



November 2013

FEDERAL AUTISM ACTIVITIES

Better Data and More
Coordination Needed
to Help Avoid the
Potential for
Unnecessary
Duplication

GAO Highlights

Highlights of [GAO-14-16](#), a report to congressional requesters

Why GAO Did This Study

Autism—a developmental disorder involving communication and social impairment—is an important public health concern. From fiscal years 2008 through 2012, 12 federal agencies awarded at least \$1.4 billion to support autism research and other autism-related activities. The CAA directed the IACC to coordinate HHS autism activities and monitor all federal autism activities. It also required the IACC to develop and annually update a strategic plan for autism research. This plan is organized into 7 research areas that contain specific objectives.

GAO was asked to examine federal autism efforts. In this report, GAO (1) analyzes the extent to which federal agencies fund potentially duplicative autism research, and (2) assesses the extent to which IACC and agencies coordinate and monitor federal autism activities. GAO analyzed agencies' data and documents, and interviewed federal agency officials and select nonfederal IACC members.

What GAO Recommends

GAO is recommending that (1) HHS improve the usefulness of IACC data to enhance coordination and monitoring of federal autism activities, and (2) DOD, Education, HHS, and NSF improve their coordination of autism research. HHS disagreed with the first recommendation stating that it was already making adequate efforts. The agencies supported the need for improved coordination but, except for DOD, disputed that any duplication occurs. GAO continues to believe the recommendations are warranted as discussed in the report.

View [GAO-14-16](#). For more information, contact Marcia Crosse at (202) 512-7114 or crossem@gao.gov.

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Better Data and More Coordination Needed to Help Avoid the Potential for Unnecessary Duplication

What GAO Found

Eighty-four percent of the autism research projects funded by federal agencies had the potential to be duplicative. Of the 1,206 autism research projects funded by federal agencies from fiscal years 2008 through 2012, 1,018 projects were potentially duplicative because the projects were categorized to the same objectives in the Interagency Autism Coordinating Committee's (IACC) strategic plan. Funding similar research on the same topic is sometimes appropriate—for example, for purposes of replicating or corroborating results—but in some instances, funding similar research may lead to unnecessary duplication. The potentially duplicative research projects included those funded by the Department of Defense (DOD), Department of Education (Education), National Science Foundation (NSF), and agencies within the Department of Health and Human Services (HHS)—Administration for Children and Families, Agency for Healthcare Research and Quality, Centers for Disease Control and Prevention (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. Each agency funded at least 1 autism research project in the same strategic plan objective as another agency. For example, 5 agencies awarded approximately \$15.2 million for 20 autism research projects related to 1 objective to test methods to improve dissemination, implementation, and sustainability of evidence-based interventions, services, and supports in diverse community settings.

The IACC's and federal agencies' efforts to coordinate and monitor federal autism activities were limited. The IACC—composed of federal and nonfederal members—met regularly and issued several reports, such as a strategic plan and portfolio analysis—a report that provides information on autism research projects, organized by the strategic plan objectives. The IACC has also released a companion database to its portfolio analysis. However, IACC members provided mixed views on the usefulness of the IACC's meetings, strategic plan, and portfolio analysis in aiding coordination and monitoring. While three agencies—CDC, DOD, and NIH—regularly used the committee's strategic plan and portfolio analysis, others did not. Shortcomings in the data the IACC used for its portfolio analysis limited its ability to coordinate HHS autism activities and monitor federal autism activities—as required by the Combating Autism Act of 2006 (CAA). For example, GAO found that the data used by the IACC was outdated, not tracked over time, inconsistent, and incomplete. These weaknesses limited the IACC's ability to monitor its progress on its coordination and monitoring efforts—which, in prior work, GAO established as a best practice for inter-agency collaboration, as well as a federal internal control standard. In addition, these weaknesses limited agencies' ability to use these data to identify coordination opportunities and avoid the potential for unnecessary duplication. Such information is important because of the involvement of multiple agencies. Lastly, apart from their participation on the IACC, there were limited instances of agencies coordinating, and agencies did not have robust or routine procedures for monitoring federal autism activities. Per federal internal control standards, agencies should establish a means of communicating with other agencies; this is important to maximize the efficiency of the federal autism investment and minimize the potential for unnecessary duplication.

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Abbreviations

| | |
|----------|---|
| ACF | Administration for Children and Families |
| ACL | Administration for Community Living |
| AHRQ | Agency for Healthcare Research and Quality |
| CAA | Combating Autism Act of 2006 |
| CDC | Centers for Disease Control and Prevention |
| CMS | Centers for Medicare & Medicaid Services |
| DOD | Department of Defense |
| EPA | Environmental Protection Agency |
| 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 |
| NSF | National Science Foundation |
| OARC | Office of Autism Research Coordination |
| RePORTER | Research Portfolio Online Reporting Tools Expenditures and Results |
| SAMHSA | Substance Abuse and Mental Health Services Administration |

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November 20, 2013

Congressional Requesters

Autism is an important public health concern, according to the Centers for Disease Control and Prevention (CDC)—an agency within the Department of Health and Human Services (HHS). CDC estimates suggest that the prevalence of autism is increasing, and that at least 1 in 88 children in the United States have been identified as having autism.¹ Autism is a complex developmental disorder that begins during early childhood, 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 disorder that can range from mild to more severe in their symptoms.²

¹CDC has recently reported 2 estimates of autism prevalence: 1 in 88 and 1 in 50 children in the United States have been identified as having autism. According to CDC, there are several differences between the 2 studies used to determine the estimates that can contribute to the differing results, such as the population covered, method of data collection, and time periods covered. CDC reported its estimate of 1 in 88 in March 2012, which was based on reviews of health and education records of children 8 years of age residing in 14 select population-based sites in the United States during calendar year 2008. The estimate of 1 in 50 was reported in March 2013 and was based on parent reports of a past diagnosis in a representative national sample of children 6 to 17 years of age in calendar years 2011 and 2012. CDC views the 2 data collection methods and estimates to be complementary. According to CDC, each provides unique supplemental information on the population of children with autism. Prior to these recent estimates, in 2009, CDC reported an estimated prevalence of 1 in 110 children in the United States, which was based on data from calendar year 2006.

²In this report, we use the term “autism” to refer to autism spectrum disorder as defined in the fourth edition of the *Diagnostic and Statistical Manual of Mental Disorders*, which was effective during the time period covered by our review. American Psychiatric Association, *Diagnostic and Statistical Manual of Mental Disorders*, 4th Edition, Text Revision (DSM-IV-TR) (Arlington, VA: American Psychiatric Association, 2000).

From fiscal year 2008 through fiscal year 2012, 12 federal agencies funded autism research and other autism-related activities.^{3,4} For example, agencies funded research to identify the causes of autism, as well as training for health care professionals on identifying and diagnosing autism. From fiscal year 2008 through fiscal year 2012, these agencies spent at least \$1.4 billion on autism research and other autism-related activities.

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 of that year.⁵ The CAA reauthorized the Interagency Autism Coordinating Committee (IACC), which is a federal advisory committee that was initially established under the Children’s Health Act of 2000.⁶ The CAA directs the IACC to coordinate all autism activities within HHS and to monitor federal activities related to autism. The IACC includes members representing 10 federal agencies—8 agencies within HHS, the Department of Defense (DOD), and the Department of Education (Education). In addition, there are 14 nonfederal members who represent individuals with autism and parents of children with autism; as well as members of the autism advocacy, research, and service-provider communities.⁷ The CAA also requires the IACC to develop and annually update a strategic plan for

³These agencies are the Department of Defense; Department of Education; Environmental Protection Agency; National Science Foundation; and eight agencies within HHS—Administration for Children and Families, Administration for Community Living, Agency for Healthcare Research and Quality, CDC, Centers for Medicare & Medicaid Services, Health Resources and Services Administration, National Institutes of Health, and Substance Abuse and Mental Health Services Administration.

⁴“Autism-related activities” include agency activities that are specific to autism as well as agency activities that are not autism-specific, but through which a project that was autism-specific or had an autism-specific component was funded.

⁵Pub. L. No. 109-416, 120 Stat. 2821 (Dec. 19, 2006). These activities were reauthorized and funding was authorized to be appropriated through fiscal year 2014 under the Combating Autism Reauthorization Act of 2011. Pub. L. No. 112-32, 125 Stat. 361 (Sept. 30, 2011). We previously reported on HHS agencies’ response to the CAA. See GAO, *Combating Autism Act: HHS Agencies Responded with New and Continuing Activities, Including Oversight*, [GAO-13-232](#) (Washington, D.C. Feb. 27, 2013).

⁶Pub. L. No. 106-310, § 104, 114 Stat. 1101, 1109 (Oct. 17, 2000).

⁷IACC membership as of November 2013.

autism research.⁸ The strategic plan is organized into 7 research areas that contain specific short- and long-term research objectives. The National Institutes of Health (NIH)—an agency within HHS—created the Office of Autism Research Coordination (OARC) to provide administrative support to the IACC. On behalf of the IACC, OARC periodically collects data from agencies on the autism research they fund and helps agencies categorize this research to the specific strategic plan objectives.

Having multiple agencies involved in autism research and other autism-related activities can be advantageous, as agencies may be able to tailor programs to suit their specific missions and needs. In some instances, funding similar research on the same topic is appropriate and necessary; for example, for purposes of replicating or corroborating prior research results. However, it is important that agencies monitor federal autism efforts and coordinate similar actions to maximize their effectiveness and efficiency and avoid the potential for unnecessary duplication. You asked us to provide information on the extent to which federal autism activities are duplicative and the extent to which federal autism activities are coordinated. In this report, we

1. analyze the extent to which federal agencies fund potentially duplicative autism research and other autism-related activities, and
2. assess the extent to which the IACC and agencies coordinate and monitor federal autism activities.

To analyze the extent to which federal agencies fund potentially duplicative autism research and other autism-related activities, we first identified the agencies funding such research and activities and collected data on the nature of the research or activities and the associated funding amounts. Specifically, we identified those federal agencies that funded autism research projects and autism-related activities from fiscal years 2008 to 2011 through interviews, review of related documentation, and database searches. We considered a federal agency to have funded autism research or an autism-related activity if the research project or activity was autism-specific or had an autism-specific component, and

⁸The CAA also requires the IACC to develop and annually update a summary of advances in autism research; and to make recommendations to the Secretary of Health and Human Services regarding any appropriate changes to federal autism activities, including recommendations with respect to the strategic plan on autism research and recommendations regarding public participation in decisions relating to autism.

was supported by federal funds awarded under mechanisms such as grants, cooperative agreements, or contracts; or was research conducted by scientists in government laboratories, known as intramural research.⁹ We compared the agency data we collected to information collected by OARC on behalf of the IACC. We also included any agencies and the related research projects they funded in fiscal year 2012, as identified in data that agencies submitted to OARC.¹⁰

Next, to determine potential duplication in autism research, we identified research projects that were categorized to the same strategic plan objectives. For those projects that were not categorized to a specific objective, but were categorized to one of the seven research areas, we assessed duplication based on whether they were categorized to the same research area. Determining that projects were categorized to the same strategic plan objective or research area suggests potential, but not actual duplication. Determining actual duplication for research projects would require a more extensive review of voluminous and scientific data, and was beyond the scope of this study.

Finally, we assessed whether there was actual duplication of non-research autism-related activities using the framework we established in our previous work. This framework considers duplication to have occurred when two or more agencies fund the same activities that target the same

⁹A cooperative agreement is an alternative assistance instrument used instead of a grant whenever substantial federal involvement with the recipient during performance is anticipated.

¹⁰We initially collected data directly from the individual federal agencies regarding the autism research and autism-related activities that were awarded funds from fiscal years 2008 to 2011. While our work was in progress, in January 2013, we learned that OARC, on behalf of the IACC, had started collecting data on research projects funded by federal agencies in fiscal years 2011 and 2012. We opted to include the fiscal year 2012 research projects that agencies reported to OARC. We relied on the agency data we collected on the non-research activities awarded between fiscal years 2008 and 2011. Also, DOD's fiscal year 2012 appropriation for its medical research programs, including autism, was available for obligation through the end of fiscal year 2013—September 30, 2013. At the time of our review, DOD had not submitted data on its fiscal year 2012 research projects in response to OARC's request. As a result, our report does not include data on DOD's fiscal year 2012 autism research.

users.¹¹ To determine if the activities and targeted users were the same, we reviewed each activity's purpose and strategy for achieving that purpose and reviewed the targeted population of the activities. We assessed the reliability of the data we obtained by comparing agency data to data collected by OARC, 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 reliable for our purposes. For more information on our scope and methodology for determining whether federal agencies fund potentially duplicative autism research and other autism-related activities, see appendix I.

To assess the extent to which the IACC and agencies coordinate and monitor federal autism activities, we reviewed IACC documents, including the strategic plan. We also interviewed OARC officials and officials from 10 federal agencies. Eight of these agencies were IACC members. The other 2 agencies were not IACC members, but funded autism-related research between fiscal years 2008 and 2012. We also interviewed select nonfederal IACC members.¹² Our review of documents and interviews allowed us to determine the methods used by the IACC to coordinate HHS activities and monitor federal autism activities. It also allowed us to determine how agencies coordinate and monitor federal autism activities apart from the IACC to prevent unnecessary duplication. We assessed the IACC's and agencies' coordination and monitoring activities against criteria established by our prior work, including key practices for interagency coordination and collaboration, and federal internal control standards related to communicating with external entities, including other

¹¹See for example, GAO, *2013 Annual Report: Actions Needed to Reduce Fragmentation, Overlap, and Duplication and Achieve Other Financial Benefits*, [GAO-13-279SP](#) (Washington, D.C.: Apr. 9, 2013) and GAO, *2012 Annual Report: Opportunities to Reduce Duplication, Overlap, and Fragmentation, Achieve Savings, and Enhance Revenue*, [GAO-12-342SP](#) (Washington, D.C.: Feb. 28, 2012).

¹²We interviewed eight federal members of the IACC. We did not interview officials from two agencies that are members of the IACC—the Administration for Children and Families (ACF) and the Food and Drug Administration. ACF awarded funds for one autism-related research project in fiscal year 2012. The Food and Drug Administration did not fund any autism research or autism-related activities during the time frame of our review. We also did not interview Substance Abuse and Mental Health Services Administration (SAMHSA) officials. SAMHSA is not a member of the IACC, but awarded funds for one autism-related research project in fiscal year 2011. We selected six nonfederal members to interview; however, in July 2013, one of the nonfederal members we interviewed stepped down from the IACC.

agencies, and measuring progress on organizational efforts, such as those established through strategic plans.¹³

We conducted this performance audit from December 2012 to November 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.

Background

Autism—a complex and pervasive developmental disability—begins during early childhood, although signs and symptoms vary.¹⁴ 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 be apparent 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 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 problems with showing or talking about their feelings and might also have trouble understanding the feelings of others.

¹³See, for example, GAO, *Managing for Results: Key Considerations for Implementing Interagency Collaborative Mechanisms*, [GAO-12-1022](#) (Washington, D.C.: Sept. 27, 2012); GAO, *Results-Oriented Government: Practices That Can Help Enhance and Sustain Collaboration among Federal Agencies*, [GAO-06-15](#) (Washington, D.C.: Oct. 21, 2005); and GAO, *Standards for Internal Control in the Federal Government*, [GAO/AIMD-00-21.3.1](#) (Washington, D.C.: November 1999).

¹⁴A 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 3 major life activities such as language, mobility, learning, self-help, and independent living. Developmental disabilities may include cerebral palsy, hearing loss, intellectual disability, and impaired vision.

Diagnosing autism can be difficult, as there is no medical diagnostic test available. 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 known cause of autism, but a variety of factors are suspected of causing or contributing to autism, including environmental, biological, and genetic factors. While there is no known cure, research shows that early intervention treatment services can greatly improve a child's 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.

To address growing concern about the increasing prevalence of autism and to stimulate research into possible autism causes and interventions, the CAA was enacted in December 2006. 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—and authorized the expansion of HHS's autism activities and funding for such activities through fiscal year 2011. The Combating Autism Reauthorization Act of 2011 reauthorized these activities and authorized funding through fiscal year 2014.

In 2008, NIH created OARC to provide administrative support to the IACC. OARC assists the IACC in fulfilling the IACC's responsibilities established by the CAA. Among other things, it conducts analyses and prepares reports for the IACC; assists with the IACC's strategic planning and monitoring of autism activities; coordinates cross-agency efforts; gathers public input to inform the work of the IACC; disseminates information about the work of the IACC and autism research activities to the public, Congress, and other government agencies; and provides logistical support for IACC meetings. In addition to assisting the IACC, OARC produced a report to Congress on federal autism activities on

behalf of the Secretary of Health and Human Services, as required by the CAA.¹⁵

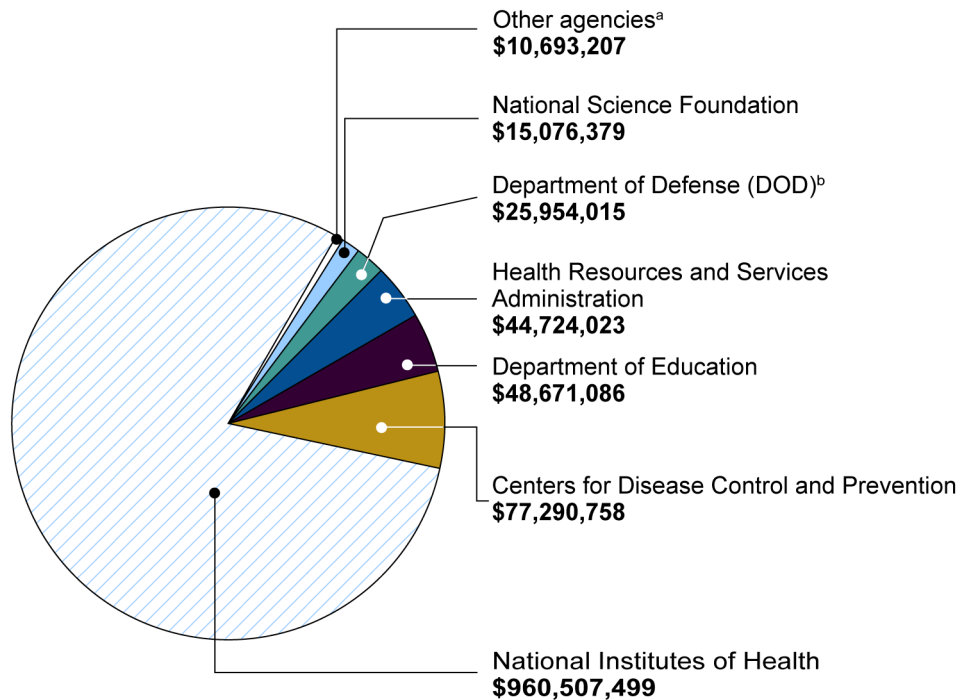
The 12 federal agencies that funded autism research and other autism-related activities between fiscal years 2008 and 2012 were DOD; Education; the Environmental Protection Agency (EPA); the National Science Foundation (NSF); and 8 agencies within HHS—Administration for Children and Families (ACF), Administration for Community Living (ACL), Agency for Healthcare Research and Quality (AHRQ), CDC, Centers for Medicare & Medicaid Services (CMS), Health Resources and Services Administration (HRSA), NIH, and Substance Abuse and Mental Health Services Administration (SAMHSA). With the exception of EPA, NSF, and SAMHSA, these agencies have representatives on the IACC.¹⁶ Eleven of these 12 agencies awarded approximately \$1.2 billion to fund autism research projects from fiscal years 2008 through 2012, as shown in figure 1.¹⁷ NIH was the biggest supporter of autism research, awarding approximately 81 percent of the funding from fiscal years 2008 through 2012.

¹⁵See 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). According to OARC officials, OARC will be preparing another report to Congress on autism activities as required by the reauthorization of the CAA. This report is expected to be submitted to Congress by the Secretary of Health and Human Services and then released to the public in the fall of 2013.

¹⁶AHRQ and DOD were not members of the IACC when the CAA was enacted in 2006, but have joined since the act's reauthorization in 2011. ACL was created in 2012. Prior to this, the component of ACL that funded an autism activity was part of ACF and a previous IACC member. SAMHSA was also a previous IACC member.

¹⁷ACL did not fund autism research from fiscal year 2008 through fiscal year 2012; ACL funded one non-research autism-related activity during this time period.

