INTERAGENCY AUTISM COORDINATING COMMITTEE

STRATEGIC PLAN

FOR AUTISM SPECTRUM DISORDER

2018-2019 UPDATE

IACC
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OFFICE OF AUTISM RESEARCH COORDINATION
NATIONAL INSTITUTES OF HEALTH

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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 2019*.

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.

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

VISION STATEMENT

The *IACC Strategic Plan for ASD* will accelerate and inspire research, and enhance service provision and access, that will profoundly improve the health and quality of life of every person on the autism spectrum across the lifespan. The *Plan* will provide a blueprint for ASD research and services efforts, engaging the participation and input of government agencies, private organizations, and the broader autism community.

MISSION STATEMENT

The purpose of the *Strategic Plan* is to focus, coordinate, and accelerate innovative research and foster development of high-quality services in partnership with stakeholders to address the urgent questions and needs of people on the autism spectrum and their families.

CORE VALUES

The IACC adopted the following core values and emphasized their significance to the *2016-2017 Strategic Plan* and to the *2018-19 IACC Strategic Plan Update*:

Sense of Urgency: We will focus on responding rapidly and efficiently to the needs and challenges of people on the autism spectrum and their families.

Excellence: We will pursue innovative scientific research of the highest quality and development and dissemination of evidence-based services and practices to maximize the quality of life for people on the autism spectrum.

Spirit of Collaboration: We will treat others with respect, listen with open minds to the diverse views of people on the autism spectrum and their families, thoughtfully consider community input, and foster discussions where participants can comfortably offer opposing opinions.

Community 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 quality of life, human rights, and dignity of people with ASD, from prenatal development forward.

Partnerships in Action: We will value cross-disciplinary approaches, data sharing, teamwork, and partnerships to advance ASD research and service activities.

Equity: We will prioritize improved access to detection, intervention, and other services and supports for individuals with ASD, and commit to the goal of reducing disparities across the lifespan, spectrum of ability and disability, sex and gender, racial and cultural boundaries, socioeconomic status, and geographic location to improve the health and quality of life of all individuals with ASD.

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.*

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 2019 under the Autism Collaboration, Accountability, Research, Education, and Support Act (Autism CARES Act; Public Law 116-60). 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 *2018-2019 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 review of the state of the field and provided a set of 23 new research, services, and policy-related objectives. Therefore, for this 2018-2019 Update, it would be most beneficial to the community to provide an update on progress that has been made by the Committee, federal agencies, and the broader autism community toward the issues and goals described in the *2016-2017 IACC Strategic Plan*. The *2018-2019 IACC Strategic Plan Update* includes:

Chapter 1: A synopsis of presentations and discussions that took place at IACC Full Committee meetings in 2018 and 2019.

Chapter 2: A recap of the activities of the IACC Working Group focused on improving health outcomes for people on the autism spectrum.

Chapter 3: A recap of the activities of the IACC Working Group focused on housing issues experienced by people on the autism spectrum and their families.

Chapter 4: 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 objectives of the *2016-2017 IACC Strategic Plan*.

Chapter 5: 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.

Together, the Committee hopes that the *2018-2019 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 IACC 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.

QUESTION 4 WHICH TREATMENTS AND INTERVENTIONS WILL HELP?

1	Develop and improve pharmacological and medical interventions to address both core symptoms and co-occurring conditions in ASD.
2	Create and improve psychosocial, developmental, and naturalistic interventions for the core symptoms and co-occurring conditions in ASD.
3	Maximize the potential for technologies and development of technology-based interventions to improve the lives of people on the autism spectrum.

QUESTION 5 WHAT KINDS OF SERVICES AND SUPPORTS ARE NEEDED TO MAXIMIZE QUALITY OF LIFE FOR PEOPLE ON THE AUTISM SPECTRUM?

1	Scale up and implement evidence-based interventions in community settings.
2	Reduce disparities in access and in outcomes for underserved populations.
3	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 HOW CAN WE MEET THE NEEDS OF PEOPLE WITH ASD AS THEY PROGRESS INTO AND THROUGH ADULTHOOD?

1	Support development and coordination of integrated services to help youth make a successful transition to adulthood and provide supports throughout the lifespan.
2	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.
3	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.

QUESTION 7 HOW DO WE CONTINUE TO BUILD, EXPAND, AND ENHANCE THE INFRASTRUCTURE SYSTEM TO MEET THE NEEDS OF THE ASD COMMUNITY?

1	Promote growth, integration, and coordination of biorepository infrastructure.
2	Develop, enhance, and link data repositories.
3	Expand and enhance the research and services workforce, and accelerate the pipeline from research to practice.
4	Strengthen ASD surveillance systems to further understanding of the population of individuals with ASD, while allowing comparisons and linkages across systems as much as possible.

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

CHAPTER

1

HIGHLIGHTS FROM IACC FULL COMMITTEE MEETINGS 2018-2019

BACKGROUND

This chapter describes presentations and discussions that took place at IACC Full Committee meetings in 2018 and 2019. The IACC regularly invites presenters to speak about topics of interest to the committee and to the broader autism community. The goal of these presentations is to inform the IACC and the autism community about recent scientific advances, new research funding announcements and service programs, policy updates, and other important issues. Invited speakers include researchers, advocates, federal agency officials, and others. These presentations and their associated discussions highlighted areas of concern or progress relevant to the seven research priority areas of the *IACC Strategic Plan*, and helped to inform the future strategic planning activities of the committee. Archived videos of each presentation and the full slide sets are available on the IACC website. The topics highlighted in 2018-2019 include research on health disparities, early detection, employment, aggression and self-injury, wandering, disability financial planning, housing, health-care, prevalence, communications technologies, and systems of care.

HIGHLIGHTS FROM THE MEETINGS

JANUARY 2018

Advancing Behavioral Health in the Indian Health System

Marcella Ronyak, Ph.D.
Deputy Director, Division of Behavioral Health, Indian Health Service (IHS)

The goal of this presentation was to inform the IACC about the IHS and its provision of mental health services to American Indians and Alaska Natives, including those with autism. The IHS takes a holistic and culturally appropriate approach to addressing ASD and other health issues in the communities that it serves. Several types of service facilities are managed by IHS and/or supported by IHS funding, including hospitals, health centers, village clinics, health stations, and school health centers. Dr. Ronyak discussed the Indian Children's Program (ICP) which provides education, training, and consultation for American Indian and Alaska Native youth, including services for autism. This program reaches individuals and families who are not able to travel to access autism diagnostic assessment and services. It also administers a series of webinars on autism for service providers. Dr. Ronyak also discussed the Telebehavioral Health Center of Excellence (TBHCE) program, which provides ASD-relevant tele-education and tele-heath technical assistance to patients and providers in IHS service areas. The activities discussed in this presentation address the committee's interest in issues related to reducing health disparities in the autism community and Questions 1, 4, and 5 of the *IACC Strategic Plan*.

Introduction to the ASD PEDS Network

Denise Pintello, Ph.D., M.S.W.
Chief, Child and Adolescent Research Program, NIMH
Acting Chief, Dissemination and Implementation Research Program, NIMH

Amy Wetherby, Ph.D., C.C.C.-S.L.P.
Distinguished Research Professor, Department of Clinical Sciences, Florida State University
Director, Autism Institute, Florida State University

Alice Carter, Ph.D.
Professor, College of Liberal Arts, University of Massachusetts, Boston

Emily Feinberg, Sc.D. C.P.N.P.
Associate Professor, Department of Community Health Sciences, Boston University School of Public Health
Associate Professor of Pediatrics, Division of General Pediatrics, Boston University School of Medicine

This panel of presentations introduced the ASD Pediatric Early Detection Engagement and Services (PEDS) Network, a group of five NIMH-funded studies exploring early detection and intervention for autism in very young children (ages 0-3 years). Dr. Pintello first discussed the development of this research network and its efforts to increase the evidence base in support of the screening of all children for ASD. She then highlighted the efforts of the investigators to coordinate their methods and measurements in order to improve the statistical power of their studies. Three of the Network's principal investigators next presented their ongoing research as part of the ASD PEDS Network. Dr. Wetherby described her work to streamline screening and build the capacity of communities to screen and provide early services for ASD. Dr. Carter discussed a new multi-stage screening protocol implemented in partnership with Medicaid Part C Early Intervention agencies. Finally, Dr. Feinberg discussed her project, which is focused on the continuum from screening to diagnostic assessment to intervention services and how this can be tailored to meet the needs of low-income families and racial/ethnic minorities. At the conclusion of

the funding period, the researchers involved in the Network hope to identify new and improved strategies for screening and diagnosis of young children in diverse communities and care settings. These efforts will help to increase access to early ASD diagnosis and services that are known to have a critical impact on cognitive and behavioral outcomes. The activities discussed in this panel follow up on a prior IACC presentation about recommendations of the U.S. Preventive Services Task Force (USPSTF) related to early screening of children for ASD, which suggested the need for additional research data to demonstrate the benefits of screening for ASD in young children for whom no concerns of ASD have been raised. These presentations on current research on ASD screening address Questions 1 and 5 of the *IACC Strategic Plan*.

APRIL 2018

Panel on Employment for People on the Autism Spectrum

Scott Michael Robertson, Ph.D.
Policy Advisor, Youth Policy Team, Office of Disability Employment Policy, U.S. Department of Labor

Jose Velasco, M.S.
Vice-President of Operations and Strategy, Global Co-Lead, Autism at Work, SAP

Marjorie Madfis, M.B.A.
Yes She Can, Inc.

Lori Ireland, M.B.A.
Co-Founder and Board Member, Extraordinary Ventures

Paige Morrow
Managing Director, Extraordinary Ventures

The participants in this panel discussed several successful employment programs and models for companies that employ autistic individuals. Dr. Robertson first discussed the need for companies to recognize both the challenges and benefits of hiring people with ASD. He also presented an overview of the U.S. Department of Labor's efforts and initiatives to improve employment outcomes for individuals with disabilities, including ASD. Mr. Velasco then discussed the Autism at Work initiative at SAP, an international software company that has committed to including individuals with disabilities in a range of positions across their entire global business. The program provides onboarding, training, and mentoring opportunities for individuals with ASD. Next, Ms. Madfis described her company Yes She Can Inc., which teaches transferrable job skills to young adults with ASD while they are employed at a resale boutique for American Girl™ dolls and accessories. This program provides a first job experience and equips individuals with job skills for future employment in other venues. Finally, Ms. Ireland and Ms. Morrow described Extraordinary Ventures, which is a non-profit organization that operates under the philosophy that all people are employable. Extraordinary Ventures creates self-supporting small business ventures that provide employment opportunities for individuals with autism and other developmental disabilities. The panelists discussed various approaches to providing job training and employment support for people on the autism spectrum, giving them the opportunity to be valued and successful employees. The activities discussed in this panel informed the committee on current employment models and address Question 6 of the *IACC Strategic Plan*.

