













# Autism Society Celebrate Differences

2023 Annual Report

## Celebrate Differences

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The experiences across the Autism spectrum are varied and unique. From Autistic individuals requiring 24/7 supported care, to Autistic adults living fully independent lives, no single experience is the same as another. **The Autism Society of America makes room for the infinite ways in which people experience life and we Celebrate Differences**.

The Autism Society believes that no one should be put into diagnostic boxes, categorized, or labeled. We are committed to creating a space where individuals can identify themselves as they choose. That is why we Celebrate Differences. No matter how you identify in the Autism community; you are a part of the connection. **No matter who you are, the person you are is infinite, and you are the only you there is**. No family or individual's story is the same as any other, and the Autism Society believes the world should recognize the infinite ways the Autism community experiences life.

### Who We Are

The Autism Society is the oldest and largest grassroots Autism organization and a leader in Autism advocacy, education, support and community programming. Through our nationwide network of 70+ affiliates, the Autism Society supports approximately half a million Autistic individuals each year. **By focusing on initiatives related to employment, safety,** health equity, education, public policy, and more, we are connecting people to the resources they need, when they need them.



## i About Us

#### **Our Mission**

We create connections, empowering everyone in the Autism community with the resources needed to live fully.

#### **Our Vision**

Creating a world where everyone in the Autism community is connected to the support they need, when they need it.

#### **Our Core Values**

**Dignity** - Where the value and selfdetermination of every individual is upheld.

**Equity** - Where everyone with Autism achieves the highest possible quality of life.

**Inclusion** - Where every person is integrated into society without barriers or exceptions in a collaborative environment.

**Diversity** - Where everyone is respected for their unique and individual differences.

**Integrity** - Where we conduct ourselves with honor, truth, and respect in our thoughts, words and actions.

## A Letter from our Leaders

The experiences across the Autism spectrum are varied and unique. From Autistic individuals who require 24/7 support to those who live fully independent lives, each person experiences Autism differently.

Since 1965, the Autism Society of America has made room for the infinite ways in which people experience life with Autism. We have made it a priority to **Celebrate Differences** — because what makes us unique is what allows us to see the world from a different perspective.

We are an organization that creates spaces where Autistic individuals can identify themselves as they choose. We also strive to be an organization that people can trust, and we've worked to build and sustain this trust for nearly six decades.

In 2023 our work — *and your trust in us* — helped change the lives of half a million people.

**Together, we offered support to people who need help now.** Whether it was a family overwhelmed by a new diagnosis, or an Autistic individual worried about their first job interview, the Autism Society provided support and guidance that matched each person's unique needs.

Together, we changed the lives of those who want to make a difference. We continued to be a trusted resource not only for Autistic individuals and their families, but also for caring friends, allies, educators, healthcare professionals, representatives in government, and other champions who want to help.

In April 2023, we launched our fifth annual #CelebrateDifferences campaign in honor of Autism Acceptance Month. Throughout the month, the Autism Society, our affiliates, and our community partners worked together to spread awareness and promote acceptance. Later in the year, our new Autism Justice Center — focused on empowerment, advocacy, and justice — began its preliminary work

### ? Did you know?

- There are approximately **5.4 million Autistic adults** in the US.
- **1 in 36 children** are diagnosed with Autism, the fastest-growing developmental disorder in the United States.
- Autism Spectrum Disorder (ASD) occurs in all racial, ethnic, and socioeconomic groups, but is 4x more common in males than females.
- Of the children who received an Autism diagnosis, and despite the majority of concerns being documented before 3 years old, the average age of diagnosis was a little under 4 and a half years old.

as a unique resource for Autistic individuals, their families, and advocates navigating the criminal justice and legal systems.

Each of these life-changing initiatives and programs was supported by Autism Society donors like you in 2023. Thank you for trusting us with your investment in this work and thank you for your continued generosity.

Your contributions help us **Celebrate Differences**, change lives, and connect the Autism community to education, resources, advocacy, and above all, to one another.

With appreciation,



Christopher Banks President and CEO

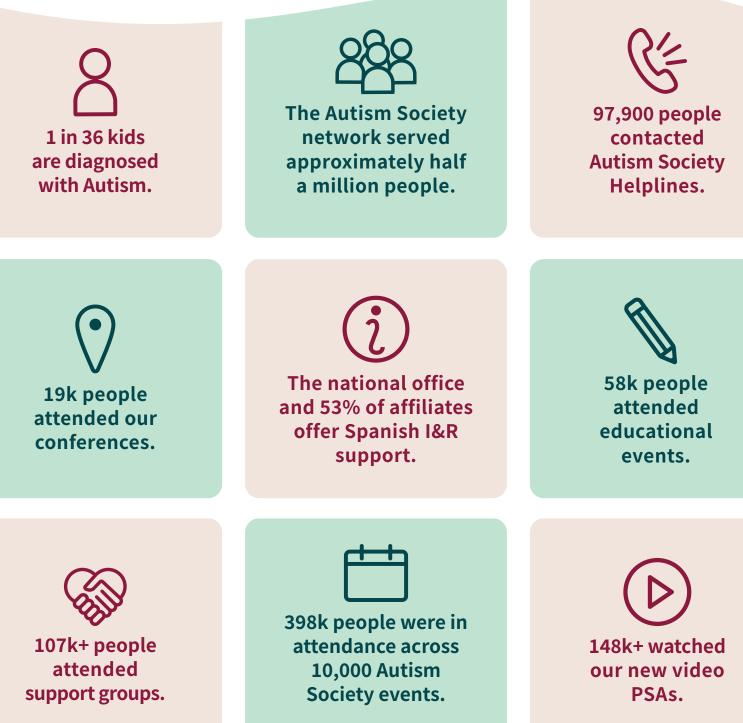


*Inacuy*, Staley, **Tracey Staley** Chair of the Board

# Autism Society Impact

Every day, the Autism Society works to create connections, empowering everyone in the Autism community to live fully. **We connect people to information, resources, advocacy, programming, and above all, each other.**  I want people to know that I'm witty, fun, smart, have a great sense of humor, want meaningful relationships with others, sometimes I do feel underestimated.

– Megan



## Autism Acceptance

Each April, we celebrate Autism Acceptance Month, a time to come together and #CelebrateDifferences, spread awareness of the importance of early diagnosis, advocate for inclusion in the greater community, and promote acceptance across all aspects of life.

