

Autism CARES Act

Issue Brief

In 2006, the Combating Autism Act (P.L. 109-416) was signed into law by President George W. Bush. The purpose of the law was to provide a coordinated federal response to the dramatically rising numbers of individuals diagnosed with autism spectrum disorder (ASD). The law increased investments across the Department of Health and Human Services to address the growing needs of individuals with ASD and their families. It also authorizes the Interagency Autism Coordinating Committee (IACC) to coordinate all federal autism efforts.

According to the Centers for Disease Control and Prevention's most recent report, approximately 1 in 58 children have been diagnosed with ASD – an increase of approximately 600 percent since 2006. ASD is a developmental disability that can cause significant social, communication, and behavioral challenges. There is often nothing about how people with ASD look that sets them apart from other people, but people with ASD may communicate, interact, behave, and learn in ways that are different from most other people. The learning, thinking, and problem-solving abilities of people with ASD can range from gifted to severely challenged. Some people with ASD need a lot of help in their daily lives; others need less.

The law was reauthorized in 2014 as the Autism Collaboration, Accountability, Research, Education, and Support (CARES) Act (P.L. 113-157). The bipartisan bill was passed unanimously in the House and Senate. The law must be reauthorized by September 2019 for these activities to continue.

Following is a summary of authorized activities under the Autism CARES Act.



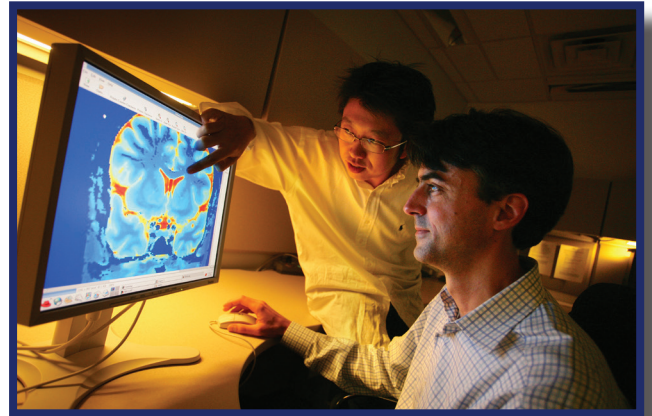
Iowa LEND Evaluation

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Research

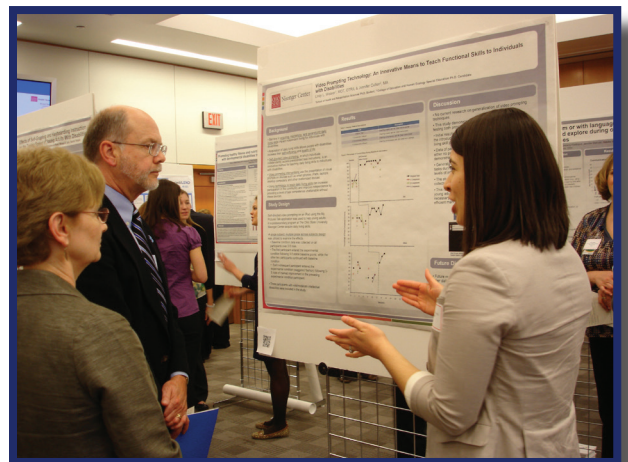
The Autism CARES Act supports NIH-funded research, including studies of the developmental processes underlying autism biology, research on the molecular and neurological underpinnings of ASD and gene function, and research on potential environmental risk factors and biomarkers for ASD, including gene-environment interactions. The National Institutes of Health (NIH) is the largest biomedical research agency in the world and houses the Office of Autism Research Coordination (OARC), which assists the IACC by communicating information about ASD/Developmental Disability (DD) research activities to Congress, government agencies and the public. The NIH Autism Centers for Excellence across the country conduct research on possible treatments and interventions, then report findings to the National Database for Autism Research which increases the efficiency and access of the research. Highlights in the NIH publication “Summary of Advances in Research for 2017” include new insight into potential biomarkers to predict risk of ASD, developmental trajectories of children with ASD, and the impact of the various prenatal exposures on ASD risk. This research investigated treatments and interventions for both ASD and co-occurring conditions, the impact of policy changes on ASD health care spending, patterns of injury mortality, and prevalence differences across demographic groups.



Vanderbilt Kennedy Center Researchers, 2015

Data and Surveillance

The Autism CARES Act has helped to build a critical infrastructure at the CDC to further advance our understanding of autism. The Autism CARES Act supports the Autism and Developmental Disabilities Monitoring (ADDM) Network, a group of programs funded by the CDC to estimate the number of children with ASD and other developmental disabilities living in different areas of the United States. The CDC also established regional centers of excellence for ASD and other developmental disabilities. These centers make up the Centers for Autism and Developmental Disabilities Research and Epidemiology (CADDRE) Network that are working in part to help identify factors that may put children at risk for ASD and other developmental disabilities.



