

**Portions of this submission, which were about
Queensland Law Reform Commission recommendations
that were not referred to the committee, have been
deleted from the published version.**

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Submission to the

Health & Disabilities Committee's

Inquiry into

Queensland Law Reform Commission

Recommendations on Guardianship laws

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Opportunities for people with a disability

Introduction

The Endeavour Foundation is a non-government, not for profit organisation founded in 1951 for people with intellectual disability. Endeavour has grown to be the largest disability services provider in Australia with an extensive network of specialist disability and business services. Endeavour Foundation currently provides:

- 1,830 people with employment opportunities unavailable in the mainstream workforce,
- 904 people with support to live in their own home in the community,
- 801 people with learning and lifestyle opportunities,
- 260 positions assisting people in the open employment market,
- 235 families with support by the provision of respite services,
- 225 people with post school services,
- 26 children with support in vacation care programs.

Preamble

The main body of this submission is taken from Endeavour's consultation and paper submitted to the Queensland Law Reform committee in 2010. Only the areas which have direct applicability to the Health & Disability Committee's current inquiry have been included. Additionally, matters of importance which bear on the Guardianship regime have also been included to assist the Committee in understanding how families view Guardianship and decision making activities in relation to their sons and daughters.

Furthermore, there are some matters commented upon which represent the views of people with intellectual disability whom Endeavour supports and/or issues of interest to Endeavours' function as a Service Provider.

Endeavour believes that the views given in the 2010 consultation remain pertinent and relevant and represent the views of families when asked in general terms about these matters.

The authors of this current 'revised' submission were able to attend the workshop held at Parliament House on the 30th November 2011 and have used this additional information and perspective in revising the document.

Due to time constraints, a limited consultation on the Health & Disabilities Committee's Issues Paper was also undertaken in a focus group format with a number of key Endeavour family members with an interest in these matters. The additional comments and reflections they provided are made clear in the body of the submission and are also reflected in the key recommendations summary.

This submission is structured as follows:

Section 1 briefly contextualises the submission by drawing attention to broader issues around advanced care planning and people with intellectual disabilities.

Section 2 outlines the consultation processes undertaken by Endeavour Foundation in preparation for the 2010 and 2011 submissions.

Section 3 contains specific responses to the key issues highlighted in the 2011 Issues paper as well as reflecting the key issues and concerns for families consulted.

Section 4 reproduces segments of Endeavour's 2010 submission that are relevant for identified issues in the 2011 Issues paper.

Section 5 briefly addresses point 2.3 from the Issues paper regarding the proposal to oblige health and disability service providers to improve and increase access to advanced health directives and enduring powers of attorney should they exist. This is dealt with in a separate section as it is a response from the organisation rather than from family members in the consultation process.

1. Contextual Issues

The focus of this submission is from the point of view of family members who have a son/daughter/brother/sister with an intellectual disability.

The principle focus of the inquiry by the parliamentary committee on Health and Disabilities is the Advanced Health Directive. It should be noted that people with intellectual disabilities are not able to access Advanced Health Directives, even though there are clearly some individuals, who with support, would be able to make such decisions for themselves.

Therefore, there is an issue of equity of access to making advanced healthcare directives which needs to be addressed for this group of people. This is borne out in the submission and is commented upon by some families who took part in the consultation process.

Necessarily, therefore, the feedback from family members relates to advanced care planning and issues relating to health care in general.

The intention of advanced health directives are for health consumers to be:

"..empowered to exercise control over their care and treatment due to the existence of a plan."¹

However, disability rights activists have raised concerns that advanced care/health directives in respect of people with a disability:

¹ Health Consumers Queensland – Issues Paper August 2011 – Advanced Care Planning & Advanced Health Directives in Queensland

"... when combined with biased and inaccurate views of patients' quality of life, encourage less aggressive care and withdrawal of life-sustaining treatment, permitting persons with disability to die earlier than warranted."²

Where the patient is not known to the treating Doctor the views of family members/carers, service providers and Family Doctors (GP) must be sought to assist in providing first hand information to assist in making determinations which are critical in nature.

