



2023 Annual Report

WE WEAVE
OUR OWN
STORY

Autistic Self Advocacy Network

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!



Letter from the Executive Director

Dear friends,

For the past seven years, I've had the honor of leading ASAN. In that time, ASAN has fought back against attacks on our community, from threats to vital services like Medicaid, to efforts to stifle the rights of our trans autistic community members. We've worked to expand community living and end dangerous practices like restraint and seclusion. We've created accessible tools to help disabled people fight for our rights. Through it all, the ASAN team has been committed to fighting for and alongside our community, and I'm so proud of what we have accomplished together.

2023 marks my last year at ASAN. I'm overwhelmed and humbled by the progress we have made in the last seven years, and I know there is so much more work to be done. In this annual report, you'll read more about what we achieved together in just this past year, and understand why I have so much confidence in ASAN's work going forward.

The theme of this year's annual report is "We Weave Our Own Story." Centering disabled people as the creators of our own advocacy, rights, and stories — and the fact that our communities' struggles are woven together — is crucial to our ongoing work. As I step back from ASAN, I take comfort in knowing our community will continue to weave networks of support and self-advocacy together. It has been an honor to be a small part of this movement, and I cannot wait to see what our community does next.

With gratitude,

Julia Bascom
Julia Bascom
Executive Director

Autistic Self Advocacy Network



Confronting Injustice

Access to gender-affirming care

In an increasingly transphobic legislative climate, we have work to do to prevent autism diagnoses from being used to deny gender-affirming care. In March, we released a statement condemning Georgia Bill SB140 and other attempts to deny gender-affirming health care to young transgender people, sometimes especially to those who are also autistic or have other disabilities. We are deeply troubled by any use of autism as a justification for transphobic efforts that would create barriers to care.

Our Rights Under Threat

The Supreme Court's decision in *Dobbs v. Jackson Women's Health Organization* threatens not only our abortion rights, but many other civil rights as well. *Dobbs* is a case about the right to abortion. But the decision in *Dobbs* affects a lot of other rights as well, including the rights to get married, have sex, get birth control, and have children. That's why we released "Our Rights Under Threat: What *Dobbs v. Jackson Women's Health Organization* means for people with disabilities". This toolkit talks about why these rights are important, and why they are in danger after the *Dobbs* decision. It also talks about what we can do to protect our rights.

Opposing budget cuts

In July, ASAN joined a Consortium of Constituents with Disabilities letter opposing budget cuts proposed by the House. These cuts to departments including the Departments of Health and Human Services, Education, Labor, Agriculture, Transportation, and Housing and Urban Development would have slashed funding to critical programs for people with disabilities.

Reproductive Health Care Accessibility Act

In May, ASAN urged Congress to reintroduce and pass the Reproductive Health Care Accessibility Act. This law would restore some reproductive autonomy and justice for disabled people, especially disabled people of color, through funding accessible and culturally competent reproductive health care.

Access to telehealth

In March, the Drug Enforcement Administration (DEA) proposed restrictions on telemedicine that could have caused disabled patients to lose access to crucial treatment. These restrictions included limiting Schedule II medications, such as some ADHD medications, to in-person visits for prescriptions. ASAN submitted public comments opposing the proposed restrictions, and shared an action alert encouraging our grassroots to do the same. After a surge of comments, the DEA announced that they would extend current telemedicine flexibilities through 2024.

Access to power

At the end of 2022, ASAN sent a request to Congress to appropriate funds for solar power for Puerto Ricans with disabilities, who at one point went six months without power and therefore basic infrastructure.

Working Towards Equity

What is Structural Racism? toolkit

Structural racism is built into our systems—that means systems that are built racist, stay racist. While laws change, structural racism still exists in new and old ways. But when racism is hidden, it's hard to prove it's happening. That's why it's so important to talk about and actively work against structural racism. This year, we released a new toolkit called "What is Structural Racism?" that talks about how these systems have evolved and continue to harm people of color. We also released a series of short animated videos on our YouTube channel that pair with the toolkit.

Spanish-language resources

Our book *Welcome to the Autistic Community* is an introductory guide to autistic people's history, community and our rights. We wrote it in plain language and made the entire book free to access online at AutismAcceptance.com to make it more accessible to more people. This year, we've made it even more accessible! Through the support of a team of translators, for Autism Acceptance Month we were proud to announce that *Welcome to the Autistic Community* is now available in Spanish as well! *Bienvenidos a la Comunidad Autista* is also available to read on AutismAcceptance.com.

