





Dear friends,

The seed from which the self-advocacy and neurodiversity movements grew was an idea: that people with intellectual and developmental disabilities are not merely objects but agents, experts in our own needs, and that we have not just the ability but the right to shape the social structures in which we live. From that idea, something remarkable has grown: a global, decades-long effort that has reshaped policies, shuttered institutions, and transformed the lives of millions of people.

We're proud to be part of that effort. Thanks to years of effort and careful cultivation, ASAN has also grown incredibly—from a small group of volunteers to a team of twenty, and one that this year has impacted a broader scope of issues than ever before, from shaping key healthcare regulations to publishing an in-depth white paper on the behavior support services landscape.

Those accomplishments and the many more in this report would not have been possible without the incredible work of Avery Outlaw as Interim Executive Director. They took on an enormous responsibility and not only kept the organization afloat but propelled it to significant success—and I am deeply grateful to be working with them as I step into this role. I am honored and humbled to have been selected to lead this remarkable organization, one whose work I have long admired, and I will do my utmost to make it prosper.

I know we have challenges on the horizon. Many threats face our community today, from efforts to erode the regulations that protect our rights to attacks on the ability of autistic people to access reproductive and gender-affirming healthcare. Yet I am confident in our ability to take on these challenges, not only because of the amazing ASAN staff but because we are part of this extraordinary grassroots movement that has flourished far beyond what anyone could have expected.

The theme of this year's report is "Grow With Us," looking at how something that begins as a tiny seed can blossom into something both massive and beautiful. Looking forward, ASAN plans to grow our impact to even greater heights. From campaigning for competitive integrated employment to expanding our community's access to housing, we will ensure our community has greater access to the resources it needs to thrive.

When we invite all of you to Grow With Us, this is what we mean—that just as ASAN is growing, all of us together can grow our own power and blossom into new possibilities.

Sincerely.

Coon kille

Colin Killick
Executive Director, Autistic Self Advocacy Network



Our Lives Are Worth Living

Explaining the end of Chevron

In June, we condemned the United States Supreme Court's decision to stop using a decades-old legal principle known as Chevron deference – which meant that when a law was ambiguous, courts would accept what federal agencies said it meant in their regulations. The end of Chevron will affect all of society, because federal regulations touch everything from food safety and environmental justice to student loans and consumer protection. It will especially affect marginalized people, including the disability community. In July, we put out a legal memo called "The End of Chevron Deference and the Disability Community: New Obstacles to Advocacy and Wellbeing," which explains the potential outcomes of this Supreme Court decision and what we think this means for disabled people.

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 29 sites both virtually and in-person across the United States, Canada, and Brazil for the 13th 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.

Our voice in autism research

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. This year, some of our comments included calling for more communications research for minimally speaking and nonspeaking people of all ages, and more research on behaviorally-informed interventions as described in our new resource, "Beyond Coercion and Institutionalization." Before each meeting, we shared our resource "Autism Research and the IACC: Your voice matters" with our grassroots and encouraged them to submit their own comments. We also submitted comments to the IACC's RFI on Co-Occurring Conditions.

#StopTheShock

This year, we continued our fight to #StopTheShock and end the use of electric skin shock devices like the one used to torture disabled people at the Judge Rotenberg Center (JRC). Through action alerts and a webinar, we encouraged our grassroots to submit comments supporting the FDA's proposed ban on electric skin shock devices. When members of Congress introduced a rider to the Agriculture, Rural Development, Food and Drug Administration, and Related Agencies funding bill that would have stopped the FDA from enacting their ban, we mobilized our grassroots again to advocate for the rider to be removed—and succeeded! ASAN will keep up the pressure until we finally #StopTheShock.

Disabled people deserve health care

Disabled people face many barriers to getting quality health care. Some of these barriers come from harmful assumptions that people with disabilities have a low quality of life and aren't worth treating. This year, ASAN pushed back against those assumptions in multiple ways. We supported HR 485, the Protecting Health Care for All Patients Act, which would extend protections against the use of Quality-Adjusted Life Years (QALYs) and similar measures to Medicaid. We also joined 300+ experts and organizations in calling on governments to prevent the practice of assisted suicide for people with eating disorders. People with eating disorders need care, compassion, and treatment—not to have their lives written off as unworthy.