Families consistently speak about the difficulty in obtaining information where they are 'informal' carers of their adult children. 'Informal' in this sense means merely that they are not 'appointed' as Guardians or Administrators to make decisions on behalf of their adult son or daughter by the Tribunal.

It has again been raised by families that the issue of their 'status' in this sense, tends to emerge when Doctors do not agree with the health decisions made on behalf of their sons or daughters, whether there is an advanced care directive active or not.

Furthermore, there is considerable concern that when parents become too old to be actively advocating in the health system or pass away, that they are not able to nominate an 'informal' Guardian who will be recognised by Doctors and within the health system in general. This concern is reflected in comments given in the body of the submission particularly in the content of Section 3. The issue of aging parents/carers and people with an intellectual disability is of the utmost concern in terms of end of life planning and for this reason it was felt that the issue needed to be brought to the attention of the Health & Disabilities committee in relation to the current Inquiry.

2. Consultation Processes

2.1 2010 Consultation Process:

The Community and Advocacy Support Unit (CAS) of Endeavour Foundation consulted with families extensively across Queensland. To ensure this submission captured the experience and views of the people Endeavour Foundation provides support to, either directly or indirectly, avenues of input were provided in the following two ways:

- Face to face group consultations
- Completing a questionnaire or writing their own stories

Twelve face to face consultations were conducted across Queensland; Cairns, Townsville, Ayr, Rockhampton, Bundaberg, Maryborough, Nambour, Warwick, Toowoomba, Gold Coast and Brisbane using the questionnaire for discussion.

1361 invitations letters were sent to families to attend one of the twelve consultations. 74 people attended the consultations in total.

² Cited in: US Department of Health & Human Services "Literature Review on Advanced Directives" 2007, Wilkinson, Wenger & Shugarmen, available from: <http://aspe.hhs.gov/daltcp/reports/2007/advdirlr.pdf>

All the families (except 3 who were 30-40 age group) who contributed to this submission were over the age of 50, with the predominant age group 70 years and over. Family groups consisted of parents, brothers and sisters.

2.2 2011 Consultation Process

Three key parent advocates were contacted to provide feedback on the Health & Disabilities Committee Issues Paper. All the parents had been involved in the 2010 consultation and regard the key recommendations made in this paper as relevant and matters of concern to families. Copies of the Issues paper were made available to them prior to the focus group. The focus group was facilitated by two of the authors of this submission.

3. Responses to Guardianship Laws Inquiry - Issues Paper November 2011

Key Issue:

[REDACTED]

Recommendation:

[REDACTED]

[REDACTED]

Key Issue:

[REDACTED]

Recommendation:

[REDACTED]

Key Issue: **Advanced care directives are not available for people with an intellectual disability**

Recommendation: Consideration is given to developing a program which may support those who do not have the capacity, to enjoy the same certainties that other Queenslanders, through advanced care directives when end of life and other health decisions need to be made. The current arrangements are clearly inequitable.

Key Issue: **Withholding and Withdrawing of Life Sustaining Measures**

Recommendation: The Adult Guardian is involved as a last resort to assist with decision making. Patients' General Practitioner may better be able to liaise with Health Professionals based on their professional history with the patient prior to the Adult Guardian involvement and at the request of family.

Key Issue: Protection of Health Providers for non-compliance with an advanced health directive

Recommendation:

- Health provider must consult with any appointed attorney (under an enduring power of attorney) before forming a belief that a direction is uncertain
- Make 'changed circumstances' a valid reason for non compliance if the adult would have considered the directive inappropriate in the light of the changed circumstances.
- Omit the protection for a health provider on the basis of not being consistent with good medical practice.

Key Issue: Common law right to consent or refuse treatment –impact of the guardianship legislation

Recommendation: Endeavour and families support amendments to the Guardianship legislation to preserve the common law right to consent or refuse treatment.

