



Intellectual Disability Mental Health

Research Update from the Chair, IDMH

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Medicine

Department of Developmental Disability Neuropsychiatry



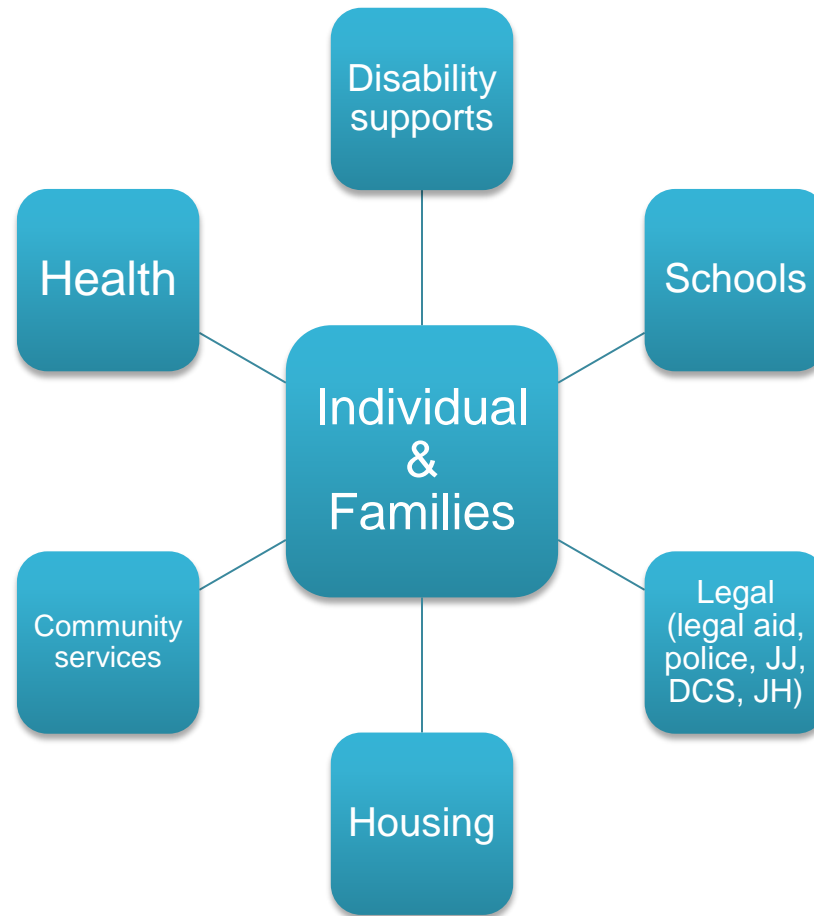
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Intellectual Disability Mental Health

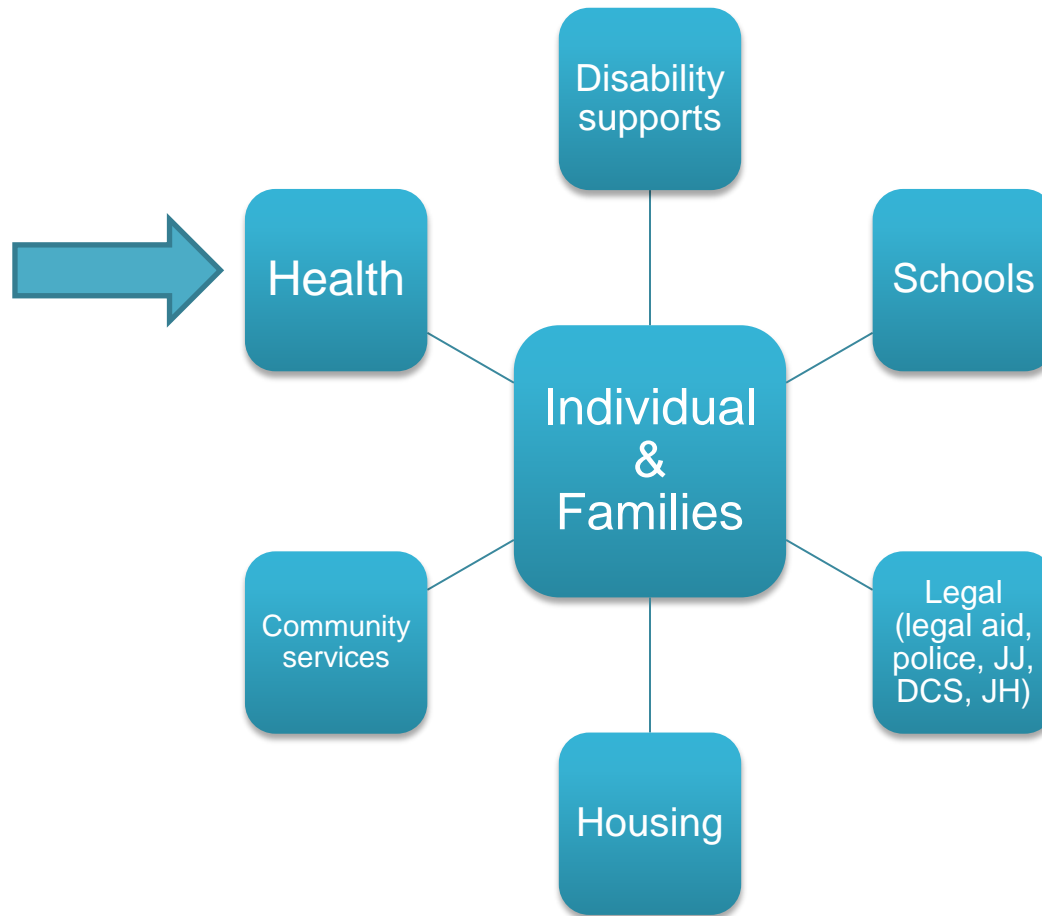
- People with an intellectual disability experience an over-representation of mental disorders
 - Conservative estimates for adults/children with ID 2.5/3-4x
 - From cradle to grave
- Access to mental health supports and treatments is limited
- High impact for people with ID, families and carers
- Complexity
- Multiple vulnerabilities



Supports for People with an Intellectual Disability



Supports for People with an Intellectual Disability



MH Services and Supports



Chair IDMH

- ADHC Funded, ST1 & 2
- 5 years
- Main focus on mental health workforce capacity and training
- Competitive tender
- UNSW Medicine successful
- Commenced 2009

Accessible Mental Health Services

3DN Strategic Plan 2013-2015

Vision

- The highest attainable standard of mental health and wellbeing for people with an intellectual or developmental disability.

Mission

- To improve mental health policy and practice for people with an intellectual or developmental disability.

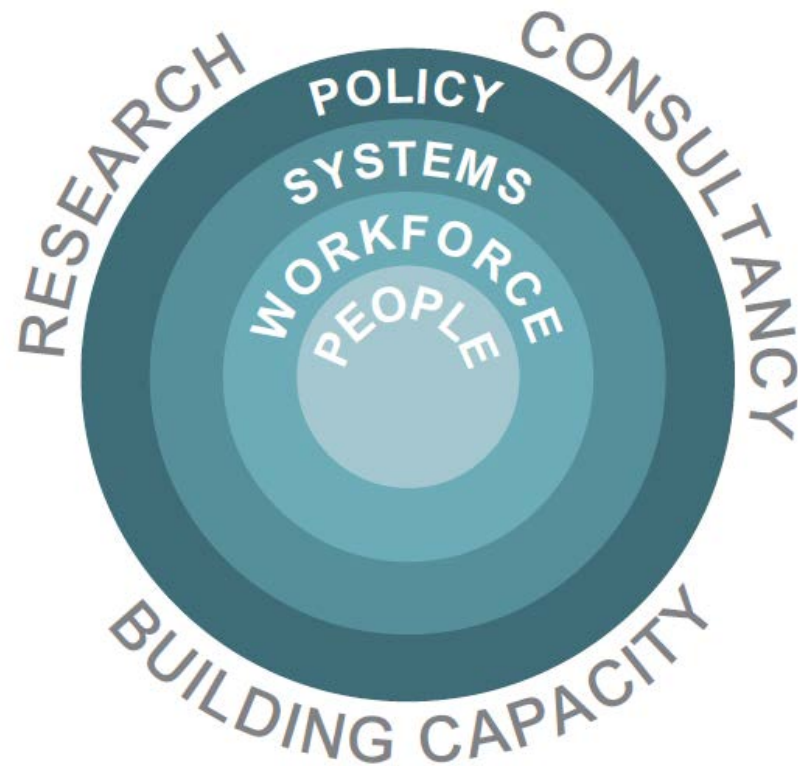
Guiding Principles

- Human rights
- Equity in mental health care
- Excellence and academic leadership
- Innovation in health services
- Collaboration
- Ethical conduct

I commend 3DN's Strategic Plan 2013 to 2015, which provides a powerful intellectual and professional framework on which a person-centred approach to support can be built.

