



## Submission of Family Planning NSW

### **General issues around the implementation and performance of the NDIS**

March 2020

Joint Standing Committee on the National Disability Insurance Scheme  
PO Box 6100, Parliament House, Canberra ACT 2600  
[ndis.sen@aph.gov.au](mailto:ndis.sen@aph.gov.au)



Family Planning NSW welcomes the opportunity to make a submission to the Joint Standing Committee on the National Disability Insurance Scheme regarding 'General issues around the implementation and performance of the NDIS'.

This submission reiterates issues raised and recommendations from our previous submissions to the Joint Standing Committee including our 2017 submission 'Transitional arrangements for the NDIS' and 2019 submission 'General issues around the implementation and performance of the NDIS'.

### About us

Family Planning NSW is the leading provider of reproductive and sexual health services in NSW and Australia. Our mission is to enhance the reproductive and sexual health and rights of our communities by supporting all people to have control over and decide freely on all matters related to their reproductive and sexual health.

We have been delivering targeted services to people with disability and those who support them for over 35 years. These include clinical services, health promotion programs, education workshops and training. Family Planning NSW is also a registered provider under the National Disability Insurance Scheme (NDIS). We provide services under the following NDIS support areas:

- specialised assessment of skills abilities and needs
- therapeutic supports.

### Recommendations

Family Planning NSW recommends that:

1. sexuality and relationship support requirements are considered as a standard inclusion for all participant plans, including puberty support for children and adolescents.
2. mechanisms are introduced to allow more responsive plan changes so that participants can access timely support for their sexuality and relationship support needs.
3. the NDIS website and associated materials provide clearer guidance about the kinds of services that can be obtained as part of sexuality and relationship support, in the form of a National Disability Insurance Agency policy or procedure document.
4. funding is provided to support the professional learning of NDIA representatives, disability sector workers and service providers, including in the areas of sexuality and relationships.
5. the NDIS website and associated materials provide clearer guidance about available supports for prospective participants accessing NDIS plans.

## Issues

### 1. Sexuality and relationship support is often considered reactively, once challenging behaviours have become concerning

Sexuality and relationship support, when given proactively, can support a person with disability to improve their decision-making and self-protection skills, and their level of community participation.(1,2) Although the responsibility of holistic sexuality and relationship education is shared between parents and carers, the school curriculum and disability services, parents are regularly left to provide their child with sexuality and relationship education as schools and disability services are often ill-equipped to do so.(3) The provision of sexuality and relationship education by parents usually occurs reactively, after the onset of challenging behaviours.

Evidence shows that parents of children with disability often struggle to support their child with the physical, emotional and social changes that happen during puberty.(4,5) Family Planning NSW is concerned about the lack of consideration of sexuality and relationship support and sexual health goals in NDIS participant plans and that where these goals are considered, it is often reactively, once health issues or behaviours have become more severe. Sexuality and relationship support should be integrated into all NDIS plans so that participants are able to utilise the support of trained, skilled professionals.

**Recommendation 1:** Sexuality and relationship support requirements are considered as a standard inclusion for all participant plans, including puberty support for children and adolescents.

### 2. Plans are not responsive to participants changing needs

Family Planning NSW is concerned about the lack of flexibility in participant's plans to accommodate developmental changes, such as those that happen during puberty. Developmental changes require a timely response to address the current needs of the participant. Often, this is not possible with the current process required to arrange a plan review. Participants and their carers who wish to respond to identified issues must at times engage with their GP to develop a Mental Health Plan as a stop-gap measure to access timely support.

As a provider under the NDIS, we have experienced situations where participants wishing to amend their plans (for instance, to include addressing sexualised behaviour or inappropriate touching) must wait up to three months for a plan review. As well as being detrimental to participant's wellbeing, this delay is concerning for the ongoing safety of that person and those around them. The *2019 Review of the National Disability Insurance Scheme Act 2013* highlighted the need for flexibility within plans and allowing a plan to be amended is one of the most effective strategies to improve the participant NDIS experience.(6)

**Recommendation 2:** Mechanisms are introduced to allow more responsive plan changes so that participants can access timely support for their sexuality and relationship support needs.

### 3. People with disability, parents, carers and NDIS providers are not currently clear about what sexuality and relationship supports can be funded, and the relevant support codes

As an NDIS service provider, we recognise that the NDIS system is complex and can be confusing for participants to navigate, particularly when trying to access sexuality and relationship support. We continue to hear of confusion around what sexuality and relationship supports can be funded and the correct codes to use for those supports. There have been multiple instances in which participants have attempted to use funding for their plans under the support code 'Capacity



Building, Relationships, Improved Relationships' when trying to access our therapeutic services for support on healthy relationships, only to find that the correct code required to access our services is different (Capacity Building, Daily Living, Improved Daily Living).

In these instances, the name of the support code 'Capacity Building, Relationships, Improved Relationships' is a misnomer, confusing people into thinking they can access any type of relationship support using this code because it contains the word 'relationships'. However, the participant needs to have funding under the 'Capacity Building, Daily Living, Improved Daily Living' support code, to enable access to our sexuality and relationship supports. Alternatively, participants need to utilise other access paths (e.g., Mental Health Care Plan), while they wait for a plan review.

