

2021 Annual Report

# ALL ABOARD!

*Autistic Self Advocacy Network*







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# 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 the Executive Director

Dear friends,

Self advocacy is about recognizing the power we have, as individual people and as a community, and using it to build a better world. The self-advocacy and neurodiversity movements have been building power through decades of work, organizing, and community building by those who came before us. This work began long before ASAN existed — it's what made ASAN possible to begin with. Our community has built networks and hubs like train tracks, stretching across the US and around the world.

This year, ASAN has continued to work to build the power of the disability community. Through accessible information in plain language and Easy Read, we are spreading the tools of civic engagement to make sure everyone is equipped to have a say in policies that affect us. We've fought to end subminimum wage, ban restraint and seclusion, expand home- and community-based services, and more. We haven't seen the finish line in many of these fights — but we are building the power to get us there. We are seeing a future where "nothing about us without us" echoes in the halls of power.

This year, like many previous years, we have been asked: who decides what happens to autistic people? Who decides what research is done about us? Who decides what therapies are used on us? This year, we've made our answer loud and clear: we decide. As we build our power, we fight to change the world for everyone. As we lay new tracks, we bring more and more of our community aboard and we move forward together.

All aboard!

*Julia Bascom*

Julia Bascom  
Executive Director  
Autistic Self Advocacy Network





# Inclusion & Representation

## Representation at the IACC



The IACC is a committee that advises the federal government on autism issues and oversees federal autism research spending. When the IACC announced its new membership this year, ASAN was excited to see a larger and more representative cohort of self-advocates than ever before. For the first time ever, one third of the IACC's public membership are self-advocates. These self-advocates include self-advocates of color, a full-time AAC user, and a self-advocate with an intellectual disability. Many of the self-advocates are themselves also parents of autistic children or representatives of autism organizations; ASAN is pleased to report that our Legal Director, Sam Crane, has returned for an additional term. We'll keep fighting for the IACC's membership to be majority autistic people, and for federal autism research spending to reflect the priorities of the autistic community.

## Reflecting on 10 Years of Autism Acceptance



2021 marked the 10th anniversary of Autism Acceptance Month. Ten years ago, when Autism Acceptance Month started, advocacy organizations run by non-autistic people spoke openly about working towards a future in which "autism is a word for the history books." In contrast, autism acceptance emphasizes that autistic people belong — that we deserve welcoming communities, inclusive schools and workplaces, and equal opportunities. In our statement reflecting on the last ten years of Autism Acceptance Month, we issued a challenge to parent- and provider-led autism organizations: Listen to and center the voices of autistic self-advocates. Learn from us and change how you think about autism, and how you work to represent autistic people. Make real, structural changes, and join self-advocate-led organizations in working to make acceptance more than just a buzzword.

## A Guide for Parents of Autistic Kids



At ASAN, we've heard from many parents of autistic children who wish they'd had a better resource to learn about autism — one that cuts through myths and misconceptions and explains autism from an autistic perspective. And we've heard from many of our autistic community members who wish their families had access to that kind of information when they were growing up. That's why this year, we worked with the Autistic Women and Nonbinary Network, Thinking Person's Guide to Autism, and Little Lobbyists to produce our new booklet, *Start Here: A Guide for Parents of Autistic Kids!*

## Defending Trans Rights in Alabama



There is a significant overlap between the autistic and transgender communities — and since autistic people first began organizing, many of our strongest leaders have been trans and intersex. An attack on trans people's rights is an attack on the autistic community. So when an Alabama law made transgender Alabamans choose between expensive, invasive surgery and being misgendered on their drivers' licenses, we joined an amicus brief explaining why the law was so harmful to trans people.

## Sharing Your Story for a Political Purpose



Telling your story is a great way to make a difference — and because it's your story, there's no one better to tell it! Our stories are powerful political tools, and we can use them to make real change. Hearing a real person talk about a policy problem gives policymakers a name and face to remember. That's why this year, we released our new plain language toolkit, *Sharing Your Story for a Political Purpose*.

## Disability Voter Registration Week



Everything from education funding to curb cuts to health care is affected by public policies, and voting is a hugely important way to have a say in those policies. That's why it's so important that all people with disabilities make our voices heard by registering to vote. In September, we participated in National Disability Voter Registration Week, sharing plain language resources about registering to vote, voting with a disability, and election day.

