2015

SUMMARY OF ADVANCES

in Autism Spectrum Disorder Research
ABOUT THE IACC

The Interagency Autism Coordinating Committee (IACC) is a Federal advisory committee charged with coordinating all activities concerning autism spectrum disorder (ASD) within the U.S. Department of Health and Human Services (HHS) and providing advice to the Secretary of HHS on issues related to autism. It was established by Congress under the Children’s Health Act of 2000, reconstituted under the Combating Autism Act (CAA) of 2006, and renewed under the Combating Autism Reauthorization Act (CARA) of 2011 and the Autism Collaboration, Accountability, Research, Education, and Support (CARES) Act of 2014.

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

THE 2015 IACC SUMMARY OF ADVANCES IN AUTISM SPECTRUM DISORDER RESEARCH

Each year, the IACC releases its annual list of scientific advances that represent significant progress in the field. The 20 studies selected have given new insight into the underlying biology of autism spectrum disorder (ASD) and potential risk factors, examined the state of the science in early screening and diagnosis, and evaluated promising early intervention strategies. The advances also address health outcomes for children and adults with autism, and issues related to education, transition to adulthood, and employment. The 2015 Summary of Advances provides short, plain language summaries of the top research breakthroughs selected by the IACC from a pool of research articles nominated by the members. Articles are grouped according to the topics represented by the questions of the IACC Strategic Plan for ASD Research. Citations for the articles selected for the Summary of Advances, as well as a complete listing of those nominated, are included at the end of the document.
Early screening of autism spectrum disorder: recommendations for practice and research

Early screening of children for ASD can be helpful to both children and their families because it enables earlier diagnosis and intervention. In 2009, the American Academy of Pediatrics (AAP) issued a recommendation that pediatricians routinely screen all children for ASD at 18 and 24 months of age using an appropriate screening tool. However, in many parts of the United States, physicians are not meeting this recommendation for ASD screening. It is believed that the debate over whether there is enough evidence to support the value of early screening for ASD of all children may be contributing to the slow uptake of the AAP recommendation into clinical practice. It was within this context that an international working group of clinical practitioners and researchers with expertise in ASD and developmental disabilities met in October 2010. Their aim was to conduct an updated review of the literature that would inform the development of their recommendations for ASD screening best practices, and to discuss ways to increase the adoption of widespread early screening. The group reviewed the evidence base represented by the scientific literature over time (through 2013) and reached agreement on recommendations that addressed the following question: “How can we optimize developmental course and outcomes through ASD screening programs for children aged ≤24 months?”

The group’s recommendations listed below focus on the usefulness of screening all children for ASD at 18 and 24 months of age and emphasize the importance of using the results of the screening to immediately refer children for evaluation if indicated, so that they may begin receiving intervention as soon as possible. Importantly, the findings indicate that an ASD diagnosis in children aged 24 months and older usually remains stable (unchanged) over time, and the group also identifies priorities for future research in ASD screening. The recommendations of the working group are as follows:

Statement 1: Evidence supports the usefulness of ASD-specific screening at 18 and 24 months. ASD screening before 24 months may be associated with higher false-positive rates than screening at ≥24 months but may still be informative.

Statement 2: The evidence indicates that siblings of children with ASD are at elevated risk for ASD and other developmental disorders and thus should receive intensified surveillance.

Statement 3: Children identified through ASD-specific screening should be immediately referred for diagnostic/developmental evaluation and appropriate intervention.
 Statement 4: The long-term stability of ASD diagnosis in children aged ≥24 months is well established. Emerging data suggest that ASD diagnoses in substantial proportions of children diagnosed before age 24 months are also stable, although further research is needed, particularly in the context of early screening.

Statement 5: Further attention to potential barriers to ASD-specific screening in the health care system is needed.

Statement 6: Methodologically rigorous research in ASD-specific screening should be a high priority.