Figure 1: Federal Funds Awarded for Autism Research Projects, Fiscal Years 2008 through 2012



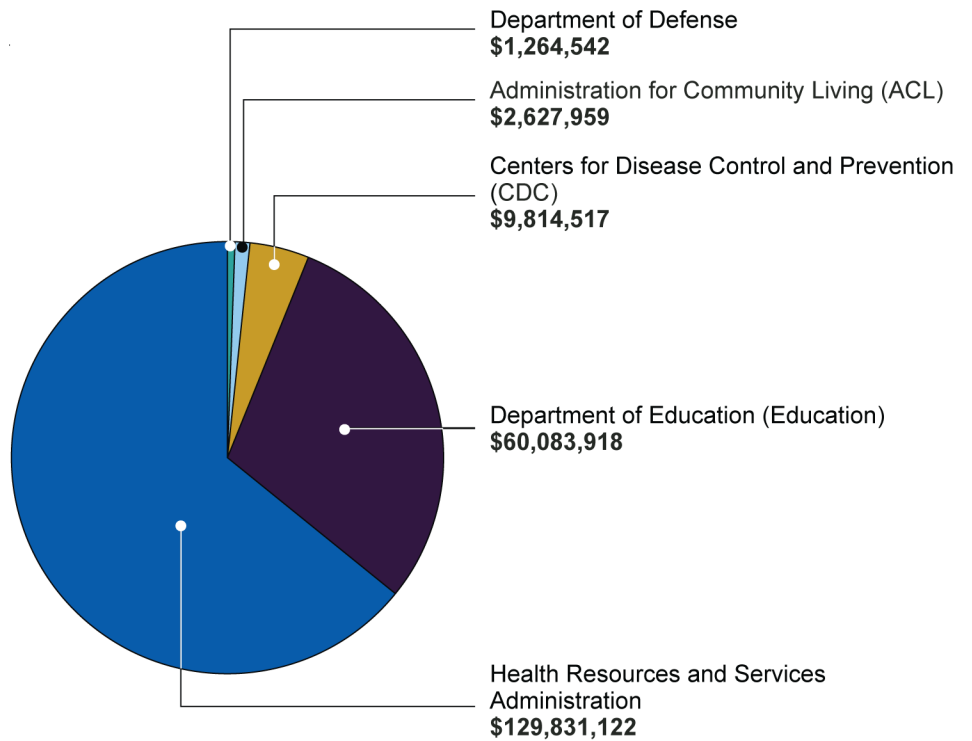
Source: GAO analysis of data from federal agencies that funded autism research.

^aOther agencies are Administration for Children and Families (1 project), Agency for Healthcare Research and Quality (5 projects), Centers for Medicare & Medicaid Services (4 projects), Environmental Protection Agency (1 project), and Substance Abuse and Mental Health Services (1 project).

^bDOD's fiscal year 2012 appropriation for its medical research programs, including autism, was available for obligation through the end of fiscal year 2013—September 30, 2013. At the time of our review, DOD had not submitted data on its fiscal year 2012 research projects in response to the Office of Autism Research Coordination's request. As a result, the funding amount for DOD does not include DOD's funding for fiscal year 2012 autism research.

In addition, of the 12 agencies, 5 awarded approximately \$204 million for non-research autism-related activities from fiscal years 2008 through 2011, as shown in figure 2.

Figure 2: Federal Funds Awarded for Non-Research Autism-Related Activities, Fiscal Years 2008 through 2011



Source: GAO analysis of data from federal agencies that funded autism-related non-research activities.

Notes: Most of Education's activities included projects that were not related to autism. The funding presented for Education represents the funding amounts that supported projects that were autism-specific or had a component to them that was autism-specific.

With the exception of CDC, funding in this figure is based on the amount awarded to fund projects under the agencies' activities from fiscal year 2008 through fiscal year 2011. CDC funded one non-research activity—an awareness campaign—from fiscal years 2008 through 2011 that was focused on autism and other developmental disabilities. The funding amount for CDC in this figure represents all funding for the activity, such as awards and activities conducted internally at the agency, with the exception of research—totaling approximately \$1.7 million.

After ACL was created in 2012, management of one autism-related activity was moved from Administration for Children and Families to ACL. Because ACL currently manages the activity, it is attributed to ACL in the figure.

Most of the autism research funded by the agencies is conducted by scientists at external research organizations—known as extramural research—and funded through mechanisms including grants, contracts, and cooperative agreements. To apply for research funding, an institution

submits an application on behalf of a principal investigator—the individual who is responsible and accountable for conducting the research—in response to an agency’s funding opportunity announcement.¹⁸ Some announcements are targeted to autism, while others are general funding opportunity announcements that may cover a number of topics, including autism, such as announcements soliciting biomedical research. Lastly, some agencies allow the submission of “unsolicited” or “investigator-initiated” applications.¹⁹ Agencies may also fund intramural research related to autism.

Since the passage of the CAA in 2006, the IACC has issued several reports as a means to coordinate HHS autism activities and monitor federal autism activities, some of which were specifically required by the act, such as the strategic plan.²⁰ The IACC published its first strategic plan in 2009. The most recent strategic plan was organized into seven questions that correspond to seven research areas. For example, the first question in the strategic plan—“When should I be concerned?”—corresponds to research related to the diagnosis of autism. Each research area contains specific short- and long-term research objectives.²¹ Over the years, more have been added, for a total of

¹⁸Principal investigators are typically individuals designated by the applicant organization, such as a university, to have the appropriate level of authority and responsibility to direct the project or program to be supported by the award. A funding opportunity announcement is a publicly available document in which a federal agency makes known its intentions to award discretionary grants or cooperative agreements, usually as a result of competition for funds. Funding opportunity announcements may be known as program announcements, requests for applications, notices of funding availability, solicitations, or other names depending on the agency and type of program. A request for proposal is a type of mechanism used to solicit proposals for a contract.

¹⁹NIH and other HHS agencies have developed omnibus parent announcements for use by investigators who wish to submit investigator-initiated research.

²⁰Another such required report is a summary of advances in autism research, which annually lists and summarizes the findings of autism research publications that the IACC deems to have significantly advanced the field.

²¹Six research areas have separate short- and long-term objectives. For one research area—infrastructure and surveillance—the IACC considers all objectives within that area to be both short- and long-term objectives.

78 objectives in the most recent plan.²² Figure 3 outlines the research areas and number of objectives.

Figure 3: Interagency Autism Coordinating Committee (IACC) Strategic Plan Research Areas, July 2012

| 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? |
| Topics covered Diagnostic and screening tests, early signs, biomarkers, symptomology, subgroups | Topics covered Neural systems, molecular pathways, developmental trajectory, cognitive studies, immune and metabolic pathways, neuropathology, biosignatures, computational studies, co-occurring conditions, sensory and motor functions | Topics covered Genetic risk factors, environmental risk factors, and the intersection of genetic and environmental risk factors, including epigenetics | Topics covered Pharmacological, behavioral, educational, complementary, dietary, occupational, sensory-based therapies, technology-based interventions and supports, model system to identify molecular targets | Topics covered Utilization and access, evidence-based practices, cost-effective service delivery, practitioner training, family well-being, safety, community inclusion | Topics covered Adult interventions, service needs, transition services, vocational rehabilitation, adult diagnosis | Topics covered Surveillance and prevalence, research infrastructure, data tools, biobanks, research subject recruitment, research workforce development |
| Total objectives: 9 Short-term: 6 Long-term: 3 | Total objectives: 9 Short-term: 7 Long-term: 2 | Total objectives: 15 Short-term: 11 Long-term: 4 | Total objectives: 12 Short-term: 8 Long-term: 4 | Total objectives: 9 Short-term: 4 Long-term: 5 | Total objectives: 8 Short-term: 4 Long-term: 4 | Total objectives: 16^a |

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.

Note: According to the IACC, the “topics covered” do not necessarily encompass all projects funded in each research area.

^aThe IACC considers the 16 objectives for the research area, infrastructure and surveillance, to be both short- and long-term objectives.

²²The 2009 strategic plan contained 6 questions and 40 objectives. The question—“What other infrastructure and surveillance needs must be met?”—as well as additional objectives were added to the 2010 strategic plan. During the IACC’s most recent update of the strategic plan—the 2012 update—the IACC did not review or change the number of objectives, but instead summarized the new advances and opportunities in the field under each of the 7 research areas. Therefore, the most recent plan that contains the research areas and objectives is the 2011 strategic plan.

The IACC also produces an annual Autism Spectrum Disorder Research Portfolio Analysis Report, which is organized by the seven research areas of the strategic plan. It includes information on research projects funded by federal and nonfederal entities related to autism, including budget information, for a single fiscal year.²³ The portfolio analysis also categorizes the research projects to the specific objectives in the strategic plan; and indicates if an objective has been fulfilled based on the funding of projects related to that objective in a given year.²⁴ In order to prepare the portfolio analysis, OARC collects data from federal and nonfederal entities on the autism-related research projects they funded in a certain fiscal year. OARC works with these entities to categorize each project according to the research areas and objectives in the strategic plan. See appendix II for a description of the reports produced by the IACC.

In July 2012, the IACC released a companion database to its portfolio analysis, referred to as the “IACC/OARC portfolio analysis web tool” (web tool).²⁵ The web tool contains information on the specific research projects included in the 2008, 2009, and 2010 portfolio analysis reports. For each project in a given fiscal year (i.e., 2008, 2009, or 2010), the web tool displays information, such as funding agency, principal investigator, funded amount, institution, project description, as well as the strategic plan research area and objective associated with the project. For example, users can sort projects by research area—such as diagnosis—and see all projects included in a particular year’s portfolio analysis related to that research area.

²³The first portfolio analysis—the 2008 portfolio analysis—which contains information on research funded in 2008, was published in April 2010. The 2009 portfolio analysis was published in June 2011. The most recent portfolio analysis—the 2010 portfolio analysis—was published in July 2012.

²⁴We consider reports and other information that are prepared by OARC, on behalf of the IACC, to be IACC information.

²⁵The web tool, accessed August 27, 2013, is available at <https://iacc.hhs.gov/apps/portfolio-analysis-web-tool/projects>.

The CAA requires the IACC to meet twice annually, and it has met, on average, five times a year since 2008.²⁶ These meetings often include presentations from experts about specific topics related to recent autism research and service activities, federal agency updates, as well as time to discuss general IACC business, such as how committee members want to move forward with specific tasks, including updating the strategic plan. The meetings also include time for public comments. The IACC subcommittees meet more frequently to further discuss activities and carry out related tasks.

For several years, we have reported on the need for the federal government to strive for greater efficiency and effectiveness by eliminating duplication.²⁷ This is particularly critical when multiple agencies are involved in the same programmatic or policy area, as is the case with autism research and other autism-related activities. Without effective monitoring and sharing of information among federal agencies about planned or funded autism research or other autism-related activities, agencies may use available funds inefficiently due to duplication of effort. Monitoring such research can be done by searching databases, such as Grants.gov and Clinicaltrials.gov, which contain information on federally funded grant programs and clinical research studies, respectively.²⁸ Also, some agencies have databases that contain information on the grants and activities they have funded, which are

²⁶For our analysis, we determined the average number of IACC full committee meetings from calendar years 2008 through 2012. In addition to these meetings, the IACC subcommittees have met, and the IACC has held town hall gatherings, scientific workshops, and planning workgroup meetings. There are two IACC subcommittees. The subcommittee for basic and translational research supports IACC activities related to biomedical and behavioral research, research collaborations and resources, and other related issues. The subcommittee for services research and policy supports IACC activities related to service research and service policy, including service provision, service research, access, housing, transition, social inclusion, health disparities, healthcare costs, the Patient Protection and Affordable Care Act, and safety issues.

²⁷See, for example, [GAO-13-279SP](#) and [GAO-12-342SP](#).

²⁸Grants.gov serves as the central grant identification and application portal for more than 1,000 federal grant programs that fund approximately \$500 billion in grants from 26 grant-making agencies for activities such as training, research, planning, construction; and the provision of services in areas such as health care, education, transportation, and homeland security. See <http://www.grants.gov>, accessed August 26, 2013. ClinicalTrials.gov is a resource for information about clinical research studies, also referred to as clinical trials. It includes information on federally funded and non-federally funded studies. See <http://www.clinicaltrials.gov>, accessed August 26, 2013.

available to the public. For example, NIH's Research Portfolio Online Reporting Tools Expenditures and Results (RePORTER) database includes information on the expenditures and results of NIH funded research, including autism research.

In addition, we have reported on the importance of coordination between federal agencies for many years. We have noted that strategic plans can be effective tools to drive agency collaboration and establish complementary goals and strategies for achieving results.²⁹ Such plans can reinforce accountability for the collaboration by aligning agency goals and strategies with those of the collaborative efforts. In our prior work we have also established that measuring and reporting progress on collaborative efforts—such as through the use of short- and long-term strategic objectives—is a best practice for interagency collaboration, as well as an important internal control standard for the federal government.³⁰

²⁹See, for example, [GAO-12-1022](#) and GAO, *Managing for Results: Critical Issues for Improving Federal Agencies' Strategic Plans*, [GAO/GGD-97-180](#) (Washington, D.C.: Sept. 16, 1997).

³⁰[GAO-06-15](#) and [GAO/AIMD-00-21.3.1](#).

The Majority of Federally-Funded Autism Research Was Potentially Duplicative, while Non-Research Activities Were Not

We found that most of the autism research projects had the potential to be duplicative. The non-research projects did not.

Most of the Autism Research Funded Was Potentially Duplicative

Of the 1,206 research projects funded by federal agencies from fiscal years 2008 through 2012, 84 percent—or 1,018 projects—had the potential to be duplicative.³¹ We found that each of the 11 agencies that funded autism research during this period funded at least 1 autism research project in the same strategic plan objective as another agency, creating the potential for duplication. Additionally, some objectives were funded by multiple agencies. For example, NIH—which funded the majority of autism research projects—funded projects in the same strategic plan objective as most of the other agencies. In many instances, 3 or more agencies funded research projects under the same objective. For example, 5 agencies—AHRQ, DOD, Education, HRSA, and NIH—awarded approximately \$15.2 million for 20 autism research projects related to 1 objective. This objective was to test methods to improve dissemination, implementation, and sustainability of evidence-based interventions, services, and supports in diverse community settings. Four

³¹We found that 84 percent of projects were potentially duplicative by identifying the number of projects that were categorized to the same strategic plan objective and funded by different agencies. For those projects that were not categorized to a specific objective, but were categorized to one of the 7 research areas, we identified the number of projects that were categorized to the same research area and funded by different agencies. We summed the projects identified and compared the results to the total number of research projects funded during the time period of our review. Our findings suggest the potential for, but not actual, duplication. We could not assess 31 projects for duplication. NIH categorized 6 of its research projects as not relating to any of the research areas. Additionally, 16 research projects were not included in IACC data. Furthermore, from fiscal years 2008 through 2011, CDC awarded funds for 9 research projects on autism and other developmental disabilities as part of its non-research autism-related activity, *Learn the Signs. Act Early*. CDC categorized the entire activity to the services research area; however, we did not categorize these 9 research projects to the same objective because it was unclear if the individual research projects under *Learn the Signs. Act Early*. would also be categorized to the services research area.

agencies—DOD, Education, HRSA, and NIH—awarded approximately \$4.1 million for eight autism research projects to develop at least two individualized community-based interventions to improve quality-of-life or health outcomes for the spectrum of adults with autism. See appendix III for the number of agency research projects and funding amounts for each strategic plan objective. In addition, many research projects, while not categorized to a specific strategic plan objective, were related to the same research area; and, therefore, may be potentially duplicative. For example, 3 agencies—DOD, NIH, and NSF—awarded approximately \$173.0 million for 264 projects in the biology research area, but these projects were not related to a specific objective.³²

In addition to identifying potential duplication among the federally-funded autism research projects, we obtained additional data from HRSA, AHRQ, and Education that allowed us to identify actual duplication in 4 of the research projects funded by these agencies.³³ HRSA and AHRQ both funded systematic reviews of scientific papers looking at examining effective interventions for children and adolescents with autism.³⁴ According to HRSA officials, 1 of the agency's grantees was charged with developing guidelines on effective autism interventions for children and adolescents. During this process, they examined 101 scientific papers. AHRQ officials contacted HRSA, and although HRSA's project was underway, AHRQ decided to fund 2 research projects: 1 project reviewing evidence from 183 papers on interventions for children, and 1 project reviewing evidence from 32 papers on interventions for adolescents and young adults. Thirty-one of these papers were reviewed by both HRSA's and AHRQ's grantees. Although HRSA's project led to the development of guidelines for interventions on behavioral health of children and

³²According to OARC officials, the strategic plan objectives represent gap areas that need additional attention or emphasis, and are not meant to cover all areas of autism research; therefore, research projects that are categorized to a research area, but not a specific objective, focus on research outside of the specific gap areas represented in the strategic plan.

³³During the course of our review, we learned that HRSA, AHRQ, and Education funded reviews of evidence regarding the effectiveness of autism interventions for children and adolescents. Using the framework established in our previous work on duplication, we obtained additional data from these agencies that allowed us to determine if there was duplication by comparing the projects' purposes, strategies, and target populations.

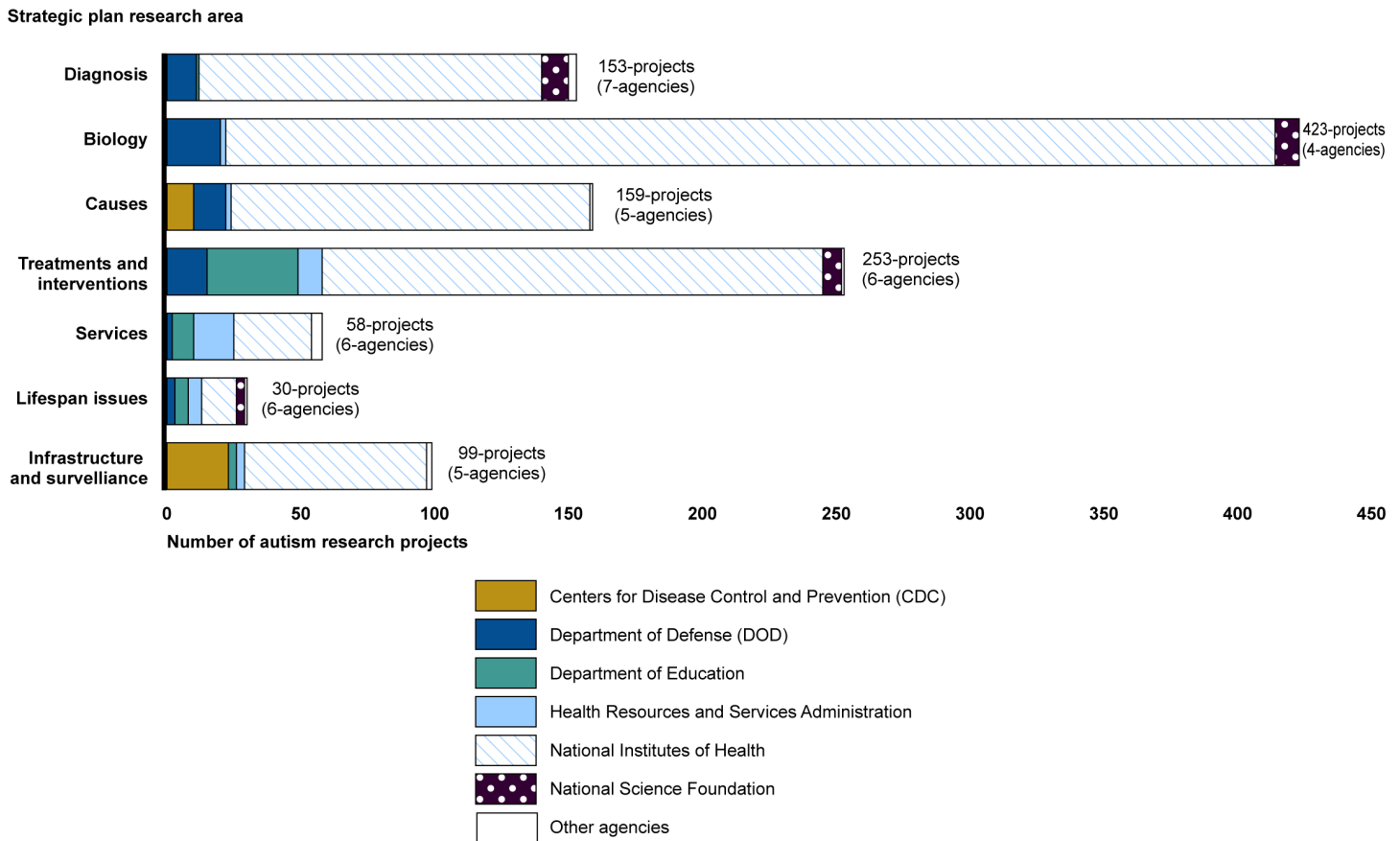
³⁴A systematic review is a critical assessment and evaluation of all research studies that address a particular clinical issue.

adolescents with autism while AHRQ's projects did not, the projects evaluated many of the same studies for the same population. In addition to the HRSA and AHRQ projects, Education funded a project examining an intervention model of applied behavior analysis for children with disabilities, including autism. The 2 studies included in Education's project were also included in 1 of the AHRQ projects.³⁵

Most agency officials we spoke with said that they consider the research funded by their agencies to be different than autism research funded by other agencies; however, we found that at least 4 agencies funded autism research in the same research area. The most commonly funded projects were in the area of biology (423 projects), followed by treatment and interventions (253 projects), and causes (159 projects). NIH funded a majority of the autism research projects in 5 of the 7 research areas. See figure 4 for the agencies that funded autism research projects by research area.

³⁵Education's project published a report of its findings in 2010, and the AHRQ project published its report in 2011.

Figure 4: Number of Federal Agencies' Autism Research Projects Funded, by Research Area, Fiscal Years 2008 through 2012



Source: GAO analysis of data from the Interagency Autism Coordinating Committee (IACC) and federal agencies that funded autism research.

