Sexual Health & Family Planning Australia

Leading the way in sexual and reproductive health

SUBMISSION TO THE SENATE INQUIRY INTO INVOLUNTARY OR COERCED STERILISATION OF PEOPLE WITH DISABILITIES IN AUSTRALIA

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ABOUT SH&FPA

Sexual Health and Family Planning Australia (SH&FPA) has shaped the sexual and reproductive health rights agenda through advocacy, networking and capacity building at the national and international levels for over 30 years. As a not-for-profit organization with charitable status, we work collaboratively with other national and international non-government organisations, governments and the private sector to achieve improved sexual and reproductive health and rights.

SH&FPA is the national peak body for the six state and two territory sexual health and family planning organisations (our Member Organisations). Collectively, we provide a range of sexual and reproductive health clinical services, community education, professional training and research.

- In 2011, we provided over a quarter of a million clinical services to the public. This included cancer prevention through pap smears and vaccinations, contraception and family planning services, and STI diagnosis and treatment.
- We are a key specialist provider of sexual and reproductive health workforce training and development in Australia. Every year we train Australia's primary health care workforce, including GPs, nurses and aboriginal health workers.
- We provide education and health promotion to primary and secondary school teachers, students, community workers, government agencies, disability workers and the general public.
- We also produce and disseminate quality research, data and policy advice to government, businesses, community organisations and the public.

SH&FPA's key objectives are to:

- Expand and strengthen a national approach to sexual and reproductive health for all Australians, with a focus on high needs and at risk populations.
- Advocate for policies that support a public and population health response to sexual health and family planning needs in Australia and internationally.
- Disseminate and educate on best practice research and policies.

SH&FPA is internationally affiliated as the Australian Member Association of the International Planned Parenthood Federation (IPPF) and a member of the Asia Pacific Alliance.

Submission to the Commonwealth Parliamentary Inquiry on the Involuntary or Coerced Sterilisation of People with Disabilities in Australia

Background

This submission has been prepared by SH&FPA's Disability Special Interest Group (DSIG), which draws together experts in the field of sexual and reproductive health and disability from across our Member Organisations. The information contained in this submission is based on research as well as the experience of our members who work on a daily basis with people with disabilities, their carers, and relevant disability service providers.

Introduction

Sexuality, sexual and reproductive health, and relationships are central parts of what it means to be a human being. However, for many people with disabilities, myths and prejudice can contribute to a lack of recognition of each individual's needs and rights in relation to sexuality, sexual and reproductive health.

While people with disabilities require the same basic sexual health information and skills development opportunities as the non-disabled population (in addition to information and skills that are specific to their disability), most often they do not have the same opportunities to learn as the general population (Johnson et al., 2001).

SH&FPA commends the broad terms of reference adopted by Senate Community Affairs References Committee, and encourages the Committee to consider the following issues.

- **Consent and informed decision making**

SH&FPA supports the rights of all individuals, including people with a disability, to make their own decisions in relation to their sexual and reproductive health. Many people who have a disability, including those with intellectual disabilities, are capable of making decisions about their sexual and reproductive health, *if provided with developmentally appropriate information and unbiased guidance*. This should include the receipt of information and education from childhood to adulthood about topics such as their bodies, sexual health, safety, sexuality, feelings, self-esteem, relationships and parenting. This enables people with a disability to create a strong foundation to draw on for making healthy decisions.

When considering issues of coerced or involuntary sterilisation, most debates centre on women with severe intellectual disabilities who are incapable of consenting to their own treatment, or girls with a physical and/or intellectual disability that are under the legal age of consent (Brady, Britton, & Grover, 2001). In both cases (yet in different contexts), decision making falls to a designated guardian, the courts or the state who are expected to make choices in accordance with the "best interests" of the person with the disability.

The steps to determine free and informed consent and "best interest" are broadly based on the following assumed abilities of the disabled individual and/or their guardian to:

- understand the facts involved
- understand the choices
- weigh up the consequences of the choices
- understand how the consequences affect them
- communicate their decision.

(New South Wales Attorney-General's Department, 2008)

SH&FPA is concerned that these steps are predicated on there being adequate active support and education services to allow individuals to fully understand the connections between fertility, menstruation management, sexual activity, pregnancy, parenting with a disability and the full range of available options.

It is our view that at present, there are insufficient support structures to help individuals, their carers, the courts and the state to make these decisions in a fully informed way. Therefore steps to determine capacity (both for individuals with a disability as well as their carers) must include a nationally endorsed, up-to-date set of education strategies, tools and resources which can be freely and easily accessed and used by health professionals, parents, support workers, and other relevant stakeholders.

- **Sterilisation, Avoiding Pregnancy and Menstruation Management**

There are multiple methods of avoiding pregnancy, including permanent sterilisation, the use of long acting reversible contraceptives (LARCs) and short term options such as the oral contraceptive pill. However, it must also be noted that sterilisation is also sometimes sought as a means of helping women with disabilities to manage menstruation (Eastgate, 2011; Grover, 2002; Keywood, 1998).

The Inquiry needs to recognise that there is a continuum of non-permanent options and strategies that can be used to help manage menstruation and/or prevent pregnancy. A structure is needed to ensure that medical practitioners and other health professionals, people with disabilities and their guardians/carers all understand the full spectrum of options, including the use of newer long acting reversible contraceptives (LARCs). More often than not, surgical management of menstruation and contraception is not needed (Grover, 2002).

