

National Advocacy Collective: Supporting the rights of parents with an intellectual disability

Submission to the NDIS Review

August 2023

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Acknowledgements

We pay our respects to the Traditional Owners of the land on which this submission was written. We acknowledge the deep spiritual connection to this land of Aboriginal and Torres Strait Islander peoples, and we extend our respects to community members and Elders past and present.

We acknowledge and thank the parents with an intellectual disability from the National Advocacy Collective who shared their stories in this submission. This submission has been possible because of your generosity in sharing your experiences.

We also recognise and stand in solidarity with the efforts of self-advocates who have courageously told their stories and worked hard over many years for equality and human rights for all.

About the National Advocacy Collective (NAC)

The National Advocacy Collective (NAC) is a group of people across Australia who support the rights of parents with an intellectual disability.

We know that there are lots of barriers for parents with an intellectual disability. We work together to change things and talk with governments to make positive change happen.

The NAC was started by a small group of allies and supporters of parents with an intellectual disability in 2022.

Parents with an intellectual disability are at the centre of all the National Advocacy Collective's work. Positive Powerful Parents, a self-advocacy group in Victoria, has been part of the group since it began, and other parents have joined since then. We would like to have as many parents with an intellectual disability part of the NAC as possible.

Our goal is to make sure the human rights of parents with an intellectual disability in Australia are recognised and upheld, and that they have the support they need to be the parents they want to be. We want government to change systems so that they are fair and give parents support they need.

We believe that:

- Everyone has the right to parent their children
- People with an intellectual disability should be able to have and raise their children with the support they need
- The rights of people with an intellectual disability to parent should be accepted as part of life, like they are for everyone else.
- Wherever possible, families should be kept together, and have the support to do this safely.

The NAC is made up of the following people and organisations:

- ACT Disability and Aged Care Services (ADACAS)
- Community Living Association
- Developmental Disability WA (DDWA)
- Family Inclusion Network, Southeast Queensland
- Family Inclusion Strategies in the Hunter (FISH)
- Inclusion Australia
- Inclusion Australia Northern Territory (IANT)

- Independent Family Advocacy and Support (IFAS), Victoria Legal Aid
- Intellectual Disability Rights Service (IDRS)
- Kathleen Fitt, RMIT
- Life Without Barriers
- Linda McKey: Family Support Services
- Margaret Spencer, University of Sydney
- Moreton Bay Ability
- NSW Council for Intellectual Disability (CID)
- Parenting Research Centre
- Positive Powerful Parents (PPP)
- Queensland Disability Network
- Queensland Independent Disability Advocacy for Inclusion (QIDAN)
- South Australian Council on Intellectual Disability (SACID)
- Speak Out Advocacy
- STAR Victoria
- Susan Collings, Western Sydney University
- VALID

Further information

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Summary of recommendations

1. The NDIS must adhere to the legislative settings and provide parents access to parenting support through their NDIS plan.
2. The NDIA works with state and territory child protection and disability support services and agencies to prevent the service failures evident in the supports provided to parents with disability, and to ensure that parents can access the supports they need to parent.
3. The NDIA makes and widely disseminates a 'how to' Easy Read guide about the right to access supports for parenting through the NDIS and how people can and do use their funding for parenting support, including how to connect with independent advocacy organisations.
4. Where NDIS supports are in place prior to parenthood, the NDIS must adjust plans for expectant parents with an intellectual disability according to the support needs of that person. As part of this process, expectant parents should be given the opportunity to connect with a relevant independent advocacy organisation.
5. Fund independent information—which should be co-designed by parents with an intellectual disability, who are remunerated appropriately—to help educate parents and expectant parents about what services they could use their NDIS funding for parenting support.
6. Consider an independent inquiry into the treatment of parents with an intellectual disability within the NDIS to build the knowledge and evidence-base of qualitative data to better guide service and policy design.
7. Significantly invest in independent training on the human rights of parents with an intellectual disability across the NDIS and mainstream services relevant to the support needs of parents with an intellectual disability.
8. Any independent rights education and training for the NDIS workforce must be codesigned and led by parents with an intellectual disability, and parents must be remunerated appropriately for their contributions.
9. Fund and promote peer support and self-advocacy programs for parents with an intellectual disability within the NDIS.

10. Work collaboratively with child protection systems across Australia to establish more inclusive and accurate reporting systems.
11. Support research activities aimed at capturing qualitative data about the experiences of parents with an intellectual disability in child protection systems to better inform Australian laws, policies, and service provision.
12. The NDIS must work collaboratively with child protection systems, NDIS and non-NDIS service providers across jurisdictions to provide greater clarity on the responsibilities of these different systems to meet the rights of parents with an intellectual disability and ensure consistent decision making at a national level.
13. The NDIS and child protection systems must work collaboratively with representative disability and children's advocacy organisations, with particular emphasis on First Nations-led and culturally and linguistically diverse-led organisations, to ensure that culturally responsive support is provided to all parents with an intellectual disability before and during contact with child protection.
14. The NDIA must audit and evaluate service providers for ableism and with respect to their responsiveness and rights- and evidence-based practice to the support needs of parents with an intellectual disability.
15. Child protection services review and revise their approach to assessments of parents with disabilities, informed by the experience of parents with disabilities, and provide or seek access to structured supports prior to child removal.
16. Children's Courts review the evidence presented to them by child protection services and insist on the presentation of strength-based reports and assessments, along with clear evidence of support provided to parents prior to the removal of a child on the basis of disability.

Background

Parenting is a fundamental and ordinary part of daily life for millions of Australians, and all parents need and benefit from formal and informal support at different times.

It is well known both empirically and anecdotally that parenting can be one of the most difficult occupations any person can experience—full of many highs and lows, achievements and missteps.

There is an abundance of evidence that demonstrates that ongoing, family-centred, and accessible evidence-based support for the challenging and essential work of parenting leads to better outcomes for parents and children.

Just like other Australian families, people with an intellectual disability can and do parent positively with the right support.

Parents with an intellectual disability have a right to parent and to be supported to parent.

And just like other parents, parents with an intellectual disability encounter challenges, successes and everything in between—that full spectrum of hilarity, distress, joy, and struggle—that is the human experience of birthing and raising children.

Parents with an intellectual disability have the same rights as others to have support through these often-universal experiences.

These rights are articulated in the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD), particularly Article 12—Equal recognition before the law,¹ which affirms the right to make one’s own decisions, and Article 23—Respect for home and the family.²

Among other important rights relating to home and family life, Article 23 expresses that:

1. States Parties shall take effective and appropriate measures to eliminate discrimination against persons with disabilities in all matters relating to marriage,

¹ Article 12—Equal recognition before the law. United Nations Convention on the Rights of Persons with Disabilities. Retrieved from: <https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities/article-12-equal-recognition-before-the-law.html>

² Article 23—Respect for home and family. United Nations Convention on the Rights of Persons with Disabilities. Retrieved from: <https://social.desa.un.org/issues/disability/crpd/article-23-respect-for-home-and-the-family>

family, parenthood and relationships, on an equal basis with others, so as to ensure that:

b) The rights of persons with disabilities to decide freely and responsibly on the number and spacing of their children and to have access to age-appropriate information, reproductive and family planning education are recognised, and the means necessary to enable them to exercise these rights are provided.

Further, the rights of all children to remain with their families and for parents to receive appropriate support for child-rearing responsibilities—except in cases of neglect or abuse where competent authorities lawfully determine separation is in the best interests of the child—are expressed in the United Nations Convention on the Rights of the Child, especially in Articles 9, 16, 18 and 20.³

However, these fundamental rights are not being upheld in Australia, and many parents with an intellectual disability experience discrimination; a lack of coordinated and accessible support; widespread negative attitudes and misguided assumptions about their ability to parent; a lack of resources invested in keeping families together; and are significantly overrepresented within the child protection system.

