



# AUTISM SOCIETY OF AMERICA

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*2016 Annual Report*



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# MESSAGE FROM AUTISM SOCIETY PRESIDENT/CEO & CHAIRMAN OF THE BOARD OF DIRECTORS

*Each year, the Autism Society of America strives to constantly improve on our measurable outcomes related to our work on advancing the quality of life for all impacted by autism. We are delighted to report that 2016 was a year of great success and accomplishments toward this goal.*

*Throughout the year, the Autism Society of America and our valued local and state affiliates served over 300,000 individuals. From helping a parent of a young child who was diagnosed with autism to helping an older autistic adult have affordable and appropriate housing and support, the Autism Society was there. From successfully advocating on behalf of the autism community in the halls of Congress to helping a parent and student obtain the most appropriate and beneficial IEP, the Autism Society was there. From always making sure that each day, an autistic person was provided the greatest opportunity for maximizing his or her quality of life, always being valued and always being respected, the Autism Society was there. And we will continue to be there!*

*This report provides information on specific activities that occurred throughout 2016. All of our work could not occur without the amazing dedication of the staff and volunteers of the Autism Society of America and its network of affiliates. To each, we say thank you! Without our important and greatly appreciated individual donors, corporate sponsors, foundations and other funders, we say thank you! Without all of your support and daily work, the success noted in this report would never occur.*

*The Autism Society of America continues to be the largest, oldest and most effective national grassroots autism organization where money raised locally stays locally and decisions impacting a local community are fully made by local affiliates. We are so proud that for over 50 years, neighbors have come together to create a society in which each individual living with autism can obtain the highest quality of life possible.*



Joe Joyce, Chairman



Scott Badesch, President & CEO

# OUR MISSION AND VISION

## Our Mission

Improving the lives of all affected by autism

## Our Vision

The Autism Society envisions a world in which individuals and families living with autism are able to maximize their quality of life, are treated with the highest level of dignity, and live in a society in which their talents and skills are appreciated and valued.

# GUIDING PRINCIPLES

**The Autism Society and its Affiliates are committed to these core principles:**

- ▶ We provide services without regard to a person's age, race, religion, disability, gender, sexual orientation, income level or level of need on the autism spectrum
- ▶ We strongly encourage and welcome families, professionals and individuals living with autism with opportunities to participate in our governance, on our committees, and as staff members
- ▶ We partner with others to advance the well-being of all living with autism
- ▶ We promote individual choice and self-determination of individuals living with autism, aided by parental and guardian advocacy
- ▶ We recognize a person living with autism can and should be able to maximize his/her quality of life and oppose any denial of their opportunities
- ▶ We oppose any discrimination and harm directed towards individuals living with autism and their families
- ▶ We are transparent, responsible and accountable to those we serve, those who support us, and the general community in our stewardship of funds
- ▶ We assure the confidentiality of our services – and adhere to required confidentiality laws, and regulations pertaining to such services
- ▶ We strive to ensure our programs, services, and decisions are outcome-driven
- ▶ We maintain independence from political partisanship and commercial interests
- ▶ We respect the work of our affiliates and do not engage in actions that enhance one organization at the expense of others
- ▶ We support data and evidence-based analyses of options informed by broad knowledge of educational, research, clinical, government, business and program services experience
- ▶ We support an options policy and provide information on all options so individuals can exercise freedom of choice in their decision-making

# QUALITY OF LIFE OUTCOMES

The Autism Society's vision is to increase the quality of life of everyone living with autism. When we say “quality of life,” we’re talking about basic human rights that allow people to interact with one another and the world on their own terms. Quality of life indicators such as the ability to communicate, the freedom to choose a career and opportunities for community involvement are essential aspects of the human experience, and we promote treatments, accommodations and acceptance with them in mind.



# AUTISM SOCIETY'S STRATEGIC PLAN

In 2014, one year from its 50th anniversary, the Autism Society began strategic planning; a very thorough process was initiated to examine how best the organization could continue to meet the needs of the rapidly growing number of individuals and families impacted by autism throughout the nation. In July 2015, the year-long effort culminated with a very comprehensive strategic plan approved by the Autism Society's Board of Directors.

The 2015 Strategic Plan was developed with one goal in mind – how can the Autism Society best help the over three million individuals with an autism diagnosis maximize their quality of life throughout their lifespan. Per the Autism Society's goal of helping a person throughout their life, the plan was developed to identify lifespan milestones that enable all with an autism diagnosis to progress to achieving the highest quality of life possible throughout the individual's life. Additionally, to assure responsiveness to individuals and families as well as donors, the Autism Society will begin measuring our success by assessing lifespan outcomes being achieved.

