

February 2013

# COMBATING AUTISM ACT

## HHS Agencies Responded with New and Continuing Activities, Including Oversight



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## Why GAO Did This Study

CDC considers autism to be an important public health concern. In 2012, CDC reported that an estimated 1 in 88 children in the United States has been identified as having autism—a 23 percent increase from its estimate of 1 in 110 reported in 2009. Autism is a developmental disorder involving communication and social impairment. Symptoms usually become evident in early childhood. There are many suspected causes and no known cure.

HHS agencies fund educational and support services for individuals diagnosed with autism and fund research in a variety of areas, such as identifying the causes of autism and intervention options. The CAA amended sections of the Children's Health Act of 2000 related to autism and established new requirements. The CAA, enacted in December 2006, authorized the expansion of HHS's activities related to autism research, surveillance, prevention, intervention, and education through fiscal year 2011. The CAA authorized, but did not appropriate, federal funding to carry out these activities.

In this report, GAO (1) describes the actions that HHS agencies have taken as a result of the CAA, and (2) examines the oversight of CAA grantees. To address these objectives, GAO reviewed CAA and HHS documents and interviewed agency officials to identify the autism activities resulting from the CAA. GAO also determined the amount certain HHS agencies spent on autism activities from fiscal year 2006—prior to the CAA—through fiscal year 2011. In addition, GAO reviewed files for a random sample of CAA grantees to examine oversight from 2008 to 2011.

View [GAO-13-232](#). For more information, contact Marcia Crosse at (202) 512-7114 or [crossem@gao.gov](mailto:crossem@gao.gov).

## COMBATING AUTISM ACT

### HHS Agencies Responded with New and Continuing Activities, Including Oversight

## What GAO Found

Department of Health and Human Services (HHS) agencies responded to the Combating Autism Act of 2006 (CAA) by establishing some new autism activities and continuing others. The Health Resources and Services Administration (HRSA) created a new initiative to address specific directives in the CAA. Through this initiative, HRSA expanded its existing training programs by requiring grantees to include training specific to autism. It also established new autism research grants and funded new state grants to improve services for children with autism. HRSA awards its autism grants under the authority of the CAA. The National Institutes of Health (NIH) and Centers for Disease Control and Prevention (CDC) continued their autism activities—some of which were undertaken in response to the Children's Health Act of 2000—but did not create new programs as a direct result of the CAA. NIH continued to fund, expand, and coordinate autism research through its Autism Centers of Excellence and autism-specific grants and contracts. CDC continued to fund its regional centers of excellence for autism epidemiology and other activities, such as an awareness campaign. HHS's Interagency Autism Coordinating Committee (IACC)—reauthorized by the CAA—assumed additional responsibilities to coordinate autism efforts within HHS and restructured its membership to include more nonfederal members. NIH created the Office of Autism Research Coordination to coordinate and manage the IACC. The CAA did not appropriate funds to any HHS agency. Nevertheless, overall spending on HRSA, NIH, CDC, and IACC autism activities increased from approximately \$143.6 million in fiscal year 2006 to approximately \$240.4 million in fiscal year 2011.

HRSA, the only HHS agency that has awarded grants specifically as a result of the CAA, regularly collects and reviews information from grantees to oversee individual CAA grantees and programs. HRSA awarded approximately \$164 million in grants to 110 CAA grantees from fiscal years 2008 to 2011; though, some of these grantees were already receiving funds prior to the CAA. To oversee these grantees, HRSA requires they regularly submit progress reports and financial reports. The agency also requires grantees to obtain prior approval before making certain changes to their projects. GAO reviewed documentation for an unbiased random sample of 22 grantees, which were representative of the 110 CAA grantees. GAO found that CAA grantees submitted all required reports. Many grantees submitted prior-approval requests for changes to their projects. Most frequently, grantees requested to carry over unobligated funds from the current year to the next budget period. GAO found that HRSA staff routinely collected and reviewed information submitted by the grantees and appropriately documented their review and approval of these submissions. HRSA also conducted site visits and provided technical assistance as a means of overseeing grantees. HRSA conducted site visits with 9 of the grantees in our sample during the period of our review, while only 2 of these were required sites visits. Besides overseeing grantees, HRSA monitors its overall CAA programs by regularly collecting performance reports from grantees. In addition, in December 2012, HRSA released a grant-management operations manual to outline its overall approach for monitoring its CAA programs.

GAO provided a draft of this report to HHS for comment. In response, HHS provided technical comments that were incorporated, as appropriate.

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## Abbreviations

CAA	Combating Autism Act of 2006
CDC	Centers for Disease Control and Prevention
DBP	Developmental-Behavioral Pediatrics
EHB	Electronic Handbook
HHS	Department of Health and Human Services
HRSA	Health Resources and Services Administration
IACC	Interagency Autism Coordinating Committee
LEND	Leadership Education in Neurodevelopmental and Other Related Disabilities
NIH	National Institutes of Health
NIMH	National Institute of Mental Health
OARC	Office of Autism Research Coordination

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United States Government Accountability Office  
Washington, DC 20548

February 27, 2013

### Congressional Requesters

The Centers for Disease Control and Prevention (CDC) considers autism to be an important public health concern. In March 2012, CDC—an agency within the Department of Health and Human Services (HHS)—reported that an estimated 1 in 88 children in the United States had been identified as having autism—a 23 percent increase from its estimate of 1 in 110 children in 2009.<sup>1</sup> Autism is characterized by impaired social interactions, problems with verbal and nonverbal communication, and repetitive behaviors, or by severely limited activities and interests. What is commonly known as “autism” is a group of disorders known as autism spectrum disorders.<sup>2</sup> Diagnoses include autistic disorder, a more severe form of autism, and Asperger syndrome, a milder form of autism.

HHS agencies fund educational and support services for individuals diagnosed with autism and fund research, such as studies to identify the causes of autism and intervention options. Some of HHS’s autism-related activities are performed internally by its agencies, while others are conducted by external organizations. For example, HHS agencies award grants to institutions to conduct autism-related research and surveillance activities. Each HHS agency is responsible for overseeing the funds that it awards to external organizations to ensure that they are properly and effectively used.

To address growing concern about the increasing prevalence of autism and to stimulate research into possible autism causes and interventions, the Combating Autism Act of 2006 (CAA) was enacted in December 2006.<sup>3</sup> The CAA authorizes the expansion of HHS’s activities related to autism research, surveillance, prevention, intervention, and education and

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<sup>1</sup>CDC’s most recent estimates are based on data collected in 14 areas of the United States. CDC’s estimate of autism prevalence in 2012 is based on data from calendar year 2008, and the 2009 estimate is based on data from calendar year 2006.

<sup>2</sup>In this report, we use the term “autism” to refer to autism spectrum disorders.

<sup>3</sup>Pub. L. No. 109-416, 120 Stat. 2821 (Dec. 19, 2006).

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authorizes funding for such activities through fiscal year 2011.<sup>4</sup> You asked us to provide information on agencies' responses to the CAA and oversight of CAA activities. In this report, we (1) describe the actions that HHS agencies have taken as a result of the CAA, and (2) examine the oversight of CAA grantees.<sup>5</sup>

To describe the actions HHS agencies have taken as a result of the CAA, we reviewed CAA and agency documents and interviewed HHS officials. We focused our work on those HHS agencies directed to conduct autism activities included in the CAA—the Health Resources and Services Administration (HRSA), the National Institutes of Health (NIH), and CDC.<sup>6</sup> We reviewed documents and interviewed agency officials to identify the autism activities each agency funded, whether those activities resulted from the CAA, and the amount spent on those activities. We included activities in our review that the agencies funded from fiscal years 2006 through 2011. Although the CAA was enacted during fiscal year 2007, we included fiscal year 2006 in our analysis to help determine the extent to which these agencies' activities and funding for autism activities changed following the enactment of the CAA.

To examine the oversight of CAA grantees, we interviewed HHS officials at HRSA, NIH, and CDC to determine whether they had awarded CAA grants; reviewed agencies' grants oversight policies and procedures; and conducted a review of selected grantees' files. Specifically, we reviewed agency guidance documents that outline protocols and procedures for overseeing grantees.<sup>7</sup> We also reviewed documents—such as funding opportunity announcements for CAA grants—that outline CAA grantees' specific reporting requirements and other responsibilities. In addition, we

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<sup>4</sup>These activities were reauthorized and additional funding was authorized through fiscal year 2014 under the Combating Autism Reauthorization Act of 2011. Pub. L. No. 111-32, 125 Stat. 361 (Sept. 30, 2011).

<sup>5</sup>A subsequent report will examine the involvement of federal agencies in autism activities and the coordination of these activities.

<sup>6</sup>HRSA was included in the review because the CAA requires the Secretary of Health and Human Services to establish various autism activities, and HRSA carries out these activities.

<sup>7</sup>This guidance includes: HHS, *Awarding Agency Grants Administration Manual* (2007); HHS, *Grants Policy Statement* (2007); and HRSA, Office of Federal Assistance Management, Division of Grants Management Operations, *Operational & Procedures Manual* (2009).

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interviewed agency officials about (1) policies and procedures for overseeing grantees and required oversight documentation, (2) the roles and responsibilities of various agency staff in the oversight process, and (3) grantee requirements. Lastly, we compared the grantee monitoring processes described by agency officials and documents to actual oversight activities. To do this, we selected an unbiased random sample of 20 percent of the CAA grantees—22 of the 110—funded between 2008 and 2011 and examined grant files and related documents.<sup>8</sup> Our file review of the selected grantees included a review of required reports and requests grantees submitted; oversight of such reports and requests; and other documentation, such as site visit summaries, for the grants awarded in fiscal years 2008 through 2011. We reviewed documentation located in two data systems—the Electronic Handbook (EHB) and the Discretionary Grant Information System—that, according to agency officials, contain all significant documentation related to monitoring CAA grantees.<sup>9</sup> To conduct this file review, we developed and used a data-collection instrument to assess whether the files included evidence of required monitoring and key monitoring documents. For example, we reviewed whether grantees submitted required reports on time, and if agency officials appropriately documented their review and approval of these reports. While we identified key monitoring actions and documents, we did not assess the quality of these actions or documents. To assess the reliability of the data collected, we compared the information contained in the oversight documents we reviewed, information provided to us by agency officials, and information contained in the two data systems. If there were discrepancies between these sources of information, we asked HRSA to resolve the discrepancies and provide associated documentation. We found the data reliable for our purposes.

