

2020 Annual Report

Doing the Impossible in Impossible Times

From the Desk of the Executive Director

Dear friends,

2020 was a year of unprecedented challenges for the disability community. Our community was suddenly facing a global pandemic and a cascade of other setbacks: health care rationing, challenges getting our basic needs met safely, a continuing crisis of anti-Black police violence, difficulty voting safely. Meeting the needs of our community in this moment seemed impossible.

Fortunately, doing the impossible is exactly what the disability community has always done. This year we celebrated the 30th anniversary of the ADA, which disability activists fought hard against powerful opponents to pass. We also celebrated the 10th anniversary of the Affordable Care Act — after many in 2017 had said repeal was inevitable. We celebrated when the FDA banned electric skin shock devices, a victory that advocates, survivors and allies fought for for decades and which had often seemed impossible to many.

In this year's Annual Report, you'll see how we confronted the impossible challenges of 2020. From fighting discrimination in COVID-19 treatment, to standing up for the human rights of all people with disabilities, to creating accessible resources on voting by mail and so much more, we've been fighting for every disabled person to have the tools they need to survive and be heard.

As we look ahead to 2021, we'll continue to confront the crises our community faces, including police violence & racial injustice, underfunding of community services, attacks on our access to health care,

and the pandemic itself. We also hope that in the coming year, there will be times when our community is not forced to spend every moment fighting for survival, and we can focus on building new things together — new partnerships, new understandings of disability justice, and new policies that will allow people with disabilities to truly thrive.

In solidarity,

Julia Bascom

Julia Bascom
Executive Director
Autistic Self Advocacy Network



ADA Toolkit

In 2020, we celebrated the 30th anniversary of the Americans with Disabilities Act becoming the law of the land. The disability community fought hard to get the ADA passed, and we continue to fight hard to protect it. As part of our celebration this year, we released a brand new plain language toolkit called A Self-Advocate's Guide to the Americans with Disabilities Act.

Welcome to the Autistic Community

Our classic Welcome to the Autistic Community resource has been fully re-imagined as a full-length book and accompanying website. The website, AutismAcceptance.com, allows readers to browse through the book's content for free in an accessible way. It also has a full glossary of important words used in the book as well as a list of other resources for both newly-diagnosed autistic people and non-autistic people who want to learn more.

Join Us!

This year, we launched our new membership program, completely restructuring the way that being an ASAN member connects you to the organization. Each member level is named after a different common special interest among autistic people, and each level also comes with its own perks! Self-advocates can get a digital membership for free and enjoy the perks that come with it.

Get Counted

Every 10 years, the government uses the Census to count how many people are in the country. The census is important because it is used to figure out how much money state and local governments get for Medicaid, housing vouchers, and more. That's why this year, we partnered with the Arc to disseminate "You Count! Be Counted.", a series of accessible promotional & educational materials about the Census, including a webinar about what the census is, why it's important, and how to get counted.

Take Action

We released our new Action Center, a one-stop shop for taking meaningful action on vital disability policy issues. The action center hosts our action alerts, plain language explanations of important policy issues, a resource library, and more! You can use it to find your legislators, learn more about issues important to you, and find ways to take action on the issues you care about.

Get Out & Vote

Understanding voting is an important part of living in the community and participating in our democracy. People with disabilities deserve to understand how to vote. This year, we've expanded the ways we can share this information by partnering with our friends at the National Disability Rights Network to make plain-language, picture-assisted videos about [election day](#) and [voting with a disability](#). We also released a new, plain-language guide to voting by mail during COVID-19, along with a full-length Easy Read toolkit called Your Vote Counts: A Self-Advocate's Guide to Voting in the U.S.

New Ways to Get Involved



Rights & Inclusion

Civil Rights in School

This year, ASAN worked closely with the Leadership Conference on Civil and Human Rights (LCCHR), a coalition of civil rights organizations, to try to ensure that all people - including people with disabilities - are able to exercise their civil rights. In particular, we worked on bills to address restraint and seclusion, ban corporal punishment, and eliminate the school to prison pipeline and other practices that hurt students with disabilities - especially students of color with disabilities.

Day of Mourning

This year, vigils were held at 37 sites across the United States, Canada, and the UK for the 9th 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.



