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 54 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.

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<tr>
<th>INSTEAD OF:</th>
<th>USE:</th>
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<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>
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<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 spectrum disorder; and advancing research into causes and better interventions for autism spectrum disorder 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 activities 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
Adult Services at Autism Speaks focuses on national initiatives promoting solutions for the needs of people with autism and their families across the spectrum and throughout the lifespan. We work to increase the quality and quantity of opportunities and resources available to youth and adults with autism related to the transition to adulthood, employment, housing and residential supports, postsecondary education and community integration. We are also working to lower the age that autistic teens start the transition process from 16 to 14 – advocating state by state.

Additionally, Autism Speaks, Best Buddies and Special Olympics, in partnership with the Entertainment Industry Foundation, teamed up to launch Delivering Jobs, an inclusion campaign dedicated to creating pathways to one million employment and leadership opportunities for people with autism, intellectual and/or developmental differences by 2025.

Science
Autism Speaks has funded more than 700 research projects, fellowships and grants to spur innovation. These studies include the Autism Speaks MSSNG (pronounced: “missing”) Project, one of the world’s largest genomic databases on autism, a collection of more than 11,000 whole-genomic sequences from people with autism and their families. Used by researchers worldwide, MSSNG is exploring the genetics of autism and paving the way for personalized treatments and supports.
Our work

Advocacy

**Autism Speaks’ advocacy efforts have resulted in $3.5 billion of federal funding for autism research and services.** The organization has invested $230 million in scientific grants resulting in an additional $729 million in funding from public sources focused specifically on autism.

Awareness

**Autism Speaks, a partner of the Ad Council since 2006, is credited with increasing awareness of autism spectrum disorder by more than 50 percent over the past decade – resulting in more people with autism receiving access to the care and support they need to live their fullest possible lives.** Our public service campaigns aim to directly advance our mission objectives, including increasing understanding and acceptance of people with autism and increasing early childhood screening and intervention. To learn about our most recent public service campaign in partnership with the Ad Council, which aims to empower parents to have their children screened, visit ScreenForAutism.org in English, or DeteccionDeAutismo.org in Spanish.
April is World Autism Month

Every year Autism Speaks leads a global campaign to increase understanding and acceptance of people with autism and their families during World Autism Month in April. This year, we invite people to create a kinder, more inclusive world for people with autism by pledging to be kind. Our 2020 goal is to reach 1 million acts of kindness, and we need the support of our community to get there!

Along with pledging an act of kindness, there are other ways to stay involved:

**Give:** Donate online or via Facebook Fundraisers, or fundraise with Kindness Breaks, with donations and fundraisers adding to the kindness tally.

**Share:** Spread kindness by sharing your “I Pledged” badge or taking our social kindness challenge to keep the kindness going.

**Learn:** Explore stories across the spectrum and throughout the life span.

**Wear:** Wear blue to show your support on April 2 and all month long.

**Participate:** Join a Walk, Hill Day, local event, partner activation and more!

Throughout the month Autism Speaks will share content, stories and opportunities to participate in the campaign, all supporting our effort to spread kindness.
How we help

- Increased understanding and acceptance by sharing stories with @autismspeaks social community of 2.6M
- Invested $220M in scientific grants, resulting in additional $729M public sourced funding focused on autism
- Successfully advocated for autism insurance benefits covering 200M people in all 50 states
- Provided tool kits offering critical information and support to over 1.2M families and professionals
- Helped lead the genomic discovery about biology of autisms
- Aided an estimated 21M people through funded services and supports
- Created an online database of nationwide autism services and resources viewed by 19M people
- Provided hundreds of thousands of people with direct assistance
- Funded $14M in local grants and scholarships throughout the U.S.
- Administered network of medical centers/academic facilities developing cutting edge care for more than 500K children
- Championed $3.5B increase in federal funding for autism

85¢ of every dollar funds research, advocacy, programs and services
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**

- **Angela Geiger**
  President & CEO
  Organizational Mission & Strategic Initiatives

- **Lisa Goring**
  Strategic Initiatives & Innovation Officer
  Strategic Partnerships
  Public Service Campaigns
  Organizational Mission

- **Andy Shih, Ph.D.**
  Senior Vice President, Public Health & Inclusion
  International Partnerships
  Caregiver Skills Training Program
  Diversity & Inclusion Initiatives

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

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

- **Kathy Headrick**
  Senior Director, State Government Affairs and Grassroots Advocacy
  Legislation
  Advocacy

**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**
  Director, Life Span Services & Supports
  Family Services and Resources
  Special Education
  Transition to Adulthood
  Autism-Friendly Events

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

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

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

- **Lindsay Naeder, MSW**
  Senior Director, Mission Delivery Programs, Services & Supports
  Safety & Wandering Prevention
  First Responder Training
  Autism Response Team
  Autism-Friendly Events

- **Val Paradiz, Ph.D.**
  Vice President, Services & Supports
  Services and Supports (childhood through adulthood)
  Employment
  Diversity & Inclusion

- **David Sitcovsky**
  Senior Director, Policy & Federal Government Affairs
  Legislation
  Advocacy

- **Judith Ursitti**
  Director, State Government Affairs
  Legislation
  Advocacy Initiatives
  Autism Ambassadors Program
**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 an 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 lower-cased; 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 multidisciplinary 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.