In April 2023, we unveiled our newest brand photos featuring Autistic individuals with higher support needs, their family members and support team members. **Our goal was to capture a varied and diverse range of experiences within the Autism community, because acceptance is welcoming unique representation in all aspects of life.** 

Our photoshoot focused on:

- **Diversity** in age, race, ethnicity, gender identity, and level of support
- Gathering authentic stories and experiences from Autistic individuals with **higher support needs**

#### For our participants:

- About half use AAC devices
- 90% with intellectual/cognitive disability
- 70% requiring full-time care

The Autism Society's brand is designed with the Autism community. Autistic self-advocates identified their lack of inclusion in decision-making within Autism organizations as a major hurdle for their engagement with those organizations. From the beginning of the brand process, the Autism Society set out to create a space that was fully inclusive, accepting, and representative of all those in the Autism community, including Autistic individuals, their families, friends, caregivers, and professionals.

I want to get a job and I want to grow up and live life for myself.

– Jaire

### **April Highlights**



**103k+ people visited our website** for additional information.



The White House Easter Egg Roll provided the first sensory-friendly hour for families and children with disabilities to enjoy festivities without sensory overload.



Approximately 400 people participated in the virtual conference at the annual Disability Policy Seminar, which was co-hosted by the Autism Society.



Chrysler and Autism Society of America announced our partnership at the New York Auto Show.

## (i)

The Autism Society created educational content with Goodnites, Nickelodeon, and Pura Vida, shared digitally, through broadcast, and retail experiences respectively.

I want people to know that it's a beautiful experience, it's extremely hard and you will need help. It's life-changing having someone in your life with Autism.

– Kaleo's family

I struggle a lot with controlling my body, especially if I'm a little bit nervous or even excited. The photoshoot was a great example. You were all so welcoming and kind. I could feel your acceptance and understanding in your eyes and your smiles. Thank you.

– Evan

# Public Policy

- Key Achievements
- Autism Justice Center

## Key Achievements in Public Policy

Everyone has the right to live fully and to understand laws that affect them. The Autism Society's Public Policy Committee and Board of Directors work together to advocate for legislation that improves quality of life.

In 2023, we continued our public policy work to ensure full representation and champion the rights and wellbeing of individuals with Autism and their families.

#### Appropriations for Autism and Disability Programs

In 2023, the Autism Society successfully leveraged its extensive grassroots network to advocate for critical funding for Autism and disability-related programs for Fiscal Year 2024. Despite facing a challenging legislative environment marked by stringent budget negotiations and political contention over the debt ceiling, our concerted efforts resulted in the protection and, in some cases, enhancement of funding levels for these vital programs. Our network's dedication was particularly evident as they rallied to send over 1,000 persuasive letters to Congress members, effectively safeguarding the financial support essential for sustaining and expanding our initiatives.

### **Federal Regulations**

This year, the Autism Society played a pivotal role in shaping federal policy affecting the Autism community by engaging with the Administration on a range of proposed regulatory changes. Our efforts were instrumental in advancing proposals aimed at fostering equitable access to healthcare and enhancing home-and-community-based services (HCBS). Additionally, we emphasized the importance of person-centered decision-making within HCBS frameworks. To facilitate community involvement, our policy team developed and disseminated a template that empowered over 50 stakeholders to submit informed comments on proposed rules designed to eliminate discrimination based on disability in healthcare services. This proactive approach  not only influenced policy formulation but also ensured that the voices of those we serve were heard at the highest levels of government decision-making.

### **Enhanced State Advocacy Efforts**

Throughout the year, our policy team collaborated closely with affiliates nationwide to champion crucial state legislative changes for the Autism community. This collaboration yielded significant legislative victories across several states, including the passage of laws to establish eligibility for wandering alerts for individuals with Autism, abolish subminimum wages, enhance police training on Autism, and boost reimbursement rates for direct support workers. Additionally, the Autism Society played a critical role in educating lawmakers about the detrimental impacts of certain proposed measures, notably the introduction of voucher systems in Texas schools.

Moreover, in response to the ongoing challenges posed by the changes in Medicaid unwinding following the pandemic, our team worked diligently with affiliates to safeguard healthcare coverage for the Autism community and maintain vital flexibilities in the waiver system. These efforts ensured the continuation of options for teleservices and compensation for family caregivers, crucial adaptations that support the diverse needs of our community.

#### **Our Advocacy Impact**

- 22k+ people attended over 130 advocacy events
- 2,702 letters sent to congress/senators through Autism Society's Action Center
- 400 attendees to Disability Policy Seminar
- 40 federal bills supported
- 30 state bills supported; 4 state bills passed

 $\widehat{i}$  Text AUTISM to 50457

to receive alerts and stay up to date on your action opportunities.

## The Autism Justice Center

In 2023, the Autism Society of America launched the Autism Justice Center, focusing on empowerment, advocacy, and justice. Through the Autism Justice Center, we champion the rights and well-being of individuals with Autism and their families.

Committed to inclusion, the Autism Justice Center represents all voices across the Autism community, including Black, Indigenous and People of Color (BIPOC), individuals of all gender and sexual identities, and immigrants. The Autism Justice Center stands as a beacon of hope and support for Autistic individuals, their families, and advocates — employing various strategies that include direct advocacy, education, and litigation support.

In addition to social justice issues, there is an urgent need for a paradigm shift in how our society responds to Autism, mental health, and behavioral health crises. The current system that relies on law enforcement intervention has proven to be inadequate, unjust, and sometimes fatal. As part of our work, we are advocating for a compassionate, informed, appropriate response to mental and behavioral health crises to expand equity and avoid preventable tragedies.

The Autism Justice Center's multi-faceted strategy includes developing resources for legal professionals to better represent Autistic clients, working with our Public Policy team on legislative initiatives, and expanding the training of first responders and other safety initiatives.

### ? Did you know?

- By age 21, approximately 20% of youth with Autism had been stopped and questioned by police, and nearly 55% had been arrested.
- 30-50% of people killed by law enforcement are people with Autism or other disabilities.

The Autism Justice Center has been extremely helpful to myself and my Autistic, incarcerated son. Their care, concern and dedication to our issue has gone above and beyond anything I could have ever expected. Thank you so much for everything you have done and for everything you will do to fight for justice for individuals on the spectrum.

– Melinda



Learn more about the Autism Justice Center: AutismSociety.org/autism-justice-center

### **Why Our Work Matters**

## One young man's story of unjust prosecution and abuse.

In 2010, Reginald "Neli" Latson was living with his mom and sister in Stafford County, Virginia. One morning, as he waited for his local library to open, someone called the sheriff's department and reported him as a suspicious Black male, "possibly in possession of a gun."

