

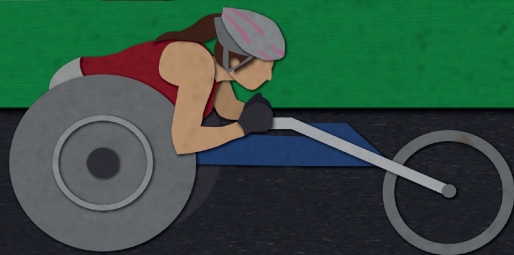
Our Movement Is A Marathon



ASAN

AUTISTIC SELF ADVOCACY NETWORK

2018 ANNUAL REPORT



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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!

From the Desk of the Executive Director



ASAN

AUTISTIC SELF ADVOCACY NETWORK

Dear friends,

“It’s a marathon, not a sprint,” is something we’ve said to each other a lot over the past two years, as we watched threats to our community emerge faster than we could respond. The battles we have faced have been overwhelming at times. Thinking of our work as a marathon—as part of a long history of advocates passing the baton to each other as we fight for our rights over generations—helps us get through times when we were pushing uphill with no end in sight.

Most of us at ASAN don’t actually run marathons, but we are reliably told by those who do that you need to train for them for a very long time, developing strength, skill and stamina as you go. For ASAN, the last several years have been all about building our power, showing up to every fight with better tools, more partners, a wider reach, and a louder voice.

And throughout the whole long course of this marathon, we have sustained each other and cheered one another on. We celebrate our milestones and lift one another up, because we know that this isn’t just about sweat and lactic acid and pulled muscles and pain. This is about embracing and celebrating the strength and grit and beauty of our community, no matter how hard the course we run may be. Our movement is, and must always be, a uniquely and powerfully autistic movement, and our Autistic Movements—our stims, our precision, our passion, and our perseverance—are what will see us home and carry us through.

The finish line is not yet in sight, but we’ve never been more determined. We’ve come farther than we ever thought possible. We have miles left to go. We’ll get there—together.

ON YOUR MARKS, GET SET...

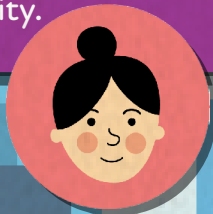
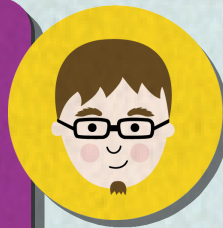
Julia Bascom
Executive Director, Autistic Self Advocacy Network



AUTISTIC VOICES

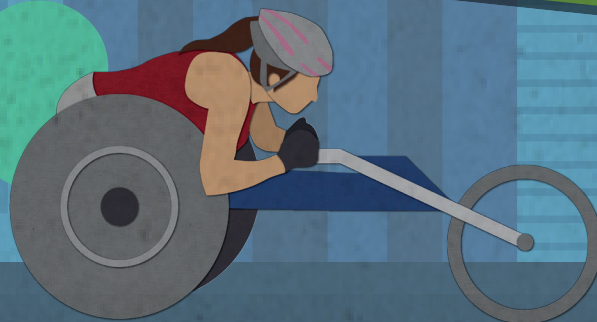
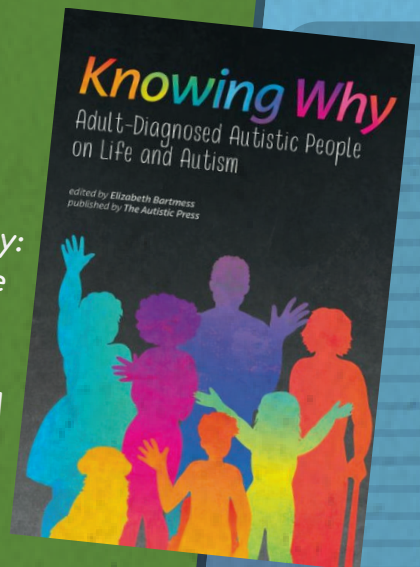
Nothing About Us Without Us

The Interagency Autism Coordinating Committee (IACC) is a federal committee that coordinates federal-level efforts related to autism. Our Legal Director and Director of Public Policy, Sam Crane, sits on the IACC. In addition, ASAN submitted comments this year about how the IACC should prioritize its efforts to better align with the needs of our community.



