

**autism speaks<sup>®</sup>**

# Impacting Lives

across the spectrum & throughout the lifespan

Presentation to the New York City Department of Corrections

Carla Sterling, Sr. Area Executive Director, New York State

# About us



## Who we are

The largest organization dedicated to **promoting evidence-based solutions for individuals with autism and their families**, through every life stage and level of need.

## Our Mission

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

## Our approach

**Do the most good for the most people with autism.**

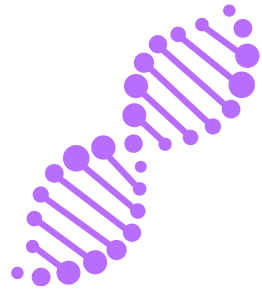
Address the greatest needs, with the highest quality, and the best opportunity for impact and scalability.

# Our Mission Objectives

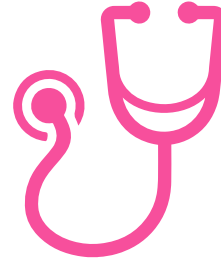
*Our five Mission Objectives set the stage for how we conduct our work!*



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

# Autism Prevalence

# The Facts – Our Children



\* The Centers for Disease Control and Prevention autism prevalence estimates are for 8-year-old children in the Autism and Developmental Disabilities Monitoring Network in 2020.

Autism affects an estimated **\*1 in 36 children**

Autism is almost 4x more prevalent among **boys than girls**

The United Nations estimates that **70 million people** are affected worldwide

**\*CDC 2023 report from 2020 data**

# The Facts – Adults

**Findings estimate autism affects 1 in 45, or 2.21 percent, of U.S. adults.**

On May 10, 2020, Centers for Disease Control and **Prevention** (CDC) published the first study to estimate the prevalence of autism in U.S. adults age 18 and older.

## Study Highlights:

- Autism prevalence in adults varied by region
- Prevalence is higher in men (3.6%) than women (0.86%)
- Many people are not diagnosed until later in life, although autism can be reliably diagnosed around 15 months of age



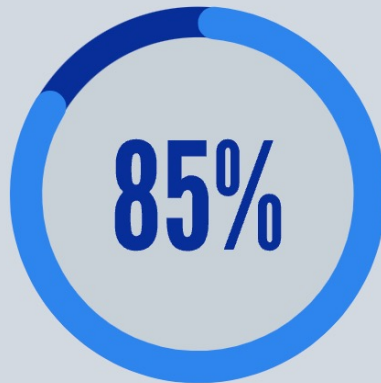
# The Facts - Employment

Autism affects more than

**70M**

people worldwide

Unemployment among those with autism is approximately



In the United States alone, studies estimate roughly 50-75% of the

**5.6M**

autistic adults are underemployed or unemployed

Nearly half of 25-year olds with autism



**What is Autism?**



# What is autism?

- Autism, or autism spectrum disorder, refers to a broad range of conditions characterized by **challenges with social skills, repetitive behaviors, speech and nonverbal communication.**
- There is not one autism but many subtypes.
- Each person with autism can have unique strengths and challenges.
- Autism is caused by a combination of genetic and environmental influences.
- Autism is often accompanied by medical issues, seizures and sleep disorders.



- Autism is a “spectrum” disorder, there is wide variation in the type and severity of symptoms people experience.
- People of all genders, races, ethnicities, and economic backgrounds can be diagnosed with ASD.
- Although ASD can be a lifelong disorder, treatments and services can improve a person’s symptoms and daily functioning.

# A person with autism may...



[Safety landing page](#) | [Autism Speaks](#)

- Not respond to their name
- Avoid eye contact
- Have trouble understanding other people's feelings or talking about their own feelings
- Communication challenges
- Repeat words or phrases
- 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 intense reactions to sensory input: sounds, smells, taste, seeing or feel
- Have increased need for safety resources

# A person with autism may...



- Attend to details
- Be highly skilled in a particular area
- Have deeply focused interests
- Employ logical decision-making
- Use high levels of visual processing
- Be loyal
- Listen without judgement
- Be direct and honest

