Senate inquiry into involuntary or coerced sterilisation of people with disabilities in Australia

Committee Secretary
Senate Standing Committees on Community Affairs
PO Box 6100
Parliament House
Canberra ACT 2600
Australia

Dr Robyn Gregory
Chief Executive Officer
Women's Health West
317-319 Barkly Street
Footscray 3011
Telephone: (03) 9689 9588
Fax: (03) 9689 3861

22 February 2013

Executive summary

Women's Health West (WHW) commends the Australia government for conducting a senate inquiry into the involuntary and coerced sterilisation of people with a disability in Australia. We expect that the results of the inquiry will lead to concrete measures that protect the human rights of women with a disability.

WHW deems that the involuntary and coerced sterilisation of women and girls with a disability to be a gendered practice and a violation of human rights. It has its origins not only in the historical control of women's bodies and their sexual and reproductive lives, but also in the discrimination and exclusion of people with a disability from society.

In an effort to prevent the involuntary and coerced sterilisation of women with a disability in Australia, WHW outlines the following legislative recommendations:

- Prohibit by law the sterilisation of children except in cases where there is serious threat to life or health

- Prohibit by law the sterilisation of adults that have not given their free and informed consent except in cases where there is serious threat to life or health,

WHW also recommends the following non-legislative reforms and initiatives:

- Fund initiatives that aim to raise community awareness of disability and that counter negative stereotypes of people with a disability, particularly women with an intellectual disability

- Include support for the management of menstruation as part of the reasonable and necessary supports funded under the National Disability Insurance Scheme

- Fund comprehensive programs that offer adequate support to people with a disability, their families and carers that is built on a thorough analysis of the gendered economy of caring

- Fund further research into developing and understanding best practice as it relates to the primary prevention of violence against women with a disability

- Fund the continuation of the Living Safer Sexual Lives: Respectful Relationships program developed by La Trobe University.

Introduction

Women's Health West (WHW) is the women's health service for the western metropolitan region of Melbourne. Our services include research, health promotion, community development, training and advocacy around women's health, safety and wellbeing. Since 1994, WHW has hosted the region's largest family violence crisis support, and prevention program. These two main arms of the service place WHW in a unique position to incorporate women's experiences directly into our research, health promotion and project work, ensuring that we clarify the connections between structural oppression and individual experience.

As a feminist organisation we focus on redressing the gender and structural inequities that limit the lives of women and girls. WHW's work is underpinned by a social model of health that recognises the important influence of, and aims to improve the social, economic and political factors that determine the health, safety and wellbeing of women and their children in our region. By incorporating a gendered approach to health promotion work that focuses on women, interventions to reduce inequity and improve health outcomes will be more effective and equitable.

Informed by our vision of equity and justice for women in the west, our work is guided by the following five strategic goals:

- Delivering and advocating for accessible and culturally appropriate services and resources for women and their children
- Improving the conditions in which women live, work and play in the western region of Melbourne
- Putting women's health, safety and wellbeing on the political agenda to improve the status of women
- Recognising that good health, safety and wellbeing begins in our workplace
- Working with others to achieve our goals.

Women's Health West's experience and expertise in working with women with a disability and female carers

WHW has specific expertise in sexual and reproductive health promotion and a long history of working with women with a disability and their female carers to enhance their health, safety and wellbeing. Our health promotion program has various programs for women with a disability and women who are carers of people who experience mental illness. These include:

- *Sunrise* – a program that offers friendship, social connectedness, information and skills development for women in the west who identify as having a disability
- *Power On* – a twelve-week strengths-based, peer education program that encourages women who experience mental illness to access information, develop skills, build support networks and enhance their health and wellbeing
- *Power On for carers* – an eight week peer education program for women who are carers of a person who experiences a mental illness that aims to enhance wellbeing.

Sexual and reproductive health is one of our three health promotion priority areas. WHW has developed a sexual and reproductive health promotion action plan for Melbourne's west, which includes strategies designed to deliver health promotion programs that promote the sexual and reproductive health and human rights of people with a disability.

WHW's family violence program has a dedicated disability intensive case manager. This position works to support women with a disability who experience family violence by building the capacity of family violence and disability services to provide collaborative and integrated intensive case management services.

Response to the terms of reference

WHW would like to take this opportunity to commend the Parliament of Australia for conducting a senate inquiry into the involuntary and coerced sterilisation of people with disabilities in Australia. WHW is of the opinion that the Senate Community Affairs Committee's Terms of Reference present important opportunities to recommend legislative and non-legislative reforms that, if passed by federal parliament, could lead to concrete measures that protect the human rights of women and girls with a disability.