Latson, who is on the Autism spectrum, didn't have a gun. Later, he and his family would learn the caller hadn't seen a gun, but that detail came too late. A deputy grabbed the teenager, and he reacted by trying to get away — as would many with Autism who are sensitive to touch. Neli was arrested and charged with assault.

In the ensuing months, prosecutors refused to consider Neli's disabilities. They claimed he was using his Autism as a "diagnosis of convenience." At trial, the prosecutors rejected an offer of disability services as an alternative to incarceration, and Neli was convicted and sentenced to 10 years in prison.

During his imprisonment, Neli was subjected to long periods of solitary confinement. At one point he was tasered and strapped into a restraint chair for more than nine hours, for behaviors related to his disabilities.

INNB

Neli's mother fought for her son's release — first on her own, and then with help from organizations in the Autism community, including the Autism Society and local affiliates. In 2015, Virginia Governor Terry McAuliffe granted a conditional pardon. This allowed Neli to leave prison and live in a group home. In 2021, Governor Ralph Northam ended state supervision, granting Neli autonomy to choose where and how he lives.

Today, Neli has his own apartment and receives community-based supports. He is still fighting for an unconditional pardon to have the felony convictions wiped from his record. And though he is finally "free," it took 11 years, two governors, and a national conversation about race and disability to get justice. In his own words at a recent White House event, we still have "a long way to go."

Neli's story is just one example of why the Autism Center for Empowerment, Advocacy and Justice is so important for our community.

The trauma that I suffered due to racism and the criminal justice system's punishment of Autistic-related behaviors still bothers me, but I am happy that the activism and publicity about my case not only helped me, but also helped to make change for others.

I look forward to serving as an advocate for the Autism Center for Empowerment, Advocacy and Justice.

– Neli Latson

Photo (left): Neli Latson with Carlean Ponder, Director, Autism Justice Center

# National Programs

Our national programs have a significant impact on individuals with Autism and are designed to be replicable across our affiliate network. Priority initiatives include our Safety on the Spectrum<sup>™</sup> programs, dedicated to first responder training and water and wandering safety, our Employment Initiative aimed at enhancing job opportunities, our Health Equity programming focused on accessible healthcare, and our National Helpline, focusing on addressing the needs of the community.

- ht impact Safety on the Spectrum<sup>™</sup>
  - First Responder Program
  - Water & Wandering Program
  - Employment Initiative
  - Health Equity
  - National Helpline

### Safety on the Spectrum<sup>™</sup> First Responder Program

The Autism Society's Safety on the Spectrum<sup>™</sup>: First Responder Program was developed to promote safe interactions between first responders and people with Autism, their support systems, and community.

### One in 5 young adults with Autism will interact with a police officer before age 21, and are:

- 12x more likely to become involved in the justice system without criminal intent
- 7x more likely to be victims of crime and 5x more likely to be incarcerated

Leveraging a "train the trainer" approach, the Autism Society will impact positive change on a national scale through local delivery of its gold-standard training and certification program. This program is designed to equip first responders with the training and resources they need to serve the Autism community safely and effectively. Training is designed to improve understanding of Autism and the benefits of Autism-informed strategies for communication, crisis prevention and de-escalation, and tools and technologies that can support safe interactions. Additional program activities include community education, outreach, and resource dissemination to promote self-advocacy and community safeguarding.

#### Long-term goals of the program include:

- increasing training, resources, and collaboration to improve interactions between first responders and the Autism community
- reducing the use of force and restraint to foster safe and effective interactions between law enforcement and Autistic individuals

Unlike any other program of its kind, the First Responders Program has been developed collaboratively through a Safety Task Force comprised of first responders, Autistic advocates, parents, social workers, and local community leaders. In 2023, 4,676 first responders were trained within the Autism Society network. This national program will expand this reach through a pilot program in 2024. As a parent of a non-speaking adult, a police encounter is one of my greatest fears. Despite my appreciation of the service our officers provide to keep our community safe, I know all too well that even the police with the biggest hearts don't have the experience or resources to support my son in crisis.

– Parent

### **Kevin & Avonte Grant**

The Autism Society is leading a national effort to prevent water and wanderingrelated deaths through proactive programming, public awareness, and public policy. With funding from the Bureau of Justice Assistance through Kevin & Avonte's law, the Autism Society is collaborating with the International Association of Chiefs of Police (IACP) and The Arc's National Center on Criminal Justice and Disability® (NCCJD®) to provide training and technical assistance to organizations and agencies within law enforcement, public safety, and the disability community. Together, we are working to identify and develop best practice guidance to support first responders, policymakers, and community leaders that improve public safety and reduce injury and death due to wandering and drowning among individuals with Autism, developmental disabilities, and Alzheimer's or dementia.

Learn more about the First Responder Program: AutismSociety.org/first-responder

### Safety on the Spectrum<sup>™</sup> Water & Wandering Program

The Autism Society's Safety on the Spectrum<sup>™</sup>: Water and Wandering Program addresses the critical issues of preventable injury and death due to water and wandering related incidents within the Autism community. **The initiative has a dual focus on increasing prevention and response.** Proactive programming includes education and awareness promoting safeguarding and skillbuilding through our accessible learn-to-swim model. Response efforts include emergency preparedness and education & awareness efforts promoting technological enhancements and efforts to enhance search & rescue in collaboration with our Safety Task Force and First Responder Program.

The Autism Society seeks to develop an accessible aquatics training and certification program that supports instructors and the Autism community nationwide.

#### The initiative focuses on:

- Proactive programming
- Prevention
- Improved responses to wandering incidents

In addition, the Water and Wandering Program supports individuals and families through **education and tangible resources** such as:

- Safety checklists
- Social narratives
- Tip sheets
- Emergency planning tools

### ? Did you know?

- People with Autism are 160x more likely to drown than their neurotypical peers.
- 91% of deaths in children 14 years or younger with Autism are due to drowning.
- Of those who eloped, **53% went missing** long enough to cause concern.
- 50% of parents report receiving no guidance on preventing or addressing elopement, and the majority identify elopement as one of the most stressful behaviors they have to cope with.
- 49% of children with Autism attempted to elope at least once after age 4.
- Almost half of Autistic children aged 4 to 7 have eloped.