Despite being a very small percentage of the parental population in Australia at about 0.4%, or around 17,000 parents,⁴ parents with an intellectual disability experience alarming rates of child removal and are overrepresented within the child protection system.⁵

During the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability (the Disability Royal Commission), advocates in almost every jurisdiction reported multiple cases of child protection taking the children of people with disabilities without cause.⁶

This corroborates Australian and international research, which over several decades has consistently identified that parents with an intellectual disability, especially mothers, are

³ United Nations Convention on the Rights of the Child. Retrieved from:

<https://www.ohchr.org/en/instruments-mechanisms/instruments/convention-rights-child>

⁴ Man, W., Wade, C., & Llewellyn, G. (2017). Prevalence of parents with intellectual disabilities in Australia. *Journal of Intellectual & Developmental Disability, 42*(2) 173-179. doi: 10.3109/13668250.2016.1218448.

⁵ McConnell, D. (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 DOI:[10.1111/j.1468-3148.2008.00435.x](https://doi.org/10.1111/j.1468-3148.2008.00435.x);

⁶ Inclusion Australia. (October 2020). Submission to the DRC – the Omnibus. Retrieved from: <https://www.inclusionaustralia.org.au/submission/submission-to-the-drc-the-omnibus/>

overrepresented as subjects of child protection allegations, investigations, and proceedings.⁷

Research shows that child protection practitioners do not work from a rights- and strengths-based lens. The system focuses on the ‘deficits’ and ‘deficiencies’ of the parent, reflecting the ableist and discriminatory mindset that equates intellectual disability with ‘risk’ or ‘incompetency’. These attitudes mean that parents are unlikely to be linked in with support services, and that where those service connections do exist, they rarely meet parents and families’ needs.

This results in devastating consequences for families and communities, including severe human rights breaches, the often-permanent removal of children from their parents, widespread discrimination, and—as a recent research report commissioned by the Disability Royal Commission names it— ‘obstetric violence’.⁸

Parents with an intellectual disability also experience poor early engagement by services and a lack of cross-agency collaboration—for example, between the NDIS and mainstream services, like antenatal education and care, or early-childhood and parenting support services.

There are also broader social and economic factors that disproportionately affect people with an intellectual disability compared with other people with disability and people without disability, and that are likely to present or exacerbate barriers to accessing crucial parenting support. These include:

- Higher rates of poverty and financial hardship⁹
- Lower rates of employment¹⁰
- Increased likelihood of a person’s primary income being a government payment¹¹
- Increased social isolation.¹²

⁷ Callow E., and Jacob, J. (2014). Parental disability in child welfare systems and dependency courts: Preliminary research on the prevalence of the population. *Child Welfare* 93 (6), pp 73–92.

⁸ Libesman, Terri., Gray, Paul., Chandler, Eloise. Briskman, Linda., Didi, Aminath., and Avery, Scott. (2023). Parents with Disability and their Experiences of Child Protection Systems, Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability. Page 2. Retrieved from: <https://disability.royalcommission.gov.au/system/files/2023-07/Research%20Report%20%20Parents%20with%20disability%20and%20their%20experiences%20of%20child%20protection%20systems.pdf>. Page 40.

⁹ Li, J., Brown, L., La. H.N., Miranti, R., and Vidyattama, Y. (2019). *Inequalities in Standards of Living: Evidence for Improved Income Support for People with Disability*. NATSEM, Institute for Governance and Policy Analysis, University of Canberra. Report commissioned by the Australia Federation of Disability Organisations. September 2019.

¹⁰ Inclusion Australia. (2023). Disability Employment Services Quality Framework. Retrieved from: <https://www.inclusionaustralia.org.au/submission/disability-employment-services-quality-framework/>

¹¹ Australian Institute of Health and Welfare. (2022). *People with disability in Australia*. Retrieved from <https://www.aihw.gov.au/reports/disability/people-with-disability-in-australia>

¹² Llewellyn, G., & McConnell, D. (2002). Mothers with learning difficulties and their support networks. *Journal of Intellectual Disability Research*, 46(1), 17-34.

The NDIS is key to Australia’s efforts to meet international human rights obligations under the UNCRPD.

A consistent finding of parliamentary and independent inquiries over the last 20 years is that mainstream and disability support services lack the capacity, rights-based knowledge and training to provide parenting support to parents with an intellectual disability. So far, the NDIS has not addressed this major gap in service provision.¹³

Recent research commissioned by the Disability Royal Commission stated that it was not clear from an extensive literature review that NDIS support is being offered to parents with disability—rather, the emphasis tended to be on providing NDIS support to children involved in child protection systems, rather than to parents.¹⁴

Academics from the University of Sydney note that this lack of support for parents within the NDIS contradicts the inclusion of parents with disability as a priority group in the latest National Framework for Protecting Australia’s Children. As they put it:

“If a mother with intellectual disability is assessed as requiring support with living skills, an NDIS funded support worker may [support] her to buy and prepare meals and do the laundry. But the same worker is often not permitted to teach her how to sterilise her baby’s bottles or wash nappies”.¹⁵

In addition, the division of responsibility between child protection departments and the NDIS is unclear and inconsistent across states and territories. It is unclear in NDIS guidelines where the responsibility for parenting supports lie. Support for parents should be universally available in the earliest stages of family planning or pregnancy, and consistently available throughout a family’s parenting journey—and not, as is often the case, as a result of contact with child protection.

This confusion and inconsistency not only exacerbates barriers to parents accessing specialised services for parenting support, but also tensions and misunderstandings between the two systems.

¹³ Libesman, Terri., Gray, Paul., Chandler, Eloise. Briskman, Linda., Didi, Aminath., and Avery, Scott. (2023). Parents with Disability and their Experiences of Child Protection Systems, Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability. Retrieved from: <https://disability.royalcommission.gov.au/system/files/2023-07/Research%20Report%20%20Parents%20with%20disability%20and%20their%20experiences%20of%20child%20protection%20systems.pdf>

¹⁴ Ibid.

¹⁵ Collings, S., Hindmarsh, G., Spencer M., and Wedgwood, N. (August 2022). Parents with intellectual disability need more support. Retrieved from: <https://www.sydney.edu.au/news-opinion/news/2022/08/19/parents-with-intellectual-disability-need-more-support.html>

For example, we have been told that there is, at times, an ableist perception within child protection that having an NDIS plan is itself a sign of incompetence, and parents are likely to have their 'parenting capacity' questioned. Conversely, if a parent doesn't have an NDIS plan (often for fear of this very judgement), they may be perceived by child protection as being 'irresponsible' for not getting the support they may need.

These issues, coupled with negative community attitudes and a lack of understanding and training on the rights of people with an intellectual disability within mainstream services, means parents with an intellectual disability often:

- Have their parenting capacity questioned or negatively judged
- Receive a lower standard—or total lack—of care in mainstream services
- Are denied supports in their NDIS plan
- Are significantly overrepresented in the child protection system
- Are more likely to have their child removed permanently from their care
- Are less likely to be referred by child protection services to parenting support services
- Are likely to experience differential and/or discriminatory treatment with respect to where, how long and with whom their children are placed following their removal
- Are likely to be met by services and systems with the ableist presumption of incompetence, which results in discrimination and, very often, child removal.¹⁶

These experiences are even more likely for culturally and linguistically diverse parents, and especially First Nations parents, whose present-day lived experiences are interconnected with the continuing intergenerational trauma of the systematic removal of children from their families, culture, Country, and communities during the Stolen Generations.¹⁷ For many First Nations families and communities, the Stolen Generations continue.