Definitions

In line with Women with Disabilities Australia, our submission is informed by the following definitions:

- Forced (involuntary) sterilisation: a medical procedure that removes the ability of the individual to reproduce, after the individual has expressly refused the procedure, does not have knowledge of the procedure or has not had an opportunity to give their consent
- Coerced sterilisation: when incentives such as financial, misinformation or intimidation tactics are used to compel an individual to undergo a procedure that renders them infertile (WWDA, 2012: 5).

WHW makes a distinction between the above definitions and the case of sterilisation procedures performed in situations where there is a serious threat to life or health. We consider these to be sterilisations for therapeutic purposes. This submission is made in relation to those involuntary or coerced sterilisation procedures that are performed for non-therapeutic purposes.

Involuntary and coerced sterilisation is a gendered practice, as it primarily affects women and girls (Frohmader, 2012). It is therefore a form of gender-based violence that violates the human rights of women and girls with a disability. While WHW acknowledges that forced sterilisation comes about for many complex reasons, we consider that this violation of human rights is related to the systemic discrimination and exclusion of people with a disability from equitable participation in society's institutions, systems and structures.

WHW advocates that sterilisation procedures should not be performed on any individual without their free and informed consent. Children are by definition unable to give their free and informed consent and therefore sterilisations should not be performed on any children for non-therapeutic purposes (Human Rights Council, 2007).

- **Recommendation: Prohibit by law the sterilisation of children except in cases where there is serious threat to life or health.**

- **Recommendation: Prohibit by law the sterilisation of adults that have not given their free and informed consent except in cases where there is serious threat to life or health.**

Australia's compliance with its international obligations as they apply to sterilisation of people with a disability

The Australian Human Rights Commission has pointed out that Australia has yet to prohibit by law the involuntary or coerced sterilisation of people with a disability. In not doing so, the federal government is allowing the continued violation of the rights of women and girls with a disability and is not meeting its international human rights obligations in relation to the:

- Convention on the Rights of Persons with Disabilities
- Convention on the Elimination of All Forms of Discrimination against Women (CEDAW)
- Convention on the Rights of the Child (CRC)
- International Covenant on Civil and Political Rights
- International Covenant on Economic, Social and Cultural Rights (Australian Human Rights Commission, 2012).

The factors that lead to sterilisation procedures being sought by others for people with disabilities

WHW's approach to sexual and reproductive health involves redressing the social determinants of sexual and reproductive health. Our research in this area shows that the determinants that drive sexual and reproductive health and wellbeing are poverty and socioeconomic status, violence and discrimination, gender norms, public policy and the law, cultural norms and access to affordable culturally appropriate health services (WHW, 2011). Given that WHW takes a social determinants of health approach, we deem our expertise and contribution to the inquiry as best placed in relation to section (g) of the Terms of Reference.

Historical context

The sterilisation of women and girls with a disability is rooted in the historical context of the control of women's bodies and sexual and reproductive decisions by medical practitioners, and the discrimination and exclusion of people with a disability.

In Australia, sterilisations have only been sought through the relevant authorities for girls with an intellectual disability (Brady, 2001). We think that the historical context of discrimination against and sterilisation of women and girls with an intellectual disability is an important part of understanding the practice today.

The eugenics movement in the United States and Europe in the first half of the twentieth century sought to eliminate disability from society by way of preventing those with an intellectual disability from reproducing (Stubblefield, 2007). Traces of this thinking are still found today in debates in the field of genetics where it is promoted as a justification for the sterilisation of women and girls with a disability (Frohmader, 2012). The fact that Australia has yet to prohibit this practice by law means that there is potential for these ideologies to continue.

Furthermore, there are cultural assumptions around people with a disability, particularly those with an intellectual disability, and their capacity to consent to sex, make decisions about contraception, and parent (Kallianes and Rubenfeld, 1997).

There is however evidence to suggest that given appropriate education and support, and because capacity is not static, people with an intellectual disability can develop capacities and skills to manage such life matters (Dukes and McGuire, 2009).

In this submission, WHW has been informed by the social model of disability. The social model of disability argues that disability is caused not by an individual's impairment, but by society's negative reaction against and failure to accommodate the impairment (Morris, 2001). The denial of women and girls' rights results from societal reaction to intellectual impairment. As a society, Australian's have also been unable to provide sufficient support for the management of menstruation, and, importantly, failed to protect women and girls with a disability from sexual violence. WHW acknowledges the great diversity within disability and the effect that intellectual impairment can have on an individual's capacity to give informed consent. We advocate that the prohibition of involuntary sterilisation will offer the greatest protection for those with more severe impairments who are unable to give their informed consent.

- **Recommendation: Fund initiatives that aim to raise community awareness of disability and that counter negative stereotypes of people with a disability, particularly women with an intellectual disability.**

Problems relating to the management of menstrual cycles

Parents and carers of women and girls with a disability in Australia have commonly stated that one reason for seeking sterilisation of their loved one is that problems exist in the management of the menstrual cycle of a woman or girl with a disability (Brady and Grover, 1997).

