

THE 2008 DISABILITY POLICY SEMINAR

THE ARC, AAIDD, AUCD,
UCP AND NACDD

FACT SHEET

AUTISM SPECTRUM DISORDER (ASD)

Background

According to the Centers for Disease Control and Prevention (CDC) on the prevalence of Autism Spectrum Disorders (ASD), approximately 1 in every 150 American children has a potential diagnosis of ASD. Continued research is needed to document trends in the growth of ASD, as well as research into and development of effective interventions. In addition, greater commitments are needed to expand access to services such as early identification, diagnosis, early intervention, education, family support, and long-term services and supports to better meet the needs of individuals with ASD and related developmental disabilities. Individuals with ASD and their families need access to accurate information about scientifically-based interventions. The training of a wide range of interdisciplinary professionals also needs to be a top priority so that the findings coming out of our research institutions can be translated and made available to parents and providers across the country as quickly as possible.

Action Taken by Congress and the Administration

Last year, President Bush signed into law the Combating Autism Act of 2006 (PL 109-416). The Act authorizes \$189 million for ASD related activities in FY 2009, an increase of \$27 million over FY 2008. This funding increase would benefit research on ASD through the National Institutes of Health (NIH) and CDC. The Act also provides the first step to expand the interdisciplinary training of professionals to identify and support children with ASD and their families. Unfortunately, the President's FY 2009 Budget would level-fund this program. Congress must act to provide these funds as they develop a joint FY 2009 Budget Resolution. Specifically, Congress should provide the level authorized in the Act:

- \$129 million to expand, intensify, and coordinate the activities of the National Institutes of Health with respect to research on autism spectrum disorder. This includes funding for research into the causes of autism, diagnosis, early detection, prevention, services, supports, intervention, and treatment of autism spectrum disorder. It also funds the Interagency Autism Coordinating Committee to coordinate all ASD efforts within the Department of Health and Human Services.
- \$18 million for the CDC's Disabilities Surveillance and Research Program. This program supports data collection, analysis, and reporting, so that we can better understand the scope of the autism epidemic. It also supports the establishment of regional centers of excellence to collect and analyze information on the number, incidence, correlates, and causes of autism spectrum disorder and other developmental disabilities.
- \$42 million to increase awareness, reduce barriers to screening and diagnosis, promote evidence-based interventions, and train professionals. This includes funding to augment and expand the Leadership Education in Neurodevelopmental and Related Disabilities program to provide interdisciplinary training to professionals to utilize valid and reliable screening tools to diagnose or rule out autism and provide evidence-based interventions for children with autism and other developmental disabilities.

Last Spring, Sens. Hillary Clinton (D-NY) and Wayne Allard (R-CO) introduced the Expanding the Promise for Individuals with Autism Act (S. 937). A companion bill was introduced in the House by Reps. Mike Doyle (D-PA) and Chris Smith (R-NJ) (H.R. 1881). Specifically, the bill authorizes funding for demonstration and state planning projects to expand services and supports for children and adults; grants to expand access to post-diagnosis care and to reduce delays in getting services; a GAO report on improving the financing structure; supports a national network to provide interdisciplinary training of professionals who diagnose and treat individuals throughout their lifespan, and other provisions to improve access to services for individuals with ASD and their families.

Recommendations

The 110th Congress should:

- Provide the necessary funds to focus our country's researchers on explaining the apparent increase in prevalence, on finding the causes, and on determining the most effective ways of supporting children and adults with Autism Spectrum Disorders by fully funding the Combating Autism Act and
- Support legislation that addresses the direct service and training needs associated with this increasing number of individuals with Autism Spectrum Disorders.

Relevant Committees

House and Senate Appropriations Committees

Senate Health, Education, Labor and Pensions Committee

House Energy and Commerce Committee (Subcommittee on Health)

House and Senate Labor, Health and Human Services and Education Appropriations Subcommittees

For more information, please contact The Arc and United Cerebral Palsy Disability Policy Collaboration (202-783-2229), Association of University Centers on Disabilities (301-588-8252), AAIDD (202-387-1968), or National Association of Councils on Developmental Disabilities (703-739-4400).

2/19/08