An Update on the DSM-5 Recommendations for Autism Spectrum Disorder and Other Neurodevelopmental Disorders

Susan E. Swedo, M.D. Chair, DSM-5 Neurodevelopmental Disorders Workgroup

DSM-5 Neurodevelopmental Disorders Workgroup (2007 – Present)

MEMBERS

- Gillian Baird
- Ed Cook
- Francesca Happe
- James Harris
- Walter Kaufmann
- Bryan King
- Catherine Lord
- Joseph Piven
- Rosemary Tannock
- Sally Rogers
- Sarah Spence
- Susan Swedo
- (Fred Volkmar)
- Amy Wetherby
- Harry Wright

ADVISORS

- Jim Bodfish
- Martha Denckla
- Maureen Lefton-Grief
- Nickola Nelson
- Sally Ozonoff
- Diane Paul
- Eva Petkova
- Daniel Pine
- Alya Reeve
- Mabel Rice
- Joseph Sergeant
- Bennett & Sally Shaywitz
- Audrey Thurm
- Keith Widaman
- Warren Zigman

DSM-5 Makes Headlines

- NY Times "New Definition of Autism Will Exclude Many"
 - Specifically, 35% of "high-functioning" and "Asperger disorder"
 - Subsequently quoted as "New Criteria Will Deny Services to 65% of Individuals with Autism"
- "Autism Statistics Worsen & Officials Want to Fudge the Numbers"
- Autism Spectrum Disorder "Diagnostic Disaster"

Concerns about ASD in DSM-5

- Sensitivity has been "sacrificed" in order to improve specificity
 - Social communication domain
 - Restrictive interests and repetitive behaviors domain
- Merging Asperger disorder (and PDD-NOS) into autism spectrum disorder results in loss of identity and ignores uniqueness of Asperger dx
- Pre-/post DSM-5 research studies won't be comparable

Proposed Changes to the Pervasive Developmental Disorders (PDD)

- Three diagnostic domains will become two (Social communication and Restricted, repetitive behaviors)
- Rett Disorder and other etiologic subgroups will be described by use of a Specifier: Associated with Known Medical or Genetic Condition or Environmental Factor
- PDD will be replaced by Autism Spectrum Disorder (ASD)
- Individual diagnoses will be merged into a single, behaviorally defined disorder

Examples of DSM-IV and DSM-5 Criteria Changes

For subcriterion A.3,

DSM-IV checklist item is "failure to develop peer relationships and abnormal social play."

DSM-5 recommendations include higherorder impairments of "difficulties adjusting behavior to suit different social contexts.

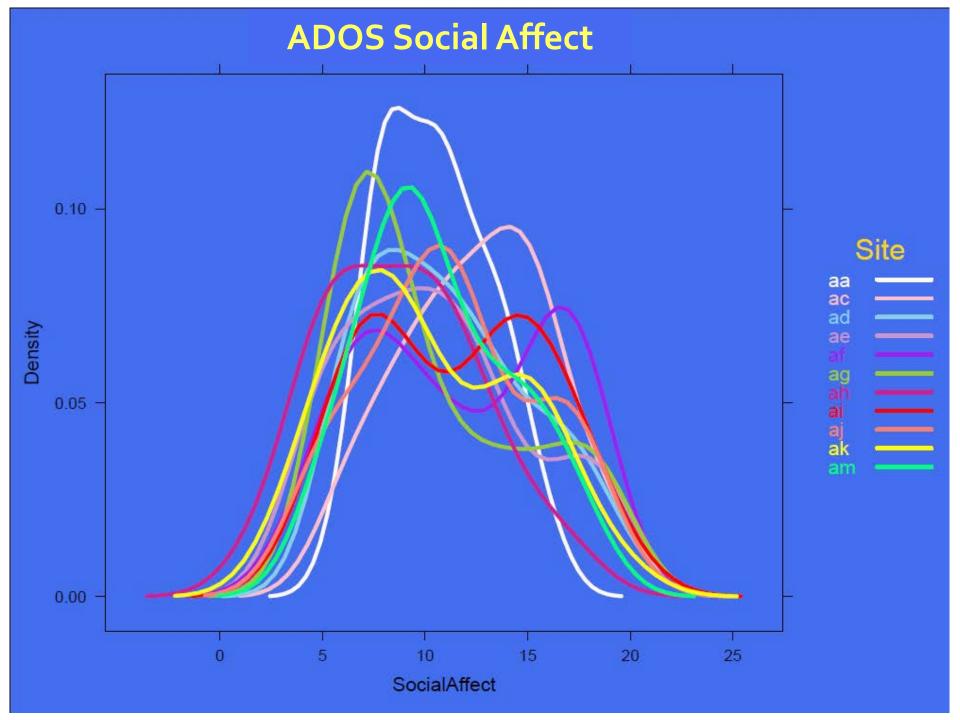
Examples of DSM-IV and DSM-5 Criteria Changes

