Representative Communication

Urgent Submission under the Optional Protocol to the UNCRPD; Immediate Risk of Harm, Limited Domestic Remedy and Intervention Sought

To:

Committee on the Rights of Persons with Disabilities

Office of the High Commissioner for Human Rights (OHCHR)

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From:

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A Disabled People's Organisation operating in accordance with Article 4(3) of the UNCRPD

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1 Introduction

The Australian Neurodivergent Parents Association (ANPA) submits this urgent representative communication under Article 1 of the Optional Protocol to the UN Convention on the Rights of Persons with Disabilities (UNCRPD).

ANPA is a Disabled People's Organisation that acts consistently with Article 4(3) of the Convention, although it is not formally recognised by the Australian Government. We assert that our recognition under Article 4(3) and the context of immediate and significant risk is sufficient grounds for The ANPA to seek swift intervention from the Committee.

We allege that recent national reforms to Disability policy and funding have been undertaken in serious and significant breach of Australia's obligations under the Convention and that these breaches have created immediate and continuing risks to life, dignity and wellbeing for Disabled people.

2 Summary of the Violation

Beginning in 2024, the Australian Government introduced major reforms to the National Disability Insurance Scheme (NDIS). This began prior to the passing of the NDIS Amendment Bill (2024) but has intensified since that time.

It is difficult to convey the extreme level of distress this has induced for Disabled Australians, as the consequence of this legislation has manifested in widespread cuts to supports. These cuts have already resulted in thousands of Disabled children and adults having supports stripped from their lives with no meaningful replacement supports.

Removal of supports with no replacement has led to a situation of increasing neglect, isolation, vulnerability to exploitation, abuse, violence, injury and death for Disabled Australians. Our collective quality of life is rapidly diminishing, and the psychological toll felt by our community is immeasurable.

The ANPA calls out to the UNCRPD Committee to intervene to safeguard us, now, before more harm is done. We do so on behalf of and in solidarity with all of our Disabled peers, regardless of Disability type.

We allege that these reforms were developed and implemented through a process that appeared consultative but, **in practice,** excluded Disabled People's Organisations from **meaningful participation and influence.**

While DPOs, including ANPA, engaged in consultations in good faith, their recommendations and warnings have been consistently overridden and ignored in practice. The Government has instead relied heavily on the advice of large charities, consultancy firms and service-provider alliances whose financial and institutional interests align with fiscal restraint rather than human-rights compliance.

We allege that the Government commissioned RedBridge Group Australia to provide political-communications advice on how to "sell" and defend cuts to disability supports, while DPO recommendations to pause, review or redesign reforms to prevent foreseeable harm were ignored.

Members of the NDIA's own Participant Reference Groups have described the process as "co-design theatre", confirming that participation has been largely symbolic and without effect. Such conduct fails to satisfy Article 4(3) and General Comment No 7, which require consultation to be effective, influential and representative.

3 Distorted Process Producing Preventable Harm

We allege that the structural marginalisation of representative voices has led directly to harmful and regressive outcomes.

The reform process has prioritised cost containment and administrative convenience over rights-based design.

Decisions have been made without the lived-experience knowledge necessary to foresee practical and ethical consequences. As a result:

• Tens of thousands of participants have been removed from the only significant system of Disability support in Australia.

• Individualised, person-centred supports for young children who are Autistic or have developmental differences are under imminent threat, with the Federal Government and Minister Mark Butler moving to replace them with block-funded, provider-controlled programs.

This contradicts the principles of autonomy and inclusion established by the Convention. Inquiry processes into this announcement are already marked by heavy provider, charity and NGO influence.

We are also concerned by the discriminatory manner of this approach; which this targets one cohort of children based on Disability type and removes individualised supports for them, without any endorsement from our community.

• Travel-funding and pricing changes have caused regional service markets to collapse, producing widespread “service deserts” and market distortion; reducing choice and control for Disabled people.

• Preventable deaths, mass hospitalisation, and the movement of young Disabled people into aged care facilities has increased due to this regression of supports. Significant suffering is occurring after people have been left without food, therapy, medication or needed 1:1 daily-living assistance. We are extremely concerned this will result in further harm over time.

- Disabled parents and Disabled children are being stripped of supports with no alternatives, breaching Article 23 and placing them at heightened risk of child protection intervention; due to supportive scaffolding that preserves family function falling away. We are especially concerned for families where a parent is funded for psychosocial Disability support or where a child is Neurodivergent; scaffolding around families where intergenerational Disability is a feature is essential for family preservation.
- Cuts to Auslan instruction have increased, with children and adults being routinely denied any more than 1 hour per week of support, and in some cases none - despite fluent Auslan acquisition requiring up to 80 hours per week of support. Language deprivation is regarded as a form of child abuse by the Deaf community; and we amplify the concerns expressed to us by Deaf advocates for their community’s children.