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<sup>8</sup>Our sample is too small to generalize the results to the 110 CAA grantees as a whole; however, our sample is representative of the population of CAA grantees.

<sup>9</sup>Agency staff use the EHB to award grants, review information related to CAA grants, and monitor CAA grantees' performance. Grantees upload information pertaining to their grant—such as required reports—and agency staff can indicate their review and approval of this information, in the EHB. While the submission of performance reports—a report grantees submit annually with performance and budget information—is documented in the EHB, it is not possible to view these reports in the EHB. These reports can be viewed in the Discretionary Grant Information System—a system that regularly collects program and performance measure data, including performance reports, submitted by grantees. We reviewed files relating to grants awarded in fiscal years 2008 through 2011 that were included in these two data systems as of early October 2012.

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We conducted this performance audit from March 2012 to February 2013 in accordance with generally accepted government auditing standards. Those standards require that we plan and perform the audit to obtain sufficient, appropriate evidence to provide a reasonable basis for our findings based on our audit objectives. We believe that the evidence obtained provides a reasonable basis for our findings and conclusions based on our audit objectives.

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## Background

Autism—a complex and pervasive developmental disability—usually becomes evident in early childhood, although signs and symptoms vary.<sup>10</sup> According to CDC, autism begins before age 3 and lasts throughout a person’s life. Some children show signs of autism within the first few months of life. In others, symptoms might not appear until 24 months or later. Still other children with autism seem to develop typically until 18 to 24 months of age and then stop gaining new skills or lose the skills they once had. Signs and symptoms of autism include a child not responding to his or her name by 12 months; not pointing at objects to show interest by 14 months; avoiding eye contact and wanting to be alone; repeating words or phrases over and over; and flapping hands, rocking, or spinning in circles. Individuals with autism might have challenges with showing or talking about their feelings and might also have trouble understanding the feelings of others.

Diagnosing autism can be difficult; however, early intervention services can greatly improve a child’s development. There is no medical diagnostic test available for autism. As a result, doctors consider a child’s behavior and development to make a clinical diagnosis. By age 2, a diagnosis by an experienced professional can be considered very reliable. However, according to CDC most children do not receive a diagnosis until after age 4. There is no single cause of autism, but a variety of factors are suspected of causing or contributing to autism, including environmental, biological, and genetic sources. While there is no known cure, research shows that early intervention services can greatly improve a child’s

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<sup>10</sup>A developmental disability is a chronic condition caused by mental impairment, physical impairment, or both that begins any time during prenatal development up to age 22 and usually persists throughout a person’s life. Individuals with developmental disabilities have substantial functional limitations in at least three major life activities such as language, mobility, learning, self-help, and independent living. Developmental disabilities may include cerebral palsy, hearing loss, intellectual disability, and vision impairment.

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development. Because of the complexity of this disorder, individuals with autism have diverse needs for medical and mental health care as well as an array of educational and social services.

The CAA authorizes and directs HHS to conduct specific autism-related activities, which may include funding external organizations to conduct these activities through grants, contracts, and cooperative agreements.<sup>11</sup> The CAA amended sections of the Children’s Health Act of 2000—which required HHS to conduct activities related to autism research, surveillance, and coordination—by revising some sections and repealing other sections of that law as well as establishing new requirements.<sup>12</sup> The CAA authorized, but did not appropriate, federal funding to carry out these activities in fiscal year 2007 through fiscal year 2011.

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<sup>11</sup>A cooperative agreement is an alternative assistance instrument used instead of a grant whenever substantial federal involvement with the recipient during performance is anticipated.

<sup>12</sup>Pub. L. No. 106-310, 114 Stat. 1101 (Oct. 17, 2000). We previously reported on federal autism activities under the Children’s Health Act. See GAO, *Federal Autism Activities: Funding for Research Has Increased, but Agencies Need to Resolve Surveillance Challenges*, [GAO-06-700](#) (Washington, D.C.: July 19, 2006).

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## HHS Agencies Responded to the CAA by Establishing New Autism Activities and Continuing Others

HHS agencies responded to the CAA with new or continuing autism activities. In fiscal year 2008, HRSA created the *Combating Autism Act Initiative* in response to specific directives included in the CAA.<sup>13</sup> Through this initiative, HRSA expanded its existing training programs to include an autism-specific component and established new autism research and state grants. HRSA conducts all of its *Combating Autism Act Initiative* programs under the authority of the CAA. HRSA staff told us that they have not analyzed whether the agency's new programs could be conducted under other HRSA authority.

HRSA expanded two of its preexisting training programs—the Leadership Education in Neurodevelopmental and Other Related Disabilities (LEND) and the Developmental-Behavioral Pediatrics (DBP) training programs—through supplemental funding to existing grantees and awards to new grantees. These two training programs account for the majority of HRSA spending under its *Combating Autism Act Initiative*; however, HRSA was funding these programs prior to enactment of the CAA.<sup>14</sup> Under the *Combating Autism Act Initiative*, LEND and DBP grantees are required to include an autism component in their training. Among other things, the programs train health care professionals, such as pediatric practitioners, residents, and graduate students, to provide evidence-based services to children with autism and other developmental disabilities and their families; and train specialists to provide comprehensive diagnostic evaluations to address the shortage of professionals who can confirm or

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<sup>13</sup>The CAA directs the Secretary of Health and Human Services to undertake autism education, early detection, and intervention activities, subject to the availability of federal funding; and HRSA and CDC carry out these activities. The CAA directives are: provide information and education on autism and other developmental disabilities to increase public awareness of developmental milestones; promote research into the development and validation of reliable screening tools for autism and other developmental disabilities, and disseminate information regarding those screening tools; promote early screening of individuals at higher risk for autism and other developmental disabilities as early as practicable, given evidence-based screening techniques and interventions; increase the number of individuals who are able to confirm or rule out a diagnosis of autism and other developmental disabilities; increase the number of individuals able to provide evidence-based interventions for individuals diagnosed with autism or other developmental disabilities; and, promote the use of evidence-based interventions for individuals at higher risk for autism and other developmental disabilities as early as practicable.

<sup>14</sup>HRSA spent approximately \$19.9 million on the LEND and DBP training programs in fiscal year 2007. In fiscal year 2008, when the *Combating Autism Act Initiative* was implemented, HRSA spent approximately \$25.8 million on the LEND and DBP training programs.

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rule out an autism diagnosis. According to HRSA, as a result of these training programs, the number of health professionals enrolled in autism courses increased from 1,887 in academic year 2008-2009 to 4,256 in academic year 2010-2011 and the number of diagnostic evaluations increased from 12,390 in academic year 2008-2009 to 44,102 in academic year 2010-2011.

Additionally, HRSA created new autism research programs to fund studies that are intended to advance the current autism knowledge base and lead to improvements in interventions that address the health and well-being of children and adolescents with autism and other developmental disabilities. HRSA also provided grants to establish two research networks that focus on the physical and behavioral health needs of children and adolescents with autism. These networks conduct research on evidence-based practices for interventions, promote the development of evidence-based guidelines for intervention, validate tools for autism intervention, and disseminate information to health professionals and the public, especially families affected by autism.

HRSA also funded new state implementation and planning grants to implement plans to improve access to comprehensive, coordinated health care and related services for children and youth with autism and other developmental disabilities. Twenty-two states received grants from fiscal years 2008 to 2011 to implement their autism plans.<sup>15</sup> These plans vary by state, but common elements include a focus on partnerships between professionals and families of children and youth with autism, access to a culturally competent family-centered medical home, access to adequate health insurance and financing of services, early and continuous screening for autism and other developmental disabilities, community services organized for easy use by families, and transition services for youth entering adult health care. Table 1 provides information on the specific autism-related programs HRSA initiated or expanded—by increasing funding and the number of grantees—as a result of the CAA.

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<sup>15</sup>The states that received state implementation and planning grants are Alaska, Colorado, Connecticut, Delaware, Georgia, Hawaii, Illinois, Maine, Maryland, Mississippi, Missouri, New Jersey, New Mexico, New York, North Dakota, Ohio, Rhode Island, Tennessee, Utah, Vermont, Washington, and Wisconsin.

