



Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability

Submission by Family Planning NSW

March 2020

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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 education. Our clinics are a safe place for people with disability to talk about intimate and sometimes difficult issues. As a registered provider under the National Disability Insurance Scheme (NDIS), we provide sexuality and relationship support to people with disability. These services are primarily delivered through psychology services at our Newcastle clinic.

Family Planning NSW continues to be one of the few services in NSW delivering targeted services to people with disability and their support people in the areas of sexuality and reproductive health. However there is also a need to expand support services to counter the systemic neglect of reproductive and sexual health for people with disability.

Family Planning NSW welcomes the opportunity to provide input into the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability.

Overview

What would you like to share with the Royal Commission about your experiences or knowledge of violence, abuse, neglect or exploitation of people with disability?

Family Planning NSW supports reproductive and sexual health and rights for everybody in every family. People with disability have the same reproductive and sexual health needs as other people, however, we know that people with disability often face barriers accessing information and services (WHO, 2009) and people with disability experience high rates of sexual violence, abuse, neglect and exploitation (Disabled People's Organisations Australia 2019).

Women with intellectual disability, specifically, face lack of access to health care and education. Examples include access to support for menstrual management, contraception, cervical screening and sexually transmissible infection (STI) testing. This lack of access places people with disability at risk of poorer health outcomes compared to the general population and jeopardises their right to make decisions about whether and when to have sex, or to start a family.

Have you shared these experiences with anyone before? Who did you tell and what happened?

Family Planning NSW has raised the above concerns in multiple submissions to public enquiries, including to the Senate Standing Committee on Community Affairs, the Federal Joint Standing Committee on the NDIS, the National Disability Strategy Survey and other forums. We are not yet aware of changes as a result of these submissions.

Is there anything else you would like to tell us?

Family Planning NSW has recently been granted funding from the National Disability Insurance Agency to develop a digital resource and webinar series as part of a two-year project to build the capacity of parents and carers to better support their children with intellectual disability and/or autism in the transition through puberty to young adulthood. Strategies for supporting children to develop protective behaviours and understand consent will be reinforced throughout this project as they are an important way to minimise the child's vulnerability to violence, abuse, neglect and exploitation.

Are there any suggestions or recommendations you would like to share, including any examples of what worked well, or ideas for how things could be done better?

Summary of recommendations	
1. Incidents of violence, abuse, neglect and/or exploitation	There is a need for systemic change to improve support for families, support workers and health professionals to support all people to have control over and decide freely on all matters related to their reproductive and sexual health.
2. Access to reproductive and sexual health care	There is a need to provide equitable and accessible health care for people with disability. This can be achieved through: <ol style="list-style-type: none"> 1. increased availability of sexuality and reproductive and sexual health care services for people with disability, particularly in regional and remote areas 2. inclusion of sexuality and relationship support as a standard item in all NDIS participant plans 3. provision of training for NDIS support workers, parents and carers and health care professionals to understand the holistic concept of sexuality and importance of reproductive and sexual health care for people with disability.
3. Access to comprehensive sexuality education in schools	Children, young people and adults with disability have the right to receive accurate and age-appropriate 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. The consistent provision of comprehensive sexuality education in Australia for people with disability can be achieved through: <ol style="list-style-type: none"> 1. implementation of a national comprehensive sexuality education framework 2. provision of funding for teachers, disability support workers and educators to attend training in providing comprehensive sexuality education to people with disability.
4. Skills and resources in disability support services	Sexuality support skills and resources in disability organisations should be improved to reduce the risk of violence, abuse, neglect and exploitation of people with disability. Actions include: <ol style="list-style-type: none"> 1. provision of clearer guidance about the kinds of services that can be obtained as part of sexuality and relationship support, in the form of an NDIA policy or procedure document 2. provision of funding for the professional learning of NDIA representatives, disability sector workers and service providers, including in the areas of sexuality and relationships 3. introduction of mechanisms to allow more responsive change to plans so that participants' sexuality and relationship support needs are met in a timely fashion.
5. Best practice and innovation	There is a need for systemic change to improve disability sector worker education, organisational policies and provide guidance about the NDIS to better support people with disability.
6. 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, and in funding allocations.

In a few sentences, what would you like to tell our nation about your hopes for the future?

An inclusive society supports the independence of all people, including those with disability and ensures their right to live free from violence, abuse, neglect and exploitation. Many people with disability have the ability to make their own decisions about their lives but are not given the opportunity to do so, particularly those with cognitive impairments. Resources, training and information should be made available to maximise the decision-making capacity of people with disability, and to ensure that support workers understand how to best support a person with disability to make decisions.

