

# Report to Congress on Autism

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**NIMH**  
National Institute  
of Mental Health

## **Report to Congress on Autism 2004: Children's Health Act of 2000**

### **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 now funded a total of eight centers under the Studies to Advance Autism Research and Treatment (STAART) Centers Program, exceeding the complement of 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 expanded activities 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 1 in 400 to 1 in 1,000 in the United States [Yeargin-Allsopp, M., Past and future perspectives in autism epidemiology, *Molecular Psychiatry*, 2002, 7, S9-S11; and Yeargin-Allsopp, M., Rice, C., Karapurkar, T., Doernberg, N., Boyle, C., & Murphy, C., Prevalence of Autism in a U.S. Metropolitan Area, *Journal of the American Medical Association*, 2003, 289 (1), 49-55]. 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 fourth 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**

#### **a. 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 NIH was delegated the authority to convene the IACC and designated NIMH 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 \$74 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 \$74 million effort encompasses a large number of grants, contracts, and intramural research programs distributed across the NIH.

In FY 2003, 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 currently consists of ten 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 development of brain structures and their functions as they relate to autism as well as the developmental course of autism. These undertakings require each CPEA to implement a cohesive, site-specific, multidisciplinary research program on the causes, brain substrates, functional characteristics, and clinical development of autism spectrum disorders and require each site to participate in some trans-Network collaborative studies for which no one individual site has the needed expertise and/or subject population. As a result of efforts of the CPEA centers, the Network is now studying the world's largest group of well-diagnosed individuals with autism for whom both genotypic and extensive phenotypic 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; University of Texas, Houston, TX; 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. Examples of scientific findings include characterization of the cognitive bases of restricted and repetitive behavior, elucidation of a specific impairment in face and emotion recognition, and identification of early deficits in learning to categorize common

objects.

Because of the number of autistic individuals enrolled in the research programs of the CPEA, the Network continues to undertake studies that would be difficult or impossible to do at a single research site. For example, scientists in the Network published a study that confirmed 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. CPEA scientists are also collaborating to continue investigating several candidate genes that may be associated with autism spectrum disorders. Another collaborative effort is a study of abnormal early brain growth in children with autism. Possible future research collaborations are currently being explored with the National Alliance for Autism Research (NAAR) to initiate studies utilizing CPEA network infrastructure to identify early markers of autism.

NIH has 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. A data-coordinating center (DCC), designed specifically to expedite and maximize analysis of the data generated by the CPEA research projects as well as the STAART network, was established this year. This DCC has started to provide administrative support for all network activities and implements a Web site to foster communication and coordination within the network.

#### *Centers for Children's Environmental Health and Disease Prevention*

NIEHS, in partnership with the U.S. Environmental Protection Agency (EPA), has continued its support of autism research through a national network of Centers for Children's Environmental Health and Disease Prevention Research. Two of the Centers, located at the University of California at Davis and the University of Medicine and Dentistry of New Jersey, focus on possible environmental aspects of autism and related neurodevelopmental disorders. Strong partnerships between scientists and community advocacy groups are used to enrich all aspects of the research process, from study planning to evaluation and dissemination of findings. Within the past year, the UC-Davis Center has begun enrollment of autistic children in the first large-scale epidemiologic case-control study of environmental risk factors for autism. This study is collecting extensive information from medical records and parent questionnaires designed to assess a variety of environmental exposures in the prenatal and postnatal period. Additional projects at this Center have made significant progress in developing animal models of social behavior deficits similar to those seen in children with autism and in defining interactions between specific neurotoxicants and immune function. These basic science projects will provide valuable information about potential neurobiological mechanisms in autism and will enable testing of a variety of hypotheses concerning environmental or immune system threats that may influence risk of autism. The Center at the University of Medicine and Dentistry of New Jersey has begun enrollment and evaluation of children in a unique study designed to provide a comprehensive evaluation of personal, residential and community environments of children with autism to identify any sources of harmful exposures and to develop strategies to minimize risk from such exposures. Several basic science projects conducted at this Center are using cellular and animal models to explore the interaction of model neurotoxicants such as lead and methyl mercury with aspects of early brain development and with the emergence of specific behavior patterns. To inform the science and lay community about current research efforts and environmental issues in autism, these two Centers sponsor an annual meeting or scientific

session on gene-environment interactions in autism. This year's event, organized by the UC-Davis Center, will be coordinated with the 2004 International Meeting for Autism Research to be held May 7-8 in Sacramento, California.

