love & kisses

TAKING ACTION

on the reproductive and sexual health and rights of

people with disability

2014-2018

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family planning nsw
Reproductive & Sexual Health

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Aboriginal Disability Network

ACON

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House With No Steps, Wollongong

Intellectual Disability Rights Service

NSW Council for Intellectual Disability

People with Disability Australia Inc

Self Advocacy Sydney Inc

Touching Base Inc

Waverley Community Living Program

Acronyms

ADHC	NSW Department of Family and Community Services, Ageing Disability and Home Care
CALD	Culturally and linguistically diverse
GPs	General Practitioners
HIV	Human immunodeficiency virus
HPV	Human papilloma virus
LARCs	Long acting reversible contraceptives
LGBTI	Lesbian, gay, bisexual, transgender, intersex
LHDs	Local Health Districts
NDIS	National Disability Insurance Scheme
NEDA	National Ethnic Disability Alliance
NSW DEC	NSW Department of Education and Communities
PDHPE	Personal development, health and physical education
STIs	Sexually transmissible infections
UNCRPD	United Nations Convention on the Rights of Persons with Disabilities

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ABOUT FAMILY PLANNING NSW

Family Planning NSW is the leading provider of reproductive and sexual health services in NSW. We are experts on contraception, pregnancy options, sexually transmissible infections (STIs), sexuality and sexual function, menstruation, menopause, common gynaecological and vaginal problems, cervical cancer screening, breast awareness and men's sexual health.

We have five fixed clinics in NSW (Ashfield, Fairfield, Penrith, the Hunter region and Dubbo) and use innovative partnerships to deliver services in other key locations across the state with around 28,000 client visits annually. We also operate a free, confidential telephone and email information and referral service, connecting our expertise to communities across NSW.

We provide information and health promotion activities, as well as education and training for doctors, nurses, teachers and other health, education and welfare professionals.

As an independent, not-for-profit organisation, we recognise that every body in every family should have access to high quality clinical services and information, and we provide a safe place for people to talk about their most intimate and personal issues.

Our services are targeted to communities, including people from culturally and linguistically diverse and Aboriginal and Torres Strait Islander backgrounds, refugees, people with disability, young people, people from rural and remote communities and lesbian, gay, bisexual, transexual and intersex (LGBTI) people.

Family Planning NSW is working to assist poor and disadvantaged communities in the Asia Pacific region to access comprehensive reproductive and sexual health services. We collaborate with organisations at national and international levels to strengthen the ability of local health providers to deliver high quality family planning services.

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.

Our work is evidence-based, and shaped by our research through the Family Planning NSW Sydney Centre for Reproductive and Sexual Health Research, our published clinical practice handbooks on reproductive and sexual health,[1-2] our nationally recognised data and evaluation unit and validated through our own extensive clinical and education practice.

OUR WORK WITH PEOPLE WITH DISABILITY

We provide education and training for teachers, disability workers, clinicians, family members and carers about sexuality for people with intellectual disability. Our clinics are a safe place for people with disability to talk about intimate and sometimes challenging issues and to access confidential reproductive and sexual healthcare. We also produce innovative easy to read resources to support our professional and community education activities.

Our work aligns with the priorities of people with a disability and organisations that support them.

Family Planning NSW has been delivering targeted services to people with disability for more than 35 years.

INTRODUCTION

Recent initiatives by the Federal and NSW Governments have laid the foundations for change in the way people with disability access services and support, with a person with disability encouraged to exercise choice and control over the planning and delivery of support services.

These initiatives include Australia's ratification of the *United Nations Convention on the Rights of Persons with Disabilities*,[3] the Productivity Commission report *Disability Care and Support (Productive Commission Inquiry Report July 2011)*,[4] The *National Disability Strategy 2010-2020*[5] and the associated *NSW Implementation Plan 2012-2014*,[6] the *NSW Service Framework to Improve the Health Care of People with Intellectual Disability (July 2012)*,[7] changes to the *NSW Disability Services Act*,[8] the *Review of the Disability Standards for Education 2005 (reviewed 2012)*[9], and the *NSW Health Framework for Women's Health 2013.*[10]

The Senate Community Affairs Legislative Committee inquiry into the *Involuntary and coerced sterilisation of people with disabilities in Australia*[11] (report released July 2013) provided stark evidence on why the reproductive and sexual health of women and men with disability must be prioritised by governments.

We welcome these initiatives and congratulate the NSW and Federal Governments for opening dialogue and debate on how we improve, in very real terms, the lives of people with disability.

It is in this context that Family Planning NSW has prepared this document to guide the Federal and NSW Governments on the policy, legislative, regulatory, service delivery and funding decisions that need to be made to ensure people with disability have equity of access to optimal reproductive and sexual health services and support. Reproductive and sexual health must be included in disability, health and education policy, the disability and health research agenda, clinical service provision, data collection and workforce development strategies.

The United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) states that impairment is a long-term condition and may be physical, mental, intellectual or sensory. A disability is the result of the interaction between people who have impairments and the attitudinal and environmental barriers that hinder their full and effective participation in society on an equal basis with others.

The UNCRPD promotes a shift in understanding that recognises the limitations created by disability not as a problem of a person but as a problem of barriers created by society. It also recognises that people with disability are holders of the same rights as everyone else including sexual and reproductive health rights.[3]

Family Planning NSW adopts the UNCRPD definition of disability. We recognise that people with disability are a diverse group. The intention of this document is to cover a range of reproductive and sexual health issues that many people with disability experience.

executive summary

The subject of sexuality is generally a silent, ignored and invisible aspect of the lives of people with disability. It's a subject that governments have largely failed to acknowledge and in doing so make the necessary changes that ensure people with disability have the opportunity to participate in loving, safe and fulfilling sexual relationships.

The responsibility for implementing change does not only rest with governments; change is required within schools and educational institutions, disability service providers, reproductive and sexual health services and public and private clinical settings.

Change is also required in the way the general community sees a person with disability. If the sexuality of a person with disability remains silent, ignored and invisible then society will continue to deny the reproductive and sexual health needs and aspirations of people with disability.

As the leading provider of reproductive and sexual health services in NSW, our role is to give voice to the rights of people with disability to make choices about their reproductive and sexual health.

Our role is to highlight the areas where action is required because we believe the sexuality of a person with disability should be celebrated not ignored.

We also believe it is our responsibility to advocate for the reproductive and sexual health rights of people with disability because we know that people with disability and women in particular, are more at risk of sexual assault and exploitation than people without disability.

It is incumbent on governments to protect the most vulnerable people in our communities by giving them the skills and information they need to live safe, happy and fulfilling sexual lives.

We now have an unprecedented opportunity for change and to acknowledge that people with disability have the same rights as people without disability in:

- reproductive health and fertility
- gender equality
- parenting
- sexual health and sexuality
- sexual behaviour and sexual orientation
- sexual safety and protective behaviours
- relationship support
- sexual function
- sexual health and relationships education

Where to from here?

