

Report to Congress on Autism

**Prepared by the National Institute of Mental Health
National Institutes of Health
Department of Health and Human Services**

February 2002

Report to Congress 2002: Children's Health Act of 2000

Although we do not know the exact prevalence of autism, estimates range from one in 500 to one in 1,000 in the United States. Autism is a complex neurobiological disorder that generally lasts throughout a person's life. Current statistics show that autism occurs in all racial, ethnic, and social groups, and, recently, there have been reports of an increase in the number of children receiving a diagnosis of autism or receiving public services for autism. In most cases, autism impairs a person's ability to communicate and to relate to others. It also is associated with rigid routines or repetitive behaviors such as obsessively following schedules or arranging belongings in very specific ways. Autistic behaviors not only make life difficult for people with autism but also make life hard for their families, their health care providers, their teachers, and anyone who comes in contact with them. Families coping with this devastating illness are searching for answers about its causes, diagnosis, prevention, and treatment. Presently, there is no effective means to prevent the disorder, no fully effective treatment, and no cure. Early intervention is critical for affected children to gain maximum benefit from current therapies.

Purpose of report

Public Law 106-310, the Children's Health Act of 2000, was signed into law on October 17, 2000. The Act authorizes the Secretary of Health and Human Services (HHS) to conduct activities relevant to autism and pervasive developmental disorders in Division A, Title I. The topics of these activities are: Section 101--Expansion, intensification, and coordination of activities of the National Institutes of Health (NIH) with respect to research on autism; Section 102--Developmental disabilities surveillance and research programs; Section 103--Information and education; Section 104--Interagency Autism Coordinating Committee; and Section 105--Providing this report to Congress.

Section 101 authorizes the Director of NIH, acting through the Director of the National Institute of Mental Health (NIMH), to expand autism research activities in general and to support the specific planning and establishing of no fewer than five Centers of Excellence in Autism Research. Each Center is to conduct basic and clinical research. The research is to include the cause, diagnosis, early detection, prevention, control, and treatment of autism. The Centers, as a group, are to conduct research including developmental neurobiology, genetics, and psychopharmacology. Support is not to exceed 5 years, although support may be extended for one or more additional periods with appropriate peer review. Section 101 also authorizes a program to collect and share genetic materials and tissue samples and to provide a means through which the public may obtain information and provide comments to the Director of NIH.

Section 102 authorizes the Secretary of HHS to act through the Director of the Centers for Disease Control and Prevention (CDC) in certain autism research areas. This portion of the Act authorizes a surveillance program on autism and pervasive developmental disorders, as well as three regional Centers of Excellence in epidemiology of autism and pervasive developmental disorders. The section also calls for establishing a clearinghouse for data.

Section 103 authorizes the Secretary to establish and implement a program of education and information for health professionals and the general public as well as a stipend program for health professionals.

Section 104 stipulates that the Secretary is to establish a committee to be known as the "Autism Coordinating Committee" to coordinate all efforts within HHS concerning autism. The Committee is to be composed of the Directors of the relevant NIH Institutes, the CDC, and other agencies and officials that the Secretary determines to be appropriate. The Secretary also may appoint to the Committee parents or legal guardians of individuals with autism or other pervasive developmental disorders and representatives of other governmental agencies that serve children with autism, such as the Department of Education.

Section 105 requires the Secretary of HHS to submit an annual report to Congress "concerning the implementation of this title and the amendments made by this title." The present report is the second annual report to Congress and reflects HHS activities in 2001. The report is organized into sections pertinent to Division A, Title I of the Act.

Section 101--Expansion, intensification, and coordination of activities of the National Institutes of Health (NIH) with respect to research on autism

a. Expansion, Intensification and Coordination of NIH Activities

Within NIH, five Institutes are members of the NIH Autism Coordinating Committee (NIH/ACC). These are the NIMH, the National Institute of Child Health and Human Development (NICHD), the National Institute of Neurological Disorders and Stroke (NINDS), the National Institute on Deafness and Other Communication Disorders (NIDCD), and the National Institute of Environmental Health Sciences (NIEHS). In addition, a staff representative from the National Institute of Allergy and Infectious Diseases participates in NIH/ACC meetings.

