Mental Health and Intellectual Disability

The need for a public mental health approach

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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

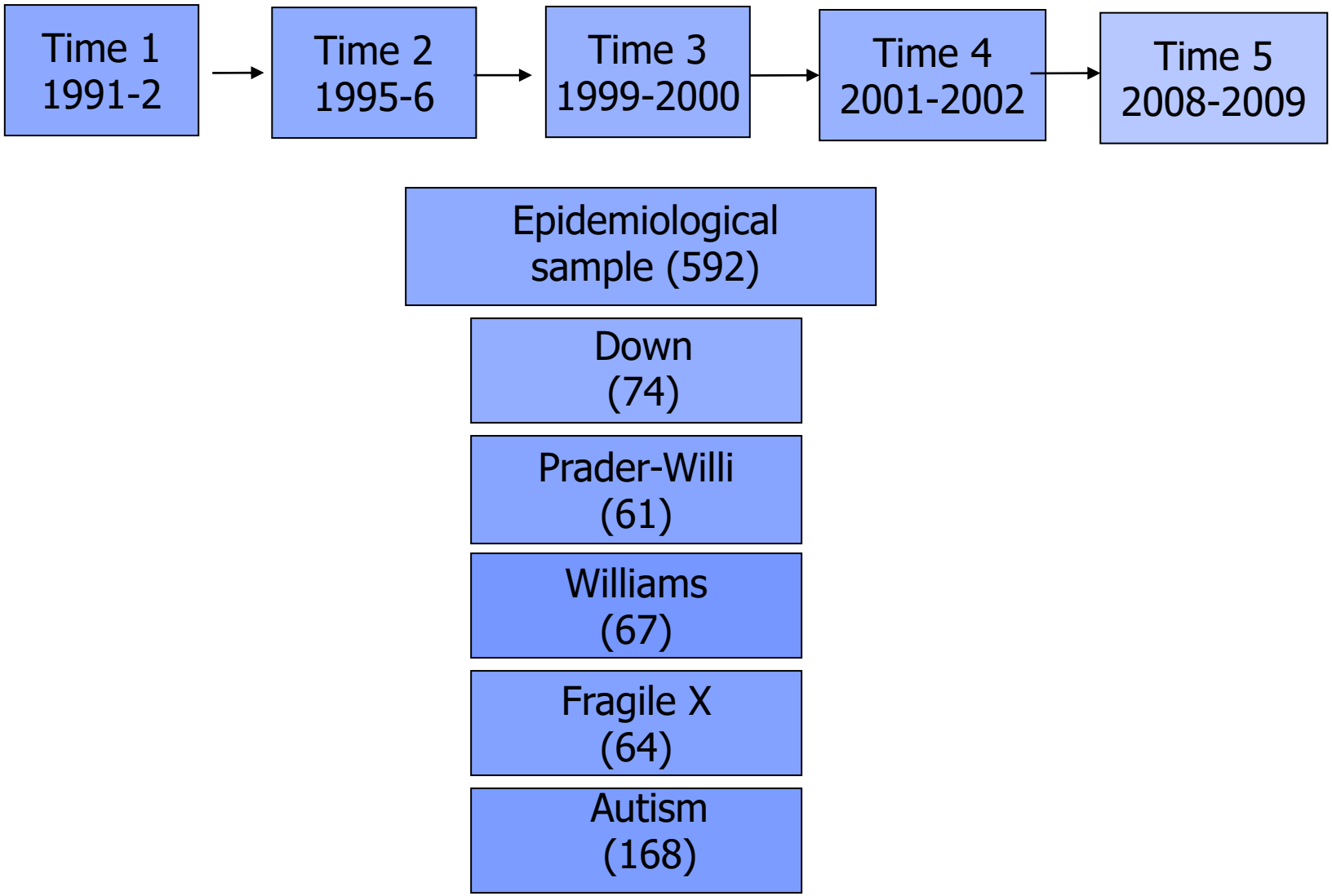
Intellectual disability (ID) is a public health and welfare burden.

What is the added burden of mental health problems?

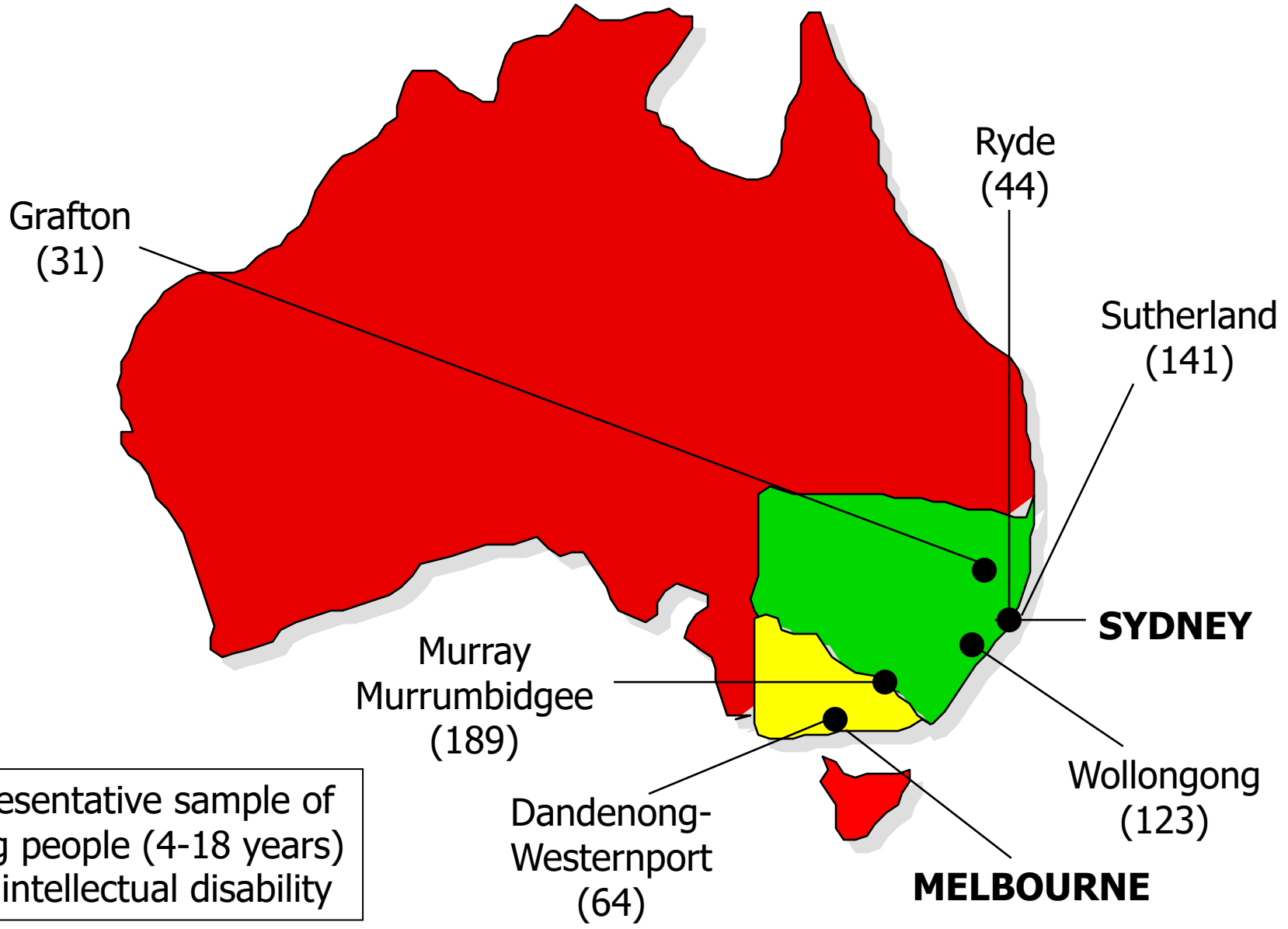
2.0 + % of Australians have ID

(subnormal IQ and adaptive functioning)

Longitudinal study



EPIDEMIOLOGICAL SAMPLE



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

Data collection

- Postal questionnaire
- Psychiatric interview of selected sample
- Medical and genetic history, investigation & examination
- Cognitive assessment

Participation rate Time 1 families at:

T 2	81%
T 3	79%
T 4	80%
T 5	73%

No significant differences (age, sex, IQ level, or degree of psychopathology) between participants and non-participants

Outcome variable: Psychopathology

Developmental Behaviour Checklist

(Einfeld & Tonge1992,2002. Mohr,Tonge & Einfeld 2004 Gray, Tonge, Einfeld, Gruber, Klein, 2018. *2nd Ed.)*

- 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

LifeSpan

Investigating the Mental Health of people with Intellectual Disability across the LifeSpan

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).