Social justice perspectives in human genome editing

Eugenics is the belief that some people have "good" traits and some people have "bad" traits, and that only people with "good" traits should get to have children. Throughout history, eugenicist movements have targeted people from marginalized communities, saying that they have "bad" traits. Today, technology is being developed to allow people to pick and choose the genes and traits of their children. We know from history that this ability will be used to devalue and decrease humanity's natural diversity. That's why this year, as a member of the Gender Justice and Disability Rights Coalition, we released "Social Justice and Human Rights Principles for Global Deliberations on Heritable Human Genome Editing." This document aims to guide policymaking by explicitly centering gender justice, disability rights, and human rights in discussions around this new technology.

Inclusion & Civil Rights

No cuts to DEI and accessibility funding

ASAN opposed appropriations legislation for 2024 that would prohibit federal agencies from funding diversity, equity, inclusion and accessibility ("DEIA") programs. Unfair barriers in education, housing, and employment continue to be major problems that harm people from marginalized backgrounds. These programs are often vital tools for ensuring that disabled people, including multiply marginalized disabled people, have equal access to our society and our democracy.

Endorsed Health Equity and Accountability Act

ASAN endorsed the Health Equity and Accountability Act - a strategic legislative roadmap that aims to eliminate racial and ethnic health inequities. HEAA builds on the progress made under the Affordable Care Act, addressing a broad set of issues including improving health care access and quality for all, ensuring behavioral health services are culturally responsive, and reducing racial and ethnic health inequities across the life span.

Speaking out for immigrant rights

Disabled immigrants to the US are an especially vulnerable part of our community. This year, ASAN took several actions to protect immigrant rights. We opposed immigration provisions under negotiation that would restrict asylum, expand expedited removal and detain families. We signed on to a letter asking the administration to protect immigrant care workers. ASAN also joined the National Taskforce to End Sexual and Domestic Violence in opposing HR 7909, which would harm immigrant survivors of domestic and sexual violence. We also made a public comment in response to the Office of Refugee Resettlement (ORR) seeking to codify the Flores agreement. Our comments focus on strengthening protections against restrictive settings and the use of psychotropic medications for disabled youth under ORR care.

Teighlor McGee Grassroots Mini Grants Program

This year, we announced our new Teighlor McGee Grassroots Mini Grants Program. Created in memory of Teighlor McGee's legacy of empowering grassroots disability work and uplifting self-advocates of color, this program features two different grant categories: The Affiliates In Action Mini Grant and Self-advocates Transforming Equitable Policy (STEP) Mini Grant. These mini grants will provide funding to projects focused on creating change for people with intellectual and developmental disabilities.

No to AI and police surveillance tech that violates student civil and human rights

Nobody should have to give up their right to privacy just to go to school. That's why this year, we joined the No Tech Criminalization in Education Coalition in calling on the Department of Education to ban the use of artificial intelligence (AI) and police surveillance technologies in public schools—technologies used to abuse the civil and human rights of students from historically marginalized communities. These technologies expose students to greater police contact and represent a dangerous new chapter in the school-to-prison pipeline, which disproportionately affects students of color and students with disabilities.

ADA video series

In July, we celebrated the 34th Anniversary of the American with Disabilities Act (ADA), one of the most important civil rights laws for disabled people. In honor of the anniversary, we released a new video series called "A Self-Advocate's Guide to the Americans with Disabilities Act." The video series is an adaptation of our Easy Read and Plain Language toolkit of the same name.

Our Democracy, Our Voices

Advocacy education

Advocacy is for everyone! ASAN believes that everyone should get the tools they need to learn about all kinds of advocacy. That's why in June, we hosted an Advocacy 101 webinar that covered the basics of systems advocacy work, how different kinds of laws and policies impact disabled people, and how everyone can play a part in solving big problems that impact disabled people.

More accessibility in voter registration

The federal government's release of the new digital form filler tool for the National Mail Voter Registration form was a step in the right direction for accessibility. However, the tool is still not fully accessible for many people with disabilities. That's why this year, we commented and signed onto comments with organizations like the Brennan Center and the National Coalition on Accessible Voting, sharing our recommendations for improving the tool's accessibility.