The NIH/ACC functions in a coordinating role for autism research activities funded and conducted by the various NIH Institutes. Representatives from the NIH/ACC will attend the Interagency Autism Coordinating Committee (IACC) meetings and conduct liaison activities between the two committees to ensure that IACC concerns and issues are addressed by NIH program staff. Oversight for the NIH/ACC activities is primarily provided by the NIMH Director, with the NICHD Director as co-chair. Because NIMH has been designated the lead for creating the IACC, the NIMH Director also serves as chairperson on the IACC.

Over the past few years, NIH has expanded considerably and enhanced its coordination of autism research. The amount of NIH support of autism research grew from \$22 million in FY 1997 to \$56 million in FY 2001. Thus, the Institute members of the NIH/ACC have made clear their commitment to the broad intensification of autism research efforts called for in the Act. This \$56 million effort encompasses a large number of grants, contracts, and intramural research programs distributed across the NIH.

In FY 2001, NIH autism research activities included the following:

Grants on Treatment of Autism

As part of a special funding initiative, NIH awarded seven grants in September 2001 to support the development and/or refinement of treatments for core and secondary symptoms of autism. The grants were funded through the NIH/ACC, with four Institutes contributing funds to this effort: NIMH, NICHD, NINDS, and NIDCD. The grants are for 3 years each, totaling \$2.9 million dollars over 3 years. These grants were solicited by a Request for Applications (RFA) on “Innovative Treatments in Autism” that NIH issued in 2000 and was part of an initiative that grew from a meeting on autism treatment methods held by the NIH/ACC in 1999. The grants address psychosocial treatments for teaching speech, imitation, and joint attention skills; psychopharmacology for behavioral problems, emotional dysregulation, and cognitive deficits; and testing of an animal model of self-injurious behavior. Awards were made to seven institutions across the country: University of Pittsburgh, Pittsburgh, PA; Mount Sinai School of Medicine, New York City, NY; University of California, Los Angeles, CA; University of Colorado Health Sciences Center, Colorado Springs, CO; Vanderbilt University, Nashville, TN; Children’s Hospital Medical Center, Cincinnati; and Rutgers State University, New Brunswick, NJ.

The NICHD/NIDCD Network on the Neurobiology and Genetics of Autism

The NICHD/NIDCD Network on the Neurobiology and Genetics of Autism consists of 10 Collaborative Programs of Excellence in Autism (CPEAs) that link together more than 75 researchers in 26 universities and more than 2500 families of people with autism. This Network requires each CPEA both to conduct a cohesive, site-specific, multidisciplinary research program on the causes, brain structure and function, and clinical development in autism disorders and to participate in some trans-Network collaborative studies that no one project has the needed expertise and/or subject population to investigate individually. The CPEA Network is in turn linked to a six-nation European autism consortium. The CPEA Network is now studying the world’s largest group of well-diagnosed people with autism for whom both genotype and extensive phenotype data will be available. In addition, because of their combined clinical and scientific resources, the CPEAs address urgent public health questions when appropriate, including the study of the neuropeptide secretin for treatment of autism and the study of regression or late onset autism. The major CPEA sites are located at Albert Einstein Medical School in New York, NY; Boston University, Boston, MA; University of California, Irvine, CA; University of California, Los Angeles, CA; University of Colorado Health Sciences Center, Colorado Springs, CO; University of Washington, Seattle, WA; University of Pittsburgh, Pittsburgh, PA; University of Rochester, Rochester, NY; University of Utah, Salt Lake City, UT; and Yale University, New Haven, CT. NIH has solicited applications from these sites for competitive review to be considered for an additional 5 years of funding. In addition, NIH will establish a data-coordinating center, designed specifically to expedite and maximize analysis of the data generated by the CPEA research projects. The NICHD and NIDCD plan to allocate \$60 million in that time period to sustain and enhance the CPEAs.

