



May 2016

# FEDERAL AUTISM ACTIVITIES

Agencies Are  
Encouraging Early  
Identification and  
Providing Services,  
and Recent Actions  
Could Improve  
Coordination

Accessible Version

# GAO Highlights

Highlights of [GAO-16-446](#), a report to congressional requesters

## Why GAO Did This Study

Research has shown that early intervention can greatly improve the development of a child with autism. Children with disabilities—including children with autism—can receive intervention services through the Individuals with Disabilities Education Act. Low income children may also receive intervention services through Medicaid or CHIP, health care programs overseen at the federal level by the Centers for Medicare & Medicaid Services and administered by the states. Children of servicemembers may receive services through TRICARE, DOD's health care program.

GAO was asked to review federal autism efforts. This report describes (1) how federal agencies encourage early autism identification and interventions, and (2) the intervention services provided by federal education and health care programs. It also (3) examines steps taken by HHS and federal agencies to improve research coordination. GAO collected information on education programs in five states that were selected for size, activities, and variation in geographic location. GAO analyzed health care program data: fiscal year 2014 TRICARE data and fiscal year 2013 Medicaid and CHIP data—the most recent data available at the time of the review—from another five states selected based on the availability of reliable data. GAO also monitored the implementation of its 2013 recommendations to improve autism research coordination. Education and HHS provided comments on a draft of this report and disagreed that there is potential for unnecessary duplication. GAO continues to believe improved coordination is needed.

View [GAO-16-446](#). For more information, contact Marcia Crosse at (202) 512-7114 or [crossem@gao.gov](mailto:crossem@gao.gov)

May 2016

## FEDERAL AUTISM ACTIVITIES

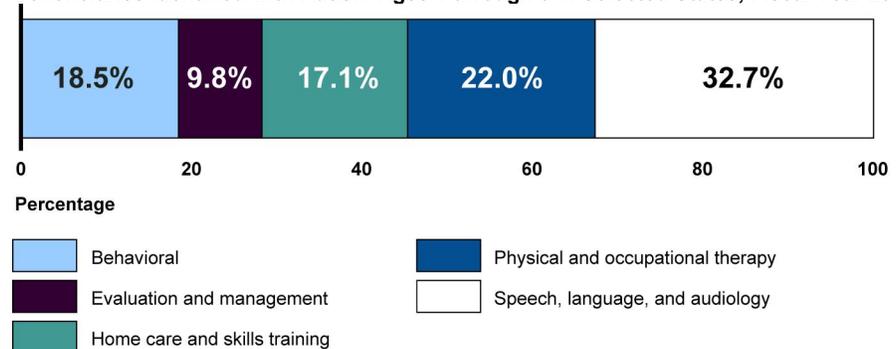
### Agencies Are Encouraging Early Identification and Providing Services, and Recent Actions Could Improve Coordination

#### What GAO Found

Federal agencies have taken various actions to encourage early autism identification and interventions, such as specifically soliciting research in these areas. From fiscal year 2012 through fiscal year 2015, the departments of Defense (DOD), Education, and Health and Human Services (HHS), awarded about \$395 million for research on early identification and interventions for autism.

Federal programs provide a variety of intervention services to young children with autism. When examining the education programs administered by five states and DOD, GAO found that specific actions were taken to help respond to the individual intervention needs of children with autism. Children enrolled in federal health care programs—Medicaid, the State Children's Health Insurance Program (CHIP), or TRICARE—received a variety of interventions. For example, GAO identified about 8,200 young children with autism in five states enrolled in Medicaid or CHIP and found that speech, language, and audiology services were the most common overall; however, the types of services commonly received varied, depending on the age of the child.

**Percentage of Total Intervention Services by Service Category, for Medicaid and CHIP Beneficiaries Identified with Autism Ages 1 through 5 in Selected States, Fiscal Year 2013**



Source: GAO analysis of fiscal year 2013 Delaware, Georgia, Illinois, Kentucky, and Minnesota Medicaid and State Children's Health Insurance Program (CHIP) data reported to the Centers for Medicare & Medicaid Services. | GAO-16-446

HHS has recently taken actions required by the Autism Collaboration, Accountability, Research, Education, and Support Act of 2014 (Autism CARES Act) that could help coordinate federal autism research and implement GAO's prior recommendations. For example, in April 2016, HHS designated an autism coordinator to oversee national autism research, services, and support activities. In 2013, GAO reported that there was limited coordination among agencies. This was especially concerning because GAO also found that 11 federal agencies funded autism research in the same areas—resulting in the potential for unnecessary duplication. At that time, GAO recommended that HHS improve the data it collects on autism research and that federal agencies develop methods to monitor and coordinate this research. GAO believes that HHS's continued fulfillment of certain provisions in the Autism CARES Act could help the department implement GAO's 2013 recommendations.

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### Abbreviations

ABA	applied behavior analysis
ACF	Administration for Children and Families
ACL	Administration for Community Living
AHRQ	Agency for Healthcare Research and Quality
Autism CARES Act	Autism Collaboration, Accountability, Research, Education, and Support Act of 2014
CDC	Centers for Disease Control and Prevention
CHIP	State Children’s Health Insurance Program

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CMS	Centers for Medicare & Medicaid Services
DOD	Department of Defense
EPSDT	Early and Periodic Screening, Diagnostic, and Treatment
FOA	funding opportunity announcement
HHS	Department of Health and Human Services
HRSA	Health Resources and Services Administration
IACC	Interagency Autism Coordinating Committee
IDEA	Individuals with Disabilities Education Act
IEP	individualized education program
IFSP	individualized family service plan
IMPAC II	Information for Management, Planning, Analysis, and Coordination
MSIS	Medicaid Statistical Information System
NIH	National Institutes of Health
NSF	National Science Foundation
PLAY	Play & Language for Autistic Youngsters

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May 20, 2016

Congressional Requesters

Autism is an important public health concern.<sup>1</sup> Research has shown that early intervention can greatly improve a child’s development; however, children are not typically diagnosed until after age 4, according to documentation from the Centers for Disease Control and Prevention (CDC)—an agency within the Department of Health and Human Services (HHS). Information on CDC’s website states that autism can sometimes be detected at 18 months or younger, and a diagnosis by an experienced professional can be considered very reliable at age 2. The Autism Collaboration, Accountability, Research, Education, and Support Act of 2014 (Autism CARES Act) continues ongoing federal activities related to autism, including research and health care provider training.<sup>2</sup> A congressional committee report accompanying the Autism CARES Act strongly encourages federal agencies to focus on early diagnosis and intervention in children ages 5 or younger when implementing the programs and research initiatives authorized by the act.<sup>3</sup> States also play a role in early diagnosis and intervention through the federal education and health care programs that they administer. They may take different approaches in providing these important services, which have the potential to improve the quality of life for children with autism and reduce the long-term costs associated with their education and health.

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<sup>1</sup>What is commonly referred to as autism is a group of developmental disorders—known as autism spectrum disorder—that can range from mild to more severe in their symptoms. In this report, the term “autism” is used to refer to autism spectrum disorder. Autism begins during early childhood and is characterized by impaired social interactions, problems with verbal and nonverbal communication, and repetitive behaviors, or by severely limited activities and interests.

<sup>2</sup>Pub. L. No. 113-157, 128 Stat. 1831 (2014).

<sup>3</sup>H.R. Rep. No. 113-490, at 6 (2014).

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In November 2013, we reported that 11 federal agencies funded autism research from fiscal years 2008 through 2012.<sup>4</sup> We found that there was limited coordination of autism research among these federal agencies. This was particularly concerning since we also found that each of the 11 agencies funded autism research during this time period in the same research objective as another agency. These research objectives are found in the strategic plan published by the Interagency Autism Coordinating Committee (IACC)—a federal advisory committee charged with monitoring and coordinating federal autism research.<sup>5</sup> To enhance coordination and monitoring of federal autism activities, we recommended that HHS take specific actions to improve the usefulness of the data it collects on these activities. We also recommended that HHS and the departments of Defense (DOD) and Education, and the National Science Foundation (NSF) develop identification and monitoring methods to promote better coordination of autism research.

In light of our prior work, as well as to obtain a better understanding of how the federal government supports early diagnosis and intervention for children with autism, you asked us to review federal autism efforts for young children, and recent actions taken by agencies to improve coordination of federally funded research activities.<sup>6</sup> In this report, we

1. describe the mechanisms federal agencies use to encourage early identification and interventions for young children with autism,

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<sup>4</sup>The 11 agencies were the Department of Defense; Department of Education; Environmental Protection Agency; National Science Foundation; and 7 agencies within HHS: Administration for Children and Families, Agency for Healthcare Research and Quality, CDC, Centers for Medicare & Medicaid Services, Health Resources and Services Administration, National Institutes of Health, and the Substance Abuse and Mental Health Services Administration. 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). We have also issued other reports related to federal autism activities, including GAO, *Federal Autism Research: Updated Information on Funding from Fiscal Years 2008 through 2012*, [GAO-15-583R](#) (Washington, D.C.: June 30, 2015). For others, see the *Related GAO Products*, at the end of this report.

<sup>5</sup>In our report, we acknowledged that 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. See [GAO-14-16](#).

<sup>6</sup>For the purposes of this report, the term “young children” refers to children ages 1 through 5.

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2. describe the intervention services young children with autism receive through federal education and health care programs, and
  3. examine the steps HHS and other federal agencies have taken to improve coordination and help avoid unnecessary duplication in autism research.

To describe the mechanisms federal agencies use to encourage early identification and interventions for young children with autism, we reviewed agency documentation, such as agency reports, and interviewed agency officials to determine relevant programs and activities conducted from fiscal year 2012 through 2015. Additionally, we interviewed selected organizations that received grants from agencies through the federal programs we identified to obtain illustrative examples of how these programs were implemented. Lastly, we identified instances when agencies specifically solicited research proposals on early autism identification and interventions for young children by reviewing federal agencies' funding opportunity announcements (FOA)—a mechanism used to solicit research.<sup>7</sup> We also obtained data on the research projects that agencies funded related to these topics, including amounts awarded in each fiscal year and the specific FOAs the research projects were funded through. We obtained most of these data directly from agencies.<sup>8</sup> In the case of the National Institutes of Health (NIH), we searched the agency's online database for fiscal years 2012 through 2015 using specific search parameters.<sup>9</sup> We talked to agency officials about the research they funded, but did not independently verify the topic and study population of the projects identified by the agencies. We assessed the

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<sup>7</sup>These FOAs were either issued during this time period or were issued prior to fiscal year 2012, but were used to accept research proposals during the time period. The FOAs identified could have also funded research projects after fiscal year 2015, but were included in our scope because the FOA was issued and solicited proposals during our time period.

<sup>8</sup>For DOD, we obtain data on the research projects the department funded through its Congressionally Directed Medical Research Program.

<sup>9</sup>We searched NIH's online database—Research Portfolio Online Reporting Tools Expenditures and Results—using the following parameters: (1) included NIH spending categories "autism" and "pediatric;" (2) limited the project search to project title, project terms, and project abstract; (3) conducted one search using the terms "early" and "intervention" or "children" and "intervention;" and (4) conducted one search for the term "diagnosis." Research projects included in both search results were only included once in our review. NIH officials agreed with our approach and confirmed the number and funding amounts of autism research projects identified through this search.

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reliability of the data we obtained by gathering information from agencies on the internal controls they use when recording and maintaining their data. We found the agency data we collected reliable for our purposes.

We used two approaches to determine the intervention services young children with autism receive through federal education and health programs. For federal education programs, we reviewed documentation on early intervention programs and special education programs that provide services to children with special needs, including autism, under the Individuals with Disabilities Education Act (IDEA), as amended. We also interviewed officials from the Department of Education (Education), the agency that oversees the administration of IDEA programs. To learn how children with autism are served through these two IDEA programs, we collected documentation and interviewed officials responsible for administering the programs at the state level, as well as officials from DOD, which administers the IDEA programs for children of servicemembers that are served by DOD schools.<sup>10</sup> We selected a non-probability sample of five states—California, Massachusetts, North Carolina, Ohio, and Texas—to include in our review. We selected states that represented different geographic regions of the United States and that served a large number of children in their early intervention and special education programs. Two states—California and Texas—were selected because they are large states, and perhaps consequently, the number of children identified with autism served in their special education programs was especially large when compared to other states based on state data reported to Education. The remaining three states—Massachusetts, North Carolina, and Ohio—were selected because they were conducting autism-specific activities aimed at young children. Our findings for these five states are not generalizable to other states; further, due to our selection criteria, the states in our review may be conducting more autism-specific activities than other states across the country. Lastly, we reviewed Education data on the number of children ages 3 to 5 in the disability category of autism that were served in states' special education programs in school year 2014-2015. To assess the reliability of these data, we reviewed documentation from Education on the completeness, accuracy, and limitations of these data, as well as interviewed Education officials. We found the data to be sufficiently

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<sup>10</sup>We interviewed DOD and state officials at the program level. We did not speak with local officials who make the decisions on the services provided to individual children with autism in early intervention and special education programs.

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reliable for our purposes, with the exception of Wyoming, for which we do not report data.

To describe the intervention services young children with autism receive through federal health care programs, we examined the experience of young children served by three federal health care programs: Medicaid and the State Children's Health Insurance Program (CHIP) in five selected states—which are overseen at the federal level by the Centers for Medicare & Medicaid Services' (CMS)—and DOD's TRICARE program. We analyzed fiscal year 2013 Medicaid and CHIP fee-for-service claims and managed care encounter data for another non-probability sample of states—Delaware, Georgia, Illinois, Kentucky, and Minnesota—chosen based on the availability and reliability of their reported Medicaid and CHIP data.<sup>11</sup> We also analyzed claims data from DOD's TRICARE program, the military's health care system. Specifically, we examined military treatment facility and purchased care claims data from fiscal year 2014. For both datasets, we analyzed children ages 1 through 5 whose claims indicated they had an autism diagnosis. We analyzed the intervention services these children received by age using a set of procedure codes we selected based on interviews we held with professional associations involved in providing interventions to children with autism, among other information. To assess the reliability and usability of the claims data for our purposes, we reviewed related documentation, such as studies that assessed the reliability of the data, interviewed knowledgeable CMS and DOD officials, and performed checks of the data for consistency and completeness. We found the data were reliable for our purposes. Because our Medicaid and CHIP data are from five states, the results of our analyses of these data are not generalizable across all states. See appendix I for a detailed description of our methodology for analyzing the Medicaid, CHIP, and TRICARE data, as well as study limitations.

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<sup>11</sup>Medicaid and CHIP enrollees may be served through a fee-for-service delivery system where health care providers are paid for each individual service, or they may be served through a managed care organization that accepts a set monthly payment per member for services. Medicaid and CHIP data on managed care services are generally referred to as "encounters." However, for reporting purposes, we use the term "claims" throughout this report to refer to both fee-for-service claims and managed care encounters, unless otherwise specified. Although we did not obtain Medicaid and CHIP claims data from Utah, in the course of our review, we learned about a change to Utah's Medicaid coverage of services for children with autism. As a result, we spoke with Utah officials to obtain additional information on this change.

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To examine the steps HHS and other federal agencies have taken to improve coordination and help avoid unnecessary duplication in autism research, we reviewed documentation and interviewed officials at DOD, Education, HHS, and NSF to determine what actions agencies have taken in response to our November 2013 recommendations.<sup>12</sup> We assessed agencies' actions against criteria established by our prior work and which were the basis of our November 2013 recommendations, including key practices for interagency coordination and collaboration, and federal internal control standards related to communicating with external entities, including other agencies.<sup>13</sup>

We conducted this performance audit from February 2015 to May 2016 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 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.

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## Background

Autism is a developmental disability that can cause significant social, communication, and behavioral challenges. Individuals with autism may communicate, interact, behave, and learn in ways that are different from others. The learning, thinking, and problem-solving abilities of individuals with autism can range from gifted to severely challenged. Some individuals with autism need extensive help in their daily lives, while

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<sup>12</sup>See [GAO-14-16](#).

<sup>13</sup>See, for example, GAO, *Standards for Internal Control in the Federal Government*, [GAO-14-704G](#) (Washington, D.C.: Sept. 10, 2014); *Managing for Results: Key Considerations for Implementing Interagency Collaborative Mechanisms*, [GAO-12-1022](#) (Washington, D.C.: Sept. 27, 2012); *Results-Oriented Government: Practices That Can Help Enhance and Sustain Collaboration among Federal Agencies*, [GAO-06-15](#) (Washington, D.C.: Oct. 21, 2005); and *Standards for Internal Control in the Federal Government*, [GAO/AIMD-00-21.3.1](#) (Washington, D.C.: November 1999).

