Combating Autism Act Report Shows Significant Progress

SILVER SPRING, MD (January 12, 2011) — A new congressionally-mandated report, released by U.S. Representatives Mike Doyle (D-PA) and Chris Smith (R-NJ) and prepared by the Office of Autism Research Coordination at the National Institutes of Health, shows that the Combating Autism Act (CAA) of 2006 (Public Law 106-416) has expanded research and surveillance and addresses the growing need for appropriately trained professionals able to assess, diagnose, treat and support individuals with Autism Spectrum Disorders (ASD).

“One of the greatest needs identified during the development of the legislation is the lack of trained professionals to provide diagnostic and clinical services for children with ASD,” says George Jesien, PhD, Executive Director of the Association of University Centers on Disabilities, a nonprofit network of university-based interdisciplinary centers and programs working to advance policy and practice for people living with disabilities and their families. “The law provided for the expansion of the existing members of the AUCD network such as the Leadership Education and Neurodevelopmental Disabilities (LEND) programs and related Developmental Behavioral Pediatrics (DBP) interdisciplinary training programs to focus on training health professionals in the use of valid, reliable screening and diagnostic tools and in the provision of evidence-based interventions for children with ASD. These training efforts are effectively reducing barriers to screening and diagnosis by increasing health professional capacity and awareness about ASD among parents and early childhood providers.”

The CAA funding allowed the LEND training program to dramatically improve the ability of health professionals to conduct screenings and assessments, and enhance the capability of the workforce to screen and treat those with ASD. In 2009, the 22 LEND programs that received funding collectively screened 12,751 infants or children and provided diagnostic evaluation services to 12,390. In FY 2010, the 39 LENDs collectively screened more than 46,000 infants and children and provided diagnostic evaluation services for more than 35,000 infants and children.

CAA funding enabled the CDC “Learn the Signs. Act Early” campaign not only to provide over 11 million health care professionals, parents, partners, and child care providers with
educational resources, but also to collaborate with the Health Resources and Services Administration (HRSA) and AUCD to convene 11 Regional “Act Early” Summits with over 900 participants from all 50 states and trust territories. Each summit brought together families, professionals, providers, and state leaders from various sectors to increase collaboration and coordination of programs and services for children with ASD and other developmental disabilities. State teams developed Summit action plans to address challenges and gaps, and they continue to update their plans and expand focus to increasing coordination and interagency collaboration and awareness efforts, as well as creating a more seamless system of care.

Though the report documents significant progress, CDC data indicate a critical need for improved access to early evaluation and diagnostic services. The typical time gap from developmental concern to diagnosis is over 2 years. “With a continued focus on ASD awareness and training, within both the public and healthcare spheres, this critical time gap can and should be reduced. Increased attention is being given to pinpointing underserved communities where diagnostic and intervention support are in the greatest need,” says Jesien. Through CAA funding, the Federal coordination provided by the Interagency Autism Coordinating Committee (IACC), will continue to identify key research and service priorities and foster communication and collaboration between Federal agencies, private foundation partners and the public.

The CAA is up for reauthorization this year. AUCD will be working with Congress to ensure that gaps in the research and service system are filled during this review and that the law is reauthorized in a timely way.

AUCD is a national network of 67 University Centers for Excellence (UCEDD); 39 Leadership Education in Neurodevelopmental and Related Disabilities (LEND) programs; and 15 Intellectual and Developmental Disabilities Research Centers (IDDRC). As the prevalence of autism has risen, University Centers have initiated many activities to help meet the growing need for children, adults, and families. Together, these programs provide a direct national impact through direct services, the development of new professionals, and the application of new knowledge generated from research. For more information and a national directory of Centers, see AUCD’s website at www.aucd.org.

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