

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

15th February 2013

Re: Senate Inquiry into Involuntary or Coerced Sterilisation of People with Disabilities in Australia

Thank you for the opportunity to respond to the Senate Inquiry into Involuntary or Coerced Sterilisation of People with Disabilities in Australia.

We congratulate the Committee on the inquiry and welcome the opportunity to make comment as the leading provider of reproductive and sexual health services in NSW.

We would also be pleased to appear before the inquiry to expand on our written submission. Our Medical Director, Dr Deborah Bateson, and our Senior Health Promotion Officer-Disability, Jane Chivers both work in this important area of reproductive and sexual health.

For further information, please contact Jodi McKay, Director Communications, Government and Community Affairs

Yours sincerely

Ann Brasil
CEO

Attachment: submission

Family Planning NSW Submission

We have limited our submission to our area of expertise in reproductive and sexual health and have not made comment on the adequacy or otherwise of laws pertaining to the sterilisation of women with disability except where those laws impact directly on our work.

About Us

Family Planning NSW is the leading provider of reproductive and sexual health services in NSW. We are experts on contraception, pregnancy options, Sexually Transmissible Infections (STIs), sexuality and sexual function, menstruation, menopause, common gynaecological and vaginal problems, cervical screening, breast awareness and men's sexual health.

We have five fixed clinics in NSW (Ashfield, Fairfield, Penrith, Newcastle and Dubbo) and use innovative partnerships to deliver services in other key locations across the state with more than 28,000 client visits annually. We also provide Family Planning NSW Talkline 1300 658 886, a confidential telephone and email information and referral service, connecting our expertise to people and communities across NSW.

We provide information and health promotion activities, as well as education and training for doctors, nurses, teachers and other health, education and welfare professionals.

As an independent, not-for-profit organisation, we recognise that every body in every family should have access to high quality clinical services and information, and we provide a safe place for people to talk about their most intimate and personal issues.

Our services are targeted to marginalised communities, including people from culturally and linguistically diverse and Aboriginal and Torres Strait Islander backgrounds, refugees, people with disability, young people, people from rural and remote communities and same sex attracted people.

Family Planning NSW is working to assist poor and disadvantaged communities in the Asia Pacific region to access comprehensive reproductive and sexual health services. We collaborate with organisations at national and international levels to strengthen the ability of local health providers to deliver high quality family planning services.

We respect the rights of our clients to make choices about their reproductive and sexual health and we treat each and every person with respect, dignity and understanding.

Our work is evidence-based, and shaped by our research through the Family Planning NSW Sydney Centre for Reproductive and Sexual Health Research, our published clinical practice handbooks on reproductive and sexual health, our nationally recognised data and evaluation unit and validated through our own extensive clinical practice.

Our work with people with disability is nationally recognised with equity of access to information and services at the heart of our work.

Family Planning NSW recognises the need to promote and protect the reproductive and sexual health rights of people with disability. We believe people with disability have the same rights as other people to make choices about their reproductive and sexual health.

Many of our services and activities are aimed at supporting people with intellectual disability who we know often face significant barriers to accessing information and services. We address

this by delivering education and training for clinicians, disability workers, family members and carers and providing clinics that offer are a safe place for people with disability to talk about intimate and sometimes challenging issues.

We also produce innovative resources designed specifically for people with intellectual disability, written in plain English, to support our education activities. We have an extensive Disability Resource Collection available for loan from the Family Planning NSW Library.

We have had a long term commitment to people with disability and we support international declarations that promote their rights.

As such, we are well placed to provide comment for consideration by the Senate Inquiry into Involuntary or Coerced Sterilisation of People with Disabilities.

Overview

Family Planning NSW supports the rights of people to make their own decisions in relation to reproductive and sexual health and so strongly opposes coerced and involuntary sterilisation of people with disability.

We define sterilisation as a medical procedure that is performed with the intention of permanently removing a person's capacity to reproduce. Female sterilisation is carried out with the intention of permanently controlling fertility and in some cases it may be performed to prevent menstruation.

