

Perspectives from Australia: Who are parents with intellectual disabilities in Australia and how are they being supported?

Dr Catherine Wade  @WadeCath

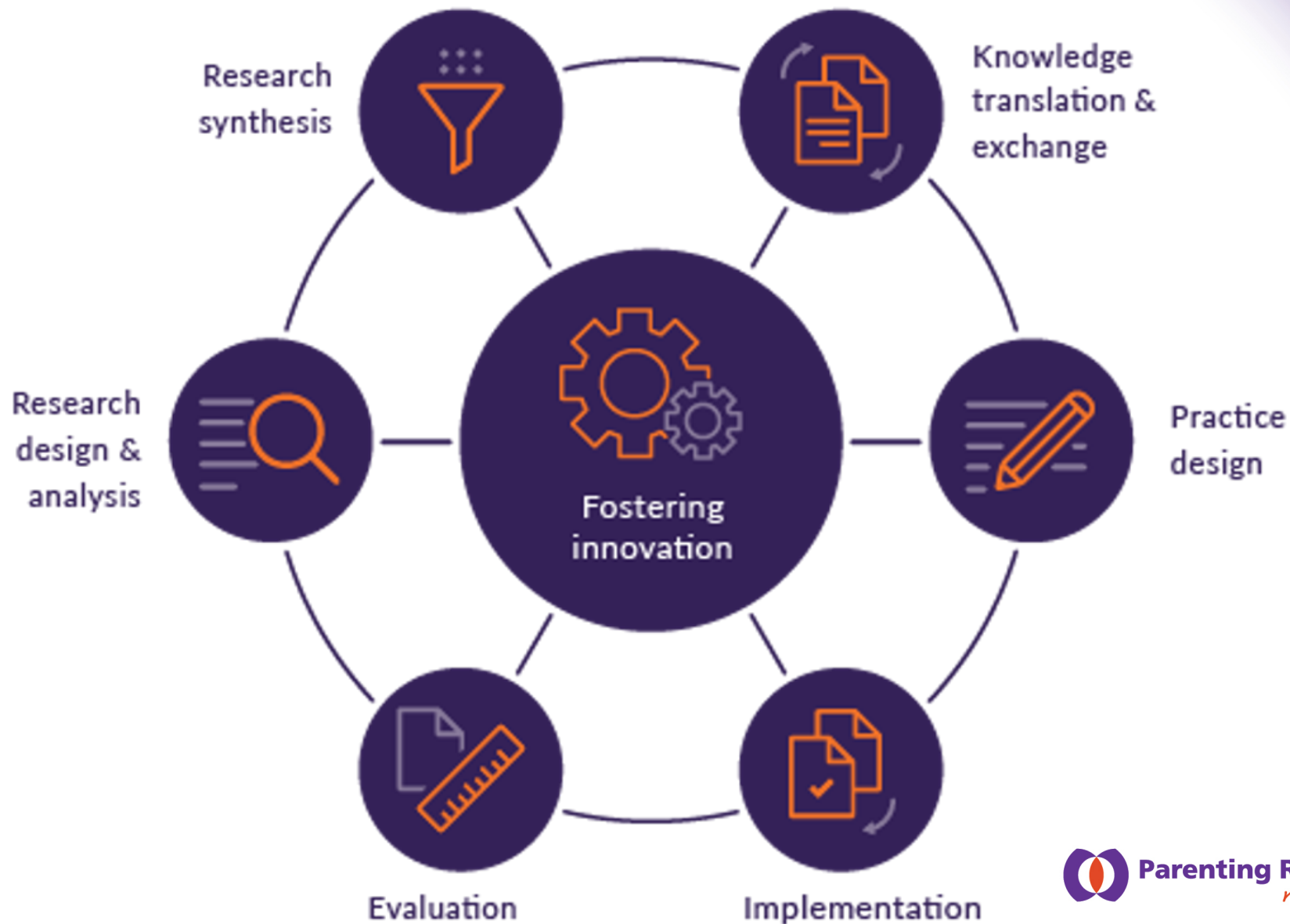
TASP Conference, October 2019



Parenting Research Centre
raising children well



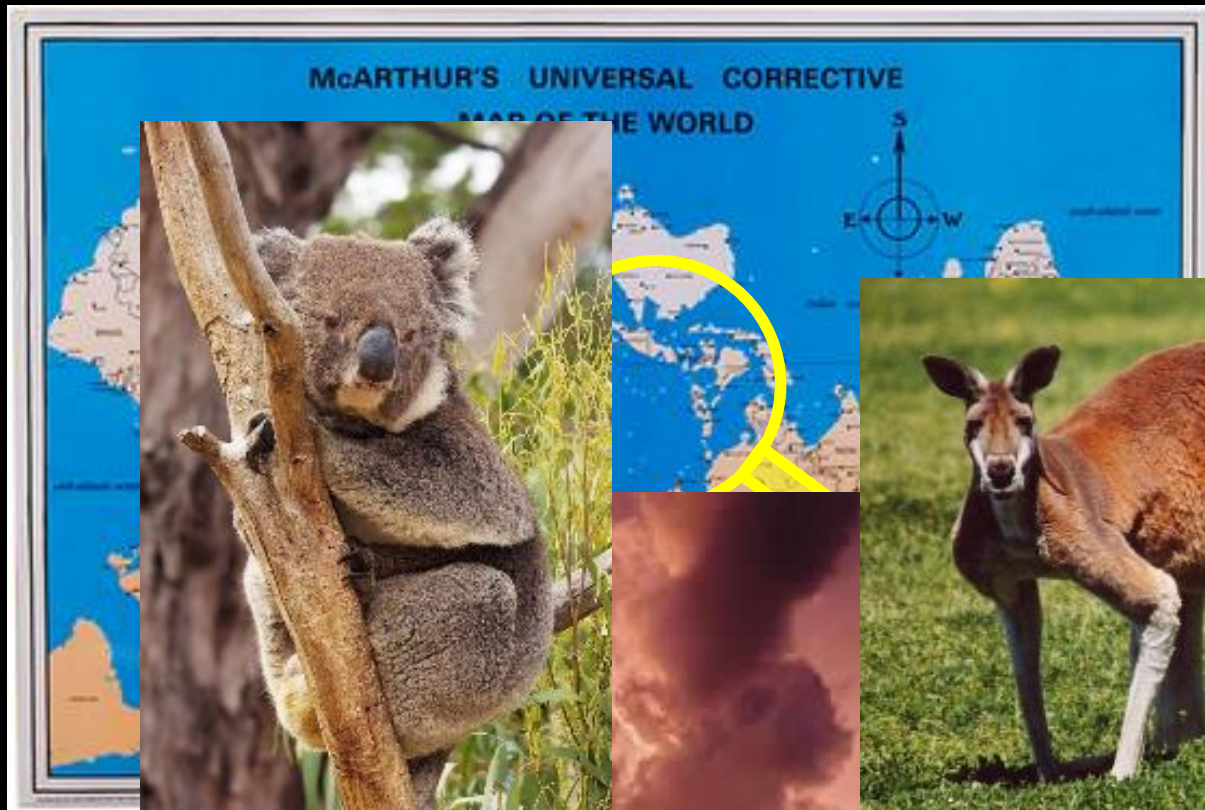
PRC's Innovation Cycle



Overview

1. Prevalence
2. Characteristics and living conditions
3. How are our systems supporting these parents – examples of best practice in Australia







First Nations Map

Know the language, know the land

*"This map should not be viewed as definitive, but
indicative of the diversity of groups and languages
that constitute the First Nations of this continent.
Some of the names and areas are contested."*