Knowing Why

This year, ASAN's in-house micropress, The Autistic Press, worked with editor Elizabeth Bartmess to publish a new anthology entitled *Knowing Why: Adult-Diagnosed Autistic People on Life and Autism*. This collection gathers essays from a diverse group of adult-diagnosed autistic people, including ASAN's own Board Vice-Chair Morénike Giwa Onaiwu.





Community Living Summit (May 2018)

Community Living is a top priority for our community, but conversations about community living policy and research still often leave out the voices of self-advocates. In May, we invited 10 autistic self-advocates to a summit on community living. During the summit, we worked to:

- ★ develop a definition of community living created solely by autistic people ourselves
- ★ figure out what autistic people need in order to live in the community
- ★ create a series of research questions and recommendations that could be used by researchers and policymakers to improve housing options and the quality of home- and community-based supports for autistic people.

A series of Easy Read reports based on the summit will be coming out in 2019.

Communication Is A Human Right

The right to communicate is a critical tool necessary for the free exercise of all other rights, including self-determination and self-advocacy. Non-speaking people have a right to use the forms of communication that are most effective for them. ASAN submitted comments to the American Speech-Language-Hearing Association urging it to consult directly with non-speaking autistic people when developing policy statements on specific AAC methods, and we opposed their position statements which did not meet this basic standard.

Self-Advocacy At The United Nations

In April, our Executive Director, Julia Bascom, gave the keynote address at a United Nations event on empowering autistic women and girls. ASAN also worked with the UN to make sure there were multiple autistic speakers on every panel.

In May, our Legal Director and Director of Public Policy, Sam Crane, traveled to Geneva to participate in a meeting of international experts on health care for people with disabilities.

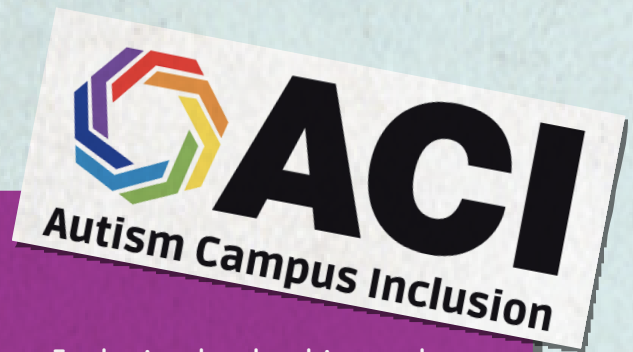


Disability Community Day Of Mourning

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

2018 was our 7th year of holding vigils for the Day of Mourning. We had 46 vigil sites across the US, Canada, and Australia as well as a livestreamed virtual vigil.

EMPOWERING NEW LEADERS



Autism Campus Inclusion

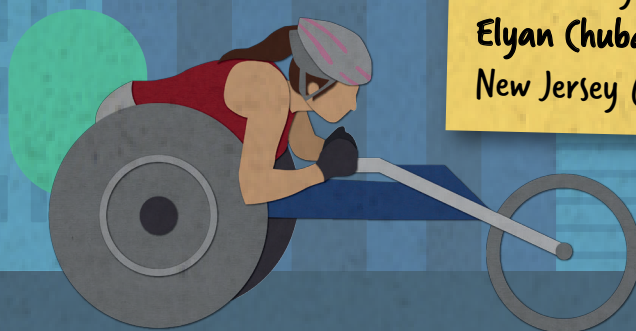
This summer, we held our 7th annual Autism Campus Inclusion leadership academy, bringing 18 rising self-advocates from 11 states to Washington, D.C. for a week of advocacy training. To date, we've trained 118 self-advocates at ACI.