Statement 7: Additional priorities for future research include studies that:

- Examine how broadband and ASD-specific tools can be used in a complementary fashion to maximize both sensitivity and specificity of early screening, perhaps in the context of multistage screening, in which a wide net is cast initially and false-positives are winnowed out in successive assessments;
- Evaluate screening strategies by using randomized experimental designs;
- Consider additional outcome metrics for screening: potential financial savings to society; unintended effects (e.g., family stress);
- Examine whether computer technology can improve screening accuracy;
- Examine the effectiveness of repeating screening for ASD;
- Evaluate how belief systems affect screening uptake and outcomes; and
- Examine potential screening strategies that include measurement of biomarkers.
Identifying children with ASD early helps to ensure that they receive treatment earlier, which leads to better long-term outcomes. It also would help reduce the average age of ASD diagnosis in the United States of 4 to 5 years, which seems to persist even though parents generally report their first concerns before their child is 18 to 24 months old. To address these concerns, an international panel of clinical practitioners and researchers met to complete an updated literature review on the advances that have been made in understanding the early development and identification of ASD in recent years. The group reached agreement on the development of recommendations based on current evidence gathered through an extensive review of the literature that addressed the following question: “What are the earliest signs and symptoms of ASD in children 24 months and younger that can be used for early identification?”

The recommendations presented below were designed to help guide clinicians and researchers in their work related to the early identification of ASD. They include a focus on the wide range of clinical characteristics seen in ASD; on the availability of evidence about behavioral risk markers, or indicators, of ASD at different ages; on the need for caution when drawing conclusions about early risk markers of ASD from certain studies; and on being cautious when generalizing findings from studies of high-risk infants. They also emphasize the importance of including diverse samples in research about these early markers and provide direction for future efforts.

The recommendations of the panel were as follows:

**Statement 1:** Evidence indicates substantial heterogeneity in the presentation and natural history of clinical features associated with ASDs. This heterogeneity has ramifications for the interpretation of research literature as well as for clinical practice.

**Statement 2:** There is evidence that reduced levels of social attention and social communication, as well as increased repetitive behavior with objects, are early markers of ASD between 12 and 24 months of age. Additional potential markers include abnormal body movements and temperament dysregulation.

**Statement 3:** Reliable behavioral markers for ASD in children aged <12 months have not yet been consistently identified.

**Statement 4:** Developmental trajectories may also serve as risk indicators of ASD.
Early intervention for children with autism spectrum disorder under 3 years of age: recommendations for practice and research

The second year of life can be a particularly critical developmental period for children with ASD: there is dynamic brain growth overall, as well as changes specifically in the nerves and their connections in the brain. Interventions during this period may therefore be able to alter the abnormal developmental trajectories associated with autism and prevent some ASD impairments. However, interventions that have been developed for older children may not be appropriate for infants or toddlers, as younger children interact and learn differently from older children. It is within this context that a multidisciplinary working group of experts met to perform a review of the literature evaluating early interventions (designed for children <2 to 3 years of age) and to develop recommendations for policy makers and clinical practitioners. The recommendations listed below represent a mix of guidelines for clinical practice as well as directions for future research. The statements focused on clinical practice emphasize that intervention should start as early as possible and use multiple approaches to target a broad range of ASD symptoms. The recommendations for both clinical practice and future research include sociocultural context as a moderating factor that should be considered and incorporated into studies and practice. The authors recommend that future research should focus on improving the rigor and consistency within and across studies, to improve applicability and utility for developing personalized intervention strategies. Lastly they recommend that researchers and clinicians consider medical comorbidities (co-existing medical conditions) that may affect the response to intervention. The recommendations of the panel were as follows:

**Statement 1:** Current best practices for interventions for children aged <3 years with suspected or confirmed ASD should include a combination of developmental and behavioral approaches and begin as early as possible.

**Statement 2:** Current best practices for children aged <3 years with suspected or confirmed ASD should have active involvement of families and/or caregivers as part of the intervention.

**Statement 3:** Interventions should enhance developmental progress and improve functioning related to both the core and associated features of ASD, including social communication, emotional/behavioral regulation, and adaptive behaviors.

**Statement 4:** Intervention services should consider the sociocultural beliefs of the family and family dynamics and supports, as well as economic capability, in terms of both the delivery and assessment of factors that moderate outcomes.

**Statement 5:** Intervention research should include socially and culturally diverse populations of participants and evaluate familial factors that may affect participation, acceptability, and outcomes of therapeutic approaches as well as willingness to participate in investigative studies.
QUESTION 4: WHICH TREATMENTS AND INTERVENTIONS WILL HELP?

Statement 6: Future research should prioritize well-defined sampling strategies, rigorous investigative design, fidelity of implementation, and meaningful outcome measurements.

Statement 7: Research is needed to determine the specific active components of effective interventions, including but not limited to the type of treatment provided, the agent implementing the intervention(s) (parent, therapist, teacher, or combination), consistency of service provision across environments and between providers, and duration of treatment and hours per week.