# Inmates With Autism Might:

- Have an impaired sense of danger.
- Wander to bodies of water, traffic or other dangers.
- Be overwhelmed by police presence.
- Fear a person in uniform (ex. fire turnout gear) or exhibit curiosity and reach for objects/equipment (ex. shiny badge or handcuffs).
- React with "fight" or "flight".
- Not respond to "stop" or other commands.
- Have delayed speech and language skills.
- Not respond to his/her name or verbal commands.
- Avoid eye contact.
- Engage in repetitive behavior (ex. rocking, stimming, hand flapping, spinning).
- Have sensory perception issues.
- Have epilepsy or seizure disorder.
- If a first responder is able to identify that an adult may have autism, he or she can then respond in a way that best supports the individual.



# When Interacting with Inmates With Autism



- Be patient and give the person space.
- Use simple and concrete sentences.
- Give plenty of time for person to process and respond.
- Be alert to signs of increased frustration and try to eliminate the source if possible as behavior may escalate.
- Avoid quick movements and loud noises.
- Do not touch the person unless necessary.
- Use information from caregiver, if available, on how to best respond.

## General training guidelines

Law enforcement agencies should proactively train their sworn workforce, especially trainers, patrol supervisors, and school resource officers, to recognize the behavioral symptoms and characteristics of an adult who has autism and learn basic response techniques.



Resources

## The Autism Response Team (ART) is an information line for the autism community

Our team members are specially trained to provide personalized information and resources to people with autism and their families.

ART has provided more than 460,000 people with direct assistance by email, phone and chat, including requests from individuals with autism and their families, as well as caregivers, teachers, professionals and community members.

### The Autism Response Team can help you learn more about:

- Where to get a diagnosis
  - Schools and special education
  - Advocacy and support
  - Adult services - including post-secondary programs and employment
  - Inclusion and community activities
- .... and much more!

# Information and Resources



[What Is Autism?](#)

[Help & Information](#)

[Our Work](#)

[Get Involved](#)

[Que es el autismo?](#)

[Donate ▶](#)

## Information by Topic

Autism Speaks is committed to providing the autism community with resources to meet each person and family's unique needs throughout every stage of life. To help with your search for support, we have organized our resources, information, expert advice and personal stories by category.

- [Financial Planning](#) | [Safety](#) | [School](#) | [Technology](#)
- [Health and Wellness](#) | [Behavioral Challenges](#) | [Medical Resources](#) | [Transition to Adulthood](#)
- [Adults](#) | [Family Support](#) | [Community Life](#) | [Miscellaneous](#)





## Information for Law Enforcement

### Autism Safety Project

[Safety in the Community ▶](#)[Safety in the Home](#)

On a daily basis police officers encounter a multitude of individuals in emergency situations. Just as each emergency differs from the next, so does the individual involved, especially in regards to people with autism. Police are trained to respond to a crisis situation with a certain protocol, but this protocol may not always be the best way to interact with people with autism. Because police are usually the first to respond to an emergency, it is critical that these officers have a working knowledge of autism, and the wide variety of behaviors people with autism can exhibit in emergency situations.

