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## Accessible Version

June 30, 2015

Congressional Requesters

### **Federal Autism Research: Updated Information on Funding from Fiscal Years 2008 through 2012**

Autism is a complex developmental disorder characterized by impaired social interactions, problems with verbal and nonverbal communication, and repetitive behaviors, or by severely limited activities and interests.<sup>1</sup> The most recent estimates from the Centers for Disease Control and Prevention (CDC)—an agency within the Department of Health and Human Services (HHS)—indicate that about 1 in 68 children have been identified as having autism.<sup>2</sup> According to CDC, there are likely many causes of autism and many factors, including environmental, biologic, and genetic, that may make a child more likely to have autism. There is no known cure for autism; however, research shows that early intervention can greatly improve a child's development.

In November 2013, we reported that 11 federal agencies awarded a combined total of approximately \$1.2 billion to fund autism research from fiscal years 2008 through 2012.<sup>3</sup> The 11 agencies are the Department of Defense (DOD); Department of Education (Education); Environmental Protection Agency; National Science Foundation; and 7 agencies within HHS: Administration for Children and Families, Agency for Healthcare Research and Quality, CDC, Centers for Medicare & Medicaid Services, Health Resources and Services Administration, National Institutes of Health (NIH), and the Substance Abuse and Mental Health Services Administration.

To advance federal activities related to autism, including research, the Autism Collaboration, Accountability, Research, Education, and Support (CARES) Act of 2014 was enacted in August of that year.<sup>4</sup> The Autism CARES Act reauthorized the Interagency Autism Coordinating Committee (IACC), which is a federal advisory committee composed of federal and nonfederal members. The act also requires IACC to develop and annually update a strategic plan for autism research.<sup>5</sup>

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<sup>1</sup>What is commonly referred to as autism is a group of disorders—known as autism spectrum disorder—that can range from mild to more severe in their symptoms. In this report, the term “autism” is used to refer to autism spectrum disorder.

<sup>2</sup>This estimate is based on a review of health and education records of 8-year-old children living in 11 communities across the United States during 2010. Centers for Disease Control and Prevention, *Prevalence of Autism Spectrum Disorder Among Children Aged 8 Years—Autism and Developmental Disabilities Monitoring Network, 11 Sites, United States, 2010*, Morbidity and Mortality Weekly Report, vol. 63, No. SS-2, (Mar. 28, 2014).

<sup>3</sup>GAO, *Federal Autism Activities: Better Data and More Coordination Needed to Help Avoid the Potential for Unnecessary Duplication*, [GAO-14-16](#) (Washington, D.C.: Nov. 20, 2013).

<sup>4</sup>Pub. L. No. 113-157, 128 Stat. 1831 (Aug. 8, 2014).

<sup>5</sup>IACC was initially established under the Children's Health Act of 2000. Pub. L. No. 106-310, § 104, 114 Stat. 1101, 1109 (Oct. 17, 2000). IACC was subsequently re-established by the Combating Autism Act of 2006, Pub. L. No. 109-

The IACC strategic plan is organized into seven questions—such as “When should I be concerned”—that correspond to seven research areas, and each research area contains specific short- and long-term research objectives. Over the years, more objectives have been added to the research areas, for a total of 78 objectives in the most recent plan.<sup>6</sup> Figure 1 outlines the seven questions, the corresponding research areas, and the number of objectives.<sup>7</sup>

**Figure 1: Interagency Autism Coordinating Committee (IACC) Strategic Plan Research Areas**

Diagnosis	Biology	Causes	Treatments and interventions	Services	Lifespan issues	Infrastructure and surveillance
1. When should I be concerned?	2. How can I understand what is happening?	3. What caused this to happen and can it be prevented?	4. Which treatments and interventions will help?	5. Where can I turn for services?	6. What does the future hold, particularly for adults?	7. What other infrastructure and surveillance needs must be met?
<b>Topics covered</b> Diagnostic and screening tests, early signs, biomarkers, symptomology, subgroups	<b>Topics covered</b> Neural systems, molecular pathways, developmental trajectory, cognitive studies, immune and metabolic pathways, neuropathology, biosignatures, computational studies, co-occurring conditions, sensory and motor functions	<b>Topics covered</b> Genetic risk factors, environmental risk factors, and the intersection of genetic and environmental risk factors, including epigenetics	<b>Topics covered</b> Pharmacological, behavioral, educational, complementary, dietary, occupational, sensory-based therapies, technology-based interventions and supports, model system to identify molecular targets	<b>Topics covered</b> Utilization and access, evidence-based practices, cost-effective service delivery, practitioner training, family well-being, safety, community inclusion	<b>Topics covered</b> Adult interventions, service needs, transition services, vocational rehabilitation, adult diagnosis	<b>Topics covered</b> Surveillance and prevalence, research infrastructure, data tools, biobanks, research subject recruitment, research workforce development
<b>Total objectives: 9</b> Short-term: 6 Long-term: 3	<b>Total objectives: 9</b> Short-term: 7 Long-term: 2	<b>Total objectives: 15</b> Short-term: 11 Long-term: 4	<b>Total objectives: 12</b> Short-term: 8 Long-term: 4	<b>Total objectives: 9</b> Short-term: 4 Long-term: 5	<b>Total objectives: 8</b> Short-term: 4 Long-term: 4	<b>Total objectives: 16*</b>

Source: GAO analysis of data from the National Institute of Mental Health, Office of Autism Research Coordination on behalf of the Interagency Autism Coordinating Committee. | GAO-15-583R

**Data Table for Figure 1: Interagency Autism Coordinating Committee (IACC) Strategic Plan Research Areas**

Diagnosis	Biology	Causes	Treatments and interventions	Services	Lifespan issues	Infrastructure and surveillance
1. When should I be concerned?	2. How can I understand what is happening?	3. What caused this to happen and can it be prevented?	4. Which treatments and interventions will help?	5. Where can I turn for services?	6. What does the future hold, particularly for adults?	7. What other infrastructure and surveillance needs must be met?
<b>Topics covered:</b> Diagnostic and screening tests, early	<b>Topics covered:</b> Neural systems, molecular pathways,	<b>Topics covered:</b> Genetic risk factors, environmental	<b>Topics covered:</b> Pharmacological, behavioral, educational, complementary,	<b>Topics covered:</b> Utilization and access, evidence-	<b>Topics covered:</b> Adult interventions, service needs,	<b>Topics covered:</b> Surveillance and prevalence,

416, 120 Stat. 2821 (Dec. 19, 2006), and received authorization of appropriations in the Combating Autism Reauthorization Act of 2011, Pub. L. No. 112-32, 125 Stat. 361 (Sept. 30, 2011).

<sup>6</sup>IACC’s strategic plan has included 78 objectives since January 2011. IACC released its most recent strategic plan update—the 2013 update—in April 2014. The objectives were created by IACC to address critical gaps and opportunities it perceived in autism research.

<sup>7</sup>IACC also refers to the “causes” research area as risk factor research.

Diagnosis	Biology	Causes	Treatments and interventions	Services	Lifespan issues	Infrastructure and surveillance
signs, biomarkers, symptomology, subgroups	developmental trajectory, cognitive studies, immune and metabolic pathways, neuropathology, biosignatures, computational studies, co-occurring conditions, sensory and motor functions	risk factors, and the intersection of genetic and environmental risk factors, including epigenetics	dietary, occupational, sensory-based therapies, technology-based interventions and supports, model system to identify molecular targets	based practices, cost-effective service delivery, practitioner training, family well-being, safety, community inclusion	transition services, vocational rehabilitation, adult diagnosis	research infrastructure, data tools, biobanks, research subject recruitment, research workforce development
<b>Total objectives: 9</b> Short-term: 6 Long-term: 3	<b>Total objectives: 9</b> Short-term: 7 Long-term: 2	<b>Total objectives: 15</b> Short-term: 11 Long-term: 4	<b>Total objectives: 12</b> Short-term: 8 Long-term: 4	<b>Total objectives: 9</b> Short-term: 4 Long-term: 5	<b>Total objectives: 8</b> Short-term: 4 Long-term: 4	<b>Total objectives: 16[Note A]</b>

Source: GAO analysis of data from the National Institute of Mental Health, Office of Autism Research Coordination on behalf of the Interagency Autism Coordinating Committee. | GAO-15-583R

Note: This figure was adapted by GAO. The original figure appears in the 2010 Autism Spectrum Disorder Research Portfolio Analysis Report published in July 2012 by IACC. According to IACC, the “topics covered” do not necessarily encompass all projects funded in each research area.

