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## ABOUT THE IACC

The Interagency Autism Coordinating Committee (IACC) is a federal advisory committee charged with coordinating federal activities concerning autism spectrum disorder (ASD) and providing advice to the Secretary of Health and Human Services (HHS) on issues related to autism. The Committee was established by Congress under the Children's Health Act of 2000, reconstituted under the Combating Autism Act (CAA) of 2006, and renewed most recently under the Autism Collaboration, Accountability, Research, Education, and Support (CARES) Act of 2014.

Membership of the Committee includes a wide array of federal agencies involved in ASD research and services, as well as public stakeholders, including self-advocates, family members of children and adults with ASD, advocates, service providers, and researchers, who represent a variety of perspectives from within the autism community. The IACC membership is composed to ensure that the Committee is equipped to address the wide range of issues and challenges faced by individuals and families affected by autism.

Under the CAA and subsequent authorizations, the IACC is required to (1) develop and annually update a strategic plan for ASD research, (2) develop and annually update a summary of advances in ASD research, and (3) monitor federal activities related to ASD.

Through these and other activities, the IACC provides guidance to HHS and partners with other federal departments, federal agencies, research and advocacy organizations, and the broader autism community to accelerate research and enhance services with the goal of profoundly improving the lives of people with ASD and their families.

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For more information about the IACC, see <http://www.iacc.hhs.gov>.

### **IACC Strategic Plan Vision Statement**

The *IACC Strategic Plan for ASD* will accelerate and inspire research that will profoundly improve the health and well-being of every person on the autism spectrum across the lifespan. The Plan will set the standard for public-private coordination and community engagement.

### **IACC Strategic Plan Mission Statement**

The purpose of the *IACC Strategic Plan* is to focus, coordinate, and accelerate high-quality research and scientific discovery in partnership with stakeholders to answer the urgent questions and needs of people on the autism spectrum and their families.

### **IACC Core Values**

The IACC adopted the below core values and emphasized their significance to the *2016-2017 Strategic Plan* and to the *2018 IACC Strategic Plan Update*:

**Sense of Urgency:** We will focus on what steps we can take to respond rapidly and efficiently to the needs and challenges of people and families affected by ASD.

**Excellence:** We will pursue innovative basic and clinical research of the highest quality to protect the safety of and to advance the interests of people affected by ASD.

**Spirit of Collaboration:** We will treat others with respect, listen to diverse views with open minds, discuss submitted public comments, and foster discussions where participants can comfortably offer opposing opinions.

**Consumer Focus:** We will focus on making a difference in the lives of people affected by ASD, including people with ASD, their families, medical practitioners, educators, and scientists. It is important to consider the impact of research on the human rights, dignity, and quality of life of people with ASD, from prenatal development forward.

**Partnerships in Action:** We will value cross-disciplinary approaches, data sharing, teamwork, and partnerships with clearly defined roles and responsibilities.

**Equity:** We will prioritize improved access to screening, diagnosis, and treatment, across race, ethnicity, socioeconomic status, and geographic location (rural vs. urban), and we affirm a commitment to reduce disparities.

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Please note: The terms “person with autism,” “person with ASD,” “autistic person,” and “person on the autism spectrum” are used interchangeably throughout this document. Some members of the autism community prefer one term, while others prefer another. The Committee respects the different opinions within the community on the use of this language and does not intend to endorse any particular preference. In addition, the terms “autism” and “autism spectrum disorder (ASD)” are used interchangeably throughout this document unless otherwise noted.

# IACC STRATEGIC PLAN – 2018 UPDATE

## INTRODUCTION

The Interagency Autism Coordinating Committee (IACC) is a Federal advisory committee that advises the Secretary of Health and Human Services on issues related to ASD. The committee was established by the Combating Autism Act (CAA; Public Law 109-416) and was most recently reauthorized in 2014 under the Autism Collaboration, Accountability, Research, Education, and Support Act (Autism CARES Act; Public Law 113-157). One responsibility of the IACC is the development of a *Strategic Plan for ASD*, to be updated annually. The *IACC Strategic Plan*, first issued in 2009, serves as a guide for federal agencies and private organizations in planning ASD-related research, services and support activities. It is produced by the IACC – including federal officials and public stakeholder members – and is informed by extensive input from researchers, adults on the autism spectrum, parents, advocates, and the general public. This inclusive process ensures that the *IACC Strategic Plan* reflects diverse perspectives from across the autism community.

The *IACC Strategic Plan*, most recently revised in 2016-2017, is organized around seven general topic areas that are represented in the *Plan* as consumer-focused Questions (e.g., Question 1, “How can I recognize the signs of ASD, and why is early detection so important?”). Each Question is assigned a chapter that provides the aspirational goal, or long-term vision; a description of the state of the field; the needs and opportunities in research, services, and policy; and three to four broad objectives for each Question’s research topic (**Figure 1**). For the 2016-2017 edition of the *Strategic Plan*, the Committee revised the seven questions to be more aligned with current and future research priorities. In addition, the committee developed 23 new strategic objectives that address autism research, services, and policy, including one cross-cutting objective on the topic of ASD in females that spans the seven questions in the *IACC Strategic Plan*. Lastly, to monitor and call for significant growth in ASD research, the Committee included a budget recommendation for a doubling of the 2015 ASD research budget over the next five years. This would require a total ASD research budget of \$685 million by 2020.

This *2018 IACC Strategic Plan Update* is the work of the IACC membership that was appointed under the Autism CARES Act of 2014. The Committee agreed that the *2016-2017 IACC Strategic Plan* reflected a comprehensive update on the state of the field and provided a set of 23 new research, services, and policy-related objectives. Therefore, for this 2018 edition, it would be most beneficial to the community to provide an update on progress that has been made in 2018 toward the issues and goals described in the *2016-2017 IACC Strategic Plan*. The *2018 IACC Strategic Plan Update* includes:

Chapter 1: A summary of the *2016 ASD Research Portfolio Analysis Report*, which is the first analysis of research activities among federal and private funders as they correspond to the new *2016-2017 IACC Strategic Plan* objectives.

Chapter 2: A synopsis of the *Department of Health and Human Services Report to Congress on Activities Related to Autism Spectrum Disorders and Other Developmental Disabilities Under the Autism Collaboration, Accountability, Research, Education and Support Act (Autism CARES Act) of 2014 (FY 2014 – FY 2018)*, highlighting recent federal activities related to ASD research and services.

Chapter 3: An update on the activities of the Working Group of the IACC focused on improving health outcomes for individuals with autism spectrum.

Together, the Committee hopes that the *2018 IACC Strategic Plan Update* will provide an insightful overview of the recent efforts in ASD research, services, and outreach as they relate to the issues and goals described in the *2016-2017 IACC Strategic Plan*.

## 2016-2017 STRATEGIC PLAN OBJECTIVES



### QUESTION 1 HOW CAN I RECOGNIZE THE SIGNS OF ASD, AND WHY IS EARLY DETECTION SO IMPORTANT?

- 1 Strengthen the evidence base for the benefits of early detection of ASD.
- 2 Reduce disparities in early detection and access to services.
- 3 Improve/validate existing, or develop new tools, methods, and service delivery models for detecting ASD in order to facilitate timely linkage of individuals with ASD to early, targeted interventions and supports.

#### CROSS-CUTTING

- 1 Support research to understand the underlying biology of sex differences in ASD, possible factors that may be contributing to underdiagnosis, unique challenges that may be faced by girls/women on the autism spectrum, and develop strategies for meeting the needs of this population.



### QUESTION 2 WHAT IS THE BIOLOGY UNDERLYING ASD?

- 1 Foster research to better understand the processes of early development, molecular and neurodevelopmental mechanisms, and brain circuitry that contribute to the structural and functional basis of ASD.
- 2 Support research to understand the underlying biology of co-occurring conditions in ASD and to understand the relationship of these conditions to ASD.
- 3 Support large-scale longitudinal studies that can answer questions about the development of ASD from pregnancy through adulthood and the natural history of ASD across the lifespan.



