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Tēnā koe ki Te Aka Matua o te Ture Law Commission

Please find below DPA’s submission on the Review of Adult Decision-Making Capacity Law.

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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 Plan](https://www.moh.govt.nz/notebook/nbbooks.nsf/0/5E544A3A23BEAECDCC2580FE007F7518/$file/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. There are a number of UNCRPD articles particularly relevant to this submission, including:

* **Article 4.3: Involving disabled people and our organisations in decisions that affect us**
* **Article 9: Accessibility**
* **Article 12: Equal recognition before the law**
* **Article 13: Access to justice**
* **Article 22: Respect for privacy**

## 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. There are a number of Strategy outcomes particularly relevant to this submission, including:

* **Outcome 4 – Rights, protection and justice**
* **Outcome 5 – Accessibility**
* **Outcome 7 – Choice and control**

## The Submission

The Disabled Persons Assembly (DPA) supports the Law Commission’s review of the law concerning adult decision-making capacity as contained in its second issues paper on this issue. We welcome the recognition made in the discussion that this country has yet to fully meet its obligations under Article 12 of the UNCRPD and that new legislation will rectify this.

DPA notes that New Zealand ratified the UNCRPD in September 2008 without reservations[[3]](#footnote-4). Article 12 of the UNCRPD is about people’s right to supported decision-making[[4]](#footnote-5). Supported decision-making is about disabled people’s right to make decisions affecting their lives, and to have access to support when making decisions, on an equal basis with others.

Supported decision-making is a right that must be reflected in law, and we welcome further advancement on the ideas contained in the first discussion paper that we submitted upon last year.

DPA supports the call made in this latest consultation for an entirely new Act to replace the existing Protection of Personal and Property Rights Act 1988 (PPPR Act).

## The case for a new Act

The Commission has compellingly outlined the reasons why a completely new Act is necessary to replace the current PPPR.

The need to recognise the UNCRPD, accommodate the interests of a more diverse range of users including people with dementia, and recognise the move away from the medical model to social model of disability within society are all factors driving this change.

The need to incorporate Te Tiriti o Waitangi and tikanga Māori within the legislation is another pivotal factor.

DPA agrees that taking a more person-centric, holistic approach to supported decision making would bring the legislation into alignment with this country’s UNCRPD and Tiriti obligations.

## Human rights considerations and the purpose(s) of a new Act

DPA agrees that the need to incorporate Article 12 of the UNCRPD is another important driver of change in the supported decision-making space.

When the PPPR was passed 36 years ago, there was no international treaty that protected the human rights of disabled people.

Now there is such an instrument in place, the need to make the Convention’s core concepts of dignity, autonomy and equality real when it comes to supporting the decisions made by disabled people is vital.

We see that the Commission has extensively outlined the case for reasonable accommodations and support[[5]](#footnote-6) for disabled people as being important for every person wanting to access supported decision making.

DPA agrees that it is important that all measures in the new legislation enable every disabled individual to exercise their legal capacity and, in doing so, have ‘the rights, will and preferences ...’ of each person who does so respected.

However, there is discussion in the document around the need to recognise that there are times when ‘it is justified to limit the rights engaged.’ The discussion paper cites practical examples of when this might occur including if a person becomes unsafe living in their own home, requires medical treatment, or if decisions need to be taken around the use and/or disposal of their property.

These types of justified limitations may equally result in unjustified discrimination against disabled people[[6]](#footnote-7) which would be in contravention of section 19 of the Bill of Rights Act. This ties in with the discussion around the content of a new purpose provision.

**The purposes of a completely new law should be to uphold people’s human rights and safeguard people from harm.**

## Decision-making capacity: conducting assessments

However, it seems that while the Commission has supported many of the key principles DPA elaborated upon in our submission to the first discussion paper, we are disappointed to see the discussion on justified limitations appear more prominently in this paper.

