Challenging Behaviour: Developing Knowledge-Based Approaches to the Prevention of Challenging Behaviours

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The Plan

- The knowledge-base for primary/secondary prevention
  - The (social) epidemiology of challenging behaviour
  - The efficacy and effectiveness of early intervention
- The SSTP programme

A Question From the World Health Organization

Social Epidemiology

Knowledge	Implications
1. High levels of (unmet) need in the population	Rationing of traditional clinical approaches or scale-up low cost alternatives
2. Early emergence and high persistence associated with environmental factors that are amenable to change	Indicates potential viability of targeted primary/secondary prevention
3. High lifetime cost (to person, family, society)	Indicates potential efficiency of targeted primary/secondary prevention

Population Need

- Children with intellectual disabilities have poorer mental health than their non-disabled peers
  - Across different types of disorders
  - Especially ‘challenging’ behaviours

Journal of Intellectual & Developmental Disability, June 2011; 36(2): 137–143

informa healthcare

LITERATURE REVIEW

Comorbidity of intellectual disability and mental disorder in children and adolescents: A systematic review

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Abstract

Background Mental disorder and intellectual disability each accounts for substantial burden of disease. However, the extent of this co-occurrence varies substantially between reports. We sought to determine whether studies in children and/or adolescents with acceptably rigorous methods can be distinguished from existing reports, and whether key risk factors could be ascertained.

Method Published studies investigating the prevalence of mental disorders in children and/or adolescents with intellectual disability were reviewed.

Results Nine studies with acceptable methods were identified, 4 which compared the prevalence of mental disorder in populations of those with and without intellectual disability, and a further 5 studies that estimated the rates of mental disorder in those with intellectual disability were identified. Collectively, these studies demonstrate rates of comorbidity for children and adolescents between 30 and 50% with a relative risk of mental disorder associated with intellectual disability ranging from 2.8–4.5. The risks for this comorbidity associated with age, gender, severity of intellectual disability, and socioeconomic status remain uncertain.

Conclusions Appreciation of this comorbidity needs to be a fundamental component of both mental health and intellectual disability services.

Keywords: *intellectual disability, mental disorder, psychopathology, prevalence, children, adolescents*

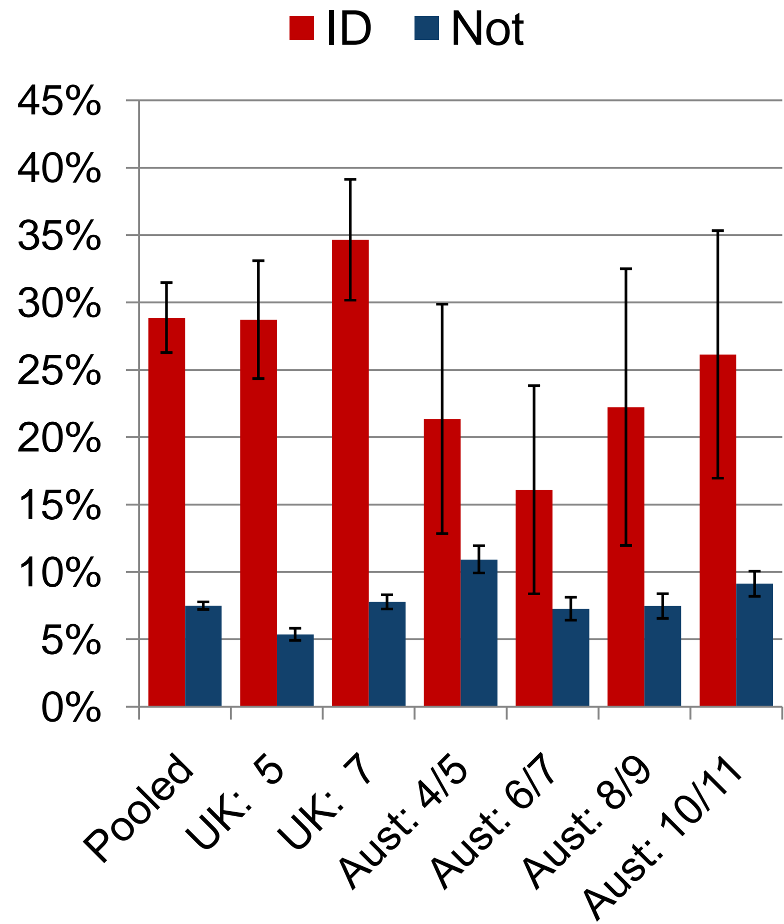
Across Diagnostic Groups

ICD-10 Diagnosis	Children with ID	Children without ID	Odds Ratio
Any disorder	36%	8%	6.5
Any emotional disorder	12%	4%	3.6
Any anxiety disorder	11%	3%	3.9
Any depressive disorder	1%	1%	1.7
Any conduct disorder	21%	4%	5.7
ADHD	8%	1%	8.4

Emerson, E., & Hatton, C. (2007). The mental health of children and adolescents with intellectual disabilities in Britain. *British Journal of Psychiatry* 191, 493-499.

