National Disability Strategy

Submission to the Department of Social Services

30 October 2020

Parenting Research Centre

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Introduction

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. We thank the Department of Social Services for the opportunity to make a submission to inform the next National Disability Strategy. We see this as an opportunity to place people with a disability at the centre of future planning, focusing on strengths rather than deficits, and as a chance to shape the broader view of people with a disability as valuable contributors to society. Our submission focuses on what is known from evidence about parenting **children with a disability** AND **parenting by people with intellectual disability**. This includes the role of effective, accessible parenting support for these families, to better support the health, safety and wellbeing of their children.

This submission draws on our research, evaluation and practice portfolio of work, and on the Australian Government-funded parenting website, raisingchildren.net.au, an initiative of the Parenting Research Centre, the Murdoch Children's Research Institute and Centre for Community Child Health, Royal Children's Hospital.

The submission looks at supports for parents, and for those professionals who work with parents and thus contribute to positive outcomes for families where a child or parent have a disability.

The Convention on the Rights of Persons with a Disability (UN General Assembly, January 2007) (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.

Parenting requires a set of skills that can be learned and, as such, can be practised and improved on. All parents can benefit from parenting support, and with the right support matched to the learning needs of parents, all parents have the capacity to learn and to provide the type of parenting that will help their children thrive.

Overview

An overview of the Parenting Research Centre

The Parenting Research Centre is an independent, non-profit organisation that helps children thrive by advising on new and better ways to support families in their parenting. We help governments and community organisations in the fields of parenting support, disabilities, child welfare, health and education to put the best evidence on family support into action. We emphasise co-designed approaches and working collaboratively with our partners across the government and non-government sectors. Our work draws on the best available evidence to ensure we help policy makers and service providers bridge the gap between evidence and practice.

Key considerations

This submission reflects where we view evidence can be brought to bear on refinements to the National Disability Strategy.

Our submission is presented under four key headings, addressing first what the evidence says about best practice parenting support for two groups of parents: (1) those with children who have a disability, and (2) parents who themselves have intellectual disability; followed by two sections that describe what is known in the evidence about supporting families where there is a disability in relation to the following key outcome areas:

- Personal and community support
- Learning and skills
- Health and wellbeing
- Inclusive and accessible communities

Section 1 – Parents of children with a disability

- Parents of children with a disability experience additional challenges, including greater financial strain and poorer health compared to parents in the community more broadly
- Non-government organisations are well-placed to provide vital and timely support to parents of children with a disability, including parenting information and skill development, and by facilitating peer support
- The Australian Department of Social Services-funded MyTime program has an established history of providing quality peer support groups for Australian parents and carers of children with a disability
- The Parenting Research Centre deliver implementation support to facilitate the successful provision of peer support groups
- Since its inception, over 20,000 parents/carers have participated in MyTime, in approximately 524 groups, attending approximately 64,000 hours
- Over 1500 facilitators have been supported to deliver MyTime, across 385 providers and 18 partner agencies
- Parents/carers report overwhelmingly positive experiences from their attendance at MyTime groups, including enhanced social connectedness, feeling supported and increased knowledge
- The Australian government has funded the evidence-based parenting website raisingchildren.net.au since 2006. The website has extensive resources for parents of all children, including children with disability and developmental delay.

Section 2 – Parents with an intellectual disability

- Parents who have an intellectual disability face parenting barriers and life challenges more so than parents without a disability

- They are more likely than other parents to be represented in the child protection system
- Parenting is a set of skills which can be learnt by parents, including by parents with intellectual disability, depending on the opportunities given and the support received
- Parenting skills have been shown to improve through interventions with teach strategies through behavioural instruction
- The world-leading Healthy Start National Strategy was Department of Social Services-funded until 2014 to deliver a range of training packages and targeted resources for practitioners to support parents with intellectual disability.

Section 3 - Strengthening evidence-informed practice to support families where there is a disability

- There is a push for non-government organisations and government to use evidence-based programs and practices, but there can be challenges to applying evidence-based programs in some contexts
- Evidence, practitioner experience and client preferences can be integrated and turned into action via a clear framework of practice
- PracticeWorks is a method of supporting organisations with developing practice frameworks to meet client needs and achieve meaningly outcomes
- Application of the PracticeWorks process allows organisations and their clients - including families where there is a disability - to shape the practices employed within a service and allows clients to also steer service delivery.

