Adult Guardian

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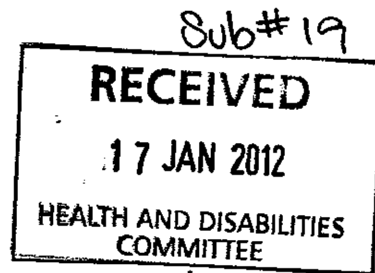

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Dear Ms Cawcutt

Submission to the Parliamentary *Health and Disabilities Committee* Queensland Law Reform Commission report on guardianship legislation

Introduction

Thank you for the opportunity to comment on the recommendations of the Queensland Law Reform Commission review of guardianship legislation. The focus of this submission is on broad brush implications for people with impaired capacity, and on the efficacy of the proposed legislative amendments in achieving the Government's overarching policy objective of protecting the rights and interests of this vulnerable group of people. In general, the technical detail of the recommendations has not been given consideration.

It is important that any legislative amendments should be easy for the general public to understand. Overly-prescriptive and unwieldy legislation will be difficult for practitioners to apply, and will carry with it unintended consequences.

The success of legislative reform in this area is dependent on its implementation by Government. This is particularly important given the highly complex and technical nature of many of the issues. Legislative change will be undermined without a commitment to:

- community awareness-raising
- education of professionals and in/formal decisions makers
- policy and program development by key sectors
- access to specialist advice and support for both the public and practitioners
- the parallel pursuit of less formal, non-legislative means of achieving the Government's policy objectives.

Legislative change is critical. In the experience of the Adult Guardian, however, the role of specialist legislation in protecting the rights and interests of people with impaired capacity is overshadowed by broader structural and systemic concerns. These include:

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- The capacity of an already-overstretched health system to provide high quality care for this marginalised group of people, and to observe the relevant decision making principles and processes.
- The availability of appropriate support and accommodation options for people with impaired capacity (both prior and subsequent to hospital admission), which has a direct impact on their health outcomes and the need for guardianship involvement.
- The availability of early intervention options to support family involvement and responsibility in decision making – in recognition that, although sometimes necessary, guardianship intervention represents an intrusion into the private lives of citizens and should be a last resort.

Advance health directives

This is a highly complex and technical area of guardianship law and the Adult Guardian notes the substantial consideration of these issues at the State and Commonwealth levels. It is suggested that approaches to legislative reform should be informed by a range of considerations, including the following.

- The legislation should be flexible and avoid over-prescription. It should be relatively easy for the lay person to understand and for the professional to apply.
- The use of formal legislative requirements (and accompanying penalty provisions) should be carefully balanced against the efficacy of achieving key policy objectives and improved outcomes for vulnerable people through other, non-legislative means.
- Legislative change will not meet the stated policy objectives without a commitment to community education, and a commitment to the ongoing provision of advice and support to the general public and relevant professional groups to help them understand their options and obligations.
- *Health Consumers Queensland* has discussed the need for people to regularly review their enduring documents to reflect changes in both medical science and in their own personal circumstances. Options to support such a process merit consideration.
- Legislative change must be translated into appropriate policy frameworks and program development within the legal, medical and guardianship arenas.
- Both the general public and relevant professional groups should be assisted to understand and navigate the complex balance which must be struck between upholding individuals' own wishes about their future health care and the role that good medical practice plays in treatment decisions.

Notification of advance health directives (QLRC Recommendation 9.11)

This recommendation is supported if it will:

- help ensure that people's wishes with respect to their future health care are upheld, and remove doubt as to what their wishes are
- support people's right to make their own decisions and to choose their own substitute decision maker, hence reducing the need for formal intervention by the guardianship system
- facilitate better decision-making on behalf of people without capacity

- enhance community awareness of enduring documents, and encourage greater involvement by service providers.

However, the Committee should consider whether the level of prescription which has been recommended best achieves these objectives. In the context of significant resource constraints faced by certain service sectors (particularly aged care facilities), overly-prescribed legislative requirements are likely to result in minimum, technical compliance only, and will not achieve the overall objectives. It is unclear whether the use of electronic health records may help mitigate this concern in hospital settings.

The Committee should consider the efficacy of alternative approaches to achieving the above objectives – those driven through community awareness-raising, education of medical and support professionals, and capacity-building within the service sectors.

