Successful Ageing for People with Intellectual Disability

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This talk aims to:

1. engage the audience in a deeper understanding of the epidemiology and presentation of age related disorders including the dementias in people with an intellectual disability (ID)
2. examine the possible explanations for the over-representation of dementia in this population group
3. examine the application of the concept of ‘successful ageing’ in people with an intellectual disability and
4. propose positive steps which can be taken to improve health and well-being in older people with an ID.
Outline

• Intellectual Disability (ID)
• ID and Ageing
• ID and Dementia
• Successful Ageing in ID
  – Aspirational goal
  – What is successful ageing?
  – Successful ageing: what does it look like for people with an ID?
  – Successful ageing: how do we get there?
• Overview of the some work in ageing and dementia in people with ID
• Conclusions
What is Intellectual Disability?

- Disorder with onset in the developmental period
  - Deficits in intellectual functions (Below average intelligence, IQ of <70, ie <2 SD below mean)
  - deficits in adaptive behaviours
  - onset before the age of 18

- Intellectual Developmental Disorder
Some Causes of Intellectual Disability

<table>
<thead>
<tr>
<th>Prenatal</th>
<th>Perinatal</th>
<th>Postnatal</th>
</tr>
</thead>
<tbody>
<tr>
<td>Chromosomal disorders</td>
<td>Intrauterine: placental insufficiency; prematurity; obstetric trauma</td>
<td>Head injury</td>
</tr>
<tr>
<td>Syndrome disorders</td>
<td>Neonatal: intracranial haemorrhage; respiratory distress; head trauma; kernicterus</td>
<td>Infections &amp; post-infectious</td>
</tr>
<tr>
<td>Inborn errors of metabolism</td>
<td></td>
<td>Degenerative disorders</td>
</tr>
<tr>
<td>Developmental brain abnormalities</td>
<td></td>
<td>Seizure disorders</td>
</tr>
<tr>
<td>Environmental factors</td>
<td></td>
<td>Toxic metabolic disorders eg lead poisoning</td>
</tr>
<tr>
<td>eg maternal malnutrition; placental insufficiency; fetal alcohol syndrome; varicella infection; irradiation</td>
<td></td>
<td>Malnutrition</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Environmental deprivation</td>
</tr>
</tbody>
</table>

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Intellectual Disability: Prevalence

- About 1.8% of the population
- About 400,000 Australians
- About 125,000,000 individuals world wide
Mental Health of People with an ID

- People with an intellectual disability experience an over-representation of mental disorders
  - Conservative estimates for adults/children with ID 2.5/3-4x
- At any one time, an estimated 20-40% of people with an ID will be experiencing a mental disorder of some kind.
- Access to mental health supports and treatments is limited
- High impact for people with ID, families and carers
- Complexity
- Multiple vulnerabilities
Ageing: an Important Issue for People with ID

- For the first time, people with ID are living into late life
- Ageing with ID carries specific health implications
- A small decline in cognition can translate to a large decline in function
- Ageing with ID
  - Has an impact on carers
  - Has service and cost implications
Ageing and ID: Increasing Life expectancy

• There is a rapid ageing of the ID population
  – does not extend to the ‘very old’ (cf general population)
  – Life expectancy varies with disorder and level of ID
  – Average life expectancy for Down Syndrome 12 years in the 1940s; over 60 years now
Lack of Ageing Data for Intellectual Disability

- No reliable specific stats available re proportion of dementia sufferers with ID, or on ageing of the ID population
- 105,600 people with ID were living in some form of care accommodation
  - 12,500 (12%) were aged under 65 years,
  - 93,100 (88%) were aged 65 years or over
Down Syndrome & Alzheimer’s Disease

- Dementia in DS 3-4 x that of general population (Strydom et al 2007)
- Dementia in DS
  - ~ 20% of persons with DS aged 45+
  - ~ 50% by 60-70 years
- greater risk of mortality for persons with DS and dementia or cognitive decline (Baird, 1988; Yang, 2002)
Down Syndrome & Alzheimer’s Disease

- majority of mid-life adults with DS have neuropathological changes of AD
Amyloid Hypothesis

• Amyloid deposition is a critical factor in Alzheimer’s disease
• It triggers a complex pathological cascade causing cell destruction and ultimately dementia
Down Syndrome and beta Amyloid

• Gene for amyloid precursor protein (APP) is on chromosome 21
• Individuals with DS have 3 copies of this gene and over-express APP
• Triplication and over-expression of APP may be related to increased risk of AD in adults with DS
Dementia in ID Without Down Syndrome

- Prevalence & incidence figures vary
- Likely 2-3 X general population
  - 13% in those aged 60+ years (Strydom, 2007)
  - 6% in those aged 60+ years (Zigman, 2004)
  - 21.6% in those aged > 65 years (Cooper, 1997)
Why is Dementia More Common?

• Association with Syndromes eg DS

• Interaction of known risk factors with specific types of ID
Why is Dementia More Common?

- Interaction between other health conditions and cognition
Why is Dementia More Common?

• Lifestyle factors
  – Diet
  – Overweight and obesity
  – Lack of exercise
Why is Dementia More Common?

• Cognitive Reserve Hypothesis
Dementia Assessment in ID

- There is no gold standard
- Important things to consider are:
  - Measurement of severity of ID
  - Establishing baseline functioning
  - Reliance on carer reports
  - Structured assessment of cognitive function, tailored to level of ID
  - the ‘bounce’ phenomenon
  - Effect of medical and psychiatric comorbidities
  - Follow-up assessment
GOAL

The Highest Attainable Standard of Health and Wellbeing for Older Persons with an Intellectual or Developmental Disability
Current Status: Services and Supports

Services and supports for people with ID are characterised by:

• Limited age-specific capacity in generic health and disability settings
• Limited availability of specialised ageing services
• Health and disability professionals with limited training in health and ageing in ID
• Lack of consensus about the preferred model, and
• A growing demand for age-related services
Current Status: Health Status and Outcomes

