

# CURRENT TRENDS IN RESEARCH ON PARENTS WITH INTELLECTUAL DISABILITY

CARLO SCHUENGEL



# PARENTS WITH ID: A FIELD WITH STRONG INTERNATIONAL SCIENTIFIC LEADERSHIP



Gwynnyth  
Llewellyn



David  
McConnell



Maurice  
Feldman

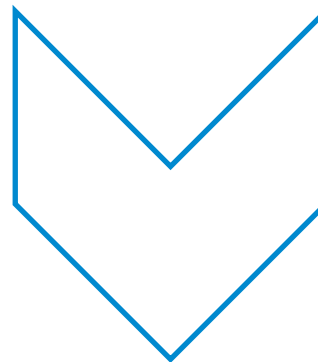
# Small-scale, clinical, single-case parent training, qualitative studies



Schuengel, Kef,  
Hodes, &  
Meppelder  
Current Opinion in  
Psychology  
*In Press*



Epidemiological  
Research



Theory-led  
Research



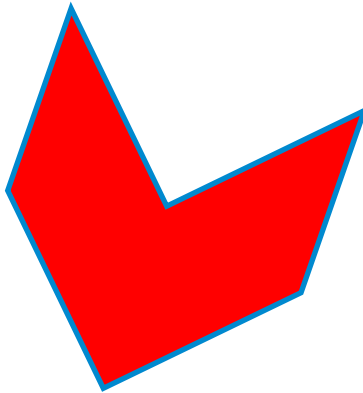
Intervention  
effectiveness

Inclusive study designs?

