

OUR ROOTS, OUR RIGHTS

AUTISTIC SELF ADVOCACY NETWORK
2017 ANNUAL REPORT



Our Mission.

The Autistic Self Advocacy Network seeks to advance the principles of the disability rights movement with regard to autism. ASAN believes that the goal of autism advocacy should be a world in which autistic people enjoy equal access, rights, and opportunities. We work to empower autistic people across the world to take control of our own lives and the future of our common community, and seek to organize the autistic community to ensure our voices are heard in the national conversation about us.

Nothing About Us, Without Us!

Contents.

EMPOWERING OUR GRASSROOTS	3
DEFENDING OUR HEALTHCARE	5
BOLSTERING INDEPENDENCE	7
THE MAKING OF A MOVEMENT	9
FOSTERING LEADERSHIP	11
BUILDING COMMUNITY POWER	13
FINANCIAL SUMMARY	15
MAKING IT ALL POSSIBLE	17

Executive Director's Message

Dear Friends,

What a year! 2017 has been a year of major battles, terrifying stakes, and hard-won victories for the disability community. We've been forced to refocus and rededicate ourselves to the core of our movement, fighting to protect our most basic rights to life, liberty, and the pursuit of happiness—and the health care and Medicaid services that make it all possible.

We came together in a way we haven't since the ADA. We called elected officials repeatedly, put our bodies on the line in protest, and got the word out on social media. We fought like our lives depended on it—because, for so many of us, they did. We came together, and together, as a community, defeated the efforts of an enemy much larger than any one of us.

We know that more fights lie ahead. The Affordable Care Act is already under attack again, and multiple bills making their way through Congress threaten the ADA. Cuts to Medicaid are the go-to way to pay for any kind of tax cut, and it is still legal to pay people with disabilities less than minimum wage for our labor. The autistic community faces huge rates of violence, suicide, and incarceration. And beyond our community, there are constant assaults against the very idea of civil rights. We must stand in solidarity with other communities under siege, because they are us, too. Autistic people can be people of color, LGBT, immigrants, and any number of other intersecting and overlapping identities. We must work to remember all of our community as we go forward, and speak out when policies threaten certain facets of our community disproportionately.

But we have done what many considered impossible, and emerged from this year stronger than ever before. The victory against ACA repeal and the continued survival of Medicaid, against incredible odds, shows that our community is up for the challenges that lie ahead. So we will keep doing the impossible, for as long as it takes. Because it is right. Because it is necessary. Because it is what we deserve.

Because, when it come to our rights, there will be *nothing about us, without us!*



Julia Bascom
Executive Director
Autistic Self Advocacy Network

Empowering our grassroots.

2017 saw a groundswell of first-time political engagement from Americans at the grassroots level, banding together to push for change on the issues that impact our communities. **We made sure that people with disabilities were central to the conversation.**

Access is a Civil Right

Too often, disabled people **are shut out of conversations** about the policies that directly affect us. Policies are discussed in technical language we can't understand, and many resources intended to help people understand these policies **are still not accessible.**

This year, ASAN pioneered publishing Easy Read policy materials—because when we say *nothing about us without us*, **we really mean it.**

Medicaid for Self-Advocates

Medicaid is the biggest health care program in the country—**and the only way many of us can access the supports and care that we need.**

But Medicaid is a complex system, and resources explaining it are often jargon-filled and inaccessible.

Our community has the most at stake when changes to Medicaid policy are proposed. Our input is critical, **but we can't speak up if we don't understand what's going on.** This year, ASAN tried something that hasn't been done before - we explained Medicaid and its complexities in an Easy Read format, enabling self-advocates to be a part of the national conversation.

This has been our most successful resource yet—since being released in May, **the toolkit has been downloaded more than 39,000 times.**

Getting Through to Our Elected Officials

Efforts to boost civic engagement **often exclude disabled people**—either by overlooking the particular barriers our community faces, or by simply failing to include us in outreach campaigns.

