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# Combating Autism Reauthorization Act of 2014

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## POLICY BRIEF

# Combating Autism Reauthorization Act of 2014

Kassandra Mores, BA; NH LEND Program Trainee 2013-14

### Executive Summary

*On May 9, 2014, Representative Smith (R-NJ) and Representative Doyle (D-PA) introduced a bill to reauthorize the Combating Autism Act (H.R. 4631) for five years. Senator Menendez (D-NJ) and Senator Enzi (R-WY) are planning to introduce a Senate bill of the Combating Autism Reauthorization Act. The Combating Autism Act of 2011, due to sunset September 30, 2014, provides federal funding for autism research, public education, and early detection and intervention in Maine. We are hoping that you will consider voting in support of the Combating Autism Reauthorization Act.*

### Prevalence and Cost of Services for People with Autism:

- In 2008, up to 1 in 6 children in the U.S. had a developmental disability, ranging from speech and language impairments to intellectual disabilities, cerebral palsy and autism.<sup>1</sup>
- One in 68 children have been identified with an Autism Spectrum Disorder (ASD).<sup>2</sup> Autism is a disorder that typically appears during the first two years of life. Autism manifests differently for each individual, but generally impacts the development in the areas of communication, social interaction and restricted or repetitive and stereotyped patterns of behavior, activities and interests. Autism is a lifelong disability.<sup>3</sup>
- In 2012, MaineCare claims data indicated that there were over 5,380 individuals with a diagnosis of ASD. This was a 29% increase from three years earlier and includes individuals from every age group.<sup>4</sup>
- The rate of students in Maine being served for special education under the category of autism has increased 34% within the last 5 years.<sup>4</sup>
- In 2012, the average lifelong supports needed by those with an ASD diagnosis were estimated to be between \$1.4 million for those without a corresponding intellectual disability, and \$2.3 million for those with a corresponding intellectual disability.<sup>5</sup>
- In 2013, the fastest growing group of individuals with ASD in Maine were young adults aged 21-26.<sup>4</sup>
- Early screening and detection of ASD can reduce lifelong costs dramatically.

1 Boyle, C. A., Boulet, S., Schieve, L. A., Cohen, R. A., Blumberg, S. J., Yeargin-Allsopp, M., Visser, S., & Kogan, M. D. (2011). Trends in prevalence of developmental disabilities in US children, 1997-2008. *Pediatrics*, 1034-1042. doi: 10.1542/peds.2010-2989.

2 Centers for Disease Control and Prevention. (March 27, 2014). US Department of Health and Human Services. Retrieved from <http://www.cdc.gov/media/releases/2014/p0327-autism-spectrum-disorder.html>

3 Autism Society of America. (2013). About autism. Retrieved April 28, 2014 from <http://www.autism-society.org/about-autism/>

4 Maine Department of Health and Human Services and the Maine Department of Education. (April 2013). Autism spectrum disorders report. Retrieved May 15, 2014 from [http://www.maine.gov/dhhs/reports/autism\\_spectrum\\_disorders-report.pdf](http://www.maine.gov/dhhs/reports/autism_spectrum_disorders-report.pdf).

5 Autism Speaks. Retrieved March 25, 2014 from <http://www.autismspeaks.org/science/science-news/autism%E2%80%99s-costs-nation-reach-137-billion-year>

## **Impact of the Combating Autism Act in Maine:**

- Data collected in 2012 from the Maine Developmental Disabilities Council shows that Maine has improved identification rates of children with ASD to a median age of 2.9 in comparison to the national average of around 5 years old.<sup>6</sup>
- In 2009, 3,500 children were screened for autism in the state of Maine.
- Between 2010 and 2012, 150 primary care physicians in Maine were trained to screen for autism.<sup>3</sup>
- Between 2010 and 2012, twelve Maine medical practices were provided with technical assistance to incorporate screening.<sup>3</sup>
- Since its implementation in Maine in 2011, the Leadership Education in Neurodevelopmental and Related Disabilities (LEND) program has provided training to 15 interdisciplinary professionals.
- The University of Maine Center for Community Inclusion and Disability Studies and the University of New Hampshire Institute on Disability collaborated on a research project to improve a number of transition-related outcomes for Maine and New Hampshire youth with ASD, and worked with family advocacy organizations to develop strategies for making the supports provided in this project available to families on a sustainable basis.<sup>7</sup>
- In 2010, Maine was awarded a three-year Autism Spectrum Disorders State Implementation Grant (AIG) of approximately \$300,000 annually, funded under the federal Combating Autism Act Initiative. These funds were used to do the following:
  - Increase early screening and detection of ASD;
  - Develop a web-based database to assist in the communication of screenings completed and facilitate access to diagnostic evaluation and early intervention services; and
  - Improve communication and coordination between medical diagnosticians and early childhood providers.<sup>4</sup>
- Maine was selected to be one of the 25 States that received a stipend and an identified Act Early Ambassador to promote “Learn the Signs. Act Early.” The Act Early Ambassador distributes learning materials and messages, provides free tools to track milestones, provides training to primary care providers, and enhances State efforts to improve screening and referral to early intervention services.<sup>4</sup>

## **The Combating Autism Reauthorization Act of 2014 ensures Maine:**

- 300 hours of leadership and clinical training for over 10 professionals.
- Up to \$150,000 to support leadership and clinical training for interdisciplinary professionals.
- Continued progress in early identification of ASD.
- One Act Early Ambassador identified and over 1,000 “Learn the Signs. Act Early” materials distributed to families across Maine.
- Continued research and improvement regarding transition services for the aging ASD population.
- Continued collaboration between leaders in the ASD field and Maine health professionals.

## **About the New Hampshire Leadership Education in Neurodevelopmental and Related Disabilities Program Partnership**

The University of Maine Center for Community Inclusion and Disability Studies is a partner with the University of New Hampshire Institute on Disability, and the Geisel School of Medicine at Dartmouth, in the New Hampshire Leadership Education in Neurodevelopmental and Related Disabilities (NH LEND) Program. The NH LEND Program provides graduate-level interdisciplinary training for students and professionals from diverse disciplines, including developmental pediatrics, early childhood education, social work, psychology, occupational therapy, health management and policy, and speech language pathology. This partnership is made possible through the NH LEND Program and is supported by a grant (#T73 MC00024) from the Maternal and Child Health Bureau, Health Resources and Services Administration, U.S. Department of Health and Human Services; and administered by the Association of University Centers on Disabilities.

6 Kurtz, A., Schickle, A., Carr, M., Bragdon-Morneault, M., Russell, S., Rainey, D., & Downs, J. (2014). Accessing healthcare: The experiences of individuals with autism spectrum disorders in Maine. Orono, ME: The University of Maine Center for Community Inclusion and Disability Studies. Manuscript in preparation.

7 Hagner, D., Kurtz, A., Cloutier, H., Arakelian, C., Brucker, D. L., & May, J. (2012). Outcomes of a family-centered transition process for students with autism spectrum disorders. *Focus on Autism and Other Developmental Disabilities*, 27(1), 42-50.