Population Need

- 2-3% of children have intellectual disability
- 29% of these young people will have significant emotional or behavioural difficulties (compared to 7% of other children)
- Children and young people with intellectual disability account for 9% of all young people with significant emotional or behavioural difficulties



Social Epidemiology

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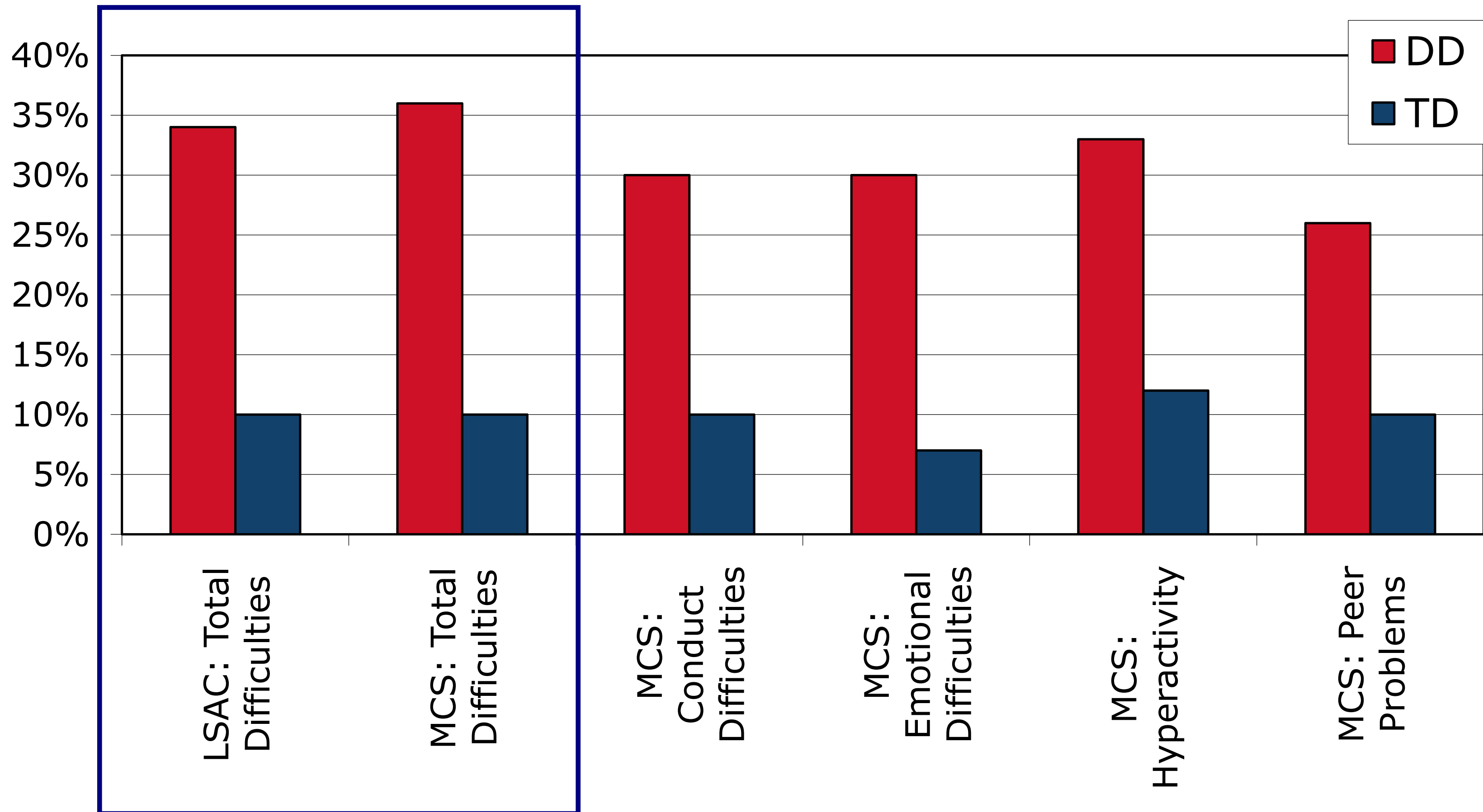
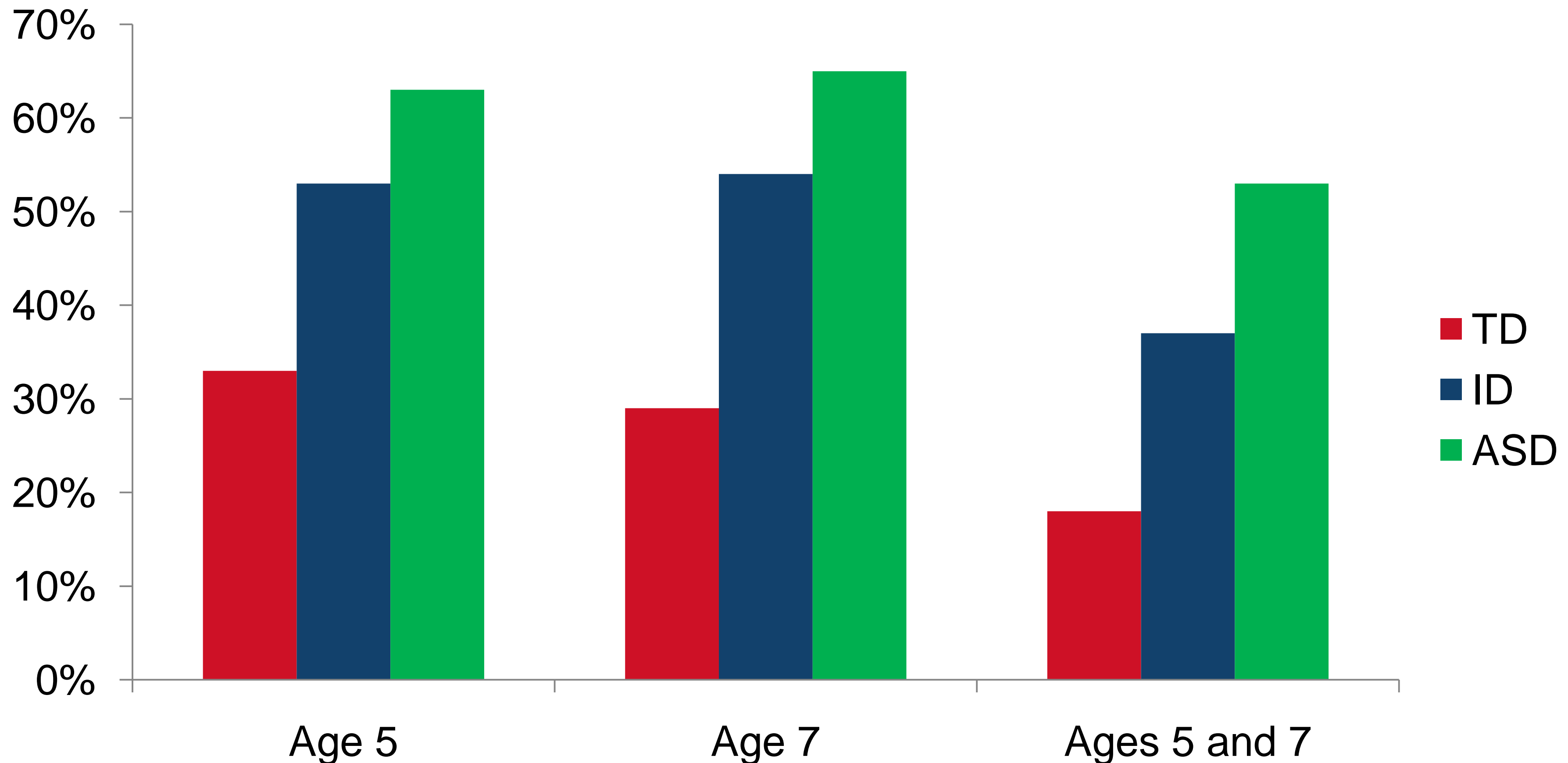
From an Early Age (2/3 years)



