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The Autism Collaboration, Accountability, Research, Education, and Support (CARES) Act

The Autism Collaboration, Accountability, Research, Education, and Support (CARES) Act (Public Law 116-60) is a federal law aimed at addressing the continued and dramatic increase of children and adults diagnosed with Autism Spectrum Disorder (ASD). According to the Centers for Disease Control (CDC), in 2006 approximately 1 in 110 children were diagnosed with autism, compared with 1 in 36 children being diagnosed in 2020 - a near 300% increase (Autism Society & AUCD, 2023). Initially signed into law in 2006 as the Combating Autism Act, the law has been critical in helping to expand research and coordination, increase public awareness and surveillance, and expand interdisciplinary health professional training, to identify and support children and youth with autism (AUCD, 2011). Most recently reauthorized in 2019, the Autism CARES Act passed unanimously in both the Senate and the House of Representatives, demonstrating bipartisan support (AUCD, 2019). With a hard sunset date of September 30, 2024, the bill will once again need bipartisan endorsement in order to continue the vital research, training, and support that everyone impacted by autism needs.

The Autism CARES Act authorizes and funds several agencies within the U.S. Department of Health and Human Services, including the National Institutes of Health (NIH), the CDC, and the Health Resources and Services Administration (HRSA) (Maternal Child Health Bureau, 2024). The CDC and HRSA are integral in addressing autism related efforts. Through its Autism and Developmental Disabilities Monitoring Network, the CDC conducts ongoing surveillance to monitor ASD prevalence across demographics and regions, while also funding research to understand causes, risk factors, and interventions. Additionally, the CDC disseminates educational resources like 'Learn the Signs, Act Early,' raising awareness for early detection. HRSA supports access to healthcare for individuals with ASD, funding health centers and clinics that provide primary and behavioral health services (Autism Society & AUCD, 2023). Leadership Education in Neurodevelopmental and Related Disabilities (LEND) programs, under HRSA, train healthcare professionals in diagnosing and treating autism, aiming to reduce wait times and meet state needs effectively. Complementing LEND, Developmental Behavioral Pediatrics (DBP) Training programs offer specialized education and foster interdisciplinary collaboration to improve outcomes for individuals with autism (Maternal Child Health Bureau, 2024). Without reauthorization, these agencies and programs will face funding shortages and limitations, resulting in decreased public support, understanding, and empathy for those affected by ASD.

The Interagency Autism Coordinating Committee (IACC) is a diverse body composed of federal employees and members of the public with lived experience, as well as professionals working in the field. They provide annual reports to Congress about the Autism CARES Act. Their findings include strategies for future research through their education and updates on policy, research, and progress of this important ongoing work. One of their most recent recommendations included implementing strategies to help individuals with autism transition into adulthood and to live successfully across their lifespan. Incorporating acceptance and inclusion, as well as independence for individuals with ASD are key components which are furthered by the efforts of this legislation (Diament, 2023). Failure to reauthorize the Autism CARES Act would result in the dissolution of the IACC. Without funding, there would be no centralized oversight and coordination among federal agencies.

Inefficiencies, duplication of efforts, gaps in services and ultimately higher costs would cause a ripple effect felt at both the federal and state level. However, individuals with autism and future generations would suffer the most.

Some key stakeholders of the Autism CARES Act include the Autism Society of America, Association of University Centers on Disabilities (AUCD), and the National Council on Severe Autism. Stakeholders, including the Autism Society of America, described as "the nation's largest and oldest organization representing individuals with Autism and their families" (Banks, 2023) have expressed public support for reauthorizing the Autism CARES Act. The Autism Society of Maine (ASM), which began as a support group for parents of children who have autism, is essential today in providing education, awareness, and assistance across the state. Without the Autism CARES Act, ASM would be one of many state-based organizations which would suffer, leading to a loss of resources for Mainers in need of support around autism (Autism Society of Maine, 2024).

Not reauthorizing the Autism CARES Act would jeopardize the progress made over the last 18 years. This would have profound consequences for individuals with ASD and their families, as well as for society as a whole. With 1 in 36 individuals being diagnosed with autism (Maenner Warren, & Williams et al., 2020), we must continue to try to understand Autism Spectrum Disorder, its causes and impacts across the lifespan, and we must continue to enact inclusive policies across all sectors of society, as well as develop effective interventions that promote well-being at all ages. The Autism CARES Act effectively encourages all these processes.

Since its inception as the Combating Autism Act in 2006 (Public Law 109-416), this legislation has been the force behind countless gains and strides in understanding autism as well as assuring that individuals and families with lived experience are seen and heard. By ensuring continued funding and support, we can sustain the progress made in understanding autism, improving interventions, and enhancing the quality of life for individuals and their families. Overall, commitment to the Autism CARES Act reaffirms our nation's awareness of our responsibility and our dedication to fostering a society that embraces and supports individuals of all abilities.

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