

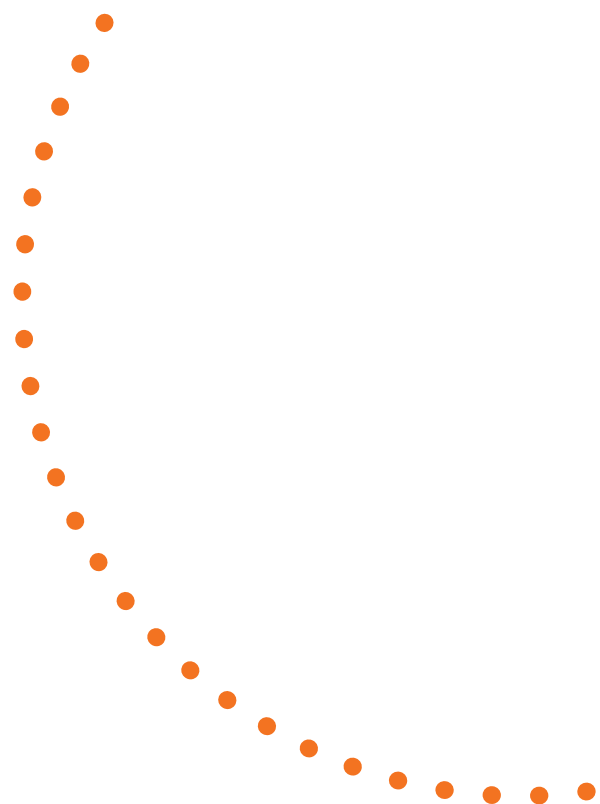


NDIS Review Submission from the Parenting Research Centre

Prepared by: Parenting Research Centre

Prepared for: The NDIS Independent Review Panel

Prepared on: 24th August 2023



Contact

Melbourne office

PO Box 582
East Melbourne Vic 8002

Sydney office

Hyde Park Hub
223 Liverpool Street
Darlinghurst NSW 2010

P: +61 3 8660 3500

E: info@parentingrc.org.au

www.parentingrc.org.au

Introduction

The [Parenting Research Centre](#) welcomes the opportunity to contribute to the review of the National Disability Insurance Scheme (NDIS). We applaud the review, which seeks to “put people with disability back at the centre of the NDIS” through genuine engagement with participants, their families, and other key stakeholders.¹

The Parenting Research Centre was established in 1997 and is Australia’s sole independent, non-profit research organisation focused on parenting support. We strive to help all children thrive through driving effective and innovative ways of supporting Australian families on their parenting journey. As a trusted and leading source of knowledge, research and practice expertise about parenting, we are regularly engaged by agencies to draw on our 25 years of experience in parenting and parenting support to help develop new knowledge and evidence-informed resources, services and policy.

We proudly deliver a diversity of projects and programs that support families, practitioners and organisations across Australia. These include initiatives that strive to help children with a disability and their parents to thrive, such as:

- The [Raising Children Network](#) – An online parenting support initiative developed by member organisations – the Parenting Research Centre, the Centre for Community Child Health, and Murdoch Children’s Research Institute – the Raising Children Network has supported all Australian children to thrive by providing trusted and engaging support for parents, carers, and professionals across sectors since 2006. This includes resources and supports for families of children with developmental concerns, developmental delay and disability.
- [Parenting Today in Victoria](#) survey – First conducted in 2016, with subsequent waves in 2019 and 2022, the *Parenting Today in Victoria* study is the most comprehensive survey of behaviours, needs and concerns of Victorian parents ever conducted. Study data includes detailed information about parents and caregivers of all children, including close to 1500 parents of children with disability. The survey is an essential source of information for service providers and policy makers – and can be drawn on to guide planning and decision-making about supporting families, including where a child has disability.
- [MyTime](#) – A facilitator-guided peer support program for parents and carers of children with disability, MyTime helps to build peer connections between parents, offers emotional and social support, provides reliable information, and supports access to local services. The Parenting Research Centre currently coordinates over 180 MyTime peer support groups across Australia, with the groups being delivered by state-based disability and family support partner agencies.

