



Submission to Te Aka Matua o te Ture / Law Commission on *Review of Adult Decision-Making Capacity Law*

INTRODUCTION

1. Thank you for the opportunity to submit on the Preliminary Issues Paper for He Arotake I te Ture mō ngā Huarahi Whakataua a ngā Pakeke I Review of Adult Decision-Making Capacity Law. The ethics and legal mechanisms related to adult decision-making is something which social workers often encounter in our mahi and so this consultation is very important to us.
2. The complexities associated with adult decision-making, particularly when capacity is affected is a common issue in mental health, older persons health, learning disability, and transition fields. Due to the specific skills and knowledge social workers bring around psychosocial assessment, including mobilising natural supports and navigating family dynamics, we are often the profession initiating proceedings. This is increasingly influenced by expectations from care home facilities and providers, who now commonly require formal substituted decision-making mechanisms to be instigated before accepting affected persons into their care. Therefore, social workers are increasingly supporting whānau in this area of care planning.
3. Our members' practice experiences suggest the current law does not place the affected person at the centre and it disregards a person's rights to retain autonomy around their choices. The current approach adopts a paternalistic legal process which is complex and difficult for the person and their supporting whānau to understand and navigate.
4. We believe the law and subsequently practice around affected decision-making capacity should be improved. We support a 'repeal and replace' of these major pieces of legislation as we believe amendments to the current Acts would not go far enough to ensure supported decision-making takes precedence over current substituted decision-making mechanisms.
5. In our submission we explore some of the complexities and provide case examples from social work to illustrate some of the issues we feel are important to this conversation. We also propose a model for supported decision-making. We have not answered specific questions relating to current mechanisms, instead choosing to discuss some of the key issues we perceive and recommendations for future solutions.

TERMS AND PRINCIPLES

6. We support the terms used by Te Aka Matua o te Ture as these reflect the social model of disability and the New Zealand Disability Strategy which, importantly have been developed through engagement with the disabled community in Aotearoa New Zealand.
7. We also support the list of principles as written. It is essential that decision-making law is grounded in a human-rights approach, which aligns with our professional ethics and values. Linked to this concept is the need to uphold Te Tiriti o Waitangi obligations and recognise and provide for tikanga Māori, something which current law fails to recognise.
8. It is important to us as social workers that the legal framework strikes the right balance between trust and flexibility and protection from abuse and neglect. There are individuals who for a range of reasons, be it severe learning disability, acquired brain injury or neurodegenerative conditions later in life, are unable to participate fully in decisions regarding them. We want to ensure this group can continue to exercise their human rights and remain safe from exploitation or harm. The current lack of protections for this group is concerning for us.

DETERMINING DECISION-MAKING CAPACITY

9. Decision-making capacity is something which, in our experience, is not always well understood. The various Acts define capacity differently and what constitutes a lack of decision-making capacity. This is a significant weakness currently, as it has led to poor understanding and at times assessment, which under the current model of substituted decision-making could have significant consequences for disabled persons through significantly limiting their human rights.
10. We recommend that documented capacity assessments are required in legislation. We support a functional assessment of capacity and recommend a clear process for this assessment be set out within legislation, such as how it is set out in section 9 of the Substance Addiction Act 2017. Additionally practice guidance is needed around the component “*use and weigh that information*” and how this links to executive capacity, essentially the ability to carry out the decision¹. Assessments should also identify what support someone needs to carry out action related to their decision.
11. We believe, that like in other jurisdictions such as the United Kingdom where approved social workers carry out capacity assessments, registered social workers here in Aotearoa New Zealand possess the skills to assess decision-making capacity. We are trained to understand the complex relational and systemic issues which surround decision-making capacity, particularly the nuances around degrees of incapacity, and the difference between a person understanding the implications of a decision and their ability to execute the decision. It could reduce pressure on the health system if approved social workers, particularly in a community setting, were able to carry out such assessments and trigger formal supported decision-making processes.
12. We also have concerns regarding the gap in applying legislation to practice, particularly the concept of degrees of capacity. Currently, the PPPR Act 1988 applies to persons who “lack, wholly or partly,

¹ Hull City Council. (2023). *6.1 Assessing Mental Capacity: Guidance*. <https://www.hullapp.co.uk/assessing-mental-capacity-guidance/>

the capacity...” (s6 (1)(a)), which suggests decision-making capacity is viewed on a spectrum. However, in practice it is treated as an ‘all or nothing’ determination as the legal implications for a person who is defined as ‘partly lacking capacity’ under the Act is the same as someone who wholly lacks capacity. Both result in a substituted decision-making process.

