

Submission to the Royal Commission into Violence,
Abuse, Neglect and Exploitation of People with Disability

Parenting with intellectual disability and learning difficulties

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CONTENTS

| | |
|---|----|
| 1. Overview of this submission..... | 3 |
| 2. Introduction | 5 |
| 3. Parents with intellectual disability..... | 6 |
| 4. Children of parents with intellectual disability..... | 8 |
| 5. 'Best practice' and parents with intellectual disability | 9 |
| 6. Connecting parents and professionals with reliable resources | 14 |
| 7. Growing gaps in evidence..... | 16 |
| 8. Conclusion..... | 17 |
| 9. Bibliography..... | 19 |
| 10. Credentials of the authors of this submission | 21 |

1. Overview of this submission

This submission to the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability addresses the topic of parenting by people with intellectual disability and learning difficulties.

Parenthood is one of the most universal transitions and central milestones in life. This submission examines the hurdles that parents with intellectual disability and learning difficulties face from the very earliest stages of their parenting journey, that are not generally experienced by Australian parents more broadly. It also draws attention to issues that impact on children and their life trajectories.

Drawing on Australian and international evidence our submission summarises what is known about what works to support parents with intellectual disability or learning difficulties in their parenting role, and in the healthy development, safety and wellbeing of their children. It draws attention to current gaps in practice across the family support, child protection and disability sectors in Australia in relation to this evidence.

The submission discusses how many of the challenges faced by parents with intellectual disability can have lifelong impacts on their children but that with the right support, parents with intellectual disability can provide the type of care and home environments that help children thrive. Examples of best practice and evidence-based supports for these families are described, including the effectiveness of parenting programs tailored to meet the specific learning styles of people with intellectual disability, as well as the promise of digital technologies for building parenting capabilities in these families.

In highlighting areas for further investigation and resourcing, the submission identifies how recent disruption to funding for research, program development and scale up of best practice offerings has halted progress in this important area of family support, with likely negative consequences for children born to parents with intellectual disability.

On the basis of what is known about best practice and evidence-based support for parents with intellectual disability and their children, implications for system and service costs in the short and longer term and current gaps and opportunities in Australia, this submission prioritises the following recommendations:

1. **Invest in renewing and growing the evidence base** addressing the factors influencing parenting and child outcomes for families headed by a parent with intellectual disability, and the experiences of children raised by these parents. This includes the evaluation of existing programs and the evaluation of innovative parenting supports, including those delivered using web-based technology. Renewing the evidence base is a key pillar in policy development and inclusive service provision for future generations.
2. **Embed the systematic use of existing, high-impact digital platforms** such as raisingchildren.net.au into professional practice across the child welfare, disability, health, education and family support sectors, and parent information seeking practice. for sharing credible parenting and child development resources online. This would enable all professionals across multiple sectors and disciplines to have immediate access to the wealth of existing best practice and evidence-based resources about supporting parents with intellectual disability and the healthy development of their children.

3. **Develop and educate the relevant workforces** of professionals working with parents-to-be and parents with intellectual disability through professional development packages specifically designed for these parents and available in every state and territory in programs.
4. **Build the capacity of parents with intellectual disability** by facilitating widespread access to evidence-based, family-centred and contextually relevant parenting education programs for parents with intellectual disability that build on what they know, are practical and provide ongoing opportunities for learning and support.
5. **Invest in the development of new co-designed resources** to fill existing information gaps for professionals and families, and design and implement a national dissemination campaign that includes an evaluation of impact.
6. **Investigate use of continually emerging digital platforms** to reach professionals and parents nationally on effective parenting support for parents with intellectual disability and learning difficulties.
7. **Invest in developing subject matter expertise on parenting with intellectual disability**, as a strategy to build the capacity of local agencies to access a source of professionals/agencies nationally of knowledge, policies, practices and resources on parenting with intellectual disability that can support best practice, peer support and innovation.

2. Introduction

Parenthood is one of the most universal transitions and central milestones in life. Many factors are associated with preparation for the challenges of parenthood, for parents of all ages and genders (Goldberg 1988). These include the degree of financial security, age, self-knowledge, social support networks and programs from which parents draw emotional support, practical assistance, advice, normative information and therapeutic interventions (Duncan & Markman 1998; Gottlieb & Pancer 1998).

The Convention on the Rights of Persons with a Disability (UN General Assembly, January 2007), to which Australia became a signatory to in 2007 and ratified in 2008, requires that people with disability have the right to equal opportunities, including to be parents. This extends to the right to suitable supports that optimise chances of successful parenting.

The focus of this submission to the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability is on the issue of parenting by people with intellectual disability and learning difficulties.

Drawing on what is known from the international evidence about parenting, we focus on the role of effective, accessible parenting support for families with parents with intellectual disability or learning difficulties, to better support the healthy development, safety and wellbeing of their children.

The Parenting Research Centre is an independent, not-for-profit research organisation. We seek better outcomes for children by increasing effectiveness and innovation in the way families are supported in their parenting. This submission draws on our research, evaluation and practice portfolios, and on the Australian government funded parenting website, raisingchildren.net.au, an initiative of the Parenting Research Centre and the Murdoch Children's Research Institute.

