

# Policy At A Glance:

## Autism CARES Act of 2024 (H.R. 7213)

*Autism spectrum disorder is a neurological and developmental condition that affects nearly 1 in 36, or 2%, of children across the nation. This brief provides an overview of the Autism and Developmental Disabilities Monitoring Network, the “Learn the Signs. Act Early.” Program, and the Autism CARES Act of 2024 (H.R. 7213).*

### Introduction

Autism spectrum disorder (ASD) is a neurological and developmental condition that affects how individuals interact, communicate, learn, and behave. Though autism can be diagnosed at any age, it is considered a developmental disorder since symptoms typically emerge within the first two years of life.<sup>1</sup> ASD presents challenges in social interaction and communication, impacts education and employment, and places significant demands on families. Additionally, quality of life is influenced by societal attitudes and the level of support from local and national authorities.<sup>2</sup>

Therefore, on December 23, 2024, President Biden signed the Autism Collaboration, Accountability, Research, Education, and Support Act of 2024 (H.R. 7213), or the Autism CARES Act of 2024, into law. This bill extends programs for autism education, early detection, and intervention while reauthorizing the Interagency Autism Coordinating Committee (IACC) through fiscal year 2029.<sup>3</sup>

This brief provides an overview of the Autism and Developmental Disabilities Monitoring Network, the “Learn the Signs. Act Early.” program, and the Autism CARES Act of 2024 (H.R. 7213).

### Key Statistics

- 1 in 36** Children in the U.S. has been diagnosed with autism spectrum disorder.<sup>4</sup>
- 1 in 45** Adults in the U.S. has been diagnosed with autism spectrum disorder.<sup>4</sup>
- 26.7%** Of 8-year-old children in the U.S. diagnosed with autism spectrum disorder have profound autism, requiring 24/7 care.<sup>5</sup>
- 8.1%** Of students with autism spectrum disorder do not graduate from high school.<sup>5</sup>

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## Autism and Developmental Disabilities Monitoring Network

Funded by the Centers for Disease Control and Prevention (CDC), the Autism and Developmental Disabilities Monitoring (ADDM) Network gathers data to assess the prevalence and characteristics of eight-year-old children in the U.S. with autism spectrum disorder (ASD), cerebral palsy, and other developmental disabilities across different regions of the nation.<sup>6,7</sup> It tracks trends over time, monitors progress in early ASD identification, and examines the timing of cerebral palsy diagnoses. Additionally, the ADDM Network assesses the impact of ASD, cerebral palsy, and related conditions on communities nationwide.<sup>6</sup>

In June 2024, the ADDM Network broadened its ASD surveillance to help communities identify healthcare needs and address gaps in planning the transition to adulthood for youth with ASD.<sup>8</sup> As adolescents with ASD transition into adulthood, they encounter unique challenges, such as limited independence, social and communication barriers, employment challenges, higher education hurdles, and lack of social support services.<sup>9,10</sup> Therefore, this expansion aims to provide valuable data to guide policymakers, educators, healthcare providers, and community organizations in developing targeted support systems. By identifying healthcare needs and gaps in transition planning, the ADDM Network's efforts can help improve access to essential services, enhance educational and employment opportunities, and promote a smoother transition to adulthood for individuals with ASD.<sup>8,11</sup>

### “Learn the Signs. Act Early.” Program

The “Learn the Signs. Act Early.” (LTSAE) program developed by the CDC is an evidence-informed initiative aimed at improving the early identification of developmental delays and disabilities, including autism.<sup>12,13</sup> It facilitates parent-engaged developmental monitoring and promotes developmental screening so that children and their families can access early services and support.<sup>12</sup> Many children with developmental disabilities go unidentified until they begin school. However, early intervention before school age can greatly enhance their ability to learn new skills and reduce the need for costly interventions later.<sup>14</sup>



# Expanding Autism Research, Training, and Services

## Background of the Autism CARES Act

First passed in 2006, the Autism Collaboration, Accountability, Research, Education, and Support Act (Autism CARES Act) is the main source of federal funding for autism research, services, training, and monitoring. Since its enactment, the Autism CARES Act has directed over \$5.2 billion to autism-related efforts at the National Institutes of Health (NIH), the Centers for Disease Control and Prevention (CDC), and the Health Resources and Services Administration (HRSA) over the past 20 years.<sup>15</sup>

## Autism CARES Act of 2024 (H.R. 7213)

Federal initiatives under the Autism CARES Act have not only expanded the scientific understanding, but have also led to meaningful improvements in the lives of those affected by ASD.<sup>16</sup> The Autism CARES Act of 2024 (H.R. 7213) builds on the progress achieved through earlier versions of the law by providing \$2 billion through FY 2029 to enhance autism research, data collection, and healthcare training.<sup>3,17</sup>

Signed into law in December 2024, H.R. 7213 continues existing programs at the National Center on Birth Defects and Developmental Disabilities, NIH, and HRSA, while increasing funding for the CDC's Developmental Disabilities Surveillance and Research Program; the HRSA autism education, early detection and intervention programs; and to the IACC and NIH research activities compared to the previous version of the Act.<sup>3,18</sup> These updates include increased support for federal ASD initiatives and eight enhancements, including:<sup>3,16</sup>

- Promoting research on the daily life challenges faced by those with ASD across the lifespan, with a focus on autism and aging.
- Advancing efforts for greater inclusivity in research to reflect the full range of support needs and ensure the safety and wellbeing of all people with ASD.
- Requiring a report to develop a strategy for expanding the developmental-behavioral pediatrician workforce.
- Establishing an Autism Intervention Research Network for Communication Needs to improve support for non-speaking autistic individuals or those needing additional communication assistance.
- Creating a technical assistance program to help states, tribal organizations, and territories provide evidence-based services, tools, and technologies that support communication needs for individuals with ASD and other developmental disabilities.
- Mandating the Department of Health and Human Services (HHS) to develop a report to Congress on the mental health of individuals with ASD.
- Increasing the minimum number of NIH Autism Centers of Excellence to enhance research on disparities in access to healthcare and support services for individuals with ASD.
- Requiring a professional judgement budget that provides Congress and the ASD community with a clear strategic direction and resource plan for future research.

A key addition to the 2024 version of the Autism CARES Act is the requirement for the NIH to develop an annual budget plan, ensuring that future federal autism research aligns with the evolving needs of the ASD community and provides greater transparency and accountability.<sup>16</sup>

## Conclusion

It is estimated that 1 in 36 children across the nation have been diagnosed with autism spectrum disorder (ASD), and 5.4 million adults are autistic.<sup>4,19</sup> For these families, the Autism CARES Act is essential for improving their lives as it provides crucial funding for various initiatives that directly enhance the quality of life for those with autism.<sup>19</sup> The healthcare needs of individuals with ASD are multifaceted and demand a variety of coordinated services, including health promotion, care, and rehabilitation.<sup>2</sup> The reauthorization of the Autism CARES Act of 2024 (H.R. 7213) will play a critical role in addressing these needs by expanding access to resources, fostering collaboration, and ensuring continued support for individuals with ASD and their families.

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## Did you know?

According to the Centers for Disease Control and Prevention (CDC), autism is most prevalent among Asian and Pacific Islander children, with 33.4 cases per 1000, followed by Hispanic (31.6), Black (29.3), and White children (24.3).<sup>5</sup>



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