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others need less. CDC estimates that about 1 in 68 children have been identified as having autism.<sup>14</sup>

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## Diagnosing Autism

Diagnosing autism involves developmental screening and a comprehensive diagnostic evaluation. According to information on CDC's website, developmental screening consists of a short test to tell if a child is learning basic skills when expected based on the child's age, or if the child might have delays. During developmental screening, a doctor might ask the parent some questions or talk and play with the child to observe whether the child plays, learns, speaks, acts, and moves as expected. A delay in any of these areas could be a sign of a problem. The American Academy of Pediatrics recommends that all children be screened for developmental delays and disabilities during regular well-child doctor visits and specifically for autism at 18 and 24 months. If a doctor identifies any signs of a problem, a comprehensive diagnostic evaluation, which provides a thorough review that may include looking at the child's behavior and development, should be performed and parents interviewed. In many cases, the doctor may refer the child and family to a specialist, such as a developmental pediatrician or child psychologist, for further assessment and diagnosis.

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## Interventions for Autism

There are a variety of interventions that are used to treat young children with autism who may face significant social, communication, and behavioral challenges. Typical therapies include physical and occupational therapy, speech and language therapy, and behavioral therapies. For example, occupational therapy can teach a child skills, such as dressing and relating to people in school and social situations, to help the child live as independently as possible. Speech and language therapy can help improve a child's communication skills, such as verbal skills or gestures. There are many types of behavioral therapies used to treat children diagnosed with autism. For example, applied behavior analysis (ABA) is a commonly used framework to provide intervention

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<sup>14</sup>This estimate is based on a review of health and education records of 8-year-old children living in 11 communities across the United States during 2012. Christensen DL, Baio J, Braun KV, et al., *Prevalence and Characteristics of Autism Spectrum Disorder Among Children Aged 8 Years—Autism and Developmental Disabilities Monitoring Network, 11 Sites, United States, 2012*, Morbidity and Mortality Weekly Report, Surveill Summ 2016;65(No. SS-3):1–23.

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services to children with autism. It uses behavior modification principles, such as positive reinforcement, to increase or decrease targeted behaviors. Other interventions can be incorporated into a treatment plan for a child with autism, such as parent-implemented interventions—structured parent training programs through which parents learn intervention practices that they can implement with their child at home and in the community.

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## Federal Education Programs that Serve Young Children with Autism

Children with disabilities—including children with autism—can receive intervention services through IDEA, which is overseen at the federal level by Education.<sup>15</sup> Part B of IDEA requires states to make a free appropriate public education available to eligible children with disabilities as a condition of grant eligibility.<sup>16</sup> In general, under Part B, Education provides formula grants to states to fund a portion of the excess costs incurred by school districts to provide special education and related services—referred to in this report as “special education services”—to students with disabilities ages 3 through 21, including those with autism, who meet certain eligibility criteria.<sup>17</sup> Part B of IDEA requires that the special education services that each individual student needs in order to receive a free appropriate public education be included in the student’s individualized education program (IEP). Each student’s IEP must include,

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<sup>15</sup>IDEA also requires states to develop a system—referred to as a “child find” system—to identify, locate, and evaluate children who are in need of special education and related services and early intervention services within the state. 20 U.S.C. §§ 1412(a)(3), 1435 (a)(5).

<sup>16</sup>There are a number of conditions that states must meet to be eligible for a Part B grant. See 20 U.S.C. § 1412.

<sup>17</sup>Special education includes specially designed instruction to meet the unique needs of a child with a disability. Related services include speech-language pathology and audiology services, psychological services, and physical and occupational therapy, among other services, as are required to assist a child with a disability to benefit from special education and to receive a free appropriate public education. In this report, “special education services” refers to the special education and related services children receive, and “special education programs” refers to the programs administered under IDEA Part B. To receive special education services, a child must have a disability as defined by IDEA, which includes autism, and need special education services because of the disability. Children ages 3 through 9 who are experiencing developmental delays—as defined by the state and as measured by appropriate diagnostic instruments and procedures—in one or more of five developmental domains may receive special education services. The five domains are cognitive development, physical development, communication development, social or emotional development, or adaptive development.

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among other information, the child's present levels of academic achievement and functional performance, measurable annual goals, and the special education and related services to be provided to enable the child to advance appropriately toward attaining the annual goals and to be involved and make progress in the general education curriculum.<sup>18</sup> The IEP is developed by a team of the child's teachers, parents, a school district representative, other related services personnel, and whenever appropriate, the child. DOD is also required to provide special education services to eligible children who are served by its schools, although the department does not receive funding from Education.<sup>19</sup>

Through Part C of IDEA, Education provides formula grants to states to fund a portion of the costs of providing early intervention services to infants and toddlers through age 2 with developmental delays or who have been diagnosed with a physical or mental condition with a high probability of resulting in developmental delays.<sup>20</sup> Under Part C, children are required to have an individualized family service plan (IFSP), which contains information about the services necessary to facilitate a child's development and enhance the family's capacity to facilitate the child's development. Through the IFSP process, family members and service providers are intended to work as a team to plan, implement, and evaluate services tailored to the family's unique resources, priorities, and concerns related to enhancing the development of the child as identified through the assessment of the family.<sup>21</sup> Again, although DOD does not

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<sup>18</sup>20 U.S.C. §§ 1412(a)(4), 1414(d).

<sup>19</sup>DOD is required to provide in its educational programs the substantive rights, protections, and procedural safeguards for students with disabilities under IDEA. 10 U.S.C. § 2164(f).

<sup>20</sup>In this report, "early intervention services" refers to the services children receive, and "early intervention programs" refers to the programs administered under IDEA Part C. A child must exhibit a developmental delay in one of five developmental domains—cognitive development, physical development, communication development, social or emotional development, or adaptive development—as defined by the state, or have a diagnosed physical or mental condition that has a high probability of resulting in a developmental delay. States' policies must define established conditions; autism can be considered an established condition. States may choose to find other children eligible to receive early intervention services, such as at-risk infants or toddlers, who would be at risk of experiencing a substantial developmental delay if early intervention services are not provided to the child.

<sup>21</sup>The IFSP differs from the IEP in several ways. For example, the IFSP revolves around the family and includes outcomes targeted for the child and family, as opposed to focusing on the eligible child as is the case with the IEP.

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receive funding from Education, DOD is responsible for providing early intervention services to infants and toddlers through age 2 who are eligible to enroll in a DOD school.

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## Federal Health Insurance Programs that Serve Young Children with Autism

Some children with disabilities—including children with autism—can receive intervention services through federal health insurance programs such as Medicaid, a joint federal-state program overseen by CMS that finances the delivery of health care services for a diverse low-income and medically needy population. Although federal law sets minimum requirements for eligibility and coverage, states are accorded significant flexibility to design and implement their Medicaid programs, resulting in over 50 state programs that vary, for example, in how health care is financed and delivered.<sup>22</sup> Children whose household incomes are above the threshold for Medicaid eligibility may have health care services financed through their state's CHIP. CHIP is also a joint federal-state program overseen by CMS that states administer under broad federal requirements; and like Medicaid, the programs vary in eligibility and services covered.<sup>23</sup> States can use Medicaid or CHIP to cover services such as physical and occupational therapy, and speech and language therapy, which may also be eligible IDEA early intervention and special education services.

DOD offers health care services for active duty and retired uniformed servicemembers and their families, as well as National Guard and Reserve members and their families through TRICARE.<sup>24</sup> Under TRICARE, beneficiaries may obtain care from military treatment facilities or through its purchased care system of civilian providers. The TRICARE program offers beneficiaries a managed care option, a preferred provider organization option, and a fee-for-service option—as well as other options available to specific eligibility groups. For example, children of active duty

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<sup>22</sup>Each state has a Medicaid state plan—approved by CMS—that describes, among other things, the services and populations that are covered under the state's Medicaid program.

<sup>23</sup>Most states' CHIP eligibility levels are between 200 and 300 percent of the federal poverty level, with the highest eligibility level being 400 percent of the federal poverty level.

<sup>24</sup>Individuals eligible for TRICARE include active duty servicemembers and their dependents, medically eligible National Guard and Reserve servicemembers and their dependents, and retirees and their dependents and survivors. We use the term "family" to describe dependents and survivors of the servicemember.

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servicemembers may also qualify for the Extended Care Health Option, which is a supplementary program that offers additional coverage to beneficiaries with special needs. Among other requirements, beneficiaries must have a qualifying medical condition, which includes autism, to register in the Extended Care Health Option.<sup>25</sup>

In recent years, DOD has had a series of demonstrations to increase the provision of ABA to servicemembers' family members who are diagnosed with autism. In March 2008, DOD began the Enhanced Access to Autism Services Demonstration to increase access to ABA for family members of active duty servicemembers by allowing ABA services to be provided by behavior technicians.<sup>26</sup> In August 2012, DOD expanded ABA coverage to non-active duty family members through the TRICARE basic program. In July 2013, DOD began the ABA Pilot to provide supplemental ABA services to non-activity duty family members who seek additional services.<sup>27</sup>

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## Coordination of Federal Autism Research and Other Activities

The Autism CARES Act 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. The act directs the IACC to monitor autism research—and to the extent practicable, services and support activities—across all relevant federal departments and agencies, including coordination of federal autism activities. The Autism CARES Act also requires the IACC to develop and

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<sup>25</sup>Qualifying conditions include moderate or severe intellectual disabilities, certain physical disabilities, or physical or psychological conditions that result in the exceptional family member being homebound. Servicemembers must also enroll in DOD's Exceptional Family Member Program to qualify for the Extended Care Health Option.

<sup>26</sup>ABA technicians are high school graduate-level paraprofessionals. Under the Enhanced Access to Autism Services Demonstration these individuals were supervised by an ABA certified professional with a bachelor's or higher-level degree. Prior to this demonstration, DOD required ABA services to be provided by an ABA-certified professional with a bachelor's or higher-level degree.

<sup>27</sup>On December 31, 2014, all beneficiaries receiving ABA services using the Enhanced Access to Autism Services Demonstration, the TRICARE basic program, or the ABA Pilot were fully transitioned into the TRICARE Comprehensive Autism Care Demonstration, which consolidated the various ABA options into one demonstration. To enroll in the Enhanced Access to Autism Services Demonstration or the ABA Pilot beneficiaries had to be at least 18 months of age; the Autism Care Demonstration does not have this age requirement. Under the Autism Care Demonstration, a certified behavior technician may provide ABA under the supervision of a master's level or above ABA provider.

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annually update a strategic plan for autism research, as well as for services and support activities, to the extent practicable, and make recommendations to ensure that federal autism activities are not unnecessarily duplicative. Further, it requires the IACC to meet at least twice annually. As of February 2016, the IACC consisted of 16 federal members and 15 nonfederal members, which included representatives from advocacy groups, university professors, individuals with autism, and parents of children with autism.<sup>28</sup>

In our November 2013 report, we found that the IACC's and federal agencies' efforts to coordinate and monitor federal autism activities were limited and that the IACC's data on autism research was outdated. We made recommendations to address these findings. The limited coordination was particularly concerning given that we also found that 84 percent of the autism research projects funded by federal agencies from fiscal years 2008 through 2012 had the potential to be duplicative, because the projects were categorized to the same research objectives in the IACC strategic plan.<sup>29</sup> The research objectives were broad enough to fund research that may not be duplicative, and agencies funding research in the same areas can be appropriate and advantageous—especially with a research topic as complex and heterogenous as autism. Further, funding similar research on the same topic is sometimes appropriate for purposes of replicating or corroborating results. However, agencies funding research in the same area can also lead to unnecessary duplication and wasting of scarce federal resources, if funding decisions are not effectively coordinated. We concluded that the limited coordination and monitoring of federal agencies' autism research 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. Consistent with our November 2013 recommendations, the

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<sup>28</sup>Federal members include representatives from the Administration for Children and Families, Administration for Community Living, Agency for Healthcare Research and Quality, CDC, CMS, DOD, Education, Environmental Protection Agency, Food and Drug Administration, Health Resources and Services Administration, and five institutes within NIH.

<sup>29</sup>Of the 1,206 autism research projects funded by federal agencies from fiscal years 2008 through 2012, we found that the 1,018 projects were potentially duplicative because the projects were categorized to the same research objectives in the IACC strategic plan. For further information, see [GAO-14-16](#).

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Autism CARES Act directs the Secretary of Health and Human Services to designate an existing official within HHS to oversee—in consultation with the Secretaries of Defense and Education—national autism research, services, and support activities. This official is required to implement autism activities, taking into account the strategic plan developed by the IACC, and ensure that federal autism activities are not unnecessarily duplicative.

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## Agencies Used a Variety of Mechanisms to Encourage Early Identification and Interventions

Agencies specifically solicited research on early autism identification and interventions, and funded research in this area as a result of these solicitations. Other mechanisms agencies used to encourage early identification and interventions included funding for access to care and services, training, information resources, and awareness campaigns. Lastly, two HHS agencies have programs that serve young children and include developmental screenings for enrollees.

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## Agencies Solicited and Funded Research on Early Autism Identification and Interventions

Through FOAs, four agencies—DOD, Education, NIH, and the Health Resources and Services Administration (HRSA), another HHS agency—solicited research proposals on early screening, diagnosis, and interventions for young children with autism from fiscal years 2012 through 2015. DOD had 3 FOAs, Education had 4, HRSA had 8, and NIH had 10 FOAs soliciting research in these areas during this time period.<sup>30</sup> As a result of these specific solicitations, these agencies funded research projects totaling approximately \$109 million during this time period.

DOD, Education, NIH, and the Administration for Community Living (ACL), an agency within HHS, funded an additional \$286 million on research related to early screening, diagnosis, and interventions for autism, though not through FOAs that specifically solicited this type of research from fiscal years 2012 through 2015. For example, Education funded autism research through FOAs that solicited projects on early intervention and early learning in special education in general, as well as

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<sup>30</sup>Some of the FOAs issued by DOD, Education, and NIH included multiple topics that a principal investigator could choose to study, including early identification and interventions. Therefore, not all of the applications the agencies received in response to these FOAs may have included research into identification or interventions for children with autism.

through FOAs that solicited research on commercially viable education technology products. NIH also funded intramural research related to autism identification and interventions.<sup>31</sup> See table 1 for the amounts that agencies awarded through FOAs that specifically solicited research on autism early identification and interventions from fiscal years 2012 through 2015, as well as research funded through other solicitations.

**Table 1: Award Amounts for Research on Early Autism Identification and Interventions by Agency, Fiscal Years 2012-2015**

Agency	Award amount for specific solicitations (in dollars in millions)	Award amount through other solicitations (in dollars in millions)	Total award amount (in dollars in millions)
Department of Health and Human Services	Not applicable	Not applicable	Not applicable
National Institutes of Health (NIH)	66.1	265.9	<b>332.0</b>
Health Resources and Services Administration (HRSA)	35.4	0.0	<b>35.4</b>
Administration for Community Living	0.0	1.1	<b>1.1</b>
Department of Education	5.1	16.7	<b>21.8</b>
Department of Defense (DOD) <sup>a</sup>	2.5	1.8	<b>4.3</b>

Source: GAO analysis of agencies' documentation. | GAO-16-446

Notes: Research award amounts in the "specific solicitation" column represent research projects that were funded through 25 funding opportunity announcements (FOA) through which four agencies—DOD, Education, HRSA, and NIH—solicited research proposals on early screening, diagnosis, and interventions for young children with autism from fiscal years 2012 through 2015. Specifically, DOD had 3, Education had 4, HRSA had 8, and NIH had 10 FOAs soliciting research in these areas during this time period. Research award amounts in the "other solicitation" column represent research projects that were funded through other FOAs during this time period.

<sup>a</sup>Department of Defense (DOD) award amounts do not include fiscal year 2015 research projects. DOD has 2 fiscal years to award their research funding; therefore, DOD has until September 30, 2016, to award its fiscal year 2015 research grants.

In addition to soliciting individual research projects, agencies provide funding for centers and networks to conduct research on a variety of autism-related topics, including early identification and interventions.<sup>32</sup> NIH solicits applications for Autism Centers of Excellence to research autism diagnosis, treatment, and optimal means of service delivery,

<sup>31</sup>Intramural research is conducted by scientists in government laboratories.

<sup>32</sup>Centers bring together expertise, infrastructure, and resources focused on major questions about autism. A network consists of multiple sites focusing on a specific topic of research.

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among other topics.<sup>33</sup> For example, officials from one Autism Center of Excellence stated that they were developing eye tracking technology to screen children for autism early in life, as a lack of eye contact is one of the signs of autism.<sup>34</sup> Additionally, CDC has provided supplemental funding to six Autism and Developmental Disabilities Monitoring Network sites to monitor the prevalence of autism in 4-year-old children to better understand their characteristics to increase early identification.<sup>35</sup>

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**Agencies Encouraged Early Autism Identification and Intervention by Providing Non-Research Grants and Developing Information Resources and Awareness Campaigns**

Agencies have established various mechanisms to encourage early screening, diagnosis, and interventions for young children with autism. These mechanisms include grants to improve access to care and services and increase provider training, as well as the development of information resources, and awareness campaigns.