Statement 8: Adopting a common set of research-validated core measures of ASD symptoms (including but not limited to cognitive function, communication, and adaptive behavior) that can be used across multiple sites will facilitate comparisons across studies of children with ASD aged <3 years.

Statement 9: Future research should examine biological and behavioral heterogeneity as moderators of individual responses to interventions.

Statement 10: Intervention providers should consider medical disorders that may affect a child's clinical presentation (especially behavior) and response to an intervention and should refer to appropriate health care providers as indicated.
INTERAGENCY AUTISM COORDINATING COMMITTEE
MEMBER ROSTER

CHAIR

Bruce Cuthbert, Ph.D.
Acting Director
National Institute of Mental Health
National Institutes of Health
Bethesda, MD

FEDERAL MEMBERS

James F. Battey, M.D., Ph.D.
Director
National Institute on Deafness and Other Communication Disorders
National Institutes of Health
Bethesda, MD

Linda Birnbaum, Ph.D., D.A.B.T., A.T.S.
Director
National Institute of Environmental Health Sciences and National Toxicology Program
National Institutes of Health
Research Triangle Park, NC

Aaron Bishop, M.S.S.W.
Commissioner
Administration on Intellectual and Developmental Disabilities
Administration for Community Living
Washington, DC

Francis S. Collins, M.D., Ph.D.
Director
National Institutes of Health
Bethesda, MD

Ruth Etzel, M.D., Ph.D.
Director
Office of Children’s Health Protection
Environmental Protection Agency
Washington, DC

Tiffany R. Farchione, M.D.
Deputy Director
Division of Psychiatry Products
U.S. Food and Drug Administration
Silver Spring, MD

Melissa L. Harris
Acting Deputy Director
Disabled and Elderly Health Programs Group
Centers for Medicare and Medicaid Services
Baltimore, MD

Elisabeth Kato, M.D., M.R.P.
Medical Officer
Agency for Healthcare Research and Quality
Rockville, MD

Laura Kavanagh, M.P.P.
Deputy Associate Administrator
Maternal and Child Health
Health Resources and Services Administration
Rockville, MD

Walter J. Koroshetz, M.D.
Director
National Institute of Neurological Disorders and Stroke
National Institutes of Health
Bethesda, MD
Cynthia Moore, M.D., Ph.D.
Director
Division of Birth Defects and Developmental Disabilities
Centers for Disease Control and Prevention
Atlanta, GA

Linda K. Smith
Deputy Assistant Secretary and Inter-Departmental Liaison
Early Childhood Development Administration for Children and Families
Washington, DC

Catherine Spong, M.D.
Acting Director
Eunice Kennedy Shriver National Institute of Child Health and Human Development
National Institutes of Health
Bethesda, MD

Larry Wexler, Ed.D.
Director
Research to Practice Division
Office of Special Education Programs
U.S. Department of Education
Washington, DC

Nicole Williams, Ph.D.
Program Manager
Congressionally Directed Medical Research Programs
U.S. Department of Defense
Frederick, MD

PUBLIC MEMBERS

David Amaral, Ph.D.
Distinguished Professor
Department of Psychiatry & Behavioral Sciences
University of California, Davis (UC)
Research Director
UC Davis MIND Institute
Sacramento, CA

James Ball, Ed.D., B.C.B.A.-D.
President and CEO
JB Autism Consulting
Cranbury, NJ

Samantha Crane, J.D.
Legal Director and Director of Public Policy
Autistic Self Advocacy Network
Washington, DC

Geraldine Dawson, Ph.D.
Professor
Department of Psychiatry and Behavioral Science
Duke University School of Medicine
Director
Duke Center for Autism and Brain Development
Durham, NC

Amy Goodman, M.A.
Self-Advocate
Charles Town, WV

Shannon Haworth
Public Health Program Manager
Association of University Centers on Disabilities
Silver Spring, MD

David S. Mandell, Sc.D.
Director
Center for Mental Health Policy and Services Research
Associate Professor
Psychiatry and Pediatrics
Perelman School of Medicine
University of Pennsylvania
Philadelphia, PA

Brian Parnell, M.S.W., C.S.W.
Medicaid Autism Waiver & Community Supports Waiver Administrator
Division of Services for People with Disabilities
Utah Department of Human Services
Draper, UT