Parents of Vision Impaired New Zealand

www.pvi.org.nz

Submission on the Draft Mental Health and Wellbeing Strategy 2026–2036

May 2026

About Parents of Vision Impaired NZ

Parents of Vision Impaired (PVI) is a national, parent-led organisation supporting families and whānau of vision impaired children and young people across Aotearoa New Zealand. Our mission is to support and empower parents and whānau, providing advocacy, information, and peer connection. PVI members are themselves carers — most are parents of children with a vision impairment, many of whom have additional or complex disabilities. Our community sits at the intersection of disability, family caring, and the systemic barriers this submission addresses.

PVI has a strong track record of policy engagement, having submitted on the Public Service Amendment Bill, Local Government Amendment Bill, Pae Ora Amendment Bill, Early Childhood Education reforms, and the New Zealand Disability Strategy.

We bring lived experience and evidence-based perspectives to this submission.

Executive Summary

Parents of Vision Impaired NZ (PVI) welcomes the opportunity to submit on the draft *Mental Health and Wellbeing Strategy 2026–2036*. We support the Strategy's overarching commitment to prevention, early intervention, lived experience leadership, and equitable access. However, we have significant concerns about critical omissions that risk undermining the Strategy's goals for disabled people and their whānau.

PVI's submission centres on two interconnected gaps:

- **The absence of disabled people and carers as distinct priority populations.** Despite robust evidence of significantly poorer mental health outcomes for both groups, neither disabled people nor family/informal carers appear as explicit priority groups with dedicated actions.

- **Failure to integrate with existing disability policy frameworks.** The Strategy does not explicitly reference or align with the Health of Disabled People Strategy (2023), the Carers' Strategy Action Plan (Mahi Aroha), or New Zealand's obligations under the UNCRPD Concluding Observations.

Our key recommendations are:

- ✓ Explicitly recognise disabled people and family carers as priority populations with targeted supports and outcome measures.
- ✓ Integrate and cross-reference the Health of Disabled People Strategy as a core guiding framework.
- ✓ Operationalise key actions from the Carers' Strategy Action Plan within mental health system design.
- ✓ Embed UNCRPD-aligned rights-based approaches, including supported decision-making and reduction of coercive practices.
- ✓ Establish disability-disaggregated data collection and reporting requirements.
- ✓ Invest in flexible, accessible respite for Carers as a mental health prevention infrastructure.

1. Context

PVI members are predominantly parents and whānau who provide care to vision impaired children, young people, and adults, many of whom have additional disabilities or complex needs. Our community experiences firsthand the intersection of disability, caring, and mental health, and the systemic gaps this submission addresses.

New Zealand data demonstrates that disabled adults experience psychological distress at rates approximately **four to five times higher** than non-disabled adults (Ministry of Health, 2021). For informal and family carers, the Carers NZ State of Caring Survey documents high rates of anxiety, depression, financial strain, and social isolation. These are not individual failings but rather structural outcomes of inadequate systems.

The Te Pou snapshot (April 2026) on working alongside tāngata whai ora and whānau with complex needs reinforces this picture. It documents that **complexity is now the norm** in mental health and addiction support work, driven by co-occurring needs including neurodiversity, cognitive impairment, physical health conditions, trauma, and material hardship. Critically, Te Pou identifies that system and funding barriers (not individual capacity) are the primary obstacle to meeting complex needs. Vision impaired children and young people, and their whānau, frequently experience exactly these intersecting complexities.

The draft Mental Health and Wellbeing Strategy's general population approach, while valuable, will not reach our community without explicit disability and carer-specific design. PVI therefore urges the Ministry to treat this submission as a practical guide to strengthening inclusion.

2. Lack of Integration with the Health of Disabled People Strategy

The draft Strategy does not explicitly reference the *Health of Disabled People Strategy* (Ministry of Health, 2023), despite that strategy establishing a clear, disability-specific framework for achieving equity in health outcomes. These outcomes are grounded in self-determination, accessibility, cross-government action, workforce capability, and improved data.

This is a significant omission. The two strategies share overlapping goals, overlapping populations, and overlapping system levers. Failing to explicitly align them risks perpetuating a siloed policy approach in which disability health and mental health operate in parallel rather than as an integrated system. Without clear mapping, disabled people will be assumed to be included in 'population-wide' approaches, yet, as evidence shows, they will in practice remain excluded.

