

Autism CARES Act (P.L. 116-60)

Detailed Summary of Changes to the Law

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President Donald Trump signed the Autism Collaboration, Accountability, Research, Education, and Support Act of 2019, or Autism CARES Act, into law on September 30, 2019 as Public Law 116-60. This Act reauthorizes the Autism Collaboration, Accountability, Research, Education, and Support Act of 2014 (originally the Combating Autism Act of 2011 and 2006) for five years. The House bill (H.R.1058) was introduced on February 7, 2019 by Rep. Chris Smith (R-NJ) and Mike Doyle (D-PA). The Senate bill was introduced on February 7, 2019 by Senators Bob Menendez (D-NJ) and Mike Enzi (R-WY) (S.427). H.R. 1058 was amended in the Subcommittee on Health of the Committee of Energy and Commerce and passed by unanimous consent in the House on July 24, 2019 and September 19, 2019 in the Senate. This bicameral, bipartisan legislation had strong support in both chambers.

Since it was first enacted in 2006, the law has helped to expand research and coordination at the National Institutes of Health (NIH), increase public awareness and surveillance at the Centers for Disease Control and Prevention (CDC), and expand interdisciplinary health professional training to identify and support children and youth with Autism Spectrum Disorders (ASD) and their families through the Health Resources and Services Administration (HRSA). The Autism CARES Act will renew these efforts and make some important improvements.

Following is a detailed summary of the changes to the law:

Section 2. Expansion, Intensification, and Coordination of Activities of National Institutes of Health with Respect to Research on Autism Spectrum Disorder

The CARES Act of 2019 directs NIH to holistically research autism by investigating the causes – including environmental causes – diagnosis or rule out, early and ongoing detection, prevention, services across the lifespan, supports, intervention, and treatment of autism. Intensification is on research being across the lifespan to continue to knowledge development of autism from birth to adulthood and expanding research disciplines to include neurobiology, genetics, genomics, psychopharmacology, developmental psychology, behavioral psychology, and clinical psychology. Additionally, it directs NIH to consider the ability of research centers applying for grants to address the growing need to reduce disparities.

Section 3. Programs Relating to Autism

The CARES Act of 2019 removed each section of the reauthorization from Sections 3 through 6 and included all under one section as “Programs Relating to Autism.”

Developmental Disabilities Surveillance and Research Program

The Combating Autism Act authorized the Centers for Disease Control (CDC) and Prevention to award grants or cooperative agreements for the collection, analysis, and report of state epidemiological data on ASD and other developmental disabilities (DD). The 2006 law also established regional centers of excellence to collect and analyze information on the number, incidence, correlates, and causes of such disabilities.

The CARES Act of 2019 specified that the CDC expand eligibility to include “an Indian tribe, or a tribal organization,” and that to be eligible to receive a grant or cooperative agreement, centers will perform activities after consulting “State, local, and Tribal public health officials, private sector developmental disability researchers, advocates for individuals with autism spectrum disorder, and advocates for individuals with other developmental disabilities.” The addition of tribal public health officials is continued step in recognizing that autism impacts all lives in all communities.

Autism Education, Early Detection, and Intervention

The Combating Autism Act of 2006 authorized additional federal activities to 1) inform, educate, and increase awareness; 2) promote research into the development and validation of reliable screening tools; 3) promote early screening; and 4) increase the number of individuals trained to confirm or rule out ASD and provide evidence-based interventions. The law also directs the Secretary of HHS to provide culturally competent information regarding ASD and other DD and evidence-based interventions for such individuals and their families. It also requires states to provide individuals with information about state and local resources. The Combating Autism Act also authorized the Secretary to 1) develop a curriculum for continuing education for professionals to understand and use valid, reliable screening tools; 2) collect, store, coordinate, and make publicly available such tools and products; 3) expand existing interdisciplinary training opportunities and increase the number

of sites able to diagnose individuals with ASD/DD (such as Leadership Education in Neurodevelopmental and Related Disabilities or LEND); 4) promote research into tools allowing for earlier diagnoses; and 5) promote research and guidelines for evidence-based interventions.

The CARES Act of 2019 re-states that the purpose is to do the above state federal activities across the lifespan of individuals with autism spectrum disorder and other developmental disabilities.

