

AUTISTIC SELF ADVOCACY NETWORK



# TAKING ACTION



2019 ANNUAL REPORT

**SPECIAL  
EDITION**

## 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!***

# A LETTER FROM JULIA

Dear friends,

2019 was a busy year for ASAN. We launched our proxy calling system to allow people with all kinds of disabilities to call our legislators. We held our first Easy Read community focus group, bringing in ten insightful editors with intellectual disabilities to improve our accessible toolkits. We ran a nationwide "wait-in" campaign to end the use of electric shock torture at the Judge Rotenberg Center, fought against dangerous regulations like the Public Charge Rule, and campaigned to end subminimum wage. We held our eighth Autism Campus Inclusion leadership training and organized our eighth Disability Community Day of Mourning. We advocated relentlessly for autistic people's voices to be heard—in policymaking, in research, in the media, and in our schools and communities—all while defending our rights from constant attack.

We didn't do this alone. So much of our work is only achievable because of a network of people with disabilities and allies taking action together. Our proxy call system only works thanks to our dedicated team of volunteers. Our focus group editors have made huge improvements to the way we approach cognitive accessibility. Our #StopTheShocks wait-ins were so effective because of dedicated site coordinators across the country; Day of Mourning works because of site coordinators across the world. And of course, everything we do happens because of the actions you take to support us, whether that looks like donating, participating in our action alerts, or spreading the word about issues that matter to the autistic community.

We've seen what can happen when we take action as a community. Disabled people continue to claim our political power on a national stage, and policymakers are taking notice. The 2018 election had the largest disability turnout to date. People with disabilities, and the issues that matter to us, are more visible on the campaign trail than ever before. As we look ahead to next year, civic engagement efforts for people with disabilities are more important than ever -- and we'll be working to make sure that all of these efforts include people with intellectual and developmental disabilities.

We're proud of the work we did in 2019. We know there's even more to do next year, and we can't wait to get started. But first, let's take a moment to celebrate what we can accomplish. As long as we take action together, there will be Nothing About Us Without Us!

*Julia Bascom*

Julia Bascom  
Executive Director  
Autistic Self Advocacy Network



# TOOLKITS



## ***FOLLOW THE MONEY***

It's important for self-advocates to understand how the federal budget gets made—so we can advocate for a budget that funds programs that help us. But the federal budget process is complicated and confusing, even to people who have worked in the government for a long time.

That's why this year, we released a new Easy Read toolkit called ***FOLLOW THE MONEY: THE U.S. BUDGET AND YOU.***

Follow the Money breaks down the federal budget process and explains what it is, how it works, and how we can influence it—all in plain language!



## ***COMMUNITY LIVING***

This year, we released a set of Easy Read toolkits based on our self-advocate summit on community living. These toolkits focus on what "community living" means, and how we can make it a reality for all people with disabilities—including information on important laws and programs, recommendations to autism researchers, and a how-to guide on making meetings more inclusive.



## ***THIS RULE RULES!***



This year, we also released a brand new Easy Read toolkit called ***THIS RULE RULES!: THE HCBS SETTINGS RULE AND YOU***. This Easy Read toolkit explains everything self-advocates need to know about how the HCBS settings rule helps us get the supports we need in truly integrated settings.

