Autism Diagnosis and Management Update

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Outline

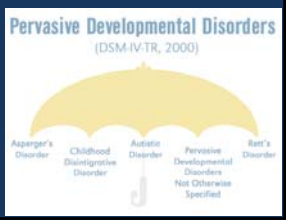
- **Autism Diagnosis**
  - Brief history
  - New, DSM-5 diagnostic criteria
  - Expressed questions and concerns
- **Management**
  - Treatment
  - Resources

History

- 1943: Symptoms first described
- DSM-I (1952) and DSM-II (1968)
  - Autism was not described
- DSM-III (1980)
  - Pervasive Developmental Disorders
    - Childhood Onset PDD
    - Infantile Autism
    - Atypical Autism
- DSM-IIIR (1987)
  - Pervasive Developmental Disorders
    - PDD-NOS
    - Autistic Disorder

History, cont'd

- DSM-IV (1994)
  - Pervasive Developmental Disorders
    - Autistic Disorder
    - Asperger's Disorder
    - Childhood Disintegrative Disorder
    - Rett's Disorder
    - PDD-NOS
- DSM-IV-TR (2000)
  - PDD-NOS rev



DSM-5

- Published in May 2013
- Significant changes to the diagnostic criteria for Autism

Rationale for Changes

Some concerns re: the DSM-IV categorization

1. Are the disorders truly different from one another?
   - For example: Asperger's Disorder v HFA
2. Misuse of diagnostic labels
   - For example: PDD-NOS, Asperger's Disorder
3. Appropriateness of Rett's Disorder (Rett Syndrome)?
4. Validity of CDD as a unique diagnosis?
5. Reliability of diagnoses
   - Differences: race, region, diagnostician
   - Some children have received multiple diagnoses

Rationale for Changes

A Multisite Study of the Clinical Diagnosis of Different Autism Spectrum Disorders

Lord, et al. (2012), *Archives of General Psychiatry, 69*(3), 306-313.

- Participants
  - n = 2102
  - 12 university-based medical centers
- Findings:
  - Clinical distinctions across subtypes of ASD were not reliable
  - Diagnostician variables; Site variables
  - Support the transition from the DSM-IV subgroupings

From: **A Multisite Study of the Clinical Diagnosis of Different Autism Spectrum Disorders**
Arch Gen Psychiatry. 2012;69(3):306-313.

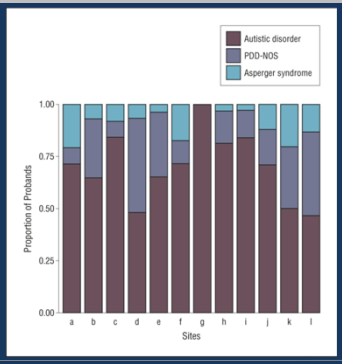


Figure 1. Best-estimate clinical diagnoses across 12 university-based sites (ie, autism service providers) for 2102 probands assigned to 3 autism spectrum disorder diagnostic categories (autistic disorder, Asperger syndrome, and pervasive developmental disorder–not otherwise specified [PDD-NOS]).

DSM-5:
Review of Changes and Current Diagnostic Criteria

DSM-5 Change: NAME

DSM-IV	DSM-5
Pervasive Developmental Disorder 1. Autistic Disorder 2. Asperger's Disorder 3. Rett's Disorder 4. CDD 5. PDD-NOS	**Autism Spectrum Disorder** No subgroupings HOWEVER, specifiers are encouraged to document individual variability

DSM-5 Change: Diagnostic Domains

DSM-IV	DSM-5
1. Qualitative impairment in Social Interaction 2. Qualitative impairment in Communication 3. Restricted, Repetitive, Stereotyped patterns of behavior or interest	1. Persistent deficits in Social Communication and Social Interaction 2. Restricted, Repetitive patterns of behavior or interest

DSM-5: Other Changes

- Recognition for changes in symptom presentation over the lifespan
- Inclusion of sensory-based symptoms
- Formally permits co-morbid ADHD diagnosis
- Specifiers (severity, genetic / medical condition)

DSM-5 Diagnostic Criteria

A: Persistent deficits in social communication and social interaction across multiple contexts, as manifested by the following, currently or by history: (must meet all of the following):

1. Deficits in social-emotional reciprocity, ranging, for example, from abnormal social approach and failure of normal back-and-forth conversation; to reduced sharing of interests, emotions, or affect; to failure to initiate or respond to social interactions.