## New Guide to Making Easy Read Resources



Easy Read resources help make sure that all people with disabilities have the tools we need to understand and speak out about policy that affects our lives. At ASAN, we have learned a lot about making Easy Read resources since we started making them in 2016. We have worked closely with people with intellectual disabilities to make our Easy Read words and icons easier to understand. We hope that by sharing what we have learned, we can help more people and organizations release accessible resources in Easy Read and Plain Language. That's why this year, we released *One Idea Per Line: A Guide to Making Easy Read Resources*.





# Supports & Self-Determination



## Supports for Everyone

In the case of *A.V. v. Tri-Counties Association for Developmentally Disabled*, A.V. was denied access to services because he had "Asperger's" and not "autism." We submitted an amicus brief explaining why the DSM-V criteria should be used when evaluating whether people qualify for DD services. The California Court of Appeals agreed that the DSM-V standard was the one that should be used. After that decision, A.V. was able to access the services he needed.

## Including HCBS in COVID Relief

The COVID-19 pandemic exposed many of the dangers of institutionalization. Expanding home- and community-based services (HCBS) would ensure that disabled people can live in our communities while also getting the services and supports we need to thrive. That's why this year, we worked with our grassroots to urge Congress to include HCBS in their COVID relief legislation—and thanks to you, we succeeded! The final package will include \$150 billion in funding for HCBS, expanding services for people with disabilities and improving wages for our support workers.

## New Guide to Managed LTSS

Many people with disabilities rely on long-term supports and services (LTSS)—like job coaches, transportation, and in-home helpers—to live independently. Managed care is one of the ways that states can run their LTSS programs. When it's done right, managed LTSS can help people move out of institutions and get better support in the community. But self-advocates need to be closely involved in managed LTSS programs if they are going to work. Our toolkit, *A Self-Advocate's Guide to Managed Long-Term Supports and Services* is an easy-to-understand guide to what managed LTSS is and how you can make sure your state's MLTSS program is designed with LTSS users in mind.

## Who's In Control?

In 1993, Roland Johnson, one of the founders of Self-Advocates Becoming Empowered, gave a famous speech called "Who's in Control?" In this speech, Johnson talked about how people with disabilities — not our service providers or staff — need to have control over our lives. Medicaid uses quality measures to find out whether someone's services are good or bad. But how do we measure who is in control? ASAN's new toolkit *Who's in Control?: Control over community services for people with disabilities* explores this question.

## HCBS Access Act

It's a fact: people with disabilities do better when we can get supports and services in our own homes and communities. For years, we've been pressuring Congress to allocate more money for home- and community-based services (HCBS) and end the institutional bias in Medicaid. This year, we were thrilled to work with Congressional offices to draft a bill called the HCBS Access Act (HAA), which would end the institutional bias and add HCBS as a mandatory Medicaid service. The HAA would build on the promises of the Americans with Disabilities Act and the Supreme Court's Olmstead decision and provide the Federal Medicaid resources necessary for states to fulfill those promises, so that no people with disabilities or older adults are forced to live segregated from their communities.

## #FreeBritney

The Autistic Self Advocacy Network joined the American Civil Liberties Union (ACLU) and numerous other civil rights organizations in filing an amicus brief in Britney Spears' conservatorship case. The brief explains that all people under conservatorship — including Ms. Spears — have the right to choose their own lawyer to represent their interests. The brief also explains that people under conservatorship should get supports to help them decide who to hire as their lawyer.





# Education & Employment



## Benchmarks to Inclusion



This year, we released a new white paper, "Benchmarks to Inclusion: Creating Core Principles to Facilitate Autistic Student Success in Higher Education". We brought together autistic college students to discuss what success looks like for autistic students, and how colleges can help them get there. Our white paper unpacks barriers to success, looks at how those barriers can be addressed, and lays out ten core principles to make higher education more accessible to autistic students. We also released summaries of our white paper in plain language, Easy Read, and academic formats.

## Wage Protections for Disabled Federal Contractors



It has been over 80 years since the Fair Labor Standards Act was passed and people with disabilities were excluded from minimum wage protections. This year, when the government passed an executive order raising the minimum wage for federal contractors, we were pleased to see that contractors with disabilities were automatically included as part of the order. We'll keep fighting to ensure that all workers are extended the same protections now afforded to federal contractors with disabilities.



