



# The Combating Autism Act: Overview and Funding

(name redacted)

Analyst in Public Health and Epidemiology

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## Summary

Autism spectrum disorder (ASD) and autism are general terms for a group of developmental disabilities that cause impairments in social skills and communication, and are often characterized by certain atypical behaviors. The federal government has a role in the financing (through Medicaid and State Children's Health Insurance Programs) and delivery (through funding of developmental disabilities programming in schools, Title V Maternal and Child Health funding, and other sources) of treatment for ASD. The number of autism cases and their appropriate diagnosis and treatment affect federal and state expenditures. As such, Congress has shown interest in financing research on ASD prevalence, causes, and optimal treatment for individuals with ASD.

On September 26, 2011, the 112<sup>th</sup> Congress passed the Combating Autism Reauthorization Act (CARA, P.L. 112-32), which reauthorized funding for autism research authorized under the Combating Autism Act of 2006 (CAA, P.L. 109-416). The CAA was enacted to address public and congressional concern with growing rates of autism; to increase existing autism research funding authorizations; and to stimulate state-level coordination of health, education, and disability programs. The CAA authorizes funding for ASD surveillance, research, and education at the Department of Health and Human Services (HHS), at the Centers for Disease Control and Prevention (CDC), the Health Resources and Services Administration (HRSA), and the National Institutes of Health (NIH).

The CAA authorizes funding for CDC to administer a grant program for states and other entities to conduct surveillance on ASD and developmental disabilities, and to establish regional centers of excellence in ASD epidemiology. The CAA also authorizes funding for HRSA to support autism education, intervention, and early detection. NIH is authorized under the CAA to conduct and fund basic scientific research on autism and other developmental disabilities. In addition, NIH is tasked with the coordination of all research, screening, intervention, and education efforts through the Interagency Autism Coordinating Committee.

The Combating Autism Act authorized appropriations for these activities from FY2007 through FY2011. The Combating Autism Reauthorization Act of 2011 extends authorizations of appropriations at FY2011 levels for FY2012 through FY2014. Funding for research authorized by CARA is discretionary and subject to the annual appropriations process. Full-year appropriations for FY2013 have yet to be enacted. However, a six-month government-wide continuing resolution (CR) was signed into law on September 28, 2012 (P.L. 112-175), which generally maintained funding for discretionary programs at their FY2012 levels, increased by 0.612%.

This report presents an overview of the CAA and CARA, HHS funding and activities under the CAA and CARA for FY2007 through FY2013, other federal activities related to autism, and selected issues for Congress.

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## Introduction

Autism spectrum disorder (ASD) and autism are general terms for a group of developmental disabilities that cause impairments in social skills and communication, and are often characterized by certain atypical behaviors.<sup>1</sup> Autism spectrum disorders include autistic disorder, Asperger disorder, and pervasive developmental disorder-not otherwise specified.<sup>2</sup> These conditions have overlapping symptoms that differ in terms of onset, severity, and nature. ASDs are referred to as “spectrum disorders” because they encompass a range of behaviorally defined conditions. The complex nature of these conditions creates diagnostic challenges; there are no consistent genetic<sup>3</sup> or biologic markers<sup>4</sup> to facilitate diagnosis.

Autism has been linked to abnormal biology and chemistry in the brain; however, the cause or causes of these abnormalities remain unknown. According to the Centers for Disease Control and Prevention (CDC), as many as 1 in 110 eight-year-olds currently have an autism spectrum disorder, with boys affected more than four times as often as girls.<sup>5</sup> This represents an increase from past autism rates, and has generated public interest in the causes of autism. The increased prevalence has also focused attention on the demand for effective treatment and support services for individuals with these conditions. In addition, some have questioned whether the current rates of ASD reflect increased awareness and diagnosis, a true increase in the incidence of ASD, or a combination of these factors.<sup>6</sup>

For many, autism is a lifelong illness whose symptoms often manifest before age three. Autistic children and adults generally display a unique set of symptoms, but common traits associated with autism include difficulty talking, repeated behaviors, and aversion to loud noises. ASD impedes an individual’s communication skills, making it difficult to learn or to integrate socially. There are no medical treatments for autism itself; however, medications and behavioral therapy can help mitigate certain symptoms. While there is currently no known cause or cure for autism, research to determine the cause or causes may identify risk factors, some of which may be modifiable. Other studies may determine optimal methods of screening and diagnosis, identify the most effective mental and behavioral health therapies, and find the best medical treatments for individuals with ASD.

The federal government has a role in the financing (through Medicaid and State Children’s Health Insurance Programs) and delivery (through funding of developmental disabilities programming in schools, Title V Maternal and Child Health funding, and other sources) of treatment for ASD.<sup>7</sup>

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<sup>1</sup> National Institute of Mental Health, *What Are Autism Spectrum Disorders?* <http://www.nimh.nih.gov/health/publications/autism/what-are-the-autism-spectrum-disorders.shtml>.