Aggression and Self-Injury: Research Needs for the Severely Affected End of the Spectrum

Matthew Siegel, M.D.
Director, Autism & Developmental Disorders Inpatient Research Collaborative (ADDIRC), Maine Medical Research Institute; Vice President Medical Affairs, Developmental Disorders Service, Maine Behavioral Healthcare

Dr. Siegel is the director of a specialized inpatient hospital for disabled individuals with severe behaviors that interfere with their daily functioning and ability to be in less restrictive settings. He described his research which seeks to understand the underlying mechanisms of aggression. He also described the framework of a treatment plan that is

highly individualized and incorporates a multidisciplinary approach, including applied behavioral analysis. Other effective therapeutic approaches may include psychotropic medication, communication strategies, medical treatment, family work and parent training, sensory regulation strategies, social skills, social cognitive strategies, and psychotherapy strategies. Dr. Siegel next discussed the Autism & Developmental Disorders Inpatient Research Collaborative (ADDIRC), an NIH-funded research network of specialty inpatient units designed to strengthen the evidence base of intensive behavioral health treatments and interventions for individuals severely affected by ASD and other developmental disorders. Early findings from the network have identified risk factors associated with psychiatric hospitalization. Lastly, he discussed his ongoing research studying physiological arousal as a potential biomarker before, during, and after aggressive behaviors. These findings may be useful to families, caregivers, and providers in the future for predicting and planning for response to incidents of aggressive behaviors.
The topics discussed in this presentation informed the committee of research findings related to individuals on the autism spectrum with high medical and support needs and address Questions 2 and 4 of the *IACC Strategic Plan*. The work described in this presentation contributes to the IACC's focused effort on co-occurring mental and physical health issues that affect individuals on the autism spectrum, culminating in two workshops that took place in 2019 (described in Chapter 2 of this report).

OCTOBER 2018

Autism Society Presentation: Unintentional Injury in Children and Youth with ASD

Jack Scott, Ph.D., B.C.B.A.-D.
Member, Autism Society Panel of Professional Advisors; Executive Director, Florida Atlantic University Center for Autism and Related Disabilities

Dr. Scott is a member of the Autism Society of America, a non-profit organization that provides advocacy, education, information and referral, support, and community at national, state and local levels. In his presentation, he reviewed data demonstrating the high risk of unintentional injury, wandering, and death in individuals with autism, especially young children who typically lack self-preservation skills and do not understand rules of conduct. He discussed various technologies available to families and communities that can help minimize the risk associated with wandering. He also discussed existing law enforcement training programs from the Autism Society of America and other organizations. Dr. Scott advocated for the potential benefits of a national agenda to train first responders, police officers, and federal officers in safety for children with autism, and the need for state education agencies to address elopement in students with ASD and other vulnerabilities. Finally, he suggested ways that federal agencies could expand their existing programs to provide better data on mortality in children with ASD, as well as develop new interventions and safety initiatives in order to better meet the need of individuals and families living with ASD. The activities discussed in this presentation address the committee's ongoing interest in the issue of wandering and efforts to reduce premature mortality in individuals on the autism spectrum. They also address Question 6 of the *IACC Strategic Plan*.

Panel: The ABLE Act and Financial Planning for People with Disabilities

Stuart Spielman, Esq.
Senior Vice President, Advocacy, Autism Speaks

Bette Ann Mobley
Director, Maryland ABLE

Colin Meeks, C.F.P., Ch.F.C., C.L.U.
Certified Financial Planner, Maryland Financial Advocates; Host, Special Needs Connection Podcast

Phoebe Ball, Esq.
Legislative Affairs Specialist, National Council on Disability

The participants in this panel discussed financial planning for autistic individuals and their families. The Achieving a Better Life Experience (ABLE) Act of 2014 was enacted in order to assist individuals with disabilities and their families as they plan for future care expenses over the lifespan of the individual. Individuals and families can contribute to ABLE accounts, which are tax-advantaged savings accounts that can fund disability expenses. Mr. Spielman first discussed the financial insecurity that many people face while planning for the futures of themselves or their family members with disabilities including ASD. He then reviewed the history of the ABLE Act and highlighted the Congressional support that it continues to receive. In order to better meet the needs of individuals and their families, ABLE accounts do not affect account holders' eligibility for programs such as Supplemental Security Income (SSI) and Medicaid. Ms. Mobley then discussed the logistics of state ABLE programs and some of the benefits of having an account. Mr. Meeks reviewed the importance of financial and legal planning for all special needs families and the need to understand all available options, including ABLE accounts and special needs trusts. He also discussed the differences between these two planning options. Finally, Ms. Ball discussed the role of the National Council on Disability (NCD), a nonpartisan, independent federal agency, in assisting people with disabilities with financial planning. She also shared NCD's hopes for the future of the ABLE program, including the need for more accountholders and for more states to provide ABLE programs. The activities discussed by this panel address Question 6 of the *IACC Strategic Plan*.

JANUARY 2019

HCBS Final Rule: Current Issues and Future Directions

Melissa Harris
Acting Deputy Director, Disabled and Elderly Health Programs Group, Center for Medicare and CHIP Services, Centers for Medicare and Medicaid Services (CMS)

Ms. Harris discussed the 2014 Home and Community-Based Settings (HCBS) Final Rule, a CMS regulation which defines criteria for home and community-based settings supported by Medicaid. This rule was instituted to ensure that individuals (including those with autism) receiving services have freedom of choice for a qualified living setting and qualified service provider, as well as to standardize HCBS criteria across states. Ms. Harris first explained how the rule was developed, including how CMS considered stakeholder input on the subject. She then reviewed the contents of the rule, which emphasize integration in and access to the greater community, as well as opportunities to seek employment and work in competitive integrated settings. Ms. Harris discussed how these criteria can be modified to accommodate different populations with varying needs, and how settings with institution-like qualities may require special attention and guidance in order to meet the regulations. Finally, she provided an update on implementation of the Rule across states and noted that CMS is developing revised guidance on the Final Rule based on stakeholder feedback. The presentation clarified some misconceptions about the Final Rule and outlined the way in which the Final Rule may help individuals with ASD and their families as they explore housing options. This presentation addresses the committee's interest in issues related to housing for autistic adults and Questions 5 and 6 of the *IACC Strategic Plan*. The committee followed up on this issue by holding a workshop on housing for individuals with disabilities in June 2019 (described in Chapter 3 of this report).

TRICARE Autism Care Demonstration

Capt. Edward Simmer, M.D.
Chief Clinical Officer, TRICARE Health Plan, Defense Health Agency, Department of Defense

Krystyna Bienia, Psy.D.
Clinical Psychologist, Senior Policy Analyst, Defense Health Agency, Department of Defense

Capt. Simmer presented an overview of the Military Health System (MHS) and TRICARE Health Plan (TRICARE), which provides health care services for US service members, military retirees, and their families. Capt. Simmer noted that standards of care can differ between military hospitals and civilian programs, so MHS is currently working to standardize rules and benefits across these entities. Primary care services covered by MHS for individuals with ASD can include applied behavioral analysis (ABA), occupational therapy, physical therapy, and speech and language therapy. Dr. Simmer discussed recent expansions of benefits for mental health services as well as the Extended Care Health Option (ECHO) for active duty families who may have difficulty retaining Medicaid coverage following moves across states. Finally, Capt. Simmer noted that benefits are typically provided based on the existence of evidence-based research showing their effectiveness, but the evidence base for many ASD interventions is not yet established. Dr. Bienia next reviewed the Autism Care Demonstration (ACD), which allows for the provision of ABA services to TRICARE-eligible beneficiaries diagnosed with ASD, despite the fact that ABA services often do not meet the typical criteria for reliable evidence. The goal of the ACD is to better target and treat the needs of each individual with ASD. Dr. Bienia reviewed the history of providing ABA benefits under TRICARE, then discussed the efforts of MHS to measure program outcomes in order to enhance the evidence base for ABA. Finally, she discussed initiatives to improve the program by soliciting input from stakeholders, including parents, service providers, and advocates. The activities discussed in this presentation address Questions 4 and 5 of the *IACC Strategic Plan*.

Panel Presentation: Kevin and Avonte's Law, and Disability Programs

Alison Singer, M.B.A.
IACC Member, President, Autism Science Foundation

Lori McIlwain
Co-Founder, Board Member, National Autism Association

Maria Fryer
Policy Advisor for Substance Abuse and Mental Health, Bureau of Justice Assistance, Office of Justice Programs, Department of Justice

Leemie Kahng-Sofer
Program Manager, Missing Children Division, National Center for Missing and Exploited Children

The participants in this panel discussed the issue of elopement/wandering in the context of Kevin and Avonte's Law, new federal legislation that authorizes grants to law enforcement agencies for first responder training and tracking technologies to help ensure the safety of individuals with ASD and other developmental disabilities who may wander from caregivers. Ms. Singer provided an overview of the issue of elopement in individuals with ASD, particularly the increase in the average age of autistic individuals who die as a result of wandering. She also described steps that the federal government, the advocacy community, and the IACC have taken to increase awareness and reduce wandering incidents in autistic individuals. Ms. McIlwain reviewed the current statistics on wandering among people with ASD, including several case studies. She also described some of the resources available to families that were developed by the National Autism Association and other advocacy groups. She noted that Kevin and Avonte's Law is a good first step, but appropriations are needed to fully implement the law. Ms. Fryer then discussed recent ASD-relevant initiatives from the Bureau of Justice Assistance, a federal agency that aims to help vulnerable populations in the justice system. She noted that the Department of Justice is developing new initiatives and engaging with law enforcement agencies, communities, and disability response teams to address the issue of wandering. Next, Ms. Kahng-Sofer reviewed the efforts and ASD-related data from the National Center for Missing and Exploited Children (NCMEC), a non-profit organization that helps find missing children, reduce child sexual exploitation, and prevent child victimization. She described how NCMEC partners

with the Department of Justice, local law enforcement and first responder agencies, and other community organizations. She also described several initiatives that have been in implemented in communities to increase safety for children with ASD. The activities discussed in this panel follow up on the committee's interest in the issue of wandering and prevention of premature mortality, and they address Question 6 of the *IACC Strategic Plan*.

APRIL 2019

CDC Autism Data Visualization Platform

Stuart Shapira, M.D., Ph.D.
Chief Medical Officer, Associate Director for Science (ADS), National Center on Birth Defects and Developmental Disabilities (NCBDDD), Centers for Disease Control and Prevention

Dr. Shapira introduced the Centers for Disease Control and Prevention (CDC)'s Autism Data Visualization Tool, an interactive website that provides up-to-date and historical ASD prevalence data and demographic characteristics among children in the United States. The tool draws data from four different sources: the CDC's Autism and Developmental Disabilities Monitoring Network, the Department of Education's Special Education Child Count, Medicaid data, and the Health Resources and Services Administration's National Survey of Children's Health. The website is designed to be user-friendly and easy to navigate for all users who seek to learn more about ASD prevalence at the national, state, and community levels. By including data from these four federal resources, the tool aims to improve understanding of ASD, its impact, and trends and changes in ASD prevalence over time. It can also be used to inform service delivery and guide future policymaking. The information provided by this resource addresses Question 7 of the *IACC Strategic Plan*.

Update from the Federal Communications Commission

Theodore Marcus, J.D.
Deputy Chief, Disability Rights Office, Consumer and Governmental Affairs Bureau, Federal Communications Commission (FCC)

The FCC is an independent U.S. government agency that regulates interstate and international communications by radio, television, wire, satellite and cable. Mr. Marcus described the efforts of the FCC to empower persons with ASD and other disabilities to have full access to and easy use of technologies. The FCC is currently seeking to better understand where and how much broadband internet is provided in communities, and which underserved populations face barriers to accessing it. He reviewed several technologies that the FCC oversees that are potentially beneficial to autistic individuals, including text and instant messaging, video conferencing, relay services, closed captioning, and audio description. Finally, Mr. Marcus encouraged individuals to contribute to policy change by informing the government of critical issues to consider, engaging with product manufacturers and providers on ways to increase accessibility, or by contacting the FCC to receive direct assistance. The activities discussed in this presentation reflect current challenges in ensuring that individuals have access to technology that enables them to participate fully in their community and society and address Questions 5 and 6 of the *IACC Strategic Plan*.