Section 4 – Community participation

- Families where there is a disability value involvement in community but are less likely to be involved in some settings, such as mainstream education and employment
- Participation can be improved by community attitudes and understanding, and if tasks and the environment are modified to support participation
- Community attitudes also affect the uptake of expert knowledge, the need for funding, the importance of supporting parenting and family help seeking
- The Parenting Research Centre’s Reframing Parenting project has found that narratives and metaphors in communications about parenting can influence community attitudes
- Our Reframing Parenting work has enabled us to develop resources that support practitioners and organisations with using effective and tested narratives and metaphors in their language and written materials
- Through coaching, implementation support, and tools such as online learning, webinars, research reports and articles, we can help the field apply these narratives and metaphors in their day to day communications and work with people with disability.
- The Raising Children Network has established Parent Panels representative of parents of families with disability, including rural and LGBTQI families and parents with intellectual disability; and extensive community engagement via social media channels.

Parents of children with a disability

Questions addressed in this section:

- The role that the non-government sector plays in improving outcomes for people with a disability (Question 5)
- Targeted Action Plans that make improvements on specific areas within a defined period of time (Question 7)

When compared with parents of typically developing children, parents of children with a disability experience more financial strain (AIHW, 2004), and poorer physical and mental health (Gilson et al., 2018; Singer, 2006). Many of these parents spend more than 40 hours a week directly in care of the child with a disability, struggle to find services for their family, feel socially isolated, find it difficult to maintain employment and feel they need more support (Davis & Gilson, 2018).

Evidence suggests that the well-being of caregivers is also linked to the well-being of the children they care for. A study of parents of children with Cerebral Palsy found positive associations between parental physical health and the physical functioning of their child (Murphy et al., 2011). This study also found positive associations between parent mental health and child emotional functioning, psychosocial functioning, and total health-related quality of life. It was not clear whether parental well-being influenced child functioning, child functioning influenced parental well-being, or both parent and child well-being was reciprocally determined. What is clear, however, is that the well-being of caregivers and of children is closely linked.

The suite of government and non-government services available to children with disabilities and their families encompass a broad range of supports covering income support, respite care, therapy and early child intervention, mental health services, aids and equipment services, housing and crisis accommodation services, and child protection. Child development and child outcomes are heavily impacted by parenting, but parenting support is often overlooked in the consideration of what is needed for parents of children with disability (Michaux & McDonald, 2016).

One form of parenting support that has been found to be valuable for caregivers of children with disabilities is peer support (Solomon, 2004). Peer support interventions aim to support caregivers with finding social support from others who may share and understand their situation. There is evidence that peer support has many benefits for caregivers including improving their knowledge of skills to deal with the day-to-day challenges of raising a child with disability, increased sense of power and belonging, shared social identity and the opportunity to learn practical information from others (Law et al, 2001; Shilling et al, 2013). Our own research attests that, participants in peer support interventions report that they value:

- the opportunity to connect with other parents
- a supportive environment
- ability to set their own agenda
- support from a knowledgeable and approachable mentor
- opportunity to express conflicting emotions
- opportunity to examine ideas about child behaviour
- practical tips about child disability
- practical assistance to attend groups.

(Sartore et al., 2013)

Furthermore, the Parenting Research Centre has a 20+ year history in leading research and service delivery to support parents of children with a disability, including as creator and implementation lead for the DSS-funded MyTime peer support strategy across each state and territory of Australia (see Case Study 1 for more information). We know first-hand how peer support can benefit families.

Case Study 1: MyTime, peer support intervention for parents/carers of children with a disability

Established in 2007 and funded by the Australian Department of Social Services, MyTime provides peer support groups for Australian parents and carers of children with a disability. MyTime Peer Support groups aim to:

- be open and accessible to parents from all sectors of the community, including mothers and fathers, carers, culturally and linguistically diverse groups, Indigenous families, families in non-metropolitan areas and single parent families
- support parenting education and skills development
- support the development of social networks for families of children with disability
- foster social capital and build local capacity, community connectedness and partnerships.

Each MyTime group consists of 4-12 parents/carers, a trained facilitator to manage group processes, and at least one play helper. The Parenting Research Centre manages the MyTime program across Australia, delivering implementation support to a network of 12 active partner agencies that have expertise in areas of disability, family support, parenting and children with special needs. The partner agencies coordinate local providers to deliver the MyTime groups, and there are over 200 groups at any one time.