<sup>2</sup> As defined by the *Diagnostic and Statistical Manual of Mental Disorders—Fourth Edition*.

<sup>3</sup> A genetic marker is a DNA sequence with a known physical location on a chromosome. Genetic markers can help link an inherited disease with the responsible gene.

<sup>4</sup> A biologic marker is a measurable and quantifiable parameter that serves as an indicator for health and physiology assessments, such as disease risk, environmental exposures, metabolic processes, etc. For example, the presence of antibodies in a blood sample may indicate an infection.

<sup>5</sup> Autism and Developmental Disabilities Monitoring Network, *Prevalence of Autism Spectrum Disorders*, United States, 2006, Atlanta, GA, December 18, 2009, <http://www.cdc.gov/mmwr/preview/mmwrhtml/ss5810a1.htm>.

<sup>6</sup> National Institute of Mental Health, “Autism: The Whys of Increased Prevalence,” press release, November 23, 2009, <http://www.nimh.nih.gov/media/video/bearman.shtml>.

<sup>7</sup> See CRS Report RL33202, *Medicaid: A Primer*, by (name redacted); CRS Report R40448, *State Children’s Health Insurance Program (SCHIP)*, by (name redacted) (continued...)

The number of cases and their appropriate diagnosis and treatment affect federal and state expenditures.<sup>8</sup> As such, Congress has shown interest in financing research on ASD prevalence, causes, and optimal treatment for individuals with ASD. This interest in ASD surveillance and research has been demonstrated through inclusion of autism research provisions in the Children's Health Act (CHA, P.L. 106-310) in 2000, enactment of the Combating Autism Act in 2006 (CAA, P.L. 109-416), and the recent enactment of the Combating Autism Reauthorization Act (CARA, P.L. 112-32) by the 112<sup>th</sup> Congress.

This report presents an overview of the CAA and CARA, Department of Health and Human Services (HHS) funding and activities under the CAA and CARA, other federal activities related to autism, and selected issues for Congress.

## **The Combating Autism Act (CAA)**

The precursor to the CAA was the Children's Health Act of 2000 (CHA), which addressed a number of child health issues. Title I of the CHA authorized the Secretary of HHS (the Secretary) to conduct certain activities relevant to autism and developmental disabilities. It established funding for autism surveillance at CDC and established the National Center on Birth Defects and Developmental Disabilities. Under the CHA, the National Institutes of Health (NIH) was authorized to expand and intensify its autism research efforts and to establish Centers of Excellence for autism research. The CHA also established an Autism Coordinating Committee to coordinate research within NIH, and authorized funds for HHS to establish and implement an information and education campaign for health care providers and the general public.

Enacted in 2006 and subsequently reauthorized by the Combating Autism Reauthorization Act of 2011, the CAA is intended to address growing concern about the increasing prevalence of autism spectrum disorders, and to stimulate research into possible autism causes and treatments. It authorized funding from FY2007 through FY2011 for autism research, screening, early intervention, and education. CARA reauthorized this funding through FY2014.

The CAA authorizes the Secretary to expand, intensify, and coordinate existing ASD research activities; to expand surveillance and epidemiological research; to increase awareness of ASD; and to provide access to screening and early intervention services. It authorizes expanded research activities at NIH, and created the Interagency Autism Coordinating Committee (IACC) to coordinate all federal autism research efforts (this expanded the mission of the Autism Coordinating Committee described above). At CDC, the CAA authorizes surveillance and establishes ASD awareness programs. At the Health Resources and Services Administration (HRSA), the CAA authorizes expanded federal efforts in autism education, early detection, and intervention. The CAA also required a report to Congress on implementation and progress four

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*Insurance Program (CHIP): A Brief Overview*, by (name redacted) and (name redacted); CRS Report R42428, *The Maternal and Child Health Services Block Grant: Background and Funding*, by (name redacted); and CRS Report R41833, *The Individuals with Disabilities Education Act (IDEA), Part B: Key Statutory and Regulatory Provisions*, by (name redacted).

<sup>8</sup> Ganz M, "The Lifetime Distribution of the Incremental Societal Costs of Autism," *Arch Pediatr Adolesc Med*, vol. 161, no. 4 (April 2007), pp. 343-349.

years after enactment, which was provided to Congress on January 7, 2011.<sup>9</sup> CARA requires a report to Congress two years after enactment.

The following sections summarize the programs and funding authorized under the CAA and subsequently reauthorized by CARA.

