



Testimony  
Before the Subcommittee on  
Government Operations, Committee on  
Oversight and Government Reform,  
House of Representatives

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# FEDERAL AUTISM ACTIVITIES

## Funding and Coordination Efforts

Statement of Marcia Crosse  
Director, Health Care

# GAO Highlights

Highlights of [GAO-14-613T](#), a testimony before the Subcommittee on Government Operations, Committee on Oversight and Government Reform, House of Representatives

## 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 Combating Autism Act 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.

This statement is based on GAO's November 2013 report, [GAO-14-16](#), with selected updates. It discusses federal autism activities, including (1) the extent to which federal agencies fund potentially duplicative autism research, and (2) the extent to which IACC and agencies coordinate and monitor federal autism activities. GAO analyzed agencies' data and documents, and interviewed federal agency officials.

## What GAO Recommends

GAO recommended in November 2013 that HHS improve IACC data to enhance coordination and monitoring. HHS disagreed and stated its efforts were already adequate. GAO also recommended that DOD, Education, HHS, and NSF improve coordination. The agencies supported improved coordination, but most disputed that duplication occurs. GAO continues to believe the recommendations are warranted and actions needed.

View [GAO-14-613T](#). For more information, contact Marcia Crosse at (202) 512-7114 or [crossem@gao.gov](mailto:crossem@gao.gov).

May 20, 2014

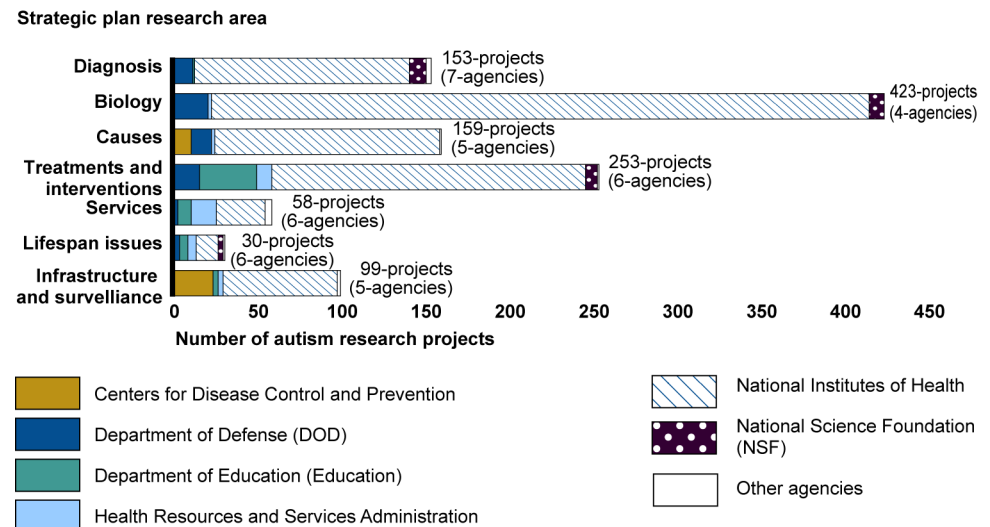
# FEDERAL AUTISM ACTIVITIES

## Funding and Coordination Efforts

### 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 other instances funding similar research may lead to unnecessary duplication. Each agency funded at least 1 autism research project in the same strategic plan objective as another agency and at least 4 agencies funded autism research in the same research area.

**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.

Note: Thirty-one of the 1,206 projects funded by federal agencies from fiscal years 2008 through 2012 are not included in this figure because they were not categorized to a specific research area. At the time of GAO's review, DOD had not submitted data on its fiscal year 2012 research projects, and therefore they were not included in this figure. The "other agencies" are: Administration for Children and Families, Agency for Healthcare Research and Quality, Centers for Medicare & Medicaid Services, Environmental Protection Agency, and the Substance Abuse and Mental Health Services Administration. Not all of these "other agencies" necessarily funded projects in every research area.

The IACC and federal agencies may have missed opportunities to coordinate and reduce the risk of duplicating effort and resources. GAO found that the IACC is not focused on the prevention of duplication, and its efforts to coordinate the Department of Health and Human Services' (HHS) autism research and monitor all federal autism activities were hindered by limitations with the data it collects. Apart from federal agencies' participation on the IACC, there were limited instances of agency coordination, and the agencies did not have robust or routine procedures for monitoring federal autism activities.