In the period 2015-2019, there were 10,369 parents/carers who participated in MyTime and 9912 in the period 2009-2015. Since 2009, on average 1400 new parents/carers joined MyTime each year and more than 3500 parents and carers attended at least one MyTime group each year. Since 2009, there have been 524 groups, with a total of 63,968 hours of peer support. More than 1500 facilitators have delivered MyTime, across 385 providers (2009-2015) and 18 partner agencies.

Evaluations (ORIMA Research, 2013; PRC, 2019) of the intervention found the following benefits for parents/carers:

- positive and valued experience in peer support group, particularly for enhancing social connectedness
- feeling supported in their caregiving role
- increased knowledge about caring for a child
- increased knowledge about services and supports

The lessons learned from MyTime have shown us that parents of children with disabilities benefit in a range of ways from support that is targeted to their needs and delivered in socially supportive environments. MyTime groups play a vital role in improving outcomes for children with a disability and their families by:

- providing the right information at the right time to families, giving due consideration to the age of the child and their stage of diagnosis and development
- developing and delivering a tailored plan of information and support to groups of parents over a sustained period (most MyTime participants join and stay in a group for around 2 years – illustrating the importance of having access to this kind of support for the ongoing needs of families).
- being open-ended – not time limited. We acknowledge that while some needs are best addressed in a defined period of time, the value of MyTime is that people know it’s there, and that if circumstances change for their family they can always return to MyTime for access to information, support and social connections in a safe space.
- Being flexibly delivered – in the past 10 months we have successfully re-positioned MyTime group to be delivered mainly online, in reaction to the social distancing requirements imposed by COVID-19. While ongoing assessment of the acceptability and usefulness of

these virtual groups is currently in place, early anecdotal reports suggest this shift has been appreciated by caregivers.

Role of the non-government sector in connecting parents with reliable online information about disability

Empowering families by connecting them to the right information, resources and services helps parents and carers make choices that support the development and wellbeing of their child. It strengthens their health literacy on development, helps families identify any potential concerns or signs of delay regarding their children's development and wellbeing in the early stages of life.

Audience survey data[1] from the Australian government funded, evidence-based parenting website, raisingchildren.net.au, shows that connecting with trusted, credible information helps parents know what to do next, try something new, feel less worried, grow their confidence and connect with support services.

Raising Children Network website analytics for October 2019 - September 2020 reflect 19.7million visits to the site with 41million pages read during that period. During the COVID-19 pandemic, website traffic has increased greatly, for example:

Metrics on raisingchildren.net.au

6,974,542 visits - increase of 46.3% on same time period in 2019

Organic search referral traffic increased by 46.7% compared to the same time period in 2019.

Disability and autism content on raisingchildren.net.au

516,108 sessions – increase of 41.2% on same time period in 2019

Autism Therapy Guides

89,978 pageviews - increase of 37% on same time period in 2019.

A further strong illustration of how raisingchildren.net.au connects families with information and empowers parents is its search terms. As at end October 2020, searching in Google using the disability and autism terms shown in the table below results in raisingchildren.net.au:

- in top 1 or 2 position
- in both top 1 and 2 positions
- as a 'featured snippet' (this displays at the top of the search page with a larger paragraph and usually an image rendered from the website).

Disability search terms	Autism search terms
Disability family life Children with disability routines Siblings children disability School children with disability Friends children with disability Children disability assessment Intellectual disability children parent relationships children with disability parent feeling child with disability	worried about autism late autism diagnosis challenging behaviour children autism changing routines children autism sensory sensitivities children autism aggressive behaviour children autism bullying children autism appointments children autism stimming children autism discipline children autism

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[1] Raising Children Network Audience Survey 2019/20 (unpublished)

reactions to your child's disability talking about your child’s disability anxiety child with disability anxiety teenager with disability depression teenager with disability employment rights teenager disability employment education rights child disability anti-discrimination laws child disability disability law Australia children	communication children autism attention children autism family relationships children autism family stress children autism having another child autism social skills children autism sleep habits children autism mood changes children autism eating habits children autism personal hygiene children autism apps children autism parties children autism social life children autism choosing primary school children autism starting primary school children autism choosing secondary school children autism anxiety school children autism employment rights children autism services children autism choosing service providers children autism state autism associations social stories medications children autism

Parents with an intellectual disability

Questions addressed in this section:

- The role that the non-government sector plays in improving outcomes for people with a disability (Question 5)

According to 2009 data there are over 17,000 parents with identified intellectual disability in Australia (Man, Wade & Llewellyn, 2017). There are also many Australians who have significant cognitive limitations impacting on their learning, and the costs to the system related to poor health and wellbeing of these families is concerning.

