Submission to Senate Committee

I wish to voice my support for the law as it stands in Australia in relation to this issue. I am concerned about the possibility of an outright ban on court-reviewed menstrual management and sterilisation of those with impaired decision-making abilities, without reference to the context of the individual and, inextricably, the care situation within which they live. In particular, the blanket ban proposed by some organizations would apply in particular to the minority of disabled people who cannot and never will be able to give consent. Further, I don't believe any law should be created or changed without strong, evidence-based reasons.

Decision-making disability

The Committee hasn't chosen to define disability, but the issue under discussion is that of consent, so it seems that 'disability' in this context is about decision-making disablilty, lack of capacity or intellectual disability[1].

Is there a problem with the current law?

Evidence-based policies

The current law requires court or tribunal authorisation for any sterilisation procedure carried out on a child except for medical reasons, and only where it is in the child's best interests and there is no alternative. Decisions about menstrual suppression, contraception and sterilisation are not made in a vacuum. They may be proposed by the disabled person's parents or carer. None of them can be carried out without medical oversight of a doctor with legal and ethical obligations, and further oversight by specialist surgeons and associate hospital staff. Where there are no immediate medical grounds, courts or tribunals are expected to provide objective oversight.

The UN Human Rights Council's 'Thematic study on the issue of violence against women and girls and disability' notes that after surveying member countries, 'in the great majority of cases, [studies and research on violence against women and girls with disabilities] is not available'[2]. Australia did not offer information to this study.

The Australian Human Rights Commission (AHRC) admits that '[t]he Commission notes that the exact number of involuntary or coerced sterilisations performed in Australia on women and girls with disability is unknown.'[3] It reports anecdotal evidence.[4] Others cite anecdotal evidence too[5]. Indeed, there seem to be many 'anecdotal reports'. Women With Disabilities Australia (WWDA) admits '[t]here is no way to quantify the anecdotal information.'[6] There also don't seem to have been any successful prosecutions under the current law. Given the apparent plethora of anecdotes, it is not clear why cases aren't prosecuted. Is it systemic corruption by doctors, police and tribunals? Ignorance of alternatives? Lack of funding for disability advocates? The cost of application to the court? The weary reluctance of carers to embark on a legal process? Significantly, though, enforcement issues don't automatically suggest that the law is inappropriate. If it is already illegal to sterilise a girl or decision-making disabled woman without court authorisation, making it illegal

altogether will only affect those who would previously have applied to the court. It is not clear how making a draconian law will make it easier to enforce when we can't even identify the reasons the current law may – or may not, in the absence of any evidence – be working.

In considering any new or change to our laws, I would hope that the Parliament could demonstrate the weakness in the current law, the scale of the wrongdoing we are seeking to address, and explicitly how the new law would address this. We shouldn't be relying on rumours. The evidence for change has not yet been properly presented in the Australian context.

Extreme perspectives

Torture

AHRC and WWDA quote from a number of UN documents which state that non-therapuetic or forced sterilization is regarded as 'violence and torture'. The UN attempts to uphold human rights for 7 billion people across the world and its reports are necessarily very general, and incomplete in terms of respondents. I question whether these broad assessments apply to the specific case of Australia, and even more whether they apply to individual Australians. The absence of legislation, data, or contribution to UN studies, is not positive evidence that torture is taking place in Australia.

Torture is defined as 'the act of inflicting excruciating pain, as punishment or revenge, as a means of getting a confession or information, or for sheer cruelty.' It also includes 'intended cruelty'. Likewise, violence is 'rough and injurious force, action or treatment'. In Australia, the high standard of the medical process of menstrual suppression or sterilisation is identical whether a woman consents or not, therapeutic or not, so I don't see how it can be torture in one doctor's surgery or hospital bed and not in another if the physical act is identical. In Australia, the vexed question is that of consent, not the procedure itself, and using the word 'torture' is emotive and inappropriate. This perspective means that from the AHRC and WWDA point of view, those who argued for, authorised and carried out sterilisation by court order are guilty of torture – judges, lawyers, doctors, parents and carers. Retired Chief Justice of the Family Court, Alastair Nicholson, who argued that sterilisation without court review could be criminal assault, also said that 'on the evidence before me in cases that I have been involved in, I have taken the view that it was warranted, but... it's got to be very carefully considered.'[7] He too would have been guilty of ordering torture under this extreme definition.

