Submission to the Senate Inquiry into the involuntary or coerced sterilisation of people with disabilities in Australia

About Family Planning Victoria

Family Planning Victoria (FPV) is a not-for-profit, leading provider of sexual and reproductive healthcare, education and advocacy and is governed by a voluntary board of directors. We provide a range of services that are accessible, culturally relevant and responsive to the needs of the Victorian community. These services include education and training as well as clinical care and aim to empower disadvantaged, at risk and marginalised people who experience difficulty accessing mainstream services.

Our key stakeholders include state, federal and local government, primary healthcare providers, hospitals and universities. FPV is a member of Sexual Health and Family Planning Australia (SH&FPA). Through SH&FPA, we are associated with the International Planned Parenthood Federation.`

In addition to standard sexual and reproductive health clinical services, FPV has been providing specialist education and counselling for people with a disability since 1982 and is an accredited disability provider. Additionally, through the disability program, FPV has provided support, information and guidance to family members, disability workers, and health and community professionals who support people with a disability. This has provided us with an understanding of the views, fears and challenges of people with disabilities, as well as those of their support people. We also provide training regarding sexuality and disability to a range of health and community professionals through courses and workshops conducted by FPV as well as external organisations such as universities and health organisations.

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FPV's disability and sexuality framework

FPV advocates that people with disabilities must be acknowledged as sexual beings, and have access to information and resources to make informed choices about their sexuality and sexual and reproductive health. It is essential that people with a disability be supported to make choices and decisions that offer the least restrictive alternative to their health and lifestyle. FPV actively promotes the right of people with disabilities to access effective sexuality education programs, resources, information and clinical services that meet their sexual and reproductive health needs. FPV supports the principles that people with disabilities have the right to:

- respect for their human worth and dignity as individuals
- realise their individual capacities for physical, social, emotional and intellectual development
- services that support their attaining a reasonable quality of life in a way that supports their family unit and their full participation in society
- participate actively in the decisions that affect their lives, including the development of disability policies, programs and services
- any necessary support, and access to information, to enable them to participate in decisions that affect their lives
- receive services in a way that results in the minimum restriction of their rights and opportunities

This is in line with our Position Statement regarding sexuality and disability, available here: http://www.fpv.org.au/advocacy-projects-research/position-statements/

FPV advocates for supportive policy frameworks and the development of sexual and reproductive health resources to address specific learning needs.

FPV thanks the Senate Community Affairs References Committee for undertaking this inquiry. We view this inquiry as an opportunity to raise the agenda of sexual and reproductive health of people with disabilities more broadly. FPV believes that people with disabilities are a marginalised group of our society who require much more support, education and opportunity to enjoy healthy sexuality and relationships.

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Response to terms of reference

In our experience, enquiries and interest in involuntary or coerced sterilisation occur almost exclusively towards females with disability however, FPV acknowledges that some males with disabilities experience this practice.

FPV considers that there are two broad groups of people with a disability who are affected by the practice of involuntary or coerced sterilisation and that these two groups, and those who support them, require different elements of support, education, and protection. These two groups are:

1. People with a disability who have the capacity (or potential for capacity, with adequate support and information) to consent to sterilisation but have this right denied through paternalistic attitudes and behaviours which treat the person as if they lack capacity to choose for themselves.
2. People with a disability who lack capacity to consent and require a substitute decision-maker.

FPV believes that many people with a disability fit into the first category but are treated as if they fall into the second. Medical practitioners require more specific support regarding the assessment of a person's capacity to consent to determine which of these categories accurately describes an individual's level of capacity.

The first category of people with a disability needs age-appropriate information and education delivered in a developmentally-appropriate way, and support so that they can make their own choices. This scenario also requires information, education and support for the family, carers and professionals who support this group of people with disabilities. Specifically, these support people need to be up-skilled to support the decision-making of the person with a disability. This may include information about what information is required, how best to communicate that information, and the importance of upholding a person's right to choose. This needs to be reflected in funding choices, policy, and practice.

The second scenario requires policy and legislation which ensure that a substitute decision-maker is only ever assigned when absolutely required and that the substitute decision-maker is in fact acting in the best interest of the person with a disability. The people who support people with disabilities who fall into this category require strategies and information to ensure appropriate, respectful and lawful procedures are upheld. For example, health professionals may erroneously believe that parents can make decisions about the sterilisation of their children.

