

 @ProfRHastings

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Stress and psychological well-being in families of children with autism

Richard Hastings

XX Congreso Nacional AETAPI 2022
18 November, Madrid

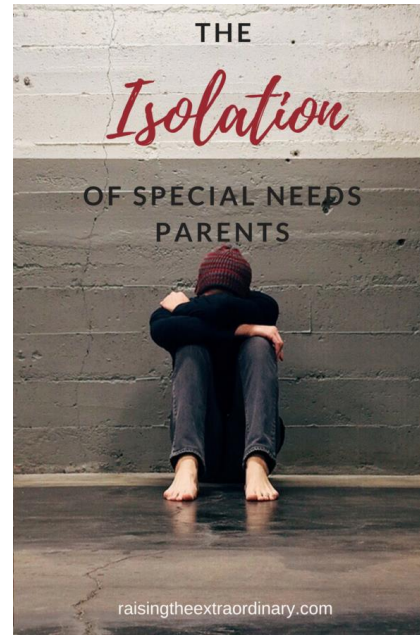
The family system

- Family systems theory suggests that family members are inter-dependent. Well-being of one member will impact across the system on other individuals/sub-systems
- Therefore, an interest in the families of children with autism and how they might be affected
- **ALSO**, well-being and actions of other family members will affect children with autism...



Under pressure

The relationships of UK parents who have a child with a learning disability



Autism Moms Have Stress Similar To Combat Soldiers

by Michelle Diamant |
November 10, 2009

DO YOU HAVE CAREGIVER BURNOUT?



1. YOU NO LONGER FIND PLEASURE IN THINGS YOU ONCE FOUND ENJOYABLE.
2. FRIENDS AND FAMILY HAVE EXPRESSED CONCERNS ABOUT YOUR WELL-BEING.
3. YOU'RE GETTING NEGATIVE FEEDBACK AT WORK.
4. YOU'RE HAVING PROBLEMS WITH YOUR SPOUSE.
5. YOU EXPERIENCE INTENSE AND RECURRENT FEELINGS OF ANGER, SADNESS, WORRY OR FEAR.
6. YOU HAVE DIFFICULTY CONCENTRATING.
7. YOU HAVE TROUBLE SLEEPING, DRASTIC WEIGHT CHANGES OR OTHER UNEXPLAINED HEALTH PROBLEMS.
8. YOU USE A SUBSTANCE TO COPE WITH, MANAGE OR SUPPRESS PAINFUL FEELINGS.