"[ACI] was an absolutely empowering and life-changing experience!...I learned so much about activism, public policy, and identity. You don't learn just about what activism and public policy are; you learn how to do them. I'm so honored that I had this opportunity and would recommend it to any autistic person who seeks to bring about systemic change." —Eryn Star

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 third cohort of Autistic Scholars:

Megan Lambert, University of California, Merced (Merced, CA)
Ashton Brock Sorrels, Brite Divinity School (Fort Worth, TX)
Huan Vuong, Northern Virginia Community College (Alexandria, VA)
Elyan Chuba, The College of New Jersey (Ewing, NJ)



HEALTH CARE IS A HUMAN RIGHT



Work Requirements Don't Work

ASAN believes that health care is a human right - and that instituting work requirements is demonstrably wrong. When Kentucky proposed adding work requirements to its Medicaid program, we took a stand against the proposal, which was ultimately blocked by a federal judge. Forcing people to work for their Medicaid does not help them find and keep jobs - but expanded access to Medicaid does.

No #LicenseToDiscriminate

ASAN released comments against a proposed rule that would give health care providers more leeway to refuse to provide information or services if it violates their religious beliefs. ASAN opposed this proposed rule on the grounds that it could potentially disenfranchise and compromise the health of the members of the autistic community who are at the greatest risk of poor health outcomes.

Comments On Citizenship Question In 2020 Census

The federal government proposed adding a question to the 2020 Census about household members' citizenship status. This question was designed to intimidate immigrant communities and would result in decreased participation in the Census. Many crucial programs, including Medicaid and CHIP, rely on census figures to determine their funding, and underreporting means underfunding. ASAN opposes the addition of this question, and we made sure the administration knows it.

United States
**Census
2020**

Fighting Organ Transplant Discrimination

In September, ASAN worked with Disability Rights North Carolina to help an autistic man who had been denied a heart transplant because of his disability. ASAN helped Disability Rights North Carolina file a complaint against the hospital. The complaint asks the federal government to help protect the man's right to life-saving care. We continue to work on this case as it develops.



CIVIL RIGHTS

The Right to Parent

People with intellectual disabilities can be great parents with the right supports - and it's wrong to deprive someone of the supports they need and then take away their child. But that's exactly what was happening in the court case *Lacey. L. v. Administration for Children's Services*. We joined an amicus brief supporting the Appellant parent with an intellectual disability in a court case. We will keep fighting for the rights of people with disabilities to get the supports we need and have the same access to parenthood and a family as anyone else.