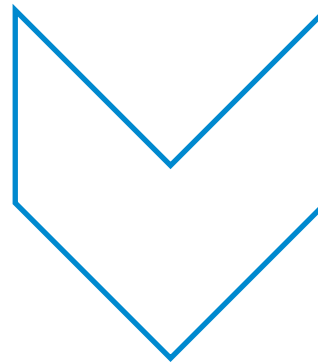


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Trends



Epidemiological Research



Theory-led Research

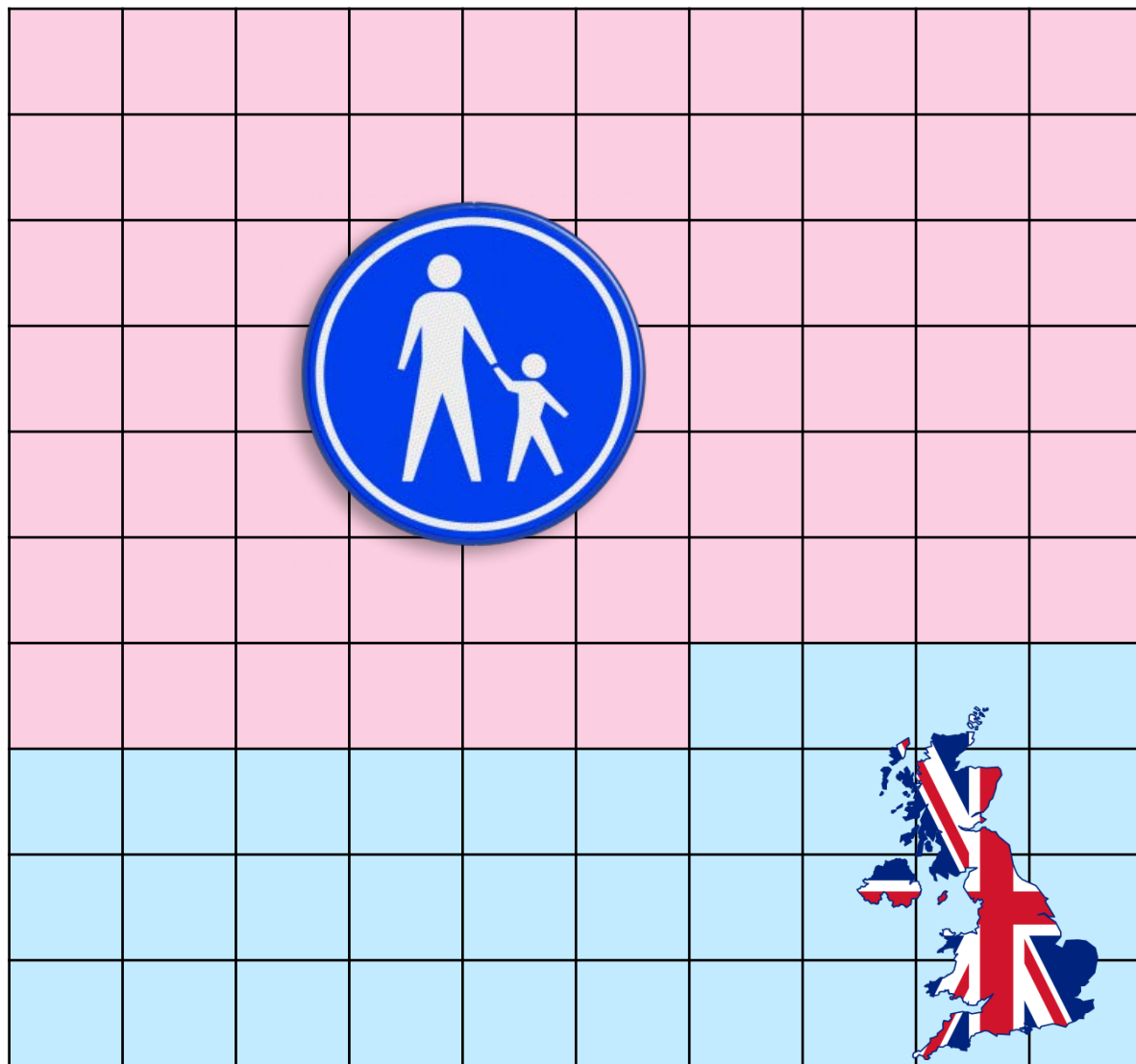


Intervention effectiveness

Inclusive study designs?

# How many adults with mild ID are parents?

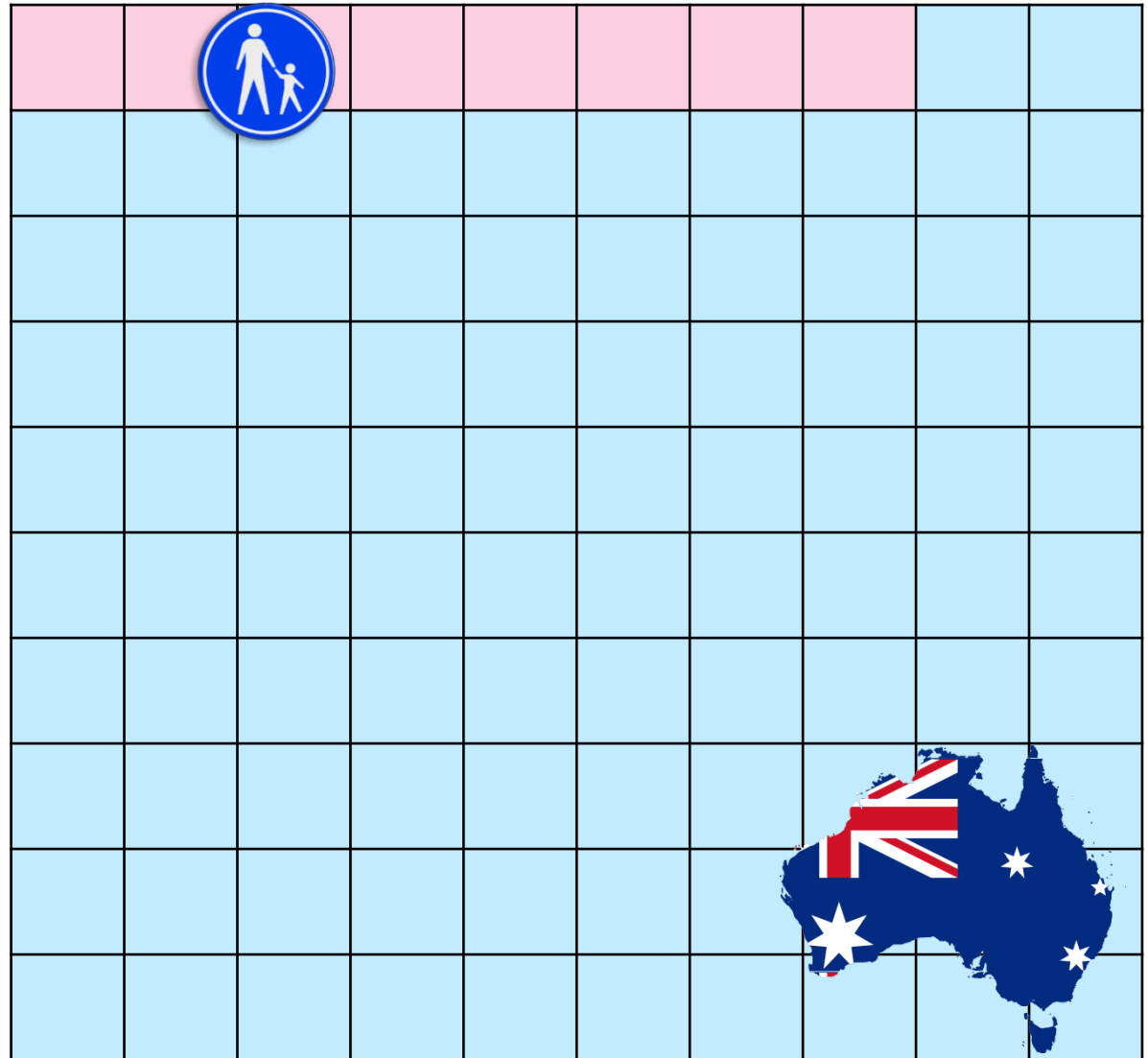
UK Household survey  
N = 14.373  
16-49 year old  
Having biological  
children