Emerson E, Einfeld S. Emotional and behavioural difficulties in young children with and without developmental delay. *Journal of Child Psychology and Psychiatry* 2010;51:583-93

More Persistent



Determinants

Individual attributes

› Behavioural phenotypes

› Impaired (intellectual) capabilities

  ○ Understanding

  ○ Problem solving

  ○ **Communication**

World Health Organization (2012). *Risks to Mental Health: An Overview of Vulnerabilities and Risk Factors: Background Paper by WHO Secretariat for the Development of a Comprehensive Mental Health Action Plan*. Geneva: WHO

Environmental Determinants

Social Determinants

- Increased risk of exposure to ‘common’ social determinants of poorer health
- Disability specific discrimination (disablism)

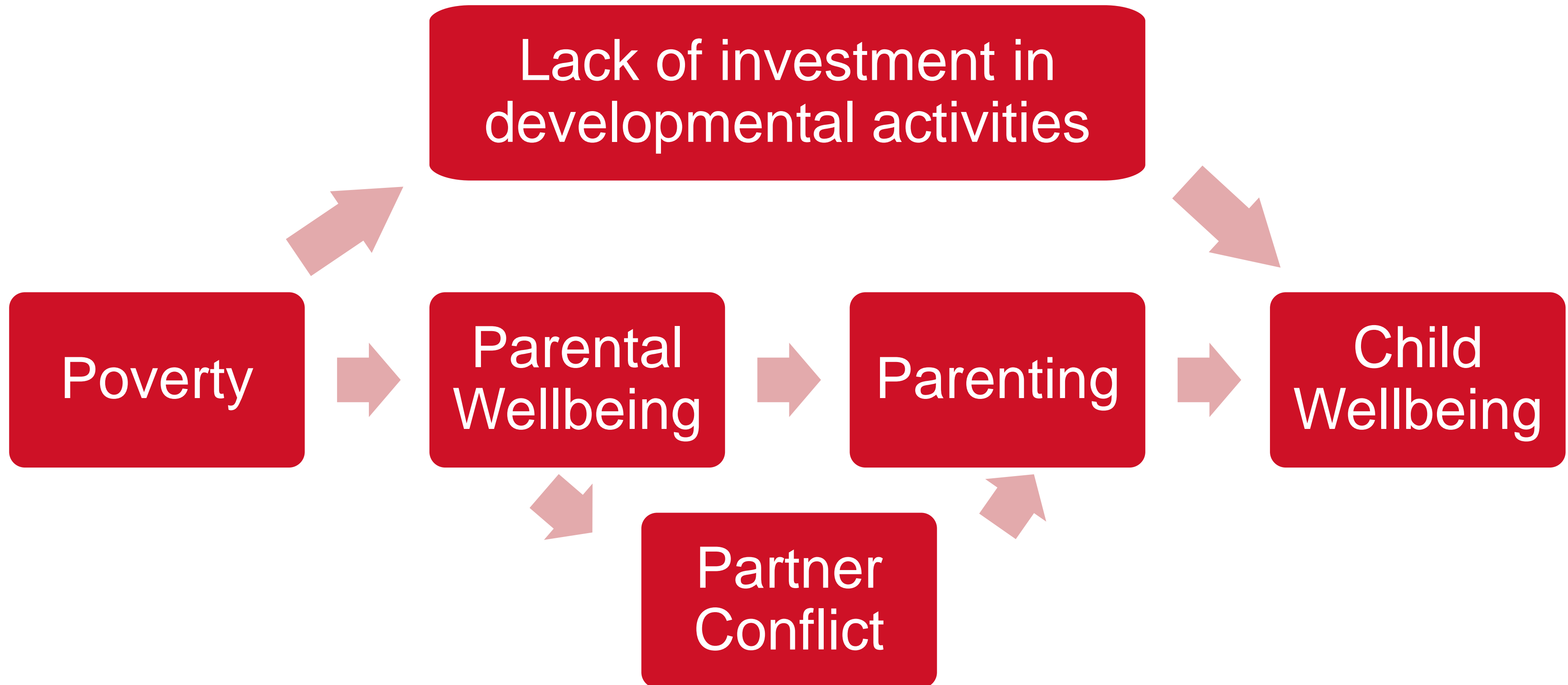
World Health Organization (2012). *Risks to Mental Health: An Overview of Vulnerabilities and Risk Factors: Background Paper by WHO Secretariat for the Development of a Comprehensive Mental Health Action Plan*. Geneva: WHO

‘Common’ Social Determinants

- Children with ID are more likely than non-disabled children to be to exposed to
  - Poverty/low socio-economic position
  - Violence
  - Other potentially adverse ‘life events’

Emerson, E. (2012). Commentary: Childhood exposure to environmental adversity and the well-being of people with intellectual disabilities. *Journal of Intellectual Disability Research* Online early