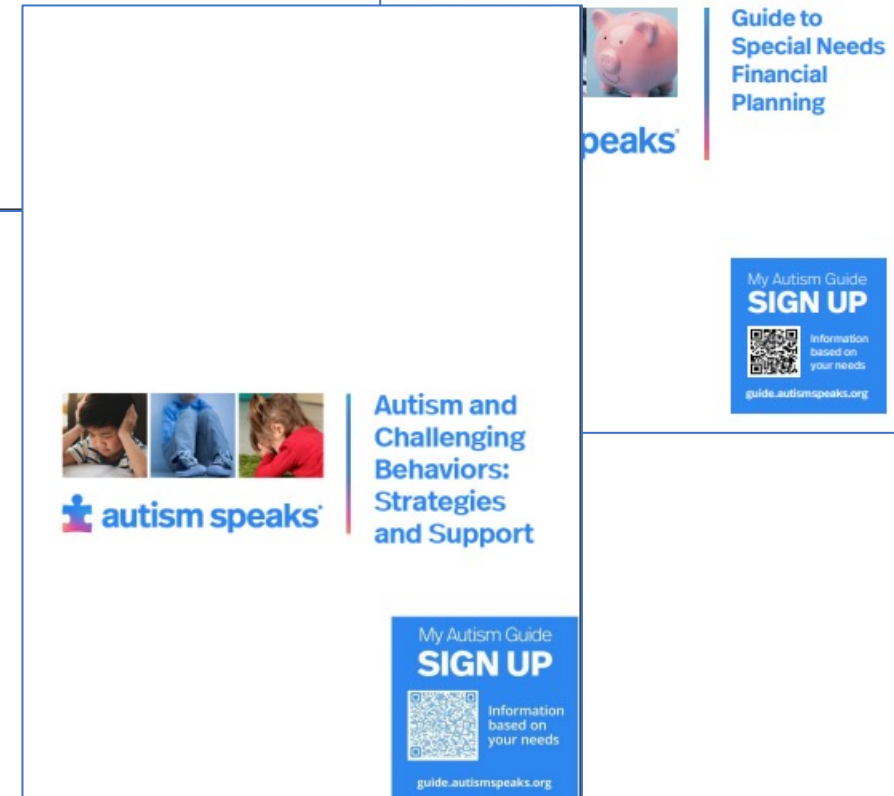
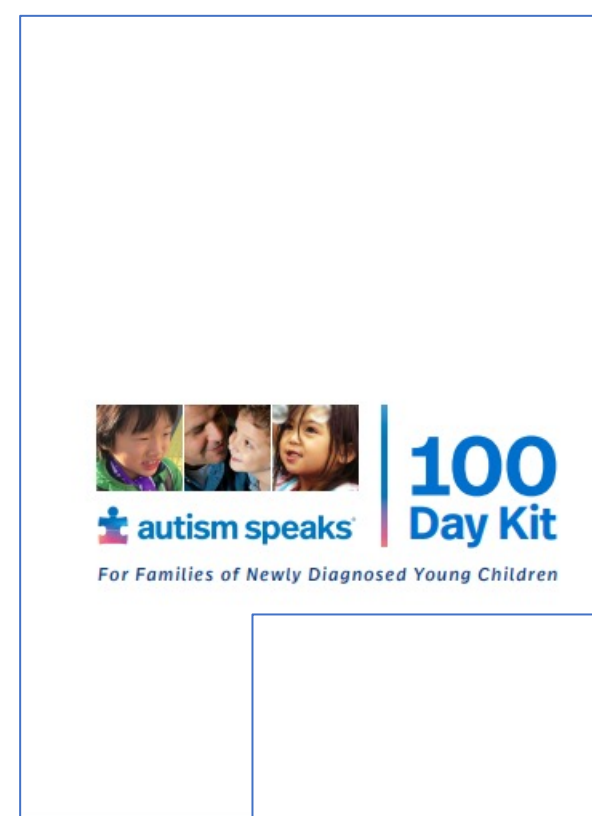
[Live Chat](#)

# Tools to get you started

Autism Speaks offers a series of comprehensive tool kits to autistics and their families to start your journey and access the services and supports you may need.

- The **100 Day Kit for Families of Newly Diagnosed Young Children** (Under 5) or (5-13)
- **Is It Autism and If So, What Next?** A Guide for Adults
- **Guide to Special Needs Financial Planning**
- **Autism and Challenging Behaviors Strategies and Support**
- **School Community Tool Kit**
- **Transition to Adulthood Tool Kit**

Access tool kits at [autismspeaks.org/tool-kit](https://autismspeaks.org/tool-kit)



# Caregiver Skills Training

The Caregiver Skills Training (CST) was developed in partnership with the World Health Organization. The Programs for Families of Children with Developmental Delays or Disabilities. The goal is to help parents and caregivers build day-to-day skills to better understand and engage with their children.

The CST program consists of 12 sessions, including nine group sessions and three home visits. Small groups of caregivers get together with a trained group leader weekly or biweekly for two-hour group sessions.

Throughout the sessions, you will learn about:

- Ways to engage your child in activities
- Using play and home routines as opportunities to teach critical skills
- Understanding your child's communication
- Strategies to teach your child communication and daily living skills
- Problem solving and self-care skills



## How to contact the Autism Response Team

**Monday through Friday  
9 a.m. to 5 p.m. in all time zones**

**By phone:** Your call will be routed to the team member for your region. We also have a dedicated Spanish language toll-free number.

