Mental Health and Intellectual Disability

The need for a public mental health approach

Emeritus Professor Bruce Tonge

Centre for Developmental Psychiatry and Psychology
Monash University
Acknowledgements

I am delivering this address on the traditional lands of the Kulin nation and acknowledge and pay my respects to their elders past, present and emerging and to any Aboriginal and Torres Strait Islanders with us today.
The Australian Child to Adult Development Study (ACAD)

Centre for Developmental Psychiatry and Psychology, Monash University

Brain and Mind Research Institute, University of Sydney
ACAD TEAM

**Monash University**
Professor Bruce Tonge  
Professor Kylie Gray  
Dr John Taffe  
A/Prof. Avril Brereton  
+ 17 PhD. Graduates  
Funding: NHMRC, NIH, ARC

**University of Sydney**
Professor Stewart Einfeld  
Professor Trevor Parmenter  
Dr. Sian Horstead  
**Oregon State University**
Professor Scott Hofer  
A/Prof Andrea Piccinin  
Dr Daniel Bontempo
Intellectual disability (ID) is a public health and welfare burden.

What is the added burden of mental health problems?

2.0 + % of Australians have ID

(subnormal IQ and adaptive functioning)
Longitudinal study

Epidemiological sample (592)

- Down (74)
- Prader-Willi (61)
- Williams (67)
- Fragile X (64)
- Autism (168)
EPIDEMIOLOGICAL SAMPLE

Representative sample of young people (4-18 years) with intellectual disability

- Grafton (31)
- Murray Murrumbidgee (189)
- Ryde (44)
- Sutherland (141)
- Wollongong (123)
- Dandenong-Westernport (64)

MELBOURNE

SYDNEY
Data collection

- Postal questionnaire
- Psychiatric interview of selected sample
- Medical and genetic history, investigation & examination
- Cognitive assessment
Participation rate Time 1 families at:

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<th>T 2</th>
<th>81%</th>
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<td>T 3</td>
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No significant differences (age, sex, IQ level, or degree of psychopathology) between participants and non-participants
Outcome variable: Psychopathology

Developmental Behaviour Checklist

- 96 item carer completed questionnaire (DBC-P) for 4-19 year olds with ID/DD or 106 item DBC-A (adult version for those over 18)
- assesses behavioural & emotional disturbance
- Mean Behaviour Problem Score (MBPS) & five subscale mean scores: (Disruptive, Self absorbed, Communication disturbance, Anxiety, Social relating)
- “Caseness” scores: (> .48 (DBC-P) or >.57 (DBC-A) indicates a clinically significant level of disturbance. Sensitive to change and treatment response.
- Screens: for Anxiety, Depression, ADHD, Psychosis, ASD
Bruce Tonge, Monash University, Stewart Einfeld, University of Sydney

Caroline Mohr, Kylie Gray, John Taffe, Monash University
Anne Rymill, Disability SA

PhD: Barbara Pennington (Elderly), Phil Flint (ATSI).

Funded by:
Australian Research Council Linkage Grant, Apex Foundation for Research into Intellectual Disability, Helen McPherson Smith Trust

Industry Partners:
Disability SA (formerly IDSC), Minda Inc., Department of Education and Children’s Services (DECS)
Why South Australia?

Disability SA Register
Interagency and inter-sectorial co-operation
10 years Dual Disability Programme
METHOD

Survey of all adults (16+ years) registered with an ID living in 21 postcodes spread across the socio-economic spectrum with urban/rural mix including one of the two state campus facilities.

contact with case workers facilitated participation

73% questionnaire return rate, N = 1610
Data collection strategy

Questionnaire mail out to carers/case workers:

Demographic/Personal Information:
DBC-A
Adaptive Behaviour Assessment System-II (ABAS-II) (Harrison & Oakland, 2003)

Procedure:

FOR ELDERLY (55+ years, N=322): 20%
Carer/Case worker interview.
Questionaires: DBC(A), Adaptive Behaviour Dementia Questionnaire (ABDQ) (Prasher, 2004).
Dementia Screening Quest. Individuals with Intellectual Disability (DSQIID) (Deb et al., 2007).
ABAS-II.

