

# Report to Congress on Autism

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

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## **Report to Congress on Autism 2005: 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 continued to make substantial progress in 2004. The Studies to Advance Autism Research and Treatment (STAART) Centers Program is currently active with eight centers, 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, including the establishment of an information clearinghouse as required by the Act. Other CDC initiatives include the National Autism and Pervasive Developmental Disabilities Surveillance Program and the recently launched awareness campaign. In addition, the report describes the ongoing functions of the Interagency Autism Coordinating Committee (IACC) established by the Act.

### **Introduction**

Autism is a complex neurobiological disorder that generally lasts throughout a person's life and is part of a group of disorders known as Autism Spectrum Disorders (ASDs). Current statistics show that autism occurs in all racial, ethnic, and social groups, and, recently, there have been reports of fluctuations in the numbers of children receiving a diagnosis of autism or receiving public services for autism. Autism impairs a person's ability to communicate and to relate to others. It is also 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 disorder are searching for answers about its causes, diagnosis, prevention, and treatment. Presently, there are 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. Although the full cost to society from autism is not known, there are tremendous economic and social burdens associated with this disorder.

### **Purpose of Report**

Public Law 106-10, 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 reflects HHS activities in 2004 pertinent to Division A, Title I, of the Act.

### **Section 101--Expansion, intensification, and coordination of activities of the National Institutes of Health 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, and the National Institute of Nursing Research has recently joined.

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 \$93 million in FY 2003. 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 \$93 million effort encompasses a large number of grants, contracts, and intramural research programs distributed across the NIH.

In FY 2004, 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 nine Collaborative Programs of Excellence in Autism (CPEAs) that link together 129 researchers in 23 universities and more than 2,200 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, 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 7 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, furthered the characterization of the phenotype and the

broader phenotype of autism spectrum disorders, explored animal lesion studies, conducted intervention studies using randomized clinical trials, 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 continues to undertake studies that would be difficult or impossible to do at a single research site. Completed Network projects focused on the effectiveness of the hormone secretin for autism, the possible roles of HOXA and Reelin genes, executive functions in autism, language functions in autism, and genetic sibling linkages in autism. Two Network projects, head circumference in autism and cognitive profiles in preschool-aged children with autism, are near completion. Furthermore, a new Network project is in planning to study girls with autism.

In 2002, NIH 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 in 2003. This DCC has provided administrative, project management, and data management support as well as customized system applications for both the CPEA and the STAART Networks. The DCC has created and maintained a Network Web site by which personnel, project, and meeting information is available to participating researchers in one central location. The DCC also developed a tracking system and 34-data entry system and provides ongoing project and data management support for the STAART Network's first pharmacologic, multi-site randomized control trial. Finally, the DCC has been collecting common data and family history data in order to create a meta-data file from all participating sites and has worked out specifications to transfer data to the NIMH genetics repository on an iterative basis.

#### *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 accelerated its 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. Biological samples are being collected to search for potential biomarkers of autism. 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 aspects of immune function. Supplemental funds have been provided to this Center in 2004 to pursue recently reported strain-related differences in sensitivity to the neurotoxic effects of organic mercury. The basic science projects at this Center 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 continued 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 community about current research efforts and environmental issues in autism, the UC-Davis Center, with financial support from NIEHS, sponsored a special session at the May 2004 International Meeting of Autism Researchers (IMFAR), held in Sacramento, California.

#### *Other Recent Activities*

Two postdoctoral training programs were funded in 2004, in response to a request for applications entitled "Interdisciplinary Health Research Training: Behavior, Environment and Biology," which is part of the overall NIH Roadmap effort to build research teams for the future. Such centers were established to create a workforce capable of crossing disciplinary boundaries and leading and participating in integrative and team approaches to complex health problems. One program, located at UC-Davis, is entitled "Interdisciplinary Training for Autism Researchers." This training program will develop a cadre of young scientists who will foster communication in a discipline that might be called Clinical Neurodevelopmental Neuroscience. Trainees will develop expertise in clinically relevant areas of neuroscience, such as human neuroanatomy, neurophysiology and neuroimaging, at the same time that they are learning the principles and protocols of sensitively conducting research with children. They will develop core competencies in areas relevant to autism research that include: epidemiology, genetics-genomics, immunology, animal behavior, human behavior, human development, and neurochemistry-pharmacology. The training program will enroll six postdoctoral fellows each year for a period of 2 years. The second program, located at the University of Minnesota Center for Neurobehavioral Development, is entitled "Postdoctoral Training in Neurobehavioral Development." This center will provide opportunities for trainees who have received a Ph.D. in child psychology, neuroscience, or developmental neuroscience-related disciplines (e.g., molecular or developmental biology) or an M.D. in various pediatric disciplines, such as neonatology, pediatric neurology, and child psychiatry. The motivation behind the creation of this program is to foster the development of junior investigators who can integrate research and theory in human behavioral development with explication of underlying neural circuitry and neurodevelopmental processes. A long-range goal is to create a discipline called neurobehavioral development. This program will initially admit three postdoctoral trainees.