Disabled people count

The Census Bureau proposed changes to the way it estimates the number of disabled people in America, which could skew official disability estimates by no longer counting millions of people with disabilities. This undercounting would make it harder to ensure disabled people can access housing, health care, legal protections, and more. That's why this year, we attended meetings and joined several comments stressing the need for the Census Bureau to engage with and include the disability in discussions around the proposed changes.

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Autism Campus Inclusion

This summer, we held our 13th annual Autism Campus Inclusion leadership academy. 2024 marked our fifth 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 10 days of training and community-building for 15 rising self-advocates. ACI participants use what they've learned to advocate for real change in their communities. To date, we've trained 211 self-advocates at ACI.

Opposed citizenship question on census

The Constitutional purpose of the census is to gather data on the entire population of the United States. Many federal programs vital to the continued health, welfare, and independence of people with disabilities use census data to make decisions. This year, ASAN opposed HR 7109, which would have added citizenship and immigration status questions to the census. Research shows that a citizenship question would likely reduce participation and result in a significant undercounting of the number of people in a state, causing a ripple effect on the lives of thousands of unrelated people with disabilities.

End felony disenfranchisement

Voting is an important part of life in the community. But right now, many people across the country have their right to vote taken away after a criminal conviction—a process known as felony disenfranchisement. With 66% of people in prisons self-reporting having a disability, felony disenfranchisement takes away the right to vote from many disabled people. This year, we urged members of Congress to co-sponsor the Inclusive Democracy Act, which seeks to end felony disenfranchisement.



Accessing Health Care & Services



Medicaid is a vital program for millions of disabled Americans. This year, we joined The Disability and Aging Collaborative to urge swift action on legislation to improve the functionality of the Medicaid program, to increase access and improve program integrity. One of the improvements we suggested was making the Money Follows the Person program permanent. MFP provides funding to allow disabled people transition from institutions to home and community based services. The Collaborative also asked to make spousal impoverishment protections permanent, increase flexibility around institutional level of care requirements, and to end estate recovery, which harms low-income disabled people.

Medicare for people returning from incarceration

Reproductive justice amicus briefs

Reproductive justice and bodily autonomy

information about how restrictions on

reproductive rights harm disabled people. In Moyle v. United States, our brief explained how the Emergency Medical Treatment and Labor Act's lifesaving protections include

emergency abortions. Our brief in FDA v.

reinforce barriers like inaccessibility of

medical facilities and difficulty accessing

transportation. And in Zurawski v. State of

Texas, we refuted the state's argument that

abortion bans protect disabled people from

discrimination and argued that these laws

actually strip us of bodily autonomy.

Alliance for Hippocratic Medicine explained

how restricting access to Mifepristone would

matter for everybody, especially people with disabilities. Disabled people already face higher risks during pregnancy and additional barriers in accessing health care. ASAN joined multiple amicus curiae briefs offering courts

Medicare regulations currently exclude anyone "in custody" from receiving Medicare reimbursed services. However, Medicare's definition of "custody" also includes people living in the community, such as people required to live in halfway houses or under supervised release. Because of this overly broad definition, many older adults and people with disabilities who have interacted with the criminal legal system, even those now living in the community, cannot access vital health care services. That's why this year, we signed on to a letter asking HHS to amend the definition of "custody" to align with Medicaid and ACA marketplace definitions, and allow more people returning from incarceration to access health insurance.

Letter to CMS: Make it easier to keep health insurance

ASAN joined Community Catalyst and several other organizations in a letter urging CMS to improve Medicaid access after the "unwinding" process. We recommended that states actively reach out to people de-enrolled for procedural reasons, helping them re-enroll or apply for alternative programs if they no longer qualify. We also pressed CMS to ensure states follow through on plans made during negotiations and enforce timely processing requirements for both Medicaid and SNAP applications.

Disability Reproductive Equity Day

Disabled people, particularly disabled women, disabled BIPOC, and LGBTQ people with disabilities, have long faced challenges to our bodily autonomy. On May 23, we joined a long list of organizations in observing the first-ever Disability Reproductive Equity Day. This day highlighted the critical need for policies that center bodily autonomy and expand access to sexual and reproductive health care for disabled people. We also supported the Senate Resolution to establish Disability Reproductive Equity Day.