In February, we released an Easy Read toolkit on civic engagement, along with stand-alone fact sheets on calling, writing, and visiting your elected officials. We also introduced Sally Jones, a fictional resident of Normaltown, California, and her advocacy campaign to #StopTheBees. The story of Sally Jones and the swarms of angry bees plaguing her hometown is woven throughout our toolkit “They Work For Us: Getting Through to Your Elected Officials.” Find out more at stopthebees.com.

Illustrating ACA Repeal

When news broke that Congress planned to repeal the Affordable Care Act, advocacy and news organizations began publishing introductory resources on the ACA. These resources emphasized the devastating impact repeal would have on people with disabilities—but **they weren’t designed with us as a target audience**.

ASAN’s plain language Affordable Care Act Toolkit for Self-Advocates was designed **to break down complex issues in the most accessible way possible**. It includes a series of comic strips illustrating the answer to an important question: “What’s The Problem with Repeal and Delay?”

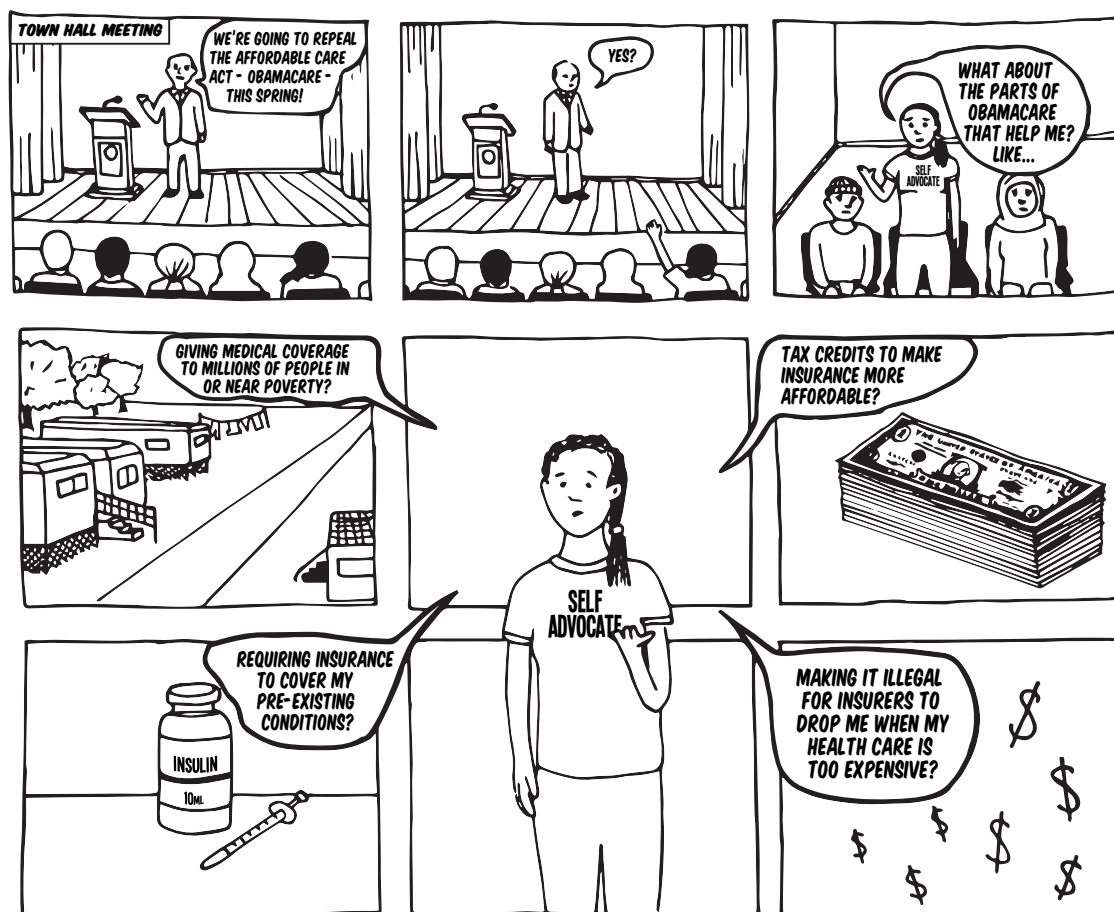


ILLUSTRATION BY PIP MALONE

Defending our health care.

