

July 2006

FEDERAL AUTISM ACTIVITIES

Funding for Research Has Increased, but Agencies Need to Resolve Surveillance Challenges





Highlights of [GAO-06-700](#), a report to the Majority Leader, U.S. Senate

Why GAO Did This Study

Autism is a developmental disorder involving communication and social impairment. It has no known cause or cure, and its prevalence is unknown. The Children's Health Act of 2000 required the Department of Health and Human Services (HHS) and HHS agencies to conduct activities related to autism research, surveillance, and coordination. This report provides information on (1) the National Institutes of Health's (NIH) and the Centers for Disease Control and Prevention's (CDC) autism activities and these agencies' funding of autism activities, (2) programs that federal agencies have under way to support services for people with autism and concerns related to providing services, and (3) coordination of federal autism activities.

What GAO Recommends

GAO recommends that the Secretaries of HHS and Education work together to promptly identify options for overcoming challenges to CDC's ability to use education records for autism surveillance. In commenting on a draft of this report, HHS and Education did not agree with the recommendation. HHS said the recommendation implied that the departments have not worked together to identify options. Education expressed concern that the recommendation did not reflect federal privacy protections. GAO revised the report to reflect these concerns but continues to believe the recommendation is warranted.

www.gao.gov/cgi-bin/getrpt?GAO-06-700.

To view the full product, including the scope and methodology, click on the link above. For more information, contact Cynthia A. Bascetta at (202) 512-7101 or bascettac@gao.gov.

FEDERAL AUTISM ACTIVITIES

Funding for Research Has Increased, but Agencies Need to Resolve Surveillance Challenges

What GAO Found

NIH and CDC have undertaken a range of autism activities, and the agencies reported that their funding of autism activities has increased. Many of NIH's activities were developed in response to requirements in the Children's Health Act for NIH to expand, intensify, and coordinate its autism activities. According to estimates from NIH, the agency increased funding for autism from about \$51.5 million in fiscal year 2000 to about \$101.6 million in fiscal year 2005. CDC supports surveillance activities in certain locations that track the prevalence of autism and other developmental disabilities, and its total funding of autism activities increased from about \$2.1 million in fiscal year 2000 to about \$16.7 million in fiscal year 2005. CDC's surveillance methodology has relied, in part, on information in student education records, but CDC officials believe that a 2003 change in the Department of Education's (Education) interpretation of relevant federal privacy law has hindered CDC's ability to use this methodology to determine the prevalence of autism. Education stated that the law does not allow CDC to access these records without written parental consent. A 2003 law required HHS and Education to submit a report to the Congress by June 2005 describing ways to overcome the challenges CDC faces in obtaining education records. As of June 2006, CDC and Education had not agreed on options for overcoming these challenges and could not estimate when the report would be completed.

Federal agencies support services for people with autism primarily through broader disability programs, and some services may not always be available to meet the needs of this population. Education and HHS's Administration for Children and Families support services for children with autism through education programs for children with disabilities. Other federal agencies support services for people with autism, generally as part of broader programs to provide services or enhance the delivery of health care to people with developmental disabilities. For example, HHS's Centers for Medicare & Medicaid Services supports services to meet the needs of people with autism through Medicaid programs targeted to people with developmental disabilities. However, many people with autism may not be able to obtain services under these Medicaid programs because they do not meet eligibility rules or because states limit enrollment.

The primary vehicle for coordinating federal agencies' autism activities is the Interagency Autism Coordinating Committee (IACC), and although it has enhanced communication and coordination among agencies, coordination remains limited. The IACC developed recommendations on how to better serve people with autism and established autism research goals. Agency officials told us that federal coordination is limited, in part because, except for education services, no agency perceives itself as having lead responsibility for supporting services for people with autism.

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Abbreviations

ACF	Administration for Children and Families
CDC	Centers for Disease Control and Prevention
CMS	Centers for Medicare & Medicaid Services
CPEA	Collaborative Programs of Excellence in Autism
FERPA	Family Educational Rights and Privacy Act of 1974
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
NIH	National Institutes of Health
NIMH	National Institute of Mental Health
SAMHSA	Substance Abuse and Mental Health Services Administration
STAART	Studies to Advance Autism Research and Treatment

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United States Government Accountability Office
Washington, DC 20548

July 19, 2006

The Honorable William H. Frist, M.D.
Majority Leader
United States Senate

Dear Senator Frist:

Autism, a complex and pervasive developmental disorder, is characterized by impairment in communication and social interaction and by repetitive behavioral patterns.¹ The disorder ranges from a severe form, called autistic disorder, to a milder form, known as Asperger syndrome. While the lifelong condition has no known cause or cure, experts generally agree that early diagnosis and treatment may be the best way to improve outcomes in later years for people with autism. Because of the complexity of this disorder, people with autism have diverse needs for an array of health, mental health, education, and social services. It is not known how many people in the United States currently have the disorder. However, the number of children diagnosed with autism has been increasing, and the Centers for Disease Control and Prevention (CDC) recently reported that at least 300,000 children had autism in the period of 2003 to 2004.²

Several federal agencies are involved in conducting research to identify the causes and prevalence of autism and effective treatments for the disorder or in supporting education and other services for people with autism. The Children's Health Act of 2000 required the Department of Health and Human Services (HHS) and agencies within it to conduct certain activities and programs related to autism research and surveillance³ and the coordination of HHS's autism activities.⁴ In

¹In this report, the term autism refers to a spectrum of disorders, including the following diagnoses: autistic disorder, Asperger syndrome, and pervasive developmental disorder not otherwise specified. These disorders are also commonly referred to collectively as autism spectrum disorders.

²Centers for Disease Control and Prevention, Fact Sheet: "MMWR - Parental Report of Diagnosed Autism in Children Aged 4-17 Years, United States, 2003-2004" (May 4, 2006).

³Surveillance is the ongoing collection, analysis, and reporting of data on health conditions that can be used to plan, implement, and evaluate public health actions.

⁴Pub. L. No. 106-310, §§ 101-105, 114 Stat. 1101, 1105-1109(2000).

preparation for considering reauthorization of certain provisions of the Children's Health Act, and because of the federal role in supporting autism research, surveillance, and services, you asked us to provide information on federal activities and programs related to autism. In this report, we discuss (1) the National Institutes of Health's (NIH) and CDC's current autism research and surveillance activities, including those undertaken in response to the Children's Health Act, and these agencies' funding of autism activities for fiscal years 2000 through 2005; (2) programs that federal agencies have under way to support services for people with autism and concerns related to the provision of services; and (3) coordination of autism activities and programs among federal departments and agencies.

To conduct our work, we obtained information from and interviewed officials at NIH; CDC; other federal agencies—including HHS's Administration for Children and Families (ACF), Centers for Medicare & Medicaid Services (CMS), Health Resources and Services Administration (HRSA), and Substance Abuse and Mental Health Services Administration (SAMHSA); and the Department of Education (Education) regarding their autism activities and the coordination of autism activities among federal agencies and departments. We also obtained information from NIH and CDC officials on their funding of autism activities in fiscal years 2000—one fiscal year before the passage of the Children's Health Act—through 2005. The funding data we obtained generally represent obligated funds—funds the agencies had legally committed to spend but might not yet have expended. In addition, NIH's data represent the agency's estimated funding of autism research. We did not verify the accuracy of these data; however, we interviewed agency officials knowledgeable about the data, and we determined that they were sufficiently reliable for the purposes of this report. It was beyond the scope of our work to identify all programs that provided services to individuals with autism; we focused on programs designed to meet the specific needs of people with autism or developmental disabilities or that have a specific program goal targeted to this population. It was also beyond our scope to evaluate the quality of the activities and programs we describe. However, we reviewed the relevant literature and interviewed experts on autism and representatives of several professional and advocacy associations to obtain their perspectives on services for people with autism. We conducted our work from August 2005 through July 2006 in accordance with generally accepted government auditing standards. (For additional information on our methodology, see app. I.)

Results in Brief

NIH and CDC have undertaken an array of autism research and surveillance activities, and the agencies reported that their funding of autism activities increased since passage of the Children's Health Act. Many of NIH's activities were developed in response to requirements in the Children's Health Act for NIH to expand, intensify, and coordinate its activities related to autism research. For example, NIH developed a network of research centers to conduct research on the causes, diagnosis, early detection, and treatment of autism. According to estimates from NIH officials, the agency increased funding of autism activities from about \$51.5 million in fiscal year 2000 to about \$101.6 million in fiscal year 2005. CDC supports surveillance programs that track the characteristics and prevalence of autism. CDC's total funding of autism activities increased from about \$2.1 million in fiscal year 2000 to about \$16.7 million in fiscal year 2005, according to CDC. Most of CDC's surveillance programs have relied, in part, on collecting information from student education records to obtain a complete and unduplicated count of the number of children with autism. However, CDC officials believe that a 2003 change in Education's interpretation of the federal law governing the privacy of education records—the Family Educational Rights and Privacy Act of 1974 (FERPA)—has hindered CDC's ability to continue using this methodology. Education officials have stated that FERPA requires CDC to obtain written parental consent to gain access to personally identifiable education records, and CDC does not believe this is an optimal research method because it is likely to result in incomplete data. A 2003 law required HHS and Education to submit a report to the Congress by June 2005 concerning CDC's autism and developmental disabilities surveillance activities, including descriptions of the challenges CDC faces in obtaining education records and options for overcoming these challenges. As of June 2006, CDC and Education officials had not agreed on options for overcoming the challenges CDC faces in using education records, and they could not estimate when the report would be ready to submit.

Federal agencies support services for people with autism primarily through broader programs that focus on disabilities, and some services may not always be available to meet the needs of this population. ACF and Education support services for children with autism through education programs for children with disabilities. However, the availability of education services for children with disabilities, including autism, varies across states and school districts, and schools face challenges in providing services for these children. For example, many children with autism have communication problems, but some school districts have encountered difficulties in providing speech and language services because of a shortage of specialists who can provide these services. CMS and HRSA

also support services for people with autism, generally as part of broader programs to provide services or enhance the delivery of health care to people with developmental disabilities. For example, CMS supports community-based services to meet the needs of people with autism through Medicaid programs targeted to people with developmental disabilities. However, many people with autism may be unable to obtain services through these Medicaid programs because they do not meet the programs' eligibility rules or because states limit enrollment.

The primary vehicle for coordinating federal agencies' autism activities is the Interagency Autism Coordinating Committee (IACC), and although it has enhanced communication and coordination among federal agencies, coordination remains limited. Federal officials from member agencies told us that the IACC improved communication and planning, identified ways to improve research and services, and helped agencies to avoid duplicative research efforts. For example, the IACC produced a research matrix that identifies goals for autism research and an action plan that describes challenges to serving people with autism and presents options for improving care. However, the IACC services action plan lacks the specificity that would help a state or federal agency to easily implement its recommendations. For example, the plan indicates there is a lack of adequately trained autism providers, but does not specify which types of providers are needed. In addition, although officials from IACC member agencies told us about programs their agencies had under way related to autism, very few of those programs represented coordinated efforts across agencies. Furthermore, agency officials told us that federal coordination is hindered because no federal agency perceives itself as having lead responsibility for addressing the service needs of adults with autism or services for children beyond education.

