August 2024

**To Parliamentary Health Select Committee**

Please find attached our submission on the Inquiry into the aged care sector's current and future capacity to provide support services for people experiencing neurological cognitive disorders

For any further inquiries, please contact:

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# Introducing Disabled Persons Assembly NZ

**We work on systemic change for the equity of disabled people**

Disabled Persons Assembly NZ (DPA) is a not-for-profit pan-impairment Disabled People’s Organisation run by and for disabled people.

**We recognise:**

* Māori as Tangata Whenua and [Te Tiriti o Waitangi](https://www.archives.govt.nz/discover-our-stories/the-treaty-of-waitangi) as the founding document of Aotearoa New Zealand;
* disabled people as experts on their own lives;
* the [Social Model of Disability](https://www.odi.govt.nz/guidance-and-resources/guidance-for-policy-makes/) as the guiding principle for interpreting disability and impairment;
* the [United Nations Convention on the Rights of Persons with Disabilities](https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities.html) as the basis for disabled people’s relationship with the State;
* the [New Zealand Disability Strategy](https://www.odi.govt.nz/nz-disability-strategy/) as Government agencies’ guide on disability issues; and
* the [Enabling Good Lives Principles](https://www.enablinggoodlives.co.nz/about-egl/egl-approach/principles/), [Whāia Te Ao Mārama: Māori Disability Action Plan](https://www.health.govt.nz/publication/whaia-te-ao-marama-2018-2022-maori-disability-action-plan), and [Faiva Ora: National Pasifika Disability Disability Plan](https://www.moh.govt.nz/notebook/nbbooks.nsf/0/5E544A3A23BEAECDCC2580FE007F7518/%24file/faiva-ora-2016-2021-national-pasifika-disability-plan-feb17.pdf) as avenues to disabled people gaining greater choice and control over their lives and supports.

**We drive systemic change through:**

**Rangatiratanga / Leadership**: reflecting the collective voice of disabled people, locally, nationally and internationally.

**Pārongo me te tohutohu / Information and advice**: informing and advising on policies impacting on the lives of disabled people.

**Kōkiri / Advocacy**: supporting disabled people to have a voice, including a collective voice, in society.

**Aroturuki / Monitoring**: monitoring and giving feedback on existing laws, policies and practices about and relevant to disabled people.

## United Nations Convention on the Rights of Persons with Disabilities

DPA was influential in creating the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD),[[1]](#footnote-2) a foundational document for disabled people which New Zealand has signed and ratified, confirming that disabled people must have the same human rights as everyone else. All state bodies in New Zealand, including local and regional government, have a responsibility to uphold the principles and articles of this convention.

The following UNCRPD articles are particularly relevant to this submission:

* **Article 9 – Accessibility**
* **Article 16 – Freedom from exploitation, violence and abuse**
* **Article 19 – Living independently and being included in the community**
* **Article 20 – Personal mobility**
* **Article 28 – Adequate standard of living and social protection**

## New Zealand Disability Strategy 2016-2026

Since ratifying the UNCRPD, the New Zealand Government has established a Disability Strategy[[2]](#footnote-3) to guide the work of government agencies on disability issues. The vision is that New Zealand be a non-disabling society, where disabled people have equal opportunity to achieve their goals and aspirations, and that all of New Zealand works together to make this happen. It identifies eight outcome areas contributing to achieving this vision.

The following outcomes are particularly relevant to this submission:

* **Outcome 5 – Accessibility**
* **Outcome 7 – Choice and Control**

# The Submission

# DPA welcomes this opportunity to give feedback to the Health Select Committee on its inquiry into the aged care sector's current and future capacity to provide support services for people experiencing neurological cognitive disorders.

As this inquiry touches on the important needs of a group of older disabled people, it is important that we give our perspective on this issue.

DPA acknowledges the strong interrelationship which exists between ageing and disability. As our population ages, the number of disabled people is projected to increase significantly.

Alongside this, as the topic of the inquiry implies, there will be (and is already) a rise in the number of people experiencing neurological cognitive impairments.

We note that neurological cognitive impairments can be experienced by people before entering old age, but most people living with these conditions will be aged 65+ years.

