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

Submission to the Department of Social Services' Consultation on the NDIS Supports Rule

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, recognising that many of the human rights issues faced by parents with intellectual disability disproportionately impact First Nations parents with intellectual disability. We acknowledge and thank First Nations self-advocates for their continued advocacy for human rights for all.

We acknowledge and thank the parents with an intellectual disability from the National Advocacy Collective who shared their lived experience and expertise – 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.

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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:

National Advocacy Collective – Supporting the rights of parents with intellectual disability		
National	First Peoples Disability Network (FPDN)	
	Inclusion Australia	
	Life Without Barriers	
	Parenting Research Centre	
	Women With Disabilities Australia (WWDA)	
ACT	ACT Disability and Aged Care Services (ADACAS)	
	ACT Down Syndrome and Intellectual Disability	
NSW	Family Inclusion Strategies in the Hunter (FISH)	
	Family Inclusion Network, Southeast Queensland	
	Intellectual Disability Rights Service (IDRS)	
	Dr Susan Collings, Western Sydney University	
	Dr Margaret Spencer, University of Sydney	
	Prof Iva Strnadová, University of NSW	
NT	Inclusion Northern Territory	
QLD	Community Living Association	
	Family Inclusion Network (FIN) Southeast Queensland	
	Queensland Independent Disability Advocacy Network (QIDAN)	

	Moreton Bay Ability
	Parent2Parent
	Queensland Disability Network (QDN)
	Dr Kathy Ellem, University of Queensland
	Linda McKey, Family Support Services
SA	South Australian Council on Intellectual Disability (SACID)
TAS	Speak Out Advocacy
VIC	Independent Family Advocacy and Support (IFAS), Victoria Legal Aid
	MacKillop Family Services
	Positive Powerful Parents (PPP)
	Victorian Advocacy League for Individuals with Disability (VALID)
	STAR Victoria
	Dr Kate Fitt, RMIT
WA	Developmental Disability WA (DDWA)
	Prof Melissa O'Donnell, Australian Centre for Child Protection
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Further information and contact

Inclusion Australia currently provides secretariat support for the NAC. You can contact the NAC via policy@inclusionaustralia.org.au

About this submission

We thank the Department of Social Services for the opportunity to respond to this consultation and share our urgent concerns about the exclusion of parenting supports from the NDIS Supports list.

This submission explicitly responds to the following question in the Consultation Paper:

"Are there any areas of the NDIS Supports rule (or lists) you think need to be changed?"

We warmly invite further conversations about any of the issues raised in our submission via the contact on page 6.

Executive Summary

It is already very difficult for parents with intellectual disability to access the supports they need both within and outside the NDIS to support their parenting and keep their families together.

Many face complex barriers that prevent them from having their support needs acknowledged and met in a timely, coordinated and rights-based way.

These barriers include:

- Discrimination and negative assumptions about their ability to parent
- Inconsistent and unclear responsibility between systems like child protection and the NDIS
- Inaccessibility or denial of relevant supports in their plans
- The individualised structure of the NDIS, which does not account for parenting as a normal life activity
- Widespread lack of understanding among planners, providers and services about the support needs and rights of parents with intellectual disability.

These barriers have led to widespread breaches of human rights, including the often permanent separation of children from their parents, disproportionate surveillance and intervention from child protection systems, and a near-total absence of coordinated, early intervention support. Despite an established body of evidence on what works, the NDIS has so far failed to deliver appropriate and equitable support for parents with intellectual disability.

In this context, the recent decision to explicitly exclude parenting supports from the list of supports that **are NDIS supports** represents a serious and deeply concerning development.

Based on the NAC's significant collective lived and professional experience, we believe this decision will exacerbate the very issues that parents and advocates have spent years trying to overcome and cause significant harm to families and communities.

Far from clarifying roles or improving access, this exclusion will further entrench discrimination, fracture service delivery, and deny parents with intellectual disability the supports they need to live an ordinary life. It also stands in direct contradiction to Australia's obligations under the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD); the United Nations Convention on the Rights of the Child; and the objects and principles of the *National Disability Insurance Scheme Act 2013*, including to "enable people with disability to exercise choice and control in pursuit of their goals".

Without urgent changes to the NDIS Supports Rule to explicitly include parenting supports, these harmful outcomes will continue and worsen, despite decades of evidence and repeated calls for reform. We therefore call on the Department of Social Services to urgently implement our recommendations below.

Our recommendations

Include the following supports related to child protection and family support to the list of supports that **are 'NDIS supports**':

- a. Parenting programs
- b. Child protection services required by families who have entered, or are at risk of entering, the relevant State or Territory statutory child protection system
- c. General parenting programs, counselling or other supports for families, which are provided to families at risk of child protection intervention and to the broader community, including making them accessible and appropriate for families with disability.