- Family Planning NSW will provide regular updates on our advocacy activities through our quarterly disability e-news
- We will also release an annual summary outlining the progress being made on the areas of action outlined in this document
- For more information and updates **www.fpnsw.org.au/loveandkissestakingaction**
- To join us in taking action, sign up for our disability e-news **www.fpnsw.org.au/subscribe**

AREAS FOR ACTION

National and state policies and strategies are developed to be inclusive of people with disability

(UNCRPD Articles 16, 21, 23, 24 and 25)

- Policies and strategies are aligned with the UN Convention on the Rights of Persons with Disabilities in relation to reproductive and sexual health

Improved access to optimal reproductive and sexual health services for people with disability

(UNCRPD Articles 23 and 25)

- Consistent data is collected to inform policy and service planning for people with disability in areas including:
  - access to reproductive and sexual health services
  - screening rates for STIs, cervical cancer and breast cancer
  - prevalence of STIs including HIV
  - prevalence of HPV related cancers and breast cancer
  - prevalence of contraception use, unintended pregnancy and termination of pregnancy
- Reproductive and sexual health services are accessible to people with disability. This includes not only access to the physical environments, but also through skilled clinical, allied health and administration staff
- Reproductive and sexual health services are sufficiently funded to provide long consultations and ongoing care for people with disability
- Education and resources about menstruation and menopause are readily available to women with disability and their families
- Education and resources about puberty are readily available to young people with disability
- Easy to read information on contraception (including LARCs) and fertility options for women with disability is developed and distributed to Medicare Locals, GPs, Local Health Districts (LHDs) and relevant service providers as outlined in the NSW Health Framework for Women's Health 2013[10]
- Clinicians and other health providers are supplied with information on referral pathways to specialised services such as Family Planning NSW
- Cervical and breast cancer screening are promoted to women with disability as outlined in the NSW Health Framework for Women's Health 2013[10]
- Provide better education and develop referral pathways for clinicians partnering with women with disability to ensure their health needs are met as outlined in the NSW Health Framework for Women's Health 2013[10]
- The reproductive and sexual health of men with disability is included in national and state men's health policy and implementation plans
- The Federal and NSW Governments implement recommendations[5] of the Community Affairs Reference Committee report into the Involuntary or Coerced Sterilisation of People with Disabilities in Australia:[11]
  - The committee abhors the suggestion that sterilisation ever be used as a means of managing the pregnancy risks associated with sexual abuse and strongly recommends that this must never be a factor in approval of sterilisation[7]
- The Federal and NSW Governments implement recommendations 9-18 and 20-28 of the Community Affairs Reference Committee report

into the Involuntary or Coerced Sterilisation of People with Disabilities in Australia[11]

Choice, independence and inclusion should be supported to allow a person with disability to achieve optimal reproductive and sexual health

(UNCRPD Articles 16, 21, 23, 24 and 25)

- Access to sexuality education, sex services and reproductive and sexual health services are included in the NDIS and person centred planning
- People with disability have access to comprehensive sexuality related education during all life stages, customised to meet their individual needs
- The NSW and Federal Governments implement recommendation 4 of the Community Affairs References Committee report into the Involuntary or Coerced Sterilisation of People with Disabilities in Australia:[11]
  - that in the development of participant plans (particularly for participants approaching puberty and in their teens), the participant work with any person assisting them with plan development, and with the NDIS, to cover the need for understanding of sexuality and sexual relationships, support for relationships and sex education that meets the participants' needs, and covers appropriate support for menstrual management for girls and women with disabilities
- The NSW Government facilitates greater awareness of the reproductive and sexual health services available to disability service providers. This should be provided at a regional level and where physical services are not available, reproductive and sexual health information, referral websites, phone and email services (such as Family Planning NSW Talkline) should be promoted to disability service providers
- Professional development is supported for disability workers to assist in managing reproductive and sexual health issues for people with disability
- Funding is provided for Family Planning NSW to deliver workshops in rural and regional areas of NSW that are customised to develop skills in communication, increased knowledge of the sexual rights of people with disability and knowledge of referral pathways. The workshops will be offered to both disability and sexual health workers to bring the two workforces together
- The NSW and Federal Governments support Recommendation 3 and 6 of the Community Affairs References Committee report into the Involuntary or Coerced Sterilisation of People with Disabilities in Australia:[11]
  - that medical workforce training include training with respect to the ethical and legal aspects of informed consent, substitute and supported decision-making and fertility control.
  - that, for a person with disability who has the capacity to consent, or to consent where provided with appropriate decision-making support, sterilisation should be banned unless undertaken with that consent
- An education and training program is developed to support clinicians and health workers in the private and public health settings to understand and appropriately support decision-making by people with disability, particularly as it relates to their reproductive and sexual health. The program should be supported by resources and other appropriate communication tools
- Sexual orientation, gender identity and intersex status are acknowledged in all disability policy,

government statements and documentation, strategies and service delivery frameworks

- People with disability from CALD backgrounds are acknowledged in all disability policy, government statements and documentation, strategies and service delivery frameworks
- People with disability from Aboriginal and Torres Strait Islander backgrounds are acknowledged in all disability policy, government statements and documentation, strategies and service delivery frameworks
- National and state policies related to reproductive and sexual health, including the NSW HIV strategy, make explicit reference to the needs of people with intellectual disability. It should be clear that people with disability are represented in all priority populations groups[51]
- Easy to read information and education resources on reproductive and sexual health are translated into key languages to support people with disability and their families and carers from CALD backgrounds
- Research is undertaken to inform reproductive and sexual health service delivery for people with disability from Aboriginal and Torres Strait Islander backgrounds
- Pathways are developed for LGBTI people with disability to access services provided by the LGBTI service sector
- Specific programs are developed to address the social isolation experienced by LGBTI people with disability. This includes opportunities for socialising
- Easy to read information and education resources on sexual orientation, gender identity and intersex status are developed and distributed

Students with disability should be provided with age appropriate, optimal sexuality and relationship education in all NSW schools

(UNCRPD Articles 21 and 24)

- That the NSW Government implement recommendation 1 of the Community Affairs References Committee report into the Involuntary or Coerced Sterilisation of People with Disabilities in Australia:[11]
  - that in education programmes relating to disability and in sex education and family planning information targeted to the disability sector, education about relationships and sexuality for people with disability should be prioritised, with an emphasis on the reasonable and normal aspirations of people with disability regarding their sexuality and relationships
- The NSW DEC conducts a review of the Life Skills Module with an emphasis on introducing best practice sexual health and relationships education for students with disability including:
  - The extent to which students with intellectual disability are being taught sexual health and relationships education
  - Identifying the barriers to providing effective sexual health and relationships education and the impact on student learning outcomes
- Pre-service teacher training is enhanced to include delivery of the Life Skills Module
- Special education teachers are provided with training to increase their skills in delivering the Life Skills Module
- The NSW DEC develops a Life Skills Module for primary school students with disability and provides guidelines and training for teachers to ensure its effective implementation

- Funding is provided for Family Planning NSW to develop easy to read information and resources to support sexual health and relationships education in schools
- The NSW Ministry of Health and the NSW DEC support the development of interactive technology for smart boards and tablets to reflect contemporary teaching practices for sexual health and relationships education for students with disability
- The NSW DEC provides clear guidelines to teachers about their role and responsibility to provide sexual health and relationships education in primary and secondary years and support teachers in the delivery of the module to students with disability
- The NSW DEC actively and openly encourages and supports parents and carers to participate in the teaching of sexual health and relationships education in schools

Parents and carers of people with disability should be provided with education and appropriate resources to positively support the sexuality and relationships education of the child in their care

(UNCRPD Articles 21 and 23)

- The NSW DEC develops appropriate resources and information, specifically addressing issues relating to sexuality and disability, for parents and carers to engage in the sexuality education of their child
- The NSW DEC provides funding support for parents and carers to attend sexuality education courses which align with the teaching of sexual health and relationships education in schools
- ADHC supports organisations such as Family Planning NSW in the coordination of education forums (including in rural and remote areas of NSW) as a positive way to convey accurate information on reproductive and sexual health issues. The forums also give parents and carers a safe place to share their experiences and concerns with other parents
- Information is provided to parents and carers through government agencies and disability service providers about where to access support around sexuality and reproductive health education

Workforce development strategies should be implemented for clinicians and health and disability workers to provide a safe place for people with disability to access optimal reproductive and sexual health services

(UNCRPD Articles 16, 21 and 25)

- Family Planning NSW receives funding to:
  - expand its professional development programme for GPs, other clinical professionals, disability workers and HIV and sexual health workers
  - develop on-line and easy to read resources to support clinicians and other clinical professionals, disability workers and HIV and sexual health workers
- The ADHC Human Relationships and Sexuality Policy is reviewed and updated and training provided to staff to ensure its effective implementation
- Disability service providers are required to implement organisational policies to protect the rights of people with disability in regard to reproductive and sexual health