Tabel 2.1 Gap Analysis: Health of Disabled People Strategy

Health of Disabled People Strategy Priority	Gap in Draft Mental Health & Wellbeing Strategy	Impact
Self-determination and disabled people's voice	No disability-led decision-making framework in mental health system design	Reduced autonomy; misalignment with rights-based care
Accessibility of health services	No disability-specific accessibility standards for mental health services	Ongoing barriers; delayed treatment and unmet need
Equitable health and wellbeing outcomes	No explicit disability equity targets or outcome measures	Persistent gap in psychological distress outcomes for disabled people
Cross-government action on determinants of health	No structured cross-sector disability–mental health integration mechanism	Structural drivers of poor mental health remain unaddressed
Workforce capability and disability competence	No explicit disability competency requirements for mental health workforce	Continued diagnostic overshadowing and poorer care quality
Improved disability data and monitoring	No requirement for disability-disaggregated mental health reporting	Disabled people's mental health inequities remain invisible in system data
Reduction of coercion and support for autonomy (UNCRPD-aligned)	No alignment with UNCRPD Articles 12 and 14 principles in mental health design	Continued risk of coercive mental health experiences for disabled people
Equitable access for high-needs disabled people	No specific design features for disabled people with co-occurring mental health needs	Service exclusion or inadequate support for highest-need groups
Whānau and family inclusion in support systems	No structured integration between disability whānau support and mental health system	Fragmented care; increased burden on families; poorer continuity

PVI recommends that the final Mental Health and Wellbeing Strategy explicitly name the Health of Disabled People Strategy as a foundational companion framework, and that the accompanying three-year action plan includes specific implementation commitments that operationalise each of these priority areas for disabled people in mental health contexts.

3. Carers are absent from the draft Strategy

Family carers, including parents of disabled children, are entirely absent from the draft Strategy. They are not mentioned as a priority population. There is no reference to the *Carers' Strategy Action Plan (Mahi Aroha)*. This is a significant policy coherence failure.

The Carers NZ State of Caring Survey documents that a substantial proportion of carers experience symptoms of depression or anxiety, alongside financial and social stressors. For PVI members this experience is resonates. Caring for a child with complex disability-related needs is associated with sustained high-intensity care demands, reduced workforce participation, financial hardship, and profound social isolation.

The Strategy's references to whānau primarily position them as **providers of support** to someone in need. Whānau are not considered as people in their own right, or as individuals with their own mental health and wellbeing needs. This framing across the Strategy appears to be grounded in an (incorrect) assumption that whānau have unlimited capacity to absorb gaps in formal services. This assumption is empirically unsupported and ethically problematic.

Table 3.1 Gap Analysis: Carers' Strategy Action Plan

Carers' Strategy Action Area	Gap in Draft Strategy	Impact on Mental Health Outcomes
Public awareness and recognition of carers	Carers are not identified as a priority group within mental health system design	Delayed support; increased stress; higher risk of anxiety and depression
Service navigation and system coordination	No dedicated navigation model for carers	System complexity remains a key driver of distress and unmet need
Early identification and proactive support	No structured pathway for early carer identification	Missed prevention opportunities; escalation into crisis presentations
Respite and breaks from caring	No recognition of respite as mental health prevention infrastructure	High risk of burnout, chronic stress, and carer breakdown
Carer wellbeing support	No carer-specific wellbeing outcomes framework	Carers' high rates of psychological distress remain unaddressed
Financial security and hardship reduction	No targeted financial stress response for carers	Financial strain persists as a major driver of anxiety and inequity
Carer inclusion in assessment and decision-making	No formal requirement for carer inclusion in care planning	Reduced agency; increased stress and fragmented coordination
Culturally safe and responsive carer support	No culturally tailored carer implementation pathway	Inequitable access and higher unmet need in priority populations
Data, monitoring, and outcome measurement	Carers not included as a distinct monitored population	Carer distress remains invisible in system accountability frameworks

PVI recommends that the final Strategy explicitly recognises family carers, and that the three-year action plan includes specific carer-focused actions. We recommend that these actions are drawn from Mahi Aroha, and are centred around identification, respite, needs assessment, navigation support, and wellbeing monitoring.

