What is Autism?
And how it’s suddenly all about to change

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Plan

• Introduce you to changes in Autism Spectrum Disorder (ASD)
• Describe our current understanding of ASD
• Current research on impact of change to criteria
• Our research on proposed changes
• Frequently asked questions about changes
• Introduce you to research interests at Flinders
Pervasive Developmental Disorders

- Complex neurodevelopmental disorder(s)
- Born with it
- Lifelong
- Developmental
- Neurological
- 1:160 people are diagnosed with ASD
- Boys : Girls 4:1 Autistic Disorder
- 8:1 Asperger’s disorder
Diagnostic Statistical Manual of Mental Disorders

DSM-IV:

Definition of Autism / PDD

- Impairment in Socialisation
- Impairment in Communication
- Restricted & Repetitive Behaviour
PERVASIVE DEVELOPMENTAL DISORDERS

- Rett Syndrome
- Childhood Disintegrative Disorder
- Autistic Disorder
- Asperger’s Disorder
- PDD-NOS

Abbreviation: PDD-NOS, pervasive developmental disorder-not otherwise specified.
Gradual Changes in Thinking

- Kanner 1943 - autism seen as a discrete disorder
- Gillberg (1991) proposed that autism was on a spectrum some
- 1994 Asperger’s disorder introduced to DSM-IV
- Gillberg (2010) proposed that autism is “hundreds of spectra”
- 2013 DSM-5 proposed Autism Spectrum Disorder
Proposed Changes

PERVASIVE DEVELOPMENTAL DISORDERS

Rett Syndrome
Childhood Disintegrative Disorder
Autistic Disorder
Asperger’s Disorder
PDD-NOS

Autism Spectrum Disorder

More Severe

Less Severe

Abbreviation: PDD-NOS, pervasive developmental disorder-not otherwise specified.
Changes

• The triad of impairments will be reduced to two main areas:
  – Social and communication
  – Ritualistic and repetitive behaviours
• Sensory behaviours will be included
• Emphasis on needs of the individual rather than and how these affect their life.
• Redefining age of onset as “early childhood”
## Severity Level for ASD

<table>
<thead>
<tr>
<th>Level</th>
<th>Support Requirement</th>
</tr>
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<tbody>
<tr>
<td>Level 1</td>
<td>Requiring support</td>
</tr>
<tr>
<td>Level 2</td>
<td>Requiring substantial support</td>
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<tr>
<td>Level 3</td>
<td>Requiring very substantial support</td>
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</tbody>
</table>
Rationale for Change

• Debate as to whether separate conditions

• Evidence to date suggests that these subtypes with same underlying condition or aetiology

• Failure to demonstrate a clear distinction between AS and AD with many children meeting criteria for both

• High concurrence rate of AS and AD in the one family
Proposed Criteria

A. Persistent deficits in **social communication** and **social interaction** across contexts, not accounted for by general developmental delays, and manifest by all three of the following:

1. Deficits in social-emotional reciprocity
2. Deficits in nonverbal communicative behaviors used for social interaction
3. Deficits in developing and maintaining relationships, appropriate to developmental level (beyond those with caregivers)
Proposed Criteria

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

1. Stereotyped or repetitive speech, motor movements, or use of objects
2. Excessive adherence to routines, ritualized patterns of verbal or nonverbal behavior, or excessive resistance to change
3. Highly restricted, fixated interests that are abnormal in intensity or focus
4. Hyper- or hypo-reactivity to sensory input or unusual interest in sensory aspects of environment
Proposed Criteria

C. Symptoms must be present in early childhood (but may not become fully manifest until social demands exceed limited capacities)

D. Symptoms together limit and impair everyday functioning.
Summary of Changes

(A) DSM IV:
- Pervasive Developmental Disorders: Autism
  - Social Impairment
  - Autism
  - Speech/Communication Deficits and Language Delay
  - Repetitive Behaviors & Restricted Interests

(B) DSM5:
- Autism Spectrum Disorders
  - Social Communication
  - Restricted & Fixated Interests
New Diagnosis Proposed?