### QUESTION 3 WHAT CAUSES ASD, AND CAN DISABLING ASPECTS OF ASD BE PREVENTED OR PREEMPTED?

- 1 Strengthen understanding of genetic risk and resilience factors for ASD across the full diversity and heterogeneity of those with ASD, enabling development of strategies for reducing disability and co-occurring conditions in ASD.
- 2 Understand the effects on ASD risk and resilience of individual and multiple exposures in early development, enabling development of strategies for reducing disability and co-occurring conditions in ASD.
- 3 Expand knowledge about how multiple environmental and genetic risk and resilience factors interact through specific biological mechanisms to manifest in ASD phenotypes.



**Figure 1.** The 2016-2017 IACC Strategic Plan’s revised seven questions and 23 new objectives.



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## **Chapter 1: SUMMARY OF THE 2016 IACC ASD RESEARCH PORTFOLIO ANALYSIS REPORT**

## Background

This chapter will provide an overview of the findings reflected in *the 2016 IACC Autism Spectrum Disorder Research Portfolio Analysis Report*, which provides the first analysis of research projects funded by federal and private research funders in the U.S. according to the objectives in the *2016-2017 IACC Strategic Plan for Autism Spectrum Disorder Research*. This overview will describe progress toward the *IACC Strategic Plan* objectives.

Following the development of the first *IACC Strategic Plan* in 2009, the Office of Autism Research Coordination (OARC) – the office within the National Institutes of Health (NIH) that manages the activities of the IACC – began issuing a series of *IACC ASD Research Portfolio Analysis Reports* to provide the IACC with comprehensive information about the status of autism research funding among federal agencies and private research organizations in the United States. The reports align data on individual research-related projects with objectives in the *IACC Strategic Plan*, providing an accounting of how much funding has supported projects related to *Strategic Plan* objectives and highlighting trends. For the *Portfolio Analyses*, the seven questions are categorized by their broad research areas (**Figure 2**); for example, Question 1 is labelled Screening & Diagnosis and Question 2 is named Biology.

The *Portfolio Analysis Reports* have been used to help the IACC in their efforts to monitor ASD research efforts and track progress made each year on the objectives in the *IACC Strategic Plan*. The *2016 IACC ASD Research Portfolio Analysis Report* is the first portfolio analysis measuring progress made toward the 23 new objectives in the *2016-2017 IACC Strategic Plan for ASD*. Funding information from 2016 federal and private funders is aligned with an objective within one of the seven questions in the *Strategic Plan*. In addition to research progress towards the objectives in the *Strategic Plan*, the *2016 IACC ASD Research Portfolio Analysis Report* provides an analysis of progress that was made in ASD research over the nine-year period from 2008-2016, subcategory analysis within each question of the *Strategic Plan*, geographical funding information, and more.

Lastly, the *2016 Portfolio Analysis Report* addresses the Committee’s recommended ASD research budget of \$685 million by 2020. To accomplish this goal, the Committee recommended a nearly 15% annual increase in ASD research funding for 2016. This summary will discuss progress towards meeting the annual budget recommendations as well as highlight some of the major findings in the *2016 Portfolio Analysis* and how they relate to the goals of the *2016-2017 IACC Strategic Plan*.

IACC STRATEGIC PLAN QUESTIONS AND CORRESPONDING RESEARCH AREAS



**Figure 2.** The seven questions and corresponding research areas of the 2016-2017 IACC Strategic Plan for ASD.

## Highlights from the Report

### ASD Research Funders and Funding in 2016

For the *2016 IACC ASD Research Portfolio Analysis Report*, OARC requested information on 2016 autism-related research projects funded by several federal agencies and private organizations. Information included the annual funding amount and the relevance of each project to the seven questions of the *2016-2017 IACC Strategic Plan for ASD*. For 2016, nine federal agencies and nine private funders provided their autism research funding information for this analysis. These 18 agencies and organizations are listed in **Table 1**.

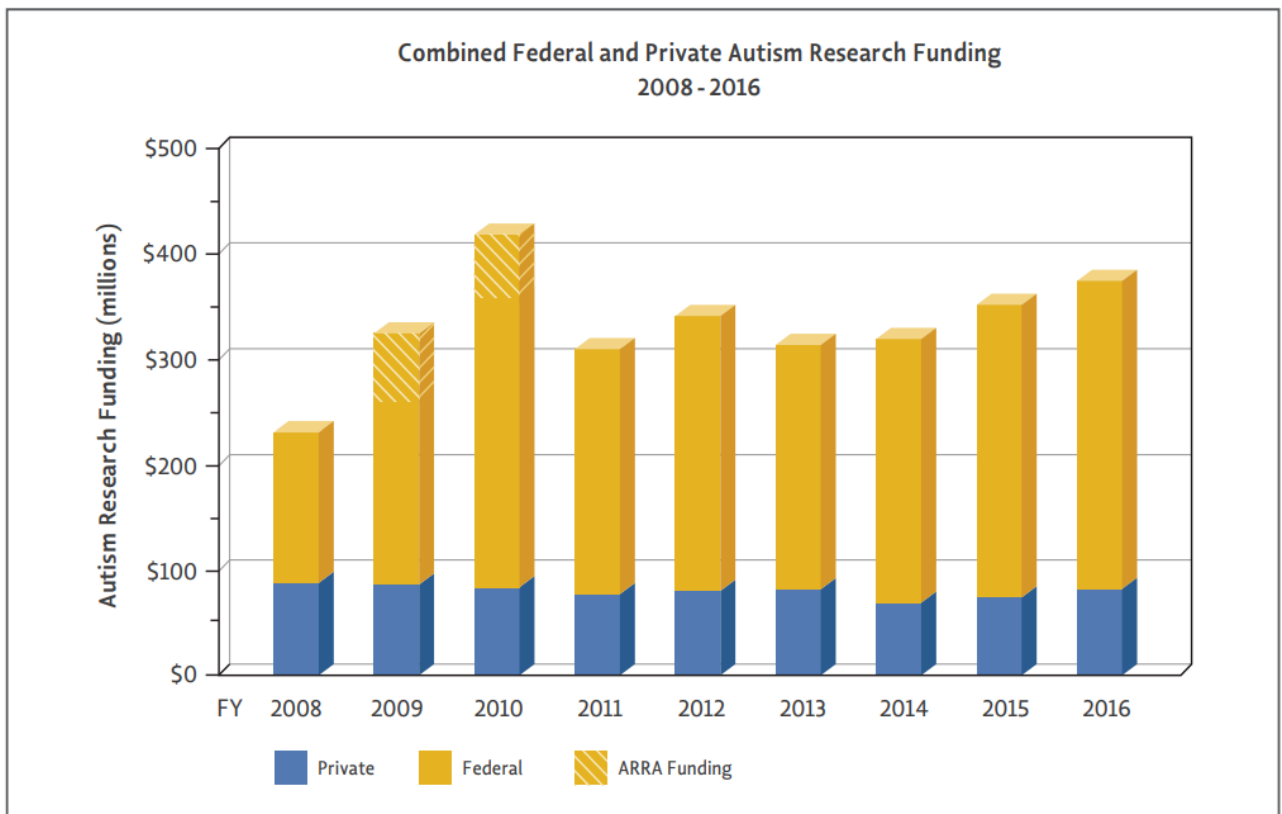
#### AGENCIES AND ORGANIZATIONS INCLUDED IN THE 2016 IACC PORTFOLIO ANALYSIS

FEDERAL AGENCIES	PRIVATE ORGANIZATIONS
<ul style="list-style-type: none"> <li>• Administration for Community Living (ACL)</li> <li>• Agency for Healthcare Research and Quality (AHRQ)</li> <li>• Centers for Disease Control and Prevention (CDC)</li> <li>• Department of Defense – Army (DoD – Army)</li> <li>• Department of Education (ED)</li> <li>• Environmental Protection Agency (EPA)</li> <li>• Health Resources and Services Administration (HRSA)</li> <li>• National Institutes of Health (NIH)</li> <li>• National Science Foundation (NSF)</li> </ul>	<ul style="list-style-type: none"> <li>• Autism Research Institute (ARI)</li> <li>• Autism Science Foundation (ASF)</li> <li>• Autism Speaks (AS)</li> <li>• Brain &amp; Behavior Research Foundation (BBRF)</li> <li>• Center for Autism and Related Disorders (CARD)</li> <li>• New England Center for Children (NECC)</li> <li>• Organization for Autism Research (OAR)</li> <li>• Patient-Centered Outcomes Research Institute (PCORI)</li> <li>• Simons Foundation (SF)</li> </ul>

**Table 1.** Projects from nine federal agencies and nine private organizations were included in the *2016 IACC ASD Research Portfolio Analysis Report*.