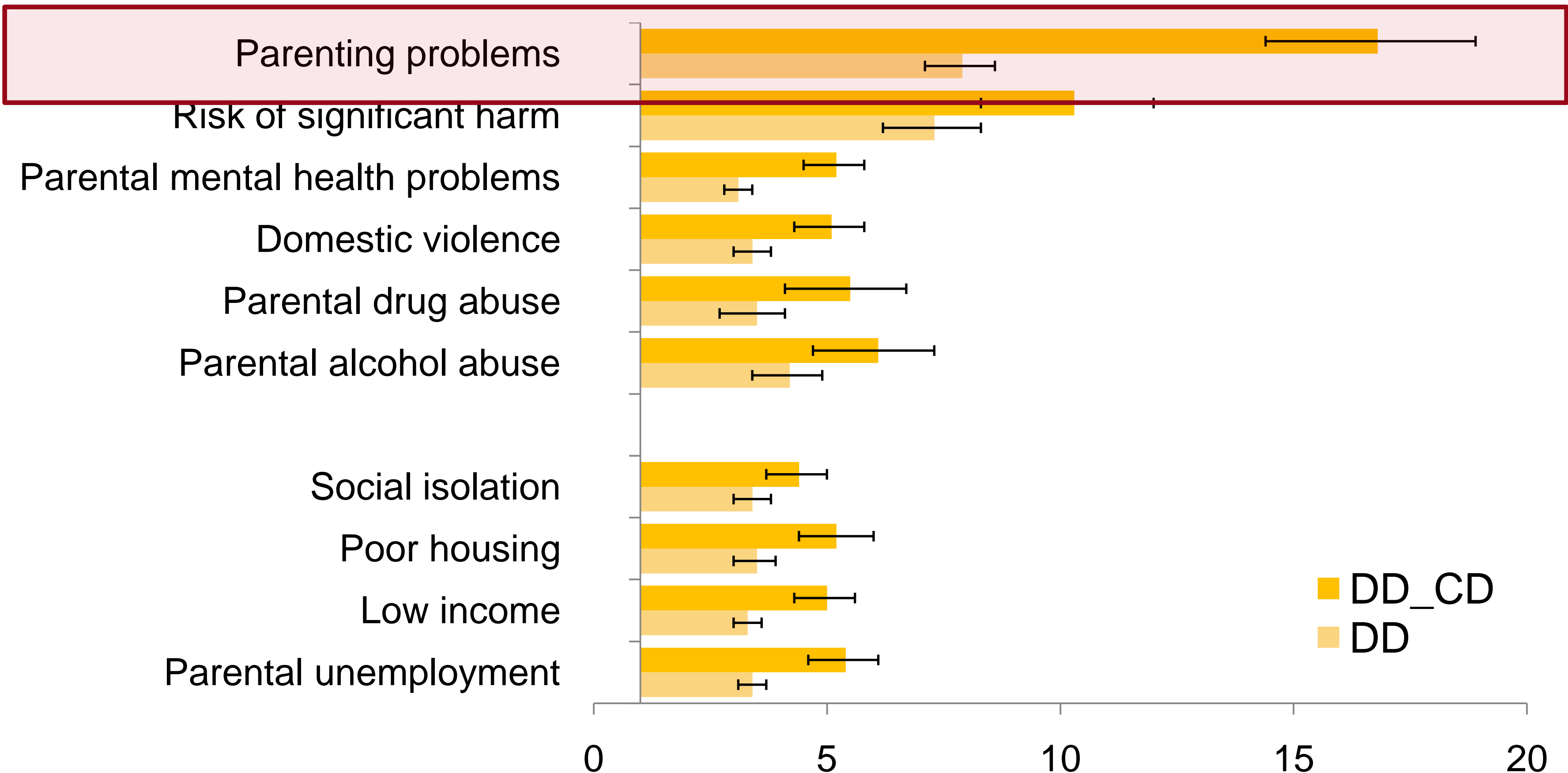
Social/Environmental Pathways



Conger, R. D., & Donnellan, M. B. (2007). An interactionist perspective on the socioeconomic context of human development. *Annual Review of Psychology, 58*, 175-199.

Common Social Determinants

Risk (OR) of exposure for children with developmental delay (DD) with/without behaviour disorders to potential social determinants of poorer mental health (46,022 English families, 2,236 with child with DD)