#### b. Centers of Excellence

There continues to be progress within the Studies to Advance Autism Research and Treatment--STAART Centers Program. These efforts were initiated by the Children's Health Act of 2000,

which called for NIH to establish at least five Centers of Excellence in Autism Research. NIH has implemented a centers program that met and now 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 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. The six centers and their directors are the University of Washington, Geraldine Dawson, Ph.D.; the University of California, Los Angeles, Marian Sigman, Ph.D.; Boston University, Helen Tager-Flusberg, Ph.D.; the University of Rochester, Patricia Rodier, Ph.D.; the Kennedy Krieger Institute, Rebecca Landa, Ph.D.; and Mt. Sinai Medical School, Eric Hollander, M.D. 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.

The STAART Centers are contributing to the understanding of autism by investigating areas such as early detection through behavioral or biological markers, efficacy of early interventions, early course of core features, biological bases of the core deficits, efficacy of treatments for social deficits, efficacy trials for pharmacotherapy, genotype and phenotype of response to treatment, and identification of susceptibility genes. As a requirement to be in the STAART Network, each center has at least one treatment project. Collaborative projects include one multi-site psychopharmacology clinical trial launched in 2004 and another in the planning stages. Interaction with the CPEA network has also been established and includes a common imaging subcommittee, as well as a combined common measures/data sharing subcommittee. The CPEA and STAART Networks held a joint meeting in May 2004. A single data coordination center supports both CPEA and STAART Network functions.

NIH spent approximately \$13 million in total funds (direct costs and facilities and administration costs) in 2004 to support the STAART Centers Program. NIH funding supports the eight centers, the data coordination center, and the collaborative projects among the centers. The Steering Committee of the STAART Centers Program determines the exact nature of the cooperative studies.

c. Facilitation of Research

The Children's Health Act of 2000 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. NIH continues to undertake activities to increase the quality and availability of genetic and tissue resources to the autism research community. The NIMH Genetics Repository ([www.nimhgenetics.org](http://www.nimhgenetics.org)) 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 2004 included an administrative supplements program for

DNA collection in ongoing STAART Center projects. NIMH committed approximately \$720,000 over 4 years to support the collection of clinical data on and DNA of 240 new autism families, as well as of 435 affected individuals and their two parents already being studied at 5 STAART Centers (Yale University, Mt. Sinai School of Medicine, University of California - Los Angeles, University of North Carolina, and Boston University). The total sample to be collected includes nearly 1,700 subjects, of which 195 autistic individuals are enrolled in a new clinical trial. All data and biomaterials will be broadly shared with the scientific community through the NIMH Autism Genetics Initiative (also at [www.nimhgenetics.org](http://www.nimhgenetics.org)).

Rapidly evolving genomic technologies provide exciting opportunities for dissecting the genetic basis of autism. On March 12 and 13, 2004, four NIH Institutes (NIMH, NINDS, the National Human Genome Research Institute, and the National Institute of Diabetes and Digestive and Kidney Diseases) sponsored a meeting entitled "Gene Discovery in Complex Disorders: How to Proceed?" Leaders in the scientific fields of statistical genetics, molecular genetics, and the genetics of complex disorders were assembled to outline short- and long-term strategies for the effective use and analysis of several large family-based data sets for mental disorders. A major focus of the meeting was how best to conduct molecular genetic analyses in large autism data sets, including those broadly available to the scientific community through the Autism Genetic Resource Exchange (<http://www.familyagre.org/>) maintained by Cure Autism Now and the NIMH Autism Genetics Initiative ([www.nimhgenetics.org](http://www.nimhgenetics.org)). Another large autism data set is included in the Autism Genome Project (AGP), an international consortium of autism researchers assembled by the National Alliance for Autism Research (NAAR). Based on the recommendations from the March meeting, an autism genetics research collaboration was initiated between the AGP and the Center for Inherited Disease Research (<http://www.cidr.jhmi.edu/>), a molecular genetics laboratory based at Johns Hopkins University and supported by 12 NIH Institutes.