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Chairman Mica, Ranking Member Connolly, and Members of the Subcommittee:

I am pleased to be here to discuss our recent work examining federally funded autism activities. 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.<sup>1</sup> The most recent estimates from the Centers for Disease Control and Prevention (CDC) indicate that at least 1 in 68 children in the United States have been identified as having autism. There is no single known cause of autism and there is no known cure. However, research shows that early intervention and treatment services can greatly improve a child's development.

A variety of federal agencies are involved in responding to this important public health concern. From fiscal year 2008 through fiscal year 2012, 12 federal agencies spent a combined total of approximately \$1.4 billion on autism activities: \$1.2 billion on autism research, such as research to identify the causes of autism, and \$200 million on other autism-related activities, such as training to help health care professionals better identify and diagnose autism.<sup>2</sup> Most of these 12 agencies are members of the Interagency Autism Coordinating Committee (IACC). The IACC is a federal advisory committee composed of federal and nonfederal members.<sup>3</sup> The Combating Autism Act of 2006 (CAA) required the IACC to coordinate all autism activities within the Department of Health and

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<sup>1</sup>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. In this statement, the term "autism" is used to refer to autism spectrum disorder.

<sup>2</sup>The 12 agencies are the Department of Defense (DOD); Department of Education (Education); Environmental Protection Agency (EPA); National Science Foundation (NSF); and 8 agencies within the Department of Health and Human Services—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), National Institutes of Health (NIH), and the Substance Abuse and Mental Health Services Administration (SAMHSA).

<sup>3</sup>Federal members of the IACC are from DOD, Education, ACF, ACL, AHRQ, CDC, CMS, HRSA, NIH, and the Food and Drug Administration. The IACC nonfederal members represent individuals with autism and parents of children with autism; as well as members of the autism advocacy, research, and service-provider communities.

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Human Services (HHS) and monitor federal activities related to autism across the federal government.<sup>4</sup> To fulfill these requirements, the IACC holds meetings and has issued several reports including a strategic plan for autism research, which the CAA requires the IACC to develop and annually update. The strategic plan is organized into seven research areas with specific short- and long-term research objectives, and contains a total of 78 objectives.<sup>5</sup> The IACC also issues an annual Autism Spectrum Disorder Research Portfolio Analysis Report. This report is organized by the same seven research areas and includes information on research projects funded by federal and nonfederal entities related to autism, including budget information, for a single fiscal year.<sup>6</sup> 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 projects they fund, helps agencies categorize this research to the specific strategic plan objectives, and prepares the portfolio analysis, which includes this data.

Having multiple agencies fund research in the same area can be appropriate and necessary—for example, for purposes of replicating or corroborating prior research results. It can also be advantageous to be able to draw on different expertise found in multiple agencies. One such advantage is that agencies may be better able to tailor research or other programs to suit their specific missions and needs. However, the involvement of multiple agencies can also make it challenging to identify gaps and efficiently allocate resources across the federal government.

My remarks today will focus on two areas: (1) the extent to which federal agencies fund potentially duplicative autism research and other autism-related activities, and (2) the extent to which the IACC and agencies coordinate and monitor federal autism activities. My remarks are based

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<sup>4</sup>Pub. L. No. 109-416, § 3, 120 Stat. 2821, 2827 (2006). The IACC and other autism activities authorized under the CAA were reauthorized through fiscal year 2014 under the Combating Autism Reauthorization Act of 2011. Pub. L. No. 112-32, 125 Stat. 361 (2011).

<sup>5</sup>The seven research areas are diagnosis, biology, causes, treatment and interventions, services, lifespan issues, and infrastructure and surveillance.

<sup>6</sup>At the time we did our work, the most recent portfolio analysis was published in July 2012 and contained information on research funded in 2010. The IACC also has a companion database to its portfolio analysis, which allows users to view and search projects included in the portfolio analysis.