Emerson E, Llewellyn G, Hatton C, Hindmarsh G, Robertson J, Man WYN, Baines S:  
*J Intellect Disabil Res* 2015, **59**:1142-1154.








How many  
adults with  
difficulty  
learning/  
understanding  
are parents?

Australian Household  
survey  
N = 61,900  
15-64 year old  
Sharing private dwelling  
with child <15 yrs



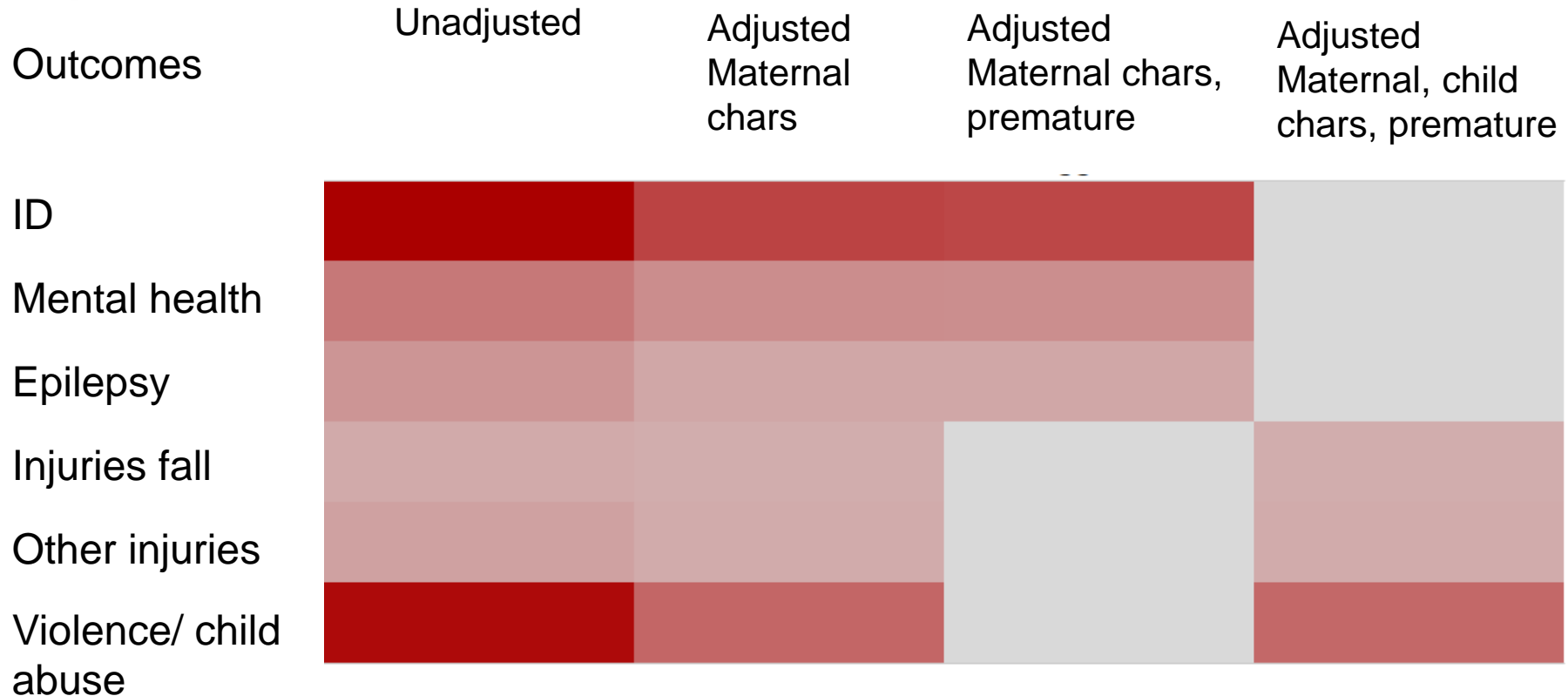
Man NW, Wade C, Llewellyn G *J Intellect Dev Dis* 2016,1-7.

