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**Report to Congress on Activities Related to Autism Spectrum
Disorders and Other Developmental Disabilities Under the
Combating Autism Act of 2006 (FY 2006-FY 2009)**

**Prepared by the Office of Autism Research Coordination
National Institutes of Health
Department of Health and Human Services**

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Executive Summary

This Report to Congress is required by Public Law 109-416, the Combating Autism Act of 2006 (CAA). The report describes progress and expenditures made in autism spectrum disorder (ASD) research and services activities since the enactment of the CAA. Information from the following Federal departments, agencies, and offices that address ASD research or services is included:

- Department of Health and Human Services:
 - Administration for Children and Families (ACF)
 - Agency for Healthcare Research and Quality (AHRQ)
 - Centers for Disease Control and Prevention (CDC)
 - Centers for Medicare & Medicaid Services (CMS)
 - Health Resources and Services Administration (HRSA)
 - National Institutes of Health (NIH)
 - Office on Disability (OD)
 - Substance Abuse and Mental Health Services Administration (SAMHSA)
- Department of Education (ED)

In support of a coordinated Federal strategy for ASD research and services, the Combating Autism Act of 2006 reconstituted the Interagency Autism Coordinating Committee (IACC). Members include the above-listed HHS agencies (with the exception of AHRQ), the Department of Education and public members, including people with autism, parents of people with autism, leaders of national autism organizations, a researcher and a physician. This report provides a summary of the IACC's efforts, in addition to those of individual Federal agencies, over the past four years. These collaborative and coordinated efforts have served well to identify promising ASD research areas as well as to pinpoint both best-practices and gaps in ASD research and supports. Recent highlights in ASD research include the development of new diagnostic tools, identification of novel genetic and environmental risk factors, clinical trials of interventions, and measures of the efficacy and cost-effectiveness of evidence-based services for people with ASD. In addition to descriptions of Federal ASD-related research and services-related efforts, this report also presents current ASD prevalence estimates, the present diagnostic and intervention landscape, ongoing efforts to identify gaps in and develop effective new ASD supports and services programs, and forward-looking strategies to address the continuing needs of diverse ASD communities.

Introduction

Autism spectrum disorder (ASD) is characterized by impaired verbal and nonverbal communication skills and social interactions, and restricted, repetitive, and stereotyped patterns of behavior, ranging in impact from mild to significantly disabling. Two decades ago, ASD was a little known, uncommon disorder. Today, with prevalence estimates of 1 in 110 U.S. children being diagnosed with an ASD (CDC, 2009), this disorder has become a top national health priority, engaging the collaborative efforts of both Federal agencies and private organizations.¹

¹ Centers for Disease Control and Prevention. "Prevalence of Autism Spectrum Disorders - Autism and Developmental Disabilities Monitoring Network," United States, 2006, *MMWR SS*. 2009;58:1-20.

In 2006, Congress passed the Combating Autism Act to coordinate Federal ASD efforts, establishing a Federal advisory committee, the Interagency Autism Coordinating Committee (IACC), to provide advice to the Secretary of Health and Human Services (HHS) regarding matters related to ASD research and services, and to guide Federal agencies in several diverse program areas related to ASD.

The cost of ASD to affected people, families, and society is enormous. Children with ASD have a wide range of healthcare and services needs, and families with a child with autism typically lose income, possibly as a result of one parent leaving the workforce in order to care for and meet the special health and educational needs.¹ A great majority of adults with ASD struggle with ongoing and mostly unmet needs for employment, housing, services, and supports. The cost to society of ASD is currently estimated to be \$35-\$90 billion annually, the higher estimate being comparable to Alzheimer's disease.^{2,3} Although research on ASD has expanded over the past decade, there remains an urgent need for continuing research and development of services and supports programs to help families facing this challenge.

In response to the heightened societal concern over ASD, Congress passed the Combating Autism Act (CAA) of 2006 (P.L. 109-416). Through this Act, Congress intended to rapidly increase, accelerate the pace of scientific discovery in ASD research and to enhance coordination of Federal efforts to provide services and supports for people with ASD and their families.

The Purpose of the Report

Public Law 109-416, the Combating Autism Act of 2006 was signed into law on December 19, 2006. The CAA authorizes expanded activities related to autism spectrum disorder (ASD) research, surveillance, prevention, treatment, and education. Provisions of the CAA encourage the integration of health, education, and community services as well as ensure that citizens have a voice in ASD-related government activities. Specifically, the CAA:

- Expands, subject to availability of appropriations, and consolidates NIH research activities in ASD
- Authorizes a review of NIH-funded centers of excellence for autism research and epidemiology
- Establishes ASD surveillance and awareness programs under the CDC
- Increases Federal efforts in autism education, early detection, and intervention
- Establishes the Interagency Autism Coordinating Committee to coordinate all ASD-related efforts within the HHS and provide advice to the Secretary of Health and Human Services on matters pertaining to ASD
- Authorizes appropriations for Federal ASD-related efforts
- Requires a Report to Congress on progress in implementing the provisions of the CAA

¹ Montes, G. and Halterman J.S. (2008). "Association of childhood autism spectrum disorders and loss of family income." *Pediatrics* 121 (4), pp. 821-826.

² Ganz, M.L. (2007). "The Lifetime Distribution of the Incremental Societal Costs of Autism." *Archives of Paediatrics and Adolescent Medicine* 161 (4), pp. 343-9.

³ Knapp, M. et al. (2009). "Economic Cost of Autism in the UK." *Autism* 13 (3), pp. 317-336.

Section 399DD states, “Not later than 4 years after the Combating Autism Act of 2006, the Secretary in coordination with the Secretary of Education, shall prepare and submit to the Health, Education, Labor, and Pensions Committee of the Senate and the Energy and Commerce Committee of the House of Representatives a progress report on the activities related to autism spectrum disorder and other developmental disabilities.”

Public Law 109-416 is available at: http://frwebgate.access.gpo.gov/cgi-bin/getdoc.cgi?dbname=109_cong_public_laws&docid=f:publ416.109.pdf.

As stated in the CAA, the report submitted shall contain—

- (1) “A description of the progress made in implementing the provisions of the Combating Autism Act of 2006”
- (2) “A description of the amounts expended on the implementation of the particular provisions of Combating Autism Act of 2006”
- (3) “Information on the incidence of autism spectrum disorder and trend data of such incidence since the date of enactment of the Combating Autism Act of 2006”
- (4) “Information on the average age of diagnosis for children with autism spectrum disorder and other disabilities, including how that age may have changed over the 4-year period beginning on the date of enactment of this Act”
- (5) “Information on the average age for intervention for individuals diagnosed with autism spectrum disorder and other developmental disabilities, including how that age may have changed over the 4-year period beginning on the date of enactment of this Act”
- (6) “Information on the average time between initial screening and then diagnosis or rule out for individuals with autism spectrum disorder or other developmental disabilities, as well as information on the average time between diagnosis and evidence-based intervention for individuals with autism spectrum disorder or other developmental disabilities”
- (7) “Information on the effectiveness and outcomes of interventions for individuals diagnosed with autism spectrum disorder, including by various subtypes, and other developmental disabilities and how the age of the child may affect such effectiveness”
- (8) “Information on the effectiveness and outcomes of innovative and newly developed intervention strategies for individuals with autism spectrum disorder or other developmental disabilities”
- (9) “Information on services and supports provided to individuals with autism spectrum disorder and other developmental disabilities who have reached the age of majority (as defined for purposes of section 615(m) of the Individuals with Disabilities Education Act (20 U.S.C. 1415(m))”

Two Federal departments and many Federal agencies and offices that address ASD research or services have contributed information provided in this Report to Congress, including: Administration for Children and Families (ACF), Agency for Healthcare Research and Quality (AHRQ), Centers for Disease Control and Prevention (CDC), Centers for Medicare & Medicaid Services (CMS), Department of Education (ED), HHS Office on Disability (OD), Health Resources and Services Administration (HRSA), Substance Abuse and Mental Health Services Administration (SAMHSA), five Institutes of the National Institutes of Health (NIH), and the NIH Director. Information sharing and Federal coordination on ASD-related activities has been greatly facilitated by the Interagency Autism Coordinating Committee (IACC). This report

begins with a summary of the IACC's role in the strategic coordination of Federal ASD efforts and the reciprocal communication of ASD relevant issues to the public. The subsequent chapters address each of the 9 sections required in the report by the CAA.

Interagency Coordination: The Role of the Interagency Autism Coordinating Committee

In 2006, Congress established the Interagency Autism Coordinating Committee (IACC) under the Combating Autism Act (P.L. 109-416) to provide advice to the Secretary of Health and Human Services (HHS) concerning issues related to autism spectrum disorder (ASD) and coordinate all ASD-related efforts within HHS. The committee was initially formed under the Children's Health Act of 2000, and was reauthorized under the CAA as a Federal advisory committee, subject to the Federal Advisory Committee Act (FACA), with specific membership requirements.

The Combating Autism Act (CAA) outlines the membership of the IACC, which includes both representatives of Federal agencies and public members representing a variety of stakeholder groups within the autism community. Currently, IACC membership includes two people with ASD, several parents of children with ASD, members of the ASD advocacy, research, and service provider communities, and officials from the following Federal agencies and offices that address ASD research or services: Centers for Disease Control and Prevention (CDC), Centers for Medicare & Medicaid Services (CMS), Department of Education (ED), HHS Office on Disability (OD), Substance Abuse and Mental Health Services Administration (SAMHSA), Administration for Children and Families (ACF), Health Resources and Services Administration (HRSA), five Institutes of the National Institutes of Health (NIH), and the NIH Director. Through its inclusion of both Federal and public members, the IACC helps to ensure that a wide range of ideas and perspectives are represented and discussed in a public forum. The Office of Autism Research Coordination (OARC) at the National Institute of Mental Health, NIH, was established shortly after the formation of the current IACC to provide the committee with logistical coordination and policy and communications support.

Under the CAA, the IACC is responsible for developing and annually updating a strategic plan for ASD research and for developing an annual summary of research advances in the ASD field. In fulfilling these requirements, the committee has produced two strategic plans for ASD research in 2009 and 2010, and three reports summarizing research advances in 2007, 2008, and 2009. In order to monitor Federal ASD research, as is also required by the CAA, the Office of Autism Research Coordination, on behalf of the committee, conducted a comprehensive analysis of the ASD funding landscape in 2008, with another analysis soon to be completed for 2009 funding. These reports include detailed information about research being conducted by both Federal agencies and private funders in the U.S. and analyze the correspondence of the research projects to the topics and specific objectives laid out in the IACC Strategic Plan. These portfolio analysis documents provide a valuable tool to the committee for tracking research progress in relation to the Strategic Plan.

In addition to the full committee, the IACC has three subcommittees:

- **The IACC Services Subcommittee** – which addresses issues related to services and supports for people with autism and their families.

- **The IACC Subcommittee for Planning the Annual Strategic Plan Updating Process** – which develops processes and plans activities related to the annual strategic plan update.
- **The IACC Safety Subcommittee** – which addresses issues related to individual and community safety for people with ASD.

The IACC and its subcommittees meet frequently, having convened 20 meetings in 2008, 17 meetings in 2009, and 16 meetings in 2010, including full committee meetings, subcommittee meetings, town hall gatherings, scientific workshops and planning workgroups.

More information about the IACC is available at: <http://iacc.hhs.gov/>.

Strategic Plan for ASD Research

The Strategic Plan for ASD Research is an important part of the IACC’s mandate to advise the Secretary of HHS on gaps, opportunities, and new knowledge in the autism research field. It also serves as the basis for partnerships with other Federal agencies and private organizations involved in autism research and services. The first version of the plan was finalized in January 2009 and is organized around six questions that are critical for families with ASD:

- (1) When should I be concerned?
- (2) How can I understand what is happening?
- (3) What caused this to happen and can it be prevented?
- (4) Which treatments and interventions will help?
- (5) Where can I turn for services?
- (6) What does the future hold?

In 2010, a seventh question, titled “What other infrastructure and surveillance needs must be met?”, was added to the Strategic Plan at the time of its update, and Question 6 was amended to read, “What does the future hold, *particularly for adults?*”

Each question addresses what is currently known in each area of research, what is currently needed in each area, and what research opportunities and specific objectives the committee has identified for each area. Objectives are classified as long or short-term and include a recommended budget figure. In total, the 2009 plan included 40 research objectives spanning a wide array of research topics, including: the development of new diagnostic tools; completing longitudinal and comprehensive studies of the biological, clinical, and developmental profiles of children; identifying genetic and environmental risk factors; conducting clinical trials of interventions; and assessing the efficacy and cost-effectiveness of evidence-based services for people with ASD of all ages in community settings. The total recommended budget for the 2009 plan was \$791,150,000 over multiple years.

The 2010 IACC Strategic Plan for ASD Research added 32 “new” objectives (including some 2009 objectives that were significantly re-worded) to address areas such as the need for additional research focus on adults with ASD, non-verbal individuals, and those with cognitive impairments. The 2010 plan also includes a new seventh chapter on building research infrastructure and improving surveillance. Other new objectives cover topics such as health

disparities in early diagnosis, characterization of children with reported regression, and the biology and treatment of co-occurring conditions, such as epilepsy and sleep and gastrointestinal disorders. The additional chapter on infrastructure development includes objectives aimed at enhancing the ASD research workforce, data sharing, surveillance programs, biological specimen repositories, and the communication and implementation of research findings. The 2010 Strategic Plan includes a total of 62 research objectives and calls for a total recommended budget of \$961,890,500 over multiple years.

The 2009 and 2010 IACC Strategic Plan for ASD Research are available at:

<http://iacc.hhs.gov/strategic-plan/2009/>

<http://iacc.hhs.gov/strategic-plan/2010/index.shtml>

The IACC Summary of Advances in ASD Research

From 2007 to 2009, the Office of Autism Research Coordination, on behalf of the IACC, has produced an annual summary of the advances in biomedical and services research identified by the committee as having made the greatest impact on the field of autism. The Summary of Advances is organized by the questions of the Strategic Plan, and the number of studies selected has varied from 54 in 2007 to 20 in the 2009 document. The 2009 Summary of Advances includes selections related to parent training to manage behavioral issues, the association between family history of autoimmune diseases and ASD, genetic risk factors, increasing prevalence rates, racial disparities in ASD identification, and the impact of parental age on ASD risk. To provide the timeliest material for updating the Strategic Plan, the members of the IACC have decided to select articles for the Summary of Advances on a biannual basis. The 2010 mid-year selection was completed in August 2010, with the completion of the final document expected in 2011.

The IACC Summary of Advances (2007-2009), as well as the complete list of articles nominated, is available at: <http://iacc.hhs.gov/summary-advances/2009/index.shtml>.