To ensure continued progress toward the development of accurate and comparable data on autism characteristics and prevalence and to provide the information the Congress required on CDC's surveillance activities, we are recommending that the Secretary of Health and Human Services and the Secretary of Education work together to promptly identify options for overcoming challenges to CDC's ability to use education records for autism surveillance.

In commenting on a draft of this report, HHS and Education did not agree with the report's recommendation. HHS said that the recommendation suggested that HHS and Education had not worked together to identify options that would enable CDC to continue to obtain and use education records for autism surveillance; we added information to our final report

to indicate that they have had discussions about this issue. Education expressed concern that the recommendation did not take into account FERPA's privacy protections. Although the draft report described the privacy rights afforded by FERPA, we added language to the final report to acknowledge that autism surveillance and protecting the privacy of information in education records are both important goals. We did not modify our recommendation because we continue to believe it is important for Education and HHS to work together to promptly identify options for overcoming the challenges CDC faces in using education records to conduct surveillance.

Background

Autism is a complex developmental disability that impairs development in social interaction and communication and is often characterized by repetitive behaviors, such as jumping up and down and rocking.⁵ In particular, people with autism may be unable to process nonverbal communication, including body language or inflection, causing them to have difficulty understanding differences in tone, such as discerning when someone is joking. People with autism also often have difficulty ascertaining the emotional state of those around them.

What is commonly referred to as autism is, more precisely, a group of disorders known as autism spectrum disorders. Autistic disorder is a more severe form of autism, and Asperger syndrome is a milder form. An individual who has symptoms of either of these disorders but does not meet their specific criteria is diagnosed with pervasive developmental disorder not otherwise specified. Other rare, severe disorders that are included in the group of autism spectrum disorders are Rett syndrome⁶ and childhood disintegrative disorder.⁷ While autism typically is detected

⁵A developmental disability is a chronic condition caused by mental impairment, physical impairment, or both that begins any time during prenatal development up to age 22 and usually persists throughout a person's life. People with developmental disabilities have problems with major life activities such as language, mobility, learning, and independent living. Developmental disabilities include cerebral palsy, hearing loss, mental retardation, vision impairment, and attention deficit hyperactivity disorder.

⁶Rett syndrome affects girls almost exclusively; after a period of normal development, at some point from 6 to 18 months, a child's mental and social development regresses.

⁷In childhood disintegrative disorder, the child has age-appropriate social and communication skills for a period of time and begins regressing between ages 3 and 4, on average; the loss of skills is more dramatic in childhood disintegrative disorder than in autistic disorder.

during the first 3 years of life, the symptoms, degree, and manner of manifestation range substantially among those with autism. An individual with autism may have some degree of mental retardation or may have above-average intelligence, an expansive vocabulary, or extraordinary abilities in certain areas, such as mathematics or music.

Symptoms that children with autism may exhibit include lack of meaningful gestures by 12 months of age, lack of speech by 16 months of age, inability to respond to one's name, a loss of language or other social skills previously gained, poor eye contact, atypical attachment to a particular toy or object, or inability to use toys or objects. Furthermore, children with autism may not respond like other children. For example, they may seem indifferent, seldom seek comfort, and resist or passively accept affection. Because it is common for individuals with autism to have difficulty regulating their emotions, they may behave inappropriately, disruptively, or even aggressively. They may become frustrated when they are placed in a new environment, and when frustrated may pull their hair, bang their heads, or attack others or themselves.

Currently, there is no consensus about the cause of autism. While autism is known to be the result of a neurological disorder that affects the normal functioning of the brain, it is not known precisely what causes the brain disorder or which factors are associated with particular severity levels within the autism spectrum. Theories include genetic components, environmental components, and some combination of genetics and the environment.

Experts generally agree that early detection is the best hope of appropriate treatment and best quality of life in later years for those with autism. Most also agree that people with autism generally respond better to highly structured programs tailored to each individual's particular developmental deficits. To date, most treatment for children with autism has focused on education interventions, which may include speech and language therapy, occupational therapy, and behavior modification. Under the Individuals with Disabilities Education Act (IDEA),⁸ states are required to provide eligible children with needed special education and related services. Some physicians may prescribe medications to treat behavioral problems such as aggression and self-injurious behavior; these medications are generally the same medications used to treat similar symptoms in other disorders.

⁸20 U.S.C. § 1400 *et seq.*

It is not known how many people in the United States currently have autism. In 1996, CDC began conducting population-based studies to determine the prevalence of and risk factors for autism,⁹ and the agency has reported prevalence rates for children in two communities.¹⁰ These rates were 3.4 and 6.7 per 1,000 children and were higher than previously reported prevalence rates.¹¹ In addition, in May 2006, CDC reported estimated autism prevalence rates for the period of 2003 to 2004 based on two national surveys, one of which indicated a rate of 5.5 per 1,000 children and the other of which indicated a rate of 5.7 per 1,000 children.¹² Some experts have attributed the reported increase in prevalence to changes in diagnostic criteria, and some have contended that it reflects improvements in early detection. The apparent increase in prevalence, coupled with the lack of a known cause or cure, has sparked concern, particularly among families with affected children.

The Children's Health Act of 2000 required HHS and certain HHS agencies to conduct various activities and programs related to autism. NIH was charged with expanding, intensifying, and coordinating research on autism and awarding grants for autism research centers of excellence. NIH was also directed to establish a program through which tissue samples and genetic materials would be made available for research and to establish a means through which the public could obtain information and provide comments on NIH's autism-related activities. In addition, the law required CDC to establish an autism and developmental disabilities surveillance program through regional centers of excellence to collect and analyze information and coordinate research related to the epidemiology of autism. The law also required the establishment of an interagency autism

⁹Prevalence refers to the number of cases present during a particular interval of time.

¹⁰Centers for Disease Control and Prevention, *Prevalence of Autism in Brick Township, New Jersey, 1998: Community Report* (Atlanta, Ga.: 2000), and Yeargin-Allsopp et al., "Prevalence of Autism in a U.S. Metropolitan Area," *Journal of the American Medical Association*, vol. 289, no. 1 (2003).

¹¹Population-based studies conducted in the 1980s yielded prevalence rates of .33 and .12 per 1,000 children.

¹²Centers for Disease Control and Prevention, Fact Sheet: "MMWR - Parental Report of Diagnosed Autism in Children Aged 4-17 Years, United States, 2003-2004" (May 4, 2006). These rates were calculated using parent-reported data from two national surveys—the National Health Interview Survey administered by CDC and the National Survey of Children's Health sponsored by HRSA and administered by CDC. The surveys asked parents if they were ever told by a doctor or other health care provider that their child had autism.

coordinating committee to coordinate efforts within HHS. Many of these activities have been funded through lump sum appropriations to NIH and CDC, and the Congress has generally not appropriated funds specifically for autism projects and activities.¹³

NIH and CDC Support an Array of Autism Activities and Report That Their Funding of Autism Activities Has Increased

NIH and CDC support an array of autism activities, and officials from both agencies told us that their funding of autism activities increased from fiscal year 2000 to fiscal year 2005. NIH's efforts include research on determining the causes of autism, improving the diagnosis and treatment of autism, and improving the delivery of autism-related services. CDC supports surveillance activities, including tracking the characteristics and prevalence of autism. CDC's surveillance programs have relied on information from multiple sources, including student education records, to obtain a complete and unduplicated count of the number of children with autism. However, CDC officials believe a 2003 change in Education's interpretation of the federal law governing the privacy of education records has hindered CDC's ability to continue to use this methodology. HHS and Education were required to submit a report to congressional committees in June 2005 identifying how to overcome the challenges CDC faces in using education records to conduct surveillance; as of June 2006, the agencies had not agreed on options for overcoming these challenges and had not completed the report. NIH's estimated funding of autism research increased from about \$51.5 million in fiscal year 2000 to about \$101.6 million in fiscal year 2005. CDC's total funding of autism activities increased from about \$2.1 million to about \$16.7 million during the same period.

NIH Supports a Wide Array of Research Related to Autism

NIH has undertaken research activities that focus on determining the causes of autism, improving the diagnosis and treatment of autism, and improving the provision of services related to autism. (See app. II for information on selected NIH autism activities.) Many of these activities were developed to respond to the Children's Health Act's general requirement that NIH expand, intensify, and coordinate its autism research activities and to the act's specific requirements, such as that NIH establish centers for conducting research on autism and establish a program

¹³One exception is a supplemental appropriation to HHS for fiscal year 2003 in which \$1 million was made available to the Geisinger Health System, Harrisburg, Pennsylvania, to establish centers of excellence for the treatment of autism. Pub. L. No. 108-11, 117 Stat. 559, 595.

through which tissue samples and genetic materials would be available for research.

NIH research that focuses on determining the causes of autism includes efforts to identify genes that increase susceptibility to the disorder and efforts to ascertain the role of environmental exposures. For example, NIH's National Institute of Environmental Health Sciences, in partnership with the Environmental Protection Agency, supports a national network of centers to examine the effect of environmental exposures on children's health. Of the 11 centers this program supports, 2 centers conduct research on environmental causes of autism and perform clinical evaluations of children with autism.

NIH also conducts research evaluating specific treatments for the symptoms associated with autism. Several federal officials and advocacy association representatives told us that there are not enough evidence-based treatments for people with autism, and NIH has several activities to help develop such treatments. For example, in response to the increasing use of medications to treat symptoms of autism, the National Institute of Mental Health (NIMH) in 1997 established a network of research sites to study the use of psychotropic drugs in the treatment of autism. In 2002, the network was renewed and expanded to include psychosocial and behavioral interventions. Support for the research is designated specifically for evaluating treatments for autism, and the networks are intended to be a national resource that will expedite clinical trials in children. For example, one study found that methylphenidate—a treatment for attention deficit/hyperactivity disorder—was often effective for improving inattention, hyperactivity, impulsivity, and distractibility in children with autism who participated in the study.¹⁴

NIH's largest investment in autism research is through its support of networks of research centers, such as the Collaborative Programs of Excellence in Autism (CPEA), consisting of nine centers,¹⁵ and the Studies

¹⁴Research Units on Pediatric Psychopharmacology Autism Network, "Randomized, Controlled, Crossover Trial of Methylphenidate in Pervasive Developmental Disorders With Hyperactivity," *Archives of General Psychiatry*, vol. 62 (2005).

¹⁵The CPEAs are located at Boston University; University of California, Davis; University of California, Los Angeles; University of Pittsburgh; University of Rochester Medical Center; University of Texas Health Science Center at Houston; University of Utah (Salt Lake City); University of Washington (Seattle); and Yale University (New Haven, Connecticut). The CPEAs collectively make up the Network on the Neurobiology and Genetics of Autism.

to Advance Autism Research and Treatment (STAART), consisting of eight centers¹⁶ and a data coordination center. NIH's National Institute of Child Health and Human Development and National Institute on Deafness and Other Communication Disorders established the CPEA network in 1997; in 2002, they renewed the network for an additional 5 years and in 2003 expanded it to include a data coordinating center. NIH began the STAART program in 2001 in response to the Children's Health Act. Some centers participate in both networks, which have similar purposes in conducting research on the causes, diagnosis, early detection, and treatment of autism. Unlike the CPEA network, the STAART network requires that each center have at least one treatment project. NIH officials told us the institutes are planning to unify the STAART centers and CPEAs into a new network—Autism Centers of Excellence—in an effort to improve coordination of NIH-sponsored efforts, avoid duplication, and maximize the efficient use of resources.