For DPA, this inquiry raises several issues which need to be addressed, besides those that have been identified by the committee in its terms of reference.

The most important consideration is the need to move towards a non-disabling society as envisaged in both the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) and the New Zealand Disability Strategy (NZDS).

We also acknowledge the importance in this submission of two other key strategies for the older persons sector, namely, *Better Later Life He Oranga Kaumātua 2019 to 2024* and *Healthy Ageing Strategy 2016*.

These strategies emphasise the importance of healthy ageing and this means access to inclusive communities where there is opportunity for social connection and nurturing.

If all these agreements and strategies were fully implemented, New Zealand will create a society that will be more welcoming and enabling of a group of people who will, most likely, not have had any previous experience of living as disabled people.

That is why we must work to eliminate the barriers to the participation of everyone in our communities, including older disabled people.

**DPA asks that political parties work collaboratively with ageing and disability communities to create a society which is age friendly, inclusive and barrier free.**

There is also a need for sufficient resources to be devoted to the aged care disability support system to provide appropriate support through ‘ageing in place’ as, for disabled people of all ages, this is the best way to live and be.

While high level care will be required for a growing number of older people with neurological impairments in terms of rest home, hospital or respite care, the recent *Whanaketia* report of the Royal Commission of Inquiry into Abuse in Care, while not having the aged care sector within its scope, laid bare the potential for abuse and neglect to occur in any health-based mass residential setting.

There is a pressing need to monitor and banish abuse from all age-related residential facilities to protect everyone who needs to live in them to ensure that the final years of all residents are comfortable and dignified ones.

DPA wants a society where disabled people have full human rights, dignity, autonomy and choices and this includes for older disabled people.

**Ultimately, everything rests on adequately funding and sustainably resourcing the disability support and ageing sectors and communities to ensure that the needs of an increasingly ageing population can be fully met.**

**The current cuts spending on healthcare, social support and disability support undermines progress on this.**

**For these reasons, DPA is very concerned about the sustainability of funding for ageing and disability support as any under-investment in these areas will have negative repercussions over the medium to long term for older disabled New Zealanders and their families/whānau.**

Below DPA answers nearly all, bar the last two questions posed by the committee and make recommendations upon them.

**Q.1) Appropriate services for people with neurological cognitive disorders across the care continuum including from home and community care to residential care, to palliative care.**

**a.) Need for better funding of aged care from home-based care through to community, residential and palliative care**

Adequate central government funding of individualised, flexible, responsive community support services is important for older people with neurological impairments wishing to age in their own way.

Having support available for everything from domestic assistance for a range of tasks from shopping and cleaning through to personal cares like dressing and bathing is important for many older disabled people, especially people living with neurological conditions.

**Recommendation 1:** that all older disabled individuals and their whānau/families have the option of accessing individualised funding to give them greater choice and control over their supports.

**Recommendation 2:** that a full continuum of funded housing options be provided to older disabled people in the form of, for example, supported flatting arrangements (i.e.,Abbeyfield), retirement villages and other options chosen by older disabled people and/or their families/whānau.

**Recommendation 3:** that all residential/hospital level care be adequately funded by government to meet projected demand as well as increasing population and rising costs.

**Recommendation 4:** that a continuum of funded respite care options be made available for all people with neurological conditions extending from in-home respite provided by support workers through to residential-based respite.

**Recommendation 5:** that decisions around moving into residential care are made by individuals with neurological conditions themselves (or through supported decision-making processes if they are not able to do so), and their families/whānau in partnership with health and ageing professionals.

**Recommendation 6:** that new models of care and a proper continuum of care is made available for all people spanning the neurological conditions continuum, based on the choices made by them and/or their families/whānau.

At the very high needs end, there will be a requirement for more dementia care units and residential homes to be established around the country to care for people with severe dementia, especially those, for example, who are prone to wander and require supervised 24-hour support to ensure their wellbeing.

When DPA requested feedback on this submission from members, we heard from some older disabled women living in rest homes about the anxiety they had experienced when, for example, men with dementia had wandered into their unlocked rooms, which signalled to them the lack of staffing and appropriate care available within the system to support people with this level of dementia.