The IACC ASD Research Portfolio Analysis

In 2009, the Office of Autism Research Coordination, on behalf of the IACC, conducted a comprehensive analysis of the ASD research portfolios of major Federal agencies and private organizations covering fiscal year (FY) 2008. The analysis was conducted to better inform the committee and interested public about the funding landscape for ASD research and how currently funded research corresponds to the priorities laid out in the 2009 IACC Strategic Plan for ASD Research. The information provided by the portfolio analysis has served as a valuable guide to both Federal agencies and private research organizations, defining the current research funding landscape and guiding future funding priorities by highlighting current gaps and opportunities in ASD research. To complete the analysis, the IACC requested data from 11 Federal and 8 private stakeholders, 13 of whom reported funding ASD research in 2008. In total, these stakeholders contributed \$222,322,460 across 745 projects. The National Institutes of Health (NIH) contributed the largest amount of research funding in 2008, spending \$118,076,888

on 340 projects,¹ followed by the Simons Foundation with 77 projects totaling \$42,985,684. Autism Speaks ranked third with \$30,828,116 spent across 200 projects. The 2009 IACC ASD Research Portfolio Analysis, covering data from fiscal year 2009, is currently underway and will be released to the public in 2011.

The report on the 2008 IACC ASD Research Portfolio Analysis is available at:

<http://iacc.hhs.gov/portfolio-analysis/2008/index.shtml>.

A public draft of the 2009 IACC ASD Research Portfolio Analysis Report is available online at:

<http://iacc.hhs.gov/events/2010/102210/materials.shtml>.

Public Engagement and Transparency

The IACC has made substantial efforts to engage the public in their activities and enhance overall transparency of the committee's activities. Between 2007 and 2010, the committee, in conjunction with the Office of Autism Research Coordination, has released five **Requests for Information (RFI)** to solicit public input on establishing and updating the Strategic Plan and identifying priorities for ASD services. During the 2010 updating process, the committee received 290 responses to the RFI (NOT-MH-09-013) from people self-identified with ASD, parents or relatives of a person with ASD, professionals involved in the diagnosis, care, and/or education of people with ASD, and researchers in ASD and other fields. These public responses were reviewed and taken into consideration during the process for planning the annual Strategic Plan update. The most recent RFI (NOT-MH-10-025) asked for public comment on gaps in the 2010 Strategic Plan and new knowledge that has been gained since its release. The committee received 53 responses. The public input gathered is being used to inform committee activities, including the 2011 update of the IACC strategic plan. Full text responses and/or summary of responses to all IACC RFIs have been made available to the public on the IACC website.

A complete list of RFIs and public responses is available at: <http://iacc.hhs.gov/public-comment/2010/index.shtml>.

The committee has also held two town hall meetings to provide an open forum to allow members of the public to share their experiences, concerns and perspectives with IACC members. The first was held on May 3, 2008, at the University of California, Davis, to gather input into research priorities for the treatment of ASD. Another town hall meeting on the topic of ASD services was held in St. Charles, Illinois, on July 24, 2009, in collaboration with the Autism Society, a major national autism advocacy organization.

The Office of Autism Research Coordination also maintains an extensive website for the IACC in order to facilitate the ability of the public to access information about the committee, committee activities and publications. The IACC website currently posts the agenda, minutes,

¹ The NIH project number stated here reflects unique NIH projects. For the purposes of the 2008 IACC Portfolio Analysis of ASD Research, in cases where a single research project was funded by more than one NIH institute ("co-funded"), the co-funds were combined and only counted as a single project. This approach differs from that used in the NIH RePORTER system, where each co-fund is counted as a separate project so that individual institute spending can be tracked. The official NIH project number from the RePORT website for 2008, in which institute co-funds for ASD projects are each counted separately, is 421 projects.

and transcripts from every meeting of the IACC and its subcommittees, as well as reports and publications produced by the committee. The website has also begun to post meeting materials and meeting slides and will continue to add new categories of IACC materials for public access in the future. In addition, the OARC began conducting live webcasts of all full committee meetings and then archiving them on the site to enhance public access and participation in meetings. To provide rapid notification of upcoming meetings and committee news, the IACC disseminates information through electronic mail listservs, the microblogging site Twitter, and a recently added RSS feed of events from the IACC website. As a Federal advisory committee, the IACC complies with the Federal Advisory Committee Act (FACA) to ensure that every in-person meeting of the committee or subcommittees is open to the public, and several remote access options are available at each meeting to enable the public to listen to or watch proceedings through conference calls, webcasts or webinars. Committee and subcommittee meetings conducted by conference call only are also made accessible to the public via a call-in number.

Through these various means of actively gathering public input, providing public access to meetings and calls of the IACC, providing public access to IACC documents, and disseminating information about IACC events and products, the IACC provides numerous opportunities for public involvement and continues to enhance the transparency of committee decision-making.

Archived webcasts of IACC meetings can be viewed at: <http://videocast.nih.gov/> or can be accessed from the IACC Meetings and Events webpage at: <http://iacc.hhs.gov/events/>.

Required Report Elements

The following chapters of this Report addresses the 9 required elements outlined in the CAA. Elements (1) and (2) have been combined into one chapter covering the general progress made and amounts expended during the past 4 years in Federal ASD research efforts by lead agencies and offices within the Department of Health and Human Services (HHS), including: Centers for Disease Control and Prevention (CDC), Centers for Medicare & Medicaid Services (CMS), Office on Disability (OD), Health Resources and Services Administration (HRSA), the National Institutes of Health (NIH), and the Substance Abuse and Mental Health Services Administration (SAMHSA). In addition to these lead agencies, a number of other Federal agencies and one department provided supporting information when applicable, including: Administration for Children and Families (ACF), Agency for Healthcare Research and Quality (AHRQ), and the Department of Education (ED).

ASD Progress and Budget Expenditures: Agency Overviews

This chapter covers subsections (1) and (2) of Section 399DD, which require: (1) “A description of the progress made in implementing the provisions of the Combating Autism Act of 2006”, and (2) “A description of the amounts expended on the implementation of the particular provisions of the Combating Autism Act of 2006.” Details are provided from the lead HHS agencies and offices for ASD research and services, including Centers for Disease Control and Prevention (CDC), Centers for Medicare & Medicaid Services (CMS), Office on Disability (OD), Health Resources and Services Administration (HRSA), the National Institutes of Health (NIH), and the Substance Abuse and Mental Health Services Administration (SAMHSA). In addition,

information was provided by the Department of Education (ED), which coordinates with HHS on issues related to autism and serves as a member of the IACC.

Centers for Disease Control and Prevention (CDC)

CDC brings a unique epidemiologic perspective to the quest to fully understand Autism Spectrum Disorders (ASDs). This perspective includes reporting data on the occurrence of ASDs, contributing to the understanding of risk and protective factors, and dissemination of information on effective prevention strategies, when available. CDC conducts both intramural and extramural activities and partners with grantees, Federal and State governments, and other stakeholders in these activities. CDC also serves on the IACC and all three of its subcommittees. Recognizing the importance of CDC's unique public health role, the Children's Health Act of 2000 established a scientific infrastructure at CDC for conducting population-based ASD monitoring and research. The Combating Autism Act of 2006 (CAA) further strengthened and expanded this infrastructure, affording CDC the ability to conduct ongoing monitoring of ASDs over time and across multiple geographic regions of the United States. Since 2006, the **Autism and Developmental Disabilities Monitoring (ADDM)** Network has published the most comprehensive estimates to date of the prevalence of ASDs in multiple areas of the U.S. The CAA also supported the implementation of a major, multisite collaborative study conducted by the **Centers for Autism Developmental Disabilities Research and Epidemiology (CADDRE)**, examining what might put children at risk for ASDs and other developmental disabilities. The CAA supported expansion of surveillance to include younger children with ASD and has supported ongoing international efforts through collaboration with Denmark to broaden our understanding of ASDs. The CAA further strengthened the capacity of CDC's health communication campaign, "**Learn the Signs. Act Early.**" (**L TSAE**) in educating parents, health care professionals, and early educators about the importance of monitoring a child's developmental milestones, seeking further evaluation when there is a concern and beginning early intervention services as soon as possible.

In the time since the enactment of the CAA, CDC has built critical infrastructure to further advance our understanding of ASDs and has seen these efforts come to fruition. CDC has coordinated the ADDM Network to characterize the prevalence and population characteristics of children with ASDs in collaboration with State Health Departments or their representatives. The ADDM Network currently conducts surveillance of ASDs and other developmental disabilities in 12 geographic areas of the United States. In 2007, CDC published the first estimate of ASD prevalence across multiple areas of the U.S., establishing the most comprehensive prevalence estimates of the spectrum of autism conditions based on modern criteria. In 2009, CDC followed this publication with a second report of prevalence. Together these reports have informed the understanding of ASD prevalence and the characteristics of children with ASD. They are routinely used to inform policy, improve service provision, and to conduct further analyses to understand ASDs among the population. The ADDM Network has now published two prevalence reports, covering a six year span of time, including children who were born in the 1990's and forward. A robust dataset now exists which can be used to examine trends in ASD prevalence over time. In addition, these data have been used to better characterize who may be at greater risk for an ASD (see Appendix i for a full list of CDC-supported ASD publications.).

In addition to ongoing population based monitoring of ASDs, the CDC's CADDRE Network has been successful in implementing the **Study to Explore Early Development (SEED)**, the largest collaborative scientific study planned to date of the causes of autism. Starting in 2006 to the present, CADDRE established and implemented this study across six sites in the U.S. SEED seeks to characterize the autism behavioral phenotype and associated developmental, medical, and psychiatric conditions of autism and to understand the genetic and environmental risk factors for autism with a special focus on immunological, hormonal, gastrointestinal, and sociodemographic features. By the end of 2010, SEED will have enrolled more than 2,700 children and their families, and initial findings are due to be released in early 2012. These results hold promise for greatly advancing our understanding of ASD etiologies.

CDC is also involved in awareness activities through the "*Learn the Signs. Act Early.*" health communication campaign. Campaign efforts are helping to change perceptions about the importance of identifying developmental concerns early and give parents and professionals the tools to help. Since the start of the campaign in October 2004, resources provided by "*Learn the Signs. Act Early.*" have been made available to over 11 million health care professionals, parents, partners, campaign champions, and child care providers. Other LTSAE activities include: the **Act Early Regional Summits**, with support from Health Resources and Services Administration (HRSA) and the Association of University Centers on Disabilities (AUCD), bringing together State-level leaders from advocacy, early intervention, education, medical, and other systems to increase collaboration and coordination among programs and services for children with autism and other developmental disabilities; and the funding of 10 extramural research projects to learn more about overcoming barriers to action by parents when a delay has been identified, why disparities in identification exist among African-Americans and Hispanics and how to reduce them, and how to measure screening, referral, and entry into early intervention services.

Finally, CDC, in partnership with the Department of the Army, is testing the theory that certain antibodies in pregnant women and infants may cause alterations in the development of the fetal brain that lead to ASDs. The types of antibodies CDC will investigate are those that react both with microbial antigens and with nerve or endocrine tissue antigens. In the **Blood Spot Project**, CDC will utilize heel stick blood samples that have been archived with consent for use in retrospective research studies. In order to determine whether the developing fetus has been exposed to cross-reactive antibodies, CDC will test archived spots (DBS) of newborn children who later developed autism and others who developed normally and did not develop autism. If the theory is correct, samples from children who develop autism will have higher levels of antibody that bind strongly to brain tissue antigens, in which case the findings of our study will aid in early diagnosis, allowing for development of possible intervention significantly impacting the research and contributing to a better understanding of the cause and eventually treatment or prevention of this often devastating brain disorder.

Table 1. CDC ASD-related budget expenditures from FY 2006-FY 2009*

CDC Autism Expenditures	FY 2006	FY 2007	FY 2008	FY 2009
Autism/Infant Health	\$15,333,483	\$15,176,472	\$16,297,110	\$19,864,294
Autism Awareness (Learn the Signs)	\$2,632,099	\$2,565,810	\$2,565,810	\$2,415,359
Blood Spot Project**	—	—	—	\$125,000
Total	\$17,965,582	\$17,742,282	\$18,862,920	\$22,404,653

* These expenditures include costs associated with both autism and other CDC program dollars in support of the Combating Autism Act of 2006 on autism and other developmental disabilities. CDC has reported spending on programs utilizing only autism program dollars to the Interagency Autism Coordinating Committee in a separate report.

** The autism program dollars do not provide funding for the Blood Spot Project.

Below is a description of specific CDC programs supported by the CAA:

- Metropolitan Atlanta Developmental Disabilities Surveillance Program (MADDSP):** Ongoing and systematic monitoring of prevalence of selected developmental disabilities (intellectual disability, hearing loss, vision impairment, cerebral palsy, and autism spectrum disorders) according to various demographic characteristics of children who reside in metropolitan Atlanta. MADDSP serves as the model for the Autism and Developmental Disabilities Monitoring (ADDM) Network and participates as a site in this collaboration. *More information is available at: <http://www.cdc.gov/ncbddd/dd/maddsp.htm>.*
- Autism and Developmental Disabilities Monitoring (ADDM) Network:** The ADDM Network is a collaborative project to characterize the population prevalence and characteristics of children with an ASD and other developmental disabilities. Cooperative agreements to conduct ADDM Network activities have been awarded to State Health Departments or their representatives to develop and improve programs that track the number of children with ASDs in their States. The ADDM Network currently conducts surveillance of ASDs and other developmental disabilities in 12 geographic areas of the United States. The ASD surveillance methodology for the ADDM Network focuses on lifetime prevalence of children who are eight years old in a given surveillance year. *More information is available at: <http://www.cdc.gov/ncbddd/autism/addm.html>.*
- Autism Spectrum Disorder Surveillance of Younger Children: (Pilot Alternative Surveillance):** In fiscal year 2006, CDC established a pilot project to investigate the feasibility of combining developmental screening and monitoring prevalence of ASD for children under the age of 4 years. Two sites (Florida and California) were funded to assess the feasibility of monitoring early signs of ASD. While these projects utilized direct screening versus the record review methodology utilized by the ADDM Network, it has been successful in showing that early ASD surveillance is feasible in helping us better understand the early identification of children with ASD. FY 2010 is the final year for these pilot projects, but has provided the support to add a new component to the ADDM Network

monitoring ASD prevalence and characteristics among children who are 4 years of age (see Early ADDM below).

- **Early ADDM Network:** In fiscal year 2010, CDC provided supplemental funding to six ADDM sites to track the prevalence of ASD among younger children (4-year-olds) using ADDM methods. These efforts have expanded surveillance focusing on younger cohorts to better understand the population characteristics of young children affected by ASDs and to increase awareness of ASDs in young children that will lead to improvements in early identification efforts. The Early ADDM Network will also allow for follow-up of the same cohorts of children when the children are 8 years of age in the ongoing ADDM Network surveillance activities.
- **Study to Explore Early Development (SEED):** This is a 5-year, multisite collaborative study, conducted by the Centers for Autism and Developmental Disabilities Research and Epidemiology (CADDRE), examining what might put children at risk for ASDs and other developmental disabilities. SEED will be the largest collaborative scientific study to date of the causes of autism. It will include about 2,700 children, 2 through 5 years of age, as well as their parents and includes diverse groups from six areas across the county. *More information is available at: <http://www.cdc.gov/ncbddd/autism/seed.html>.*
- **Denmark Collaboration:** The CDC-Denmark Program was established to examine a variety of public health issues including ASDs and other developmental disabilities – drawing on the unique research resources in Denmark. Denmark has a combination of national public health data systems currently in place that are not found elsewhere in the U.S. or abroad. This unique combination includes more than 200 long established national disease and administrative registries and a complete bio-bank of archived newborn blood samples of all children born in Denmark from 1982 and onwards. This collaboration has been fruitful and has added greatly to our understanding of ASDs.
- **“Learn the Signs. Act Early.”:** This health communication campaign aims to improve early identification of children with autism and other developmental disabilities so they can get the services they need. Many children with a developmental disability are not identified until after entering school; however, early intervention can have a significant impact on a child’s ability to learn new skills. CDC’s program promotes awareness of healthy developmental milestones in early childhood; promotes early identification of signs of delay; and works with State and national partners to enhance coordination of efforts at the State level to improve screening and referral to early intervention services. *More information is available at: <http://www.cdc.gov/ncbddd/actearly/index.html>.*

A complete list of CDC-supported published studies on ASD from 2006-2010 is provided in Appendix i.