NIH also supports programs that provide research resources, such as genetic materials and tissue samples, to scientists working on autism. For example, NIH's National Institute of Neurological Disorders and Stroke and NIMH are providing support to the Harvard Brain Tissue Resource Center to increase the collection of brains from individuals diagnosed with autism, which is expected to facilitate neurobiological research on autism. In addition, several NIH institutes and centers support the collection, sharing, and distribution of genetic and tissue materials across the scientific community through NIMH's Autism Genetics Initiative.

NIH officials told us that through the agency's internal Autism Coordinating Committee, five NIH institutes collaborate closely on their autism activities, such as managing grant programs, developing research program announcements, and responding to inquiries from researchers.¹⁷ For example, to encourage investigator-initiated studies, the five institutes jointly sponsor a broadly based program announcement that solicits research proposals designed to elucidate various issues related to autism,

¹⁶The STAART centers are located at Boston University; Kennedy Krieger Institute (Baltimore, Maryland); Mt. Sinai Medical School (New York, New York); University of California, Los Angeles; University of North Carolina, Chapel Hill; University of Rochester; University of Washington (Seattle); and Yale University (New Haven, Connecticut).

¹⁷The five institutes are the National Institute of Child Health and Human Development, National Institute on Deafness and Other Communication Disorders, National Institute of Environmental Health Sciences, NIMH, and National Institute of Neurological Disorders and Stroke.

including causes and the optimal way of delivering services. NIH officials told us that there is usually no obvious scientific demarcation for which institute is the best fit for a grant application, so the committee generally determines the distribution of grants according to available resources. The committee is also working with the NIH Center for Information Technology to create and implement a National Database for Autism Research. NIH officials expect the database to allow researchers to share data; make disparate databases available through a single source; and coordinate data with other federal databases, such as NIMH's Autism Genetics Repository. NIH officials also told us that the committee drafted the request for applications for the new Autism Centers of Excellence program.

CDC Supports Autism Surveillance, but Faces Challenges in Its Ability to Report Accurate Prevalence Data

CDC supports surveillance activities in certain locations that track the prevalence of autism and other developmental disabilities in children.¹⁸ In 1996, CDC began collecting information on the prevalence of autism as a part of its Metropolitan Atlanta Developmental Disabilities Surveillance Program, and in 1999, CDC began supporting autism surveillance in West Virginia. CDC expanded its surveillance activities in fiscal year 2000 to form the Autism and Developmental Disabilities Monitoring Network, which initially consisted of 5 project sites established to conduct surveillance in 6 states. Subsequent expansions of the network in fiscal years 2002 and 2003 added additional project sites and states, and as of February 2006, the network consisted of 10 project sites established to conduct surveillance in 11 states.¹⁹ CDC also supports surveillance at 6 additional sites through its Centers of Excellence for Autism and Developmental Disabilities Research and Epidemiology, established in 2001 in response to the Children's Health Act.²⁰ In addition to engaging in surveillance, these sites conduct research to determine the causes of and

¹⁸These other developmental disabilities are cerebral palsy, hearing loss, mental retardation, and vision impairment.

¹⁹The states are Alabama, Arizona, Arkansas, Florida, Illinois, Missouri, New Jersey, South Carolina, Utah, West Virginia, and Wisconsin.

²⁰The centers are at the California Department of Health Services, CDC's National Center on Birth Defects and Developmental Disabilities, Colorado Department of Public Health and Environment, Johns Hopkins University, University of North Carolina at Chapel Hill, and University of Pennsylvania.

risk factors for autism.²¹ CDC, through its autism surveillance activities, also collects information on the characteristics of autism, including the severity of symptoms and the presence of co-occurring disorders.

To obtain a complete and unduplicated count of the number of children with autism, most of CDC's surveillance sites have shared the same method of comparing information from multiple data sources—including student education records, medical records, and vital records. For example, according to CDC officials, information in education records has been used to identify children with autism who were not identifiable from other sources.²² In addition, a child with autism may be identified in multiple data sources, and comparing these sources helps ensure the child is not counted more than once. CDC officials said that to compare multiple data sources accurately, the surveillance sites must have personally identifiable data, such as the child's name or Social Security number. To protect the privacy of information in children's education records, after CDC researchers are sure they have an unduplicated count, all personally identifiable markers in the data sets are replaced with codes that are not linked to personally identifiable data, according to CDC officials.

CDC officials believe the agency's surveillance programs will not be able to continue using this methodology because of a 2003 change in Education's interpretation of FERPA.²³ FERPA guarantees parents access to their child's education records and protects the privacy of these records by prohibiting their disclosure without parents' prior written consent,

²¹In response to a requirement of the Children's Health Act to establish an information clearinghouse, CDC established a Data Coordinating Center to collect and store data and to coordinate data management between the Autism and Developmental Disabilities Monitoring Network grantees and the Centers of Excellence for Autism and Developmental Disabilities Research and Epidemiology grantees.

²²Centers for Disease Control and Prevention, National Center on Birth Defects and Developmental Disabilities, *Developmental Disabilities Surveillance: Methods and Results from the Metropolitan Atlanta Developmental Disabilities Surveillance Program (MADDSP)* (Atlanta, Ga., 2004). To identify autism cases, the site applied diagnostic criteria for autism contained in the *Diagnostic and Statistical Manual of Mental Disorders - Fourth Edition* to information obtained from student education records, which included behavioral descriptions and information on the child's developmental history.

²³20 U.S.C. § 1232g.

except in limited circumstances.²⁴ In December 2000, CDC entered into a memorandum of agreement with Education that designated CDC an authorized representative of Education, which allowed CDC access to data in personally identifiable education records for its surveillance program in Atlanta. Several other sites in the monitoring network entered into similar agreements with their respective state education agencies to gain access to this type of data. However, in 2003, Education determined that this sharing of information was not consistent with FERPA, stating that only employees, contractors, and others under the direct control of a state education agency can be designated as its authorized representative. In response to subsequent inquiries, Education sent letters to two states' education agencies informing them of this reinterpretation of FERPA. It posted these letters on the Education Web site.²⁵ The agreement between Education and CDC that governed the surveillance program in Atlanta expired in December 2005, and based on its 2003 interpretation of the statute, Education did not renew it. According to CDC, as of May 2006, 9 of its 16 autism surveillance sites²⁶ were operating under state-level memorandums of agreement to access education records, while the Atlanta site had stopped collecting data and the other sites were using other methodologies, such as collecting data only from medical sources.

CDC and Education officials have discussed issues related to CDC's use of education records for autism surveillance. Education officials have stated that FERPA requires CDC to obtain written parental consent to gain access to personally identifiable education records and that as an alternative, CDC could choose to conduct its surveillance activities using aggregated data. CDC officials said that obtaining parental consent is not an optimal research method because, in general, low proportions of

²⁴FERPA permits disclosure of personally identifiable education records without the written consent of parents to, for example, an authorized representative of Education or a state education agency, provided that the disclosure is in connection with the audit and evaluation of federally supported education programs or the enforcement of federal legal requirements that relate to such programs. The records must also be protected so that personally identifiable information is not improperly disclosed and the records are destroyed when no longer needed.

²⁵Education told us that it has also provided training to local school districts, state departments of education, and others on the requirements of FERPA.

²⁶These 16 sites consist of the 10 sites conducting surveillance in CDC's Autism and Developmental Disability Monitoring Network and the 6 sites conducting surveillance through CDC's Centers of Excellence for Autism and Developmental Disabilities Research and Epidemiology.

parents of school-aged children respond to such requests, resulting in incomplete data. They also said that personally identifiable data are needed during the initial stage of surveillance to ensure an unduplicated count of individuals with autism. CDC officials discussed with us approaches that they believe would allow CDC to continue surveillance using personally identifiable education records. The options CDC identified would require either legislative or administrative action, including amending FERPA, the Children's Health Act, or the Public Health Service Act to permit autism surveillance activities without parental consent or to provide for a passive consent system for parents;²⁷ or allowing staff from education agencies to oversee or participate in data collection.

The Birth Defects and Developmental Disabilities Prevention Act of 2003 required the Secretary of HHS and the Secretary of Education to submit a report to congressional committees²⁸ by June 2005 concerning CDC's autism and developmental disabilities surveillance activities, including a description of challenges to CDC's obtaining education records.²⁹ The report is also to describe methods for overcoming these challenges, such as efforts to increase parental consent, and to describe the justifications for any recommendations for legislative changes, including changes to FERPA. As of June 2006, CDC and Education had not agreed on options for overcoming the challenges CDC faces in using education records, and CDC and Education officials told us they could not estimate when the report would be ready for submission. CDC officials told us that the agency was developing a draft of the report, which Education would then need to review.

²⁷In a passive consent system, access to education records would be granted automatically unless parents informed the school that they did not want anyone else to have access. Passive consent systems are not authorized under FERPA.

²⁸The report is to be submitted to the Senate Committee on Health, Education, Labor, and Pensions and the House Committees on Energy and Commerce and Education and the Workforce.

²⁹42 U.S.C. § 247b-4b note.

**NIH and CDC Reported
That Their Funding of
Activities Related to
Autism Increased from
Fiscal Year 2000 to Fiscal
Year 2005**

NIH's funding of autism research increased from about \$51.5 million in fiscal year 2000 to about \$101.6 million in fiscal year 2005, based on estimated funding data provided by NIH. (See table 1.) NIH data show that NIMH has provided the greatest amount of support for autism research among NIH's institutes, and its estimated funding for autism research increased from about \$22.6 million in fiscal year 2000 to about \$58.4 million in fiscal year 2005. NIMH considers the total amount awarded for each project as autism funding, even when autism is only one of several disabilities being studied. According to NIMH, many of the institute's grants target a broad question related to neurodevelopment that has implications for autism and many other developmental disabilities. Because the research has the potential to produce important information about autism, however, NIMH believes that 100 percent of the grant amount should be considered autism funding even though the grant also covers other disabilities.

Table 1: NIH's Estimated Funding of Autism Activities, by Institute/Center, Fiscal Years 2000-2005

Dollars in thousands

Institute/center	Fiscal year					
	2000	2001	2002	2003	2004	2005
National Institute of Mental Health	\$22,629	\$24,816	\$36,279	\$51,096	\$54,102 ^a	\$58,406
National Institute of Child Health and Human Development	15,409	15,803	19,889	21,852	21,530	19,461
National Institute of Neurological Disorders and Stroke	5,321	6,625	8,451	12,888	12,242	13,826
National Institute on Deafness and Other Communication Disorders	1,782	1,857	2,470	2,923	2,751	4,129
National Institute of Environmental Health Sciences	^b	972	1,025	1,333	1,480	1,424
National Center for Research Resources	1,338	1,924	1,499	1,014	1,049	920
National Human Genome Research Institute	4,505	2,857	3,458	1,831	440	554
National Institute on Aging	380	311	400	389	332	341
National Institute of Nursing Research	110	320	327	^b	^b	288
Roadmap for Medical Research ^c	^b	^b	^b	^b	296	2,283
Total	\$51,474	\$55,485	\$73,798	\$93,326	\$94,222	\$101,632

Source: GAO analysis of NIH data.