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Why South Australia?

LifeSpan
Investigating the Mental Health of people with Intellectual Disability across the LifeSpan

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

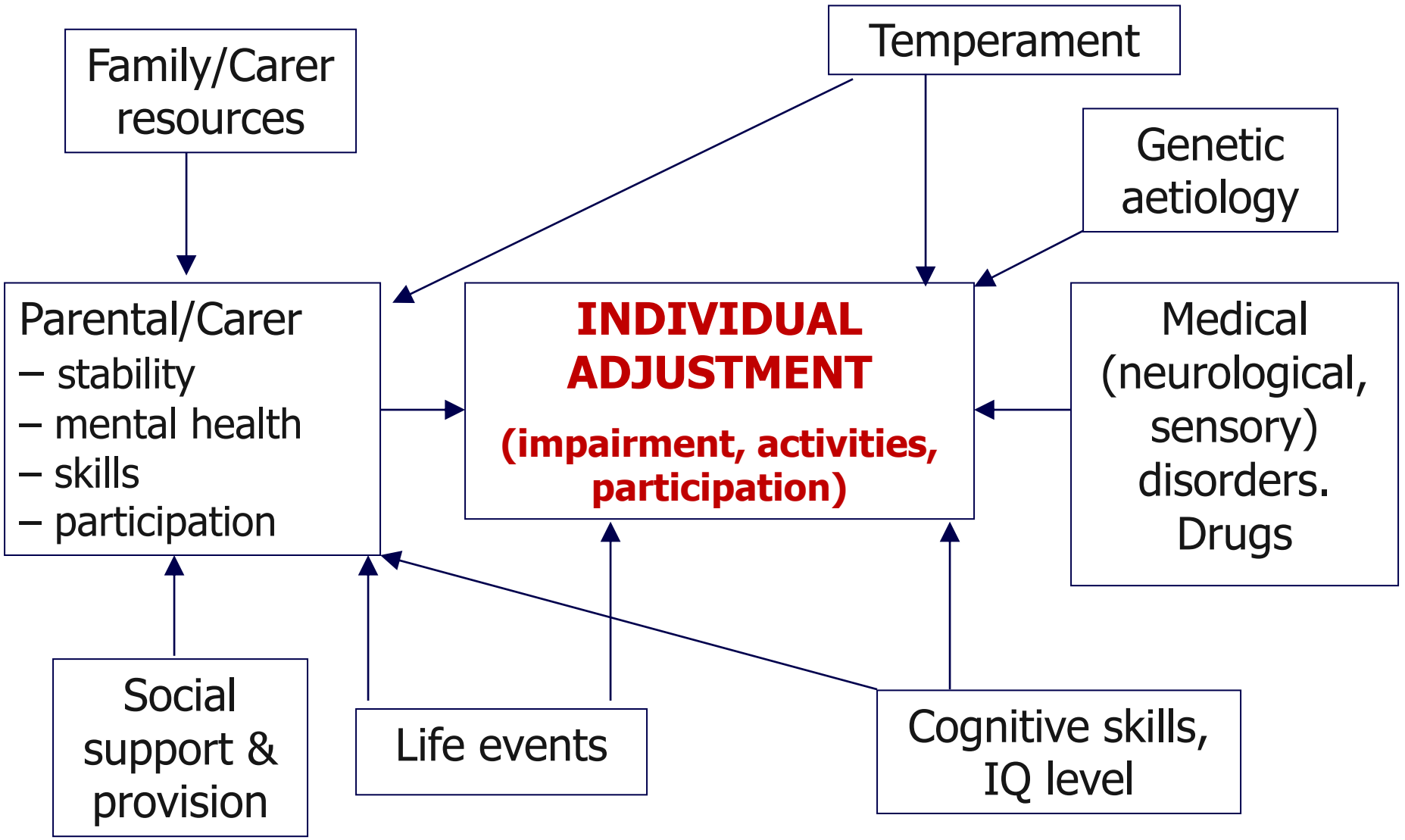
Serious psychopathology:

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

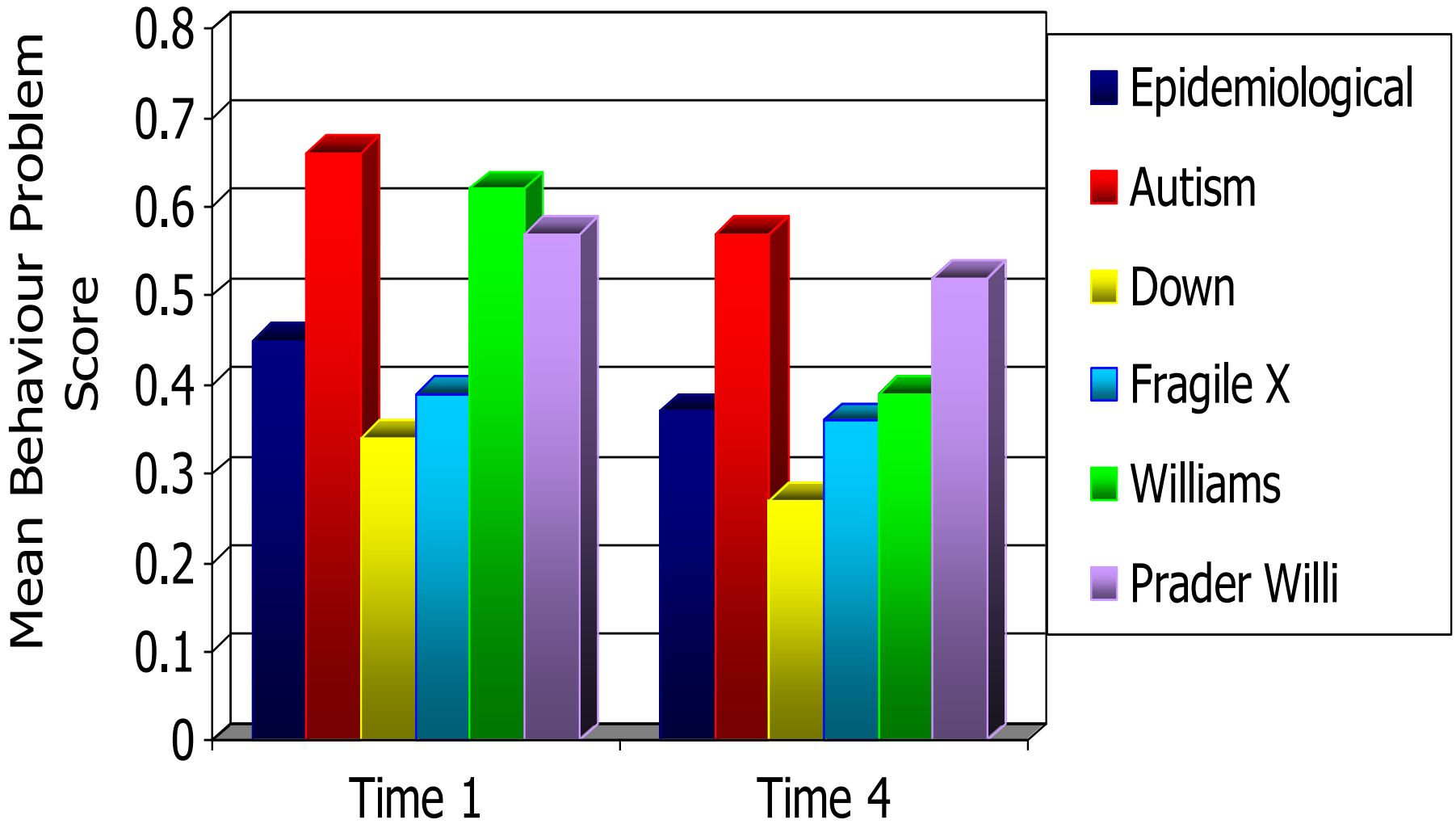
is the greatest cause of family stress

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

increases the risk of injury three-fold


ENVIRONMENTAL
PSYCHOLOGICAL
BIOLOGICAL
Family/Carer resources
Temperament
Genetic aetiology
Parental/Carer
– stability
– mental health
– skills
– participation
INDIVIDUAL ADJUSTMENT
(impairment, activities, participation)
Medical (neurological, sensory) disorders. Drugs
Social support & provision
Life events
Cognitive skills, IQ level