Common terms – international differences

Mental retardation

Low IQ

Intellectual disability

Developmental Disabilities

Learning difficulties

Learning disabilities

Low achievement

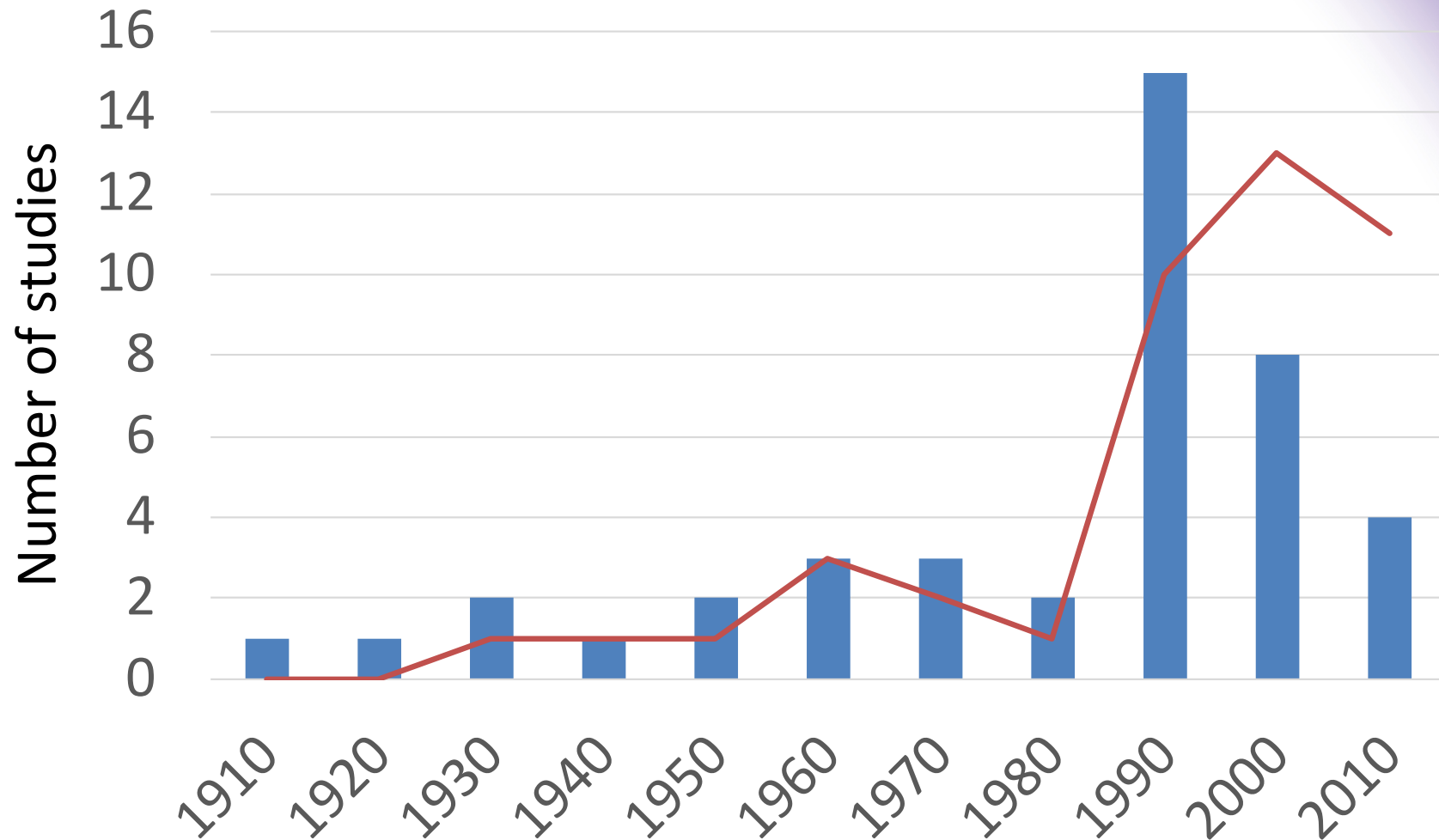


Scoping review of prevalence studies

53 papers reported on 42 original studies reported in English that estimated the prevalence of parents with intellectual disability in populations.