Panel Presentation: Disability Employment

Julie Taylor, Ph.D.
Assistant Professor of Pediatrics, Vanderbilt University Medical Center Investigator, Vanderbilt Kennedy Center, Vanderbilt University Medical Center

Paul Wehman, Ph.D.
Professor of Physical Medicine and Rehabilitation, Chairman Division of Rehabilitation Research, Director of VCU-RRTC, Medical College of Virginia, Virginia Commonwealth University

Erik Carter, Ph.D.
Cornelius Vanderbilt Professor, Department of Special Education, Vanderbilt University

Hala Annabi, Ph.D.
Associate Professor, Information School, University of Washington

The participants on this panel discussed challenges, current research, and future directions related to disability employment. Dr. Taylor gave an overview of disability employment issues and shared results from her research that seeks to understand unemployment, underemployment, and job stability among adults on the autism spectrum. In particular, she noted the influence of factors such as gender, family functioning, and family mental health on employment outcomes. Dr. Wehman then discussed his research using an internship model to discover evidence-based pathways to competitive integrated employment for people with ASD, including those with intellectual disabilities. He stressed the importance of a strengths-based approach to employment among adults with ASD rather than a deficits-based approach. He also noted that students who participated in his supported employment program had a positive impact on their supervisors and coworkers, and they were subsequently able to access jobs across diverse sectors. Next, Dr. Carter discussed the TennesseeWorks initiative, a systems change effort involving more than 50 state agencies, organizations, and community groups who work together to provide employment supports and opportunities for young people with disabilities. He emphasized the importance of elevating expectations among families, educators, and professionals, making information about programs accessible, and investing in partnerships between parent support organizations, disability nonprofits, employment-related agencies, and state departments. Dr. Annabi presented her research to understand employment opportunities in the autism community from the perspective of employers, businesses, and for-profit organizations. She noted that autism-specific hiring initiatives that identify strengths and break down traditional recruitment barriers have great potential, but they should also align within the company's values and existing diversity initiatives. She also emphasized that organizations should rely on leadership support to catalyze and reinforce culture changes. Finally, she noted that it will be important to encourage schools to begin early workplace preparation and include the voices of self-advocates as initiatives are developed and improved. This panel provided multiple perspectives on challenges and opportunities related to employment for autistic adults; the activities discussed address Question 6 of the *IACC Strategic Plan*.

JULY 2019

Panel Presentation: Using Innovation and Collaboration to Develop a Community Continuum of Care Model – Baton Rouge, Louisiana

Representative Franklin Foil
Louisiana House of Representatives

Lauren Crapanzano Jumonville, M.B.A.
Director, Civic Leadership Initiatives, Baton Rouge Area Foundation

Traci Olivier, Psy.D.
Pediatric Neuropsychologist, Our Lady of the Lake Physician Group

Melissa Juneau, CCC-SLP
Former CEO, The Emerge Center for Communication, Behavior, and Development

Stephen Whitlow, J.D.
Executive Director of Transition Services, Merakey Gateway

The participants on this panel discussed the Capital Area Autism Network (CAAN), a multi-tiered effort to increase and optimize ASD services across the lifespan in the Baton Rouge, LA area. Representative Foil gave a brief history of these efforts and an overview of the many local organizations involved. He also described his family's efforts to find job opportunities and other resources for his child with ASD. Ms. Jumonville then described the work of the Baton Rouge Area Foundation, a non-profit organization that has been integrally involved in building the CAAN local network of ASD services. Additional key organizations involved in CAAN are the Emerge Center (an early intervention pediatric care center), Our Lady of the Lake Pediatric Development and Therapy Center,

and Families Helping Families (a family resource center). Dr. Olivier provided background about the Our Lady of the Lake Children's Health program for children with ASD, which provides diagnostic and intervention services. She also described the Center's current partnerships and future directions. Ms. Juneau next described the work of the Emerge Center, which assists children with communication, behavioral, and developmental issues by providing audiology, occupational therapy, therapeutic classrooms, ABA, behavioral health services, and family support. Of note is the Emerge School for Autism, a charter school for children with ASD that aims to prepare them for general education classrooms. Finally, Mr. Whitlow noted the barriers to accessing transition services, transportation, and housing faced by individuals with ASD. He described the work of Merakey Gateway, an organization that provides job training and other transition services to young adults with ASD. The speakers in this panel emphasized the importance of diverse partners coming together to address the existing and emerging problems faced by their local communities. The activities presented by this panel demonstrated a model of community-based autism and disability services coordination and address Questions 1, 4, 5, and 6 of the *IACC Strategic Plan*.

Panel Presentation: Racial and Ethnic Disparities in Autism

Sandy Magaña, Ph.D., M.S.W.
Professor in Autism and Neurodevelopmental Disabilities, Steve Hicks School of Social Work, University of Texas at Austin

Temple Lovelace, Ph.D., B.C.B.A.-D.
Associate Professor of Special Education, Department of Counseling, Psychology, and Special Education, Duquesne University

Sarah Dababnah, Ph.D., M.P.H., M.S.W.
Assistant Professor, University of Maryland, Baltimore

Camille Proctor
Founder, The Color of Autism Foundation; Founding Member, National African American Autism Community Network

Matiana M. Ovalle
Grupo SALTO

Jose Luis Ovalle
Regional Coordinator Region 1, The Autism Program of Illinois (TAP); Senior Advisor, Grupo SALTO

The participants on this panel discussed various research and community efforts to address the racial and ethnic disparities in autism screening, diagnosis, treatment, and services. Dr. Magaña first described the results of the CDC's prevalence studies demonstrating that black and Latinx children tend to access ASD interventions later than other children, often due to misdiagnosis. She then described her work to develop culturally tailored interventions for Latinx families, as well as her research demonstrating reduced access to and utilization of general health care services among Latinx children compared to white children. Next, Dr. Lovelace discussed her research examining the difficulties that African American mothers in Philadelphia, PA experience in accessing autism services for their children. She presented qualitative data about these challenges, such as the significant stressors and barriers to locating services, accessing insurance, and finding providers who are a good cultural fit. Dr. Lovelace also discussed her work with the National African American Autism Community Network (NAAACN), a network devoted to fostering education and awareness of ASD in African American communities. Next, Dr. Dababnah presented her research that seeks to build community partnerships and develop culturally tailored interventions for African American families in Baltimore, MD. Using international autism research to inform their local program development, her team has determined that engaging community liaisons to tailor interventions, training parents, and recruiting non-specialist workers are key factors for success. Ms. Proctor then described her work with NAAACN advocating for African American

individuals with ASD and their families. She highlighted the difficulties these families often face in overcoming stigma and stressed the need for research that is culturally relevant, multilevel, multidisciplinary, and inclusive of all families. Finally, Mr. and Mrs. Ovalle spoke about their work with Grupo SALTO (Sociedad de Autismo Latina Trabajando con Optimismo), a support group that aims to educate Hispanic families with children with disabilities, including autism. The group aims to educate parents and other extended family members of individuals with autism, focusing on leadership, self-care, and self-advocacy. The activities presented by this panel address the committee's interest in issues related to reducing disparities in autism services and Questions 1, 4, 5, and 6 of the *IACC Strategic Plan*.

Department of Labor Apprenticeship Initiative

Scott Robertson, Ph.D.
Office of Disability Employment Policy, U.S. Department of Labor

Carolyn Jones, M.B.A.
Office of Disability Employment Policy, U.S. Department of Labor

Dr. Robertson and Ms. Jones described the Apprenticeship Inclusion Model (AIM) initiative, developed by the Department of Labor's Office of Disability Employment Policy (ODEP). The goal of this program is to research, test, and evaluate inclusive apprenticeships and integrated apprenticeship training for youth and adults with disabilities. The initiative works closely with companies in emerging industries that pay a livable, sustainable wage (including Microsoft, Amazon, and the Industry Manufacturing Technician program). AIM has funded several pilot programs, including two that are specifically focused on individuals with ASD. Dr. Robertson and Ms. Jones also discussed several other ODEP programs designed to increase and enhance employment opportunities for individuals with disabilities. The activities discussed in this presentation address Question 6 of the *IACC Strategic Plan*.

SUMMARY

In 2018 and 2019, the IACC held 6 full committee meetings featuring presentations that address all seven of the *IACC Strategic Plan* research areas, in order to inform the committee of current issues, innovative approaches, and advances being made in each of these areas. Many of these presentations demonstrate progress towards the objectives established in the *2016-2017 Strategic Plan*. Other presentations provide insight into research and services areas that need additional attention, investment, and/or improvement.

In the future, the IACC will continue to provide a platform at committee meetings for researchers and advocates to present their latest findings as well as inform the committee of current issues facing the community. This, along with input gathered through public comments, will continue to be used by the committee to develop activities and recommendations to federal agencies that can help improve the lives of people on the autism spectrum and their families.

CHAPTER

2

IACC WORKING GROUP ACTIVITIES: IMPROVING HEALTH OUTCOMES FOR INDIVIDUALS ON THE AUTISM SPECTRUM

BACKGROUND

During the Autism CARES Act of 2014 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 Working Group, composed of IACC members and invited external stakeholders with expertise in a variety of areas, was formed to gather information, discuss issues, and develop activities and recommendations for consideration by the full IACC. The Working Group focused their efforts on identifying the challenges people on the autism spectrum face 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 that people on the autism spectrum have shortened lifespans because of a host of co-occurring medical conditions.[1] There is a growing body of research on the 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 health issues. 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 begin to address these particular needs of the autism community, the Working Group planned several activities. The Working Group met by conference call in 2018 and convened public workshops in September 2018 and May 2019. The September 2018 workshop addressed 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 topics of epilepsy, sleep, gastrointestinal disorders, and patient-provider and healthcare services issues. In May 2019, the Working Group convened a workshop focused on the mental health issues experienced by individuals with ASD. Some of the topics discussed at the workshop included anxiety, depression, suicide, self-injurious behaviors, aggression, and mental health services. This update on the Working Group includes highlights from the September 2018 and May 2019 workshops that focused on co-occurring physical and mental health conditions of individuals with ASD and their health care experiences. The Working Group plans to present its findings and recommendations back to the IACC in the form of a written report for further consideration, potential adoption, dissemination, and action.

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 across the lifespan. Six main topics were explored at the workshop:

- **Health and Healthcare for Adults on the Autism Spectrum**
- **Overview of Physical and Mental Health in ASD**
- **Epilepsy**
- **Gastrointestinal (GI) Disorders**
- **Sleep Disturbances**
- **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. The workshop participants also debated potential options for the Working Group's involvement in alleviating the challenges associated with these health conditions. The discussions of each topic are summarized below.

HEALTH AND HEALTHCARE FOR ADULTS ON THE AUTISM SPECTRUM

Jeremy Parr, M.D.
Professor of Pediatric Neurodisability
Newcastle University Institute of Neuroscience

Presentation Highlights

Dr. 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 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.

Discussion of Challenges and Desired Outcomes

The workshop participants discussed the representation of the adult ASD population in research, the aging out of individuals from pediatric care as they transition to adulthood, and the hardships experienced by individuals with autism or other disabilities who are 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. Participants also considered 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, for 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 these 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.

