

Report to Congress on Autism

**Prepared by the National Institute of Mental Health
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Executive Summary

This is the annual report to Congress on autism required by the Children's Health Act of 2000. It provides an overview of activities at the National Institutes of Health (NIH), the Centers for Disease Control and Prevention (CDC), the Health Resources and Services Administration (HRSA), and elsewhere that constitute the implementation of each section of the Act. We have made substantial progress this past year, for example, in implementing the NIH centers program called for in the Act. We have funded two centers under the Studies to Advance Autism Research and Treatment (STAART) Centers program. Applications for a second round of competition have undergone peer review, and we are in the process of finalizing funding decisions. The awardees from this second round of competition will fulfill, in 2003, the complement of at least five centers required by the Act. The report describes a wide variety of other NIH activities, including Centers for Children's Environmental Health and Disease Prevention and the renewal and expansion of the Collaborative Programs of Excellence in Autism. This report also summarizes CDC activities, such as the National Autism and Pervasive Developmental Disabilities Surveillance Program, including the establishment of an information clearinghouse as required by the Act. In addition, the report describes the ongoing functions of the Interagency Autism Coordinating Committee (IACC) established by the Act.

Introduction

Although we do not know the exact prevalence of autism, estimates range from one in 250 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 increases in the numbers 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, and their teachers. 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. Division A, Title I of the Act authorizes the Secretary of Health and Human Services (HHS) to conduct certain activities relevant to autism and pervasive developmental disorders, as follows: 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 topics are to include causes, 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 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 "Interagency Autism Coordinating Committee" (IACC) 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 third and reflects HHS activities in 2002 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

1. Expansion, Intensification and Coordination of NIH Activities

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 to coordinate autism research activities funded and conducted by the various NIH Institutes. Representatives from the NIH/ACC attend meetings of the IACC and conduct liaison activities between the two committees to ensure that IACC concerns and issues are addressed by NIH program staff. The Director, NIMH, and the Director, NICHD, as co-chairs, oversee NIH/ACC activities. Because NIMH has been designated the lead for creating the IACC, the NIMH Director also serves as chairperson of the IACC.

Over the past few years, NIH has considerably expanded its autism research portfolio and enhanced its coordination of autism research. NIH support of autism research grew from \$22 million in FY 1997 to \$73 million in FY 2002. 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 \$73 million effort encompasses a large number of grants, contracts, and intramural research programs distributed across the NIH.

In FY 2002, NIH autism research activities included the following:

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

Established in 1997, the NICHD/NIDCD Network on the Neurobiology and Genetics of Autism consists of nine Collaborative Programs of Excellence in Autism (CPEAs) that link together 129 researchers in 23 universities and more than 2,000 families of people with autism. This Network conducts research on the possible genetic, immunological, neurobiological, and environmental causes of autism. The Network also investigates the developing brain structure and/or function, and the developmental course of autism.

It requires each CPEA to conduct a cohesive, site-specific, multidisciplinary research program on the causes, brain structure and function, and clinical development in autism disorders and requires each site to participate in some trans-Network collaborative studies for which no one project has the needed expertise and/or subject population to investigate individually. As a result of the CPEA efforts, the 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.

The major CPEA sites are located at Boston University, Boston, MA; University of

California, Irvine, CA; University of California, Los Angeles, CA; University of California, Davis, CA; 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. Over the last 5 years, individual CPEA sites completed genetic studies of autism, undertook studies of early brain function and abnormal brain anatomy in children with autism, developed methods for early recognition and diagnosis of autism and a new method for assessing social functioning in individuals with autism, and described environmental factors associated with improved development in children with autism spectrum disorders. Because of the number of autistic individuals enrolled in the research programs of the CPEA, the Network is able to undertake studies that would be difficult or impossible to do at a single research site. For example, scientists in the Network published a recent study that demonstrated that secretin, a hormone that had been reported to be effective in the treatment of autism, was ineffective when administered in a carefully controlled clinical trial (Owley et al., 2001). In its collaborative work, CPEA scientists are continuing investigations of several candidate genes proposed to be associated with autism spectrum disorders. Another collaborative effort is studying the early developmental indicators of autism in very young children. Dr. Marie Bristol-Power, the founding program director at NICHD for the CPEAs, was honored recently with the Dale Richmond Award for her very important work in initiating the CPEA program.