**Table 1: Autism Programs and Funding Sponsored by the Health Resources and Services Administration (HRSA) as a Result of the Combating Autism Act, Fiscal Years 2008-2011**

<b>Programs</b>	<b>Type of program</b>	<b>Purpose of program</b>	<b>Number of grantees, fiscal years 2008-2011</b>	<b>Total funding, fiscal years 2008-2011 (dollars in millions)</b>
Leadership Education in Neurodevelopmental and Other Related Disabilities (LEND) Training Program	Training	Improve the health of children who have, or are at risk for developing, neurodevelopmental and other related disabilities by training professionals to assume leadership roles, and to ensure high levels of interdisciplinary clinical competence in an effort to increase diagnosis of or rule out individuals with developmental disabilities, including autism.	47 <sup>a</sup>	\$107.2 <sup>a</sup>
Developmental-Behavioral Pediatrics (DBP) Training Program	Training	Train the next generation of leaders in developmental-behavioral pediatrics; and provide pediatric practitioners, residents, and medical students with essential biopsychosocial knowledge and clinical expertise. This program is focused on developmental disabilities, including autism.	10	7.3
National Combating Autism Interdisciplinary Training Resource Center	Training	Improve the health of children who have, or are at risk for developing, autism and other developmental disabilities by providing technical assistance to LEND and DBP programs to better train professionals to utilize valid and reliable screening tools for diagnosing or ruling out autism, and provide evidence-based interventions for children.	1	2.5
Autism Intervention Research Program and Autism Intervention Secondary Data Analysis Studies Program	Research	Support research on evidence-based practices for interventions to improve the health and well-being of children and adolescents with autism and other developmental disabilities. The Autism Intervention Secondary Data Analysis Studies Program utilizes the analysis of existing secondary data.	26 <sup>b</sup>	10.0 <sup>b</sup>
Autism Intervention Research Network on Physical Health	Research	Establish and maintain a network infrastructure designed to be the platform from which to conduct research on evidence-based practices for interventions to improve the physical health and well-being of individuals with autism and other developmental disabilities; develop evidence-based guidelines and validate tools for interventions; and disseminate critical information on its research findings, guidelines, and tools.	1	15.6

<b>Programs</b>	<b>Type of program</b>	<b>Purpose of program</b>	<b>Number of grantees, fiscal years 2008-2011</b>	<b>Total funding, fiscal years 2008-2011 (dollars in millions)</b>
Autism Intervention Research Network on Behavioral Health	Research	Establish and maintain a network infrastructure designed to be the platform from which to conduct research on evidence-based interventions to improve the behavioral, mental, social, or cognitive health, or a mix of those, and well-being of children and adolescents with autism and other developmental disabilities; develop evidence-based guidelines and validate tools for interventions; and disseminate critical information on its research findings, guidelines, and tools.	1	7.9
Developmental-Behavioral Pediatric Research Network	Research	Establish a multicenter scientific and clinical research network that will promote coordinated research activities and address health issues. Build a developmental behavioral pediatric research infrastructure that supports multidisciplinary research, focuses on the translation of research to practice, and provides the environment in which to train a new generation of developmental behavioral pediatric researchers.	1	0.4
State Implementation and Planning Grants <sup>c</sup>	Other	Improve access to comprehensive, coordinated health care and related services by implementing state plans to improve the system of services.	22	11.8 <sup>d</sup>
State Public Health Coordinating Center	Other	Improve the health of children who have, or are at risk for developing, autism and other developmental disabilities by coordinating with the state implementation and planning grantees; and by developing a strategy for defining, supporting, and monitoring the role of state public health agencies in assuring early and timely identification, diagnosis, and intervention.	1	1.1
<b>Total</b>			<b>110</b>	<b>\$163.8<sup>e</sup></b>

Source: GAO analysis of HRSA documents and interviews with HRSA officials.

Notes: HRSA's funds shown in this table were not appropriated by the Combating Autism Act (CAA). To fund these programs, HRSA used funds appropriated to the agency annually through the budget and appropriations process for the purpose of carrying out a variety of programs. Although the LEND and DBP training programs were established prior to the act, HRSA expanded these programs as a result of the act.

<sup>a</sup>These totals include one funding supplement to an existing cooperative agreement to provide technical assistance to LEND grantees. A cooperative agreement is an alternative assistance instrument used instead of a grant whenever substantial federal involvement with the recipient during performance is anticipated.

<sup>b</sup>These totals include one funding supplement to an existing cooperative agreement to examine current knowledge, research gaps, and methodological challenges about the life-course trajectory of individuals with autism, and develop a life-course-focused autism research agenda.

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<sup>c</sup>This program comprises: State Implementation Grants for Improving Services for Children and Youth with Autism Spectrum Disorder and other Developmental Disabilities, and State Planning Grants for Improving Services for Children and Youth with Autism Spectrum Disorder and other Developmental Disabilities.

<sup>d</sup>This total includes supplemental funding provided to four state implementation and planning grantees to expand implementation of the Centers for Disease Control and Prevention's (CDC) *Learn the Signs. Act Early.* campaign, through an interagency agreement between HRSA and CDC.

<sup>e</sup>Individual funding entries do not sum to total due to rounding.

NIH and CDC continued the autism activities each implemented prior to the enactment of the CAA, but did not create new programs as a direct result of the CAA. Some of these activities had been undertaken in response to the Children's Health Act of 2000, which, like the CAA, charges NIH with expanding, intensifying, and coordinating research on autism. In addition, under both laws, CDC is required to conduct activities related to establishing regional centers of excellence to collect and analyze certain information on autism.<sup>16</sup> Since the enactment of the CAA, NIH continued to fund, expand, and coordinate autism research through its Autism Centers of Excellence and autism-specific grants and contracts. According to agency officials, NIH awards these grants and contracts under its general Public Health Service Act authorities and not under the specific authorities provided in the CAA.<sup>17</sup> CDC continued to fund its regional centers of excellence for autism epidemiology and other activities, such as an awareness campaign on autism and other developmental disabilities. While enactment of the CAA did not result in any change to CDC's autism activities, CDC officials stated that the CAA provided additional focus on these efforts. According to CDC officials, the CAA's enactment also strengthened the agency's *Learn the Signs. Act Early.* awareness campaign by elevating the importance of increasing awareness of developmental milestones to national visibility. See appendix I for a list of NIH's and CDC's autism efforts.

As required by the CAA, the Interagency Autism Coordinating Committee (IACC)—initially established under the Children's Health Act—restructured its membership and assumed additional responsibilities to coordinate autism efforts within HHS. The CAA reauthorized the IACC

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<sup>16</sup>In contrast to the requirement contained in the Children's Health Act, however, the CAA directs NIH and CDC to undertake these activities subject to the availability of appropriations.

<sup>17</sup>See, for example, Public Health Service Act, § 301 (codified at 42 U.S.C. § 241) (providing NIH broad authority to award grants to public and private institutions to conduct scientific research).

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and specified that the IACC include both federal and nonfederal members.<sup>18</sup> IACC membership expanded to include 11 nonfederal members that represented individuals with autism and parents of children with autism. In addition, it included members of the autism advocacy, research, and service-provider communities in accordance with the CAA's membership requirements. The CAA also directed the IACC to develop and annually update a strategic plan and summary of advances in autism research, and monitor federal autism activities.<sup>19</sup> Since fiscal year 2007, the IACC issued several reports as a means to coordinate HHS autism efforts and monitor federal autism activities, some of which were specifically required by the CAA, such as the development of an autism strategic plan and a summary of advances in autism research.<sup>20</sup> See appendix II for a description of the documents produced by the IACC.

In addition to the changes to the IACC, in 2008, NIH created the Office of Autism Research Coordination (OARC) within the National Institute of Mental Health (NIMH) to coordinate and manage the IACC and related cross-agency activities, programs, and policies. OARC assists the IACC by conducting analyses and preparing reports for the IACC, assisting with the IACC's strategic planning and autism research monitoring, and providing logistical support for IACC meetings. It also supports communications through the IACC website and press releases, and

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<sup>18</sup>The CAA specified that the IACC include certain federal members, such as officials from CDC, NIH, and the Department of Education. It also required the Secretary to appoint a minimum number of nonfederal members, which must include at least one person with autism; at least one parent or legal guardian of a person with autism; and at least one representative of a leading research, advocacy, or service organization for individuals with autism. The Children's Health Act did not require that nonfederal entities or officials from the Department of Education be included as IACC members. However, the Children's Health Act authorized the Secretary of Health and Human Services to appoint parents or legal guardians of individuals with autism to the committee. Prior to the enactment of the CAA, the committee included four nonfederal members.

<sup>19</sup>The CAA also requires the IACC to make recommendations to the Secretary of Health and Human Services on any changes to federal activities, including recommendations made in the strategic plan on autism research.

<sup>20</sup>Prior to the CAA, the IACC produced a research matrix that NIH officials viewed as a comprehensive list of autism research goals. It also issued an autism roadmap that provided a synthesis of issues and challenges related to services for individuals with autism and a set of performance measures and recommendations for improving services.

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responds to inquiries from the public and other government agencies.<sup>21</sup> OARC officials told us that although HHS could establish an advisory committee similar to the IACC under other authority, the CAA has provided the IACC with greater visibility and increased involvement of the public and federal agencies, through, for example, the annual update of the IACC's autism strategic plan.

Following the enactment of the CAA, HHS agencies continued to fund existing activities and funded new activities.<sup>22</sup> Overall, spending on HRSA, NIH, CDC, and IACC autism activities increased from approximately \$143.6 million in fiscal year 2006 to approximately \$240.4 million in fiscal year 2011. HRSA spent more money on its autism programs beginning in fiscal year 2008 as a result of implementing its *Combating Autism Act Initiative*. From fiscal year 2008 through fiscal year 2010 HRSA increased this spending by an average of \$5.75 million annually. HRSA's spending on autism programs totaled approximately \$47.9 million in fiscal year 2010. In fiscal year 2011, HRSA spent slightly less on these programs.<sup>23</sup> Although the CAA did not provide appropriations for NIH's and CDC's autism activities, nor did Congress provide the agencies a specific autism appropriation after the CAA's enactment, NIH and CDC increased their overall spending on autism from fiscal year 2006 to fiscal year 2011. NIH spent more money on its autism activities in fiscal years 2009 and 2010 as a result of an appropriation for scientific research that it received under the American Recovery and

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<sup>21</sup>In addition, on behalf of the Secretary of Health and Human Services, OARC produced a report to Congress on autism activities as required by the CAA. See HHS, OARC, NIH, *Report to Congress on Activities Related to Autism Spectrum Disorder and Other Developmental Disabilities Under the Combating Autism Act of 2006 (FY 2006 – FY 2009)* (Rockville, Md.: December 2010, revised April 2011).

<sup>22</sup>While the CAA authorized appropriations for HRSA, NIH, and CDC autism activities, the CAA did not appropriate funds for this purpose. Instead, to fund these activities, HRSA, NIH, and CDC used funds appropriated to the agencies annually through the budget and appropriations process for the purpose of carrying out a variety of programs.