WHW sees that this points to two problems: one is the lack of support for girls and women with a disability to deal with menstruation and the other is the lack of support for the parents and carers of women and girls with a disability.

Draft legislation for the National Disability Insurance Scheme (NDIS) states that the scheme will provide or fund 'reasonable and necessary supports' for people with a disability (FaHCISA, 2012: 26). However, it has also been stated that the forthcoming rules for the scheme will determine whether certain supports are more appropriately provided by other sectors, such as the school or health system (NDIS, 2013). WHW is of the view that support for the management of menstruation for women and girls with a disability should be funded by the scheme. Evidence shows that girls and women with a disability are able to manage their menstruation successfully in similar ways to girls and women without a disability if well supported (Grover, 2002). Notably, all of the applications made to the family court in Australia have identified girls with an intellectual disability, and none have been made for girls without a disability. Many of these applications were sought at least in part following the presence of menstrual problems (Brady, 2001). WHW is of the opinion that this shows that extra support to manage menstruation is a need particular to girls and women with a disability.

- **Recommendation: Include support for the management of menstruation as part of the reasonable and necessary supports funded under the National Disability Insurance Scheme.**

WHW recognises that the management of menstruation of some women and girls with a disability can also be a concern for families that care for their loved ones. WHW see that caring for family members with a disability is also a gendered

phenomenon, as over two thirds of primary carers in Australia are women (ABS, 2009). Furthermore, the gendered nature of this concern with regards to carers is accentuated by the reactions of family members to dealing with menstruation. As those who have already contributed to this inquiry have pointed out, some families where care for a family member with a disability is shared between women and men, caring duties relating to menstruation remain the responsibility of the female carer (Community Affairs References Committee, 2012).

Extensive research has been carried out into the stresses and strains that parents of women and men with a disability face in their role as carer (Cuskelly, 2006). It is possible that many of these strains, including fears around sexual harm, the perceived threat of pregnancy and its consequences could be prompting the extreme nature of measures sought by families of girls and women with a disability. This is indicative of the lack of support for women and their families. However, some call for a more nuanced research context, particularly one that focuses on gaining an understanding of the experiences of care in this situation, not just on the stresses and strains (Hopkins, 2000). The contribution of families and carers of women and girls with a disability must be valued and given adequate support to ensure their capacity to uphold the human rights of women with a disability.

- **Recommendation: Fund comprehensive programs that offer adequate support to people with a disability, their families and carers that is built on a thorough analysis of the gendered economy of caring.**

The prevention of pregnancy, including pregnancy as a result of sexual abuse

Along with reasons pertaining to menstrual management, the prevention of pregnancy resulting from the sexual abuse of a girl or woman with a disability is also among reasons given for seeking or deciding upon involuntary sterilisation (Jones and Basser, 1997).

It is widely acknowledged that women with a disability are at increased risk of sexual and other forms of violence in comparison with the general community (Frohmader and Meekosha, 2012). WHW is concerned that forced sterilisation on this basis will not protect a woman from sexual abuse, but will in fact make her more vulnerable to such violence, as it allows perpetrators to have their violence go undetected (Frohmader, 2012).

WHW deems that rather than taking measures to protect women and girls with a disability from pregnancy resulting from sexual abuse, the Australian government must act to prevent violence against women and girls with a disability. Australia's National Plan to Reduce Violence Against Women and their Children acknowledges women with a disability as a group that must be given priority in the primary prevention of violence against women. However, the plan contains little detail in how efforts will be implemented. While internationally there is a dearth of research relating to violence against women with a disability and how primary prevention efforts are best targeted, there is a strong call for such efforts to move beyond the teaching of 'protective behaviours' and to include a more comprehensive approach that examines the systems and structures that lead to women's vulnerability (Barger, Wacker, Macy and Parish, 2009).

- **Recommendation: Fund further research into developing and understanding best practice as it relates to the primary prevention of violence against women with a disability.**

In Australia, the Living Safer Sexual Lives: Respectful Relationships program has been developed to prevent violence against women with an intellectual disability. The program uses a peer education model that puts women with an intellectual disability at the centre, and as key agents of social change. Women with an intellectual disability have been key in the development and implementation of the program, working alongside researchers as research assistants, project workers, and peer educators (Frawley, Barrett and Dyson, 2012). WHW endorses the program as, in line with best practice primary prevention of violence against women, it seeks to redress violence and abuse on individual, community and societal levels. It offers a strong contribution to the development of an evidence base with regard to the prevention of violence against women with a disability.

- **Recommendation: Fund the continuation of the Living Safer Sexual Lives: Respectful Relationships program developed by La Trobe University.**

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