NIH has recently renewed the CPEA sites for an additional 5 years of funding. NICHD and NIDCD plan to allocate \$60 million in this time period to sustain and enhance the CPEAs. Currently, NIH is in the process of establishing a data-coordinating center (DCC), designed specifically to expedite and maximize analysis of the data generated by the CPEA research projects. This DCC will be instrumental in facilitating communication, standardizing protocols and measures across sites, and collating and analyzing data for collaborative CPEA projects. A request for applications (RFA) for the CPEA DCC has been recently published in the NIH Guide. Applications for the DCC were due to NICHD by November 26, 2002, and we anticipate that the DCC award will be made in the summer of 2003.

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

NICHD and CDC have been 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. Current estimates suggest that more than 20 percent of children with autism experience such a course, with the remainder following a slower, more gradual development of symptoms beginning in infancy. We began the study of the possible association of MMR vaccinations and regressive autism in September 2000, and the initial phase of the study is now nearing completion. This study involves a comparison of subjects with the regressive form of autism and subjects with the more typical form of this developmental disorder. We will begin analysis of data from the subjects enrolled in this study shortly. After data from the initial phase have

been analyzed, we will reassess the future directions for this line of research based upon the findings, and we will consider further refinements of a research strategy. NICHD remains strongly committed to identifying the causes, methods of prevention and treatments for children with autism spectrum disorders. This commitment is reflected in the large and growing portfolio of investigator-initiated and other grants related to the basic physiology, neuropathology, genetics, behavior, communication and learning problems, therapy, and prevention of autism and related conditions.

Centers for Children's Environmental Health and Disease Prevention

NIEHS, in partnership with the Environmental Protection Agency (EPA), continues its support of autism research through its national network of Centers for Children's Environmental Health and Disease Prevention. Two of the Centers in this network focus on potential environmental influences in autism and related disorders. The Center for Childhood Neurotoxicology and Exposure Assessment is located at the University of Medicine and Dentistry of New Jersey. This Center supports basic science projects to examine facets of brain development and their interaction with selected environmental agents, beginning with neuron formation and growth and proceeding to the overall behavior of the organism. Clinical sciences projects in this Center are exploring links between environmental chemicals that may alter brain function and regional brain growth. Scientists affiliated with this project work closely with community groups representing children with learning disabilities and their families, with a particular emphasis on autism. Through an exposure assessment and intervention project, NIEHS is characterizing the personal, residential, and community exposures of children with autism.

To review relevant research findings and explore further the potential role of environmental influences in autism etiology, this NIEHS- and EPA-supported New Jersey Center for Childhood Neurotoxicology and Exposure Assessment hosted a 2-day conference "Autism, Genes and the Environment" on October 3-4, 2002. More than 150 individuals attended this conference to hear leading autism researchers discuss current developments and potential outcomes in their area of research expertise, especially as regards the relationship of environmental factors to other influences in the development and progression of autism. The conference included a parent/scientist open forum to bring together autism researchers, parents, and clinicians to address concerns and offer insights and solutions pertaining to the direction of research, diagnosis, treatment, and support services, with the goal of improving the quality of life for individuals with autism. In addition, NIEHS organized a "brainstorming" session at the conclusion of the scientific conference. Invited participants at this session included many of the conference speakers and representatives from the major autism advocacy groups. With the prior meeting presentations and discussions as background, the goal of this special concluding session was to identify and prioritize research and resource needs for elucidating the etiology of autism, particularly the role of environmental factors as triggering events or modifiers of disease progression.

The second NIEHS- and EPA-supported Center for Children's Environmental Health and Disease Prevention with a focus on autism is located at the University of California

at Davis. This Center is planning the first major epidemiologic case control study to examine a broad range of environmental exposures, including chemicals with known or suspected neurodevelopmental toxicity, such as PCBs, certain pesticides and metals, and endogenous susceptibility factors. This study will pursue several hypotheses that have recently gained attention involving vaccines given during infancy and early childhood. Additionally, the study will examine biochemical susceptibility through characterization of metabolic, immunologic and neuronal gene expression profiles and genetic polymorphisms. Another project at this Center is establishing batteries of behavioral tasks that will provide sensitive assessments of normal mouse and rhesus monkey social behavior. With the establishment of the animal models, animals will be exposed to xenobiotics, including thimerosal and methyl mercury, to determine any effects on social behavior.