OVERVIEW OF PHYSICAL AND MENTAL HEALTH IN ASD

David G. Amaral, Ph.D.
Distinguished Professor, Department of Psychiatry and Behavioral Science, University of California, Davis (UC), UC Davis MIND Institute

(on behalf of)

Lisa Croen, Ph.D.
Senior Research Scientist, Division of Research, Kaiser Permanente Northern California
Director, Kaiser Permanente Autism Research Program

Presentation Highlights

On behalf of Dr. Croen, Dr. Amaral presented an overview of co-occurring conditions in individuals with ASD, such as obesity, seizures, sleep problems, gastrointestinal (GI) issues, and immune problems. He highlighted Dr. Croen's work with the large health database of the Kaiser Permanente Autism Research Program, which has 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.

Discussion of Challenges and 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 potential 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 clinician 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 challenges that create barriers to care, and to develop the accommodations needed to improve quality of care. Increased funding for research from genetic and patho-physiological perspectives could 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

Gregory Barnes, M.D., Ph.D.
Director, University of Louisville Autism Center
Associate Professor, Child Neurology, Department of Neurology, University of Louisville School of Medicine

Sarah Spence, M.D., Ph.D.
Co-Director, Autism Spectrum Center, Boston Children's Hospital
Assistant Professor of Neurology, Harvard Medical School

Presentation Highlights

Dr. 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. Spence discussed the epidemiology of epilepsy with ASD, reviewing the prevalence across age groups and other clinical conditions that overlap with 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.

Discussion of Challenges and 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

Timothy Buie, M.D.
Attending Physician, Division of Gastroenterology, Hepatology and Nutrition, Boston Children's Hospital
Assistant Professor of Pediatrics, Harvard Medical School

Presentation Highlights

Dr. 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. 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.

Discussion of Challenges and Desired Outcomes

The workshop participants discussed research on the impact of the microbiome on the brain, the genetic factors that impact 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 that individuals with ASD often face in accessing specialty GI care.

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 for individuals with ASD.

The workshop participants suggested that guidance about standard GI care practices would be helpful for individuals with autism 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 DISTURBANCES

Beth Ann Malow, M.D., M.S.
Burry Chair in Cognitive Childhood Development, Professor of Neurology and Pediatrics, Vanderbilt Kennedy Center
Director, Vanderbilt Sleep Disorders Division

Presentation Highlights

Dr. 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 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.

Discussion of Challenges and 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 in ASD 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 impact 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. 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 an incomplete 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 gene activity 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

Micah Mazurek, Ph.D.
Associate Professor of Education,
Curry School of Education, University of Virginia

Christina Nicolaidis, M.D., M.P.H.
Professor and Senior Scholar in Social Determinants of Health, School of Social Work, Portland State University
Adjunct Associate Professor, Division of General Internal Medicine, Oregon Health and Science University

Dora Raymaker, Ph.D.
Research Assistant Professor, Portland State University
Co-Director, Academic Autism Spectrum Partnership in Research and Education (AASPIRE)

Presentation Highlights

Dr. Mazurek discussed 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.

Drs. Nicolaidis and 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 into the 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.

Discussion of Challenges and 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 experienced by the transition-aged ASD population, the need for physician continuing education programs 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.

HIGHLIGHTS FROM THE IACC WORKSHOP: ADDRESSING THE MENTAL HEALTH NEEDS OF PEOPLE ON THE AUTISM SPECTRUM

In May 2019, the Working Group convened a workshop to address the mental health needs of people on the autism spectrum. The workshop agenda included discussion of community stakeholders' experiences with mental health issues and services, premature mortality related to mental health issues, and parental and family mental health, among other concerns raised by participants at the workshop. Six main topics were explored:

- **Mental Health Needs of People on the Autism Spectrum**
- **Personal Perspectives on Mental Health Issues in ASD**
- **Anxiety and OCD**
- **Depression and Suicide**
- **Self-Injurious Behaviors (SIB) and Aggression**
- **Mental Health Services for People on the Autism Spectrum**

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. 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.

MENTAL HEALTH NEEDS OF PEOPLE ON THE AUTISM SPECTRUM

Carla Mazefsky, Ph.D.
Associate Professor of Psychiatry and Psychology, University of Pittsburgh

Presentation Highlights

Dr. Mazefsky presented an overview of mental health issues in people with ASD. She explained that individuals with ASD are more likely to have co-occurring mental health disorders, and that as a result they, their families, and the community often experience challenges such as distress, high health care utilization, barriers to school and workplace success, and disciplinary actions. However, service delivery to address these needs is inhibited by providers with a limited understanding of ASD and its associated lifespan implications. Dr. Mazefsky recommended three ways to address these issues: first, to create more sensitive diagnostic assessments for identifying co-occurring mental health conditions; second, to design more effective and targeted treatments for mental health in autism; and third, to seek fresh perspectives on risk and vulnerability of developing co-occurring mental health conditions.

Discussion of Challenges and Desired Outcomes

The workshop participants discussed the role of trauma in cognitive changes and emotional dysregulation among children and adults with ASD. Specifically, they noted that although genetics plays a role in mental health issues, social issues such as bullying and adversity that affect individuals with disabilities may also be contributing factors.

The participants also highlighted the importance of considering positive aspects related to autism rather than focusing only on perceived negative aspects. This could facilitate expanding research beyond conditions such as depression to include broader issues, such as resilience, temperament, and mindfulness.

Workshop participants discussed ways to improve provider awareness of issues related to autism and mental health. Although providers do not need to be experts in autism to treat this population, they need to be familiar with the challenges that children and adults with ASD face in order to best deliver services and interventions. The participants suggested that providers could consider ASD co-occurring mental health conditions in the context of more familiar issues and populations, such as treating anxiety or PTSD in veterans. They also noted that there is a critical need for longitudinal studies to understand the trajectory of co-occurring mental health symptoms and their early predictors, allowing researchers to design treatments aimed at early prevention.

The participants concluded that there is a lot to learn from mainstream mental health practices, which should be considered for both research and application in individuals with ASD. In parallel, the Working Group has significant potential to contribute knowledge about autism to mainstream awareness of these issues.

PERSONAL PERSPECTIVES ON MENTAL HEALTH ISSUES IN ASD

Lindsey Nebeker
Development Specialist, Autism Society of America, Freelance Presenter/Speaker

Dennis Mashue
Co-Founder, Tuck's Tooques, LLC
Founder, OuterSelf Initiatives

Alison Morantz, JD, Ph.D.
James and Nancy Kelso Professor of Law
Director of the Stanford Intellectual and Developmental Disabilities Law and Policy Project
Senior Fellow and Steering Committee Member, Stanford Institute for Economic Policy Research

Presentation Highlights

Three individuals provided their personal perspectives on managing ASD and co-occurring mental health issues. Ms. Nebeker, an autistic self-advocate, shared her personal story of the challenges of co-occurring mental health conditions and her experience with issues related to suicide. She discussed the need for community members to prioritize treating each other with kindness and providing support for people who are struggling with mental health conditions.

Mr. Mashue is an autistic self-advocate and the father of a son with ASD who is minimally verbal. He spoke about the difficulties he has experienced in obtaining Medicaid services for his son, which has led to financial hardships and exacerbated mental health issues. He urged the Working Group to engage with the community, focusing on supporting adults with autism and caregivers.

Ms. Morantz is a professor at Stanford Law School and mother to a child with autism and early-onset schizophrenia. Ms. Morantz discussed the critical need for individualized supports, inpatient treatment, and residential living options for children with autism who experience co-occurring mental illness, as well as an increase in training and oversight of health professionals.

Discussion of Challenges and Desired Outcomes

The workshop participants agreed that these personal perspectives were compelling and that the challenges and barriers that were highlighted are critical to consider. They also emphasized the importance of considering the potential impact of mental health issues on attainment of services and supports and, as a result, workplace opportunities.

ANXIETY AND OCD WITH ASD

Connor Kerns, Ph.D.
Assistant Professor, Department of Psychology, University of British Columbia

Judy Reaven, Ph.D.
Associate Professor, Departments of Psychiatry and Pediatrics, University of Colorado Anschutz Medical Campus

Presentation Highlights

Dr. Kerns discussed the common co-occurrence of anxiety disorders and/or obsessive-compulsive disorder (OCD) in the ASD population, diagnoses which are often overlooked because symptoms frequently overlap with autism-related behaviors. She noted that when anxiety disorders are co-morbid with ASD, they are commonly associated with a severe clinical profile that includes additional problems with social skills, repetitive and restricted behaviors, depression, and self-injury, sleep problems, and GI disturbances. Dr. Kerns noted the significant barriers to researching and diagnosing these conditions, including communication barriers and a lack of mental health measures tailored specifically for this population.

Dr. Reaven discussed treatment for anxiety in individuals with ASD; she noted that many individuals with ASD use cognitive behavioral therapy (CBT) to treat anxiety symptoms. A variety of CBT-based treatments for anxiety and OCD are available across different ages, settings, and individual needs, although more research is needed to continue to tailor these services to autistic individuals. Medication (such as sertraline) is a commonly used treatment approach for anxiety in the general population, but there is still a need to study anxiety medications in the ASD population. Dr. Reaven recommended that future funding efforts focus on implementation science for anxiety treatments, applying research in clinical settings, understanding anxiety and ASD in underserved groups, and developing telehealth approaches (such as iPad applications and virtual reality).

Discussion of Challenges and Desired Outcomes

The workshop participants addressed challenges related to sensory responses and anxiety in individuals with ASD; some data suggest that sensory issues may be predictive of problems with anxiety later on. Participants considered the need to improve strategies for reducing anxiety and/or OCD symptoms in real-life settings. They noted that application-based research may be particularly useful in helping people with autism build coping and compensatory strategies. The workshop participants also discussed the need to promote awareness about high rates of anxiety in the ASD community to ensure that early anxious tendencies are prevented from developing into maladaptive behaviors.

DEPRESSION AND SUICIDE IN ASD

Katherine Gotham, Ph.D.
Assistant Professor, Department of Psychiatry and Behavioral Sciences, Vanderbilt University Medical Center

Anne Kirby, Ph.D., OTR/L
Assistant Professor, Occupational & Recreational Therapies, University of Utah

Darren Hedley, Ph.D.
Olga Tennison Autism Research Centre, School of Psychology and Public Health, La Trobe University

Sarah Cassidy, Ph.D.
Assistant Professor, School of Psychology, University of Nottingham

Presentation Highlights

Dr. Gotham presented a summary of her research on depression in autistic individuals. She noted that people with ASD are four times more likely to experience depression than the general population, which can further impair their social skills and adaptive behaviors. Because common depression symptoms (such as flat affect and social withdrawal) may be overshadowed by overlapping ASD features, assessing and diagnosing depression in the ASD population can pose significant challenges. People with ASD may be more likely to experience depression

because they tend to be less socially connected and they often struggle with repetitive thinking patterns, which can trap them in negative thought cycles. Dr. Gotham also discussed cognitive behavioral therapy and medications as successful interventions for depression in the general population, and with appropriate modifications—based on tailored measurement tools and research studies—they may also be useful for people with ASD.