Our definitions

“**Parenting** is the task of raising and nurturing children. This task is performed by a child’s primary caregiver, who may or may not be the child’s biological parent. It is the relationship that primary carers form with their children, together with what they do in the daily process of childrearing, that we define as ‘parenting.’

Parenting support focuses upon the nature and quality of parent-child interactions and relationships. It takes the form of information, advice and skills development, and is offered by a range of services across the health, welfare and education sectors.”² Parenting supports are appropriate and necessary for all children regardless of levels of vulnerability and disability.

¹ National Disability Insurance Scheme Review Secretariat (2023)

² Parenting Research Centre (unpublished, p. 1); Parenting Research Centre (2017)

This submission to the NDIS Review Panel draws on the Parenting Research Centre's research, evaluation, practice, and sector knowledge and expertise. It includes the results of a tailored analysis conducted using data from the *Parenting Today in Victoria* surveys³ to provide the NDIS Review with up-to-date evidence about parents of children with a disability⁴ that is specifically tailored to the NDIS context. We also draw on what is known about parenting and parenting support from the Australian and international evidence base, including for families of children with a disability.

Our submission focuses on the following **key messages** as critical for supporting the healthy development and wellbeing of children with a disability and for the Panel's consideration in the NDIS Review:

- Parents are their child's most important support. Parents are also critical agents of change in the lives of their children. For young children in particular, the role of the parent must be considered central to any child-focused intervention or support.
- Parents of children with a disability are showing increasing levels of distress over time – and these levels are higher than for parents of children without a disability.
- A concerning proportion of parents of children with a disability are facing parenting challenges, which is likely to impact negatively on children.
- Parent-mediated supports for children are key for improving developmental outcomes for all children – including children with a disability. But challenges in the current context and state of the NDIS are creating barriers to accessing NDIS-funded supports beyond those that are delivered by professionals directly to children.

We fully support the Review's aim of putting "people with a disability back at the centre", but also highlight that family-focused approaches must be kept in sight, including through allowing funding to be used to support the capacity of families to address the child's needs. Key to this approach is harnessing the power of parents as critical 'agents of change' by increasing awareness, clarity, access and funding in relation to parent-mediated interventions and parenting supports. In turn, this will achieve stronger child developmental outcomes, enhance the child's participation in the community, and place the child at the centre of everyday family life.

Parents are critical 'agents of change' for children with a disability

Parents are the most important source of support for their child with a disability. Parents are not simply 'consumers' of services but are critical 'agents of change' who are best positioned to have the greatest positive impact on their child's life.⁵ Parent capacity to be a change agent is strengthened by their engagement with evidence-based parenting programs and through collaboration with the professionals who are supporting the child.

Children develop in the context of their relationships and families, which is why the parent-child relationship is the most important influence on a child's development and wellbeing. For children with disability to flourish it is important that programs (parenting or otherwise) be incorporated into child and family routines.⁶

³ Parenting Research Centre (2023)

⁴ By 'disability' we mean intellectual or developmental disability or learning difficulties, sensory impairments or Autism Spectrum Disorder.

⁵ Dyches, et al. (2012); Kaminski et al. (2022); Keating and Hertzman (1999); Meisels and Shonkoff (2000); Parenting Research Centre (2022); Doyle et al. (2023)

⁶ McWilliams (2010)

Parent-mediated supports offer a range of benefits for children with a disability and their families.⁷ For example, evidence-based parenting programs for families where a child has disability (e.g. Signposts, Stepping Stones Triple P) improve child wellbeing, reduce children's behaviours of concern, and support child development through enhancing parenting skills and confidence.⁸ Furthermore, in the early childhood period, evidence-based parenting supports have been found to be the most effective interventions for child emotional and behavioural problems – with this pattern evident across a diverse range of groups, including children with disabilities.⁹

Supporting parents is key to improving outcomes for children with a disability

Research has shown that children's development, health and wellbeing, including during their early years, is significantly dependent on the quality of parenting.¹⁰ Parenting practices that are nurturing, positive and responsive are linked with a variety of improved outcomes for children.¹¹ Importantly, parenting skills can be 'learned' and are not 'fixed' – with the right supports and environments, parents can acquire the knowledge, approaches and strategies they need to best support their child's wellbeing and development.¹² It is for all these reasons that it is critical to support parents throughout their parenting journey – and so that both children and parents can thrive.