- Mandatory training in reproductive and sexual health is introduced for disability workers
- The Community Service Training Package CHC08 is reviewed by the Community Services and Health Industry Skills Council to include reproductive and sexual health as a core unit of competency for qualifications in disability, youth work and other relevant sectors
- Undergraduate clinicians are trained to better understand the rights of people with disability and develop skills to uphold these rights
- Medicare Locals and LHDs promote education to GPs and other health workers about the reproductive and sexual health needs of people with disability
- That the NSW and Federal Governments implement recommendations 2 and 19 of the Community Affairs References Committee report into the Involuntary or Coerced Sterilisation of People with Disabilities in Australia:[11]
  - that medical workforce training with respect to sexual and reproductive health includes content on supporting sexual relationships and sexual and reproductive health needs for people with disability
  - that courts and tribunals develop information packs and questionnaires to provide guidance for medical experts in sterilisation cases. The information packs should specify the factors that courts and tribunals consider under the relevant legislation, and should also note issues that the courts and tribunals are not authorised to consider such as outdated and paternalistic attitudes to disability, eugenic arguments or assessments of the person's current or hypothetical capacity to care for children. Questionnaires should seek the medical expert's advice about the procedures that could usefully be adopted in the particular case to facilitate both a robust medical assessment and the person's participation in the proceedings
- The NSW Government and Medicare Locals facilitate greater awareness of the reproductive and sexual health services available to support people with disability. This should be provided at a regional level and where physical services are not available, reproductive and sexual health information and referral websites, and phone and email services (such as Family Planning NSW Talkline) should be promoted to disability service providers
- The NSW Government includes data collection for people with disability in the reporting requirements for government contracts for all reproductive and sexual health

a human rights framework

Photographer: Belinda Mason

1. a human rights framework

In 2008, Australia ratified the *UN Convention on the Rights of Persons with Disabilities* (UNCRPD)[3] including the Optional Protocol which gives the UN the power to inquire about a nation's reported breach of the Convention. The UNCRPD is a powerful statement of what Australia and the world believe are the fundamental rights of people with disability, and goes some way towards reducing discrimination. Family Planning NSW acknowledges Australia's commitment to the UNCRPD and believes the Convention provides fundamental principles for all decision-making by the Federal and NSW Governments.

We draw attention in particular to Articles 16, 21, 23, 24 and 25 which specifically address rights around reproductive and sexual health including:

Article 16: Freedom from exploitation, violence and abuse

- Taking all appropriate legislative, administrative, social, educational and other measures to protect persons with disabilities, both within and outside the home, from all forms of exploitation, violence and abuse, including their gender-based aspects

Article 21: Freedom of expression and opinion, and access to information

- Providing information intended for the general public to persons with disability in accessible formats and technologies appropriate to different kinds of disabilities in a timely manner and without additional cost

Article 23: Respect for home and the family

- Eliminating discrimination for people with disability in all matters relating to marriage, family, parenthood and relationships
- The right of people with disability to decide freely and responsibly on the number and spacing of their children and to have access to age appropriate information, reproductive and family planning education, and the means necessary to enable them to exercise these rights
- The right of people with disability to retain their fertility on an equal basis with others

Article 24: Education

- Recognising the right of people with disability to education without discrimination and on the basis of equal opportunity ensuring an inclusive education system at all levels and life long learning
- Enabling people with disability to learn life and social development skills to facilitate their full and equal participation in education and as members of the community

Article 25: Health

- Providing people with disability with the same range, quality and standard of free or affordable health care and programmes as provided to other persons, including the area of sexual and reproductive health

People with disability face a wide range of myths from society about their sexuality. These myths serve to discount the sexuality of people with disability and justify the silence, discrimination, violence and inaction around their reproductive and sexual rights as outlined in the UNCRPD.

> *"People with disability have a right to have sexual relationships together and go out together and enjoy life"*
>
> *Louise, Love & Kisses/the DVD*

AREAS FOR ACTION

National and state policies and strategies are developed to be inclusive of people with disability

(UNCRPD Articles 16, 21, 23, 24 and 25)

- Policies and strategies are aligned with the UN Convention on the Rights of Persons with Disabilities in relation to reproductive and sexual health

Myths about the sexuality of people with disability:

- people with disability are asexual[24-32]
- women with disability who are single are celibate[24]
- all people with disability are heterosexual[24]
- only independently functioning people can handle relationships[24]
- women with disability cannot be mothers[24]
- people with disability will have children with disability and this should be prevented
- women with disability should be grateful for any sexual activity they have[24]
- people with disability are not sexually active and do not have sufficient life expectancy to warrant preventative screening [33]
- youth and beauty are essential to sexuality[24]
- men with disability cannot control their sexuality – they may be dangerous[34]
- no one would sexually assault a person with disability
- educating people with disability about sexuality will only make them want to have sex

These myths reflect negative attitudes and stereotypes about the sexuality and abilities of people with disability.

The facts are:

- people with a disability have the right to choose whether they are sexual or not, whether they have sexual relationships with people of the same or different sex and whether they will have children
- people with disability have the right to live free from exploitation, abuse and violence
- education and information are essential if people with disability are to make healthy decisions, form positive relationships and reduce vulnerability to abuse

reproductive and sexual health

2. reproductive and sexual health

2.1 Contraception and family planning

Clinicians can find it difficult to talk to a woman with disability about contraceptive options[25] while parents and carers can find the situation confronting and are unsure of where to turn for assistance.

The Federal Government's Community Affairs References Committee inquiry into the involuntary or coerced sterilisation of people with disabilities in Australia[11] demonstrated why governments need to provide support to people with disability to access clinical pathways and appropriate information to allow for informed decision-making about reproductive and sexual health. While Family Planning NSW's submission to the inquiry related primarily to the reproductive and sexual health of people with disability, we support the Committee's recommendations to improve and strengthen the legal framework as it relates to the sterilisation of people with disability.

Women with disability are often denied the information, education and support they need to make informed decisions about contraception, family planning and parenthood. Men with disability also require an understanding of contraception for themselves and their female partners, and education about being a father if this is an aspiration they have.

For all women choosing and planning for pregnancy and parenthood is important. For women with disability such choice accompanied by support and planning is often denied to them due to:

- discrimination - women with disability who make this choice can be discriminated against by people who assume a person with disability is non-sexual, not capable of having a relationship or parenting a child
- clinicians and support workers being ill equipped to talk to a woman with disability about having a child and therefore unable or unwilling to assist with pregnancy and parenting information.[35] General Practitioners (GPs), nurses and other health providers require information, resources and training to support people with disability in the practice setting
- the risk of exploitation and abuse in relationships. The power imbalance in the relationships of women with intellectual disability often contributes to their lack of control over their fertility

Family Planning NSW supports the rights of people with disability to choose to have children and families. Women with disability should have access to the same contraceptive options as women without disability. Women with disability should have access to information on all available contraceptives, including long acting reversible contraceptives (LARCs), which are safe, highly effective and don't rely on daily compliance and can assist in managing menstruation.

Photographer: Belinda Mason

Family Planning NSW supports the rights of people with disability to have children and families.

2.2 Puberty

Puberty is a time of great change in a child's life. Most people with disability progress through the same reproductive and sexual development as people without disability. This is normal and healthy. Children have a right to information and education about the changes that happen during puberty. Easy to read information should be readily available to help parents, support workers and clinicians to educate, inform and support children with intellectual disability approaching or going through the physical and emotional changes that occur with puberty.

Girls have a right to learn how to be as independent as possible around managing menstruation and most girls have the ability to manage their periods independently or with minimal supervision. Education should start prior to menarche so that a girl is prepared for these changes when they occur. An open and positive approach is essential to assisting the girl to feel that menstruation is normal and part of growing up. Clinicians should be equipped to support the girl and her family and be able to offer up to date and practical advice.