#### **Program Outcomes:**

- Increased number of aquatics staff trained to support swim students with Autism
- Increased participation and completion in learn-to-swim programs among Autistic individuals
- Increased community collaboration between aquatics organizations, schools, families, and the Autism community
- Decreased preventable drowning deaths and non-fatal submersion injuries within Autism community

7,559 people supported with water & wandering efforts

Learn more about the Water & Wandering Program: AutismSociety.org/water-and-wandering

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### **Why Our Work Matters**

### **66** Testimonial

It was an early September weekend afternoon when the school group chat started going off repeatedly. A coworker received a Ring camera notification showing a familiar face as missing and alerted the staff. The student was new to the school, but everyone felt the gut-wrenching tug when seeing his face in the post. It was mere minutes before a group of us started to search for him, using what we knew of the 5-year-old in hopes of recovering him safely. My team and I had only worked with him twice before this devastating day, but his affinity and love for the water was abundantly clear. It was not until later that night that law enforcement found the boy deceased in the canal just steps from his front door.

The little boy had a personality grander than any five-year-old I had ever met. He made sure you knew he was in the room with his vivacious energy, zest for life, and infectious smirk. The second I heard that he had gone missing my heart sunk and I desperately tried to ignore the gutwrenching feeling, knowing he was likely heading straight for the water. In my short time working with him in our school's learn to swim program, it was clear that he loved the water and found tranquility in it. He loved going underwater often to the bottom of the pool, not realizing he could not swim.

Unfortunately, a repair man had come to his house, leaving a door ajar, and the child managed to quietly and quickly wander from his home. The family knew within minutes that he had left by checking their Ring camera footage, but they couldn't find him. They alerted law enforcement and the search ensued. Unfortunately, despite best efforts the little boy was found deceased in the canal, steps from his home. This experience, although not 'my' child, broke me in so many ways. The disparity in resources and services for individuals with Autism became glaringly obvious. I had created and implemented a school-based learn to swim program, but I knew I could do more to help the community that means so much to me. I keep his picture on my desk and am reminded daily of my why - this is for him, and everyone like him. I landed here with the Autism Society living our mission and vision in the hopes of creating, implementing, and finetuning a learn to swim curriculum and wandering initiative so that individuals with Autism can live fully and safely.

– Katie Wentley Water and Wandering Program Manager

## Employment Initiative

The Autism Society's Employment initiative addresses the significant employment disparities facing individuals on the Autism spectrum. Employment plays a pivotal role in transitions to adulthood, independent living, socialization, self-worth and confidence. With alarmingly high rates of unemployment and underemployment among Autistic adults, our program strives to rethink systems and reshape employment policies and practices to ensure equitable opportunities for all members of the Autism community.

Leading with a "Fulfillment Mindset," the Employment Initiative creates connections - between Autistic individuals, caregivers and supporters, and employers to advance access to resources, training, and opportunities for meaningful work experiences, acceptance, and belonging. We advocate for equitable systems and offer employer training, tailored resources, and direct support to build effective and inclusive policies and practices that help Autistic employees thrive. Our comprehensive resource guides are designed to help individuals with Autism prepare for and navigate each stage of the employment process. Through our research and discovery phase, we have supported more than 2,000 community members and 65 engaged employers through employment workshops across our network.

Every person with Autism deserves access to meaningful and inclusive work experiences. The Employment Initiative is breaking down barriers at every stage of employment to transform the employment landscape through advocacy, education & training, and community engagement.

– Aaron Rock

Director of the Employment Initiative

### ? Did you know?

- More than 66% of Autistic young adults are unemployed and are typically not engaged in higher education after high school
- 58% of workplace accommodations cost absolutely nothing, while the remaining typically cost approximately \$500.
- The unemployment rate for people with disabilities is typically twice that of the general working population.



Learn more about the Employment Program: AutismSociety.org/employment

## **Health Equity**

The Autism Society is dedicated to advancing health equity by breaking down barriers and promoting accessible healthcare. People with Autism experience higher rates of medical and mental health conditions, poor health outcomes, and premature mortality. In addition to social and economic barriers, the Autistic community faces sensory, communication, cognitive, and other unique barriers to accessible healthcare. **The Autism Society is working holistically to address health equity outcomes including healthcare, mental health, suicide prevention, employment, and home and community-based services.** 

## ? Did you know?

- **1 in 3 adults with disabilities ages 18-44** do not have a primary care provider.
- Only 40% of physicians were very confident about their ability to provide equal quality of care to disabled patients. People with disabilities account for almost 40% of the annual visits made to emergency departments in the US each year.
- **18% of physicians strongly agreed** that the healthcare system often treats disabled patients unfairly.

#### Vaccine Education Initiative

Historically, people with Autism and other developmental disabilities have lower immunization rates than their peers without Autism, leaving them vulnerable to vaccine-preventable diseases and comorbidities; this places them at higher risk of hospitalization, ICU admission, and even death. In March of 2023, the Autism Society received a multimillion-dollar grant from the USAging's Aging and Disability Vaccination Collaborative (ADVC), an initiative funded by the US Administration for Community Living. This grant helped expand the Autism Society's highly successful Vaccine Education Initiative (VEI).

#### The Vaccine Education Initiative is designed to improve health by ensuring children, adults, and seniors with disabilities are included and supported in healthcare settings.

As part of the Vaccine Education Initiative, we also provide healthcare professional training, advocacy, and community education, resources, outreach, and support. The Autism Society is rewriting the vaccine experience to increase accessibility, reduce trauma, and build connected, supportive, and inclusive communities.

#### VEI tools, models, and resources include:

- The VEI vaccine clinic model, which has proven to increase accessibility, reduce stress, and improve outcomes with a 99% success rate.
- Our <u>Guide to Accessible Vaccination</u>, which provides practical recommendations for healthcare providers and family members on appointment preparation, sensory and space considerations, and injection tools.
- Our Accessible Vaccine Kit, which supports sensory, communication, and social differences. These kits help provide a more positive vaccination experience for all ages with a variety of calming and sensory tools, including noise-reducing headphones, stress balls to decrease anxiety, ShotBlocker<sup>®</sup>, a non-invasive way to lessen the pain and anxiety of needles, and more.

