



Reframing parenting with intellectual disability: From a problem to solution frame

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Acknowledgment of Country

I acknowledge and pay respects to the traditional custodians of the lands on which we meet today, the Warundjuri people of the Kulin Nation. I pay respect to Elders past, present and emerging for their continuing care and custodianship of Country.

Artwork created by Bradley Burns, Gamilaroi artist and PhD candidate, Western Sydney University.



Background



We have nearly eight decades of research exploring parenting with ID.

In sum, this research tells us

1. that Intelligence or IQ is a poor predictor of parenting ability
2. Parents with ID can learn parenting skills with access to appropriately designed and adapted parent education techniques.
3. Children of parents with ID fare just as well as their peers (who experience socio-economic adversities).
4. Moreover, children of parents with ID do not want to be removed from their parents, rather, they want their family to be supported.
5. Support works best for these families when offered in a non-threatening and timely manner and is designed in partnership with the parents to address the family's priorities.

Yet, despite this research, parents with ID continue to fare poorly.

Internationally, parents with ID report feeling afraid of and frustrated by the systems that should be there to support them.

They are over-represented in care proceedings, and their children are removed at persistently high rates. This begs the question....

If we know what works to support parents with learning disabilities, why aren't we doing it?



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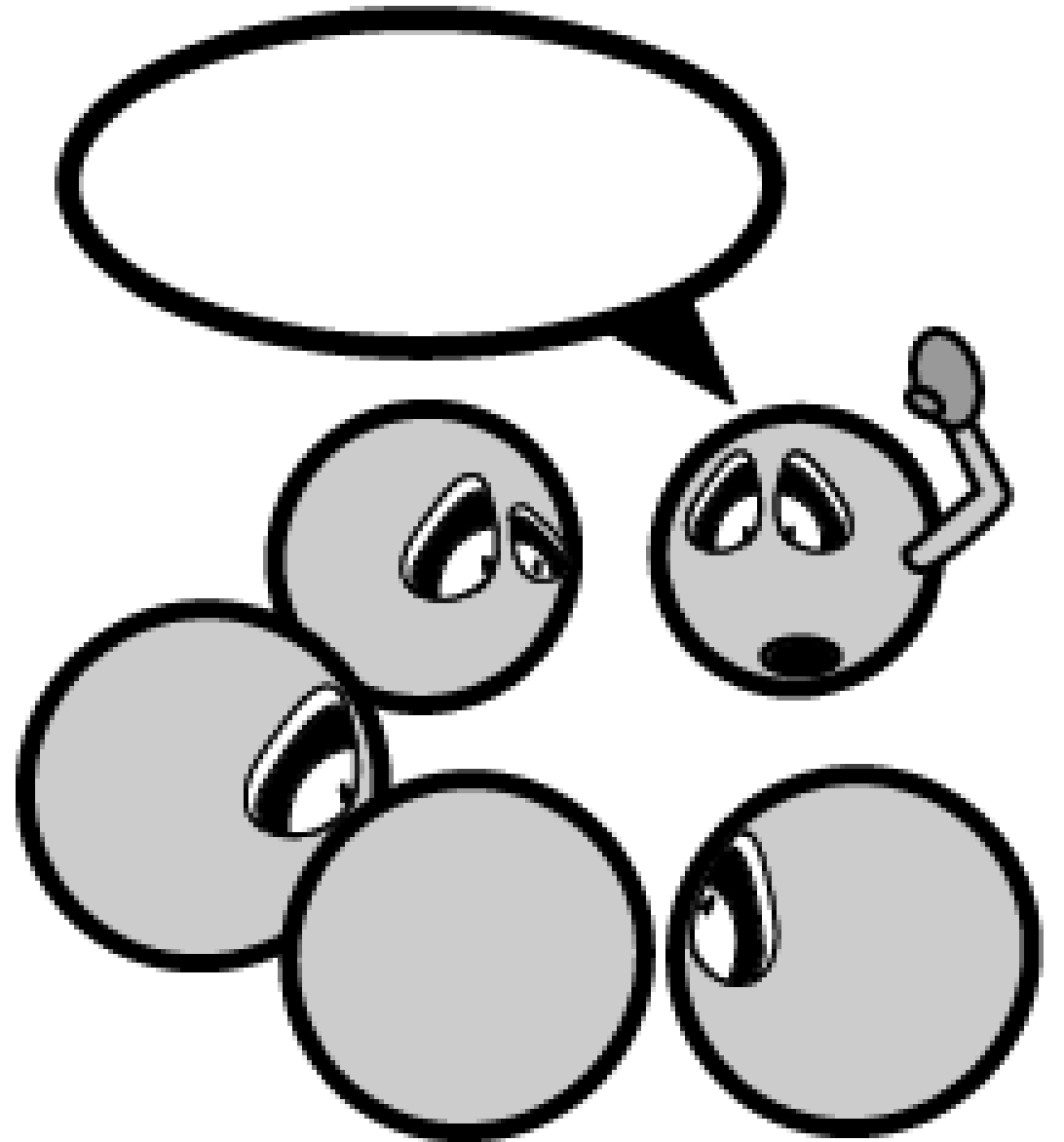


This is a compelling social issue warranting policy attention and reform.

