



Report to Congress

on Activities Related to Autism Spectrum Disorder
and Other Developmental Disabilities
Under The Autism Collaboration, Accountability,
Research, Education, and Support Act
(Autism CARES Act) of 2014 (FY 2014 – FY 2018)

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



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Introduction

Autism Spectrum Disorder

Autism spectrum disorder (ASD) is a neurodevelopmental condition characterized by persistent impairments in social communication and social interaction, as well as restricted, repetitive, and stereotyped patterns of behavior, leading to difficulty in developing, maintaining, and understanding relationships with others. Recent research suggests that, using brain imaging techniques, differences in development indicative of ASD may be observed as early as 6 months of age. However, overt signs and traits of ASD usually emerge between 1 and 2 years of age. Because ASD is a lifelong condition and the combination and severity of characteristics can differ greatly from one individual to another, its associated challenges and support needs can range widely from modest to very extensive. Services and supports are available to help maximize health and wellbeing among children and adults on the autism spectrum, but the needs for earlier identification, improved interventions, and broadly available access to services remain a challenge. ASD continues to be a top national health priority, engaging the collaborative efforts of federal agencies, academic institutions, and private organizations to advance research and improve services and support systems. This report describes the efforts supported by federal departments and agencies to address research, health, education, and other related service and support needs that will improve the quality of life among 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 ASD and to strengthen federal efforts around this issue. The CAA amended the [Public Health Service Act](#) to authorize the expansion and enhancement of federal activities related to ASD research, surveillance, early detection, prevention, treatment, education, and disability programs. The law also reconstituted the [Interagency Autism Coordinating Committee \(IACC\)](#), originally created under the Children's Health Act of 2000, 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. The CAA authorized \$945 million in federal funds to support ASD-related federal efforts through September 30, 2011. Additionally, the CAA required the Department of Health and Human Services (HHS), in conjunction with the Department of Education (ED), 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. The [Report to Congress on Activities Related to Autism Spectrum Disorder and Other Developmental Disabilities under the Combating Autism Act of 2006 \(FY 2006 - FY 2009\)](#) was submitted in accordance with the requirement.

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. The CARA also authorized \$693 million in federal funds to support ASD-related federal efforts through 2014. The CARA again required HHS, in conjunction with ED, to submit a Report to Congress on the progress made in implementing provisions of the CARA, no later than 2 years after the law's enactment. This report, 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)*, was submitted in accordance with this requirement.

The Autism CARES Act

The Autism Collaboration, Accountability, Research, Education and Support Act (Autism CARES Act) of 2014 (P.L. 113-157) was signed into law on August 8, 2014. The Autism CARES Act reauthorized the ASD-related activities that began in 2006 under the CAA, and continued in 2011 under CARA, thus sustaining support for these activities related to ASD research and services through 2019. The Autism CARES Act states, “Not later than 4 years after August 8, 2014, the Secretary, in coordination with the Secretary of Education and the Secretary of Defense, 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, and make publicly available, including through posting on the Internet Web site of the Department of Health and Human Services, a progress report on activities related to autism spectrum disorder and other developmental disabilities.” Additionally, the Autism CARES Act required the preparation of a second report “concerning young adults with autism spectrum disorder and the challenges related to the transition from existing school-based services to those services available during adulthood.” This report, the *2017 Report to Congress: Young Adults and Transitioning Youth with Autism Spectrum Disorder*, was submitted in accordance with this second requirement. The Autism CARES Act also authorized \$1.3 billion in federal funds to support ASD-related efforts through 2019.

Provisions of the Autism CARES Act of 2014

- Continues efforts in autism surveillance, research, education/awareness, early detection, and intervention, including efforts to increase cultural competency and provider training across several federal departments/agencies.
- Reauthorizes the Interagency Autism Coordinating Committee to coordinate federal agencies in ASD-related efforts, serve as a forum for public input, and provide advice to the HHS Secretary on matters pertaining to ASD.
- Requires the appointment of a National Autism Coordinator within HHS to ensure implementation and accountability of activities detailed in the Autism CARES Act.

- Requires a report to Congress on federal activities related to youth and young adults with ASD and the challenges they face regarding the transition from school-based to adult service systems.
- Requires a Report to Congress on progress made in implementing the provisions of the Autism CARES Act.
- Authorizes \$1.3 billion in appropriations for federal ASD-related efforts through September 30, 2019.

Requirements for the Autism CARES Act Report to Congress

As with the CAA and CARA, the Autism CARES Act requires a report on federal ASD activities to be submitted to Congress. The following elements are required for this report:

- “A description of the progress made in implementing the provisions of the Autism CARES Act of 2014”
- “A description of the amounts expended on the implementation of the amendments made by the Autism CARES Act of 2014”
- “Information on the incidence and prevalence of autism spectrum disorder, including available information on the prevalence of autism spectrum disorder among children and adults, and identification of any changes over time with respect to the incidence and prevalence of autism spectrum disorder”
- “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 August 8, 2014, and, as appropriate, how this age varies across population subgroups”
- “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 August 8, 2014, and, as appropriate, how this age varies across population subgroups”
- “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 and, as appropriate, on how such average time varies across population subgroups”
- “Information on the effectiveness and outcomes of interventions for individuals diagnosed with autism spectrum disorder, including by severity level as practicable, and other developmental disabilities and how the age of the child or other factors, such as demographic characteristics, may affect such effectiveness”
- “Information on the effectiveness and outcomes of innovative and newly developed intervention strategies for individuals with autism spectrum disorder or other developmental disabilities”
- “A description of the actions taken to implement and the progress made on implementation of the strategic plan developed by the Interagency Autism Coordinating Committee”

Report to Congress (FY 2014 – FY 2018)

This *Report to Congress on Activities Related to Autism Spectrum Disorder and Other Developmental Disabilities Under the Autism CARES Act of 2014 (FY 2014 – FY 2018)* describes ASD-related activities and coordination efforts that span multiple federal agencies and departments. The report includes updates from the Interagency Autism Coordinating Committee, Departments of Defense and Education, and agencies within the Department of Health and Human Services, as required by the Autism CARES Act. It also contains updates from the Environmental Protection Agency, National Science Foundation, Social Security Administration, and the Departments of Housing and Urban Development, Justice, Labor, and Transportation, which also conduct activities related to autism or individuals with disabilities. The report covers all elements required in the Autism CARES Act for the period of fiscal years 2014-2017. Some information regarding federal programs and projects in FY 2018 is included in this report, but it should be noted that the information pertaining to FY 2018 may not be complete, as FY 2018 was still underway as this report was being prepared.

Interagency Coordination

The Autism CARES Act specifies two mechanisms for coordination of autism activities across the federal government. The Act reauthorized the Interagency Autism Coordinating Committee (IACC) to coordinate federal agencies and collect input from autism community stakeholders to formulate advice and recommendations that can be used to guide federal activities. The Act also required the designation of a National Autism Coordinator (NAC), “an existing official within the Department of Health and Human Services to oversee, in consultation with the Secretaries of Defense and Education, national autism spectrum disorder research, services, and support activities.” The National Autism Coordinator also plays a role in ensuring that federal agencies are coordinated internally to implement advice provided by the IACC. The roles of the IACC and the NAC are described below.

The Interagency Autism Coordinating Committee

The IACC was established in its current form by Congress under the Combating Autism Act (CAA) of 2006 (P.L. 109-416) and was most recently reauthorized under the Autism Collaboration, Accountability, Research, Education, and Support (Autism CARES) Act of 2014 (P.L. 113-157) to provide advice to the HHS Secretary concerning issues related to ASD and to coordinate federal ASD-related efforts. Among other functions, the IACC serves as a forum for public input on issues related to ASD. The committee uses this input to inform its activities, including the development of the *IACC Strategic Plan for ASD* which serves as a guide for federal agencies in planning ASD-related research, service and support activities. 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.

The Autism CARES Act outlines the membership of the IACC, which includes representatives of federal agencies and public members representing a variety of stakeholder groups within the autism community. Public membership includes individuals with ASD, family members of children and adults with ASD, autism researchers, and leaders of national research, service, and advocacy organizations. Federal members represent the following departments and agencies that address ASD research or services:

Department of Health and Human 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)
- Food and Drug Administration (FDA)
- Health Resources and Services Administration (HRSA)
- Indian Health Service (IHS)
- National Institutes of Health (NIH)

Department of Defense (DoD)

Department of Education (ED)

Environmental Protection Agency (EPA)

Social Security Administration (SSA)

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) was established in 2008 at NIH to manage the committee and provide policy and communications support to enable the committee to carry out its Congressionally-mandated responsibilities.

IACC Fulfillment of Autism CARES Act Mandates

The activities of the IACC described below fulfill the committee’s Congressional mandates under the Autism CARES Act:

“Develop and Annually Update a Strategic Plan for Autism Spectrum Disorder Research”

The IACC’s original *Strategic Plan* was completed in 2009, and updates were issued for 2010, 2011, 2012, and 2013. These documents were submitted to Congress as required. Following the passage of the Autism CARES Act, new members were nominated to re-establish the committee, and the IACC resumed regular meetings in late 2015. The committee undertook a major revision of the *IACC Strategic Plan* in 2016 that was completed in 2017. The *2016-2017 IACC Strategic Plan* provides a whole new set of updated objectives that cover both ASD research and services activities.

Since 2009, the *IACC Strategic Plan* has been organized around seven community-based Questions. These Questions were updated in the 2016-2017 edition of the *Strategic Plan*, although they remained focused on the same topics:

1. How Can I Recognize the Signs of ASD, and Why is Early Detection So Important?
(Screening and Diagnosis)
2. What is the Biology Underlying ASD? (Biology)

3. What Causes ASD, and Can Disabling Aspects of ASD be Prevented or Preempted? (Risk Factors)
4. Which Treatments and Interventions Will Help? (Treatments and Interventions)
5. What Kinds of Services and Supports are Needed to Maximize Quality of Life for People on the Autism Spectrum? (Services)
6. How Can We Meet the Needs of People with ASD as They Progress into and through Adulthood? (Lifespan Issues)
7. How Do We Continue to Build, Expand, and Enhance the Infrastructure System to Meet the Needs of the ASD Community? (Infrastructure and Surveillance)

Each of the seven chapters of the *IACC Strategic Plan* describes the state of research and services activities in that area, the recent progress achieved, the most pressing needs of the community and the research field in that area, and what 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.

“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, 2012, 2013, 2014, 2015, 2016, and 2017. The *Summary of Advances* documents provide lay-friendly summaries of the year’s top advances in ASD research as identified by the committee, covering specific areas mentioned in the Autism CARES Act: causes, prevention, treatment, early screening, diagnosis, interventions, and access to services and supports for individuals with ASD. Summaries are organized in alignment with the seven Question areas of the *IACC Strategic Plan*.

“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, researchers, and private organizations that are involved in ASD research and services activities, allowing the committee to stay abreast of recent developments and best practices. The IACC also reviews the research literature for *Strategic Plan* updates and to prepare its annual *Summary of Advances in ASD Research*.

OARC annually prepares an *ASD Research Portfolio Analysis Report* to assist the IACC in assessing progress on the *IACC Strategic Plan*. The *Portfolio Analysis Report* analyzes information about autism-related research projects funded by federal agencies and private organizations. The report describes progress that is being made toward achieving the objectives set forth in the *IACC Strategic Plan* 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 provides valuable information about ASD research funding to both federal agencies and private research organizations.

The 2008, 2009, 2010, 2011-2012, 2013, 2014-2015, and 2016 ASD Research Portfolio Analysis Reports are available on the IACC website. The data collected for those reports have also been made available to the public in an online database, the IACC/OARC Autism Research Database, which provides members of the public with a user-friendly way to search, sort, and view analyses 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 2016-2017 IACC Strategic Plan contains 23 objectives that serve as recommendations for further efforts in specific priority areas. In addition to the HHS Secretary, all of the federal agency representatives on the committee receive the IACC Strategic Plan and its updates for use in planning activities within their agencies. The IACC Strategic Plan is also sent to Congress and the President, and it is posted on the IACC website for public access.

The committee has also used advisory letters to the HHS Secretary as a method for providing advice. In recent years, the committee has written letters to the Secretary advising on emerging issues in the ASD community and recommending adjustments or improvements to federal activities to benefit the autism community: Letter to the Secretary on Wandering (2011), Letter to the Secretary on Seclusion and Restraint (2011), and Letter to the Secretary on Health Coverage (2013).

“The Committee Shall Meet not Fewer than Two Times Each Year”

The table below highlights IACC full committee, subcommittee, workgroups and planning groups, 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, with two exceptions. The committee initially formed in 2007 and was only able to meet once that year. Following the passage of the Autism CARES Act, the committee was reconstituted in late 2015 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 Full Committee Meetings, 2007-2018												
Meeting	2007	2008	2009	2010	2011	2012	2013	2014	2015	2016	2017	2018
Full Committee	1	5	7	5	4	4	4	3	1	4	4	3

Table 1. The number of IACC Full Committee meetings that took place from 2007-2018.

Other IACC Meetings and Events, 2007-2018												
Meeting	2007	2008	2009	2010	2011	2012	2013	2014	2015	2016	2017	2018*
Sub-committee	0	5	8	10	5	4	4	0 [‡]	0 [‡]	0 [‡]	0 [‡]	0 [‡]
Planning Groups/ Workgroups	0	5	0	0	0	12	12	2	0	21	0	2
Workshops and Other Events	0	5	2	1	1	0	1	1	0	0	0	1
Totals	1	15	10	11	6	16	17	3	0	21	0	3

Table 2. The number of IACC Subcommittee, Workgroups and Planning Groups, Workshops and other meetings and events that took place from 2007-2018.

‡Since 2014, the IACC has used planning groups/workgroups instead of sub-committees to complete specific tasks, such as strategic plan updates and projects related to issues of public interest.

IACC/OARC Outreach and Transparency

OARC maintains an extensive website to facilitate public access to information about the IACC, its activities, and its publications. The IACC website currently posts the agenda, minutes, meeting materials, slides, and transcripts from the meetings of the IACC, its subcommittees and workgroups, 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 list of ASD-relevant meetings and events that are open to the public.

OARC also launched and maintains the Autism Research Database (ARD), a publicly accessible database that makes available project data for all ASD research projects included in the *IACC ASD Research Portfolio Analysis Reports*. The ARD 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.

As a federal advisory committee, the IACC complies with the Federal Advisory Committee Act to ensure that every in-person meeting of the committee or subcommittees/working groups is open to the public. There are currently several remote access options available at each meeting, enabling the public to listen to or watch proceedings through conference calls, webcasts or webinars. In 2009 OARC began conducting live webcasts of all full committee meetings and then archiving them on the website. IACC-related meetings conducted by conference call only are made accessible to the public via a call-in number. To provide rapid notification of upcoming meetings and committee news, the IACC disseminates information through electronic mail listservs, Twitter, and an email newsletter.

At every IACC full committee meeting, the IACC seeks input from the public through **open public comment periods**. Members of the public may appear in person and present oral comments or submit written comments that are summarized during each meeting. Members of the IACC discuss the presented comments and often develop action items based on issues discussed. In addition, the committee periodically issues formal **Requests for Information (RFI)** to gather public input for strategic planning purposes. The last IACC RFI was issued in 2016 and was used to develop the *2016-2017 IACC Strategic Plan*.

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.

The National Autism Coordinator

The duties of the National Autism Coordinator (NAC) specified in the Autism CARES Act include implementation of federal ASD activities based on the recommendations of the IACC, as well as ensuring that federal ASD efforts are not unnecessarily duplicative. The first NAC was appointed by the HHS Secretary in April 2016. In October 2016, the NAC convened an Interagency Workgroup (IWG) to provide input into the *Report to Congress on Young Adults and Transitioning Youth with ASD*, which is required by the Autism CARES Act. This report was completed and submitted to Congress in August 2017. The report recommends that increased research efforts, as well as service and resource expansion, should be considered to better serve the population of transitioning youth and adults with ASD.

A new NAC was appointed in February 2018, and the IWG was reconvened in June 2018 as the Federal Interagency Workgroup on ASD (FIWA). The goal of FIWA is to address the recommendations of the *Report on Young Adults and Transitioning Youth with ASD* as well as other important federal ASD issues.

The agencies and departments currently represented on the FIWA include:

Department of Health and Human Services (HHS)

Administration for Children and Families (ACF)

Administration for Community Living (ACL)

Agency for Healthcare Research and Quality (AHRQ)

Assistant Secretary for Planning and Evaluation (ASPE)

Centers for Disease Control and Prevention (CDC)

Centers for Medicare & Medicaid Services (CMS)

Health Resources and Services Administration (HRSA)

Indian Health Service (IHS)

National Institutes of Health (NIH)

Substance Abuse and Mental Health Services Administration (SAMHSA)

Department of Education (ED)

Department of Defense (DoD)

Department of Justice (DOJ)

Department of Labor (DOL)

Department of Transportation (DOT)

Environmental Protection Agency (EPA)

Social Security Administration (SSA)



Required Elements of the Report to Congress (FY 2014 – FY 2018)

In addition to a summary of the role of the OARC, IACC, and NAC in coordinating ASD efforts, this Report to Congress provides an overview of each federal agency that supports projects or programs related to ASD, as well as highlights information on current ASD prevalence 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 21 federal departments and agencies, this report addresses ASD research and services according to the required elements outlined in the Autism CARES Act (see page 2 for a complete list of required elements). Elements (A) and (B) have been combined into one chapter covering the general progress made and amounts expended during the past 5 years in federal ASD research efforts by lead agencies and offices. Elements (G) and (H) 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 and 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)

Indian Health Service (IHS)

National Institutes of Health (NIH)

Substance Abuse and Mental Health Services Administration (SAMHSA)

Department of Education (ED)

Department of Defense (DoD)

Army (DoD-Army)

Air Force (DoD-Air Force)

Military Health System (MHS)/TRICARE

Environmental Protection Agency (EPA)

Department of Housing and Urban Development (HUD)

Department of Justice (DOJ)

Department of Labor (DOL)

National Science Foundation (NSF)

Social Security Administration (SSA)

Department of Transportation (DOT)

ASD Progress and Expenditures

This chapter covers subsections (A) and (B) of Section 399DD of the Autism CARES Act, which require: (A) “A description of the progress made in implementing the provisions of the Autism CARES Act of 2014;” and (B) “A description of the amounts expended on the implementation of the particular provisions of the Autism CARES Act of 2014.” 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, IHS, and SAMHSA, as well as ED and DoD. Additional details are provided from EPA, HUD, DOJ, DOL, NSF, SSA, and DOT, which also conduct activities that concern or are related to ASD.

Department of Health and Human Services

The mission of the U.S. Department of Health and Human Services (HHS) is to enhance and protect the health and well-being of all Americans by providing for effective health and human services and fostering advances in medicine, public health, and social services. HHS includes more than 300 programs and 11 operating divisions covering a wide spectrum of activities. The 10 HHS operating divisions represented in this report support research and services that address the needs of individuals with ASD and their families.

Administration for Children and Families

The [Administration for Children and 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 to have a positive impact on quality of life and the development of children;
- Improve access to services through planning, reform and integration;
- Create partnerships with front-line service providers, states, localities, and tribal communities to identify and implement solutions that transcend traditional program boundaries; and
- Address the needs, strengths and abilities of vulnerable populations including people with developmental disabilities (DD), refugees and migrants.

The ACF does not have any programs or funding specifically focused on provisions of the Autism CARES Act or for individuals on the autism spectrum. However, ACF funds [Head Start](#) services, including those for children with ASD. 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. Table 3 outlines the total funds spent on Head Start services for children with ASD between 2014 and 2017.

In April of 2013, ACF launched a web page, “[Autism Awareness and Acceptance in Early Childhood Education](#),” which focuses 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 to the ASD website, ACF has focused its attention on developmental and behavioral screening. While the emphasis of this priority is broad screening, rather than screening for specific disorders, the initiative has helped 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 the Tribal Early Childhood Research Center to do a feasibility study of the Survey of Well-Being of Young Children. The study examined the use of a first-line screening instrument on Native American reservations. The instrument includes an ASD screen as part of a broader screen of development. The study assessed the cultural sensitivity of each individual item in the screening instrument. This was the first time a developmental and behavioral screening instrument had been tested or culturally adapted to fit the needs of young Native American children. [The results of this feasibility study](#) were published in 2015, and [additional information and resources](#) from the study are available online.

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.

Interagency Coordination and Implementation of the *IACC Strategic Plan*

ACF serves as a member agency on the Interagency Autism Coordinating Committee (IACC) and the Federal Interagency Workgroup on ASD (FIWA). ACF research activities described above address Question 1 (Screening and Diagnosis) of the *IACC Strategic Plan*.

ACF Head Start ASD-Related Expenditures, (FY 2014 - FY 2018)			
FY 2014	FY 2015	FY 2016	FY 2017
\$21.8M	\$24.1M	\$31.6M	\$29.2M

Table 3. ACF Head Start Expenditures for Children with ASD, FY 2014 - FY 2017 (Millions)

Administration for Community Living

The Administration for Community Living (ACL) works to increase access to community support systems for older Americans and for people with disabilities across the lifespan. Its main activities and statutory authorities include administration of disability programs that support community living from which individuals with ASD may benefit.

National Institute on Disability, Independent Living, and Rehabilitation Research

The National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR) within ACL conducts research and development in disability and rehabilitation (including research and development in ASD) as authorized by the Workforce Innovation and Opportunity Act (WIOA), 45 CFR Part 1330.

Research in autism currently funded by NIDILRR is field initiated, i.e. the projects were developed and proposed by researchers in the field. None of these projects were agency-directed, but they do address Questions 4, 5, and 6 of the *IACC Strategic Plan*.

Current projects include work in the following areas:

- Improving employment outcomes for transition age youth with ASD
 - A multi-site randomized control trial of **an internship model to improve employment outcomes** for transition-age youth with ASD. A previously funded single-site randomized control trial of this model demonstrated greater employment rates, which were maintained over time, for the internship group.
 - A randomized control trial of **a customized employment intervention** to improve employment outcomes for transition-age youth with ASD.
- Parent education and training
 - A scale-up project of OASIS (Online and Applied System for Intervention Skills), a model of **intervention skills training for parents** of children with autism.
 - A parent education program designed to **meet the needs of Latino parents of children with ASD**.
- Effects of policy
 - A study of **impacts of implementation of Medicaid Home and Community Based Services (HCBS) Waiver initiatives** in support of children and families who experience autism.
- Improving community living and participation in transition age youth and/or adults with autism
 - Development of a technology-supported instructional system to **teach social competence, problem-solving skills, and organizational/self-monitoring skills** for adolescents and young adults with ASD.
 - Phase I Small Business Innovation Research (SBIR) project to develop and test **an Incident Alerting System** to enable real-time crossflow of information to law enforcement officials and caregivers of individuals with cognitive/communication disorders.
 - Phase I SBIR proof-of-concept project to determine if affective and physiological regulation in individuals with ASD can be promoted through **dynamic adjustments in the environment**.

- Phase I SBIR project combining commercially-available modules with cloud computing and state-of-the-art software to **develop the memBRAIN system to assist young adults with ASD** to safely and effectively transition into independent living.
- Phase II SBIR project to develop and evaluate the effectiveness of a web application that enables individuals with intellectual disabilities and ASD to **effectively manage self-defined goals** for everyday living across personal, educational, and vocational life domains.
- Phase II SBIR project to develop **a cognitively accessible life-experience communication tool** that grows and changes throughout transition and later life, providing an easily accessible life and work history in appropriate formats to students with disabilities, families, educators, and other transition-team members.

Administration on Intellectual and Developmental Disabilities

The Administration on Intellectual and Developmental Disabilities (AIDD) within ACL provides oversight of the following programs authorized under the Developmental Disabilities Assistance and Bill of Rights Act (DD Act):

- State Councils on Developmental Disabilities
- Protection and Advocacy Systems
- University Centers for Excellence in Developmental Disabilities (UCEDD)

These programs carry out a variety of activities in states and territories to assure that individuals with DD and their families participate in the design of and have access to needed community services, individualized supports, and other forms of assistance that promote self-determination, independence, productivity, and integration and inclusion in all facets of community life.

Interagency Coordination and Implementation of the *IACC Strategic Plan*

ACL participates as a member agency on the IACC and the FIWA.

While the DD Act programs listed above do not focus specifically on individuals with ASD, their work to improve the quality of life of individuals with DD will address the needs of such individuals in the following areas under the *2016-2017 IACC Strategic Plan for ASD*:

- Question 5 (Services)
 - Scale up and implement evidence-based interventions in community settings.
 - Reduce disparities in access and in outcomes for underserved populations.
 - Improve service models to ensure consistency of care across many domains with the goal of maximizing outcomes and improving the value that individuals get from services.

- Question 6 (Lifespan Issues)
 - Support development and coordination of integrated services to help youth make a successful transition to adulthood and provide supports throughout the lifespan.
 - Support research and implement approaches to reduce disabling co-occurring physical and mental health conditions in adults with ASD, with the goal of improving safety, reducing premature mortality, and enhancing quality of life.
 - Support research, services activities, and outreach efforts that facilitate and incorporate acceptance, accommodation, inclusion, independence, and integration of people on the autism spectrum into society.

In addition, NIDILRR is funding research efforts that address these two Questions with results as described above.

ACL/NIDILRR ASD-Related Expenditures, (2014-2018)				
2014	2015	2016	2017	2018
\$1,856, 443	\$1,728,392	\$2,073,019	\$1,222,987	\$1,189,960

Table 4. ACL/NIDILRR funding* for projects focused on ASD, 2014-2018
 *funded under the Workforce Innovation and Opportunity Act (WIOA)

Agency for Healthcare Research and Quality

The **Agency for Healthcare Research and Quality (AHRQ)** produces evidence for the nation focused on health care safety and quality. AHRQ does not receive funds from the Autism CARES Act but does support research to determine the effectiveness and outcomes of interventions for individuals with ASD. These research projects and AHRQ publications are described below.

AHRQ-funded Research Projects

“**Adapting Electronic Medical Record to Measure Medical Outcomes in ASD Populations**” aims to better understand the hospital-based and outpatient healthcare utilization patterns of patients with ASD. The researchers will develop methods for using an Electronic Medical Record (EMR) to capture and to measure medical treatment utilization patterns among patients with ASD, including primary care, specialty, and urgent care/emergency department use. They will also create the necessary data warehouse to support this comparative effectiveness research of medical treatments in patients with ASD. In the long term, the experience and data generated by this Mentored Research Scientist Development Award are expected to lead to larger studies implementing comparative effectiveness research using multi-site data warehouses.

“Creating Integrated Healthcare Services for People with Autism Spectrum Disorder” supported a conference that aimed to stimulate new and different approaches to the provision of medical care to people with ASD across the lifespan. The conference brought together healthcare providers to promote interdisciplinary discussion of ways to enhance integrated healthcare services for people with ASD. It is expected that, over time, better integration of care will reduce costs, improve treatment outcomes, and improve the quality of life for people with ASD. Goals for participants and panelists at the conference included: a) defining and describing the ideal environmental, behavioral, and/or individual supports during the provision of medical care to people with ASD; b) identifying barriers to the delivery of integrated care in emergency departments and in-patient acute care settings; c) proposing technology or information system improvements to eliminate the barriers to inter-professional communication, across acute care settings; and d) defining measures to demonstrate effectiveness of policies to improve treatment outcomes and efficiency of care.

“Reducing Disparities in Timely Autism Diagnosis through Family Navigation” proposes to test the feasibility of an intervention to decrease disparities in timely ASD diagnosis that occur at a critical point in the continuum of the delivery of ASD services for young children. The patient navigation model has been implemented to reduce institutional- and individual-level barriers to cancer diagnoses and has demonstrated efficacy in both improving adherence to follow-up visits after a screening abnormality and decreasing the time from an abnormal screen to diagnostic resolution. This study will assess a novel application of patient navigation to support families of low-income and minority children, ages 15 months to 3 years. The researchers have reframed the model from patient to family navigation and will focus on a defined episode of care, beginning with an abnormal autism screen and ending with the completion of the diagnostic assessment.

“A Deliberative Approach to Develop Autism Data Collection in Massachusetts” is a health services research grant funded in 2016 that involves a deliberative citizen jury, the majority of which are individuals on the autism spectrum, to provide guidance to the Massachusetts Executive Office of Health and Human Services regarding the creation of a statewide registry for ASD. A patient registry is a collection of standardized information about a group of patients who share a particular condition or experience. When complete, the registry will provide an integrated data system to track diagnosis, treatment, services, and outcomes for individuals with ASD, with the long-term goal of improving coordination of care and disseminating information on best practices. The registry will also provide a way to track services and outcomes for various subpopulations of autistic individuals in Massachusetts.

“Partnership for Research & Dissemination of Evidence-Based Medicine in Autism” proposes to use innovative methods to develop customized content (including videos, webisodes, and interactive media products) of existing evidence-based medicine (EBM) products for ASD. The researchers will then disseminate this content through technology-based and social media channels to enable rapid and easy downloading by targeted stakeholder audiences, including parents of children with ASD as well as teachers and health care providers of autistic individuals from underserved populations. The trans-disciplinary team proposes to extend this work

and develop a highly effective, unified, and sustainable high-throughput dissemination strategy to improve the use of customized EBM products at health and educational systems, clinical practice, caregiver, and family levels.

“Enabling large-scale research on autism spectrum disorders through automated processing of EHR using natural language understanding” aims to increase the utility of electronic health records (EHR) by developing scalable and effective computational methods to capture structured data from the text contained therein. This will be particularly advantageous in advancing knowledge about ASD and other mental health disorders, where records describe symptoms and interventions that are highly individualized and are often composed of rich data not easily captured in structured templates. This project has the potential to significantly shift away from the current paradigm of relying on small-scale data from individual ASD interventions and the lack of integration between different data sources, to leveraging information from existing large-scale data sources to propose novel analyses and hypotheses.

AHRQ Publications

Medical Therapies for Children with Autism Spectrum Disorder — An Update

The goal of this systematic review, published in 2017, was to evaluate the comparative effectiveness and safety of medical interventions for children with ASD. Studies of medical interventions that included at least 10 children with ASD were included. The 76 unique comparative studies meeting the inclusion criteria included 72 randomized controlled trials (RCTs), 2 non-randomized trials, and 2 retrospective cohort studies; populations, treatment approaches, and outcomes assessed varied across studies. Risperidone and aripiprazole ameliorated challenging behaviors in the short term, but with clinically significant side effects [high strength of evidence (SOE)]. Methylphenidate and atomoxetine were also associated with improvements in hyperactivity in small short-term RCTs (low SOE), with improvements maintained over 6 months for atomoxetine (low SOE for longer term effects). Methylphenidate was associated with clinically significant harms (low SOE), while atomoxetine was associated with clinically moderate harms (low SOE). Omega-3 fatty acid supplementation, N-acetylcysteine, and tetrahydrobiopterin failed to show benefits (low SOE). Evidence for other interventions and outcomes studied was insufficient. While the conduct of studies has improved considerably over time (i.e., growing number of RCTs and use of standardized measures), data on longer term (≥ 6 months) results and harms of most interventions are lacking. Similarly, more research is needed to understand characteristics of the child or treatment that modify outcomes, whether effectiveness of interventions generalizes across different settings such as the home or school, and how components of interventions may drive effects.

Interventions Targeting Sensory Challenges in Children with Autism Spectrum Disorder - An Update

The goal of this systematic review, published in 2017, was to evaluate the effectiveness and safety of interventions targeting sensory challenges in children with ASD. Studies included 20 RCTs, 1 nonrandomized trial, and 3 retrospective cohort studies (3 low, 10 moderate, and 11 high risk of bias); populations, intervention approaches, and outcomes assessed varied across studies. Some interventions targeting sensory challenges

may produce modest short-term (<6 months) improvements, primarily in sensory-related outcomes and outcomes related to ASD symptom severity; however, the evidence base for any category of intervention is small, and durability of effects beyond the immediate intervention period is unclear. Sensory integration–based approaches improved outcomes related to sensory challenges (low SOE) and motor skills (low SOE), and massage improved sensory responses (low SOE) and ASD symptoms (low SOE). Environmental enrichment improved nonverbal cognitive skills (low SOE). Auditory integration–based approaches did not improve language outcomes (low SOE). Some positive effects were associated with other approaches studied (music therapy, weighted blankets), but findings in these small studies were not consistent (insufficient SOE). Data on longer term results are lacking, as are data on characteristics that modify outcomes, effectiveness of interventions across environments or contexts, and components of interventions that may drive effects. In sum, while some therapies may hold promise and warrant further study, substantial needs exist for continuing improvements in methodologic rigor in the field.