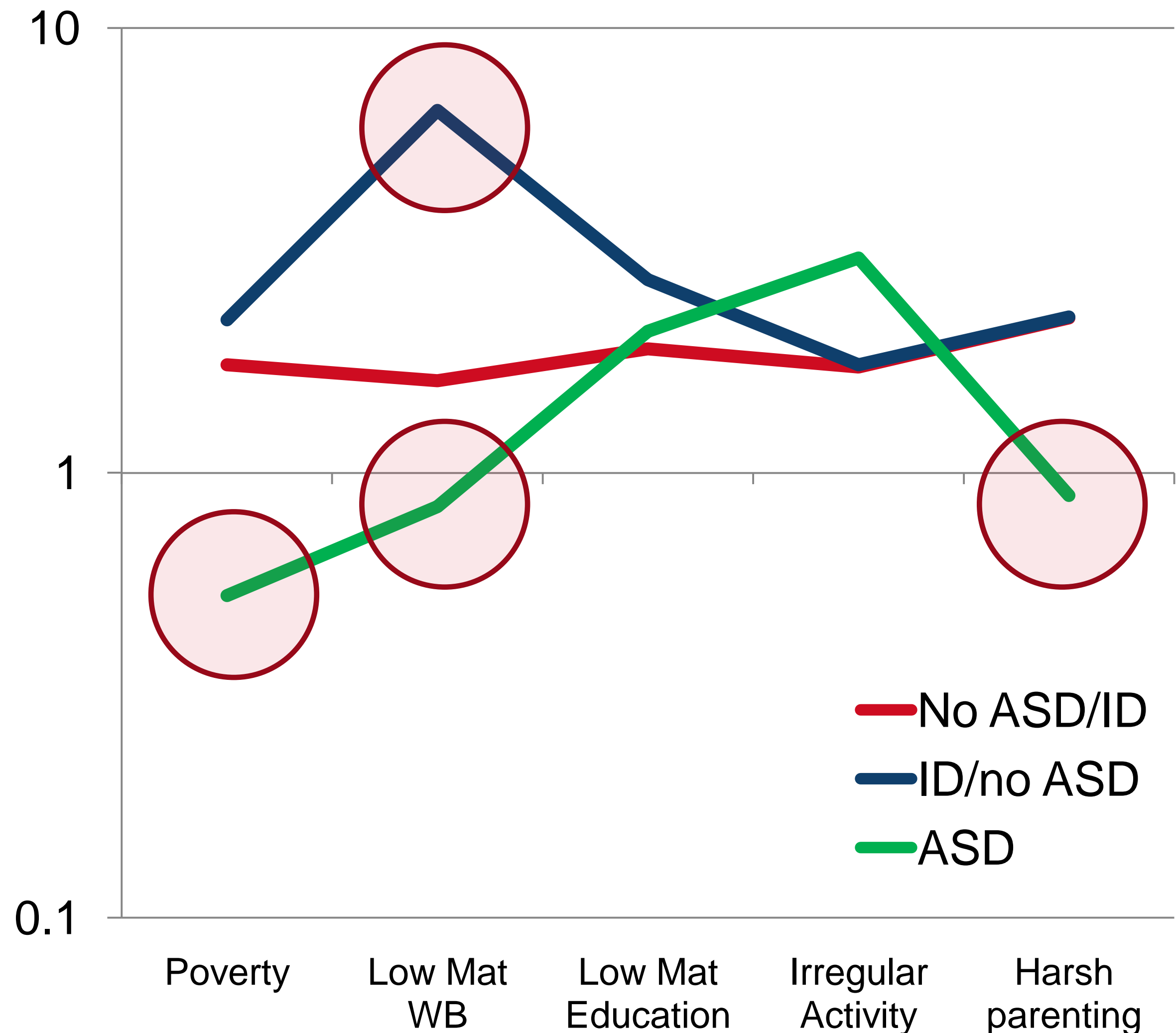
Trajectories & Persistence

- **Persistent** conduct difficulties across childhood are strongly associated with later violent and anti-social behaviour, incarceration, poor health and social exclusion
- Persistence of CD between 4/5 and 8/9 years in Australian children
  - Is greater if children are exposed to a wider range of environmental adversities at age 4/5 (and exposure rates are greater for children with *borderline* ID than their ‘typically developing’ peers)
  - The *strength* of this relationship was greater among children with borderline ID (interaction effects?)
- Do these relationships also hold true for children with ID or ASD?

Emerson, E., Einfeld, S., & Stancliffe, R. (2011). Predictors of the persistence of conduct difficulties in children with cognitive delay. *Journal of Child Psychology & Psychiatry and Allied Disciplines* 52, 1184-1194

Different Risk Profiles?

- Strength of association (OR) between environmental risk at age 9 months and 3 years and the persistence of conduct difficulties from age 3 to ages 5 and 7 in UK children with/without intellectual and developmental disabilities



Determinants

Social Determinants

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World Health Organization (2012). *Risks to Mental Health: An Overview of Vulnerabilities and Risk Factors: Background Paper by WHO Secretariat for the Development of a Comprehensive Mental Health Action Plan*. Geneva: WHO

Social Epidemiology

Knowledge	Implications
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Costs

- To the person
  - Social exclusion
  - Abuse
    - *Count Me In* census: 35% of people with learning disabilities in Assessment and Treatment Units had been assaulted in the last year, 6% had been subject to 10 or more assaults
- To families
- To society
  - Castlebeck, 2009: £31 million profit out of £85 million ‘sales’ (Sunday Times)

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The Need for Early Intervention

- Given that increased levels of behavioural problems in this population are evident from age 4, early intervention is vital.
- However, parents of young children with ID are often busy with achieving developmental skills such as toileting, mobility and language development,
- When young, behaviour problems are containable while the child is small.
- However, it is crucial that parents appreciate the need to introduce healthy behaviour patterns, which if not implemented will often lead to much greater burden of care later.

Parenting Programmes

- A potential approach to intervening early is through provision of parenting programs, which have the potential to ameliorate some of the child and parent risk factors.
- Research findings from several studies demonstrate that there is a significant reduction in parent stress and an increase in self-efficacy gained through parents learning to manage behaviour and emotional problems in children with ID.

Reaching the Population in Need

- However, traditional models of service delivery, eg through health services or university clinics, reach relatively few families.
- The 6-8% that do access parenting programs do not necessarily access evidence-based programs.
- Therefore, service provision needs to move towards public health types of interventions, which have the capacity to to achieve a population-level reduction in the prevalence of social, emotional and behavioural problems in children with DD

Why Do So Few Families Access Efficacious Interventions?

- Scarce resources (expertise, services)
- Problems of access (poverty, transport)
- Competing life demands (‘goodness of fit’)

How Do We Respond?

- A public health approach is required to reach more families
- The goal of a public health approach is to achieve a population-level reduction in the prevalence of social, emotional and behavioural problems in children with ID.

How can we measure the success of a public health approach?

