



**Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability: Health care for people with cognitive disability issues paper**

**Submission by Family Planning NSW**

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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 intellectual disability and those who support them for over 35 years, including clinical services, health promotion and 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 intellectual disability are much more likely to experience violence, particularly sexual violence, compared to people without disability (Disabled People's Organisations Australia 2019).

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 *Health care for people with cognitive disability issues paper*. We use the term 'intellectual disability' instead of 'cognitive disability' as this is our common practice.

## Question 1 - What do you think about the quality of health care for people with cognitive disability?

Family Planning NSW is concerned about the quality of health care for people with intellectual disability, particularly the quality of reproductive and sexual health care.

### Health of people with an intellectual disability

People with intellectual disability experience concerning physical and mental health inequities including high rates of undiagnosed and poorly treated health conditions, a higher rate of avoidable deaths (more than twice the rate of the general population), and a lower life expectancy than the general population (a mortality rate up to 27 years earlier) (Council for Intellectual Disability 2019).

There is evidence to suggest that women with intellectual disability:

- do not access cervical screening or breast screening at the same rate as women without disability (Haider, Ansari, Vaughan, Matters & Emerson 2013)
- have poorer reproductive and sexual health outcomes than women without intellectual disability (Verlenden, Bertolli & Warner 2019)
- experience forced sterilisation and forced contraception (Frohman & Sands 2015).
- have lower levels of human papillomavirus (HPV) vaccine coverage compared to adolescents without intellectual disability (O'Neill, Elia & Perrett 2019).

### Lack of comprehensive data

There is a significant lack of comprehensive data on the quality of health care received by people with intellectual disability and their experiences in the health care system. While we know that they are active participants in the health care system, the data collected on quality of health care and health outcomes is often poor (Abualghaib, Groce, Simeu et al. 2019). 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.

## **Quality of health care**

We are concerned about the quality of reproductive and sexual health care for people with intellectual disability leading to the potential neglect, violence, abuse and exploitation in health care settings. For example, 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.

Health professionals should support their clients to understand their options and make their own decisions. The Family Planning NSW (2018b) 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* is an example of a resource that health professionals can use.

## **Question 2 - Can you tell us about any barriers that people with cognitive disability have experienced in accessing health care?**

People with intellectual disability have the right to access the highest attainable standard of health without discrimination (United Nations 2006). However, they often face multiple barriers and discrimination in reproductive and sexual health from both the disability and health care systems. Misconceptions and prejudices surround the reproductive and sexual health of people with intellectual disability, both in families and in the professional community (Tamas et al. 2019).

### **Support from disability service providers to access health care**

Poor attitudes and education for workers and families about reproductive and sexual health care and rights can contribute to limited opportunities and discrimination. Of concern, people with intellectual disability lack support to access reproductive and sexual health care and health care providers often lack skill and confidence in supporting people with intellectual disability, leading to low-quality services (Thompson et al 2014). Disability service providers and clinicians may pathologise the sexual health of people with intellectual disability rather than viewing it within the context of general health and wellbeing.

### **Access to health services**

People with intellectual disability have multiple barriers to timely, affordable and appropriately equipped health services. Attitudinal access barriers to reproductive and sexual health care include:

- stereotyping: support people and health professionals may make assumptions that people with intellectual disability are non-sexual and not capable of having a relationship or parenting. These assumptions lead people to think that people with disability do not require sexuality education or access to reproductive and sexual health care (FPNSW 2014)
- stigma, prejudice, and discrimination: where support people and health professionals may prejudge a person's ability to make decisions about their reproductive and sexual health and exclude them from reproductive and sexual health care. For example, health professionals who assume women with intellectual disability do not need cervical cancer screening because they have not had sex (Cobigo et al. 2013).

