



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](http://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](mailto: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.