

Public Policy Goals of the Autism Society of America for the 119th Congress and the Administration

The Autism Society of America has joined eight other national organizations representing individuals with intellectual and developmental disabilities, their families, and the professionals who serve them to provide [joint legislative goals](#) to Congress. Together, we will urge Congress to protect civil rights and support programs and services that achieve our mission to create connections empowering everyone in the Autism community with the resources needed to live fully. From these broad goals, the Autism Society has chosen a focused set of goals to guide our work over the next two years.

Appropriations

Congress and the Administration must provide sufficient funding to support programs that impact individuals with Autism, including those with developmental disabilities that are more complex and lifelong, and their families. These include:

- Mandatory funding for Social Security, Medicare, and Medicaid programs. These programs provide the bulk of supports for individuals with Autism who live at home or in community-based settings and require significant lifelong support.
- Discretionary funding for programs, such as the Individuals with Disabilities Education Act, Autism CARES Act, Lifespan Respite Care Act, DD Act programs (DD Councils, Protection and Advocacy, and University Centers for Excellence in DD), supported employment, and health and mental health programs that support people with disabilities.

Revenue

- Reform tax policy in a manner that raises sufficient revenues to finance the federal government's role in providing essential supports, services, and benefits for people with disabilities and their families over the lifespan.
- Support the expiration, roll back, or repeal of tax cuts and adjustments of other tax policies, such as those that allow high income individuals and large corporations to minimize their U.S. tax obligations, that put people with disabilities at risk due to lower contributions to federal revenues.

Autism CARES Act

The Autism Collaboration, Accountability, Research, Education, and Support (CARES) Act was originally enacted in 2006. The law increased and coordinated the federal

government's response to the increasing number of individuals diagnosed with Autism Spectrum Disorders (ASD). The 118th Congress reauthorized and improved the law. The 119th Congress and Administration must ensure its full implementation:

- Add additional Centers of Excellence, one of which should focus on those with complex medical and behavioral support needs, such as those with intellectual disabilities, seizures, aggressive or self-injurious behaviors or other needs requiring significant and ongoing care by trained professionals.
- Establish a new Autism Intervention Research Center (AIR-C) to focus on communication needs for those who are non-speaking or minimally-speaking to increase access to devices, evidence-based methods, and training.
- Ensure that people with Autism across the full spectrum are included in clinical studies within HHS and will continue to do so.

Medicaid and Home and Community-Based Services

There are about 700,000 individuals on waiting lists to receive services and support through Medicaid home and community-based services (HCBS) waivers.¹ In addition, the United States is experiencing a severe shortage of direct support professionals (DSP) resulting in many individuals not receiving the support they need, and are entitled to receive, to live in their community. The 119th Congress should:

- Protect Medicaid from cuts via block grants, per capita caps, changes to eligibility rules and any other proposals that aim to cut the program.
- Increase long-term federal funding through an enhanced Federal Medicaid Assistance Percentage (FMAP) dedicated to supporting and growing the direct care workforce and increasing access to HCBS, such as the [Better Care Better Jobs Act](#), [HCBS Relief Act](#), and the [HCBS Access Act](#).
- Urge the Centers for Medicare and Medicaid (CMS) to work with states to support states to take up existing HCBS expansion options, such as the [Community First Choice](#) option under Medicaid 1915(k) and 1915 (i). Both options align with the broader Medicaid goal of supporting individuals in their own homes and communities rather than institutional settings, enhancing choice and independence for beneficiaries.
 - 1915(i) HCBS State Plan Option provides states with the flexibility to offer HCBS through their Medicaid State Plan, rather than needing a waiver, enabling more people with disabilities and older adults to receive care in their homes or community settings.
 - 1915(k) Community First Choice (CFC) Option is designed to give states the option to offer attendant care services to Medicaid recipients in their homes, promoting independence and preventing institutionalization.

¹ Kaiser Family Foundation, Medicaid HCBS Waiver Waiting List Enrollment by Target Population, 2023.

- Protect regulations that assure individual rights to person-centered planning and autonomy.