Dr. Kirby reviewed current research on suicide in the ASD population, which currently suggests that people with autism in the United States are six to eight times more likely to attempt or die by suicide. Differences in suicide rates are especially pronounced among girls and women; autistic women are three times more likely to die by suicide than their non-autistic female counterparts. In the general population, men are at much higher risk of dying by suicide than women, but in the ASD population the rates tend to be more similar among autistic males and females. Suicide death is still relatively rare and is only one consideration in terms of quality of life for people with ASD. However, there is a need to study the risk factors and co-occurring conditions associated with suicidality in the ASD population, especially for women and other vulnerable subgroups, such as older adults and those without intellectual disability.

Dr. Hedley discussed the relationship between autistic traits and suicide risk, as well as common mechanisms that underlie suicide risk and autism. Current research indicates that an autism diagnosis independently predicts suicide risk, while depression, high IQ, and level of satisfaction with living arrangements are potential predictors of suicide in individuals with ASD. Additionally, autistic people, especially those whose autism is more severe, often experience isolation, disconnectedness, and loneliness—factors that may significantly contribute to suicidality. Studies have found that successful social supports can mediate the effects of depression in people with ASD, decreasing loneliness and suicidal ideation.

Dr. Cassidy reviewed ideas for the future of research and prevention of suicide in ASD and, more generally, mental health. Currently funded research priorities often do not align with what people with ASD think is important, and it is important to directly consult people with ASD before developing priorities. Since 2016, Dr. Cassidy has managed a series of national (in the United Kingdom) and international data-gathering activities and workshops to engage individuals with ASD and their families about suicide in collaboration with researchers and stakeholders in the ASD community. During these initial workshops, participants identified topics of importance to them; these suggestions were used to develop a top ten priority list for research. Identifying barriers to services and supports, a topic that has been consistently under-funded, was named the top priority for research to prevent suicide in people on the autism spectrum, as difficulty accessing appropriate services and supports is thought to be a contributing factor to suicidality in this population. She concluded by encouraging researchers to work with people with autism to ensure that community priorities and research priorities are aligned.

Discussion of Challenges and Desired Outcomes

Workshop participants discussed stories related to traumatic events, misdiagnosis and delayed diagnosis, and misunderstandings of autism that can contribute to depression and other mental health problems. Sleep disturbances, which are common in people with autism, is another critical factor in understanding the relationship between depression and suicide in ASD. Because these problems can be difficult to manage alone, many people with autism report a need for a services system navigator.

The workshop participants discussed common warning signs for depression and suicide, and how these signs differ in autistic individuals compared to the general population. There is a critical need to be watchful for conventional signs—both verbal and non-verbal, such as

sleeping a lot or losing interest in activities—even when the person with autism doesn't specifically communicate about suicide. Some people with autism may under-report their struggles because they fear being institutionalized. The participants discussed issues related to employment and employment-related stress, which may be linked to suicidality in people with ASD. More research is needed to determine the association between mental health and jobs in this population.

Currently, there is a lack of validated tools for assessing suicidality in ASD, and many existing studies have only used surveys developed by individual clinics. Current data indicates that only a small portion of those who died by suicide had a clinical event or measure of previous suicidal ideation in their clinical record.

SELF-INJURIOUS BEHAVIORS AND AGGRESSION IN ASD

Matthew Siegel, M.D.
Director, Autism & Developmental Disorders Inpatient Research Collaborative, Maine Medical Research Institute Vice President Medical Affairs, Developmental Disorders Service, Maine Behavioral Healthcare

Craig A. Erickson, M.D.
Director, Fragile X Research and Treatment Center, Medical Director, Psychiatry Neurobehavioral Continuum of Care, Director of Research, The Kelly O'Leary Center for Autism Spectrum Disorders, Cincinnati Children's Hospital Medical Center

Presentation Highlights

Dr. Siegel discussed current research opportunities and gaps in self-injurious behaviors and aggression in autism. Families report that aggression and self-injury can be more impactful than other autism-related symptoms, because these behaviors are often associated with increased stress, isolation, and financial burden. Aggression and self-injurious behaviors also tend to limit the child's development because they can no longer attend school or engage with non-specialized support systems. Common treatment options include ABA and psychotropic medication, but most of these options lack a strong evidence base, tend to be time-intensive, and have inconsistent outcomes. Dr. Siegel's current research has shown that physiological arousal (such as increased heart rate) can predict an aggressive episode with 80 percent accuracy, which is particularly important when the child is unable to communicate this information his/herself. However, more research is needed to better understand the mechanisms and to develop better diagnostic tools and treatments.

Dr. Erickson reviewed medication management for aggression and self-injurious behaviors, recommending medication use as a secondary intervention to evidence-based behavioral interventions or in combination with these interventions. Currently, there are two FDA-approved medications—risperidone and aripiprazole—for the treatment of irritability, which is defined by the FDA as aggression, self-injurious behaviors, and severe tantrums. Although effective in reducing aggressive behaviors, these medications are known to have undesirable side effects, such as abnormal movements and significant weight gain. Some alternative medications have demonstrated less severe side effects, such as less weight gain, but there is not yet enough scientific evidence to support greater use among individuals with ASD. Dr. Erikson noted that electroconvulsive therapy (ECT) is a last-resort approach that can be used when other interventions fail.

Discussion of Challenges and Desired Outcomes

The workshop participants discussed the role of ECT in treating aggressive and self-injurious behaviors, expressing the importance of overcoming stigmas related to this potential treatment. They also discussed the underlying mechanisms of medication-related weight gain, which are not known but may be related to increased appetite or changes in metabolism. Additionally, the participants discussed de-escalation strategies that can be applied in the moments before an aggressive episode occurs, which can include breathing exercises or going to a quiet space.

Lastly, participants debated the use of wearable sensors to identify physiological arousal in order to predict an aggressive episode and how these tools are not useful unless paired with an intervention to prevent or de-escalate the episode.

MENTAL HEALTH SERVICES ISSUES FOR PEOPLE ON THE AUTISM SPECTRUM

Brenna B. Maddox, Ph.D., LCP
Post-Doctoral Fellow and Licensed Clinical Psychologist, Penn Center for Mental Health, University of Pennsylvania

Presentation Highlights

Dr. Maddox reviewed the main barriers to mental health services among people with autism, as well as possible solutions. Common barriers include insufficient clinician training, lack of ASD-specific treatment designs, and historical difficulties accessing mental health care as a result of chasms between developmental disability systems and mental health systems. Some possible solutions include clinician training, which is needed at the pre-service level and should be offered to providers of both adult and child services. Community-academic partnerships may also be useful in ensuring that individuals with ASD have access to evidence-based services and supports. Finally, coordination between mental health and developmental disability systems may begin to bridge existing gaps that can contribute to service barriers in the ASD population.

Discussion of Challenges and Desired Outcomes

The workshop participants discussed the problem that many providers lack confidence and/or knowledge in treating co-occurring mental health conditions in people on the autism spectrum, often adding more obstacles for individuals with autism and their family members. In addition, participants discussed modular treatment approaches that may be effective for broader implementation across diagnoses and age ranges; these approaches may help to ensure continuity of access to services across the lifespan. The workshop participants debated the potential benefits and drawbacks of having separate State agencies for health services (e.g., developmental disability services and mental health services).

Also, because autism and mental health issues have significant overlap, workshop participants recommended other federal advisory committees such as the Interdepartmental Serious Mental Illness Coordinating Committee (ISMICC) that may be able to contribute to the ongoing conversation about autism and mental health.

SUMMARY

The IACC recognizes that physical and mental health concerns are major factors in the quality of life of people on the autism spectrum. There are many physical and mental 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 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 workshops in 2018 and 2019 in which the participants identified several ideas that could improve ASD research efforts in understanding the root causes of co-occurring physical and mental health issues, accelerate development of effective treatments across the spectrum and across the lifespan, and improve healthcare services for people on the autism spectrum, such as physician education and development of best practices in healthcare, toolkits, and training approaches. The Working Group is using the information gathered in these workshops to develop a summary document to describe the state of research on co-occurring physical and mental health conditions in ASD, current treatments and guidelines, challenges in delivering healthcare to this population in a way that addresses these needs, and future directions for research, services, and policy. This information will be reviewed by the IACC and, upon completion and approval, published and shared with the public at a future meeting of the IACC.

REFERENCE

1. 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.

CHAPTER

3

IACC WORKING GROUP ACTIVITIES: ADDRESSING THE HOUSING NEEDS OF PEOPLE ON THE AUTISM SPECTRUM

BACKGROUND

During the Autism CARES Act of 2014 authorization period, the IACC voted to convene a working group to address housing concerns among individuals on the autism spectrum and their families. The goal of the Working Group was to research best practices on housing, review implementation of current federal regulations, and address housing issues faced by autistic individuals, including those with more severe disabilities. The mission statement for the Working Group states:

In the autism community we face a mounting housing crisis, with a growing population of autistic adults with diverse needs lacking appropriate living situations. The goal of this working group is to examine a wide variety of housing options and service models for people with autism, and to develop strategies to achieve a broad array of supported housing options throughout all of our communities that enable autistic individuals to achieve person-centered outcomes.

The Working Group convened in 2019, beginning with a conference call in June to discuss potential activities to improve housing issues. The Working Group decided to organize a workshop in July 2019 that would address the housing needs of people on the spectrum. The workshop included advocates in the community that have established different successful housing models for individuals with autism across the spectrum. This Update will include highlights presented and discussed at the workshop.

Members of the IACC discussed the outcome of the workshop at their July 2019 full committee meeting, which was the last IACC meeting to be held under the Autism CARES Act of 2014, and decided that the issues highlighted at the workshop will serve as an excellent base for the next iteration of the IACC to consider further activities and action related to housing for people on the autism spectrum.

HIGHLIGHTS FROM THE IACC WORKSHOP: ADDRESSING THE HOUSING NEEDS OF PEOPLE ON THE AUTISM SPECTRUM

On July 23, 2019, the Interagency Autism Coordinating Committee (IACC) Housing Working Group convened a workshop to address housing issues for people on the autism spectrum. The Working Group aimed to explore housing options and person-centered outcomes for a diverse population of people with autism spectrum disorder (ASD) across the lifespan, whose housing opportunities are often limited. Four main topics related to addressing housing issues were discussed at the workshop, with the goal of representing several diverse and innovative models of housing and housing-related services to meet the needs of people on the autism spectrum:

- **Overview of Housing Issues**
- **Intentional Community Models**
- **Apartment/Dispersed Community and Service Delivery Models**
- **Personalized Adult Services and Housing Navigation**

For each topic, there were presentations on current housing models and development efforts. Descriptions of specific housing programs were meant to be illustrative of the range of existing models and do not represent specific endorsement by the IACC. Presentations were followed by a thorough discussion of the gaps, needs, and hopes for future research and services in that area. The workshop participants also discussed potential options for the IACC's involvement in alleviating the challenges related to housing needs for people with ASD. The discussions of each topic are summarized below.

OVERVIEW OF HOUSING ISSUES

Heidi Eschenbacher, Ph.D.
Researcher, Institute on Community Integration, University of Minnesota

Desiree Kameka, M.T.S.
Director of Community Education & Advocacy, Madison House Autism Foundation

Presentation Highlights

Dr. Eschenbacher reviewed the **Residential Information Systems Project (RISP)**, an ongoing initiative to study the long-term services and supports used by people with intellectual and developmental disabilities (IDD). In the United States, about 17 percent of people with IDD receive services for residential and associated supports through IDD agencies, but this estimate varies drastically across states. Most of the individuals who receive these long-term services and supports are funded by a Medicaid Alternative Care Facility (ACF) waiver or Intermediate Care Facility (ICF) waiver. In 2016, the average funding cost for a Medicaid Waiver across all age groups was just under $44,000, and in some states, most of this funding is allocated towards community care facilities. Dr. Eschenbacher also presented data from the National Core Indicators (NCI), which includes autism-specific data. The NCI data indicates that while more than half of adults with ASD receive services in a parent's or family member's home, they would prefer to live elsewhere and that personal autonomy is a critical factor.