<sup>a</sup>IACC considers the 16 objectives for infrastructure and surveillance to be both short- and long-term objectives.

You asked us to review how federal funding for autism research has changed over time. This report describes how the amount of federal funding in each of the research areas specified in the IACC strategic plan changed from fiscal years 2008 through 2012.

To identify changes in agency funding awarded from fiscal years 2008 through 2012, we analyzed data we previously collected from federal agencies for our November 2013 report.<sup>8</sup> Such data by strategic plan research area for fiscal years 2013 and 2014 are not currently available. When collecting and reviewing the data, we included research projects in the fiscal year in which they were awarded funds, even if funds remained available for obligation by the awardee in future fiscal years. We used these data to calculate changes in federal autism funding from fiscal years 2008 through 2012 and we analyzed the data by IACC strategic plan research area and agency. All funding awards are reported in nominal amounts, unless otherwise noted.<sup>9</sup>

Federal agencies periodically provide data to the Office of Autism Research Coordination (OARC)—which was created by NIH to provide administrative support to IACC—on the autism research they fund. With assistance from OARC, the agencies categorize this research to the seven strategic plan research areas, as well as specific objectives within the research areas. The categorization of projects to the strategic plan questions and objectives can vary over time.<sup>10</sup> Because we are using the most recent fiscal year’s strategic plan question and objective

<sup>8</sup>See [GAO-14-16](#).

<sup>9</sup>When we adjusted for inflation, we used fiscal year 2012 dollars.

<sup>10</sup>According to OARC officials, this is mainly due to more objectives being added to the strategic plan, as well as improved accuracy in the categorization by agencies.

categories, all of the funding for a project is attributed to the most recent category assigned, regardless of whether the project was categorized differently in previous years. Autism research projects that were not categorized to any of the seven research areas are included in the total autism research funding amounts presented in this report, but are not included in the analysis presented on changes in funding by research area.<sup>11</sup>

We have made several updates to the information contained in our November 2013 report. First, at the time we did our work for that report, DOD had not submitted data on its fiscal year 2012 autism research projects. DOD's appropriation for its medical research programs for that year, including autism, was available for obligation through the end of fiscal year 2013. As a result, the number of autism research projects we reported for DOD did not include its projects for fiscal year 2012. DOD provided us with 2012 data and we have incorporated it in this report.<sup>12</sup> Second, DOD recently determined that the data it previously provided to us for fiscal years 2008 through 2011 were actually the recommended budget amounts and not the award amounts. Additionally, DOD did not include six autism research projects funded with its fiscal year 2008 appropriation. As a result, DOD provided updated funding amounts for fiscal years 2008 through 2011. These figures represent about an additional \$4 million in funding compared to our November 2013 report. Third, after our November 2013 report was issued, Education, in consultation with OARC, reexamined the autism research projects it funded for fiscal years 2008 through 2012. While the information Education provided to us for our November 2013 report was correct at the time, it no longer reflects the agency's assessment of its autism research projects. We have adjusted our data to reflect Education's current assessment. Specifically, we removed three research projects because Education determined that these projects studied multiple disabilities and the number of children with autism in those samples was too small to draw conclusions about autism. We also added four research projects because Education found that the projects' results would be relevant to individuals with autism. These project changes resulted in approximately \$1.4 million in additional funding compared to the figures we reported in November 2013.<sup>13</sup>

We assessed the reliability of the data we obtained by comparing agency data to data collected by IACC, following up with agency officials regarding discrepancies in the data, and gathering information from agencies on the internal controls they use when maintaining their data. We found the data were sufficiently reliable for the purposes of this report.<sup>14</sup>

We conducted this performance audit from March 2015 to June 2015 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

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<sup>11</sup>For our analysis, we did not have a strategic plan research area categorization for 41 of the 1,225 autism research projects funded by federal agencies from fiscal years 2008 through 2012. These 41 projects were awarded approximately \$85 million during this time period and included 7 projects awarded funds by NIH that totaled approximately \$69 million. Although these 7 research projects were not included in the IACC data, NIH provided us with funding data on these projects—and indicated that the projects were for autism research—for our November 2013 report, [GAO-14-16](#).

<sup>12</sup>DOD provided fiscal year 2012 awards funded under its Autism Research Program, which is included in its Congressionally Directed Medical Research Programs.

<sup>13</sup>Education also suggested that we remove one other project from our data; however, upon further review of project information, we determined that the project was specific to autism and it remains in our data.

<sup>14</sup>For further information on our data collection process and analyses of the data collected, see appendix I in [GAO-14-16](#).

findings and conclusions 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.

### **Total Federal Funding of Autism Research Fluctuated from Fiscal Years 2008 through 2012, but Increased Overall and Funding by Research Area Varied**

Although federal funding for autism research fluctuated from fiscal years 2008 through 2012, it increased overall during this period, from approximately \$169 million in fiscal year 2008 to \$245 million in fiscal year 2012—about a 45 percent increase (about a 37 percent increase when adjusted for inflation). See table 1 for federal funding by agency for fiscal years 2008 through 2012.

**Table 1: Federal Funds Awarded for Autism Research from Fiscal Years (FY) 2008 through 2012, by Agency**

<b>Agency</b>	<b>FY 2008 awards</b>	<b>FY 2009 awards</b>	<b>FY 2010 awards</b>	<b>FY 2011 awards</b>	<b>FY 2012 awards</b>	<b>Total</b>
Administration for Children and Families	\$0	\$0	\$0	\$0	\$100,000	<b>\$100,000</b>
Agency for Healthcare Research and Quality	800,000	1,806,032	3,400,022	491,768	490,038	<b>6,987,860</b>
Centers for Disease Control and Prevention	13,657,568	17,307,741	17,767,365	13,806,755	14,751,329	<b>77,290,758</b>
Centers for Medicare & Medicaid Services	190,690	314,628	290,374	88,154	0	<b>883,846</b>
Department of Defense	8,807,514	8,502,260	7,082,059	5,599,296	4,126,940	<b>34,118,069</b>
Department of Education	7,585,718	11,647,378	13,111,921	7,313,460	10,367,830	<b>50,026,307</b>
Environmental Protection Agency	0	1,514,473	757,028	0	0	<b>2,271,501</b>
Health Resources and Services Administration	6,569,342	8,824,142	9,968,768	10,012,964	9,348,807	<b>44,724,023</b>
National Institutes of Health	128,881,037	216,944,410	229,428,874	181,222,736	204,030,442	<b>960,507,499</b>
National Science Foundation	2,820,675	3,326,122	6,300,680	798,318	1,830,584	<b>15,076,379</b>
Substance Abuse and Mental Health Services Administration	0	0	0	450,000	0	<b>450,000</b>
<b>Total</b>	<b>169,312,544</b>	<b>270,187,132</b>	<b>288,107,091</b>	<b>219,783,451</b>	<b>245,045,970</b>	<b>1,192,436,188</b>

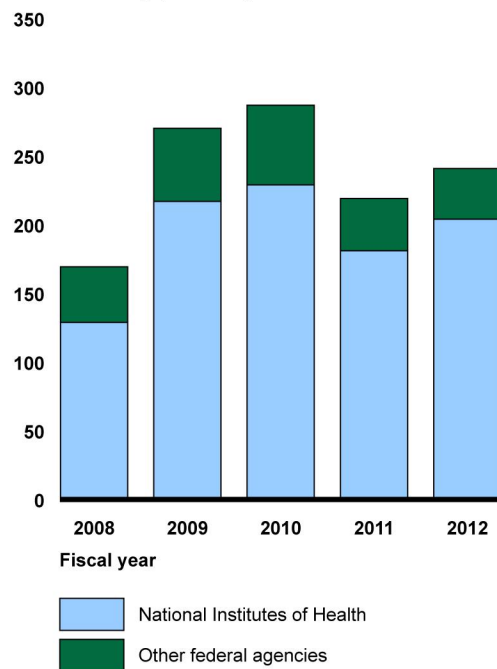
Source: GAO analysis of agency data. | GAO-15-583R

Note: In this table, all dollars are expressed in nominal terms.