FPV believes that this distinction is an important part of the current issue under inquiry and must be considered. We do not consider that sterilisation that is required as emergency treatment, or where an adult with a disability has provided informed and valid consent for the procedure, is included in this investigation.

FPV considers that there are two broad groups of people with a disability who are affected by the practice of involuntary or coerced sterilisation and that these two groups, and those who support them, require different elements of support, education, and protection.

a. the types of sterilisation practices that are used, including treatments that prevent menstruation or reproduction, and exclusion or limitation of access to sexual health, contraceptive or family planning services;

FPV considers that a common way that parents, carers and health professionals approach involuntary or coerced sterilisation of women with disabilities is through knowingly concealing information about contraceptive options thereby denying the right to informed consent. Parents, carers and health professionals often report that they are comfortable informing the girl or woman with a disability that the contraceptive method is to suppress menstruation but avoid any discussion of contraception, thereby avoiding discussion of sex and conception. While it is true that some forms of contraception can reduce menstruation, it is not the whole truth. Sometimes, not even the effects on menstruation are discussed and the girl or woman is instead lead to believe that the contraceptive method is either to prevent something else (e.g. generic illness) or is unaware of the reason for being on the contraceptive method at all. Less frequently we receive requests for information about having girls or women surgically sterilised.

b. the prevalence of these sterilisation practices and how they are recorded across different state and territory jurisdictions;

No comment.

c. the different legal, regulatory and policy frameworks and practices across the Commonwealth, states and territories, and action to date on the harmonisation of regimes;

As per the 'Marion' case[1], applications for the surgical sterilisation of children must be made to the Family Court of Australia. In Victoria, the Guardianship and Administration Act 1986 directs the Victorian Civil and Administrative Tribunal (VCAT) to authorise surgical sterilisations performed on adults with disabilities. FPV would support a consistent approach across Australia for the consideration of applications for surgical sterilisation. We acknowledge that it is considerably more difficult to monitor other forms of involuntary or coerced sterilisation, such as the prescription of contraception without informed consent. This further supports the need for useful and accessible training, support and education for health professionals who may provide sexual and reproductive healthcare to people with disabilities.

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

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

FPV believes that there is a lack of accessible and useful frameworks to support health professionals in determining the wishes of a person with a disability. Where there are no formal frameworks, the system inherently relies on individual professionals to have the motivation and expertise to effectively determine the wishes of a person with disabilities. However, during our experience training health professionals and offering secondary consultation, it has become evident that many health professionals do not feel confident communicating with people with disabilities, particularly around sexual and reproductive health issues. It also appears that many health professionals do not consider, and in some cases do not respect, the sexual and reproductive health rights of people with disabilities. A respect for human rights plus a willingness and competence in communicating with people with disabilities are vital in determining the wishes of a person a disability.

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

There is no widely-accepted, easily administered standardised assessment of capacity to provide free, informed and valid consent. This is a subjective process that is affected by the health professional's competence and attitudes. There are broad guidelines which include the person's ability to understand, remember and evaluate information in order to arrive at, and communicate, a decision.[2] However, it is not clear how the health professional determines the ability of the person with a disability to complete each of these steps. FPV believes that this again highlights the need for education, training and support of health professionals as well as the development of a standardised and validated tool that could assist the assessment of an individual's capacity to provide valid consent to sterilisation.

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

No comment.

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

No comment.

e. the impacts of sterilisation of people with disabilities;

Involuntary or coerced sterilisation violates basic human rights of girls and woman with disabilities to make choices about their own bodies and reproduction. In our experience, this can lead to significant psychological distress for the girls and women who have experienced this practice.

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

In 2011, The United Nations Human Rights Council as part of the Universal Periodic Review specifically recommended Australia to prohibit non-therapeutic sterilisation of girls and women with disabilities[3] in line with our human rights obligations as outlined by the Convention on the Rights of Persons with Disabilities[4] and the Convention on the Rights of the Child[5].

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

FPV believes that the primary reason that family members wish to seek sterilisation for a girl or woman with a disability is to prevent pregnancy for several reasons:

- The parent or carer does not believe that the girl or woman with a disability will be/is capable of enduring pregnancy and/or parenting.
- The parent or carer feels that they would be responsible for the care of any child born to the girl or woman with a disability and they do not want this responsibility.
- The parent or carer believes that it is better not to continue the "genetic defect".
- The parent or carer believes that sterilisation will protect the girl or woman from sexual assault.