A critical success factor in supporting families on their parenting journey is the provision of parenting support and interventions, which the evidence tells us is a key strategy for improving outcomes for children with a disability and their families – both now and into the future.¹³ Parenting support can play a critical role in helping to enhance the wellbeing of parents¹⁴ – and we also know that parental wellbeing is vital for supporting stronger outcomes for children and families.¹⁵ A wealth of research also shows that interventions that improve parenting knowledge, skills and confidence are amongst some of the most effective ways of supporting child wellbeing and improving child developmental trajectories.¹⁶

Supporting adults in their parenting role has also been found to produce a diverse range of improvements for families of children with a disability, including enhancements in various domains of child development (e.g. language/communication, social, daily living skills, behaviour, social, emotional), and fostering happier relationships and improved functioning between family members.¹⁷ There are a range of evidence-based parenting programs for children with a disability that have been shown to lead to positive outcomes.¹⁸ For example, there are parenting programs for children who are neurodiverse that have been shown to produce lasting improvements in children's skill development and daily functioning, as well as reductions in concerning behaviours and increased participation in their communities.¹⁹ These parenting programs have also been found to have positive effects on both parent and child wellbeing.²⁰

⁷ Doyle et al. (2023)

⁸ Doyle et al. (2023); Hudson, Cameron & Matthews (2008); Mazzucchelli et al. (in print)

⁹ Doyle et al. (2023); Gardner, Montgomery & Knerr (2016); Michelson et al. (2013); Ruane & Carr (2019); Spencer, Topham & King (2020)

¹⁰ Davidov & Grusec (2006); Davis-Kean (2005); Mazzucchelli et al. (in print); Morris, Criss, Silk, and Houttberg (2017); Repetti, Taylor & Seeman (2002)

¹¹ Jeong et al. (2021)

¹² FrameWorks Institute (2018); Hackworth et al. (2013; 2017); Parenting Research Centre (2017)

¹³ Doyle et al. (2023); Hackworth et al. (2013); Jeong et al. (2021); Petrovic et al. (2019); Parenting Research Centre (2017)

¹⁴ Doyle et al. (2023)

¹⁵ Parenting Research Centre (2018); Reupert, Maybery, and Kowalenko (2018); Rioseco, Warren & Daraganova (2020)

¹⁶ Doyle et al. (2023); Hackworth et al. (2013); Jeong et al. (2021); Petrovic et al. (2019); Parenting Research Centre (2017); Mazzucchelli et al. (in print)

¹⁷ Mazzucchelli et al. (2023)

¹⁸ Doyle et al. (2023); Mazzucchelli et al. (2023); Mazzucchelli et al. (in print); Hudson et al. (2008)

¹⁹ Mazzucchelli et al. (2023); Mazzucchelli et al. (in print)

²⁰ Mazzucchelli et al. (in print)

There is also emerging evidence of the benefits of digital/online and self-directed parenting supports to a range of parents, including parents of children with disability.²¹

Peer support interventions, such as the MyTime facilitator-guided peer support program coordinated by the Parenting Research Centre and funded by the Australian government through the Department of Social Services, also offer an opportunity for supporting parents of children with disability. Evidence suggests that parents value this type of support and that there are benefits for parents in relation to: self-confidence and improved wellbeing,²² fostering a sense of hope and optimism for the future,²³ and providing a sense of belonging and validation.²⁴ The benefits of peer support intervention likely extend to children with disability themselves. There is a broader and well-established research base demonstrating that parental wellbeing impacts on child wellbeing and development.²⁵

The Parenting Today in Victoria Study – Implications for the NDIS

Increasing numbers of parents are reporting that their child has a disability

The *Parenting Today in Victoria* study provides a comprehensive snapshot every three years of the behaviours, needs and concerns of a representative sample of parents.²⁶

The study reveals important findings relevant to the NDIS Review, particularly in relation to a rise in parent reports of child disability, alongside concerning rates of poor wellbeing among parents of children with disability.²⁷

Table 1 shows the number and proportion of parents reporting their ‘target child’²⁸ had a disability²⁹ across the waves of the survey. The proportion of parents reporting their child had a disability appears to have increased over the past seven years. In 2022, almost one in five parents surveyed reported that their child had a disability. The NDIA will need to consider how it responds to the rising numbers of families likely to be seeking support through NDIS.