Social Security

People with disabilities often rely on Social Security disability or Supplemental Security Income (SSI) benefits, sometimes both. These programs are crucial to people with disabilities. SSI benefits are extremely modest but are intended to help people meet their basic needs and pay for medical care and disability-related costs. It is critical that SSI is updated to allow individuals with disabilities to have economic security and independence. Congress should:

- Protect Social Security from proposals aimed at cutting the program.
- Support reforms to Social Security that increase asset limits and income disregards and allow people to work without losing their benefits, such as the [SSI Savings Penalty Elimination Act](#), the [Social Security 2100 Act](#), and the [Work Without Worry Act](#) that may be reintroduced in this Congress.

Family Support

The majority of people with Autism, including those with significant behavioral challenges, live with families. It is important that families have access to information and resources to best support their loved ones with Autism. Congress should:

- Significantly increase funding for the [Lifespan Respite Care Act](#) so that every state is funded to serve everyone who needs this family support. Provide oversight to ensure respite services are serving people with intellectual and developmental disabilities.
- Support legislation that provides training and support, such as the [Autism Family Caregiver Act](#). The Autism Family Caregivers Act would establish a five-year pilot program providing grants to nonprofit organizations, community health centers, hospital systems, or a consortium, to provide evidence-based caregiver skills training to family caregivers of children with autism and other developmental disabilities or delays. Caregiver skills training teaches family caregivers how to use everyday routines and home activities to improve the mental and physical well-being of children with autism and other developmental disabilities or delays, and their caregivers, including by addressing communication skills, daily living skills, social engagement, and behavior management.
- Support legislation to provide crisis respite care for those in mental health crisis and those with significant behavioral support needs.
- Support legislation that provides tax credits for family caregivers, such as the Credit for Caring Act.

Health/Mental Health

Research indicates that individuals with Autism have a significantly increased risk of developing mental health disabilities, such as anxiety and depression. Trained health professionals able to appropriately serve individuals with Autism, especially those with complex behavioral health needs, are in short supply. Congress should:

- Support efforts to add disability to the definition of “medically underserved population” designation, such as the [HEADS Up Act](#), that will increase the number of trained health professionals to appropriately serve people with developmental disabilities.
- Increase funding for the [Leadership Education and Neurodevelopmental Disabilities \(LEND\)](#) program that provides interdisciplinary training to health professionals on how to screen, diagnose and provide interventions for people with Autism and other developmental disabilities.
- Protect the Affordable Care Act, including the requirement to provide behavioral health and habilitation as part of the [essential benefits package](#). Behavioral therapists work with individuals with autism to identify triggers for challenging behaviors and develop strategies to manage them. Habilitation services often focus on teaching basic self-care skills, such as dressing, grooming, cooking, and cleaning. These services help individuals with autism learn the routines and techniques needed to manage daily life more independently.
- Ensure that the provisions of the [Mental Health Parity and Addiction Equity Act](#) along with the mental/behavioral health and substance use services provisions in the ACA are fully funded and implemented.

Education

Access to a free, appropriate public education in the least restrictive environment is a right for students with Autism, including those with complex medical and behavioral support needs. Educational services must be individualized and provided in the least restrictive environment to the greatest extent appropriate. Schools must offer a range of placements, from full inclusion in the general education classroom to special education classes or separate facilities, depending on the student's individual needs. Congress should:

- Fully fund the [Individuals with Disabilities Education Act \(IDEA\)](#) and increase funding for Part C early intervention and Part D which supports personnel development and other support services.
- Pass legislation, such as the [Keeping All Students Safe Act \(KASSA\)](#), to reduce the use of restraints and seclusion in schools and provide training in positive supports and interventions. Students with disabilities (under IDEA) represent about 13% of the student population but account for 80% of students subjected to physical restraint and 77% of those subjected to seclusion. Among students with disabilities, those with Autism are disproportionately affected, especially those who are non-speaking or have behavioral needs -- it's reported that they account for around 34%

of students with disabilities who are restrained and 41% of those who are secluded. KASSA provides training to school personnel to understand how to identify triggers, learn de-escalation techniques, and provide positive behavioral supports and interventions.

