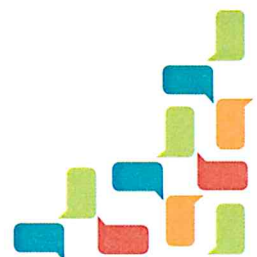


Submission of Family Planning NSW

Implementation of the National Disability Insurance Scheme and the provision of disability services in New South Wales

August 2018



NSW Legislative Council
Portfolio Committee No. 2 – Health And Community Services
Inquiry into the implementation of the National Disability Insurance Scheme and the provision of disability services in New South Wales
Parliament House, Macquarie Street, Sydney NSW 2000.

Family Planning NSW welcomes this opportunity to contribute to the Inquiry into the implementation of the National Disability Insurance Scheme and the provision of disability services in New South Wales

About us

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

We are experts on reproductive and sexual health and provide clinical services and health information to people throughout NSW.

We are an independent, not for profit organisation responsible to a voluntary board of directors and we rely on government funding, donations and self-generated income to provide our services. Our government funding comes from the Federal and NSW governments, as well as Local Health Districts.

Founded in 1926 Family Planning NSW is the oldest family planning service in Australia, providing reproductive and sexual health care services and information to the community for 90 years.

Family Planning NSW has been delivering targeted services to people with disability and those who support them for over 35 years. Family Planning NSW is also a registered provider of the National Disability Insurance Scheme (NDIS). Family Planning NSW provides services under the following NDIS support area:

- Daily Living (therapy supports)

Who we are

We work to ensure everybody has access to quality reproductive and sexual health.

We respect the rights of our clients to make choices about their reproductive and sexual health and we treat each and every person with respect, dignity and understanding.

We are experts on contraception, pregnancy options, sexually transmissible Infections (STIs), sexuality and sexual function, menstruation, menopause, common gynaecological and vaginal problems, cervical screening, breast awareness and men's sexual health.

Our Sydney Centre for Reproductive and Sexual Health Research undertakes nationally and internationally recognised research which underpins our clinical practice. We publish clinical practice handbooks on reproductive and sexual health for medical professionals and are recognised leaders in this field.

What we do

We provide clinical services, health promotion and education and training at clinics in Ashfield, Fairfield, Penrith, Newcastle and Dubbo and use partnerships to deliver services in other key locations.

We also provide health information and education and training for doctors, nurses, teachers and other health, education and welfare professionals.

We see more than 28,000 clients annually at our clinics and our education services conduct courses with over 1200 professionals each year.

Our NSW Talkline service 1300 658 886 provides a confidential, non-judgemental telephone and email information and referral service for all who need advice across NSW.

We also work to provide reproductive and sexual health services in the Pacific through funding from Australian aid and donations. Find out about our international development work at www.fpnsw.org.au/international

Who we help

Our clinics welcome everyone and provide high quality reproductive and sexual health services.

Our education and training services provide expert education for doctors, nurses, teachers and other health, education and welfare services.

We reach out in particular to priority communities including people from culturally and linguistically diverse and Aboriginal and Torres Strait islander backgrounds, people with disability, young people, and people from rural and remote communities.

Terms of Reference:

1. In regards to point a) in the Terms of Reference: *the implementation of the National Disability Insurance Scheme and its success or otherwise in providing choice and control for people with disability*, Family Planning NSW would like to make the following comments:
 - 1.1. Family Planning NSW is concerned about the lack of consideration of sexuality, relationships and sexual health goals in participant plans and the impact on the choice and control that people with disability have over their future health and relationships. In particular, we are concerned about the following:
 - 1.1.1. The lack of planning and consideration given to the needs and support requirements of children and their families as that child approaches puberty. Research shows that parents of children with disability often struggle to support their child with the physical, emotional and social changes that happen during puberty (Brown & Pirtle, 2008). This is particularly problematic as research continues to show that there are numerous barriers to providing children and young people with appropriate sexuality support and education at school (Family Planning NSW, 2012; Thompson et al, 2011; Barnard-Brak, 2014)
 - 1.1.2. The inconsistent advice provided to participants and their families about the availability of funds for sexuality support and education. Family Planning NSW is aware of some parents being advised by NDIA staff that the NDIS does not cover *any* sexuality support and education in *any* circumstances and that they need to do it themselves. This includes instances where ongoing therapeutic supports are required to address ongoing behaviours of concern and enable the person to participate and contribute in community and work life. As an NDIS provider of such supports, these responses from NDIA staff are plainly inaccurate, unhelpful and inconsistent with the broader NDIS approach of supporting families and family life.
 - 1.2. Where it is considered, sexuality, relationships and sexual health is too often considered *reactively* when health issues or behaviours of concerns have become more severe, rather than being considered *proactively* to improve understanding, skills and community participation. Proactive sexuality support maximises choice and control for people with disability. Where reactive support needs to be provided for the health and safety of that person and the people around them, the choice and control for the person with disability is necessarily reduced.