Notes: The funding data in this table represent obligated funds—funds NIH had legally committed to spend but might not yet have expended—and represent NIH's estimated funding of autism research. NIMH considers the total amount awarded for each project as autism funding, even when autism is only one of several disabilities being studied. According to NIH, the other institutes prorate the research dollars, estimating a percentage of the project that focuses on autism. The table includes the NIH institutes and centers that NIH reported to us as funding autism research in fiscal year 2005. According to NIH, the National Center for Complementary and Alternative Medicine funded a relatively small amount of autism research in fiscal years 2000 and 2001 and the National Institute on Alcohol Abuse and Alcoholism similarly funded a relatively small amount of autism research in fiscal years 2001 through 2003; neither funded autism research in fiscal year 2005.

^aThis amount differs from the amount NIH has used when publicly reporting its total funding of autism activities. It has used the amount \$59,708,000 for NIMH's funding of autism for fiscal year 2004. NIMH officials told us that this figure was incorrect because of a clerical error.

^bNIH did not report autism funding for the institute in this year.

^cIn addition to funding research for autism through institutes and centers, NIH funded research for autism through its Roadmap for Medical Research. The goal of the roadmap is to identify research opportunities and gaps in biomedical research that no single institute at NIH can undertake alone and that NIH officials believe the agency as a whole must address.

Estimated combined funding for autism research at other NIH institutes increased from about \$28.9 million in fiscal year 2000 to about \$43.2 million in fiscal year 2005.³⁰ Unlike NIMH, these institutes prorate the research dollars, estimating a percentage of the project that focuses on autism, but NIH officials told us that there is variability in how these institutes estimate the prorated amounts. NIH officials told us that the agency is developing a single system for disease coding across all NIH institutes; the agency anticipates implementing this system in October 2007.

CDC's funding of autism activities increased from about \$2.1 million in fiscal year 2000 to about \$16.7 million in fiscal year 2005. The National Center on Birth Defects and Developmental Disabilities has provided the most support for CDC's autism activities, and agency officials told us that the center's funding of these activities increased from about \$1.1 million to about \$14.9 million during this period. CDC's funding amounts include the agency's funding of autism and developmental disabilities surveillance activities and of research to determine the causes and characteristics of autism. CDC officials told us that CDC counts the total amount of its funding of the surveillance activities as autism funding because researchers need to collect information on other developmental disabilities to identify autism cases. (See table 2 for CDC's funding of autism activities for fiscal years 2000 through 2005.)

³⁰According to NIH, the funding for autism research in fiscal year 2005 includes funding provided through the agency's Roadmap for Medical Research. The goal of the roadmap is to identify research opportunities and gaps in biomedical research that no single NIH institute can undertake alone and that NIH officials believe the agency as a whole must address to make the greatest impact on the progress of medical research.

Table 2: CDC’s Funding of Autism Activities, Fiscal Years 2000-2005

Dollars in thousands

Center/office	Fiscal year					
	2000	2001	2002	2003	2004	2005
National Center on Birth Defects and Developmental Disabilities ^a	\$1,140	\$5,500	\$8,443	\$10,811	\$13,242	\$14,873
National Immunization Program	1,000	1,000	2,749	3,298	3,592	370
National Center for Infectious Diseases	0	0	0	0	15	15
National Center for Environmental Health/Agency for Toxic Substances and Disease Registry	0	20	25	30	5	113
Office of Public Health Research	0	0	0	0	600	600
Other ^b	0	1,234	0	248	695	744
Total	\$2,140	\$7,754	\$11,217	\$14,387	\$18,149	\$16,715

Source: GAO analysis of CDC data.

Notes: These funding amounts include CDC’s funding of autism and developmental disabilities surveillance activities and of research to determine the causes and characteristics of autism. CDC counts the total amount of its funding of the surveillance activities as autism funding because researchers need to collect information on other developmental disabilities to identify autism cases. The funding data in this table generally represent obligated funds—funds CDC had legally committed to spend but might not yet have expended. Dollars are rounded to the nearest thousand.

^aThe funding for this center represents appropriated amounts that CDC allocated to autism activities.

^bAccording to CDC officials, these funds were awarded as grants to organizations listed in conference reports accompanying appropriations legislation, and the grants were awarded under the authority of the Public Health Service Act.

Federal Agencies Support Services for People with Autism Primarily Through Broader Disability Programs, and Some Services May Not Always Be Available

Federal agencies support services for people with autism primarily through broader programs that focus on disabilities, and some services may not always be available to meet the needs of this population. ACF and Education support education services for children with autism through broader programs for people with disabilities. ACF’s Head Start program provides early childhood education to young children in low-income families and is often the first opportunity to identify a child’s disability. Education supports programs that provide special education services for children and young adults with disabilities, but schools face challenges in providing services. Other federal agencies, including HRSA and CMS, support programs that provide services or enhance the delivery of health care for people with developmental disabilities. For example, CMS supports community-based services to meet the needs of people with autism through Medicaid programs; however, many people with autism may not be able to obtain services through these programs.

Services for Children with Autism Are Delivered Primarily through Education Programs for Children with Disabilities, and Schools Face Challenges in Providing Services

ACF and Education administer programs that identify and educate children with disabilities, including autism. ACF's Head Start program provides early childhood education and services to children from low-income families, generally from birth to age five,³¹ with the goal of increasing school readiness. Head Start policies and procedures must ensure that at least 10 percent of all enrollment opportunities in each state are available to children with disabilities and ensure that services are provided to meet their individual needs.³² For a child enrolled in Head Start, the program is often the first opportunity to identify a disability affecting the child's development. According to ACF, in fiscal year 2004, about 55 percent of the children with disabilities enrolled in Head Start had their disabilities identified after becoming enrolled.

Education has responsibility for implementing IDEA,³³ whose purpose is to provide a free and appropriate public education to children with disabilities. Under IDEA, Education supports early intervention services for children under age 3 through the Early Intervention Program for Infants and Toddlers with Disabilities, which provides grants to states to implement programs to reduce the risk that children will have a substantial developmental disability in the future.³⁴ Beginning at age 3 and generally through age 21,³⁵ children with disabilities are eligible to receive special education and related services that conform with an individualized education program (IEP). IDEA requires parents, teachers, school personnel, and sometimes the student to work as a team to develop an IEP that includes annual goals that reflect the child's educational, behavioral, and physical needs and describes the services that the student will receive. Each school is responsible for ensuring that the IEP is carried out as written, notifying parents of the child's progress, and reevaluating the child at least every 3 years. Under IDEA, parents have several options to

³¹Head Start is authorized to serve children at any age prior to compulsory school attendance in the state.

³²20 U.S.C. § 9835(d).

³³Autism is one of several disabilities for which children are eligible to receive special education services under IDEA.

³⁴See GAO, *Individuals with Disabilities Education Act: Education Should Provide Additional Guidance to Help States Smoothly Transition Children to Preschool*, [GAO-06-26](#) (Washington, D.C.: Dec. 14, 2005).

³⁵20 U.S.C. § 1401(9), 1412(a)(1)(A). Eligibility terminates when the child receives a high school diploma or when the child is not otherwise eligible under state law. 20 U.S.C. § 1414(c)(5)(B)(i).

advocate and negotiate for what will be included in the IEP. If parents disagree with the education plan determined by the IEP team, they may discuss their concerns with other members of the team; if agreement is not reached, parents may ask for mediation, file a complaint with the state education agency, or request a hearing before the appropriate education agency.³⁶ Parents who are not satisfied with the outcome of the hearing may file a lawsuit under certain circumstances.

The availability of education services for children with disabilities, including autism, varies across states and school districts, and schools face challenges in providing services for these children. For example, many children with autism have communication problems, but some school districts have encountered difficulties in providing speech and language services because of a shortage of specialists who can provide these services.³⁷ In addition, some school districts have found it difficult to provide certain recommended interventions for particular children—such as one-to-one instruction—because of their high cost. The National Academies’ National Research Council reported that schools, faced with high costs for some of the recommended treatments for their students with autism, have tried to find a way of providing services they believe are appropriate but that will not overburden their budgets.³⁸ The National Research Council concluded that school districts need financial help to provide appropriate services for children with autism, and the council recommended that states develop strategies for coordinating state education agencies with other state agencies to fund interventions for children with autism.³⁹

Education also supports transition services that are designed to provide skills training, job training, and job placement to young adults with disabilities who are in transition from high school to postsecondary education or employment. When a child receiving special education

³⁶Parents may also obtain an independent education evaluation of their child at any time at their own expense.

³⁷See GAO, *Special Education: Numbers of Formal Disputes Are Generally Low and States Are Using Mediation and Other Strategies to Resolve Conflicts*, [GAO-03-897](#) (Washington, D.C.: Sept. 9, 2003).

³⁸National Research Council, *Educating Children with Autism* (Washington, D.C.: 2001).

³⁹The council recommends that states develop a state fund for intensive intervention or consider other sources of funding currently in place in some states to provide education services to children with autism.

services under IDEA reaches age 16, the IEP must identify the transition services needed to reach the post-high school goals set in the IEP. Education supports state vocational rehabilitation agencies that can help individuals with disabilities prepare for and engage in gainful employment.⁴⁰ State vocational rehabilitation programs must develop individualized plans for employment for students eligible for vocational rehabilitation services before they leave school.⁴¹ Furthermore, for a student with a disability who is receiving special education services, this plan must be coordinated with the goals, objectives, and services in the student's IEP.

Children with disabilities, including autism, may not always receive the transition services they need. For example, under the vocational rehabilitation program, although all people with physical or mental impairments are potentially eligible for services, we previously reported that states may serve only those with the most significant disabilities in times of funding constraint, and that according to Education officials, a number of states have waiting lists for vocational rehabilitation services.⁴² We also reported that many local school systems do not have transition coordinators or work preparation programs to adequately plan for student transitions, and that the task of linking schools with adult service providers falls on special education personnel who may not be trained to address the transition needs of young adults with disabilities. In addition, according to representatives of advocacy associations, special education programs may not sufficiently prepare students for life beyond the classroom. For example, although job skills training in schools may be able to help young adults with autism obtain employment, the young adults may not have developed the social or independent living skills, such as the ability to navigate the public transportation system, necessary to keep their jobs.

⁴⁰Children with disabilities, including autism, may also be eligible for transition services through the Department of Labor's Workforce Investment Act youth program and the Social Security Administration's Ticket to Work and Self-Sufficiency program. For additional information on the transition services provided by these programs, see GAO, *Special Education: Federal Actions Can Assist States in Improving Postsecondary Outcomes for Youth*, [GAO-03-773](#) (Washington, D.C.: July 31, 2003).

⁴¹A student is eligible for vocational rehabilitation services if the state vocational rehabilitation agency determines that the student has a physical or mental disability that constitutes or results in a substantial impediment to employment.

⁴²[GAO-03-773](#).