Person-Centered Planning

The person-centered planning process can help make sure that people with disabilities have control over how our own services and supports work. The National Quality Forum was tasked with convening a committee to give recommendations on standards for person-centered planning. The Committee was originally formed without the input of self-advocates who would most benefit from improved person-centered planning—but we pushed back and insisted self-advocates be given a seat at the table. As a result, the committee's final report is strengthened by the perspectives of the people most impacted.

Training Self-Advocates

This summer, we held our 9th annual Autism Campus Inclusion leadership academy. This was our first year holding a virtual ACI, and we were pleased that despite the new format we were still able to create autistic space for our students and provide a week of training and community-building for 14 rising self-advocates. 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 151 self-advocates at ACI.

Flying with ESAs

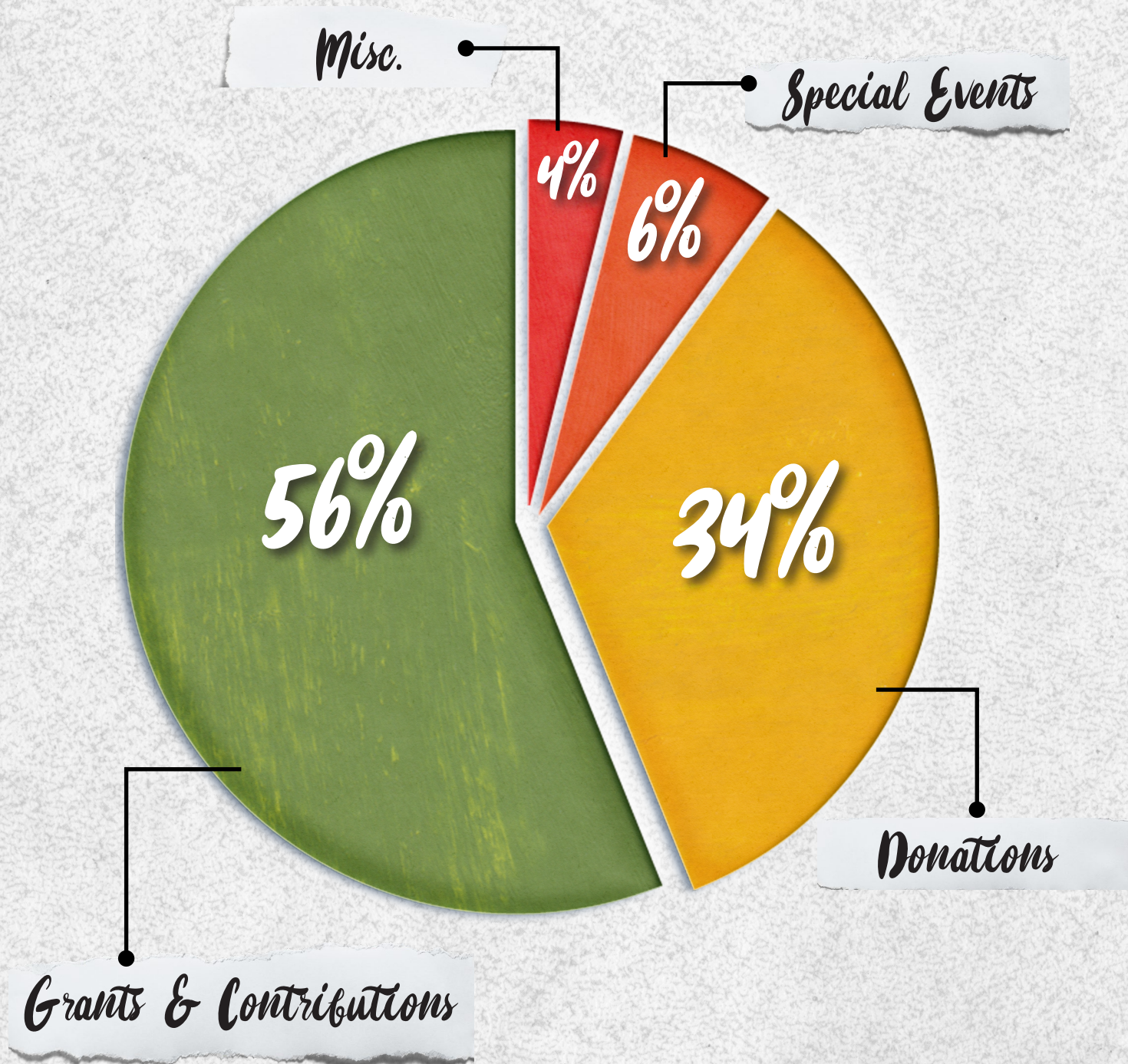
Emotional support animals are disability accommodations. That shouldn't be up for debate. So this year, when the Department of Transportation proposed a rule that would officially bar ESAs from being considered service animals, we were quick to oppose the rule and explain how this would result in extensive discrimination against people with disabilities.