2. Deficits in nonverbal communicative behaviors used for social interactions, ranging, for example, from poorly integrated verbal and nonverbal communication; to abnormalities in eye contact and body language or deficits in understanding and use of gestures; to a total lack of facial expressions and nonverbal communication.

3. Deficits in developing, maintaining, and understanding relationships, ranging, for example, from difficulties adjusting behavior to suit various social contexts; to difficulties in sharing imaginative play or in making friends; to absence of interest in peers

*NOTE: Examples are illustrative, not exhaustive

DSM-5 Diagnostic Criteria

B: Restricted, repetitive patterns of behavior, interests, or activities, as manifested by at least two of the following, currently or by history:

1. Stereotyped or repetitive motor movements, use of objects, or speech (e.g., motor stereotypies, lining up toys or flipping objects, echolalia, idiosyncratic phrases).

2. Insistence on sameness, inflexible adherence to routines, or ritualized patterns of verbal or nonverbal behavior (e.g., extreme distress at small changes, difficulties with transitions, rigid thinking patterns, greeting rituals, need to take same route or eat same food every day).

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 hyporeactivity to sensory input or unusual interest in sensory aspects of the environment (e.g., apparent indifference to pain/temperature, adverse response to specific sounds or textures, excessive smelling or touching of objects, visual fascination with lights or movement)

DSM-5 Diagnostic Criteria

C: Symptoms must be present in the early developmental period (but may not become fully manifest until social demands exceed limited capacities, or may be masked by learned strategies in later life)

D: Symptoms cause clinically significant impairment in social, occupational, or other important areas of functioning.

E: These symptoms are not better explained by intellectual disability or global developmental delay.

DSM-5 Diagnostic Criteria
(Specifiers)

Specify if:

With or without accompanying intellectual impairment

With or without accompanying language impairment

Associated with a known medical or genetic condition

Associated with another neurodevelopmental, mental, or behavioral disorder

With catatonia

DSM-5 Diagnostic Criteria
(Severity Specifiers)

Severity Level	Social Communication and Social Interaction	Restricted, Repetitive Behaviors
Level 3: **"Requiring very substantial support"**	Severe deficits in verbal and nonverbal social communication skills cause severe impairments in functioning; very limited initiation of social interactions and minimal response to social overtures from others	Inflexibility of behavior, difficulty coping with change, or other restricted / repetitive behaviors markedly interfere with functioning in all spheres. Great distress difficulty changing focus or action.
Level 2: **"Requiring substantial support"**	Marked deficits in verbal and nonverbal social communication skills; social impairments apparent even with supports in place; limited initiation of social interactions and reduced or abnormal response to social overtures from others.	Inflexibility of behavior, difficulty coping with change, or other restricted / repetitive behaviors appear frequently enough to be obvious to the casual observer and interfere with functioning in a variety of contexts. Distress and / or difficulty changing focus or action.
Level 1: **"Requiring Support"**	Without supports in place, deficits in social communication cause noticeable impairments. Difficulty initiating social interactions and clear examples of atypical or unsuccessful responses to social overtures of others. May appear to have decreased interest in social interactions.	Inflexibility of behavior causes significant interference with functioning in one or more contexts. Difficulty switching between activities. Problems of organization and planning hamper independence.

Expressed Concerns

Does change in diagnostic criteria mean loss of diagnosis for some individuals?

- Intimately tied to concern re: services
- Huerta, et al. (2012): 91% of individuals with an established DSM-IV PDD diagnosis will continue to meet diagnostic criteria under the new, DSM-5 criteria (largest study)
- Other studies: 57%, 75%, 86%
- Is reevaluation necessary?