John Feneley, NSW Mental Health Commissioner

Chair IDBS: Domains of Work



Priorities

STRATEGIC PRIORITY 1

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

STRATEGIC PRIORITY 2

- Increase the knowledge, skills and confidence of the health workforce to deliver quality care and support to people with an intellectual or developmental disability.

STRATEGIC PRIORITY 3

- Promote greater integration between disability and mental health systems and improve access for people with an intellectual or developmental disability

STRATEGIC PRIORITY 4

- Highlight the importance of initiatives and funding in intellectual and developmental disability mental health

Research Strategy

- Development of 3DN as a hub of academic excellence in IDMH, and the establishment of a disability hub at UNSW
- The conduct of ethical research which engages people with ID and their carers
- The focus on translational projects which both identify and propose solutions to the over-representation of mental disorders in people with an ID
- The identification and mentoring of junior researchers in IDMH, and the sponsoring of higher degree students
- The involvement of clinical IDMH Fellows in research activities

Research Collaborators

Collaborator Groups	Research Domains
UNSW Faculty of Arts and Social Sciences Professor Eileen Baldry and Dr Leanne Dowse	intellectual disability, psychiatric disorders and the criminal justice system Indigenous offenders with cognitive disabilities
UNSW Social Policy Research Centre, A/Prof Karen Fisher	Workforce capacity
LaTrobe University Rural Health School, Faculty of Health Sciences, Prof Teresa Iacono; Monash University Centre for Developmental Disability Health Victoria, Dr Jenny Torr	Ageing and Dementia in Intellectual Disability
Professor Randy Hagerman and the MIND Institute, University of California Davis, USA; Monash University Developmental Neuropsychology, Prof Kim Cornish; Murdoch Children's Research Institute, Genetics Education and Health Research, Prof Sylvia Metcalfe; Hunter Genetics, Dr Anna Hackett; Monash University School of Psychology and Psychiatry, Faculty of Medicine, Prof Nellie Georgiou-Karistianis	Fragile X Disorders
Dementia Collaborative Research Centre, and Centre for Healthy Brain Ageing, University of New South Wales, Scientia Prof Henry Brodaty AO, and Scientia Prof Perminder Sachdev AM; Assoc. Prof Wei Wen, School of Psychiatry	Dementia in Intellectual Disability Ageing in the General population Genetics of Ageing and age-related disorders Neuroimaging in ageing and dementia
National Ageing Research Institute, Prof David Ames; QIMR Berghofer Medical Research Institute, Prof Nick Martin and A/Prof Margie Wright; EUroDisco Twin Consortium led by Prof Tim Spector, Institute of Psychiatry London	Genetics of Age-related Disorders
University of Adelaide School of Medicine: Prof Bernhard Baune, Garvan Institute, Sydney, Prof Leslie Campbell, Prof Katherine Samaras, Prof Sam Breit, A/Prof David Brown	Neuroinflammation Metabolic and cardiovascular factors in brain aging
Cooperative Research Centre for Living with Autistic Spectrum Disorders: Curtin University, Griffith university, LaTrobe University, Mater Medical Research Institute, Queensland University of Technology, University of Queensland University of Western Australia, AEIOU Foundation, Autism Queensland, Autism Spectrum Australia, Queensland Department of Education, Training and Employment	Autism Research Program including improving health, mental health and social participation



Capacity Building Research

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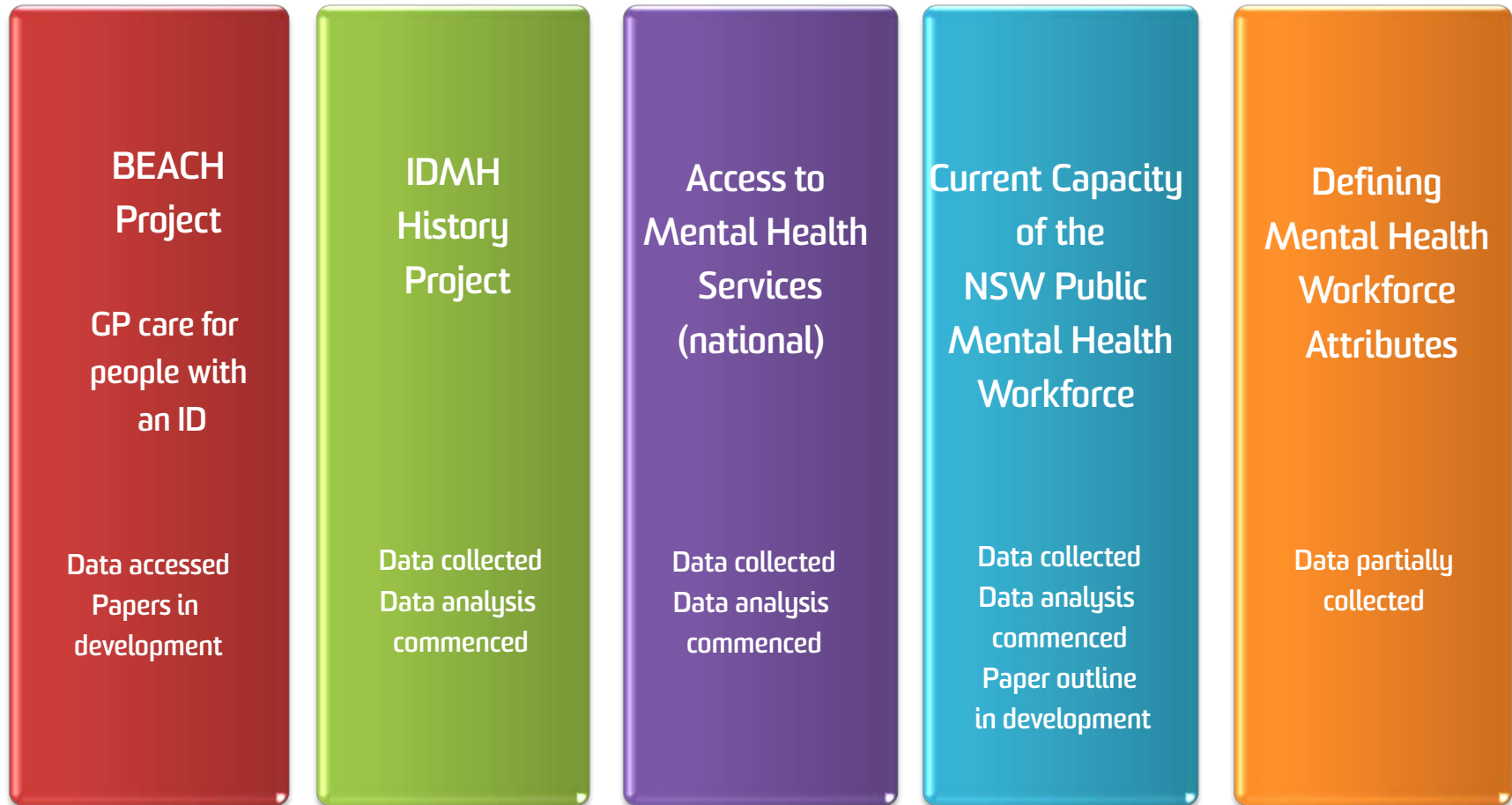
Overarching aims and objectives

Aim: To develop and maintain a skilled mental health workforce that is able to deliver high quality mental health care to people with an intellectual disability.