For ATSI Group (n=199): 12.4% : 1/3 Remote: 40% NESB.
Culturally approved methodology in undertaking research
Personalised approach through the indigenous carer/elder to data collection
The public health burden of behavioural and emotional problems in intellectual disability
Serious psychopathology:

is the most common complication and added burden of ID (affecting approximately 40% children, 25% young adults, 20% adults, 15% elderly) That is 2-3 times more prevalent than the general population

is the greatest cause of family stress

is the major cause of failure in community, educational and employment participation

increases the risk of injury three-fold
Biological Cause

Mean Behaviour Problem Score

Epidemiological
Autism
Down
Fragile X
Williams
Prader Willi

Time 1 vs. Time 4
Biological cause: Behavioural phenotypes

Down Syndrome (Trisomy 21)
Relatively lower levels of psychopathology
Externalising disorders
Affective disorders and dementia in adulthood

Prader Willi Syndrome: (Chromosome 15; paternal deletion, maternal uniparental disomy, imprinting defect).
Increased appetite & food obsession
OCD
Impulsive, defiant behaviour
anxiety & depression in adolescence
Psychosis (maternal disomy form)
Reported main cause of ID in ATSIs

- Perinatal 9%
- ABI 9%
- CP 8%
- FA/Substance abuse Syndrome 7%
- Genetic abnormalities 5%
- Down Syndrome 3%
- ASD 4%
- Not Known in 45%

65% have Chronic health conditions
Medical factors

Epilepsy and its control

Current and Chronic ill health

Drug benefits and side effects
Epilepsy: Mean DBC item score vs age

Mean item score is higher among those with epilepsy, but declines more with age.
Chronic Health Conditions in the elderly

- 79% report chronic health conditions compared to 59.5% <55yrs
  - Epilepsy & asthma more prevalent in <55 yrs
- Health conditions more prevalent with increase in age (range 0-7 conditions each)
Public Mental Health Response

- Ante/post-natal genetic/metabolic screening, obstetric & maternal-infant health care & education (e.g. alcohol/substance use)

- Genetic/behaviour phenotype research (eg. animal models of depression & psychosis. Telomere studies of stress and recovery), clinician education, tailoring of psychosocial interventions.

- Regular health checks (eg. Lennox/Davis) tied to NDIS including monitoring of response to psychotropic medication and side effects.
Psychological factors:

Adult history of Mental Illness

- 38% recorded mental illness diagnosis, decreasing with age
- 30% received help for emotional/behavioural disturbance in last year
- 5% admitted to hospital (10% ATSI)
- 36% prescribed psychotropic medication

Evidence of the work of a Dual Diagnosis Clinic in SA.

Types of mental illness:
- Schizophrenia: 13%
- Bipolar: 18%
- Depression: 27%
- Anxiety: 27%
- Other: 13%
- MDDNOS: 2%

Evidence of the work of a Dual Diagnosis Clinic in SA.
Psychological Factors:

Level of intellectual disability (adaptive behaviour) in ATSI Group

*Only 40% had a formal IQ test (this level decreases further from cities) ? Cultural validity.

ATSI Caseness:
Mild. 38%
Mod. 30%
Sev. 32%
Public Mental Health Response

• Improvement in reliable and valid diagnostic criteria and formulation for mental illness in individuals with ID (eg. DCLD, DM-ID, WHO guidelines).

• Development of reliable mental health screening and clinical assessment procedures and tools (eg. for depression, dementia).

• Development of diagnostic, adaptive behaviour and cognitive assessment tools and psycho-social treatments suited to ID and cultural context

• Workforce training in assessment diagnosis and treatment of mental illness and dedicated multidisciplinary DD clinics.
Psychosocial Factors:
Developmental predictors and correlates of psychopathology (regression/pathway analyses)

Significant

- Psychopathology in childhood +
- Ability to speak and communicate -
- Social networks -
- Family functioning (antisocial behaviours) +
- Parental overprotection (anxiety in girls with more severe ID) +
- Parent/Carer mental health problems +
- Stressful events +
- Financial Hardship +
Little is known about the phenomenology of problematic school non-attendance in students with neurodevelopmental disorders or developmental disability (DD).
Results – Epidemiological sample

- 16% children had school refusal.

The likelihood of school refusal associated with:

- Increasing age

- Children with severe ID were 67% \((p=0.01)\) less likely to have school refusal compared with children with mild and moderate ID

- Higher levels of behaviour and emotional problems \((p<0.001)\).

- Higher levels of anxiety \((p=0.002)\).

- Children with school refusal at Time 1 had significantly higher DBC total mean item scores at Times 4 and 5 \((p<0.001)\)
FAMILY FUNCTIONING
Case vs Non-case

Mean score

Low TBPS vs High TBPS

Low TBPS
High TBPS

Significant
One-way analysis of variance revealed significant group differences at p < .05
Change in parental mental health: Epidemiological sample
Why families of children with disabilities need support

• Significant behavioural and emotional disturbance is an added burden for over 40% of parents of children with DD and is usually already present by the age of five
  • 3-4 times the rate of their typically developing peers

• Behaviour and emotional problems within DD is **not** a phenomenon that children “grow out of” by the time they reach young adulthood

• Parents and caregivers of children with DD experience greater parental stress, and mental health difficulties
  • parental stress is associated with child behaviour and emotional problems
ACAD Evidence based support for families of children with DD

RCT efficacy studies of Parenting education and skill building programmes for parents/carers of:

• Preschool children with ASD (Brereton et al)
• Young adolescents (12-15 years) with ASD (Brereton et al.)
• Youth with ASD: transition to post school options (Brereton and Bull)
• Grandparents of children with ASD (Brereton et al.)
• Anxious children with DD (Ciechomksi et al.)

