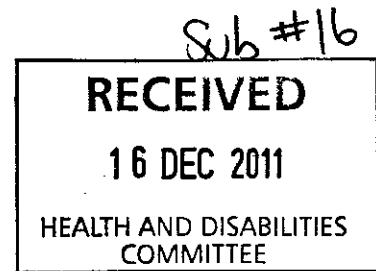




Queensland Advocacy Incorporated

Systems and Legal Advocacy for vulnerable people with Disability

The Research Director
Health and Disabilities Committee
Parliament House
BRISBANE QLD 4000



11.1.4.3

Dear Committee,

Re: Queensland Law Reform Commission Recommendations on Guardianship Laws Inquiry

We are pleased to contribute to the Inquiry on the QLRC's recommendations. We would particularly like to thank the Committee for inviting us to appear at the public hearing and we look forward to future opportunities to do the same.

Yours Sincerely,

Ken Wade, Director

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Patron: Her Excellency, Ms Penelope Wensley, AO Governor of Queensland

About QAI

QAI's mission is to promote, protect and defend, through advocacy, the fundamental needs and rights and lives of the most vulnerable people with disability in Queensland. QAI does this by engaging in systems advocacy work - through campaigns directed to attitudinal, law and policy change, and by supporting the development of a range of advocacy initiatives in this State.

QAI also provides individual legal advocacy in support of persons whose disability is at the centre of their legal issue. This is done by way of advice or advocacy within the limitations of QAI's resources.

Summary

Personal autonomy is not an absolute but located in social and familial circumstances.

Informed consent is vital to Advanced Health Directives (AHDs). They should therefore be by default time-limited. Consent must be timely if it is to be properly informed.

Families need adequate time, information and support to consider the benefits and burdens of treatment when a person lacks capacity to do so.

Where doubt exists a presumption must always be made in favour of providing care and treatment.

The current limits on when a direction can operate should be retained.

QAI has long-standing reservations about the use of advance health directives (AHDs). The idea that impaired cognitive function, dependence on technology to maintain life or support its quality, or that disability in general makes life undesirable or unbearable can be prejudicial to the conception of AHDs. It is clear that the discussion of advance health directives in the Issues Paper proceeds from the assumption that over-treatment, rather than lack of access to treatment is the most pressing issue. For people with disability, this is frequently not the case.

QAI believe that the ethical challenges associated with life sustaining measures are best resolved when there is a view that every life is valuable and worthwhile – and where families are given adequate time, information and support to consider the benefits and burdens of treatment. Prematurely or unilaterally withholding or withdrawing treatment which a family member wants instituted or continued (even where such actions are clearly “good medical practice”) may have a long-lasting negative impact on family members, not to mention the individual whose treatment has been withdrawn.

Numerous issues arise in relation to the use of advance health directives in the withdrawal or withholding of life sustaining treatment. These concerns permeate our responses to the ‘Issues for Comment’ and include:

- the extent to which advance health directives constitute informed consent;
- the impact of social context on decisions made in advance directives;
- the need for protections against duress; and,
- the impact that legal recognition of ‘quality of life judgments’ has upon societal values (such as views on the value of the lives of people with disability) and upon other issues such as service provision for people with disability.

Consideration of these issues, and our concern for the application of the *Convention on the Rights of Persons with Disabilities* compels us to suggest that the problems surrounding

advance health directives are broader than the questions posed by the Issues Paper. We will try to raise some of our concerns in our responses to the 'issues for comment'.

Issues for Comment on QLRC Recommendations on Guardianship Laws Inquiry

Should the POA Act be amended to clearly state that an advance health directive cannot operate if the directive is uncertain or if circumstances have changed to the extent that, had the patient known of the changed circumstances they would think the advance health directive was inappropriate?

With an established opposition to advance health directives, QAI would support this limitation on the legitimate operation of advance health directives under the POA Act.

According to studies cited last year in the *Hastings Center Report* by a medical researcher and a law professor at the University of Michigan, Angela Fagerlin and Carl E. Schneider, almost a third of such decisions, after periods as short as two years, no longer reflect the wishes of those who made them.¹

Restrictions on the application of advance health directives should be increased in accordance with the view that only consent offered at the time of deciding whether to undertake treatment is true consent. The addition of Section 103 POA provisions would go some way to limiting the application of advance health directives under Section 36 POA, but we argue that the 'Right to Life' under Article 10 of the *Convention on the Rights of Persons with Disabilities* requires the application of advance health directives to be further constrained.