In DPA’s previous submission, we stated that everyone can be supported to make decisions. We held that:

*‘... it is often stated as fact that there is a group of disabled people who, because of their high support, care and communication needs, cannot make their own decisions.*

*It may be that only those close to them are able to understand what they want when they express their needs and be able to interpret/translate for them. However, like the rest of society, they have the right to supported decision-making and being appropriately supported to have choice and control over their lives. Well supported decision-making recognises that a person who might be deemed to lack capacity or competence can in fact make some decisions.’*

In answer to the questions as to whether there are any other issues with decision making assessments that should be considered and as to whether the presumption of decision-making capacity should be retained in law we answer as follows:

**In terms of decision-making assessments, DPA strongly urges that the presumption should remain in place that every individual, even if they have a high level of impairment, retain even some legal capacity to make decisions even though these decisions maybe made with the support of another individual or collective group that best knows and/or understands the wishes/will of the person at any given time.**

**Recommendation 1:** that any assessments performed to determine a person’s decision-making capacity on a particular issue should be a simple process, that incorporates the human rights and social models of disability, and is undertaken in a location of the assessed individual’s choice, respects tikanga Māori and/or the relevant culture of the person being assessed and that any assessors are fully trained in disability and human rights issues[[7]](#footnote-8).

**Recommendation 2:** that any decision-making assessment process provide for reasonable accommodations to be made including, for example, the provision of information/communication in accessible formats including New Zealand Sign Language, Braille, Easy Read or other means of communication required by the person.

**Recommendation 3:** that any person undergoing a decision-making assessment is given the legal right to have any whānau/family or support person/people they choose present as witnesses and in support.

**Recommendation 4:** that a clause is inserted into the new Act to specify other factors that, by themselves, are insufficient to find that a person does not have decision making capacity on a particular issue including, for example, that any decision is based on a person’s age, whether they have a disability, their behavioural state, methods of communication, history of alcohol or drug abuse, and any other factors.

Doing so would reduce or even eliminate the possibility of discrimination being practised against any person in terms of their ability to independently make decisions being arbitrarily stripped away from them on any of the above grounds.

**Recommendation 5:** that only accredited, trained assessors conduct assessments of decision-making capacity according to the human rights and social models of disability.

**Recommendation 6:** that every assessor have full training in and knowledge of the human rights and social models of disability. They should also have either have direct knowledge of or a willingness to be trained in te ao Māori and safe cultural practises.

**Recommendation 7:** that people able to be accredited as assessors could include disabled people, disability rights advocates, disability support workers, lawyers/legal professionals, indeed anyone who is willing and able to fulfil the criterion to become a Supported Decision-Making Assessor.

**Recommendation 8:** that the process of accessing an assessor should be as simple as possible in that they are available in every part of the country.

**Recommendation 9:** that all assessors are subject to a strict code of practice developed in a co-design partnership with disabled people, disabled people’s organisations (DPOs) and other key stakeholders.

**Recommendation 10:** that all assessors are registered on an Assisted Decision-Making Assessor Register that lists their name, qualifications and contact details.

**Recommendation 11:** that the responsibility for registering assessors sit with a central body, akin to the United Kingdom’s Office of the Public Guardian, which would be tasked with overseeing the supported decision-making making process including the responsibility for monitoring it and receiving/investigating complaints.

## Decision-making support

DPA welcomes the Commission’s inclusion in this second paper of a discussion about the possible formal duties and responsibilities of a decision-making supporter, something that we recommended in our submission on the first discussion paper.

**Recommendation 11:** the primary duties of a formal supporter would be to always uphold the will and wishes of the individual being supported. This would be done through a duty to reasonably communicate with the person being supported about what their decisions are or, in cases where a person’s decision-making capacity is impacted, have a high degree of understanding of what they would be.

**Recommendation 12:** that the provision of support not necessarily hinge on mental capacity assessments alone as the UN Committee on the Rights of Persons with Disabilities has recommended.

**Recommendation 13:** that courts have the power to appoint a decision-making supporter if a person does not have decision making capacity but only as a last resort.

We agree that this would be useful if it were to avoid the courts from having to make more intrusive orders in the form of a court-appointed representative. We also agree that the courts should be satisfied that the appointment of a supporter is fully consistent with the wishes of the individual requiring decision making support.