Table 1. Number and proportion of parents reporting children with disability, 2016, 2019 and 2022.

Year	2016	2019	2022
Number (proportion)	269 (10.6%)	440 (16.9%)	492 (18.9%)

²¹ Baker et al. (2017); Hinton et al. (2017); Hudson et al. (2003)

²² Sartore et al. (2021); Strawa & Sartore (2023)

²³ Mehta et al. (2019)

²⁴ Chakraborti et al. (2021); Jackson et al. (2018)

²⁵ Rioseco, Warren, & Daraganova (2020); Reupert, Maybery & Kowalenko (2013)

²⁶ Parenting Research Centre (2022): The *Parenting Today in Victoria* survey used computer assisted telephone interviews, using random dialling, to obtain a representative sample of Victorian parents of children aged birth to 18 years. In 2022, over 107, 000 phone calls were made to Victorian households to obtain a sample of 2602 parent (40% fathers). The final sample of parents broadly matched the demographic characteristics of Victorian parents in the 2016 Census. To improve sample representative, the sample was weighted on parent education.

²⁷ Parenting Research Centre (2023)

²⁸ The *Parenting Today in Victoria* survey asks parents to think about a single child of theirs (the one with the most recent birthday), so this data reflects complex needs in the ‘target child’. Hence this data does not tell us anything about the multiple complex needs within a family and underestimates need at the family level.

²⁹ The way ‘disability’ was defined for data from both the 2019 and 2022 waves of the *Parenting Today in Victoria* survey is: ‘children with intellectual or developmental disability or learning difficulties, sensory impairments or Autism Spectrum Disorder’. Due to the way the data was collected in 2016, the definition is slightly different for the 2016 data, when ‘disability’ defined as ‘children with a developmental delay or disability (including intellectual or sensory), and children with a major syndrome (Cerebral Palsy, Downs, Autism, Global delay & other syndromes).

Parents of children with a disability are showing increasing levels of distress – and these levels are higher than for parents of children without a disability

Table 2 summarises rates of parent psychological distress³⁰ in 2022 according to the NDIS age groups, for parents of children *with* and *without* disability. Parents of children with disability reported higher levels of distress compared to parents of children without disability, and this difference was most pronounced for children in the youngest group followed by the oldest age group.

Table 2. The proportion of parents in each distress level in each NDIS child age group in 2022.

Parents of children with complex needs			
	K6 Low	K6 Medium	K6 High
0-6 years	39 (37.50%)	44 (42.30%)	21 (20.20%)
7-14 years	118 (43.20%)	118 (43.20%)	37 (13.60%)
15-18 years	45 (39.50%)	48 (42.10%)	21 (18.40%)
Parents whose target child does not have complex needs			
0-6 years	576 (59.60%)	351 (36.30%)	39 (4.00%)
7-14 years	482 (56.60%)	323 (37.90%)	47 (5.50%)
15-18 years	170 (59.00%)	97 (33.70%)	21 (7.30%)

Psychological distress among parents has increased across the waves of the *Parenting Today in Victoria* survey for parents of children both with and without disability, and parents of children with a disability consistently report higher levels of psychological distress compared to parents of children without a disability. This difference was most pronounced among parents of preschool children (i.e. birth to age 6). In 2022, 42% of parents of children without disability reported at least moderate levels of psychological distress (5% reported serious distress) compared to 59% of parents of children with disability (16% reported serious distress).

These increasing rates of psychological distress among parents of children with a disability likely reflect the broader societal situation whereby more families are experiencing challenges, complexities and have multiple ‘issues’.

The rising rate of parent mental ill-health has important implications for the support needs of children with a disability and their families. Firstly, there is a wealth of research demonstrating that parent wellbeing impacts on child wellbeing and development.³¹ In particular, moderate or high levels of psychological distress in parents has been associated with greater levels of child emotional and social difficulties across time.³² So, if parents of children with a disability are experiencing heightened levels of psychological distress, then there is potential for flow-on effects on the wellbeing of the child themselves.

