

Submission of Family Planning NSW

Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability: Issues Paper Rights and Attitudes

July 2020

About Family Planning NSW

Family Planning NSW is the leading organisation for reproductive and sexual health in New South Wales and Australia. Our mission is to enhance the reproductive and sexual health and rights of our communities by supporting all people to have control over and decide freely on all matters related to their reproductive and sexual health throughout their lives.

Family Planning NSW has been delivering targeted services to people with disability and those who support them for over 35 years, including clinical services, health promotion and professional education. As a registered provider under the National Disability Insurance Scheme (NDIS), we provide sexuality and relationship support to people with disability, primarily delivered through psychology services at our Newcastle clinic.

We firmly believe in the right of all people to make decisions about their own body and relationships, and the right of all people to live without violence, abuse, neglect and exploitation. However, the evidence is clear that people with disability are much more likely to experience violence, particularly sexual violence, compared to people without disability.(1)

Family Planning NSW welcomes the opportunity to provide input into the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability. This submission responds to the *Rights and attitudes issues paper*.

Recommendations

Summary of recommendations	
1. A more inclusive society	Human rights principles, including the reproductive and sexual health and rights of people with disability, should be actively included in the development of policies and programs. People with disability should also be consulted about their experiences and ways to improve the realisation of rights.
2. Awareness of the rights of people with disability	There is a need to improve the accessibility of education and training opportunities for teachers, disability support workers, health professionals, parents and carers, and other community members about the rights of people with disability. Actions include increased access to: <ul style="list-style-type: none">• disability rights training and education• resources to maximise the decision-making ability of people with disability• training for clinicians on providing disability inclusive reproductive and sexual health services• supported decision-making resources, training and information for professionals, parents, carers and disability support workers.
3. Access to reproductive and sexual health services	There is a need to provide equitable, accessible and affordable health care for people with disability. This can be achieved through: <ul style="list-style-type: none">• increased availability and accessibility of sexuality and reproductive and sexual health care services for people with disability, particularly in regional and remote areas
4. Access to sexuality expression and sexuality support	People with disability have a right to access sexuality expression and support services. Actions to ensure this right include: <ul style="list-style-type: none">• clearer guidance about the kinds of services that can be obtained as part of sexuality and relationship support, in the form of a National Disability Insurance Agency (NDIA) policy or procedure document• inclusion of sexuality and relationship support as a standard item in all NDIS participant plans.
5. Access to comprehensive sexuality education	People with disability have the right to receive accurate and age-appropriate, evidence-based, targeted comprehensive sexuality education. Comprehensive sexuality education programs should be developed in consultation with people with disability to ensure that their reproductive and sexual health needs are met.

Summary of recommendations

6. Access to advocacy services	Ensuring access to advocacy services is essential in realising and promoting the rights of people with disability. Actions include: <ul style="list-style-type: none">• committing to funding advocacy services so that they are fully resourced to deliver timely and competent support• ensuring advocacy training is available for people with disability and support people.
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Question 1 – Where and when in life do people learn about the rights of people with disability? How could this be reinforced and/or improved?

Family Planning NSW is concerned that there is little opportunity for professionals and people in the general community to learn about the rights of people with disability, particularly their reproductive and sexual health rights. Little guidance is available on the places where communities and professionals are supported to learn about these rights, contributing to the poor realisation and lack of promotion of the rights of people with disability.

In some cases, disability support workers and other professionals learn about the rights of people with disability in formal courses and qualifications. For example the *Certificate IV in Disability* at TAFE NSW seeks to build the capacity of disability support workers to facilitate empowerment of people with disability. Often rights based education is integrated into core units of study which can diminish its importance. The rights of people with disability should be taught explicitly, with further study and qualifications being a minimum requirement for disability support workers.

Other professionals - including teachers, community workers and health professionals - may not receive formal education or training about the rights of people with disability. Workers should be supported to access information and training.

