Autism Spectrum Disorders in DSM-5: What's Changing? What's Staying the Same?

Presentation to the April 2010 Meeting of the IACC

Susan E. Swedo, M.D.

Chair of DSM-5 Neurodevelopmental Workgroup

DSM-5 Neurodevelopmental Disorders Workgroup

- Multidisciplinary, international group with expertise in:

  Child psychiatry, child psychology (clinical and experimental), early development, speech & language pathology, pediatrics and child neurology.

- Members:

  Susan Swedo (Chair), Edwin Cook, Francesca Happe, James Harris, Walter Kaufmann, Bryan King, Cathy Lord, Joe Piven, Sally Rogers, Sarah Spence, Amy Wetherby and Harry Wright. Poul Thorsen on leave of absence.

- Consultants and Advisors – Experts invited to provide advice and recommendations to Workgroup (which in turn is advisory to DSM-5 Task Force and APA.)
- Biweekly teleconferences, semi-annual in-person meetings and additional web conferences, other “meetings” as needed.
- Literature reviews, secondary data analyses and expert testimony utilized in suggesting criteria changes.

DSM-5 vs. DSM-IV

- DSM-5 Task Force began in 2007 and is chaired by Drs. David Kupfer & Darrell Regier
- Charged with recommending changes that would reflect our increased knowledge base, including contributions from clinicians as well as researchers
- DSM-5, not DSM-V, to facilitate revisions and updates being made in a timely fashion, whenever empiric data warrant changes – 5.1, 5.2, etc.
- “Transparency” of process important, so the draft criteria changes were available for public review and comment from mid-Feb to April 20th.

“Autism” in DSM-IV

- Pervasive Developmental Disorders
  - Autism
  - Asperger disorder
  - Rett syndrome
  - Childhood disintegrative disorder (CDD)
  - PDD-NOS (Pervasive Developmental Disorder – Not Otherwise Specified)

Proposed Changes: Name of Category

- Delete the term “Pervasive Developmental Disorders”
  - Symptoms are not pervasive – they are specific to social-communication domain plus restricted, repetitive behaviors/fixated interests
  - Overuse of PDD-NOS leads to diagnostic confusion
  - Lack of distinction between PDD-NOS and Asperger disorder
- Recommend new diagnostic category: “Autism Spectrum Disorder”

Proposed Changes: Symptom Domains

- THREE will become TWO
  - Social Communication domain will be created by merger of key symptoms from the DSM-IV Social and Communication domains
  - Fixated interests and repetitive behavior or activity

JUSTIFICATION:

- Deficits in communication are intimately related to social deficits. The two are “manifestations” of a single set of symptoms that are often present in differing contexts.
- This de-emphasizes language skills not employed in the context of social communication.

Proposed Changes: Merging of the ASD's into a Single Dx

- AUTISM, ASPERGER's and PDD-NOS will be collapsed into a single diagnosis: AUTISM SPECTRUM DISORDER
  - JUSTIFICATION:
    - A single spectrum better reflects the clinical presentation, time-course and interventions.
    - Separation of ASD from typical development is reliable & valid while separation of disorders within the spectrum is inconsistent (e.g. Asperger's and PDD-NOS used interchangeably, as are HFA and Asperger's)
    - Severity is often used to differentiate autism, Asperger's and PDD-NOS – but not consistently across centers.

Proposed Changes: Merging of the ASD's into single Dx

- More than 600 of the public comments were about the deletion of Asperger's disorder as a separate entity
  - Many were concerned about loss of identity
  - Some were concerned about loss of services
  - None described the DSM-IV symptoms of Asperger's disorder
    - Unique strengths of "Aspies" were mentioned often
    - Deficits ascribed to autism that aren't part of its definition

Other Changes for ASD

- Inclusion of Specifiers, such as:
  - “Associated with Known Medical or Genetic Condition” (e.g. Fragile X, VCFS)
  - Verbal abilities
  - Cognitive abitilies
- Text description to include symptoms unique to various ages/developmental stages and verbal abilities
- Rating of severity?

Proposed Changes in DSM-5: Deletion of RETT SYNDROME

- Rett will be removed as a separate disorder
  - JUSTIFICATION:
    - ASD behaviors are not particularly salient in Rett Syndrome patients except for brief period during development.
    - ASD are defined by specific sets of behaviors, not etiologies (at present) so inclusion of Rett Disorder is atypical.
    - Patients with Rett Syndrome who have autistic symptoms can still be described as having ASD, and clinicians should use the specifier “with known genetic or medical condition” to indicate symptoms are related to Rett

Proposed Changes: Delete Childhood Disintegrative Disorder (CDD)

- New knowledge that developmental regression in ASD is a continuous variable, with wide range in the timing and nature of the loss of skills, as well as the developmental milestones that are reached prior to regression
- Rarity of CDD diagnosis makes systematic evaluation difficult, but review of accumulated world's literature shows that CDD has important differences from other ASD's, including the acuity and severity of regression, as well as co-occurring physical symptoms, such as loss of bowel and bladder control.
- DSM-5 will include a specifier for ASD to indicate nature of regression (if present)

Items left for discussion/decision

- Should “impairment” be used in diagnostic criteria, or only in severity descriptors? (DSM-5-wide discussion)
- How to improve the specificity of ASD diagnostic criteria without sacrificing sensitivity
  - DSM-IV criteria for ASD overlap with those for ADHD and OCD, also for intellectual disabilities (without specific social deficits)
  - Threshold for clinical diagnosis must be set
    - Difficult to do because symptoms are on a continuum with normal behaviors and not a dichotomous distinction
    - Where we set the “Disorder” threshold is crucial
      - Will impact prevalence rates
      - May change individuals’ access to services

Next Steps

- Continued workgroup deliberations via teleconference and webinars
- Field Trials of draft criteria
- Another period for public comments
- Another set of revisions
- Drafting text to accompany criteria
- Linking ASD with other disorders in DSM-5