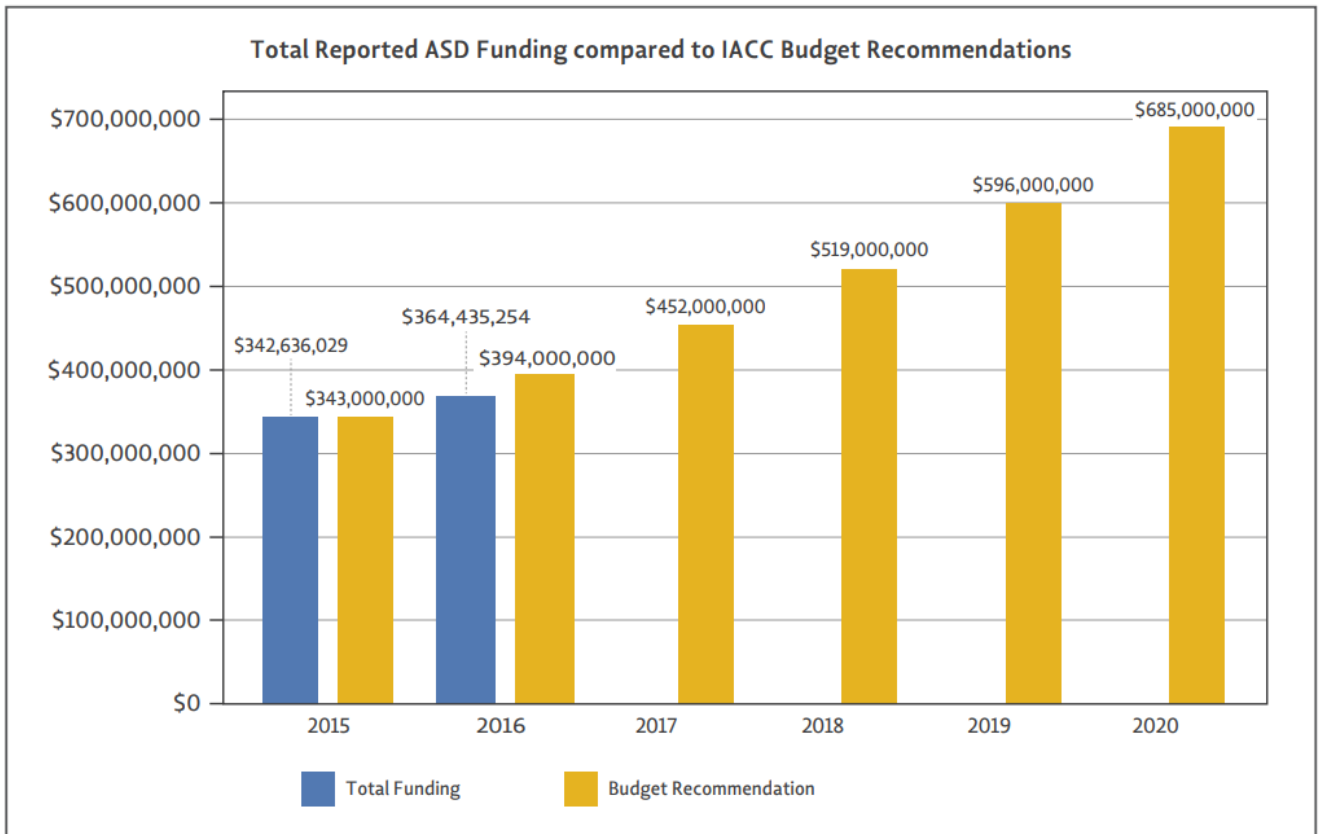
In 2016, the estimated federal and private investment in ASD research totaled \$364,435,254 and included 1,360 projects. The federal government provided 80% of total ASD research funding, which amounted to \$291.7 million. One-fifth of funding was supported by private organizations that invested \$72.7 million. Compared to the previous year, there was an increase in federal and private investment in 2016, which supported the overall increase in funding.

Over the nine-year span from 2008-2016, funding increased by 64.3%, suggesting a continued overall growth in support of ASD research. Although, there have been fluctuations from one year to the next (**Figure 3**). Autism research reached a peak in funding (including funds from the American Recovery and Reinvestment Act) in 2010 and then experienced lower, but overall increasing levels of funding over the next few years. By 2016, the ASD research portfolio was funded at the highest level since 2010, suggesting increased interest in ASD research.



**Figure 3.** This figure illustrates levels of autism research funding from combined federal and private sources during 2008-2016 based on data collected for the *IACC Portfolio Analysis* of those years.

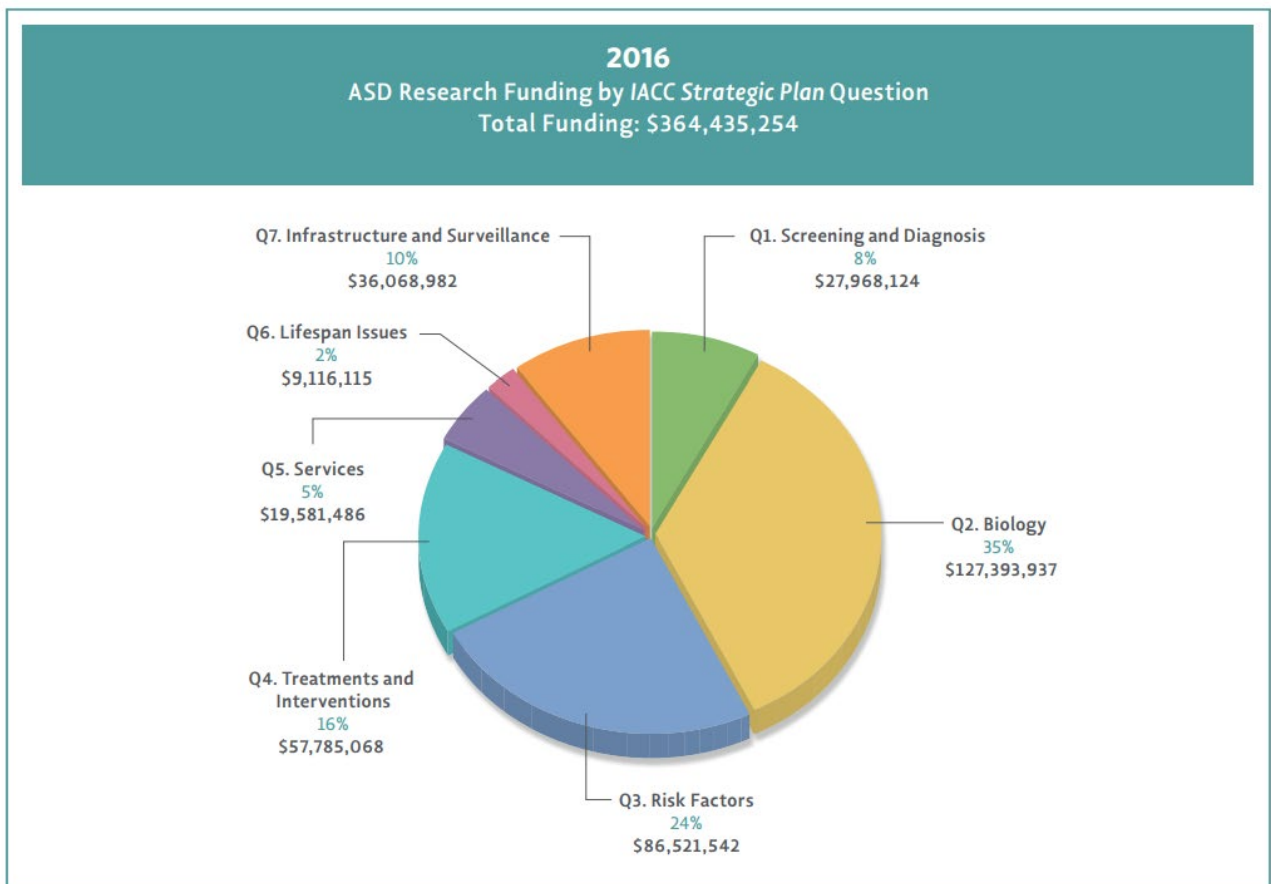
With regard to the 2016-2017 IACC Strategic Plan’s budget plan, the 2016 funding amount of \$364.4 million did not reach the recommended budget of \$394 million for that year. However, the overall funding for autism research increased by \$21.7 million from 2015 to 2016, an increase of 6.3%. While this did not achieve the budget recommendation, ASD research did experience a substantial growth in funding for 2016 (Figure 4). In future years, funding trends will continue to be monitored to determine progress toward meeting the IACC’s recommended budget.