Centers for Medicare & Medicaid Services (CMS)

CMS' involvement in implementing the CAA in FYs 2006-2010 is focused on Sections 399BB and 399CC, "Autism Education, Early Detection, and Intervention" and "Interagency Autism Coordinating Committee." A CMS official is appointed to the IACC, is a member of the Subcommittee for Planning the Annual Strategic Plan Updating Process, and co-chairs the Services Subcommittee.

Regarding Section 399BB, CMS has supported items (a)(1) and (6) and also item (c)(v). The former discusses awareness of ASD and evidence-based interventions for people with ASD or other developmental disabilities. The latter specifically references "programs under title XIX of the Social Security Act (Act) (particularly the Medicaid Early and Periodic Screening, Diagnosis and Treatment Program (EPSDT))."

In 2007, CMS issued three "**Promising Practices**" papers on ASD. The Papers describe California's Single Process for Early Diagnosis and Service Delivery, Connecticut's Pilot Program for Non-Medicaid Eligible Young Adults with ASD and Delaware's Supported Employment Program for Adults with ASD. *These Promising Practices reports are available at:*

<http://www.cms.gov/PromisingPractices/Downloads/CA-CollaborativeClinics6-7.pdf>.

<http://www.cms.gov/PromisingPractices/Downloads/ConnecticutPromisingPractices8-3.pdf>.

<http://www.cms.gov/PromisingPractices/Downloads/DelawarePromisingPractices6-11.pdf>.

In 2010, CMS issued a report entitled "**Autism Spectrum Disorders (ASD) Services Final Report on Environmental Scan,**" the result of a comprehensive review of scientific evidence regarding the efficacy, effectiveness, safety, and availability of ASD-related psychosocial services and supports for children, transitioning youth, and adults with ASD, including data on the evidence based interventions for people with ASD across the lifespan and data on the costs associated with providing services to people with ASD. *CMS' Final Report on Environmental Scan is available at:* <http://www.impaqint.com/files/4-content/1-6-publications/1-6-2-project-reports/finalasdreport.pdf>.

CMS administers the Medicaid program, Title XIX of the Act, which includes **Early and Periodic, Screening, Diagnostic and Treatment (EPSDT)**. The EPSDT benefit entitles children enrolled in Medicaid under age 21 to a comprehensive package of preventive health care and medically necessary services. EPSDT includes screening, vision, dental, and hearing services as well as "[s]uch other necessary health care, to correct or ameliorate defects and physical and mental illnesses and conditions discovered by the screening services, whether or not such services are covered under the [Medicaid] State plan." The EPSDT benefit includes all mandatory and optional services in Section 1905(a) of the Act such as physical therapy, occupational therapy, speech therapy, and rehabilitative services. CMS is in the process of establishing a workgroup for stakeholders to provide input on the EPSDT program and data reporting. CMS has increased training for its EPSDT regional coordinators and other staff to ensure State compliance with the full array of services required for children served under EPSDT.

CMS expended approximately \$10,000 on the three Promising Practices papers issued in 2007. CMS expended approximately \$206,000 in 2009 and \$179,000 in 2010 related to activities for the Environmental Scan and other general ASD project preparation activities completed in 2010. Approximately \$75,000 has been expended in 2010 on activities related to the nine-State study. CMS has also spent approximately \$175,000 in 2010 related to activities surrounding a future report, the “**State of the States on ASD,**” scheduled for completion in 2011. This report will assess existing State programs and supports for families living with ASD in 50 States and the District of Columbia, providing a comprehensive view of services available through State program across the country. This project is included as an objective in Chapter 7 of the IACC 2010 Strategic Plan.

Office on Disability (OD)

Under the Combating Autism Act (CAA), the Office on Disability, under the Office of the Secretary of Health and Human Services, does not receive any appropriations, and therefore has no direct program or research responsibilities funded by CAA. However, the Office on Disability indirectly serves and supports people with autism in several ways through coordination of efforts and resources across the U.S. Department of Health and Human Services. The Office on Disability is primarily a policy office and its initiatives are organized around the following three themes: a) Improve Access to Community Living Services and Supports; b) Integrate Health Services and Social Supports; and, c) Provide Strategic Support on Disability Matters. Under these themes the office works across Federal agencies to streamline and coordinate programs that improve the lives of people with disabilities including expanding access to home and community-based services and support. The Office on Disability endorses, therefore, the efforts and initiatives reported by HHS agencies.

The Office on Disability is leading a new initiative on Comparative Effectiveness Research, which was awarded on May 5, 2010, funded under the American Recovery and Reinvestment Act of 2009, as a 2-year contract mechanism awarded to Mathematica Policy Research Inc. in the amount of approximately \$7 million. A **Center of Excellence for Research on Disability Services, Care Coordination, and Integration** has been established to create data infrastructure to support and conduct comparative effectiveness research on health services and supports for people with disabilities. This initiative directly links to health reform provisions related to improving health care quality programs through the development of a national strategy for quality improvement in health care and the expansion of health care delivery system research including person centered outcomes research. This initiative may also provide relevant information that can be used to improve community living for people with disabilities. To date the following has been accomplished: a data-user agreement has been signed with CMS to allow the center to use CMS Chronic Conditions Data Warehouse; a systematic review of the literature on home and community-based services, care coordination and integration is ongoing; a Web site has been launched. Building data infrastructure will allow for future development of a health services research agenda around access and quality of services and supports provided to people with autism. To date, tasks and deliverables under the initiative are on time.

More information is available at: <http://www.hhs.gov/od/cerds.html>.

Health Resources and Services Administration (HRSA)

Under the Combating Autism Act of 2006 (CAA), the Health Resources and Services Administration (HRSA)'s Maternal and Child Health Bureau (MCHB) received funding to address five CAA objectives to: 1) increase awareness of autism spectrum disorder (ASD) and other developmental disabilities (DD); 2) reduce barriers to screening and diagnosis; 3) support research on evidence-based interventions; 4) promote the development of guidelines for evidence-based practices; and 5) train health care professionals to use valid, reliable screening tools, to confirm or rule out an ASD diagnosis and, if diagnosis is confirmed, to provide evidence-based, early intervention. HRSA's MCHB was awarded approximately \$37 million in FY 2008 and approximately \$42 million in FY 2009 to implement the CAA. However, this included a transfer of approximately \$20 million of **Special Projects of Regional and National Significance (SPRANS)** funds to the **Autism and Other Developmental Disorders** program. To meet these objectives, MCHB developed and implemented the **Combating Autism Act Initiative (CAAI)**. This initiative is designed to combat ASD and other DD through research, training, and the development of State-level infrastructures that improve access to health care services for children with ASD and other DD. CAAI funding was provided to four separate but interrelated program areas: **1) Leadership Education in Neurodevelopmental Disabilities (LEND)** training programs, **2) Developmental Behavioral Pediatric (DBP)** training programs, **3) State Implementation Programs**, and the **4) Research Programs**. Table 2 includes a brief description of these four grant programs with amounts expended in FY 2008 and 2009.

More information is available on the following websites:

<http://www.mchb.hrsa.gov/training/projects.asp?program=9>.

<http://www.mchb.hrsa.gov/training/projects.asp?program=6>.

<http://mchb.hrsa.gov/autism/states/default.htm>.

<http://mchb.hrsa.gov/autism/research/default.htm>.

Table 2. HRSA/MCHB activities and amounts expended under the CAAI.

TRAINING PROGRAMS	
<i>Leadership Education in Neurodevelopmental Disabilities (LEND) training programs</i>	FY 2008: 18 existing grantees received additional funding of approximately \$200,000 each per year for 3 years to focus on ASD and other DD and 4 new LEND programs were funded at approximately \$550,000 per year for 3 years. FY 2009: 16 existing LEND grantees received additional funding of approximately \$100,000 per year for 2 years and 1 new LEND was funded at \$450,000 per year for 2 years.
<i>Developmental Behavioral Pediatrics (DBP) training programs</i>	FY 2008: 6 existing DBP grantees received additional funding of approximately \$50,000 per year for 3 years to focus on ASD and other DD.
In addition to these grants, HRSA/MCHB awarded approximately \$500,000 FY 2008 and \$550,000 in FY 2009 to establish a National Combating Autism Interdisciplinary Training Resource Center to coordinate the training program grantees, provide technical assistance to the training programs, and to ensure coordination between CAAI projects.	

RESEARCH PROGRAMS

MCH Autism Intervention Research Network on Physical Health (AIR-P)

FY 2008: The General Hospital Corporation of Boston received \$4 million per year for 3 years to conduct research on interventions to improve the physical health and well-being of children and adolescents with ASD and other DD.

MCH Autism Intervention Research Network on Behavioral Health (AIR-B)

FY 2008: The Regents of the University of California at Los Angeles received \$2 million per year for 3 years to conduct research on the behavioral, mental, social, and/or cognitive health and well-being of children and adolescents with ASD and other DD.

MCH Autism Intervention Research Program

FY 2009: 5 grantees received funds of approximately \$400,000 per year for 2 years to conduct research leading to improvements in interventions that address the health and well-being of children and adolescents with ASD and other DD.

MCH Autism Intervention Secondary Data Analysis Studies Program (SDAS)

FY 2009: 2 grantees received funds of approximately \$100,000 to conduct research leading to improvements in interventions that address the health and well-being of children and adolescents with ASD and other DD utilizing existing secondary data.

STATE IMPLEMENTATION PROGRAMS

State Implementation Grantees

FY 2008: 6 States received funds of approximately \$300,000 per year for 3 years to implement State autism plans and develop models for systems of services for children with ASD and other DD.

FY 2009: 3 States received funds of approximately \$300,000 per year for 2 years to implement State autism plans and develop models for systems of services for children with ASD and other DD.

In addition to these grants, HRSA/MCHB awarded \$250,000 per year to establish a State Public Health Coordinating Center to coordinate with the State Implementation grantees to develop and implement a strategy for defining, supporting, and monitoring the role of State public health agencies in assuring that children and youth with ASD and other DD receive early and appropriate identification, diagnosis, and intervention.

MCHB has made significant progress toward meeting the five objectives of the CAAI. However, the majority of the grant programs are still in the second year of funding.¹ As such, the full impact of their activities will not be seen until later in the grant period. The data in this progress report provides a preliminary snapshot of the grantees' accomplishments to date. More detailed results will be forthcoming in MCHB's future Report to Congress.

Training Programs

The 39 **LEND** and 6 **DBP** training programs that received CAAI grant funding cover 32 States and the District of Columbia, and their reach extends beyond those States, because of partnerships formed and services provided across State lines. To date, their efforts have focused on 1) training health professionals in the use of valid, reliable screening and diagnostic tools and

¹ CAAI grantees began work in FY 2009, and several CAAI grantees began work in FY 2010.

in the provision of evidence-based interventions for children with ASD or other DD and 2) providing continuing education to practicing health care providers and technical assistance to agencies, community based organizations, and other entities that serve women, children, and their families. These training efforts are effectively reducing barriers to screening and diagnosis by increasing professional capacity and increasing awareness about ASD among providers in the community. With the CAAI funding, the training programs have significantly expanded their didactic, clinical, and community-based training activities and their recruitment and support of trainees who will obtain instruction and practical experience in screening, diagnostic evaluation, or evidence-based intervention services for children with ASD and other DD. Table 3 shows the increase in the number of trainees enrolled in each program from FY 2009 to FY 2010 when 17 additional LENDS received CAAI funding, as well as the increase in the number of individuals who received didactic or clinical training in the areas of screening, diagnosis, and evidence-based interventions for ASD and other DD. Table 4 shows the number of training events hosted by each program, by fiscal year, and the number of participants at each event.

Table 3. HRSA-supported Trainees by Grant Program in FY 2009 and FY 2010

Number of Trainees by Grant Program	2009			2010		
	LEND	DBP	Total	LEND	DPB	Total
TOTAL TRAINEES						
Short term	*	1,137	1,137	5,826	2,611	8,437
Medium term	1,148	229	1,377	2,249	247	2,496
Long term	486	24	510	1,367	24	1,391
DIDACTIC TRAINING						
Medium term	916	124	1,040	1,529	231	1,760
Long term	391	24	415	1,019	24	1,043
PRACTICA/FIELDWORK**						
Medium term	317	100	417	1,353	107	1,460
Long term	219	24	243	989	24	1,013

*Data not available

** Trainees who participated in practice/fieldwork that addressed early signs of ASD/DD, screening, diagnosis, and/or evidence-based interventions for ASD/DD.

Table 4. HRSA-supported Training Events and Participants in FY 2009 and FY 2010

Number of Training Events/Participants	2009			2010		
	LEND	DBP	Total	LEND	DPB	Total
UNIVERSITY COURSES						
Addressing screening tools, diagnostic tools, and/or evidence-based interventions	139	*	139	369	10	379
Participants reached	2,987	*	2,987	8,415	582	8,997
Addressing advocacy, counseling, and coordination of care	*	*	*	250	6	256
Participants reached	*	*	*	4,757	137	4,894
CONTINUING EDUCATION EVENTS						
Addressing screening tools, diagnostic tools, and/or evidence-based interventions	324	*	324	721	60	781
Participants reached	26,478	*	26,478	89,092	3,160	92,252
OTHER TRAINING EVENTS**						
Addressing screening tools, diagnostic tools, and/or evidence-based interventions	1,201	*	1,201	1,665	82	1,747
Participants reached	62,658	*	62,658	51,443	2,398	53,841

*Data not available
** Includes brown bags, grand rounds, workshops, seminars, or presentations. Does not include Continuing Education events.

The CAAI funding also contributed to a considerable rise in the number of infants and children who were screened or evaluated in grantee-affiliated clinics between FY 2009 and FY 2010. The LEND training program has dramatically improved health professionals' ability to conduct screenings and assessments, and LEND funding has enhanced the capability of the workforce to screen and treat those with ASD. In 2009, the 22 LEND programs that received CAAI funding collectively screened 12,751 infants or children and provided diagnostic evaluation services to 12,390. In FY 2010, the 39 LENDs collectively screened more than 46,000 infants and children and provided diagnostic evaluation services for more than 35,000 infants and children.

Research Programs

MCHB's **Autism Intervention Research Programs (AIR)** have focused their efforts on supporting research on interventions to improve the health and well-being of children and adolescents with ASD and other DD, developing evidence-based guidelines, and validating tools for interventions. The 11 research studies that are currently in progress are addressing key issues such as diet and nutrition, sleep behaviors, social skills, communication and speech deficits, family well-being, and transitioning to adult life. Six of these studies also address issues specific to underserved populations. The Research Networks are also testing and validating tools that could be used to improve outcome measures of treatment studies in autism, and developing evidence-based guidelines for clinicians in the areas of sleep, gastrointestinal conditions and neurology, and genetic and metabolic screenings. Refer to Table 7 in the **Effectiveness and Outcomes of Interventions** chapter for a complete list of the research projects currently in progress.

