Report to Congress

on Activities Related to Autism Spectrum Disorder and Other Developmental Disabilities

Under the Combating Autism Act of 2006 and
Combating Autism Reauthorization Act of 2011
(FY 2010 – FY 2012)

Prepared by the
Office of Autism Research Coordination
National Institutes of Health

On Behalf of the
Office of the Secretary
Department of Health and Human Services

U.S. Department of Health and Human Services

Report to Congress on Activities Related to Autism Spectrum Disorder and Other Developmental Disabilities

UNDER THE COMBATING AUTISM ACT OF 2006 AND COMBATING AUTISM REAUTHORIZATION ACT OF 2011 (FY 2010-FY 2012)

Prepared by the Office of Autism Research Coordination
National Institutes of Health
On Behalf of the Office of the Secretary
U.S. Department of Health and Human Services

February 2014

NIH publication No. 14-8012

Copyright Information

Suggested Citation

U.S. Department of Health and Human Services, Office of Autism Research Coordination, National Institutes of Health (On behalf of the Office of the Secretary). Report to Congress on Activities Related to Autism Spectrum Disorder and Other Developmental Disabilities Under the Combating Autism Act of 2006 and Combating Autism Reauthorization Act of 2011 (FY 2010 – FY 2012). February 2014. Retrieved from the Department of Health and Human Services Interagency Autism Coordinating Committee website at: http://iacc.hhs.gov/reports/reports-to-congress/FY2010-2012/index.shtml

This report is publicly available on the Department of Health and Human Services Interagency Autism Coordinating Committee website at: http://iacc.hhs.gov/reports/reports-to-congress/FY2010-2012/index.shtml. All hyperlinked materials (indicated in green text) within this document can be directly accessed online in the web version of this report.

Table of Contents

BACKGROUND

REQUIRED ELEMENTS

- ► Department of Health and Human Services

CONCLUSION

List of Tables

Appendices

Introduction

AUTISM SPECTRUM DISORDER

Autism spectrum disorder (ASD) is a neurodevelopmental condition characterized by persistent impairments in social communication and social interaction, including impaired verbal and nonverbal communication skills and social interactions, restricted, repetitive, and stereotyped patterns of behavior, and difficulty in developing, maintaining, and understanding relationships with others. Depending on the level of severity of the impairments in different areas, ASD can range in overall impact from mild impairment to significantly disabling. Research suggests that ASD may arise very early in brain development, but overt signs and symptoms of ASD usually emerge between 1 and 3 years of age. ASD is a condition that lasts throughout life, but in some individuals, impairments can improve or change to varying degrees over time. Interventions and other services and supports are available to help improve the quality of life for children and adults with ASD, but the needs for earlier identification, improved interventions, and broadly available access to services remain a challenge. With the current prevalence of ASD in the U.S. estimated at 1 in 88 children, ASD continues to be a top national health priority, engaging the collaborative efforts of both federal agencies and private organizations to advance research and improve services to assist individuals and families affected by ASD.[1] This report describes the work being done through programs and activities supported by multiple federal departments and agencies to address medical, educational, service and other related needs in order to improve quality of life for children, adolescents and adults on the autism spectrum.

LEGISLATIVE BACKGROUND

The Combating Autism Act (CAA) of 2006 (P.L. 109-416) was enacted on December 19, 2006 to address public concerns about the increasing prevalence of autism spectrum disorder (ASD) and to strengthen federal efforts around this issue. The CAA amended the Public Health Service Act to authorize the expansion and enhancement of activities related to ASD research, surveillance, early detection, prevention, treatment, education, and disability programs. The law also reconstituted the Interagency Autism Coordinating Committee as a federal advisory body with specific membership requirements and a charge to provide federal coordination of ASD-related activities, as well as a venue for public input on issues related to ASD. Additionally, the CAA required the Department of Health and Human Services (HHS), in conjunction with the Department of Education, to submit, no later than 4 years after the enactment of the CAA, a Report to Congress on the progress made in implementing provisions of the CAA. This report, the Report to Congress on Activities Related to Autism Spectrum Disorder and Other Developmental Disabilities under the

---

[1] Centers for Disease Control and Prevention. Prevalence of Autism Spectrum Disorders—Autism and Developmental Disabilities Monitoring Network, 14 Sites, United States, 2008. *Morbidity and Mortality Weekly Report (MMWR) Surveillance Summaries*. March 20, 2012; 61 (SS-03): 1-19. [PMID:22456193]

Combating Autism Act of 2006 (FY 2006- FY 2009)[2], was submitted in accordance with the requirement. Finally, the CAA authorized $945 million in federal funds to support ASD-related federal efforts through 2011.

On September 30, 2011, Congress enacted the Combating Autism Reauthorization Act (CARA) of 2011 (P.L. 112-32), which extended the authorizations of the CAA past its sunset date of September 30, 2011 to September 30, 2014. This ensured the continuation of programs authorized by the CAA for another 3 years. Under CARA's provisions, Section 399DD was amended to state, "Not later than 2 years after the date of enactment of the Combating Autism Reauthorization Act of 2011, 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." The CARA also authorized $693 million in federal funds to support ASD-related federal efforts through 2014.

PROVISIONS OF THE COMBATING AUTISM ACT OF 2006 AND COMBATING AUTISM REAUTHORIZATION ACT OF 2011

- Authorizes NIH to expand, intensify, and coordinate ASD research activities, subject to the availability of appropriations, and consolidate research programs to enhance efficiency.
- Authorizes CDC to conduct ASD and developmental disabilities surveillance and research programs.
- Increases federal efforts in autism education/awareness, early detection, and intervention, including efforts to increase cultural competency and provider training across several agencies/programs within HHS, including HRSA and ACF, and the Department of Education.
- Reconstitutes the Interagency Autism Coordinating Committee to coordinate all ASD-related efforts within the HHS, serve as a forum for public input, and provide advice to the Secretary of Health and Human Services on matters pertaining to ASD.
- Requires a Report to Congress on progress made in implementing the provisions of the CAA.
- Authorizes $1.64 billion in appropriations for federal ASD-related efforts through September 30, 2014.

---

[2] U.S. Department of Health and Human Services, Office of Autism Research Coordination, National Institutes of Health (On behalf of the Office of the Secretary). *Report to Congress on Activities Related to Autism Spectrum Disorder and Other Developmental Disabilities Under the Combating Autism Act of 2006 (FY 2006 – FY 2009)*. December 2010 (Rev. April 2011). Retrieved from the Department of Health and Human Services Interagency Autism Coordinating Committee website at: http://iacc.hhs.gov/reports/reports-to-congress/FY2006-2009/index.shtml.

REQUIREMENTS FOR THE CAA REPORT TO CONGRESS

The Combating Autism Act and the Combating Autism Reauthorization Act require reports on federal ASD activities to be submitted to Congress. The following elements are required:

As stated in the CAA, the Report to Congress shall contain the following—

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))"

PREVIOUS REPORT TO CONGRESS (FY 2006 – FY 2009)

In 2010, the Office of Autism Research Coordination within the National Institute of Mental Health/NIH prepared the Report to Congress required by the Combating Autism Act of 2006 on behalf of the Office of the Secretary of Health and Human Services. The report was submitted to Congress by HHS in December 2010 and was published on the Interagency Autism Coordinating Committee's website for public access. The *Report to Congress on Activities Related to Autism Spectrum Disorder and Other Developmental Disabilities under the Combating Autism Act of 2006 (FY 2006-FY 2009)*[3] describes the efforts of the Interagency Autism Coordinating Committee (IACC), the Department of Education, and eight individual agencies within the Department of Health and Human Services with regard to progress and expenditures made in autism spectrum disorder (ASD) research and services in fiscal years 2006 through 2009. The report also highlights federal research and services activities related to prevalence of ASD, diagnosis and intervention, early screening and intervention, effectiveness and outcomes of interventions and innovative strategies, and services and supports for children and adults. The summary and highlights of the *Report to Congress on Activities Related to Autism Spectrum Disorder and Other Developmental Disabilities under the Combating Autism Act of 2006 (FY 2006-FY 2009)* can be found in Appendix ii of this report.

REPORT TO CONGRESS (FY 2010 - FY 2012)

The *Report to Congress on Activities Related to Autism Spectrum Disorder and Other Developmental Disabilities Under the Combating Autism Act of 2006* and *Combating Autism Reauthorization Act of 2011 (FY 2010-FY 2012)* includes updates from the Interagency Autism Coordinating Committee and agencies within the Department of Health and Human Services and from the Department of Education, as required by the CAA and CARA, as well as updates from the Department of Defense and the National Science Foundation. This report describes ASD-related activities and coordination efforts that span multiple federal agencies and departments. The report covers all of the elements required in the CAA/CARA for the period of fiscal years 2010-2012. Some information regarding federal programs and projects in FY 2013 is included in this report, but it should be noted that the information pertaining to FY 2013 may not be complete, as FY 2013 was still underway as this report was being developed.

---

[3] U.S. Department of Health and Human Services, Office of Autism Research Coordination, National Institutes of Health (On behalf of the Office of the Secretary). *Report to Congress on Activities Related to Autism Spectrum Disorder and Other Developmental Disabilities Under the Combating Autism Act of 2006 (FY 2006 – FY 2009)*. December 2010 (Rev. April 2011). Retrieved from the Department of Health and Human Services Interagency Autism Coordinating Committee website at: http://iacc.hhs.gov/reports/reports-to-congress/FY2006-2009/index.shtml.

Interagency Coordination

THE ROLE OF THE INTERAGENCY AUTISM COORDINATING COMMITTEE

The current Interagency Autism Coordinating Committee (IACC) was established by Congress under the Combating Autism Act (CAA; P.L. 109-416) and reauthorized in 2011 under the Combating Autism Reauthorization Act (CARA; P.L. 112-32) to provide advice to the Secretary of Health and Human Services (HHS) concerning issues related to autism spectrum disorder (ASD) and to coordinate all ASD-related efforts within HHS. The IACC serves as a forum for public input on issues related to ASD, and the committee uses this input to inform its activities, including the annual update of the *IACC Strategic Plan for ASD Research*, which serves as a guide for federal agencies in planning ASD-related research programs and activities, and the development of advisory letters and public statement on a variety of issues that are relevant to individuals and families affected by ASD.[4] In addition, the committee monitors federal and community activities related to ASD and compiles an annual *IACC Summary of Advances in ASD Research* to inform Congress and the public of major advances in ASD research.[5]

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. The current committee is composed of public members including family members of children and adults with ASD, individuals with ASD, leaders of national advocacy and research organizations and service providers, as well as officials from the following federal agencies and offices that address ASD research or services: Administration for Children and Families (ACF), Administration for Community Living (ACL), Agency for Healthcare Research and Quality (AHRQ), Centers for Disease Control and Prevention (CDC), Centers for Medicare & Medicaid Services (CMS), Department of Defense (DoD), Department of Education (ED), Food and Drug Administration (FDA), Health Resources and Services Administration (HRSA), five Institutes/Centers of the National Institutes of Health (NIH), and the NIH Director.[6] 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 to enable it to carry out its Congressionally-mandated responsibilities.

---

[4] Interagency Autism Coordinating Committee (IACC). *IACC Strategic Plan for Autism Spectrum Disorder (ASD) Research—2012 Update*. December 2012. Retrieved from the U.S. Department of Health and Human Services Interagency Autism Coordinating Committee website: http://iacc.hhs.gov/strategic-plan/2012/index.shtml.

[5] Interagency Autism Coordinating Committee (IACC). *2012 IACC Summary of Advances in Autism Spectrum Disorder Research*. April 2012. Retrieved from the U.S. Department of Health and Human Services Interagency Autism Coordinating Committee website: http://iacc.hhs.gov/summary-advances/2012/index.shtml.

[6] NIH IC's on the IACC: NIDCD, NIMH, NIEHS, NINDS, NICHD.

In addition to the full committee, the IACC currently has two subcommittees and several planning groups:

- IACC Subcommittee for Basic and Translational Research - addresses issues related to biomedical and behavioral research, research collaborations and resources, and other related topics.

- IACC Subcommittee for Services Research and Policy- addresses issues related to services research and services policy, including services provision, services research, access, housing, transition, social inclusion, health disparities, healthcare costs, the Affordable Care Act and safety issues.

IACC FULFILLMENT OF CAA MANDATES

The activities of the IACC described above fulfill the committee's Congressional mandates under the CAA:

"Develop and Annually Update a *Strategic Plan for Autism Spectrum Disorder Research*."

- The IACC's original Strategic Plan was completed in 2009, and in 2010, 2011, and 2012, the IACC provided annual Strategic Plan updates. These documents were submitted to Congress as required.[7]

- The *IACC Strategic Plan* is organized around seven consumer-based questions:
    1. When should I be concerned? (Diagnosis)
    2. How can I understand what is happening? (Underlying biology of ASD)
    3. What caused this to happen and can it be prevented? (Risk factors)
    4. Which treatments and interventions will help? (Treatments and interventions)
    5. Where can I turn for services? (Services for children)
    6. What does the future hold for adults? (Issues that affect people with ASD across the lifespan)
    7. What other infrastructure and surveillance needs must be met? (Research infrastructure, workforce, surveillance, and information dissemination)

- Each of the seven chapters of the *IACC Strategic Plan* describes the state of research and related activities in that area, the most pressing needs of the community and the research field in that area, the recent progress achieved, and what gaps and opportunities remain. Each question area also contains a list of specific objectives that represent priorities or recommendations from the committee for activities that will advance knowledge and development in the seven areas.

---

[7] Interagency Autism Coordinating Committee (IACC). *IACC Strategic Plan for Autism Spectrum Disorder (ASD) Research—2012 Update*. December 2012. Retrieved from the U.S. Department of Health and Human Services Interagency Autism Coordinating Committee website: http://iacc.hhs.gov/strategic-plan/2012/index.shtml.

"Develop and Annually Update a *Summary of Advances in Autism Spectrum Disorder Research*"

- The IACC has issued an annual *Summary of Advances in ASD Research* for each of the following years: 2007, 2008, 2009, 2010, 2011 and 2012.[8] The most recent *Summary of Advances* documents provide a short summary of each of the top 20 advances identified by the committee in each year, covering each of the seven question areas in the *IACC Strategic Plan* which roughly correlate with the specific areas mentioned in the law: causes, prevention, treatment, early screening, diagnosis or rule out, intervention, and access to services and supports for individuals with autism spectrum disorder.

"Monitor Federal Activities With Respect to Autism Spectrum Disorder."

- The IACC monitors federal and community ASD activities in several ways. At IACC meetings, the committee regularly hears presentations from federal and state agencies and private organizations that are involved in ASD research and services activities, allowing them to stay abreast of recent developments and best practices. The IACC also reviews the research literature each year for its annual Strategic Plan update and to prepare its annual *Summary of Advances in ASD Research*.

- The IACC annually requests that the NIH Office of Autism Research Coordination prepare an *ASD Research Portfolio Analysis Report*, which analyzes information about autism-related projects funded by federal agencies and private organizations.[9] The report describes progress that is being made toward achieving the objectives set forth in the *IACC Strategic Plan for ASD Research* in terms of both funding and projects, providing a snapshot of the research landscape and allowing the committee to determine which areas of its Strategic Plan are currently well-covered by ongoing research and which areas are still in need of additional efforts. This report has served as a valuable source of information about ASD research funding to both federal agencies and private research organizations. OARC is currently preparing a report on 2011 and 2012 funding, to be released in 2014.

- The 2008, 2009 and 2010 *ASD Research Portfolio Analysis Reports* are available on the IACC website, and all the data collected for those reports have been made available to the public in an online database, the IACC/OARC Portfolio Analysis Web Tool, which provides members of the public with a user-friendly way to search, sort and view analysis of various aspects of federally and privately-funded ASD research projects.

"Make Recommendations to the Secretary Regarding any Appropriate Changes to Federal Activities"

- The IACC makes recommendations to the HHS Secretary in several ways. The 2011 IACC Strategic Plan for ASD Research contains 78 objectives that serve as recommendations for further efforts in specific priority areas. In addition to the HHS Secretary, the NIH Director, as required in the CAA, and all the federal agency

---

[8] Interagency Autism Coordinating Committee (IACC). *2012 IACC Summary of Advances in Autism Spectrum Disorder Research*. April 2012. Retrieved from the U.S. Department of Health and Human Services Interagency Autism Coordinating Committee website: http://iacc.hhs.gov/summary-advances/2012/index.shtml.

[9] Office of Autism Research Coordination, National Institute of Mental Health, on behalf of the Interagency Autism Coordinating Committee (IACC). *2010 IACC Autism Spectrum Disorder Research Portfolio Analysis Report*. July 2012. Retrieved from the U.S. Department of Health and Human Services Interagency Autism Coordinating Committee website: http://iacc.hhs.gov/portfolio-analysis/2010/index.shtml.

representatives on the committee receive the IACC Strategic Plan and its updates for use in planning activities within their agencies. The Strategic Plan is also sent to Congress and posted on the IACC website for public access.[10]

- The committee has also used advisory letters to the HHS Secretary as a method for providing advice. The committee has written three letters to the Secretary, advising her of emerging issues in the ASD community and recommending changes in federal activities and improved interagency coordination on these issues to benefit the autism community: Letter to the Secretary on Wandering (2011), Letter to the Secretary on Seclusion and Restraint (2011), Letter to the Secretary on Health Coverage (2013).

- In 2012 the IACC issued a Statement on the Sandy Hook Tragedy as a mode of communicating their opinions and advice to the Secretary, agencies and the community. The statement supported the prevention of violence and other undesirable outcomes through availability and accessibility of appropriate medical, educational, mental health and community supports for people with ASD.

"The Committee Shall Meet not Fewer than Two Times Each Year."

- The table below highlights IACC full committee, subcommittee, workgroup and planning group, workshops and other meetings and events (in-person and conference call) that have taken place each year since 2007. The committee has met more than twice in every year since 2007. The committee initially formed in 2007 and was only able to meet once that year.

- All in-person and phone meetings of the full committee, subcommittees, planning groups, workshops and town hall meetings of the IACC are open to the public.

IACC Meetings and Events 2007-2013

MEETING	2007	2008	2009	2010	2011	2012	2013	TOTALS
Full Committee	1	5	7	5	4	4	5	**31**
Subcommittee	0	5	8	10	5	4	3	**35**
Planning Groups/ Workgroups	0	5	0	0	0	12	17	**34**
Workshops	0	4	1	1	1	0	1	**8**
Other Events	0	1	1	0	0	0	0	**2**
Totals	**1**	**20**	**17**	**16**	**10**	**20**	**26**	**110**

Table 1. This table shows the number of IACC Full Committee, Subcommittee, Workgroup and Planning Group, Workshops and other meetings and events that took place from 2007-2013.

---

[10] Interagency Autism Coordinating Committee (IACC). *2011 IACC Strategic Plan for Autism Spectrum Disorder Research*. January 2011. Retrieved from the U.S. Department of Health and Human Services Interagency Autism Coordinating Committee website: http://iacc.hhs.gov/strategic-plan/2011/index.shtml.

OUTREACH AND TRANSPARENCY

The Office of Autism Research Coordination (OARC) 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, meeting materials, slides and transcripts from the meetings of the IACC, its subcommittees and planning groups, as well as reports and publications produced by the committee. The website also contains background information about the committee and its work, links to non-IACC documents that are of interest to the autism community, and a page showing ASD-related meetings and events that are open to the public. The website will continue to add new categories of IACC materials for public access in the future.

In 2012, OARC launched a publicly accessible database called the IACC/OARC ASD Research Portfolio Analysis Web Tool that makes the grant and other project data for all ASD research projects included in the *IACC ASD Research Portfolio Analysis Report* available to the public. The database allows keyword searching, sorting and specialized reports, which enables members of the public to quickly access detailed information about projects that have been funded both by the federal agencies and by participating private funders.[11]

In addition, in 2009 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 RSS feeds 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, subcommittee and other IACC-related 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.

---

[11] Office of Autism Research Coordination, National Institute of Mental Health, on behalf of the Interagency Autism Coordinating Committee (IACC). *2010 IACC Autism Spectrum Disorder Research Portfolio Analysis Report*. July 2012. Retrieved from the U.S. Department of Health and Human Services Interagency Autism Coordinating Committee website: http://iacc.hhs.gov/portfolio-analysis/2010/index.shtml.

Required Elements of the Report to Congress (FY 2010-FY 2012)

In addition to a summary of the role of the Interagency Autism Coordinating Committee and NIH Office of Autism Research Coordination in coordinating ASD efforts, this Report to Congress overviews each federal agency that supports projects or programs related to ASD, as well as highlights information on current ASD incidence estimates, the present diagnostic and intervention landscape, ongoing efforts in ASD supports and services, and strategies to address the continuing needs of diverse ASD communities.

With data from the Department of Education (ED), Environmental Protection Agency (EPA), Department of Defense (DoD), National Science Foundation (NSF), and nine federal agencies within the Department of Health and Human Services (HHS), this report addresses ASD research and services according to the required elements outlined in the CAA (see Page 3 for a complete list of required elements). Elements (1) and (2) have been combined into one chapter covering the general progress made and amounts expended during the past 3 years in federal ASD research efforts by lead agencies and offices. Elements (7) and (8) have been combined into one chapter covering the effectiveness and outcomes of interventions for individuals with ASD.

FEDERAL DEPARTMENTS AND AGENCIES INCLUDED IN THIS REPORT

- Department of Health and Human Services [HHS]
    - Administration for Children and Families [ACF]
    - Administration for Community Living [ACL]
    - Agency for Healthcare Research & Quality [AHRQ]
    - Centers for Disease Control and Prevention [CDC]
    - Centers for Medicare & Medicaid Services [CMS]
    - Food and Drug Administration [FDA]
    - Health Resources and Services Administration [HRSA]
    - National Institutes of Health [NIH]
    - Substance Abuse and Mental Health Services Administration [SAMHSA]
- Department of Education [ED]
- Environmental Protection Agency [EPA]
- Department of Defense [DoD]
- National Science Foundation [NSF]

FEDERAL DEPARTMENTS SUPPORTING ASD ACTIVITIES

The U.S. Department of Health and Human Services (HHS) is the chief U.S. agency for protecting the health of all Americans and providing essential human services. HHS includes more than 300 programs and 10 operating divisions covering a wide spectrum of activities, and includes nine federal agencies represented in this Report to Congress. The following HHS operating divisions' autism research and services activities are described in this report: Administration for Children and Families, Administration for Community Living, Agency for Healthcare Research & Quality, Centers for Disease Control and Prevention, Centers for Medicare & Medicaid Services, Food and Drug Administration, Health Resources and Services Administration, National Institutes of Health, and Substance Abuse and Mental Health Services Administration.

The U.S. Department of Education's (ED's) mission is to promote student achievement and preparation for global competitiveness by fostering educational excellence and ensuring equal access. ED also supports programs to develop and implement evidence-based practices for educating children with autism. Although the Department of Education does not receive appropriations under the Combating Autism Act, ED does contribute significantly to ASD-related services and supports under the Individuals with Disabilities Education Act (IDEA).

The U.S. Department of Defense (DoD) is charged with coordinating and supervising all agencies and functions of the government concerned directly with national security and the United States Armed Forces. Within the DoD's Defense Health Research Program, the Autism Research Program (ARP) was established in 2007 with the mission to improve the lives of individuals with ASD by promoting innovative research that advances the understanding of ASD and leads to improved outcomes for those with ASD. Although the DoD is not one of the federal agencies identified under the 2006 Combating Autism Act (CAA), this report includes updates on the Defense Health Research Program, ARP, as well as TRICARE (the health care program of the United States Department of Defense Military Health System), which aids military families affected by ASD, and the DoD-Air Force, which helps establish infrastructure to monitor rates of autism, improve care, and act as a resource for research into the causes of ASD.

ASD Progress and Expenditures

This chapter covers subsections (1) and (2) of Section 399DD of the CAA, 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." In accordance with the statute, details are provided from the agencies and offices within HHS that are involved in ASD research and services activities, including ACF, ACL, AHRQ, CDC, CMS, FDA, HRSA, NIH, and SAMHSA, as well as the Department of Education (ED), Environmental Protection Agency (EPA), Department of Defense (DoD), and National Science Foundation (NSF), which also conduct activities that concern or are related to ASD.

THE DEPARTMENT OF HEALTH AND HUMAN SERVICES

The mission of the Department of Health and Human Services (HHS) is to help provide the building blocks that Americans need to live healthy, successful lives. This mission is fulfilled by providing millions of children, families, and seniors with access to high-quality health care, by helping people find jobs and parents find affordable child care, by keeping the food on Americans' shelves safe and infectious diseases at bay, and by pushing the boundaries of how to diagnose and treat disease. Several agencies within HHS support research and services that address the needs of the people with ASD and their families.

ADMINISTRATION FOR CHILDREN AND FAMILIES (ACF)

The Administration for Children & Families (ACF) promotes the economic and social well-being of families, children, individuals and communities. ACF programs aim to:

- Empower families and individuals to increase their economic independence and productivity
- Encourage strong, healthy, supportive communities that have a positive impact on quality of life and the development of children
- Create partnerships with front-line service providers, states, localities, and tribal communities to identify and implement solutions that transcend traditional program boundaries
- Improve access to services through planning, reform and integration
- Address the needs, strengths and abilities of vulnerable populations including people with developmental disabilities, refugees and migrants

The ACF does not have any programs or funding specifically focused on provisions of the CAA or for individuals on the autism spectrum. However, ACF funds Head Start services for children with ASD. Table 2 outlines the total funds spent on Head Start services for children with ASD between 2010 and 2012. Head Start promotes the school readiness of children ages birth to 5 from low-income families, including those with ASD, by enhancing their cognitive, social and emotional development. In April of 2013, ACF launched a web page titled "Autism Awareness and Acceptance in Early Childhood Education," which is focused on providing information on ASD to early childhood teachers. The webpage includes fact sheets, helpful tips, advice on finding local resources, and links to multiple relevant websites. The tip sheets, compiled by ACF and the *Eunice Kennedy Shriver* National Institute of Child Health and Human Development (NICHD) at the NIH, contain numerous strategies for working with children with ASD, suggested by experts from across the country. In addition, the site contains a video of a speech given by Linda Smith, the ACF Deputy Assistant Secretary for Early Childhood Development, and a speech in Spanish by Wilma Pastrana, First Lady of Puerto Rico, emphasizing the importance of autism awareness and acceptance.

In addition to the ASD site, ACF has named developmental and behavioral screening a priority in its strategic plan, The ACF Strategic Initiatives. While the focus of this priority in the ACF strategic plan is broad developmental and behavioral screening, rather than screening for specific disorders, the initiative will help inform the early childhood field and ultimately help children with all disabilities, including those with ASD. As part of ACF's activities in this domain, in FY 2012, ACF provided $100,000 in funding to examine the use of a first line screening instrument on Native American reservations. The instrument under study includes, as part of a broader screen of development, an ASD screen. The funds were added to an existing contract with the Tribal Research Council and will serve to assess the cultural sensitivity of each individual item in the screening instrument. Of note, this is the first time a developmental and behavioral screening instrument has been tested or culturally adapted to fit the needs of young Native American children.

The ACF Office of Refugee Resettlement (ORR) helps new populations immigrating into the United States to maximize their potential, providing people in need with critical resources to assist them in becoming integrated members of American society. Resources disseminated by ORR include ASD-related materials developed by ACF and CDC (i.e., Learn the Signs. Act Early) to assist families with recognizing and addressing autism-related needs. ORR is also planning a webinar for its stakeholders on ASD in 2014.

Other Activities

In addition to the activities described above, ACF participates as a member agency on the Interagency Autism Coordinating Committee.

ACF Head Start Funding for ASD-related Activities

	FY 2010	FY 2011	FY 2012	FY 2010-FY 2012
Head Start funding for children with ASD	$16.8 M	$19 M	$22.3 M	$58.1 M

Table 2. Administration for Children & Families Head Start Expenditures for Children with ASD, FY 2010-2012 (Millions).

ADMINISTRATION FOR COMMUNITY LIVING (ACL)

On April 16, 2012, the U.S. Department of Health and Human Services combined the Administration on Intellectual and Developmental Disabilities (AIDD), the Administration on Aging, and the Office on Disability into a new agency called the Administration for Community Living. In addition, the Administration on Intellectual and Developmental Disabilities was known formerly as the Administration on Developmental Disabilities.

The Administration for Community Living (ACL)/Administration on Intellectual and Developmental Disabilities (AIDD) does not receive any appropriations under the Combating Autism Act, and therefore has no direct program or research responsibilities funded by CAA. However, ACL/AIDD programs do serve and support a full range of individuals with disabilities, including those with ASD, through several programs with resources appropriated under the Developmental Disabilities Assistance and Bill of Rights Act of 2000 (P.L. 106-402). These programs are described in this section of the report. Funding from FY 2010-FY 2012 for Autism NOW, a program supported by the AIDD-administered Projects of National Significance that specifically addresses the needs of people on the autism spectrum, can be found in Table 3.

State Councils on Developmental Disabilities (SCDD)

Each state and territory has a Developmental Disabilities Council (DDC) supported by ACL's Administration on Intellectual and Developmental Disabilities (AIDD) that functions to increase the independence, productivity, inclusion, and community integration of people with intellectual and developmental disabilities, including individuals with autism. Council members are appointed by the governor and composed of key stakeholders, including individuals with intellectual and developmental disabilities, parents and family members, and representatives of state agencies and non-governmental organizations that provide services to people with intellectual and developmental disabilities. DDC activities support a variety of systems change and capacity building efforts, including projects demonstrating new ideas for enhancing people's lives, training activities, community education and support, making information available to policy-makers, and working to eliminate barriers to full participation in various life areas such as education, employment, and community living.

Protection and Advocacy Agencies (P&A)

ACL/AIDD supports a Protection and Advocacy (P&A) Agency in each state and territory and a P&A for Native Americans. P&As empower, protect, and advocate on behalf of persons with intellectual and developmental disabilities, including individuals with autism. The P&As are independent of service-providing agencies. They offer a range of services to enhance the quality of life of people with developmental disabilities and resolve problems for individuals and groups of clients, including information and referral for legal, administrative, and other remedies and investigations of incidents of abuse and neglect and discrimination based on disability. The P&As provide an annual opportunity for the public to comment on the objectives and priorities of the system. This gives clients and others in the community an opportunity to voice their needs to the P&A.