Knowledge on the molecular basis of Fragile X syndrome--a disorder with a known genetic basis in which approximately 25-30 percent of affected children also have autism--offers innovative new perspectives on understanding the etiology and pathophysiology of autism. On July 7-8, 2004, three NIH Institutes (NIMH, NICHD, NINDS) sponsored a meeting entitled "Autism and Fragile X: At the Crossroads." Analysis by the meeting participants of the accumulated scientific knowledge on Fragile X at multiple levels--cellular, circuit and brain region--provided valuable hints on possible shared mechanisms between autism and Fragile X. These NIH Institutes in partnership with private foundations are developing a research initiative to encourage studies focused on the overlap in neurobiology and shared etiologic mechanisms in autism, Rett syndrome, and Fragile X. A key feature of this initiative will include encouragement of research that aims to identify novel targets for the development of new compounds to treat autism.

This is a time of unparalleled opportunity as multiple Government agencies and private foundations are starting to work in a concerted way to stimulate autism research. Five NIH Institutes (NIMH, NINDS, NIDCD, NICHD, NIEHS), three institutes of the Canadian Institutes of Health Research (the Institute of Neurosciences, Mental Health and Addiction; the Institute of Human Development, Child and Youth Health; and the Institute of Genetics) and NAAR are developing a new research initiative (\$15 million over 5 years) to identify specific genes and



gene variants in localized chromosomal regions that produce susceptibility to autism. Fine mapping of disease loci is expected to occur in very large datasets of pre-existing samples that have high statistical power for fine mapping autism susceptibility loci. This groundbreaking initiative is expected to be launched later in 2005.

NINDS also 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 the use of a private Internet network linking the laboratories.

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 2004 continued to focus on a combined effort by NIMH, NINDS and NIDCD to supplement 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 grant reviewers. 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. The National Library of Medicine's MedlinePlus Web site has a focused health topic page on autism at <http://www.nlm.nih.gov/medlineplus/autism.html>. This is a searchable site with links to the latest news and information on diagnosis, treatment, current research, names of autism advocacy organizations, rehabilitation approaches, genetics, and specific conditions such as Rett syndrome. Much of the information is also available in Spanish through direct links from the English versions. The autism page also provides direct searches of the research literature in PubMed/MEDLINE, clinical studies in clinicaltrials.gov, and a separate health topic page on Asperger's Syndrome. See also:

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

<http://www.nimh.nih.gov/publicat/autismresfact.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/voice/autism.asp>

## **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 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 FY 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. These States are known collectively as the Autism and Developmental Disabilities Monitoring Network (ADDM Net). With FY 2001 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 FY 2003, 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. Congress provided a \$5,244,000 increase for autism surveillance and education activities in the FY 2004 appropriation for CDC (from \$10,811,000 to \$16,055,000). Of this amount, \$3,000,000 was directed towards CDC's surveillance activities (the other \$2,200,000 supports autism awareness activities described below in Section 103 of the Act). In addition to supporting CDC's model program for autism monitoring and research in Atlanta, this funding was used to enhance and support CDC's extramural autism research and monitoring activities, specifically bringing to full funding the three monitoring sites for which Congress provided initial funding in FY 2003. This will enhance their ability to establish population-based autism prevalence information in their regions and will contribute to our understanding of the national burden of autism, including 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.

With FY 2004 congressional appropriations for autism, CDC made additional investments in its autism extramural research infrastructure, which, when complete, will be able to carry out the largest study of autism ever conducted and provide important information on potential causes of autism and its effects on families and communities. These activities include the establishment of an autism data-coordinating center to improve efficiency and facilitate additional collaboration on autism research and enhanced funding for the five extramural CADDRE sites. These investments have allowed CDC to further develop the infrastructure needed for the large-scale collaborative study the network is uniquely positioned to carry out. In the interim, the sites are continuing to participate in population-based surveillance of autism and are conducting individual special studies on potential causes of autism.

