Mental health problems in children with intellectual disability: Implications for intervention

Richard Hastings

Cerebra Chair of Family Research, University of Warwick
Monash Warwick Professor, Department of Psychiatry, Monash University, Australia

Today's presentation

- The neglect of mental health in people with ID
- Mental health problems in adults with ID
- Mental health inequalities emerge early in the lives of children with ID
- The mental health of children with ID is a ***mainstream*** policy issue
- Supporting families is a central part of intervention to improve mental health
- What do researchers and practitioners need to do to improve mental health for children with ID?

Neglect of mental ill-health

- Only since late 1970s/early 1980s that mental health problems of people with ID have been clearly recognised by *specialist* ID professionals
- *Diagnostic overshadowing*: Reiss et al. (1982) coined the term - tendency to inaccurately assess the degree of mental ill health in people with ID compared with people without ID
- There remains a lack of recognition that underlying mental health problems may partly explain problems that bring people with ID into contact with services

Glasgow adult ID study

- Professor Anna Cooper and colleagues in the Greater Glasgow area
- Methodology:
  - All people 16+ with ID in the Glasgow area were identified via social services and GP services
  - Nurses and GPs carried out case note reviews and a structured clinical interview (often facilitated by a carer) to identify possible, probable or definite mental health problem
  - All such identified were assessed by psychiatrists who carried out detailed clinical case note reviews and structured clinical interviews and assessments
  - Diagnoses of psychiatric disorders were made using four methods: expert clinical diagnosis, DC-LD, ICD-10, and DSM-IV-TR
  - Carried out physical health screens to rule out potential physical causes

Prevalence [Cooper et al., 2007]

- Total N = 1023, 70% of those eligible for the study
- Overall affective disorder prevalence 3.6-6.6% (typical population roughly 10-20%)
- Overall psychotic disorder prevalence 2.6-4.4% (typical population roughly 0.5 - 1.5%)
- Findings for mental ill health of any type:

	Clinical	DC-LD	ICD-10	DSM-IV
Any type	40.9%	35.2%	16.6%	15.7%
Exc. Behaviour probs	28.3%	22.4%	16.5%	15.6%
Exc. BPs and ASD	22.4%	19.1%	14.5%	13.9%

Existing research

- Case-control studies typically include referred and self-referred (volunteer) individuals and families