Biological Cause



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

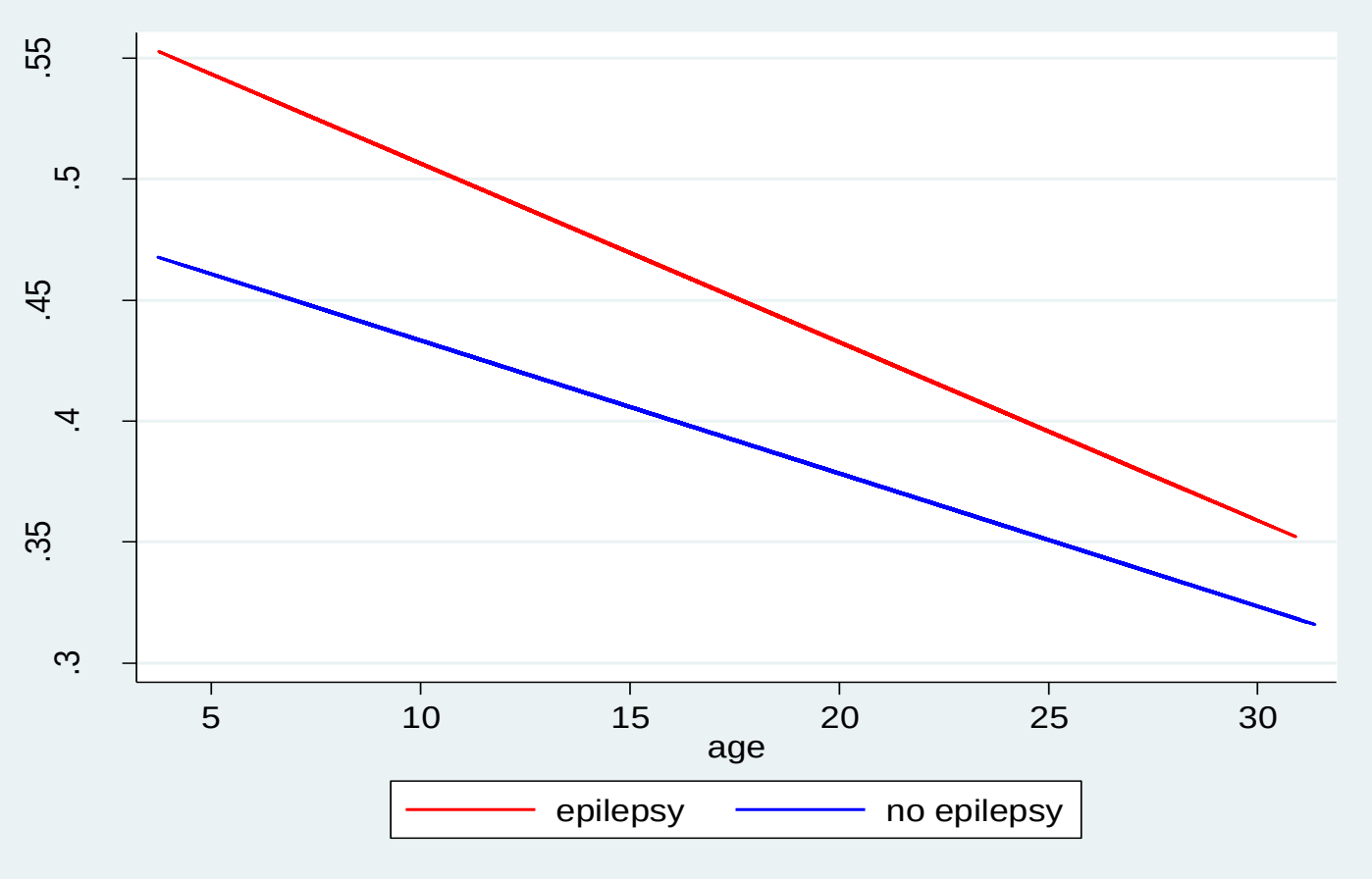
Medical factors

Epilepsy and its control

Current and Chronic ill health

Drug benefits and side effects

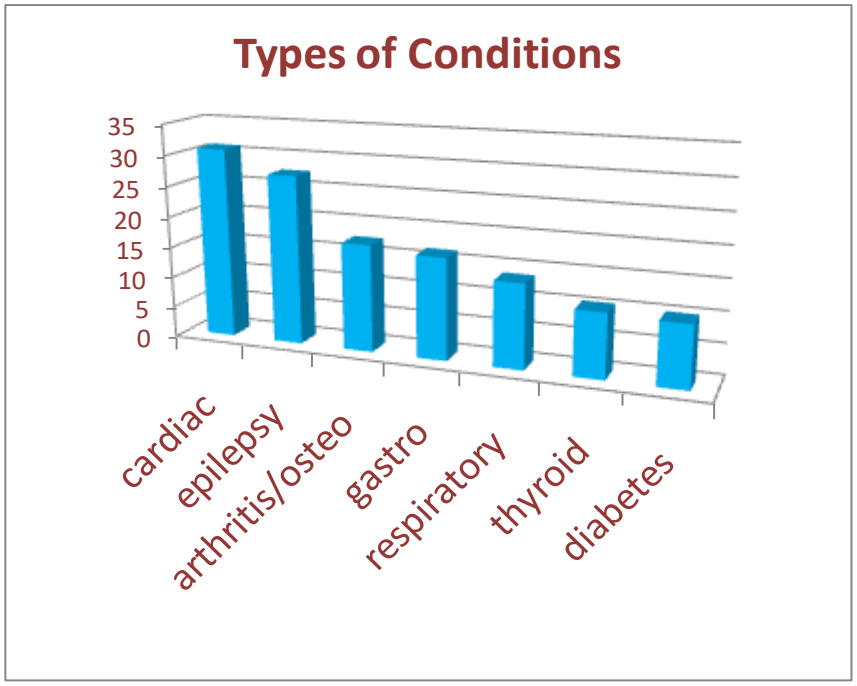
Epilepsy: Mean DBC item score vs age

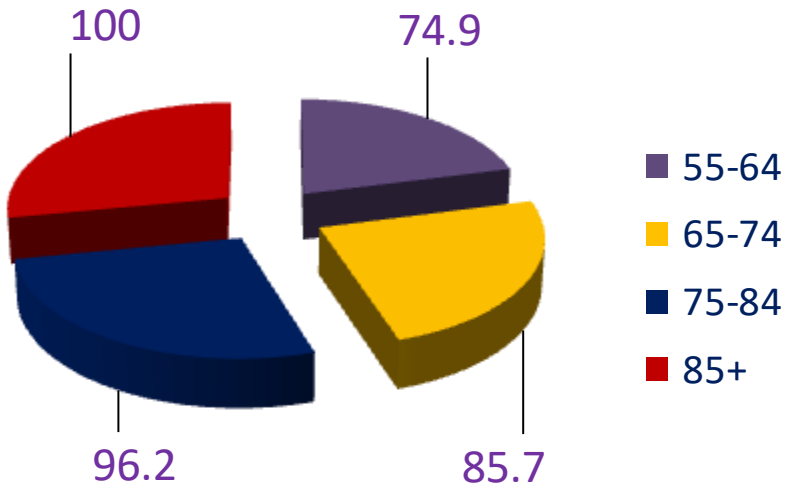


Mean item score is higher among those with epilepsy, but declines more with age

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)*





LifeSpan
Investigating the Mental Health of people with Intellectual Disability across the LifeSpan