Over this time period, NIH consistently provided the majority of autism research funding—between about 76 and 83 percent of the total funding awarded each fiscal year. See figure 2 for the amount of funding NIH provided by fiscal year compared to the remaining 10 agencies that funded autism research during the same time period.

**Figure 2: Autism Research Funding Provided by National Institutes of Health Compared to Other Federal Agencies from Fiscal Years 2008 through 2012**

Federal funding (in millions)



Source: GAO analysis of agency data. | GAO-15-583R

**Data Table for Figure 2: Autism Research Funding Provided by National Institutes of Health Compared to Other Federal Agencies from Fiscal Years 2008 through 2012**

Federal funding (in millions)

Fiscal year	NIH	All other agencies
2008	\$128,881,037	\$40,431,407
2009	\$216,944,410	\$53,242,776
2010	\$229,428,874	\$58,678,217
2011	\$181,222,736	\$38,560,715
2012	\$204,030,442	\$36,888,588

Source: GAO analysis of agency data. | GAO-15-583R

Note: The other federal agencies are the Department of Defense; Department of Education; Environmental Protection Agency; National Science Foundation; and six agencies within the Department of Health and Human Services: Administration for Children and Families, Agency for Healthcare Research and Quality, Centers for Disease Control and Prevention, Centers for Medicare & Medicaid Services, Health Resources and Services Administration, and the Substance Abuse and Mental Health Services Administration. In this figure, all dollars are expressed in nominal terms.

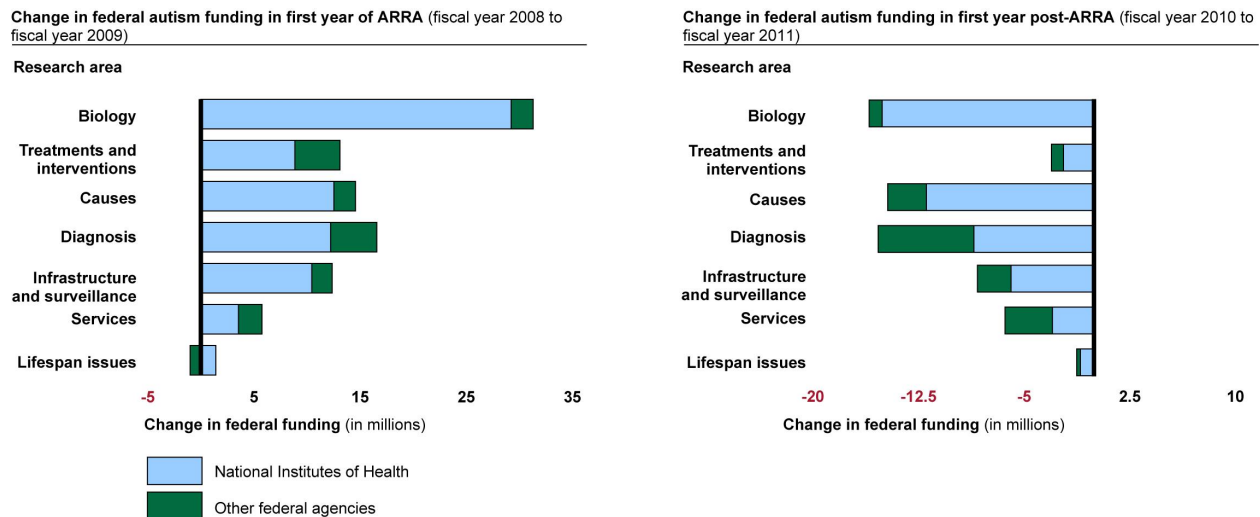
While overall federal autism research funding increased from fiscal year 2008 to fiscal year 2012, there were fluctuations in funding from year to year. Specifically, the highest funding levels were in fiscal years 2009 and 2010, in part, as a result of an additional appropriation to NIH under the American Recovery and Reinvestment Act of 2009 (ARRA).<sup>15</sup> In fiscal year 2009,

<sup>15</sup>Pub. L. No. 111-5, 123 Stat. 115 (Feb. 17, 2009). NIH spent an additional \$64 million in fiscal year 2009 and \$57.5 million in fiscal year 2010 on autism research from its reported \$10.4 billion in ARRA funding for scientific research. The National Science Foundation (NSF) also received an additional appropriation from ARRA. NSF reported a total of \$3.2 billion from ARRA and spent approximately \$2.6 million on autism research in fiscal year 2009.



NIH increased the amounts awarded in each of the seven research areas. In fiscal year 2011, when the additional appropriation was no longer available, funding from NIH decreased in each of the research areas. However, NIH's base funding—funding excluding ARRA funds—for autism research increased each fiscal year from 2008 through 2012. See figure 3 for the increase in federal autism funding by research area from fiscal year 2008 to fiscal year 2009 and the subsequent decrease in funding from fiscal year 2010 to fiscal year 2011—when the ARRA appropriation was no longer available.

**Figure 3: Changes in Federal Autism Research Funding During and After the American Recovery and Reinvestment Act of 2009 (ARRA), by Research Area**



**Data Table for Figure 3: Changes in Federal Autism Research Funding During and After the American Recovery and Reinvestment Act of 2009 (ARRA), by Research Area**

Change in federal funding (in millions)

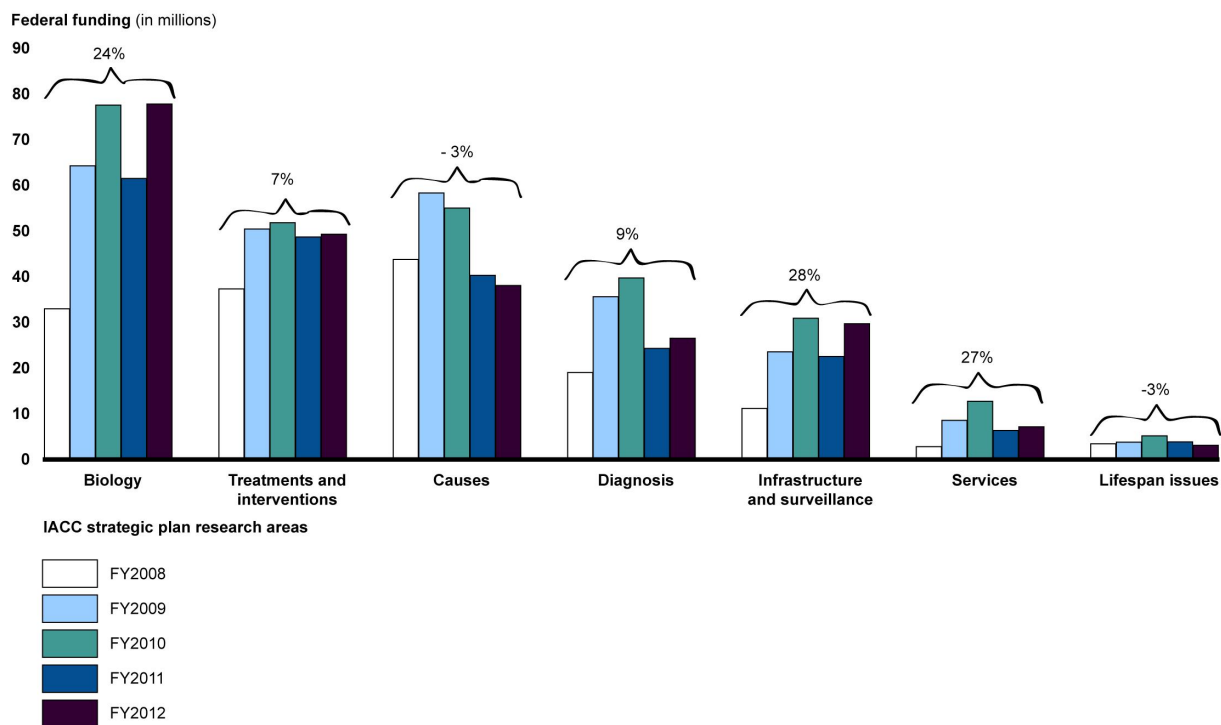
Research area	NIH	Other federal agencies	NIH	Other federal agencies
	2008-2009	2008-2009	2010-2011	2010-2011
Biology	\$29,225,984	\$2,077,683	-\$15,126,361	-\$925,298
Treatments and interventions	\$8,859,203	\$4,246,427	-\$2,253,355	-\$854,106
Causes	\$12,531,267	\$2,037,864	-\$11,987,149	-\$2,741,924
Diagnosis	\$12,224,504	\$4,344,175	-\$8,612,878	-\$6,799,865
Infrastructure and surveillance	\$10,448,283	\$1,925,073	-\$5,982,801	-\$2,384,371
Services	\$3,548,361	\$2,213,037	-\$3,046,267	-\$3,363,503
Lifespan issues	\$1,410,853	-\$1,063,734	-\$1,052,172	-\$269,541

Source: GAO analysis of agency data. | GAO-15-583R

Note: The research areas noted in the figure were established by the Interagency Autism Coordinating Committee's strategic plan. The other federal agencies are the Department of Defense; Department of Education; Environmental Protection Agency; National Science Foundation; and six agencies within the Department of Health and Human Services: Administration for Children and Families, Agency for Healthcare Research and Quality, Centers for Disease Control and Prevention, Centers for Medicare & Medicaid Services, Health Resources and Services Administration, and the Substance Abuse and Mental Health Services Administration. In this figure, all dollars are expressed in nominal terms.

