Sub# 2

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The Chair, Health and Disabilities Committee, parliament of Queensland.

HEALTH AND DISABILITIES COMMITTEE

111-4-3

RE: Queensland Law Reform Commission Recommendations - Advanced Health Directives (Capacity) and the role, consent or otherwise of substitute decision makers.

Since attending and participating in the public forum I have given these matters further consideration and suggest that:

- The QLRC recommendations are intended to reach an optimal balance between the General Principles (human rights based on adult autonomy) and the Health Care Principles (expert power and service provision), Part of this question of balance is the Commission's intention to afford a degree of protection for professionals exercising sound judgement.
- Key difficulties are the limitations currently on Common Law rights. These limitations can create or reproduce social or economic exclusion and can impact upon cultural, systemic, structural, language, regional or other barriers. Given that the Common Law test remains at the standard of a prudent patient no justification exists for placing the medical profession above all others nor should a raft of legal excuses be drawn from a lack of evidence, clarity or certainty.
- The Constitution provides for the Common Law to deal with private and personal rights and therefore implies a right of consent or refusal to the best of one's capacity and ability. The Parliament may act to change, clarify or reinforce Laws within its jurisdiction. Until this occurs the Common Law is supreme and provides a sound suite of interpretive tools.
- As I understand it, limitations of Common Law arise either intentionally such as in the Civil Liabilities Act or unintentionally through lack of consistency with the stated purpose, principles and values of an Act of Parliament
- A person with capacity exercises their rights to make provisions for their future health care through the Advanced Health Directive or appointing of a Power of Attorney; this is a private and personal matter. The role of the medical or legal profession in the matter should be as the provider of information and advice not that of professional gate-keeper. Who can determine what a person knew, should or ought to know about advances in medical technology?

- Enduring documents are intended to protect a person's rights consistent with their intentions and purposes. It is therefore of paramount importance that substitute decision makers acting either formally or informally be treated with respect. The protection of administrative law whereby a full and proper accounting is given to both what is known and what should be known is necessary, relevant and appropriate.
- Some professionals see for example the Mental Health Act as stand alone legislation and a provider of legal excuse for what might elsewhere be seen as an abuse of power. I seek to ensure that the family and other substitute decision-makers are afforded the opportunity for legitimate inputs and consent or refusal around lifestyle decisions. Excessive and inappropriate use of ECT can occur because of the reliance the Mental Health Review Tribunal places on the professional treating team. Evidence of treatment efficiency and effectiveness might be expected before continuation of ECT past the first order.
- The medical profession should not by custom and practice become the sole gatekeepers of AHD's or POA's. A difficulty therefore exists in the current regulatory environment whereby a Justice of the Peace cannot witness an AHD without a signature by a doctor. Attempts to do the same with POA's also appear unwarranted
- Promotion of professional education and development together with enhanced public awareness of individuals' rights, 'responsibilities, risks and resources must become a reality if autonomy is to be enhanced. No singular source of knowledge can provide all the answers and practices should be informed by theory, research and practice wisdom t at a minimum and enhanced personal autonomy at a maximum.

The National Framework assumption is unhelpful if it avoids the prudent patient test and limits an adult or substitute decision-maker in their capacity to consent or refuse consent to treatment options that are offered..

Recommendations:

• Where actions or inactions under an enduring document raise questions about the extent, appropriateness, certainty or clarity of the provisions fact and law questions can and should be determined by a duly authorised Tribunal or Court. Optimal, appropriate and reasonable decision-making processes should occur with respect and dignity, certainty and clarity. I give in principle support to the recommendation to change in the law to mandate consultation with the person's attorney. I suggest mature engagement involves a sharing of power whereby

each informs and educates the other so as to reach informed consent and an outcome consistent with the interests of the person that is the subject of the decision-making process.

- Respect and dignity is integral to sound human service practice. The person in charge should have a holistic understanding of person's under their care. Enduring documents should be requested as these support principled good faith responses to representations made.. Clarity of who can give consent, when and how should be afforded. Privacy laws require proper storage, access, management and consent around information especially when dealing with third parties.
- Enduring documents are activated when a person judgement or capacity becomes impaired. Protecting their human rights at the time of making the document must be afforded greater respect. Currently as I understand it doctors wish to take a person through the process of making an advanced health directive and then it is witnessed by a Justice of the Peace. What training, special knowledge or other consideration does either possess for ensuring capacity and consent, purpose and intent etc. Medical discovery or technology changes may occur across the decades, regulators must assess new medications and techniques before approval and ethics committees govern research. What insight is within the capacity of even gifted or educated persons yet alone the population at large? Respect for their wishes when appointing attorneys or making advanced health directives is essential...

Decisions made for the future (Advanced Health Directive) or appointing of person or persons as attorneys is a consent right by a person with capacity and communicates their intentions about health and other care matters when their capacity becomes impaired. The person has put their faith in that process and it is not for the medical profession or relatives to second guess but rather to respect and afford dignity. Courts and Tribunals exist for the purposes of resolving unintentional outcomes. What is a private matter of personal rights remain...

Decisions to withhold or withdraw a life sustaining measure should be consent issues with action on appropriate advice and with necessary safeguards. I see no reason to limit directions or decisions and support the QLRC recommendations in full. Clarity and operational certainty remain the preserve of the Parliament and the Courts and should not be questions determined by vested interests, protections or limitations as these would be contrary to the autonomy of an adult. I see no reason for the Law to distinguish between different types of life sustaining treatments..

I support the recommendation to amend the Criminal Code to ensure clarity and consistency. I support the requirement to obtain consent where this is reasonably and practicably available. Physical medicine easily determines imminent risk to life or health. Unfortunately the Mental Health Act, the explanatory notes nor application of everyday English determine such questions. Remedying this inconsistency to ensure all persons share basic values, principles and care as intended under both common and statute law should be a matter of high priority.

Registration of enduring documents is not practicable nor desirable. The non-existence of registration may address privacy issues. Moreover it does not remove the duty to inform and be informed. Education of the professions, empowerment of clients and their families or representatives enhances a culture of respect and may ensure the resources of the Adult Guardian and Public Trustee are places of last resort. Their roles and Courts or Tribunal engagement with them provides an unfair, unreasonable and unnecessary intrusion into private matters on occasion and should not become a further source of fee based revenue.

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