

## **Submission to the Senate inquiry on the involuntary or coerced sterilisation of people with disabilities in Australia.**

As the parent of a teenage daughter with an intellectual disability I am concerned that the outcome of this inquiry could impact on my daughter's future wellbeing and quality of life.

The areas relevant to my submission within the terms of reference include:

1(a) the types of sterilisation practices that are used, including treatments that prevent menstruation or reproduction,

(b) the prevalence of these sterilisation practices

(d) whether current legal, regulatory and policy frameworks provide adequate:

(i) steps to determine the wishes of a person with a disability,

(ii) steps to determine an individual's capacity to provide free and informed consent,

(iii) steps to ensure independent representation in applications for sterilisation procedures where the subject of the application is deemed unable to provide free and informed consent, and

(iv) application of a 'best interest test' as it relates to sterilisation and reproductive rights;

(e) the impacts of sterilisation of people with disabilities;

(f) Australia's compliance with its international obligations as they apply to sterilisation of people with disabilities;

(g) the factors that lead to sterilisation procedures being sought by others for people with disabilities, including:

(i) the availability and effectiveness of services and programs to support people with disabilities in managing their reproductive and sexual health needs,

(ii) the availability and effectiveness of educational resources for medical practitioners, guardians, carers and people with a disability around the consequences of sterilisation, and

(iii) medical practitioners, guardians and carers' knowledge of and access to services and programs to support people with disabilities in managing their reproductive and sexual health needs;

Our daughter was born with a chromosomal abnormality which causes intellectual and physical disabilities and we have worked through challenges at each stage of her development. Our daughter lives with low verbal skills, sensory integration disorder and low muscle tone. She has an acute sense of humour and enjoys quoting funny movie lines at appropriate moments. At age 9 she was a good swimmer, with a skill level similar to children without disabilities. She also enjoyed school, horse riding, singing and dancing. Her passage into puberty began early at age eight, menstruation beginning at age 10. We were well equipped to meet this challenge, sourcing educational resources suited to her intellectual level through parent networks, local library and a support group.

Things quickly went out of control with long heavy painful periods every two weeks. Our daughter was incapable of being able to ingest a pill so medication to control the menstruation was limited to progesterone injections which did not work. There were only a handful of days each month when she was period-free.

By the third year of uncontrollable bleeding our daughter was no longer swimming, horseriding, dancing, she could not manage school full time. She caught every virus that came near her and suffered double the dose. She did not want to go out and would fall asleep through the funny movies she loved.

The sensory integration disorder that our daughter lived with meant that she could not tolerate and felt threatened by some types of sensations orally, in some foods including taking tablets. She would experience stress through sensations to her skin, some fabrics, and sticky things. Wearing pads was challenging. She would often decide that she had more than she could take, and remove the pad.

It was through continued efforts to source a solution for our daughter that I eventually found an occupational therapist who suggested a therapy that was able to help her reduce the effects of her sensory

disorder. After rigorously applying the therapy she was able to take an estrogen/progesterone pill and gain control of her hormones. The therapy is not a cure to sensory integration disorder, but calms the intolerance and threat that she felt when presented with some sensations. The good news end to the saga was that our daughter now has control of her menstruation.

***In reference to section 1, a & b.***

Our daughter now uses the contraceptive pill to suppress menstruation, and uses it continuously so that she doesn't get periods, except once or twice a year. She is chemically sterilised. This is a common practice by many young women (including sportswomen, models and travelers) and the option should not be denied her by any introduced form of legislation that would propose to "protect her rights to fertility". She is under 18 and it would be discriminatory against her as opposed to young women without disability in her society to force her to seek approval from a state or federal body for this practice. I have a concern that if regulations were introduced to "protect" girls under 18 from access to medical means to suppress menstruation, then GPs would prescribe contraception differently to girls with disabilities, that pharmacists would not dispense for fear of legal reprisals.

***In reference to section 1, d.***

While this section primarily concerns educating professionals to be able to determine if a person with disability is able to provide free and informed consent, I think it is important to ensure that a person with a disability has the education available to them in a format that suits to assist them to understand what a permanent sterilisation means to them. If the senate report were to recommend changes in the steps to determine a persons capacity to consent, the provision of a personal program of education for the formation of consent (or not) should be included. A person's wishes should not be disregarded automatically because they are deemed to have an intellectual disability.

***In reference to section 1, e.***

The effects of living without periods for my daughter have been liberating; she attends school full time, has sporting activities, social activities, she lives a full and rewarding life (like her peers). The periods themselves were debilitating and disabling. I think it is important to remember that many women without disabilities in Australia decide to live life without the encumbrance of monthly periods, regardless of whether there was a "therapeutic" need to do so. In legislating to protect women with disabilities, we should remember to assist them to be able to live the best and most fulfilling life they can, to enable them to participate in the community alongside their sisters and friends, in freedom and confidence, in a lifestyle of their own choice.

***In reference to section 1, f.***

The concept of sterilisation for eugenic purposes is repugnant. Along with the majority of Australian society, I am opposed to discrimination against people with disabilities.

With over 10,000 elective hysterectomies performed in Australian hospitals 2011 – 2012 (Aust. Hospital statistics 2011/12) many women choose this surgery to correct health issues in their lives without waiting for a serious threat to life or health. Enacting laws to prevent women with intellectual disabilities from accessing elective hysterectomies effectively legislates for discrimination against these women, and in doing so, is in contradiction to the social norms and anti-discrimination legislation currently in place within Australian society.

I understand the obligation for Australia to comply with UN recommendations. In formulating a response to the Working Groups recommendation Australia should seek to protect vulnerable women, to enable those

with disabilities to participate broadly within society, with rights to enjoy or manage their fertility as they wish.

We seek liberation and freedom for people with disabilities, not an increased sense of surveillance and control, and most significantly, legislation that effectively enables (however tacitly) discrimination.

***In reference to section 1, g.***

It has been suggested that parents and carers predominately attempt to service their own needs in seeking to suppress or permanently stop their young woman's menstruation. While I do not dispute that this happens, on my own behalf as a parent I have found menstruation to be further disabling for my daughter, at its simplest to be life limiting, at its worst to be progressively damaging to her health, social and educational pursuits. Like most parents, I want the best for my child, the best she can get, the best she can possibly achieve out of life. I want to take away pain and discomfort, to make her feel better when she feels sad. Those are some of the reasons parents seek sterilisation or suppression of their daughter's menstruation. GPs who are aligned to the family unit are likely to be supportive.

Many GPs and Carers are unaware of the Commonwealth funded Carer support information service. <http://www9.health.gov.au/ccsd/index.cfm> With a phone call, people are there to link you to services that you need. I have found these information services are a valuable source of information, for direction when I have been seeking services. Finding this information hub can appear complicated. I recommend that the service is remodeled so that it is more "user friendly", that GPs be educated to the existence of the network. Posters for doctors surgeries, included in "fact sheet" handouts at hospitals and care centres, etc.

I look forward to my daughter's future, I expect that she will live away from her parents; I hope that she will explore relationships and find a loving partner in life. I wonder whether she will ever learn to independently take medication, and if permanent sterilisation is a possible solution for her. Should that situation ever arise, I hope that she will be treated sensitively and compassionately, counseled and educated, not necessarily against any one treatment, but for the best possible outcome for her life and wellbeing. I hope that she will not be treated as a statistic that needs to be "adjusted" to suit international guidelines.