Therapies for Children With Autism Spectrum Disorder: Behavioral Interventions Update

This 2014 update of a prior systematic review of interventions for children (0–12 years) with ASD focused on recent studies of behavioral interventions. Sixty-five unique studies comprising 48 randomized trials and 17 non-randomized comparative studies (19 good, 39 fair, and 7 poor quality) were included in the analysis. The quality of studies improved compared with that reported in the earlier review; however, assessment of the SOE and confidence in the stability of effects of interventions in the face of future research, remains low for many intervention/outcome pairs. Early intervention based on high-intensity applied behavior analysis over extended timeframes was associated with improvement in cognitive functioning and language skills (moderate SOE for improvements in both outcomes) relative to community controls in some groups of young children. The magnitude of these effects varied across studies, potentially reflecting poorly understood modifying characteristics related to subgroups of children. Early intensive parent training programs modified parenting behaviors during interactions; however, data were more limited about their ability to improve developmental skills beyond language gains for some children (low SOE for positive effects on language). Social skills interventions varied in scope and intensity and showed some positive effects on social behaviors for older children in small studies (low SOE for positive effects on social skills). Studies of play/interaction-based approaches reported that joint attention interventions may demonstrate positive outcomes in preschool-age children with ASD when targeting joint attention skills (moderate SOE); data on the effects of such interventions in other areas were limited (low SOE for positive effects on play skills, language, social skills). Studies examining the effects of cognitive behavioral therapy on anxiety reported positive results in older children with IQs ≥ 70 (high SOE for improvements in anxiety in this population). Smaller short-term studies of other interventions reported some improvements in areas such as sleep and communication, but data were too sparse to assess their overall effectiveness. In summary, despite improvements in the quality of the included literature, a need remains for studies of interventions across settings and continued improvements in methodologic rigor. Substantial scientific advances are needed to enhance our understanding of which interventions are most effective for specific children with ASD and to isolate elements or components of interventions most associated with effects.

Genetic Testing for Developmental Disabilities, Intellectual Disability, and Autism Spectrum Disorder

This Technical Brief collects and summarizes information on genetic tests clinically available in the United States to detect genetic markers that predispose to DD. It also identifies, but does not systematically review, existing evidence addressing the tests' clinical utility. This Brief primarily focuses on patients with idiopathic or unexplained DD, particularly intellectual disability, global developmental delay, and ASD. Patient-centered health outcomes (e.g., functional or symptomatic improvement) and intermediate outcomes (e.g., changes in clinical decisions or family reproductive decisions, and the tests' diagnostic accuracy and analytic validity) are examined. A search of the Genetic Testing Registry database identified 672 laboratory-developed tests offered by 63 providers in 29 states. The authors also identified one test cleared by the Food and Drug Administration. Common genetic testing methods used include array comparative genomic hybridization, microarray, DNA sequencing (the Sanger method or next-generation sequencing), and polymerase chain reaction. The authors did not identify any studies that directly assessed the impact of genetic testing on health outcomes. Most of the clinical studies identified for indirect assessment of clinical utility are case series reporting on a test's diagnostic yield.

Screening for Autism Spectrum Disorder in Young Children, Systematic Evidence Review for the U.S. Preventive Services Task Force

This systematic review, published in 2016, examined the evidence about benefits and harms of routine screening for ASD in primary care settings, explicitly focusing on studies of screening instruments for use in young (≤ 36 months of age), unselected populations (e.g., universal screening approaches). The authors identified 17 unique screening studies reported in 22 papers. The most commonly studied tool was the Modified Checklist for Autism in Toddlers (M-CHAT), including the most recently available variant (M-CHAT-Revised with Follow-up [M-CHAT-R/F]), which has a positive predictive value of 48 percent in diverse populations of children ages 16 to 30 months. Forty-two studies of good and fair quality addressed interventions for young children. Among these, 20 studies overall measured cognitive outcomes and 11 reported greater benefit for the intervention group compared to the control group. Language outcomes were significantly improved in treatment versus comparison arms in 13 of 28 studies assessing language. Twelve studies focused on play and interaction and typically measured joint attention as the outcome. Nine out of 10 studies evaluating joint attention outcomes reported greater benefit in the treatment arm compared to the control arm. None of the studies focused on screen-detected children. In summary, early intensive interventions demonstrate statistically significant improvements in cognitive and language outcomes in children compared to eclectic treatments obtained in the community or other comparison groups, although the studies are generally small, and, within the studies, some children benefit while others do not. The authors found no studies that directly compared long-term outcomes of screened versus non-screened children. More research is needed to determine the benefits and harms of screening the general population.

Interagency Coordination and Implementation of the IACC Strategic Plan

AHRQ serves as a member agency on the IACC and FIWA. AHRQ-funded projects and agency activities address the following areas of the *IACC Strategic Plan*: Question 1 (Screening and Diagnosis), Question 4 (Treatments and Interventions), Question 5 (Services), and Question 7 (Infrastructure and Surveillance).

AHRQ ASD-Related Expenditures*, (FY 2014 - FY 2018)

FY 2014	FY 2015	FY 2016	FY 2017	FY 2018	Total
\$763,292	\$740,158	\$276,836	\$424,762	\$146,202	\$2,351,250

Table 5. AHRQ ASD-Related Expenditures on research projects listed above.

*Note: AHRQ does not have a specific budget dedicated to ASD research; rather, these grants were funded through AHRQ's investigator-initiated health services research grant mechanisms and contract mechanisms.

Centers for Disease Control and Prevention

The Centers for Disease Control and Prevention (CDC) brings a unique public health perspective to the effort to fully understand 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 DD. 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.

Recognizing the importance of CDC's unique public health role, the [Children's Health Act of 2000](#) established a scientific infrastructure at CDC for conducting population-based ASD monitoring and research. The [CAA](#) and the [CARA](#) 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 [Autism CARES Act of 2014](#) reauthorized CDC's work for a further five years and expanded the epidemiological focus to include children and adults. Although the CAA, CARA and Autism CARES Act only provided additional legislative authority to bolster ongoing CDC autism-related activities that were already authorized, the Autism CARES Act focus on the transition from childhood to adulthood has broadened the focus of CDC's work.

While the Autism CARES Act did not provide any new appropriations for CDC's autism work, it strengthened CDC's unique surveillance and supported the continued expansion to explore autism at younger ages. The Autism CARES Act allowed CDC's public health research to expand to include more children, allowing exploration into more risk factors, and development of a pilot project to understand the transition to adolescence and adulthood. The Autism CARES Act continued support for "[Learn the Signs. Act Early.](#)" and the mission of 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 Monitoring

ADDM Network

CDC's autism surveillance activities continue to advance the understanding of ASD with support from the Autism CARES Act. CDC's surveillance data provide a clear picture of the impact of autism on the nation's families and communities and are the foundation for national, state, and local policy and planning. Since 2000, the **Autism and Developmental Disabilities Monitoring (ADDM)** Network has conducted population-based ASD surveillance on geographic populations ranging in size from 172,335 to 407,578 8-year-old children, totaling nearly 2.5 million children. The ADDM surveillance has resulted in the most robust estimates to date of the prevalence of ASD in the United States. This information provides the foundation for research into who is likely to develop autism, why autism develops, and how to best support individuals, families, and communities affected by autism.

The ADDM Network currently conducts surveillance of ASD, and other DD, among children aged 8 years whose parents or guardians reside within in **11 geographic areas of the United States**. In **2014, 2016, and 2018** CDC published updated prevalence reports. The **2018 report** is the first to compare surveillance case status based on two different diagnostic systems [i.e., *Diagnostic and Statistical Manual of Mental Disorders (DSM) Fourth Edition – Text Revision* and *DSM-5*]. By applying both the previous (*DSM-IV*) and current (*DSM-5*) diagnostic criteria to generate prevalence estimates based on the different surveillance case definitions, CDC provides a direct evaluation of the impact of revised diagnostic criteria on prevalence trends. The 2014, 2016, and 2018 data inform the understanding of ASD prevalence and the characteristics of children who have ASD, and are used to monitor progress toward CDC's **Healthy People 2020** objectives. A list of publications using ADDM Network data can be found in Appendix iii.

Surveillance in Younger Children: Early ADDM

In 2010, CDC also began collecting data on 4-year-old children with ASD, using the same methodology as ADDM Network surveillance, to better understand ASD in younger children. This surveillance is called the Early ADDM Network and currently includes sites in six states that are part of the ADDM Network (described above). Early ADDM surveillance of ASD among 4-year-old children helps health care providers, educators, and policy makers better understand the characteristics of young children affected by ASD and improve early identification efforts. **Findings from Early ADDM Network** provide valuable information about the early identification of children with ASD, age at first comprehensive evaluation, and differences in characteristics, such as intellectual disability, among 4-year-old children with ASD compared to 8-year-old children with ASD in the same communities. **Data published from Early ADDM Network** in 2016 suggest that progress has been made over time in identifying some children with ASD at younger ages, but with a concerning racial disparity: black preschool-aged children with ASD were less likely than white preschool-aged children with ASD to be evaluated for developmental concerns by age three years. (Appendix iii)

National Health Interview Survey

The **National Health Interview Survey** (NHIS) is a nationally representative household survey conducted by the National Center for Health Statistics, which monitors the health of the civilian noninstitutionalized population living in the United States on a broad range of health topics, including the presence of developmental disorders among children. The NHIS collects data continuously throughout the year with an annual release, thereby allowing for annual prevalence estimates of ASD, ID, attention-deficit/hyperactivity disorder, developmental delay, and learning disability. The NHIS is not named in nor does it receive authorization under the Autism CARES Act, but is authorized by title 42, United States Code, section 242k.

Research

The Autism CARES Act supports CDC research on risk factors that may be related to the development of ASD. CDC's **Study to Explore Early Development (SEED)** is the largest collaborative scientific study in the United States examining various risk factors for autism. SEED was started in 2006 and has multiple goals:

- **To understand the genetic and environmental risk factors for autism.** SEED explores risk factors during pregnancy and the early years of life, including genetics, maternal infections, maternal hormonal factors (such as infertility conditions and treatments), family history of autoimmune and other immunological conditions, and obstetric risk factors.
- **To characterize the autism behavioral phenotype and associated developmental, medical, and psychiatric conditions of autism.**
 - SEED's description of the full spectrum of autism can help better define autism and guide research into risk factors and interventions.
 - SEED comparison of health conditions and health-related issues (such as sleeping and eating patterns) can help improve care for children with ASD.

Between 2007 and 2016, SEED enrolled more than 6,000 children, aged 2 through 5 years, and their families in the first two phases of data collection (SEED 1 and SEED 2). The third phase of SEED, SEED 3, was funded in 2016, and enrollment and data collection are ongoing. Altogether, the six SEED 3 sites are expected to enroll over 2,100 children and their families.

CDC began publishing findings from SEED data in 2014 (See Appendix iii). These results provide valuable information about the spectrum of behaviors and characteristics of children with ASD and contribute to understanding risk factors, including fertility treatments and maternal chronic medical conditions such as diabetes and hypertension. As findings from SEED continue to be analyzed and published, SEED will continue to advance understanding of ASD etiologies and phenotypes. The expanded sample size from SEED 3 will allow SEED investigators to explore research questions in more depth, such as considering how risk factors and health conditions might vary by ASD subtypes or by different demographic groups, such as boys versus girls.

Exploring the Needs of Autism in Transition

With direction from the Autism CARES Act, SEED began exploring the transition from childhood to adulthood for people with ASD. Research on people with ASD becomes more challenging as they age from children to adults. In 2016, CDC funded a pilot extension of SEED, called SEED Teen, to explore if the unique infrastructure of SEED could reach adolescents with autism. The goals are to better understand the following:

1. Research methods for capturing the needs of adolescents and adults
2. How children with and without ASD develop as they become adults
3. The health care and social service needs of adolescents with and without ASD and other DD
4. The needs of families caring for adolescents with and without ASD and other DD.

SEED Teen will be piloted in four of the SEED 1 sites, pending Office of Management and Budget approval. Findings from the SEED Teen pilot will guide future research into this critical transition from childhood to adulthood. Results from SEED Teen will inform services and treatments for teenagers with autism and other DD and their families and add insight into similarities and differences between teens with autism and teens without autism and teen development overall.

Early Identification

CDC's "Learn the Signs. Act Early." program improves early identification through education and tools to identify developmental concerns so that children and their families receive the services and support they need as early as possible. Between May 2013 and December 2017, more than 16 million "Learn the Signs. Act Early." materials were distributed. The "Learn the Signs. Act Early." webpages have received more than 25 million page views and are utilized by health care professionals, parents, early childcare providers, partners, program champions, and other early childhood professionals.

The core activity of "Learn the Signs. Act Early." is providing information to help all families with children under the age of five years monitor their child's development. This is important because the signs of developmental delays can be subtle; the more parents are aware of and track their child's developmental milestones, the sooner they may be able to recognize a potential concern. The program provides free tools and resources for families and professionals, which have been evaluated through multiple methods. New materials shared in 2014-2018 include the following:

- *Milestone Tracker App* makes it easy for parents to track, support, and celebrate their young child's development, as well as take action when there is a developmental concern. This free app offers illustrated and interactive milestone checklists, tools to discuss development and concerns with a health care provider, and reminders for appointments and developmental screening.
- *Where is Bear? A Terrific Tale for Two-Year-Olds* is an award-winning book that engages children while parents learn about important child development milestones.

- *Milestones In Action* is a photo and video library that provides parents and caregivers with a visual format for understanding developmental milestones. The library includes photos and videos of children showing each developmental milestone and is an excellent resource to assist parents as they complete developmental milestone checklists.
- *Watch Me! Celebrating Milestones and Sharing Concerns* is a free online training course that provides early care and education providers with tools and best practices for working with families to monitor every young child's development and for helping children with developmental delays get the early support they need. The course is approved for continuing education credit.

In addition to a range of information resources, "Learn the Signs. Act Early." has worked to establish partnerships to integrate developmental monitoring into programs and systems that serve young children and their families, including public health programs and childcare programs. There continues to be 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)*, the Health Resources and Services Administration (HRSA) *Maternal, Infant, and Early Childhood Home Visiting* and *Healthy Start* programs, and the Administration for Children and Families (ACF) *Child Care Development Fund* and *Early Head Start/Head Start* programs.

CDC has also supported five cohorts of *Act Early Ambassadors* since 2011. Ambassadors are state or territorial leaders working to increase collaboration and coordination among early childhood programs and improve early identification. There were 45 ambassadors in the 2016-2018 cohort. By May 2018, the program brought additional ambassadors on board and has an ambassador in 49 states, the District of Columbia, and all but two territories. This program has proven to be very effective in putting developmental monitoring into practice. *Act Early Ambassadors* continue to succeed in integrating developmental monitoring resources into state or territory-wide early childhood systems, including child care, home visiting, maternal-child health programs, *Help Me Grow*, early intervention, and care coordination.

CDC continues to collaborate with the *Association of Maternal and Child Health Programs* to fund 12 small, two-year grants to states and territories to strengthen early identification systems and improve coordination of early intervention services for children with autism and other DD. CDC has actively collaborated with other federal agencies and non-federal organizations working to improve early identification and linkage to services for children with ASD and other DD. For example, CDC and HRSA continue to engage in Autism Coordination meetings. CDC worked closely with ACF and the Department of Education to lead *Birth to Five: Watch Me Thrive!*, a coordinated federal effort to encourage healthy child development, universal developmental and behavioral screening for children, and support for the families and providers who care for them. CDC and the American Academy of Pediatrics (AAP) are collaborating in several ways to improve early identification in pediatric health care settings including a messaging campaign, quality improvement projects, and participating in AAP's *National Early Childhood Screening Initiative*.

Interagency Coordination and Implementation of the *IACC Strategic Plan*

Understanding autism and its impact on families has been a focus of the National Centers on Birth Defects and Developmental Disabilities (NCBDDD) at CDC for the past 20 years, and it continues to be a major component of its activities. CDC participates as a member agency on the IACC and FIWA. CDC-funded projects and agency activities address the following areas of the IACC Strategic Plan: Question 1 (Screening and Diagnosis), Question 3 (Risk Factors), Question 5 (Services), and Question 7 (Infrastructure and Surveillance). Moreover, NCBDDD scientists served on three *IACC Strategic Plan* workgroups: Question 1 (Screening and Diagnosis), Question 3 (Risk Factors), and Question 7 (Infrastructure and Surveillance). NCBDDD science and communication investments such as the ADDM Network, SEED, and “Learn the Signs. Act Early.” address each of these strategic plan objectives; numerous other science and communication products are in progress that will facilitate implementation of these and other *IACC Strategic Plan* goals.

Listed below are a sample of materials developed from NCBDDD programs and their relation to the *IACC Strategic Plan*.

Question 1: How can I recognize the signs of autism, and why is early detection so important?

- “Learn the Signs. Act Early” milestone tracker application, “Watch Me! Training,” milestone booklets and checklists, and children’s books (e.g., *Where is Bear? A Terrific Tale for Two Year Olds*).
- Moody, E.J., Reyes, N., Ledbetter, C., et al. (2017). Screening for autism with the SRS and SCQ: Variations across demographic, developmental and behavioral factors in preschool children. *Journal of Autism and Developmental Disorders*, 47(11), 550-3561.

Question 3: What causes autism, and how can disabling aspects of autism be prevented or preempted?

- Singer, A.B., Windham, G.C., Croen, L.A., et al. (2016). Maternal exposure to occupational asthmagens during pregnancy and autism spectrum disorder in the Study to Explore Early Development. *Journal of Autism and Developmental Disorders*, 46(11), 3458-3468.
- Schieve, L.A., Drews-Botsch, C., Harris, S., et al. (2017). Maternal and paternal infertility disorders and treatments and autism spectrum disorder: Findings from the Study to Explore Early Development. *Journal of Autism and Developmental Disorders*, 47(12), 3994-4005.

Question 7: How do we continue to build, expand, and enhance the infrastructure system to meet the needs of the autism community?

- Christensen, D.L., Baio, J., Van Naarden Braun, K., et al. (2016). Prevalence and characteristics of autism spectrum disorder among children aged 8 years — Autism and Developmental Disabilities Monitoring Network, 11 sites, United States, 2012. *Morbidity and Mortality Weekly Report Surveillance Summaries*, 65(3), 1-23.
- Baio J, Wiggins L, Christensen DL, et al. (2018). Prevalence of autism spectrum disorder among children aged 8 years — Autism and Developmental Disabilities Monitoring Network, 11 sites, United States, 2014. *Morbidity and Mortality Weekly Report Surveillance Summaries*, 67(No. SS-6), 1–23.

CDC ASD-Related Expenditures, (FY 2014 - FY 2017)					
CDC Autism Expenditures	FY 2014	FY 2015	FY 2016	FY 2017	FY 2014-FY 2017 Total
Autism Surveillance and Research*	\$17,831,094	\$18,884,512	\$16,086,159	\$17,766,661	\$70,568,426
Awareness of Developmental Milestones and Early Identification (“Learn the Signs. Act Early.”)**	\$2,499,907	\$3,046,689	\$2,568,604	\$4,154,815*	\$12,270,015
Total	\$20,331,001	\$21,931,201	\$18,654,763	\$21,921,476	\$82,838,441

Table 6. CDC ASD-Related Expenditures, FY 2014 - FY 2017

* Autism Surveillance and Research is authorized under the Autism CARES Act. 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 Autism CARES Act.

** Awareness of Developmental Milestones and Early Identification (“Learn the Signs. Act Early.”) is authorized under the Autism CARES Act. These expenditures include costs associated with CDC’s autism budget lines, infant health budget line, and public health leadership 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 Autism CARES Act.

Centers for Medicare & Medicaid Services

The **Centers for Medicare & Medicaid Services (CMS)** is committed to strengthening and modernizing the nation’s healthcare system to enhance quality, accessibility, and improved outcomes in the most cost-effective manner possible. CMS administers several programs that are available to individuals with disabilities, including those with ASD. These programs do not receive appropriations from the Autism CARES Act.

The **Medicaid program** is a state-federal partnership which provides health coverage to millions of Americans, including eligible low-income adults, children, pregnant women, elderly adults, and people with disabilities. States establish and administer their own Medicaid programs and determine the type, amount, duration, and scope of services within federal laws, regulations, and other requirements. CMS also provides guidelines to states about various topics. Federal law requires states to provide certain mandatory benefits and allows states the choice of covering other optional benefits. The Medicaid program is funded jointly by states and the federal government.

Medicaid’s **Early and Periodic Screening, Diagnostic and Treatment (EPSDT)** benefit includes a comprehensive array of preventive, diagnostic, and treatment services for low-income infants, children, and adolescents under age 21. The EPSDT benefit requires screening services as well as physical, mental, vision, hearing, and dental services for such persons under age 21 that are needed to correct or ameliorate a physical or mental condition.

CMS issued an [informational bulletin](#) on July 7, 2014 that provided information on approaches available for providing services to eligible individuals with ASD under the Medicaid program. CMS has approved a number of state plan amendments that include ASD treatment services for children and/or that update their state plans with reimbursement methodologies for ASD treatment services.

[Medicare](#) is the federal health insurance program for people who are 65 or older, certain younger people with disabilities, and people with end-stage renal disease (permanent kidney failure requiring dialysis or a transplant).

The [Children's Health Insurance Program \(CHIP\)](#) provides health coverage to eligible children, through both Medicaid and separate CHIP programs. CHIP is administered by states, pursuant to federal requirements.

The [Medicaid Health Home State Plan Option](#), authorized under the Affordable Care Act (section 2703), allows states to design Health Homes to provide comprehensive care coordination for Medicaid beneficiaries with chronic conditions. States receive enhanced federal funding during the first 8 quarters of implementation to support the roll out of this integrated model of care; thereafter, they will receive their regular service match rate. The new SUPPORT for Patients and Communities Act includes an amendment that would extend the enhanced match for 2 additional quarters for health home services only, under a substance-use-disorder-focused health home state plan amendment.

Health Home services include:

1. Comprehensive Care Management
2. Care Coordination and Health Promotion
3. Comprehensive Transitional Care, including appropriate follow-up, from inpatient to other settings
4. Patient and Family Support (including authorized representatives)
5. Referral to Community and Social Support Services, if relevant
6. Use of health information technology to link services, as feasible and appropriate

CMS issued a [State Medicaid Director Letter #10-024](#) (Nov. 6, 2010) that indicates services must be person- and family-centered, include self-management support to individuals and their families, and provide access to individual and family support services. Individual and family supports could include providing caregiver counseling or training on: skills to help the individual improve function, obtaining information about the individual's disability or conditions, and navigating the service system. In addition, individual and family supports could include helping families identify resources to assist individuals and caregivers in acquiring, retaining, and improving self-help, socialization, and adaptive skills, and providing information and assistance in accessing services such as self-help services, peer support services, and respite services. These supports and services are available to those who meet the eligibility requirements, including individuals with ASD.

The **Home and Community Based Authorities** provide opportunities for adults and children to receive Home and Community Based Services (HCBS) as an alternate to institutional settings. These programs allow states to provide services to various targeted populations which include those with intellectual and/or developmental disabilities (including persons diagnosed with ASD), physical disabilities, and mental illness. States may provide HCBS to certain populations, and they manage their own waiting lists. The Center for Medicaid and CHIP Services has published information on HCBS, including **guidance**. CMS is available to provide technical assistance to states on the various HCBS options, including state plan amendments and HCBS waivers. Additionally, CMS has published **ASD-related guidance** on the implementation of the Community First Choice State Plan Option, another home and community-based services option available to states to promote community integration.

Interagency Coordination and Implementation of the *IACC Strategic Plan*

CMS participates as a member agency on the IACC and FIWA. While CMS is not directly involved in implementing the *IACC Strategic Plan*, services provided by the agency are available to individuals with ASD and their families.

Food and Drug Administration

The mission of the **Food and Drug Administration (FDA)** 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. 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.

On May 4, 2017, FDA held a public meeting to hear perspectives from individuals with autism, caregivers, and other patient representatives on the most significant health effects and currently available therapies for autism. FDA conducted the meeting as part of the Agency's Patient-Focused Drug Development initiative, an FDA commitment under the fifth authorization of the Prescription Drug User Fee Act (PDUFA V) to more systematically gather patients' perspectives on their condition and available therapies to treat their condition. A "**Voice of the Patient**" report summarizing the input provided by patients and patient representatives at this meeting was published on February 1, 2018.

Interagency Coordination and Implementation of the *IACC Strategic Plan*

FDA has a representative on the IACC who provides insight into drug development and regulation. While FDA is not directly involved in implementing the *IACC Strategic Plan*, agency activities impact individuals with ASD and their families.

Health Resources and Services Administration

The Health Resources and Services Administration (HRSA) is the primary federal agency for improving healthcare to people who are geographically isolated, economically or medically vulnerable. Under the Autism CARES Act of 2014, HRSA received funding to increase awareness of ASD and other DD; reduce barriers to screening and diagnosis; support research on evidence-based interventions; promote the development of guidelines for evidence-based practices; and train health care professionals to provide screening, diagnostic, and early, evidence-based intervention services for children with a confirmed diagnosis. To meet these objectives, HRSA funded grant programs in three areas: Training, Research, and State Systems Development. HRSA also funded two national resource centers to provide technical assistance to and promote collaboration among grantees.

Through their collective efforts, HRSA's programs are increasing access to early and appropriate developmental screening, diagnostic, and intervention services, and improving effectiveness of support services available to youth making the transition to adulthood. A description of significant progress follows.

Training Programs

HRSA supports 52 **Leadership Education in Neurodevelopmental and Other Related Disabilities (LEND) training programs** and 10 **Developmental-Behavioral Pediatric (DBP) training programs** to address the shortage of trained professionals who can provide screening, diagnostic services, and treatment for children and youth with ASD/DD. Programs are in 44 states, with partnerships that extend to the six remaining states and several U.S. territories. In 2016, HRSA expanded the LEND program from 43 to 52 grants.

Interdisciplinary clinics associated with the LEND and DBP training grants are making evidence-based interdisciplinary services available across the nation, particularly in underserved communities. The LEND programs provide interdisciplinary clinical training and leadership development to professionals from multiple disciplines who have a role in identifying, evaluating, or caring for children with ASD/DD. The DBP training programs prepare developmental-behavioral pediatric fellows with essential biopsychosocial knowledge and expertise, and for leadership roles as teachers, investigators, and clinicians. Each year, the LEND and DBP programs enroll long-term fellows to receive at least 300 hours of intensive didactic training and clinical experience working in hospitals, clinics, and community-based settings that provide diagnostic or intervention services for children and youth with ASD/DD. Collectively, the programs also provide 40–299 hours of training to others, including medical residents, to increase their understanding of ASD/DD and make them aware of emerging evidence regarding ASD evaluation and interventions.

In FY 2014 and FY 2015, the LEND and DBP programs collectively reached more than 1,300 long-term trainees, 3,500 medium-term trainees, and 15,000 short-term trainees (see Table 26). By preparing these professionals to implement recommended screening practices and use evidence-based diagnostic tools, the training programs are improving early identification of ASD/DD. The training programs also reach an extensive network of providers with continuing education, reaching 203,289 and 212,833 participants in FY 2014 and FY 2015, respectively.

Data collected from the LEND and DBP programs show the direct impact of these investments on families with a child who screens positive for ASD. The programs provided interdisciplinary diagnostic services for more than 108,000 infants and children in FY 2014 and more than 112,000 in FY 2015. By continuing to meet the growing demand for services, the programs are reducing wait times for diagnostic evaluation and entry into intervention services. The training programs are helping to address disparities in early identification of ASD by expanding their reach to underserved populations through innovative mechanisms, including telehealth and tele-consultation.

Research Programs

HRSA's research programs support national research networks, field-initiated research projects, secondary data analyses and single investigator innovation projects to advance the evidence base on effective interventions to improve the health and well-being of children and adolescents with ASD and other DD. These programs address the needs of underserved populations, such as low-income, racial/ethnic minorities, individuals who have limited access to services, and other underserved populations. The research programs promote the development of evidence-based guidelines for intervention, validate tools for screening and intervention, and disseminate information to health professionals and the public.

The **Autism Intervention Research Network on Physical Health (AIR-P)** provides national leadership in research designed to improve the physical health and wellbeing of children and adolescents with ASD/DD. From FY 2014-2018, AIR-P had 26 active studies, published two empirically based guidelines for the management of anxiety and treatment of irritability and problem behaviors (published in a **2016 *Pediatrics* Supplement**), and developed 11 toolkits for parents and providers on topics such as preparing for and completing an electroencephalogram (EEG), melatonin and sleep, and puberty and adolescence. AIR-P research studies 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. AIR-P is also investigating how a collaborative telehealth intervention using Extension for Community Healthcare Outcomes Autism technology may increase provider knowledge, improve clinical practice, and enhance the self-efficacy of providers in their care of children with ASD. See Tables 27-28 for a complete listing of AIR-P research studies and products.

Autism Intervention Research Network on Behavioral Health (AIR-B) seeks to advance evidence-based behavioral treatments for children with ASD, particularly those in underserved and minority communities. AIR-B has forged strong partnerships with school districts to conduct community participatory research with teachers, paraprofessionals, parents, and administrators with community providers to implement evidence-based interventions effectively and sustainably in real-world settings. AIR-B completed six studies and has two RCTs in progress. AIR-B developed three tools and one practical guideline: Schedules, Tools, and Activities for Transitions in the Daily Routine (STAT) Manual, AIR-B Social Dynamics of Intervention (SoDI), the AIR-B PARTNER Tool, and a guideline for facilitating more successful transitions within the daily routine for children with ASD.

One intervention, Remaking Recess, was effective in increasing social engagement between children (ages 5-11 years) with autism and their typical peers during the less structured times of the school day. Tables 29-30 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 ASD/DD. One study, for example, is assessing the ability of a family navigator to improve access to ASD diagnostic and treatment services and outcomes. Ten active DBPNet studies are listed in Table 31. DBPNet developed consensus research priorities for the field of developmental-behavioral pediatrics and completed a study that assessed research training methods and outcomes at accredited Developmental and Behavioral Pediatrics (DBP) fellowship training programs. DBPNet also provides the mentoring environment in which a new generation of developmental behavioral pediatric researchers are trained.

The **Maternal and Child Health (MCH) Research Network on Promoting Healthy Weight (HW-RN) among Children with ASD/DD** is an interdisciplinary, multi-site research forum for scientific collaboration and infrastructure building, providing national leadership in research that furthers scientific understanding of obesity risk factors and facilitates the development of interventions designed to improve the health and well-being of children with ASD and other DD. The HW-RN has implemented 17 research studies on topics including nutrition, physical activity, and weight management in this subpopulation. A total of 6 toolkits are under development or in the pilot phase and one clinical guideline is underway (see Tables 32-33). HW-RN provided the first nationally representative estimates of obesity in children and adults with ASD/DD, along with obesity-related risk factors for this population. The HW-RN also published a **groundbreaking study** that found that although there has been an age-related decline in obesity prevalence in the typically developing population, no such decline has occurred among children with ASD.

MCH Health Care Transitions Research Network (HCT-RN) for Youth and Young Adults with Autism Spectrum Disorders (ASD) was funded from 2014 through August 2017, as an interdisciplinary, multi-center research forum for scientific collaboration and infrastructure-building, with a focus on research designed to improve healthcare transitions and promote an optimal transition to adulthood among youth and young adults with ASD, including optimal physical, psychosocial, educational, and vocational outcomes. HCT-RN addressed the critical lack of research on life course influences at the person, family, community, health system, and policy levels prior to, during, and following the transition of youth and young adults with ASD from pediatric to adult health care settings. HCT-RN had 11 active research studies, finalized five tools, and published five clinical guidelines for transitioning youth, parents/caregivers, and providers to facilitate the transition from pediatric to adult health care. These research studies, tools, and toolkits are listed in Tables 34-35. In addition, the HCT-RN published three National Autism Indicators Reports, which continue to draw attention to the issue of transition to adulthood and are a resource for researchers, policymakers, and the public.