¹⁶ Booth, T., Booth, W., & McConnell, D. (2004). Parents with learning difficulties, care proceedings and the family courts: Threshold decisions and the moral matrix. *Child and Family Law Quarterly*, 16, 409-422.

Collings., S. and Spencer., M. (2000). Practices that support parenting by parents with intellectual disability. *Australian Institute of Family Studies*. Retrieved from: <https://aifs.gov.au/resources/short-articles/practices-support-parenting-parents-intellectual-disability#footnote-0010>;

Llewellyn, G., McConnell, D., & Ferronato, L. (2003). Prevalence and outcomes for parents with disabilities and their children in an Australian court sample. *Child Abuse and Neglect*, 27(3), 235-251.

¹⁷ Libesman, Terri., Gray, Paul., Chandler, Eloise. Briskman, Linda., Didi, Aminath., and Avery, Scott. (2023). Parents with Disability and their Experiences of Child Protection Systems, Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability. Page 2. Retrieved from: <https://disability.royalcommission.gov.au/system/files/2023-07/Research%20Report%20Parents%20with%20disability%20and%20their%20experiences%20of%20child%20protection%20systems.pdf>

It is well known that—just like other parents—parents with an intellectual disability can and do parent positively when they receive timely and appropriately-delivered supports, combined with informal assistance from family, friends and allies.¹⁸

Research demonstrates time and again that parents with an intellectual disability do well when they are given “genuine chances to practice new skills in their own home, have training matched to individual need, and receive support from workers who understand them and offer help with things they consider a priority”.¹⁹

The NDIS is key to Australia’s efforts to meet our international human rights obligations under the UNCRPD, and to ensure that every family can thrive.

Our submission puts forward several key recommendations we believe must be implemented as part of the NDIS Review to ensure parents with an intellectual disability can access the support they need in line with Australia’s international human rights obligations.

¹⁸ Collings, S., Grace & Llewellyn. (2017). Home and the social worlds beyond: Exploring influences in the lives of children of mothers with intellectual disability. *Child: Care, Health & Development*, 43(5), 697-708. doi:10.1111/cch.12456;

Collings, S., Strnadová, I., Loblinzk, J., & Danker, J. (2020). The benefits and limits of peer support for mothers with intellectual disability affected by domestic violence and child protection. *Disability & Society*, 35 (3), 413-434. doi:10.1080/09687599.2019.164715;

Tarleton, B., & Turney, D. (2020). Understanding ‘successful practice/s’ with parents with learning difficulties when there are concerns about child neglect: The contribution of social practice theory. *Child Indicators Research*, 13, 387-409. <https://doi.org/10.1007/s12187-019-09682-y>;

Libesman, Terri., Gray, Paul., Chandler, Eloise, Briskman, Linda., Didi, Aminath., and Avery, Scott. (2023). Parents with Disability and their Experiences of Child Protection Systems, Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability. Retrieved from: <https://disability.royalcommission.gov.au/system/files/2023-07/Research%20Report%20%20Parents%20with%20disability%20and%20their%20experiences%20of%20child%20protection%20systems.pdf>

¹⁹ Collings, S., Spencer., M., Wedgwood, N., & Hindmarsh, G. (2022). Supporting the Woman, Supporting the Mother: Final Report. Research Centre for Children and Families, University of Sydney. p. 20.

Key issues

In this section we put forward current evidence to describe five issues parents with an intellectual disability face in relation to the NDIS, and our related recommendations to the NDIS Review. These recommendations are listed throughout this section and summarised on page 5 of this submission.

We also highlight evidence from parents with an intellectual disability through several case studies contributed by members of the NAC, who are parents with an intellectual disability.

While there is an ever-growing body of academic research on the experiences of parents with an intellectual disability in Australia and internationally, lived experience from parents can often be absent in the literature.

Yet parents with an intellectual disability are the experts of their own lives. It is parents themselves who have the clearest and most robust understanding of the issues they and their families face.

Their stories provide essential insights into understanding how the NDIS is and isn't working.

Importantly, they also clearly demonstrate that the barriers and challenges parents experience relate to systemic issues (economic, social, political and cultural), and not to a person's intellectual disability. This is crucial evidence that demonstrates the utter necessity and breadth of systemic change that is needed so parents with an intellectual disability can exercise their right to parent with privacy, dignity and without discrimination and prejudice, on an equal basis with others.

The NDIS Review must meaningfully recognise these issues and urgently implement our recommendations to bring Australia in line with rights and evidence-based practice, and to meet Australia's obligations under the UNCRPD.

1. Parents with an intellectual disability cannot consistently access parenting support through the NDIS

As we have mentioned earlier in this submission, a consistent finding of parliamentary and independent inquiries over the last 20 years is that mainstream and disability support services lack the capacity, rights-based knowledge and training to provide parenting support to parents with an intellectual disability. So far, the NDIS has not addressed this major gap in service provision.²⁰

Recent research commissioned by the Disability Royal Commission stated that it was not clear from an extensive literature review that NDIS support is being offered to parents with disability—rather, the emphasis tended to be on providing NDIS support to children involved in child protection systems, rather than to parents.²¹ While some parents may access support through their NDIS plans, many cannot.

Because of these issues, accessing support for parenting has become a lottery, not a right.

Furthermore, parents have a well-founded fear that their children will be taken from them if they are assessed to have a disability and are therefore deemed a risk to their child or children. Inability to access individualised, rights-based supports that can help them cope—particularly as they may struggle more than the average parent due to the various structural inequities a parent with a disability is likely to face—can mean they end up in a crisis that could have been avoided with timely, appropriate interventions. Australia’s child protection processes discriminate against parents with disability, and internationally, Australia is not alone.²²

However, as we have noted earlier in this submission, Australia has obligations to meet the human rights of parents with disability no matter where they live and regardless of the inconsistencies that may be present across different jurisdictions.

²⁰ Libesman, Terri., Gray, Paul., Chandler, Eloise. Briskman, Linda., Didi, Aminath., and Avery, Scott. (2023). Parents with Disability and their Experiences of Child Protection Systems, Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability. Retrieved from: <https://disability.royalcommission.gov.au/system/files/2023-07/Research%20Report%20%20Parents%20with%20disability%20and%20their%20experiences%20of%20child%20protection%20systems.pdf>

²¹ Ibid.

²² Collings, S., Spencer., M., Wedgwood, N., & Hindmarsh, G. (2022). Supporting the Woman, Supporting the Mother: Final Report. Research Centre for Children and Families, University of Sydney.

The NDIS promised a different approach to disability supports. It passed choice and control to the individual, with plans built around achieving their life goals and supports to ensure their disability was no longer a barrier to achieving those goals.

Sadly, this has not been the experience of many parents with disability, and particularly those with intellectual disability. Many state-based disability and family support services have dried up, and those who do have NDIS plans often find they are prevented from achieving their parenting goals through inconsistent and arbitrary decisions of plan managers who decree that core and capacity building supports cannot be used for parenting.

This is counter to the purpose of the *NDIS Act 2013*, which has a main objective of providing all Australians who acquire a permanent disability before the age of 65 and which substantially impacts how they manage everyday activities, with the reasonable and necessary supports they need to live an ordinary life. An ordinary life includes being a parent, as this is a normal part of life.

Despite the promises that the NDIS would deliver an equitable and rights-based disability care system that would sit alongside and complement state-funded services, it is increasingly obvious that neither the NDIS nor state funded programs are providing or funding parenting and early intervention services that can support parents with intellectual disability.

These issues are exacerbated by making disability services a consumer market comprised of individual consumers and service providers, meaning NDIS plans are developed for the needs of the participant as an individual, not their needs as a parent.