Education also supports programs to develop and implement evidence-based practices for educating children with autism. Under IDEA, Education administers a discretionary grant program that in fiscal year 2004 made over 40 awards for projects focused on autism and related developmental disabilities. The grant projects currently under way include research on education-based treatment interventions and training for parents and professionals working with children with autism. Education supports six Professional Development in Autism sites across the nation through which school personnel and families are provided training, support, and information on how to use evidence-based practices for students with autism.⁴³ In addition, Education's Institute of Education Sciences reported that it will sponsor a competitive grant research program in fiscal year 2007 to develop or test the effectiveness of comprehensive pre-school and school-based interventions that improve the cognitive, communication, academic, social, and behavioral outcomes of children with autism.

Other Federal Programs That Support Autism Services Also Generally Have a Broader Disability Focus, and Experts and Officials Report Autism Services Are Limited

Several federal agencies support services for people with autism through programs that provide services or enhance the delivery of care for people with developmental disabilities. Experts and officials from federal agencies told us there are not enough services—including behavioral therapy, speech therapy, occupational therapy, and supported living services—to meet the needs of people with autism. In addition, experts and federal officials have said that the shortage of professionals trained to serve people with autism makes it difficult for people with this disability to obtain the full range of services they need.

Through programs targeted to people with developmental disabilities, ACF supports services for people with autism and training for professionals who work with this population. The agency supports the following grant programs to help meet the needs of individuals with developmental disabilities: the State Councils on Developmental Disabilities, Projects of National Significance, and State Protection and Advocacy Agencies. (See table 3 for a description of these programs.)

⁴³The sites are located at the University of Washington (Seattle); University of Colorado at Denver; University of Kansas (Kansas City); Oakstone Academy (Columbus, Ohio); Maryland Coalition for Inclusive Education (Hanover); and University of South Florida (Tampa).

Table 3: ACF Programs That Support Services for People with Autism and Other Disabilities

Program	Purpose	Services/activities
State Councils on Developmental Disabilities	To increase the independence, productivity, inclusion, and integration of people with developmental disabilities in their community	Supports training and education of local service providers and policymakers on the needs of individuals with developmental disabilities
Projects of National Significance	To promote independence, productivity, inclusion, and community integration for people with developmental disabilities	Supports projects that seek to improve quality of life in the community for people with disabilities, such as projects that provide career development programs for people with developmental disabilities
State Protection and Advocacy Agencies	To protect the legal and human rights of people with developmental disabilities	Supports services that provide legal help for people with developmental disabilities and their families

Source: GAO analysis of ACF documents.

In addition, ACF supports the operation and administration of 65 University Centers for Excellence in Developmental Disabilities Education, Research, and Service. The centers, which receive program funding from other sources, conduct research, disseminate information, and provide interdisciplinary training for medical residents, pediatricians, and other health care professionals on treating autism and other developmental disabilities.

HRSA supports two programs to train professionals who work with people with developmental disabilities, including autism.⁴⁴ HRSA’s Leadership Education in Neurodevelopmental Disabilities program has 35 centers across the nation that focus on training professionals with a variety of professional backgrounds—such as psychologists, pediatricians, and speech-language pathologists—to improve health care for children with developmental disabilities. HRSA also supports the Developmental-Behavioral Pediatrics Training Program to enhance the behavioral,

⁴⁴HRSA also supported the Quentin N. Burdick Program to address issues in rural health care. A goal of the Burdick Program was to train health professionals to deliver medical services to people with developmental disabilities, including autism. HRSA ended the Burdick program in December 2005 because of budget constraints.

psychosocial, and developmental aspects of general pediatric care. The program consists of 9 centers located in institutions of higher learning, which support fellows in behavioral pediatrics to help prepare them for leadership roles as teachers, researchers, and clinicians.

CMS supports services to meet the needs of people with autism through Medicaid autism and developmental disability programs.⁴⁵ These programs operate under CMS's home and community-based services waivers that allow individuals who would otherwise need long-term care in nursing homes or other institutional settings to receive coverage for long-term care services in community settings. States determine the types of long-term care services they wish to offer under the waiver. For example, states with autism or developmental disabilities waiver programs may cover the costs for specific disability-related services—such as speech therapy, occupational therapy, and respite care⁴⁶—when those services are not otherwise covered under the state's Medicaid program. States' autism waiver programs generally offer the same services as their developmental disability waiver programs; the primary difference is that the autism waiver program may offer early intervention behavioral therapies targeted to young children. According to CMS, as of April 2006, 44 states and the District of Columbia had developmental disability waiver programs, and 3 states had autism waiver programs.⁴⁷ In the 2 states operating both waiver programs, a person eligible for the state's autism waiver program could also be eligible for the state's developmental disability waiver program. However, in these states, a person can receive services under only one waiver program at a time.

⁴⁵Medicaid is a federal-state program that finances health care for certain low-income Americans. The Medicaid autism and developmental disability programs operate under Section 1915(c) of the Social Security Act, which authorizes CMS to waive certain Medicaid requirements, including (1) statewideness, which requires that services be available throughout the state; (2) comparability, which requires that all services be available to all eligible individuals; and (3) income and resource rules, which require states to use a single income and resource standard when determining eligibility for Medicaid, with the exception of institutional care. A waiver of the last requirement allows states to exclude parental income when determining the income eligibility of children with autism and other developmental disabilities.

⁴⁶Respite care services are services provided to individuals unable to care for themselves and are furnished on a short-term basis because of the absence of or need for relief for those persons normally providing the care.

⁴⁷The states CMS reported to us as having waiver programs specific to autism are Indiana, Maine, and Maryland.

Although Medicaid autism and developmental disability waiver programs support the provision of treatment services for people with autism, many people with autism may be unable to obtain services through these programs because they do not meet the programs' eligibility rules or because states limit enrollment. To be eligible to receive services under the programs, a person would need long-term care in a nursing home or other institutional setting in the absence of the waiver. As a result, people at the higher functioning end of the autism spectrum, including people with Asperger syndrome, are generally not eligible to receive services under the waiver programs. Furthermore, states are allowed to cap the number of people who can enroll in these programs. In some states, enrollment waiting lists for the waiver programs are several years long. Because some autism interventions have been found to be effective only when applied by a certain early age, children with autism who remain on waiting lists for several years may exceed the eligible age range for the intervention before they can enroll in the waiver program. Officials in one state told us the average length of time a person is on the waiting list for either its autism or developmental disability waiver program exceeds 5 years. This state requires that a specific intensive one-on-one intervention be covered under its autism waiver program; however, state officials told us that in practice no child has ever received the service through the Medicaid waiver program. Because a child must receive the intervention by age six, and children are not usually diagnosed with autism until age three, by the time they come off the waiting list, they are no longer eligible for the intervention.

CMS has another waiver program that can assist people with autism and other disabilities. According to CMS, as of April 2006, 12 states were operating Independence Plus waiver programs.⁴⁸ These waiver programs, which allow participant input, support services that teach skills, such as planning, budgeting, and decision making. The Independence Plus waiver programs also support home and community-based services—such as respite care and transportation—for people with disabilities, including developmental disabilities.

⁴⁸States with Independence Plus waiver programs are Alabama, Connecticut, Delaware, Louisiana, Maryland, Mississippi, Montana, New Hampshire, North Carolina, North Dakota, Rhode Island, and South Carolina.

Interagency Autism Coordinating Committee Enhances Communication among Federal Agencies, but Coordination Is Limited

The primary vehicle for coordinating federal agencies' autism activities is the IACC. In accordance with the Children's Health Act, NIH in 2001 established the IACC to enhance effective collaboration within HHS and among other agencies conducting autism-related activities and to improve constructive dialogue with members of the public and interest groups. NIMH was designated the lead agency for the IACC, which includes representation from other NIH institutes, other HHS agencies,⁴⁹ and Education. The IACC meets semiannually and has facilitated the exchange of information on autism activities among member agencies by providing a forum for federal agencies to share information on existing and planned autism-related activities and to obtain comments from participating agencies and the public. For example, CDC officials told us they shared information with the IACC from a series of listening sessions the agency conducted with parents, health care professionals, and others, because the concerns raised at the sessions touched on issues related to research or providing services that were outside of CDC's purview. Officials from member agencies told us that the interagency committee has increased communication; improved planning; and helped agencies avoid duplicative research, such as on environmental risk factors for autism.

The IACC has enhanced federal coordination in the development of research priorities and of recommendations for improving service delivery. In 2003, the IACC produced a research matrix (see app. III), which NIH officials view as a comprehensive list of autism research goals. NIH officials told us the agency's institutes have used the matrix to guide their funding of autism-related activities and programs. For example, NIH has indicated that the focus of its planned Autism Centers of Excellence will relate to the research matrix goals of determining the causes of and best treatments for autism. NIH officials told us that the matrix is not a static document and that it will need to be updated to reflect goals that have been achieved and new priorities. HHS officials told us that a portion of the IACC's November 2006 meeting will be devoted to updating the matrix's goals.

In addition to focusing on research, the IACC has also supported efforts related to early identification and screening for autism and to the provision of services for people with autism. The IACC established a screening subcommittee to develop a screening campaign and work on

⁴⁹The other HHS agencies participating in the IACC are ACF, Agency for Healthcare Research and Quality, CDC, CMS, Food and Drug Administration, HRSA, and SAMHSA.

ways to link families to referrals for services. One of the accomplishments of the subcommittee was CDC's autism awareness campaign: "Learn the Signs. Act Early." This campaign is aimed at encouraging awareness of early childhood development, including warning signs of autism and other developmental disabilities. Through the campaign, CDC disseminates information, provides educational materials, and supports online resources to inform parents and health care providers of the importance of early screening and intervention for children with autism and other developmental disabilities. In addition, because of its concern that services for people with autism are fragmented, poorly coordinated, and not always available, the IACC established a services subcommittee—currently cochaired by officials from Education and the Autism Society of America⁵⁰—to consider the service needs of people with autism. The services subcommittee defined its mission as identifying the service needs of individuals with autism and their families, describing current federal efforts to meet those needs, identifying challenges to meeting those needs, and making recommendations for action.

In July 2004, the services subcommittee convened a panel of autism experts to develop an action plan for enhancing existing service systems, expanding services for individuals with autism and their families, and coordinating services across systems. This document—the Autism Spectrum Disorders Roadmap—was presented to the IACC in May 2005. The roadmap provided a synthesis of issues and challenges related to serving people with autism and a set of performance measures and recommendations for improving services. A subcommittee member told us that the subcommittee's vision was that each agency could begin to implement the recommendations without much difficulty. (See app. IV for additional information on the roadmap.)

The services subcommittee also presented a report to the IACC that identified agencies' existing activities related to the recommendations in the roadmap. The report also identified recommendations that could be implemented in the short term and assigned lead responsibility to specific agencies for implementing them. Some agencies have begun to address the short-term recommendations. For example, in light of the goal of improving access to comprehensive information about autism services, the Agency for Healthcare Research and Quality is planning to develop a single autism Web site to consolidate all government information for

⁵⁰The services subcommittee was initially cochaired by officials from HRSA and SAMHSA.

parents and service providers. An agency official told us that the agency is exploring the possibility of linking information from Education and other agencies with HHS's existing autism Web site.⁵¹ In addition, to respond to the recommendation related to identifying Medicaid waiver programs for people with autism, a CMS official told us that the agency is working on a report that will discuss promising practices supported by autism waiver programs in two states and expects to post the report on its promising practices Web site⁵² by September 2006.