Notes: From fiscal years 2008 through 2012, 6 autism projects were included in IACC data, but were categorized as “not specific to any research area,” and 16 projects were not included in IACC data and, therefore, not categorized to the research areas. Furthermore, from fiscal years 2008 through 2011, CDC awarded funds for 9 research projects on autism and other developmental disabilities as part of its non-research autism-related activity, *Learn the Signs. Act Early*. CDC categorized the entire activity to the services research area; however, these 9 research projects are not included in the figure because it was unclear if the individual research projects under *Learn the Signs. Act Early* would also be categorized to the services research area. DOD’s research projects include projects funded from DOD’s fiscal years 2008 through 2011 appropriations. DOD’s fiscal year 2012 appropriation for its medical research programs, including autism, was available for obligation through the end of fiscal year 2013—September 30, 2013. At the time of our review, DOD had not submitted data on its fiscal year 2012 research projects in response to the Office of Autism Research Coordination’s request. As a result, the number of autism research projects for DOD does not include DOD’s projects for fiscal year 2012.

The agencies included as “other agencies” in each research area are: Administration for Children and Families, Agency for Healthcare Research and Quality (AHRQ), and Substance Abuse and Mental Health Services Administration in diagnosis; Environmental Protection Agency in causes; AHRQ in treatments and interventions; AHRQ and Centers for Medicare & Medicaid Services (CMS) in services; AHRQ in lifespan issues; and CMS in infrastructure and surveillance.

Non-Research Autism-Related Activities Were Not Duplicative

The five agencies that funded non-research autism-related activities from fiscal years 2008 through 2011—ACL, CDC, DOD, Education, and HRSA—funded activities that were not duplicative.

HRSA and Education both funded training activities related to autism, but we determined that these activities were not duplicative. Among other things, HRSA's training activities 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 rule out an autism diagnosis. Education's training activities focus on the education setting; for example, to prepare personnel in special education, related services, early intervention, and regular education to work with children with disabilities, including autism.

Additionally, DOD and ACL both funded a publicly available website to provide information on services available to individuals with autism. However, we determined that these websites were not duplicative. DOD's website was developed for military families to provide them with information on the educational services that are close to specific military installations in select states. The ACL website is broader than the DOD website, focusing on individuals with autism and other developmental disabilities, their families, and other targeted key stakeholders concerned with autism.

We determined that CDC is the only agency funding an awareness campaign on autism and other developmental disabilities. CDC's *Learn the Signs. Act Early.* 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.³⁶ This activity also includes an initiative that works with state, territorial, and national partners to improve early childhood systems by enhancing collaborative efforts to improve screening and referral to early

³⁶Although CDC's *Learn the Signs. Act Early.* campaign is generally a non-research autism-related activity, one institution received funding from CDC through this campaign to conduct research on autism and other developmental disabilities. We included the funds awarded to this institution for research as research in our analysis.

intervention services; and to promote *Learn the Signs. Act Early.* messages and tools and improve early identification efforts in their state.

See appendix IV for a list of non-research autism-related activities, as well as the purpose, strategy, and target populations of those activities.

The IACC's and Federal Agencies' Efforts to Coordinate and Monitor Federal Autism Activities Were Limited

We found that the IACC members' views regarding the committee's efforts to coordinate HHS autism activities and monitor federal autism activities were mixed; and the IACC's efforts to coordinate HHS autism activities and monitor federal autism activities were limited by the data the IACC uses. Further, agencies' own efforts to coordinate and monitor autism activities were limited.

Members' Views on IACC Coordination and Monitoring Efforts were Mixed

Members of the IACC provided mixed views on the usefulness of the IACC's efforts to coordinate HHS autism activities and monitor federal autism activities through its meetings and select documents. Many of the IACC members we spoke with said the IACC meetings aided coordination and monitoring. Specifically, five of the eight federal members—ACL, CDC, CMS, HRSA, and NIH—as well as two of the six nonfederal members we spoke with, stated that the IACC meetings aided coordination and monitoring among HHS and other federal IACC members by providing an opportunity for agencies to learn about others' activities and investments. However, five federal IACC members—AHRQ, CMS, DOD, Education, and HRSA—and one nonfederal member also stated that the information shared during the meetings is typically at a high level and the structure of the meetings provides little opportunity to discuss detailed information. Therefore, it would be difficult to prevent duplication of autism activities through the meetings alone. Education and CMS officials commented that more information sharing would be helpful. A CMS official stated that it would be beneficial for federal agencies to discuss autism activities they are considering funding. However, an Education official stated that while this type of exchange would be beneficial, the official cautioned about the type of information that could be shared in a public setting, such as an IACC meeting. For example, the official stated that providing information to the public on the focus and requirements of a funding opportunity announcement before it is officially released could provide some parties with a competitive advantage and could violate federal regulations. HRSA officials stated that, while specific projects are not usually discussed at meetings, the high-level information

shared during meetings is useful; if they need more information they would contact the agency directly. For example, HRSA officials told us that, in one instance, officials from DOD contacted HRSA after hearing about HRSA's autism activities during an IACC meeting. In addition, following an IACC meeting, officials from NIH, CDC, and a nonfederal IACC member organization came together to fund a research project to investigate reports of elevated prevalence of autism among Somali American children in Minneapolis, Minn.

Officials from three agencies—CDC, DOD, and NIH—told us that they use the strategic plan and portfolio analysis—which are key documents used by the IACC to coordinate and monitor federal autism activities—when setting priorities for their autism programs and to learn of autism activities conducted by other agencies. For example, NIH officials stated that the specific objectives in the strategic plan allowed them to quickly develop announcements for new projects in fiscal years 2009 and 2010, for which the agency was appropriated additional funds under the American Recovery and Reinvestment Act of 2009. In addition, within DOD, the Office of Congressionally Directed Medical Research Programs' Autism Research Program Integration Panel—an advisory group that reviews autism research applications submitted to DOD—used information from the IACC's strategic plan and portfolio analysis, as well as other sources of information, when determining its autism research priorities.³⁷

In contrast, officials from three agencies that are members of the IACC, and two agencies that are not IACC members, but fund autism research,

³⁷The Autism Research Program Integration Panel is comprised of experts and leaders in the field, including doctors, scientists, and consumers. It recommends the office's autism research priorities and recommends projects to be funded annually.

told us that they do not regularly use these IACC documents.³⁸ Some of the agencies stated that the type of research they fund is different from the type of research identified in the strategic plan. For example, although we found that NSF has funded projects related to autism, officials from NSF—which is not a member of the IACC—said that the agency does not specifically solicit autism research, so they do not consider the strategic plan when selecting research proposals. Education officials also stated that the type of autism-related research the agency funds involves the development and testing of interventions to improve developmental and educational outcomes, which do not fit with the strategic plan objectives. However, we found that the strategic plan did include a research area focused on interventions, as well as one related to lifespan issues—two areas that could encompass the type of autism-related research funded by Education.³⁹ Education officials also stated that, because the agency provides broad guidance for research applications, much of Education’s research is investigator-initiated; therefore, the agency would not be able to direct much research toward the objectives in the strategic plan.

We also found that the IACC may have missed opportunities to coordinate federal autism activities and reduce duplication of effort and resources. Although the CAA requires the IACC to coordinate HHS autism activities and monitor federal autism activities, OARC officials told us that the prevention of duplication among individual projects in agency portfolios is not specified in the CAA as one of the IACC’s statutory responsibilities, and therefore, is not a focus of the IACC. OARC officials

³⁸We asked agency officials about the extent to which they used the strategic plan and portfolio analysis. The agencies that do not regularly use these documents are ACL, AHRQ, Education, EPA, and NSF. While AHRQ does not regularly use these documents, AHRQ officials stated that they consulted the IACC when developing their systematic reviews related to autism. Additionally, CMS officials stated that while they do not use the portfolio analysis, the autism research projects they funded resulted from strategic plan objectives, among other things, such as the general rise of autism and CMS’s own initiative and interest in providing information to the professionals who work with CMS. In addition, HRSA officials stated they used the strategic plan when first creating their autism activities and on an ongoing basis. Officials stated that they included language in their autism funding opportunity announcements about their interest in intervention research, underserved populations, and other broad areas noted as gaps in the strategic plan; however, HRSA officials made no mention of using the portfolio analysis.

³⁹In its comments on a draft of this report, Education stated that after holding a meeting with OARC officials in August 2013, it determined that its research related to interventions could be categorized to the strategic plan; subsequently, it has categorized those projects accordingly.

explained that it is up to individual federal agencies to use the information contained in the IACC's strategic plan and portfolio analysis and the related web tool to prevent duplication. OARC officials acknowledged that the IACC could choose to use the portfolio analysis to make recommendations for increased interagency coordination, but to date this has not occurred. In terms of the role of OARC, OARC officials said they do not review the data that they collect on behalf of the IACC for duplication or for coordination opportunities. Instead, they said that they fulfill their role in assisting the IACC in its cross-agency coordination activities in other ways, such as by facilitating interagency communication and gathering information.

Shortcomings in the IACC's Data Limited Its Ability to Coordinate and Monitor Federal Autism Activities

We found that the data the IACC used and reported in its portfolio analysis and related web tool had limitations that prevented the IACC from effectively monitoring and coordinating federal autism research and non-research activities. Specifically, we found that the data used by the IACC had the following limitations:

- *Outdated information.* The most recent portfolio analysis and web tool contained data from 2010, which was not useful in identifying gaps in current research as they relate to the strategic plan objectives. For example, CDC officials commented that a more up-to-date portfolio analysis would have been helpful when developing the 2012 strategic plan update, which was prepared in the summer and fall of 2012. Additionally, agencies could not use these data to determine whether a prospective autism-related research project was potentially duplicative of a new project funded since 2010.
- *Not tracked over time.* Information on the research projects relating to autism was reported for one year only and not for multiple years combined. The portfolio analysis and web tool included information on whether a certain objective in the strategic plan had been met for a particular year; however, information on the progress of the objectives over time had not been presented.⁴⁰ OARC officials stated that the goal of the portfolio analysis and web tool has not been to compare funding year to year.

⁴⁰The portfolio analysis and web tool indicate whether an objective has been fulfilled based on the funding of projects related to that objective in a given year and annualized funding goals for each objective set by the IACC.

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- *Inconsistent.* The guidance and methodology for determining what projects constitute research has changed over the years. As a result, the projects included in the portfolio analysis and web tool have varied. Specifically, the 2010 portfolio analysis included projects HRSA funded under its training activities—training health professionals on evidenced-based services for those with autism and other developmental disabilities, and how to confirm or rule out an autism diagnosis. According to OARC officials, these projects were not included in prior years because they were not aware that HRSA’s training projects could have possible relevance to the objectives in the strategic plan. Once OARC learned about these projects, OARC officials asked HRSA to include these projects in the portfolio analysis. Subsequently, in response to feedback from the IACC, OARC’s recent request to agencies for 2011 and 2012 funding data included guidance stating that agencies should not include projects that solely involve the training of professionals.⁴¹
 - *Incomplete.* We identified 16 autism research projects that were not included in the IACC data, such as a DOD Air Force study on autism gene sequencing and other topics, and autism research projects funded by Education and HRSA.⁴² For example, Education officials told us that the agency funded a study in 2008 to address challenges faced by geographically remote families in accessing effective intervention services for their young children diagnosed with autism; however, this project was not included in the IACC’s data.⁴³

Besides autism research projects, the portfolio analysis and strategic plan contain limited information on non-research autism-related activities, and the IACC did not have a mechanism to collect information on such activities. As part of its data collection for the portfolio analysis, the IACC sometimes obtained information from agencies on non-research autism-related activities that related to the strategic plan, which were

⁴¹The guidance states that project information should only be provided if a project relates to evaluating training for service providers. Projects that solely involved the administration of services were not to be provided.

⁴²The DOD Air Force study, *Comprehensive Clinical Phenotyping and Genetic Mapping for the Discovery of Autism Susceptibility Genes*, was conducted with the Research Institute at Nationwide Children’s Hospital in Ohio and awarded funds in 2008 and 2009.

⁴³The Education study, *Combining Technologies to Maximize Outcomes: Telemedicine and Online Training Program for Parents of Children with Autism*, was awarded funds in 2008.

subsequently included in the portfolio analysis. However, agencies, organizations, and individuals seeking information on non-research autism-related activities would likely not expect to find such information in the portfolio analysis and web tool because the titles and descriptions imply that they are focused on autism research.⁴⁴ According to many nonfederal IACC members, as well as some federal members, the IACC has not given enough attention to the coordination and monitoring of non-research autism-related activities. As a result, a complete accounting of federal non-research activities was lacking.

These data limitations hindered the IACC's efforts to coordinate HHS autism research and monitor the federal autism environment, as required by the CAA. We have previously reported that tracking and monitoring are key activities that can benefit interagency collaborative mechanisms, such as the IACC.⁴⁵ In addition, federal internal control standards state that organizations should monitor and assess their performance over time to help ensure that they meet their goals and objectives. Federal internal control standards also call for data that allows for comparisons and assessments on organizational progress.⁴⁶ However, the shortcomings in the IACC's data prevent accurate measurement of its effort to coordinate and monitor. For example, without assessing data over time, information on progress and gaps in autism research may be misleading and incomplete. We found that, when looking across multiple years, some agencies funded more autism research projects than were suggested in the associated strategic plan objective, whereas other objectives were not funded by an agency.⁴⁷ In addition, inconsistency in the data made it difficult to accurately determine how much an increase in the funding of autism research was due to an actual increase in research versus the inclusion of more projects in the analysis. For example, in its most recent portfolio analysis, the IACC stated that, while many funders participating

⁴⁴The most recent portfolio analysis is described as including information on autism research funded by major federal agencies. The portfolio analysis also includes information on autism research funded by certain nonfederal organizations.

⁴⁵In prior work, we established certain key features that benefit collaborative mechanisms (see [GAO-12-1022](#)).

⁴⁶[GAO/AIMD-00-21.3.1](#).

⁴⁷For example, while 1 objective recommended launching 3 projects related to underlying biological pathways of genetic conditions related to autism, 72 projects were funded from fiscal year 2008 through 2012.

in the previous analysis increased their investment levels, the increase in autism research funding, when compared to the prior year's report, was largely attributed to the inclusion of more projects and funders. Lastly, we believe that such shortcomings in the data limited agencies ability to use these data to identify opportunities for coordination of resources or projects, or identify duplicative research that could have been avoided, consolidated, or eliminated.

In fiscal year 2013, during the course of our review, the IACC took actions to reduce some of its data limitations. In January 2013, OARC, on behalf of the IACC, began collecting data on the autism research projects agencies funded in 2011 and 2012. OARC officials stated that they were collecting this data in order to have more recent information for the IACC to use when developing the 2013 strategic plan update. In addition, during its July 2013 committee meeting, the IACC discussed its intentions to update the strategic plan, including reviewing more recent agency data, as well as data over time. For the IACC's review, for example, OARC planned to prepare data on agencies' autism research projects funded from 2008 through 2012 for each research area and the objectives within those areas. When we asked whether this dataset would be made publicly available, OARC officials stated that the data would be published around the time the portfolio analysis is published, which OARC expects to be in the first quarter of calendar year 2014.⁴⁸ In September 2013, OARC began providing certain IACC members with draft templates for how some of these data could be presented. The committee planned to develop the 2013 update to the strategic plan in the fall of 2013 and expected to complete the report by December 31, 2013.

Federal Agencies' Coordination and Monitoring of Autism Activities was Limited

We found limited instances of coordination among the 10 agencies that we reviewed and found that all of these agencies lacked robust or routine procedures for monitoring federal autism activities. Two agencies, CDC and HRSA, coordinated their autism activities by holding regular meetings to, for example, share information on project updates and explore potential opportunities for collaboration. These agencies coordinated their

⁴⁸According to OARC officials, the web tool will also be released in the first quarter of calendar year 2014. At the time of our review, OARC officials were not certain whether the portfolio analysis would include 2011 and 2012 data combined or separated; however, they stated that the web tool would report the data separately, similar to the presentation of prior years' data.

autism activities in a manner that was consistent with key collaboration practices to enhance and sustain coordination that we have identified in prior work.⁴⁹ These key practices include agreeing on roles and responsibilities and establishing a means to operate across organizational boundaries. For example, officials from CDC and HRSA worked together with HRSA grantees to promote and evaluate CDC's awareness campaign for autism and other developmental disabilities. CDC officials said that they and HRSA officials have a good understanding of each other's roles and autism activities.

A few agencies co-managed individual autism research projects and held joint meetings with their grantees.⁵⁰ For example, EPA and NIH jointly funded research studying environmental exposures in relation to children's health and autism. Similarly, CDC and NIH jointly funded a research project to investigate reports of elevated prevalence of autism among Somali-American children in Minneapolis. According to CDC officials, the joint effort allowed CDC to provide scientific oversight and technical assistance to the grantee, which used CDC's surveillance methods, while NIH provided scientific consultation. The two agencies, along with a nonfederal organization, held regular meetings with their grantee.

A few agencies also had officials that served on other agencies' advisory committees related to autism research or other autism-related activities. For example, DOD's Autism Research Program Integration Panel included a representative from NIH in fiscal years 2008 and 2009, and recently included a representative from CDC who had been on the panel since fiscal year 2011. In addition, a CDC official served on an advisory council related to research HRSA funded on autism interventions for physical health; and a HRSA official served as a liaison on an advisory board for a non-research autism-related activity funded by Education.

Agencies also provided examples of informal communications they had with other agencies. For example, although there were no regularly scheduled formal meetings with NIH, officials from CDC and HRSA stated

⁴⁹[GAO-06-15](#).

⁵⁰We found some other instances where an agency funded another agency to conduct research or other activities through an interagency agreement or memorandum of understanding; however, the projects were not co-managed.

that their staff have ongoing informal communication with NIH staff and may involve them in grant reviews, workshops, and meetings. CDC and HRSA may also preview NIH funding opportunity announcements. NIH officials told us that, when NIH is considering funding research similar to that of another agency, NIH staff discuss their plans with that agency to pre-empt unnecessarily duplicative research; NIH officials provided one example of a recent instance when they contacted another agency in this regard. However, NIH officials also stated that because many of the agency's research project applications, including those related to autism research, are investigator-initiated, coordination with other agencies during program development is not always possible.

Nevertheless, we noted that agencies did not have robust and routine monitoring procedures or methods to ensure that duplication is minimized. As established in our recent duplication work, it is important for agencies that fund research on topics of common interest, such as autism, to monitor each others' activities in order to reduce the potential for unnecessary duplication.⁵¹ It is also a federal internal control standard that agencies establish a means of communicating with, and obtaining information from, other agencies that could impact their operations, performance, and resource allocations.⁵² Of the 10 agencies we spoke with, 5 agencies stated that they monitored federal autism activities by searching databases or websites, but those searches were limited and some agencies did not have formal policies or procedures that staff must follow. For example, DOD and NIH conducted searches to ensure that the principal investigator was not receiving funding from another agency for the same project.⁵³ AHRQ also may conduct a similar search related to the principal investigator. However, these limited searches would not identify whether these agencies were funding similar projects led by

⁵¹See for example, [GAO-13-279SP](#) and [GAO-12-342SP](#).

⁵²See federal internal control standard for information and communications. [GAO/AIMD-00-21.3.1](#).

⁵³In addition, NIH officials stated that, before awarding funding, NIH program and grants management staff are to ensure that there is no budgetary, scientific, or commitment overlap by reviewing documentation of "other support" identified by the applicant (which includes all financial resources, whether federal, nonfederal, commercial or organizational, available in direct support of an individual's research endeavors, including, but not limited to, research grants, cooperative agreements, contracts, or organizational awards, but not training awards, prizes, or gifts). Officials from AHRQ, DOD, Education, and NSF also told us they rely on similar disclosure from applicants.

different principal investigators. The 5 agencies told us they conducted the following searches:

- AHRQ officials told us that, before funding a systematic review, they reviewed a number of databases, such as RePORTER and www.clinicaltrials.gov, a database that contains information on federally funded as well as non-federally funded studies. AHRQ officials said that they search the databases to determine if a similar systematic review has been conducted or if a major clinical trial is underway. In the latter instance, AHRQ may wait to fund a systematic review until the clinical trial is complete so it can be included in its review. AHRQ officials told us that for those projects that are not systematic reviews, they searched databases using the principal investigator's last name and the term "autism."
- CDC officials stated that they informally review Grants.gov, the central grant identification and application portal for federal grant programs, when developing a new program announcement.
- DOD officials told us that, before funding a project, they search the NIH database RePORTER—which includes projects funded by NIH—using the principal investigator's name and other terms. DOD officials also stated that they review NIH's institutes' websites as a source of information when determining their autism research priorities.
- HRSA officials said that they check RePORTER for similar autism projects on a quarterly basis using the search terms "autism" and "ASD;" however, the agency does not have written policies for the search. HRSA officials told us that they do not search other agencies' websites or databases on a regular basis.
- NIH officials told us that they search their own databases, including a database that contains information about research funded by NIH, AHRQ, CDC, and other agencies.