ASAN also released Spanish-language factsheets and videos about the COVID-19 vaccine and Long Covid, as part of our series of bilingual COVID resources.

Staff book club

ASAN's Equity Plan includes making opportunities for ongoing learning about anti-racism. As part of that, we host a book club for staff. Our most recent book club meeting included discussion about *Medical Apartheid* by Harriet A. Washington, a book detailing the long history of medical experimentation on Black Americans.

Equity Plan weeks

In 2023, ASAN had 3 work weeks dedicated to our Equity Plan, one each in January, May, and August. During these weeks, instead of external meetings and other regular work, staff devote time to projects and planning related to our Equity Plan. This can include projects like our toolkit on structural racism, ongoing work to make programs like ACI more equitable and inclusive, creating professional development opportunities for staff, or making sure that equity is built into our standard operating procedures, among other work.

Research

Autism Research for Us symposium

In September, we worked together with the Policy and Analytics Center (PAC) based at A.J. Drexel Autism Institute at Drexel University to hold a symposium about autism research. We held focus groups to center autistic people that have most often been left out of research in the past, and used their input to help us decide what to focus on at the symposium. At the symposium we discussed the future of research and how autistic people can lead and guide research. We're currently working to create a research agenda based on the perspectives of our focus group members and symposium attendees. We will publish this research agenda for everyone to see, in multiple formats including plain language and Easy Read. We want this research agenda, and the process used to generate it, to be used to guide autism research. We want the government to create policy that matches what autistic people want from autism research, and give more money to research that actively incorporates autistic voices, perspectives, and priorities. The results of our research, and the symposium, will help create these policies.

Response to ADDM Network report

March marked the release of the Autism and Developmental Disabilities Monitoring (ADDM) Network report which estimates how many autistic 8-year-olds there are in certain areas of the country. The report shows that better recognition of autism and continued efforts to reduce racial and gender disparities have caused rates of diagnosis to continue to rise. However, there is still more work to do to address the remaining disparities in diagnosis. We put out a statement in response to the report. ASAN has previously noted the importance of providing additional data on older autistic populations, and we were pleased to note that for the first time ADDM's report included efforts to follow and understand the experiences of autistic individuals across the lifespan and through adulthood.

IACC comments

The Interagency Autism Coordinating Committee (IACC) advises on federal funding for autism research. They make recommendations on how autism research funding is prioritized. One way we can push the IACC to advocate for research that matters to our community by submitting public comments before their meetings. In January, we urged the IACC to continue to support communication access efforts, promote full compliance with the HCBS Settings Rule, and follow up with the FDA on banning the use of electric shock for behavior modification. For their April meeting, we updated the IACC about the #StopTheShock efforts and encouraged them to take an active role in that and in guiding the implementation of the HCBS Settings Rule. We also supported the reintroduction of the Transformation to Competitive Integrated Employment Act (TCIEA). TCIEA would end sub-minimum wage for disabled people over the next five years.

NIDCD research comments

The National Institute on Deafness and Other Communication Disorders (NIDCD) put out a call asking for input on 4 topics related to the needs of nonspeaking people and the best directions for research to support them. We were pleased to have the opportunity to respond in-depth to the NIDCD. We highlighted the importance of access to robust AAC and support for learning AAC systems, and how the routine deprivation of access to effective communication is a violation of human rights. We also emphasized that the highest priority research should focus on the quality of life for people with speech disabilities, and that there must be community-based participatory research and research led by AAC users and people with speech disabilities.

People with disabilities designated a health disparity population

Disabled people face significant disparities in health care access and outcomes. After the National Institute of Minority Health and Health Disparities Advisory Committee recommended *against* designating people with disabilities as a health disparity population, ASAN joined a coalition letter urging the department of Health and Human Services (HHS) to overrule the recommendation. On September 26, after consideration of input from the disability community and a review of the science and evidence, HHS formally designated people with disabilities as a population experiencing health disparities for National Institutes of Health (NIH) research. This means that research projects focusing on disabled people's health can now receive NIH funding that is set aside to address health disparity populations. ASAN has also endorsed the HEADs UP Act, which would direct the Health Services and Resources Administration (HRSA) to designate people with intellectual and developmental disabilities as a Special Medically Underserved Population.