The Autism Intervention Research Program supports multi-year applied research and secondary data analysis research on evidence-based practices for interventions to improve the health and well-being of children and adolescents with ASD/DD. This program consists of the Autism Field Initiated and Innovative Research Studies (Autism FIRST) program and the Autism Secondary Data Analysis Research (Autism SDAR) program. The 17 currently-funded research projects are addressing several high-priority topics pertaining to ASD. Several studies focused on disparities in access to care, quality of care, and health care utilization. Some studies are testing parent- or teacher-mediated interventions, or increasing the capacity of families and schools to help improve developmental outcomes for children with ASD/DD. Other studies are assessing the effectiveness of medical or behavioral interventions and practices intended to improve outcomes for children with ASD and support their families. Tables 36-37 list both ongoing and completed studies.

The Autism Single Investigator Innovation Program was established in 2017 and supports two distinct projects: The Autism Longitudinal Data Project (ALDP) and the Autism Transitions Research Project (ATRP). ALDP supports the implementation and completion of research studies that examine longitudinal data on ASD and other DD, to study risk factors for these conditions, the effects of various interventions, and trajectories of child development over the life course. The ALDP will provide leadership and education in studies of ASD intervention using longitudinal methods which address the following: physical and behavioral aspects of development and assessment at different stages of life course development, underserved populations, including minority, urban or rural populations, early life origins and onset, maternal and perinatal origins, high-risk populations, development and course of condition, and primary prevention (See Table 38). The ATRP supports the implementation and completion of programmatic research studies that examine factors associated with healthy life transitions among adolescents and young adults with ASD who are transitioning to adulthood. ATRP's goals are to: 1) advance the evidence base available to researchers, providers, policy makers, educators, adolescents and young adults with ASD and their families, and the public regarding factors associated with healthy life (physical, social, mental health, and educational/occupational) outcomes among this population; 2) address the critical need that exists for ASD transitions research that targets the social environment and not just the individual; and 3) provide national leadership and education in research on healthy transitions to adulthood for this population. Findings from the programmatic series of three ATRP studies will advance the evidence base on factors associated with healthy life outcomes among adolescents and young adults with ASD in order to improve transition care and services for this population (See Table 39).

State Implementation, Planning, and Innovation in Care Integration

Between 2013 and 2014, MCHB awarded grants to 13 states with the goal of improving access to comprehensive, coordinated services, including health care, education, and social services, for children and youth with ASD/DD. Four states received grants to develop strategic plans for improving the state's system of care for children with ASD/DD, and nine states with existing plans received grants for implementation. MCHB awarded grants to four states in 2016 under a new program title, Innovation in Care Integration for Children and Youth with Autism Spectrum Disorders and Other Developmental Disabilities. The Innovation grants aim

to promote integration of services for children and youth with ASD/DD across health care, education, and social service systems and improve access to appropriate screening, referral, diagnosis, care coordination, and intervention services. Furthermore, to facilitate peer learning and the widespread implementation of effective practices, 2016 grantees formed a learning community through which participants could share their successes and challenges, engage in collaborative problem-solving, and test rapid-cycle improvement strategies.

Data provided by state grantees indicate measurable improvements in screening and referral practices. State grantee activities included forming quality improvement learning collaboratives with pediatric practices to increase screening rates and working with communities to strengthen infrastructure and increase the number of professionals using reliable, valid tools to identify children with ASD. Table 40 lists the state grantees.

Additional Investments

HRSA supports two additional investments through the Title V Maternal and Child Health Services Block Grant Program (Section 501(a) of Title V of the Social Security Act). This program intends “to improve the health of all mothers and children consistent with the applicable health status goals and national health objectives....” Administered through well-established federal/state partnerships, states have broad discretion in implementing programs that meet their specific priority needs. The grantees are public health programs that are responsible for assessing needs in their state for the entire MCH population and prioritize programs to meet those needs. States and jurisdictions use their Title V funds to design and implement a wide range of MCH and Children with Special Health Care Needs (CSHCN) activities, which may include children with ASD.

The National Survey of Children’s Health (NSCH), funded and directed by HRSA, provides national and state level estimates of key measures of child health and well-being of American children 0-17 years old. Information is collected annually on factors including access to and utilization of health care, receipt of care in a medical home, family interactions, parental health, school and after-school experiences, and neighborhood characteristics. The NSCH includes questions on the prevalence of ASD, as well as age at diagnosis, type of provider who gave the diagnosis, parent assessment of condition severity, and types of ASD treatment received. The NSCH is supported through the Special Projects of Regional and National Significance (SPRANS) of Title V Maternal and Child Health Services Block Grant Program (Section 501(a) of Title V of the Social Security Act).

Interagency Coordination and Implementation of *IACC Strategic Plan*

HRSA participates as a member agency on the IACC and FIWA. In addition, HRSA MCHB utilizes the *IACC Strategic Plan* to inform the development of its research funding opportunities, promoting the support of autism research investments that address the *IACC Strategic Plan* while also addressing the authorizing legislation and HRSA’s mission. Research and training programs together are addressing all seven of the *IACC Strategic Plan* Questions. One particular area of focus is research to advance the evidence base on the effectiveness of clinical and behavioral interventions to improve the physical and behavioral health of

children and adolescents with ASD (*IACC Strategic Plan* Question 4). HRSA research programs are also working to improve early identification of ASD and other DD, to reduce disparities in early detection and access to services, and to improve outcomes for underserved populations (*IACC Strategic Plan* Question 1). Research and Training programs are expanding and enhancing the research and services workforce, accelerating the pipeline from research to practice, and developing an interdisciplinary workforce with the clinical expertise and leadership skills to provide the best possible services and supports for children with ASD and other DD and their families (*IACC Strategic Plan* Question 7). These programs are also advancing the knowledge base and implementing approaches to ensure successful transition of youth with ASD into adulthood (*IACC Strategic Plan* Question 6). HRSA investments are supporting the optimal health and well-being of children and adolescents with ASD and other DD from the earliest stages of identification, effective treatment and comprehensive coordinated care, and support for transition and care into adulthood.

HRSA ASD-Related Expenditures, FY 2014 - FY 2017				
Program Title	FY 2014	FY 2015	FY 2016	FY 2017
Training Programs				
Leadership Education in Neurodevelopmental Disabilities (LEND) training programs (T73)	\$27,938,271	\$28,004,199	\$31,079,181	\$31,655,250
Developmental Behavioral Pediatrics (DBP) training programs (T77)	\$1,903,362	\$1,833,323	\$1,948,555	\$1,848,853
Interdisciplinary Resource Center (UA5)	\$659,182	\$666,201	\$627,141	\$621,000
Research Programs				
MCH Autism Intervention Research Networks (Physical Health, Behavioral Health and Developmental Behavioral Pediatrics) (UA3; UJ2 FY 2017)	\$4,893,750	\$5,774,704	\$5,824,895	\$6,524,914
MCH Autism Intervention Research Program (R40; Replaced by R41 FY 2017)	\$4,587,081	\$3,782,969	\$2,577,301	\$598,740
State Implementation Programs				
State Implementation Grants and State Planning Grants (H6M)	\$2,956,984	\$2,916,786	\$1,680,000	\$1,680,000
Technical Assistance Center (U01)	\$272,103	\$275,000	\$455,000	\$455,000
Total	\$43,210,733	\$43,253,182	\$44,192,073	\$43,383,757

Table 7. HRSA Autism CARES Act Funding, FY 2014 - FY 2017

Indian Health Service

The **Indian Health Service (IHS)** is responsible for providing federal health services to American Indians and Alaska Natives. The provision of health services to members of federally-recognized Tribes grew out of the special government-to-government relationship between the federal government and Indian Tribes. This relationship, established in 1787, is based on Article I, Section 8 of the Constitution, and has been given form and substance by numerous treaties, laws, Supreme Court decisions, and Executive Orders. The IHS is the principal federal healthcare provider and health advocate for Indian people, and its goal is to raise their health status to the highest possible level. The IHS provides a comprehensive health service delivery system for approximately 2.2 million American Indians and Alaska Natives who belong to 573 federally recognized tribes.

The IHS does not have any programs or funding specifically for individuals on the autism spectrum. However, as a federal health care organization, IHS does provide services to American Indian/Alaska Natives (AI/AN) patients with ASD. As part of the IHS mission to raise the physical, mental, social, and spiritual health of American Indians and Alaska Natives to the highest level, IHS is committed to providing education, training, consultation, and resources to clinicians treating patients with ASD through the IHS **Indian Children’s Program (ICP)**. The ICP has historically been a regionally-based program that provided consultative services to AI/AN youth diagnosed with neurodevelopmental disorders, including ASD. In 2016, the ICP transitioned to the IHS Telebehavioral Health Center of Excellence (THBCE) to become a national program. The TBHCE currently provides training and support to clinicians regarding behavioral health, family, and social issues facing AI/AN youth diagnosed neurodevelopmental disorders, including ASD. These services are available to all IHS, Tribal, and urban Indian providers and include no-cost continuing education credits. From FY 2014 through FY 2017, 76 webinars on ASD and autism-related topics were provided, with a total of 2,216 clinicians trained.

To complement these training opportunities and to further support providers, the ICP also provides twice monthly, provider-to-provider consultation clinics that address ASD, Fetal Alcohol Spectrum Disorders, and other neurodevelopmental issues experienced by AI/AN youth.

Interagency Coordination and Implementation of the IACC Strategic Plan

In addition to the activities described above, IHS participates as a member agency on the IACC and FIWA. While IHS is not directly involved in implementing the *IACC Strategic Plan*, services provided by the agency are available to individuals with autism and their families.

IHS ASD-Related Expenditures, (FY 2014 - FY 2017)				
	FY 2014	FY 2015	FY 2016	FY 2017
ASD-focused spending	\$10,500	\$16,500	\$52,500	\$36,000

Table 8. IHS Funding for ASD-related Activities, FY 2014 - FY 2017 *

*The amounts reflected do not account for direct health services for the treatment and management of autism.

National Institutes of Health

The **National Institutes of Health** (NIH) is the nation's medical research agency. NIH makes coordinated efforts to invest in a wide range of ASD research.

NIH Research Programs

- Autism Centers of Excellence (ACE):** NIH created the ACE Program in 2007 with a series of five-year awards to launch an intense and coordinated research program into the causes of ASD and to find new treatments. The second iteration of the ACE Program launched in FY 2012. In 2017, new ACE grants were awarded where ASD research efforts focused on studying infant social interactions to identify signs of ASD in early infancy, evaluating if early developmental screening lowers the average age of ASD diagnosis and leads to earlier interventions and improved outcomes, examining how ADHD may influence the diagnosis and treatment of ASD, investigating how ASD differs among girls and boys particularly during the transition from adolescence into adulthood, and developing interventions appropriate for different subtypes of children with ASD. The National Institute of Mental Health (NIMH), the Eunice Kennedy Shriver National Institute of Child Health and Human Development (NICHD), the National Institute on Deafness and Other Communication Disorders (NIDCD), the National Institute of Neurological Disorders and Stroke (NINDS), and the National Institute of Environmental Health Sciences (NIEHS) support the ACE Program.
- The Children's Environmental Health and Disease Prevention Research Centers:** The **Children's Environmental Health and Disease Prevention Research Centers** is a long-standing program jointly supported by NIEHS and the Environmental Protection Agency (EPA) to fund research on understanding how genetic and environmental factors interact to influence children's health and to engage with communities and healthcare providers to improve dissemination and translation of research findings. The **University of California (UC) Davis Center for Children's Environmental Health (CCEH)**, which focuses its research on environmental risks for autism, is one of the few NIEHS/EPA Children's Environmental Health and Disease Prevention Research Centers that has been continuously funded. For more than a decade, the UC Davis CCEH has supported interdisciplinary research to understand the risk of autism from environmental exposures and underlying biologic mechanisms that confer these risks as well as helped to prepare the next generation of autism researchers. Recent research has focused on understanding the influence of environmental exposures (including air pollution and pesticides) on metabolic, immune, and epigenetic risks for autism diagnosis. Several publications have resulted from CCEH supported research (Appendix v). Work under the UC Davis Center ends in May 2019 and future funding for Children's Environmental Health and Disease Prevention Research Centers remains uncertain.
- National Database for Autism Research (NDAR):** Data from over 115,000 consenting, de-identified research participants are available for secondary analysis by other qualified researchers. All data within NDAR are harmonized (e.g., the same names for each piece of data collected are used) and validated (e.g., values are consistent with other projects) to a community-established common data definition. At the NIH, most newly awarded human-subject grants related to ASD are or will be contributing raw data to NDAR (PMID: 26446859), and are expected to share analyzed data specific to published results using NDAR's

Study feature. Furthermore, the NDAR platform now supports the sharing of human subjects research data in most mental health and certain substance use initiatives.

- **NIH NeuroBioBank (NBB):** Supported by NIMH, NINDS, and NICHD, the NBB is a network of Brain and Tissue Banks which aim to systematically collect, store, and distribute post-mortem brain and other tissues for research to improve understanding, care, and treatment of individuals with developmental, neurological, and movement disorders. Each of the six sites collects approximately 100 brains/year. NIH coordinates sharing post-mortem brain tissue with the neuroscience community.
- **Consortium on Biomarker and Outcome Measures of Social Impairment for Use in Clinical Trials in ASD:** NIMH, NICHD, NINDS, the Foundation for the NIH, and the Simons Foundation Autism Research Initiative, funded a four-year, multisite project to test several EEG, eye tracking and lab-based measures to determine if they can be used to identify subtypes of ASD, or serve as early indicators of treatment response, and improve clinical research tools for studying ASD. The project will receive a total of \$28 million to test and refine clinical measures of social impairment in ASD in order to better evaluate potential behavioral and drug therapies. The researchers will conduct a multi-site study of preschool (4-5 years) and school-aged (6-11 years) children, both with and without ASD, over the course of several months. Research sites include Yale University, Duke University, the University of California at Los Angeles, the University of Washington, and Boston Children's Hospital.
- **Services Research for ASD across the Lifespan (ServASD):** Since 2014, NIMH has issued a series of Funding Opportunity Announcements (FOAs) based on the objectives underpinning the 2012 and 2013 editions of the *IACC Strategic Plan*. **The Services Research for Autism Spectrum Disorder across the Lifespan (ServASD) FOAs** were framed to address the seven Question areas from these two *Strategic Plans* and focused on stimulating new research to develop and test the effectiveness of service system interventions to improve functional and health outcomes for people with ASD at three key life stages: early childhood, transition from youth to adulthood, and adulthood. In 2014, NIMH funded a three-component initiative that resulted in funding 12 studies:
 - Research on Early Identification and Linkage to Services for ASD
 - Pilot Research on Services for Transition-Age Youth
 - Pilot Studies of Services Strategies for Adults with ASD

In an effort to further expand the science base for services research addressing transition-age youth and adults with ASD, two FOAs (Pilot Research on Services for Transition-Age Youth and Pilot Studies of Services Strategies for Adults with ASD) were re-issued, resulting in funding for 5 additional studies.
- **Biomarkers to Enable Therapeutics Development in Neurodevelopmental Disorders:** NINDS – in collaboration with NICHD, NIMH, the National Center for Advancing Translational Sciences (NCATS), and several non-profit organizations – sponsored a workshop on biomarker development for neurodevelopmental disorders strongly associated with ASD and intellectual disability (ID) in December 2017. Workshop discussions focused on physiological and functional biomarkers that can enable clinical trial readiness and success, with participants from basic, translational and clinical research; industry; the FDA; and funding organizations.

- **Clinical trials in ASD-related Disorders**

NINDS is supporting two new clinical trials on ASD-related conditions that will be informative to the broader ASD research and patient community.

- The NINDS PREVeNT trial ([NCT02849457](#)) is a study that builds on recent work showing EEG biomarkers can predict seizure activity prior to onset in infants with Tuberous Sclerosis Complex (TSC). This trial will test whether presymptomatic treatment with anti-seizure medication prevents development of epilepsy in infants with Tuberous Sclerosis Complex and if treatment improves cognitive and behavioral outcomes or reduces risk of developing ASD.
- NINDS, NICHD, and NIDCD will test whether an mGluR5 inhibitor, in combination with an intensive language intervention, can boost language learning in children with Fragile X Syndrome (FXS) as part of the NeuroNext clinical trial network. This study ([NCT02920892](#)) will also identify biomarkers that are correlated to developmental outcome measures, and assess whether the intervention alters developmental trajectory of children with FXS including whether they develop autism.

- **Developmental Synaptopathies Consortium:** NINDS, NICHD, and NIMH support the Developmental Synaptopathies Consortium, which includes teams of researchers conducting mechanistic studies of genetic conditions related to ASD and ID, to uncover shared molecular pathways and potential new therapeutic targets. Many genes have been implicated in a spectrum of rare disorders associated with autism, and they appear to converge on a few common pathways. Deeper understanding of the shared pathophysiology may elucidate mechanisms of other causes of ASD, and pave the way for shared treatment possibilities. This consortium has projects related to three well-established genetic syndromes that are associated with high penetrance for ASD: TSC1/2, PTEN, and SHANK3 mutations.

- **Advances from this consortium include:**

- **Utility of the Autism Observation Scale for Infants in Early Identification of Autism in Tuberous Sclerosis Complex:** In this study, investigators used the Autism Observation Scale for Infants (AOSI), a semi-structured assessment designed as a research tool to evaluate ASD-related areas of concern, to identify early predictors of autism risk in children with tuberous sclerosis complex. At 12 months of age, an AOSI total score cutoff of 13 could predict ASD with the Autism Diagnostic Observation Schedule-2 (ADOS-2) at 24 months (specificity of 0.89) AOSI total score was also associated with a diagnosis with Autism Diagnostic Interview-Revised (ADI-R) at 24 months. This study demonstrates the utility of the AOSI as a tool to identify TSC infants most at risk for developing autism and in need of early intervention. ([PMID: 28844798](#))
- **Development of an Objective Autism Risk Index Using Remote Eye Tracking:** In this study, investigators created an objective eye-tracking risk index for ASD by using remote eye tracking among children with or without ASD diagnosis. In initial and replication samples, the autism risk index had high diagnostic accuracy and was strongly associated with ADOS-2 severity scores. This eye-tracking based risk index may provide a useful objective measure of autism in children at risk and could inform clinical diagnosis and intervention effects ([PMID: 27015721](#)).

Other Relevant Research Advances

- **Molecular Mechanisms of UBE3A Genetic Contributions to Autism:** NINDS-funded investigators explored potential mechanisms by which elevation of UBE3A activity, a gene implicated in both autism and Angelman syndrome, increases risk for autism. The researchers discovered that an autism-linked mutation in an upstream regulation site, T485, leads to abnormal elevation of UBE3A and impaired synapse formation. Further, the researchers demonstrated that targeting upstream regulators of this pathway with pharmacological interventions could reduce UBE3A activity, suggesting potential therapeutic strategies (PMID: 26255772).
- **Autism Birth Cohort study:** NINDS supported the Autism Birth Cohort study, which is nested within the Norwegian Mother and Child Cohort Study, to search for factors associated with autism risk. Use of folic acid supplementation around conception was associated with a lower risk of autism (PMID: 23403681), and paternal obesity was found to be an independent risk factor for autism in a father's child (PMID: 24709932).
- **Identifying Chemicals that Cause Similar RNA Expression in Autism, Aging, and Brain Disorders:** NICHD-, NIEHS-, and NINDS-supported investigators found that mouse brain cells exposed to a pesticide and some fungicides showed patterns of RNA that are similar to RNA expressed in brain cells from humans with autism, advanced age, or neurodegenerative disorders. Cells exposed to these chemicals showed decreased effects after treatment with a compound that can help protect microtubules and other cellular functions (PMID: 27029645).
- **Genes in Somatosensory Neurons Underlie Tactile and Behavioral Deficits in ASD:** Investigators supported by NINDS and the National Institute on Dental and Craniofacial Research (NIDCR) found that deletion of the genes *Mecp2* or *Gabrb3* in peripheral somatosensory neurons in mice caused synaptic and mechanosensory dysfunction, tactile impairments, and deficits in social interaction and anxiety-like behaviors. Restoring *Mecp2* expression rescued the deficits. These data indicate a role for mechanosensory processing dysfunction in behavioral impairments in mouse models of ASD (PMID: 27293187).
- **Mutations of the SHANK3 gene are associated with ASD:** NINDS- and NIMH-supported researchers found that SHANK3 mutations were associated with impaired Ih (hyperpolarization-activated cation) channels in human neurons. The mechanism by which SHANK3 mutations cause synaptic dysfunction may contribute to ASD and related disorders (PMID: 26966193).
- **ASD in Adulthood:** NIMH funded a longitudinal study of brain and cognitive changes during mid-to-late adult life in individuals with ASD (R01MH103494). NIMH also funded a randomized control trial in adults with ASD examining the effects of a cognitive rehabilitation intervention that targets social and cognitive functioning and integrates computer-based training with a group-based curriculum (R01MH106450). Results from this study are expected sometime in 2021.

NIH Autism Funding Opportunity Announcements (FOAs)

- Research on Autism Spectrum Disorders (R01-Clinical Trial Optional) PA-18-401
- Research on Autism Spectrum Disorders (R03-Clinical Trial Optional) PA-18-399
- Research on Autism Spectrum Disorders (R21-Clinical Trial Optional) PA-18-400
- Environmental Contributors to Autism Spectrum Disorders [PAR-14-202 (R21) and PAR-14-203 (R01)]

Interagency Coordination and Implementation of the IACC Strategic Plan

NIH-funded research addresses all 7 Question areas of the *IACC Strategic Plan*. The NIH Institutes and Centers (ICs) engaged in funding research on ASD make ongoing efforts to address objectives of the *Strategic Plan* that align with the research priorities as defined by their respective ICs. These efforts are facilitated through regular monthly meetings of the NIH Autism Coordinating Committee (ACC), an internal committee that communicates information about research initiatives and results. The NIH ICs represented on the ACC include NICHD, NIDCD, NIEHS, NIMH, and NINDS. OARC and the NIMH National Database for Autism Research (NDAR) office also participate in NIH ACC meetings.

The NIH Director, as well as the directors of NICHD, NIDCD, NIEHS, NIMH, and NINDS, are all members of the IACC. NIH also participates as a member agency of the FIWA.

NIH ASD-Related Expenditures by Institute/Center (FY 2014 - FY 2018)

Participating Institutes/Centers	FY 2014 Actual	FY 2015 Actual	FY 2016 Actual	FY 2017 Actual	FY 2018 Estimate*
National Center for Advancing Translational Sciences (NCATS)	77	78	301	263	–
National Center for Complementary and Integrative Health (NCCIH)	–	–	5	327	–
National Cancer Institute (NCI)	209	270	321	321	–
National Eye Institute (NEI)	52	452	396	403	–
National Human Genome Research Institute (NHGRI)	809	1,654	1,952	1,044	–
National Heart, Lung, and Blood Institute (NHLBI)	–	418	418	418	–

Participating Institutes/Centers	FY 2014 Actual	FY 2015 Actual	FY 2016 Actual	FY 2017 Actual	FY 2018 Estimate*
National Institute of Biomedical Imaging and Bioengineering (NIBIB)	-	131	-	-	-
Eunice Kennedy Shriver National Institute of Child Health and Human Development (NICHD)	31,345	31,523	35,487	38,506	-
National Institute on Drug Abuse (NIDA)	-	-	-	226	-
National Institute on Deafness and Other Communication Disorders (NIDCD)	6,844	6,594	7,887	7,384	-
National Institute of Dental and Craniofacial Research (NIDCR)	719	633	618	622	-
National Institute of Environmental Health Sciences (NIEHS)	8,912	12,111	14,186	15,717	-
National Institute of General Medical Sciences (NIGMS)	2,789	3,006	2,178	3,659	-
National Institute of Mental Health (NIMH)	113,877	127,634	135,365	140,746	-
National Institute of Neurological Disorders and Stroke (NINDS)	20,819	21,276	25,133	23,974	-
Office of the Director (OD)	534	1,454	7,312	10,587	-
NIH Roadmap for Medical Research (Roadmap)	1,105	391	157	374	-
National Library of Medicine (NLM)	48	48	-	-	-
Total NIH	188,138	207,672	231,717	244,571	260,000

Table 9. National Institutes of Health Autism Funding, FY 2014 - FY 2018 (Thousands of Dollars)

Table shows all NIH expenditures on ASD, as reported through the NIH Research Portfolio Online Reporting Tool (NIH RePORT) for **Estimates of Funding for Various Research, Condition, and Disease Categories (RCDC)** (Total NIH FY 2018 data are an estimate based on the FY 2017 actual)

*FY 2018 data have not been finalized in RePORT RCDC and are estimated.

NIH Autism Centers of Excellence (ACE) Program Expenditures				
Institutes	FY 2014	FY 2015	FY 2016	FY 2017
National Institute on Deafness and Other Communication Disorders (NIDCD)	1,818	1,788	1,781	150
Eunice Kennedy Shriver National Institute of Child Health and Human Development (NICHD)	10,409	8,304	9,580	10,409
National Institute of Mental Health (NIMH)	9,907	9,625	7,103	14,247
National Institute of Neurological Disorders and Stroke (NINDS)	3,464	1,361	2,271	933
National Institute of Environmental Health Sciences (NIEHS)	200	200	200	250
Total NIH	25,798	21,278	20,935	25,990

Table 10. NIH funding (Thousands of Dollars) of the Autism Centers of Excellence (ACE) program, which includes centers (P50s) and cooperative agreements (U01).

Substance Abuse And Mental Health Services Administration

The **Substance Abuse and Mental Health Services Administration (SAMHSA)** leads public health efforts to advance the behavioral health of the nation. SAMHSA's mission is to reduce the impact of substance abuse and mental illness on America's communities.

Since 1993, SAMHSA has implemented the Congressionally-mandated Comprehensive Community Mental Health Services for Children with Serious Emotional Disturbances Program, also known as the Children's Mental Health Initiative (CMHI). CMHI serves children and young adults (birth through 21) who are at risk for or meet criteria for serious emotional disturbance. Approximately 3.7% of this population also has a comorbid pervasive developmental disorder (PDD), which may include ASD.

This initiative provides funds to public entities to create “systems of care,” which are defined as a spectrum of effective, community-based services and supports for children and youth with or at risk for mental health or other challenges and their families, that is organized into a coordinated network, builds meaningful partnerships with families and youth, and addresses their cultural and linguistic needs, in order to help them to function better at home, in school, in the community, and throughout life.

From FY 2011 to FY 2015, SAMHSA funded 127 CMHI grants to support expansion of systems of care. These included 50 one-year Expansion Planning grants, as well as 77 four-year systems of care Expansion and Sustainability grants to stimulate the widescale adoption of the system of care approach. These grants promote the expansion of system of care services and supports, including infrastructure development and collaboration and partnership between child-serving systems (e.g., child welfare, education, juvenile justice, primary care and substance abuse services and systems, and strategic financial planning), so that the system of care framework can be brought to scale and sustained after grant funding has ended. The most recent [Report to Congress](#) on this program details outcomes from a national evaluation of nine demonstration grants and presents information on Expansion and Sustainability grants.

Interagency Coordination and Implementation of the *IACC Strategic Plan*

SAMHSA participates on the FIWA. While SAMHSA is not directly involved in implementing the *IACC Strategic Plan*, services provided by the agency are available to individuals with autism and their families.

Department of Education

The mission of the [U.S. Department of Education](#) (ED) is to promote student achievement and preparation for global competitiveness by fostering educational excellence and ensuring equal access. ED supports programs to develop and implement evidence-based practices for services to youths and postsecondary students, as well as programs for individuals with disabilities who have graduated from high school or a postsecondary institution and are seeking vocational rehabilitation services. Although the Department of Education does not receive appropriations under the Autism CARES Act, ED does support ASD-related services, supports, and research through programs administered by ED's Institute of Education Sciences, the Office of Special Education and Rehabilitative Services, and the Office of Postsecondary Education. An overview of these programs is provided below.

Institute of Education Sciences

The [Institute of Education Sciences](#) is the independent research, evaluation, and data collection arm of the Department of Education. IES's mission is to provide scientific evidence on which to ground education practice and policy, and to share this information in formats that are useful and accessible to educators, parents, policymakers, researchers, and the public. Each of the four IES Centers supports work related to ASD. The programs and projects administered by the four IES Centers are described below.

National Center for Special Education Research

The National Center for Special Education Research (NCSER) funds research on ASD under several of its standing research topics. The [Autism Spectrum Disorders](#) topic supports research on *comprehensive* school-based interventions (i.e., interventions that directly target, in a coordinated fashion, multiple outcomes) intended to improve outcomes for students identified with ASD or at risk for ASD. Additional grant programs within NCSER support research on ASD targeted toward a single outcome (e.g., social outcomes under the [Social and Behavioral Outcomes to Support Learning](#) topic) or improving developmental outcomes such as communication skills for infants, toddlers, and preschoolers at risk for or identified with ASD under the [Early Intervention and Early Learning in Special Education](#) topic. NCSER's [Transition Outcomes for Secondary Students with Disabilities](#) topic includes projects that focus on the improvement of transition outcomes of secondary students with disabilities, many with ASD. In 2012, NCSER funded the [Center on Secondary Education for Students with Autism Spectrum Disorders \(CSESA\)](#) to develop and test a comprehensive, school-based intervention to improve the cognitive, communicative, academic, social, behavioral, functional, and transition outcomes of secondary students with ASD. CSESA also disseminates information regarding evidence-based practices and reviews of research.

NCSER's [Early Career Development and Mentoring in Special Education](#) program supports researchers in special education and early intervention in their first years at institutions of higher education as they develop their own line of independent research, including those focused on students with ASD. NCSER's [Postdoctoral Research Training in Special Education Program](#) supports the training of postdoctoral fellows within institutions of higher education in the conduct of special education and early intervention research, with some programs including autism as a focus of research.

National Center for Education Evaluation and Regional Assistance

Through the Special Education Studies and Evaluation program, the National Center for Education Evaluation and Regional Assistance (NCEE) supports large-scale studies focused on children or youth with disabilities, including those with ASD. The [National Longitudinal Transition Study 2012](#) (NLTS 2012) supports the collection of data on the characteristics, school experiences, and outcomes after high school for a nationally representative sample of over 10,000 transition-aged youth with disabilities (ages 13-21), including approximately 1,000 youth with ASD. In 2017, NCEE released reports using NLTS 2012 data that included comparisons of youth with individualized education programs (IEPs) to youth without IEPs, as well as outcomes for youth by disability category.

National Center for Education Statistics

The National Center for Education Statistics (NCES) conducts longitudinal surveys as part of its mission to collect and analyze data related to education in the United States. The [Early Childhood Longitudinal Study, Kindergarten Class of 2010-11 \(ECLS-K:2011\)](#), is a part of a series of longitudinal studies supported by NCES that provide information about children's cognitive, social, emotional, and physical development as well as their home environment, educational activities, school and classroom environment, classroom curriculum, and before- and after-school care. This study included a nationally representative sample of kindergartners selected from public and private schools in 2010-11 with approximately 2,570 students with disabilities and approximately 1,570 of those students followed through fourth grade. Approximately 240 of these students were reported by their parents as having an ASD diagnosis.

National Center for Education Research

The National Center for Education Research (NCER) supports the Department of Education's [Small Business Innovation Research \(SBIR\)](#) program, which funds the development and testing of education technology products to improve education outcomes. One priority area within the SBIR program focuses on improving outcomes for children with or at risk for disability. As part of this priority area, NCER has supported the development of products aimed at improving outcomes for students with ASD. NCER may also support projects focused on students with disabilities under their [Postsecondary and Adult Education](#) research topic and their [Researcher-Practitioner Partnerships in Education Research](#) program, though no studies focused on ASD have been funded to date under these programs.

Office of Special Education and Rehabilitative Services

OSERS supports programs to assist states and school districts in serving children and youth with disabilities, provides for the rehabilitation of youth and adults with disabilities, and supports discretionary grant programs to improve the lives of individuals with disabilities. Through its two main components, the Office of Special Education Programs (OSEP) and the Rehabilitation Services Administration (RSA), OSERS supports a comprehensive array of programs and projects that support individuals with disabilities, including individuals with ASD. OSEP administers IDEA and RSA administers the Rehabilitation Act of 1973, as amended by WIOA.