Bupports & Community Living shoot

REAL WORK FOR REAL PAY

Disabled people deserve to work at the same places and for the same pay as nondisabled people. This isn't news—but in 2024, some of us are still being paid less than the minimum wage in segregated workplaces. This is called subminimum wage, and it most commonly happens in sheltered workshops. This year, ASAN joined the American Association of People with Disabilities and the National Council on Independent Living on a webinar to talk about why we need policy change to end this harmful practice. We also continued our fight to get the Transformation to Competitive Integrated Employment Act (TCIEA) passed, mobilizing our grassroots to urge their Senators to take action to support the bill. TCIEA is a bill that would give states and businesses the help they need to create competitive integrated employment opportunities for disabled people. We also provided written testimony to Congress on the importance of Competitive Integrated Employment to the disability community.



Federal law currently requires state Medicaid programs to seek repayment of costs for long term supports and services (LTSS) used by people 55 and older. This is known as Medicaid estate recovery. Medicaid estate recovery specifically targets people with disabilities, older adults, and their families. Many people end up selling their family homes to pay for estate recovery costs of their relatives' LTSS. Estate recovery punishes families for being poor, undermines families' efforts to build wealth, and adversely affects homelessness and access to affordable housing. That's why this year, we supported the Stop Unfair Medicaid Recoveries Act. The Act would ban Medicaid estate claims except in rare cases where benefits were incorrectly paid.

LONG-TERM CARE WORKFORCE SUPPORT ACT

Many people with disabilities and older adults rely on the support of direct care workers to live independently. Right now, there is an extreme shortage of care workers to fill those positions. Medicaid and Medicare service providers cannot compete on wages with for-profit businesses unless the government provides the funding to raise wages. That's why this year, we joined the Disability and Aging Collaborative in supporting S.4120, the Long-Term Care Workforce Support Act, which would increase funding to support and expand the direct care workforce.

HOUSING INSECURITY IS NOT A CRIME

People with disabilities are more likely to be unhoused or deal with housing insecurity than people without disabilities. In 2023, the Department of Housing and Urban Development (HUD) estimated nearly one-third of people experiencing homelessness are experiencing chronic homelessness and have a disability. This year, we joined an amicus brief in the case of City of Grants Pass, Oregon v. Johnson. The case was about whether enforcing camping bans on public property against unhoused people is cruel and unusual punishment. All people deserve to live self-directed lives in the community of their choosing. Criminalization and institutionalization of people experiencing homelessness cannot be the answer—we must end the housing crisis and ensure that all people have access to safe and adequate places to live.

Occupational Classification for Direct Support Professionals

Direct support professionals (DSPs) are crucial for many disabled people who get services through Medicaid Home and Community Based Services (HCBS). The ongoing shortage of DSPs threatens many people's ability to live in the community. Right now, there's no way to collect comprehensive employment and wage data specifically about DSPs, making it difficult for the government to understand the workforce crisis. Creating a unique standard occupational code (SOC) for DSPs would help the government collect this data. That's why this year, we supported the Recognizing the Role of Direct Support Professionals Act, a bill that would help create SOCs for direct support professionals. We also commented in support of a revision to the SOC Manual that would create the new code.