The research areas of biology, treatments and interventions, and causes had the most total funding over time, while total funding for lifespan issues and services remained lower, in comparison. However, in terms of overall growth, biology, services, and infrastructure and surveillance saw the largest increases in funding relative to their funding levels in fiscal year 2008. Figure 4 shows the changes in funding by fiscal year for each of the seven research areas, as well as the overall average annual percent change in funding for each research area. The average annual percent change for the causes and lifespan issues research areas was negative, as funding in these areas was less in fiscal year 2012 than in fiscal year 2008. Each of the research areas, with the exception of lifespan issues, saw the largest increase in funding from fiscal year 2008 to fiscal year 2009, in part, due to the additional funding that NIH received and used for autism research through ARRA.

**Figure 4: Federal Funding and Average Annual Percent Change by Autism-Related Research Area from Fiscal Years (FY) 2008 through 2012**



Source: GAO analysis of agency data. | GAO-15-583R

**Data Table for Figure 4: Federal Funding and Average Annual Percent Change by Autism-Related Research Area from Fiscal Years (FY) 2008 through 2012**

Federal funding (in millions)						
IACC strategic plan research areas	FY2008	FY2009	FY2010	FY2011	FY2012	Annual percentage change
Biology	\$32,940,501	\$64,244,168	\$77,545,920	\$61,494,261	\$77,780,671	24%
Treatments and interventions	\$37,305,791	\$50,411,466	\$51,794,193	\$48,686,732	\$49,271,304	7%
Causes	\$43,747,640	\$58,316,771	\$54,998,022	\$40,268,949	\$38,044,396	-3%
Diagnosis	\$19,017,792	\$35,586,471	\$39,708,408	\$24,295,665	\$26,495,036	9%



Infrastructure and surveillance	\$11,155,162	\$23,528,518	\$30,876,013	\$22,508,841	\$29,691,638	28%
Services	\$2,766,844	\$8,528,242	\$12,716,332	\$6,306,562	\$7,112,371	27%
Lifespan issues	\$3,402,645	\$3,749,764	\$5,148,510	\$3,826,797	\$3,068,966	-3%

Source: GAO analysis of agency data. | GAO-15-583R

Note: The research areas noted in the figure were established by the Interagency Autism Coordinating Committee's (IACC) strategic plan. The federal agencies that funded autism research during the time period are the Department of Defense; Department of Education; Environmental Protection Agency; National Science Foundation; and seven agencies within the Department of Health and Human Services: Administration for Children and Families, Agency for Healthcare Research and Quality, Centers for Disease Control and Prevention, Centers for Medicare & Medicaid Services, Health Resources and Services Administration, National Institutes of Health, and the Substance Abuse and Mental Health Services Administration. In this figure, all dollars are expressed in nominal terms.

See enclosure 1 for more detailed information regarding the change in funding for the seven research areas established by the IACC strategic plan, as identified in figure 4. Further, a detailed, interactive list of funding by strategic plan research area and the area's objectives for each agency for fiscal years 2008 through 2012 is available at [http://www.gao.gov/multimedia/GAO-15-583R/interactive\\_graphic?layout=iframe](http://www.gao.gov/multimedia/GAO-15-583R/interactive_graphic?layout=iframe).

## Agency Comments

We provided a draft of this report to DOD, Education, the Environmental Protection Agency, HHS, and the National Science Foundation for review and comment. We received technical comments from DOD, Education, HHS, and the National Science Foundation, which we incorporated as appropriate. The Environmental Protection Agency did not provide any comments.

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As agreed with your offices, unless you publicly announce the contents of this report earlier, we plan no further distribution until 30 days from the report date. At that time, we will send copies of this report to the appropriate congressional committees, the Secretary of the Department of Defense, the Secretary of the Department of Education, the Administrator of the Environmental Protection Agency, the Secretary of Health and Human Services, the Director of the National Science Foundation, and other interested parties. 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. Key contributors to this report are Geri Redican-Bigott, Assistant Director; Deirdre Brown; Muriel Brown; Cathleen Hamann; Jackie Hamilton; Giselle Hicks; Ernest Powell, Jr.; Sarah Resavy; and Jessica C. Smith.



Marcia Crosse  
Director, Health Care

Enclosure – 1

*List of Requesters*

The Honorable Lamar Alexander  
Chairman  
Committee on Health, Education, Labor, and Pensions  
United States Senate

The Honorable Patty Murray  
Ranking Member  
Committee on Health, Education, Labor, and Pensions  
United States Senate

The Honorable Michael B. Enzi  
United States Senate

The Honorable James Lankford  
United States Senate

The Honorable Michael S. Lee  
United States Senate

The Honorable Katherine Clark  
House of Representatives

The Honorable Hank Johnson  
House of Representatives

The Honorable Sheila Jackson Lee  
House of Representatives

The Honorable John Lewis  
House of Representatives

The Honorable Zoe Lofgren  
House of Representatives

The Honorable Mike Rogers  
House of Representatives

The Honorable David Scott  
House of Representatives

The Honorable Rob Woodall  
House of Representatives

## Change in Federal Funding by Research Area from Fiscal Years 2008 through 2012

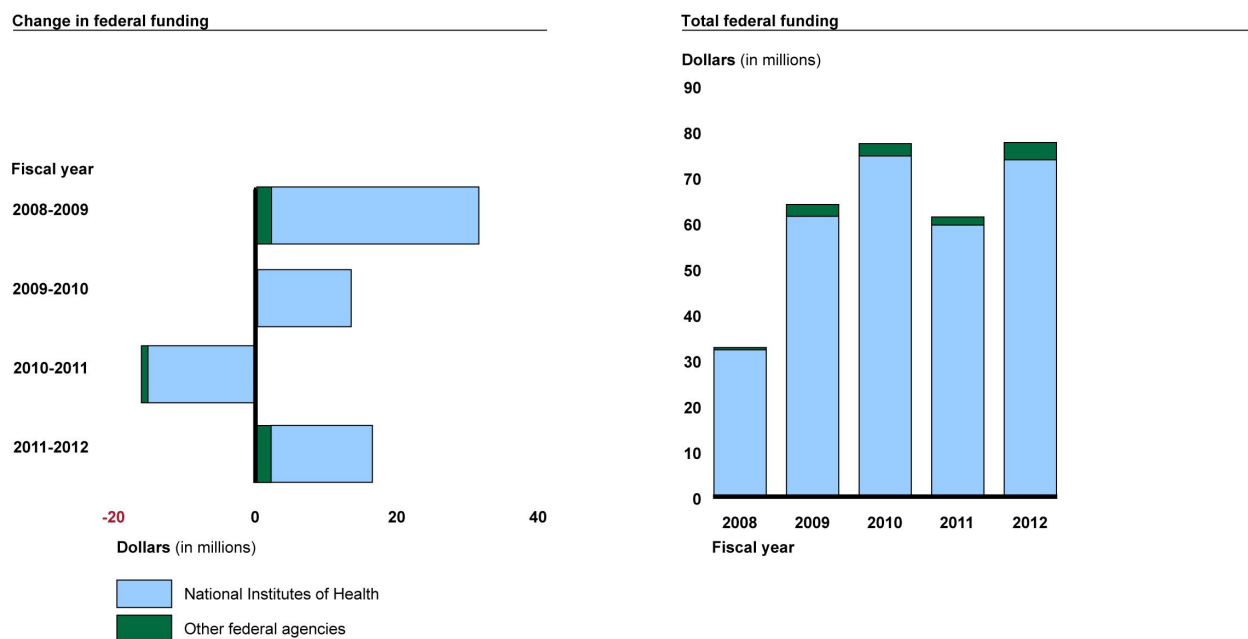
Summarized below is a description of the change in the amount of federal funding awarded from fiscal years 2008 through 2012 for each of the seven research areas as specified in the Interagency Autism Coordinating Committee's (IACC) strategic plan. They are, in order of funding magnitude: biology, treatment and interventions, causes, diagnosis, infrastructure and surveillance, services, and lifespan issues. Overall, most research areas saw a large increase in funding from fiscal years 2008 to 2009, and a subsequent decrease in funding from fiscal years 2010 to 2011. These changes can be, in part, attributed to the National Institutes of Health's (NIH) use of American Recovery and Reinvestment Act of 2009 (ARRA) funding in fiscal years 2009 and 2010, and the subsequent absence of ARRA funding beginning in fiscal year 2011.