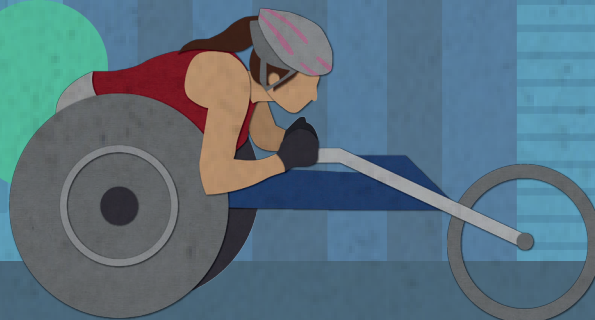
Gun Violence Policy Brief

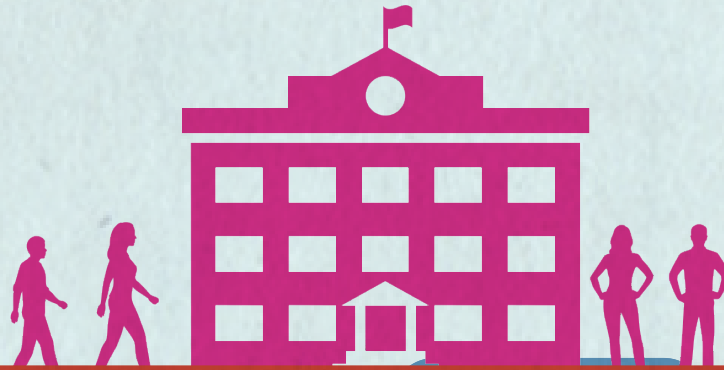
Gun violence is an epidemic in this country. And almost like clockwork, after any mass shooting, there is a rush to scapegoat people with mental health disabilities. This year, we worked to change that by publishing a document called *Make Real Change On Gun Violence*. This document pulls together all the research backing up what we've known all along: people with disabilities are much more likely to be victims and much less likely to be perpetrators of gun violence. Now self-advocates and our allies have a ready-to-use resource to keep the conversation focused on real solutions, not stigma.



Inclusion for All

Self-advocates know that there's a lot of overlap between the LGBT community and the autistic community—and more importantly, we know that human rights are for everyone. That's why we joined an amicus brief supporting a school district's policy allowing transgender students to use the bathrooms consistent with their gender identity. We explained how allowing students to use the correct restrooms reduces bullying and stigma and creates a better school climate. As disabled people, we know how important access to public accommodations is, and we support school districts that want to make sure all of their students feel included and welcome.





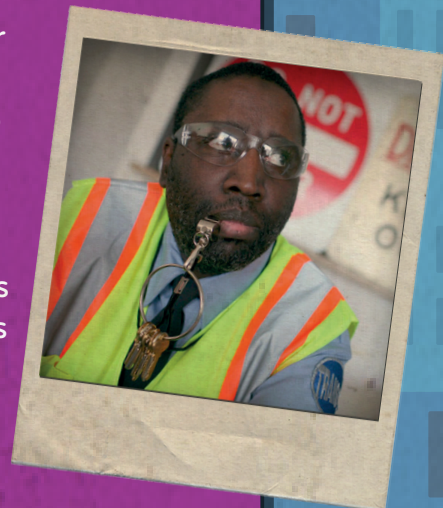
Justice Delayed

The Department of Education decided to delay a rule meant to help schools comply with the IDEA's requirement that they collect data on racial/ethnic disproportionality in special education. ASAN liked how this Rule would work. It would provide advocates with valuable data on bias in school discipline, and let us know where students of color are being over- or under-identified as students with disabilities.

That's why we opposed the delay in implementing the rule. Collecting data on disproportionality is a vital step towards policies which reduce discrimination against students of color. Schools have had plenty of time to determine how to comply; delaying the rule only delays justice for students experiencing discrimination.

#FreeDariusNow

In March, ASAN wrote a letter to the court in support of Darius McCollum. Darius, who is fascinated with buses and trains, is facing indefinite institutionalization after he tried to drive a Greyhound bus without authorization. ASAN's letter explained that with the right supports, Darius could be supported safely in the community.



MOVING FORWARD, NOT BACKWARD

#StopTheShock



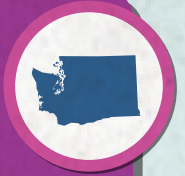
In 2014, the FDA prepared a rule that would finally ban the use of electric shock devices like those used at the Judge Rotenberg Center. 4 years later, that rule still hasn't been finalized.

This year, we launched a social media campaign telling the FDA to #StopTheShock. Our fact sheet was downloaded thousands of times, and our petition garnered over 290,000 signatures. In June, we secured an in-person meeting with the FDA to deliver boxes full of petition signatures and tell them to release the rule. We will keep putting pressure on the FDA until the rule is final.

19 Years Is Too Long To Wait

In 1999, the Supreme Court ruled in *Olmstead v L.C.* that disabled people have the right to get services in the community—but in 2018, we're still waiting for that ruling to become reality. This year, we supported the plaintiffs in *Brown v. D.C.*, who are physically disabled people living in nursing homes and fighting to receive services in their communities instead. All disabled people have a right to live fully included and supported in our communities—now.