# HEALTH AND SAFETY OUTCOMES?

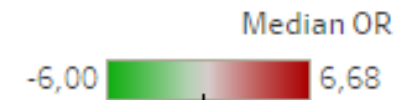
	Millenium cohort babies (Hindmarsh ea 2011)*	Fragile Families 3-year olds (Powell ea 2016)
Vaccinations		
Accidents		
Fine motor development		
Gross motor development		
Health rating		
Asthma		
Overweight/obesity		

\* Possible selection effect

# DEVELOPMENTAL AND BEHAVIOURAL OUTCOMES?



Sweden  
N = 478,577

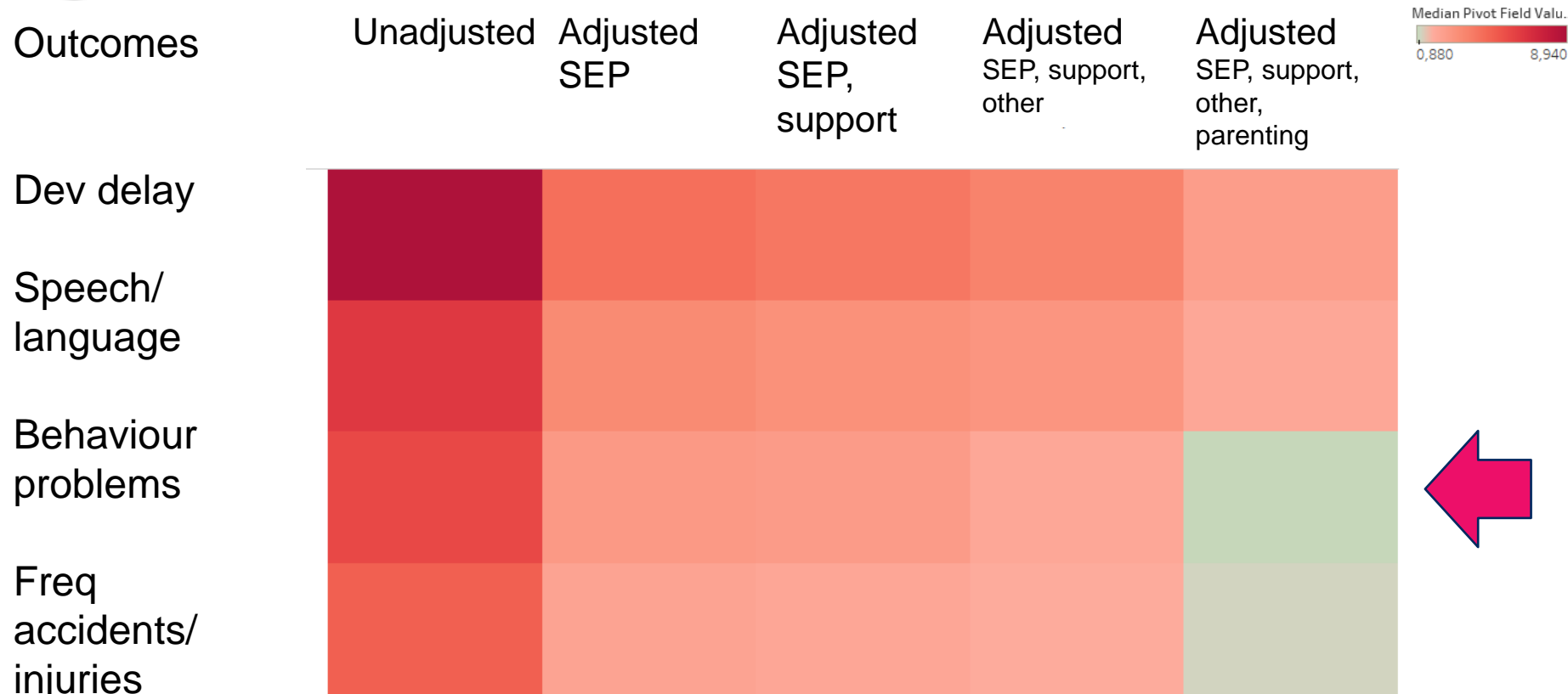


Wickström M, Höglund B, Larsson M, Lundgren M ***Child Abuse & Neglect*** 2017, 65:124-131.





