



# Northern Territory Health Care Decision Makers

## Submission by Darwin Community Legal Service (DCLS)

DCLS is a multi-disciplinary service providing general legal advice, a Tenancy Advice Service, and a specialised Seniors and Disability Rights Service providing advocacy support in the areas of ageing and disability. We create awareness and empower our community, support access to services and rights, and advocate for change that promotes fairness and justice.

The Seniors and Disability Rights Service assists, and can advocate for, older people or people with disabilities and their representatives to:

- Understand their rights through information and community education
- Receive aged care services or disability support
- Engage with the Guardianship process
- Respond to Elder Abuse
- Raise systemic issues

## NT CONTEXT

Overall, the NT population experiences high levels of disadvantage. Aboriginal people form a significant part of our clientele (as they do for all mainstream services in the NT) and generally have the most complex and immediate needs. With 25.5 % of the NT population identifying as Aboriginal or Torres Strait Islander (compared with 2.8% of the total Australian population), and 76.6% living in remote areas<sup>1</sup>, the NT faces unique challenges in addressing many issues. These include the tyranny of distance, the lack of infrastructure, high costs relative to other jurisdictions, and the lack of economies of scale.

Remote locations are characterised by small populations, minimal infrastructure, and a lack of ancillary services. Basic services are generally provided by government or not-for-profit providers. Health care, and the associated decisions around such care, are a significant issue for the NT, with long-term health conditions affecting 90% of Aboriginal and Torres Strait Islander people over the age of fifty-five. <sup>2</sup>

The incidence of public guardianship in the NT is significantly greater than at other States and Territories. In 2018-2019, 62% of guardianship orders listed the Public

<sup>1</sup> ABS, 2016 Census,

<https://www.abs.gov.au/ausstats/abs@.nsf/MediaReleasesByCatalogue/02D50FAA9987D6B7CA25814800087E03>

<sup>2</sup> <https://www.aihw.gov.au/reports/older-people/older-australia-at-a-glance/contents/diverse-groups-of-older-australians/aboriginal-and-torres-strait-islander-people>

Guardian as sole or joint guardian, and 78% of represented adults under public guardianship identify as Aboriginal or Torres Strait Islander.<sup>3</sup>

The guardianship legislative framework in the NT is focused on 'substitute decision-making', a model that is out of step with current best practice and with Australia's commitments under the United Nations Convention on the Rights of Persons with Disabilities. There is a lack of services to support the exercise of the person's rights and wishes and limited take up of Advance Personal Plans (APPs).

## RESPONSE TO THE DISCUSSION PAPER

Outlined below are a number of critical issues which we consider need to be addressed as part of the reform process.

### Additional Burden on Family

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The proposed reforms seem to involve a shifting of responsibility to family and carers who may be ill-equipped, through lack of information or because of their relationship with the person, to make good decisions or deal with the decisions objectively. It is difficult to make an informed choice on behalf of another person when there is asymmetry of information. People do not necessarily have the health literacy to make critical decisions about loved ones at a time of crisis.

Medical professionals are trained to make appropriate decisions in the circumstances and have a professional responsibility to act in the best interests of the health and wellbeing of the client. There is some recourse in this situation for potential bad decisions, which may be waived if family members influence decision-making.

Many people may not wish to have this decision-making power and may choose to 'opt-out', resulting in possible delays and confusion.

DCLS would recommend that any movement away from public bodies to individuals comes with a requirement on health care providers to provide sufficient information for nominated decision makers to make an informed choice and independent support to assist in the process.

### Human Rights Focus

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The Discussion paper makes reference to the general principle of every adult having the right to determine their own health care, and that interference with an adult's human rights should be least restrictive. However, the proposed reform is clearly a form of substitute decision-making and does not sufficiently focus on the essential human rights for people who need decision-making support.

In assessing these provisions and how they fit within the NT guardianship framework reference should be made to the 2014 Australian Law Reform Commission (ALRC) Report, *Equality, Capacity and Disability in Commonwealth Laws* which recommends that

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<sup>3</sup> Office of the Public Guardian, 2018-2019 Annual Report

the reform of relevant Commonwealth, state and territory laws should be consistent with the National Decision-Making Principles:

***Principle 1: The equal right to make decisions***

*All adults have an equal right to make decisions that affect their lives and to have those decisions respected.*

***Principle 2: Support***

*Persons who require support in decision-making must be provided with access to the support necessary for them to make, communicate and participate in decisions that affect their lives.*

***Principle 3: Will, preferences and rights***

*The will, preferences and rights of persons who may require decision-making support must direct decisions that affect their lives.*

***Principle 4: Safeguards***

*Laws and legal frameworks must contain appropriate and effective safeguards in relation to interventions for persons who may require decision-making support, including to prevent abuse and undue influence.*

These principles emphasise the “autonomy and independence of persons with disability who may require support in making decisions—their will and preferences must drive decisions that they make, and that others make on their behalf.”<sup>4</sup>

In relation to existing statute law, we consider that the *Advance Personal Planning Act 2013* principles are more aligned with a human rights focus than those in the *Guardianship of Adults Act 2016*. If the reforms are to be enacted, then we support the exercise of decision-making authority in accordance the principles in Section 22 of the *Advance Personal Planning Act 2013*.

