
**Council on the Ageing New South Wales**

## Submission

# Review of the Guardianship Act 1987 (NSW)

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## The focus of the COTA NSW submission

The focus of our submission is on the application of the NSW Guardianship Act 1987 and the impact that any proposed reforms will have on the lives of older people living in New South Wales. All too often people's rights and autonomy are taken from them as they age, regardless of their disability status or mental capacity.

## Introduction

The proportion of older people in the population is increasing with the number of people aged 65 and over more than tripled over the past fifty years, rising to 3.4 million in 2014. In that same period there has been a nine-fold increase in the number of people aged 85 and over, to 456,600 in 2014. Based on population projections by the Australian Bureau of Statistics, there will be 9.6 million people aged 65 and over and 1.9 million people aged 85 and over by 2064 (AIHW 2016).

The Australian Institute of Health and Welfare (AIHW) reports that Australians are living healthier and longer lives than previous generations, with the majority of older Australians reporting that they are in good health. Nevertheless, an increased lifespan generally results in increasing levels of disability and complex health conditions, including dementia.

We know that as people age they become more vulnerable to having their rights and autonomy taken from them, regardless of their physical or mental capacity. Carers, family, care providers and others can, with good intentions or with bad, feel justified in taking over responsibility for many aspects of an older person's life, often without consideration of their wishes, because they believe they are acting in the person's best interests.

COTA NSW believes that the existing framework of the Guardianship Act 1987 (NSW) does not adequately address the needs of the increasing numbers of older people in the NSW population - particularly those with impaired mental capacity. In addition, the Act does not reflect current international, Commonwealth and state-based social policy and legal regimes.

COTA NSW supports the development of a new legislative framework that acknowledges every person's right to dignity and autonomy and protects a person's right to make decisions for themselves. Where a person is found to have impaired decision making, COTA NSW supports a system that encourages supported decision-making, with the person maintaining their full legal rights under the law for as long as possible. Substitute decision-making (other than by a person appointed by the patient themselves), where someone is appointed to make decisions on someone else's behalf should be seen as a last resort, even if the decisions are made 'in a person's best interest'.

## The rights of older people

Some disability advocates maintain that any substitute decision-making instrument takes away a person's basic human right to autonomy and self-determination. They argue that removing a person's fundamental right to make their own decision with a substitute decision-making instrument contravenes the United Nations *Convention on the Rights of Persons with Disabilities* (2008) to which Australia is a signatory.

COTA NSW agrees with the principles enshrined in the CRPD, which constitute a seismic shift away from the concept of substitute decision-making to that of supported decision-making, where a person with a physical or mental disability maintains their rights under the law to make their own decisions wherever possible. However, COTA NSW also believes that the disability paradigm, around which the current Act and many of the arguments for changing the Act exist, also needs to be changed.

Older people's rights in general have been neglected under human rights law. The Convention on the Rights of Persons with Disabilities (CRPD) offers some protection for older people (although not all older persons have disabilities) but the CRPD does not single out elderly people for special protection.

Acknowledging that elder abuse is a real problem and that the human rights of older people are often violated, COTA NSW believes that more needs to be done to protect the rights of people as they age. There have been moves in recent years to consider a separate convention on the rights of older people, with some nation states pushing for a stronger international human rights instrument (Fredvang & Biggs, 2004). The Open-ended Working Group on Ageing (OEWG), established by the UN General Assembly in 2010, seeks to strengthen the rights of older people by examining how existing instruments address older people's rights, identify gaps in protection, and explore the feasibility of new human rights instruments.

COTA NSW believes that an International Convention on the Rights of Older People would help set the standard in a similar way to what the UN Convention on the Rights of Persons with Disabilities has done for people with disabilities. It would also help establish legal standards and expectations of behavior and explicitly articulate how states should undertake their human rights obligations in relation to people as they age, as well as provide a broad framework for policy and law-making.

## The Aged Care Act 1997

Reflecting changes in the disability sector, the aged care sector has also undergone significant changes over the last few years, beginning with the Productivity Commission's Inquiry into aged care, summarised in the 2011 report, *Caring for Older Australians*. The Commission recognised that people "generally want to remain independent and in control of how and where they live; to stay connected and relevant to their families and communities; and be able to exercise some measure of choice over their care" (Productivity Commission, 2011, p XIX).

The age care reforms ushered in as a result of the Inquiry have shifted the focus of caring from institutionalised residential aged care to a system based around supporting people to live at home for as long as possible. It has also shifted the decision-making power from the service provider to the 'consumer' with a concept know as consumer directed care (CDC).

Consumer directed care puts the person, known as the 'consumer,' at the centre of decision-making, with the aim of giving them more choice, control and autonomy when making decisions about their own care. It allows the person receiving care to have ccontrol over the design and the delivery of the care they receive. This focus on consumer directed care in the aged care sector mirrors changes in the delivery of disability services as reflected in the National Disability Insurance Scheme (NDIS).