University Centers for Excellence in Developmental Disabilities Education, Research and Service (UCEDD)

The University Centers for Excellence in Developmental Disabilities Education, Research and Service (UCEDD) is a grant program of ACL/AIDD that provides a national network of University Centers that conduct interdisciplinary training, exemplary community services, research, and information dissemination activities. This network of 68 University Centers throughout the states and territories positively affects 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 engage in a variety of initiatives to address the needs of individuals with ASD. Examples include:

- Over 30 UCEDDs receive *Leadership Education in Neurodevelopmental and Related Disabilities* (LEND) grants funded under the 2006 Combating Autism Act and administered by the Health Resources and Services Administration's (HRSA) Maternal and Child Health Bureau (MCHB). LEND programs provide long-term, graduate level interdisciplinary training as well as interdisciplinary services and care.

- Multiple UCEDDs provide community-based services such as the Alaska UCEDD's *Multidisciplinary Diagnostic Team and Comprehensive Referral for Autistic Spectrum Disorders* project that screens, diagnoses, and refers children with autism spectrum disorder and other developmental disabilities.

- UCEDDs are a engaged in a variety of research efforts, such as the *Sustainable Implementation of Family-Centered Transition Planning for Young Adults with Autism Spectrum Disorders* study co-implemented by the University of New Hampshire Institute on Disability and the University of Maine Center for Community Inclusion and Disability Studies to develop a sustainable process for implementing a Family-Centered Transition Planning model for youth and young adults with ASD.

- UCEDDs maintain a variety of information dissemination activities, which include newsletters specific to autism and webpages that provide resources on autism. UCEDDs also develop presentations to different audiences on autism and provide resources on issues specific to autism across the age span. The Tarjan Center at the University of California, Los Angeles, recently released the *PEERS Virtual Coach* mobile application, which is a companion to Dr. Elizabeth Laugeson's new book, *The Science of Making Friends*, and contains important skills, strategies, role-play videos, and tools for making and keeping friends all within a mobile device.

Projects of National Significance (PNS)

The Projects of National Significance (PNS) program, administered by ACL/AIDD, 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.

Autism NOW

With funding from PNS, the Autism NOW National Autism Resource and Information Center began in October 2010 as part of a national initiative of The Arc of the United States. The initiative seeks to empower stakeholders by 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.

In April 2011, the Autism NOW website was launched. The website provides a dynamic and interactive, highly visible, and effective central point of quality resources and information for members of the autism community. Autism NOW has reached thousands of individuals—including parents and family members, individuals with autism spectrum disorder and other developmental disabilities, advocates, and policymakers—through its website, Facebook and Twitter pages, webinars, summits and conferences, e-newsletters, and personal interactions.

Autism NOW hosts free webinars, allowing self-advocates, families, and professionals to discuss a wide variety of topics affecting autism spectrum disorder and other developmental disabilities. In addition to its online presence, in 2011 Autism NOW conducted five regional summits across the United States that emphasized and created a safe environment for sharing experiences and building community. A total of 650 individuals attended the five summits. After the summits, Autism NOW gathered lessons learned and developed a report, "Light at the End of the Tunnel," which was released in December 2011. The report provides demographic information on summit registrants, survey results from attendees, and quotations resulting from round table discussions.

Autism NOW also produces resources such as its employment handbook, An Autistic View of Employment. This tool aims to help self-advocates better navigate the world of employment. It contains stories, advice, and the perspectives of self-advocates on various aspects of the employment process. Topics covered include the Americans with Disabilities Act, vocational rehabilitation, characteristics of good managers, disclosure and self-care, employment scams, clear communication, and networking.

In 2012, Autism NOW began offering an answer series using YouTube. Visitors to the Autism NOW website can submit questions, and each month experts select two questions and provide 2–4 minute video answers. Topics have included assistive technology and how it can help an individual with an intellectual or developmental disability, self-advocacy, how to obtain a driver's license, and how parents can talk to their son or daughter about sex.

President's Committee for People with Intellectual Disabilities (PCPID)

The President's Committee for People with Intellectual Disabilities (PCPID) is a federal advisory committee to the President and the Secretary of Health and Human Services on matters relating to persons with intellectual disabilities. The PCPID promotes policies and initiatives that support independence and lifelong inclusion of people with intellectual disabilities in their respective communities. The Administration on Intellectual and Developmental Disabilities (AIDD) provides oversight and support for PCPID, which comprises 34 members, including 21 citizen members and thirteen ex officio (heads of cabinet level departments of government) members. A variety of individuals are appointed as citizen members, including individuals with intellectual and developmental disabilities, parents and family members of the individuals with intellectual and developmental disabilities, scientists and professionals employed in the field of intellectual and developmental disabilities, community and business representatives, and systems advocates.

Aging & Disability Resource Centers Program

As the dynamics of care changes considerably with age (both for individuals with autism and that of their caregivers) one of the important issues in autism concerns the provision of appropriate services for older adults with autism. ACL's Aging & Disability Resource Centers Program is a collaborative effort of ACL, CMS, and the Veterans Health Administration (VHA). The program supports state efforts to streamline access to long-term services and support (LTSS) options for older adults and individuals with disabilities, including those with autism spectrum disorder.

Other Activities

In addition to the activities described above, ACL participates as a member agency on the Interagency Autism Coordinating Committee.

ACL/AIDD Funding for Autism NOW Program

PROGRAM	FY 2010	FY 2011	FY 2012	FY 2010-FY 2012
Autism NOW	$2	$0.75	$0.35	$3.1

Table 3. Administration for Community Living (ACL)/Administration on Intellectual and Developmental Disabilities (AIDD) Autism NOW Expenditures FY 2010-2012 (Millions).

AGENCY FOR HEALTHCARE RESEARCH AND QUALITY (AHRQ)

The Agency for Healthcare Research & Quality (AHRQ) was not named in and did not receive an authorization in the CAA, and has no specific initiatives to implement the CAA. However, AHRQ has supported and continues to support a number of projects with direct relevance to ASD, including the following:

National Patterns in the Outpatient Pharmacological Management of Children and Adolescents with Autism Spectrum Disorder: A recent AHRQ-supported study found that there has been a recent and significant national increase in outpatient psychotropic treatment of young people with ASD. By 2001-2005, psychotropic medicines were prescribed in almost 80 percent of ASD visits, with stimulants, antidepressants, and antipsychotics as the most commonly prescribed medication classes.

- AHRQ Hospital Cost and Utilization Project (HCUP): In 2011, AHRQ published a report on the number of hospitalizations during 2008 and trends in hospitalizations by gender for "Autism/Other Childhood Disorders." Among males, hospitalizations for "Autism/Other Childhood Disorders" ranked the highest of all hospitalizations for mental health and substance abuse disorders.

- U.S. Preventative Services Task Force (USPSTF): AHRQ also provides administrative, research, technical, and dissemination support to the U.S. Preventive Services Task Force (USPSTF), an independent panel of non-federal experts in prevention and evidence-based medicine that conducts scientific evidence reviews of a broad range of clinical preventive health care services (such as screening, counseling, and preventive medications) and develops recommendations for primary care clinicians and health systems. The USPTF is composed of primary care providers (such as internists, pediatricians, family physicians, gynecologists/obstetricians, nurses, and health behavior specialists). This body periodically issues "Recommendation Statements" directed at primary care providers to guide them on issues concerning preventive services in primary care. USPSTF recommendations highlight the opportunities for improving delivery of effective services and have helped others provide preventive care in different populations. USPSTF recommendations have also formed the basis of the clinical standards for many professional societies, health organizations, and medical quality review groups. In 2013, the USPSTF prepared and posted a draft research plan on "Screening for Autism Spectrum Disorder in Young Children" for public comment. The research plan, when it is finalized, will be used to guide a systematic review of the evidence by researchers at an Evidence-based Practice Center. The resulting Evidence Report will form the basis of the USPSTF Recommendation Statement on this topic.

- Computer Assisted Autism Care (CAAC): In this AHRQ-funded project, investigators employed a novel decision support system for implementing clinical guidelines in pediatric practices, known as CHICA (Child Health Improvement through Computer Automation), to aid in ASD screening, diagnosis, and treatment parameters. To evaluate the effect of the CHICA system on ASD treatment and management, researchers assessed children between the ages of 18 months and 5 years with a formal diagnosis of ASD.[12]

- Innovative Adaptation & Dissemination of CER Products: Autism (iADAPT-ASD): This project will create a website that demonstrates, through state-of-the-art, high definition video, the best practices for treating autism, based on the AHRQ comparative effectiveness report on Therapies for Children with Autism Spectrum Disorders. The website will provide information to parents, educators, and clinicians, to enable them to make more informed decisions about treatments.

- Comparative effectiveness of therapies for children with autism spectrum disorders: Focused on children ages 2-12 years with ASDs, this AHRQ-funded review assessed the comparative effectiveness of therapies including behavioral, educational, medical, allied health, and complementary and alternative medicine (CAM) interventions.

- Comparative effectiveness of interventions for adolescents and young adults with autism spectrum disorders: Focused on adolescents and young adults, ages 13-30 years with ASD, this AHRQ-funded review assessed the comparative effectiveness of therapies including behavioral, educational, medical, allied health, and complementary and alternative medicine (CAM) interventions.

- Center for Education and Research on Mental Health Therapeutics (CERTs): The Mental Health CERTs will build on strong existing collaborations to create a coherent, multidisciplinary program targeting improvement

---

[12] Anand V, Biondich PG, Liu G, Rosenman M, Downs SM. Child Health Improvement through Computer Automation: the CHICA system. *Stud Health Technol Inform*.2004;107(Pt 1):187-91. [PMID:15360800]

of outcomes of psychotropic medication use. It aims to become a national resource on mental health therapeutics, trusted for its expertise and its independent, rigorous, and objective work. It will bring together outstanding research teams to develop and implement strategies for improving treatment patterns and outcomes in problem areas selected for impact on a population basis, emphasizing the large populations receiving care through major public programs such as Medicare and Medicaid. Most of the work in this grant is on treatment of children with antipsychotics, which includes children with autism, and has led to several research articles such as "National patterns in the outpatient pharmacological management of children and adolescents with autism spectrum disorder."[13]

- Partnership for Sustainable Research and Dissemination of Evidence-based Interventions: Initiated in 2013, this AHRQ-supported partnership proposes to build new and/or enhance existing capacity in research and dissemination infrastructure that will bridge the gap between clinical and health services research and everyday practice. This collaboration aims to build a knowledge base about how to improve the translation and dissemination of evidence-based health information, interventions, and clinical practices to populations not traditionally reached by such information or practice.

Other Activities

In addition to the activities described above, AHRQ participates as a member agency on the Interagency Autism Coordinating Committee.

AHRQ ASD-Research Funding (FY 2010 – FY 2012)

PROJECT	FY 2010	FY 2011	FY 2012	TOTAL FUNDING	ARRA FUNDED
Computer Assisted Autism Care (CAAC)	$489,000	$492,000	$490,000	$1,471,000 (2009-2012)	No
Innovative Adaptation & Dissemination of CER Products: Autism (iADAPT-ASD)	$1,486,000	--	--	$1,486,000 (2010-2012)	Yes
Center for Education and Research on Mental Health Therapeutics	$800,000	--	--	$800,000 (2006-2012)	No
Comparative effectiveness of interventions for adolescents and young adults with autism spectrum disorders	$625,000	--	--	$625,000 (2009-2011)	No
Comparative effectiveness of therapies for children with autism spectrum disorders	--	--	--	$575,000 (2009-2011)	No
Total	$3,400,000	$492,000	$490,000	$4,382,000 (2010-2012)	

Table 4. AHRQ-Supported ASD Research FY 2010-2013.

---

[13] Gerhard T, Chavez B, Olfson M, Crystal S. National patterns in the outpatient pharmacological management of children and adolescents with autism spectrum disorder. *J Clin Psychopharmacol.* June 2009;29(3):307-10. [PMID:19440093]

CENTERS FOR DISEASE CONTROL AND PREVENTION (CDC)

The Centers for Disease Control and Prevention (CDC) brings a unique epidemiologic perspective to the effort to fully understand autism spectrum disorder (ASD). This perspective includes reporting data on the occurrence of ASD, contributing to the understanding of risk and protective factors, and working to improve early identification of ASD and other developmental disabilities. CDC conducts both intramural (internal) and extramural (i.e., grant and contract) activities and partners with grantees, federal and state governments and programs, and other stakeholders in these activities. CDC also serves on the Interagency Autism Coordinating Committee (IACC) and both of its subcommittees.

Recognizing the importance of CDC's unique public health role, the Children's Health Act (CHA) of 2000 (P.L. 106-310) established a scientific infrastructure at CDC for conducting population-based ASD monitoring and research. The Combating Autism Act (CAA) of 2006 further strengthened and expanded this infrastructure, affording CDC the ability to conduct ongoing monitoring of ASD over time and across multiple geographic regions of the United States. The Combating Autism Reauthorization Act (CARA) of 2011 reauthorized the CAA of 2006 for an additional 3 years, through September 30, 2014. Although the CAA and CARA only provided additional legislative authority to bolster ongoing CDC autism-related activities that were already authorized, the CAA provided the only authorization to support the establishment of the Interagency Autism Coordinating Committee (IACC), an advisory body that has greatly improved communication and coordination among federal agencies and non-federal member organizations in addressing autism issues.

While the CAA/CARA did not provide any new appropriations for CDC's autism work, it 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 ASD and other developmental disabilities. The CAA/CARA 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 ASD. The CAA/CARA also strengthened CDC's legislative authority for "Learn the Signs. Act Early" (LTSAE) by elevating the national visibility of the importance of increasing awareness of developmental milestones. CAA/CARA further strengthened the capacity of the LTSAE program in educating parents, health care professionals, and early childhood 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.

Surveillance and Epidemiology

In the time since the enactment of the CAA, CDC has built critical infrastructure to further advance understanding of ASD and has seen these efforts come to fruition. The Autism and Developmental Disabilities Monitoring (ADDM) Network has published the most comprehensive estimates to date of the prevalence of ASD in multiple areas of the United States. CDC has coordinated the ADDM Network to characterize the prevalence and population characteristics of children with ASD in collaboration with State Health Departments or their representatives. The ADDM Network currently conducts surveillance of ASD 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. In 2009 and 2012, CDC published updated ASD prevalence reports and plans to continue publishing these reports every few years.[14, 15, 16]

These three reports, which cover an eight year span of time and include children born in the 1990s and forward, 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 conduct further analyses to understand ASD among the population. 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 ASD (see Appendix iii. for a full list of CDC-supported ASD publications).

CDC is also leading more focused epidemiologic studies. In October 2010, a member of the public gave testimony at a meeting of the Interagency Autism Coordinating Committee regarding her concerns about the prevalence of ASD among Somali-American children in Minneapolis, Minnesota (where Somali-American children had recently been shown in a study to be up to seven times more likely to receive autism services than their peers, suggesting that autism may be more prevalent in this population). In response to this testimony, several IACC member agencies coordinated efforts to launch a research project that would examine disparities in ASD prevalence and children's participation in special education programs in Minneapolis. Co-funded by the NIH and Autism Speaks through an Association of University Centers on Disabilities (AUCD) research grant in 2011, the CDC National Center on Birth Defects and Developmental Disabilities (NCBDDD) assumed a lead role in investigating this issue in collaboration with the University of Minnesota's Leadership Education in Neurodevelopmental and Related Disabilities (MN LEND) program. Researchers conducting the Minneapolis Autism Prevalence Study are now evaluating autism rates in Somali-American children ages 7-9 years and that of age-matched children in other populations located in Minneapolis via existing surveillance methods (i.e., those used by the CDC Autism and Developmental Disabilities Monitoring (ADDM) Network).

Risk Factors Research

CDC is supporting research on risk factors that may be related to the development of ASD. CDC's CADDRE Network has been successful in implementing the Study to Explore Early Development (SEED), which is currently the largest collaborative scientific study in the United States examining various risk factors for autism. SEED was started in 2006 and 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. SEED risk factor focus areas include genetics, maternal infections, maternal hormonal factors such as infertility conditions

---

[14] Centers for Disease Control and Prevention. Prevalence of Autism Spectrum Disorders—Autism and Developmental Disabilities Monitoring Network, United States, 2006. *Morbidity and Mortality Weekly Report (MMWR) Surveillance Summaries*. December 18, 2009; 58(Vol. 10):1-20. [PMID: 20023608]

[15] Centers for Disease Control and Prevention. Prevalence of Autism Spectrum Disorders—Autism and Developmental Disabilities Monitoring Network, 14 Sites, United States, 2008. *Morbidity and Mortality Weekly Report (MMWR) Surveillance Summaries*. March 20, 2012; 61 (SS-03): 1-19. [PMID:22456193]

[16] Centers for Disease Control and Prevention. Prevalence of Autism Spectrum Disorders—Autism and Developmental Disabilities Monitoring Network, Six Sites, United States, 2000. *Morbidity and Mortality Weekly Report (MMWR) Surveillance Summaries*. February 9, 2007; 56(SS-1):1-11. [PMID: 17287714]

and treatments, family history of auto-immune and other immunological conditions, and obstetric risk factors. Other SEED focus areas include gastrointestinal symptoms and disorders in children with ASD and sociodemographic features of children with ASD and their families. By the end of 2010, SEED enrolled more than 3,000 children and their families, and initial findings are due to be released in 2014. These results hold promise for greatly advancing our understanding of ASD etiologies. The CADDRE Network initiated a second phase of SEED, called SEED 2, in 2011 (implemented in 2012). This expansion will allow for more detailed analyses of genetic and phenotypic ASD subtypes. Enrollment and data collection are ongoing. To date, over 1,200 children have enrolled in SEED 2.

Immunization Safety Office

CDC's Immunization Safety Office published a study in the Journal of Pediatrics in 2013 that evaluated the association between immunological-stimulating protein and polysaccharide contents in vaccines and development of autism and adverse neuropsychological outcomes.[17] This study was the first of its kind to evaluate the CDC recommended childhood immunization schedule and autism spectrum disorder (ASD). This case-control study was conducted in three U.S. managed care organizations (MCOs) of 256 children with ASD and 752 matched controls to evaluate the number of vaccine antigens (substances, such as bacterial protein fragments, that stimulate an immune system response) were received in the first two years of life and whether or not the number of antigens correlated with the subsequent development of autism. Researchers examined two subcategories of ASD: autistic disorder (AD) and ASD with regression. The findings showed that the amount of antigens from vaccines received on one day of vaccination or in total during the first two years of life is not related to the development of ASD. This study provides relevant data for the current immunization schedule. It strengthens the conclusion of a 2004 comprehensive review by the Institute of Medicine (IOM) that there is not a causal relationship between certain vaccine type and autism.[18]

CDC, in partnership with the Department of Defense-Autism Research Program (DoD-ARP), conducted the Blood Spot Project to investigate the relationship between development of ASD and the presence of cross-reactive antibodies (antibodies that may have been produced to help the body eliminate infectious agents such as bacteria, but that also bind to human body proteins, also known as antigens) present in pregnant women and infants. The project aimed to investigate whether such cross-reactive antibodies interact strongly with brain tissue molecules in the fetus during pregnancy to subsequently lead to changes in fetal brain development.

Archived dried blood spot (DBS) samples (with consent for use in retrospective research studies) were analyzed to determine whether the developing fetus was exposed to antibodies that react with antigens of bacterial, neural, and endocrine association. The study evaluated archived DBS from newborn children who later developed autism and from others who developed normally and did not develop autism. The results did not reveal any antigen-specific antibody binding that was associated with an increased risk for autism. However, antibody binding to pneumococcal polysaccharide antigens (antibodies produced to respond to the presence of pneumococcus bacteria) was

---

[17] Destefano F, Price CS, Weintraub ES. Increasing exposure to antibody stimulating proteins and polysaccharides in vaccines is not associated with risk of autism. *J Pediatr*. August 2013;163(2):561-7. [PMID:23545349]

[18] Immunization Safety Review Committee. (2004) *Immunization Safety Review: Vaccines and Autism*. Institute of Medicine of the National Academies. Washington, D.C. The National Academies Press.

associated with a modest but statistically-significant decrease in risk for ASD, suggesting the potential that this antibody actually provides protective immunity. A manuscript describing these results is in preparation.

Early Identification

CDC is also involved in multiple early identification activities through the "Learn the Signs. Act Early." health education program. Program efforts are helping to change perceptions about the importance of identifying developmental concerns early so that children and their families receive the services and support they need. Since January 2010, more than 3.3 million LTSAE materials have been distributed, and another approximately 1 million items have been downloaded. The LTSAE webpages have received more than 7 million page views by health care professionals, parents, partners, campaign champions, and early child care providers.

"Learn the Signs. Act Early." starts with providing information to help all families with children under the age of five years monitor their child's development. This is important because many developmental delays do not have physical signs and the more parents are aware of what children typically should do at certain ages, the sooner they may be able to recognize when there is a concern. The program provides free tools and resources for families and professionals. For example:

- The *Milestone Moments* booklet is a practical and appealing booklet for parents with milestone checklists, warning signs, and tips for parents. The Milestone Moments brochure lists important milestones for parents of children ages 6 months to 4 years in a game board format. These materials are also available in Spanish.
- A children's book, *Amazing Me: It's Busy Being 3!*, teaches parents about developmental milestones and the importance of tracking them in their young children as they read the book to their toddler.
- The *Autism Case Training (ACT): A Developmental Behavioral Pediatrics Curriculum* is designed to educate future healthcare providers on fundamental components of identifying, diagnosing, and managing autism spectrum disorder through real life scenarios. The curriculum was developed through a collaborative effort between CDC and the HRSA/MCHB Developmental-Behavioral Pediatrics Fellowship Training Program and has also been endorsed by the American Academy of Pediatrics and the Society for Developmental and Behavioral Pediatrics. The online ACT training, which provides continuing medical education credits, has been approved by the American Board of Pediatrics to meet Maintenance of Certification requirements for pediatricians.

The "Learn the Signs. Act Early." program has also supported multiple evaluation and research projects to inform the content of the information on early developmental monitoring and acting early, and on the strategies used to get this information into the hands of those that need them – parents of young children, healthcare providers, and early care and education providers.

In addition to a range of information resources, "Learn the Signs. Act Early." has worked to establish partnerships to embed the monitoring of early child development into programs and systems that serve young children and their families, including public health programs and childcare centers. There has been a particular focus on reaching low resource families through partnerships with the U.S. Department of Agriculture (USDA) Special Supplemental Nutrition Program for Women, Infants, and Children (WIC) and the Administration for Children and Families (ACF) Head Start programs.

Also as part of the Act Early Network Initiative, CDC has supported three cohorts of Act Early Ambassadors since 2011. These ambassadors identify at least two specific projects they can achieve to improve early identification and linkage to services in their state during their tenure. There are currently 25 Act Early Ambassadors who are state-level leaders from advocacy, early intervention, education, medical, and other systems working to increase collaboration and coordination among programs and services for children with autism and other developmental disabilities. This program has proven to be very effective in expanding the reach of LTSAE materials and in developing and supporting a cadre of professionals at the state level interested in early identification issues. Building on the momentum from the collaborative Act Early state team work, in 2010, CDC collaborated with the Association of Maternal and Child Health Programs to annually fund 10 small grants to states to implement one or two high-priority activities from their Act Early state plans.

CDC personnel have also been actively involved with other federal and non-federal agencies working to improve early identification and linkage to services for children with ASD and other developmental disabilities. For example, CDC and HRSA engage in Autism Coordination meetings and have worked together on initiatives such as the development of the Healthy People 2020 objectives for early screening and start of services for young children with autism and other developmental disabilities. CDC has worked closely with ACF on the HHS Developmental Screening Workgroup to develop tools to improve developmental screening within childcare settings. In addition, CDC has worked with Autism Speaks to provide input and coordination with their "Early Access to Care" initiative to improve early identification of autism.

The following is a description of specific CDC programs strengthened by the CAA/CARA:

- Metropolitan Atlanta Developmental Disabilities Surveillance Program (MADDSP): This project conducts ongoing and systematic monitoring of prevalence of selected developmental disabilities (intellectual disability, hearing loss, vision impairment, cerebral palsy, and autism spectrum disorder) 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.

- Autism and Developmental Disabilities Monitoring (ADDM) Network: This is a collaborative project to characterize the population prevalence and characteristics of children with ASD and other developmental disabilities. Cooperative agreement grants 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 ASD in their States. The ADDM Network currently conducts surveillance of ASD and other developmental disabilities in 12 geographic areas of the United States. ADDM surveillance has traditionally focused on 8-year-olds, but recently added a component looking at 4-year-olds in six ADDM sites (see Early ADDM below).

- Autism Spectrum Disorder Surveillance of Younger Children (Pilot Surveillance): In 2006, two ADDM sites (Florida and California) were funded to conduct a pilot project to assess the feasibility of monitoring the early signs of autism in children under the age of 4. FY 2010 was the final year for these pilot projects, but they showed that early ASD surveillance is feasible in helping us better understand the early identification of children with ASD and 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 ASD and to increase awareness of ASD in young children, leading to improvements in early identification efforts. The Early ADDM Network will also allow for follow-up of the same cohorts of children when they are 8 years of age in the ongoing ADDM Network surveillance activities.

- Study to Explore Early Development (SEED): SEED is a multi-site, multi-year collaborative study funded by CDC. It is currently the largest study in the United States to help identify factors that may put children at risk for ASD and other developmental disabilities. The first phase of SEED includes more than 3,000 children who were enrolled when they were ages 3 through 5. This study includes diverse groups from six areas across the country. Additional children are currently being enrolled in the second phase of SEED, which was implemented in 2012.

- Denmark Collaboration: The CDC-Denmark Program was established to examine a variety of public health issues, including ASD 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. Funding for this project ended in FY 2011.

- “Learn the Signs. Act Early.”: This program 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.

- A complete listing of CDC funded publications is available in Appendix iii.

Other Activities

In addition to the activities described above, CDC participates as a member agency on the Interagency Autism Coordinating Committee.

CDC ASD-Related Expenditures

CDC AUTISM EXPENDITURES	FY 2010	FY 2011	FY 2012	FY 2010-FY 2012
Autism Surveillance and Research	$21,337,650	$20,700,550	$20,585,784	$62,623,984
Autism Awareness ("Learn the Signs. Act Early.")	$3,372,400†	$3,241,675†	$2,762,228	$9,376,303
Total	$24,710,050	$23,942,225	$23,348,012	$72,000,287

Table 5. CDC ASD-related budget expenditures from FY 2010-FY 2012. These expenditures include costs associated with CDC's autism budget lines and infant health budget line in support of programs on autism and other developmental disabilities. Appropriations for these activities are a part of the annual appropriations provided to CDC and are not appropriated under the CAA/CARA. †In FY 2010, CDC provided $420,000 to HRSA through an interagency agreement and in FY 2011 CDC transferred funds in the amount of $392,028 to HRSA as supplemental support of HRSA 08-144 grantees.

CDC Blood Spot Project Funding (FY 2010 – FY 2012)

PROJECT	FY 2010	FY 2011	FY 2012	FY 2010-FY 2012
Blood Spot Project	$125,000	$62,500	$62,500	$250,000

Table 6. Funding for Blood Spot Project (Funding for this project is not included as part the CDC's of overall autism budget).

CENTERS FOR MEDICARE & MEDICAID SERVICES (CMS)

The Centers for Medicare & Medicaid Services (CMS)'s involvement in implementing the CAA of 2006 in FYs 2010-2013 is focused on Sections 399BB and 399CC, "Autism Education, Early Detection, and Intervention" and "Interagency Autism Coordinating Committee."

Regarding Section 399BB, "Autism Education, Early Detection, and Intervention," 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 while the latter specifically references "programs under title XIX of the Social Security Act, particularly the Medicaid Early and Periodic Screening, Diagnostic and Treatment (EPSDT) benefit.

In 2010, CMS issued a report entitled *Autism Spectrum Disorders (ASDs) Services Final Report on Environmental Scan* describing the results of an extensive literature review conducted of the scientific evidence regarding the efficacy, effectiveness, safety, and availability of ASD-related Medicaid-funded services and supports, including those funded through federal sources, that support daily living for people of all ages with ASD. The report includes service categories and descriptions, evidence-based services 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. The scan highlighted the lack of research into effective services for adults, and interventions that can be implemented successfully in the community. CMS expended approximately $191,000 related to activities to complete the Environmental Scan.

In 2011, CMS issued a report on a nine-state study entitled, *Report on State Services to Individuals with Autism Spectrum Disorders (ASD),* which assessed the implementation of evidence-based/promising practices through the lens of state experience, summarizing the current state of ASD-related services covered by Medicaid and other sources in Arizona, California, Connecticut, Indiana, Maine, Missouri, New Mexico, Pennsylvania, and Wisconsin. The report describes the types of services and supports provided by state and local governments, the sources of funding for programs, and the policy, staffing and implementation issues that states and localities encounter in the administration of programs that serve people with ASD. Approximately $198,000 was expended on activities related to the Nine-State study.

In 2014, CMS issued a report, "Autism Spectrum Disorders (ASD): State of the States of Services and Supports for People with ASD," describing the results of the "State of the States" project. This study assessed existing state programs and supports for families living with ASD in 50 states and the District of Columbia, providing a comprehensive view of services that received support from various federal sources and were made available through state programs across the country. This project is named as an objective in Chapter 7 of the 2011 *IACC Strategic Plan* and approximately $350,000 has been spent to support this project and related activities.

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, diagnostic services, treatment, and other measures described in section 1905(a) [of the Act] 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.

Through Medicaid programs, many states currently offer coverage for services for ASDs through waivers, primarily through Home and Community-Based Services (HCBS) waivers. For these waivers, states develop and operate HCBS programs based on state needs, priorities and legislative direction. All 50 states and the District of Columbia have HCBS or 1115 Research and Demonstration Project waivers for individuals with intellectual or developmental disabilities and many states serve people with ASD under their primary HCBS waiver. More specifically, more than 30 states have explicitly listed autism as a related condition or explicitly included autism in the definition of people served under the state's HCBS waiver for people with intellectual disabilities. Also, states offer ASD waivers for children and some specifically for adults (ages 18+ or 21+). In addition, states are beginning to use the 1915(i) HCBS state plan authority to offer services to individuals with ASD. Furthermore, individuals who meet the supplemental security income (SSI) federal definition of disability may qualify for Medicaid services under a HCBS waiver in their state for individuals with disabilities or under section 1902 of the Social Security Act that may include individuals with autism.