Female sterilisation is achieved through occluding or disrupting the patency of the fallopian tubes. It may also be achieved through a hysterectomy in which the uterus is removed. Sterilisation procedures without removal of the uterus do not impact on menstruation. Women who have undergone a hysterectomy no longer have the capacity for menstruation.

Fertility control and menstruation management

In the general population in Australia the use of female sterilisation is decreasing. This is due to the availability and accessibility of long-acting reversible methods of contraception (LARCs).¹ Some of the LARC methods are also used to reduce menstrual blood loss. The range of contraceptives now available provide appropriate and effective options for the prevention of pregnancy or, if required, the management of menstrual problems.

The most appropriate pregnancy prevention procedures are those that are reversible rather than permanent.

Reversible methods include the oral contraceptive Pill. This requires daily action and may be medically contraindicated in some instances. Other options include the LARC methods, specifically the hormonal or copper-bearing intrauterine devices (IUDs) and the contraceptive implant. These provide highly effective and cost-effective contraception which is immediately reversible on removal. The hormonal IUD is highly beneficial for the management of heavy menstrual bleeding. Information about these methods is available from all GPs or family planning clinics.

¹ LARCs that are available in Australia are implants which are effective for up to 3 years, intrauterine devices (IUDs) which are effective between 5-10 years and an injectable which is effective for 3 months. IUDs and implants are immediately reversible upon removal. In addition they can have secondary benefits. Specifically the hormonal IUD can be recommended in the management of heavy menstrual bleeding in women of all reproductive ages.

Menstruation can be challenging for some women with a disability, and in some instances their family or carers, to manage. Some women may have menstrual disorders which result in heavy or painful menses. Women with a disability have a right to decide whether and how they wish to control their menstruation. Increasing numbers of women without a disability are choosing to suppress their menstruation using a contraceptive Pill, a hormonal IUD or a contraceptive injection and women with a disability may make the same choice.

People should not be provided with contraception against their will or without their knowledge.

Supporting the decision making process

Many people who have an intellectual disability can make decisions about their reproductive and sexual health. This can include decisions relating to fertility, fertility control and menstruation. Too often people are presumed to not have the ability to make their own decisions because they have a disability. A clinician should always start from a position of assumed competence in decision making. Also if a person makes a decision that others do not agree with it does not mean that the person does not have the ability to make a decision.

Some people with disability will need support to make decisions. They may not previously have received adequate education about reproductive and sexual health to enable them to have the knowledge and skills to make decisions. The subject of sexuality generally is a silent, invisible or ignored aspect of the lives of people with disability. They will require support from clinicians, parents and support workers to develop their knowledge to be better equipped in this area.

If a person lacks capacity to make decisions about a medical issue then a substitute decision maker, such as a parent or spouse, is able in some situations to make that decision on their behalf. This should only happen if everything has been done to increase the person's ability to make that decision, they have been told what is going to happen and shown no opposition. Despite their inability to make a decision, a person still retains the right to access the same services and interventions as other people. This requires that those people who are supporting them are well informed about the choices available.

Sterilisation is classified by law, in all states and territories, as a *special medical treatment*. If a person lacks the capacity to consent to the procedure then, legally, the decision to proceed with the procedure can only be made under the direction of the appropriate state authority. It is important that legal processes offer protection but that they also uphold people's right to receive quality reproductive and sexual health services that are offered to other people in the community.

The role of clinicians in supporting decision making

Clinicians have a responsibility to uphold the rights of people with disability by supporting them with the decision making process. To effectively and legally assist a person with disability in this process a clinician must have the skills and expertise to talk about reproductive and sexual health issues including understanding how informed consent relates to a person with disability making a decision about their reproductive and sexual health.

They also need access to materials that can support them in this role. The use of health education resources designed to meet the learning needs of people with disability that provide information about topics such as puberty, menstruation, contraception, pregnancy and parenting, sexual health and healthy relationships are important to support the clinical consultation. A range of specially designed resources already exist, so it is important that clinicians are familiar with them. These include plain English picture based booklets on safe sex, girl's and women's health and general sexuality topics. There is a need for resources that cover contraceptive choices and making a decision to have a baby. All resources should reflect the rights of people with disability.

