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**Congress of the United States**  
**House of Representatives**

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DEAN, NEW JERSEY DELEGATION

April 6, 2017

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 DC, 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 (FY) 2018 Labor, Health, and Human Services, Education and Related Agencies 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 \$31,317,485 million for the Leadership Education in Neurodevelopmental and Related Disabilities (LEND) program. This is the amount that was provided in FY 2017 that resulted in an increased number of sites available to screen, diagnose and provide evidence-based interventions to individuals with ASD/DD as authorized under the Autism CARES Act. This request would maintain the funding for these programs.

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 ASD. The LEND network is currently made up of 52 programs in 44 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 a Report to Congress on the Combating Autism Act, the LEND programs provided interdisciplinary diagnostic evaluations for close to 56,000 infants and children in 2012. With the expanded number of LEND grantees and trainees, the LEND programs provided interdisciplinary diagnostic evaluations for over 94,000 infants and children in 2014-15. By continuing to meet the growing demand for these services, the LEND programs are reducing wait times for diagnostic evaluation and entry into intervention services.

The latest CDC numbers show that ASD affects about 1 in 68 children, and in New Jersey that number is 1 in 45. It is difficult for these individuals to obtain an appropriate diagnosis, as well as access early intervention and treatment services because of the lack of trained health and allied health care providers. The increase in FY 2017 allowed additional programs to be established in states that did not have one in order to address this shortage. FY 2018 funding will allow LEND programs to continue training professionals to diagnose and provide care for individuals with ASD/DD.

Accordingly, I am requesting that you include \$31,317,485 for LEND programs in this year's bill and the accompanying report language:

*The Committee has also provided \$31,317,485 for the LEND program within HRSA Autism and Other Developmental Disabilities to allow the LEND programs to maintain their capacity to train professionals to screen, diagnose, and provide evidence-based interventions to individuals with autism spectrum disorder and other developmental disabilities as authorized by the Autism CARES Act. This funding will also enable LEND network to assist in ongoing developmental monitoring, especially for children exposed to lead and other environmental toxins and for infants exposed to the Zika virus with its resulting complications. LEND programs are a strong community link to services and supports for these newest members of the disability community and their families. In addition, the funding will allow these programs to develop innovative strategies to integrate and enhance existing investments, including translating research findings on interventions, guidelines, tools and systems management approaches to training settings, communities and into practice; and promote life-course considerations, from developmental screening in early childhood to transition to adulthood issues.*

Additionally, I am also requesting that you appropriate at least \$40 million under the ACL/AIDD program for the University Centers for Excellence in Developmental Disabilities (UCEDDs), a \$1 million increase over the expected FY 2017 level. 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 disincentives 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 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".

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Christopher H. Smith  
Member of Congress