Wade & Macvean (2016)

Prevalence studies



■ First year of data collection — Date reported

Prevalence of parenting with ID

STUDY	RATE	LOCATION & DATE
ID among parents		
Hoglund (2012)	.10% of mothers had ID (approx. 1 in 1,000)	Sweden, 1999-2007
Maughan (1999)	.74% of people born in 1958 were parents with ID in 1991 (approx. 7 in 1000)	Britain, 1991
Anderson (2005)	.07% of people in US were mothers with ID (approx. 7 in 10,000)	USA, 1994-5
McConnell (2008)	3.76% of mothers attending antenatal care had ID	Sydney, Aust, 2002
Man (2011)	.40% of parents had ID (approx. 4 in 1000)	Aust, 2009
Parenting by people with ID		
Servais (1992)	1% of women with ID had children	Walloon Brabant, Belgium, 1998 - 1999
Emerson (2005)	7% of adults with LD had children	England, 2003-4

Court Records

McConnell, Aunos et al	10.12% of cases involved families where a parent had ID	Canada, 2003
Booths & McConnell	15.14% of cases involved families where a parent had ID	Leeds & Sheffield, Eng, 2000
Llewellyn et al (2003)	8.77% of cases involved families where a parent had ID	Courts in NSW, Aust 1989-9
Glaun (1999)	1.83% of cases involved families where a parent had ID	Victoria, Australia 1996-7
Taylor (1991)	6.31% of cases involved a parent with ID	Boston, 1985-86

Incidence of child births

STUDY	RATE (children per family)	LOCATION & DATE
Brandon (1960)	2.29	London, 1922-58
Shaw (1960)	1.91	Sheffield, Eng, 1915-1960
Lewis (1934)	2.39	England & Wales, unclear dates
Gillberg (1983)	2.66	Sweden, 1943-54
Brandon (1957)	2.05	London, unclear dates
Laxova (1973)	1.79	England, 1961-1971
Weiber (2011)	1.11	Blekinge, Sweden, 1975-1989
Hockey (1979)	1.16	WA, Australia, unclear dates
San Augustin (1999)	1.94	NYC, USA, 1990-1993
Pixa-Kettner (2008)	1.03	Germany, 1990-2005
Pixa-Kettner 1998; 1999)	1.41	Germany, up to 1993
Seltzer (2005)	1.0	Wisconsin, USA, 1992-94
Woodhouse (2001)	1.78	Clinic in Wales, 1995-97
Llewellyn et al (2003)	2.12	Courts in NSW, Aust 1989-9
Mirfin-Veitch (1999)	2.09	Otago and Southland, NZ, unclear dates





Journal of Intellectual & Developmental Disability

ISSN: 1366-8250 (Print) 1469-9532 (Online) Journal homepage: <http://www.tandfonline.com/loi/cjid20>

