



**Submission by Family Planning NSW**

**Select Committee on Autism inquiry into the services, support and life outcomes for autistic people in Australia and the associated need for a National Autism Strategy**

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Select Committee on Autism  
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Family Planning NSW welcomes the opportunity to contribute to this inquiry by the Select Committee on Autism.

### **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.

We have been delivering targeted services to people with disability and those who support them for over 35 years, including clinical services, health promotion programs and education workshops and training. As a registered provider under the National Disability Insurance Scheme (NDIS), we provide sexuality and relationship support to people with disability.

### **Recommendations**

To improve services, support and life outcomes for people with autism, our recommendations are to:

1. ensure comprehensive sexuality education and proactive sexuality and relationship support for people with autism is a priority, especially during puberty
2. improve support for families, support workers and health professionals to empower people with autism to have control and choice about all matters related to their reproductive and sexual health
3. increase access and availability of reproductive and sexual healthcare services for people with autism, particularly in regional and remote areas
4. enact systemic changes to improve disability sector worker education, organisational policies and guidance about the NDIS to better support people with autism
5. recognise the needs of people with autism in policies to promote access comprehensive sexuality education, sexuality and relationship support and reproductive and sexual health services across the lifespan and regardless of their background or circumstances
6. integrate sexuality and relationship support as a standard item in NDIS participant plans
7. increase funding for research with people with autism in relation to sexuality, sexuality support and their access to, and engagement with, reproductive and sexual healthcare services.

### **Key points**

Family Planning NSW supports reproductive and sexual health and rights for everybody in every family. People with autism have the same reproductive and sexual health needs as other people, however, we know that they often face barriers to accessing reproductive and sexual health information and services.(1)

In line with the United Nation's *Convention on the Rights of Persons with Disability*(2), we recognise that disability is an evolving concept where physical, mental, intellectual or sensory impairments interact with social and environmental barriers. We acknowledge that this definition of disability includes autism spectrum disorders, but not all people with autism identify as having a disability. In our submission, we comment on particular items (d, e, g, h.iii and j) in the *Select Committee on Autism Inquiry Terms of Reference*.

### **(d) International best practice with regards to diagnosis, support services and education, effectiveness, cost and required intensity**

As a reproductive and sexual health organisation, we would like to draw the Committee's attention to international best practice regarding the provision of comprehensive sexuality education, access to sexuality and relationship support and to reproductive and sexual healthcare for people with autism.

### **Comprehensive sexuality education**

From a rights perspective, it is crucial that all people with autism receive high-quality and evidence-based comprehensive sexuality education. Even with a national curriculum, Australia does not provide

comprehensive sexuality education consistently across the country. A global review found that comprehensive sexuality education increases safe sexual behaviours, delays sexual debut, and reduces unintended pregnancy and sexually transmitted infections (STIs). The review found that "failing to provide marginalised 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".(3)

Comprehensive sexuality education provided to children and young people with autism should include adjustments to communication techniques and strategies to enable the child or young person to learn and retain key messages and information.(4) However, currently, there are insufficient guidelines to direct the systematic provision of sexuality education and support to people with autism, particularly for those with higher support needs.(5) The provision of comprehensive sexuality education in Australia for people with autism can be achieved through consistent implementation of the national Personal Development, Health and Physical Education (PDHPE) curriculum.

### **Sexuality and relationship support**

Sexuality and relationship support refers to a broad range of topics including healthy relationships, sexual and gender identity, reproductive and sexual health, reproductive and sexual rights, and health behaviours. The provision of sexuality and relationship support can include disability support workers providing a person with resources or information, making a referral and assisting a person in accessing a service. Sexuality educators, counsellors and psychologists provide sexuality and relationship support services for people with autism.

People with autism may experience high levels of anxiety about their potential to develop and maintain intimate relationships.(4) Parents of children with autism often struggle to support their child with the physical, emotional and social changes associated with puberty.(6) Research shows that proactive sexuality and relationship education and support is crucial to help people with autism to adjust to the physical, social and psychological changes associated with puberty.(7) Education and support provided within mainstream settings promotes positive friendships and relationships and minimises isolation.(5) Proactive sexuality and relationship education and support also helps people with autism engage in healthy, safe and socially acceptable sexual behaviours.(7)

### **Access to reproductive and sexual healthcare**

Promoting equitable access to healthcare for people with autism would minimise the risk of poor sexual health outcomes, including STIs, unintended pregnancy, sexual exploitation and abuse.(6, 8)

### **(e) The demand for and adequacy of Commonwealth, state and local government services to meet the needs of autistic people at all life stages**

Family Planning NSW advocates for improved availability and quality of education and information, sexuality support services, reproductive and sexual health services for people with autism and their families.

