Submission to the Senate Committee on the Involuntary or Coerced Sterilisation of People with Disabilities in Australia.

This submission is made by:
Mrs Cynthia Hughes and Mr Chris Hughes

We commend the Senate for examining this difficult moral, ethical and highly fraught issue for individuals with disabilities and their carers in Australia.

We have read the terms of reference and in particular wish to comment on the matter of the sterilisation of girls with severe mental disabilities. Presently, before such a girl turns 14, the case for her involuntary sterilisation can be heard before the Family Court in NSW, and the individual case is heard with input from doctors, psychologists and other health professionals as well as from carers and parents. The best interests of the young woman, her dignity and comfort in her everyday life, can be looked at compassionately and a wise decision can be made on her behalf. We ask that the Senate Committee make a decision to uphold this approach. Through this mechanism of the law, each case can be examined individually, as no two cases are the same.

A member of our family is an 11 year old girl who faces the onset of puberty.
This child was brain damaged at birth. She is severely mentally disabled and barring miracles there is no foreseen chance that she would regain any of the functions which sadly have been lost. There are dozens of medical reports that confirm this. She has little to no cognitive functioning, no ability to communicate, her vision is partial, she has cerebral palsy. She has no control over her bowels or bladder. She sits in a wheel chair most of the time, unable to walk by herself. She needs to be fed, dressed, washed, exercised (through physiotherapy and hydrotherapy) and nappy changed. She cries loudly at times and it is difficult to work out why, as she cannot communicate. It takes a lot of comforting to keep her settled and happy.

Whilst this child has such profound left brain damage, her parents have loved and cared for her so that she does relate to human warmth and care. Every day of her life she has been treated with compassion as her parents have made hundreds of decisions about her care and about her future well being. Because of the close contact she has had with parents, siblings, grandmothers, aunts, uncles, great aunts, cousins and other members of her extended family and wonderful carers, she does relate on an emotional level. She loves to be cuddled and sung to. She does seem to feel happiness, but she also feels fear and insecurity.

This child now faces menstruation. We have read the articles that talk about the rights of the disabled to be women who can have relationships and children of their own. We have read about the right to bodily integrity. The fact is that this child sadly, because of her profound brain damage, lost her bodily and mental integrity at birth. The idea that she could make a mature decision about her fertility when she turns 18 is not a possibility. Any idea that she could mother a child of her own is simply out of the question. She cannot understand, and she cannot make decisions.

If the law changes to make it impossible the courts to approve that she can undergo a small laparoscopic procedure to remove her uterus, she could be sentenced to 40 years of menstruation.

The voices presently calling for the complete end to sterilisation of intellectually impaired women seem to derogatorily judge parents who have difficulty coping with their daughter's menstrual flow and period pain. The argument that in this modern day there are hormone treatments, pain control tablets and IUD's is freely given. How much more of a violation of a person's dignity and comfort is it to have the child/woman on hormone tablets every day, pain killers for days each month, and possibly insertion of IUD's under general anaesthetic every 3 years? Indeed, to allow her to be subject to period pain when she can't communicate that she is in pain, but cries loudly and becomes extremely agitated and distressed is cruel. How much dignity and comfort is there in sitting in a wheel chair with nappy, not only with faeces and urine, but also menstrual blood? How would these moralistic people cope with such a situation month after month, year after year? As parents grow older they are less able to cope. Then there could be the decision to put the child/woman more and more into institutional care where it is not loved ones who regularly change the nappy, and where it has been shown women with intellectual disabilities are more like to be physically abused so parents have to consider birth control measures. It is emotionally difficult enough to make all the other decisions about their loved one's comfort and well-being without that nightmare as well.

Not all intellectually disabled girls/women are the same. They all have different levels of capacity. What we are asking is that the Committee recognise that there are cases such as that of our loved member of the family, and not rule out the option of sterilisation. The present system where each case is heard before the Family Court of NSW, where all the medical, psychological and social worker reports are heard, and where the parents can have their feelings and arguments heard by a compassionate and unbiased judge, must remain as a legal alternative. To take away this alternative is to subject not only the intellectually disabled woman but her family to suffering upon suffering.

Thank you for considering our submission.

(Mrs) Cynthia and (Mr) Chris Hughes