No Health Care Discrimination

Health care is a human right. Section 1557 of the Affordable Care Act prevents health care providers from discriminating on the basis of "race, color, national origin, sex, age, or disability" -- giving many Americans the ability to access health care that works for us, with information that we can understand. This year, we fought back against attempts to undo those protections, alongside a wide coalition of other civil rights organizations.

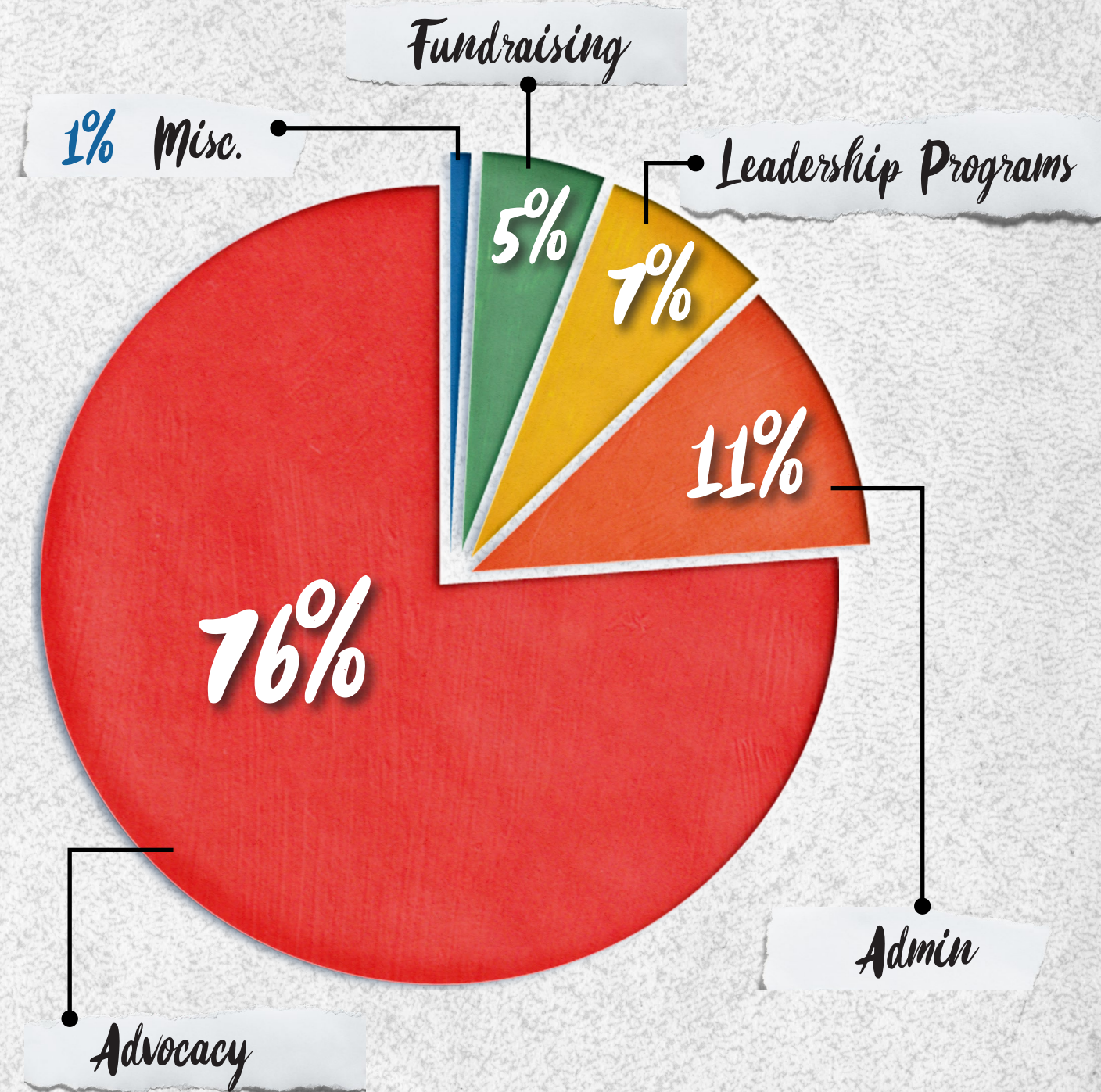
Revenue

\$1,014,159



Expenses

\$835,055



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.

More Just Policy

We applauded the House of Representatives for passing the Justice in Policing Act, which establishes a police misconduct registry and eliminates qualified immunity for police officers. This bill is a good first step, but we know these reforms do not go far enough - so ASAN urged Congress to eliminate police presence in schools, eliminate qualified immunity for all government employees, and significantly shrink the amount of money being funneled to police departments. We particularly campaigned for stronger accountability for police officers who injure or kill civilians and for the redistribution of law enforcement resources towards community-based, high quality, trauma-informed mental health services for people in crisis.

Justice for Matthew Rushin

We submitted a letter to Virginia Governor Northam, alongside the Autistic Women & Nonbinary Network, about the case of Matthew Rushin, a Black autistic man who was jailed following a driving collision. We are concerned that Matthew was not given the supports he needed to fully understand and participate in his hearing, casting doubts on the validity of his conviction. Additionally, the prison system is ill-equipped to accommodate his health care needs. We urged Governor Northam to review Matthew's case critically and to focus on a transformative justice solution rather than defaulting to incarceration. This November, Matthew was given a partial pardon and is set to be released in early 2021, according to his legal team.

Justice

Disability Rights are Human Rights

After every civil rights victory for people with disabilities, we see a backlash claiming that some people are "too disabled" to have the rights that our community has fought for. But our basic human rights are not meant to be selectively distributed. They are for everyone — no exceptions. That's why this year, ASAN and 30 supporting organizations released a joint statement on the universal civil & human rights of people with high support needs.

#FreeNeli