Several agency officials also told us that they rely on their peer reviewers, other experts, and project officers to have knowledge of the current autism research environment. For example, officials at AHRQ, DOD, Education, and NIH stated that they consider the opinions of peer reviewers, who are typically scientists or professors who review proposals for scientific merit, to determine whether applications may be duplicative of other research. DOD officials also told us that they rely on their Autism Research Program Integration Panel to be knowledgeable of research funded by other agencies. NIH officials stated that project officers have an in-depth understanding of the scientific subject matter related to their

grant portfolios.⁵⁴ According to NIH officials, their project officers keep abreast of the scientific literature, attend professional and scientific meetings, and interact with the principal investigator and other scientific staff at the grantee institution.

Apart from their participation on the IACC, some agencies did not provide examples of actions they had taken to coordinate with or monitor other agencies' autism activities. For example, when we asked about the mechanisms used to coordinate and monitor autism activities, CMS stated that it interacted with other federal agencies through its IACC participation. Officials also stated that it is not common for CMS to fund autism research projects. In addition, although HRSA told us that one of their staff participated on an advisory committee for one Education non-research autism-related activity, Education officials did not provide examples of coordination efforts; Education is a member of the IACC. NSF, which is not an IACC member, does not coordinate or monitor its autism activities with other agencies to prevent unnecessary duplication. NSF officials stated that while they may fund research related to autism, they generally do not solicit autism research.

Given that each agency we reviewed funded at least one autism research project in the same strategic plan objective as another agency from fiscal years 2008 through 2012, and some objectives were funded by multiple agencies, current coordination and monitoring efforts may be insufficient. For example, while DOD officials told us that they review NIH websites when determining their autism research priorities, we found that DOD funded autism research projects related to most of the same strategic plan objectives as NIH, which could potentially result in unnecessarily duplicative research.⁵⁵ In addition, NSF—an agency that did not coordinate with other agencies regarding autism research—funded

⁵⁴Project officers are agency officials that are responsible for managing and overseeing grants.

⁵⁵Our prior work identified limitations in the ability of DOD and NIH to readily access comprehensive medical research information funded by other agencies. See [GAO-12-342SP](#). DOD officials stated that DOD and NIH are working together to address these concerns. Specifically, NIH has provided a DOD official with access to an NIH database that contains information about certain funded health research projects. According to DOD officials, they intend to begin expanding this effort to all programs funded by DOD's Office of Congressionally Directed Medical Research Programs in the beginning of calendar year 2014, but could not provide specifics on when it would be expanded to autism research.

research projects that related to the same objectives as projects funded by both NIH and DOD.

Conclusions

Funding similar research on the same topic area—such as autism—is sometimes appropriate and necessary; for example, for purposes of replicating or corroborating prior research results. In addition, having multiple agencies with different expertise involved in autism activities—both research and other related activities—can be advantageous. One such advantage is that agencies may be better able to tailor research or other programs to suit their specific missions and needs. However, having multiple agency involvement can also make it challenging to identify gaps and allocate resources across the federal government efficiently. Given that 12 federal agencies spent at least \$1.4 billion on autism research and other autism-related activities from fiscal years 2008 through 2012, and that multiple agencies have funded autism research related to the same objectives, it is incumbent on the agencies to effectively coordinate and monitor each other's autism research. Not doing so could lead to numerous projects being funded to address a few specific areas within the realm of autism research—some of the projects having the potential to be unnecessarily duplicative—while other areas may be left unexplored.

Interagency committees—such as the IACC—can aid agencies' efforts to coordinate and monitor. The IACC's charge to coordinate autism activities of HHS and to monitor federal autism activities provides the IACC with the opportunity to play an important role in maximizing the effectiveness and efficiency of the federal investment in autism activities, and in minimizing the inefficient use of federal resources due to unnecessary duplication of effort. However, the weaknesses in the IACC's data limits agencies' abilities to identify the autism research that has been recently funded, any gaps in or potential opportunities for funding, possible opportunities for efficiencies, or possible duplication. In addition, the focus of the strategic plan and portfolio analysis on autism research and limited focus on non-research activities restricts the ability of the IACC to monitor non-research autism-related activities funded by the federal government, and may affect agencies' abilities to identify duplicative efforts related to these activities.

Apart from the IACC, there are limited instances of agencies independently coordinating their own autism activities. Agencies lack robust and routine procedures for monitoring the projects that other agencies are funding. Such monitoring would help avoid unnecessary

duplication of autism research. It may also help identify potential opportunities for further coordination, since agencies can only coordinate with each other when they are aware of relevant research or other activities. Ultimately, agency coordination and monitoring would help ensure that scarce federal resources are used as efficiently as possible.

Recommendations

To improve the usefulness of IACC data and enhance its efforts to coordinate HHS autism activities and monitor all federally funded autism activities, we recommend that the Secretary of Health and Human Services direct the IACC and NIH, in support of the IACC, to take the following three actions:

- provide consistent guidance to federal agencies when collecting data for the portfolio analysis and web tool so that information can be more easily and accurately compared over multiple years;
- create a document or database that provides information on non-research autism-related activities funded by the federal government and make this document or database publicly available; and
- identify projects through its monitoring of federal autism activities—including OARC’s annual collection of data for the portfolio analysis and the IACC’s annual process to update the strategic plan—that may result in unnecessary duplication and thus may be candidates for consolidation or elimination, and identify potential coordination opportunities among agencies.

To promote better coordination among federal agencies that fund autism research and avoid the potential for unnecessary duplication before research projects are funded, we recommend that the Secretary of Health and Human Services, the Secretary of Defense, the Secretary of Education, and the Director of NSF each determine methods for identifying and monitoring the autism research conducted by other agencies, including by taking full advantage of monitoring data the IACC develops and makes available.

Agency Comments and Our Evaluation

We provided a draft of this report to DOD, Education, HHS, and NSF for comment, which are reprinted in appendixes V through VIII, respectively. Our first recommendation was directed to HHS exclusively. HHS did not concur with this recommendation. Our second recommendation was directed toward all four agencies. DOD agreed with this recommendation. Although the other three agencies did not explicitly state agreement with

the recommendation, their comments suggested that they view the opportunity to enhance the coordination of federal autism research activities positively. These three agencies also expressed concern about certain of the report's conclusions as described in detail below. In addition to general comments, Education and HHS also provided technical comments, which we incorporated as appropriate.

HHS did not concur with our first recommendation that the agency take three specific actions to improve the usefulness of the IACC data. First, HHS did not concur that the IACC and NIH should take action to provide consistent guidance to federal agencies when collecting data for the portfolio analysis. HHS commented that OARC has used a consistent methodology and provided consistent guidance to agencies when collecting data for the portfolio analysis on behalf of the IACC. It also emphasized that it has balanced the need for consistency with the need to be responsive to feedback from the IACC and from those participating in the portfolio analysis. While we agree with HHS that it is important to be responsive to feedback and make adjustments to guidance as necessary to improve data collection, we believe that annual changes of the type we observed are not productive. The exclusion of training projects in one year of data collection, their inclusion in the subsequent year, and their partial exclusion in the next year is a change in methodology and guidance that makes it difficult to analyze and interpret data over time. Additionally, OARC did not provide consistent guidance to organizations—both federal and nonfederal—that submit information for inclusion in the portfolio analysis. For example, in the year that OARC requested HRSA to include its training projects in the portfolio analysis, it did not make the same request of other organizations and its guidance did not mention that these specific types of projects should be included in the data submitted to OARC. We therefore continue to believe that guidance should be developed so that accurate, consistent, and meaningful comparisons of changes in federal funding of autism research can be made over time and used to inform future funding decisions.

Second, HHS did not concur that the IACC and NIH should take action to create a document or database that provides information on non-research autism-related activities. HHS commented that this information was already publicly accessible and cited a report to Congress published by

OARC in December 2010.⁵⁶ While this report contained information on federally funded autism activities from fiscal years 2006 through 2009, it did not include all of the non-research autism-related activities we identified in our report. In addition, while helpful, the report is nonetheless a static document. There is no single repository for information on non-research autism-related activities funded by the federal government since 2009—a shortcoming that has prevented effective monitoring of these activities since that year. HHS also commented that, as required by the reauthorization of the CAA, it would be providing a report to Congress to be released to the public in the fall of 2013. HHS stated that this report would include information on research, services, and other non-research autism activities that were supported by federal agencies from fiscal years 2010 through 2012. While this document could be a starting point from which the IACC could begin to regularly catalog non-research autism-related activities, we believe that having a document or database that contains current information on these activities is an important aspect of fulfilling the IACC's responsibility to monitor all federal autism activities, not just research.

Third, HHS did not concur that, through its monitoring activities, the IACC and HHS should take action to identify projects that may result in unnecessary duplication and thus may be candidates for consolidation or elimination. However, HHS said that it will continue to support the IACC in its activities to coordinate HHS efforts and identify opportunities for cross-agency coordination. HHS stated that an analysis by the IACC to identify duplication would not likely provide the type of information on actual duplication needed by agency officials when making funding decisions. HHS said that even if the IACC further refined its analysis to identify several grants on the same general topic within each research objective as potentially duplicative, this type of information would lack adequate specificity to be useful to agency officials who are involved in the grant award process. We agree that the specific projects identified in the analysis proposed by HHS would need to be reviewed further to identify actual duplication—defined as projects with the same purpose, strategies, and target population that are not necessary to, for example, corroborate or replicate prior research results. However, we believe that the IACC's identification of such projects would be worthwhile as it could effectively

⁵⁶See 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).

lead to their further review by the funding agencies. In addition, HHS commented that it does not believe there is too much federal activity related to autism and that the IACC role should not include identification of autism-related projects for elimination. It should be noted that our report does not state—and should not be interpreted as suggesting—that there is too much federal activity related to autism. We recognize that autism is an important public health concern affecting a large number of people. However, this makes it all the more important that scarce federal resources be used wisely. Prudent stewardship requires a careful assessment of research spending. Many agencies currently devote considerable time to identifying and providing HHS with spending information and HHS invests in this data collection. However, we question the purpose of devoting federal resources to collecting these data, if they are not then used to ensure federal funds are used appropriately. The IACC data can be used to drill down to help identify unnecessary duplication and opportunities to enhance coordination. A thorough review of autism data is particularly important to ensure federal funds are used efficiently and effectively. While, we agree that the IACC does not have the authority to eliminate duplicative projects, it does have the responsibility to make recommendations to the Secretary of Health and Human Services. If unnecessary duplication or opportunities to enhance coordination between HHS agencies were identified, the IACC could make related recommendations that would carry important weight.

DOD concurred with our second recommendation to improve coordination among federal agencies, and comments from Education, HHS, and NSF suggest that these agencies support improving the coordination of federal autism research activities. DOD, Education, and NSF commented that they intend to work with the IACC and other agencies to share information related to autism research. HHS agreed that there should be continued coordination to avoid unnecessary duplication across research projects.

However, with the exception of DOD, the agencies included comments suggesting that they were concerned with the report's conclusion that some federal autism research projects had the potential to be duplicative. Specifically, the agencies stated the following:

- Education did not concur with the conclusions that the majority of federally-funded autism research projects had the potential to be duplicative. The agency stated that, because the IACC's strategic plan objectives are broad, projects categorized under the same objective cannot be fairly judged as potentially duplicative without more substantial exposition.

-
- HHS stated that research funded under the same objective does not necessarily indicate duplication, as the objectives represent broad and complex areas of research.
 - NSF stated that the categorization of its projects to, for example, the research area of biology, does not indicate that these projects are duplicative of other agencies' projects about the biology of autism.

We stated in our draft report that our methodology of using the categorization of projects to the same strategic plan objective or research area does not indicate actual duplication; however, we added language to the final report to make this point clearer. We agree that more information on the specific projects funded within each objective would need to be assessed in order to determine actual duplication. However, the fact that research is categorized to the same objectives suggests that there may be duplicative projects being funded. Education, HHS, and NSF did not provide any information throughout the course of our work or in their comments indicating that they had reviewed these projects to ensure that they were not unnecessarily duplicative.

In addition, two agencies—HHS and NSF—included comments suggesting that they were concerned about the report's conclusion that the coordination and monitoring of federal autism activities were limited. Specifically,

- HHS did not concur with the conclusion that federal agencies' coordination and monitoring of autism activities was limited. HHS commented that it has extensive policies in place to prevent duplicative projects and that it would continue its procedures for avoiding duplication. HHS stated that an NIH research project applicant is required to indicate the other agencies to which the application has been submitted. In addition, the applicant is required to indicate the financial support received for the project. According to HHS, it is the responsibility of NIH staff to review this information to ensure that NIH is not funding the applicant for the same research project funded by another agency. HHS also cited an NIH database that is used extensively by NIH staff to obtain and manage information related to research project funding decisions.
- NSF also commented on activities it undertakes to avoid duplication and stated that it takes steps to ensure that it does not fund the same research project by the same applicant if it is already supported by another agency.

The procedures described by both agencies were outlined in our draft report. While important, they are not sufficiently comprehensive and are limited in that they only look to identify duplicative projects led by the same principle investigator. They do not identify project applications led by another principle investigator that may be unnecessarily duplicative of a project that has already been federally funded—a project with the same purpose, strategies, and target population that is not necessary to, for example, corroborate or replicate prior research results. For example, while the NIH database cited in HHS's comments could be a helpful coordination tool, our report points out that NIH's database search was limited in that its purpose was to ensure that a principal investigator was not receiving funding from another agency for the same project. The search would not identify similar projects led by different principal investigators. Therefore, we stand by our conclusion that these agencies' methods to monitor and coordinate autism activities are limited.

HHS also commented that our draft report implied that it is wasteful for more than one federal agency to address a strategic plan objective. HHS said that the strategic plan objectives describe the minimum effort that would be required to address the complex issues set in each objective. Our report does not state this, nor do we believe that having more than one project per objective is inappropriate. Our report acknowledges that funding similar research on the same topic is sometimes appropriate and necessary. We agree that it may be beneficial to have multiple projects and agencies associated with the same strategic plan objective; however, we contend that it is important to carefully review the data to ensure that projects are indeed essential to achieve research goals and not unnecessarily duplicative. Using the data collected by HHS and analyzing it over time, provides an important opportunity for the IACC to determine whether its coordination efforts are successful. Doing so can provide important information on both progress and gaps in autism research, and identify areas of potential duplication to investigate further. For example, as we noted in our draft report, we found that 1 objective—which recommended testing 4 methods to improve dissemination, implementation, and sustainability of evidenced-based interventions, services, and supports in diverse community settings—had 20 projects associated with it that were funded by 5 different agencies from fiscal years 2008 through 2012. We believe it is important that these projects be reviewed further. While all of these projects are perhaps necessary to achieve research goals and are not duplicative, without conducting a thorough review of the data, it is not clear that this is, indeed, the case.

Finally, HHS stated that our draft report was incorrect in stating that we had identified 16 projects that were omitted from the IACC's data. HHS said that the number we reported should have been 14. We disagree. We provided OARC with a list of 18 projects that we initially identified as missing from the IACC's data. OARC provided us with additional information for 2 of these projects. As a result, there were 16 projects—with total award funding of approximately \$74 million—that we identified that were not included in the IACC's data. Further, HHS explained that the projects that were not included in the IACC data were either projects that the agencies funded before the agencies had been included in the portfolio analysis, or projects that agencies did not submit to OARC during data collection for the portfolio analysis. We understand that, to a certain extent, OARC must rely on federal agencies to disclose the autism research projects they fund. However, 7 of these 16 projects—which were awarded funds totaling approximately \$69 million—were NIH-funded projects, the agency in which OARC resides.

We are sending copies of this report to the Secretary Health and Human Services, the Secretary of the Department of Defense, the Secretary of the Department of Education, the Director of the National Science Foundation, and to other interested parties. The report will also be 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. Contact points for our Office of Congressional Relations and Public Affairs may be found on the last page of this report. GAO staff who made major contributions to this report are listed in appendix IX.



Marcia Crosse
Director, Health Care

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: Methodology for Analyzing Potential Duplication of Federally Funded Autism Research and Other Activities

Identifying Autism Research Projects and Other Autism-Related Activities

First, we identified federal agencies that funded autism research and other autism-related activities from fiscal years 2008 through 2011 by interviewing the federal agencies on the Interagency Autism Coordinating Committee (IACC) and select nonfederal IACC members; reviewing IACC and agency documentation describing federal autism activities; and searching Grants.gov and the Catalog of Federal Domestic Assistance.¹ We also included any agencies and the related research projects they awarded in fiscal year 2012, as identified in data that agencies submitted to the IACC.

We considered a federal agency to have funded autism research or an autism-related activity if the research project or activity was autism-specific or had an autism-specific component and was supported by federal funds awarded through mechanisms such as grants, cooperative agreements, or contracts, or was research conducted by scientists in government laboratories, known as intramural research.² We excluded activities that provided a direct benefit to individuals with autism, such as insurance coverage to specific populations; housing assistance; and supplemental income. We also excluded funding provided to states to offer direct services to individuals with autism or their families, such as educational services. Additionally, we excluded federally funded workshops and meetings from our review. Furthermore, with the exception of intramural research, we excluded activities that the agencies undertook directly. These included, for example, the inclusion of information on an agency website or fact sheets. Finally, we excluded research projects and non-research autism-related activities funded by nonfederal organizations. Based on our analysis, 12 agencies funded autism research and other autism-related activities between fiscal years 2008 and 2012 that met our criteria.

¹We interviewed federal members of the IACC, with the exception of Administration for Children and Families (ACF) and the Food and Drug Administration. ACF awarded funds for one autism-related project in fiscal year 2012. The Food and Drug Administration did not fund any autism-related projects during the time frame of our review. We selected six nonfederal members to interview; however, in July 2013, one of the nonfederal members we interviewed stepped down from the IACC.

²A cooperative agreement is an alternative assistance instrument used instead of a grant whenever substantial federal involvement with the recipient during performance is anticipated.

We collected and reviewed the project information from each agency, such as research project numbers, award amounts, and project titles, where applicable, for fiscal years 2008 through 2011.^{3,4} We compared the agencies' research projects to the projects in the IACC's Autism Spectrum Disorder Portfolio Analysis Report and web tool data for fiscal years 2008, 2009, and 2010—the most recent portfolio analyses available at the time of our review—and reconciled any differences with the agencies.⁵ In January 2013, while our work was in progress, we learned that the Office of Autism Research Coordination (OARC), on behalf of the IACC, requested fiscal years 2011 and 2012 autism research project data from the agencies for its forthcoming portfolio analysis and web tool,

³When collecting and analyzing data, we included a research project or a non-research autism-related activity in the fiscal year in which it was awarded funds—even if funds remained available for obligation in future fiscal years—or, as is the case with the Department of Defense, the fiscal year of the appropriation from which the project or activity was awarded funds. For example, if a research project was ongoing in another fiscal year, but did not receive an award in that year, we included the project in the fiscal year in which it received an award only. The Agency for Healthcare Research and Quality (AHRQ) and Centers for Medicare & Medicaid Services (CMS) each awarded one contract under which multiple autism-related projects were conducted. The Department of Education (Education) and Substance Abuse and Mental Health Services Administration (SAMHSA) also awarded contracts of which an autism project was one component. Funding is not broken out in these contracts by research project; therefore, the award amounts that we report for the AHRQ, CMS, Education, and SAMHSA autism projects under each contract are the agencies' estimates of the amount of the overall contract awards that was intended to support these projects or activities.

⁴We counted a project once if the project had the same project number unless the title changed. If the project title changed during the time of our review period, we confirmed that the project start dates were the same. If the start dates were the same, we considered the project to be the same and counted it once. If the project start dates were different, we counted the project as a separate project. If the project start date was not available, we looked to see if other distinguishing characteristics, such as project description, were similar. We did not count a project as a "new" or "separate" project if the project received a new award for another project period—the total period for which support of a project has been programmatically approved. For example, a principal investigator may submit a competing continuation application to continue the project after the initial project period. In addition, the National Institutes of Health (NIH) supports discrete projects performed by investigators in their specific area of interest. It also supports organized efforts of several principal investigators conducting related research projects. In this latter case, we counted each project run by a separate principal investigator as a separate project.

⁵For example, if the portfolio analysis included a project number not in the list provided by the agency, we inquired with the agency whether the project was autism-specific or had an autism-specific component and should therefore be included in our review. We obtained fiscal years 2009 and 2010 data online via the web tool. For fiscal year 2008, we obtained the portfolio analysis data from the Office of Autism Research Coordination.

which we obtained from each agency to include in our analysis.⁶ We were unable to obtain fiscal year 2012 data for the Department of Defense (DOD). DOD's fiscal year 2012 appropriation for its medical research programs, including autism, was available for obligation through the end of fiscal year 2013—September 30, 2013. At the time of our review, DOD had not submitted data on its fiscal year 2012 research projects in response to OARC's request. As a result, our report does not include data on DOD's fiscal year 2012 autism research.

The research projects and related award amounts included in our review differ from the research projects and funding amounts included in the portfolio analysis and web tool for several reasons:

- The portfolio analysis and web tool included projects funded by nonfederal organizations, which we did not include in our review.
- The portfolio analysis and web tool included research using broader criteria than that used in our review. For example, projects that focused on developmental disabilities in general may have been included in the portfolio analysis even if they did not have a component specific to autism. In addition, the portfolio analysis and web tool included some projects that we did not consider to be research, based on information collected and discussions with the agencies.⁷
- The portfolio analysis and web tool reported projects differently than what we used in our methodology. For example, a project was included twice in the portfolio analysis and web tool if the project received a supplemental award and base funding in the same year. In our analysis, we added the award amounts and counted the project once.⁸

⁶We initially collected data directly from the individual federal agencies on their autism research and autism-related activities for which funds were awarded from fiscal years 2008 to 2011. We opted to include the fiscal year 2012 research projects that agencies reported to OARC. We relied on the agency data we collected on the non-research activities awarded between fiscal years 2008 and 2011.

