Changes to the DSM-5:
Implications for Diagnostic Identification and Accessing Services relating to Autism Spectrum Disorder and Intellectual Disability

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Presentation objectives / overview

- Introduction: Diagnostic and Statistical Manual (DSM) and the revision
- Review of changes to the diagnostic criteria for Intellectual Disability and Autism Spectrum Disorder
- Rationale for and implication of changes
- Case examples and discussion

Why do we use the DSM?

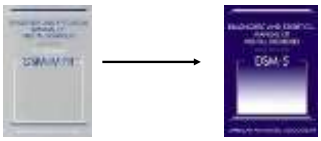
- DSM sets out the diagnostic criteria for mental disorders
  - To ensure that diagnoses are valid and reliable.
- Implications of DSM
  - Effective communication between clinicians of their understanding of the person's difficulties
  - Provision of information to insurance companies
  - Provision of public health statistics to relevant ministries and policy makers
  - Criteria used in research

DSM		Interval (in yrs)
DSM-I	1952	
DSM-II	1968	16
DSM-III	1980	12
DSM-III-R	1987	7
DSM-IV	1994	7
DSM-IV-TR	2000	
DSM-5	2013	19

Why do we keep revising it?

- Diagnoses are based on the consensus i.e. agreement among experts with regard to the existence of a disorder and the required symptoms
- Over time, with increased knowledge from scientific discoveries and research, our understanding of the disorders changes
- As a result of revision
  - Disorder may be removed
  - New disorder may be added
  - Required symptoms may change (type of symptoms & numbers)
  - No change

From DSM-IV-TR to DSM-5



2000 2013

Revision of DSM-IV

Took over 12 years

13 Work Groups and Chairs

Neurodevelopmental Disorders Work Group led by Susan E. Swedo, M.D. revised criteria for Intellectual Disability and ASD

Revision Principles

- Clinical utility
- Recommendations for change should be guided by research evidence
- Where possible, maintain continuity with previous editions of DSM and also International Classification of Diseases (ICD)
- Yet, no *a priori* constraints on the degree of change between DSM-IV and DSM-5

Clinical Utility: Is the DSM-5 diagnosis likely to…

- Increase diagnosis of the condition (DSM-IV too restrictive)?
- Decrease diagnosis of the condition (DSM-IV too diffuse and over-inclusive - e.g., will reduce use of an NOS category)?
- Be clearer and less confusing to clinicians?
- Draw attention to an important clinical condition that may currently go unrecognized or undiagnosed?
- Be more culturally sensitive and inclusive and/or less stigmatizing?

Intellectual Disability
(Intellectual Developmental Disorder)

Intellectual Disability: What changed?

- Classification: linking to brain functioning
  - DSM-IV: Disorders Usually First Diagnosed in Infancy, Childhood, or Adolescence
  - DSM-5: Neurodevelopmental Disorders
- Name
  - DSM-IV: Mental Retardation
  - DSM-5: Intellectual Disability (Intellectual Developmental Disorder)

Intellectual Disability: What changed?

- Less focus on IQ, more focus on adaptive behavior
  - DSM-IV: essential feature: Deficits in intellectual functioning
  - DSM-5: essential feature: Deficits in BOTH cognitive and adaptive functioning
  - DSM-IV: levels of severity based on IQ
  - DSM-5: levels of severity based on adaptive functioning
- Age criterion more loosely defined
- Emphasis on both clinical assessment and standardized testing

Intellectual Disability

Intellectual Disability is a disorder with onset during developmental period that includes both intellectual and adaptive deficits in conceptual, social, and practical domains. The following three criteria must be met:

DSM-5, p.33

Intellectual Disability
diagnostic criteria

DSM-IV-TR	DSM-5
A. Significantly subaverage intellectual functioning: an IQ of approximately 70 or below on *an individually administered IQ test*	**A.** Deficits in intellectual functions, such as reasoning, problem solving, planning, academic learning and learning from experience, and practical understanding *confirmed by both clinical assessment and individualized, standardized intelligence testing*