Public Mental Health Response

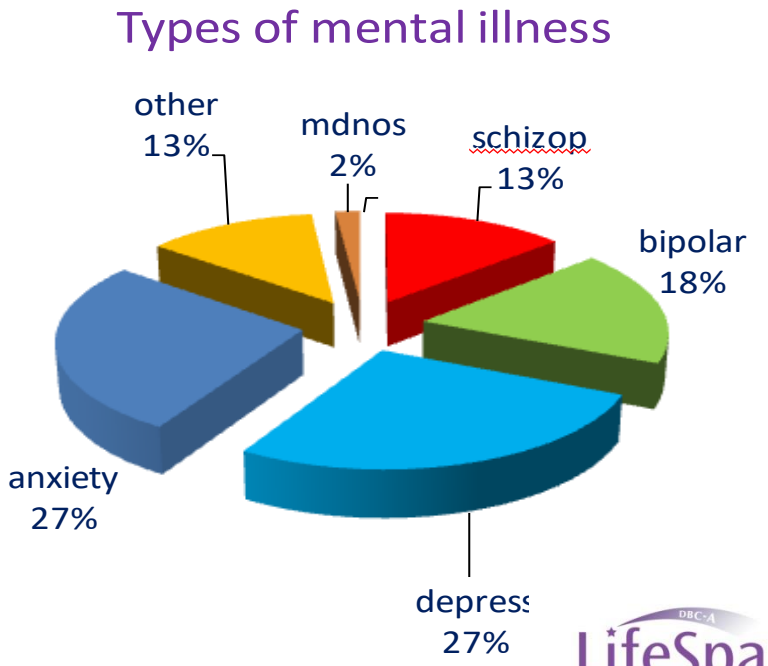
- Ante/post-natal genetic/metabolic screening, obstetric & maternal-infant health care & education (e.g. alcohol/substance use)
- Genetic/behaviour phenotype research (eg. animal models of depression& psychosis. Telomere studies of stress and recovery), clinician education, tailoring of psychosocial 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.



LifeSpan
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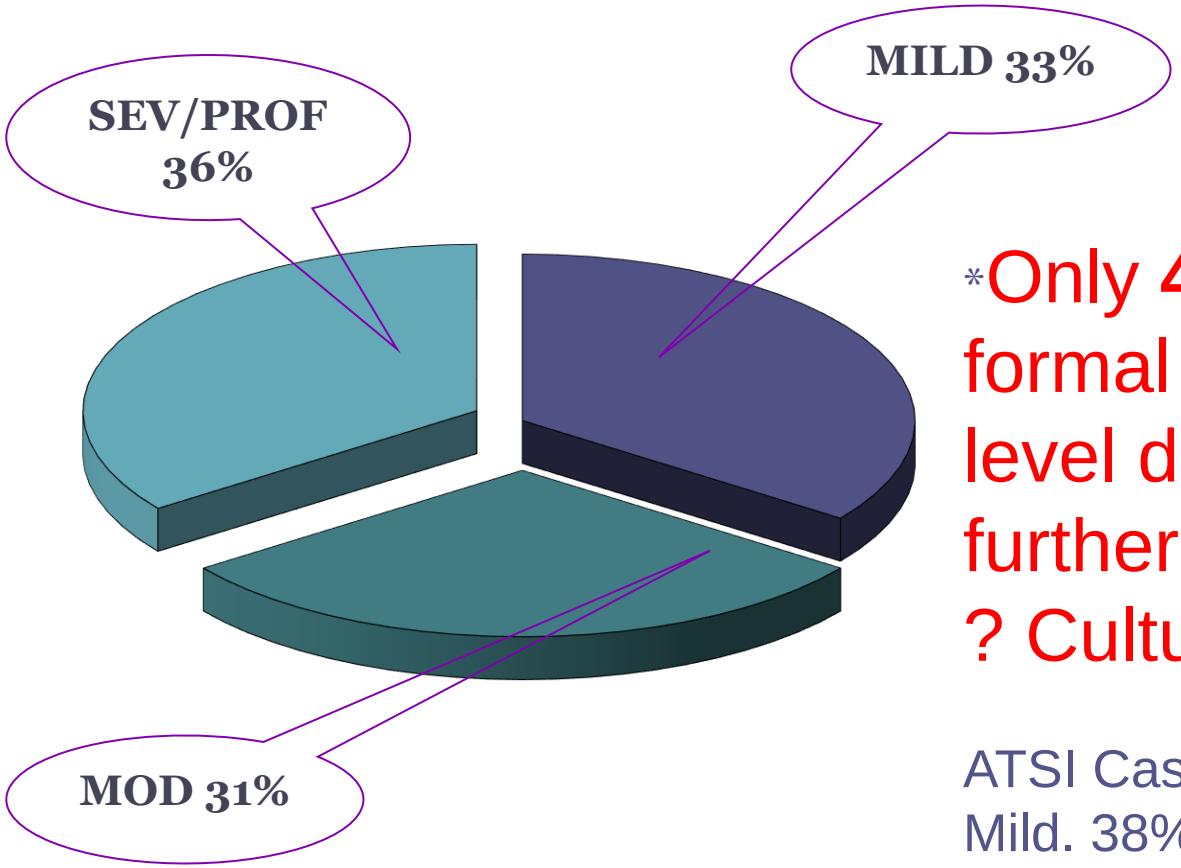
Psychological Factors:

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).

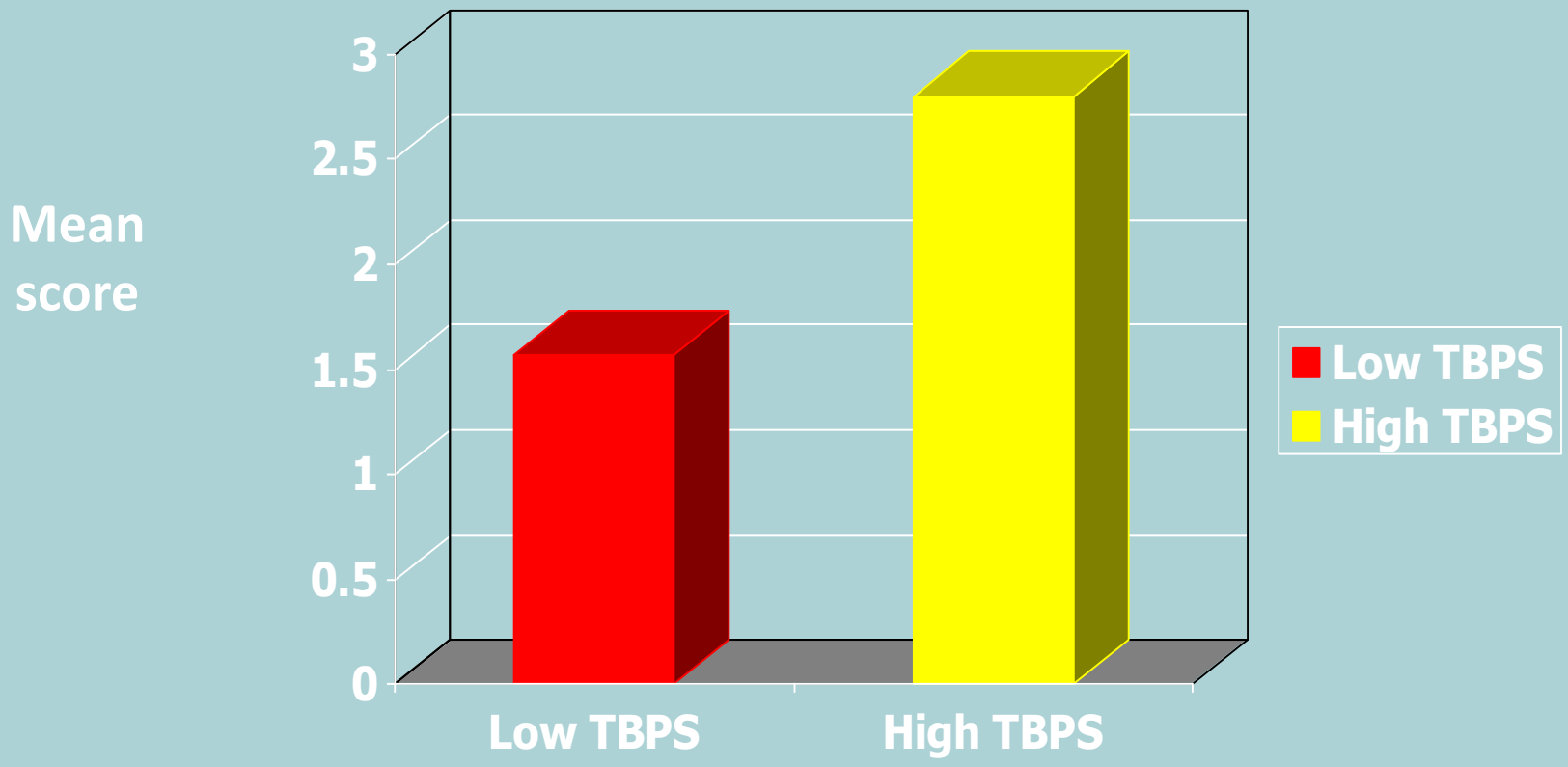
Phenomenology of problematic SNA in DD - ACAD study

- **Results – Epidemiological sample**
  - 16% children had school refusal.