Office of Special Education Programs

The *Office of Special Education Programs (OSEP)* is responsible for overseeing the administration of IDEA to assist eligible children and youth with disabilities, including those with ASD. OSEP provides funding to states to make available early intervention services to infants and toddlers with disabilities under IDEA Part C. OSEP also provides funding to states, and through them to local educational agencies, to assist in making a free appropriate public education available to children with disabilities, ages three through 21, under IDEA Part B. Through these formula grants, children with ASD are served as part of all children with disabilities. “Autism” is one of the thirteen disabilities that is included in IDEA’s definition of “child with a disability” in 20 U.S.C. 1401(3). OSEP also provides funds through IDEA’s Part D discretionary grants to benefit children with disabilities, including some grants that have a focus on improving services for children with ASD. These grants are not specifically in place to implement the Autism CARES Act. OSEP currently funds 22 grants that prepare master’s level personnel (e.g., early interventionists, special educators, and related services providers) to serve children with disabilities, including children with ASD, or doctoral level personnel to conduct research and teach children with disabilities, including within the area of ASD.

OSEP also funds projects that generate products and services that are relevant to children with ASD even though they do not focus specifically on children with ASD. Some examples include:

- The *Center on Positive Behavioral Interventions and Supports (PBIS)*, which provides schools with 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 including behavior related to ASD;
- The *State Personnel Development Grants program*, which authorizes competitive grants to State Educational Agencies to provide in-service professional development to personnel serving children with disabilities, including children with ASD;
- The *IRIS Center*, which develops evidence-based professional development and college coursework instructional modules that have addressed aspects of ASD; and
- *Autism Focused Intervention Resources and Modules (AFIRM)*, which are professional development modules that address instructional and behavioral interventions for young children with ASD.

In addition, through **Parent Training and Information Centers** across the nation, OSEP funds training and information for families of children with disabilities, including children with ASD. These parent centers, comprised of Parent Training and Information Centers (PTIs) and Community Parent Resource Centers (CPRCs), provide a variety of services including one-to-one support and assistance, workshops, publications, and resource-rich 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 IDEA; and
- Connect with other local, state, and national resources that assist children with disabilities.

Rehabilitation Services Administration

The **Rehabilitation Services Administration (RSA)** is responsible for overseeing the administration of the Rehabilitation Act of 1973 (Rehabilitation Act), as amended by title IV of WIOA, to assist individuals with disabilities, including those individuals with the most significant disabilities, to achieve competitive integrated employment. RSA funds state vocational rehabilitation agencies under titles I, III, and VI of the Rehabilitation Act to assist them in providing training and services to individuals with disabilities, including individuals with ASD. RSA also assists states to provide supported employment services to individuals with the most significant disabilities, including the provision of ongoing support services, to enable them to succeed in competitive integrated employment. Under WIOA, there is a heightened emphasis on serving students and youth with disabilities. The Rehabilitation Act authorizes the provision of pre-employment transition services to students with disabilities, the provision of extended services to youth with the most significant disabilities seeking supported employment outcomes, and requirements under section 511 of the Rehabilitation Act for youth with disabilities under section 511 for youth seeking subminimum wage employment to ensure an informed choice regarding opportunities for competitive integrated employment. Additionally, under title I of the Rehabilitation Act, RSA funds discretionary grants for the American Indian Vocational Rehabilitation Services program to provide services to American Indians with disabilities who live on or near reservations. Individuals with ASD, including students and youth with ASD, are served through all of these programs.

RSA awards discretionary grants, including four career pathways grants to assist individuals with disabilities, a national Parent Training and Information center (PTI), and seven state/regional PTIs to support families of students and youth with disabilities, including those with ASD.

Office of Postsecondary Education

OPE works to strengthen the capacity of colleges and universities to promote reform, innovation and improvement in postsecondary education, promote and expand access to postsecondary education and increase college completion rates for students, and broaden global competencies that drive the economic success and competitiveness of the nation.

The **Model Comprehensive Transition and Postsecondary Programs for Students with Intellectual Disabilities (TPSID)**, in ED's Office of Postsecondary Education (OPE), provides grants to institutions of higher education (IHE) or consortia of IHE to enable them to create or expand high quality, inclusive model comprehensive transition and postsecondary programs for students with ID.

TPSID projects establish model comprehensive transition and postsecondary programs that:

1. serve students with ID;
2. provide individual supports and services for the academic and social inclusion of students with ID in academic courses, extracurricular activities, and other aspects of the institution of higher education's regular postsecondary program;
3. with respect to the students with ID participating in the model program, provides a focus on —
 - a. academic enrichment;
 - b. socialization;
 - c. independent living skills, including self-advocacy skills; and
 - d. integrated work experiences and career skills that lead to gainful employment;
4. integrate person-centered planning in the development of the course of study for each student with an ID participating in the model program;
5. participate with the coordinating center established under section 777(b) in the evaluation of the model program;
6. partner with one or more local educational agencies to support students with ID participating in the model program who are still eligible for special education and related services under IDEA, including the use of funds available under part B of such Act to support the participation of such students in the model program;
7. plan for the sustainability of the model program after the end of the grant period; and
8. create and offer a meaningful credential for students with ID upon the completion of the model program.

ED also supports the coordinating center under Sec 777(b) of the Higher Education Act of 1965, as amended - Part D - Programs to Provide Students with Disabilities with a Quality Higher Education. The coordinating center works with IHE that offer inclusive comprehensive transition and postsecondary programs for students with intellectual disabilities, including institutions funded under the TPSID Program. The coordinating center provides technical assistance to IHEs that offer comprehensive transition and postsecondary programs for students with intellectual disabilities, and it will work with these programs to evaluate program components and recommend standards for such programs.

Based on program-level data collected by the TPSID Coordinating Center, approximately 27 percent of the students served by the TPSID program had autism, most in conjunction with an ID. The percentage breaks down as follows:

- In Cohort 1 (2010-2015) there were 545 students identified as having autism, a number that represents approximately 25 percent of the full population of 2,170 TPSID students.
- In Cohort 2 (2015-2018) there were 275 of 1,016 TPSID students (approximately 27 percent) were identified as having autism.
- The overall percentage of students served who indicated that they had autism is 26 percent (for both cohorts).

Interagency Coordination and Implementation of the IACC Strategic Plan

The Department of Education participates as a member agency on the IACC and FIWA.

ED-funded projects and agency activities address the following areas of the *IACC Strategic Plan*: Question 1 (Screening and Diagnosis), Question 4 (Treatments and Interventions), Question 5 (Services), Question 6 (Lifespan Issues), and Question 7 (Infrastructure and Surveillance). Within the ED’s Institute of Education Sciences, the National Center for Special Education Research continues to encourage a broad range of research on ASD in its field-initiated research competition. This research includes the development and testing of innovative interventions (including programs, policies, and practices) intended to improve the developmental and education outcomes for students identified with or at risk for ASD from birth through Grade 12. It also includes support for evaluating new or widely-used interventions for efficacy and effectiveness. The grants funded are those rated highly for their research rigor and significance to the field by peer-reviewers, and as evidenced by the projects reported elsewhere in this document, are often relevant to the objectives of the *Strategic Plan* developed by the IACC.

ED ASD-Related Expenditures (FY 2014 - FY 2017)						
Office		FY 2014	FY 2015	FY 2016	FY 2017	TOTAL
IES*		\$18,720,177	\$35,406,514	\$27,329,600	\$20,204,788	\$101,661,079
OSERS	84.325D & 84.325K	\$10,500,000	\$10,000,000	\$8,000,000	\$7,250,000	\$35,750,000
	AFIRM	\$400,000	\$0	\$0	\$0	\$400,000
Total		\$29,620,177	\$45,406,514	\$35,329,600	\$27,454,788	\$137,811,079

Table 11. Department of Education Funding for ASD Activities.

* IES projects with a focus or partial focus on children/youth with autism are included.

Department of Defense

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. This report provides details on research and service and support activities in the Army (DoD-Army) and the Air Force (DoD-Air Force), as well as the health care activities of the Military Health System (MHS).

Army

Autism Research Program

The DoD **Autism Research Program** (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 \$7.5M for research on ASD in the military. Following in FY 2008 through FY 2017, the DoD ARP has continued through the Defense Health Program with additional appropriations. From FY 2007-2017 a total of \$74.4M has been designated for research into ASD through an addition to the DoD appropriation bill. This program is not authorized or funded through the Autism CARES Act.

The ARP is a partnership between the DoD, researchers, and consumers. 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. This sense of urgency has resulted in funding research aimed at having an immediate impact on those with ASD. Examples include:

- A study conducted by Drs. Nancy Minshew and Shaun Eack (University of Pittsburgh) to investigate the use of Cognitive Enhancement Therapy (CET) for adults with ASD. **Findings showed** that CET improves neurocognition, social cognition and employment in adults with ASD.
- Dr. Christopher Lopata (Canisius College) is investigating the use of an innovative outpatient psychosocial treatment, MAXout. The effects of this treatment on social and computation skills in children with ASD are currently being studied.
- A clinical trial conducted by Dr. James Adams (Arizona State University) is investigating the use of Microbiota Transfer Therapy in adults with ASD to reduce gastrointestinal problems often seen in those with ASD as well as several related symptoms of autism.

Over the past several years the ARP has focused efforts on funding interventions that support ASD youth during the transition to adulthood. Examples include:

- A study being conducted by Dr. Paul Wehman (Virginia Commonwealth University) is looking at the effects of a job internship program for transition aged military dependents with ASD. Individuals with ASD often experience unemployment and underemployment; this study has the potential to increase employment, social communication and overall quality of life for those military dependents with ASD.

- The use of virtual reality smart glasses for people with ASD to enhance their transition into a workplace environment is being investigated by Dr. Joseph Salisbury (Brain Power LLC). By combining off the shelf technology with software to visualize workplaces and interact with job coaches, this study has the potential to promote independence for those with ASD.
- The Carolina Autism Transition Study, which is conducted by Dr. Laura Carpenter (Medical University of South Carolina), is assessing service utilization patterns for individuals with ASD during the transition from adolescence to adulthood. This study will identify critical time periods where individuals with ASD are at risk of losing support services or encountering negative life events. Findings from this study will allow for large scale efforts to target specific ASD youth at certain time points to minimize these issues.

Another critical initiative of the ARP is to fund research to understand and alleviate co-occurring conditions that are often observed in those with ASD. Examples of projects funded in this area include:

- Dr. Zohreh Talebizadeh (Children’s Mercy Hospitals and Clinics) found that a particular gene, RFXP3, may contribute to the higher rate of obesity seen in those with ASD. Obesity and its complications are twice as common in children with ASD.
- Dr. Cade Nylund (Uniformed Services University of the Health Sciences) conducted a retrospective analysis of health system records to identify co-morbid conditions observed with ASD. **This study found** that there is almost a two times increase in the odds of a child with ASD developing obesity complications including Type 2 diabetes, hypertension and hyperlipidemia. Anxiety disorders are very common in individuals with ASD, but little is known about the early risk factors for anxiety in the disorder.
- Drs. Geraldine Dawson, Kimberly Carpenter and Brian Boyd (Duke University and University of North Carolina Chapel Hill) are conducting an in-depth study to investigate the inter-relationship between sensory over-responsivity, attention and anxiety symptoms to identify early risk factors for anxiety disorders in individuals with ASD.

Each year the advisory panel 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 panel will utilize the information contained in the *2016-2017 IACC Strategic Plan* when developing the ARP’s objectives for the coming year and beyond. The ARP will continue to complement the funding efforts of the various funding agencies within the IACC, while keeping the program’s sense of urgency at the forefront.

Interagency Coordination and Implementation of the IACC Strategic Plan

In addition to the activities described above, DoD-Army participates as a member agency on the IACC and FIWA. DoD-Army-funded projects and agency activities address the following areas of the IACC Strategic Plan: Question 1 (Screening and Diagnosis), Question 2 (Underlying Biology), Question 3 (Risk Factors), Question 4 (Treatments and Interventions), Question 5 (Services) and Question 6 (Lifespan Issues).

Air Force

The **Department of Defense-Air Force** (DoD-Air Force) first became involved with ASD research in 2008 when it was designated to manage a Congressionally-funded project sponsored by Senator Deborah Pryce of Ohio. The project, *Comprehensive Clinical Phenotyping and Genetic Mapping for the Discovery of Autism Susceptibility Genes* (2009-2012) 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, DoD-AF executed Research, Development, Technology, and Evaluation dollars to fund a follow-on effort titled, *“A Collaborative Translational Autism Research Program for the Military”* (2012-2015) which formally closed out in 2016. This collaborative research project with the NCH enabled the continued expansion of the CORA with the addition of 65 families (259 individuals) being enrolled in the existing CORA, including 26 families from Wright-Patterson Air Force Base (WPAFB). Ninety-six percent of these families had a chromosomal microarray analysis performed. Exome sequencing was performed on 210 individuals from both projects with the identification of 7 clinically relevant, likely pathogenic variants in probands related to their ASD diagnosis. Transcriptome analysis and subsequent analysis in CORA trios of 14 single nucleotide polymorphisms in relevant genes found a significant association between a variant in the serotonin receptor 2A gene that modulates its expression. Preliminary data also suggest an association between ASD and the immune-related genes C4A and DEFA3. Finally, using a mouse model for an X-linked gene involved in cholesterol synthesis, it was demonstrated that behavioral abnormalities consistent with a role for the pathway in neural development and, perhaps, ASD. Families enrolled in CORA were able to participate in cutting edge molecular and genetic research studies. Direct benefits to families from WPMC included improved clinical care through the interaction of the WPMC developmental pediatricians with an experienced clinical geneticist who has expertise in the genetics of autism. In addition, families received a newsletter twice a year that contained important information about autism, CORA, and ongoing research studies. Medically significant findings from the research were shared with families who indicated on the consent forms that they wish to receive this information.

The research was distributed through the following means:

Publications:

- Smith Herman GE, Hansen-Kiss, E, Wolfgang S, & Barrie, E. A Collaborative Translational Autism Research Program for the Military. 2016: Defense Technical Information Center, available at: <http://www.dtic.mil/dtic/tr/fulltext/u2/a631878.pdf>
- Whole transcriptome RNA-Seq allelic expression in human brain. BMC Genomics. 2013; 14:571.

- Smith RM, Banks W, Hansen E, Sadee W, Herman GE. Family-based clinical associations and functional characterization of the serotonin 2A receptor gene (HTR2A) in autism spectrum disorder. *Autism Res.* 2014; 7(4):459-467.
- Smith RM, Webb A, Papp AC, Newman LC, Handelmann SK, et al. Whole transcriptome RNA-Seq allelic expression in human brain. *BMC Genomics.* 2013; 14:571.

Abstracts and Posters:

- Banks W, Cunningham D, Hansen E, Ratliff-Schaub K, Butter E, et al. Exome sequencing of 43 sporadic cases with an autism spectrum disorder in a local cohort of families identifies severe de novo variants and implicates additional genes in ASD pathogenesis. Poster presented at the American Society of Human Genetics Annual Conference; 2014 Oct 18-22; San Diego.
- Wang H, Lintner K, Hansen E, Zhou B, Wu YL, et al. DEFA3/A1 and complement C4A are medium effect-size risk factors for human autism spectrum disorders (ASD). Poster presented at the American Society of Human Genetics Annual Conference; 2013 Oct 23-26; Boston.

Presentations:

- Smith R. Identifying common functional regulatory polymorphisms in autism spectrum disorders using RNA AmpliSeq. Presentation to the Society of Neuroscience Annual Conference; 2013 Nov 9-13; San Diego.

Interagency Coordination and Implementation of the IACC Strategic Plan

While DoD-AF is not a member of the IACC or the FIWA, Air Force-funded projects address Question 2 (Underlying Biology) of the *IACC Strategic Plan*.

Military Health System (MHS)/TRICARE

TRICARE offers comprehensive medical care to over 9.4 million beneficiaries (active duty service members, military retirees, and their eligible family members), including over 2 million children. This also includes over 29,000 individuals diagnosed with autism spectrum disorder. The MHS includes physician and other licensed independent provider services, pharmacy coverage, psychosocial treatment, psychological testing, occupational therapy, physical therapy, and speech and language pathology for the treatment of ASD to all eligible TRICARE beneficiaries under the TRICARE Basic Program, which is the medical benefit plan of the MHS. A separate but related TRICARE program, the **Extended Care Health Option (ECHO)**, offers supplemental services to Active Duty Family Members (ADFM) with a qualifying physical or psychologically disabling condition, including ASD. The Department has provided coverage for Applied Behavior Analysis (ABA) services to family members of active duty service members since 2001 under either the ECHO program or a demonstration project. Coverage for retiree family members was added on July 26, 2012.

On July 25, 2014, all prior ABA service programs were consolidated into one demonstration, the Comprehensive Autism Care Demonstration (ACD), which provided a consistent ABA benefit program to all TRICARE eligible

beneficiaries diagnosed with ASD. Approximately 14,500 TRICARE eligible beneficiaries are currently enrolled in the ACD, with over 25,000 ABA providers rendering ABA services. Participation in ABA service programs has significantly increased since FY 2009, when 2292 beneficiaries receiving ABA services. For FY 2017, the ACD costs totaled \$268 million dollars. The ACD was originally scheduled to end December 31, 2018, however, the ACD has been extended until December 31, 2023 to obtain more information on how to classify ABA services under the TRICARE benefit and best serve military beneficiaries with ASD. The ACD removed all quantitative and non-quantitative limits on ABA services, including dollar caps, hour caps, and age caps. Over the course of the demonstration, the Defense Health Agency (DHA) has hosted various round table and information sessions for interested stakeholders to include but not limited to: ABA providers, Active Duty military providers, advocates, families, and congressional staff. Additionally, current ACD initiatives include TRICARE quality management audits, outcome measures, parent surveys, and DoD Office of the Inspector General audits. The Department is currently working on a number of improvements to the ACD, including enhanced support to parents and caregivers, improved care coordination, and ensuring that services are directed to those beneficiaries who will benefit the most, with the focus always being on helping military beneficiaries diagnosed with ASD to reach their maximum potential.

Most services for military beneficiaries are provided through a contracted network of civilian providers, however several military treatment facilities have recently developed programs to support beneficiaries diagnosed with ASD and their families. These initiatives include

- The Fort Belvoir Community Hospital (FBCH) Autism Resource Center (ARC), which is designed to provide resources for beneficiaries newly diagnosed with ASD and their families.
- The Joint Based Lewis McCord Center for Autism Resources, Education and Services (JBLM CARES) program which provides patient-centered care services for beneficiaries diagnosed with ASD and their families during the transition period of locating purchased care services.
- The Play & Language for Autistic Youngsters (P.L.A.Y.) Project, first launched within the MHS at Wright Patterson Air Force Base (WPAFB), which provides training of a portable parent-focused early childhood intervention to beneficiaries diagnosed with ASD.

To acquire additional information on ABA services under TRICARE, the Defense Health Agency has been working with the Congressionally Directed Medical Research Program (CDMRP), which has awarded a \$7 million contract to a research group from the University of Rochester. The results of the CDMRP study will further DHA's understanding of the impact of ABA services delivered to ACD participants and aims to provide important data regarding the most beneficial amount of ABA services. Additionally, findings from this study may benefit the larger community of individuals diagnosed with ASD and their families in several ways, including but not limited to, offering more choices to families, potentially identifying response to treatment through predictive factors, and lowering cost while increasing access. The CDMRP study was awarded September 2018. This study will provide an annual report starting in 2020 and has a duration of five years.

Interagency Coordination and Implementation of the *IACC Strategic Plan*

TRICARE participates as a member agency on the FIWA.

Other Agencies and Departments

The Environmental Protection Agency, National Science Foundation, Social Security Administration, and the Departments of Housing and Urban Development, Justice, Labor, and Transportation are not mentioned in and do not have programs authorized under the Autism CARES Act, 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, ED and DoD.

Environmental Protection Agency

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 **Children’s Environmental Health and Disease Prevention Research Centers** (Children’s Centers), an extramural grant program jointly funded by EPA and the National Institute for Environmental Health Sciences (NIEHS), has a goal of understanding how environmental factors affect children’s health, and promoting translation of basic research findings into intervention and prevention methods to prevent adverse health outcomes. While the Children’s Centers are not specifically in place to implement the Autism CARES Act, ASD research has been supported by the following authorities:

- The **Safe Drinking Water Act**, Section 1442, 42 U.S.C. 300j-l
- The **Toxic Substances Control Act**, Section 10, 15 U.S.C. 2609
- The **Federal Insecticide, Fungicide, and Rodenticide Act**, Section 20, 7 U.S.C. 136r
- The **Clean Air Act**, Section 103, 42 U.S.C. 7403
- The **Clean Water Act**, Section 104, 33 U.S.C. 1254
- The **Solid Waste Disposal Act**, Section 8001, 42 U.S.C. 6981
- The **National Environmental Policy Act**, Section 102(2)(F)

The 2013 EPA Children’s Centers award to **UC Davis** was funded under EPA’s Science to Achieve Results (STAR) grant program and focuses on environmental risk factors for ASD and developmental delays. Specifically, the UC Davis center studies the epigenetic mechanisms of toxicant exposure on immune function; develops and applies new biomarkers of autism risk; characterizes the potential health effects of environmental exposures and various life stages; and predicts long-term clinical and behavioral consequences. The environmental chemicals that this center examines with regard to ASD include polybrominated diphenyl ethers (PBDEs), perfluorooctanoic acid (PFOA), perfluorooctanesulfonic acid (PFOS), and pesticides. EPA funding for this project totaled \$1,867,642 from FY 2014-2018 and was awarded by EPA in incremental payments.

Several notable research findings have resulted from this project. Children’s Centers researchers have identified potential links between air pollution, pesticides, occupational exposures, phthalates, and risks of ASD. Some examples are listed in Appendix v. Work under the UC Davis Center ends in May 2019 and future funding for Children’s Environmental Health and Disease Prevention Research Centers remains uncertain.

Interagency Coordination and Implementation of the *IACC Strategic Plan*

EPA participates as a member agency on the IACC and FIWA. EPA-funded research addresses Question 3 (Risk Factors) of the *IACC Strategic Plan*.

Department of Housing and Urban Development

The U.S. Department of Housing and Urban Development (HUD) works to strengthen the housing market in order to bolster the economy and protect consumers; meet the need for quality affordable rental homes; utilize housing as a platform for improving quality of life; and build inclusive and sustainable communities free from discrimination. HUD administratively enforces several civil rights laws prohibiting housing discrimination, including the Fair Housing Act, Section 504 of the Rehabilitation Act, and the Americans with Disabilities Act (ADA). With few exceptions, the Fair Housing Act covers housing throughout the country.

Section 504

Section 504 provisions apply to recipients of HUD financial assistance, including the Community Development Block Grant, Public Housing, Multifamily, Housing Choice Voucher, and other programs. HUD’s Section 504 regulations (at 24 CFR § 8.4c) permit exclusion of non-disabled persons from the benefits of a program if the program is limited by federal statute or executive order to individuals with disabilities, and also permits exclusion of a specific class of individuals with disabilities from a program if the program is limited by federal statute or executive order to a different class of individuals. However, HUD does not have disability-specific programs, such as housing specifically for persons with ASD.

Section 811 Supportive Housing for Persons with Disabilities

Section 811 program, HUD provides funding to develop and subsidize rental housing with the availability of supportive services for very low- and extremely low-income adults with disabilities.

Interagency Coordination and Implementation of the *IACC Strategic Plan*

While HUD is not directly involved in implementing the *IACC Strategic Plan*, services provided by the agency are available to individuals with disabilities, including those with ASD and their families.

Department of Justice

The U.S. Department of Justice (DOJ) ensures fair and impartial administration of justice for all Americans.

Civil Rights Division

Within DOJ, the **Civil Rights Division** works to uphold the civil and constitutional rights of people with disabilities, including people with ASD and other DD. The Division coordinates the activities of the various federal agencies that have obligations under Section 504 and Title II of the ADA.

The **Educational Opportunities Section** enforces anti-discrimination statutes in elementary and secondary schools and institutions of higher education, including the ADA, Section 504 of the Rehabilitation Act, the Equal Educational Opportunities Act, Title VI of the Civil Rights Act, and upholds rights under the 14th Amendment to the U.S. Constitution in educational settings.

- In August 2016, DOJ filed suit against the State of Georgia for allegedly discriminating against students with disabilities in its operation of the Georgia Network for Educational and Therapeutic Supports (GNETS), a statewide network of segregated special education programs operated by the State. Approximately 4,000 students are enrolled in segregated GNETS facilities across the State, including students with autism. GNETS facilities are often far from students' homes and lack appropriate resources.
- Since 2014, DOJ has reached numerous agreements with school districts to ensure that English learner (EL) students who have disabilities, including students with autism, receive the educational services to which they are entitled. Most recently, in August 2018, DOJ reached an agreement with Providence, Rhode Island public schools under the Equal Educational Opportunities Act. Under the agreement, the school district will provide appropriate services to EL students with disabilities and will effectively communicate with limited-English proficient parents about their children's educational programs.

The **Disability Rights Section** administers and enforces the ADA to achieve equal opportunity for people with disabilities in the United States. The Section also coordinates the activities of federal agencies under Section 504 of the Rehabilitation Act and Title II of the ADA. Key concepts that are common to DOJ's section 504 and ADA regulations include: reasonable accommodations/modifications; program accessibility; and effective communication.

- **ADA Requirements: Testing Accommodations** was released in 2015 to ensure that people with disabilities who are taking standardized examinations for the purpose of gaining entry to high school, college, or graduate programs, or for those attempting to obtain professional licensure or certification for a trade, have the opportunity to fairly compete for and pursue such opportunities. The guidance addresses a testing entity's obligation to offer exams in a manner that is accessible to people with disabilities and does not measure a person's disability, but instead measures the individual's aptitude or achievement level.

- *ADA Requirements: Effective Communication* was released in 2014 to ensure that state and local governments, as well as businesses and nonprofit organizations that serve the public, communicate with people with vision, hearing, or speech disabilities in a manner that is equally as effective as their communication with people without disabilities.
- In collaboration with ED's Office for Civil Rights and Office of Special Education and Rehabilitative Services, DOJ released *Frequently Asked Questions on Effective Communication for Students with Hearing, Vision, or Speech Disabilities in Public Elementary and Secondary Schools* in 2014 to address the obligation of public schools to meet the communication needs of students with disabilities.

The **Special Litigation Section** enforces Title II of the ADA, the Civil Rights of Institutionalized Persons Act, and Section 14141 of the Violent Crime Control and Law Enforcement Act of 1994. The Section's work has addressed conditions at healthcare facilities for individuals with disabilities, the rights of individuals with disabilities to live in their communities and not be unnecessarily segregated in institutional facilities, and the appropriate diversion of individuals with disabilities from the criminal justice system.

Office of Justice Programs

The DOJ **Office of Justice Programs** (OJP) provides leadership to federal, state, local, and tribal justice systems through national dissemination of state-of-the-art knowledge and practices, and the provision of grants, training, and technical assistance for the implementation of crime and violence reduction strategies. Within OJP, the **Bureau of Justice Assistance** (BJA) provides leadership and assistance to local criminal justice agencies that improve and reinforce the nation's criminal justice system. BJA works to reduce and prevent violent and drug-related crime, support law enforcement, and combat victimization.

In 2013 BJA funded The Arc of the United States, Inc.'s project for the National Center on Criminal Justice and Disability (NCCJD), to build a national resource center to address challenges the justice system faces when it encounters people with disabilities in the areas of law enforcement, courts, and corrections. The Center's "**Pathways to Justice**" initiative works to increase capacity of criminal justice professionals to respond to individuals with disabilities by providing training, technical assistance, and education. The Center brings together professionals from the disability and criminal justice fields to share expertise and provides training using a team approach, with the goal of becoming the go-to resource in their community or state on issues related to criminal justice and disability. The program had a budget of \$800,000 in FY 2013-2017 and is currently providing technical assistance through the "Serving Safely" initiative, under a cooperative agreement between Vera Institute of Justice and the Bureau of Justice Assistance. Products and resources developed through the Serving Safely program are made publicly available to law enforcement and their behavioral health partners. The Pathways to Justice initiative was established pursuant to the Edward Byrne Memorial Justice Assistance Grant Program (42 USC 3751(a) et seq.), and funding for the Serving Safely initiative is provided through the Consolidated Appropriations Act, 2017 (P.L. 115-31) 131 Stat 135, 203.

Interagency Coordination and Implementation of the *IACC Strategic Plan*

DOJ participates as a member agency of the FIWA.

Question 5 of the *2016-2017 IACC Strategic Plan* emphasizes the implementation of evidence-based interventions in community settings. The Office of Justice Programs, Bureau of Justice Assistance provided grant support to The Arc to fund the NCCJD, which serves as a resource focusing on people with ID and DD who interact with the criminal justice system as suspects, offenders, victims, or witnesses. The NCCJD's "Pathways to Justice" initiative works to increase the capacity of criminal justice professionals to respond to individuals with disabilities by providing training, technical assistance, and education.

Question 6 of the *Strategic Plan* emphasizes activities that facilitate and incorporate acceptance, accommodation, inclusion, independence, and integration of people on the autism spectrum into society. DOJ works continually to ensure the accommodation, inclusion, independence, and integration of people with ASD by upholding the civil and constitutional rights of people with disabilities, including people with ASD and other DD.

Department of Labor

The **U.S. Department of Labor (DOL)** works to improve full access to gainful employment opportunities for all Americans, including Americans with disabilities. DOL also supports career pathways for youth and adults through its support for workforce development and job training programs. The ASD-relevant initiatives described below have received funding since FY 2014, but they are not specifically in place to implement the Autism CARES Act of 2014.

American Apprenticeship Grants

The **Employment and Training Administration (ETA)** within DOL has funded 2 **American Apprenticeship Initiative Grants**, which are authorized by the American Competitiveness and Workforce Improvement Act of 1998 (ACWIA), as amended [Section 414(c)].

The AHIMA Foundation received an award in 2015 for its **Managing the Talent Pipeline in Health Information Apprenticeship** program. This five-year grant (2015-2020) supports the development of a competency-based, on-the-job training program in health informatics for approximately 1,200 recent college graduates and working learners. This training program supports on-ramps for participants to health care data management careers. It also incorporates a medical coding apprenticeship with a track specifically for adults on the autism spectrum. The total amount of this award is \$4,919,839.

ETA also awarded an American Apprenticeship grant to Managed Career Services, Inc. in 2015 for its [OpenTech LA Regional Apprenticeship Collaborative](#). This five-year grant (2015-2020) supports the development of a collaborative that connects youth and young adults to apprenticeship and pre-apprenticeship programs in the Los Angeles, California metropolitan area. This collaborative proposes to support 300 apprentices and 200 pre-apprentices in fields including health information technology, biotechnology, computer programming, and computer systems. One of OpenTech LA's 18 partner organizations is the Exceptional Minds Studio, a computer animation studio with a three-year vocational training program for young adults on the autism spectrum. Participating young adults receive customized instruction in digital animation and visual effects, earn two to three certifications for Adobe software programs, and complete work readiness courses. Students at the Exceptional Minds studio have recently worked on television and movies that include *Game of Thrones*, *The Hunger Games*, and *Dr. Strange*. The total amount of this award is \$2,974,070.

H-1B Tech Hire Partnership Grant

ETA awarded a [H1-B Tech Hire Partnership Initiative Grant](#) to the Exceptional Family Center in 2016 for its [Next Step Job Training and Employment Partnership](#). This five-year grant (2016-2021) supports the development of a market-driven, job training and employment partnership to train and employ individuals on the autism spectrum in three California counties (Kern, Inyo, and Mono). Targeted job seekers are young adults aged 18-27 who are out of secondary school and diagnosed on the autism spectrum. The Next Step partnership proposes to support job development in health care and information technology for approximately 450 people on the autism spectrum over a four-year period. It includes boot camps for training on soft skills to improve employability and job performance; these camps incorporate trainings on effective communication, workplace behavior, and independent living skills. The partnership also supports employer education to reduce workplace barriers. The total amount of this award is \$3,997,504 and is authorized by the ACWIA, as amended [Section 414(c)].

