Module 1:

Diagnostic Assessment of Transitioning Youth and Adults on the Autism Spectrum

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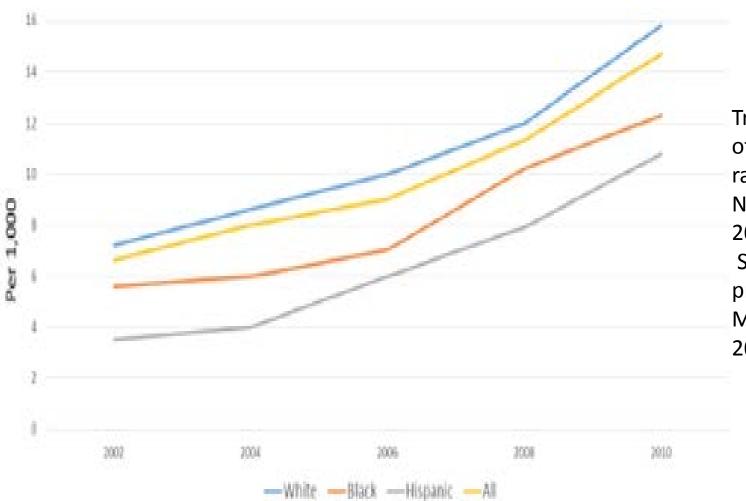
Identified Prevalence of Autism Spectrum Disorder

ADDM Network 2000 – 2012 Combing Data from All Sites

Surveillance Year	Birth Year	Number of ADDM Sites Reporting	Prevalence per 1,000 Children (Range)	This is about 1 in X children
2000	1992	6	6.7 (4.5 – 9.9)	1 in 150
2002	1994	14	6.6 (3.3-10.6)	1 in 150
2004	1996	8	8.0 (4.6 – 9.8)	1 in 125
2006	1998	11	9.0 (4.2-12.1)	1 in 110
2008	2000	14	11.3 (4.8 - 21.2)	1 in 88
2010	2002	11	14.7 (5.7 – 21.9)	1 in 68
2012	2004	11	14.6 (8.2 – 24.6)	1 in 68



Trends in Prevalence

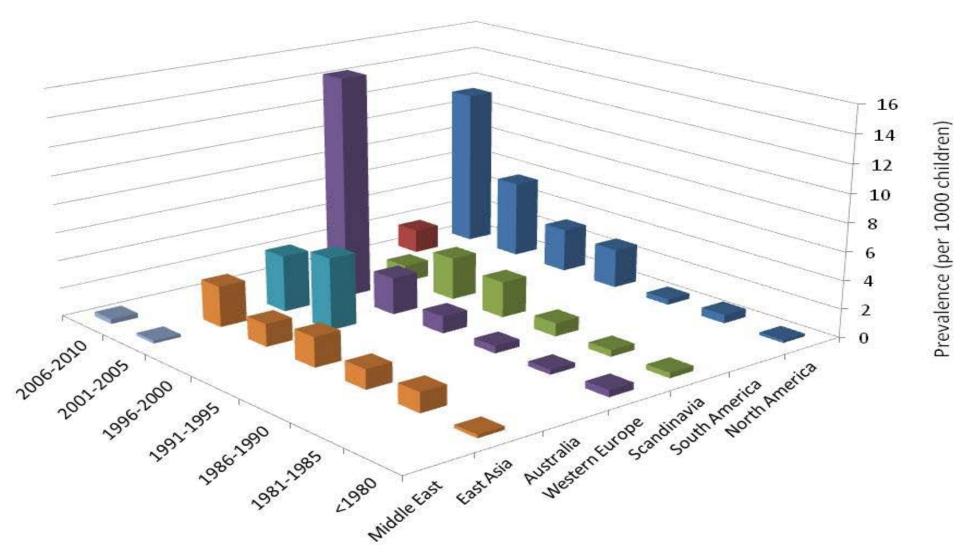


Trends in the prevalence (per 1,000) of ASD among 8-year-old children by race and ethnicity, U.S. ADDM Network Surveillance Sites, 2002–2010.

SOURCE: ADDM Network ASD prevalence reports published in Morbidity and Mortality Reports, 2007–2014.



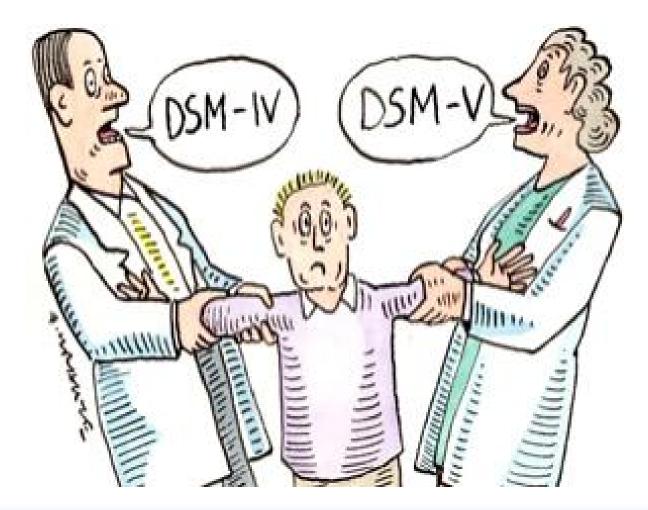
Estimated prevalence of autism in the world



