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 the same access, rights, and opportunities as all other citizens.

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!
Dear friends,

Over the last nine years, the Autistic community has grown and changed. The Autistic Self Advocacy Network was founded to defend our community’s interests and champion our voice against those who speak about us, without us. Since then, Autistic people have secured greater visibility in public discussions around autism, a seat at the table in policy conversations about us and the ability to respond when we continue to be excluded.

We’re proud of what we’ve done - in partnership with you and a growing community of autistic-run organizations and initiatives - to help bring about that change. But more is needed. Hundreds of thousands of people with disabilities still languish in institutions and are paid less than minimum wage. Toxic stereotypes about autism still pervade the public discourse and hurt our people and our families. Too much of our community goes without needed services. We can still do better.

That’s why we remain committed to working with the Autistic community to continue to build our movement’s strength. We’re proud to be the premier autistic-run disability rights organization in the United States, and we know that it is because of our dedicated grassroots supporters and activists that everything we have accomplished was made possible. As we approach the end of our first decade, we are proud of what our community has accomplished to date - and even more so of what will be accomplished still.

As always, Nothing About Us, Without Us!

Ari Ne’eman
President
ASAN has worked hard this year to accomplish significant work supporting our mission, pushing forward our long-term advocacy goals while incorporating new concerns from our constituency. Our growing staff spent a tremendous amount of time and energy this past year working on these advocacy accomplishments, but none of it could have happened without the support and tireless work of our volunteers and grassroots supporters. ASAN is grateful and proud to tell you about some of our major victories from the past year and wants to thank you for your part in accomplishing them.
More than 200,000 people with disabilities earn subminimum wage because of Section 14(c) from the Fair Labor Standards Act that allows business to pay workers with disabilities less than the federal minimum wage if they get permission from the Department of Labor. ASAN has expended much effort over the past months to end subminimum wages for workers with disabilities and to encourage states to shift toward more integrated models of employment and day services. People with disabilities deserve the right to be included in all aspects of life—including the workplace.

On this front, ASAN has supported Senators Chuck Grassley (R-IA), Ron Wyden (D-OR), and Robert Casey (D-PA) as they have introduced the Transition to Independence Act (S.1604), which supports those employment goals. The legislation, which emerged from within the disability community, and was crafted with technical assistance from the National Council on Disability, will create a ten-state demonstration program, within which states will receive bonus payments from the federal government for achieving increases in the number of people with disabilities in competitive integrated employment and reducing the number of people with disabilities in segregated sheltered workshop and facility based day habilitation settings. It also allows for people with disabilities who earn too much money to get normal Medicaid to pay money to use it, hopefully eliminating the need for people with disabilities to have to choose between healthcare and work.

Furthermore, the Transition to Integrated and Meaningful Employment Act (HR 188), also known as the TIME act, would phase out the Fair Labor Standards Act Section 14(c). ASAN continues to work to ensure the passage of these two bills to ensure that workers with disabilities will work for the same amount of money as everyone else.

These efforts build upon last year’s victory in which ASAN, working jointly with a wide variety of cross-disability and labor organizations, successfully called upon President Barack Obama and Secretary of Labor Tom Perez to include workers with disabilities in an executive order raising the minimum wage for employees of federal service and concession contractors to $10.10 per hour.

All of these efforts have relied—and will continue to rely—heavily on support from our grassroots members and supporters, as well as our partners in the disability community. It is only with help from all of you that we can continue to accomplish our goals of making sure that workers with disabilities earn the same wages as our non-disabled peers.
ASAN is taking a lead position on discrimination in organ transplantation. As ASAN found in our 2013 report, when people with intellectual and developmental disabilities need an organ transplant to treat a life-threatening condition, they frequently face barriers to receiving this life-saving care. Doctors and transplant centers may refuse to approve organ transplants for people with disabilities who might need help in order to follow complicated post-transplant treatment plans. Others may refuse to approve transplants for people with disabilities based on the belief that people without disabilities should have a higher priority.