## **Surveillance and Epidemiological Research**

The CAA authorizes CDC to award competitive grants for the collection, analysis, and reporting of state-level epidemiological data on ASD and other developmental disabilities. CDC must establish guidelines for reporting these data, in collaboration with other public and private entities. CDC is also required to coordinate the federal response to potential or alleged clusters of ASD or developmental disabilities (DD).

The CAA also requires CDC to award grants or cooperative agreements for the establishment of regional centers of excellence in the epidemiology of ASD and other developmental disabilities. The purpose of the centers of excellence is to collect and analyze information on the number, incidence, correlates, and causes of ASD and other DD. The centers are required to collect and report data according to the guidelines established by CDC. In addition, centers are required to develop an area of special research expertise (such as genetics, epigenetics, or environmental epidemiology), and to identify suitable cases and controls for research into potential causes or risk factors for ASD.

## **Autism Education, Early Detection, and Intervention**

The CAA authorizes the Secretary to provide grants for projects designed to (1) increase awareness of ASD; (2) reduce barriers to screening and diagnosis; (3) promote evidence-based interventions for individuals with ASD or other developmental disabilities; (4) train health care professionals to use valid, reliable screening tools; and (5) provide early intervention if needed. The Secretary must use an interdisciplinary approach that also focuses on specific issues for children who are not receiving early diagnosis and interventions. These activities are carried out through HRSA.

The Secretary must, subject to funding, provide information and education on ASD to increase public awareness of developmental milestones; promote research into the development and validation of reliable screening tools; promote early screening of high-risk individuals; increase the number of individuals who are able to diagnose or rule out ASD; increase the number of individuals who are able to provide evidence-based interventions; and promote the use of evidence-based interventions for high-risk individuals.

The Secretary must, subject to funding, collaborate with a number of federal programs for low-income individuals to provide culturally competent information regarding ASD and

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<sup>9</sup> Office of Autism Research Coordination, National Institutes of Health, Report to Congress on Activities Related to Autism Spectrum Disorder and Other Developmental Disabilities Under the Combating Autism Act of 2006, U.S. Department of Health and Human Services, December 2010, <http://iacc.hhs.gov/reports/reports-to-congress/FY2006-2009/index.shtml>.

developmental disabilities, in collaboration with the Department of Education and the Department of Agriculture. These programs include Head Start; Early Start; Healthy Start; programs under the Child Care and Development Block Grant Act of 1990; Medicaid, including the Early and Periodic Screening, Diagnosis, and Treatment Program (EPSDT); the State Children's Health Insurance Plan (CHIP); the Maternal and Child Health Block Grant; Individuals with Disabilities Education Act Parts B and C; and the Special Supplemental Nutrition Program for Women, Infants, and Children (WIC).

The CAA authorizes the Secretary to require states to designate a lead agency responsible for disseminating the information described above available to individuals in the state. This information may be provided through toll-free numbers, Internet websites, mailings, or other means, as determined by the governor of each state. In addition, the Secretary, through the states, must promote and assist the development and use of screening tools. The Secretaries of HHS and the Department of Education must provide for the collection, storage, coordination, and public availability of screening tools and educational materials. The CAA also authorizes the Secretary to fund grants to expand existing interdisciplinary training and leadership programs (authorized in Title V of the Social Security Act). The Secretary must also promote best practices in autism screening and diagnosis.

## **Centers of Excellence in Autism Research, and Research Coordination**

The CAA authorizes the Secretary of HHS to expand, intensify, and coordinate ASD research activities at NIH, and to consolidate existing program activities if necessary. It directs NIH to investigate the cause, diagnosis, early detection, prevention, services, supports, intervention, and treatment of ASD.

The CAA also authorizes the Interagency Autism Coordinating Committee (IACC) at NIH to coordinate all ASD research, screening, intervention, and education efforts within HHS. Members of the IACC are appointed for a term of four years and may be reappointed once. Members must include representatives of the following: Administration for Children and Families (ACF), CDC, Centers for Medicare and Medicaid Services (CMS), HRSA, NIH, HHS Office on Disability, Substance Abuse and Mental Health Services Administration (SAMHSA), and the Department of Education. No fewer than six members, or one-third of the committee (whichever is greater) must be non-federal public members, including people with autism, parents of people with autism, and leaders of national autism organizations.

The IACC is required to meet at least twice per year in public session. It is responsible for formulating and annually updating the strategic plan for ASD research, and presenting those recommendations to the Secretary and to Congress. The IACC must also monitor all federal ASD activities, make recommendations to the Secretary and to NIH regarding changes to these activities, and make recommendations on public participation in decision making to the Secretary.

