FACT SHEET

AUTISM CARES ACT

SUMMARY

The Autism CARES Act (H.R. 113-157) was reauthorized in June of 2014 for five years (through 2019). CARES stands for Collaboration, Accountability, Research, Education, and Support. Originally titled the Combating Autism Act (P.L. 109-419) and signed by President George W. Bush in 2006, the purpose of the law is to increase the federal government’s response to the increasing numbers of individuals diagnosed with Autism Spectrum Disorders (ASD). The law expanded and coordinated existing federal efforts: research being conducted within the National Institutes of Health (NIH), surveillance and awareness activities at the Centers for Disease Control and Prevention (CDC), and professional development and research into evidence-based interventions at the Health, Resources, and Services Administration (HRSA). An Interagency Autism Coordinating Committee (IACC) ensures all federal agencies are coordinating their efforts, sharing information, and obtaining input from people on the autism spectrum and family members as well as other outside experts.

Due to a sunset provision, the law will expire in September 30, 2019 if it is not reauthorized before that date.

BACKGROUND

Since its enactment, the Autism CARES Act has helped to expand the number of health professionals trained to screen, diagnose (or rule out) autism and other developmental disabilities and to develop evidence-based interventions. The professional development for physicians and other providers that has resulted in additional diagnostic clinics, reducing wait time for families in many localities; increased understanding regarding autism and interdisciplinary teams, including families as critical team members; and comprehensive state plans focusing on work related to ASD, translating to critical services for families and much needed systems change at the state and local level.

The law has also helped to build a critical infrastructure at the CDC to further advance our understanding of autism. CDC has coordinated the ADDM Network to characterize the prevalence and population characteristics of children. The ADDM reports are used to inform policy, improve service provision, and to conduct further analyses to understand ASD. In addition to ongoing population-based monitoring of ASD, the CDC’s CADDRE Network has been successful in implementing the Study to Explore Early Development (SEED), the largest collaborative scientific study the causes of autism.

The Autism CARES Act also supports NIH-funded research, including studies of the developmental processes underlying autism biology, research on the molecular and neurological underpinnings of ASD and gene function, and research on potential environmental risk factors and biomarkers for ASD, including gene-environment interactions.

During the 2014 reauthorization, the law required a General Accounting Office (GAO) report on transition services for students with disabilities. The report was published in August of 2017. It is hoped that the information from this report will lead to legislation to increase services for transitioning youth.

The Autism CARES Act has provided the most comprehensive attention to autism spectrum disorders (ASD) ever passed by Congress. While the law has made significant gains, there is still much more work to be done to help improve the quality of lives of individuals with autism and to support their families. With the most recent prevalence indicating 1 in 59 individuals being diagnosed with ASD, it is imperative that the law be reauthorized.

Autism Society, July 12, 2018
**RECOMMENDATIONS**

Congress should:

- Reauthorize the law before it expires in 2019. This law is still needed to address the rising numbers (now one in 59) of individuals diagnosed with ASD and their pressing needs.

- Consider improvements to the law to address the pressing needs of individuals with ASD across the lifespan, including better health care, education, employment, and home and community-based services and supports.

- Focus research on the needs of individuals across the lifespan, including research on health and well-being, safety, employment, residential and long term services and supports needs.

- Encourage more individuals on the autism spectrum to participate on Interagency Autism Coordinating Committee, including those with intellectual developmental disabilities (with accommodations).