Successful Ageing for People with Intellectual Disability

Associate Professor Julian Trollor
Chair, Intellectual Disability Mental Health
Head, 3DN
School of Psychiatry, UNSW
j.trollor@unsw.edu.au

3dn.unsw.edu.au
Outline

• Aspirational goal
• Current status
• 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
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
Our findings show that people with intellectual disabilities were likely to die, on average, 16 years earlier than the general population. A range of potentially modifiable factors were related to care and service provision, and all aspects of care provision, planning, coordination, and documentation were significantly poorer for people with intellectual disabilities than for the comparator group of people without intellectual disabilities. The findings suggest that although some individual factors are of importance, factors relating to care and service provision contribute to excess mortality in people with intellectual disabilities. Multidisciplinary overview panel.

Table 2: Most frequent ICD-10 categories of underlying cause of death for the study cohort of people with intellectual disabilities and for all deaths in England and Wales in 2011

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 and ICD-10</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Epilepsy</td>
<td></td>
</tr>
<tr>
<td>Cerebral palsy</td>
<td></td>
</tr>
<tr>
<td>Pneumonitis due to solids and liquids</td>
<td></td>
</tr>
<tr>
<td>Ischaemic heart diseases</td>
<td></td>
</tr>
<tr>
<td>Down syndrome</td>
<td></td>
</tr>
<tr>
<td>Pneumonia</td>
<td></td>
</tr>
<tr>
<td>Other heart diseases</td>
<td></td>
</tr>
<tr>
<td>Cerebrovascular diseases</td>
<td></td>
</tr>
<tr>
<td>Inhalation and ingestion of food causing obstruction of respiratory tract</td>
<td></td>
</tr>
<tr>
<td>Pneumonia</td>
<td></td>
</tr>
<tr>
<td>Ischaemic heart diseases</td>
<td></td>
</tr>
<tr>
<td>Sequelae of transport accidents</td>
<td></td>
</tr>
<tr>
<td>Chronic lower respiratory diseases</td>
<td></td>
</tr>
<tr>
<td>Malignant neoplasm of colon, rectum and anus</td>
<td></td>
</tr>
</tbody>
</table>

## Table 9: Underlying cause of death

<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>
<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 causing 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 top 10 underlying causes in disability services:**

<p>| | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>N</td>
<td>95</td>
</tr>
<tr>
<td>%</td>
<td>51.08%</td>
</tr>
</tbody>
</table>

## Table 10: NSW deaths

<table>
<thead>
<tr>
<th>NSW deaths</th>
<th>Average Crude Mortality Rate 2002-2010</th>
</tr>
</thead>
<tbody>
<tr>
<td>Number of Deaths 2002-2010</td>
<td></td>
</tr>
<tr>
<td>54</td>
<td>773</td>
</tr>
<tr>
<td>35</td>
<td>198</td>
</tr>
<tr>
<td>35</td>
<td>3,618</td>
</tr>
<tr>
<td>56</td>
<td>73,671</td>
</tr>
<tr>
<td>56</td>
<td>158</td>
</tr>
<tr>
<td>77</td>
<td>7,805</td>
</tr>
<tr>
<td>17</td>
<td>23,834</td>
</tr>
<tr>
<td>77</td>
<td>39,110</td>
</tr>
<tr>
<td>98</td>
<td>17,873</td>
</tr>
<tr>
<td>58</td>
<td>137</td>
</tr>
</tbody>
</table>
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?
‘My Thinker’s Not Working’

National Dementia and Intellectual Disabilities Action Plan

Goal A: To better understand dementia and how it affects adults with an intellectual disability and their caregivers

Number | Recommendation | Who could do it
--- | --- | ---
1 | Conduct a national survey of families and caregivers of adults with intellectual disabilities to assess their understanding of dementia and its impact. | National agencies and institutes on Developmental Disabilities, Administration on Aging, National Institute on Disability and Rehabilitation Research.
2 | Conduct studies to identify the characteristics of dementia that are common in adults with intellectual disabilities. | Universities’ academic and research centers.
3 | Conduct studies on the impact of dementia on caregivers. | Universities’ academic and research centers.
4 | Conduct studies on the impact of dementia on the support and care of adults with intellectual disabilities in home settings. | Universities’ academic and research centers.
5 | Conduct studies on the impact of dementia on adults with intellectual disabilities in various community settings. | Universities’ academic and research centers.