## **Combating Autism Reauthorization Act (CARA)**

Funding for CAA programs was authorized through FY2011; the Combating Autism Reauthorization Act (CARA), which extends funding at current levels through FY2014, was signed into law on September 30, 2011. CARA authorizes appropriations through FY2014 for

CAA activities, but does not include funding or authorizations for an expansion of research and/or other services as some autism advocates had requested.<sup>10</sup>

## Funding

**Table 1** presents authorizations of appropriations for the provisions of the CAA and CARA. The table includes authorizations of appropriations from FY2007 through FY2014. **Table 2** provides details of funding for CAA activities, as reported by HHS.<sup>11</sup> Full-year appropriations for FY2013 have yet to be enacted and therefore are not included in **Table 2**. However, the six-month FY2013 CR (P.L. 112-175, signed into law on September 28, 2012) provided funding at FY2012 levels, increased by 0.612%. As such, the funding levels for FY2013 are estimates.<sup>12</sup> For CAA activities, FY2012 funding totaled \$237 million. Funding for FY2013 activities is estimated at \$238 million, a \$1 million increase.

CAA authorizations and funding are presented in two separate tables because funding for autism-related activities is not specifically limited to the authorizations shown in **Table 1**, and may be more or less in a given year. In addition, agencies typically do not have disease-specific budget lines. Autism-related activities may also be funded at CDC and NIH through general authorizations. The information on agency level spending in **Table 2** is compiled from the Moyer Report, a report published by the HHS Office of the Assistant Secretary for Financial Resources. The Moyer Report presents information as reported by the agencies on spending for selected diseases and conditions, including autism.

Federally funded autism research not authorized under the CAA, including activities carried out by the Departments of Defense and Education, is discussed below in the section “Other Federal Activities Related to Autism Research.”

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<sup>10</sup> A number of bills addressing expansion of research, global surveillance, and services for individuals with autism were introduced in the 112<sup>th</sup> Congress.

<sup>11</sup> FY2013 Moyer Material, Office of the Assistant Secretary for Financial Resources, HHS, February 2012.

<sup>12</sup> The President’s Budget Requests for CDC and HRSA for FY2013 can be found at Health Resources and Services Administration, *Justification of Estimates for Appropriations Committees*, Fiscal Year 2013, February 13, 2012, <http://www.hrsa.gov/about/budget/budgetjustification2013.pdf>; and Centers for Disease Control and Prevention, *Justification of Estimates for Appropriations Committees*, Fiscal Year 2013, February 13, 2012, [http://www.cdc.gov/fmo/topic/Budget%20Information/appropriations\\_budget\\_form\\_pdf/FY2013\\_CDC\\_CJ\\_Final.pdf](http://www.cdc.gov/fmo/topic/Budget%20Information/appropriations_budget_form_pdf/FY2013_CDC_CJ_Final.pdf). NIH does not have an autism-specific budget line.



**Table 1. Authorizations of Appropriations in the Combating Autism Act of 2006 and the Combating Autism Reauthorization Act of 2011**

Dollars in millions

	FY2007	FY2008	FY2009	FY2010	FY2011	FY2012	FY2013	FY2014
Developmental Disabilities and Surveillance Program (PHSA 399AA)	15.0	16.5	18.0	19.5	21.0	22.0	22.0	22.0
Autism Education, Early Detection, and Intervention (PHSA 399BB)	32.0	37.0	42.0	47.0	52.0	48.0	48.0	48.0
Interagency Autism Coordinating Committee, Autism Centers of Excellence (PHSA 399CC, 409C, and 404H)	100.0	114.5	129.0	143.5	158.0	161.0	161.0	161.0
Total	147.0	168.0	189.0	210.0	231.0	231.0	231.0	231.0

**Source:** For FY2007 through FY2011, CAA, P.L. 109-416; FY2012 through FYFY2014, CARA, P.L. 112-32.

**Notes:** Appropriations are authorized in Section 399EE of the PHSA.

**Table 2. Funding for Activities Related to the Combating Autism Act**

Dollars in millions

	FY2007	FY2008	FY2009	FY2010	FY2011	FY2012	FY2013
Centers for Disease Control and Prevention	14.8	16.2	20.4	22.1	21.4	21.3	21.3
Health Resources and Services Administration <sup>a</sup>	0	36.4	42.0	47.9	47.7	47.1	47.1
National Institutes of Health	126.8	118.1	254.1	159.6	168.7	169.2	169.7
Total	141.6	170.7	316.5	229.6	237.8	237.6	238.1

**Sources:** Compiled by the Congressional Research Service from the FY2011 Moyer Material, Office of the Assistant Secretary for Financial Resources, HHS, February 2010; the FY2012 Moyer Material, Office of the Assistant Secretary for Financial Resources, HHS, March 2011, the FY2013 Moyer Material, Office of the Assistant Secretary for Financial Resources, HHS, February 2012.