- Support personnel such as paraeducators are essential to the safety of students with complex needs. Legislation such as the [PARA Educators Act](#) can help recruit and retain these vital supports.
- Oppose federal funding for School Resource Officers (SRO). The presence of SROs in schools has been associated with an increased likelihood of students, particularly those with Autism and those belonging to minority groups, being arrested and entering the criminal justice system—a phenomenon often referred to as the "school-to-prison pipeline."
- Protect the civil and educational rights of students with disabilities by opposing any proposal that directs federal funds toward or in support of education that does not adhere to IDEA, the Rehabilitation Act of 1973, the Americans with Disabilities Act, and other civil rights laws.

Employment

Recent data shows that approximately 85 percent of Autistic adults with a college education are unemployed, and over 90 percent of adults with Autism are under-employed or unemployed.² Congress should:

- Support legislation to increase employment opportunities, such as the bipartisan [Transformation to Competitive Integrated Employment Act \(TCIEA\)](#), that provides grants to states to help build capacity to provide employment opportunities that pay at least minimum wage and slowly phase out the use of subminimum wage certificates (14c of the Fair Labor Standards Act, FLSA). TCIEA has provisions addressing the needs of individuals with significant or complex disabilities. Each application to the State Grant Program under TCIEA must include a description of how the funds will be used to create service delivery infrastructure that will, among other things, provide “enhanced integrated services to support people with the most significant disabilities.” Applications to the State Grant Program must include assurances that “individuals with the most significant disabilities, including intellectual and developmental disabilities, who will be affected by such a transformation will be given priority in receiving the necessary employment supports and integrated services to succeed during and after such a transformation.” States that successfully complete this grant are eligible to receive a 25% increase in their allotment for supported employment services for individuals with the most significant disabilities. Supported employment must be customized

² Rowe, Autism Spectrum Disorder on the Rise, NACE, 2017.

and intensive for those with complex needs. Wrap-around services must be provided to those unable to achieve CIE.

- Provide additional tax incentives, such as the [Disability Employment Incentives Act](#), to incentivize employers to hire individuals with disabilities.

Criminal Legal

Individuals with Autism are seven times more likely to be victims of crime due to vulnerability, twelve times more likely to become involved in the criminal justice system without criminal intent, and five times more likely to be incarcerated than the general population.³ Once incarcerated, individuals are often not provided accommodations and are vulnerable to serious abuse and neglect. Congress should:

- Pass legislation such as the [Safe Interactions Act](#), which authorizes grants to non-profits to train law enforcement officers and first responders with knowledge about Autism and other developmental disabilities.
- Pass legislation, such as the [Data on Interactions and Accountability for Law Enforcement with Individuals with Disabilities \(DIALED\) Act](#) that collects data on interactions with law enforcement so that policies can be put into place to prevent injuries and deaths.
- Support legislation that prevents discrimination based on disability by criminal legal systems against victims, witnesses, and those accused of crimes and promote best practice alternatives to incarceration, including diversion, for people with Autism and intellectual and developmental disabilities.
- Support the implementation of the 988 mental health crisis helpline and pass legislation that supports mobile crisis units and training for those responding to calls for help from Autistics in need of help. Support funding to establish mental health teams responding to behavioral health crises, such as aggressive behaviors and self-injurious crises.
- Increase funding for [Kevin and Avonte’s Law](#) that supports prevention programs for individuals who may wander or become separated from loved ones. Individuals with complex medical and behavioral support needs are more likely to wander from safe environments.
- Advance public policy around people with disabilities and the criminal legal system, including crisis response and diversion at each stage of the criminal process.

Access to Communication

Communication is essential to self-determination, social inclusion, and emotional and physical well-being. Autistic adults use various communication methods, including speech

³ Debbaudt and Rothman, 2001, <https://www.ojp.gov/ncjrs/virtual-library/abstracts/contact-individuals-autism-effective-resolutions>

and augmentative and alternative communication (AAC). Spoken language can be a significant barrier to communication for individuals with Autism as 40 percent are non-verbal.⁴ Congress should:

- Support legislation such as the “Augmentative and Alternative Communication Centers to Establish National Training Act” or the “AACCENT Act” or similar legislation to provide national training and technical assistance to ensure that all individuals with significant disabilities affecting communication have access to the communication devices, services, and supports the individuals need to fully participate in society.
- Significantly increase research into communication devices and training on how to use them, including for those with complex medical and behavioral support needs.

⁴ Kjelgaard & Tager-Flusberg, 2001; Norrelgen et al., 2014; Rose et al., 2016