As the leading provider of reproductive and sexual health education in NSW, Family Planning NSW facilitates a number of education courses for disability support workers, teachers, health professionals and community members about the rights of people with disability. We have provided training to over 13,500 doctors, nurses, teachers, disability workers and community workers since 2008. Our clinical programs build the capacity of clinicians to ensure their services are disability inclusive. Overall, the majority of our course participants report a high level of satisfaction (87% in 2018-2019).

See recommendation 1-2.

Question 2 – What stops the rights of people with disability being respected, promoted or realised? How is this linked to violence, abuse, neglect and exploitation?

People with disability have the right to access the highest attainable standard of reproductive and sexual health without discrimination, to make decisions about their own body and relationships, and live without violence, abuse, neglect and exploitation.(2) However, they often face multiple barriers and discrimination from both the disability and health care systems. Misconceptions, prejudices, stereotypes and negative attitudes surround the reproductive and sexual health and rights of people with disability and contribute to an overall increased risk of sexual violence, abuse, neglect and exploitation.(3,4)

Attitudes of support people and service providers

Poor attitudes, often resulting from limited disability education, of disability support workers and support people about reproductive and sexual health care and rights, can contribute to limited opportunities that hinder the realisation of the rights of people with disability. Of concern, people with disability often lack support to access reproductive and sexual health information and services and health care providers often have limited skill and confidence in supporting people with disability.(5)

Stigma and prejudice contribute to the lack of acknowledgement and realisation of the reproductive and sexual health rights of people with disability, resulting in exclusion from reproductive and sexual health care.

For example, some health professionals assume that women with intellectual disability do not need cervical cancer screening or contraception because they have not engaged in sexual activity.(6)

Access to reproductive and sexual health services

People with disability experience multiple barriers to timely, affordable and accessible health services. Evidence shows that often health professionals and support people make assumptions that people with disability are non-sexual and not capable of having a relationship or parenting.(7,12) These assumptions can lead to a lack of access to sexuality education and reproductive and sexual health care.(7)

Community-based reproductive and sexual health services are often unable to see people with disability due to the inaccessibility of facilities (e.g. the size and layout of consult rooms), medical equipment (including examination beds, mammography machines), and accessibility of resources and information. Other barriers, including provider's attitudes, lack of understanding regarding consent for clients with intellectual disability and poor communication with clients, compound the often lower quality of health service delivery.(8) Inaccessible health services contribute to the lack of acknowledgement and realisation of the reproductive and sexual health rights of people with disability, resulting in exclusion from optimal reproductive and sexual health care.

Access to comprehensive sexuality education

Access to rights-based comprehensive sexuality education is essential for people with disability. Although the reproductive and sexual health needs of people with disability are similar to the general population, people with disability are at a greater risk of sexual abuse, sexually transmissible infections (STIs), and misinformation, likely due in part to inadequate comprehensive sexuality education.(9)

A global review conducted by United Nations Education, Scientific and Cultural Organization found that "failing to provide marginalized adolescents and young people with comprehensive sexuality education will deepen the social exclusion that many experience, limiting their potential and putting their health, futures and lives at greater risk".(10) Without comprehensive sexuality education, people with disability, their support people and other professionals may not learn about their reproductive and sexual health rights, limiting the realisation and promotion of such rights.

Teachers and support people require the skills and confidence to provide accessible and inclusive comprehensive sexuality education. It is commonly presumed that comprehensive sexuality education is unnecessary for young people with disability, particularly those with higher support needs. The failure to provide this education can result in neglect as it leaves people with disability more vulnerable to violence, exploitation and abuse.

The consistent provision of comprehensive sexuality education in Australia for people with disability could be achieved through implementation of a national comprehensive sexuality education framework and provision of funding for teachers, disability support workers and educators to attend training in providing disability inclusive comprehensive sexuality education.

See recommendations 2-5.