Key points

1. Incidents of violence, abuse, neglect and/or exploitation

Family Planning NSW believes 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, people with disability are much more likely to experience violence, particularly sexual violence, when compared to people without disability (Disabled People's Organisations Australia 2019).

As NSW's leading reproductive and sexual health service, our clients include people with disability who have experienced violence, abuse, neglect or exploitation. We frequently receive enquiries (via events, education workshops, phone or email) from disability workers or parents seeking advice on how to respond to the sexual behaviour of a person with disability they are supporting. Through these enquiries we are aware of instances where there have been questions about the appropriateness of the response by disability workers and parents, raising concerns about the potential neglect, violence, abuse and exploitation of people with disability. Examples are described below.

People with disability are being prevented from engaging in sexual relationships or other sexual behaviours. For example, people with disability are being denied private time in their bedrooms, specifically for the purpose of preventing masturbation, a healthy behaviour, or consensual sexual activity. This is a restrictive practice and a violation of the person's privacy and dignity and is a form of abuse. All people have the right to engage in consensual relationships of their choosing and to have privacy.

Parents seek advice on contraception and sterilisation for their daughters without their daughter's consent. Some parents are unaware of, and question the need to refer a request for sterilisation to the guardianship tribunal as required by law in NSW. Every person has the right to be informed of treatment options, be consulted about their preference and choose if they want to reproduce. Forced sterilisation is abuse.

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 sugar pill to women in a supported accommodation service to ensure that they do not experience the period-like bleeding while on the oral contraceptive pill. This is often done without the woman's knowledge. Workers reported the purpose was to eliminate the need to support women to manage menstrual bleeding. This forced treatment is abuse as workers should be supporting people to make decisions about their body, not making decisions for them.

Some doctors provide women with contraception without explaining what it is for, based on the requests of the parent/carers or support person. Women may be told that contraception is only for skincare or other non-contraceptive purposes such as period management. This forced treatment and removal of the person with disability's right to make decisions about health care is abuse. Health professionals should support their clients to understand their options and make their own health-related decisions. The Family Planning NSW (2018) resource *Supporting decision making in reproductive and sexual health for people with disability: A tool to assist clinicians in supporting the decision making of clients with intellectual disability* can be used by health professionals to support clients.

A systemic lack of sexuality support means that sexuality and relationships are often responded to reactively, once behaviours have become more concerning. These behaviours can lead to social, physical and emotional harm for the person with disability and/or those around them. All people have the right to support that minimises their vulnerability to situations of exploitation, violence and abuse.

Recommendation 1

There is a need for systemic change to improve support for families, support workers and health professionals to support all people to have control over and decide freely on all matters related to their reproductive and sexual health.

2. Access to reproductive and sexual 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, particularly in the areas of sexual relationships, contraception, family planning and parenthood. 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. (Verlenden, Bertolli & Warner 2019; Family Planning NSW 2014).

People with disability have the right to access the highest attainable standard of health care without discrimination. For example, service providers can assume that a person with disability is not capable of having a relationship or parenting (Family Planning NSW 2014), or assume women do not need cervical cancer screening because they have not had sex (Cobigo et al 2013). Limited availability of accessible services, discrimination and gatekeeping compound the challenges for people with disability seeking to access reproductive and sexual health services.

Without health care access, people with disability are at risk of poorer reproductive and sexual health outcomes compared to the general population (Verlenden, Bertolli, & Warner 2019; Family Planning NSW 2014). Limited access to health care reduces access to contraception, cervical screening and STI testing which is an example of neglect of the reproductive and sexual health of people with disability. A lack of access to health care also has significant impacts on a person with disability's self-determination and decision making about whether and when to have sex, or to start a family.

There is limited access to sexuality and relationship support and specialised sexuality therapeutic supports in disability services and the NDIS. Parents of children with disability often struggle to support their child with the physical, emotional and social changes that happen during puberty (Manor-Binyamini & Schreiber-Divon 2019; Stein, Kohut & Dillenburg 2018). However, sexuality and relationship support, when given proactively, can support a person with disability to improve their decision-making, self-protection skills and their level of community participation (Sala et al 2019; Gonzalez et al 2018). We are concerned about the lack of sexuality, relationships and sexual health goals in NDIS participant plans. Where these goals are included, they are often considered reactively, once health issues or behaviours of concern have become more severe. Support needs to be more proactive.

There is limited availability of services that are able to support people with disability with more complex sexuality or reproductive and sexual health needs, particularly in regional and remote areas. The limited availability of support increases vulnerability to poor reproductive and sexual health outcomes, violence, exploitation and abuse. This is a major concern for people with disability, especially those who live in regional and remote areas.