A parent with disability may receive support with living skills which might fund a support worker to buy and prepare food for the parents, but will not allow the support worker to extend this to include the child or children. The support worker may wash up dishes, but will not be allowed to sterilise baby bottles. And that same worker may do laundry for the parent, but be instructed not to wash the children's clothes.

This is a perversity that separates the needs of the parent as a person with disability who needs and receives support, from their needs as a parent. The NDIS is therefore guilty of failing to provide the person-centred support for a parent with disability even though parenting is a fundamental human right and a legitimate life goal.

This is recognised in Libesman et al's recent report for the Disability Royal Commission that states "...it is apparent that the current manner in which the NDIS is administered makes it difficult for parents with disability to access the supports and entitlements they need."²³

Some parents have been able to access supports that have enabled them to keep their child or children in their care, but this seems to be the exception, not the rule. It can also depend on the attitude of the child protection workers assigned to that family. One team may be willing to accept that the necessary supports are in place, while another may question the legitimacy of the provision of supports and seek to have them disregarded by the court, or worse, removed by NDIS plan review.

Recommendations

1. The NDIS must adhere to the legislative setting and provide parents access to parenting support through their NDIS plan.
2. The NDIA works with state and territory child protection and disability support services and agencies to prevent the service failures evident in the supports provided to parents with disability, and ensure that parents are able to access the supports they need to parent.
3. The NDIA make and widely disseminate a 'how to' Easy Read guide about the right to access supports for parenting through the NDIS and how people can and do use their funding for parenting support, including how to connect with independent advocacy organisations.

²³ Libesman, Terri., Gray, Paul., Chandler, Eloise. Briskman, Linda., Didi, Aminath., and Avery, Scott. (2023). Parents with Disability and their Experiences of Child Protection Systems, Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability, p.96.

2. There is inconsistency between the NDIS Act and how the NDIS operates

There is inconsistency between what the *NDIS Act*—which gives effect to the NDIS (Support for Participants) Rules 2013—says, and the day-to-day operation of the NDIS, including what participants are aware they are entitled to through their NDIS supports.

The key inconsistency is that the principles of the Rules, which articulate the expectations of NDIS and other service systems, do not translate to the support parents can actually get (and are entitled to) through the NDIS.

Schedule 1 of the Rules, amongst other points, provides guidance on whether a support is more appropriately funded or provided by another (mainstream) system as part of that system's "universal services obligation or in accordance with reasonable adjustments required under a law dealing with discrimination on the basis of disability".

It also states that these considerations are:

Derived from the Principles to determine the responsibilities of the NDIS and other service systems, agreed to by the Council of Australian Governments, and dated Friday 19 April 2013.²⁴

These Principles to determine the responsibilities of the NDIS, as agreed on by the Council of Australian Governments (the COAG agreement) provide the basis for the *NDIS Act* and subsequent NDIS (Support for Participants) Rules 2013.

The COAG agreement included the following key points, which set the expectations of the NDIS in providing support to families, including parents with disability, under the current legislative setting. The following is quoted directly from the COAG agreement, with emphasis added.

Applied Principles:

- The NDIS will be responsible for support for children, families and carers required as a direct result of the child's or parent's disability, ***including supports that enable families and carers to sustainably maintain their caring role***, including community participation, therapeutic and behavioural supports, additional respite, aids and equipment and supports to help build capacity to navigate mainstream services.
- The ***NDIS and the systems providing child protection and family support will work closely together at the local level to plan and coordinate streamlined services for individuals requiring both child protection***

²⁴ *NDIS Act 2013* (Cth). www.legislation.gov.au/Details/F2013L01063

and/or family support and disability services recognising that both inputs may be required at the same time or that there is a need to ensure a smooth transition from one to the other.

Reasonable and Necessary NDIS Supports for Eligible People:

- Funding disability-specific family supports, which are required due to the impact of the person’s impairment/s on their functional capacity, ***including for parents with disability.***
- Disability-specific and carer parenting training programs both for when the child has a disability, ***or the parent has a disability.***²⁵

The model set by the legislative context, including the above excerpts from the COAG agreement, demonstrate that a fundamental expectation of the NDIS is to provide parenting support, and where relevant to provide these in collaboration with child protection systems.

Yet, it is clear that parents do not receive parenting support through the NDIS, and as other parts of this submission demonstrate, the interfaces between NDIS and other service systems are unclear, which creates and exacerbates negative outcomes for families.

Recommendations

4. Where NDIS supports are in place prior to parenthood, the NDIS must adjust plans for expectant parents with an intellectual disability according to the support needs of that person. As part of this process, expectant parents should be given the opportunity to connect with a relevant independent advocacy organisation.
5. Fund independent information—which should be co-designed by parents with an intellectual disability, who are remunerated appropriately—to help educate parents and expectant parents about what services they could use their NDIS funding for parenting support.

²⁵ Department of Social Services. (2015). Principles to determine the responsibilities of the NDIS and other service systems. Retrieved from: www.dss.gov.au/sites/default/files/documents/09_2021/ndis-principles-determine-responsibilities-ndis-and-other-service-1.pdf

3. Parents with an intellectual disability experience negative attitudes and discrimination within the NDIS

The conflation of disability and risk is one of the most explicit forms of discrimination parents with disability face.

Disability Royal Commission (2023). Research Report—Parents with disability and their experiences of child protection systems, p. 2.

There is a widespread, ableist presumption of ‘incompetence’ or ‘risk’ associated with parents with an intellectual disability in relation to their ‘capacity’ to parent.

However, this has been debunked time and again by a plethora of national and international research.

This research clearly shows that there is no evidence of a causal link between parenting incapacity, or likelihood of abuse or neglect, and intellectual disability.²⁶

Yet many parents with an intellectual disability experience negative attitudes and discrimination in society at large, and this extends to the NDIS itself. Parents experience indirect and direct judgement, differential treatment and discrimination from NDIS planners, individual support workers, or other parts of the disability service provider workforce.

Several clear examples of these judgements and negative attitudes that misguidedly call into question the ‘competence’ of parents with an intellectual disability were included in the Independent Advisory Council’s 2019 report to the NDIS.²⁷ We urge the NDIS Review Panel to consider the recommendations made in that report, as many of them are yet to be implemented.

The perception that intellectual disability is in itself a ‘risk’ to one’s children or results in an ‘incompetent’ parenting ability—aside from being manifestly untrue, ableist, and creating a tremendously unjust double standard between parents with and without an intellectual disability—is itself disabling. Those perceptions create structural barriers to parents accessing support that meets their needs, and to ensuring resources are invested in keeping families together.

²⁶ Lamont, A., and Bromfield, L. (2009). Parental intellectual disability and child protection: key issues. *Australian Institute of Family Studies*. Retrieved from: <https://aifs.gov.au/resources/policy-and-practice-papers/parental-intellectual-disability-and-child-protection-key>

²⁷ Independent Advisory Council for the NDIS. (2019). NDIS support for participants who are parents. Retrieved from: <https://static1.squarespace.com/static/5898f042a5790ab2e0e2056c/t/5f1a5e5f446e9f2897911caf/1598501122938/NDIS+support+for+participants+who+are+parents+%28September+2019%29+Paper.pdf>

These judgements also ignore and delegitimise the very real structural realities parents with an intellectual disability disproportionately experience compared with other people with disability and people without disability.

These are systemic issues that present major barriers to parents in being able to access parenting support:

- Higher rates of poverty and financial hardship²⁸
- Lower rates of employment²⁹
- Increased likelihood of a person's primary income being a government payment³⁰
- Increased social isolation.³¹

Even when negative attitudes or discrimination do not occur explicitly, parents with an intellectual disability very often face implicit or indirect attitudinal barriers to accessing NDIS supports.