Question 3 – Thinking about rights of people with disability, what are the particular experiences of children, Australian First Nations people, culturally and linguistically diverse people, women and LGBTIQ+ people in having these rights realised?

There is strong evidence to suggest that marginalised groups, including Aboriginal and Torres Strait Islander, culturally and linguistically diverse, women, and lesbian, gay, bisexual transgender, queer and intersex (LGBTIQ) people with disability, experience violence, abuse, neglect or exploitation in health care differently to the rest of the population, contributing to the limited realisation of their reproductive and sexual health rights, as described below.

Aboriginal and Torres Strait Islander people with disability

The prevalence of disability in Aboriginal and Torres Strait Islander communities is approximately twice that of the non-Aboriginal population, with Aboriginal and Torres Strait Islander people also experiencing poorer reproductive and sexual health outcomes than non-Aboriginal people.(11) The discrimination and isolation experienced by Aboriginal and Torres Strait Islander people with disability is compounded by poor availability of culturally appropriate disability support services.(11) The culturally appropriate services that do exist are often not equipped or resourced to support Aboriginal and Torres Strait Islander people with disability to access specialised reproductive and sexual health services. As a result, the majority of Aboriginal and Torres Strait Islander people with disability may not have their reproductive and sexual health needs met in any significant way.(11)

Culturally and linguistically diverse people with disability

There is very little literature about the reproductive and sexual health needs of people with disability from culturally and linguistically diverse backgrounds in Australia, and no known literature that deals specifically with reproductive and sexual health issues. To understand the unique reproductive and sexual health needs of people with disability from culturally diverse backgrounds, Family Planning NSW interviewed four disability peak bodies. They reported that, in general, the disability and health sectors do not have the capacity to deal appropriately with sexuality and disability nor with the required cultural competency.(7) The inequity faced by people with intellectual disability from culturally diverse backgrounds may be exacerbated by limited referral pathways and lack of translated information and resources.

Women with intellectual disability

As previously described, people with disability often face discrimination, for instance, from service providers who assume that a person with disability is non-sexual, or not capable of having a relationship or parenting.(7,12) Women with intellectual disability in particular often face a lack of support in relation to accessing menstrual management, contraception and cervical and breast screening services.(12) Limited access to such services places women with disability at risk of worse outcomes, including sexual violence and lower rates of cancer screening, compared to the general population.(1)

Lesbian, gay, bisexual, transgender, intersex and queer (LGBTIQ) people with disability

LGBTIQ people with disability can experience significant barriers in accessing health services and supports. These barriers are often compounded by the denial of their identity, lack of inclusive information and service provision from disability services and a lack of accessible information and services.(13)

Although data in relation to these communities is scarce, research shows that over one-third of lesbian, bisexual or queer women are overdue for cervical screening and that trans men are significantly less likely to access cervical screening compared to the general population.(14,15) The *Australian Trans and Gender Diverse Sexual Health Survey* found that trans and gender diverse people experience marginalisation and gender insensitivity in sexual health care, ultimately undermining their care.(16) These experiences, including denial of gender-affirming care, may impact important public health goals, including reducing HIV diagnoses and increasing STI testing, resulting in higher levels of psychological distress and a lack of realisation of rights.(16)

See recommendations 1-2.

Question 4 – What advocacy assistance is currently available to people with disability? What are your suggestions for reform or improvement to advocacy, to help prevent and improve responses to violence, abuse, neglect and exploitation of people with disability?

