

Submission of Family Planning NSW

Transitional Arrangements for the NDIS

August 2017



Joint Standing Committee on the National Disability Insurance Scheme
PO Box 6100
Parliament House
Canberra ACT 2600

Family Planning NSW welcomes this opportunity to contribute to the Inquiry into transitional arrangements for the NDIS.

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 areas:

- Specialised assessment of skills, abilities and needs;
- Therapeutic supports;
- Behaviour support.

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 here.

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

- a) the boundaries and interface of NDIS service provision, and other non-NDIS service provision, with particular reference to health, education and transport services;

1. Intersection between the NDIS and education.

1.1 Family Planning NSW is concerned about the gap between the sexuality education provided to students with disability through schools and the services available under the NDIS to provide that education and support, particularly where the education provided by the school has been insufficient or unsuited to the person's learning style.

1.2 Through our work as a provider of training to special education teachers, Family Planning NSW has been made aware of the frequency with which schools inconsistently fulfil their responsibilities to provide sexuality education at school under the Personal Development, Health and Physical Education (PDHPE) syllabus to students with disability, particularly students with intellectual disability. Our own needs analysis conducted in 2012 identified a number of key barriers to schools providing this education: a lack of resources; insufficient teacher training; and a lack of teacher confidence. This is confirmed by research (e.g., Thompson et al, 2011; Barnard-Brak, 2014).

1.3 This means that some students are finishing school without the required skills and knowledge to allow them to successfully transition into post-school programs or education. This is relevant within the NDIS context as there continues to be inconsistent advice provided to participants and their families about the availability of funds to support additional sexuality education. Family Planning NSW is aware of some parents being advised by NDIA staff that the NDIS does not cover any sexuality 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. Such responses from NDIA staff are plainly inaccurate, unhelpful and inconsistent with the broader NDIS approach of supporting families and family life.

1.4 It is therefore imperative that greater consistency and clarity is provided to families about accessing supports for sexuality education for a participant to help bridge the known gap in sexuality education provided at school.

2. Intersection between the NDIS and reproductive and sexual health services.

2.1 Family Planning NSW is concerned about the mutual shifting of responsibilities between health and the NDIS in meeting the reproductive and sexual health needs of people with disability. Health services, including allied health are often inexperienced or avoidant in providing reproductive and sexual health care and support, particularly where there are sexualised behaviours of concern or concerns about a person's capacity to make decisions (Eastgate, 2011). At the

same time, it has been clearly stated that the NDIS does not fund treatment for such needs when they arise, only maintenance for known issues.

2.2 This potentially leaves a large gap where a person's reproductive and sexual health needs are not addressed by health or the NDIS, leaving the person and their families with few options for support and limited recourse for complaint.

2.3 It is therefore imperative that greater consistency and clarity is provided to participants and their families about the types of the supports that can be provided under the NDIS to meet a person's reproductive and sexual health needs, and the types of support that Health should be providing. A list to this effect, with examples, would be most helpful.

2.4 It is also imperative that NDIA staff is sufficiently trained to provide consistent and clear advice, as at 2.3.

- b)** the consistency of NDIS plans and delivery of the NDIS and other services for people with disabilities across Australia.
3. Family Planning NSW is concerned about the lack of consideration of sexuality, relationships and sexual health goals in participant plans. Where it is considered, it 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. We strongly recommend that sexuality, relationships and sexual health goals be a standard item for consideration in all participant plans.
 4. Family Planning NSW is particularly concerned about 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). Research also 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 et al, 2005). Family Planning NSW therefore strongly recommends that puberty support and education requirements be included as a standard component of all plans for all children with disability by the time then are 10 years old.
 5. Family Planning NSW is also concerned about a lack consistency in the amount of flexibility built into people's plans to accommodate for developmental changes and other changes in needs, particularly where the need requires a more timely response than is possible with process required to arrange a plan review.
 6. To enable greater inclusion of sexuality, relationships and sexual health goals in participant plans, it is therefore imperative that NDIA staff is 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 such support. As described above, advice from NDIA staff in this area is inconsistent, often incorrect, and unhelpful to participants and their families.

7. Family Planning NSW is concerned about the inconsistency of access to services relating to sexuality, relationships and sexual health needs, particularly in regional and rural areas.

Recommendations

8. Given the gaps identified between the NDIS and education and the NDIS and health, and also given the inconsistent consideration given to sexuality support under the NDIS, Family Planning NSW is concerned about the unclear future of information and advocacy services within NSW. This is particularly concerning as there is already a distinct lack of information for participants and their families regarding the inclusion of sexuality supports in participant plans.

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

1. Sexuality support requirements to be considered as a standard inclusion for all participant plans, including puberty support for children and adolescents.
2. 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. The creation of an NDIA statement or policy about the types of sexuality supports covered by the NDIS is essential to this. As examples, Family Planning NSW recommends the Committee review the NSW Ageing, Disability and Home Care 'Sexuality and Relationships Guidelines' and the Victorian Department of Human Services 'Personal relationships, sexuality and sexual health' policy.
3. 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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