¹ Fagerlin, Angela and Carl E Schneider. 2004. 'Enough. The failure of the living will'. *The Hastings Center Report*. 34(2):30-42.

QAI believes that responsible legislators must understand the negative perceptions which exist in society about the value of people with disability. They must also understand that these perceptions, which disparage life with disability, can encourage people used to living without disability to prefer death to life with disability and to draft their advance health directives accordingly. People with disability are not immune from these negative perceptions. A lifetime spent with disability can be a lifetime spent learning from others that disability diminishes your human worth. These mendacious and bigoted lessons do not need to be overtly taught to exercise their damaging effect. Even prejudices that are unconsciously held and subtly expressed can over time severely damage a person's self esteem and sense of self worth in ways that can lead someone to conclude that life with disability is unworthy of living. These destructive sentiments can be held by family members charged with authorising the withholding or withdrawal of life sustaining measures, or by the doctors ultimately responsible for their withholding or withdrawal. Consequently, we would endorse this measure and encourage further restrictions.

Should a health provider be required to consult with an attorney appointed under an enduring power of attorney before forming a reasonable belief that a direction in an advance health directive is uncertain (consistent with the current legislation, to consult with an attorney appointed under an advance health directive)?

As noted in the Issues Paper, the purpose and effect of this proposed amendment is to reinforce the effectiveness of a direction in an advance health directive by requiring a health provider to defer to an attorney before deciding to ignore it. We are not opposed in principle to checks and balances that safeguard an individual's wishes, but given our inherent reservations about consent for the withholding or withdrawal of life sustaining measures offered by way of advance health directives, we would argue that amendments such as that offered by QLRC recommendation 9.18 would be detrimental to the extent that it inhibits a health provider's ability to make timely judgements about treatment. There may be emergency circumstances that make it impossible to consult an attorney, and in such cases it should not be required. However, in circumstances that do not require a decision about emergency treatment, but which potentially elevate for consideration the withholding or withdrawal of life sustaining measures and there is uncertainty about this matter in the

terms of an AHD, then the health provider should consult with an appointed attorney to attempt to resolve the uncertainty.

Should the protection for a health provider who does not follow a direction in an advance health directive because of changed circumstances be modified so that it is a valid reason only if the adult would have thought their direction to be inappropriate if they had known of the change in circumstances?

QAI has long criticised advance health directives for their difficulty in application to unknown circumstances. This amendment goes some way to acknowledging and overcoming this problem, and consequently, we would support this change. The view of the adult should always be the relevant perspective in relation to treatment decisions. However, it must be noted that this will be a subjective test and thus we would argue for the application of the general principle that where doubt exists as to whether to provide care and treatment, a presumption must always be made in favour of providing such care and treatment.

Should the protection for a health provider who does not follow a direction in an advance health directive because he or she believes it is inconsistent with good medical practice be omitted?

QAI considers this recommendation to be of significant concern to the rights of people with disabilities. The Issue Paper's justification for this recommendation is that the current protection offered to health providers who do not follow directions in advance health directives under s103 POA Act is inconsistent with autonomy and self-determination.

One's support of or opposition to this recommendation intrinsically relates to one's views on the legitimacy and operation of advance health directions.

A statement of a person's wishes or views may be very useful and should be taken into account in deciding whether or not to provide consent for treatment.

The *Issues Paper* argues that the current law is inconsistent in respecting a person's autonomous choice and right to self-determination, but this emphasis on autonomy

overlooks the fact that future decisions are inherently unstable. Such consent is not always 'informed'. Judgements about a possible future with disability may be distorted by fear, historical prejudice and discrimination (*Miller 1993*) – and we must be wary of codifying such prejudices.

We believe that the devalued perception of people with disabilities has significant impact on the decisions that people make in advance health directives. For example, for many people who acquire their disability later in life, there is a period of resistance or grief prior to adjustment to their impairment. But many people make this adjustment and, indeed, research shows similar levels of life satisfaction between people with disability and those without. It is very common for people in full health to consider life with an impairment untenable – a tragedy they would want to avoid – yet, when faced with that position, they adapt positively to new circumstances. Consequently, this notion of adaptation must be regarded in legislative amendments in relation to advance health directives.