Prevalence of parents with intellectual disability in Australia

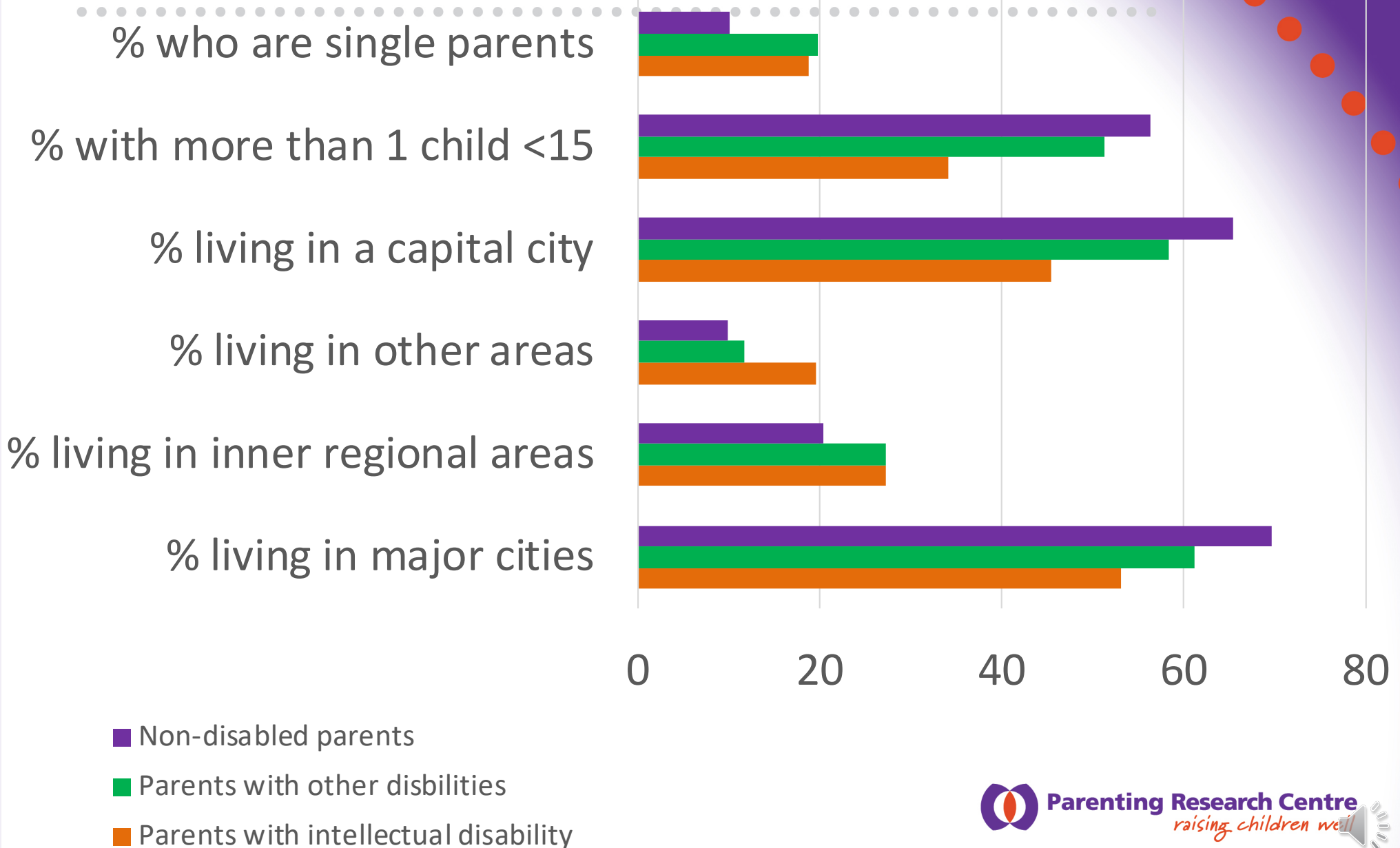
Nicola Wing Man, Catherine Wade & Gwynnyth Llewellyn

17,000 parents with identified intellectual disability in Australia

- 4 in 1000 Aust parents have an intellectual disability
- 8% of people with intellectual disability in Australia are parents