State Implementation Grants

Nine States were awarded implementation grants (AK, IL, MO, NM, NY, RI, UT, WA, and WI). The State grantees are using their grant funds to implement State autism plans and develop models for systems of services for children with ASD and other DD. State activities have focused on building infrastructure, reducing barriers to care, raising awareness, and enhancing the training available for families of children with ASD and other DD and the professionals who serve them. Although the diversity of grant activities is considerable across the nine States, all have focused on improving access to screening and diagnostic services by building the capacity of the primary care service system and early childhood service providers (such as early intervention and childcare providers) to recognize the signs and conduct initial screening and diagnosis of ASD and other DD. All grantees have active awareness building campaigns, particularly during National Autism Awareness Month (April). Some State grantees are working to enhance frontline services through either the direct development of medical homes for children with ASD and other DD, enhancing existing medical homes, or helping communities build their local referral systems. Other grantees are focused on developing State or regional infrastructure. Activities at these wider levels include developing online trainings for families and providers that can be accessed at any time, the development of regional referral systems, and working on private insurance and Medicaid policy changes that would make ASD services more accessible. All grantees are either the organizing entity or active participant of a statewide autism taskforce, council, or commission and meet frequently with a core group of partners to achieve project goals.

National Institutes of Health (NIH)

Over the past four years, NIH has undertaken a number of activities to advance research on autism spectrum disorders (ASD) and other related developmental disabilities, as stipulated by the Combating Autism Act of 2006 (CAA), P.L. 109-416. The NIH has also been an active participant in interagency efforts, being represented on the Interagency Autism Coordinating Committee by the NIH Director and the directors of five NIH Institutes and Centers: The *Eunice Kennedy Shriver* National Institute on Child Health and Human Development (NICHD), National Institute on Deafness and Other Communication Disorders (NIDCD), National Institute of Environmental Health Sciences (NIEHS), National Institute of Mental Health (NIMH), and the National Institute of Neurological Disorders and Stroke (NINDS). This chapter provides details on the coordination and consolidation of the NIH's ASD research efforts under the authority of the CAA as well as progress and expenditures made by the many NIH Institutes and Centers that contribute to ASD research.

Intra-Agency Coordination

In 1997, at the request of Congress, the NIH formed an **Autism Coordinating Committee (ACC)** to enhance the quality, pace, and coordination of efforts at the NIH to find a cure for autism. Since then, the NIH ACC has been instrumental in the research into, understanding of, and advances in autism. Currently, staff from eleven NIH Institutes and Centers serve on the committee, including the National Center for Complementary and Alternative Medicine

(NCCAM), National Institute on Alcohol Abuse and Alcoholism (NIAAA), *Eunice Kennedy Shriver* National Institute on Child Health and Human Development (NICHD), National Institute on Deafness and Other Communication Disorders (NIDCD), National Institute of Environmental Health Sciences (NIEHS), National Institute of Mental Health (NIMH), National Institute of Neurological Disorders and Stroke (NINDS), National Institute of Nursing Research (NINR), NIH Office of the Director, and NIH Office of Dietary Supplements. The National Institute of Allergy and Infectious Diseases participates but is not a member of the committee. In addition, the NIMH Office of Autism Research Coordination (OARC) and the NIMH National Database for Autism Research (NDAR) Office, participate in NIH ACC meetings, keeping NIH program offices abreast of their activities and coordinating on projects of mutual interest. The NIH ACC continually monitors the NIH autism research portfolio and the agency's progress toward meeting the goals of the Interagency Autism Coordinating Committee (IACC) Strategic Plan. The NIH ACC will plan initiatives for FY 2012 and beyond to address gap areas the IACC identifies as it prepares the annual revision to its Strategic Plan.

As part of its mission to advance ASD research, the NIH ACC also coordinates the **Autism Centers of Excellence (ACE)** program, which focuses on identifying the causes of ASD and developing new and improved treatments. Among its provisions, the CAA emphasized the need for expanding research and improving coordination among NIH centers of excellence focused on ASD. The ACE program, which comprises 11 research centers and networks at major research institutions and universities across the country, focuses on identifying the causes of ASD and developing new and improved treatments. Currently, five NIH Institutes provide funding for ACE centers: NIMH, NICHD, NIDCD, NINDS, and NIEHS. These centers were initially funded in FY 2007 and FY 2008 and will be supported through FY 2013. ACE centers support research on biomarkers, genetic susceptibility, pharmacotherapy, language development, early intervention, and risk and protective factors, while maximizing coordination and cohesion of NIH-sponsored ASD research efforts. A feasibility study for evaluating the centers is near completion.

Table 5 presents NIH expenditures on the Autism Centers of Excellence (ACE) program, which includes centers (P50s), a cooperative agreement (U01), and networks (R01s). Funding totaled \$16.4M in FY 2007, \$25.2M in FY 2008, and \$26.5M in FY 2009, including \$1.89 million from FY 2009 ARRA funds.

Table 5. NIH Autism Centers of Excellence Program Funding (Dollars in Thousands)

Institute	FY 2007 Actual	FY 2008 Actual	FY 2009 Actual
NIMH	5,240	8,303	8,926
NINDS	300	2,192	1,092
NIDCD	1,560	1,930	1,930
NICHD	8,990	11,743	12,491
NIEHS	300	1,044	2,042
Total NIH	16,390	25,212	26,481

NIH-wide Research Programs

NIH has initiated activities focused on identifying environmental and genetic risk factors for ASD, as recommended in objectives of the IACC Strategic Plan. For example, the **Early Autism Risk Longitudinal Investigation (EARLI)** study will explore the impacts and interplay of environmental factors and genetic predisposition in the cause of ASD. About 1,200 mothers of children with ASD will be followed during a new pregnancy and throughout the early life of the new baby. Through extensive data collection on a number of possible ASD environmental risk factors and biomarkers, the study holds great promise in advancing understanding of the causes and progression of ASD. *More information on the EARLI program is available at:* <http://www.earlistudy.org/>.

NIH has also sponsored several important scientific workshops within the past year on topics of significant interest in the ASD field. In April 2010, NIDCD, NIMH, and NICHD convened a workshop to discuss the state of the empirical knowledge about, and research opportunities regarding the substantial subgroup of children with ASD who have not developed functional verbal language by five years of age, and a funding opportunity announcement based on some of the recommendations of the workshop is planned. In April 2010, NIDCD, NIMH, and NICHD convened a workshop to discuss the state of the empirical knowledge about, and research opportunities regarding the substantial subgroup of children with ASD who have not developed functional verbal language by five years of age, and a funding opportunity announcement based on some of the recommendations of the workshop is planned. In August 2010, NICHD and members of the NIH Autism Coordinating Committee convened a symposium to discuss assessment with particular emphasis on children of diverse backgrounds. Finally, in September 2010, NIEHS and Autism Speaks convened a workshop to identify innovative approaches to accelerate research on environmental factors and ASD. *More information on these workshops is available at:*

<http://www.nidcd.nih.gov/funding/programs/10autism/>.

<http://www.nichd.nih.gov/about/meetings/2010/081910.cfm>.

<http://www.niehs.nih.gov/news/events/highlight/autism/index.cfm>.

NIH is also contributing to ASD research infrastructure. For example, one objective of the IACC Strategic Plan involves donation of brain and tissue samples to biobanks and subsequent access and use of these biospecimens by ASD researchers. Therefore, NIH is supporting the **Eunice Kennedy Shriver NICHD Brain and Tissue Bank for Developmental Disorders** program that was expanded in 2009 and funded through FY 2014. *More information on this program is available at:* <http://medschool.umaryland.edu/BTBank/>.

The IACC Strategic Plan also highlights the importance of data sharing and the significant role played by the NIH **National Database for Autism Research (NDAR)**. This database is standardizing data formats across the field and has federated with a number of external database programs, now housing data on thousands of human subjects participating in research projects. In the past year, NDAR has undertaken numerous activities to meet the objective of the IACC Strategic Plan that aims to make 90 percent of human ASD research data available in or through NDAR to autism researchers around the world by FY 2012. *More information on NDAR is available at:* <http://ndar.nih.gov/ndarpublicweb/>.

On the NIH campus itself, Federal scientists in several laboratories of the intramural research program are running seven clinical studies on ASD, as well as a screening protocol to provide careful diagnostic evaluations for use in more specific studies, and to evaluate the presence of ASD symptoms in people with known genetic disorders.

In addition to domestic projects, NIH is seeking knowledge related to research on autism spectrum disorders internationally. Through the FIC trans-NIH research program, 'Brain Disorders in the Developing World,' a collaboration has developed between U.S. scientists and colleagues in India on the etiology and epidemiology of autism through the International Clinical Epidemiology Network (INCLLEN). *More information on these programs is available at:* http://www.fic.nih.gov/programs/research_grants/brain_disorder/ and <http://www.inclen.org/>.

NIH Funding for ASD Research

NIH funding of ASD research has increased substantially since the passage of the Combating Autism Act in 2006. Starting at \$108 million in FY 2006, funding rose to \$196 in FY 2009 with contributions from the American Recovery and Reinvestment Act (ARRA) passed in February 2009. NIH actively encourages research on ASD through funding opportunity announcements (FOAs), which include investigator-initiated research and targeted research. A number of FOAs have been released to solicit research that will implement the IACC Strategic Plan. Finally, the three standing FOAs that broadly solicit ASD research (PA-10-158, PA-10-159, and PA-10-160) were revised in 2010 to encourage studies that specifically address IACC Strategic Plan objectives.

The arrival of ARRA funds in 2009 provided NIH with a unique opportunity to jumpstart many of the short term objectives in the IACC Strategic Plan. In spring 2009, NIH issued a **Request for Applications (RFA) on the Heterogeneity of ASD**, a theme taken from the IACC plan, to solicit research proposals for potential funding under ARRA. NIH is also supporting ASD research with ARRA funding through the **Challenge Grants in Health and Science Research Program** (RFA-OD-09-003) and the **Grand Opportunity** grants (RFA-OD-09-004). In September 2009, NIH awarded more than 50 autism research grants, totaling more than \$64 million, in addition to the \$132 million awarded to autism researchers through NIH's regular base funding. Importantly, other ARRA funds, outside of the heterogeneity RFA, will also support new autism research, with the ARRA total for both fiscal years 2009 and 2010 expected to surpass \$116M. *More information on ARRA at HHS and NIH is available at:* <http://www.hhs.gov/recovery/> and <http://recovery.nih.gov/>.

ASD projects funded in FY 2009 and 2010 under ARRA include research on rapid screening instruments, identifying at-risk children, identifying biomarkers for early diagnosis, studying epigenomics to understand how environmental risk factors may interact with the genome to cause ASD, researching services for individuals in urban areas, and understanding autism in the second half of life. Additionally, awards are supporting several innovative genomics studies of ASD, utilizing data from thousands of samples from the **NIMH Center for Collaborative Genetic Studies of Mental Disorders** and the **Simons Simplex Collection**. These projects represent some of the most ambitious studies to date to identify ASD candidate genes, and one of the first attempts to find a diagnostic biomarker. According to FY 2010 estimates, NIH will have

committed an additional \$52 million in ARRA funds and \$136 million of base funding, totaling \$188 million. *More information on these programs is available at: https://www.nimhgenetics.org/available_data/autism/ and <https://sfari.org/simons-simplex-collection>.*

Table 6. National Institutes of Health: Autism Funding FY 2006-2009 (Dollars in Thousands)

Participating Institutes/Centers	FY 2006 Actual	FY 2007 Actual	FY 2008 Actual	FY 2009 Actual Base	FY 2009 Actual ARRA	FY 2009 Actual Total	Participating Institutes/Centers
NINDS	13,524	10,553	9,244	9,618	4,227	13,845	NINDS
NCI	0	0	0	22	0	22	NCI
NEI	0	0	0	0	68	68	NEI
NICHD	20,974	22,353	26,323	28,001	13,809	41,810	NICHD
NIEHS	1,808	3,679	3,764	4,369	4,931	9,300	NIEHS
NIA	328	887	666	500	0	500	NIA
NIDCD	5,108	5,406	6,269	9,067	2,161	11,228	NIDCD
NIMH	61,557	76,658	55,136	72,386	33,477	105,863	NIMH
NIAAA	0	0	5	124	0	124	NIAAA
NINR	249	241	237	0	0	0	NINR
NHGRI	818	821	0	104	0	104	NHGRI
NCRR	1,709	1,209	811	3,737	420	4,157	NCRR
NCCAM	194	189	222	0	0	0	NCCAM
FIC	n/a	n/a	188	193	0	193	FIC
NHLBI	n/a	n/a	403	403	0	403	NHLBI
NIDDK	n/a	n/a	321	313	0	313	NIDDK
NIGMS	n/a	n/a	341	486	426	912	NIGMS
NLM	0	0	0	0	603	603	NLM
OD	n/a	n/a	11,385	5	3,847	3,852	OD
NIBIB	n/a	n/a	404	0	0	0	NIBIB
Roadmap	2,051	4,847	2,358	3,074	0	3,074	Roadmap
Total NIH*	108,320	126,843	118,077	132,402	63,969	196,371	Total NIH
Participating Institutes/Centers	FY 2006 Actual	FY 2007 Actual	FY 2008 Actual	FY 2009 Actual Base	FY 2009 Actual ARRA	FY 2009 Actual Total	Participating Institutes/Centers

* This table presents all NIH expenditures on autism spectrum disorder (ASD), as reported through the NIH Research Portfolio Online Reporting Tool (RePORT). Please note that funding levels prior to 2008 were calculated using the former NIH coding system. The change from the old NIH coding system to the new Research Condition and Disease Categorization (RCDC) system results in what appears to be a decrease in funding in 2008 from 2007, but this only reflects a change in accounting methodology and not an actual decrease in funding. Prior to FY 2008, official data were manually collected and categorized by the NIH Institutes and Centers, compiled by NIH Office of the Director and released to the public. In 2008, the NIH switched to the new RCDC automated system in order to determine in a standardized and consistent way which NIH-funded projects should be categorized into each research category, eliminating the wide variability across the Institutes and Centers in defining the research categories reported. *For more information, please see the NIH RePORT website, <http://report.nih.gov/rcdc/categories/>.*

Substance Abuse and Mental Health Services Administration (SAMHSA)

SAMHSA does not have any programs or funding specifically focused on provisions of the CAA or for individuals on the Autism Spectrum. SAMHSA did not receive any ARRA funds so did not implement ARRA-specific programs in 2009 or 2010. The only SAMHSA program that involves individuals with Autism Spectrum Disorders (ASD) is the **Comprehensive Community Mental Health Services for Children and Their Families Program (CMHI)** which is mandated by congressional legislation to serve children and youth with serious emotional disorders. The service population of this program includes children with autism spectrum disorders.

The CMHI grant program provides funding to develop the infrastructure for a coordinated system of services and supports and to provide services to an eligible population. Children and their families served in this program are provided a full system of family-driven services and supports that are delivered in home and community-based care, in the least restrictive environment, and are individualized, strengths-based and culturally competent. The system of care includes formal treatments and services and natural and community supports that are wrapped around the child and family to promote full functioning in the community. Services are coordinated by a Child and Family Team that individualizes services to the specific needs of the child.