Advance health directives overwhelmingly relate to resistance to treatment- nowhere in case studies do we see someone asking for treatment to the fullest extent possible- and thus we would argue that the omission of this protection for health providers who do not follow advance health directives based on inconsistency with good medical practice will inherently lead to the loss of life that could have been saved. Further, this loss could be attributable at least in part to the apprehensions medical practitioners felt about the risk of facing a civil suit for failing to follow a direction contained in an advance health directive. We cannot allow the concerns medical practitioners might hold about prospective legal action to influence, however marginally, their decision about whether or not to do what is consistent with good medical practice. . Article 10 of the *Convention on the Rights of Persons with Disabilities* provides the 'Right to Life', stipulating that every human being has the inherent right to life and that all signatory States shall take all necessary measures to ensure its effective enjoyment by persons with disabilities on an equal basis with others. Given the reduction in treatment and care that would inevitably stem from this recommended amendment, and the

lack of real consent we attribute to advance health directives, we would argue that this proposal is risks contravention of Article 10.

It is relevant to note that the thrust of the argument in the Issues Paper centres on identifying the means to refuse treatment, but in the current social context, we would ask: Where is the same enthusiasm for people with impaired capacity to be given supports to live?

Should the guardianship legislation be amended to ensure that common law rights to consent to or refuse health care are not affected by the legislation?

The common law right to consent or refuse health care espoused in *Hunter and New England Area Health Service v A²* acts to increase the effectiveness of advance health directives. It requires that such directives must be respected if it is made by a capable adult, is clear and unambiguous, and extends to the situation at hand. Similar to the recommendation above, this amendment would lead to an increase in adherence to advance health directives, and consequently, due to the inherent nature of such directives in restricting treatment and care, we would argue that this amendment would risk contravention of the 'Right to Life' provided by Article 10 of the *Convention on the Rights of Persons with Disabilities*.

Should any limitations on the effect of decisions about health care be more clearly stated in the body of the Act, rather than in a definition?

The objective of this recommendation is to remove limitations on the operation of advance decisions by a competent adult or on decisions made on their behalf by a substitute decision maker. The Issues Paper argues that this recommendation is underpinned by recognition of a competent adult's autonomy to make health care choices that will continue to be respected if the adult's decision making capacity is later impaired. The National Framework also emphasises respect for an adult's autonomy and entitlement to make decisions about personal and health matters.³ As indicated above, QAI believes that this emphasis on autonomy is misguided, as advance health directives do not increase autonomy due to the

² [2009] NSWSC 761 at paragraph 40.

³ National Framework, p.14 ff.

fact that consent can only be properly given at the time of deciding upon treatment. We would agree that users of the legislation need to be easily able to identify the validity of a direction in an advance health directive, or consent by a substitute decision maker,²⁰ and would consequently support amendments that increase the clarity of the Act. However, we would note that any increase in the effectiveness of advance health directives should not be promoted on the basis of 'autonomy' arguments, as the reasoning behind these views fails to regard social context and the prejudicial views that society holds toward the quality of life experienced by people with disability.

Should it be an offence to withhold or withdraw a life-sustaining measure without consent or authorisation when continuation or commencement of the life-sustaining measure would not be inconsistent with good medical practice?

There is presently far greater public enthusiasm for people with disability being given assistance to die than there is for providing them with adequate assistance to live. QAI believe that issues surrounding the continuation of life through life sustaining measures are best resolved with an inherent understanding of the value and worth of every life. We believe that families must be provided with substantial time, information and support to consider the benefits and burdens of treatment. QAI consequently believes that withholding or withdrawing life-sustaining measures without consent or authorisation when the continuation or commencement of such measures would be consistent with good medical practice should be an offence. Any other conclusion on this issue would risk contravention of the 'Right to Life' under Article 10 and the 'Prevention of discriminatory denial of health care or health services or food and fluids on the basis of disability' under Article 25(f) of the *Convention on the Rights of Persons with Disabilities*.

Should the limitations on when a direction in an advance health directive to withhold or withdraw a life-sustaining measure can operate be omitted?

Section 36(2) of the *POA Act* limits the circumstances in which a direction in an advance health directive to withhold or withdraw life-sustaining measure can operate. A direction cannot operate unless the adult is in one of the following categories:

1. has a terminal condition and the treating doctor and another doctor consider the patient may reasonably be expected to die within one year
2. is in a persistent vegetative state, with severe and irreversible brain damage which allows some bodily functions to continue, e.g. breathing
3. is permanently unconscious (in a coma) with brain damage so severe that there is no reasonable prospect of regaining consciousness, or
4. there is no reasonable prospect of recovery to the extent that life can be sustained without continued life-sustaining measures.

In addition, if the direction in an advance health directive is to withhold or withdraw artificial hydration or nutrition, it can not operate unless:

1. the commencement or continuation of artificial hydration or nutrition would be inconsistent with good medical practice; and
2. the adult has no reasonable prospect of regaining capacity for health matters.