As a group, parents with intellectual disability experience a range of challenging circumstances that put them and their children at greater risk of poor outcomes, such as poverty, social isolation, homelessness, and poor health, as well as poor health care (Llewellyn, et al., 2003; Man, et al., July 2014; October 2014; 2017).

Parents with intellectual disability face hurdles from the very earliest stages of their parenting journey not experienced by the general population. This includes:

- Failure to welcome news of pregnancy with the positivity that most other parents enjoy
- Failure 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 support offerings
- Removal of children from parents in the hospital immediately following childbirth
- Failure to communicate appropriately with parents about their rights, about what's happening to them and why, and about next steps
- Setting parents up for failure by requiring they demonstrate near perfect parenting even in the face of having been denied access to their child to practice and hone their skills.

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

Research from Australia, the UK, US and Canada show 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). There is evidence that once these families are in the court system, outcomes are different to other families - they are more likely to have their children permanently removed from their care and for their children to be placed in non-kinship out-of-home care (Llewellyn et al., 2003; McConnell et al., 2011). There is also often a failure to have anyone acknowledge or address their grief at losing custody of a child or to plan for their future access to their child following removal.

Parents with intellectual disabilities are frequently expected to be unable to care for their children by their own family and professionals who could support them. These prejudicial beliefs and assumptions lead to a lack of opportunity to show their ability to parent and a lack of support.

An intellectual disability is not a strong predictor of how competent a person is with parenting. People learn parenting skills, including by people with an intellectual disability, while doing the job of parenting and will depend on the opportunities the parent has to use the skills as well as the amount of support they receive. Parents possess different preferences on how to learn, including reading information, watching others use the skills, and structured support. Assumptions should not be made about what will work for a particular parent, rather, parenting support should be individually tailored to best support the parent's learning.

Much is known about what works to support parenting for people with intellectual disability. Four systematic reviews form part of the body of evidence in best practice for supporting parents with intellectual disability (Coren et al., 2010; Feldman, 1994; Wade et al., 2008; Wilson et al., 2014).

Our own research, and our practical experience in designing, delivering, and evaluating innovative programs for these parents have informed us that supports are most effective when they:

- occur in the setting they will be used i.e. the home
- are skill-focused
- use behavioural teaching strategies such as modelling, practice, corrective 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 needs to be intensive and long-term to allow parents with intellectual disability to generalise parenting skills to a range of contexts as children get older. Ongoing support for parenting may be needed. This can include skill maintenance checks, strategies to generalise skills, booster sessions, repeated intensive delivery during higher risk times, such as just prior to developmental transitions or when there are crises (IASSID Special Interest Research Group on Parents and Parenting with Intellectual Disabilities, 2008).

Evidence supports the use of particular teaching approaches to improve parenting skills among parents with intellectual disability. There is some evidence that curriculum-based didactic instruction in a group setting can work, and self-instructional materials have been shown to be an effective and relatively rapid for teaching new skills in child care for parents with intellectual disability (Feldman, 2004; Feldman & Case, 1997, 1999; Llewellyn, McConnell, Honey, Mayes & Russo, 2003). However, the greatest evidence supports use of a tailored, individualised approach which includes behavioural instruction delivered in the home setting.

Evidence also suggests that parent education programs will be more effective with parents with intellectual disabilities if they are:

- **Specific** to the parent's individual needs
- **Parent-directed** and based on parent needs. Educator and parents are in a partnership and the parent is involved in planning and operation of the program
- **Skill-focused** in its teaching to complement the knowledge gained by the parent
- **Contextually relevant**, considering the characteristics of family members and the family environment. Strengths and challenges are considered when developing and implementing the parent education program.

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

Case Study 3 illustrates how a major national initiative was able to draw together the scientific evidence with known best practice to deliver a workforce capacity-building strategy focused specifically on the children of parents with intellectual disability. The Heathy Start National Strategy was ground-breaking and world renowned, and still offers a platform which can be built upon to better meet the needs of this highly vulnerable population of children and parents.

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, 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 Facility 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.