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primarily on our report, released in November 2013, entitled *Federal Autism Activities: Better Data and More Coordination Needed to Help Avoid the Potential for Unnecessary Duplication*.<sup>7</sup> For this report, we collected data on the research federal agencies funded, including funding amounts, from fiscal years 2008 to 2012 through database searches, review of related documentation, interviews, as well as through the use of data that agencies submitted to OARC.<sup>8</sup> To determine potential duplication in autism research, we identified research projects that were categorized to the same strategic plan objectives. For 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 and was beyond the scope of our study. Additionally, we collected data on non-research activities funded by federal agencies from fiscal years 2008 through 2011, and assessed whether there was actual duplication of these 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 users.<sup>9</sup>

To assess the extent to which the IACC and agencies coordinate and monitor federal autism activities, we reviewed IACC documents, including the strategic plan, and interviewed OARC officials and officials from 10 federal agencies and select nonfederal IACC members. We assessed the IACC's and agencies' coordination and monitoring activities against criteria established by our prior work. These criteria include key practices for interagency coordination and collaboration, and federal internal control standards related to communicating with external entities, including other

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<sup>7</sup>GAO, *Federal Autism Activities: Better Data and More Coordination Needed to Help Avoid the Potential for Unnecessary Duplication*, [GAO-14-16](#) (Washington, D.C.: Nov. 20, 2013).

<sup>8</sup>At the time of our review, DOD had not submitted data on its fiscal year 2012 research projects. As a result, our review did not include data on DOD's fiscal year 2012 autism research.

<sup>9</sup>See, 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).

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federal agencies, and measuring progress on organizational efforts, such as those established through strategic plans.<sup>10</sup>

We conducted the work on which this statement is based, and made selected updates in May 2014, in accordance with generally accepted government auditing standards.<sup>11</sup> Those standards require that we plan and perform the audit to obtain sufficient, appropriate evidence to provide a reasonable basis for our findings and conclusions based on our audit objectives. We believe that the evidence obtained provides a reasonable basis for our findings and conclusions based on our audit objectives. Further details on our scope and methodology are included in our November 2013 report.

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## The Majority of Federally-Funded Autism Research Had the Potential to Be Duplicative

Of the 1,206 autism research projects funded by federal agencies from fiscal years 2008 through 2012, 84 percent—or 1,018 projects—had the potential to be duplicative because the projects were categorized to the same strategic plan objectives or research areas.<sup>12</sup> We found that each of the 11 federal agencies that funded autism research during this period funded at least 1 autism research project in the same strategic plan objective as another agency.<sup>13</sup> In many instances, 3 or more agencies funded research projects under the same objective. For example, 5 agencies awarded approximately \$15.2 million for 20 autism research projects related to one 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 agencies awarded approximately \$4.1 million for 8 autism research projects to develop at least two individualized community-based interventions to improve quality-of-life or health outcomes for the

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<sup>10</sup>See, for example, GAO, *Managing for Results: Key Considerations for Implementing Interagency Collaborative Mechanisms*, [GAO-12-1022](#) (Washington, D.C.: Sept. 27, 2012), and GAO, *Standards for Internal Control in the Federal Government* [GAO/AIMD-00-21.3.1](#) (Washington, D.C.: November 1999).

<sup>11</sup>Our updates were limited to reviewing certain publically available information, such as the most recent strategic plan released by the IACC.

<sup>12</sup>Our findings suggest potential, not actual duplication. Thirty-one projects could not be assessed for potential duplication.