Bodily Autonomy In Washington

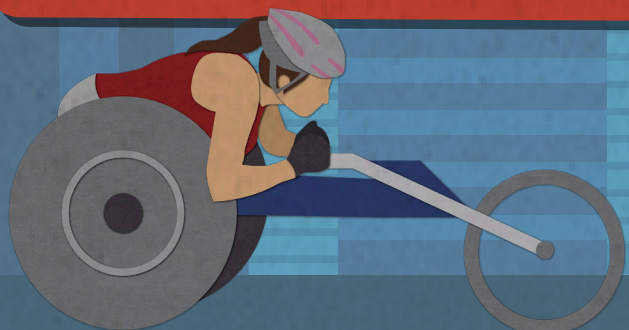


The state of Washington was preparing to make a form for use when a guardian wanted to sterilize the person under their guardianship. The state thought this would reduce the number of sterilizations - but we supported local state advocates who explained that in practice, this might make it easier to sterilize people with disabilities under guardianship. We sent a letter to Commissioner Rebekah Zinn explaining the problem and urging Washington state to not go forward with the form - and they listened.

Our Rights On The Line

ASAN strongly opposed the nomination of Brett Kavanaugh to the Supreme Court. We were especially appalled by his decision in *Doe ex rel. Tarlow v. D.C.*, where he wrote that because the plaintiffs lacked "capacity" to make their own medical decisions independently, they had no right even to be consulted before being forced to undergo elective surgeries, including abortions. We spent 3 months educating civil rights organizations and Senate offices about this case and the rights of people with disabilities.

Because of the advocacy of the disability community, many more people now know what happened to these women. We lost this fight, but we are proud to have been a part of it.



Employment First Toolkit

This year, we released *Real Work For Real Pay*. *Real Work For Real Pay* is the latest entry in our successful series of Easy Read toolkits on important policy issues. This accessible toolkit focuses on important issues in employment policy, including:

- ★ What Employment First is and why it's important
- ★ What sheltered workshops are and why/how to get rid of them
- ★ Issues disabled people face in trying to get employment
- ★ What work requirements are and why they don't work

The purpose of this toolkit is to help self-advocates understand employment policy and how things could be different—so that we can effectively advocate for an end to policies that hurt us, and for the implementation of policies that help us.

SELF-DETERMINATION

Supported Decision-Making

In 2016, we held a summit focusing on supported decision-making and whether that can help bring people out of institutions and integrate them into the community. In the two years since the summit, we have built on what we learned - and this year, we published ASAN's *Invitational Summit on Supported Decision-Making and Transition to the Community: Conclusions and Recommendations*. This document outlines concrete recommendations for the use of supported decision-making in four aspects of successful community living: Housing, Relationships and Natural Supports, Health Care, and Long-Term Services and Supports.