**Grants for Improving Access to Care and Services**

HRSA's autism state implementation grant program provides funding to improve access to comprehensive, coordinated health care and related services for children and youth with autism and other developmental disabilities.<sup>36</sup> Most recently, HRSA provided multi-year funding to nine

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<sup>33</sup>The NIH Autism Centers of Excellence could be a center or a network—at the time of our review, NIH funded three centers and eight networks. In fiscal year 2012, NIH required that centers include at least one project related to the identification and evaluation of interventions or services research. While not a requirement, NIH networks can choose to address interventions and evaluation of interventions and services for autism.

<sup>34</sup>This research includes observing how children ages 18 to 28 months with both developmental delays and typical development look at people and perceive speech. Specifically, children in the study watch pictures of objects and people on a computer screen, as well as watch several short videos in an effort to develop eye tracking methods to diagnose developmental delays early, including autism.

<sup>35</sup>The Autism and Developmental Disabilities Monitoring Network is a group of programs funded by CDC to estimate the number of 8-year-old children with autism and other developmental disabilities living in different areas of the United States. There were 12 sites in the last surveillance year.

<sup>36</sup>HRSA funds the State Public Health Autism Coordinating Center, which coordinates with the state implementation grantees and develops a strategy for defining, supporting, and monitoring the role of state public health agencies in assuring early and timely identification, diagnosis, and intervention.

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states beginning in fiscal years 2013 and 2014.<sup>37</sup> HRSA required its grantees that received funding in September 2013 or later to focus their efforts on promoting early identification, diagnosis, and entry into services based on lessons learned from early state program investments and expressed needs in the field.<sup>38</sup> Officials from one of these states told us that they pursued the grant to connect the siloed infrastructure that exists within the state and identify children with autism at an earlier age than was occurring in the state. This grantee has conducted activities related to screening, assessment, and early intervention—including offering training to primary care providers, health department officials, interdisciplinary child development centers, and other professionals on developmental and autism screening and autism warning signs—and has plans for sustaining the activities beyond the 3-year grant.

## Training

Federal agencies provide funding to train educators and practitioners. For example, in fiscal year 2013, HRSA's two training programs—Leadership Education in Neurodevelopmental and Other Related Disabilities, and Leadership Education in Developmental Behavioral Pediatrics—trained more than 18,000 professionals, including psychologists and pediatricians. These programs provide training on evidence-based services for children with autism and developmental disabilities, and on providing comprehensive diagnostic evaluations to confirm or rule out an autism diagnosis.<sup>39</sup> HRSA also collaborated with CDC in developing Autism Case Training, which is available to the public on CDC's website. Autism Case Training is designed to educate future health care providers on fundamental components of identifying, diagnosing, and managing autism. Education also funds grants for training scholars and

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<sup>37</sup>These states are Arkansas, Georgia, Iowa, Maryland, Michigan, Minnesota, North Carolina, Oregon, and Virginia.

<sup>38</sup>According to HRSA officials, those lessons learned included states describing challenges related to time and reimbursement associated with screening, not knowing where to refer a child for further evaluation, lack of validated screening tool usage by providers, and the lack of trained health care professionals in evaluation and diagnosis.

<sup>39</sup>HRSA also funds the National Interdisciplinary Training Resource Center, which supports HRSA's training grantees by providing technical assistance, disseminating information and resources, and providing program coordination to promote collaboration across the grantees.

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professionals in special education, early intervention, and related services programs, which could include training specific to autism.<sup>40</sup>

## Information Resources

Agencies have developed documents and websites to provide information and resources on interventions for young children with autism. For example, Education funded the National Professional Development Center on Autism Spectrum Disorder to promote the use of evidence-based practices for children and youth with autism. The center identified 27 evidence-based interventions that were shown to be effective through scientific research for individuals with autism. These interventions are included on the center's website, as well as instructions on implementing the interventions and an implementation checklist.<sup>41</sup> ACL funded the organization Autism NOW, which maintains a website that provides information and links to resources, including for early detection, early intervention, and early education.<sup>42</sup> DOD also developed a directory for military families to provide them with information on the educational services that are close to specific military installations in select states.<sup>43</sup> HHS and some of its agencies, such as CDC and HRSA, maintain websites that provide resources for families and individuals with autism, including information on diagnosing autism and interventions. Also, another HHS agency, the Agency for Healthcare Research and Quality (AHRQ) published a report in August 2014 on behavioral interventions for

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<sup>40</sup>See [GAO-14-16](#), appendix IV for more information on HRSA's and Education's training programs.

<sup>41</sup>These interventions include functional behavioral assessment, parent-implemented intervention, and social skills training. For the National Professional Development Center's list of evidence-based interventions, see National Professional Development Center for Autism Spectrum Disorder, *Evidence-Based Practices*, accessed February 2, 2016, <http://autismpdc.fpg.unc.edu/evidence-based-practices>.

<sup>42</sup>For the website, see <http://autismnow.org/>, accessed January 22, 2016.

<sup>43</sup>The directory 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. The directory can be found at [http://apps.militaryonesource.mil/pls/psgprod/f?p=EFMP\\_DIRECTORY:HOME:0::::EKMT:37.10.0.0.0.0.0.0](http://apps.militaryonesource.mil/pls/psgprod/f?p=EFMP_DIRECTORY:HOME:0::::EKMT:37.10.0.0.0.0.0.0), accessed January 22, 2016. This information is also available in a pdf format.

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autism that focused on children from birth to age 12.<sup>44</sup> According to AHRQ documentation, this report could be used to, among other things, provide clinicians who treat children with autism the evidence needed for different treatment strategies.

Furthermore, ACL provides funding to the University Centers for Excellence in Developmental Disabilities Education, Research, and Service, which was established in 1963 to help ensure that Americans with disabilities can be independent and productive.<sup>45</sup> ACL's funding supports, in part, the centers' core functions, which include information dissemination, research, and training of students and fellows in multiple professional disciplines, as well as community training to professionals working in multiple disciplines supporting individuals with disabilities. According to ACL officials, while autism is not a specific area of emphasis for the centers, a substantial number of their information dissemination, research, and training activities address autism. For example, according to ACL officials, one center disseminated autism guidelines to programs that serve young children in its state, while another center implemented a project to examine ways to reduce barriers to conduct screening for developmental disabilities, including autism, in underserved populations.

## Awareness Campaigns

Multiple federal agencies are involved in producing awareness campaigns related to the identification of developmental delays. In March 2014, a group of HHS agencies—the Administration for Children and Families (ACF), ACL, CDC, CMS, HRSA, NIH, and the Substance Abuse and Mental Health Services Administration—and Education launched the *Birth to 5: Watch Me Thrive!* initiative to encourage developmental and behavioral screening and support for children—including those with autism—their families, and the providers who care for them. The initiative seeks to celebrate milestones, promote universal screening, identify possible delays and concerns early, and enhance developmental supports. In addition, CDC's "*Learn the Signs. Act Early.*" initiative promotes awareness of healthy developmental milestones in early

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<sup>44</sup>AHRQ also funded a systematic evidence review conducted by the Vanderbilt Evidence-based Practice Center to support the U.S. Preventive Services Task Force in making new clinical preventive recommendations for screening for autism in young children. The review concluded that additional research is needed to determine the benefits and harms of screening the general population.

<sup>45</sup>There are currently 67 such centers located in university settings in every state and territory.

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childhood, the importance of tracking each child’s development, and the importance of acting early if concerns are identified. The 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, to promote “*Learn the Signs. Act Early.*” messages and tools, and improve early identification efforts in their states and territories.

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### Two Federal Agencies’ Programs that Serve Children Include Screenings to Identify Developmental Concerns Early

ACF and HRSA have programs that include developmental screenings for enrollees. ACF’s Head Start and Early Head Start programs promote the school readiness of young children from low-income families from birth to age 5.<sup>46</sup> Head Start and Early Head Start programs also support the mental, social, and emotional development of children. In addition to education services, programs provide children and their families with health, nutrition, social, and other services. All children in Head Start are required to receive developmental screening—including speech, hearing, and vision—within 45 days of the child’s entry into the program.<sup>47</sup> Children who need further specialized assessment to determine whether they have a disability, such as autism, may be referred for an evaluation.

HRSA has three programs that seek to reduce the age at which children are screened for developmental delays.

- **Title V Block Grant:** This program provides grants to all states to implement plans that address the health services needs within the state for the target population of mothers, infants, and children, including children with special health care needs.<sup>48</sup> According to HRSA officials, as part of this program, 40 states have selected to address a new National Performance Measure looking at the percent of children ages 10 months to 71 months receiving a developmental screen using a parent-completed screening tool. The states’ intent in

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<sup>46</sup>ACF expanded Early Head Start to infants and toddlers in child care and family child care settings through Early Head Start-Child Care Partnerships. This program provides resources to enhance learning environments and provides comprehensive services, including health and developmental screening and linkages to medical, dental, nutrition, vision, and mental health services.

<sup>47</sup>Screening consists of standardized health screening and developmental screening. 45 C.F.R. § 1308.6(b) (2015).

<sup>48</sup>Social Security Act, as amended, Tit. V, § 501(a), codified at 42 U.S.C. § 701(a).

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selecting this measure is to increase the proportion of children, including those with autism, who are screened at a younger age and who receive treatment.<sup>49</sup>

- **Early Childhood Comprehensive Systems Program:** This program awards grants to states and organizations with the goal of ensuring that all children birth to age 3 are receiving the appropriate services at the appropriate time. The program brings together primary care providers, teachers, families, and caregivers to develop seamless systems of care for children from birth to age 3 using one of three strategies. One of these strategies is increasing developmental screening of young children to identify and treat problems early, such as autism.<sup>50</sup> In 2013—the most recent grant competition—15 states received grants to implement this strategy.<sup>51</sup>
- **Federal Home Visiting Program:** HRSA, in partnership with ACF, provides funding to states for the Home Visiting Program, which supports pregnant women and families, and helps at-risk parents of children from birth to kindergarten access resources and develop skills to raise children who are physically, socially, and emotionally healthy and ready to learn. According to HRSA officials, children enrolled in the Home Visiting Program receive an initial baseline developmental screening and may receive additional screening depending on how the program is administered in the state.<sup>52</sup> In 2014, HRSA revised this program to support the goal of reducing the age of diagnosis of developmental disabilities, including autism, by bringing together a select group of grantees to, among other things, identify

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<sup>49</sup>According to HRSA officials, the data for the National Performance Measure will be collected annually as part of the National Survey of Children's Health; and beginning in 2016, the newly revised National Survey of Children's Health will be administered by the U.S. Census Bureau. State data will be reported in the annual application or report beginning in calendar year 2017.

<sup>50</sup>The other strategies are mitigating toxic stress and trauma in infancy and early childhood, and improving state infant and toddler child care quality improvement efforts.

<sup>51</sup>These states are: Arizona, Connecticut, Hawaii, Iowa, Kansas, Minnesota, New Jersey, New Mexico, Nevada, North Dakota, Oregon, Texas, Utah, Washington, and Wyoming.

<sup>52</sup>Each state has its own system in place to determine eligibility for the Home Visiting Program. The frequency of developmental screening thereafter would depend on each state's specific program protocol for developmental screening, the evidence-based model that is delivering the services, and the results of the initial developmental screening.

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methods to increase the percentage of children who receive a developmental screening.

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## State and Federal Education and Health Care Programs Provide a Variety of Intervention Services to Young Children with Autism

Individualized intervention services are provided to young children with autism through IDEA early intervention and special education programs; additionally, the five states we examined and DOD have taken specific actions to help respond to the needs of children with autism that they serve. Data on children with autism served through IDEA special education programs is likely underreported as some of these children may be counted in other disability categories, such as the development delay category. Children enrolled in federal health care programs—Medicaid, CHIP, or TRICARE—received a variety of intervention services through these programs.

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## Education Programs Provide Young Children with Autism Individualized Interventions; Selected States and DOD Conducted Autism-Specific Activities

Intervention services provided to young children with autism through IDEA early intervention and special education programs are individualized to the needs of each child; additionally, selected states and DOD have taken specific actions to help respond to the needs of children with autism that they serve. According to IDEA regulations, the services a child with autism receives are determined by the team that develops the child's IFSP (for children in early intervention programs) and IEP (for children in special education programs), which includes the child's parent, and must be individualized to the child.<sup>53</sup> Officials from some of the five states we spoke with—California, Massachusetts, North Carolina, Ohio, and Texas—and DOD made comments regarding the need for individualized services regardless of a child's diagnosis. For example, some state officials commented that specific methodologies or services—such as ABA—could be provided to a child within the context of IDEA-required services if these services are identified as a need for that child, regardless of whether the child has autism or another type of developmental disability. Further, children with autism have needs that can vary considerably and therefore the services provided to these children would vary. DOD officials stated that children with autism who are eligible for special education services—like children with other disabilities—can be provided specialized instruction, intervention

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<sup>53</sup>Among other things, the IFSP and IEP outline the services a child is to receive. When developing the IFSP, the team must also consider the unique needs of the child and family to achieve the results and outcomes identified in the IFSP.

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strategies, modifications of the general education curriculum, and other related services, such as occupational therapy, physical therapy, and speech and language services, depending on the individual needs of the child.

The five states we examined and DOD reported taking specific actions to help respond to the needs of young children with autism that they serve. Some of these actions are provided to children as part of IDEA early intervention or special education programs, while others are provided in addition to these programs. The following are examples of actions taken.

#### California

California has 21 regional centers in the state that administer California's early intervention program. According to California officials, funding is made available to each center in order to have an autism specialist on staff that coordinates and directs the diagnostic and treatment practices for the families that they serve.

#### Massachusetts

In 1998, Massachusetts began the autism specialty services program to supplement its early intervention program. If a child has an autism diagnosis and is enrolled in Massachusetts' early intervention program, the child can also enroll in the autism specialty services program and receive autism-specific early intervention services, in addition to general early intervention services. According to Massachusetts officials, the state began the autism specialty services program because many general early intervention providers did not have the appropriate skill set to work with children with autism. Massachusetts has approved 17 providers for autism specialty services across geographic areas. The families choose providers, who are generally in their area, and the providers conduct intake assessments. According to state officials, under the autism specialty services program, children usually receive 10 to 30 hours a week of intensive behavioral intervention in their homes or care centers, in addition to general early intervention services. The autism specialty services program uses interventions for autism including the Early Start Denver Model, Floortime, and ABA.<sup>54</sup>

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<sup>54</sup>The Early Start Denver Model is a parent-implemented intervention and is designed for children 12-36 months up to 48-60 months and emphasizes development of play skills, relationships, and language. Floortime is a specific technique to both follow the child's natural emotional interests and at the same time challenge the child toward increased mastery of the social, emotional, and intellectual capacities.

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According to Massachusetts officials, 1,842 children up to age 3 received autism specialty services in the state's fiscal year 2015. At the time of our review, Massachusetts did not have waiting lists for the autism specialty services program. Massachusetts officials stated that there are waiting lists to get an autism diagnosis—a requirement to receive the specialty services—especially in the western part of Massachusetts.<sup>55</sup> Massachusetts uses a combination of state funding, Medicaid, and private insurance to pay for the program.

## North Carolina

In 2010, North Carolina partnered with the Carolina Institute for Developmental Disabilities at the University of North Carolina at Chapel Hill to develop clinical guidelines for early intervention services for children with autism. This effort was partially funded by ACL and HRSA grants. The guidelines outline how to integrate information on autism into the state's early intervention program and contain information on screening for autism, primary models of interventions for autism, and working with parents to implement interventions. Additionally, in 2014, North Carolina worked with professionals at the University of North Carolina at Chapel Hill's TEACCH Autism Program to organize and conduct training for clinicians in 11 of the state's 16 Children's Developmental Services Agencies—the agencies that administer the state's early intervention program.<sup>56</sup> The training, funded by a HRSA grant, featured the use of the Autism Diagnostic Observation Schedule, Second Edition—a semi-structured assessment of communication, social interaction, play, and restricted and repetitive behaviors for individuals suspected of having autism.

North Carolina's special education program has developed an autism plan that outlines goals related to building capacity within the school districts to strengthen the provision of autism interventions. For example, this plan includes goals for providing training to teachers related to serving children with autism. North Carolina's special education program also holds an annual conference that gathers together education

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<sup>55</sup>While a child is waiting for a diagnosis, the child could already be receiving general early intervention services, which can include services to address autism, such as occupational therapy.