Health care is a human right—and attacks on our health care system inevitably target disabled people. **This year, we went all out to fight back against attempts to destroy health care in America.**



#ProtectOurCare

The best way to bring legislators' attention to an issue **is to ensure that they can't ignore it.** This summer, we joined other organizations involved in the #ProtectOurCare campaign to give you as many ways as possible to speak out.

We released postcard and letter templates that grassroots advocates could use to contact their Members of Congress.

We also held an **accessible online phone bank**, which matched disabled advocates who can't use phones with volunteers who called Congressional offices on their behalf.

Setting the Tone

In response to vicious attacks on the American health care system, **the disability community formed a united front** to push back.

Along with a handful of other key disability rights organizations, **ASAN led the disability community** in a multi-pronged strategy that included grassroots activism, communication with policymakers, and working with groups outside the disability community to #SaveMedicaid.

Mobilization & Communication

ASAN reached an audience of 68,000+ people through our mobilization efforts to defend health care. We recognize the diversity of our community and the multitude of barriers faced by people with disabilities, so our calls to action included options and scripts for a broad audience—including users of augmentative and alternative communication methods.

We're not done.

We'll say it as many times as it takes:
health care is a human right.

Advancing the rights of people with disabilities is our mission, and **we will not back down.** With you on our side, we'll win this fight as many times as we have to.

Bolstering independence.

Independence is a fundamental American value. For people with disabilities, independence means exercising our right to self-determination, making decisions about our own lives, and accessing the supports we need to live the lives we want to live. **ASAN continues to fight back against efforts to deprive disabled people of our independence.**

The Right to Make Choices

Disabled people under guardianship do not have the same rights as other adults. While guardianship takes away choices from people with disabilities, **supported decision-making respects our agency and self-determination.**

This year, ASAN continued to promote supported decision-making as an alternative to guardianship, whether we were presenting webinars on medical decision-making, or speaking at the United Nations. **Advocating for supported decision-making will remain one of ASAN's top priorities** until disabled people have equal rights worldwide.

Dispelling Dangerous Myths

Disabled people are often presumed to be incompetent, dangerous, or both. But research shows that people with disabilities are **much more likely to be the victims—not the perpetrators—of violence.**

This year, we advocated for Congress to reverse a regulation that would have prevented some people with disabilities from buying guns. This regulation would have prevented people who get support managing their SSI/SSDI payments from passing a background check.

We were ultimately successful, and **we will continue to fight back attempts to criminalize disability** based on stereotypes, fear, or political convenience.

Everybody Communicates

People with disabilities have a right to effective communication. In October, we released our new toolkit called 'Everybody Communicates: a toolkit for accessing communication assessments, funding, and accommodations.'

With the right tools, **everyone can advocate for themselves**—from health care, to housing, to everyday decision-making.

Autism & Safety

Autistic people have the right to be safe and live independently in our communities. We also face significant threats to our safety, including higher rates of abuse, institutionalization, suicide, and police violence.

Too often, autistic voices have been erased from conversations about autism and safety—so this year, ASAN published our Autism & Safety Toolkit. The toolkit describes safety risks we face, discusses different ways to address them, and debunks myths about safety that are sometimes used to curtail our independence and access to the community.

“Independent living is not doing things **by yourself**. It is **being in control** of how things are done.”

—*Judy Heumann*

The Making of a Movement

1970

Judy Heumann formed **Disabled in Action** in New York City

1972

First **Center for Independent Living** founded in Berkeley, California

1973

The Rehabilitation Act, an important disability rights bill, was signed into law.