As an aside, the AHRC also argues that '[f]or the purposes of the present submission, sterilisations which are performed in an emergency situation where there is a serious threat to life or health are not considered to be 'involuntary or coerced' sterilisations.' The AHRC is absolute in its insistence that consent must be sought from the disabled person for sterilisation, but that consent can be overridden if a medical reason is given. This is at odds with, for example, the *Medical Treatment Act* in Victoria, which allows a patient to refuse treatment and it is not clear why a person with a decision-making disability should not have their rights to decline medical treatment respected under the AHRC's arguments. Also not explored is the psychological aspect of 'medical reasons' – life-threatening distress and self-harm. In the debate around abortion, the mental health (and risk to life) of the pregnant woman has been held to be as important as physical health and this issue remains grey here.

No 'best interests of disabled person'

According to the UN, coerced treatment of people with intellectual disabilities is prohibited, 'regardless of arguments of their "best interests"'[8]. WWDA endorses this view, supporting the Committee on the Rights of the Child: 'An adult's judgment of a child's best interests cannot override the obligation to respect all the child's rights [including bodily integrity].'[9] It is notable that the UN Human Rights Council's Thematic report mentions 'caregivers' eight times, and in every case it is in the context of caregivers being violent to disabled people. Parents are mentioned once, as those who 'respond with violence' to disabled offspring. Guardians appear twice, as last resorts for care. The care context of the disabled person is either absent or presented in a totally negative way by the UN. It seems to argue that parents, carers or guardians are inherently violent and suddenly become cruel and untrustworthy as soon as menstrual suppression or sterilisation is suggested. Parents and carers apparently disregard their love and ethical and legal duties to inflict torture on someone they previously cared so much for that they gave up most of their life to care for them.

The Australian approach – that the court can make such decisions to consider context and best interest – was confirmed as recently as May 2011 in the report to the UN.[10] It's not clear what events have happened to suddenly find this approach inadequate. In particular, the Family Court has 'rejected prescriptive criteria recommended by law reform agencies. It adopted this position because in its view prescriptive responses might only compromise consideration of the particular circumstances of individual children.'[11]

The AHRC state that 'sterilisation is 'involuntary' when it is performed (or, in the case of menstrual suppression medication, administered) against the person's will, or without the person being aware that it has happened (that is, without any form of consent from that person)'[12] Prohibition of menstrual suppression without consent would prohibit the recommended solutions of gynaecologists such as Dr Sonia Grover from recommending menstrual control as she advised in the *Four Corners* program in 2003.[13] Parents were seeking sterilisation for menstrual control for their daughter with the intellectual age of a 14-month old. She required 24-hour care, was not toilet trained, had no self-care and suffered violent tantrums. Dr Grover advised that they could put their daughter on the contraceptive pill continuously or insert an IUD to control menstruation. As this young woman could not consent to either of these options, and it was not for medical purposes, Dr Grover would be prohibited from recommending this option by bans proposed by the AHRC. Menstrual control is also limited by contraindications[14], side effects[15] (including irreversible significant bone loss with some contraceptives[16]) and other drug interactions which may make it impossible to use even if consent is given.

Further, a person who is not disabled, or a disabled person with some decision-making ability can consent to their sterilisation in their own best interests. Those who can't give valid consent would lose this option, or the option to have someone make the decision on their behalf, under any proposed laws to make sterilisation illegal.