  The likelihood of school refusal associated with:

  - Increasing age
  - Children with severe ID were 67% (*p*=.01) less likely to have school refusal compared with children with mild and moderate ID
  - Higher levels of behaviour and emotional problems (*p*<.001).
  - Higher levels of anxiety *(p=.002)*.
  - Children with school refusal at Time 1 had significantly higher DBC total mean item scores at Times 4 and 5 (p< .001)

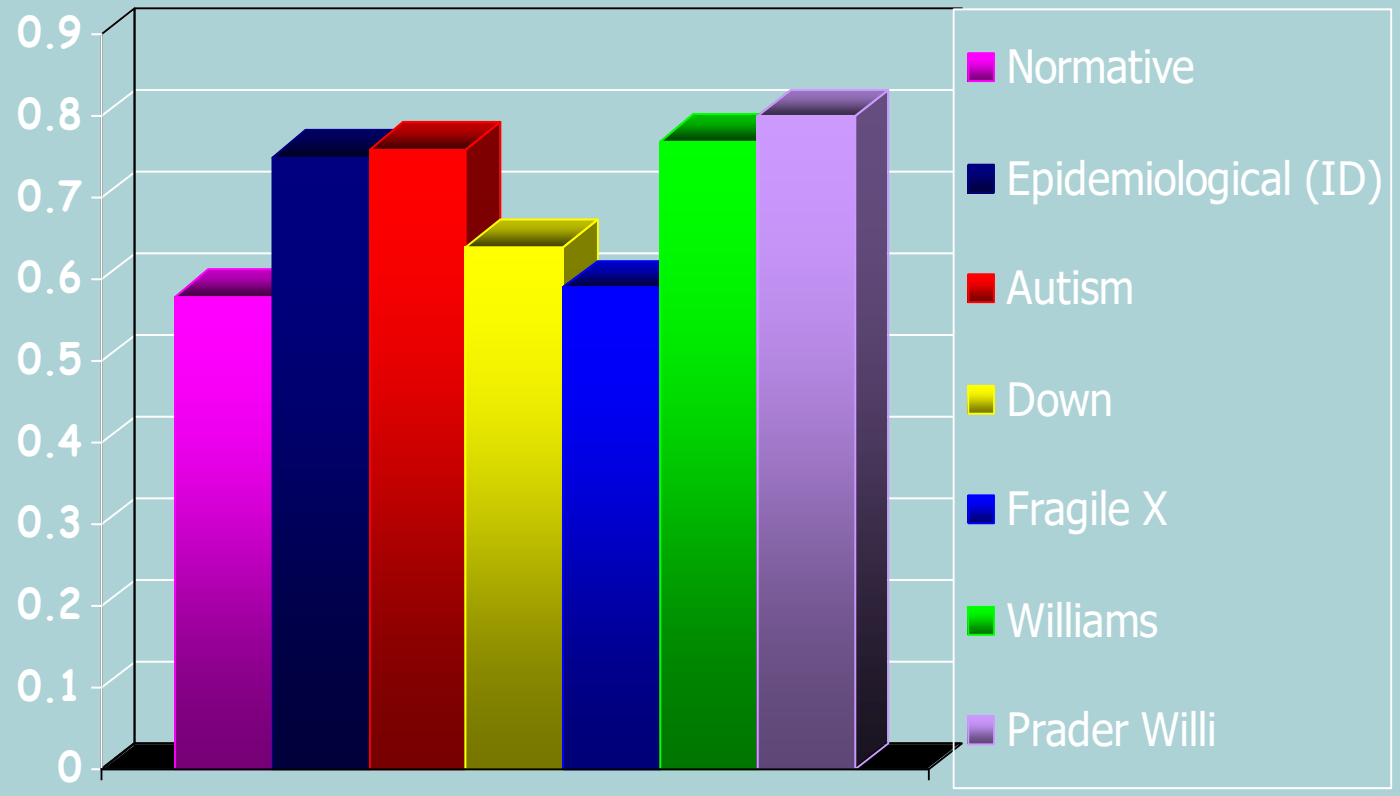
FAMILY FUNCTIONING
Case vs Non-case



Significant

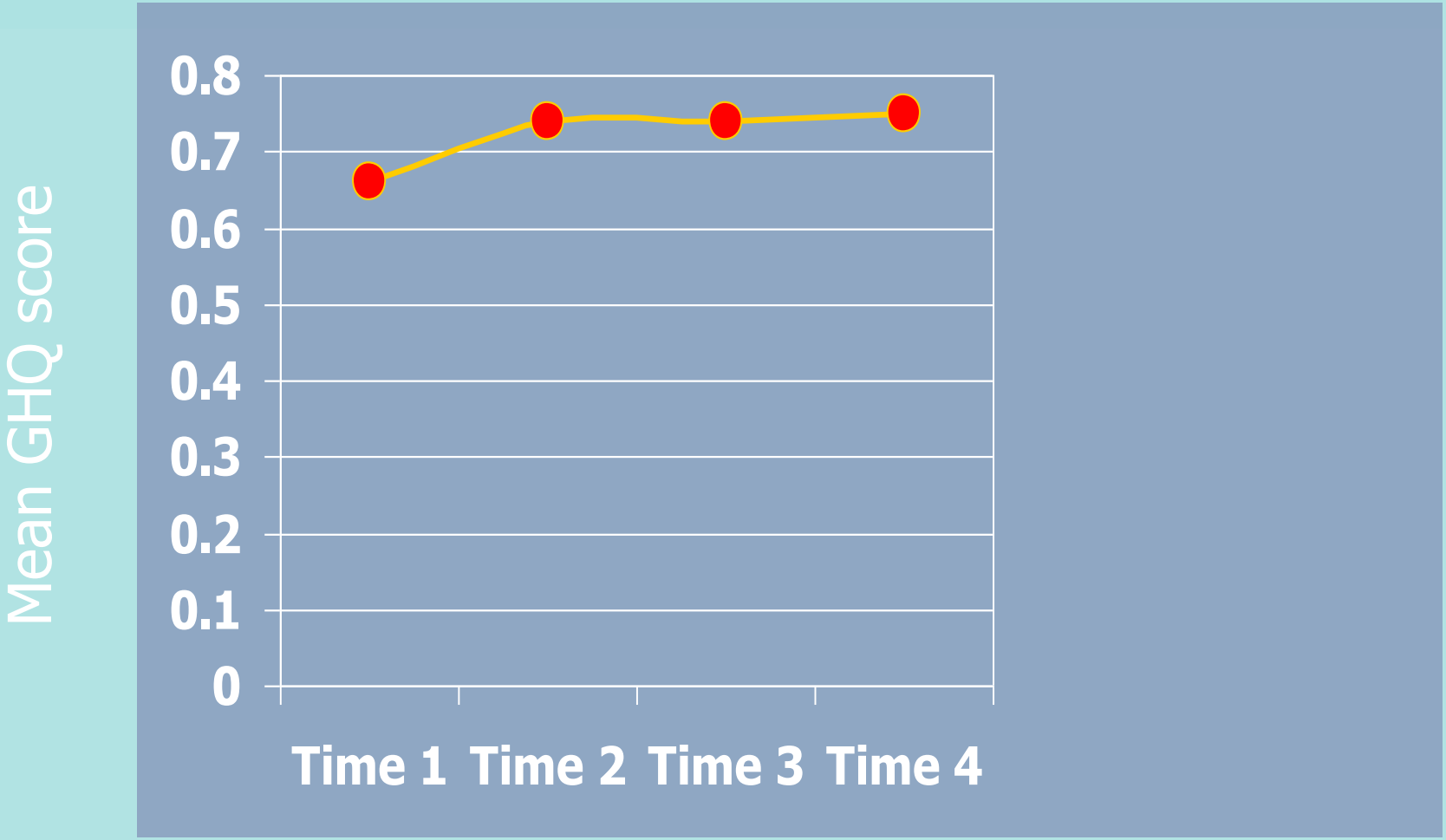
Parental mental health

Mean GHQ score



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 progammes 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 progammes led to improvements in child/youth behaviour and emotions and for their parents and caregivers a reduction in stress, and improved mental health.