This submission examines the hurdles that parents with intellectual disability and learning difficulties face from the very earliest stages of their parenting journey, that are not generally experienced by parents more broadly. It also draws attention to issues that impact on children and their life trajectories. It examines best practice in regard to strengthening parenting by people with intellectual disability, gaps in the evidence, and the opportunities that digital technologies offer to provide support to parents, and to professionals who work with parents.

3. Parents with intellectual disability

The prevalence of people with identified intellectual disability who are parents in Australia is over 17,000 (based on 2009 data; Man, Wade & Llewellyn, 2017). That number is likely to be far greater when considering the number of people in Australian communities with significant cognitive limitations impacting on their learning.

Parents with intellectual disability are among the most vulnerable parents in Australia. Many parents with learning difficulties experience living conditions and life experiences that are associated with risk to children, including risks to children's physical and mental health as a result of poorly communicated health and parenting information (Llewellyn, McConnell & Mayes, 2003; Man, Llewellyn & Wade, July 2014 and October 2014; Man, Wade & Llewellyn, 2017; McConnell, Llewellyn, Mayes, Russo, & Honey, 2003; McConnell, Mayes & Llewellyn, 2008,).

Parents with intellectual disability face hurdles from the very earliest stages of their parenting journey that are not generally experienced more broadly. These include:

- Failure by others to welcome news of pregnancy with the positivity that most other parents enjoy
- Failure by others to identify opportunities to enhance supports and information giving early during pregnancy, to maximise the parents' chances of positive birth outcomes and good early parenting experiences
- Pre-birth notifications to child protection agencies in the absence of any support offerings
- Removal of children from parents in the hospital immediately following birth
- Failure to communicate appropriately with parents about their rights, about what's happening to them and why, and about next steps
- Being required to demonstrate near perfect parenting even in the face of having been denied access to their child in order to practice and hone their skills.

(IASSID Special Interest Research Group on Parents and Parenting with Intellectual Disabilities, 2008)

Our own research demonstrates that, when compared with non-disabled parents and with parents with other disabilities, parents with intellectual disability are significantly more likely to:

- be in a jobless household
- be in households in the lowest three deciles of equivalised weekly income
- be on government pensions as the main source of personal income
- have ever been without a permanent place to live
- have ever stayed in a shelter, squatted in an abandoned building and/or slept rough
- have less frequent contact with family and friends
- have negative or mixed feelings about life
- have poorer self-assessed health.

(Man, et al., July 2014)

Parents with intellectual disability are also more likely to be:

- unemployed or not in the labour force compared to non-disabled parents (Man, et al., July 2014)
- more likely than non-disabled parents to have only one child, be in a single-parent family, and to reside outside a capital city (Man, et al., 2017)

- more likely to be caring for a child with disability, more likely to be in public housing and less likely to be home-owners (Man, et al., October 2014).

Other Australian research also attests to the poorer health of parents with intellectual disability. In their investigation of the health status of fifty mothers with intellectual disability in New South Wales, Llewellyn, McConnell and Mayes (2003) found significant deficits in many aspects of the health (e.g., vitality, mental health) of mothers with intellectual disability compared to an Australian normative sample.

In sum, parents with intellectual disability – as a cohort – experience a range of complicating life circumstances that place them and their children at greater risk of poor outcomes – poverty, social isolation, homelessness, and poor health as well as poor health care. In addition to the proximal impact on parents and children, these have implications for system and service costs in the short and longer term.

4. Children of parents with intellectual disability

Research suggests that the children of parents with intellectual disability:

- face increased health risks as a result of pregnancy-related issues such as low birth weight, pre-eclampsia, and prematurity (McConnell et al., 2003; McConnell, et al., 2008, Mitra, Parish, Clements, Cui & Diop, 2015); and
- are less likely to be breastfed (Goldacre, Gray & Goldacre, 2015; Hindmarsh, Llewellyn & Emerson, 2015).

There is a dearth of evidence on the preparation for childbirth and early parenting of parents with intellectual disability, which are also likely factors in a positive trajectory for infants' early outcomes.

A significant and disproportionate number of child protection cases across at least three continents involve a parent with intellectual disability. Research from Australia, the UK, the US and Canada confirms that parents with intellectual disability are represented in the child protection system up to 50% more than would be expected given their prevalence in the general population (e.g., Booth & Booth, 2004; Booth, Booth, & McConnell, 2005; Lightfoot, Hill, & LaLiberte, 2010; Llewellyn, McConnell, & Ferronato, 2003; McConnell, Feldman, Aunos, & Prasad, 2011). Data from 1998/1999 (McConnell, Llewellyn, & Ferronato, 2002) illustrated that one in ten cases before the Children's Court in New South Wales involved a parent with intellectual disability.

Further, evidence indicates that once in the court system, outcomes for these families with parents with intellectual disability are different to other families (Llewellyn et al., 2003; McConnell et al., 2011). For example, they:

- are more likely to have their children removed than parents with other disabilities, such as those with mental illness or emotional disturbance
- have their children removed more often than parents with emotional impairment and nearly as often as parents with substance abuse issues
- often have their children removed at the first presentation to court with no offer of support prior to court involvement
- are typically brought to court on the basis of evidence that would not hold up against parents without a disability
- are less likely to be offered the opportunity of family restoration
- are more likely to have their children permanently removed from their care
- are more likely to have their parental rights terminated
- are more likely to have their child placed in non-kinship out-of-home care
- are likely to have decisions made about child custody that are based on inappropriate measures (e.g. IQ assessments) or insufficient evidence
- often fail to have their grief at losing custody of a child acknowledged or addressed
- rarely have any support or planning to address their future access to their child following removal.