Decisions to withhold or withdraw a life-sustaining measure (QLRC Recommendations 11.1 -11.10, 11.15 & 11.16)

This is also a highly complex and sensitive part of guardianship legislation, and one that can obviously have profound implications for people with impaired capacity and their families. In 2010-11, the Adult Guardian provided consent to the withholding or withdrawing of life-sustaining measures in 130 cases. The experience of the Office of the Adult Guardian in this area may be helpful in informing the Committee's consideration of the recommendations.

Not uncommonly, the Adult Guardian is asked to consent to the withholding or withdrawing of life-sustaining measures in situations where subjective "quality-of-life" judgements, rather than good medical practice or the wishes of the person, are guiding the medical practitioner's decision making. (This routinely occurs despite substantial efforts over recent years to educate medical practitioners about their legal obligations.) In these cases, medical decisions are being based on value-judgements about whether a person with an impairment will have a good quality of life following a particular medical event, rather than whether the decision making observes the legislation, follows good medical practice, or takes appropriate account of a person's wishes. In these cases, without robust analysis and careful testing of the evidence by the Adult Guardian, and without the advocacy of family members, the person's rights and life may at risk.

In cases where guardians/attorneys are believed to be acting inappropriately with respect to health care decisions, it is important that formal guardianship intervention be activated as a last resort, once all other options have been exhausted.

- In 2010-11, there were **26** requests by medical practitioners for the Adult Guardian to exercise its powers under s.43 of the *GAA* (i.e. to make a decision when an attorney/guardian's decision is contrary to the health care principle). In **7** of these cases, the Adult Guardian's power to override the guardian/attorney was exercised. In the remaining **19** cases, the issue was resolved in other, less intrusive ways.
- In 2010-11, there were **no** requests by medical practitioners for the Adult Guardian to exercise its powers under s.42 of the *Guardianship and Administration Act 2000* (i.e. for the Adult Guardian to make a decision where there is disagreement between guardians/attorneys about the decision).

In responding to s.42 and s.43 requests, the Adult Guardian exhausts all efforts to have the issue resolved informally, either by the family or by medical practitioners. As a first step, advice and information will be provided to medical staff to assist them to resolve the matter with the family. If this fails, the Adult Guardian may engage directly with the family and provide information/advice/mediation to them. The Adult Guardian may suggest or engage the assistance of other third parties (for example, religious representatives) in this process if necessary, and will usually initiate a second independent medical assessment of the person. Only if all informal attempts have failed will the Adult Guardian step in formally to make the decision in place of the family. For particularly important decisions (e.g. withholding or withdrawing a life-sustaining measure), the family will be advised of their right to seek a review of the matter by the Queensland Civil and Administrative Tribunal, and be given an opportunity to do so if they wish.

Under the *GAA*, the Adult Guardian has the ability to mediate/conciliate between guardians/attorneys. In relation to complex health matters involving the withholding or withdrawing of life-sustaining measures, the Adult Guardian may be well positioned to mediate between family members, or between family and medical practitioners, by virtue of its independent statutory role and level of expertise in these matters. However, it should be recognised that even the exercise of this function represents a level of intrusion by guardianship into a family's personal affairs; the Adult Guardian will not always be the most appropriate person to do this mediation. It is suggested that formal intervention by the Adult Guardian through mediation should occur only as a last resort, when other means of mediation are inappropriate or have been unsuccessful. This highlights the need for hospital staff to have well developed mediation skills, and for more independent mediation options to be readily available for these situations. (The decision about choice of mediator may also be influenced by the fact that, under s.42 of the *GAA*, the final decision may be made by the Adult Guardian if the disagreement between guardians/attorneys cannot be resolved.)

In some cases, the person's medical circumstances will allow sufficient time to explore options, arrange for second medical opinions, conduct mediation and, if necessary, seek a QCAT review. However in other cases, for medical reasons a decision will need to be reached quickly, sometimes after-hours. Although the Office of the Adult Guardian provides a 24-hour service in relation to health care decision making (including decisions about the withholding or withdrawing of life-sustaining measures), other necessary steps identified above (e.g. second independent medical opinions) may not always be immediately available. Any legislative amendment regarding decision making processes involving the withholding or withdrawal of life-sustaining measures should take this factor into account.