Strengthening evidence-informed practice to support families where there is a disability

Questions addressed in this section:

- The role that the non-government sector plays in improving outcomes for people with a disability (Question 5)
- Targeted Action Plans that make improvements on specific areas within a defined period (Question 7)
- How could people with disability, and the disability community be involved in the delivery and monitoring of the next Strategy (Question 8)

Non-government organisations in Australia support families and children in preservation, out-of-home care and restoration services, and in educational settings, including settings where a child or parent/carer have a disability. There has been a push from non-government organisations and government departments for services to incorporate more evidence-based practice to help practitioners and families achieve desired outcomes. There are often times when ready-made evidence-based programs may need to be tailored to a specific context which requires added time and cost. Evidence-based programs may not be applicable for some contexts. It can be more suitable to combine the best evidence with the practitioner's skill and knowledge with the individual client's values and preference (see Figure below), then turning this knowledge into action via a practice framework. This allows for services to:

- make explicit *how* the service works
- provide a common language and approach to working with clients (Cook and Brown, 1999)
- make knowledge held by individuals accessible to others (Lin and Lee, 2004)
- enable a process of systematically developing and evaluating practice for improvement

The Parenting Research Centre has created a method to support agencies to develop practice frameworks to meet client needs and achieve meaningly outcomes. This method – called *PracticeWorks* - allows organisations and their clients - including families where there is a disability - to shape the practices employed within a service and allows clients to also steer service delivery (see Case Study 3 for further information about PracticeWorks). We believe there is a clear role for

PracticeWorks for the future of disability supports in Australia – bringing good evidence, good practice and the clients preferences together to shape best practice in parenting support for families affected by disability.

Case Study 3: Operationalising evidence with non-government organisations – PracticeWorks

The Parenting Research Centre has worked with multiple non-government organisations to develop a Practice Framework for their service and agency context which can drive their continuous practice improvement system. The following steps facilitate tailoring evidence-based practices and the implementation of these practices by practitioners. The steps are planned ahead of time and may involve months or years of work with key decision makers at the non-government organisation:

1. Program analysis
    - looking at what is in place for the service
    - exploring how the non-government organisation sees the service working
    - discover what outcomes the non-government organisation thinks are needed to successfully help the service users and produce an outcomes chain
2. Evidence analysis
    - to support the outcomes chain
    - to modify the outcomes chain
3. Practice design
    - develop activities and practices alongside the non-government organisation to operationalise the outcomes chain
4. Rapid test and learn cycles
    - test the activities and practices
    - adjust activities and practices to ensure they can be applied in the service context
5. Data-based feedback system
    - work with non-government organisation to design prototype data feedback loops
    - engineer team-based processes to put data in the hands of those who can use it best, in order to drive continuous improvement and highlight the service's effectiveness
6. Implementation support
    - technical support to implement the practice framework into business-as-usual
    - strategies informed by implementation science

Within step 3, the practices are developed using evidence, and modified based on practitioner feedback. Step 4 allows the opportunity for input from parents/carers, including those with a disability. After practitioners test the practices with parents/carers, the feedback is incorporated into the final version of the Practice Framework; this Practice Framework will guide the service that parents/carers ultimately receive.

The Practice Frameworks which have been produced are premised on genuine collaboration between practitioners and the change agent - the parents/carers. This means:

- working alongside the parent/carer to achieve outcomes
- sharing a purpose and sharing power
- seeing that parents are the solution, not the problem
- working on goals that parent/carer wants for the child, rather than setting the goals for them
- supporting parents/carers with bringing knowledge, strengths, and ideas to the work that is done

Services which are guided by this type of collaboration will inherently seek out and involve the parent/carer to steer service delivery, and in turn the monitoring in step 5 above.

Community participation

Questions addressed in this section:

- The role that the non-government sector plays in improving outcomes for people with a disability (Question 5)
- View on a stronger emphasis on improving community attitudes (Question 3)

Understanding that community participation is vital to the individual and important for society more broadly, we are concerned about how individual and community attitudes can impinge on the engagement of the person with disability in the community.

When interviewing parents and carers of children with an intellectual disability, Johnson and colleagues (2020) found that families valued involvement in their local communities. Families expressed the importance of inclusion and normality, including being supported to be part of the community as any other family would, rather than having services that were "service-provider-centred".

The Parenting Research Centre's own research shows that parents with intellectual disability prefer support that is family*-centred rather than professional-centred. This means, support should:* acknowledge and respect that parents are the experts about their children and their family circumstances; be sensitive and responsive to the individual, taking into account their circumstances, including learning style; work on building connections with parents, viewing them as partners in parenting support; and provide support without judging.