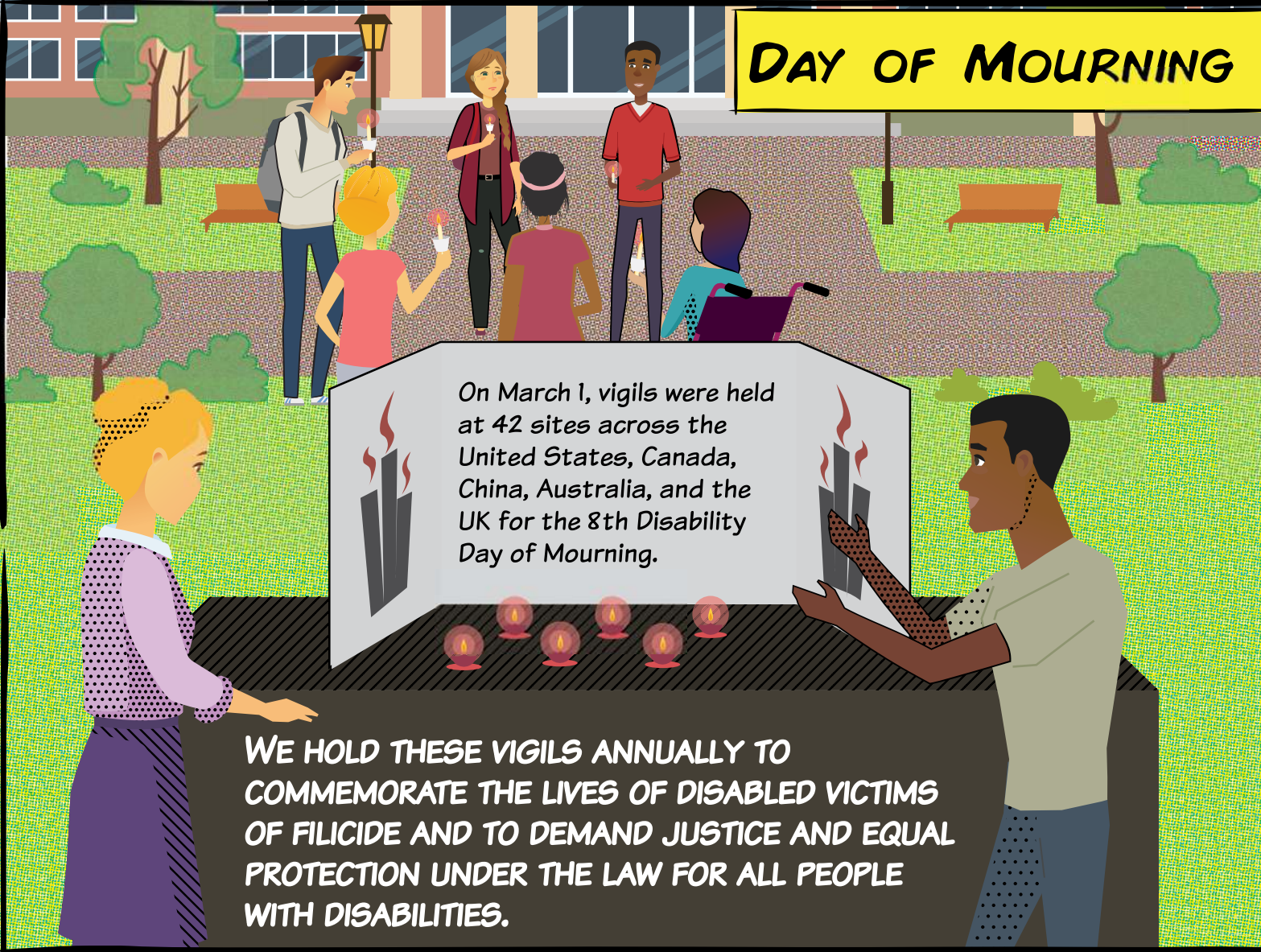
## ***YOUR VOTE COUNTS***



ASAN's newest Easy Read toolkit is called ***YOUR VOTE COUNTS: A SELF-ADVOCATE'S GUIDE TO VOTING IN THE U.S.***

Your Vote Counts covers everything you need to know about voting, including how to vote, when to vote, and what you can expect when you show up to vote. Generations of disabled activists fought for our rights to have a say in the policies that affect us, and we want to ensure that as many of us as possible are able to exercise that right.

## DAY OF MOURNING



On March 1, vigils were held at 42 sites across the United States, Canada, China, Australia, and the UK for the 8th Disability Day of Mourning.

**WE HOLD THESE VIGILS ANNUALLY TO COMMEMORATE THE LIVES OF DISABLED VICTIMS OF FILICIDE AND TO DEMAND JUSTICE AND EQUAL PROTECTION UNDER THE LAW FOR ALL PEOPLE WITH DISABILITIES.**

*Restraint and seclusion are dangerous and harmful practices that traumatize students with disabilities.*

*Every student deserves a safe place to learn—so this year, in conjunction with students, families, and other disability rights organizations, ASAN joined a lawsuit against Fairfax County public schools over their use of these abusive practices.*

*This year, ASAN focused on access to higher education as part of our work with the Leadership Conference on Civil and Human Rights. We contributed to LCCHR's Civil Rights Principles for Higher Education, helping them ensure that disability rights were a strong focus.*