⁷Over the years, OARC has changed its guidance on the types of projects to include in the portfolio analysis. The most recent guidance has more narrow criteria than past years, but since we reviewed data from multiple years, overall, the criteria was different.

⁸If supplemental awards were categorized differently from the base project in the same year, we counted them as separate projects.

- We identified more research projects than those included in the portfolio analysis web tool.

Determining Potential Duplication of Autism Research Projects

We analyzed potential duplication using the portfolio analysis data, which categorized each project to the research areas and objectives in the IACC's Strategic Plan for Autism Spectrum Disorder Research.⁹ Objectives have been added to the strategic plan since its first issuance in 2009. For projects that span multiple years, we used the most recent year's strategic plan research area and objective categories.¹⁰

To determine potential duplication in autism research, we identified research projects that were categorized to the same strategic plan objectives. For those projects that were not categorized to a specific objective, but were categorized to one of the seven research areas, we assessed duplication based on whether they were categorized to the same research area. Determining that projects were categorized to the same strategic plan objective or research area suggests potential, but not actual duplication. Funding similar research on the same topic is sometimes appropriate and necessary; for example, for purposes of replicating or corroborating prior research results. Determining actual duplication for research projects would require a more extensive review of voluminous and scientific data, and was beyond the scope of this study.

⁹As part of its analysis for the portfolio analysis and web tool, OARC reviews the agency submissions and can change the strategic plan question and objective categorization if it thinks that a project should be categorized differently for consistency and accuracy purposes. At the time of our review, OARC had not conducted its analysis of some of the agencies' fiscal year 2011 and 2012 data. Therefore, some of the projects in our review may be categorized to the strategic plan research areas and objectives differently than in the forthcoming fiscal year 2011 and 2012 portfolio analysis and web tool. This applies to approximately 34 projects. In addition, in its comments on a draft of this report, Education stated that, in August 2013, OARC and Education officials held a meeting to clarify the terms used to categorize projects. As a result, Education changed the categorization of select projects; however, Education officials stated that these changes would not have a material effect on this report.

¹⁰Projects may have been categorized to the strategic plan questions and objectives differently over time. 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. Because we are using the most recent fiscal year's strategic plan question and objective categories, all of the funding for a project will be attributed to that category, regardless of whether the project was categorized differently in previous years.

Determining Duplication of Non-Research Autism- Related Activities

To assess whether there was actual duplication of non-research autism-related activities we used the framework we established in our previous work, which states that duplication occurs when two or more agencies fund the same activities that target the same users.¹¹ To determine if the activities were the same, we reviewed each activity's purpose and strategy for achieving that purpose and reviewed the targeted population of the activities.

Data Reliability Assessment

We took several steps to ensure that the data used to produce this report were sufficiently reliable. In addition to comparing agency data to data collected by OARC and following up with agency officials regarding any discrepancies in the data, we also gathered information from agencies on the internal controls they use for maintaining their data. We determined that the data were sufficiently reliable for the purposes of our study.

¹¹See for example, [GAO-13-279SP](#) and [GAO-12-342SP](#).

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

| Report | Description |
|---|---|
| Strategic Plan for Autism Spectrum Disorder Research (2009, 2010, 2011, 2012) | 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 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) ^a | 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’s 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. |
| Summary of Advances in Autism Spectrum Disorder Research (2007, 2008, 2009, 2010, 2011, 2012) | 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 ^b | 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 the 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 documents.

Note: The years listed next to the report title are the years to which the report applies, which may not be the same year the report was published. For example, the 2010 Autism Spectrum Disorder Research Portfolio Analysis Report was published in July 2012.

^aOARC, National Institute of Mental Health, prepared this report on behalf of the IACC. For the 2009 report, OARC, National Institute of Mental Health, and Acclaro Research Solutions, Inc., prepared the report on behalf of the IACC.

^bOARC, National Institute of Mental Health, and Thomson Reuters, Inc. prepared this report on behalf of the IACC.

Appendix III: Federal Autism Research Projects by Interagency Autism Coordinating Committee Strategic Plan Objective

Eleven federal agencies awarded approximately \$1.2 billion to fund autism research projects from fiscal years 2008 through 2012.¹ These agencies are Department of Defense (DOD); Department of Education (Education); the Environmental Protection Agency (EPA); the National Science Foundation (NSF); and 7 agencies within the Department of Health and Human Services—Administration for Children and Families (ACF), Agency for Healthcare Research and Quality (AHRQ), Centers for Disease Control and Prevention (CDC), Centers for Medicare & Medicaid Services (CMS), Health Resources and Services Administration (HRSA), National Institutes of Health (NIH), and Substance Abuse and Mental Health Services Administration (SAMHSA). This appendix includes the autism research projects funded by these agencies, as categorized to the Interagency Autism Coordinating Committee's (IACC) strategic plan objectives. Research projects were categorized to the objective that best describes each project according to the strategic plan; however, research projects may not address all aspects of the objective.

¹Twelve agencies were included in the scope of our review. However, the Administration for Community Living (ACL) did not fund autism research from fiscal year 2008 through fiscal year 2012. ACL funded one non-research autism-related activity during this time period and so it is not discussed in this appendix.

**Appendix III: Federal Autism Research
Projects by Interagency Autism Coordinating
Committee Strategic Plan Objective**

Table 1: Number of Federal Agency Autism Research Projects and Funding by Interagency Autism Coordinating Committee Strategic Plan Objective, by Agency, Fiscal Years 2008 through 2012

| Strategic Plan Research Area and Objectives^a | Description of Objective | Agency | Number of Research Projects | Funds Awarded |
|--|---|---------------|------------------------------------|----------------------|
| Research area 1: Diagnosis | | | | |
| 1.S.A | Develop, with existing tools, at least one efficient diagnostic instrument (i.e., briefer, less time intensive) that is valid in diverse populations for use in large-scale studies by 2011. | NIH | 11 | \$12,863,563 |
| 1.S.B | Validate and improve the sensitivity and specificity of new or existing screening and diagnostic tools, including comparative studies of general developmental screening versus autism-specific screening tools, in both high-risk and population-based samples, including those from resource-poor international settings and those that are diverse in terms of age, socio-economic status, race, ethnicity, gender, characteristics of autism, and general level of functioning by 2012. | ACF | 1 | 100,000 |
| | | AHRQ | 1 | 1,901,626 |
| | | NIH | 7 | 4,620,220 |
| 1.S.C | Conduct at least three studies to identify reasons for the health disparities in accessing early screening and diagnosis services, including identification of barriers to implementation of and access to screening, diagnosis, referral, and early intervention services among diverse populations, as defined by socioeconomic status, race, ethnicity, and gender of the child, by 2012. | NIH | 2 | 455,081 |
| | | SAMHSA | 1 | 450,000 |
| 1.S.D | Conduct at least two studies to understand the impact of early diagnosis on choice of intervention and outcomes by 2015. | | No federal projects funded | |
| 1.S.E | Conduct at least one study to determine the positive predictive value and clinical utility (e.g., prediction of co-occurring conditions, family planning) of chromosomal microarray genetic testing for detecting genetic diagnoses for autism in a clinical setting by 2012. | NIH | 4 | 5,282,439 |
| 1.S.F | Convene a workshop to examine the ethical, legal, and social implications of autism research by 2011. The workshop should define possible approaches for conducting future studies of ethical, legal, and social implications of autism research, taking into consideration how these types of issues have been approached in related medical conditions. | | No federal projects funded | |
| 1.L.A | Identify behavioral and biological markers that separately, or in combination, accurately identify, before age 2, 1 or more subtypes of children at risk for developing autism, and evaluate whether these risk markers or profiles can improve early identification through heightened developmental monitoring and screening by 2014. | DOD | 7 | 3,401,458 |
| | | NIH | 34 | 38,116,800 |
| 1.L.B | Develop at least five measures of behavioral and/or biological heterogeneity in children or adults with autism, beyond variation in intellectual disability, that clearly relate to etiology and risk, treatment response, and/or outcome by 2015. | DOD | 2 | 694,989 |
| | | NIH | 35 | 39,065,410 |
| | | NSF | 9 | 8,602,000 |

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Committee Strategic Plan Objective**

| Strategic Plan Research Area and Objectives^a | Description of Objective | Agency | Number of Research Projects | Funds Awarded |
|--|---|---------------|--|----------------------|
| 1.L.C | Identify and develop measures to assess at least three “continuous dimensions” (e.g., social reciprocity, communication disorders, and repetitive/restrictive behaviors) of autism symptoms and severity that can be used by practitioners and/or families to assess response to intervention for people with autism across the lifespan by 2016. | DOD | 1 | 615,000 |
| | | NIH | 13 | 11,921,270 |
| 1.Other | Not specific to any objective within research area 1. | DOD | 1 | 546,577 |
| | | Education | 1 | 1,971,978 |
| | | NIH | 22 | 14,291,166 |
| | | NSF | 1 | 14,510 |
| Research area 2: Biology | | | | |
| 2.S.A | Support at least four research projects to identify mechanisms of fever, metabolic and/or immune system interactions with the central nervous system that may influence autism during prenatal-postnatal life by 2010. | DOD | 2 | 615,787 |
| | | HRSA | 1 | 294,904 |
| | | NIH | 18 | 8,873,917 |
| 2.S.B | Launch three studies that specifically focus on the neurodevelopment of females with autism, spanning basic to clinical research on sex differences by 2011. | NIH | 5 | 5,320,506 |
| 2.S.C | Identify ways to increase awareness among the autism spectrum community of the potential value of brain and tissue donation to further basic research by 2011. | | No federal projects funded | |
| 2.S.D | Launch three studies that target improved understanding of the underlying biological pathways of genetic conditions related to autism (e.g., fragile X, Rett syndrome, tuberous sclerosis complex) and how these conditions inform risk assessment and individualized intervention by 2012. | DOD | 2 | 269,444 |
| | | NIH | 70 | 46,269,699 |
| 2.S.E | Launch three studies that target the underlying biological mechanisms of co-occurring conditions with autism, including seizures/epilepsy, sleep disorders, wandering/elopement behavior, and familial autoimmune disorders, by 2012. | DOD | 5 | 633,738 |
| | | HRSA | 1 | 412,872 |
| | | NIH | 12 | 16,788,241 |
| 2.S.F | Launch two studies that focus on prospective characterization of children with reported regression to investigate potential risk factors by 2012. | NIH | 1 | 1,612,511 |
| 2.S.G | Support five studies that associate specific genotypes with functional or structural phenotypes, including behavioral and medical phenotypes (e.g., nonverbal individuals with autism and those with cognitive impairments) by 2015. | DOD | 2 | 663,751 |
| | | NIH | 25 | 29,749,080 |
| | | NSF | 1 | 276,000 |
| 2.L.A | Complete a large-scale, multidisciplinary, collaborative project that longitudinally and comprehensively examines how the biological, clinical, and developmental profiles of individuals, with a special emphasis on females, youths, and adults with autism, change over time as compared to typically developing people by 2020. | NIH | 8 | 24,365,831 |

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| Strategic Plan Research Area and Objectives^a | Description of Objective | Agency | Number of Research Projects | Funds Awarded |
|--|---|---------------|------------------------------------|----------------------|
| 2.L.B | Launch at least three studies that evaluate the applicability of autism phenotype and/or biological signature findings for performing diagnosis, risk assessment, or clinical intervention by 2015. | NIH | 6 | 2,379,375 |
| 2.Other | Not specific to any objective within research area 2. | DOD | 9 | 2,614,769 |
| | | NIH | 247 | 167,289,408 |
| | | NSF | 8 | 3,097,145 |
| Research area 3: Causes | | | | |
| 3.S.A | Coordinate and implement the inclusion of approximately 20,000 subjects for genome-wide association studies, as well as a sample of 1,200 for sequencing studies to examine more than 50 candidate genes by 2011. Studies should investigate factors contributing to phenotypic variation across individuals who share an identified genetic variant and stratify subjects according to behavioral, cognitive, and clinical features. | NIH | 18 | 37,608,106 |
| 3.S.B | Within the highest-priority categories of exposures for autism, identify and standardize at least three measures for identifying markers of environmental exposure in biospecimens by 2011. | NIH | 2 | 116,367 |
| 3.S.C | Initiate efforts to expand existing large case-control and other studies to enhance capabilities for targeted gene-environment research by 2011. | EPA | 1 | 2,271,501 |
| | | NIH | 7 | 19,628,501 |
| 3.S.D | Enhance existing case-control studies to enroll racially and ethnically diverse populations affected by autism by 2011. | NIH | 2 | 188,455 |
| 3.S.E | Support at least two studies to determine if there are subpopulations that are more susceptible to environmental exposures (e.g., immune challenges related to infections, vaccinations, or underlying autoimmune problems) by 2012. | NIH | 4 | 1,027,991 |
| 3.S.F | Initiate studies on at least 10 environmental factors identified in the recommendations from the 2007 Institute of Medicine report "Autism and the Environment: Challenges and Opportunities for Research" as potential causes of autism by 2012. | CDC | 2 | 846,247 |
| | | DOD | 2 | 227,360 |
| | | NIH | 3 | 2,423,008 |
| 3.S.G | Convene a workshop that explores the usefulness of bioinformatic approaches to identify environmental risks for autism by 2011. | | No federal projects funded | |

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| Strategic Plan Research Area and Objectives ^a | Description of Objective | Agency | Number of Research Projects | Funds Awarded |
|--|---|---------------------------|-----------------------------------|--|
| 3.S.H | Support at least three studies of special populations or use existing databases to inform our understanding of environmental risk factors for autism in pregnancy and the early postnatal period by 2012. Such studies could include: comparisons of populations differing in geography, gender, ethnic background, exposure history (e.g., prematurity, maternal infection, nutritional deficiencies, toxins), and migration patterns; and comparisons of phenotype (e.g., cytokine profiles), in children with and without a history of autistic regression, adverse events following immunization (such as fever and seizures), and mitochondrial impairment. These studies may also include comparisons of phenotype between children with regressive autism and their siblings. Emphasis on environmental factors that influence prenatal and early postnatal development is particularly of high priority. Epidemiological studies should pay special attention to include racially and ethnically diverse populations. | CDC DOD HRSA NIH | 1 1 1 4 | 1,950,669 143,162 383,243 9,065,939 |
| 3.S.I | Support at least two studies that examine potential differences in the microbiome of individuals with autism versus comparison groups by 2012. | DOD | 1 | 132,750 |
| 3.S.J | Support at least three studies that focus on the role of epigenetics in the etiology of autism, including studies that include assays to measure DNA methylations and histone modifications, and those exploring how exposures may act on maternal or paternal genomes via epigenetic mechanisms to alter gene expression, by 2012. | DOD NIH | 4 12 | 1,446,871 17,650,924 |
| 3.S.K | Support two studies and a workshop that facilitate the development of vertebrate and invertebrate model systems for the exploration of environmental risks and their interaction with gender and genetic susceptibilities for autism by 2012. | NIH | 2 | 1,582,038 |
| 3.L.A | Conduct a multi-site study of the subsequent pregnancies of 1,000 women with a child with autism to assess the impact of environmental factors in a period most relevant to the progression of autism by 2014. | NIH | 1 | 15,154,483 |
| 3.L.B | Identify genetic risk factors in at least 50 percent of people with autism by 2014. | DOD NIH | 1 47 | 142,113 49,834,683 |
| 3.L.C | Determine the effect of at least five environmental factors on the risk for subtypes of autism in the prenatal and early postnatal period of development by 2015. | NIH | 4 | 1,715,618 |
| 3.L.D | Support ancillary studies within one or more large-scale, population-based surveillance and epidemiological studies, including U.S. populations, to collect data on environmental factors during preconception, and during prenatal and early postnatal development, as well as genetic data, that could be pooled (as needed) to analyze targets for potential gene/environment interactions by 2015. | CDC NIH | 7 11 | 39,560,462 24,271,103 |

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| Strategic Plan Research Area and Objectives^a | Description of Objective | Agency | Number of Research Projects | Funds Awarded |
|--|--|---------------|--|----------------------|
| 3.Other | Not specific to any objective within research area 3. | DOD | 3 | 328,091 |
| | | HRSA | 1 | 99,235 |
| | | NIH | 17 | 7,301,273 |
| Research area 4: Treatments and interventions | | | | |
| 4.S.A | Support at least three randomized controlled trials that address co-occurring medical conditions associated with autism by 2010. | HRSA | 1 | 12,724,207 |
| | | NIH | 3 | 906,662 |
| 4.S.B | Standardize and validate at least 20 model systems (e.g., cellular and/or animal) that replicate features of autism and will allow identification of specific molecular targets or neural circuits amenable to existing or new interventions by 2012. | DOD | 10 | 3,490,339 |
| | | NIH | 71 | 64,969,825 |
| 4.S.C | Test safety and efficacy of at least five widely used interventions (e.g., nutrition, medications, assisted technologies, sensory integration, medical procedures) that have not been rigorously studied for use in autism by 2012. | DOD | 2 | 1,967,113 |
| | | NIH | 8 | 3,008,201 |
| 4.S.D | Complete two multi-site randomized controlled trials of comprehensive early intervention that address core symptoms, family functioning and community involvement by 2013. | Education | 3 | 3,849,576 |
| | | HRSA | 1 | 9,324,929 |
| | | NIH | 8 | 22,409,176 |
| 4.S.E | Convene a workshop to advance the understanding of clinical subtypes and treatment personalization (i.e., what are the core symptoms to target for treatment studies) by 2011. | | No federal projects funded | |
| 4.S.F | Launch randomized controlled trials of interventions, including biological signatures and other measures to predict response, and monitor quality of life and functional outcomes in each of the following groups: Five trials in infants and toddlers by 2013. Three trials in school-aged children and/or adolescents by 2013. Three trials in adults by 2014. | DOD | 2 | 1,905,130 |
| | | HRSA | 1 | 564,816 |
| | | NIH | 18 | 22,593,856 |
| | | NSF | 2 | 585,833 |
| 4.S.G | Support at least five studies on interventions for nonverbal individuals with autism by 2012. Such studies may include: projects examining service-provision models that enhance access to augmentative and alternative communication supports in both classroom and adult service-provision settings, such as residential service-provision and the impact of such access on quality of life, communication, and behavior; studies of novel treatment approaches that facilitate communication skills in individuals who are nonverbal, including the components of effective augmentative and alternative communication approaches for specific subpopulations of people with autism; and studies assessing access and use of augmentative and alternative communication for children and adults with autism who have limited or partially limited speech and the impact on functional outcomes and quality of life. | Education | 1 | 594,514 |
| | | NIH | 10 | 8,085,134 |

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| Strategic Plan Research Area and Objectives^a | Description of Objective | Agency | Number of Research Projects | Funds Awarded |
|--|--|---------------|--|----------------------|
| 4.S.H | Support at least two studies that focus on research on health promotion and prevention of secondary conditions in people with autism by 2012. Secondary conditions of interest include weight issues and obesity, injury, and co-occurring psychiatric and medical conditions. | NIH | 2 | 1,324,994 |
| 4.L.A | Complete at least three randomized controlled trials on medications targeting core symptoms in people with autism of all ages by 2014. | HRSA | 1 | 571,147 |
| | | NIH | 13 | 8,222,554 |
| 4.L.B | Develop interventions for siblings of people with autism with the goal of reducing the risk of recurrence by at least 30 percent by 2014. | NIH | 3 | 890,088 |
| 4.L.C | Conduct at least one study to evaluate the safety and effectiveness of medications commonly used in the treatment of co-occurring conditions or specific behavioral issues in people with autism by 2015. | DOD | 1 | 588,750 |
| | | NIH | 9 | 6,517,612 |
| 4.L.D | Support at least five community-based studies that assess the effectiveness of interventions and services in broader community settings by 2015. Such studies may include comparative effectiveness research studies that assess the relative effectiveness of: different and/or combined medical, pharmacological, nutritional, behavioral, service-provision, and parent- or caregiver-implemented treatments; scalable early intervention programs for implementation in underserved, low-resource, and low-literacy populations; and studies of widely used community intervention models for which extensive published data are not available. Outcome measures should include assessment of potential harm as a result of autism treatments, as well as positive outcomes. | Education | 22 | 28,852,321 |
| | | HRSA | 3 | 1,635,606 |
| | | NIH | 9 | 5,676,567 |
| 4.Other | Not specific to any objective within research area 4. | AHRQ | 1 | 575,000 |
| | | Education | 8 | 3,196,869 |
| | | HRSA | 2 | 912,968 |
| | | NIH | 33 | 21,515,583 |
| | | NSF | 5 | 1,656,731 |
| Research area 5: Services | | | | |
| 5.S.A | Support two studies that assess how variations in and access to services affect family functioning in diverse populations, including underserved populations, by 2012. | HRSA | 7 | 2,295,114 |
| | | NIH | 5 | 4,329,526 |
| 5.S.B | Conduct one study to examine how self-directed community-based services and supports impact children, youth, and adults with autism across the spectrum by 2014. | HRSA | 1 | 625,994 |

