Inquiry: The involuntary or coerced sterilisation of people with disabilities in Australia

I would like to start by saying that I almost didn't bother to make a submission because a reading of the Hansard of your initial committee meeting clearly demonstrated that all members share a remarkable homogeneity of opinion on this matter. This unfortunately is a poor representation of the diversity of views in the general community. It left me feeling quite powerless as a parent to influence any sort of outcome for my child.

I am the mother and full time carer of an 11 year old child who has severe physical and intellectual disability as a result of a subdural haematoma at birth. I strongly identify with much of what has been expressed in many submissions by parents, especially number 64.

Our beautiful daughter requires the care of an infant. She is fed pureed food by spoon and liquids via gastrostomy. She wears nappies, uses a wheelchair and is totally dependent on us for her every physical need. She suffers severe separation anxiety when her parents or close family members are not close by and paying her attention. This results in long bouts of hysterical screaming when we are not present. When we are present, she is soothed by the constant singing of nursery rhymes and by watching toddler age DVDs such as Hi 5 and Bananas in Pyjamas. Due to her lack of weight bearing capacity, our daughter is already osteopaenic and has a very high risk of developing osteoperosis.

In the case of our daughter and others who have a similar level of severe - profound intellectual disability along with severe physical disability, I make the following assertions:-

- there is no possibility at the present time or at any time in the future of her having the capacity to consent to any medical procedure or intervention.
- there is no possibility at the present time or at any time in the future of her having the capacity to consent to any form of sexual contact. Any such contact initiated by another person would be totally inappropriate and would be deemed sexual abuse or assault. (However, I am in no way advocating sterilisation as a means of avoiding pregnancy resulting from sexual abuse). It will never be appropriate for her to have a child.
- Therefore, the age of 18 is arbitrary and meaningless for any application of law regarding sterilisation or any other medical procedure or intervention. I.e. None of the above can or will change between now and when she is 18.
- Menstruation will reduce our daughter's quality of life because:-
    - She can not tell us when she has pain / discomfort and where the source of it is. She cries a lot but it is often very hard to know what the reason for her distress is.
    - It will reduce her ability to attend hydrotherapy sessions which is an activity she thoroughly enjoys and is important for her muscle tone and skeletal health
    - It will reduce the length and type of outings we can take her on because of the lack of adult sized change tables in public places. Currently, tube feeds are timed to allow for longer outings. Therefore, her access to her community will be compromised.
    - It will subject her to thousands more nappy changes over her life time which often distress her emotionally and will increase her risk of fractures.
- The removal of her uterus, if less invasive interventions fail, would be no more an "act of violence", "coercion" , "forced" or an infringement of her "right to bodily integrity" than any other medical procedure she has had to undergo already in her life, all of which were deemed to be in her best interests. It would be a well considered and informed decision made by her loving parents in consultation with relevant medical practitioners.

I would really like the committee to get some expert advice, probably from RANZCOG, about the relative risks **over a person's reproductive lifetime** of the following:-

- Continual use of the oral contraceptive pill
- Continual use of Mirena IUD and associated general anaesthetics. (To be replaced every 3 years if the smaller version which is recommended for use by nulliparous women is assumed to be used).
- Partial hysterectomy via laparoscopy.
- Various other surgical / non surgical interventions that could be used for menstrual management

Are the "less invasive" interventions actually any less risky to a person's health? This information does not seem to be readily available and is essential in making judgements about what is in a person's best interests.

In the case of very severe intellectual disability, there is no capacity to consent to any procedure at any age and a blanket ban on sterilisation prior to age 18 is likely to cause more harm than it seeks to avoid. Many submissions have described cases where less invasive methods of menstrual management have either been tried and failed or have been unsuitable for use. If a girl's quality of life is being significantly compromised from age 8 because of menstrual issues, 10 years is a dreadfully long time for her and her family to cope with the resultant trauma. (Precocious puberty is much more common in girls with neurological issues than it is in the general population).

If one right (bodily integrity) leads to the contravention of other rights (comfortable and dignified life & community access) then neither can be held as an absolute – this is simple logic. Another test, a judgement based on circumstances is required to decide which right should prevail. Yet what is being proposed is a blanket ban without even allowing a court to consider facts and medical requirements of the minor. Case law and the English court system have a deeply established suspicion of absolutes which has served countries applying the system pretty well. European systems tend to like absolutes and this leads to extremes and tyranny. The blanket ban is a personal tyranny. It is based on ideology rather than true concern for and understanding of all those it will impact.