The new strategic plan was designed around five core services: **Information & Referral, Support, Community, Advocacy, and Education.**

To learn more about these five core services, and to read about the 15 outcome measures, please click on the links below:

**[Strategic Plan Quick Reference Guide:](http://www.autism-society.org/wp-content/uploads/2014/04/National-Outcomes-Core-Services-Lifespan-Planning-Guide.pdf)** <http://www.autism-society.org/wp-content/uploads/2014/04/National-Outcomes-Core-Services-Lifespan-Planning-Guide.pdf>

**[Autism Society Strategic Plan:](http://www.autism-society.org/wp-content/uploads/2014/04/ASA-Strategic-Plan-2016-2020-v1-short-5.pdf)** <http://www.autism-society.org/wp-content/uploads/2014/04/ASA-Strategic-Plan-2016-2020-v1-short-5.pdf>

# ADVOCACY AND PUBLIC POLICY



## **National Statement on Policy**

As a mission-based organization, the Autism Society represents individuals and families living with autism and partners with organizations to support people with intellectual and developmental disabilities (I/DD). We believe each family and the individual with autism should have the right to learn about and then select the options they feel are most appropriate for the individual with autism. By connecting people to policy, the Autism Society relies upon a network of self-advocates, parents, guardians, family members, professionals and other partners to respond to issues across the lifespan. The Autism Society actively promotes nonpartisanship and we work across both ends of the political spectrum. We are currently focused on education, employment, family caregiving, Medicaid, social security and community living and for upholding fundamental human rights.



# ADVOCACY AND PUBLIC POLICY – NATIONAL PRIORITIES

**Education:** Promote creation of school communities in which all students are welcome, safe, and valued, with appropriate supports to participate alongside their peers. Youth with disabilities need a seamless and successful transition into post-secondary education, employment or meaningful day activities. School communities should ensure that children reach their full potential by embracing diversity among all learners, providing flexible learning and assessments, and laying the foundation for education equity in all aspects of students' lives.

**Community Living and Housing:** Encourage expansion options for housing and community living, as well as long-term supports. Services should be individualized to the needs of the person with a disability and reflect the choices, desires, and culture and ethnic needs of that person, in conjunction with his or her family when necessary.

**Employment:** Seek to increase the employment rate for people with autism. Presume that they are all capable of competitive employment, community service, volunteerism or appropriate day activities. Promote creation of programs to build capacity for providing employment to every person who desires it.

**Family Caregiving:** Advocate for the expansion of federal, state and local initiatives that provide a comprehensive family caregiving support system. Increase funding for respite and other critical family support programs that provide a safety net for family caregivers across the lifespan.

**Human Rights:** Strive to protect inalienable human and civil rights of people with autism to live freely, without the risk of harm. Actively promote abolishing the use of aversive processes, stigmatization, and abuse and neglect by supporting protective policies and legislation.

**Health Care:** Expand access to high quality, comprehensive, accessible and affordable health care services for all persons with autism. Maintain diverse, flexible insurance options to meet complex care needs of individuals living with autism.

**Medicaid:** Work toward protecting and maintaining the lifeline and entitlement of a full range of Medicaid health and long-term supports and services for individuals with disabilities. Aim to safeguard federal state open-expenditure sharing partnership and reject efforts to restructure an essential lifeline for people with autism and other disabilities.

**Social Security & SSDI:** Make every effort to maintain the solvency of Social Security while preserving the program's structure and functioning. Social Security should continue to function as a government-administered entitlement program without privatization.

# ADVOCACY AND PUBLIC POLICY – POSITION STATEMENTS

*To read all our national position statements regarding advocacy and public policy, please refer to the links below:*

**National Position Statement on Education:** <http://www.autism-society.org/about-the-autism-society/national-position-statements/national-position-statement-education/>

**National Position Statement on Community Living and Housing:** <http://www.autism-society.org/about-the-autism-society/national-position-statements/national-position-statement-community-living-housing/>

**National Position Statement on Employment:** <http://www.autism-society.org/about-the-autism-society/national-position-statements/national-position-statement-employment/>

**National Position Statement on Family Caregiving:** <http://www.autism-society.org/about-the-autism-society/national-position-statements/national-position-statement-family-caregiving/>

**National Position Statement on Human Rights:** <http://www.autism-society.org/about-the-autism-society/national-position-statements/national-position-statement-human-rights/>

**National Position Statement on Health Care:** <http://www.autism-society.org/about-the-autism-society/national-position-statements/national-position-statement-health-care/>

**National Position Statement on Medicaid:** <http://www.autism-society.org/about-the-autism-society/national-position-statements/national-position-statement-medicaid/>

**National Position Statement on Social Security:** <http://www.autism-society.org/about-the-autism-society/national-position-statements/national-position-statement-social-security/>

# ADVOCACY AND PUBLIC POLICY - 2016 HIGHLIGHTS



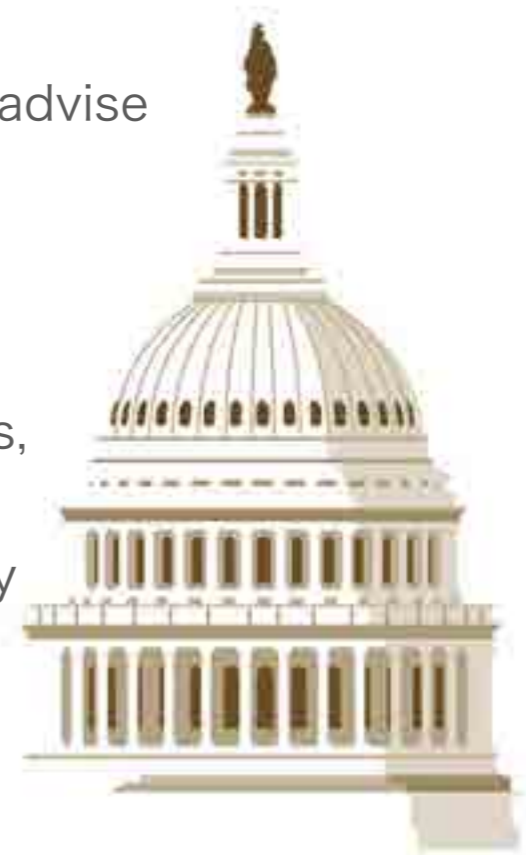
In 2016, the Autism Society of America made great strides toward improving outcomes for people living with autism. Public policy priorities for the organization in 2016 included:

- Advocate for federal initiatives that recognize the need for comprehensive family supports while ensuring that any such initiatives recognize they cannot be a substitute for creating a national solution to provide appropriate long-term supports and services for person with disabilities.
- Advocate for healthcare coverage that provides people with disabilities with access to services and technologies they need to engage in community life.
- Strengthen the relationship between the autism and aging communities in establishing and creating home and community-based supports.

# ADVOCACY AND PUBLIC POLICY - 2016 HIGHLIGHTS

## Program Service Accomplishments:

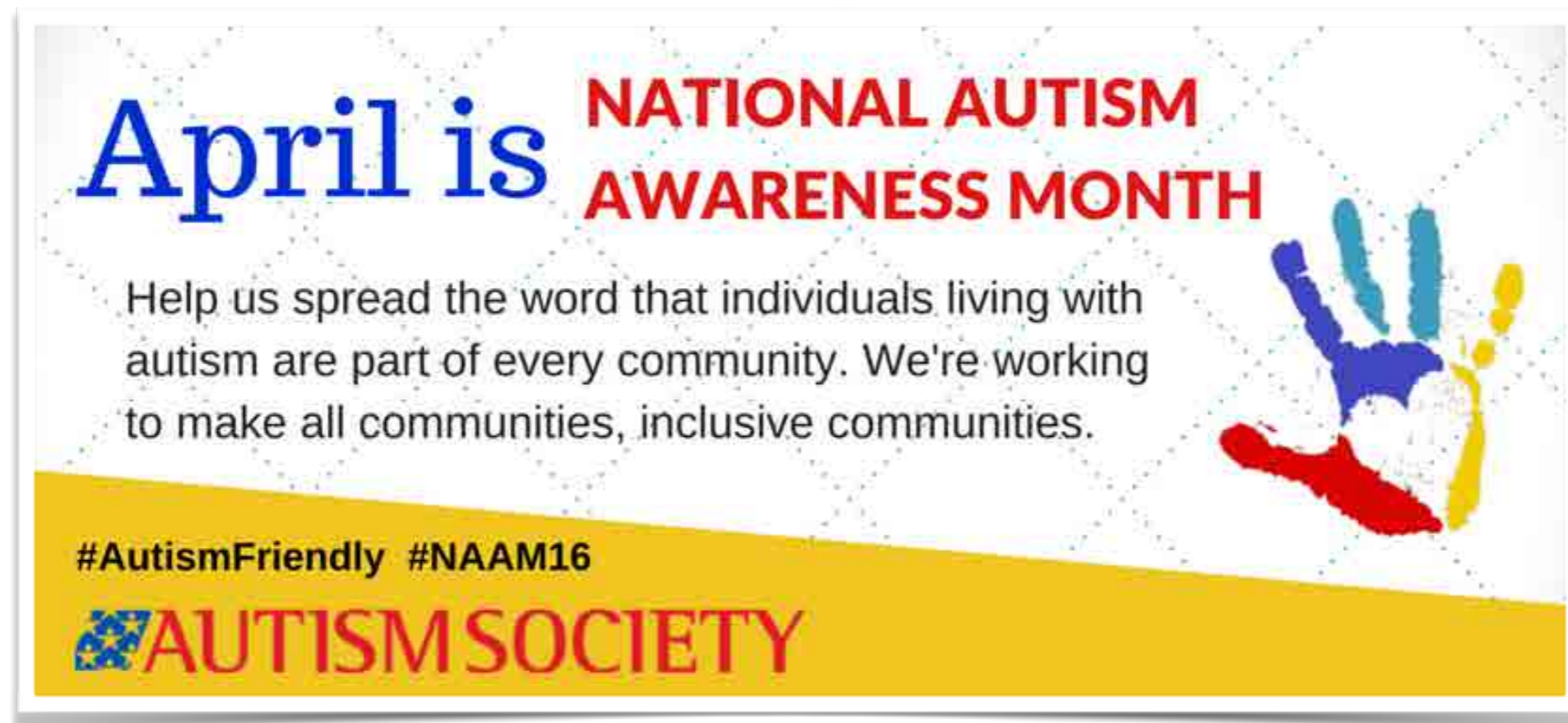
- [Kevin and Avonte's Law of 2016](#) introduced to provide funds for competitive grants to healthcare agencies, state and local law enforcement agencies, public safety agencies, and nonprofit organizations to assist in planning, establishing or operating programs to prevent wandering and to locate missing individuals with developmental disabilities and forms of dementia.
- [RAISE Family Caregivers Act](#) introduced to bring together relevant federal agencies, private and public sectors, family caregivers, older adults and persons with disabilities, state and local officials, an advisory council to advise and make recommendations regarding the national strategy and lay the groundwork for a national family caregiver network.
- Launched Autism Society of America's **Public Policy Advisory Committee (PPAC)**, consisting of national staff, affiliate representatives, board, partner organizations, parent volunteers, and policy subject matter experts, to shape, guide and advance public policy and advocacy programs and initiatives.