Goal B: To institute effective screening and assessment of adults with an intellectual disability at-risk, or showing the early effects of dementia

6 | Develop and implement a screening tool for adults with intellectual disabilities at-risk or showing the early effects of dementia. | American Academy of Developmental Medicine and Dentistry.
7 | Develop and implement a screening tool for adults with intellectual disabilities who are at risk of dementia. | State development disabilities authorities.
8 | Develop and implement a screening tool for adults with intellectual disabilities who are at risk of dementia. | State development disabilities authorities.
9 | Develop and implement a screening tool for adults with intellectual disabilities who are at risk of dementia. | State development disabilities authorities.

Goal C: To promote health and function among adults with an intellectual disability


Goal D: To produce appropriate community and social supports and care for adults with an intellectual disability affected by dementia

15 | Enhance family, support services to include efforts to help caregivers to identify and receive assistance for adults with an intellectual disability affected by dementia. | State development disabilities authorities.
16 | Enhance family, support services to include efforts to help caregivers to identify and receive assistance for adults with an intellectual disability affected by dementia. | State development disabilities authorities.
17 | Enhance family, support services to include efforts to help caregivers to identify and receive assistance for adults with an intellectual disability affected by dementia. | State development disabilities authorities.
18 | Enhance family, support services to include efforts to help caregivers to identify and receive assistance for adults with an intellectual disability affected by dementia. | State development disabilities authorities.

Goal E: To produce a capable workforce and produce education and training materials

19 | Develop and implement a national program of training using workshops and learning, as well as social awareness, for staff and families. | American Academy of Developmental Medicine and Dentistry.
20 | Develop and implement a national program of training using workshops and learning, as well as social awareness, for staff and families. | American Academy of Developmental Medicine and Dentistry.
21 | Develop and implement a national program of training using workshops and learning, as well as social awareness, for staff and families. | American Academy of Developmental Medicine and Dentistry.
22 | Develop and implement a national program of training using workshops and learning, as well as social awareness, for staff and families. | American Academy of Developmental Medicine and Dentistry.

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
Ageing and ID
Projects and Potential Synergies
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
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><em>Mohr, Tonge, Einfeld, &amp; Gray (2005)</em></td>
</tr>
<tr>
<td>Sleep</td>
<td>Basic Nordic Sleep Questionnaire <em>Partinen &amp; Gislason (1995)</em> Epworth Adapted</td>
<td></td>
</tr>
<tr>
<td>Health and care service use</td>
<td>Client Service Receipt Inventory (CSRI)</td>
<td><em>Beecham &amp; Knapp (2001)</em></td>
</tr>
<tr>
<td>Significant Life Events</td>
<td>PAS-ADD checklist</td>
<td><em>Moss et al. (1998)</em></td>
</tr>
<tr>
<td></td>
<td>Down' Syndrome (CAMDEX)</td>
<td></td>
</tr>
</tbody>
</table>

