15.2M in local grants and scholarships throughout the U.S.</td>
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<tr>
<td>Genomic Research</td>
<td>Administered network of medical centers/academic facilities developing cutting edge care to more than 500K children</td>
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<tr>
<td>Storytelling</td>
<td>Provided more than 535K people with direct assistance by email, phone and chat</td>
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<tr>
<td>Online Database</td>
<td>Created an online database of nationwide autism services and resources viewed by over 21M people</td>
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Spokespeople

Autism Speaks leadership can offer a wide array of expertise on topics relevant to the autism community. Spokespeople include but are not limited to:

Leadership team

Keith Wargo
President & CEO
Organizational Mission & Strategic Initiatives

Andy Shih, Ph.D.
Interim Chief Science Office
International Partnerships
Caregiver Skills Training Program
Diversity & Inclusion Initiatives

Stuart Spielman, Esq.
Senior Vice President,
Advocacy
Legislation
Advocacy Initiatives
Autism Ambassadors Program

Subject matter experts

Pamela Dixon, Ph.D.,
Clinical Psychologist
Director, Clinical Services & Inclusion
Caregiver Skills Training Program
Global Autism Public Health Initiative
Diversity & Inclusion

Arianna Esposito
Vice President, Services & Supports
Lifespan Programs
Family Services and Resources
Special Education
Transition to Adulthood
Autism-Friendly Events

Dean Hartley, Ph.D.
Senior Director, Genomic Discovery & Translational Science
MSSNG Genomic Program
Autism Research

Kelly Headrick
Senior Director, State Government Affairs & Grassroots Advocacy
Legislation
Advocacy

Arun Karpur, M.D.
Director, Data Science & Evaluation Research
Epidemiology
Autism Research

Angela Lello
Director, Housing Policy
Transition to Adulthood
Housing & Community Living

Dave Kearon
Director, Adult Services & Support
Transition to Adulthood
Employment Initiatives

Donna Murray, Ph. D.
Vice President, Clinical Programs
Autism Treatment Network
Clinical Research & Care

Lindsay Naeder, MSW
Vice President, Services & Supports
Community Impact
Programs, Services & Supports
Safety & Wandering Prevention
First Responder Training
Autism Response Team
Autism-Friendly Events

David Sitcovsky
Senior Director, Policy & Federal Government Affairs
Legislation
Advocacy
**Applied behavior analysis (ABA):** ABA is a therapy based on the science of learning and behavior that applies our understanding of how behavior works to real situations. The goal is to increase behaviors that are helpful and decrease behaviors that are harmful or affect learning.

**Autism Response Team (ART):** ART is Autism Speaks’ information helpline for the autism community. Our team members are specially trained to provide personalized information and resources to people with autism and their families.

**Asperger syndrome:** Asperger syndrome, or Asperger’s, is a previously used diagnosis on the autism spectrum. In 2013, it became part of one umbrella diagnosis of autism spectrum disorder (ASD) in the Diagnostic and Statistical Manual of Mental Disorders 5 (DSM-5). Though this term is rarely used anymore, when writing about Asperger syndrome the “s” is always lowercased; in Asperger’s there is always an apostrophe.

**Autism Treatment Network (ATN):** The ATN is a collaboration of Autism Speaks and some of the finest children’s hospitals and academic institutions in North America, specializing in multi-disciplinary medical care for children and teens with autism. Together, they work to develop evidence-based protocols and standards of care for many of the most challenging medical conditions surrounding autism today.

**Autism spectrum disorder:** 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.

**Genomes:** A genome is the entirety of an individual’s hereditary material.

**MSSNG:** The MSSNG (pronounced: “missing”) research program has sequenced the whole genomes of more than 11,000 people with autism and their families, creating one of the world’s largest genomic databases on autism. This project creates a window into the biology of autism, with the goal of developing personalized, more effective treatments. MSSNG is a groundbreaking collaboration between Google and Autism Speaks, The Hospital for Sick Children (SickKids), in Toronto, Google, Verily and DNAStack. MSSNG leaves out the vowels to symbolize the missing answers researchers are seeking.

**Sensory-Friendly:** Any time auditory, visual and olfactory stimulation is adjusted to levels acceptable for the autism community (or another group).

**Spectrum:** 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.