Structural access barriers to reproductive and sexual health care include (Centers for Disease Control and Prevention 2019):

- poor communication and accessibility of information, including a lack of easy read, plain English and screen reader compatible information available for people with intellectual disability
- a lack of physical accessibility: community health services are often unable to see people with intellectual disability who may have limited mobility due to the inaccessibility of medical equipment including examination beds, mammography machines and the size and layout of consult rooms
- programmatic barriers: issues affecting the quality of health service delivery, including communication with people with intellectual disability about their health care needs, insufficient time for appointments and poor attitudes, knowledge and understanding from health care providers

### **Consequences of a lack of support**

We are concerned about the consequences of not having access to sexuality support. For example, people exhibiting 'inappropriate' sexual behaviours can be denied access to services or be subject to restrictive practices because of their behaviour. Restrictions can be implemented without appropriate measures to address the reasons behind the behaviour. Some inappropriate behaviours may be the result of underlying health issues. The behaviours may indicate the need for education on consent and privacy or be a sign that the person is experiencing or has experienced violence or abuse. The behaviours may also be entirely normal, healthy and consensual, but are perceived as inappropriate (due to factors separate to that person, such as organisational policy or the comfort of support people). These people may be unable to find suitable therapeutic or supportive services to manage the behaviour, leaving the person and others around them at greater risk of violence, abuse and exploitation.

### **Question 3 - Can you tell us about any problems that people with cognitive disability have had with the NDIS and accessing health care?**

Family Planning NSW is concerned about the shifting of responsibilities between health and the NDIS in meeting the reproductive and sexual health needs of people with intellectual disability. Health services are often inexperienced or avoid providing reproductive and sexual health care and support, particularly where there are sexualised behaviours or a person's capacity to make decisions are of concern (Eastgate 2011). At the same time, disability service providers are often unsure about their role in facilitating access to reproductive and sexual health care (Thompson et al. 2014; FPNSW 2019b). As a result, reproductive and sexual health needs are not being addressed.

### **Access to professional training**

The NDIS funding model has had a significant and negative impact on professional training around disability and sexuality support within the sector. Since the rollout of the NDIS, enrolments by disability support workers has reduced. A disability sector Needs Assessment conducted by Family Planning NSW in 2019 identified that the majority (69.2%) of our 45 respondents had not completed any formal sexuality and disability training. Workers reported that a lack of support to complete training and limited awareness of the availability of sexuality and relationship training were the primary reasons (Family Planning NSW 2019b).

### **Guidance to access sexuality support**

The NDIS should provide better guidance on sexuality support so that disability service providers are clear about what sexuality supports they can provide, and what should be provided through the health care system. People with intellectual disability should be aware of their reproductive and sexual health and rights and what supports they can reasonably expect. In the current NDIS environment sexuality support often cannot be provided because funds can only be allocated with a 'goal', and participants are often unaware that reproductive and sexual health can be incorporated into their goals. This leaves people with intellectual disability without sufficient information and resources about reproductive and sexual health care or support services that are accessible through their NDIS funding.

### **Sexuality policy**

Family Planning NSW supports principles in 'A call for a rights-based framework for sexuality in the NDIS' a joint position statement to develop a comprehensive sexuality policy to provide support for sexual expression through NDIS funding (Disabled People's Organisation, 2019). The current lack of any adequate policy around sexuality under the NDIS leaves people with intellectual disability without support to make decisions about their reproductive and sexual health and also does not provide guidance for disability service providers and health care workers to provide this support. Lack of clear policy and procedure compounds challenges in accessing reproductive and sexual health care and places people with intellectual disability at risk of poorer health outcomes compared to the general population (Verlenden, Bertolli, & Warner 2019; FPNSW 2014). Greater consistency and clarity is needed to provide participants and their families' knowledge about the types of supports that can be provided under the NDIS to meet a person's reproductive and sexual health needs. It would also inform health services about what they should be providing. A holistic sexuality policy in the NDIS is

needed to promote the rights under the United Nations Convention on the Rights of People with Disability (United Nations, 2006).

### **Case study illustrating a narrow, reactive approach to sexuality support**

A woman, Olivia, in supported care, suffered repeated vaginal infections from masturbating with her hairbrush. These infections were treated with repeat prescriptions of antibiotics with no other efforts to understand the behaviour or support the person to adopt healthier behaviours. A support worker eventually supported Olivia to purchase a sex toy to minimize the risk of infection and lost their job as a result as this was considered inappropriate by the organization's management.

This case study illustrates a lack of appropriate response from disability service providers and health care providers. All people have the right to the enjoyment of the highest attainable standard of health and should be free to explore their sexuality and should be supported to do so in a way that is not detrimental to their health.