Pathways to Careers: Community Colleges for Youth and Young Adults with Disabilities Demonstration Grants

The Office of Disability Employment Policy (ODEP) awarded Pathways to Careers Demonstration grants to Pellissippi State Community College (PSCC) in Knoxville, TN and Onondaga Community College (OCC) in Syracuse, NY in 2014. These grants to PSCC and OCC support researching, developing, testing, and evaluating innovative approaches to providing comprehensive, coordinated, and integrated inclusive education and career development to youth and young adults with disabilities aged 14-24. The grants also increase institutional capacity within the community college system by building an evidence base of policies and practices that are most effective in helping youth and young adults with disabilities to thrive. As of fall 2018, approximately 43 percent of students who participate in PSCC's [Universal Pathways to Employment Project](#) identify as persons on the autism spectrum. Approximately 22 percent of students who participate in OCC's [Pathways to Careers project](#) identify as persons on the autism spectrum.

Interagency Coordination and Implementation of the *IACC Strategic Plan*

DOL participates as a member agency on the FIWA. While DOL is not directly involved in implementation of the *IACC Strategic Plan*, DOL-funded projects and agency activities broadly impact individuals with disabilities and their families, including those with ASD.

DOL ASD-Related Expenditures (FY 2014 - FY 2018)					
Initiative Funded	FY 2014	FY 2015	FY 2016	FY 2017	FY 2018
American Apprenticeship Grant to AHIMA Foundation			\$4,919,839*		
American Apprenticeship Grant to Managed Career Services, Inc.			\$2,974,070*		
H-1B Tech Hire Partnership Grant awarded to Exceptional Family Center			\$3,997,504*		
Pathways to Careers Demonstration Grant awarded to Onondaga Community College	\$978,453	\$1,024,323	\$812,616	\$978,573	\$978,453
Pathways to Careers Demonstration Grant awarded to Pellissippi Community College	\$1,028,869	\$1,028,716	\$989,441	\$991,625	\$1,028,000
Pathways to Careers Demonstration Grants: Combined Funding for both grants by FY	\$2,007,322	\$2,053,039	\$1,802,057	\$1,970,198	\$2,006,453

Table 12. DOL funding for ASD-related activities.

*ETA awards its full grant amount in total; the total budgeted amounts per fiscal year for each of their grants are not publicly sharable.

National Science Foundation

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. While NSF does not have an ASD research program, the agency has awarded numerous research grants through the years that include research on ASD and other DD. These research awards, including current active awards, fall under a portfolio that emphasizes neuroscience, cognitive sciences, and education and learning research. The NSF’s [award search website](#) offers the public the opportunity to learn about specific NSF awards.

Interagency Coordination and Implementation of the IACC Strategic Plan

NSF does not participate as a member agency on the IACC or FIWA, but it has continued efforts to regularly monitor the agency’s funding of basic science and science education research about, and including, persons with ASD. NSF conducts searches of the IACC Autism Research Database searches to avoid funding duplication. NSF participates in the Interagency Committee on Disability Research as a statutory member, to monitor and contribute to interagency actions relevant to basic science and science education research about, and including, persons with disabilities. NSF also monitors the implementation and progress made on implementation related to the *IACC Strategic Plan* by virtually observing the quarterly IACC meetings, reviewing the relevant IACC reports, and examining the annual and final reports of NSF-funded projects about, and including, persons with ASD. NSF-funded research projects address all seven Question areas of the *IACC Strategic Plan*.

NSF ASD-Related Expenditures (FY 2014 - FY 2017)				
	FY 2014	FY 2015	FY 2016	FY 2017
Number of Projects (Awards)	15	9	16	7
Total Obligations	\$2,881,721	\$1,291,726	\$4,777,599	\$1,921,163

Table 13. NSF basic science and science education funding related to, or including, persons with ASD.

Social Security Administration

The mission of the **Social Security Administration** is to deliver quality Social Security services to the public. SSA administers two disability programs authorized under the Social Security Act – the Social Security Disability Insurance program (SSDI; title II) and the Supplemental Security Income (SSI) program (title XVI). Under these programs, the SSA evaluates claims involving allegations of ASD for both adults and children. These programs are not specifically in place to implement the Autism CARES Act.

Currently, over 300,000 individuals with a primary impairment of Autistic Disorders **receive SSI payments**, including almost 175,000 children and over 125,000 adults. Relatively few **SSDI beneficiaries** have an Autistic Disorder (<65,000).

SSA follows a five-step sequential evaluation process for evaluating adult disability claims:

1. Consider whether the adult is engaging in substantial gainful activity.
2. Consider whether he or she has a severe medically determinable impairment. At this step, SSA considers allegations of ASD in conjunction with the medical and other evidence to establish the medically determinable impairment and its severity.

3. Consider whether the severe medically determinable impairment(s) meets or medically equals one of the listings. At this step, ASD is considered under mental disorders listing 12.10 in 20 CFR Part 404, Subpart P, Appendix 1. If the adult does not have an impairment that meets or medically equals a listing, SSA determines the residual functional capacity (RFC) resulting from the ASD and any co-existing medically determinable impairments.
4. Determine whether the person's RFC would permit him or her to perform any past relevant work he or she may have.
5. Determine whether the person's RFC would permit him or her to perform any other work that exists in the national economy.

SSA follows a three-step sequential evaluation process for evaluating child disability claims: First, we

1. Consider whether the child is engaging in substantial gainful activity.
2. Determine whether the child has a severe medically determinable impairment that meets or medically equals a listing. At this step, ASD is considered under mental disorders listing 112.10 in 20 CFR Part 404, Subpart P, Appendix 1.
3. Determine whether the child's ASD and co-existing medically determinable impairments functionally equal the listings, using the whole child approach.

In FY 2017, SSA processed 20,592 initial adult claims for ASD. Of those claims, 63.4 percent were found to meet our requirements and were allowed benefits. SSA processed 35,296 initial child claims for ASD and 81.4 percent were allowed benefits. Overall, 74.8 percent of adult and child claims for ASD were allowed compared with an overall allowance rate for initial claims of 34.7 percent.

For calendar year 2017, the sum of the monthly payment amounts at the time of the award for the 25,786 SSI children recipients with a primary diagnosis of autistic disorders was \$15,993,742, while the sum for 12,367 SSI adult recipients with a primary diagnosis of autistic disorders was \$7,641,597.

The sum of the monthly benefit amounts at the time of the award for the 9,840 Title II beneficiaries (SSDI) with a primary diagnosis of autistic disorders was \$6,265,226.

SSA recently began working with researchers at the A.J. Drexel Autism Institute to produce research describing participation in the SSI program by adults with ASD. The first publications from this work, describing general trends of adult SSI participation by this population, are expected to be available in 2019.

Interagency Coordination and Implementation of the *IACC Strategic Plan*

SSA participates as a member agency on the IACC and FIWA. While SSA is not directly involved in implementing the *IACC Strategic Plan*, services provided by the agency are available to individuals with disabilities, including those with ASD and their families.

Department of Transportation

The U.S. Department of Transportation (DOT) works to ensure transportation that is fast, safe, efficient, accessible and convenient to improve the quality of life of people in the United States.

The DOT's **Accessible Transportation Technologies Research Initiative** (ATTRI) is a joint multi-modal, multi-agency initiative, co-led by the Federal Highway Administration, Federal Transit Administration, and Intelligent Transportation Systems Joint Program Office, with support from the National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR) within HHS/ACL, and other federal partners. The ATTRI Program is leading efforts to develop and implement transformative applications to improve mobility options for all travelers, particularly those with disabilities. ATTRI research focuses on removing barriers to transportation for people with visual, hearing, cognitive, and mobility disabilities. Emerging technologies and creative service models funded by ATTRI will offer all Americans enhanced travel choices and accessibility at levels once only imagined. DOT has awarded application development funding for **Wayfinding and Navigation, Pre-trip Concierge & Virtualization, Safe Intersection Crossing** with NIDILRR awarding a grant in the **Robotics and Automation** technology area.

Working together, the four technology areas will provide the basis for an accessible transportation network that is far more economical, expansive, and welcoming than we have now, which is of increasing importance not only to travelers with disabilities, but to all travelers in the United States. A number of ATTRI technology sites are exploring different solutions and applications are envisioned to assist travelers with cognitive disabilities including those with ASD.

The ATTRI program is not specifically in place to implement the Autism CARES Act and is executed using the Fixing America's Surface Transportation Act (FASTACT) and other DOT authorizing legislation or other authority that supports the conduct of the DOT program(s).

Interagency Coordination and Implementation of the *IACC Strategic Plan*

DOT participates as a member agency on the FIWA. While DOT is not directly involved in implementing the *IACC Strategic Plan*, DOT-funded research and activities broadly impact individuals with disabilities, including those with ASD and their families.

Prevalence of Autism Spectrum Disorder

This section addresses Subsection (C) of 399DD: “Information on the incidence and prevalence of autism spectrum disorder, including available information on the prevalence of autism spectrum disorder among children and adults, and identification of any changes over time with respect to the incidence and prevalence of autism spectrum disorder.” Information on the prevalence of ASD is provided by the CDC, ED, and HRSA.

Centers for Disease Control and Prevention

The CDC surveillance efforts reported in this section 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 ASD in the population. 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.

Identified Prevalence of Autism Spectrum Disorder				
ADDM Network 2000-2014, Combining Data from All Sites				
Surveillance Year	Birth Year	Number of ADDM Sites Reporting	Prevalence per 1,000 Children (Range)	This is about 1 in X children
2000	1992	6	6.7 (4.5-9.9)	1 in 150
2002	1994	14	6.6 (3.3-10.6)	1 in 150
2004	1996	8	8.0 (4.6-9.8)	1 in 125
2006	1998	11	9.0 (4.2-12.1)	1 in 110
2008	2000	14	11.3 (4.8-21.2)	1 in 88
2010	2002	11	14.7 (5.7-21.9)	1 in 68
2012	2004	11	14.6 (8.2-24.6)	1 in 68
2014	2006	11	16.8 (13.1-29.3)	1 in 59

Table 14. ASD prevalence data from CDC's Autism and Developmental Disabilities Monitoring (ADDM) Network.

The ADDM Network has estimated prevalence of ASD among 8-year-old children every two years since 2000 in communities located in states across the United States; states that participated in at least one surveillance year include Alabama, Arizona, Arkansas, Colorado, Florida, Georgia, Maryland, Minnesota, Missouri, New Jersey, North Carolina, Pennsylvania, South Carolina, Tennessee, Utah, West Virginia, and Wisconsin. Estimated ASD prevalence at age 8 has ranged from 1 in 150 children born in 1992 and 1994 to 1 in 68 children born in 2004. The ADDM Network published a new report for surveillance year 2014, showing that the estimated prevalence in 11 participating communities was 1 in 59 for 8-year-olds born in 2006. ADDM Network data have shown significant variation in ASD prevalence by geographic area, sex, race/ethnicity, and level of intellectual ability. Among children with ASD, the ratio of boys to girls had remained consistent over time with boys having approximately 4.5 times the prevalence of girls, although in the recent ADDM report, the ratio was closer to four

boys to one girl. Notably, the percentage of children with ASD who also have ID has decreased substantially, from 46-62% in 2000 to 31% in 2014, likely reflecting greater identification of children with ASD who have average to above-average cognitive function. Estimated prevalence has been higher in surveillance sites where education records were reviewed in addition to health records, underscoring the role of special education systems in providing comprehensive evaluations and services to children with DD. Non-Hispanic white children are more likely to be identified with ASD, but the prevalence gap is narrowing between non-Hispanic white children and other races/ethnicities. In the most recent data, non-Hispanic white children were less than 10% more likely to be identified with ASD compared with non-Hispanic black children (previously was 20% more likely). Similarly, non-Hispanic white children were 20% more likely to be identified with ASD compared with Hispanic children (previously was 50% more likely). This reduction in the prevalence disparity for non-Hispanic black and Hispanic children may be due to more effective outreach directed toward minority communities and efforts to have all children screened for ASD.

Disparities by race/ethnicity in estimated ASD prevalence, particularly for Hispanic children, suggest that access to treatment and services might be lacking or delayed for some children. If prevalence disparities by race/ethnicity reflect under-identification of black and Hispanic children rather than differences in risk factors, estimated ASD prevalence may continue to rise as identification increases among these children. **One report** on ADDM data published in 2010 suggests that these disparities in identified prevalence may be associated with socioeconomic status. Differences in heritable factors as well as exposure to various risk and protective factors may also influence differences in identified prevalence among certain groups, so ongoing monitoring is needed to better understand these factors.

Data from the ADDM Network show an increase in the identified prevalence of ASD between 2000 (6.7 per 1,000 children) and 2014 (16.8 per 1,000 children). These results are based on the average prevalence from all participating sites during a specific year; however, the composition of sites and the specific geographical areas within each site have varied over time. Therefore, a rigorous analysis was undertaken to assess prevalence trends for a group of sites with data from both 2002 and 2008, restricted to the common geographic areas for each year, showing a 78% increase in estimated ASD prevalence between 2002 and 2008. 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, including improved identification and awareness. Whether identified ASD prevalence estimates will plateau, decrease, or continue to increase is unknown and continued examination of ASD prevalence changes is important.

In 2010, CDC funded six sites to expand ADDM methodology to younger children. 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 yet have a diagnosis). 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 are evaluated for developmental concerns. Continued monitoring of ASD among 8-year-olds, previously shown to be “peak prevalence,” or the age at which most children have been identified, is essential to understanding the complex changes occurring in ASD over time.

In May 2013, the American Psychiatric Association released the 5th edition of the *Diagnostic and Statistical Manual of Mental Disorders (DSM)* with revised diagnostic criteria for ASD. In 2014, investigators from CDC and the ADDM Network completed an **evaluation** of the new diagnostic criteria for ASD (DSM-5) to estimate the impact on prevalence estimates originally based on the last iteration (DSM-IV-TR) criteria. Currently, CDC is applying both DSM-IV-TR and DSM-5 diagnostic criteria to generate prevalence estimates based on the different surveillance case definitions and evaluate the impact on prevalence trends. Thus, CDC has been able to evaluate the effect of changes in diagnostic criteria. The current DSM-5 criteria consider children with a well-established DSM-IV-TR ASD diagnosis to meet DSM-5 diagnostic criteria as well, regardless of behavioral symptoms displayed, in order to provide continuity of services. CDC surveillance methods are able to distinguish between children meeting DSM-5 behavioral criteria for ASD and those who met DSM-5 criteria solely through a previous ASD diagnosis, thus providing estimates of the proportion of children who would not have an ASD diagnosis under DSM-5 without the provision for children with a previous diagnosis. This provides important information about the effect of the change to DSM-5 criteria on ASD prevalence, since moving forward fewer children will have been evaluated and diagnosed under DSM-IV-TR criteria. The report, including the comparison of prevalence estimates based on DSM-IV-TR and DSM-5 surveillance criteria was published in spring 2018. It reported that ASD prevalence was similar, although about 4% higher among children who met the surveillance case definition based on DSM-IV-TR compared with the ASD prevalence among children who met the surveillance case definition based on DSM-5. It may be too soon to determine the long-term impact of the changes in the diagnostic criteria on ASD prevalence and characteristics, so CDC will continue to monitor this in the next ADDM Network report.

Department of Education

The Office of Special Education Programs (OSEP) collects data from States on the number of students with ASD that receive services under the Individuals with Disabilities Education Act (IDEA), Part B. These and other data are reported in the [39th Annual Report to Congress on IDEA, 2017](#).

Students with ASD served under IDEA, Part B				
Year	Age 6-11	Age 12-17	Age 18-21	Ages 6-21
2012	231,165	179,020	33,809	443,994
2013	244,272	198,653	36,058	478,983
2014	257,714	217,960	38,014	513,688
2015	271,175	238,607	40,623	550,405
2016	282,842	252,477	43,446	578,765

Table 15. Number of children ages 6-21 with Autism served under IDEA, Part B, by year: Fall 2012 through fall 2016

Percentage of the population ages 6 through 21 with ASD served under IDEA, Part B, by year										
Disability	2006	2007	2008	2009	2010	2011	2012	2013	2014	2015
Autism	0.3	0.4	0.4	0.5	0.5	0.6	0.7	0.7	0.8	0.8

Table 16. Percentage of the population ages 6 through 21 with Autism served under IDEA, Part B, by year: Fall 2006 through fall 2015. Percentage was calculated by dividing the number of students ages 6 through 21 served under IDEA, Part B, in the disability category in the year by the estimated U.S. resident population ages 6 through 21 for that year, then multiplying the result by 100.

Percentage of the population ages 6 through 21 served under IDEA, Part B, reported under the category of *autism*, by year and age group

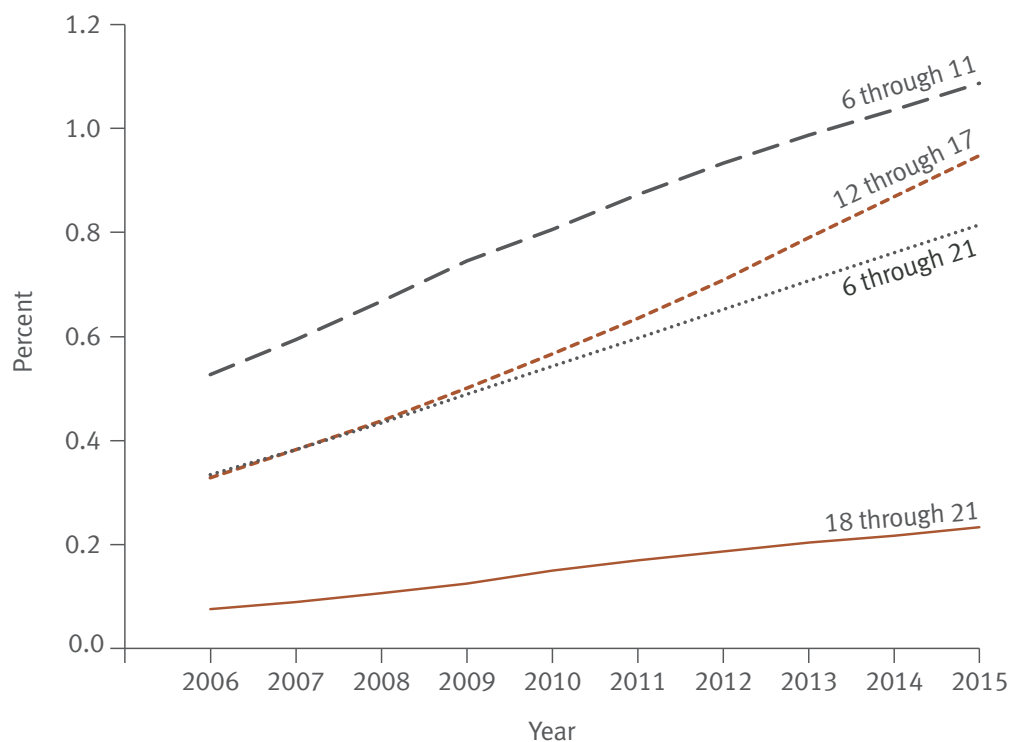


Figure 1. Percentage of the population ages 6 through 21 served under IDEA, Part B, reported under the category of autism, by year and age group: Fall 2006 through Fall 2015. Percentage was calculated by dividing the number of students ages 6 through 21 served under IDEA, Part B, in the disability category in the year by the estimated U.S. resident population ages 6 through 21 for that year, then multiplying the result by 100.

Notes:

- Children aged 6 through 11 make up the largest age group reported under the category of autism.
- Since 2011, children aged 12 through 17 have been reported under the category of autism at a pace greater than that of the other age groups during this time.

Health Resources and Services Administration

Data from the 2016 National Survey of Children's Health (NSCH) indicates that among U.S. children aged 3-17 years, 2.5% had ever received an ASD diagnosis and currently had the condition. This percentage is based on a sample of 43,021 children whose parents completed the survey.

The NSCH is a cross-sectional survey and thus does not provide incidence data. In 2016, the NSCH was significantly redesigned; changes were made in the survey's mode of data collection and sampling frame, as well as adjustments to item wording. Therefore, comparisons to previous NSCH data should not be made.

Average Age of Diagnosis

This section addresses Subsection (D) of 399DD: “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 August 8, 2014, and, as appropriate, how this age varies across population subgroups.” Information on the average age of diagnosis for individuals with ASD is provided by the CDC and HRSA.

Centers for Disease Control and Prevention

Most children who have autism are not diagnosed until after they reach age 4 years, even though many children can be identified before age 2 years. For the most recently published 2018 [ADDM Network ASD prevalence study](#), which was based on children who were 8 years old in 2014 and the diagnostic criteria in the DSM-IV-TR, the median age of earliest known diagnosis was reported by subtype category. Age of first diagnosis ranged from 46 months for children diagnosed with autistic disorder (a more restrictive category suggesting higher severity of symptoms), to 56 months for children diagnosed under the more general category of pervasive developmental disorder (PDD) or ASD, and 67 months for children whose first diagnosis was Asperger disorder (a category describing children without significant delays in language development or intellectual ability).

In 2014, the [ADDM Network reported](#) the median age of earliest ASD diagnosis 4 years and 5 months for children aged 8 years living in ADDM Network communities. Data published in [a previous report](#) indicated that 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 PDD, but only 9 percent of children had an initial diagnosis of Asperger disorder.

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 who 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. A more recent analysis of data from the 2016 NSCH indicated that an estimated 30 percent of parents with children aged 9-35 months report that they were asked to fill out a questionnaire by a healthcare provider about their child’s developmental, communication, or social behaviors in the last year, and an estimated 37 percent of parents report that their children aged 9-35 months had received developmental surveillance from a healthcare professional in the past year. Data from the ADDM

Network are used to monitor progress toward the Healthy People 2020 goal of increasing the proportion of children with ASD who have a first evaluation by 36 months of age to 47%. Insufficient progress has been made toward achieving this goal. The proportion of children aged 8 years with a first evaluation by age 3 was 43.3% as reported in 2014, 42.8% as reported in 2016 and 41.9% as reported in 2018 by the ADDM Network. It should be noted that the American Academy of Pediatrics recommendations for population screening of young children for ASD were published in 2007 and ADDM Network data for 8-year-old children may reflect improvement related to increased screening beginning in the 2014 and 2016 surveillance years (corresponding to births in 2006 and 2008).

Health Resources and Services Administration

The following are data from the 2016 National Survey of Children's Health (NSCH).

- For children 3-17 years, who had ever received an ASD diagnosis and currently had the condition, the average age of diagnosis was 4.9 years old.
- The average age by gender was 4.8 for males and 5.4 for females.
- The average age by race/ethnicity was 3.3 for Hispanics, 5.7 non-Hispanic whites, 4.7 for non-Hispanic blacks, and 5.8 for multi-race/other non-Hispanics.
- The average age by type of health insurance was 4.9 for public insurance only, 5.0 for private insurance only, and 5.3 for not insured.
- The average age by Federal Poverty Level (FPL) was 4.5 for < 100% of the FPL, 5.4 for 100-199% of the FPL, 4.7 for 200-399% of the FPL, and 5.3 for => 400% of the FPL.

Average Age for Intervention

This section addresses subsection (E) of 399DD: “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 August 8, 2014, and, as appropriate, how this age varies across population subgroups.” Information on the average age of intervention for individuals with ASD is provided by the CDC.

Centers for Disease Control and Prevention

Early identification and service initiation play an important role in the expression and progression of ASD. One of the goals of the Healthy People 2020 (HP2020) initiative on Maternal, Infant, and Child Health is to increase the proportion of children with ASD enrolled in special services by 48 months of age. More specifically, the HP2020 target was set to 57.6%, reflecting a 10% increase from baseline year 2006. CDC does not collect information on average age of intervention for individuals diagnosed with ASD and other DD through their ADDM Network; however, data from the Metropolitan Atlanta Developmental Disabilities Surveillance Program (MADDSP) at CDC are linked to special education data to estimate the percentage of children with ASD who begin receiving special education services by age 48 months. According to data from MADDSP, initiation of special education services by 48 months of age among children with ASD reached 52.4% in 2006, 51.5% in 2008, 52.0% in 2010, and dropped to 46.4% in 2012. The trend was similar among males-only, remaining close to 50% from 2006 to 2010, and then dropping to 46.9% in 2012. Among females, the proportion reached a high of 65.5% in 2008, but gradually decreased to a low of 44.2% in 2012. With regard to race/ethnicity, non-Hispanic whites had the highest proportion of early service initiation almost at any given time-point (ranging from 47.1% in 2012 to 58.4% in 2008), followed by non-Hispanic blacks (ranging from 49.3% in 2008 to 52.7% in 2006), and Hispanics (ranging from 35.5% in 2008 to 49.3% in 2010). CDC will continue to monitor progress towards this goal and provide input into the development of the HP2030 goals.

Average Time Between Screening, Diagnosis, and Intervention

This section addresses section (F) of 399DD: “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 and, as appropriate, on how such average time varies across population subgroups.” Information on the average time between screening, diagnosis, and intervention for individuals with ASD is provided by the CDC.

Centers for Disease Control and Prevention

Before an ASD evaluation can be conducted on a child, someone must express concern about that child’s development. In the [2018 ADDM Network report](#), there was documentation of concerns about development by age 36 months for 85 percent of the children identified with ASD; however, only 41.9 percent of all children identified with ASD and 48.3 percent of children with ASD and documentation of concerns about development by age 36 months received a first developmental evaluation by age 36 months. Notably, this has not changed significantly from the [2016 ADDM Network report](#) data where 42.8% of children identified with ASD had a first evaluation by age 36 months. Tracking the age at first developmental evaluation is important because services can begin immediately to address the specific impairments identified in a comprehensive evaluation, even before a diagnosis of ASD is made. Data from the ADDM Network are used to evaluate progress toward the HP2020 goal of increasing the proportion of children with ASD having a first evaluation by 36 months of age. In addition, for the children who had a documented diagnosis of ASD by a community provider (69.3% of all children who met the ADDM Network ASD case criteria), the median age of ASD diagnosis was 4 years, 4 months. Together, these data indicate that work is still needed to close the gap between age of concern and subsequent ages at first developmental evaluation and ASD diagnosis, suggesting a significant delay between evidence of concerns and diagnosis. Although the ADDM Network does not currently collect data on developmental screening, the establishment of the Early ADDM Network in 2010 will further enhance our understanding of the early developmental concerns and a child’s path to diagnosis. In an effort to address delay in diagnosis of ASD and other DD and to promote early intervention, CDC’s [“Learn the Signs. Act Early.”](#) program continues to work to improve early identification of ASD and other DD, and to enhance communication and coordination among state and local systems providing services to children with developmental delays.

Effectiveness and Outcomes of Interventions

This section addresses subsections (G) and (H) of 399DD, which require: (G) “Information on the effectiveness and outcomes of interventions for individuals diagnosed with autism spectrum disorder, including by severity level as practicable, and other developmental disabilities and how the age of the child or other factors, such as demographic characteristics, may affect such effectiveness,” and (H) “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 ACL, AHRQ, ED, HRSA, and NIH.

Administration for Community Living

NIDILRR has funded research on interventions for people (children, transition-age youth, adults) with ASD and other DD. Studies relevant to ASD include:

- Employment interventions
 - An internship model, which includes ASD supports, to improve employment outcomes for transition-age youth with ASD
 - A customized employment intervention to improve employment outcomes for transition-age youth with ASD
 - Interventions to improve employment outcomes for people with intellectual and developmental disabilities
 - Self-Determined Career Development Model intervention to improve employment outcomes for people with intellectual and developmental disabilities
- Parent & caregivers: education and training interventions
 - Scale-up project of OASIS, a model of intervention skills training for parents of children with autism
 - Parent education program designed to meet the needs of Latino parents of children with ASD
 - An intervention that prepares youth with DD, ages 14-21, to respond to environmental barriers and increases participation in school, work, and the community
- Interventions to improve community living and participation in transition age youth and/or adults
 - A technology-supported instructional system to teach social competence, problem-solving skills, and organizational/self-monitoring skills for adolescents and young adults
 - A web application that enables individuals with intellectual disabilities and autism to effectively manage self-defined goals for everyday living
 - Project to determine if affective and physiological regulation in individuals with ASD can be promoted through dynamic adjustments in the environment
 - System to assist young adults with ASD to safely and effectively transition into independent living
 - System to assist young adults with ASD to safely and effectively transition into independent living

- Intervention that prepares youth with DD ages 14-21 to respond to environmental barriers and increase participation in school, work, and the community
- Toolkits to Improve Community Living and Participation for People with Intellectual and Developmental Disabilities
- Interventions related to community participation through self-determination, social inclusion, employment, and the direct support workforce in a variety of community living service settings including family and individual homes
- Health interventions
 - Interventions to improve health outcomes of people with DD
 - Health promotion curriculum for people with intellectual and developmental disabilities

Agency for Healthcare Research and Quality

The following awards and publications provide information on the effectiveness and outcomes of interventions for individuals with ASD.

“[Reducing Disparities in Timely Autism Diagnosis through Family Navigation](#)” proposes to test the feasibility of an intervention to decrease disparities in timely ASD diagnosis that occur at a critical point in the continuum of the delivery of ASD services for young children. The patient navigation model has been implemented to reduce institutional- and individual-level barriers to cancer diagnoses and has demonstrated efficacy in both improving adherence to follow-up visits after a screening abnormality and decreasing the time from an abnormal screen to diagnostic resolution. This study will assess a novel application of patient navigation to support families of low-income and minority children, ages 15 months to 3 years. The researchers have reframed the model from patient to family navigation and will focus on a defined episode of care, beginning with an abnormal autism screen and ending with the completion of the diagnostic assessment.

“[A Deliberative Approach to Develop Autism Data Collection in Massachusetts](#)” is a health services research grant funded in 2016 that involves a deliberative citizen jury, the majority of which are individuals on the autism spectrum, to provide guidance to the Massachusetts Executive Office of Health and Human Services regarding the creation of a statewide registry for ASD. A patient registry is a collection of standardized information about a group of patients who share a particular condition or experience. When complete, the registry will provide an integrated data system to track diagnosis, treatment, services, and outcomes for individuals with ASD, with the long-term goal of improving coordination of care and disseminating information on best practices. The registry will also provide a way to track services and outcomes for various subpopulations of autistic individuals in Massachusetts.

“Partnership for Research & Dissemination of Evidence-Based Medicine in Autism” proposes to use innovative methods to develop customized content (including videos, webisodes, and interactive media products) of existing evidence-based medicine (EBM) products for ASD. The researchers will then disseminate this content through technology-based and social media channels to enable rapid and easy downloading by targeted stakeholder audiences, including parents of children with ASD as well as teachers and health care providers of autistic individuals from underserved populations. The trans-disciplinary team proposes to extend this work and develop a highly effective, unified, and sustainable high-throughput dissemination strategy to improve the use of customized EBM products at health and educational systems, clinical practice, caregiver, and family levels.

“Enabling large-scale research on autism spectrum disorders through automated processing of EHR using natural language understanding” aims to increase the utility of electronic health records (EHR) by developing scalable and effective computational methods to capture structured data from the text contained therein. This will be particularly advantageous in advancing knowledge about ASD and other mental health disorders, where records describe symptoms and interventions that are highly individualized and are often composed of rich data not easily captured in structured templates. This project has the potential to significantly shift away from the current paradigm of relying on small-scale data from individual ASD interventions and the lack of integration between different data sources, to leveraging information from existing large-scale data sources to propose novel analyses and hypotheses.

Medical Therapies for Children with Autism Spectrum Disorder — An Update

The goal of this systematic review, published in 2017, was to evaluate the comparative effectiveness and safety of medical interventions for children with ASD. Studies of medical interventions that included at least 10 children with ASD were included. The 76 unique comparative studies meeting the inclusion criteria included 72 randomized controlled trials (RCTs), 2 non-randomized trials, and 2 retrospective cohort studies; populations, treatment approaches, and outcomes assessed varied across studies. Risperidone and aripiprazole ameliorated challenging behaviors in the short term, but with clinically significant side effects [high strength of evidence (SOE)]. Methylphenidate and atomoxetine were also associated with improvements in hyperactivity in small short-term RCTs (low SOE), with improvements maintained over 6 months for atomoxetine (low SOE for longer term effects). Methylphenidate was associated with clinically significant harms (low SOE), while atomoxetine was associated with clinically moderate harms (low SOE). Omega-3 fatty acid supplementation, N-acetylcysteine, and tetrahydrobiopterin failed to show benefits (low SOE). Evidence for other interventions and outcomes studied was insufficient. While the conduct of studies has improved considerably over time (i.e., growing number of RCTs and use of standardized measures), data on longer term (≥ 6 months) results and harms of most interventions are lacking. Similarly, more research is needed to understand characteristics of the child or treatment that modify outcomes, whether effectiveness of interventions generalizes across different settings such as the home or school, and how components of interventions may drive effects.