# RAISING AWARENESS, ACCEPTANCE AND APPRECIATION

Raising awareness of autism is part of everything we do. The Autism Society founded National Autism Awareness Month, which helps focus attention on autism in April every year. The United States recognizes April as a special opportunity for everyone to educate the public about autism and issues within the autism community and foster acceptance and appreciation of individuals on the autism spectrum as the valued members of our community that they are. The Autism Society is also the home of the Autism Awareness Puzzle Ribbon, one of the most recognizable cause-related symbols.


In 2016, the Autism Society of America and its Affiliates served a combined 138,615 individuals through Community programs (walks/runs/bikes, summer camps, community events, and sensory friendly events like film screenings and holiday parties) and 50,938 through Education (conferences, webinars, workshops, and first responder training).

A promotional poster for National Autism Awareness Month. The background is white with faint, dotted outlines of puzzle pieces. The text 'April is' is in a large, blue, serif font, followed by 'NATIONAL AUTISM AWARENESS MONTH' in a bold, red, sans-serif font. Below this, a message in black text reads: 'Help us spread the word that individuals living with autism are part of every community. We're working to make all communities, inclusive communities.' To the right of the text is a colorful handprint graphic with fingers in blue, teal, yellow, and red. At the bottom, a yellow banner contains the hashtags '#AutismFriendly #NAAM16' and the Autism Society logo, which consists of a blue square with white puzzle pieces and the text 'AUTISM SOCIETY' in red, bold, sans-serif font.

**April is** **NATIONAL AUTISM AWARENESS MONTH**

Help us spread the word that individuals living with autism are part of every community. We're working to make all communities, inclusive communities.

#AutismFriendly #NAAM16

 **AUTISM SOCIETY**

# EDUCATION AND TRAINING



In 2016, the Autism Society hosted its 47th National Conference and Exposition in New Orleans, Louisiana. The conference uniquely addresses autism and its comprehensive issues, which include early intervention, education, employment, communication, social skills, and other issues across the lifespan. With nearly 1,000 in attendance, our three-day conference provided individuals, families, affiliate leaders and professionals an opportunity to hear keynote speakers such as Steve Silberman, John Donvan and Caren Zucker, and more. Attendees could choose from over 100 breakout sessions on topics of interest to those impacted by autism. Over 60 companies and organizations that provide autism-related supports and services participated in our Exposition. Bringing together the expertise and experiences of family members, professionals and individuals on the autism spectrum, attendees are able to learn how to effectively advocate and obtain supports for the individual with autism.

The evaluations from those attending the conference once again showed that this conference, the oldest and longest running national conference is highly valued in terms of networking, information gathering and learning.

# COMMUNICATIONS

In 2016, the Autism Society of America continued the ongoing efforts of making sure that individuals and families impacted by autism were informed about issues impacting their well being.



## Autism Advocate digital magazine archive

The Autism Society maintains a digital archive of the Autism Advocate (our flagship digital magazine) on its website. The magazine offered a diverse collection of the latest issues in autism (e.g., employment, education, environmental health, therapies/interventions, adult issues, caregiving, etc.), Autism Society news, personal perspectives of families and individuals living with autism, and tips from parents and professionals.



## Autism Matters E-newsletter

Autism Matters is the Autism Society's free monthly e-newsletter, sent to over 100,000 members and supporters with the latest updates on news, advocacy, research, education, conferences and resources. [Sign up for Autism Society's free e-newsletter.](#)



## Autism Society Action Alerts

The Autism Society is active in the public policy arena and encourages our members to get involved and take action on important issues through Action Alerts on our website and in our online newsletter. Our action alerts inform constituents with autism, family members, professionals, organizational partners, and the general public about critical federal legislative activities affecting the autism community and equip advocates with essential tools to influence public policy. [Sign up to receive Action Alerts.](#)

# COMMUNICATIONS (CONTINUED)

## Social Media and Website



[Facebook](#) fans: 636,000+

[Twitter](#) followers: 91,000+



Listing of resources maintained on [www.autism-society.org](http://www.autism-society.org): 34,500+

Autism Society monthly email newsletter subscribers: 100,000+

## Resource Materials

The Autism Society offers several free publications, including our “Living with Autism” series, which offer practical information on a wide range of topics such as education, law enforcement, puberty, transition, and addressing what to do if your loved one is a victim of crime. These resources can be downloaded using Adobe Reader and are available at <https://www.autism-society.org/about-the-autism-society/publications/resource-materials/>.





# SERVICES AND SUPPORT

In 2016, the Autism Society of America's National Contact Center, which operates from 9 am to 9 pm Eastern Standard Time, five days a week and [AutismSource™](#), our national resource database accomplished the following:

- Answered calls live 78% of the time.
- Maintained a less than one day response for calls and emails.
- Comprehensive quality assurance surveys - 74% of callers anticipate their quality of life to improve after reaching out to the Autism Society.
- 80 Affiliates nationwide set up on our inquiry and resource database to serve their local communities.
- Through our national contact center and affiliate network, we served 77,071 individuals through I&R in 2016.