With regard to recommendation 11.3 of the QLRC regarding s.36(2) of the *Powers of Attorney Act 1988*, the contribution of the former Adult Guardian to the QLRC review is noted; no further views on this matter wish to be advanced.

The general principle behind recommendation 11.5 of the QLRC report is supported. That is, any interested person should have the right to raise concerns about a health care decision being made for another person, and for this to apply to all health care decisions. It is suggested that the appropriate review mechanism for any concerns about the Adult Guardian's health care decision making should be the Tribunal.

Adult's objection to health care (QLRC Recommendations 12.6, 12.7 & 12.8)
These recommendations are supported, and are consistent with the way in which the Adult Guardian exercises its decision-making role as statutory health attorney or guardian for health matters.

- The Adult Guardian will generally not provide consent to a particular treatment if it is known that the person previously had capacity to make a decision about the treatment and, at that time, had refused the treatment.
- If it is known that another, more appropriate decision-maker exists, the Adult Guardian will only make a health care decision as statutory health attorney in exceptional circumstances. (For example – if the attorney cannot be located and all reasonable efforts to contact them have been exhausted and, on the advice of the medical professionals, further delays will compromise the person's health or well-being).

Registration of an enduring power of attorney (QLRC Recommendation 16.15)
The advantages of having a mandatory EPA registration scheme are noted, particularly if such a scheme would:

- allow a relevant party to quickly ascertain whether a person has an EPA in place and who their attorney is
- assist in determining whether an EPA is valid, particularly in situations where a person has more than one EPA
- provide a mechanism for the easy detection of abuse by attorneys.

However it is submitted that there are broader issues the Committee should consider.

- A mandatory registration scheme is likely to be costly to establish and administer. Although the exact number is unknown, there are likely to be many thousands of EPAs across the State. (The Adult Guardian currently holds 1,370 appointments as attorney under Enduring Powers of Attorney, 53 of which are active.)
- A mandatory registration scheme would be ineffective in detecting and preventing abuse unless a raft of other measures are also put in place. This would include additional legislative powers, and may require considerable investment in creating mechanisms to investigate allegations, proactively monitor all active EPAs for compliance/abuse, and respond appropriately when abuse is detected.
- Should a mandatory registration scheme and accompanying investigative regime be established, the likely impact on public attitudes and responses should be carefully tested. (For example, would it be considered that Government has intruded too far into people's personal affairs? Would a mandatory scheme discourage the community's take-up of EPAs? Would a voluntary registration scheme be better?)
- For the purpose of detecting and preventing abuse, is the resource investment proportionate to the level of risk? How much abuse by attorneys acting under an EPA is actually occurring, relative to the thousands of active EPAs across the State? (Over the past several years, the Adult Guardian has needed to exercise its statutory power to temporarily suspend an attorney's decision-making in only a very small number of cases.) What return would the community receive on the significant investment

necessary for a mandatory registration scheme, relative to other less significant measures?

- Can such a significant investment be justified, given that an EPA registration scheme will cover only a small portion of all people who have impaired capacity? There are significant numbers of people with impaired capacity who are less likely to have EPAs in place. This includes people born with an intellectual disability or other cognitive impairment, people with chronic psychiatric disorders living in long-term institutions, people from CALD or Indigenous backgrounds, people who are homeless or who have low literacy levels, people who have no family/friends to act as their attorney etc. These "less visible" groups of people are unlikely to have significant assets and hence less likely to attract the interest of the legal profession, yet their vulnerabilities may in fact be more complex. Significant financial investment by Government in an EPA registration scheme at the expense of broader measures to protect the much larger group of people with impaired capacity raises fundamental questions of equity and social justice.
- What does the empirical evidence from other jurisdictions suggest about the effectiveness and viability of a mandatory registration scheme?

To help medical practitioners quickly identify appropriate substitute decision-makers in order to administer health care, there has been significant progress around the use of electronic health records. It is recommended that the Committee consider this as potentially a better option for this purpose.

<u>Appointment of a litigation guardian (QLRC Recommendations 28.1 and 28.2)</u>
Vulnerable people with impaired decision making capacity should enjoy equitable access to justice, including the assistance necessary to bring or defend legal action in the pursuit of their rights. In some cases, this may mean the need for a litigation guardian to pursue a person's rights. It is accepted that, where necessary and appropriate, people with impaired capacity should have access to a litigation guardian to represent their interests.