## Autism Campus Inclusion



This summer, we held our 10th annual Autism Campus Inclusion leadership academy. This was our second year holding a virtual ACI, and we were pleased that even via a virtual format we were still able to create autistic space for our students and provide a week of training and community-building for 21 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 173 self-advocates at ACI.

## Fighting for a Fair Wage



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 at dead-end, segregated workshops that pay pennies on the dollar. That's why this year, we've continued our fight for an end to subminimum wage. In January, we supported the introduction of the Raise the Wage Act, which would raise the federal minimum wage from \$7.25 to \$15 an hour and phase out subminimum wages. We supported the introduction of the The Transformation to Competitive Integrated Employment Act (TCIEA), which would end the discriminatory practice of subminimum wage and give states and service providers the resources they need to create better employment support programs. We also successfully fought for the Build Back Better Act to include incentives for states to transition away from subminimum wage. Every day, we get closer to ending subminimum wage and winning fair pay for all disabled workers!





# Health Care

## Working with HHS Leadership

When the new administration took office, we were grateful to be one of the disability organizations invited to meet with Health and Human Services (HHS) Secretary-designate Xavier Becerra for a roundtable discussion about ensuring access to quality, affordable health care, home and community-based services, and the current barriers to access for people with disabilities. We discussed our community's needs and challenges during the COVID-19 pandemic and welcomed the chance to hear the new administration's plans for addressing our concerns.

## Louisiana HB 255 Withdrawn

Everyone deserves to have their bodily autonomy respected - including people under guardianship. This year, ASAN helped advocate against Louisiana bill HB 255. The bill would have banned abortion entirely for people under guardianship, regardless of their wishes or medical needs. Thanks to the advocacy of ASAN and many other groups, the bill was ultimately withdrawn.

## Organ Transplant Bill Based on Our Model

ASAN created model legislation on organ transplant discrimination, providing an example of effective anti-discrimination legislation that advocates can propose to their state legislatures. This year, a bill based on our model legislation, the Charlotte Woodward Organ Transplant Discrimination Prevention Act, was re-introduced in Congress.

## Intersectional Crisis Standards of Care

In February, as part of a national coalition of civil rights groups and legal scholars, ASAN released a new report: "Examining How Crisis Standards of Care May Lead to Intersectional Medical Discrimination Against COVID-19 Patients." Crisis standards of care are used to decide who should receive priority for treatment when there are not enough resources to serve everyone. The report explains crisis standards of care policies implemented by states and hospital systems and how they may discriminate against people with disabilities, older adults, higher weight people, Black people, Indigenous people, and other people of color, in hospital care. It also outlines principles that can help prevent discrimination, the relevant civil rights legal framework, and recommended strategies to ensure that crisis standards do not discriminate during the pandemic or in the future.

## End of Medicaid Work Requirements

We've been fighting for years against adding work requirements to Medicaid. Work requirements tie the ability to receive Medicaid benefits to the ability to work. This harms people with disabilities—and everyone who relies on Medicaid for health care. We know that work requirements are cruel, ineffective, and unnecessary. The Trump Administration had approved work requirements in several states, and we were glad to see the Biden Administration reverse those approvals. Going forward, ASAN will keep up the fight for Medicaid programs in every state to cover more services and people—not fewer.

## Reproductive Rights and Disability Justice

Reproductive health, rights, and justice are all crucial issues - and they're also disability issues. That's why this year, ASAN partnered with the National Partnership for Women & Families to produce "Access, Autonomy, and Dignity: A Series on Reproductive Rights and Disability Justice." This series of issue briefs explores four areas at the intersection of reproductive and disability rights: access to abortion, access to contraception, sex education, and the right to parent. The briefs delve into the unique challenges people with disabilities face in seeking reproductive justice and present recommendations for laws and policies that will protect our rights and uphold our dignity.

## Accessible COVID-19 Resources

We continued to work to make sure that information about COVID-19 — and the benefits of COVID relief legislation — are accessible to all people with disabilities. COVID-19 is especially dangerous to people with intellectual and developmental disabilities, but too often, the facts about COVID-19 are not shared in ways that are accessible to us. That's why this year, we've expanded our library of accessible COVID-19 resources to include a vaccine fact sheet as well as videos in both English and Spanish.