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. It is training nurses, physicians, educators, and other providers of health and educational services to screen children for signs of developmental disabilities and ASDs.

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" (Section 102 (c)(1) of the Act).

As part of the Centers of Excellence in Autism and Pervasive Developmental Disabilities Epidemiology, CDC established 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 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/aic/about/default.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” (Section 102 (c)(2) of the Act).

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 I of the Children’s Health Act of 2000, 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 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 2004, the Maternal and Child Health Bureau's Division of Services for Children with Special Health Care Needs supported the development of comprehensive, coordinated, community-based service systems for children with autism and their families through two separate grant initiatives. A new 2004 grant recipient, the Waisman Center at the University of Wisconsin-Madison, will serve as a model of how comprehensive care, in the context of a medical home, can help promote

early identification and intervention for children with ASD. This newly funded program will also demonstrate the usefulness of increased surveillance in identifying other children with developmental delay. The Geisinger Health System in Danville, PA, a 2003 grant recipient, is developing a model of care and related set of tools that are being used for early detection, access to diagnostic and evaluation services, and continuity and appropriateness for care. Educational tools and models developed by both grantees will be disseminated to State programs and communities to strengthen and expand integrated community services for children with autism spectrum disorder. The 2004 budget for the program was \$1,200,000.

CDC has also launched a new activity in awareness and education. In FY 2003, CDC laid the groundwork for an autism awareness campaign, "Learn the Signs. Act Early." The focus of the campaign is to encourage early screening and detection of autism and other developmental disabilities in order to help children develop and reach their full potential. Congressional appropriations in FY 2004 for autism included approximately \$2,200,000 million to support autism awareness activities. These funds are being used to launch the campaign and to produce and disseminate materials to parents and providers, stressing the importance of early screening and intervention for children with disabilities, especially autism.

#### **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 NIH in April 2001. The NIMH at the NIH has been designated the lead for this activity. The Committee has held seven 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 (SAMHSA), 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/autismiacc/index.cfm>).

c. Activities

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

*IACC Services Subcommittee*

The Services Subcommittee is co-chaired by IACC members representing SAMHSA and HRSA. In similar fashion to the panel of experts who were brought together to develop a research matrix (see below), the Services Subcommittee convened a panel of expert workgroup members consisting of members from State programs that deal with autism, related service providers, physicians, educators, community program coordinators, consumers, and family members of persons with ASD to develop an Autism Services Roadmap. The expert workgroup convened in September 2004 and worked to address barriers, best practices, and service implementation in six areas outlined by the New Freedom Commission on Mental Health's initiative: build family and professional partnerships; provide early and continuous developmental and medical screenings; provide availability of all needed health, education, and social services and access to adequate public/private insurance or other financing mechanisms as well as easy access to community-based, coordinated service systems; and ensure youth transition to adult services, work, and independence. This Services Roadmap will serve as a companion to the IACC Research Matrix, submitted in an April 2004 report to Congress. The goal of the Roadmap is to review where the field of autism services is at this time and serve as a guiding plan to future services for persons with ASD. The draft Roadmap was presented to the IACC at the November 2004 meeting.

*IACC Screening Subcommittee*

The screening subcommittee has been actively engaged in activities to facilitate the implementation of screening practices into the community. It held a workshop, "Scientific Workshop on Developmental Screening," on April 22, 2004, bringing together experts in autism and screening to address roadblocks to improving screening practice.

*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, 2003. 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. The planning committee for this conference was composed of several Federal and public members of the IACC, and the meeting was officially cosponsored 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. A summary of this conference may be found at: <http://www.nimh.nih.gov/autismiacc/summitssummary.pdf>.

### *IACC Autism Research Matrix*

The House and Senate conferees considering the FY 2003 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." 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, the membership of the IACC approved the final version of the matrix on November 21, 2003. The Congressional Appropriations Committee Report on the State of Autism Research, summarizing the Autism Research Matrix and plans for implementation, was submitted in April 2004 and may be found at <http://www.nimh.nih.gov/autismiacc/CongApprCommRep.pdf>. The plan for implementation of the matrix has thus far included the April 2004 reissue of the program announcement "Research on Autism and Autism Spectrum Disorders" and the funding of projects that will advance individual matrix items. In addition, NIH sponsored a meeting in May 2004 to specifically address the need to improve outcome measures for treatment studies.

### **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 fifth annual report reflects HHS activities through November 2004.