Safety for our Community

Leadership Conference Education Fund address

In January, our policy analyst AJ Link joined the Leadership Conference Education Fund to speak about urgent education priorities for 2023. AJ pointed out the need to remove police from schools in order to actually keep students safe, stating that “all students deserve safe, healthy, and inclusive school climates. Every student deserves the opportunity to attend positive school environments that support their rights, protect against harassment and discrimination, and ensure their health and safety.”

Safer sex resources

Everyone deserves access to sex education. But information about what sex is, and ways to make sex safer for everyone involved, isn't always accessible. People with intellectual and developmental disabilities can and do have sex and deserve accessible sex education. People with disabilities are also at a higher risk of sexual abuse, and we deserve accessible information to recognize sexual abuse and seek help when it happens to us. That's why this year, we released two new resources available in both Easy Read and plain language formats. “A Self-Advocate's Guide to Safer Sex” covers topics like safer sex, pregnancy, STIs, and sexual and reproductive health care. “What Do I Need to Know About Sexual Assault?” covers topics like consent, sexual assault, what to do if you've been assaulted, and how to support others who have been assaulted.

Disability Day of Mourning

Each year, our community comes together to hold vigils for the Disability Day of Mourning. This year, vigils were held at 38 sites both virtually and in-person across the United States, Canada, and Ireland for the 12th 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.

Safer Schools

In December 2022, ASAN joined a Leadership Conference on Civil and Human Rights letter asking the administration to issue guidance on the Bipartisan Safer Communities Act in order to avoid law enforcement in schools as much as possible. ASAN has also endorsed the Protecting Our Students in Schools Act; a bill that prohibits the use of corporal punishment in schools.

Fighting for our Social Safety Net

Medicaid unwinding

When the COVID-19 pandemic began, Congress required that Medicaid keep people continuously enrolled, without requiring them to renew their Medicaid enrollment. Continuous enrollment ended this year, requiring many people to renew or lose their Medicaid enrollment, a process known as “Medicaid unwinding.” ASAN worked with Drexel’s Policy Impact Project to create a factsheet called “Unwinding the Medicaid Unwinding Process,” which explained the impact of Medicaid unwinding on the autistic community, and included policy recommendations to mitigate the negative effects of Medicaid unwinding and monitor its impact on people with disabilities.

Better policies for beneficiaries

ASAN submitted comments encouraging a streamline of the Social Security’s in-kind support and management (ISM) policy, including omitting food from the ISM calculations. ISM calculations are ridiculous and often cruel, having SSI recipients calculate the monetary value of sleeping on someone’s couch, for example – with the risk of losing their benefits even if they do it right!

No cuts to lifeline programs

In May, the House of Representatives passed a bill to make spending cuts in exchange for raising the debt ceiling – spending cuts that would deprive millions of people of access to crucial programs like Medicaid, housing assistance, and SNAP. We put out an urgent action alert calling on our community to contact their Senators and tell them it’s imperative that they defend these lifeline programs, alongside additional background information and a script that callers could use.

Increasing access to the social safety net

ASAN endorsed two proposed laws which would promote access to social safety net programs for immigrants: the Health Equity and Access Under the Law (HEAL) for Immigrant Families Act, which would lift the ban on Medicaid and other vital programs for everyone regardless of immigration status; and the reintroduced LIFT The BAR Act, which would restore access to programs like Medicaid and SNAP by lifting the five-year ban and other barriers that deny support to people who are lawfully present, including “green card” holders.

Autistic Voices

Autism Campus Inclusion

This summer, we held our 12th annual Autism Campus Inclusion leadership academy. 2023 marked our fourth year holding ACI virtually, and we were delighted that even without being physically together we were able to create a distinctly autistic space and provide 9 days of training and community-building for 18 rising self-advocates, 50% of whom are students of color. ACI participants take the skills they've gained and use what they've learned to advocate for real change in their communities. To date we've trained 207 self-advocates at ACI.

SARTAC webinars

People with disabilities deserve equal access to information. Over the years, ASAN has worked hard to develop plain language and Easy Read resources on a variety of complex topics. Easy Read is a format that includes accessibility features like illustrations to ensure the information is accessible to as wide an audience as possible, especially people with intellectual and developmental disabilities. We want more people to start making accessible resources, so we worked with the Self Advocacy Resource and Technical Assistance Center (SARTAC) to give a series of presentations about how to write and format plain language and Easy Read documents to both self-advocate and government/nonprofit audiences.