Sterilisation is not acceptable as a means of stopping menstruation unless it's medically required for the health of a woman.

2.3 Menopause

Menopause has been a stage of reproductive development that has been neglected for women with disability. For some this may be a time of physical and emotional change. Women should receive education and support to understand this time in their lives and if necessary have medical support. Too often behavioural and emotional changes are attributed by others as just being part of the disability.

Women with disability of all ages should be able to access the same clinical care for gynaecological issues as women without disability. Women with disability need to feel able to discuss gynaecological problems with their clinicians. Clinicians need to feel comfortable communicating with women with disability to enquire about symptoms that need further investigations.

The Community Affairs Reference Committee[11] concluded there is a shocking lack of resources available for people with disability to assist them with:

- choices about relationships and sexuality
- sexual and reproductive health, including contraception and sterilisation
- menstrual management

Many of the attitudes reported to the committee and experienced by people with disabilities regarding reproductive and sexual health have contributed towards a perception by some that irreversible sterilisation is the best solution to a range of needs and issues, particularly for women with disabilities.[11]

2.4 Prevention of HPV related and breast cancers

People with disability have the same risk factors for human papilloma virus (HPV) related cancers, such as cervical and anal cancer, as people without disability. They have the right to accessible information and education about ways to reduce their risk of cancer, including information about vaccination and screening programs. Adolescents with disability should be included in HPV vaccination programs at schools and adults need to be supported to access screening programs.

GPs, teachers, carers and parents may need information to raise their awareness of the benefits of such programs for people with disability. This will need to address some of the reasons why support is not offered including negative attitudes that stereotype people with disability as asexual.

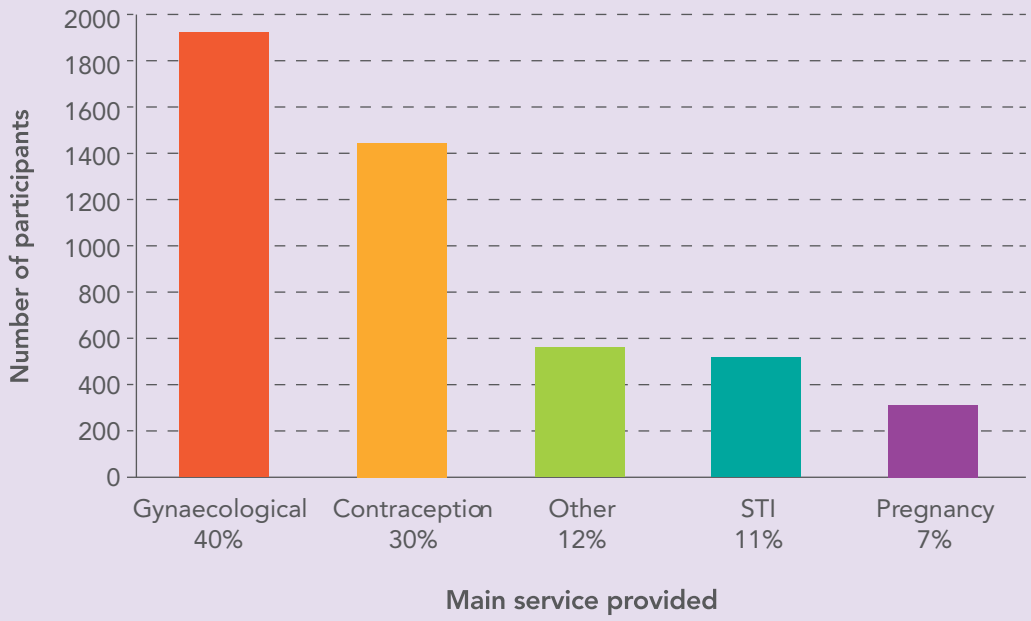
A 2004 literature review by the Cancer Institute NSW[36] found that women with disability remain under screened for cervical and breast cancer, but the actual prevalence of under screening in NSW is unknown due to a lack of data. The review found three main causes for reduced screening rates amongst women with disability:

- knowledge and attitudes of general practitioners
- knowledge of women with disability and their preventative health needs
- accessibility to general practitioners' premises and examination equipment

Reproductive health issues have often been ignored in women with disabilities because of the myth that they are asexual beings and therefore not in need of screening services.[25, 28, 31]

Since 2010, 1,638 people who reported having disability accessed our clinical services making just over 4,800 visits. They visited Family Planning NSW clinics for gynaecological, contraception, sexually transmissible infections, pregnancy and other reproductive and sexual health issues.

Figure 1. Main services provided to Family Planning NSW clients who reported having disability 2010-2012



2.5 Sexually transmissible infections including HIV

People with intellectual disability are exposed to all the same risk factors for STIs and HIV as people without disability however their utilisation of reproductive and sexual health services is anecdotally reported to be low. The actual number of people accessing services is unknown due to a lack of service level data.[37]

Data and research regarding the reproductive and sexual health of men with disability is particularly limited. Current sexual health and men's health policies fail to acknowledge the needs of men with disability.

> *The lack of data keeps people with intellectual disability invisible to government decision-makers and support services and means health promotion and education strategies to support people with disability are not prioritised.*

Those people who are particularly at risk include:[37]

- Young people leaving school and not linked to disability services
- People who are living in boarding houses, correctional facilities and other institutional settings
- People who are homeless
- People who have not been diagnosed with a disability but are struggling with understanding or are not receiving preventative health messages, or developing skills in negotiating safe sex
- People who are experiencing sexual violence or exploitation
- People accessing sex on premises or beats who are not understanding health messages in these settings

> *"And the precautions we have to take because sometimes things unintentionally happen and that's not good. The contamination of sexually related diseases or infections is the worst and no one ever wants it to happen but unfortunately if either side of it doesn't do the right thing, the right time, well that's when the disaster can easily and at first unknowingly happen which ends up causing great sadness."*
>
> *Malcolm, Love & Kisses/the DVD*

2.6 Sexual assault

People with disability have the right to live free from abuse and exploitation. However they are significantly more likely to be sexually assaulted at all ages than people without disability.[12]

Women with developmental and intellectual disability are most at risk of being sexually assaulted.[13-16] It is unlikely that a person with disability who experiences sexual assault will only have one experience of this in their life time.[13,17-18]

Many people with disability will have experienced repeated incidences of sexual assault by the time they are 18 years of age.[19]

When people with disability do report sexual assault they are typically not believed and or the systemic response to the assault is not appropriately dealt with. [20-23]

To address these issues there is a need for:

- Coordination of disability, sexual assault, advocacy and police services
- Organisational culture and policies that prioritises violence prevention
- Education of disability workers to recognise and respond to sexual assault[56]

- The poor accessing of services is exacerbated by a pervasive stereotype that people with disability are not sexually active
- Many people working in the disability sector do not know about, or believe there is a need for reproductive and sexual health services for their clients
- Carers and family members are uncomfortable in supporting the person with disability to access services
- There is a lack of accessible information and education about STI and HIV transmission

People with Disability Australia is aware that many sexual health and family planning organisations across Australia lack the necessary funding to provide comprehensive, targeted, gender and age specific services to people with disability.[11]

AREAS FOR ACTION

Improved access to optimal reproductive and sexual health services for people with disability

(UNCRPD Articles 23 and 25)