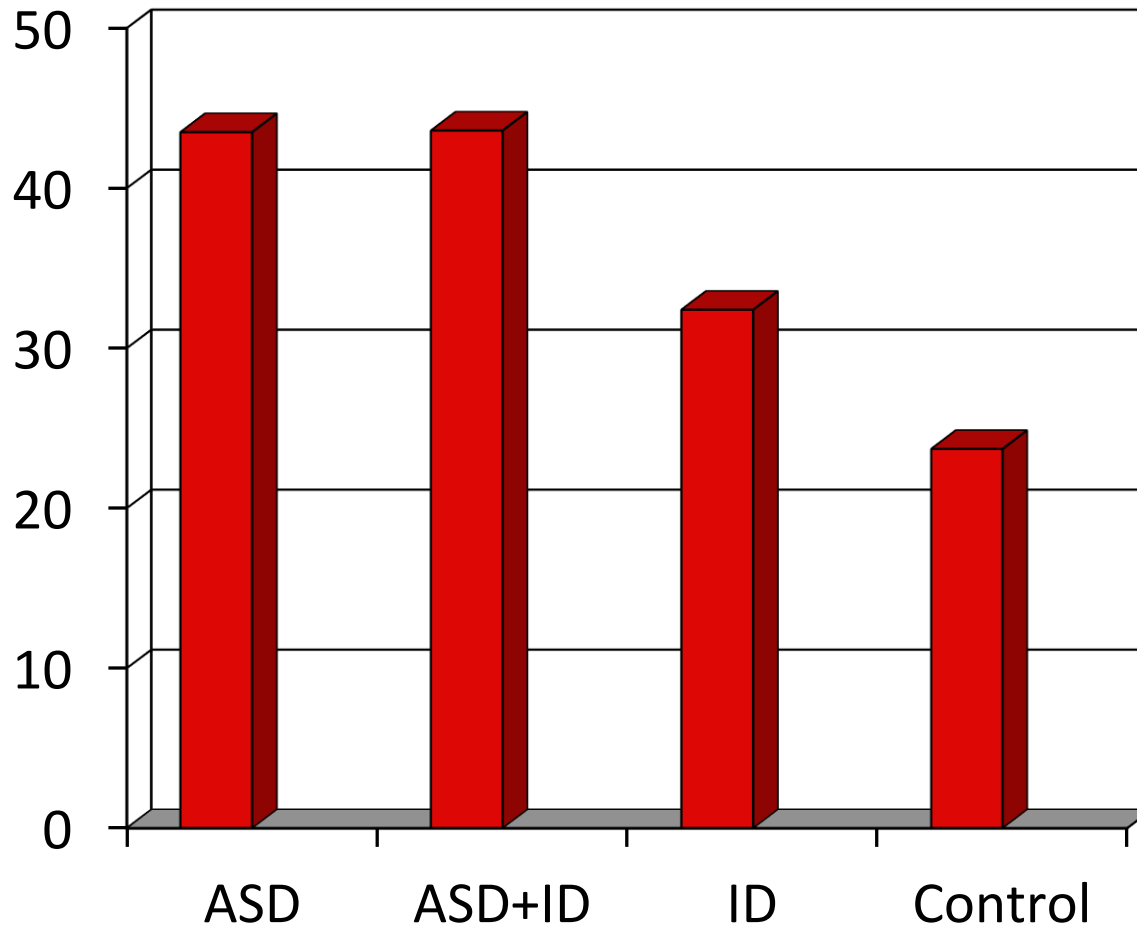
Bias in research

- Small size of samples – too few people
- Representativeness of the autism families – have people with fewer or more problems been more likely to participate?
- Representativeness of the comparison group
- How do we know families involved in the research are caring for a child with autism?
- File drawer problem – more likely to publish studies where interesting differences are found

ONS CYP MH surveys

- UK ONS surveys 1999 and 2004 N= 18,415 children age 5-16 years, 50.6% boys; population based sample across the UK; high response rate (80% across both surveys)
- Emerson identified a group with likely intellectual disability [ID] (N= 641), 3.5% of total sample
- 98 children met clinical criteria for diagnosis of ASD and 52% of these children were also in the ID group
- *Totsika, Hastings et al (2011): 4 group comparison of maternal well-being*