We also know that parental stress and mental health are key factors that can impact on parenting strategies and practices – as well as on the relationship and interactions between parent and child.³³ For example, parents who are experiencing greater difficulties with their mental health are more likely to show parenting practices that reflects frustration and irritability, and are less likely to be well equipped with positive parenting strategies like praise for desired behaviour.³⁴

³⁰ As measured by the Kessler Psychological Distress Scale (K6), which is a simple self-report measure of psychological distress consisting of 6 questions about a person's emotional state.

³¹ Rioseco, Warren, & Daraganova (2020); Reupert, Maybery & Kowalenko (2013)

³² Rioseco, Warren, & Daraganova (2020)

³³ Deater-Deckard (1998)

³⁴ Parenting Research Centre (2018)

Parent support offerings for families of children with a disability, including parenting programs, offer great promise here, as they have been shown to have positive effects on both parent and child wellbeing, in addition to offering a ‘means to an end’ that can produce lasting improvements in children’s skill development, daily functioning, and community participation via parent-mediated support.³⁵

Many parents of children with a disability are experiencing parenting-related challenges

In addition to their own mental health concerns, parents of children with a disability are reporting higher than usual challenges in other aspects of their lives, including parenting. Our *Parenting Today in Victoria* research found that parents of children with a disability were experiencing a range of parenting-related challenges – and that greater proportions of these parents were experiencing these challenges compared to parents of children without a disability. For example, parents of children with a disability (relative to parents of children without a disability) were more likely to report that:

- Parenting is frustrating (34.0% compared to 16.1%)
- Parenting is demanding (61.6% compared to 48.9%)
- They are often hard on themselves for not being the kind of parent they want to be (49.9% compared to 33.7%)
- They struggle with feelings of guilt or shame about their parenting (24.6% compared to 13.8%)

That the rate of frustration in parenting is almost double that of parents of children without disability is concerning, as frustration in parent-child interactions can be a trigger for negative responses to challenges. Furthermore, the close-to-double the rate of parenting guilt and shame among parents of children with a disability - paired with the finding that one in two of such parents report they are overly harsh on themselves - signals these parents are viewing themselves as ‘not stacking up,’ but are unable to shift this thinking or adjust their parenting to feel better about their situation. Without awareness of, or access to, supports to address this, the impacts of ongoing frustration, guilt and shame are likely to accumulate, with significant consequences for the wellbeing and outcomes of both parent and child.

Parents of children with disability were also less likely to report they had confidence in themselves as a parent, with around 71% feeling confident compared to around 87% for parents of children without a disability. Also concerning was that parenting confidence decreased substantially across the waves (from 2016 to 2022) for parents of children with a disability (87% in 2016, 80.9% in 2019, 71.1% in 2022); in 2022, three in ten parents of children with disability were not feeling confident in themselves as a parent.

These findings highlight the valuable opportunity presented by support offerings delivered to families via parents. These can include peer supports, parenting information and resources (e.g., available online), and parenting programs, which aim to ‘skill build’ parents to provide environments in which their children can thrive. In this way, parent support offerings can be viewed as a ‘means to an end,’ whereby the ‘means’ of supporting parents will ultimately lead to the desired ‘end’ of better outcomes for child health, wellbeing and development. Not only can parent-mediated supports have positive effects on parental wellbeing and parenting confidence, but also on the child’s own wellbeing and development of healthy, adaptive behaviours.³⁶

³⁵ Mazzucchelli et al. (2022); Mazzucchelli et al. (in print)

³⁶ Mazzucchelli et al. (2022); Mazzucchelli et al. (in print)

Current state of the NDIS: Challenges accessing parenting support for families where a child has a disability

A 'drift away' from family-focused approaches

Best practice in supporting children with developmental concerns and/or a disability emphasises a family-focused approach.³⁷ Importantly, a family-focused approach not only incorporates child-focused components, but also family-focused and parent-mediated components, including parenting support and support for family members as individuals (e.g. addressing parental wellbeing).

