



autism speaks[®]

Inclusion of Family Voices:
Advocacy Ambassador Program

Forum for Children's Well-Being Spring Virtual Workshop, May 2020

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



Impact Statement

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.

What is autism?

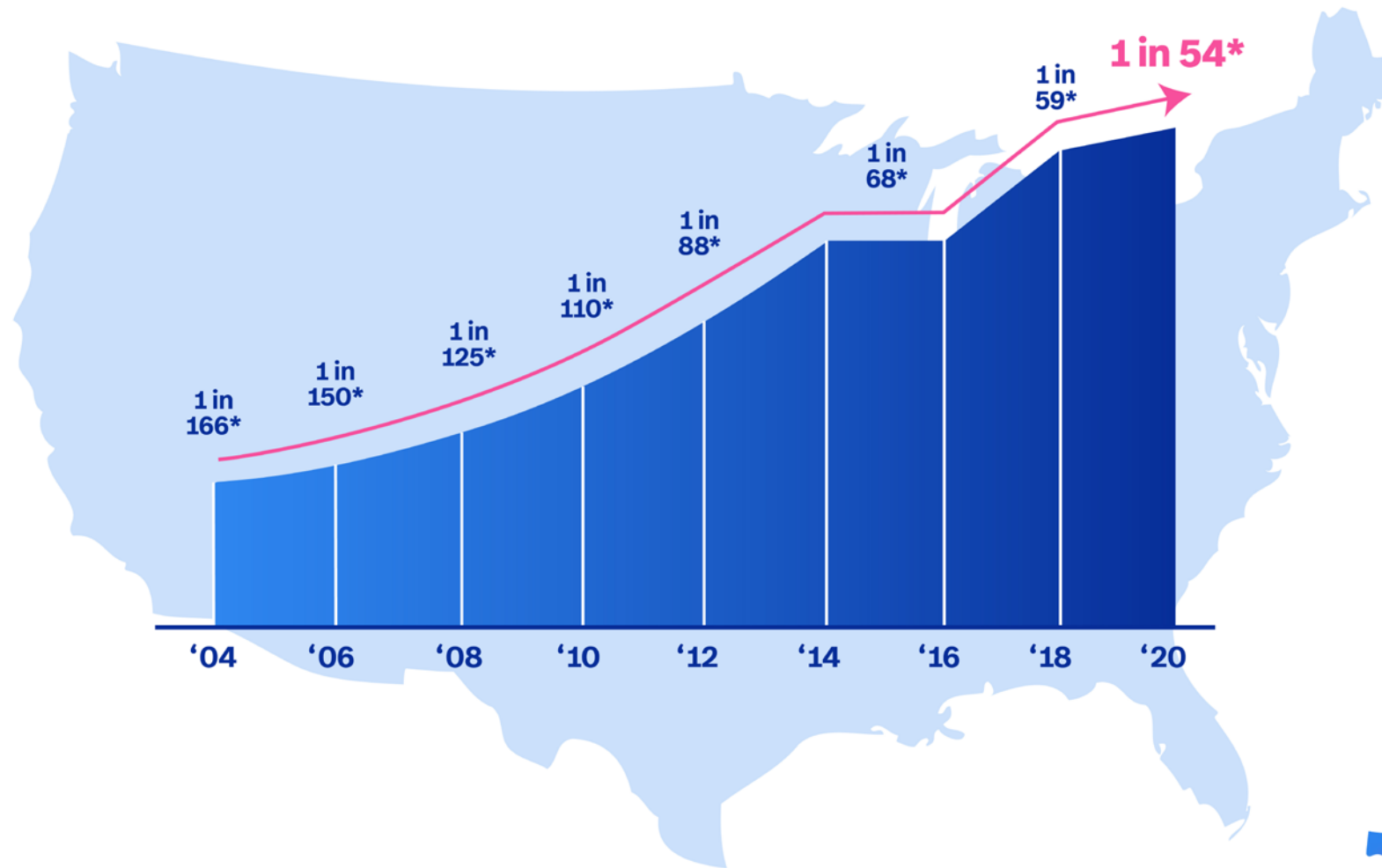
- Autism, or autism spectrum disorder
- Refers to a broad range of conditions characterized by **challenges with social skills, repetitive behaviors and nonverbal communication.**
- There is not one autism, but many subtypes
- Caused by a combination of genetic and environmental influences.



A person with autism may

- Not respond to his or her name
- Avoid eye contact
- Have trouble understanding other people's feelings or talking about their own feelings
- Communication challenges
- Repeat words or phrases over and over
- Become upset by changes in routine
- Have intense interests
- Repetitive Behavior – a 'stim' can be flapping hands, rock their body, spin in circles, etc.
- Have unusual reactions to senses: sounds, smells, taste, seeing or feel
- Have increased need for safety resources

Estimated Autism Prevalence 2020



* Centers for Disease Control and Prevention (CDC) prevalence estimates are for 4 years prior to the report date (e.g. 2020 figures are from 2016)