Epidemiological Data
  mental health
  age-related disorders
  physical health

Mortality Data
The Confidential Inquiry into premature deaths of people with intellectual disabilities in the UK: a population-based study
Pauline Heslop, Peter S Blair, Peter Fleming, Matthew Hoghton, Anna Marriott, Lesley Russ *Lancet* 2014; 383: 889–95
### NSW Deaths Data for People in Disability Services

#### Table 30: Cause of death and ICD-10

<table>
<thead>
<tr>
<th>Cause of death</th>
<th>N</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Epilepsy</td>
<td>15</td>
<td>8.06</td>
</tr>
<tr>
<td>Pneumonitis due to solids and liquids</td>
<td>12</td>
<td>6.45</td>
</tr>
<tr>
<td>Cerebral palsy</td>
<td>12</td>
<td>6.45</td>
</tr>
<tr>
<td>Other heart diseases</td>
<td>9</td>
<td>4.84</td>
</tr>
<tr>
<td>Down syndrome</td>
<td>7</td>
<td>3.76</td>
</tr>
<tr>
<td>Cerebrovascular diseases</td>
<td>7</td>
<td>3.76</td>
</tr>
<tr>
<td>Inhalation and ingestion of food caused obstruction of respiratory tract</td>
<td>6</td>
<td>3.23</td>
</tr>
<tr>
<td>Pneumonia</td>
<td>6</td>
<td>3.23</td>
</tr>
<tr>
<td>Ischaemic heart diseases</td>
<td>6</td>
<td>3.23</td>
</tr>
<tr>
<td>Sequelae of transport accidents</td>
<td>5</td>
<td>2.69</td>
</tr>
<tr>
<td>Chronic lower respiratory diseases</td>
<td>5</td>
<td>2.69</td>
</tr>
<tr>
<td>Malignant neoplasm of colon, rectum and anus</td>
<td>5</td>
<td>2.69</td>
</tr>
</tbody>
</table>

Total N = 95

#### Table 9: Top 10 leading causes of death in 2010 and 2011 for people in disability services

<table>
<thead>
<tr>
<th>Underlying cause of death</th>
<th>N</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Epilepsy</td>
<td>15</td>
<td>8.06</td>
</tr>
<tr>
<td>Pneumonitis due to solids and liquids</td>
<td>12</td>
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<tr>
<td>Malignant neoplasm of colon, rectum and anus</td>
<td>5</td>
<td>2.69</td>
</tr>
</tbody>
</table>

Total top 10 underlying causes in disability services = 95

Average Crude Mortality Rate 2002-2010

<table>
<thead>
<tr>
<th>NSW deaths</th>
<th>Average Crude Mortality Rate 2002-2010</th>
</tr>
</thead>
<tbody>
<tr>
<td>54</td>
<td>0.012</td>
</tr>
<tr>
<td>35</td>
<td>0.003</td>
</tr>
<tr>
<td>35</td>
<td>0.058</td>
</tr>
<tr>
<td>56</td>
<td>1.191</td>
</tr>
<tr>
<td>56</td>
<td>0.003</td>
</tr>
<tr>
<td>77</td>
<td>0.126</td>
</tr>
<tr>
<td>77</td>
<td>0.385</td>
</tr>
<tr>
<td>98</td>
<td>0.289</td>
</tr>
<tr>
<td>58</td>
<td>0.002</td>
</tr>
</tbody>
</table>
Our Own Data
What is Successful Ageing?

- ‘objective’- Rowe and Kahn’s (1987)
  - absence of disease
  - engagement in life
  - intact physical and cognitive functions

- ‘subjective’ (Diener et al., 1985)
  - well-being approach

For some, the difference between these 2 is substantial
Successful Ageing in the General Population

• ‘Objective’
  – large population based studies (Hank, 2011; McLaughlin et al., 2010)
    o 8.5% of people aged 50 years and over across 15 European countries were successfully ageing;
    o 11.9% in the USA.

• ‘Subjective’
  – 50.3% of people aged 65-99 ‘ageing successfully’, only 18.8% met objective criteria (Strawbridge et al. 2002)
  – 92% of people aged 60+ ‘ageing successfully’, only 5% met objective criteria. (Montross et al. 2006)
Successful Ageing in Intellectual Disability
Successful ageing in people with an ID: - absence of disease

Current Situation
• Health conditions associated with ID
  – Specific
  – Non-specific
• Health conditions as complications of treatment
• Health conditions arising from risks and misadventure associated with ID

What it should look like
• Health conditions associated with ID
  – optimally managed, disability minimised
• Minimal complications of treatment
• Mitigating risks and misadventure associated with ID
Successful ageing in people with an ID:
- engagement in life

Current Situation
• Numerous barriers
• Magnified with age

What it should look like
• Maximised opportunity for choice
• Full access to appropriate supports
• Every possibility of participating in the community
• “a participating life”
• A valued elder
Successful aging in people with an ID:
- **intact physical and cognitive functions**

**Current Situation**
- Some individuals have lifelong physical disability
- Cognitive dysfunction
- Higher rates of cognitive decline and dementia

**What it should look like**
- Preventative health
- Mitigating the effect of age on exacerbation of long-term physical disability
- Addressing risks factors for cognitive dysfunction
- Screening for cognitive decline
- Access to skilled assessment and management in situations where cognition declines
- Cohesive array of supports
Successful ageing in people with an ID- how do we get there?
The following slides have been adapted from:
Three Key Goals

1. To understand how ageing affects people with an intellectual disability and their carers

2. To develop and refine suitable models of care and support for people with ID and their carers as they age

3. Disability and health professionals who provide quality services in the prevention, assessment & management of health conditions associated with ageing in people with an ID
Goal: To understand how ageing affects people with an intellectual disability and their carers

**What’s needed?**

- Large scale longitudinal studies of ageing adults with an intellectual disability and their carers which establish:
  - the prevalence of psychiatric disorders, cognitive disorders (including mild cognitive impairment & dementia) and physical disorders
  - change in psychiatric, cognitive and physical health status over time
  - modifiable risk factors for cognitive and physical decline
  - reliability and validity of screening and assessment instruments
  - the impact of aging on family caregivers, service use

- With translational components which:
  - Develop national and state policy frameworks
  - develop prevention strategies
  - develop and support the implementation of screening in primary care and skilled assessment in specialist services
  - develop management guidelines
  - develop consumer and carer resources
Goal: To develop and refine suitable models of care and support for people with ID and their carers as they age

What’s Needed?