Family Planning NSW is concerned that not enough advocacy assistance is available to people with disability, particularly for those from marginalised groups. The NSW Council for Intellectual Disability stated that “without advocacy, there would be no one to speak up about the issues”.(17) Disability organisations provide individual and systemic advocacy and information that protect and promote the rights of people with disability.(17) Without adequate availability of individual and systemic advocacy, people with disability will not have a voice to express concerns relating to reproductive and sexual health right infringements, including experiences of violence, abuse, neglect and exploitation.(18)

Systemic and individual advocacy that addresses reproductive and sexual health rights is critical to ensure that people with disability's rights are met, yet there are limited advocacy services that specialise in this. Organisations providing specialist individual and systemic advocacy need to be funded on an ongoing basis to promote the reproductive and sexual health rights of people with disability and to provide timely and effective responses to violence, abuse, neglect and exploitation of people with disability. Further improvements can be made by ensuring there is ongoing advocacy training and support to enable people with disability to lead public debate and influence government decision-making.

See recommendation 1-2, 4, 6.

Question 5 – How do attitudes contribute to violence, abuse, neglect and exploitation against people with disability?

There are multiple complex factors contributing to people with disability's experience of violence, abuse, neglect and exploitation in health care. People with disability have the right to make their own decisions about their bodies, their health and their relationships, but are often denied the information, education and support they need to make such decisions.

Supported decision making

The attitudes of support people often impact on the rights of people with disability to make their own decisions about their body, health care and reproductive and sexual health. To address this, supported decision making should be embedded within practice. Many decisions about access to reproductive and sexual health care and information are made on behalf of people with disability by those who support them.(5)

Family Planning NSW receives enquiries from a range of individuals seeking advice on how to support individual's access to reproductive and sexual health care. These enquires often reflect the poor attitudes of support people that contribute to the potential neglect, violence, abuse and exploitation of people with disability. Examples include:

- parents seeking advice on contraception and sterilisation for their child without their child's consent
- workers being directed to alter contraception management for women with disability
- doctors providing women with contraception without explaining what it is for, based on the requests of the parent/carer or support person.

These examples indicate that the human rights of people with disability are often not understood or realised when making decisions about their reproductive and sexual health care. Disability support people and clinicians have a responsibility to assist clients to make decisions, rather than making decisions for them.

Myths about people with intellectual disability and sexuality

Myths contribute to negative attitudes about the reproductive and sexual health rights of people with disability. As such, there is a need to counter myths as these seek to discount the sexuality of people with disability and justify silence and inaction around reproductive and sexual health rights as outlined in the United Nations Convention on the Rights of People with Disability.(2) Common examples of myths include:

- people with disability will have children with disability and this should be prevented
- people with disability are not sexually active and do not need preventative screening (e.g. cervical cancer screening, STI screening) or contraception
- people with disability do not get sexually assaulted
- educating people with disability about sexuality will only make them want to have sex.(7)

These myths reflect negative attitudes and stereotypes about the sexuality and abilities of people with disability and can impact significantly on the provision of services and programs. There is also significant concern that pervasive myths and negative stereotypes can result in a lack of disclosure of violence, abuse, neglect or exploitation and responding to disclosures seriously.

See recommendation 2.

Question 6 – How do attitudes affect responses to violence, abuse, neglect and exploitation of people with disability?

Negative attitudes by support people and health professionals significantly affect responses to violence, abuse, neglect and exploitation of people with disability. Such attitudes may contribute to the disbelief of reports of violence and sexual abuse of people with disability by services and ultimately the justice system leaving them vulnerable to ongoing instances of violence and sexual abuse.

People with intellectual disability are particularly vulnerable to prejudicial assessments of their competence, reliability and credibility because judicial officers and juries may have preconceived views.(19) Similarly, they are at increased risk of having evidence discredited in court due to communication issues associated with their disability.(19) The Tasmanian Anti-Discrimination Commissioner reports that this perception often leads to the decision to not prosecute alleged perpetrators, further heightening the vulnerability and ongoing risk of violence, abuse, neglect and exploitation of people with disability.(20)

See recommendations 1-2.

Question 7 – How do poor rights awareness and negative attitudes contribute to laws, policies and practices that discriminate against people with disability, ignore the experiences of people with disability, or lead to unintended consequences for people with disability? Please provide specific examples in your response.