Children with ASD, compared to children with other diagnoses, were most often referred to CMHI program services because of disruptive behaviors, social interaction difficulties and unusual behavior and less likely referred for drug use, truancy or running away. Some of the children with ASD had family histories of mental illness, substance abuse and domestic violence. In the CMHI treatment population, caregivers reported that over 18 percent of children with ASD had been physically abused and over 16 percent had been sexually abused.

From 2002-2008, 77 CMHI grantees were funded; the breakdown per year is provided below. Each grantee is funded for six years at approximately \$9 million dollars in total. There is an ascending match requirement for each grant.

2002 (n=18 communities)

2003 (n= 7 communities)

2004 (n= 4 communities)

2005 (n=25 communities)

2006 (n=5 communities)

2008 (n=18 communities)

TOTAL N=77 grantee communities

Out of 21,967 cases with a diagnosis from these 77 CMHI-funded communities, there were 730 total cases on the Autistic spectrum (equivalent to 3.3 percent of all children/youth served in CMHI with a diagnosis). *More information on this program is available at:*

<http://www.systemsofcare.samhsa.gov/headermenu/cmhi.aspx>.

Department of Education (ED)

The Department of Education (ED) supports programs to develop and implement evidence-based practices for educating children with autism. ED does not receive appropriations under the CAA but does provide services to individuals with ASD under the Individuals with Disabilities Education Act (IDEA). IDEA Part B and Part C authorize formula-based grants to States to improve results for infants, toddlers, children, and youth with disabilities, from ages birth through 21. Under IDEA Part C, States must make available appropriate early intervention services to infants and toddlers with disabilities from birth through age two. Under IDEA Part B, States must make available a free, appropriate, public education to eligible children with disabilities, including children with autism, from ages three through 21. In 2008, 292,818 individuals, ages 6-21, received services under the category of Autism. *More details on the provisions of IDEA are available at: <https://www.ideadata.org/>.*

In 2010, through the Office of Special Education Programs (OSEP), ED funded over 40 ASD-related projects through various programs under Part D of the Individuals with Disabilities Education Act (IDEA). The projects currently under way include grants to institutions of higher education that train professionals at the doctoral and master's levels to increase the supply of highly qualified personnel to work with children ASDs.

OSEP also supports the **National Professional Development Center on Autism Spectrum Disorders**, a multi-university center to promote the use of evidence-based practice for children and adolescents with autism spectrum disorders. The Center operates through three sites that include the Frank Porter Graham Child Development Institute at the University of North Carolina at Chapel Hill, the M.I.N.D. Institute at University of California at Davis Medical School, and the Waisman Center at the University of Wisconsin at Madison. The Center works in coordination with each State's Department of Education, Part C agency, and University Center for Excellence in Developmental Disabilities to provide professional development to teachers and practitioners who serve individuals from birth through twenty-two years with autism spectrum disorders. *More information on this program is available at: <http://autismpdc.fpg.unc.edu/>.*

Through 106 **Parent Training and Information Centers** across the nation, ED provides training for parents of children with ASDs. OSEP also funds technology/media grant projects designed to improve educational and transitional services for children with ASDs while in school and as they transition to adulthood. *More information on the Parent Training and Information Centers is available at: <http://www.taalliance.org/>.*

ED's **Institute of Education Sciences (IES)** houses the National Center for Special Education Research (NCSER), which supports research designed to improve educational and developmental outcomes for children with disabilities or those at risk for disabilities. NCSER's Autism Spectrum Disorders program funds projects that develop or test the effectiveness of comprehensive preschool and school-based interventions that improve the developmental, cognitive, communicative, academic, social, behavioral, and functional outcomes of children with ASD. Additional grant programs within NCSER support research targeted toward a single

outcome of children with ASD (e.g., language or social skills). *More information on the Institute for Education Sciences is available at: <http://ies.ed.gov/>.*

Prevalence of Autism Spectrum Disorders

This section addresses Subsection (3) of 399DD: “Information on the incidence of autism spectrum disorder (ASD) and trend data on such incidence since the date of enactment of the CAA of 2006.” The CDC surveillance efforts reported in this chapter provide current ASD prevalence information rather than incidence. Incidence measures are typically more limited and indicate the number of newly diagnosed people with a disorder during a specific time period. In comparison, prevalence data indicate the total number of people affected at any given time in the population studied. Given the variability in the age of diagnosis of ASD and that not all children identified by the CDC surveillance efforts have a documented diagnosis, capturing prevalence, rather than incidence, is a more complete method for estimating the impact of ASDs in the population. CDC has been tracking the prevalence of developmental disabilities since the early 1980s and of ASD since 1996. To maintain the ability to track trends over time and to ensure the most complete count of the disorder among the population, CDC continues to report prevalence rather than incidence of the condition.

CDC’s autism surveillance provides important information on the numbers of children affected with an ASD and helps describe the characteristics of the population. Surveillance tracks trends over time, and is an essential building block for population-based research—providing clues about potential risk factors that warrant further study. Surveillance also provides critically important data for communities to use when planning for services. Ultimately, surveillance helps evaluate the progress of prevention and intervention programs.

In 2007, CDC’s **Autism and Developmental Disabilities Monitoring (ADDM)** Network published its first report of ASD prevalence. In this study, six ADDM sites (Arizona, Georgia, Maryland, New Jersey, South Carolina and West Virginia) reported the prevalence for children who were eight years old in 2000 (born in 1992). An additional eight sites (Alabama, Arkansas, Colorado, Missouri, North Carolina, Pennsylvania, Utah, and Wisconsin) participated in the second study year—determining the prevalence for children who were eight years old in 2002 (born in 1994). The reported prevalence estimates ranged from 1 in 300 to 1 in 100, with an average ASD prevalence of 1 in 150 children. In December 2009, CDC and the ADDM Network published an updated report of ASD prevalence estimates. ASD prevalence in 2006 was approximately 1 in 110 8-year-old children living in the 11 communities participating in the 2006 surveillance year. This report also indicated that there were 4.5 times as many boys with ASDs than girls. Among children aged 8 years, ASD prevalence was 14.5 per 1,000 males compared with 3.2 per 1,000 females. ADDM also reported that about 40 percent of the children with ASDs also had an intellectual disability.

The prevalence of autism over time (2002-2006 study years)

Data from the 10 ADDM sites with results from multiple surveillance years indicate a significant average increase (57 percent) in identified ASD prevalence in 2006 compared with 2002. The only site not showing a statistically significant increase was Colorado; this probably was

attributable to the relatively small population of children aged 8 years in the surveillance area and the slightly lower magnitude of change, limiting the power to detect change compared with other sites. On average, ASD prevalence increased across all sex, racial/ethnic, and cognitive functioning subgroups. For all sites, the most consistent pattern was the increase in identified ASD prevalence for males, with some sites showing better identification among some groups of children, such as those without intellectual disability or children of Hispanic ethnicity. No single factor explains the changes identified in ASD prevalence over time and much needs to be done to understand the relative contribution of the multiple factors involved, although some of these increases can be accounted for by improved identification and awareness. Understanding the relative contribution of multiple factors is important and efforts to further understand these contributions are underway. Whether identified ASD prevalence estimates will plateau, decrease, or continue to increase is unknown and continued examination of ASD prevalence changes is important.

Looking towards the future

CDC has been working to develop methods to track the population characteristics of ASDs in younger children. In 2010, CDC funded six sites to expand ADDM methodology to younger cohorts. Through Early ADDM surveillance of ASDs among 4-year-old children, CDC can better understand the population characteristics of young children affected by ASDs and better inform early identification efforts. To understand ASD prevalence, it is important to identify children who have the diagnosis *and* children who have the symptoms (but do not have a diagnosis). The ADDM Network uses a retrospective record review methodology and casts a wide net to ensure the most accurate estimate of prevalence. Expanded surveillance of 4-year-olds can provide a more complete picture of the impact of ASD; however, it is particularly important to note that because methods are dependent on record review, prevalence estimates are impacted by the age at which children receive services. Continued monitoring of ASD among 8-year-olds, which we know is “peak prevalence”, or the age at which most children have been identified, is essential to understanding the complex changes occurring in ASDs over time.

Average Age of Diagnosis

This section addresses Subsection (4) of 399DD: “Information on the average age of diagnosis for children with ASD and other developmental disabilities, including how that age may have changed over the 4-year period beginning on the date of enactment for this Act.” Average age of diagnosis information and data are provided by the CDC.

Before a child can be diagnosed with an ASD, someone needs to be concerned about their development. The ADDM Network has found that there are often significant concerns early in life about the child’s development, but that there is a lag in actual diagnosis of an ASD by community professionals. In the 2002 ADDM surveillance year, more than half (range: 51.0 percent to 91.4 percent) of children meeting surveillance criteria for ASD by age 8 years had a documentation of concerns about the child’s development before the age of 3 years. The most commonly documented early developmental concern was for language skills, followed by social concerns. By the surveillance year 2006, there were still concerns documented about the vast majority of children with ASDs in all sites (range: 70 percent [Maryland] to 95 percent

[Alabama]); however, the age of this concern went down to 2 years of age or earlier, on average. The most commonly documented early developmental concern was still language delay. Despite these early concerns before the age of 2 and 3 years, the median age of earliest ASD diagnosis was 4 years, 11 months in 2002 and 4 years, 6 months in 2006.

From 2002-2006, the median age of earliest documented ASD diagnosis decreased in all sites ranging from a decrease of 1 month in Wisconsin to 15 months in Alabama with an overall trend across all sites of a reduction of approximately 5 months across all sites. However, these data indicate a greater than two year gap from developmental concern to diagnosis, indicating a dire need for improved access to early evaluation and diagnostic services.

Disparities in identification

Access to appropriate educational and health services improves a child's chance of being identified by the ADDM Network surveillance system, and disparities may be reflected in the observed prevalence among some groups. In all four ADDM Network surveillance years to date (2000, 2002, 2004, 2006), some but not all sites have reported significant disparities in the identified prevalence of ASDs among Black children as compared to White children. Since 2002, some but not all sites have identified significantly higher prevalence in White children compared to Hispanic children as well, although in 2006 one site observed a higher prevalence in Hispanic children as compared to either White or Black children. One report on ADDM data published in 2010 suggests that these disparities in identified prevalence may be associated with socioeconomic status. Differences in heritable factors as well as exposure to various risk and protective factors may also influence differences in identified prevalence among certain groups, so ongoing monitoring is needed to better understand these factors. CDC supports the Healthy People 2020 objective of increasing the proportion of children who are screened for autism and other developmental delays at 18 and 24 months of age and have a first evaluation by 36 months of age. For those with ASD, CDC supports increasing the proportion of children that are enrolled in special services by 48 months of age.

Average Age for Intervention

This section addresses subsection (5) of 399DD: "Information on the average age for intervention for individuals diagnosed with ASD and other developmental disabilities, including how that age may have changed over the 4-year period beginning on the date of enactment of this Act." Information and data on the average age for intervention in ASD cases is provided by the CDC.

The ADDM Network reports the average age of diagnosis, which may be used as a rough proxy for initial intervention (see above). As noted, there has been some reduction in the age of ASD diagnosis, but significant delays still exist. Although an ASD diagnosis is not required to begin intervention, knowing that a child's developmental disability is consistent with an ASD may inform the appropriateness and type of intervention applied. In 2006, the ADDM Network reported that children identified with ASDs were slightly more likely to be classified with an ASD by community professionals (physicians, psychologists, special education teams, etc.) as compared with 2002 findings (72 percent in 2002 to 77 percent in 2006). This may indicate that

more children are able to receive ASD-specific intervention, including children eligible for special education services under IDEA Part B. For the 2006 surveillance year, 76 percent to 96 percent of children were receiving special education support from the public schools with 34 percent to 76 percent receiving these services under a classification of “autism.” Other common special education eligibilities included "specific learning disabilities," "speech and language impairments," "other health impairments," and "intellectual disabilities," with these proportions also varying by site. Many children who did not have an ASD diagnosis recorded in their record as of 2006 were receiving special education and related services under IDEA Part B through an autism eligibility in the public schools. In addition to community professionals providing diagnosis, public schools are playing a crucial role in evaluating, identifying, and serving children with ASDs.

Average Time Between Screening, Diagnosis, and Intervention

This section addresses section (6) of 399DD: “Information on the average time between initial screening and then diagnosis or rule out for individuals with ASD or other developmental disabilities, as well as information on the average time between diagnosis and evidence-based intervention for individuals with ASD or other developmental disabilities.” Information and data on the average time between ASD screening and diagnosis or rule out is provided by the CDC.

As noted above, someone must be concerned about a child’s development before an ASD evaluation can be conducted. In the latest ADDM Network report, there was documentation of concerns about development for 70-95 percent of the children identified with an ASD; however, the median age of ASD diagnosis was 4 years, 6 months of age indicating a significant delay between evidence of concerns and early diagnosis. Although the ADDM Network does not currently collect data on developmental screening, the establishment of the Early ADDM Network in 2010 will further enhance our understanding of the early developmental concerns and a child’s path to diagnosis. In an effort to address delay in diagnosis of ASDs and other developmental disabilities and to promote early intervention, CDC’s “*Learn the Signs. Act Early.*” program continues to work to improve early identification of ASDs and other developmental disabilities, and to enhance communication and coordination among State and local systems providing services to children with developmental delays.

Effectiveness and Outcomes of Interventions

This section addresses subsection (7) of 399DD: Information on the effectiveness and outcomes of interventions for individuals diagnosed with autism spectrum disorder, including by various subtypes, and other developmental disabilities and how the age of the child may affect such effectiveness. Information on the effectiveness of outcomes and interventions is provided by AHRQ, CMS, HRSA, NIH, and ED.

Agency for Healthcare Research and Quality (AHRQ)

Under the Combating Autism Act, AHRQ does not receive any appropriations, and therefore has no direct program or research responsibilities funded by CAA. However, AHRQ programs have

contributed substantially to research on the effectiveness of intervention strategies in ASD, including:

Completed Projects:

- a) In 2007 a systematic review of published studies on atypical antipsychotics found that the most common off-label uses of the drugs were treatment of autism among other personality and behavioral disorders. It concluded that, with few exceptions, there was insufficient high-quality evidence overall to reach conclusions about the efficacy of any off-label indications of these medications. It also found strong evidence that atypical antipsychotics can increase chances of adverse events. This report is being updated (see below).
The clinician guide is available at:
<http://www.effectivehealthcare.ahrq.gov/index.cfm/search-for-guides-reviews-and-reports/?pageaction=displayproduct&productID=8>.
The systematic evidence review report is available at:
<http://www.effectivehealthcare.ahrq.gov/index.cfm/search-for-guides-reviews-and-reports/?pageaction=displayproduct&productid=64>.
- b) An AHRQ supported study (Grant HS 16097) characterized national trends and patterns using 10 years of data in the outpatient pharmacological management of children and adolescents with autism spectrum disorder (ASD).¹
- c) AHRQ identified for Medicaid Title XIX Home and Community-Based Services, **Standards for the Development of Lifelong Supports and Community Resources for Persons with Autism Spectrum Disorder and their Families**. The standards are intended to provide a blueprint for community providers, local communities, as well as State and Federal government for supporting individuals with autism. *The report is available at:* <http://www.ahrq.gov/research/ltc/hcbsreport/hcbsapiic.htm>.
- d) In 2009, AHRQ created a report describing to readers a practical approach to creating a school-based all-hazards emergency response plan from the national literature in combination with "lessons learned" in the field. *The publication addresses needs of children with ASD and is available at:* <http://www.ahrq.gov/prep/schoolprep/>.