- Consistent data is collected to inform policy and service planning for people with disability in areas including;
  - access to reproductive and sexual health services
  - screening rates for STIs, cervical cancer and breast cancer
  - prevalence of STIs including HIV
  - prevalence of HPV related cancers and breast cancer
  - prevalence of contraception use, unintended pregnancy and termination of pregnancy
- Reproductive and sexual health services are accessible to people with disability. This includes not only access to the physical environments, but also through skilled clinical, allied health and administration staff
- Reproductive and sexual health services are sufficiently funded to provide long consultations and ongoing care for people with disability
- Education and resources about menstruation and menopause are readily available to women with disability and their families
- Education and resources about puberty is readily available to young people with disability
- Easy to read information on contraception (including LARCs) and fertility options for women with disability is developed and distributed to Medicare Locals, GPs, Local Health Districts (LHDs) and relevant service providers as outlined in the NSW Health Framework for Women's Health 2013[10]
- Clinicians and other health providers are supplied with information on referral pathways to specialised services such as Family Planning NSW
- Cervical cancer and breast screening are promoted to women with disability as outlined in the NSW Health Framework for Women's Health 2013[10]
- Provide better education and develop referral pathways for clinicians partnering with women with disability to ensure their health needs are met as outlined in the NSW Health Framework for Women's Health 2013[10]
- The reproductive and sexual health of men with disability is included in national and state men's health policy and implementation plans
- The Federal and NSW Governments implement recommendations[5] of the Community Affairs Reference Committee report into the Involuntary or Coerced Sterilisation of People with Disabilities in Australia:[11]
  - The committee abhors the suggestion that sterilisation ever be used as a means of managing the pregnancy risks associated with sexual abuse and strongly recommends that this must never be a factor in approval of sterilisation[7]
- The Federal and NSW Governments implement recommendations 9-18 and 20-28 of the Community Affairs Reference Committee report into the Involuntary or Coerced Sterilisation of People with Disabilities in Australia[11]

choice, independence and inclusion

Photographer: Belinda Mason

3. choice, independence and inclusion

People with disability want the same choices as other people and the opportunity to live independent lives. They have the right to make their own decisions about their relationships and reproductive and sexual health. However, people with disability may require different levels of support in order to experience the same rights as others.

There are limited opportunities for a person with disability to access education, health and support services for reproductive and sexual health, particularly as it relates to sexual health, sexuality, sexual behaviour, sexual orientation, sexual safety and protective behaviours, relationship support and sexual function. Lack of support in these areas has resulted in people with disability being denied their reproductive and sexual rights and left vulnerable to exploitation and abuse.

3.1 Relationships and inclusion

People with disability have the same desire for relationships and intimacy as anyone else. However, the societal myths that prevail about the sexuality of people with disability often present significant barriers to the development of a range of different types of relationships.

People with disability often have limited access to opportunities to socialise, to make friends and to form intimate relationships.[38]

> *"Sexuality and sexual expression is the last bastion in lots of ways. People with disability want connection and intimacy and touch"*
>
> *Denise, Touching Base Inc.*

For some people with disability their social opportunities may be so limited that their relationships are restricted to family members and care givers. For others their opportunities to socialise may be confined to programs for people with disability with few prospects to meet people without disability and to participate in community life. Disability support services lack formalised programs that provide education about relationships and provide practical support in developing healthy relationships including intimate relationships. This further entrenches the social exclusion and isolation faced by many people with disability and is a factor in contributing to the higher rates of mental illness experienced by people with disability.[39]

> *"You see intimacy and you try; you struggle with it yourself."*
>
> *Tony, Love & Kisses/the DVD*

For people with disability to experience full lives and be included in community life they need to be actively supported to meet people, form friendships, learn relationship skills and develop intimate relationships. Programs and services aimed at improving the reproductive and sexual health of people with disability therefore need to address these issues in the context of peoples' sexual lives and relationships. Safe and supportive environments are required so people with disabiility can explore their sexuality safely without being at risk of exploitation.

3.2 Person centred approach to disability support

Family Planning NSW supports the establishment of person centred plans for people with disability. We believe person centred plans should provide the opportunity for people with disability to access reproductive and sexual health services including education, resources, and clinical and health promotion services.

The plans should not be focused only on aspects of a person's life that have traditionally been supported by government. A person centred system will only be effective if Federal and State legislation and service delivery frameworks allow for a broader view of what makes a person whole.

The NDIS provide the vehicle for improving the way people with disability access reproductive and sexual health services

The first stage of the NDIS in NSW will be focused on the Hunter region, providing an opportunity for the NSW Government to include and support access to reproductive and sexual health services for people with disability. Family Planning NSW's Hunter clinic is well placed to provide this service and work in partnership with NSW Department of Family and Community Services Ageing Disability and Home Care (ADHC) to deliver reproductive and sexual health services.

People with disability should have a range of opportunities to explore and express their sexuality on an equal basis with others, including access to the sex industry. We support the work of Touching Base Incorporated, an organisation which provides information, referral and training to facilitate access to sex work services for people with disability. We believe these services should not be excluded from the services able to be accessed through NDIS or related schemes, nor should the person who chooses these services be discouraged, discriminated against, disadvantaged or questioned about their ability to manage their plan.

"I'm scared to have sex because I'm not ready to have it. And I know some issues about having sex but I'm just not ready for it."

Danielle, Love & Kisses/the DVD

"It's just good to have Ron close because he's a good companion and good boyfriend. He's good to have sex with."

Louise, Love & Kisses/the DVD

…when we provide training we are building the capacity of disability workers, parents and carers to then provide education to people with disability. At Family Planning NSW we currently do not have funding or the services to provide that direct education to people with a disability.[11]

3.3 Decision-making

Family Planning NSW supports the rights of people with disability to make their own decisions about their reproductive and sexual health.

Most people with disability are able to make their own decisions about their reproductive and sexual health when given the appropriate level of support and/or information.

Some people with disability (including those under the age of 18 years) will need support to improve their capacity to make decisions. They may not previously have received adequate education about reproductive and sexual health to enable them to have the knowledge and skills to make decisions and they will require support from clinicians, parents and support workers to develop their knowledge.

Access to education about sexual health, sexuality, safety and relationships is a necessary and lifelong need for people with disability. Many people, especially those who are older, have not had any education that can assist them with making decisions in these areas. Strategies for providing this education need to be customised to the individual requirements of the person. Generally, one-off education is not sufficient. Rather it should be a planned programme that builds knowledge and life skills relevant to the person's circumstances and life stage.

Both disability – specific and mainstream services need to provide education and information to the people they support. However currently there is a serious gap in services that are able to meet this need.

To effectively and legally assist a person with disability the clinician, health or disability worker must have the skills and expertise to talk about reproductive and sexual health issues including understanding how informed consent relates to a person with disability making a decision about their reproductive and sexual health.

Family Planning NSW has developed a range of unique resources to meet the learning needs of people with intellectual disability to increase their capacity to make informed decisions about reproductive and sexual health issues. Our publications are easy to read with clear illustrations to reinforce key messages. All our resources are focus tested in partnership with people with intellectual disability.

- *Sex Safe and Fun* – an easy English resource aimed at providing positive safe sex messages to people with intellectual disability. The resource can be used by inexperienced educators including parents and carers, and includes topics such as good and bad sex, safe sex, and the law
- *All About Sex* - a series of 19 easy to read fact sheets covering a range of reproductive and sexual health issues including puberty, relationships, pregnancy and birth, menopause and sexual assault
- *Love & Kisses/the DVD* - developed in partnership with actors with disability from the Altogether Drama Group. The DVD has four educational scenes covering safe sex, dating, marriage and socially appropriate sexual behaviour as well as interviews with the drama group members about relationships, love and sex. The DVD shows people with disability as sexual beings with dreams and aspirations just like anyone else
- *About Masturbation* (for males and females) are social stories for people with intellectual disability to explain the differences between public and private (appropriate) masturbation
- *Clinical Guidelines: Supporting people with a disability* is a best practice framework for clinicians working in reproductive and sexual health services

If a person lacks capacity to make a particular decision then a substitute decision-maker, such as a parent or spouse, is able in some situations to make that decision on their behalf. Clinicians and carers need to understand when a substitute decision-maker is necessary and who that can be. This should only happen if everything has been done to increase the person's ability to make that decision, they have been told what is going to happen and they have shown no opposition. Despite their inability to make a decision, a person still retains the right to access the same services and interventions as other people. This requires that those people who are supporting them are well informed about the choices available.