To illustrate, evidence-based child behaviour support programs such as *'Signposts for Building Better Behaviour'* and *'Stepping Stones Triple P'* are parent-mediated interventions aimed at guiding children towards positive behaviours that will support their development and wellbeing. These programs have demonstrated benefits for children with a disability, as well as other family members.³⁸ These programs hold parents in a central role as interventionists and also encompass parenting support as an important component. When parents play an active role in their child's behaviour support programs, they tend to be regularly interacting with professionals. In turn, these interactions support the development of increased confidence in parents (e.g. in parenting and supporting their child), allow for professionals to provide direct support to parents themselves, and facilitate referrals (where needed) to more-targeted supports for parenting and parental wellbeing support.

Thus, family-focused approaches and parent-mediated behaviour support programs offer valuable parenting support to families of children with a disability, as well as being evidence-based programs that address child needs. Yet the shift to programs and supports that are delivered directly to children by professionals – a consequence of funding models outlined in the existing NDIS guidelines – has fostered a 'drift away' from such evidence-based approaches. While there are certainly clear benefits that arise from the NDIS aim of placing the child with disability at the center and allowing for greater control, choice and tailoring in relation to supports, there is also evidence emerging of unintended consequences of this.³⁹ For example, there is a risk that NDIS supports are not viewed as a tool that supports the child's development in the context of their family. Family wellbeing, including parent wellbeing and child wellbeing, is in jeopardy if parent-mediated supports for the child are overlooked in favor of child-directed therapies. The role of parents as central to the delivery of behaviour support programs within the home has been largely replaced by professional intervention, missing an opportunity to build parental capacity and family autonomy. Best practice disability support models position the professional's role as supplementary and supportive of the parent to the greatest extent possible. Services and professionals should focus on building the capacity and confidence of the parent, rather than considering the child in isolation.

Unfortunately, issues of reduced access to parenting support have been further exacerbated by the shift away from block funding (whereby the offering of family support to families was routine), which means that families, professionals and NDIS planners now require an awareness of family-focused supports and their advantages in order to try to access such support.⁴⁰

We feel that the 'drift away' from family-focused approaches is particularly concerning in the context of the *Parenting Today in Victoria* research finding that parents of children with a disability are demonstrating increasing levels of psychological distress over time. If parents are not receiving the help they need in relation to their parenting and their own mental health needs, then parents are at a greater

³⁷ Dunst, Trivette & Hamby (2007)

³⁸ Ruane & Carr (2019); Tellegen & Sanders (2013)

³⁹ Boaden et al. (2021)

⁴⁰ Mazzucchelli et al. (in print)

risk of poorer wellbeing – which we know from the evidence, in turn, impacts negatively on children’s own wellbeing and developmental outcomes.

Reduced clarity about parenting support as a NDIS-funded activity

Despite the strong evidence base for parenting support and parenting programs that benefit children with disability, it remains unclear to families, professionals, Early Childhood Partners, Local Area Coordinators, NDIS planners and other key stakeholders whether these supports are included as NDIS-funded activities.

There are certainly general statements in the current NDIS Guidelines that appear to suggest that parenting support and parenting programs might be included as supports for children with developmental delays or disabilities through helping families to meet child-focused goals, to build children’s capacity, and to give children the best start to life. For example, The NDIS early childhood intervention guidelines state:

*“... through early childhood intervention, infants and young children **as well as their families** can get specialist supports and services. These services aim to promote the:*

- *child’s development*
- *family and child’s wellbeing*
- *child taking part in their community”⁴¹*

The NDIS early intervention guidelines also state:

*“The **family** is at the centre of all services and supports – the family and early childhood professionals work together in partnership. Services and supports are based on the **family’s needs and choices.**”⁴²*

However, a statement in the guidelines’ section on child protection and family support systems seems to contradict the inclusion of parenting support and parenting programs as NDIS-funded activities. While this issue is discussed in detail in the next section, it is worth recognising the ‘mixed messaging’ that results from the only mention of “parenting programs” within the guidelines being made in a section about the responsibilities of child protection and family support systems.

Given the lack of clarity about whether parent-mediated interventions and parenting support are NDIS-funded activities, it is unsurprising that parents, NDIS planners, service providers and advocates are expressing to us their confusion about what families can access via the NDIS.⁴³ Acceptable NDIS-funded activities should be defined by their ends (e.g. promoting positive child development and wellbeing) rather than their means (i.e. specific activities). Parenting support is an evidence-based intervention for promoting child development and wellbeing, a means to a relevant NDIS ends.

