

# autism speaks® media guide



Autism Speaks is dedicated to creating an inclusive world for all individuals with autism throughout their lifespan.



## 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 36 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.”**

*– Dr. Stephen Shore*



# 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.

 INSTEAD OF:	 USE:	 WHY:
high-functioning / low-functioning	<b>less affected or impacted</b> <b>more significantly affected or impacted</b>	Autism encompasses a broad, diverse spectrum of behaviors and abilities. A person who struggles in one area may be highly capable in another.
living with autism / touched by autism	<b>has autism / is on the autism spectrum /</b> <b>is autistic</b> can and should be used interchangeably	Autism Speaks utilizes both person-first (person with autism) and identity first language (autistic person). However, when interacting or writing about someone on the spectrum, we follow their lead, whether it is person-first or identity-first language.
Autism / Autism Spectrum Disorder	<b>autism</b> <b>autism spectrum disorder</b>	Both autism and autism spectrum disorder should be lowercase, except at the start of a sentence.



## 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.



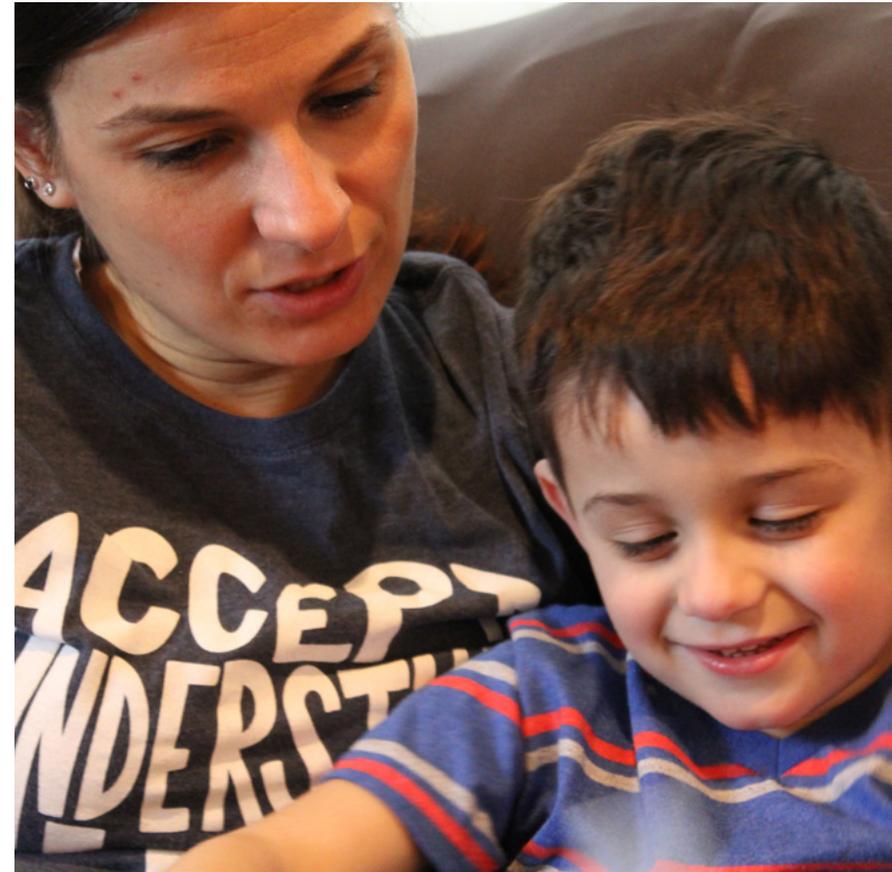


## About Autism Speaks

### Our mission

Autism Speaks is dedicated to creating an inclusive world for all individuals with autism throughout their lifespan. We do this through advocacy, services, supports, research and innovation, and advances in care for autistic individuals and their families.

**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 helping all autistic people reach their full potential. 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](mailto:help@autismspeaks.org) | **In Spanish:** [ayuda@autismspeaks.org](mailto:ayuda@autismspeaks.org)

**Live chat** is also available between 9:00 a.m. and 7:00 p.m. ET

## Adult Services

**Autism Speaks offers free online resources to accelerate delivery of solutions for adult quality of life needs, including adult diagnosis, transition to adulthood, employment, education and housing and community living.** Our Workplace Inclusion Now (WIN), program is an integrated employment initiative, to harness the collective power of three key changemakers – job seekers, employers and communities. Autism Speaks holds regional employment pathways events reaching thousands of autistic job seekers and employers.

## Science

**Autism Speaks supports research and innovation that drives towards improved quality of life and well-being for autistic people throughout their lives. Our work 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 database; have invested millions of dollars in scientific grants and projects and championed substantial increases in federal funding for autism. We remain steadfast in the promotion of solutions, across the spectrum and throughout the life span, for the needs of people with autism.



# Our work

## Advocacy

**Through advocacy, partnerships and collaboration, we support efforts to ensure that billions of dollars each year are dedicated at the federal and state levels,** funding autism research and improving and expanding the services and supports available to autistic people throughout their lives. Autism Speaks has successfully championed billions of dollars in federal funding for autism since 2007 and advocated for autism insurance benefits in all 50 states. Autism Speaks continues to play an important role in lowering the state required age of transition planning from 16 to 14 years of age or lower for students with autism and other disabilities.

## 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 autism spectrum is. You can find some of these stories at [AutismSpeaks.org/Profile](https://AutismSpeaks.org/Profile), and anyone who would like to share their story can submit a story at [surveymonkey.com/r/AutismSpeaksShareYourStory](https://surveymonkey.com/r/AutismSpeaksShareYourStory).

We are also proud to share that Autism Speaks public service campaigns have increased autism awareness by more than 50 percent – helping to create a more understanding, inclusive world for all.



# 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.**

#### **Chief Science Office**

International Partnerships  
Caregiver Skills Training Program  
Diversity & Inclusion

### **Stuart Spielman, Esq.**

#### **Senior Vice President, Advocacy**

Legislation  
Advocacy  
Autism Ambassadors Program

### **Kelli Seely**

#### **Chief Marketing Officer**

Organizational Mission &  
Strategic Initiatives

## Subject matter experts

### **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

### **Janet Jones-Jordan**

#### **Senior Director, Community Inclusion**

Family Services and Resources  
Diversity & Inclusion

### **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

## Autistic spokespeople

### **Tony Hernandez**

#### **Autism Response Team Associate**

Autism Response Team  
Early Diagnosis and Intervention  
Diversity and Inclusivity

### **Eileen Lamb**

#### **Senior Manager, Social Media & Digital Strategy**

Adult Diagnosis  
Diversity and Inclusion

### **Anne Grego-Nagel**

#### **Human Factors Engineer**

Employment  
Diversity and Inclusion  
Adult Diagnosis



# glossary

**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 and are available nationwide by email, phone and chat.

**Asperger syndrome:** Asperger syndrome, or Asperger's, was previously used as a diagnosis for those on the autism spectrum with lower support needs. 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). While the term was replaced in the clinical world it is still used by those diagnosed with it. When writing about Asperger syndrome the "s" is always lowercased; in Asperger's there is always an apostrophe.

**Autism Care Network:** The Network 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.





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