<sup>56</sup>The University of North Carolina's TEACCH Autism Program is a system of community regional centers that offer clinical services and conduct trainings and research to meet needs of individuals with autism, their families, and professionals across the state of North Carolina.

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professionals and parents of children with disabilities and includes sessions on serving children with autism. According to North Carolina officials, the state also provides funding to autism teams in local school districts that submit a plan on how they will strengthen the instructional practices and services for children with autism in their district, including the use of best practices.

## Ohio

Beginning in 2008, Ohio funded the Autism Diagnosis Education Project, which facilitates partnerships between community-based primary care physicians and professionals providing early intervention services to increase access to local and timely standardized, comprehensive diagnostic evaluations for children suspected of having autism. In this program, once an early intervention team has a question about whether a child being served might have autism, the team works with a physician located near the child to make (or rule out) an autism diagnosis. Since its inception, the project has expanded to include 46 participating counties, 330 early intervention professionals, and 39 partner physicians, and the average age of diagnosis has decreased to 29 months. From January 1, 2013, through May 21, 2015, 301 children were assessed in the program and 52 percent were diagnosed with autism. This project is funded through state funds.

In 2011, Ohio began to implement an early intervention program across the state, referred to as the Play & Language for Autistic Youngsters (PLAY) project. PLAY is a parent-implemented intervention. Specifically, the PLAY project trains early intervention specialists on certain principles, methods, and techniques that emphasize following the child's lead as a means for improving social impairment, a core symptom of autism. These early intervention specialists teach parents how to implement and use the intervention in everyday interactions with their child—PLAY providers ask parents to implement PLAY 15 to 20 hours a week. The state has held four trainings since 2011 with about 150 participants.<sup>57</sup> According to Ohio officials, of Ohio's 88 counties, 45 have early intervention specialists who are either trained, or are in the process of being trained, in PLAY. An additional 17 counties have access to PLAY providers. For children enrolled in Ohio's early intervention program, the PLAY curriculum may be indicated as an early intervention service need on a child's IFSP if the

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<sup>57</sup>The intensive training included a 4-day initial training, as well as follow-up training over the course of a year. Once an individual completes all the training, he or she becomes certified in PLAY.

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Texas

IFSP team believes that the PLAY methods and strategies can better help address the family's outcomes than more traditional service delivery methods, according to Ohio officials. The state, which funds the PLAY project trainings through its general revenue fund, has received positive feedback from the providers and families involved in the PLAY project.

In 2007, Texas began requiring the team that develops an IEP to consider 11 strategies when forming IEPs for children diagnosed with autism enrolled in its special education program through what is known as the Autism Supplement.<sup>58</sup> According to Texas officials, the Autism Supplement was designed so that the IEP team would look at the unique characteristics of children with autism. Because not all strategies may be suitable for use with every child, the team has the option to exclude any of the 11 strategies from the IEP, but must provide a written rationale for the exclusion.

In 2008, Texas established the Autism Program, which provides ABA to children diagnosed with autism. According to Texas officials, the purpose of the program is to make ABA more accessible, particularly to children diagnosed with autism who are having difficulty in school. The Autism Program is not part of Texas' special education program, but frequently serves children who are enrolled and receiving services through its special education program. According to Texas officials, the program works with the school districts to avoid duplication of services the districts provide and to make ABA services available after school. Board certified behavior analysts provide oversight and treatment plans; actual treatment services are largely provided by registered behavior technicians.

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<sup>58</sup>Prior to 2007 the Autism Supplement included 7 strategies for the IEP to consider; however, in 2007 it was updated to include 11 strategies. These strategies are based on peer-reviewed or research-based educational programming. The 11 strategies are (1) extended educational programming, including extended school day/extended school year services; (2) daily schedules reflecting minimal unstructured time; (3) in-home and community-based training to assist the student with acquisition of social/behavioral skills; (4) use of positive behavior support strategies; (5) futures planning for integrated living, work, community, and education environments; (6) parent and family training; (7) a suitable staff-to-student ratio based on the student's learning level; (8) communication interventions; (9) social skills support; (10) professional development for those working with students with autism; and (11) teaching strategies based on peer-reviewed research for students with autism (e.g., ABA, visual supports). The 11 strategies listed are not specific to children with autism and may apply to any children who need an IEP; however, the requirement that the strategies be considered applies to children diagnosed with autism only.

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According to Texas officials, about 295 children were served by the Autism Project in the state's fiscal year 2014—84 of which were ages 3 through 5. According to these officials, the program is funded through Texas' general revenue fund and a limited amount of private insurance reimbursement. At the time of our review, the program maintained a waiting list of about 1,150 children and had eight providers in six communities due to limited funding, so very few counties in Texas were covered. State officials noted that this number was likely to increase due to action taken during a previous state legislative session to increase funding.

## DOD

In April 2015, after learning about the PLAY project in Ohio, the Wright-Patterson Air Force Base in Ohio began a PLAY project pilot funded for one year by the Air Force Surgeon General. Two full time staff were hired and trained in PLAY. The pilot has provided PLAY training to 24 enrolled families as an intervention parents can implement with their children diagnosed with autism ages 18 months to 6 years to improve social interactions.<sup>59</sup> PLAY is a transportable intervention parents can take with them when they move to a new duty station. In April 2016, Air Force officials told us that the pilot had been funded through fiscal year 2019. DOD officials told us that it supports continued Air Force funding to allow sufficient time to determine outcomes of the pilot. Additionally, according to DOD officials, autism specialists are available to all DOD schools needing assistance with the education of a child age 3 and older with autism.

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## Number of Children with Autism Receiving Intervention Services through Special Education Programs is Likely Underreported

Data reported to Education from 49 states and the District of Columbia indicate that approximately 66,000 children ages 3 through 5 with autism received services in school year 2014-2015.<sup>60</sup> However, this is likely an undercount of the children with autism receiving special education services, because children with autism may not be reported to Education under the autism disability category. For children enrolled in special education programs, states are required to report to Education the number of children receiving services by disability category, including

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<sup>59</sup>Although focused on children age 18 months to 6 years, one child age 17 is enrolled in the pilot.

<sup>60</sup>Wyoming's data were not available due to questionable data quality, according to Education documentation.

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autism. However, states may use a general disability category, “developmental delay,” when reporting, either because the child may not yet be diagnosed with autism, or the child may be diagnosed, but the parents prefer to use the general disability category for privacy purposes.<sup>61</sup> Further, communication difficulties are a typical symptom of autism, and Education, DOD, and some state officials also told us that children with autism may be reported under the disability category “speech and language impairment.”<sup>62</sup> Children who are placed in the “developmental delay” or “speech and language impairment” category would not appear in the autism category. Certain states’ use of disability categories may also influence the number of children with autism reported by the state. For example, California and Texas do not allow the use of the “developmental delay” category. Ohio pays its school districts based on the number of children served and their disability categories; school districts get more funding for students in the “autism” disability category than those in the “developmental disability” category.<sup>63</sup> See appendix II for the number of children ages 3 through 5 in states’ special education autism category, by state, in school year 2014-2015.<sup>64</sup>

The actual number of children with autism receiving early intervention services is also unknown. States are required to report to Education the total number of children served under early intervention programs, but not by disability category. DOD also does not collect these data. DOD and Education officials both stated the specific disability designation of a child does not dictate the types of early intervention services that a child receives. Further, it is common for children under age 3 to not have a specific diagnosis.

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<sup>61</sup>Under IDEA, states may use the “developmental delay” category until a child is age 9. States have flexibility to adopt an earlier age range than this.

<sup>62</sup>We also heard other categories children with autism could be placed under. For example, DOD officials commented that children with autism could be placed in the “other health impaired” or “intellectual disability” category. An official from one state also commented that children with autism could be placed in the “other health impaired” category.

<sup>63</sup>Other states may have similar funding structures, but of the five states we spoke with, Ohio was the only one with this funding structure.

<sup>64</sup>DOD officials told us that in September 2015, DOD provided special education services to 40 children ages 3 through 5 identified as being diagnosed with autism, according to a single day total generated via a system-wide snapshot.

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## Young Children with Autism Enrolled in Selected States' Medicaid or CHIP Programs, or TRICARE Received a Variety of Intervention Services

### Medicaid and CHIP

Children enrolled in Medicaid or CHIP from our five selected states—Delaware, Georgia, Illinois, Kentucky, and Minnesota—received a variety of intervention services during fiscal year 2013.<sup>65</sup> Specifically, we identified 8,208 children ages 1 through 5 with autism in these states and almost all received intervention services.<sup>66</sup> Children age 5 accounted for the largest age group of children that we identified with autism; however, a large proportion of children were ages 3 and 4.<sup>67</sup> We also found that nearly 20 percent of children identified with autism were ages 1 or 2. See figure 1 for the distribution of children enrolled in Medicaid or CHIP from these five states and identified with autism by age.

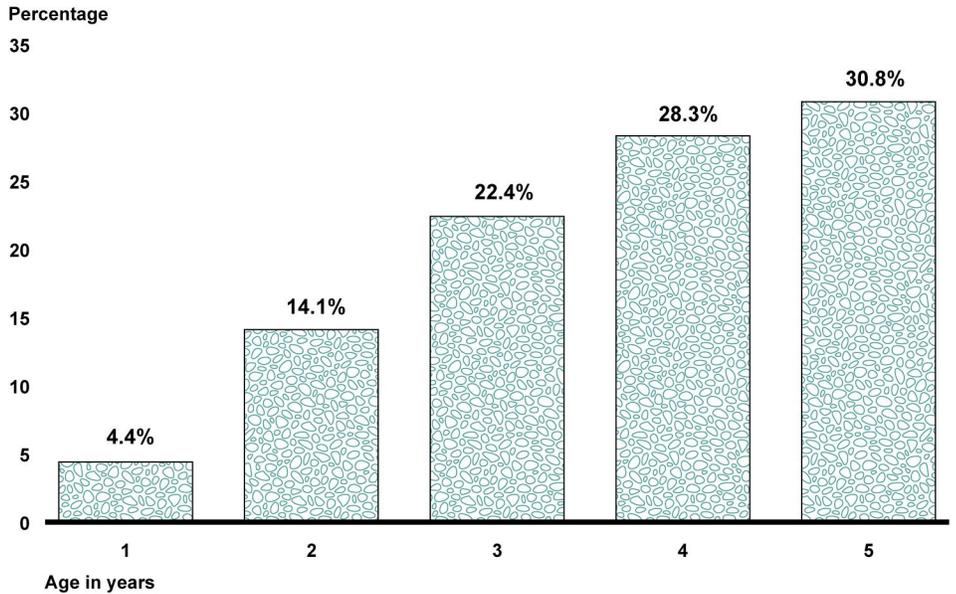
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<sup>65</sup>Among other requirements, children's families must meet states' income threshold to be eligible to enroll in Medicaid or CHIP.

<sup>66</sup>About 1 percent of children we identified with autism did not receive intervention services in fiscal year 2013 through Medicaid or CHIP. This could be for a variety of reasons. For example, some children may not have needed the intervention services included in our review during this time period. In addition, children could have received services through other means, such as private health insurance.

<sup>67</sup>Reported age reflects the age of the child at the beginning of fiscal year 2013.

**Figure 1: Age of Children Identified with Autism Enrolled in Medicaid or CHIP in Selected States, Fiscal Year 2013**

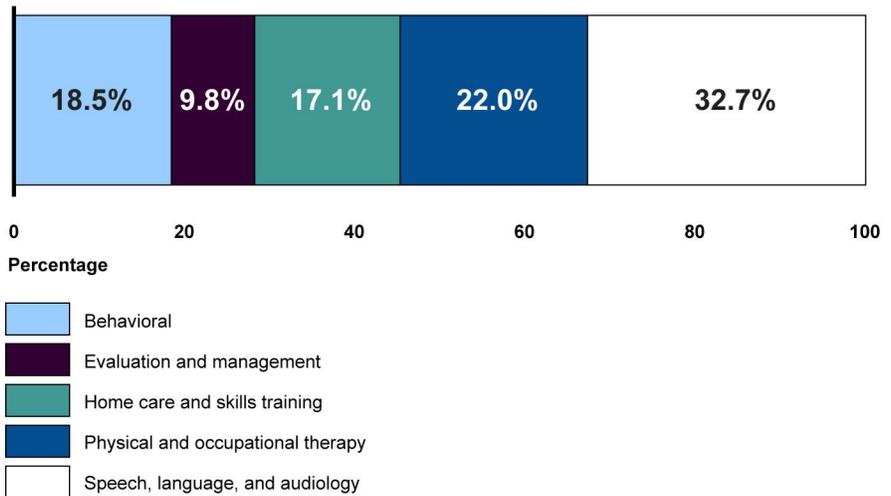


Source: GAO analysis of fiscal year 2013 Delaware, Georgia, Illinois, Kentucky, and Minnesota Medicaid and State Children's Health Insurance Program (CHIP) data reported to the Centers for Medicare & Medicaid Services. | GAO-16-446

Note: Age reflects the child's age at the beginning of fiscal year 2013.

Over half of the services young children identified with autism received were within the speech, language, and audiology category and the physical and occupational therapy category—with the former category making up about one-third of the total intervention services received by these children in fiscal year 2013. See figure 2 for the percentage of intervention services received by service category.

**Figure 2: Percentage of Total Intervention Services by Service Category, for Medicaid and CHIP Beneficiaries Identified with Autism, Ages 1 through 5 in Selected States, Fiscal Year 2013**

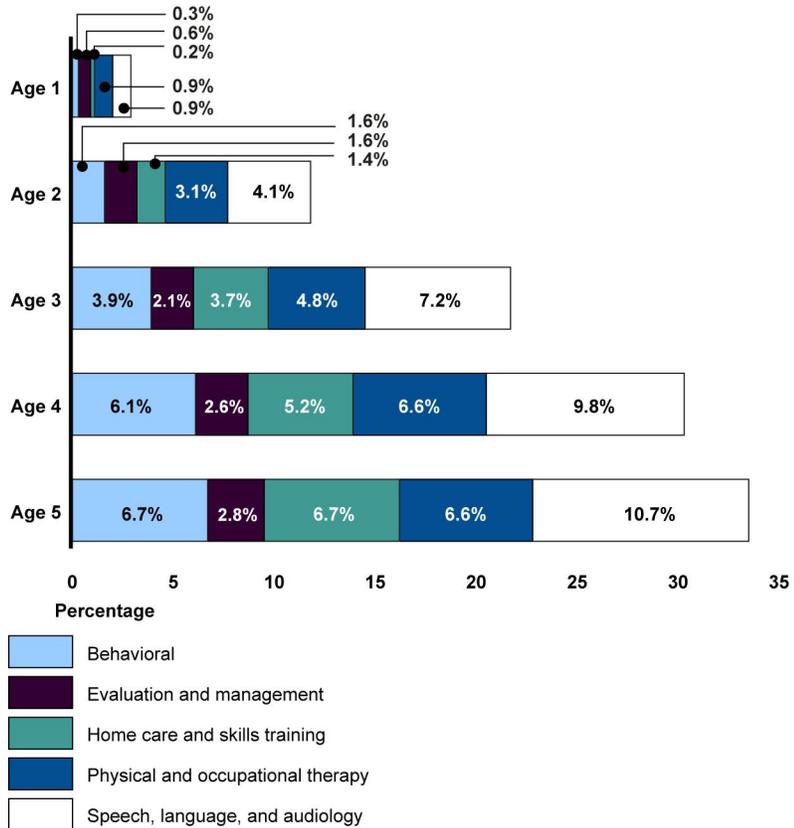


Source: GAO analysis of fiscal year 2013 Delaware, Georgia, Illinois, Kentucky, and Minnesota Medicaid and State Children's Health Insurance Program (CHIP) data reported to the Centers for Medicare & Medicaid Services. | GAO-16-446

Note: Percentages do not add to 100 percent due to rounding.

When services received are examined by age group, speech, language, and audiology services remain the most commonly received services; however, there is variation in the other categories of services received. Among children ages 1 and 2, physical and occupational therapy were nearly as common as speech, language, and audiology services, and behavioral services and home care and skills training were less common. Beginning at age 3, behavioral services and home care and skills training became more frequently received. Figure 3 shows the category of services received by young children identified with autism by age group.

**Figure 3: Percentage of Total Intervention Services Received by Age and Service Category, for Medicaid and CHIP Beneficiaries Identified with Autism, Ages 1 through 5 in Selected States, Fiscal Year 2013**



Source: GAO analysis of fiscal year 2013 Delaware, Georgia, Illinois, Kentucky, and Minnesota Medicaid and State Children's Health Insurance Program (CHIP) data reported to the Centers for Medicare & Medicaid Services. | GAO-16-446

Note: Age reflects the child's age at the beginning of fiscal year 2013. Percentages do not add to 100 percent due to rounding.