Furthermore, this situation represents a clear breach of state responsibilities to uphold the rights of parents under Article 23 of the United Nations Convention on the Rights of Persons with Disability (2008), and of children under Article 9 of the Convention on the Rights of the Child (1989).

Our approach

- **Co-operative inquiry:** A Co-operative Inquiry involves the co-inquirers joining together to form an Inquiry group about a mutual interest, concern or practice (Reason & Heron, 2013)
- To guide our response to this question we drew on Bacchi's "**What's the problem represented to be?**" (WPR) approach to explore policy and practice in this area (Bacchi, 2012).



How have parents with ID been problematised?

- There is an attitudinal legacy that originated in the Eugenic movement of the early 20th Century
- ‘The feeble-minded’ (i.e., persons with ID) having children was constructed as a burden and a threat to society, harming the next generation and “producing more of their kind.” (see Garton 2010, p247)
- This construction of parenthood by persons with ID legitimised state policies and practices denying persons with ID their reproductive rights.
- For over a century (and to this day) the reproductive rights of parents with ID have been repressed and controlled by policies endorsing segregation and institutionalisation.
- In the last 30-50 years, the tightening of laws related to sterilisation and policies promoting de-institutionalisation (at least in the Global North) have resulted in more persons with ID exercising their reproductive rights.
- Child welfare and disability policies and practices have continued to perpetuate this problematisation of parents with ID

What presuppositions or assumptions continue to underpin this representation of the 'problem'?

- Parents with ID are inherently incapable of parenting.
- Intellectual Disability is an irremediable condition.
- Parents with an intellectual disability have a limited capacity to change and develop.
- Parents with intellectual disability's need for support is considerable, ongoing, and unsustainable.
- They are a liability to their children and potentially will harm their children.
- It is more sustainable and safer to invest in their children in the OOHC.

How is problematization reinforced and played out in policies and practice?

- Sexual health and sexual rights policies and practices fail to embrace Article 23 of the UNCPRD. Persons with ID do not have equal access to information, guidance and support to enact their reproductive rights. Family planning information is commonly targeted at how not to become pregnant than how to start a family.
- When persons with ID announce they are pregnant, they are given the message (covertly and overtly) that they have done something wrong. They have entered into 'territory' not meant for them.
- They find themselves awkwardly (and unsafely) positioned between the siloed systems of healthcare, adult(disability)services and child and family services.

Child Protection policies and practices

- Child Protection legislation and policies (Australia or UK) have not been reformed or altered to comply with UNCRPD (Article 12 & 23)
- Child and Family practitioner report feeling 'out of their depth' when it comes to supporting parents with ID.
- The inability to provide support that parents with ID and their children need and want is exacerbated by the impact of neoliberalism on family support, increasingly, relational support has been converted into a transactional commodity.
- Interventions are made with the aim of removing the presenting issue and closing the case rather than providing long-term support.
- Child and family services have become risk-averse, time-limited, performance and task-focused, and outcome-oriented
- This, combined with statutory timescales that are often very short, are not conducive to supportive relationship-based practice.
- When economic rationalism prevails, calculations will inevitably be made about families deemed most likely to drain precious public resources. Families headed by parents with learning disabilities can come to be seen as a poor investment of time and financial resources if they are perceived to need ongoing support.

How could this representation of the 'problem' be questioned, disrupted and replaced?

At a legislative and policy reform level:

1. We need to call out and confront Ableism.
 2. Adopt a ['Disability Informed Practice Framework'](#) underpinned by a rights perspective (adhering to the UNCRPD). This Framework must reframe and guide policy and legislative reform, particularly in the child and family sector.
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1. Have Affirmative Action Policies that acknowledge and address the social disadvantage and barriers faced by parents with ID and their children.

At practice level we need to:



1. Confront and critique ableist assumptions and constructs we use to evaluate parenting, such as the expectation of independent parenting. Instead, it should recognise that parenting is an interdependent activity and that there are diverse ways of raising children.
2. Shift our energies and attention away from assessing *whether a parent is capable (based on normative standards)* to assessing whether a parent can be *supported*.
3. Promote worker competency – ensuring workers are resourced – i.e. they have the knowledge, skills and availability to
 - a) engage in relational-based practice, including building trust, enabling healing, and supporting change. See Tarleton & Turney (2020) 6 Ts - time, trust, truthfulness, transparency and tailored support (e.g. make reasonable accommodations adjusting communication and the teaching parenting skills)
 - b) Keep sight of the main aim of ensuring the child who is being parented is faring well.

Lastly,

We need to listen to families.

If we are to change how parent has ID are problematised in our policies and practices, we need to stop assuming we:

- (1) Understand who they are,
- (2) What they are capable or not capable of, and
- (3) What they want and need.

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"NOTHING ABOUT US WITHOUT US"

NO

**NOTHING SHOULD
BE WITHOUT US**

A photograph of wooden blocks spelling out the word 'CHANGE'. The blocks are arranged in two rows: 'C H A N' on the top row and 'G C E' on the bottom row. A finger with a white manicure is pointing to the 'C' block in the second row. The background is a solid yellow color.

C H A N
G C E

Over the years, the most common thing parents have said when we have co-presented on this topic has been, "Just give us a chance." To achieve this, it is we who need to change.

Margaret Spencer

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