CMS is preparing to implement provisions under the Affordable Care Act in 2014 that will benefit individuals with autism and related conditions. In particular, the Health Insurance Marketplace will expand access to affordable insurance options for individuals on the autism spectrum and families of children on the autism spectrum. In addition, rehabilitative and habilitative services devices, as well as mental health and substance abuse disorder services, including behavioral health treatment, will be covered as essential health benefits required for non-grandfathered health plans, which will include insurance options under the Marketplace.

Other Activities

In addition to the activities described above, CMS participates as a member agency on the Interagency Autism Coordinating Committee.

CMS ASD-Related Expenditures (FY 2010 – FY 2012)

CMS ASD-RELATED ACTIVITIES	FY 2010	FY 2011	FY 2012	FY 2010-FY 2012
State of the states in services and supports for persons with ASD (2009-2013)	$92,026	$88,154	$0	$180,180
Report on state services to individuals with ASD - Nine state study (2008-2011)	$198,348	$0	$0 (Completed)	$198,348
Meeting the needs of individuals with ASD through comprehensive services- Environmental Scan (2008-2011)	$40,540	$0	$0 (Completed)	$40,540

Table 7. CMS ASD-Related Expenditures from FY 2010-FY 2012.

FOOD AND DRUG ADMINISTRATION (FDA)

The Food and Drug Administration (FDA)'s mission is to protect and advance public health by ensuring food safety and by helping to speed innovations that provide the nation with safe and effective medical products. The Agency achieves this by applying the latest technology and science-based standards to the regulatory challenges presented by drugs, biologics (i.e., vaccines, blood products, cell and gene therapy products, and tissues), medical devices, food additives, and, since 2009, tobacco. The FDA reviews protocols for clinical trials to assess study design and to ensure the protection of human subjects. FDA also reviews new drug applications to ensure that new drugs are safe and effective. Many clinical studies include individuals with ASD. Drugs used to ameliorate various symptoms of autism including anxiety, depression, aggression, and seizures are a few of the many pharmacologic treatments that are subject to rigorous regulatory review by the FDA.

FDA has a representative on the Interagency Autism Coordinating Committee who provides insight into drug development and regulation. In addition, medical officers from the Division of Psychiatry Products have participated in conferences relevant to clinical trials and drug development for autism treatment. Examples include the Autism Speaks Outcomes Meeting, which focused on clinical assessments for measuring outcomes in clinical trials in the areas of Social Communication and Repetitive Behaviors and Anxiety, and the Foundation for the National Institutes of Health Biomarkers Consortium Autism Initiative Meeting.

HEALTH RESOURCES AND SERVICES ADMINISTRATION (HRSA)

Under the Combating Autism Act of 2006 (CAA) and the Combating Autism Reauthorization Act of 2011 (CARA), the Health Resources and Services Administration's (HRSA) Maternal and Child Health Bureau (MCHB) received funding 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
5. Train health care professionals to provide screening, diagnostic and early, evidence-based intervention services for children with a confirmed diagnosis.

To meet these five objectives, MCHB developed and implemented the Combating Autism Act Initiative (CAAI). The CAAI provides grants for training, research, and the development of comprehensive, coordinated state systems of care for ASD and other DD. Four separate but complementary program areas have received CAAI grants:

1. Leadership Education in Neurodevelopmental Disabilities (LEND) training programs
2. Developmental Behavioral Pediatric (DBP) training programs
3. Autism Intervention Research Programs (Autism Intervention Research Network on Behavioral Health (AIR-B Network), Autism Intervention Research Network on Physical Health (AIR-P Network), Developmental Behavioral Pediatrics Research Network (DBPNet), R40 Autism Intervention Research and Secondary Data Analysis Studies)
4. State Implementation and State Planning Grants Program

In addition to these grants, MCHB also funded two national resource centers to provide technical assistance to grantees and to promote collaboration within and across the grant programs. The National Combating Autism Interdisciplinary Training Resource Center supports the LEND and DBP grantees by providing technical assistance, disseminating information and resources, and providing program coordination. The State Public Health Autism Resource Center (SPHARC) provides technical assistance to the State Implementation and State Planning Grants to improve systems of care and support the role of State Public Health Agencies in fostering early identification, diagnosis, and intervention of ASD and other developmental disabilities (DD).

To maximize the return on these federal investments, HRSA developed a strategic interdisciplinary approach aimed at ensuring the Initiative's effectiveness and efficiency. The MCHB autism research programs have created three Networks and a cadre of researchers that continue to develop and disseminate evidence about the effectiveness of specific treatments and interventions for ASD and other developmental disabilities. That research informs the work of the training programs and the state grants. Coordination and collaboration across programs and agencies—a key performance indicator for these grants—eliminate redundancies and create synergies that can spur broad improvements in the system of services for ASD and other DD. Finally, by generating new evidence, training professionals in evidence-based practices, and promoting the development of comprehensive, coordinated delivery systems, the CAAI investments are improving access to early and appropriate screening, diagnostic, and intervention services, which should lead to better outcomes for individuals on the autism spectrum for years to come. The sections that follow document specific examples of progress to date.

Training Programs

HRSA's Leadership Education in Neurodevelopmental and Related Disabilities (LEND) grants provide interdisciplinary training to enhance the clinical expertise and leadership skills of professionals dedicated to caring for children with neurodevelopmental and other related disabilities and special health care needs. The Leadership Education in Developmental-Behavioral Pediatrics Program (DBP) provides training for the next generation of leaders in developmental-behavioral pediatrics and to provide pediatric practitioners, residents, and medical students with essential biopsychosocial knowledge and clinical expertise. The 43 LEND and 10 DBP training programs with CAAI funding continued to address the shortage of trained professionals who can provide screening and diagnostic services for ASD and other DD. These programs span 39 states, and their reach extends beyond those states as a result of partnerships formed and services provided across state lines. These programs have focused on:

1. Training health professionals to use valid, reliable screening and diagnostic tools and to provide evidence-based interventions for children with ASD or other DD

2. Providing continuing education to practicing health care providers

3. Providing technical assistance to MCHB Title V agencies, community-based organizations, and other entities that serve children with ASD and other DD and their families

Each year, the LEND and DBP programs enroll long-term fellows that receive at least 300 hours of intensive didactic training and clinical experience working as part of a developmental screening or diagnostic team in hospitals, clinics, and community-based settings. In addition, both programs provide "medium-term" training to medical residents who participate in 40–299 hours of training. Finally, both programs also reach a large number of "short-term trainees" every year who receive up to 40 hours of training (Table 8). Table 9 shows the number of training events delivered per year between 2009 and 2010.

With every subsequent year of funding, the LEND and DBP programs continued to expand their training capacity, as evidenced by the increase in the number of short-, medium- and long-term trainees reached each year since 2010. Collectively, the LEND and DBP programs reached more than 10,500 short-term and more than 3,000 medium-term trainees in 2012. Many of the medium-term trainees are medical residents and practicing professionals who provide direct services to children and families. By preparing these professionals to implement recommended screening practices and to use evidence-based screening tools such as the Modified Checklist for Autism in Toddlers (M-CHAT), the training programs are improving early identification of ASD and other DD.

HRSA Number of Trainees by Fiscal Year and Grant Program

	2010			2011			2012		
TOTAL TRAINEES	**LEND**	**DBP**	**TOTAL**	**LEND**	**DBP**	**TOTAL**	**LEND**	**DBP**	**TOTAL**
Short term	5,826	2,611	8,437	9,447	492	9,939	9,361	1,261	10,622
Medium term	2,249	247	2,496	2,589	213	2,802	2,608	431	3,039
Long term	1,367	24	1,391	1,405	26	1,431	1,420	54	1,474
DIDACTIC TRAINING									
Medium term	1,529	231	1,760	1,717	176	1,893	1,652	293	1,945
Long term	1,019	24	1,043	1,155	26	1,181	1,052	51	1,102
PRACTICAL/FIELDWORK*									
Medium term	1,353	107	1,460	1,374	96	1,470	1,545	268	1,813
Long term	989	24	1,013	1,125	26	1,151	1,212	50	1,262

*Table 8. The data for 2010 and 2011 include 39 Leadership Education in Neurodevelopmental and Other Related Disabilities (LEND) programs and 6 Developmental-Behavioral Pediatrics (DBP) programs that had Combating Autism Act Initiative grants at that time. With the reauthorization, 43 LEND and 10 DBP programs received CAAI funding. The data for 2012 comes from these 43 LEND and 10 DBP programs. *Includes brown bags, grand rounds, workshops, seminars, or presentations. Does not include CE events.*

The enrollment of long-term trainees in the LEND and DBP programs has also increased every year since 2010, from 1,391 in 2010 to 1,474 in 2012. The impact of this increase is likely to have far-reaching effects since these long-term trainees typically take on leadership positions in the field, which enable them to direct the training of future physicians and to establish new programs for ASD and other DD.

Data collected from the LEND programs over the past 4 years show the direct impact of these investments on families with a child who screens positive for ASD. In 2010, LEND programs provided interdisciplinary diagnostic evaluations for more than 35,000 infants and children. With the expanded number of LEND grantees and trainees, the LEND programs provided interdisciplinary diagnostic evaluations for close to 56,000 infants and children in 2012. By continuing to meet the growing demand for these services, the LEND programs are reducing wait times for diagnostic evaluation and entry into intervention services. Moreover, because the LEND programs typically target underserved populations, their efforts are also helping to address disparities in early identification of ASD.

HRSA ASD-Related Training Events (FY 2010 – FY 2012)

	2010			2011			2012		
COURSES	LEND	DBP	TOTAL	LEND	DBP	TOTAL	LEND	DBP	TOTAL
Number of university courses addressing screening tools, diagnostic tools, and/or evidence-based interventions	369	10	379	432	8	440	490	12	502
Number of participants reached via university courses addressing screening tools, diagnostic tools, and/or evidence-based interventions	8,415	582	8,997	11,079	508	11,587	12,408	594	13,002
Number of university courses addressing advocacy, counseling, and coordination of care	250	6	256	350	7	357	505	7	512
Number of participants reached via university courses addressing advocacy, counseling, and coordination of care	4,757	137	4,894	7,937	113	8,050	10,266	148	10,414
CONTINUING EDUCATION EVENTS									
Number of continuing education events addressing screening tools, diagnostic tools, and/or evidence-based interventions	721	60	781	805	69	874	806	108	914
Number of participants reached via continuing education events addressing screening tools, diagnostic tools, and/or evidence-based interventions	89,092	3,160	92,252	49,989	5,331	55,320	56,958	9,460	66,418
OTHER TRAINING EVENTS									
Number of other training events addressing screening tools, diagnostic tools, and/or evidence-based interventions	1,665	82	1,747	2,108	146	2,254	1,927	201	2,128
Number of participants reached via other training events addressing screening tools, diagnostic tools, and/or evidence-based interventions	51,443	2,398	53,841	51,897	2,691	54,588	63,378	4,708	64,086

Table 9. Number of Training Events and Participants Reached by Fiscal Year and Grant Program. "Other training events" include trainees who participated in practical/fieldwork that addressed early signs of ASD and other developmental disabilities (DD), screening, diagnosis, and/or evidence-based interventions for ASD and other DD.

Research Programs

HRSA's research programs support national research networks and field-initiated research projects on evidence-based interventions to improve the health and well-being of children and adolescents with autism spectrum disorders and other developmental disabilities. These programs address the needs of underserved populations, such as low-income, racial/ethnic minorities, immigrants, individuals who have limited access to services, and other underserved populations. The Autism Intervention Research Network on Physical Health (AIR-P Network) is a multi-site research network that works to strengthen the evidence base for interventions through research, development of clinical practice guidelines, and the dissemination and transfer of network findings on interventions, guidelines, tools and systems management approaches broadly into practice settings and improved care. MCHB's research programs have made strides in:

1. Advancing research on ASD interventions

2. Developing evidence-based guidelines to support practitioners and families in providing appropriate care for children with ASD and other DD

3. Validating intervention tools

Since 2010, the Autism Intervention Research Network on Physical Health (AIR-P) has completed five studies; published empirically based physician guidelines for the management of gastrointestinal (GI) issues, sleep, and attention deficit hyperactivity disorder (ADHD); and developed 10 tool kits for parents and providers. In addition, this Network currently supports six current/active studies that address an array of medical and related issues associated with ASD, such as obesity induced by antipsychotic medication use, treatment of sleep disorders, gastrointestinal symptoms, and toilet training. See Tables 19, 20, and 23 for a complete listing of AIR-P research studies and products.

The Autism Intervention Research Network on Behavioral Health (AIR-B) is a multi-site research network that works to advance behavioral health for children and adolescents with autism spectrum disorders (ASD). The intervention research conducted by the AIR-B Network is delivered in home and community settings and focuses on underserved and underrepresented groups of children and families. The AIR-B network has forged strong partnerships with community providers to implement evidence-based interventions effectively and sustainably in real-world settings.

The AIR-B Network has completed guidelines for the implementation of psychosocial and related interventions for children with ASD and their families; these guidelines were published in a *Pediatrics* journal supplement in 2012. In addition, the AIR-B has completed four studies and has four studies in progress. The AIR-B has developed three tools, Playground Observation of Peer Engagement (and Teen Observation of Peer Interaction), Social Networks Survey, and Active Engagement Rating Scale; it is validating two additional tools, ADOS-Change and the Pragmatic Rating Scale. In all AIR-B initiatives, the focus continues to be on underserved, underrepresented, and under-resourced contexts and families of children with autism. The AIR-B has forged strong partnerships with school districts, which is critical in the success of conducting community participatory research with key stakeholders including teachers, paraprofessionals, parents, and administrators. Tables 21-22 list AIR-B research studies and products.

The Developmental Behavioral Pediatrics Research Network (DBPNet) is a multi-site research network that promotes and coordinates research activities in behavioral, psychosocial, and developmental aspects of pediatric care to improve clinical services and health outcomes for, but not limited to, children with autism spectrum disorder (ASD) and other developmental disabilities. The DBPNet also provides the mentoring environment in which to train a new generation of developmental behavioral pediatric researchers.

The DBPNet, initially funded in 2010, has developed consensus research priorities for the field of developmental-behavioral pediatrics and completed a study that assessed research training methods and outcomes at accredited DBP fellowship training programs. One study has been completed and six studies are currently in progress. These studies are listed in Table 10. The DBPNet also launched its Network Web site in 2011, which provides information on the member site's current research activities and will serve as a repository for Network resources.

HRSA Developmental Behavioral Pediatrics Research Network (DBPNet) Research Studies

YEAR INITIATED	STUDY TITLE	BRIEF DESCRIPTION
2010	What are Important Research Questions in Developmental-Behavioral Pediatrics: The DBPNet Perspective	The primary goal of this study is to identify the most important research questions in developmental-behavioral pediatrics that should be pursued in the next 5 years. A secondary objective is to identify the important research questions that are most feasible for a developmental-behavioral pediatrics research network.
2011	A Survey of Research Training in DBPNet Fellowship Programs	This study is a descriptive survey, aimed at characterizing the content and methodologies used for research training in DBP Fellowship Programs. This study provides information on the qualities of programs which promote strong fellowship, scholarly activity, and productivity.
2012	Nature of Referrals to Outpatient Services at DBPNet sites	This is a prospective descriptive study of the clinical practices of DB pediatricians at DBPNet sites. The study will: describe the referral population, the reason for referral, the assessment, initial diagnoses, and recommendations for children referred for DBP consultation; quantify the variability of time and resources devoted to initial DBP consultation by referral question and patient characteristics; and describe diagnoses given to children referred for evaluation of ADHD or ASD, but not found to have these conditions.
2012	Practice Variation in the Assessment and Management of Attention Deficit Hyperactivity Disorder and Autism Spectrum Disorders by Developmental Pediatricians: A DBPNet Study	This is a prospective descriptive study of the clinical practices of DB pediatricians at DBPNet sites to describe practices and identify variations in the practices of DB pediatricians related to the assessment and management of ADHD and ASD.
2012	Extracting Electronic Health Record Data on Use of Psychotropic Medications in DBPNet: Costs, Feasibility, and Practice Variation	This is a retrospective descriptive study to: collect already existing data from EHRs at multiple sites within DBPNet to determine the feasibility and costs of collecting and sharing deidentified data, describe the diagnoses seen in DBP practice and the use and laboratory monitoring of psychotropic medications by site, clinician and child characteristics.

YEAR INITIATED	STUDY TITLE	BRIEF DESCRIPTION
2013	Maternal Immune Status and Autism Severity	This study proposes to replicate the presence of maternal autoantibodies in mothers of children with Autism Spectrum Disorder (ASD) in a geographically diverse population utilizing the DBPNet and determine the association of these antibodies with autism severity and behavioral impairments.
2013	Family Navigation to Reduce Disparities in Timely Autism Diagnosis and Access to Early Intervention	This project will assess the feasibility of patient navigation, a care management approach designed to target patients from underserved populations who have been identified as at-risk for a specific condition and are likely to face a variety of barriers to diagnosis and quality care, to support early diagnosis and receipt of recommended services among young children at-risk for autism from low-income minority families.

Table 10. Developmental Behavioral Pediatrics Research Network (DBPNet) Research Studies.

The R40 MCH Autism Intervention Research Program supports applied research and secondary data analysis studies (SDAS) on evidence-based practices for interventions to improve the health and well-being of children and adolescents with autism spectrum disorders (ASD) and other developmental disabilities. The 17 currently funded R40 research projects are addressing several high-priority topics pertaining to ASD. Three studies specifically address issues surrounding the transition to adulthood. Other studies are assessing the effectiveness of various interventions and practices intended to improve outcomes for children with ASD and to support their families. Several R40 studies also focus on minority and underserved populations. Table 11 lists completed and active studies.

A total of six 1-year secondary data analysis studies (SDAS) were completed in 2011. These studies addressed disparities in access to care and quality of care, health care utilization and financing for children with autism and their families, and transition services for young adults reaching the age of majority.

HRSA R-40 Research Grants

YEAR INITIATED	GRANT TYPE	STUDY TITLE	BRIEF DESCRIPTION
2009	Multiyear	Supporting the Well-Being of Families of Young Children With ASDs	The objective of this project is to determine whether an evidenced-based empowerment strategy, Problem Solving Education (PSE), targeted to mothers of young children with autistic spectrum disorder (ASD), promotes family well-being by decreasing the burden of maternal depressive symptoms and parenting stress and improving maternal social functioning.
2009	Multiyear	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 underserved toddlers with ASD. Results of this study will impact Part C intervention paradigms, and initiate a series of studies aimed at determining active ingredients of early intervention, moderators, and mediators of treatment response, and how best to translate evidence-based findings into community practice involving young minority and underserved children with ASD.
2009	Multiyear	Family-Centered Transition Planning for Students With ASDs	This study demonstrates a Family-Centered Transition Planning model designed to empower families and high school students with ASD transitioning to adult life. The model has three components, designed to empower families and transitioning students to take a leading role in the process of transition planning.

YEAR INITIATED	GRANT TYPE	STUDY TITLE	BRIEF DESCRIPTION
2009	Multiyear	Telehealth Delivery of a Family-Focused Intervention to Reduce Anxiety in Youth With ASDs 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.
2009	Multiyear	Assessing a participant directed service system for low income children with ASD	This study evaluates a Medicaid supportive services waiver program in Massachusetts that uses a participant direction (PD) model to choose and manage services for young children with ASD and their families.
2009	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. Outcomes considered include key measures of academic, social, behavioral, functional, and motor skills.
2009	SDAS	Services and Outcomes for Transition Age Young Adults with ASDs: Secondary Analysis of the NLTS2 and RSA 911	This study conducted descriptive and predictive analyses of the factors associated with and influencing a successful transition into adulthood for young adults with ASD using secondary data sources.
2010	SDAS	Autism Insurance Policy and Access to Care for Children With Autism: A State-Level Analysis	This study seeks to determine to what extent state insurance policies on autism are associated with better access for children with autism. The investigators had three aims: 1) assess whether access to care for children with autism varies across states, 2) assess the extent that state characteristics, such as insurance policy on autism, enhance access to care for children with autism, and 3) identify the states that have achieved the best access to care for children with autism for future study.
2010	SDAS	Medical Service Utilization by Medicaid-Eligible Children With Autism in Georgia: An Analysis of One Year of Claims and Provider Data	This study examines the service utilization patterns of children diagnosed with autism living in urban and rural areas of Georgia using Medicaid fee-for-service data from calendar year 2005. This is one of the first studies to use a large administrative dataset to study rural and urban differences in the utilization of health services in a publicly-insured population of children in the United States.
2010	Multiyear	Transition to Adult Health Care for Youth With ASDs	This study sought to understand barriers to transition for youth with ASD and to uncover current best practices. This information was used to design and test the feasibility of intervention strategies for improving the health care transition.
2010	Multiyear	Predictors of Effects of Propranolol on Language & Connectivity in Autism	The aim of this study was to examine how markers of sympathetic reactivity predict response to propranolol in autism. Unlike other agents under exploration for treatment of core features of autism, propranolol is available in a generic form and is inexpensive, increasing its availability for underserved patients.
2010	SDAS	Racial and Ethnic Disparities in Family Burden and the Access, Service Utilization, and Quality of Health Care for Children With Autism	This study has four aims: 1) To identify the extent and correlates of racial and ethnic disparities in health care access, health care quality, and health service utilization of Black and Hispanic children with autism and other developmental disabilities; (2) To examine differences in the health care access, health care quality, and health service utilization of Hispanic children with autism and other developmental disabilities by 1 dimension of acculturation and parental primary language.
2010	Multiyear	Use of a Family Navigator in Families with Children Newly Diagnosed with ASD	The objective of this study is to determine whether an evidenced-based strategy, Patient Navigation, for families of young children newly diagnosed with ASD, improves the services the children receive, decreases the burden of parenting stress, and improves family functioning.

YEAR INITIATED	GRANT TYPE	STUDY TITLE	BRIEF DESCRIPTION
2010	Multiyear	Improved Identification of Autism Among Latino Children	The overall goal of the present project, a collaboration of researchers, primary care providers, and families, is to provide evidence for the effectiveness of a "Supported Screening" model to enhance identification and successful referral for Latino children.
2010	Multiyear	A Parent-to-Parent Model of Service Coordination for Families of Preschool Age Children with ASD	The purpose of this study is to investigate the effects of a culturally compatible parent-to-parent model of service coordination on the outcomes of preschool ages children just diagnosed with ASDs and their families.
2010	Multiyear	Parent-Implemented Training for Autism Through Teleconsultation (PITA-T)	The purpose of this study was to conduct innovative research on an evidence-based intervention that improves the health and well-being of children with ASDs.
2010	Multiyear	Evaluating the Impact of Early Intervention Services on Young Children with Autism: A State Systems Approach	The aim of the proposed study is to model a cost-effective approach to evaluating the impact of participation in early intervention systems on children with ASDs and their families that can be used in New York, other states, and nationally for program evaluation and quality improvement purposes.
2011	Multiyear	Controlled Trial of Sertraline in Young Children with Fragile X Syndrome	This project is a controlled trial of sertraline, a selective serotonin reuptake inhibitor (SSRI), for the treatment of children with fragile X syndrome (FXS) who are between 24 and 68 months of age.
2011	SDAS	Autism Intervention Challenges for Low-Income Children	This study addresses the important gaps in our knowledge about the challenges that disadvantaged or underserved children with ASD face accessing early intervention services and participating fully in intervention programs.
2011	Multiyear	Comprehensive Support for Families With Autism: A Parent-Based Mentoring Approach	This study is aimed at developing a novel intervention to improve quality of life for families who have children newly diagnosed with autism. The intervention uses a comprehensive strategy to determine individual challenges and develop coping strategies, train families in systems of care, and provide emotional support.
2011	Multiyear	Behavioral Treatment Through In-Home Telehealth for Young Children with Autism	The goals of this study are 1) to evaluate the effectiveness and efficiency of delivering an empirically validated behavioral treatment for challenging behavior in young children with ASD by using an in-home telehealth to reach underserved areas of a rural state, and 2) to evaluate the relation of family variables to treatment outcomes and acceptability of treatment procedures.
2011	Multiyear	Studying the Impact of Service-Learning on Career Development, Self-determination, and Social Skill Building for Youth with ASDs	This study will use a pre-test/post-test control group design to investigate the impact of the intervention using field-tested, standardized scales pertaining to three variables: career development, self-determination, and social skills.
2011	SDAS	Transition-Age Young Adults With Autism: The Role of Self-Determination, Social Skills, Job Search, Transportation, and Rehabilitation Services in Employment Outcomes	The objective of this project is to support the design of effective transition services and supports for students with autism by identifying personal and programmatic factors that are related to positive employment outcomes. The specific goals of this research project include documenting the roles of four domains—self-determination, social skills, job search strategies, and transportation—in promoting the transition of youth with autism into employment following high school.
2011	SDAS	Access, Quality, and Financial Implications of the Transitions of Children With Autism	This study builds on earlier research that identifies state-level Medicaid and private insurance strategies to improve access and reduce financial burden. The proposed study will determine when families are most at risk of problems accessing care for their children and most at risk of incurring financial burden, to best target effective policy strategies.

YEAR INITIATED	GRANT TYPE	STUDY TITLE	BRIEF DESCRIPTION
2011	Multiyear	Efficacy of the Home TEACCHing Program for Toddlers With Autism	This study examined the efficacy of this home-based, manualized intervention program for toddlers with autism in a randomized controlled study comparing the HTP to a services-as-usual (SAU) control condition.
2012	Multiyear	Predicting Obstructive Sleep Apnea in Down Syndrome	The overarching goal of this study was to develop a tool that is comfortable, practical, and effective for diagnosing OSA in individuals with Down syndrome.
2012	Multiyear	Efficacy of a Qigong Massage Methodology for Children With ASD Ages 3-11 Years	This study replicated and expanded on previous work by conducting a larger, Phase-2 trial of the efficacy of the QST intervention in the younger than age 6 group and an exploratory trial in the 6- to 11-year-old group (45 children).

Table 11. R-40 Research Grants by Year.

HRSA MCHB’s Combating Autism Act Initiative (CAAI) Funding (FY 2010 – FY 2012)

TRAINING PROGRAMS*	FY 2010	FY 2011	FY 2012	FY 2010-FY 2012
Leadership Education in Neurodevelopmental Disabilities (LEND) training programs	$27,423,411	$28,740,816	$28,128,964	$84,293,191
Developmental Behavioral Pediatrics (DBP) training programs	$1,904,628	$1,901,217	$1,857,203	$5,663,048
RESEARCH PROGRAMS				
MCH Autism Intervention Research Networks (Physical Health, Behavioral Health and Developmental Behavioral Pediatrics)	$4,013,405	$7,602,509	$6,096,710	$17,712,624
MCH Autism Intervention Research Program	$4,103,084	$3,761,878	$3,938,931	$11,803,893
STATE IMPLEMENTATION PROGRAMS[†]				
State Implementation Grants and State Planning Grants	$4,485,824	$3,107,487	$2,997,671	$10,590,982

*Table 12. Maternal and Child Health Bureau (MCHB)’s Combating Autism Act Initiative (CAAI) Funding. *In addition to these grants, HRSA/MCHB awarded $571,915 in FY 2010, $637,641 in FY 2011, and $666,201 in FY 2012 to support 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. In addition to these grants, HRSA/MCHB awarded $275,000 per year in FY 2010, 2011, and 2012 to support 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. [†] In FY 2010 and FY 2011, CDC made interagency transfers to HRSA in the amounts of $420,000 and $430,800, respectively. The total in the table for FY 2010 includes $399,000 in transfer funds from CDC for implementation of “Learn the Signs. Act Early.” This includes supplements to four states (AK, WA, UT, MO) for $99,750 each. The total in the table for FY 2011 includes $392,028 in transfer funds from CDC for implementation of “Learn the Signs. Act Early.” This includes supplements to four states (AK, WA, UT, and MO) for $98,007 each. This table reflects grant totals only; additional costs associated with operating the program include a PHS evaluation tap as required by the appropriation, salaries, rent, travel, and other costs.*

State Implementation and Planning Grants

The State Implementation Grants implement existing state plans to improve access to health care and related services for children and youth with Autism Spectrum Disorder (ASD) and other developmental disabilities (DD). The State Implementation Planning Grants develop state plans to improve the system of services for children and youth with special health care needs who have ASD and other developmental disabilities. Eighteen State Implementation Grantees (SIGs) and four State Planning Grants (SPGs) worked at the local, regional, and State levels to improve access to coordinated, comprehensive, timely, and evidence-based screening, diagnostic, and intervention services for ASD and other DD. By taking a public health approach that includes identifying available resources and gaps in services, building awareness among professionals and the public of the need for early identification and intervention for ASD, and building a more integrated system of services for ASD, the SIGs and SPGs have achieved significant gains that will continue to spur improvements past their grant periods. States implemented different approaches in their efforts to improve services. Strategies included: partnering with existing programs, such as the U.S. Department of Agriculture (USDA) Special Supplemental Nutrition Program for Women, Infants, and Children (WIC) to promote regular developmental screenings for this underserved population; training primary care practices on medical home concepts and how to develop care coordination plans for children with special health care needs; and piloting quality improvement learning collaboratives to increase early screening and reduce wait times for diagnostic services.

Although SIGs do not generally provide direct services, many states have seen measurable improvements in access to and coordination of services following their efforts to improve systems of care for individuals with ASD and other DD. Specific improvements reported by SIGs include the following:

- Improved access to timely ASD screening for underserved populations (Alaska, Maine)
- Increased universal screening practices (Utah, Hawaii)
- Decreased time between screening and diagnosis (Utah, Maine)
- Measurable improvements in the provisions of comprehensive, coordinated, community-based care (Vermont, Nevada, Rhode Island)

Other Activities

In addition to the activities described above, HRSA participates as a member agency on the Interagency Autism Coordinating Committee.