(i) Learn more about the Vaccine Education Initiative:

AutismSociety.org/VEI

### **Why Our Work Matters**

### Our impact

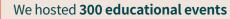
**30,000 vaccine kits distributed** to community members and healthcare providers (1,185% increase YoY)

**29,263 – Total number of vaccinations** (5,116% increase YoY)



**5,000 healthcare professionals trained** (299% increase YoY)

Our network hosted or supported **750 accessible vaccine clinics** 



**250 partners joined our efforts** to create equitable healthcare experiences

A 1.8 M people reached through education and outreach

### **66** Testimonials

Everyone was awesome and provided such a positive experience for both me and my child. **Thank you for the best vaccination experience ever!** Our family was overjoyed to have been part of this clinic.

– Parent

It was so nice to have the flu shot finally available to me! - Participant

The Autism Society's webinar received great attention across our network and requests to utilize their educational resources, tools, and vaccine kits. – Dr. Kelly Moore, President/CEO of Immunize.org

There's no reason why we can't do this in every clinic. **We can and we should.** 

- Participating Healthcare Provider



## National Helpline

Finding resources and navigating complicated service systems can be overwhelming. The Autism Society's National Helpline was established to connect everyone in the Autism community with the resources they need, when they need them.

Our trained Information and Referral (I&R) Specialists provide guidance for Autistic individuals and the extended community on topics such as, diagnosis, therapies and interventions, family training, mental health, housing, legal advocacy, employment, community inclusion, and more. Additionally, the Autism Society offers AutismSource™, a self-directed, comprehensive database that provides credible information and referrals for targeted support needs.

#### National Helpline goals include:

- Improving timely access to critical community services.
- Connecting the Autism community to their local Autism Society affiliate for support.
- Reducing feelings stress, confusion, and isolation within the Autism community.
- Strengthening connections between individuals in the Autism community and local resources.

#### Collectively, our Helpline reinforces the Autism Society's position as a trusted leader within the Autism community.



#### **Our impact**



8,174 people contacted the **National Helpline** 

47% of total cases are from Parents/Guardians



19% of total cases are from **Autistic Adults** 



14% of total cases are from Professionals



#### Most popular topics:

- Diagnosis (Adults & Children)
- Intervention and Therapies
- Adult Services



97,900 people were supported through Autism Society Helplines across the country

**Get connected through** the National Helpline: AutismSociety.org/contact-us

### **Why Our Work Matters**

### **66** National Helpline Testimonials

I contacted several organizations to find resources for my niece in Philadelphia, who has a 5-year-old son on the spectrum. I was discouraged when I got no responses from the other organizations I contacted. My experience with the Autism Society was totally different. When I called the National Helpline, Lindsey responded to my call promptly. She was very pleasant, knowledgeable, supportive, professional, and efficient. She listened to my concerns patiently, identified the major issues, and provided very helpful suggestions and resources (with phone numbers). Lindsey kindly invited me to call her again if my niece or I had additional questions or concerns. After the call, She followed up with an email providing links for each of the resources she provided, and additional resources! I am extremely grateful to Lindsey for her assistance and to the Autism Society for providing such a much-needed service to the community.

– Helpline user

I can't thank you enough for this useful information that you've gathered for us so speedily and delivered exactly when you said you would. I'd also like to thank you for listening in our phone conversation - **your understanding and support were exactly what I needed**. With gratitude and best wishes.

- Helpline user

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Thank you so much. I was searching in the middle of the night one night to see where I could get help. All the information you provided is an absolute blessing. I'm grateful. My wife and my brother are copied on this response because caring for my child is a family affair. I can't thank you enough.

– Helpline user

**Wow, this is so much amazing information.** I'm truly grateful. This is the beginning of my journey as a parent and hoping through education I can better support our daughter. Thank you for sending so many links and resources!

– Helpline user

# Affiliate Relations

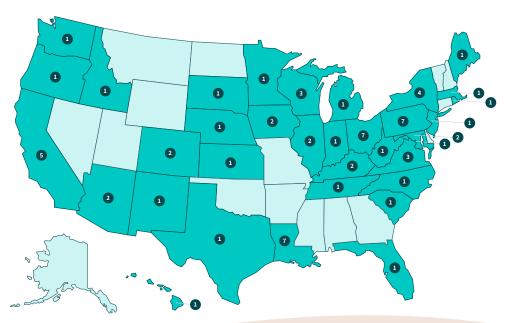
- The Network
- Affiliate of the Year
- Affiliate Spotlights

The Autism Society's network of 70+ affiliates serve their communities across the U.S. in the areas of advocacy, education, support, community and Information & Referral. The Autism Society acknowledges the significant value of affiliates and has demonstrated that importance by identifying "affiliate support". The Autism Society services the affiliates daily by providing resources and guidance, delivering network-wide and affiliate –specific training, providing lunch and learns and various development and networking opportunities, through development of an Affiliate Onboarding Handbook to quickly and efficiently onboard new affiliate leaders, by conducting regular check-ins to see how best we can support our affiliates, through facilitating and overseeing grant opportunities, by coordinating, funding and delivering an annual Affiliate Conference, providing disaster relief support, coordinating special events and activities, and more. As a testament to the effectiveness of this initiative, affiliate leaders showed 90% agreement of the Autism Society's commitment, engagement and responsiveness to the affiliates.

## **The Network**

### **Our Reach**

- 70+ affiliates across 34 states
- 775 affiliate team members
- 397,508 people attended 9,600 events hosted nationwide
- 487,234 people served by affiliates



#### Arizona

- Greater Phoenix
- Southern Arizona

#### California

- Inland Empire
- Los Angeles
- San Diego
- San Francisco Bay Area
- Ventura County

#### Colorado

- Boulder County
- Colorado

#### District of Columbia

District of Columbia

#### Florida

Florida

#### Hawaii

• Hawaii

#### Idaho

Idaho

#### Illinois

- Southern Illinois
- Greater Chicago

#### Indiana

Indiana

#### lowa

- Iowa
  - Quad Cities

#### Kansas

The Heartland

#### Kentucky

- Bluegrass
- Kentuckiana

#### Louisiana

- Acadiana
- Bayou
- Greater Baton Rouge
- Greater New Orleans
- Louisiana
- North LouisianaSouthwest Louisiana

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#### Maine

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#### Massachusetts

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Maryland

#### Michigan

Greater Detroit

#### Minnesota

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#### Nebraska

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#### New Jersey

• Southwest New Jersey

#### **New Mexico**

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New Mexico

#### **New York**

- Central New York
- Greater Hudson Region
- Nassau-Suffolk
- Western New York

#### North Carolina

• North Carolina

#### Ohio

- Central Ohio
- Dayton
- Greater Akron
- Greater Cleveland
- Mahoning Valley
- Northwest Ohio
- Ohio
- Oregon
  - Oregon

#### Pennsylvania

#### Greater Harrisburg

- Greater Philadelphia
- Lehigh Valley
- Northeastern Pennsylvania
- Northwestern Pennsylvania
- Westmoreland County
- Berks County

#### **Rhode Island**

Rhode Island

#### South Carolina

South Carolina

#### South Dakota

Black Hills

#### Tennessee

East Tennessee

• Central Virginia

Tidewater

Washington

West Virginia

Greater Wisconsin

South Central Wisconsin

Southeastern

20

Wisconsin

Washington

**West Virginia** 

Wisconsin

Northern Virginia

#### Texas

Virginia

Texas

## Affiliate of the Year Award

The Autism Society's Affiliate of the Year award is given to an affiliate that has effectively worked together to use its resources and members to positively influence and impact the lives of selfadvocates, parents, and professionals coping with Autism in their community.