Ongoing Activities:

- a) AHRQ is systematically reviewing the global English literature since 1980 on therapies for children (2-12 years) with ASD and those under 2 years of age and at risk of developing ASD. The review will be looking for short term and long term outcomes of the interventions in social interactions, language and communications, adaptive and academic skills development, etc. The review was begun in 2009 and will be completed in 2011. *The research protocol with detailed study design and methodology is available at:*
<http://effectivehealthcare.ahrq.gov/index.cfm/search-for-guides-reviews-and-reports/?pageaction=displayproduct&productid=366>.
- b) AHRQ is also currently supporting a systematic review of the comparative effectiveness of first and second generation antipsychotics in the pediatric and young adult population. The objective of this **Comparative Effectiveness Review (CER)** is

¹ Gerhard, T. et al. (2009). "National patterns in the outpatient pharmacological management of children and adolescents with autism spectrum disorder." *Journal of Clinical Psychopharmacology* 29 (3), pp. 307-310.

to provide a comprehensive synthesis of the evidence examining the benefits and harms associated with first and second generation antipsychotics while treating disorders/illness including ASD among children, youth and young adults. The review will conclude in 2011. *The research protocol with detailed study design and methodology is available at:*

<http://effectivehealthcare.ahrq.gov/index.cfm/search-for-guides-reviews-and-reports/?pageaction=displayproduct&productid=453>.

- c) An update to the earlier review of comparative effectiveness of off-label use of antipsychotics will be carried out according to a protocol released by AHRQ in 2010. An update of the original report is necessary (see above). Further, the review will address two key questions which remained unclear due to insufficient information in the previous study: subpopulation (i.e., race/ethnicity, gender) that would benefit most from atypical antipsychotics, and appropriate dose and time limit. *The research protocol with detailed study design and methodology is available at:*
- <http://effectivehealthcare.ahrq.gov/index.cfm/search-for-guides-reviews-and-reports/?pageaction=displayproduct&productid=443>.

Centers for Medicare & Medicaid Services (CMS)

CMS' Final Report on **Environmental Scan** is available at: <http://www.impaqint.com/files/4-content/1-6-publications/1-6-2-project-reports/finalasdreport.pdf>. It includes intervention categories and descriptions, evidence-based interventions for children, emerging interventions, unestablished interventions, and the same categories for transitioning youth and adults. It also includes an intervention-specific analysis and addresses the economic impact of ASD.

Office on Disability (OD)

The Office on Disability has been actively involved with the work of the IACC Services Subcommittee. The office provided extensive input to enrich the 2010 IACC Strategic Plan to focus on issues related to access to and quality of health services and supports provided to people with autism, with particular attention to adults with autism. The office also recommended the identification of what interventions work best, what are the gaps in access and provision of quality health services and supports, and the development of quality improvement interventions that focus on the functional limitations experience by those with autism. The Office on Disability also emphasized the need to bring additional expertise to the committee membership to include health services researchers.

Health Services and Resources Administration (HRSA)

HRSA's Maternal and Child Health Bureau (MCHB) used a variety of funding mechanisms to provide training grantees, State agencies, and the public with information on the effectiveness of interventions for individuals with ASD and other DD. The MCH **Autism Intervention Research Network** program, initially funded in September 2008, includes support for two networks, one focusing on physical/medical health interventions (the MCH **Autism Intervention Research Network on Physical Health**, or **AIR-P**) and another focusing on behavioral, mental, social, and/or cognitive health interventions (the MCH **Autism Intervention**

Research Network on Behavioral Health, or AIR-B). These networks were designed with a goal of developing two self-sustaining multi-site research networks to advance the scientific knowledge base on interventions and guidelines that will be disseminated broadly to the public, including clinicians, researchers and families, and result in improved health and well-being of children and adolescents impacted by ASD and other DD. The R40 grant programs, which include the Autism Intervention **Secondary Data Analysis Studies (SDAS)** Program and the MCH Autism Intervention Research Program, were established 1 year later to support research on evidence-based practices for ASD interventions. The R40 Grant program has provided support for two 1-year grants and five 2-year grants. At present, the research studies being conducted by the Research Networks and the R40 grantees are still in progress; as such, further detail on the study findings will be provided in MCHB's forthcoming Report to Congress.

In the first 2 years of the grant, the research programs have implemented a total of 11 studies on interventions for children with ASD in the following topic areas: diet and nutrition, sleep behaviors, social skills, communication and speech deficits, family well-being, transitioning to adult life, and underserved populations. A summary of these studies is provided in Table 7. The research studies being conducted range from randomized controlled designs, considered the gold standard in research, to studies using secondary data analysis methods. These studies also focus on various age groups, including pre-school-aged children (2-5 years of age), school-aged children (5-7 years of age), and individuals transitioning to adulthood. Most of the studies are targeting children from underserved populations, which is particularly important because, up to now, little evidence has been gathered on the effectiveness of interventions for underserved children with ASD.

Table 7. HRSA Research Studies on Interventions for Children with ASD

Research Program	Study Title	Purpose	Anticipated Final Products
1 AIR-P	Diet and Nutrition in Children with Autism Spectrum Disorders: An Autism Treatment Network Collaborative Study	Gastrointestinal complaints, feeding difficulties, restricted food interests, and food allergies are widely reported among children and adolescents on the autism spectrum. These issues are thought to be linked to problem behaviors and sleep disturbances. This study is investigating the food and supplement intake of children and adolescents with ASD. Researchers plan to examine the correlation between nutritional status and medical and behavioral symptoms, with the goal of developing a nutritional screening tool and educational materials for nutritional counseling in primary care settings.	Tool for nutritional screening of children with ASD in primary care settings Educational materials for nutritional counseling in primary care settings Peer-reviewed publications
2 AIR-P	Development of a Parent-Based Sleep Education Program for Children With Autism Spectrum Disorder	Sleep disturbances are among the most common medical conditions reported by parents with children on the autism spectrum. Children with ASD are known to suffer from a number of sleep problems including delayed sleep onset, night waking, early awakening, obstructive sleep apnea, sleep epilepsy and reduced need for sleep. The study compares two nurse-led parent education interventions to potentially impact the sleep and night-time behaviors of children with ASD.	Screening tool Detailed implementation manual for preferred intervention Peer-reviewed publications
3 AIR-B	Parent-Mediated Joint Engagement Intervention	A significant number of children with autism continue to make very slow progress in spoken communication. This study examines an intervention for <u>underserved</u> children with autism. This study is using a randomized controlled multi-site design to examine the effectiveness of a parent training model of joint attention/joint engagement in building social communication skills in toddlers with ASD.	Treatment manuals from study Reports on outcome findings from study Peer-reviewed publications
4 AIR-B	Peer Social Skills/Relationship Intervention at School	The outcome of the study will determine if working through parents is effective enough to change school peer interactions and friendships or if direct peer-mediated instruction at school is necessary. This study examines an intervention for <u>underserved</u> children with autism. The purpose is to assess a social skills intervention among 150 high functioning ASD elementary school children who are in general education and who do not often receive school based services.	Treatment manuals from study Reports on outcome findings from study Peer-reviewed publications

Research Program	Study Title	Purpose	Anticipated Final Products
5 AIR-B	Web-Based Social Skills Intervention	The study was developed to reach <u>underserved</u> children with ASD who live in rural and underserved areas. The project developed a Web-based delivery of social skills instruction. The target population is 3 rd -to 5 th -grade students.	Treatment manuals from study Reports on outcome findings from study
6 AIR-B	Teen-Based Social Skills Intervention in Schools	This study involves an upward extension of the Peer Social Skills/ Relationship Intervention at School study (#4 above) to <u>underserved</u> middle school and high school students with ASD.	Treatment manuals from study Reports on outcome findings from study Peer-reviewed publications
7 MCH Autism Intervention Research Program	Supporting the Well-being of Families of Young Children With Autism Spectrum Disorders	This study determines whether an evidence-based empowerment strategy targeted to mothers of young children with ASD promotes family well-being by decreasing the burden of maternal depressive symptoms and parenting stress and improving maternal social functioning.	Academic Study peer- reviewed publications
8 MCH Autism Intervention Research Program	Parent-Mediated vs. Center-Based Intervention for Toddlers With ASD: A Randomized Control Trial	This study evaluates whether a parent-mediated intervention and center-based intervention provided by a clinician yield comparable outcomes for minority and <u>underserved</u> toddlers with ASD.	Academic Study peer- reviewed publications
9 MCH Autism Intervention Research Program	Family-Centered Transition Planning for Students With Autism Spectrum Disorders	This study demonstrates a Family-Centered Transition Planning model designed to empower families and high school students with autism spectrum disorders transitioning to adult life.	Academic Study peer- reviewed publications
10 MCH Autism Intervention Research Program	Telehealth Delivery of a Family-Focused Intervention to Reduce Anxiety in Youth With Autism Spectrum Disorders in Rural Colorado	This study develops and evaluates the use of interactive televideo technology to deliver a promising mental health intervention to families of children with ASD who are geographically removed from specialty medical centers.	Academic Study peer- reviewed publications

Research Program	Study Title	Purpose	Anticipated Final Products
11 SDAS	The Effectiveness of Special Education Services for Children With Autism: A National Longitudinal Study	This study assesses the effectiveness of special education services for children with ASD by measuring the effect of high quality treatment on outcomes.	Academic Study peer- reviewed publications

The Research Networks are also actively developing evidence-based clinical practice guidelines to support clinicians in decision-making, diagnosis, management, and treatment of children with ASD. Although these guidelines are not, in themselves, interventions, they are critical to accurate identification and treatment of physical and behavioral conditions in children with ASD, which is a necessary prerequisite for effective intervention. The Networks are also working on developing tools designed to assist physicians and families in managing the care of children with ASD. These tools may, for example, help physicians to quickly assess a child’s engagement level on the playground, or help parents manage their child’s sleep behavior. These guidelines and tools are summarized below in Table 8.

Table 8. HRSA Development of Clinical Guidelines and Tools

Research Program	Topic Area	Overview	Anticipated Final Products
1 AIR-P	Gastrointestinal Conditions: Constipation, Chronic Diarrhea, Food Allergies	<p>Gastrointestinal (GI), or stomach and digestive problems, are a major concern for many families of children affected by autism. To increase the ability of pediatricians and other doctors to treat the GI conditions that often trouble children with autism, the Autism Treatment Network’s (ATN) GI committee has been drafting algorithms for Constipation, Chronic Diarrhea and Food Allergies. Because constipation seems to be a common issue for children with ASD, the committee has made a priority of finalizing and testing the constipation algorithm.</p> <p>The constipation algorithm guides pediatricians in diagnosing and treating the condition and helps them determine when it is appropriate to refer on to a GI specialist. It also helps GI specialists choose the right treatment approaches. This flow diagram has been adapted from the NASPGHAN guideline (Constipation Guideline Committee, 2006) which was developed for typically developing children with constipation. Supporting text and tools will be tailored to inform pediatricians on how to address these issues in children with ASD.</p>	<p>Algorithm for diagnosing and treating constipation, chronic diarrhea, and food allergies in children with ASD</p> <p>Tool for answering parents’ questions about food allergies</p>

Research Program	Topic Area	Overview	Anticipated Final Products
		<p>The chronic diarrhea algorithm assists pediatricians in diagnosing, treating, and deciding whether to refer a child to a GI specialist, and it assists the GI specialist in the accurate diagnosis and categorization of specific conditions and the treatment and intervention options to consider.</p> <p>The food allergies algorithm helps pediatricians recognize GI symptoms commonly associated with food allergy and to distinguish between food allergies and symptoms of other GI conditions. A tool is also being developed that will help physicians answer parents' questions.</p>	
2	AIR-P Managing Sleep Behavior	<p>Children with ASD are known to suffer from a variety of sleep problems including delayed sleep onset, night waking, early awakening, obstructive sleep apnea, sleep epilepsy, and reduced need for sleep. The ATN Sleep Committee has produced a draft algorithm for physicians and a <i>Draft Guideline for Evaluation of Sleep Problems in Children with Autism Spectrum Disorders</i>. The algorithm is focused mainly on managing insomnia and is intended to guide general pediatricians in carrying out the initial diagnostic and treatment steps and help them determine when to refer the family to a sleep specialist.</p> <p>To accompany the algorithm the ATN Sleep Committee is developing a sleep hygiene toolkit, which will assist physicians in screening sleep disorders and parents in managing their child's sleep behavior. This toolkit will include an <i>ATN Sleep Strategies</i> guide, which addresses sleep behavior in children under the age of 12, and a Sleep Log. A sleep strategies guide for adolescents with ASD is currently in the early testing stages as well.</p>	<p>Guideline for Evaluation of Sleep Problems in Children with Autism Spectrum Disorders</p> <p>Sleep hygiene toolkit</p>
3	AIR-P Neurological, Genetic and Metabolic Screenings	<p>ASDs are neurologically based and many children with ASD have neurological abnormalities. About 30 percent of children with ASD suffer from seizure disorders such as epilepsy. In addition, metabolic abnormalities are sometimes identified in children with ASD. The ATN's Neurology-Genetics-Metabolics Committee has been focused on compiling guidelines to inform pediatricians about when certain diagnostic tests are necessary. The committee has drafted flow diagrams indicating red flags for the use of the electroencephalogram (EEG) to measure the brain's electrical activity, and magnetic resonance imaging (MRI) to look at the brain itself.</p>	<p>Guidelines for diagnostic testing</p>

Research Program	Topic Area	Overview	Anticipated Final Products
4 AIR-B	Playground Engagement Tool	The AIR-B is developing a set of observational measures that can be used on a school playground to assess and measure whether a child with ASD is engaged or not. The tool is supported by Web-based manuals and a video. One tool, called playground observation peer engagement (POPE), is a fairly elaborate tool to assess playground engagement; the AIR-B is trying to simplify it so that it can be used more quickly and easily.	Tool for quickly assessing playground engagement with peers
5 AIR-P	Behavioral Treatments Toolkit	The AIR-P also has under development a behavioral treatments toolkit that focuses on toileting, ABA (Applied Behavioral Analysis basics for parents), behavior management basics, and feeding and diet.	Behavioral treatments toolkit
6 AIR-B	Psychological and Related Interventions for Children with Autism	The AIR-B has conducted a systematic, extensive review of the evidence around the impacts of various interventions on identified core deficits in autism. Further, the effectiveness of these interventions in children and adolescents has been documented in the Evidence Report.	Evidence Report, and Guidelines on Evidence-based Practices

Finally, MCHB funded a variety of studies that help to identify factors involved in a successful intervention. These studies are investigating issues related to identification and treatment of physical and behavioral problems common in children with ASD, as well as services for children and youths with ASD who are transitioning to adulthood. The studies are listed below in Table 9.