Perceptions that parenting support is a matter for other services

Unfortunately, the lack of clarity in NDIS guidelines about how parenting supports can be funded often means that parenting supports or parent-mediated interventions are perceived by parents, by planners and by services as not to be a funding concern for the NDIS – but rather as a child protection or child and family services matter.

⁴¹ National Disability Insurance Scheme (2023a)

⁴² National Disability Insurance Scheme (2023a)

⁴³ We note that this lack of clarity has fostered various awareness raising efforts by third party organisations in an attempt to increase clarity for parents that parent-mediated supports can be funded to help their child achieve their NDIS goals.

This can mean that families avoid seeking the support they need in order to avoid any potential contact with ‘the system’ that places them under scrutiny; this is a particular concern for families who are most in need of - and who would most benefit from - evidence-based parenting support. For example, parents with cognitive impairment are more likely than other parents to have their parenting capacity questioned - and to have their children removed from their care following contact with family services or with child protective services. Thus, many parents with disability are reluctant to voluntarily nominate themselves for parenting programs, particularly if they can only be accessed via family services or child protection systems.

Perceptions that parenting support is not a NDIS matter are compounded by unclear NDIS guidelines. The only reference to ‘parenting programs’ in the guidelines is made in a section about what the child protection and family support systems are responsible for.⁴⁴ This communicates a message to parents, professionals and other stakeholders that those supports are a responsibility of those systems – rather than of the NDIS.

Misperceptions also exist among some NDIS planners that parenting programs, as well as psychological services, are purely for child mental health or behaviour concerns – and thus responsibility for these programs lies with the mental health system rather than the NDIS. This is particularly concerning given the wealth of evidence demonstrating a range of benefits of parenting programs for both child and parent beyond simply mental health or behaviour.

A ‘hard to navigate’ system

It is well established that the current NDIS system can be difficult for parents to navigate. Not only must parents of children with a disability understand and navigate the complexities of the eligibility requirements and application process – but also steer their child’s journey through a range of obstacles once their child is accepted (e.g. liaising with and advocating for their child with Early Childhood Partners, Local Area Coordinators and NDIS planners to ensure their child’s needs are met, sourcing therapists and navigating waiting lists). Adding to this, parents are constantly required to make high-level considerations and decisions to support their child, such as: what needs and supports should be prioritised, what supports and services are effective, evidence-based, high quality and/or offer ‘value for money.’⁴⁵

This ‘hard to navigate’ system places high demands on parents, creating additional pressures and stressors in an era when parents themselves are reporting higher levels of psychological distress than in the past seven years.⁴⁶ In the context of increasing rates of parent psychological distress in our communities, we are concerned about the gaps in parenting support fundable through the NDIS, which we feel will impact negatively on family wellbeing and therefore on child wellbeing.

Recommendations

1. Parenting support and parent-mediated interventions should be funded activities with clear inclusion in NDIS guidelines and pricing guides.

At the Parenting Research Centre, we believe that NDIS service models should adopt a truly family-focused approach whereby funding can be used to support the **child at the centre** of the family system.

⁴⁴ National Disability Insurance Scheme (2023b): “What are the child protection and family support systems responsible for? General parenting programs, counselling or other supports for families at risk of entering the child protection system, and to the broader community – this includes adjusting these programs to make them suitable for families with disability.”

⁴⁵ Mazzucchelli et al. (2023)

⁴⁶ Parenting Research Centre (2022)

This would involve supporting the people most closely connected to the child to build their capacity to work towards the child's goals.

Parents are their child's most important source of support, as well as being critical 'change agents' and interventionists who are best placed to have a positive impact on their child's development and wellbeing. A wealth of evidence demonstrates the clear benefits of parenting support and evidence-based parenting programs for both children with disabilities and their families. **We recommend that parenting support, including parent-mediated child-focused intervention (via parenting programs), are clearly included as funded activities in the NDIS.**

One of the numerous benefits of parenting support and parenting programs is building the capacity of parents themselves to support their child's development, health and wellbeing. This is why investing in parenting supports and programs that equip and upskill parents also have cost-benefit savings in the long-term through building a sustainable support system for children and families to thrive.