The NICHD/CDC Study on the Relationship between Autism and Vaccines

The NICHD and CDC are co-sponsoring a study of the possible association of symptoms of regressive autism with measles, mumps, and rubella (MMR) vaccinations. Regressive autism involves a relatively rapid onset of loss of a child's skills, typically involving loss of speech or words, but can include changes in social behavior or the onset of repetitive behaviors that can interfere with development. Regressive autism usually occurs during the second year of life. Among children diagnosed with autism, it is estimated that between 20-39 percent experienced regressive autism. The remainder of these children experience a more gradual development of symptoms related to autism. The MMR study, which began in September 2000, is examining the medical and developmental records of 1,200 well-diagnosed cases of autism (including regressive and non-regressive) and a large number of healthy controls to assess whether there is a temporal relation between receipt of the MMR vaccine (and possibly other vaccines) and the onset of symptoms in early onset autism and regressive autism. The next phase of the study will use laboratory tests to assess the levels of measles antibody titers and to search for evidence of persistent measles infection in blood that could be attributed to the MMR vaccine in early onset and regressive autism cases and matched controls. Data have been collected on regressive vs. nonregressive autism at several CPEA sites. Those data are being consolidated for analysis; they are necessary to establish that the regressive autism group differs from nonregressive autism and to facilitate more precise comparisons to normal controls. Preliminary results were presented at the International Meeting For Autism Research in November 2001.

Children's Centers for Environmental Health and Disease Prevention

NIEHS and the Environmental Protection Agency (EPA) have funded two new Children's Centers for Environmental Health and Disease Prevention that will focus research on potential environmental factors that may be related to autism. The centers will each be funded at \$5 million, or approximately \$1 million per year for 5 years beginning in August 2001. The new Children's Center at the University of California at Davis (UC Davis) will investigate how environmental risk factors may contribute to childhood autism. There has been speculation among both parents and health professionals that prenatal or early postnatal exposure to various metals or chemicals or even vaccines may trigger autism. To help address this concern, the Center's research will include a large case-control epidemiological study of various exposures and the development of autism. This Center will also conduct research to develop new animal models for studying social interaction and the impact of neurotoxicants on social behavior. Additional studies will focus on elucidating the cellular and molecular mechanisms by which specific neurotoxicants can perturb critical neuronal functions during development. The team of investigators will include scientists from the NIEHS Environmental Health Sciences Center at UC Davis and the NIEHS Superfund Basic Research program, also at UC Davis. The work will be carried out within the infrastructure of the UC Davis M.I.N.D. (Medical Investigation of Neurodevelopmental Disorders) Institute, which has a strong relationship with the autism advocacy community.

The newly funded Children's Center at the Robert Wood Johnson Medical School of the University of Medicine and Dentistry of New Jersey will seek to determine the possible influence of mercury, lead, and valproic acid (a drug commonly used to control seizures) on

autism, learning disabilities, and regression. Studies to be conducted will look at critical windows for brain development in the forebrain and hindbrain and will attempt to link exposures or disturbances at these times to subsequent behavior. Researchers also will look for differences in genetic susceptibility of children to environmental toxicants. Researchers will use brain imaging to determine whether children with higher exposures to environmental toxicants have different patterns of brain growth and development.

NIH/ACC Annual Scientific Meeting

Each year, the NIH/ACC organizes a conference to focus attention on a selected topic in autism. NICHD and NIEHS sponsored this year's conference, held September 6-7, 2001, in Bethesda, MD, with NIMH, NINDS and NIDCD as cosponsors. The overall objective was to discuss possible cellular and molecular mechanisms for autism and related disorders, as well as new animal models and methodologies to study autism. The meeting included a special session on potential environmental factors that may be relevant to autism. Over 140 individuals attended the meeting, including scientists from the United States and abroad who study autism and related disorders and representatives from many of the major autism advocacy groups. NIH is preparing a meeting report that summarizes the findings presented and that identifies needs and opportunities for future research. The final report will be available on the NICHD Web site.

Identification of Biomarkers

Better understanding of the etiology and pathophysiology of autism is essential to the development of strategies for prevention and treatment. The identification of biological markers, functional and behavioral measures, and neuroanatomical correlates for the disorder would enable progress toward this understanding. In March 2001, the NINDS assembled a small group of extramural and NINDS intramural researchers with expertise in autism or brain growth factors and brain anatomy for an exploratory discussion of current understanding in these areas. The Institute is considering the information from this meeting to chart future research directions.

