

## **Submission of Family Planning NSW**

### **Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability: The Experiences of Culturally and Linguistically Diverse People with Disability: Issues Paper**

June 2021

Family Planning NSW welcomes the opportunity to make a submission to the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability regarding the 'The experiences of culturally and linguistically diverse people with disability' issues paper. We have a strong history of contributing to the Royal Commission with the aim to improve the reproductive and sexual health experiences and outcomes of people with disability.

## 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 operating for over 95 years, working with communities across NSW, including in regional, rural and remote areas.

We have significant experience in the provision of reproductive and sexual health information and services. We provide more than 31,000 clinical occasions of service to clients annually, information and health promotion activities to communities, and best practice education and training in reproductive and sexual health for health professionals, educators, disability support workers and welfare professionals.

Family Planning NSW has been delivering targeted services to people with disability and those who support them for over 35 years, including clinical services, health promotion and professional education. As a registered provider under the National Disability Insurance Scheme (NDIS), we provide sexuality and relationship support and education via psychology services to people with disability, face to face through our Newcastle clinic, and via telehealth state wide.

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 disability are much more likely to experience violence, particularly sexual violence, compared to people without disability.(1)

## Recommendations

Family Planning NSW recommends to:

1. invest in research and comprehensive health-related data to better understand the experiences of people with disability from CALD backgrounds
2. increase access to cultural responsiveness and accessibility training for health professionals, disability community workers to expand the accessibility of appropriate and inclusive reproductive and sexual health services for people with disability from CALD backgrounds
3. ensure reproductive and sexual health information is available in multiple languages and accessible formats, including plain language and Easy Read
4. implement a national comprehensive sexuality education framework that is inclusive of people with disability
5. provide funding for teachers, disability support workers, educators parents and carers to attend training in providing comprehensive sexuality education to people with disability
6. include reproductive and sexual health data collection as part of the National Disability Data Asset

## Key points

Family Planning NSW is committed to promoting the reproductive and sexual health and rights of people with disability. We are guided by the United Nations Convention on the Rights of Persons with Disabilities(1) and work collaboratively with people with disability and their support people to ensure that our work meets the needs of our consumers.

Family Planning NSW is concerned that people with disability from culturally and linguistically diverse (CALD) backgrounds face increased barriers to accessing reproductive and sexual health services, and as such are not provided every opportunity to experience optimal reproductive and sexual health. Additionally, we are concerned that these barriers may result in increased risk of people disability from CALD backgrounds experiencing violence, abuse, neglect and exploitation. In developing this submission, we consulted with an advocate and CALD person with disability to look at their experience and inform our submission.

### How is disability understood or described in your family, culture, community or language?

“There is a lot of stigma attached to being from a different culture. There is also a lot of stigma in ethnic groups around having a disability. Things are slowly changing as people are getting more aware... this has a lot to do with social media campaigns and awareness in the media. They are providing more information about people with disability.

Disability is not well understood in CALD cultures. There can be experiences of shame. You have to have a very thick skin and strong family bond.”

- Nidhi, advocate and CALD person with disability

### 1. Investment in research and commitment to community consultations is needed

There is very little literature about the reproductive and sexual health needs of people with disability from a CALD background in Australia, and no known literature that deals specifically investigates reproductive and sexual health issues and needs. The National Ethnic Disability Alliance estimates that people from CALD backgrounds with disability comprise one in 20 Australians, or approximately one million people.(2)

Most health and wellbeing related research about people with disability, particularly regarding experiences of sexuality and relationships, has been undertaken with parents or caregivers, rather than directly with people with disability themselves. It is essential that people with disability are engaged in research to ensure their voice is heard.

Alongside a lack of literature, there is a significant lack of comprehensive data on the quality of health care received by people with disability and their experiences engaging with the health care system.(3) We are concerned that Australian state-based and national registers for reproductive and sexual health data, including the National Cervical Screening Register and the NSW Sexually Transmissible Infections Surveillance Reports, do not have disability or CALD disaggregated data.

Investment in research and comprehensive health-related data is needed to better understand the experiences of people with disability from CALD backgrounds, including those from diverse groups such as people who are sexuality and/or gender diverse. Further research is needed to identify health priorities, gaps in current service provision and develop evidence-based programs and services to ensure they have full access to reproductive and sexual health services, information and education. Additionally, Family Planning NSW strongly recommend consistent and meaningful engagement and consultation with people with disability from CALD backgrounds to ensure their needs are reflected in policy and programming.

Family Planning NSW is pleased to learn that the Government is currently developing and piloting the National Disability Data Asset which aims to provide a more complete picture of the life experiences of

people with disability. We encourage the Government to include reproductive and sexual health data collection as part of this data set to better understand the reproductive and sexual health experiences and outcomes of people with disability.

**Recommendation one:** invest in research and comprehensive health-related data to better understand the experiences of people with disability from CALD backgrounds.

**Recommendation two:** include reproductive and sexual health data collection as part of the National Disability Data Asset.

## 2. Access to reproductive and sexual health services

It is well established that people with disability face multiple barriers to timely, affordable and accessible health care and associated services.(4) Research shows that the rate of access to disability services, including health referral services, by people with disability from CALD backgrounds is highly disproportionate to their presence in society.(5)

CALD communities, including members of the community who have a disability, are often impacted by cultural, personal and structural barriers including language constraints, health literacy levels, socioeconomic status, confidentiality concerns, unfamiliarity with the health system, and education surrounding reproductive and sexual health service access.(6) Experiences of stigma surrounding disability as well as the taboo subject of reproductive and sexual health in some CALD communities further isolate people with disability. Cultural and language barriers are most difficult to overcome, with health services often having limited access to face-to-face interpreters and in-language resources. Further, there is a lack of available CALD specialised reproductive and sexual health services and accessible information for people with disability.