For children, being actively involved in their community provides opportunities to explore their own personal interests, to grow as people and to enjoy their lives (Case-Smith & O'Brien, 2010). This is especially important for people with disabilities as they are less likely to participate in mainstream education and employment settings (Johnson & West, 2020).

According to Australian parents, children's participation can be improved by the attitudes and understanding from families, community members, and service providers; it would also help if tasks and the environment were modified to allow for participation (Johnson et al., 2020; Foo et al., 2012).

While positive attitudes can assist participation, societal attitudes have also been found to be a barrier to participation for people with disabilities (Barr & Shields, 2011; Thompson et al. 2016). Community attitudes affect the uptake of expert knowledge, including about what works to build parenting skills, the need to fund parenting support and the importance of collectively improving parenting for the good of society.

During recent parent consultations for Raising Children Network's NDIS-ILC funded project, we have heard parents with intellectual disability talk about the challenges of invisible disability, of community perceptions of them and how they parent. Community perceptions and the attitudes of professionals can be quite negative and impact upon the opportunity for learning and growth that we offer to families – if we assume no effect, we tend to offer no opportunities. Thus, we need to challenge widespread prejudiced and unfounded attitudes about disability and about capacity for learning. Otherwise community participation by parents and children with disability will continue to suffer.

Better understanding how the public think about disabilities and parenting, can better predict how messages are likely to be received and help avoid making information hard to apply (Volmert et al., 2016).

Our recent experiences in coming to understand the importance of framing communications about parents offer a solution here. As illustrated in Case Study 4, we believe there is great power in the creation of narratives that can shift perceptions and shape responses. The Parenting Research Centre is ready to explore how our Reframing Parenting work can be tailored to craft a new narrative about disability, particularly in relation to their parenting and community participation.

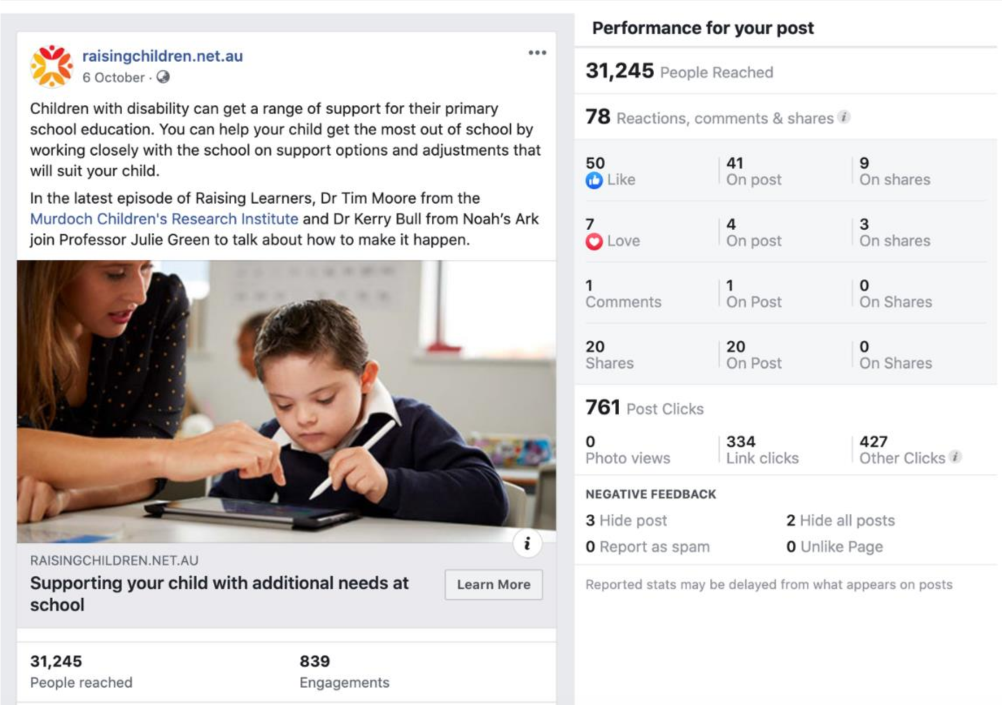
And, raisingchildren.net.au, as part of its commitment to continual improvement and consistency is adopting several strategies in its review of its NDIS content to be more inclusive of diverse families.

Enabling parent and community participation

The Raising Children Network has extensive parent and community engagement via social media channels.