### Biology

The biology research area received the largest amount of total federal funding during the time period—approximately \$314 million—and, with the exception of funding from fiscal year 2010 to fiscal year 2011, experienced an increase in funding every fiscal year. According to NIH, the decrease from fiscal year 2010 to fiscal year 2011 was the result of the loss of ARRA funding beginning in fiscal year 2011.

- The largest increase in funding occurred from fiscal year 2008 to fiscal year 2009, with funding almost doubling from approximately \$33 million to \$64 million.
- The increases in funding can be primarily attributed to funding provided by NIH. Not only was this increase in overall funding mainly due to an increase in funding from NIH, but NIH accounted for more than 95 percent of federal funding in the biology research area in each fiscal year from 2008 through 2012. (See fig. 5.)

**Figure 5: Change in Federal Funding for Autism Biology Research by the National Institutes of Health and Other Federal Agencies from Fiscal Years 2008 through 2012**



**Data Tables for Figure 5: Change in Federal Funding for Autism Biology Research by the National Institutes of Health and Other Federal Agencies from Fiscal Years 2008 through 2012**
**Change in federal funding**

<b>Fiscal year</b>	2008-2009	2009-2010	2010-2011	2011-2012
<b>NIH</b>	\$29,225,984	\$13,204,078	(\$15,126,361)	\$14,277,515
<b>Other federal agencies</b>	\$2,081,608	\$122,180	(\$953,555)	(\$503,492)

**Total federal funding**

<b>Fiscal year</b>	2008	2009	2010	2011	2012
<b>NIH</b>	\$32,421,521	\$61,647,505	\$74,851,583	\$59,725,222	\$74,002,737
<b>Other federal agencies</b>	\$519,208	\$2,600,816	\$2,722,996	\$1,769,441	\$1,265,949

Source: GAO analysis of agency data. | GAO-15-583R

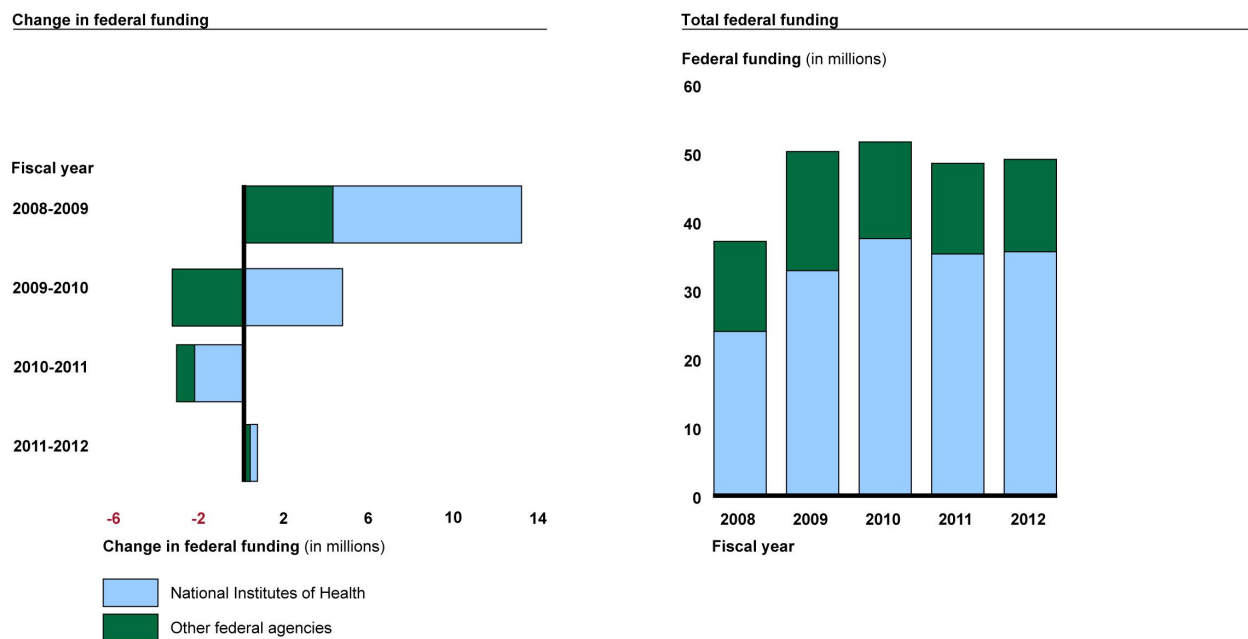
Note: The other federal agencies are the Department of Defense; National Science Foundation; and two agencies within the Department of Health and Human Services: Agency for Healthcare Research and Quality and Health Resources and Services Administration. In this figure, all dollars are expressed in nominal terms.

**Treatments and Interventions**

Treatment and interventions had the second largest amount of total federal funding from fiscal years 2008 through 2012—approximately \$237 million.

- Funding in this area increased by 35 percent, or approximately \$13 million, from fiscal year 2008 to fiscal year 2009. The majority of the increase was due to a \$9 million increase in funding from NIH. However, other agencies also contributed to the increase. For example, the Department of Education (Education) increased its funding in this area by approximately \$3 million.
- The change in federal funding in this area in subsequent years was much less—between approximately \$1 million and \$3 million each fiscal year—and was the result of some agencies increasing funding and others decreasing funding.
- In each fiscal year, NIH provided the majority of funding in this area—ranging from about 65 to 73 percent of the total federal funding in each fiscal year. (See fig. 6.) Education and the Health Resources and Services Administration (HRSA) were the second and third largest providers of funds in each fiscal year.

**Figure 6: Change in Federal Funding for Autism Treatments and Interventions Research by the National Institutes of Health and Other Federal Agencies from Fiscal Years 2008 through 2012**



**Data Tables for Figure 6: Change in Federal Funding for Autism Treatments and Interventions Research by the National Institutes of Health and Other Federal Agencies from Fiscal Years 2008 through 2012**

**Change in federal funding**

Fiscal year	2008-2009	2009-2010	2010-2011	2011-2012
<b>NIH</b>	\$8,859,203	\$4,695,132	(\$2,253,355)	\$336,624
<b>Other federal agencies</b>	\$4,261,840	(\$3,218,849)	\$1,233,167	(\$2,622,123)

**Total federal funding**

Fiscal year	2008	2009	2010	2011	2012
<b>NIH</b>	\$24,153,626	\$33,012,829	\$37,707,961	\$35,454,606	\$35,791,230
<b>Other federal agencies</b>	\$13,152,165	\$17,414,005	\$14,195,156	\$15,428,323	\$12,806,200

Source: GAO analysis of agency data. | GAO-15-583R

Note: The other federal agencies are the Department of Defense; Department of Education; National Science Foundation; and two agencies within the Department of Health and Human Services: Agency for Healthcare Research and Quality and Health Resources and Services Administration. In this figure, all dollars are expressed in nominal terms.