It will also be important that current inequities in NDIS remuneration between parent-mediated and child-directed therapeutic services are addressed so that these services are remunerated at the same rate. This will encourage professionals and providers to offer parent-mediated services, thus helping to increase access to these effective supports and programs for families.⁴⁷

2. The inclusion of parenting support and parent-mediated interventions as NDIS funded activities needs to be accompanied by clear communications.

While the clear inclusion of these supports and interventions as NDIS funded activities will be a critical first step, it will be equally important that this is followed up with appropriate and effective communications that will let stakeholders know that these activities are funded (e.g. parents, Early Childhood Partners, Local Area Coordinators, NDIS planners). Communications strategies could include:

- At a minimum, updating the NDIS guidelines and the 'NDIS Pricing Arrangements and Price Limits' to reflect the inclusion of parenting support and parent-mediated interventions
- Consider what communications activities can be deployed to inform stakeholders of the inclusion of these activities (e.g. alerts to Early Childhood Partners, Local Area Coordinators and NDIS planners).
- Ensure future marketing or communications from the NDIS are aligned in their messaging in relation to these being funded activities.

We also recommend that any communications from the NDIS are informed by the latest research on 'framing' information. A range of evidence-based toolkits have been developed (some of which have been developed with the Parenting Research Centre's support) that provide guidance about framing communications and 'messages' to maximise impact when talking about child development, child wellbeing, the early years, and parenting. These toolkits include:

- *Navigating Waters: Talking about parenting*⁴⁸
- *Raising Community Awareness of Parenting*⁴⁹
- *Framing Child Development and Care in Australia*⁵⁰
- *Moving Early Childhood up the Agenda: A Core Story of Early Childhood Development in Australia*⁵¹

⁴⁷ Mazzucchelli et al. (in print)

⁴⁸ FrameWorks Institute (2018)

⁴⁹ Parenting Research Centre and the Murdoch Children's Research Institute (2017)

⁵⁰ FrameWorks Institute (2014)

⁵¹ L'Hote et al. (2020)

- *Reframing Children’s Mental Health*⁵²

3. Efforts are needed to raise awareness among families of the existence, benefits and access pathways of parenting support.

While parenting support (including evidence-based parenting programs) can offer many benefits for families of children with a disability, there is currently low awareness among parents of the existence and benefits of this effective and valuable support, as well as ‘how to access’ this via non-stigmatising pathways. This is particularly concerning given that parents should be viewed as key decision-makers and ‘gate keepers’ in their child’s NDIS journey. And some of the most vulnerable children and families in our communities are especially at risk of missing out – the fear of scrutiny of their parenting means they are less likely to seek out supports. By normalising access to parenting support through NDIS many more children and parents with disability will benefit from evidence-based family-centred interventions.

There is a clear need for the NDIS to engage in promotion and awareness raising efforts that will help to increase parents’ understanding of the existence, benefits and access pathways for parenting supports.

The NDIS should also engage or partner with organisations or initiatives that are trusted sources of information for families of children with a disability (e.g. the Raising Children Network, Children and Young People with a Disability Australia, Association for Children with a Disability, MyTime) to fund the dissemination information about parenting support and parent-mediated interventions as NDIS funded activities – as well as the benefits and access pathways.

Ensuring that any communications (including documentation) from the NDIA clearly indicates that parenting supports are NDIS-funded will aid in increasing awareness of the existence and benefits of parenting support among parents, planners, Early Childhood Partners, Local Area Coordinators and service providers.

4. Awareness raising and development in the disability workforce in relation to parenting support.

For children with a disability and their families to thrive, disability service providers must be able to respond effectively to their support needs. Currently, there is confusion about what is NDIS-fundable for the ‘missing piece of the puzzle’ (i.e. parenting support) across the disability sector (that is, among Early Childhood Partners, Local Area Coordinators, NDIS planners, NDIS service providers and professionals).

It will be essential that the disability workforce – from the point of intake to assessment – are the focus of communications strategies, awareness raising efforts, and workforce development initiatives about the existence and importance of parenting support. This will equip professionals to appropriately inform and guide parents to access these services. This will be particularly important given that some disability professionals (e.g. NDIS planners) can be viewed as critical ‘gate keepers’ to access.

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