It has established Parent Panels to guide its ILC project with specific cohorts of parents, working with rural, and rainbow families and parents with developmental delay.

Parents engage daily with Raising Children Network's social channels. For example, via its 265,000+ Facebook followers. Illustrations of engagement with disability related Facebook posts are below:



raisingchildren.net.au
6 October ·

Children with disability can get a range of support for their primary school education. You can help your child get the most out of school by working closely with the school on support options and adjustments that will suit your child.

In the latest episode of Raising Learners, Dr Tim Moore from the Murdoch Children's Research Institute and Dr Kerry Bull from Noah's Ark join Professor Julie Green to talk about how to make it happen.

RAISINGCHILDREN.NET.AU
Supporting your child with additional needs at school

31,245 People reached
839 Engagements

Performance for your post

31,245 People Reached

78 Reactions, comments & shares

50 Like	41 On post	9 On shares
7 Love	4 On post	3 On shares
1 Comments	1 On Post	0 On Shares
20 Shares	20 On Post	0 On Shares

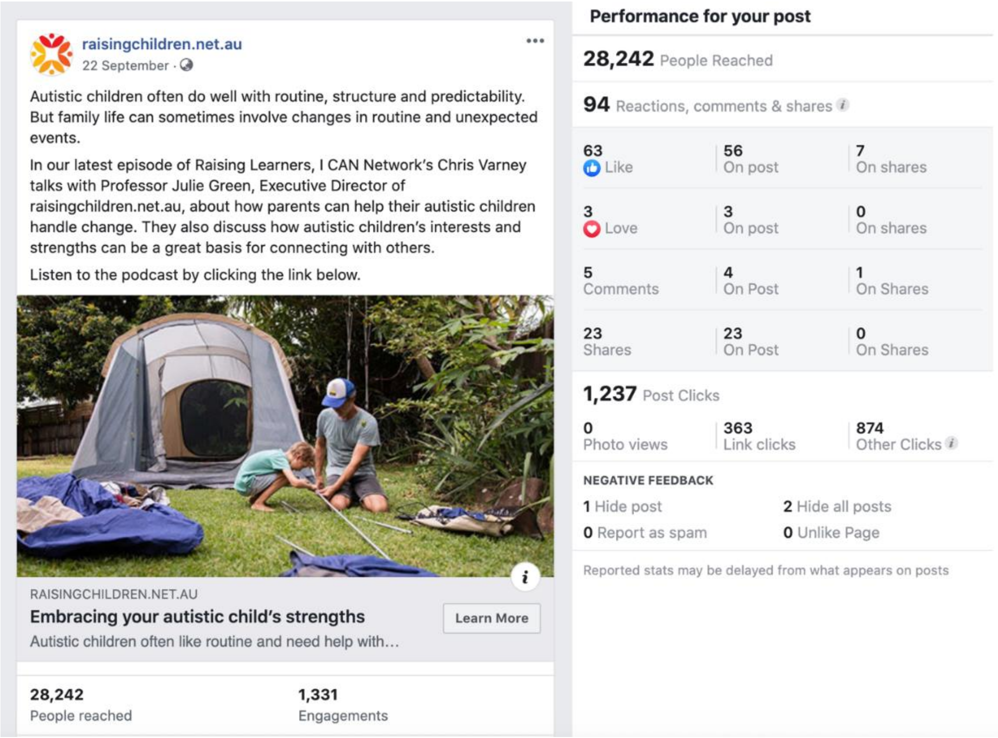
761 Post Clicks

0 Photo views	334 Link clicks	427 Other Clicks

NEGATIVE FEEDBACK

3 Hide post	2 Hide all posts
0 Report as spam	0 Unlike Page

Reported stats may be delayed from what appears on posts



raisingchildren.net.au
22 September ·

Autistic children often do well with routine, structure and predictability. But family life can sometimes involve changes in routine and unexpected events.

In our latest episode of Raising Learners, I CAN Network's Chris Varney talks with Professor Julie Green, Executive Director of raisingchildren.net.au, about how parents can help their autistic children handle change. They also discuss how autistic children's interests and strengths can be a great basis for connecting with others.

Listen to the podcast by clicking the link below.