All decisions should be reviewed regularly with the person, and steps should continue to be taken to build their ability to make decisions, particularly as they get older.

3.4 The many faces of diversity

People with disability are often stereotyped or seen as one homogenous group, which means they are not viewed as unique individuals least of all sexual beings who have a right to the same diversity of sexual expression as everyone else. For people with disability to be fully included in community life requires action which acknowledges their diversity including the provision of services which are sensitive and flexible to meet a range of different needs. Family Planning NSW values and celebrates diversity in our work with people with disability.

Sexual orientation, gender identity and intersex status

Lesbian, gay, bisexual, transgender and intersex (LGBTI) people with disability in Australia face multiple exclusions and discriminations in the expression and enjoyment of their sexuality.[40] Throughout history both LGBTI people and people with disability have had their reproductive and sexual rights ignored and denied.[41] In recent years increased recognition of LGBTI people and people with disability in human rights legislation[3,42] and Australian anti-discrimination laws[43-45] have led to improved opportunities however progress is slow. The health and wellbeing of LGBTI people and people with disability continues to be disproportionately poorer than the general population and heterosexism, homophobia and transphobia dominate as leading causes of social exclusion and discrimination.[46-49] Limitations in the available data demonstrate the invisibility of people with disability in LGBTI research and the lack of consideration of LGBTI in disability research. There are currently no Australian health education resources that provide comprehensive information about sexual orientation, gender identity and intersex status for people with intellectual disability. A person with disability should not be discriminated against based on their sexual orientation, gender identity and intersex status and this should be stated in all published material related to government policy, legislation, strategy and health service design and delivery.

Cultural diversity

There is very little literature about the health needs of people with intellectual disability from a culturally and linguistically diverse (CALD) background in Australia and no known literature that deals specifically with reproductive and sexual health issues. The National Ethnic Disability Alliance (NEDA), in its 2010 report on people with disability in Australia, estimates that people from CALD backgrounds with disability comprise one in 20 Australians or approximately one million people.[50] The report does not distinguish between physical and intellectual disability, sensory or other impairments.

Typically people with disability from CALD backgrounds are disadvantaged and marginalised. They remain hidden from mainstream services relying on informal community and family supports.[44] They typically present to disability service providers as a result of a crisis and therefore their reproductive and sexual health needs are a low priority in comparison to the housing, financial, legal and acute health needs that often stimulate first contact with service providers.

The stigmatising effect of disability as well as the taboo subject of sexuality in some CALD communities further isolates people with disability.

In 2011, Family Planning NSW interviewed four disability peak bodies about the reproductive and sexual health needs of people with intellectual disability from CALD backgrounds. They reported that the service system in general did not have capacity to deal appropriately with sexuality and disability nor with the degree of cultural competency that is required to meet the needs of people with disability from CALD backgrounds. The inequality faced by people with disability from CALD backgrounds is exacerbated by a lack of referral pathways and translated information and resources.

Aboriginal and Torres Strait Islander people

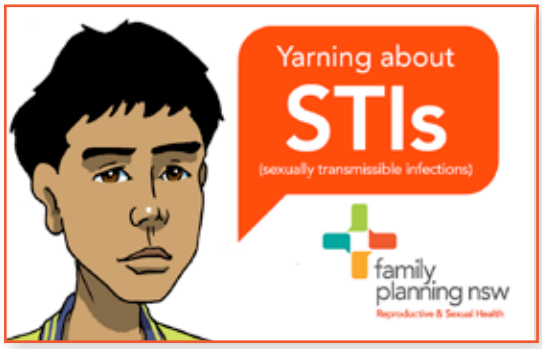
The prevalence of disability in Aboriginal and Torres Strait Islander communities is approximately twice that of the non-Indigenous population, and they experience poorer reproductive and sexual health outcomes.[55]

The discrimination and isolation experienced by Aboriginal and Torres Strait Islander people with disability is compounded by support services which are poorly targeted and located.

The culturally appropriate disability support services that do exist are not equipped or resourced to support Aboriginal and Torres Strait Islander people with disability to access specialised reproductive and sexual health services. This has resulted in a landscape where the vast majority of Aboriginal and Torres Strait Islander people with disability do not have their needs met in any significant way.[55] There is limited understanding about the most effective service delivery models that would best meet the needs of this group of people. Models that could be explored include:

- outreach services to encourage increased inclusiveness
- training Aboriginal Liaison workers to educate communities to support Aboriginal people with disability to make their own choices

In NSW the situation is particularly acute in rural and remote areas.



Family Planning NSW has developed a suite of Aboriginal specific resources to provide culturally appropriate reproductive and sexual health information to Aboriginal and Torres Strait Islander communities

AREAS FOR ACTION

Choice, independence and inclusion should be supported to allow a person with disability to achieve optimal reproductive and sexual health

(UNCRPD Articles 16, 21, 23, 24 and 25)

- Access to sexuality education, sex services and reproductive and sexual health services are included in the NDIS and person centred planning
- People with disability have access to comprehensive sexuality related education during all life stages, customised to meet their individual needs
- The NSW and Federal Governments implement recommendation 4 of the Community Affairs References Committee report into the Involuntary or Coerced Sterilisation of People with Disabilities in Australia:[11]
  - that in the development of participant plans (particularly for participants approaching puberty and in their teens), the participant work with any person assisting them with plan development, and with the NDIS, to cover the need for understanding of sexuality and sexual relationships, support for relationships and sex education that meets the participants' needs, and covers appropriate support for menstrual management for girls and women with disabilities
- The NSW Government facilitates greater awareness of the reproductive and sexual health services available to disability service providers. This should be provided at a regional level and where physical services are not available, reproductive and sexual health information, referral websites, phone and email services (such as Family Planning NSW Talkline) should be promoted to disability service providers
- Professional development is supported for disability workers to assist in managing reproductive and sexual health issues for people with disability
- Funding is provided for Family Planning NSW to deliver workshops in rural and regional areas of NSW that are customised to develop skills in communication, increased knowledge of the sexual rights of people with disability and knowledge of referral pathways. The workshops will be offered to both disability and sexual health workers to bring the two workforces together
- The NSW and Federal Governments support Recommendation 3 and 6 of the Community Affairs References Committee report into the Involuntary or Coerced Sterilisation of People with Disabilities in Australia:[11]
  - that medical workforce training include training with respect to the ethical and legal aspects of informed consent, substitute and supported decision-making and fertility control.
  - that, for a person with disability who has the capacity to consent, or to consent where provided with appropriate decision-making support, sterilisation should be banned unless undertaken with that consent
- An education and training program is developed to support clinicians and health workers in the private and public health settings to understand and appropriately support decision-making by people with disability, particularly as it relates to their reproductive and sexual health. The programme should be supported by resources and other appropriate communication tools[8]
- Sexual orientation, gender identity and intersex status are acknowledged in all disability policy, government statements and documentation, strategies and service delivery frameworks

- People with disability from CALD backgrounds are acknowledged in all disability policy, government statements and documentation, strategies and service delivery frameworks
- People with disability from Aboriginal and Torres Strait Islander backgrounds are acknowledged in all disability policy, government statements and documentation, strategies and service delivery frameworks
- National and state policies related to reproductive and sexual health, including the NSW HIV strategy, make explicit reference to the needs of people with intellectual disability. It should be clear that people with disability are represented in all priority populations groups[51]
- Easy to read information and education resources on reproductive and sexual health are translated into key languages to support people with disability and their families and carers from CALD backgrounds
- Research is undertaken to inform reproductive and sexual health service delivery for people with disability from Aboriginal and Torres Strait Islander backgrounds
- Pathways are developed for LGBTI people with disability to access services provided by the LGBTI service sector
- Specific programs are developed to address the social isolation experienced by LGBTI people with disability. This includes opportunities for socialising
- Easy to read information and education resources on sexual orientation, gender identity and intersex status are developed and distributed

sexual health and relationships education in schools

4. sexual health and relationships education in schools

People with disability should receive information and education from childhood to adulthood about topics such as their bodies, sexual health, safety, sexuality, diversity, feelings, self-esteem and relationships. Sexual health and relationships education should start from a young age so people with disability gain the knowledge and skills they need to make informed decisions and keep themselves safe.