### **Education support for adolescents transitioning through puberty**

There is a need to develop the skills and confidence of teachers and the inclusiveness and accessibility of comprehensive sexuality education. Through our work as a provider of training to teachers, including special education teachers, we are aware of gaps in the skills and confidence of teachers and the inclusiveness and accessibility of comprehensive sexuality education. Schools do not consistently fulfil their responsibility to provide sexuality and relationship education under the PDHPE syllabus to students with autism.

### **Availability of sexuality and relationship support**

There is a need to increase availability and quality of sexuality and relationship support for people with autism at all life stages, but especially as they transition through puberty. Currently, there is a lack of planning and consideration given to the needs and support requirements of children approaching puberty and their families.

We are also concerned about the lack of sexuality and relationship support services for people with autism, particularly for those people with higher support needs and for adolescents as they transition through puberty. Availability of sexuality and relationship support services for people with autism in regional and remote areas also needs expansion. In NSW there are 11 locations where sexuality educators, counsellors and psychologists who have experience in supporting people with autism with more complex sexuality matters (including our Sexuality and Disability Service in Newcastle), however, the majority are located in the Sydney metropolitan region.

### **Access to quality reproductive and sexual health services**

Increased availability of reproductive and sexual healthcare services, particularly in regional and remote areas, is a priority. Healthcare workers are often inexperienced or avoid providing reproductive and sexual healthcare and support, particularly where there are sexualised behaviours of concern or concerns about a person's capacity to make decisions.(9) In addition to making services more appropriate, disability sector workers need to actively facilitate access to reproductive and sexual healthcare.

### **(g) The social and economic cost of failing to provide adequate and appropriate services, including to support key life stage transitions of autistic people**

Family Planning NSW is concerned about the short- and long-term implications of failing to provide adequate comprehensive sexuality education, sexuality and relationship support and sexual and reproductive health services to people with autism, especially for transition through puberty into adulthood. People with autism experience increased vulnerability to poor reproductive and sexual health outcomes, including STIs, abuse and sexual exploitation.(8)

### **Comprehensive sexuality education**

Failure to provide comprehensive sexuality education means that adolescents with autism may struggle to adjust to the physical, social and psychological changes associated with puberty.(7) Some students finish school without the required skills and knowledge to allow them to successfully transition into post-school programs, education or employment, leaving people with autism more vulnerable to violence, exploitation and abuse. As a result, sexuality and relationship education and support for adolescents is falling to parents (who may also lack professional support and information resources).(6)

A systemic lack of support and education through the school system and into disability services can lead to schools responding reactively to address issues of sexuality and relationships, once behaviours have become more concerning. Concerning behaviours can lead to social, physical and emotional harm for the person with autism and those around them. All people have the right to supports that assist them in making decisions about their own life and minimising their vulnerability to exploitation, violence and abuse.

### **Sexuality and relationship support**

Without proactive sexuality and relationship support and education, adolescents with autism may have difficulty expressing their feelings in a socially appropriate manner and understanding emotions expressed by others.(7) They may also experience difficulty coping with the physical, social, and psychological changes associated with puberty without appropriate support.(7)

Adolescents with autism are more likely to engage in inappropriate sexual behaviours, including non-consensual touching and sexual behaviour in public than their neurotypical peers.(7) Due to a combination of the lack of social understanding and the perseverative nature of some individuals with autism, behaviours may evolve into a determined pursuit, harassment, or intimidation.(4)

People with autism may have fewer social opportunities, have more significant anxiety about finding a life partner and worry that others misinterpret their behaviour.(4, 10) Community misunderstandings and misconceptions about people with autism can lead to experiences of social exclusion.(7) However, there may be a range of reasons behind the behaviour (for example, sexual behaviours viewed as 'inappropriate' may be a sign of possible underlying health issues, a need for education on consent

and privacy or experiences of violence or abuse). The behaviours may also be normal, healthy and consensual, but are perceived as inappropriate.

Sexuality and relationship support is important for people with autism to develop positive relationships and lead healthy lives, reducing the risk of violence, abuse and exploitation.