Although some federal agencies have begun to address some of the roadmap's recommendations, the document lacks the specificity that would help a state or federal agency easily implement all of its findings. For example, the roadmap indicates there is a lack of adequately trained autism providers, but does not specify which types of providers are needed. The roadmap also indicates there is a lack of understanding and communication regarding autism, but does not specify the type of training and technical assistance professionals and families of people with autism need.

While the IACC has created a forum for sharing information and identifying areas to pursue to improve research and services, officials told us that there is limited coordination of federal agencies' autism-related activities. For example, although officials from IACC member agencies told us about programs their agencies had under way related to autism, very few of those programs represented coordinated efforts across agencies. Officials from federal agencies and representatives of advocacy associations told us that federal coordination is hindered because no agency on the IACC actively monitors federal agencies' responses to recommendations to ensure that tasks are completed. In addition, because it is simply a coordinating body, the IACC does not have authority to ensure that agencies follow up on committee or subcommittee recommendations. Moreover, no federal agency perceives itself as having lead responsibility for addressing the service needs of adults with autism or services for children beyond education.

⁵¹See <http://www.hhs.gov/autism/>.

⁵²See <http://www.cms.hhs.gov/PromisingPractices/>.

Conclusions

NIH and CDC have increased their funding to support autism activities and have pursued many avenues of research, including those specified in the Children's Health Act and in the IACC's research matrix. In addition to developing research goals for its member agencies, the IACC has provided a forum for federal agencies to inform each other and the public about their current autism activities and has recommended approaches for improving services for people with autism. However, coordination among agencies in carrying out their autism activities remains limited. Furthermore, successful implementation of IACC research goals and services recommendations will depend on individual agencies taking the initiative to develop new programs or tailor existing ones and coordinating with other public and private agencies as appropriate. This is especially critical for improving the availability and delivery of services, because although ACF and Education have primary responsibility for federal programs that support education services for children with autism, no single agency has a lead role in supporting the delivery of other types of services for people with autism.

The information on the characteristics and prevalence of autism being tracked through CDC's surveillance activities could also help federal agencies better develop or tailor services for people with autism. However, the current limitation on CDC's ability to use information in education records has presented challenges to the agency's ability to report accurate and complete data. Conducting autism surveillance and protecting the privacy of sensitive information in education records are both important goals. The Congress required HHS and Education to jointly develop a report describing the challenges to CDC's obtaining education records for autism surveillance and identifying options for overcoming them. As of June 2006, HHS and Education had not completed this report, which could help the Congress determine how to accommodate both of these goals. Resolving the challenges facing CDC would facilitate continued progress toward identifying the characteristics and prevalence of autism. These efforts are essential for advancing knowledge about autism diagnosis, treatment, and services, which could help improve the lives of people with autism and their families.

Recommendation for Executive Action

We recommend that to ensure continued progress toward the development of accurate and comparable data on autism characteristics and prevalence and to provide the information the Congress required on CDC's surveillance activities, the Secretary of Health and Human Services and the Secretary of Education work together to promptly identify options

for overcoming challenges to CDC's ability to use education records for surveillance of autism.

Agency Comments and Our Evaluation

We provided a draft of this report to HHS and Education for comment. (HHS's and Education's comments are reprinted in appendixes V and VI, respectively.) In addition to general comments, HHS and Education also provided technical comments, and we revised our report to reflect the comments where appropriate.

HHS and Education did not agree with the report's recommendation. In its comments, HHS said that the recommendation suggested that HHS and Education had not worked together to identify options that would enable CDC to continue to obtain and use education records for autism surveillance. Although the draft report did not indicate that the departments had not worked together, we added a statement that HHS and Education have had discussions about this issue. However, as of June 2006, HHS and Education had not agreed on options or submitted the report due to the Congress in June 2005 describing these options, as required by the Birth Defects and Developmental Disabilities Prevention Act of 2003. Education expressed concern in its comments that the recommendation did not take into account the privacy protections provided by FERPA. We added language to the final report to acknowledge that autism surveillance and protecting the privacy of information in education records are both important goals. We did not modify our recommendation because we continue to believe it is important for Education and HHS, consistent with the Birth Defects and Developmental Disabilities Prevention Act of 2003, to work together to promptly identify options for overcoming the challenges CDC faces in using education records so that the Congress can make an informed decision on how to accommodate both of these goals.

Education's comments included several points about the draft report's treatment of FERPA's privacy protections. Education said that protecting the privacy of sensitive information in education records should not be viewed as a challenge to overcome, but as an important public safeguard. Our use of the word challenge does not negate the importance of protecting the privacy of education records. We have used this word because the Birth Defects and Developmental Disabilities Prevention Act of 2003 specifically required Education and HHS to describe the challenges to CDC's obtaining education records and identify methods for overcoming them. In its description of the act's discussion of methods for overcoming these challenges, Education emphasized the methods related

to increasing parental consent and said that this was the Congress' primary concern. However, the act specifically instructed the departments to provide justifications for any recommendations to change existing statutory authority, including FERPA, indicating that the Congress contemplated possible changes to current privacy protections.

Education stated that it is willing to discuss with CDC options related to CDC's use of information in education records for autism surveillance. In its response to the draft report's discussion of CDC's description of possible approaches that would allow it to continue using personally identifiable education records for surveillance, Education noted that FERPA does not permit schools to use a passive consent model for the disclosure of education records. We revised the report to clarify that passive consent systems are not authorized under FERPA.

The draft report stated that Education sent letters to two states' education agencies, in response to their inquiries, informing them of Education's reinterpretation of FERPA, but had not communicated this change to other states' education agencies. Education commented that this was inaccurate and said that it had posted these letters on its Web site and that it provides training on FERPA to education officials. We revised the report to reflect this information.

Regarding the draft report's discussion of services for children with autism, Education expressed concern that the draft report implied that there was a widespread problem of schools violating IDEA in their provision of services to children with disabilities, including autism. We did not intend to imply this, and we revised the report to emphasize that schools face challenges in providing such services.

As arranged with your office, unless you publicly announce the contents of this report earlier, we plan no further distribution of it until 30 days after its issue date. At that time, we will send copies of this report to the Secretary of Health and Human Services, the Secretary of Education, the Director of the Centers for Disease Control and Prevention, the Director of the National Institutes of Health, the Administrator of the Centers for Medicare & Medicaid Services, the Administrator of the Health Resources and Services Administration, the Administrator of the Substance Abuse and Mental Health Services Administration, and other interested parties. We will also make copies available to others upon request. In addition, the report will be available at no charge on GAO's Web site at <http://www.gao.gov>.

If you or your staff have any questions about this report, please contact me at (202) 512-7101 or bascettac@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 major contributions to this report are listed in appendix VII.

Sincerely yours,

A handwritten signature in black ink that reads "Cynthia A Bascetta". The signature is written in a cursive style with a large, sweeping initial "C".

Cynthia A. Bascetta
Director, Health Care

Appendix I: Scope and Methodology

To determine the autism-related activities and programs that the Department of Health and Human Services' (HHS) National Institutes of Health (NIH) and Centers for Disease Control and Prevention (CDC) have under way, we collected documents from and interviewed agency officials about their fiscal year 2005 research and surveillance activities. To help confirm that we had a complete list of agencies' programs, we compared the information agency officials gave us with programs in the online Catalog of Federal Domestic Assistance and the Computer Retrieval of Information on Scientific Projects. We identified in the Children's Health Act of 2000 the specific autism-related mandates and authorizations for NIH and CDC and reviewed agency-provided lists of activities and interviewed agency officials to determine which activities the agencies had conducted to respond to the act. We also compared the agencies' autism-related programs to goals developed by the Interagency Autism Coordinating Committee (IACC). To determine NIH's and CDC's funding of activities related to autism, we asked agency officials to provide funding for autism, by institute and center, for fiscal year 2000—one fiscal year before passage of the Children's Health Act—through fiscal year 2005. The funding data we obtained generally represented obligated funds—funds the agencies had legally committed to spend but might not yet have expended. In addition, NIH's data represent the agency's estimated funding of autism research. We did not verify the accuracy of these data; however, we interviewed agency officials knowledgeable about the data, and we determined that the data were sufficiently reliable for the purposes of this report. We relied primarily on agency-reported program descriptions and funding amounts; we did not independently verify the use of grant money by recipients and therefore could not determine any causal link between enactment of the Children's Health Act and changes in funding for autism-related projects.

To identify the programs federal agencies have under way to support services for people with autism, we interviewed officials from other HHS agencies—the Administration for Children and Families, Agency for Healthcare Research and Quality, Centers for Medicare & Medicaid Services, Food and Drug Administration, Health Resources and Services Administration, Office on Disability, and Substance Abuse and Mental Health Services Administration. We also interviewed officials from the Environmental Protection Agency and the Department of Education's Family Policy Compliance Office, Institute of Education Sciences, Office of Elementary and Secondary Education, and Office of Special Education and Rehabilitative Services.

To determine how federal departments and agencies coordinate their autism activities and programs, we reviewed minutes and reports of interagency meetings and interviewed federal agency officials. We also attended the November 2005 meeting of the IACC to observe how member agencies shared information and coordinated programs and activities. In addition, we interviewed federal agency officials on the challenges of and potential areas for improvement in federal agencies' coordination efforts.

It was beyond the scope of this engagement to identify all federal programs that provide services to people with autism and all coordination activities among federal agencies and departments. We focused on programs designed to meet the specific needs of people with autism or developmental disabilities or that have specific program goals targeted to this population. It was also beyond our scope to evaluate the quality of the activities and programs we described. However, we reviewed the relevant literature and interviewed experts in autism and representatives from several professional and advocacy associations to identify concerns about federal agencies' current activities and coordination efforts and potential areas for improvement. Specifically, we interviewed officials from the American Academy of Pediatrics, American Psychiatric Association, American Speech-Language-Hearing Association, National Association of State Directors of Developmental Disabilities Services, National Association of State Directors of Special Education, and National Association of State Medicaid Directors. We also interviewed representatives from two advocacy associations that focus on autism research and representatives from two advocacy associations with a broad focus on autism research, services, and public awareness. We conducted our work from August 2005 through July 2006 in accordance with generally accepted government auditing standards.