Interventions Targeting Sensory Challenges in Children with Autism Spectrum Disorder - An Update

The goal of this systematic review, published in 2017, was to evaluate the effectiveness and safety of interventions targeting sensory challenges in children with ASD. Studies included 20 RCTs, 1 nonrandomized trial, and 3 retrospective cohort studies (3 low, 10 moderate, and 11 high risk of bias); populations, intervention approaches, and outcomes assessed varied across studies. Some interventions targeting sensory challenges may produce modest short-term (<6 months) improvements, primarily in sensory-related outcomes and outcomes related to ASD symptom severity; however, the evidence base for any category of intervention is small, and durability of effects beyond the immediate intervention period is unclear. Sensory integration–based approaches improved outcomes related to sensory challenges (low SOE) and motor skills (low SOE), and massage improved sensory responses (low SOE) and ASD symptoms (low SOE). Environmental enrichment improved nonverbal cognitive skills (low SOE). Auditory integration–based approaches did not improve language outcomes (low SOE). Some positive effects were associated with other approaches studied (music therapy, weighted blankets), but findings in these small studies were not consistent (insufficient SOE). Data on longer term results are lacking, as are data on characteristics that modify outcomes, effectiveness of interventions across environments or contexts, and components of interventions that may drive effects. In sum, while some therapies may hold promise and warrant further study, substantial needs exist for continuing improvements in methodologic rigor in the field.

Therapies for Children With Autism Spectrum Disorder: Behavioral Interventions Update

This 2014 update of a prior systematic review of interventions for children (0–12 years) with ASD focused on recent studies of behavioral interventions. Sixty-five unique studies comprising 48 randomized trials and 17 non-randomized comparative studies (19 good, 39 fair, and 7 poor quality) were included in the analysis. The quality of studies improved compared with that reported in the earlier review; however, assessment of the SOE and confidence in the stability of effects of interventions in the face of future research, remains low for many intervention/outcome pairs. Early intervention based on high-intensity applied behavior analysis over extended timeframes was associated with improvement in cognitive functioning and language skills (moderate SOE for improvements in both outcomes) relative to community controls in some groups of young children. The magnitude of these effects varied across studies, potentially reflecting poorly understood modifying characteristics related to subgroups of children. Early intensive parent training programs modified parenting behaviors during interactions; however, data were more limited about their ability to improve developmental skills beyond language gains for some children (low SOE for positive effects on language). Social skills interventions varied in scope and intensity and showed some positive effects on social behaviors for older children in small studies (low SOE for positive effects on social skills). Studies of play/interaction-based approaches reported that joint attention interventions may demonstrate positive outcomes in preschool-age children with ASD when targeting joint attention skills (moderate SOE); data on the effects of such interventions in other areas were limited (low SOE for positive effects on play skills, language, social skills). Studies examining the effects of cognitive behavioral therapy on anxiety reported positive results in older children with IQs ≥ 70 (high SOE for improvements in anxiety in this population). Smaller short-term studies

of other interventions reported some improvements in areas such as sleep and communication, but data were too sparse to assess their overall effectiveness. In summary, despite improvements in the quality of the included literature, a need remains for studies of interventions across settings and continued improvements in methodologic rigor. Substantial scientific advances are needed to enhance our understanding of which interventions are most effective for specific children with ASD and to isolate elements or components of interventions most associated with effects.

Genetic Testing for Developmental Disabilities, Intellectual Disability, and Autism Spectrum Disorder

This Technical Brief collects and summarizes information on genetic tests clinically available in the United States to detect genetic markers that predispose to DD. It also identifies, but does not systematically review, existing evidence addressing the tests' clinical utility. This Brief primarily focuses on patients with idiopathic or unexplained DD, particularly intellectual disability, global developmental delay, and ASD. Patient-centered health outcomes (e.g., functional or symptomatic improvement) and intermediate outcomes (e.g., changes in clinical decisions or family reproductive decisions, and the tests' diagnostic accuracy and analytic validity) are examined. A search of the Genetic Testing Registry database identified 672 laboratory-developed tests offered by 63 providers in 29 states. We also identified one test cleared by the Food and Drug Administration. Common genetic testing methods used include array comparative genomic hybridization, microarray, DNA sequencing (the Sanger method or next-generation sequencing), and polymerase chain reaction. We did not identify any studies that directly assessed the impact of genetic testing on health outcomes. Most of the clinical studies identified for indirect assessment of clinical utility are case series reporting on a test's diagnostic yield.

Screening for Autism Spectrum Disorder in Young Children, Systematic Evidence Review for the U.S. Preventive Services Task Force

This systematic review, published in 2016, examined the evidence about benefits and harms of routine screening for ASD in primary care settings, explicitly focusing on studies of screening instruments for use in young (≤ 36 months of age), unselected populations (e.g., universal screening approaches). The authors identified 17 unique screening studies reported in 22 papers. The most commonly studied tool was the Modified Checklist for Autism in Toddlers (M-CHAT), including the most recently available variant (M-CHAT-Revised with Follow-up [M-CHAT-R/F]), which has a positive predictive value of 48 percent in diverse populations of children ages 16 to 30 months. Forty-two studies of good and fair quality addressed interventions for young children. Among these, 20 studies overall measured cognitive outcomes and 11 reported greater benefit for the intervention group compared to the control group. Language outcomes were significantly improved in treatment versus comparison arms in 13 of 28 studies assessing language. Twelve studies focused on play and interaction and typically measured joint attention as the outcome. Nine out of 10 studies evaluating joint attention outcomes reported greater benefit in the treatment arm compared to the control arm. None of the studies focused on screen-detected children. In summary, early intensive interventions demonstrate statistically significant improvements in cognitive and language outcomes in children compared to eclectic treatments obtained in the community or other comparison groups, although the

studies are generally small, and, within the studies, some children benefit while others do not. We found no studies that directly compared long-term outcomes of screened versus non-screened children. More research is needed to determine the benefits and harms of screening the general population.

Department of Education

National Center for Special Education Research (NCSER)

Through the *Special Education Research Grants Program* competition, the *National Center for Special Education Research (NCSER)* has funded a number of projects that have demonstrated positive effects on children and youth with ASD. These projects are described below.

An RCT was conducted to determine the efficacy of *Joint Attention Mediated Learning (JAML)*, an intervention for toddlers with ASD. This intervention directly targets foundational, preverbal social-communication competencies through parent-child interactions. These early competencies include focusing on faces, taking turns, and engaging in joint attention. The researchers found that compared to children in the control group, children in the *JAML* group made significantly greater gains in four targeted preverbal social-communication competencies: social visual orientation (focusing on faces), reciprocity (turn taking), responding to others' joint attention overtures, and initiating joint attention. Three of these four competencies (all except initiating joint attention) *continued to show significant impacts* 6 months after treatment ended.

A recently completed NCSER-funded *follow-up study* of the RCT study of *Learning Experiences—An Alternative Program for Preschoolers and Parents (LEAP)* is the second in a series of studies of this comprehensive intervention on children with ASD who are in inclusive preschool classroom settings. In the *LEAP* program, children without ASD learn to facilitate interaction with their peers with ASD, preschool teachers use naturally-occurring classroom situations for incidental teaching, and parents receive training in behavioral teaching strategies to reduce stress at home. This second study was a follow-up study of the children who participated in the previous RCT study that found *LEAP* to be an effective intervention. The *positive effects* of prior *LEAP* participation *were largely sustained* into elementary school. In the follow-up study, children in the *LEAP* group had significantly higher cognitive and social skills scores than those in the control group. Exploratory analyses indicated that for children in both groups, those placed in inclusive classrooms in elementary school had significantly higher outcome scores compared to those placed in other settings. The third and recent NCSER-funded *study* involves an exploration of the malleable factors (e.g., staff readiness and buy-in, leadership, promotion of implementation) that predict teacher fidelity to the *LEAP* model following training and over time.

The *Social Competence Intervention for Adolescents (SCI-A)* was developed with NCSER funds to help middle school students with high-functioning ASD navigate their social environment. This intervention is a modified clinic-based intervention for use in classrooms in school-based settings. *Preliminary evidence* suggested that

this intervention improved social skills, executive functioning, and facial-expression recognition. Adding a peer-mediated intervention to the SCI-A program further enhanced the generalization of social skills. The effect of this classroom intervention on a variety of outcomes – social problem solving, executive functioning, social perception, emotion regulation, and social communication – is now being evaluated using an RCT with middle school students. Initial results indicate that students in the intervention group experience improvements in outcomes, especially those with lower levels of cognitive functioning, at rates higher than students in the control group.

An RCT was conducted to evaluate the efficacy of peer support interventions for improving social and behavioral outcomes for high school students with severe intellectual disabilities, including those with ASD. The peer supports intervention involves one or more peers without disabilities providing social and/or academic support to a student with severe disabilities within an inclusive classroom. The peer networks intervention connects a student with severe disabilities to a peer group of four to six students who meet regularly with the support of an adult facilitator. Results indicate that students in these peer support interventions experienced increased interactions with peers, higher levels of academic engagement and social participation, and greater numbers of new friendships that were sustained over time compared to those students in the control group.

Project Summer is an intervention designed to improve transition services for high school students with disabilities and to maximize engagement in summer employment and related activities. The intervention is aimed at students with a variety of disabilities, including those with ASD. A pilot test of the intervention using an RCT indicated that youth with severe disabilities, including youth with ASD in the treatment group, were significantly more likely (i.e., 3.5 times) to participate in community-based work experiences during the summer and work more hours per week than their peers at the same schools in the control group, who did not participate in the intervention.

Rehabilitation Services Administration (RSA)

The Rehabilitation Services Administration (RSA) has analyzed data from the RSA-911, Case Service Report, for FY 2014 through FY 2017. For FY 2014-2016, the RSA-911 includes information on individuals whose service records under the Vocational Rehabilitation (VR) Services program were closed during each of those fiscal years. Service records are closed after an individual achieves an employment outcome in competitive integrated employment or supported employment and is stable for a period of at least 90 days. Service records are also closed if services provided do not result in an employment outcome competitive integrated employment or the individual chooses to exit the VR program. RSA implemented a revised RSA-911 on July 1, 2017, pursuant to amendments made to the Rehabilitation Act of 1973 by the Workforce Innovation and Opportunity Act, so the FY 2017 data include information on individuals whose cases were closed between October 1, 2016 and June 30, 2017.

RSA has provided the total number of individuals with autism as a primary or secondary cause of disability and the number of individuals whose primary disability was an intellectual disability. RSA also computed the average age at application for all individuals who were eligible for VR services and whose case service records were closed in FY 2014 – FY 2017.

Individuals Eligible for VR Services				
Disability	FY 2014	FY 2015	FY 2016	FY 2017
Individuals with Autism as a Primary or Secondary Cause of Disability	7,255	9,118	10,405	8,187
Individuals with Intellectual Disability as the Primary Disability	108,730	111,584	111,156	77,669

Table 17. Number of individuals who were eligible for VR services and whose cases were closed in FY 2014 - FY 2017.

Source: RSA-911

Note: FY 2017 includes cases that were closed between October 1, 2016 and June 30, 2017.

Average Age of Individuals Eligible for VR Services				
Disability	FY 2014	FY 2015	FY 2016	FY 2017
Individuals with Autism as a Primary or Secondary Cause of Disability	21.6	21.7	21.6	21.6
Individuals with Intellectual Disability as the Primary Disability	30.4	30.5	30.3	30.3

Table 18. Average Age at application (in years) for individuals who were eligible for VR services and whose cases were closed in FY 2014 - FY 2017. Source: RSA-911

Note: FY 2017 includes cases that were closed between October 1, 2016 and June 30, 2017.

RSA has also analyzed the number of individuals with employment outcomes by age group, gender, and race for individuals whose primary or secondary cause of the disability was reported as Autism or whose primary disability was identified as being an ID.

Individuals with Autism and an Employment Outcome by Age at Application				
Age	FY 2014	FY 2015	FY 2016	FY 2017
<16	78	95	90	90
16-18	2,690	3,295	3,638	2,860
19-24	2,973	3,738	4,353	3,413
25-44	1,305	1,725	2,038	1,624
45-54	160	187	205	148
55-59	33	59	62	36
60+	16	19	19	16
Total	7,255	9,118	10,405	8,187

Table 19. Individuals with Autism as a Primary or Secondary Cause of Disability and an Employment Outcome by Age at Application: FY 2014 - FY 2017. Source: RSA-911

Note: FY 2017 includes cases that were closed between October 1, 2016 and June 30, 2017.

Individuals with Intellectual Disability and an Employment Outcome by Age at Application

Age	FY 2014	FY 2015	FY 2016	FY 2017
<16	725	680	692	535
16-18	29,352	29,764	30,201	21,720
19-24	23,770	24,403	24,201	16,466
25-44	35,045	36,185	35,597	24,740
45-54	14,582	14,719	14,188	9,660
55-59	3,767	4,235	4,386	3,112
60+	1,489	1,598	1,891	1,436
Total	108,730	111,584	111,156	77,669

Table 20. Individuals with Intellectual Disability as a Primary Disability and an Employment Outcome by Age at Application: FY 2014 - FY 2017. Source: RSA-911

Note: FY 2017 includes cases that were closed between October 1, 2016 and June 30, 2017.

Individuals with Autism and an Employment Outcome by Gender

Gender	FY 2014	FY 2015	FY 2016	FY 2017
Male	6,135	7,684	8,746	6,903
Female	1,120	1,434	1,659	1,284

Table 21. Individuals with Autism as a Primary or Secondary Cause of Disability and an Employment Outcome by Gender: FY 2014 - FY 2017. Source: RSA-911

Note: FY 2017 includes cases that were closed between October 1, 2016 and June 30, 2017.

Individuals with Intellectual Disability and an Employment Outcome by Gender				
Gender	FY 2014	FY 2015	FY 2016	FY 2017
Male	64,579	66,262	66,628	46,173
Female	44,151	45,321	44,528	31,496

Table 22. Individuals with Intellectual Disability as a Primary Disability and an Employment Outcome by Gender: FY 2014 - FY 2017. Source: RSA-911

Note: FY 2017 includes cases that were closed between October 1, 2016 and June 30, 2017.

Individuals with Autism and an Employment Outcome by Race				
Race/Ethnicity	FY 2014	FY 2015	FY 2016	FY 2017
White	6,435	8,060	9,055	7,076
Black or African American	665	886	1,092	895
American Indian or Alaska Native	101	120	167	98
Asian	172	237	325	257
Native Hawaiian or Other Pacific Islander	43	37	76	50
Ethnicity – Hispanic or Latino	390	577	704	562

Table 23. Individuals with Autism as a Primary or Secondary Cause of Disability and an Employment Outcome by Race: FY 2014 - FY 2017. Source: RSA-911

Note: FY 2017 includes cases that were closed between October 1, 2016 and June 30, 2017.

Note: More than one race variable can be selected for an individual.

Individuals with Intellectual Disability and an Employment Outcome by Race				
Race/Ethnicity	FY 2014	FY 2015	FY 2016	FY 2017
White	80,015	82,060	81,231	57,104
Black or African American	26,472	27,156	27,530	19,020
American Indian or Alaska Native	2,263	2,441	2,330	1,498
Asian	1,573	1,824	2,009	1,439
Native Hawaiian or Other Pacific Islander	477	527	632	438
Ethnicity – Hispanic or Latino	13,004	13,491	14,497	10,580

Table 24. Individuals with Intellectual Disability as the Primary Disability and an Employment Outcome by Race: FY 2014 - FY 2017. Source: RSA-911

Note: FY 2017 includes cases that were closed between October 1, 2016 and June 30, 2017.

Note: More than one race variable can be selected for an individual.

Health Resources and Services Administration

The HRSA Autism CARES Research Program funds research to support studies that advance the current knowledge base pertaining to ASD/DD and lead to improvements in interventions that address the health needs of children and adolescents with ASD/DD. Thirty-one studies conducted between October 2014 (FY 2014) and January 2018 (first quarter of FY 2018) are described below. Additional details on HRSA-funded studies can be found in Appendix iv.

Eight Autism Intervention Research Network on Behavioral Health (AIR-B) studies focus on the effectiveness and outcomes of behavioral interventions for children with ASD in school and community-based settings. For example, the Building Better Bridges randomized controlled trial study is testing an intervention to improve school transition outcomes for children with ASD and their families. Community partners, parents, teachers and school administrators have been consulted in the design of the intervention to ensure that the specific challenges faced by each group are addressed in the intervention. Parents who have already been through school transitions with a child on the autism spectrum are trained to implement the intervention with other parents who are currently managing school transitions.

The Autism Intervention Research Network on Physical Health (AIR-P) had 12 studies focusing on the effectiveness and outcomes of interventions for individuals diagnosed with ASD. One study tested an intervention to improve the physical health of individuals with ASD by developing a manualized wireless

moisture alarm intervention for toilet training children with ASD. The intervention was successfully piloted in school settings. AIR-P is also investigating how a collaborative telehealth intervention using Extension for Community Healthcare Outcomes Autism technology may increase the provider knowledge, improve the clinical practice, and enhance the self-efficacy of providers in their care of children with ASD. Participating providers reported improved self-efficacy, increased adherence to ASD screening guidelines, and a positive influence on the quality of and access to healthcare for children with ASD. AIR-P also employed secondary data analyses to examine factors associated with ASD symptoms and diagnosis.

The Developmental-Behavioral Pediatrics Research Network (DBPNet) had three studies that will improve diagnosis and treatment of youth with ASD in developmental behavioral pediatrics clinical settings. One study focused on the feasibility of extracting electronic health records to examine the relationship between prescribed psychotropic medications and the physicians' diagnoses. The study found that there is large variation in prescription of psychotropic medication to children with ASD across three academic DBP program sites, and that for young children aged 3 to 5 with ASD, those with medical assistance were more likely to have medications prescribed than children with private insurance. However, this relationship is not true for older children with ASD.

Two DBPNet studies aim to determine whether the NIH Patient Reported Outcome Measurement Information System (PROMIS®) measures, which are valid with the typically developing population, may be useful in assessing intervention effectiveness for children with ASD. The first study found that the PROMIS Pediatric Parent-Proxy Peer Relationships Measure (where the parents completed the measure about their children) may be an efficient, precise, and valid measure of peer relationships for 5- to 12-year-old children with ASD. Preliminary findings from the second study of PROMIS measures indicate that the peer relationships and stress experiences measures are reasonably valid when used in a population of youth, aged 12-17, with ASD who are literate at a third-grade reading level. Specifically, the peer relationships measure was highly correlated with another measure of social responsiveness, which is commonly used to measure autism severity.

The MCH Health Care Transitions Research Network for Youth and Young Adults with ASD (HCT-RN) implemented one study focused on this topic. This study consisted of a collaborative improvement network where pediatric residency training programs conduct rapid cycle improvement tests to refine and optimize the process of implementing the previously developed Health Care Transition Curriculum for Primary Care Residents. The specific results of the improvement process were published in a supplement to the *Journal of Pediatrics*, in April 2018.

Overall, seven Autism FIRST research projects focused on the effectiveness and outcomes of interventions for individuals diagnosed with ASD. Four of the Autism FIRST studies tested specific interventions for children with ASD across various environments such as the clinic, home, or school setting and at different age levels ranging from 2-12 years old. For example, one FIRST study used low dose sertraline (2.5 to 5.0mg/d) in children with ASD who are between 2 and 6 years old to improve language, behavior, and development issues. Three of the Autism SDAR Program studies covered a wide range of topics including developing an abbreviated scoring

procedure for an ASD screener, determining out-of-pocket costs that families with ASD incur when using private health insurance, and adversities that families with ASD experience and their relationships to diagnosis and access to treatment.

Effectiveness and outcomes by severity level, age, or other demographic factors

HRSA supported 38 research studies that focused on how factors, such as severity level, age of child, and demographic characteristics may affect the effectiveness and outcomes of interventions for individuals diagnosed with ASD/DD. This includes eight Autism FIRST projects, nine AIR-B, thirteen AIR-P, five DBPNet, and three HW-RN studies.

Six of the Autism FIRST studies tested modified interventions that address barriers to intervention effectiveness with minimally verbal children, parental stress, racial/ethnic minorities, disadvantaged geographic location, and low income. For example, one FIRST study was effective in lowering stress level and improving caregiver skills, while also improving engagement, play frequency, and joint attention behaviors in toddlers. Two Autism SDAR studies identified barriers to early intervention such as measurement bias (i.e. age, gender, ethnic group) in diagnostic tools and the impact of adverse family experiences of underrepresented minorities on seeking services (i.e., children with ASD experience more adverse childhood experiences, including neighborhood violence, parental divorce, parental mental illness, and parental substance abuse). Research is addressing disparities in early identification of ASD and subsequent service utilization. One study demonstrated the effectiveness of an evidence-based screening program and evidence-based training protocols for primary care staff that was adapted for use with Latino families. This early screening intervention increased the rate of completion of the Modified Checklist for Autism in Toddlers (M-CHAT), a standardized developmental tool for eligible children ages 18 and 24 months, which increased from less than 5% prior to the onset of the intervention to approximately 60% after 3 months of implementation to nearly 100% at 6 months into the intervention.

Nine AIR-B studies focus on developing and testing the efficacy of behavioral interventions for children with ASD in school and community-based settings. Results from the multi-site, formative research phase of AIR-B's Mind the Gap study found that the best place to intervene was with families waiting to receive services. Informed by the formative research with parents and providers of low-income, minority children with ASD, the ongoing Mind the Gap intervention is a community-driven intervention for low-income parents and minority children with ASD that is low intensity, and likely to be both effective and sustainable resulting in increased access to care for under-resourced children.

AIR-P implemented thirteen research studies, which examined factors such as diagnosis and treatment of co-morbidities, to improve outcomes in individuals receiving treatment for ASD. One study found that a fixed dose of metformin can be effective for decreasing weight gain associated with atypical antipsychotic medication used to treat ASD in children and adolescents.

DBPNet's Project EARLY is a multi-site study that builds on evidence from a small pilot family navigation study to examine whether a family navigator can improve access to ASD diagnostic and treatment services, and improve outcomes for children who screen positive for ASD at pediatric primary care centers serving low-income communities. Approximately 255 racial and ethnic minority families from historically underserved communities have enrolled in the study and are receiving family navigation services.

Three studies by the Healthy Weight Research Network (HW-RN) are examining feeding and weight management in children and adolescents diagnosed with ASD. One study in particular is evaluating the impact, acceptability, and feasibility of a pilot adaptive weight management intervention for overweight children with ASD aged 4 to 8 years old.

Innovative and newly-developed intervention strategies

Ten Autism FIRST studies measure the effectiveness and outcomes of innovative and newly developed intervention strategies for individuals with ASD/DD. Seven of these studies conducted and tested innovative interventions across study settings, developmental stages, and subpopulations. The studies focused on a broad range of topics to include telehealth parent training, mindfulness training to enhance parent-coaching, and teacher-mediated toilet training using a manualized moisture alarm. One study examined a telehealth intervention that trained parents in implementing applied behavior analysis (ABA) to treat challenging behavior in young children with autism that demonstrated successful reduction of problem behavior similar to in-home therapy. The findings support the potential for using telehealth at significantly less cost than in-home therapy to provide research based behavioral treatment to families with limited access to providers such as in rural and geographically isolated communities.

Another FIRST study examining the effects of an adaptive intervention implemented by therapists and parents to improve communication outcomes for 3-4 year-old minimally-verbal children with ASD has been rated by parents as effective, worthwhile, and able to improve their competence as a language teacher for their child with ASD. Three of the autism SDAR studies developed and tested innovative approaches. One SDAR study created and measured a more effective and efficient Social Communication Questionnaire (SCQ) screening process.

HRSA's Autism Longitudinal Data Project is studying the association of maternal and cord blood metabolomes, placental histological findings, and in utero fetal growth patterns with ASD risk to improve early prediction and to test interventions. The Autism Transitions Research Project is conducting two innovative studies that will examine factors associated with healthy life outcomes among adolescents and young adults with ASD transitioning to adulthood.

Among the Research Networks, AIR-B has eight studies measuring the effectiveness of innovative strategies. One AIR-B study entitled, “Remaking Recess” was effective in increasing social engagement between school-aged children ages 5-11 years with autism and their peers during recess time. AIR-P has 14 studies covering a broad range of topics such as oral health for underserved children, physical exercise, sleep disturbance, resiliency, and the use of probiotics to improve GI health and emotional stability. DBPNet has three studies focused on this topic. In one study, DBPNet investigators are examining the role of family navigators to improve ASD diagnosis, treatment, and outcomes. HW-RN has six studies demonstrating innovation. Study topics include family-based weight loss treatment, physical activity among adolescents, and piloting an adaptive weight management intervention in 4-8 year-old children with ASD.

National Institutes of Health

The following NIH-funded projects provide information on the effectiveness and outcomes of interventions for those with ASD and other DD:

Predicting Treatment Outcomes in ASD: In a study of 6-year-old children diagnosed with ASD, NIMH-supported researchers using advanced brain imaging techniques found that specific neural patterns in response to certain visual stimuli were effective in predicting these children’s response to behavioral treatments. Advancements in treatment prediction will enable researchers and clinicians to better identify and steer children to the most effective treatments and services specific to their needs and core deficits [PMID: 27845779].

Interventions to Improve Skills for Minimally Verbal Children with ASD: Focused on a sample of minimally-verbal children, for which effective interventions are very scarce, this study supported by NICHD randomly assigned children to the intervention with and without a speech-generating assistive device, as part of a 6-month behavioral intervention program. Children in both conditions saw significant improvements in the functional and symbolic play skills, indicating that minimally-verbal children respond to and benefit from intervention efforts [PMID: 29170936].

Improving Social Attention in ASD with a Parent-delivered Intervention: NICHD-supported researchers found that infants at increased risk for ASD (6-18 months of age) who received an innovative parent-delivered intervention program showed greater improvements in social attention and engagement than infants who did not receive any type of developmental intervention. The findings suggest that early parent-mediated intervention may have promising developmental impact on social and cognitive attention skills for children at very young ages [PMID: 28244271].

Interventions for Minimally Verbal Children with ASD: In this longitudinal study, NIMH researchers found that a combination of three intervention approaches (Joint Attention, Symbolic Play, Enhanced Milieu Teaching, and a Speech-Generating Device), led to the greatest gains in spontaneous communication utterances and joint attention among minimally-verbal children with ASD [PMID: 26954267].

Autism Dissemination Education to Hispanic Community: Low income Hispanic families experience multiple barriers to accessing evidence-based information on ASD. This NIMH-funded study utilized a mixed-strategy intervention to create access to information in published biomedical research articles on ASD by distilling the content into parent-friendly English- and Spanish-language ASD Science Briefs and presenting them to participants using two socially-oriented dissemination methods. There was a main effect for short-term knowledge gains associated with the Science Briefs but no effect for the dissemination method. After 5 months, participants reported utilizing the information learned and 90% requested greater access to Science Briefs. These findings highlight the benefits of distilling biomedical research articles on ASD into parent-friendly educational products for currently underserved Hispanic parents [PMID: 26563948].

Transition Supports for College-age Students with ASD: Based on pilot research supported by NIMH, the Stepped Transition in Education Program for Students with ASD (STEPS) was developed to support students with ASD transitioning to college. Level One supports high school students and Level Two is for postsecondary students. The impact of STEPS on promotion of successful transition into college and positive outcomes for students during higher education is currently being evaluated in a randomized controlled trial [PMID: 28685409].

Intervention Therapies for Minimally Verbal Children with ASD: Researchers supported by an NIDCD Autism Centers of Excellence grant at Boston University focused on minimally verbal individuals with ASD and proposed an innovative intonation-based intervention. They published findings of an intervention trial where children provided with auditory mapping motor training showed significantly greater advances in producing more syllables and consonants than children given speech repetition therapy. Results from this intervention trial offer a promising new interventional approach for teaching spoken language to minimally-verbal children with ASD [PMID: 28928645].

Healthcare Assessment Tool for Individuals with ASD: An NIMH-supported study gathered data from adults with ASD and primary care providers (PCPs) to develop and evaluate tools to facilitate the primary health care of adults with ASD. The Autism Healthcare Accommodations Tool allows patients to create a personalized report that includes general health care and autism-related information and other resources for use by the PCP and patient. Preliminary results indicated that the tool positively impacted health care interactions between patients with autism and their providers [PMID: 27271730].

Virtual-reality Job Interview Tools for Individuals with ASD: Four RCTs funded by NIMH revealed that virtual-reality job interview training improved interviewing skills and the odds of obtaining a job offer among trainees with severe mental illness or ASD [PMID: 28292223].

Implementation of the *IACC Strategic Plan*

This section addresses subsection (l) of 399DD: “A description of the actions taken to implement and the progress made on implementation of the strategic plan developed by the Interagency Autism Coordinating Committee.” The table below summarizes the research and services activities of each agency listed in this Report that contribute to implementation of the *IACC Strategic Plan*. Details on the implementation activities of each agency are provided in the “ASD Progress and Expenditures” section of this Report.

Federal Involvement in the Implementation of the <i>IACC Strategic Plan</i> , by Agency								
Department/Agency	Research							Services
	Funds research relevant to <i>IACC Strategic Plan for ASD</i>							Administers ASD-relevant services and support programs
	Question 1 (Screening and Diagnosis)	Question 2 (Underlying Biology)	Question 3 (Risk Factors)	Question 4 (Treatments and Interventions)	Question 5 (Services)	Question 6 (Lifespan Issues)	Question 7 (Infrastructure and Surveillance)	
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 - Air Force (DoD-Air Force)		✓						
Department of Defense - Army (DoD-Army)	✓	✓	✓	✓	✓	✓		✓
Department of Education (ED)	✓			✓	✓	✓	✓	✓

Department/Agency	Research							Services
	Funds research relevant to IACC Strategic Plan for ASD							Administers ASD-relevant services and support programs
	Question 1 (Screening and Diagnosis)	Question 2 (Underlying Biology)	Question 3 (Risk Factors)	Question 4 (Treatments and Interventions)	Question 5 (Services)	Question 6 (Lifespan Issues)	Question 7 (Infrastructure and Surveillance)	
Department of Housing and Urban Development (HUD)								✓
Department of Justice (DOJ)								✓
Department of Labor (DOL)						✓		✓
Department of Transportation (DOT)								✓
Environmental Protection Agency (EPA)			✓					
Food and Drug Administration (FDA)								✓
Health Resources and Services Administration (HRSA)	✓	✓	✓	✓	✓	✓	✓	✓
Indian Health Service (IHS)								✓
National Institutes of Health (NIH)	✓	✓	✓	✓	✓	✓	✓	
National Science Foundation (NSF)	✓	✓	✓	✓	✓	✓	✓	
Social Security Administration (SSA)								✓
Substance Abuse and Mental Health Services Administration (SAMHSA)								✓

Table 25. Research and services activities of federal agencies that contribute to implementation of the IACC Strategic Plan.



Conclusion

Since the enactment of the Combating Autism Act in 2006, and its most recent reauthorization under the Autism CARES Act of 2014, federal agencies, in partnership with the community, have made significant strides in addressing many of the pressing needs of individuals and families affected by ASD. In the period covered by this report (FY 2014 - FY 2018), federally-funded programs and projects have increased knowledge on the prevalence of ASD in the U.S. population and how early in life ASD can be detected.

Recent studies supported by NIH have uncovered distinct differences in the brain development of children with ASD, as early as 6 months of age (i.e. before a formal diagnosis can currently be made). Federally-supported research is also revealing more about how autism develops and what risk factors may be involved. Studies supported by multiple agencies, including CDC, EPA, and NIH, have identified potential contributions to ASD risk from diverse environmental risk factors including dietary factors, air pollutants, and pesticides. Future research activities will need to weigh the impact of each of these factors in order to best develop personalized treatments for Individuals with ASD.