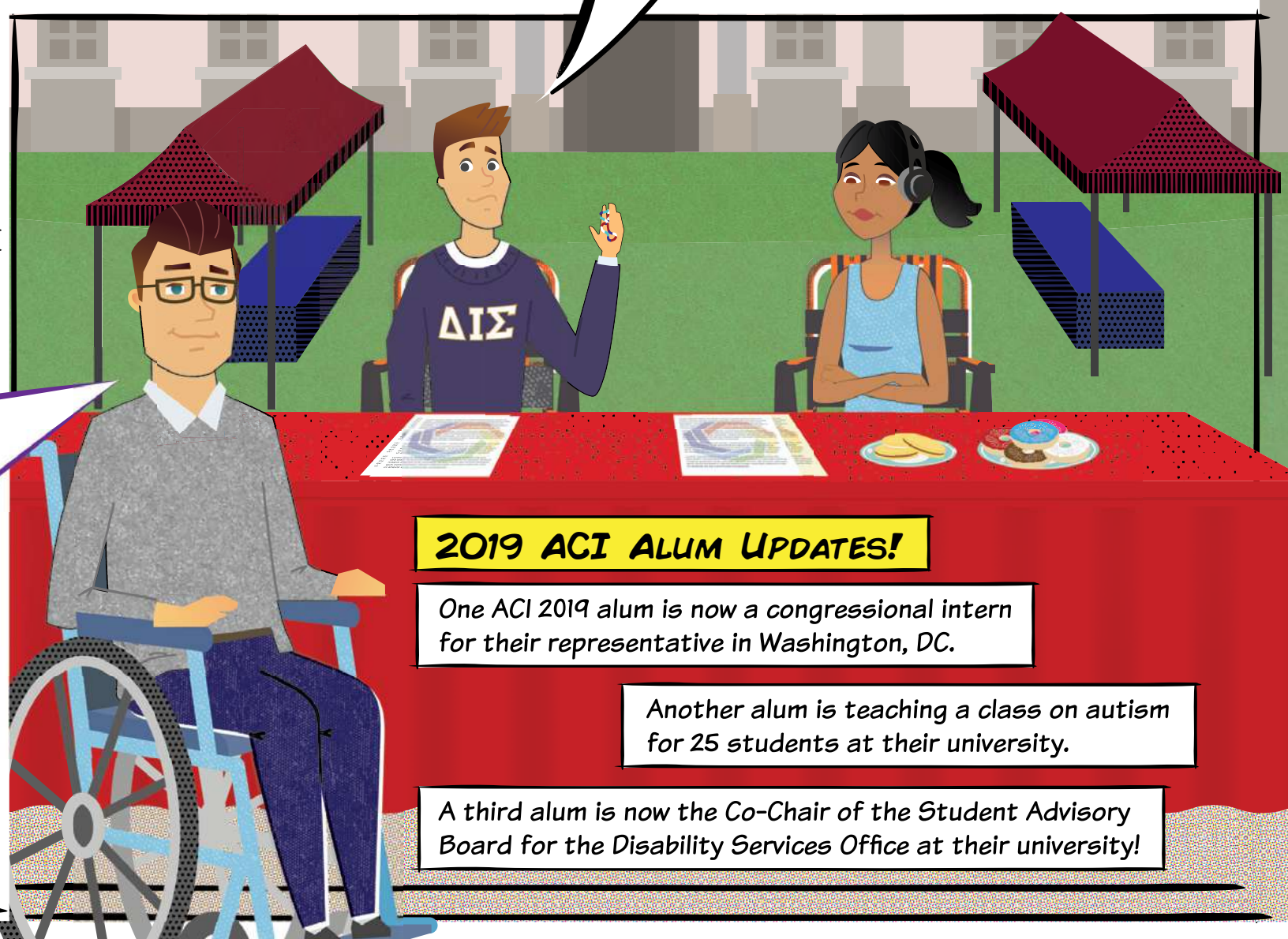
*We also presented at a Congressional briefing and are preparing a white paper on equity in higher education for people with cognitive disabilities.*

# AUTISM CAMPUS INCLUSION

This summer, we held our 8<sup>th</sup> annual Autism Campus Inclusion leadership academy. We brought 19 rising self-advocates to Washington, DC for a week of training and community-building.