- a. Prior to FY2008, HRSA autism activities were funded within the Special Projects of Regional and National Significance (SPRANS) set-aside of funds from the Maternal and Child Health Block Grant, and were not provided a separate line of funding. For the FY2013 HRSA budget request for autism activities, see <http://www.hrsa.gov/about/budget/budgetjustification2013.pdf>.

## **Autism Activities Under the Combating Autism Act**

The activities carried out by CDC, HRSA, and NIH under the CAA are summarized below. As discussed previously, CDC focuses on surveillance and epidemiological research, NIH on basic science and research coordination, and HRSA on autism education, detection, and early intervention. For further detail on agencies' autism-related activities and publications, refer to the IACC's Report to Congress on Activities Related to Autism Spectrum Disorder and Other Developmental Disabilities Under the Combating Autism Act of 2006.<sup>13</sup>

### **Centers for Disease Control and Prevention (CDC)**

Under the Combating Autism Act, the CDC is responsible for ASD and developmental disabilities surveillance and epidemiological research. Under the CHA and CAA, CDC formed the National Center on Birth Defects and Developmental Disabilities, the Autism and Developmental Disabilities Monitoring Network (ADDM), and the Centers for Autism and Developmental Disabilities Research and Epidemiology (CADDRE), an ASD education campaign for caregivers and health professionals, and has collaborated on the International Autism Epidemiology Network (IAEN).<sup>14</sup> CDC also coordinates with other agencies, including HRSA and the Department of the Army, on other epidemiologic ASD research.

The National Center on Birth Defects and Developmental Disabilities established the ADDM network for the collection, analysis, and reporting of state-level epidemiological data on ASD and other developmental disabilities. ADDM monitors the prevalence of ASD among eight-year-olds at selected sites. The sites, which are regional or state-based public or private nonprofit entities, collect data on ASD prevalence using uniform surveillance methods, which include screening health and education records at multiple sources. Pilot surveillance sites were established with funding from the Children's Health Act; the program was expanded to additional sites under the CAA. ADDM has published two widely cited reports on ASD prevalence, one in 2007 and another in 2009.<sup>15</sup>

Under the CAA, CDC established a grant program for states or other entities (e.g., private nonprofits institutions, including institutions of higher education and hospitals) to establish regional centers of excellence in ASD. These centers, called the Centers for Autism Developmental Disabilities Research and Epidemiology (CADDRE), are part of a multi-site collaborative study examining the risk factors for ASD and other developmental disabilities.<sup>16</sup>

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<sup>13</sup> Office of Autism Research Coordination, National Institutes of Health, *Report to Congress on Activities Related to Autism Spectrum Disorder and Other Developmental Disabilities Under the Combating Autism Act of 2006*, U.S. Department of Health and Human Services, December 2010, <http://iacc.hhs.gov/reports/reports-to-congress/FY2006-2009/index.shtml>.

<sup>14</sup> See <http://www.autismpidemiology.net/>.

<sup>15</sup> Prevalence of Autism Spectrum Disorders, Autism and Developmental Disabilities Monitoring Network, Six Sites, United States, 2000, Autism and Developmental Disabilities Monitoring Network, Atlanta, GA, February 9, 2007, <http://www.cdc.gov/mmwr/preview/mmwrhtml/ss5601a1.htm>; Prevalence of Autism Spectrum Disorders, Autism and Developmental Disabilities Monitoring Network, United States, 2006, Autism and Developmental Disabilities Monitoring Network, Atlanta, GA, December 18, 2009, <http://www.cdc.gov/mmwr/preview/mmwrhtml/ss5810a1.htm>.

<sup>16</sup> See <http://www.cdc.gov/ncbddd/autism/caddre.html>.

The CADDRE network is currently working on the Study to Explore Early Development (SEED), which seeks to characterize ASD-related traits.<sup>17</sup>

CDC has partnered with the autism advocacy organization Autism Speaks to compile statistics on the global prevalence of autism. This partnership is called the International Autism Epidemiology Network.<sup>18</sup> The IAEN has produced a fact sheet that summarizes global autism prevalence from 2000 to 2008.<sup>19</sup>

In addition to research and surveillance activities, CDC has established a health communication campaign, entitled “Learn the Signs. Act Early,” to improve early identification of children with ASD. The campaign is intended to educate parents, health care professionals, and early educators on the developmental milestones of early childhood.

## **Health Resources and Services Administration (HRSA)**

Under the CAA, the Maternal and Child Health Bureau of HRSA must ensure that children with ASD are screened, diagnosed, and receive appropriate treatment. It is also tasked with addressing the shortage of trained professionals who provide autism treatment. HRSA received funding to address the five following objectives: (1) to increase awareness of ASD; (2) to reduce barriers to screening and diagnosis; (3) to promote evidence-based interventions for individuals with ASD or other developmental disabilities; (4) to train health care professionals to use valid, reliable screening tools; and (5) to provide early intervention if needed. To address these objectives, HRSA established or increased support for four programs: Leadership Education in Neurodevelopmental Disabilities (LEND), Developmental Behavioral Pediatric training programs, state implementation programs, and research programs.