It's recognised that while the NSW Department of Education and Communities (DEC) has a significant role in providing age-appropriate sexual health and relationships education to young people with disability, the NSW Ministry of Health, ADHC, disability service providers, parents and carers, GPs and other health professionals also play an important role in the provision of education and information.

4.1 Secondary school education

Sexual health and relationships education in NSW secondary schools is taught through the Personal Development, Health and Physical Education (PDHPE) syllabus which includes a *Life Skills Module* specifically designed to meet the learning needs of students with intellectual disability. The module is ambiguous and open to interpretation and therefore students' access to comprehensive sexuality education that meets their individual learning needs is dependent on the ability and interest of individual teachers and schools. There is also little accountability for schools or teachers to meet these learning outcomes.

> *"Well it was from school when I did PE and we spoke about having sex. And Liz showed me a lot of sex as well in books and on video tapes and I'm learning quite a lot of sex terms for what it means."*
>
> *Danielle, Love & Kisses/the DVD*

With little guidance and without a clear requirement for the provision of sexual health and relationships education, teachers are concerned that by talking about sex to students with intellectual disability that will be a risk. Competing demands in the PDHPE syllabus Life Skills Module (e.g. drug education, nutrition, and exercise) means that teachers do not have time to adequately teach students about important sexual health topics.

The Life Skills Module for secondary students does not promote a positive and holistic approach to sexual health and relationships education. Teachers need a framework that will help them recognise education as being more than just addressing risks or perceived problems such as menstruation, inappropriate touching and unwanted sex. The importance of building students' understanding of body ownership, capacity to consent, and skills in making friends and negotiating relationships need to be stated explicitly within the syllabus. The module should reflect a whole of school approach to providing sexual health and relationships education, which involves parents and carers who can reinforce consistent messages and provide safe learning in environments outside of school hours.

> *"There's lots of barriers in delivering it [sexual health and relationships education]…but with this certainly one of the key things would be to make sure that information they then took on would be directed appropriately."*
>
> *Special school teacher,*
> *Family Planning NSW teacher consultation*

4.2 Primary school education

Unlike secondary school, primary schools do not have a specific disability module for teaching sexuality and relationships education. The PDHPE syllabus for primary aged students is generic and provides no guidance around the specific sexuality learning needs of children with intellectual disability including protective behaviours, puberty, friendships and feelings. It is important that appropriate sexual health and relationships education starts at a young age to prepare and increase the person with disability's capacity to make healthy decisions and develop protective behaviours. Teachers need a framework that provides specific guidance in teaching sexual health and relationships education to students with intellectual disability.

4.3 Training for teachers

Special education teachers often lack training in sexual health and relationships education, while PDHPE teachers often have no training in working with young people with disability. With limited training opportunities which specifically address sexual health and relationships education for students with disability, many teachers are left feeling unsupported and inadequately prepared to teach this important part of the syllabus.[52]

Findings of the May 2012 Family Planning NSW consultation with teachers involved in delivering the Life Skills Module:

- Teachers generally do not feel confident or adequately trained to deliver sexual health and relationships education, specifically information on sexual activity (e.g. masturbation) and safe sex (e.g condom use) to older students
- Female teachers may feel uncomfortable providing sexual health and relationships education to male students with disability
- Teachers (specifically PDHPE teachers) are unsure of resources that support the delivery of content and where to access those resources. They don't feel confident in adapting mainstream resources
- Most special education teachers are qualified in either early childhood or primary education and have not been trained in high school level sexual health and relationships education
- Smart boards and tablets are used for teaching students with disability, however online or digital resources (e.g. Apps) are not available for teaching sexual health and relationships education
- Teachers believe there is a significant role for parents in sexuality and relationships education for students with disability but are unsure how to engage with them

AREAS FOR ACTION

Students with disability should be provided with age appropriate, optimal sexuality and relationship education in all NSW schools

(UNCRPD Articles 21 and 24)

- That the NSW Government implement recommendation 1 of the Community Affairs References Committee report into the Involuntary or Coerced Sterilisation of People with Disabilities in Australia:[11]
  - that in education programs relating to disability and in sex education and family planning information targeted to the disability sector, education about relationships and sexuality for people with disability should be prioritised, with an emphasis on the reasonable and normal aspirations of people with disability regarding their sexuality and relationships
- The NSW DEC conducts a review of the Life Skills Module with an emphasis on introducing best practice sexual health and relationships education for students with disability including:
  - The extent to which students with intellectual disability are being taught sexual health and relationships education
  - Identifying the barriers to providing effective sexual health and relationships education and the impact on student learning outcomes
- Pre-service teacher training is enhanced to include delivery of the Life Skills Module
- Special education teachers are provided with training to increase their skills in delivering the Life Skills Module
- The NSW DEC develops a Life Skills Module for primary school students with disability and provides guidelines and training for teachers to ensure its effective implementation
- Funding is provided for Family Planning NSW to develop easy to read information and resources to support sexual health and relationships education in schools
- The NSW Ministry of Health and the NSW DEC support the development of interactive technology for smart boards and tablets to reflect contemporary teaching practices for sexual health and relationships education for students with disability
- The NSW DEC provides clear guidelines to teachers about their role and responsibility to provide sexual health and relationships education in primary and secondary years and support teachers in the delivery of the module to students with disability
- The NSW DEC actively and openly encourages and supports parents and carers to participate in the teaching of sexual health and relationships education in schools

education and support for parents and carers

5. education and support for parents and carers

Parents and carers play a critical role in educating young people with disability about issues including puberty, relationships and safe sexual behaviour. Parents and carers are generally supportive of sexuality education for young people but can feel lost and isolated when dealing with the issues.[53] On one hand parents and carers want their child to grow up and live rich and fulfilling lives including the right to intimate relationships and sexual expression. On the other hand they can be overwhelmed by the potential risks and negative consequences associated with sexuality and an innate need to protect their child. Some parents and carers can find it challenging to recognise the physical development of the young person believing for instance that the child will never have a sexual relationship or become a parent.

> *"One of the things that I have noticed with parents is that there are several times during their child's development where they experience loss; and the whole discussion around sexuality is another moment where they experience loss. I've had several parents just break down when they realise that their children are unlikely to be parents themselves."*
>
> *Primary special school teacher,*
> *Family Planning NSW teacher consultation*

A child's sexuality education comes from a range of sources, including parents, school and friends. A child with a disability can face a number of barriers when it comes to receiving sexuality education:

- Some people hold the misconception that people with a disability shouldn't have fulfilling sex lives or have access to sexuality education, in case it 'gives them ideas'
- Children with an intellectual disability who do receive sexuality education can find it confusing, unless the information is delivered in a way they understand
- Children with an intellectual disability might have trouble with social rules e.g. identifying the difference between private and public behaviours
- Sexuality education is usually general in nature and doesn't cover sexual issues that might be associated with certain disabilities. For example, children who are blind from birth need to tell the difference between males and females by touch. It's helpful for these students to have anatomically correct 'life dolls' when learning about sexuality and relationships
- Parents might not have the information they need to help their child deal with puberty and changes to their bodies

The lack of resources, both for people with disabilities and their carers, was a recurring theme in submissions to the committee.[11]

Our work with families and carers of people with disability is across the lifespan. We equip families and carers with knowledge, skills and information to assist them support the reproductive and sexual development of the person under their care. We do this in a way that takes into account the potential vulnerability of the person with disability and their right to personal safety throughout their life.

