Formal diagnosis

Redefining autism. Recent developments in diagnostic criteria.

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Introduction

- This talk is about:
  - How medical diagnosis works.
  - The rules diagnosticians use to determine what condition someone has.
- This talk is not about
  - Whether medical professionals ought to be diagnosing autism.
  - Whether autism is a disability or disorder.
  - How to get a diagnosis.

My interest in diagnostics

boxes & sorting + medicine ≈ DIAGNOSTICS

Outline

- Part 1: Diagnosis basics
  - what is diagnosis
  - what diagnosis is for (and what it isn't)
  - biological tests
  - versions of diagnostic criteria
- Part 2: Recent changes
  - change from 'triad' to 'dyad'
  - change name to Autism Spectrum Disorder
  - changes to sub-categories
  - inclusion of sensory processing

Diagnosis basics

Diagnosis

- Best guess as to what is 'wrong' with someone
- Criteria
  - List of characteristics
  - Distinguish one condition from another
  - Apply hierarchy of diagnoses

What is diagnosis for?

- Treatment
- Predicting outcomes
- It also may help with:
  - Access to services
  - Asserting rights
  - Understanding
  - Finding similar people

What diagnosis doesn't do

- Describe everything about a person
- Describe everything about a condition or what it is like to live with it
- Label aspects of people that don't cause problems or need special consideration

Why don't we use biological tests to diagnose autism?

- Autism is a syndrome, a collection of symptoms, not a disease, a specific biological process that causes a specific outcome.
- Many different 'autisms' we are calling one name.
- Many genes involved.
- Biological markers (e.g. metabolic proteins) are not specific to autism.

Versions of diagnostic criteria

- Diagnostic and Statistical Manual of Mental Disorders (DSM)
- International Classification of Diseases (ICD)
- Gillberg's Asperger's criteria
  - Includes coordination problems
- Wing's 'triad of impairments'
  - Includes deficits in 'social imagination'

Main diagnostic manuals

	DSM	ICD
Full name	Diagnostic and Statistical Manual of Mental Disorders	International Classification of Diseases
Publisher	American Psychiatric Association	World Health Organisation
Edition	DSM-5 2013	ICD-10 1992, ICD-11 2018?
Region	Mainly English speaking countries, also others	International
Approach	Starts from specific criteria	Starts from clinical picture and derives specific (research) criteria later

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Reason

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Good

Recent changes

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Bad

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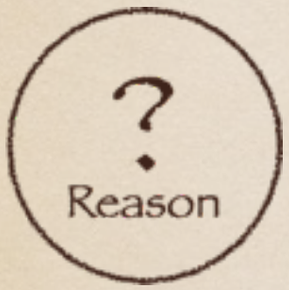
Effects

Recent and upcoming changes

Change	DSM	ICD
From triad of impairments to dyad	Yes	Yes
Re-named 'Autism Spectrum Disorder' without named subtypes (e.g. Asperger's)	Yes	Yes
Sub-categorisation	Severity	Intellectual & language ability
Added sensory behaviours	Yes	No

Change from 'triad' to 'dyad'

(DSM & ICD)



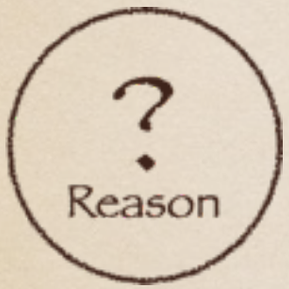
- Better understanding of autistic communication.
- Some have language impairments but ALL have social communication impairments (differences).

- Reflects true inheritance patterns as social and repetitive behaviour aspects are inherited separately.
- Easier identification of verbal autistics.

- May diminish importance of communication impairments
- Does not include impairment in 'social imagination'

- Giving nearly equal weight to social and rigid/repetitive characteristics good for some, bad for others

Re-naming of autism and subtypes (DSM & ICD)



- Research has shown no meaningful difference between high functioning autism and Asperger Syndrome.

- More clarity that Asperger's is autism.
- Rett Syndrome removed as its genetic basis is now known.

- Asperger's no longer a distinct condition.
- Concerned that needs will be misjudged.
- Some sub-classification with dubious basis retained.

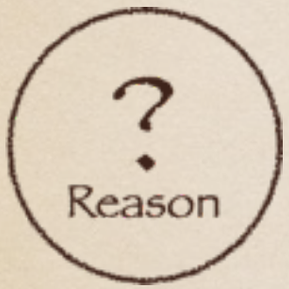
- People who have a diagnosis of Asperger's do not need to be re-diagnosed.

Categories in ICD-11

		Intellectual disability	
		Without (-)	with (+)
Functional language	Mild or no impairment	(was Asperger's)	
	Impaired		
	Absent	?	

Speech & intellectual function categories

(ICD, 'severity' in DSM)



- Deeply-held belief that language and intellectual abilities are very important in autism.

- Disassociates speech and intellect function.
- Explicitly allows for unimpaired speech and intellect (formerly HFA/AS).

- Central place of language not supported by research.
- No impairment of intellectual function and no language?
- Doesn't help with difficulty defining boundaries.

- Hard to predict impact as it's not clear how much these specifiers will be used.

Added unusual sensory behaviour (DSM)

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Reason

- The experiences of autistic people and families said that sensory issues were an essential part of autism and often one of the most disabling.

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Good

- Better reflection of autistic experience.

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Bad

- Not universal or specific to ASD.
- Comes under 'repetitive behaviour' criterion when it's not necessarily repetitive or focussed.

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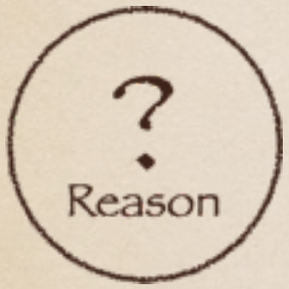
Effects

- Sensory sensitivity may be considered 'behaviour' to be changed.
- A little easier to meet rigid/repetitive criteria.

Introduction of Social Communication Disorder (DSM)



- Just the communication part of the ASD dyad.
- Diagnosed as 'Semantic Pragmatic Disorder', especially in the USA.

- Allows those who have significant social impairment but not rigid or repetitive behaviour to have a diagnosis.

- Questionable whether this should be a language disorder (as it is categorised) or autism spectrum disorder.

- May interfere or distract from ASD diagnosis for some autistic people.

Other Changes

- Recognition that difficulties "may not become fully manifest until social demands exceed limited capacities." (DSM & ICD)
- No longer strictly in all settings. (ICD)
- Improved language, e.g. 'persistent deficits' rather than 'abnormal functioning' and 'psychopathology'. (ICD)
- Recognition of range of presentations for each criterion and that examples are only examples. (DSM)
- No longer excludes ADHD. (DSM)

Conclusion

Room for improvement?

- Variations to reflect age or gender differences
- Recognition of non-linear severity of impairment
- Removal of speech as all-important
- Removal of intelligence as all-important
- There is communication-only 'Social Communication Disorder', what about rigid/repetitive only? The best fit now is a Personality Disorder.

Summary

- Diagnostic criteria are to distinguish one condition from another.
- The DSM and ICD approach things differently, but international research forces them to work on compatibility.
- Re-named 'Autism Spectrum Disorder' - no more separate 'Asperger's' diagnosis.
- Sub-categories are controversial and boundaries difficult to define.
- Both DSM and ICD have made some improvements.
- Both have done some things that don't make sense.