

Autism and Other Developmental Disabilities

FACT SHEET



2014 DISABILITY POLICY SEMINAR
— APRIL 7-9, 2014 —

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Background

In 2006, President Bush signed into law the Combating Autism Act (CAA, P.L. 109-416) in response to increasing numbers of children being diagnosed with Autism Spectrum Disorder (ASD). ASD presently affects 1 out of 68 children in the U.S. (Centers for Disease Control and Prevention: Morbidity and Mortality Weekly Report, March 28, 2014). The CAA targets every federal department, agency, and office that addresses ASD research, surveillance, and services in order to accelerate the pace of scientific discovery and translation to services. The law focuses on expanding research and coordination at the National Institutes of Health (NIH), increasing public awareness and surveillance at the Centers for Disease Control (CDC), and expanding the interdisciplinary training of health professionals to identify and support children with ASD and their families through programs of the Health Resources and Services Administration (HRSA). The law was reauthorized in 2011 (P.L. 112-32) and is scheduled for reauthorization this year. If it is not reauthorized, the activities authorized under the law will expire on September 30, 2014.

According to a recent Congressionally mandated report to Congressⁱ, since the law was enacted, significant advances have been made in our understanding of ASD. Notably, reliable estimates of the prevalence and a clearer picture of both the opportunities and gaps in ASD research and services are now available. With federal support, researchers continue the crucial task of evaluating interventions that provide lasting, meaningful benefit to people with ASD. Large-scale efforts in data collection and sharing are empowering researchers and health practitioners with knowledge not available only a few years ago. Within the biomedical research community, there is increasing optimism that a continued rigorous focus on identifying genetic and environmental triggers will yield innovative prevention and intervention strategies.

While federal agencies are actively identifying best practices and implementing programs to increase quality of life for people with ASD, significant gaps remain in access to evidence-based interventions, education, supported employment, family supports, and transition services across the lifespan. Progress made under CAA in increasing the capacity of professionals and service systems to address these gaps must be sustained and expanded. In particular, the training of a wide range of interdisciplinary professionals to provide needed services and supports, to translate the newest research into practice, and to provide accurate information to people with ASD and their families about scientifically supported interventions must continue, with ongoing focus on strategic efforts aimed at underserved populations. Legislation to support services and supports for adults with ASD is also needed.

The Developmental Disabilities Assistance and Bill of Rights Act (DD Act) is long overdue for reauthorization. Its purpose is to assure that individuals with developmental disabilities, including ASD, and their families participate in the design of, and have access to, needed community services, individualized supports, and other forms of assistance that promote self-determination, independence, productivity, and integration and inclusion in all facets of

community life, through culturally competent programs authorized under the law. These programs include: State Councils on Developmental Disabilities; Protection and Advocacy systems; University Centers for Excellence in Developmental Disabilities Education, Research and Service; and Projects of National Significance.

Action Taken by Congress

In the House, Representatives Mike Doyle (D-PA) and Christopher Smith (R-NJ) are preparing to introduce a bipartisan bill to reauthorize the Combating Autism Act. Senators Robert Menendez (D-NJ) and Michael Enzi (R-WY) are also preparing a draft bipartisan bill to reauthorize the law. The House and Senate bills are expected to include a change in the name of the legislation that is less offensive to people with ASD.

In addition, Senator Menendez introduced the “Assistance in Gaining Experience, Independence and Navigation (“AGE-IN”) Act of 2013 (S. 1259) on June 27, 2013. The bill would provide federal funding to research and evaluate services currently available for young people “aging out” of existing education and support systems, develop a national strategic action plan, and provide training grants to put the plan into action in helping transitioning youth to lead productive, independent lives. Senator Menendez may seek to include this bill in the reauthorization of the Combating Autism Act.

No bills to reauthorize the DD Act have been introduced to date. DD Act programs have been cut through sequestration.

Recommendations

The 113th Congress should:

- Reauthorize the Combating Autism Act before it sunsets.
- Reauthorize and fully fund the Developmental Disabilities Act.
- Support AGE-IN and other legislation that addresses the needs of youth with Autism Spectrum Disorders transitioning into postsecondary education and work.

Relevant Committees

Senate Health, Education, Labor and Pensions Committee
House Energy and Commerce Committee (Subcommittee on Health)

For more information, please contact The Arc at (202) 783-2229, United Cerebral Palsy at (202)776-0406, Association of University Centers on Disabilities at (301) 588-8252, American Association on Intellectual and Developmental Disabilities at (202) 387-1968, National Association of Councils on Developmental Disabilities at (202) 506-5813, or Self-Advocates Becoming Empowered at SABEnation@gmail.com

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¹ U.S. Department of Health and Human Services, Office of Autism Research Coordination, National Institutes of Health (On behalf of the Office of the Secretary). Report to Congress on Activities Related to Autism Spectrum Disorder and Other Developmental Disabilities Under the Combating Autism Act of 2006 and Combating Autism Reauthorization Act of 2011 (FY 2010 - FY 2012)