MONASH University

Medicine, Nursing and Health Sciences

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.

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National Health & Medical Research Council, Australia

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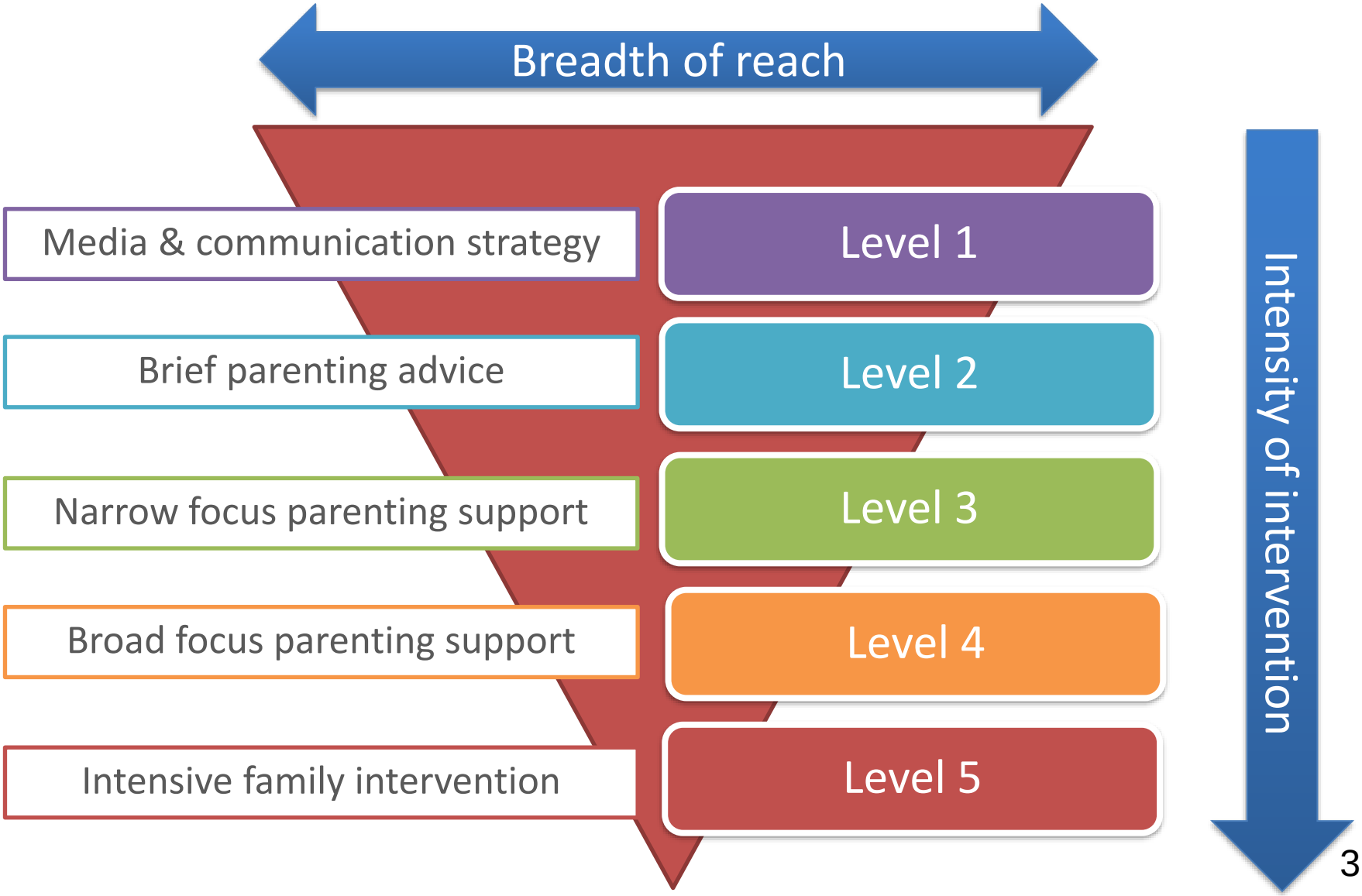
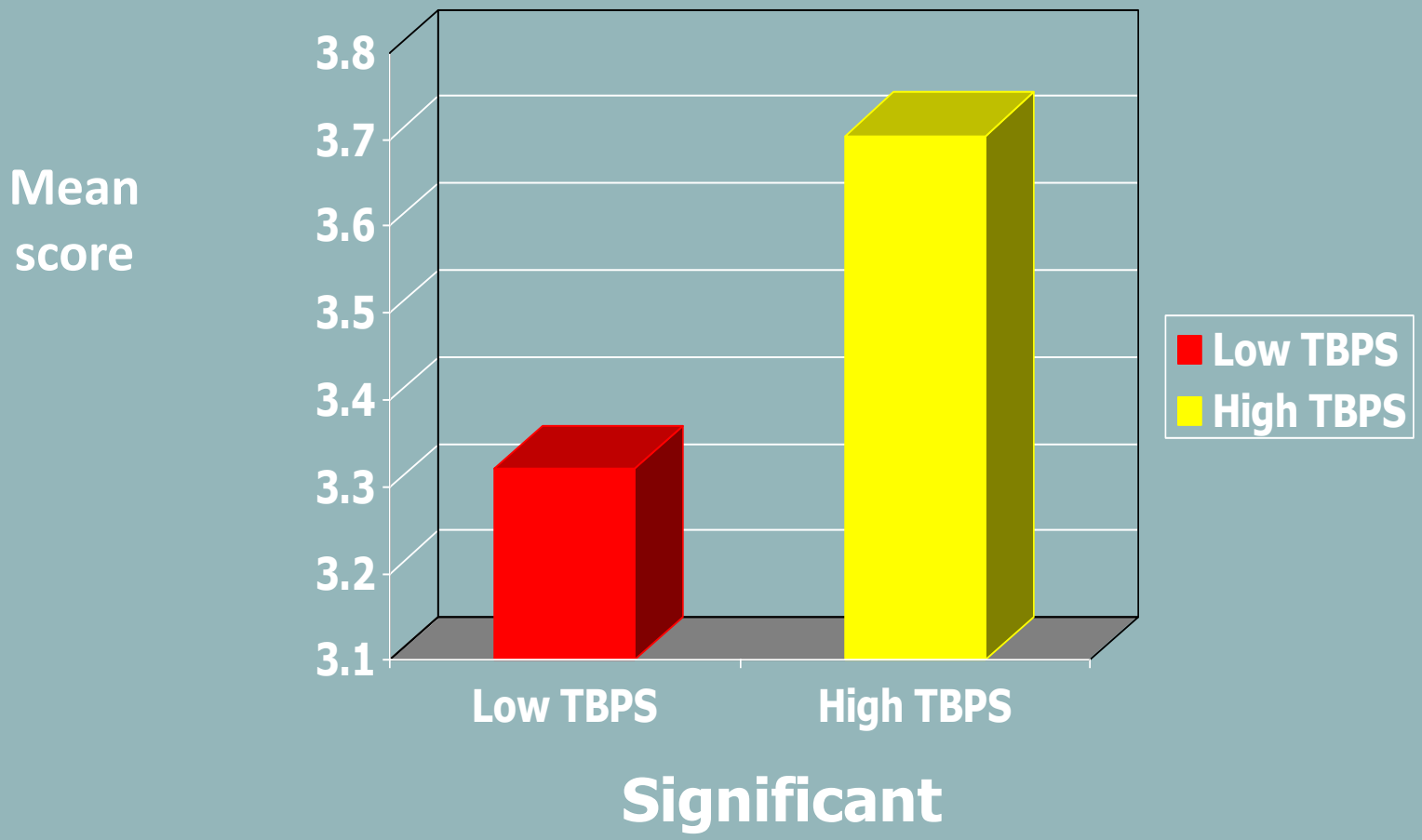
Triple P Stepping Stones system of intervention



Key take home messages…..