NATIONAL INSTITUTES OF HEALTH (NIH)

In accordance with mandates outlined by the Combating Autism Act of 2006 (CAA), P.L. 109-416 and the Combating Autism Reauthorization Act of 2011 (CARA), P.L. 112-32, the National Institutes of Health (NIH) has developed and promoted research initiatives designed to address the needs of children and families affected by Autism Spectrum Disorder (ASD). Under its general Public Health Service Act authorities, NIH follows the mandates of the CAA through the award of competitive grants and contracts, as well as through its support for the intramural research program. Funding for autism activities at NIH are provided through NIH's annual appropriations, and in 2009 and 2010, NIH supported some autism related activities through funds provided by the American Recovery and Reinvestment Act (P.L. 111–5).

NIH Intra-Agency Coordination

In 1997, at the request of Congress, the NIH formed an internal Trans-NIH Autism Coordinating Committee (NIH/ACC) to enhance the quality, pace, and coordination of autism research efforts at the NIH. Since then, the NIH ACC has been instrumental in planning trans-NIH research initiatives to advance the understanding of autism. Currently, staff from seven NIH Institutes and Centers (ICs) serve on the committee. The NIH ICs represented include the National Center for Complementary and Alternative Medicine (NCCAM), *Eunice Kennedy Shriver* National Institute of 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 National Institute of Neurological Disorders and Stroke (NINDS). The National Institute of Allergy and Infectious Diseases (NIAID) participates but is not a member of the committee. The National Institute on Drug Abuse (NIDA) is not a member of the committee, but future efforts of the institute include issues related to comorbidity, marijuana use, and prescription drug use for autism youths (particularly as they reach adolescence). In addition to program staff from each of these ICs, 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 for ASD Research*.

Science Advances

NIH-supported research has improved the ability to screen and diagnose ASD earlier in life; advanced our understanding of the potential causes of autism; and informed innovative treatments, interventions, and services for individuals with ASD.

Early detection means the possibility of early intervention

Although clinicians usually consider 18 to 24 months to be the earliest time to make a diagnosis of ASD, electroencephalography (EEG) and brain imaging studies of children at risk show reproducible differences in brain activity before 12 months of age.[19, 20] A study supported through the American Recovery and Reinvestment Act (ARRA) identified an innovative technique for advancing accurate, early diagnosis of ASD. Using a brain imaging technology known as diffusion tensor imaging (DTI), researchers discovered deficits in neuronal fibers that conduct long-distance communications between brain regions. The investigators were able to use this non-invasive, anatomically based imaging technique to distinguish–with high accuracy–between individuals with ASD and those serving as controls. Another group of ARRA-funded researchers also demonstrated an accurate method to assess the risk of ASD in infancy through the analysis of older affected siblings as predictors of ASD recurrence. In this prospective study, investigators analyzed data from 664 infants who had older siblings with ASD and were able to develop a reliable estimate of the risk for ASD among these infants via the Autism Diagnostic Observation Schedule (ADOS) and a clinical diagnosis from an expert clinician conducted at 36 months.[21] Additionally, investigators at an Autism Center of Excellence demonstrated the feasibility and effectiveness of conducting a 5-minute screener, consisting of a simple survey that can be filled out by a parent during a child's 1-year well-baby check-up that can be used to detect subtle signs of ASD around the age of one year.[22]

Understanding the underlying causes of autism will likely lead to improved treatment and risk reduction

Three studies point to potentially modifiable risk factors for ASD. First, as part of the Childhood Autism Risk from Genes and Environment (CHARGE) study, researchers found a protective association in children and mothers who carried a common genetic variant linked to inefficient folate metabolism. This finding indicates that a sufficient amount of supplemental folic acid in the first month of pregnancy may reduce a child's risk for ASD.[23] Second, a separate large population-based study in Norway, designed to examine the potential role of a number of prenatal and perinatal risk factors, found evidence supporting a protective role for folic acid. Initial results demonstrate that prenatal folic acid supplementation is associated witha decreased risk for autism.[24] Third, reports of specific genetic mutations that cause alterations in the synthesis of carnitine, a chemical involved in fat metabolism, suggest that dietary treatments may be helpful in treating some forms of ASD.[25] Three independent studies by the Autism

---

[19] Bosl W, Tierney A, Tager-Flusberg H, Nelson C. EEG complexity as a biomarker for autism spectrum disorder risk. *BMC Med*. February 22, 2011;9:18. [PMID:21342500]

[20] Tierney AL, Gabard-Durnam L, Vogel-Farley V, Tager-Flusberg H, Nelson CA. Developmental trajectories of resting EEG power: an endophenotype of autism spectrum disorder. *PLoS One*. 2012;7(6):e39127. [PMID:22745707]

[21] Ozonoff S, Young GS, Carter A, Messinger D, Yirmiya N, Zwaigenbaum L, Bryson S, Carver LJ, Constantino JN, Dobkins K, Hutman T, Iverson JM, Landa R,Rogers SJ, Sigman M, Stone WL. Recurrence risk for autism spectrum disorders: a Baby Siblings Research Consortium study. *Pediatrics*. September 2011;128(3):e488-95. [PMID:21844053]

[22] Pierce K, Carter C, Weinfeld M, Desmond J, Hazin R, Bjork R, Gallagher N. Detecting, studying, and treating autism early: the one-year well-baby check-up approach. *J Pediatr*. September 2011;159(3):458-465.e1-6. [PMID:21524759]

[23] Schmidt RJ, Tancredi DJ, Ozonoff S, Hansen RL, Hartiala J, Allayee H, Schmidt LC, Tassone F, Hertz-Picciotto I. Maternal periconceptional folic acid intake and risk of autism spectrum disorders and developmental delay in the CHARGE (CHildhood Autism Risks from Genetics and Environment) case-control study. *Am J Clin Nutr*. July 2012;96(1):80-9 [PMID:22648721]

[24] Surén P, Roth C, Bresnahan M, Haugen M, Hornig M, Hirtz D, Lie KK, Lipkin WI, Magnus P, Reichborn-Kjennerud T, Schjølberg S, Davey Smith G, Øyen AS,Susser E, Stoltenberg C. Association between maternal use of folic acid supplements and risk of autism spectrum disorders in children. *JAMA*. February 2013 13;309(6):570-7. [PMID:23403681]

[25] Celestino-Soper PB, Violante S, Crawford EL. A common X-linked inborn error of carnitine biosynthesis may be a risk factor for nondysmorphic autism. *Proc Natl Acad Sci U S A*. May 22, 2012;109(21):7974-81. [PMID:22566635]

Sequencing Consortium found that an increased risk of ASD was associated with spontaneous genetic mutations found more commonly among older fathers.[26, 27, 28] Finally, several environmental factors, such as exposure to air pollution, agricultural pesticides, and antidepressants, have been reported to increase ASD risk, mostly based on exposure during pregnancy.[29, 30, 31]

Funding Opportunity Announcements

The NIH continues to encourage rigorous, evidenced-based research on ASD through both investigator-initiated and targeted Funding Opportunity Announcements (FOAs). Overall NIH funding for ASD research (excluding 2010 American Recovery and Reinvestment Act (ARRA) funds) increased by 5.7 percent from FY 2010 to FY 2011, and by 13.9 percent from FY 2011 to FY 2012. The three standing FOAs that broadly solicit ASD research (PA-13-216, PA-13-217, PA-13-218) continue to encourage research that addresses the objectives of the *IACC Strategic Plan for Autism Spectrum Disorder Research*. NIH has intensified efforts to bring much-needed treatments and interventions to affected individuals through several targeted FOAs that invite research on services for individuals with ASD across the lifespan (RFA-MH-14-100, RFA-MH-14-101, RFA-MH-102). In addition, a number of FOAs that were not specifically focused on ASD were successful in stimulating research studies relevant to ASD (PAR-11-177, PA-11-283, PAR-13-195, and PAR-13-213). For more information about ASD research projects funded by the NIH, please refer to the IACC portfolio analysis web tool or the NIH RePORT website.

Building Resources and Infrastructure

The *IACC Strategic Plan* highlights the importance of data sharing. Most autism researchers whose research involves human subjects have now made data sharing with the NIH National Database for Autism Research (NDAR) part of their proposed research. Sharing data with NDAR will allow other researchers to use and extend the initial research. In addition, other private and public autism organizations such as the Autism Genetic Resource Exchange (AGRE), the Autism Tissue Program (ATP), and the Interactive Autism Network (IAN) are now linked with NDAR. Collectively, this means that de-identified data from more than 61,000 consenting research participants are available across more than 400 clinical, imaging, and genomic instruments for secondary analysis by other qualified researchers. NDAR now holds over 100 terabytes of data, including genomic data from 10,000 subjects and imaging data from 600 subjects. All data within NDAR are harmonized (e.g., uses the same names for each piece of data collected) and validated (e.g., reported values are consistent with the expectations for that piece of information) to a

---

[26] Numata S, Ye T, Hyde TM, Guitart-Navarro X, Tao R, Wininger M, Colantuoni C, Weinberger DR, Kleinman JE, Lipska BK. DNA methylation signatures in development and aging of the human prefrontal cortex. *Am J Hum Genet*. February 2012. 10;90(2):260-72. [PMID:22305529]

[27] O'Roak BJ, Vives L, Girirajan S, Karakoc E, Krumm N, Coe BP, Levy R, Ko A, Lee C, Smith JD, Turner EH, Stanaway IB, Vernot B, Malig M, Baker C, Reilly B,Akey JM, Borenstein E, Rieder MJ, Nickerson DA, Bernier R, Shendure J, Eichler EE. Sporadic autism exomes reveal a highly interconnected protein network of de novo mutations. *Nature*. April 4, 2012;485(7397):246-50. [PMID:22495309]

[28] Neale BM, Kou Y, Liu L, Ma'ayan A, Samocha KE. Patterns and rates of exonic de novo mutations in autism spectrum disorders. *Nature*. April 4, 2012;485(7397):242-5. [PMID:22495311]

[29] Volk HE, Lurmann F, Penfold B, Hertz-Picciotto I, McConnell R. Traffic-related air pollution, particulate matter, and autism. *JAMA Psychiatry*. January 2013;70(1):71-7. [PMID:23404082]

[30] Shelton JF, Hertz-Picciotto I, Pessah IN. Tipping the balance of autism risk: potential mechanisms linking pesticides and autism. *Environ Health Perspect*. July 2012;120(7):944-51. [PMID:22534084]

[31] Croen LA, Grether JK, Yoshida CK, Odouli R, Hendrick V. Antidepressant use during pregnancy and childhood autism spectrum disorders. *Arch Gen Psychiatry*. November 2011;68(11):1104-12. [PMID:21727247]

community-established common data definition. More than 900 peer-reviewed papers refer to data that have been deposited in NDAR, and papers based on data pulled from NDAR are starting to appear.

NIH is also contributing to research infrastructure to accelerate the pace of ASD research. 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. The NIH Brain and Tissue Bank for Developmental Disorders is a dedicated pediatric repository for tissues from individuals with autism and other developmental and hereditary conditions. The bank is designed to systematically collect, store, and distribute brain and other tissues for research dedicated to the improved understanding, care, and treatment of individuals with developmental disabilities, including ASD.

Autism Centers of Excellence

NIH continues to support the Autism Centers of Excellence (ACE) program described in the CAA of 2006. Initially funded in FY 2007-FY 2008, the ACE program is composed of both individual research centers at a single institution and networks of research teams at different institutions working together on a common research problem. The ACEs are designed to conduct intensive and coordinated research programs into the causes of ASD and to develop and disseminate new interventions and treatments. In 2012, NIH made nine new ACE awards—three centers and six networks—to be funded over 5 years. In 2013, two additional networks were awarded. The *Eunice Kennedy Shriver* National Institute of Child Health and Human Development (NICHD), the National Institute of Mental Health (NIMH), the National Institute of Neurological Disorders and Stroke (NINDS), the National Institute on Deafness and Other Communication Disorders (NIDCD), and the National Institute of Environmental Health Sciences (NIEHS) support the ACE program. The newly awarded ACEs will address a variety of critical research areas, such as using brain imaging technology to chart brain development of children at risk for ASD; identifying potential environmental and familial factors that may confer autism risk; investigating sex differences in ASD; evaluating the effectiveness of widely-used treatments to improve social interaction and communication, including exploring mechanisms of verbal communication and new interventions for minimally verbal children with ASD; and developing effective in-school and at-home interventions for youngsters with ASD.

In 2011, through a National Association of University Centers on Disabilities (AUCD) research grant, the NIH co-funded the Minneapolis Autism Prevalence Study, headed by the CDC. Details on this study can be found within the CDC's description of ASD progress and expenditures in Table 5.

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*, such as the Early Autism Risk Longitudinal Investigation (EARLI), a clinical study that is following mothers and babies through pregnancy during the first 3 years of life. Because the study is relatively new, very few babies have reached the critical period of three years when a definitive ASD diagnosis can be made. To date, the study has issued one publication describing the study design and benefits, but has not yet published results.[32]

---

[32] Newschaffer CJ, Croen LA, Fallin MD, Hertz-Picciotto I, Nguyen DV, Lee NL, Berry CA, Farzadegan H, Hess HN, Landa RJ, Levy SE, Massolo ML, Meyerer SC,Mohammed SM, Oliver MC, Ozonoff S, Pandey J, Schroeder A, Shedd-Wise KM. Infant siblings and the investigation of autism risk factors. *J Neurodev Disord*. April 18, 2012;4(1):7. [PMID: 22958474]

On the NIH campus, federal scientists in the NIMH Division of Intramural Research Program (DIRP) are running clinical studies on ASD, as well as a screening protocol to provide careful diagnostic evaluations to assess the presence of ASD symptoms. The DIRP is also conducting in-depth studies that follow children with ASD over the course of several years. Over 750 individuals have taken part in these studies, which have allowed researchers to explore potential brain markers that may be associated with ASD. Results of these studies include identification of a deficiency of the Rapid Eye Movement (REM) phase of sleep in children with ASD relative to typical children. A randomized controlled trial is now underway to determine if increasing REM sleep will benefit children with ASD. The NIMH DIRP also collaborates extensively with researchers in the external academic research community across the US. Together they conduct state-of-the-art investigations in areas such as neuroimaging, genome sequencing (to identify novel genetic abnormalities), and studies of "at-risk" populations, such as toddlers showing early signs of ASD and children with rare genetic abnormalities known to increase risk for ASD.

The Fogarty International Center's Brain Disorders in the Developing World: Research across the Lifespan (FIC BRAIN) program aims to enhance research capacity in the neurosciences in low- and middle-income country settings and has supported investigators working on ASD in Uganda, India, and Jamaica. Limited data exist on the prevalence of neurodevelopmental disabilities (NDDs) in developing countries. To address this issue in Uganda, FIC-funded investigators modified an existing, culturally-appropriate, neurodevelopment assessment tool to include questions on ASD. The researchers administered the household survey, door-to-door, to 1,169 children 2-9 years of age in both rural and urban settings.[33] Follow-up clinical assessments were used to validate the accuracy of the survey. While the adapted survey successfully screened children with NDDs, it was no more successful than the original survey in identifying individuals with ASD. Nevertheless, the investigators suggest that strategies to develop more culturally-specific questions to screen for ASD may improve the sensitivity of this survey in the future. FIC BRAIN researchers funded in Jamaica are also engaged in studies to understand risk factors for ASD. One study demonstrated that both advanced maternal and paternal age are jointly associated with childhood ASD in Jamaica.[34] A second FIC BRAIN-supported study found no link between blood mercury concentration acquired via seafood consumption and ASD in Jamaican children ages 2-8 years.[35] The FIC BRAIN program has funded the International Clinical Epidemiology Network (INCLEN) in Delhi to conduct NDD screenings that will include questions on ASD at five different sites around India on a pilot sample of 953 cases and controls.

The NIMH Center for Collaborative Genomic Studies on Mental Disorders houses a large collection of samples from patients with ASD and their families. The Center stores and distributes biomaterials (DNA samples and cell lines), clinical data, and genetic data to aid researchers in identifying genetic variants involved in causing ASD. The Center has a collection of over 26,000 DNA samples from ASD patients and their family members, including approximately 9,000 samples from the Autism Genetic Resource Exchange—a program of Autism Speaks. The Center also provides links to the genetic data for biomaterials stored in other public data repositories, such as the NIH Database of

---

[33] Kakooza-Mwesige A, Ssebyala K, Karamagi C, Kiguli S, Smith K, Anderson MC, Croen LA, Trevathan E, Hansen R, Smith D, Grether JK. Adaptation of the 'ten questions' to screen for autism and other neuro-developmental disorders in Uganda. *Autism*. November 8, 2013. [PMID:23536263]

[34] Rahbar MH, Samms-Vaughan M, Loveland KA, Pearson DA, Bressler J, Chen Z, Ardjomand-Hessabi M, Shakespeare-Pellington S, Grove ML, Beecher C,Bloom K, Boerwinkle E. Maternal and paternal age are jointly associated with childhood autism in Jamaica. *J Autism Dev Disord.* September 2012;42(9):1928-38. [PMID:22230961]

[35] Rahbar MH, Samms-Vaughan M, Loveland KA, Ardjomand-Hessabi M, Chen Z, Bressler J, Shakespeare-Pellington S, Grove ML, Bloom K, Pearson DA, Lalor GC, Boerwinkle E. Seafood consumption and blood mercury concentrations in Jamaican children with and without autism spectrum disorders. *Neurotox Res*. January 2013;23(1):22-38. [PMID:22488160]

Genotypes and Phenotypes and the National Database for Autism Research. The NIMH Stem Cell Resource, a recent expansion of the Center, stores stem cells and provides these cell lines to investigators.

The Center has enabled large scale genome wide association studies (GWAS) and sequencing efforts in ASD, such as the Psychiatric Genomic Consortium and the Autism Sequencing Consortium. The Center stores genetic data from GWAS studies on 7,015 cases and 8,755 case controls. Several significant genetic signals associated with ASD were found through these studies. Such findings establish the contribution of rare genetic variations and deletions or duplications of genetic material in the development of ASD, and identify the elements of shared genetic risk with other psychiatric disorders.

Table 13 shows all NIH expenditures on ASD, as reported through the NIH Research Portfolio Online Reporting Tool (NIH RePORT). For more information, please see the RePORT website.

NIH Autism Funding by Institute/Center (FY 2010 – 2012)

PARTICIPATING INSTITUTES/CENTERS	FY 2010 ACTUAL ARRA	FY 2010 ACTUAL BASE	FY 2011 ACTUAL	FY 2012 ACTUAL
NIMH	31,664	88,548	90,318	107,185
NICHD	13,466	35,069	31,878	35,151
NINDS	4,139	13,058	21,362	26,447
OD	3,431	115	20	50
NIEHS	1,530	5,241	6,332	6,687
NIDCD	1,440	8,461	10,398	9,550
NCRR	646	1,552	824	0
NLM	608	0	0	0
NIGMS	426	1,213	1,000	2,092
NIDCR	186	0	234	297
NIAAA	0	123	122	0
NIA	0	594	399	191
NCI	0	0	4	0
NIDA	0	5	0	344
NIDDK	0	323	0	0
NIBIB	0	0	185	215
NEI	0	542	488	90

PARTICIPATING INSTITUTES/CENTERS	FY 2010 ACTUAL ARRA	FY 2010 ACTUAL BASE	FY 2011 ACTUAL	FY 2012 ACTUAL
NHGRI	0	816	929	1,046
NINR	0	306	313	299
Roadmap	0	3,425	3,765	2,584
FIC	0	193	138	0
Total NIH	57,536	159,583	168,709	192,227

Table 13. National Institutes of Health Autism Funding (Dollars in Thousands).

NIH Autism Centers of Excellence (ACE) Program Funding

INSTITUTES	FY 2010 ACTUAL	FY 2011 ACTUAL	FY 2012 ACTUAL
NIMH	8,780	8,488	9,593
NINDS	1,989	2,452	5,701
NIDCD	1,908	1,851	2,306
NICHD	11,629	11,519	13,043
NIEHS	1,269	1,238	942
Total NIH	25,575	25,548	31,585

Table 14. NIH expenditures (Dollars in Thousands) on the Autism Centers of Excellence (ACE) program, which includes centers (P50s), a cooperative agreement (U01), and networks (R01s).

Other Activities

In addition to the activities described above, the NIH participates as a member agency on the Interagency Autism Coordinating Committee.

SUBSTANCE ABUSE AND MENTAL HEALTH SERVICES ADMINISTRATION (SAMHSA)

The Substance Abuse and Mental Health Services Administration (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 American Recovery and Reinvestment Act (ARRA) funds and so did not implement ARRA-specific programs in 2009 or 2010.

Comprehensive Community Mental Health Services for Children and Their Families Program

The only SAMHSA program that involves individuals with autism spectrum disorder (ASD) is the Comprehensive Community Mental Health Services for Children with Serious Emotional Disturbances (the short title for this program is Child Mental Health Initiative (CMHI)) which serves children and youth with serious emotional disorders. The service population of this program includes children with ASD only if there is a co-occurring serious emotional disturbance (Section 561 of the Public Health Service Act, as amended).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, delivered in home and community-based settings or in the least restrictive environment. Services 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.

In 2011, 24 1-year System of Care Expansion Planning grants were awarded to prepare states/communities for service delivery implementation at an approximate total of $18 million. In 2009 and 2010, 29 grantees received approximately $9 million each, for 6 years, with ascending match requirements. Out of 6,418 cases with a diagnosis from these 29 CMHI-funded communities, there were 180 total cases on the autistic spectrum (equivalent to 2.8 percent of all children/youth with a diagnosis served in CMHI).

Behavioral Health Electronic Clinical Quality Measure Development Project

In FY 2012, SAMHSA supported the Behavioral Health Electronic Clinical Quality Measure Development project (funding: $450,000 in FY 2011 awarded in FY 2012), which developed, tested, and validated electronically-specified clinical quality measures related to primary care screening for depression, suicide, drug use, alcohol use, trauma, and autism. These clinical quality measures were designed for potential inclusion in the Centers for Medicare & Medicaid Services (CMS) Electronic Health Record (EHR) Incentive Program, which is a program that provides incentives to eligible professionals and hospitals for adopting, implementing, upgrading, or demonstrating meaningful use of certified electronic health record technology to improve and enhance patient care. The project was coordinated with the HHS Office of the National Coordinator for Health Information Technology (ONC) and CMS measurement development, testing and validation activities. The project aimed to develop consensus on the issues surrounding clinical quality of care measures, define additional quality measures that need to be developed to support quality care, complete technical and electronic specifications, and perform field testing when necessary. These measures may be used to facilitate the measurement of disparities in early diagnosis and screening.

DEPARTMENT OF EDUCATION (ED)

The Department of Education (ED) supports programs to develop and implement interventions for individuals with ASD. 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 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 3 through 21.

Institute of Education Sciences

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 infants, toddlers, children, and youth with disabilities or those at risk for disabilities. NCSER's Autism Spectrum Disorders topic 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 (e.g., social) or focused on infants and toddlers with ASD. The ED Small Business Innovation Research (SBIR) program, which provides funds to small businesses for the research and development (R&D) of commercially viable education technology products, has funded a number of projects aimed at helping children with autism. The Postdoctoral Research Training in Special Education program supports programs within institutions of higher education that train postdoctoral fellows in conducting special education research, with some programs including autism research as a training focus. In FY 2012, NCSER began funding a new Research and Development Center, the Center for Secondary Education in Students with Autism Spectrum Disorders. These programs are not specifically in place to implement the CAA. NCSER is authorized through the Individuals with Disabilities Act (IDEA; P.L. 108-446) that amended the Education Sciences Reform Act to include NCSER as the fourth IES Center.

Department of Education Institute of Education Services (IES) ASD-Related Funding (FY 2010 – FY 2012)

	FY 2010	FY 2011	FY 2012	FY 2010-FY 2012
IES funds for autism	$11,716,635	$5,630,463	$8,342,165	$25,689,263

Table 15. Institute of Education Sciences (IES) total funds spent on projects with a specific focus on autism. These total amounts include three postdoctoral research training program grants in which autism research is just one of several training foci. The remaining awards are National Center for Special Education Research-funded research projects that have a total or partial focus on children with autism.

Please also note that these are the total funds actually provided to the projects in the fiscal years specified above. For grants awarded in 2010, the entire award amount was forward funded in 2010 no matter how many years the project period included, which accounts for the higher expenditure that year relative to the next 2 years. In 2011 and 2012, most awards were not fully forward funded, though some were forward funded an additional year.

Office of Special Education Programs (OSEP)

Office of Special Education Programs (OSEP) funds grants with a focus on ASD. These grants are not specifically in place to implement the CAA. OSEP funds grants that prepare doctoral level personnel to conduct research and teach within the area of ASD. OSEP also funds grants that prepare master's level personnel (e.g. early interventionists, special educators, and related services providers) to serve children with ASD. Additionally, OSEP funds State Personnel Development Grants, which provide funds to State Educational Agencies to provide in-service professional development to special educators. Grantees may focus the professional development on ASD. The authority to administer these grants is in Section D of the Individuals with Disabilities Education Act.

OSEP also funds projects that, while they may not focus specifically on children with ASD, generate products and services that are relevant to children with ASD. For example, OSEP funds the Center on Positive Behavioral Interventions and Supports (PBIS). This Center gives schools capacity-building information and technical assistance for identifying, adapting, and sustaining effective school-wide disciplinary practices and provides resources on how to prevent and address challenging behavior. In 2012, the Department of Education released a Restraint and Seclusion: Resource Document that outlines principles for educators, parents and other stakeholders to consider when developing or refining policies and procedures for schools to support positive behavioral interventions and avoid the use of restraint and seclusion. While this publication is not specific to children with ASD, it is relevant to children with ASD and other disabilities.

Department of Education Office of Special Education Programs (OSEP) ASD-Related Funding (FY 2010 – FY 2012)

	FY 2010	FY 2011	FY 2012	FY 2010-FY 2012
Office of Special Education Programs	$2,500,000	$3,000,000	$2,000,000	$7,500,000

Table 16. Office of Special Education Programs (OSEP) Expenditures by FY. The amounts expended were not specifically for the implementation of the CAA. The grants are authorized under Part D of the Individuals with Disabilities Education Act. The amounts are new awards to prepare doctoral level and master level personnel with a focus on autism spectrum disorder.

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 ASD. The Center works in coordination with each state's Department of Education and IDEA Part C agency to provide professional development to practitioners who serve children from birth through age 21 years with ASD. The Center has developed resources and modules on evidence-based practices for children with ASD and provided training to professional development providers and practitioners on the use of these evidence-based practices.

Through Parent Training and Information Centers across the nation, ED provides training for parents of children with ASD. Parent Centers, comprised of Parent Training and Information Centers (PTIs) and Community Parent Resource Centers (CPRCs), provide training and assistance to families of children with disabilities, including families of children with autism. These Parent Centers provide a variety of services including one-to-one support and assistance, workshops, publications, and websites, and they help families to:

- Better understand their children's disabilities and educational, developmental, and transitional needs
- Communicate more effectively with special education, early intervention, and related services professionals
- Understand their rights and responsibilities under the Individuals with Disabilities Education Act (IDEA)
- Connect with other local, state, and national resources that assist children with disabilities

National Institute on Disability and Rehabilitation Research (NIDRR)

The National Institute on Disability and Rehabilitation Research (NIDRR), in the U.S. Department of Education, is authorized by the Rehabilitation Act to fund research related to disability in general. There is no authorization that specifically addresses research in the area of ASD.

Department of Education NIDRR Funds for ASD-Related Funding (FY 2010 – FY 2012)

	FY 2010	FY 2011	FY 2012	FY 2010-FY 2012
NIDRR Funds for ASD Research	$1,695,286	$2,032,996	$2,375,664	$6,103,946

Table 17. National Institute on Disability and Rehabilitation Research (NIDRR) Funds for ASD Research by FY. Amounts expended were not specifically for implementation of the CAA.

Office of Postsecondary Education (OPE)

The Office of Postsecondary Education (OPE) grant program is authorized under The Higher Education Act of 1965, as amended, Title VII, Part B. One small part of this grant's activities is related to autism, but this grant program is specifically targeted for undergraduate students who are going to study in Brazil to take coursework on items such as, "cross-linguistic communication disabilities in children resulting from diverse etiologies; including cleft lip and/or palate, children with speech disorders, hearing impairment, and autism spectrum disorders." The grant was first awarded in FY 2010 as a 4-year grant. So far, two annual reports for this grant have been submitted and do not yet reference autism-related activities. The primary component of this grant is student exchange between the U.S. and Brazil. In FY 2009, an award was made to Texas A&M University for a project to develop a research-based Master's Degree in Education Interventions for Autism. An innovative Teacher Quality evaluation model was embedded within the degree program to respond to the call in the professional literature for a Teacher Quality evaluation model in special education. No new monies were expended for this project in following fiscal years. This grant has now been completed, a final reported received, and a response prepared.

Interagency Committee on Disability Research (ICDR)

Authorized by the 1973 Rehabilitation Act, the Interagency Committee on Disability Research (ICDR) was established “to promote interagency disability research coordination and collaboration, and enhance communication and information sharing among federal agencies and stakeholders conducting rehabilitation research programs and activities.” The mission of the ICDR is to identify, assess, and coordinate all federal programs, activities, projects, and relevant plans with respect to research related to rehabilitation of individuals with disabilities. To fulfill this mission, the ICDR:

- Gathers information from individuals with disabilities and their representatives
- Recommends activities to be funded through grants, contracts, cooperative agreements and other mechanisms
- Promotes joint research
- Seeks to prevent unnecessary duplication of research efforts
- Encourages a cohesive strategic program of federal disability and rehabilitation research

The ICDR continuously secures input from a broad range of stakeholders with diverse interests and perspectives, thus utilizing the spectrum of knowledge and experience available from subject matter experts within the federal government and the non-federal community. Individuals serving in positions designated as an ICDR member by the President provide leadership and oversight for the committee. These individuals are referred to as ICDR statutory members. Through committee activities, the statutory members secure the input of other federal departments, offices, and agencies that are referred to as non-statutory members.

Other Activities

In addition to the activities described above, the Department of Education participates as a member agency on the Interagency Autism Coordinating Committee.

OTHER AGENCIES AND DEPARTMENTS

The Environmental Protection Agency, Department of Defense, and the National Science Foundation are not mentioned in and do not have programs authorized under the CAA or CARA, but they have provided information about their relevant programs and projects in this report to help Congress understand their contributions to the federal ASD effort, along with HHS and ED.

