

Submission of Family Planning NSW

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

June 2021

Family Planning NSW welcomes the opportunity to make a submission to the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability. This submission responds to the 'Promoting Inclusion' issues paper. We have a strong history of contributing to the Royal Commission with the aim to improve the reproductive and sexual health experiences and outcomes of people with disability.

About us

Family Planning NSW is the leading provider of reproductive and sexual health services in NSW 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.

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 state-wide sexuality and relationship support to people with disability, primarily delivered through psychology services based out of 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, than people without disability.(1)

Recommendations

Summary of recommendations	
1. Access to services, information and education	There is a need to ensure services, information and education are accessible for people with disability. These can be achieved through: <ul style="list-style-type: none"> • development of information and education utilising physical and digital accessibility principles, including Easy Read and in multiple languages • physical and financial accessibility considerations regarding service access • increased availability and accessibility of sexuality and reproductive and sexual health care services for people with disability
2. Supported decision making	There is a need to improve the accessibility of education and training opportunities for community members and professionals to ensure they facilitate supported decision making processes. This can be achieved through: <ul style="list-style-type: none"> • resources to maximise the decision-making ability of people with disability • training for clinicians, support workers and educators on providing disability inclusive reproductive and sexual health care and education • supported decision-making resources, training and information for professionals, parents, carers and disability support workers
3. Meaningful consumer engagement	People with disability should be consulted about their experiences and engaged in the development, implementation and evaluation of programs and policies that affect them.
4. Invest in research	Meaningful data about the reproductive and sexual health experiences and outcomes of people with disability should be collected in a consistent and appropriate way.
5. Invest in sector training	There is a need for systemic change to improve disability sector worker education, organisational policies and provide guidance around accessing sexuality support through the NDIS to better support people with disability.
6. 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.

Question 1: What does inclusion mean to you?

Family Planning NSW is committed to promoting the reproductive and sexual health and rights of people with disability. We are guided by the United Nations Convention on the Rights of Persons with Disabilities(2) and work collaboratively with people with disability and their support people to ensure that our work meets the needs of our consumers.

We are committed to working with people with disability to normalise conversations about sexuality support and what it looks like in practice, and to creating reproductive and sexual health services, information and education that are accessible and inclusive. We will continue to work with people with disability to make sure our training programs are accessible and meet their needs, and advocate for the inclusion of sexuality support within NDIS participant plans including the development of NDIS policy around sexuality support. In developing this submission, we consulted people with disability to find out what inclusion means to them.

What does inclusion mean to you?

“To me inclusion means being able to experience the community in the same way everyone else does. [It also means] feeling accepted and being able to do community activities. Fully experiencing inclusion is feeling empowered and having informed choice to make your own decisions.”

- Nidhi, advocate and person with disability

“Inclusion is letting people make their own decisions and supporting them. It depends on the people’s ability and the situation. All people should be able to make their decisions. Treating me the same as everyone else is important. Just because I have a different outlook, it doesn’t mean I should be treated differently.”

- Steve, advocate and person with disability

Question 2: What makes an inclusive society?

An inclusive society supports the independence of people with disability and their right to live free from violence, abuse, neglect and exploitation. It also supports people with disability to have their reproductive and sexual health and rights recognised and met, and enables them to engage fully and meaningfully in society.

a) What are the characteristics of an inclusive society?

Family Planning NSW outline the following characteristics as essential components of an inclusive society that upholds the reproductive and sexual health and rights of people with disability:

Inclusive and accessible resources, services and environments

Health information, programs and services must be accessible to all people and take health literacy levels into consideration during planning and development. Examples of accessible health information include resources that are written in Plain English for people with low literacy and numeracy levels as well as resources developed using Easy Read principles for people with intellectual disability. Further, health services should ensure that they are culturally, physically, financially and intellectually accessible to all people.

Supported decision making

Supporting the decision-making of people with disability and recognising their rights are essential characteristics of a society that supports the inclusion and 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 to support workers, health and education professionals, as well as the wider community, to ensure they understand how to maximise the decision-making capacity of people with disability along with rights-based advocacy training.

Family Planning NSW create environments in which people with disability can be supported to make their own decision. For example, our clinics provide accessible information, offer longer appointment times and have staff who are trained in how to best work with clients with disability. Further, our reception staff ask clients if they have any accessibility and/or support needs and consult with clients to determine if they would like a support person to attend appointments with them.

What makes an inclusive society?

“An inclusive society is basically working to break down barriers and making changes to the built environment to ensure that it is accessible to everyone. [It also means] making systemic change to breakdown stereotypes about people with disability.”

- Nidhi, advocate and person with disability

“An inclusive society is where there is no judgement, including people with disability in everything is important. There is more than one disability – everything needs to be accessible for everyone. Things in all places need to be inclusive. For a person with disability it can be a big struggle to go somewhere that is not inclusive. There are a lot of barriers in everyday society that people don’t think about, particularly the norms.”