People with disability from CALD backgrounds, and their support workers, parents and carers, are often unaware of the need to engage in regular reproductive and sexual health screening services due to misconceptions around the sexuality and health related needs of people with disability. Women with intellectual disability specifically face a lack of education and access to support in relation to menstrual management, contraception and cervical screening, and as such anecdotally access reproductive and sexual health services at a significantly lower rate than the wider population.

### Access to reproductive and sexual health services

“People don’t know there are health checks and screening you need to do each year for their health. People don’t know that.

Health services often aren’t accessible. Without training, they [disability support workers and health professionals] don’t know how to support us, people with disability to access health services.”

- Nidhi, advocate and CALD person with disability

Health information, programs and services must be accessible to all people and take health literacy levels into consideration during planning and development. Examples of accessible health information include resources that are written using Easy Read principles for people with intellectual disability and in multiple languages. Further, health and education services should ensure they have access to trained and qualified interpreters to assist people with disability from CALD backgrounds prior to, during and after their clinical appointments.

Health professionals, disability and community workers require training to develop skills in providing effective and culturally safe reproductive and sexual health care and support to people with disability from CALD backgrounds. Funded training and up to date information and resources should be provided to health

professionals, disability and community workers on an ongoing basis to ensure they are able to safely and sensitively support the reproductive and sexual health needs of people with disability from CALD backgrounds.

**Recommendation three:** increase access to cultural responsiveness and accessibility training for health professionals, disability and community workers to expand the accessibility of appropriate and inclusive reproductive and sexual health services for people with disability from CALD backgrounds.

**Recommendation four:** ensure reproductive and sexual health information is available in multiple languages and accessible formats, including plain language and Easy Read.

### 3. Access to comprehensive sexuality education for people with disability, their parents and carers

It is crucial that people receive high-quality and evidence-based comprehensive sexuality education. In Australia, comprehensive sexuality education is not currently provided consistently across the country. A global review conducted by United Nations Education, Scientific and Cultural Organization found comprehensive sexuality education has a positive impact on safer sexual behaviour, delays sexual debut, and can reduce unintended pregnancy and STIs.(7) The review found that “failing to provide marginalized 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”.(7)

Comprehensive sexuality education is particularly important for people with disability. Often, people with disability are not able to engage with accessible comprehensive sexuality education that is tailored to their needs. Additionally, some cultural barriers may prevent people with disability from CALD backgrounds from accessing such education. Teachers require the skills and confidence to provide comprehensive sexuality education that is evidence-based, accessible and inclusive. It is commonly presumed that such education is unnecessary for students and people with disability, particularly those with higher support needs or additional language requirements.

#### What are the experiences of children and young people from CALD backgrounds?

“There is some, but not a lot, of information out there for CALD children and young people with disability, especially around the areas of puberty which can be sensitive. There is no training for puberty or sexual health.

People from CALD communities don’t talk about it and there are very little open discussions. All people need this information. Information needs to be made available with translation...interpreter services and in multiple languages so everyone can use it.”

- Nidhi, advocate and CALD person with disability

Family Planning NSW has been supporting parents and carers of people with disability over the last decade by running face to face workshops, forums and online webinars that help to equip them with knowledge, skills and information to support the reproductive and sexual development of people with disability. A recent evaluation of these workshops indicated that parents and carers had significant improvement in their knowledge and confidence in providing sexuality support, inclusive of comprehensive sexuality education, to people with disability.

Family Planning NSW also delivers training to teachers, disability support workers and other health professionals to build their capacity to support people with disability in reproductive and sexual health. A recent needs assessment investigating the current landscape of sexuality support provision from the perspective of disability sector workers and Disability People’s Organisations across NSW, found that the majority of respondents had not completed any formal sexuality and disability training and did not know such training existed or were not supported by their organisation to complete the training.(8)

**Recommendation five:** implement a national comprehensive sexuality education framework that is inclusive of people with disability.

**Recommendation six:** provide funding for teachers, disability support workers, educators parents and carers to attend training in providing comprehensive sexuality education to people with disability.

## Conclusion

The reproductive and sexual health experiences of people with disability from CALD backgrounds must be considered as an essential element of policy and programming. The government must provide opportunity for research into this specialised area, so that we can better understand their needs and create services and societies are that culturally safe, inclusive and accessible. Further, meaningful and genuine consultation with people with disability from CALD backgrounds should be prioritised to ensure that policy and programming is inclusive of their needs and represents their priorities. It is essential that the reproductive and sexual health and rights of people disability, including those from CALD backgrounds, are recognised and advanced and that services, information and education are provided in accessible formats to ensure inclusivity and accessibility.

### What are the hopes for the future of CALD people with disability?

“Multiculturalism is unique and differences and diversity is valued. I hope that people think culture is unique and their disabilities are unique which improves our society. Inclusion has to come from everyone. Inclusion comes from people, people have to accept people as people and not discriminate based on culture or disability.”

- Nidhi, advocate and CALD person with disability

## References

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4. People With Disability Australia. Healthcare. Strawberry Hills: People with Disability Australia; 2020.
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8. Family Planning NSW. Disability Needs Assessment. Unpublished report. Ashfield: Family Planning NSW; 2019.