Op-eds for Autism Acceptance Month

For Autism Acceptance Month this year, we encouraged our community to write opinion editorials (also known as op-eds) for their local news. Op-eds are a powerful way to make your voice heard, and let people know what issues matter to our community. We gave our community resources to learn more about writing op-eds and suggested they use their voices to educate their communities about important topics like Andre's Law and the HCBS Settings Rule.

#StopTheShock

Virtual Hill Day

At the end of 2022, we had another legislative opportunity to #StopTheShock: the end of the year omnibus bill. We called on Congress to include the ban on JRC's use of skin shock devices in the end of year omnibus bill. We hosted a training about meeting virtually with your representatives, and produced a guide with everything you need to know about meeting virtually with your elected officials in the lead up to our virtual Hill Day. Our virtual Hill Day rallied members of our community to tell Congress to use their power to #StopTheShock.

Letter to FDA about #StopTheShock

In 2020 the Food and Drug Administration (FDA) issued a rule that banned the use of electric skin shock devices as aversive therapy. In 2021, the DC Circuit Court overturned the original rule because of a technicality that the FDA couldn't ban just one use of a device. Since then, Congress has passed a law clarifying that the FDA does have that authority, which means that the FDA can and must make a new rule banning the device that the United Nations has called torture. In May, we submitted a letter to the FDA alongside over 100+ partner organizations urging them to restart the rulemaking process that would ban the use of electric shock devices like those used at the Judge Rotenberg Center. Since then, we've found out that the FDA will release a new rule. We're committed to keeping the pressure on the FDA, Congress, and state legislatures until we finally win this fight.

Andre's Law call to action

For years, the disability community has worked to end torture at the Judge Rotenberg Center. While we work towards an FDA ban on the use of electric shocks, there is critical state-level legislation that would affect the Judge Rotenberg Center. In February, we put out an action alert urging our New York members to contact their state legislators to tell them to support Andre's Law (S.900 / A.1166). The New York State bill is named after Andre McCollins, who has spoken out along with his family after he was tortured at the Judge Rotenberg Center. More of the JRC's residents come from New York than from any other state, and Andre's Law would stop the state from sending any more people to the JRC. ASAN is committed to #StopTheShock and we'll keep making our voices heard at all levels until it gets done.

Policy & Regulations

ADA 33rd anniversary roundtable

The disability community fought hard to get the Americans with Disabilities Act passed into law, and we continue to fight hard to protect it. In July, we joined a roundtable hosted by CMS' Office of Minority Health in recognition of the ADA's 33rd anniversary. Deputy Director of Public Policy Greg Robinson represented ASAN. He shared our organization's ongoing work and provided recommendations for where we'd like to see CMS provide additional support, including on the HCBS Access Rule.

HCBS Settings Rule

In March, we hosted a two-day training on the Home- and Community-Based Services (HCBS) Settings Rule. This Rule is all about our right to receive services that are truly community-based and that respect our rights, rather than being stuck in "institutions in disguise." The training prepared self advocates to inform people in their communities about the Settings Rule, and gave strategies on what to do if your state is not following the rule. The training videos are also available on our YouTube channel for anybody to watch.

To give our community more information about the Settings Rule, ASAN also updated our resource "This Rule Rules!," adding sections on how to raise grievances, and what rights people have in different settings.

Section 504 regulations

Before the Americans with Disabilities Act (ADA) existed, people with disabilities relied on Section 504 to defend ourselves from discrimination in federal programs. In September, the Department of Health and Human Services (HHS) proposed updates to its Section 504 regulations. There have not been updates to the regulations since they started in 1977. We knew our community could make an impact on crucial health care policy for disabled people by showing our support for these changes and submitting comments. That's why in October, we held a webinar called "Pushing for Change: Commenting on the Proposed 504 Regulations" to talk about the proposed updates and how to submit your own comments. We also published an action alert explaining more about some of the proposed changes and how we could use comments to support them.

ASAN is also submitting comments, on our own and in coalition, on the Section 504 regulations. We are including extensive comments on the sections covering child welfare. We will also be highlighting the intersection of medical ableism and medical racism, sexism, homophobia, and transphobia.

