Disability Voices in Healthcare

Submission to the Joint Standing Committee on the National Disability Insurance Scheme

Rejecting Funding for 24-Hour Nursing Care and the Safeguarding of Participants with Complex Medical Needs

Prepared by Melissa Ryan
Founder, Disability Voices in Healthcare
23 March 2026

Submission focus	NDIS funding refusal of 24-hour nursing care, clinical risk, and participant safeguarding
Document contents	Main submission, recommendations, and supporting attachments (Appendices A-J)
Intended use	Parliamentary committee submission
Author	Melissa Ryan, Disability Voices in Healthcare

This document includes a formal submission together with supporting appendices intended to assist committee consideration of high-acuity disability support needs.

Contents

- NDIS Quality and Safeguards Commission. Practice Alert - Transitions of care between home and hospitals.
- Joint Standing Committee on the NDIS. Transitional arrangements for the NDIS - Recommendation on hospital discharge.
- NDIS Quality and Safeguards Commission. A scoping review of causes and contributors to deaths of people with disability in Australia.
- NDIS Quality and Safeguards Commission. Death of people with disability.
- AIHW. Potentially avoidable deaths - Health and wellbeing.

Appendix H - Personal Statement

This submission argues that for some NDIS participants, refusal of 24-hour nursing care is not merely a funding decision. It can become a safeguarding failure when clinically necessary supports are not provided and foreseeable harm is allowed to occur.

Appendix I - Mortality and Death Review Evidence Sheet

Appendix J - Transitions of Care and Hospital Discharge Risk Evidence Sheet

Executive Summary

The NDIA's participant safeguarding framework is intended to minimise the risk of violence, abuse, neglect and exploitation. This submission argues that funding decisions themselves can become safeguarding issues when clinically necessary nursing care is not funded for participants whose safety depends on continuous clinical oversight.

The submission therefore recommends a specific high-acuity decision framework, stronger weighting of specialist clinical evidence, mandatory safeguarding-risk assessment in nursing-support decisions, urgent review pathways for medically vulnerable participants, and clearer health-NDIS interface arrangements.

Recommendations

No.	Recommendation
1	That the NDIA develop and publish a high-acuity supports decision framework for NDIS participants with complex medical needs, including those who require continuous nursing oversight.
2	That where 24-hour nursing care is sought, the NDIA give substantial and documented weight to the evidence of treating specialists, nurse practitioners, clinical nurse consultants, hospital teams, complex care clinicians, and discharge planners.
3	That all decisions to refuse, reduce, or substitute requested nursing supports for medically complex participants include an explicit safeguarding risk assessment.
4	That the NDIA assess whether refusal of nursing supports is likely to create avoidable hospital presentations, delayed discharge, unsafe delegation of clinical tasks, reliance on unpaid carers, or foreseeable neglect or deterioration.
5	That urgent internal and external review mechanisms be available where a participant's health, safety, or discharge viability is jeopardised by refusal of clinically necessary nursing supports.
6	That the Australian Government examine the downstream costs of refusing 24-hour nursing care, including emergency presentations, ambulance use, hospital admissions, extended inpatient stays, failed discharge planning, family carer breakdown, and safeguarding complaints and incidents.

7	That the NDIA, state and territory health systems, and the NDIS Commission develop a clearer shared high-acuity protocol for participants whose needs sit at the interface of disability support and ongoing clinical care.
8	That the Committee hear directly from participants with complex medical needs, families and unpaid carers, nurses providing disability-related clinical care, hospital clinicians and discharge coordinators, disability advocates, and experts in safeguarding and clinical governance.
9	That the Committee recognise that for some participants, 24-hour nursing care is a safeguarding measure essential to life, health, dignity, and safe community living.

1. About the Author

My name is Melissa Ryan, and I am the founder of Disability Voices in Healthcare.

Disability Voices in Healthcare exists to ensure that people with disability are not treated as 'less than' within the healthcare system, and that people with disability, families and carers are better equipped to advocate for safe, dignified and equitable care.

This submission is informed by lived experience, advocacy experience, and concern about the systemic consequences of denying clinically appropriate supports to participants with complex medical needs.

2. Purpose of This Submission

The purpose of this submission is to ask the Joint Standing Committee to examine the consequences of rejecting funding for 24-hour nursing care for NDIS participants with complex medical needs, and to consider this issue not only as a planning or funding matter, but as a matter of participant safeguarding, clinical risk, and disability rights.

The Committee's scrutiny role makes it an appropriate forum to examine whether current funding practices are producing unsafe outcomes for a medically vulnerable cohort of participants.