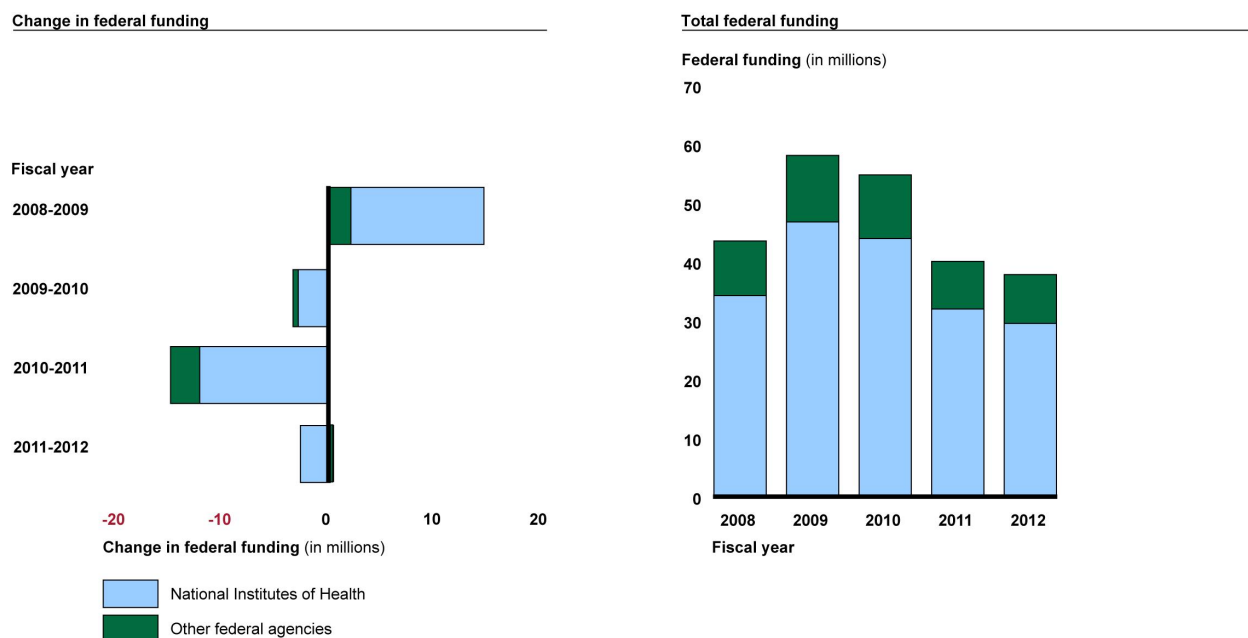
### Causes

From fiscal years 2008 through 2012, federal funding for the causes research area totaled approximately \$235 million.

- Similar to the treatments and interventions research area, the funding in the causes area increased 33 percent, or approximately \$15 million from fiscal year 2008 to fiscal year 2009, and most of this increase can be attributed to funding increases from NIH. According to NIH, the increase was due to the agency receiving ARRA funding in fiscal year 2009.

- However, after fiscal year 2009, federal funding decreased so that the amount of federal funding in fiscal year 2012 was less than in fiscal year 2008. The decrease can mainly be attributed to decreases in funding by NIH.
- NIH was the largest provider of federal funds in this area with approximately 80 percent of the federal funding coming from the agency each fiscal year. (See fig. 7.) The majority of the remaining funding in the area came from the Centers for Disease Control and Prevention (CDC) each year.

**Figure 7: Change in Federal Funding for Autism Causes Research by the National Institutes of Health and Other Federal Agencies from Fiscal Years 2008 through 2012**



**Data Tables for Figure 7: Change in Federal Funding for Autism Causes Research by the National Institutes of Health and Other Federal Agencies from Fiscal Years 2008 through 2012**

**Change in federal funding**

Fiscal year	2008-2009	2009-2010	2010-2011	2011-2012
<b>NIH</b>	\$12,531,267	(\$2,825,859)	(\$11,987,149)	(\$2,462,984)
<b>Other federal agencies</b>	\$2,037,825	(\$492,891)	(\$2,741,924)	(\$37,195)

**Total federal funding**

Fiscal year	2008	2009	2010	2011	2012
<b>NIH</b>	\$34,471,656	\$47,002,923	\$44,177,064	\$32,189,915	\$29,726,931
<b>Other federal agencies</b>	\$9,276,024	\$11,313,849	\$10,820,958	\$8,079,034	\$8,041,839

Source: GAO analysis of agency data. | GAO-15-583R

Note: The other federal agencies are the Department of Defense; Environmental Protection Agency; and two agencies within the Department of Health and Human Services: Centers for Disease Control and Prevention and Health Resources and Services Administration. In this figure, all dollars are expressed in nominal terms.



## Diagnosis

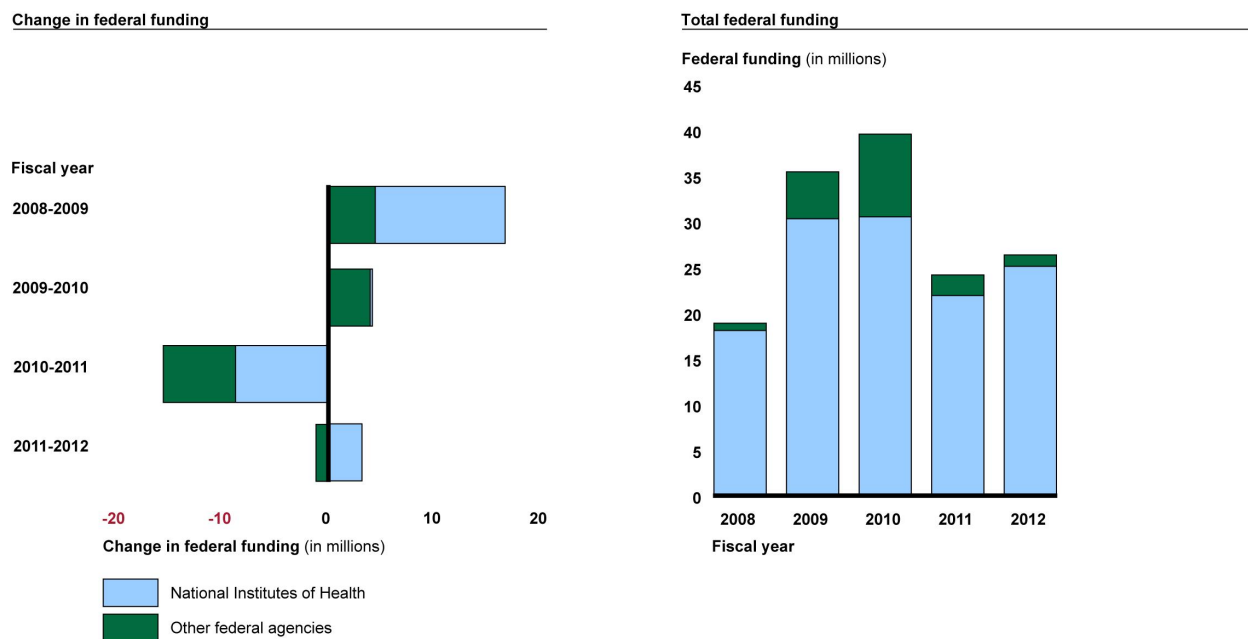
Total federal funding in the diagnosis research area was approximately \$145 million from fiscal years 2008 through 2012.

- The largest increase in federal funding in the area occurred from fiscal year 2008 to fiscal year 2009, with funding almost doubling from approximately \$19 million to \$36 million. The majority of the increase was due to a \$12 million increase in funding from NIH. However, other agencies also contributed to the increase. For example, the Department of Defense (DOD) increased its funding by about \$3 million.
- The increase in fiscal year 2009 was followed by a smaller increase in fiscal year 2010 of approximately \$4 million, and then a decrease in funding of about \$15 million in fiscal year 2011. Much of the decrease in fiscal year 2011 can be attributed to a decline in funding from NIH (approximately \$9 million). According to NIH, the changes in funding in these years can largely be attributed to the receipt and then subsequent absence of ARRA funding. However, the National Science Foundation (NSF) and Education also played a role in the decrease from fiscal year 2010 to fiscal year 2011, reducing funding by about \$6 million and \$2 million, respectively. Some of these agency decreases were offset by a total increase of over \$1 million by other agencies.<sup>1</sup>
- For fiscal years 2008, 2011, and 2012, NIH funded over 90 percent of research in this area. In fiscal years 2009 and 2010, NIH's funding for research in this area increased; however, NIH's percentage of total funding in this area decreased as DOD and NSF funded more research in the area. Specifically, DOD accounted for approximately 8 percent of the funding in fiscal year 2009 and NSF accounted for about 15 percent of the funding in fiscal year 2010. (See fig. 8.)