- An *efficacy* study examines whether an intervention works under ideal conditions, eg a university clinic.
- The ultimate test of *efficacy* is the randomised controlled trial.
- In a public health intervention, we need to test *effectiveness,* that is, does the intervention work in the real world of communities?
- The strategy for testing the effectiveness of a public health strategy is RE-AIM

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RE-AIM

- **Reach**: % of the target population receiving the intervention
- **Effectiveness**: for those receiving the intervention.
- **Adoption**: % of settings offering the intervention
- **Implementation**: Ensuring that the program is delivered as it is intended
- **Maintenance**: longer-term effects of the program on targeted outcomes for familes, *and*, whether agencies continue to provide the program after the research is finished.

Glasgow RE, Vogt TM, Boles SM. Evaluating the public health impact of health promotion interventions: The RE-AIM framework. *American Journal of Public Health* 1999;89:1322-27

Evidence Base

3 available parent education programs are

- Parent Plus Early Years
- Stepping Stones Triple P
- Incredible Years Parent Training
- Signposts

- For a review of these, see

Einfeld SL, Tonge BJ, and Clarke KS. Prevention and early intervention for behaviour problems in children with developmental disabilities Current Opinion in Psychiatry, 26(3), 2013, p 263-269

- Stepping Stones Triple P has the strongest evidence base. Stepping Stones is a version of Triple P for parents of children with developmental disabilities.
- The parent program, Triple P, has demonstrated population-level effectiveness in large scale public health trials.
- See, for example, Prinz, Sanders et al., (2009) *Prevention Science*
- Stepping Stones Triple P has demonstrated efficacy in 3 RCT's.

The Triple P System of Intervention

Media & communication strategy	Level 1
Brief parenting advice	Level 2
Narrow focus parenting support	Level 3
Broad focus parenting support	Level 4
Intensive family intervention	Level 5

Intensity of intervention

Level 1: Media Campaign & Service Engagement

- Reducing the stigma of seeking help/support
  - Posters & brochures
  - Television, radio and newspapers/magazines
- Engaging with government departments and service providers
- Engaging with parents and professionals

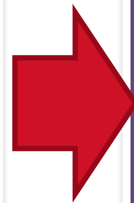
Just like any other child...
Chloe can put on a show in the supermarket

Stepping Stones Triple P – Positive Parenting for parents of children with a disability

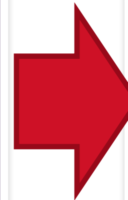
www.triplep-steppingstones.net

Level 2: Stepping Stones Seminar Series

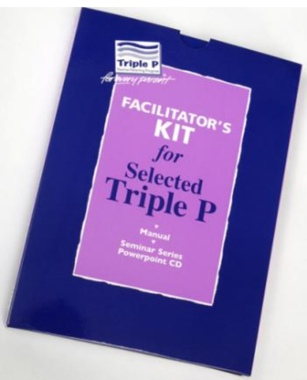
Seminar 1
Positive Parenting for Children with a Disability



Seminar 2
Helping your Child Reach their Potential



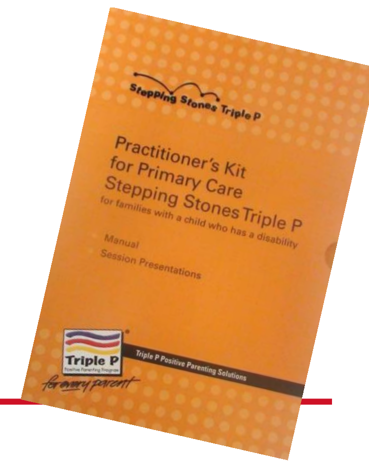
Seminar 3
Turning Problem Behaviours into Positive Behaviours



90 minute
Large group seminars
Invitation to return

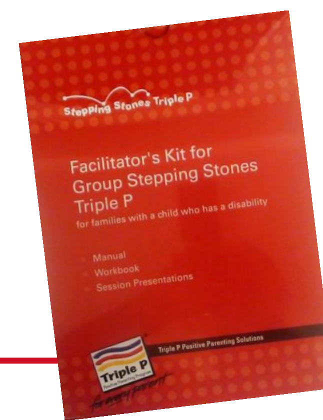
Level 3:
Primary Care Stepping Stones

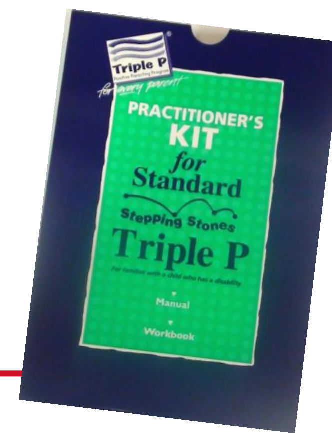
- 3-4 brief (15-30mins) individual sessions with practitioner
- Target 1-2 discrete child problems
- 11 booklets containing tip sheets



Level 4:
Standard/Group Self-directed/Online

- Mode
  - Standard: one-to-one sessions
  - Group: Group sessions
  - Self-directed: workbook at home
- Active skills training
- Teaches parents multiple skills
- Parents apply skills to diverse behaviors and settings