HRSA has used CAA funding to support 43 LEND programs and 10 Developmental Behavioral Pediatric training programs by public and private nonprofit agencies in FY2011. The programs focus on the use of screening and diagnostic tools, and continuing education for health care providers that serve women, children, and families. These programs are designed to address the shortage of qualified professionals available to assess and assist autistic individuals.

The governor of each state must designate a lead agency to coordinate the HRSA-funded activities in that state. HRSA state-level grantees have used their funds to implement state autism plans, promote autism awareness, and develop model systems of services for children with ASD and developmental disabilities.<sup>20</sup> The primary focus of state implementation grants is to improve access to ASD and developmental disabilities screening and diagnostic services.

HRSA has established Autism Intervention Research programs, focusing on interventions to improve the health and well-being of children and adolescents with ASD and other developmental disabilities. These grants are provided to develop research networks among public and non-profit private institutions that focus on evidence-based research and the development of best practices in

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<sup>17</sup> See <http://www.cdc.gov/ncbddd/autism/seed.html>.

<sup>18</sup> Centers for Disease Control and Prevention and Autism Speaks, “International Autism Epidemiology Network,” press release, 2009, <http://www.autismepidemiology.net/>.

<sup>19</sup> International Autism Epidemiology Network, “Autism Prevalence Around the World (2000-2008),” press release, 2009, <http://www.worldautismawarenessday.org/atf/>.

<sup>20</sup> See <http://mchb.hrsa.gov/programs/autism/statedempolicy.html>.

physical health, behavioral health, and the general health and well-being of individuals with ASD. Autism Intervention Research programs develop evidence-based guidelines and test and validate tools for measuring treatment outcomes.

## **National Institutes of Health (NIH)**

CAA funding at NIH supports intramural and extramural research<sup>21</sup> at multiple institutes and centers. Under the CAA, NIH-funded researchers are tasked with studying potential risk factors and causes of autism, and to coordinate and consolidate its research on ASD and other developmental disabilities with other agencies.

NIH supports and coordinates the Autism Centers of Excellence Program, consisting of 11 research centers and networks that focus on identifying the causes of ASD and developing treatments. This includes research on biomarkers, genetic susceptibility, pharmacotherapy, language development, early intervention, and risk and protective factors. Another study, the Early Autism Risk Longitudinal Investigation, is looking into the interaction of environmental and genetic factors in ASD.<sup>22</sup>

NIH has sponsored a number of scientific workshops and symposia on ASD-related research. NIH also supports ASD research infrastructure, including biobanking (storage and archiving of biological samples) support, and the establishment of a common database (the National Database for Autism Research) to warehouse data collected in NIH-funded ASD studies.

The Children's Health Act required NIH to form a committee to coordinate research among the Institutes. The CAA broadened the mission of the coordinating committee to include other entities, both within and outside of HHS. The Interagency Autism Coordinating Committee (IACC), chaired by the director of the National Institute for Mental Health, is intended to facilitate the exchange of information on autism activities among the member agencies, and coordinates HHS autism-related programs and initiatives. The CAA required the IACC to present a strategic plan for ASD research, focusing on gaps, opportunities, and new knowledge in the autism research field. The strategic plan must be updated annually. The 2011 IACC Strategic Plan, released on February 28, 2011, includes a new focus on interventions for non-verbal people with ASD, health promotion efforts, and safety.<sup>23</sup>

## **Other Federal Activities Related to Autism Research**

Federal funding for autism research is not limited to the Combating Autism Act, and is supported by the Department of Defense and the Department of Education in addition to HHS. Many of the stakeholders in the IACC do not receive funding under the CAA, but through their participation in autism research, these stakeholders have an interest and a guiding role. Following is a brief description of the autism-related research activities of the other federal participants in the IACC.

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<sup>21</sup> *Extramural research* is performed by non-federal scientists using NIH grant or contract money; *intramural research* is performed by NIH scientists in the NIH laboratories and Clinical Center.

<sup>22</sup> See <http://www.earlistudy.org/>.

<sup>23</sup> Interagency Autism Coordinating Committee, *2011 Strategic Plan for Autism Spectrum Disorder Research*, January 2011, [http://www.iacc.hhs.gov/strategic-plan/2011/IACC\\_2011\\_Strategic\\_Plan.pdf](http://www.iacc.hhs.gov/strategic-plan/2011/IACC_2011_Strategic_Plan.pdf).