ACI participants take the skills they've gained in the nation's capital back home, where they use what they've learned to advocate for real change in their communities.

To date, we've trained **137** self-advocates at ACI.



## 2019 ACI ALUM UPDATES!

One ACI 2019 alum is now a congressional intern for their representative in Washington, DC.

Another alum is teaching a class on autism for 25 students at their university.

A third alum is now the Co-Chair of the Student Advisory Board for the Disability Services Office at their university!



## OUR VOICES MUST BE HEARD!

"Nothing about us without us" means that autistic people must have a voice in all levels of government.

This year, we are helping an autistic school board member in Connecticut to challenge the school board's denial of her disability accommodations—because we all have the right to accommodations that enable our participation.

Conversations about health care reform must center the voices and concerns of people with disabilities, who are too often failed by the current health care system.

One urgent example is the lack of access to Home and Community-Based Services (HCBS), which remain out of reach for far too many people with disabilities.

This year, ASAN worked closely with Rep. Jayapal, Rep. DeLauro, and Sen. Sanders' offices to ensure that HCBS would be folded into every legislative plan for universal health care.

For 14 years, Georgetown University's Health Initiative contract with the DC government has provided vital health services for people with intellectual and developmental disabilities.

When DC planned to abruptly cancel the contract, we joined other disability rights groups to fight to protect access to these services.

We ran the #BringBackTheContract social media campaign, helped DC residents contact their council members, and testified in front of the DC Council to make sure they knew just how important the program is.

The Administration for Community Living and the National Quality Forum put together a panel of people to set national standards for Person-Centered Planning—but the panel did not include any leaders with intellectual disabilities.

We submitted comments and called for the panel to be reformed and expanded until at least one-third of its members are self-advocates with disabilities, including people with mental health disabilities, older adults, and people of color.

As a result of our advocacy, the panel has added voting members with disabilities. Nothing about us, without us!



## FREE SPEECH FOR ALL

In June, the Access to Free Speech for All Act (S. 1836) was introduced by Senator Casey. The bill would expand access to alternative and augmentative communication methods for all people who need them.


We've been advocating for this bill for a long time, and we worked closely with the Senator's office to get the bill written and introduced. We'll keep working to ensure that access to communication supports becomes the law of the land!



## #WORKWITHUS

With the right supports, people with all kinds of disabilities and support needs can have good jobs that pay us well—but too many of us are still warehoused in dead-end, segregated workshops that pay pennies on the dollar.

This year, we ran a campaign asking Congress to #WorkWithUs to pass the legislation that would finally end subminimum wage and make integrated employment the law of the land.



Too often, the subject of gun violence has been used to scapegoat people with mental health disabilities. Whenever dangerous myths re-circulated, we worked to remind our communities of the facts: **people with disabilities are not to blame for mass violence.**

And when Congress tried to distract from their inaction on gun violence by pursuing discriminatory policies that would harm our community, ***we fought back.***



## PUBLIC CHARGE

This year, the White House introduced the "public charge" rule, which makes it harder for people with disabilities to immigrate to the U.S. We fought this rule at every step—through formal comments to the government and by educating our grassroots about the issue, their rights, and how they can help.

In October, ASAN joined an amicus brief supporting the ongoing lawsuits against this heinous rule. We will continue to fight to ensure that all immigrants are able to access the path to American citizenship, regardless of disability.



**#STOPTHESHOCK**

We closed out Autism Acceptance Month with a nationwide day of action calling on the FDA to **#STOPTHESHOCK** and finally ban the electric shock devices used at the Judge Rotenberg Center.

Advocates across the country gathered at "wait-ins," called and emailed the FDA and their members of Congress, wrote op-eds, and spread the word on social media. Our #StopTheShock and #WeAreStillWaiting hashtags reached **MORE THAN HALF A MILLION PEOPLE ON SOCIAL MEDIA!**

When the Washington State Bar Association refused to grant a law license to a woman solely because she'd been under guardianship, a lawsuit followed—and we made our voices heard by backing the lawsuit and filing an amicus brief.



**BANG!**

There is **no excuse** for discrimination.

The court agreed with us, and the woman is now a licensed lawyer.

We led a coalition of disability rights organizations in releasing statements on the deaths of 11 children at the Wanaque Center for Nursing and Rehabilitation. These deaths were preventable; they were a result of the neglect and lack of care that is endemic to congregate settings.