Free access to  
trained professionals  
9am–9pm (ET) Monday–Friday • English & Spanish

Call us for Information, Referrals & Resources.

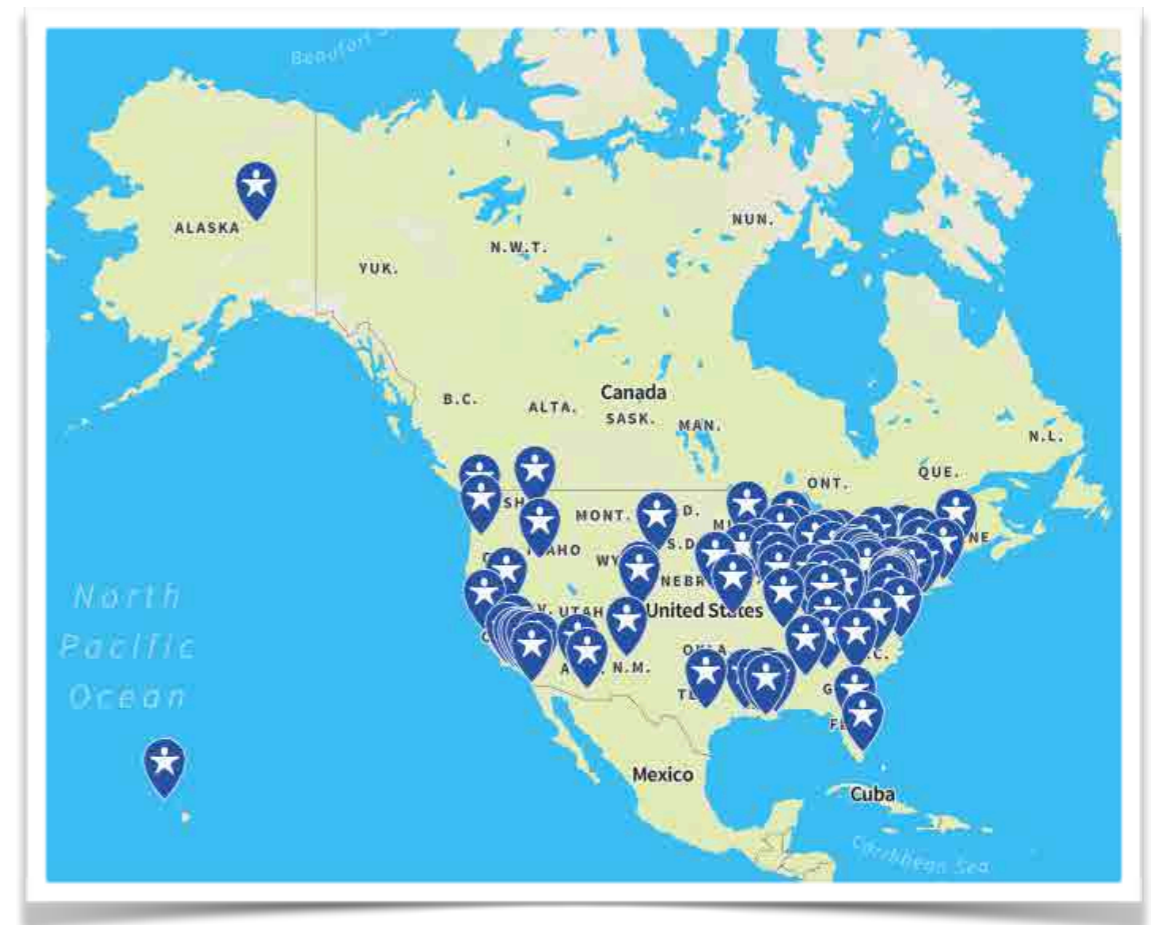
**Autism  
Source™**  
#1 in Autism Information

# AFFILIATE NETWORK

The Autism Society relies upon the tremendous work and support of our Affiliate Network. Our national network of 90 Affiliates are the primary approach through which the Autism Society helps individuals and families throughout the United States.

Each Autism Society Affiliate is its own organization with its own governing board making decisions that best support the needs of families and individuals impacted by autism in their local community. If a local community does not have an Affiliate serving its residents, the Autism Society National office supports the needs of individuals and families by providing Information and Referral services, advocacy and education.

To find your Autism Society Affiliate, please visit:  
<http://www.autism-society.org/about-the-autism-society/affiliate-network/>



# AFFILIATE NETWORK - 2016 SERVICE HIGHLIGHTS

Through the exchange of resources, problem-solving ideas, understanding personal struggles, celebrating individual successes and sharing lessons learned, Affiliates can make your journey with autism a little easier. Most Affiliates are volunteer-led by groups of parents, professionals, community leaders and individuals on the autism spectrum.