Advocacy team roles

- Relationships with our community members – listen and help advocates use their voices to influence public policy
- Coordination with our colleagues and external partners who work on autism-related and disability-related science, public health, education, supports & services, and organizational development and advancement
- Relationships with elected officials – educate and persuade on legislation that meets the needs of our community
- Relationships with government agencies – educate and persuade on regulatory items and coordinate on some activities

Advocacy team roles

- Some of our specific public policy objectives:
 - Federal autism research funding – NIH, CDC, etc.
 - Services and supports coverage in private and public insurance plans (speech/behavioral/occupational/physical therapies etc.)
 - Home and Community-Based Services (HCBS) funding and regulation
 - Special education, including transition services into the school system and then from it into adulthood
 - Personal safety and anti-discrimination
 - New: Employment



Our Ambassadors

- Advocacy Ambassadors are grassroots volunteers selected to serve as the main point of contact for their respective federal legislator(s).
- They may also choose to engage in our state government affairs work.
- Most ambassadors have a loved one on the autism spectrum or are themselves a self-advocate with autism. Apart from direct family members, many are health providers or special education teachers that work with autistic people.



The Advocacy Ambassador Role

- Each Advocacy Ambassador has four main responsibilities:
 - Establish and maintain relationships with legislators at the federal level
 - Serve as a local media advocacy stakeholder and use media tactics that influence elected officials at the federal level
 - Recruit other volunteers in their area to engage in autism advocacy efforts
 - Report district activities, meetings and events and their respective outcomes to Autism Speaks Advocacy staff



Ambassador Recruitment and Training

- Every Fall, there is a formal application and interview process
- New ambassadors participate in a 90 minute training the December before their program year begins. The training includes a review of responsibilities, Congress 101, fundamental advocacy skills and our specific priorities
- A Welcome Committee of returning Ambassadors also serve as a peer resource for their first couple months in the program
- Ambassadors are given regular briefings and public policy information, but the focus is upon telling their story and relating it to the ask – not having to be an expert on the policy



Ambassador Activities & Support

- Monthly all-ambassador video calls
- Facebook group for sharing best practices and other information from us and between ambassadors
- Regular email and telephone contact
- Calls to action – clearly communicated requests for each month. Meeting with their elected official about a given topic, posting on social media, recruiting volunteers, etc.
- Annual Advocacy Forum in DC (unfortunately cancelled for 2020)



What Does It Take To Be Successful?

- Staying positive while facing adversity
- Autism Speaks is non-partisan
- We focus on building and maintaining relationships with legislators, regardless of their position or political affiliation
- We are always respectful
- Remaining consistent, patient and persistent
- We aim to have consistent messaging across all platforms
- We never give up!
- Keeping a unified voice



Ambassador Benefits & Recognition

- Sense of satisfaction to influence their elected officials and be part of a caring team
- Volunteer service/leadership development and resume-building activities
- Shout outs on monthly calls
- Speaking or leadership opportunities with other areas of our organization
- Strengthened advocacy skills that are transferrable to how they advocate in other environments for themselves or loved ones

Quotes from staff about our ambassadors

“Thank you is simply not enough to say for all that you do for Autism Speaks. You are our eyes and ears on the ground. You are passionate. You are leaders. We thank you for volunteering your time and efforts on behalf of the autism community.”

“When I’m asked what my favorite part of my job is, I can always easily answer that it is working with our volunteer ambassadors. Your motivation, passion and never-ending perseverance is inspiring. Every day I come to work I’m grateful to know, work with and support each of you.”

Quotes from staff about our ambassadors

“Thank you all for the time, energy, and care you put into advocating for the autism community. Because of what you do – after hours and on your own – Autism Speaks’ advocacy is more responsive to the community of autistic individuals and those who love them than it ever could be otherwise.”

“It takes kindness. It takes patience. It takes persistence. And most of all, it takes love. The path an advocate walks is a particularly steep one, but the view is absolutely breathtaking. Thank you for believing in people with autism. Thank you for putting that belief into action through your work as an Advocacy Ambassador. I'm so glad to be on this journey with all of you!”

Quotes from ambassadors

“I love working as an ambassador because it allows me to become a part of the larger community and more effectively channel my time, energy and resources. Autism Speaks not only provides resources, but also allows us to connect with other families to ultimately promote greater understanding and gain support for those on the spectrum. There is strength in our collective energy. This organization has truly been a Godsend and I thank the early pioneers and those who continue to chart a positive course for change. I am honored to be a part of the solution.”

Quotes from ambassadors

“This program is great because it brings a community of people who might otherwise have never met and we all work together to make a difference. I love working as an ambassador because I believe that even if it is a 'small step' together those steps become miles and those miles come together to make changes for those on the spectrum along with their families.”

Quotes from ambassadors

“I have been involved with Autism Speaks for 7 years as a Walk Chair and have done many things locally. But I never really thought one individual affected by Autism could effect changes across the country, until I was brought into this program. Seeing first hand how my fellow ambassadors in the program have brought about change in their states, and how I made an impact, by garnering my Congressman's support this year was an incredible and inspiring feeling.”



If you or someone you know needs assistance

Call **ART** at 888-AUTISM2 (English)

or 888-772-9050 (Español)

Help@AutismSpeaks.org



Thank you!

Questions?