ASAN calls for justice for these children, and we continue to fight for policy changes that will bring people with disabilities out of institutions and back into our communities.



## UNITED NATIONS

In early April, our voices were elevated on the global stage when ASAN staffers Noor Pervaz and Finn Gardiner spoke at the United Nations. They explained how assistive technologies help autistic people participate in our communities, and their remarks are now a part of the UN's online video archives.

ASAN also worked with the UN during the planning stages of this event, which focused on assistive technologies, to make sure that the voices of nonspeaking autistics were centered.

## NCD REPORTS

We prepared extensive reports for the National Council on Disability about organ transplant discrimination and Quality-Adjusted Life Years, two ways that our health system devalues and discriminates against people with disabilities. NCD reports are used to educate the public, drive advocacy, and provide critical reference material for policymakers.

## PROXY CALLER

We finally unveiled a project that we've been working on for a while—our new proxy calling system! People who can't use the phone because of a disability can use this system to participate in our action alerts.

Our proxy calling system was designed and developed by Elizabeth Bartmess, one of our 2018 Service to the Self Advocacy Movement Awardees. This new system has made civic engagement accessible to many more members of our community.

## HCBS REGS

Home and community-based services are an important source of support for many people with disabilities who need help to live in the community. The disability rights community worked closely with the federal government for several years to design a new federal rule to help people get the services they need in truly integrated settings.

When this administration proposed relaxing the HCBS rule, we spoke up in defense of keeping the federal HCBS rule—which prevents Medicaid money for community living from being misappropriated to institutions—strong and clear.