3. Policy and Safeguarding Context

The NDIA's participant safeguarding framework is intended to improve participant safety and minimise the risk of violence, abuse, neglect and exploitation. At the same time, the NDIS Act provides the legal framework for the approval of participant supports under the reasonable and necessary support framework.

The core concern raised in this submission is that there is a gap between safeguarding principle and funding practice. A participant may be recognised in policy as entitled to safeguards against harm, neglect and exploitation, yet still be denied the level of clinical support required to remain safe in everyday life.

4. The Core Issue

For some participants, the need is not merely for assistance with daily living tasks. The need is for continuous clinical oversight, nursing judgment, monitoring, assessment, and timely intervention across a full 24-hour period.

The issue is not whether support is needed. The issue is whether the system properly recognises that clinical care may be integral to safe disability support in the community.

When 24-hour nursing care is rejected, participants may be left with a support model that depends on non-clinical substitution, unsafe task delegation, unpaid family vigilance, and hospital admission as the fallback safety mechanism.

5. Why This Is a Safeguarding Issue

This issue should be understood as a safeguarding issue because predictable exposure to harm can result from inadequate support design.

Neglect is not limited to intentional misconduct by individuals. It can also arise structurally, where a participant's needs are known, risks are foreseeable, and the system nevertheless leaves the person in an arrangement that is plainly unsafe.

When clinically necessary nursing care is not funded, foreseeable outcomes may include missed signs of deterioration, delayed escalation to health services, medication errors or inadequate monitoring, aspiration events, infections, preventable complications, carer exhaustion, repeated emergency presentations, unsafe discharge, and prolonged inpatient stays.

6. The Problem of Underestimating Clinical Need

A recurring concern in complex cases is that clinical need may be re-described as ordinary support need.

This can happen when the participant's condition is viewed as 'stable' simply because a family member is already absorbing the risk, intermittent crises are treated as isolated events rather than evidence of constant vulnerability, or the need for nursing judgment is reduced to a list of tasks.

A person may appear manageable only because someone else is providing constant vigilance, unpaid monitoring, and unofficial clinical backup. That does not mean the person is safely supported. It may simply mean that invisible labour is masking systemic failure.

7. Delegation Is Not a Substitute for Nursing Care

There is a serious difference between support workers carrying out clearly bounded tasks within a safe and well-governed framework, and a participant requiring ongoing nursing assessment, interpretation, and rapid clinical intervention.

Where continuous nursing judgment is needed, delegation cannot safely replace the presence of qualified nursing care.

In some situations, the attempt to substitute nursing with delegated or lower-cost models creates only an appearance of adequacy while leaving the participant exposed to escalating risk.

8. Family Carers as the Default Risk Absorber

One of the most troubling effects of denying 24-hour nursing care is the burden placed on families and unpaid carers.

When the formal system refuses appropriate clinical support, families often become night monitors, emergency responders, care coordinators, risk managers, medication overseers, and the backup system when everything else fails.

A support system should not be considered safe merely because families are still holding it together. In many cases, apparent stability exists only because unpaid carers are absorbing unsustainable levels of risk and labour.

9. The Health-NDIS Interface Problem

The refusal of 24-hour nursing care also reflects a deeper structural problem at the boundary between disability and health systems.

In practice, participants with complex medical needs can become trapped in a cycle of under-support, deterioration, hospital admission, difficult discharge, and unresolved responsibility disputes.

This pattern is harmful to participants and inefficient for government. It is inconsistent with the purpose of a disability support system that is meant to enable safe participation in community life.

11. The Existence of 24/7 Nursing Within the Scheme Landscape

The existence of provider registration and regulation arrangements for 24/7 nursing and medical services demonstrates that round-the-clock nursing support is recognised within the broader NDIS service environment.

That does not mean every participant should receive 24-hour nursing care. It does mean the concept is not foreign to the scheme. The real issue is whether participants who genuinely require this level of support can obtain it without being forced into repeated crisis, review, hospitalisation, or evidentiary overload.

12. Financial Sustainability Cannot Override Safety

Concerns about NDIS financial sustainability are real. However, cost restraint cannot justify unsafe support arrangements.

A support model is not genuinely economical if it shifts clinical risk to unpaid carers, depends on emergency departments to fill routine gaps, causes avoidable admissions, prolongs hospital stays, generates crisis-driven rather than planned care, or results in family burnout and safeguarding concerns.

The relevant question is not only what 24-hour nursing costs. It is also what refusal costs when that support is clinically necessary.

13. Disability Rights and Equal Worth

This issue goes to the value placed on the lives of people with disability.

When participants with complex medical needs are expected to tolerate support arrangements that would be unacceptable in other care contexts, the message is that their safety can be compromised in ways others would not be expected to endure.