## ASAN-DREDF SCOTUS Amicus Brief

Reproductive freedom is a disability rights issue. This year, ASAN partnered with the Disability Rights Education and Defense Fund (DREDF) to submit an amicus brief to the Supreme Court explaining the harms of a Mississippi law banning abortions before 15 weeks. ASAN and DREDF's amicus brief explains that when the government decides what happens to our bodies, that can hurt us. To write the amicus brief, ASAN talked to many disabled people who got abortions, including people of color and trans people. They talked about how much it mattered to be able to make their own decision. Some said they would have died if they had been forced to stay pregnant. We're grateful to them for sharing their stories, and we will continue to fight for the reproductive rights of all people.





# Safety

## Day of Mourning



This year, vigils were held at 37 sites both virtually and in-person across the United States, Canada, South Africa, Mexico, the Netherlands, and Australia for the 10th 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.

## Keeping All Students Safe Act



This year, ASAN continued fighting for Congress to pass the Keeping All Students Safe Act (KASSA). Restraint and seclusion can be life-threatening and are often incredibly traumatic. They are disproportionately used on students with disabilities and students of color. KASSA would ban almost all kinds of restraint and all kinds of seclusion across all 50 states, and would require school districts to collect data to prevent further use of these dangerous practices. Disabled students deserve better than restraint and seclusion, and passing KASSA is an important step forward that our community wants and needs.

## Full Pardon for Neli Latson



After more than a decade of unjust prosecution and abuse in the criminal justice system, Neli Latson, a Black autistic man with multiple disabilities, was finally granted a full pardon by Virginia Governor Ralph Northam. ASAN has been seeking justice for Mr. Latson since 2014. A coalition of nearly 50 advocacy groups and legislators sent a letter to Governor Northam in July 2020 calling for him to grant Mr. Latson a full pardon. Neli's unjust treatment is just one example of the systemic harm inflicted on disabled people of color by the criminal justice system. While we celebrate Neli's pardon, ASAN will continue to fight for a more just and transformative vision of justice.

## #StopTheShock



All of us were stunned and outraged when a federal appeals court overturned the FDA's ban on the electric shock devices used at the Judge Rotenberg Center. The FDA appealed the court's decision; while the appeal is pending, the ban is still overturned. As long as the residents of the JRC, most of whom are disabled people of color, are in danger, our work is not done. This year, we continued our #StopTheShock campaign, publishing statements explaining the court's decision and the FDA's appeal alongside urging our grassroots to support efforts in the Massachusetts state legislature to ban electric shock devices as well as to call on prominent organizations to denounce the JRC.

## Police-Free Mental Health Responses



Police are ill-equipped to respond to mental health crisis calls. We've seen time and time again that involving law enforcement in mental health-related emergencies is far more dangerous than it is helpful. That's why this year, we signed on to a letter to the U.S. Department of Health and Human Services calling on them to implement guidance and provide technical assistance to help states develop police-free mobile crisis response programs that are equitable, safe, and effective. We submitted comments to the Department of Education explaining the benefits of ending funding for police in schools, and then using that funding to hire mental health and physical health professionals. We endorsed the Counseling Not Criminalization in Schools Act, which would ban schools from using federal funds for increasing police presence, instead providing grant funding to help get more social workers, counselors, and other health services into schools. We also endorsed the People's Response Act, which would, among other investments in non-carceral public safety initiatives, provide funding to state, local, and tribal governments alongside community organizations to improve police-free crisis responses and hire more social workers, substance use counselors, and mental health counselors.





# Equity Plan

Since the beginning of 2020, ASAN has been working with Epiphanies of Equity, a BIPOC-led social equity group, to examine our internal structures and practices and develop detailed plans to increase equity and inclusion throughout our organization and in our work. Here are some highlights from our plans.

## Recruit, Hire & Promote Staff of Color



ASAN wants to make sure that our staff members come from a variety of backgrounds and bring a variety of experiences to the job. Part of our plan focuses on how we're going to increase the inclusion of underrepresented groups in outreach and recruitment for all new positions, including mid- and high-level positions. We also want to make sure that our management and leadership reflect the diversity of our community. So, our plan details how we're going to invest in staff of color by providing them with professional development opportunities, including opportunities to take on management roles at ASAN. Current senior staff will also be proactively participating in succession planning, working to remove barriers to staff of color assuming senior-level roles. We will also increase the availability of internships for people from underrepresented groups and make sure we promote these internship opportunities to groups who often don't have access to internships.