- Steve, advocate and person with disability

See recommendations: 1, 2, 3.

b) How can the supports people with disability need be provided in a way that is consistent with promoting an inclusive society?

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 *Just Checking* project which aimed to increase people with disability’s access to cervical, breast and bowel screening. The 2016 *Just Checking* project, funded by the Cancer Institute NSW aimed to increase the uptake of cancer screening by addressing the underlying barriers that prevent people with disability from accessing services at levels equal to others. This was done by improving access to information for people with intellectual disability while educating disability service providers and health care workers to ensure clients with intellectual disability are given the same reproductive and sexual health care as other clients.

See recommendation: 3.

c) What is the role of governments through legislation, policy making, funding and operation of public systems and services, in achieving an inclusive society?

Governments have a significant role in creating structures that promote an inclusive society, primarily through legislation, policy making and provision of funding. Governments must ensure that people with disability have an active role in the consultation, development and review of all legislation and policy, and programs developed that have a direct and/or indirect impact on them.

Family Planning NSW commend the World Health Organization guidance note on *Promoting sexual and reproductive health for persons with disabilities* to the Commission.(3) 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.

Additionally, Family Planning NSW encourage the government to invest in research regarding the reproductive and sexual health experiences and outcomes of people with disability at local, national, and international levels. There is a systemic lack of available data on the reproductive and sexual health needs

and outcomes of people with disability leading to gaps in health, education and workforce related policy and legislation.

See recommendation: 4.

d) What is the role of non-government institutions and the private sector in achieving an inclusive society?

Non-government organisations work directly with people with disability, their families and support workers and are well positioned to address the needs of people with disability, through provision of services, support, advocacy and education. This, however, requires adequate government funding, resourcing and ongoing workforce development.

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 which contributes to the development of an inclusive society.

Family Planning NSW, a not-for-profit organisation, 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 stories from LGBTIQ people with disability at art venues across Australia.

See recommendations: 3, 5.

Outing Disability – Exhibition Project

[Outing Disability](#) is a series of portraits that provide 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, raise awareness of this and increase representation of LGBTIQ people with disability in society.

Question 4: How can an inclusive society support the independence and choice of people with disability?

Family Planning NSW is concerned that limited rights awareness, barriers to inclusion 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, sexual violence and exclusion from health decision making and health systems.

People with disability have the right to make choices about their bodies, sexual expression and lives, yet often are denied this opportunity. Support people and health professionals 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 health preferences particularly in relation to their reproductive and sexual health.

We are very concerned that some disability support workers are being directed by their organisation's management 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.

Health professionals, disability support workers and communities must have access to resources, information and training that promote understanding of the rights of people with disability, as well as the tools required to support people with disability to make health related decisions.

See recommendation: 5.

Question 5: How can an inclusive society support a person with disability's right to live free from violence and abuse, neglect and exploitation?

An inclusive society supports the independence of people with disability, their ability to be involved in making health related decisions that affect them, and their right to live free from violence, abuse, neglect and exploitation.(2) People with disability, however, are often viewed as non-sexual, leading to a lack of access to comprehensive sexuality education and reproductive and sexual health care and limited development of health protective skills and behaviours.(4, 5) Provision of comprehensive sexuality education is an essential strategy to ensure people with disability live free from violence, abuse, neglect and exploitation.

Negative attitudes by support people, educators and health professionals, as well as preconceptions of non-sexual behaviour can 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.(6) Similarly, they are at increased risk of having evidence discredited in court due to communication issues associated with their disability.(6) 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.(7)

It is essential that people with disability are supported to make reports of violence, abuse, neglect and exploitation in settings that are accessible, inclusive and do not hold preconceived biases. The provision of comprehensive sexuality education and communication supports to make reports and provide evidence will support a person with disability's right to live freely from violence, abuse, neglect and exploitation.

See recommendations: 1, 2, 5.

Question 6: What practical and sustainable steps can governments take to promote a more inclusive society for people with disability?

The government has an important role in creating systemic change to promote a more inclusive society for people with disability. Governments must work to create a society that is accessible for all people and promotes the independence of people with disability. Further, governments must create meaningful opportunities for people with disability to engage in and influence decisions that affect them.

Funding for disability advocacy services

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”.(8) Disability organisations, funded by government often through the NDIS, provide individual and systemic advocacy and information that protect and promote the rights of people with disability.(8) 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.(9)

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 and may increase their risk of violence, abuse, neglect and exploitation.

Governments must recognise people with disability’s right to access NDIS funded sexual expression services and support. We believe that the NDIA, a government funded entity, 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’.(10) 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.

Access to reproductive and sexual health services

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.

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.(11) 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.(11)

We encourage the government to invest in a robust, flexible and evidence-based health-related data collection framework that is inclusive of people with disability.

