AUTISM SPECTRUM DISORDERS IN MIDDLE TO LATE ADULTHOOD

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• Autism is a neuro-developmental disorder

• Defined by behaviour
  • Social interaction is difficult
  • Atypical social use of language
  • Restricted, repetitive, and stereotyped behaviours
AUTISM IN ADULTS

AUTISM IS A LIFELONG CONDITION
AUTISM IS A LIFELONG CONDITION

• Originally described as a childhood disorder

• Recent studies have confirmed autism is a lifelong condition

• However, does the condition differ across the lifespan?
**PREVALENCE OF ASD IN ADULTS**

- Brugha et al., 2011.

- First study to compare ASD prevalence across age groups in a community sample

- Comparable rates to children

<table>
<thead>
<tr>
<th>AGE</th>
<th>WITH ASD</th>
</tr>
</thead>
<tbody>
<tr>
<td>16-44</td>
<td>1.1%</td>
</tr>
<tr>
<td>45-74</td>
<td>0.9%</td>
</tr>
<tr>
<td>75+</td>
<td>0.8%</td>
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ESTIMATING PREVALENCE

• ABS
  • Estimates unreliable for adults 30+
  • Too few were identified
• WA Health Department Data Linkage
  • Small numbers identified.
  • Issue of known prevalence vs true prevalence
AUTISM IN ADULTS

• LESS THAN 5% OF ADULTS WITH ASD IN THE UK HAVE A DIAGNOSIS
• NO FIGURES FOR AUSTRALIA
HOW IS AUTISM DIFFERENT IN ADULTS

- Little is known about adults with ASD
- Few studies have focused on older adults
- Trajectory of ASD is unknown beyond early adulthood
- 50-75% of people with AD have intellectual disability *
- Symptomatology based on childhood

AUTISM IN ADULTS: ISSUES

• Diagnostic issues
  • Lack of appropriate instruments
• Influence of ageing: coping and learning
• No adult specific interventions
• Are these factors biasing our samples?
WHY IS IT DIFFICULT TO STUDY OLDER ADULTS WITH ASD?

• Lack of a suitable informant
  • No living parent
  • Getting parents to contribute to improving a system that has let them down
  • Reliability of memories sometimes 50+ years old
  • Confirming a diagnosis without childhood information
AUTISM IN ADULTS
CURRENT RESEARCH
AUTISM IN MIDDLE TO LATE ADULTHOOD

• Multi-centre study

• University of North Carolina

• University of Wisconsin

• University of Miami

• University of Western Australia

• 20+ participants per site

• Battery of assessments
WESTERN AUSTRALIAN PERSPECTIVE

• 40 participants over 40 years of age recruited

• Assistance from Disability Services Commission, Autism Clinic at Fremantle Hospital, Autism Association of Western Australia

• Majority of sample have some degree of intellectual disability

• Many had no formal diagnosis of ASD
EARLY FINDINGS

• Some social skills appear to improve in a subset of individuals

• The core autistic symptoms remain largely consistent with age, but improve in some

• Rate of behavioural problems is high

• Links with other health issues, epilepsy and Parkinsonism
COST OF AUTISM

• Australian Data
  – Total annual cost ~ $5.8 billion
  – Average incremental cost ~ $56,000

• Medical expenditure
  – 6x greater for children with ASD than non-ASD controls
  – 2.7x greater than ASD alone when comorbidity (ID, ADHD, Epilepsy) present

• Cost of adult care is the greatest lifetime expenditure

• Investing in AS will outweigh public expenditure

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