Appendix II: Selected NIH Autism-Related Activities

Activity	Description
Autism Genetics Exchange	Part of the National Institute of Mental Health's Human Genetics Initiative that makes genetic resources and biomaterials available to autism researchers
Brain and Tissue Bank for Developmental Disorders	Repositories at the University of Maryland at Baltimore and the University of Miami School of Medicine that collect, store, and distribute brains and other tissues for research dedicated to improving the knowledge, care, and treatment of people with developmental disorders, including autism
Centers for Children's Environmental Health and Disease Prevention Research	A collaboration with the Environmental Protection Agency to examine the effect of environmental exposures on children's health through a multidisciplinary research approach that includes basic, applied, and community-based research; 2 of the program's 11 centers focus wholly or partly on environmental causes of autism
Collaborative Programs of Excellence in Autism	Network of nine programs in which investigators conduct basic and clinical research on the possible genetic, immunological, neurobiological, and environmental causes of autism and investigate the development of brain structures and their functions as they relate to autism
High Risk/Baby Sibling Autism Research Project	A multisite consortium designed to enhance research with populations of young children at high risk for autism, particularly the siblings of children with autism, with the goal of identifying behavioral and biological markers for autism; this consortium is a public-private collaboration between the National Institute of Child Health and Human Development and the National Alliance for Autism Research
Identifying Autism Susceptibility Genes	A request for applications that encouraged research to identify specific genes that relate to susceptibility to autism
Intramural Program on Autism Research	A program of clinical research on autism that will offer a multidisciplinary approach to the evaluation and treatment of children, adolescents, and adults with autism; the program was launched in the summer of 2005
MRI Study of Normal Brain Development	A longitudinal study to map the structural development of the brain by age and sex
National Autism Brain Bank at Harvard	A resource center that collects, stores, and disseminates postmortem human brain specimens for the study of autism
National Database for Autism Research	A collection of information systems supporting autism research activities that includes laboratory, clinical, and behavioral data
Research on Autism and Autism Spectrum Disorders	A program announcement that solicits research on various topics related to autism: diagnosis, epidemiology, etiology, genetics, treatment, and service delivery; high priority areas include clinical and applied research that may lead to the development of diagnostic research instruments, treatments, and intervention strategies
Research Units on Pediatric Psychopharmacology and Psychosocial Interventions Network	Five groups of investigators that are specifically funded to evaluate treatments for autism; several studies are examining various aspects of medication, including dose ranges, regimens, safety, and effect on cognition, behavior, and development
Studies to Advance Autism Research and Treatment	Eight centers of excellence designed to unite expertise, infrastructure, and resources for conducting research on causes, diagnosis, early detection, prevention, and treatment of autism

Source: GAO analysis of NIH documents.

Appendix III: Interagency Autism Coordinating Committee Research Goals

Area of research	Goals
Characteristics of autism	<p>Define and plan Autism Phenome Project and study existing data to begin to characterize the autism phenome</p> <p>Establish resources for genotype and phenotype studies (e.g., genetic repository)</p> <p>Develop nonbrain biomarkers (e.g., blood levels of specific molecules) to provide the biological characteristics of autism</p> <p>Implement multisite longitudinal study of subsequent pregnancies and infant siblings of children with autism to identify risk factors, broader phenotype, and early characteristics of autism</p> <p>Identify genes that increase susceptibility for autism and animal models of autism for further study of phenotypic characteristics of autism</p>
School- and community-based interventions	<p>Expand, disseminate, and implement effective interventions, including transition services, to improve outcomes in school and community settings throughout a person with autism's life span</p> <p>Develop, evaluate, implement, and disseminate innovative intervention strategies, including transition services, to improve outcomes in school and community settings throughout a person with autism's life span</p> <p>Continue formulating, evaluating, and implementing appropriate and effective intervention strategies incorporating research-based findings to improve outcomes in school and community settings throughout the life span of a person with autism</p> <p>Ensure appropriate and effective interventions are widely recognized and broadly implemented in school and community settings throughout the life span of a person with autism</p>
Epidemiological studies	<p>Implement first-generation, intensive community-based prevalence studies with clinical evaluations; the studies will produce initial data for detecting changes in prevalence of autism</p> <p>Plan and implement second-generation intensive community-based prevalence studies with clinical evaluations</p>
Early intervention	<p>Develop a randomized clinical trial for evaluating the effectiveness of early behavioral interventions and factors predicting response to interventions</p> <p>Implement a multisite, randomized clinical trial to identify moderators and effective components of early intervention treatments (e.g., dose, intensity, mode of delivery, age of onset)</p> <p>Develop intervention methods for infants and toddlers to lower the age for which there are effective interventions</p> <p>Implement longitudinal follow-up of early intervention randomized clinical trial</p> <p>Provide evidence that the symptoms associated with 25 percent of cases of autism can be secondarily prevented through early identification and early treatment</p> <p>Develop methods that allow 90 percent of people with autism to develop speech</p>

**Appendix III: Interagency Autism
Coordinating Committee Research Goals**

Area of research	Goals
Specific treatments	<p>Improve outcome measures to enhance effectiveness in evaluating treatment studies</p> <p>Determine effectiveness of pharmacological, behavioral, and other treatments that target symptoms associated with autism</p> <p>Identify individual characteristics that predict response to behavioral, pharmacological, and other treatments</p> <p>Develop treatment algorithm for autism to provide guidance for practitioners and educators</p> <p>Develop effective drug treatments that target core symptoms of autism</p>
Neuroscience	<p>Establish infrastructure (e.g., enhanced brain acquisition) for neuropathological investigations to characterize morphological aspects of the pathophysiology of autism</p> <p>Develop technology and infrastructure for multisite imaging studies to identify the neuropathology of autism</p> <p>Characterize the neuropathology of autism to identify brain structures and functions associated with autism</p> <p>Characterize the developmental timeline for alterations in brain structures and connections in autism</p> <p>Define neural circuitry and neurochemistry for several functions impaired in autism</p> <p>Define basic, common neuropathological and neurochemical features of autism</p>
Screening	<p>Evaluate sensitivity and specificity of existing screening tools and continue developing effective screening measures</p> <p>Develop research on implementing strategies for early identification of children with autism in community settings, using a population-based longitudinal cohort</p> <p>Identify biological markers, behavioral markers, or both to develop indices of risk for the development of autism in infants</p> <p>Develop feasible, sensitive autism screening method for young infants</p>
Other	<p>Develop local and national Research Communication Network to disseminate findings among researchers and the public to increase ongoing communication</p> <p>Develop twin resource to study heritability and environmental factors influencing autism</p> <p>Identify environmental factors (e.g., viruses, medications) that contribute to the development of autism and their associated developmental windows</p> <p>Identify genetic and nongenetic causes of autism and their interactions</p>

Source: GAO analysis of Interagency Autism Coordinating Committee Research Matrix, 2003.

Appendix IV: Interagency Autism Coordinating Committee Services Roadmap Goals and Recommendations

Goals	Recommendations
<p>All people with autism and their families will have a well-established, trusting, and mutually respectful relationship with a health care professional (medical home) who listens and responds to concerns and who acts as an equal partner in providing a clearly defined plan of coordinated services.</p>	<p>Provide ongoing training and technical assistance for professionals and families to engage as full partners</p> <p>Increase autism information and education resource capacity at national and local levels</p> <p>Integrate autism into existing initiatives to strengthen family support and involvement and to establish integrated systems of care</p>
<p>There will be universal early identification of signs of autism, followed by appropriate referral to a coordinated and comprehensive service system.</p>	<p>Support IACC Screening Subcommittee efforts to increase public awareness and incorporate autism into routine screening</p> <p>Develop guidelines for autism screening, diagnoses, and referral for follow-up</p> <p>Improve and standardize developmental and autism screening methodologies</p> <p>Incorporate autism guidelines into curriculum for residency, professional certification, and other training programs</p> <p>Promote linkages between medical homes and existing resource networks for developmental, educational, rehabilitative, social, and specialty services for autism</p> <p>Provide technical assistance and disseminate educational materials, checklists, and implementation tools for autism screening to families and professionals</p>
<p>Individuals with autism and their families will have ready access to integrated and coordinated health, mental health, education, and social services provided by well qualified autism providers throughout the life span of individuals with autism.</p>	<p>Promote use of autism practice guidelines to define standards of care in health, mental health, social services, and education</p> <p>Incorporate autism service guidelines into curriculum for residency, professional certification, and other training</p> <p>Provide incentives to ensure greater availability of well trained providers and a more equitable distribution of services across geographical areas</p> <p>Develop an action plan for collaboration at all levels to identify services and meet the service needs of persons with autism within the broader initiatives to develop community-based systems of services for all persons with disabilities</p>
<p>Community-based services will be organized so that individuals with autism and their families can use them easily.</p>	<p>Support family-driven state and community development initiatives to implement creative and effective practices</p> <p>Provide technical assistance to states and communities to implement effective service delivery models</p> <p>Provide a user-friendly Web-based resource for families and providers that includes information on autism (e.g., successful screening models, autism providers)</p> <p>Ensure that individualized plans of care coordinate a comprehensive continuum of services across all necessary service sectors and support people with autism throughout their life span</p> <p>Identify and analyze effective models that organize, integrate, and deliver comprehensive services</p> <p>Develop models that allow providers and families to have systematic access to shared records and examples of exemplary practices</p>

**Appendix IV: Interagency Autism
Coordinating Committee Services Roadmap
Goals and Recommendations**

Goals	Recommendations
All individuals with autism will receive the services necessary to make transitions to all aspects of adult life, including health care, work, and independent living.	<p>Collect data about the life experiences and needs of adults with autism</p> <p>Start transition planning services early</p> <p>Develop and support skill-building opportunities that promote self-determination in youth with autism</p> <p>Provide an array of services and support in the community for individuals with varying degrees of ability</p> <p>Incorporate aging issues—such as estate planning and long-term care—into transition planning</p> <p>Formalize federal partnerships to ensure collaboration across service sectors providing transition planning</p> <p>Establish an interagency federal task force that identifies the needs of adults with autism and determines how best to meet them</p>
Public and private financing of autism-related services will be expanded and standardized so people with autism and their families have access to early and continuous screening; comprehensive diagnosis; and needed health care, mental health, education, and social services.	<p>Demonstrate the cost effectiveness of early intervention</p> <p>Expand health insurance benefits for autism, taking into account the need for a broad array of services</p> <p>Develop model financing, public and private insurance packages, and Medicaid waiver programs</p> <p>Conduct a national study of cost and insurance to determine policies and practices that affect financing, eligibility, and service delivery</p> <p>Develop innovative approaches, such as use of tax-exempt medical savings accounts and financial planning assistance, that blend funding from multiple sources to create a coordinated approach to financing services</p>

Source: GAO analysis of Autism Spectrum Disorders Roadmap.

Note: The IACC Services Subcommittee presented the roadmap to the full committee on May 16, 2005.

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



DEPARTMENT OF HEALTH & HUMAN SERVICES

Office of Inspector General

JUN 29 2006

Washington, D.C. 20201

Cynthia A. Bascetta
Director, Health Care
U.S. Government Accountability Office
441 G Street, NW
Washington, DC 20548

Dear Ms. Bascetta:

The Department of Health and Human Services (HHS) appreciates the opportunity to review and comment on the U.S. Government Accountability Office's (GAO) draft report entitled, "FEDERAL AUTISM ACTIVITIES: Funding for Research Has Increased, but Agencies Need to Resolve Surveillance Challenges" (GAO-06-700), before its publication.

HHS does not concur with the draft report's recommendation, in that GAO's draft report and recommendation suggest that the Departments of HHS and Education have not worked together to identify options to enable the CDC to continue to obtain and use educational records for autism surveillance. HHS discussed with the Department of Education the potential renewal of the Memorandum of Agreement (MOA) between the CDC and the Department of Education, under which Education was working with CDC to perform autism surveillance, consistent with the terms of the MOA; and HHS also discussed with Education potential mechanisms by which CDC could continue to obtain data for an effective surveillance program. However, in December of 2005, the Department of Education advised HHS that it had concluded that it would not renew the MOA.