In 2010, Neli Latson was arrested for simply being a Black, disabled man. For years he was imprisoned and punished for behaviors related to his disabilities. The prosecutors rejected an offer of disability services as an alternative to incarceration. In 2015, Neli received a conditional pardon — but the terms of this pardon require him to live in a restrictive residential setting and be subjected to on-going supervision by the court system. This year, as part of a coalition of nearly 50 advocacy groups and legislators, we continued our fight to demand that Governor Northam use his pardon power to #FreeNeli and rectify this egregious miscarriage of justice.

#StopTheShock

In March, the Food and Drug Administration finally released their ban on the electric shock devices used to torture children and adults with disabilities at the Judge Rotenberg Center. The FDA final ban was released after decades of work from advocates in every sector who brought the abuse to light, insisted that it was wrong, and fought to end it. We are grateful to everyone who took a stand, and to the volunteers and grassroots organizers who joined ASAN's advocacy campaigns and helped us hold the FDA accountable. Most of all, we are grateful to the JRC survivors, without whose testimony the ban would never have been achieved. There's still more work to be done - the ban has not yet been fully implemented, and the JRC remains open and able to use other inhumane methods - but we are emboldened by this first victory on the path to many, many more.

What is Police Violence?

Standing against police violence is a critical part of fighting for disability rights. With protests against anti-Black police violence going on all over the country, we wanted to provide an accessible resource for learning about what is happening — and how all of us can help create change. That's why this year, we worked with the American Association of People with Disabilities and Green Mountain Self-Advocates to make "What is Police Violence?: a plain language booklet about anti-Black racism, police violence, and what you can do to stop it".





Institutions: The Old, the New, and What We Should Do

Community living is a human right for everyone. Unfortunately, many members of our community are still unjustly segregated in institutions away from everyone else. The disability community has been fighting for deinstitutionalization for years, and we want to make sure everybody has the tools they need to join the fight. That's why this year, we released two new Easy Read toolkits: "Institutions: The Old, The New, And What We Should Do" and "The Cycle of Institutions." These toolkits explain the history of institutions in America from the 1840s to the present, the laws related to institutions, and what we can do now to ensure community living for all people with disabilities.