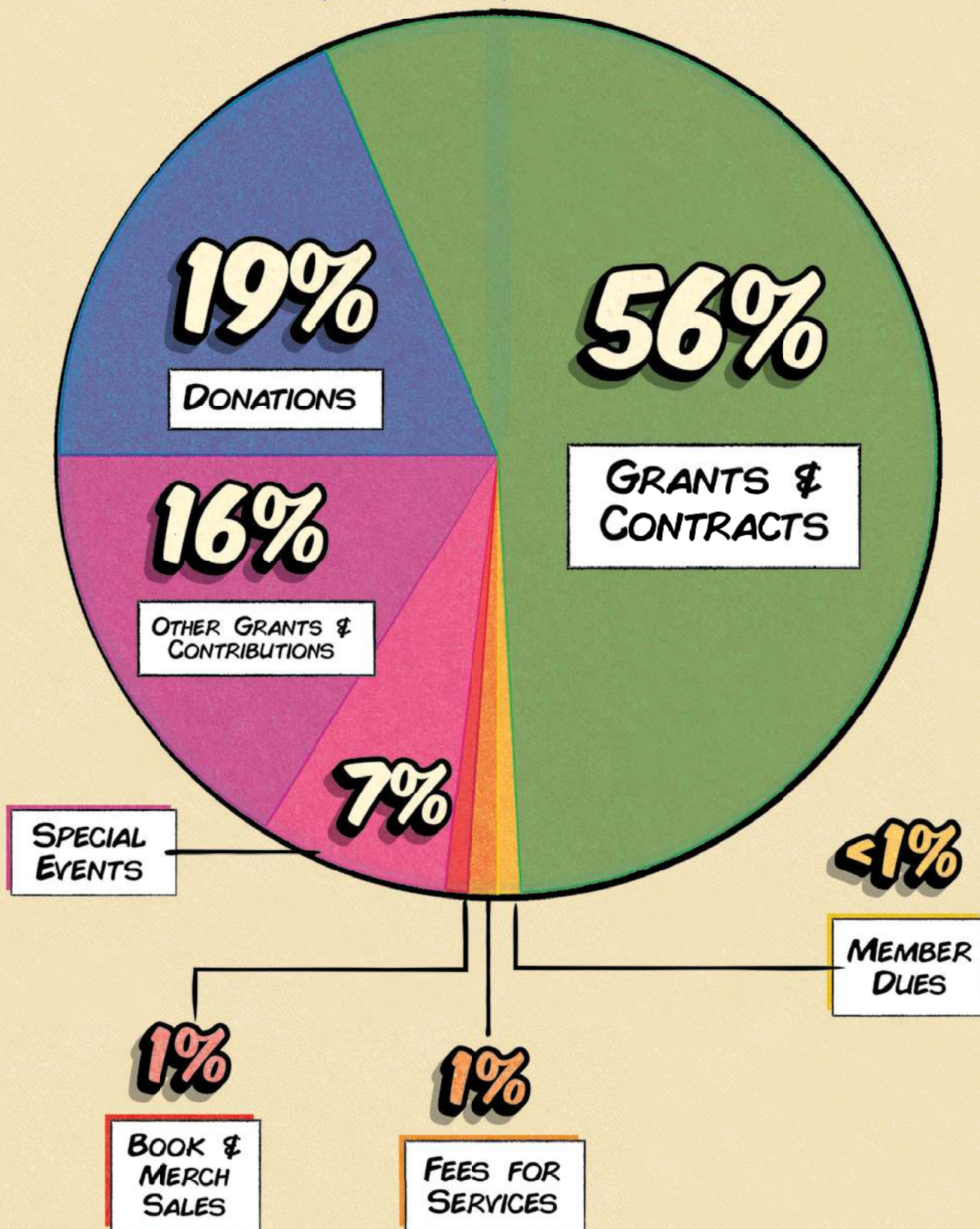
## HEALTHCARE REGS

When the Trump Administration released its "Religious Refusals of Care Rule", we took a firm stand against it. This regulation would put up yet another barrier to health care access for disabled Americans. But while the administration may try to use regulation to weaken our rights, the law remains. We still have legal rights to access health care that works for us, and ASAN will continue to fight to defend that right.

Section 1557 of the Affordable Care Act protects patients from discrimination in healthcare settings. This year, the White House proposed a new rule that would roll back many of the current protections we have under Section 1557. ASAN represents a diverse community of autistic people, many of whom would be directly impacted by such a rule change. ASAN spoke out against this proposed rule, and we'll continue to fight any attempts to roll back our protections.