Biology and sterilisation

The AHRC suggests that involuntary or coerced sterilisation, including menstrual suppression, is 'predominantly directed against women and girls' and for this reason is sexual discrimination. I'm not sure how menstrual suppression or hysterectomy can be applied to boys or men. There's a reason not many boys are sterilised: only women menstruate and only women conceive and bear children. Any reproductive consequences and responsibilities fall almost entirely on women – and

for some disabled women, on their carers – for this reason, and it is disingenuous to suggest that addressing biology is discrimination.

What if?

If Australia did move to make court-authorised sterilisation illegal, then there are foreseeable consequences. Carers Victoria notes that '[n]ationally, there are 2.6 million carers, with 1.5 million people providing direct and primary care to another person.'[17] 'For some, the decision to take on a caring role is a choice; for others, it is not.'[18] At no point is it easy, and with a disabled person this commitment can last for the whole life of the carer. Australia's trend seems to have been to support those with disabilities as much as possible to remain with their family or in well-supported small communities rather than institutions.

The carer is crucial to the best interests of the person with a decision-making disability. To disregard their role and emotional investment, as well as the best interests of the decision-making disabled person, is astonishing. At issue for me is not that consent should be overridden – it should not be – but that those proposing a blanket ban on treatments without consent **have failed to acknowledge that in some cases consent cannot and will never be able to be given**. Outside the issue of the decision-making disabled person's ability to consent to any and all medical procedures, can someone with the mental abilities of a 14-month old fully understand the consequences of sexual activity, pregnancy, childbirth and child-raising? Can they agree to contraception? The carer who can't cope surrenders their disabled dependent into state care. Will this be as good for the disabled person? Will the disabled person understand this as part of the consent decision? If the disabled person falls pregnant, they face having their offspring child removed from their care by the state, in the best interests of the offspring. Will the disabled person consent to this, and will her consent be overridden by the state? Will her emotional state be worse than if she had no child? Can she consent to an abortion? Can she consent to sexual relations? (If children legally can't consent, can the severely disabled woman? Will her lover be charged with rape if she can't consent?) And, as discussed above, what of those who cannot consent, the extremely mentally disabled, who would be treated less favourably by not having anyone able to act on their behalf. The ability of the justice system to consider the individual needs of the disabled person, and their carer, would be removed by a total ban on all options.

Susan Brady and Sonia Grover cite the difficult case of Annie, an eleven-year old with severe intellectual and physical disability as a result of a near drowning when she was two years old.[19] According to the AHRC recommendations, Annie's carers (her parents) should not be able to suppress her menstruation or request her sterilisation without her 'free and informed consent'. Annie should be able to 'retain [her] fertility, found a family and make [her] own decisions about reproduction.'[20] It's hard for me to imagine this discussion, even with guided support. How many children does Annie want? Does she in fact not want children? What decisions will she make about their care? If she can't look after them, does she understand about adoption? Does she understand the still-evolving evaluation of risks of menstrual suppression? Will she ever be able to make those decisions? Did she consent to all the other medical procedures conducted on her? This is the purpose of a medical and court review, and there is no other way to account for the circumstances of each individual. If a blanket prohibition on menstrual suppression and sterilisation is brought in,

then this ban must accommodate all cases, and include the parents and carers of young women like Annie who have to consider every single aspect of Annie's life and care.

The other aspect of the proposed law is that it be made illegal to take a disabled-person overseas to be sterilised. In Ireland, abortion is illegal, yet 'twelve women travel from Ireland to the UK each day to access abortion services.'[21] These women break the law because they feel they have no choice, despite the financial and emotional cost. In Australia, assisted suicide for the terminally ill is illegal, yet there are regular news stories on people travelling to Switzerland to use their facilities. I cannot imagine it will be different for the small proportion of Australian carers who, after education and attempts to manage, feel they have no other options, because the last resort – court review – would no longer be available. Given that many carers are already in a financially highly-precarious position, however, perhaps fewer will manage to follow through.