13. Legislation should instead recognise that all people have the right to make decisions, regardless of their “degree of incapacity”. Affected decision-making capacity should not minimise the need to establish a person’s will and preferences and provide all support necessary to maintain a person’s decision-making autonomy. This would ensure that our legislation better reflects the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) purpose and articles which aspire to “promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity”².
14. Some have argued, in light of UNCRPD discussions that legislative frameworks around supportive decision-making should not require a determination of capacity at all, as all people, regardless of their decision-making capacity retain legal decision-making responsibility³⁴. Whilst we agree that all should retain legal decision-making responsibility, we wonder how an approach which does not require an assessment of capacity could ensure adequate protections. Instead, we feel that a consistent definition and assessment for decision-making capacity across all law could support UNCRPD’s intent.

Recommendation:

Decision-making capacity, and the assessment of this is consistently defined across all legislation, such as in Section 9 of the Substance Addiction Act 2017.

Legislation is orientated around supported decision-making principles included in UNCRPD, namely:

- **Recognising that disabled people (no matter their decision-making capacity) should enjoy legal capacity on an equal basis with others in all aspects of life.**
- **That disabled people should receive the support they require in exercising their legal capacity, and freedom to make their own choices.**

PROTECTION OF ADULTS WHOSE DECISION-MAKING IS SIGNIFICANTLY AFFECTED

15. A nuance which needs to be considered further, is the needs of the small group of individuals who not only ‘wholly’ lack capacity but are severely limited in their ability to contribute to decision-making because of the impact of their disability.

Case example 1:

P is a 40-year-old who was born with a severe brain injury. She is able to walk and can show her preferences such as which activity she’d like to engage in, or where she would like to go. However, she needs support with any daily activities including eating, washing, dressing and

² United Nations. (2006). Convention on the Rights of Persons with Disabilities. Retrieved from: <https://www.un.org/disabilities/documents/convention/convoptprot-e.pdf>

³ Law Commission of Ontario. (2015). Legal Capacity, Decision-Making and Guardianship: Interim Report. <https://www.lco-cdo.org/wp-content/uploads/2016/01/capacity-guardianship-interim-report.pdf>

Harding, R.; Taşcıoğlu, E. Supported Decision-Making from Theory to Practice: Implementing the Right to Enjoy Legal Capacity. *Societies* 2018, 8, 25. <https://doi.org/10.3390/soc8020025>

⁴ Harding, R.; Taşcıoğlu, E. Supported Decision-Making from Theory to Practice: Implementing the Right to Enjoy Legal Capacity. *Societies* 2018, 8, 25. <https://doi.org/10.3390/soc8020025>

toileting. P does not communicate verbally, and is unable to use communication tools, however, does express discomfort and anger via sounds which her family recognise and respond to. P lives with her parents who are now getting older and finding full time care of P increasingly challenging because of their own health needs. Decisions need to be made around P's ongoing care and living arrangements.

16. This case example shows the complexity associated when disabled persons are unable to fully express their wills and preferences in relation to a decision due to the severity of their disability. Under the current law, it is likely that P would have a welfare guardian (probably one of her parents) under the PPPR Act. Her welfare guardian would therefore be able to make decisions regarding her care without her input (under the premise of best interests), however, under this legal framework there are no safeguards for P around her rights, or ensuring living arrangements are working for her, particularly should her parent's health deteriorate further.
17. This is an area of law which needs strengthening to ensure that the rights of disabled people with severely affected decision-making are protected, and their whānau adequately supported to apply supported decision-making principles when substituted decision-making cannot be avoided. The United Kingdom seeks to achieve these protections via an Office of the Public Guardian, which protects the interests of those whose decision-making capacity is affected by maintaining a register of attorneys, deputies and guardians and ensuring they are carrying out their legal duties, investigating concerns, and generally providing support and guidance⁵. Similarly, the Australian Office of the Public Guardian carries out investigations of abuse of an adult with affected decision-making capacity as well acting as a guardian for those who do not have suitable family or others⁶.
18. We do not necessarily agree with a model where decision-making can be relinquished to an institution such as the Office of the Public Guardian, however, increasingly we are working with disabled persons who have limited support and cannot identify anyone suitable as an EPOA, welfare guardian, or property manager. Welfare Guardian Trusts are used in such circumstances here in Aotearoa New Zealand, however, such arrangements are fraught, particularly because of the use of volunteers and lack of safeguards within our law. The issue of how the law should address what to do when no suitable person can be found to support someone whose decision-making capacity is affected needs careful consideration.
19. A parallel issue relevant to protection of decision-making rights is that it is becoming more common for residential care providers to require a legal substituted decision maker be appointed (whether via an activated EPOA or a court order) before they will accept a person with affected decision-making capacity into their care. This tends to be regardless of whether the person and whānau are in agreement regarding the placement. This practice does not align with social work professional values nor principles of supported decision-making as it again suggests an 'all or nothing' approach to decision-making capacity and essentially requires removal of a disabled persons legal decision-making rights in order for them to access care. Clarity is needed around prioritising supported and whānau-led decision-making processes to mitigate such interpretations, whether it relates to day-to-day choices or larger decisions whilst a person with affected decision-making capacity is in their care.
20. Regular formal reviews of decision-making arrangements are essential. Instead of reapplications to the court as per the current processes, annual review processes could include reassessment of