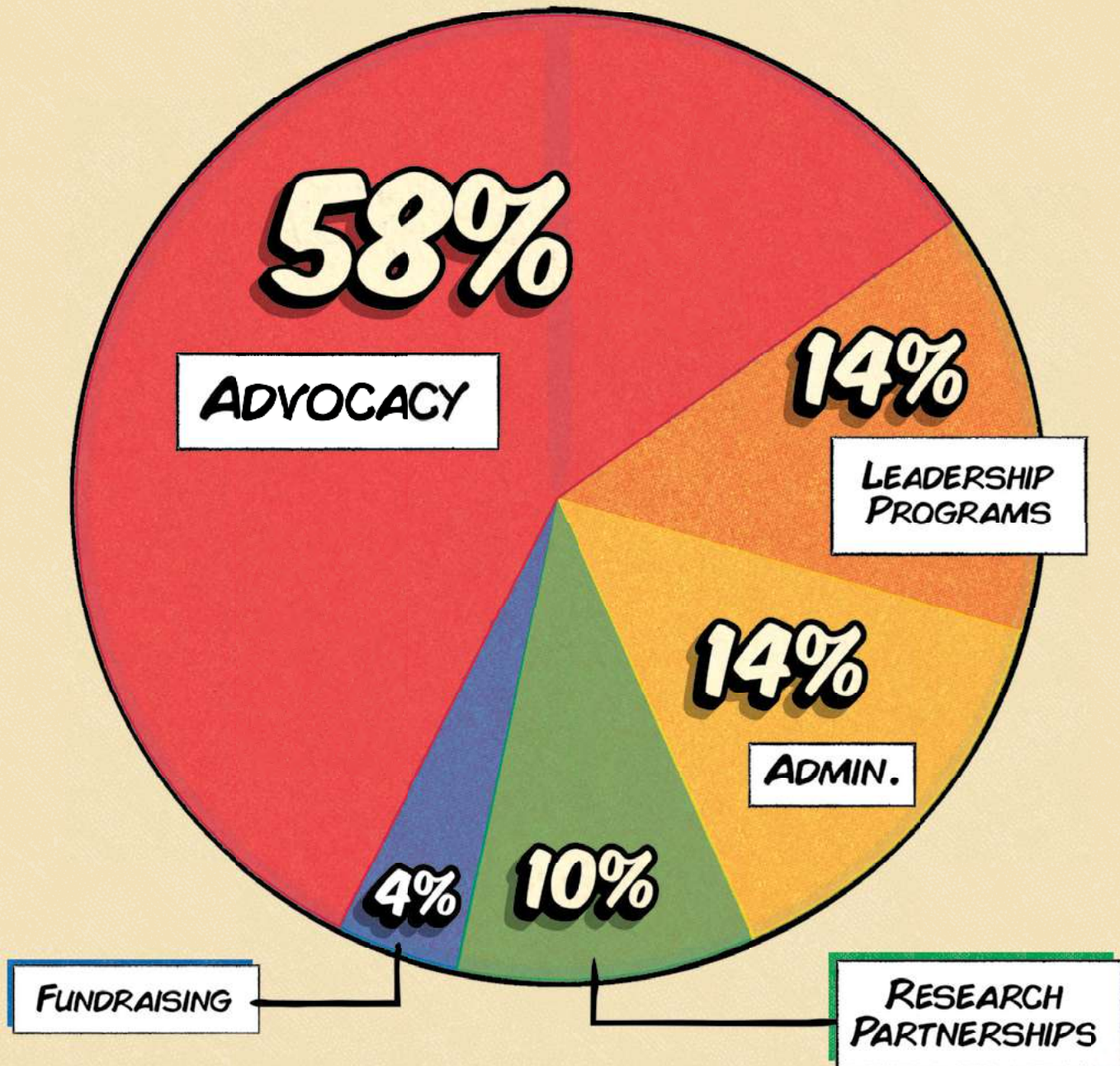
# REVENUE

## \$1,171,575



# ***EXPENSES***

## ***\$789,140***



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.



# GET CONNECTED

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](http://autisticadvocacy.org/join).

To make a **TAX-DEDUCTIBLE DONATION** to the Autistic Self Advocacy Network, go to [autisticadvocacy.org/donate](http://autisticadvocacy.org/donate).

**SHOP ONLINE** at the ASAN store at [autisticadvocacy.org/shop](http://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](mailto:jwinegardner@autisticadvocacy.org).

## WANT TO TAKE ACTION?

We rely on our grassroots. You can view current and past action alerts at [AUTISTICADVOCACY.ORG/ACTION](http://AUTISTICADVOCACY.ORG/ACTION), or get them sent straight to your inbox by signing up at [AUTISTICADVOCACY.ORG/NEWSLETTER](http://AUTISTICADVOCACY.ORG/NEWSLETTER).

**FACEBOOK:** /AUTISTICADVOCACY

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**TUMBLR:** AUTISTICADVOCACY



# ACKNOWLEDGMENTS

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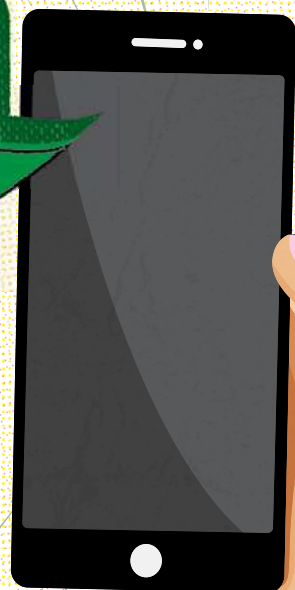
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**JEAN WINEGARDNER**, OFFICE MANAGER

Thank you to everybody who volunteered to be a Day of Mourning vigil site coordinator, a #WeAreStillWaiting wait-in coordinator, or a proxy caller. We also want to thank our focus group editors, and our media intern, Katherine Crater, whose hard work made this report possible.

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 13 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.



**NEW! INCREDIBLE! ACCESSIBLE!**

# ADVOCACY OF THE FUTURE!



**1. Visit ProxyCaller.org.**

**2. Answer a few  
questions.**



**3. A volunteer calls  
your elected official  
and passes along  
your message!**



**AUTISTIC SELF ADVOCACY NETWORK  
WASHINGTON, DISTRICT OF COLUMBIA**

This special offer is available all year! Whether you're looking to become a volunteer or get matched with one, it's totally free and easy! Just use the World Wide Web to navigate to ProxyCaller.org. There's nothing to send in.

*I want to volunteer* ☐ *I want to match with a volunteer* ☐

NAME.....

ADDRESS.....

CITY.....STATE.....ZIP.....