Prejudicial beliefs, perceptions and expectations held about parents with intellectual disability persist (IASSID Special Interest Research Group on Parents and Parenting with Intellectual Disabilities, 2008). For instance, they are commonly expected to be incapable of meeting the demands of parenting by those who are in positions to support them (their own family, support staff). As a consequence of these assumptions they may not be offered the opportunity to demonstrate competence in parenting or may not be provided with the support needed to demonstrate such competence.

5. 'Best practice' and parents with intellectual disability

There is now a good evidence base, including four systematic reviews of the empirical literature, on what works to improve parenting by people with intellectual disability (Coren, Hutchfield, Thomae & Gustafsson, 2010; Feldman, 1994; Wade, Llewellyn & Matthews, 2008; Wilson, McKenzie, Quayle & Murray, 2014).

Parenting is a learned set of skills, developed 'on the job'. Supporting parents is a powerful way to improve children's wellbeing, health and educational outcomes (Parenting Research Centre, 2017). All parents need opportunities and support to learn about their children's needs and development, and to care for their own needs as parents.

People with intellectual disabilities can learn parenting skills but may require more time, more structured learning opportunities, repeated opportunities to practice, and specific teaching strategies.

In tailoring and delivering parenting support to parents with intellectual disability, the evidence for best practice suggests:

- A. *Assessment of parenting skills using direct observation of the person performing the skill* using structured and validated task analysed checklists specifically developed for use in assessing parenting by people with intellectual disability (Feldman & Aunos, 2011; Spencer, 2001).

Assessment articulates what a parent can already do, as a platform from which to begin building new or improved skills. It should cover:

- what parents already know, how this was learned, and how they learn best (i.e., their strengths)
- the family context, as this will also be important to understand when developing and implementing a parenting support intervention
- parent stress and self-esteem
- co-parenting relationships
- child behaviour or developmental concerns, and
- the home setting.

Case study 1: Best practice in parenting assessment

In November 2017, professionals in Victoria, New South Wales and Queensland attended professional training in the use of the type of parenting assessments described above as best practice. This training was delivered by Professor Maurice Feldman (Brock University, Canada) - an internationally renowned expert on parenting assessment for competency development.

Professor Feldman's parenting skills assessment and intervention program - referred to as 'Step by Step' - illustrates best practice in the area of parenting assessment and intervention for parents with intellectual disability.

Developed by Feldman and colleagues and evaluated on many occasions, the resources are widely used in the United States and Canada for assessment of parenting by people with intellectual disability for child custody hearings and termination of parenting rights cases.

Further, since 2005, the Parenting Research Centre has been training professionals in the 'Parenting Young Children' parent education program, which incorporates pre-intervention assessment adapted from Feldman's Step by Step program to be suitable for the Australian context.

B. *Best practice teaching strategies* for building parenting skills in people with intellectual disability are well researched, with consensus among researchers and experts that parenting interventions are most effective when they:

- occur in the setting they will be used (i.e. usually in the parent's own home)
- are skill-focused
- use behavioural teaching strategies such as modelling, practice, feedback, praise, and tangible reinforcement
- use task analysis as a way of breaking down complex childcare tasks into steps to be taught individually.

(Feldman, 1994; Wade et al., 2008)

Parenting support should also be intensive and long-term if parents are to use new parenting skills as their children grow, with contingencies built in for ongoing support. Such contingencies can include maintenance checks, generalisation strategies, booster sessions, and repeated intensive delivery at higher risk times such as just prior to developmental transitions such as pre-school entry, school entry, or when there is a crisis in the family (IASSID Special Interest Research Group on Parents and Parenting with Intellectual Disabilities, 2008).

Curriculum-based didactic instruction and a combination of group and individualised intervention using behavioural instruction can also work to improve parenting skills in people with intellectual disability. In addition, teaching via specifically designed self-instructional materials (written and audio-visual) has been shown to be an effective and relatively rapid way of teaching parents with intellectual disability new skills in childcare (Feldman, 2004; Feldman & Case, 1997, 1999; Llewellyn, McConnell, Honey, Mayes & Russo, 2003).

Furthermore, evidence suggests that parent education programs will be more effective with parents with intellectual disabilities if they have the following elements:

- **Specific:** programs must be suited to the parent's individual needs for learning. This is why individual programs work best for skill development compared to group programs.
- **Parent-directed:** parent education programs should be based on the needs identified by families and on the goals prioritised by families. Effective interventions have parents involved in the planning and implementation of a program. The relationship between educator and parent should be a partnership, acknowledging that each person can be a resource to the other.
- **Skill-focused:** programs are most beneficial to parents and children when they are skill focused. That is, programs that aim to increase a parent's *knowledge* about parenting may be helpful, but that's not sufficient for change. We need to teach *skills* too.
- **Contextually relevant:** the family's environment and the characteristics of family members must be considered when developing and implementing a parent education program. Each family is different and has different strengths and challenges. The individual context of each family will influence the effectiveness of a program.