Intellectual Disability
diagnostic criteria

DSM-IV-TR	DSM-5
B. Concurrent deficits or impairments in present adaptive functioning (i.e., the person's effectiveness in meeting the standards for his/her age by his/her cultural group) in at least two areas: *communication, self-care, home living, social/interpersonal skills, use of community resources, self direction, functional academic skills, work, leisure, health, and safety*	**B.** Deficits in adaptive functioning that result in failure to meet developmental and socio-cultural standards for personal independence and social responsibility. Without ongoing support, the adaptive deficits limit functioning in one or more activities of daily life, *such as communication, social participation, and independent living, across multiple environments, such as home, school, work, and community*

DSM-5: Criterion B - adaptive functioning domains

- **Conceptual (academic) domain**

Memory, language, reading, writing, math, reasoning, practical knowledge, problem solving and judgment in novel situations, among others

- **Social domain**

Awareness of others' thoughts, feelings, and experiences; empathy, interpersonal communication skills, friendship abilities, social judgment, and self-regulation, among others

- **Practical domain**

Learning and self management across life settings, including personal care, job responsibilities, money management, recreation, managing one's behavior, and organizing school and work tasks, among others

Intellectual Disability
diagnostic criteria

DSM-IV-TR

C. The onset is before age 18 years

DSM-5

C. Onset of intellectual and adaptive deficits during the developmental period

Severity levels in DSM-IV

- Subtypes/ Severity levels based on IQ impairments

- Mild Mental Retardation IQ level 50-55 - 69
- Moderate Mental Retardation IQ level 35-40 - 54
- Severe Mental Retardation IQ level 25-30 - 39
- Profound Mental Retardation IQ level < 25

Severity levels for ID in DSM-5

	Conceptual	Social	Practical
Mild	…somewhat concrete approach to problems and solutions compared with age-mates.	…limited understanding of risk in social situations; social judgment is immature for age…	…may function age-appropriately in personal care. Individuals need some support with complex daily living tasks in comparison to peers...
Moderate			
Severe			
Profound			

Severity levels for ID in DSM-5

	Conceptual	Social	Practical
Mild			
Moderate	…academic skill development typically at an elementary level, and support is required for all use of academic skills in work and personal life…	…social judgment and decision-making abilities are limited…significant social and communicative support is needed in work settings for success…	…can care for personal needs involving eating, dressing, elimination, and hygiene as an adult, although an extended period of teaching and time is needed …
Severe			
Profound			

Severity levels for ID in DSM-5

	Conceptual	Social	Practical
Mild			
Moderate			
Severe	…generally little understanding of written language or of concepts involving number, quantity, time, and money…	Spoken language is quite limited in terms of vocabulary and grammar…	The individual requires support for all activities of daily living, including meals, dressing, bathing, and elimination…
Profound			

Severity levels for ID in DSM-5

	Conceptual	Social	Practical
Mild			
Moderate			
Severe			
Profound	…may use objects in goal directed fashion for self-care, work, and recreation…	…may understand some simple instructions or gestures…expresses own desires and emotions largely through nonverbal, nonsymbolic communication..	The individual is dependent on others for all aspects of daily physical care, health, and safety…

Rationale for Changes

- So IQ score is not the defining factor of a person's overall ability without adequately considering adaptive functioning
  (particularly relevant in forensic cases)
- The assessment across three domains ensures the consideration of the impact of the deficits in general mental abilities on functioning needed for everyday life
- Assessment procedures and diagnosis must take into account factors other than ID that may limit performance
  (e.g., socio-cultural background, native language, associated communication/ language disorder, motor or sensory handicap)
- A single full-scale IQ score is generally less useful in describing intellectual abilities than cognitive profiles

Case example: Kate

- Age 18
- Full Scale IQ 68
  - Areas of abilities in borderline or even higher range: verbal comprehension, perceptual reasoning, processing speed, expressive vocabulary
- Adaptive functioning
  - Academic skills except for math between grade 4.5 – 9 level
  - Personal and community living skills very limited to negligible (age equivalent 4 – 6 years old)
  - Requires high level of support with basic personal self-care (washing, bathing, tooth brushing), home and community safety, social interactions (age equivalent 2 – 3.5 years old)

Questions?