In addition, NINDS intramural researchers are working hard to study the biology of autism, using neonatal bloodspot specimens for microassays and several new techniques for their analysis; to study biomarkers in conjunction with longitudinal studies of volumetric MRI brain imaging; and to pursue questions about immune function in autism.

Program Announcement on Research on Autism and Autism Spectrum Disorders

NIH issued a program announcement on Research on Autism and Autism Spectrum Disorders (see <http://grants.nih.gov/grants/guide/pa-files/PA-01-051.html>) in February 2001. This is a standing announcement from the NIH/ACC Institutes to encourage grant applications for the support of research designed to elucidate the diagnosis, epidemiology, etiology, genetics, treatment, and optimal means of service delivery in relation to Autistic Disorder ("autism") and autism spectrum disorders (Rett's Disorder, Childhood Disintegrative Disorder, Asperger's Disorder, Pervasive Developmental Disorder-Not Otherwise Specified, or "Atypical Autism").

b. Centers of Excellence

The Children's Health Act of 2000 calls for NIH to establish at least five Centers of Excellence in Autism Research. NIH took several steps in 2001 to begin implementing a centers program that will meet all of the specifications of the Act regarding the organization, scientific goals, and other activities of these centers.

To help interested groups of investigators prepare to submit high-quality applications to become autism centers, the NIH issued an RFA on "Developmental Grants for Autism Centers of Excellence" (see <http://grants.nih.gov/grants/guide/rfa-files/RFA-MH-01-013.html>). The RFA is jointly sponsored by the NIMH, NICHD, NINDS, NIDCD and NIEHS. This RFA, issued in April 2001, was designed to provide developmental grants to teams of investigators to enhance their ability to plan, organize, and demonstrate the feasibility of their autism research efforts as they prepared applications for comprehensive center support over the following year. The deadline for developmental grant applications submitted in response to this RFA was July 12, 2001. Each award under this RFA was for 1 year and a maximum of \$100,000 for direct costs (\$125,000 if multiple institutions were involved; thus, the total cost--direct costs and facilities and administration costs--of each grant would range from about \$150,000 to \$175,000). NIH anticipates that the developmental grants RFA will be a one-time solicitation. These developmental grants are intended for investigators who will apply for centers support by an August 2002 deadline to become part of the centers program; NIH anticipates funding of successful applications in FY 2003. Under the developmental grant RFA, six grants were awarded by the targeted funding date of October 1, 2001. NIH made these awards to teams of investigators engaged in promising autism research at the University of California, Davis, M.I.N.D. Institute; Emory University, Atlanta; the University of Florida, Gainesville; the University of Utah, Salt Lake City; the University of Missouri, Columbia; and Washington University, St. Louis.

NIH also implemented a parallel funding initiative intended for applicants who wished to apply for center support on an earlier timeline, without participating in the developmental grant process. To this end, NIH released, in mid-June 2001, an RFA (see <http://grants.nih.gov/grants/guide/rfa-files/RFA-MH-02-001.html>) that formally solicited proposals for comprehensive centers of excellence in autism research, with a deadline for applications of November 29, 2001. The comprehensive centers required by the Children's Health Act will be called STAART (Studies to Advance Autism Research and Treatment) Centers. NIH anticipates beginning funding of successful STAART applications in June 2002, with contributions from the NIMH, NICHD, NINDS, NIDCD and NIEHS. In addition, researchers who unsuccessfully applied for developmental grants (the July 12, 2001, deadline) or comprehensive center grants (the November 29, 2001, deadline) may submit a revised application for STAART center support by the August 2002 deadline. New applicants also may apply for STAART center support. NIH will issue a new RFA to solicit applications for the second receipt date. Thus, applicants can compete for STAART support in one of three ways: (1) applying for a developmental grant in July 2001, with the intention of then applying for a comprehensive center grant in August 2002; (2) applying for a comprehensive center grant in November 2001, with the option to re-apply in August 2002 if unsuccessful; or (3) applying for a comprehensive center grant in August 2002.