• Development and evaluation of models of care, with appropriate consultation
• An understanding of the perspective of the person with ID and the family on the preferred service models, and workforce attributes
• Economic modelling:
  – cost/benefit associated with differing models of care
  – of supporting family carers
  – specific disorders incl MCI and dementia
  – Prevention, screening, and intervention.
Goal: Disability and health professionals who provide quality services in the prevention, assessment & management of health conditions associated with ageing in people with an ID

**What’s Needed?**

- A focus on the health of adults with ID at an undergraduate level
- The availability of enhanced material for postgraduate studies in relevant fields and for professional associations
- A health and disability workforce strategy which includes a focus on ageing in ID (vocational training, competency frameworks)
- An enhanced focus on age-related conditions in health screening eg in the CHAP tool
- The development of specialist models of practice in health and disability fields with a focus on age-related conditions (geriatricians, psychiatry of old age, behaviour support specialists).
- Education and training in age-related health conditions in ID (an opportunity) for:
  - disability workers
  - health professionals
  - carers and consumers
Many Challenges
Can we agree on whether a dementia or mild cognitive impairment are present?

- Informant history
- Individual’s history (subjective cognitive complaints)
- Compounding effects of mental and physical health problems
- Functional status (IADLs/ADLs): sensitivity to environmental changes, changes in physical status
- Lack of robust cognitive assessment tools
- Interpretation subjective
Preventative measures: physical exercise
Preventative measures: exercising the brain
Preventative measures: enriched social networks and participation
Preventative measures: Good Eating
INSPIRED Study

The INSPIRED Study: Improving Services for Younger Onset Memory and Related Disorders.

FOR PATIENTS AND CARERS

We want to hear from as many different people with memory and related disorders as possible, and from their carers and supporters. Find out how you can share your experiences and contribute to this important study.

FOR PROVIDERS

Help ensure that the INSPIRED study accurately represents the diverse population with younger onset memory and related disorders. You can also participate in a focus group for providers.

About the INSPIRED Study

The INSPIRED study is the first Australia-based prevalence study on younger onset dementia. Our goal is to determine the needs, barriers and facilitators to services for this diverse population and its families.
The Successful Ageing in Intellectual Disability Study (Sage-ID)
SAge ID Aims

• Conduct a comprehensive investigation of the predictors and correlates of healthy ageing, and physical and cognitive decline in people with ID.
  – Prevalence of dementia and age specific mental disorders
  – Level of cognitive reserve
  – Investigate met and unmet mental health problems
  – Model pathways to mental health care
  – Investigate mental health needs and service use of family carers and carer burden
SAge ID Study Population

- Men and women aged 40 years and over
- With intellectual disability, any functional level

- Locations:
  - NSW
    - Metro Sydney
    - Metro and Rural Illawarra
  - Victoria
    - Rural Bendigo
Sage ID Methodology

- Methodology: mixed methods
- Analysis: SPSS, Interpretative phenomenological analysis
- Dissemination:
  - papers
  - Conferences, newsletters
  - Time1 report

People with ID:
- Questionnaires, Assessments, Blood Tests, MRI scans, Dysmorphology

Carers:
- Questionnaires & Focus Groups

Professionals:
- Focus Groups
SAge ID Procedures

• Participant with ID:
  – Questionnaire – completed by main paid/family carer
  – Cognitive & Physical assessment – completed with person with ID (NSW)

• Family Carers:
  – Questionnaire
  – Focus Groups (NSW)
  – Semi-structured Interview (Vic)

• Professionals
  – Focus groups (NSW)
Sage ID Measures 1

<table>
<thead>
<tr>
<th>Domain(s) Measured</th>
<th>Instrument Name</th>
<th>Reference</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Questionnaire completed by main carer about the person with ID</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Behaviour problems and psychiatric status</td>
<td>Developmental Behaviour Checklist for Adults (DBC)</td>
<td>Mohr, Tonge, Einfeld, &amp; Gray (2005)</td>
</tr>
<tr>
<td>Sleep</td>
<td>Basic Nordic Sleep Questionnaire</td>
<td>Partinen &amp; Gislason (1995) Epworth Adapted</td>
</tr>
<tr>
<td>Health and care service use</td>
<td>Client Service Receipt Inventory (CSRI)</td>
<td>Beecham &amp; Knapp (2001)</td>
</tr>
<tr>
<td>Significant Life Events</td>
<td>PAS-ADD checklist</td>
<td>Moss et al. (1998)</td>
</tr>
<tr>
<td></td>
<td>Down' Syndrome (CAMDEX)</td>
<td></td>
</tr>
</tbody>
</table>
## Sage ID Measures 2

<table>
<thead>
<tr>
<th>Domain(s) Measured</th>
<th>Instrument Name</th>
<th>Reference</th>
</tr>
</thead>
<tbody>
<tr>
<td>Dementia screening</td>
<td>Dementia Questionnaire for People with Intellectual Disabilities (DLD)</td>
<td><em>Evenhuis, Kengen &amp; Eurlings</em> (2006)</td>
</tr>
<tr>
<td></td>
<td>Dementia Screening Questionnaire for Individual with Intellectual Disability (DSQIID)</td>
<td><em>Deb, Hare, Prior &amp; Bhaumik</em> (2007)</td>
</tr>
<tr>
<td></td>
<td>Adaptive Behaviour Dementia Questionnaire (ABDQ)</td>
<td><em>Prasher, Farooq &amp; Holder, 2004</em></td>
</tr>
<tr>
<td></td>
<td>Cambridge Examination for Mental Disorders of Older People with Down' Syndrome (CAMDEX)</td>
<td><em>Ball, Holland, Huppert, Treppner &amp; Dodd</em> (2006)</td>
</tr>
</tbody>
</table>