⁵ Office of the Public Guardian (UK). (n.d). *About Us*. <https://www.gov.uk/government/organisations/office-of-the-public-guardian/about>

⁶ Office of the Public Guardian (Aust). (n.d). *What we do*. <https://www.publicguardian.qld.gov.au/about-us/our-purpose>

circumstances which would ensure that supported decision-making is still being followed, and any change in circumstances, i.e., if there are additional whānau members providing more support, or conversely if those who were initially identified are no longer able to fulfil their roles. Social workers bring skills around human-rights and strengths-based approaches and are skilled at mobilising natural supports and clarifying unspoken family dynamics, therefore including social workers in this review process could be an effective way of supporting disabled persons and their whānau with longer-term decision-making arrangements.

21. We support establishing a separate statutory body whose role it is to support and protect those with affected decision-making, including an investigative safeguarding and review function which would better ensure accountability and protection for this group of disabled adults. The Abuse in Care Inquiry has highlighted how adults with affected decision-making capacity have been failed by institutions who were meant to care for them. Much stronger protections are needed for disabled adults to avoid repeating these horrific circumstances and ensure their right to make choices is upheld.

Recommendation:

Careful consideration is given to the issue of how the law should address what to do when no suitable person can be found to support someone whose decision-making capacity is affected.

Formal annual reviews of decision-making arrangements be required, and that social workers are delegated to carry these out alongside whānau.

A statutory body is established to support and protect adults with affected decision-making capacity and oversee, review arrangements and support whānau and others who play a role in supported decision-making.

SIMPLIFYING APPLICATION PROCESSES AND INFORMATION

22. We commonly hear from whānau their frustration in understanding and completing court applications. Complex legal language and jargon makes them extremely difficult to understand, particularly when whānau are already experiencing heightened stress. Many whānau simply cannot afford legal advice or assistance during this process. Social workers increasingly find themselves supporting or making applications on behalf of whānau they are engaged with. This support clearly does not constitute any sort of legal advice given this falls well outside of our scope of practice.

Case Example 2:

S is in her 70s and has a diagnosis of dementia. Recently, it has been getting worse, she has started wandering at night and getting aggressive towards her husband who cares for her. One night S falls and is admitted to hospital. The team at the hospital is recommending that S moves into dementia care but she doesn't understand and has no one to make this decision for her. S's husband assumed he could make decisions for her as her 'next of kin'. He's now been asked to apply to the Family Court so that she can go to the care home, but he's never been much of a reader and is having trouble making sense of the forms - there's so many pages and he can't understand what they're saying. A social worker helps S's husband with understanding the application and tells him more about Enduring Powers of Attorney. He wishes he had known about them before this, but from the information he's been given they probably couldn't afford the legal fees to make one anyway.

23. There is very limited information available for those making applications in simple language. This is a significant barrier for whānau, and often results in applications having to be made while in 'crisis' when an urgent decision is necessary. These situations have flow-on affects particularly in mental health and hospital settings where people with affected decision-making capacity may not be able to be discharged into more suitable care while their court application is pending.
24. Legal costs associated with making Enduring Powers of Attorney act as a significant barrier and may contribute to inequitable outcomes. Disabled persons who are already experiencing financial disadvantage, are less likely to have chosen their own representative via creating an EPOA prior to their decision-making capacity becoming compromised. This is more likely to result in mechanisms where decision-making is made by those who are not close to them or aware of their will or preferences. Therefore, all legal decision-making processes need to be truly accessible to all, via both simplicity and accessibility of information and application processes, and cost. Legal aid is not always accessible nor available in these situations and funding for EPOA's when a hearing is required before the Family Court was only introduced in September 2022.

