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Senate Community Affairs Committee Inquiry into the Involuntary and Coerced Sterilisation of People with Disabilities in Australia

Thank you for accepting this submission regarding the above Inquiry. We write as the parents of a 31 year old daughter with moderately severe intellectual disability, and we have read the UN Convention on the Rights of Persons with Disabilities along with the NSW Disability Services Act 1993 and the Guardianship Act 1987, particularly with respect to "Special Medical Treatment – Hysterectomy or Endometrial Ablation". We believe the current laws make it extremely difficult for a young woman with moderately severe or severe intellectual disability to obtain permission for a Hysterectomy or Endometrial Ablation and the current laws do not differentiate clearly between physical and intellectual disability in this area. Most women with mild intellectual disability can cope with menstruation but would also be able to give informed consent for a Hysterectomy if there were a medical indication. Women with a profound intellectual disability generally have 24 hour care and menstruation is managed by carers but women with moderate to severe intellectual disability can have major problems. However, there are many moderate-severe intellectually disabled women who are extremely distressed due to their inability to cope with menstruation leading to loss of dignity & in addition there are the ongoing worries regarding sexual abuse and the possibility of pregnancy. A number of such disabled women have an aversion to menstruation and the sight of blood and are unable to independently cope with menstrual pads, etc. Some of these women are unable to attend supported employment (Sheltered Workshops) or attend respite weekends or camps or stay overnight at an intellectually disabled friend's house, during menstruation. We are aware of a number of instances where an intellectually disabled woman has remained in the bathroom at the supported employment with blood over her clothes, due to the onset of menstruation. Consequently, there can be a significant reduction in quality of life and thus damage to the person's emotional or psychological health.

The NSW Disability Services Act 1993 outlines relevant principles with respect to people with disabilities, including:-

1. Have the right to live in and be part of the community
2. Have the right to realise their individual capacity for physical, social, emotional and intellectual development
3. Have the same right as other members of Australian society to services which will support their attaining a reasonable quality of life
4. Have the right to protection from neglect, abuse and exploitation.

These principles are consistent with the UN Convention on the Rights of Persons with Disabilities.

One of us (JNC) recently appeared at the Guardianship Tribunal in Sydney on behalf of a 23 year old female with moderately severe intellectual disability who was applying for permission to have a hysterectomy performed. At the first hearing, the application was rejected because the Tribunal was not convinced that the young woman could not undertake hormonal therapy, which may have been able to prevent menstruation. At the second hearing, JNC, as a Consultant Endocrinologist (an "expert witness") indicated that hormonal therapy was inappropriate for this particular woman due to a strong family history of breast cancer and the head of the Tribunal, after all the submissions, indicated that they accepted that hormonal therapy was inappropriate and they agreed that menstruation was causing "serious damage to her health", but stated that they were not convinced that it was "sufficiently serious" for them to give permission for the "special medical treatment". The relevance of these comments is that the NSW Disabilities Act 1993 states that permission can only be given for "Special Medical Treatment – Hysterectomy or Endometrial Ablation" if it is felt that the treatment is "necessary to save the persons life or prevent serious damage to their health" (no differentiation is made between physical and psychological health). The Head of the Guardianship Tribunal, when asked to define the word "serious", indicated that there was no definition of the word in the Act and thus, the Tribunal had to rely on rulings in the Supreme Court and the case they quoted related to a profoundly intellectually disabled lady who was deaf and mute and wheelchair bound and the Judge declared that the problem was sufficiently serious to warrant a hysterectomy. We believe that most Australians would not accept that this should be the benchmark definition of the word "serious" with respect to this issue.

The NSW Disability Services Act 1993 was passed by the NSW State Government to protect the rights of people with a disability in the provision of services. It sets out a list of principles relating to the rights of people with disabilities and it states how these principles should be applied, and four of the main principles are tabulated above.

From this, it would appear logical to conclude that if a young lady with a moderate or severe degree of intellectual disability has menstruation that is causing a significant disruption to her social and emotional development and which affects her quality of life, most people would surely agree that treatment to prevent menstruation would be both desirable and a logical form of treatment. Hormonal therapy is often mentioned as the preferred means of preventing menstruation (in addition to minimising the risk of pregnancy should sexual abuse occur), and the forms of hormonal therapy usually suggested include continuous oral contraceptive agents, Depo Provera and Intra-uterine devices such as Mirena and Implanon implants. None of these forms of treatment can guarantee cessation of menstruation and each of them do carry medical risks, such as an increased incidence of endometrial and breast cancer, along with osteoporosis. In addition, if an intellectually disabled woman is being given continuous oral contraceptive agents (for perhaps over 30 years), there is the ongoing problem of who ensures that the tablets are given on a regular basis if the person is in respite care, in supported accommodation or in whatever accommodation is available following the parents' death.

We are aware of instances where parents have taken their daughters to Thailand or New Zealand to have a hysterectomy because their request to have a hysterectomy performed in Australia was rejected by the Guardianship Tribunal. For a country that is allegedly as caring and compassionate as Australia to have citizens undertaking such trips strongly suggests that the current situation is far from ideal and we believe that significantly greater flexibility needs to be demonstrated in our legal system and by bodies such as the Guardianship Tribunal when deliberating on applications.

We are aware that the Inquiry is into "The Involuntary and Coerced Sterilisation of People with Disabilities in Australia" and that hysterectomy, by definition, causes sterilisation. We would like to reiterate that this submission specifically relates to women with moderately severe or severe intellectual disability who have no concept regarding menstruation or how to apply sanitary pads, etc. However, we strongly believe that any caring and compassionate person would understand that there are circumstances where a hysterectomy, performed to prevent serious psychological damage and not primarily because of sterilisation, would be the most appropriate intervention for these women. This approach is consistent with the principals of the UN Convention on the Rights of Persons with Disabilities.

We believe this problem needs to be urgently addressed and reiterate that this submission specifically relates to women with moderately severe or severe intellectual disability and not to the entire spectrum of women with intellectual disability or those with a physical disability.

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