The QLRC again reverts to their common justification in arguing that these restrictions are inconsistent with personal autonomy. QAI would strongly oppose the proposed amendment to withdraw these limitations. This amendment would greatly increase the instances where advance health directives could validly be followed, removing the safeguards that are afforded by the current limitations. We believe that this amendment contravenes the 'Right to Life' under Article 10 and the 'Prevention of discriminatory denial of health care or health services or food and fluids on the basis of disability' under Article 25(f) of the *Convention on the Rights of Persons with Disabilities*. Again, we would note our support for the general principle that where doubt exists as to whether to provide care and treatment, a presumption must always be made in favour of providing such care and treatment.

Should the limitations on a direction to withhold or withdraw artificial nutrition or hydration be treated differently to other life-sustaining measures?

QAI will always endorse the continuation of life. It should be noted that under the *Convention on the Rights of Persons with Disabilities*, the provision of food and fluid is dealt with specifically, with Article 25(f) providing for the 'Prevention of discriminatory denial of

health care or health services or food and fluids on the basis of disability'. Guardianship legislation currently places additional limitations on whether a direction in an advance health directive to withhold or withdraw artificial nutrition or hydration can operate. A direction cannot operate unless the health provider considers that to commence or continue artificial hydration or nutrition would be inconsistent with good medical practice, and the adult has no reasonable prospect of regaining capacity. With our inherent objection to the validity of advance health directives, we would argue that rather than removing these limitations, these more stringent restrictions should apply to directions to withhold or withdraw both artificial nutrition/hydration and other life-sustaining measures.

Should the limitations on operation of a substitute decision maker's consent to withhold or withdraw a life-sustaining measure be omitted? Alternatively, if a substitute decision maker's consent cannot operate under s.66A of the GAA Act, should the legislation allow the health provider to refer the decision to the adult guardian to make a decision (if the adult guardian is the guardian for the adult, for the Tribunal to make a decision)?

Section 66A of the *GAA Act* limits the circumstances when consent by a substitute decision maker to withholding or withdrawing a life-sustaining measure can operate. A substitute decision maker's consent cannot operate unless the adult's health provider reasonably considers the commencement or continuation of the measure for the adult would be inconsistent with good medical practice. Both of the proposed amendments would act to reduce the utilisation of life-sustaining measures. Bearing in mind our view that any decisions relating to life-sustaining measures should be dealt with by having due regard to the value and worth of every life, which is equal regardless of race, colour, creed, disability or other status. However, this valuation is not always equally held. A substantial portion of people despise life if it cannot be lived with a sound body and mind. This opinion can be held by people with disability or by those around them. It is an opinion that can lead them to disparage not only the quality of life enjoyed by someone with disability, but also the life of that unique individual in ways that would render the decision to terminate that life less troubling than if the person did not have a disability.. On this basis we would oppose any amendments that increase the instances of withholding/withdrawing life sustaining

measures. It is acknowledged that the current legislation often leads to situations of 'stalemate' where the health care provider and substitute decision maker are at odds, however, it is clear that the current limitations act to safeguard the rights of the adult. We do not believe that either of the proposed amendments are sufficient to safeguard the adult against inappropriate decision making about end of life care.

Should consent be required to withhold (not commence) a medically futile life-sustaining measure? Should consent be required to withdraw a medically futile life-sustaining measure that has been commenced?

QAI would strongly argue that consent should be required to both withhold and withdraw a medically futile life-sustaining measure. As previously stated, there is a commonly held prejudice that life with disability is less meaningful, less enjoyable, less rich and colourful than life without disability. This prejudice passes beyond the quality of life that one may enjoy and attaches to the individual with disability. This prejudice reached its ultimate form in Nazi Germany, where people with disability were classified as 'life unworthy of life'. We would never say that the extremes of bigotry that prevailed in the Third Reich and which permitted the wholesale extermination of people with disability prevail in Australia today. However, we would say that a prejudice much diluted by time and social development and which is often unconsciously held does exist and this prejudice could influence the minds of people faced with the decision to withhold a medically futile life-sustaining measure. We believe that a lack of requirement for consent would create a risk that a health provider may incorrectly form the view that the life-sustaining measure is futile and withdraw/withhold it without the opportunity to test that view. Further, we would argue that such consent should not be acquired by way of an advance health directive, as these directives do not in themselves constitute informed consent. An amendment to withdraw the consent requirement would risk contravention of Article 10 of the *Convention on the Rights of Persons with Disabilities*, providing for the 'Right to Life'.