A participant should not have to become critically unwell, repeatedly hospitalised, or visibly unsafe before the system accepts the legitimacy of their need.

14. Matters the Committee Should Examine

I urge the Committee to examine the decision-making criteria applied to requests for 24-hour nursing care, the weight given to specialist medical and nursing evidence, and whether safeguarding consequences are properly assessed when nursing supports are refused or reduced.

The Committee should also examine the extent to which complex clinical care is being substituted with lower-cost arrangements, whether refusal contributes to avoidable admissions and delayed discharge, the burden being shifted to unpaid carers, and whether review systems are fast enough for medically vulnerable participants.

15. Proposed Reform Approach

A better approach would include a clearly defined NDIA pathway for participants with complex medical needs involving high clinical risk.

It should require consistent consideration of diagnosis and comorbidity, deterioration risk, need for monitoring and assessment, night-time risk, discharge safety, availability and sustainability of informal supports, and the consequences of delayed clinical intervention.

It should also include an explicit safeguarding screen and expedited review where a participant is in hospital, at risk of hospitalisation, or medically unsafe without an urgent decision.

16. Conclusion

For some NDIS participants, 24-hour nursing care is not excessive, optional, or aspirational. It is the clinically appropriate support required to remain safe and alive in the community.

When that support is rejected despite clear evidence of need, the consequences may include neglect, crisis, hospitalisation, unsafe family burden, and erosion of dignity and autonomy.

For participants with complex medical needs, refusal of clinically necessary 24-hour nursing care can itself become a safeguarding failure.

References

- Parliament of Australia. Joint Standing Committee on the National Disability Insurance Scheme.
- NDIA. Participant Safeguarding Policy.
- NDIS. Safeguards.
- NDIS. Role of the NDIS Quality and Safeguards Commission.
- Federal Register of Legislation. National Disability Insurance Scheme Act 2013.

Appendix A - Author Biography

Melissa Ryan is the founder of Disability Voices in Healthcare, a lived-experience advocacy initiative focused on the rights, dignity and safety of people with disability within the healthcare system.

Melissa lives with disability and her advocacy is informed by firsthand experience of the barriers, risks and inequities that people with disability can face when interacting with health and disability systems.

Her work is driven by a clear mission: to ensure that no person with disability is treated as 'less than' in healthcare, and to strengthen the voice of people with disability, families and carers in discussions about safety, access, clinical care, dignity and reform.

Appendix B - De-Identified Case Examples

Case Example 1 - Continuous Monitoring Need Reframed as Routine Support

A participant with significant physical disability and complex medical needs required close monitoring across a 24-hour period due to risks associated with respiratory compromise, medication complexity, and sudden deterioration. Despite evidence that the participant's safety depended not only on completion of care tasks but on continuous vigilance, the required level of support was not recognised as nursing care. Instead, the participant was expected to rely on a lower-cost support arrangement that did not provide equivalent clinical oversight.

Case Example 2 - Unsafe Reliance on Family as Backup System

A participant with complex care needs was unable to safely rely on standard disability support alone, particularly overnight. However, the refusal to fund a clinically appropriate level of nursing care effectively assumed that family would absorb the risk. The participant's family became the default after-hours safety system, taking on monitoring responsibilities, emergency escalation, and practical coordination far beyond what should reasonably be expected of unpaid carers.

Case Example 3 - Hospital as the Fallback Safeguard

A participant with high clinical vulnerability was unable to secure adequate nursing support in the community. As a result, hospital effectively became the only place where the participant's safety could be consistently maintained. This created a damaging pattern of unstable community arrangements, deterioration, admission, and difficult discharge.

Case Example 4 - Delegation Beyond Safe Limits

A participant with multiple interacting health risks required ongoing assessment and timely escalation when subtle signs of deterioration emerged. In practice, there was pressure to rely on delegated models of care rather than continuous nursing support. Tasks may have been capable of being delegated in theory, but the participant's safety depended on interpretation, reassessment, and nursing judgment across the day and night.

Appendix C - Clinical Risk and Need for 24-Hour Nursing Care

This statement supports the proposition that some NDIS participants with complex medical needs require 24-hour nursing care not as a preference, but as a clinically necessary safeguard.

For certain participants, risk arises not only from identified care tasks, but from the need for continuous observation of changes in condition, nursing assessment across a 24-hour period, medication management and clinical monitoring, timely recognition of deterioration, skilled intervention, and rapid escalation to acute care where necessary.

Where continuous nursing support is clinically necessary, refusal of such support may expose the participant to delayed response to deterioration, preventable medical crises, unsafe reliance on family, inappropriate use of emergency services, repeated hospitalisation, and unsafe discharge arrangements.