# DEVELOPMENTAL AND BEHAVIOURAL OUTCOMES?



UK  
N = 46.035

Parenting problems  
ID: 56%  
Non-ID: 6%

Emerson E, Brigham P: *Research in Developmental Disabilities* 2014, **35**:917-921.



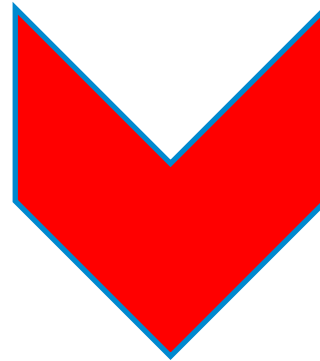
# EMERGING INSIGHTS FROM EPIDEMIOLOGICAL AND SECONDARY ANALYSIS STUDIES

- > Among people with ID, being a parent not a rare phenomenon
  - > Still small relative to general population
- > ID in parents associated with risk factors and risk outcomes
  - > Association ID-outcomes not completely accounted for by other risk factors
  - > Risk outcomes found in minority of cases
  - > Parenting problems may partly explain risk outcomes

Small-scale, clinical, single-case parent training, qualitative studies



Epidemiological Research



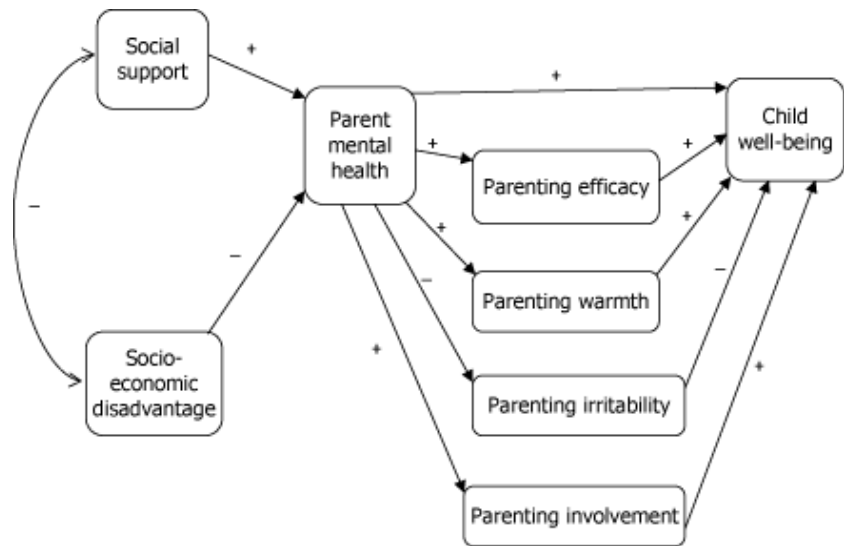
Theory-led Research



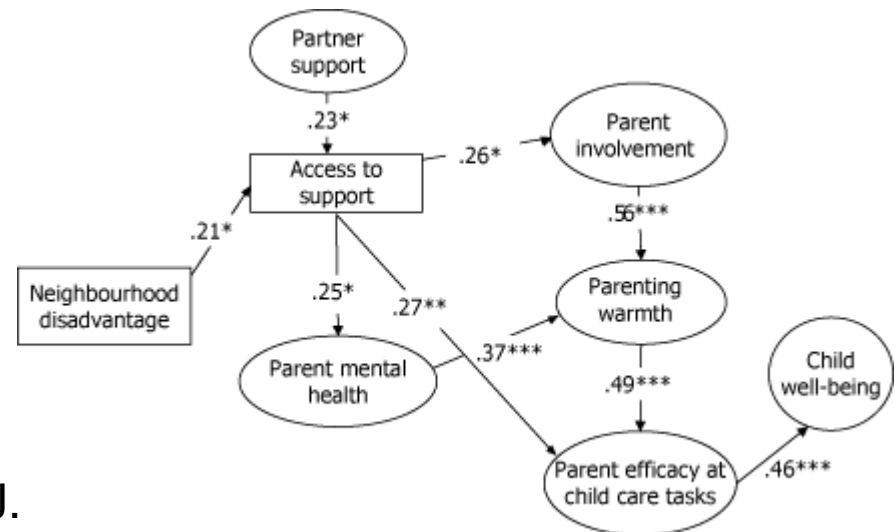
Intervention effectiveness

Inclusive study designs?