For criterion C, DSM-IV requires that symptoms begin prior to the age of 3 years.

The DSM-5 requires that symptoms begin in early childhood, with the caveat that "symptoms may not be fully manifest until social demands exceed capacity" (during middle-school years, later adolescence, or young adulthood). Decision to include Asperger Syndrome & PDD-NOS within one ASD diagnosis

Scientific validity

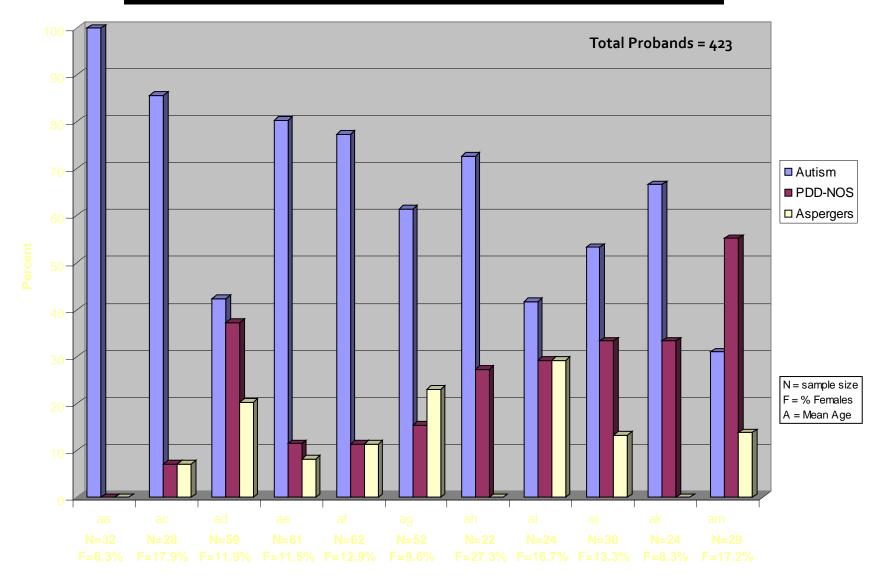
- Lack of specificity and sensitivity in separating the diagnoses
- Lack of accurate historical information about very early language development put emphasis on current speech (trainable)
- Overlap in samples when VIQ controlled
- Consideration of access to services



Data from Simons Collection

- Over 2200 validated singletons with ASD;
 8500 family members (two biological parents and, in most cases, at least one unaffected sibling) with DNA and intensive behavioral and neuropsychological phenotyping
- Recruited from 12 sites in the US and Canada

ASD Distribution of Probands



Single Spectrum but Significant Individual Variability

- Severity of ASD Symptoms
- Pattern of Onset and Clinical Course
- Etiologic factors
- Associated conditions
- Individual weaknesses and strengths

CLINICIANS WILL BE ENCOURAGED TO DESCRIBE THESE DETAILS WITH DIAGNOSTIC SPECIFIERS

Sensitivity and Specificity of DSM-5 Criteria for Autism & Related Disorders

| DSM-5 | Completed | Completed | |
|------------------|-----------|------------------|--|
| FIELD TRIALS | V1 | V2 | |
| Pediatric Sites: | | | |
| Stanford | 158 | 148 | |
| The Children's | | | |
| Hospital | 216 | 193 | |
| Baystate Medical | | | |
| Center | 164 | 145 | |
| Columbia/Cornell | 127 | 120 | |
| Pediatric Sites | 665 | 606 (293) | |