**Figure 4.** The IACC recommends a doubling of the combined federal and private ASD research budget to \$685 million by 2020. Based on 2015 and 2016 funding amounts, ASD research investment is lagging behind IACC budget recommendations.

## ASD Research Areas and Progress in 2016

To better understand what areas of research were funded in 2016, projects were aligned with the questions in the *2016-2017 IACC Strategic Plan*. **Figure 5** illustrates the breakdown of the research funding per each of the Strategic Plan's seven questions, which are related to **Screening and Diagnosis (Q1)**, **Biology (Q2)**, **Risk Factors (Q3)**, **Treatments and Interventions (Q4)**, **Services (Q5)**, **Lifespan Issues (Q6)**, and **Infrastructure and Surveillance (Q7)**. Identifying how current research investments correspond to the *Strategic Plan* provides an understanding of how funders have directed investments across each of the priority areas identified by the IACC, as well as an indication of which areas are well-supported versus those that may need additional attention or development.



**Figure 5.** The seven questions of the *Strategic Plan*, beginning with Screening and Diagnosis (Question 1) and ending with Infrastructure and Surveillance (Question 7).

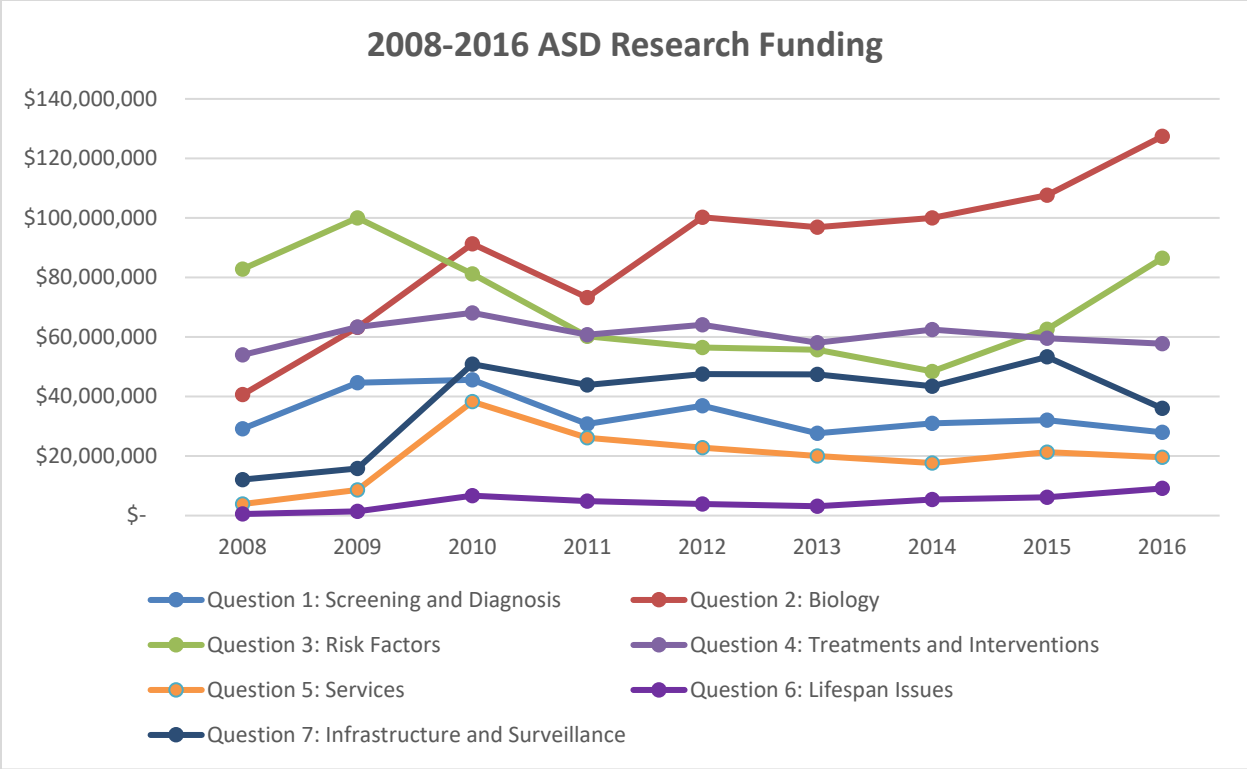
ASD research funding in 2016 supported projects relevant to all seven questions in the *IACC Strategic Plan for ASD*. As in previous years, the largest portion of funding addressed the underlying biology of ASD (35%). Projects assigned to this research area seek to understand the biological differences and mechanisms in early development and throughout life that contribute to ASD symptoms, as well as the characterization of the behavioral and cognitive aspects of ASD. The next largest funded research area was risk factors, with research aimed at identifying potential causes, genetic and/or environmental, for ASD (24%). Research into treatments and interventions for ASD followed in funding (16%), which included funding towards behavioral therapies, pharmacological treatments, and technology-based interventions. In 2016, ASD funders supported research towards infrastructure and surveillance, which consisted of 10% of total funding. Projects within infrastructure and surveillance include large-scale studies that require coordinating centers and dissemination of data to the community as well as investment towards large databases. Research to improve screening and diagnosis of ASD followed closely with 8% of research funding. Projects within screening and diagnosis include research to develop and improve biomarkers, screening tools, and diagnostic instruments to aid in early identification. Research focused on services and lifespan issues were the least funded research areas. Services, which includes research on improving the efficacy, cost-effectiveness, and dissemination of evidence-based practices in community settings, received 5% of ASD research funding. Lifespan Issues, which encompasses research to identify and address the needs of transitioning youth with ASD to adulthood and throughout the lifespan, received 2% of funding.

The *2016 Portfolio Analysis* represents the first time funding information was aligned with the 23 new objectives in the *2016-2017 IACC Strategic Plan*. For 2016, there was funding and/or projects associated with each of the 23 new objectives, reflecting alignment of the IACC's research goals with those of federal and private funders. In the following years, OARC will continue to assess funding levels among the new objectives.

While the IACC has created 23 new objectives to track ASD research investments, funding information related to the seven question areas of the *IACC Strategic Plan* has been collected across a nine-year span (**Figure 6**). Over the years, research into understanding the underlying biology of ASD and infrastructure and surveillance have seen significant increases in funding. The areas of services research and lifespan issues have been consistently less well funded than other research areas. Research towards screening and diagnosis, risk factors, and treatments and interventions have fluctuated in funding through the years.

Over time, the IACC will update and replace objectives in the *Strategic Plan* to reflect advances in research and changes in services and policy, however, the framework of the seven question areas will remain constant, allowing the tracking of funding trends over extended periods. This is helpful for the Committee as well as stakeholders within the ASD community in identifying areas and priorities for future research investment.