NIH/ACC Annual Scientific Meeting

NIH held a workshop entitled "Research on Psychosocial and Behavioral Interventions in Autism: Confronting the Methodological Challenges" on September 5-6, 2002, in Bethesda, Maryland. The meeting was sponsored by NIMH, NINDS, NIDCD, NICHD, and the NIH Office of Rare Diseases. The primary aim of the meeting was to review the state of the science with regard to psychosocial, behavioral, and educational interventions for children with autism; to examine the barriers to progress in the field; and to discuss potential strategies for overcoming these barriers. Meeting participants included experts in autism interventions research from the United States and abroad, experts in methodology, and public participants. We are 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 NIMH Web site.

Enhancing Mental Health Services

NIMH will support an innovative research network, entitled "Enhancing Mental Health Services to Children with Autism," submitted in response to a Request for Applications for Child and Adolescent Interdisciplinary Research Networks (CAIRNs). Principal Investigator Thomas Nesbitt of the University of California-Davis and co-Investigator Sally Rogers of the M.I.N.D. (Medical Investigation of Neurodevelopmental Disorders) Institute will lead a ground-breaking, interdisciplinary partnership of researchers and stakeholders to develop strategies and guidelines for effective telehealth technologies in the delivery of high-quality, empirically supported, and well-coordinated mental health services for children with autism and their families living in rural communities.

2. Centers of Excellence

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

In 2001, to help interested groups of investigators prepare to submit high-quality

applications to become autism centers, NIH issued an RFA entitled “Developmental Grants for Autism Centers of Excellence” (see <http://grants.nih.gov/grants/guide/rfa-files/RFA-MH-01-013.html>). The awards made under this RFA were jointly sponsored by NIMH, NICHD, NINDS, NIDCD and NIEHS. The grants were designed to provide developmental support to teams of investigators to enhance their ability to plan, organize, and demonstrate the feasibility of their autism research efforts as they prepared, over a several-month period, their applications for center of excellence support. The developmental grants RFA was a one-time solicitation, intended for investigators who would apply for centers support by an August 2002 deadline to become part of the centers program, with funding of successful applications in FY 2003.

Under the developmental grant RFA, NIH awarded six grants 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, the 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 centers of excellence in autism research [to be called STAART (Studies to Advance Autism Research and Treatment) Centers], with a deadline for applications of November 29, 2001. NIH received a number of proposals in response to this RFA, and these were reviewed in March 2002 and presented to appropriate advisory council meetings in May 2002. Two of the applications (Yale University and University of North Carolina) were funded in September 2002 with contributions from NIMH, NICHD, NINDS, NIDCD, and NIEHS. In order to complete the network of at least five centers, NIH issued another RFA for a second round of competition with an August 2002 deadline for applications (see <http://grants1.nih.gov/grants/guide/rfa-files/RFA-MH-03-005.html>). Researchers who unsuccessfully applied for developmental grants (the July 12, 2001, deadline) or comprehensive center grants (the November 29, 2001, deadline) were allowed to submit a revised application for STAART Center support by this deadline. New applicants were also eligible to apply. NIH received a number of applications, conducted a peer review meeting in December 2002, and will be completing council reviews by the end of February 2003. Thus, NIH anticipates that at least three awards will be made from this second round of competition in order to establish the full network of at least five centers required by the Children’s Health Act. The total number of centers funded will depend upon the merit of the applications received and the funds available.

NIH estimates that the total funds (direct costs and facilities and administration costs) available to support all the awards made under these 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. 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. This past year, for example, the repository made available genetic biomaterials and associated clinical data that had been collected in an autism study conducted by the Stanford University Medical School (<http://grants.nih.gov/grants/guide/notice-files/NOT-MH-02-004.html>). NIMH has also worked with the Autism Genetic Resource Exchange (AGRE) genetics data bank supported by Cure Autism Now, which resulted in a grant application that received high marks in peer review and NIMH has now funded. This grant supports the continued activities of this 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. NINDS continues to support promising research in the genetics of autism, including core grant support for the development and expansion of genetics resources. This support will enhance the ability of research groups located in the United States, Canada, Europe, and Israel to work collaboratively to discover genes that contribute to autism. These research groups have created a genetic data bank that can be shared across laboratories, greatly increasing the power to discover genes involved in autism. In addition, the research groups will share data and research findings through regular workshops and through the use of a private internet network linking the laboratories together.