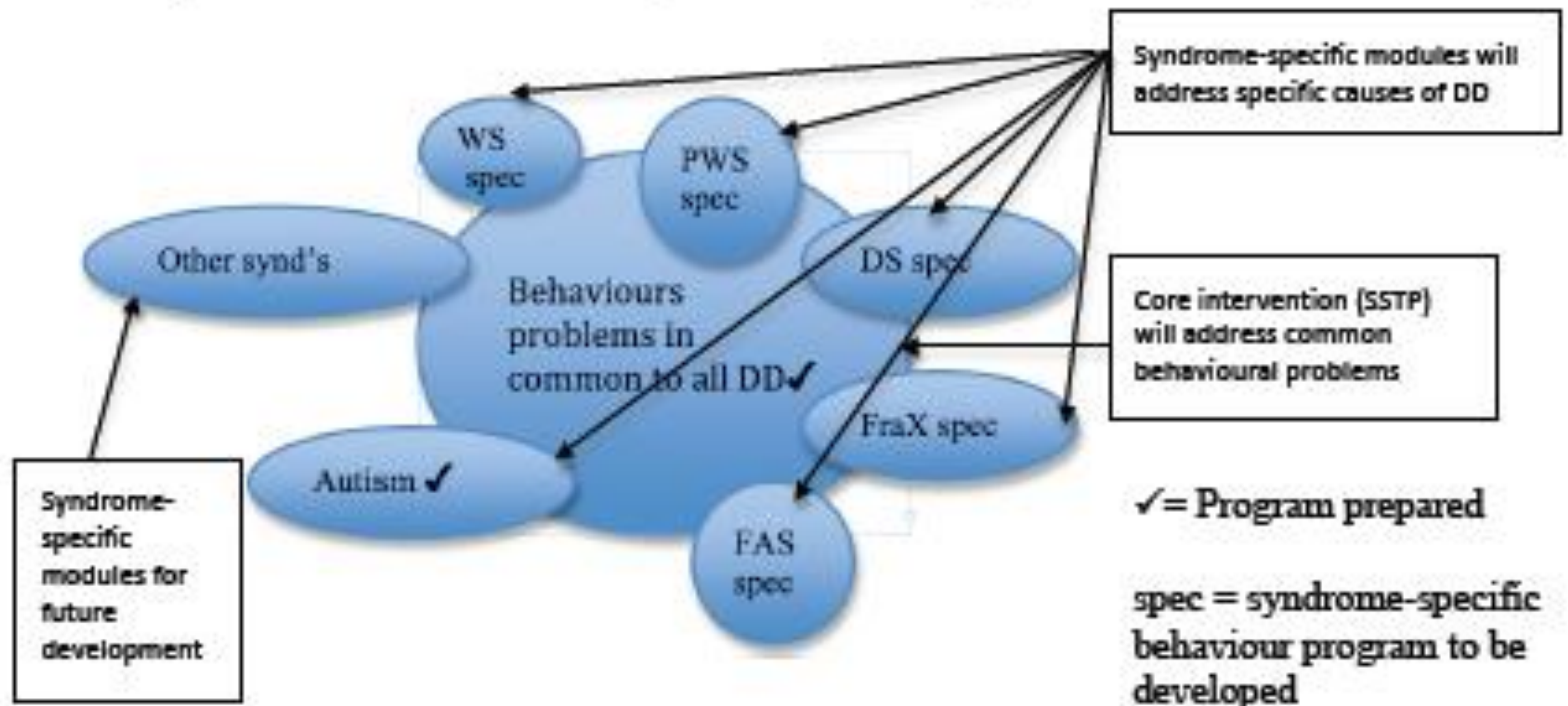


Level 5: Enhanced Triple P

- Modules for parents with specific mental health problems that are likely to impair their capacity to parent effectively
  - Partner Support
  - Stress and Coping
  - Anger management

Current study
(Einfeld, Sanders, Tonge, Emerson et al)

- We are currently conducting a rollout of all levels of Stepping Stones Triple P across 3 Australian states with a total population of 15 million. About 0.5% are parents of children with developmental disabilities age 3-12.
- We are following a subset of 900 families more intensively.
- The RE-Aim strategy is the basis of the evaluation


Syndrome-specific modules will address specific causes of DD
WS spec
PWS spec
Other synd's
DS spec
Behaviours problems in common to all DD✓
Core intervention (SSTP) will address common behavioural problems
FraX spec
Autism ✓
FAS spec
Syndrome-specific modules for future development
✓= Program prepared
spec = syndrome-specific behaviour program to be developed

Current study

- There is also a cost-benefit study
- In addition, we are adding specialised behaviour phenotype modules for parents of children with ID due to specific causes, namely:
- Fragile X , Down, Williams, Prader Willi, Velocardiofacial syndromes and Fetal Alcohol Spectrum Disorders

Syndrome specific SSTP materials

- Parent tip sheet
- Practitioner tipsheet
- Modifications of the 23 standard SSTP strategies

For a Copy of the Presentation

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