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

<table>
<thead>
<tr>
<th></th>
<th>DSM</th>
<th>ICD</th>
</tr>
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<tbody>
<tr>
<td><strong>Full name</strong></td>
<td>Diagnostic and Statistical Manual of Mental Disorders</td>
<td>International Classification of Diseases</td>
</tr>
<tr>
<td><strong>Publisher</strong></td>
<td>American Psychiatric Association</td>
<td>World Health Organisation</td>
</tr>
<tr>
<td><strong>Region</strong></td>
<td>Mainly English speaking countries, also others</td>
<td>International</td>
</tr>
<tr>
<td><strong>Approach</strong></td>
<td>Starts from specific criteria</td>
<td>Starts from clinical picture and derives specific (research) criteria later</td>
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Recent changes

Reason

Good

Bad

Effects
## Recent and upcoming changes

<table>
<thead>
<tr>
<th>Change</th>
<th>DSM</th>
<th>ICD</th>
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<tbody>
<tr>
<td>From triad of impairments to dyad</td>
<td>Yes</td>
<td>Yes</td>
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<tr>
<td>Re-named ‘Autism Spectrum Disorder’ without named subtypes (e.g. Asperger’s)</td>
<td>Yes</td>
<td>Yes</td>
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<tr>
<td>Sub-categorisation</td>
<td>Severity</td>
<td>Intellectual &amp; language ability</td>
</tr>
<tr>
<td>Added sensory behaviours</td>
<td>Yes</td>
<td>No</td>
</tr>
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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

<table>
<thead>
<tr>
<th>Functional language</th>
<th>Intellectual disability</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mild or no impairment</td>
<td>Without (-)</td>
</tr>
<tr>
<td>Impaired</td>
<td>(was Asperger’s)</td>
</tr>
<tr>
<td>Absent</td>
<td>with (+)</td>
</tr>
<tr>
<td></td>
<td>?</td>
</tr>
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</table>
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)

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

- Better reflection of autistic experience.

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

- 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.