## Other HHS Agencies

Certain HHS agencies employ general authorities to direct funds as needed to address public health concerns. For example, CDC may provide funding for autism programs under its general authorities to fund public health activities. Other relevant activities may focus broadly on developmental disabilities and receive funding under different authorities. Within HHS, ACF, CMS, the Office on Disability, and SAMHSA conduct activities that contribute to the growing body of research on ASD. The CAA does not authorize appropriations for these agencies.

ACF is the HHS agency responsible for federal programs that promote the economic and social well-being of families, including Head Start and Temporary Assistance for Needy Families. The agency participates in the IACC and provides services for children with ASD through funds authorized under the Developmental Disabilities Assistance and Bill of Rights Act of 2000 (P.L. 106-402). ACF funds state Developmental Disabilities Councils; Protection and Advocacy Agencies; Centers for Excellence in Developmental Disabilities Education, Research, and Services; and Projects of National Significance.<sup>24</sup>

CMS administers the Medicare, Medicaid, and State Children's Health Insurance Program. The agency participates in the IACC and supports autism education, early detection, and intervention services under the CAA through Medicaid's EPSDT program.<sup>25</sup> CMS has also conducted several studies on best practices in autism treatment, and is planning to issue a report of all state services available to individuals with ASD.

The HHS Office on Disability is primarily a policy office that supports coordination of resources across HHS and federal agencies to support individuals with disabilities, including those with autism.<sup>26</sup>

Finally, SAMHSA is the HHS agency responsible for supporting mental health and substance abuse programs.<sup>27</sup> The agency provides services to children with ASD through the Child Mental Health Initiative, a grant program mandated by Congress to serve children and youth with serious emotional disorders. This program provides grants for the development of coordinated support systems for children who are referred to the program.

## Non-HHS Agencies

Federal autism activities are not limited to HHS agencies. Other federal entities use general authorities and previously established programs to address ASD. These entities include the Department of Defense (DOD) and the Department of Education.

The DOD does not receive funds under the CAA. However, it maintains a congressionally directed research program for ASD research, which was first funded in FY2007.<sup>28</sup> The program,

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<sup>24</sup> See the Administration on Developmental Disabilities, ACF: <http://www.acf.hhs.gov/programs/add/>.

<sup>25</sup> See CRS Report RL33202, *Medicaid: A Primer*, by (name redacted).

<sup>26</sup> See the Office on Disability: <http://www.hhs.gov/od/index.html>.

<sup>27</sup> See SAMHSA: <http://www.samhsa.gov/>.

<sup>28</sup> U.S. Congress, Senate Committee on Appropriations, *Department of Defense Appropriations Bill, 2007*, report to accompany H.R. 5631, 109<sup>th</sup> Cong., 2<sup>nd</sup> sess., July 25, 2006, 109-292 (Washington: GPO, 2006), p. 223.

which supports a range of scientific and clinical research on autism, received \$41 million in total funding from FY2007 to FY2012.<sup>29</sup>

The Department of Education does not receive appropriations under the CAA.<sup>30</sup> However, it funds a number of research programs and collects data on individuals served by special education programs. Programs and services in the Department of Education are geared toward individuals with disabilities in general, and not autism or developmental disabilities specifically.

## **Coordination of Public and Private Autism Research Funding**

In 2010, the IACC conducted an analysis of autism research spending by private and federal entities that are represented on the IACC.<sup>31</sup> Analysts found that private entities funded 24% of autism research in the United States in 2009, while the federal government funded 76%. The report also gauged the relevance of the funded projects to the topic areas that were identified in the IACC strategic plan.<sup>32</sup> These objectives for 2009 were (1) When should I be concerned? (2) How can I understand what is happening? (3) What caused this to happen and can it be prevented? (4) Which treatments and interventions will help? (5) Where can I turn for services? (6) What does the future hold, particularly for adults? (7) What other infrastructure and surveillance needs must be met? The vast majority (95%) of ASD research aligned with research questions in the IACC strategic plan, with the largest proportion of research focused on the causes and prevention of ASD. Research on access to ASD-related services and lifespan issues received the least amount of funding.

## **Issues for Congress**

During CAA enactment and reauthorization, several issues were highlighted, some of which are of general interest to Congress when deciding whether to support disease-specific legislation. Specifically, concerns were raised about barriers to data sharing and confidentiality across state and federal government entities; the coordination of surveillance and research, across both agencies and diseases; and the pros and cons of Congress directing funding to specific diseases (or groups of diseases). These concerns apply not only to autism research policy, but can be applied broadly to any disease-specific legislation, and the consequent policy decisions may affect access to care and treatment for individuals with autism.

