



**Submission to Te Aka Matua o te Ture | Law Commission on
the Review of Adult Decision-Making Capacity Law:
Preliminary Issues Paper.**

28 February 2023

About the NZACA

1. This submission is from the New Zealand Aged Care Association (NZACA), the peak industry body for the aged residential care (ARC) sector in New Zealand. We represent over 37,000 beds of the country's care home industry, or about 93% of the total supply. Our members' services include four categories of care – rest home, hospital, dementia and psychogeriatric, as well as short-term care, such as respite.
2. Thirty-four percent of services are operated by publicly listed companies, and the remaining 66 percent are made up of religious institutions, charitable trusts, family-owned, not-for-profits, and privately owned facilities.
3. We provide leadership, policy, and advocate for a sustainable and thriving aged residential care sector where every person can access care where and when they need it.
4. We offer professional development, research, information, and publications to help our members make informed business decisions, improve capability (both business and clinical) and keep them up to date with sector developments.
5. The NZACA welcomes the opportunity to make a submission to Te Aka Matua o te Ture | Law Commission and assist in shaping the very important law on adult decision-making capacity.
6. A summary of key recommendations can be found at the end of this submission.

ARC and affected decision-making

7. New Zealand's population is ageing rapidly. By 2030, one in four people will be aged over 65. This major change, together with multiple factors reducing the number of potential family carers, means that there is a corresponding year on year increase in demand for long term aged care.
8. Dementia is also on the increase, with the number of Kiwis living with the condition predicted to more than double in the next 30 years.
9. A person with dementia may be assessed as needing one of the following two levels of long-term care:
 - a. Dementia: This level of care is for those who need a secure home, usually because there are safety concerns for themselves or others.
 - b. Psychogeriatric Specialist Hospital: This level of care is designed for people with a mental health or dementia disorder who require a high level of nursing care and management of challenging behaviour. They need a secure environment and the skills of specially trained staff.
10. At of 30 September 2022, 12.6 per cent or around 6,000 of the country's aged care beds were dedicated to dementia or psychogeriatric care. 5,366 residents occupied these beds, most being long-term residents, but also some short-term respite stays as well as YPD (younger people with disabilities) aged under 65 years.

11. This is not to say only 5,366 residents in ARC have dementia; it is common for residents receiving care at rest home or hospital level to have some degree of dementia or age-related cognitive decline which affects their decision-making.
12. NZACA estimates the national average occupancy rate for dementia beds, taking into account beds non-operational due an ongoing shortage of registered nurses (RNs), to be 91 per cent. Dementia beds are at or near full occupancy in at least six districts. Many people in need of care are unable to find a bed within their community; this is a particular issue in rural and low socio-economic areas.
13. ARC has also become a primary provider of end-of-life care, with increasing numbers of people in New Zealand admitted-to-die (within three months of admission), including those under 65 years. The public hospital environment is considered inappropriate and costly for those dying over weeks to months of incurable illness, and hospice capacity is increasingly strained.¹
14. Enduring Powers of Attorney (EPOAs) in ARC will be a key focus of our submission, but we will also cover the role of other arrangements including decision-making supporters.

Overall comment

Chapter 2: The language we use in our review.

Question 1. Do you agree with the terms we propose to use in our review? If not, what changes should we make?

15. Dementia is not a specific disease but is rather a general term for the impaired ability to remember, think, or make decisions that interferes with doing everyday activities. Alzheimer's disease is the most common type – which around two-thirds of people with dementia have. Dementia is progressive, and for most people the changes gradually spread through the brain and lead to the symptoms getting worse.
16. Some of the impairments caused by Alzheimer's or other types of dementia meet the definition of a disability in that they affect a person's ability to do certain activities and interact with the world around them. However, we do not feel as though the term 'disabled person' is suited to describe older New Zealanders with dementia. Some people with dementia may prefer the term 'person with a disability', and as the Commission has recognised, others may not identify with the language of disability at all.
17. We agree with the term 'mental distress'. This could cover some shorter term conditions which commonly affect older people such as delirium and medication side effects.
18. Given the significant, and increasing, population of older people experiencing cognitive decline, including dementia, having terminology that fits this group is important.