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. This past year, NIMH has funded supplements received in response to an RFA to enhance activities in this arena for several disorders, including 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 advisory council meetings, and specially conducted public forums around the country. In addition, some Institutes, such as NIMH, solicit public participant reviewers on Scientific Review Groups for treatment and services research grant applications. 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 2 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 of the e-mail addresses of advocacy group members. NIMH maintains the list and 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, 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

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. Data from the first year of monitoring have been submitted for publication and will provide one of the most complete and comprehensive assessments of autism 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 track the number of children with ASDs in their States. Known collectively as the Autism and Developmental Disabilities Monitoring Network (ADDM Net), these States are adapting the model developed in CDC's Atlanta monitoring program for their local area. In September 2001, CDC provided continued funding to four of the States (Arizona, New Jersey, South Carolina, and West Virginia; Maryland/Delaware received continued funding through the Centers mechanism--see below). Data collection in these States began in 2002. CDC funded three more ADDM States (Arkansas, Florida, and Utah) in the fall of 2002. First-year activities for the three new ADDM States will focus on hiring staff, developing protocols, establishing collaborations with education agencies and clinical providers, and obtaining institutional review board and other approvals.

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

In September 2001, CDC funded four Centers for Autism and Developmental Disabilities Research and Epidemiology (CADDRE) to conduct collaborative studies on the number, incidence, and causes of autism and related developmental disabilities. The four Centers were: (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 State-wide, with more intensive monitoring in the San Francisco Bay area. In September 2002, CDC funded a fifth center at the University of North Carolina. In addition to conducting surveillance of autism in their areas, the Centers will also collaborate on combined case-control studies into factors that may cause autism and related developmental disabilities. Much of the first year has been devoted to developing the scientific protocol and data collection procedures for the collaborative case-control study. The Centers investigators held three meetings during the first year of the project. Each of the Centers has expertise in diverse areas relevant to the epidemiology of autism, its causes, and possible interventions. Each Center will conduct specific research focusing on its areas of particular strength, such as genetics, immunology, biological markers, and screening. As one example, given the accumulating evidence of the benefits of early intervention, the Pennsylvania Center is conducting a pilot study of screening toddlers 18 to 24 months of age in general pediatric clinics. The Pennsylvania Center plans to train nurses, physicians, educators, and other providers of health and educational services to screen children for signs of developmental disabilities and ASDs.

3. 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. The CDC will make available through the clearinghouse any materials or information developed by the ARCHE network (Centers and States) that may be useful for the public or other researchers (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 continued their efforts to increase awareness of autism in each State, assessing information needs. The Committee has begun to survey physicians about their current knowledge and education needs related to early identification of children with autism. Information from these surveys will be used in planning specific educational programs in each State. CDC launched the Web-based Autism Information Center in September 2002. The information center focuses on the activities of Federal and federally funded programs and the resources offered by these programs. It includes information for both families and professionals. Current topics include (a) general information about autism spectrum disorders (ASDs); (b) activities at CDC and other Federal agencies; (c) State activities funded by CDC; (d) education and services resources for families; (e) resources for researchers; and (f) activities to help children use the Internet to learn more about ASDs. The information center can be found at <http://www.cdc.gov/ncbddd/dd/ddautism.htm>.

(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.”

The State surveillance projects and Centers surveillance activities will provide vital background data for evaluating potential clusters of autism. In 2001, CDC completed and reported the results of a community-based prevalence study designed in response to the concern of parents regarding a possibly larger than expected number of children with ASD (Brick Township, New Jersey). The study found 6.7 cases of ASD per 1000 children in the community. Currently, CDC is not investigating any active clusters.

Section 103--Information and education

Under Title 1 of the Public Health Service (PHS) Act, Section 103 authorizes 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 the 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. Funds may be used to provide stipends for health

professionals who are enrolled in training programs under this section.

HRSA's Bureau of Health Professions' Quentin N. Burdick Program for Rural Interdisciplinary Training supports the interdisciplinary education and training of health professionals in rural communities and addresses rural health care workforce problems. There is a great need for behavioral/mental health services in rural areas. Burdick projects support the interdisciplinary education and training of health professionals to address a variety of health care problems, including behavioral/mental health and developmental disabilities in children and adults. The Burdick Program funds the West Virginia University Center for Excellence in Disabilities, which addresses the interdisciplinary education and training of health professionals in developmental disabilities including autism. The purpose of this project is to (1) improve access to person-centered, quality home health care through the development of clinically competent health care professionals skilled in the interdisciplinary process and (2) improve access to a diverse and culturally competent health professions workforce. These goals are being accomplished by providing interdisciplinary pre-service training for a person-centered approach to home assessments for individuals with disabilities including those with developmental disabilities and autism, chronic conditions, and the elderly. The proposed number of trainees is 39 health professions undergraduate and graduate students. The grantee was awarded \$219,878 in FY 2002.