ENVIRONMENTAL PROTECTION AGENCY (EPA)

The U.S. Environmental Protection Agency (EPA) aims to protect human health and the environment through such activities as the development and enforcement of environmental regulations, the support of grants and laboratories for scientific research and the publication of materials for public access. The EPA does not receive appropriations under the CAA or CARA, but EPA has collaborated with the National Institute of Environmental Health Sciences (NIEHS) to establish the Center for Children's Environmental Health (CCEH) at the University of California, Davis. Research at this Center focuses on understanding risk factors that may contribute to a person's susceptibility to neurodevelopmental disorders such as autism. Researchers at CCEH study how environmental exposures can interact with a person's genes and immune system to influence the risk and severity of autism. Through both epidemiological and rodent models, the center's scientists are looking into how environmental triggers affect brain development. They are also examining how biological markers, such as those related to immune system dysfunction, could help clarify why some children develop these disorders. Ultimately, their aim is to improve autism diagnosis and treatment and better inform the public about managing and preventing developmental disorders such as autism. In fiscal years 2006-2013, both EPA and NIEHS each contributed close to $4 million in funding to support the CCEH and the Center is expected to receive additional grants of about $4 million from each agency (about $8 million total) between fiscal years 2013 and 2017.

DEPARTMENT OF DEFENSE (DOD)

Department of Defense-Autism Research Program (DoD-ARP)

The Department of Defense, United States Army Medical Research and Material Command, Office of Congressionally Directed Medical Research Programs (CDMRP) executes and manages funding programs under the Defense Health Research Program. The Defense Health Research Program is appropriated yearly by the US Congress designating funding programs for a variety of diseases, conditions and injuries that affect military families, including autism. The DoD-Autism Research Program (DoD-ARP) was first established through language in the 109th United States Congress, House of Representatives Conference Report (H.R. 5631) in FY 2007 with an appropriation of $7.5 million for research on Autism Spectrum Disorder in the military. Following in FY 2008 through FY 2013, the DoD-ARP has continued through the Defense Health Program with additional appropriations. From FY 2007- FY 2013, a total of $47.4 million has been designated for research into ASD through an addition to the Department of Defense appropriation bill. This program is not authorized or funded through the Combating Autism Act.

From the beginning of the program, the vision and mission of the ARP has been to improve the lives of individuals with ASD now by promoting innovative research that advances the understanding of ASD and leads to improved outcomes. The initiative to improve lives of individuals with ASD now has spurred the funding of important work including the recent study, highlighted by the *IACC ASD Research Portfolio Analysis*, by Dr. Paul Patterson from the California Institute of Technology where he showed that beneficial gastrointestinal bacteria can ameliorate both immune and behavioral issues associated with ASD.[36]

Environmental exposures and probable effects on the development of ASD have been one of the focus areas of the ARP through the funding years. In an effort to understand the causative agents of ASD, Drs. Alberto Ascherio (Harvard School of Public Health), Marc Weisskopf (Harvard University), and Susan Santangelo (Massachusetts General Hospital) were funded by the ARP in a joint effort and examined maternal risk factors for ASD. Dr. Weisskopf reported that exposure to high pollution levels during pregnancy may increase the risk of ASD.[37]

One critical initiative of the ARP is funding research which will help allow greater access to early intervention for children with ASD. Access to professionals trained in early intervention is an issue for those in demographically underserved areas as well as military families due to deployments and reassignments. To address this issue, the ARP funded Dr. Wayne Fisher at the University of Nebraska Medical Center to develop a technology based early intervention service training for paraprofessionals. Through telemedicine training of paraprofessionals within remote or demographically underserved areas, Dr. Fisher is answering one critical need in the ASD community today – access to care.

Each year the advisory board of the ARP, consisting of scientists, clinicians, psychologists, and consumer advocates, reviews and revises the initiatives and focus areas of the program to respond to the needs of the research and consumer community alike. The ARP is a partnership between the Department of Defense, researchers, and consumers with a mission to improve the outcomes of individuals with autism now.

Office of Community Support for Military Families with Special Needs (OSN)

The Department of Defense (DoD) Office of Community Support for Military Families with Special Needs (OSN) is responsible for establishing policy and overseeing the implementation of the Exceptional Family Member Program (EFMP) and the provision of early intervention services and special education within the DoD. The EFMP is a multi-component mandatory enrollment program serving military families with special needs and includes identification of the family member's special needs and enrollment in the program as well as assignment coordination and family support. Over 126,000 military family members are enrolled in the EFMP, including children and adults who have autism spectrum disorder (ASD).

---

[36] Malkova NV, Yu CZ, Hsiao EY, Moore MJ, Patterson PH. Maternal immune activation yields offspring displaying mouse versions of the three core symptoms of autism. *Brain Behav Immun*. May 2012;26(4):607-16. [PMID: 22310922]

[37] Roberts AL, Lyall K, Hart JE, Laden F, Just AC, Bobb JF, Koenen KC, Ascherio A, Weisskopf MG. Perinatal air pollutant exposures and autism spectrum disorder in the children of nurses' health study II participants. *Environ Health Perspect.* August 2013;121(8):978-84. [PMID: 23816781]

All military installations currently have either a full-time or part-time EFMP family support staff person or point of contact for military families with special needs. Military OneSource is also a DoD-funded "one-stop" call center providing resources and support to military services members and their families 24 hours a day, 7 days a week. One important component of Military OneSource is the telephonic consultations that are available from their Special Needs Specialty Consultants. In 2012, over 2,500 military families received special needs consultations. Military OneSource also has a Special Needs/EFMP web page providing military families with special needs, including ASD, with access to 12 online learning modules on a variety of disability-related topics as well as other valuable information, tools and resources.

The OSN has been collaborating with the U.S. Department of Agriculture under a memorandum of understanding (MOU) that addresses certain research efforts by land-grant universities and the Cooperative Extension Services. The following research has been conducted:

- *Education Services for Military Dependent Children with Disabilities*: In 2010, the Ohio State University conducted a review to identify special education services for children age 3 to 21 in public schools near installations with a large military population that serve military children. More specifically, the review included the access and availability of evidence-based educational practices for military dependent children with ASD, intellectual disabilities and emotional disorders. A review of early intervention services for infants and toddlers with disabilities (birth to 3) in 15 states with high concentrations of military families was also conducted. A product of the review has been the development of an online *Education Directory for Children with Special Needs*. The directory provides families with tools and resources to help with the transition to a new location such as information to make informed decisions about the availability of educational services and to assist with making a smooth transition from one public school district to another within the United States. The directory will be expanded this year to include all 50 states.

- *Medicaid Study*: West Virginia University has conducted field research, data and regulatory analyses for the Medicaid Study to determine to what extent military families with special needs are accessing Medicaid Waiver services and to examine the issues families face when attempting to access these services especially as they relocate from state to state. Qualitative data has been gathered from the six joint military base installation site visits. An analysis of findings is being conducted and findings and recommendations for legislative or policy changes will be published this year.

- *Benchmark Study*: Cornell University and the Beach Center of the University of Kansas has conducted a benchmark study to identify the concerns of military families with special needs, the support they require, and the systems that have been effective in providing services. The research team has conducted focus groups with military families from all of the Services. The final report will be published in 2013 and include recommendations for OSN and the military Departments for the standardization and enhancement of EFMP family support services across DoD.

- The *Family Support Metrics project*, a continuation of the Benchmark Study, supports the Department in its efforts to standardize outcome data for families using the EFMP family support program. Cornell University, in coordination with OSN, is conducting a study to develop standardized metrics across the DoD on program activities and family outcomes for the EFMP family support services. The set of reporting requirements based on research findings will provide actionable data so that the OSN and military Services can assess services being provided and how well Service member and family member needs are being met.

TRICARE

Although the Department of Defense (DoD) is not one of the federal agencies identified under the 2006 Combating Autism Act (CAA), the Department is pleased to report on recent developments regarding TRICARE benefits designed to help meet the needs of all military families affected by ASD.

TRICARE offers physician services, pharmacy coverage, psychosocial treatment, psychological testing, occupational therapy (OT), physical therapy (PT) and speech and language pathology (SLP) for the treatment of ASD to all eligible TRICARE beneficiaries under the TRICARE Basic Program, which is the medical benefit plan of the Military Health System (MHS). A separate program, the Extended Care Health Option (ECHO), offers supplemental services to Active Duty Family Members (ADFMs) with a qualifying physical or psychologically disabling condition, including ASD. Prior to July 26, 2012, Applied Behavior Analysis (ABA) provided by Board Certified Behavior Analysts at the master's-level (BCBA) or doctoral-level (BCBA-D) has been offered to ADFMs under ECHO and its predecessor program since 2001. In 2008, the Department implemented the ECHO *Enhanced Access to Autism Services Demonstration* (or *ECHO Autism Demonstration*) for ADFMs to provide ABA reinforcement under a tiered service delivery model where ABA reinforcement is administered by ABA "technicians" or "tutors" working under the supervision of a BCBA. The number of beneficiaries receiving services for ASD under ECHO has almost tripled, from 2,292 beneficiaries in FY 2009 shortly after the *ECHO Autism Demonstration* began to a total of 6,560 beneficiaries in FY 2012. Government costs for ECHO program participants with an ASD diagnosis in FY 2012 totaled $107.7 million dollars. The *ECHO Autism Demonstration* continues to provide ABA under the tiered model described above to ADFMs.

Since July 26, 2012, TRICARE has cost-shared ABA provided by BCBAs and BCBA-Ds under the TRICARE Basic program for all eligible TRICARE beneficiaries, both ADFMs and Non-ADFMS (e.g., retirees, eligible Reservists, and eligible family members). On June 25, 2013, DoD published this revised TRICARE Basic Program policy and a new policy, the *ABA Pilot for Non-Active Duty Family Members (NADFMs)*, which was scheduled to begin July 25, 2013. The *ABA Pilot* is authorized by Section 705, National Defense Authorization Act FY 2013 for 12 months and requires DoD to submit a report to Congress regarding the cost of extending this coverage, as well as any recommendations for additional legislation, within 270 days of enactment. The *ABA Pilot* will offer one year of ABA reinforcement under the tiered service delivery model (analogous to the *ECHO Autism Demonstration* for ADFMs) to NADFMs for the first time.)

DEPARTMENT OF DEFENSE-AIR FORCE (AF)

The Department of Defense-Air Force (AF) first became involved with ASD research in 2008 when it was designated to manage a congressionally funded project sponsored by Senator Deborah Pryce (R-OH). The project, *Comprehensive Clinical Phenotyping and Genetic Mapping for the Discovery of Autism Susceptibility Genes* (2009-2012; Nationwide Children's Hospital, Ohio), was a collaborative effort between Nationwide Children's Hospital (NCH); Wright Patterson Medical Center (WPMC), Wright Patterson Air Force Base; and Dayton Children's Medical Center (DCMC). The purpose of this project was to develop a multidisciplinary autism research and services program for military families enrolled at WPMC as well as other central Ohio families enrolled at NCH. The specific aims of the project included expansion of the Central Ohio Registry for Autism (CORA) to provide higher quality data for autism clinical and genetics research and expansion of clinical services to WPAFB families through a subcontract with DCMC. The final aim included identification of autism susceptibility variants in candidate genes by gene sequencing at NCH's Center for Molecular Human Genetics, as well as screening for regulatory polymorphisms by measuring allelic mRNA expression imbalances at The Ohio State University.

In 2012, the AF, using research, development, technology, and evaluation dollars, funded the follow-on effort, *A Collaborative Translational Autism Research Program for the Military* (2012-2015; Nationwide Children's Hospital, Ohio). This collaborative research project enables the continued expansion of the CORA as well as the performance of exome sequencing on at least 60 individuals in CORA per year (20 trios of an affected child and both parents) and whole transcriptome RNA sequencing to discover new DNA variants affecting regulation and expression of RNA in the brain. The project proposes to enroll 150 families from central Ohio in which one or more family members have a diagnosis of an autism spectrum disorder. Approximately 50 percent of the families will be enrolled in collaboration with developmental pediatricians at WPMC. Families enrolled in CORA will be able to participate in cutting edge molecular and genetic research studies. Direct benefits to families from WPMC will include improved clinical care through the interaction of the WPAFB developmental pediatricians with an experienced clinical geneticist with expertise in the genetics of autism. In addition, families will receive a newsletter twice a year that will contain important information about autism, CORA, and ongoing research studies. Medically significant findings from the research will be shared with families who have indicated on the consent forms that they wish to receive this information.

Other Activities

In addition to the activities described above, the Department of Defense participates as a member agency on the Interagency Autism Coordinating Committee.

NATIONAL SCIENCE FOUNDATION (NSF)

The mission of the National Science Foundation (NSF) is to promote the progress of science; to advance the national health, prosperity, and welfare; and to secure the national defense. NSF is the only federal agency whose mission includes support for all fields of fundamental science and engineering, except for medical sciences. NSF has awarded numerous research grants through the years that include research on ASD and other developmental disabilities. These research awards, including current active awards, have been made across NSF's nine directorates.

In addition to NSF's contributions to the 2013 White House Brain Research through Advancing Innovative Neurotechnologies (BRAIN) Initiative via the agency's existing neuroscience and cognitive sciences portfolios, NSF's research awards in ASD fall under a portfolio that emphasizes education and learning research. One project highlighted in a NSF March 2013 article entitled, "NSF-funded Superhero Supercomputer Helps Battle Autism," describes a novel way of identifying a process in the brain that can be used to guide the development of treatments for mental disorders such as autism. A NSF article from January 2013 entitled, "Exploring the Brain's Relationship to Habits," describes a researcher's study of neurological conditions where repetitive movements commonly occur, including autism, and how the research may lead to novel treatments and therapies. In addition to these examples, NSF's Human Resource Development division within the Directorate for Education and Human Resources includes a Research in Disabilities Education Program. The National Science Foundation does not participate as a member agency on the Interagency Autism Coordinating Committee.

NSF Funding for Research Projects on Topics Related to ASD (FY 2010 – FY 2012)

	FY 2010	FY 2011	FY 2012
National Science Foundation (NSF)	$12,222,206	$1,428,639	$6,539,622

Table 18. This table indicates the total amount expended in fiscal years 2010-2012 in support of basic science projects on topics related to autism spectrum disorder.

Prevalence of Autism Spectrum Disorder

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.” Information on the prevalence of ASD is provided by the CDC.

CENTERS FOR DISEASE CONTROL AND PREVENTION (CDC)

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 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 8 years old in 2000 (born in 1992).[38] 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 8 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.[39] In December

---

[38] Centers for Disease Control and Prevention. Prevalence of Autism Spectrum Disorders—Autism and Developmental Disabilities Monitoring Network, Six Sites, United States, 2000. *Morbidity and Mortality Weekly Report (MMWR) Surveillance Summaries*. February 9, 2007; 56(SS-1):1-11. [PMID: 17287714]

[39] Centers for Disease Control and Prevention. Prevalence of Autism Spectrum Disorders—Autism and Developmental Disabilities Monitoring Network, 14 Sites, United States, 2002. *Morbidity and Mortality Weekly Report (MMWR) Surveillance Summaries*. February 9, 2007; 56(SS-1):12-28. [PMID: 17287715]

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.[40] This report also indicated that there were 4.5 times as many boys with ASD as 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 ASD also had an intellectual disability.

In March 2012, CDC and the ADDM Network published a third report of ASD prevalence estimates. ASD prevalence in 2008 was approximately 1 in 88 among 8-year-old children living in the 14 communities that participated in the 2008 surveillance year.[41] This report also indicated that more children were diagnosed at earlier ages—a growing number of them by 3 years of age, even though most children were not diagnosed until after age 4, and that ASD prevalence among boys was almost five times as high as it was for girls (1 in 54 compared to 1 in 252).

The prevalence of ASD over time (2002-2008 study years)

Data from the 13 ADDM sites with results from both 2002 and 2008 surveillance years indicated a significant increase (78 percent) in identified ASD prevalence over this 6 year period. Combining data from these 13 sites, ASD prevalence increased across all gender, racial/ethnic, and cognitive functioning subgroups. For the 2008 surveillance year, a wider range of site-specific ASD prevalence estimates were identified than in previous ADDM Network surveillance years.[41] Variation in estimated ASD prevalence was associated primarily with sites having access to education records and also appeared to be associated with improved identification among children without intellectual disability. 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.

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. Since the earliest ADDM Network report on ASD prevalence, some but not all sites have identified significantly higher ASD prevalence among White children compared to Black or Hispanic children. One report on ADDM data published in 2010 suggests that these disparities in identified prevalence may be associated with socioeconomic status.[42] 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.

---

[40] Centers for Disease Control and Prevention. Prevalence of Autism Spectrum Disorders—Autism and Developmental Disabilities Monitoring Network, United States, 2006. *Morbidity and Mortality Weekly Report (MMWR) Surveillance Summaries*. December 18, 2009; 58(Vol. 10):1-20. [PMID: 20023608]

[41] Centers for Disease Control and Prevention. Prevalence of Autism Spectrum Disorders—Autism and Developmental Disabilities Monitoring Network, 14 Sites, United States, 2008. *Morbidity and Mortality Weekly Report (MMWR) Surveillance Summaries*. March 20, 2012; 61 (SS-03): 1-19. [PMID:22456193]

[42] Durkin MS, Maenner MJ, Meaney FJ, Levy SE, Diguiseppi C, Nicholas JS, Kirby RS, Pinto-Martin JA, Schieve LA. Socioeconomic inequality in the prevalence of autism spectrum disorder: evidence from a U.S. cross-sectional study., *PLoS One*. July 2010. 12;5(7):e 11551. [PMID: 20634960]

Looking towards the future for ASD surveillance

CDC has been working to develop methods to track the population characteristics of ASD in younger children. In 2010, CDC funded six sites to expand ADDM methodology to younger cohorts. Through Early ADDM surveillance of ASD among 4-year-old children, CDC can better understand the population characteristics of young children affected by ASD 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 ASD over time.

Changes in diagnostic criteria

In May 2013 the American Psychiatric Association (APA) released an updated edition of the *Diagnostic and Statistical Manual of Mental Disorders (DSM)*. The new edition, the *DSM-5*, recommends a single diagnosis of "Autism Spectrum Disorder" as a replacement to the broader category of Pervasive Developmental Disorders (PDD) and five separate autism diagnoses, such as Asperger syndrome and PDD-not otherwise specified (PDD-NOS). The diagnostic criteria were modified to place the emphasis on the core elements of ASD–deficits of social communication and reciprocity, and presence of repetitive behaviors and restricted interests (rather than verbal abilities as was done in the *DSM-IV* definition). In addition, several clinical specifiers (e.g., intellectual disability, language delay, medical conditions such as seizures and pattern of onset) were added to help measure each individual's level of impairment and facilitate more customized approaches to treatment and interventions.

Investigators from CDC and the ADDM Network recently completed an evaluation of the new (*DSM-5*) diagnostic criteria for ASD to estimate the impact on prevalence estimates originally based on the last iteration (*DSM-IV-TR*) criteria. Findings from this evaluation were accepted for publication in 2013. In the future, CDC will be able to apply both the previous (*DSM-IV*) and current (*DSM-5*) diagnostic criteria to generate prevalence estimates based on the different definitions and evaluate the impact on prevalence trends and diagnostic practices. Thus CDC will be able to provide comparable trend data despite changes in diagnostic criteria.

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.” Information on the average age of diagnosis for individuals with ASD is provided by the CDC and HRSA.

CENTERS FOR DISEASE CONTROL AND PREVENTION (CDC)

Most children who have autism are not diagnosed until after they reach age 4, even though many children can be identified before age 2. For the most recently published ADDM Network ASD prevalence study, which was based on children who were 8 years old in 2008 and the diagnostic criteria in the *Fourth Edition, Text Revision of the Diagnostic Statistical Manual of Mental Disorders (DSM-IV-TR)*, the median age of earliest known diagnosis was reported by subtype category.[43] Age of first diagnosis ranged from 48 months for children diagnosed with Autistic Disorder (a more restrictive category suggesting higher severity of symptoms), to 53 months for children diagnosed under the more general category of Pervasive Developmental Disorder or autism spectrum disorder, and 75 months for children whose first diagnosis was Asperger Disorder (a category describing children without significant delays in language development or intellectual ability). About 20 percent of these children had a different subtype diagnosed after their initial diagnosis, so there is some instability in these subtypes over time. It is unclear if this instability is due to challenges in the diagnostic presentation of the children. Relatively equal mixes of children were initially diagnosed with Autistic Disorder or Pervasive Developmental Disorder, but only 9 percent of children had an initial diagnosis of Asperger Disorder.

Many people have asked whether the 23 percent increase in identified prevalence between 2006 and 2008 could be attributed to an increase in the proportion of children diagnosed under any particular subtype. Combined data from the 11 sites that completed both the 2006 and 2008 surveillance years shows virtually no change in the distribution of subtypes, the proportion of children with information available on subtype, or the median age of earliest known diagnosis under each subtype. While the median age and distribution of autism diagnoses has not changed substantially over time, there has been improvement in the proportion of children diagnosed by 3 years of age. In sites completing both the 2002 and 2008 surveillance years, the proportion of children diagnosed by 3 years of age increased from 12 percent to 18 percent.

---

[43] Centers for Disease Control and Prevention. Prevalence of Autism Spectrum Disorders—Autism and Developmental Disabilities Monitoring Network, 14 Sites, United States, 2008. *Morbidity and Mortality Weekly Report (MMWR) Surveillance Summaries*. March 20, 2012; 61 (SS-03): 1-19. [PMID:22456193]

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. An analysis of data from the 2007 National Survey of Children's Health (NSCH) indicates that only 21 percent of parents with children aged 10-47 months report that they were asked to fill out a questionnaire by a health care provider about their child's developmental, communication, or social behaviors in the last year.

HEALTH RESOURCES AND SERVICES ADMINISTRATION (HRSA)

The Health Resources and Services Administration's Maternal and Child Health Bureau provides funding for the National Survey of Children with Special Health Care Needs, which collects data on the prevalence of ASD as reported by parents of school age children. Data for the survey were collected at three points in time: in 2001, in 2005-2006 and in 2009-2010. No longitudinal data are available following the last survey. Although some CAAI grantees are tracking age of diagnosis, the data they collect are limited to specific regions. Relevant data are available, however, from CDC, through the Autism and Developmental Disabilities Monitoring (ADDM) Network. The National Survey of Children with Special Health Care Needs is currently being revised to change from a phone survey to an address-based sample survey. It will also be combined with the National Survey of Children's Health and conducted yearly. However, we will continue to collect information on ASD and age at diagnosis.

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 on the average age of intervention for individuals with ASD is provided by the CDC.

CENTERS FOR DISEASE CONTROL AND PREVENTION (CDC)

CDC monitors progress on the Healthy People 2020 objective of increasing the proportion of children with ASD who receive a comprehensive evaluation by a qualified professional before age 3. A baseline of 39 percent was established for 2010 (based on data from the ADDM 2006 surveillance year), with a goal of increasing this proportion by 10 percent during 2010-2020, or 2 percent in each of the 5 biennial surveillance years between 2006 and 2016. For the first reporting period, based on the 2008 surveillance year, the proportion of children with ASD receiving a comprehensive evaluation by age 3 increased from 39 percent to 41.8 percent. This represented a 7 percent increase over baseline, exceeding the 2 percent target. The more recent numbers are also higher than previous numbers from 2000-2004, where only about 32-33 percent of children with ASD received a comprehensive evaluation by age 3. This provides evidence that more children with ASD are being evaluated at an early age, which may indicate that more children with ASD are receiving interventions by age 3 as well.

The six Early ADDM sites described previously, funded in 2010 to monitor ASD prevalence among children at age 4, have begun collecting data on specific interventions children were receiving by that age. Findings from the first Early ADDM study are expected to be published in 2014.

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 on the average time between screening, diagnosis, and intervention for individuals with ASD is provided by the CDC.

THE CENTERS FOR DISEASE CONTROL AND PREVENTION (CDC)

As noted above, someone must be concerned about a child's development before an ASD evaluation can be conducted. In the 2006 ADDM Network report, there was documentation of concerns about development for 70-95 percent of the children identified with ASD; however, the median age of ASD diagnosis was 4 years, 6 months, indicating a significant delay between evidence of concerns and diagnosis.[44] 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 ASD 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 ASD and other developmental disabilities, and to enhance communication and coordination among state and local systems providing services to children with developmental delays.

---

[44] Centers for Disease Control and Prevention. Prevalence of Autism Spectrum Disorders—Autism and Developmental Disabilities Monitoring Network, United States, 2006. *Morbidity and Mortality Weekly Report (MMWR) Surveillance Summaries*. December 18, 2009; 58(Vol. 10):1-20. [PMID: 20023608]

Effectiveness and Outcomes of Interventions

This section addresses subsections (7) and (8) of 399DD, which require: (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,” and (8) “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 the effectiveness and outcomes of interventions is provided by AHRQ, CMS, ED, DoD, HRSA, NIH, and SAMHSA.

AGENCY FOR HEALTHCARE RESEARCH AND QUALITY (AHRQ)

AHRQ is supporting several projects that are developing innovative intervention strategies:

- The research and demonstration grant project, “Innovative Adaptation & Dissemination of CER Products,” is developing, implementing, and evaluating highly interactive and engaging evidence-based interventions for disseminating information about treatments for autism and autism spectrum disorder to over 16,000 individuals in important clinician, parent and teacher audiences. The researchers are partnering with a social networking site for parents, public school districts and a state healthcare delivery system. The project’s novel approaches to both content and delivery are expected to enhance the translation of new scientific evidence on ASD therapeutics in an accelerated format and its integration into practice and decision-making in families, the education system, the health care system and public policy.

- “The Partnership for Sustainable Research and Dissemination of Evidence-based Interventions” is developing a highly effective, unified and sustainable high-throughput dissemination infrastructure with key partners in ASD care to improve the penetration and use of customized evidence based medicine products at health and educational systems, clinical practice, caregiver and family levels.

- “The Computer-Assisted Autism Care (CAAC)” project expands the application of Dr. Downs’ group’s novel decision support system for implementing clinical guidelines in pediatric practice (CHICA) to include ASD screening, diagnosis, and treatment parameters, and to test its effectiveness in a randomized clinical trial. The primary outcomes of interest are a) the percent of children who are screened for ASD at the 18 or 24-month visit; and b) the number of guideline recommended activities/involvements that a child diagnosed with ASD receives.

- AHRQ supported a systematic review published in 2011, "Therapies for Children with Autism Spectrum Disorders," conducted at the Vanderbilt Evidence-based Practice Center that reviewed evidence on therapies for children ages 2 to 12 with autism spectrum disorder (ASD). The reviewers focused on treatment outcomes, modifiers of treatment effectiveness, evidence for generalization of outcomes to other contexts, and evidence to support treatment decisions in children ages 0–2 at risk for an ASD diagnosis. The report concludes that medical interventions including risperidone and aripiprazole show benefit for reducing challenging behaviors in some children with ASDs, but side effects are significant. Some behavioral and educational interventions that vary widely in terms of scope, target, and intensity have demonstrated effects, but the lack of consistent data limits our understanding of whether these interventions are linked to specific clinically meaningful changes in functioning. The needs for continuing improvements in methodologic rigor in the field and for larger multisite studies of existing interventions are substantial. Better characterization of children in these studies to target treatment plans is imperative.[45]

- AHRQ also supported a systematic review published in 2012, "Medications for adolescents and young adults with autism spectrum disorders," that focused on interventions for adolescents and young adults with ASD. Eight studies of medications were identified that focused on 13- to 30-year-olds with ASD and the reviewers concluded that four of the studies were of fair quality and that the strength of evidence was insufficient for all outcomes associated with medications tested in this population. However, the two available studies of the atypical antipsychotic medication risperidone in this age range were found to be consistent with the moderate evidence in children with ASD for treating problem behaviors, including aggression, and they found high strength of evidence for adverse events, including sedation and weight gain.[46]

CENTERS FOR MEDICARE & MEDICAID SERVICES (CMS)

In 2010, CMS issued a report entitled Autism Spectrum Disorders (ASD) Services Final Report on Environmental Scan, which describes the results of an extensive literature review conducted of the scientific evidence regarding the efficacy, effectiveness, safety, and availability of ASD-related Medicaid-funded services and supports that support daily living for people of all ages with ASD.[47] The report includes service categories and descriptions, evidence-based services 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. The scan highlighted the lack of research into effective services for adults, and interventions that can be implemented successfully in the community. CMS expended approximately $191,000 related to activities to complete the Environmental Scan.