¹ <https://journal.nzma.org.nz/journal-articles/what-does-palliative-care-look-like-in-a-new-zealand-aged-residential-care-facility-when-patients-are-admitted-to-die>

Chapter 3: Why is reform needed?

19. While there are no specific consultation questions in this chapter, we take the opportunity to address point 3.4 on institutionalisation. In 3.4, use of the term disabled appears to reference people with an intellectual disability or those experiencing mental distress (and no doubt some with dementia) who, in the past, were removed from society. This was a period in which these conditions and best practices for care were sorely misunderstood. Many of these people now live full and valuable lives as part of their communities.
20. For those with advanced dementia, often an aged care home is the best, and safest place to live. Moving to a care home does not mean whānau are no longer involved with care, rather, they now have the support of dementia professionals and can work in partnership with them to continue caring and supporting their loved one.

Chapter 4: Legal context to the review.

21. ARC is a heavily regulated sector, undergoing regular certification and spot audits by the Ministry of Health (MOH). Some of the legislation with which providers must comply includes the Pae Ora (Healthy Futures) Act 2022, the Health and Disability Services (Safety) Act 2001 and the Health and Disability Commissioner (Code of Health and Disability Services Consumers' Rights) Regulations 1996.
22. Since July 2021, the Office of the Ombudsman has been carrying out Optional Protocol to the Convention against Torture (OPCAT) inspections of dementia and psychogeriatric units within aged care facilities to check residents' treatment and conditions.
23. In the document *OPCAT – Expectations for conditions and treatment of residents in health and disability places of detention – aged care, June 2022* it states the Ombudsman's expectation that, "Residents, their Enduring Power of Attorney or Welfare Guardian (authorised representative), whānau and others, including staff members, have a role in decision-making. They are able to share their views and concerns, in particular about the conditions and treatment of residents. Residents, authorised representatives, whānau and community members have a high degree of trust in leadership and staff."
24. Many different decision-making arrangements take place in ARC every day, with our highly specialised RN and healthcare assistant (HCA) workforce supporting residents and their whānau in these processes.

Chapter 5: Te ao Māori me ōna tikanga

25. The updated Ngā Paerewa Health and Disability Services Standard (HDSS) NZS 8134:2021 came into effect in February 2022. Ngā Paerewa reflects the shift towards more person- and whānau-centred health and disability services. This is the Standard upon which ARC facilities, and other health and disability providers, are audited by HealthCERT for the MOH.
26. The updated HDSS includes additional responsibilities for service providers under te Tiriti o Waitangi to be responsive to the needs of Māori and to actively promote te reo Māori and tikanga Māori throughout organisations and their activities. While our members have worked to quickly

meet Ngā Paerewa, increased auditing requirements have not been funded by government making truly meaningful change out of reach for many.

27. Along with many of its members, the Association's te ao Māori journey is one in progress. We welcome this review recognising te Tiriti and tikanga Māori.

Chapter 6: Principles for our review

Question 5. Do you agree with the seven guiding principles we have developed? If not, what changes should we make?

28. Overall, yes, a strong set of principles have been identified.
29. We question the use of the 'lead flourishing lives' in Principle 4. While aspirational, it may not be realistic for some adults with affected decision-making capacity to be seen as living a life in which they thrive due to the severity or degenerative nature of their condition. We agree that all people should be empowered to be involved in making decisions for themselves wherever possible to reach the best outcome for their health and wellbeing.
30. We agree with Principle 5 that the law should recognise and facilitate relationships built on trust. In ARC, the role of supportive decision makers is an important one. These may include a resident's whānau and loved ones, care home staff, outside support organisations such as Age Concern or an advocacy service, and religious groups. Unfortunately, our members do report instances of these trust-based relationships being abused by resident's families.
31. The review identifies that a significant proportion of elder abuse cases involve family members. It is very important that a person, while they have the decision-making capacity, make their wishes for later life clear and in writing. This includes who they wish to support them in decision-making, both informally and as an EPOA if/when the time comes.