In our experience, the underlying concern that the parent or carer will be left with the responsibility of caring for a child born to a girl or woman with a disability is the most pervasive and appears to be at the core of most enquiries into the practice of involuntary or coerced sterilisation. A second significant reason parents or carers wish to seek sterilisation relates to fears that menstruation will be distressing and unmanageable.

FPV considers that, in most cases, with adequate education and support the above concerns could be resolved without the need for involuntary or coerced sterilisation. We believe that there is an underlying fear and resistance to discussing sex and managing the sexual and reproductive health needs of girls and women with a disability. We believe that this lack of confidence in, and fear of consequences of, sex education is a universal issue for parents and carers whether the young person has a disability or not and we acknowledge the difficulty that parents and carers, as well as health, community, and education professionals experience in talking about sexual and reproductive health matters. This is a key component of our training and education with health and community professionals.

However, there are some important differences for girls and women with disabilities which make this resistance to sex education from their parents and carers more problematic than for their peers. Compared to their peers, girls and women with disabilities:

- experience less opportunity for appropriate information and learning about their sexual and reproductive health
- experience a lack of services supporting their sexual and reproductive health needs (including in primary health care)
- experience many negative, unhelpful and inaccurate prejudices about their capacity for safe and healthy sexual relationships and decision-making
- are vulnerable to abuse of their human rights, including the right to be free from violence (e.g. sexual assault) and the right to make decisions about their own bodies.

i. the availability and effectiveness of services and programs to support people with disabilities in managing their reproductive and sexual health needs, and whether there are measures in place to ensure that these are available on a non-discriminatory basis,

FPV considers there is a great lack of service across all areas of sexual and reproductive health care for people with disabilities and the approach to services has focused on the prevention or management of problems (i.e., unwanted pregnancy, sexual assault, sexual offending, pregnancy and abuse) rather than positive sexuality or supporting the full rights for reproductive health (including the right to reproduction). FPV advocates for increased support for people with disabilities and parents, carers and professionals who support them.

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

FPV believes there is a lack of accessible, useful resources regarding the consequences of involuntary or coerced sterilisation, particularly regarding the psychosocial consequences of this practice.

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; and

There is a need for improved education, training and support of health professionals to ensure that they are competent in issues related to valid and informed consent. It is our belief that medical students, trainees and practitioners are not provided with adequate education to ensure that they are upholding their responsibilities to protect the rights of people with a disability regarding informed consent. This is a common concern communicated by doctors in our sexual and reproductive health training courses. The concern is often expressed as a fear of personal consequences and managing personal moral beliefs rather than from a human rights framework which places the rights, needs and desires of the girl or woman with a disability first. Medical doctors also often report being unclear on how to appropriately assess capacity to consent, and the correct procedure to follow if they believe the person with the disability does in fact lack capacity to consent and are fearful of legal and professional ramifications. We believe that health professionals would benefit from specific training in managing issues regarding informed and valid consent when working with people with disabilities at the trainee level as well as continuing professional development. Consideration should be given to how participation in such training could be made more desirable to health professionals due to the reality of competing demands on the professional development requirements of health professionals.

h. any other related matters.

No comment.

References

[1] *Department of Health and Community Services v JWB and SMB* (1992) 175 CLR 218 (*Marion'sCase*), 250-252 (Mason CJ, Dawson, Toohey and Gaudron JJ).

[2] Bird, S 2011, 'Capacity to consent to treatment', Australian Family Physician, vol. 40, no. 4, pp. 249-250.

[3] UN 2011, Report of the Working Group on the Universal Periodic Review: Australia, UN, viewed 1 March 2013, < http://www.ohchr.org/EN/HRBodies/UPR/PAGES/AUSession10.aspx >.

[4] United Nations (UN) 2008, Convention on the Rights of Persons with Disabilities, UN, viewed 1 March 2013, <http://www.un.org/disabilities/convention/conventionfull.shtml>.

[5] United Nations Children's Fund (UNICEF) 1990, Convention on the Rights of the Child, UNICEF, viewed 1 March 2013, <http://www.unicef.org/crc>.

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