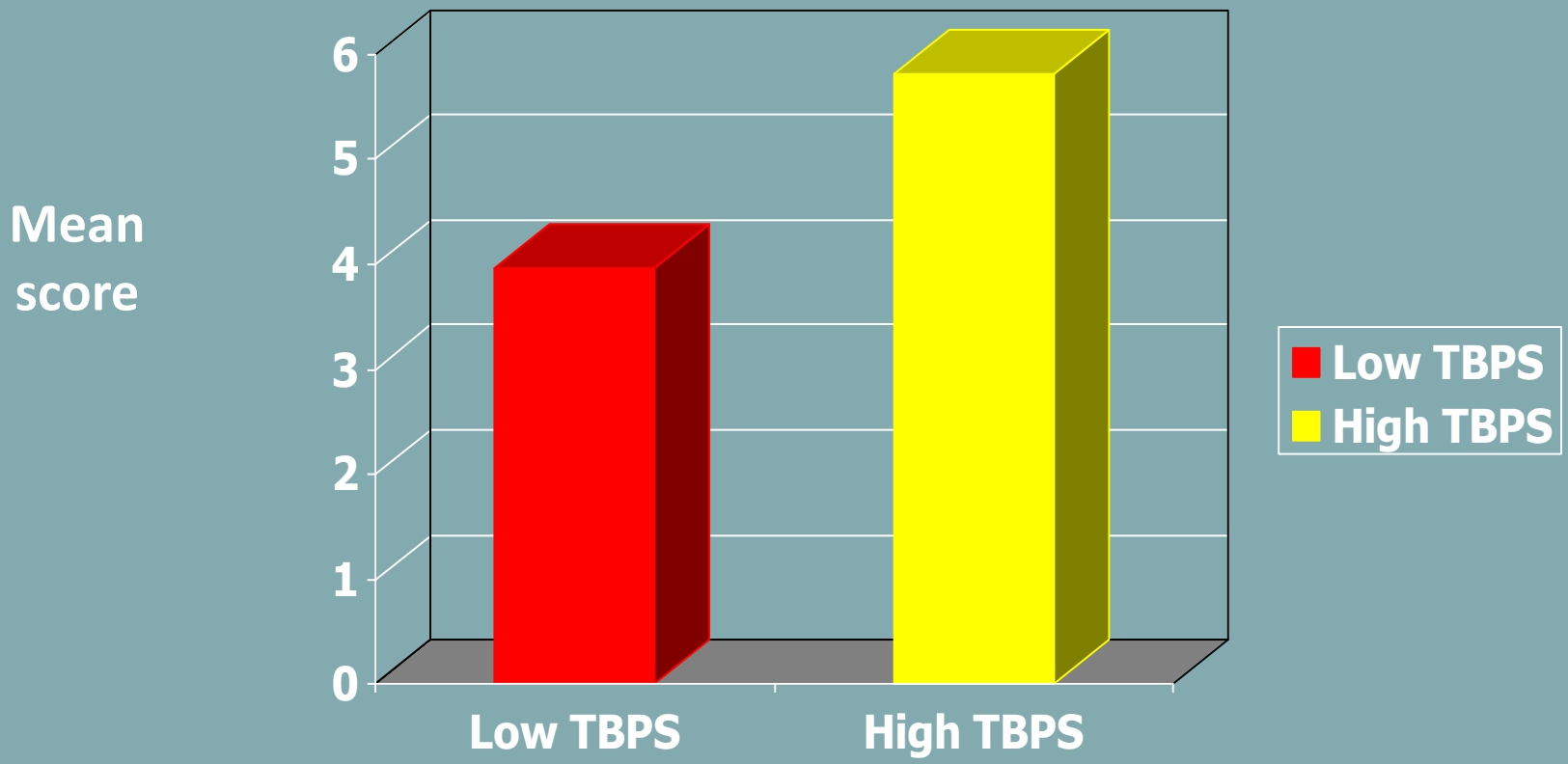
- SSTP can be successfully implemented in the community, with community-based practitioners (broad range of disciplines)
- Improvements in child behaviour and emotional problems
- Improvements for parents – depression, anxiety, stress
- Improvements in parenting skills
- Reduction in use of coercive 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