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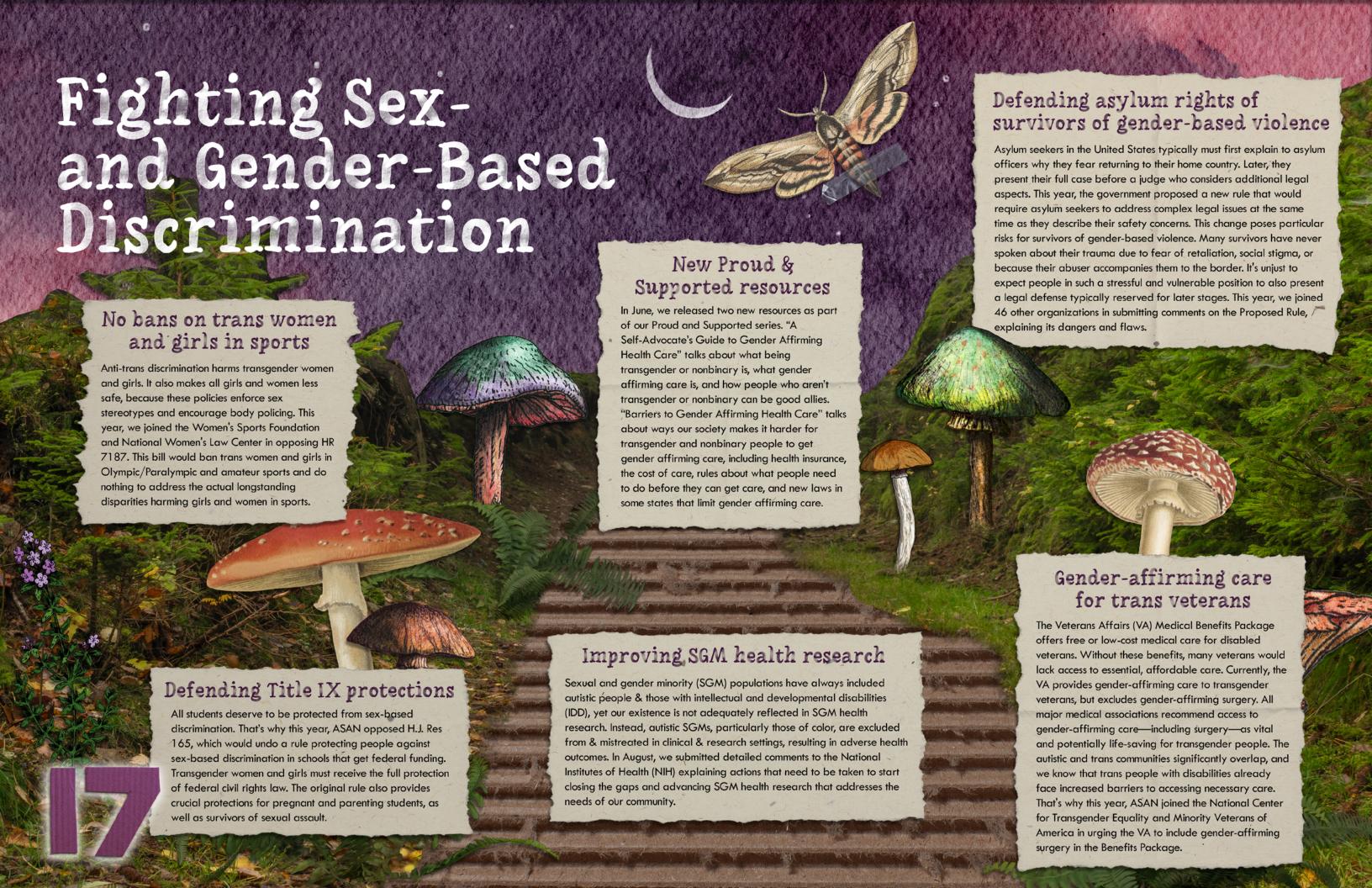
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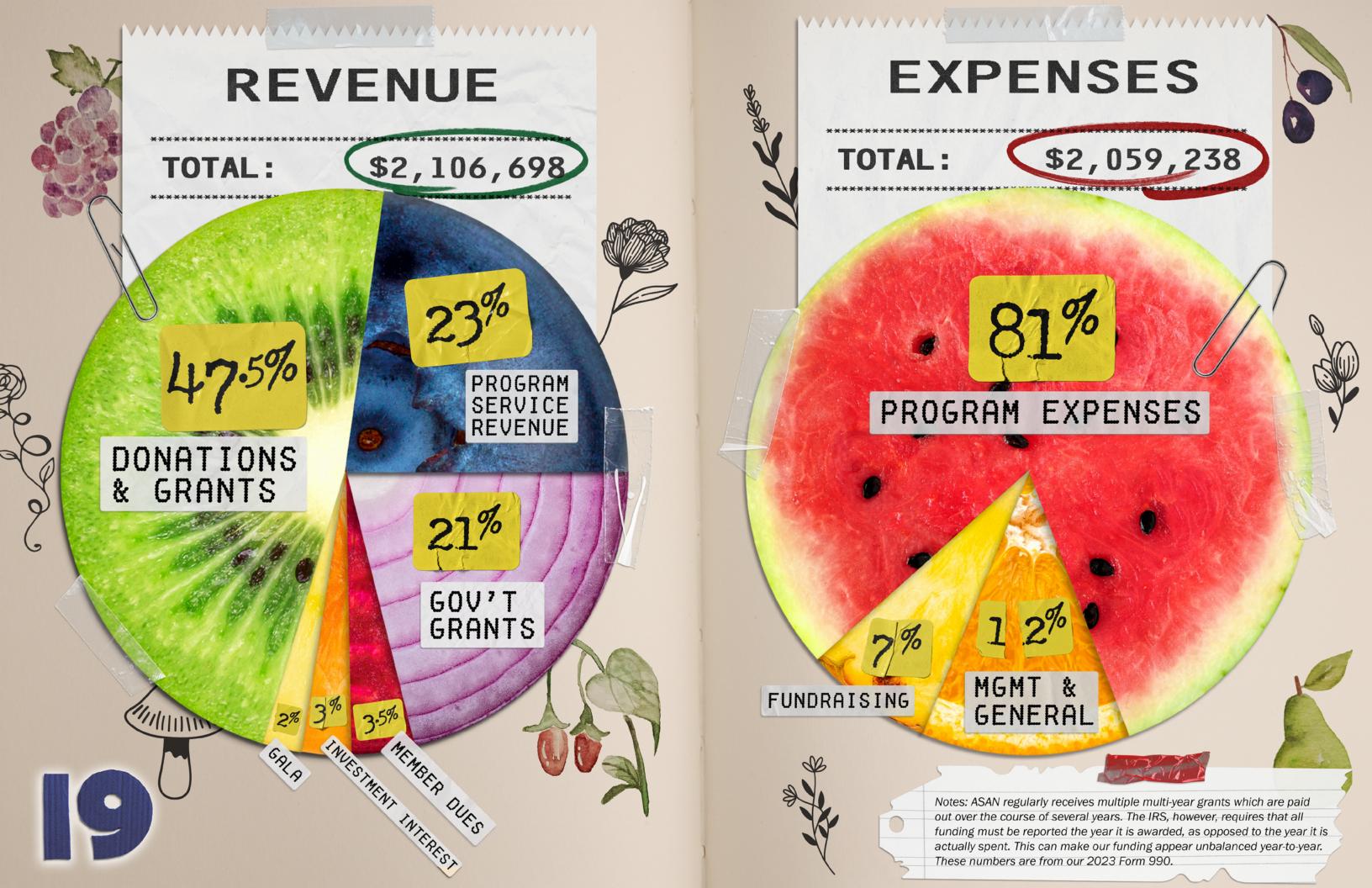
Increasing Housing Access for Disabled People with Criminal Records

All disabled people have the right to live in our communities. But there are often many barriers to accessing affordable housing, especially for people with criminal records. People with disabilities are overrepresented in that group, with 2/3 of incarcerated people self reporting having a disability. That's why this year, we joined the Consortium for Constituents with Disabilities in supporting the Department of Housing and Urban Development (HUD)'s work to make it easier for people with arrest and conviction histories to apply to HUD-assisted housing.

NEW RESOURCE ON BEHAVIOR SUPPORT SERVICES

For decades, self-advocates with intellectual and developmental disabilities (IDD) have pointed out that behavior is communication, and all behavior happens for a reason. When people with IDD want help changing our behavior — or more often, when other people want to change our behavior — we sometimes get services called "behavior supports." What people call "behavior supports" covers a wide variety of services, and not all of these services are truly helpful to people with IDD. Our new resource, "Beyond Coercion and Institutionalization: People with Intellectual and Developmental Disabilities and the Need for Improved Behavior Support Services" takes a deeper look at the history of behavior supports, what's available today, and what needs to change.





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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Thank you to our volunteer Day of Mourning vigil site coordinators, those who interviewed with us for research projects, and everyone who joined our advocacy campaigns or wrote public comments this 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 18 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.