Sensitivity and Specificity of DSM-5 Criteria for Autism & Related Disorders

| | NONE | | Autistic Disorder | Asperger Disorder | PDD- NOS | TOTAL | | |
|--------------------|--------------|--|----------------------|----------------------|-------------|-------|--|--|
| DSM-IV | 214 | | 35 | 21 | 23 | 79 | | |
| DSM-5 ASD | 19 | | 31 | 16 | 17 | 83 | | |
| DSM-5 SCD | 10 | | 4 | 2 | 1 | 17 | | |
| No DSM5 ASD/SCD | 185 (86%) | | 0 | 3 | 5 | | | |

NOTE: Some DSM-IV cases "lost" their diagnosis with DSM-5 criteria, but overall, there was an increase in ASD cases. Further, when SCD cases are added, there was a 14% increase in new cases of ASD/SCD.

Summary of DSM-5 Field Trials Data

Specificity and Sensitivity of DSM-5 ASD Criteria are comparable to DSM-IV. ND Workgroup will examine validity or DSM-5 Criteria from archived patient interviews.

For More Information

American Psychiatric Association www.dsm5.org Neurodevelopmental Disorders

Autism Spectrum Disorder in DSM-IV Currently, OR BY HISTORY, must meet criteria A,

B, C, and D

A. Persistent deficits in social communication and social interaction across contexts, not accounted for by general developmental delays, and manifest by all 3 of the following:

- 1. Deficits in social-emotional reciprocity
- 2. Deficits in nonverbal communicative behaviors used for social interaction
- 3. Deficits in developing and maintaining relationships

B. Restricted, repetitive patterns of behavior, interests, or

activities as manifested by at least two of the following:

- 1. Stereotyped or repetitive speech, motor movements, or use of objects
- 2. Excessive adherence to routines, ritualized patterns of verbal or nonverbal behavior, or excessive resistance to change
- 3. Highly restricted, fixated interests that are abnormal in intensity or focus
- 4. Hyper-or hypo-reactivity to sensory input or unusual interest in sensory aspects of environment;

C. Symptoms must be present in early childhood (but may not become fully manifest until social demands exceed limited capacities)

D. Symptoms together limit and impair everyday functioning.

A. Persistent deficits in social communication and social interaction across contexts, not accounted for by general developmental delays, and manifest by all 3 of the following:

- 1. **Deficits in social-emotional reciprocity**; ranging from abnormal social approach and failure of normal back and forth conversation through reduced sharing of interests, emotions, and affect and response to total lack of initiation of social interaction,
- 2. **Deficits in nonverbal communicative behaviors used for social interaction**; ranging from poorly integrated- verbal and nonverbal communication, through abnormalities in eye contact and body-language, or deficits in understanding and use of nonverbal communication, to total lack of facial expression or gestures.

3. Deficits in developing and maintaining relationships, appropriate to developmental level (beyond those with caregivers); ranging from difficulties adjusting behavior to suit different social contexts through difficulties in sharing imaginative play and in making friends to an apparent absence of interest in people

2. All individuals must have or have had restricted interests and repetitive behaviors (in at least 2 of 4 domains)

- 1. **Stereotyped or repetitive speech, motor movements, or use of objects** (e.g. simple motor stereotypies, echolalia, repetitive use of objects, or idiosyncratic phrases).
- 2. Excessive adherence to routines, ritualized patterns of verbal or nonverbal behavior, or excessive resistance to change (e.g., motoric rituals, insistence on same route or food, repetitive questioning or extreme distress at small changes).
- 3. **Highly restricted, fixated interests that are abnormal in intensity or focus**; (e.g. strong attachment to or preoccupation with unusual objects, excessively circumscribed or perseverative interests).
- 4. Hyper-or hypo-reactivity to sensory input or unusual interest in sensory aspects of environment; (e.g. apparent indifference to pain/heat/cold, adverse response to specific sounds/textures, smelling or touching of objects, fascination with lights or spinning objects).