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<sup>1</sup>Agency funding may not add to the total funding due to rounding.

**Figure 8: Change in Federal Funding for Autism Diagnosis Research by the National Institutes of Health and Other Federal Agencies from Fiscal Years 2008 through 2012**



**Data Tables for Figure 8: Change in Federal Funding for Autism Diagnosis Research by the National Institutes of Health and Other Federal Agencies from Fiscal Years 2008 through 2012**

**Change in federal funding**

Fiscal year	2008-2009	2009-2010	2010-2011	2011-2012
NIH	\$12,224,504	\$211,302	(\$8,612,878)	\$3,193,323
Other federal agencies	\$4,793,317	\$3,461,493	(\$6,772,837)	(\$1,686,435)

**Total federal funding**

Fiscal year	2008	2009	2010	2011	2012
NIH	\$18,223,292	\$30,447,796	\$30,659,098	\$22,046,220	\$25,239,543
Other federal agencies	\$794,500	\$5,587,817	\$9,049,310	\$2,276,473	\$590,038

Source: GAO analysis of agency data. | GAO-15-583R

Note: The other federal agencies are the Department of Defense; Department of Education; National Science Foundation; and three agencies within the Department of Health and Human Services: Administration for Children and Families, Agency for Healthcare Research and Quality, and the Substance Abuse and Mental Health Services Administration. In this figure, all dollars are expressed in nominal terms.

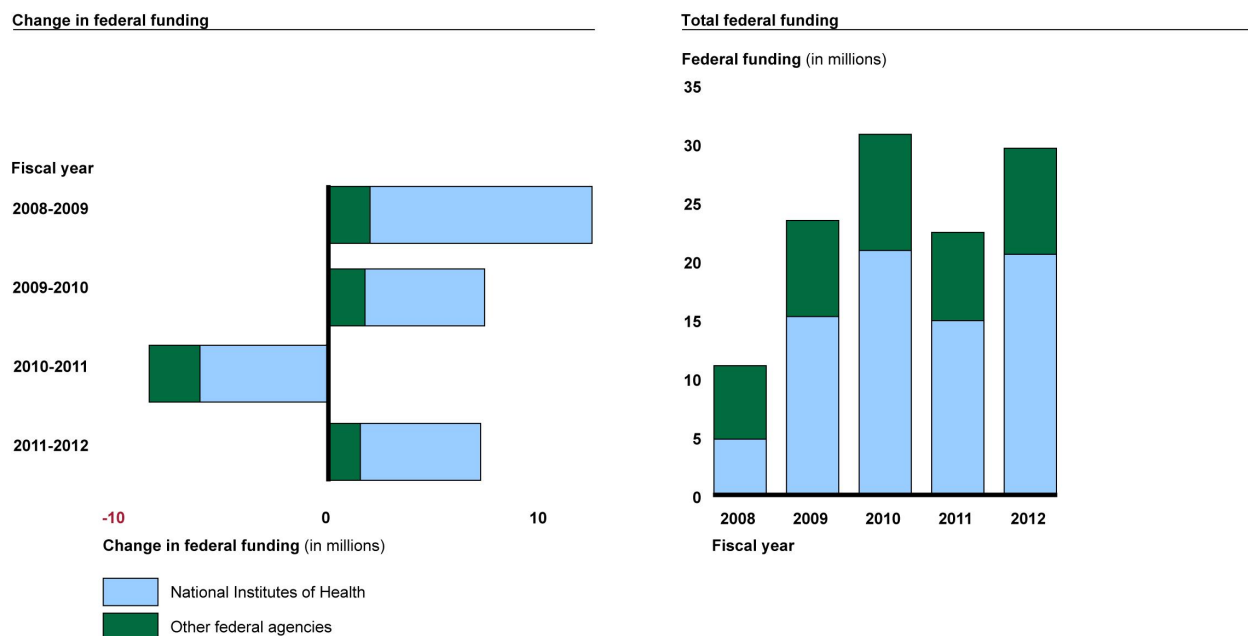
### Infrastructure and Surveillance

Federal funding for the infrastructure and surveillance research area totaled approximately \$118 million from fiscal years 2008 through 2012.

- The largest increase in funding in this research area occurred from fiscal years 2008 to 2009, with funding more than doubling from approximately \$11 million to \$24 million. The increase in funding can be primarily attributed to an increase in funding from NIH of about \$10 million, largely due to ARRA funding, according to agency officials.

- From fiscal year 2009 to fiscal year 2010, funding increased by approximately \$7 million, and while the majority of this increase can be attributed to NIH, other agencies, such as HRSA, also contributed to the increase. For example, during this time period, HRSA increased funding in this area by approximately \$2 million. The decrease of approximately \$8 million from fiscal year 2010 to fiscal year 2011 was mostly the result of an approximately \$6 million decrease in funding from NIH, which according to NIH was the result of the loss of ARRA funding, as well as a decrease in its base funding in this area. The remaining \$2 million was due to a decrease in funding from four other agencies, including a \$1 million decrease in funding from CDC.
- CDC contributed the most federal funding in fiscal year 2008. Starting in fiscal year 2009, the majority of funding in this area—between 65 and 70 percent—came from NIH, with the majority of the remaining funding coming from CDC. (See fig. 9.)

**Figure 9: Change in Federal Funding for Autism Infrastructure and Surveillance Research by the National Institutes of Health and Other Federal Agencies from Fiscal Years 2008 through 2012**



**Data Tables for Figure 9: Change in Federal Funding for Autism Infrastructure and Surveillance Research by the National Institutes of Health and Other Federal Agencies from Fiscal Years 2008 through 2012**

**Change in federal funding**

Fiscal year	2008-2009	2009-2010	2010-2011	2011-2012
NIH	\$10,448,283	\$5,635,509	(\$5,982,801)	\$5,662,466
Other federal agencies	\$1,925,073	\$1,711,986	(\$2,384,371)	\$1,520,331

**Total federal funding**

Fiscal year	2008	2009	2010	2011	2012
NIH	\$4,887,216	\$15,335,499	\$20,971,008	\$14,988,207	\$20,650,673
Other federal agencies	\$6,267,946	\$8,193,019	\$9,905,005	\$7,520,634	\$9,040,965

Source: GAO analysis of agency data. | GAO-15-583R

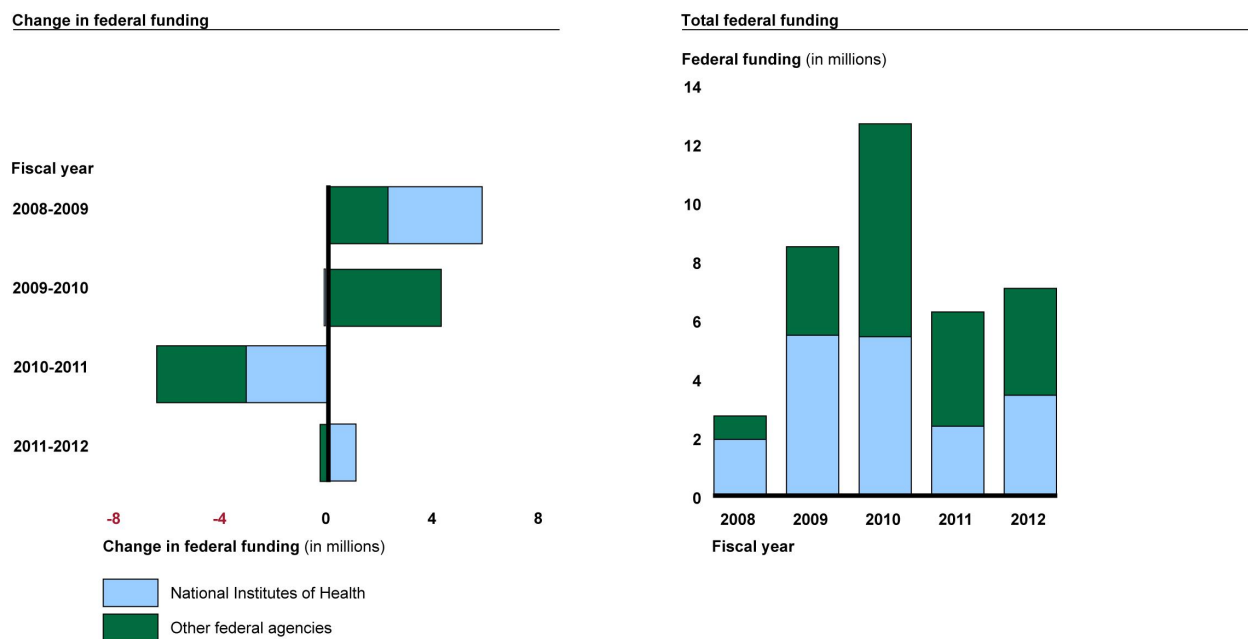
Note: The other federal agencies are the Department of Education; and three agencies within the Department of Health and Human Services: Centers for Disease Control and Prevention, Centers for Medicare & Medicaid Services, and Health Resources and Services Administration. In this figure, all dollars are expressed in nominal terms.