Mothers' MH problems



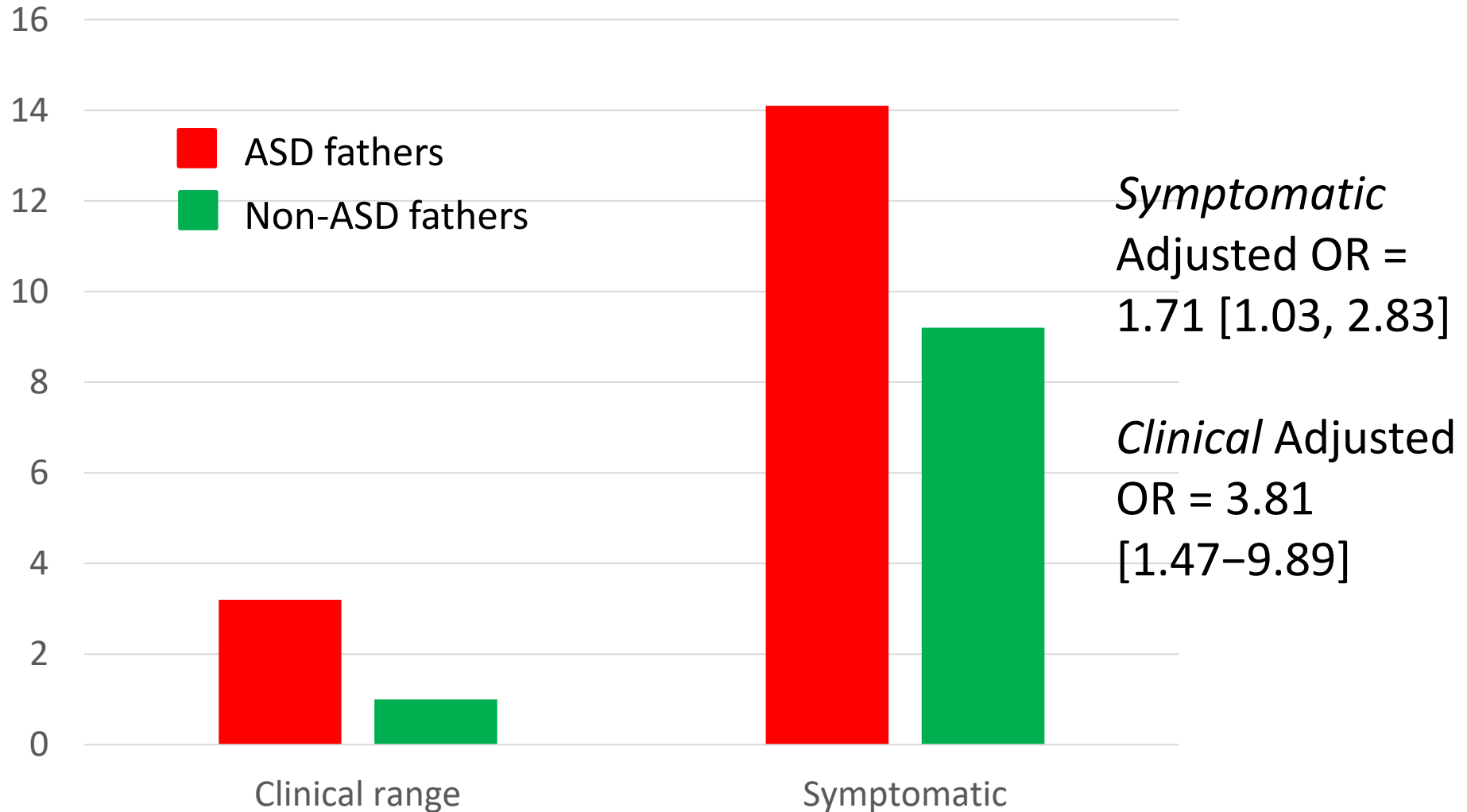
■ % Emotional disorder

LSAC – Fathers

Seymour et al., 2017 RIDD

- Longitudinal Study of Australian Children
- Children age 8-9 years and their fathers; 159 ASD fathers, 6578 non-disability fathers
- 97% ASD fathers in paid employment, 99% in two parent families
- Autism self-reported by parents
- Psychological distress of fathers, measured using Kessler 6

