

The Executive Director
Australian Law Reform Commission
GPO Box 3708
Sydney, NSW 2001

Thank you for the opportunity to make comment on the Australian Law Reform Commission Inquiry into Equality, Capacity and Disability in Commonwealth Laws.

We congratulate the Federal Government on the review of Commonwealth laws and legal frameworks that deny or diminish the equal recognition of people with disability as persons before the law and their ability to exercise legal capacity.

We have made comment only as it relates to our area of expertise in reproductive and sexual health, mostly in regard to the following areas:

- Decision making and consent
- Medical treatment and sterilisation
- Intimate relationships and parenthood
- Discrimination

We also believe UNCRPD is a powerful statement of what Australia and the world believe are the fundamental rights of people with disability, and goes some way towards reducing discrimination. Family Planning NSW acknowledges Australia's commitment to the UNCRPD and believes the Convention provides fundamental principles for all decision-making by the Federal and NSW Governments.

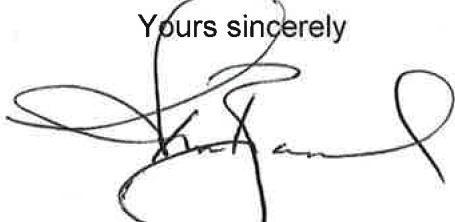
We draw attention in particular to Articles 16, 21, 23, 24 and 25 which specifically address rights around reproductive and sexual health, and believe Australian Laws must reflect Australia's adherence to those articles.

We also refer you to our action plan, which details the areas we believe need to be addressed by government in regard to the reproductive and sexual health for people with disability. The plan was launched in December 2013 by the Australian Disability Discrimination Commission, Graeme Innes. The plan can be downloaded at www.fpnsw.org.au/loveandkissestakingaction

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Yours sincerely



Ann Brassil
CEO

About us

Family Planning NSW is the state's leading provider of reproductive and sexual health services. 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 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

We provide education and training for teachers, disability workers, clinicians, family members and carers about sexuality for people with intellectual disability. Our clinics are a safe place for people with disability to talk about intimate and sometimes challenging issues and to access confidential reproductive and sexual healthcare. We also produce innovative easy to read resources to support our professional and community education activities.

Our work aligns with the priorities of people with a disability and organisations that support them.

Family Planning NSW has been delivering targeted services to people with disability for more than 35 years.

Our Comments

Decision making and consent

Family Planning NSW supports the rights of people with disability to make their own decisions about all aspects of their life including their reproductive and sexual health. However we believe there is confusion among clinicians, parents and carers, and disability workers about what constitutes consent and the role of supported and substitute decision making. We are pleased that this is an area of focus for the inquiry.

We share the concerns of disability organisations in regard to Australia's Interpretative Declaration of Article 12.

We believe the Australian Government must provide clarity around decision making and consent more generally for people with disability, in particular its support for substitute decision making only "as a last resort and subject to safeguards". The development of a legal framework about supported decision making would be an important step in upholding people's rights in the area of reproductive and sexual health.

Most people with disability are able to make their own decisions about their reproductive and sexual health when given the appropriate level of support and/or information. A supported decision making framework needs to encompass the requirement for clinicians, other health and support workers to take on the role of assisting a person to make decisions. This means that they need to develop the skills necessary to talk about reproductive and sexual health in ways that encourage the person to make their own decisions.

It is probable that many clinicians use substitute decision makers, both formal and informal, as their main approach when seeing a person with a disability, particularly if the patient has a cognitive impairment. Clinicians and carers need to understand when a substitute decision maker is necessary and who that can be. 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 they have shown no opposition. Reproductive and sexual health and disability is a sensitive topic area that many clinicians are uncomfortable in addressing. They may find it easier to discuss a medical intervention or a person's sexual behaviour with the carer or a support worker. This can result in other people making decisions instead of the person with disability. In our experience, examples of this include whether to use contraception and the method to use, and how to manage menstruation.

Even if a person is unable to make a decision, they still retain 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.

All decisions should be reviewed regularly with the person, and steps should continue to be taken to build their ability to make decisions, particularly as they get older.