---

[45] Warren Z, Veenstra-VanderWeele J, Stone W, Bruzek JL, Nahmias AS, Foss-Feig JH, Jerome RN, Krishnaswami S, Sathe NA, Glasser AM, Surawicz T,McPheeters ML. Therapies for Children With Autism Spectrum Disorders. *AHRQ Comparative Effectiveness Reviews*. Rockville (MD): Agency for Healthcare Research and Quality (US); April 2011. Report No.: 11-EHC029-EF. [PMID:21834171]

[46] Dove D, Warren Z, McPheeters ML, Taylor JL, Sathe NA, Veenstra-VanderWeele J. Medications for adolescents and young adults with autism spectrum disorders: a systematic review. *Pediatrics*. October 2012;130(4):717-26. [PMID:23008452]

[47] Young J, Corea C, Kimani J, Mandell D. *Autism Spectrum Disorders (ASDs) Services: Final Report on Environmental Scan.* Prepared for the Centers for Medicare & Medicaid Services, United States Department of Health and Human Services. March 9, 2010. Available at: https://www.impaqint.com/sites/default/files/project-reports/Autism_Spectrum_Disorders.pdf

DEPARTMENT OF DEFENSE (DOD)

Through the Autism Research Program (ARP), the Department of Defense has supported several projects aimed at exploring innovative strategies and interventions for individuals with ASD. Such studies include a randomized clinical trial conducted by Dr. Nancy Minshew (University of Pittsburgh) that assesses the effects of cognitive enhancement therapy for adults with ASD, and Dr. Evdokia Anagnoustou's work at the Bloorview Research Institute evaluating intranasal oxytocin as a treatment for children and adolescents (ages 10-17 years) with ASD.[48, 49] Other interventions-related research supported by the Department of Defense include Dr. Michael Jarstfer's study (University of North Carolina at Chapel Hill) involving preclinical testing of novel oxytocin receptor activators in models of autism phenotypes and Dr. Georgianna Gould's identification of novel therapeutic targets to treat social behavior deficits in ASD (University of Texas, Health Science Center San Antonio). The ARP is also funding a study that aims to develop an internet-based parent training intervention for children with ASD (conducted by Dr. Brooke Ingersoll, Michigan State University), and a randomized, controlled trial of intranasal oxytocin administration as an adjunct to behavioral therapy for adults with ASD ages 18-30 years (Dr. John Gabrieli, Massachusetts General Hospital).[50]

DEPARTMENT OF EDUCATION (ED)

Institute of Education Sciences (IES)

The National Center for Special Education Research (NCSER) funded a randomized controlled trial of *LEAP* (*Learning Experiences –An Alternative Program for Preschoolers and Parents*), a comprehensive intervention for preschool children with autism who are in inclusive classroom settings. In the *LEAP* intervention, typically-developing children learn to facilitate interaction with their peers with autism, preschool teachers use naturally-occurring classroom situations for incidental teaching, and parents receive skills training. The study found *LEAP* to be an effective intervention: Children with autism who experienced the full-scale *LEAP* intervention model, compared to children who experienced a reduced model, demonstrated more positive child outcomes in cognition and language, a reduction in symptom severity, growth in social skills, and a reduction in problem behavior. The study is published and meets What Works Clearinghouse standards of evidence without reservation. The investigators are currently conducting a follow-up study to examine whether these gains persist 3 years after the intervention ends.[51]

---

[48] Fitzpatrick LB, Minshew NJ, and Eack SM. 2013 Mar. A systematic review of psychosocial interventions for adults with autism spectrum disorders. *J Autism Develop Disorders*. March 2013 (43) 687-94. [PMID:22825929]

[49] Eack SM, Bahorik, AL, Hogarty SS, Greenwald DP, Litschge MY, Mazefsky CA, Minshew NJ. Is cognitive rehabilitation needed in verbal adults with autism? Insights from initial enrollment in a trial of cognitive enhancement therapy. *J Autism Develop Disorders*. September 2013. 43(9):2233-7. [PMID:23381484]

[50] Wainer A and Ingersoll B. Disseminating ASD interventions: a pilot study of a distance learning program for parents and professionals. *J Autism Develop Disorders*. January 2013 (43) 11-24 [PMID:22547028]

[51] Strain, PS, & Bovey II, EH. Randomized, controlled trial of the LEAP model of early intervention for young children with autism spectrum disorders. *Topics in Early Childhood Special Education*. 2011. 31(3), 133–154.

National Institute on Disability and Rehabilitation Research (NIDRR)

The Department of Education's National Institute on Disability and Rehabilitation Research (NIDRR), authorized by the Rehabilitation Act of 1973 (29 U.S.C. § 701), provides leadership and support for a comprehensive program of research related to the rehabilitation of individuals with disabilities including autism. 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. Several NIDRR-supported grants are focused around technological interventions including video games to develop daily living skills, parent training via video-conferencing, virtual reality training and using animation of symbols to enhance understanding. Other grants are developing new training for both parents and children with ASD. Note that study populations do not necessarily include children. The following section describes NIDRR-funded interventions studies organized by year.

Department of Education NIDRR Interventions Studies

2007

A Means of Expression: Online Communication Assessment to Improve Outcomes for Individuals with Severe Disabilities: Individuals with severe disabilities often experience complex communication disorders. Deficits in communication and language skills are so basic that they affect many other skill areas including social relationships, community integration, educational achievement and employment outcomes. The proposed Development project will adapt, refine, evaluate and market an innovative technological e-tool designed to provide appropriate assessment of communication skills for individuals with severe disabilities. The novel e-tool will harness the potential of an online communication assessment protocol to achieve immediate and meaningful individual-level outcomes in the form of cost effective and appropriate assessment, generation of appropriate educational and therapeutic goals, and monitoring of progress.

2008

Vocational Rehabilitation Service Models for Individuals with Autism Spectrum Disorders (VCU ASD Career Links): VCU ASD Career Links conducts evidence-based research on vocational rehabilitation (VR) service models for individuals with ASD. The project is based at Virginia Commonwealth University (VCU) and is a collaborative initiative between VCU and the Virginia Department of Rehabilitative Services (DRS). The scope of research covers four areas: (1) the impact of intensive, community-based work experiences on the employment outcomes of youth with ASD; (2) the postsecondary school participation and ultimate employment of college students with ASD; (3) the impact of personal digital assistants (PDAs) on the employment outcomes of individuals with ASD; and (4) a longitudinal analysis of VR service delivery and employment outcomes among DRS clients with ASD.

Daily Living and Community Skills Video Game for Children with Developmental Disabilities: This project develops and evaluates a simulation video game to teach children with developmental disabilities, including autism and intellectual disabilities, skills for independence. The project teaches chained tasks in an engaging and effective game format. This system provides an innovative and inexpensive way to increase opportunities for instruction while providing correction procedures, giving multiple exemplars, monitoring progress, and including clips from each student's community. Project goals include: (1) to expand on the successful techniques demonstrated in preliminary studies to create a fully-functional game with 24 skills, and (2) to verify through a single subject design, specifically multiple probes across behaviors, that the simulation video game alone teaches the skills to 24 children with developmental disabilities in elementary and middle school.

2009

Experimental Evaluation of the Online and Applied System for Intervention Skills (OASIS) Training Program Using Video-Conferencing for Parents of Children with an Autism Spectrum Disorder: This project evaluates the Online and Applied System for Intervention Skills (OASIS) Training Program, a program that uses a Research-to-Practice Outreach Training model to teach parents of children with an ASD how to implement empirically-based interventions with their children. The evaluation of the OASIS program includes two studies. The purpose of Study 1 is to: (1) conduct a between-group experimental analysis of the effectiveness of the final iteration of the OASIS training program developed during a previously funded development project, and (2) conduct a within-subject analysis of the effects of OASIS on parent knowledge and skill fluency with implementation of behavioral techniques with their child, family quality of life, and child language and social engagement post treatment and during follow-up measures. The purpose of Study 2 is to assess the long-term impact of the OASIS program on parents and children who previously completed training.

The Effects of a Bicycle Training Intervention on Health, Physical Activity, Sleep, and Community Participation in Youth with Down Syndrome and Autism Spectrum Disorders: This 3-year study utilizes a randomized trial design to determine the effects of an individualized bicycle training intervention on functional performance, time spent in moderate to vigorous physical activity, patterns of sleep, and community participation and integration of youth with Down Syndrome (DS) and autism spectrum disorder, aged 9 to 18 years.

2010

Do Animations Facilitate Symbol Understanding in Children with Autism? This project investigates the use of animation to facilitate the understanding of graphic symbols for verbs and prepositions in children with autism and/or pervasive developmental disorders - not otherwise specified, and if successful, which animated graphic set is most effective. This project designed two studies involving the widely used Picture Communication Symbols (PCS) and the newly designed ALP Animated Graphics Set to gather benchmark data on the effects of animations versus static images for verbs and prepositions in preschoolers without disabilities across three age groups.

Virtual environment for social information processing (VESIP): This project creates an immersive, theory-based tool that can assess, and eventually train, social information processing (SIP) skills in children with ASD. The VESIP system provides a significant improvement over existing measures of social skills in the following ways: (1) providing a standardized, computer-delivered form that reduces training requirements and scoring time, and increases comparability across populations; (2) theory-based assessments designed to pinpoint specific deficits in the SIP process for later individualized intervention; and (3) building an immersive, easily-customizable, game-like interface that is more engaging leading to greater ecological validity and a more accurate assessment of real-world skills.

2011

System for Intervention Skills (OASIS) Training Program with Parents of Children with an Autism Spectrum Disorder: This project seeks to address the access and training deficit for Spanish-speaking parents of children with ASD by adapting the Online and Applied System for Intervention Skills (OASIS) Training Program for use with parents who speak Spanish and have a child with an ASD to teach them how to implement empirically-based interventions with their child. During training, parents practice the techniques discussed in that week's online tutorials with their child while receiving guidance and immediate feedback from a bilingual clinician with a background in behavior analysis and trained to implement OASIS. Program effectiveness is evaluated based on: parental knowledge and skill fluency, child adaptive behaviors, and reported family quality of life. In addition, families complete exit surveys to elicit feedback regarding program improvement and any problems they experienced, particularly regarding cultural and/or language barriers experienced.

Sustainable Implementation of Family-Centered Transition Planning for Young Adults with Autism Spectrum Disorders: This project develops a sustainable process for implementing a Family-Centered Transition Planning model for youth and young adults with autism spectrum disorder. Based on research demonstrating the effectiveness of Family-Centered Transition Planning in increasing student and parent expectations for adult life, student career decision-making, and student participation in employment and postsecondary education, this project develops an implementation package to embed this method of independent transition planning into the existing service and funding system on a long-term basis across multiple states.

HEALTH RESOURCES AND SERVICES ADMINISTRATION (HRSA)

Between 2010–2012, the HRSA Maternal and Child Health Bureau Autism Intervention Research program supported three research networks and 25 R40 grants. The MCH Autism Intervention Research Network on Physical Health (AIR-P) and the MCH Autism Intervention Research Network on Behavioral Health (AIR-B) have been conducting studies on ASD interventions since they were initially funded in FY 2008. A third Network, the Developmental-Behavioral Pediatrics Research Network (DBPNet) was funded in 2010 to support multidisciplinary research, the translation of research to practice, and training for a new generation of developmental behavioral pediatrics researchers. The R40 grant programs, which include the Autism Intervention Secondary Data Analysis Studies (SDAS) Program and the MCH Autism Intervention Research Program, support research on evidence-based practices for ASD interventions. Generating evidence of the effectiveness and outcomes of interventions for individuals with ASD is still evolving, as researchers continue to develop and test valid and reliable measurement tools. To address the need for psychometrically sound measurement tools that are sensitive to changes in core ASD symptoms, the AIR-P tested the reliability of the Autism Impact Measure (AIM). Results indicated that the AIM is a valid and reliable tool for measuring changes in core areas of social interaction, communication, and repetitive behavior as a result of medical treatments in children with ASD. The study was published in the *Journal of Autism and Developmental Disorders* in June 2013.[52] Although this study does not provide direct information on the effectiveness of a particular intervention, it does provide researchers with a means to reliably assess ASD treatment outcomes.

---

[52] Kanne SM, Mazurek MO, Sikora D, Bellando J, Branum-Martin L, Handen B, Katz T, Freedman B, Powell MP, Warren Z. The Autism Impact Measure (AIM): Initial Development of a New Tool for Treatment Outcome Measurement. *J Autism Dev Disord*. January 2014. 44(1):168-79 [PMID:23748386]

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

YEAR INITIATED	STUDY TITLE	BRIEF DESCRIPTION
2009	Diet and Nutrition in Children With Autism Spectrum Disorders: An Autism Treatment Network Collaborative Study	This study investigated the food and supplement intake of children and adolescents with ASD. Researchers examined 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.
2009	Parent-Based Sleep Education Program for Children With Autism Spectrum Disorder	The objective of this study was to determine the most effective education/behavioral intervention for addressing insomnia for children with autism. Investigators provided training in the use of various behavioral treatments to promote sleep.
2010	Bone Mineral Density in Children With Autism Spectrum Disorders	This cross-sectional study aimed to determine whether 20 boys ages 8 to 14 years old with autism have lower bone mineral density than age-matched controls, and explored risk factors for low bone mineral density.
2010	Defining the Relation of Sleep Disturbance in Autism Spectrum Disorder to Psychiatric and Behavioral Comorbidities	The goal of this cross-sectional study was to provide a foundation for future intervention studies that can inform treatment guidelines. Investigators used the Autism Treatment Network registry to define the psychiatric and behavioral comorbidities associated with disordered sleep across the spectrum of age, IQ, and functional status.
2010	Markers of Iron Status and Metabolism in Children With Autism Spectrum Disorders	The objective of this cross-sectional, observational study was to evaluate associations among iron intake, iron status, GI symptoms, and novel markers of iron status, iron absorption, and inflammation in children ages 2 to 11 years old.
2010	Prevalence of Creatine Deficiency Syndromes and Genetic Variability in Creatine Metabolism in Children With Autism Spectrum Disorder – A Pilot Study	The study objective is to determine prevalence of CDS in 600 children with autism and to assess the interaction of genotypic variability of the three known genes involved in creatine metabolism with the autism phenotype.
2011	Constipation and Toilet Training in Autism	This study focused on the development of an effective behavioral treatment protocol to complement and enhance the medical treatment of constipation in children with ASD. Investigators are examining a novel wireless moisture alarm to promote daytime toileting in children with ASD. This study uses the wireless alarm to facilitate more rapid acquisition of toileting skills.
2011	Epileptiform Discharges and its Relation to Cognition and Behavior in Children With Autism Spectrum Disorders	The objective of the study is to test putative links between interictal epileptiform discharges, sleep, and behavior/cognition in children ages 3 to 7 years old.
2011	Maternal Cholesterol and Autism	The objective of this pilot study is to characterize maternal sterol metabolism in mothers of children with autism, including mothers at risk to have another autistic child, in part to evaluate the rationale of cholesterol supplementation on the incidence of autism in children.
2011	The Autism Impact Measure (AIM): A New Tool to Measure Treatment Outcome in ASD	The objective of this study was to determine reliability and validity of a new clinical tool (AIM) to measure changes in core areas of social interaction, communication, and repetitive behavior as a result of medical treatments in children with ASD. Study results provided evidence that the AIM shows promising psychometric properties, with excellent internal consistency, test-retest reliability, inter-rater reliability, and relations to measures of related constructs.

YEAR INITIATED	STUDY TITLE	BRIEF DESCRIPTION
2011	The Study of Toddlers With Autism and Regression (STAR) Protocol – Screening for Treatable Disorders and Biomarkers of Inflammation and Immune Activation in the Plasma and CNS	The objective of this study is to determine if children ages 18 to 36 months have increased signs of systemic inflammation and oxidative stress compared to children with autism and no regression.
2012	Evaluating the Impact of Emergency Room Services for Children and Adolescents With Autism Spectrum Disorders	This project is a 2-year, multisite research effort, examining emergency room accessibility and experience among children and adolescents with ASD.
2012	Evaluation for Functional Causes of Gastrointestinal Symptoms in Children With ASD	This 1-year study will gather pilot data to explore mechanisms associated with functional gastrointestinal disorders in children with ASD.
2012	Iron Treatment of Sleep Disorders in Children With Autism Spectrum Disorder	This 3 year, 2-phase study is designed to evaluate the effect of iron supplementation on restless legs syndrome and periodic limb movement of sleep. The first phase is an open label trial of oral elemental iron for children with ASD and low ferritin levels. The second phase is a randomized placebo-controlled trial of oral elemental iron treatment for insomnia in children with ASD and low ferritin levels.
2012	Relationship Between Gastrointestinal Disorders and Stress Reactivity, Immunity, and Blood Serotonin in Autism Spectrum Disorder	This 2-year, multisite research will examine factors related to immune markers and serotonin and how stress response, gastrointestinal disorders, immunity, and the serotonin system interact in autism.
2012	Treatment of Overweight Induced by Antipsychotic Medication in Young People With ASD	The objective of this 3-year study is to conduct a 16-week, double blind, placebo-controlled randomized trial of fixed dose metformin to decrease weight gain associated with atypical antipsychotic medication in children with ASD.

Table 19. Autism Intervention Research Network on Physical Health (AIR-P) Research Studies.

The AIR-P has also released a series of toolkits through the Autism Speaks Web site, providing intervention information on such topics as medication decision making for children with ASD, sleep, and toileting. Table 20 includes a complete list of toolkits available for download from the web site.

HRSA Autism Intervention Research Network on Physical Health (AIR-P) Tool Kits

ATN/AIR-P TOOL KIT*	RELEASE DATE	NUMBER OF CUMULATIVE DOWNLOADS**
Sleep Quick Tips for Parents	February 2013	186
Applied Behavioral Analysis	June 2012	8,780
Introduction to Behavioral Health Treatments	June 2012	4,960
Toileting	June 2012	6,617
Dental Provider's Guide	February 2012	3,234
Sleep Parent Booklet	February 2012	7,458
Visual Supports	November 2011	13,282
Blood Draws – Guide for Parents	September 2011	2,936
Blood Draws – Guide for Providers	September 2011	1,456
Medication Decision Aid	September 2011	6,891

*Table 20. Autism Intervention Research Network on Physical Health (AIR-P) Tool Kits. *These are available for download at http://www.autismspeaks.org/family-services/tool-kits.**As of May 17, 2013.*

The AIR-B Network convened a Technical Expert Panel to develop consensus-based guidelines on nonmedical interventions that address cognitive function and core deficits in children with ASD. Interventions that have shown efficacy include Applied Behavioral Analysis (ABA), integrated behavioral/developmental programs, the Picture Exchange Communication System, and various social skills interventions. A recently completed AIR-B study examined whether evidence-based interventions tested in clinical settings with high-resource families would be equally effective with less advantaged participants in the community. Results showed that hands-on interventions for parents conducted in the homes of underserved families are more effective at improving core deficits than information-only interventions provided to parents. The study did not find effects of child chronological age for children ages 2–5 years with a clinical and research confirmed diagnosis of autism. The intervention was as effective with older children as with younger children.

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

YEAR INITIATED	STUDY TITLE	BRIEF DESCRIPTION
2008	Early Intervention Protocol: Parent Mediated Intervention for Low-Resourced Families of Preschoolers With Autism and Early Intervention Service Utilization Among Underserved Children with Autism	This study aimed to explore whether evidence based interventions focused on core deficits carried out in clinical settings with high-resource families would be as effective with less-advantaged participants in the community.
2009	Social Skills at School for Underserved Children with Autism	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 underserved 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.
2010	Teen-Based Social Skills Intervention in Schools	This study involves an upward extension of the Peer Social Skills/Relationship Intervention at School study to underserved middle school and high school students with ASD. The project is comparing SKILLS to ENGAGE adapted for middle school and high school fully included teens with ASD. It will provide the first randomized controlled test of social skills interventions delivered at school for teens with ASD.
2011	AIR-B Web-Based Social Skills Intervention	This project involved a Web-based social-skills intervention (content developed by a junior investigator at KKI) and a Web-based format implemented by a junior investigator at UCLA. Feedback from piloting via IAN network (family-based Web network) suggested the intervention content needed major revision to be acceptable by children. This project is currently undergoing a different format that involves a "choose your adventure" format for illustrated stories that are delivered via an iPad. One storyboard is completely written and illustrated and is undergoing pilot testing. Two other storyboards are written and will be illustrated depending on feedback from the pilot.
2011	Autism Intervention Research in Behavior – Deployment in Elementary Schools	This project aims to move evidence-based psychosocial interventions for children with ASD from research to practice settings, focusing on large, urban school districts. The current study is an initial step toward moving evidence-based psychosocial interventions for children with ASD from research to practice settings, focusing on large, urban school districts.

Table 21. Autism Intervention Research Network on Behavioral Health (AIR-B) Research Studies.

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

NAME	BRIEF DESCRIPTION
Playground Observation of Peer Engagement (and Teen Observation of Peer Interaction)	An observation measure for collecting peer engagement of children at school (used across multiple studies and by many other investigators now).
Social Networks Survey	A method for collecting peer engagement and friendship data from children in classrooms. Computer-based application that develops social network maps. Available for use by other researchers.
Active Engagement Rating Scale	Rating scale for assessing how engaged children are with others in natural environments (currently used in our home observations of preschoolers across daily routines)
ADOS-Change	Developed to assess subtle changes in core deficits similar to what the ADOS measures but using other situations such as mother-child interactions. AIR-B data is currently being used to validate measure.
Pragmatic Rating Scale	A briefer rating scale applied to any child interaction with others. Currently undergoing validation using AIR-B data of peer interactions of verbal children with ASD.

Table 22. Autism Intervention Research Network on Behavioral Health (AIR-B) Tools.

A completed R40 project assessed a specially designed intervention content and parent training delivered via home-based and center-based (classroom) intervention. The study compared the impact of the home-based versus the center-based intervention on the social, communication, and cognitive functioning of 2-year-old toddlers with ASD. Both interventions improved the participating toddlers' nonverbal cognition and language (receptive and expressive) functioning. Children in the center-based condition showed more developmentally comprehensive gains across nonverbal cognitive, language, and social domains. Gains from pre- to post-intervention were comparable for children from minority and non-minority families (controlling for SES) despite the fact that the minority children entered the treatment with greater impairment in communication functioning.

Another R40 study evaluated the effectiveness of Problem Solving Education (PSE), an evidence-based behavioral intervention, on the burden of depressive symptoms, parenting stress, and social functioning among English- and Spanish-speaking mothers who have children younger than 6 years old with ASD. The study showed statistically significant differences between intervention and control group participants, with intervention group mothers having fewer episodes of clinically significant depressive symptoms, assessed every 6 weeks over 9 months of follow-up.

One R40 study evaluated the effectiveness of a family-centered transition planning intervention for 16- to 18-year-old high school students with ASD. The goal of the intervention was to empower families and transitioning students to take a leading role in the process of transition planning. The intervention effectively produced significant gains in student expectations, parent expectations, student self-determination, and vocational decision-making.

To address sleep problems that are common among children with ASD and quite disruptive to families, the AIR-P piloted an innovative intervention designed to help parents teach their children with ASD to become better sleepers.[53] In response to previous studies that found that printed informational materials had limited effectiveness in helping parents foster better sleep patterns in their autistic children as compared to a control group, this study tested the effectiveness of physician-led parent education workshops that provided training in the use of various behavioral treatments to improve their children's sleep. Investigators found that the workshops were effective in improving subjective and objective measures of sleep and sleep habits. These results indicate that group trainings may offer opportunities to reach more families with an effective, evidence-based intervention. Another AIR-P study is examining a novel wireless moisture alarm to promote daytime toileting in children with ASD. As part of this pilot study, investigators will develop training manuals for clinicians and parents.

HRSA Autism Intervention Research Network on Physical Health (AIR-P) Clinical Practical Guidelines

TOPIC AREA	OVERVIEW	PUBLICATION
Managing Sleep Behavior	This report describes the development of a practice pathway for the identification, evaluation, and management of insomnia in children and adolescents who have autism spectrum disorder (ASDs). The Sleep Committee of the Autism Treatment Network (ATN) developed a practice pathway, based on expert consensus, to capture best practices for an overarching approach to insomnia by a general pediatrician, primary care provider, or autism medical specialist, including identification, evaluation, and management. A field test at four ATN sites was used to evaluate the pathway. In addition, a systematic literature review and grading of evidence provided data regarding treatments of insomnia in children who have neurodevelopmental disabilities.	Malow, B.A., Byars, K., Johnson, K., Weiss, S., Bernal, P., Goldman, S.E., ...Glaze, D.G. (Sleep Committee of the Autism Treatment Network). (2012). A practice pathway for the identification, evaluation, and management of insomnia in children and adolescents with autism spectrum disorder. Pediatrics, 130(Supplement 2), S106-24
Toileting Behavior	The Gastroenterology Committee of the Autism Speaks Autism Treatment Network (ATN), a multisite consortium of centers dedicated to improving standards of medical care for children with ASDs, guided the development of the constipation algorithm through expert opinion and literature review. The algorithm was finalized based on results of field testing by nongastrointestinal, ATN autism medical specialists at four ATN sites. A systematic review and grading of the literature pertaining to constipation and children with ASDs was also performed. Consensus among the ATN Gastroenterology Committee identified that in children with ASDs, 1) subtle or atypical symptoms might indicate the presence of constipation; 2) screening, identification, and treatment through a deliberate approach for underlying causes of constipation is appropriate; 3) diagnostic-therapeutic intervention can be provided when constipation is documented; and 4) careful follow-up after any intervention be performed to evaluate effectiveness and tolerance of the therapy. Literature review revealed limited evidence for the clinical evaluation or treatment strategies of children with ASD and constipation.	Furuta, G.T., Williams, K., Kooros, K., Kaul, A., Panzer, R., Coury, D.L., & Fuchs, G. (2012). Management of constipation in children and adolescents with autism spectrum disorder. Pediatrics, 130(Supplement 2), S98-S105.

---

[53] Malow BA, Adkins KW, Reynolds A, Weiss SK, Loh A, Fawkes D, Katz T, Goldman SE, Madduri N, Hundley R, Clemons T. Parent-Based Sleep Education for Children with Autism Spectrum Disorders. *J Autism Dev Disord*. January 2014. 44(1):216-28. [PMID:23754339]

TOPIC AREA	OVERVIEW	PUBLICATION
Treating Children and Adolescents With ASD and ADHD	Hyperactivity, impulsivity, and inattention (referred to as "ADHD [attention-deficit/hyperactivity disorder] symptoms") occur in 41% to 78% of children with ASDs. These symptoms often affect quality of life, interfering with learning or interventions that target primary ASD symptoms. This practice pathway describes the guidelines for evaluation and treatment of children and adolescents with ASD and comorbid ADHD symptoms. Current research in this area is limited, and, therefore, these recommendations are based on a systematic literature review and expert consensus in the Autism Speaks Autism Treatment Network Psychopharmacology Committee. For children for whom medication is being considered to target the ADHD symptoms, the medication choice pathway provides guidance on the selection of the appropriate agent based on a review of available research, assessment of specific advantages and disadvantages of each agent, and dosing considerations. These recommendations provide a framework for primary care providers treating children who have ASD and ADHD symptoms. Our systematic review of the current evidence indicates the need for more randomized controlled trials of the medications for ADHD symptoms in ASD. There will also be a need for studies of the effectiveness of these practice pathways in the future.	Mahajan, R., Bernal, M.P., Panzer, R., Whitaker, A., Roberts, W., Handen, B., Hardan, A., ...Veenstra-VanderWeele, J. (Autism Speaks Autism Treatment Network Psychopharmacology Committee). (2012). Clinical practice pathways for evaluation and medication choice for attention-deficit/hyperactivity disorder symptoms in autism spectrum disorder. Pediatrics, 130(Supplement 2), S125-38.
Treatment of Anxiety Symptoms in ASD	In progress	Peer-reviewed publication
Treatment of Irritability Symptoms in ASD	In progress	Peer-reviewed publication
EEG Testing in ASD	In progress	Peer-reviewed publication

Table 23. Autism Intervention Research Network on Physical Health (AIR-P) clinical practice guidelines.

The AIR-B is continuing research on an innovative, Web-based social skills intervention available for both desktop computers and the iPad. The Network aims to deliver the program to children with ASD at home or in the school setting and to test for generalization on the playground or in the school cafeteria.

Two active R40 studies are testing new and innovative approaches to improve access to ASD treatment for families in rural and remote areas. One study, "Behavioral Treatment through In-Home Telehealth for Young Children With Autism," is evaluating the effectiveness of using in-home telehealth to deliver an empirically validated behavioral treatment for challenging behavior to families in underserved areas of rural Iowa. Another study, "Efficacy of the Home TEACCHing Program for Toddlers with Autism," is evaluating an innovative home-based version of the TEACCH (Treatment and Education of Autistic and Communication-handicapped CHildren) program, which has been adapted to be more developmentally appropriate for toddlers with ASD, and more responsive to needs of families in rural communities.

Another completed R40 project aimed to improve access to evidence-based treatment for families of youth with ASD who live far from specialty medical centers. This study tested the feasibility and potential efficacy of using a videoconferencing program to connect families of psychiatrically complex youth with ASD, living in rural Colorado, with clinical psychologists who specialize in treatment of anxiety and coping problems in youth with ASD. Telehealth delivery of the intervention was found to be acceptable and feasible with promising preliminary efficacy for youth self-report of fears and anxieties and parent report of impact on family.

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. The types of intervention studies are diverse and examples include: developing new treatments that improve autism symptoms, language development, and social behaviors in children; computerized training programs for adults with autism to improve their ability to recognize and process facial expressions; jobs programs that help high school graduates who have ASD; and providing rapid ways to test new or repurposed compounds for their potential to treat ASD.

Through NIH's support of the Autism Center of Excellence (ACE) program, a number of the centers and networks funded through FY 2012-FY 2017 involve projects that develop new and innovative treatments and services for children with ASD. For example, investigators are conducting a multi-site randomized clinical trial to determine the effectiveness of the Early Start Denver Model (ESDM), a behavioral intervention designed to improve language and communication development of young children with ASD. An earlier study indicated the ESDM intervention can significantly increase IQ scores, and improve communication, motor, and daily living skills in children with ASD.[54] In a related study, 18- to 30-month-old children with autism who participated in ESDM showed brain activity associated with improvements in social behavior.[55]

Three separate NIH-supported intervention studies highlight research geared toward improving the social skills of children and adults with ASD. The first study found that programs incorporating same-age peers not affected by ASD in social skills development were a more successful intervention approach than programs that focus on children with ASD alone.[56] A second study found that targeting the core social deficits of ASD in early intervention programs yielded sustained improvements in social and communication skills even in very young children with ASD.[57] The third study showed that an intervention in which adults actively engaged the attention of preschool children with ASD by pointing to toys and using other gestures to focus their attention results in a long-term improvement in

---

[54] 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. [PMID:19948568]

[55] Dawson G, Jones EJ, Merkle K, Venema K, Lowy R, Faja S, Kamara D, Murias M, Greenson J, Winter J, Smith M, Rogers SJ, Webb SJ. Early behavioral intervention is associated with normalized brain activity in young children with autism. *J Am Acad Child Adolesc Psychiatry*. November 2012;51(11):1150-9. [PMID:23101741]

[56] Kasari C, Rotheram-Fuller E, Locke J, Gulsrud A. Making the connection: randomized controlled trial of social skills at school for children with autism spectrum disorders. *J Child Psychol Psychiatry*. April 2012;53(4):431-9. [PMID:22118062]

[57] Landa RJ, Holman KC, O'Neill AH, Stuart EA. Intervention targeting development of socially synchronous engagement in toddlers with autism spectrum disorder: a randomized controlled trial. *J Child Psychol Psychiatry*. January 2011;52(1):13-21. [PMID:21126245]

language skills.[58] Treatment innovations are also being pursued for adults on the autism spectrum. Face recognition is a social impairment that impacts both children and adults with autism. Using a computerized training program, investigators demonstrated that adults with ASD can gain expertise in face processing and recognition skills.[59]

NIH-funded researchers recently demonstrated that a subset of children correctly diagnosed with ASD at a young age eventually improved to the point of "optimal outcome," or losing their ASD diagnoses later in life. The results suggest that the children who eventually lost their diagnosis had fewer social deficits than the mild autism group in early childhood, but had other symptoms, related to communication and repetitive behavior, that were as severe as in the latter group.[60]

Early detection will likely be an essential component in reducing the level of disability associated with ASD through early intervention. Recent science advances from the Infant Brain Imaging Study (IBIS), supported through the NIH ACE program, could lead to earlier and improved diagnostic methods. One study showed that patterns of brain development in the first 2 years of life are distinct in children who are later diagnosed with ASD compared to their unaffected siblings. The researchers suggest that certain brain circuits developed faster in the children who did not have ASD. In another study, researchers reported that at age 7 months, children who are later diagnosed with autism take a split second longer to shift their gaze during a task measuring eye movements and visual attention than do typically developing infants of the same age. They showed that this measurable delay could be accounted for by differences in the structure and organization of actively developing neurological circuits of a child's brain. Ultimately, differences in gaze detected at 7 months of age might help doctors identify children likely to develop autism later on.