*Pink – Family carer
Blue – Paid Carer*
<table>
<thead>
<tr>
<th>Domain(s) Measured</th>
<th>Instrument Name</th>
<th>Reference</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cognitive and functional level of ID</td>
<td>Peabody Picture Vocabulary Test (PPVT)</td>
<td>Dunn &amp; Dunn (2007)</td>
</tr>
<tr>
<td>Motor function, language, comprehension, delayed memory, (TSI)</td>
<td>Test of Severe Impairement</td>
<td>Albert &amp; Cohen (1992)</td>
</tr>
<tr>
<td>General knowledge and conceptualisation</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Memory encoding, recall and retrieval</td>
<td>Cued Recall Test (CRT)</td>
<td>Buschke (1984), Grober &amp; Buschke (1987)</td>
</tr>
<tr>
<td>Executive function - planning and working memory</td>
<td>Scrambled Boxes Test (SBT)</td>
<td>Adapted from Griffith et al. (1999), Ball et al. (2008)</td>
</tr>
<tr>
<td>Dementia-related cognitive skills: Neuropsychitric Assessment of memory, orientation, language and praxis</td>
<td>Dementia in Individuals with ID (NAID)</td>
<td>Oliver, Crayton, Holland, Hall, &amp; Bradbury (1998)</td>
</tr>
</tbody>
</table>
# SAge ID Wave 1

<table>
<thead>
<tr>
<th></th>
<th>Male (N=64)</th>
<th>Female (N=57)</th>
<th>Total (N=121)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Mean Age (years)</strong></td>
<td>48.7</td>
<td>50.3</td>
<td>51.2</td>
</tr>
<tr>
<td><strong>Marital Status</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Married</td>
<td>0%</td>
<td>3.4%</td>
<td>1.6%</td>
</tr>
<tr>
<td>Single</td>
<td>98.4%</td>
<td>91.4%</td>
<td>95.1%</td>
</tr>
<tr>
<td>Divorced</td>
<td>1.6%</td>
<td>1.7%</td>
<td>1.6%</td>
</tr>
<tr>
<td><strong>Location</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>NSW (Sydney)</td>
<td>45.3%</td>
<td>46.6%</td>
<td>45.9%</td>
</tr>
<tr>
<td>NSW (Illawarra)</td>
<td>35.9%</td>
<td>27.6%</td>
<td>32%</td>
</tr>
<tr>
<td>Victoria</td>
<td>19.8%</td>
<td>25.9%</td>
<td>22.1%</td>
</tr>
<tr>
<td><strong>Living situation</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Home w/family</td>
<td>10.9%</td>
<td>6.9%</td>
<td>9%</td>
</tr>
<tr>
<td>Small residential</td>
<td>50%</td>
<td>41.4%</td>
<td>45.9%</td>
</tr>
<tr>
<td>Large residential</td>
<td>20.3%</td>
<td>20.7%</td>
<td>20.5%</td>
</tr>
<tr>
<td>Independently</td>
<td>7 (6%)</td>
<td>13.8%</td>
<td>12.3%</td>
</tr>
<tr>
<td>Aged care facility</td>
<td>0</td>
<td>6.9%</td>
<td>4.9%</td>
</tr>
<tr>
<td><strong>Currently have a job (paid/voluntary)</strong></td>
<td></td>
<td></td>
<td>55.3%</td>
</tr>
</tbody>
</table>
### Sage ID Physical health:

<table>
<thead>
<tr>
<th>Condition</th>
<th>% of sample</th>
</tr>
</thead>
<tbody>
<tr>
<td>BMI: overweight +</td>
<td>75%</td>
</tr>
<tr>
<td>1 or more Stroke</td>
<td>4.1%</td>
</tr>
<tr>
<td>High blood pressure</td>
<td>26.2% (13.1% on meds)</td>
</tr>
<tr>
<td>Cholesterol</td>
<td>25.4% (12.3% on meds)</td>
</tr>
<tr>
<td>Diabetes</td>
<td>19.6%</td>
</tr>
<tr>
<td>Thyroid disease</td>
<td>12.3% ; 10.7% hypo 1.6% hyper</td>
</tr>
<tr>
<td>Epilepsy</td>
<td>36% (30.3% meds)</td>
</tr>
<tr>
<td>History of contact with psychiatrist/psychologist</td>
<td>48%</td>
</tr>
<tr>
<td>Impaired sight</td>
<td>27.7%</td>
</tr>
<tr>
<td>Physical disability</td>
<td>36% (13% confined to wheelchair)</td>
</tr>
<tr>
<td>Developmental Disorder</td>
<td>15% (Autism/ASD/Aspergers)</td>
</tr>
</tbody>
</table>
Sage ID CNS Medications - Summary

- 62% on at least one CNS acting medication
- Significant predictors of CNS medication:
  - diagnosis of psychiatric and/or neurological disorder
  - not age, gender, DBC-A
- Anti-convulsants and antipsychotics most commonly used classes
- Documented indications for CNS medication usage were low with no reported indication for:
  - 75% of people treated with movement disorder medications
  - 67% of people treated with anti-psychotics
  - 46% of people treated with anti-depressants
CNS medication polypharmacy

- Of those 67 participants on CNS medication:
  - 72% (48) were on more than one
  - 15% (10) were on four or more CNS medications

<table>
<thead>
<tr>
<th>number of CNS meds</th>
<th>n</th>
<th>% of medicated group (n = 67)</th>
<th>% of sample (n = 107)</th>
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<tbody>
<tr>
<td>1</td>
<td>19</td>
<td>28.4</td>
<td>17.8</td>
</tr>
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<td>2</td>
<td>19</td>
<td>28.4</td>
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<tr>
<td>6</td>
<td>1</td>
<td>1.5</td>
<td>0.9</td>
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# SAge ID Carer Questionnaires:

<table>
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<tr>
<th>Domain(s) Measured</th>
<th>Instrument Name</th>
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<tr>
<td><strong>Questionnaire-family carer regarding themselves</strong></td>
<td><strong>Objective Carer Burden</strong></td>
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<tr>
<td><strong>Subjective Carer Burden</strong></td>
<td>Zarit Burden Scale</td>
<td>Zarit, Orr &amp; Zarit (1985)</td>
</tr>
<tr>
<td><strong>Mental and Physical health of family carer</strong></td>
<td>General health Questionnaire 28 (GHQ)</td>
<td>Goldberg (1978)</td>
</tr>
<tr>
<td>Patient Health Questionnaire 9 (PHQ-9)</td>
<td></td>
<td>Kroenke, Spitzer &amp; Williams (2001)</td>
</tr>
<tr>
<td>Short-Form 12 Health Survey (SF-12)</td>
<td></td>
<td>Ware, Kosinski &amp; Keller (1996)</td>
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<tr>
<td><strong>Quality of Life (health related)</strong></td>
<td>Assessment of Quality of Life survey (AQoL)</td>
<td>Richardson, Atherton Day, Peacock &amp; Iezzi (2004)</td>
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<tr>
<td><strong>Social Supports</strong></td>
<td>Social Support Questionnaire 6 (SSQ6)</td>
<td>Sarason, Sarason, Shearin &amp; Pierce (1987)</td>
</tr>
<tr>
<td><strong>Coping responses</strong></td>
<td>Breif COPE</td>
<td>Carver (1997)</td>
</tr>
</tbody>
</table>

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Yellow – Family Carer burden
Carer Focus Group Methodology

• Participants:
  – 19 family carers (13 parents; 5 siblings; 1 family friend)
  – Mean age: 68 years (51-89 years)
  – 14 women, 5 men

• Semi-structured focus groups (2 Sydney, 1 Illawarra)
  – Experience of caring
  – Accessing services
  – Impact of ageing

• Data:
  – 9 hours of audio recordings transcribed
  – Text analysed using Interpretive Phenomenological Analysis (IPA) to identify key themes and build a picture of carer experience
“The lifetime job”: Family carers’ experience of caring for adults with intellectual disability across the lifespan

<table>
<thead>
<tr>
<th>Theme</th>
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<tbody>
<tr>
<td>1. Carer Burden</td>
<td>1.1 Lifetime Job</td>
</tr>
<tr>
<td></td>
<td>1.2 Individual needs</td>
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<td></td>
<td>1.3 Alternate lives</td>
</tr>
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<td></td>
<td>1.4 Acceptance, stigma and discrimination</td>
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<tr>
<td>2. Health and wellbeing</td>
<td>2.1 Psychological distress</td>
</tr>
<tr>
<td></td>
<td>2.2 Coping strategies</td>
</tr>
<tr>
<td></td>
<td>2.3 Physical health</td>
</tr>
<tr>
<td>3. Transitions of care</td>
<td>3.1 Managing change</td>
</tr>
<tr>
<td></td>
<td>3.2 Taking on the caring role</td>
</tr>
<tr>
<td></td>
<td>3.3 Fear of the future</td>
</tr>
<tr>
<td>4. Family relationships</td>
<td>4.1 Parent/child relationships</td>
</tr>
<tr>
<td></td>
<td>4.2 Child/parent relationships</td>
</tr>
<tr>
<td></td>
<td>4.3 Sibling relationships</td>
</tr>
<tr>
<td></td>
<td>4.4 Family dynamics</td>
</tr>
</tbody>
</table>

**It’s just this feeling that it’s all on my shoulders**

“If I can’t talk about it, unfortunately, I drink too much. So, that’s my friend sometimes, as much as I hate to admit it.”

“I couldn’t have looked after her. I couldn’t have her at home. She just had to be looked after.”

“As much as I don’t want to admit it, he did have an effect on the other children.”
Output

- Methodology paper
- CNS Medications
- Family carers’ experience
  - Physical health profile of ID sample
  - Mental health and cognitive decline profile of ID sample
  - Service access of ID sample to health and community services
  - Pathways to services across the lifespan of ID sample/ help-seeking
  - Feasibility of assessing cognitive decline and diagnosing dementia in adults with ID
- Sleep disturbance in adults with ID
- Physical profile of family carers
- Mental health profile and stress coping of family carers
- Family quality of life and social support of family carers
- Utilisation of services by family carers
- Impact of ageing and experiences of disability
Why Sage is important…..

Time 1 data:
• Unique sample, breadth of data collected, rich information on biological & environmental risk factors for dementia
• Linking cognitive & functional decline
• CSRI & DBC allow us to identify extent of unmet health and mental health
• Focus groups & face-to-face interviews with carers of help-seeking; contribute to guidelines on health & mental health policy

Time 2 data:
• Testing robustness & validity of screening instruments, development of cost-effective screening, early detection & appropriate use of resources
• Development of interventions to promote healthy ageing
• Longitudinal follow-up through questionnaires, possible to also do follow-up of assessments.
• Other strengths of Sage:
  – Sample from metro, regional and rural Australia, therefore results generalizable
  – Study of at-risk population could lead to understanding dementia in general population
  – Inclusion of younger age groups, collected more accurate base-line data before onset of cognitive decline
The Guide: What is it?

- A national framework of understanding and action for mental health professionals and service providers.
- Documents the understanding of ID mental health, current national and international practices.
- Provides an overview of ID mental health, why accessible services are important, the principles that should guide service delivery, practical strategies for inclusive and accessible services, and the implications for the service system.
- Facilitates and encourages incremental steps to adjustments to practice, accessible service and knowledge and capacity building.
Accessible Mental Health Services for People with ID: A Guide for Providers (‘The Guide’)  

Methodology  
- Funding  
- Core Reference Group formation  
- Background research and collation  
- Draft sections for CRG consultation  
- Focus group consultation  
- Second Draft and circulation  
- Final Draft  
- Publication  
- Launch  
- Follow-up actions
The Vision

Accessible mental health services for people with an intellectual disability.
Core Reference Group

The Core Reference Group (CRG) was consulted throughout the development of The Guide.