(Llewellyn, McConnell, Russo, Mayes & Honey, 2002)

Our own research with parents with intellectual disability highlights what type of support they prefer, including the aspects of service delivery that are helpful to the learning of parenting skills by these parents (Wade, Mildon & Matthews, 2007). Broadly, support that is family-centred, as opposed to professionally-centred, is optimal; and help that is practical, as opposed to relational, is preferred. Thus, best practice for services and supports to adopt to increase the likelihood and quality of parental engagement are:

Family-centred

- acknowledge and respect that parents are the experts about their children and their family's circumstances
- be sensitive and responsive to each individual family taking into account their circumstances, including learning style
- help parents set goals that are meaningful to them
- work on building connections with parents, viewing them as partners in parenting support
- provide support without judging

Practical

- work with parents on making their goals realistic and achievable and, if necessary, help them prioritise potentially conflicting goals
- be flexible in how to provide services, thinking about what's most useful to the particular family
- provide information to parents in formats and language that they understand
- check parents' understanding of information by asking open ended questions to verify the parent has heard and comprehends messages
- look for strengths in the parent and work from these to build new and improved skills and knowledge
- give families the information they need to make informed choices
- help parents build confidence and independence by supporting them to make their own decisions about their own lives
- consider the parents' own wellbeing, as the wellbeing and development of a child depends upon the wellbeing of other family members
- help families find and engage appropriately with informal (including family) or community supports and resources that can reinforce the learning that occurs in more formal settings
- provide clear, truthful information.

In the view of international experts, Australia has an excellent past record of high-quality research and national investment in applying best practice to supporting parents with intellectual disability. Australian examples of best practice in supporting parents with intellectual disability are highlighted in Case Studies 2 and 3 below.

Case study 2: Best practice in parenting support – Healthy Start

Between 2005 and 2014 the Australian Government funded '[Healthy Start](#)' – a national strategy to support those who were working with parents with intellectual disability and their children.

The Healthy Start capacity building strategy allowed over 700 professionals across every state and territory to be trained in two evidence-informed parenting programs developed in Australia specifically for parents with intellectual disability. Since 2014, professional training in these programs has been provided to professionals in Australia, Sweden, Norway and Japan on a cost-recovery basis.

Healthy Start designed and delivered a range of additional professional training packages and developed a suite of innovative resources e.g., Step by Step DVDs to teach parenting skills 'in video', the [Australian Supported Learning Program](#), and a Healthy Start for Me and My Baby pregnancy preparation kit.

Healthy Start supported multiple 'champions' in most states and territories to become subject matter experts on parenting with intellectual disability, and therefore 'go-to people' in their local area. Healthy Start funded these champions to obtain their Graduate Certificate in Parenting with Developmental Disability through a post-graduate program offered by the Faculty of Health Sciences at the University of Sydney.

Healthy Start funded these champions to design and implement 'Local Area Action Plans' to address a gap or area of need in their local area. Some used this funding to maintain regular meetings for professionals to receive peer support in use of training they had received. Others used the funding to develop new resources to support best practice in their services.

Healthy Start was a 'world first' nation-wide capacity building strategy with a strong reputation. Sustaining its achievements is compromised. Far fewer professionals in Australia are being trained now compared to during Healthy Start's funded period – their organisations are challenged by constraints in being able to procure training for their staff. As a consequence, Australia has seen a significant decline in the number of professionals from NGOs and government child protection and disability departments receiving training and support to work with people with intellectual disability in their parenting.

With the cessation of previous financial support for these programs, the Parenting Research Centre has been unable to continue to update, promote and deliver the innovative and evidence-informed products that were developed as part of the Healthy Start strategy or to make these resources accessible to the professionals and parents who need them.

Beyond Healthy Start, there are a number of other supports available for parents with intellectual disability in Australia, mostly on a small scale, limited locality basis.

Case study 3: Best practice in parenting support – the WASHHouse

The WASHHouse (Women’s Activities & Self Help House) in New South Wales provides a program and resources for parents with intellectual disability whose children have been taken into care. The program addresses issues related to grief at losing a child, and maintaining contact and a positive relationship with your child.

A recently-funded research project is currently exploring aspects of the WASHHouse approach to supporting parents with intellectual disability, through an NDIS ILC funded project in partnership with the Intellectual Disability Rights Service and researchers at the University of Sydney.

Other exemplary models of best practice happening around Australia include self-advocacy groups run by and for parents with intellectual disability to advocate and lobby for protection of individual rights and to support one another. Strong groups in Victoria (Positive Powerful Parents), Queensland (the BOLD Network) and Tasmania (Speak Out Advocacy) are examples that have both longevity and success.

The Women’s Individual Needs Clinic at the Royal Women’s Hospital in Melbourne offers a model of care for pregnant women with intellectual disability who present at the hospital, whereby a social worker and specialist midwife guide the woman through the pregnancy and early parenting journey with sensitivity and individually tailored support.

If resourced, these services could be replicated, extended and evaluated.

6. Connecting parents and professionals with reliable resources

Whilst family and friends remain the most popular source of advice on parenting, the online environment has become an increasingly important destination for parents seeking out information about raising children and families (Parenting Research Centre, 2017).