These outcomes were repeatedly predicted by DPOs and other advocates but were nevertheless allowed to occur.

The resulting harm is therefore a **completely foreseeable** and preventable consequence of a decision-making process that deliberately excluded Disabled people in substance, even if not in form (***substantia praevalet formae***).

4 Community Testimony Regarding the Scale and Nature of Harm

The community-run Harm Tracker has documented more than four hundred direct reports from participants, families and providers, supplemented by data showing that between 32,000 and 37,000 thousand participants have lost meaningful access to supports since July 1st, 2025.

Eighty percent of respondents report deterioration in mental health, social isolation or suicidal distress. Many have lost therapy, support workers, transport and nutrition supports. Providers confirm that numerous regions, particularly rural and remote areas, are now manifesting areas without any viable service coverage.

A further example of psychological distress and risk of harm can be found in the continued pushing of The Inklings Program, suggested for roll-out under the Thriving Kids initiative and already in operation in Western Australia (WA) and South Australia (SA).

Inklings was introduced without independent and appropriate safety evaluation or ethical oversight from DPROs despite repeated warnings from us. ANPA's Red Alert report of 3 October 2025, tabled with the Thriving Kids Inquiry, documents foreseeable risks, including trauma and self-harm among Autistic mothers with impacts foreseen on children.

We have raised these and other concerns repeatedly with government, and with the provider that owns the program, yet there has been no effort made to stop the rollout of the program.

Efforts made to alter the program have not altered the basic mechanisms and aims of the program, by the provider's own admission. It appears that any changes have, again, been in form and not substance. DPROs have not had access to, nor been consulted transparently the program and our government has not listened to our concerns about the many breaches of the UNCRPD it poses. This is unacceptable and grave.

We know too from the Harm Tracker that Disabled people utilising support to live independently in the community are being pressured by the NDIA to give up this autonomy, and to move back into shared accommodation - against their wishes. This is an incredibly serious regression that must be stopped immediately.

Every Disabled person has the right to live with dignity and support in the community, with choice and control over their own life.

5 Procedural History

A Notice of Concern - Breach of the UNCRPD was lodged on 26 August 2025 with Ministers for Disability and Health.

No substantive response or corrective action has been received or taken.

The Thriving Kids Inquiry has declined to publish or acknowledge many submissions from Disabled People's Organisations while promoting those of large NGOs and consultancy firms.

Government communications continue to describe the reforms as beneficial despite extensive evidence of harm that will result from a return to block funded programs for this cohort of children, and the strongly and broadly expressed opposition of the Autistic community in Australia.

6 State Knowledge and Deliberate Exclusion

We allege that the Australian Government acted with knowledge of foreseeable harm and intentionally marginalised representative organisations.

Internal documents released under the Freedom of Information Act, specifically the NDIA Incoming Minister Brief (FOI 24 25-1973 page 5 of 58), reveal that **senior officials anticipated community opposition and characterised those concerns as emotion rather than legitimate policy critique.**

The document states verbatim:

> "This is a significant program of reform, across not just the NDIS, but the broader disability ecosystem. The change impact will be **felt** deeply [s47C – deliberative processes] particularly over the next 2 to 3 years as the most significant changes roll out. … An example is the action which calls for 'participants who need 24 7 living supports being generally funded at a 1 3 support ratio'. This recommendation has caused much **angst** in the disability community, as it has brought back **fears** of returning to the group homes of the past."

This language trivialises legitimate rights-based objections from Disabled people and their organisations as mere "angst". It demonstrates an institutional decision to dismiss representative advocacy as irrational.

Other examples include the fact that **DPROs issued a joint statement with DROs after the announcement of the Thriving Kids initiative, stating that they were not consulted and had no knowledge of the announcement prior**; and the fact that multiple members of NDIS Participant Reference Groups have said they feel senior executives bring them pre-determined decisions for them to "rubber stamp" and not influence.

We allege that this constitutes constructive discrimination and bad-faith consultation, contrary to Articles 4(3), 5 and 29 of the Convention and to General Comment No 7 paragraphs 23 to 25.

7 Regression from Rights to Charity

We allege that the Australian Government, together with large charities, consultancy firms and peak bodies, is leading a policy shift backwards, toward block-funded and program-based service models. Transcripts and evidence from the Thriving Kids Inquiry confirm that these peaks have advocated strongly for a return to block funding and program based supports as a preferred framework for delivering supports.

This will also mean the broader loss of other supports, such as support workers in home; tailored approaches; and the end of accessible, free allied health support with no lifetime limit for young children. This model of early support is a pillar of the NDIS and attempts to erode or excise it threaten the future of the Scheme. Early, individualised and free support was always intended to be part of the Scheme and must remain so.