History of DSM 5 & Autism

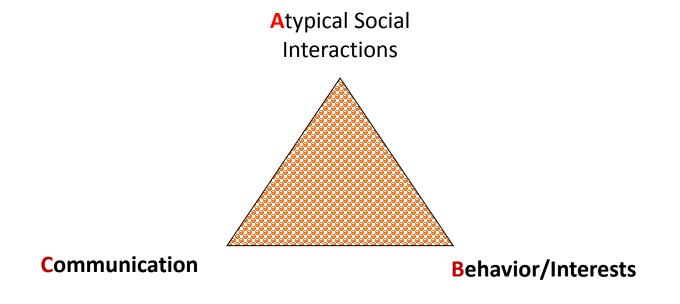
- DSM-I (1952) & DSM II (1968)
 - No term autism or Pervasive Developmental Disorder
 - Closest term: schizophrenic Reaction (Childhood type)
- DSM III (1980)
 - Pervasive Developmental Disorders: Childhood Onset PDD, Infantile Autism, Atypical Autism
- DSM III R (1987)
 - Pervasive Developmental Disorders: PDD-NOS, Autistic Disorder
- DSM IV (1994)
 - Pervasive Developmental Disorders: PDD-NOS, Autistic Disorder, Childhood Disintegrative Disorder, Rett Syndrome
 - 2027 possible combinations to dx; DSM 5, 11
- DSM IV TR (2000) Same dx; text correction for PDD-NOS







Autism Spectrum Disorders



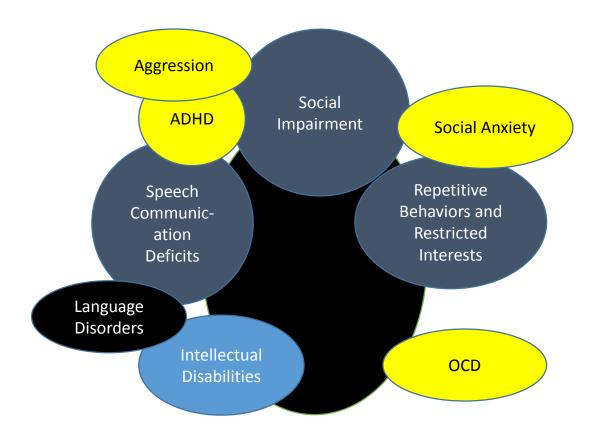


What was the problem with PDD-NOS?

"This category should be used when there is severe and pervasive development of reciprocal social interaction associated with impairment in either verbal or nonverbal communication skills OR with the presence of stereotyped behavior, interests and activities, but the criteria are not met for a specific PDD...For example this category includes "atypical autism"-presentations that do not meet the criteria for Autistic disorder because of late age at onset, atypical symptomatology, or subthreshold symptomatology."



DSM 5- bimodal





Specific Changes

- PDD-NOS deleted
 - Symptoms aren't pervasive
 - Overuse leads to diagnostic confusion
 - Overlap with Asperger
- Deletion of Rett syndrome as a specific ASD (genetic disease)
- Deletion of CDD: developmental regression in ASD is a continuous variable
- Elimination of Asperger Disorder: no clinical or research evidence for separation
- 12 distinct categories in DSM IV TR with DSM 5 having 7 criteria which describe more general principles and behaviors
- DSM 5 allows consideration of historical as well as current



	DSM-IV-TR Diagnostic Criteria
1) Qu	alitative impairment in social interaction
	Marked impairment in the use of multiple nonverbal behaviors such as eye-eye gaze, facial expression, body postures, and gestures to regulate social interaction
	Failure to develop peer relationships appropriate to developmental level
	A lack of spontaneous seeking to share enjoyment, interests, or achievements with other people (e.g., by a lack of showing, bringing, or pointing out objects of interest)
	Lack of social or emotional reciprocity
(2) Qu	alitative impairments in communication
	Delay in, or total lack of, the development of spoken language (not accompanied by an attempt to compensate through alternative modes of communication such as gesture or mime)
	In individuals with adequate speech, marked impairment in the ability to initiate or sustain a conversation with others
	Stereotyped and repetitive use of language or idiosyncratic language
	Lack of varied, spontaneous make-believe play or social imitative play appropriate to developmental level
(3) Re activit	stricted repetitive and stereotyped patterns of behavior, interests, and ies
	Encompassing preoccupation with one or more stereotyped and restricted patterns of interest that is abnormal either in intensity or focus
	Apparently inflexible adherence to specific, nonfunctional routines or rituals
	Stereotyped and repetitive motor mannerisms (e.g., hand or finger
	flapping or twisting, or complex whole body movements)