While autism services are not a specified Medicaid benefit, CMS issued an informational bulletin in July 2014 that may result in more children receiving these services under Medicaid.<sup>68</sup> Specifically, the informational bulletin clarified states' options for providing autism-related services to

<sup>68</sup>Centers for Medicare & Medicaid Services, *Center for Medicaid & CHIP Services Informational Bulletin: Clarification of Medicaid Coverage of Services to Children with Autism*, accessed on April 9, 2015, <https://www.medicaid.gov/Federal-Policy-Guidance/Downloads/CIB-07-07-14.pdf>.

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children under various Medicaid authorities. It also discussed requirements related to services for children under the Early and Periodic Screening, Diagnostic, and Treatment (EPSDT) benefit.<sup>69</sup> Some states have been using other Medicaid authorities, such as home and community-based services waivers, to provide behavioral therapy services, such as ABA.<sup>70</sup> Because waivers cover a limited number of beneficiaries, states' Medicaid programs may not have been able to fulfill the need for services of children with autism through a waiver. CMS officials told us that the clarifying bulletin would likely result in an increase in the number of children receiving such services, as states may have to transition these individuals to the EPSDT benefit under their state plans, which must be furnished to beneficiaries statewide.<sup>71</sup> For at least one state, this may already be the case. Utah Department of Health officials told us that they transitioned to provide ABA services under their state plan in July 2015 as a result of this guidance.<sup>72</sup> While about 380 children received services under Utah's autism waiver in the state's fiscal year

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<sup>69</sup>The EPSDT benefit provides comprehensive and preventative health care screenings, diagnostic services, and treatment services for children under age 21 who are enrolled in Medicaid. EPSDT entitles enrolled children to any treatment or procedure that fits within any of the categories of Medicaid-covered services listed in section 1905(a) of the Social Security Act if that treatment or service is medically necessary to "correct or ameliorate" defects and physical and mental illnesses or conditions, regardless of whether the service is included in the state's Medicaid state plan. See section 1905(r)(5) of the Social Security Act codified at 42 U.S.C. § 1396d(r)(5). According to CMS, EPSDT is key to ensuring that children receive appropriate preventative, dental, mental health, developmental, and specialty services.

<sup>70</sup>The 1915(c) home and community-based services waivers are an option available to states to allow the provision of long-term care services in home and community-based settings under Medicaid. States can offer a variety of services under a home and community-based services waiver program, including a combination of standard medical services and non-medical services.

<sup>71</sup>In summarizing the informational bulletin on its website, CMS pointed out that states currently furnishing services to treat autism under home and community-based services waivers and certain other Medicaid authorities, may have to transition those individuals to coverage under the EPSDT benefit.

<sup>72</sup>Utah officials stated that the primary change to the state plan was to add the provision of ABA. Under the revised state plan, all services are provided by or under the direction of a psychologist or board certified behavior analysts. These clinicians are responsible for assessment and treatment planning. In addition, these individuals are responsible for supervision of registered behavior technicians, who provide the majority of the one-on-one services to the child. Services are provided primarily on a one-on-one basis, but can be provided in small groups. In addition, family training services and social skills building are available services.

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2015, that number increased to about 455 in the first 5 months following the transition, and officials estimate that approximately 4,000 children may now be able to receive autism services through their state plan.<sup>73</sup> CMS officials stated that states may choose to amend their state plan to include autism treatment services in an effort to be more transparent about the services available to children diagnosed with autism.<sup>74</sup> At the time of our review, CMS officials indicated that 7 states had recently approved Medicaid state plans to include autism treatment services, and an additional 18 states have either submitted draft changes to their Medicaid state plan—known as amendments—to cover such services or are in discussions with CMS officials about the autism treatment services they propose to cover in the state plan.

## TRICARE

Children enrolled in DOD's TRICARE that were identified with autism received a variety of intervention services in fiscal year 2014. Specifically, 8,103 children ages 1 through 5 identified with autism were eligible to receive services through TRICARE and almost all received services.<sup>75</sup> About half of the children identified with autism were ages 3 and 4, and about 30 percent of children identified with autism were ages 1 or 2. See figure 4 for the distribution of children identified with autism by age.

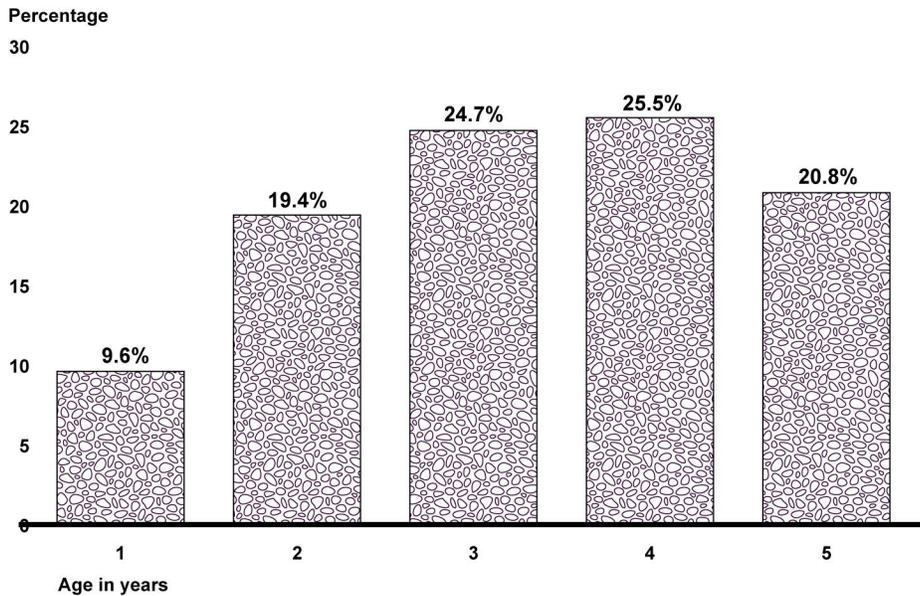
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<sup>73</sup>Estimates of service utilization under Utah's revised state plan included individuals with autism up to age 21.

<sup>74</sup>Regardless of whether they are in a state's Medicaid state plan, autism treatment services are required to be provided to children if determined to be medically necessary, in accordance with the EPSDT benefit.

<sup>75</sup>About 1 percent of children we identified with autism did not receive intervention services in fiscal year 2014 through TRICARE. This could be for a variety of reasons. For example, some children may not have needed the intervention services included in our review during this time period. In addition, children could have received services through other means, such as private health insurance.

**Figure 4: Age of Children Identified with Autism Enrolled in TRICARE, Fiscal Year 2014**

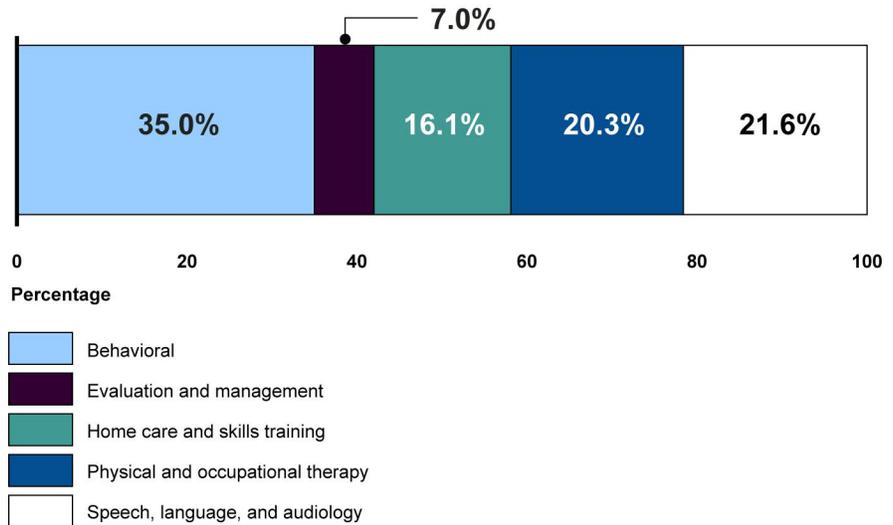


Source: GAO analysis of fiscal year 2014 Department of Defense TRICARE data. | GAO-16-446

Note: Age reflects the child's age at the beginning of fiscal year 2014.

Unlike Medicaid and CHIP beneficiaries, we found that young children enrolled in TRICARE and identified with autism most commonly received behavioral services, which comprised about one-third of intervention services received by these children. However, speech, language, and audiology services, and physical and occupational therapy services still made up a large portion of the intervention services received by these children. See figure 5 for the percentage of intervention services received by service category.

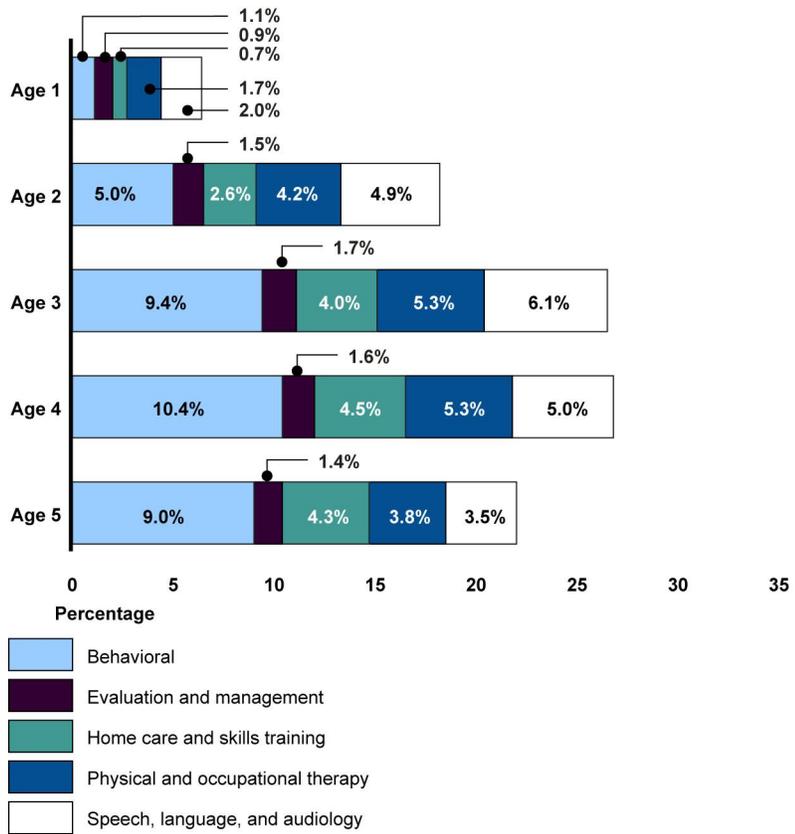
**Figure 5: Percentage of Total Intervention Services by Service Category, for TRICARE Beneficiaries Identified with Autism, Ages 1 through 5, Fiscal Year 2014**



Source: GAO analysis of fiscal year 2014 Department of Defense TRICARE data. | GAO-16-446

When services received are examined by age group, behavioral services remain the most commonly received services by children in most age groups; however, there is variation in the other categories of services received. At age 1, children most commonly received speech, language, and audiology services; physical and occupational therapy were also commonly received. Among children age 2, behavioral services were about as common as physical and occupational therapy, and speech, language, and audiology services. Behavioral services were notably more common than other services among children ages 3 through 5. (See fig. 6.)

**Figure 6: Percentage of Total Intervention Services Received by Age and Service Category, for TRICARE Beneficiaries Identified with Autism, Ages 1 through 5, Fiscal Year 2014**



Source: GAO analysis of fiscal year 2014 Department of Defense TRICARE data. | GAO-16-446

Notes: Age reflects the child's age at the beginning of fiscal year 2014. Percentages do not add to 100 percent due to rounding.

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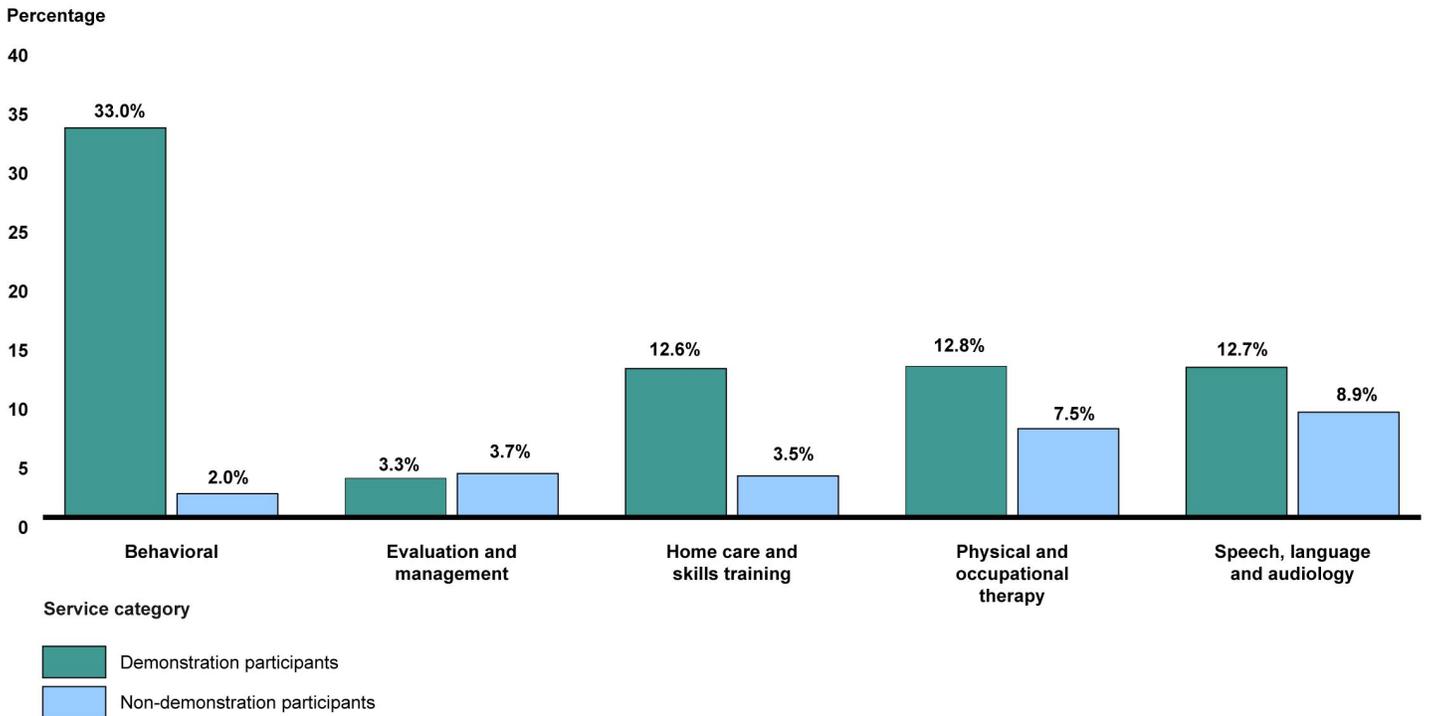
In 2014, DOD offered ABA to children—who were TRICARE beneficiaries and had an autism diagnosis—through autism demonstrations.<sup>76</sup> Of the approximately 8,103 children enrolled in TRICARE that we identified with autism, 3,788 (47 percent) were enrolled in the demonstrations.<sup>77</sup> Most of the behavioral services received by children through TRICARE went to those who participated in the demonstration—an expected finding given that the demonstration focused on providing ABA and related behavioral services that may not have been as readily accessible by non-participants. Overall, children enrolled in the demonstrations received nearly three times as many intervention services as children who were not enrolled in the demonstrations. See figure 7 for the percentage of total intervention services received by children who were enrolled in the demonstrations compared to those who were not enrolled in the demonstrations.

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<sup>76</sup>For reporting purposes, we use the term “autism demonstrations” to include two ABA demonstrations administered by DOD during fiscal year 2014—the Enhanced Access to Autism Services Demonstration, which applied to active duty servicemembers’ family members, and the ABA pilot, which applied to non-active duty servicemembers’ family members, enrolled in those demonstrations. By December 31, 2014, all beneficiaries using the Enhanced Access to Autism Services Demonstration or the ABA Pilot were fully transitioned into the TRICARE Comprehensive Autism Care Demonstration, which consolidated the various ABA options into one demonstration.

<sup>77</sup>We considered demonstration participants to be those children enrolled in DOD’s Enhanced Access to Autism Services Demonstration and the ABA pilot at any point in fiscal year 2014.

