



AUSTRALIAN CATHOLIC BISHOPS CONFERENCE

Bishops Commission for Pastoral Life

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Committee Secretary
Senate Standing Committees on Community Affairs
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Dear Sir/Madam

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

The Catholic Church in Australia and its agencies (the Church) contribute in a wide variety of ways across the spectrum of Australian society. As an integral part of its core mission, the Church seeks to assist people to experience the fullness of life. It is concerned with all that impacts on human wellbeing.

The Australian Catholic Bishops Conference (ACBC) is a permanent institution of the Catholic Church in Australia and the instrumentality used by the Catholic Bishops in Australia to act nationally and address issues of national significance.

The Church will argue:

- Human beings long for deep relationships and to be accepted as who they are;
- Society tends to portray disability as a burden and people with disability as lacking sexual identity or sexual needs. It is suggested that medical professionals, and staff of government services and agencies, have a sound understanding of the dignity, sexuality and value of persons with disability in our society, so as to encourage whole hearted support for life;

- Support and counselling must be the first consideration for any unplanned pregnancy. Careful consideration must be given to supporting those women with an intellectual disability who have an unplanned pregnancy. Amniocentesis and *Chorionic Villus Sampling* have a high risk of causing injury or death to the foetus. Such tests need to be fully explained to the woman, so that she can make a well-informed decision about whether to continue with the test. Other forms of non-invasive testing should be offered as an alternative to ensure foetuses are protected;
- Preimplantation genetic diagnosis identifies foetuses with disability or abnormalities. In all cases these foetuses are discarded, rather than there being medical intervention, counselling or appropriate support offered to assist in maintaining life. Discarding foetuses, due to disability, abnormality or illness, is a direct breach of Article 10 of the United Nations Convention on the Rights of Persons with Disabilities, which states that all persons with disability have the right to life;
- Coerced or non-voluntary and non-therapeutic sterilisation impacts on a person's human dignity, because it robs them of their autonomy and deprives them of their fertility;
- There is an urgent need for improved education, practices and policies for women with disability, their families, carers and support staff, around the management of menstruation and menstrual pain;
- People with disability should be encouraged to have deep relationships, including marriage and a family life, according to their ability and beliefs;
- Formation and education in sexuality and relationships for people with disability must always be considered from a whole of life viewpoint.

A UNIVERSAL NEED FOR RELATIONSHIPS

Human beings long for meaningful relationships and flourish when they are accepted as they are. But this longing is in tension with a general social tendency to try to control or change people, rather than accept their imperfections.¹ The involuntary or coerced sterilisation of people with disability is a product of that tension.

People with disability should be allowed the opportunity to participate fully in all parts of family and social life, according to their abilities.² This includes the right to marry and have a family.

¹ Swinton, J, Jean Vanier: A Theology. See: http://www.jean-vanier.org/en/his_message/a_theology and Cushing, P, Jean Vanier on Becoming Human. See: http://www.jean-vanier.org/en/his_message/jean_vanier_on_becoming_human

² Pontifical Council for Justice and Peace, *Compendium of the Social Doctrine of the Church*. Burns and Oates, London, 2009. Section 148.

Depending on ability, people may need education on issues of sexuality and access to good support if they are to start a family.³ But they also need a good understanding of the spiritual context of their sexuality and the importance of marriage as a stable platform in which to found a family.

Having children is one of the greatest human needs, and having children and contributing to future generations is a very rich experience that should not be denied to people with disability who have that ability.⁴

With this in mind, it is imperative that agencies provide increased opportunities and formation for people with disability to foster long-term friendships and friendship circles through specifically designed training opportunities around relationships.

Couples with intellectual disability should be provided with meaningful and appropriate natural family planning. Contraception via chemical or other means is detrimental and harmful to a woman's health. Both men and women need to be educated in all aspects of their reproductive responsibilities, in a positive life giving formation and education.

There is a need to provide pre marriage education in accessible formats to encourage all couples with disability to attend pre marriage education. There is a great need for meaningful and practical marriage preparation for people with intellectual disability to be made available.