NIH estimates that the total funds (direct costs and facilities and administration costs) available to support all the awards made under these and subsequent RFAs for the STAART Centers Program will be \$12 million per year. NIH will use this amount to fund the complement of at least five centers, a data coordination center, and collaborative projects among the centers. Whether there are subsequent rounds of competition will depend on the number of centers funded in these first two rounds. The ultimate number of centers funded will be at least five and will depend upon the merit of the applications received and the funds available. NIH will distribute the majority of the \$12 million pool of funds to successful center applicants to support the activities specific to each center. NIH will distribute a separate portion of the funds for specific cooperative projects among the centers and another portion of the pool for a data coordination center (for which there will be a separate RFA in the future). The Steering Committee of the STAART Centers Program will determine the exact nature of the cooperative studies.

c. Facilitation of Research

NIH has undertaken several activities to increase the quality and availability of genetic and tissue resources to the autism research community. The NIMH Genetics Repository has expanded its activities in the domain of collecting blood samples, creating cell lines, and distributing genetic materials to be used in autism research. This is a national resource that collects, stores, and distributes such materials very broadly across the scientific community. NIMH has also worked with the genetics data bank supported by Cure Autism Now, which resulted in a grant application that received high marks in peer review and can now be funded. This grant, to be funded by multiple NIH Institutes, will support the continued activities of the genetic data bank, a resource that distributes genetic materials broadly to the autism research community. Also, NIH structured the RFA for the STAART Centers Program so that these centers, when funded, will become a national resource for genetics studies, greatly expanding available resources. The CPEA program also will continue its ongoing, extensive activities in the collection of genetic data within its research network. The NINDS continues to support promising research in the genetics of autism, including core support for the development and expansion of genetics resources.

In the area of tissue resources, NIH Institutes have continued and expanded their support of existing tissue collection and distribution resources at several sites. Postmortem brain tissue offers a unique, high-resolution window into the inner workings of brain cells. Only with access to brain tissue can researchers uncover the underlying neuropathology of autism. NIH currently supports ongoing efforts at four tissue banks around the country (Harvard, UCLA, the University of Maryland and the University of Miami) to collect and make this vital resource available to researchers. Recently, NICHD awarded special supplements to target acquisition of necessary biologic materials from individuals with autism for focused study. In addition, NIMH has just issued an RFA to enhance activities in this arena for several disorders, including autism. NIH also anticipates that the STAART Centers Program will provide enhanced resources for tissue-based research in autism.

d. Public Input

NIH is committed to bringing public views to its activities, programs, and decision-making; to conveying information about NIH processes and progress to a broad public; and to seeking comment about its operations and help evaluating its performance. NIH offers many opportunities for public participation, including the NIH Director's Council of Public Representatives (COPR) meetings, the individual Institute council meetings, and specially conducted public forums around the country. In addition, some Institutes, such as the NIMH, solicit public participant reviewers on Scientific Review Groups for treatment and services research grant applications. The NIMH also widely disseminated an invitation with nomination procedures to patients, consumers, family members, service providers, policymakers, and educators regarding serving as public participants. NIMH staff reviewed the nominations and chose public participants after a rigorous review process. Members of the autism advocacy community are among the public participants currently serving and offering unique perspectives on NIMH scientific review committees.

Each Institute and Center and the Office of the NIH Director have set up Public Liaison Offices. They reach out to constituency groups and serve as contact points for the public, especially with regard to policy matters. The Office of Public Liaison is also the central point within an Institute to which Members of Congress can refer their constituents. For the last two years, the NIH Public Liaison Officers have held a special meeting with members of the autism advocacy community to exchange information.

As a result of the first meeting, NINDS developed a listserv (maintained by NIMH) of the e-mail addresses of advocacy group members, which continues to update those who register with news of interest to the autism community. Also, the National Library of Medicine's Medline Plus Web site for autism became a significant topic of discussion and increased effort in response to the autism parents meeting last year (<http://medlineplus.nlm.nih.gov/medlineplus/autism.html>). This is a searchable site with numerous links. It provides the latest news, research (with the ability to do a Medline search of the relevant scientific literature), names of autism advocacy organizations, information on rehabilitation and treatment news on specific conditions such as Asperger's, information on related issues such as vaccines (with a link to the CDC), and links to the specific NIH/ACC Institutes:

<http://www.nimh.nih.gov/publicat/autism.cfm>

<http://www.nichd.nih.gov/autism/>

http://www.ninds.nih.gov/health_and_medical/disorders/autismshortdoc.htm

http://www.nidcd.nih.gov/health/pubs_vsl/autism.htm

On March 30, 2001, the NIH/ACC held a meeting with representatives of autism research advocacy groups. NIH has held such a meeting each year since 1998. The 2001 meeting was well attended, with the majority of the major national groups represented. The Directors of four NIH/ACC member Institutes were present, as were a number of program staff from these and other Institutes, agencies, and the Department of Education. The group frankly discussed many issues, most of them having to do with aspects of the Children's Health Act. For example, the group extensively discussed the strategy for implementing the Centers of Excellence program, plans for the CPEA program, and the Interagency Autism Coordinating Committee (IACC).

Section 102--Developmental disabilities surveillance and research programs

a. National Autism and Pervasive Developmental Disabilities Surveillance Program

In 1998, CDC initiated one of the few programs in the world that conducts active, ongoing monitoring of the prevalence of autism spectrum disorders (ASD) in children in Atlanta, Georgia. CDC currently is analyzing data from the first year of monitoring, which will provide one of the most complete and comprehensive assessments of ASD prevalence in a large U.S. metropolitan area.

In 2000, CDC funded six States--Arizona, New Jersey, Delaware and Maryland (joint), South Carolina, and West Virginia--to monitor the prevalence of ASD. These States are adapting the model developed in CDC's Atlanta monitoring program for their local area. In the first year, the States focused on hiring staff, developing protocols, establishing collaborations with education agencies and clinical providers, and obtaining institutional review board and other approvals. In September 2001, CDC provided additional funding to 4 of the States (Arizona, New Jersey, South Carolina, and West Virginia) to continue their surveillance projects (Maryland/Delaware received funding through the Centers mechanism--see below). Data collection in these States is expected to begin in 2002. The established surveillance programs, whether as a State Autism Surveillance Project or as part of a Center of Excellence, will collaborate in their surveillance efforts under the newly established Alliance for Research in Child Health and Epidemiology (ARCHE) network.

b. Centers of Excellence in Autism and Pervasive Developmental Disabilities Epidemiology

In September 2001, CDC funded four Centers of Excellence in Autism and Pervasive Developmental Disabilities Epidemiology to conduct collaborative studies on the number, incidence, and causes of autism and related developmental disabilities. The four Centers are the following: (1) Johns Hopkins University, which will identify cases of autism in northeastern Maryland and the entire state of Delaware; (2) the University of Pennsylvania, which will cover the Philadelphia metropolitan area; (3) the Colorado Department of Public Health, which will concentrate on identifying cases in the Denver area; and (4) the California Department of Health Services, which will ascertain cases of autism statewide, with more intensive monitoring in the San Francisco Bay area. In addition to conducting surveillance of autism in their areas, the Centers will also collaborate on combined case-control studies of factors that may cause autism and related developmental disabilities. Each Center has expertise in diverse areas relevant to the epidemiology of autism, its causes, and possible interventions; each will conduct specific research focusing on its areas of particular strength, such as genetics and immunology (Johns Hopkins University), biological markers (California), screening (Pennsylvania), and comorbidity (Colorado). The first meeting of the Centers investigators was held November 27-29, 2001, in Atlanta, Georgia.

c. Clearinghouse

(1) “The Secretary shall establish a clearinghouse within the Centers for Disease Control and Prevention for the collection and storage of data generated from the monitoring programs established by this title.”

As part of the Centers of Excellence in Autism and Pervasive Developmental Disabilities Epidemiology, CDC will establish a clearinghouse on policies and research methods that can be used to facilitate the establishment and operation of surveillance projects and epidemiological studies of autism and related pervasive developmental disabilities. Any materials or information developed by the ARCHE network (Centers and States) that may be useful for the public or other researchers will be made available through the clearinghouse (for example, results of epidemiological studies; publications; research protocols, including questionnaires and other instruments; guidelines on accessing educational and clinical records, including privacy and confidentiality of records and databases; community outreach strategies; and educational materials for professionals, families, schools and the general public). Planning for a clearinghouse function has been under way as part of the State surveillance programs. An Education and Outreach Committee has been canvassing the autism information resources in each State, assessing information needs, and planning a central interactive Web site. The Centers now will also be included in these efforts. This communication tool will provide timely access to reports and other information among CDC staff, grantees, and the general public. It is expected that at least a first stage of a Web site will be operational by September 2002.