Further, prosecutions already don't exist for the current law. Assuming a prosecution was brought, It seems unlikely that juries would convict parents who take this step when the context is known. Laws making actions such as (previously) abortion and assisted suicide for the terminally ill illegal are rarely prosecuted and often return perverse verdicts because jurors understand context - Australians seem to prefer compassion and pragmatism to absolutes in difficult moral decisions. Neither they nor the government have, as WWDA suggests, an 'on-going indifference'[22] to these complex situations.

Education and support

Complex ethical issues such as sterilisation with court-authorisation, abortion, assisted suicide for the terminally ill, are not resolved with a blanket ban. They become, as they were in the past, unspoken and hidden. To briefly continue the analogies above, the Netherlands has seen a large drop/low uptake of abortion as a result of 'ongoing sexual and contraceptive education related to the actual experiences of the target groups, and low barrier family planning services.'[23] Countries where assisted suicide is available for the terminally ill have seen the concurrent growth of a high standard of palliative care, where both are viewed together and based on 'medical and ethical values of patient autonomy and caregiver beneficence and non-maleficence'.[24]

Susan Brady notes that protocols and practice guides exist in several states to divert parents and carers to less invasive alternatives than sterlisation, and (in 2001) 'there is good reason to believe, however, that many applications will be diverted if appropriate services are offered early in the piece, before partisan legal involvement.'[25] Some state Tribunals are closely linked with the disability service systems in their respective States. There is active community education funded by States. As above, with funding and support it is to be hoped that sterilization becomes non-existent with this support.

Consent of any individual in their medical care should be respected wherever possible and always where legally required. But it is not always possible to have valid consent and I think that alternatives such as menstrual suppression or sterilisation, after careful review by medical practitioners and a court or tribunal (with the least cost to all parties) should remain options of last resort where in the court-reviewed best interests of a person with a decision-making disability.

Thank you for this opportunity to address the Committee.