**Recommendation 14:** that the list of duties of formal supporters include that they treat the supported person with dignity and respect, act honestly, diligently and in good faith and identify actual or potential conflicts of interest and ensure that the interests of the supported person are the primary consideration in the event of any conflict.

**Recommendation 15:** that the proposed Office of the Public Guardian have responsibility for monitoring decision-making supporters to ensure that they comply with their obligations.

**Recommendation 16:** that the Office is also made responsible for administering easily accessible education, oversight or registration requirements for decision-making supporters[[8]](#footnote-9).

**Recommendation 17:** that decision making supporters are also restricted as to the areas they cannot make decisions on[[9]](#footnote-10).

There are currently very few ‘automatic’ rights about which the guardian and/or property manager cannot make decisions on. For example, a welfare guardian cannot decide about an individual getting married or divorced. It is essential that the law limits the power of a decision-making supporter and ensures the protection of the individual and access to their private information.

## Collective decision-making arrangements and decisions

DPA is pleased that this discussion paper takes up the discussion inclusion of collective decision-making arrangements, especially around Māori[[10]](#footnote-11). For example, networks such as circles of support made up of a range of supporters chosen by the person requiring assistance to make decisions, can collectively come to a decision which involves the supported person being able to demonstrate their will and preference.

**Recommendation 18:** that the new Act make provision for collective supported decision-making arrangements.

Such arrangements would benefit Māori, Pasifika and other ethnic communities which have cultures that emphasise collective decision-making.

These would also benefit any disabled person who may opt to have support from a wide range of individuals who they deem important to them.

**Recommendation 19**: that collective decision-making groups have the same responsibilities and duties as individual decision-making supporters.

## Advanced Directives

An Advanced Directive allows an individual to declare in advance what processes they would like to put in place when their decision-making is affected[[11]](#footnote-12). Whilst they are commonly applied to health care decisions, their legal status in Aotearoa New Zealand and ability to bind other people is unclear[[12]](#footnote-13).

DPA notes the extensive discussion of this issue in the issues paper.

**Recommendation 20:** that court appointed representatives and attorneys continue to have regard to advanced directives as communicating the individual’s expressed wishes.

**Recommendation 21:** that firm legal rules and protections are developed to ensure that advanced directives are not misused or abused by those charged with administering them and that these are grounded in human rights and disability rights principles.

**Recommendation 22:** that the ability to file a statement of wishes that would sit alongside any advanced directive is legally recognised.

**Recommendation 23:** that supported decision-making arrangements are mandatorily recorded in a centralised register of Advanced Directives which would sit with the Office of the Public Guardian[[13]](#footnote-14).

## Enduring Powers of Attorney

An Enduring Power of Attorney (“EPOA”) is a decision-making arrangement where a person (individual) gives another person (the attorney) the ability to decide, or make a series of decisions, for them in the future[[14]](#footnote-15). EPOAs take effect once the individual is assessed as not having decision-making capacity and can cover decisions about personal welfare or financial/property matters, as per the PPPR Act.

**Recommendation 24:** that a central register of EPOAs is created and that this be administered by the proposed Office of the Public Guardian

**Recommendation 25:** that an Office of the Public Guardian also have the responsibility for monitoring compliance with and the ability to receive any complaints about EPOAs.

**Recommendation 26:** that all EPOAs are required to be mandatorily filed with the Office of the Public Guardian as a basic legal protection.

**Recommendation 27:** that EPOAs remain confidential in that they can only be viewed by the individual in whose name they are made, the attorney, or any person or organisation nominated by the individual in advance as well as by approved employees of the Guardian’s Office.

However, this discussion paper does not adequately tackle the issues of the costs involved in preparing an EPOA as this can be a real barrier to many people. Cost can deter people from getting an EPOA prepared while their decision-making is unaffected, yet this is the ideal time to have one prepared.