# BUILDING ON THE FAMILY STRESS MODEL



N = 120



Wade, C., Llewellyn, G., & Matthews, J.  
(2015). *Clinical Psychologist*, 19(1), 28-38.  
doi:10.1111/cp.12055

# BUILDING ON ATTACHMENT THEORY

- > Lower sensitivity ( $n = 23$ ) compared to controls ( $n = 25$ ), matched by SES and neighbourhood adversity
- > Sensitivity associated with attachment disorganization
  - > Sweden, Lindberg *et al.* *in press*, Granqvist *et al.* 2015
- > Social adaptation → harmonious interaction ( $\beta = 0,24$ ) and sensitive discipline ( $\beta = 0,27$ )
  - > Parents ( $N = 85$ ) with mild ID or borderline functioning
  - > Dissertation Marja Hodes (2017)



# EMERGING INSIGHTS FROM THEORY-LED RESULTS

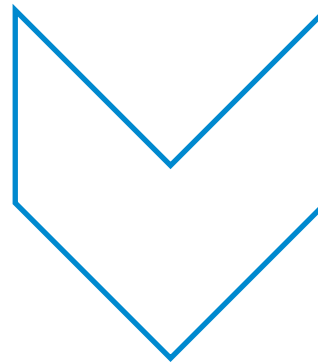
- > Parenting and developmental theory help to identify areas of difficulty
- > For increase generalizability and pragmatic validity of these theories, more inclusive empirical approach is needed



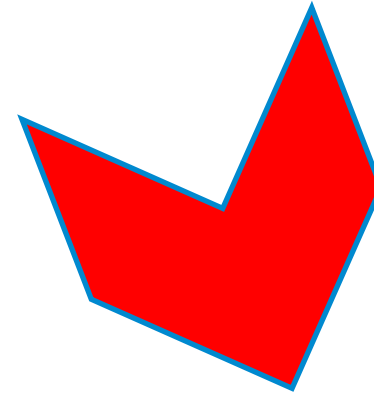
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# GENERALIZABILITY ISSUES IN INTERVENTION RESEARCH

- > Knowles ea 2013
  - > Majority studies are single case experiments
  - > Inferences to populations? Parents of older children? Other skills?
  - > Long term gains?
  - > Benefit for children?
- > Synthesis of evidence and assessment of (publication) bias difficult
- > Randomized group effect studies limited (Coren ea 2010 – update in progress)
  - > Feldman ea 1992 (n = 22)
  - > Keltner wa 1995 (n = 40)
  - > Llewellyn ea 2003 (n = 45)

# WHAT WORKS FOR PARENTS WITH DISABILITY



Home Over ons Nieuws Thema's Community's Markant Contact & Support

Home > Artikel

1 februari 2017 00:00

Lees voor

## Promotie Marja Hodes over ouderschap van mensen met een verstandelijke beperking

door Johan de Koning

Datum: 8 februari 2017

Tijd: 15:45

Locatie: Vrije Universiteit Amsterdam (Hoofdgebouw – Aula), De Boelelaan 1105, 1081 HV Amsterdam

Op 8 februari promoveert Marja Hodes, psycholoog bij ASVZ, op het ondersteunen van ouders met een verstandelijke beperking. De titel van haar proefschrift luidt 'Testing the effect of parenting support for people with intellectual disabilities and borderline intellectual functioning'.



[Slideshow](#)

beperkingen. Hodes heeft deze interventie nu toegankelijk gemaakt voor ouders met verstandelijke beperkingen (VIPP-Learning Difficulties).