### **Question 4 - What do you think should be done to fix the problems people with cognitive disability have in getting health care?**

In order to fix structural issues in accessing health care, consultation with people with intellectual disability is essential to identify and address the problems they have in accessing health care (National Disability Services 2018). Further, our 2019 needs assessment (a survey of disability support workers) found that to improve people with intellectual disability's access to health care, there is a need for a multifaceted approach that focusses on sexuality policy, training, and providing more accessible services and resources (FPNSW 2019b).

#### **Sexuality policy**

There is a need for clear NDIS and organisational policy to provide clarity to workers. It is important that clarity is provided about the types of the supports that can be provided under the NDIS to meet reproductive and sexual health needs. Further, disability service providers should develop and implement organisational sexuality policies and guidelines which emphasise proactive strategies to support reproductive and sexual health care (reducing the need to react to behavioural and health issues).

#### **Professional training**

There is a need to support access to professional training. Disability sector workers identified that they lacked any formal training in supported decision making and reproductive and sexual health, and viewed training as important to improve the support they provide. Workers said they are not adequately supported to access training due to limited funding for professional development. There is a need for the NDIS to support workers to access training as standard practice. Continued evaluation of training programs and resources are needed to improve the effectiveness of health care and disability support workers.

#### **Information and resources**

Information and resources should be provided to professionals and informal support people about reproductive and sexual health topics to ensure that people with intellectual disability can be supported to make informed decisions about their reproductive and sexual health care. Family Planning NSW has developed a range of sexuality and reproductive and sexual health materials written in an accessible format. The Family Planning NSW (2018b) resource *Supporting decision making in RSH for PWID: A tool to assist clinicians in supporting the decision making of clients with intellectual disability* is an example of a resource that health professionals can use to assist people with intellectual disability to make health decisions.

It is also important that health services and their staff take steps to understand and meet complex and multiple health needs of people with intellectual disability and their carers. Family Planning NSW recommends the NSW Agency for Clinical Innovation's (2017) framework *Building capability in NSW health services for people with intellectual disability: the essentials*.

## Just Checking project

A recent example of an implementation solution is the *Just Checking* project which aims to increase 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 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 and information as other clients.

This multi-faceted project incorporated a range of activities including the development of *Just Checking* resources:

- easy-English social story resources to increase awareness and knowledge of cervical, breast and bowel cancer screening
- audio-visual resources about cancer screening
- a tool to help disability support workers, parents and carers support people with intellectual disability to access screening services
- an update of the Family Planning NSW *Supporting Decision Making Tool* to assist clinicians to support people with intellectual disability within the clinical setting
- a microsite for the *Just Checking* project housed on the Family Planning NSW website

The project also involved the development and delivery of face-to-face and online training for:

- Disability support workers in how to support people with intellectual disability to access cancer screening.
- clinicians in how to support WWID to access cervical screening

Key results from this two-year project include:

- 735 clinicians trained, with 83% of survey respondents reporting that they were confident in discussing cervical screening for women with an intellectual disability
- 161 disability support workers were trained face-to-face at 10 locations across metropolitan Sydney and regional NSW. A further 57 disability support workers attended a webinar delivered as part of the National Disability Practitioners (NDP) virtual conference in 2018
- Over 1,600 engagements on the *Just Checking* microsite
- 1,505 community members, including disability support workers and parents and carers, were engaged in conversations about cancer screening at over 20 events across metropolitan and regional NSW
- Resource distribution of 6,304 social stories, 4,246 support person's tools and 14,654 video views (full video and social media cut-downs)

Family Planning NSW will continue to monitor the impact of the *Just Checking* project. Initial results are promising in minimising the neglect of cervical, breast and bowel screening in people with intellectual disability.

## How could the NDIS and health systems work better for people with cognitive disability?

Ensuring that the NDIS and health systems work better for people with intellectual disability in accessing reproductive and sexual health care requires a proactive, holistic approach to support.

### Consultation with people with intellectual disability

There is a need for better consultation with people with intellectual disability to understand their needs and identify how to promote access to reproductive and sexual health care. Mechanisms already exist that enable consultations, but they must be consistently applied and documented in policies and procedures. Engaging with people with intellectual disability is already a core component of a person-centred approach, and the *National Safety and Quality Health Service Standards* (Australian Commission on Safety and Quality in Health Care 2017).