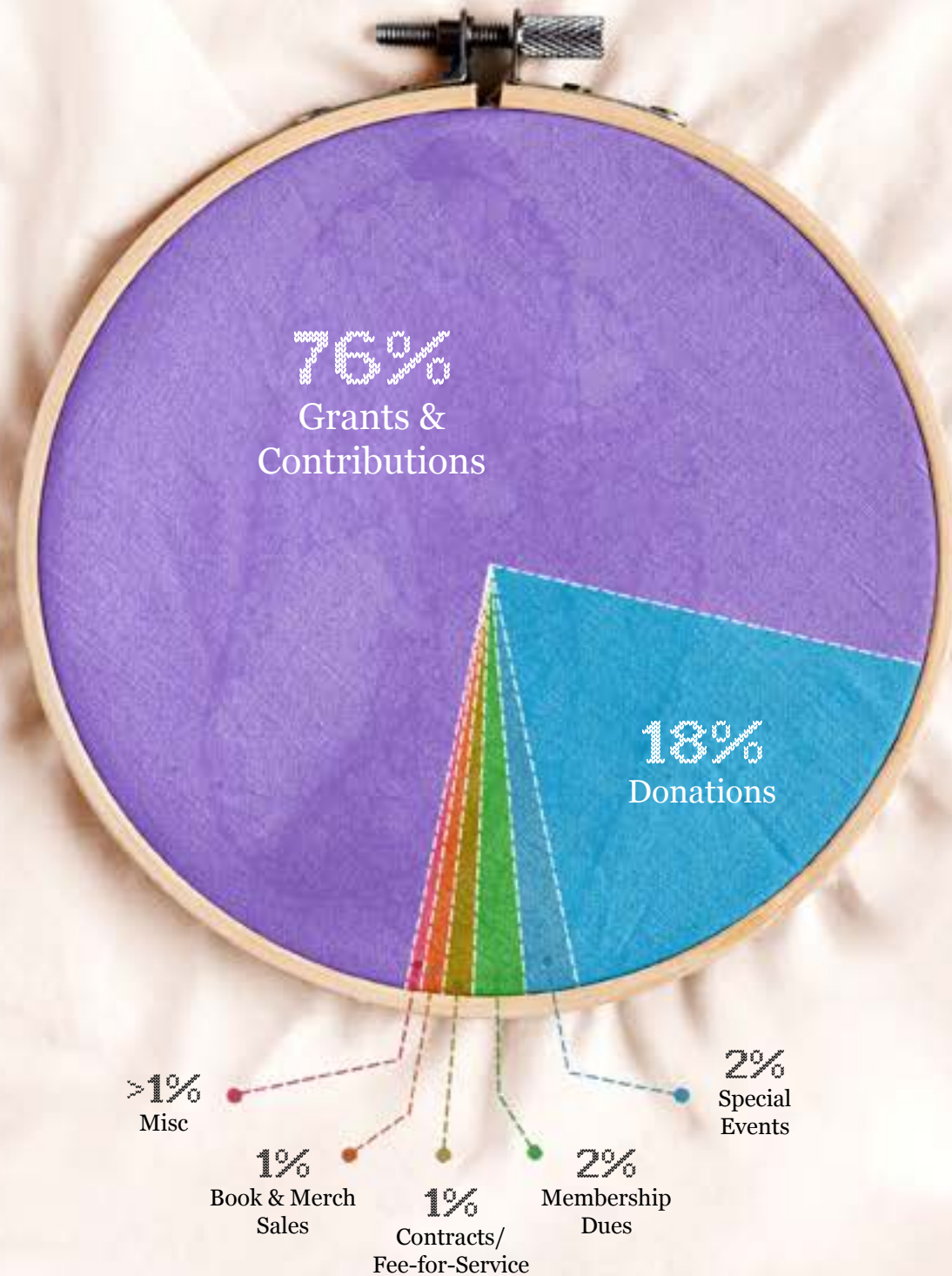
Real work for real pay

In May, ASAN demanded that the Acting Secretary of Labor Julie Su stop issuing new 14(c) Fair Labor exceptions, which allow companies to pay sub-minimum wages to people with disabilities. In September, the Department of Labor announced a "comprehensive review" of the 14(c) program, which may determine whether it continues to issue any new exceptions. ASAN and other disability organizations met with the Department of Labor to call for an end to the program. ASAN continues to work in coalition and with our grassroots towards ending sub-minimum wage.