Population-based samples are needed

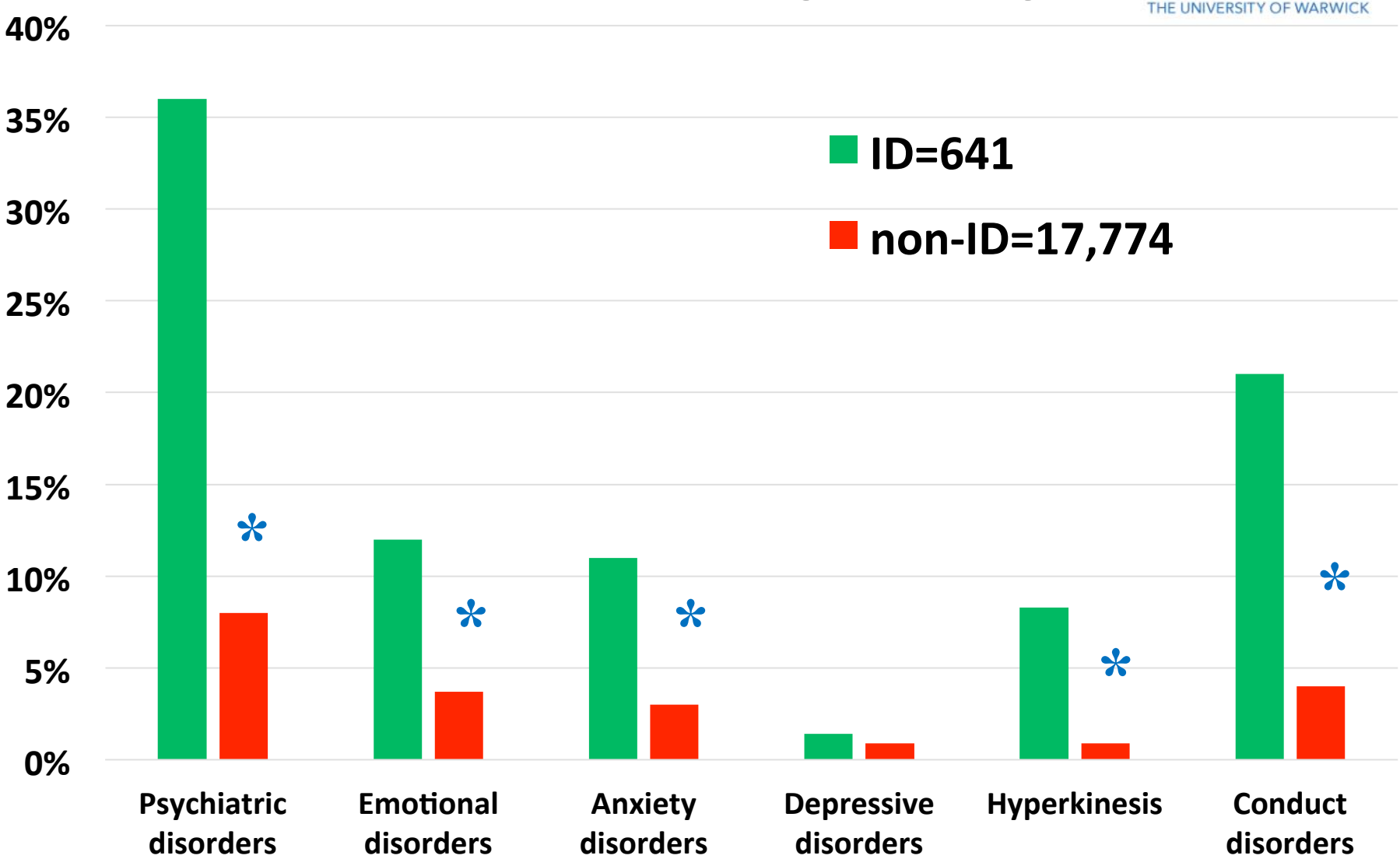
- Diagnosis of ID not always confirmed clinically, by a recognised diagnostic assessment, or some other method

