CATHOLIC WOMEN'S LEAGUE AUSTRALIA INC.

Member Organisation of the World Union of Catholic Women's Organisations (WUCWO)
NGO in consultative (Roster) status with the Economic and Social Council of the United Nations

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Senate Standing Committees on Community Affairs
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Submission from

Catholic Women's League Australia Inc. to the

Senate Community Affairs Committee inquiry into

The involuntary or coerced sterilisation of people with disabilities in Australia.

1. Introduction

Catholic Women's League Australia Inc. (CWLA) is the national peak body representing the League's seven member organisations located throughout Australia.

We are a Non-Government Organisation and have consultative (Roster) status with the Economic and Social Council of the United Nations. We are also a member organisation of the World Union of Catholic Women's Organisations which enables us to work with 5 million women in more than 60 countries to promote the presence, participation and co-responsibility of Catholic women in society and the Church.

Addressing social justice and ethical questions is one of our primary tasks. We seek to influence legislative and administrative bodies at all levels in order to preserve the dignity and rights of the human person, with particular focus on women and children. The subject matter of the current consultation, therefore, is of particular interest to our members and we are grateful for the opportunity to contribute to this important inquiry.

2. Terminology

Throughout this submission 'sterilisation' is taken to mean the performance of a surgical procedure which permanently removes a person's ability to procreate, and/or the administration of medicine to suppress fertility and menstruation. Sterilisation which occurs as a side-effect of another

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emergency surgical or medical intervention where there is a serious threat to life or health is not considered to be 'involuntary or coerced sterilisation.'

3. General principles

Opposition to involuntary or coerced sterilisation of people with disabilities is often expressed in terms of human rights violations. Women With Disabilities Australia (WWDA), for instance, state:

> Like their non-disabled counterparts, women and girls with disabilities have the right to bodily integrity, the right to procreate, the right to sexual pleasure and expression, the right for their bodies to develop in a natural way, and the right to be parents.
>
> …Like their non-disabled counterparts, women and girls with disabilities have a right to retain their fertility on an equal basis with others. Women with disabilities have a fundamental right to 'found a family', to experience sexual relationships; to experience parenthood and all that it entails; to decide on the number and spacing of their children and to have access to the information, education and means to enable them to exercise these rights. These rights are expressed in a number of international human rights treaties and instruments, and are clearly articulated in the UN Convention on the Rights of Persons with Disabilities (CRPD). [1]

CWLA supports, in principle, the view that involuntary or coerced sterilisation is a serious infringement upon the abovementioned rights. We also note that the Australian Government, through the ratification of the *Convention on the Rights of Persons with Disabilities*, has made a commitment to take all appropriate measures to promote, protect and respect these rights.

At the same time, however, CWLA recognises the potential for this type of 'rights talk' to polarise this sensitive and complex issue. The noted Harvard Professor of Law, Mary Ann Glendon, observed over twenty years ago:

> Our rights talk, in its absoluteness promotes unrealistic expectations, heightens social conflict, and inhibits dialogue that might lead toward consensus, accommodation, or at least the discovery of common ground. [2]

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[1] Frohmader, Carolyn. (2012) *Moving Forward and Gaining Ground: The Sterilisation of Women and Girls with Disabilities in Australia*. Women With Disabilities Australia, pp. 9-10. http://www.wwda.org.au/Moving_Forward_Gaining_Ground.pdf

[2] Glendon, M. (1991). *Rights talk: The impoverishment of political discourse*. New York: Free Press, p. 14.

Sadly, this phenomenon is sometimes seen in relation to the issue now before the Committee, where the mere assertion of rights (rather than reason-giving) can shut down discussion and/or place impractical demands on others. It can be tempting to assert a right without attending to the desirability or even the possibility of burdening others with the corresponding obligations.[3] However this approach is clearly not sufficient for those rights, including the 'right to procreate' and the 'right to parent', whose legitimate exercise demands a significant degree of personal responsibility and duty towards others (such as children), and where others (such as relatives or the state) will be asked to assume these duties when they are unable to be met.