Beperkingen en opvoedstress

Ouders met verstandelijke beperkingen komen in hun rol als ouder meer problemen tegen dan ouders zonder verstandelijke beperkingen. Eerder onderzoek toonde aan dat deze ouders geholpen kunnen worden met professionele opvoedhulp. Tot nu toe is vooral gekeken naar concrete verzorgingstaken. Promovenda Marja Hodes onderzocht een opvoedinterventie die gericht is op sensitief opvoeden. De basis hiervoor was het programma Videofeedback Intervention for Positive Parenting with the focus on Sensitive Discipline (VIPP-SD), ontwikkeld door het Centrum voor Gezinsstudies (Universiteit Leiden) en effectief gebleken in binnen- en buitenland voor ouders zonder



# WAt WERkt?



GEMIVA-SVG GROEP



ZonMw

Philadelphia



's Heeren Loo



SIG

organisatie voor ondersteuning van mensen met een beperking

syndion

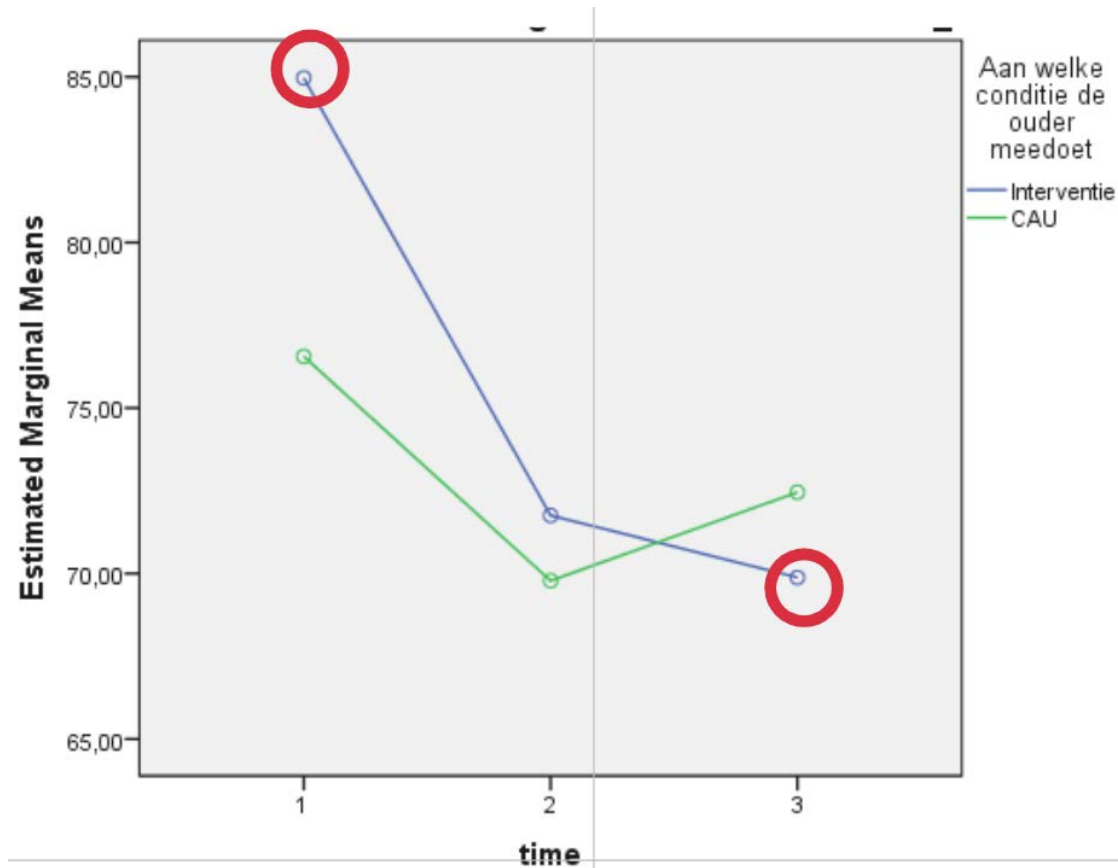


cordaan



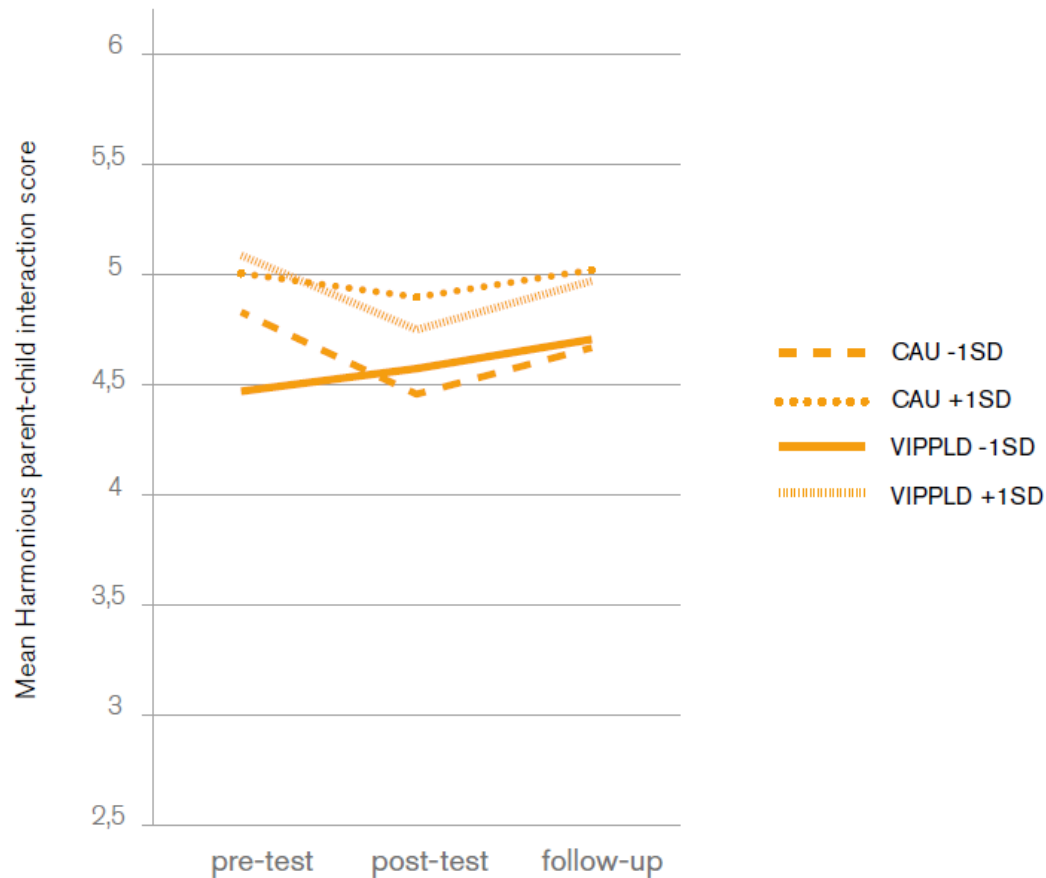
# INTERVENTION GROUNDED IN ATTACHMENT THEORY (VIPP-LD) REDUCED PARENTING STRESS

Time x group effect  
 $F(1.73, 143.5) = 4.42, p = .02$



Marja W. Hodes, Marieke Meppelder, Marleen de Moor, Sabina Kef, & Carlo Schuengel  
*Journal of Applied Research in Intellectual Disability*, November 2016  