Characteristics

Source: SDAC 2009



Characteristics

Source: GSS 2010

0

50

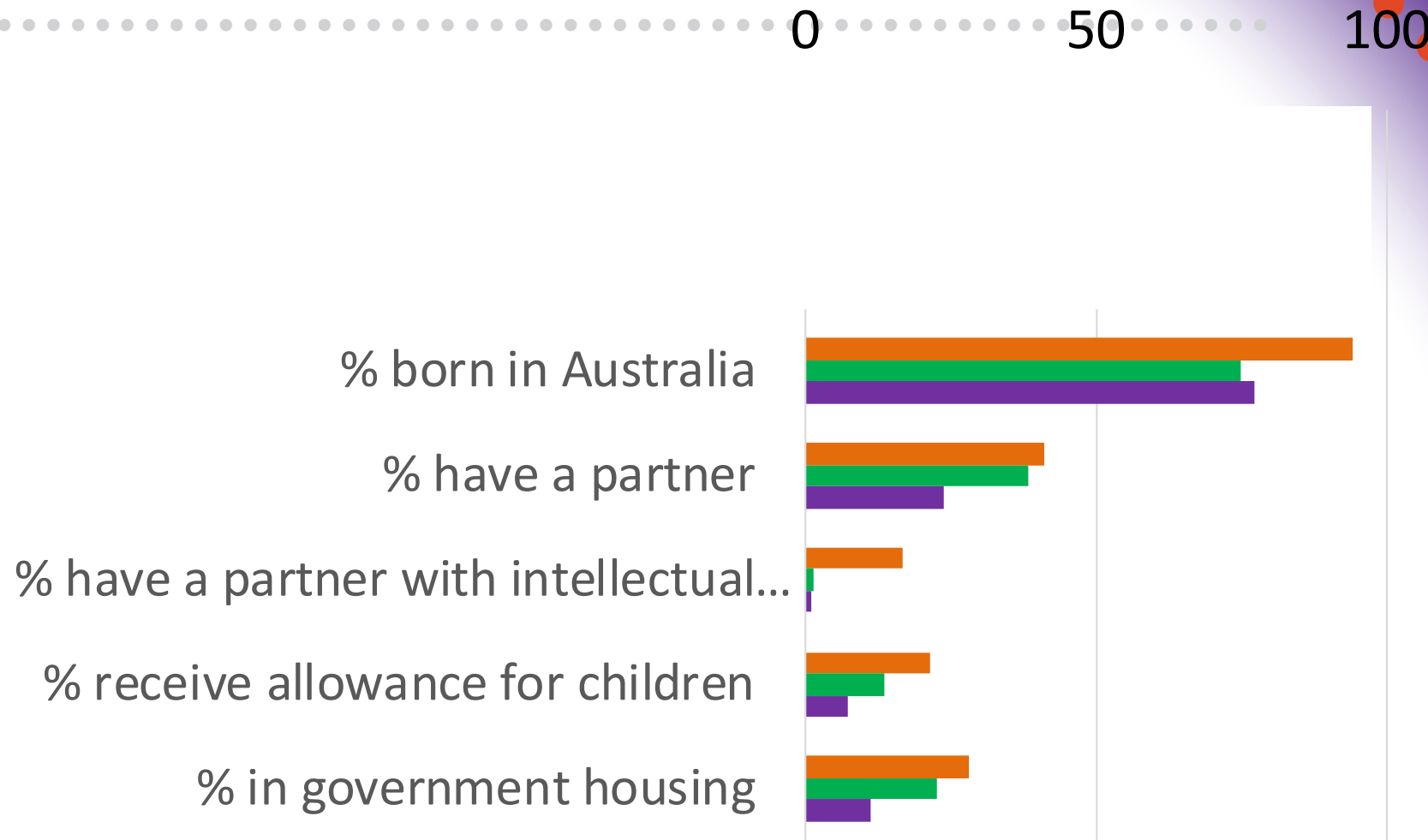
100



- Parents with intellectual disability
- Parents with other disabilities
- Non-disabled parents

Characteristics

Source: Centrelink, 2011



- Parents with intellectual disability
- Parents with other disabilities
- Non-disabled parents

Health

Vulnerable to mental and physical health problems

Feldman, Leger, & Walton-Allen (1997)

Feldman, Varghese, Ramsay, & Rajska (2002)

Llewellyn, McConnell & Mayes (2003)

McConnell, Mayes, & Llewellyn (2004)

McConnell, Mayes, & Llewellyn (2008)

Aunos et al. (2008)

O'Keeffe & O'Hara (2008)

Social support

- Limited social support from family, friends, or the community
- Many mothers with learning difficulties want help with meeting people and making friends, and 'getting out and about' in their community
- Social support important for mental health and parenting

Wade, Llewellyn & Matthews, (2008)

Kroese et al. (2002)

Llewellyn et al. (1998)

Walton-Allen & Feldman (1991)

Vulnerable to social problems

- Poverty
- Social isolation
- Unemployment
- Communication difficulties
- Lack of parent role models

Aunos et al. (2008)

Feldman et al. (2002)

McConnell & Llewellyn (2005)

Tymchuk & Andron (1990)

Wise (1997)

Wade, Llewellyn & Matthews (2008)



Research Article

Pregnancy Outcomes Among Women with Intellectual and Developmental Disabilities

Monika Mitra PhD ^a ✉, Susan L. Parish PhD, MSW ^c, Karen M. Clements ScD, MPH ^b, Xiaohui Cui ScD ^d, Hafsatu Diop MD, MPH ^d

 [Show more](#)

<https://doi.org/10.1016/j.amepre.2014.09.032>

[Get rights and content](#)

Referred to by **Mitra M, Parish SL, Clements KM, Cui X, Diop H. Pregnancy Outcomes Among W...**

American Journal of Preventive Medicine, Volume 49, Issue 2, August 2015, Pages 331



[Download PDF](#)

Background

There is currently no population-based research on the maternal characteristics or birth outcomes of U.S. women with intellectual and developmental disabilities (IDDs). Findings from small-sample studies among non-U.S. women indicate that women with IDDs and their infants are at higher risk of adverse health outcomes.