- **AUTISM SPECTRUM DISORDER**

Many 'faces' of Autism: Leo Kanner to DSM-5

Leo Kanner coined 'Autism' in 1943

Hans Asperger 'Autistic Psychopathy' (1943) – 'Asperger Syndrome' (1981) by Lorna Wing

Lorna Wing 'Asperger Syndrome' in 1981 'Triad of deficits'- DSM-III

Judith Gould 'Triad of deficits'- DSM-III

Fred Volkmar DSM-IV lead Asperger Disorder CDD, Rett's Disorder and PDD-NOS

Susan Swedo DSM-5 ASD group lead

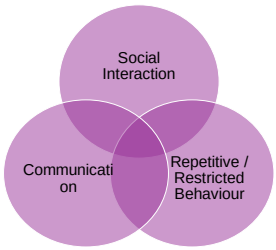
Autism: Leo Kanner to DSM-5

- **Kanner (1943):** Use of the term 'Autism' inadvertently connected this condition with schizophrenia – Kanner didn't mean it to indicate Schizophrenia
- **Hans Asperger (1943)** – Autistic Psychopathy – later, Asperger Disorder
- **DSM-I (1952):** infantile autism / autism was considered an early form of schizophrenia
- **1970-1990s:** Several researchers (Kolvin, Rutter, Wing, Gould) distinguished Autism from Psychosis and formulated diagnostic criteria.
- Autism was conceptualized as a pervasive disorder of development.
- **DSM-III (1980):** Autism was demarcated from schizophrenia
- **DSM-IV (1994) and DSM-IV-TR (2000):** Asperger Disorder, Rett's, CDD, PDD-NOS added
- **DSM-5 (2013)** - "Autism Spectrum Disorders (ASD)"

DSM-IV-TR Pervasive Developmental Disorder

- Autistic Disorder
- Asperger disorder (***New in DSM-IV)***
- Rett's Disorder (***New in DSM-IV)***
- Childhood disintegrative disorder (CDD) ***(New in DSM-IV)***
- PDD-NOS (Pervasive Developmental Disorder – Not Otherwise Specified) ***(New in DSM-IV)***

Autism: Triad of Impairments



DSM-IV-TR criteria for Autism

- Three symptom domains:
  - Social interaction
  - Social communication (verbal and non-verbal)
  - Repetitive, restricted behaviors / interests
- 12 Symptoms in total, 4 per domain
- Required number of Symptoms: 6 or more; Symptoms in each domain, at least 2 in social interaction
- Age of onset before 3

DSM-IV-TR criteria for Autistic Disorder

- **Qualitative impairment in social interaction**
  - Deficient regulation of social interaction through nonverbal behaviors (eye contact, facial expression, body posture, gestures)
  - Failure to develop peer relationships
  - Lack of spontaneous seeking to share enjoyment, interests
  - Lack of social or emotional reciprocity

Current (DSM-IV-TR) criteria for Autistic Disorder

- **Qualitative impairment in communication**
  - Absent or delayed spoken language
  - Immediate & delayed echolalia
  - Repetitive, stereotyped or idiosyncratic language
  - Deficiency in ability to begin or sustain conversation
  - Intonation, volume, rhythm, rate
  - Absence of social imitative or make-believe play

DSM-IV-TR criteria for Autistic Disorder

- **Repetitive, restricted, stereotyped patterns of behaviors, interests & activities**
  - Abnormal (focus or intensity) preoccupation with interests
  - Rigid performance of non-functional routines or rituals
  - Motor mannerisms
  - Persistent preoccupation with parts of objects
- **Onset before age 3**

DSM-IV-TR Asperger Disorder and PDD-NOS

- **Asperger Disorder**:
  - Qualitative impairment in social interaction + Restricted/Repetitive behaviors and interests
  - No significant delay in language, cognitive development, adaptive behaviors.
- **PDD-NOS**:
  - To be used when specific criteria for subcategories are not met.
  - Allows clinicians to make this diagnosis even when symptoms are 'atypical' or 'sub-threshold'; e.g., people presenting only with significant impairment of social interaction and communication will fulfill the criteria of PDD-NOS.