K6 cut-offs %

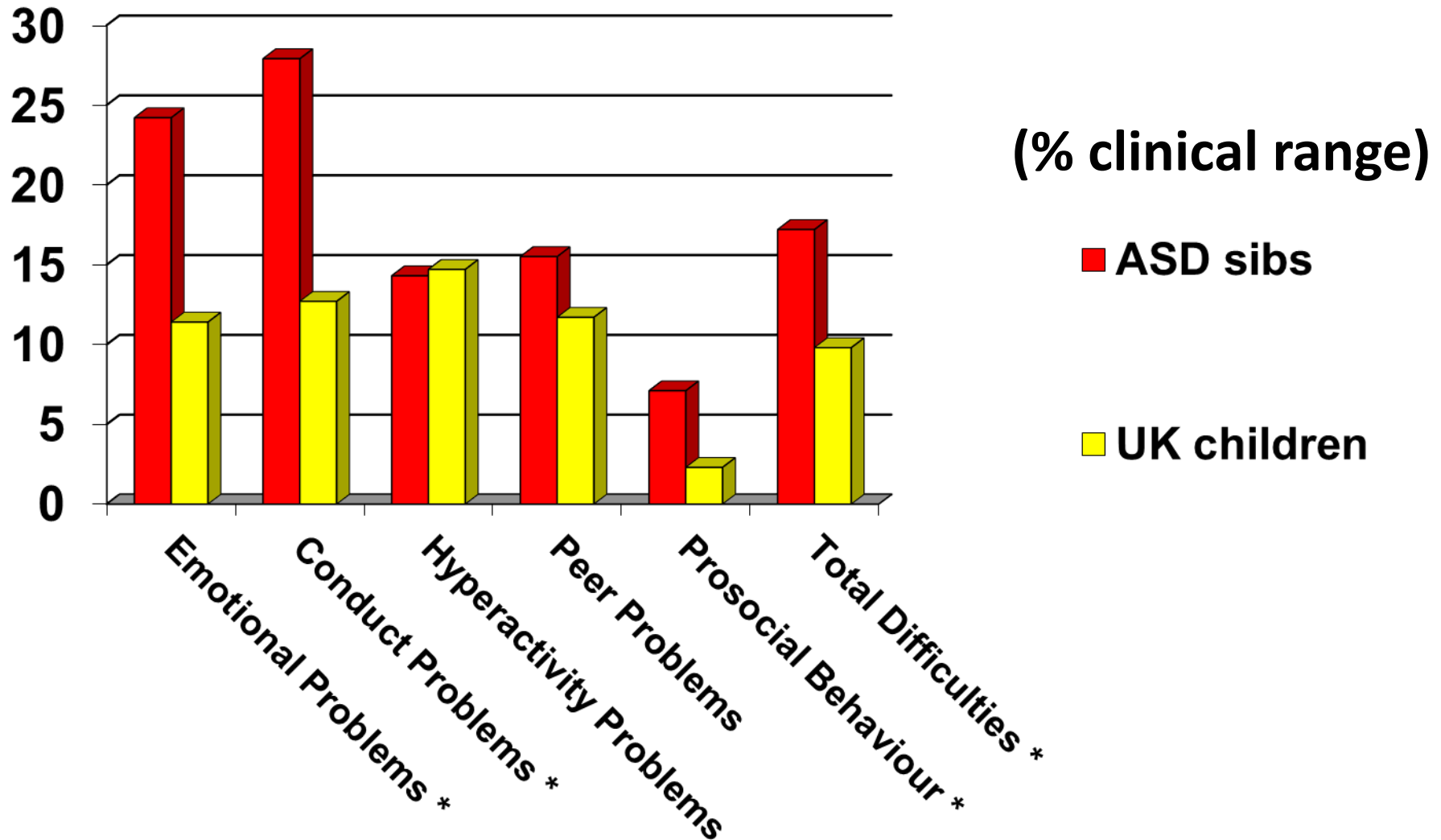


Shivers et al 2019

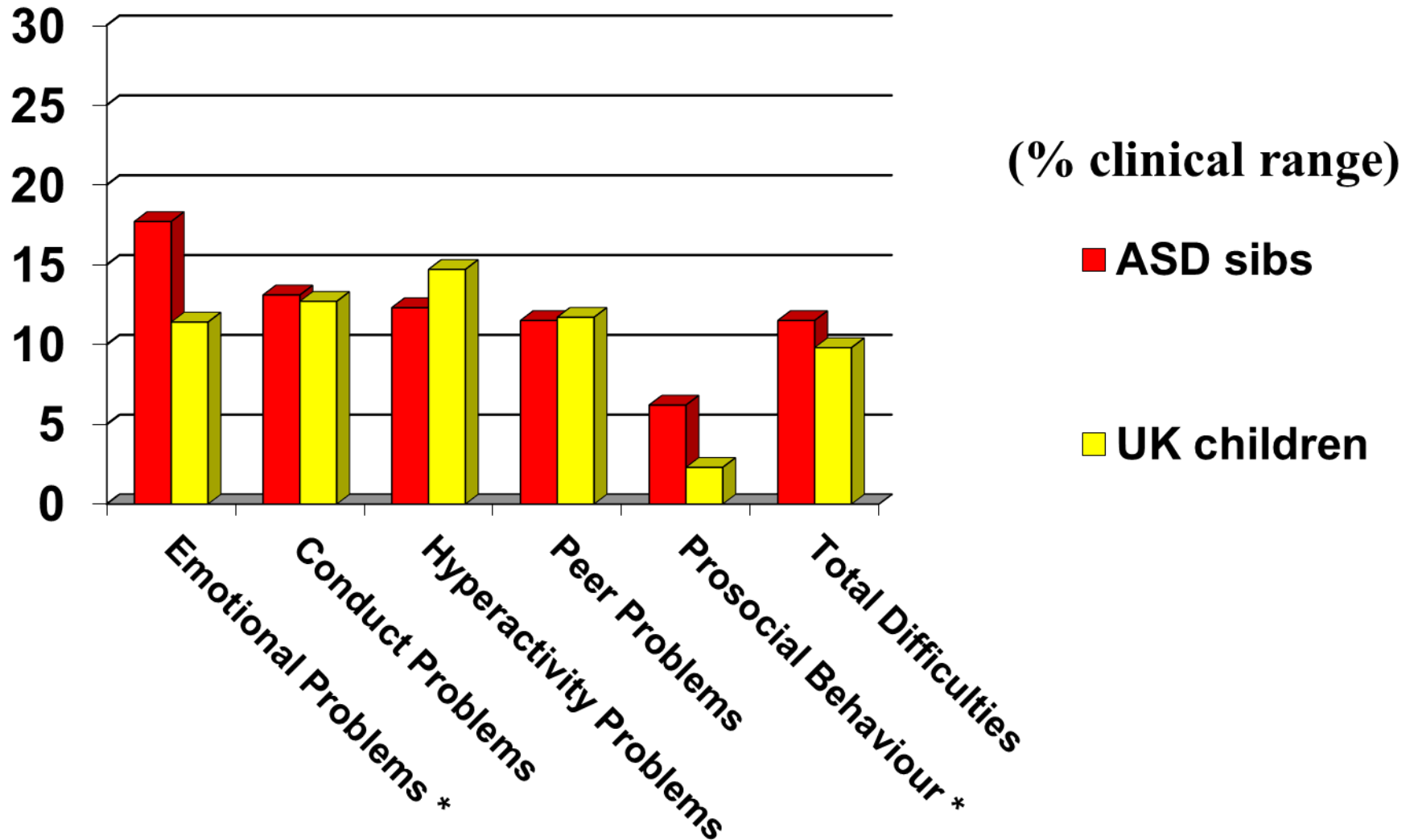
Meta-analysis of 69 studies comparing siblings of children with and without ASD

Outcome	Hedge's <i>g</i>	95% CI
Overall functioning	-0.26	-0.37, -0.15
Internalising problems	-0.29	-0.41, -0.08
Externalising behaviour problems	-0.08	-0.24, 0.08