Chapter 7: Decision-making arrangements.

Question 6. Has someone supported you to make a decision, or have you been a decision-making supporter to someone with affected decision-making? If so, how well do you think that process worked? What could be improved?

32. While supported decision-making relationships generally work well in ARC, they can become complicated when family disagree over the care of a loved one. Managing these relationships and the expectations of different family members can be difficult and time consuming for care home staff. In ARC, information can be shared with a nominated next of kin or EPOA and it is expected they will disseminate to relevant other persons.
33. When thinking about giving decision-making supporters power to access relevant personal information (subject to appropriate confidentiality obligations) the Commission must consider a provider's capacity to share this information with multiple people. Should a resident with decision-making capacity wish to share their medical notes or other information with a decision-making supporter, they can request copies to do so.

Question 7. Have you experienced making, or been involved in using, an advance directive? If so, how well did you think that process worked? What could be improved?

34. It is uncommon for an older person to enter aged care having prepared advance directives or an advanced care plan. Upon admission to ARC, the RN-led healthcare team will work with the new resident and their next of kin or EPOA (where applicable) on their care plan. Doing this at the time of admission, and reviewing the plan regularly, gives the healthcare team a good understanding of the residents wishes and can help ensure their preferences are being met right through to end-of-life care.
35. When a resident is admitted with an EPOA already enacted and no advance directives or advanced care plan written, the attorney is relied on to act in their best interests and convey their preferences when it comes to the care they receive. This can be difficult for the attorney if the donor has not made their wishes clear.
36. There are many resources available including from the Health Quality and Safety Commission and the Health and Disability Commission. If New Zealanders were better educated on advance directives and advanced care plans, we would likely see an increase of older people entering aged care more prepared. We see that Te Whatu Ora and Te Aka Whai Ora, along with the GP network would have a role to play in communicating with consumers.

Question 8. Have you made, or been involved in using, an enduring power of attorney? If so, how well did you think that process worked? What could be improved?

37. When an older person living in the community requires support, they must undergo a needs assessment by their local Needs Assessment Service Coordination (NASC) agency. The assessment will determine the needs of the person and what type of care they should receive, from home support to secure care in an ARC facility.
38. In New Zealand, trained nurses and registered healthcare workers use interRAI (a suite of clinical assessment instruments) to assess an older person's care needs both in the community and in ARC and public hospital settings.
39. If a person is assessed from their home as needing dementia level care, the NASC team will support them to prepare for this move, including enacting an EPOA. If there is no EPOA, a care home has the right to decline the admission, however in practice, rather than leave the new resident at home where they are unsafe, the facility will take the admission providing there is firm evidence that the Welfare Guardian Order has been filed.
40. Designated Auditing Agencies (DAAs) regularly audit all care homes on behalf of HealthCERT/Ministry of Health (MOH). The MOH DAA Handbook states that, in relation to specialist dementia services, an auditor shall check that "all residents have an Enduring Power of Attorney that has been enacted, where an EPOA is not in place the provider is supporting actions to have one appointed." ARC providers will not be meeting their contractual obligations if they have residents in dementia care without an EPOA.
41. A serious issue arises for care homes when residents at either rest home or hospital level care are interRAI assessed as needing dementia level care, or there is a medical event which affects their

decision-making capacity, and they have not prepared an EPOA. This can cause delays with the resident receiving appropriate care services and payment delays to the facility. Around two-thirds of care homes are privately-owned or run by charitable or religious trusts. With the historic and chronic underfunding of the sector, a delay in receiving any payment owed represents a serious threat to some of our members' ability to remain operational.