### **Support for informed decision making**

Families, workers and health care providers need to be trained to provide information and support on an individual level to understand consent, reproductive and sexual health rights and provide support so that people with disability can make informed decisions about their health. Many people with intellectual disability have the ability to make their own decisions about their lives but are not given the opportunity to do so. There is a lack of training for clinicians to improve skills and build confidence in supporting people with intellectual disability to make decisions about their reproductive and sexual health care (Thompson et al. 2014). Pathologising reproductive and sexual health issues can lead to reproductive and sexual health care being caught between the health care system and specialised support services. Guidance is required from the NDIS on this. Accessible resources, training and information should be made available to maximise the decision-making capacity, and to ensure that health care and support workers understand how to support people with intellectual disability to make these decisions.

### **Policies to guide NDIA navigation**

Clear sexuality policies from the NDIA and health departments at the national and state level would assist people with intellectual disability, carers and providers in navigating the complex NDIS system and how it can be utilised to better access reproductive and sexual health care. Useful documents include:

- *Sexuality and Relationships Guidelines* (NSW Ageing, Disability and Home Care 2016)
- *Personal Relationships, Sexuality and Sexual Health* (Victorian Department of Human Services 2006)
- *Building capability in NSW health services for people with intellectual disability: the essentials* (NSW Agency for Clinical Innovation 2017)

## **Question 5 - Why do people with cognitive disability experience violence, abuse, neglect or exploitation in health care? What are the causes?**

There are multiple complex factors contributing to people with intellectual disability's experience of violence, abuse, neglect or 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. The systemic neglect of the reproductive and sexual health and rights of people with disability has resulted in people with intellectual disability being denied their reproductive and sexual health rights and left vulnerable to exploitation and abuse (FPNSW 2014).

### **Supported decision making**

There is the need to embed supported decision making. We commonly find that many decisions about access to reproductive and sexual health care and information are made on behalf of people with intellectual disability by those who support them, rather than being supported to make their own decisions (Thompson et al. 2014). 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. While often well-meaning, these enquiries themselves often raise concerns about the potential neglect, violence, abuse and exploitation. Examples include:

- parents seeking advice on contraception and sterilisation for their daughters without their daughter's consent
- workers being directed by their organisation to alter contraception management without consultation
- 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 quite often the human rights of people with intellectual disability are not considered or included when making decisions about their reproductive and sexual health care. While we acknowledge that supported decision making in health care can be difficult for disability support people and clinicians, there is a responsibility to assist clients to make decisions rather than making decisions for them.

## **Sexuality policy**

There is a need for a sexuality policy. The current lack of NDIS sexuality policy leaves people with intellectual disability without support to make decisions about their reproductive and sexual health and provides no guidance for disability service providers and health care workers to provide this support (Thompson et al, 2014). Lack of clear policy and procedures compound challenges for those seeking to access to services and can result in information and services being withheld. Withholding information and access to services is a restrictive practice and is an example of neglect.

## **Myths about people with intellectual disability and sexuality**

There is a need to counter myths about people with intellectual disability and sexuality. These myths serve to discount the sexuality of people with intellectual disability and justify the silence, discrimination, violence and inaction around their reproductive and sexual health rights as outlined in the United Nations Convention on the Rights of People with Disability (2006). Common examples of myths include:

- people with disability will have children with disability and this should be prevented
- women with disability should be grateful for any sexual activity they have
- people with disability are not sexually active and do not have sufficient life expectancy to warrant preventative screening (e.g. cervical cancer screening)
- men with disability cannot control their sexuality – they may be dangerous
- no one would sexually assault a person with disability
- educating people with disability about sexuality will only make them want to have sex (FPNSW 2014).

These myths reflect negative attitudes and stereotypes about the sexuality and abilities of people with intellectual 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 a lack of taking disclosures seriously.

## **Question 7 - How does a person's gender, age, or cultural or sexual identity impact on people with cognitive disability getting health care?**

There is strong evidence to suggest that marginalised groups – including women, lesbian, gay, bisexual transgender, queer and intersex (LGBTIQ), culturally and linguistically diverse, Aboriginal and Torres Strait Islander people with intellectual disability – experience violence, abuse, neglect or exploitation in health care differently to the rest of the population.