Ms. Kameka discussed recent trends and insights from the **Autism Housing Network (AHN)**. She explained that a lack of residential supports has left many adults with ASD vulnerable to isolation, homelessness, abuse, and financial stress. AHN launched the Empowering Communities Initiative (ECI), which educates people on the autism spectrum and their families about housing and support options in their communities. The ECI surveyed 126 people with ASD in Colorado about their support needs. Individuals reported requiring one-on-one provider support, services that promote social interaction, accessible transportation, and planned community resources. However, the data also revealed that many people with ASD and their families are unaware of current options, indicating a disconnect between autistic adults, their caregivers, and the service system. Ms. Kameka pointed out that states have an obligation to meet these needs while preventing forced institutionalization and abuse. Existing efforts (such as ECI) to address these issues are promising indicators that the ASD housing crisis can be solved with ongoing stakeholder collaboration and advocacy.

Discussion of Challenges and Desired Outcomes

Workshop participants addressed the need for increased and improved data collection related to housing and ASD. There is a lack of data on housing funding, the current living situations and conditions for individuals with autism, as well as information on quality of life factors. Current data do not typically compare different housing models, leaving policymakers to regulate housing based on personal values rather than objective measures. Additionally, most of the data about homelessness and ASD comes from the United Kingdom, indicating a need for increased attention to homelessness of individuals with ASD in the United States. The participants also expressed concern that nonverbal people with ASD may be underrepresented in the data, particularly when researchers use means of data collection that do not provide accommodations for communication barriers.

The workshop participants also discussed the concern that too few people with ASD receive supports that meet all of their needs, and it was suggested that Medicaid waivers could be revised to ensure that services are not "cherry picked." However, they note that it is important to consider that the **Housing & Community Based Services (HCBS) Final Rule** does not officially designate a comprehensive listing of needs and services, and the data may not accurately capture the scope of long-term services and supports that people with ASD actually require and receive.

INTENTIONAL COMMUNITY MODELS

Denise Resnik
CEO and Co-Founder, DRA Collective

Krista Mason
Executive Director, Benjamin's Hope

Terry Hamlin, Ed.D.
Associate Executive Director, Center for Discovery

Lindsay Johnson
Director of Policy and Partnerships, The Kelsey

Presentation Highlights

Ms. Resnik discussed **First Place AZ**, a specialized apartment complex in Arizona designed to foster community and independence for neurodiverse people. The program provides a curriculum of practical skills to teach residents about finance, technology, and communication. First Place AZ reports that among individuals who graduate from the facility's transition program, 94 percent are able to sustain gainful employment and 89 percent become able to thrive outside of their family home. In addition, the First Place AZ facility supports the First Place Global Leadership Institute, which collaborates with international experts and industry leaders to address priority issues in housing and IDD. The apartment complex receives funding from philanthropy, private investors, and new markets tax credits.

Ms. Mason is a parent of a young adult with ASD, named Ben, and the co-founder of **Benjamin's Hope**, a farmstead community in Michigan that offers care and community to 33 adults with intellectual and developmental disabilities (IDD). The organization takes a "whole-person" approach to care, helping residents to engage with the community, health and wellness, the arts, and spirituality. In addition to gardening and caring for animals, residents at Benjamin's Hope volunteer at the local museum and hospital. Medicaid funding covers about 75 percent of the program's care-related costs, which range from $4,000 to $8,000 depending on the resident's care needs. The remaining costs are covered by charitable giving.

Dr. Hamlin is the associate executive director at the **Center for Discovery**, a rural continuous learning program for autistic individuals with severe, aggressive, or maladaptive behaviors in New York. At the Center, members understand that lifestyle and environment significantly impact wellbeing among people with autism. The Center collaborated with autistic self-advocate Temple Grandin to design homes that promote privacy and reduce stress, including elements such as private bathrooms, natural light, and muted color palettes. The Center for Discovery also aims to improve health and wellbeing by ensuring that residents receive an organic whole food diet, on-site medical care, regular exercise, sleep hygiene, social connectedness, and limited exposure to environmental toxins. Currently, the Center supports 1,200 individuals, including 336 who currently live in-residence. In addition to housing, the Center also houses a research institute where ASD and its co-occurring conditions are studied. The Center is collaborating with the local town and relies on significant philanthropic donations to fund new facilities.

Ms. Johnson discussed **The Kelsey**, a residential community in the Bay Area of California that serves individuals with and without disabilities across a wide range of incomes. The program recently convened a three-part stakeholder workshop to develop actionable solutions for scaling and sustaining these residential models. Their top priorities included finding permanent funding sources for IDD housing issues and piloting inclusive communities in the Bay Area. Ms. Johnson explained that although city developers are interested in creating diverse, affordable housing, they need guidance from inclusion-minded organizations. The Kelsey model addresses three primary barriers to care: affordability, accessibility, and inclusivity. Ms. Johnson encouraged communities and disability advocates to form partnerships to address and overcome these barriers. The Kelsey is funded through a blend of public and private funding, as well as a significant donation from the Chan Zuckerburg Initiative.

Discussion of Challenges and Desired Outcomes

The workshop participants discussed issues related to cost of living and employment. Ms. Resnik described the efforts of First Place AZ to address some of these issues, by creating jobs for people with and without ASD. They are also including the voices of people on the autism spectrum by working with an IT firm that employs individuals with ASD.

Workshop participants expressed concern about the costs associated with supportive housing, suggesting that community organizers might consider developing models that rely on existing amenities in order to cut down on costs. Ms. Resnik mentioned that the typical cost of supports, community life, amenities, and home at First Place AZ is about $3,800, which is not significantly more than the average cost through Medicaid at $3,600. She said they are working with policymakers to begin to blend public and private funds based on proof points.

APARTMENT/DISPERSED COMMUNITY AND SERVICE DELIVERY MODELS

Jim Whittaker
President/CEO, The Arc Jacksonville

Matthew Osborne, M.S., B.C.B.A.
Director of Adult and Residential Services, Faison Center

Maedi Tanham Carney
Founder and Executive Director, Integrated Living Opportunities

Mary Anderson
Executive Director, ABLE Inc.

Presentation Highlights

Mr. Whittaker described **The Arc Jacksonville Village**, a residential community in Florida serving 120 individuals with IDD through a non-structured, independence-focused living program. The Village was designed with input from family members who wanted to ensure that their children have opportunities for social engagement and inclusion. Accordingly, the community offers classes, dining services, a fitness center, a movie theater, a game room, and other services. The community fosters a spirit of independence by allowing residents to come and go without restriction, while maintaining campus safety. Mr. Whittaker explained that the Arc Jacksonville is able to offer apartments at rents substantially lower than others in the area because it receives funding support from a blend of public, private, and nonprofit partnerships—including affordable housing federal tax credits, government grants, corporate grants, and foundations.

Mr. Osborne next talked about the **Faison Residence**, an inclusive semi-independent apartment complex and community for adults with ASD in Virginia. The program promotes autonomous living by offering support systems without continually monitoring residents. To ensure that residents remain safe and healthy, first responders and other service providers also live in the apartment complex. Although staff members offer a few supportive services, residents must demonstrate some life skills such as the ability to cook, clean, and manage their own care. The community also offers an educational program to teach valuable independent living skills, such as learning to use public transportation or ride-sharing. The Faison Residence remains committed to meeting residents' needs while promoting personal growth, stability, and autonomy. The facility accepts Medicaid Waivers, housing vouchers, private insurance, and private pay.

Ms. Tanham Carney discussed **Integrated Living Opportunities (ILO)**, a non-profit organization in the Washington, DC area that helps families develop support networks to enable people with IDD to live as integrated, contributing members of the community. Each family-centered community village at ILO is called a "pod." Family members convene here twice a month to discuss their needs with a Community Builder, a staff member trained to help residents navigate the community. Before moving into the community, potential residents take a Life Process Skills assessment and receive personalized support from staff Life Coaches. The organization is working to become sustainable in the long term with continuous support from grant and foundation funding.

Ms. Anderson discussed **ABLE Inc.**, an assisted living community dedicated to serving adults with IDD in North Dakota. The program emphasizes the importance of affordable housing options for individuals on the autism spectrum. Ms. Anderson explained that in the early days of ABLE Inc., the program only had the capabilities to provide multi-family group homes. However, they discovered that the group living structure caused problems among roommates, who often had incompatible personalities or incompatible financial means. They used these lessons learned to build a new apartment complex designed specifically for their community, using a proximity housing model rather than a scattered housing model. Ms. Anderson said that despite these recent successes, ABLE Inc. still struggles to secure adequate resources and staffing support.

PERSONALIZED ADULT SERVICES AND HOUSING NAVIGATION

Gail Godwin, M.A.
Executive Director, Shared Support Maryland

Presentation Highlights

Ms. Godwin discussed her experiences as executive director of **Shared Support Maryland**, where she provides personalized housing support to people with severe disabilities. The program currently supports 110 people, 45 of whom identify as autistic. Ms. Godwin explained that although Shared Support Maryland has no assets or real estate, the model successfully helps individuals gain control and responsibility over their own housing. The program recognizes that one of the housing issues among people with IDD is that individuals lack the resources to connect with landlords or realtors—despite an abundance of housing programs and vacant homes. In general, Shared Support Maryland aims to provide people with IDD with the same set of tools and resources that all individuals use to independently manage their own housing and community settings.

Discussion of Challenges and Desired Outcomes

The workshop participants discussed the recurring theme of housing and support costs. Some participants suggested that housing itself is a small portion of overall costs and remains similar across most housing models—the most significant increases and variations in cost are the result of individualized services, particularly for severely affected individuals who require the most significant supports. To address the costs of housing and services delivered, Ms. Godwin noted that her organization has developed prosperous relationships with funders and other organizations by holding annual fundraisers and offering for-fee state certification and training services.

The participants also discussed the topic of supporting romantic relationships among residents. Service providers explained that most community living settings have some couples (both married and unmarried) and that these relationships do not pose an issue. However, some long-term couples may face regulatory barriers to combining their funding and supports.

SUMMARY

The workshop offered an opportunity to view several housing models at different care levels and different levels of integration into the community. Throughout the workshop, it was clearly expressed that adults with autism want autonomy and the opportunity to make their own choices about their housing. Yet, it was also discussed that there is a need for more options for autistic people with severe disability who cannot function in places requiring a higher level of independence than they can manage. Workshop participants agreed there is a need for a diverse set of options for the diverse population; the autism spectrum is heterogenous and includes people who need a high degree of supervision or care, and also includes adults who may need some support but can otherwise function independently and may be harmed by overly intrusive support.

There was an underlying theme of cost throughout the workshop. Many of the presenters described the difficulty in obtaining funding to build residences; additionally, many self-advocates and family members expressed concerns about the costs of some of the housing model options in their communities. Based on the discussion, the cost of the physical structure of a home seems relatively constant across the different models; instead, cost differences are

based predominantly on the varying services and supports that are provided in the residences. However, there were many successful models that used different means of funding to support housing and services costs as well as maintain an affordable lifestyle for the tenants. While many of the models excel at providing quality housing for people with ASD, it was also noted that it may be challenging to scale these models to the capacity needed to accommodate this growing population. Future considerations should address the scalability, sustainability, and funding for replication projects.