Key Issue: Adult Guardian to charge for services

Recommendation: Endeavour Foundation and families do not support this idea.

Key Issue: The Court's power to appoint a litigation guardian for an adult if no-one is available

Recommendation: That the Adult Guardian or Public Trustee should remain potential litigation guardians of last resort and that the Courts should be able to appoint them without consent. A preferable system would mean an appropriately experienced individual should step into the role but not be liable for associated costs. This would ensure good legal representation.

Key Issue: **Ensuring that health providers are aware of advanced health directives and enduring powers of attorney**

Recommendation: Endeavour would in principle give support to the obligation for disability service providers to take reasonable steps to improve access and awareness to any advanced health directives or enduring powers of attorney. This would be an extension of duty of care obligations to service users to access the health outcomes they wish for. However, details of how any such obligation may impact upon services would have to be ascertained before full support could be given.

4. Guardianship Laws Inquiry, 2010: Relevant sections of 2010 Submission

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4.2 Advance Health Directives

Advanced Health Directives

Families believed that an Advanced Health Directive was important to parents and also to their adult with impaired capacity. They also were aware that currently a person with impaired capacity cannot make an Advanced Health Directive, and would like to see this changed.

"People with disability can decide what they want, it should also be allowed for them to do Advanced Health Directive, especially as me as her mother will die before her and the people around her then may not be able to listen to what she wants."

"Advanced Health Directive – it's an excellent thing to have, both for myself and my child."

Withholding and withdrawal of life-sustaining measures

When it came to decisions about this situation applying to them, parents stated they would want family to make this decision in conjunction with medical professionals. Some families said that the decision should only be made by families even if it differs from medical professionals. Some made objections to the process of withdrawal of life-sustaining measures.

"Family should only make that decision. I don't believe in starving a person. But if they die just by removing treatment to keep them alive then that is ok."

Many agreed that this situation would be less stressful for family members if there were an Advanced Health Directive.

“Should be a joint discussion, should include family, and medical staff. My ex husband was brought back to life, and he is not happy with it.”

Families also commented on the perceived lesser value of life equated to people with disability by some medical professionals and would not like “disability” to be the reason for withdrawal of life-sustaining measures.

“My daughter when she was young and had an epileptic fit at hospital, they moved her to another room and withdrew medication hoping that she would die, but she didn’t.”

“You don’t know what attitudes nursing staff and doctors have towards people with intellectual disability; they may think that her life is not worth living, which is the wrong place to start from.”

In relation to this issue the 2011 Focus group reiterated the importance of the involvement of the Adult Guardian in such matters be a last resort, preferring that family members and other health professionals such as the patients General Practitioner be involved in decision making. The involvement of the GP is predicated upon the fact that they will have medical knowledge of the patient as well as well as a better understanding of their history and quality of life.

Adult’s Objection to Health Care

Most families said that they have had to deal with this situation. Again there were a range of views from:

“If a person was not able to understand, should a person be forced to take the medication – yes.”

to

“I think the adult should be listened too.”

and

“Their objection should be respected.”

Many families thought appropriate health care was their responsibility or “duty of care”; therefore at times would override the adult’s objection in favour of their appropriate health needs.

“Doesn’t duty of care come into this somewhere, where the best has to be done for people with impaired capacity? And this must be appropriate to the level of impairment and understanding of the risks of not taking it.”

"Because of my daughter's impairment I have had to overrule her decision not to get health care and it is my responsibility to keep her in good health."

Some families commented that the adult did not have the choices that are open to other people in society.

"It depends, I think all their choices have been taken away. Like with menstruation, my daughter doesn't want it, but is forced to keep going through with it. Especially in my daughter's case where there is a hereditary factor to the disability."

Some families had considered which circumstances they would object to health care for their adult family member.

"if my daughter gets cancer, I will not let her go through all that medical intervention, chemotherapy etc. She would hate it, it would be cruel, for what benefit?"