In 2014, we published a comprehensive Toolkit for Advocates on Ending Discrimination in Organ Transplantation. Our organ transplant toolkit includes a “know your rights” guide to provide people with disabilities and their families with information on existing laws and policies, a guide for advocates who want to fight organ transplant discrimination on a wider basis, model anti-discrimination legislation, a guide for clinicians, and a checklist of available supports and services that will give doctors and other health professions concrete advice on how to serve people with disabilities who may need an organ transplant.

Last spring, legislators in the state of Maryland based SB 792 on ASAN’s model legislation on organ transplant discrimination, ultimately passing a bill making it illegal for doctors, hospitals, and transplant centers to deny a necessary organ transplant based solely on a patient’s disability. The bill was signed by the Maryland governor in May 2015, making it the third state to have an organ transplant anti-discrimination law, joining New Jersey and California.

Healthcare Discrimination

85% of pediatric transplant centers consider neurodevelopmental status as a factor in their determinations of transplant eligibility at least some of the time.

46% of heart programs indicated that even mild or moderate cognitive impairment would be a relative contraindication to eligibility.
ASAN wants to see people with disabilities living and working in the community, rather than in segregated settings. We want to ensure that people with disabilities receive Medicaid-funded Home and Community Based Services in integrated settings that offer full access to the community. In January 2014, after years of pressure, the Centers for Medicare and Medicaid Services issued a new regulation spelling out for the first time what Home and Community Based Services are—and more importantly, what they are not.

Thanks to this new rule and ASAN’s toolkit, published last fall, on how to make it work, advocates have a new tool to move our people out of sheltered workshops and group homes and into truly inclusive environments. ASAN continues to do substantive work to help people with disabilities live and work in the community. This includes lobbying against new construction of isolating group settings, educating the public and professionals about the importance of integrated environments.

One of ASAN’s core advocacy goals is to make sure that people with developmental disabilities are able to access the same services and infrastructure as those without disabilities. To that end, we work with many agencies to help them understand what accommodations are necessary for autistic people.

Responding to reports of Autistic people and people with other developmental disabilities being denied access and even removed from airlines on the basis of their disability alone, ASAN worked with the Department of Transportation this year to help them create educational pamphlets for air travelers who have developmental disabilities. The pamphlets include information for self-advocates, airlines, and airline staff. These materials explain that airline staff must disclose within 10 days why they have removed someone from their scheduled flight if it was related to their disability. They must also modify their flight policies for a person with a disability before denying access due to safety concerns.

The new materials clearly explain what developmental disabilities are and address typical behaviors or communication issues that might cause airline staff to misinterpret the person with a disability. These guidelines are the result of a mutually beneficial dialogue between the Department of Transportation and the Autistic community regarding the discrimination and difficulties faced by people with developmental disabilities in traveling.
The Autistic Self Advocacy Network has continued to speak out against use of guardianship law to overcome the wishes of people with disabilities. ASAN has engaged in extensive community outreach to educate people about supported decision-making as an alternative to guardianship. Supported decision-making allows a person with a disability to choose who helps them make important decisions in their life, while retaining the ability to make all of their own decisions - much like the strategy that many non-disabled people use when making important decisions.

In 2014, ASAN issued model supported decision-making legislation that would allow people to appoint health care decision-making supporters without signing away the right to make decisions for themselves. Our toolkit on Health Care Transition to Adulthood explains how supported decision-making can improve people’s access to health care while maintaining the presumption that autistic adults can and should make their own choices.

This year, ASAN has continued to educate the public and professionals about how supported decision-making can promote integration, protect individual rights, and improve health care. ASAN has offered its expertise on supported decision-making in high-profile cases of guardianship abuse. ASAN is in the process of collaborating with community members in Delaware, Maryland, and California to create supported decision-making legislation in those states.

ASAN is also in the process of writing informational materials for self-advocates that compare different countries’ laws on guardianship and supported decision-making.

“Research has found that guardianship can cause a ‘significant negative impact on physical and mental health, longevity, ability to function, and reports of subjective well-being.’”

- March 2015 ASAN Action Alert: Speak Out Against Guardianship Abuse

“There are nationally recognized, less-restrictive alternatives to guardianship that provide people with the help they need while preserving their personal autonomy, increasing their self-determination, and protecting their legal rights.”