In 2023, the award went to the Autism Society Northwestern Pennsylvania. They are actively involved in several initiatives and programs aimed at supporting individuals with Autism and promoting neurodiversity in the workplace.

#### Some of their efforts include:

- Skills to Pay the Bills: Empowering individuals with essential life and job skills like banking, cooking, and household tasks.
- Friends & Pals Teen Club Bridge to Success: The group uses the "Healthy Relationships" curriculum to support individuals with Autism in developing vital social skills like social media safety.
- Autism 101: Embracing Neurodiversity in the Workplace: This new program is a significant step toward creating inclusive workplaces. It raises awareness about Autism and promotes the understanding of neurodiversity among employers, fostering a more inclusive and supportive work environment.
- Drive to Success: Participants gain hands-on experience and training by interacting with local law enforcement, simulating real traffic stops to prepare for potential encounters on the road.
- Family Sensory & Social Outings: These events are offered monthly for families to experience structured community events in a calm sensory-friendly environment.









## Affiliate Spotlights

#### **Autism Society of Idaho**

<u>Autism Society of Idaho</u> achieved a major milestone in 2023 when the organization successfully merged two affiliates to represent Autistic individuals and their families across the entire state of Idaho. This change brought many benefits to the Autism community in Idaho including; allowing the Autism Society to speak with one voice at the state legislature in advocating for policies and funding that support Autistic residents.

### **Autism Society of Maryland**

The Autism Hiring Program, an initiative of the Autism Society of Maryland, advances workplace neurodiversity, connecting businesses to an untapped workforce of skilled Autistic adults, and targeting jobseekers not supported by existing systems in Maryland. Since its start in 2021, the program has placed 55 Autistic workers in meaningful jobs and built a pipeline of 25+ employers. Graduates of the program, many of them with some college or college degrees, are currently working in Cyber/ IT, Retail, Administration, Recreation, Engineering, Warehouse, Manufacturing, Hospitality, Security, Manufacturing, among other professions.

#### **Autism Society of Texas**

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Thanks to the Vaccine Equity Initiative, the <u>Autism Society of Texas</u> was able to increase health equity among people with Autism through community training events and practical support techniques across Texas. They offered free, interactive seminars in English and Spanish, to local hospitals and doctor's offices, dental practices, as well as for parents and other support professionals in the Autism community. Training healthcare professionals to work effectively with members of the Autism community benefited both groups immensely, improving healthcare access, communication and treatment outcomes.

Receiving the 2023 Affiliate of the Year award is a great honor, motivating us to continue making a difference in the lives of those we serve. This recognition reaffirms that our work has a real impact, inspiring us to redouble our efforts in the years ahead. With humility, we accept this award, renewing our commitment to building stronger, more resilient, and thriving families and individuals in our community.

- Tish Bartlett, Executive Director of Autism Society NWPA

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- Partner Highlight: Database and Technology
- Finance
- Development
- Corporate & Cause Partnerships

## Partner Highlight: Database and Technology

As part of our current strategic plan, the Autism Society is committed to a digital transformation, ensuring that our technological systems are modernized, efficient, and effective. This includes our recent website re-launch, <u>AutismSource™</u> improvements, data cleanup, and systems architecture.

#### IBM

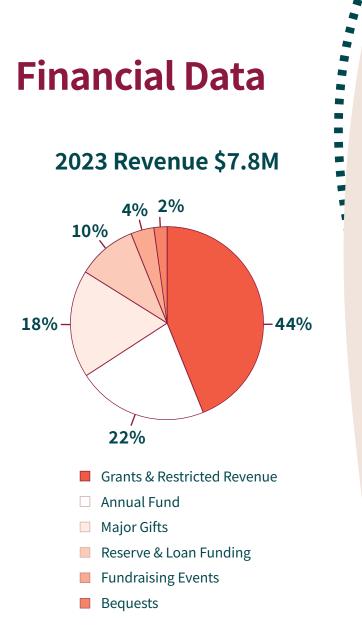
IBM's generous contribution of over \$200,000 of in-kind technology services has been transformative for the Autism Society. Through their partnership, we've been equipped with IBM's proprietary mapping software, a powerful tool that redesigned and enhanced our AutismSource™ platform. This software enables our constituents to effortlessly locate vital local resources, thereby streamlining access to crucial support services. IBM's dedication to leveraging technology for social good exemplifies their commitment to making a tangible difference in the lives of Autistic individuals and their families.

#### **Liberty Mutual**

In 2023, Liberty Mutual exemplified acceptance in action by surpassing our call to action and generously donating over \$600,000 in in-kind technology services to the Autism Society. Their invaluable support played a pivotal role in enhancing our organizational infrastructure.

Their efforts included facilitating the migration of our business software, optimizing our database systems for both our National Helpline and Affiliate Relations teams, and enhancing the overall user experience of our website. Liberty Mutual's proactive engagement underscores their unwavering commitment to advancing our mission and empowering individuals in the Autism community.