Recommendation 2

Provide equitable and accessible health care for people with disability. This can be achieved through:

1. increased availability of sexuality and reproductive and sexual health care services for people with disability, particularly in regional and remote areas
2. inclusion of sexuality and relationship support as a standard item in all NDIS participant plans
3. provision of training to NDIS support workers, parents and carers and health care professionals to understand the holistic concept of sexuality and importance of reproductive and sexual health care for people with disability.

3. Access to comprehensive sexuality education in schools

It is crucial that all children and people with disability receive high-quality and evidence-based comprehensive sexuality education. In Australia, comprehensive sexuality education is not currently provided consistently across the country. A global review conducted by United Nations Education, Scientific and Cultural Organization found comprehensive sexuality education has a positive impact on safer sexual behaviour, delays sexual debut, and can reduce unintended pregnancy and STIs. The review 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” (UNESCO 2015).

Comprehensive sexuality education is particularly important for students and 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, STIs, and misinformation partly due to inadequate comprehensive sexuality education (Daniels & Fleming 2016).

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

Recommendation 3

Children, young people and adults with disability have the right to receive accurate and age-appropriate 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. The consistent provision of comprehensive sexuality education in Australia for people with disability can be achieved through:

1. implementation of a national comprehensive sexuality education framework
2. provision of funding for teachers, disability support workers and educators to attend training in providing comprehensive sexuality education to people with disability.

Case study illustrating the need for better educational support for young people

A mother, Sofia, contacted us via phone seeking support for her teenage son to receive sexuality education at his school. Her son is having difficulties in transitioning through puberty, with behaviours indicating a lack of understanding about the differences between public, private and personal boundaries with classmates.

The support unit at the school delivered one sexuality education session in previous years that involved all students across grades in one session. Sofia requested the school run another session. The school reported that their staff did not feel equipped to deliver to the support unit’s students nor was there funding available to train staff onsite or attend external training.

Sofia was seeking additional support for her son, but the only local provider of this support is not taking any new clients and Sofia is unable to travel to other locations for services. Sofia was trying to locate and engage services that could provide this support in the school. She then planned to ask the P&C committee to fund the program. There were no funds within the son’s NDIS plan to fund this support.

There are multiple issues of concern in this case study: a lack of consistently delivered CSE in schools; a lack of available alternative services for people seeking additional sexuality support; and a failure to consider sexuality support needs in NDIS plans. This case study illustrates an access issue that places Sofia’s son and others around him at greater risk of violence, abuse and exploitation the longer his behavioural issues are left unaddressed.

4. Skills and resources in disability support services

Family Planning NSW is concerned about the lack of sexuality support skills and resources in disability organisations and the increased risk of violence, abuse, neglect and exploitation that may result. People with disability have the right to live without fear of violence, abuse, neglect and exploitation, and disability services have a responsibility to uphold these rights. Minimising the risk of sexual violence, abuse, neglect and exploitation requires disability support services to do more than just report incidents when they occur. It requires a proactive, holistic approach to sexuality that enables workers to provide information and support that empowers people with disability to have healthy relationships, understand consent, and make decisions for themselves.

As a Registered Training Organisation Family Planning NSW has provided training to over 12,000 doctors, nurses, teachers, disability workers and community workers since 2008. Our courses and information resources assist professionals to better understand their role in supporting people with disability with reproductive and sexual health, sexuality and relationships. Overall, the majority of our course participants report a high level of satisfaction (87% in 2018-2019).

However, a needs assessment has identified gaps in disability sector workers and organisations ability to provide consistent, quality sexuality support. In May 2019, Family Planning NSW conducted a needs assessment to investigate sexuality support from the perspective of disability sector workers and organisations. In a survey of 45 disability support workers, we found that there is poor understanding of what sexuality support entails. Further, only half of the survey respondents agreed or strongly agreed that it was within their role to provide sexuality support to people with disability. Interviews with representatives from Disabled People's Organisations and managers from disability services, found the disability sector did not provide consistent, quality sexuality support to people with disability (Family Planning NSW 2019).

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 National Disability Insurance Agency (NDIA) representatives and those who work in the disability sector are sufficiently trained to understand the holistic nature of sexuality, 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.

Once a person with disability has decided to access sexuality support through the NDIS, they may experience significant confusion navigating the system. For instance, participants may attempt to use the support code 'Capacity Building, Relationships, Improved Relationships' to access Family Planning NSW's therapeutic services for support on healthy relationships. However, the code required to access our services is different ('Capacity Building, Daily Living, Improved Daily Living'). If the participant does not also have funding under the latter support code, and we are unable to support them to utilise other access paths (e.g. Mental Health Care Plan), this leads to lengthy delays while the participant waits for a plan review.