Family Planning NSW delivers parent forums across NSW that address many of the concerns and information needs of parents and carers and increases their confidence in providing support to the person under their care. Topics include relationships and dating, puberty, decision-making and safety, sexual health and safe sex, and contraception.

"I just wanted say thanks for coming up to Dubbo to share your wealth of information to our small group of carers. I got a lot out of the day and although it may be boring listening to our stories, it's a great opportunity for us to talk and share. Having my daughter with Down Syndrome means for me having to step outside my comfort zone on so many more occasions than I ever thought I would do in my life. Thank you for assisting us to learn and to look at things from all different angles."

Parent, Family Planning NSW parent forum

Since 2010, more than 1,200 people have participated in Family Planning NSW disability related community education activities.

"I went to the forum and it was the most highly relevant course I have done in years. My daughter has mild/ moderate intellectual delay and it really helped me feel positive and excited about her future. It made me realise she can be a sexual being as long as she is educated in good versus bad relationships and private and public body parts and places. The presenters were obviously very experienced in their fields and handled the course delicately and promoted thought provoking discussion"

Parent, Family Planning NSW parent forum

AREAS FOR ACTION

Parents and carers of people with disability should be provided with education and appropriate resources to positively support the sexuality and relationships education of the child in their care

(UNCRPD Articles 21 and 23)

- The NSW DEC develops appropriate resources and information, specifically addressing issues relating to sexuality and disability, for parents and carers to engage in the sexuality education of their child
- The NSW DEC provides funding support for parents and carers to attend sexuality education courses which align with the teaching of sexual health and relationships education in schools
- ADHC supports organisations such as Family Planning NSW in the coordination of education forums (including in rural and remote areas of NSW) as a positive way to convey accurate information on reproductive and sexual health issues. The forums also give parents and carers a safe place to share their experiences and concerns with other parents
- Information is provided to parents and carers through government agencies and disability service providers about where to access support around sexuality and reproductive health education

training and skill development for clinicians, health professionals and disability workers

6. training and skill development for clinicians, health professionals and disability workers

6.1 Capacity building of health professionals and disability service providers

All organisations that support people with disability should be required to have policies that present a human rights and positive approach to sexuality and relationships. To ensure that the policies are implemented, there needs to be a monitoring process, overseen by the relevant agency, that requires staff are trained and supported to apply the policies.

Currently many disability service providers in NSW lack detailed and appropriate policies that guide their work in the area of reproductive and sexual health. Where policy exists, such as the ADHC Policy on Human Relationships and Sexuality, staff lack guidelines and training on implementation to ensure a positive impact on the lives of people with disability.

Training of disability workers and government staff is currently ad hoc and inadequate. To be successful, a workforce development programme should build:

- Skills in communication and provide information on the availability of reproductive and sexual health education low literacy resources
- Awareness of human rights and inclusive service delivery for people with disability
- Skills in assessing and building the capacity of people with disability to consent and make decisions
- Knowledge about the disability and reproductive and sexual health service system including referral pathways and support services such as Family Planning NSW Talkline

Information should be provided to disability workers in accommodation, transition to work and other programmes about topics such as puberty, menstruation, contraception, pregnancy and parenting, sexual health and healthy relationships to support their front line work with people with disability.

Heatlh workers and disability workers can support people in a more comprehensive way if they have clear, coordinated referral pathways to education providers and clinical services.

> *"Disability organisations want people to have a good life but based on what they think is a good life for people with disability. Supporting sexual expression for people with intellectual disability looks pretty radical to service providers. They grapple with their role to support people with intellectual disability in their sexuality."*
>
> *Policy officer, Family Planning NSW Disability and HIV consultation*

Family Planning NSW has an extensive reproductive and sexual health Disability Resource Collection, with publications and digital resources available for purchase or for loan to carers as well as service providers. The Family Planning NSW Library has around 340 members, almost half of which are disability workers.

Since 2010, close to 900 disability workers have attended the Family Planning NSW education and training courses.

6.2 Building clinical competence and confidence

To improve the reproductive and sexual health of people with disability there must be a focus on building the capacity of people who work within health services. Professional development must occur not just within disability service organisations, but also sexual health clinics, general practices and the hospital setting.

While all health professionals want to provide quality health and support services for people with disability, the majority of clinicians and health workers do not receive training or skill development to assist them in supporting and educating people with intellectual disability on reproductive and sexual health issues.

Information and resources should be provided to health professionals about topics such as puberty, menstruation, contraception, pregnancy and parenting, sexual health and healthy relationships to support front line work with people with disability. Health education resources are important in supporting appropriate and meaningful communication with people with intellectual disability about reproductive and sexual health. These resources should include easy to read and picture-based materials and should also take into account people with disability from non-English speaking backgrounds.

Family Planning NSW conducts highly successful education programmes in reproductive and sexual health for GPs which include a comprehensive review of contraceptive options with a case-study approach to the management of reproductive and sexual health issues for people with disability. This includes a review of the law in relation to fertility control and skills-based training in communication and supported decision-making.

It is an oversight on the part of a general practitioner to assume that a woman with a disability is unable to be sexually active due to her level of physical impairment.[51] Furthermore, to assume that a woman has never been sexually active on the basis of her disability ignores the fact that women with disability are more likely to have experienced sexual abuse than the general female population.[54]

AREAS FOR ACTION

Workforce development strategies should be implemented for clinicians and health and disability workers to provide a safe place for people with disability to access optimal reproductive and sexual health services

(UNCRPD Articles 16, 21 and 25)

- Family Planning NSW receives funding to:
  - expand its professional development programme for GPs, other clinical professionals, disability workers and HIV and sexual health workers
  - develop on-line and easy to read resources to support clinicians and other clinical professionals, disability workers and HIV and sexual health workers
- The ADHC Human Relationships and Sexuality Policy is reviewed and updated and training provided to staff to ensure its effective implementation
- Disability service providers are required to implement organisational policies to protect the rights of people with disability in regard to reproductive and sexual health
- Mandatory training in reproductive and sexual health is introduced for disability workers
- The Community Service Training Package CHC08 is reviewed by the Community Services and Health Industry Skills Council to include reproductive and sexual health as a core unit of competency for qualifications in disability, youth work and other relevant sectors
- Undergraduate clinicians are trained to better understand the rights of people with disability and develop skills to uphold these rights
- Medicare Locals and LHDs promote education to GPs and other health workers about the reproductive and sexual health needs of people with disability
- That the NSW and Federal Governments implement recommendations 2 and 19 of the Community Affairs References Committee report into the Involuntary or Coerced Sterilisation of People with Disabilities in Australia:[11]
  - that medical workforce training with respect to sexual and reproductive health includes content on supporting sexual relationships and sexual and reproductive health needs for people with disability
  - that courts and tribunals develop information packs and questionnaires to provide guidance for medical experts in sterilisation cases. The information packs should specify the factors that courts and tribunals consider under the relevant legislation, and should also note issues that the courts and tribunals are not authorised to consider such as outdated and paternalistic attitudes to disability, eugenic arguments or assessments of the person's current or hypothetical capacity to care for children. Questionnaires should seek the medical expert's advice about the procedures that could usefully be adopted in the particular case to facilitate both a robust medical assessment and the person's participation in the proceedings
- The NSW Government and Medicare Locals facilitate greater awareness of the reproductive and sexual health services available to support people with disability. This should be provided at a regional level and where physical services are not available, reproductive and sexual health information and referral websites, and phone and email services (such as Family Planning NSW Talkline) should be promoted to disability service providers
- The NSW Government includes data collection for people with disability in the reporting requirements for government contracts for all reproductive and sexual health

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