> Get connected to local support through AutismSource<sup>™</sup>: Source.AutismSociety.org



#### Revenue

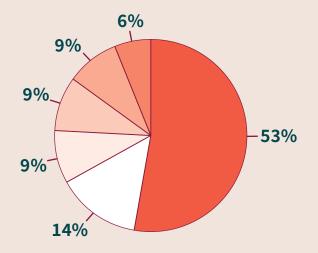
Grants & Restricted Revenue	\$3,390,670
Annual Fund	\$1,709,729
Major Gifts	\$1,390,133
Reserve & Loan Funding	\$761,315
Fundraising Events	\$322,659
Bequests	\$214,684
	1

\$7,789,190

#### Change in net Assets: (386,674)\*

\*excluding reserve and loan funding

### 2023 Expenses \$7.4M



- National Programs
- Education & Awareness
- Affiliate Relations & Support
- Public Policy & Advocacy
- Fundraising
- Management & General

#### Expenses Program Expenses

National Programs	\$3,948,363
Education & Awareness	\$1,002,900
Affiliate Relations & Support	\$666,233
Public Policy & Advocacy	\$634,735

#### **Support Services**

Fundraising	\$709,505
Management & General	\$452,813

\$7,414,549

## Development

The Autism Society's development department plays a vital role in securing the resources necessary to support the organization's mission and programs. In 2023, the Autism Society's annual Keystone Fore Autism Golf Classic, raised \$207,672, surpassing over one million dollars over nine years of support.

Thanks to the incredible generosity of our foundation partners, we're able to innovate, expand our National Programs, and better support our affiliate network.

### **The Impact**



**10,583 donations were made** to the Autism Society of America (7.5% increase YOY)

#### **1,085 people hosted Facebook Fundraisers**, and 11 hosted GiveLively fundraisers demonstrating the power of peer-to peer impact



\$288 was the average dollar amount donated

MAKESS WAVES

#### **Make Waves Family Foundation**

The Make Waves Family Foundation continued its significant support of the Autism Society's employment initiative. Make Waves supports leading programs dedicated to independent living, employment, and home and communitybased services. Their ongoing work supports law enforcement training, replicable employment models, and inclusive housing.

The foundation benefactors are committed to creating meaningful job opportunities for all Autistic individuals to pursue their interests and passions; additionally, networking with corporate partners and employers to partner with the Autism Society for inclusion training and beyond, is a priority.

Thanks to a \$250,000 donation plus an additional \$11,000 from a match campaign, the Autism Society is poised to make a meaningful impact with their strategic employment initiative through this strategic plan and future work.



#### **The Hussman Foundation**

The Hussman Foundation continued its generous annual support with a \$100,000 gift, which the Autism Society used to provide grants to affiliates across the country. 59 affiliates, approximately 85% of our network, received grants ranging between \$1500 to \$3000. Tens of thousands of Autistic individuals and community members participated in a wide variety of events and programming that was executed with these funds, including, advocacy efforts, social events like cooking, camps, and movie outings, to first responder and water safety trainings.

Through the generosity of The Hussman Foundation, affiliates across the country were able to greatly impact their local communities with resources, support and connection.

## **Corporate & Cause Partnerships**

2023 marked the beginning of a concerted effort to forge alliances with forward-thinking corporate partners, igniting a transformative journey to amplify our resources and broaden our impact. **These strategic collaborations are powerful alliances that merge the expertise, resources, and expansive reach of the corporate world with our steadfast dedication to the Autism community.** 



The Autism Society and Chrysler joined hands in a long-term partnership that seeks to revolutionize the driving experience for individuals with Autism and their families. Through this partnership, Chrysler introduced the Calm Cabin package, which includes calm lighting, weighted blankets and other features designed to turn every journey in a Chrysler Pacifica into a sanctuary of comfort and support. **Chrysler seeks to create an inclusive experience on and off the road; together, we envision a future of thoughtful, supported vehicle designs, and Autism training for dealership employees to better serve their communities.** 

I have purchased vans since my son was in grade school at the same [Chrysler] dealership in Chantilly, Virginia. He is now 30. He does not drive himself and just until this past year he had his spot that he sits in in the very back to the right. The members of the team have changed over the 20 years, but have still been just as magnificent, and have gone above and beyond for us. Our van needs to look the same-- black van with similar interior. They have conducted meetings in the new van we are buying so that Conner can sit in the back and get used to it. When we picked it up, in the seat of Conner's choice was a Disney sticker book.



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Driven by a profound commitment to shatter the bedwetting stigma, Goodnites is committed to supporting the Autism community by providing education, resources and communal connection. Through an ongoing partnership with the Autism Society of America, the two organizations will support the community through educational resources and community events. Designed with these families' needs in mind, Goodnites unveiled a resource hub to provide free access to bedwetting education tailored to the Autism and ADHD communities, with contributions from the Autism Society of America. Through this partnership, we're building a community of unwavering support, one that embraces, uplifts, and champions every individual's journey with compassion.

### **? iHeart**MEDIA

iHeartMedia has demonstrated its commitment by contributing just under \$200,000 worth of in-kind media advertising to the Autism Society. This significant donation underscores iHeartMedia's dedication to using its platform to raise awareness and support initiatives that benefit communities and individuals in need. With strategic radio ads placed across national inventory, iHeartMedia offered widespread awareness and advocacy for the Autism community. Their actions speak volumes, amplifying the experiences of those in need and fostering empathy and support on a scale that matters.

– Sharon

### pura**vida**

Pura Vida launched two updated bracelet styles adorned with the vibrant hues of the Autism Society's brand colors. With every purchase from our Autism Society bracelet collection, 5% of the purchase price is pledged to fuel our mission. Through creativity and thoughtful design, Pura Vida and the Autism Society demonstrate the impact of collaborative partnerships, fostering connections and empowerment within the Autistics community.

## nickelodeon.

The dynamic partnership between the Autism Society and Nickelodeon continues to evolve, weaving together education, content creation, and invaluable learning resources tailored specifically for children and youth. Our collaborative efforts have yielded a variety of enriching content, from the Autism Acceptance Month guide, to our back-to-school resource pack, all thoughtfully designed to drive inclusion, and support Autistic students and their teachers on their educational journey. In addition to educational resources, we've jointly created short form media content for socials, Nick News, and digital activities. Our ongoing partnership is further invigorated through employee and ERG learning sessions on Autism, authentic representation, and inclusion.

### WELLS FARGO

Wells Fargo has emerged as a beacon of change, propelling the Autism Society's Employment program to new heights. This partnership works

to dismantle longstanding systemic barriers that have hindered the professional growth and inclusion of Autistic individuals. Through a blend of knowledge dissemination, stakeholder engagement, and coalition building, this supported our community listening sessions orchestrated by the Employment Taskforce. These sessions offer a deeper understanding of the diverse needs and aspirations within the Autism community. By actively involving Autistic individuals in the development of strategies that shape their future, this research phase helps design the future programmatic trainings for employers and employees alike.

## Join us in making a tangible difference...

in the lives of individuals in the Autism community! If you're passionate about fostering inclusivity and driving meaningful change, we invite you to explore corporate partnership opportunities with the Autism Society of America.