Need samples that include clear method for identification of ID

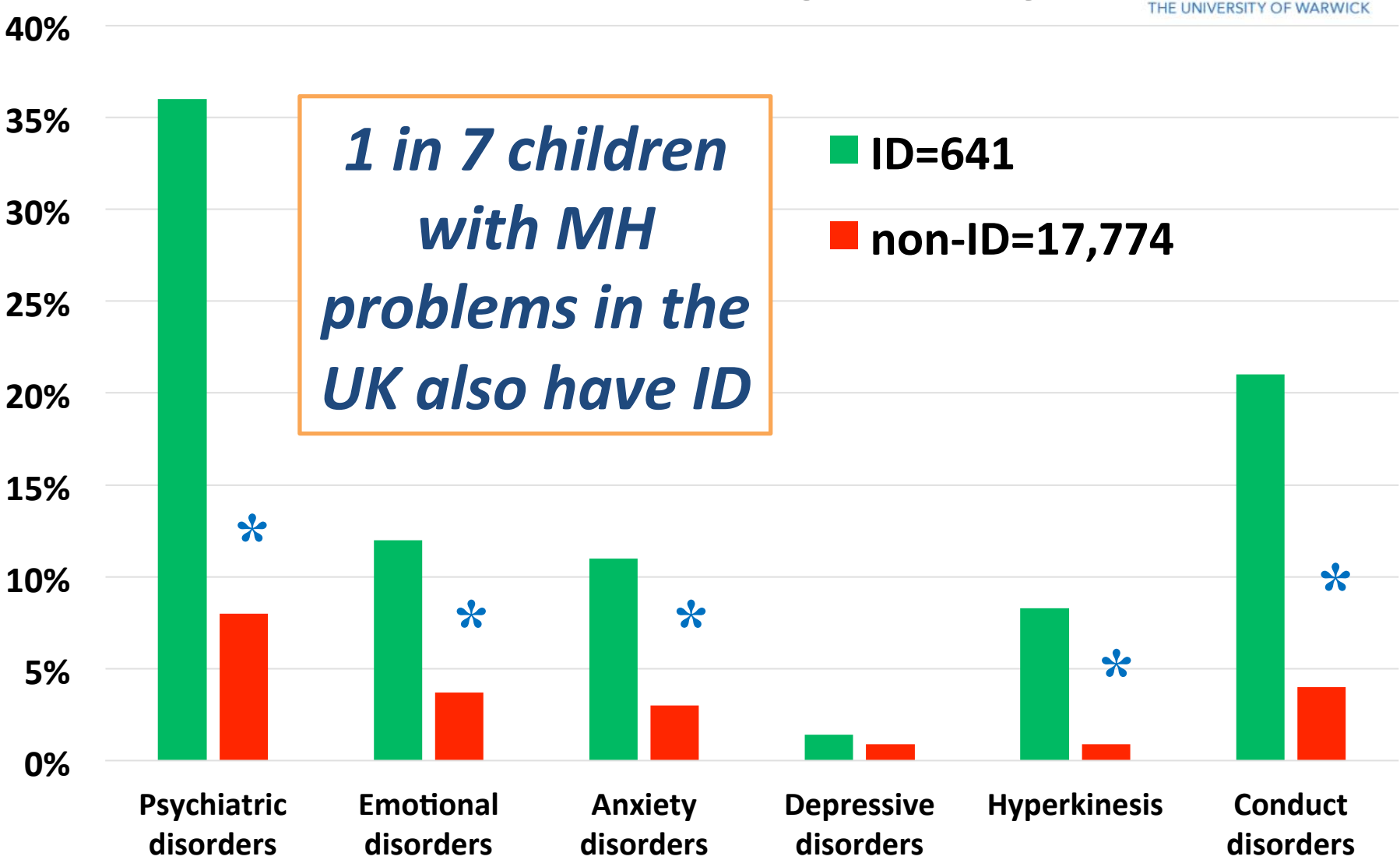
ONS mental health surveys

- N= 18,415 children age 5-16 years; population based sample across the UK with high response rate (80% across both surveys – 1999 and 2004)
- Structured clinical interview used with all children leading to ICD-10 diagnoses (carer interview, plus child interview 11+ and able to participate)
- Emerson identified a sub-sample with likely ID (N= 641), 3.5% of total sample
- Emerson & Hatton (2007) compared prevalence of childhood psychiatric disorders in ID and non-ID groups. ***Found increased risk of comorbidity***

Emerson & Hatton (2007)



