Advancing positive change for people with impaired decision-making capacity



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Ms Sue Cawcutt

**Research Director** 

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Health and Disabilities Committee hdc@parliament.qld.gov.au Parliament House BRISBANE QLD 4000

**Dear Ms Cawcutt** 

## Health and Disabilities Committee Inquiry – QLRC Recommendations on Guardianship Laws

Thank you for the opportunity to comment on the Health and Disabilities Committee's inquiry into specific referred recommendations arising from the Queensland Law Reform Commission (QLRC) review of the guardianship laws. I submit the following submission by the Office of the Public Advocate. I further acknowledge the submissions made to the initial QLRC review of the guardianship laws by previous Public Advocate appointees.

The role of our office is to protect and promote the rights, autonomy and participation of all Queenslanders with impaired decision-making capacity through statutory systems advocacy. Our work focus is not limited to guardianship and specialist services. Rather, we promote the inclusion of all people with impaired decision-making capacity in all aspects of community life, including fair access to mainstream goods and services. We are committed to evidence-based systems advocacy that explores and extends our knowledge and influence on inclusive policy, programs and practices to promote improved life opportunities and outcomes for Queenslanders with impaired decision-making capacity.

I note with interest the Victorian guardianship review by the Victorian Law Reform Commission which is due to submit its report to the Attorney-General by 23 December 2011 and the response which the NSW Government made to the Standing Committee on Social Issues inquiry into 'Substitute decision-making for people lacking capacity' in March 2011.

Advance health directives, the decision to withhold or withdraw life sustaining measures, and objection to urgent health care are extremely complex and personal issues for the community. It is not our intention to comment on the technical matters associated with these areas. Rather, broad comment on a range of foundational aspects are outlined below, in line with the knowledge and evidence which the Office has developed in our systems advocacy work for people with impaired decision-making capacity.

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## Legislative and administrative framework

User-friendly and flexible legislation which is not over-prescriptive and applies consistent requirements across Australia is vital. Enabling the mutual recognition of instruments across jurisdictions is also important, particularly with an increasingly mobile population.

It is also acknowledged that the recently adopted *National Framework for Advance Care Directives* by the Australian Health Ministers is a significant step forward. The Framework sets out an approach for government, legislators, policy makers and administrators. The potential effectiveness and application of the framework is yet to be tested.

The associated paperwork and process must also be simplified and cater for all people (including indigenous people, persons with a disability (which is not related to decision-making capacity), and people from CALD backgrounds). The form must be easy to follow, with minimal risk of invalidation resulting from the process. I note the 'Enduring Documents: Improving the forms, improving the outcomes' joint research project by the University of Queensland and the Queensland University of Technology which is underway and the recommendations in its recent report.

As noted in the Office of the Public Advocate's annual report for 2010-11, it is important that public confidence in the efficacy of enduring instruments is sustained and the revocation of enduring instruments is of last resort. The public may have less confidence in making enduring instruments in the absence of strict revocation standards.

It is also essential that current enduring instruments are available and accessible to the medical professional quickly as timing is a critical element in medical treatment decisionmaking. The Office of the Public Advocate supports investigating the use of the pending e-health records system as a repository for this information.

## Education and support for the community

Health Consumers Queensland undertook a project to explore consumer views in relation to advance care planning and advance health directives in 2010. The project findings were reported in its Issues Paper in August 2011 and identified improved information and support for consumers and for health practitioners as key themes from their consultation. The Office of the Public Advocate strongly agrees there is a need for an effective public awareness campaign on enduring instruments such as enduring power of attorney and advance health directives, including palliative care.

The information campaign should extend to providing information to the community about what the 'good medical practice' threshold entails for medical professionals and their duties and responsibilities under the *Good Medical Practice: A Code for Conduct for Doctors in Australia* and the *Australian Medical Association Code of Ethics*. These are complex issues which at the core relate to informed knowledge about the capability, risks, and outcomes of medical treatments. The Office advocates that members of the public be able to consult and involve medical experts in the development of these planning tools. It is recognised however that medical treatment is only one element and that emotional, spiritual, cultural and religious beliefs are also personal factors for consideration.

The public education exercise should include the dissemination of simplified and clear supplementary information, including contacts or sources for further assistance. Distribution at local outlets such as medical centres, libraries, community facilities, and shopping centres is recommended (not limited to health related outlets). Given these instruments are

applicable to a broad range of age groups, the information must also be made accessible through both hard copy and electronic mediums.

With a growth in the number of people with impaired decision-making capacity due to ageing, acquired disabilities and other conditions it is essential that Queenslanders are encouraged to plan for their futures. More generally, we think individuals should be encouraged to make their own decisions about consenting or refusing future health treatments including medical, surgical, dental and other treatments.

It is also important that strategies to involve families and carers at an early stage in health care planning are promoted. This will assist in understanding wishes for future medical treatments and potentially avoid confusion or conflict at a later date when medical treatment is required. Where there is conflict, the use of social workers at hospitals or local and informal mediation options should be explored, rather than a heavy-handed approach through the guardianship or legal system. The person's family and support network or private guardians may benefit from the initiation of a mediation process. A dispute amongst family members should not immediately escalate to a guardianship matter.

The introduction of an ethics committee decision-making forum involving a range of medical and social work experts and the persons family, carer (unpaid) or guardian may also be a more practical, sensitive and suitable approach. Invoking the guardianship process should only be a measure of last resort.

## Education, training and support for health professionals

The issues around the education of medical professionals are also highlighted by current research led by the Queensland University of Queensland into 'Withholding and withdrawing life-sustaining treatment from adults who lack capacity: The role of law in medical practice'. The Office of the Public Advocate is a research partner and we support the researchers' conclusions for law reform that results in legislation that is able to be understood and can be applied, and promotes best practice in the medical management of end-of-life decision-making.

It is critical that medical professionals understand the law regarding end-of-life decision making. A clearer legal framework and improved information is required to achieve this. We think that an over-prescribed or highly regulated approach may not meet the needs of patients or the medical practitioners who care for them.

I trust this information is of assistance. Please do not hesitate to contact me by telephone 3224 7362 or email <u>susan.brady@justice.qld.gov.au</u> if you require any clarification or further information.

Yours sincerely

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