HRSA's Maternal and Child Health Bureau (MCHB) has two long-standing programs that are relevant to the training of health professionals to serve persons with autism and other developmental disabilities. MCHB's Leadership Education in Neurodevelopmental Disabilities (LEND) Program funds 35 LEND programs across the United States to train individuals from a wide variety of professional disciplines to assume leadership roles and to ensure high levels of clinical competence to improve the health of children who have, or are at risk of developing, neurodevelopmental or other related disabilities such as autism and mental retardation. Interdisciplinary faculty and trainees include audiologists, dentists, health administrators, nurses, nutritionists, occupational therapists, physical therapists, physicians, psychologists, social workers, special education professionals, and speech language pathologists. The FY 2002 budget for the program was \$18,748,097. The Developmental-Behavioral Pediatrics Program funds nine programs, located in institutions of higher learning, to enhance the behavioral, psychosocial and developmental aspects of general pediatric care. The programs support fellows in behavioral pediatrics to help prepare them for leadership roles as teachers, researchers, and clinicians. The FY 2002 budget for the program was \$1,143,545.

Elsewhere in the HHS, the Administration on Developmental Disabilities supports a National Network of University Centers for Excellence in Developmental Disabilities Education, Research, and Service. At the CDC, a new National Center on Birth Defects and Developmental Disabilities addresses the prevention of birth defects and developmental disabilities and the improvement of the health and wellness of people with disabilities. The Department of Education administers programs under the Education of Individuals with Disabilities Act that address services for people with developmental disabilities.

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 HHS. Secretary Tommy Thompson delegated the authority to establish the IACC to the National Institutes of Health (NIH) in April 2001. The NIMH at the NIH has been designated the lead for this activity. The Committee has now been established and has had three semi-annual meetings.

b. Membership

The Committee's primary mission is 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 bring to HHS the concerns and interests of members of the autism community. The IACC serves as a forum and help to increase public understanding of the member agencies' activities, programs, policies, and research and brings important matters of interest forward for discussion. The Secretary has appointed four public members.

Government agencies represented include the following: NIH/ACC members (NIMH, NICHD, NIDCD, NIEHS, and NINDS), CDC, HRSA, the Substance Abuse and Mental Health Services Administration, the Administration for Children and Families (specifically, the Administration on Developmental Disabilities), the Food and Drug Administration (FDA), the Agency for Toxic Substances and Disease Registry, the Centers for Medicare and Medicaid Services, and the Department of Education. A summary of each meeting is posted when available on the NIMH Web site (see <http://www.nimh.nih.gov/events/interagencyautism.cfm>).

3. Activities

The IACC has established subcommittees on autism screening and the organization of autism treatment services. Both subcommittees are now working to coordinate activities among IACC members and with the relevant stakeholders in the medical and services communities.

The IACC provides updated information to its members on activities that involve coordination across agencies and organizations. For example, in the area of research expansion, intensification, and coordination, FDA has undertaken several activities that are coordinated with other IACC member organizations. In the area of product safety, specifically thimerosal toxicology, studies in non-human primates have been supported in an FDA-led research program in collaboration with NIEHS and the National Toxicology Program (NTP). The FDA-nominated toxicology study proposal was unanimously approved by the NTP to evaluate the pharmacological, neurotoxicological and cognitive effects of thimerosal in non-human primates and will be performed at the National Center for Toxicology Research (NCTR)/FDA. FDA has also supported studies of neurodevelopmental outcomes of virus infections of the brain. In collaboration with extramural NIH-funded academic scientists, the Center for Biologics Evaluation and Research (CBER) supports a program in vaccine neurovirulence to study the mechanisms of virus-induced developmental brain damage, including behavioral outcomes in an animal model of autism, and to develop new animal tissue culture and molecular biology assays to evaluate vaccine safety for the nervous system. In the Developmental Disabilities and Surveillance Research Programs, FDA collaborates with CDC on the Vaccine Adverse Events Reporting System (VAERS). They are supporting an investigation of Autism Spectrum Disorder Reports to VAERS: Vaccine Risk Perception. This study is performed as follow-up to spontaneous VAERS reports of autism following vaccination. Interviews are conducted regarding the clinical characteristics (including medical review) and regressive features of autism and perceptions of the adverse event reporters (typically the parents) as to the linkage between vaccination and autism.

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." This third annual report reflects HHS activities through December 2002.