Table 9. HRSA Research to Identify Successful Intervention Factors

Research Program	Topic Area	Overview	Anticipated Final Products
1 AIR-P	Bone Mineral Density in Children with Autism Spectrum Disorders	This study investigates the degree to which bone mineral density is impaired in children with autism and to explore specific additional risk factors.	Practice Guidelines/Toolkits Peer-reviewed publications
2 AIR-P	Prevalence of Creatine Deficiency Syndromes and Genetic Variability in Creatine Metabolism in Children with ASD: A Pilot Study	This study is the first comprehensive population-based study looking at the prevalence of Creatine Deficiency Syndromes in autism in a diverse ethnic group.	Practice Guidelines/Toolkits Peer-reviewed publications

Research Program	Topic Area	Overview	Anticipated Final Products
3 AIR-P	Markers of Iron Status and Metabolism in Children with ASD	This study evaluates iron intake, iron status and associated sleep disorders in a large, well characterized sample of children with ASD.	Practice Guidelines/Toolkits Peer-reviewed publications
4 AIR-P	Defining the Relation of Sleep Disturbance in Autism Spectrum Disorder to Psychiatric and Behavioral Co-morbidities	This study defines the psychiatric and behavioral comorbidities associated with disordered sleep in children with ASD.	Practice Guidelines/Toolkits Peer-reviewed publications
5 MCH Autism Intervention Research Program	Assessing a Participant Directed Service System for Low Income Children with Autism	This study evaluates a Medicaid supportive services waiver program in Massachusetts that uses a participant direction model to choose and manage services for young children with ASD and their families.	Academic Study Peer-reviewed publications
6 SDAS	Services and Outcomes for Transition Age Young Adults with Autism Spectrum Disorders: Secondary Analysis of the NLTS2 and RSA 911	This study identifies factors associated with and influencing a successful transition into adulthood for young adults with ASD.	Academic Study Peer-reviewed publications

National Institutes of Health (NIH)

NIH has undertaken a number of activities to address the effectiveness and outcomes of interventions for individuals diagnosed with ASD, including randomized, controlled studies of behavioral and medical treatments. While behavioral interventions have been previously shown to be effective, research since 2006 has demonstrated the impact of implementing behavioral interventions for children before age 3. A randomized comparison of a modification of Applied Behavioral Analysis (ABA) versus typical community-based treatment for children as young as 18 months resulted in significant greater improvement over two years. In this NIH-supported study, the group receiving the modified early intervention showed more than double the increase in IQ (average increase of 17.6 points) and greater gains in adaptive behavior relative to usual care. These results support the importance of intervening early and demonstrate that aggressive

behavioral treatment can be an effective treatment for many children with ASD, conferring improvements in social behavior.¹

Regarding medical treatments for ASD, research since 2006 has mostly focused on symptoms of irritability and repetitive behaviors. In an NIH-supported 8-week multisite, double-blind, randomized trial of risperidone in 101 children with ASD, a relatively low dose improved irritability, hyperactivity, and stereotyped behavior. Treatment effects were maintained over 16 weeks of treatment, and discontinuation of the medication resulted in return of behavioral symptoms. Side effects included weight gain, and mild to moderate fatigue in about half of the children. In another NIH-supported study, a multisite investigation with 149 children with ASD and high levels of repetitive behavior (ages 5 to 17 years) evaluated the efficacy of citalopram in reducing those behaviors. In 12 weeks of treatment with a flexible dose schedule, citalopram did no better than placebo in the primary outcome measures. Adverse events were significantly more likely to occur in the citalopram-treated group.²

The NIH-supported **Research Units on Pediatric Psychopharmacology Autism Network** conducted a randomized, double-blind, placebo-controlled trial of methylphenidate in children with ASD and high levels of hyperactivity and/or impulsiveness (ages 5 to 14 years). Doses at the 0.25 and 0.5 mg/kg level were effective in reducing hyperactivity and impulsivity, but less effective in reducing inattention, at 4 weeks and after 8 weeks continuation. The response rate was about 35 percent compared to typical response rates of around 70 percent in children with attention deficit hyperactivity disorder, but no pervasive developmental disorders. About 18 percent of subjects withdrew due to side effects, primarily irritability. The authors noted that some children responded best to lower doses of methylphenidate. Importantly, a separate NIH-funded study demonstrated that adding a parent training program to medication management for severe behavior disturbances in ASD was more beneficial than medication intervention alone, and allowed for maintenance on a lower dose of the medication.³

Regarding dietary interventions for ASD, results of an early NIH-supported study suggest that dairy-free diets and unconventional food preferences could put boys with ASD at higher than normal risk for thinner, less dense bones when compared to a group of boys the same age who do not have ASD. Risk for poor bone development may be due to lack of exercise, reluctance to eat

¹ Dawson G, Rogers S, Munson J, Smith M, Winter J, Greenson J, Donaldson A, Varley J. Randomized, controlled trial of an intervention for toddlers with autism: the Early Start Denver Model. *Pediatrics*. January 2010;125(1):e17-23.

² King BH, Hollander E, Sikich L, McCracken JT, Scahill L, Bregman JD, Donnelly CL, Anagnostou E, Dukes K, Sullivan L, Hirtz D, Wagner A, Ritz L: STAART Psychopharmacology Network. Lack of efficacy of citalopram in children with autism spectrum disorders and high levels of repetitive behavior: citalopram ineffective in children with autism. *Arch Gen Psychiatry*. June 2009;66(6):583-90.

³ Aman MG, McDougle CJ, Scahill L, Handen B, Arnold LE, Johnson C, Stigler KA, Bearss K, Butter E, Swiezy NB, Sukhodolsky DD, Ramadan Y, Pozdol SL, Nikolov R, Lecavalier L, Kohn AE, Koenig K, Hollway JA, Korzekwa P, Gavaletz A, Mulick JA, Hall KL, Dziura J, Ritz L, Trollinger S, Yu S, Vitiello B, Wagner A; the Research Units on Pediatric Psychopharmacology Autism Network. Medication and Parent Training in Children With Pervasive Developmental Disorders and Serious Behavior Problems: Results From a Randomized Clinical Trial. *J Am Acad Child Adolesc Psychiatry*. December 2009;48(12):1143-1154.

a varied diet, lack of vitamin D, digestive problems, and diets excluding casein, a milk protein. It may be beneficial for parents of children with ASD to include a dietitian in their care.¹

Department of Education (ED)

The National Center for Special Education Research (NCSEER), within ED's Institute of Education Sciences (IES), supports projects to develop innovative education interventions or improve existing interventions. These projects require an iterative process of designing, testing, revising, and testing to produce a product or system that functions with fidelity and can be implemented in actual education delivery settings (e.g., schools), and must provide a preliminary evaluation of outcomes. For example, one NCSEER-funded project is developing a 3D-based virtual learning environment to enhance the social competence of middle school students with ASD. Another project is developing a school-based summer treatment program to address the cognitive, communicative, social and behavioral needs of elementary school age students with high functioning ASD. *More information on these and additional NCSEER research projects is available at: <http://ies.ed.gov/ncser/>.*

Innovative Intervention Strategies

This section addresses subsection (8) of 399DD: "Information on the effectiveness and outcomes of innovative and newly developed intervention strategies for individuals with autism spectrum disorder or other developmental disabilities." Information on innovative intervention strategies is provided by AHRQ, CMS, HRSA, and the NIH.

Agency for Healthcare Research and Quality (AHRQ)

In 2009, AHRQ initiated support for research (R01 HS18453-01; PI-Stephen Downs, Indiana University) to demonstrate that a computer decision support program, **CHICA (Child Health Improvement through Computer Automation)**, will provide much needed computer decision support to implement clinical guidelines in pediatric practice. This study will include a randomized trial in which screening, diagnosis, and management of ASD before and after implementation of the CHICA system in intervention practices will be compared to control practices. The study concludes in 2013. *More study details and abstract are available at: http://gold.ahrq.gov/projectsearch/grant_summary.jsp?grant=R01+HS18453-01&QUICK=AUTISM.*

Centers for Medicare & Medicaid Services (CMS)

CMS' Final Report on **Environmental Scan** is available at: <http://www.impaqint.com/files/4-content/1-6-publications/1-6-2-project-reports/finalasdreport.pdf>. It includes intervention categories and descriptions, evidence-based interventions for children, emerging interventions,

¹ Hediger ML, England LJ, Molloy CA, Yu KF, Manning-Courtney P, Mills JL. Reduced bone cortical thickness in boys with autism or autism spectrum disorder. *Journal of Autism and Developmental Disorders*. May 2008;38(5):848-56.

unestablished interventions, and the same categories for transitioning youth and adults. It also includes an intervention-specific analysis, and addresses the economic impact of ASD.

Health Services and Resources Administration (HRSA)

The MCH **Autism Intervention Research Networks** and the **R40 Grant Programs** were established to conduct and support research on ASD, including physical/medical health interventions as well as behavioral, mental, social, and/or cognitive health interventions. Many of the studies are investigating the effectiveness of newly developed interventions for children and families affected by ASD and other developmental disabilities. Because the grantees are either in their first or second year of funding, most of the research studies are still in progress, so outcome data is not yet available. Detailed and updated findings will be provided in MCHB's forthcoming Report to Congress. Below, we provide two examples of studies that are currently evaluating the effectiveness of particularly innovative interventions for individuals with ASD. The first study is testing a new intervention aimed at changing the peer relationships of children with ASD in their natural environments. The second study described below is investigating the use of telemedicine to deliver an intervention to rural families. The complete list of interventions being evaluated can be found in Table 7.

Peer Social Skills Interventions for Underserved Children with Autism in Schools

The Autism Intervention Research on Behavioral Health (AIR-B) is conducting a randomized, controlled trial to compare an experimental peer-mediated social skills intervention to a standard practice parent-mediated intervention among 200 high-functioning elementary school children (ages 5-7) with ASD. The study aims to determine if peer-mediated social skills instruction at school is effective in addition to parent-mediated instruction in increasing peer interactions and friendships. The experimental intervention is innovative in two primary ways. First, it aims to change children's peer relationships in their *natural* environments. This is an important innovation because generalization of existing lab-based social skills interventions to children's natural environments remains poor. Second, the intervention is targeted to children with ASD who are typically underserved, including low-income children and children from racial/ethnic minority groups. This aspect of the study is important because these groups of children have much less access to evidence-based interventions and typically receive parent-based education interventions, hypothesized to be less effective.

Telehealth Delivery of a Family-Focused Intervention to Reduce Anxiety in Youth with Autism Spectrum Disorders in Rural Colorado

This 2-year study is being conducted at the University of Colorado School of Medicine. The aim of this study is to develop and evaluate an innovative strategy to improve access to a mental health intervention and reduce clinically significant anxiety for families of youth with ASD in rural and underserved areas. This intervention is innovative in its use of telemedicine to deliver a promising mental health intervention to families of children with ASD who are geographically removed from specialty medical centers. Through the use of interactive video technology, families can participate from home and therapists can participate from their offices.

National Institutes of Health (NIH)

NIH has undertaken a number of activities to address the effectiveness and outcomes of innovative and newly developed intervention strategies for individuals diagnosed with autism spectrum disorders (ASD) or other developmental disabilities. NIH established an intramural research program to accelerate development and testing of innovative treatments. This program has already evaluated over 500 children and tested three novel compounds: riluzole (a glutamate antagonist approved for amyotrophic lateral sclerosis), minocycline (an antibiotic which is also anti-inflammatory), and donepezil (a cholinergic drug used for Alzheimer's disease). The program is also studying children from around the nation who have recovered from ASD to detect novel interventions that may be effective in subsets of those with ASD. *More information on these studies is available at:*

<http://clinicaltrials.gov/ct2/show/NCT00251303?term=riluzole+and+autism&rank=1>

<http://clinicaltrials.gov/ct2/show/NCT00409747?term=minocycline+and+autism&rank=1>

<http://clinicaltrials.gov/ct2/show/NCT01053156?term=minocycline+and+autism&rank=2>

<http://clinicaltrials.gov/ct2/show/NCT00695136?term=donepezil+and+autism&rank=1>

<http://clinicaltrials.gov/ct2/show/NCT00047697?term=donepezil+and+autism&rank=2>

<http://clinicaltrials.gov/ct2/show/NCT01098383?term=donepezil+and+autism&rank=3>

NIH also supports an **Autism Center of Excellence (ACE)** network with a long-term goal of understanding the underlying biology of ASD, which would then be used to develop new and better treatments for ASD. Brain imaging studies have shown abnormalities in the synthesis of the neurotransmitter serotonin during critical developmental periods in children with ASD, suggesting that normalizing serotonin signaling may alleviate symptoms of the disorder. Building on this finding and a small pilot trial, this ACE network is conducting a multi-site clinical trial to further test the safety and efficacy of buspirone, a drug that stimulates serotonin signaling, as an intervention in children less than six years of age with ASD. Another NIH-supported clinical trial recently suggested the efficacy of divalproex sodium (an FDA-approved drug used to treat epilepsy, bipolar disorder, and migraine) for treating irritability in children and adolescents with ASD.¹

Although these findings are promising for young children with ASD, there is limited evidence when considering intervention programs or treatment options for older children, adolescents, and adults with ASD. To address this challenge, a small NIH-funded, randomized, controlled trial tested the efficacy of the **Program for the Education and Enrichment of Relational Skills (PEERS)** for adolescents with ASD. This group-based intervention integrates parents into the program to help with generalization of skills into the home and community. Results of this study demonstrated benefits in social skills and increased frequency of peer socialization.² To treat anxiety in high-functioning ASD, NIH-funded researchers conducted a randomized, controlled

¹ Hollander E, Chaplin W, Soorya L, Wasserman S, Novotny S, Rusoff J, Feirsen N, Pepa L, Anagnostou E. Divalproex sodium vs. placebo for the treatment of irritability in children and adolescents with autism spectrum disorders. *Neuropsychopharmacology*. March 2010;35(4):990-98.

² Laugeson EA, Frankel F, Mogil C, Dillon AR. Parent-assisted social skills training to improve friendships in teens with autism spectrum disorders. *Journal of Autism and Developmental Disorders*. April 2009;39(4):596-606.

trial of cognitive behavioral therapy (CBT) in 7- to 11-year-old children with ASD, demonstrating the benefit of CBT in reducing anxiety symptoms.¹

Adult Services and Supports

This section addresses subsection (9) of 399DD: “Information on services and supports provided to individuals with autism spectrum disorder and other developmental disabilities who have reached the age of majority (as defined for purposes of section 615(m) of the Individuals with Disabilities Education Act (20 U.S.C. 1415(m)).” Information on ASD adult services and supports is provided by the Administration on Children and Families (ACF), the Centers for Medicare & Medicaid Services (CMS), the Health Resources and Services Administration (HRSA), and the Department of Education (ED).

Administration on Children and Families (ACF)

Under the Combating Autism Act, ACF (including the Administration on Developmental Disabilities, ADD) does not receive any appropriations, and therefore have no direct program or research responsibilities funded by CAA.