<sup>23</sup>In fiscal year 2008, certain agencies, including HHS agencies, were subject to an across-the-board rescission. All nondefense discretionary programs were subject to an across-the-board rescission in fiscal year 2011. According to HRSA officials, HRSA spent less on its autism activities in these years as a result of the rescissions. NIH officials told us that the agency reduced funding for research grants as a result of the rescissions, but could not measure the precise effect on autism-related grants. According to CDC officials, CDC spent less on its autism activities in fiscal year 2011 as a result of the rescission in that year. In addition, the IACC received less funding in fiscal years 2008 and 2011 as a result of the rescissions.

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Reinvestment Act of 2009. And, according to CDC officials, the agency redirected a portion of its funding for infant health activities to support pilot projects implementing the agency's awareness campaign on autism and other developmental disabilities. The IACC's funding increased significantly from fiscal year 2006 to 2011. From fiscal year 2008 through fiscal year 2011, as directed by Congress in the annual HHS appropriations act, the Secretary of Health and Human Services transferred funds to NIMH for the IACC. From fiscal year 2006 through fiscal year 2011, the IACC also received funds from the annual NIH appropriation. See appendix III for information on the funding for these agencies' and the IACC's autism-related activities.

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## HRSA Routinely Collects and Reviews Information to Oversee CAA Grantees

HRSA, the only HHS agency that awarded grants specifically as a result of the CAA, regularly collects and reviews information from grantees to oversee individual CAA grantees as well as to provide oversight to its CAA programs.<sup>24</sup> HRSA awarded approximately \$164 million in grants to 110 CAA grantees from fiscal years 2008 to 2011. The majority of funding—about \$107 million—was awarded to 47 grantees within HRSA's LEND training program, some of which were already receiving funds prior to the CAA. In addition, nearly \$24 million was awarded to two grantees to support HRSA's two autism intervention research networks. For all grantees, the amount of the grant award per year ranged widely from about \$36,000 to \$4 million depending on the CAA program, as shown in appendix IV.

As part of the agency's oversight of its CAA grantees, HRSA requires periodic reports from these grantees, which are reviewed by HRSA staff. HRSA project officers within the Maternal and Child Health Bureau—the bureau that administers the CAA programs—are responsible for working with CAA grantees in overseeing the programmatic and technical aspects of the grant. HRSA grants management specialists and their supervisors—grants management officers—oversee compliance with financial reporting requirements and agency grant policies and regulations. The required reports that are reviewed by HRSA staff include the following:

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<sup>24</sup>HRSA issued these grants as part of its *Combating Autism Act Initiative*. For the purpose of this report we are referring to the programs and grantees in HRSA's *Combating Autism Act Initiative* as CAA grantees or CAA programs.

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- **Annual federal financial report.** The annual federal financial report is an accounting of expenditures under the project in the budget period—the period for which HRSA has awarded funds to the grantee—and cumulatively for the project period.<sup>25</sup> The report is due after the end of the budget year.
  - **Annual progress reports.** The annual progress report is part of a grantee’s noncompeting continuing application and describes grantees’ progress on their grant objectives. Progress reports are due before the end of the budget period because HRSA staff use these reports to assess progress and, except for final progress reports, to determine whether to provide funding for the budget period subsequent to that covered by the report.<sup>26</sup>
  - **Mid-project progress reports.** Mid-project progress reports provide information on grantees’ progress on research objectives. These reports are required of certain research grantees and are due midway through the project period.<sup>27</sup>
  - **Semiannual progress reports.** Semiannual progress reports include information on the grantees’ most significant achievements and problems encountered during the reporting period as well as the grantees’ progress on established objectives. These reports are required of research network grantees and are due midway through each budget period.<sup>28</sup>

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<sup>25</sup>The annual federal financial reports were formerly called financial status reports. A budget period is the interval of time (usually 12 months each) into which a project period is divided for budgetary and funding purposes. The project period refers to the total period for which support of a project has been programmatically approved.

<sup>26</sup>Grantees who submit a competing continuation application include a progress report summarizing progress made over the entire previous project period along with their application. Grantees who do not reapply for a grant, and complete the period of project support from HRSA, must submit a comprehensive final report. This report covers the last year of the project period and includes information on progress over all years of the project period.

<sup>27</sup>HRSA started requiring mid-project reports of grantees in its Autism Intervention Research and Autism Intervention Secondary Data Analysis Studies Programs in fiscal year 2010. Because Autism Intervention Secondary Data Analysis Studies Program grants are 1-year grants, the reports are referred to as mid-year progress reports.

<sup>28</sup>The research networks are the Autism Intervention Research Network on Physical Health, Autism Intervention Research Network on Behavioral Health, and Developmental-Behavioral Pediatric Research Network.

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In addition to reports, HRSA also requires grantees to submit written requests before making certain changes to the grant project, known as prior-approval requests. For example, a change in the director of the grant project requires prior approval, as does a request to carry over unobligated funds to the next budget period or a request for a no-cost extension—an extension for a limited period beyond the end of the project period so that the grantee can complete project activities.

When reviewing these reports and grantee prior-approval requests, HRSA staff are required to fill out checklists in the EHB in which they indicate their review and approval of the report or request.<sup>29</sup> The content of the review checklists varies by the type of report or request being reviewed. For example, among other questions, a progress report checklist asks if the report reflects the program’s goals. The federal financial report checklist asks HRSA staff to compare the report with data in HRSA’s payment management system.<sup>30</sup> All review checklists include a question where HRSA staff can indicate if they have identified any issues or concerns with the report or request. In addition, when reviewing grantee information, HRSA staff may request that a report be revised with additional or corrected information.

Our review found that HRSA routinely collects and reviews information submitted by CAA grantees. Generally, grantees submitted required reports and HRSA staff documented their review of these reports. Specifically, the 22 grantees in our unbiased random sample<sup>31</sup> submitted

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<sup>29</sup>Progress reports that are submitted as part of competing continuation applications are reviewed with the application. HRSA staff use a checklist when reviewing the application.

<sup>30</sup>HRSA grantees request funds that they have available at any time during the budget period through the use of an online form that is submitted to the HRSA Payment Management System. The Payment Management System keeps track of how often and what amount of funds are withdrawn by the grantee during the course of the budget period.

<sup>31</sup>Our unbiased random sample of 22 grantees consisted of 11 training grantees, 7 research grantees, and 4 state implementation and planning grantees. This sample is representative of the 110 CAA grantees. The grantees in our sample received about \$28 million—about 17 percent—of the total awards CAA grantees received from fiscal years 2008 through 2011. HRSA officials stated that no CAA grantees were high-risk grantees, and we found this to be accurate for the grantees we reviewed. “High risk” is used to describe a grantee that is at risk of financial failure or failure to perform based on a history of poor performance or poor business practices, financial instability, or inadequate management systems.

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all of the 106 reports they were required to submit and most of these reports were submitted on time.<sup>32</sup> We found that HRSA staff filled out checklists approving all of the reports submitted or required report revisions. In many cases, HRSA staff filled out a checkbox indicating a “yes,” “no,” or “n/a” response to the questions. However, we noted that there were some cases where staff provided a narrative description to support their response to the question, such as a description of how the grantee is meeting the program’s goals—a question in the progress report checklist. HRSA officials stated that staff are required to answer the questions in the checklist, but they are not required to provide a narrative supporting their answers.

We observed that there were few instances of HRSA staff either documenting a concern or asking for a report revision before approving the report. We encountered seven instances where a project officer approved a report, but documented a concern in a checklist. In all these instances, the project officer provided narrative describing the concern.<sup>33</sup> For example, in one instance, the project officer wrote that the grantee’s recruitment of study subjects—parents of children with autism or other developmental disabilities—was slow. However, the project officer also stated that the grantee modified its enrollment process, which seemed to be having some positive effect and that the project officer and grantee were working together to monitor enrollment. We also identified another seven instances where HRSA staff asked for a report to be revised either with additional or corrected information. In almost all instances, the grantees submitted a revised report and HRSA staff completed a checklist indicating approval of the revised report.<sup>34</sup>

We also found that grantees submit a number of prior-approval requests, which HRSA staff review and generally approve. Most frequently, grantees request to carry over unobligated funds from the current year to

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<sup>32</sup>This includes 46 federal financial reports, 54 progress reports, 4 mid-project progress reports, and 2 comprehensive final reports. This count includes one annual federal financial report per grantee per year. Grantees are allowed to revise and resubmit their federal financial report if they find that information needs to be corrected.

<sup>33</sup>The question in the checklist is: “Are there any areas of concern: programmatic, budgetary, or other?”

<sup>34</sup>In one instance, the grantee had not yet submitted the revised report at the time of our review.

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the next budget period. For example, 13 of the 22 grantees in our review requested to carry over unobligated balances at least once during the period of our review, and many of them requested it for multiple years—equaling 32 separate requests. The amount of unobligated balances that grantees requested to carry over in a given year ranged from \$1,518 to \$172,514. In all instances, HRSA approved these requests as indicated by the issuance of a revised notice of award.<sup>35</sup> Almost all requests related to awards in fiscal year 2010 and later contained an associated checklist in the EHB filled out by HRSA staff approving the request to carry over unobligated balances.<sup>36</sup>

In addition to reviewing information submitted by grantees, HRSA provides additional oversight to grantees. First, it conducts site visits in person or by means of the web. During a site visit, HRSA staff may collect information on preliminary research findings, data and analysis, and any challenges the grantee is facing. Site visits are only required of certain research grantees, although HRSA may conduct site visits with other grantees, depending on available resources.<sup>37</sup> HRSA officials target site visits for CAA grantees on the basis of six criteria: (1) the grantee is new, (2) there has been a change in the grantee's project director, (3) there has been a change in the grantee's scope of work, (4) there are budgetary issues or the grantee has not made adequate progress on the project goals, (5) the grantee has requested technical assistance, or (6) there has been a change in the project officer overseeing the grantee. HRSA uses a site-visit report to document the visit and has guidance on

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<sup>35</sup>The notice of award is the official document that states the terms, conditions, and amount of a grant award and is signed by the official who is authorized to obligate funds on behalf of HRSA. A notice of award shows the amount of federal funds available to the grantee and is issued at the start of each budget period. A revised notice of award may be issued during a budget period to effect an action resulting in a change in the amount of support or other change in the terms and conditions of award, such as a carryover of funds.