HCBS Rule

The Home- and Community-Based Services Settings Rule, or HCBS Settings Rule, allows people with disabilities to access resources we need to live in the community. The Rule was supposed to go into effect in 2019, but CMS keeps pushing the date back. During COVID-19, the best way to protect the health and well-being of people with disabilities is to ensure that all of us can live in the community. The HCBS Settings Rule would help make that possible, but only if CMS commits to a timely implementation of the Rule. We published a statement in opposition to any further delay on implementation. We will continue to fight until our community finally gets the rights we have been promised.

Keeping Us in Our Communities

People with disabilities do best when we're able to get supports in our communities. Preadmission Screening and Resident Review (PASRR) helps prevent people with some kinds of mental disabilities on Medicaid from being institutionalized against their will when community options are available. The Center for Medicaid Services proposed a rule that would make PASRR less effective. We submitted comments protesting those changes.

Housing Rights

People with disabilities have the right to live in our communities with the services and supports we need. Federal regulations protect the housing rights of people with disabilities, people of color, and other marginalized groups by promoting integrated communities. But this year, the Department of Housing and Urban Development proposed a rule that would undermine those rights and strengthen segregation instead. ASAN pushed back by submitting extensive comments outlining the ways this change would drastically impact the ability of people with disabilities, people of color, and other marginalized groups to live in our communities.

Community
Living

Ensuring Good Care

Crisis standard of care plans are used to decide who receives life-saving treatment during COVID-19. In many states, these plans discriminate against people with disabilities, older adults, and people of color, placing these communities at risk of being denied basic and emergency treatment during the pandemic. This year, we worked with our partners to create resources for states on what a good visitor policy and a good crisis standard of care plan would look like. We also joined our coalition partners in challenging Arizona, Texas, Washington, Alabama, Kansas, Tennessee, Oklahoma, North Carolina, Oregon, and Utah's crisis care plans, as well as participating in advocacy around supporters in Rochester, New York. As of this writing, the complaint against Utah's plan As of this writing, the complaint against care plans in Utah, Alabama, and Tennessee have been resolved, ensuring that people with disabilities will receive the care they need.

Accessible Guides to COVID-19

The pandemic has dramatically changed the lives of millions of Americans - including people with disabilities. But a lot of the key information about COVID isn't written in an accessible way, effectively barring many people with disabilities from accessing critical information. That's why this year, we collaborated with Green Mountain Self-Advocates to release A Self-Advocate's Guide to COVID-19, a plain-language toolkit available in both English and Spanish covering everything from bringing supporters with you to the hospital to understanding the stimulus check. We also worked with Rooted in Rights to create a 5-minute long animated video called "What You Need to Know About COVID-19".

Mobilizing the Community

Throughout the COVID-19 pandemic, we mobilized our community through sustained call-in and email campaigns to pressure Congress to protect the disability community and pass a COVID-19 relief bill that included emergency funding for home- and community-based services (HCBS).

Tracking Cases in Institutions

COVID-19 fundamentally changed how we lived this year. Early on in the pandemic, we realized that while new infection numbers were published daily, there was no accurate accounting of infections and deaths among people in institutions across the US. The federal government refused to collect the full data, or require states to do so; states that did choose to collect data on COVID-19 in institutions released it in non-standardized ways. Rather than wait for someone else to take the lead, we created the COVID-19 Case Tracker in just two days. Continuously updated by ASAN staff, our Case Tracker combines information from news articles and state & local government reports, to give us the most complete picture possible of how COVID-19 is affecting people with disabilities in institutions.

Support for Supporters

Many people with disabilities need supports in order to safely get care in a hospital or doctor's office. During the COVID-19 crisis, some hospitals were enforcing capacity limits by selectively allowing supporters to accompany children and people giving birth, while barring people with disabilities from having their supporters with them. We led a letter along with more than a hundred national, state and local advocacy organizations urging governors and hospital administrators to update their guidance to allow exceptions for all people with disabilities who need supports.



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 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 14 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.