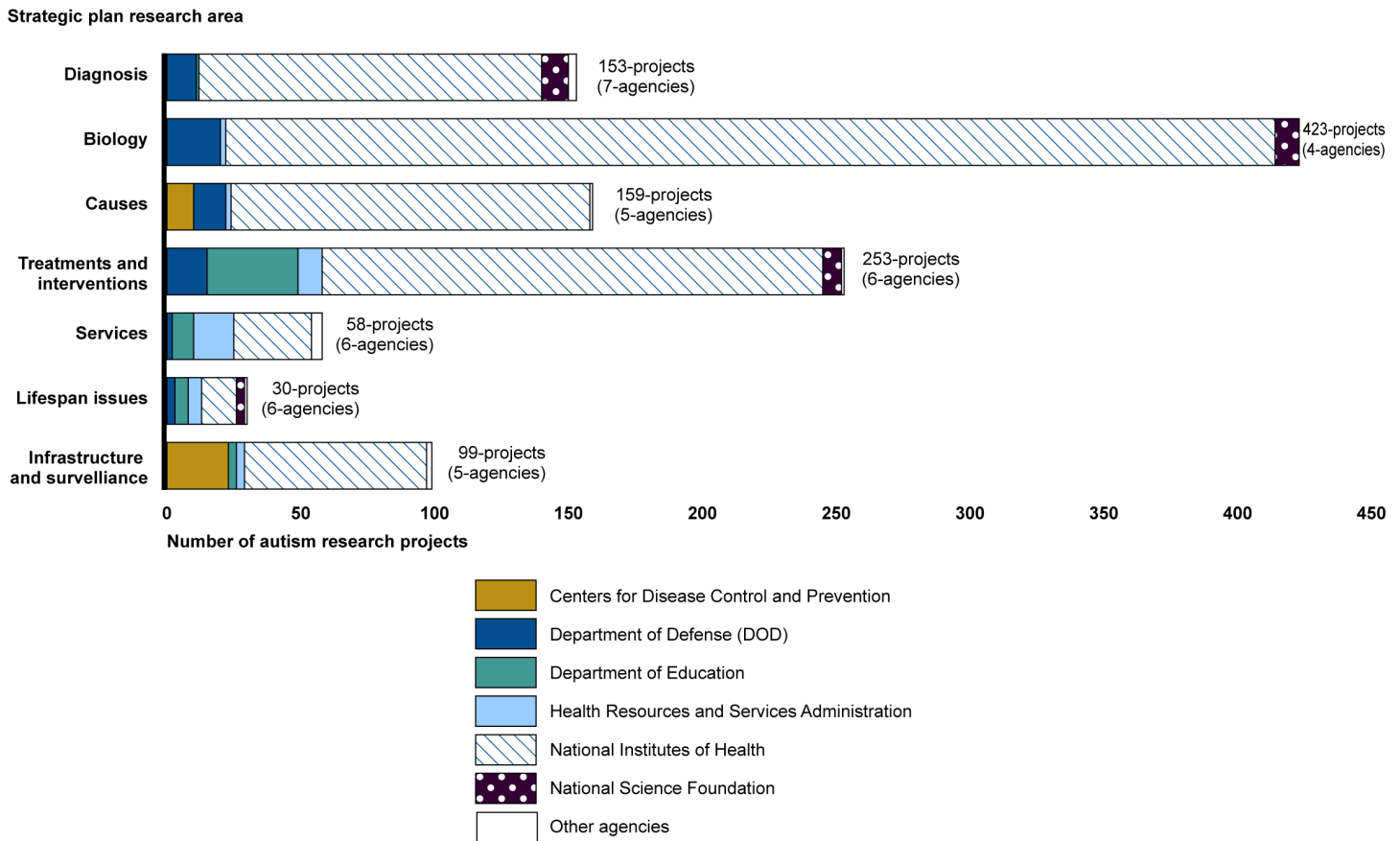
<sup>13</sup>ACL, within HHS, did not fund autism research from fiscal year 2008 through fiscal year 2012; ACL funded one non-research autism-related activity during this time period.

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spectrum of adults with autism. Funding autism research on the same topic may be appropriate and necessary—for example, for purposes of replicating or corroborating results—but in some instances, funding similar autism research may lead to unnecessary duplication and inefficient use of funds.

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 each research area included projects funded by at least four agencies. For example, the diagnosis research area included projects funded by seven different agencies. 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 five of the seven research areas. (See fig. 1.)

**Figure 1: 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.

Note: Thirty-one of the 1,206 projects funded by federal agencies from fiscal years 2008 through 2012 are not included in this figure because they were not categorized to a specific research area. At the time of our review, DOD had not submitted data on its fiscal year 2012 research projects, and therefore DOD's fiscal year 2012 autism research projects were not included in this figure. 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.

Five agencies that funded non-research autism-related activities from fiscal years 2008 through 2011—Administration for Community Living (ACL), CDC, Department of Defense (DOD), Department of Education (Education), and the Health Resources and Services Administration (HRSA)—funded activities that were not duplicative. HRSA and Education both funded training activities related to autism. HRSA's activities included training health care professionals, such as pediatric



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practitioners, residents, and graduate students, to provide evidence-based services to children with autism and other developmental disabilities and their families. The activities also included training 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 focused 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. 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, while the ACL website is broader by focusing on all individuals with autism and other developmental disabilities, their families, and other targeted key stakeholders concerned with autism. Finally, 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.