This is because their rights to parent—plus the many interconnected structural barriers parents with an intellectual disability are likely to be experiencing—are not acknowledged or meaningfully addressed in any way.

Being made invisible in this way is often how, as many researchers have noted, parents with an intellectual disability fall through the cracks of the NDIS and mainstream support services.³²

The NDIS Review has already put forward³³ a more contemporary understanding of 'risk', recognising the historic belief—along with all its continuing contemporary manifestations—that risk is a quality inherent in having a disability. This is a good starting point.

However, there is far more to be done to counter historic prejudices and build rights-based knowledge throughout the NDIS workforce (as well as in mainstream services) that 'risk' largely results from external conditions and circumstances. That is, other peoples' views, attitudes, actions, or systemic failures to uphold human rights and provide safe places to live, work, socialise and belong.

²⁸ Li, J., Brown, L., La. H.N., Miranti, R., and Vidyattama, Y. (2019). *Inequalities in Standards of Living: Evidence for Improved Income Support for People with Disability*. NATSEM, Institute for Governance and Policy Analysis, University of Canberra. Report commissioned by the Australia Federation of Disability Organisations. September 2019.

²⁹ Inclusion Australia. (2023). Disability Employment Services Quality Framework. Retrieved from: <https://www.inclusionaustralia.org.au/submission/disability-employment-services-quality-framework/>

³⁰ Australian Institute of Health and Welfare. (2022). *People with disability in Australia*. Retrieved from <https://www.aihw.gov.au/reports/disability/people-with-disability-in-australia>

³¹ Llewellyn, G., & McConnell, D. (2002). Mothers with learning difficulties and their support networks. *Journal of Intellectual Disability Research*, 46(1), 17-34.

³² Collings, S., Hindmarsh, G., Spencer M., and Wedgwood, N. (August 2022). Parents with intellectual disability need more support. Retrieved from: <https://www.sydney.edu.au/news-opinion/news/2022/08/19/parents-with-intellectual-disability-need-more-support.html>

³³ Particularly in its recent 'Participant Safeguarding Proposals Paper':

This explains the widespread view that a parent having an intellectual disability may be seen as an intrinsic deficit or inferiority. This misguided attitude can, and does, diminish a person's humanity, dignity, and autonomy. It stigmatises individuals, families, and whole communities, and makes people less safe.³⁴

Parents with an intellectual disability have a right to parent, and to get the support they need to parent with privacy, dignity and without judgement or discrimination.

For the NDIS to be able to support people in the way it was envisioned, and in a way that supports (and not hinders) Australia's international human rights obligations, the following recommendations must be implemented.

Recommendations

6. Consider an independent inquiry into the treatment of parents with an intellectual disability within the NDIS to build the knowledge and evidence-base of qualitative data to better guide service and policy design.
7. Significantly invest in independent training on the human rights of parents with an intellectual disability across the NDIS and mainstream services relevant to the support needs of parents with an intellectual disability.
8. Any independent rights education and training for the NDIS workforce must be codesigned and led by parents with an intellectual disability, and parents must be remunerated appropriately for their contributions.
9. Fund and promote peer support and self-advocacy programs for parents with an intellectual disability within the NDIS.

³⁴ Our Watch & Women with Disabilities Victoria. (2022). Prevention of violence against women and girls with disabilities: Background paper. Melbourne, Australia: Our Watch.

4. Parents with an intellectual disability and their children are overrepresented in the child protection system, which interacts inconsistently with the NDIS across jurisdictions

There is limited data on the numbers and experiences of parents with disability, including people with an intellectual disability, in the child protection system. Data collection systems used by child protection services in Australia do not consistently record or publish the number of parents with disability within these systems.

As well as breaching Article 31 of the UNCRPD,³⁵ this lack of adequate data collection has led to a major gap in understandings about parents with disability within child protection systems across states and territories.

This knowledge gap also means, as Libesman et al's report says, "attempts to design policy, services and infrastructure supportive of people with disability's rights to parent with privacy, dignity and without prejudice, are compromised".³⁶

Recommendations

10. Work collaboratively with child protection systems across Australia to establish more inclusive and accurate reporting system
11. Support research activities aimed at capturing qualitative data about the experiences of parents with an intellectual disability in child protection systems to better inform Australian laws, policies and service provision.

³⁵ Article 31 requires state parties to 'collect appropriate information, including statistical research data, to enable them to formulate and implement policies to give full effect to' the human rights articulated in the UNCRPD.

³⁶ Libesman, Terri., Gray, Paul., Chandler, Eloise. Briskman, Linda., Didi, Aminath., and Avery, Scott. (2023). Parents with Disability and their Experiences of Child Protection Systems, Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability, p.2. Retrieved from: <https://disability.royalcommission.gov.au/system/files/2023-07/Research%20Report%20-%20Parents%20with%20disability%20and%20their%20experiences%20of%20child%20protection%20systems.pdf>

Despite this significant knowledge gap, research over a number of decades shows that parents with an intellectual disability are overrepresented in child protection systems around Australia.

During the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability (the Disability Royal Commission), advocates in almost every jurisdiction reported multiple cases of child protection taking the children of people with disabilities without cause.³⁷ This corroborates with Australian and international research, which has consistently identified that parents with disability, especially mothers, are overrepresented as subjects of child protection allegations, investigations and proceedings.

This finding is not new.

In Victorian child protection cases first investigated in 1996-97, cases in which a parent had an intellectual disability were almost twice as likely than cases where parents did not have an intellectual disability.³⁸

In reviewing 285 court files in two children's courts in New South Wales in 2000, researchers found that 8.8% of cases featured a parent with an intellectual disability.³⁹

Research suggests that factors contributing to this over-representation include discrimination and a lack of accessible information and support services in the antenatal period and beyond.

Libesman et al found that “decades of entrenched approaches to child protection have ignored and discriminated against parents with disability”.⁴⁰ In particular, the authors highlight:

- Parents with disability are significantly more likely to have their children removed from their care than parents without disability
- Parents with disability experience differential treatment with respect to where, how long and with whom their children are placed following their removal

³⁷ Inclusion Australia. (October 2020). Submission to the DRC – the Omnibus. Retrieved from:

<https://www.inclusionaustralia.org.au/submission/submission-to-the-drc-the-omnibus/>

³⁸ Allen Consulting Group. (2003). Protecting children: The Child Protection Outcomes Project. Melbourne: Victorian Department of Human Services. Retrieved from

<http://www.allenconsult.com.au/publications/download.php?id=301&type=pdf&file=1>

³⁹ McConnell, D., Llewellyn, G., & Ferronato, L. (2000). Parents with a disability and the NSW Children's Court. Sydney: University of Sydney. Retrieved from: https://aifs.gov.au/sites/default/files/publication-documents/issues31_0.pdf

⁴⁰ Libesman, Terri., Gray, Paul., Chandler, Eloise. Briskman, Linda., Didi, Aminath., and Avery, Scott. (2023). Parents with Disability and their Experiences of Child Protection Systems, Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability. Page 22.

- Child protection authorities are less likely to work towards reunifying parents with disability and children or to refer parents with disability to parenting support services
- For many parents with disability involved in the child protection system, the removal of their children from their care is permanent
- First Nations parents with disability experience all of the above to an even greater extent
- Similarly, these experiences are magnified for cultural and linguistically diverse parents with disability, but there is little published research on the experiences of this cohort.⁴¹

The authors of that research report also put forward a suite of recommendations, which we fully endorse and urge the NDIS Review to consider in terms of how the proposed changes to the child protection system may impact the NDIS.⁴²

In particular, we wish to highlight their recommendation that:

Investment in support services must be proportionate to the engagement of parents with disability with child protection agencies and distributed in accordance with the demography of clients. Particular attention must be directed to equity in funding for First Nations and culturally and linguistically diverse parents with disability. Services must be provided by organisations staffed by disability and culturally competent staff and services. First Nations-led commissioning approaches must be developed to direct investment for service provision to First Nations families and communities.⁴³

The authors also detail the ambiguous relationship between child protection systems, mainstream parenting support services and the NDIS.