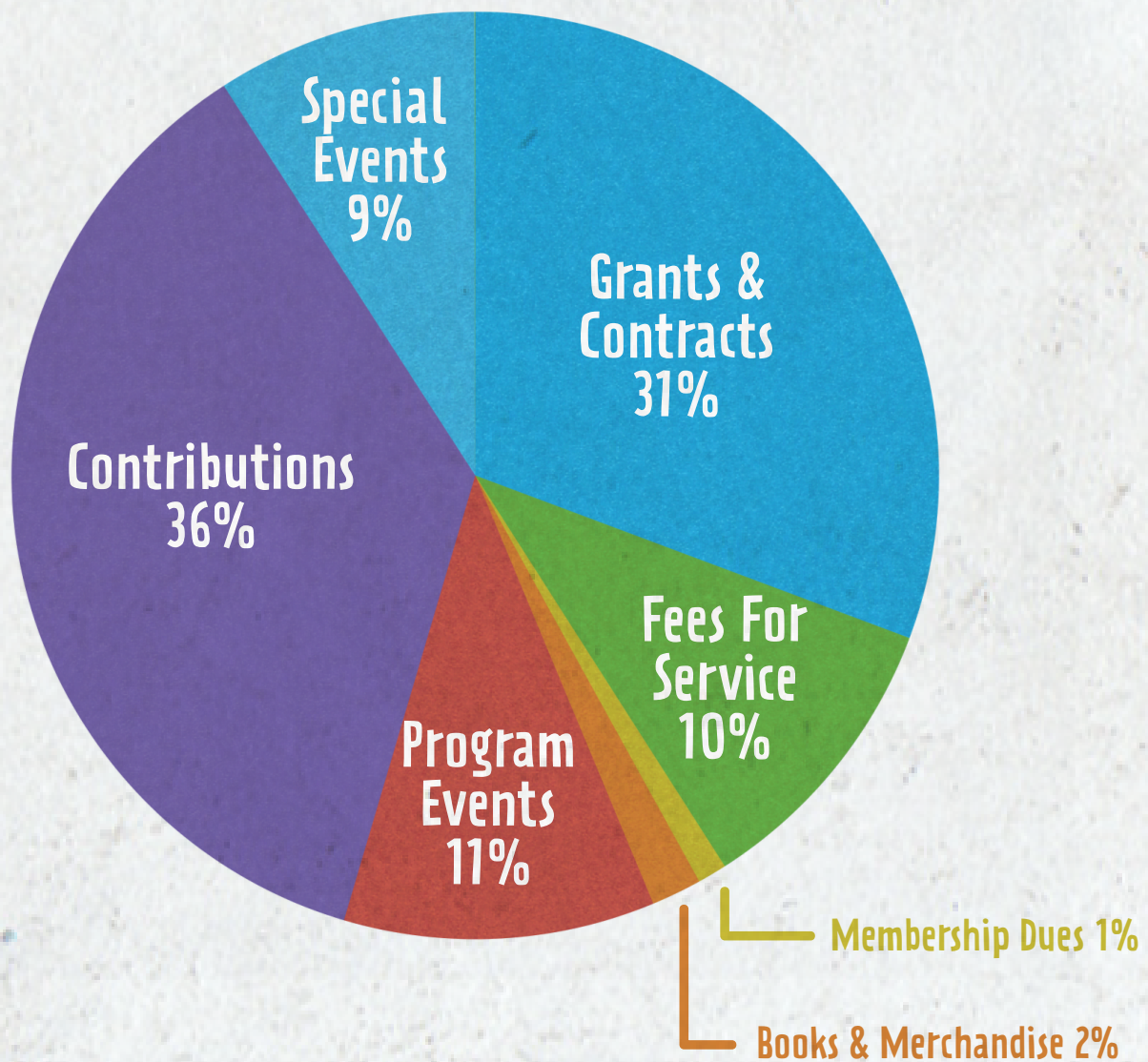
Get Out The Disability Vote!

People with disabilities have fought for generations to make our voices heard. We protest, we meet with elected officials, we run for office, and we vote. Voting is a powerful tool that the disability community can use to shape policies that affect our lives — but like all tools, it only works if we use it. This year, we unveiled our voting resource center, autisticadvocacy.org/vote. Our resource center includes information on how to register to vote, how to learn more about your ballot and local races, how the voting process works, and what to do if your rights are violated. People with developmental disabilities voting is a radical act. We are proud to do our part to make that possible.