## Build Coalitions



ASAN is building and strengthening partnerships with many organizations, especially those whose work centers on racial justice. We want to collaborate with organizations led by people of color so we can learn more from their expertise. We'll share resources and work together on projects and advocacy campaigns, and ASAN will use our social media to boost the work and voices of the groups we partner with. We'll also work closely with ASAN affiliate groups, self-advocate groups, and disability rights and disability justice groups. We'll get their feedback on how ASAN can support them and how we can make our work work for them.

## Listen to Our Community



We want to know how our community feels about the work we do and whether we should make changes. So, our plan details how ASAN is going to find new ways to listen to our community and incorporate suggestions about what kind of work we do and how we do it. We'll use surveys, a website feedback tool, listening sessions, and focus groups to learn how our community interacts with the work we do and how we could make it better. We'll take all of this feedback and then make and follow plans for how to put the feedback into practice in our work.

## Increase Equity in Leadership Trainings



Every year, we hold our Autism Campus Inclusion (ACI) leadership training for college students across the United States and Canada. We aim to bring a diverse group of students together in each cohort, but there are ways we can improve. We're going to expand and change the ways we advertise for ACI. For example, we're going to work with organizations in U.S. territories to do more recruiting from places like Puerto Rico and the U.S. Virgin Islands. We're also going to look for ways to get training materials to people who aren't in college. For example, by expanding our Resource Library, we can provide training materials to more people. We will look for funding to provide leadership trainings for people who aren't in college. We're also going to add more information about anti-racism into all of our trainings.

## Increase Equity in Our Resources



ASAN creates lots of resources on different topics like Medicaid, voting, the Americans with Disabilities Act, and more. We want to get more feedback on our resources to find out how people are using them and how we can improve. We also want to make sure our resources incorporate a racial justice lens and explain how intersectionality plays a part in all the topics we write about. We are also making plans to translate more of our resources into Spanish. We will work with autistic people who speak Spanish to help us.



# Revenue

\$1,447,743

# Expenses

\$936,982

47 percent Grants/Contributions

78 percent Education/Outreach/Advocacy

Admin 13 percent

Fundraising 9 percent

Donations 37 percent

Contracts/  
Fee-for-Service 8 percent

5 percent Special Events

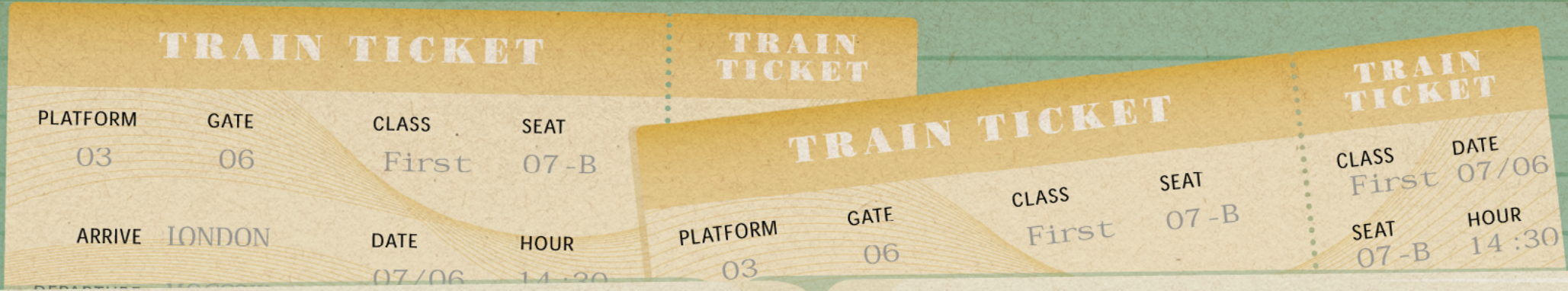
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1 percent Book/Merch Sales

2 percent Membership Dues

*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

### JOIN

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)

### GIVE

To make a tax-deductible donation to the Autistic Self Advocacy Network, go to [AUTISTICADVOCACY.ORG/DONATE](http://AUTISTICADVOCACY.ORG/DONATE)

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

### SHOP

Shop online at the ASAN store at [AUTISTICADVOCACY.ORG/SHOP](http://AUTISTICADVOCACY.ORG/SHOP)

### 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)



## ACKNOWLEDGMENTS

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- KATHERINE CRATER**, Media Intern

*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.*