Purpose

To describe the maternal characteristics and outcomes among deliveries to women with IDDs and compare them to women with [diabetes](#) and the general obstetric population.

Methods

Data from the 1998–2010 Massachusetts Pregnancy to Early Life Longitudinal database were analyzed between November 2013 and May 2014 to identify in-state deliveries to Massachusetts women with IDDs.





THE UNIVERSAL DECLARATION
OF **Human Rights**



ADOPTED BY THE UNITED NATIONS GENERAL ASSEMBLY AT
THE THIRD MEETING, HOLD IN PARIS ON 10 DECEMBER, 1948



HealthyStart





HealthyStart

A national strategy for children of
parents with learning difficulties

AUSTRALIAN SUPPORTED PARENTING CONSORTIUM



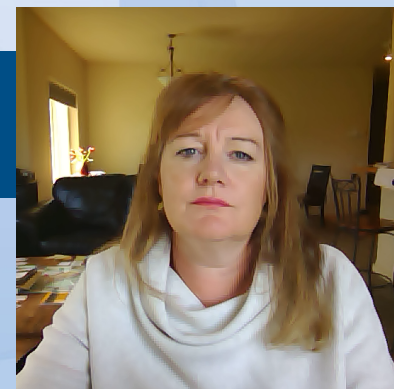
THE UNIVERSITY OF
SYDNEY



Parenting Research Centre
raising children well

- Prof Gwynnyth Llewellyn
- Dr Gabrielle Hindmarsh
- Dr Nicola Man
- Dr Rachael Mayes
- Dr Marg Spencer
- Prof David McConnell
- Dr Catherine Wade
- Dr Robyn Mildon
- Dr Melinda Polimeni
- Olivia Clayton
- Derek McCormack
- Kate Naish

www.healthystart.net.au



Healthy & Safe

AN AUSTRALIAN
PARENT EDUCATION KIT





Parenting Young Children







Parenting Young Children



Parenting Young Children

A program for parents with learning difficulties

Produced by the Parenting Research Centre



	Pre-intervention <i>M (sd)</i>	Post-intervention <i>M (sd)</i>	3-month follow-up <i>M (sd)</i>
Parenting Daily Hassles Scale			
Frequency	45.7 (10.6)	42.4 (9.0)*	42.5 (11.8)
Intensity	54.0 (16.7)	52.7 (17.0)	50.2 (18.7)
Parenting Sense of Competence Scale			
Satisfaction	26.9 (10.9)	29.2 (8.0)	27.2 (10.1)
Efficacy	17.7 (9.3)	23.5 (11.7)	23.3 (10.0)
Eyberg Child Behaviour Inventory			
Intensity	133.5 (41.5)	117.8 (44.4)*	126.2 (45.9)
Problem	17.3 (8.8)	14.5 (11.5)	16.2 (12.2)
HOME			
Early Childhood	29.4 (11.1)	35.9 (8.0)*	32.4 (10.0)
Infant	25.8 (6.8)	30.0 (8.4)	33.4 (5.4)

* $p < .05$





**POSITIVE
POWERFUL
PARENTS**



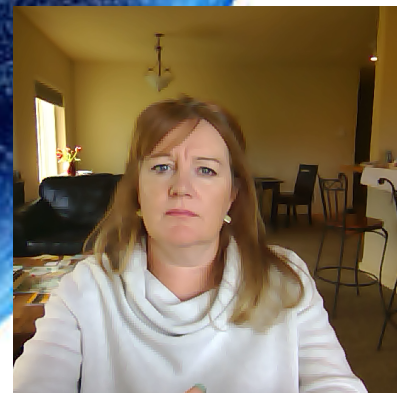


WASH House Inc.

RESOURCING WOMEN







Dr Catherine Wade



Email: cwade@parentingrc.org.au



@WadeCath
@healthystart_au