Once diagnosed, early intervention will likely lead to better health outcomes for children with ASD and other developmental disabilities. NIH has undertaken a number of activities to address the urgent need for innovative and effective intervention strategies, including biomedical interventions. Investigators supported by an ACE network are examining whether a nasal spray of oxytocin, a hormone that influences social behavior, can improve social interaction and communication in children with ASD. The 5-year study will determine if oxytocin improves social functioning in ASD, evaluate the medication's safety in children, and identify factors that influence a child's response to oxytocin. Fragile X syndrome (FXS) is the most commonly inherited cause of intellectual disability and individuals with FXS often exhibit traits that resemble autism. NIH-supported work provided an understanding of the root cause of FXS, allowing researchers to take a precision approach in trying to correct it.[61] This work is the basis for ongoing NIH-funded early clinical trials of a compound that may correct a central neurochemical defect underlying Fragile X syndrome and alleviate symptoms of ASD. Finally, a clinical trial of donepezil—a medication typically used for Alzheimer's disease–demonstrated enhanced REM sleep in young children with autism. The investigators are currently developing a randomized controlled study using donepezil to target symptoms of ASD.

---

[58] Kasari C, Gulsrud A, Freeman S, Paparella T, Hellemann G. Longitudinal follow-up of children with autism receiving targeted interventions on joint attention and play. *J Am Acad Child Adolesc Psychiatry*. May 2012;51(5):487-95. [PMID:22525955]

[59] Faja S, Webb SJ, Jones E, Merkle K, Kamara D, Bavaro J, Aylward E, Dawson G. The effects of face expertise training on the behavioral performance and brain activity of adults with high functioning autism spectrum disorders. *J Autism Dev Disord*. February 2012;42(2):278-93. [PMID:21484517]

[60] Fein D, Barton M, Eigsti IM, Kelley E, Naigles L, Schultz RT, Stevens M, Helt M, Orinstein A, Rosenthal M, Troyb E, Tyson K. Optimal outcome in individuals with a history of autism. *J Child Psychol Psychiatry*. February 2013;54(2):195-205. [PMID:23320807]

[61] Dölen G, Osterweil E, Rao BS, Smith GB, Auerbach BD, Chattarji S, Bear MF. Correction of fragile X syndrome in mice. *Neuron*. December 2007. 20;56(6):955-62. [PMID:18093519]

To hasten the development of new potential drug candidates to address ASD symptoms, NIH has launched the Fast-Fail Trials in Autism Spectrum Disorders (FAST-AS) initiative. Given that over 95 percent of compounds fail during the clinical phases of development - a fact not fully apparent when looking at the published literature which is more focused on positive results - success may require rapid failures in order to conserve resources by moving quickly to the next candidate ("fast-fail"). This initiative's goal is to implement an experimental medicine paradigm of "fast fail" *Proof of Clinical Mechanism and Proof of Concept* trials to quickly test and analyze novel compounds and identify molecular and/or clinical targets for treating ASD.

SUBSTANCE ABUSE AND MENTAL HEALTH SERVICES ADMINISTRATION (SAMHSA)

SAMHSA also supports the Behavioral Health Electronic Clinical Quality Measure Development project, which is developing, testing, and validating electronically-specified clinical quality measures related to primary care screening for depression, suicide, drug use, alcohol use, trauma, and autism, for potential inclusion in the Centers for Medicare & Medicaid Services (CMS) Electronic Health Record (EHR) Incentive Program. The project is being coordinated with the Office of the National Coordinator for Health Information Technology (ONC) and CMS measurement development, testing and validation activities. The project aims to develop consensus on the issues surrounding clinical quality of care measures, define additional quality measures that need to be developed to support quality care, complete technical and electronic specifications, and perform field testing when necessary. These measures may be used to facilitate the measurement of disparities in early diagnosis and screening. Funding: $450,000 in FY 2011 awarded in FY 2012.

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 AHRQ, CMS, ED, DoD, HRSA, NIH, and SAMHSA.

AGENCY FOR HEALTHCARE RESEARCH AND QUALITY (AHRQ)

- AHRQ's *Health Care Innovations Exchange* notes 11 examples of "Innovations in autism management and QualityTools." For instance, the Exchange provides as an example of how a nonprofit organization enhances access to medical and dental care for both adults and children with disabilities by helping them to overcome their fears. A snapshot of how this program was used with a 48-year-old man with autism is provided on the program website.

- In 2012, AHRQ released a set of guidelines for recognition, referral, diagnosis and management of adults on the autism spectrum. The guidelines provide advice to practitioners and professional teams who may be working with adults on the spectrum and to family partners and carers about how to potentially identify ASD in adults, how to identify the correct interventions and monitor their use, and how to organize and deliver care for an adult.

CENTERS FOR MEDICARE & MEDICAID SERVICES (CMS)

In 2010, CMS issued a report entitled *Autism Spectrum Disorders (ASD) Services Final Report on Environmental Scan*, which describes the results of an extensive literature review conducted of the scientific evidence regarding the efficacy, effectiveness, safety, and availability of ASD-related Medicaid-funded services and supports that support daily living for people of all ages with ASD.[62] The report includes service categories and descriptions, evidence-based services 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. The scan highlighted the lack of research into effective services for adults, and interventions that can be implemented successfully in the community. CMS expended approximately $191,000 related to activities to complete the Environmental Scan.

---

[62] Young J, Corea C, Kimani J, Mandell D. *Autism Spectrum Disorders (ASDs) Services: Final Report on Environmental Scan.* Prepared for the Centers for Medicare & Medicaid Services, United States Department of Health and Human Services. March 9, 2010. Available at: https://www.impaqint.com/sites/default/files/project-reports/Autism_Spectrum_Disorders.pdf

In 2011, CMS issued a report on a nine-state study entitled, *Report on State Services to Individuals with Autism Spectrum Disorders (ASD),* which assessed the implementation of evidence-based/promising practices through the lens of state experience, summarizing the current state of ASD-related services in Arizona, California, Connecticut, Indiana, Maine, Missouri, New Mexico, Pennsylvania, and Wisconsin. The report describes the types of services and supports provided by state and local governments, the sources of funding for programs; and the policy, staffing and implementation issues that states and localities encounter in the administration of programs that serve people with ASD. Approximately $198,000 was expended on activities related to the Nine-State study.

DEPARTMENT OF DEFENSE (DOD)

To improve the lives of adults currently living with ASD, the Autism Research Program (ARP) has invested in research by Drs. Daniel Cox and Ronald Reeve from the University of Virginia to enhance driving skills of individuals with ASD. This research orients around the use of a virtual reality training device that was developed in a previous ARP-funded study by Dr. Cox. The current study looks to train, evaluate, and enhance driving skills of high functioning autistic individuals to promote independence and higher quality of life.[63]

DEPARTMENT OF EDUCATION (ED)

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 (OSERS) at the U.S. Department of Education. 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. Once determined eligible for vocational rehabilitation, an individual with ASD could access any of the services listed under section 103(a) of the Rehabilitation Act of 1973, as amended, if such services were determined necessary to help such an individual achieve the employment goal specified in the individualized plan for employment.

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.

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

---

[63] Cox NB, Reeve RE, Cox SM, Cox DJ. Brief report: driving and young adults with ASD: parents' experiences. *J Autism Dev Disord*. October 2012;42(10):2257-62. [PMID:22359179]

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

NIDRR also funds research projects that specifically focus on ASD and the transition to adult life. The Westbrook group at Southwest Educational Development Laboratory (SEDL) is collaborating with the Center for Autism and Related Disabilities at the University of Central Florida (UCF CARD) to study which vocational rehabilitation services are effective in increasing employment success for people with ASD. The Wehman group at Virginia Commonwealth University is testing whether specific vocational rehabilitation services are beneficial in improving employment and post-secondary education of those with ASDs. They are examining intensive, community-based work experience, impact of personal digital assistants, and their longitudinal effects on employment outcomes. The Wehman group is also testing the efficacy of a nine-month internship in improving employment outcomes for individuals with ASD. Lastly, the Dague group at the University of New Hampshire is developing a process to implement Family-Centered Transition Planning to improve persons with ASD participation in postsecondary education, employment, and long-term planning. The following section describes each of the NIDRR-funded adult services studies organized by year.

Department of Education NIDRR Adult Services Studies

2008

SEDL's Vocational Rehabilitation Service Models for Individuals with Autism Spectrum Disorders: For this project, SEDL partners with the Center for Autism and Related Disabilities at the University of Central Florida (UCF CARD) to create a knowledge translation initiative to address the growing need for improvement in vocational rehabilitation (VR) and transition services for persons with ASD. SEDL and UCF CARD conduct a multifaceted set of research activities to identify and document VR and transitional behavior management practices that are linked to employment successes for people with ASD, to identify factors that are strongly predictive of such success, to study the activities and impact of a statewide VR service provider network, and to document examples of success among individuals with ASD in long-term employment placements.

Vocational Rehabilitation Service Models for Individuals with Autism Spectrum Disorders (VCU ASC Career Links): VCU ASD Career Links conducts evidence-based research on vocational rehabilitation (VR) service models for individuals with ASD. The project is based at Virginia Commonwealth University (VCU) and is a collaborative initiative between VCU and the Virginia Department of Rehabilitative Services (DRS). The scope of research covers four areas: (1) the impact of intensive, community-based work experiences on the employment outcomes of youth with ASD; (2) the postsecondary school participation and ultimate employment of college students with ASD; (3) the impact of personal digital assistants (PDAs) on the employment outcomes of individuals with ASD; and (4) a longitudinal analysis of VR service delivery and employment outcomes among DRS clients with ASD.

2011

Sustainable Implementation of Family-Centered Transition Planning for Young Adults with Autism Spectrum Disorders: This project develops a sustainable process for implementing a Family-Centered Transition Planning model for youth and young adults with ASD. Based on research demonstrating the effectiveness of Family-Centered

Transition Planning in increasing student and parent expectations for adult life, student career decision-making, and student participation in employment and postsecondary education, this project develops an implementation package to embed this method of independent transition planning into the existing service and funding system on a long-term basis across multiple states.

2012

Facilitating Employment for Youth with Autism: A Replication Study of an Internship Model to Identify Evidence Based Practices: This project is designed to determine the efficacy of a 9-month hospital-based internship intervention for transitioning young adults with ASD. This internship program, based on the Project SEARCH model, is currently being tested and evaluated in a randomized clinical trial at two Bon Secours Hospitals in Richmond, Virginia. The intervention consists of two components: (1) 900 hours of onsite training over 9 consecutive months at the host hospital site, and (2) training and support provided by employment specialists with expertise in autism, applied behavior analysis, supported employment, and business networking.

HEALTH RESOURCES AND SERVICES ADMINISTRATION (HRSA)

To support youth with ASD in making the transition to adult health care services, employment, and independence, State Implementation Grantees (SIGs) developed electronic information resources (e.g. Web sites, resource guides, and training modules), hosted conferences on transition, and conducted workshops targeting individuals with ASD, their families, educators, and health care providers. The table below highlights several transition-related resources that state grantees developed in partnership with several stakeholders, including other CAA grantees.

The LEND and DBP training programs have addressed the need for transition services and supports for individuals with ASD in several ways. The University of Minnesota LEND has incorporated a seminar focused on transition services into its didactic curriculum. Trainees at the Ohio State University LEND participate in the development of educational and/or health transition plans in coordination with families, educators, and self-advocates.

Some curricular and clinical activities focused on transition have resulted in the development of new materials for families or new clinical policies. The Yale DBP program has focused on transition planning for children with DD in its Guidelines Seminar, where clinic policies are developed, implemented, and evaluated. Through this seminar, the program developed new materials for families and new interventions during its clinic, in conjunction with a social worker and families of children with DD. Trainees at the LEND and DBP program at the Children's Hospital of Philadelphia have developed and implemented community-based projects focused on the transition to adulthood; one trainee is working to expand the program's Transition to Adulthood and Employment services to a community-based provider of employment services for individual disabilities, while another trainee is investigating supports at universities and colleges for children with ASD who want to transition to higher education.

The LEND and DBP training programs are also partnering with other entities to address the need for more services focused on transition to adulthood in the broader community. The University of Pittsburgh LEND, for example, initiated transition-planning services within the community by hosting a conference on transition planning, collaborating around transition with community organizations and state agencies, and offering CMEs in health care transition planning. Trainees from the Dartmouth LEND collaborated with the Center for Medical Home Improvement to support the MCH-funded program "Got Transition?" a national health care transition center. Through this collaboration, trainees have developed practice guidelines and readiness materials regarding health care transition. Finally, the Children's Hospital of Boston DBP has leveraged NIH funding to develop a new initiative entitled "Project Opening Doors," which is a partnership with 10 multicultural community organizations aimed at improving identification, education, integration, and transition of children and youth with DD.

An R40 grant, Transition to Adult Services for Youth with Autism Spectrum Disorder, developed a resource on transition for persons with autism, a list of online tools to help families and youth learn how to make smooth change to adult healthcare. Several other R40 grants focus on the needs of transition age youth; one developed and tested an intervention on family-centered transition planning that demonstrated significant gains in empowering families to taking leadership in the process of transition planning. The findings of these studies will add to the evidence-base on effective services and supports that will benefit the health and well-being of adolescents and young adults transitioning to adulthood.

ASD Resources Developed by HRSA State Implementation Grant (SIG) Grantees

ELECTRONIC RESOURCES	**Missouri's SIG developed a Web site for families and service providers entitled "Roadmap to the Future: Transitioning into Adulthood With ASD." This transition Web site was ranked as one of the three best Web sites in the country for youth with ASDs by Autism After 16.**
	Vermont's SIG developed the "ASD Transition Guide" Web site. The Web site includes sections for young adults, parents, and professionals. The Web site also aims to identify medical homes for young adults transitioning to adult healthcare. Vermont Family Network and the Howard Center have agreed to work collaboratively to continue to expand and maintain the transition guide past the end of the contract.
	Hawaii developed the "Patient-Centered Medical Home Transition Checklist and the ASD PCMH Care Plan – Initial Transition Plan" and the "ASD Transition Checklist."
	Rhode Island developed the "RI DOH Pediatric to Adult Healthcare Transition Guidance and Checklist."
TRAINING RESOURCES	**Missouri's SIG developed the "Autism Spectrum Disorders: Transition to Adulthood" training module. This 1-hour training highlights five major areas of transition that need to be addressed for youth as they move toward adulthood. The module was targeted toward families and service providers.**
	Hawaii's SIG-T provided technical assistance and training to families and professionals (including case managers, special education teachers, children with special health care needs coordinators) on issues surrounding the transition to adulthood.
	New Jersey's SIG hosted countywide "Transition to Adult Systems of Care" teleconferences. Participants received a "Transition to Adult Life" information packet, a "Transition Resources" CD, a "Transition Resources for Health Practitioners" packet, and "Youth Transition" workbooks.

Table 24. State Implementation Grantees (SIG)-developed electronic and training resources.

NATIONAL INSTITUTES OF HEALTH (NIH)

Research that develops innovative services for people with ASD is essential to improving their quality of life

In the area of ASD services, an American Recovery and Reinvestment Act (ARRA)-funded grant created the JobTIPS website to provide young people with ASD and their families with helpful tips and information on developing job skills, such as interviewing, interacting with supervisors and co-workers, and using effective and appropriate ways of communicating at work. The website also offers resources to clinicians and therapists who support people with ASD, as well as parents, educators, and job coaches. JobTIPS is one of the first online employment resources tailored to people with autism that promotes their efforts toward independence and self-determination. To date, JobTIPS is visited by over 30,000 new users each month and at least 25 schools in the nation have implemented the site into a curriculum for high school seniors. In North Carolina, JobTIPS will be implemented in a full curriculum for students with ASD.

SUBSTANCE ABUSE AND MENTAL HEALTH SERVICES ADMINISTRATION (SAMHSA)

SAMHSA developed and continues to offer a toolkit to implement the evidence-based program, “Supported Employment,” which is a system of services and supports for people with disabilities to enable them to secure and maintain jobs in the community. “Supported Employment” builds on the concept of “jobs first” or “place and train,” which is different from traditional vocational rehabilitation and sheltered workshop concepts. This toolkit promotes the use of job coaches, development and retention, assistive technology, specialized job training, and individually tailored supervision. It also includes both development of employment opportunities and ongoing support for individuals to sustain employment. “Supported Employment” has made it possible for individuals with moderate to severe levels of disabilities to become active, productive wage-earners in the mainstream workforce.

Conclusion

Since the enactment of the Combating Autism Act in 2006, and its reauthorization under the Combating Autism Reauthorization Act of 2011, federal agencies, in partnership with the community, have made significant strides in addressing many of the pressing needs of individuals and families affected by autism spectrum disorder. In the period covered by this report, from 2010-2013, federally-funded programs and projects have increased knowledge about how prevalent ASD is in the U.S. population and how early in life ASD can be detected. While CDC most recently estimated the prevalence of autism in U.S. children at 1 in 88, they also found evidence suggesting that more children are being diagnosed by age 3 and potentially may be gaining the opportunity for early intervention.[64] NIH research resulting in new and improved instruments for identifying children with ASD at increasingly young ages and a strengthened evidence base for early behavioral treatments, as well as efforts by ACF, CDC, HRSA, and the Department of Education to expand outreach to underserved populations, has also yielded new opportunities for improving skills and reducing disability both before school age and once a child enters the education system.

Federally-supported research is also revealing more about how autism develops and what risk factors may be involved. Recent studies supported by NIH have uncovered distinct differences in the brain development of infants who later are diagnosed with ASD, while studies supported by NIH, DoD, and EPA have identified potential contributions to ASD risk from diverse environmental risk factors including nutrients, air pollutants, pesticides, and paternal age. NIH- and HRSA-supported studies of conditions that often co-occur with ASD such as gastrointestinal disorders, sleep disruptions, and epilepsy are contributing to interventions strategies, and panels of experts, such as those convened through the HRSA Autism Intervention Research Programs, are rapidly assembling guidelines to help individuals with ASD, families, and practitioners address these needs in the context of daily living. NSF supports several basic and applied science projects encompassing topics related to ASD in its neuroscience and cognitive sciences portfolios and Research in Disabilities Education Program, as well as projects exploring computer simulation and robotics technologies that may have applications in helping people with ASD and other disabilities acquire important communication and social skills.

The Department of Education's efforts to develop and evaluate educational interventions, as well as provide guidance for schools on how to make school environments safe and conducive to learning for students with disabilities, are improving the ability of schools to meet the needs of students on the autism spectrum. Through comparative analyses of the effectiveness of therapies and interventions for children and adolescents with ASD, AHRQ is similarly providing communities with valuable guidance on the evidence base of such therapies as computer assisted care and mental health therapeutics.

Federal efforts at agencies such as CMS and HRSA are also identifying and evaluating best practices among services and supports across the states, and agencies including DoD, HRSA, SAMHSA, and NIH are developing practitioner

---

[64] Centers for Disease Control and Prevention. Prevalence of Autism Spectrum Disorders—Autism and Developmental Disabilities Monitoring Network, 14 Sites, United States, 2008. *Morbidity and Mortality Weekly Report (MMWR) Surveillance Summaries*. March 20, 2012; 61 (SS-03): 1-19. [PMID:22456193]

training and disseminating information to individuals and families affected by ASD through toolkits, websites, and telehealth delivery systems to reach more isolated parts of the community. The Autism NOW website, supported by the Administration for Community Living, offers videos and toolkits on a range of issues spanning from early interventions to relationship building, employment, and family supports and training.

To ensure continuing coordination among federal agencies and between federal and private partner organizations, the Interagency Autism Coordinating Committee provides strategic guidance and a forum for public input into federal planning efforts, helping federal agencies and members of the public work together toward meeting the needs of the autism community. While the collaborative efforts of federal and state agencies and community partners have resulted in many research advances and improvements in services over the past 7 years, all acknowledge the growing needs of the community and the work that remains to be done. Continued collaborative efforts between the public and private sectors will be essential to drive the innovations that will lead to improved identification, interventions, services, and policies that will enhance the lives of people with ASD and their families.

Appendix i.

LIST OF ACRONYMS

ABA-Applied Behavioral Analysis

ACC-Autism Coordinating Committee

ACE-Autism Centers of Excellence

ACF-Administration for Children and Families

ACL-Administration for Community Living

ADDM-Autism and Developmental Disabilities Monitoring Network

ADFM-Active Duty Family Member

AGRE-Autism Genetic Resource Exchange

AHRQ-Agency for Healthcare Research & Quality

AIDD-Administration on Intellectual and Developmental Disabilities

AIR-P-Autism Intervention Research Network on Physical Health

AIR-B-Autism Intervention Research Network on Behavioral Health

ARRA-American Recovery and Reinvestment Act

ASD-Autism Spectrum Disorder

ATP-Autism Tissue Program

AUCD-Association of University Centers on Disabilities

CAA-Combating Autism Act of 2006

CAAC-Computer Assisted Autism Care

CAAI-Combating Autism Act Initiative

CADDRE-Centers for Autism and Developmental Disabilities Research and Epidemiology Network

CAM-Complementary and Alternative Medicine

CARA-Combating Autism Reauthorization Act of 2011

CDC-Centers for Disease Control and Prevention

CDMRP-Congressionally Directed Medical Research Programs

CERT-Center for Education and Research on Mental Health Therapeutics

CHICA-Child Health Improvement through Computer Automation

CER-Comparative Effectiveness Review

CMHI-Child Mental Health Initiative

CMS-Centers for Medicare & Medicaid Services

CPRC-Community Parent Resource Center

DBP-Developmental Behavioral Pediatrics

DBPNet-Developmental Behavioral Pediatrics Research Network

DDC-Developmental Disabilities Council

DIRP-Division of Intramural Research Program

DoD-Department of Defense

DoD-ARP-Department of Defense Autism Research Program

DoD-AF-Department of Defense Air Force

DSM-Diagnostic and Statistical Manual of Mental Disorders

EARLI-Early Autism Risk Longitudinal Investigation

ECHO-Extended Care Health Option

ED-Department of Education

EFMP-Exceptional Family Member Program

EHR-Electronic Health Record

EPA-Environmental Protection Agency

EPSDT-Early and Periodic Screening, Diagnosis, and Treatment Program

ESDM-Early Start Denver Model

FACA-Federal Advisory Committee Act

FAST-AS-Fast-Fail Trials in Autism Spectrum Disorders

FDA-Food and Drug Administration

FIC-Fogarty International Center

FXS-Fragile X Syndrome

HCBS-Home and Community-Based Services

HCUP-Hospital Cost and Utilization Project

HHS-Department of Health and Human Services

HRSA-Health Resources and Services Administration

IC-NIH Institutes and Centers

IACC-Interagency Autism Coordinating Committee

IBIS-Infant Brain Imaging Study

IAN-Interactive Autism Network

ICDR-Interagency Committee on Disability Research

IDEA-Individuals with Disabilities Education Act

IES-Institute of Education Sciences

INCLEN-International Clinical Epidemiology Network

IOM-Institute of Medicine

LEAP-Learning Experiences—An Alternative Program for Preschoolers and Parents

LEND-Leadership Education in Neurodevelopmental Disabilities

LTSAE-Learn the Signs. Act Early.

MADDSP-Metropolitan Atlanta Developmental Disabilities Surveillance Program

M-CHAT-Modified Checklist for Autism in Toddlers

MCHB-Maternal and Child Health Bureau

MCO-Managed Care Organization

MHS-Military Health Systems

NADFM-Non-Active Duty Family Member

NCBDDD-National Center on Birth Defects and Developmental Disabilities

NCI-National Cancer Institute

NCRR-National Center for Research Resources

NCSER-National Center for Special Education Research

NEI-National Eye Institute

NHGRI-National Human Genome Research Institute

NIA-National Institute on Aging

NIAAA-National Institute on Alcohol Abuse and Alcoholism

NIAID-National Institute of Allergy and Infectious Diseases

NIBIB-National Institute of Biomedical Imaging and Bioengineering

NICHD-*Eunice Kennedy Shriver* National Institute of Child Health and Human Development

NIDA-National Institute on Drug Abuse

NIDCD-National Institute on Deafness and Other Communication Disorders

NIDCR-National Institute of Dental and Craniofacial Research

NIDDK-National Institute of Diabetes and Digestive and Kidney Diseases

NIDRR-National Institute on Disability and Rehabilitation Research

NIEHS-National Institute of Environmental Health Sciences

NIGMS-National Institute of General Medical Sciences

NIH-National Institutes of Health

NIH RePORT-NIH Research Portfolio Online Reporting Tool

NIMH-National Institute of Mental Health

NINDS-National Institute of Neurological Disorders and Stroke

NINR-National Institute of Nursing Research

NDAR-National Database for Autism Research

NLM-National Library of Medicine

NSCH-National Survey of Children’s Health

NSF-National Science Foundation

OARC-Office of Autism Research Coordination

OD-Office of the Director, NIH

ONC-HHS National Coordinator for Health Information Technology

OPE-Office of Postsecondary Education

ORR-Office of Refugee Resettlement

OSEP-Office of Special Education Programs

OSERS-Office of Special Education and Rehabilitative Services

PBIS-Positive Behavioral Interventions and Supports

PCPID-President’s Committee for People with Intellectual Disabilities

PDD-Pervasive Developmental Disorders

PNS-Projects of National Significance

PTI-Parent Training and Information Centers

RSA-Rehabilitation Services Administration

SAMHSA-Substance Abuse and Mental Health Services Administration

SBIR-Small Business Innovation Research

SCDD-State Councils on Developmental Disabilities

SDAS-Secondary Data Analysis Studies

SEED-Study to Explore Early Development

SIG-State Implementation Grantee

SPHARC-State Public Health Autism Resource Center

SPG-State Planning Grants

TEACCH-Treatment and Education of Autistic and Related Communication Handicapped Children

UCEDD-University Centers for Excellence in Developmental Disabilities Education, Research, and Service

USDA-U.S. Department of Agriculture

USPSTF-U.S. Preventative Services Task Force

WIC-Special Supplemental Nutrition Program for Women, Infants, and Children

Appendix ii.

REPORT TO CONGRESS ON ACTIVITIES RELATED TO AUTISM SPECTRUM DISORDER AND OTHER DEVELOPMENTAL DISABILITIES UNDER THE COMBATING AUTISM ACT OF 2006 (FY 2006-FY 2009): SUMMARY & HIGHLIGHTS[65]

Cross-Agency Coordination

- [In 2010] The Interagency Autism Coordinating Committee (IACC) consists of 11 public and 13 federal members who convene on a regular basis (20 times in 2008, 17 times in 2009, and 16 times in 2010) to coordinate all efforts in autism spectrum disorder (ASD) research within HHS and provide advice to the Secretary of HHS on ASD research and services.

- The Office of Autism Research Coordination (OARC) at NIH provides coordination for IACC member agencies, support for all IACC activities and publications, and serves as a liaison between the IACC and federal agencies, Congress, and the public.

- The IACC developed and has annually updated a *Strategic Plan for ASD Research*.[66] The first IACC Strategic Plan was issued in 2009, the first update of the Strategic Plan was issued in 2010, and the second update of the Strategic Plan was released in 2011.

- In 2008, the IACC published the *ASD Research Portfolio Analysis Report*,[67] which is the first comprehensive analysis of both federally and privately funded autism research projects and funding. The analysis tracks research progress made under the IACC Strategic Plan. The *2009 IACC ASD Research Portfolio Analysis Report* is underway and will be released in 2011.[68]

---

[65] U.S. Department of Health and Human Services, Office of Autism Research Coordination, National Institutes of Health (On behalf of the Office of the Secretary). *Summary & Highlights: Report to Congress on Activities Related to Autism Spectrum Disorder and Other Developmental Disabilities Under the Combating Autism Act of 2006 (FY 2006 – FY 2009)*. April 2011. Retrieved from the Department of Health and Human Services Interagency Autism Coordinating Committee website at: http://iacc.hhs.gov/reports/reports-to-congress/FY2006-2009/caa-report-summary-highlights.shtml

[66] Interagency Autism Coordinating Committee (IACC). *IACC Strategic Plan for Autism Spectrum Disorder (ASD) Research—2012 Update*. December 2012. Retrieved from the U.S. Department of Health and Human Services Interagency Autism Coordinating Committee website: http://iacc.hhs.gov/strategic-plan/2012/index.shtml.

[67] Office of Autism Research Coordination, National Institute of Mental Health, on behalf of the Interagency Autism Coordinating Committee (IACC). *2008 IACC Autism Spectrum Disorder Research Portfolio Analysis Report*. Retrieved from the U.S. Department of Health and Human Services Interagency Autism Coordinating Committee website: http://iacc.hhs.gov/portfolio-analysis/2008/index.shtml.

[68] Office of Autism Research Coordination, National Institute of Mental Health & Acclaro Research Solutions, Inc., on behalf of the Interagency Autism Coordinating Committee (IACC). *2009 IACC Autism Spectrum Disorder Research Portfolio Analysis Report*. June 2011. Retrieved from the Department of Health and Human Services Interagency Autism Coordinating Committee website: http://iacc.hhs.gov/portfolio-analysis/2009/index.shtml.

