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Congress of the United States
House of Representatives

March 25, 2015

SENIOR MEMBER, FOREIGN AFFAIRS
COMMITTEE

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DEAN, NEW JERSEY DELEGATION

Chairman Tom Cole
House Committee on Appropriations
Subcommittee on Labor, HHS,
Education, and Related Agencies
Washington DC, 20515

Ranking Member Rosa DeLauro
House Committee on Appropriations
Subcommittee on Labor, HHS,
Education, and Related Agencies
Washington, D.C. 20515

Dear Chairman Cole and Ranking Member DeLauro:

As the Cochairman of the Coalition for Autism Research and Education (CARE), I am writing to request that you include at least \$52 million for Autism and other developmental disabilities in the Fiscal Year 2016 Labor, Health and Human Services, Education Appropriations Act. While I understand the fiscal restraints governing your decisions in preparing this bill, I am hopeful that you will include this funding to continue the progress we have made in understanding, diagnosing and treating autism.

Of this amount, I am specifically requesting \$30,042,255, a \$2 million increase, for the Leadership Education in Neurodevelopmental and Related Disabilities (LEND) program to provide resources for up to two new LEND programs in states, like my state of New Jersey, that do not have one. The increase would expand the number of sites and professionals to screen, diagnose, and provide interventions to individuals with autism spectrum disorder and other developmental disabilities.

As you are likely aware, LEND programs provide advanced training to students and fellows from at least 12 disciplines in the identification, assessment, and treatment of children and youth with a wide range of developmental disabilities, including autism spectrum disorders (ASD). The LEND network is currently made up of 43 programs in 37 states that are making significant strides toward improved screening and diagnosis of autism among younger children and helping to train healthcare professionals who treat a number of different developmental and intellectual disabilities.

According to the Report to Congress on the Combating Autism Act issued last year, the LEND programs provided interdisciplinary diagnostic evaluations for close to 56,000 infants and children in 2012. While continuing to meet the growing demand for these services, the LEND programs are reducing wait times for diagnostic evaluation and entry into intervention services. However, nationally, there are tremendous shortages of personnel trained to screen, diagnose and treat individuals with developmental disabilities, and as a result, families often have to wait months to get a comprehensive diagnosis. Further, because of the lack of trained health and allied

Co-Chairman of the following Congressional Member Organizations: Task Force on Alzheimer's Disease • Bi-Partisan Coalition for Combating Anti-Semitism
Lyme Disease Caucus • Coalition for Autism Research and Education • Bi-Partisan Congressional Pro-Life Caucus • Bosnia Caucus • Poland Caucus
Ad Hoc Congressional Committee for Irish Affairs • Congressional Caucus on Human Trafficking • Vietnam Caucus • Congressional Heart and Stroke Coalition

health care professionals, it is increasingly difficult for these individuals who obtain an appropriate diagnosis, to also receive early intervention and treatment services. Yet we know that if intervention and treatment start earlier, we can significantly raise the quality of life and long-term development of children with autism—permitting them to have more fulfilling, productive and independent lives.

The latest CDC numbers show that ASD affects about 1 in 68, and in New Jersey that number is 1 in 45. Unfortunately, without additional funding to establish LEND programs in states that do not currently have one, children in my state will continue to be shut out from receiving these resources.

Accordingly, I am requesting that you include \$30,042,255 for LEND programs in this year's bill and the accompanying report language:

The Committee provides \$30,042,255 for the LEND program within the HRSA Autism and Other Developmental Disabilities to allow the programs to maintain their current capacity and expand the number of sites and professionals trained to diagnose, treat, and provide interventions to individuals with ASD and related developmental disabilities. The increased funding should be used to initiate LEND programs in states where they do not currently have an established program, yet have a high incidence rate of ASD, to ensure children with ASD and related developmental disabilities across the country have access to the valuable resources that LEND programs provide.

Additionally, I am also requesting that you match the President's Budget Request of \$39 million under the ACL/AIDD program for the University Centers for Excellence in Developmental Disabilities (UCEDDs). Authorized under Section 156 of the Developmental Disabilities Assistance and Bill of Rights Act (P.L. 106-402, Subtitle D), HHS/ACL supports a network of 67 UCEDDs that provide interdisciplinary pre-service preparation of students and fellows, continuing education, community training, research, model services, technical assistance, and information dissemination. UCEDDs exist to provide a unique, expert state and community resource to facilitate the independence and full participation in the community of people of all ages living with developmental and other disabilities.

UCEDDs are on the frontlines of many emerging national issues impacting individuals with ASD, including the transition from school to postsecondary education—which I believe is a crisis we must address with a concerted, national effort. Every year, 50,000 young people on the autism spectrum matriculate into adulthood and are in the process of losing essential services. Individuals with autism in the aging out generation and their parents find themselves entering into a system unprepared to meet their needs, and one that disincentivizes opportunity and independence.

UCEDDs support a network of independent but interlinked centers, representing an expansive national resource for addressing issues, finding solutions, and advancing research related to the needs of individuals with developmental disabilities and their families. They are a valuable resource now and with the funding requested in the President's budget, they will

continue to train future professionals with the specialized expertise in developmental disabilities necessary to address the aging out crisis.

Thank you for your time and attention to this request.

Sincerely,

A handwritten signature in blue ink, appearing to read "Chris Smith", is written over a horizontal line.

Rep. Christopher H. Smith
Member of Congress