#### Get connected with our dedicated Corporate and Cause Partnerships team

today at **partners@autismsociety.org**. Together, we can create a world where everyone in the Autism community is embraced and empowered to thrive.

# Getting Involved

- Thought Leadership
- Ways to Get Involved

## Thought Leadership

We are a team of learners, leaders, and connectors. With subject matter experts at the intersection of Autism and education, employment, safety, health, public policy, and justice - our team connects leaders across industries and experiences nationwide.





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CHRYSLER







## Ways to Get Involved

#### Join us in making a meaningful impact on the lives of individuals in the Autism community!

If you're passionate about creating positive change and fostering inclusivity, we invite you to explore opportunities to support the Autism Society of America. **Together, we can empower and advocate for a brighter future for everyone affected by Autism.** 



Autism for me, is me, it's my essence, it's who I am. Sure there's the science of having a brain that works differently, but it's so being unique and not fitting inside of rigid boxes.

- Community Member

#### **Opportunities include:**

- You can make a difference and further the Autism Society's impact by donating your time, talent, in-kind or financial support.
- Become a sustaining **monthly donor** at <u>AutismSociety.org/donate</u>.
- Become a corporate partner by reaching out to partners@autismsociety.org.
- Attend or sponsor an event like our golf tournament, affiliate training event, annual gala or Autism Acceptance Month.
- Include Autism Society in your will. To help you start your planned gift, you can use our online will-writing tool created by our partner, <u>FreeWill</u>, and write your will in 20 minutes online, completely for free.
- Donate a life insurance policy, or an unwanted vehicle.
- Donate as part of the **Combined Federal Campaign** or other workplace giving campaign. We are CFC #11808.
- Create your own personal Facebook fundraiser benefiting Autism Society at: <u>facebook.com/fund/AutismSociety</u>.
- Take action and support our public policy efforts through our online Action Center at: takeaction.AutismSociety.org.

Discover how your partnership can make a difference: Development@AutismSociety.org

## Governance

- Board of Directors
- Panel of Professional Advisors
- Council of Autistic Advisors
- • Executive and Senior Management Team

## **Board of Directors**



**Christopher Banks** President & CEO



**Tracey Staley** Chair of the Board



**Brian Roth** Chair-Elect



**Donna Roth** Secretary



**Howard Miller** Treasurer



Neal Beggan







Elizabeth Benevides Michael J. Brown Esq.





**Stephen DeStefani** 





Joan Fallon, DC, Ped



Leslie Goedken



**Tim Goldstein** 



Marc Ellison, Ed.D.

Joe Ireland



**Robert Johnston** 



**Joseph Joyce** 



As a National Board Director, I am honored to be part of the amazing work being done by the Autism Society of America. Every day we are making connections through our local affiliates, information & referral, and our key national programs that positively impact the Autism community.

– Brian Roth

As a diversity, equity, inclusion, and belonging coach and consultant, the importance of inclusion of individuals on the Autism Spectrum resonates with me. I have learned so much as a Board member, and it is exciting to see the difference we are making in the Autism community. – Asila Calhoun



**Edward Mahon** 



Jose S. Velasco



Jan-Maarten Mulder



Nicole Vele



### **Panel of Professional Advisors**

Marc Ellison, Ed.D., Chair Ruth Aspy, Ph.D. James Ball, Ed.D., BCBA-D Barbara Becker-Cottrill, Ed.D. Diane Cullen, Ph.D., CCC-SLP Geraldine Dawson, Ph.D. Stephen M. Edelson, Ph.D. Marc Ellison, Ed.D. June Groden, Ph.D. Barry Grossman, Ph.D. Martha Herbert, MD, Ph.D. Anne Holmes, Ph.D. Douglene Jackson, Ph.D., OTR/L, LMT, ATP, BCT Susan Kabot, Ed.D., CCC-SLP Gary LaVigna, Ph.D. Bennett L. Leventhal, M.D. Kristie Lofland, MS, CCC-A Kristen Lyall, Sc.D. Kiya Olson MA, MS, BCBA, LCPC Robert Naseef, Ph.D. Cathy Pratt, Ph.D., BCBA Kathleen Ann Quill, Ed.D., BCBA-D Amanda Randall, BCBA-D, LBA Christine Reeve, Ph.D., BCBA-D Wendy Ross, M.D. Stephen M. Shore, Ed.D. Jennifer Townsend, M.Ed. Jennifer Twachtman Bassett, M.S., CCC-SLP Amy Van Hecke, Ph.D. Paul Wehman, Ph.D. Patricia Wright, Ph.D., BCBA, MPH Vanessa Zuber

### **Council of Autistic Advisors**

Carly Ott, Committee Chair Elizabeth Bonker Sam Brandsen, Ph.D. Jennifer Cook O'Toole Darrius Frazier Michael Gilberg, Esq. Kate Gladstone Kris Guin Anthony Ianni Kris King Anita Lesko Kerry Magro Sara RS Miller Rhonda Moore, Ph.D. Chloe Rothschild Hari Srinivasan Regi Theodore-Wise

I'm very grateful for the opportunity to be a part of the Autism Society of America - not only has it provided me with the chance to meet some wonderful people, but it has also been encouraging to learn about several initiatives (related to healthcare, employment, and Autismrelated policies) that I believe have the opportunity to deeply impact the quality of life for Autistic individuals. More generally, it has been encouraging to see a slow but steady shift towards acceptance of Autistic individuals in society, and I believe this shift has been reflected in the Autism Society as well through the creation of an Autism advisory committee. - Sam Brandsen, Ph.D.

### Autism Society Executive and Senior Management Team

**Christopher Banks**, President and Chief Executive Officer

**John Dabrowski**, Chief Financial Officer / Chief Operating Officer

**Kim Musheno**, Vice President of Public Policy

Kristyn Roth, Chief Marketing Officer **Peter Schwarz**, Vice President of Affiliate Relations

Allie Tasche, Vice President of National Programs

# Looking to the Future

The Autism Society is exploring the landscape of future initiatives essential for navigating the opportunities and challenges that lie ahead.

### **Road to Acceptance**

The Autism Society's National Conference

The Autism Society's 60th Anniversary

### Thank you.

A sincere thank you for the dedicated work, commitment and passion from the Autism Society of America team. Our work is possible because of you. Because of you, more people within the Autism community are connected to the support they need, when they need it. **The connection is you**.

800.328.8476 AutismSociety.org