DSM-5 Diagnostic Criteria

A. Persistent deficits in social communication and social interaction across contexts

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

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

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

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

Stereotyped or repetitive speech, motor movements, or use of objects; (such as simple motor stereotypies, echolalia, repetitive use of objects, or idiosyncratic phrases)

Excessive adherence to routines, ritualized patterns of verbal or nonverbal behavior, or excessive resistance to change; (such as motoric rituals, insistence on same route or food, repetitive questioning or extreme distress at small changes)

Highly restricted, fixated interests that are abnormal in intensity or focus; (such as strong attachment to or preoccupation with unusual objects, excessively circumscribed or perseverative interests)

Hyper-or hypo-reactivity to sensory input or unusual interest in sensory aspects of environment; (such as apparent indifference to pain/heat/cold, adverse response to specific sounds or textures, excessive smelling or touching of objects, fascination with lights or spinning objects)

Becomes a specifier

Special note (of ambiguity)

"Individuals with well established DSM IV dx of autistic disorder, Asperger's disorder or PDD NOS should be given the dx of ASD. Individuals who have marked deficits in social communication, but whose symptoms do not otherwise meet criteria for ASD, should be evaluated for social (pragmatic) communication disorder."



Severity Level

Severity level	Social Communication	RRB
3: requiring very substantial support	Severe deficits in verbal and nonverbal SC cause severe impairments in functioning, very limited initiation of social interactions and minimal response to social overtures from others	Inflexibility of behavior, extreme difficulty coping with change
2: Requiring substantial support	Marked deficits; social impairments evident even w/ supports in place	Difficulty coping with change; RRB appear frequently enough to be obvious to the casual observer and interfere w/ functioning
1:Requiring support	W/o supports in place deficits cause noticeable impairments. Difficulty initiating social interactions and clear examples of atypical or unsuccessful responses	Inflexibility causes significant interference in one or more contexts. Difficulty switching between activities. Problems of planning and organization hamper independence



Social Communication Disorder: The New Kid on the Block

- A. Persistent difficulties 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 social context.
 - 2. Impairment in 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 meaning of language (e.g., idioms, humor, metaphors, multiple meanings that depend on the context for interpretation.)
- 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 or to low abilities in the domains of word structure and grammar, and are not better explained by autism spectrum disorder, intellectual disability (intellectual developmental disorder), global developmental delay, or another mental disorder.



SCD

- Little evidence that SCD has either reliability or validity as a distinct category of neurodevelopmental disorder
- Do these problems warrant a separate clinical diagnosis or are they better viewed as comorbid symptoms seen in individuals with other neurodevelopmental disorders?
- SCD is probably even more vulnerable to cultural bias or interpretation
- "Autism lite" (Robison)



Controversy

- "We'll call the kid a zebra if he needs to be called a zebra to get the educational and other services that he needs and deserves."- Judy Rappaport MD, NIMH
- Who might be affected:
 - Milder forms of disorder
 - Higher cognitive function
 - Younger and les likely to show full range of sx



Moving from Research to Practice in the Primary Care of Youth/Adults with ASD



Best Practice in ASD Assessment in Transitioning and Adolescent Youth

- Record review
- Developmental and medical history
- Evidence-Based Assessment for ASD
- Medical screening and/or evaluation
- Parent/caregiver interview
- Parent/teacher ratings of social competence
- Direct child observation
- Cognitive assessment
- Academic assessment
- Adaptive behavioral assessment
- Communication and language assessment (Wilkinson, 2016)



Gold Standard

- Autism Diagnostic Interview-Revised (ADI-R; Lord, Rutter, & Le Couteur, 1994)
- Autism Diagnostic Observation Schule-2 (ADOS-2; Lord, Rutter, DiLavore, Risi, Gotham, & Bishop, 2012).



ADI-R

93 questions that are summed into 3 functional domains

- Language/Communication
- Reciprocal Social Interactions
- Restricted, Repetitive, and Stereotyped Behavior and Interest

Not sensitive to differences among children with mental ages below 20 months or Intelligence Quotients (IQs) below 20 and the ADI-R is not at all recommended for use with individuals with a mental age below 18

Administration is lengthy and labor intensive, requiring 2 ½-3 hours to complete



ADOS

- Module 1- Children 31 months and older who do not consistently use phrase speech.
- Module 2- Children of any age who use phrase speech but are not verbally fluent. Focus on social interest, joint attention, communicative behaviors, symbolic play, and atypical behaviors (excessive sensory interests and hand mannersisms)
- Module 3- Verbally fluent children and young adolescents.
- Module 4- Verbally fluent older adolescents and adults. Focus on conversational reciprocity, empathy, insight into social relationships, and special interests.
- Toddler Module- Children between 12 and 30 months of age who do not consistently use phrase speech.



Disclosure and Diagnosis

- Person-first language: person before the disability or the condition, and emphasizes the value and worth of the individual by recognizing them as a person instead of a condition.
- Diagnosis: suggests that the person can be separated from autism, which simply isn't true.



References

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