A primary requirement of a legal framework for supported decision making should be that people with disability are provided with education to enable them to make decisions. In relation to reproductive and sexual health this needs to start in childhood and continue through life. Access to education about sexual health, sexuality, safety and relationships is a necessary and lifelong need for people with disability. Many people, especially those who are older, have not had any education that can assist them with making decisions in these areas. Strategies for providing this education need to be customised to the individual requirements of the person. Generally, one-off education is not sufficient. Rather it should be a planned programme that builds knowledge and life skills relevant to the person's circumstances and life stage.

Medical treatment and sterilisation

The Federal Government's 2013 Community Affairs References Committee inquiry report into the involuntary or coerced sterilisation of people with disabilities in Australia demonstrated why governments need to provide the legal frameworks and support to people with disability to allow for informed decision-making about reproductive and sexual health.

While Family Planning NSW's submission to the inquiry related primarily to the reproductive and sexual health of people with disability, we support the Committee's recommendations to improve and strengthen the legal framework as it relates to the sterilisation of people with disability.

We support the Committee's recommendations, and believe that while they relate specifically to sterilisation, many of the recommendations are relevant to the broader reproductive and sexual health issues.

Intimate relationships and parenthood

The subject of sexuality and intimate relationships are generally silent, ignored and invisible aspect of the lives of people with disability. It's a subject that governments have largely failed to acknowledge and in doing so make the necessary changes that ensure people with disability have the opportunity to participate in loving, safe and fulfilling sexual relationships.

Family Planning NSW has participated in a number of consultations related to the NDIS and the NDS and has urged the Australian and NSW Governments to include recognition of the rights and wellbeing of people with disability when it comes to intimate relationships, and their reproductive and sexual health. While we do not believe the NDIS excludes the issues we have raised, there is certainly no explicit recognition of the importance of these issues. Family Planning NSW advocates that the area of sexuality, and reproductive and sexual health should be deemed 'necessary' and 'reasonable' when considering the services and support people with disability are able to access under the NDIS.

There is little recognition within the NDS of the issues we have raised.

We believe that NDIS planners and disability service providers require specific workplace policies and procedures to ensure people with disability's rights are upheld in the area of sexuality, relationships, family, and reproductive and sexual health.

In relation to marriage, Family Planning NSW believes people with disability have the right to marry on an equal basis with others however, this right is often not upheld due to the negative attitudes of family members, support staff and service providers. Entrenched societal myths and misconceptions about the sexuality of people with disability justify this discrimination. The opinion of a person with disability's guardian should not be taken into account when determining a person's capacity to consent to marriage.

People with disability should have a range of opportunities to explore and express their sexuality on an equal basis with others, including access to the sex industry. We support the work of Touching Base Incorporated, an organisation which provides information, referral and training to facilitate access to sex work services for people with disability. We believe these services should not be excluded from the services able to be accessed through NDIS or related schemes, nor should the person who chooses these services be discouraged, discriminated against, disadvantaged or questioned about their ability to manage their plan.

Family Planning NSW supports the rights of people with disability to choose to have children and families.

Women with disability are often denied the information, education and support they need to make informed decisions about contraception, family planning and parenthood. Men with disability also require an understanding of contraception for themselves and their female partners, and education about being a father if this is an aspiration they have.

For all women choosing and planning for pregnancy and parenthood is important. For women with disability such choice accompanied by support and planning is often denied to them due to:

- discrimination - women with disability who make this choice can be discriminated against by people who assume a person with disability is non-sexual, not capable of having a relationship or parenting a child
- clinicians and support workers being ill equipped to talk to a woman with disability about having a child and therefore unable or unwilling to assist with pregnancy and parenting information. General Practitioners (GPs), nurses and other health providers require information, resources and training to support people with disability in the practice setting
- the risk of exploitation and abuse in relationships. The power imbalance in the relationships of women with intellectual disability often contributes to their lack of control over their fertility

People with disability have the right to live free from abuse and exploitation. However they are significantly more likely to be sexually assaulted at all ages than people without disability. Women with developmental and intellectual disability are most at risk of being sexually assaulted. It is unlikely that a person with disability who experiences sexual assault will only have one experience of this in their life time. Many people with disability will have experienced repeated incidences of sexual assault by the time they are 18 years of age.