1977

Disability rights activists staged the **longest occupation of a federal building in U.S. history**, calling for implementation of Section 504 of the Rehabilitation Act, which prohibits federally funded programs from discriminating against disabled people—the **sit-ins ended in victory**

1983

ADAPT began its national campaign for wheelchair lifts on buses and access to public transit for people with disabilities

1999

The Supreme Court ruled in *Olmstead v. LC* that people with disabilities have the right to get support services in our own communities **instead of being institutionalized**

2006

The Autistic Self Advocacy Network was founded by autistic self-advocates **in response to the lack of representation** of autistic voices in national conversations about autism

"The greatest lesson of the civil rights movement is that the moment you let others speak for you, you lose."

—Ed Roberts

1974

Self-advocates with developmental disabilities organized **the first People First convention** in Oregon

1975

Congress enacted EAHCA, today known as the Individuals with Disabilities Education Act (IDEA)

1988

Deaf students at Gallaudet University in Washington, D.C. **led the Deaf President Now movement**, resulting in the appointment of the first deaf president in Gallaudet's history

1990

The Americans with Disabilities Act was signed into law by President George H.W. Bush

2010

The Affordable Care Act was signed into law by President Barack Obama, **prohibiting insurers from discriminating against people with disabilities**

2017

Coordinated advocacy by disability rights activists across the nation **defeated three separate attempts by Congress** to repeal the Affordable Care Act and defund vital disability services

Fostering leadership.

Some of the greatest achievements of the early disability rights movement blossomed out of campus-level activism by disabled self-advocates. We're committed to building on the legacies of these pioneers **by supporting a new generation of student self-advocates.**

Autistic Scholars Fellowship

The Autistic Scholars Fellowship awards tuition scholarships to autistic college students showing a strong commitment to disability rights advocacy and strengthening autistic culture and community. This year, **we gave out \$20,000 in scholarships** to our second cohort of Autistic Scholars:

Christopher Uzzell

State University of New
York at Purchase

CD Highland

University of Nebraska –
Lincoln

Shannon Deyong

Oklahoma State University

Lucy Michaela Ryan

Tulane University



“[ACI] was the first place I was able to embrace **all of my identities** at the same time and not prioritize one over another.

I left ACI with so much more than I got there with...

I learned that while my advocacy looks different than what others expect, **I’m still making a difference** by doing the work I do and just by existing.

ACI gave me myself back and I now live with no shame for the person I am.”

—*Dai Guerra,*
ACI 2017 alumnus

Autism Campus Inclusion

In June, we brought 18 rising autistic leaders from 11 states and Canada to our nation’s capital for our annual Autism Campus Inclusion leadership academy.

During the week, we provided training and tools to take back to their home states and their campuses.

With the skills they have learned, our ACI alumni can change their communities—**and the world.**

Building community power.

Our community is the bedrock of our advocacy work. Recognizing that our struggles are interlinked, **we join forces with other civil rights groups and movements**—and the events of this year have proven that we are strongest when we speak out together. But our strength and power as self-advocates aren't built by political actions alone. Because we work to create a shared history, culture, and future that belongs to all autistic people, our community continues to build momentum until we're absolutely unstoppable.

Preserving Our Collective Memory

Each year on March 1st, the disability community comes together to remember disabled victims of filicide—disabled people murdered by their family members or caregivers.

2017 was our 6th year of holding vigils for the Day of Mourning. We had 39 vigil sites across the US, Canada, and Australia as well as a livestreamed virtual vigil.

The annual Day of Mourning is a somber occasion with a powerful purpose: **to assert that our humanity will not be denied in life or in death.**

Acceptance, Not “Awareness”

Autism Acceptance Month is about treating autistic people with respect, listening to what we have to say about ourselves, and making us welcome in the world. But this April, **the White House tried to reverse the progress we have made** by participating in the Autism Speaks: Light It Up Blue campaign and calling for a “cure” for autism.