4. UNCRPD Obligations and Rights-Based Approaches

The UNCRPD Committee's Concluding Observations on New Zealand (2022) highlight several issues directly relevant to the draft Strategy: the continued use of substituted decision-making and compulsory treatment; inadequate implementation of supported decision-making under Article 12; insufficient access to psychosocial supports; and ongoing reliance on coercive practices in mental health settings.

The draft Strategy does not mention UNCRPD obligations or rights-based approaches at any point.

For disabled people, including vision impaired young people who may also experience mental health challenges, this exposes a fundamental design flaw of the mental health system they are being asked to navigate.

PVI recommends that:

- The Strategy explicitly acknowledge New Zealand's obligations under the UNCRPD, including the Concluding Observations.
- Supported decision-making be embedded as a design principle across all mental health services, not just specialist settings.
- The Strategy set explicit goals for reducing coercive practices, with monitoring indicators.
- Mental health workforce training requirements include disability rights competencies, aligned with the Health of Disabled People Strategy.

5. Devaluing of Professional and Clinical Expertise

The draft Strategy appears to emphasise peer/lived experience over more professional support and clinical care. For disabled people and families, peer support is valuable and welcomed. However, this alone is insufficient. There is potential for harm if peer support becomes a substitute for appropriately skilled clinical assessment and treatment. There is also a risk of peer support workers being inadequately trained to recognise co-occurring factors with disability.

The draft Strategy blurs the distinction between peer support/lived experience workers and clinical care in ways that risk people with complex needs not receiving appropriate assessment or treatment. Disability-related complexity frequently requires clinicians who understand the intersection of disability and mental health. This is a specialist skill set that goes beyond generalised peer support. Diagnostic overshadowing (where mental health needs are attributed to disability rather than assessed properly) is a real risk when clinical input is deprioritised.

A core concern is that this workforce substitution is a cost-saving measure, not a clinical decision. The heavy emphasis on peer and lived experience workers more likely reflects workforce cost pressures due to underfunding, rather than best practice and evidence-based approaches.

The Strategy needs to more clearly and explicitly map what clinical services will be available, at what level of need, and with what waiting time expectations. There is a risk that peer support workers will end up doing the work of a clinical service by default.

PVI values the contribution of peer support and lived experience workers. These are an important part of any mental health system. However, the Strategy's emphasis on these roles must not come at the expense of adequate clinical provision. For disabled people with complex co-occurring needs, peer support is most effective as a post-treatment-complement to clinical care. The Strategy needs to explicitly map the clinical tier of the system and set expectations for access to professional assessment and treatment, particularly for priority populations.

6. Responses to Consultation Questions

Q1. What most gets in the way of people or whānau getting the support they need?

From our members' experience, the primary barriers are:

- **Fragmented, difficult-to-navigate systems.** Parents of vision impaired children report significant difficulty identifying and accessing entitlements across health, disability, education, and social support — contributing to unmet need and avoidable distress.
- **Exclusion from decision-making.** Carers are frequently excluded from needs assessments and service planning, despite their central role. Evidence indicates 86% of carers support having their own needs assessment.
- **Financial and employment pressures.** Half of carers reduce or leave employment. Financial hardship is strongly associated with poor mental health outcomes. This is acutely felt in families caring for disabled children with complex needs.
- **Inaccessible and disability-unresponsive services.** Services remain poorly designed for disabled people. For vision impaired children and young people, this includes inaccessible information formats, lack of adapted communication, and services that do not understand the specific intersection of vision impairment and mental health.
- **Workforce capacity and complexity.** Te Pou's April 2026 snapshot confirms that support workers are managing increasing complexity — including co-occurring disability, neurodiversity, physical health conditions, and trauma — but lack adequate training and system support. NGO managers note that services are expected 'to be the everything to somebody' in a fragmented contracting environment that makes collaboration difficult.

Q2. What most helps people or whānau stay mentally well or get the support they need?

Evidence consistently shows that mental wellbeing improves when systems reduce pressure on carers and provide accessible, coordinated support. Key enablers from our members' experience:

- **Flexible and reliable respite.** Regular, planned respite is essential to prevent burnout and sustain caring roles. Almost half of carers report insufficient or emergency-only access to respite.
- **Whanaungatanga and relational support.** Te Pou's 2026 findings confirm that relationship-based support — whanaungatanga — is essential when working alongside people with complex needs. This aligns with how PVI whānau describe what helps them most: being genuinely known and supported, not just navigated through systems.