Family Planning NSW believes that the NDIS has a responsibility to enable access to sexuality and relationship education, support and resources for people with disability and their carers in navigating the complex NDIS system. An NDIA policy or procedure document could address this issue. Useful examples include the NSW Ageing, Disability and Home Care's 'Sexuality and Relationship Guidelines' and the Victorian Department of Human Services' 'Personal relationships, sexuality and sexual health'.

FPNSW endorses '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.(7) Without a sexuality policy under the NDIS, people with disability do not have the support they need to make decisions around their reproductive and sexual health. Disability service providers and healthcare workers also have little guidance to provide this type of support.

**Recommendation 3:** The NDIS website and associated materials provide clearer guidance about the kinds of services that can be obtained as part of sexuality and relationship support, in the form of a NDIA policy or procedure document.

#### **4. The current NDIS funding model has had a significant and negative impact on professional learning in the disability sector**

As a Registered Training Organisation, Family Planning NSW has provided training to over 12,000 doctors, nurses, teachers, disability support workers and community workers. Our courses and resources assist parents, carers, disability support workers and 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).

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, we have noticed a marked drop in enrolments by disability support workers and professionals who work in the disability sector due to decreased availability of funding for professional learning. Further, our recent needs assessment 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.(3)

Workforce skill and knowledge gaps are of concern as they may directly or indirectly contribute to a person with disability's risk of violence, abuse, neglect and exploitation. The NSW Department of



Family and Community Services previously stated that workers who support people with disability have a role to inform and educate people about their rights in relation to sexuality and relationships.(8) To achieve this, a skilled workforce is needed. NDIA representatives and NDIS providers need full support to access opportunities for professional development in sexuality and relationships. The following case study highlights the importance of ensuring a skilled NDIS workforce to meet the support needs of participants.

#### **Case Study**

Family Planning NSW was contacted by the parent of a young person with intellectual disability looking for specialist one-to-one sexuality and relationships education and support. The young person had an NDIS plan and a number of professionals involved in their support. None of the professionals could agree, however, on who could do this specialist work and the parent was left to coordinate this issue which caused her considerable distress and put her son at risk of harm through the delay in access to support. The client needed a skilled NDIS support coordinator with an understanding of how to manage care packages in regard to sexuality and relationship support.

It is imperative that NDIA representatives and disability sector workers are trained to understand the holistic nature of sexuality, the importance of sexuality and relationship support and education to a person's health, wellbeing and participation, and the rights of people with disability to access support.

**Recommendation 4:** Funding is provided to support the professional learning of NDIA representatives, disability sector workers and service providers, including in the areas of sexuality and relationships.

#### **5. Individuals find it difficult to access an initial NDIS assessment thus impacting access to essential reproductive and sexual health services**

We are concerned that some individuals do not have access to essential reproductive and sexual health services and support due to the complex nature of the NDIS. As an NDIS service provider, we continue to hear of individuals who find it difficult to access reproductive and sexual health services due to the intricate NDIS application requirements and limited support resources. The *2019 Review of the National Disability Insurance Scheme Act 2013* found the NDIS is impacted by complexity which can make it difficult for individuals to navigate.(6) It is important that the NDIA provides support services and resources available to prospective participants to ensure ease of navigation throughout the application process as seen through the following case study.

#### **Case study**

Family Planning NSW was contacted by a client with mobility impairment. The client had complex psycho-social difficulties, which included mental health problems, financial distress, lack of accessible housing and isolation. The client had been trying to access an NDIS assessment for over a year but had been unable to compile the supporting paperwork. She was housebound and could not find a bulk-billing GP to visit her at home to help her complete the application. The client needed a disability case manager from a free, universal service to support her to complete her NDIS application and get basic services in place. In the meantime, she was missing out on essential reproductive and sexual health services, including the support needed to see a doctor at Family Planning NSW.



The NDIS has a responsibility to enable access to structures that support prospective participants to navigate the NDIS application process. Ultimately this will ensure that people with disability are able to be supported to access essential reproductive and sexual health services.

**Recommendation 5:** The NDIS website and associated materials provide clearer guidance about available supports for prospective participants accessing NDIS plans.

## References

1. Sala G, Hooley M, Attwood T, Mesibov GB, Stokes MA. Autism and intellectual disability: A systematic review of sexuality and relationship education. *Sexuality and Disability*. 2019, 37: 353-382.
2. González C, Fernández-Sogorb A, Sanmartín R, Vicent M, Granados L, García-Fernández JM. Efficacy of sex education programs for people with intellectual disabilities: A meta-analysis. *Sexuality and Disability*. 2018, 36: 331-347.
3. Family Planning NSW. Disability needs assessment. Sydney: Family Planning NSW; 2019, unpublished report.
4. Manor-Binyamini I, Schreiber-Divon M. Parental perceptions of the sexuality of adolescents with intellectual disabilities. *Sexuality and Disability*. 2019, 37: 599–612.
5. Stein S, Kohut T, Dillenburger K. The importance of sexuality education for children with and without intellectual disabilities: What parents think. *Sexuality and Disability*. 2018, 36: 141–148.
6. Tune, D. Review of the National Disability Insurance Scheme Act 2013: Removing the red tape and implementing the NDIS participant service guarantee. Canberra: Government Services; 2019.
7. Disabled People’s Organisations Australia. Joint Position Statement: A call for a rights-based framework for sexuality in the NDIS. Sydney: Disabled People’s Organisations Australia; 2019.
8. Department of Family and Community Services. Sexuality and relationship guidelines. Sydney: Department of Family and Community Services; 2016.