Like all parents, parents with an intellectual disability may require additional support with their parenting. As we have mentioned earlier in our submission, we strongly believe this support should be tailored to individual needs.

However, when parents are in contact with child protection systems, accessing funding and supports can be very difficult: accessing supports requires interface with multiple agencies which are very often inaccessible and not inclusive of people with an intellectual disability.

⁴¹ Libesman, Terri., Gray, Paul., Chandler, Eloise. Briskman, Linda., Didi, Aminath., and Avery, Scott. (2023). Parents with Disability and their Experiences of Child Protection Systems, Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability, p.2.

⁴² Ibid., Chapter 12.

⁴³ Ibid., Recommendation 11, p.292.

Parents may face a number of bureaucratic barriers and complex navigation of different systems that do not interface well.

Once children are removed from parents, parents' rights to support are often ignored as child protection authorities focus services and resources on children and carers.⁴⁴

However, this focus on children and carers to the exclusion of the rights and support needs of parents fails to account for:

- The potential harm caused to children through removal
- The benefit of safe restoration of families if possible
- The rights of children to be supported to remain safely at home
- The rights of parents with an intellectual disability to be supported to safely look after their children.⁴⁵

Further, within the systems themselves there is immense confusion about which agency is responsible for providing parenting support to parents with an intellectual disability, and this results in some parents not receiving the support that would enable them to look after their children.

This also has implications for how these agencies interact with other services, such as hospital maternity systems.

A recurrent theme in Libesman et al's research is the intersection of experiences of domestic and family violence and contact with child protection systems. Researchers found that many parents are subject to scrutiny and intervention from child protection authorities after seeking help to deal with domestic and family violence, where very often the outcome is child removal. As the researchers put it: "that is, being subject to state violence—rather than assistance and support to address the experiences of domestic and family violence".⁴⁶

This only underscores the need for greater clarity between the responsibilities of child protection systems and the NDIS; the dire need for capacity building towards rights education among the workforce of all these systems; and the key role of the NDIS to enable parents to access the parenting support they need according to their fundamental human rights under the UNCRPD.

⁴⁴ Libesman, Terri., Gray, Paul., Chandler, Eloise. Briskman, Linda., Didi, Aminath., and Avery, Scott. (2023). Parents with Disability and their Experiences of Child Protection Systems, Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability, p.296.

⁴⁵ Ibid.

⁴⁶ Ibid., 291.

Recommendations

- The NDIS must work collaboratively with child protection systems, NDIS and non-NDIS service providers across jurisdictions to provide greater clarity on the responsibilities of these different systems to meet the rights of parents with an intellectual disability and ensure consistent decision making at a national level.
- The NDIS and child protection systems must work collaboratively with representative disability and children's advocacy organisations, with particular emphasis on First Nations-led and culturally and linguistically diverse-led organisations, to ensure that culturally responsive support is provided to all parents with an intellectual disability before and during contact with child protection.
- The NDIA must audit and evaluate service providers for ableism and with respect to their responsiveness and rights- and evidence-based practice to the support needs of parents with an intellectual disability.

5. The danger of deficiency-based reports and how they are used by the child protection system

Access to the NDIS for core and capacity building supports is based on a deficit model. This requires the participant to highlight all the areas in which their disability impairs them, in order to then articulate goals and the supports that are needed to achieve them. While this is effective in the context of the NDIS and how it helps people with disability express choice and control in the supports they can access, these reports can, if used in another context, have devastating consequences. This is highlighted in the case of parents with disability, and particularly parents with intellectual disability when they come into contact with child protection services.

Child protection services operate in the context of risk to the child. In Victoria, for example, grounds for a protection application to the Children's Court are often based on risk of physical injury, emotional or psychological harm, sexual abuse, and neglect. This risk approach means that child protection services will focus on deficits, and a known disability of a parent can be escalated to a potential harm to the child. Ableist attitudes do not see the harm to the family unit in removing a child, and in many cases a newborn, to out-of-home care.

Deficiency reports, such as neuropsychological reports carried out by professionals in an unnatural setting, focus on what the parent is unable to do. Couple this with being a new parent who has had their child removed from them and only sees them at supervised contact sessions, often in the offices of child protection services. They are then expected to demonstrate "near perfect" parenting skills in a natural manner, despite the primary care of their child having been given to someone else against their will and therefore making it impossible to practice and improve their skills.

These reports become dangerous weapons in a court setting, where a magistrate is required to make a decision about where a child lives based on the evidence provided. If that evidence is skewed towards what the parent cannot do, the magistrate will have little choice but to agree to the child being cared for by others.

All families have their own blend of available supports, strengths and challenges, and families where one or more parent has a disability are no exception. All new parents need help and support, but not all parenting programs are appropriate for parents with disabilities.

Appropriate assessments need to be carried out with care and over time within a stable family environment, including attachment assessments and in-home parenting capacity assessments. Adaptive functioning assessments are better suited to identifying existing

strengths, areas for improvement, and changing needs over time, instead of the blunt instrument of the point in time neuropsychological report.

Over-reliance on the neuropsychological assessment pulls the focus of child protection services to the deficits, not the strengths, and maintains the risk frame on the impairment, not the possibilities presented by appropriate and timely supports.

Recommendations

- **Child protection services** review and revise their approach to assessments of parents with disabilities, informed by the experience of parents with disabilities, and provide or seek access to structured supports prior to child removal.
- **Children's Courts** review the evidence presented to them by child protection services and insist on the presentation of strength-based reports and assessments, along with clear evidence of support provided to parents prior to the removal of a child on the basis of disability.

Case study: Raising Children Network – parenting with an intellectual disability

The Raising Children Network recently published information about parenting with intellectual disability, plus 3 videos in which parents with an intellectual disability share their stories about using the NDIS to get parenting support.

This was developed in collaboration with parents with disability and NAC members Linda McKey, AASW accredited disability social worker, and Dr Catherine Wade, Principal Research Specialist, Parenting Research Centre.

Please use the links below to access the videos.

[Ash's story: using the NDIS as a parent with intellectual disability](#)



'Helped me with my parenting, was able to keep my children': in this video, Ash explains that support from the NDIS helped her to achieve important things for herself and her family. Ash has used support from the NDIS to learn to drive and to have support workers at home to help with day-to-day life. In the future, Ash would like to use support to go to mothers groups. Ash says that it's important to speak up for yourself and say what you want to get from the NDIS.

<https://raisingchildren.net.au/grown-ups/videos/ashes-story-using-the-ndis-as-a-parent-with-intellectual-disability>

[Richelle's story: using the NDIS as a parent with intellectual disability](#)



Richelle has 5 children, ranging in age from 13 to 18 years. She also has intellectual disability. For Richelle, the best thing about parenting is just being with all her kids.

Richelle found out about the NDIS from workers at government agencies, who encouraged her to apply and helped her to fill out forms. Through the NDIS, Richelle gets help from a support worker. The support worker gives Richelle parenting information and helps Richelle in meetings. For example, the support worker helps Richelle talk about her parenting and family life.

<https://raisingchildren.net.au/grown-ups/videos/richelless-story-using-the-ndis-as-a-parent-with-intellectual-disability>

Chantelle's story: using the NDIS as a parent with intellectual disability



Chantelle has 3 young children. She also has intellectual disability. For Chantelle, the best thing about parenting is the cuddles.