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| Strategic Plan Research Area and Objectives^a | Description of Objective | Agency | Number of Research Projects | Funds Awarded |
|--|---|---------------|--|----------------------|
| 5.S.C | Implement and evaluate five models of policy and practice-level coordination among state and local agencies to provide integrated and comprehensive community-based supports and services that enhance access to services and supports, self-determination, economic self-sufficiency, and quality of life for people with autism across the spectrum and their families, (which may include access to augmentative and alternative communication technology), with at least one project aimed at the needs of transitioning youth, and at least one study to evaluate a model of policy and practice-level coordination among state and local mental health agencies serving people with autism, by 2015. | CMS | 1 | 198,348 |
| | | HRSA | 2 | 1,500,000 |
| 5.S.D | Support two studies to examine health, safety, and mortality issues for people with autism by 2012. | | No federal projects funded | |
| 5.L.A | Test four methods to improve dissemination, implementation, and sustainability of evidence-based interventions, services, and supports in diverse community settings by 2013. | AHRQ | 1 | 1,486,234 |
| | | DOD | 2 | 2,043,525 |
| | | Education | 3 | 1,399,235 |
| | | HRSA | 4 | 3,179,367 |
| | | NIH | 10 | 7,090,682 |
| 5.L.B | Test the efficacy and cost-effectiveness of at least four evidence-based services and supports for people with autism across the spectrum and of all ages living in community settings by 2015. | Education | 1 | 499,995 |
| 5.L.C | Evaluate new and existing pre-service and in-service training to increase skill levels in service providers, including direct support workers, parents and legal guardians, education staff, and public service workers, to benefit the spectrum of people with autism and to promote interdisciplinary practice by 2015. | NIH | 3 | 2,245,210 |
| 5.L.D | Evaluate at least two strategies or programs to increase the health and safety of people with autism that simultaneously consider principles of self-determination and personal autonomy by 2015. | Education | 1 | 592,007 |
| | | NIH | 1 | 59,998 |
| 5.L.E | Support three studies of dental health issues for people with autism by 2015. This should include: one study on the cost-benefit of providing comprehensive dental services, including routine, non-emergency medical and surgical dental services, denture coverage, and sedation dentistry to adults with autism as compared to emergency and/or no treatment; one study focusing on the provision of accessible, person-centered, equitable, effective, safe, and efficient dental services to people with autism; one study evaluating pre-service and in-service training programs to increase skill levels in oral health professionals to benefit people with autism and promote interdisciplinary practice. | NIH | 3 | 915,605 |

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Projects by Interagency Autism Coordinating
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| Strategic Plan Research Area and Objectives^a | Description of Objective | Agency | Number of Research Projects | Funds Awarded |
|--|--|---------------|--|----------------------|
| 5.Other | Not specific to any objective within research area 5. | AHRQ | 1 | 2,400,000 |
| | | CMS | 1 | 145,007 |
| | | Education | 3 | 1,444,552 |
| | | HRSA | 1 | 793,013 |
| | | NIH | 7 | 4,192,955 |
| Research area 6: Lifespan issues | | | | |
| 6.S.A | Launch at least two studies to assess and characterize variation in the quality of life for adults on the autism spectrum as it relates to characteristics of the service delivery system (e.g., safety, integrated employment, post-secondary educational opportunities, community inclusion, self-determination, relationships, and access to health services and community-based services), and determine best practices by 2012. | HRSA | 2 | 700,000 |
| | | NIH | 3 | 892,536 |
| | | NSF | 1 | 217,996 |
| 6.S.B | Evaluate at least one model, at the state and local level, in which existing programs to assist people with disabilities (e.g., Social Security Administration, Rehabilitation Services Administration) meet the needs of transitioning youth and adults with autism by 2013. | Education | 2 | 3,500,000 |
| 6.S.C | Develop one method to identify adults across the autism spectrum who may not be diagnosed, or are misdiagnosed, to support service linkage, better understand prevalence, and track outcomes with consideration of ethical issues (insurance, employment, stigma) by 2015. | | No federal projects funded | |
| 6.S.D | Conduct at least one study to measure and improve the quality of lifelong supports being delivered in community settings to adults across the spectrum with autism through provision of specialized training for direct care staff, parents, and legal guardians, including assessment and development of autism-specific training, if necessary, by 2015. | NIH | 1 | 749,919 |
| 6.L.A | Develop at least two individualized community-based interventions that improve quality-of-life or health outcomes for the spectrum of adults with autism by 2015. | DOD | 3 | 713,298 |
| | | Education | 1 | 75,000 |
| | | HRSA | 1 | 835,499 |
| | | NIH | 3 | 2,496,347 |
| 6.L.B | Conduct one study that builds on carefully characterized cohorts of children and youth with autism to determine how interventions, services, and supports delivered during childhood impact adult health and quality of life outcomes by 2015. | NIH | 3 | 5,468,332 |

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| Strategic Plan Research Area and Objectives^a | Description of Objective | Agency | Number of Research Projects | Funds Awarded |
|--|--|---------------|--|----------------------------|
| 6.L.C | Conduct comparative effectiveness research that includes a cost-effectiveness component to examine community-based interventions, services, and supports to improve health outcomes and quality of life for adults on the autism spectrum over age 21 by 2018. Topics should include: community housing for people with autism; successful life transitions for people with autism, including from post-secondary education to adult services, employment, sibling relationships, and day programs; and meeting the service and support needs of older adults with autism. | HRSA | 1 | 793,024 |
| | | NIH | 1 | 772,496 |
| 6.L.D | Conduct implementation research to test the results from comparative effectiveness research in real-world settings, including a cost-effectiveness component to improve health outcomes and quality of life for adults over 21 on the autism spectrum by 2023. | | | No federal projects funded |
| 6.Other | Not specific to any objective within research area 6. | AHRQ | 1 | 625,000 |
| | | Education | 2 | 729,398 |
| | | HRSA | 1 | 100,000 |
| | | NIH | 2 | 878,187 |
| | | NSF | 2 | 393,237 |
| Research area 7: Infrastructure and surveillance | | | | |
| 7.A | Conduct a needs assessment to determine how to merge or link administrative and/or surveillance databases that allow for tracking the involvement of people living with autism in health care, education, and social services by 2009. | | | No federal projects funded |
| 7.B | Conduct an annual "State of the States" assessment of existing state programs and supports for people and families living with autism by 2011. | CMS | 2 | 540,491 |
| 7.C | Develop and have available to the research community a means by which to merge or link databases that allow for tracking the involvement of people in autism research by 2010. | NIH | 1 | 2,040,353 |

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| Strategic Plan Research Area and Objectives^a | Description of Objective | Agency | Number of Research Projects | Funds Awarded |
|--|---|---------------|--|----------------------|
| 7.D | Establish and maintain an international network of biobanks for the collection of brain tissue, fibroblasts for pluripotent stem cells, and other tissue or biological material, by acquisition sites that use standardized protocols for phenotyping, collection, and regulated distribution of limited samples by 2011. This includes support for post-processing of tissue, such as genotyping, RNA expression profiling, and MRI. Protocols should be put into place to expand the capacities of ongoing large-scale children's studies to collect and store additional biomaterials, including newborn bloodspots, promoting detection of biological signatures. Support should also be provided to develop an international web-based digital brain atlas that would provide high-resolution 3-D images and quantitative anatomical data from tissue of patients with autism and disease controls across the lifespan, which could serve as an online resource for quantitative morphological studies, by 2014. | NIH | 1 | 2,303,588 |
| 7.E | Begin development of a web-based toolbox to assist researchers in effectively and responsibly disseminating their findings to the community, including people with autism, their families, and health practitioners, by 2011. | NIH | 1 | 25,000 |
| 7.F | Create funding mechanisms that encourage rapid replication studies of novel or critical findings by 2011. | | No federal projects funded | |
| 7.G | Develop a web-based tool that provides population estimates of autism prevalence for States based on the most recent prevalence range and average identified by the Autism and Developmental Disabilities Monitoring Network by 2012. | | No federal projects funded | |
| 7.H | Create mechanisms to specifically support the contribution of data from 90 percent of newly initiated projects to the National Database for Autism Research, and link with other existing data resources by 2012. | NIH | 6 | 9,583,653 |
| 7.I | Supplement existing Autism and Developmental Disabilities Monitoring Network sites to use population-based surveillance data to conduct at least five hypothesis-driven analyses evaluating factors that may contribute to changes in autism prevalence by 2012. | CDC | 14 | 28,544,177 |
| 7.J | Develop the personnel and technical infrastructure to assist states, territories, and other countries that request assistance describing and investigating potential changes in the prevalence of autism and other developmental disabilities by 2013. | CDC | 1 | 324,072 |
| | | NIH | 1 | 150,000 |
| 7.K | Encourage programs and funding mechanisms that expand the research workforce, enhance interdisciplinary research training, and recruit early-career scientists into the autism field by 2013. | Education | 3 | 1,457,164 |
| | | HRSA | 1 | 2,868,488 |
| | | NIH | 22 | 7,479,509 |

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| Strategic Plan Research Area and Objectives^a | Description of Objective | Agency | Number of Research Projects | Funds Awarded |
|--|--|---------------|------------------------------------|----------------------------|
| 7.L | Expand the number of Autism and Developmental Disabilities Monitoring sites in order to conduct autism surveillance in children and adults; conduct complementary direct screening to inform completeness of ongoing surveillance; and expand efforts to include autism subtypes by 2015. | CDC | 8 | 4,381,177 |
| 7.M | Support 10 “Promising Practices” papers that describe innovative and successful services and supports being implemented in communities that benefit the full spectrum of people with autism, which can be replicated in other communities, by 2015. | | | No federal projects funded |
| 7.N | Enhance networks of clinical research sites offering clinical care in real-world settings that can collect and coordinate standardized and comprehensive diagnostic, biological (e.g., DNA, plasma, fibroblasts, urine), medical, and treatment history data that would provide a platform for conducting comparative effectiveness research and clinical trials of novel autism treatments by 2012. | HRSA | 1 | 670,000 |
| 7.O | Create an information resource for autism researchers (e.g., PhenX Project) to share information to facilitate data sharing and standardization of methods across projects by 2013. This includes common protocols, instruments, designs, and other procedural documents, and should include updates on new technology and links to information on how to acquire and utilize technology in development. This can serve as a bidirectional information reference, with autism research driving the development of new resources and technologies, including new model systems, screening tools, and analytic techniques. | HRSA | 1 | 2,142,000 |
| | | NIH | 1 | 997,747 |
| 7.P | Provide resources to centers or facilities that develop promising vertebrate and invertebrate model systems, and make these models more easily available or expand the utility of current model systems, and support new approaches to develop high-throughput screening technologies to evaluate the validity of model systems by 2013. | NIH | 1 | 1,588,780 |
| 7.Other | Not specific to any objective within research area 7. | NIH | 34 | 52,663,973 |

Source: GAO analysis of data from the Interagency Autism Coordinating Committee (IACC) and federal agencies that funded autism research.

Notes: The number of autism research projects in the table reflects a project that HRSA broke-up into 7 sub-projects and categorized into different objectives for fiscal years 2010, 2011, and 2012. This project was not broken out in previous years; therefore, all funding for the project is attributed to objective 4.S.A for fiscal years 2008 and 2009. NIH jointly funded 1 autism research project with CDC and 1 project with EPA. These joint projects are counted separately in the total number of autism research projects for each of these agencies because the projects were awarded funding from different agencies. Additionally, from fiscal years 2008 through 2012, 6 autism projects were included in IACC data, but were categorized as “not specific to any research area,” and 16 projects were not included in IACC data and, therefore, not categorized to the research areas. Furthermore, from fiscal years 2008 through 2011, CDC awarded funds for 9 research projects on autism and other developmental disabilities as part of its non-research autism-related activity, *Learn the Signs. Act Early*. CDC categorized the entire activity to the services research area; however, these 9 research projects are not included in the table because it was unclear if the individual research projects under *Learn the Signs. Act Early*. would also be categorized to the services research area. DOD’s research

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projects include projects funded from DOD's fiscal years 2008 through 2011 appropriations. DOD's fiscal year 2012 appropriation for its medical research programs, including autism, was available for obligation through the end of fiscal year 2013—September 30, 2013. At the time of our review, DOD had not submitted data on its fiscal year 2012 research projects in response to OARC's request. As a result, the number of autism research projects for DOD does not include DOD's projects for fiscal year 2012.

When collecting and analyzing data, we included a project in the fiscal year in which it was awarded funds, even if funds remained available for obligation in future fiscal years—or, as is the case with DOD, the fiscal year of the appropriation from which the project or activity was awarded funds. For example, if a project was ongoing in another fiscal year, but did not receive an award in that year, we included the project in the fiscal year in which it received an award only. AHRQ and CMS each awarded one contract under which multiple autism-related projects were carried out. Education and SAMHSA also awarded contracts, of which an autism project was one component. Funding is not broken out in these contracts by project; therefore, the award amounts that we report for the AHRQ, CMS, Education, and SAMHSA autism projects under each contract are the agencies' estimates of the overall contract awards that were intended to support these projects.

^aThe strategic plan objective numbers are composed of the following components: the number indicates the strategic plan question, or research area, that the objective relates to; for strategic plan questions 1 through 6, the "S" and "L" indicate whether the objectives are short-term or long-term; and the final letter refers to the specific objective. Each of the 7 research areas includes an "Other" category. Although this category is not included in the strategic plan as an objective, it is used to categorize autism research that relates to a specific research area, but not a specific objective.

Appendix IV: Agencies' Non-Research Autism-Related Activities, Fiscal Years 2008 through 2011

Five agencies funded non-research autism-related activities from fiscal year 2008 through 2011—Administration for Community Living (ACL), Centers for Disease Control and Prevention (CDC), Department of Defense (DOD), Department of Education (Education), and Health Resources and Services Administration (HRSA). The agencies funded activities that we categorized by the following activity type: awareness campaign, information dissemination, training, and other types of activities. This appendix includes a list of each activity, by agency and by activity type. Also included is the amount of funding awarded by the agency—that was related to autism—under each activity between fiscal years 2008 and 2011; as well as a brief description of the primary purpose, strategy for achieving that purpose, and target population of each activity.¹

ACL: Information Dissemination Activity

Autism NOW: National Autism Resource and Information Center

- **Funding:** \$2.6 million
- **Purpose:** Gather, organize, and provide diverse stakeholders with readily accessible, high-quality resources and information related to community-based services that support independent living and self-determination, treatment protocols that promote community-based experiences (e.g., education, employment, recreation, transportation, early intervention, and child care), and evidence-based interventions.
- **Strategy:** Website provides information and links to resources related to four main components: (1) at home, (2) on the job, (3) in the classroom, and (4) in the community. The website also offers webinars and blogs on various topics related to autism and other developmental disabilities.

¹Most of Education's activities included projects that were not related to autism. The funding presented for Education represents the funding amounts that supported projects, under each activity, that were autism-specific or had a component to them that was autism-specific. CDC funded one non-research activity—*Learn the Signs. Act Early.*—between fiscal years 2008 and 2011. The funding amount for *Learn the Signs. Act Early.* reflects funding to support contracts and cooperative agreements, as well as activities conducted internally at the agency, such as funding for staffing and personnel costs.

- Target Population: Individuals with autism and other developmental disabilities, their families, and other targeted stakeholders concerned with autism.

CDC: Awareness Campaign/Information Dissemination Activity

Learn the Signs. Act Early.

- Funding: \$9.8 million²
- Purpose: Improve early identification of children with autism and other developmental disabilities so children and families can get the services and support they need as early as possible.
- Strategy: The program is made up of three components: (1) the 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) the 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 to promote *Learn the Signs. Act Early.* messages and tools, and improve early identification efforts in their states and territories; and (3) the research and evaluation component improves campaign materials and implementation activities, and increases the understanding of the factors that influence early identification and referral.
- Target Population: Parents, early educators, and health care providers.

²This funding amount reflects CDC's total funding for *Learn the Signs. Act Early.*, with the exception of research funded under this activity—totaling approximately \$1.7 million.

DOD: Information Dissemination Activity

Extension & Military Partnership Autism Project

- **Funding:** \$1.3 million
- **Purpose:** Assessment of educational services for children with autism, emotional/behavioral disorders, and intellectual disabilities near military installations; and national review of best practices around educational support for children with the identified disabilities. Data is used to update the current online Education Directory for Children with Special Needs, which provides assignment personnel and families of military dependents with information they need to make informed assignment decisions.
- **Strategy:** Website consists of two main components that provide tools and resources to help with the transition to a new military installation: (1) the Early Intervention Directory focuses on early intervention services for children from birth to 3 years old; and (2) the School-Age Directory focuses on education services for children with special needs, 3 to 21 years of age.
- **Target Population:** Military families, who have children with autism or other developmental disabilities, using educational services in selected states.

Education: Training Activities

Personnel Development to Improve Services and Results for Children with Disabilities

- **Funding:** \$42.4 million
- **Purpose:** To help address state-identified needs for highly qualified personnel by preparing personnel in special education, related services, early intervention, and regular education to work with children with disabilities; and to ensure that those personnel have the skills and knowledge—derived from practices that have been determined through research and experience to be successful—needed to serve these children. This could include preparing personnel to work with children with autism and their families.

- **Strategy:** This activity supports two types of personnel preparation projects. (1) Projects designed to prepare special education early intervention, or related services personnel to serve as higher education faculty and researchers. These projects culminate in a doctoral degree or provide postdoctoral learning opportunities. (2) Projects designed to prepare special education, early intervention, or related services, direct service providers or administrators to work in state educational agencies, lead agencies, local educational agencies, early intervention services programs, or schools. They culminate in a baccalaureate, master's, education specialist, or doctoral degree; or state certification, endorsement, or licensure. The projects may provide specialization in conducting autism research or providing services for children with autism and their families.
- **Target Population:** Scholars in special education, early intervention, and related services programs.

Personnel Development to Improve Services and Results for Children with Disabilities; National Professional Development Center on Autism Spectrum Disorders

- **Funding:** \$4 million
- **Purpose:** Provides resources, professional development, and technical assistance to help address state-identified needs for highly qualified personnel in special education, related services, early intervention, and regular education to work with infants, toddlers, and children with disabilities; and ensure that those personnel have the necessary skills and knowledge, derived from practices that have been determined through scientifically based research and experience, to be successful in serving those children.
- **Strategy:** The project goals are organized around four content areas: (1) content development, (2) professional development, (3) technical assistance, and (4) evaluation. Content development involves translating information about evidence-based practices—or educational interventions—for children with autism into resources for service providers. Professional development entails providing training to state professional development providers and practitioners, as well as establishing training sites that model evidence-based practices in participating states. Technical assistance includes providing ongoing site-based training and

establishing a network of professional development sites, trainees, and professional consultants. Evaluation involves collecting follow-up data on the use of evidence-based practices, practitioner skills, and child and family outcomes.

- Target Population: States' departments of education receiving funds under Part B and state lead agencies under Part C of the Individuals with Disabilities Education Act, and those that they provide professional development to, such as teachers and practitioners who serve individuals from birth through 21 years of age with autism.³

State Personnel Development Grants Program

- Funding: \$6.5 million
- Purpose: Assist state educational agencies in reforming and improving their systems for personnel preparation and professional development in early intervention, education, and transition services in order to improve results for children with disabilities.
- Strategy: Supports implementation of a State Personnel Development Plan. This plan must identify and address the state and local needs for the personnel preparation and professional development of personnel, as well as individuals who provide direct supplementary aids and services to children with disabilities. The projects must use evidence-based professional development practices that will increase implementation of evidence-based practices and result in improved outcomes for children with disabilities; provide ongoing assistance to personnel receiving professional development that supports the implementation of evidence-based practices; and use technology to more efficiently and effectively provide ongoing professional development to

³The Individuals with Disabilities Education Act is a federal law that provides federal funds on a formula grant basis to assist states in providing early intervention, special education, and related services to eligible children with disabilities. Part B of the act is a program administered by state educational agencies to make a free appropriate public education available to children with disabilities beginning at age 3, and potentially until age 22, depending on state law or practice. Part C of the act is a program administered by a lead agency in a state to make available early intervention services to infants and toddlers with disabilities from birth until age 3, and their families.

personnel, including to personnel in rural areas and to other populations, such as personnel in urban or high-need local educational agencies.

- Target Population: State educational agencies in the 50 states, the District of Columbia, the Commonwealth of Puerto Rico, Guam, Virgin Islands, American Samoa, and the Commonwealth of the Northern Mariana Islands that have a State Personnel Development Plan and those personnel they train, such as teachers, administrators, and early intervention providers.