"I have thought about this for my son, I would rather let nature take its course."

Protection of Health Providers for non-compliance with an advanced health directive
The 2011 Focus group agreed with the Queensland Law Reform Commission's position on this issue and that the principle of autonomy was important to uphold with regard to advanced health directives and that the 'changed circumstances' should be viewed from the adults perspective rather than the health providers. They support the notion that family members should be consulted and their views given primary consideration.

Common law right to consent or refuse treatment –impact of the guardianship legislation

The 2011 Focus Group upheld the proposal to amend the Guardianship legislation to ensure common law rights to refuse or consent to health care are not affected. For family members who are Statutory Health Attorneys it is vital to retain this common law right notwithstanding the feedback above regarding issues of recognition and access of 'informal' decision makers to information from Health providers and Doctors. People with an Intellectual Disability can have extremely complex health needs and decisions pertaining to these needs require careful deliberation based on a whole number of social and behavioural factors.

4.3 Adult Guardian to charge for services

Most discussion around this was short lived, the predominant answer being a resounding no.

"No! No! No! The intellectually disabled adult doesn't ask for these things, and if they do, then they're not as disabled as would appear. "

"Absolutely no. Aren't they (Adult Guardian) already being paid? Why would they need more money?"

"No. They are a government organization. The people are on a pension and can't afford it."

Those that had an alternate view saw this as a revenue raising exercise although had some reservations around unintended consequences. Another thought instituting charges could have the potential to weed out spurious complaints.

"Sort of yes, because there needs to be some funds coming into the Adult Guardian to keep them financially sustainable. Should be means tested. But should not become a two tiered system where payer gets the service and those who don't have the money don't get the service."

"People will make complaints, if one of the family is doing the complaining (mischief making) then they should maybe pay for the services."

4.4 The Court's power to appoint a litigation guardian for an adult if no-one is available

All families agreed that the court should be able to appoint a litigation guardian. Families recommended that the litigation guardian should have some knowledge of the person, if not some extensive knowledge of disability and how the disability may impact on the Court proceedings.

"Yes, but must be a person with legal knowledge and who understands people with disability and how they tick, and they all tick differently. Might say yes when they mean no. Just depends on how the question is asked."

"Yes, very much so. Would be nice to know if they could go the extra effort to get someone involved who the person knows, because people need to have a face they know."

The 2011 Focus group stated that the Adult Guardian or Public Trustee should remain potential litigation guardians of last resort and that the courts should be able to appoint them without consent. However, the ideal situation would be the consensual appointment of a litigation Guardian who has knowledge of the person or of issues in disability who does not hold responsibility for costs etc. And who may therefore be able to get the best result for the person with impaired capacity.

5.1 Ensuring that health providers are aware of advanced health directives and enduring powers of attorney

In principle, Endeavour Foundation would support an obligation with intent to improve health providers' awareness of and access to advanced health directives and enduring powers of attorney which users of the service may have made. This support would be in terms of Endeavour's duty of care requirements by facilitating access to the wishes of that individual, regarding their care, to an 'external' health provider.

Endeavour Foundation, along with several other large Queensland disability service providers, is in the processing of developing an electronic health record in order to enhance health outcomes for our service users. As was noted in the Issues paper, an electronic health record system may be an optimum method of ensuring any advanced health directives or enduring power of attorney documents are made available in an appropriate and timely fashion where they are needed.

Endeavour Foundation also notes the 23rd November 2011 Federal Government announcement from former Minister for Health and Aging Nicola Roxon regarding the introduction of e-health legislation for a national e-health records system.

If an appropriate system of e-health records is either developed 'in-house' or through the national scheme then the impact of the obligation may be negligible. If an obligation was put upon disability services providers prior to any such e-health record scheme then there may be some impact depending upon the nature of the obligation. More detail would be needed as well as adequate consultation if either option eventuated. On this basis, cautious support is given to the Queensland Law Reform Commission's recommendations.