## Capacity as the basis of legislative reform

COTA NSW believes that the focus of legislation should be around assessing capacity for decision-making and not be confined to a person's disability status.

Under the common law, and consistent with Article 12 of the UN Convention on the Rights of Persons with Disabilities, COTA NSW agrees that all people should be presumed to have the capacity to make their own decisions and be supported to make such decisions while ever they maintain full legal capacity. In addition, the onus of proof that a person does not have capacity rests with the person making the claim, not with the person who is the subject of that claim. We believe that this right should extend to all people, regardless of their disability status.

When considering guiding principles, definitions of capacity, and guidelines for assessing capacity, COTA NSW suggests that the NSW *Capacity Toolkit* (NSW Attorney Generals Dept., 2008) provides a good basis for reframing the legislation, although it was originally written to operate within the current guardianship and substitute decision-making regime in NSW.

In 2012 the Victorian Law Reform Commission recommended that Victorian Guardianship legislation contain similar principles to the six capacity assessment principles outlined in the Toolkit (VLRC, 2012). COTA NSW suggests that when reframing the NSW legislation, both the definition of capacity and the principles in the Capacity Toolkit should be considered, as they more adequately reflect current international law and policy than the current Guardianship legislation.

We also agree with the Victorian Law Reform Commission, which recognises the complexity of capacity as a concept and as a legal issue and notes that any reform to the legislation must acknowledge the fact that people have different levels of cognitive impairment, and that the level of impairment can change over time, e.g. those people living with long term mental illness and those people in the early stages of dementia (VLRC, 2012).

We also support the Victorian Law Reform Commission's recommendation to provide a wide range of decision-making assistance to people needing such assistance, on a continuum of decision-making support ranging from autonomous decision-making to substitute decision-making (VLRC,2012).

## Decision-making models

COTA NSW believes that people's rights and ability to exercise their legal capacity should be supported for as long as possible, with substitute decision-making being the last resort.

This position is supported by the *International Convention on the Rights of Persons with Disabilities* and recent Commonwealth policy changes related to disability and aged care that emphasise consumer choice and control, as well as recent Guardianship law reforms in both Queensland and Victoria. We support legislation that includes both types of decision-making models (i.e., supported and substitute), but with broad principles that ensure that an individual's legal capacity to make their own decisions is maintained wherever possible.

In the Queensland Government's 2014 paper, *A journey towards autonomy? Supported decision making theory and practice, a review of the literature*, critics of substitute decision-making raised concerns that it is overused and misapplied. "This is worrying because of the significant impact on a person's civil rights as a result of a determination of a lack of capacity and an appointment of a substitute decision-maker" (Queensland Government, 2014). (Note, however, that where a person has appointed their own substitute decision-maker, those rights are much less likely to be infringed, except where loss of capacity is determined inappropriately).

In the *2006 Commonwealth Inquiry into Older People and the Law*, the Committee received numerous complaints in relation to the operation of guardianship boards and tribunals throughout Australia. Complaints received with regard to the NSW Guardianship Tribunal included: a lack of transparency and accountability in dealing with family members; lack of communication from the Tribunal; accounts from witnesses of being intimidated bullied or victimised by guardianship authorities; and (most serious), the denial of representation at a hearing (Commonwealth Government, 2006 p123). The Committee subsequently recommended that the "Australian Government propose that the Standing Committee of Attorneys-General conduct a review into the legal needs of older people appearing before guardianship boards and tribunals and consider options for improving their access to legal representation at hearings" (Commonwealth Government, 2006 p126).

We recognise that violations and abuse can happen with both substitute decision-making and supported decision-making models. We acknowledge that, in places where substitute decision-making is used, such as Canada, there is some criticism that there is not a lot of evidence about how successful supported decision-making models have been, with some critics arguing that the supported decision-making models are open to abuse.

However, we believe that, given the evidence that substitute decision-making can potentially lead to instances of abuse and exploitation, supported decision-making models should be integrated into the processes and practices of decision-making. The Office of the Public Guardian is well placed to promote supported decision-making models and even acknowledges in its December 2014 newsletter, *on the way to supported decision making,* that guardianship laws may "need to change" in response to the UNCRPD ( Public Guardian, Dec 2014).

## The language

COTA NSW believes that the language in the Act needs to be reframed and should be based around the determination of a person's decision-making capacity, regardless of their disability status.

In the United Kingdom, the *Mental Capacity Act 2005* emphasises supporting people to make decisions for themselves. That is, the UK Act applies to any person who requires help to make decisions and is not confined to people determined to have a disability. For example, under the Principles in Part 1, Section 1 of the Act "(3) a person is not to be treated as unable to make a decision unless all practicable steps to help him do so have been taken without success and (4) a person is not treated as unable to make a decision merely because he makes an unwise decision." There is no reference to a person's disability status.