Family Planning NSW is concerned that limited rights awareness and negative attitudes significantly contribute to laws, policies and practices that discriminate against and ignore the experiences of people with disability. This can lead to unintended consequences, particularly in regard to reproductive and sexual health rights and sexual violence.

Access to sexual expression services and support

Recently, the Administrative Appeals Tribunal ruled in favour of people with disability to receive funding for equal access to sexual expression services and support funded through NDIS plans. Disability organisations are still advocating for the NDIS to accept this decision and therefore recognise and uphold the reproductive and sexual health rights of people with disability. Denial of access to funding, along with negative attitudes of support people and health professionals, contributes to practices that discriminate against people with disability.

We believe that the NDIA has a responsibility to enable access to sexuality expression and support services for people with disability. Family Planning NSW endorses the joint position statement 'A call for a rights-based framework for sexuality in the NDIS'.(4) The position statement recommends developing a comprehensive sexuality policy to provide support for sexual expression through NDIS funding. Without an NDIS sexuality policy, people with disability may not have the support they need to make healthy decisions around their reproductive and sexual health. Individuals who support people with disability also have little guidance to provide this type of support. An NDIA policy could support the NDIS workforce and provide clarity on the sexuality and relationship support services available to people with disability.

Access to reproductive and sexual health services

While there is no data available to determine the number of people with disability accessing preventive cancer screening, many indicators suggest that people with disability, particularly women, are not accessing cancer screening at rates comparable to people without disability.(21) Often, this is due to the limited education provided to people with disability about the importance of cancer screening, but also, the assumption that some health professionals and support people make in determining that people with disability do not require cancer screening, particularly cervical screening, due to the myth that people with disability are non-sexual.(21)

Family Planning NSW is concerned that state-based and national registers for reproductive and sexual health data (e.g. NSW Sexually Transmissible Infections data reports; National Cervical Screening Register) do not

have disability disaggregated data which ignores the experiences of people with disability engaging with reproductive and sexual health services.

Access to comprehensive sexuality education

From a rights perspective, it is crucial that all people with disability receive high-quality and evidence-based comprehensive sexuality education. Failure to provide comprehensive sexuality education means that people with disability may struggle to adjust to the physical, social and psychological changes associated with puberty.(22) Some students finish school without the required skills and knowledge to allow them to successfully transition into post-school programs, education or employment, leaving people with autism more vulnerable to violence, exploitation and abuse.(22) As a result, comprehensive sexuality education and support for adolescents is falling to parents, who may also lack professional support and resources.(23)

A systemic lack of support and education through the school system and into disability services can lead to schools responding reactively to address issues of sexuality and relationships, once behaviours have become more concerning. Concerning behaviours can lead to social, physical and emotional harm for the person with autism and those around them. All people have the right to supports that assist them in making decisions about their own life and minimising their vulnerability to exploitation, violence and abuse.

Discrimination in reporting sexual violence

People with disability are up to four times more likely to experience sexual violence when compared to the general population.(24) The majority of these experiences go under-reported, partly due to the numerous barriers in seeking support from health care professionals, law enforcement and the criminal justice system.(24) Sexual violence experiences may go unreported to law enforcement due to concerns regarding the credibility and capacity of people with disability. Poor rights awareness and under-reporting can leave people with disability at higher risk of ongoing sexual violence, abuse and exploitation.

Substitute decision-making

People with disability have the right to make choices about their bodies, sexual expression and lives, yet often are denied this opportunity. Support people often presume that people with disability lack the capacity to make such decisions, therefore resulting in substitute decision making without people with disability being involved. Every person has the right to be informed of treatment options, and be consulted about their preference and choice to reproduce.