Education and formation for support persons assisting couples with intellectual disability in their daily life need to be developed, so that couples with intellectual disability are fully supported in their marriage and family life.

The importance of stable relationships, especially within marriage, has been well documented. Suitable and significant programmes need to be developed to enrich and endorse marriages and the sexual relationships of people with disability, especially for couples with intellectual disability.

STERILISATION

Involuntary or coerced sterilisation damages the person and their human dignity for three key reasons:

- The method by which their sterilisation is achieved takes away their autonomy;
- it gives a clear message that the concerns of others have priority over their own wellbeing; and,
- it takes away their fertility, which is the natural expression of a healthy human body.

³ Eastgate, G (2011), Sex and intellectual disability: dealing with sexual health issues. *Australian Family Physician*, Vol 40(4), April, pages 188-191.

⁴ Vanier, J (1997) *Our Journey Home: Rediscovering a Common Humanity Beyond our Differences*. Hodder and Staughton, London. Page 106.

The Church does not support non-therapeutic sterilisation of any person, whether by surgical or chemical means, because it is a deliberate move to take away an essential part of offering oneself to another in love through sexual intercourse, damaging the person's human dignity.⁵

In particular, subjecting people with disability to involuntary, non-therapeutic sterilisation is not ethical.⁶

One powerful test of proposals to sterilise a child is, "whether the proposed surgery would be justified 'but for' the child's intellectual disability".⁷ It is important to ensure the consideration is focused on the dignity and needs of the person with disability, rather than the needs of their carers.

Instead of sterilisation, parents and carers should provide appropriate education and supervision.⁸ Thus, appropriate and accessible training for families, carers and support workers in sexual development and management specifically around the support requirements of people with disability will assist in providing the best support for persons with disability.

INTERNATIONAL HUMAN RIGHTS INSTRUMENTS

The right of people with disability to marry and have a family, and to not be subject to involuntary or coerced sterilisation, is also supported by a number of international human rights instruments, including the United Nations Convention on the Rights of Persons with Disabilities (Article 23(1)), the International Covenant on Civil and Political Rights (Articles 7 and 17), the International Covenant on Economic, Social and Cultural Rights (Article 10) and the Universal Declaration of Human Rights (Article 16(1)).

SUPPORT FOR FAMILIES AND CARERS

While there are clear ethical reasons against involuntary or coercive sterilisation, it does not mean the practicalities of life for families or carers are any easier. It is quite understandable that families and carers would have concerns about managing menstruation and avoiding pregnancy. The difficult situations families can face are detailed in at least two submissions the Senate Standing Committees on Community Affairs have received.⁹ There is no point to demanding the rights of people with disability, if we cannot also support families and carers in their challenging role to help achieve that.

⁵ Sacred Congregation for the Doctrine of the Faith, *Responses to Questions Concerning Sterilisation in Catholic Hospitals*. 13 March 1975.

http://www.vatican.va/roman_curia/congregations/cfaith/documents/rc_con_cfaith_doc_19750313_quaecumque-sterilizatio_en.html

⁶ Conclusions of a Vatican Conference on the Family and Integration of the Disabled, 4 March 2000.

http://www.vatican.va/roman_curia/pontifical_councils/family/documents/rc_pc_family_doc_20000304_integratio-disabled_en.html

⁷ Brady, S et al, *The Sterilisation of Girls and Young Women in Australia: issues and progress*. HREOC, 2001, Page 45 See: http://humanrights.gov.au/disability_rights/sterilisation/index.html

⁸ Submission by the Catholic Archdiocese of Adelaide to the Standing Committee of Attorneys General on the Sterilisation of Intellectually Disabled Minors in response to an issues paper dated September 2006.

⁹ See submissions 2 and 4.

