We would like to clarify our thoughts after our presentation to the Senate Inquiry in Sydney on March 27 this year. At present the Guardianship Act in NSW states that Special Medical Treatment such as Hysterectomy or Endometrial Ablation can only be approved if it is necessary to save the person's life or to prevent serious damage to their health. Because the word "serious" can be interpreted in various ways, we strongly believe that the words "in the best interests" of the person should be used in any rewriting of the relevant laws in regards to this matter. As we discussed in our submission there is no definition of the word "serious" and this has created problems in a recent Tribunal hearing. All states and territories apart from NSW have rulings based on the "best interests" of the child or young adult and these words would be preferable to those stated in the Guardianship Act 1987.

In determining what is "in the best interests" consideration should be given to many factors including:
- overall quality of life,
- ability to be as independent as possible in the community at leisure and at work,
- dignity,
- the reasons for the surgery such as aversion to blood,
- the ability to apply local measures,
- hygiene,
- impact on overall health & potential side effects of long acting medical (as opposed to surgical) interventions to control menstruation.

We also believe that input from primary & secondary carers & relevant medical personnel should be obtained to assist decision making.

All of these points are consistent with the UN Convention on the Rights of Persons with Disabilities. They are also consistent with the submission to this Inquiry by the Australian Human Rights Commission although you have to look hard to find the relevant comments. In paragraph 12, they indicate that "the Commission understands the term 'involuntary or coerced sterilisation' to exclude sterilisation performed in an emergency situation where there is a serious threat to life or health" while in paragraph 25 various UN bodies such as the Commission for Human Rights are quoted & it is stated that Australia has an obligation to prohibit by law sterilisation of women with disability without their consent except where there is a serious threat to life or health. There is no other reference in the Commission's 16 page submission relating to the health of the disabled person & as we indicated in both our written & oral submissions, we strongly believe that in the small subgroup of women with moderate-severe intellectual disability, some but not all have a marked reduction in quality of life due to problems associated with menstruation & are unable to realise their individual capacity for physical, social, emotional & intellectual development, leading to a serious impact on psychological health. This group of women, under current Australian law, are not being treated with the care & compassion they deserve.

Yours sincerely
Professor John & Mrs Merren Carter

Sent from my iPad