**Figure 6.** Trends in ASD Funding for each *Strategic Plan* Question over the nine-year period of reporting (2008-2016).

## Summary

The *2016 IACC ASD Research Portfolio Analysis Report* provides the ninth year of data collected and the seventh comprehensive report of U.S. ASD research funding across both the federal and private sectors. It is also the first analysis to measure research progress against the 23 new objectives from the *2016-2017 IACC Strategic Plan*. ASD research project information was collected from 18 federal and private funders. Similar to previous years, federal agencies continued to fund majority (80%) of ASD research while private organizations contributed nearly 20% of funding. Overall, funding for ASD research among both federal and private funders totaled \$364.4 million and spanned 1,360 projects in 2016. With nine years of ASD research funding data available (2008-2016), it was possible to continue analyzing the long-term progress in ASD research. Since 2008, autism research showed an overall upward trend in funding, increasing by 64.3%.

The framework of the seven questions in the *Strategic Plan* has remained unchanged since in their inception in 2008, which is beneficial to tracking trends in research investments. For 2016, each *Strategic Plan* question sustained similar proportions in funding compared to recent years, showing consistent support for certain research areas of the *Strategic Plan*. However, this was the first year assessing funding towards the new objectives in the *2016-2017 IACC Strategic Plan*. Although it was the first year monitoring progress on these objectives, every objective in the *2016-2017 Strategic Plan* had associated projects and/or funding in 2016. This indicates that the priority areas identified by the IACC in the *Strategic Plan* objectives were also identified as priority areas by federal and private research funders, though some areas still have much room for growth. For an in-depth analysis of the new objectives, please refer to the *2016 IACC Portfolio Analysis Report*.

In response to the budget recommendation set out in the *2016-2017 IACC Strategic Plan*, the 2016 ASD research budget experienced less growth (6.3%) in funding for the year than the 15% increase which would have kept the recommendation on track to be reached. While this amount did not hit the annual goal requested in the *Strategic Plan*, it still signifies growth in ASD research funding. Over the next few years, OARC will continue to track funding trends and determine progress toward meeting the IACC's budget recommendation.

The annual *IACC ASD Research Portfolio Analysis Report* assists the Committee with carrying out its charge to monitor autism activities and to inform the process of updating the *IACC Strategic Plan*. Future portfolio analyses tracking the *2016-2017 IACC Strategic Plan's* 23 objectives will continue to serve as a resource for the Committee, funders, and the broader ASD community to monitor progress, identify knowledge gaps, recognize emerging trends and new opportunities, and guide future research investments to better meet the needs of families and individuals affected by ASD.

To see the full analysis of the 2016 funding data, including funder information, geographical funding data, trends in ongoing versus new research, subcategory analysis, and more, please view the [2016 IACC ASD Research Portfolio Analysis Report](#) at the IACC website. The project data are publicly accessible on the IACC/OARC [Autism Research Database](#) on the IACC website.

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**SUMMARY OF THE *REPORT TO CONGRESS ON  
ACTIVITIES RELATED TO AUTISM SPECTRUM DISORDER  
AND OTHER DEVELOPMENTAL DISABILITIES (FY 2014-  
2018)***

## Background

This chapter provides an overview of the [Department of Health and Human Services Report to Congress on Activities Related to Autism Spectrum Disorder and Other Developmental Disabilities Under the Autism CARES Act of 2014 \(FY 2014 – FY 2018\)](#), a report prepared to meet the requirements of the Autism CARES Act of 2014 that describes federal agency activities related to ASD during the specified time period. This overview provides a summary of federal agency activities and programs that are addressing various areas that are targeted in the [2016-2017 IACC Strategic Plan for Autism Spectrum Disorder](#).

The *Department of Health and Human Services 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 information from 21 federal agencies and departments, addressing ASD research and services according to the required elements outlined in the Autism CARES Act.

The federal departments and agencies included in the Report 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)

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)

The following sections summarize major federal programs, activities and accomplishments between FY 2014 and 2018. They include details on coordination across the federal government; ASD surveillance, awareness, and outreach activities; progress investigating the biology and risk factors associated with ASD; and investments in innovative screening, diagnosis, and intervention tools. They also include

information on efforts to improve training of ASD practitioners and service providers, to identify and disseminate best practices in education and service provision, and to provide ASD services and supports across the lifespan.

## Highlights from the Report

### Cross-Agency Coordination

The Interagency Autism Coordinating Committee coordinates federal agency activities related to ASD and provides advice to the Secretary of HHS on ASD research and services. The committee also serves as a forum for gathering public input on issues of importance to the autism community to aid the IACC in its advisory function. 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 National Autism Coordinator role was created within the Autism CARES Act of 2014 to provide additional support for coordination of federal activities. The duties of the National Autism Coordinator specified in the Autism CARES Act include ensuring that recommendations of the IACC are being implemented by federal agencies as well as ensuring that federal ASD efforts are not unnecessarily duplicative. In October 2016, the NAC convened an Interagency Workgroup (IWG) to provide internal federal coordination of ASD activities. Their first project was to provide input toward the development of the [2017 Report to Congress on Young Adults and Transitioning Youth with ASD](#), which is required by the Autism CARES Act. The 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. 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 National Autism Coordinator gives updates regarding internal federal implementation activities at meetings of the IACC.

### ASD Surveillance, Awareness, and Outreach

The activities in this section are related to Questions 5 and 7 of the *IACC Strategic Plan*.

In 2018, CDC's [Autism and Developmental Disabilities Monitoring \(ADDM\)](#) Network published autism prevalence data estimating that 1 in 59 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. In 2010, CDC also began a new surveillance program, the Early ADDM Network, to better understand ASD in younger children. [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.

CDC's "[Learn the Signs. Act Early.](#)" campaign has played an important role nationwide in raising awareness about early developmental milestones. The program has played a significant role 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. Several new materials have recently been developed, including books, online training materials, and a milestone tracking mobile application for parents. Since 2011, the CDC has supported five cohorts of [Act Early Ambassadors](#), who work to improve early identification and linkage to services in their state during their tenure.

ED provides training for parents of children with ASD through [Parent Training and Information Centers](#) across the nation. 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 funded a study exploring the feasibility of adapting the Survey of Well-Being of Young Children, a first-line screening instrument, for use on Native American reservations. The study assessed the cultural sensitivity of each individual item in the screening instrument; this is 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.

FDA recently held a Patient-Focused Drug Development 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. A "[Voice of the Patient](#)" report summarized the input provided by patients and patient representatives at this meeting.

### **Investigating the Biology and Risk Factors Associated with ASD**

The activities in this section are related to Questions 2 and 3 of the *IACC Strategic Plan*.

The CDC 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). 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. CDC began publishing findings from SEED data in 2014, providing valuable information about the spectrum of behaviors and characteristics of children with ASD and contribute to understanding risk factors.

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 their probable effects on the development of ASD have been one of the focus areas of the ARP through the funding years.

DoD-AF funded a collaborative research project at the Nationwide Children's Hospital that expanded an ASD data bank for clinical and genetics research. Results from this project include linkages between ASD and genes involved in immune function and cholesterol metabolism.

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. Recent findings have shed light on the influence of exposures such as air pollution and pesticides on metabolic, immune, and epigenetic risks for autism diagnosis.

In 2018, NIH's [Autism Centers of Excellence \(ACE\)](#) comprised 9 research centers and networks at major research institutions and universities across the country. ACE researchers are actively working to identify the causes and early signs of ASD, and to 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 115,000 consenting research participants are available across more than 400 clinical, imaging, and genomic instruments for secondary analysis by other qualified researchers.

### **Innovative Screening, Diagnosis, and Intervention Investments**

The activities in this section are related to Questions 1 and 4 of the *IACC Strategic Plan*.

Since 2014, AHRQ has published and/or updated three systematic reviews evaluating the comparative effectiveness and safety of [medical therapies](#), [behavioral interventions](#), and [interventions targeting sensory challenges](#) in children with ASD.