In addition, the Act urges to “promote evidence-based screening techniques and interventions for individuals with autism spectrum disorder and other developmental disabilities across their lifespan.”

The Act also adds that Maternal and Child Health developmental-behavioral pediatrician training programs (or DBP) be located in rural or underserved areas. It directs the Secretary of Health Resources and Services Administration to prioritize awards to applicants of DBP training programs in underserved areas.

Interagency Autism Coordinating Committee

The Combating Autism Act reauthorized the Interagency Autism Coordinating Committee (IACC), originally established under the Children's Health Act. The purpose of the IACC is to coordinate all efforts within the Department of HHS concerning ASD activities; develop and update advances in research; monitor and make recommendations to the Secretary of HHS; make recommendations regarding public input; and develop and update a strategic plan for research to be submitted to Congress.

The CARES Act of 2019 reauthorizes and amends the IACC by requiring it to monitor activities across the lifespan of individuals with autism spectrum disorder. The Act also changes the statutory membership of the IACC. First, it adds additional federal members to include the Department of Labor, the Department of Justice, the Department of Veterans Affairs, the Department of Housing and Urban Development, and the Department of Education. The Act also allows additional non-federal members: at least three (rather than two) individuals on the autism spectrum, at least three (rather than two) parents or legal guardians of individuals on the autism spectrum, and at least three (rather than two) representatives of leading research, service, and advocacy organizations. The members now may be reappointed for only one additional 4 year term instead of more than one.

Reports to Congress

Since the original authorization, a progress report was required to be submitted to Congress. The CARES Act of 2019 adds additional content to the report on “information on how States use home- and community-based services and other supports to ensure that individuals with autism spectrum disorder and other developmental disabilities are living, working, and participating in their community.”

The CARES Act of 2014 required a new Congressional report devoted to the challenges of youth transitioning from school to adult services, education, and employment opportunities. The CARES Act of 2019 reauthorizes this additional report to focus on “The Health and Well-being of Individuals with Autism Spectrum Disorder Across Their Lifespan.” For this report, the U.S. Secretary of HHS must coordinate with the secretaries of Education, Transportation, Labor, and Housing and Urban Development. The report must be delivered to the Senate HELP and House Energy and Commerce Committees not later than two years following enactment of the CARES Act.

The new report must contain (from the text of the law):

(A) demographic factors associated with the health and well-being of individuals with autism spectrum disorder;

(B) an overview of policies and programs relevant to the health and well-being of individuals with autism spectrum disorder, including an identification of existing Federal laws, regulations, policies, research, and programs;

(C) recommendations on establishing best practices guidelines to ensure interdisciplinary coordination between all relevant service providers receiving Federal funding;

(D) comprehensive approaches to improving health outcomes and well-being for individuals with autism spectrum disorder, including—

(i) community-based behavioral supports and interventions;

(ii) nutrition, recreational, and social activities; and

(iii) personal safety services related to public safety agencies or the criminal justice system for such individuals; and

(E) recommendations that seek to improve health outcomes for such individuals, including across their lifespan, by addressing—

- (i) screening and diagnosis of children and adults;
- (ii) behavioral and other therapeutic approaches;
- (iii) primary and preventative care;
- (iv) communication challenges;
- (v) aggression, self-injury, elopement, and other behavioral issues;
- (vi) emergency room visits and acute care hospitalization;
- (vii) treatment for co-occurring physical and mental health conditions;
- (viii) premature mortality;
- (ix) medical practitioner training; and
- (x) caregiver mental health.

Authorization of Appropriations

The Act authorizes level funding (at FY 2019 levels). According the Congressional Budget Office (CBO), the CARES Act reauthorizes funding for activities under the law at a level of \$369.6 million per year or approximately \$1.8 billion over the five-year authorization period (2019-2024). According to CBO the amounts are targeted in the following way:

- \$23.1 million annually (\$115.1 million over five years) for the developmental disabilities surveillance and research program at the CDC;
- \$50.5 million annually (\$252.9 million over five years) for HRSA autism education, early detection, and intervention, and;
- \$296 million annually (\$1.48 billion over five years) for research grants at the National Institutes of Health (NIH) and the operations of the Interagency Autism Coordinating Committee (IACC).