Recommendation:

Information is accessible to everyone, avoiding complicated forms and language.

Processes enable disabled persons and applicants to access legal aid.

COLLECTIVE DECISION-MAKING AND TE TIRITI O WAITANGI

25. Within current legislation, there is no provision for collective decision-making. For example, under the PPPR Act only one person can be appointed as a welfare guardian or EPOA, and under the Mental Health and Substance Addiction Acts it is specialists who make the decision regarding assessment and treatment. This is particularly concerning when considered within the context of the Crown's obligations under Te Tiriti o Waitangi.
26. Colonisation has eroded trust, particularly for Māori in institutions and care settings where structural racism remains very real. An individualistic, paternal approach to decision-making is not only inconsistent with collective worldviews such as tangata-ō te whenua, but actively maintains colonising processes by prioritising the 'expertise' of practitioners. We argue that this breaches Article 2 of Te Tiriti as it does not allow Māori to exercise tino rangatiratanga in their decision-making, and instead through legal processes mana is trampled upon and tikanga disregarded. Such an individualistic model is no longer fit for purpose in Aotearoa New Zealand.
27. As noted in the consultation document, culturally specific practices and values also influence decision-making, however they are not necessarily homogenous and can differ within cultures such as with tikanga. This needs to be recognised via collective decision-making processes which better reflect real life and diversity within whānau and cultural worldviews and practices.
28. There are examples of collective decision-making processes in other fields which could be drawn on in this mahi. For example, Family Group Conferences are legislated in the Oranga Tamariki Act 1989. This process, used in care and protection and youth justice, supports collective decision-making for children and young people. Children/young people and their whānau, relevant professionals and trusted others come together to consider the care and protection or offending concerns the child or young person, and develop a whānau led plan, including the support whānau

identify they need to carry it out successfully⁷. Such a framework could be translated into the adult decision-making field, but like Family Group Conferences, would need to be included in legislation to ensure consistent application. Documenting decisions could provide care providers with the reassurance they need whilst ensuring an inclusive and collective supported decision-making approach is adopted. A consistent threshold would need to be established around what sorts of decisions should be addressed via this process, however, it could substantially look like the sorts of decisions set out in section 10 of the PPPR Act currently⁸. This would mitigate the risk of day-to-day decisions requiring such a process, yet the legal framework should still make it clear that collective and supported decision-making approaches, led by whānau, should be encouraged outside of these parameters.

Recommendation:

Collective decision-making frameworks which prioritise whānau-led decision-making should be adopted within legalisation.

AN ALTERNATIVE LEGISLATIVE MODEL

29. Here we propose an alternative model which addresses what we believe are some key tensions in the current process. The features of this process are:

- Moving from a court to a tribunal process
- That determination of affected decision-making capacity triggers a formal supported decision-making process for decisions which fall under remit of legislation
- Ensuring access to legal representation for the affected person
- Ensuring access to an approved social worker to facilitate the supported decision-making process
- Establishing iwi-led processes to ensure Māori are leading in decisions for Māori
- Providing for an appeal and review process

Establishing an Adult Decision-Making Tribunal

30. Currently, the Family Court in Aotearoa New Zealand makes decisions relating to a wide range of matters including child protection, family violence, separation and custody, challenges to wills, changing birth certificates, division of property as well as decisions relating to affected decision-making capacity. As a result, the Family Court experiences significant pressure. This often leads to delays in hearing cases and making orders.

31. We propose that all matters relating to affected adult decision-making capacity are moved to a tribunal model for two reasons. Firstly, this would ensure cases were heard in a timelier manner, as matters resolved through supported decision-making processes would be the only delegation held by this tribunal. Secondly, it would reinforce principles which sit behind collective and supported decision-making as determinations would no longer be based upon a single judges' legal opinion, but multiple tribunal members with various perspectives and expertise in matters relating to affected decision-making capacity. Legislation could specify the requirements of appointed panel members to ensure legal representation, medical representation, social work representation, lay representation, and Māori representation. This would ensure considered and holistic assessment of applications in often complex social and medical matters.