### **Women with intellectual disability**

People with intellectual 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 (Verlenden, Bertolli & Warner 2019; FPNSW, 2014). Women with intellectual disability specifically face a lack of education and access to support in relation to menstrual management, contraception and cervical screening. This neglect has implications for access to contraception, cervical screening and STI testing, prenatal care, and places them at risk of worse health outcomes compared to the general population. It also has significant impacts if it takes away the right to make decisions about whether and when to have sex, or to start a family.

### **Lesbian, gay, bisexual, transgender, intersex and queer people with disability**

LGBTIQ people with disability experience barriers accessing health services and supports. These barriers are compounded by the denial of their identity, lack of inclusive information and service provision from disability services and a lack of accessible LGBTIQ information and services (Leonard & Mann 2018). A lack of services or supports leaves the person at an increased risk of violence, abuse, neglect and exploitation. Although data in relation to these communities are scarce, research shows that over one-third of lesbian, bisexual or queer women were overdue for cervical screening (Mooney-Somers et al. 2018) and that trans men are significantly less likely to access cervical screening compared to the general population (James et al. 2016). The *Australian Trans and Gender Diverse Sexual Health Survey* found that trans and gender diverse people experience marginalisation in sexual health care and that experiences of gender-insensitivity undermines their care. These experiences, including denial of gender-affirming care, may impact important public health goals, including



reducing HIV and increasing STI testing, resulting in higher levels of psychological distress (Callander et al. 2019).

### **Culturally and linguistically diverse people with disability**

There is very little literature about the reproductive and sexual health needs of people with intellectual disability from culturally and linguistically diverse backgrounds in Australia and no known literature that deals specifically with reproductive and sexual health issues. People with intellectual disability from culturally and linguistically diverse backgrounds can remain hidden from mainstream services relying on informal community and family supports (FPNSW, 2014). When they present to the health or welfare system it may be as a result of a crisis and therefore their reproductive and sexual health needs are considered a low priority in comparison to the acute health and other support needs.

To understand the unique reproductive and sexual health needs of people with intellectual disability from culturally diverse backgrounds, Family Planning NSW interviewed four disability peak bodies. They reported that, in general, the service system does not have the capacity to deal appropriately with sexuality and disability nor with the required cultural competency (FPNSW 2014). The inequity faced by people with intellectual disability from culturally diverse backgrounds is exacerbated by limited referral pathways and translated information and resources.

### **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 (Aboriginal Disability Network of NSW, 2012). The discrimination and isolation experienced by Aboriginal and Torres Strait Islander people with intellectual disability is compounded by poor availability of disability support services. The culturally appropriate services that do exist are often not equipped or resourced to support Aboriginal and Torres Strait Islander people with intellectual disability to access specialised reproductive and sexual health services. As a result the vast majority of Aboriginal and Torres Strait Islander people with intellectual disability do not have their needs met in any significant way (Aboriginal Disability Network of NSW 2012). There is limited understanding of the most effective service delivery models, particularly in rural and remote areas.

## **Question 8 - What could prevent people with disability experiencing violence, abuse, neglect or exploitation in health care?**

There is significant work to be done across the disability and health care sector to prevent people with disability experiencing violence, abuse, neglect or exploitation in health care.

Strategies or solutions to prevent violence, abuse, neglect or exploitation in health care should be developed with the full engagement of people with intellectual disability. It is important that they are supported to make decisions about what they think would best work, including how services are effectively developed and delivered. Health services should consider the needs of consumers with intellectual disability under *Standard 2: Partnering with Consumers* in the *National Safety and Quality Health Service Standards* (Australian Commission on Safety and Quality in Health Care 2017). Family Planning NSW's consumer engagement framework is an example of our ongoing commitment to consulting with people with intellectual disability in all aspects of our service delivery, including the accessibility of services, education and development of resources. We do this to ensure access to appropriate reproductive and sexual health care and information to prevent violence, abuse, neglect and exploitation.

Preventing the risk of violence, abuse, neglect and exploitation requires services to do more than just report incidents when they occur. It requires a proactive, holistic approach to sexuality support that enables support people and health care providers to provide information and support that enables people with intellectual disability to have healthy relationships, understand consent, and make decisions for about their own health care.