**Figure 7: Percentage of Total Intervention Services Received by Demonstration Participants and Non-Participants by Service Type, for TRICARE Beneficiaries Identified with Autism, Ages 1 through 5, Fiscal Year 2014**



Source: GAO analysis of fiscal year 2014 Department of Defense TRICARE data. | GAO-16-446

Note: Demonstration participants are those enrolled in DOD's Enhanced Access to Autism Services Demonstration and the ABA pilot at any point in fiscal year 2014. Demonstration participants were required to be at least 18 months of age.

Information on the expenditures related to providing intervention services to young children identified with autism enrolled in Medicaid, CHIP, and TRICARE is available in appendix III.

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## Recent Actions by HHS Could Improve Monitoring of Federally Funded Autism Research to Avoid Unnecessary Duplication

HHS has recently taken steps that could help address recommendations we made in November 2013. Specifically, to promote better federal coordination and avoid the potential for unnecessary duplication, we recommended that (1) the IACC and NIH identify projects through the department's monitoring of federal autism activities that may be unnecessarily duplicative and thus candidates for consolidation or elimination, and (2) DOD, Education, HHS, and NSF determine methods for identifying and monitoring the autism research conducted by other agencies. To develop these recommendations, we applied criteria from federal internal control standards and best practices for collaboration from our prior work, which state that tracking and monitoring are key activities that can benefit interagency collaborative mechanisms.<sup>78</sup> Since our 2013 report was issued, HHS has continued to disagree that our recommendations were warranted.

HHS has recently taken actions required by the Autism CARES Act that could help coordinate federal autism research and implement our recommendations. First, as directed by the act, the Secretary of Health and Human Services designated an official to serve as the Autism Coordinator to oversee national autism research, services, and support activities and ensure that autism activities funded by HHS and other federal agencies are not unnecessarily duplicative.<sup>79</sup> HHS announced this designation in April 2016, while a draft of this report was at the department for comment.<sup>80</sup> Second, the Autism CARES Act requires that the IACC's strategic plan include recommendations to ensure that autism research funded by HHS and other federal agencies is not unnecessarily

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<sup>78</sup>Federal internal control standards state that agencies establish a means of communicating with, and obtaining information from, external stakeholders that could have a significant impact on their operations, performance, and resource allocations; organizations should monitor and assess their performance over time to help ensure that they meet their goals and objectives; activities, such as accurate and timely recording of data, need to be established for comparisons and assessments on organizational progress. See [GAO-14-704G](#) and [GAO/AIMD-00-21.3.1](#). For best practices, see [GAO-12-1022](#). For our report see [GAO-14-16](#).

<sup>79</sup>See the Autism CARES Act, Pub. L. No. 113-157, § 2, 128 Stat. 1831 (2014).

<sup>80</sup>HHS officials told us that they had previously selected another individual to serve as the Autism Coordinator, but this individual left HHS prior to serving in the position. HHS officials said that this circumstance delayed the designation of an Autism Coordinator, which ultimately occurred 20 months after the enactment of the Autism CARES Act.

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duplicative.<sup>81</sup> While the 2013 strategic plan—released in April 2014—is the most recent plan, an update to the plan has been under discussion since late 2015. Specifically, the IACC met for the first time as a full committee in November 2015—16 months after its last full committee meeting.<sup>82</sup> During this meeting, as well as subsequent meetings in January and April 2016, NIH staff and IACC members discussed updating the strategic plan. The requirement to include the aforementioned recommendations was discussed; however, no specific details for how this will be accomplished were identified.

In addition to recent steps taken by HHS in response to Autism CARES Act requirements, NIH also released fiscal year 2011 and 2012 data on federal autism research, which the agency collects on behalf of the IACC. These data were made available in April 2016, while a draft of this report was at the department for comment. Specifically, these data were released into the Autism Spectrum Disorder Research Portfolio Analysis Web Tool (Web Tool), the IACC's online database on autism research. Prior to this new release, the Web Tool contained fiscal year 2008 through 2010 data.<sup>83</sup> NIH, on behalf of the IACC, also released the *2011-2012 IACC Portfolio Analysis Report*, which provides an analysis of autism research funding in 2011 and 2012, as well as a five-year overview of autism research funding by the U.S. government and private sector and five-year trends (2008 through 2012) by each of the seven

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<sup>81</sup>The Autism CARES Act directs the IACC to develop, and annually update, a strategic plan for the conduct of, and support for, autism research. Pub. L. No. 113-157, § 5, 128 Stat. 1831, 1832-1833 (2014).

<sup>82</sup>NIH officials attributed this lag to reconstituting the IACC membership after the enactment of the Autism CARES Act in August 2014. Prior to this, the IACC met four times as a full committee since our November 2013 report—December 2013, January 2014, April 2014, and July 2014. IACC meetings are one mechanism used by the IACC to fulfill its coordination responsibilities. 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 updating the strategic plan. The meetings also include time for public comments.

<sup>83</sup>The Web Tool contains information on the specific autism research projects funded. For each fiscal year, it 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. The web tool, accessed May 3, 2016, is available at <https://iacc.hhs.gov/apps/portfolio-analysis-web-tool/projects>.

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research areas in the IACC's strategic plan.<sup>84</sup> NIH officials told us that they have also collected data on autism research that was federally funded in fiscal year 2013 and plan to release that data in the second half of calendar year 2016.

Although HHS continues to disagree that our recommendation to develop methods for improved cross-agency coordination was warranted, HRSA took a positive step in April 2014 by contacting DOD to determine whether any potential overlap existed between the agencies' programs. HRSA officials told us that they reviewed abstracts of all currently funded DOD research projects and found no scientific overlap. HRSA officials also used information from DOD, HHS agency websites, and NIH's online database when developing new FOAs. For example, in two FOAs HRSA chose to focus exclusively on populations served by HRSA's Maternal and Child Health Bureau in order to help avoid potential duplication with other federal agencies.<sup>85</sup>

During our review, NIH officials reiterated their position that they believe their processes are adequate to avoid unnecessary duplication and provided us with the 2012 program officer handbook, which outlines the responsibilities of NIH program officers—some of which will help avoid potential unnecessary duplication and were included in our November 2013 report. According to NIH officials, a fundamental part of an NIH program officer's responsibility is to assure that federal taxpayer funds are expended on research projects that will produce the most effective, efficient, and productive results. The program officer handbook outlines project officers' responsibility to stay abreast of the scientific literature and attend professional and scientific meetings, which we reported in November 2013. It also discusses the officers' role in reviewing the "other support" section of research applications. This section details the other active and pending funding available in direct support of an individual's research endeavors and is provided by the applicant for all individuals designated in a research application as a principal investigator. Program

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<sup>84</sup>Office of Autism Research Coordination, National Institute of Mental Health, on behalf of the Interagency Autism Coordinating Committee. *2011-2012 IACC Autism Spectrum Disorder Research Portfolio Analysis Report*. (Washington, D.C.: April 2016), accessed May 3, 2016 [https://iacc.hhs.gov/publications/portfolio-analysis/2012/portfolio\\_analysis\\_2012.pdf](https://iacc.hhs.gov/publications/portfolio-analysis/2012/portfolio_analysis_2012.pdf)

<sup>85</sup>The maternal and child health population includes women, infants, children, adolescents, young adults, and their families.

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officers must review this section for scientific overlap, among other information.<sup>86</sup> While this type of review is important, as we described in our November 2013 report, it only helps to ensure that an applicant, and the applicant's principal investigator, is not submitting essentially the same research application to multiple funding sources. This review would not uncover research from different applicants with different principal investigators, which have already been funded, and that may be unnecessarily duplicative of the applicant's research; in other words, a project with the same purpose, strategies, and target population that is not necessary to corroborate or replicate prior research results. The program officer handbook also includes a description of several databases and web-based tools that are available for the program officers' use in fulfilling their responsibilities. However, although this information is provided to program officers, NIH officials told us that the agency does not dictate which specific tools or databases program officers should use to identify similar grants by a different principal investigator for each grant funding decision. NIH continues to have limited procedures in place to help ensure that program officers identify potentially unnecessarily duplicative research by different principal investigators when making funding decisions.

Officials from the other agencies that were included in our recommendation—DOD, Education, and NSF—told us that they have taken initial steps to monitor other federal agencies' research. DOD officials told us that the department has finalized an interagency agreement with NIH to complete a pilot study aimed at developing requirements and testing the feasibility of transferring DOD medical research application data to a NIH data system. According to DOD officials, this transfer of data would allow multiple agencies and the public to view research application data to assist in the identification of potential duplication and facilitate funding decisions. DOD officials anticipate that the feasibility studies will conclude by June 2016. Additionally, Education officials told us that they have reached out to HHS and are awaiting guidance on coordination from HHS and in the interim will continue to participate in IACC meetings. Education officials also stated that the

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<sup>86</sup>Project officers look for scientific overlap as it relates to the applicant and their key personnel to ensure that (1) substantially the same research is not proposed in more than one application or submitted to two or more funding sources for review and funding consideration, or (2) a specific research objective and the research design for accomplishing the objective are the same or closely related in two or more applications.

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department anticipates funding, pending congressional appropriations, model demonstrations projects focused on autism. These projects will build on existing research on promising evidence-based practices for autism by identifying challenges associated with their implementation. According to Education officials, the department will coordinate with the IACC and review relevant research prior to soliciting applications related to these research projects. Also, even though the agency is not a member of the IACC, NSF officials told us that they observe IACC meetings when convened and check the IACC's Web Tool to monitor autism research funded by other federal agencies and to help avoid unnecessarily duplicative research.

We acknowledge the steps taken by the agencies to respond to our November 2013 recommendation, as well as in response to the Autism CARES Act; however, continued action is needed to develop these initial steps into methods for identifying and monitoring federal autism research that are consistently applied. This is especially important given that, as we previously reported in November 2013, agencies are funding research in the same areas, which creates the potential for unnecessary duplication. While we are not making additional recommendations, we believe that our 2013 recommendations remain valid, and that HHS's continued fulfillment of the provisions in the Autism CARES Act could help the department implement our recommendations.

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## Agency Comments

We provided a draft of this report to DOD, Education, HHS, and NSF for review and comment. Education and HHS provided written comments, which are reprinted in appendixes IV and V. These departments, along with DOD, also provided technical comments, which we incorporated as appropriate. NSF did not provide any comments.

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Education and HHS directed many of their comments to our third finding, which updated the status of agency actions to implement recommendations contained in our November 2013 report. In that report, we found that many autism research projects funded by federal agencies had the potential to be duplicative, because the projects were categorized to the same research objectives in the IACC strategic plan.<sup>87</sup> In their comments on this report, Education and HHS disagreed that there was potential for duplication and questioned the basis of our analysis. The departments stated that the 78 research objectives—which our analysis was based on—are broad, and therefore, may require attention from researchers of different disciplines in order to address the complexity and heterogeneity of autism. This may necessarily involve funding of multiple projects from more than one federal agency. Education stated that a careful review of the projects themselves is needed to determine actual duplication.

As we noted in our 2013 report, we agree that it may be appropriate and advantageous to have multiple projects and agencies address the same research objective. We also agree that the specific projects identified as potentially duplicative would need to be reviewed further to identify actual duplication and believe such a review of these data is important to ensure federal funds are used efficiently and effectively so that informed decisions can be made. Our finding that agencies are funding research in the same research areas highlights how imperative it is that agencies effectively coordinate and monitor each other's autism research. It was the limited coordination and monitoring that we identified in our prior work that was the basis for our prior recommendations. Based on the comments received, we revised the report to acknowledge the breadth of the research objectives and to emphasize our prior findings as they relate to the need for improved coordination and monitoring.

HHS also commented that staff in its agencies, including NIH, avoid clear and obvious overlap or unnecessary duplication. HHS stated that they do this by utilizing the research project information in their internal database, Information for Management, Planning, Analysis, and Coordination (IMPAC II), which contains detailed pre-award and award data for four HHS agencies— AHRQ, CDC, the Food and Drug Administration, and

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<sup>87</sup>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. See [GAO-14-16](#).

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HRSA—and some research applications and grants of the Department of Veterans Affairs, as well as participating in the IACC. Further, HHS stated that NIH's internal autism coordinating committee coordinates research internally within NIH. The use of databases and participation in the IACC as a means to coordinate and monitor across agencies is information that we have reported on in this report and our November 2013 report. We continue to believe that these methods are limited. Further, while we appreciate HHS's comment that it is taking steps to avoid clear and obvious unnecessary duplication, this is not sufficient given the substantial federal investment in this area. From fiscal years 2008 through 2012, agencies awarded funds of about \$1.2 billion for autism research, and many funded research in the same areas. Autism is an important and complex public health concern affecting a large number of individuals, which makes it all the more important that scarce federal resources be used efficiently and strategically. Prudent stewardship requires a careful assessment and coordinated effort to look for unnecessary duplication that may be less than obvious.

Lastly, HHS stated that our draft report was incorrect in stating that the Web Tool was the primary tool by which potentially duplicative autism research is to be identified. The department stated that IMPAC II database is used by NIH program officers when evaluating research grant applications. Our draft report did not state that the Web Tool was the primary tool used to identify potentially duplicative autism research; however, we revised the report to clarify information presented on the Web Tool.

In its comments, Education also stated that the draft report properly acknowledged the health care and educational programs that provide intervention services to young children with autism. Further, the department stated that it stands ready to work with HHS as HHS implements the Autism CARES Act and that a significant body of research is still needed to better understand and address the developmental academic needs of students with autism, especially given the great variations across the autism spectrum and the range of student learning needs.

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As agreed with your offices, unless you publicly announce the contents of this report earlier, we plan no further distribution until 30 days from the report date. At that time, we will send copies of this report to the appropriate congressional committees, the Secretary of Health and Human Services, Secretary of the Department of Defense, the Secretary

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of the Department of Education, the Director of the National Science Foundation, and to other interested parties. In addition, the report is available at no charge on the GAO website at <http://www.gao.gov>.

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

A handwritten signature in black ink that reads "Marcia Crosse". The signature is written in a cursive style with a long horizontal flourish at the end.

Marcia Crosse  
Director, Health Care

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*List of Requesters*

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

The Honorable Michael B. Enzi  
Chairman  
Subcommittee on Primary Health and Retirement Security  
Committee on Health, Education, Labor, and Pensions  
United States Senate

The Honorable James Lankford  
United States Senate

The Honorable Michael S. Lee  
United States Senate

The Honorable Katherine Clark  
House of Representatives

The Honorable Hank Johnson  
House of Representatives

The Honorable Sheila Jackson Lee  
House of Representatives

The Honorable John Lewis  
House of Representatives

The Honorable Zoe Lofgren  
House of Representatives

The Honorable Mike Rogers  
House of Representatives

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The Honorable David Scott  
House of Representatives

The Honorable Rob Woodall  
House of Representatives

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# Appendix I: Detailed Scope and Methodology for Analyzing Health Care Data

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We examined the intervention services that are provided to children with autism through federal health care programs. More specifically, to do this we analyzed fiscal year 2013 fee-for-service claims and managed care encounter data from the Centers for Medicare & Medicaid Services' (CMS) Medicaid and Statistical Information System (MSIS) for five select states.<sup>1</sup> We also analyzed fiscal year 2014 Department of Defense (DOD) TRICARE military treatment facility and purchased care claims data. At the time we began our review, these were the most recent fiscal years for which CMS's and DOD's data were available. Our analysis consisted of the following three steps: (1) state selection for CMS data, as well as assessing data reliability for both our selected states' and DOD's data; (2) identification of children with autism; and (3) identification of intervention services for children with autism. Lastly, we describe the limitations of our methods.

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## State selection and data reliability

We selected five states to include in our analysis of health care data—Delaware, Georgia, Illinois, Kentucky, and Minnesota. We chose these five states based on the availability and reliability of their reported Medicaid and State Children's Health Insurance Program (CHIP) data in MSIS. Specifically, at the time we began our review, there were 35 states that had validated fiscal year 2013 MSIS data from which we could choose. To determine which of these 35 states to include in our review, we reviewed reports with information on states use of managed care organizations and the completeness and reliability of states' managed care encounter data in MSIS. Similarly, we reviewed reports on states' use of behavioral health organizations to provide certain services—since those organizations may be used to provide some of the intervention services included in our review—and the extent to which states' data in MSIS on services provided by behavioral health organizations is reliable

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<sup>1</sup>Medicaid and CHIP enrollees may be served through a fee-for-service delivery system where health care providers are paid for each individual service, or they may be served through a managed care organization that accepts a set monthly payment per member for services. Medicaid and CHIP data on managed care services are generally referred to as "encounters;" however, for reporting purposes, we use the term "claims" throughout this report to refer to both fee-for-service claims and managed care encounters, unless otherwise specified. We obtained MSIS data from CMS, which is used by the agency to gather key Medicaid and CHIP eligibility, enrollment, program, utilization, and expenditure data from states.

and complete. Lastly, we reviewed reports with information on the completeness and reliability of states' CHIP data in MSIS.<sup>2</sup>

We discussed the reliability and usability of the five states' data with knowledgeable officials from CMS, its contractor responsible for processing Medicaid and CHIP data reported from states (Mathematica Policy Research), and selected state officials. We discussed the reliability and usability of the TRICARE data with knowledgeable DOD officials. We performed data checks, such as examining the data for missing values and obvious errors, to test the internal consistency and reliability of the data. These data were found to be reliable for our purposes.