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[1] These terms suggested in the 'Issues Paper prepared by the Australian Standing Committee of Attorneys-General (SCAG) Working Group' in 2004.
[2] *Thematic study on the issue of violence against women and girls and disability: Report of the Office of the United Nations High Commissioner for Human Rights*, UN Doc A/HRC/20/5 (2012), para 13.
[3] *The Involuntary or Coerced Sterilisation of People with Disabilities in Australia*, AUSTRALIAN HUMAN RIGHTS COMMISSION SUBMISSION TO THE SENATE COMMUNITY AFFAIRS REFERENCES COMMITTEE, 20 November 2012, para 27.
[4] The reference is to information provided by the WWDA, which is admitted to be very imprecise. http://www.wwda.org.au/brady.htm#num, accessed 5/2/13. The data covers a broad range of ages (well into adulthood) and procedures with no information on whether the subjects were disabled, whether consent was given, whether it was medically necessary, or whether it was illegal. Much of the data is over 20 years old and occurs before and after a significant High Court decision in 1992.
[5] People such as then Public Advocate Julian Gardner and then Chief Justice of the Family Court Alastair Nicholson – see http://wwda.org.au/4corners.htm, accessed 5/2/13.
[6] http://wwda.org.au/brady2.htm#three, accessed 5/2/13.
[7] http://wwda.org.au/4corners.htm, accessed 5/2/13.
[8] *Thematic study on the issue of violence against women and girls and disability: Report of the Office of the United Nations High Commissioner for Human Rights*, UN Doc A/HRC/20/5 (2012), para 29.
[9] Women With Disabilities Australia, *Submission to the Australian Attorney-General on the Sterilisation of Girls and Women with Disabilities* (July 2012), p 3. At http://www.wwda.org.au/WWDASubtoAGJuly2012.pdf, accessed 5/2/13.
[10] Report of the Working Group on the Universal Periodic Review, A/)RC/17/10/Add.1
[11] http://wwda.org.au/brady2.htm#three, accessed 5/2/13
[12] *The Involuntary or Coerced Sterilisation of People with Disabilities in Australia*, AUSTRALIAN HUMAN RIGHTS COMMISSION SUBMISSION TO THE SENATE COMMUNITY AFFAIRS REFERENCES COMMITTEE, 20 November 2012, para 9.
[13] http://wwda.org.au/4corners.htm, accessed 5/2/13.
[14] Moderate obesity; diabetes; history of gestational diabetes; hypertension; history of pancreatitis, gallbladder or liver disease; physical evidence of xanthomatosis; age over 30 and smoker; age over 35; family history of hyperlipidemia; and family history of early atherosclerotic vascular disease - http://www.ncbi.nlm.nih.gov/pubmed/7026112, accessed 5/2/13.
[15] Weight gain, nausea, breast tenderness, breakthrough bleeding, painful and heavy periods, swollen legs are commonly listed side-effects of the contraceptive pill.
[16] Pfizer cites irreversible bone loss, particularly when used during teen years for Depo Provera (http://www.pfizer.com/products/rx/rx_product_depo_provera.jsp). Other Depo risks include depression, infection risk, heavy abnormal uterine bleeding and diabetes (http://www.webmd.com/sex/birth-control/progestin-only-hormonal-methods-mini-pills-shots) – accessed 5/2/13.
[17] http://www.carersvictoria.org.au/file-assets/governance/strategic-plan/, page 5, accessed 5/2/13.
[18] http://www.carersvictoria.org.au/file-assets/governance/strategic-plan/, page 3, accessed 5/2/13.
[19] http://www.wwda.org.au/brady.htm#num, accessed 5/2/13.
[20] *The Involuntary or Coerced Sterilisation of People with Disabilities in Australia*, AUSTRALIAN HUMAN RIGHTS COMMISSION SUBMISSION TO THE SENATE COMMUNITY AFFAIRS REFERENCES COMMITTEE, 20 November 2012, para 6.
[21] Irish Family Planning Association, http://www.ifpa.ie/node/506, accessed 5/2/13. 'Women's reasons for choosing abortion, such as financial worries, concern about the well-being of other children, diagnosis of serious foetal abnormality, pre-existing health problems, including mental health problems, and relationship issues, can all be extremely stressful. The stress involved in making the decision is exacerbated by having to travel to another country to access abortion services, by the expense involved, by feelings of fear and stigma, by secrecy, by a sense of isolation or by lack of support.'
[22] Women With Disabilities Australia, *Submission to the Australian Attorney-General on the Sterilisation of Girls and Women with Disabilities* (July 2012), p 3. At http://www.wwda.org.au/WWDASubtoAGJuly2012.pdf),

accessed 5/2/13.

[23] 'Contraception in The Netherlands: the low abortion rate explained', Ketting E, Visser AP, http://www.ncbi.nlm.nih.gov/pubmed/7971545, accessed 5/2/13.

[24] 'Development of palliative care and legalisation of euthanasia: antagonism or synergy?' Jan L Bernheim, Reginald Deschepper, Wim Distelmans, Arsène Mullie, Johan Bilsen and Luc Deliens, 'BMJ. 2008 April 19; 336(7649): 864–867, http://www.ncbi.nlm.nih.gov/pmc/articles/PMC2323065/, accessed 5/2/13.

[25] http://wwda.org.au/brady2.htm#three, accessed 5/2/13. 'The experience in Queensland has been relatively positive. It has shown that where services are accessed by families, before lawyers are engaged or an application is made to the court, they will more often than not chose less invasive options: "Between September 1994 and December 1997 ten out of eleven matters in Queensland were successfully diverted from court. The 'guidelines and protocols' have facilitated the identification and delivery of information and advice to the child's parents and referral for needs-based programs and support."