- 1.3. We therefore strongly recommend that sexuality, relationships and sexual health goals be a standard item for consideration in all participant plans. We also recommend that puberty support and education requirements be included as a standard component of all plans for all children with disability by the time they are 10 years old.
 - 1.4. Where funding has been allocated in a person's plan to access sexuality supports, Family Planning NSW is concerned that the delay in review times of plans has a significant impact on the continuation and planning of therapy supports. As an NDIS provider of Daily Living (therapy supports), it is difficult for us to implement a program when we are unsure of what funding is available, which in turn limits participants' choice and control. We echo the concerns raised in the Commonwealth Ombudsman's recent report regarding the timeliness of NDIS plan reviews, and strongly recommend that implementation of the Ombudsman's recommendations (Commonwealth Ombudsman, 2018).
2. In regards to point i) in the Terms of Reference: *incidents where inadequate disability supports result in greater strain on other community services, such as justice and health services*, Family Planning NSW would like to make the following comments:
 - 2.1. As stated in 1.2 above, sexuality, relationships and sexual health is too often considered *reactively* when health issues or behaviours of concerns have become more severe, rather than being considered *proactively* to improve understanding, skills and community participation. Family Planning NSW regularly receives enquiries from disability support workers and parents looking for support services for a person with disability who is displaying sexual behaviours of concern, and unfortunately the availability of services with experience in providing this support is extremely limited, even within metropolitan NSW. Where health issues have become more severe or behaviours of concern lead to contact with the justice system, this therefore impacts on other community services. The strain on justice and health services is particularly relevant as often those services have limited skills and experience in supporting a person with disability around sexuality issues (Houtrow, 2014; Riches, Parmenter, Wiese & Stancliffe, 2006).
 - 2.2. At the same time, research shows that sexuality support, when given proactively, can support a person with disability to improve their decision making skills, their self-protection skills and their level of community participation (Hayashi et al, 2011; Khemka, Hickson & Reynolds, 2005).
 - 2.3. Yet Family Planning NSW continues to be concerned that sexuality needs are inadequately addressed by disability services, impinging on each person's right to have good sexual health and healthy relationships. The lack of policy direction from the NDIA is key here, and will be discussed in greater depth in section 3.

3. In regards to point j) in the Terms of Reference: *policies, regulation or oversight mechanisms that could improve the provision and accessibility of disability services across New South Wales*, Family Planning NSW would like to make the following comments:
 - 3.1. Family Planning NSW is concerned that the lack of an overarching policy regarding sexuality supports leaves disability services without any guidance on how such support can be provided in an appropriate way that empowers people with disability to have choice and control. Such guidance was previously provided by NSW Ageing, Disability and Home Care's *Sexuality and Relationships Guidelines* (2016). The current policy vacuum may leave disability services too scared to provide sexuality support, and makes it easier for services to provide support in a way that is inappropriate or disempowering or dismiss it as being outside the scope of their practice.
 - 3.2. The reproductive and sexual health rights of people with disability, coupled with high rates of sexual assault and abuse experienced by people with disability, and women with intellectual disability in particular, warrants the creation of a policy that assists disability services to work proactively to empower people with disability to have choice and control over their reproductive and sexual health and relationships, rather than creating more opportunities for sexuality support to be dismissed as being too difficult or illegal.

Recommendations

Accordingly, Family Planning NSW makes the following recommendations for priorities of action:

1. The creation of an NDIA statement or policy about the types of sexuality supports covered by the NDIS is essential. As examples, Family Planning NSW recommends the Committee review the NSW Ageing, Disability and Home Care (2016) *Sexuality and Relationships Guidelines* and the Victorian Department of Human Services (2006) *Personal Relationships, Sexuality and Sexual Health* policy.
2. Sexuality support requirements to be considered as a standard inclusion for all participant plans, including puberty support for children and adolescents.
3. All NDIA representatives, including staff of organisations funded to conduct participant plan meetings, undergo compulsory training on the sexuality needs of people with disability and the provisions for support under the NDIS.

4. Mechanisms to allow more responsive changes to plans are introduced to allow sexuality supports to be added or amended in more timely fashion where there is concern for the current and/or future safety of the participant and/or others.



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A/CEO
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August 2018

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