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## Beneficiary identification

Based on eligibility information in the MSIS eligibility file and the TRICARE beneficiary file, we restricted our study to children who were (1) age 1 through age 5 at the beginning of the fiscal year, and (2) enrolled in one of these programs for at least 10 months.<sup>3</sup> We limited our review to only those children we identified with autism. For purposes of this report, we considered a child to have autism if the child had at least one claim with an autism diagnosis code at any point in the fiscal year.<sup>4</sup>

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<sup>2</sup>Reports we reviewed included an August 2013 policy memo to CMS from its contractor, Mathematica Policy Research, entitled *State Reporting of Separate Children's Health Insurance Program (CHIP) Data to MSIS: A Status Report*, as well as the following studies by Mathematica Policy Research: *Medicaid Policy Brief: The Availability and Usability of Behavioral Health Organization Encounter Data in MAX 2009, Brief 14* (Washington, D.C.: July 2013); *Medicaid Policy Brief: Assessing the Usability of Encounter Data for Enrollees in Comprehensive Managed Care Across MAX 2007–2009, Brief 15* (Washington, D.C.: December 2012); and *Medicaid Policy Brief: CHIP Data in the Medicaid Statistical Information System (MSIS): Availability and Uses, Brief 12* (Washington, D.C.: October 2012).

<sup>3</sup>To be included in our review, a child had to be enrolled in Medicaid or CHIP for at least 10 months in fiscal year 2013, or enrolled in TRICARE for at least 10 months in fiscal year 2014.

<sup>4</sup>To identify an autism diagnosis, we used diagnosis codes beginning with 299 per the ninth edition of the International Classification of Diseases, which was effective during the time period covered by our review.

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## Service identification

We focused our review on non-institutional services contained within the MSIS other services file and the TRICARE non-institutional file.<sup>5</sup>

There is no standard set or list of procedure codes that are used by providers to report the provision of intervention services to children with autism. Therefore, we developed a list of procedure codes that could closely reflect the provision of intervention services to young children with autism. To do this, we took the following four steps.

1. We reviewed documentation and interviewed federal agency officials, as well as officials from non-federal entities, such as the American Academy of Pediatrics, to gather general information on typical interventions for young children with autism.
2. We identified the procedure codes found on claims with an autism diagnosis code in our dataset and examined the definitions of these codes.<sup>6</sup>
3. We discussed procedure codes relevant to providing interventions to children with autism with representatives from the following seven professional associations: American Academy of Child & Adolescent Psychiatry; American Physical Therapy Association; American Occupational Therapy Association; American Psychiatric Association; American Psychological Association; American Speech, Hearing, and Language Association; and Association of Professional Behavioral Analysts.
4. In recognition of variations in the practice of medicine across geographic regions, we gathered information from all five selected states about their use of certain procedure codes to determine if the use of these codes typically reflected the delivery of an intervention service for autism in their respective states.

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<sup>5</sup>MSIS data includes four claims files—inpatient care, institutional long-term care, prescription drug, and other services. Our review only includes services reported in the other services file and therefore does not include inpatient care, institutional care, or prescription drugs.

<sup>6</sup>The procedure codes in our dataset fell under the Healthcare Common Procedure Coding System, which is a coding system used to ensure that health care claims are processed in an orderly and consistent manner.

Based on the information gathered, we identified a list of procedure codes that appeared to reflect common autism-related interventions.<sup>7</sup> The intervention services in our review also include related diagnostic or evaluation services. When generating the list of procedure codes, it was not possible for us to parse out intervention services from assessment-type services because, in general, an assessment is needed in order to determine the best intervention approach and to adjust that approach over time. Further, we heard from the association officials we interviewed that providers are frequently assessing at the same time they are providing an intervention.

For reporting purposes, we categorized the procedure codes we identified into five broad categories.

1. **Behavioral**, which includes psychiatry services, health and behavioral assessments and intervention services, and applied behavior analysis.<sup>8</sup>
2. **Evaluation and management**, which includes central nervous system tests, office or other outpatient visits or consultations, and medical team conferences to diagnose and develop intervention strategies.
3. **Home care and skills training**, which includes teaching skills to the child and the child's family to promote the child's development and independent living.<sup>9</sup>

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<sup>7</sup>Although gastrointestinal disorders may be associated with autism, we excluded medical nutrition therapy and gastroenterology from our scope, because federal and non-federal officials we interviewed did not identify these areas as common intervention services provided to young children with autism. Claims for nutrition therapy and gastroenterology made up less than 0.1 percent of the claims in our dataset. Additionally, we excluded claims for medical devices from our review, but included therapies that may be associated with the use of these devices in our scope. For example, we would include claims for therapy sessions to assist a child learning to walk with braces, but we would exclude the claim for the braces themselves.

<sup>8</sup>Applied behavior analysis is a framework that uses behavior modification principles, such as positive reinforcement, to increase or decrease targeted behaviors.

<sup>9</sup>Procedure codes within the skills training category were identified by many of the associations we interviewed as being relevant to their fields; therefore this category may encompass services that overlap with other categories, such as behavioral and physical and occupational therapy.

4. **Physical and occupational therapy**, which includes the provision of therapies to, for example, teach a child how to develop movements involved with walking, eating, or communicating.
5. **Speech, language, and audiology**, which includes evaluation and treatment of speech, language, voice, communication, and auditory processing.

To the extent possible, we based our categorization on the American Medical Association’s Current Procedural Terminology codebook, although our categories are broader than those found in this codebook.<sup>10</sup> We asked experts from each of the seven professional associations to comment on our categorization. We received responses from five of the seven associations.<sup>11</sup> Three of the five associations—American Academy of Child & Adolescent Psychiatry, American Physical Therapy Association and Association of Professional Behavioral Analysts—agreed with our categorization. The other two—American Occupational Therapy Association, and American Speech-Hearing-Language Association—were concerned that putting a procedure code in the “behavioral” category, for example, might imply that the code cannot appropriately be used by professionals, such as speech and language pathologists or occupational therapists. This is not the intention of our categorization, nor should our categories be considered as billing advice to be associated with or used for billing purposes. In fact, we found that four of the seven associations stated that their professionals used codes that fall within our “behavioral” category, and five of the seven used codes that fall with our “evaluation and management” category, among others. See table 2 for the procedure codes included in our review and the categories of interventions they fall under for the purposes of our report.

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<sup>10</sup>Healthcare Common Procedure Coding System is divided into two principal subsystems, referred to as level I and level II of the Healthcare Common Procedure Coding System. Level I of the Healthcare Common Procedure Coding System is comprised of Current Procedural Terminology, a numeric coding system maintained by the American Medical Association.

<sup>11</sup>The American Psychiatric Association and the American Psychological Association did not comment on our categorization.

**Table 2: Categorization of Procedure Codes from Claims Data**

<b>Service category</b>	<b>Procedure codes</b>
Behavioral	90785, 90791-90792, 90801-90802, 90804-90808, 90810-90814, 90817, 90832-90834, 90836-90840, 90846-90847, 90849, 90853, 90857, 90862-90863, 90882, 90885, 90887, 90899, 96150-96155, 0359T-0361T, 0364T-0365T, 0368T-0369T, G8539, G8542, H0002, H0004, H0031-H0032, H0046, H2011-H2012, H2015, H2017, H2019, H2021, S9480, S9484-S9485, T1023, T1025-T1026
Evaluation and management	96101-96103, 96105, 96110-96111, 96116, 96118-96120, 96125, 99201-99205, 99211-99215, 99241-99245, 99342-99345, 99347-99350, 99354-99355, 99366-99368, S0302
Home care and skills training	98960-98962, H2014, S5108, S5110, S5115
Physical and occupational therapy	97001-97004, 97012, 97014, 97016, 97032-97033, 97035, 97110, 97112-97113, 97116, 97124, 97139-97140, 97150, 97530, 97532-97533, 97535, 97542, 97750, 97755, 97760-97762, 97799, G0151-G0152, H2032, S9129, S9131
Speech, language, and audiology	92506-92508, 92511-92512, 92520-92524, 92526, 92541, 92543, 92545-92547, 92550-92553, 92555-92558, 92560-92562, 92565, 92567-92568, 92570, 92577, 92579, 92582-92588, 92590-92595, 92597, 92601-92603, 92606-92611, 92620-92621, 92626-92627, 92630, G0153, S9128, S9152, V5008, V5010-V5011, V5014, V5020

Source: GAO analysis of fiscal year 2013 Delaware, Georgia, Illinois, Kentucky, and Minnesota Medicaid and State Children's Health Insurance Program data reported to the Centers for Medicare & Medicaid Services, and fiscal year 2014 TRICARE data reported to the Department of Defense. | GAO-16-446

Note: Procedure codes include codes from the Healthcare Common Procedure Coding System level I and level II codes.

## Limitations

Because our Medicaid and CHIP data are from five states, the results of our analyses of these data are not generalizable across all states. The intervention services in our review only reflect services identified by the procedure codes included in our review, and as a result, the amount of services we report may be an undercount. Based on our methodology, we believe the list of procedure codes is appropriate and fairly represents interventions provided to children with autism. Because we included all claims of children identified with autism (with relevant procedure codes) due to the potential for inconsistency in the diagnosis codes included on a claim, some of the services in our review may not have been provided for, or relate to, the treatment of autism. In these cases, the amount of services we report may be over reported.

# Appendix II: Number of Children Age 3 through 5 in States' Special Education Autism Category

The Department of Education requires states to report the number of children ages 3 through 5 enrolled in the states' special education program by disability category—such as autism. The number of children reported in the autism category is likely less than the actual number of children with autism being served by states. Children with autism may be categorized under other categories including a general disability category, “developmental delay,” or the category, “speech and language impairment,” because communication difficulties are a typical symptom of autism. The data provided to Education indicate that approximately 66,000 children ages 3 through 5 under the autism category received services in school year 2014-2015, as shown in table 3.

**Table 3: Number of Children Age 3 through 5 in States' Special Education Autism Category, School Year 2014-2015**

State	Children
Alabama	493
Alaska	112
Arizona	459
Arkansas	300
California	16,414
Colorado	480
Connecticut	882
Delaware	198
District of Columbia	169
Florida	3,469
Georgia	1,101
Hawaii	277
Idaho	155
Illinois	1,970
Indiana	1,027
Iowa	73
Kansas	416
Kentucky	651
Louisiana	493
Maine	447
Maryland	886
Massachusetts	2,945
Michigan	1,389
Minnesota	1,432

**Appendix II: Number of Children Age 3 through 5 in States' Special Education Autism Category**

<b>State</b>	<b>Children</b>
Mississippi	343
Missouri	546
Montana	83
Nebraska	263
Nevada	1,082
New Hampshire	317
New Jersey	1,275
New Mexico	265
New York	3,147
North Carolina	2,026
North Dakota	82
Ohio	2,040
Oklahoma	263
Oregon	1,027
Pennsylvania	3,519
Rhode Island	183
South Carolina	913
South Dakota	120
Tennessee	967
Texas	7,464
Utah	291
Vermont	41
Virginia	1,388
Washington	1,066
West Virginia	82
Wisconsin	945
Wyoming	—
<b>Total</b>	<b>65,976</b>

Source: GAO analysis of state data reported to the Department of Education. | GAO-16-446

Note: These data are a snapshot count collected by states in the fall of the identified school year. Wyoming's data were not available due to questionable data quality, according to Department of Education documentation.

# Appendix III: Selected Federal Health Expenditures for Intervention Services Provided to Children with Autism

We examined certain expenditures for the provision of intervention services to children ages 1 through 5 identified with autism and enrolled in the Centers for Medicare & Medicaid Services' Medicaid program, the State Children's Health Insurance Program (CHIP), and the Department of Defense's (DOD) TRICARE program.

## Medicaid and CHIP Fee-For-Service Expenditures

We examined fiscal year 2013 Medicaid and CHIP expenditure data in fee-for-service claims for five states: Delaware, Georgia, Illinois, Kentucky, and Minnesota. Fee-for-service claims were about 87 percent of the total intervention services provided to children identified with autism that we reviewed, with managed care encounters making up the remaining portion of services provided.<sup>1</sup> See table 4 for the expenditures on intervention services provided to children identified with autism enrolled in Medicaid and CHIP, by service category.

**Table 4: Expenditures for Medicaid and CHIP Beneficiaries Identified with Autism, Ages 1 through 5 in Five States, Fiscal Year 2013, by Service Category**

Service category	Expenditures (in dollars in millions)
Behavioral	7.7
Evaluation and management	1.7
Home care and skills training	11.8
Physical and occupational therapy	5.0
Speech, language, and audiology	5.9
<b>Total</b>	<b>32.1</b>

Source: GAO analysis of fiscal year 2013 data from Delaware, Georgia, Illinois, Kentucky, and Minnesota Medicaid and State Children's Health Insurance Program (CHIP), as reported to the Centers for Medicare & Medicaid Services. | GAO-16-446

Note: Medicaid and CHIP enrollees may be served through a fee-for-service delivery system where health care providers are paid for each individual service, or they may be served through a managed care organization that accepts a set monthly payment per member for services. Due to the payment structure for managed care, we are not able to report expenditures for intervention services provided to young children through managed care. Expenditures in this table reflect only fee-for-service claims for the intervention services included in our review.

<sup>1</sup>Medicaid and CHIP enrollees may be served through a fee-for-service delivery system where health care providers are paid for each individual service, or they may be served through a managed care organization that accepts a set monthly payment per member for services. Due to the payment structure for managed care, we were not able to report expenditures for intervention services provided to young children through managed care.

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## TRICARE Purchased Care Expenditures

We examined fiscal year 2014 expenditures for TRICARE purchased care claims. Purchased care claims were about 96 percent of the total intervention services provided to children identified with autism that we reviewed, with military treatment facility claims comprising the remainder of services provided.<sup>2</sup> We examined the expenditures for those young children who were enrolled in DOD's autism demonstrations—which offered increased access to applied behavior analysis (ABA) to servicemembers' family members diagnosed with autism—as well as those who were not enrolled in the demonstration.<sup>3</sup> See table 5 for expenditures on intervention services provided to children identified with autism enrolled in the TRICARE autism demonstrations, and those who received such services but were not enrolled in the demonstration, by service category.

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<sup>2</sup>TRICARE beneficiaries may obtain medical care through a direct-care system of military treatment facilities or a purchased care system consisting of network and non-network private sector primary and specialty care providers. Due to the expenditure structure associated with providing services through military treatment facilities, we were not able to reliably report expenditures for intervention services provided through military treatment facilities.

<sup>3</sup>ABA is a framework that is commonly used when providing intervention services to children with autism. It uses behavior modification principles, such as positive reinforcement, to increase or decrease targeted behaviors. For reporting purposes, we use the term "autism demonstrations" to include the two ABA demonstrations administered by DOD during fiscal year 2014—the Enhanced Access to Autism Services Demonstration, which applied to active duty servicemembers, and the ABA pilot, which applied to non-active duty servicemembers, enrolled in those demonstrations. By December 31, 2014, all beneficiaries using the Enhanced Access to Autism Services Demonstration or the ABA Pilot were fully transitioned into the TRICARE Comprehensive Autism Care Demonstration, which consolidated the various ABA options into one demonstration. DOD officials stated that, beginning in the spring of 2016, ABA reimbursement rates will be reviewed and appropriately adjusted each year, like other TRICARE rates.

**Appendix III: Selected Federal Health  
Expenditures for Intervention Services  
Provided to Children with Autism**

**Table 5: Expenditures for TRICARE Beneficiaries Identified with Autism, Ages 1 through 5, Fiscal Year 2014, by Service Category**

Service category	Expenditures (in dollars in millions)		Total
	Autism demonstration participants (N=3,788)	Non-autism demonstration participants (N=4,315)	
Behavioral	30.0	1.3	<b>31.3</b>
Evaluation and management	1.4	1.6	<b>3.1</b>
Home care and skills training	24.3	8.1	<b>32.4</b>
Physical and occupational therapy	6.8	4.0	<b>10.8</b>
Speech, language, and audiology	6.1	4.1	<b>10.3</b>
<b>Total</b>	<b>68.7</b>	<b>19.2</b>	<b>87.9</b>

Source: GAO analysis of fiscal year 2014 Department of Defense TRICARE data. | GAO-16-446

Notes: TRICARE beneficiaries may obtain medical care through a direct-care system of military treatment facilities or a purchased care system consisting of network and non-network private sector primary and specialty care providers. Expenditures in the table reflect only purchased care claims for the services included in our review.