Appendix D - Family and Carer Impact Statement

When NDIS participants with complex medical needs do not receive clinically appropriate nursing support, the burden frequently shifts to families and unpaid carers.

This burden may include overnight monitoring, emergency response responsibilities, medication oversight, coordination between services, informal clinical observation, ongoing fear of deterioration, and responsibility for identifying when to escalate to hospital or ambulance services.

A support system should not be considered safe merely because families are still holding it together. In many cases, apparent stability exists only because unpaid carers are absorbing unsustainable levels of risk and labour.

Appendix E - Hospital and Discharge Risk Statement

Participants with complex medical needs may experience repeated or prolonged interaction with hospital systems when clinically appropriate community-based supports are not funded.

Risks associated with inadequate community nursing support may include avoidable hospital admission, prolonged inpatient stay, discharge delays, repeat emergency presentations, discharge into fragile or unsustainable arrangements, and breakdown of continuity of care.

Where clinicians identify that a participant cannot be safely discharged without continuous clinical oversight, this evidence should be given significant weight in NDIS planning and review decisions.

Appendix F - When Refusal Becomes a Safeguarding Failure

The refusal of 24-hour nursing care for an NDIS participant with complex medical needs may become a safeguarding failure where the participant's risks are known, the level of need is clinically evidenced, lower-level supports are inadequate, the arrangement depends on unsafe substitution or family overreach, and the likely harms are foreseeable.

Safeguarding must include protection not only from interpersonal abuse or neglect, but from structural decisions that expose participants to predictable and preventable harm.

Appendix G - Evidence Guide for Additional Documents

Useful additional evidence may include treating clinician letters, hospital discharge evidence, a record of crises or hospital presentations, family or carer statements, participant statements, and a short advocacy note explaining the broader systemic issue.

Helpful content in clinical letters includes diagnosis and complexity, specific day and night risks, why nursing care is required, why ordinary support work is insufficient, and likely consequences if nursing care is not funded.

Appendix H - Personal Statement

I make this submission because I believe there is a serious gap in how the NDIS responds to participants with complex medical needs.

Too often, decisions about support are framed as if this is simply a budgeting issue, when in reality it is an issue of safety, dignity and human worth.

For participants who require 24-hour nursing care, refusal of that support can expose them to neglect, repeated crisis, and unsafe reliance on family or non-clinical workers.

Appendix I - Mortality and Death Review Evidence Sheet

Official mortality and death-review evidence strengthens the case that safeguarding failures and unsafe support arrangements can have fatal consequences for people with disability. The Australian Institute of Health and Welfare reports that in 2021-22 there were 238 potentially avoidable deaths per 100,000 people with disability during hospital admission or emergency department presentation, compared with 33 per 100,000 people without disability. Earlier national analysis also found that the age-adjusted rate of potentially avoidable deaths in the disability support study population was 3.6 times that of the general population.

The NDIS Quality and Safeguards Commission has published a report summarising 9,062 deaths among 526,515 people accessing disability support services between 2013 and 2018. It has also published a scoping review drawing on death reviews of 901 people with disability across Victoria, Queensland and New South Wales. That review identified problematic practices that potentially contributed to some deaths.

These materials do not appear to provide a national count of deaths specifically caused by refusal of 24-hour nursing funding. That limitation should not be misunderstood as proof that such risk does not exist. Rather, it highlights the need for closer scrutiny of how funding decisions, support design, clinical governance, and safeguarding interact for participants with complex medical needs.

Suggested use in advocacy: this evidence can be used to support the proposition that medically unsafe under-support, delayed escalation, and weak system safeguards are matters of life, health and dignity, not merely funding efficiency.

Appendix J - Transitions of Care and Hospital Discharge Risk Evidence Sheet

Hospital discharge and transitions of care are well-recognised risk points for people with disability. The Joint Standing Committee on the NDIS previously recommended that the NDIA establish a specialist unit to deal with hospitalised participants in order to ensure smoother transitions from hospital, avoid discharge delays, and avoid discharge to inappropriate settings.

The NDIS Quality and Safeguards Commission has also issued practice guidance on transitions of care between home and hospitals, recognising that transitions are critical points to manage because there is risk of harm to people with disability if they do not occur safely and with clear communication, coordination and risk management.

This evidence is directly relevant to participants with complex medical needs seeking 24-hour nursing care. If clinically appropriate community supports are not funded, the consequences may include delayed discharge, repeated hospital presentation, fragile home arrangements, and avoidable deterioration after discharge.

Suggested use in advocacy: this material supports the argument that refusal of adequate nursing care does not simply affect budgets. It can destabilise hospital discharge, shift risk into the home, and increase pressure on health services while leaving medically vulnerable participants unsafe.