Some disability support workers are being directed by their organisation to alter contraception management without consultation. For example, some workers have been directed to withhold administering the non-hormonal pills (in the oral contraceptive pill pack) to women in a supported accommodation service to ensure that they do not experience the period-like bleeding while on the oral contraceptive pill, often without the woman's knowledge. Workers reported the purpose was to eliminate the need to support women to manage menstrual bleeding. It may be that women choose this management; however, workers should support them to make decisions about their body, not be making decisions for them.

See recommendations 1- 6.

Question 8 – What can be done to improve attitudes towards people with disability? Please consider policy, laws and other approaches. What good practice examples should we know about?

Education of support people and the general public, visibility of people with disability, and advocacy services can contribute to improving attitudes towards people with disability. In May 2019, Family Planning NSW conducted a needs assessment to investigate sexuality support needs from the perspective of disability sector workers and organisations. The needs assessment identified gaps in disability sector workers and organisations ability to provide consistent, quality sexuality support, often due to lack of training and clear organisational and NDIA policy. A less-skilled and less-informed workforce is of concern as it may contribute to a person with disability's risk of violence, abuse, neglect and exploitation. It is imperative that NDIA representatives and those who work in the disability sector are sufficiently trained to understand the

importance of sexuality support and education to a person's health, wellbeing and participation, and the rights of people with disability to access support.

People with disability must be at the centre of decision making processes and be consulted about matters that affect them. Family Planning NSW has a strong history of working in partnership with people with disability to develop accessible services, information and resources. One example of this is the *Outing Disability Project* that showcases LGBTIQ people with disability at art venues across Australia.

Outing Disability – Exhibition Project

Outing Disability is a series of portraits that provides a rare insight into the hopes and dreams of LGBTIQ people with disability as they share their struggles and triumphs of coming out, exploring identity, discovering love and finding pride. Outing Disability was launched in 2014, and produced in collaboration with internationally acclaimed photographer Belinda Mason.

For people with disability who identify as LGBTIQ, ongoing misunderstanding, stigma and discrimination means that they may experience even greater difficulties in accessing their rights. It is increasingly acknowledged that recognition of the diversity of sexual behaviour and expression contributes to people's overall sense of wellbeing and health. Family Planning NSW embarked on the Outing Disability project to bring to light the challenges faced by LGBTIQ people with disability and raise awareness of this.

See recommendations 1-2, 6.

Question 9 – What should the role of the media and social media be in helping to improve rights awareness and attitudes towards people with disability? How can they support or drive changes in policy and laws? What good practice examples should we know about?

There is currently very little representation of people with disability in media and social media, and what representation there is often focuses on highly stereotyped and negative portrayals that ignore the diversity of people with disability across everyday life.⁽²⁵⁾ Media and social media is likely to play an important role in raising awareness and improving attitudes towards people with disability. However, there is insufficient research on how media and social media might be best used to drive positive change for people with disability. Further discussion, led by people with disability, about the role of media and social media in improving rights awareness and societal attitudes is needed.

See recommendation 1.

Question 10 – How can improvements in rights awareness and attitudes towards people with disability support a more inclusive society?

An inclusive society supports the independence of people with disability and their right to live free from violence, abuse, neglect and exploitation. Too many people with disability are not given the opportunity to make their own decisions, particularly those with cognitive impairments. Supporting the decision-making of people with disability and recognising their rights are essential components of a society that supports the independence of people with disability and their right to live free from violence, abuse, neglect and exploitation. Resources, training and information should be made available so support workers understand how to maximise the decision-making capacity of people with disability along with rights-based advocacy training.

Family Planning NSW commends the World Health Organization (WHO) guidance note on *Promoting sexual and reproductive health for persons with disabilities* to the Commission.⁽²⁵⁾ This document outlines best practice methods which include the need to establish partnerships with people with disability and organisations that focus on people with disability. Policies and programmes are consistently better when people with disability and organisations that focus on people with disability are involved in their

development. There is also a need to promote research on reproductive and sexual health about persons with disabilities at local, national, and international levels.

See recommendations 1-6.

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