From DSM-IV-TR to DSM-5

DSM-IV	DSM-5
Disorders first diagnosed in Infancy, Childhood or Adolescence	**Neurodevelopmental Disorders**
Pervasive Developmental Disorders	Autism Spectrum Disorder
Autistic Disorder	
Asperger Disorder	
Pervasive Developmental Disorder NOS (PDD-NOS)	
(Childhood Disintegrative Disorder)	Removed
(Rett's Disorder)	

DSM-5: Autism Spectrum Disorder

- **Persistent deficits in social communication & social interaction across contexts, not accounted by general developmental delays, *manifest by ALL***
  - Deficits in social-emotional reciprocity
  - Deficits in nonverbal communicative behaviors used for social interaction
  - Deficits in developing & maintaining relationships (beyond those with caregivers)

DSM-5: Autism Spectrum Disorder

- **Restricted, repetitive patterns of behaviors, interests, and activities** *manifest by at least 2*
  - Stereotyped or repetitive speech, motor movements or use of objects
  - Excessive adherence to routines, ritualized patterns of verbal or non-verbal behaviour, or excessive resistance to change
  - Highly restricted, fixated interests abnormal in intensity or focus
  - Hyper- or hypo-reactivity to sensory input or unusual interest in sensory aspects of environment

DSM-5: Autism Spectrum Disorder

- Symptoms must be present in the 'early developmental period', may not become apparent until social demands exceed limited capacities.
- Symptoms together limit and impair everyday functioning
  - Current severity level (1-3) related to level of support required
- **Specifiers**
  - With or without intellectual impairment
  - With or without language impairment
  - Associated with known medical or genetic condition or environmental factor
  - Associated disorders
  - Catatonia

DSM-5: Autism Spectrum Disorder: Summary of Key Changes

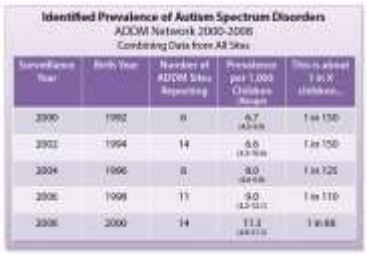
- Replacing three-domain model with two-domain model
  - **Social communication & social interaction**
  - Restricted, repetitive patterns of behaviors, interests, and activities
- Adding symptoms not previously included
  - E.g., sensory interests and aversions, difficulties with change
- Relaxing age of onset
  - Symptoms must be present in early childhood but may not become fully manifest until social demands exceed limited capacities
- Greater proportions of symptoms has to be met (6/12 vs 5/7)

DSM-IV Criteria -Past Imperfect?

- Pervasive Developmental Disorder is a 'misnomer'.
- DSM IV subcategories were not consistently applied across different clinics and treatment centers.
- Over-inclusive: In doubtful situation, individuals were given the 'catch-all' diagnosis PDD-NOS.
- Overuse of PDD-NOS leads to diagnostic confusion (and may have contributed to autism "epidemic")
- Age of onset too specific
- Not developmentally equivalent

Prevalence of ASD

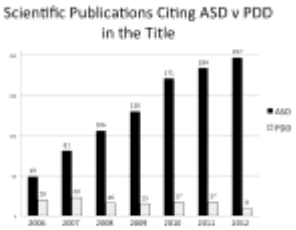
Centers for Disease Control and Prevention, US



Why 'Autism Spectrum'?