Objectives:

- To determine the **attributes** that people with an ID, their families, support networks and specialist IDMH clinicians believe are essential for quality practice
- To determine the **current capacity** within the mainstream MH workforce and identify **future training needs**
- To understand how services and the workforce have evolved – what **lessons can be learnt**
- To identify **barriers and facilitators** experienced by the workforce in the delivery of services to people with an ID
- To develop an **IDMH core competencies framework**

CAPACITY Building Research



Objectives for the year:

- Finalise data collection
- Finalise data analysis
- Submit BEACH papers and Staff Survey paper
- Draft papers for DELPHI and History Project
- Presentations at RANZCP
- Continue to liaise with MH Commission and HWA
- Seek out opportunities for future funding - implementation

Challenges and ideas for sustainability

Challenges:

- Work at a national and state level in the area of competencies/capabilities is under development
- Gap between current and ideal capabilities
- Implementation of work

Ideas for future projects:

- Implementation resources
- Development of competencies/capabilities at a service and advanced clinician level
- Consideration for competencies/capabilities for primary care and disability sector
- Measuring impact of the implementation of framework



Renewal of medical and nursing intellectual disability curriculum

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Renewal of Medical and Nursing Intellectual Disability Curriculum

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Department of developmental disability neuropsychiatry, University of New South Wales



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Faculty of Health Sciences, La Trobe University

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Centre for Disability Studies, University of Sydney



Dr Margo Lane

School of Medicine, University of Queensland

Prof Les White

NSW Kids and Families & NSW Agency for Clinical Innovation



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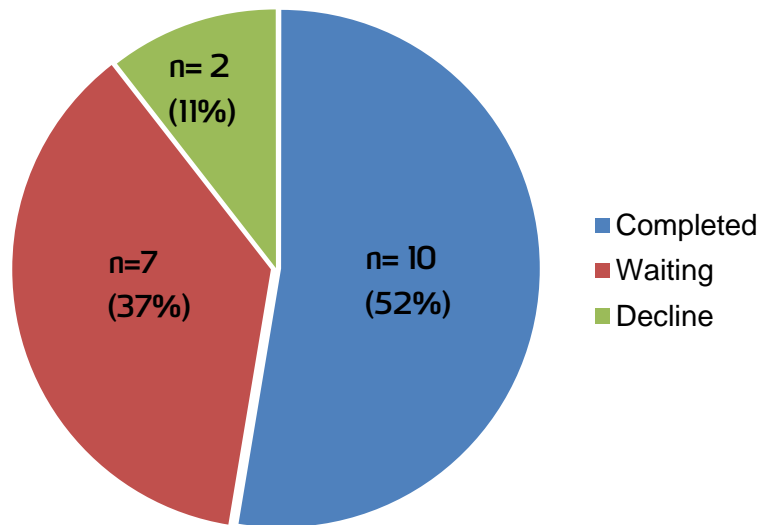
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Renewal of Medical and Nursing Intellectual Disability Curriculum

- **Aim:** to improve the health status of people with an intellectual disability by building capacity in the medical and nursing workforce.
- **Objectives:**
 1. Identify ID health content *currently* delivered to medical and nursing students across Australia
 2. Engage leaders in intellectual disability health in Australian Medical and Nursing schools
 3. Compile and develop high quality educational resources in ID health
- **Methods:**
 - Interview completed with medical and nursing Deans from universities across Australia to review course structure and identify staff who currently teach ID content.
 - Online survey completed by identified university staff to detail current ID physical and mental health content within the course.

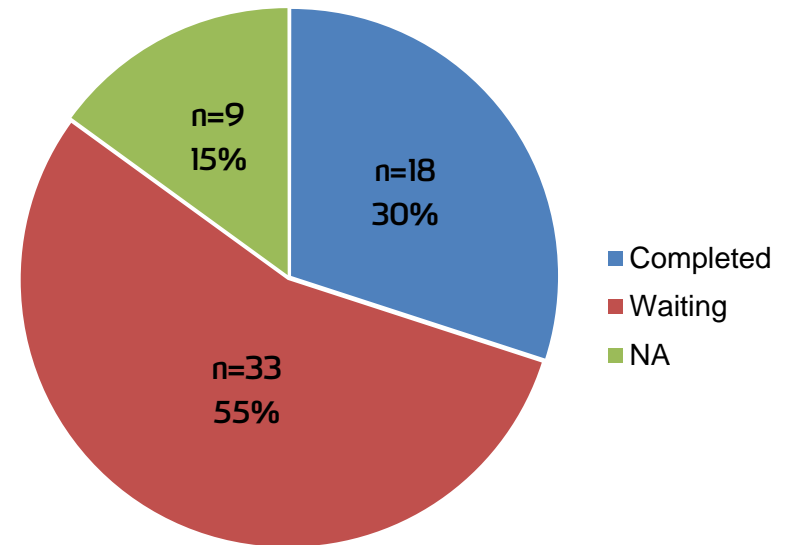
Renewal of Medical and Nursing Intellectual Disability Curriculum

Interviews completed by Deans delegate



*universities contacted n= 19

Surveys completed by university staff



*universities responded n= 7

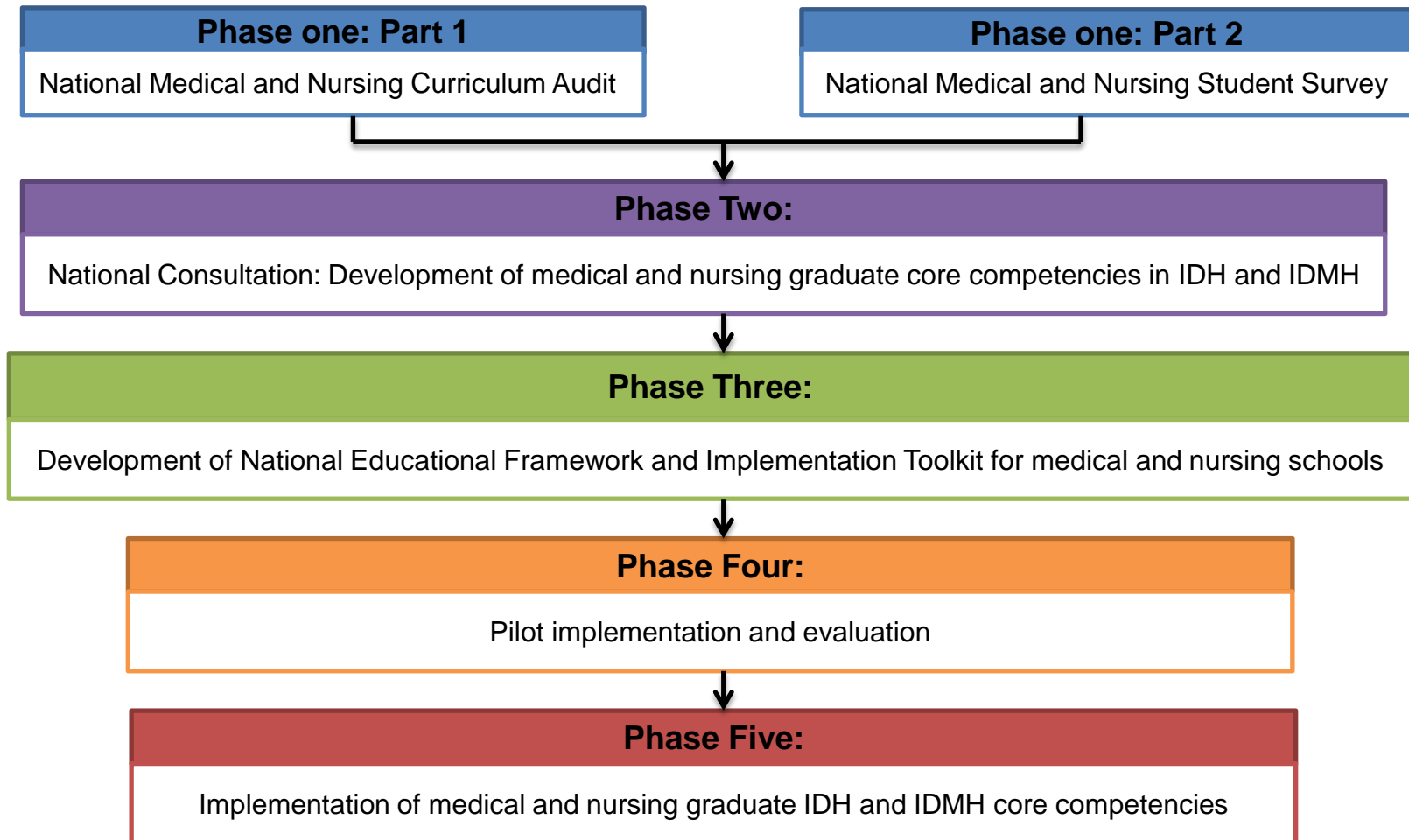
Renewal of Medical and Nursing Intellectual Disability Curriculum

Objectives for 2014:

- **Data collection** for Nursing curriculum project
- **Data analysis** for Medical curriculum project
- Secure further **funding**
- **Reports**
 - ADHC
 - Medical and Nursing Deans
- Dissemination
 - Conferences
 - Papers- journal articles

Renewal of Medical and Nursing Intellectual Disability Curriculum

The “bigger picture”





Successful Ageing in Intellectual Disability (Sage-ID)