- **Clear navigation and system coordination.** Accessible information and dedicated navigation support reduce missed entitlements and associated stress.
- **Integrated disability and mental health services.** Coordinated services reduce fragmentation and improve continuity of care — a persistent gap for families of disabled children who interact with multiple agencies.
- **Financial and employment support.** Financial security and workplace flexibility are strongly associated with improved carer mental health outcomes.
- **Access to appropriately skilled clinical assessment and treatment.** Particularly for disabled people with co-occuring needs. Peer support helps when it sits alongside clinical care, not instead of it.

Q3. What parts of the Strategy feel most right or important?

PVI strongly supports the Strategy's commitment to:

- Prevention and early intervention as the primary orientation of the system.
- Lived experience leadership in system design and governance.
- Addressing stigma and building community connection.
- Recognition of the role of whānau and informal support (but implementation must go further to recognise whānau as recipients of support, not just providers).

The Strategy's recognition of social determinants of mental health is also welcome, though it must be operationalised with explicit disability and carer-specific mechanisms. The *Health of Disabled People Strategy* (2023) provides the ready-made framework for doing so.

Q4. What changes would make the Strategy work better?

- **Recognise disabled people and carers as distinct priority populations** with explicit actions, not just acknowledgement in general equity language.
- **Integrate the Health of Disabled People Strategy** as a foundational companion document with cross-referenced implementation requirements.
- **Integrate Mahi Aroha / Carers' Strategy Action Plan** as a core upstream mental health intervention framework.
- **Embed UNCRPD-aligned rights-based approaches** including supported decision-making and reduction of coercive practice.
- **Mandate disability-disaggregated data collection** in all mental health monitoring frameworks.
- **Ensure accessibility is defined specifically** to include physical, financial, sensory, cognitive, and communication accessibility — not simply proximity to services.
- **Develop disability competency requirements** for the mental health workforce, aligned with the Health of Disabled People Strategy.
- **Clarify and strengthen the clinical tier of the system.** The Strategy should explicitly map what *clinical services* will be available, at what threshold of need, and with what access expectations, so that peer support complements rather than substitutes for professional care.

Q5. Most important steps in the first three years

- Establish a formal cross-strategy implementation mechanism linking the Mental Health and Wellbeing Strategy, Health of Disabled People Strategy, and Carers' Strategy Action Plan.
- Introduce mandatory carer needs assessments and carer-specific wellbeing support pathways.
- Significantly expand flexible, accessible respite services — including emergency, planned, in-home, and out-of-home options.

- Develop and resource disability-competent mental health workforce capability, including vision impairment-specific awareness.
- Establish disability-disaggregated mental health outcome indicators and report them publicly.
- Invest in accessible community-based navigation support for disabled people and their whānau.

Q6. If we could choose just one thing

Guarantee access to adequate, flexible, and regular respite for all family carers. This is the single most effective intervention for reducing psychological distress, preventing burnout, and sustaining informal care systems. For PVI families, who can access DSS services, this support evaporates once caring for elderly parents or a spouse. Carers within the Ministry of Health should not be subjected to burnout or expected to endlessly provide care for a family member without training, support, and access to respite.

Q7. What should we stop doing?

- Stop relying on crisis-driven service access as the primary point of contact for carers and disabled people.
- Stop assuming carers have unlimited capacity to absorb gaps in formal service systems.
- Stop treating disability as a subset of general population equity without specific targeted actions.
- Stop maintaining fragmented contracting and service systems that make collaboration between mental health, disability, and social services structurally difficult.
- Stop under-investing in respite, navigation, and carer wellbeing infrastructure.

Q8. What should we be measuring?

For disabled people:

- Disability-disaggregated psychological distress and wellbeing measures.
- Access to community-based mental health and disability supports.
- Equity of service access and experience (including vision impairment and sensory disability).
- Waiting times for *clinical assessment and treatment* (not just community or peer support contacts)
- Rates of *unmet clinical need* disaggregated by disability status.