It is important to recognize that there are many differences in state laws that may make it challenging to replicate successful models. The working group members agreed that there is a need for better understanding of the state-by-state differences. They also spoke of the challenges of housing service delivery, such as maintaining high quality direct support staff. In addition, program service providers often bundle services, which sometimes forces individuals to use their limited resources to pay for services that they don't want or need in order to get services that they do want or need.

The Working Group agreed that a top goal for addressing housing needs is to define and improve outcomes, which will help researchers understand the real-life implications of housing policy and funding mechanisms. Researchers and policymakers also need more basic information about what housing options are available across states and how these differences drive economic and quality-of-life outcomes. Currently, there is a lack of research to define what is considered to be a good outcome or what contributes to a good outcome; having this fundamental data would make it easier to affect the type of public policy changes and support new housing initiatives, including funds to build new sites and support attendance at these residences, as well as ways to increase capacity.

Importantly, it is necessary to consider the values of the ASD community in order to determine meaningful outcomes and outcome measures.

While the workshop provided a space to address many of the housing issues that are facing the autism community, there were some items that were not fully addressed. There is still a need to focus more on how these models can be scaled to meet the growing demand. Currently, there are groups of people who receive no services while they remain on waitlists to receive funding. There is also a need to expand discussions beyond adult housing to include the entire lifespan, including options for children and adolescents. Lifespan issues also include consideration for the population of people living with an older caregiver who may be left without support systems when that caregiver passes away. Additionally, there is a need to support research to understand the cost of not providing housing and the societal financial impact.

Overall, workshop participants agreed there are areas for the IACC, policymakers, and other stakeholders to improve and fill the gaps on housing issues for people with autism. The Working Group hopes that these important discussions will resume in future iterations of the IACC, in order to continue and expand these efforts.

CHAPTER

4

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 publishing 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

Question 1: When should I be concerned?
SCREENING & DIAGNOSIS

Question 2: How can I understand what is happening?
BIOLOGY

Question 3: What caused this to happen and can it be prevented?
RISK FACTORS

Question 4: Which treatments and interventions will help?
TREATMENTS & INTERVENTIONS

Question 5: Where can I turn for services?
SERVICES

Question 6: What does the future hold, particularly for adults?
LIFESPAN ISSUES

Question 7: What other infrastructure and surveillance needs must be met?
INFRASTRUCTURE & SURVEILLANCE

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
• Administration for Community Living (ACL) • Agency for Healthcare Research and Quality (AHRQ) • Centers for Disease Control and Prevention (CDC) • Department of Defense – Army (DoD – Army) • Department of Education (ED) • Environmental Protection Agency (EPA) • Health Resources and Services Administration (HRSA) • National Institutes of Health (NIH) • National Science Foundation (NSF)	• Autism Research Institute (ARI) • Autism Science Foundation (ASF) • Autism Speaks (AS) • Brain & Behavior Research Foundation (BBRF) • Center for Autism and Related Disorders (CARD) • New England Center for Children (NECC) • Organization for Autism Research (OAR) • Patient-Centered Outcomes Research Institute (PCORI) • Simons Foundation (SF)

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 provided by private organizations, which 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.

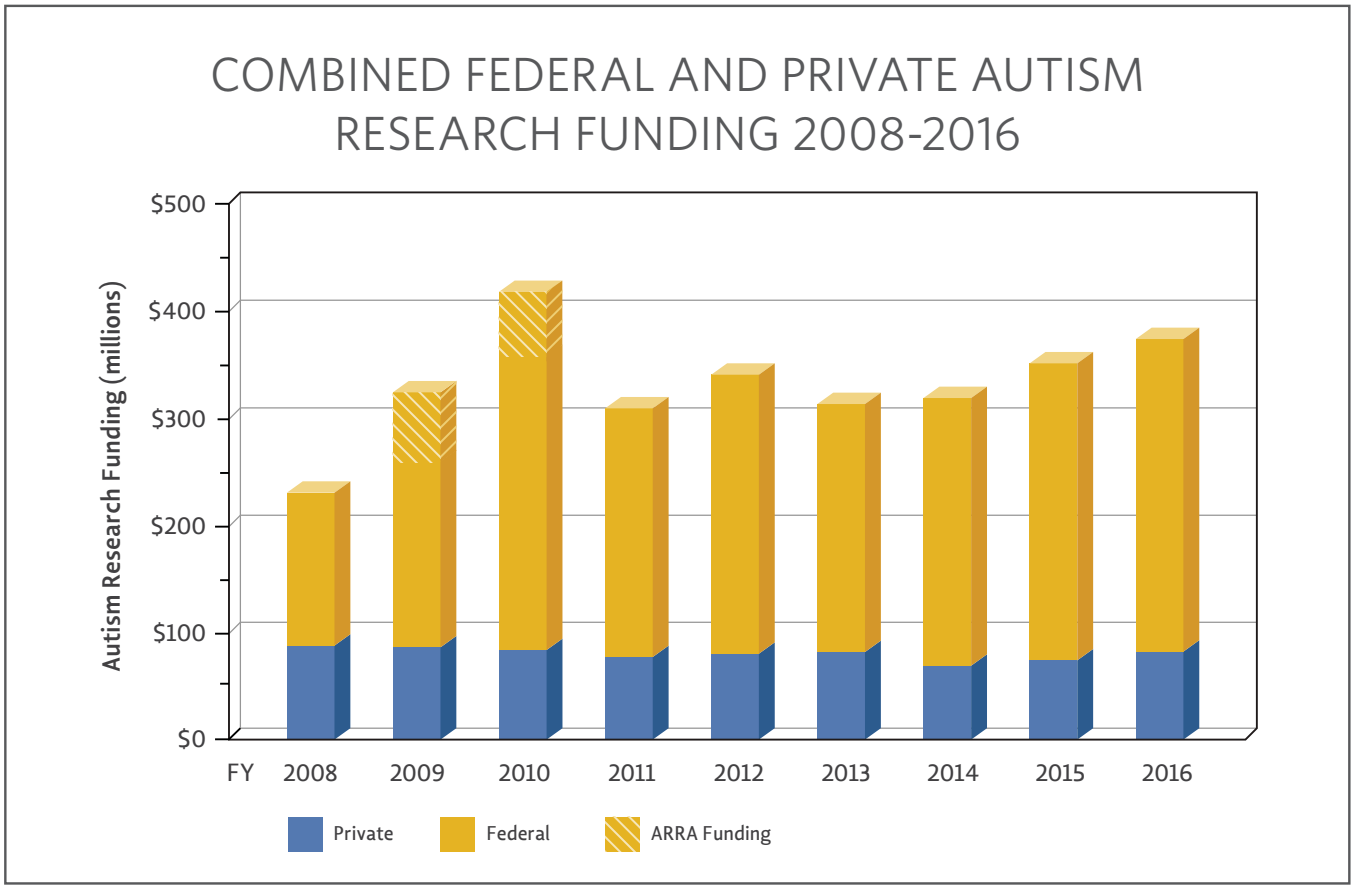

Figure 3. This figure illustrates levels of autism research funding from combined federal and private sources during 2008-2016 based on data collected for the *IACC Portfolio Analysis* of those years.

With regard to the *2016-2017 IACC Strategic Plan's* budget recommendation, 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 meet 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.

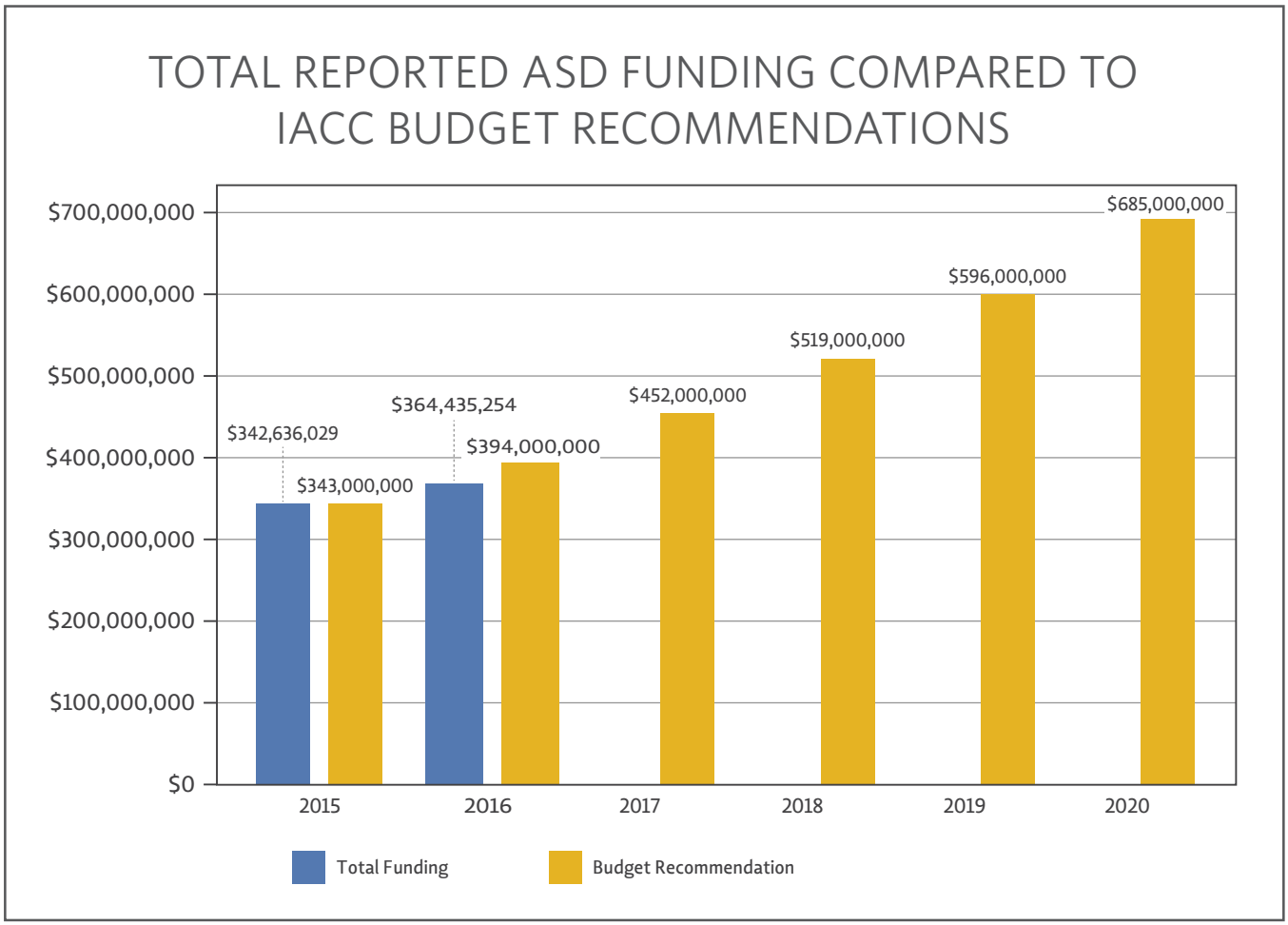

Figure 4. The IACC recommends a doubling of the combined federal and private ASD research budget to $685 million by 2020. Based on 2015 and 2016 funding amounts, ASD research investment is lagging behind IACC budget recommendations.