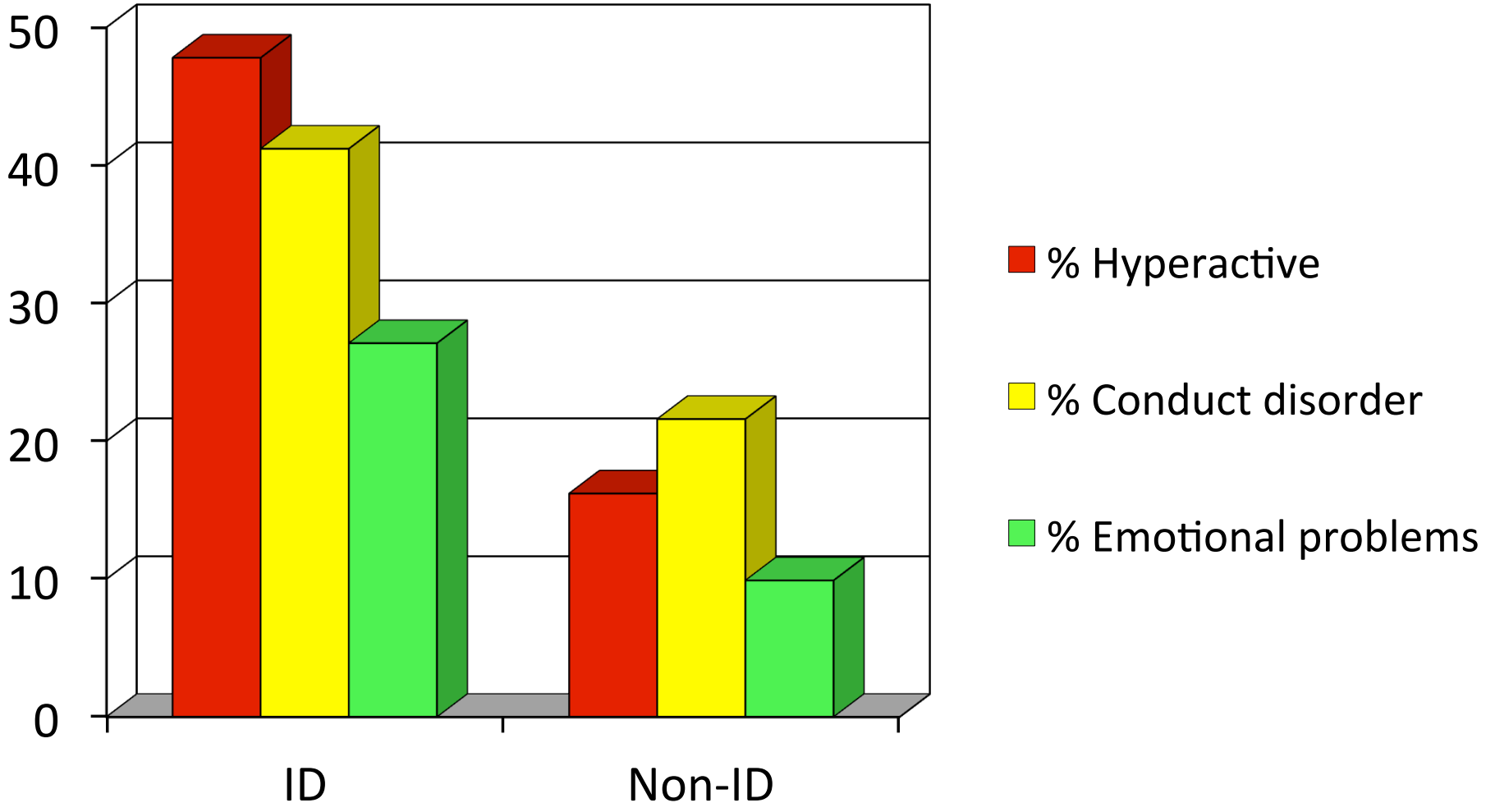
Emerson & Hatton (2007)



Early emergence

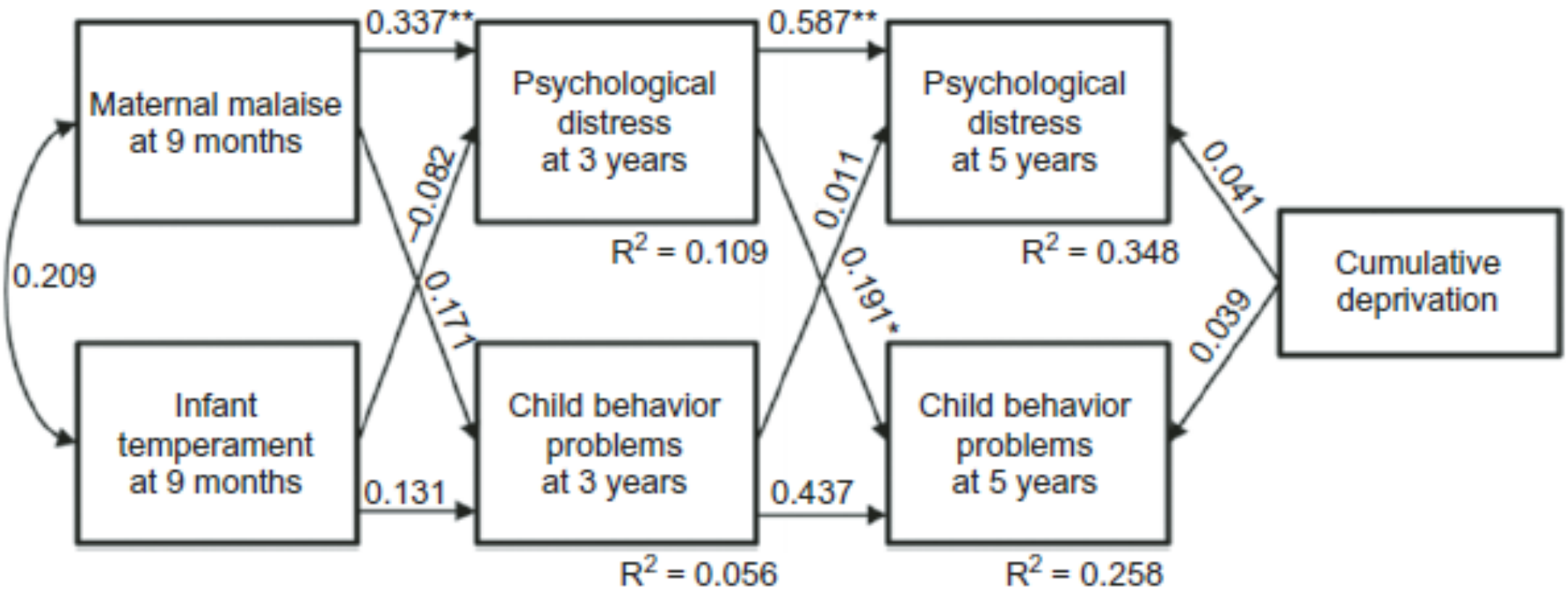
- N = 15,246 from the *Millennium Cohort Study* Wave 3
- Secondary analysis by Totsika, Hastings et al (2011) *JAbCP*
- *ID*: British Ability Scales 3.07% (n = 479)
- *Child outcomes*: hyperactivity, emotional symptoms, conduct problems (SDQ)