They told us that this lack of care was caused by the shortage of locked care units and homes as well as a shortage of trained staff for supporting people with dementia.

**Recommendation 7:** that a new model of dementia care and a proper continuum of care is developed spanning from community-based through to residential options.

**Q.2) The funding model, amount of funding available, including best practice and international examples of funding models.**

**a.) More universal funding model needed**

A more universal, individualised funding model is needed to support all older people, including those with neurological related conditions.

The proposed new disability support model outlined in legal researcher Warren Forster’s report on *Removing Disabling Experiences: a vision for the future* (commonly referred to as the Forster Report) (2022), while solely focused on the disability support system (DSS) for disabled people aged under 65 years contained some ideas worthy of further exploration within the disability aged care support context.

Forster outlined the need for an integrated, seamless disability support system which would see the DSS systems administered by Whaikaha Ministry of Disabled People (moving to Ministry of Social Development in October 2024) and Accident Compensation Corporation (ACC) merged.

Forster’s recommendations were aimed at eliminating the inequities and inconsistencies that have long existed between Ministry of Health/Whaikaha Ministry of Disabled People and ACC-funded DSS clients in terms of the funding and supports they receive.

DPA acknowledges that these inconsistencies do not exist to the same extent within the aged care sector given that this is funded through the Ministry of Health, meaning that there is a single agency responsible for funding and overseeing the aged care sector.

However, there is still the issue of disabled people who reach 65 years and are required to make the transition from being under Ministry of Disabled People/MSD to the Ministry of Health disability support system.

There is also the issue of the interface between disabled people aged over 65 years who are either existing ACC clients when they enter the age-related disability system or who acquire injuries after they enter the system which also sees them becoming ACC clients as well.

People with neurological conditions are at higher risk of sustaining injuries from falls or other adverse events and entering the ACC system that way.

DPA recognises that there is the need for greater health system involvement when it comes to the provision of age-related disability support, especially for older people with neurological conditions, but this should not be used to medicalise the ageing process either.

**Recommendation 8:** that the Forster Report is used by government as the basis for developing a new aged care disability support funding system co-designed in partnership with older people, older disabled people, their families/whānau, ageing sector organisations, Māori and other stakeholders.

**Recommendation 9:** that Government creates a funding mechanism which provides for the adequate, sustainable and viable funding of the aged care sector.

**Recommendation 10:** that any new funding system enable an easier and more seamless transition for users between the disability support systems provided for younger (under 65) and older (over 65) age groups.

**Q.3) Resources available and the ability for the health system to provide appropriate care and what support enables 'ageing in place', including for priority populations.**

1. **Need for community-based care and natural supports to ‘age in place’**

DPA agrees that aged care and support services must be appropriate and responsive to the individual needs of people with neurological cognitive impairments.

**Recommendation 11:** that central and local government work collaboratively with older disabled people, families/whānau, local communities, and Māori to develop age friendly communities where people with neurological conditions, amongst others, can live independently with support.

**Recommendation 12:** that central and local government develop policies and fund initiatives which support the creation of age-friendly communities.

Making our physical and built environments accessible will be an important aspect of this through making access into all housing, shops, parks, community facilities, health care centres, hospitals and social venues fully inclusive so that everyone, including people with neurological impairments can fully participate in community life.

**b.) Need to better support carers and frontline support workers**

The needs of older people and their whānau/family support networks can often be neglected in terms of their mental, physical and spiritual wellbeing if wraparound support is only partially available or non-existent.

Carers New Zealand *State of Caring Report* (2022) outlined the many stresses, frustrations and barriers that the carers of older people encountered, with many being either older disabled people themselves or people living with health conditions. [[3]](#footnote-4) Many carers reported experiencing poor physical and mental health, not feeling valued and facing issues around accessing respite care to give them much needed breaks.

The need for individualised respite care and other wraparound supports including healthcare and social opportunities for both older people and carers is something that will be increasingly needed as the population ages to prevent the health and aged care system from breaking down entirely.

Government also needs to adequately invest in the ageing and disability sector workforces in terms of training, pay and recruitment/retention to ensure that there are sufficient, fully trained frontline support workers available to meet growing demand.