Demonstration participants are those enrolled in the Enhanced Access to Autism Services Demonstration and the Applied Behavior Analysis pilot at any point in fiscal year 2014. In fiscal year 2014, demonstration participants were required to be at least 18 months of age.

Columns and rows may not sum to total due to rounding.

# Appendix IV: Comments from the Department of Education



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

THE ASSISTANT SECRETARY

APR 20 2016

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

Dear Dr. Crosse:

Thank you for providing the U.S. Department of Education (Department) the opportunity to review and comment on the U.S. Government Accountability Office (GAO) draft report, "Federal Autism Activities: Agencies Are Encouraging Early Identification and Providing Services, but Research Coordination Remains Limited" (GAO-16-446). The majority of the content of the draft report discusses health program activities of the Department of Health and Human Services (HHS) and the Department of Defense, but the very significant roles of early intervention services and special education and related services under the Department's Individuals with Disabilities Education Act also are properly acknowledged. The Department stands ready to work with HHS as HHS implements the Autism Collaboration, Accountability, Research, Education and Support Act of 2014, the Autism CARES Act, including responding to requests for information on research plans and funded project activities.

GAO is making no recommendations to the Department in the draft report. GAO is, however, stating that the recommendations made in the 2013 report: "Federal Autism Activities: Better Data and More Coordination Needed to Help Avoid the Potential for Unnecessary Duplication (GAO-14-16)" remain warranted, "given the potential for unnecessary duplication." The Department continues to disagree with GAO's conclusion that "the majority of federally-funded autism research was potentially duplicative...." The objectives in the classification taxonomy are broad, and projects classified under the broad categories cannot be fairly judged "potentially duplicative" without a more careful review of the projects themselves. Research projects with similar descriptors or titles may have different subject populations, sample sizes, methodologies and outcomes measured, and may explore different mechanisms or hypotheses. We note also that growth of the scientific knowledge base for any subject is dependent upon multiple studies investigating similar research questions. Meeting the educational needs of students with autism involves extraordinary demands on schools, staff, teachers, families and, of course, the students themselves. A significant body of research is still needed to better understand and address the developmental and academic needs of students with autism, especially given the great variations across the autism spectrum and the range of student learning needs.

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www.ed.gov

*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 – Dr. Marcia Crosse, GAO

The Department appreciates your continuing work on the important topic of autism. We are transmitting technical comments with this letter, for your consideration, and remain available if you have additional questions or concerns. We look forward to receiving the final report.

Sincerely,

A handwritten signature in blue ink, appearing to read "Michael K. Yudin", with a long horizontal flourish extending to the right.

Michael K. Yudin

# Appendix V: Comments from Department of Health and Human Services



DEPARTMENT OF HEALTH & HUMAN SERVICES

OFFICE OF THE SECRETARY

Assistant Secretary for Legislation  
Washington, DC 20201

APR 22 2016

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: Agencies Are Encouraging Early Identification and Providing Services, but Research Coordination Remains Limited*" (GAO-16-446).

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

Sincerely,

A handwritten signature in black ink 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 DRAFT REPORT ENTITLED: FEDERAL AUTISM ACTIVITIES: AGENCIES ARE ENCOURAGING EARLY IDENTIFICATION AND PROVIDING SERVICES, BUT RESEARCH COORDINATION REMAINS LIMITED (GAO-16-446)**

The Department of Health and Human Services thanks the Government Accountability Office (GAO) for the opportunity to provide general comments in response to its report, "Federal Autism Activities: Agencies are Encouraging Early Identification and Providing Services, but Research Coordination Remains Limited (GAO-16-446)."

**Research Coordination Addressing the IACC Strategic Objectives for ASD Research**

The current report concludes that research coordination among the federal agencies that fund autism research is limited and potentially duplicative, on the basis that some research projects were categorized to the same research objective under the Interagency Autism Coordinating Committee's (IACC) Strategic Plan for Autism Spectrum Disorder (ASD) Research. However, the NIH again disagrees with this conclusion and points out that the IACC's strategic objectives are broad-based, multidisciplinary goals that require attention from researchers of different disciplines which may necessarily involve funding of multiple relevant (but non-duplicative) projects by more than one federal agency in order to address the complexity and heterogeneity of autism. It is entirely appropriate for different agencies to support studies using the resources and methodologies specific to their mission to approach the research questions from different scientific perspectives. Therefore, program staff from the various HHS agencies, including the NIH, are vigilant to avoid any potential for clear and obvious overlap or unnecessary duplication of grants, utilizing the research grant information provided through the IMPAC II database, as well as through regular communication and collaboration through the internal NIH Autism Coordinating Committee and the Interagency Autism Coordinating Committee.

**IACC Web Tool and the IMPAC II Database**

The current GAO report incorrectly points to the Autism Spectrum Disorder Research Portfolio Analysis Web Tool as the primary tool by which potentially duplicative ASD research is to be identified. As the Office of Autism Research Coordination (OARC) has stated previously, the Web Tool is an additional resource for the IACC, non-federal funders, and the general public to view information about government-supported and non-government supported research projects and their alignment with the IACC Strategic Plan for ASD Research. While the Web Tool is an important resource for some federal agencies, the NIH wishes to make clear that the Web Tool is not the primary resource that it utilizes to manage and track funded autism research projects for potential duplication and overlap prior to funding. The information contained in the Web Tool is public information and does not include sufficient detail to be used by program staff to determine scientific and budgetary overlap. Through fiscal years 2008-2012, the NIH awarded approximately 81 percent of the federal funding for autism research. The IMPAC II Database, which is not accessible to the public for privacy reasons, is utilized by NIH program staff and program staff from other participating federal agencies as it contains the more detailed information about researchers' funding history and grant-specific research aims, which provides the appropriate level of information. This information is used by Program Officers, who can then evaluate and identify potential instances of clear overlap or unnecessary research duplication. In addition, IMPAC II allows NIH program officials to identify similar grants

**GENERAL COMMENTS OF THE DEPARTMENT OF HEALTH AND HUMAN SERVICES (HHS) ON THE GOVERNMENT ACCOUNTABILITY OFFICE'S DRAFT REPORT ENTITLED: FEDERAL AUTISM ACTIVITIES: AGENCIES ARE ENCOURAGING EARLY IDENTIFICATION AND PROVIDING SERVICES, BUT RESEARCH COORDINATION REMAINS LIMITED (GAO-16-446)**

awarded to different investigators or institutions. This includes preaward and award data for 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 Veterans Affairs research applications/grants that are processed through the IMPAC II Grants System.

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# Appendix VI: GAO Contact and Staff Acknowledgments

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## GAO Contact

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

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## Staff Acknowledgments

In addition to the contact named above, Geri Redican-Bigott, Assistant Director; Deirdre Gleeson Brown; Jackie Hamilton; Giselle Hicks; Drew Long; Brandon Nakawaki; Vikki Porter; Sarah Resavy; and Eric Wedum made key contributions to this report.

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# Appendix VII: Accessible Data

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## Agency Comment Letter

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Text of Appendix IV:  
Comments from the  
Department of Education

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Page 1

UNITED STATES DEPARTMENT OF EDUCATION

OFFICE OF SPECIAL EDUCATION AND REHABILITATIVE SERVICES

THE ASSISTANT SECRETARY

APR 20 2015

Marcia Crosse, Ph.D.

Director, Health Care

U.S. Government Accountability Office

441 G Street, NW

Washington, DC 20548

Dear Dr. Crosse:

Thank you for providing the U.S. Department of Education (Department) the opportunity to review and comment on the U.S. Government Accountability Office (GAO) draft report, "Federal Autism Activities: Agencies Are Encouraging Early Identification and Providing Services, but Research Coordination Remains Limited" (GAO-16-446). The majority of the content of the draft report discusses health program activities of the Department of Health and Human Services (HHS) and the Department of Defense, but the very significant roles of early intervention services and special education and related services under the Department's Individuals with Disabilities Education Act also are properly acknowledged. The Department stands ready to work with HHS as HHS implements the Autism Collaboration, Accountability, Research, Education and Support

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Act of 2014, the Autism CARES Act, including responding to requests for information on research plans and funded project activities.

GAO is making no recommendations to the Department in the draft report. GAO is, however, stating that the recommendations made in the 2013 report: "Federal Autism Activities: Better Data and More Coordination Needed to Help Avoid the Potential for Unnecessary Duplication (GAO-14-16)" remain warranted, "given the potential for unnecessary duplication." The Department continues to disagree with GAO's conclusion that "the majority of federally-funded autism research was potentially duplicative...." The objectives in the classification taxonomy are broad, and projects classified under the broad categories cannot be fairly judged "potentially duplicative" without a more careful review of the projects themselves. Research projects with similar descriptors or titles may have different subject populations, sample sizes, methodologies and outcomes measured, and may explore different mechanisms or hypotheses. We note also that growth of the scientific knowledge base for any subject is dependent upon multiple studies investigating similar research questions. Meeting the educational needs of students with autism involves extraordinary demands on schools, staff, teachers, families and, of course, the students themselves. A significant body of research is still needed to better understand and address the developmental and academic needs of students with autism, especially given the great variations across the autism spectrum and the range of student learning needs.

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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.

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The Department appreciates your continuing work on the important topic of autism. We are transmitting technical comments with this letter, for your consideration, and remain available if you have additional questions or concerns. We look forward to receiving the final report.

Sincerely,

Michael K. Yudin

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Text of Appendix V:  
Comments from  
Department of Health and  
Human Services

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Page 1

DEPARTMENT OF HEALTH & HUMAN SERVICES

OFFICE OF THE SECRETARY

Assistant Secretary for Legislation

Washington, DC 20201

APR 22 2016

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: Agencies Are Encouraging Early Identification and Providing Services, but Research Coordination Remains Limited" (GAO- 16-446).

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

Sincerely,

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 DRAFT REPORT ENTITLED: FEDERAL AUTISM ACTIVITIES: AGENCIES ARE ENCOURAGING EARLY IDENTIFICATION AND PROVIDING SERVICES, BUT RESEARCH COORDINATION REMAINS LIMITED (GA0-16-446)

The Department of Health and Human Services thanks the Government Accountability Office (GAO) for the opportunity to provide general comments in response to its report, "Federal Autism Activities: Agencies are Encouraging Early Identification and Providing Services, but Research Coordination Remains Limited (GA0-16-446)."

Research Coordination Addressing the IACC Strategic Objectives for ASD Research

The current report concludes that research coordination among the federal agencies that fund autism research is limited and potentially duplicative, on the basis that some research projects were categorized to the same research objective under the Interagency Autism Coordinating Committee's (IACC) Strategic Plan for Autism Spectrum Disorder (ASD) Research. However, the NIH again disagrees with this conclusion and points out that the IACC's strategic objectives are broad-based, multidisciplinary goals that require attention from researchers of different disciplines which may necessarily involve funding of multiple relevant (but non-duplicative) projects by more than one federal agency in order to address the complexity and heterogeneity of autism. It is entirely appropriate for different agencies to support studies using the resources and methodologies specific to their mission to approach the research questions from different scientific perspectives. Therefore, program staff from the various HHS agencies, including the NIH, are vigilant to avoid any potential for clear and obvious overlap or unnecessary duplication of grants, utilizing the research grant information provided through the IMPAC II database, as well as through regular communication and collaboration through the internal NIH Autism Coordinating Committee and the Interagency Autism Coordinating Committee.

IACC Web Tool and the IMPAC II Database

The current GAO report incorrectly points to the Autism Spectrum Disorder Research Portfolio Analysis Web Tool as the primary tool by which potentially duplicative ASD research is to be identified. As the Office of Autism Research Coordination (OARC) has stated previously,

the Web Tool is an additional resource for the IACC, non-federal funders, and the general public to view information about government -supported and non-government supported research projects and their alignment with the IACC Strategic Plan for ASD Research. While the Web Tool is an important resource for some federal agencies, the NIH wishes to make clear that the Web Tool is not the primary resource that it utilizes to manage and track funded autism research projects for potential duplication and overlap prior to funding. The information contained in the Web Tool is public information and does not include sufficient detail to be used by program staff to determine scientific and budgetary overlap. Through fiscal years 2008-2012, the NIH awarded approximately 81 percent of the federal funding for autism research. The IMPAC II Database, which is not accessible to the public for privacy reasons, is utilized by NIH program staff and program staff from other participating federal agencies as it contains the more detailed information about researchers' funding history and grant-specific research aims, which provides the appropriate level of information. This information is used by Program Officers, who can then evaluate and identify potential instances of clear overlap or unnecessary research duplication. In addition, IMPAC II allows NIH program officials to identify similar grants

Page 3

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## Data Tables

**Data Table for Figure 1: Age of Children Identified with Autism Enrolled in Medicaid or CHIP in Selected States, Fiscal Year 2013**

Age in years	Percent
1	4.4%
2	14.1%
3	22.4%
4	28.3%
5	30.8%

**Data Table for Highlights Figure and Figure 2: Percentage of Total Intervention Services by Service Category, for Medicaid and CHIP Beneficiaries Identified with Autism, Ages 1 through 5 in Selected States, Fiscal Year 2013**

Service Categories	Percentage
Behavioral	18.5%
Evaluation and management	9.8%
Home care and skills training	17.1%
Physical and occupational therapy	22.0%
Speech, language, and audiology	32.7%

**Data Table for Figure 3: Percentage of Total Intervention Services Received by Age and Service Category, for Medicaid and CHIP Beneficiaries Identified with Autism, Ages 1 through 5 in Selected States, Fiscal Year 2013**

	Behavioral	Evaluation and management	Home care and skills training	Physical and occupational therapy	Speech, language, and audiology
Age 1	0.3%	0.6%	0.2%	0.9%	0.9%
Age 2	1.6%	1.6%	1.4%	3.1%	4.1%
Age 3	3.9%	2.1%	3.7%	4.8%	7.2%
Age 4	6.1%	2.6%	5.2%	6.6%	9.8%
Age 5	6.7%	2.8%	6.7%	6.6%	10.7%

**Data Table for Figure 4: Age of Children Identified with Autism Enrolled in TRICARE, Fiscal Year 2014**

Age in years	Percentage
1	9.6%
2	19.4%
3	24.7%
4	25.5%
5	20.8%

**Data Table for Figure 5: Percentage of Total Intervention Services by Service Category, for TRICARE Beneficiaries Identified with Autism, Ages 1 through 5, Fiscal Year 2014**

Service Categories	Percentage
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Service Categories	Percentage
Behavioral	35.0%
Evaluation and management	7.0%
Home care and skills training	16.1%
Physical and occupational therapy	20.3%
Speech, language, and audiology	21.6%

**Data Table for Figure 6: Percentage of Total Intervention Services Received by Age and Service Category, for TRICARE Beneficiaries Identified with Autism, Ages 1 through 5, Fiscal Year 2014**

	Behavioral	Evaluation and management	Home care and skills training	Physical and occupational therapy	Speech, language, and audiology
Age 1	1.1%	0.9%	0.7%	1.7%	2.0%
Age 2	5.0%	1.5%	2.6%	4.2%	4.9%
Age 3	9.4%	1.7%	4.0%	5.3%	6.1%
Age 4	10.4%	1.6%	4.5%	5.3%	5.0%
Age 5	9.0%	1.4%	4.3%	3.8%	3.5%

**Data Table for Figure 7: Percentage of Total Intervention Services Received by Demonstration Participants and Non-Participants by Service Type, for TRICARE Beneficiaries Identified with Autism, Ages 1 through 5, Fiscal Year 2014**

Service Categories	Demonstration Participants Percentage	Non-Demonstration Participants Percentage
Behavioral	33.0%	2.0%
Evaluation and management	3.3%	3.7%
Home care and skills training	12.6%	3.5%
Physical and occupational therapy	12.8%	7.5%
Speech, language, and audiology	12.7%	8.9%

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# Related GAO Products

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*Federal Autism Research: Updated Information on Funding from Fiscal Years 2008 through 2012.* [GAO-15-583R](#). Washington, D.C.: June 30, 2015.

*Federal Autism Activities: Funding and Coordination Efforts.* [GAO-14-613T](#). Washington, D.C.: May 20, 2014.

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

*Combating Autism Act: HHS Agencies Responded with New and Continuing Activities, Including Oversight.* [GAO-13-232](#). Washington, D.C.: February 27, 2013.

*Federal Autism Activities: Funding for Research Has Increased, but Agencies Need to Resolve Surveillance Challenges.* [GAO-06-700](#). Washington, D.C.: July 19, 2006.

*Special Education: Children with Autism.* [GAO-05-220](#). Washington, D.C.: January 14, 2005.

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