Should 'withholding or withdrawing a life-sustaining measure' be omitted from the definition of health care for the purpose of s.67 of the GAA Act?

Section 67 of the *GAA Act* states the effect of an adult's advance objection to *health care* when a decision is made by a substitute decision maker s.38 in circumstances other than an emergency, a substitute decision maker's consent to withholding or withdrawing a life-sustaining measure or the commencement or continuation of a life-sustaining measure is not effective if the health provider knows that the adult objects to the health care.

Under common law, an adult may object to health care while he or she has capacity. Because *health care* is defined to include withholding or withdrawing a life-sustaining measure, an objection to health care could be an objection to the commencement or continuation of a life-sustaining measure, or to the withholding or withdrawing of a life-sustaining measure.

The QLRC recommends that a substitute decision maker should not generally be able to give an effective consent to the withholding or withdrawing of a life-sustaining measure if the health provider knows that the adult objects. QAI supports the preservation of life. We would argue that the withholding or withdrawal of life-sustaining measures should not be a decision to which the substitute decision-maker can consent. Further, we would argue that in situations of doubt, a presumption must be made in favour of the continuance of life-sustaining measures.

Should the Criminal Code be amended to remove any doubt that a health provider who withholds or withdraws a life-sustaining measure in accordance with the guardianship legislation is not criminally responsible?

The guardianship legislation provides that a person carrying out health care on an adult with impaired capacity is not liable for an act or omission to any greater extent than if it had occurred with the consent of the adult (if they had capacity to consent).³⁹

However, the operation of these sections is limited by s.238 of the *GAA Act* (and s.37 of the *POA Act*) which provides:

238 Act does not authorise euthanasia or affect particular provisions of Criminal Code

To remove doubt it is declared that nothing in this Act—

- (a) authorises, justifies or excuses killing a person; or
- (b) affects the Criminal Code, section 284 or chapter 28.

While the purpose of this amendment is merely to remove uncertainty in the legislation, and QAI supports clarity in the Act, we would suggest that this amendment may also lead to an increase in the withholding and withdrawal of life sustaining measures, as health providers become less concerned with criminal liability. Given the value which we place on all human life, we would argue that this amendment risks the lives of people with disabilities and consequent contravention of Article 10 (CRPD).

The risk we fear to the lives of people with disability lies, as we have discussed earlier, with the prejudice, whether overtly or unconsciously held against life with disability. The prejudice attaches not merely to the quality of life enjoyed by someone with disability but to their right to life. Their right is as honest and firm and real as anyone else's, but there are people who refuse to attribute to those with disability this right in its fullest form. They prefer to retain that unlimited expression for people who do not have a disability, that is, for people in their opinion who deserve it and are able to use it. These prejudices are real. They are not figments of fevered minds. And because they are real we must ensure that any decisions made concerning the withholding or withdrawal of life-sustaining measures involving people with disability are not influenced by those prejudices.

Should the authority to provide urgent health care without consent to meet an imminent risk to life or health be clarified so that it is consistent with the authority to provide health care without consent to prevent significant pain or distress, that is, where it is not reasonably practicable to get consent from a person who could give it under the guardianship legislation?

The QLRC recommendation 12.6 proposes consistent requirements for urgent health care without consent, whether the health care was to meet an imminent risk to life or health, or

to prevent significant pain or distress. The recommendation provides that urgent health care to meet an imminent risk to life or health could be administered without consent to an adult with impaired capacity, only if it was not reasonably practicable to obtain consent from a person who could consent under the guardianship laws. It is noted in the Issues Paper that when an adult arrives unconscious at a hospital emergency department and health care is necessary to keep them alive, no express consent is required. Consent is implied. The proposed amendment would mean that if the adult was accompanied by their spouse, the spouse's consent would be required to provide health care.

At QAI, we believe that the relevant consent to obtain is that of the adult. Further, we place immeasurable weight on the value of human life, regardless of individual status and believe that any dispute surrounding the application of health care and life-sustaining measures should always be decided with regard to this value for life, irrespective of the prejudices or personal beliefs of the decision maker. Consequently, QAI would oppose this amendment as it acts to decrease the instances where life-sustaining treatment can be validly undertaken. The 'Integrity of the Person' is protected under Article 17 of *Convention on the Rights of Persons with Disabilities*, providing that 'every person with disabilities has a right to respect for his or her physical and mental integrity on an equal basis with others'. By permitting a Guardian to consent on behalf of the adult in instances of imminent risk to life or health, this QLRC recommendation 12.6 risks contravention of Article 17.