COTA NSW therefore suggests that the language and definitions in the General Principles under Part 1 (4) of the current Guardianship Act need to be reframed. For example, the Act and its principles should not be limited to 'persons who have disabilities' but should apply to every person. Importantly, the term 'capacity' is not mentioned in the current principles, but should be the focus of a new set of principles in any reforms.

As suggested before, COTA NSW believes that when reframing the legislation, both the definitions of capacity and the language and intent of the principles in the NSW *Capacity Toolkit* should be considered, as they more adequately reflect current international law and policy.

## The need for regular reviews

COTA NSW supports yearly automatic review of financial management orders. We believe that the current situation, where financial management orders operate on a perpetual basis and are not automatically subject to review, presents opportunities for abuse. In addition, COTA NSW recommends that all financial management orders are lodged with the respective bank and/or other financial institution of the person who is subject of the order, and with transaction limits set to trigger a response, to guard against any unusual transactions.

## Other matters

### The 'Person Responsible'

The Act does not sufficiently articulate the rights and responsibilities of the 'person responsible' below the level of Enduring Guardian. It recognises the right of any relevant 'person responsible' to provide consent to medical and dental treatment, and also notes that a medical practitioner 'should give the person responsible all the information they would ordinarily give a patient who has capacity to make treatment decisions' (NSW Justice Public Guardian website http://www.publicguardian.justice.nsw.gov.au/Documents/fs2_person_responsible_jan2014.pdf). However, it makes no mention of the right of the 'person responsible' below the

level of Enduring Guardian to determine where the person should receive such treatment (e.g., at home, in hospital or in residential care) or where the person should live. These are issues about which there is often family conflict and it essential that the Act clearly states who has the legal authority to make such decisions.

An additional problem relating to 'person responsible' is that, if the first person in the 'person responsible' hierarchy does not want to be the decision-maker, the role does not automatically move to the next person in line; the first person in the hierarchy has to say in writing that they do not want to make the decisions.

An example of this might be, where an older woman has lost capacity and a decision is needed about whether or not an invasive procedure, which may be merely prolonging the dying process, should be continued or withheld (where withholding will lead to the woman dying). The woman had previously told family members she would not want such treatment continued. Her husband of 50 years cannot bring himself to consent to stopping the treatment but under the legislation as it stands, he must say in writing that he does not want to make the decision. While the requirement that he does so affords protection to the medical staff (providing evidence that the correct 'person responsible' made the decision), making him do so is likely to compound his grief with guilt about not being able to ensure that his wife's wishes were respected.

In Queensland, the Statutory Health Attorney (the equivalent of Person Responsible below the level of Enduring Guardian in NSW) is the first "readily available and culturally appropriate" of the same hierarchy as in NSW, and if the first in line does not want to take on that role they are considered not to be "readily available" and the responsibility moves automatically to the next person in line. We strongly recommend that NSW adopts these same provisions. The treating medical practitioner can make a note in the patient's file that this is what occurred, if they are concerned for their own protection.

**Enduring Guardianship forms and Advance Care Directives**

There is little in the legislation regarding the relationship between Enduring Guardianship forms and Advance Care Directives, two important substitute decision-making instruments. COTA NSW recommends that there needs to be explicit instructions regarding the relationship between these two instruments in the legislation. For example, many hospitals and health care providers still do not understand that if a person has completed an Advance Care Directive which meets the current situation, it is legally binding and takes precedence over the decisions of an Enduring Guardian, other 'person responsible', other family member or treating medical practitioner.

There is also further work required to ensure that both documents are readily available to treating health care providers. The *Inquiry into Older People and the Law* recommended that the Commonwealth Government, "investigate ways of encouraging those with advance health care planning arrangements to inform their health care providers of their arrangements." (P.119). COTA NSW strongly supports this position and recommends that that Enduring Guardian forms be included with the Advance Care Directive in each person's eHealth Record.

Finally, COTA NSW strongly recommends that additional resources be made available to conduct an education campaign with staff in acute, community and residential aged care services, as well as with the wider community, regarding the 'order of authority' for substitute decision-making. A case has just come to our attention where a major hospital in NSW said that the reason they allowed the wrong family member (a younger son) to consent to withdrawing treatment from an adult who lacked capacity was because he was listed as 'next-of-kin' on the medical records. As next-of-kin has no legal status with respect to substitute decision-making, and the primary carer was present and willing to make the decisions, such actions put the hospital at risk of legal prosecution. It is surprising – and disappointing – that despite the NSW Guardianship Act (which outlines the order of authority) having been in place for 29 years, state-funded health care facilities still do not have proper, correct processes in place.

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