

Legislative Goals of the Autism Society of America for the 118th Congress

The Autism Society of America has joined eight other national organizations representing individuals with intellectual and developmental disabilities, their families, and the professionals that 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, and other developmental disabilities, and their families.

These include:

- Mandatory funding for Social Security, Medicare, and Medicaid programs.
- 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.

Autism CARES Act Reauthorization

The Autism Collaboration, Accountability, Research, Education, and Support (CARES) Act was originally enacted in 2006.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). Due to a sunset provision, the law must be reauthorized before the September 30, 2024 deadline. Congress should:

- Reauthorize and strengthen the Autism CARES Act.

Home and Community-Based Services and direct support professionals

There are some 800,000+ individuals on waiting lists to receive services and support through Medicaid home and community-based services (HCBS) waivers.¹ In addition, we are 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. Congress should:

- 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](#) and the HCBS Access Act.
- Expand mandatory HCBS state plan benefits and require all states to cover personal care and respite services for people with disabilities.
- Urge the Centers for Medicare and Medicaid (CMS) to work with states to maximize the longevity of American Rescue Plan Act (ARPA) funding initiatives and support states to take up existing HCBS expansion options, such as the [Community First Choice](#) option under Medicaid 1915(k).

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 them build capacity to provide employment opportunities that pay at least minimum wage and phases out the use of subminimum wage certificates (14c of the FLSA).

¹ Kaiser Family Foundation, Medicaid HCBS Waiver Waiting List Enrollment, by Target Population, 2020.

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

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

Education

Access to quality education is crucial to securing long-term, stable employment and independence for individuals with Autism and other developmental disabilities. Students and teachers must feel safe while learning. Congress should:

- Fully fund the [Individuals with Disabilities Education Act](#) (IDEA) and increase funding for 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.
- Ensure that measures intended to protect the safety of students and school personnel do not violate due process, civil liberties, and the right to reasonable accommodations, or result in profiling of students based on disability or other status.

Safe Interactions with Law Enforcement

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 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.
- Pass legislation that [collects data on interactions](#) with law enforcement so that policies can be put into place to prevent injuries and deaths.

³ Debbaudt and Rothman, 2001,

<https://www.ojp.gov/ncjrs/virtual-library/abstracts/contact-individuals-autism-effective-resolutions>

- Support legislation that prevents discrimination on the basis of 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 IDD
- Support the implementation of the newly established 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.
- Increase funding for [Kevin and Avonte’s Law](#) that supports prevention programs for individuals who may wander or become separated from loved ones.

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 those on the spectrum 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 disabilities.
- Increase funding for the [Leadership Education and Neurodevelopmental Disabilities](#) (LEND) program that provides interdisciplinary training to health professionals on how to serve people with developmental disabilities.
- Protect the Affordable Care Act, including the requirement to provide behavioral health and habilitation as part of the [essential benefits package](#).
- 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.

Family Support

The majority of people with Autism 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](#).

Social Security

People with disabilities often rely on Social Security disability or Supplemental Security Income (SSI) benefits, sometimes both. These programs are crucially important 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:

- 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](#).

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 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

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

individuals with significant disabilities affecting communication have access to the communication devices, services, and supports the individuals need to fully participate in society.