ASAN released a statement that made one thing very clear: autistic self-advocates have been successful in reshaping the national conversation about autism, **and we refuse to go back.**

FAST FACT:

This year, ASAN became a member organization of the Leadership Conference on Civil and Human Rights—a broad coalition of **more than 200 national civil rights organizations**.

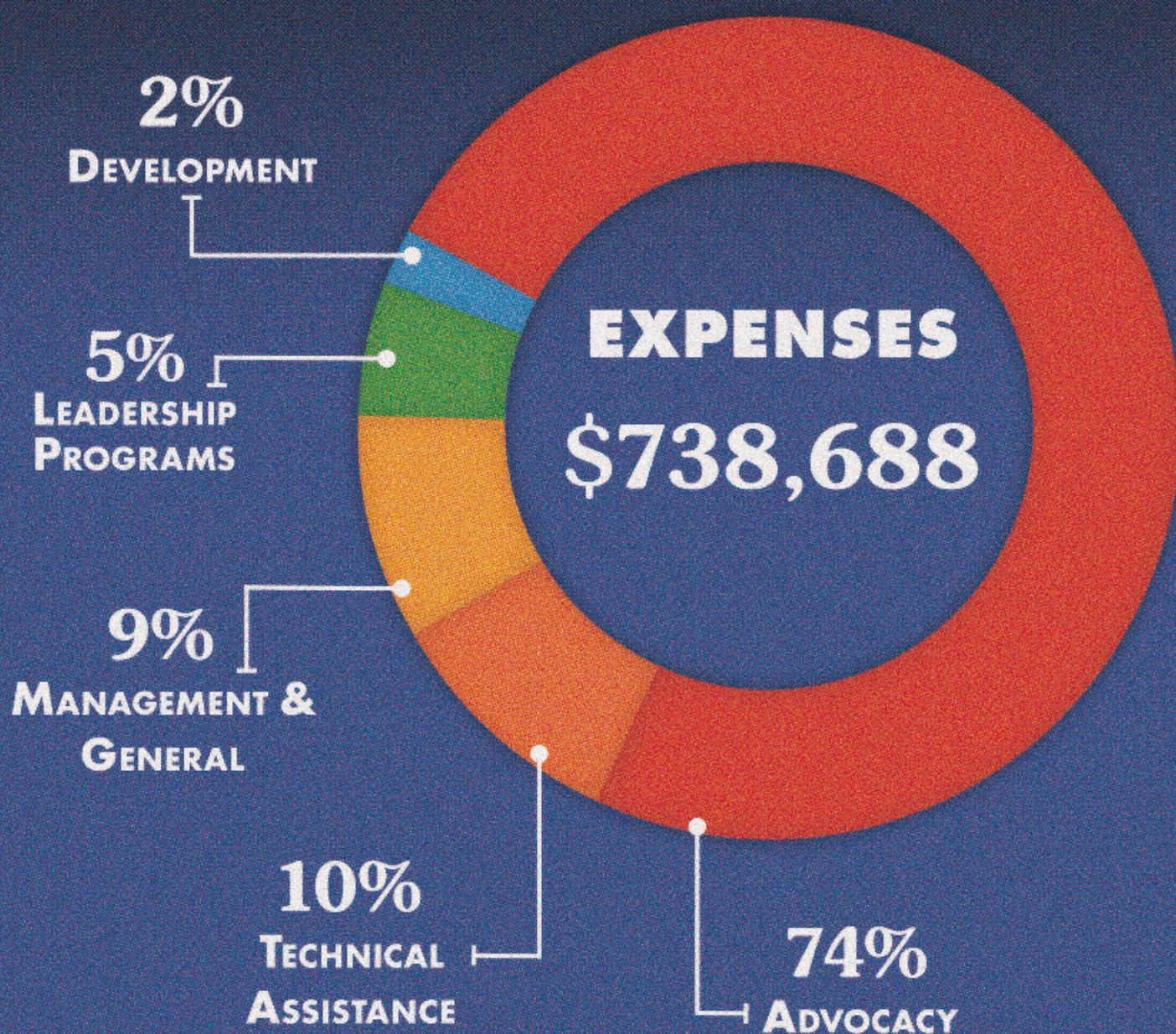
An Injury to One is an Injury to All

Any attack on a civil rights law is an attack on all civil rights—and 2017 has seen renewed attacks on civil rights across the board. In response, **we've joined forces with other civil rights organizations** inside and outside the disability community, on issues like Cabinet appointments, health care, DACA, and the federal budget.