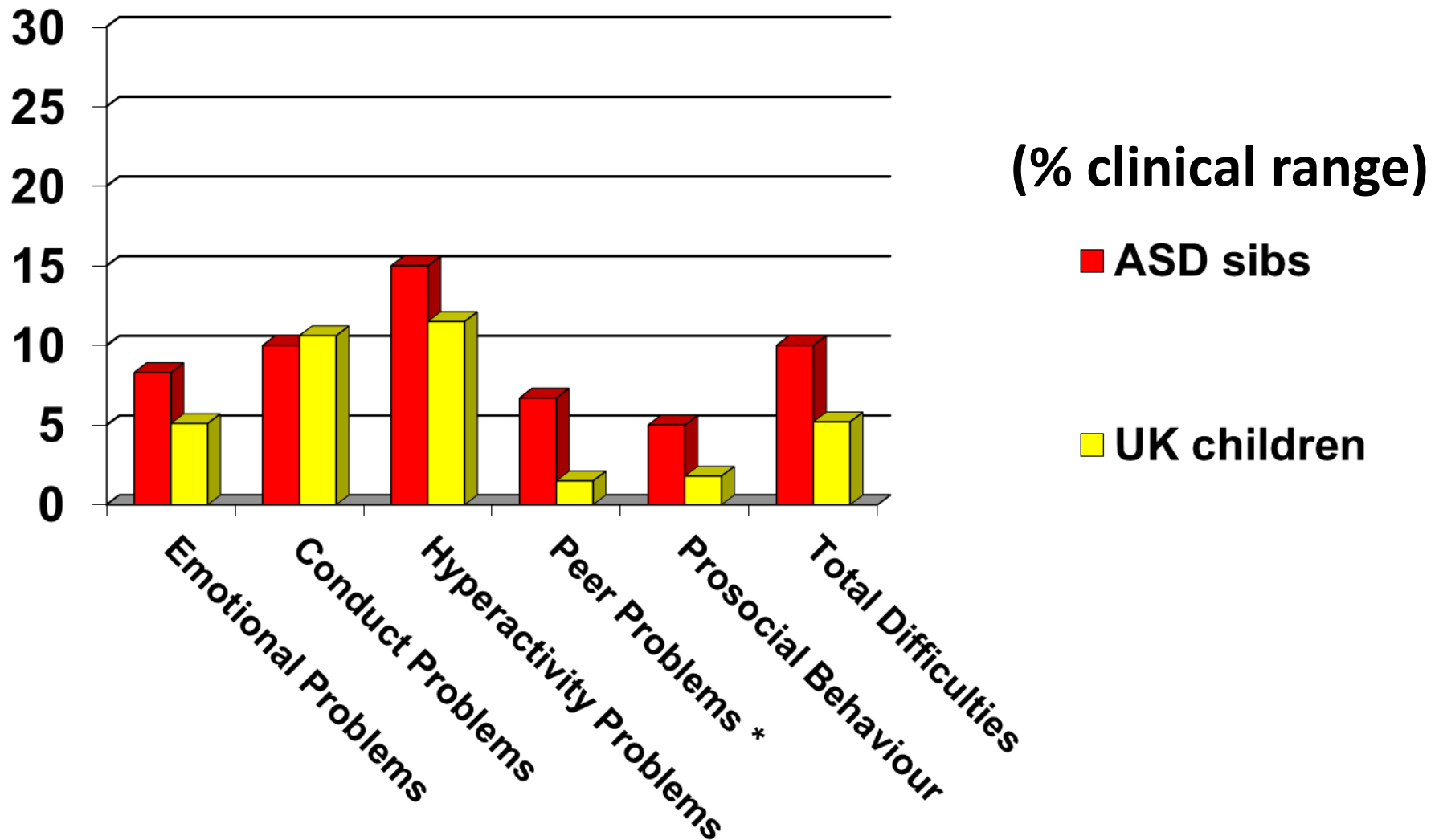
SDQ - 168 mothers' reports



SDQ - 130 fathers' reports



SDQ – 60 self-reports



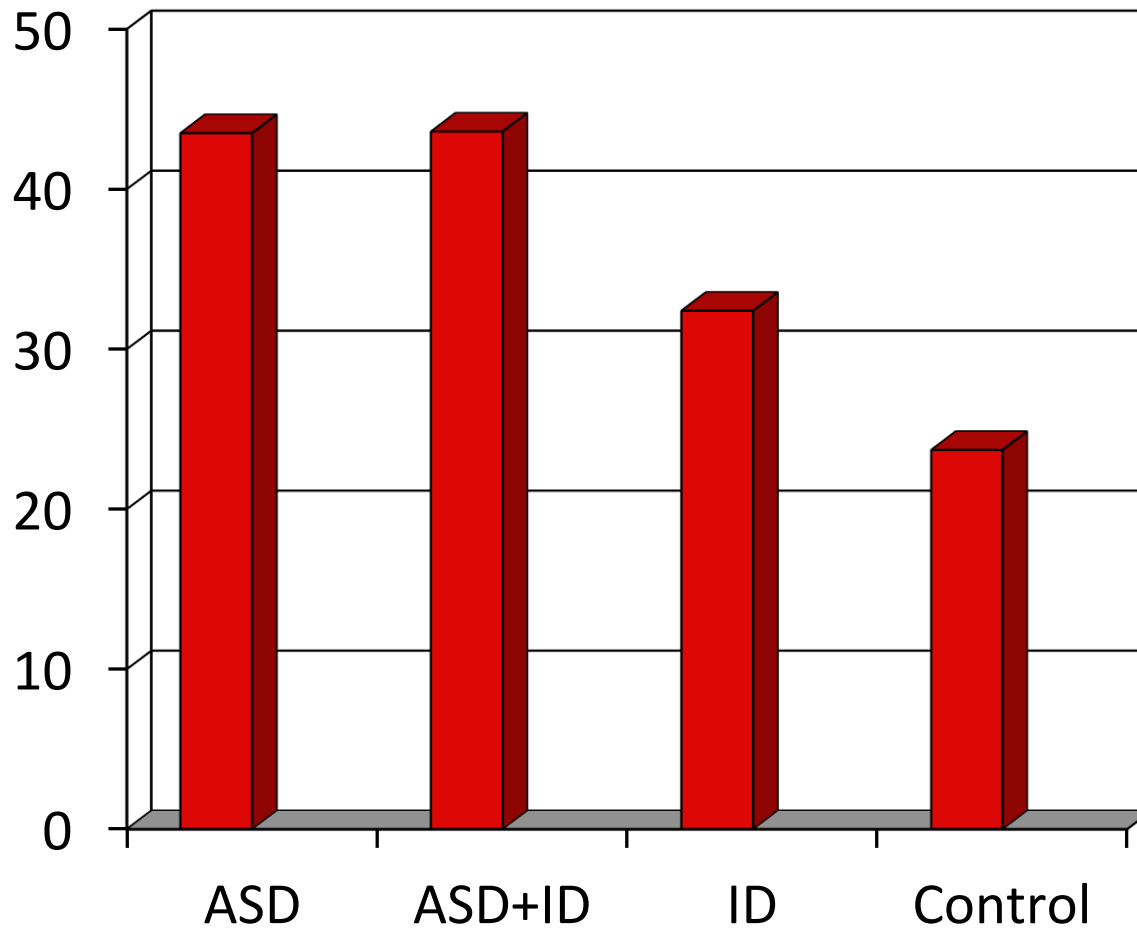
Why more “stress”?

- Socio-economic status (poverty) is a big factor
- The child with ASD’s behaviour problems
- Lack of support from/access to health, social care, and education services
- The nature of caring – more hours of “care” per week, more daily physical and personal care
- Other people’s attitudes - affiliate stigma
- Worry about future care
- Less social support available
- *Possible contribution of Broad Autism Phenotype?*