42. We have heard that, on occasion, our members will pay out of their own pocket for an EPOA to be organised for a resident in their care, because they consider that not doing so would represent a greater financial risk. Others will support a next of kin through the Family Court process, which we hear is long and many families find the amount of paperwork daunting.
43. Prior to the commencement of the Ombudsman's function under OPCAT to inspect secure dementia units in ARC, we raised with Ombudsman Mr Peter Boshier the matters surrounding EPOAs.
44. For several years, both District Health Boards and the NZACA between them tried to address the issue where some residents in ARC do not have an EPOA in place as they enter and then reside in a secure dementia unit. Together, we sought support (without success) from both the Ministry of Health and Ministry of Justice for policy assistance to resolve the matter so that EPOAs are in place for all residents prior to admission to a secure dementia unit.
45. There can be a variety of reasons why a resident does not have an EPOA, one of which is cost that can be prohibitive for both a resident and their family. Sometimes there can also be cultural and family factors existing that mean an EPOA or even a care plan is not in place.
46. We support reviewing the process for making an EPOA. However, simplification and accessibility must be balanced with the legal safeguards and accountability mechanisms currently in place to ensure a person fully understands the process and there are no elements of coercion.
47. The Association strongly recommends that it should be a legal requirement for a person to have a written EPOA arranged prior to admission to all levels of long-term aged residential care. We suggest that in the instance where there is no EPOA for urgent rest home or hospital level admissions, agreement is made at time of admission to complete the process within three months. Having an EPOA should be mandatory prior to admission to dementia or psychogeriatric care.
48. With the above, it is not our intention to delay access to care for any New Zealander. As such, we recommend:
 - a. the Government provide financial support to those unable to afford an EPOA;
 - b. an education programme targeted at specific population groups including those reaching the age of 65, and cultural groups known to have low instances of EPOAs;
 - c. information on EPOAs be in an accessible format for different population groups;
 - d. people be supported by Te Whatu Ora/NASC to prepare an EPOA prior to admission to ARC.
49. We support the idea of a central register of EPOAs. When thinking about who can access this register, an aged care provider would need access to see contact details of both the personal care

and welfare and property attorney(s) for its current residents and those in the process of being admitted. We would expect that an ARC RN would have access to this register.

Question 9. Have you been involved in a process of making decisions for someone else under a court order, or having decisions made for you under a court order? If so, how well did you think that process worked? What could be improved?

50. When an older person is assessed as lacking decision-making capacity and there is no EPOA in place, a welfare guardian is appointed through the courts. This can be a lengthy process and again, delay access to the appropriate level of care for the resident. Having an EPOA as a requirement to enter ARC would avoid this process, which would also take pressure off the court system.
51. Where there is no next of kin or EPOA, the weight of decision-making falls to the ARC Facility Manager and the resident's GP. Some aged care providers have had to apply for a Personal Order, so they have the legal mandate to have someone with lack of capacity in their care. This is a difficult situation for the provider, particularly when trying to make decisions in the best interests of the resident at end-of-life.

Question 10. Do you think there should be more ways for other people to be involved, in a more collective way, in decision-making arrangements when a person's decision-making is affected? If so, how?

52. A key principle of the Ngā Paerewa HDSS is "Best practice through collaboration – Appropriate care includes understanding of the lived experience of people and whānau and shared decision making with them". Section 1.7 sets out the following rights for health and disability service users:
 - 1.7.2. I shall be empowered to actively participate in decision making.
 - 1.7.3. I shall have a right to supported decision making.
 - 1.7.4. My whānau shall be included in decision making with my consent and shall be enabled to do so through access to quality information, advice, and resources.
 - 1.7.6. My legal representative shall only make decisions on my behalf in compliance with the law. If my legal representatives make decisions for me, I still have the right to be included.
 - 1.7.7. My advance directives (written or oral) will be followed wherever possible.
53. We note the definition of whānau within Ngā Paerewa is "the family, extended family, or family group of people important to a person who is receiving a service... their partners, friends guardian, or other representatives chosen by the person".
54. The health and disability sector is already skilled in facilitating collective decision-making, and providers are audited on how they enable and empower decision-making for those using their services. We do not believe further formalising these relationships in law is necessary.

Question 12. What things might make decision-making arrangements easier or more effective?

55. We agree that some decision-making arrangements may benefit from template documents which could help set the boundaries of that arrangement in writing.