- Demarcating 'Autism Spectrum' from 'typical development' is possible, but research has not been able to distinguish different PDD disorder subtypes.
- Rates of PDD subtypes vary widely across sites. Clinicians have NOT been separating subcategories in clinical practice.
- Diagnosis is often associated with severity, language level or IQ, rather than features of disorder. Therefore, DSM-5 has taken a 'dimensional view' of symptoms and focuses on 'shared features' of the Autism Spectrum.
- DSM-5 is consistent in their approach, e.g. Schizophrenia also does not have any subtype in DSM-5

ASD is already preferred term for research



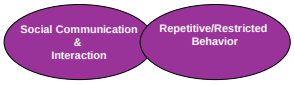
Curtsey: Walter Kaufmann, Department of Neurology, Harvard Medical School

DSM-5: Rationale for Changes

Replacing 3-domain model with 2-domain model

- Deficits in communication are intimately related to social deficits. Research indicates that the two are "manifestations" of a single set of symptoms that are often present in differing contexts.

2-Domain model of DSM-5 ASD



DSM-5: 'Social (Pragmatic) Communication Disorder'

New Diagnostic entity.

People with Social Interaction and Communication difficulties minus Restricted/Repetitive Behavior will get this new diagnosis.

In clinical practice, a group of individuals with DSM –IV PDD-NOS diagnosis is likely to fulfill criteria.

DSM-5: Rationale for Changes

Removal of Rett's Disorder

- ASD behaviors are only prominent in Rett's Disorder patients during brief period during development.
- In DSM-5, ASD are defined by specific sets of behaviors, not etiologies (at present). The cause of Rett is now known to be genetic (mutation in MECP2 gene) so inclusion of Rett can not be justified.
- Patients with Rett's Disorder with 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.

DSM-5: Rationale for Changes

Removal of Childhood Disintegrative Disorder

- Age range and regression were too 'specific'. Research indicates that there is a wide range with regard to timing and nature of loss of skills.
- CDD is a very rare condition so systematic evaluation is difficult
- CDD is different from other ASD with regard to the severity of regression and presence of physical symptoms.
- Most clinicians across the world have not been using this term.

Validity of DSM-5 ASD diagnosis

1. Is their any concern regarding the DSM-5 process?
2. Did DSM-5 group examine 'the new criteria' before making the actual changes?
3. How valid is this new DSM-5 ASD diagnosis?
   - Will the new criteria be able to diagnose all 'true' cases of Autism (sensitivity)?
   - Will the new criteria be able to reduce 'false positive' diagnosis (specificity)?
4. Has any study compared DSM-IV with DSM-5 criteria?

Studies addressing Question 3 & 4 will continue to come. At this point it is too early to make any firm conclusions.

Validity of DSM-5 ASD diagnosis

- General concerns regarding DSM-5 process
  - Concerns regarding the financial conflicts disclosure
  - Concerns with regard to diagnostic inflation

However, DSM-5 applied more rigorous methods for conducting field trials.

Validity of DSM-5 ASD diagnosis

DSM-5 field trials

- First time included kappa statistic (indicator of agreement among expert raters, correcting chance agreement due to high prevalence)
- 2 distinctive designs: A. Large, diverse medical-academic settings (11 North American sites, CAMH was the sole non-U.S. site for adults); B. Routine clinical practices
- Field Trial result indicate good (kappa 0.69) reliability of DSM-5 ASD diagnosis (*Regier et al, Am J Psychiatry, 2013)*

Validity of DSM-5 ASD diagnosis

	Clinical ASD Diagnosis-Sensitivity	Clinical ASD Diagnosis-Specificity
DSM IV TR	0.95	0.86
DSM-5: Field Trial Phase I	0.81	0.97
DSM-5: Relaxed Algorithm (1 less criterion)	0.93	0.95

Results indicate that DSM-5 criteria are valid

This study and 6 other studies also indicate DSM-5 criteria may be 'too stringent'

Frazier et al. Validation of Proposed DSM-5 Criteria for Autism Spectrum Disorder. *JAACAP*, 2012