## Services

Federal funding for the services research area totaled approximately \$37 million from fiscal years 2008 through 2012.

- Federal funding in this research area varied from year to year, with the largest increase in federal funding from fiscal year 2008 to fiscal year 2009. During this period, funding increased by over 200 percent from approximately \$3 million to approximately \$9 million. This increase was primarily due to an increase in funding of approximately \$4 million from NIH and a \$1 million increase in funding from HRSA.
- Funding further increased from approximately \$9 million in fiscal year 2009 to approximately \$13 million in fiscal year 2010. This rise was due to increased funding from agencies other than NIH, such as the Agency for Healthcare Research and Quality (AHRQ), DOD, Centers for Medicare & Medicaid Services, and HRSA. Subsequently, from fiscal year 2010 to fiscal year 2011, federal funding in the services area decreased by 50 percent—with about half of the decrease attributable to NIH and the other half attributable to AHRQ and DOD—bringing the total federal funding level back down to about \$6 million in fiscal year 2011. According to NIH, its decrease in funding in this area was the result of the loss of ARRA funding.
- After fiscal year 2009, NIH accounted for approximately half of the funding in this area, as other agencies, such as AHRQ, DOD, Education, and HRSA, funded more research in the area. (See fig. 10.)

**Figure 10: Change in Federal Funding for Autism Services Research by the National Institutes of Health and Other Federal Agencies from Fiscal Years 2008 through 2012**



**Data Tables for Figure 10: Change in Federal Funding for Autism Services Research by the National Institutes of Health and Other Federal Agencies from Fiscal Years 2008 through 2012**
**Change in federal funding**

<b>Fiscal year</b>	2008-2009	2009-2010	2010-2011	2011-2012
<b>NIH</b>	\$3,548,361	(\$51,461)	(\$3,046,267)	\$1,053,229
<b>Other federal agencies</b>	\$2,219,053	\$4,233,535	(\$3,363,503)	(\$247,420)

**Total federal funding**

<b>Fiscal year</b>	2008	2009	2010	2011	2012
<b>NIH</b>	\$1,966,844	\$5,515,205	\$5,463,744	\$2,417,477	\$3,470,706
<b>Other federal agencies</b>	\$800,000	\$3,019,053	\$7,252,588	\$3,889,085	\$3,641,665

Source: GAO analysis of agency data. | GAO-15-583R

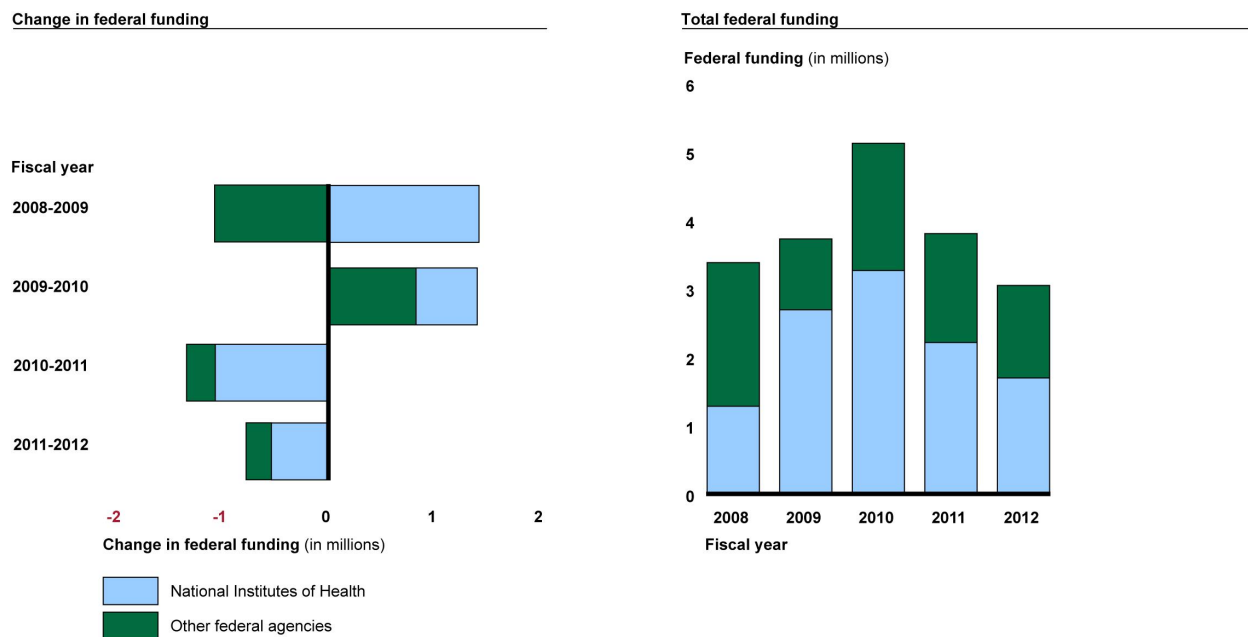
Note: The other federal agencies are the Department of Defense; Department of Education; and three agencies within the Department of Health and Human Services: Agency for Healthcare Research and Quality, Centers for Medicare & Medicaid Services, and Health Resources and Services Administration. In this figure, all dollars are expressed in nominal terms.

**Lifespan Issues**

From fiscal years 2008 through 2012, federal funding in the lifespan issues research area accounted for the least amount of funding out of all the research areas, totaling approximately \$19 million.

- While there were some changes in funding from year to year, federal funding in fiscal year 2012—approximately \$3.1 million—was about 10 percent less than the level of funding in this area in fiscal year 2008—approximately \$3.4 million. When adjusted for inflation, funding decreased about 15 percent from fiscal year 2008 to fiscal year 2012.
- The change in federal funding in this area was no greater than approximately \$1 million each year, and was the result of some agencies increasing funding and others decreasing funding.
- For most years, NIH provided the majority of funding in the lifespan issues area, and the rest of the funding came from a variety of agencies, including AHRQ, DOD, Education, HRSA, and NSF. (See fig. 11.)

**Figure 11: Change in Federal Funding for Autism Lifespan Issues Research by the National Institutes of Health and Other Federal Agencies from Fiscal Years 2008 through 2012**



**Data Tables for Figure 11: Change in Federal Funding for Autism Lifespan Issues Research by the National Institutes of Health and Other Federal Agencies from Fiscal Years 2008 through 2012**

**Change in federal funding**

Fiscal year	2008-2009	2009-2010	2010-2011	2011-2012
NIH	\$1,410,853	\$574,900	(\$1,052,172)	(\$519,196)
Other federal agencies	(\$1,063,734)	\$823,846	\$128,970	(\$292,070)

**Total federal funding**

Fiscal year	2008	2009	2010	2011	2012
NIH	\$1,302,649	\$2,713,502	\$3,288,402	\$2,236,230	\$1,717,034
Other federal agencies	\$2,099,996	\$1,036,262	\$1,860,108	\$1,989,078	\$1,697,008

Source: GAO analysis of agency data. | GAO-15-583R

Note: The other federal agencies are the Department of Defense; Department of Education; National Science Foundation; and two agencies within the Department of Health and Human Services: Agency for Healthcare Research and Quality and Health Resources and Services Administration. In this figure, all dollars are expressed in nominal terms.