Problems @age 5

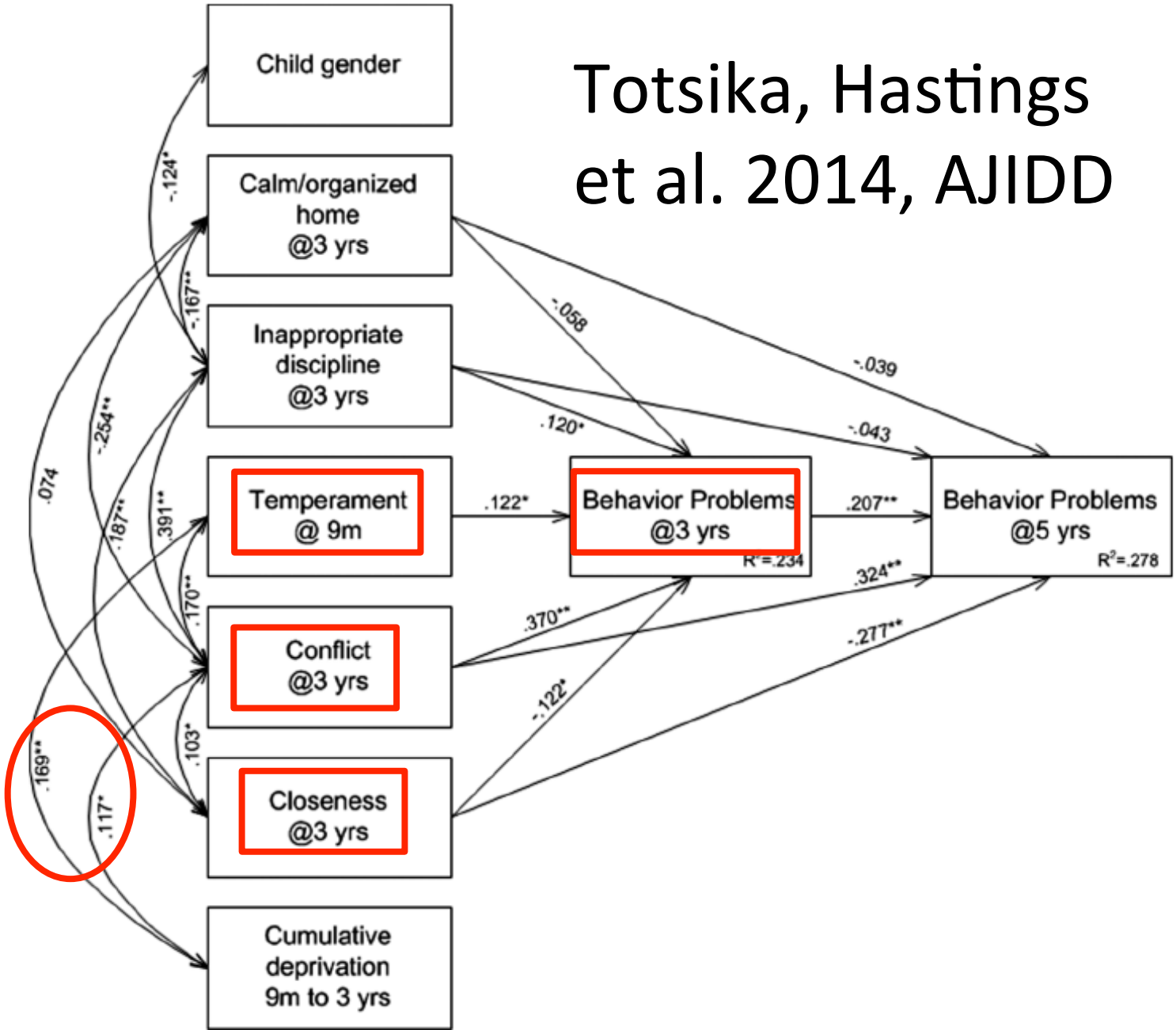


MCS Mothers: Autism

[Totsika, Hastings et al. 2011]