Ohio Joint LEND trainee poster session, 2013

Training

Nationally, there continue to be tremendous shortages of personnel trained to screen, diagnose, and treat individuals with developmental disabilities. The Maternal and Child Health Branch of the Health Resources and Services Administration was authorized to increase its efforts to provide training to health professionals to screen for and diagnose (or rule out) ASD, and to increase evidence-based interventions for children and youth with ASD. Some of the activities authorized follow.

Professionals are trained through the Leadership Education in Neurodevelopmental and Related Disabilities (LEND) program and the Developmental Behavioral Pediatrics (DBP) Training program. For fiscal years 2011-2014, the LEND and DBP programs provided interdisciplinary diagnostic evaluations to more than 224,000 children, trained nearly 16,000 pediatricians and other health professionals, and initiated more than 3,000 continuing education events for practicing and pre-service professionals on screening, diagnosis, and intervention. By continuing to meet the growing demand for these services, the LEND and DBP programs are reducing wait times for diagnostic evaluation and entry into intervention. These programs are designed to be flexible to meet the needs of individual states.

Research programming supports five networks and eight autism intervention research projects. From 2011-2014, Autism CARES Act-funded research programs conducted 57 studies on physical and behavioral health issues, screening and diagnosis, early intervention, and transition to adulthood. The Autism Intervention Research Network on Physical Health (AIR-P Network) conducts research on evidence-based interventions that improve the physical health of children and adolescents with ASD/DD. One way that the AIR-P is working to improve support for people with ASD/DD is the development of practical guides for families and practitioners, called toolkits. These toolkits address common needs, such as what to do after a child has been diagnosed with ASD/DD. There are guides for parents, grandparents, siblings, and friends. Even how-to guides for common routines such as getting a haircut or going to the dentist are available. Professional guides have been developed to support providing meaningful feedback to families impacted by ASD/DD. All of these toolkits are available as free downloads.

The Autism Intervention Research Network on Behavioral Health (AIR-B Network) advances evidence-based behavioral treatments for children with ASD/DD. The Network is composed of nine sites across the country. By enrolling participants in their research, AIR-B sites have led to the expansion of evidence-based practices, clinical guides, virtual professional development, and over 140 published research articles. Among the tools developed by the AIR-B Network are tools for teachers, including assessments for social skills and practical guides for facilitating social interactions with peers. Another useful tool developed by AIR-B is the Guidelines for Treatment document which helps families learn about treatments that have a strong evidence base.



Army clinic, Murores-Meyer Institute, Nebraska 2011



LEND trainees, Mallman Center, Miami, FL 2013

State Systems grants increase awareness of ASD/DD, train professionals and families, and reduce barriers to access. State Implementation Grants provide funds to states to plan and implement ways to increase their capacity to provide quality, coordinated care and support to individuals and families. Recipients of these grants have increased access for families by opening a specialty clinic in a rural public school, piloting a telemedicine project, and developing strategies to address barriers caused by cultural and linguistic disparities. Improvement plans have been developed resulting in increased access to quality care and the development of resource materials, toolkits, and community resource guides for professionals and families.

States can also access the State Public Health Autism Resource Center (SPHARC), a web-based resource designed to increase the capacity of states. This center provides technical assistance with resource development, screening tools, and publications, along with a peer learning component that includes site visits and peer-to-peer exchanges. For example, using the Resource Center the Colorado grantee trained personnel from more than 100 pediatric and family medical practices in local communities to increase early identification and referral within the medical home.

Next Steps

The Autism CARES Act has provided the most comprehensive attention to autism spectrum disorder (ASD) ever passed by Congress. While the law has made significant gains, there is still much more work to be done to improve the quality of lives of individuals with ASD and to support their families. The IACC has developed broad goals for future efforts outlined in its strategic plan. These include efforts to answer these seven research questions that have a practical impact on people affected by autism:

- Screening and Diagnosis: When should I be concerned?
- Biology: How can I understand what is happening?
- Risk Factors: What caused this to happen and can it be prevented?
- Treatment and Interventions: Which treatments and interventions will help?
- Services: Where can I turn for services?
- Lifespan Issues: What does the future hold, particularly for adults?
- Infrastructure and Surveillance: What infrastructure and surveillance needs must be met?

The Autism CARES Act must be reauthorized by September 30, 2019, or these important activities will expire. Senators Mike Enzi (R-WY) and Bob Menendez (R-NJ) and Representatives Chris Smith (R-NJ) and Mike Doyle (D-PA) plan to introduce a bipartisan bill to extend the law soon. The Autism Society of America and the Association of University Centers on Disabilities (AUCD) will work, along with other stakeholders, to assist Congress and the Administration to reauthorize this law as soon as possible.