All programmes led to improvements in child/youth behaviour and emotions and for their parents and caregivers a reduction in stress, and improved mental health.
A Community-Based Parenting Intervention for Parents of Children with Developmental Disability (DD) : Outcomes in the Australian Stepping Stones Triple P Project for 3000+ children in Qld, NSW, Vic.
A public health effectiveness study.

Bruce Tonge¹ Kylie Gray¹, Nan Hu¹, Matthew Sanders³, Kate Sofronoff³, Stewart Einfeld²

¹Centre for Developmental Psychiatry & Psychology, Department Psychiatry, Monash University, Australia
²University of Sydney and Brain Mind Research Institute, Sydney, Australia
³University of Queensland, Brisbane, Australia
Key take home messages…..

• SSTP can be successfully implemented in the community, with community-based practitioners (broad range of disciplines)
• Improvements in child behaviour and emotional problems
• Improvements for parents – depression, anxiety, stress
• Improvements in parenting skills
• Reduction in use of coercive parenting strategies a key mechanism of change in child behaviour and emotional problems
• Cost effective, of economic benefit- parents return to work.
DSM-IV Axis IV
Psychosocial & Environmental Problems
Case vs. Non-case

Mean score

Significant

Low TBPS
High TBPS

Mean score

Low TBPS
High TBPS

Significant

Low TBPS
High TBPS

Significant
SOCIOECONOMIC STATUS

Case vs Non-case

Mean score

- Low TBPS
- High TBPS

Significant
LIFE EVENTS: ATSI
TWICE as many life events as Non ATSI (2.7LE to 1.3LE)
70% ATSI with 1 LE or more (55% non ATSI)
28% ATSI have moved residence in last 12 months
Age negatively associated with number of Life Events
Accommodation and Employment Outcomes for young adults (21-38yr old) with ID. (Gray et al 2014).

Living with parents: Mild ID, 77%; Moderate ID, 70%; Severe ID, 27%; Profound ID, 13%.

25% of parents caring for their adult child in the home reported poor physical health.

30% of parents reported suffering anxiety and depression.

Only 11.3% in paid employment and 22.5% in sheltered workshops.

Limited/No daytime activities: Mild ID 12%, Moderate ID 7%, Severe ID 6%

Behaviour problems associated with limited activities and social exclusion.
Adults with ID in SA.

Usual daytime activity

- School class
- Special unit
- Special School
- TAFE
- Day activity centre
- Supported workshop
- Open employment
- Home duties
- Nothing 15% ATSI 43%
Social networks & daytime activities in the elderly

- 43.7% have a relationship with paid staff, 38.9% with families but 31.3% no relationships
- 71.5% mix in home or day placement, 25.9% in community but 17.5% did not mix at all
- 64.8% retirement/day activity (40%<10hrs/wk)
  - 14.4% no activity at all

Remember 70% are under 64 yrs.
Participation in sport/physical activity

- The World Health Organisation (WHO) has identified that all physical activity bestows health benefits to fitness, physical health, mental health, and psychosocial outcomes for children, adults and older adults.

ACAD StudyTime 6 (2016-2019): age 30-44 (mean 35) years

Outcome measure
- Any regular level of participation in sport and physical activity in the past 3 months
ACAD sample results

42% participated in sport/physical activity in past 3 months

Physical mobility – strong correlation between being physically mobile and participation in physical activity (x2.36 increase)

Degree of ID – more mild ID associated with increased likelihood to participate in physical activity

Living situation – living in supported accommodation associated with increased likelihood to participate in physical activity (compared to living at home or living independently)

Behaviour and emotional problems – no significant impact on participation

Socioeconomic status – no significant impact on participation

Down syndrome associated with higher likelihood of participation in sport/physical activity but of low intensity.
Public Mental Health Response

- Evidence based Early Parent education and skills training intervention such as Stepping Stones Triple P: the MHYPEDD program (Einfeld, Sanders & Tonge), addresses problem behaviour, safety, care, communication, developmental disability, and parent stress and mental health.

- Family/carer financial and respite care support.

- Integration of health, education, employment, welfare, housing, and disability services in policy development and service delivery. (e.g. Trollor et al.) Focus of NDIS on individual non-health services has potential to fragment services, encourage individual non-evidence based activities and bypass population wide interventions.

- Build social inclusion and community participation (e.g. Recreation, arts and sport).
The process of clinical research

Systematically defined populations

Discovery

Empirically derived interventions

Biopsychosocial phenomenology
List of publications and further information

http://www.med.monash.edu.au

/scs/psychiatry/developmental/clinical-research/acad.html