It is not sufficient, however, to adopt rights-based principles if they are not enabled. Implementation of these changes requires an accompanying piece of work and investment of resources in support of decision-making.

The Victorian law, referenced throughout the discussion paper, has a supported decision-making framework in place. “*Supported Decision Making in Victoria – a guide for families and carers*” provides people accepting decision-making appointments with practical information about supported decision-making and sets out when and how individuals may

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<sup>4</sup> <https://www.alrc.gov.au/publication/equality-capacity-and-disability-in-commonwealth-laws-alrc-report-124/>

be supported to have input into decisions concerning them.<sup>5</sup> It is a companion piece to the four Victorian laws which allow for supported decision-making:

- The National Disability Insurance Scheme Act 2013
- Powers of Attorney Act 2014
- Mental Health Act 2014
- Medical Treatment Planning and Decisions Act 2016.

It is recommended that the NT enact a similar framework to appropriately support the proposed changes.

## Substitute Decision-Making

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The Discussion paper focuses heavily on the concept of a ‘substitute decision-maker’ as the basis for proposed legislative change. The change omits the provision of support to ensure the decisions of the represented person take precedence. The wishes of the person must always be paramount. Substitute decision-making should be a last resort.

More work should be done in supporting decision-making of the person rather than seeking, in retrospect, substitute decisions based on a subjective assessment of best interests rather than the person’s rights.

The General Principles outlined in the Discussion Paper refer to every adult having the right to determine their own health care, and to protecting the adult’s rights to autonomy of decision-making in the least-restrictive way. These statements appear to support the concept of supported decision-making, yet reference to supported decision-making only appears once in the Discussion paper - in regard to law reform proposals elsewhere in Australia.

The Discussion Paper refers to the reformed legislation promoting the “least restrictive interference of an adults’ right of autonomy of decision and action.” This by definition would be supported decision-making, not substitute decision-making.

Fundamentally, substitute decision-making takes away an individual’s right to make their own decisions, or to participate in that decision-making to the extent they are able. Although theoretically a substitute decision-maker makes decisions in accordance with the person’s views and wishes, from DCLS’s work with older people and those with disability, the decision made by a substitute decision-maker does not always accord with the decision the individual themselves would have made, had they been able to at the time. There is limited use of APPs in the NT and often little information available to guide these decisions.

The use of the term ‘best interests’ in the Discussion Paper is also problematic, as without a supported decision-making model in place, there may be confusion around when a person should be consulted regarding decisions concerning their life, and when the decision-maker determines ‘best interests’ without consultation.

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<sup>5</sup> Victorian Office of the Public Advocate, 2017, Supported Decision Making in Victoria – a guide for families and carers

The Discussion Paper comments that the “NT has drawn from the work of other jurisdictions and most recently the work of the Victorian Department of Health and Human Services in the development of the *Medical Treatment Planning and Decisions Act 2016* (Vic). The Victorian legislation reflects contemporary thinking in relation to health care decision-making for adults with impaired decision-making capacity and has informed the content of this discussion paper.” The Victorian Government has also developed a series of support and a comprehensive accompanying document<sup>6</sup> which outlines the legally-recognised roles for decision-supporters (in relation to medical treatment and planning). We see this work as a crucial part of any reform.

Other states and territories also have a foundation of supported decision-making on which to build and therefore the risks in substitute decision-making are mitigated. Victoria’s supported decision-making legislation will come into effect on 1 March this year.

The 2018/19 Annual Report of the Office of the Public Guardian<sup>7</sup> indicates that future changes to the *Guardianship of Adults Act 2016* would hopefully move “towards a will and preference focus, fully embracing supported decision-making.”

The proposed Health Care Decision Making arrangements do not indicate a step in this direction.

## Definitions of Restricted Health Care - Restrictive Practices

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There may be confusion regarding restrictive practices (such as seclusion, chemical, mechanical, physical and environmental restraint) being considered as non-therapeutic care. The NT is a party to the 2014 Australian Government *National Framework for Reducing and Eliminating the Use of Restrictive Practices in the Disability Service Sector* and the guidance contained in the framework should be clearly articulated in the proposed legislative reform.

Clarity in the definition of health care must preclude any possibility of a decision being made by a family decision-maker about restrictive practices.

Restrictive practices may also be an area in which families may require additional education, as it is not generally a well-known area.

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<sup>6</sup> Victorian Office of the Public Advocate, 2017, Supported Decision Making in Victoria – a guide for families and carers

<sup>7</sup> [http://publicguardian.nt.gov.au/sites/default/files/2018-19\\_annual\\_report\\_opg.pdf](http://publicguardian.nt.gov.au/sites/default/files/2018-19_annual_report_opg.pdf) , p24