In determining whether the courts should have the power to appoint the Adult Guardian as litigation guardian without consent, it is recommended that the Committee consider the possible unintended consequences, which include the following.

- If demand for litigation guardian services is great, this is likely to divert resources away from the delivery of frontline guardianship services, the exercise of our investigatory powers, and the delivery of the Community Visitor Program. (Relative to the exercise of these other functions, the provision of legal services or representation is significantly more costly.)
- This is likely to discourage other parties from acting as litigation guardian, effectively making the Adult Guardian the litigation guardian of *first resort*. This would be inconsistent with the policy intention of guardianship, under which the statutory guardian should be appointed only as a last resort.
- This may potentially cause a conflict of duties, in cases where the Adult Guardian has separate, pre-existing obligations to an individual deriving from a guardianship appointment involving other personal matters.

- Courts may not have sufficient understanding of the guardianship jurisdiction and the scope of the Adult Guardian's role to make appointments which are appropriate in the circumstances.
- This will expose the office to costs (without relevant provisions in place to avoid this exposure), with a potential impact on the office's operational viability and the exercise of the Adult Guardian's broader statutory obligations.

An alternative route to protecting the legal rights of people with impaired capacity may be pursued through the guardianship jurisdiction. That is, the Tribunal may appoint the Adult Guardian as guardian for legal matters (not relating to property or finances) for the period of the litigation, with a direction that the Adult Guardian act as litigation guardian for the person in the conduct of this matter. It is within the guardianship arena, and the responsibility of the Tribunal, that the appropriateness of such an appointment can be tested (i.e. whether the person lacks capacity for the litigation; whether a guardian is needed to protect their rights in the litigation; whether there is anyone else more appropriate than the Adult Guardian to represent the person in the litigation etc.).

There is currently no legislative impediment to the Adult Guardian assuming the role of litigation guardian, however the concerns around resource burden and exposure to costs would remain.

Of all guardianship clients, some 9% of OAG clients have current legal matters on foot at any one point in time (currently 173 clients). For most of these clients, the Adult Guardian exercises a protective and monitoring role, rather than one of direct representation. It does this, for example, by sourcing legal representation, instructing counsel, oversighting the carriage of the matter, acting as friend of the court, ensuring that all relevant information is put before the court, and advising the court as to the options available for a person's care, support or accommodation. The Adult Guardian is able to directly provide/fund legal representation in exceptional cases only. This is due both to resources constraints, and to the level of specialist legal expertise which would be required in a range of different areas of law.

Remuneration of Adult Guardian (QLRC Recommendations 29.1)

The recommendation of the QLRC (that the *GAA* not be amended to enable the Adult Guardian to charge for services) is supported, for reasons largely consistent with those outlined in the QLRC report.

- The policy intent behind guardianship is that the State has an obligation to protect the human rights of vulnerable people with incapacity when there is no one else to do so, and that this protection should not financially disadvantage people.
- A user-pays system would undermine this policy intent (i.e. if access to rights protection was only available to those who can pay).
- Most of the Adult Guardian's substituted decisions are made as appointed guardian or statutory health attorney. (In only a very small number of cases are decision-making powers exercised when a person has previously appointed the Adult Guardian as decision maker under an enduring document.) In these cases, the person has not elected to have the State make these decisions for them, raising concerns about whether they should be charged for these services.

- A cost-benefit analysis would be unlikely to support the charging of fees: most guardianship clients have limited income and assets, and a scheme for levying fees is likely to be costly to administer relative to the funds recouped.
- Charging for guardianship services would be inconsistent with other jurisdictions.

Notwithstanding this position, it is appropriate for the Government to be mindful of the ongoing investment needed to sustain guardianship services into the future. [1]

Lindsay Irons
Acting Adult Guardian

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[1] **Ongoing investment to sustain guardianship services.** There has been exponential growth in the number of Tribunal appointments to the Adult Guardian in recent years. For example, the total number of guardianship appointments held by the Adult Guardian rose from 641 in 2005-06 to 1,900 in 2010-11. In 2010-11, there were more than 650 new Tribunal appointments to the Adult Guardian. If this trend continues, it will outstrip any benefit which has been realised through the additional resource allocations by Government to the Office of the Adult Guardian over the past two years.