<sup>36</sup>According to HRSA officials, HRSA staff began using a checklist to indicate their review and approval of prior-approval requests at the end of calendar year 2009. Prior to this, the issuance of a new notice of award indicated HRSA review and approval of such requests. We reviewed one carryover request related to an award in fiscal year 2010 that did not have a review checklist in the EHB; however, a new notice of award indicated that the carryover request had been approved.

<sup>37</sup>Grantees in HRSA's Autism Intervention Research and Autism Intervention Secondary Data Analysis Studies Programs are required to have a web-based site visit at project end.

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what should be included in the report. For example, for training grants, the report should include a narrative summary of the visit including highlights, performance measure progress, strengths and challenges, and any technical assistance needed by the grantee. Second, HRSA officials stated that HRSA project officers provide routine technical assistance to certain grantees and others on an as-needed basis. For example, all research grantees have either a monthly, biweekly, or mid-project telephone call with HRSA project officers.

Our review confirmed that HRSA has conducted a number of site visits to monitor CAA grantees. For example, nine of the grantees in our review had documentation indicating that a site visit had been conducted, with only two of these being required site visits. While none of the site-visit reports identified major issues that required corrective action, some did record challenges the grantees were facing or made suggestions. For example, one report stated that the grantee may encounter challenges in the recruitment of trainees. We identified documentation related to technical assistance that HRSA staff provided to some grantees but not all. For example, we did not always see documentation of routine telephone calls with research grantees that HRSA officials say occur on a regular basis. In response, HRSA officials stated that not all technical assistance is recorded in the EHB; only when a significant issue arises is the telephone call, e-mail, or other assistance recorded.

Besides overseeing specific grantees, HRSA monitors its CAA activities at the program level by regularly collecting performance reports from grantees.<sup>38</sup> The 22 CAA grantees in our sample submitted all the required performance reports. According to HRSA officials, the primary purpose of performance reports is to gauge program performance. For example, data in performance reports is currently being used by a HRSA contractor to prepare a report on the progress of the CAA programs for Congress.<sup>39</sup> In addition, according to HRSA officials, performance data can be used to modify program performance measures over time. While performance reports are used to monitor CAA programs—as opposed to grantees—

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<sup>38</sup>Performance reports include financial forms, project abstracts and other grant summary data, and performance measures. Grantees submit initial performance reports at the beginning of the project period, annual performance reports after the end of each budget year, and project period end performance reports after the end of the project period.

<sup>39</sup>HRSA expects to submit this report to Congress in the middle of calendar year 2013.

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HRSA officials stated that some performance information is also included in annual progress reports, which are used to oversee specific grantees. For example, progress reports require grantees to include information on whether they are having problems meeting their performance measures. Finally, to further help oversee CAA programs and consolidate information on its monitoring approach for these programs, in December 2012 HRSA released a grant-management operations manual to outline its overall approach for monitoring these programs.<sup>40</sup> According to HRSA officials, this manual will be included in the program folder of the EHB for each of its CAA programs and will be reviewed annually, consistent with HHS guidance.<sup>41</sup>

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## Agency Comments

We provided a draft of this report to HHS for comment. HHS provided technical comments that we incorporated, as appropriate.

We are sending a copy of this report to the Secretary of Health and Human Services. In addition, the report is available at no charge on the GAO website at <http://www.gao.gov>.

If you or your staff have any questions about this report, please contact me at (202) 512-7114 or [crossem@gao.gov](mailto:crossem@gao.gov). Contact points for our Offices of Congressional Relations and Public Affairs may be found on the last page of this report. GAO staff who made key contributions to this report are listed in appendix V.



Marcia Crosse  
Director, Health Care

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<sup>40</sup>HRSA, Maternal and Child Health Bureau, *Operations Manual, Combating Autism Act Initiative* (Rockville, Md.: December 2012).

<sup>41</sup>HHS guidance indicates that a program-wide approach to monitoring grantees must be established and reviewed at least annually to determine if the approach needs to be modified. This annual review should be documented, as appropriate, in the program information file. HHS, *Awarding Agency Grants Administration Manual*.

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*List of Requesters*

The Honorable Tom Coburn, M.D.  
Ranking Member  
Committee on Homeland Security and Governmental Affairs  
United States Senate

The Honorable Ron Johnson  
United States Senate

The Honorable Mike Lee  
United States Senate

The Honorable Robert Menendez  
United States Senate

# Appendix I: National Institutes of Health's (NIH) and Centers for Disease Control and Prevention's (CDC) Autism Activities

During fiscal year 2006 through fiscal year 2011, NIH and CDC funded a number of autism activities. Table 2 lists the activities these agencies funded, including the type and purpose of each activity.

**Table 2: NIH's and CDC's Autism Activities during Fiscal Years 2006 through 2011**

Agency	Activity	Type of activity	Purpose of activity
NIH	Autism Centers of Excellence Program <sup>a</sup>	Research	NIH initiative that supports large-scale multidisciplinary studies on autism, with the goal of determining the disorders' causes and the best treatments for them.
	Collaborative Programs of Excellence in Autism <sup>a</sup>	Research	Conduct research to learn about the possible causes of autism, including genetic, immunological, and environmental factors; as well as diagnosis, early detection, behavioral and communications characteristics, and treatment of autism.
	Studies to Advance Autism Research and Treatment Network <sup>a</sup>	Research	Support and conduct both individual and collaborative projects to learn more about the causes, diagnosis, early detection, prevention, and treatments of autism.
	Children's Environmental Health and Disease Prevention Research Centers (with Environmental Protection Agency) <sup>b</sup>	Research	Examine the effect of environmental exposures on children's health.
	Research Units on Pediatric Psychopharmacology Autism Network	Research	Clinical trials evaluating psychopharmacological treatments for co-occurring behavior disorders in autism.
	Research to Address the Heterogeneity in Autism Spectrum Disorders	Research	Address gaps identified in the Interagency Autism Coordinating Committee's Strategic Plan and other knowledge gap areas related to autism, and to ensure appropriate attention is given to the most critical short-term objectives within the Strategic Plan. Applications for research projects were solicited within the following topic areas [relevant to research on the heterogeneity of autism]: measurement development, biomarkers/biological signatures, immune and central nervous systems interactions, genetics/genomics, environmental risk factors, model development, treatment and intervention, and services research.
	Challenge Grants in Health and Science Research <sup>b</sup>	Research	Support research on topic areas that address specific scientific and health research challenges in biomedical and behavioral research that would benefit from significant 2-year startup funds.

**Appendix I: National Institutes of Health's (NIH)  
and Centers for Disease Control and  
Prevention's (CDC) Autism Activities**

<b>Agency</b>	<b>Activity</b>	<b>Type of activity</b>	<b>Purpose of activity</b>
	Grand Opportunities grants <sup>b</sup>	Research	Support high-impact ideas that lend themselves to short-term funding, and may lay the foundation for new fields of investigation. The grants program will support large-scale research projects that accelerate critical breakthroughs, early and applied research on cutting-edge technologies, and new approaches to improve the synergy and interactions among multi- and interdisciplinary research teams. The initiative seeks novel approaches in areas that address specific knowledge gaps, scientific opportunities, new technologies, data generation, or research methods that would benefit from an influx of funds to quickly advance the area in significant ways.
	Initiative related to nonverbal school-age children	Research	Opportunity for investigators and U.S. institutions/organizations with certain active grants to submit revision applications to support an expansion of the scope or research protocol to develop preliminary investigations into the characterization and/or treatment of nonverbal school-aged children with autism.
	Contract related to Health Outcomes for Children with Autism and their Families	Research	Describe the health and health care trajectories of individuals with autism and their families, and evaluate the feasibility of using a large population-based database for research on risk factors for autism.
	National Institute of Mental Health Intramural Research Program, Autism Research	Research	Accelerate development and testing of innovative treatments. NIH has undertaken activities to address the effectiveness and outcomes of innovative and newly developed intervention strategies for individuals diagnosed with autism or other developmental disabilities.
	Eunice Kennedy Shriver National Institute of Child Health and Human Development Brain and Tissue Bank for Developmental Disorders <sup>b</sup>	Research	Advance the research of developmental disorders. The objective of this human-tissue repository is to systematically collect, store, and distribute brain and other tissues for research dedicated to the improved understanding, care, and treatment of individuals with developmental disorders.
	NIH National Database for Autism Research	Research	Accelerate autism research by creating an infrastructure that integrates heterogeneous datasets allowing access to much more quality research data than investigators would be able to collect on their own.
	National Institute of Mental Health Center for Collaborative Genetic Studies of Mental Disorders <sup>b</sup>	Research	Accelerate progress toward understanding genetic origins of mental disorders including autism, schizophrenia, bipolar disorder, and depression. Encourage the sharing of biological as well as clinical and genetic data from individuals or families with these disorders, and perform and disseminate analyses of these data.