56. A central register for advance directives could be useful. However, their legal status would need to first be clarified along with a process for recording and updating any advance directive(s) a person holds.

Question 13. Do you think there needs to be safeguards or accountability mechanisms when a person with affected decision-making has an informal decision-making supporter? If so, what should they be?

57. There are already safeguards in place within ARC – including the resident having their wishes set out in a regularly reviewed care plan, and close relationships between staff and residents and their whānau meaning possible exploitation or abuse can be quickly identified. The ARC admission agreement sets out who has the right to be formally involved in decisions relating to the resident’s care and welfare or property.

Question 14. Do you think there needs to be safeguards or accountability mechanisms when a person uses an enduring power of attorney? If so, what should they be?

58. We would support an official process to monitor or investigate actions taken under EPOAs or respond to concerns, however we do not believe this needs to be in the form of a specific oversight or complaints body. This function could exist within HDC or Ministry of Justice. Often this role lands on the care home which does not have the resource nor expertise in this area.
59. A further accountability mechanism could be that, when setting up an EPOA, a donor nominates an additional individual or individuals who could support decision-making or be called on should concerns be raised about the actions of the appointed attorney.

Question 15. Do you think there needs to be safeguards or accountability mechanisms when a person moves to a rest home or care facility? If so, what should they be?

60. We find the terminology used in Scenario 3 unfortunate as it reinforces negative stereotypes and misconceptions held about aged care.
61. A number of our members are providing worldclass, innovative dementia services. We particularly draw your attention to The CARE Village in Rotorua, whose concept is inspired by the renowned Dutch dementia village, De Hogeweyk (<https://thecarevillage.co.nz/about/>). Also, Summerset Group which has just launched its first Memory Care Centre (<https://www.summerset.co.nz/about-us/news/summerset-wins-national-award-for-innovative-memory-care/>).
62. Depending on the severity of their condition, residents with dementia can go on outings with whānau. However, for many, leaving the confines of their home can be frightening and cause them to become upset and agitated. Inside a secure dementia facility is where they feel, and are, safest.
63. There are 650 aged care homes across Aotearoa, and they are filled with aroha and manaakitanga. One example of this came over the COVID-19 lockdown, when a number of care staff from dementia units across the motu moved into the facility to keep their residents safe. They sacrificed being with their own families for weeks to do so, knowing that leaving the facility would represent a risk to their residents should they contract COVID-19.

64. While we understand the move to a care home represents a massive life change and is often filled with trepidation, we think it's important the Commission, and government, use language around care homes that does not further stereotypes.
65. In Scenario 3, Linda's "family and clinicians decide she should be in a secure care home environment". For this move to happen Linda would need to have been assessed by a NASC agency as requiring dementia level care, i.e., that she was no longer being able to make decisions for herself or live safely at home. Family cannot simply decide to move a person into secure dementia care. Linda's case highlights the importance of having planned for an EPOA.
66. We do not support adding a specialist court or tribunal, or an independent person to authorise a move to aged care. This would add an unnecessary level of bureaucracy and further delay a person's move to ARC, where they will receive the care they need. In appointing an EPOA, a donor is trusting that person to make a good decision for them and this relationship should be honoured. It is only once a person is assessed by both a physician and NASC as lacking decision-making capacity that an EPOA can authorise the move to residential care.
67. We do not support a further process to monitor residents continued stay in a care home as a robust process already exists. Residents' care needs are regularly assessed using the interRAI tool, while care homes are regularly audited by HealthCERT and secure units by the Ombudsman. There is a robust complaints procedure in place for all residents and their families and providers must comply with the Code of Health and Disability Services Consumers' Rights.
68. In March 2022, the inaugural Aged Care Commissioner took office within HDC. The Commissioner makes statutory decisions on complaints and formal investigations into older people's health and disability services, to protect their rights under the Code.

Question 16. Do you think there needs to be safeguards or accountability mechanisms if a person has a welfare guardian? If so, what should they be?

