

TALKING POINTS:

- The Combating Autism Act serves all people with developmental disabilities, not just autism. Every year LEND programs train thousands of professionals to better care for individuals with a broad range of developmental disabilities, including but not limited to autism spectrum disorders. Given the long waiting lists families often endure to receive diagnostic and treatment services these training programs are essential in addressing an urgent national health need.
- If the CAA is not reauthorized, all of the activities authorized under the law would expire due to the September 30, 2011 sunset provision. The LEND programs would be seriously threatened!
- I understand that there is some resistance to authorizing “disease specific” legislation in the House at this time. However, I would emphasize that despite the name, the Combating Autism Act improves services for children with many different developmental disorders and conditions such as Down Syndrome, Cerebral Palsy, spina bifida, intellectual disabilities and epilepsy. Moreover, our program is also involved in a number of efforts related to prevention and early detection which improve the health infrastructure for all children in our region.
- There continues to be a staggering number of children affected by Autism Spectrum Disorders (1 in 110, according to CDC estimates). The numbers of children with ASDs is on the rise. Estimates show that there has been a 57% increase in the prevalence in autism. Recent CDC figures also show a rise in developmental disabilities of up to 17%. We need to figure out why this is happening.
- According to a recent congressionally mandated report to Congress, in the past four years under the provisions of the CAA, significant advances have been made in our understanding and treatment of ASDs. For example, we now have treatments for toddlers as young as 15-months of age as well as research identifying the genetic and environmental risk factors for autism.
- Due to CAA funding, we now have much more reliable estimates of the prevalence of autism and a clear picture of the gaps that exist in ASD research and services. These data offer us valuable information about how and where to allocate funds so that we achieve maximum positive outcomes.
- CAA funding directly contributed to dramatic improvements in the numbers of children receiving screening and diagnostic assessments for ASDs and other developmental disabilities through public awareness efforts and training of health professionals. The addition of 4 new Leadership Education in Neurodevelopmental and related Disabilities (LEND) programs and additional funding to existing programs has resulted in:
 - developmental and autism screening of over 46,000 infants and children

- new university coursework, continuing education events and other events to over 155,000 participants
 - an increased workforce capability to screen and treat those with ASDs and other developmental disabilities.
- New screening and diagnostic tools being developed as a result of the CAA are leading to earlier diagnoses. Research conducted through CAA funding has shown that the earlier children are treated the more likely they are to have successful outcomes which lead to cost savings
- CAA funding has also shed light on the critical issue of racial and ethnic disparities in access to early evaluation and diagnostic services for children who may be at risk for autism and other developmental disabilities. Studies identify a gap in the screening of children of color when compared to Caucasian children of approximately 18-24 months
- Through CAA funding researchers have been able to identify several best practices in implementation of programs to increase quality of life for people with ASD. However, it is clear that significant gaps remain in evidence-based interventions for: education, supported employment, family supports, and transition services across the lifespan.
- Workforce development and training is the key component in addressing the needs of individuals with ASD and other developmental disabilities and their families. Evidence has demonstrated that students and professionals who receive interdisciplinary training are best suited to address the specific challenges of individuals with autism. Without a well trained workforce the efforts of CAA research will NOT reach the individuals and families that are desperate for help