(2) “The Secretary shall coordinate the Federal response to requests for assistance from State health department officials regarding potential or alleged autism or developmental disability clusters.”

In 2001, CDC completed and reported the results of a community-based prevalence study conducted in response to the concern of parents regarding a possibly larger than expected number of children with ASD in Brick Township, New Jersey. The study found 6.7 cases of ASD per 1000 children, a relatively high rate compared with European studies, but little information on rates in the United States exists for comparison. The State surveillance projects and Centers surveillance activities will provide vital background data for evaluating potential clusters of autism.

Section 103--Information and education

Section 103 is not included in this report because it calls for the Secretary to “establish and implement a program to provide information and education on autism to health professionals and the general public, including information and education on advances in diagnosis and treatment of autism and training and continuing education through programs for scientists, physicians, and other health professionals who provide care for patients with autism.” The establishment of such a program was discussed at the inaugural Interagency Autism Coordinating Committee (IACC) meeting on November 19 at NIH, and another agency that will be instrumental in implementing this section of this Act--the Health Resources and Services Administration--was invited to participate in the IACC. NIH does provide education and information to the public about

research results on diagnosis and treatment, but it is not authorized to provide education programs specifically for physicians and public health professionals.

Section 104--Interagency Autism Coordinating Committee

a. Establishment

Section 104 mandated the establishment of an interagency autism coordinating committee to coordinate autism research and other efforts within the Department of Health and Human Services (DHHS). Secretary Tommy Thompson delegated the authority to establish the IACC to the National Institutes of Health (NIH) in April 2001. The National Institute of Mental Health (NIMH) at the NIH has been designated the lead for this activity.

b. Membership

The Committee's primary mission will be to facilitate the effective and efficient exchange of information on autism activities among the member agencies and to coordinate autism-related activities.

P.L. 106-310 specifies that the Secretary may appoint parents or legal guardians of individuals with autism or other pervasive developmental disorders to the Committee. Such appointments are necessary and vital to the conduct of the Committee's mission. In particular, public members of the IACC will bring to DHHS the concerns and interests of members of the autism community. The IACC will serve as a forum and help to increase public understanding of the member agencies' activities, programs, policies, and research and will bring important matters of interest forward for discussion. The Secretary appointed four public members.

Governmental agencies represented include the following: NIH/ACC members (NIMH, NICHD, NIDCD, NIEHS, and NINDS), CDC, the Administration for Children and Families [(ACF) the Administration on Developmental Disabilities], the Food and Drug Administration (FDA), the Agency for Toxic Substances and Disease Registry (ATSDR), and the Department of Education. The Secretary selected four public members. A summary of the meeting is posted when available on the NIMH Web site (see <http://www.nimh.nih.gov/events/interagencyautism.cfm>). The agenda and highlights from this inaugural meeting are attached as an appendix to this report.

Section 105--Report to Congress

Section 105 requires the Secretary of HHS to submit an annual report to Congress "concerning the implementation of this title and the amendments made by this title." The first annual report was submitted in July 2001. This second annual report reflects HHS activities through November 2001.

Other Autism-Related Activities

The Food and Drug Administration's Center for Biologics Evaluation and Research (CBER) participated, by invitation, in the March and July 2001 meetings of the Institute of Medicine's Immunization Safety Review Committee.

Researchers at CBER continue to characterize and develop the first virus-induced animal model for autism as well as conduct studies on vaccine safety and the developing nervous system. Further, CBER is conducting a follow-up study of reports made to the Vaccine Adverse Event Reporting System (VAERS) of cases of autism following vaccination.

| [Agenda](#) | [Meeting Highlights \(pdf format, 18 page\)](#) | [Participant List](#) |