Ongoing and regular family support needs to be provided to families to assist in the day-to-day care and the needs of the person with disability within the family. At all times, the family unit needs to be supported and encouraged by providing regular, meaningful and effective respite from caring, which are suitable to their needs and take into account their circumstances, for example, families that are without extended family or community assistance. This is especially true for families in remote and rural areas.

Sibling support programmes should be increased and supported financially to ensure siblings of children with disability, or children with parents with intellectually disability or mental health issues, are properly supported and encouraged to continue to seek and achieve their own goals and dreams.

There is an urgent need to support families where one or both parents have disability. Families facing difficulties in parenting, for many different reasons, are able to access (albeit limited) supports to ensure equality of life and opportunity for children. If such support were available more widely to families, where a parent or parents have a disability, which compromises their capacity to parent, it would benefit those families and possibly alleviate the fears of carers and extended families.

In addition to the practical need for assistance, support to carers is essential so that they do not become isolated and feel that they are 'solely responsible' for their family member. Increased respite and support through formalised and informal support groups for families living with disability is vital.

Sterilisation is administered to prevent pregnancy, but it implies that somehow the subject of sterilisation will be able to consent to sexual intercourse while they are not able to consent to sterilisation.¹⁰

Thus, service providers and government agencies need to provide opportunities that aim to create a better and more accessible understanding of the illegality of forced or coerced sterilisation without consent. Understanding the process for consent and the basis for decision making will assist all parties to understand why decisions are made.

To assist medical professionals and families, further research and information on the effects of chemical and surgical sterilisation is required to assist in decision making, especially in the case of long term chemical sterilisation or the long term medical, social, spiritual and emotional effects of surgical sterilisation, neither of which the Church believes are in the best interests of people.

Additionally, there is a need to provide appropriate and accessible training and practical support for people with disability on fertility, pregnancy, birth, child development and support available to assist people with disability and their families.

¹⁰ Submission by the Catholic Archdiocese of Adelaide to the Standing Committee of Attorneys General on the Sterilisation of Intellectually Disabled Minors in response to an issues paper dated September 2006.

Pregnancy may not be the best outcome for a woman with disability, but sterilisation is just one option to help prevent pregnancy. Pregnancy is a natural outcome of sexual intercourse. It is the circumstance of the sexual activity that may or may not be desirable. Sterilisation, on the other hand, is an unnatural procedure, which may cover up an abusive situation.¹¹

The government needs to protect people with disability from abuse. Policies and procedures need to be evaluated and monitored to ensure abuse does not occur within the family, the community, or government and private institutions or services.

When an unplanned pregnancy results, open adoption and/or fostering options should be better promoted and explored as a temporary option for families living with disability. Again, policies need to be developed to ensure all parties understand the decision making process and that all materials or resources are in accessible formats.

People with disability and their families in remote and rural areas, older parents caring for children with disability, people with a dual diagnosis (people with both intellectual disability and mental health issues), young carers, aboriginal people, and migrants and refugees are often marginalised, and often miss out on appropriate assessment, educational opportunities and services. There is an urgent need to ensure that all people with disability are appropriately supported.

The United Nations Convention for the Rights of Persons with Disabilities reaffirms that all persons with disability are entitled to all human rights and fundamental freedom. There is an urgent need to address the historical discrimination and exclusion of people with disability within our society. Ongoing discrimination and exclusion have led to a limited and negative attitude regarding disability, which has promoted and encouraged the acceptance of practices that exclude and deny the explicit right to life and fundamental freedoms of some individuals with disability.

Governments need to ensure that the rights of persons with disability are upheld by clarifying and acting upon policies that directly relate to the historical discrimination and exclusion of persons with disability. This will ensure that every person with disability in Australian society enjoys all human rights and fundamental freedoms.

Yours faithfully

Bishop D Eugene Hurley
Chairman
Bishops Commission for Pastoral Life
Australian Catholic Bishops Conference

¹¹ Submission by the Catholic Archdiocese of Adelaide to the Standing Committee of Attorneys General on the Sterilisation of Intellectually Disabled Minors in response to an issues paper dated September 2006.