b. Centers of Excellence

The Children's Health Act of 2000 called for NIH to establish at least five Centers of Excellence in Autism Research. NIH has implemented a centers program that meets or exceeds the specifications of the Act regarding the organization, scientific goals, and other characteristics of the program. The goal was to establish several research centers that would bring together expertise, infrastructure, and resources focused on major questions about autism. In 2002, two centers were funded under this new program, termed the Studies to Advance Autism Research and Treatment--STAART Centers Program. These centers are at the University of North Carolina, Chapel Hill, directed by Joseph Piven, M.D., and at Yale University, directed by Fred Volkmar, M.D. In 2003, the five participating NIH Institutes (NIMH, NINDS, NICHD, NIDCD, and NIEHS) funded six additional centers after a Request for Applications (RFA) was issued. The six new centers and their directors, are: University of Washington, Geraldine Dawson, Ph.D.; University of California, Los Angeles, Marian Sigman, Ph.D.; Boston University, Helen Tager-Flusberg, Ph.D.; University of Rochester, Patricia Rodier, Ph.D.; Kennedy Krieger Institute, Rebecca Landa, Ph.D.; and Mt. Sinai Medical School, Eric Hollander, M.D. The STAART Centers will contribute to the understanding of autism by investigating early detection through behavioral and/or biological markers, efficacy of early interventions, early course of core features, biological basis of the core deficits, efficacy of treatments for social deficits, efficacy trials for pharmacotherapy, genotypic and phenotype of response to treatment, and identification of susceptibility genes. Plans for collaborative projects include multi-site clinical trials within the STAART network, as well as interaction with the CPEA. A single data coordination center supports both CPEA and STAART network functions. Previous funding for the STAART Centers Program included 1-year developmental grants funded at six universities and research institutes to help research teams prepare applications for future centers.

NIH estimates that the total funds (direct costs and facilities and administration costs) available to support the STAART Centers Program will be \$13 million per year, for a total of approximately \$65 million over the next 5 years. NIH will use this amount to fund the eight centers, the data coordination center, and collaborative projects among the centers. NIH will distribute the majority of the \$13 million pool of funds to grantees to support the activities specific to each center. It 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. The Steering Committee of the STAART Centers Program will determine the exact nature of the cooperative studies.

c. Facilitation of Research

The Children's Health Act of 2000 also calls on NIMH to take the lead in expanding a program under which samples of tissues as well as genetic materials are donated, collected, preserved, and made available for autism research. The sharing of materials and data is critical to accelerate the understanding of disorders like autism that are genetically complex and clinically heterogeneous. Data sharing facilitates the assembly of large samples with adequate statistical power for genetic analysis, the rapid replication of new findings, new directions for translational research, the availability of needed clinical resources to promising young investigators, and the rapid application of state-of-the-art scientific tools and technologies. Therefore, 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. Activities for 2003 include the following: (1) An administrative supplements program to promote data sharing in ongoing NIH autism projects. Four NIH Institutes and Centers committed \$2.25 million to support the collection and timely sharing of family data and DNA through the NIMH Autism Genetics Initiative (<http://nimhgenetics.org>), an ongoing effort by which data and materials for genetic studies are distributed to the broader scientific community. Eight applications were funded to provide data and materials on 500 new autism families. (2) An administrative supplements program to promote data sharing in ongoing STAART Center projects. Clinical data and DNA on 100 new autism families, 500 unrelated affected individuals, and 150 autistic individuals enrolled in a new clinical trial will be shared with the scientific community through the NIMH Autism Genetics Initiative.

In addition to these efforts, the CPEA program funded by NICHD and NIDCD also will continue its ongoing, extensive activities in the collection of genetic data within its research network. In addition, 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.

This is also time of unparalleled opportunity as multiple government agencies and private foundations are starting to work in a concerted way to stimulate autism research. NAAR has assembled a large consortium of autism researchers (Autism Genome Project, AGP), including those utilizing biomaterials from the Autism Genetic Resource Exchange (AGRE) sponsored by the Cure Autism Now Foundation (CAN), to conduct a genome-wide scan of over 1,200 pedigrees collected worldwide. This scan is expected to identify several candidate genomic regions containing vulnerability genes. Identification of these genomic regions will be a critical first step in gene discovery. The NAAR AGP-sponsored genomic scan will support saturation analysis of single nucleotide polymorphisms (SNPs) in multiple candidate regions of interest.

High-density SNP maps of these candidate regions will be used to characterize patterns of linkage disequilibrium and ultimately to identify functional variants in candidate genes that affect specific neural circuits and pathways. As noted above, NIH is strongly supporting this effort and recently funded a fast-track administrative supplements program to encourage the collection and timely sharing of research resources for use in AGP and other genetic studies on autism. Data and DNA on 1,000 autistic families will be added to NIMH's Human Genetics Initiative for sharing with AGP and the broader scientific community. NIH is considering for future funding in FY 2005 an autism genetics initiative to support ascertainment in AGP of a new independent sample of autistic subjects and suitable controls in order to perform association analysis on genomic regions of interest.