In this video, Chantelle says that she found the NDIS very confusing to start with, but a support worker helped her get started. Through the NDIS, Chantelle gets help from a support worker to learn about parenting. Chantelle's support worker also helps her with school, hospital and doctor's appointments, shopping, and parent groups. Chantelle says it's important to build trust with your support worker, so you can share your needs and feelings with them.

<https://raisingchildren.net.au/grown-ups/videos/chantelles-story-using-the-ndis-as-a-parent-with-intellectual-disability>

Case study: Laura Kirby, Family Inclusion Strategies in the Hunter (FISH)

FISH is a parent-led organisation providing support and advocacy with parents and families involved in child protection and out-of-home care systems.⁴⁷

I am a peer worker with the FISH peer support and advocacy service in Newcastle, New South Wales. I have lived experience of child removal and restoration/reunification in the NSW child protection system. I navigated the system and faced huge barriers. My kids are home with me now and I want to help others. Me and my team provide peer support and advocacy with parents and family, including with parents with intellectual disability.

FISH's Committee and membership is made up of parents, carers, and community members, some with lived experience and some with qualifications and experience in fields like social work. We all have a passion for change and for family inclusion in child protection and out-of-home care.

As a peer worker with FISH, I provide support and advocacy with parents, including a phone peer support line, peer court support, and peer run workshops to help parents navigate the system and get their kids home safely. In the future, we hope to increase and expand the support we provide for parents. For example, we want to offer parents support and advocacy when they have meetings with the Department of Communities and Justice (DCJ). We are finding this is where parents are really needing and wanting support.

We're also doing systemic work. For example, we recently did a listening campaign with other stakeholders in the system. Our peer team, our Committee, and some parents we support organised a workshop so that DCJ and OOHHC [out-of-home care] managers could listen to parents. Then the whole group discussed how the system needs to change and improve.

At FISH we aim to build up the parents to learn skills and self-advocate. We want them to have more control of the situation they are in and to know their rights and their children's rights. I know from personal experience that once the kids are taken, it feels like control and respect have gone out the window.

FISH gets some funding from philanthropy. We also charge fees when we do workshops and training with agencies. We don't have enough money and we get no government funding. We really want to partner with government to bring parent and family peer advocacy and support to more people. It is really badly needed.

⁴⁷ Along with several other people from FISH, Laura is a member of the NAC.

The power of peer support

As peer workers we use our personal experience of child protection and out-of-home care systems to assist others. We communicate our stories skilfully and with care. We work with other organisations to educate and raise awareness.

Peers understand what it's like. As someone that's been through the system and sat in that court, the exact same courtroom, I can connect with parents in a way that other workers can't. That's the *power of peer advocacy and peer support*. We have a similar experience so the shame parents feel is lessened, we can create a safe space.

Peer support and advocacy is a skilled job. It's not enough to just connect parents with lived experience to other parents. Peer workers need training and supervision. At FISH we spend a lot of time in individual and group supervision, and we do a lot of training. This is really important for the parents we serve; it helps us to respond to diversity among parents and in the community, and it helps us succeed in our jobs and to build careers.

FISH is not the only place doing peer support and advocacy in the child protection system but there is not enough and most parents with intellectual disability in Australia will not get support and advocacy from a peer. We need to fund and support peer parent and family advocacy in child protection in Australia.

What needs to change

Everybody's journey is different. Every family looks different. Every story is different. *We urgently need services that can accommodate those differences and diversities, including peer support and advocacy.*

Earlier intervention is needed that genuinely stops children from being removed. Including helping to support parent's mental health and wellbeing. I've seen the persistence in parents with intellectual disability, how hard they fight to keep the children safe and how much they love their kids. But the services don't match the need and they don't work together. One lady I spoke to recently, she's doing everything she can. She has support from the NDIS and they are helping her to find a job and with accommodation. *But they're not helping with parenting.* The NDIS treats her as if she is not a parent and the child protection system treats her as if she should be able to parent without any help at all.

Parents need support that respects our rights and helps us where help is needed. Parents might need education and someone to come to the home for an hour a day or more. They might need help with parenting skills, shopping, and budgeting. Help with doctor's appointments, appointments for the child's early development, transport, psychology. Whatever is needed to help the parent and the child to thrive. Looking for and getting help with parenting is something everyone needs, including people with intellectual disability and their children.

The everyday things that people take for granted can make a huge difference. For example, going to playgroups, community support, access to one-on-one parenting courses. Parents need someone that they can ring in those early stages of having a baby and just say: “hey, I need help with this”.

Non-judgemental, early-intervention support

I know from experience that if you say that you need NDIS because your kids have medical needs, then child protection systems can use your financial status against you, saying that you don't have enough money for kids. If I could change one thing about the current system, it would be having non-judgemental and early intervention.

For example, I had someone there with me when I had my third baby. At first they were there all day, they supported me. If I needed help with anything or if I didn't know something they'd tell me. They could give me reassurance and just emotionally support me. In my experience as a peer worker, it's the same for parents with intellectual disability. As peers we don't judge. It's not our job to judge, it's our job to support the parent.

Case Study: parent with an intellectual disability, Queensland Disability Network and Family Inclusion Network

This parent has a powerful voice and works for positive change within the disability, child safety and domestic and family violence sectors. They are a Forgotten Australian who sustained her acquired brain injuries in care as a child. The following is in her words.

I have a disability

I'm a woman with a disability. I'm a mum with a disability for [over] 22 years...Being a mum with a disability I'm not being heard or listen [to] my rights. Me, being a mum with a disability has been taken from me by child safety, children's court judges, DCPL...Judging discriminating people in the community. I'm not being treated with respect me being a mum and a woman with disability. I have been and continue to be punished and discriminated for having children as a woman with disability. I had to put up with child safety since birth till now...Child safety have said to me heaps of times over the years [that] I'm a burden to the society's welfare systems, taxpayers, Medicare, support services.

All of my children were taken into care. Child safety failed to notify me back in August 2017 that one of my daughters had a SIDS episode. She was 4-5 weeks old and the carer was sleeping with her. I found out in court and child safety maintained my disability was the cause of my daughter's SIDS episode. My children have had multiple injuries in care. My 8 year old has a permanent brain injury that was sustained on June 21, 2021. Child safety do not seem to recognise her ABI. When this child was 6 months old child safety said to me my child is a burden to taxpayers, and Centrelink and doctors. Child safety gave me a hard time for not having an abortion. Child safety did the same thing for my next 2 daughters.

I have children in child safety's care. Child safety are not letting me see my children on their birthdays, my birthdays, mother's days, Easter, Christmas days...I do not have my rights being a mum and a woman with a disability to look after my children at home. I got NDIS support people to help me to look after my children in my home. Child safety have labelled me a neglect[ful] mum over the years...A lot of people in the community don't have the qualifications to support me. Child safety has stopped working toward reunification with me. Child safety wants to keep my children in child safety's care till they are 18 years old. Me being a mum and a woman with a disability I should have the rights to raise my children in my QLD housing home. Mums in the community who don't have disabilities have their rights to raise their child or children in their homes... My children miss being with me every day. My children want to come home to me...

I am a mum and a woman with a disability for life. I love all my children and I miss my children every day. I want my children home.

Supporting Mums with Disabilities/NDIS and Housing to team up together

The NDIS assessment was used against me for my children not to return home. Systems are failing us. I met with an occupational therapist who was supposed to do an assessment on my parenting abilities. She did not believe I had an ABI and said I needed to get mental health support. IQ based assessments should not be allowed for parents with intellectual disabilities. Support workers have been discriminatory toward me because I have kids in care.