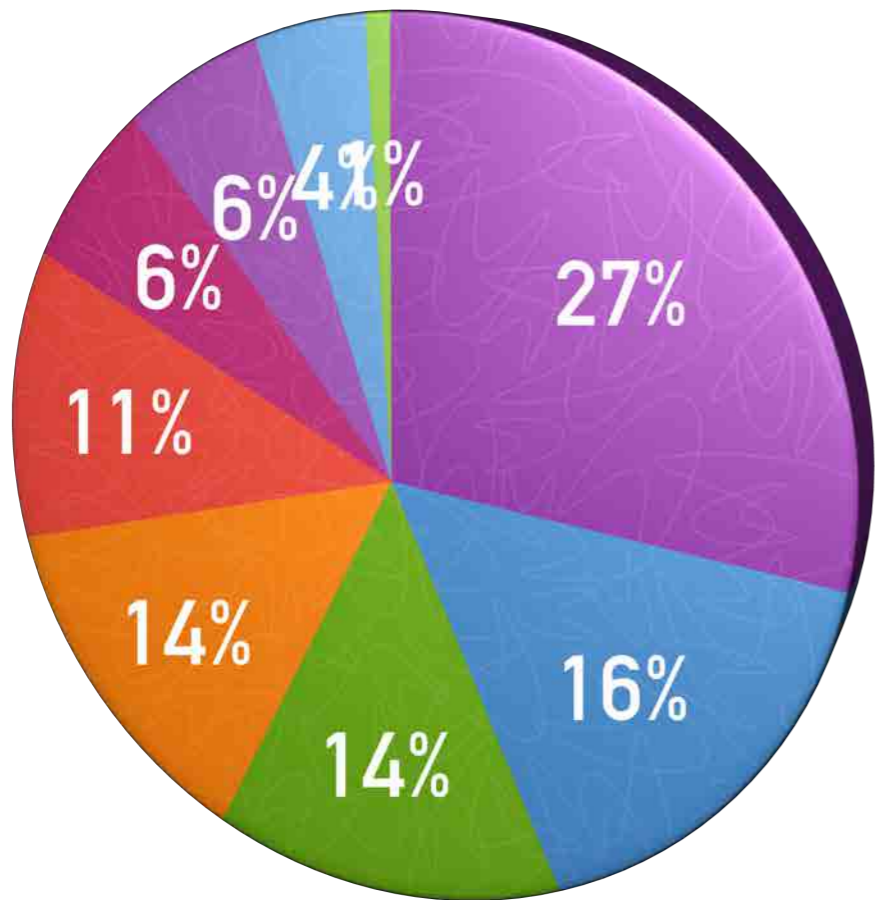


Autism Society Affiliates advance 15 [quality of life outcomes](#) through five core services. These core services include **Information and Referral, Support, Community, Advocacy, and Education.**

In 2016, The Affiliates and national combined served over 300,000 individuals. On the next page are charts that show percentages by programs and four of the five core services (does not include Advocacy). Keep reading to see how we served those individuals!

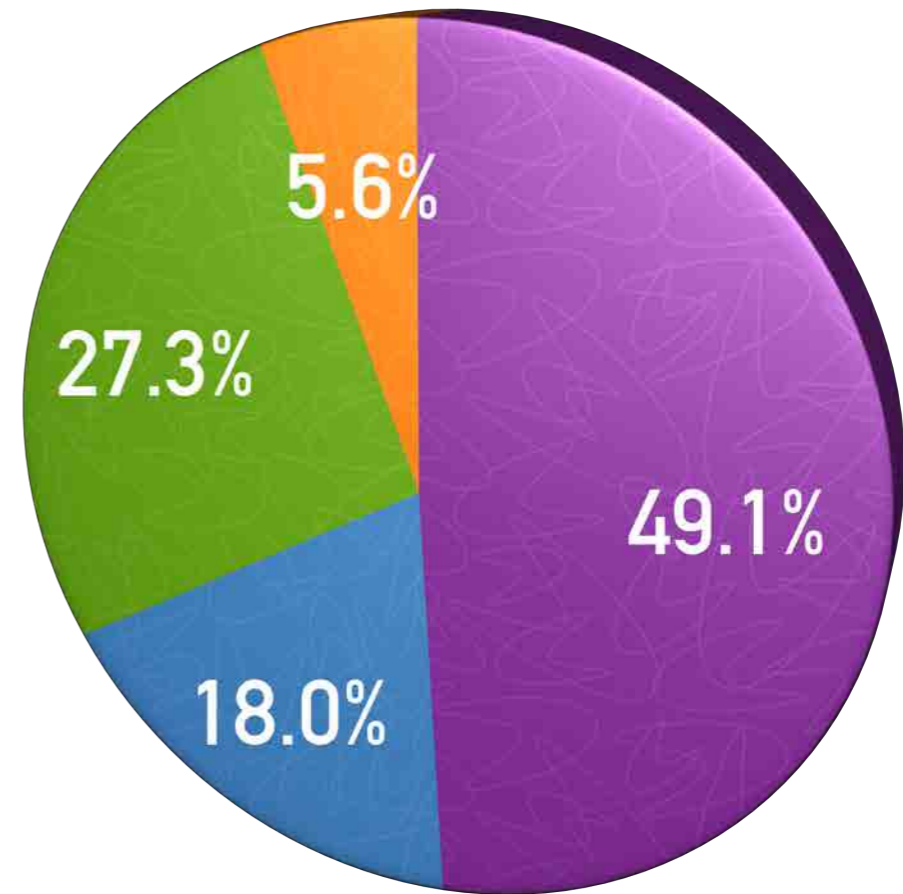
# AFFILIATE NETWORK - 2016 SERVICE HIGHLIGHTS