- Each year, the IACC publishes the *Summary of Advances in ASD Research* [69], which is a lay-friendly summary of research articles identified by the committee as having made the greatest impact on the field of autism (the 2007, 2008, 2009, and 2010 editions are available on the IACC website).

- The IACC/OARC strive for a high level of public engagement and transparency by actively disseminating all committee activities, decisions, and publications through the IACC website, webcasts, webinars, print materials, listservs, RSS feeds, and Twitter updates. The IACC seeks input from the public on a frequent basis through open comment periods during every full committee meeting, formal Requests for Information (RFI), and town hall meetings.

Expansion of ASD Research

- The National Institutes of Health (NIH) used American Recovery and Reinvestment Act (ARRA) funds to support nearly $64 million in new autism research projects in 2009, and committed another $58 million in ARRA funding to autism in 2010, bringing the total ARRA investment in autism research for both fiscal years to $122 million. New research supported including studies on development and testing of diagnostic screening tools for different populations; assessing risk from prenatal or early life exposures; initiating clinical trials to test early interventions; and adapting existing, effective pediatric treatments for older children, teens, and adults with ASD.

ASD Surveillance, Awareness, and Outreach

- In 2009, CDC's Autism and Developmental Disabilities Monitoring (ADDM) Network published the most recent autism prevalence data indicating that 1 in 110 children in the U.S. has an autism spectrum disorder.[70] Since 2006, the ADDM Network has been tracking and providing the most comprehensive estimates to date of the prevalence of ASD in multiple areas of the U.S.

- CDC's "Learn the Signs. Act Early." campaign has played an important role in raising awareness nationwide among parents, health care professionals, and early educators about the importance of monitoring a child's developmental milestones, identifying developmental delays, and providing appropriate early interventions.

- The Department of Education's 106 Parent Training and Information Centers provide training and information to parents of infants, toddlers, children, and youth with disabilities and to professionals who work with them. This assistance helps parents to participate more effectively with professionals in meeting their children's educational needs.

---

[69] Interagency Autism Coordinating Committee (IACC). *2012 IACC Summary of Advances in Autism Spectrum Disorder Research*. April 2012. Retrieved from the U.S. Department of Health and Human Services Interagency Autism Coordinating Committee website: http://iacc.hhs.gov/summary-advances/2012/index.shtml.

[70] Centers for Disease Control and Prevention. Prevalence of Autism Spectrum Disorders—Autism and Developmental Disabilities Monitoring Network, United States, 2006. *Morbidity and Mortality Weekly Report (MMWR) Surveillance Summaries*. December 18, 2009; 58(Vol. 10):1-20. [PMID: 20023608]

- NIH's Autism Centers of Excellence (ACE) were expanded under the CAA and now comprise 11 research centers and networks at major research institutions and universities across the country that are actively working to identify the causes of ASD and develop new and improved treatments.

- NIH launched the Early Autism Risk Longitudinal Investigation (EARLI) study to follow and collect comprehensive data on ~1,200 families that already have a child with an ASD who are pregnant, or who might become pregnant in the future, to determine the role of environmental factors and genetic predisposition in the cause of ASD.

Investigating the Causes of Autism

- CDC's Centers for Autism and Developmental Disabilities Research and Epidemiology (CADDRE) network supports the Study to Explore Early Development (SEED) program, which is the largest study in the United States dedicated to identifying factors that put children at risk for autism (including genes, health conditions, and environmental exposures). SEED will include ~ 2,700 children, 2 through 5 years of age, as well as their parents, representing diverse groups from six areas across the country.

- CDC's Blood Spot Project is collecting, banking, and testing dried blood spots from newborn infants to determine whether the developing fetus has been exposed to harmful antibodies that may have had a role in causing ASD.

- NIH is accelerating the pace of ASD research discoveries through large-scale, unprecedented resource and data-sharing initiatives, including National Database for Autism Research (NDAR) and the NIMH Genetics Repository, which gather, standardize, and disseminate ASD research participant data and biological samples from thousands of human subjects participating in research projects.

Development of Evidence-Based Autism Treatments

- NIH has supported numerous randomized double-blind clinical trials on ASD treatments, establishing the beneficial effect of several behavioral and drug interventions (e.g., Applied Behavioral Analysis, Cognitive Behavioral Therapy, methylphenidate, and risperidone).[71, 72, 73, 74]

---

[71] 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):17-23. [PMID: 19948568]

[72] Wood J. J., Drahota A., Sze K., Har K., Chiu A. and Langer D. A. 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): 224–234. [PMID:19309326]

[73] Posey DJ, Aman MG, McCracken JT, Scahill L, Tierney E, Arnold LE, Vitiello B, Chuang SZ, Davies M, Ramadan Y, Witwer AN, Swiezy NB, Cronin P, Shah B ,Carroll DH, Young C, Wheeler C, McDougle CJ. Positive effects of methylphenidate on inattention and hyperactivity in pervasive developmental disorders: analysis of secondary measures. *Biological Psychiatry*. February 2007;61(4):538-44. [PMID: 17276750]

[74] Aman MG, Hollway JA, McDougle CJ, Scahill L, Tierney E, McCracken JT, Arnold LE, Vitiello B, Ritz L, Gavaletz A, Cronin P, Swiezy N, Wheeler C, Koenig K, Ghuman JK, Posey DJ. Cognitive effects of risperidone in children with autism and irritable behavior. *J Child Adolesc Psychopharmacol*. June 2008;18(3):227-36. [PMID:18582177]

- Through funds provided by the Combating Autism Act Initiative (CAAI) under the CAA, HRSA established two national networks, the Autism Intervention Research Network on Physical Health (AIR-P) and the Autism Intervention Research Network on Behavioral Health (AIR-B) that are allowing researchers to gather data from different sites in order to identify promising treatments and interventions for autism. Examples include studies of nutritional status, sleep disorders, and the effectiveness of parent-mediated and peer-mediated behavioral interventions.

- AHRQ is currently supporting a Comparative Effectiveness Review (CER) to provide a comprehensive synthesis of evidence examining the benefits and harms associated with antipsychotic medications in the treatment of numerous disorders including ASD among children, youth, and young adults. This study will provide a basis for the development of clinical guidelines, as well as guidance for patients and their care providers, clinicians, researchers, policymakers, and federal agencies to support safe and appropriate use of these medications in pediatric and young adult populations.

Innovative Intervention Investments

- Through the NIH Clinical Center and the Autism Centers of Excellence (ACE) network, the NIH supports several ongoing clinical trials for novel autism drug treatments (e.g. riluzole; minocycline for regressive autism and fragile X-related ASD; donepezil for core symptoms, cognitive deficits and sleep; buspirone; and divalproex sodium for irritability).

- The Department of Education is funding a project to develop a 3D-based virtual learning environment which could enhance the social competence of middle school students with ASD.

- HRSA launched a study, Telehealth Delivery of a Family-Focused Intervention to Reduce Anxiety in Youth with Autism Spectrum Disorders in Rural Colorado, 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.

High-Quality Training of ASD Practitioners and Service Providers

- The Department of Education supports the National Professional Development Center on Autism Spectrum Disorders, which is a multi-university center that trains educators on the use of evidence-based practice for children and adolescents with ASD.

- Through funds provided by the Combating Autism Act Initiative (CAAI) under the CAA, HRSA supports two programs that focus on professional and community training of health professionals in ASD diagnosis and treatment: the Leadership Education in Neurodevelopmental Disabilities (LEND) and Developmental Behavioral Pediatrics (DBP) training programs. The training efforts supported by these programs are effectively reducing barriers to screening and diagnosis by increasing professional capacity and raising awareness about ASD among providers in the community.

- ACF's Administration on Developmental Disabilities (ADD) supports the University Centers for Excellence in Developmental Disabilities Education, Research and Services (UCEDD) to fund interdisciplinary training, exemplary services, technical assistance, and information/dissemination activities in community settings.

Best Practices in Service Provision

- In 2007, CMS issued three "Promising Practices" papers on ASD to highlight innovative service provision systems and practices: *California - Single Process for Early Diagnosis and Service Delivery, Connecticut - Pilot Program for Non-Medicaid Eligible Young Adults with ASD, and Delaware - Supported Employment Program for Adults with ASD.*

- In 2009, AHRQ initiated support for an ongoing randomized trial of Child Health Improvement through Computer Automation (CHICA), a computer decision support program to aid implementation of clinical guidelines in pediatric practice. The CHICA program is designed to streamline and improve the screening, diagnosis, and management of ASD symptoms by clinicians.

- In 2010, CMS released the *Autism Spectrum Disorders (ASD) Services Final Report on Environmental Scan*, providing 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.[75]

- In 2011, CMS plans to release two studies that will highlight available services and best practices being implemented across the United States. *The Report on State Services to Individuals with Autism Spectrum Disorders (ASD)* is an assessment of the implementation of evidence-based/promising practices through the lens of state experience across nine states. The State of the States on ASD study 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 programs across the country.[76]

ASD Services and Supports across the Lifespan

- SAMHSA oversees the Congressionally-mandated Comprehensive Community Mental Health Services for Children and Their Families Program (the short title for this program is Child Mental Health Initiative (CMHI)) which provides funding for the development and evaluation of formal treatments and services, including natural and community supports that are wrapped around the child and family to promote full functioning in the community. Since 2002, the CMHI program has assisted 730 youths with ASD, representing 3.3 percent of all individuals served in the program.

---

[75] Young J, Corea C, Kimani J, Mandell D. *Autism Spectrum Disorders (ASDs) Services: Final Report on Environmental Scan.* Prepared for the Centers for Medicare & Medicaid Services, United States Department of Health and Human Services. March 9, 2010. Available at: https://www.impaqint.com/sites/default/files/project-reports/Autism_Spectrum_Disorders.pdf

[76] Mauch D, Pfefferle S, Booker C, Pustell M, Levin J. Prepared for the Centers for Medicare & Medicaid Services, United States Department of Health and Human Services. *Report on State Services to Individuals with Autism Spectrum Disorders (ASD).* April 1, 2011. Available at: http://www.cms.gov/apps/files/9-State-Report.pdf

- Through funds provided by the Combating Autism Act Initiative (CAAI) under the CAA, HRSA established a State Public Health Coordinating Center for Autism to help states ensure that children and youth with ASD receive early and appropriate identification, diagnosis, and intervention services. In addition, nearly $2.7 million in grant funds was provided to nine states to assist them with improving services for these young people.

- HRSA's Leadership Education in Neurodevelopmental Disabilities (LEND) training program has supported 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 Department of Education's National Institute on Disability and Rehabilitation Research (NIDRR) is supporting a model project to examine 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.

- The Department of Education's Rehabilitation Services Administration (RSA) oversees grant programs that provide supports such as counseling, medical and psychological services, job training, and other individualized services to individuals with physical or mental disabilities to help them to obtain employment and live more independently. For example, in 2009, state vocational rehabilitation agencies supported by RSA grant funds served 6,434 individuals with autism and 2,314 individuals with autism were assisted to achieve an employment outcome.

- SAMHSA has developed a toolkit to implement the evidence-based program, "Supported Employment," which is a system of services and supports for people with disabilities to enable them to secure and maintain jobs in the community. "Supported Employment" builds on the concept of "jobs first" or "place and train" which is different from traditional vocational rehabilitation and sheltered workshop concepts. This program provides job coaches, development and retention; assistive technology; specialized job training and individually tailored supervision. It also includes both development of employment opportunities and ongoing support for individuals to sustain employment. "Supported Employment" has made it possible for individuals with moderate-to-severe levels of disabilities to become active, productive wage-earners in the mainstream workforce.

- The Department of Education is supporting projects that are investigating how technology can be used to enhance an individual's access to services and participation in community settings.

- The Office on Disability recently established the Center of Excellence for Research on Disability Services, Care Coordination, and Integration to create data infrastructure to support and conduct comparative effectiveness research on health services and supports for people with disabilities, including autism. The Center is part of a national strategy for quality improvement in health care and the expansion of health care delivery system research with a focus on person-centered outcomes research.

- ACF's Administration on Developmental Disabilities (ADD)[77] supports the State Councils on Developmental Disabilities (SCDD), which are independent state bodies composed of key stakeholders, including individuals with developmental disabilities, family members, and representatives of state and non-governmental services agencies, that work to identify needs and support state services and activities that increase the independence, productivity, inclusion, and community integration of people with developmental disabilities, including individuals with autism.

- ACF's Administration on Developmental Disabilities (ADD) manages the Protection & Advocacy (P&A) Agencies program which supports agencies in each state to that protect the legal and human rights of people with autism and other developmental disabilities. The P&As empower people by offering information and referral services for legal, administrative, and other remedies to resolve problems and by investigating incidents of abuse and neglect and discrimination based on disability.

- In 2011, ACF's Administration on Developmental Disabilities (ADD) will launch the Autism NOW National Autism Resource and Information Center, 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.

To access the complete report, please refer to the Report to Congress on Activities Related to Autism Spectrum Disorder and Other Developmental Disabilities Under the Combating Autism Act of 2006 (FY 2006- FY 2009).[78]

---

[77] Please note that in 2012,the Administration on Developmental Disabilities (ADD), became the Administration for Intellectual and Developmental Disabilities (AIDD), which is a component of the Administration for Community Living, also formed in 2012.

[78] U.S. Department of Health and Human Services, Office of Autism Research Coordination, National Institutes of Health (On behalf of the Office of the Secretary). *Report to Congress on Activities Related to Autism Spectrum Disorder and Other Developmental Disabilities Under the Combating Autism Act of 2006 (FY 2006 – FY 2009)*. December 2010 (Rev. April 2011). Retrieved from the Department of Health and Human Services Interagency Autism Coordinating Committee website at: http://iacc.hhs.gov/reports/reports-to-congress/FY2006-2009/index.shtml.

Appendix iii.

CDC-SUPPORTED AUTISM PUBLICATIONS (2010-AUGUST 2013)

Anderson C, Law JK, Daniels A, Rice C, Mandell DS, Hagopian L, Law PA. Occurrence and family impact of elopement in children with autism spectrum disorders. *Pediatrics*. November 2012;130(5):870-7. [PMID: 23045563]

Atladóttir HÓ, Henriksen TB, Schendel DE, Parner ET. Autism after infection, febrile episodes, and antibiotic use during pregnancy: an exploratory study. *Pediatrics*. December 2012;130(6):e1447-54. [PMID: 23147969]

Atladóttir HÓ, Henriksen TB, Schendel DE, Parner ET. Using maternally reported data to investigate the association between early childhood infection and autism spectrum disorder: the importance of data source. *Paediatric and Perinatal Epidemiology*. July 2012;26(4):373-85. [PMID: 22686389]

Atladóttir HO, Schendel DE, Lauritsen MB, Henriksen TB, Parner ET. Patterns of contact with hospital for children with an autism spectrum disorder: a Danish register-based study. *Journal of Autism Developmental Disorders*. August 2012;42(8):1717-28. [PMID: 22160299]

Atladóttir HO, Thorsen P, Østergaard L, Schendel DE, Lemcke S, Abdallah M, Parner ET. Maternal infection requiring hospitalization during pregnancy and autism spectrum disorders. *Journal of Autism and Developmental Disorders*. December 2010;40(12):1423-30. [PMID: 20414802]

Avchen R, Wiggins LD, 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*. February 2011;41(2):227-36. [PMID:20568003]

Berry RJ, Crider KS, Yeargin-Allsopp M. Periconceptional folic acid and risk of autism spectrum disorders. *Journal of the American Medical Association*. February 13;309(6):611-3. [PMID: 23403688]

Boyle CA, Boulet S, Schieve L, Cohen RA, Blumberg SJ, Yeargin-Allsopp M, Visser S, Kogan MD. Trends in the Prevalence of Developmental Disabilities in US Children, 1997 - 2008. *Pediatrics*. June 2011;127(6):1034-42. [PMID: 21606152]

Centers for Disease Control and Prevention. Prevalence of Autism Spectrum Disorders - Autism and Developmental Disabilities Monitoring Network, United States, 2006. *Morbidity and Mortality Weekly Report Surveillance Summaries*. December 18, 2009;58(Vol. 10):1-20. [PMID: 20023608]

Centers for Disease Control and Prevention. Prevalence of Autism Spectrum Disorders — Autism and Developmental Disabilities Monitoring Network, 14 Sites, United States, 2008. *Morbidity and Mortality Weekly Report*. March 30, 2012. 61(SS03); 1-19. [PMID:22456193]

Cheely CA, Carpenter LA, Letourneau EJ, Nicholas JS, Charles J, King LB. The prevalence of youth with autism spectrum disorders in the criminal justice system. *Journal of Autism and Developmental Disorders*. September 2012;42(9):1856-62. [PMID: 22187108]

Christensen J, Grønborg TK, Sørensen MJ, Schendel D, Parner ET, Pedersen LH, Vestergaard M. Prenatal valproate exposure and risk of autism spectrum disorders and childhood autism: a population-based study. *Journal of the American Medical Association*. April 24, 2013;309(16):1696-703. [PMID: 23613074]

Durkin MS, Maenner MJ, Meaney FJ, Levy SE, Diguiseppi C, Nicholas JS, Kirby RS, Pinto-Martin JA, Schieve LA. Socioeconomic inequality in the prevalence of autism spectrum disorder: evidence from a U.S. cross-sectional study. *PLoS One*. July 12, 2010;5(7):e 11551. [PMID: 20634960]

Giarelli E, Wiggins LD, Rice CE, Levy SE, Kirby, RS, Pinto-Martin J, Mandell D. Sex differences in the evaluation and diagnosis of autism spectrum disorders among children. *Disability and Health Journal*. April 2010;3(2):107-116. [PMID: 21122776]

Grinker, R. R., Yeargin-Allsopp, M., and Boyle, C. (2011). Culture and autism spectrum disorders: The impact on prevalence and recognition. In Autism spectrum disorders, edited by D. G. Amaral, G. Dawson, and D. H. Geschwind, pp. 112–136. New York: Oxford University Press, 2011.

Gronborg TK, Schendel DE, Parner ET. Recurrence of autism spectrum disorders in full and half siblings and trends over time: A population-based cohort study. *JAMA Pediatr.* October 2013;167(10):947-53. [PMID: 23959427]

Hilton CL, Fitzgerald RT, Jackson KM, Maxim RA, Bosworth CC, Shattuck PT, Geschwind DH, Constantino JN. Brief report: Under-representation of African-Americans in autism genetic research: a rationale for inclusion of subjects representing diverse family structures. *Journal of Autism and Developmental Disorders*. May 2010;40(5):633-9. [PMID: 19936905]

Hoffman K, Kalkbrenner AE, Vieira VM, Daniels JL. The spatial distribution of known predictors of autism spectrum disorders impacts geographic variability in prevalence in central North Carolina. *Environmental Health*. October 31, 2012;11:80. [PMID: 23113973]

Hoffman K, Vieira VM, Daniels JL. Brief Report: Diminishing Geographic Variability in Autism Spectrum Disorders Over Time? *Journal of Autism and Developmental Disorders*. August 20, 2013. [Epub ahead of print] [PMID: 23959585]

Hvidtjørn D, Grove J, Schendel D, Schieve LA, Sværke C, Ernst E, Thorsen P. Risk of autism spectrum disorders in children born after assisted conception: a population-based follow-up study. *Journal of Epidemiology and Community Health*. June 2011; 65(6):497-502. [PMID: 20584728]

Jarquin VG, Wiggins LD, Schieve LA, Van Naarden-Braun K. Racial disparities in community identification of autism spectrum disorders over time; Metropolitan Atlanta, Georgia, 2000-2006. *Journal of Developmental and Behavioral Pediatrics*. April 2011;32(3):179-87. [PMID: 21293294]

Johnson NL, Giarelli E, Lewis C, Rice CE. Genomics and Autism Spectrum Disorder. *Journal of Nursing Scholarship*. March 2013;45(1):69-78. [PMID: 23368711]

Kalkbrenner AE, Braun JM, Durkin MS, Maenner MJ, Cunniff C, Lee LC, Pettygrove S, Nicholas JS, Daniels JL. Maternal smoking during pregnancy and the prevalence of autism spectrum disorders, using data from the autism and developmental disabilities monitoring network. *Environmental Health Perspectives*. July 2012;120(7):1042-8. [PMID: 22534110]

Kalkbrenner AE, Daniels JL, Chen JC, Poole C, Emch M, Morrissey J. Perinatal exposure to hazardous air pollutants and autism spectrum disorders at age 8. *Epidemiology*. September 2010; 21(5):631-641. [PMID: 20562626]

Kalkbrenner AE, Daniels JL, Emch M, Morrissey J, Poole C, Chen JC. Geographic access to health services and diagnosis with an autism spectrum disorder. *Annals of Epidemiology*. April 2011;21(4):304-10. [PMID: 21376278]

Kancherla V, Van Naarden Braun K, Yeargin-Allsopp M. Childhood vision impairment, hearing loss and co-occurring autism spectrum disorder. *Disability and Health Journal*. October 2013;6(4):333-42. [PMID: 24060256]

Lauritsen M, Jorgensen M, Madsen K, Lemcke S, Toft S, Grove J, Schendel D, Thorsen P. Validity of childhood autism in the Danish psychiatric central register - findings from a cohort sample born 1990-1999. *Journal of Autism and Developmental Disorders*. February 2010; 40(2):139-148. [PMID: 19728067]

Lauritsen MB, Astrup A, Pedersen CB, Obel C, Schendel DE, Schieve L, Yeargin-Allsopp M, Parner ET. Urbanicity and autism spectrum disorders. *Journal of Autism and Developmental Disorders*. February 2014. [PMID: 23807204]

Levy S, Giarelli E, Lee L, Schieve L, Kirby R, Cunniff C, Nicholas J, Rice C. Autism spectrum disorders and co-occurring developmental, psychiatric, and medical conditions among children in multiple populations of the United States. *Journal of Developmental & Behavioral Pediatrics*. May 2010; 31(4):267-275. [PMID: 20431403]

Logan SL, Nicholas JS, Carpenter LA, King LB, Garrett-Mayer E, Charles JM. High prescription drug use and associated costs among Medicaid-eligible children with autism spectrum disorders identified by a population-based surveillance network. *Annals of Epidemiology*. January 2012;22(1):1-8. [PMID: 22153288]

Lopez M, Schulz EG, Baroud T, Hudson A, Wilson M. J. The Arkansas Autism Developmental Disabilities Monitoring (AR ADDM) project: statewide autism surveillance in a rural state. *The Journal of the Arkansas Medical Society.* March 2012;108(10):220, 222-4. [PMID: 22479981]

Maenner MJ, Arneson CL, Levy SE, Kirby RS, Nicholas JS, Durkin MS. Brief report: Association between behavioral features and gastrointestinal problems among children with autism spectrum disorder. *Journal of Autism and Developmental Disorders*. July 2012;42(7):1520-5. [PMID: 22012246]

Maenner MJ, Schieve LA, Rice CE, Cunniff C, Giarelli E, Kirby RS, Lee LC, Nicholas JS, Wingate MS, Durkin MS. Frequency and pattern of documented diagnostic features and the age of autism identification. *Journal of the American Academy of Child and Adolescent Psychiatry*. April 2013;52(4):401-413. [PMID: 23582871]

Miller JS, Bilder D, Farley M, Coon H, Pinborough-Zimmerman J, Jenson W, Rice CE, Fombonne E, Pingree CB, Ritvo E, Ritvo RA, McMahon WM. Autism Spectrum Disorder Reclassified: A Second Look at the 1980s Utah/UCLA Autism Epidemiologic Study. *Journal of Autism and Developmental Disorders*. January 2013;43(1):200-10. [PMID: 22696195]

Nicholas JS, Carpenter LA, King LB, Jenner W, Wahlquist A, Logan S, Charles JM. Completeness of case ascertainment for surveillance of autism spectrum disorders using the autism developmental disabilities monitoring network methodology. *Disability and Health Journal.* July 2012;5(3):185-9. [PMID: 22726859]

Parner ET, Baron-Cohen S, Lauritsen MB, Jørgensen M, Schieve LA, Yeargin-Allsopp M, Obel C. Parental Age and Autism Spectrum Disorders. *Annals of Epidemiology*. March 12, 2012. 22(3):143-50. [PMID: 22277122]

Peacock G, Amendah D, Ouyang L, Grosse S. Autism spectrum disorders and health care expenditures: The effects of co-occurring conditions. *Journal of Developmental and Behavioral Pediatrics*. January 2012. 33(1):2-8. [PMID: 22157409]

Perou R, Bitsko RH, Blumberg SJ, Pastor P, Ghandour RM, Gfroerer JC, Hedden SL, Crosby AE, Visser SN, Schieve LA, Parks SE, Hall JE, Brody D, Simile CM, Thompson WW, Baio J, Avenevoli S, Kogan MD, Huang LN. Mental health surveillance among children - United States, 2005-2011. *Morbidity and Mortality Weekly Report, Surveillance Summaries*. May 2013. [PMID: 23677130]

Pettygrove S, Pinborough-Zimmerman J, Meaney FJ, Van Naarden Braun K, Nicholas J, Miller L, Miller J, Rice C. Predictors of ascertainment of autism spectrum disorders across nine US communities. *Journal of Autism and Developmental Disorders.* August 2013;43(8):1867-79. [PMID: 23239097]

Pinborough-Zimmerman J, Bakian AV, Fombonne E, Bilder D, Taylor J, McMahon WM. Changes in the administrative prevalence of autism spectrum disorders: contribution of special education and health from 2002-2008. *Journal of Autism and Developmental Disorders*. April 2012;42(4):521-30. [PMID: 21538173]

Pinborough-Zimmerman J, Bilder D, Bakian A, Satterfield R, Carbone PS, Nangle BE, Randall H, McMahon WM. Sociodemographic risk factors associated with autism spectrum disorders and intellectual disability. *Autism Research*. December 2011;4(6):438-48. [PMID: 21905245]

Powell KC, Van Naarden Braun K, Singh RH, Shapira SK, Olney RS, Yeargin-Allsopp M. Prevalence of developmental disabilities and receipt of special education services among children with an inborn error of metabolism. *Journal of Pediatrics*. March 2010;156:420-426. [PMID: 19914633]

Rice C, Nicholas J, Baio J, Pettygrove S, Lee L, Van Naarden Braun K, Doernberg N, Cunniff C, Newschaffer C, Meaney FJ, Charles J, Washington A, King L, Kolotos M, Mancilla K, Mervis CA, Carpenter L, Yeargin-Allsopp M. Changes in autism spectrum disorder prevalence in 4 areas of the United States. *Disability and Health Journal*. July 2010; 3(3):186-201. [PMID: 21122784]

Schendel DE, Diguiseppi C, Croen LA, Fallin MD, Reed PL, Schieve LA, et al. The Study to Explore Early Development (SEED): A Multisite Epidemiologic Study of Autism by the Centers for Autism and Developmental Disabilities Research and Epidemiology (CADDRE) Network. *Journal of Autism and Developmental Disorders*. October 2012;42(10):2121-40. [PMID: 22350336]

Schieve LA, Baio J, Rice CE, Durkin M, Kirby RS, Drews-Botsch C, Miller LA, Nicholas JS, Cunniff C. Risk for cognitive deficit in a population-based sample of U.S. children with autism spectrum disorders: Variation by perinatal health factors. *Disability and Health Journal*. July 2010; 3(3):202-212. [PMID: 21122785]

Schieve LA, Boulet SL, Blumberg SJ, Kogan MD, Yeargin-Allsopp M, Boyle CA, Visser SN, Rice C. Association between parental nativity and autism spectrum disorder among US-born non-Hispanic white and Hispanic children, 2007 National Survey of Children's Health. *Disability and Health Journal*. January 2012. 5(1):18-25. [PMID: 22226294]

Schieve LA, Boulet SL, Kogan MD, Yeargin-Allsopp M, Boyle CA, Visser SN, Blumberg SJ, Rice C. Parenting aggravation and autism spectrum disorders: 2007 National Survey of Children's Health. *Disability and Health Journal*. July 2011;4(3):143-52. [PMID: 21723521]

Schieve LA, Rice C, Devine O, Maenner MJ, Lee LC, Fitzgerald R, Wingate MS, Schendel D, Pettygrove S, Van Naarden Braun K, Durkin M. Have Secular Changes in Perinatal Risk Factors Contributed to the Recent Autism Prevalence Increase? Development and Application of a Mathematical Assessment Model. *Annals of Epidemiology.* December 2011;21(12):930-45. [PMID: 22000328]

Schieve LA, Rice C, Yeargin-Allsopp M, Boyle CA, Kogan MD, Drews C, Devine O. Parent-Reported Prevalence of Autism Spectrum Disorders in US-Born Children: An Assessment of Changes within Birth Cohorts from the 2003 to the 2007 National Survey of Children's Health. *Maternal and Child Health Journal.* April 2012;16 Suppl 1:S151-7. [PMID: 22476793]

Sell NK, Giarelli E, Blum N, Hanlon AL, Levy SE. A comparison of autism spectrum disorder DSM-IV criteria and associated features among African American and white children in Philadelphia County. *Disability and Health Journal*. January 2012;5(1):9-17. [PMID: 22226293]

Tang YL, Guo Y, Lee LC, Rice CE, Wang YF, Cubells JF, Wu YY. Autism Diagnostic Observation Schedule (ADOS)--A Standardized direct observation assessment for autism spectrum disorders. *International Journal of Psychiatry*. 2010:37(1). Please note that this publication is in Mandarin Chinese.

Thomas P, Zahorodny W, Peng B, Kim S, Jani N, Halperin W, Brimacombe M. The association of autism diagnosis with socioeconomic status. *Autism*. March 2012;16(2):201-13. [PMID: 21810908]

Wiggins LD, Baio J, Schieve L, Lee LC, Nicholas J, Rice CE. Retention of autism spectrum diagnoses by community professionals: findings from the autism and developmental disabilities monitoring network, 2000 and 2006. *Journal of Developmental and Behavioral Pediatrics*. June 2012;33(5):387-95. [PMID: 22580734]

Wiggins LD, Robins DL, Yeargin-Allsopp M. Short report: Improving record-review surveillance of young children with an autism spectrum disorder. *Autism*. September 2013;17(5):623-9. [PMID: 22987886]

NIH publication No. 14-8012

U.S. Department of Health and Human Services
www.hhs.gov