Parents, and professionals who work with parents, are now drawing on websites, webinars, online parenting courses, online forums and other emerging technologies to build their knowledge and skills. The full potential of digital technologies in the field of parenting support is yet to be realised.

Since 2006, the Raising Children Network - raisingchildren.net.au - has been funded by successive Australian governments to provide evidence-based resources for Australian parents, and professionals working with parents, children and families. Now an established and highly trusted parenting website with 3000+ evidence-based resources, raisingchildren.net.au receives 70,000 visits per day, or 17+ million visits/year accessing 30 million pages/year, and has 233,000+ Facebook followers. Eighty per cent of visitors use a mobile device.

Raising Children Network co-develops multilingual resources, resources for Aboriginal and Torres Strait Islander communities and same-sex families (2017). We co-design content with peak disability organisations and directly with parents of children with disabilities. We have delivered on disability-specific contracts (HCWA since 2008, Better Start from 2011-2019 and NDIS in 2016) producing dedicated resources for parents of children with disability. In the last 6 months alone, this disability content had 1.7million page views.

Raising Children Network, an initiative of the Parenting Research Centre and the Murdoch Children's Research Institute, is frequently called on by the Australian government to lend its expertise in high quality and effective communication with a mass parent audience to significant government/parliamentary initiatives examining major child and family health issues, including on family and domestic violence, child sexual abuse, the NDIS and the First 1000 Days national awareness raising campaign.

Raising Children Network delivers primary prevention messages to mothers and fathers from pregnancy through to raising teenagers. The website connects parents with information through a range of formats that cater to wide-ranging literacy levels. Its resources are embedded into child health records and other government resources in several jurisdictions across Australia. It is championed by child and family health nurses, hospitals, paediatricians and GPs, early childhood service providers, allied health professionals, schools and disability organisations. Raising Children Network is continuously exploring the use of emerging digital platforms to extend its reach to parents and professionals.

Parents with intellectual disability often face challenges in accessing and making use of available guidance on parenting. Raising Children Network's expertise and effective infrastructure in communicating with parent audiences and the diverse professional workforces who work with families has recently been acknowledged by the National Disability Insurance Agency (NDIA). The NDIA has funded Raising Children Network (2019-2022) via its Information, Linkages and Capacity Building grants scheme to develop online resources specifically for parents with intellectual disability and learning difficulties on issues related to accessing the NDIS. This work is summarised, below, in Case Study 4.

Case Study 4: Raising Children Network: Development of new digital resources for parents with intellectual disability and learning difficulties

Background

Most parents/carers of children in the NDIS face a steep learning curve to understand NDIS processes and make decisions about goals, support needs and services to exercise the choice and control the NDIS offers. Information is urgently needed that enables people with disability to harness the potential of the NDIS and other relevant supports regardless of geography, sexuality, gender presentation or ability. There is a strong need for quality, trusted information products to support informed choice and control in how families experience disability support.

The project

The NDIA has funded Raising Children Network to develop information products to support parents and families with disability (2019-2022). One of the priority cohorts is parents with intellectual disability and learning difficulties.

Using raisingchildren.net.au's co-design approach, in conjunction with the establishment of a Parent Panel, we will develop a suite of online resources designed to increase choice and control in how parents access disability supports. We will customise existing NDIS resources on accessing disability services for a parent audience and will co-design resources with parents with disability. Online articles, videos, and Easy English resources will cater for diverse parent literacy levels and will be published on raisingchildren.net.au. The resources will link parents and families with relevant supports in their geographic area. A communications and dissemination strategy will guide promotion of the resources and a project evaluation will focus on reach and effectiveness of these products.

Scaling up

Raising Children Network's infrastructure and extensive networks in disability, infant, child and teenage health and development offer enormous potential to scale up the project in sectors such as early childhood, mainstream health services, and other online health and workplace portals. The Easy English resources will have the capacity to be scaled up in future into resources for other low literacy parent populations and translated into a wide range of community languages at low cost for parents from culturally and linguistically diverse backgrounds.

7. Growing gaps in evidence

Whilst Australia has had a strong track record in parenting supports for parents with intellectual disability, resourcing the growth of this evidence base has slowed considerably in recent years.

Australian research into the incidence and experiences of parents with intellectual disability in the child protection and court systems is widely cited in the international peer-reviewed literature (e.g., McConnell et al., 2006), as is our past research into the experiences, health and wellbeing of children of parents with intellectual disability (McConnell et al., 2008; Collings & Llewellyn, 2012; Hindmarsh et al., 2015), grief in mothers who have had a child removed (Mayes & Llewellyn, 2012), and professionals' support needs when working with parents with intellectual disability (Clayton, Chester, Mildon & Matthews, 2008).

However, the University of Sydney's randomised controlled trial (RCT) into the effectiveness of the Healthy and Safe parent education program (published paper in 2003 by Llewellyn et al.) remains the only gold-standard RCT on interventions for parents with intellectual disability in Australia.

The Parenting Research Centre's evaluation of the Parenting Young Children program (published in 2008 by Mildon et al.) remains the only published evaluation of that program (see Case Study 5).