However, ADD programs do serve and support people with autism in several ways with resources appropriated under The Developmental Disabilities Assistance and Bill of Rights Act of 2000, including:

State Councils on Developmental Disabilities (SCDD) (FY 2010 \$75M)

Each State has a Developmental Disabilities Council that functions to increase the independence, productivity, inclusion, and community integration of people with developmental disabilities, including individuals with autism. DDC activities demonstrate new ideas for enhancing people's lives through training activities, through community education and support, by making information available to policy-makers, and by eliminating barriers. *More information is available at: <http://www.acf.hhs.gov/programs/add/states/ddcs.html>.*

Protection and Advocacy Agencies (P&A) (FY 2010 \$41M)

Each State has a Protection and Advocacy (P&A) System to empower, protect, and advocate on behalf of persons with developmental disabilities, including individuals with autism. The P&As are independent of service-providing agencies and offer information and referral services for legal, administrative, and other remedies to resolve problems for individuals and groups of clients. P&As enhance the quality of life of people with developmental disabilities by investigating incidents of abuse and neglect and discrimination based on disability. The P&As also provide an annual opportunity for the public to comment on the objectives, priorities, and activities of the system. This gives clients and others in the community an opportunity to voice

¹ Wood JJ, Drahota A, Sze K, Har K, Chiu A, Langer DA. Cognitive behavioral therapy for anxiety in children with autism spectrum disorders: a randomized, controlled trial. *Journal of Child Psychology and Psychiatry*. March 2009;50(3):224-34.

their concerns and needs to the P&A. *More information is available at:*
<http://www.acf.hhs.gov/programs/add/states/pas.html>.

University Centers for Excellence in Developmental Disabilities Education, Research and Services (UCEDD) (FY 2010 \$39M)

UCEDD is a grant program of the ACF providing support to a national network of University Centers to support interdisciplinary training, exemplary services, technical assistance, and information/dissemination activities. University Centers positively affect the lives of individuals with developmental disabilities, including individuals with autism, and their families by increasing their independence, productivity, and integration into communities. University Centers have four broad tasks: conduct interdisciplinary training, promote community service programs, provide technical assistance at all levels (from local service delivery to community and State governments), and conduct research and dissemination activities. *More information is available at:* <http://www.acf.hhs.gov/programs/add/states/ucedds.html>.

Projects of National Significance (PNS) (FY10 \$14M)

The PNS program, administered by the ACF, awards grants and contracts that promote and increase the independence, productivity, inclusion and integration into the community of persons with developmental disabilities. These projects focus on the most pressing issues for people with developmental disabilities across the country. These projects may involve data collection and analysis, research, technical assistance, projects which improve supportive living and quality of life opportunities, projects to educate policymakers, and efforts to create interagency Federal collaboration.

From the PNS funds, **The National Autism Resource and Information Center** (FY 2010 \$1.88M) will be established in 2011, providing access to high-quality resources and information on community-based services and interventions for people with ASD and their families, through a national dissemination network, regional events, training and technical assistance and an innovative Web presence. *More information on the PNS program is available at:*
<http://www.acf.hhs.gov/programs/add/pns/pns.html>.

Centers for Medicare & Medicaid Services (CMS)

Three major laws, the Deficit Reduction Act (DRA) of 2005, the Children's Health Insurance Program Reauthorization Act of 2009 (CHIPRA), and the Affordable Care Act of 2010 have had or will have an effect on services and supports provided to youth and adults with ASD and other developmental disabilities. The DRA, through the Family Opportunity Act, permitted States to optionally permit parents with specified income who have disabled children and youth to "buy-in" to Medicaid. It also established an opportunity for States to offer home and community-based services (HCBS) to people with disabilities, instead of requiring the traditional Medicaid "waiver." The DRA also established the **Money Follows the Person Rebalancing (MFP) and Psychiatric Residential Treatment Facilities for Individuals under age 21 (PRTF) Demonstrations**, which may impact some people with ASD by expanding their ability to access HCBS.

The CHIPRA reauthorization expanded the program and provided additional funding for States to offer coverage through Medicaid and CHIP to low-income children and young adults. CHIPRA also provided outreach grant funding that may impact youth with developmental disabilities and ASD and enhanced funding for interpretation and translation. CHIPRA requires States to include dental services in State CHIP plans (as well as Medicaid), establishes improved quality measures, and increases support for electronic health records.

The Affordable Care Act expanded the parameters of the HCBS State plan option and established the **Community Living Assistance Services and Supports (CLASS) Plan** and the **Community First Choice Option** to support community living. The MFP Demonstration was also extended. Several other provisions of the Affordable Care Act will impact people with ASD and developmental disabilities, including improvements in access to health care, greater focus on improved quality and service delivery, “balancing” incentives for States to rely more on HCBS and less on institutional care, and improved quality measures for children, youth, and adults enrolled in Medicaid and CHIP. New delivery models with the potential to improve services include Accountable Care Organizations, an optional health home benefit in Medicaid, medical homes for people with chronic conditions, enhancements to the health/supportive services workforce, and screening and background checks for employees of long-term care facilities.

Of particular note are the changes made to Section 1915(i) of the Medicaid State plan, which include an optional benefit for States to serve people in integrated settings and ‘target’ particular populations (e.g., “people with ASD”). Under this option, a State could choose to provide services to people with ASD who do not meet the institutional “level of care” requirements in typical HCBS programs.

CMS has strived to meet its obligation to people with developmental disabilities and ASD in other ways, including spotlighting its efforts to promote State compliance with the Olmstead decision and the Americans with Disabilities Act (ADA). CMS offers technical assistance to States serving people with disabilities and ASD to improve the design, quality, and operation of programs, with an emphasis on enlarging capacity for full community inclusion. The Medicaid program also offers focused technical assistance for States that want to create or continue programs for people with ASD. CMS has recently highlighted its efforts to provide States with information on the use of managed care delivery systems; established strong partnerships with an array of entities at the Federal, State and local levels to encourage affordable housing; performed outreach to stakeholders to develop guidance on community-based services and waiver streamlining; and encouraged States to utilize Medicaid alternatives that promote self-determination, offer self-direction, and make caregiver and peer supports available. CMS is also in the process of refining its data collection process to include an improved array of data regarding Medicaid beneficiaries, including those with ASD.

Health Resources and Services Administration (HRSA)

Many of the **Leadership Education in Neurodevelopmental Disabilities (LEND)** training programs and the State Implementation grantees are engaged in efforts to improve support systems for older youths with ASD and other DD in successfully transitioning to adulthood. In FY 2010, 28 of the 39 LENDs were involved in research, technical assistance, training, service

delivery or the development of educational materials pertaining to postsecondary education, employment, independent living, health care, and other issues of consideration for transition-age young adults. These same grantees generated over 70 products, including book chapters, conference presentations, print brochures, DVDs, and Web sites dedicated to disseminating information about interventions and resources to assist older youths with ASD/DD and their families in transition planning and effectively navigating the steps towards more independent living.

One current LEND project involves the delivery of a social and vocational support group and job training program for young adults between the ages of 18 and 30 with Asperger syndrome and high functioning Autism. The “Aspirations” program is aimed at providing young adults on the autism spectrum with a support network that can help them with their social and emotional adjustment to adult life. In addition to offering the program through the affiliated University Center for Excellence in Developmental Disabilities (UCEDD), one LEND program is working on expanding the program to include an adolescent component. Another LEND program has been involved in the development and dissemination of a widely used curriculum, called “My Future, My Plan: A Transition Planning Resource for Life After High School,” to assist students, parents, and professionals in planning for a successful transition to adulthood. The curriculum includes a DVD, a discussion guide for students and families, a student workbook, and a guide for family members and teachers. Another LEND is actively involved in the development of a gender equitable self-directed education to employment model to enable young women with disabilities to direct their own education and transition paths, to gain skills, experience, and support in nontraditional vocational areas, and to achieve competitive employment outcomes in their chosen careers. The curriculum is currently being field-tested in 21 schools. A middle school version focusing on transitioning to high school is also being pilot-tested. Finally, several LEND programs are conducting research studies pertaining to transition issues and services. As an example, one study used data from the National Survey of Children with Special Health Care Needs to evaluate the role of family-centered care on health related transition counseling for youth with Special Health Care Needs in clinical settings. HRSA supports two research projects addressing the needs of young adults transitioning into adult life. One study demonstrates a family-centered transition planning model, designed to empower families and transitioning students to take a leading role in the process of transition planning. A second study, using secondary data sources, conducts descriptive and predictive analyses of the factors associated with and influencing a successful transition into adulthood for young adults with ASD.

The State Implementation grantees are working towards improving services and supports through system-based changes. Examples of progress to date include: coordination and planning of training summits for State agencies and providers who serve youths with ASD and other DD (AK); development of a model resource center for adults with ASD and their families and planning for a multistate conference focusing on transition to adulthood (IL); development and dissemination of resource guides for families to assist them in arranging a successful transition to adult services (MO, WA); a training module for transitioning-age youths focusing on education, health, and employment (MO); development of a portable medical summary of a young adult’s pediatric care for the adult health care provider (RI); expansion of a State Medical Home portal to include information on transition services (UT); and formation of practice groups

to conduct research on how to improve the delivery of care, including how the system can be improved for youth transitioning to adulthood (WA).

Department of Education (ED)

Although the Department of Education (ED) does not receive appropriations under the Combating Autism Act, ED does contribute significantly to ASD-related services and supports. The Rehabilitation Services Administration (RSA) and the National Institute on Disability and Rehabilitation Research (NIDRR) are located within the Office of Special Education and Rehabilitative Services at the U.S. Department of Education.

The Rehabilitation Services Administration (RSA)

The Department of Education's Rehabilitation Services Administration (RSA) oversees grant programs that help individuals with physical or mental disabilities to obtain employment and live more independently through the provision of such supports as counseling, medical and psychological services, job training and other individualized services.

RSA's major Title I formula grant program authorized by the *Rehabilitation Act of 1973, as amended*, provides funds to state vocational rehabilitation (VR) agencies to provide employment-related services for individuals with disabilities, giving priority to individuals who are significantly disabled. In 2009, 6,434 individuals with autism were served and the VR program assisted 2,314 individuals with autism to achieve an employment outcome.

RSA's Regional Continuing Education programs and Technical Assistance and Continuing Education programs have developed materials and conducted trainings in recent years to improve preparation of VR counselors who serve individuals with autism. In 2007, the RSA-funded Institute on Rehabilitation Issues published the guide, "Rehabilitation of Individuals with Autism Spectrum Disorders." The document identifies issues and conditions for effective transition from school to work, training, or postsecondary education; describes strategies for building effective partnerships between academic, training, health, housing, and other community-based social programs and agencies; improves VR counselors' and employers' knowledge about employment opportunities; and reports evidence-based strategies for effective job development, placement, and retention. *The guide can be found at:* http://iriforum.org/download/32IRI_autism.pdf. *More information on RSA is available at:* <http://www2.ed.gov/about/offices/list/osers/rsa/index.html>.

The National Institute on Disability and Rehabilitation Research (NIDRR)

The Department of Education's NIDRR provides leadership and support for a comprehensive program of research related to the rehabilitation of individuals with disabilities. NIDRR's mission is to generate new knowledge and promote its effective use to improve the abilities of people with disabilities to perform activities of their choice in the community and also to expand society's capacity to provide full opportunities and accommodations for its citizens with disabilities. Toward this end, NIDRR conducts comprehensive and coordinated programs of

research and related activities to maximize the full inclusion, social integration, employment, and independent living of individuals of all ages with disabilities.

NIDRR funds research projects that specifically focus on autism. Within their field-initiated research program, NIDRR has projects that are investigating how technology can be used to support an individual's access and participation in community settings. For example, one project is examining how families can access effective intervention services for their young children with autism through telemedicine and online training programs while another project is examining the use of video-conferencing for accessing effective intervention practices. NIDRR is also funding model projects that conduct research on vocational rehabilitation service models for individuals with autism. One of the model projects is creating a knowledge translation initiative to address the growing need for improvement in vocational rehabilitation and transition services that link to successful employment outcomes for individuals with autism. Another model project is examining the impact of community-based work experiences on the employment outcomes of youth with autism as well as postsecondary school participation and ultimate employment of college students with autism. *More information about NIDRR is available at: <http://www2.ed.gov/about/offices/list/osers/nidrr/index.html>.*

Conclusion

In the past four years under the provisions of the CAA, significant advances have been made in our understanding of ASDs. Notably, reliable estimates of the prevalence of ASDs and a clearer picture of both the opportunities and gaps that exist in ASD research and services are now available. With substantial Federal support, researchers continue the crucial task of evaluating interventions that provide lasting, meaningful benefit to people with ASDs. Large-scale efforts in data collection, consolidation, and sharing are empowering researchers and health practitioners with knowledge not available only a few years ago. With increasing phenotypic and biological knowledge, medical practitioners are beginning to classify sub-categories of the wide spectrum of autistic disorders, which will be crucial in future efforts to provide individually tailored interventions. Within the biomedical research community, there is optimism that a continued rigorous focus on identifying genetic and environmental triggers to ASDs will yield innovative treatment and prevention strategies.

Through intensive surveillance and research efforts, researchers and Federal agencies can also better identify the unmet societal needs surrounding ASDs. While the median age for ASD diagnosis (~4.5 years of age) appears to be favorably on the decline, CDC data indicates a critical need for improved access to early evaluation and diagnostic services. The typical time gap from developmental concern to diagnosis is over 2 years. With a continued focus on ASD awareness and training, within both the public and healthcare spheres, this critical time gap can be lessened. Increased attention is being given to pinpointing underserved communities where diagnostic and intervention support is in the greatest need. Strategic efforts aimed at underserved populations are under way to encourage ASD awareness, early diagnosis, and intervention, but additional efforts will be needed to provide the necessary evidence base to support a wide variety of new interventions and services and supports to provide for the needs of people on the autism spectrum. In addition, services and supports programs across several Federal agencies are actively identifying best practices and implementing programs to increase quality of life for people with ASD across the lifespan. Finally, the Federal coordination

provided by the Interagency Autism Coordinating Committee (IACC), has successfully identified key research and services priorities and has fostered enhanced communication and collaboration between Federal agencies, private foundation partners and the public. This Federal coordination will continue to be needed to monitor progress, provide a forum for public input into Federal ASD policy, and help agencies bring critical research into practice in the form of effective programs to help people with ASD and their families.

Appendix i. CDC-supported Autism Publications 2006-September 2010

- Atladóttir HO, Thorsen P, Schendel DE, Østergaard L, Lemcke S, Parner ET. Association of hospitalization for infection in childhood with diagnosis of autism spectrum disorders: a Danish cohort study. *Archives Pediatric Adolescent Medicine*. May 2010; 164(5):470-7.
- Atladóttir HÓ, Parner ET, Dalsgaard S, Schendel D, Thomsen PH, Thorsen P. Variation in incidence of neurodevelopmental disorders with season of birth: an evaluation of four childhood-onset neuropsychiatric conditions. *Epidemiology*. 2007;18:240-245.
<http://www.ncbi.nlm.nih.gov/pubmed/17202868>
- Atladóttir HÓ, Parner ET, Schendel D, Dalsgaard S, Thomsen PH, Thorsen P. Time trends in reported diagnoses of childhood neuropsychiatric disorders: a Danish cohort study. *Archives of Pediatrics & Adolescent Medicine*. 2007;161:193-198.
<http://www.ncbi.nlm.nih.gov/pubmed/17283306>
- Avchen, R., Wiggins, L.D., Devine, O., Van Naarden-Braun, K., Rice, C., Hobson, N., Schendel, D., Yeargin-Allsopp, M. Evaluation of a records-review surveillance system used to determine the prevalence of autism spectrum disorders. *Journal of Autism and Developmental Disorders*. June 2010. (Epub ahead of print)
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