<table>
<thead>
<tr>
<th>CRG Member</th>
<th>Position</th>
<th>Organisation / Professional Association and Interest Group</th>
</tr>
</thead>
<tbody>
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<td>Ms Andrea Ching</td>
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<td>Department of Developmental Disability Neuropsychiatry, School of Psychiatry University of New South Wales</td>
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<td>Dr Catherine Franklin</td>
<td>Senior Lecturer and Consultant Psychiatrist</td>
<td>Queensland Centre for Intellectual and Developmental Disability at the University of Queensland</td>
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<td>Dr Linda Goddard</td>
<td>President</td>
<td>Professional Association of Nurses in Developmental Disability Australia</td>
</tr>
<tr>
<td>Dr Nick Hagiasiss</td>
<td>Psychologist and Committee member</td>
<td>Australasian Society for Intellectual Disability</td>
</tr>
<tr>
<td>Prof Nick Lennox</td>
<td>President</td>
<td>Australian Association of Developmental Disability Medicine</td>
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<td>A/Prof Keith McVilly</td>
<td>Coroner, Special Interest Group on People with Intellectual and Other Developmental Disabilities</td>
<td>Australian Psychological Society</td>
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<td>Member, Mental Health Nurse Practitioner</td>
<td>Australian College of Mental Health Nurses</td>
</tr>
<tr>
<td>Mr Jim Simpson</td>
<td>Senior Advocate</td>
<td>NSW Council of Intellectual Disability</td>
</tr>
<tr>
<td>Dr Jennifer Torr</td>
<td>Chair, Special Interest Group in the Psychiatry of Intellectual and Developmental Disabilities</td>
<td>Royal Australian and New Zealand College of Psychiatrists</td>
</tr>
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<td>A/Prof Julian Tello</td>
<td>Chair, Core Reference Group</td>
<td>Chair Intellectual Disability Mental Health, School of Psychiatry University of New South Wales</td>
</tr>
</tbody>
</table>
Introduction

WHAT IS INTELLECTUAL DISABILITY?

Intellectual disability (abbreviated as ‘ID’ throughout this Guide) is the term used to describe permanent impairment of general mental abilities which has a significant impact on adaptive function. An ID is a lifelong disability which first becomes apparent during the developmental period, before the age of 18. An ID is diagnosed using a combination of results from standardised tests of intelligence and adaptive functioning.

On tests of intelligence, people with an ID generally perform about two standard deviations or more below the average for the population, which is an Intelligence Quotient (IQ) score of approximately 70 or below. Current diagnostic criteria emphasise measurement of adaptive functioning rather than reliance on IQ scores alone. Adaptive functioning describes how well an individual copes with everyday tasks, for example conceptual, social and practical skills. A more detailed definition can also be found in the Glossary at the end of this document.

At all stages of life, people with an ID are at least two to three times more likely to have a mental disorder than the general population.

The severity of ID can be mild, moderate, severe or profound. People with an ID are therefore a diverse group with highly varied support needs depending on their level of disability. Having an ID is associated with a high rate of co-occurring medical conditions and mental disorders. The mental health support needs of people with a mild ID can often be met within mainstream mental health services. However, people with communication deficits, more severe ID, and comorbid health problems often require a more specialised approach to mental health care.

The focus of the Guide is people with an ID, rather than the broader group of people with developmental disability. Developmental disability refers to permanent mental or physical impairment arising in the developmental period. While many people with developmental disability have an ID, some do not. For example, someone may have cerebral palsy or autistic disorder with no intellectual impairment.

MENTAL HEALTH IN PEOPLE WITH AN INTELLECTUAL DISABILITY

At all stages of life, people with an ID are at least two to three times more likely to have a mental disorder than the general population.

Despite this, many people with an ID experience major barriers when trying to access mental health services. The development of accessible mental health services for people with an ID in Australia lags behind internationally accepted practice. The experience of family, carers and consumers is that mainstream mental health services are not adequately accommodating the needs of people with an ID. Workforce capacity in this area is lacking, and mental health professionals have limited training, education and expertise in ID mental health. While preventative mental health programs are broadly aimed at all Australians, programs that specifically assist people with an ID are largely non-existent.

Specialist ID mental health services are uncommon and are limited to a few highly specialised professionals and centres. Service models and pathways of care for people with an ID and mental disorders are generally unclear.

Data on mental health service use or mental health outcomes for people with an ID is not systematically collected. Key national mental health policy documents recognise the needs of people with disabilities, including those with an ID. However, the implementation of mental health policy does not uniformly address the needs of people with an ID.

People with an ID represent a diverse population with diverse needs. The development and provision of accessible mental health services for people with an ID requires deliberate and sustained action of individuals, services and policy makers. This Guide highlights opportunities for action at each level of the mental health service system in order to meet the fundamental right of people with an ID to access free or affordable mental health care.
Background

THE RELATIONSHIP BETWEEN INTELLECTUAL DISABILITY AND MENTAL HEALTH

People with an ID experience very poor mental health compared to the general population, with common mental disorders occurring around two to three times more frequently.6,8 This predisposition to mental ill-health is apparent across the lifespan, including in children, young people and adults.4 At any one time, an estimated 20-40% of people with an ID will be experiencing a mental disorder of some kind.3,6 Simple examples of this vulnerability include the over-representation of schizophrenia by two to four times, and its earlier onset in people with an ID compared to the general population.4 In addition, higher rates of dementia are apparent in older persons with an ID compared to the general population.11

Vulnerability to mental disorders in people with an ID is underpinned by a variety of biological, psychological, and social factors. Specific genetic conditions associated with ID can increase the risk of psychopathology as can developmental brain abnormalities and pharmacological treatments and their side effects. People with an ID are also at increased risk of a range of physical health conditions which may increase the risk of mental ill-health.3,6,11

The presence of an ID usually affects a person’s coping skills and autonomy, creating greater susceptibility to stress, and thereby increasing psychological vulnerability.11 Further risk arises from the reduced opportunities to engage in a range of life choices, and restricted social networks that people with an ID often experience.