Rehabilitation Continuing Education Program

- Funding: \$2.8 million
- Purpose: This program is designed to ensure that skilled personnel are available to serve the rehabilitation needs of individuals with disabilities. It is also designed to provide support to the public vocational rehabilitation system; provide advice, technical support, and training to the state vocational rehabilitation agencies and their community partners.
- Strategy: There are 10 regional Technical Assistance and Continuing Education centers that serve either a federal region or another geographical area and provide for a broad integrated sequence of training activities that focus on meeting recurrent and common training needs of employed rehabilitation personnel throughout a multi-state geographical area. One center has developed materials to train vocational rehabilitation staff on autism. These materials are made available to other Technical Assistance and Continuing Education centers and to state vocational rehabilitation agencies for staff training purposes.
- Target Population: State vocational rehabilitation agencies and the professionals they train.

Education: Other Activity Types

Developing Hispanic-Serving Institutions Program-Title V

- Funding: \$0.3 million
- Purpose: To assist Hispanic-serving institutions to expand educational opportunities for, and improve the attainment of,

Hispanic students. It also enables these institutions to expand and enhance their academic offerings, program quality, and institutional stability.

- Strategy: Activities supported include: scientific or laboratory equipment for teaching; construction or renovation of instructional facilities; faculty development; purchase of educational materials; academic tutoring or counseling programs; funds and administrative management; joint use of facilities; endowment funds; distance learning academic instruction; teacher education; and student support services.
- Target Population: Hispanic students and the postsecondary institutions that serve them.

Fund for the Improvement of Education

- Funding: \$1.6 million
- Purpose: To support nationally significant programs to improve the quality of elementary and secondary education at the state and local levels, and help all students meet challenging state academic content standards and student achievement standards.
- Strategy: Types of projects funded include activities to promote systemic education reform at the state and local levels, including scientifically based research, development, and evaluation designed to improve student academic achievement at the state and local levels; and strategies for effective parent and community involvement.
- Target Population: Students

Fund for the Improvement of Postsecondary Education Congressionally Directed Projects

- Funding: \$1.4 million
- Purpose: Address critical national needs and support Education's mission of increasing access to quality postsecondary education.
- Strategy: These are noncompetitive grants that Education manages pursuant to Congress' direction to provide such grants

to certain recipients for specified purposes and in specified amounts.

- Target Population: Individuals or institutions involved in or impacted by postsecondary education.

Technology and Media Services for Individuals with Disabilities program: Steppingstones of Technology Innovation for Children with Disabilities

- Funding: \$1.0 million
- Purpose: (1) Improve results for children with disabilities by promoting the development, demonstration, and use of technology; (2) support educational media service activities designed to be of educational value in the classroom setting to children with disabilities; and (3) provide support for captioning and video description that are appropriate for use in the classroom setting.
- Strategy: Develop, implement, and evaluate innovative technology approaches designed to improve results for children with disabilities. Phase 1 projects must develop, refine, and test the feasibility of specific technology-based approaches. Phase 2 projects must subject technology-based approaches to rigorous field-based research to determine their effectiveness.
- Target Population: Children served under the Individuals with Disabilities Education Act, including children with autism.

HRSA: Training Activities

Developmental-Behavioral Pediatrics Training Program

- Funding: \$7.3 million
- Purpose: The primary goal 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. The program also supports continuing education for pediatricians and other providers to implement evidence-based interventions for autism and other developmental disabilities.

- **Strategy:** The 3-year program curriculum includes course work and clinical exposure to psychosocial and biological sciences, growth and development, adaptation, injury prevention, disease prevention, and health promotion. Projects are also encouraged to cosponsor, with child psychiatry, an ongoing Collaborative Office Rounds group as a training experience for fellows and a continuing education experience for community providers. Grantees also provide continuing education activities for practicing physicians and are encouraged to offer technical assistance and consultation to pediatric residency training programs so that they can improve their own developmental-behavioral program components.
- **Target Population:** Fellows in developmental-behavioral pediatrics preparing for leadership roles as teachers, investigators, and clinicians advancing the field of developmental-behavioral pediatrics; pediatric practitioners, residents, and medical students.

Leadership Education in Neurodevelopmental and Other Related Disabilities (LEND) Training Program

- **Funding:** \$107.2 million
- **Purpose:** Improve the health of children who have, or are at risk for developing, neurodevelopmental and other related disabilities by providing high quality interdisciplinary graduate leadership training to child health professionals from diverse backgrounds and preparing those professionals to assume leadership roles. This includes supporting the training of individuals who can provide screening, diagnostic evaluation, and evidence-based interventions for autism and other developmental disabilities.
- **Strategy:** Provides interdisciplinary leadership training and encourages providers to think holistically about the needs of children with autism and other developmental disabilities, as well as their families. The training curriculum includes graduate education at the master's, doctoral, and postdoctoral training levels, with an emphasis on developing a knowledge and experience base that includes: (1) knowledge of all aspects of neurodevelopmental and related disabilities, including autism; (2) acquisition of interdisciplinary team skills; and (3) knowledge of the family environment and cultural competency.

- Target Population: Trainees are individuals working toward a graduate degree across 14 disciplines—including medicine, dentistry, psychology, social work, nutrition, language and motor therapies, audiology, genetics, health administration, special education, and nursing—or are enrolled in a postgraduate program with an emphasis on infants, children, and adolescents with special health care needs. Trainees show promise to become leaders in the material and child health field in the areas of teaching, research, clinical practice, and/or administration and policymaking.

National Combating Autism Interdisciplinary Training Resource Center

- Funding: \$2.5 million
- Purpose: 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 Developmental-Behavioral Pediatrics grantees to better train professionals to utilize valid and reliable screening tools for diagnosing or ruling out autism and provide evidence-based interventions for children.
- Strategy: The center supports LEND and Developmental-Behavioral Pediatrics grantees by providing technical assistance, disseminating information and resources, and providing program coordination to promote collaboration across the grantees.
- Target Population: LEND and Developmental-Behavioral Pediatrics grantees.

HRSA: Other Activity Types

State Implementation and Planning Grants

- Funding: \$11.8 million
- Purpose: Improve access to comprehensive, coordinated health care and related services by implementing state plans to improve the system of services.

- Strategy: Although the plans vary widely by state, 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.
- Target Population: States with an existing plan for improving the system of services for children with autism and developmental disabilities.

State Public Health Coordinating Center

- Funding: \$1.1 million
- Purpose: Improve the health of children who have, or are at risk for developing, autism and other developmental disabilities.
- Strategy: Coordinating with the state implementation and planning grantees and developing a strategy for defining, supporting, and monitoring the role of state public health agencies in assuring early and timely identification, diagnosis, and intervention.
- Target Population: State implementation and planning grantees, and broader state public health programs.

Appendix V: Comments from the Department of Defense



THE ASSISTANT SECRETARY OF DEFENSE

1200 DEFENSE PENTAGON
WASHINGTON, DC 20301-1200

HEALTH AFFAIRS

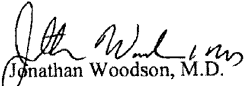
OCT 04 2013

Ms. Marcia Crosse
Director, Health Care
U.S. Government Accountability Office
441 G Street, NW
Washington, DC 20548

Dear Ms. Crosse:

This letter is the Department of Defense's (DoD) response to the Government Accountability Office (GAO) Draft Report, GAO-14-16, "FEDERAL AUTISM ACTIVITIES: Better Data and More Coordination Needed to Help Avoid the Potential for Unnecessary Duplication," dated September 11, 2013 (GAO Code 291093). Thank you for the opportunity to review and comment on the draft report. After careful review, we concur with the draft report findings and conclusion. The DoD will participate and cooperate with the Interagency Autism Coordinating Committee (IACC), the National Institutes of Health, and other federal agencies in efforts to prevent unnecessary duplication of federal autism research activities. Such efforts will include a determination of methods for identifying and monitoring the autism research conducted by other agencies, including taking full advantage of monitoring data the IACC develops and makes available.

My points of contact on this matter are Dr. Terry Rauch (Functional) and Mr. Gunther Zimmerman (Audit Liaison). Dr. Rauch may be reached at (703) 681-8390, or Terry.Rauch@ha.osd.mil. Mr. Zimmerman may be reached at (703) 681-4360, or Gunther.Zimmerman@dha.mil.


Jonathan Woodson, M.D.

GAO DRAFT REPORT DATED SEPTEMBER 11, 2013
GAO-14-16 (GAO CODE 291093)

**“FEDERAL AUTISM ACTIVITIES: BETTER DATA AND MORE COORDINATION
NEEDED TO HELP AVOID THE POTENTIAL FOR UNNECESSARY DUPLICATION”**

**DEPARTMENT OF DEFENSE COMMENTS
TO THE GAO RECOMMENDATION**

RECOMMENDATION 1: To improve the usefulness of the Interagency Autism Coordinating Committee (IACC) data and enhance its efforts to coordinate Health and Human Services (HHS) autism activities and monitor all federally funded autism activities, we recommend that the Secretary of HHS direct the IACC and National Institutes of Health (NIH), in support of IACC, to take the following three actions:

- Provide consistent guidance to federal agencies when collecting data for the portfolio analysis and web tool so that information can be more easily and accurately compared over multiple years;
- Create a document or database that provides information on non-research autism-related activities funded by the federal government and make this publicly available; and
- Through its monitoring of federal autism activities—including The Office of Autism Research Coordination’s annual collection of data for the portfolio analysis and the IACC’s annual process to update the strategic plan—identify projects that may result in unnecessary duplication and thus may be candidates for consolidation or elimination, and identify potential coordination opportunities among agencies.

DoD RESPONSE: Overall, the Department concurs with the draft report findings and conclusion and has no additional comments at this time.

RECOMMENDATION 2: To promote better coordination among federal agencies that fund autism research and avoid the potential for unnecessary duplication before research projects are funded, we recommend that the Secretary of HHS, the Secretary of Defense, the Secretary of Education, and the Director of National Science Foundation each determine methods for identifying and monitoring the autism research conducted by other agencies, including by taking full advantage of monitoring data the IACC develops and makes available.

DoD RESPONSE: The DoD will participate and cooperate with IACC, NIH, and other federal agencies in efforts to prevent unnecessary duplication of federal autism research activities. Such efforts will include a determination of methods for identifying and monitoring the autism research conducted by other agencies, including taking full advantage of monitoring data the IACC develops and makes available.

Appendix VI: Comments from the Department of Education



UNITED STATES DEPARTMENT OF EDUCATION
OFFICE OF SPECIAL EDUCATION AND REHABILITATIVE SERVICES

October 21, 2013

Ms. Marcia Crosse
Director
Health Care
U.S. Government Accountability Office
441 G Street, NW
Washington, DC 20548

Dear Ms. Crosse:

I am writing to provide the U.S. Government Accountability Office (GAO) with comments from the U.S. Department of Education (Department) on the draft report, "FEDERAL AUTISM ACTIVITIES: Better Data and More Coordination Needed to Help Avoid the Potential for Unnecessary Duplication" (GAO-14-16). The Department appreciates the work that went into this study. The draft report contains two recommendations.

Recommendation 1: To improve the usefulness of IACC data and enhance its efforts to coordinate HHS autism activities and monitor all federally funded autism activities, we recommend that the Secretary of Health and Human Services direct the IACC and NIH, in support of the IACC, to take the following three actions:

- provide consistent guidance to federal agencies when collecting data for the portfolio analysis and web tool so that information can be more easily and accurately compared over multiple years;
- create a document or database that provides information on non-research autism-related activities funded by the federal government and make this publicly available; and
- through its monitoring of federal autism activities--including OARC's annual collection of data for the portfolio analysis and the IACC's annual process to update the strategic plan--identify projects that may result in unnecessary duplication and thus may be candidates for consolidation or elimination, and identify potential coordination opportunities among agencies.

Response: This three-part recommendation mentions the Interagency Autism Coordinating Committee (IACC), the Department of Health and Human Services (HHS), the National Institutes of Health (NIH), and the Office of Autism Research Coordination (OARC). While it does not mention Education directly, we intend to work with the OARC to ensure the most accurate reporting possible. Our technical comments provide examples of the ways in which we have worked with the OARC on coding issues in the past, and how we hope to continue to work in the future. The Department has recently shared information on non-research autism activities

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The Department of Education's mission is to promote student achievement and preparation for global competitiveness by fostering educational excellence and ensuring equal access.

Page 2 - Ms. Marcia Crosse

with the OARC for the HHS Report to Congress on Activities Related to Autism Spectrum Disorders and Other Developmental Disabilities Under the Combatting Autism Act of 2006 (FY 2010-2012), and we will continue to provide relevant information about Department programs for similar efforts to monitor and report autism non-research activities.

Recommendation 2: To promote better coordination among federal agencies that fund autism research and avoid the potential for unnecessary duplication before research projects are funded, we recommend that the Secretary of Health and Human Services, the Secretary of Defense, and the Secretary of Education, and the Director of NSF each determine methods for identifying and monitoring the autism research conducted by other agencies, including by taking full advantage of the monitoring data the IACC develops and makes available.

Response: The Department would be pleased to participate in development of more refined methods for the identification and monitoring of multiagency autism research, as described in GAO's second recommendation. I am the Department's representative on the IACC and will continue to work with the OARC and the IACC to provide them with information for Congress and the public.

The Department is concerned about, and does not concur with, GAO's conclusion that "the majority of federally-funded autism research was potentially duplicative..." The IACC objectives are broad and projects classified under them cannot be fairly judged "potentially duplicative" without more substantial exposition. Research projects with similar descriptors or titles may have different subject populations, sample sizes, methodologies, and outcome measures, and may explore different mechanisms or hypotheses. We note also that growth of the scientific knowledge base for any subject, and certainly for a subject as complex as autism, is dependent upon multiple studies investigating similar research questions.

Thank you for the opportunity to comment on this draft report. We also are including technical comments with this response.

Sincerely,



Michael K. Yudin
Acting Assistant Secretary for Special Education
and Rehabilitative Services

Appendix VII: Comments from the Department of Health and Human Services



DEPARTMENT OF HEALTH & HUMAN SERVICES

OFFICE OF THE SECRETARY

Assistant Secretary for Legislation
Washington, DC 20201

OCT 24 2013

Marcia Crosse
Director, Health Care
U.S. Government Accountability Office
441 G Street NW
Washington, DC 20548

Dear Ms. Crosse,

Attached are comments on the U.S. Government Accountability Office's (GAO) report entitled, "Federal Autism Activities: Better Data and More Coordination Needed to Help Avoid the Potential for Unnecessary Duplication" (GAO-14-16).

The Department appreciates the opportunity to review this report prior to publication.

Sincerely,

A handwritten signature in cursive script that reads "Jim R. Esquea".

Jim R. Esquea
Assistant Secretary for Legislation

Attachment

GENERAL COMMENTS OF THE DEPARTMENT OF HEALTH AND HUMAN SERVICES (HHS) ON THE GOVERNMENT ACCOUNTABILITY OFFICE'S (GAO) DRAFT REPORT ENTITLED, "FEDERAL AUTISM ACTIVITIES: BETTER DATA AND MORE COORDINATION NEEDED TO HELP AVOID THE POTENTIAL FOR UNNECESSARY DUPLICATION" (GAO-14-16)

The Department appreciates the opportunity to review and comment on this draft report.

HHS recognizes and supports the essential function and critical importance of coordination among research investments funded by Federal agencies. However, we are concerned that this report may provide a risk of misinforming policy makers and the public. This report indicates that it did not assess the research projects for actual duplication, because such an effort would be outside of the scope of the report, according to the report.

Although this report acknowledges that duplication is necessary in science for the sake of replicating or corroborating results, it does not appreciate the full extent of the necessity of replication and the extensive policies in place at HHS and other federal agencies to prevent redundant projects. HHS recognizes that scientific endeavors and the path of research discovery are not linear undertakings and often require verification and validation efforts. In addition, the advancement of scientific knowledge builds upon the cumulative efforts of what may seemingly be similar research undertakings on the surface, but in effect take what has been learned from previous research findings to another discovery frontier via the application of that knowledge.

HHS is concerned about the report's implication that it is wasteful when more than one funding Agency addresses an objective or aim of the Strategic Plan for Autism Research. It must be recognized that the goals and objectives of the Strategic Plan represent complex scientific questions that require a multidisciplinary approach, with multiple scientific strategies. For example, to develop effective interventions for autism spectrum disorder (ASD) that will address the full range of symptoms and degrees of disability found in the ASD population, research studies on multiple intervention types, such as behavioral, pharmacological, educational, and occupational, may need to be undertaken simultaneously to facilitate rapid progress that benefits individuals with varying needs. Based on the urgent need to address rapidly the health and services issues that are the most pressing in the community, it is not only appropriate, it is critical that multiple agencies address the complex questions related to understanding the neurobiology of ASD and identifying efficacious intervention strategies for use across the lifespan.

HHS is supportive of and committed to the call for greater coordination among federal research funding agencies and actively engages in efforts to minimize risk of research duplication in all activities. HHS agrees that there should be continued vigilance and coordination to avoid unnecessary duplication across research projects, and the HHS will continue its procedures for avoiding duplication.

In the report, it is cited that "84 percent of the autism research projects funded by federal agencies were potentially duplicative." HHS believes that this statement is misleading or could be easily misconstrued. It is important to recognize the difference between appropriately addressing complex problems using multiple strategies and funding redundant or duplicative projects. We do not believe that research is necessarily duplicative if two agencies fund the same broad objective in the IACC Strategic Plan. GAO does not outline in the report the purpose and process for developing the strategic plan, yet for several areas that were determined

GENERAL COMMENTS OF THE DEPARTMENT OF HEALTH AND HUMAN SERVICES (HHS) ON THE GOVERNMENT ACCOUNTABILITY OFFICE'S (GAO) DRAFT REPORT ENTITLED, "FEDERAL AUTISM ACTIVITIES: BETTER DATA AND MORE COORDINATION NEEDED TO HELP AVOID THE POTENTIAL FOR UNNECESSARY DUPLICATION" (GAO-14-16)

to be gap areas in research and that were highlighted in the strategic plan, such as services to underserved populations and research regarding services to adults on the spectrum, it is a testament to agencies' responsiveness to needs expressed by the field that multiple research projects were funded to address these areas of need.

GAO made the following statement while addressing the shortcomings of the Interagency Autism Coordinating Committee (IACC)'s data: "We found that, when looking across multiple years, some agencies funded more autism research projects than were suggested in the associated strategic plan objective...." This sentence implies that this is an indicator of wasteful spending, but that could be misleading. IACC stated as it developed its Strategic Plan that it intended the objectives to describe the minimum effort that would be required to address the complex issues set in each objective. The recommended number of projects or amount of funding in the objectives was described by IACC as a "floor, not a ceiling," recognizing that this minimum effort may only begin to address the gap areas described in each objective and that, in most cases, further efforts were likely to be required to fully address these areas of need.

GAO Recommendation 1: To improve the usefulness of IACC data and enhance its efforts to coordinate HHS autism activities and monitor all federally funded autism activities, we recommend that the Secretary of Health and Human Services direct IACC and NIH, in support of IACC, to provide consistent guidance to federal agencies when collecting data for the portfolio analysis and web tool so that information can be more easily and accurately compared over multiple years.

HHS Response: While HHS appreciates the value of consistency, we do not concur with the GAO characterization of the process or the quality of the Portfolio Analysis. Autism science has moved quickly in the past five years, with new funders as well as new areas of funding. It is important to appreciate that in such a changing landscape of scientific funding, accuracy may need to trump consistency and that guidelines must evolve to be responsive to new opportunities.

The Office of Autism Research Coordination (OARC), which conducts the IACC Portfolio Analysis and publishes the data in a publicly accessible report and online database on behalf of IACC, has used a consistent methodology and provided consistent guidance to funders participating in IACC ASD Research Portfolio Analysis during the past five years, but has balanced the need for consistency with the need to be responsive to feedback from IACC and from participating funders. This feedback has included suggestions for improving the clarity of the instructions in the guidance, addressing problems encountered in the previous year, and addressing issues that are unique to a specific participating agency or organization. OARC made updates to each year's guidance to address those types of issues and feedback, with the goal of improving the guidance to make the process easier and clearer for participating funders and to ensure the most current, accurate, and precise reporting of data. The updates did not, however, change the overall strategy or methodology for conducting the analysis.

GENERAL COMMENTS OF THE DEPARTMENT OF HEALTH AND HUMAN SERVICES (HHS) ON THE GOVERNMENT ACCOUNTABILITY OFFICE'S (GAO) DRAFT REPORT ENTITLED, "FEDERAL AUTISM ACTIVITIES: BETTER DATA AND MORE COORDINATION NEEDED TO HELP AVOID THE POTENTIAL FOR UNNECESSARY DUPLICATION" (GAO-14-16)

One example of such a clarification, mentioned in the GAO report, was the addition of text to the 2011 and 2012 IACC Portfolio Analysis guidance to clarify the types of projects that fit within two IACC Strategic Plan objectives related to evaluation of new and existing pre-service and in-service training programs. IACC requested that OARC make a clarification in the guidance to assist funders in determining which projects fit within these two objectives, to improve the accuracy and precision of reporting. The following clarification was added in response to IACC's request: *"For these objectives, please include projects that are related to evaluating pre-service or in-service training for service providers. This may include projects that are launching, piloting or testing new or innovative services practitioner training approaches in community based settings, evaluating the effectiveness of these programs in order to improve service practitioner training efforts, and/or contributing to the evidence base supporting various practitioner training methods. This may also include efforts to test new or innovative services approaches in various settings, make improvements in services methodologies, test effectiveness, develop best practices and improve targeting and dissemination of services. Many of these projects may be focused on practical, field-based and community-based approaches used by services agencies and organizations in their efforts to improve services. When including these projects, please be sure to note the evaluative component in the project description to ensure that the projects that are included are designed to test and improve programs rather than simply to administer them (service provision)."* This change in the guidance, which provided additional detail about coding to those two particular objectives, fulfilled IACC's request to OARC for the guidance to be clarified with regard to those objectives, and enabled agencies to report more accurately and precisely the projects that were responsive to these two objectives.