**Appendix I: National Institutes of Health's (NIH)  
and Centers for Disease Control and  
Prevention's (CDC) Autism Activities**

<b>Agency</b>	<b>Activity</b>	<b>Type of activity</b>	<b>Purpose of activity</b>
	Psychosocial/Behavioral Interventions and Services Research in Autism Spectrum Disorders	Research	Facilitate exploratory research on psychosocial/behavioral treatments and innovative services research for autism, including the development of instruments to evaluate the impact of interventions on core features of autism, and comorbid symptomatology.
	Research on Autism and Autism Spectrum Disorders	Research	Supports research designed to elucidate the etiology, epidemiology, diagnosis, treatment, and optimal means of service delivery in relation to autism.
	Shared Neurobiology of Fragile X Syndrome and Autism	Research	Aimed at characterizing, understanding, and treating etiological and pathophysiological mechanisms common to both Fragile X syndrome and autism.
	Minnesota Somali Project (with CDC) <sup>c</sup>	Surveillance	Investigate reports of elevated prevalence of autism among children born to Somali immigrants living in Minneapolis, Minn.
CDC	Metropolitan Atlanta Developmental Disabilities Surveillance Program	Surveillance	Provide regular and systematic monitoring of prevalence rates of selected developmental disabilities according to various demographic characteristics of children and their mothers and provide a framework for initiating special studies of children who have the selected developmental disabilities by establishing a population-based case series of such children.
	Autism and Developmental Disabilities Monitoring Network	Surveillance	Collaborative project to characterize the population prevalence and characteristics of children with autism and other developmental disabilities. Goals are to: provide data about how common autism is in a specific place and time period; describe the population of children with autism; compare how common autism is in different areas of the country; identify changes in autism occurrence over time; and understand the impact of autism and related conditions in U.S. communities.
	Autism Spectrum Disorder Surveillance of Younger Children (Pilot Alternative Surveillance)	Surveillance	Investigate the feasibility of combining developmental screening and monitoring prevalence of autism for children under the age of 4.
	Centers for Autism and Developmental Disabilities Research and Epidemiology Network	Research	Regional centers of excellence for autism and other developmental disabilities. The primary activity of the network is to conduct the Study to Explore Early Development—a collaborative, multisite epidemiologic study of risk factors for autism.
	Centers for Autism and Developmental Disabilities Research and Epidemiology Data Coordinating Center	Research	Provide a centralized, web-based, automated-workflow system that supports all of the study activities for the Study to Explore Early Development, cited above.
	Georgia Study to Explore Early Development	Research	The Study to Explore Early Development is a multiyear, multisite study in six diverse areas that looks at possible causes of and risks for autism and other developmental delays.

**Appendix I: National Institutes of Health's (NIH)  
and Centers for Disease Control and  
Prevention's (CDC) Autism Activities**

<b>Agency</b>	<b>Activity</b>	<b>Type of activity</b>	<b>Purpose of activity</b>
	CDC-Denmark Program	Research	Examine a variety of public health issues, including autism and other developmental disabilities. All studies in this program have a basic activity of either improving existing registries, conducting registry-based studies, or both.
	Minnesota Somali Project (with NIH) <sup>c</sup>	Surveillance	Investigate reports of elevated prevalence of autism among children born to Somali immigrants living in Minneapolis, Minn.
	Blood Spot Project (award managed by the Department of Defense)	Research	Investigate the relationship between development of autism and cross-reactive antibodies that may cause alterations in fetal brain development. Archived dried blood spots from newborn children who later developed autism and from others who developed normally will be analyzed for specific antibodies. This project is funded by the Department of Defense.
	Learn the Signs. Act Early. <sup>b</sup>	Awareness campaign/ information dissemination	The program is made up of three components: (1) health education campaign promotes awareness of healthy developmental milestones in early childhood, the importance of tracking each child's development, and the importance of acting early if there are concerns; (2) Act Early Initiative works with state, territorial, and national partners to improve early childhood systems by enhancing collaborative efforts to improve screening and referral to early intervention services and supporting the work of Act Early Ambassadors to promote <i>Learn the Signs. Act Early.</i> messages and tools and improve early identification efforts in their state; and (3) research and evaluation improves campaign materials and implementation activities, and increases our understanding of the factors that influence early identification and referral.

Source: GAO analysis of NIH and CDC documents and interviews.

Notes: NIH and CDC funded these autism activities at some point between fiscal years 2006 through 2011, but did not necessarily fund each activity in every fiscal year. In addition to the autism research funded through these activities, NIH funded autism research through other mechanisms, such as through general grant announcements not specific to autism.

<sup>a</sup>In fiscal year 2007 and 2008, respectively, the Collaborative Programs of Excellence in Autism and the Studies to Advance Autism Research and Treatment Network expired. NIH consolidated the funding and goals of these programs into the Autism Centers of Excellence Program.

<sup>b</sup>While these activities are not autism-specific, they include an autism component, such as autism-specific research grants.

<sup>c</sup>This activity was also partially funded by a private organization.

# Appendix II: List of Interagency Autism Coordinating Committee (IACC) Reports

Report	Description
Strategic Plan for Autism Spectrum Disorder Research (2009, 2010, 2011)	According to the IACC, the Strategic Plan provides a blueprint for autism research that is advisory to the Department of Health and Human Services and serves as a basis for partnerships with other agencies and private organizations involved in autism research and services. The 2011 Strategic Plan is organized around seven questions asked by individuals with autism and their families (such as “When should I be concerned?”). Each of the seven sections includes a description of what is generally known from autism research for that particular question and what gaps remain, followed by what was learned during the previous year. The report also sets up short- and long-term research objectives based on autism research opportunities. The Combating Autism Act of 2006 (CAA) requires that the Strategic Plan be updated on an annual basis.
Autism Spectrum Disorder Research Portfolio Analysis Report (2008, 2009, 2010) <sup>a</sup>	The Portfolio Analysis features autism project and funding information for certain federal agencies and private organizations. According to officials within the National Institutes of Health Office of Autism Research Coordination (OARC), the agencies and organizations in these reports have been identified by the IACC and OARC as being involved in autism research and have agreed to participate. According to the IACC, the intent of these analysis reports is to better inform the IACC and interested stakeholders about the funding landscape for a particular year. Additionally, the analysis examines the extent to which a particular year’s funding and research topics align with the IACC’s most recent Strategic Plan. The IACC reports that the Portfolio Analysis may also be used by federal agencies and private research organizations to help guide future funding priorities by outlining current gaps and opportunities in autism research, as well as serving to highlight current activities and research progress. OARC officials told us that they plan to issue the 2011 report in 2013.
Summary of Advances in Autism Spectrum Disorder Research (2007, 2008, 2009, 2010, 2011)	Each year the IACC releases its list of scientific advances in autism research. As reported by the IACC, the report highlights studies on autism published in the previous year in peer-reviewed journals and selected by members of the IACC. The number of studies featured over the years ranges from 20 to 54. The CAA requires that the IACC produce the Summary of Advances annually.
Autism Spectrum Disorder Research Publications Analysis: The Global Landscape of Autism Research <sup>b</sup>	As reported by the IACC, this report describes several key aspects of worldwide autism research publications, which may be used to inform planning and strategic funding decisions for future autism research. Autism-related research articles published between 1980 and 2010 were analyzed to identify historical trends and publication outputs across the seven questions and research areas of the 2011 IACC Strategic Plan. Information found in research publications was also used to assess the institutions conducting autism research, funding organizations supporting the research publications, and the extent of collaboration between authors from different countries and research institutions. Additionally, measures, such as citation counts, were used as an assessment of the impact of the published research. OARC officials told us that there are no plans to update this report annually.

Source: GAO review of IACC and OARC documents.

<sup>a</sup>In 2008 and 2010, OARC, National Institute of Mental Health, prepared this report on behalf of the IACC. In 2009, OARC, National Institute of Mental Health, and Acclaro Research Solutions, Inc., prepared this report on behalf of the IACC.

<sup>b</sup>OARC, National Institute of Mental Health, and Thomson Reuters, Inc., prepared this report on behalf of the IACC.

# Appendix III: Department of Health and Human Services (HHS) Funding for Autism Activities for Fiscal Years 2006 through 2011

Dollars in millions

HHS component	Fiscal year					
	2006	2007	2008	2009	2010	2011
Health Resources and Services Administration (HRSA)	\$20.0 <sup>a</sup>	\$19.9 <sup>a</sup>	\$36.4	\$42.0	\$47.9	\$47.7
National Institutes of Health (NIH)	108.3	126.8	118.1	196.4 <sup>b</sup>	217.1 <sup>b</sup>	168.7
Centers for Disease Control and Prevention (CDC)	15.1	14.8	16.2	20.4	22.1	21.4
Interagency Autism Coordinating Committee (IACC)	0.2	0.1	1.2	2.6	2.6	2.6
<b>Total<sup>c</sup></b>	<b>\$143.6</b>	<b>\$161.6</b>	<b>\$171.8</b>	<b>\$261.4</b>	<b>\$289.7</b>	<b>\$240.4</b>

Source: GAO analysis of HRSA, NIH, CDC, and IACC documents and interviews.

Notes: While the Combating Autism Act (CAA) authorized appropriations for HRSA, NIH, CDC, and IACC autism activities, the CAA did not appropriate funds for this purpose. Instead, to fund these activities, HRSA, NIH, and CDC used funds appropriated to the agencies annually through the budget and appropriations process for the purpose of carrying out a variety of programs. As directed by Congress in the annual HHS appropriations acts for fiscal years 2008 through 2011, the Secretary of Health and Human Services transferred funds to NIH's National Institute of Mental Health (NIMH) for the IACC. The IACC also received funds from the annual NIH appropriation for fiscal years 2006 through 2011.

HRSA's totals include autism grant awards, as well as, for example, funding used for HRSA's personnel expenses, travel, supplies, and overhead related to reviewing these grants. NIH's totals include funding for research that is conducted outside of NIH's autism-specific grant announcements. According to NIH officials, much of the autism research funded by NIH is done under general grant announcements soliciting biomedical research. IACC's totals for fiscal years 2008 through 2011 include funding for the Office of Autism Research Coordination within NIMH.