SOCIOECONOMIC STATUS

Case vs Non-case



Significant

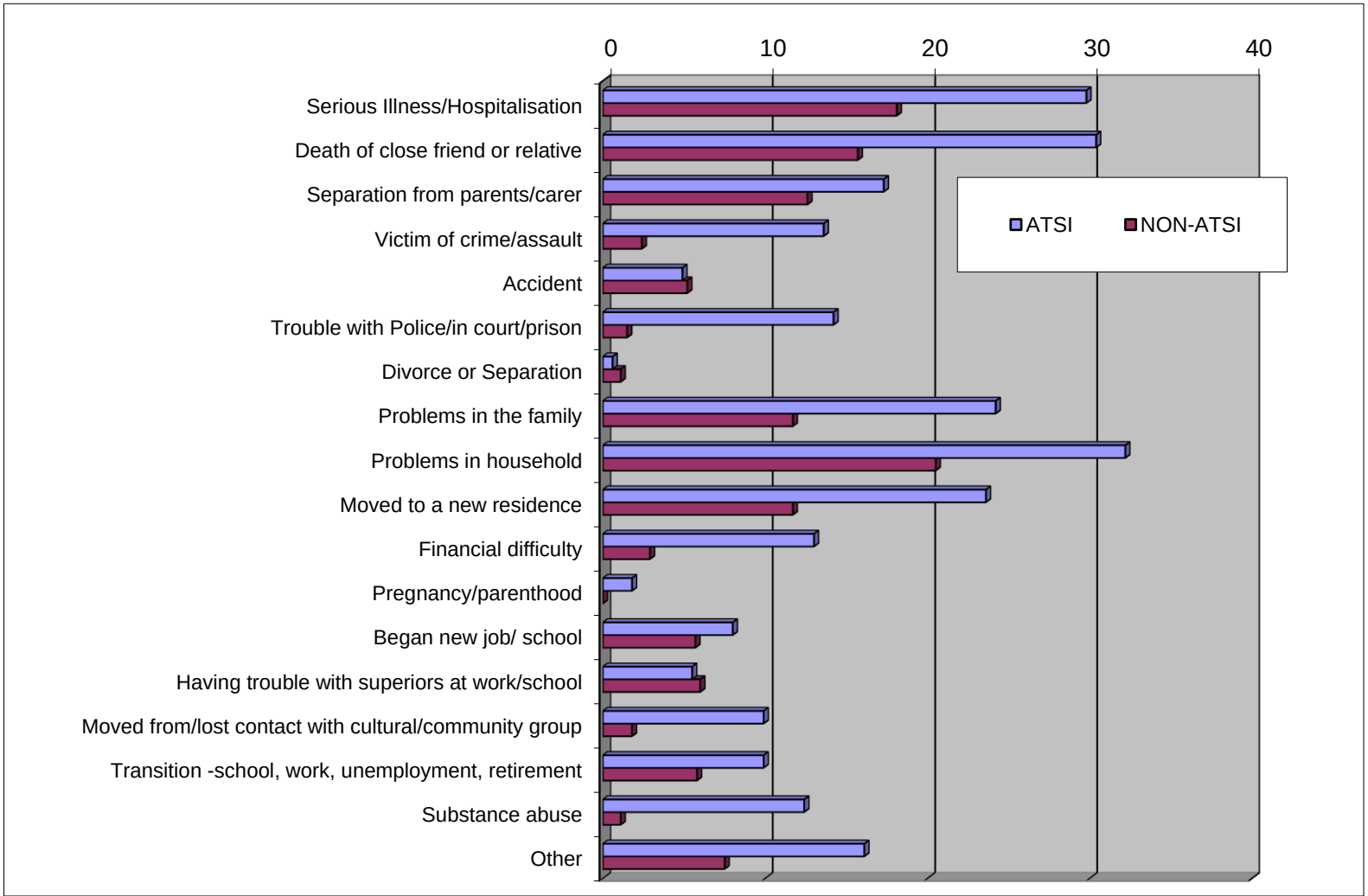
LIFE EVENTS: ATSI

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

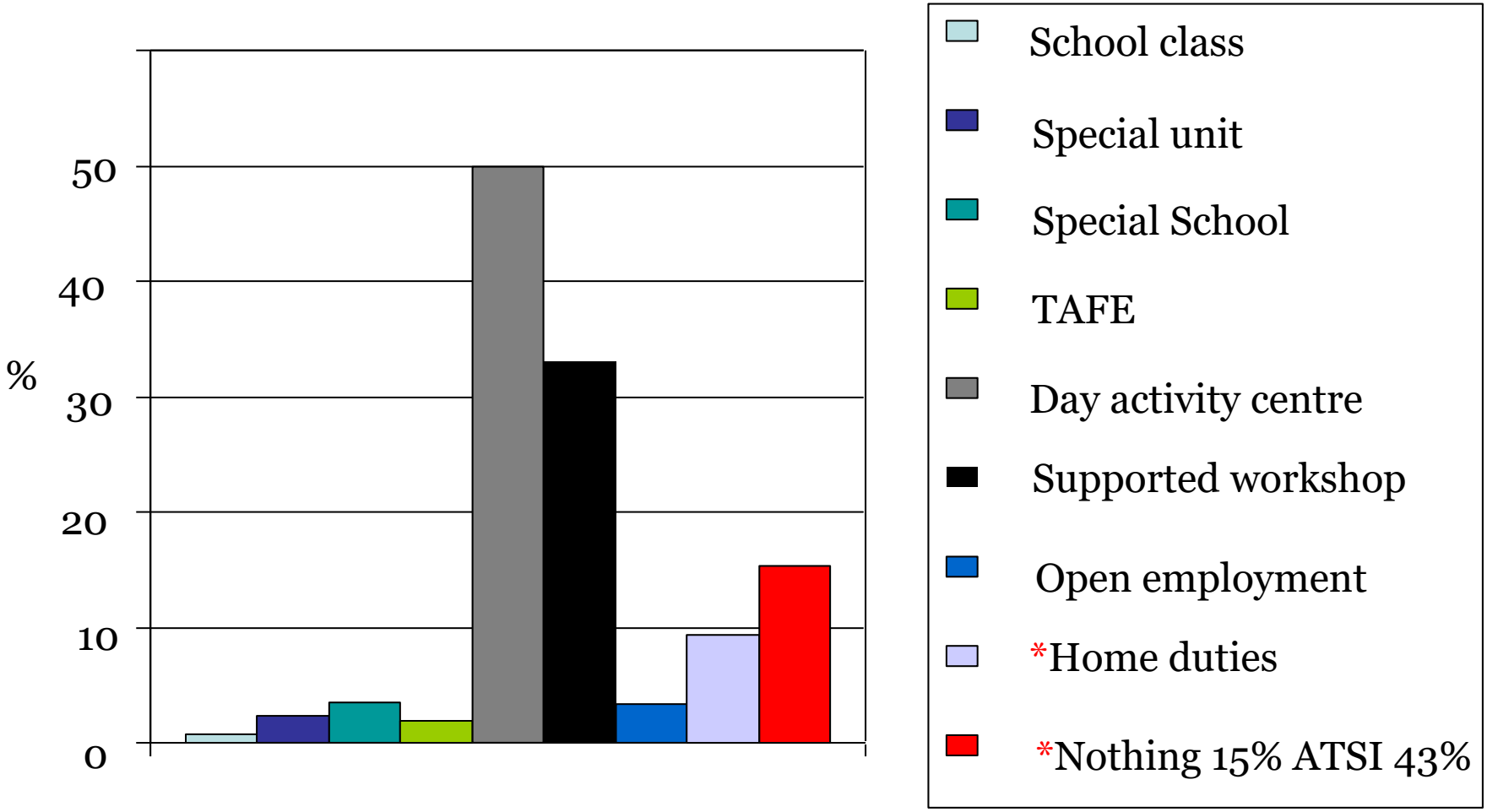
Limited/No daytime activities: Mild ID 12%, Moderate ID 7%,

Severe ID 6%

Behaviour problems associated with limited activities and social exclusion

Adults with ID in SA.

Usual daytime activity



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.

LifeSpan
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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

<u>Outcome measure</u>

- 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 3months

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

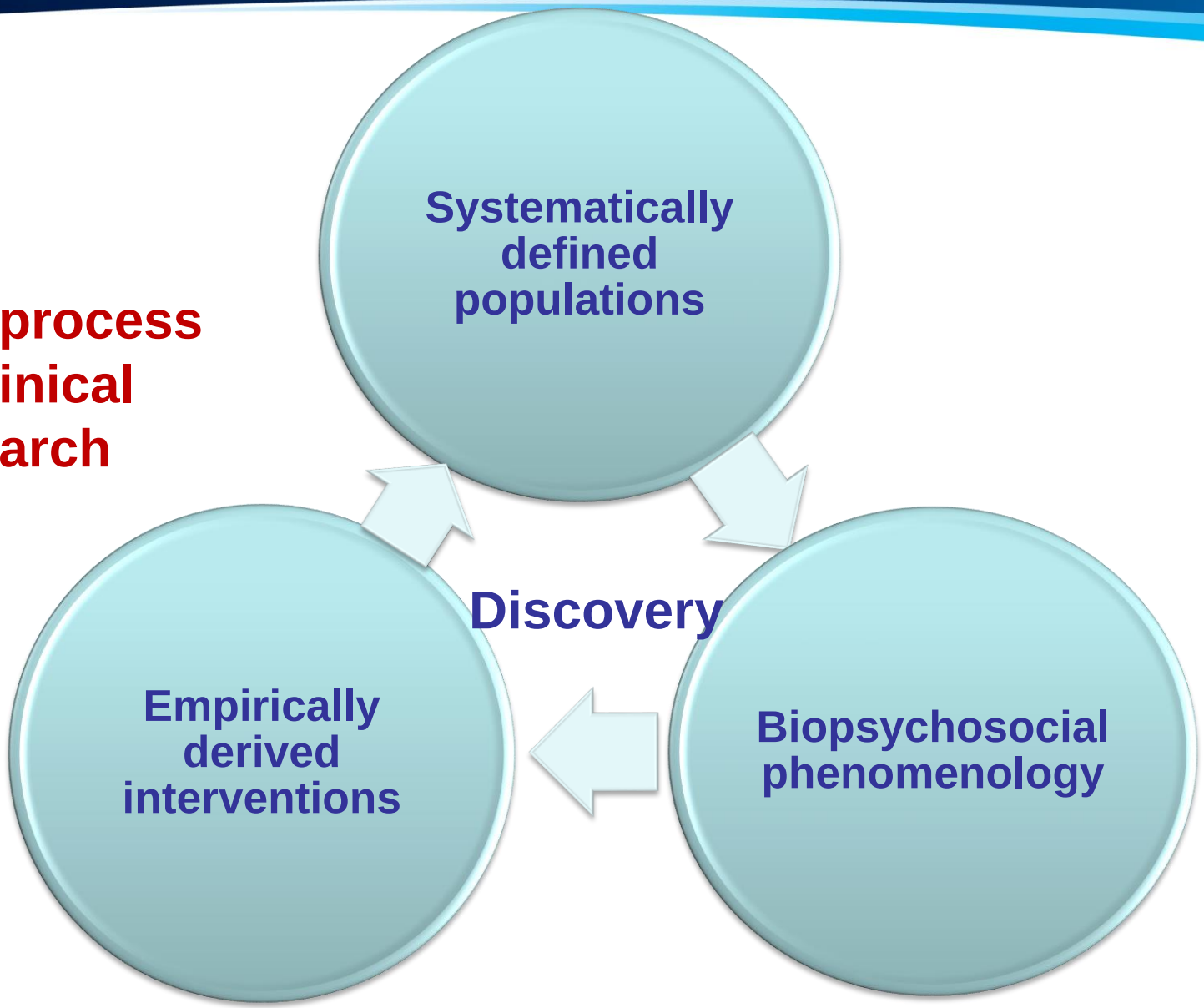
- Evidence based Early Parent education and skills training intervention such as Stepping Stones Triple P: the MHYPEDD program (Einfeld, Sanders & Tonge), addresses problem behaviour, safety, care, communication, developmental disability, and parent stress and mental health

- 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



List of publications and further information

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

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