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Sage-ID team

Department of Developmental Disability Neuropsychiatry
School of Psychiatry, UNSW



Investigators/researchers in the study:

A/Professor Julian Trollor*

Dr Liz Evans*

Scientia Professor Henry Broadaty*

Scientia Professor Perminder Sachdev*

Professor Peter Schofield^

Dr David Mowat*

Dr Wei Wen*



Dr John Crawford*

Professor Teresa Iacono#

Dr Jennifer Torr&

Dr Anjali Bhardwaj*

Beth Turner*

Kate Chitty*

Natalie Crothers #

University of New South Wales, Sydney*; Neuroscience Research Australia, Sydney^; La Trobe University, Melbourne #; Monash University, Melbourne &



UNSW
AUSTRALIA



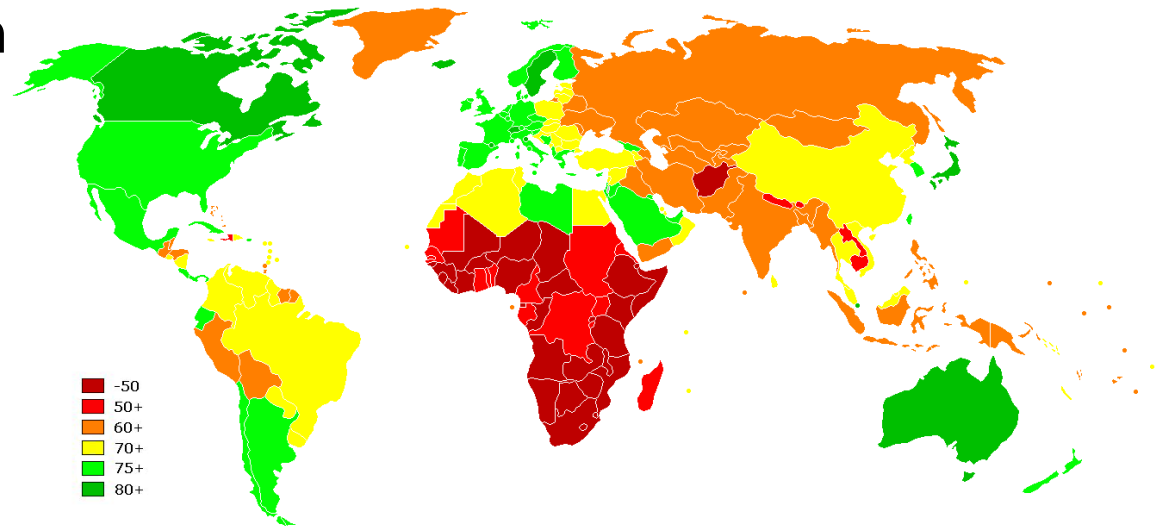
UNSW
AUSTRALIA



The SAGE-ID Study

What are the issues?

- Life expectancy of people with ID are increasing world wide
- Increased risk of dementia in ID population
- Mental and physical health declines rapidly compared to non-ID population



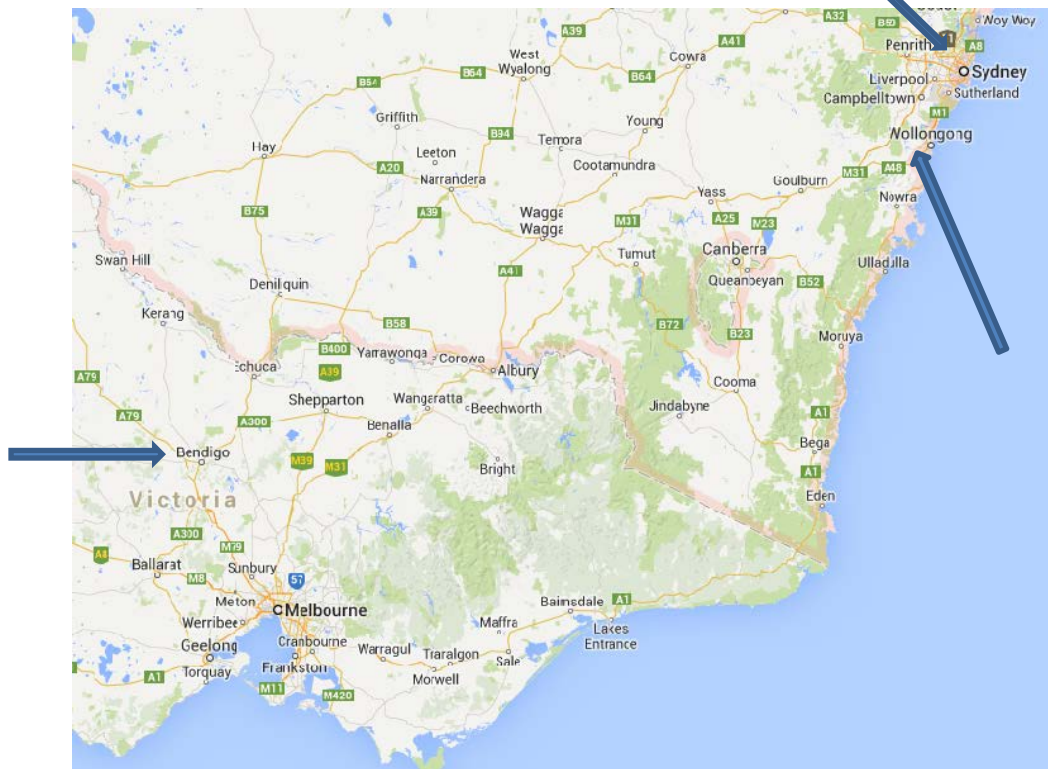


Aim of research:

- 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

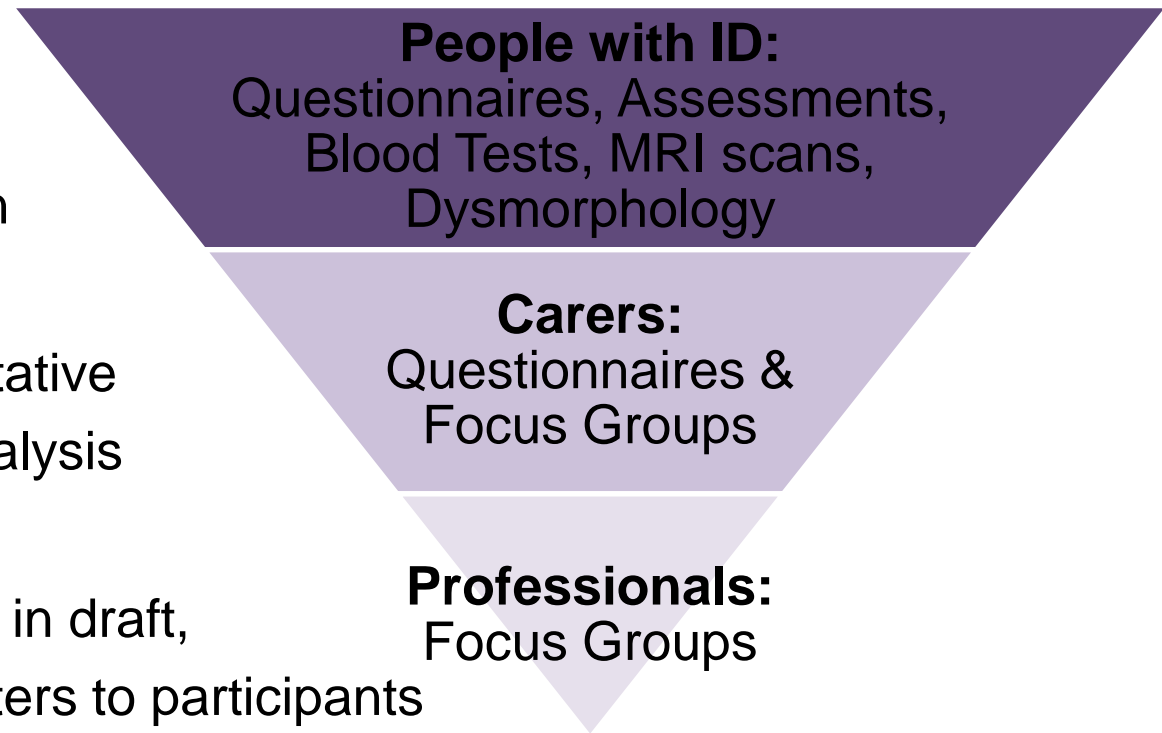
Our Population Requirements:

- Men and women aged **40 years and over**
- Has and intellectual disability of any functional level
- Location:
 - **NSW** => Metro Sydney
Rural Illawarra
 - **Victoria** => Rural Bendigo



SAGE Methodology:

- **Sample:** People with ID ≥ 40 years old, ranging mild -> profound level ID
- **Location:** Sydney (NSW), Illawarra (NSW), Bendigo (Vic)
- **Methodology:**
Mixed methods design
- **Analysis:** SPSS, Interpretative Phenomenological analysis
- **Dissemination:** 3 papers in draft, Conferences, newsletters to participants Time1 report





Procedures:

- **Participant with ID:**

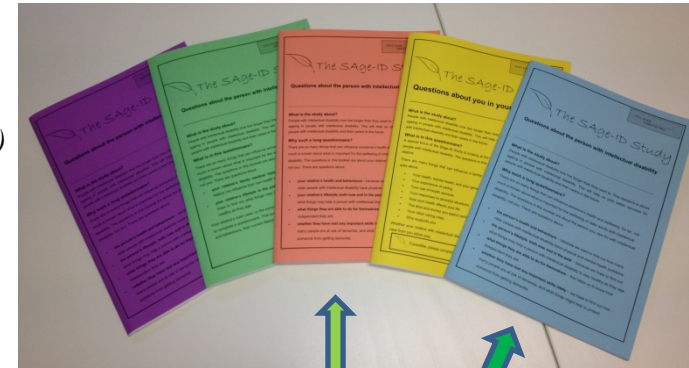
- Questionnaire – completed by main paid/family carer
- Cognitive & Physical assessment – completed with person with ID
(*Metro Sydney only*)

- **Family Carers:**

- Questionnaire
- Focus Groups (*NSW only*)
- Semi-structured Interview (*Victoria only*)



Domain(s) Measured	Instrument Name	Reference
<i>Questionnaire completed by main carer about the person with ID</i>		
Adaptive Behaviour	Scales of Independent Behaviour - Revised (SIB-R)	<i>Bruininks, Woodcock, Weatherman & Hill (1997)</i>
Behaviour problems and psychiatric status	Developmental Behaviour Checklist for Adults (DBC)	<i>Mohr, Tonge, Einfeld, & Gray (2005)</i>
Sleep	Basic Nordic Sleep Questionnaire	<i>Partinen & Gislason (1995) Epworth Adapted</i>
Health and care service use	Client Service Receipt Inventory (CSRI)	<i>Beecham & Knapp (2001)</i>
Significant Life Events	PAS-ADD checklist	<i>Moss et al. (1998)</i>
Dementia screening	Dementia Questionnaire for People with Intellectual Disabilities (DLD)	<i>Evenhuis, Kengen & Eurlings (2006)</i>
	Dementia Screening Questionnaire for Individual with Intellectual Disability (DSQIID)	<i>Deb, Hare, Prior & Bhaumik (2007)</i>
	Adaptive Behaviour Dementia Questionnaire (ABDQ)	<i>Prasher, Farooq & Holder, 2004)</i>
	Cambridge Examination for Mental Disorders of Older People with Down' Syndrome (CAMDEX)	<i>Ball, Holland, Huppert, Treppner & Dodd (2006)</i>



Pink – Family carer
Blue – Paid Carer

Cognitive Assessment:

Domain(s) Measured	Instrument Name	Reference
Cognitive and functional level of ID	Peabody Picture Vocabulary Test (PPVT)	<i>Dunn & Dunn (2007)</i>
Motor function, language, comprehension, delayed memory, general knowledge and conceptualisation	Test of Severe Impairment (TSI)	<i>Albert & Cohen (1992)</i>
Vocabulary, grammatical morphemes and elaborated phrases and sentences	Test for Auditory Comprehension of language - 3rd Edition (TACL-3)	<i>Carrow-Woolfolk (1999)</i>
Memory encoding, recall and retrieval	Cued Recall Test (CRT)	<i>Buschke (1984), Grober & Buschke (1987)</i>
Executive function - planning and working memory	Scrambled Boxes Test (SBT)	<i>Adapted from Griffith et al. (1999), Ball et al. (2008)</i>
	Tower of London (TOL)	<i>Shallice (1982)</i>
Dementia-related cognitive skills: memory, orientation, language and praxis	Neuropsychiatric Assessment of Dementia in Individuals with ID (NAID)	<i>Crayton & Oliver (1993), Oliver, Crayton, Holland, Hall, & Bradbury (1998)</i>



Our Time 1 ID sample so far... (n=121)

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

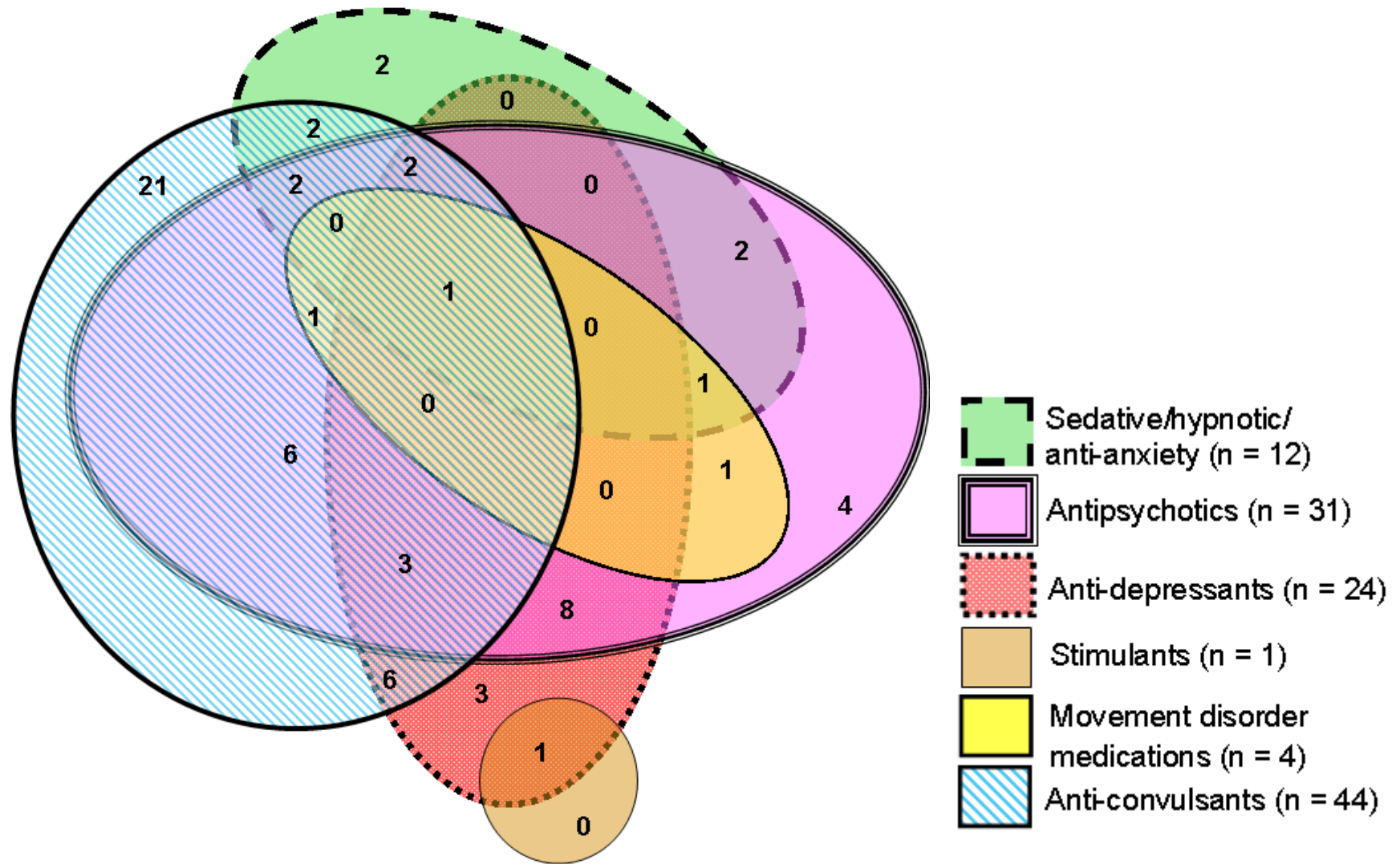
Physical health:

- BMI range 18.5 – 49.9; **75% ranged overweight → morbidly obese!**
- Stroke – 4.1% 1 or more
- High blood pressure – 26.2% (only 13.1% meds)
- **Cholesterol – 25.4%** (only 12.3% meds)
- Diabetes – 19.6%
- Thyroid – 12.3% (Underactive 10.7%; Overactive 1.6%)
- **Fits/Epilepsy – 36%** (30.3% meds)
- **Consulted a psychiatrist/psychologist – 48%**
- Sight problems – 27.7%
- **Physical disability – 36%** (13% confined to wheelchair)
- Diagnosed with Autism/ASD/Aspergers – 15%
- **12 flagged dementia cases** - CCC

CNS Medications - Summary

- 62% on at least one CNS acting medication
- The medicated group had significantly higher DBC-A total score
- Diagnosis of psychiatric and/or neurological disorder were significant predictors of CNS medication usage (age, gender, DBC-A were not significant)
- Anti-convulsants and antipsychotics most commonly used classes:
 - Sodium valproate, lamotrigine and carbamazepine most common medications
- Of those on a CNS medication, 72% were on more than one CNS medication
 - There were 10 participants on four or more CNS medications
- Documented indications for CNS medication usage were low
 - 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

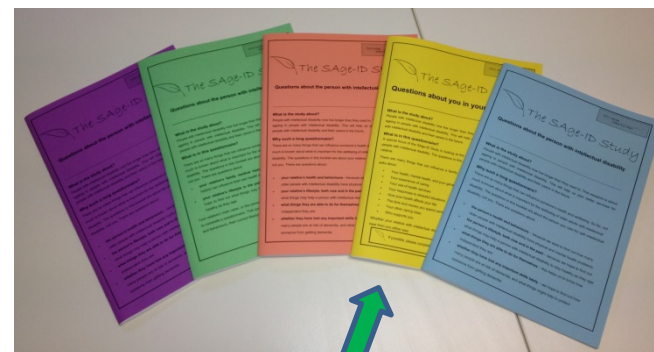
CNS Medication Polypharmacy



Carers

- Questionnaires
- Semi-structured focus groups (2 Sydney, 1 Illawarra)

Domain(s) Measured	Instrument Name	Reference
<i>Questionnaire completed by family carer regarding themselves</i>		
Objective Carer Burden	National Mental Health and Wellbeing survey	<i>Australian Bureau of Statistics (2007)</i>
Subjective Carer Burden	Zarit Burden Scale	<i>Zarit, Orr & Zarit (1985)</i>
Mental and Physical health of family carer	General health Questionnaire 28 (GHQ)	<i>Goldberg (1978)</i>
	Patient Health Questionnaire 9 (PHQ-9)	<i>Kroenke, Spitzer & Williams (2001)</i>
	Short-Form 12 Health Survey (SF-12)	<i>Ware, Kosinski & Keller (1996)</i>
Quality of Life (health related)	Assessment of Quality of Life survey (AQoL)	<i>Richardson, Atherton Day, Peacock & Iezzi (2004)</i>
Social Supports	Social Support Questionnaire 6 (SSQ6)	<i>Sarason, Sarason, Shearin & Pierce (1987)</i>
Coping responses	Breif COPE	<i>Carver (1997)</i>



Yellow – Family Carer burden

Our Time 1 carer sample so far... (n=80)

		Male (N=13)	Female (N=67)	Total (N=80)
Mean Age (years)		62.9	68.6	67.8
Marital Status				
	Married	91%	82.6%	60%
	Single	9%	8.7%	6.3%
	Divorced/Widowed	0%	8.7%	1.3%
Relationship to Person with ID				
	Mother	0%	67.7%	58.6%
	Father	40%	0%	5.3%
	Sibling	50%	23.1%	26.6%
Work Status				
	Not working due to person w/ ID	10%	12.3%	12%
	Not working for other reasons	40%	29.2%	30.6%
	Full time homemaker	10%	38.5%	34.6%
	Working full time	30%	7.7%	10.6%
	Working part time	0	7.7%	6.6%
	Working casually	0	4.6%	4%

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

Carer Burden

"It's just this feeling that it's all on my shoulders"

Health and Wellbeing

"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"

Focus Groups, N = 19

Main themes on experience of caring

Transitions of Care

"I couldn't have looked after her. I couldn't have her at home. She just had to be looked after"

Family Relationships

"As much as I don't want to admit it, he did have an effect on the other children"

Professionals

- Semi-structured focus groups (Sydney, Illawarra)

Current and Future.....

- **Current Papers:**

- Time 1 Methodology of sage-id
- CNS Medications in ID sample
- Family carers' experience

- **Future Papers:**

- 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



Cognitive and neuropsychiatric profiles among *FMR1* premutation carriers

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Collaboration: UNSW, Monash University, LaTrobe University, Hunter Genetics, MCRI, University of Melbourne

Funding: ARC DP, DCRC, NSW IOP

Project life: 2010-2014

Outline

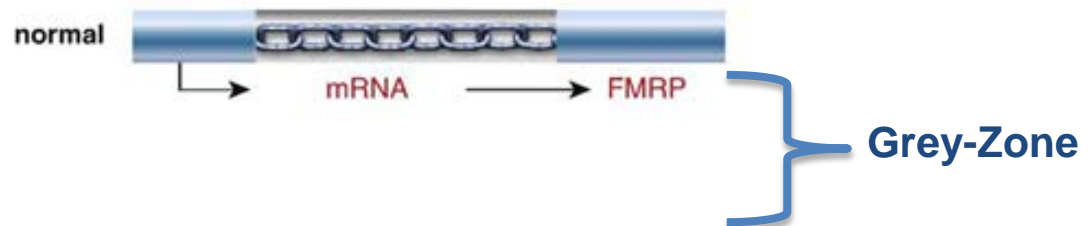
- *FMR1* gene
- Fragile X-associated disorders (FXDs):
 - Fragile X Syndrome
 - Fragile X-associated Primary Ovarian Insufficiency (FXPOI)
 - Fragile X-associated Tremor Ataxia Syndrome (FXTAS)
- Australian premutation carrier study
- FXTAS treatments

Fragile X Mental Retardation 1 (*FMR1*) Gene

The *FMR1* gene is located in the 5' untranslated region of the long arm of the X chromosome and contains a DNA segment of CGG repeats

Normal Population:

<45 CGG repeats



Premutation Carriers:

55-200 CGG repeats



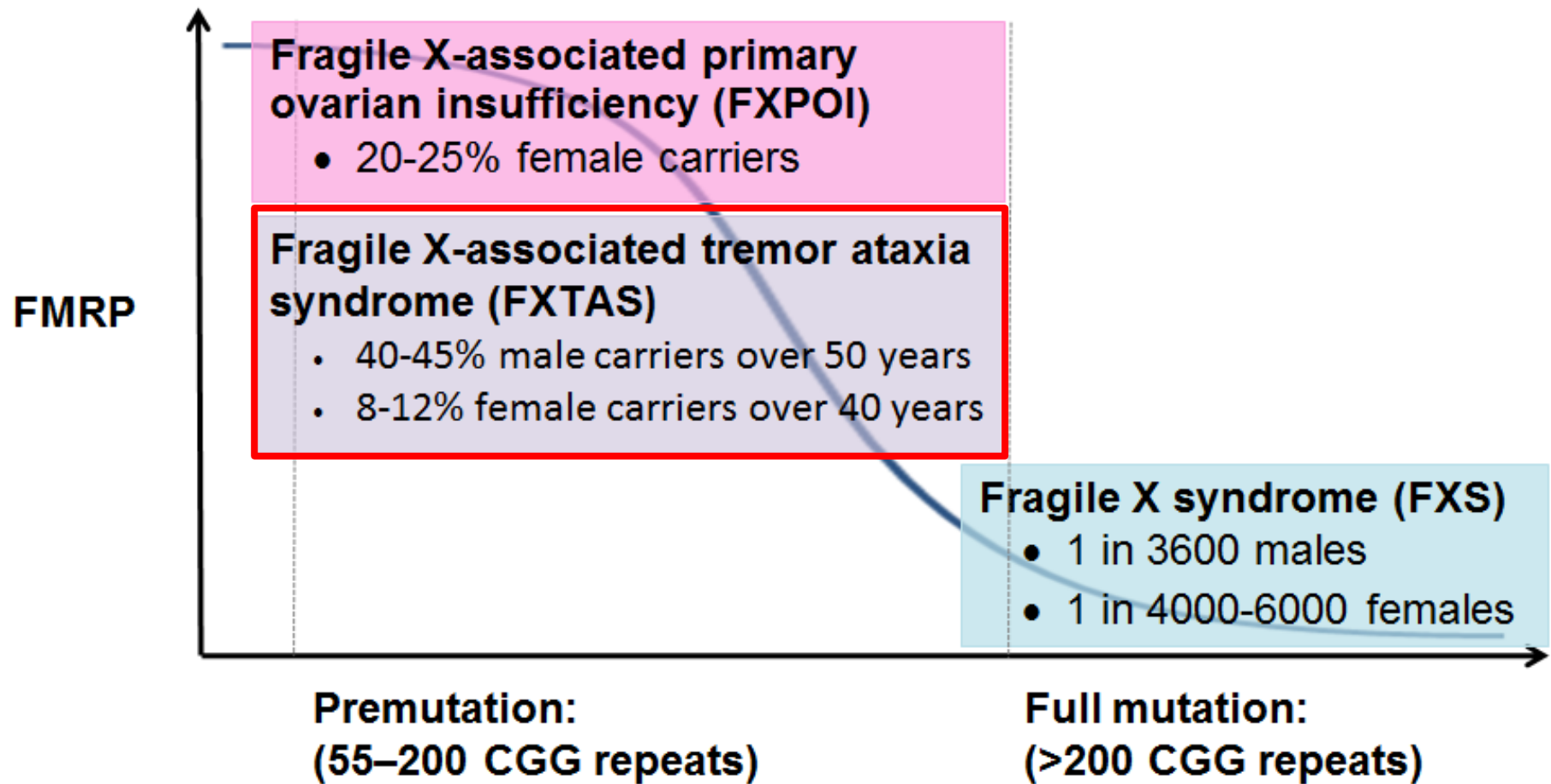
Full-mutation:

>200 CGG repeats



Oostra & Willemsen (2009), Biochimica Et Biophysica Acta-General Subjects, 1790(6), 467-477

Fragile X-associated Disorders



FXTAS: Neurological manifestations

Central

- Tremor
- Gait ataxia
- Parkinsonism
- Cognitive Decline
- Behavioural & Psychiatric

Peripheral

- Neuropathy
- Hearing loss

Autonomic

- Orthostatic hypotension

Neuropsychiatric profile

Cognitive Deficits

- Executive functioning
- Working memory
- Information processing
- Fine motor

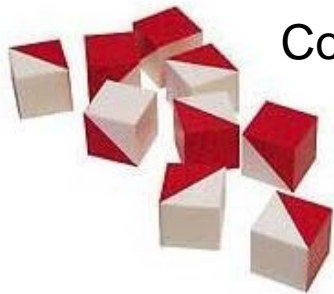
Rates of Mental Disorders

- Depression
- Anxiety
- Irritability
- Agitation / Aggression
- Disinhibition
- Apathy

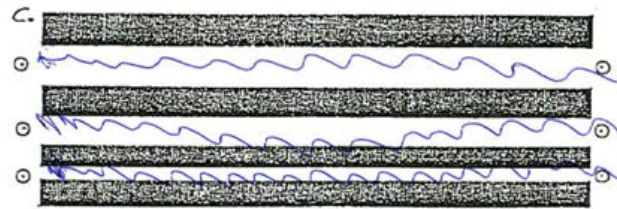
[1] Bacalman, S., et al. Journal of Clinical Psychiatry, 2006. **67**(1): p. 87-94. [2] Grigsby, J., et al. Neuropsychology, 2008. **22**(1): p. 48-60. [3] Brega, A.G., et al. Journal of Clinical and Experimental Neuropsychology, 2008. **30**(8): p. 853-869. [4] Cornish, K.M., et al. Cortex, 2008. **44**(6): p. 628-636. [5] Cornish, K.M., et al. Brain and Cognition, 2009. **69**(3): p. 551-558. [6] Allen, E.G., et al. Neuropsychology, 2011. **25**(3): p. 404-411. [7] Bacalman, S., et al. Journal of Clinical Psychiatry, 2006. **67**(1): p. 87-94. [8] Hashimoto, R.-i., et al. Brain, 2011. **134**(3): p. 863-878. [9] Adams, P.E., et al. American Journal of Medical Genetics Part B-Neuropsychiatric Genetics, 2009. **153B**(3): p. 775-785.

Overarching Aims

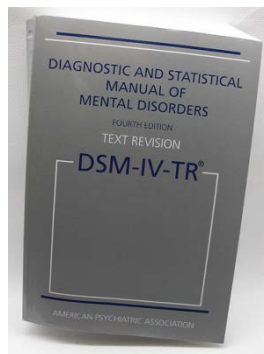
- a) Recruit a cohort of male *FMR1* premutation (PM) carriers
- b) Determine the prevalence and correlates of cognitive and psychiatric symptoms among cohort



Cognitive

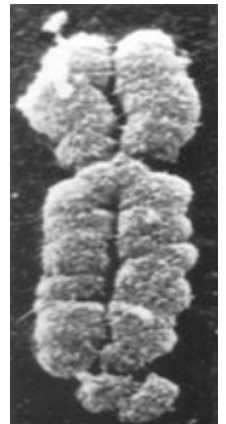


Motor



Psychiatric

Imaging



Genetic

Progress to date

- 25 male PM and 25 controls assessed
- Data entered and cleaned (mostly)
- Commencing data analysis
- 2 review papers submitted
- Multiple international and domestic conference presentations



Data Linkage

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Department of Developmental Disability Neuropsychiatry

Importance of Data

- Not systematically collected anywhere but WA.
- In NSW, IDMH data is collected by two separate agencies:
 - ADHC
 - NSW Ministry of Health.
- Datasets do not currently talk to one another.

Pilot IDMH Data Linkage Project NSW



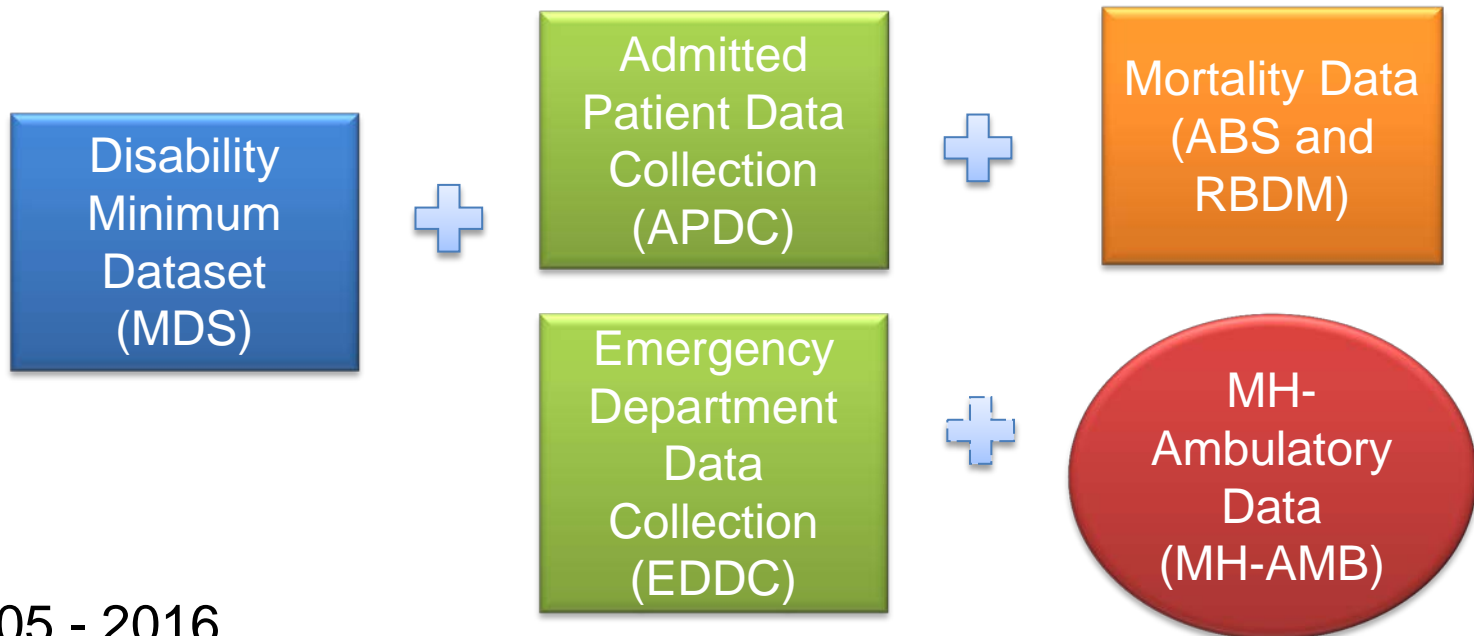
- 2011 - pilot test of linkage (ADHC Funding)
- NSW Health Mental Health Ambulatory data + ADHC Disability Minimum Dataset (MDS)
- 2005-2010.
- Representative area of NSW:
 - Local Health Districts (formerly Area Health Services): South Eastern Sydney (SESLHD), Illawarra Shoalhaven (ISLHD), Sydney (SLHD) & South Western Sydney (SWSLHD)
 - ADHC Regions: Metro South and Southern.