I have come up with a good brainstorm idea to support mums with disabilities and their children and for NDIS to fund this program in their NDIS plan.

- Have a supporting communal home for mums with disabilities and their children with mentors
- Have parenting disability programs: disability circle of security program, children's development programs, children's behavior programs
- Healthy, balance nutritionist eating and cooking healthy meals on a budget programs
- Cleaning programs, budget savings skills programs
- Planning outings and activities budget programs
- Personal care programs
- Life skills workshops to build confidence

The mums with disabilities and their children to be supported for 6 months in the communal homes and outreach mentors support when they leave the communal homes and go back to their homes with their children.

Also, NDIS should offer cars to families as children are not allowed in support workers' cars. There should be family packages and NDIS covers the rego, insurance, roadside assistance etc.

The reason I want this support program [is] to put a stop to child safety and the children's courts removing children from parents with disabilities. This program is not to [be] funded by child safety not to be paid by child safety. I don't trust child safety and parents with disabilities they don't trust child safety.

The reason child safety shouldn't fund it [is because] they don't support parents with disabilities. They discriminate parents with disabilities...I have been blamed in all areas: a

woman with a disability, a survivor of domestic and family violence, and being raised in State care.

Case study: parent with an intellectual disability

Barriers to getting support

It's been really hard to get support. I found when I had the kids at home, I was linked in with a support service. But when the kids were removed, they couldn't continue to support me. So I've only just got linked in with another service now. But that was not easy—it took a lot of time. There was so many reports and paperwork to go through.

It's really important in the child protection system that things happen quickly, because the child protection system's timing is so tight. If parents don't get the support they need when they need it, this has really big consequences and makes it so much harder for parents.

I'm still waiting for my NDIS application—after about a year I have finally linked in with another service to support me to get on the NDIS. Someone from that service came to the courts with me to give me that support, but before that I didn't really have support people in place. Like once the kids were taken, everyone just kind of disappeared.

That is a really big barrier. A lot of places just won't take you unless you've got your kids at home. Once you don't have kids in your care, the support system is very low.

Once they're taken into care, you're 'flagged', and people start looking at you differently. There's a lot of stigma about having your children removed, and that leads to discrimination. So services are taken away right when you need them most.

I've found it really hard to trust different services who have supported me over the years. I put my trust in different people and those people end up going against me, it's sometimes just backfired.

Getting the support you need

Some things that have been helpful in the supports I have now is that someone has come with me to court, which was a good support. It also meant that it showed the Magistrate and others that I was getting support. Especially because I have to show the court that I am able to look after my kids and I've got support around me.

It's actually really hard to do that because the evidence that parents need is so difficult to collect and show. It is hard to know what the Department wants and what the court wants. So having support in court is a way for us to show that I can engage with services, I can get support and I can be a Mum to my kids.

The majority of the time I have done that alone, and it's so much harder to do it alone.

Honesty and trust

If I could change one thing about the child protection system and other systems, it would be about honesty and trust. I don't think a lot of people in these systems are honest with parents at all.

When your children are removed, child protection gives you all these papers. I think that shouldn't happen. You go through so many emotions when that happens, at that time I wasn't thinking of sitting and reading a paper. I don't think child protection realises that when our children are removed, we go through grief and so many other emotions. They just expect you to sit down and read all these papers.

It's so triggering at times because one minute I was told by health services I was doing everything right, but then the Department of Child Protection were saying something different. At the time I was living on 2 hours sleep a night, doing my best, I just would have appreciated more honesty and more help to process the information.

I feel like parents with an intellectual disability get judged and we are discriminated against. A lot of parents with an intellectual disability are just not believed because of the stigma of disability but also the stigma of having your kids removed.

Different people within the child protection system will use things against you too—when I was told it wasn't right because I didn't have my daughter with me all the time. But then they told me that I needed to get childcare. I felt like I couldn't do anything right. Your choices can be used against you and misinterpreted.

I wish people would just give all parents a chance to show that we are capable of parenting. I think everyone can parent—we just need the right supports in place early on to help us.

Case study: Research Centre for Children and Families—interviews with mothers with an intellectual disability

In 2021-22, the Research Centre for Children and Families interviewed mothers with an intellectual disability as part of research about the intersection between the NDIS and state-based family support services in NSW.

The videos included in the links below demonstrate the common experiences and challenges faced by parents with an intellectual disability across multiple states.

The videos embedded below were co-designed with parent co-researchers.

More interviews can be found at: <https://rccf-parenting-disability.sydney.edu.au/resources-and-publications/videos/>





Other stories from advocates working with parents with disability

1. The importance of a strengths-based approach

Good working relationships between parents and practitioners, and between practitioners in both Child Protection and the NDIA, can influence outcomes for parents and children. A few years ago, a family with parents who have intellectual disability were subject to Child Protection involvement and removal of the children. The children had been out of home for a fairly lengthy time when a new Child Protection case manager transferred in from Disability Services.

The parents were not accessing the NDIS. The parents felt considerable distrust of Child Protection staff and were hesitant to provide details about their disability and day-to-day needs to the case manager for fear it would be further misinterpreted and used against them, and that their children would never come home.

Despite the parents' requests for review of the case and having an advocate assist them, which in other cases has sometimes resulted in Child Protection practitioners becoming somewhat obstinate, this case manager persevered with respect for all. She assisted the parents to submit an application to the NDIS. She acted as an intermediary and advocate with the NDIA, and generally promoted discussion of how to meet this family's needs without using this information to further damn the parents.

Once granted participant status with the NDIS, the same worker continued to provide support to ensure that day to day management of the family home and the parents' needs could be achieved—even to the point of helping to identify and link in with potential services and options. These options were not forced upon the family but presented as a choice which required skill in allaying fears, supported decision making and strength-based practice.

She worked through issues of which support was for the parents and which was for the children but successfully brought in a range of well targeted service system responses from education, disability and the child and family welfare fields. The worker maintained a balanced approach and also helped to improve relationships within the family and within the service system. She remained calm and objective at all times. She didn't denigrate the parents to the children's carers or vice-versa. Neither did she denigrate parts of the service system to other services.

It was refreshing to observe a practitioner truly implement a strength-based approach. The children came home with support and a stronger overall family and community network.

This case stands in contrast to another case in a different region where in a meeting between the NDIA, Child Protection and a parent, the two sets of workers spent the meeting yelling at each other about why their organisation was not responsible for supporting the parent. No positive outcomes have been achieved for this second parent.

2. Access to parenting supports via the NDIS

Geraldine (not her real name) is a woman in her 30s who has had a number of children taken into care. Geraldine lives with intellectual disability, and previously had a number of intersectional issues that presented a risk to her children, including unstable housing and family violence. When Geraldine found she was pregnant again, she wanted her experience this time to be different. She had stable housing, was not in a violent relationship, and had a NDIS package that gave her the supports she needed to live independently. Geraldine's support circle, including her support coordinator, plan manager and disability advocate, worked with her during her pregnancy to ensure her plan was amended to provide the supports she would need when the new baby arrived.

Unfortunately for Geraldine, child protection workers had a fixed, negative and ableist view of Geraldine's capacity. They questioned the legitimacy of the NDIS supports that were being presented as evidence to the court that she would have the supports she needed to care for her new baby. Child protection rang the NDIS to query these supports, claiming they were out of scope for NDIS, and presented the same argument to the court. On the direction of the court, child protection then instructed NDIS to provide a letter stating that Geraldine's NDIS supports could not be used to support her parenting. Geraldine's baby is currently in out of home care, and she is devastated that despite all she has done to prove her ability to care for her child, she is denied the opportunity to be a mother.