ASD RESEARCH AREAS AND PROGRESS IN 2016

To better understand which 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.

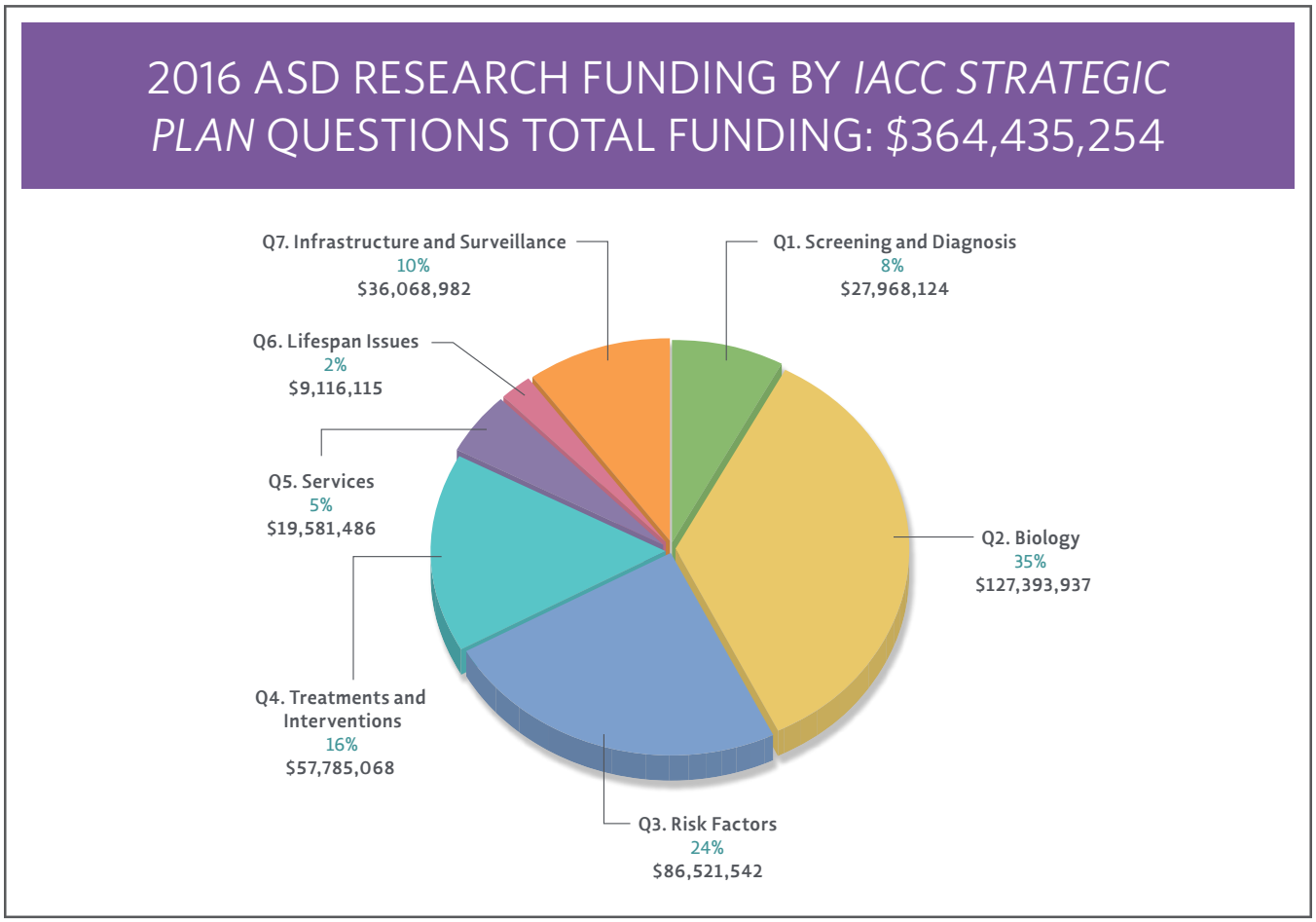

Figure 5. The seven questions of the *Strategic Plan*, beginning with Screening and Diagnosis (Question 1) and ending with Infrastructure and Surveillance (Question 7).

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 the infrastructure and surveillance category 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 that 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.

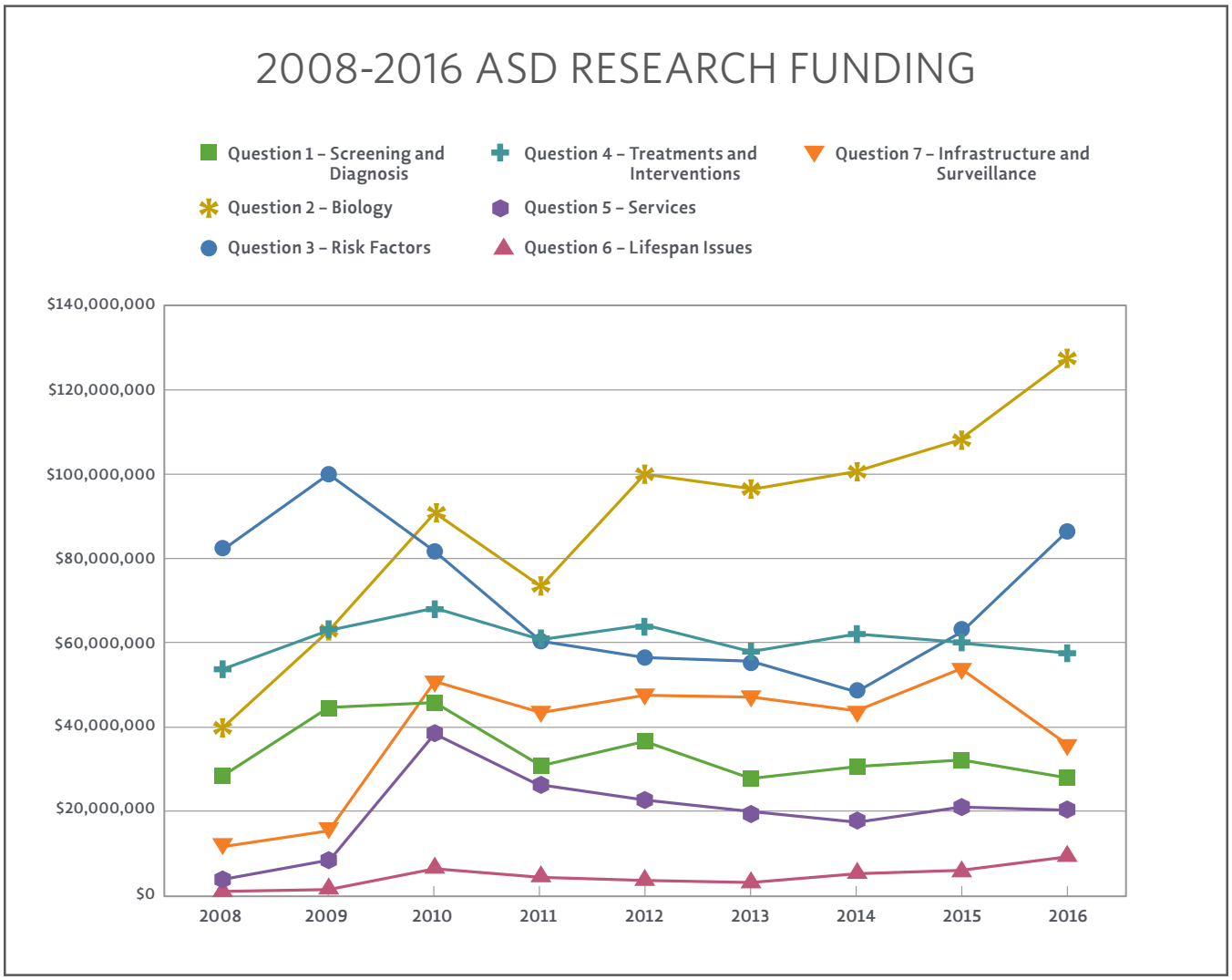

Figure 6. Trends in ASD funding for each *Strategic Plan* Question over the nine-year period of reporting (2008-2016).

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 the 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** on the IACC website. The project data are publicly accessible in the IACC/OARC **Autism Research Database**, also available on the IACC website.

CHAPTER

5

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 (IACC) 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 (NAC) role was created within the Autism CARES Act of 2014 to provide additional support for coordination of federal activities. The duties of the NAC 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 was required by the Autism CARES Act of 2014. 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 young adults with ASD. The IWG was reconvened in June 2018 and re-named 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 NAC gives updates regarding internal federal implementation activities at meetings of the IACC.

ASD SURVEILLANCE, AWARENESS, AND OUTREACH

The activities in this section address 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 educated 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 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.

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 address 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 the program, 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 comprised 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 address 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 randomized controlled trials (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 address 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 of 2014, 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 address Questions 4 and 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 address 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. 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 with 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. SSA has been working with researchers at the A.J. Drexel Autism Institute to produce research on national and state trends for adults with autism who receive Supplemental Security Income.

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 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 research and services programs and projects have increased knowledge on the prevalence of ASD in the U.S. population, approaches for early detection and early intervention, the biology and risk factors that contribute to ASD, interventions that can address needs across the lifespan, and educational and adult services programs, including those focusing on employment, housing, and community living. In various ways, these programs and activities are addressing all 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 NAC 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 stakeholders 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)*** on the IACC website.

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 2018-2019 update of the *Strategic Plan* reviews recent activities of the IACC and its working groups, research progress, and federal ASD-related programs.

Full committee meetings of the IACC regularly feature presentations on topics relevant to the ASD community. These presentations include summaries of recent research and services activities, as well as discussions about the needs of individuals with ASD, their families, and service providers. By discussing issues in this public forum, the IACC is able to raise awareness of important needs and ultimately inform the committee's strategic planning activities. In 2018 and 2019, IACC meeting presentations covered a wide range of issues that have been identified by community stakeholders as important, including childhood screening and early intervention, aggressive and self-injurious behavior, wandering behavior and premature mortality, health disparities, employment, housing, and disability financial planning.

In 2018 and 2019, the IACC chose to focus special attention on the areas of health outcomes and housing, all of which were highlighted in the *2016-2017 IACC Strategic Plan* as areas of importance to the autism community but that remained gap areas. To this end, the IACC convened two working groups to focus on these issues. The Health Outcomes Working Group sought to address some of the major physical and mental health-related concerns of individuals with ASD and their families and the Housing Working Group sought to address the varied housing needs of individuals with ASD throughout the lifespan. Over the course of three workshops, these IACC Working Groups continued the national dialogue on these issues and began to identify strategies to address them. The committee is in the process of developing a report on physical and mental health issues in ASD. In the future, the IACC will continue to address these and other issues, potentially by working to develop recommendations to advance progress.

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 analysis nine years of ASD research funding data 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.

Finally, The *HHS Report to Congress on Activities Related to Autism Spectrum Disorder and Other Developmental Disabilities FY 2014- FY 2018* summarizes federal efforts that 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. Additionally, 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 federal collaboration and continued support for ASD activities that impact the ASD community.

The IACC continues to coordinate federal agency efforts on autism in partnership with the public stakeholder community 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 enhancing autism research, services, and policy in an effort to meet the most pressing needs of the autism community.

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