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<sup>29</sup> Congressionally Directed Medical Research Programs: <http://cdmrp.army.mil/arp/default.shtml>.

<sup>30</sup> However, individuals with autism are entitled to a free and appropriate public education under the Individuals with Disabilities Education Act (IDEA, P.L. 101-476, as amended), and public school systems provide services for children with autism from ages 6 to 21. Currently, 300,000 children with autism receive services under IDEA, and more than 6,000 individuals with autism participate in their vocational rehabilitation programs.

<sup>31</sup> Office of Autism Research Coordination, Interagency Autism Coordinating Committee, *2009 Autism Spectrum Disorder Research Portfolio Analysis Report*, June 2011, [http://iacc.hhs.gov/portfolio-analysis/2009/2009\\_portfolio\\_analysis.pdf](http://iacc.hhs.gov/portfolio-analysis/2009/2009_portfolio_analysis.pdf).

<sup>32</sup> Interagency Autism Coordinating Committee, *2011 Strategic Plan for Autism Spectrum Disorder Research*, January 2011, [http://www.iacc.hhs.gov/strategic-plan/2011/IACC\\_2011\\_Strategic\\_Plan.pdf](http://www.iacc.hhs.gov/strategic-plan/2011/IACC_2011_Strategic_Plan.pdf).

Coordination of research and sharing of the resulting data is an ongoing interest of Congress. Researchers call for accurate case estimates in order to study common characteristics of autistic individuals and potential risk factors for autism. Federal and state-funded programs provided through health care providers and schools must provide certain services for individuals with ASD, and need accurate estimates to anticipate the need for those services. However, enumerating autism cases for researchers, health care providers, and schools has presented an ongoing challenge at the state, local, and federal levels.<sup>33</sup>

During the reauthorization process, some Members of Congress raised the concern that continuing to pass disease-specific legislation allows Congress to prioritize one disease (or group of diseases, in this case developmental disabilities) over another, and that priority-setting should be left to the agencies that perform the research. The issue of prioritizing one developmental disability over another has also been raised among researchers and families of children with developmental disabilities and other conditions. Advocates for CARA argued that allowing authorization of these programs to lapse would interrupt the progress made under the CAA.

Autism services research, such as the development and adoption of new screening tools and implementation of best practices in autism therapy, has effects on both health care cost and coverage decisions made at the government and individual level. The Patient Protection and Affordable Care Act (ACA, P.L. 111-148) includes provisions that may affect coverage for individuals with autism, including prohibitions on the cancellation of coverage by an insurer due to a preexisting condition, elimination of lifetime caps on insurance benefits and annual limits on coverage, and eligibility for tax subsidies to assist low- and middle-income individuals in the purchase of coverage from state health insurance exchanges. In addition, Medicaid eligibility will be broadened to include single adults. The long-range impact of health reform on individuals with ASD (specifically, the coverage of recommended treatments for ASD) is unknown.

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<sup>33</sup> U.S. Government Accountability Office, *Federal Autism Activities: Funding for Research has Increased, but Agencies Need to Resolve surveillance Challenges*, 06-700, July 2006, p. 12, <http://www.gao.gov/new.items/d06700.pdf>.

## Appendix. List of Acronyms

<b>ACA</b>	Patient Protection and Affordable Care Act, P.L. 111-148
<b>ACF</b>	Administration for Children and Families
<b>ADDM</b>	Autism and Developmental Disabilities Monitoring Network
<b>ASD</b>	Autism Spectrum Disorder
<b>CAA</b>	Combating Autism Act
<b>CADDRE</b>	Centers for Autism and Developmental Disabilities Research and Epidemiology
<b>CARA</b>	Combating Autism Reauthorization Act
<b>CDC</b>	Centers for Disease Control and Prevention
<b>CHA</b>	Children's Health Act
<b>CHIP</b>	State Children's Health Insurance Program
<b>CMS</b>	Centers for Medicare and Medicaid Services
<b>DD</b>	Developmental Disabilities
<b>DOD</b>	Department of Defense
<b>EPSDT</b>	Early Periodic Screening, Diagnosis, and Treatment Program
<b>HHS</b>	Department of Health and Human Services
<b>HRSA</b>	Health Resources and Services Administration
<b>IACC</b>	Interagency Autism Coordinating Committee
<b>IAEN</b>	International Autism Epidemiology Network
<b>LEND</b>	Leadership Education in Neurodevelopmental Disabilities
<b>NIH</b>	National Institutes of Health
<b>SAMHSA</b>	Substance Abuse and Mental Health Services Administration
<b>WIC</b>	State Supplemental Nutrition Program for Women, Infants, and Children

## Author Contact Information

(name redacted)  
Analyst in Public Health and Epidemiology  
/redacted/@crs.loc.gov, 7-....



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