



IACC Subcommittee for Basic and Translational Research

DSM-5 Planning Group Update

Geraldine Dawson, Ph.D.

Director, Duke University Center on Autism Diagnosis and Treatment
Co-Director, Duke University Developmental Neuroscience Research Program,
and Member, IACC

These slides do not reflect decisions of the IACC and are for discussion purposes only.



IACC Subcommittee for Basic and Translational Research

- **Geraldine Dawson, Ph.D. (Chair)**
Director, Duke Center for Autism Diagnosis and Treatment
Duke University
- **Laura Carpenter, Ph.D., BCBA (Invited Expert)**
Associate Professor of Pediatrics
Medical University of South Carolina
- **Jan M. Crandy**
Parent
Case Manager
Nevada State Autism Treatment Assistance Program
- **Laura Kavanagh, M.P.P.**
Director, Division of Research, Training and Education
Health Resources and Service Administration
- **John P. O'Brien, M.A.**
Senior Policy Advisor
Disabled and Elderly Health Programs
Center for Medicare and Medicaid Services
- **Diane Paul, Ph.D., CCC-SLP, CAE (Invited Expert)**
Director, Clinical Issues in Speech-Language Pathology
American Speech-Language-Hearing Association
Rockville, Maryland
- **Cathy Rice, Ph.D. (for Coleen Boyle, Ph.D.)**
National Center on Birth Defects and Developmental Disabilities
Centers for Disease Control and Prevention
- **Scott Michael Robertson, M.H.C.I.**
Self-Advocate
University Park, Pennsylvania
- **John Elder Robison**
Self Advocate and Author
Amherst, Massachusetts
- **Susan E. Swedo, M.D. (Invited Expert)**
Behavioral Pediatrics Section
Pediatrics and Developmental Neuropsychiatry Branch,
NIMH
- **Amy M. Wetherby, Ph.D. (Invited Expert)**
Laurel Schendel Professor of Communication Science and Disorders
Florida State University
- **Larry Wexler, Ph.D.**
Division Director
Research to Practice Division
U.S. Department of Education

IACC Subcommittee for Basic and Translational Research

Implications for Research

Data to understand impact of changes

- *Who is diagnosed?*
 - Reliability and validity of criteria (including SCD) and components (e.g., severity ratings)?
 - Differences in who is identified?
- *How are people diagnosed?*
 - What changes are needed for screening and assessment tools? How can SCD be assessed?
 - Will there be a change in the way clinicians, community members, researchers conceptualize and identify ASD?
 - How are the criteria being applied in educational and service settings?
- *What does it mean to be diagnosed with ASD?*
 - How does the removal of subtypes affect the culture of people with ASD?
 - How will severity levels and specifiers be used to inform support services?
 - Will the way services are qualified for and provided change (especially related to PDD-NOS and SCD)?

IACC Subcommittee for Basic and Translational Research

Key issues for practice and policy

1. Use of severity ratings to prescribe services is not appropriate.
2. Little prospective data on reliability and validity of criteria for young children, individuals from diverse ethnic backgrounds, and adults.
3. Some children who have ASD might not manifest full range of symptoms before age three. Services should be based on need rather than diagnosis.
4. Clinicians need to be aware that diagnosis can be made based on historical symptoms to avoid misdiagnosis.
5. There is no need for individuals to “re-qualify” for an ASD diagnosis based on DSM-5.
6. Clear treatment guidelines for SCD are lacking. Individual need rather than SCD versus ASD diagnosis should dictate what services are recommended.
7. More information is needed for clinicians and educators on the appropriate and reliable use of the diagnostic specifiers and severity ratings.

IACC Subcommittee for Basic and Translational Research

Next...

- Document can inform research and policy efforts now
- Consider for next IACC Strategic Research Plan update