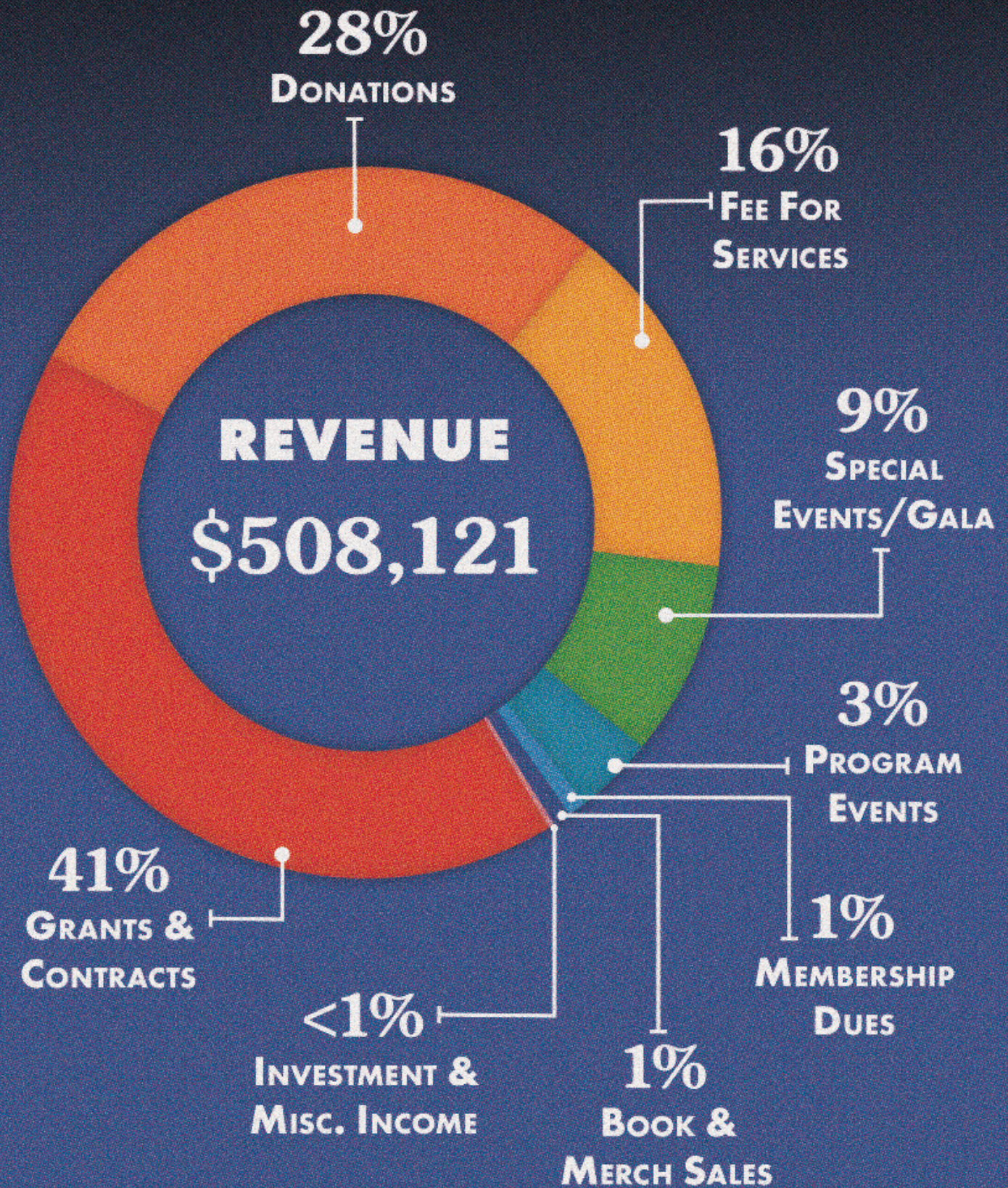
Autistic people are people of all genders, people with other disabilities, people of color, people of all faiths, LGBT people, and immigrants.