### **Access to quality reproductive and sexual health services**

Women with autism have poorer reproductive and sexual health outcomes.(11) The economic cost of reproductive and sexual health includes the impact of late STI treatment and fertility complications. Failing to provide adequate and appropriate services, leaving behaviours of concern unaddressed, can have flow-on effects that can be more expensive in the longer term - for example, the cost of providing justice responses or acute healthcare.

### **(h. iii) The adequacy and efficacy of the NDIS for autistic people, including the ability of the NDIS to support autistic people with complex needs**

To promote systemic change for the disability sector, including NDIS support for people with autism and complex needs, the *Disability Needs Assessment* found there is a need to enhance professional learning, provide sexuality policies in disability organisations and guidance from the NDIA on sexuality support.(12)

### **Enhance professional learning**

Workers have an important role in providing information and support to empower people with autism to have healthy relationships, understand consent, and make decisions for themselves. To achieve this, there is a need to provide disability support workers, parents and carers and healthcare professionals with training to understand the holistic nature of sexuality and the importance of reproductive and sexual healthcare for people with autism.

Since the rollout of the NDIS, there has been a marked drop in course enrolments by the disability sector. Our 2019 *Disability Needs Assessment* identified that the majority (69.2%) of respondents had not completed formal sexuality and disability training.(12)

We commend the NDIS Commission's current development of an *NDIS Workforce Capability Framework*, which aims to improve the overall quality and effectiveness of services to provide better outcomes for NDIS participants. The NDIS Commission should include the provision and referral of sexuality and relationship support within the *NDIS Workforce Capability Framework* as a 'core capability' for all service providers.

### **Provide sexuality policies in disability organisations**

There is also a need for disability organisations to develop sexuality policies. Our 2019 *Disability Needs Assessment*, found only 25% of respondents agreed or strongly agreed that their organisation had clear guidelines on how to provide sexuality support.(12) Sexuality policies are needed to provide clarity about proactive strategies to support good reproductive and sexual health, preventing the need for reactive management behavioural and health issues.

### **Guidance from the NDIA on sexuality support**

There is a need to improve disability sector organisational policies and guidance about the kinds of services that can be obtained as part of sexuality and relationship support via NDIA policy. Proactive consideration of sexuality, relationships and sexual health can be achieved through consideration of sexuality, relationships and sexual health goals in NDIS participant plans. Puberty support and education requirements should be included as a standard component of all NDIS plans.

In the current NDIS environment, sexuality support can only be provided towards an identified goal. However, participants are often unaware that reproductive and sexual health can be incorporated into their goals. Inconsistent advice provided to participants and their families about the availability of funds for sexuality support means people with autism are missing out on support. Information about

reproductive and sexual healthcare and sexuality and relationship support services accessible through NDIS funding is needed.

There is also a need to allow more flexibility for plan changes to enable the timely provision of sexuality and relationship support. This flexibility is both reasonable and necessary to minimise gaps in sexuality support, particularly during key periods of transition (e.g. puberty) or where behaviours of concern are emerging.

### **(i) The development of a National Autism Strategy and its interaction with the next phase of the National Disability Strategy**

People with autism can benefit from support across the lifespan. However, much of the current focus within autism policy and service provision is on supporting children. For example, the *National Disability Strategy 2010-2020* refers only to providing early intervention to children with ASD.(13) Young people transitioning through puberty, adults and older adults should also be provided with appropriate support and services. This is particularly relevant as people may be diagnosed with autism later in life.

Policies should acknowledge the vulnerability experienced by people with autism to promote access comprehensive sexuality education, sexuality and relationship support and reproductive and sexual health services when they need them, across the lifespan and regardless of their background or circumstances. People with autism and their representative groups should be engaged in developing policy, particularly given the diversity of experiences across the autism spectrum.

### **(j) The adequacy of funding for research into autism**

To date, globally, most research about sexuality and relationships with people with autism has been undertaken with parents or caregivers, rather than based on direct reports from people with autism.(14) The limited research that has been conducted on sexuality with people with autism has begun to dispel views that people with autism are asexual or disinterested in relationships. However, research has also found that inappropriate sexual behaviours can be the result of a lack of access to education combined with sensory preferences associated with autism.(15)

Future research is needed to better understand the experiences of people, including those from diverse groups such as culturally diverse populations and people who are sexuality and/or gender diverse. Research into people with autism's access to, and engagement with, reproductive and sexual healthcare services is also needed. Increased funding for research with people with autism is required.

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