*Pink – Family carer Blue – Paid Carer*
# 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>Evenhuis, Kengen &amp; Eurlings (2006)</td>
</tr>
<tr>
<td></td>
<td>Dementia Screening Questionnaire for Individual with Intellectual Disability (DSQIID)</td>
<td>Deb, Hare, Prior &amp; Bhaumik (2007)</td>
</tr>
<tr>
<td></td>
<td>Adaptive Behaviour Dementia Questionnaire (ABDQ)</td>
<td>Prasher, Farooq &amp; Holder, 2004</td>
</tr>
<tr>
<td></td>
<td>Cambridge Examination for Mental Disorders of Older People with Down' Syndrome (CAMDEX)</td>
<td>Ball, Holland, Huppert, Treppner &amp; Dodd (2006)</td>
</tr>
<tr>
<td>Domain(s) Measured</td>
<td>Instrument Name</td>
<td>Reference</td>
</tr>
<tr>
<td>--------------------------------------------------------</td>
<td>-----------------------------------------------------</td>
<td>------------------------------------------------</td>
</tr>
<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></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:</td>
<td>Neuropsychitric Assessment of memory, orientation, language and praxis</td>
<td>Crayton &amp; Oliver (1993), 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</strong></td>
<td></td>
<td></td>
<td>55.3%</td>
</tr>
<tr>
<td>(paid/voluntary)</td>
<td></td>
<td></td>
<td></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>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>19</td>
<td>28.4</td>
<td>17.8</td>
</tr>
<tr>
<td>2</td>
<td>19</td>
<td>28.4</td>
<td>17.8</td>
</tr>
<tr>
<td>3</td>
<td>19</td>
<td>28.4</td>
<td>17.8</td>
</tr>
<tr>
<td>4</td>
<td>6</td>
<td>9.0</td>
<td>8.4</td>
</tr>
<tr>
<td>5</td>
<td>3</td>
<td>4.5</td>
<td>2.8</td>
</tr>
<tr>
<td>6</td>
<td>1</td>
<td>1.5</td>
<td>0.9</td>
</tr>
</tbody>
</table>
### SAge ID Carer Questionnaires:

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

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>
<th>Categories</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Carer Burden</td>
<td>1. Lifetime Job</td>
</tr>
<tr>
<td></td>
<td>1.1 Individual needs</td>
</tr>
<tr>
<td></td>
<td>1.2 Alternate life</td>
</tr>
<tr>
<td></td>
<td>1.3 Acceptance, stigma and discrimination</td>
</tr>
<tr>
<td>2. Health and wellbeing</td>
<td>2. 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. 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
Accessible Mental Health Services for people with an Intellectual Disability – A Guide for Providers

The Outline

• A national framework of understanding and action for mental health professionals and service providers.
• Research current national and international practices, understanding of ID mental health and knowledge and staff attitudes.
• 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.
• Facilitate and encourage incremental steps to adjustments to practice, accessible service and knowledge and capacity building.
The Guide

Promote greater integration between disability and mental health services and improve access.

The Vision
“Accessible mental health services for people with an intellectual disability”

Highlight the importance of intellectual disability mental health initiatives and funding.

Increase the knowledge, skills and confidence of the health workforce to deliver quality care and support to people.

Improve mental health outcomes for people with an intellectual or developmental disability.
The Guide

The Objectives – 2014

• The Official Launch – May 2014 RANZCP Congress Perth

• Implementation and dissemination strategy

• Obtain funding for the next phases of the project:
  o An Implementation and Self Assessment Toolkit
  o A Carer and Consumer Resource Package

• Potential publication
‘Accessible Mental Health Services for People with ID: A Guide for Providers’

Invitation to Official Launch

Accessible Mental Health Services for People with an Intellectual Disability: A Guide for Providers

Wednesday 14 May 2014 12.30pm
Light lunch 12.30pm – Official Launch 1.30pm
Royal Australian & New Zealand College of Psychiatrists
2014 Congress
Level 2 River Room 5
Perth Convention and Exhibition Centre

The Guide is a national framework of understanding and action for frontline mental health service providers with respect to people with an intellectual disability. It provides an overview of intellectual disability 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.

The Guide will enable health services in providing equitable access, a skilled workforce and appropriate treatment to people with an intellectual disability and a mental disorder.

To obtain a copy of The Guide, go to 3dn.unsw.edu.au or the Department of Health, Mental Health Publications page.

For further information please contact Andrea Ching andrea.ching@unsw.edu.au
IDMH e-learning
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
3DN February 2014
Acknowledgements/Declarations

Funding: Core
- Ageing Disability and Home Care | Family and Community Services NSW
- 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