Discrimination

People with disability are often stereotyped or seen as one homogenous group, which means they are not viewed as unique individuals least of all sexual beings who have a right to the same diversity of sexual expression as everyone else. For people with disability to be fully included in community life requires action which acknowledges their diversity including the provision of services which are sensitive and flexible to meet a range of different needs, *sexual orientation, gender diversity and intersex status*.

Lesbian, gay, bisexual, transgender and intersex (LGBTI) people with disability in Australia face multiple exclusions and discriminations in the expression and enjoyment of their sexuality. Throughout history both LGBTI people and people with disability have had their reproductive and sexual rights ignored and denied. In recent years increased recognition of LGBTI people and people with disability in human rights legislation and Australian anti-discrimination laws have led to improved opportunities however progress is slow. The health and wellbeing of LGBTI people and people with disability continues to be disproportionately poorer than the general population and heterosexism, homophobia and transphobia dominate as leading causes of social exclusion and discrimination.

A person with disability should not be discriminated against based on their sexual orientation, gender identity and intersex status and this should be reflected in law, and stated in all published material related to government policy, legislation, strategy and health service design and delivery.

Cultural diversity

There is very little literature about the health needs of people with intellectual disability from a culturally and linguistically diverse (CALD) background in Australia and no known literature that deals specifically with reproductive and sexual health issues. The National Ethnic Disability Alliance (NEDA), in its 2010 report on people with disability in Australia, estimates that people from CALD backgrounds with disability comprise one in 20 Australians or approximately one million people. The report does not distinguish between physical and intellectual disability, sensory or other impairments.

Typically people with disability from CALD backgrounds are disadvantaged and marginalised. They remain hidden from mainstream services relying on informal community and family supports. They typically present to disability service providers as a result of a crisis and therefore their reproductive and sexual health needs are a low priority in comparison to the housing, financial, legal and acute health needs that often stimulate first contact with service providers.

In 2011, Family Planning NSW interviewed four disability peak bodies about the reproductive and sexual health needs of people with intellectual disability from CALD backgrounds. They reported that the service system in general did not have capacity to deal appropriately with sexuality and disability nor with the degree of cultural competency that is required to meet the needs of people with disability from CALD backgrounds. The inequality faced by people with disability from CALD backgrounds is exacerbated by a lack of referral pathways and translated information and resources.

People with disability CALD backgrounds need to be specifically acknowledged in all disability policy, government statements and documents, strategies and service delivery frameworks.

Aboriginal and Torres Strait Islander people

The prevalence of disability in Aboriginal and Torres Strait Islander communities is approximately twice that of the non-Indigenous population, and they experience poorer reproductive and sexual health outcomes.

The discrimination and isolation experienced by Aboriginal and Torres Strait Islander people with disability is compounded by support services which are poorly targeted and located.

The culturally appropriate disability support services that do exist are not equipped or resourced to support Aboriginal and Torres Strait Islander people with disability to access specialised reproductive and sexual health services. This has resulted in a landscape where the vast majority of Aboriginal and Torres Strait Islander people with disability do not have their needs met in any significant way. There is limited understanding about the most effective service delivery models that would best meet the needs of this group of people. Models that could be explored include:

- outreach services to encourage increased inclusiveness
- training Aboriginal Liaison workers to educate communities to support Aboriginal people with disability to make their own choices

In NSW the situation is particularly acute in rural and remote areas.

Aboriginal and Torres Strait Islander people with disability need to be specifically acknowledged in all disability policy, government statements and documents, strategies and service delivery frameworks. There is a lack of research in relation to people with disability who are LGBTI, Aboriginal and Torres Strait Islander, and from CALD backgrounds. Improved data collection and more inclusive research would assist in planning appropriate service systems to ensure the rights of people with disability from diverse backgrounds and identities are upheld.