**1-888-AUTISM2 (1-888-288-4762)**

**En español: 1-888-772-9050**

**By email:** Reach us at [help@autismspeaks.org](mailto:help@autismspeaks.org)

**Monday through Friday**

**9 a.m. to 7 p.m. ET**

**By live chat:** Connect at [autismspeaks.org](https://autismspeaks.org)





Other Ways We Help



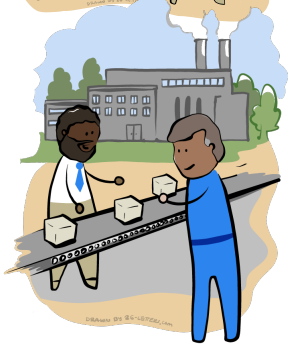
## People

**People with autism and related challenges are ready and willing to work** – and they have the skills and talents for a range of industries and roles. WIN **equips students, job seekers and employees with information, resources and support** to find meaningful work and navigate the workplace.



## Communities

WIN is **founded on the idea that by working together as a community, we can make the greatest impact** in transforming employment for people with autism and related challenges. WIN works with community partners to **support autistic people in finding, applying, getting and maintaining a job.**



## Employers

National data shows that **most autistic adults are unemployed or underemployed**, despite having the skill sets and expertise to excel in the workplace. **WIN helps businesses committed to inclusion to transform this** through consultation, training, programs and opportunities to access this untapped talent pool.

# Participating WIN Companies



As of today, nine companies are participating in WIN, with an additional **30+ companies** actively reviewing WIN digital courses for program implementation.



**Autism Speaks Cares Grants** provides limited direct assistance to individuals and families in financial need due to a catastrophic life event or natural disaster. Support includes financial support with groceries, utilities, childcare, medication, or therapy. Over the last two years calls regarding financial support has increased significantly. More than \$1,356,973 has been awarded.



### Groceries



### Bills



### Childcare



### Medications



### Therapy





# Local Engagement Opportunities

# Community Engagement



## 2023 Events:

- **Monday, June 26, 2023**  
**Golf Classic** - Winged Foot Golf Club, Mamaroneck, NY
- **Sunday, October 1, 2023**  
New York City Walk - South Street Seaport, Pier 17
- **Sunday, October 8, 2023**  
Long Island Walk - ones Beach- Field 5
- **Sunday, October 15, 2023**  
Westchester Greater Hudson Valley - New York Presbyterian - Westchester Behavioral Health Center, White Plains, NY
- **Sunday, October 22, 2023**  
Staten Island Walk College of Staten Island, NY

# LEAD WITH KINDNESS

A Company-led Kindness Campaign



Lead with Kindness



Company employees donate \$25 and be rewarded with a great company perk. Throughout this quick and easy campaign, we'll provide you with daily messages of kindness and autism awareness to help grow employee engagement. Studies show that employees feel good working for a company that cares. Send an even stronger message by offering to match employee donations. A simple but impactful way to make a meaningful difference where everyone wins.

[www.autismspeaks.org/kindness](http://www.autismspeaks.org/kindness)

# Volunteer



- **Market or Walk Committees** : Offers the opportunity to lead revenue-generating initiatives, as well as partner on priority programs and advocacy efforts.
- **Event Day Volunteers:** Volunteers play a vital role in the success of our Autism Speaks Events. We have a host of event related opportunities leading up to and on the day of our events.

## Connect with us

To find the latest resources, information and activities in our community, join us on social media



@autismspeaks



@autismspeaks



linkedin.com/company/  
autism-speaks

[facebook.com/autismspeaks](https://facebook.com/autismspeaks)



### **Closed Facebook groups for individuals and families:**

[Navigating a New Autism Diagnosis](#)

[Voces Latinas de Autism Speaks](#) for Spanish-speaking families

[Transition to Adulthood: An Autism Speaks Community](#)

[Adulthood on the Spectrum: Networking for Autistic Adults](#)

[Employment WINS: An Autism Speaks Community](#)

**Thank you!**