In fiscal year 2008, certain agencies, including HHS agencies, were subject to an across-the-board rescission. All nondefense discretionary programs were subject to an across-the-board rescission in fiscal year 2011. According to HRSA officials, HRSA spent less on its autism activities in these years as a result of the rescissions. NIH officials told us that the agency reduced funding for research grants as a result of the rescissions, but could not measure the precise effect on autism-related grants. According to CDC officials, CDC spent less on its autism activities in fiscal year 2011 as a result of the rescission in that year. In addition, the IACC received less funding in fiscal years 2008 and 2011 as a result of the rescissions.

<sup>a</sup>HRSA's fiscal year 2006 and 2007 funding represents total funding for its Leadership Education in Neurodevelopmental and Other Related Disabilities and Developmental-Behavioral Pediatrics training programs, through which the agency awarded grants that could have had an autism-specific component; however, an autism-specific component was not a requirement of the grants. Beginning in fiscal year 2008, these training programs were required to have an autism-specific component.

<sup>b</sup>NIH's fiscal year 2009 and 2010 funding totals include additional funds appropriated to NIH under the American Recovery and Reinvestment Act of 2009. NIH spent \$64 million of these funds in fiscal year 2009 and \$57.5 million in fiscal year 2010 on autism activities.

<sup>c</sup>Individual funding entries may not sum to total due to rounding.

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# Appendix IV: Combating Autism Act Grantees from Fiscal Years 2008 through 2011 by Program

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In fiscal year 2008, in response to the Combating Autism Act, the Health Resources and Services Administration (HRSA) created the *Combating Autism Act Initiative*. Under this initiative, HRSA has a number of programs that fund grants specific to autism. This appendix includes a description of the purpose of each program. Tables 3 through 11 list the grants that have been awarded under each program for fiscal years 2008 through 2011.<sup>1</sup>

**Program: Leadership Education in Neurodevelopmental and Other Related Disabilities (LEND) Training Program.** The purpose of this program is to improve the health of children who have, or are at risk for developing, neurodevelopmental and other related disabilities by training professionals to assume leadership roles, and to ensure high levels of interdisciplinary clinical competence in an effort to increase diagnosis of or rule out individuals' developmental disabilities, including autism.

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<sup>1</sup>The fiscal years in tables 3 through 11 are based on the start date of the budget period for which the grant was awarded. The budget period for some of these grantees is from July 1 through June 31, and the budget period for other grantees is from September 1 through August 31. Under its *Combating Autism Act Initiative*, HRSA also provided supplemental funding to two existing cooperative agreements. A cooperative agreement is an alternative assistance instrument used instead of a grant whenever substantial federal involvement with the recipient during performance is anticipated. The first supplement is to provide technical assistance to grantees under one of HRSA's *Combating Autism Act Initiative* Programs—Leadership Education in Neurodevelopmental and Other Related Disabilities. The grantee is Georgetown University in Washington, D.C., and the grantee received \$22,000 and \$43,550 in fiscal years 2010 and 2011, respectively. The second supplement is to examine current knowledge, research gaps, and methodological challenges about the life-course trajectory of individuals with autism, and develop a life-course-focused autism research agenda. The grantee is the Regents of the University of California at Los Angeles and the grantee received \$30,785 in fiscal year 2011.

**Appendix IV: Combating Autism Act Grantees  
from Fiscal Years 2008 through 2011 by  
Program**

**Table 3: Leadership Education in Neurodevelopmental and Other Related Disabilities Training Program Grantees from Fiscal Years 2008 through 2011**

Dollars

Grant number	Grantee name	Fiscal year			
		2008 award	2009 award	2010 award	2011 award
T73MC00003	University of Alabama at Birmingham	\$755,326	\$755,326	\$755,326	\$680,758
T73MC00008	Children's Hospital of Los Angeles, School of Physical Therapy	818,784	818,784	818,785	650,973
T73MC00013	University of Miami	629,576	729,576	814,576	787,500 <sup>a</sup>
T73MC00014	University of Hawaii at Manoa	495,166	595,166	670,166	595,000
T73MC00015	Indiana University, School of Medicine	681,440	681,440	681,440	632,046
T73MC00016	University of Iowa	491,265	591,265	666,265	586,537
T73MC00019	The Johns Hopkins University	884,277	35,840	0	0
T73MC17245	Kennedy Krieger Children's Hospital, Inc.	0	948,416	1,059,256	850,000
T73MC00020	Children's Hospital (Boston, MA)	755,326	755,326	755,326	745,000 <sup>a</sup>
T73MC00022	Curators of University of Missouri at Columbia	393,012	493,012	568,012	574,811
T73MC00023	Board of Regents of the University of Nebraska	612,663	612,663	612,663	622,943
T73MC00024	Trustees of Dartmouth College	651,964	651,964	651,964	848,868
T73MC00025	University of New Mexico Health Sciences Center	527,560	627,560	702,560	680,000
T73MC00027	Albert Einstein College of Medicine	691,265	691,265	691,265	679,299
T73MC00029	University of Rochester	691,265	691,265	691,265	684,028
T73MC00030	University of North Carolina at Chapel Hill	768,691	768,691	798,691	910,004 <sup>a</sup>
T73MC00032	University of Cincinnati	766,373	866,373	941,373	800,167
T73MC00033	University of Oklahoma HSC	442,139	542,139	617,139	595,000
T73MC00034	Oregon Health & Sciences University	685,979	785,979	860,979	742,050
T73MC00036	University of Pittsburgh	393,012	493,012	568,012	659,779 <sup>a</sup>
T73MC00037	University of South Dakota	432,313	532,313	607,313	602,466 <sup>a</sup>
T73MC00038	University of Tennessee at Knoxville	953,109	953,109	953,459	807,500 <sup>a</sup>
T73MC00039	University of Vermont	651,964	587,125	651,964	550,000
T73MC00040	Virginia Commonwealth University	451,964	504,798	626,964	584,773
T73MC00041	University of Washington	940,435	940,435	940,435	891,030 <sup>a</sup>
T73MC00043	West Virginia University Research Corporation	639,822	639,822	639,822	567,935
T73MC00044	University of Wisconsin at Madison	569,576	669,576	744,576	738,483 <sup>a</sup>
T73MC00049	Ohio State University Research Foundation	393,011	493,011	568,011	821,027
T73MC00050	Vanderbilt University Medical Center	593,012	593,012	623,012	651,500
T73MC00051	The Children's Hospital of Philadelphia	790,966	784,966	790,966	764,391
T73MC00054	University of Utah	755,241	755,241	785,241	823,048 <sup>a</sup>
T73MC00056	University of Massachusetts Medical School	604,256	704,256	779,256	685,732

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Dollars

Grant number	Grantee name	Fiscal year			
		2008 award	2009 award	2010 award	2011 award
T73MC03181	Children's Research Institute (Washington, DC)	593,012	593,012	593,012	0
T73MC04320	New York Medical College	620,597	720,597	795,597	693,003
T73MC06623	University of Kansas Medical Center Research Institute	743,630	743,630	743,630	641,760
T73MC11044	University of Colorado at Denver	550,000	550,000	550,000	617,500 <sup>a</sup>
T73MC11045	University of Arkansas for Medical Sciences	550,000	549,999	549,114	757,995
T73MC11046	University of Connecticut Health Center	550,000	550,000	550,000	0
T73MC11047	University of Illinois at Chicago, College of Medicine	549,999	549,998	550,000	661,752
T73MC12835	Regents of the University of Minnesota	0	450,000	550,000	627,616
T73MC19939	Georgia State University Research Foundation, Inc.	0	0	150,000	545,898
T73MC19940	Board of Regents, Nevada System of Higher Education, on behalf of University of Nevada at Reno	0	0	150,000	508,533
T73MC20662	University of Arizona	0	0	150,000	568,353
T73MC20663	University of Alaska Anchorage	0	0	150,000	530,039
T73MC22233	Medical University of South Carolina	0	0	0	486,440
T73MC22236	The University of Texas Health Science Center at Houston	0	0	0	509,748

Source: GAO analysis of Health Resources and Services Administration (HRSA) information.

<sup>a</sup>Total funding in fiscal year 2011 includes \$65,000 of supplemental funds that the grantee received from HRSA's Universal Newborn Hearing Screening program to support additional audiology trainees.

**Program: Developmental-Behavioral Pediatrics (DBP) Training Program.** The purpose of this program is to train the next generation of leaders in developmental-behavioral pediatrics; and provide pediatric practitioners, residents, and medical students with essential biopsychosocial knowledge and clinical expertise. This program is focused on developmental disabilities, including autism.

**Appendix IV: Combating Autism Act Grantees  
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Program**

**Table 4: Developmental-Behavioral Pediatrics Training Program Grantees from Fiscal Years 2008 through 2011**

Dollars

Grant number	Grantee name	Fiscal year			
		2008 award	2009 award	2010 award	2011 award
T77MC00004	Case Western Reserve University	\$192,467	\$192,467	\$192,467	\$192,453
T77MC00009	Montefiore Medical Center	192,467	192,467	192,467	192,467
T77MC00011	Children's Hospital (Boston, MA)	192,467	192,467	192,467	192,467
T77MC00012	The Children's Hospital of Philadelphia	229,048	191,943	191,944	191,943
T77MC00015	Boston Medical Center	192,467	192,467	240,467	237,019
T77MC00024	Yale University	209,605	222,467	192,467	192,467
T77MC09796	Board of Trustees of the Leland Stanford Junior University	142,467	162,467	192,467	192,467
T77MC09797	Rhode Island Hospital	142,467	142,467	192,467	222,467
T77MC09798	University of Arkansas for Medical Sciences, Cancer Research Center	111,143	140,102	144,948	145,000
T77MC09799	University of Oklahoma, Health Sciences Center	142,467	142,467	172,467	142,467

Source: GAO analysis of Health Resources and Services Administration (HRSA) information.

**Program: National Combating Autism Interdisciplinary Training Resource Center.** The purpose of this program is to improve the health of children who have, or are at risk for developing, autism and other developmental disabilities by providing technical assistance to LEND and DBP programs to better train professionals to utilize valid and reliable screening tools for diagnosing or ruling out autism, and provide evidence-based interventions for children.