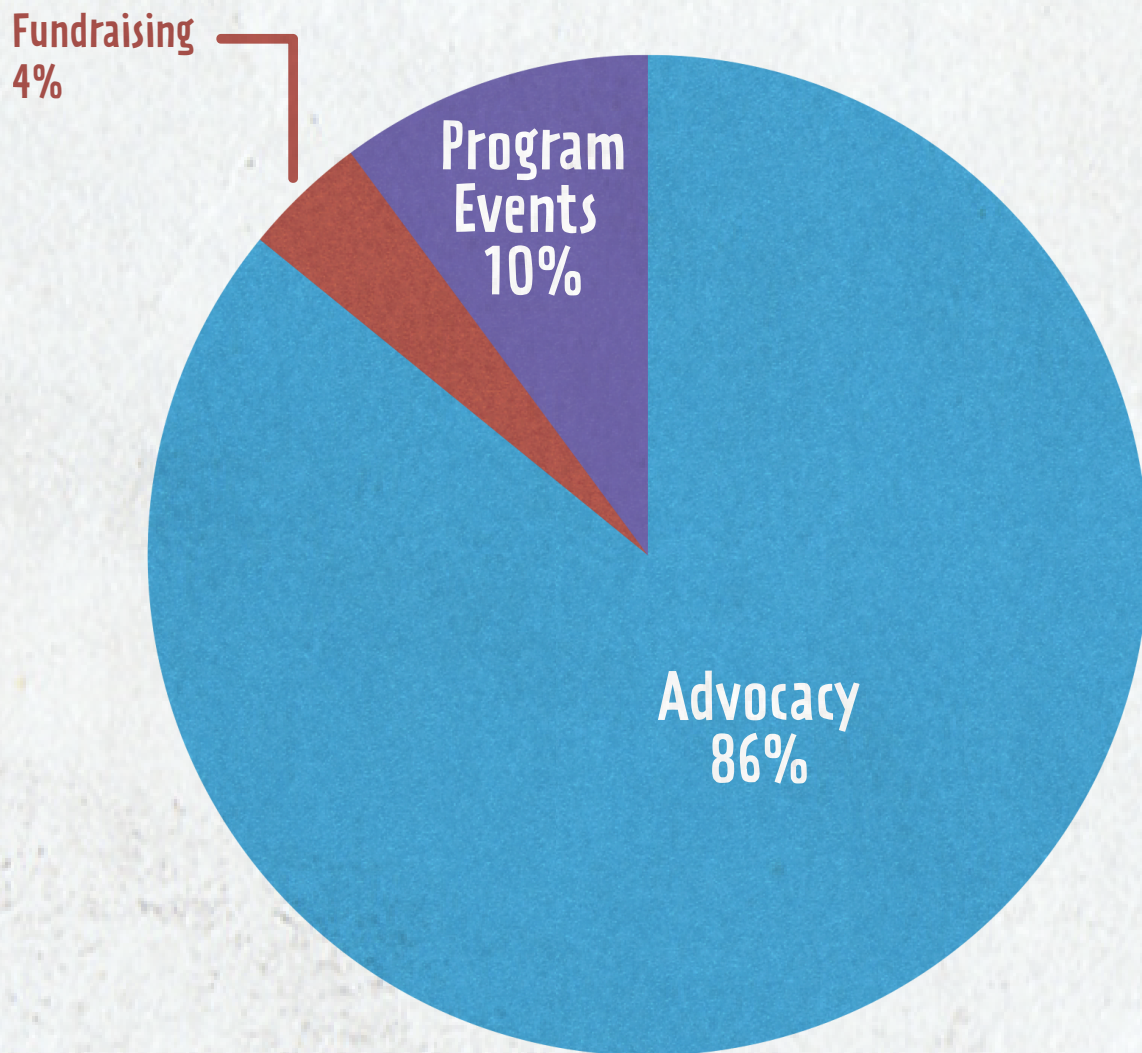


FINANCIALS

2018 Revenue: \$506,902



2018 Expenses: \$682,845



Note: ASAN regularly 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.

**WE NEED YOUR
HELP TO...**

PROTECT access to health care and
other critical services
ADVANCE our civil rights
COMBAT abusive "therapies" used on
autistic people
PROMOTE alternatives to guardianship
INCLUDE everyone in advocacy 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

 Facebook: [/AutisticAdvocacy](https://www.facebook.com/AutisticAdvocacy)

 Twitter: [@AutSelfAdvocacy](https://twitter.com/AutSelfAdvocacy)

 Tumblr: [autisticadvocacy](https://autisticadvocacy.tumblr.com)

ACKNOWLEDGMENTS



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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 12 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.