Family Planning NSW has identified areas for action around reproductive and sexual health care that can contribute to the prevention of violence, abuse, neglect or exploitation in health care in our “Love and Kisses” advocacy report (2014). These include:

1. development of policies, documents, service delivery and strategies that are aligned with the *United Nations Convention on the Rights of Persons with Disabilities* in relation to reproductive and sexual health (emphasising proactive approaches and acknowledge sexual and gender diversity).
2. consistent collection of data to inform policy and service planning
3. development and distribution of easy to read information on reproductive and sexual health care
4. promoting awareness of reproductive and sexual health care services to disability service providers, particularly in regional areas
5. provision of comprehensive sexuality and disability education for disability workers to assist in supporting clients across their lifespan and parents and informal carers
6. access to sexuality education and reproductive and sexual health care services under the NDIS.

## **What would make a person with cognitive disability feel safe when getting health care?**

### **Consumer engagement**

Direct consultation with people with intellectual 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 (FPNSW 2019a).

### **Support capacity to make decisions**

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. Some people (including those under the age of 18 years) will need education and support to improve their capacity to make decisions. Support workers need to understand how to support a person with disability to make decisions.

### **Use a trauma-informed approach**

Services should be delivered in line with the principles of trauma-informed care, acknowledging that many people with intellectual disability have experienced violence, abuse, neglect or exploitation. Trauma-informed care principles acknowledge that people can access multiple services, may have previous negative experiences engaging with organisations and may have also experienced and/ or witness high levels of abuse, violence and other traumas in their daily life (Marcal & Trifoso 2017). A trauma-informed approach builds supportive and reflective practices to respond to challenges with safety, accompanying distress, and ‘behaviours of concern’ while also supporting supported-decision making.

## **Question 9 - What would stop a person with cognitive disability reporting violence, abuse, neglect or exploitation in health care?**

People with intellectual disability may experience significant difficulties in reporting violence, abuse, neglect or exploitation in health care due to not being believed by support people and services, a lack of clear reporting pathways and a lack of advocacy services for lodging these complaints. It can also be difficult to report violence, abuse, neglect and exploitation due to communication problems, high support needs, and behaviours of concern (Ombudsman NSW 2017). People in supported accommodation are also at high risk due to their reliance on support staff and health care workers who may be consistently involved in their day to day life (Ombudsman NSW 2017).

## A case study illustrating the challenges in supporting people with intellectual disability experiencing violence

Alex is a young woman in her early 20s with intellectual disability. She lives at home with her mother, who is her primary caregiver. Alex attended our clinic for a pregnancy test and an STI check, disclosing sexual assault by three men the week before. Alex has the contraceptive injection every 12 weeks from her GP (organized by her mother), but wanted to have a baby. After disclosure, Alex was referred to the local sexual assault service. We also discussed with Alex about disclosing to her mother, which she did not want to do.

One week later the counsellor at the local sexual assault service called us to advise that when they contacted Alex to make an appointment, Alex passed the phone on to her mother, and her mother told the counsellor that Alex was retracting the disclosure as she had made up the story. Alex has not attended our service since.

This case study illustrates the broader context of women of intellectual disability not being believed when reporting instances of violence, abuse, neglect or exploitation (Maher et al 2018). There is concern about Alex's right to choice and control over her contraceptive options and to decide about whether and when to reproduce. This case study also demonstrates that many of the current complaint mechanisms in health care services can be inaccessible. If a person with intellectual disability requires a support person or family member to assist in lodging a complaint or has issues with verbal or written communication, this can be a challenge. Current NDIS reporting pathways are unclear, as many general health care services, (e.g. GP practice), are not NDIS services and therefore may not be reportable under the NDIS Quality and Safeguards Commission.

## What would make it easier for a person with cognitive disability to complain about violence, abuse, neglect or exploitation in health care?

Improving reporting pathways is important in preventing violence, abuse, neglect or exploitation in health care. Strategies to make it easier for people with intellectual disability to complain about violence, abuse, neglect or exploitation in health care include:

- engage with people with intellectual disability
- provide training for people with intellectual disability and health care services in identifying reports or disclosures from people who may have difficulty with communication, high support needs and behaviours of concern
- provide information and resources for parents, carers, and disability service providers written in accessible formats (e.g. easy to read documents, screen reader compatible PDFs)
- provide clear policy and procedures within health services in responding to disclosures of violence, abuse, neglect or exploitation
- deliver inclusive and accessible clinical services
- provide training for clinicians, health care workers, organisations and individuals
- advocate for the reproductive and sexual health and rights of people with a disability (FPNSW 2018a)

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