In the area of tissue resources, NIH Institutes have continued and expanded their support of existing tissue collection and distribution resources at several sites. Such 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. For example, by using radioactive tracers on thinly sliced sections of brain tissue, scientists can detect and pinpoint abnormal activity of genes within cells. To take advantage of emerging opportunities for discovery in postmortem tissue made possible by the new molecular methodologies, NIMH, in collaboration with the autism community and other NIH Institutes, is stepping up efforts to establish brain bank collections to study autism. Activities in 2003 included an Autism Brain Banking Workshop in March 2003 that was sponsored by NIMH along with the other NIH/ACC Institutes. This workshop evaluated current best practices for tissue collection and distribution and proposed effective new mechanisms and infrastructure needed to enhance tissue research in autism. Subsequently, NIMH, NINDS and NIDCD announced a joint effort in supplementing the Harvard Brain Tissue Resource Center (whose principal funding comes from NINDS and NIMH) for the creation and maintenance of a National Autism Brain Bank. In addition to other federally funded efforts, this national resource will help collect, store, and disseminate postmortem human brain specimens for the study of 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.

NIMH maintains a listserv of interested individuals and continues to update those who register with news of interest to the autism community. Also, the National Library of Medicine's MedlinePlus Web site for autism is frequently used (<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.ninds.nih.gov/health_and_medical/disorders/autismshortdoc.htm)  
[http://www.nidcd.nih.gov/health/pubs\\_vsl/autism.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 (ASDs) in children. Data from the first year of monitoring were published in January 2003, providing one of the most complete and comprehensive assessments of autism prevalence in a large U.S. metropolitan area (Atlanta, Georgia). The rate of autism found in this study (3.4 per 1,000 children) is higher than the rates found from studies conducted in the United States during the 1980s and early 1990s but consistent with those of more recent studies (mostly from Europe and Asia).

With funding provided by Congress for FY2000, 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. These States are known collectively as the Autism and Developmental Disabilities Monitoring Network (ADDM Net). With FY2001 funds, 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). In 2002, these States began collecting data, and CDC funded three more States to participate in the network (Arkansas, Florida, and Utah). In FY2003, CDC provided funding to four additional States [Alabama, Missouri and Illinois (joint), and Wisconsin], bringing the total number of States involved in autism monitoring to eighteen (including CDC's Atlanta program). The monitoring activities of the States are based on the methodology used by CDC's autism and developmental disabilities program in Atlanta. First-year activities for the four 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. Programs collecting information on autism prevalence will help determine trends over time and whether rates of ASDs vary by geographic region, race, or other characteristics.

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 spectrum disorder and related developmental disabilities. The four Centers are: (1) Johns Hopkins University, which is identifying cases of autism in northeastern Maryland and the entire State of Delaware; (2) the University of Pennsylvania, which covers the Philadelphia metropolitan area; (3) the Colorado Department of Public Health, which concentrates on identifying cases in the Denver area; and (4) the California Department of Health Services, which is ascertaining cases of autism statewide, with more intensive monitoring in the San Francisco Bay area. In September 2002, CDC funded a fifth center at the University of North Carolina.

Each of the Centers has expertise in diverse areas relevant to the epidemiology of autism, its causes, and possible interventions. In addition to conducting autism surveillance in its regions, 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.

The Centers are also collaborating on an innovative research initiative, the largest of its kind, to look at a wide array of potential causes of autism and related developmental disabilities, such as the roles of infection, alcohol and drug use, and family characteristics. A study of this size holds great promise for discovering what causes autism. The scientific protocol (specifying the instruments and procedures to be used for data collection) is almost finalized for submission to an institutional review board.

#### 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 with information to facilitate the establishment and operation of surveillance projects and epidemiological studies of autism and related pervasive developmental disabilities. CDC makes available through the clearinghouse any materials or information developed by the CDC-funded Centers and States that may be useful for the CDC-funded researchers (for example, publications of epidemiological studies; data management manuals; training materials; research protocols, including questionnaires and other instruments; information on privacy and confidentiality of data; community outreach strategies; and educational materials for professionals, families, schools, and the general public). The State surveillance programs have an Education and Outreach Committee, which has continued its efforts to increase awareness of autism in each State by assessing information needs. The Committee has begun to survey stakeholder's groups, such as parents and

professionals, about their current knowledge and education needs related to early identification of children with ASDs. Information from these surveys will be used in planning specific educational programs in each State aimed at increasing the early and accurate identification of children with autism.

In September 2002, CDC launched its Web-based Autism Information Center. The information center focuses on the activities of Federal and federally funded programs and the resources offered by these programs. It includes information for the general public, families, and professionals. Current topics include (a) general information about autism spectrum disorders; (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.”

