

Submission to Senate enquiry into the sterilisation of women and girls with intellectual disabilities.
February 2013

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Thank you for this opportunity to advocate for people with ID. I am deeply concerned about inadequate advocacy for people with ID and this enquiry raises the possibility of further legislative discrimination.

I should also note that I consider it to be a major problem with the terms of reference in this enquiry, as with all broad disability policy, that all people with disabilities are grouped together. This greatly muddies the discussion, because it would be absurd and wrong to suggest that women with physical disabilities should have any limitations put on their fertility, because they are able to make informed choices. Women with ID, however, may not have that facility and there is a need for allowing therapeutic sterilisation within this group for compassionate reasons, and for practical, management reasons. Therapeutic, in this case, must be extended to include the carers.

Refusing sterilisation to some young women with ID, could create huge management problems for carers that will only serve to make that individual more difficult to care for, putting extra and unnecessary strain on the carer, which stress would then flow on to be to the detriment of the person with ID. If carers conclude that sterilisation will ease the burden of work they carry, then that is their decision. It should also be within their rights to judge whether or not it is in the woman's best interests to be informed about the procedure. Consultation should be limited to

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medical professionals and not ethics committees , which may bring moral or religious values into the argument, which are irrelevant to the situation and may deflect the focus from the woman's best interests. The only considerations should be medical, and the quality of life of the individual. And their carers. If the procedure is legal, then morality need not be considered, and any legal procedures should be as accessible to people with ID as they are to the general population, if not more so. Normal people do not have to consult an ethics committee before making personal decisions about their fertility.

The government's role is to support these carers, particularly parents and familial carers, to continue to provide care, not make it harder. Issues of rights and public opinion are not relevant, and the carers' needs should be a priority in this circumstance. Parents and familial carers, particularly, have demonstrated enormous love and courage and must continually sacrifice their own lives to care for their child. It seems unconscionable that their decisions should be questioned by people, who are not caring for a fertile daughter with an ID and who can only speak in terms of abstract ideals. Normal people neither understand nor can conceive what it is like to be a person with ID (C. Bigby in Clegg 2010) and yet normal aspirations, values and ideals are often inappropriately applied to them.

Below is an excerpt from a PhD thesis I am just completing, which is due for submission early this year (2013). I do hope this submission is useful to you in your deliberations.

Yours faithfully

Lynne Bertram