Loss of Asperger's Disorder as a diagnosis

- Loss of identity, culture
- Unique presentation

Expressed Concerns

Loss of the "NOS" diagnostic option

- What about those individuals who don't *quite* meet criteria but appear very similar to individuals with ASD?
- **New DSM-5 Disorder:**

Social (Pragmatic) Communication Disorder

(social impairments, without significant RRBs)

Social (Pragmatic) Communication Disorder

A: Persistent deficits in the social use of verbal and nonverbal communication as manifested by all of the following:

1. Deficits in using communication for social purposes, such as greeting and sharing information, in a manner that is appropriate for the social context.

2. Impairment of the ability to change communication to match context or the needs of the listener, such as speaking differently in a classroom than on a playground, talking differently to a child than to an adult, and avoiding use of overly formal language

3. Difficulties following rules for conversation and storytelling, such as taking turns in conversation, rephrasing when misunderstood, and knowing how to use verbal and nonverbal signals to regulate interaction.

4. Difficulties understanding what is not explicitly stated (e.g., making inferences) **and nonliteral or ambiguous meanings of language** (e.g., idioms, humor, metaphors, multiple meanings that depend on the context for interpretation).

Social (Pragmatic) Communication Disorder

B: The deficits result in functional limitations in effective communication, social participation, social relationships, academic achievement, or occupational performance, individually or in combination

C: The onset of the symptoms is in the early developmental period (but deficits may not become fully manifest until social communication demands exceed limited capacities)

D: The symptoms are not attributable to another medical or neurological condition ... And are not better explained by Autism Spectrum Disorder, Intellectual Disability, global developmental delay, or another mental disorder

Autism Spectrum Disorder: Management Information

Management of ASD

Behavioral / Educational	Medical Management
Evidence-based treatment: Interventions based on the principles of Applied Behavior Analysis (ABA)	Treatment of core symptoms vs. **Treatment of common related symptoms**

Behavioral / Educational Treatment

Applied Behavior Analysis

- Application of behavioral science to address problems of social importance; Broad field
- Much research exists supporting the effectiveness of ABA-based intervention approaches with individuals with ASD:
  - To increase behaviors and teach new skills
  - To support generalization and maintenance
  - To address the occurrence of challenging behaviors that cause significant interference
  - Parent Training

Behavioral / Educational Treatment

Many ABA-Based Procedures and Approaches

- Early Intensive Behavioral Intervention (EIBI)
- Positive Behavioral Support
- Functional Behavior Assessment, Functional Analysis
- Pivotal Response Training
- Verbal Behavior
- Functional Communication Training
- Self-Management
- Activity Schedules
- Incidental Teaching
- Errorless Learning
- Discrete Trial Instruction (DTT)
- Prompting, Modeling, Shaping, Chaining, Reinforcement
- ... and many more

Behavioral / Educational Treatment

Some (of the many) misconceptions about ABA

- "ABA is an intervention designed for children with autism"
- "ABA = Discrete Trial Teaching"
- "ABA always requires 1:1 instruction"
- "ABA is always done at a table"
- "can't be used with individuals who are 'higher functioning'"
- "ABA only focuses on consequences to address behavior problems"
- "ABA is very rigid"

Where to find evidence?

- Association for Science in Autism Treatment
  http://www.asatonline.org/
  NOTE: they link to: Report of the Maine Administrators of Services for Children with Disabilities (MADSEC)
- CDC
  http://www.cdc.gov/ncbddd/autism/treatment.html
- National Autism Standards Report (NAC)
  www.nationalautismcenter.org
- Autism Speaks
  www.autismspeaks.org

Medical Management: Medication

- No medications currently available to treat the core symptoms of ASD
- Medications are used to treat common related symptoms and conditions
- Benefit of co-occurring behavioral intervention
  - e.g., Aman, et al. (2009)