A mental health inequality

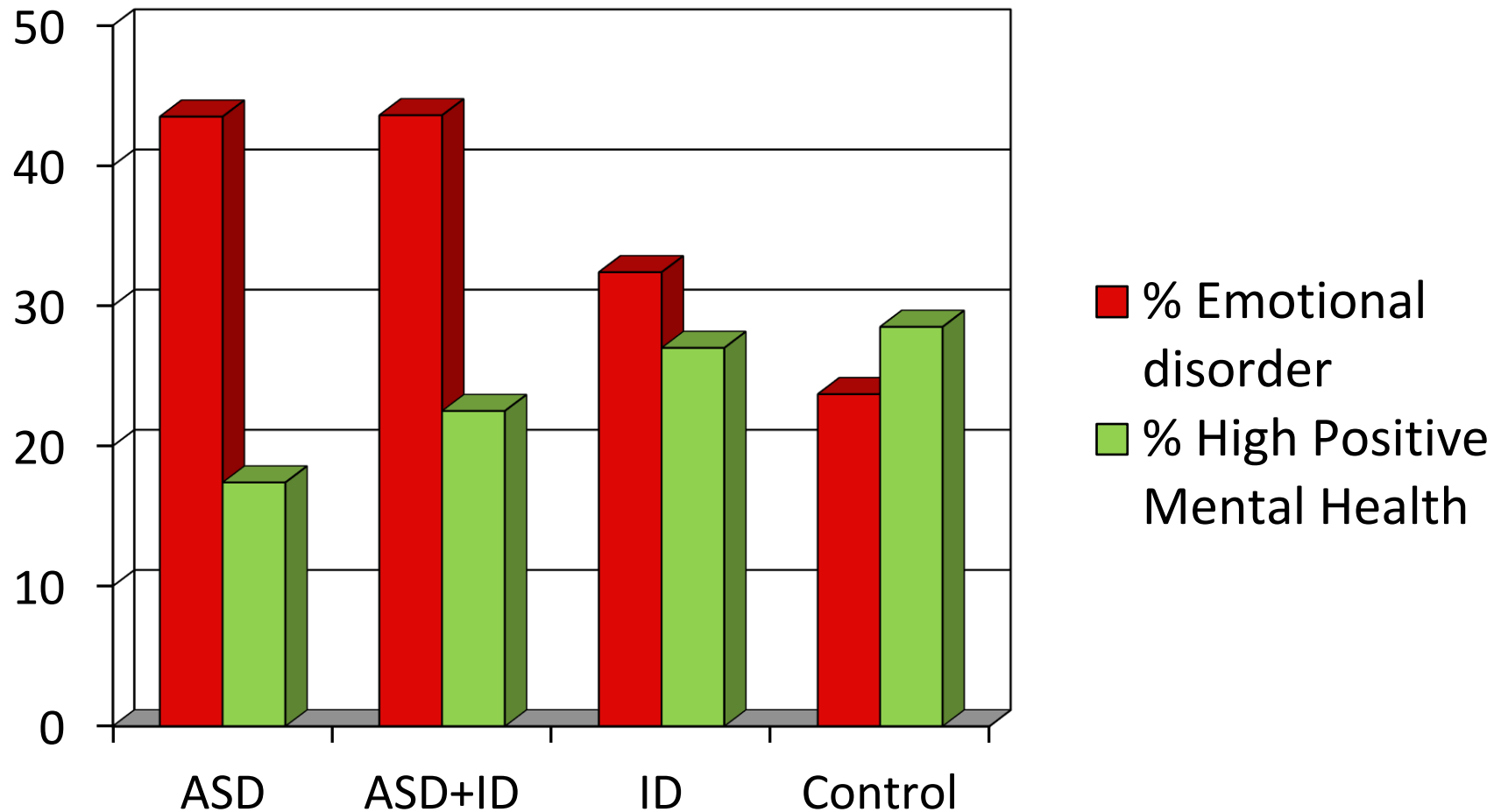
- Nearly all of the factors/reasons for increased “stress” in parents (especially mothers) are *associated with ASD, but they are not the ASD*
- These factors can be changed/improved or “fixed” with the right support
- Therefore, family members (mothers and fathers, possibly siblings) of children with ASD as a group face a mental health *inequality* – a difference that exists that does not have to exist

Mothers' MH problems



■ % Emotional disorder

Mothers' positive MH



Family “stress”

- The majority of parents and siblings of children with ASD ***are not*** “suffering” from psychological problems
- Mothers of children with ASD are 2-3 times more likely, and fathers 1.5 times more likely, to report worrying levels of psychological distress
- Parents of children with ASD also experience and report significant positivity - at least as much as other parents
- Most of the factors that increase parents’ psychological stress can be changed
- Family stress also has consequences for the psychological well-being and mental health of children with ASD

What can we do?

- Multiple interventions designed to support the family system. No silver bullet
- Stress management/coping skills for parents
- Parent training focused on managing child behaviour problems (all children in the family)
- Strengthen family relationships and family resilience
- Improve support from, consistency, knowledge within, and personalised approach of services/professionals
- Help parents to get into work and to stay in work
- Awareness-raising (changing attitudes)
- Helping families prepare for future care
- Social support between families (e.g., Parent-to-Parent)

R.Hastings@warwick.ac.uk



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