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. 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, and developed 11 toolkits for parents and providers. Similarly, the AIR-B Network has completed six studies and has two RCTs in progress. The Network has also developed three tools and one practical guideline for facilitating more successful transitions within the daily routine for children with ASD.

NIH supports several ongoing efforts to improve methods for ASD screening and diagnosis. The National Institute of Mental Health (NIMH) launched a three-component initiative addressing services research for ASD across the lifespan. One component funded several projects focused on improving tools for early identification of ASD in children. Investigators funded through the Autism Centers of Excellence program are investigating 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.

Additionally, the NIH, together with the Foundation for the NIH and the Simons Foundation Autism Research Initiative, funded a four-year, multisite project to identify [biomarkers and outcome measures of ASD](#). The project will test several electroencephalogram (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.

NSF research awards relevant to ASD fall under a portfolio that emphasizes neuroscience, cognitive sciences, and education and learning research. The agency has funded a range of ASD-relevant research, including innovative interventions and technology-driven tools to identify ASD symptoms.

### **High-Quality Training of ASD Practitioners and Service Providers**



The activities in this section are related to Question 5 of the *IACC Strategic Plan*.

ACF maintains 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.

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.

Under the Autism CARES Act, HRSA supports two activities 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. In FY 2018, there were 52 LEND programs and 10 DBP programs.

### **Best Practices in Education and Service Provision**

The activities in this section are related to Question 5 of the *IACC Strategic Plan*.

Several AHRQ-funded projects seek to improve various aspects of service provision for individuals with ASD. One group of investigators is testing [a family navigator model](#) to reduce racial disparities in screening and diagnosis. AHRQ also supported a conference that aimed to stimulate [new and different approaches to the provision of medical care](#) to people with ASD across the lifespan.

DOJ has released guidance on testing accommodations and effective communication to ensure equal opportunities for individuals with disabilities. In collaboration with ED’s Office for Civil Rights and Office of Special Education and Rehabilitative Services, DOJ has also released [guidance](#) to address the obligation of public schools to meet the communication needs of students with disabilities.

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 addition, ED funds 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.

### **ASD Services and Supports across the Lifespan**

The activities in this section are related to Questions 5 and 6 of the *IACC Strategic Plan*.

ACL 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. ACL also manages the [Protection & Advocacy \(P&A\)](#) Agencies program which supports agencies in each state 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 addition, ACL funds several projects aimed at improving employment outcomes and community living in transition-age youth and young adults with ASD.

CDC has leveraged the unique infrastructure of SEED to launch the SEED Teen program, a pilot extension designed to better understand the needs of adolescents with ASD. Findings from the SEED Teen pilot will guide future research into this critical transition from childhood to adulthood. Additionally, results from SEED Teen will inform services and treatments for teenagers with autism and other developmental disabilities and their families and add insight into similarities and differences between teens with autism and teens without autism and teen development overall.

CMS has published guidance on their website relevant to individuals with ASD, including information on the [implementation of the Community First Choice State Plan Option](#), a home and community-based benefit package available to states to promote community integration, can be found online. The Center for Medicaid and CHIP Services has published information on [Medicaid home and community based services \(HCBS\)](#), including [guidance](#). CMS is available to provide technical assistance to states on the various coverage authorities for treatment of ASD, including state plan and HCBS waiver authorities.

DOJ funded a project 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.

DOL has funded apprenticeship and employment partnership programs designed to improve employment outcomes among young adults with ASD. It also awarded Pathways to Careers Demonstration grants to two community colleges. These demonstration grants will 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.

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. Programs administered by HUD are available to individuals with disabilities, including ASD.

Through the [Indian Children’s Program \(ICP\)](#), IHS provides services to American Indian/Alaska Natives (AI/AN) patients with ASD. ICP recently transitioned to the IHS Telebehavioral Health Center of Excellence (THBCE) program, providing training and support to clinicians regarding behavioral health, family, and social issues facing AI/AN youth diagnosed neurodevelopmental disorders, including ASD.

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. From FY 2011 to FY 2015, SAMHSA also funded 127 CMHI grants to support expansion of systems of care.

SSA administers two disability programs, the [Social Security Disability Insurance \(SSDI\)](#) program and the [Supplemental Security Income \(SSI\)](#) program, for individual with disabilities including ASD. Recently, SSA began working with researchers at the A.J. Drexel Autism Institute to produce research describing participation in the SSI program by adults with ASD.

TRICARE offers physician 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. The Department has provided coverage for Applied Behavior Analysis (ABA), for family members of active duty service members since 2001.

## Summary

The *Report to Congress on Activities Related to Autism Spectrum Disorder and Other Developmental Disabilities* details several ASD research and services activities across the federal government. 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 2014-2018), 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. In various ways, these programs and activities are addressing the seven Question areas of the IACC Strategic Plan.

To ensure continuing coordination among federal agencies and between federal and private partner organizations, the IACC 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. In addition, the National Autism Coordinator and the FIWA will continue internally coordinating federal efforts to implement advice provided by the IACC and addressing recommendations of reports to Congress related to ASD. 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.

For the full report, please view the [\*Report to Congress on Activities Related to Autism Spectrum Disorder and Other Developmental Disabilities \(FY 2014 - FY 2018\)\*](#) at the IACC website.

[section break]

## **Update on the Working Group: Improving Health Outcomes for Individuals on the Autism Spectrum**

## Background

During the Autism CARES Act authorization period, the IACC voted to convene a working group on health and wellness issues for individuals with ASD. In response, the IACC established the Working Group: Improving Health Outcomes for Individuals on the Autism Spectrum. The goal of the Working Group is to identify the challenges of people on the autism spectrum pertaining to health and general wellness, as well as co-occurring physical and mental health challenges. Co-occurring physical and mental health conditions have been reported by the community and documented in research as an important factor that can reduce quality of life when not acknowledged, recognized, and properly addressed. Recent research findings also reveal people on the autism spectrum have shortened lifespans because of a host of co-occurring medical conditions.<sup>1</sup> There is a growing body of research on co-occurring physical and mental health conditions that affect people with ASD, but further research is needed. Additionally, there is a need to address the lack of adequate healthcare services to address co-occurring physical and mental health. Availability of trained personnel who can address health needs across the lifespan and access to healthcare services continue to present challenges in addressing these health needs.

In order to address these particular needs of the autism community, the Working Group has planned several activities to address these issues. The working group met by phone calls that took place in 2018 and convened a public workshop in September 2018 to address several of the most common physical health issues that are reported by the autism community as areas of concern. The workshop featured speakers who addressed the issues of epilepsy, sleep, gastrointestinal disorders, and patient-provider and healthcare services issues. This Update on the Working Group includes highlights from the September 2018 Workshop that focused on co-occurring health conditions of ASD and health care experiences for individuals with ASD. The Working Group will present its findings and recommendations back to the IACC for further consideration, potential adoption, dissemination, and action.

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<sup>1</sup> Hirvikoski, T., Mittendorfer-Rutz, E., Boman, M., Larsson, H., Lichtenstein, P., & Bölte, S. (2016). [Premature mortality in autism spectrum disorder](#). *The British Journal of Psychiatry*, 208(3), 232-238.

## **Highlights from the IACC Workshop: Addressing the Health Needs of People on the Autism Spectrum**

In September 2018, the Working Group convened a workshop to address the health and quality of life for people on the autism spectrum. The Working Group aimed to improve access to care for co-occurring physical health conditions; increase community and provider awareness of these conditions and their treatment; and facilitate the development of practice guidelines, policies, training, and service approaches to enable better patient-provider interactions and improved health outcomes. Six main topics were explored at the workshop:

- **Health and Healthcare for Adults on the Autism**
- **Physical and Mental Health**
- **Epilepsy**
- **Gastrointestinal Issues (GI)**
- **Sleep**
- **Healthcare Experiences of Children and Adults with ASD**

For each topic, there were presentations on current research efforts followed by a thorough discussion of the gaps, needs, and hopes for future research and services in that area of research. The workshop participants also debated potential options for the working group's involvement in alleviating the challenges to these health conditions. The discussions of each topic are summarized below.