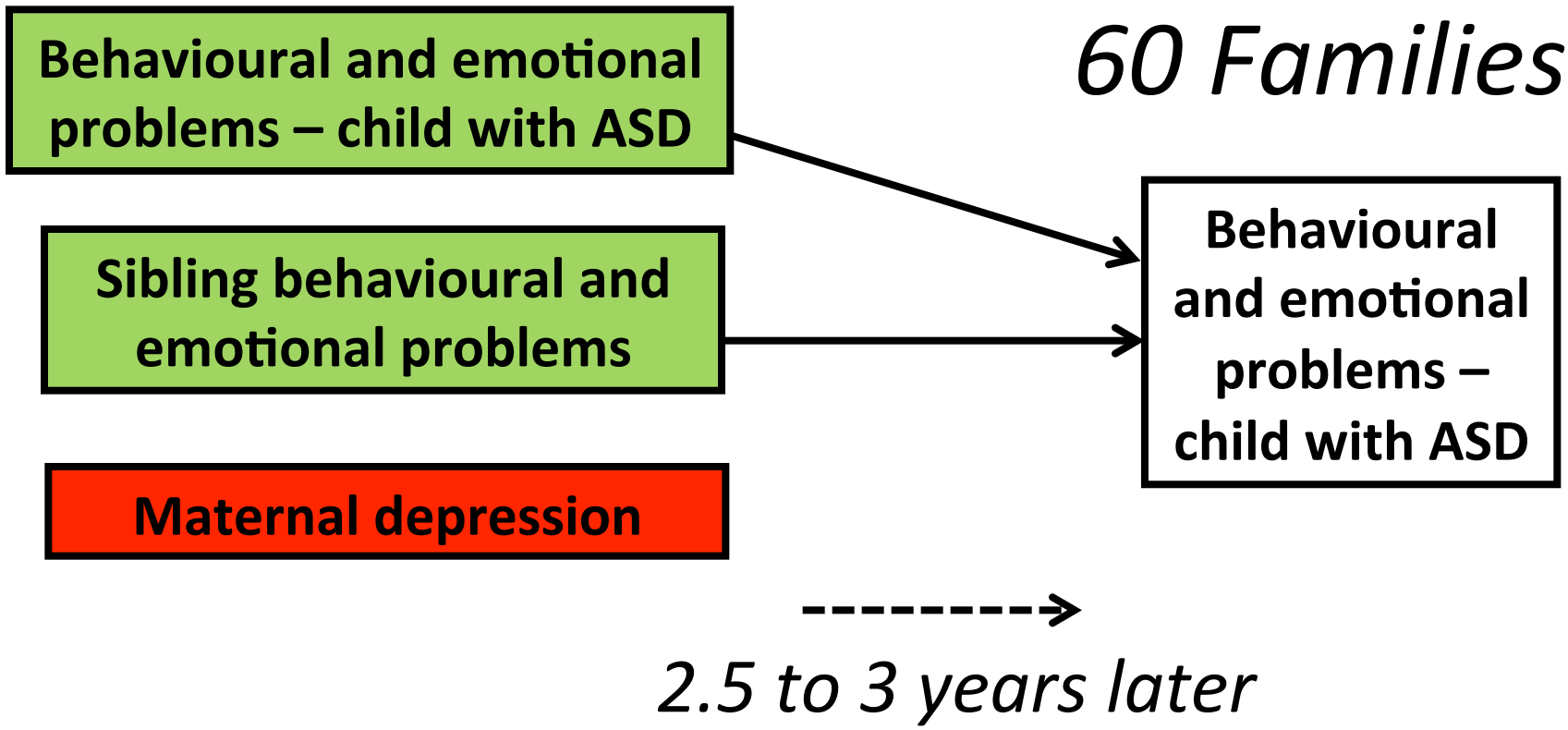


Totsika, Hastings et al. 2014, AJIDD



Siblings, not just parents

[Hastings et al. 2014 RASD]



Why the differences?

- Family socio-economic adversity (2-3 x rates of parental unemployment, income and subjective poverty, neighbourhood deprivation: MCS child age 9mo.—5years)
- Exposure to negative life events
- Lack of access to mental health services (*Toms et al., 2015*: 27.9% ID/MH population past 12 mo.)
- Parents' own mental health problems/sibling problems
- Poorer quality parent-child relationships (more conflict, less closeness when child age 3 [MCS])
- Difficulty learning effective coping skills, communicating needs, identifying emotions

Strengthening families

- Economic investment in families, and support for parents to gain (and keep) paid employment
- Supporting parent and sibling well-being
- Helping parents develop closer/warmer relationships with their children with ID
- Early intervention to support the communication and social skills of children with ID
- Advocacy skills for families to help them to access mainstream and specialist services

Evidence gaps

- Mental health (inequality) of children with ID is a mainstream (i.e., a big!) mental health, and early intervention, policy issue
- ***NICE Mental Health Problems in People with Learning Disabilities*** (September 2016), and ***MH-LD Quality Standard*** (January 2017)
  - Parenting programmes for parents of CYP
  - Mental health checks annually 13+ years of age
  - *Psychological therapies for CYP*
  - *Severe/profound ID: assessment and treatment*
  - *Organisation/delivery of services*

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Editorial

Running to catch up: rapid generation of evidence for interventions in learning disability services†

Richard P. Hastings

Summary
Few high-quality trials have been conducted in intellectual disability mental health. Trials such as Willner *et al*'s have a 'close-to-market' focus. I argue that rapid generation of evidence for individuals with intellectual disability is the priority, alongside a new research focus on those with severe intellectual disability.

Declaration of interest
None.

Running to catch up

- Large gap between practice in ID and existing research evidence
  - Contributes to the inequalities experienced by children and adults with ID
  - Practitioners/researchers need to play the evidence game on behalf of those with ID and families
- "Basic" applied research is still needed
- Immediate priority is high quality intervention evaluation research
  - Following through the evidence process will take too long - good evidence is needed ***now***

Rapid evidence generation

- "Close to market" effectiveness and implementation research (probably RCTs)
  - Test established specialised interventions
  - Adapt and test psychological interventions from the mainstream
- The challenge of severe ID
  - Define/describe conceptually coherent practice, standardise/manualise, and test

The role of practitioners?

- ***Educate*** other professionals about the mainstream impact of MH problems in people with ID, and the early emergence of mental health inequalities
- ***Do*** intervention research
  - Focus on questions "close to market" and of highest value to services and stakeholders (biggest potential impact)
  - Collaborate with multi-disciplinary research teams
- Model evidence-based practice, don't compromise, don't hide under the "eclectic" banner, and **COLLECT DATA**!

WARWICK
THE UNIVERSITY OF WARWICK

R.Hastings@warwick.ac.uk

 @ProfRHastings

 http://profhastings.blogspot.co.uk/