ASAN is an organization for all autistic people, and that means **intersectionality and solidarity must be at the heart of the work that we do.**

2016 Financial Summary



ASAN receives multiple multi-year grants which are paid out over the course of several years. The IRS, however, requires that all funding must be reported the year it is awarded, as opposed to the year it is actually spent. This can make our funding appear unbalanced year-to-year. 2016 was the final year for several multi-year grants for ASAN. Those revenues were reported in previous years.



Making it all possible.

We need your help to...

- ▶ **KEEP FIGHTING** for equal health care coverage
- ▶ **PROMOTE** alternatives to guardianship
- ▶ **COMBAT** abusive “therapies” used on autistic people
- ▶ **FIGHT** for communication access
- ▶ **MAKE** activism more accessible by expanding our library of plain language toolkits for self-advocates

SUPPORT OUR WORK

Our members make it possible for us to quickly mobilize in response to attacks on the civil rights of disabled people.

JOIN US AS A MEMBER by visiting autisticadvocacy.org/join.

To make a **TAX-DEDUCTIBLE DONATION** to the Autistic Self Advocacy Network, go to autisticadvocacy.org/donate.

SHOP ONLINE at the ASAN store at autisticadvocacy.org/shop.

TO GIVE BY MAIL, make a check payable to Autistic Self Advocacy Network and send it to:

**PO BOX 66122
WASHINGTON, DC 20035**

For more information about other giving options, contact Jean Winegardner at jwinegardner@autisticadvocacy.org.

TAKE ACTION

We rely on our grassroots. You can view current and past action alerts at autisticadvocacy.org/action, or get them sent straight to your inbox by signing up at autisticadvocacy.org/newsletter.

STAY CONNECTED

Our members make it possible for us to quickly mobilize in response to attacks on the civil rights of disabled people.



/AutisticAdvocacy



@AutSelfAdvocacy



@AutisticSelfAdvocacy

Acknowledgements

BOARD OF DIRECTORS

SARAH SCHNEIDER, Chair

MORÉNIKE GIWA ONAIWU,
Vice-Chair

MEG EVANS, Secretary

DAVID PATE, Treasurer

KATIE MILLER

AMY SEQUENZIA

ARI NE'EMAN

REYMA MCCOY MCDEID

STAFF

JULIA BASCOM, Executive Director

SAMANTHA CRANE, Legal Director
& Director of Public Policy

ZOE GROSS, Director of Operations

IAN THE BELISLE DEMPSEY,
Publications & Communications
Coordinator

KELLY ISRAEL, Policy Analyst

REID CAPLAN, Leadership Programs
Coordinator

NOOR PERVEZ, Community
Engagement Coordinator

JEAN WINEGARDNER, Office
Manager

FINN GARDINER, Regional Policy
Analyst

Thank you to everybody who volunteered to be a Day of Mourning vigil site coordinator.

ASAN would like to express our deepest gratitude to our funders of the ASAN Autistic Scholars Fellowship, Michael and Chelsea Leger.

ASAN is very proud to be financially supported by so many members of our community. We're incredibly grateful to each of you for supporting us, not just with your actions, but with your hard-earned money for the past 11 years. Each and every donation, no matter how large or small, makes it possible for us to continue fighting for equal rights for all people with disabilities.

Thank you to our sustaining donors, who set up monthly recurring donations to support ASAN and the work we do. Your ongoing support plays a big role in both the plans we make and the projects we can take on every year.