Clear guidance materials would assist plan participants, carers and providers in navigating the complex NDIS system. The NSW Ageing, Disability and Home Care's *Sexuality and Relationships Guidelines* and the Victorian Department of Human Services' *Personal Relationships, Sexuality and Sexual Health* policy could usefully inform these documents.

Case study illustrating the challenges in supporting a person with disability to access their rights

A support coordinator contacted us via phone seeking assistance for a man with disability, Ali, who is having difficulties with his current accommodation provider. Ali's accommodation provider has refused to allow Ali to close his bedroom door, citing it is a fire door that therefore must remain open at all times. Ali's bed is positioned to be in direct view of anyone walking past. When Ali has private time in his room it is with the door open in full view of the rest of the house. The accommodation provider refuses to install any sort of privacy screen or have other options for privacy for Ali. Ali reports staff have referred to him as 'dirty'.

The support coordinator was concerned about Ali's privacy, the lack of dignity and respect afforded him and the restrictive practices put in place. The support coordinator also reported that instances of Ali having private time for masturbation in his room have been logged in behaviour support plan notes with the intention of circulating this to the staff at his day program.

This case study highlights multiple significant violations of Ali's privacy and dignity that are abusive. The support coordinator was directed to make a complaint to the NDIS Quality and Safeguards Commission.

Recommendation 4

Sexuality support skills and resources in disability organisations should be improved to reduce the risk of violence, abuse, neglect and exploitation of people with disability. Actions to do so include:

1. provision of clearer guidance about the kinds of services that can be obtained as part of sexuality and relationship support, in the form of an NDIA policy or procedure document
2. provision of funding for the professional learning of NDIA representatives, disability sector workers and service providers, including in the areas of sexuality and relationships
3. introduction of mechanisms to allow more responsive change to plans so that participants' sexuality and relationship support needs are met in a timely fashion.

5. Best practice and innovation

The reproductive and sexual rights of people with disability should inform any strategy to address violence, abuse, neglect and exploitation. Family Planning NSW commends the WHO (2009) guidance note on *Promoting sexual and reproductive health for persons with disabilities* to the Commission. This document outlines best practice, including specific considerations for programming, ensuring full inclusion, and the need for further research as part of the framework to achieve societal inclusion. Examples include involving people with disability and organisations focusing on people with disability in the development of policies and programs, and for more research on the sexual and reproductive health of people with disability. A stronger evidence base will help to improve the sexual and reproductive health programmes for people with disability and therefore health outcomes.

Understanding the barriers for disability services in providing quality sexuality support to people with disability can shed light on why the reproductive and sexual health and rights of people with disability are being neglected. Our needs assessment investigating the provision of sexuality support in NSW allowed us to identify enablers, barriers and worker knowledge levels to tailor and target programs, resources and partnerships, and to focus on areas of policy needing improvement. When asked what would help disability support workers to feel more confident in providing sexuality support, the majority of respondents suggested: more training (79.5%); more resources (66.7%); clearer organisational policy (56.4%); and, clearer NDIS policy (56.4%)(Family Planning NSW, 2019).

Three major barriers restricting the quality of sexuality support provided by disability-specific services were identified:

1. the NDIS funding model has had a significant and negative impact on professional learning in the disability sector. Our needs assessment identified that the majority (69.2%) of our 45 respondents had not completed any formal sexuality and disability training. When asked why they had not completed any training, nearly one quarter reported they were not supported by their organisation to complete the training.
2. most disability organisations do not have sexuality policies. The 2019 needs assessment found that only 25% of respondents agreed or strongly agreed that their organisation had clear guidelines on how to provide sexuality support. An organisational sexuality policy or guidelines that provide clarity and proactive strategies, important in supporting reproductive and sexual health and mitigating the need for strategies to react to behavioural and health issues.
3. the NDIS to provide guidance on sexuality support. People with disability may not be aware of their own reproductive and sexual health and rights and what supports they can reasonably expect. This

is particularly relevant within an NDIS environment where sexuality support can be provided if funds are allocated. However, this requires a goal and participants often do not know that sexuality can be incorporated into their goals.

Recommendation 5

There is a need for systemic change to improve disability sector worker education, organisational policies and provide guidance about the NDIS to better support people with disability.

6. 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 have the ability to make their own decisions about their lives but are not given the opportunity to do so, particularly those with cognitive impairments. Supporting the decision making of people with disability and a legal assumption of capacity to consent 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 to maximise the decision-making capacity of people with disability, and to ensure that support workers understand how to support the decision-making of a person with disability. These strategies need to be accompanied by legal frameworks to ensure consistent application.

Family Planning NSW commends the WHO (2009) guidance note on *Promoting sexual and reproductive health for persons with disabilities* to the Commission. 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 sexual and reproductive health about persons with disabilities at local, national, and international levels.

Recommendation 6

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, and in funding allocations.

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