### **Health and Healthcare for Adults on the Autism Spectrum**

#### **Presentation Highlights**

Dr. Jeremy Parr presented on his research program, the Adult Autism Spectrum Cohort-UK, which is based in the United Kingdom (UK) and aims to better understand and improve the life experiences of adults with autism spectrum disorder (ASD). Dr. Parr reviewed various considerations involved in conducting research on healthcare for adults with autism. These considerations included working in collaboration with individuals with autism on the development of research methods; assessing quality of life as an important outcome metric; the presence, clinical burden, and life course of co-occurring conditions; unmet clinical needs; and health accommodations. Dr. Parr highlighted that implementation science is critical for change within services, and that longitudinal studies with standardized data and protocols are important to accelerate discovery across the lifespan.

#### **Summary of Discussion, Challenges, Desired Outcomes**

The workshop participants discussed representativeness of the adult population in research, the aging out of individuals from pediatric care as they transition to adulthood, and the hardships for individuals with autism or other disabilities who were also caregivers for a person with ASD. They also discussed incorporating feedback from individuals with autism to better inform research methodology and service development, implementing evidence-based practices for challenges in daily living, and adapting standard practices and delivery methods for healthcare services within the ASD community. Finally, the participants discussed access to care, especially in rural areas, and the need for change in Medicare/Medicaid reimbursement for health services.

A challenge mentioned in both research and clinical care was that physicians can sometimes experience difficulty completing parts of physical exams, such as blood draws or electrocardiograms, on individuals with ASD. Another challenge for young adults transitioning out of pediatric care was the lack of adult specialists with experience treating individuals with ASD. These challenges could be met by either the

creation of a subspecialty or increased training and education programs for primary care physicians and specialists, such as neurologists or gastroenterologists.

Additionally, the workshop participants discussed the availability of tools to educate community providers about ASD and co-occurring conditions. There are several such tools available in the United States (US), such as [Project ECHO](#), and the participants noted the need for a more effective dissemination and implementation plan for bringing those tools to clinicians and the public. Reward systems may help motivate primary care physicians to complete physical exams or attend specialty training programs. The workshop participants highlighted targeted implementation of evidence-based healthcare practices for people on the autism spectrum and broad dissemination of information on ASD as an overall desired outcome.

## **Physical and Mental Health and ASD**

### **Presentation Highlights**

On behalf of Dr. Lisa Croen, Dr. David Amaral presented an overview of co-occurring conditions, such as weight, seizures, sleep problems, gastrointestinal (GI) issues, and immune problems, in individuals with ASD. He highlighted Dr. Croen's work with the large health database of the Kaiser Permanente Autism Research Program, which had revealed several insights into the prevalence of co-occurring conditions and other health outcomes in the autism population. Dr. Croen's research has demonstrated that autistic individuals experience a shorter lifespan, greater numbers of health challenges, higher utilization of healthcare due to co-occurring conditions, higher prevalence of certain health conditions, clustered health conditions, and changes in prevalence in co-occurring conditions over time. Dr. Amaral also discussed relevant research gaps to understanding and treating co-occurring conditions for individuals with ASD and challenged the Working Group to explore why individuals with ASD experience these co-occurring conditions.

### **Summary of Discussion, Challenges, Desired Outcomes**

The workshop participants discussed various barriers in access to healthcare for individuals seeking treatment for co-occurring conditions, as well as risk factors that can lead to increased co-occurring health issues. They also discussed the difficulties in access to care experienced by individuals with ASD, often because their symptoms have been overlooked or ignored, they have co-occurring conditions with overlapping symptoms, or they have been misdiagnosed. The participants also discussed the biological, social, and behavioral factors that contribute to co-occurring conditions in ASD. Additionally, they discussed potential solutions, reviewed the topic of creating a subspecialty versus increased training in specialty practices related to common co-occurring conditions, and considered financial and insurance reimbursement structures that could improve healthcare outcomes.

A challenge in access to care for co-occurring conditions is the difficulty that some individuals with ASD face when communicating their symptoms and healthcare needs, due to social, verbal, and/or executive function issues. There is also a significant problem of the clinician perception of fear and inexperience in working with individuals with autism. The participants noted the need to develop an improved approach among physicians to overcome the communication problems and other disabilities that create barriers to care, and to develop the accommodations needed to improve quality of care. Increased funding for research from genetic and pathophysiological perspectives would improve understanding of co-occurring conditions, identify subtypes, and reduce misdiagnoses. The workshop participants discussed the need to consider different models of technical assistance and training to support clinicians unfamiliar with ASD and related health issues.



## **Epilepsy in Individuals with ASD**

### **Presentation Highlights**

Dr. Gregory Barnes summarized the shared genetic and neurobiological mechanisms of epilepsy and ASD. He also reviewed the characteristics of seizures across the lifespan and the co-occurrence of intellectual disabilities in this population.

Dr. Sarah Spence presented on the epidemiology of epilepsy with ASD, reviewing the prevalence across age groups and other clinical conditions that overlap epilepsy and autism. She discussed the higher mortality rates in individuals with autism and epilepsy, the risk differences between sexes, and how epilepsy affects different autistic behaviors. She reviewed treatment options for epilepsy and suggested that, since autism and epilepsy are most often studied separately, better integration of the two would help improve understanding and treatment.

### **Summary of Discussion, Challenges, Desired Outcomes**

The workshop participants discussed the contributions of sex, family history, parental IQ, and social determinants in the development of epilepsy in individuals with ASD. Additionally, the participants discussed the effect of anti-seizure medications on ASD behaviors and the challenges in treating multiple health issues at once. Better behavioral supports may help individuals with ASD become more comfortable with clinical assessment, treatment, and research protocols. Another challenge is a lack of data on ASD with co-occurring epilepsy because the two are often studied separately by researchers. Integrated research efforts for both epilepsy and autism would be valuable for improved understanding and outcomes. The participants also discussed existing and emerging technologies to assess and treat seizures. The cost of these technologies may be prohibitive for many families; the participants discussed the need to advocate for reimbursement of these interventions.

## **ASD and Gastrointestinal (GI) Disorders**

### **Presentation Highlights**

Dr. Timothy Buie presented on the history of research and the current state of science on GI disorders in autism. He reviewed past hypotheses on GI issues in autism, including theories on gluten, casein, enterocolitis, intestinal inflammation, and immune disruption. More recent research has more closely investigated the role of inflammation, immune response, intestinal permeability, and microbiota disruption. Dr. Buie talked about challenges that families face with feeding and food restrictions, and the need to consult with a gastroenterologist to assess and treat symptoms.

### **Summary of Discussion, Challenges, Desired Outcomes**

The workshop participants discussed research on the impact of the microbiome on the brain, the genetic factors involved with the GI tract and ASD, oxidative stress, and serotonin regulation related to gut sensitivity. They also discussed the correlations between issues such as sensory sensitivity or anxiety and GI issues. They reviewed the efficacy and long-term safety of treatment options, and they discussed the difficulties in accessing specialty GI care that individuals with ASD often face.

One challenge identified by the participants was that individuals with ASD and their families have difficulty finding educational and clinical resources related to GI issues. Another challenge is that recent research findings are promising, but still emerging, and may take years to transition to practice. Additionally, there is not currently enough data on the effects of long-term use of current GI treatments in individuals with ASD.

The workshop participants suggested guidance towards other recommendations for standard care practices for individuals with autism would be helpful for those who have GI issues and may need additional clinical supports. Continued research into the mechanisms of GI issues in autism may result in novel treatments that may be safer and more effective than current treatments.

## **ASD and Sleep**

### **Presentation Highlights**

Dr. Beth Ann Malow summarized research on sleep issues in individuals with ASD and considerations for assessment and treatment. She reviewed a case study of a boy with autism who experienced multiple sleep issues at once, and she presented a systematic approach for identifying the underlying problems and a treatment approach for improved sleep. She also discussed research on melatonin levels in children with ASD and noted that not all sleep issues in autism are related to a melatonin deficiency. Dr. Malow provided recommendations and tools to assess sleep problems for individuals with ASD and proposed several actions that the Working Group could take in addressing sleep issues.