The result is a slowing evidence base on what works and why in best practice of support of parents with intellectual disability to raise their children. There is a strong case for further investment in development, implementation and evaluation of interventions designed to improve outcomes for parents with intellectual disability and their children.

Gaps in the evidence base include:

- robust evaluation of programs and models of support tailored to parents with intellectual disability, especially of programs and supports for parents of children in the primary school years and adolescence, and of self-directed and tech-based resources
- exploration of the experiences of children born to and/or raised in families headed by a parent with intellectual disability
- research into how family context (socio-economic and living conditions, past history of trauma, abuse and parenting, partner support and mental health, for example) impact on parenting and on children's welfare.

Case study 5: Evaluation of the parenting program 'Parenting Young Children'.

The Parenting Young Children (PYC) parent education program was developed by the Parenting Research Centre based on high quality evidence-based programs in the US and Canada. The program is suitable for parents of children 0-6 years in a preventative and early intervention context. However, it is also suitable for families at the tertiary end, where concerns about child abuse and neglect have already been raised.

The Australian evaluation of PYC (Mildon, Wade & Matthews, 2008) showed significant improvements in parents' involvement with their children, the provision of variety in the home, parent satisfaction and confidence and the quality of the home environment, as well as a reduction in the frequency of disruptive child behaviour.

In recent years, the Parenting Research Centre have been working with agencies in Sweden, Norway and Japan to develop in-language versions of PYC, and have conducted professional training (to over 200 professionals) and are engaged in research on its implementation in those nations.

8. Conclusion

Parents with intellectual disability are one of the most vulnerable groups in the Australian community. We endorse the UN Convention on the Rights of Persons with Disability to support the right of a person with intellectual disability to become a parent and to be adequately supported in that role.

Parenting support for families with parents with intellectual disability or learning difficulties can positively impact on the healthy development, safety and wellbeing of their children.

While examples of best practice in regard to strengthening parenting by people with intellectual disability have been identified, the rich evidence base of effective interventions in Australia is at risk of obsolescence without continuing investment.

Gaps in what we know works and why, and to further refine and evaluate existing programs and innovations are known.

The full potential of digital platforms for education and learning initiatives for parents with intellectual disability and learning difficulties, and the many health, education, justice, community and disability professions who work with parents so that their children thrive, is yet to be harnessed.

On the basis of what is known about best practice and evidence-based support for parents with intellectual disability and their children, implications for system and service costs in the short and longer term and current gaps and opportunities in Australia, this submission prioritises the following recommendations:

1. **Invest in renewing and growing the evidence base.** addressing the factors influencing parenting and child outcomes for families headed by a parent with intellectual disability, and the experiences of children raised by these parents. This includes the evaluation of existing programs and the evaluation of innovative parenting supports, including those delivered using web-based technology. Renewing the evidence base is a key pillar in policy development and inclusive service provision for future generations.
2. **Embed the systematic use of existing, high-impact digital platforms** such as raisingchildren.net.au into professional practice across the child welfare, disability, health, education and family support sectors, and parent information seeking practice. for sharing credible parenting and child development resources online. This would enable all professionals across multiple sectors and disciplines to have immediate access to the wealth of existing best practice and evidence-based resources about supporting parents with intellectual disability and the healthy development of their children.
3. **Develop and educate the relevant workforces** of professionals working with parents-to-be and parents with intellectual disability through professional development packages specifically designed for these parents and available in every state and territory in programs.
4. **Build the capacity of parents with intellectual disability** by facilitating widespread access to evidence-based, family-centred and contextually relevant parenting education programs for parents with intellectual disability that build on what they know, are practical and provide ongoing opportunities for learning and support.
5. **Invest in the development of new co-designed resources** to fill existing information gaps for professionals and families, and design and implement a national dissemination campaign that includes an evaluation of impact.

6. **Investigate use of continually emerging digital platforms** to reach professionals and parents nationally on effective parenting support for parents with intellectual disability and learning difficulties.
7. **Invest in developing subject matter expertise on parenting with intellectual disability**, as a strategy to build the capacity of local agencies to access a source of professionals/agencies nationally of knowledge, policies, practices and resources on parenting with intellectual disability that can support best practice, peer support and innovation.