Other social factors which impact mental health include poverty, a higher likelihood of contact with the criminal justice system, negative experiences during schooling, and financial and emotional strain within the family.3,6 Furthermore, people with an ID experience higher rates of physical and sexual abuse which can further magnify their vulnerability to mental ill-health.

THE PRESENTATION OF MENTAL DISORDERS IN PEOPLE WITH AN INTELLECTUAL DISABILITY

The presentation of both physical and mental health problems can be influenced by a person’s level of ID and the presence of any associated communication difficulties. People with mild ID and good communication skills are usually able to describe what they are experiencing, and typically present in a manner familiar to most mental health professionals.

However, presentation is often atypical in those with more severe ID or in people with communication difficulties. This can mean that mental disorders mainly present as problematic behaviours.3,11 Therefore, individuals showing behavioural changes require careful assessment for a range of potential contributing factors including underlying mental or physical health conditions. Such complex presentations highlight the importance of a multidisciplinary approach to assessing behavioural difficulties in people with an ID.

It is critical for those working within the mental health profession to understand the phenomenon of ‘diagnostic overshadowing’. Diagnostic overshadowing means that symptoms of mental ill-health are misattributed to the ID rather than being recognised as part of the manifestation of a mental disorder.11 Mental health professionals should familiarise themselves with assessment and management of mental disorders in people with an ID by seeking specific training opportunities and resources (see Appendix 7 – Training and Education p. 67).

“Comprehensive assessment is central to making an accurate diagnosis and treatment.”

– Psychologist, ID mental health service
Guiding Principles

Mental health services for people with an ID must be underpinned by a human rights framework which promotes the inclusion and independence of people with an ID. Mental health service provision should be grounded in a person-centred approach and adopt recovery-oriented practices.

Furthermore, the Mental Health Statement of Rights and Responsibilities states that Australian governments have a responsibility to support the ongoing development of a range of timely, high-quality, recovery-oriented, and evidence-based services. These should be built around both community-based and specialist social support, and integrated with mental health, general health and disability services. Those principles are outlined below.

RIGHTS

A human rights framework in health care identifies people with a disability as having a right to health and health care. In relation to health services, the United Nations Convention on the Rights of Persons with Disabilities (CRPD) (see p. 69), in which Australia is a signatory, commits all levels of government in Australia to ensuring the right of people with disability to the highest attainable standard of health without discrimination. In a mental health context for people with an ID, this means ensuring:

- the same range and quality of free or affordable mental health care available to those without an ID;
- mental health services which address mental health conditions arising concurrently with an ID, and services which assist in preventing secondary disabilities;
- accessible mental health services which are provided as close as possible to the person's own community, including in rural and remote areas;
- mental health professionals who provide a high quality of mental health care and uphold ethical principles; and
- a system which prevents discriminatory denial of mental health care and promotes high standards of mental health care.

Mental health consumers with reduced capacity, including those with an ID, should be supported to understand and exercise their rights.

INCLUSION

People with an ID have the right to full participation in all aspects of community life. People with an ID should be able to access all components of mental health services, including mainstream and specialised mental health services. They should not be refused access to a service due to the presence of an ID. This extends to access to population health programs aimed at the prevention of mental disorders. To achieve this, some people with an ID will require support and the provision of accessible materials about mental health. To ensure inclusion, mental health services and providers may need to significantly adjust their approach, including addressing issues of the preparedness of services and staff. This includes their willingness to engage and actively include family members and support staff in the planning, implementation and review of treatment programmes. Mental health services need to promote and facilitate an inclusive approach towards people with an ID and act in a way that is guided by positive and non-discriminatory beliefs and attitudes.

PERSON-CENTRED APPROACH

A person-centred approach to mental health maximises the involvement of the person with an ID in decision-making, rather than viewing them as passive recipients of care.

In a person-centred approach, the individual is central to their care plan and to any decisions made with respect to their mental health. The person-centred approach seeks to understand the situation from the person's own perspective, discovering what is important to them, taking into account their age, community and culture.

The person with an ID should be provided with choices about their mental health care, in keeping with their age and capacity. While the person is the focus, family and carers should be consulted where appropriate. Service providers in both health and disability networks can be viewed as partners in this approach, working together to provide a cohesive system of person-centred mental health supports.

"The person is the expert of their own experience."
- Mental health professional, disability service

PROMOTING INDEPENDENCE

Mental health care for people with an ID should recognise the autonomy of individuals with an ID whilst acknowledging their age and capacity, and work in a manner that maximises independence.

Given the differing capacities of individuals with an ID, mental health services must ensure that
Key Components of Accessible Mental Health Services

Incorporating the following major elements into clinical practice will substantially improve accessibility and the quality of mental health care for people with an ID.

ADAPTATION OF CLINICAL APPROACH

In order to best meet the mental health needs of a person with an ID, mental health professionals must adapt their clinical approach. The key adaptations which will assist the delivery of mental health consultations are described below. More information can be found in the Implications for Mental Health Services section, p. 26.

Preparation and Reasonable Adjustments

Preparing for a consultation with a person with an ID may involve making the following adjustments:

- simplifying appointment and referral letters by using Easy English (see Appendix 9 – Other Resources p. 62) and making reminder phone calls;
- booking an extended consultation to accommodate possible complexity;
- trying to avoid long waiting times in high stimulation environments;
- arranging appointments which accommodate the person’s preference and facilitate accessibility, such as time, location or any other health considerations;
- avoid cancelling appointments at short notice and where possible, prepare the person for change;
- preparing for communication needs, for example, ensuring that their preferred communication system is available during the appointment, and where necessary, arranging an interpreter;
- identifying and accommodating other physical support needs such as those arising from mobility and sensory impairments;

- establishing who will be accompanying the person with an ID, and accommodating them in the consultation;
- identifying and communicating with those who can provide an accurate history, further information, or data related to the presenting problem; or
- with consent, obtaining and reviewing detailed background health and mental health information from a range of relevant sources.