What we found

- People with ID compared to those without ID:
 - Under represented in MH-AMB (only 1.6%)
 - Mean age of 28 years
 - 94% aged under 65 years
 - More likely to be treated for psychotic disorders
 - Less likely to be treated for common disorders: depression & anxiety.
 - No significant difference in personality disorders.
- Uncertainty in diagnosis - 'Unknown category'
- Complexity of those with ID apparent from service use profile:
 - - 1.5x more face-to-face contacts than those without ID.
 - - 2.2x as long than those without ID.

NSW IDMH data linkage - Current

- 2012 – State-wide linkage
- (funding - Mental Health & Drug & Alcohol Office (MHDAO), NSW Ministry of Health)



- 2005 - 2016
- Longitudinal, establishing annually refreshed link feed

Challenges to using data

- Ethics & other approvals processes
 - Burden of administration
 - Variable processes
 - No clear articulation of requirements at outset
 - Approvals processes not at pace with technology
 - Not supportive of exploratory projects

Possible ideas for data in future

- Integration of data in policy making & service development in IDMH.
- Monitoring effectiveness of policy interventions in IDMH.
- Establish a data cube format portal for policy makers, clinicians, consumers & researchers etc.
- Establish register of persons with ID (akin to WA IDEA register).
- The NHMRC Partnerships Grant – 4 years
- Other collaborations and opportunities – NHMRC Partnerships



Other Projects

Never Stand Still

Medicine

Department of Developmental Disability Neuropsychiatry

Indigenous Australians with Cognitive Disabilities

- An ARC linkage grant (Baldry, Trollor, Dowse, Dodson and others)
- focus on aboriginal people with cognitive disabilities
- examines data related to aboriginal offenders and also collects qualitative data obtained from fieldwork in metro, rural and remote indigenous communities.
- substantial bearing on the understanding of the individual and service system factors associated with offending and re-offending in aboriginal people with cognitive disabilities, and on the planning of appropriate supports for these highly vulnerable populations.

INSPIRED Study

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

☒ This Site ☐ UNSW

[Home](#) [About INSPIRED](#) [About Younger Onset Dementia](#) [About Us](#) [Sign me up](#)



[DOWNLOAD STUDY MATERIALS](#)

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.



Future Projects

Never Stand Still

Medicine

Department of Developmental Disability Neuropsychiatry

NHMRC Partnerships for Better Health

Accessible Mental Health Services for People with An Intellectual Disability

- About \$1.8M
- Annualised linkage of administrative minimum datasets of our partners to enable a detailed examination of mental health profiles and service utilisation, patterns of cross-sector service provision including specific gaps, the impact of recent service initiatives for people with ID, and to enable comprehensive development of ID mental health services in NSW.
- Analyse Commonwealth and State mental health policy to determine the current representation of people with ID and to establish strategies which will enhance ID mental health policy.
- Engage with stakeholders including consumers and support persons (including family and non-family carers), to inform improved recognition of mental ill health, accessibility of mental health services and mental health policy for people with ID across the lifespan.



Potential Projects

Never Stand Still

Medicine

Department of Developmental Disability Neuropsychiatry

Cooperative Research Centre for Inclusion and Participation of People with Cognitive Disability

Concept Overview and Benefits Analysis

Workshop Sydney 5 February, 2014



Cooperative Research Centre for Inclusion
and Participation of People with Cognitive Disability



UNSW
THE UNIVERSITY OF NEW SOUTH WALES



Work in Progress

- ▶ Consortium likely to comprise La Trobe University, Griffith University, University of NSW and ANU.
- ▶ Engagement with key State and Federal Government agencies and major service providers.
- ▶ A proposed \$7 m p.a. industry consortium.
- ▶ Looking to realise benefits over 15 years of >\$200million
- ▶ The CRC proposes five research programs:
 1. Improving social connectedness
 2. Increasing economic participation
 3. Upholding justice
 4. Enabling safe and effective hospital encounters
 5. Greater workforce capacity

CRC Program

“The CRC program supports medium to long-term end user driven research collaborations to address major challenges facing Australia. CRCs pursue solutions to these challenges that are innovative, of high impact and capable of being effectively deployed by the end users.”

- Federal Government’s major research funding program
Typically award \$3 to \$4 million p.a. to successful applicants each round
- Funding is for 5 to 10 years (7 years for this CRC)

Aim of the consortium

“The CRC will focus on enriching the lives of adults with non-progressive cognitive disability”

This will be achieved by improving the capacity of service providers to deliver the most appropriate support and for people with cognitive disability to achieve higher rates of participation and contribution to the community.



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

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Medicine

Department of Developmental Disability Neuropsychiatry



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.

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

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

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

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

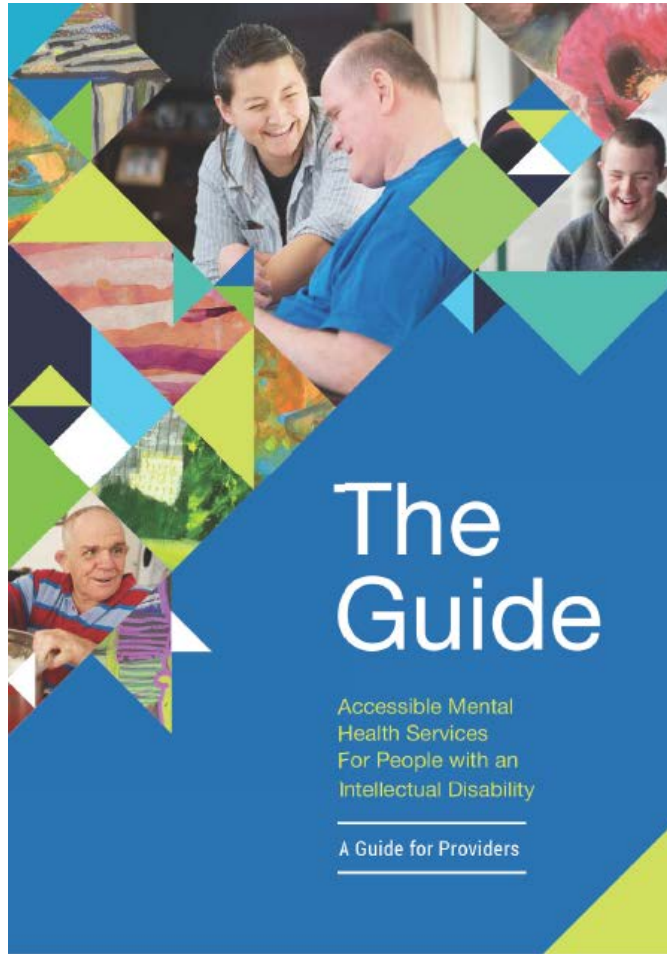
The Guide

The Objectives – 2014

- Finalise and publish The Guide
- The Official Launch – May 2014 RANZCP Congress Perth
- Implementation and dissemination strategy
- Obtain funding for the next phases of the project:
 - An Implementation and Self Assessment Toolkit
 - A Carer and Consumer Resource Package
- Potential publication

Belinda Bennie

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



Launch

- *May 2014*
- pre-launch from late March on web 3dn.unsw.edu.au



IDMH e-learning

Never Stand Still

Medicine

Department of Developmental Disability Neuropsychiatry

IDMH e-learning

Goal

To improve mental health outcomes for people with an ID by enhancing the knowledge, skills, confidence & attitudes of relevant stakeholders

Objectives

To deliver structured education which is relevant, comprehensive, evidence-based, peer-reviewed, accessible and user-friendly

To deliver education tailored to distinct stakeholder groups: health professionals; disability professionals; families/carers; people with an ID

To raise the profile and increase the visibility of people with an ID

To support positive relationships and collaboration between stakeholder groups

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

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



3DN February 2014



Discussion Points

- FACS research strategy directions and input
 - relationship with UNSW Chair IDMH & IDBS
 - Relationship to NDIS research
 - Capacity building approach
- Data
 - Preservation of capacity to link to other data sets is critical
- Funding
 - Focus, value & future of competitive rounds
- NDIS & NGOs- new environment for research