69. We see any safeguards or accountability mechanisms for a person with a welfare guardian as being the same as for an EPOA (refer answers to Question 14).
70. Again, education and accessibility are paramount to avoid older Kiwis finding themselves in the position of being without an EPOA at a time they need one.

Question 17. Do you think there needs to be safeguards or accountability mechanisms to help supporters? If so, what should they be?

71. The safety and wellbeing of decision-making supporters, both formal and informal, is an important consideration. We agree with the Commission's suggested mechanisms to assist decision-making supporters.
72. The Nationwide Health and Disability Advocacy Service could have a role to play in supporting decision-making supporters and resolving disputes between the decision-making supporter and the supported person. We note it would need to be adequately resourced to provide such a service.

Conclusion/ key recommendations

73. Currently the law around EPOAs is not working well for the ARC sector and is affecting our members' ability to provide their residents with the right care at the right time.
74. The Association strongly recommends that it should be a legal requirement for a person to have a written EPOA arranged prior to admission to all levels of long-term aged residential care. We suggest that in the instance where there is no EPOA for urgent rest home or hospital level admissions, agreement is made at time of admission to complete the process within three months. Having an EPOA should be mandatory prior to admission to dementia or psychogeriatric care.
75. With the above, it is not our intention to delay access to care for any New Zealander. As such, we recommend:
 - a. the Government provide financial support to those unable to afford an EPOA.
 - b. an education programme targeted at specific population groups including those reaching the age of 65, and cultural groups known to have low instances of EPOAs.
 - c. information on EPOAs be in an accessible format for different population groups.
 - d. people be supported by Te Whatu Ora/NASC to prepare an EPOA prior to admission to ARC.
76. We support the idea of a central register of EPOAs. When thinking about who can access this register, an aged care provider would need access to see contact details of both the personal care and welfare and property attorney(s) for its current residents and those in the process of being admitted. We would expect that an ARC RN would have access to this register.
77. We would support an official process to monitor or investigate actions taken under EPOAs or respond to concerns, however we do not believe this needs to be in the form of a specific oversight or complaints body. This function could exist within HDC or Ministry of Justice. Often this role lands on the care home which does not have the resource nor expertise in this area.
78. We do not support adding a specialist court or tribunal, or an independent person to authorise a move to aged care. This would add an unnecessary level of bureaucracy and further delay a person's move to ARC, where they will receive the care they need. In appointing an EPOA, a donor is trusting that person to make a good decision for them and this relationship should be honoured. It is only once a person is assessed by both a physician and NASC as lacking decision-making capacity that an EPOA can authorise the move to residential care.
79. We do not support a further process to monitor a residents continued stay in a care home. Residents' care needs are regularly assessed using the interRAI tool, while care homes are regularly audited by HealthCERT and secure units by the Ombudsman. There is a robust complaints procedure in place for all residents and their families and providers must comply with the Code of Health and Disability Services Consumers' Rights.
80. Aged care provides an excellent service to older New Zealanders and to the Government in cost savings. While not a focus of this review, we have taken the opportunity to raise the benefits of ARC and address misconceptions throughout. In doing so we have highlighted the decision-making

arrangements already existing in ARC, how these are supported by highly specialised staff, and how care homes are audited to ensure they are meeting their obligations to residents.

81. The Association and its members are dedicated to seeing a thriving aged care sector. Subsequent governments have failed to adequately fund aged care leaving the sector in a precarious position. Without increased government funding to allow providers to invest in facilities and technology, Aotearoa's health system will be unprepared for the aptly named silver tsunami of aging baby boomers about to reach its doorstep.
82. Our above recommendations will be beneficial to older New Zealanders by helping ensure they have access to the care they need, when they need it, and that their wishes are clear when that time comes. Changes to the law should also support Aotearoa's ARC providers to have a clear process for resident admissions and ongoing decision-making, allowing them to focus on providing the highest quality services to the nearly 35,000 residents in their care.
83. We would be pleased to provide Te Aka Matua o te Ture with any further information required. For any questions regarding any part of this submission, please contact Policy Analyst Rebecca Chapman at rebecca@nzaca.org.nz or 04 473 3159.