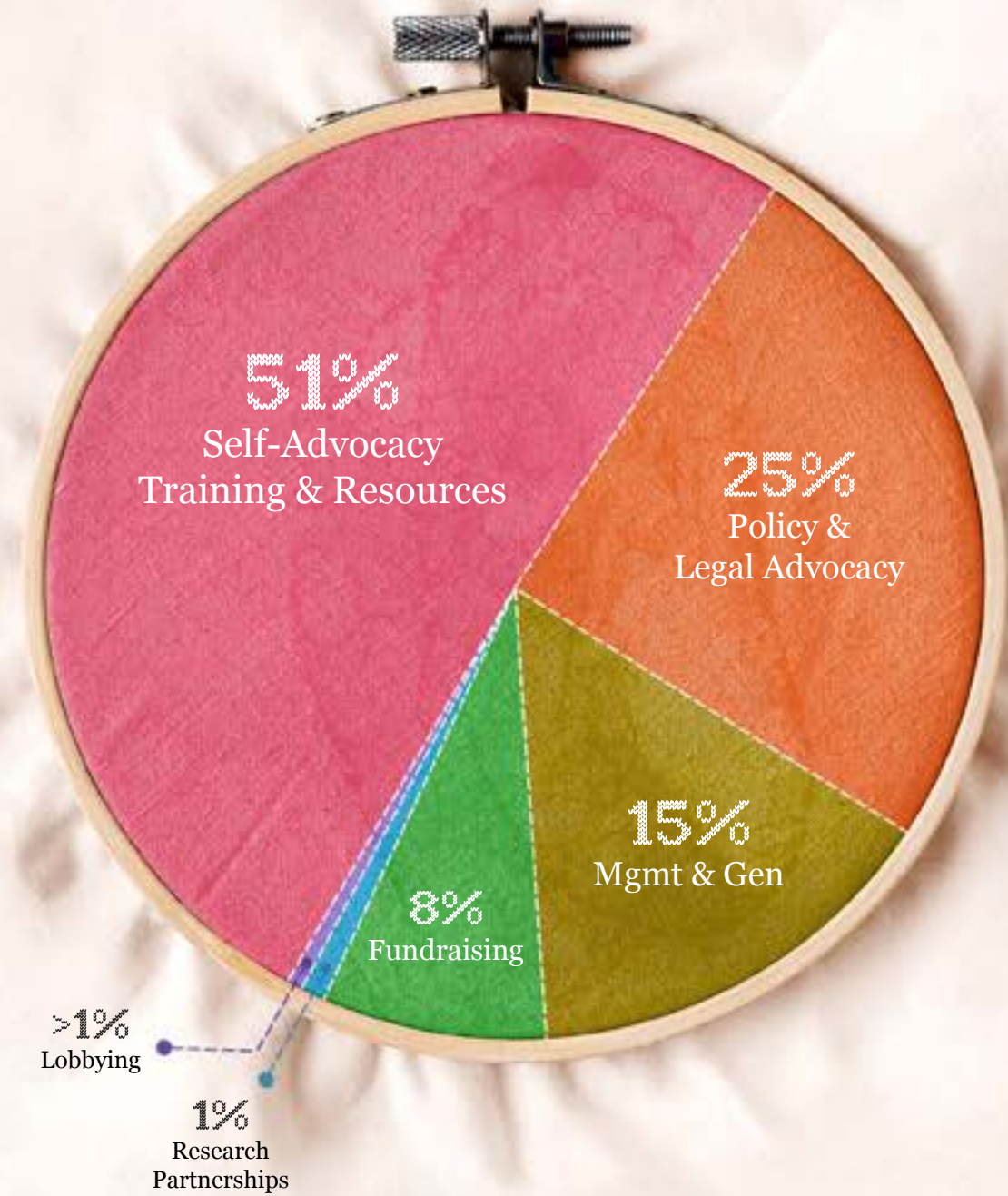
Revenue

\$3,417,478



Expenses

\$1,449,992



Notes: 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. These numbers are from our 2022 Form 990.

Get Connected

Join Us

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

Donate

To make a tax-deductible donation to the Autistic Self Advocacy Network, go to autisticadvocacy.org/donate

Shop

Shop online at the ASAN store at autisticadvocacy.org/shop

By Mail

To give by mail, make a check payable to **Autistic Self Advocacy Network** and send it to:
P.O. Box 66122
Washington, DC 20035

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



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Acknowledgements

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Katherine Crater, Media Associate
Elias Bouderdaben, Grassroots Associate
Mar Zapanta-Rosales, Communications Associate

Thank you to everybody who volunteered to be a Day of Mourning vigil site coordinator, a proxy caller, or to help us in another way. We also want to thank our focus group editors and everybody who joined our advocacy campaigns throughout the year.

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 17 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.