Percent Served By Program\*



- I & R 27.3%
- Walk/Run 16.1%
- Community Events 14.1%
- Autism Training 13.9%
- Other 11.5%
- Sensory Friendly 6.5%
- Support Groups 5.6%
- First Responder 4.2%

Percent Served By Core Services\*

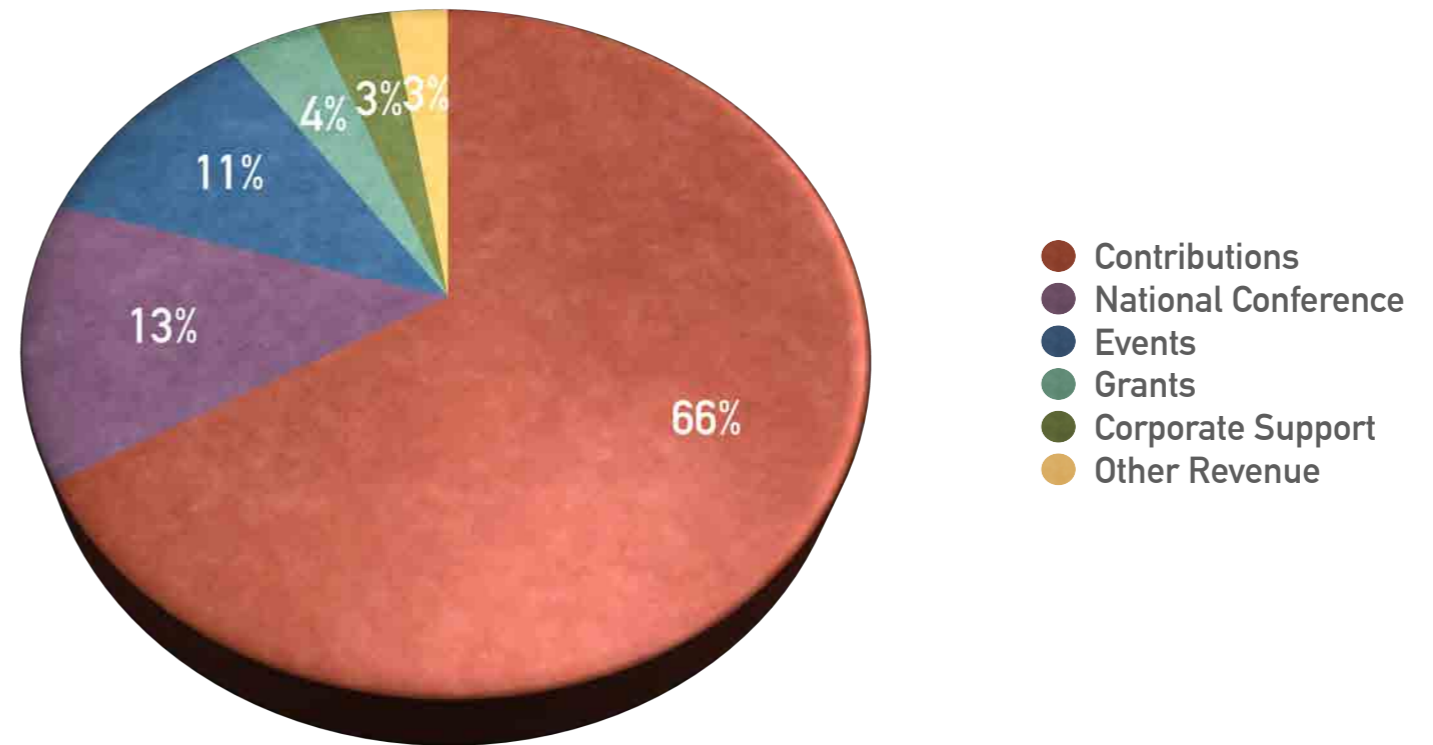


- Community 49.1%
- Education 18%
- I & R 27.3%
- Support 5.6%

\* excludes Advocacy

# 2016 FINANCIAL HIGHLIGHTS

2016 Revenue \$2.5 million

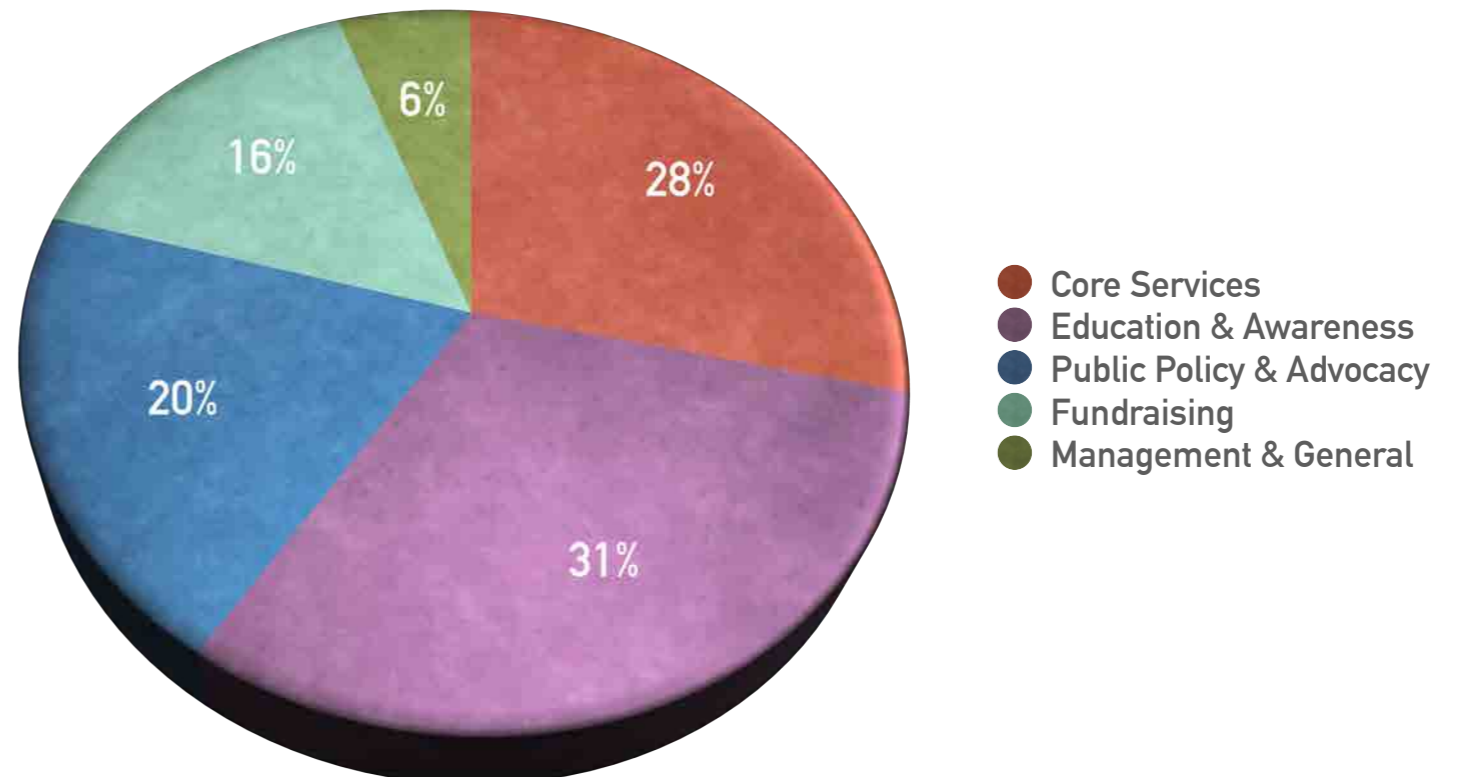


## Revenue

Contributions	\$1,641,891
National Conference	\$319,963
Events	\$68,702
Grants	\$98,000
Corporate Support	\$83,330
Other Revenue	<u>\$63,423</u>
 Total Revenue	 \$2,475,309

## Expenses

2016 Expenses \$2.4 million



### Program Expenses:

Core Services	\$671,496
Education & Awareness	\$756,605
Public Policy & Advocacy	\$476,452

### Support Services:

Fundraising	\$379,740
Management & General	<u>\$137,411</u>

Total Expenses: \$2,421,704

**Change in net assets:** 53,605

# BOARD OF DIRECTORS

The Autism Society's Board of Directors is composed of dedicated volunteer representatives, many of whom are parents of persons with autism. The Board, chaired by Joseph P. Joyce, CPCU, CWCA, serves as the governing body of the organization and sets the vision for the Society's future. Through active use of standing and ad hoc committees, the national Board carries out its goal of fulfilling the Autism Society's mission while also being responsive to the needs of its members and the autism community.