Common Co-occurring Symptoms and Conditions

- **ADHD**
  - Inattention; impulsivity; organization
- **Anxiety**
  - Rigidity; compulsive behaviors
- **Mood Disorders**
  - Higher vulnerability
  - May be difficult to identify in individuals with ASD
- **Irritability, Aggression, SIB**

Common Co-occurring Symptoms and Conditions

- **Sleep Disorders, Disruptions**
  - Sleep onset; Sleep maintenance
  - Studies estimate 40 – 80% of children with ASD
- **Seizures**
  - Higher rates in children with ASD compared to neurotypical children
- **GI issues**
  - Constipation, diarrhea

Resources

AAP Toolkit

Autism: Caring for Children with Autism Spectrum Disorders

A Resource Toolkit for Clinicians - New 2nd Edition

- **Practice-focused guidelines and recommendations**
- **Developmental screening and surveillance tools**
- **Clinician Fact Sheets**
- **AAP Webinar**
- **Family Handouts (English and Spanish)**

Autism Speaks Toolkits

- 100 Day Kit
- Advocacy Tool Kit
- Asperger Syndrome and High Functioning Autism Tool Kit
- An Introduction to Behavioral Health Treatments
- Autism and Medication: Safe and Careful Use
- Blood Draw Tool Kit
- Dental Professionals' Tool Kit
- Guide for Managing Constipation
- Medication Decision Aid
- Parent's Guide to ABA
- Parent's Kit to Toilet Training in ASD
- Sleep Tool Kit
- Dental Tool Kit
- Challenging Behaviors Tool Kit
- Visual Supports and ASD
- Employment Tool Kit
- Family Support Tool Kits
- IEP Guide and Other Resources
- Participant's Guide to Autism Drug Research
- Postsecondary Educational Opportunities Guide
- School Community Tool Kit
- Talking to Parents About Autism Kit
- Tips for Successful Haircuts
- Transition Tool Kit

Resources - Maine

Child Development Services (CDS)

- Provides Early Intervention (0-3) and school-aged (3-5) services under the supervision of the Maine Department of Education.
- This includes special education preschool programs for children with developmental disabilities and mental health diagnoses.
- Parents or providers may make referrals.
- A list of all the sites in Maine is available at: http://www.maine.gov/doe/cds/sitelocations.html

Resources - Maine

Katie Beckett Benefit

- Maine Care for children with significant health care needs

Case Management

- Case management services designed to help coordinate and advocate for children with developmental or mental health needs.
- Case managers coordinate educational, legal, vocational, financial, and supportive services
- Eligibility: Maine children, 0-20, living in Maine, currently receiving Maine Care

Resources: In-Home Support

Section 28

- Habilitation services for children who have a developmental disability that affects everyday functioning
- Services include skill building in activities of daily living and behavior management, by working in the home and community on goals identified in a treatment plan.
- Children must show significant delays in adaptive skills.

Specialized Section 28

- Applied Behavior Analysis for the following target symptoms and groups:
  - Early Intensive Behavioral Intervention (Ages 2-7) w/ ASD diagnosis
  - Challenging Behavior, Ages 2-21 w/ ASD
  - Communication, Ages 2-11 w/ ASD
  - Social Skills, Ages 3-10 w/ ASD

Resources: In-Home Support

Section 65

- **HCT** (Home and Community Based Treatment)
- Habilitation services for children who have a developmental disability that affects everyday functioning
- Offer support for the child and family to manage behavioral challenges and mental health symptoms
- Goals: improve functioning in the home, school, and community; prevent hospitalization or other more intensive support requirements

References

Aman, M.G., et al. (2009). Medication and parent training in children with pervasive developmental disorders and serious behavior problems: Results from a randomized clinical trial. *Journal of the Academy of Child and Adolescent Psychiatry, 48*(12), 1143-1154.

Huerta, M., Bishop, S., Duncan, A., Hus, V, & Lord, C (2012). Application of DSM-5 criteria for autism spectrum disorder to three samples of children with DSM-IV diagnoses of pervasive developmental disorder. *American Journal of Psychiatry, 169l, 1056-1064.*

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