⁷ Oranga Tamariki. (n.d). About family group conferencing. <https://practice.orangatamariki.govt.nz/our-work/interventions/family-group-conferencing/about-family-group-conferencing/>

⁸ Protection of Personal and Property Rights Act 1998. <https://www.legislation.govt.nz/act/public/1988/0004/latest/whole.html#DLM126583>

Legislating a Formal Supported Decision-Making Process

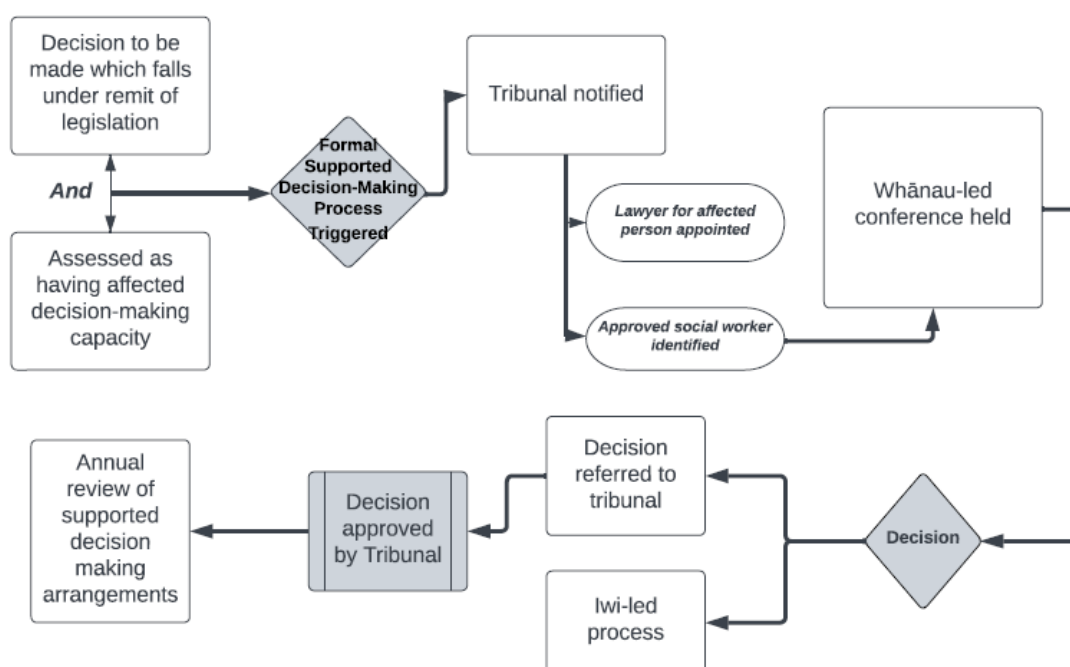
32. Before a decision is referred to the tribunal, it should go through a formal supported decision-making process. This process should be triggered by a need to resolve a decision which falls under the remit of legislation *and* a determination of affected decision-making capacity by a medical practitioner or approved social worker. Decisions which should fall under the remit of this formal process are adequately set out in the PPPR Act (s10). However, matters which relate to decision-making around assessment and treatment under the Mental Health Act and the Substance Addiction Act would also need to be included.
33. If a formal supported decision-making process is triggered, this should be referred to an approved social worker who could facilitate this process. We recommend that approved social workers be appointed by the tribunal or be a registered social worker who is already working with the disabled person and their whānau (such as in a hospital, primary care, mental health, iwi or community setting).
34. Supported decision-making processes could look similar to family group conferences, where a whānau-led meeting is held to consider the issues at hand, and a decision is made by whānau alongside the person whose decision-making is affected. This meeting should also include other supports as identified by the person, and relevant professionals who can provide advice and support when the affected person and whānau request it. Given the possible implications on an individual's human rights, a tribunal appointed lawyer should be present, having already met with the affected person to establish their views and wishes and concerns, so that the person has legal representation throughout this process. Whoever completed the capacity assessment should also be present to ensure that the affected person is supported appropriately, encouraging them to exercise their decision-making capacity to the degree in which they are capable of and supported in further decision-making by their whānau and trusted others.
35. The decision reached by the affected person and their whānau should then be referred to the tribunal with supporting evidence as to why the supported decision-making process was triggered under the legislation. The tribunal would then issue a determination which supports this decision before it is carried out.
36. If the tribunal wishes to issue a determination which differs from whānau outcomes agreed at the supported decision-making conference, this should be escalated to the Family Court for resolution. Although this would then enter the Family Court process, it's anticipated that only a small number of cases would be referred. This provides accountability for the tribunal in ensuring it is acting in accordance with supported decision-making principles.
37. Importantly, an iwi led process should be available when the affected person is Māori. This would ensure legislation reflects the Crown's commitment to Te Tiriti o Waitangi, and processes reflect tikanga Māori. We recommend further work with iwi to determine what this process should look like, to ensure decisions related to Māori are made by Māori. Ideally, those working with whānau Māori (i.e., social workers and lawyer) would be Māori.