Effective Communication

People with an ID and health professionals have identified poor communication as a barrier to accessing health care. People with an ID often experience communication difficulties. While these are more apparent in people with more severe levels of disability, even a person with mild ID may have difficulty understanding abstract concepts or complex questions. Effective communication requires considerable thoughtfulness, time, attention to the person and their needs and adaptation of the professional’s communication. The person’s age and cultural background should also be taken into account during any interaction.

“Detailed review of historical information including developmental, medical and medication histories in addition to specialist reports, school and psychological reports can be illuminating.”

– Psychologist, ID mental health service
Implications for Mental Health Services

Developing mental health services that are accessible for people with an ID can be achieved by:

1) making adaptations to existing services;
2) utilising collaborative and multi-disciplinary approaches;
3) providing appropriate education and training; and
4) introducing new systems.

The following section details adaptations that mental health providers could make to their existing services to improve accessibility for people with an ID. For each broad service category, adjustments and strategies at organisational and individual levels are suggested. These adaptations are divided into key roles and responsibilities and further improvement strategies for a comprehensive health service.

Some mental health service providers may not strictly identify within one classification and may fall across the various health service categories identified.

“The expertise in mental health is an important component of effective care management.”

— Consumer, disability service

IMPLICATIONS FOR ALL MENTAL HEALTH SERVICE PROVIDERS

The following responsibilities have been identified for all mental health professionals and organisations which treat people with an ID and co-occurring mental disorders:

- Provide accessible mental health services that are person-centred and recognise the right that persons with an ID have to accessing treatment as core business. This includes:
  - providing a physical environment or outreach service that is accessible to a person with an ID and their care(s), and
  - providing information for consumers and their families using easy-to-understand language or using augmentative and alternative communication where appropriate.

- Work in a collaborative and coordinated manner with key disability and related specialist supports. This includes, but is not limited to:
  - family and care(s);
  - teachers and education sector staff;
  - case managers and support workers;
  - primary care providers;
  - specialist medical services including private, public and specialised ID mental health service providers;
  - allied health practitioners, for example, those providing behaviour support; and
  - specialist cultural services including Aboriginal and Torres Strait Islander and culturally and linguistically diverse organisations.

- Support the individual’s optimal functioning and their return to full capacity.
- Ensure linkage to the client’s primary health care practitioner to facilitate continuity of care.
- Facilitate optimal access to services by utilising mechanisms such as Telehealth (see Glossary p.42) to ensure appropriate care and support is received.
- Maintain awareness of appropriate consumer and carer advocacy services.
- Foster the development of skills in ID mental health. This includes either through the provision of education and access to training resources at an organisational level or through attendance and pursuit of these skills at an individual level.
Tools for Inclusive Practice

The following section provides a selection of tools and resources which have a specific focus for people with an ID requiring mental health services and support.

APPENDIX 1: ASSESSMENT AND DIAGNOSTIC TOOLS

People with an ID and mental health issues should receive comprehensive, timely and accurate assessment with regular review of their progress provided to the service user and their carer(s). A range of assessment tools and resources which may assist in providing accurate and timely assessments of people with an ID are provided below.


The ABAS-II is an adaptive behaviour assessment tool which covers the lifespan with age-specific versions.

Assessing Mental Health Concerns in Adults with Intellectual Disabilities - A Guide to Existing Measures

This resource provides an overview of the various measures used to assess mental health concerns in adults with an ID.

Camberwell Assessment of Need for Adults with Developmental and Intellectual Disabilities (CANDID)

www.rcpsych.ac.uk/usefulresources/publications/books/cpp/1901242994.aspx
The CANDID has been developed and tested by a multidisciplinary team at the Institute of Psychiatry in London. This instrument has been designed for mental health staff to undertake a comprehensive assessment for use with adults with all levels of ID.

The Developmental Behaviour Checklist

The Developmental Behaviour Checklist is a suite of instruments for the assessment of behavioural and emotional problems of children, adolescents and adults with developmental and intellectual disabilities.

Diagnostic Manual - Intellectual Disability (DM-ID): A Textbook of Diagnosis of Mental Disorders in Persons with Intellectual Disability

www.dm-id.org
A manual designed to be an adaptation of the Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition (DSM-IV) developed by the National Association for the Dually Diagnosed, in association with the American Psychiatric Association.

DC-LD: Diagnostic Criteria for Psychiatric Disorders for use with Adults with Learning Disabilities

www.rcpsych.ac.uk/publications/collegereports/op/op498.aspx
A classification system providing operationalized diagnostic criteria for psychiatric disorders, intended for use with adults with moderate to profound learning disabilities. It may also be used in conjunction with the ICD-10 and DSM-IV manuals in a complementary way, when working with adults with mild learning disabilities. Suitable for use by professionals trained in psychiatric diagnosis.
Free e-learning intellectual disability mental health

www.idhealtheducation.edu.au

- Introduction to Intellectual Disability
- Living with Intellectual Disability
- Changing Perspectives of Intellectual Disability
- Introduction to Mental Disorders in Intellectual Disability
- Communication: the basics
- Improving your Communication
- Assessment of Mental Disorders in Intellectual Disability
- Management of Mental Disorders in Intellectual Disability
- Coming Soon:
  - interagency work
  - emergency presentations
  - carer intro to mental disorders in people with ID
  - legal and ethical Issues
  - challenging behaviour
Summary

• A long way from “The Highest Attainable Standard of Health and Wellbeing for Older Persons with an Intellectual or Developmental Disability”

• Current status:
  – inequity in access to quality physical and mental health care
  – poor capacity in age-related health and disability care

• The concept of successful ageing may be useful

• Goals are identifiable

• There are multiple potential barriers

• Debate and prioritisation is needed
Acknowledgements/Declarations

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• UNSW Medicine

Funding: Research and Projects
• NSW Ministry of Health & Related Organisations
  – MHDAO, MH Kids, HETI, ACI ID Network
• Australian Government Department of Health and Ageing
• Australian Research Council (ARC)
• National Health and Medical Research Council (NHMRC)
• NSW Institute of Psychiatry
• Autism CRC