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

We noted in our November 2013 report that the IACC and federal agencies may have missed opportunities to coordinate federal autism activities and reduce the risk of duplication of effort and resources. Although the CAA requires the IACC to coordinate HHS autism activities and monitor federal autism activities, OARC officials stated 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 stated that it was up to the individual federal agencies to use the information contained in the IACC's strategic plan and portfolio analysis to prevent duplication. Officials from three federal 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. OARC officials acknowledged that the IACC could choose to use data from the portfolio analysis as the basis for specific recommendations regarding areas where interagency coordination could be increased, but to date this has not occurred. OARC officials stated that they do not consider it to be their responsibility to review the data that they collect on behalf of the IACC for

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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.

In our November 2013 report, we recommended that the Secretary of Health and Human Services direct the IACC and NIH, in support of the IACC, to

- identify projects through their 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.

HHS did not concur with our recommendation. The agency stated that such an analysis by the IACC to identify duplication would not likely provide the detail needed to determine actual duplication, and that the role of the IACC should not include identification of autism-related projects for elimination. We agree that further analysis would be needed to identify actual duplication. While the strategic plan objectives, which represent broad and complex areas of research, are useful to identify the potential for unnecessary duplication, we believe that such identification is worthwhile as it can effectively lead to further review by the funding agencies to ensure funds are carefully spent. Agencies can review specific project information to confirm whether research projects associated with an objective are, for example, necessary to replicate prior research results. While funding more than one study per objective may often be worthwhile and appropriate, this type of analysis by agencies would help provide assurance that agencies are not wasting federal resources due to unnecessary duplication of effort. Further, such an analysis could help identify research needs—such as research that is needed to complement or follow-up prior research, or research that requires further corroboration—and move autism research forward in a coordinated manner. We also question the purpose of using federal resources to collect data, if the data are not then carefully examined to ensure federal funds are being used appropriately and efficiently.

Further, we found that the IACC’s efforts to coordinate HHS autism research and monitor all federal autism activities were hindered due to limitations with the data it collects. For example, the guidance and

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methodology for determining what projects constitute research, and therefore should be included in the portfolio analysis, has changed over the years. As a result, the projects included in the portfolio analysis have varied. Such inconsistency makes 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. Additionally, 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.

In our November 2013 report, we made recommendations that the Secretary of Health and Human Services direct the IACC and NIH, in support of the IACC, to

- provide consistent guidance to federal agencies when collecting data for the portfolio analysis so that information can be more easily and accurately compared over multiple years; and
- 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.

HHS did not concur with these recommendations. HHS emphasized that, when collecting data for the portfolio analysis, 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. 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. Additionally, HHS commented that information on non-research autism-related activities was publicly accessible through a report to Congress that the CAA, and its reauthorization in 2011, required of HHS. 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 and regularly-updated information on these activities is an important aspect of fulfilling the IACC's responsibility to monitor all federal autism activities, not just research.

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We also reported in November 2013 that the data used by the IACC was outdated and not tracked over time, and therefore not useful for measuring progress on the strategic plan objectives or identifying gaps in current research needs. Although the IACC did not examine research projects over time, our analysis 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.<sup>14</sup> Recently, in April 2014, the IACC released an update of its strategic plan. This plan included the number of research projects funded from fiscal years 2008 through 2012 under each objective, and the corresponding funding amounts, which may help identify those objectives that have received more funding than others. Although OARC collected specific information on the more recently funded projects—those funded in fiscal years 2011 and 2012—this information was not included in the plan. Detailed project information is needed to effectively coordinate and monitor autism research across the federal government and avoid duplication.

Lastly, we found limited instances of coordination among federal agencies, apart from participation on the IACC. We also found that agencies did not have robust or routine procedures for monitoring federal autism activities. While 5 of the 10 agencies with which we spoke stated that they monitored federal autism activities by searching databases or websites, these searches were narrowly focused or undefined, and some agencies lacked formal policies or procedures for staff to follow. For example, some agencies conducted federal database searches to ensure that a principle investigator was not receiving funding from another agency for the same project; however, these searches would not identify whether agencies were funding similar projects led by different principal investigators.<sup>15</sup> After our November 2013 report was released, HHS informed us that NIH program officials use a database for detection of duplication of scientific content across research applications to help identify similar projects led by either the same or different principal investigators. Although the use of this database may be helpful, HHS did

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<sup>14</sup>For example, while one objective recommended launching 3 projects related to underlying biological pathways of genetic conditions related to autism, 72 projects were funded from fiscal years 2008 through 2012.

<sup>15</sup>Principal 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.