Providing for an Appeal and Review Process

38. There are often situations where decision-making capacity is not affected permanently, there are disputes regarding decision-making capacity or the decisions made. Therefore, an appeals process should be available. This appeals process should be via the tribunal, where the matter could be referred to an approved social worker to investigate and establish whether an immediate review is required to resolve the concerns.

39. A review process should be an annual requirement whilst an affected person is requiring formal supported decision-making. This should be led by an approved social worker who convenes whānau conferences and makes recommendations to the tribunal regarding whether the original determination is still relevant for the affected person and their whānau and proportionate. At this stage further determinations may be necessary and so the supported decision-making process may be triggered again if it cannot be resolved as part of a review conference.
40. This review process would act as a protection for persons with affected decision-making capacity, ensuring that a formal supported decision-making process is still appropriate, and that in implementing the decisions originally agreed, they are being adequately supported and cared for. Approved social workers to carry out these reviews could be contracted from community providers by the tribunal or established as a separate review and assessment arm of the tribunal.

Figure 1: Proposed Formal Supported Decision-Making Process



SUMMARY OF RECOMMENDATIONS

1. Decision-making capacity, and the assessment of this is consistently defined across all legislation, such as in Section 9 of the Substance Addiction Act 2017.
2. Legislation is orientated around supported decision-making principles included in UNCRPD, namely:
 - Recognising that disabled people (no matter their decision-making capacity) should enjoy legal capacity on an equal basis with others in all aspects of life.
 - That disabled people should receive the support they require in exercising their legal capacity, and freedom to make their own choices.
3. Careful consideration is given to the issue of how the law should address what to do when no suitable person can be found to support someone whose decision-making capacity is affected.

4. Formal annual reviews of decision-making arrangements be required, and that social workers are delegated to carry these out alongside whānau.
5. A statutory body is established to support and protect adults with affected decision-making capacity and oversee, review arrangements and support whānau and others who play a role in supported decision-making.
6. Information is accessible to everyone, avoiding complicated forms and language.
7. Processes enable disabled persons and applicants to access legal aid.
8. Collective decision-making frameworks which prioritise whānau-led decision-making should be adopted within legalisation.
9. That consideration is given to our proposed legislative model.

CONCLUSION

41. As a profession which is passionate about social justice and equitable outcomes for all, this issue strikes at our heart. We hope to see a future where legislative mechanisms around decision-making capacity uphold the inherent dignity and worth of disabled people, ensuring that they retain autonomy around their choices and are supported in a holistic, inclusive, and collective way. We also hope to see protections for those with affected decision-making capacity, to ensure that atrocities of the past such as those uncovered during the Abuse in Care Inquiry cannot be repeated.
42. We thank you for providing the opportunity to submit on the Preliminary Issues Paper for He Arotake I te Ture mō ngā Huarahi Whakatau a ngā Pakeke I Review of Adult Decision-Making Capacity Law. Please find our contact details below should you wish to discuss any of our submission content, we would be happy to engage with you on this further.

ABOUT ANZASW

The Aotearoa New Zealand Association of Social Workers (ANZASW) is the professional association for social work in Aotearoa New Zealand. We have over 3,600 members who work throughout the community in both statutory social work and community social work settings. We advocate on behalf of members for social change and justice.

Definition of social work

Social work is a practice-based profession and an academic discipline that promotes social change and development, social cohesion, and the empowerment and liberation of people. Principles of social justice, human rights, collective responsibility and respect for diversities are central to social work. Underpinned by theories of social work, social sciences, humanities and indigenous knowledges, social work engages people and structures to address life challenges and enhance wellbeing.⁹

⁹ Global Definition of Social Work - International Federation of Social Workers and International Association of Schools of Social Work

Social work in Aotearoa New Zealand

Social workers in Aotearoa are required to be registered with the Social Workers Registration Board. Social workers are registered under the Social Workers Registration Act 2003 and are not included in the Health Practitioners Competence Assurance Act 2003.

Contact details

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