For family carers:

- Anxiety, depression, and wellbeing indicators specific to carers.
- Access to respite, navigation, and financial support.
- Workforce participation impacts of caring.

For the system:

- Unmet need and waitlist data, disaggregated by disability status.
- Continuity of care across disability and mental health systems.
- Crisis service utilisation rates and reduction over time.
- Workforce disability competency levels.

Q9. Any other thoughts

The Te Pou snapshot (April 2026) highlights a workforce facing increasing complexity and burnout risk. It identifies that system and funding barriers (not workforce motivation!) are the primary obstacle to quality care. The Strategy must address these structural conditions, not only workforce training, to produce sustainable improvement.

PVI notes with concern the draft Strategy's silence on carers. This risks communicating to an already exhausted and often invisible community that their wellbeing is not a priority. This is more than a minor drafting omission. It is clear that, under this Strategy, people and families who are already at the limit of their capacity are going to be expected to absorb more and more. This is unfair, untenable, and must be addressed.

We ask the Ministry to listen carefully to carer voices in this consultation and to respond with the specificity and commitment this community deserves.

6. Summary of Recommendations

1. Recognise disabled people and family carers as explicit priority populations in the Strategy and three-year action plan.
2. Formally integrate and cross-reference the Health of Disabled People Strategy (2023) as a core guiding framework.
3. Operationalise key actions from the Carers' Strategy Action Plan (Mahi Aroha) within mental health system design.
4. Embed UNCRPD-aligned rights-based approaches, including supported decision-making and reduction of coercive practices.
5. Define accessibility specifically and comprehensively to include physical, financial, sensory, cognitive, and communication dimensions.
6. Mandate disability-disaggregated data collection and public reporting in all mental health monitoring frameworks.
7. Develop disability competency requirements for the mental health workforce.
8. Urgently expand respite as a core mental health prevention infrastructure.
9. Establish a cross-strategy implementation mechanism linking mental health, disability, and carer policy.
10. Clarify and strengthen the clinical tier of the system so that the strategy explicitly maps what clinical services will be available, at what threshold of need, and with what access expectations.

References

Carers NZ (2022) State of Caring Survey Report. Wellington: Carers New Zealand. https://carers.net.nz/state-caring-report/

Ministry of Health (2021) New Zealand Health Survey: Psychological distress by disability status. Wellington: Ministry of Health. https://www.health.govt.nz/monitoring-statistics/surveys/new-zealand-health-survey/publications/202021-survey-publications/snapshots-from-the-202021-survey/psychological-distress-by-disability-status

Ministry of Health (2023) Health of Disabled People Strategy. Wellington: Ministry of Health. https://www.health.govt.nz/strategies-initiatives/health-strategies/health-of-disabled-people-strategy

Ministry of Health (2026) Consultation on the Mental Health and Wellbeing Strategy 2026–2036. Wellington: Ministry of Health. https://www.health.govt.nz/publications/consultation-on-the-mental-health-and-wellbeing-strategy

Swain, Nicola (2018) 'Distress in informal carers of the elderly in New Zealand', New Zealand Medical Journal, 131(1485). https://nzmj.org.nz/media/pages/journal/vol-131-no-1485/distress-in-informal-carers-of-the-elderly-in-new-zealand/d4d8895335-1696476804/distress-in-informal-carers-of-the-elderly-in-new-zealand.pdf

Radcliffe P, Bolling SA and Patrick JH (2025) Caring under pressure: economic social determinants of health influence family caregivers. *Front. Public Health* 13:1676656. doi:10.3389/fpubh.2025.1676656

Te Pou (2026) Working alongside tāngata whai ora and whānau with complex needs: Snapshot of key insights. April 2026. https://www.tepou.co.nz/resources/working-alongside-tangata-whai-ora-and-whanau-with-complex-needs-snapshot

UN Committee on the Rights of Persons with Disabilities (2022) Concluding observations on the combined second and third periodic reports of New Zealand (CRPD/C/NZL/CO/2-3). Geneva: United Nations. https://digitallibrary.un.org/record/3988748

Whaikaha – Ministry of Disabled People (2023) Disabled people experiencing poorer health and wellbeing than non-disabled people. Wellington: Whaikaha. https://www.whaikaha.govt.nz/news/news/disabled-people-experiencing-poorer-health-and-wellbeing-than-non-disabled-people