*Joseph P. Joyce, CPCU, CWCA, Executive Chair*

*Barbara Becker Cottrill*

*Honorary Board Members:*

*Lori A. Ireland, Vice Chair*

*Kevin Custer*

*Temple Grandin, Ph.D.*

*Tracey Staley, Treasurer*

*Andres Filippi*

*Ruth Christ Sullivan, Ph.D.*

*Lars Perner, Ph.D., Secretary, PSA Chair*

*John Hussman, Ph.D.*

*James Ball, Ed.D., BCBA-D, Immediate Past Chair*

*Terry Murphy*

*Scott Badesch, President/CEO*

*Kate Palmer*

*Jon Basinger*

*William Parker*

*Andrew Bauman*

*Alison Peterson*

*Richard Bohne*

*Kristyn Roth*

*Michael J. Brown, Esq.*

*Richard Wolf*

*Catherine Purple Cherry, AIA, LEED AP*

Copies of board of directors meeting minutes are available upon request.

Information about each board member, including their bio, can be found at: <http://www.autism-society.org/about-the-autism-society/boardadvisors/board-of-directors/>

## Better Business Bureau Designation

The Autism Society and its affiliates meets all 20 Better Business Bureau (BBB) Wise Giving Alliance Standards for Charity Accountability. The BBB Wise Giving Alliance is a national charity monitoring organization affiliated with the Better Business Bureau system.



*The Autism Society appreciates its many donors and volunteers who help us fulfill our mission of improving the lives of all affected by autism. Together, we are stronger.*



Autism Society

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[www.autism-society.org](http://www.autism-society.org)