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 ASDs (Brick Township, New Jersey). The study found 6.7 cases of ASD per 1,000 children in the community, a rate similar to autism prevalence estimates from small investigations previously conducted in the United States and abroad. However, the fact that this was a small study conducted in just one community made it difficult to generalize these findings to the larger population and further underscored the need for dependable, large population-based autism prevalence data. In addition to providing information needed to answer questions about trends in autism, CDC’s program and the seventeen States CDC supports to conduct autism monitoring in their regions will provide the vital background data necessary to evaluate other potential autism 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--Under Title VII of the Public Health Service (PHS) Act, as amended by the Health Professions Education Partnerships Act of 1998, P.L. 105-392, section 754, authorizes the Quentin N. Burdick Program for Rural Interdisciplinary Training to support the interdisciplinary education and training of health professionals in rural communities and address 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 2003 budget was \$221,546.

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 2003 budget for the program was \$18.8 million.

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 2003 budget for the program was \$1.3 million.

In 2003 The Maternal and Child Health Bureau's Division of Services for Children with Special Health Care Needs (DSCSHN) awarded a grant to the Geisinger Health System in Danville, PA, to develop a model of care and related set of tools that will be used to improve early detection, access to diagnostic and evaluation services, and continuity and appropriateness for care for individuals with ASD and their families. In addition, the DSCSHN is holding a 2-day (October 27- 28) Expert Workgroup meeting for families of children with autism. The primary goal of the workgroup will be to provide the Division information on service needs from the families' perspective and to discuss with families potential strategies to address the identified needs. The information obtained from the workgroup meeting will be shared with the IACC, on which HRSA serves and co-chairs the Services Subcommittee. Educational tools from the Geisinger grant and the family workgroup will be disseminated to the State programs and communities to strengthen and expand integrated community services for children with autism. The 2003 budget for the program was \$1,000,000.

#### **Section 104--Interagency Autism Coordinating Committee**

##### **a. Establishment**

Section 104 mandated the establishment of an interagency autism coordinating committee to coordinate research and other efforts with regard to autism 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 five 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 helps 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), HRSA, CDC (specifically, the Agency for Toxic Substances and Disease Registry and the National Center on Birth Defects and Developmental Disabilities), 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 (specifically, the Center for Biologics Evaluation and Research), the Centers for Medicare and Medicaid Services, the Agency for Healthcare Research and Quality, and the Department of Education (specifically, the Office of Special Education and Rehabilitative Services). A summary of each meeting is posted when available on the NIMH Web site (see <http://www.nimh.nih.gov/events/interagencyautism.cfm>).

c. 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.

*IACC Science Panel and Matrix Development*

The House and Senate conferees considering the FY2003 appropriations for the Departments of Labor, Health and Human Services and Education, Conference Report 108-10, requested that the IACC "convene a panel of outstanding scientists to assess the field of autism research, and identify roadblocks that may be hindering progress in understanding its causes and best treatment options." The final product was to be the development of a research matrix focusing on the causes and best treatment options for autism. In response to this request, the IACC convened a panel of science experts to document both roadblocks to understanding causes and best treatment options for autism, as well as goals and activities to overcome these roadblocks.

A list of roadblocks was created, and the autism research matrix was designed to include goals and activities for the next 10 years. Goals and activities that comprise the autism research matrix generally fall within the following categories: characterization of autism (i.e., phenotype), screening, early intervention, school and community interventions, specific treatments, neuroscience and epidemiology. After the science panel suggested items for the matrix last July, the membership of the IACC approved the final version of the matrix on November 21.

### *Autism Summit Conference*

In order to expand on the work of the IACC, particularly the work of the subcommittees on early screening and services, a national conference focusing on the Federal Government's role in biomedical research, early screening and diagnosis, and improving access to autism services was held on November 19 and 20 at the Washington Convention Center in Washington, DC. This event was entitled "The Autism Summit Conference: Developing a National Agenda." The goal of the meeting was to provide information to the public on Federal activities relevant to autism and to provide an opportunity to the public to share information with Federal agencies. This was a preliminary activity in developing a national agenda for Federal autism activities. The planning committee for this conference was composed of several Federal and public members of the IACC, and the meeting was officially co-sponsored by the U.S. Department of Health and Human Services and the U.S. Department of Education. The biomedical research component provided an opportunity to engage in a public presentation of the autism research matrix. The theme on autism screening and diagnosis allowed for review of existing screening instruments and discussion of current clinical practices. The section on autism services throughout the lifespan included discussion of integrating services provided by several different systems of service providers.

### **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 fourth annual report reflects HHS activities through December 2003.