DSM-5 ASD: Potential Impact on Access to Services

- DSM-5 guide note says everyone with well-established DSM-IV TR diagnosis should get a DSM-5 diagnosis of ASD.
- It is believed that use of a single spectrum of diagnosis will improve access to services.
- Validation research studies indicate that DSM-5 criteria could be more stringent
- There is a legitimate concern that few, especially high functioning cases such as Asperger Disorder, and PDD-NOS may no longer be eligible for services.
- It is likely that some DSM-IV PDD-NOS will get the new DSM-5 diagnosis of 'Social Communication Disorder'

DSM-5 ASD: Potential Impact on Access to Services

- **This study compared diagnostic outcomes for autism spectrum disorders under DSM-IV-TR with the proposed DSM-5 revision (Gibbs et al, JADD, 2012) in 132 children utilizing DSM-5 phase 1 field trial data**
- Of the 111 participants who received an ASD diagnosis under DSM-IV-TR, 26 did not meet DSM-5 criteria.
- The majority of these had received a DSM-IV-TR PDD-NOS diagnosis.

DSM-5 ASD: Potential Impact on Access to Services

Huerta et al, Am J Psychiatry, 2012

- Assessed 4, 453 children (largest data so far) with DSM-IV PDD diagnoses and 690 without; items from assessment instruments (ADOS & ADI-R) matched with DSM-5 criteria. Parent data alone identified 91%
- Results indicate that a substantial majority of individuals with DSM-IV PDD will continue to be eligible for DSM-5 ASD diagnoses.
- DSM-5 criteria were able rule out those without 'PDD' [specificity]
- This study obtained equivalent sensitivity and specificity for DSM-IV and DSM-5 criteria.

DSM-5 ASD: Potential Impact on Access to Services

Interpretation of Existing Studies:

- **It seems likely that majority with DSM-IV PDD will continue to be eligible for services.**
- Only a few (especially PDD-NOS) might miss out, but it remains to be seen if those cases already had false positive diagnoses.
- The impact of the removal of 'Asperger Disorder' label needs further evaluation.

DSM-5 ASD: Potential Impact on Access to Services

Interpretation of Existing Studies: Limitations

- Studies evaluating potential impact of diagnosis used retrospective dataset and tools developed on DSM-IV TR criteria. Therefore, the results may not capture true reality.
- New tools need to be developed incorporating DSM-5 criteria and then future studies should make attempts to prospectively evaluate potential impact .
- **Therefore, at this point, the precise impact of DSM-5 on access to services is not clearly known.**

DSM-5 ASD: A Critique

Progress

- **Clearer symptom description and grouping**
- **Improves reliability of diagnosis**
- **Acknowledged 'spectrum' nature of Autism**

Disappointments

- **Failure to include biological Factors** in the diagnostic criteria, e.g. *Increased head size during pre-school years, Epileptic Seizures, Valproic Acid Exposure during pregnancy*, Genes, etc.
- **Again completely ignored 'special abilities'** that comes with Autism, e.g. Savant Skills, etc.
- **Failure to acknowledge inherent heterogeneity of Autism** – this is crucial for research.

Case example: David

- Age 12
- Mild intellectual disability
- Verbal but communication limited; uses over-learned phrases, comments off topic
- Does not maintain eye contact; limited social smiling, limited facial expression
- Difficulty understanding social games, peer interactions have to be supported by adults
  - taking toys away, disrupting other children
- No imaginative play but play with toys appropriate
- No restricted, repetitive of stereotyped patterns of behaviour
- No sensory issues but high tolerance for pain

Case example: George

- Age 10
- Moderate intellectual disability
- Referred because of ignoring teachers, poor peer interactions
- No friends, not interest in peers
- Preoccupation with bicycles
- Inappropriate incessant questioning
- Poorly modulated eye contact
- Sniffing others
- Early Hx: no social play, no play with toys, banging objects for hours, rocking, whirling around, delayed speech, reversing pronouns, inappropriate emotional responses

Case example: Mathew

- Age 9
- Normal IQ, ADHD
- No friends, gets into difficulties with peers
- Conversations off topic
- Inappropriate emotional responses
- Anxious about weather, lightning
- Many solitary interests (astronomy, computers, maps), none excessive

Questions?

THANK YOU