Any legislative move to protect the fertility rights of people with disabilities must take care to not abandon families and carers who might have otherwise contemplated sterilisation for the person in their care, by leaving them to deal with fertility-related problems on their own. Furthermore, particular care should be taken to avoid the alienation of care-givers who, believing to be acting in the best interests of the person in their care (often a much loved daughter or sister), have already sought sterilisation. The following personal story by a member of the Catholic Women's League clearly illustrates the good will which often guides decision making in this area:

> *As the mother of a 32 year old daughter with a severe intellectual disability I know there was no alternative but for our daughter to have a partial hysterectomy.*
>
> *We didn't enter into this decision lightly and talked with other parents, medical staff and carers of girls with severe disabilities.*
>
> *Our daughter has no understanding of her bodily functions and would not be a candidate for education on fertility and sexuality. Anyone could take advantage of her when we are no longer around and this was our main concern, especially as she has no speech and very limited communication skills.*
>
> *She could never handle having her period as she wouldn't wear a pad. She is incontinent and will often strip off all her clothes regardless of her whereabouts.*
>
> *We did not make this decision as a convenience for ourselves. Her wellbeing and her safety were our main concerns and we have never regretted the decision. She has suffered no ill effects.*

In balancing these considerations, CWLA affirms the approach outlined in *The Code of Ethical Standards for Catholic Health and Aged Care Services in Australia*.[4]

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[3] Wenar, Leif. (2011). Rights. In Edward, N. Zalta (Ed.) *The Stanford Encyclopedia of Philosophy (Fall Edition),* URL = <http://plato.stanford.edu/archives/fall2011/entries/rights/>.

[4] Catholic Health Australia (2001). *The Code of Ethical Standards for Catholic Health and Aged Care Services in Australia*. Retrieved from http://www.cha.org.au/code-of-ethical-standards.html

> Because sexuality and fertility are God's gifts and parts of our common human nature, interventions upon the intellectually disabled, such as sterilisation and hysterectomy which are not therapeutic but which are simply aimed at resolving social problems, are unacceptable. Catholic disability services should seek to assist people with disabilities in their vocations as single people, spouses or parents. (4.12)
>
> Every effort should be made to ensure sufficient understanding and consent to any marriage, sexual intercourse and responsible parenthood by persons with an intellectual disability. If a person is intellectually impaired to the point that he or she does not understand the consequences of sexual intercourse or is easily manipulated to give supposed consent, then sexual intercourse with that person may constitute an assault. Caregivers have an obligation to take all reasonable care to protect people with intellectual disability from sexual assault. Only where this is genuinely impracticable may temporary measures to prevent conception be used as a last resort. (4.13)

While this *Code* unequivocally affirms that the sexuality and fertility of all women are inherent goods which should always be respected, it avoids the extrapolation of a range of absolute 'rights' and concedes that on rare occasions sterilisation could be performed, but only ever as a temporary measure while a women is at significant risk of sexual assault (non-consensual sex). Implicit here, is the expectation that *every available* means will be taken to ensure that women with intellectual disability are able to live in a safe environment where their sexuality and fertility are protected from exploitation. Sterilisation should never be seen as a solution to 'social' problems.

CWLA recommends that the principle goal of any coordinated National approach to this issue, whether by legislation or regulation, should be to eliminate the demand for all forms of involuntary or coerced sterilisation by addressing the factors that lead to sterilisation procedures being sought by others for people with disabilities.

4. Specific comments on Inquiry Terms of Reference.

In relation to the terms of reference of the inquiry, CWLA also makes the following points.

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

As a general observation, the development of appropriate legal, regulatory and policy frameworks is dependent upon accurate information. Unfortunately, however, information about the number of applications and orders, the processes sought, as well as the reasons that involuntary or coerced sterilisation is sought, is at best, sketchy.

Given the current failure of State based monitoring of this practice, CWLA recommends that consideration is given to the development of a national monitoring system.