Counseling is an important intervention in the decision making process if for example, a woman or couple is talking about wanting to have a baby. This will explore not just pregnancy and childbirth but also effective parenting of babies, children and adolescents, financial and emotional considerations and supports that are needed and their availability. Effective communication, sufficient time and appropriate resources are important to making counseling successful.

All decisions should be reviewed regularly with the person, and steps should continue to be taken to build their ability to make decisions. People will have a greater ability to make decisions if they receive education about sexuality, relationships and reproductive and sexual health.

The role of parents and carers

The concerns of parents for the current and future health and safety of their son or daughter need to be acknowledged and respected. Their anxiety about the consequences of the decisions their family member makes, particularly about having a child, is of course understandable. This is an area of potential conflict because one person's decisions may significantly and negatively impact on another person. There needs to be support offered that helps to resolve this situation but it needs to be managed without taking away a person's right to make their own decisions.

Information, education and opportunities to discuss their concerns may assist with this.

Some parents have little, or outdated, knowledge about reproductive and sexual health. This could be addressed in part by the development of resources about available options to prevent unintended pregnancy and manage menstruation. Common concerns about contraceptive methods including side-effects, ease of use, effectiveness and preventing sexually transmissible infections could be addressed in a Q&A format. It is also important to provide information to parents and carers to assure them that they are not alone in the issues they face. Some parents feel uncomfortable about raising issues and seeking expert assistance around their child's physical and sexual growth and development.

Clinicians and organisations like Family Planning NSW play an important role in providing this support and can work collaboratively with parents and paid support workers to understand and uphold the rights of people with disability. The type of support offered may include providing accessible information in the form of health resources, education and counseling.

Sexuality education for people with disability

The ability of a person with disability to make decisions can be developed over time, with information and experience. People with disability should receive information and education from childhood to adulthood about topics such as their bodies, sexual health, safety, sexuality, feelings, self-esteem and relationships. This enables them to create a strong foundation to draw on for making healthy decisions.

Parents, schools and services beyond school can all take on different roles in relation to providing this education. The consequences of keeping people poorly informed are that they are left vulnerable to abuse and exploitation, have limited skills to develop relationships, and have less independence and self-determination in some of the most important aspects of their lives. In reality, the prevention of pregnancy or management of menstruation by sterilisation reflects a narrow perspective on a much broader area of the lives of people with disability.

Recommendations

1. Increase the knowledge and skills of clinicians to offer information, support and counseling about reproductive and sexual health issues for people with disability. This should include directed skills-based training for clinicians to assist in their understanding of a rights based approach to fertility control options. Family Planning NSW conducts highly successful education programs in reproductive and sexual health for GPs which include a comprehensive review of contraceptive options with a case-study approach to the management of reproductive and sexual health issues for people with disability. This includes a review of the law in relation to fertility control and skills-based training in communication and supported decision-making
2. Support the development of resources such as plain English fact sheets and brochures that can assist the clinician in communicating effectively with a person with disability. They need to be easily accessible for example by being available online
3. Support the development of more resources specifically for people with disability that align with the clinician resources
4. Support the development of parent and carer resources that align with the clinician and plain English resources
5. Support the development of resources for parents about current contraception options, including support organisations (such as Family Planning NSW and our telephone and email information and referral service-Family Planning NSW Talkline) and relevant pathways of clinical care
6. Support a cross-government response to provide people with disability with ongoing education about sexual health, relationships and sexuality appropriate for the stage of life and experience
7. Support organisations such as Family Planning NSW in the coordination of parent forums as a positive way to convey accurate information on reproductive and sexual health issues. The forums also give parents and carers a safe place to share their experiences and concerns with other parents. Parents have a right to the best available information that will enable them to support and uphold the rights of their family member
8. Ensure the National Disability Scheme (NDIS) allows and supports a person with disability the opportunity to access services around reproductive and sexual health.
9. Support the strengthening of Government policy that guides services to uphold the rights of people with disability to access quality reproductive and sexual health services offered by staff trained in responding to their issues and receive positive information and education about relationships, reproductive and sexual health, and sexuality