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13 DEC 2011

HEALTH AND DISABILITIES
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11-1-4-3

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To the Queensland Parliamentary Health and Disabilities Committee on the Queensland Law Reform Commission Recommendations on Guardianship Laws Inquiry - Issue Paper

International conventions

We understand that common law is informed by international conventions. How do these proposed changes align with international conventions such as the UN Convention on the Rights of Persons with Disability? Article 25 [1] states that the Convention, to which Australia is a signatory, will:

(d) Require health professionals to provide care of the same quality to persons with disabilities as to others, including on the basis of free and informed consent by, inter alia, raising awareness of the human rights, dignity, autonomy and needs of persons with disabilities through training and the promulgation of ethical standards for public and private health care.

With a strong emphasis on informed consent, is the medical system sufficiently skilled in seeking genuinely informed consent and what is their role with regard to the health decisions described in the Issues paper?

Similarly, Article 25 [1] states that the Convention seeks to:

(f) Prevent discriminatory denial of health care or health services or food and fluids on the basis of disability.

The Issues paper however discusses in Section 4.6 the withholding or withdrawing of artificial nutrition or hydration. Is there a potential conflict herein?

Social status

There is a societal hierarchy which attributes value to life and those with intellectual disability are low down on the hierarchy of value. These values are carried by all decision makers and influence 'good medical practice' [2]. People with intellectual disability receive poor healthcare and their needs remain invisible to primary healthcare [3]. There are over 500,000 Australians who have intellectual disabilities. This is a similar proportion of the population as Indigenous people and "with health outcomes at least as bad" [4]. The Australian research shows:

- Only 29% of health conditions being diagnosed and appropriately treated in people with intellectual disabilities.

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- Very high rates of dental disease and both obesity and being underweight.
- Life expectancy up to 20 years lower than the general population.

This stark inequality arises from a range of factors including challenges to communication between health professionals and patients, high rates and complex ranges of health problems, problems with skills and available time in the mainstream health workforce, a lack of specialised intellectual disability health services to back up the mainstream, health promotion and research tending to ignore people with intellectual disabilities, and lack of co-ordination within and between governments. Without good healthcare, a person's health suffers and puts them at risk of consequent problems in employment, daily living, learning, participating in society and more. The lives of people with intellectual disability are already impoverished by discrimination [5, 6], and yet as a society, we continue to accept their poor health status.

Sterilisation

How will these proposed changes alter the current practice in substituted decision making around sterilization of individuals with intellectual disability? Whilst *A National Framework for Advance Care Directives* states that "an adult (or substitute decision maker) cannot demand treatment that is not medically indicated", the disability sector is aware of treatments of convenience to care providers (whether individuals or organizations) being performed by medical practitioners, including hysterectomies of women with intellectual disability under the guise of appendectomy[7], and pharmaceutical sterilization of men with intellectual disability under the guise of behavior management [8]. How will the right to bodily integrity be protected?

Disability organisation responses

The introduction of advanced health directives may spark reactions by disability organisations to write AHDs into the life planning processes of people with intellectual disability without involving people with expertise in safeguarding decision making. Do these organisations require guidance on how to proceed with such complexities in decision making?

We are grateful for the opportunity to submit our ideas.

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