**Recommendation 28:** that the costs of preparing and filing an EPOA are mitigated through Government providing funding to community organisations like Age Concern or Community Law Centres to assist people to

1. prepare their EPOA,
2. carry out the legal requirements re explaining exactly what a prepared EPOA means, and
3. sign it off.

## Te Tiriti o Waitangi

DPA aims to affirm and adhere to the principles of Te Tiriti o Waitangi. Te Tiriti o Waitangi is a guiding principle in the New Zealand Disability Strategy for 2016–2026.

It is encouraging to see that the Law Commission acknowledges that precedence, or at least considerable weight, should be given to the Māori text and ensuring tino rangatiratanga in the context of adult decision-making arrangements of the individual within their community[[15]](#footnote-16).

## Tikanga Māori

DPA supports the two considerations to enable Māori disabled to live according to tikanga and to enable Māori disabled to have collective involvement in decision-making that concerns Māori[[16]](#footnote-17). The new Act should avoid unnecessary specification of what tikanga might involve in any circumstance or specify the nature of the collective involvement that tikanga may require as tikanga differ between iwi, hapū, marae or whānau.[[17]](#footnote-18)

Māori have the highest rates of intellectual disability (1.3 percent), followed by Pacific peoples (0.9) and Europeans (0.8)[[18]](#footnote-19) and it is positive to see that the government is obliged to both care for Māori and to ensure outcomes for them are equivalent to those enjoyed by non-Māori.

As outlined in your report, Māori are currently disproportionately affected by experiences of impairment that affect decision-making and are also underrepresented in accessing many health and disability services, including decision-making arrangements under the PPPR Act.

An example of when tikanga is often used is by a person acting as their whānau member’s ‘mangai’ (mouthpiece or speaker) after a brain injury. DPA recommends that any whānau member go through a decision-making supporter process based on tikanga to ensure that the safety and wellbeing of the Māori disabled person is the highest priority.

1. United Nations. (2006). *United Nations Convention on the Rights of People with Disabilities.* Retrieved from: <https://www.un.org/disabilities/documents/convention/convoptprot-e.pdf> [↑](#footnote-ref-2)
2. Office for Disability Issues. (2016). *New Zealand Disability Strategy.* Retrieved from: <https://www.odi.govt.nz/nz-disability-strategy/> [↑](#footnote-ref-3)
3. United Nations Convention on the Rights of Persons with Disabilities, 2008

   <https://www.justice.govt.nz/justice-sector-policy/constitutional-issues-and-human-rights/human-rights/international-human-rights/crpd/> [↑](#footnote-ref-4)
4. See Article 12, Equal recognition before the law at

   <https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities/article-12-equal-recognition-before-the-law.html> [↑](#footnote-ref-5)
5. Law Commission, SIP at [3.23-3.28] [↑](#footnote-ref-6)
6. Law Commission, SIP at [3.31] [↑](#footnote-ref-7)
7. Law Commission, SIP at [7.55-7.59] [↑](#footnote-ref-8)
8. Law Commission, SIP at [8.26] [↑](#footnote-ref-9)
9. Law Commission, SIP at [8.51(d)] [↑](#footnote-ref-10)
10. Law Commission, SIP at [7.27] [↑](#footnote-ref-11)
11. Law Commission, PIP at [7.16]. [↑](#footnote-ref-12)
12. Law Commission, PIP at [7.17]. [↑](#footnote-ref-13)
13. Law Commission, PIP at [7.18 and 7.19]. [↑](#footnote-ref-14)
14. Law Commission, PIP at [7.22]. [↑](#footnote-ref-15)
15. Law Commission, SIP at [4.9]. [↑](#footnote-ref-16)
16. Law Commission, SIP at [5.16-5.18]. [↑](#footnote-ref-17)
17. Law Commission, SIP at [5.3]. [↑](#footnote-ref-18)
18. [From Data to Dignity: Health and Wellbeing Indicators for New Zealanders with Intellectual Disability (full report) (ihc.org.nz)](https://www.ihc.org.nz/publications/from-data-to-dignity-health-and-wellbeing-indicators-for-new-zealanders-with-intellectual-disability) [↑](#footnote-ref-19)