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not provide information indicating that NIH has policies requiring program officials to actually search this database before awarding each research grant. Several agency officials also stated that they rely on their peer reviewers, other experts, and project officers to have knowledge of the current autism research environment. As established in our recent duplication work,<sup>16</sup> it is important for agencies that fund research on topics of common interest, such as autism, to monitor each others' activities. Such monitoring helps maximize effectiveness and efficiency of federal investments, and minimize the potential for the inefficient use of federal resources due to unnecessary duplication.

To promote better coordination among federal agencies that fund autism research and avoid the potential for unnecessary duplication before research projects are funded, we recommended that the Secretary of Health and Human Services, the Secretary of Defense, the Secretary of Education, and the Director of the National Science Foundation (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. DOD concurred with our recommendation to improve coordination among federal agencies, and comments from Education, HHS, and NSF suggested that these agencies support improving the coordination of federal autism research activities. However, Education, HHS, and NSF disputed that any duplication occurs. 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. During the course of our work, Education, HHS, and NSF did not provide any information to show that they had reviewed research projects to ensure that they were not unnecessarily duplicative.

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Chairman Mica, Ranking Member Connolly, and Members of the Subcommittee, this concludes my prepared statement. I would be pleased to respond to any questions that you may have.

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<sup>16</sup>See for example, GAO, *2014 Annual Report: Additional Opportunities to Reduce Fragmentation, Overlap, and Duplication and Achieve Other Financial Benefits*, [GAO-14-343SP](#) (Washington, D.C.: Apr. 8, 2014) and [GAO-13-279SP](#).

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## GAO Contact and Staff Acknowledgements

For questions about this statement, please contact me at (202) 512-7114 or [crossem@gao.gov](mailto:crossem@gao.gov). Contact points for our Offices of Congressional Relations and Public Affairs may be found on the last page of this statement. GAO staff who made key contributions to this statement include Geri Redican-Bigott, Assistant Director; Deirdre Brown; Sandra George; Drew Long; and Sarah Resavy.

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# GAO Highlights

Highlights of [GAO-14-613T](#), a testimony before the Subcommittee on Government Operations, Committee on Oversight and Government Reform, House of Representatives

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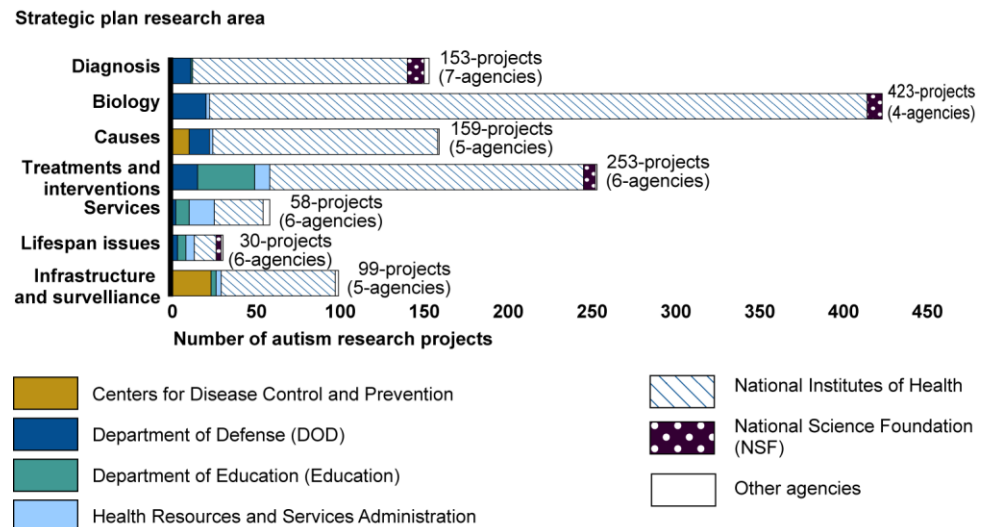
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The IACC and federal agencies may have missed opportunities to coordinate and reduce the risk of duplicating effort and resources. GAO found that the IACC is not focused on the prevention of duplication, and its efforts to coordinate the Department of Health and Human Services' (HHS) autism research and monitor all federal autism activities were hindered by limitations with the data it collects. Apart from federal agencies' participation on the IACC, there were limited instances of agency coordination, and the agencies did not have robust or routine procedures for monitoring federal autism activities.

**Marcia Crosse, Ph.D.**  
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