Advances in screening and diagnosis in ASD are also needed to maximize outcomes for people with ASD. Researchers are developing new screening and diagnostic tools that are more sensitive to ASD symptoms as well as more easily adopted by care practitioners. NIH-funded researchers are working to establish an evidence base for the impact of universal ASD screening by age 2. Meanwhile, activities funded by the CDC and other agencies aim to reduce the amount of time between initial ASD screening and first diagnostic evaluation. Combined, these efforts will likely lead to an increase in the number of children with ASD receiving early intervention, which has been demonstrated to lead to better behavioral outcomes.

While CDC most recently estimated the prevalence of autism in U.S. 8-year-old children at 1 in 59, data suggest that some racial disparities in diagnosis are decreasing. Agencies are increasingly harnessing the power of technology to facilitate information dissemination and service accessibility. For example, the Milestone Tracker app developed by the CDC educates parents about typical milestones during early childhood development. Research funded by AHRQ will enhance electronic health records, increasing their operability across systems. Additional efforts by ACF, HRSA, NIH, ED, and other agencies to increase outreach and service accessibility in underserved populations will potentially further reduce disparities in screening, diagnosis, and intervention.

NIH- and HRSA-supported studies of conditions that often co-occur with ASD (such as gastrointestinal disorders, sleep disruptions, and epilepsy) are contributing to intervention strategies. Also, 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. NSF also funds 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.

ED-funded activities 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 computer-assisted care and mental health therapeutics, AHRQ is similarly providing communities with valuable guidance on the evidence base of such therapies and interventions.

Recently, federal agencies have increased their attention on adolescents and adults with ASD. Both this Report and the *Report to Congress on Young Adults and Transitioning Youth with Autism Spectrum Disorder* have highlighted federal efforts to address this population as they age out of the public education system. ED supports several vocational rehabilitation programs to prepare and support young adults as they seek and gain employment. ACL provides assistive technologies that increase the independence of those with communication difficulties. HRSA-supported activities prepare individuals with ASD as the transition from pediatric to adult medical care. Additional research is needed to understand how to best meet the service needs of adults with autism as they continue their education, enter the workforce, seek appropriate housing, and otherwise live their lives to their maximum potential.

Recruiting and retaining trained care practitioners for individuals with ASD has long been an issue; this problem is particularly acute in rural and other underserved communities. Activities at agencies such as CMS, DOJ, DOL, HRSA, HUD, and SSA are identifying and evaluating best practices among services and supports across the country to bolster this workforce. Meanwhile, agencies including DoD, HRSA, IHS, SAMHSA, and NIH are developing practitioner 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.

Federal ASD efforts have greatly benefitted from increased interagency coordination in the period covered by this report. The Interagency Autism Coordinating Committee has engaged new federal partners that bring enhanced insight into services and support systems for individuals with ASD. Several multi-agency efforts, such as *Birth to Five: Watch Me Thrive!* (ACF, CDC, ED), the Center for Children’s Environmental Health (EPA, NIH), and the Accessible Transportation Technologies Research Initiative (ACL, DOT), will combine individual agency expertise in order to maximize effectiveness. The designation of a National Autism Coordinator and the convening of the Federal Interagency Workgroup on ASD (FIWA) has improved collaboration and information-sharing among federal agencies and departments. In particular, the completion of the *Report to Congress on Young Adults and Transitioning Youth with ASD* has identified key opportunities for enhanced collaboration in federally-funded research and services activities for this population.

To ensure continuing coordination among federal agencies and between federal and private partner organizations, the Interagency Autism Coordinating Committee will continue to provide 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, 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

- AAP:** American Academy of Pediatrics
- ABA:** Applied Behavioral Analysis
- ACC:** NIH Autism Coordinating Committee
- ACD:** Comprehensive Autism Care Demonstration
- ACE:** Autism Centers of Excellence
- ACF:** Administration for Children and Families
- ACL:** Administration for Community Living
- ADA:** Americans with Disabilities Act
- ADDM:** Autism and Developmental Disabilities Monitoring
- ADFM:** Active Duty Family Member
- ADOS:** Autism Diagnostic Observation Schedule
- AHRQ:** Agency for Healthcare Research & Quality
- AI/AN:** American Indian/Alaska Natives
- 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
- AOSI:** Autism Observation Scale for Infants
- ARP:** Department of Defense Autism Research Program
- ASD:** Autism Spectrum Disorder
- ASPE:** Office of the Assistant Secretary for Planning and Evaluation
- ATRP:** Autism Transitions Research Project
- ATTRI:** Accessible Transportation Technologies Research Initiative
- Autism CARES Act:** Autism Collaboration, Accountability, Research, Education, and Support Act of 2014
- BJA:** Bureau of Justice Assistance
- CAA:** Combating Autism Act of 2006
- CAAI:** Combating Autism Act Initiative
- CARA:** Combating Autism Reauthorization Act of 2011
- CCEH:** Center for Children’s Environmental Health

CDC: Centers for Disease Control and Prevention

CDMRP: Congressionally Directed Medical Research Programs

CER: Comparative Effectiveness Review

CHA: Children’s Health Act of 2000

CHIP: Children’s Health Insurance Program

CMHI: Children’s Mental Health Initiative

CMS: Centers for Medicare & Medicaid Services

CORA: Central Ohio Registry for Autism

CSESA: Center on Secondary Education for Students with Autism Spectrum Disorders

DBP: Developmental Behavioral Pediatrics

DBPNet: Developmental Behavioral Pediatrics Research Network

DD: Developmental Disability

DD Act: Developmental Disabilities Assistance and Bill of Rights Act

DHA: Defense Health Agency

DoD: Department of Defense

DoD-Army: Department of Defense-Army

DoD-AF: Department of Defense-Air Force

DOJ: Department of Justice

DOL: Department of Labor

DOT: Department of Transportation

DSM: Diagnostic and Statistical Manual of Mental Disorders

EBM: Evidence-Based Medicine

ECHO: Extended Care Health Option

ED: Department of Education

EEG: Electroencephalogram

EHR: Electronic Health Record

EMR: Electronic Medical Record

EPA: Environmental Protection Agency

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

ETA: Employment and Training Administration

FACA: Federal Advisory Committee Act

FDA: Food and Drug Administration

FIRST: Field Initiated and Innovative Research Studies

FIWA: Federal Interagency Workgroup on ASD

FOA: Funding Opportunity Announcement

FXS: Fragile X Syndrome

FY: Fiscal Year

HCBS: Home and Community-Based Services

HCT-RN: Health Care Transitions Research Network for Youth and Young Adults with ASD

HHS: Department of Health and Human Services

HRSA: Health Resources and Services Administration

HUD: Department of Housing and Urban Development

HW-RN: Healthy Weight Research Network

IACC: Interagency Autism Coordinating Committee

IC: NIH Institutes and Centers

ICDR: Interagency Committee on Disability Research

ICP: Indian Children’s Program

ID: Intellectual Disability

IDEA: Individuals with Disabilities Education Act

IEP: Individualized Education Program

IES: Institute of Education Sciences

IHE: Institution of Higher Education

IHS: Indian Health Service

IWG: Interagency Workgroup

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

LEND: Leadership Education in Neurodevelopmental Disabilities

MADDSP: Metropolitan Atlanta Developmental Disabilities Surveillance Program

M-CHAT: Modified Checklist for Autism in Toddlers

M-CHAT-R/F: Modified Checklist for Autism in Toddlers Revised with Follow-up

MCH: Maternal and Child Health

MCHB: Maternal and Child Health Bureau

MHS: Military Health System

NAC: National Autism Coordinator

NADFM: Non-Active Duty Family Member

NBB: NeuroBioBank

NCATS: National Center for Advancing Translational Sciences

NCBDDD: National Center on Birth Defects and Developmental Disabilities

NCCIH: National Center for Complementary and Integrative Health

NCCJD: National Center on Criminal Justice and Disability

NCEE: National Center for Education Evaluation and Regional Assistance

NCER: National Center for Education Research

NCES: National Center for Education Statistics

NCI: National Cancer Institute

NCSE: National Center for Special Education Research

NDAR: National Database for Autism Research

NEI: National Eye Institute

NHGRI: National Human Genome Research Institute

NHIS: National Health Interview Survey

NHLBI: National Heart, Lung, and Blood Institute

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

NIDILRR: National Institute on Disability, Independent Living, and Rehabilitation Research

NIEHS: National Institute of Environmental Health Sciences

NIGMS: National Institute of General Medical Sciences

NIH: National Institutes of Health

NIH RePORTer: NIH Research Portfolio Online Reporting Tool

NIMH: National Institute of Mental Health

NINDS: National Institute of Neurological Disorders and Stroke

NDAR: National Database for Autism Research

NLM: National Library of Medicine

NLTS 2012: National Longitudinal Transition Study 2012

NSCH: National Survey of Children's Health

NSF: National Science Foundation

OARC: Office of Autism Research Coordination

OD: Office of the Director, NIH

OJP: Office of Justice Programs

ORR: Office of Refugee Resettlement

OSEP: Office of Special Education Programs

OSERS: Office of Special Education and Rehabilitative Services

PCP: Primary Care Provider

PDD: Pervasive Developmental Disorder

PROMIS: NIH Patient Reported Outcome Measurement Information System

PTI: Parent Training and Information Centers

RCT: Randomized Controlled Trial

RFC: Residual Functional Capacity

RSA: Rehabilitation Services Administration

SAMHSA: Substance Abuse and Mental Health Services Administration

SBIR: Small Business Innovation Research

SDAR: Secondary Data Analysis Research Program

SEED: Study to Explore Early Development

SOE: Strength of Evidence

SSA: Social Security Administration

SSDI: Social Security Disability Insurance Program

SSI: Supplemental Security Income Program

STEPS: Stepped Transition in Education Program for Students with ASD

THBCE: Telebehavioral Health Center of Excellence

TPSID: Model Comprehensive Transition and Postsecondary Programs for Students with Intellectual Disabilities

TSC: Tuberous Sclerosis Complex

UC: University of California

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

VR: Vocational Rehabilitation

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

WIOA: Workforce Innovation and Opportunity Act of 2014

Appendix ii: Report to Congress on Activities Related to Autism Spectrum Disorder and Other Developmental Disabilities under the Combatting Autism Act of 2006 and the Combatting Autism Reauthorization Act of 2011 (FY 2010 – FY 2012): Summary and Highlights

Cross-Agency Coordination

The Interagency Autism Coordinating Committee (IACC) consists of 15 public and 15 federal members (in 2013) who convene on a regular basis (16 times in 2010, 10 times in 2011, 20 times in 2012, and 26 times in 2013) 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*. The first IACC Strategic Plan was issued in 2009 and updates were issued in 2010, 2011, 2012, and 2013.

Since 2008, the IACC has published the *ASD Research Portfolio Analysis Report*, which is a 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* was published in 2011, and the *2010 IACC ASD Research Portfolio Analysis Report* was published in 2012.

Each year, the IACC publishes the *Summary of Advances in ASD Research*, 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, 2010, 2011, and 2012 editions are available on the IACC website).

The IACC and 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, newsletters, 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](#) and formal [Requests for Information \(RFI\)](#). An RFI was issued in June 2010 concerning the 2011 update to the *IACC Strategic Plan*.

ASD Surveillance, Awareness, and Outreach

In 2012, CDC's [Autism and Developmental Disabilities Monitoring \(ADDM\)](#) Network published autism prevalence data indicating that 1 in 88 children in the U.S. has an autism spectrum disorder. 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. The CDC also played a lead role in conducting more focused epidemiologic studies of ASD among Somali-American children in Minneapolis.

CDC's "[Learn the Signs. Act Early.](#)" campaign has played an important role nationwide in raising awareness about early developmental milestones. The CAA/CARA strengthened the capacity of the program in educating parents, health care professionals, and early childhood educators about the importance of monitoring a child's development, seeking further evaluation when there is a concern, and beginning early intervention services as soon as possible. Since 2011, the CDC has supported three cohorts of [Act Early Ambassadors](#), who work to improve early identification and linkage to services in their state during their tenure.

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.

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, including 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), contain numerous strategies for working with children with ASD, suggested by experts from across the country.

With funding from ACL, 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.

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). 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. A second phase of SEED was initiated in 2011 (implemented in 2012). This expansion will allow for more detailed analyses of genetic and phenotypic ASD subtypes. By 2013, over 1,200 children have enrolled in SEED 2.

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 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 strengthens the conclusion of a [2004 comprehensive review by the Institute of Medicine](#) that there is not a causal relationship between certain vaccine type and autism.

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 present in pregnant women and infants. 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 was associated with a modest but statistically-significant decrease in risk for ASD, suggesting the potential that this antibody actually provides protective immunity.

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 environmental risk factors that may contribute to a person's susceptibility to neurodevelopmental disorders such as autism. They are also examining how biological markers, such as those related to immune system dysfunction, could help clarify why some children develop these disorders.

DoD-Army's Autism Research Program (ARP) aims to improve the lives of individuals with ASD now by promoting innovative research that advances the understanding of ASD and leads to improved outcomes. 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 2013, NIH's [Autism Centers of Excellence \(ACE\)](#) comprised 11 research centers and networks at major research institutions and universities across the country. ACE researchers are actively working to identify the causes of ASD and develop new and improved treatments.

NIH is also accelerating the pace of ASD research discoveries through large-scale, unprecedented resource and data-sharing initiatives. Most autism researchers whose projects involve human subjects have now made data sharing with the NIH [National Database for Autism Research \(NDAR\)](#) part of their proposed research. In addition, other private and public autism organizations are now linked with NDAR, meaning 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.

Development of Evidence-Based Autism Treatments

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.

- Since 2010, the AIR-P Network has completed five studies; published empirically based physician guidelines for the management of gastrointestinal issues, sleep, and attention deficit hyperactivity disorder (ADHD); and developed 10 toolkits for parents and providers.
- The AIR-B Network has completed and published guidelines for the implementation of psychosocial and related interventions for children with ASD and their families. The AIR-B has also 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.

AHRQ completed two Comparative Effectiveness Reviews (CERs) to provide a comprehensive synthesis of evidence examining the benefits and harms associated with various therapies for children (ages 2-12), and for adolescents and young adults (ages 13-30).

Innovative Screening, Diagnosis, and Intervention Investments

NIH supports several ongoing efforts to improve methods for ASD screening and diagnosis. An NIH-funded study supported by the American Recovery and Reinvestment Act identified an innovative brain imaging technique for advancing accurate, early diagnosis of ASD. Additionally, [investigators at an Autism Center of Excellence](#) demonstrated the feasibility and effectiveness of 5-minute parent survey that can screen for subtle signs of ASD during a child's 1-year well-baby check-up.

High-Quality Training of ASD Practitioners and Service Providers

Through funds provided by the 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. The capacity of these training programs increased every year between from 2010 to 2012.

ACL's Administration on Intellectual and Developmental Disabilities (AIDD) 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.

ED 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 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.

Best Practices in Service Provision

An AHRQ-funded project, [Innovative Adaptation & Dissemination of CER Products: Autism \(iADAPT-ASD\)](#), 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.

In 2011, CMS issued a [Report on State Services to Individuals with Autism Spectrum Disorders \(ASD\)](#), summarizing a nine-state study which assessed the implementation of evidence-based/promising practices covered by Medicaid through the lens of state experience. The report describes the types of ASD-related 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.

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.

ED's Office of Special Education Programs (OSEP) funds the [Center on Positive Behavioral Interventions and Supports \(PBIS\)](#), giving 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, ED 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.

ASD Services and Supports across the Lifespan

SAMHSA oversees the Congressionally-mandated Comprehensive Community Mental Health Services for Children and Their Families Program (short title: Child Mental Health Initiative (CMHI)), which provides funding to develop the infrastructure for a coordinated system of services and supports and to provide services to children with serious emotional disorders. 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.

ACL/AIDD supports [Developmental Disabilities Councils \(DDCs\)](#) in every state and territory. 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.

TRICARE has recently expanded availability of applied behavior analysis (ABA) services for eligible beneficiaries. In addition to expanding services available to Active Duty Family Members (ADFM), DoD launched a pilot program in 2013 to revise coverage of applied behavior analysis (ABA) services for Non-Active Duty Family Members (NADFM).

ACL/AIDD also 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 2010, ACL/AIDD launched 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. 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.

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 and the Combatting Autism Reauthorization Act of 2010 (FY 2010-FY 2012)*.

Appendix iii: CDC-Supported ASD Publications (2014 to May 2018)

Autism and Developmental Disabilities Monitoring (ADDM) Network

Baio J, Wiggins L, Christensen DL, et al. Prevalence of Autism Spectrum Disorder Among Children Aged 8 Years — Autism and Developmental Disabilities Monitoring Network, 11 Sites, United States, 2014. *MMWR Surveill Summ* 2018;67(No. SS-6):1-23.

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Bakian AV, Bilder DA, Carbone PS, Hunt TD, Petersen B, Rice CE. Centers for Disease Control and Prevention. Prevalence of Autism Spectrum Disorder Among Children Aged 8 Years — Autism and Developmental Disabilities Monitoring Network, 11 Sites, United States, 2010. *MMWR Surveill Summ*. 2014;63(SS02);1-21.

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Christensen DL, Bilder DA, Zahorodny W, Pettygrove S, Durkin MS, Fitzgerald RT, Rice C, Kurzius-Spencer M, Baio J, Yeargin-Allsopp M. Prevalence and characteristics of autism spectrum disorders among 4-year-old children in the Autism and Developmental Disabilities Monitoring Network. *Journal of Developmental and Behavioral Pediatrics*. January 2016.

Dickerson AS, Rahbar MH, Han I, Bakian AV, Bilder DA, Harrington RA, Pettygrove S, Durkin M, Kirby RS, Wingate MS, Tian LH, Zahorodny WM, Pearson DA, Moyé LA 3rd, Baio J. Autism spectrum disorder prevalence and proximity to industrial facilities releasing arsenic, lead or mercury. *Science of the Total Environment*. July 2015.

Durkin MS, Maenner MJ, Baio J, Christensen D, Daniels J, Fitzgerald R, Imm P, Lee LC, Schieve LA, Van Naarden Braun K, Wingate MS, Yeargin-Allsopp M. Autism spectrum disorder among us children (2002-2010): Socioeconomic, racial, and ethnic disparities. *Am J Public Health* 2017;107:1818-1826.

Maenner MJ, Rice CE, Arneson CL, Cunniff C, Schieve LA, Carpenter LA, Van Naarden Braun, Kirby RS, Bakian AV, Durkin MS. [Potential impact of DSM-5 criteria on autism spectrum disorder prevalence estimates](#). JAMA Psychiatry. March 2014.

Rubenstein, E, Daniels, J, Schieve, LA, Christensen, DL, Van Naarden Braun, K, Rice, CE, Bakian, AV, Durkin, MS, Rosenberg, SA, Kirby, RS, Lee, LC. [Trends in special education eligibility among children with autism spectrum disorder, 2002-2010](#). Public Health Rep. 2018;133(1):85-92.

Schieve LA, Clayton HB, Durkin MS, Wingate MS, Drews-Botsch C. [Comparison of perinatal risk factors associated with autism spectrum disorder \(ASD\), intellectual disability \(ID\), and co-occurring ASD and ID](#). Journal of Autism and Developmental Disorders. March 2015.

Schieve LA, Tian LH, Baio J, Rankin K, Rosenberg D, Wiggins L, Maenner MJ, Yeargin-Allsopp M, Durkin M, Rice C, King L, Kirby RS, Wingate MS, Devine O. [Population attributable fractions for three perinatal risk factors for autism spectrum disorders, 2002 and 2008 Autism and Developmental Disabilities Monitoring \(ADDM\) Network](#). Annals of Epidemiology. January 2014.

Soke GN, Maenner MJ, Christensen D, Kurzius-Spencer M, Schieve LA: [Brief report: Estimated prevalence of a community diagnosis of autism spectrum disorder by age 4 years in children from selected areas in the United States in 2010: Evaluation of birth cohort effects](#). J Autism Dev Disord 2017a;47:1917-1922.

Study to Explore Early Development (SEED)

Andrews SV, Ellis SE, Bakulski KM, Sheppard B, Croen LA, Hertz-Picciotto I, Newschaffer CJ, Feinberg AP, Arking DE, Ladd-Acosta C, Fallin MD: [Cross-tissue integration of genetic and epigenetic data offers insight into autism spectrum disorder](#). Nature Communications 2017.

Andrews SV, Ladd-Acosta C, Feinberg AP, Hansen KD3, Fallin MD: [“Gap hunting” to characterize clustered probe signals in Illumina methylation array data](#). Epigenetics Chromatin 2016.

Bradley CB, Browne EN, Alexander AA, Collins J, Dahm JL, DiGuseppi CG, Levy SE, Moody EJ, Schieve LA, Windham GC, Young L, Daniels JL: [Demographic and operational factors predicting study completion in a multisite case-control study of preschool children](#). Am J Epidemiol 2018.

DiGuseppi CG, Daniels JL, Fallin DM, Rosenberg SA, Schieve LA, Thomas KC, Windham GC, Goss CW, Soke GN, Currie DW, Singer AB, Lee LC, Bernal P, Croen LA, Miller LA, Pinto-Martin JA, Young LM, Schendel DE. [Demographic profile of families and children in the Study to Explore Early Development \(SEED\): Case-control study of autism spectrum disorder](#). Disability and Health Journal. January 2016.

DiGuseppi C, Levy SE, Sabourin KR, Soke GN, Rosenberg S, Lee LC, Moody E, Schieve LA: *Injuries in children with autism spectrum disorder: Study to explore early development (seed)*. J Autism Dev Disord 2017.

Ladd-Acosta C, Shu C, Lee BK, Gidaya N, Singer A, Schieve LA, Schendel DE, Jones N, Daniels JL, Windham GC, Newschaffer CJ, Croen LA, Feinberg AP, Daniele Fallin M. *Presence of an epigenetic signature of prenatal cigarette smoke exposure in childhood*. Environmental Research. January 2016.

Mitra I, Tsang, K, Ladd-Acosta C, Croen L, Aldinger, KA, Hendren, RL, Weiss, LA: *Pleiotropic Mechanisms Indicated for Sex Differences in Autism*. PLoS Genetics 2016.

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Rubenstein E, Edmondson Pretzel R, Windham GC, Schieve LA, Wiggins LD, DiGuseppi C, Olshan AF, Howard AG, Pence BW, Young L, Daniels J: *The broader autism phenotype in mothers is associated with increased discordance between maternal-reported and clinician-observed instruments that measure child autism spectrum disorder*. J Autism Dev Disord 2017.

Rubenstein E, Schieve L, Bradley C, DiGuseppi C, Moody E, Thomas K, Daniels J: *The prevalence of gluten free diet use among preschool children with autism spectrum disorder*. Autism Res 2017.

Rubenstein E, Wiggins LD, Schieve LA, Bradley C, DiGuseppi C, Moody E, Pandey J, Pretzel RE, Howard AG, Olshan AF, Pence BW, Daniels J: *Associations between parental broader autism phenotype and child autism spectrum disorder phenotype in the Study to Explore Early Development*. Autism 2018.

Schieve LA, Drews-Botsch C, Harris S, Newschaffer C, Daniels J, DiGuseppi C, Croen LA, Windham GC: *Maternal and paternal infertility disorders and treatments and autism spectrum disorder: Findings from the study to explore early development*. J Autism Dev Disord 2017;47:3994-4005.

Schieve LA, Tian L, Dowling N, Croen L, Hoover-Fong J, Alexander A, Shapira SK: *Associations between the 2nd to 4th digit ratio and autism spectrum disorder in population-based samples of boys and girls: Findings from the Study to Explore Early Development*. J Autism Dev Disord 2018.

Schieve LA, Tian LH, Drews-Botsch C, Windham GC, Newschaffer C, Daniels JL, Lee LC, Croen LA, Fallin MD: [Autism spectrum disorder and birth spacing: Findings from the study to explore early development \(SEED\)](#). *Autism Res* 2017.

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Soke GN, Rosenberg SA, Rosenberg CR, Vasa RA, Lee LC, DiGuseppi C: [Self-injurious behaviors in children with autism spectrum disorder enrolled in the Study to Explore Early Development](#). *Autism* 2017.

Wiggins LD, Barger B, Moody E, Soke G, Pandey J, Levy S: [Brief report: The ADOS calibrated severity score best measures autism diagnostic symptom severity in pre-school children](#). *J Autism Dev Disord* 2017a.

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Wiggins LD, Tian LH, Levy SE, Rice C, Lee LC, Schieve L, Pandey J, Daniels J, Blaskey L, Hepburn S, Landa R, Edmondson-Pretzel R, Thompson W: [Homogeneous subgroups of young children with autism improve phenotypic characterization in the study to explore early development](#). *J Autism Dev Disord* 2017b.

Appendix iv: HRSA-Supported ASD Research Details

Number of Trainees by Fiscal Year and Grant Program						
Trainee type	FY 2014			FY 2015		
	LEND	DBP	Total	LEND	DBP	Total
Short term	12,547	2,683	15,230	12,772	2,454	15,226
Medium term	3,703	431	4,134	3,196	441	3,637
Long term	1,297	48	1,345	1,339	50	1,389

Table 26. Number of HRSA-supported trainees by fiscal year and grant program. Source: Discretionary Grant Information System

Autism Intervention Research Network on Physical Health (AIR-P) Studies		
Year Initiated	Study Title	Brief Description
2016	Two-Phase Study of Probiotics for Quality of Life Through Gastrointestinal (GI) and Emotional Stability in Youth With ASD and Anxiety: Single-Site Pilot Trial Followed by 3-Site RCT	This study aimed to improve quality of life for children with ASD and their parents by exploring the microbiome-mental/physical function connection for ASD, GI dysfunction, and anxiety to potentially improve GI and emotional function.
2016	First Impressions: Strategies To Enhance Initial Adult Care Visits for Transitioning Youth With ASD	This study aimed to test an intervention designed to prepare youth and their families for the transition to adult care, increase the capacity of physicians and office staff in primary care adult clinics to welcome referred youth with ASD. The study also intended to establish a single point of contact in the adult primary care office by working with community health center pediatric and adult primary care clinics.
2016	A Novel Walking Route Pilot Program Aimed at Promoting Physical Activity in Children With Autism	This study aimed to increase physical activity levels among children with ASD by creating a walking route protocol for the children, determining the feasibility of using walking routes as a new physical activity opportunity, and determining the preliminary efficacy of walking routes for children with ASD who are obese.
2016	Study of Oxytocin in ASD To Improve Reciprocal Social Behaviors	This study aimed to investigate the effects of intranasal oxytocin, a bone anabolic hormone, on bone mineral density (BMD) and structure in children with ASD by conducting BMD assessments.

Year Initiated	Study Title	Brief Description
2016	Development of a Resiliency Program for Parents of Children With Autism Spectrum Disorder	This study aimed to implement a national parental resiliency program by refining the resiliency treatment program consisting of eight virtual 1-hour group sessions.
2016	Clonidine and Trazodone for Sleep Disturbance in Children With ASD	This study aimed to evaluate the feasibility of conducting a large multisite trial of Clonidine and Trazodone for sleep disturbance to address the general lack of systematic data available to guide practitioners by testing the efficacy of Clonidine following a brief sleep hygiene intervention.
2015	Extension for Community Healthcare Outcomes (ECHO) Autism	This study aimed to increase provider knowledge, improve clinical practice, and enhance self-efficacy in the care of children with autism spectrum disorder (ASD) by assessing the impact of a collaborative telehealth intervention using ECHO technology with primary care providers.
2015	Improving Participation in Dental Care and Oral Health Outcomes for Underserved Children With ASD	This study aimed to improve home dental hygiene, oral health, and compliance with dental procedures in underserved populations with ASD by comparing the efficacy of the AIR-P Dental Toolkit with a combined regimen involving the toolkit and a parent-mediated behavioral intervention.
2015	Physical Exercise To Reduce Anxiety in Underserved Children With ASD	This study aimed to provide critical insight into the feasibility and efficacy of a physical exercise intervention to reduce anxiety in children from underserved families and aid in the development of an evidence-based physical exercise intervention toolkit for the treatment of anxiety as well as other behaviors and improvement of physical health in children with ASD from underserved populations.
2015	Exploration of the Development and Trajectory of Daily Living Skills in Children and Adolescents With Autism Spectrum Disorder	This study aimed to (1) explore the effects of demographic variables (e.g., age, gender, race, family size) and individual variables (i.e., IQ, ASD symptomatology, internalizing/externalizing symptoms, and language abilities) on the development of daily living skills as measured by the Vineland Adaptive Behavior Scales, 2nd Edition; (2) determine if there are subtypes of daily living skills in children and adolescents with ASD; and (3) explore the trajectory of daily living skills development over time using longitudinal data.
2015	Exploration of the Relationship Between Race/Ethnicity and Behavioral Co-Morbidities and Medication Treatment in Children With Autism Spectrum Disorder	This secondary data analysis aimed to understand whether disparities in diagnosis and treatment of behavioral co-morbidities in children with ASD exist by exploring in a population of children with ASD the relationship among (1) race/ethnicity; (2) behavioral co-morbidities (attention deficit hyperactivity disorder [ADHD], anxiety, depression, aggression, and disrupted sleep); and (3) the use of medications for those co-morbidities.
2015	Characterizing Underserved Populations Participating in the ATN: Evaluating Disparity Through Demographic Influences	This secondary data analysis of populations participating in the Autism Treatment Network (ATN) aimed to (1) understand the disparity of services found in ASD populations, including those with low socioeconomic status; (2) expand the ability to generalize the results; and (3) share the findings with clinicians, social workers, and the public, which would lead to earlier diagnosis and treatment of ASD by examining demographic factors found to affect the age of diagnosis.

Year Initiated	Study Title	Brief Description
2014	Effectiveness of Early Intensive Behavioral Intervention Services for Children With Autism Spectrum Disorders	This study aimed to identify variation in the receipt of early intensive behavioral intervention (EIBI) services for children with ASD in relation to the severity of the condition and other characteristics and to calculate quality-adjusted life year gains for children with ASD from EIBI services.
2014	Communication Deficits and the Motor System in ASD: Dissecting Patterns of Association and Dissociation Between Them	This study aimed to understand the relationship between motor, language, and social measures in individuals on the autism spectrum by exploring the ATN database.
2014	Relationship Between Subtypes of Restricted and Repetitive Behaviors and Sleep Disturbance in ASD	This study aimed to explore the relationship between insistence on sameness behaviors and repetitive sensory motor behaviors associated with sleep disturbance in individuals with ASD by examining factors related to immune markers and whole blood serotonin. The study also intended to determine how stress response, gastrointestinal disorders, immunity, and the serotonin system interact in ASD.
2014	Bone Accrual Rates in Boys With Autism Spectrum Disorder	This study aimed to reexamine boys with ASD and controls from an earlier AIR P research study and evaluate changes in BMD over time and to examine volumetric BMD, microarchitecture, and strength estimates.
2014	Expanding Capacity of Primary Care To Care for Children With Autism Spectrum Disorder	This study aimed to incorporate an evidence supported toolkit and clinical pathway for identifying and managing associated physical problems for primary care clinicians by developing a system to support primary care clinicians in caring for children with ASD.
2014	Improving Hospitalizations for Children With ASD: Testing the Cost and Clinical Efficacy of Integrated Behavioral Intervention	This study aimed to implement and test a specific brief Applied Behavior Analysis model for assessing and responding to severe challenging behavior during acute medical and behavioral hospitalization for children with ASD. The study also intended to evaluate the impact of this program by conducting a randomized trial across both medical and psychiatric hospital settings to improve outcomes at the child (e.g., medical/behavioral needs); family (e.g., improved satisfaction with care); provider (e.g., improved morale and sense of efficacy in providing care); and system (e.g., diminished stays, dramatic reduction in costs and noncompensated care) levels.
2012	Treatment of Overweight Induced by Antipsychotic Medication in Young People With ASD	This double blind, placebo controlled randomized trial aimed to determine whether metformin can decrease weight gain among children with ASD on atypical antipsychotic medication.

Table 27. Autism Intervention Research Network on Physical Health (AIR-P) studies.