9. Bibliography

- Booth, T., & Booth, W. (2004). Parents with intellectual disability (ID), child protection and the courts. *Journal of Intellectual Disability Research*, 48(4&5), 379.
- Booth, T., Booth, W., & McConnell, D. (2005). The prevalence and outcomes of care proceedings involving parents with learning difficulties in the family courts. *Journal of Applied Research in Intellectual Disabilities*, 18, 7-17.
- Clayton, O., Chester, A., Mildon, R., & Matthews, J. (2008). Practitioners who work with parents with intellectual disability: Stress, coping and training needs. *Journal of Applied Research in Intellectual Disabilities*, 21(4), 367-376.
- Collings, S., & Llewellyn, G. (2012). Children of parents with intellectual disability: facing poor outcomes or faring okay? *Journal of Intellectual & Developmental Disability*, 37(1), 65-82.
- Coren, E., Hutchfield, J., Thomaes, M., Gustafsson, C. (2010) Parent training support for intellectually disabled parents. *Campbell Systematic Reviews*, 6(6), CD007987.
- Duncan, S., & Markman, H. (1988). Intervention programs for the transition to parenthood: Current status from a prevention perspective. In Michaels, G., & Goldberg, W. (Eds.), *The Transition to Parenthood: Current Theory and Research* (pp. 270-310). Cambridge: Cambridge University Press.
- Feldman, M. (1994). Parenting education for parents with intellectual disabilities: A review of outcome studies. *Research in Developmental Disabilities*, 15(4), 299-332.
- Feldman, M. (2004). Self-directed learning of child-care skills by parents with intellectual disabilities. *Infants and Young Children*, 17(1), 17-31.
- Feldman, M., & Aunos, M. (2011). *Comprehensive, Competence-Based Parenting Assessment For Parents With Learning Difficulties and Their Children*. Kingston, NY, US: NADD Press.
- Feldman, M., & Case, L. (1997). The effectiveness of audiovisual self-instructional materials in teaching child-care skills to parents with intellectual disabilities. *Journal of Behavioral Education*, 7(2), 235-257.
- Feldman, M., & Case, L. (1999). Teaching child-care and safety skills to parents with intellectual disabilities through self-learning. *Journal of Intellectual & Developmental Disability*, 24(1), 27-44.
- Goldacre, A. D., Gray, R., & Goldacre, M. J. (2015). Childbirth in women with intellectual disability: characteristics of their pregnancies and outcomes in an archived epidemiological dataset. *Journal of Intellectual Disability Research*, 59(7), 653-663.
- Goldberg, W. (1988). Introduction: Perspectives on the transition to parenthood. In Michaels, G., & Goldberg, W. (Eds.), *The Transition to Parenthood: Current Theory and Research* (pp. 1-20). Cambridge: Cambridge University Press.
- Gottlieb, B. & Pancer, M. (1988). Social networks and the transition to parenthood. In Michaels, G., & Goldberg, W. (Eds.), *The Transition to Parenthood: Current Theory and Research* (pp. 235-269). Cambridge: Cambridge University Press.
- Hindmarsh, G., Llewellyn, G., & Emerson, E. (2015). Mothers with intellectual impairment and their 9-month-old infants. *Journal of Intellectual Disability Research*, 59(6), 541-550.
- IASSID Special Interest Research Group on Parents and Parenting with Intellectual Disabilities (2008). Parents labelled with Intellectual Disability: Position of the IASSID SIRG on Parents and Parenting with Intellectual Disabilities. *Journal of Applied Research in Intellectual Disabilities*, 21(4), 296-307.
- Lightfoot, E., Hill, K., LaLiberte, T. (2010). The inclusion of disability as a condition for termination of parental rights. *Child Abuse & Neglect*, 34(12), 927-34.
- Llewellyn, G., McConnell, D., Honey, A., Mayes, R., & Russo, D. (2003). Promoting health and home safety for children of parents with intellectual disability: A randomized controlled trial. *Research in Developmental Disabilities*, 24(6), 405-431

- Llewellyn, G., McConnell, D., Ferronato, L. (2003). Prevalence and outcomes for parents with disabilities and their children in an Australian court sample. *Child Abuse & Neglect*, 27, 235–51.
- Llewellyn, G., McConnell, D., & Mayes, R. (2003). Health of mothers with intellectual limitations. *Australian and New Zealand Journal of Public Health*, 27(1), 17-19.
- Llewellyn, G., McConnell, D., Russo, D., Mayes, R., & Honey, A. (2002). Home-based programmes for parents with intellectual disabilities: Lessons from practice. *Journal of Applied Research in Intellectual Disabilities*, 15, 341-353.
- Man, N., Llewellyn, G., & Wade, C. (July 2014). *Estimated Prevalence and Living Circumstances of Parents with Intellectual Disability in Australia from Selected National Surveys: Technical Report 1*. Lidcombe, NSW: University of Sydney.
- Man, N., Llewellyn, G., & Wade, C. (October, 2014). *The Number and Characteristics of Parents with Intellectual Disability from Centrelink Income Support Administrative Data: Technical Report 2*. Lidcombe, NSW: University of Sydney.
- Man, W., Wade, C., & Llewellyn, G. (2017). Prevalence of parents with intellectual disabilities in Australia. *Journal of Intellectual & Developmental Disability*, 42(2) 173-179.
- Mayes, R., & Llewellyn, G. (2012). Mothering differently: narratives of mothers with intellectual disability whose children have been compulsorily removed. *Journal of Intellectual & Developmental Disability*, 37(2), 121-130.
- McConnell, D., Feldman, M., Aunos, M. & Prasad, N. (2011). Parental cognitive impairment and child maltreatment in Canada. *Child Abuse & Neglect*, 35, 621-32.
- McConnell, D., Llewellyn, G. & Ferronato, L. (2002). Disability and decision-making in Australian care proceedings. *International Journal of Law, Policy and the Family*, 16, 270-99.
- McConnell, D., Llewellyn, G., Mayes, R., Russo, D., & Honey, A. (2003). Developmental profiles of children born to mothers with intellectual disability. *Journal of Intellectual & Developmental Disability*, 28(2), 122-134.
- McConnell, D., Mayes, R., & Llewellyn, G. (2008). Women with intellectual disability at risk of adverse pregnancy and birth outcomes. *Journal of Intellectual Disability Research*, 52(6), 529-535.
- Mitra, M., Parish, S.L., Clements, K.M., Cui, X. & Diop, H. (2015). Pregnancy Outcomes Among Women with Intellectual and Developmental Disabilities. *American Journal of Preventive Medicine*, 48(3), 300-308.
- Mildon, R., Wade, C., & Matthews, J. (2008). Considering the contextual fit of an intervention for families headed by parents with an intellectual disability: An exploratory study. *Journal of Applied Research in Intellectual Disabilities*, 21(4), 377-387.
- Parenting Research Centre (March 2017). *Parenting Today in Victoria: Report of Key Findings* (report produced for the Department of Education and Training, Victoria). Melbourne: Parenting Research Centre.
- Spencer, M. (2001). Proceed with caution: The limitations of current parenting capacity assessments, *The Child, Youth and Family Work Journal*, 1, 16-24.
- UN General Assembly (January, 2007). *Convention on the Rights of Persons with Disabilities : resolution / adopted by the General Assembly*. Accessed 16 October 2019. Available at: <https://www.refworld.org/docid/45f973632.html>
- Wade, C., Llewellyn, G., & Matthews, J. (2008). Review of Parent Training Interventions for Parents with Intellectual Disability. *Journal of Applied Research in Intellectual Disabilities*, 21, 351-366.
- Wade, C., Mildon, R., & Matthews, J. (2007). Service delivery to parents with an intellectual disability: Family-centred or professionally-centred? *Journal of Applied Research in Intellectual Disabilities*, 20, 87–98.
- Wilson, S., McKenzie, K., Quayle, E. & Murray, G. (2014). A systematic review of interventions to promote social support and parenting skills in parents with an intellectual disability. *Child Care Health & Development*, 40(1), 7-19.