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, and misinformation, likely due in part to inadequate comprehensive sexuality education.(12)

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”.(13) 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. It is well established that teachers often do not have the resources to tailor education to the needs of student’s with disability. This may result in the educational needs of students being neglected. As a not-for-profit, Family Planning NSW work to fill this gap through the provision of accredited teacher training and resource development to facilitate the provision of comprehensive sexuality education to students with disability. However, funding to support this is very limited.

Governments should prioritise the development of a national comprehensive sexuality education curriculum that is inclusive of people with disability. Investment in professional development for teachers, disability support workers and educators to attend training in providing disability inclusive comprehensive sexuality education is also needed. Teachers and support people require the skills and confidence to provide accessible and inclusive comprehensive sexuality education.

See recommendations: 1, 2, 3, 5, 6.

Question 7: What practical and sustainable steps can non-government institutions, the private sector and communities take to promote a more inclusive society for people with disability?

Non-government organisations, the private sector and the Australian community have a significant role in upholding the rights of people with disability and creating environments that are inclusive and accessible to all. Family Planning NSW recommend the following strategies are prioritised:

Greater representation of people with disability in the community

There is currently very little representation of people with disability in the workforce and private sector, media, social media and the wider community. Existing representation often focuses on highly stereotyped and negative portrayals that ignore the diversity of people with disability across everyday life. Ensuring positive representation of people with disability in all aspects of life is likely to play an important role in raising awareness and improving attitudes towards people with disability, therefore creating a more inclusive society. Further discussion, led by people with disability, about best practice approaches to positive representation to create a more inclusive society is needed.

Supported decision making

Most people with intellectual disability are able to make their own decisions about their reproductive and sexual health when given the appropriate level of support and/or information. Non-government organisations must promote the autonomy of people with disability, and support them to make decisions about their lives. Family Planning NSW developed a tool to assist clinicians in supporting the decision making of clients with intellectual disability to make their own decisions relating to their reproductive and sexual health. We encourage non-government organisations to develop a guidance document that provides practical strategies to ensure people with disability are supported to make decisions.

Consumer engagement

Direct consultation and meaningful co-design with people with disability is essential to inform how we can support them to feel safe in accessing health care. Consumer engagement is an essential part of Family Planning NSW’s service delivery and acknowledges the importance and value of our consumers in contributing to governance, planning, design, quality improvement, delivery and evaluation of our services

and programs. Family Planning NSW has an ongoing commitment to consulting with people with intellectual disability in all aspects of our services including the accessibility of services, education and development of resources.

See recommendations: 2, 3.

Planet Puberty – Working collaboratively to address service gaps

Family Planning NSW works with people with disability to identify current gaps in reproductive and sexual health information, education and service provision, and to ensure our services and programs are inclusive, accessible and relevant to all people. Family Planning NSW, with the support of the Department of Social Services, has recently launched [Planet Puberty](#), a website designed in consultation with people with disability. Planet Puberty is a website that provides parents and carers of children with intellectual disability and autism with information, advice and resources to help them support their children through puberty. The website has information on a wide variety of puberty related topics, including hygiene, periods, masturbation, relationships, consent and emotions. The website is also accompanied by a webinar series and a podcast.

Question 8a: What are the barriers and challenges to inclusion for people with disability?

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 to inclusion 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.(14)

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.(15)

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.(16)

Access to reproductive and sexual health services

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.(17) 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.

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. 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.(4)

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 recommendations: 1, 3, 5.

Question 8b: What are the barriers and challenges to inclusion for people with disability for marginalised populations?

Strong evidence suggests that marginalised groups, including Aboriginal and Torres Strait Islander, culturally and linguistically diverse, lesbian, gay, bisexual transgender, queer and intersex (LGBTIQ), and women with disability, experience violence, abuse, neglect or exploitation in health care differently to the rest of the population. Marginalised groups often face greater barriers to societal inclusion, health care access and education, which contributes to the limited realisation of their reproductive and sexual health rights.

First Nations 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 peoples also experiencing poorer reproductive and sexual health outcomes than non-Aboriginal people.(18) The discrimination and isolation experienced by Aboriginal and Torres Strait Islander peoples with disability is compounded by poor availability of culturally appropriate disability support services.(18) The culturally appropriate services that do exist are often not equipped or resourced to support Aboriginal and Torres Strait Islander peoples with disability to access specialised reproductive and sexual health services. As a result, the majority of Aboriginal and Torres Strait Islander peoples with disability may not have their reproductive and sexual health needs met in any significant way.(18)

People with disability from culturally and linguistically diverse communities

There is very little research about the reproductive and sexual health needs of people with disability from culturally and linguistically diverse backgrounds in Australia, and no known research 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.(4) 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.

People with disability who identify as LGBTIQ

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.(19) 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.(20) 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.(21) 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.(21)

Women and girls with disability

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.(5) 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)

See recommendation: 1, 3, 5.

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