

Commemorating 40 Years Of Disability Advocacy 1973-2013

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Dear Representative/Senator,

Since the enactment of the Combating Autism Act in 2006 and its reauthorization by the Combating Autism Reauthorization Act of 2011, federal agencies, in partnership with the private sector, have made significant strides in addressing one of our nation's top health priorities. The Centers for Disease Control and Prevention estimates, 1 in 68 children has an autism spectrum disorder, a 30% increase over its 2012 estimate of 1 in 88 children.

The Combating Autism Act will expire if it is not reauthorized by September 30, 2014. The Consortium for Citizens with Disabilities (CCD) Developmental Disabilities, Autism, and Family Support Task Force strongly urges you to introduce and timely pass a bill to reauthorize the law.

While a number of federal ASD efforts were in existence prior to the Combating Autism Act, the law has dramatically increased the number, scope, pace, and coordination of ASD research, surveillance, public education, and professional training efforts. This comprehensive strategy is accelerating our efforts to better understand this increasingly prevalent developmental disability. Because of this law, today there is growing awareness in our schools, doctors' offices, and communities about ASD and how to best serve individuals and families. Among its many notable achievements are an increase in the proportion of infants screened for ASD, an increase in the proportion of children diagnosed by three from 12 to 18 percent, and continuing improvements to decrease the time between diagnosis and intervention.

A <u>new congressionally mandated report</u> describes the work being done through activities supported by federal agencies and highlights the progress that has been made under the Combating Autism Act. Below are but a few notable examples:

The National Institutes of Health (NIH) has advanced our understanding of the potential causes of autism. For instance, one NIH study found a protective association in children and mothers who carried a common genetic variant linked to inefficient folate metabolism. This finding indicates that a sufficient amount of supplemental folic acid in the first month of pregnancy may reduce a child's risk for ASD.

The Centers for Disease Control and Prevention (CDC) has increased public awareness and expanded surveillance of ASD. More than 4.3 million materials have been distributed or downloaded from the CDC's <u>Learn the Signs Early</u> campaign since January of 2010 and the

website has received more than 7 million page views. CDC's expanded <u>autism and</u> <u>developmental disabilities surveillance</u> now includes 14 communities and younger children.

The Health Resources and Services Administration (HRSA) has increased the number of trained professionals to screen and diagnose ASD. For instance, HRSA's Leadership Education in Neurodevelopmental and Related Disabilities (LEND) and Developmental-Behavioral Pediatrics Program (DBP) trained 13,500 medical residents and practicing professionals in 2012 alone to implement recommended screening practices and to use evidence-based screening tools such as the Modified Checklist for Autism in Toddlers (M-CHAT). LEND programs provided interdisciplinary diagnostic evaluations for approximately 56,000 infants and children the same year. In addition, HRSA supports programs to conduct research on the behavioral and physical health leading to improvements in interventions that impact the health and well-being of children and adolescents with ASD and other developmental disabilities.

Continued collaborative efforts between the public and private sectors are essential to drive the innovations that will lead to prevention and improved identification, interventions, and services for people with ASD and their families. With the increasing prevalence of ASD, we cannot scale back our national effort by letting provisions of the Combating Autism Act sunset.

CCD is a coalition of approximately 115 national disability organizations working together to advocate for national public policy that ensures the self-determination, independence, empowerment, integration and inclusion of children and adults with disabilities in all aspects of society. The CCD Autism and Developmental Disabilities Task Force strongly urges you to ensure that action is taken quickly to reauthorize this before the law expires in September.

We stand ready to assist you as you undertake the important task of reauthorization. Please contact one of the Task Force Co-chairs above for more information.

Sincerely,

American Association of Intellectual and Developmental Disabilities

ACCSES

American Academy of Pediatrics

American Association on Health and Disability

American Dance Therapy Association

American Occupational Therapy Association

American Speech-Language-Hearing Association

Association of Maternal and Child Health Programs

Association of University Centers on Disabilities

Autism Speaks

Autism National Committee

Brain Injury Association of America

Council for Learning Disabilities

Daniel Jordan Fiddle Foundation

Disability Rights Education and Defense Fund

Division for Early Childhood of the Council for Exceptional Children

Epilepsy Foundation

Easter Seals

Family Voices

IDEA Infant Toddler Coordinators Association

Lutheran Services in America Disability Network
National Alliance on Mental Illness
National Association of Councils on Developmental Disabilities
National Down Syndrome Society
National Respite Coalition
Self-Advocates Becoming Empowered
School of Social Work Association of America
SourceAmerica
The Advocacy Institute
The Arc of the United States

Other National Organizations American Academy of Child and Adolescent Psychiatry National Association of Pediatric Nurse Practitioners March of Dimes