### **Summary of Discussion, Challenges, Desired Outcomes**

The workshop participants discussed concerns about the use of melatonin during puberty, and the need for additional research to understand medical and biological causes of sleep issues among individuals with ASD. They also talked about sleep issues across the lifespan, the potential for sleep problems to be misdiagnosed as other psychiatric conditions, and case studies of more rare sleep issues such as REM sleep behavior disorder or dramatically short sleepers. They discussed the effect of cortisol on waking and daytime sleepiness, the cycle of not being able to fall or stay asleep and excessive daytime sleepiness, and the implications that sleep issues may have on employment. Finally, they reviewed co-occurring conditions alongside sleep-related issues that would be beneficial to research, such as GI problems, anxiety, sleep medications, and developmental differences.

One challenge identified is that many individuals with ASD already practice basic sleep hygiene yet still experience sleep issues, and their medical providers often do not offer more targeted guidance. The sleep issues may be caused by multiple factors, and it may be difficult to identify a root cause and effective treatment. Another challenge is that there is not enough data on the long-term use of melatonin or the use of alternative medications to improve sleep outcomes in the autism population. Additionally, there is not enough understanding of the underlying drivers of sleep problems in autism.

Participants advocated for expanded research efforts to understand underlying drivers of sleep problems, sleep issues over the life cycle, and how functions such as circadian clock genes differ in individuals with autism. There are opportunities to expand existing research efforts and leverage current data resources such as the Simons Foundation's [SPARK](#) study.

## **Healthcare Experiences of Children and Adults with ASD**

### **Presentation Highlights**

Dr. Micah Mazurek presented on the healthcare experiences of children with autism, discussing the negative impact of multiple co-occurring conditions on functioning, finances, daily life, and families and caregivers. She discussed research demonstrating that children with autism experience worse access to care, more costly care needs, uncomfortable care environments, and communication and sensory difficulties during clinical visits. She reiterated the importance of expanding clinical training and education for primary care providers, especially given that there are a limited number of specialists

available. Dr. Mazurek also discussed her work with Project ECHO to explore telehealth approaches for autism and its potential for future implementation across more sites.

Dr. Christina Nicolaidis and Dr. Dora Raymaker presented on the healthcare experiences of adults with autism, discussing their work on the [Academic Autism Spectrum Partnership in Research and Education \(AASPIRE\)](#) and with Kaiser Permanente to better understand unmet healthcare needs, healthcare utilization, and patient satisfaction. They summarized their study outcomes showing significantly low clinician confidence in treating adults with autism and little planning to pursue additional training, despite high willingness to accept an adult with autism in their practice. They discussed the specific barriers to healthcare for adults with autism, including high costs, anxiety, difficulty processing information quickly, and sensory and communication issues. They also discussed challenges in developing and implementing specialty training for the clinical care of people with autism. Finally, they reviewed their [Autism Healthcare Accommodation Toolkit](#), a tool for individuals with autism to complete for their healthcare providers that could improve clinical visits.

### **Summary of Discussion, Challenges, Desired Outcomes**

The workshop participants discussed the potential cost and effectiveness of genetic testing towards advocating for more specific treatment approaches, and the intersectionality of health and employment. They talked about the challenges in the transition-aged population, the need for physician continuing education program with ASD-related content, and approaches for increasing clinician motivation with regard to working with adults on the autism spectrum. Another challenge noted is the reliance on self-reporting in healthcare and healthcare research, which may result in research outcome errors or clinical inaccuracies due to communication difficulties faced by some individuals with ASD.

The financial burden of healthcare in autism is a substantial challenge, especially for families in rural areas and families with children who have significant health issues. Concepts such as concierge care, though potentially helpful for some, may also increase health disparities. There is a general lack of representation of different minority, socioeconomic, and rural populations in autism research. Future research efforts in healthcare for people with autism should focus on including hard-to-reach or otherwise marginalized populations. Better understanding of the social determinants of health outcomes in autism could improve assessment and treatment effectiveness.

The participants also discussed the utilization and effectiveness of different clinical educational approaches; the development of simple tools such as decision trees, checklists, or short quizzes; and lessons learned from other models of clinical education. The workshop participants noted that training and education tools for healthcare providers should be developed with feasibility and sustainability in mind and future efforts should focus on practical implementation of health services.

## Summary

The IACC recognizes that physical health concerns are a major factor in the quality of the life of people on the autism spectrum. There are many physical health needs within the autism community that are currently not adequately met due to lack of research and practical understanding of the relationship of these conditions with ASD, inadequacy of current treatments, lack of an adequate number of medical personnel with understanding of ASD and physical health needs across the lifespan, and challenges within the healthcare system. The Committee recognized these concerns by implementing an objective in the *2016-2017 IACC Strategic Plan* directed at improving the understanding of co-occurring conditions associated with ASD as well as forming a Working Group to address the challenges and barriers in research and healthcare services.

The Working Group held a workshop in 2018 in which the workshop participants identified several ideas that could improve ASD research efforts in understanding the root causes of co-occurring physical health issues, and improve healthcare services for people on the autism spectrum, such as physician education and development of best practices, toolkits, and training approaches. The next steps for the Working Group include a focus on priorities that had not been covered during the workshop, such as co-occurring mental health issues. The Working Group expects to draft a document with its findings in the coming months. Discussions and activities of the Working Group will continue in through the end of the Autism CARES Act authorization in September 2019 with follow-up conference calls, a second workshop focused on mental health needs for people on the autism spectrum, and upcoming full Committee meetings.

## CONCLUSION

Since 2009, the *IACC Strategic Plan for Autism Spectrum Disorder* has outlined priority areas for enhanced research, services, and policy issues to address the needs of autistic individuals and their families across the spectrum and across the lifespan and has served as a guide for federal ASD activities. This 2018 update of the *Strategic Plan* reviews recent research progress, federal ASD-related programs, and working group activities of the IACC.

The *IACC ASD Research Portfolio Analysis Report* continues to serve as a mechanism to monitor federal ASD research efforts and assess ASD research funding trends in relation to the *IACC Strategic Plan* objectives. The 2016 edition of the *IACC Portfolio Analysis Report* provided nine years of ASD research funding as well as insight into the alignment of current research investments with the 23 new objectives in the *2016-2017 IACC Strategic Plan*. Future iterations of the *Portfolio Analysis* will continue to track funding towards the new objectives and monitor annual goals towards the 2020 recommended budget of \$685 million for ASD research.

The *HHS Report to Congress on Activities Related to Autism Spectrum Disorder and Other Developmental Disabilities FY 2014- FY 2018* summarizes federal efforts to address the objectives in the IACC in the *2016-2017 Strategic Plan*. Federally-supported research is revealing more about how autism develops and what risk factors may be involved as well as advances in screening and diagnosis in ASD. Also, there are ongoing federal initiatives to increase access to efficacious services and supports as well as research efforts to increase knowledge on autism throughout the lifespan. The Report highlights through federal collaboration and continued support for ASD activities there can be an impact on the ASD community.

Finally, the IACC Health Outcomes Working Group is conducting activities to address some of the major physical and mental health-related concerns of individuals with ASD and their families. The *2016-2017 Strategic Plan* outlined in its objectives a need for increased understanding of co-occurring conditions and improving the health needs of children and adults with autism. The working group held a workshop in September 2018 that included the topics of gastrointestinal issues, sleep, and epilepsy, as well as patient-provider issues that impact the health and well-being of individuals on the autism spectrum. In May 2019, the committee plans to convene a second workshop on mental health issues in ASD. Through the end of the Autism CARES authorization in September 2019, the Working Group will continue its work to develop a set of findings and recommendations it can provide to the IACC on these issues.

The IACC continues to coordinate autism research efforts and reaffirms its commitment to our core values: responding with urgency to the needs and challenges presented by ASD, pursuing excellence in research, building a spirit of collaboration, remaining focused on the needs of the community, developing strategic partnerships, and striving for equity. In the future, the IACC will continue to work towards meeting the critical needs of the autism community.

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