**Table 5: National Combating Autism Interdisciplinary Training Resource Center Grantees from Fiscal Years 2008 through 2011**

Dollars

Grant number	Grantee name	Fiscal year			
		2008 award	2009 award	2010 award	2011 award
UA5MC11068	Association of University Centers on Disabilities	\$487,641	\$547,641	\$637,314	\$784,641

Source: GAO analysis of Health Resources and Services Administration (HRSA) information.

Note: Funding in fiscal years 2010 and 2011 includes supplemental funds of \$89,673 and \$147,000, respectively, which the grantee received from HRSA's Universal Newborn Hearing Screening program to support audiology training within HRSA's Leadership Education in Neurodevelopmental and Other Related Disabilities training program.

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**Program: Autism Intervention Research Program and Autism Intervention Secondary Data Analysis Studies Program.** The purpose of this program is to support research on evidence-based practices for interventions to improve the health and well-being of children and adolescents with autism and other developmental disabilities. The Autism Intervention Secondary Data Analysis Studies Program utilizes the analysis of existing secondary data.

**Table 6: Autism Intervention Research Program and Autism Intervention Secondary Data Analysis Studies Program Grantees from Fiscal Years 2008 through 2011**

Dollars

Grant number	Grantee name	Fiscal year			
		2008 award	2009 award	2010 award	2011 award
R40MC15593	University of Colorado at Denver	\$0	\$393,024	\$400,000	\$0
R40MC15594	Kennedy Krieger Institute, Inc.	0	393,024	400,000	0
R40MC15595	University of North Carolina at Chapel Hill	0	93,533	0	0
R40MC15596	Boston Medical Center	0	393,019	399,994	0
R40MC15597	University of New Hampshire	0	393,024	400,000	0
R40MC15598	Brandeis University	0	334,359	291,635	0
R40MC16396	University of Massachusetts at Boston	0	100,000	0	0
R40MC17158	University of North Carolina at Chapel Hill	0	0	100,000	0
R40MC17170	Georgia State University Research Foundation, Inc.	0	0	100,000	0
R40MC19925	The General Hospital Corporation	0	0	256,917	294,647
R40MC19926	The Curators of the University of Missouri	0	0	184,288	188,378
R40MC19927	Brandeis University	0	0	98,962	0
R40MC19928	Boston Medical Center Corporation	0	0	299,906	298,072
R40MC20171	Georgetown University	0	0	299,993	299,955
R40MC20172	University of Connecticut Health Center	0	0	300,000	300,000
R40MC20444	West Virginia University Research Corporation	0	0	296,372	296,146
R40MC20611	Health Research, Inc. / New York State Department of Health	0	0	300,000	300,000
R40MC22641	Regents of the University of California	0	0	0	285,177
R40MC22642	Regents of the University of California	0	0	0	99,988
R40MC22643	University of Colorado at Denver	0	0	0	300,000
R40MC22644	University of Iowa	0	0	0	299,972
R40MC22645	University of Massachusetts	0	0	0	300,000
R40MC22646	University of Massachusetts at Boston	0	0	0	100,000
R40MC22647	University of North Carolina at Chapel Hill	0	0	0	100,000
R40MC22648	University of North Carolina at Chapel Hill	0	0	0	299,997

Source: GAO analysis of Health Resources and Services Administration (HRSA) information.

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**Program: Autism Intervention Research Network on Physical Health.**

The purpose of this program is to establish and maintain a network infrastructure designed to be the platform from which to conduct research on evidence-based practices for interventions to improve the physical health and well-being of individuals with autism and other developmental disabilities; develop evidence-based guidelines and validate tools for interventions; and disseminate critical information on its research findings, guidelines, and tools.

**Table 7: Autism Intervention Research Network on Physical Health Grantees from Fiscal Years 2008 through 2011**

Dollars

Grant number	Grantee name	Fiscal year			
		2008 award	2009 award	2010 award	2011 award
UA3MC11054	The General Hospital Corporation	\$3,999,342	\$3,997,824	\$3,651,425	\$3,999,847

Source: GAO analysis of Health Resources and Services Administration (HRSA) information.

**Program: Autism Intervention Research Network on Behavioral Health.**

The purpose of this program is to establish and maintain a network infrastructure designed to be the platform from which to conduct research on evidence-based interventions to improve the behavioral, mental, social, or cognitive health, or a mix of those, and well-being of children and adolescents with autism and other developmental disabilities; develop evidence-based guidelines and validate tools for interventions; and disseminate critical information on its research findings, guidelines, and tools.

**Table 8: Autism Intervention Research Network on Behavioral Health Grantees from Fiscal Years 2008 through 2011**

Dollars

Grant number	Grantee name	Fiscal year			
		2008 award	2009 award	2010 award	2011 award
UA3MC11055	Regents of the University of California	\$2,000,000	\$1,930,288	\$1,989,276	\$2,000,000

Source: GAO analysis of Health Resources and Services Administration (HRSA) information.

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**Program: Developmental-Behavioral Pediatrics Research Network.**

The purpose of this program is to establish a multicenter scientific and clinical research network that will promote coordinated research activities and address health issues. The program is intended to build a developmental behavioral pediatric research infrastructure that supports multidisciplinary research, focuses on the translation of research to practice, and provides the environment in which to train a new generation of developmental behavioral pediatric researchers.

**Table 9: Developmental-Behavioral Pediatrics Research Network Grantees from Fiscal Years 2008 through 2011**

Dollars

Grant number	Grantee name	Fiscal year			
		2008 award	2009 award	2010 award	2011 award
UA3MC20218	The Children's Hospital of Philadelphia	\$0	\$0	\$200,000	\$220,000

Source: GAO analysis of Health Resources and Services Administration (HRSA) information.

**Program: State Implementation and Planning Grants.** The purpose of this program is to improve access to comprehensive, coordinated health care and related services by implementing state plans to improve the system of services.<sup>2</sup>

<sup>2</sup>This program comprises: State Implementation Grants for Improving Services for Children and Youth with Autism Spectrum Disorder and other Developmental Disabilities, and State Planning Grants for Improving Services for Children and Youth with Autism Spectrum Disorder and other Developmental Disabilities.

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**Table 10: State Implementation and Planning Grants Grantees from Fiscal Years 2008 through 2011**

Dollars

Grant number	Grantee name	Fiscal year			
		2008 award	2009 award	2010 award	2011 award
H6MMC11059 <sup>a</sup>	The Curators of the University of Missouri	\$297,957	\$295,703	\$467,729	\$0
H6MMC11061 <sup>a</sup>	Utah Department of Health	300,000	300,000	497,757	0
H6MMC11062	The Hope School (Springfield, IL)	300,000	300,000	300,000	0
H6MMC11063	Wisconsin Department of Health & Family Services	300,000	300,000	300,000	0
H6MMC11064 <sup>a</sup>	State of Alaska, Department of Health & Social Services	300,000	300,000	497,757	0
H6MMC11065 <sup>a</sup>	State of Washington Department of Health	300,000	300,000	497,757	0
H6MMC15102	Rhode Island Department of Health	0	300,000	300,000	0
H6MMC15103	University of New Mexico Health Sciences Center	0	300,000	300,000	0
H6MMC15104	Health Research, Inc. / New York State Department of Health	0	300,000	300,000	0
H6MMC20326	Vermont State Department of Health	0	0	272,463	300,000
H6MMC20327	Hawaii Pediatric Association Research & Education Foundation	0	0	272,463	300,000
H6MMC20328	Statewide Parent Advocacy Network of New Jersey	0	0	272,463	300,000
H6MMC20329	Maine Department of Health and Human Services	0	0	272,463	300,000
H6MMC22710	Georgia State University Research Foundation	0	0	0	75,000
H6MMC22711	Tennessee Disability Coalition	0	0	0	75,000
H6MMC22712	The Parents' Place of Maryland	0	0	0	75,000
H6MMC22713	University of Delaware	0	0	0	74,999
H6MMC22737	Autism Society of Colorado	0	0	0	243,092
H6MMC22738	Connecticut Department of Public Health	0	0	0	243,092
H6MMC22739	Minot State University	0	0	0	243,092
H6MMC22740	University of Southern Mississippi	0	0	0	243,092
H6MMC22849	Ohio Department of Developmental Disabilities	0	0	0	243,092

Source: GAO analysis of Health Resources and Services Administration (HRSA) information.

<sup>a</sup>Totals for this grantee in fiscal year 2010 include supplemental funding to expand its implementation of the Centers for Disease Control and Prevention's (CDC) *Learn the Signs. Act Early.* campaign. This supplement is funded through an interagency agreement between HRSA and CDC.

**Program: State Public Health Coordinating Center.** The program purpose is to improve the health of children who have, or are at risk for developing, autism and other developmental disabilities by coordinating with the state demonstration grantees; and by developing a strategy for defining, supporting, and monitoring the role of state public health agencies in assuring early and timely identification, diagnosis, and intervention.

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**Table 11: State Public Health Coordinating Center Grantees from Fiscal Years 2008 through 2011**

Dollars

Grant number	Grantee name	Fiscal year			
		2008 award	2009 award	2010 award	2011 award
U01MC11069	Association of Maternal & Child Health Programs	\$250,000	\$250,000	\$275,000	\$275,000

Source: GAO analysis of Health Resources and Services Administration (HRSA) information.

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# Appendix V: GAO Contact and Staff Acknowledgments

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## GAO Contact

Marcia Crosse, (202) 512-7114 or [crossem@gao.gov](mailto:crossem@gao.gov)

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## Staff Acknowledgments

In addition to the contact named above, Geri Redican-Bigott, Assistant Director; Katherine L. Amoroso; George Bogart; Deirdre Brown; Sandra George; Cathleen Hamann; Kristin Helfer Koester; Drew Long; and Sarah Resavy made key contributions to this report.

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