Regarding the application of a 'best interest test' as it relates to sterilisation and reproduction rights [d (iv)] CWLA affirms the approach of Women With Disabilities Australia:

> We need to be clear about whether 'best interests' is judged according to human rights principles or whether the judgement is about the 'best compromise between the competing interests' of parents, carers, service providers and policy makers. To really determine 'best interest' for women and girls with disabilities it is crucial to focus on the fact that a person will be subjected to an irreversible medical procedure with life-long consequences without informed consent. [5]

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

This inquiry is an important opportunity to formally 'listen and learn' from the experiences of people with disabilities who have been the victims of involuntary or coerced sterilisation. As well as looking towards the future, attention should be given to healing and reconciliation.

CWLA recommends that professional counselling should be provided, where appropriate, to those women who have been subject to involuntary or coerced sterilisation, and to the carers who were involved in sterilisation decisions.

CWLA notes, too, that in the absence of any long-term studies into the health effects of long-term hormonal suppression of menstruation on young women, it is difficult to fully ascertain the physical impact that sterilisation may have upon women with disabilities. This also counts as a serious reason against chemical forms of involuntary or coerced sterilisation.

[5] WWDA. *Moving Forward*, p.12.

CWLA recommends further research and reporting into the long term physical and psychological effects of both chemical and surgical sterilisation.

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

Social factors are cited as the commonest reasons for sterilisation of people with disabilities. These include eugenics-based practices of population control, menstrual management and personal care, and pregnancy prevention (including pregnancy that results from sexual abuse).[6]

There is a pressing need, therefore, to address the social drivers of sterilisation decisions including: the poor support of caregivers; the lack of adequate measures to protect against the sexual abuse and exploitation of women and girls with disabilities; and the lack of adequate and appropriate services to support women with disabilities in their decision to become parents.

To this end CWLA recommends

- *Providing appropriate and accessible education and support in sexual development, health, hygiene and relationships for people with disabilities and their families/carers*
- *Providing appropriate and accessible education on fertility, pregnancy and birth, parenting, and support available for people with disabilities and their families/carers*
- *Providing appropriate and accessible education and formation in relationships, and where necessary, self defence and assertiveness training to people with disabilities.*
- *Providing appropriate and accessible training for families, carers and support workers in sexual development, health, hygiene, fertility management specifically around the support requirements of people with disability*
- *Disability Awareness training for health care professionals that includes training on sexual development, fertility management and sexuality.*
- *Providing increased respite and support for families living with disability*
- *Providing the necessary personal assistance and support services in the community that will reduce the risk of sexual abuse*
- *Monitoring closed settings in which women and girls with disabilities are often placed (such as orphanages, psychiatric hospitals, and institutions).*

5. Summary

CWLA recommends:

I. **That the principle goal of any coordinated National approach to this issue, whether by legislation or regulation, should be to eliminate the demand for all forms of involuntary or coerced sterilisation by addressing the factors that lead to sterilisation procedures being sought by others for people with disabilities;**

II. **That consideration is given to the development of a national monitoring system of the sterilisation of people with disabilities;**

III. **That professional counselling is provided, where appropriate, to women who have been the subjects of involuntary or coerced sterilisation, and their carers who were involved in sterilisation decisions;**

IV. **The undertaking of further research and reporting into the long term physical and psychological effects of both chemical and surgical sterilisation;**

V. **Providing appropriate and accessible education and support in sexual development, health, hygiene and relationships for people with disabilities and their families/carers;**

VI. **Providing appropriate and accessible education on fertility, pregnancy and birth, parenting, and support available for people with disabilities and their families/carers;**

VII. **Providing appropriate and accessible education and formation in relationships, and where necessary, self-defence and assertiveness training to people with disabilities;**

VIII. **Providing appropriate and accessible training for families, carers and support workers in sexual development, health, hygiene, fertility management specifically around the support requirements of people with disability;**

IX. **Disability Awareness training for health care professionals that includes training on sexual development, fertility management and sexuality;**

X. **Providing increased respite and support for families living with disability;**

XI. **Providing the necessary personal assistance and support services in the community that will reduce the risk of sexual abuse; and**

XII. Monitoring closed settings in which women and girls with disabilities are often placed (such as orphanages, psychiatric hospitals, and institutions).

Thank you, again, for the opportunity to contribute to this inquiry. CWLA wishes the Committee well in its deliberations.

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