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- March 2015 ASAN Action Alert: Speak Out Against Guardianship Abuse
ASAN is committed to making the knowledge we have been able to gather as a national organization available to the public at no cost. To that end, we publish several toolkits and resource guides each year aimed at helping self-advocates, families, and professionals navigate systems that might otherwise be too complicated or overwhelming.

ASAN has published several toolkits over the past several months, the most recent being our Behavioral Health Toolkit. This guide, published in July, has already been downloaded more than 3600 times. This guide explains the evidence base for promising developmental interventions, including alternatives to Applied Behavioral Analysis (ABA), and provides instruction on how to advocate for coverage for these interventions. It is the first of several upcoming publications about health coverage for behavioral health.

Another extremely important resource we created this year is our Anti-Filicide Toolkit. When people with disabilities are murdered by their parents or caregivers, we gather their names and mourn their loss. What’s more, when the media and the court system treat these murders as justifiable and even inevitable due to the “burden” of having a disabled person in the family, we work to make sure the murderer is prosecuted appropriately to the full extent of the law.

This year, in addition to leading our annual international series of Day of Mourning Vigils in March, we created a toolkit to address filicide of disabled people. The toolkit includes sections on what filicide is, how to talk about it, how to prevent it, and what to do if it happens in your community. There is also an anti-filicide FAQ and a guidebook on how to hold your own Day of Mourning Vigil in your community alongside ASAN each year on March 1.

These toolkits join those we have published prior to the past year, including our Toolkit for Advocates on Ending Discrimination in Organ Transplantation, Toolkit for Advocates on Health Care and the Transition to Adulthood and our Toolkit for Advocates on New Home and Community-Based Settings Rules.
ASAN has worked hard this year to accomplish significant work supporting our mission, pushing forward our long-term advocacy goals while incorporating new concerns from our constituency. Our growing staff spent a tremendous amount of time and energy this past year working on these advocacy accomplishments, but none of it could have happened without the support and tireless work of our volunteers and grassroots supporters. ASAN is grateful and proud to tell you about some of our major victories from the past year and wants to thank you for your part in accomplishing them.
Our fourth annual Autism Campus Inclusion summer leadership academy (ACI) kicked off the summer; to date, ASAN has provided 64 autistic college students training in campus organizing, disability advocacy, and autistic pride via our week-long training.

We’ve also trained 47 state-level leaders with developmental disabilities in our regional academies on the West Coast and in Tennessee, focusing on grassroots organizing, disability advocacy, and state policy issues such as community living and Employment First. Following the academies, we work with the participants to develop and implement advocacy plans on their campuses and in their states and local communities.

“I left ACI with a sense of competence I didn’t have before. Like, being around people who accepted the way I work for what it is and not judging me negatively for that, as well as being given tools for doing community work. That experience has helped me set aside some insecurities that get in the way. I feel more capable of doing the things I want to do.”

- Jane Edwards-Simpson, 2015 ACI graduate

“I just felt like my brain was understood there among all these other autistic people who have similar experiences to my own... [ACI] was like going home to a family I didn’t know I had.”

- Adia Heuser, 2015 ACI graduate
“Self advocacy begins by understanding that rights are never granted from above. They are grasped from below by those with the courage and determination to seize that to which they are entitled.”

- Tony Coelho

“Empowerment is when you have gained the confidence in yourself to have the light bulb go on in your head. You realize you can take control of your life and you understand that now you have done it.”

- Nancy Ward
Finally, we've dedicated time to several different events that have become fundamental to the self-advocacy community. On March 1st, we held our fourth annual Day of Mourning to mourn disabled victims of filicide and call for justice, with 25 vigil sites across 4 countries. In April, we celebrated Autism Acceptance Month and collected your responses to “I Like Being Autistic Because” and “Autism Acceptance Is.” Throughout the year, we worked hard to coordinate and assist with a variety of other hashtag campaigns as they arose. We look forward to closing 2015 with a celebration of self-advocacy, as we prepare new ways to make sure that in 2016, there is truly Nothing About Us, Without Us!
Financial Update