- Social and Communication disorder
  - Capture people who only have the social and communication issues.
  - Argued that these people usually do have restricted or repetitive behaviours and interests, but have been able to mask them.
  - Therefore debated that this group is a sub-group of people on the autism spectrum.
FAQ Related to Change

Q: Will this change my diagnosis?
A: No – current diagnoses will stand

Q: Does this mean Asperger syndrome won’t exist anymore?
A: May be phased out

Q: Will these criteria be used to make diagnoses?
A: Yes - newly diagnosed may fail to meet criteria
Will this mean that fewer people will be diagnosed with ASD?

- To date, only a few studies have looked at the validity of the proposed DSM-5 criteria.
- General consensus from these studies is that the new criteria have high specificity but this may have come at a cost of sensitivity.
  - Worley and Matson (2012) found many of those currently diagnosed with PDD did not meet DSM-5 criteria.
  - Mandy, Charman and Skuse (2012) high functioning missed out.
  - Requiring individuals to meet one less criterion in each of the two domains increased the identification of ASD by as much as 11-12%.
Young and Rodi (under review) found:

- Of the 210 participants diagnosed with a PDD (AD, AS or PDD-NOS) using the DSM-IV-TR criteria, only 120 (57.1%) met the proposed DSM-5 criteria.
- None of the 23 participants who did not meet criteria for a PDD using the DSM-IV-TR met the proposed DSM-5 criteria.
- No significant relationship between gender and age meeting the overall DSM-5 criteria.
Diagnosis and New Criteria

- No person with PDD-NOS met DSM-5
- PDD group membership predicted whether an individual met the social-communication criteria
  - 90% of those with PDD-NOS did not meet criteria in this domain
  - 38.6% of those with AS did not meet these criteria
  - 23.6% of those with AD did not meet these criteria
- PDD group membership also predicted whether an individual met the repetitive-ritualistic domain
  - 50% of those with PDD-NOS not meeting the domain
  - 11.4% of those with AS
  - 2.6% of those with AD
Conclusion

- Large portion will no longer be recognized as having an ASD using the new criteria
- May be that the old criteria were over inclusive or led to misdiagnosis
- However, given a large percentage from all three groups met the DSM-5 repetitive-ritualistic domain criteria (i.e., 50% PDD-NOS, 88.7% AS) suggest on spectrum
- May need to educate us better in applying criteria
- May need to reduce requirements
Current Research Interests at Flinders

- Validation of the ADEC (Young, 2007)
- Validation of SPECTRA (Young, Partington and Goren, 2009)
- ASD in Females
- Development of adult diagnostic tools e.g., A-ToM
- Research into factors that may make one vulnerable to criminal involvement whether victim or perpetrator
Questions?
Is Autism Genetic?

- Complex, yet strong genetic factors influencing
- Strongest evidence from twin studies with 60% of monozygotic twins concordant for full syndrome; 90% for related social or cognitive abnormalities
- Risk of any form of PDD for sibling of proband with autism as high as 5%
- Relatives may be affected by difficulties that are conceptually related to autistic behaviors (broader autistic phenotype)
Is Autism caused by vaccinations?

- Currently no evidence to support a relationship between vaccines and autism
- Retraction of *Lancet* article
- Families still “caught in the middle” between research and media
Is Autism on the Rise?

*Recent research has indicated that changes in diagnostic practices may account for at least 25% of the increase in prevalence over time, however much of the increase is still unaccounted for and may be influenced by environmental factors.*
What will happen with the NDIS / Disability Care Australia?

- Ms Macklin recently confirmed the scheme would support "most" people with autism.
- Stressed the government will work with people to identify their individual needs.
- FaHCSIA currently $6000 a year for two years.
- Ms Macklin said that where an early intervention therapy is deemed "reasonable and necessary" Disability Care would be able to fund its full cost.
- Funding applied behaviour analysis therapy could cost the scheme more than $300 million a year once it is fully operational.
- Ms Macklin said Disability Care would over time replace the autism program, but no family would see their level of support reduced.
What is the Prognosis?

• Previous studies summarized:
  – 10–15% with good outcomes
  – 15–25% with fair outcomes
  – 15–25% with poor outcomes
  – 30–50% with very poor outcomes

• Few current longitudinal studies exist

• Issues of diagnostic “shift,” diagnostic stability