DOI: 10.1111/jar.12302

# EFFECT ON PARENT-CHILD INTERACTION UNCLEAR



Harmonious interaction:  
Time x group effect  
 $F(2, 166) = 0.49, p = .61$

Moderation by IQ: n.s.

Moderation by adaptive functioning:  
 $F(2, 150) = 3.18, p = .04$

# EMERGING INSIGHTS FROM INTERVENTION STUDIES

- > Equivocal empirical evidence
  - > numerous replications of parenting education effectiveness in single case experiments, versus...
  - > Group effect studies show variable results, with the largest controlled study showing no benefit on parent-child interaction

Euser et al. *BMC Public Health* (2015) 15:1068  
DOI 10.1186/s12889-015-2387-9



## RESEARCH ARTICLE

Open Access



## A gloomy picture: a meta-analysis of randomized controlled trials reveals disappointing effectiveness of programs aiming at preventing child maltreatment

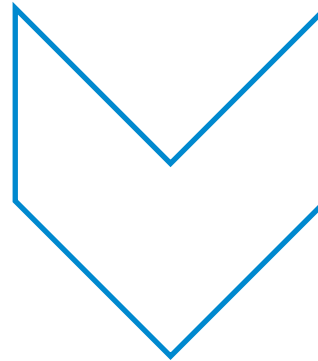
Saskia Euser, Lenneke RA Alink, Marije Stoltenborgh, Marian J. Bakermans-Kranenburg and Marinus H. van IJzendoorn\*



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Intervention effectiveness

**Inclusive study designs?**

Questions, reprints, remarks:

[c.schuengel@vu.nl](mailto:c.schuengel@vu.nl)



Twitter: @carloschuengel