The Department provided several technical comments directly to your staff. These comments and the nonconurrence with the recommendation represent the tentative position of the Department and are subject to reevaluation when the final version of the report is received.

Sincerely,

A handwritten signature in cursive script that reads "Daniel R. Levinson".

Daniel R. Levinson
Inspector General

Enclosure

The Office of Inspector General (OIG) is transmitting the Department's response to this draft report in our capacity as the Department's designated focal point and coordinator for U.S. Government Accountability Office reports. OIG has not conducted an independent assessment of these comments and therefore expresses no opinion on them.

Appendix VI: Comments from the Department of Education



UNITED STATES DEPARTMENT OF EDUCATION

OFFICE OF INNOVATION AND IMPROVEMENT

ASSISTANT DEPUTY SECRETARY

June 5, 2006

Ms. Cynthia A. Bascetta
Director, Health Care
Government Accountability Office
Washington, D.C. 20548

Dear Ms. Bascetta:

Thank you for the opportunity to review and comment on the Government Accountability Office (GAO) draft report, *Federal Autism Activities: Funding for Research Has Increased, but Agencies Need to Resolve Surveillance Challenges*.

The report recommends that the Secretaries of Health and Human Services (HHS) and Education (ED or the Department) “work together to promptly identify options for overcoming challenges to CDC’s ability to use education records for autism surveillance.” As explained more fully below, we do not support this recommendation. We believe that this recommendation does not accurately reflect the important privacy protections established by the Family Educational Rights and Privacy Act (FERPA) nor Congress’ concern, as evidenced by recent legislation, with preserving the rights of parents to be notified of attempts to obtain access to their children’s education records and to consent, or refuse consent, to disclosure of their children’s education records. The Department and HHS have had a number of meetings and discussions on this issue, and we have consistently advised HHS that FERPA requires CDC to obtain written parental consent in order to gain access to education records. In this regard, the Department has offered to assist by providing technical assistance to school districts on parental consent requirements and to help CDC construct an appropriate consent form.

FERPA applies to an educational agency or institution that receives funds under any program administered by the Secretary of Education, which includes virtually all public school districts, as well as most public and private postsecondary institutions. 34 CFR § 99.1. An educational agency or institution subject to FERPA may not have a policy or practice of disclosing education records, or non-directory, personally identifiable information from education records, without the prior written consent of the parent or eligible student, except as provided by law. 20 U.S.C. § 1232g(b). (“Eligible student” means a student who has reached 18 years of age or is attending a postsecondary institution at any age. 34 CFR §§ 99.3.) “Education records” are defined as “those records, files, documents, and other materials which –

- (i) contain information directly related to a student; and
- (ii) are maintained by an educational agency or institution or by a person acting for such agency or institution.”

20 U.S.C. § 1232g(a)(4)(A); 34 CFR § 99.3.

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Page 2 – Ms. Cynthia A. Bascetta

Additionally, States receiving assistance under Part B of the Individuals with Disabilities Education Act (IDEA) have responsibilities under that law to protect the confidentiality of personally identifiable information. The specific IDEA confidentiality requirements are codified at 34 CFR §§ 300.560 – 300.577. The Part B confidentiality requirements contain many of the same provisions that exist in FERPA and apply, along with FERPA, to the education records of children with disabilities in any State receiving Part B funds. FERPA and IDEA establish clear and comprehensive requirements for protecting the privacy rights of students with disabilities in elementary and secondary schools.

FERPA is intended to protect the privacy interests of parents and students in education records maintained by educational agencies and institutions on students. These records contain sensitive personal, behavioral, financial, medical, and other information. Protecting the privacy of this information should not be viewed as a barrier or “challenge” to be overcome or circumvented, but as an important public safeguard to be protected and strengthened.

GAO’s recommendation refers to “challenges to CDC’s ability to use education records for autism surveillance.” However, the challenge Congress has described is not in “using” education records but in “obtaining” them. The Birth Defects and Developmental Disabilities Prevention Act of 2003, Pub. L. No. 108-154, 117 Stat. 1933 (December 3, 2003), the legislation requiring HHS and ED to issue a joint report concerning surveillance activities under section 102 of the Children’s Health Act of 2000, asks for a “description of the challenges provided to obtaining education records (in the absence of parental or patient consent) . . .” and “a description of the manner in which such challenges [to obtaining consent] can be overcome, including *efforts to educate parents . . . and increase the rate of parental or patient consent. . .*” Pub. L. No. 108-154, section 4(6)-(7)(emphasis added). Accordingly, we believe that Congress’ primary concern was not to circumvent the important parental consent requirements in FERPA and IDEA, but rather that CDC increase parental awareness concerning the surveillance so that it could more easily secure consent from parents or try to secure the necessary information from other sources.

This reading of the joint report language in the Birth Defects and Developmental Disabilities Prevention Act of 2003 is also supported by the fact that the following year Congress amended the Children’s Health Act to require parental consent for disclosure of education records for a study. In December 2004, as part of the reauthorization of and amendments to IDEA, Congress amended § 1004 of the Children’s Health Act of 2000 to require that parents provide consent before information from students’ education records is provided to CDC. Specifically, this section added ED to the consortium of Federal agencies working on a national longitudinal study of environmental influences on children’s health and development, including, in part, developmental disorders. The amendment requiring parental consent specifically states that the FERPA provision permitting disclosures, without consent, to “authorized representatives of the Secretary of Education” shall not be applied. In floor remarks concerning this amendment, which was offered by Senator Clinton, Senator Gregg stated the following:

This amendment ensures that, should any collection of information from the study involve student education records, parents must provide prior consent before the information is released. This ensures compliance with the Family Educational Rights and

Page 3 – Ms. Cynthia A. Bascetta

Privacy Act of 1974 (20 U.S.C. 1232g) (FERPA) and comports with the federal policy of preserving parental consent.

Quite simply, information in records maintained by schools about individual children should not be accessible by the CDC, or Federal agencies, or their contractors without the knowledge and prior consent of those children's parents.

150 Congressional Record S 5348 (May 12, 2004). While this specific amendment appears in another section of the Children's Health Act, we believe that it indicates legislative intent that parents should provide consent before their children's schools disclose personally identifiable information from their education records to the CDC.

By way of additional relevant context, in December 2000, in response to direction from the previous Administration, the Department entered into a Memorandum of Agreement (MOA) with CDC to permit school districts in the Atlanta area to disclose to CDC personally identifiable information from students' education records, without first obtaining the consent from parents as generally required by FERPA. Under the MOA, CDC was designated as an "authorized representative" of the Department of Education so that Atlanta area schools would be permitted to disclose education records, without consent, to CDC under a provision in FERPA that permits schools to disclose education records to the Secretary of Education for the audit or evaluation of Federal or State supported *education* programs. (34 CFR § 99.31(a)(3) and § 99.35.) This agreement, which applied only to schools in the Atlanta area participating in the Metropolitan Atlanta Developmental Disabilities Surveillance Program (MADDSP), expired on December 11, 2005.

Prior to the expiration of the MOA, some Members of Congress raised concerns about the Department's interpretation of FERPA permitting individuals outside the control of educational agencies and institutions to access sensitive student data, including Social Security numbers. Some Federal and State agencies and other parties had sought to expand the scope of this FERPA provision by attempting to obtain designation as an "authorized representative" of Federal and State education officials so that personally identifiable information could be disclosed, without consent, for data matching, enrollment verification, research, and other purposes. As a result, the Department undertook an extensive legal review of the "authorized representative" provision and concluded that the expansive interpretation that was used to support the MOA was not consistent with FERPA's statutory language and essentially nullified the specific statutory conditions for disclosure of education records without consent. On January 30, 2003, with substantial input from Congressional staff, the Department rescinded previous guidance permitting this practice and explained that the multiple references to "officials" in the statutory provision reflect a Congressional concern that "authorized representatives" means those under the direct control of officials that may receive information under § 99.31(a)(3), that is, an employee, official, or contractor of the Secretary of Education or State and local educational authorities. By letter dated April 18, 2006, we advised Members of Congress who had inquired about the expired MOA with the CDC that, while the Department does not question the value or importance of the work on autism that the CDC conducted through MADDSP and other surveillance programs, we have concluded that FERPA does not permit us to renew the agreement with CDC.

Page 4 – Ms. Cynthia A. Bascetta

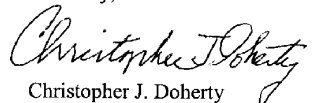
The statement in the Report concerning the Department not fully communicating with State educational agencies regarding the issuance of the January 30, 2003, memo is inaccurate. The Report states: “In response to subsequent inquiries, Education sent letters to two states’ education agencies informing them of this reinterpretation of FERPA. Education has not communicated its position to other states’ education agencies.” We posted these letters and the January 30, 2003, memorandum on the Family Policy Compliance Office’s well-visited website. We also carry out extensive training on FERPA for school officials nationwide, as well as providing technical assistance in response to requests for information. Our training and technical assistance includes clarification of the limitations in FERPA on designating outside entities as authorized representatives of State educational authorities.

The Report also states that CDC has identified “a number of measures that would require either legislative or administrative action, including amending FERPA, the Children’s Health Act, or the Public Health Service Act to permit autism surveillance activities without parental consent; allowing staff from education agencies to oversee or participate in data collection; or providing for a passive consent system for parents.” While the Department is willing to discuss options with CDC, it should be noted that FERPA requires that parents provide written consent *before* personally identifiable information from their children’s education records is disclosed to outside entities such as the CDC. The law does not permit schools subject to FERPA to disclose education records based on a passive consent model.

Finally, we have concerns about statements on pages 20 and 21 of the draft report that may imply that services for children with disabilities (including those with autism) under the Individuals with Disabilities Education Act (IDEA) may be inadequate. IDEA provides a consistent framework for determining children’s needs through the evaluation process and the appropriate educational and related services for children with disabilities through the development of individualized education programs (IEPs). IDEA requires that children receive the services that have been determined appropriate through that IEP process, but does not require the provision of all services that may have been recommended to that process. Unfortunately, though, the report may be confusing education services that might have been recommended for children with autism with services that an IEP Team has determined are appropriate for a particular child, and, in doing so, seems to imply that the GAO has found evidence of widespread failure to provide education services to children with autism in violation of the IDEA. We are not aware of this type of violation, but if GAO has more specific information on this issue that would show violation, we would appreciate receiving that information.

Our technical comments on the report are enclosed. We appreciate GAO’s analysis and work.

Sincerely,



Christopher J. Doherty
Acting Assistant Deputy Secretary

Enclosure

Appendix VII: GAO Contact and Staff Acknowledgments

GAO Contact

Cynthia A. Bascetta, (202) 512-7101 or bascettac@gao.gov

Acknowledgments

In addition to the contact named above, Helene F. Toiv, Assistant Director; Jennie Apter; Janina Austin; Julian Klazkin; Robert Lepore; and KaSandra Rogiérs made key contributions to this report.

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