AIR-P Tools and Guidelines	
Tool/Guideline Name	Brief Description
EEG Guide for Parents	Parents and providers may have concerns or questions about how to help children with ASD successfully complete an EEG. Two toolkits (one for parents and one for providers) were made available to provide information about the EEG procedure, how a child's ASD diagnosis might affect his or her experience, and how to help children with ASD successfully prepare for and complete an EEG.
EEG Guide for Providers	Parents and providers may have concerns or questions about how to help children with ASD successfully complete an EEG. Two toolkits (one for parents and one for providers) were made available to provide information about the EEG procedure, how a child's ASD diagnosis might impact his or her experience, and how to help children with ASD successfully prepare for and complete an EEG.
Guideline on the treatment of irritability and problem behaviors	The combined AIR-P/ATN network developed systematic ways to assess and treat irritability and problem behaviors when they coexist with ASD. This guideline provides methods for managing this and other coexisting conditions for which management was previously highly variable or sporadic. This guidance is intended for parent and professional communities.
Guideline on treatment of anxiety	The combined AIR-P/ATN network developed systematic ways to assess and treat coexisting conditions such as ASD and anxiety. This guideline provides methods for managing this and other coexisting conditions for which management was previously highly variable or sporadic. This guidance is intended for parent and professional communities.
Melatonin and Sleep Problems: A Guide for Parents	Melatonin is a common medicine a doctor or healthcare provider may suggest to help improve sleep. This toolkit provides parents with information about melatonin and helps parents decide if melatonin is right for their child.
Puberty and Adolescence	All parents eventually face the challenge of teaching their children about the natural changes of puberty. However, parents of preteens with ASD may need the help of additional strategies to ease the transition. This tool provides guidance on the subject of puberty that can be directly applied to preteens with ASD. The tool aims to increase families' understanding of puberty and their ability to adapt to these changes with confidence.

Table 28. AIR-P tools and guidelines.

Autism Intervention Research Network on Behavioral Health (AIR-B) Studies		
Year Initiated	Study Title	Goal of Study
2015	Mind the Gap	This study aimed to address the critical need to increase access to care for underresourced children with ASD and their families by conducting several focus groups and interviews with parents of low-income, minority children with ASD across different sites (UCLA, UC Davis, U Penn, and U Rochester) to better understand challenges, barriers, and needs in the community.
2015	Building Better Bridges	This study aimed to identify the barriers to successful transitions between educational systems for children with ASD by conducting focus groups and interviews with parents of children with ASD across different sites (UCLA, UC Davis, U Penn, and U Rochester) to identify transition barriers. The findings informed an intervention to improve transition outcomes for children with ASD and their families.
2011	Remaking Recess	Remaking Recess is an intervention that focuses on increasing social engagement between children with ASD (ages 5–11 years old) and their typical peers during the less structured times of the school day. Trained interventionists worked with school staff members (particularly the one-on-one aides) to employ strategies that aimed to increase the quantity and quality of peer engagement.
2011	Tools for Teachers	The STAT (Schedules, Tools, and Activities for Transitions in the Daily Routine) intervention was designed to improve behavior and transitions among students with ASD in special education classrooms by using behavioral strategies found in functional routines to address classroom management and environmental structures in these classrooms.

Table 29. Autism Intervention Research Network on Behavioral Health (AIR-B) studies.

AIR-B Tools	
Tool Name	Description
PARTNER	This tool consists of surveys to measure the impact of engagement on the interagency collaboration of community partners.
Playground Observation of Peer Engagement	This tool is an approach to coding and observing the way that children interact with each other on the playground. Using this measure, one can track a child's engagement in activities, engagement with each other, and whether they initiated and responded to others. Use of this tool can help to determine the efficacy of interventions and areas where additional support is needed.
Remaking Recess Booklet	This booklet was developed to improve the social inclusion of elementary school-aged children with ASD through facilitated interactions with their peers. This booklet provides school personnel with naturalistic strategies to use within their daily routine and during interactions with their students with ASD and their peers.
Social Dynamics of Intervention	This network tool explores the different networks and individuals supporting the student with ASD as they transition through school.
Social Menus	Social menus are an intervention tool created to generate conversations and increase engagement between children with ASD and their peers during lunch time at school. Much like "ice-breakers," these menus are fun and interesting ways for children to connect with the students around them.
Social Networks	This tool is a measure of children's interconnectivity in the classroom. Children are asked to name their closest friends and recall who hangs out with whom. This information is then used to track how well children integrate with their peers' social structure, noting who is popular, who is isolated, and who is in between.
STAT Manual	This manual was developed to support the STAT program. The manual's goal is to provide professionals with guidelines for assisting K–5 students with ASD in daily classroom routine transitions.

Table 30. AIR-B tools.

Developmental Behavioral Pediatrics Research Network (DBPNet) Studies		
Year Initiated	Study Title	Brief Description
2018 planned	Autism Diagnostic Observation Schedule (ADOS) Study	This study aimed to identify when the ADOS is needed or not needed to enhance clinical decisionmaking regarding an ASD diagnosis.
2018 planned	A Retrospective Description of the Effectiveness and Adverse Effects of Stimulants and Alpha-2 Agonists Used by Developmental-Behavioral Pediatricians for the Treatment of ADHD in Preschool Aged Children	The primary objectives of this study were to determine the percentage of preschool-aged children with ADHD who responded positively to stimulants and alpha-2 agonists (A2A) based on a review of data in the EHR and to determine if there was a difference in the positive response rate to these two classes of medication. The secondary objectives were to describe the type and frequency of adverse effects to stimulants and A2A when prescribed for the treatment of preschool-aged children for ADHD.
2017	Enhancing Care of Children With Complex Autism	This study aimed to assess the effect of an educational intervention on shared decisionmaking in the care of children with complex ASD.
2015	Project EARLY	This study aimed to determine if a family navigator could improve access to ASD diagnostic and treatment services (including early intervention services) and improve outcomes for children who screen positive for ASD at pediatric primary care centers serving low-income communities.
2014	Preliminary Validation of Selected Pediatric PROMIS Measures in Children With ASD	This study aimed to examine the validity of three NIH PROMIS measures (Stress Experiences, Family Involvement, and Peer Relationship) in children with ASD.
2014	Preliminary Validation of PROMIS Self-Report Measures of Peer Relationships and Psychological Stress in Youth With ASD	This study investigated the validity of two measures developed as part of NIH PROMIS when completed by youth aged 12–17 with ASD reading at a third grade level and by their parents.
2013	Maternal Immune Status and Autism Severity	This study investigated whether mothers of children with ASD have specific antibodies in their blood that predict the severity of ASD in their children. The study was conducted to determine if findings at one DBPNet site could be replicated at two other sites.
2012	Extracting Electronic Health Record (EHR) Data on Use of Psychotropic Medications in DBPNet: Costs, Feasibility, and Practice Variation	This study aimed to determine the feasibility of using EHR data for research on the clinical practices and variation in clinical practices across sites by extracting data on the diagnoses children received and the psychotropic medications prescribed at three DBPNet sites.
2011	Developmental-Behavioral Pediatrics Practice Variation in the Diagnosis and Treatment of ADHD and Autism	This study aimed to identify similarities and differences in the assessment and treatment of ADHD and ASD across sites.
2011	What Is the Scope of Practice for DBPs at Academic Medical Centers	This study aimed to identify the reasons that children are referred to developmental and behavioral pediatricians (DBPs).

Table 31. Developmental Behavioral Pediatrics Research Network (DBPNet) studies.

Healthy Weight Research Network (HWRN) Studies

Year Initiated	Study Title	Goal of Study
2017	Trajectory of Body Mass Index in Children With Autism Spectrum Disorders: A Follow-Up to a Feeding Intervention	This project followed up with participants from a randomized controlled (wait-list) trial on parent training for feeding, in which 42 parents of children with ASD aged 2–7 learned behavioral strategies to increase their children’s acceptance of new foods, improve their children’s behavior during meals, and teach self-help skills related to meals.
2017	Exploring Physical Activity Among Preschoolers With Developmental Delay and Autism	This study aimed to (1) develop a reliable observational instrument to measure the PA of preschoolers with developmental delay (2) describe the PA behaviors of preschoolers with DD in the preschool setting; and (3) identify associations between the PA behaviors of preschoolers with DD and features of the social and physical environment within the preschool setting.
2017	Does Food Addiction Mediate the Relationship Between BMI and Autism Spectrum Disorder?	This study sought to identify possible psychological mechanisms underpinning overeating and its links to increased body mass index (BMI) in children with ASD.
2017	Facilitating Management of Overweight and Obesity in Children With Autism in Primary Care	This project sought to provide an in-depth understanding of the potential barriers and facilitators to the successful implementation of guideline-recommended care or interventions for children with ASD.
2017	How Concerned Are Parents About Obesity in Their Children With ASD? (working title)	This study aimed to use newly released data from the 2016 National Survey of Children’s Health to update obesity prevalence estimates and explore how parental concern may differ between parents of children with and without ASD.
2016	HWRN Research Agenda Survey	A survey was developed to obtain input on the HWRN research agenda. The survey was disseminated to HWRN members, associate members, newsletter subscribers, and through community networks.
2015	Diet Quality, Parental Perceptions and Weight Gain Among Adolescents With Intellectual and Developmental Disabilities	This study aimed to identify important predictors of diet quality among adolescents with IDD enrolled in an ongoing treatment trial. Funding from HWRN allowed the team to leverage a larger NIH-funded study to obtain data on key variables hypothesized to play important roles in influencing diet quality and weight loss for adolescents with an IDD.
2015	An Adaptive Research Design to Optimize Weight Management Intervention in Young Children	This study aimed to determine the impact of a pilot adaptive weight management intervention on health outcomes for families of 4- to 8-year-olds with ASD and overweight, and to evaluate the acceptability and feasibility of the intervention.
2015	Using Dance to Promote Fitness and Well-Being in Adolescent Girls With Intellectual Disabilities	This pilot study tested the feasibility of a 10-week dance intervention for 16–20 adolescent girls with IDs that included group dance classes held at a YMCA and an at-home practice component. Changes in cardiorespiratory fitness and participants’ physical self-perception were evaluated.

Year Initiated	Study Title	Goal of Study
2015	Contextual Correlates of Regular Physical Activity (PA) in Children With and Without Intellectual Disability (ID)	Researchers conducted an exploratory secondary data analysis using data from the National Center for Health Statistics of the PA of youth with and without IDs.
2015	The Effect of Age on the Prevalence of Obesity Among US Youth With Autism Spectrum Disorder	This study sought to assess the association between age and the prevalence of obesity among children with and without ASD in the 2011–2012 National Survey of Children’s Health.
2015	Management of Overweight and Obesity in Children With Autism Spectrum Disorders by Developmental and Behavioral Pediatricians	This project aimed to understand how developmental pediatricians viewed obesity in the population of children with ASD/DDs. Using electronic medical records available from three DBP practices in DBPNet, the study examined the prevalence of obesity in children with ASD/DDs and determine the extent to which this problem is identified by DBPs. Factors associated with providers’ identification of obesity were examined.
2015	Becoming Obese: The Incidence of Obesity in Early Elementary Grade Schoolchildren With Autism Spectrum Disorder (working title)	This study sought to compare incidence of obesity between children with and without ASD in second grade and third grade using data from the Early Childhood Longitudinal Study-Kindergarten cohort.
2014	Family-Based Weight Loss Treatment for ASD (FBT-ASD)	This project implemented a weight-loss treatment that combines parenting skills and weight-loss strategies tailored for parents of overweight and obese children ages 5–13 with a diagnosis of ASD.
2014	Promotion of Physical Activity in Adolescents With Intellectual and Developmental Disabilities	This 12-week pilot study explored using technology to deliver a physical activity program to 30 adolescents with intellectual and developmental disabilities (IDDs) using video conferencing via tablet computer.
2014	Intellectual Disability Is Associated With Increased Risk for Obesity in a Nationally Representative Sample of US Children	This study sought to determine the prevalence of obesity in children aged 10–17 with IDs in comparison to children without an ID in the U.S. population. The study also compared family meal frequency, physical activity, and sedentary behavior of those with and without IDs.
2013	Influence of Race/Ethnicity and Sex on Food Selectivity Among Children With Intellectual Disabilities (ID)	Selective eating is linked to poor nutrient intake and may put children at increased risk of adult chronic disease. Research has suggested that children with developmental disabilities (DDs) are more food selective than typically developing children, but race/ethnicity and sex differences have not been explored. Therefore, this study examined food selectivity in a diverse community-based convenience sample of children with IDs aged 3–8 years.

Table 32. Healthy Weight Research Network (HWRN) studies.

HWRN Tools and Guidelines	
Tool Name	Description
“Let’s Go” toolkits by Maine Medical Center and HWRN	These toolkits support professionals who work with children with IDs and DDs. The objective of these toolkits is to provide resources for creating opportunities for all children to lead healthy lives. The toolkits aim to increase healthy eating and physical activity and decrease the risk of obesity among children with these disabilities.
Assessing Community Satisfaction With Community Based Participatory Research	This survey assesses the satisfaction of HWRN Advisory Board members and conference participants with their level of their engagement in projects about children and families with disabilities.
Expert Panel Recommendations on Obesity Management by Primary Care Providers for Children With ASD	The expert panel prepared the first set of recommendations on obesity management in children with ASD for dissemination to the public.
Measure of Adaptive Behaviors Surrounding Eating	This tool is used by clinicians and researchers to assess adolescents’ ability to engage in behaviors such as assisting with meal preparation and feeding themselves. These questions respond to a lack of appropriate existing measures to assess engagement in adaptive behaviors surrounding eating. Although this new adaptive eating behaviors measure is not fully validated, it provides a useful tool for research and clinical communities interested in assessing adaptive behaviors surrounding eating.
Nutrition Education Workshops for Adults With Disabilities	This manualized series of 11 workshops is a 6-month interactive curriculum for people with DDs and their care providers. Its development was supported in part by a 2014 grant from the National Institutes of Health.
Positive Health Practices Curriculum for Adults With Developmental Disabilities	This manualized intervention—available in paper and web-based formats—promotes healthy eating and physical activity for adults with disabilities. Its development was sponsored in part in 2015 by the Pennsylvania Office of Developmental Programs’ Department of Public Welfare.
Strategies to Optimize Healthy Eating on a Low Budget	This tool was developed for people on a limited food budget to assist in buying and preparing healthy food. Because many people with disabilities have modest incomes, the tool provided information on how they and their families can navigate this difficult subject.
Video Sports Illustrated for Children With Disabilities	This interactive tool shows a video of children with disabilities playing half a dozen sports: baseball, soccer, swimming, track and field, basketball, and Wii-sports. Children who watch the video have the opportunity to describe their level of enthusiasm for each sport. At the end, they list their two favorite sports. Because the tool is visual rather than verbal, it is most appropriate for children with disabilities who have communication difficulties.

Table 33. HWRN tools and guidelines.

Health Care Transitions Research Network (HCT-RN) Studies		
Year Initiated	Study Title	Goal of Study
2017	Collaborative Improvement Network for Transition in Residency Training	Medicine-Pediatrics residency training programs will be recruited for a collaborative improvement network to conduct rapid cycle improvement tests to refine and optimize the process of implementing the Health Care Transition Curriculum for Primary Care Residents.
2016	A National Research Agenda for the Transition of Youth With Autism	A Delphi survey was distributed to HCT-RN Advisory Board members that asked them to rate lists of research topics according to perceived importance. Participants asked to provide their ratings in multiple phases because the list of topics presented was refined over the course of each round of participant ratings. The top-rated research topics set the official HCT-RN research agenda.
2015	Stakeholder Perspectives on Research and Practice in Autism and Transition	This study aimed to identify gaps in current research and practice, as well as current research infrastructure needs. Key-informant interviews were conducted with researchers, professionals/clinicians, young adults with ASD, and parents of young adults with ASD.
2015	A Health Care Transition Curriculum for Primary Care Residents: Identifying Goals and Objectives	Medical professionals with expertise in healthcare transition were recruited to participate in a survey to assist in the development of a healthcare transition curriculum for primary care physicians using a modified Delphi process to determine curricular goals and objectives, feasibility of developing activities for objectives, and appropriateness of objectives for specified learners.

Table 34. Health Care Transitions Research Network (HCT-RN) studies

HCT-RN Tools and Guidelines	
Tool/Guideline Name	Brief Description
Medical Summary for Young Adults With Intellectual Disabilities or Developmental Disabilities (Essential Clinical Information)	This summary of key medical record elements contains essential, disease-specific information needed for communication between pediatric and adult clinicians. This record is to be completed by the pediatric or other sending clinician, shared with the youth and family, and then sent to the receiving adult clinician.
Self-Care Assessment for Parents and Caregivers of Young Adults With Intellectual Disabilities or Developmental Disabilities	This assessment tool is filled out by the parent and/or caregiver of the youth with IDs and used by the adult care team to assess any remaining gaps in self-care knowledge and skills or additional issues that must be addressed to ensure optimal management of the medical condition(s).
Self-Care Assessment for Young Adults With Intellectual Disabilities or Developmental Disabilities	This assessment tool, written at a fourth grade literacy level, is to be filled out by the youth with IDs and used by the adult care team to assess any remaining gaps in self-care knowledge and skills or additional issues that must be addressed to ensure optimal management of the medical condition(s).
Transition Care Guideline	Consensus-building activities to establish transition care guidelines occurred during the HCT-RN Design Meeting through the designated Quality Improvement and Practice work group. The HCT-RN developed transition care guidelines in collaboration with key stakeholders as part of the network's overall mission to promote best practices in healthcare transitions in national professional organizations for physicians.
Transition Readiness Assessment for Parents and Caregivers of Youth With Intellectual Disabilities or Developmental Disabilities (Pediatric)	This assessment tool is filled out by parents and/or caregivers of the youth with IDs and then used by the pediatric or clinical care team to facilitate conversation about the youth's needs for management of his/her health and healthcare. This tool indicates the elements related to the clinical condition that should be assessed and documented by the transferring pediatric practice.
Transition Readiness Assessment for Youth With Intellectual Disabilities or Developmental Disabilities (Pediatric)	This assessment tool is filled out by the youth with intellectual disabilities (IDs) and then used by the pediatric or clinical care team to facilitate conversation about the youth's knowledge and skill needs for management of his/her health and healthcare. This tool is written at a fourth grade literacy level and indicates the elements related to the clinical condition that should be assessed and documented by the transferring pediatric practice.

Table 35. HCT-RN tools and guidelines.

Field-Initiated Innovative Research Program (FIRST) Studies		
Year Initiated	Study Title	Brief Description
2014	Comparative Efficacy of a Self-Directed and Therapist-Assisted Telehealth Parent Training Intervention for Children With ASD	This study aimed to examine the effect of ImpACT Online—a novel, telehealth parent-mediated intervention for children with ASD—on parent and child outcomes to identify moderators and mediators of treatment response and to identify predictors of parent adherence to the program.
2014	A Controlled Trial of Sertraline in Young Children with ASD	This study aimed to assess the effects of sertraline treatment in children with ASD aged 24–72 months.
2014	Screening and Linkage to Services for Autism (SaLSA)	The overall goal of SaLSA was to test the effectiveness and feasibility of patient navigation to facilitate screening follow-up and referral, diagnostic evaluation, and linkage to services in young minority and disadvantaged populations.
2014	Parent Mediated Interventions in Autism: The Search for Meaningful Outcomes	This study aimed to partner with families to redefine “success” in parent-mediated interventions with very young children with ASD. The goal of the study was for parents and families to influence clinical practice and intervention outcomes research.
2014	Investigation of Teacher-Mediated Toilet Training Using a Manualized Moisture Alarm Intervention	The purpose of this study was to develop a teacher-mediated model of toileting instruction for children with ASD in school settings that incorporates an innovative, manualized moisture pager intervention and compare its efficacy with a standard behavioral treatment.
2014	Does Mindfulness Training Enhance Early Evidence-Based Parent-Coaching Interventions?	This study aimed to develop a novel treatment paradigm that could significantly increase the efficacy of parent training programs and positively impact children, caregivers, and families in both the short term and long term.
2014	Comprehensive Communication Intervention for Minimally Verbal Children With Autism	This study built on the existing Joint Attention, Structured Play, Engagement and Regulation and Enhanced Milieu Teaching (JASP-EMT) intervention to test the effectiveness of a comprehensive communication intervention (i.e., JASP-EMT-Plus, or JEP), which includes a direct teaching component to improve spoken language and social communication, and to reduce the proportion of children with ASD who are minimally verbal at age 5.
2013	Improving Part C Services and Outcomes for Underserved Children With ASD	This study aimed to increase Part C practitioners’ implementation of EIBI practices. Providers were trained with a professional development program to improve caregiver-child engagement outcomes and improve child social and communication outcomes.
2013	Addressing Health Disparities in Autism Diagnosis, Service Utilization, and School Engagement Among Young Children Living in the Circle of Promise	The goal of this intervention was to increase ASD diagnosis and reduce disparities in diagnosis and service-use outcomes by providing universal access to the diagnostic process to all EI-enrolled children in Boston’s Circle of Promise.
2013	Toddlers and Families Together: Addressing Early Core Features of Autism	The goal of the study was to test the efficacy of a group-based intervention, Toddlers and Families Together (Together), for families of young children with or suspected of having ASD. The intervention targeted behavior regulation, joint attention, and play to improve maternal health and child developmental outcomes.

Table 36. Field-Initiated Innovative Research Program (FIRST) studies.

Secondary Data Analysis Research Program (SDAR) Studies

Year Initiated	Study Title	Brief Description
2015	Medical Care Utilization and Costs Among Transition-Age Young Adult Medicare Beneficiaries With Autism Spectrum Disorder	This study examined healthcare use and costs associated with medical care among transition-aged young adults with ASD who were moving from pediatric to adult care providers. The study also analyzed racial and ethnic differences in utilization and potential disparities between young adults with ASD and young adults with other IDs.
2015	Racial and Ethnic Disparities in Autism Diagnosis and Educational Therapy Utilization: Quantifying the Contribution of Modifiable Mediators	The purpose of the study was to advance understanding of the composition of racial and ethnic disparities in ASD diagnosis and treatment among children using the framework and methods put forth in the Institute of Medicine's 2003 report <i>Unequal Treatment</i> . The study aimed to determine the extent to which geography contributes to racial and ethnic disparities in ASD diagnosis and treatment.
2015	Family Adversity and Health Disparities for Young Children With Autism	This study aimed to examine whether racial and ethnic disparities in timing and receipt of diagnosis and treatment for children with ASD vary based upon adverse family experiences.
2014	Racial and Ethnic Disparities in Diagnostic and Health Services of Children With Developmental Disabilities	This study assessed whether there were significant differences in pathways to diagnosis, early service utilization, and care among racial and ethnic minority children with ASD/DDs. Informed by Goldberg and Huxley's pathway to care model, this study examined several stages of help seeking, including parental perceptions of problems, use of primary care services, recognition within primary care, and referral to or use of specialty care services among children with ASD/DDs.
2014	Making a More Effective and Efficient SCQ	The purpose of the study was to develop a more effective and more efficient Social Communication Questionnaire (SCQ) as a screening instrument for early identification of ASD. The revised version of the SCQ addresses measurement bias according to age, gender, and ethnic group, as appropriate.
2014	Peer-Victimization of Adolescents With ASD: Filling the Knowledge Gaps to Create Anti-Bullying Interventions	This study aimed to examine peer victimization in adolescents with ASD who spend most of the day in a regular education setting. The study examined relationships between peer victimization and both academic outcomes and ASD symptoms.
2014	Tough Choices: Autism, Private Health Insurance and Family Out-of-Pocket	The purpose of this study was to develop firmer evidence about the relationships between private health insurance plans and family needs. The researchers hypothesized that families value low-deductible plans, and that low-deductible plans expose families to unanticipated expenditures.
2014	Patterns and Variations in Emergency Department Visits for U.S. Children With Autism: A Rural-Urban Comparison	The purpose of this study was to determine whether disparities in emergency department utilization exist between children with ASD in rural versus urban settings.

Year Initiated	Study Title	Brief Description
2013	A Longitudinal Analysis of Maternal Depression and Its Associations With Child Obesity and Health Care Use	This was one of the first U.S. studies to longitudinally examine the associations between maternal depression, child obesity, the moderating effect of children’s healthcare use, and the mediating effect of parenting behaviors using a nationally representative sample.
2013	Trends in Racial and Ethnic Health Care Disparities for Children With Autism/DD	This study examined whether racial and ethnic disparities in healthcare quality, access, and utilization for children with ASD/DDs have diminished over time. The study examined longitudinal population trends and correlates of disparities between Black, Latino, and White children with ASD/DDs.
2013	Access to Therapy for Children With Autism: A Population-Based Analysis	The purpose of this study was to examine access to therapy services among children with ASD before and after the implementation of the Combating Autism Act of 2006.
2013	Dental Homes for Medicaid-Enrolled Children With ASD in the Iowa I-Smile Program	This study compared dental home and preventive dental care utilization rates for Medicaid-enrolled children by ASD status, examined the factors associated with having a dental medical home, and assessed the outcomes of having a medical home—specifically, the use of an emergency department for nontraumatic dental problems and the use of the operating room for dental treatment under anesthesia.

Table 37. Secondary Data Analysis Research Program (SDAR) studies.

Autism Longitudinal Data Project		
Year Initiated	Study Title	Brief Description
2017	Autism Longitudinal Data Project	This project leverages the 20 year Boston Birth Cohort to examine the role of maternal and cord blood metabolomes, placental histological findings, and in utero fetal growth patterns in relation to the risk of ASD; and integrate multi-dimensional data to develop early prediction models and test interventions using both empirical data and virtual birth cohort.

Table 38. Autism Longitudinal Data Project.

Autism Transitions Research Project (ATRP)		
Year Initiated	Study Title	Brief Description
2017	Factors Associated with Healthy Life Outcomes and Access to Needed Services among Transition Age Youth	Secondary data analysis using Social Security Administration and the Vocational Rehabilitation system as well as national surveys of Social Security beneficiaries, college students and recipients of services via State Developmental Disabilities agencies. Aims are to describe changes over time in the size, demographics, health and disability characteristics (i.e. needs), access to services and related life outcomes, and to describe the distribution and correlates of access to services and related life outcomes.
2017	Service Network Coordination and Social Capital	Mixed methods approach to adapt a method to measure transition-aged youth and adolescents (TAYA) social capital and the coordination of intervention team members. The aims are to adapt a measure of social capital for the postsecondary transition, and to pilot test the adapted social capital measure with TAYA, their parents and transition coordinators before and after high school leaving.
2017	Transition Odyssey	To develop and pilot test a scalable interview protocol to understand TAYA, family and provider insights about the transition process, the genesis of disparities and factors that influence outcomes. The aims are to understand the unique transition-related service access experiences of TAYA, and to understand participant perspectives about what constitutes healthy life outcomes.

Table 39. Autism Transitions Research Project (ATRP).

State Implementation, Planning, and Innovation in Care Integration Grants		
Period of Performance	State	Grantee
2013 Planning Grants		
9/1/2013–8/31/2016	NH	New Hampshire Department of Health And Human Services
9/1/2013–8/31/2016	AR	University of Arkansas
9/1/2013–8/31/2016	MA	University of Massachusetts
9/1/2013–8/31/2016	TX	University of Texas Health Science Center Houston
Implementation Grants		
9/1/2013–8/31/2016	NC	University of North Carolina At Chapel Hill
9/1/2013–8/31/2016	MD	Parents’ Place of Maryland
9/1/2013–8/31/2016	OR	Oregon Health & Science University
9/1/2013–8/31/2016	VA	Virginia Commonwealth University
9/1/2014–8/31/2016	GA	Georgia State University Research Foundation
9/1/2014–8/31/2016	AR	Arkansas Children’s Hospital Research Institute
9/1/2014–8/31/2016	IA	University of Iowa—School of Medicine
9/1/2014–8/31/2016	MI	Michigan Department of Community Health
9/1/2014–8/31/2016	MN	Department of Health Minnesota
Innovation in Care Integration Grants for Children and Youth With Autism Spectrum Disorders and Other Developmental Disabilities		
9/1/2016–8/31/2019	WA	Washington State Department of Health
9/1/2016–8/31/2019	DE	University of Delaware
9/1/2016–8/31/2019	RI	The Autism Project
9/1/2016–8/31/2019	WI	University of Wisconsin System

Table 40. State Implementation, Planning, and Innovation in Care Integration Grants

Appendix v: Selected NIH- and EPA-Supported UC Davis Center for Children's Environmental Health (CCEH) Publications

Edmiston E, Jones KL, Vu T, Ashwood P, Van de Water J. Identification of the antigenic epitopes of maternal autoantibodies in autism spectrum disorders. *Brain Behav Immun*. 2018 Mar;69:399-407. [PMID: 29289663]

Goodrich AJ, Volk HE, Tancredi DJ, McConnell R, Lurmann FW, Hansen RL, Schmidt RJ. Joint effects of prenatal air pollutant exposure and maternal folic acid supplementation on risk of autism spectrum disorder. *Autism Res*. 2018 Jan;11(1):69-80. [PMID: 29120534]

Hertz-Picciotto I, Schmidt RJ, Krakowiak P. Understanding environmental contributions to autism: Causal concepts and the state of science. *Autism Res*. 2018 Apr;11(4):554-586. [PMID: 29573218]

Jones KL, Croen LA, Yoshida CK, Heuer L, Hansen R, Zerbo O, DeLorenze GN, Kharrazi M, Yolken R, Ashwood P, Van de Water J. Autism with intellectual disability is associated with increased levels of maternal cytokines and chemokines during gestation. *Mol Psychiatry*. 2017 Feb;22(2):273-279. [PMID: 27217154]

Jones KL, Pride MC, Edmiston E, Yang M, Silverman JL, Crawley JN, Van de Water J. Autism-specific maternal autoantibodies produce behavioral abnormalities in an endogenous antigen-driven mouse model of autism. *Mol Psychiatry*. 2018 Jun 28. [PMID: 29955164]

Jones KL, Van de Water J. Maternal autoantibody related autism: mechanisms and pathways. *Mol Psychiatry*. 2018 Jun 22. [PMID: 29934547]

Kerin T, Volk H, Li W, Lurmann F, Eckel S, McConnell R, Hertz-Picciotto I. Association Between Air Pollution Exposure, Cognitive and Adaptive Function, and ASD Severity Among Children with Autism Spectrum Disorder. *J Autism Dev Disord*. 2018 Jan;48(1):137-150. [PMID: 28921105]

Kim D, Volk H, Girirajan S, Pendergrass S, Hall MA, Verma SS, Schmidt RJ, Hansen RL, Ghosh D, Ludena-Rodriguez Y, Kim K, Ritchie MD, Hertz-Picciotto I, Selleck SB. The joint effect of air pollution exposure and copy number variation on risk for autism. *Autism Res*. 2017 Sep;10(9):1470-1480. [PMID: 28448694]

Krakowiak P, Walker CK, Tancredi D, Hertz-Picciotto I, Van de Water J. Autism-specific maternal anti-fetal brain autoantibodies are associated with metabolic conditions. *Autism Res.* 2017 Jan;10(1):89-98. [PMID: 27312731]

Rose DR, Yang H, Serena G, Sturgeon C, Ma B, Careaga M, Hughes HK, Angkustsiri K, Rose M, Hertz-Picciotto I, Van de Water J, Hansen RL, Ravel J, Fasano A, Ashwood P. Differential immune responses and microbiota profiles in children with autism spectrum disorders and co-morbid gastrointestinal symptoms. *Brain Behav Immun.* 2018 May;70:354-368. [PMID: 29571898]

Schmidt RJ, Kogan V, Shelton JF, Delwiche L, Hansen RL, Ozonoff S, Ma CC, McCanlies EC, Bennett DH, Hertz-Picciotto I, Tancredi DJ, Volk HE. Combined Prenatal Pesticide Exposure and Folic Acid Intake in Relation to Autism Spectrum Disorder. *Environ Health Perspect.* 2017 Sep 8;125(9):097007. [PMID: 28934093]

Schmidt RJ, Schroeder DI, Crary-Dooley FK, Barkoski JM, Tancredi DJ, Walker CK, Ozonoff S, Hertz-Picciotto I, LaSalle JM. Self-reported pregnancy exposures and placental DNA methylation in the MARBLES prospective autism sibling study. *Environ Epigenet.* 2016 Dec;2(4). pii: dww024. [PMID: 28781890]

Schroeder DI, Schmidt RJ, Crary-Dooley FK, Walker CK, Ozonoff S, Tancredi DJ, Hertz-Picciotto I, LaSalle JM. Placental methylome analysis from a prospective autism study. *Mol Autism.* 2016 Dec 15;7:51. [PMID: 28018572]

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