This includes the need for additional home/disability support workers, residential-based support workers, nurses, nursing assistants, family/whānau carers, and specialists working in older people’s health and wellbeing.

**Recommendation 13:** that all older disabled people, including those with neurological conditions, and their families/whānau are offered individualised-based wraparound supports and funding by government.

**Recommendation 14:** that there be adequate government funding to pay the living wage or greater to all people employed within the older person’s sector.

**Recommendation 15:** that central government introduce a carers payment for those involved in the home/whāre-based care and support of all older and disabled people set at the level of the living wage or higher.

**Recommendation 16:** that all people working in older people’s and disabled people’s carer and support people roles (including family/whānau carers) are given the opportunity to access high quality training, qualifications and career pathways within aged care.

**c.) Need to prevent abuse in residential care settings**

The recently released *Whanaketia* report(s) of the Royal Commission of Inquiry into Abuse in Care (2024), while not having abuse in aged care in within its scope, reminded New Zealanders of the need to protect at risk groups, including older disabled people, from abuse.

In the case of older disabled people, this abuse can be encountered as both disablist/ableist abuse and elder abuse as the two sometimes intersect.

There have been numerous reported instances of the abuse of older and disabled people both in family/whānau and residential settings over the years.

**As a country, both government and communities need to work collaboratively to eliminate abuse and violence from the lives of everyone, including disabled and older people.**

**Recommendation 17:** that Government task the Ministry of Health, Office for Seniors, Office of the Health and Disability Commissioner and other relevant agencies with reviewing elder abuse policies across the aged care sector with a view to strengthening them.

**Recommendation 18:** that a review panel should be appointed to oversee this process and include representatives of disabled people, older disabled people, Māori, Pacifika, carer organisations and other stakeholder groups.

**Q.4) The process of applying for funding and care resources.**

**Q.5) Appropriate and sustainable asset thresholds for people with neurological cognitive disorders.**

We will answer these two questions as one given that they are inter-related.

Earlier in this submission, we outlined the need for individualised funding to be used more in aged care disability support.

If this is done, then the amount of bureaucracy involved in accessing care and support should be reduced in terms of the need for form filling and assessments through more streamlined processes and the ability to let older people and families/whānau access individualised budgets.

**Recommendation 19:** that once any older person receives a diagnosis of neurological cognitive impairment, that they are offered funding and support options in a timely manner.

**Recommendation 20:** that referral pathways for health, disability and other support services for people with neurological cognitive impairments should be seamless and efficient.

**Māori perspectives**

Kaumatua and Kuia Māori contribute to their communities, whānau, hapū and iwi as their knowledge are treasures passed down to successive generations. Kaumatua and Kuia Māori and their ability to care for mokopuna enables their parent/s to work and save for their future and building a safe home. It also gives them time to teach skills and cultural traditions that their parent/s do not have the time to teach.

Kaumatua and Kuia Māori provide cultural education in terms of teaching the knowledge and traditions of whānau, hapū and iwi.

Kaumatua and Kuia Māori who are also Tangata Whaikaha ā Hinengaro and who may experience memory loss can share stories of their childhood which is important for each generation to understand what their tupuna have dealt with. It is important for each new generation to learn their history and even those with neurological impairments can provide knowledge.

Many whānau want to care for their Kaumatua and Kuia Māori who are also Tangata Whaikaha ā Hinengaro in their home but due to inadequate funding, it has become financially and physically challenging for Kaitiaki (carers). With additional cuts to benefits and the ramping up of benefit sanctions, whānau who choose to care for their Kaumatua and Kuia Māori are being put under extreme levels of stress and hardship.

**Recommendation 21:** that a whānau based approach is taken to the care and support of Tangata Whaikaha ā Hinengaro through the Crown adequately funding kaitiaki to do so.

1. <https://social.desa.un.org/issues/disability/crpd/convention-on-the-rights-of-persons-with-disabilities-articles> [↑](#footnote-ref-2)
2. <https://www.odi.govt.nz/nz-disability-strategy> [↑](#footnote-ref-3)
3. <https://carers.net.nz/wp-content/uploads/2022/07/State-of-Caring-Report-Aug2022.pdf> [↑](#footnote-ref-4)