In 2011 and 2012, IACC Portfolio Analysis guidance also was updated in response to participant feedback requesting an option for the OARC to assist participating agencies by offering to conduct the initial coding of projects submitted by the agency, followed by verification by agency officials, to reduce the burden on contributing agencies. Feedback on the new option was overwhelmingly positive. Incorporating such suggestions from participating funders provides important opportunities for refining and optimizing the data collection process, which has been especially important because the Portfolio Analysis is a relatively new effort, having begun in 2008, and this scope and type of data have not been previously collected for most disease/disorder areas, so the process itself was relatively new. With any new process, refinement and adjustments are to be expected and are desirable for the purpose of improving processes. Changes in the guidance such as those described in these two examples did not change the overall methodology of the analysis, but they did provide an opportunity to refine and clarify the instructions, enabling more efficient, accurate, and precise data collection. In the future, OARC will continue to balance the need for maintaining consistency in the methodology of the Portfolio Analysis and accompanying guidance while also solving problems encountered and being responsive to IACC and participant feedback.

With regard to accuracy, GAO cited 16 projects that were missed by OARC's data collection efforts. OARC examined this list of projects and determined that two of the projects cited by GAO were included within OARC's data sets, and the remaining 14 projects either pre-dated the

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involvement of those particular funders in the Portfolio Analysis effort or were projects that were not submitted by the agency at the time of the Portfolio Analysis project but may have been identified as relevant to the autism portfolio at a later date. Since the IACC Portfolio Analysis effort is dependent on agency submissions and cross-verification between the agency and OARC, projects can only be reflected in the report if they are submitted by a participating agency at the time of the data collection for any given year's report. Nevertheless, with the over 5,500 autism-research-related projects spanning both federal agencies and private organizations that have been captured by OARC's Portfolio Analysis effort in the past five years, OARC has provided IACC with access to a level of data describing the public-private research landscape that is not available for most other diseases, disorders, and health conditions either through government or private efforts, enabling them to use this information to assess the status of the field year by year and to make informed recommendations to guide future efforts.

While a core group of funders have been involved in the IACC Portfolio Analysis effort since its inception in 2008, other funders have been invited or have volunteered to participate as the effort has continued. IACC in its discussions of the Portfolio Analysis effort has recognized that the addition of new funders over time may make comparisons of the overall funding from year to year challenging, but decided during its discussions that having the most current and comprehensive information regarding research-related efforts that are ongoing throughout the community is its highest priority. To keep the Portfolio Analysis effort up to date and as comprehensive as possible, IACC has expressed the intent to continue including new funders who may be supporting projects that are relevant to ASD research as the opportunity arises. It is expected that in the future, the pool of funders included in the analysis will largely stabilize as a large proportion of the relevant funders become participants in the effort, and this will enhance comparability of overall funding data over time.

In addition to changes in funders over time, dramatic changes in the number and scope of the objectives in the early years of the IACC Strategic Plan—due to the committee's effort to continually update the Strategic Plan to reflect the current needs of the ASD community—have presented a challenge in terms of comparing data across years in the first three years of the effort. However, in the most recent three years, the stabilization of the Strategic Plan itself, due to the lack of new objectives or major revisions to the objectives made by the committee, has provided improved opportunities for meaningful multi-year comparisons. As the Portfolio Analysis effort continues in future years and the group of participating funders also increasingly stabilizes, OARC anticipates additional opportunities to make meaningful comparisons of data across multiple years. The first of such comparative data, reflecting five years of funding, will be used by IACC to assist them in their 2013 Strategic Plan Update process in the fall of 2013 and will be published in the upcoming edition of the IACC Portfolio Analysis Report and Web Tool that are in preparation. As in past years, all documents used by the committee, the reports, and the database updates will be fully accessible to the public via the IACC website at <http://iacc.hhs.gov/index.shtml>.

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GAO Recommendation 2: To improve the usefulness of IACC data and enhance its efforts to coordinate HHS autism activities and monitor all federally funded autism activities, we recommend that the Secretary of Health and Human Services direct IACC and NIH, in support of IACC, to create a document or database that provides information on non-research autism-related activities funded by the federal government and make this publicly available.

HHS Response: HHS agrees that it is important for Congress and the public to have access to information about non-research autism-related activities. HHS does not concur with the recommendation that IACC and NIH be directed to create a new document or database to catalogue these efforts, as such a project may duplicate ongoing efforts. IACC and several federal agencies already provide publicly accessible information on non-research autism-related activities in several ways described below.

For example, in 2010, OARC, on behalf of the Office of the Secretary of HHS, coordinated the *Report to Congress on Activities Related to Autism Spectrum Disorders and Other Developmental Disabilities Under the Combating Autism Act of 2006 (FY 2006-FY 2009)* to provide information requested by Congress in Section 399DD of the Combating Autism Act of 2006. This report was provided to Congress by the Secretary of HHS to inform Congress of the broad scope of both research and non-research activities that were being supported across HHS and the Department of Education. The 76-page report describes research and services programs and projects across 9 agencies, including education, transition planning, employment, home- and community-based services, legal services, rehabilitative services, inclusion and a variety of other services, and other non-research-related programs, in addition to descriptions of government research programs. The report is available to the public on the IACC website at <http://iacc.hhs.gov/reports/reports-to-congress/FY2006-2009/index.shtml>. The next Report to Congress on federal autism activities, which will encompass descriptions of a broad array of research, as well as services and other non-research programs and projects that were supported by 13 federal agencies and Departments from 2010-2012 is in preparation and is expected to be sent to Congress by the Secretary of HHS and then released to the public in the fall of 2013.

Given that OARC and several federal agencies are already making significant efforts to provide Congress and the public with detailed information about a wide array of federal non-research autism-related activities in publicly accessible formats, it will be important for IACC and OARC to continue to post links to these reports and resources on the IACC web site. OARC will also continue to ensure that IACC sets aside time during its meetings to discuss these kinds of documents, projects, and resources to facilitate coordination and public awareness of these important federal activities.

GAO Recommendation 3: To improve the usefulness of IACC data and enhance its efforts to coordinate HHS autism activities and monitor all federally funded autism activities, we recommend that the Secretary of Health and Human Services direct IACC and NIH, in support of IACC, through its monitoring of federal autism activities – including OARC's annual collection of data for the portfolio analysis and IACC's annual process to update the strategic plan –

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identify projects that may result in unnecessary duplication and thus may be candidates for consolidation or elimination, and identify potential coordination opportunities among agencies.

HHS Response: HHS does not concur with the GAO recommendation if the intent is for the Secretary of HHS to direct the IACC to conduct analysis with the specific goal of identifying duplication of effort, as such an effort would not be likely to provide the type of information on "actual duplication" needed by agency officials in determining overlap prior to making funding decisions. However, HHS will continue to support IACC in the many different types of activities it conducts on an annual basis to coordinate HHS efforts and identify opportunities for cross-agency coordination. HHS does not concur that there is too much federal activity related to autism and that the IACC role should include identification of autism-related projects for elimination.

IACC conducts many different types of activities as a part of its process to monitor federal activities and coordinate federal agency efforts on ASD. These include hosting presentations from and discussions with agency officials regarding their programmatic activities during IACC meetings, examining and discussing published studies and government reports related to government-funded efforts, gathering information on federal activities during the annual Strategic Plan updating process, and conducting quantitative analyses of publications and grant funding. All of these activities help agencies gain various levels of information about other agencies' projects and programs and help agencies identify opportunities for enhanced coordination of efforts.

The IACC Portfolio Analysis and Strategic Plan update processes are designed to do the following: help IACC gather information that can be used to support their efforts to provide advice to the Secretary of HHS, develop an annual Summary of Advances in ASD research, develop and annually update a Strategic Plan for ASD research using the latest information about advances in the field and the status of research funding across the federal government and private funders, monitor federal activities, and coordinate HHS activities. While the Portfolio Analysis and Strategic Plan processes cover a broad range of information about research activities and funding, they are not designed to provide the types of information that would be needed to make individual funding decisions about federal grants. These processes examine the portfolio of Strategic Plan-related activities and funding at a high level, analyzing aggregate data from multiple agencies and organizations, and they examine the portfolio after funding decisions have already been made because the analysis relies on publicly available federal data.

To determine whether or not particular grants may overlap with other grants and thus whether certain grants would be candidates for budget reductions or elimination from consideration for funding would require the determination of "actual duplication" prior to award and not "potential duplication" post-award, which is what is provided by GAO in this report. For example, if IACC were to determine that having more than one grant assigned to each objective in the IACC Strategic Plan constituted "potential duplication" and that, therefore, almost all grants awarded are "potentially duplicative," this would not give program officials enough specificity to help

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them identify actual instances of duplication that they would not have otherwise identified through the extensive processes they already use to determine duplication/grant overlap during the grant award process. Even if IACC further refined its analysis to identify several grants on the same general topic within an objective as "potential duplication," this type of information still would lack adequate specificity to be useful to agency officials who are involved in the grant award process.

IACC's Strategic Plan questions and objectives encompass broad and complex areas of research for which multiple agencies and projects, often using different approaches, would be expected and needed in order to achieve the desired progress and advances in the ASD field. Thus, evidence of multiple projects addressing a question within a field of research would not be deemed to be duplicative. While any time that more than one project is funded there is a potential for duplication, agency funding decisions would not be changed based on potential duplication. They would only be changed in cases of actual duplication, which may be defined as the same researchers requesting funding from more than one source to conduct the same aspects of the same project. Co-funding of the same project by two agencies, the same researcher conducting follow-on projects to a previously funded project, or two researchers addressing a similar question with different approaches would be examples of projects that could look related to a non-expert but are not considered to be overlap or actual duplication.

Determination of "actual duplication" or grant overlap requires detailed subject matter expertise that would allow an individual to distinguish related activities from duplicative activities and access to pre-award data during the period prior to when an award is made. Agency program officials have the responsibility to check each grant for potential overlap with other funding sources prior to award, and these officials have both the expertise and access to grant application data and federal databases, as well as the knowledge of federal rules and policies, that would be required to determine if actual overlap exists. In addition to these issues (lack of adequate subject matter expertise and lack of access to pre-award grant data) that would prevent IACC from being able to add an effective layer of information to the federal grant award process, the committee would be limited by the amount of time the members have in their meetings during the year to carry out such an effort.

IACC typically meets four to six times per year as a full committee (in addition to subcommittee and working group meetings) and is responsible for providing advice to the HHS Secretary, completing an annual update of the Strategic Plan, developing an annual summary of research advances, coordinating HHS activities, and monitoring federal activities. Monitoring federal activities includes not only the Portfolio Analysis effort but also interactions with external invited experts and discussion of agency activities during IACC meetings. Even if all future IACC meeting time were to be used solely to examine the ASD research portfolio, it would be unlikely that the committee could complete a more detailed analysis than that resulting from GAO's intensive one and a half year analysis, which identified only potential duplication. Such information that is limited to potential duplication would not provide an added value for program officials in their already extensive process to determine actual grant overlap prior to funding.

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Program officials already have access to the broad types of information, such as which projects are categorized under each Strategic Plan objective, through the IACC Portfolio Analysis Report and the IACC/OARC Portfolio Analysis Web tool, which they can use as a source of information when making determinations. The IACC/OARC Portfolio Analysis Web Tool is publicly available online at <https://iacc.hhs.gov/apps/portfolio-analysis-web-tool/projects>.

GAO Recommendation 4: To promote better coordination among federal agencies that fund autism research and avoid the potential for unnecessary duplication before research projects are funded, we recommend that the Secretary of Health and Human Services, the Secretary of Defense, and the Secretary of Education, and the Director of NSF each determine methods for identifying and monitoring the autism research conducted by other agencies, including by taking full advantage of monitoring data the IACC develops and makes available.

HHS Response: HHS does not concur with the finding that "Federal Agencies' Coordination and Monitoring of Autism Activities was Limited." HHS agrees with GAO's conclusion that it is critically important to avoid unnecessary duplication in research related to Autism Spectrum Disorders. We have not encountered any actual examples of unnecessary duplication in interactions between agencies, and none were cited in the GAO's report.

HHS has robust procedures in place for avoiding duplication before grant and contract awards are made and to keep the funding decision-making process fair and equitable. In addition, the internal NIH Autism Coordinating Committee (NIH ACC) and IACC provide opportunities for monitoring and collaboration within NIH and across federal Agencies. These policies and coordinating bodies have served HHS well in terms of identifying and preventing duplication prior to making funding decisions. We will continue to monitor the internal NIH ACC procedures, as well as participation on the IACC, to make full use of these opportunities.

IACC is able to use its Portfolio Analysis to broadly track progress of Federal agencies in achieving Strategic Plan objectives. IACC is not equipped with the scientific expertise or access to pre-award data that would be necessary to make an accurate determination regarding grant overlap issues. As the GAO report indicates, NIH funded 81 percent of the autism-related research from fiscal years 2008 through 2012. Therefore, coordination among the NIH Institutes and Centers (ICs) that fund autism research represents a large component of HHS' ongoing efforts to avoid unnecessary duplication in research. To achieve this coordination, NIH convenes meetings of its internal ACC at least monthly. Program, communications, and policy staff from the National Institute of Mental Health (NIMH), the *Eunice Kennedy Shriver* National Institute of Child Health and Human Development (NICHD), the National Institute of Neurological Disorders and Stroke (NINDS), the National Institute on Deafness and Other Communication Disorders (NIDCD), and the National Institute of Environmental Health Sciences (NIEHS) are members of the ACC. ACC members collaboratively plan and co-fund major autism-related research initiatives and scientific workshops, and they review the IACC

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Portfolio Analysis for gaps in research when planning such activities. Moreover, they share information related to autism research activities at their respective Institutes, including information about activities in which the NIH ICs participate or coordinate with other federal agencies. They also share information they learn about nongovernment-funded autism research through participation in scientific meetings and other activities sponsored by nongovernment organizations. Therefore, collaborations and information exchanges through the NIH ACC provide important opportunities for averting unnecessary duplication before it happens, both within and beyond the NIH.

IACC affords another opportunity for cross-Agency information-sharing. It is a forum for announcing major funding initiatives to all IACC members and to others who attend or listen to IACC meetings, including staff from federal agencies and non-government organizations and members of the patient, provider, and research communities, as well as the general public. For example, in the past two years, the following major research initiatives and scientific workshops have been presented to the IACC:

- CDC-sponsored Study to Explore Early Development
- CDC-sponsored Read the Signs Act Early campaign
- NIH-supported Autism Centers of Excellence initiatives
- ARRA-supported JobTIPS Web site
- HRSA-sponsored Combating Autism Act initiatives
- CDC-sponsored Autism Prevalence Workshop
- Workshop on Epilepsy and Autism Co-sponsored by private funders and the NIH
- CDC-NIH sponsored Minnesota Somali Project
- NIMH-sponsored Study of Health Outcomes in Children with Autism and their Families
- NICHD-sponsored National Children's Study
- CDC/HRSA-sponsored study on Changes in Prevalence of Parent-reported Autism Spectrum Disorder in School-aged U.S. Children
- NIH-sponsored workshop and funding initiative on Minimally Verbal ASD

In addition to the NIH ACC and IACC, NIH as a whole has extensive policies in place concerning monitoring and managing potential overlap in funding. Avoidance of duplication *before* funding is the goal, but monitoring and addressing duplication also occurs during review of yearly progress reports from the funded investigators. Avoiding overlap is a formal and critical responsibility of NIH staff, including grants management, program, and review staff. Further, NIH's comprehensive internal database, Information for Management, Planning, Analysis, and Coordination (IMPAC II), provides information systems to support the full life cycle of grants administration, including information about grant applications prior to award. IMPAC II is the database used extensively by NIH grants and program staff to obtain and manage detailed information used for funding decisions, among other things. IMPAC II currently includes grants and applications for NIH, the Food and Drug Administration, the Centers for Disease Control and Prevention, the Agency for Healthcare Research and Quality, the Substance Abuse and Mental Health Services Administration, and the Department of

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Veterans Affairs. The U.S. Department of Agriculture will be added to the database in the next year, and discussion is ongoing with the Department of Defense and the National Science Foundation to investigate the addition of their applications and grants to IMPAC II.

NIH addresses any type of overlap, whether it is scientific, budgetary, or commitment of effort, prior to the issuance of a Notice of Grant Award and while reviewing annual progress reports. Submission of identical applications to one or more components of the Public Health Service (PHS) is not allowed, and NIH will not accept similar grant applications with essentially the same research. If there is partial duplication, the pending application, other applications, or the active award will be modified prior to NIH's funding the pending application. To make these determinations, staff consult, as necessary, with the Principal Investigator, other funding components within NIH, other government agencies, or nongovernment organizations to resolve questions of overlap.

The application instructions require the applicant (1) to indicate whether his/her application has been sent to other agencies outside the PHS and (2) to include on the cover of the application to which agencies the application has been submitted. This information is part of every electronic application. It is also important to note that the application instructions, as well as the NIH Grants Policy Statement (10/2011), which is a term and condition of all NIH grant awards, contain the NIH's policy on similar, essentially identical, or identical applications. To prevent duplicate research from a single investigator or institution, it is the responsibility of program and grants management staff to review routinely Other Support documentation that is provided in the grant application and updated prior to award (and which includes all financial resources whether federal, nonfederal, commercial, or organizational, available in direct support of the key personnel's research endeavors) to determine if there is budgetary, scientific, or time commitment overlap. Review of IMPAC II grants information and Other Support documentation is used to identify potentially overlapping or duplicative applications from different research teams.

Additionally, applications to NIH are grouped by scientific discipline for review by individual Scientific Review Groups. The reviewers can thus easily identify multiple grant applications for essentially the same project. In these cases, application processing may be delayed or the application(s) may not be reviewed. In addition, peer reviewers are asked to rate the significance and innovation of grant applications, including whether it will substantially advance the field and whether the research projects utilize innovative and novel approaches, or address an unmet need.

Appendix VIII: Comments from the National Science Foundation



NATIONAL SCIENCE FOUNDATION

4201 WILSON BOULEVARD, ARLINGTON, VA 22230 | WWW.NSFGOV

October 23, 2013

Dr. Marcia Crosse
Director, Health Care
U.S. Government Accountability Office
441 G Street, NW, Room 5A-14
Washington, DC 20548

Dear Dr. Crosse:

Thank you for providing the National Science Foundation (NSF) an opportunity to comment on the U.S. Government Accountability Office's (GAO) draft report entitled *FEDERAL AUTISM ACTIVITIES: Better Data and More Coordination Needed to Help Avoid the Potential for Unnecessary Duplication* (GAO-14-16).

NSF supports fundamental research across all areas of science and engineering from astronomy to geology to zoology. However, NSF does not generally support biomedical research. With an annual budget of nearly \$7 billion (fiscal year 2013), NSF funds approximately 21 percent of all federally supported fundamental research conducted by America's colleges and universities. NSF support results in scientific and engineering advancements that are central to our nation's future well-being. NSF also supports the preparation of tomorrow's science, technology, engineering and mathematics (STEM) workforce.

As the draft report accurately indicates, NSF is not a member of the Interagency Autism Coordinating Committee (IACC). NSF does not have autism research initiatives or programs. As a result, NSF makes an extremely limited number of autism-related annual awards. Appendix III of the draft report identifies 28 NSF-supported, autism-focused research projects from 2008-2012; during that same period, NSF made on the order of 55,000 awards. Proposals that align with NSF programmatic areas and that might have relevance to autism are reviewed for scientific merit using two criteria: intellectual merit and broader impacts. Reviewers and NSF program officers, who are scientific experts, determine whether the proposed research activity is meritorious. Such research may be funded for reasons not identified in the IACC strategic plan.

Contrary to the draft report's statement, NSF does take steps to prevent duplication. NSF requires that proposals submitted to NSF provide complete information about current and pending support, including funding from other federal agencies, regarding the proposed research activity. As necessary, NSF consults with other agencies regarding potentially duplicative research proposals to ensure that NSF does not fund the same research activity supported by another agency. It should be noted that the cataloging by the IACC of NSF research awards does not suggest that grants in a category, such as "Biology," are necessarily duplicative of other agency awards about the biology of autism. Additionally, NSF provides publicly available information about our research and education awards on NSF's website. NSF also provides this information to the IACC for their portfolio reporting.

NSF welcomes the opportunity to collaborate and exchange information with other federal agencies about science related to autism. NSF will continue to identify NSF-supported research related to autism and provide this information to the IACC. We look forward to receiving your final report.

Sincerely,



Kathryn Sullivan
Senior Advisor
Office of the Director/Office of International and Integrative Activities

Appendix IX: GAO Contact and Staff Acknowledgments

GAO Contact

Marcia Crosse, (202) 512-7114, crossem@gao.gov

Staff Acknowledgments

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

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