- **Access, Availability and Effectiveness of Sexual Health, Contraception and Family Planning Services and Programs**

People with disabilities, parents, carers and health professionals all need confidence, skills and resources to effectively manage issues relating to sexual and reproductive health. This is generally no different than for people who do not have disabilities (Grover, 2002). However for people with disabilities, information and access is critical in order to understand the range of options, provide support, avoid ongoing frustration and distress and prevent applications for involuntary sterilisation which may not be supported.

Services that are needed to help women with disabilities and their carers include:

- Menstruation management
- Education about the range of options to protect against the possibility and consequences of unwanted pregnancy
- Support for sexual behaviours of concern
- Strategies to prevent and protect against sexual abuse or exploitation
- Support for those women with disabilities that do wish to have children or already have children
- Relationships and sexuality education for people with disabilities (both physical and intellectual)

While many of SH&FPA's Member Organisations already provide specific disability focused sexual and reproductive health services, these services vary greatly both in reach and content. In many cases, insufficient human or financial resources make it difficult to address all of the requests effectively. Furthermore, while a variety of educational resources also exist, there is no national mechanism to endorse these resources or to make these widely accessible.

SH&FPA is trying to address some of the issues in relation to sharing of knowledge and resources through the Disability Special Interest Group, however, members of the group are often overstretched in their roles within their Member Organisations and there is no dedicated funding to support the work of the group in an ongoing manner. What is needed is a fully funded and supported network of specific disability sexual and reproductive health service trainers and providers and qualified teachers that also includes comprehensive pre and post education assessment to evaluate learning, decision making processes and capacity to consent.

SH&FPA believes that if the development and implementation of the National Disability Insurance Scheme includes consideration of sexual and reproductive health services, this could potentially provide a key opportunity to help better integrate sexual and reproductive health services with other disability services.

- **Sterilisation , Sexual Abuse and Education**

SH&FPA believes that involuntary or coerced sterilisation should never be seen as a means to protect women and girls with a disability from sexual abuse and to prevent any pregnancies that may result from such abuse. As indicated above, the focus of such debates should be centred first on broad crime prevention measures targeting sexual offenders, next on creating community and institutional cultures that reduce opportunities for sexual offending against people with disabilities to prevent such abuse from occurring, and then also on education and training approaches with women and men with disabilities about:

- sexual & reproductive awareness
- personal rights and consent
- rules about touch and relationships (in which relationships sexual touch is ok and in which it is not) (e.g. family members & support workers)
- personal safety skills
- how to recognise an experience as abusive and what to do.

SH&FPA Member Organisations already undertake such work in some states. For example, Sexual Health and Family Planning ACT and Family Planning Tasmania offer training to education and disability services sectors in the SoSAFE! Program. Designed by teachers with extensive experience in education of students with disabilities, and based on demonstrated sound teaching practices, SoSAFE! is a set of visual and conceptual tools designed to facilitate sexuality education, social safety and social skills training. The program was designed specifically to the common learning needs of students with moderate-severe intellectual disability and autism spectrum disorders, and makes use of high levels of visual learning and system and explicit instruction.

Family Planning Queensland (FPQ) has developed numerous resources to support learning about bodies, puberty, relationships, contraception and personal safety for people with a disability. The teaching kit *Every Body Needs to Know* is used in schools and disability support services across Australia. It utilises visual resources to assist with learning and provides educators and service providers with a resource that is based on evidence. Importantly FPQ also produces resources for parents and carers to support them to feel confident in having conversations with young people about their bodies, relationships and being safe.

- **The bigger picture**

SH&FPA acknowledges that while this Inquiry specifically focuses on the involuntary or coerced sterilisation of people with a disability, we urge the Committee to consider this

within the broader framework of the importance of sexual and reproductive health services and education for all people with disabilities, including men, and their carers (and also not just those that do not or are unable to consent to medical procedures).

SH&FPA 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. In particular, children and adolescents with disabilities need and are entitled to the same educational opportunity and information as their peers without disability. Indeed, there is no significant distinction between young people with disabilities and their age-cohort peers in the interest in and need for accurate, age- and developmentally-appropriate information about relationships, sexual development, sexual health and social safety.

Students with disabilities:

- Generally mature biologically and reproductively on par with or earlier than their peers, but restricted social environments may limit parallel social and emotional development (Elias & Murphy, 2006; Greydanus, Rimsza, & Newhouse, 2002);
- Commence sexual relationships *with or without* adequate education and information to protect their sexual health and psychological wellbeing (Murphy & Young, 2007);
- Require explicit and systematic education/training, often over a longer period of time, with high levels of reinforcement and cognitive prosthesis and a simplified social model, to navigate the complex social world around them to be successfully 'included' in social environment during adolescence and post-school.

Without doubt, society cannot on the one hand demand sexually responsible behaviour from people with disabilities if they have never been taught what constitutes sexually responsible behaviour. Similarly, people in the general community without disabilities also need to be better informed about the needs of those with a disability, and have common misconceptions and stigma about the sexuality of people with disabilities challenged.

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