Further detail and supporting evidence for this recommendation are provided below.

Parenting is a normal part of life and a human right

The NDIS is key to Australia's efforts to meet international human rights obligations for all parents with disability, including intellectual disability, under the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD).

Yet the barriers to accessing NDIS supports for parenting are already high, and we are deeply concerned that excluding parenting supports from list of supports that **are NDIS supports** – with no appropriate alternative support pathways currently in place, including through <u>foundational</u> <u>supports</u> – will exacerbate these barriers.

At the heart of the NDIS is the promise that people with disability will have the support they need to live an ordinary life. Parenting is a normal part of life for millions of Australians, and all parents need and benefit from formal and informal support at different times.

These rights are articulated in the UNCRPD, particularly Article 12—Equal recognition before the law¹ 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, 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 UN Convention on the Rights of the Child, especially in Articles 9, 16, 18 and 20.³

Barriers to accessing timely and appropriate supports

These fundamental rights are not being upheld in Australia, and many parents with 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.⁴

These inequities were recently explored at length in a detailed <u>report by the Queensland Public</u> <u>Advocate</u>, which was tabled in Queensland Parliament in June 2025. While the report has a state-based focus, decades of research demonstrate that the issues it identifies are national.

With this being the current state of supports for parents with intellectual disability, the decision to remove parenting supports from the NDIS needs urgent reconsideration.

Despite being a very small percentage of the parental population in Australia at about 0.4%, or around 21,000 parents,⁵ parents with intellectual disability experience very high rates of child removal and are overrepresented within the child protection system.⁶

A consistent finding of parliamentary and independent inquiries – together with academic research and the self-advocacy of parents with intellectual disability – is that mainstream and disability support services lack the capacity, rights-based knowledge and training to provide parenting support to parents with intellectual disability. ⁷ So far, the NDIS has not sufficiently addressed this major gap in service provision.

Research commissioned by the Disability Royal Commission found that, based on an extensive literature review, it is unclear whether NDIS support is being provided to parents with disability. The focus appears to be primarily on supporting children involved in child protection systems, rather than on meeting the needs of parents themselves.⁸

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 <u>National</u> <u>Framework for Protecting Australia's Children.</u> 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". 9

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 current state of confusion and inconsistency creates barriers to parents accessing specialised services for parenting support, which also contributes to tensions and misunderstandings between the two systems. For example, 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 a 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. In many cases these discriminatory attitudes also extend to the NDIS itself.

However, research clearly shows that there is no evidence of a causal link between parenting incapacity, or likelihood of abuse or neglect, and intellectual disability. 10

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 National Disability Insurance Agency (NDIA).¹¹

These attitudes are themselves disabling. They create structural barriers to accessing appropriate support and prevent the investment needed to help families stay together. This is often how, as many researchers have noted, parents with an intellectual disability fall through the cracks of the NDIS and mainstream support services.¹²

For many parents, the lack of access to timely supports that genuinely meet needs results in crisis.

Over several decades, Australian and international research has consistently demonstrated that parents with intellectual disability, especially mothers, are overrepresented as subjects of child protection allegations, investigations, and proceedings. ¹³ These experiences are even more likely for 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. ¹⁴

Involvement in child protection systems can result 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 research commissioned by the Disability Royal Commission called it – 'obstetric violence'. These systemic failures are explored in <u>Positive Powerful Parents</u> (PPP)'s recent short film, *Compare the Parents*.

Parenting supports must be accessible through the NDIS

It is well known that, just like other parents, parents with intellectual disability can and do parent positively when they receive timely and appropriately delivered supports, combined with informal assistance from family, friends and allies, and equal access before the law.¹⁶

Research demonstrates that parents with 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".¹⁷

Inability to access individualised, rights-based supports that genuinely meets needs can mean they end up in a crisis that could have been avoided with timely, appropriate interventions.

We are very concerned that excluding parenting supports from the NDIS Support Rules will compound the barriers to accessing timely and inappropriate supports, as well as existing inequities and harms disproportionately experienced by parents with intellectual disability.

As the <u>NAC outlined in our recent submission</u>, foundational supports must contribute to addressing these gaps when they are rolled out. However, they are not yet available, and uncertainty remains about how they will meet the specific needs of parents.

In the meantime, and in the continued absence of adequate support in mainstream systems, the explicit exclusion of parenting supports from the NDIS risks deepening inequity, causing further harm, and taking Australia even further away from our international human rights obligations.

We strongly recommend amending the NDIS Support Rules to explicitly include parenting-related supports, in line with the recommendation on page 9 of this submission.

This change is essential to ensure that people with intellectual disability are genuinely supported to live ordinary lives on an equal basis with others, including as parents.

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