Many Disabled people oppose this direction and our DPROs are critical and concerned. The Neurodivergent Parent community is almost unanimous in opposing the move.

We know our history; the NDIS was established to *replace block-funded, provider-controlled systems* with individualised and flexible funding that upholds autonomy, choice and control.

Moving back to block funding contradicts the purpose and spirit of the Convention, which recognises that human rights cannot be realised through charity, pathologisation or segregation.

We allege that this deliberate shift constitutes a **policy regression from the rights-based model achieved through the Convention and the NDIS Act and is a corruption of the Act.** It violates Article 4(2), which prohibits retrogression in the enjoyment of recognised rights, and Article 28, which guarantees an adequate standard of living and social protection. It also undermines Article 19, which affirms the right to live independently and be included in the community.

The direction now being advanced by government-funded peak bodies demonstrates how consultation structures have elevated non-representative voices while diminishing the influence of Disabled People's Organisations, while purporting to listen.

This imbalance of power has produced reforms that erode human-rights protections and restore provider control over the lives of Disabled people.

To this we say: no.

We will never go back.

8 Legal Basis for Escalation

The conduct described above, taken cumulatively, amounts to violations of:

- Article 4(3) Failure to ensure active, influential consultation through Disabled People's Organisations.

- Article 4(2) Regression from previously realised rights.
- Article 5 Discriminatory treatment and delegitimisation of representative voices.
- Article 7 Failure to protect children affected by loss of supports.
- Article 10 Violation of the right to life through foreseeable and preventable deaths.
- Article 19 Loss of community living and autonomy.
- Articles 24 and 26 Denial of educational and habilitation supports.
- Article 28 Failure to maintain an adequate standard of living.
- Article 29 Suppression of Disabled people's participation in public and political life.
- General Comment No 7 paragraphs 23 to 25 Systemic substitution of representative organisations with NGOs and consultancies constitutes structural distortion and bad faith.
- Optional Protocol Article 1 Continuing harm and absence of effective domestic remedies justify urgent, representative admissibility.

ANPA respectfully requests that the Committee consider referral of this matter to the International Court of Justice for an authoritative interpretation of State obligations under Articles 4(3) and 4(2).

9 Remedies Requested

1 A finding that Australia has breached Articles 4(3), 4(2), 5, 7, 10, 19, 24, 25, 26, 28 and 29 of the Convention.

2 Immediate interim protective measures under Rule 64 to suspend harmful pricing and travel reforms, all eligibility reassessments; and restoration of all supports cut since October 2024 with transitional NDIS plans in place pending independent review of those assessments by a third party and in partnership with Australia's DPROs.

3 Establishment of an independent harm-monitoring mechanism incorporating the Harm Tracker.

4 A directive requiring the Government to restore equality of decision-making power to Disabled People's Organisations.

5 An independent investigation into the influence of charities, NGOs and consultancy firms on disability-policy formation.

6 Referral to the International Court of Justice for binding clarification of Articles 4(3) and 4(2).

10 Conclusion

In summary, we allege that Australia's Disability-policy process has become co-design theatre: whereby Disabled People's Organisations are invited to consultations but denied decisive influence or real, substantive leadership.

Decisions made through this distorted process have dismantled the rights-based foundation of the NDIS and are moving to replace individual choice and control with a regression to provider-led, block-funded systems - that replicate the charity and medical model era that the Convention sought to end.

The consequences are widespread loss of supports, increasing isolation and preventable death; the removal of our children into care, and increased surveillance of us by States and Territories as the required individualised supports collapse.

These outcomes were foreseeable, preventable and directly caused by a consultation framework that silences Disabled people while empowering those who profit from their exclusion; while telling us the opposite.

Our view of this is clear, and we will not stand for it to be done without our resistance.

ANPA submits this communication to reaffirm that all Disabled people in Australia, through their own representative organisations, must hold equal power in all decisions that affect their safety, dignity and future.

We would be happy to make ourselves available to substantiate all of the concerns above, which we amply can. For now, we are attaching preliminary examples of the points outlined.

In Solidarity, always, with our community. We stand on the power of the UNCRPD and in the dignity and determination of our struggle; the promise of liberation and one day, equality.

Respectfully submitted,

Sarah Langston

President, Australian Neurodivergent Parents Association (ANPA)

“Nothing About Us Without Us”

Annexes (to be sent in a separate email)

Annex 1 – Harm Tracker Overview (Community Data)

Annex 2 – Harm Tracker Summary of Findings

Annex 3 – NDIA FOI 24 25-1973 Excerpt (Page 5 of 58)

Annex 4 – Red Alert on the Inklings Program (ANPA 3 October 2025)

Annex 5 – Matrix of Breached UNCRPD Articles and Types of Harm