As a growing nonprofit organization, ASAN is working hard to raise and spend funds in an effective and fiscally responsible manner. Our funds are raised from grants, individual donors, organizational supporters, and sponsors.
As ASAN receives multiple multi-year grants which are paid out over the course of several years, our funds here are reflected on a modified cash basis, meaning that restricted multi-year grants are reflected in the year they were spent rather than the year they were committed. This may differ from the organization’s 990, which reflects funds in the year in which they were committed/received in all instances.
Looking Ahead

ASAN has exciting plans for the coming months as we continue laying the foundation for the years ahead. The immediate future is a bright one for our growing organization, with expansion in a variety of areas on the horizon.
Goals & Projects

We will work to support our chapters and grassroots in becoming more sustainable, active, and independent so they have the resources to advocate for the needs of autistic people in their own communities.

We will increase the availability of our resources in multiple formats and languages to better serve a diverse community of self advocates.

We will work to increase knowledge of pertinent policy issues among self-advocates at all levels and supporting our community to exercise our rights as disabled people.

We will continue to work on developing further resources and toolkits, including more on behavioral health coverage, transition, and supported decision making. The Autistic Press, ASAN’s micropress, will continue to grow this year.

ASAN is actively seeking to increase inclusion, representation, and support of a more diverse and intersectional population of autistic people. In order to do this, we will begin work on translating ASAN web and print content into different languages, as well as adding subtitles to our videos. Furthermore, we will identify coalitions representing different diverse groups that we can align with and work with them to develop mutually beneficial strategies.

We are also very proud to present the ASAN Autistic Scholars Fellowship. This program will provide 3 to 5 autistic students $5,000 tuition scholarships each to create systems change on their college campuses. Fellows will establish or participate in a leadership role within an ASAN campus chapter or a disability rights student organization, work to promote autistic culture and community, and take steps to improve disability accessibility and inclusion on their college campuses. Our first class of Fellows will be selected by January 2016.
Nothing About Us, Without You!

Take an active role in empowering the Autistic community and join us as a member.

You’ll get a monthly newsletter updating you on the work that your membership contribution is making possible.

We have ambitious plans for 2016 - but we need your support!
ASAN is proud to receive grant funding and support from the following organizations:
ASAN would like to express our deepest gratitude to our funders of the ASAN Autistic Scholars Fellowship, Michael and Chelsea Leger and Stimtastic.

Thank you to James Bishop and his team at the Pokéthon Evolution, who fundraised for ASAN throughout their 72-hour online gaming marathon.

Thank you to our sustaining donors, who set up monthly recurring donations to support ASAN and our initiatives. Knowing we have your regular support makes it possible for us to count your donations into our planning.

ASAN is proud to be financially supported by so many members of our community. Thank you to each of you for supporting us, not just with your actions, but with your hard earned money. We understand how difficult it can be to give money and we are grateful for each and every donation of any dollar amount.

We would like to thank the members of our Board of Trustees. The direction, oversight, and support of our board has been invaluable in guiding ASAN over the years.

Sarah Schneider, Chair
Katie Miller, Vice-Chair
Meg Evans, Secretary
Carol Quirk, Treasurer
Ari Ne’eman, President, ASAN
Amy Sequenzia, Trustee

As ASAN senior staff, Ari Ne’eman, Julia Bascom, and Samantha Crane would like to thank our staff for their hard work throughout the year. Each of you helps us accomplish our goals in innumerable ways.

Janthe Belisle Dempsey, Publications & Communications Coordinator
Natalia Rivera Morales, Leadership Programs Coordinator
Kris Guin, Technical Assistance Coordinator
Savannah Logsdon-Breakstone, Social Media Coordinator
Lydia Brown, Policy Analyst (through August 2015)
Kelly Israel, Policy Fellow

Finn Gardiner, Boston Community Coordinator
Jean Winegardner, Office Manager
ASAN would also like to thank our wonderful interns, Kylie Boazman, who works on the Loud Hands project, and Simon Margolis, our Summer Policy Intern.

We would like to thank our volunteers, who help us to produce accessible resources and to continue having Day of Mourning and Autism Acceptance Month events.

ASAN is proud to be supported by our Autistic community and our allies across the United States and the world. There truly could be Nothing About Us, Without You.

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Julia Bascom
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Sam Crane, J.D.
Legal Director & Director of Public Policy