RAISINGCHILDREN.NET.AU
Embracing your autistic child's strengths
Autistic children often like routine and need help with…

28,242 People reached
1,331 Engagements

Performance for your post

28,242 People Reached

94 Reactions, comments & shares

63 Like	56 On post	7 On shares
3 Love	3 On post	0 On shares
5 Comments	4 On Post	1 On Shares
23 Shares	23 On Post	0 On Shares

1,237 Post Clicks

0 Photo views	363 Link clicks	874 Other Clicks

NEGATIVE FEEDBACK

1 Hide post	2 Hide all posts
0 Report as spam	0 Unlike Page

Reported stats may be delayed from what appears on posts

Case Study 4: Community attitudes – Reframing Parenting

Our research shows that attitudes and cultural models about parenting in Australia make people resistant to thinking about parenting as a conscious, skill-based practice that can be improved. One example is the belief that 'parenting cannot be addressed or solved' making people more likely to disregard evidence that is put forward (Volmert et al., 2016) and can affect help seeking (Michaux, 2019).

To change the conversation about parenting, increase public support for policy solutions, and increase public engagement regarding supports for parents and parenting, studies were conducted to test the effects of variety of frames and narratives to use when communicating about parenting. This includes identifying an effective master narrative to influence public attitudes by telling audiences what the issue is about, why it matters, what will happen if action is not taken, and what needs to be done (L'Hote et al., 2017).

These studies found two common narrative strategies:

1. *Effective parenting* – focusing on how to improve parenting, and parent skills, practices and behaviours
2. *Child development* – focusing on the importance of healthy child development

Participants received the same information about an initiative ensuring children grow up in conditions that enable them to do well. One group received information that was framed with *Effective Parenting* master narrative and another group received information framed with *Child Development*. Compared with a control group, the *Effective Parenting* frame reduced general policy support and willingness to engage in civic action, e.g. signing a petition, writing to an elected official etc. The *Child Development* frame increased support on several levels and increased the participants' willingness to pay additional taxes.

Metaphor is another device that enhances the understanding of parenting. A key part of this research involved the testing of promising metaphors to help explain parenting. Of the metaphors tested, only one was shown to be successful in switching on productive ways of thinking about parenting and help people avoid unproductive thinking. The successful candidate was a 'navigating waters' metaphor. This describes parenting as a journey that requires skill and support, where one may encounter smooth or rough seas and where safe harbours and lighthouses can protect parents from these challenges.

The Parenting Research Centre has made these findings available to non-government organisations through:

- Online learning course
- Webinars
- Research report online
- Article on government website

133 users accessed the online learning course within the first two weeks after it launched in July 2020 and 224 participants joined the June 2020 webinar. The Parenting Research Centre also provided coaching and implementation support to nine initiatives, including the National Association for Prevention of Child abuse and Neglect, Every Child, Parentline and raisingchildren.net.au. This includes building strong connections between stakeholders using the reframing parenting approach. Members of these initiatives reported that they:

- Have changed their conversations and language around supporting parents
- Have increased guidance for developing messages and confidence about their impact
- Now question how messages are formulated and how language is used in practice
- Shape their discussions and look at problems differently
- Have updated their marketing materials
- Have greater turnout due to a new workshop name and increased engagement on social media
- Have observed that organisations are using the 'navigating waters' language

Conclusion

With necessary supports in place, parents of children with a disability and parents with an intellectual disability can improve outcomes for their children. Continuing investment in best practice interventions can help provide parents with this support. This submission prioritises the following specific recommendations:

1. **Invest in peer support groups (pp 7,8)** which are run by trained facilitators to support parents of children with a disability. Making these groups available to parents can increase positive experiences for parents, enhance their social connectedness and improve their knowledge.
2. **Build capacity in the relevant workforces (pp 9-13)** of practitioners working with parents-to-be and parents with intellectual disability through training, coaching support and implementation support to use best practice and evidence-supported strategies in their interactions with parents.
3. **Invest in a co-design process with the non-government sector (p 13-14)** to help organisations incorporate evidence in their practices and to involve families where there is a disability in service delivery. Support organisations to continue to self-monitor the use of evidence-based and evidence-informed practices, while continuing to share power with the families they work with.
4. **Invest in empowering families (pp 9, 16)** to access reliable, evidence-based information and support for their child early via trusted sources, including online, which will enable parents to identify developmental delay or disability early, and access early intervention supports – all of which are linked to better longer-term outcomes for young children and their families.
5. **Shape community attitudes (pp 15,17)** to support community participation for people with a disability and their families. Increase support for policy solutions, funding, and the uptake of expert knowledge.

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