10. Credentials of the authors of this submission

Dr Catherine Wade

Ph.D. (University of Sydney), Master of Psychology (RMIT University), Graduate Diploma of Applied Child Psychology (RMIT University), Bachelor of Behavioural Science (La Trobe University)

Dr Wade is a Psychologist with over 18 years of experience conducting social policy research spanning a range of public health priority groups including parents with intellectual disability. Dr Wade has been employed by the Parenting Research Centre continuously since 2001, and since 2015 has been in the position of the Principal Research Specialist.

Dr Wade was awarded her PhD by the University of Sydney in 2010. Her thesis topic was 'Modelling contextual influences on children of parents with intellectual disability', and was supported with a prestigious NHMRC Scholarship. She continues her connection with the University of Sydney through Research Affiliateship with the Faculty of Health Sciences.

Dr Wade was a founding member of the team that created Healthy Start – the national strategy to support parents with learning difficulty and their children (Federally funded 2005-2014), and was Healthy Start's national manager from 2008 to 2010. Dr Wade has delivered professional training to over 1000 practitioners, in evidence-informed parenting programs for parents with intellectual disability (in Australia, Sweden, and Japan) and has developed and evaluated innovative resources aimed at these parents. She was a research clinician during her time developing and evaluating the *Parenting Young Children* parent education program, drawing on best practice and evidence about what works to teach parents with intellectual disability child care and parent-child interaction skills.

Dr Wade was the Australian representative for six years on the Board of Management of The Association for Successful Parenting in the USA (supporting parents with intellectual disability) and is a member of the Parenting Special Interest Research Group of the International Association for the Scientific Study of Intellectual Disability.

Dr Wade has authored or co-authored over 25 peer-reviewed publications and is an internationally recognised expert on parenting with intellectual disability, with regular requests for her advice, training and representation on steering committees and reference groups as a result of her clinical and research experience with these families.

Associate Professor Julie Green

Ph.D. (University of Melbourne), Master of Public Health (La Trobe University), Graduate Diploma, Adult Education & Training (University of Melbourne), Certificate in Midwifery (Royal Women's Hospital Melbourne), General Nurse Training, (Mercy Private Hospital, East Melbourne).

Associate Professor Julie Green is Executive Director and Board Member of the Raising Children Network (raisingchildren.net.au), Australia's premier evidence-based and multi-award-winning parenting website funded by the Australian government, and an initiative of the Murdoch Children's Research Institute and the Parenting Research Centre. She is also Director and Executive member, Parenting Research Centre, and Principal Research Fellow, Murdoch Children's Research Institute.

Julie is a senior leader in child and family wellbeing and parenting. She is expert in health literacy and health communication, particularly in connecting health consumers from diverse backgrounds to trusted information sources, particularly in support of positive parenting and the healthy development of children and families in community settings.

Julie leads Raising Children Network's collaborations with the Australian, state and international governments, business and community organisations. Membership of advisory groups relevant to

this submission include National Office for Child Safety, Child Safe Sectors Leadership Group, Department of Prime Minister and Cabinet; Ministerial Advisory Panel – Baby Bundle, Victorian Department of Health & Human Services; Perinatal Society of Australia and New Zealand Consumer Advisory Panel; National Health & Medical Research Council Expert Working Committee, ‘Mental Health and Parenting’ (2014-2017); and Australian government Department of Human Services, Child Support Stakeholder Committee (2015-16).

Julie regularly contributes to the media on issues of raising children and has co-authored more than 70 peer-reviewed publications.



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