



FAMILY PLANNING NSW

2006-2009 DISABILITY STRATEGIC PLAN





FAMILY PLANNING NSW

Forward

Ann Brassil, Chief Executive Officer

It was nearly twenty years ago in 1979 when our minds were challenged and hearts inspired by the International Year of Disabled Persons (IYDP). For the first time, governments, business, professionals and community groups were encouraged to think and act in new ways concerning people living with a disability.

We were encouraged to think about the different abilities of those members of the community with physical and intellectual differences, and the ways in which they could fully participate in family and community life. Ignored or patronised at best, confined and abused at worst, IYDP marked a new start for people living with a disability and their friends and family members.

Family Planning NSW has been a part of those changes during the past two decades. There is no more complex or important area of life for all of us than our ability to make informed, responsible and safe decisions concerning our sexualities, relationships and family life.

In our specialist field of sexual and reproductive health, Family Planning NSW is a recognised leader in the provision of training, education and clinical services for people with an intellectual disability. This Plan summarises the achievements of Family Planning NSW, but more importantly it sets down our intentions and practical program measures to extend that work.

I commend the Plan and look forward to ways in which we can continue this important part of our vision of sexual and reproductive health services and rights for all.

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GLOSSARY

ACON	AIDS Council of NSW
CALD	Culturally and Linguistically Diverse
CDDS	Centre for Developmental Disability Studies
DADHC	NSW Department of Ageing Disability and Home Care
DET	NSW Department of Education and Training
HPO	Health Promotion Officer
FPNSW	Family Planning NSW
MDAA	Multicultural Disability Advocacy Association
PDHPE	Personal Development, Health and Physical Education
SHPO	Senior Health Promotion Officer
SHPU	State Health Promotion Unit
SH&FPA	Sexual Health and Family Planning Australia
SWOP	Sex Worker Outreach Project

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EXECUTIVE SUMMARY

This document describes the direction for Family Planning NSW disability services for 2006-2009. The foundations for this plan are based on the experience gained by the organisation over the past 20 years in delivering disability related services, a sound evidence base drawn from Australian and international literature and the knowledge and vision of staff across the organisation.

Family Planning NSW has a history and a reputation for being committed to advocating for the sexual and reproductive health rights of people with a disability. The plan aims to build on this and to promote a shared purposeful commitment among Family Planning NSW staff to supporting people with a disability.

All the managers consulted for this plan described their commitment to responding to the needs of people with a disability. The plan acknowledges current work for each unit in the organisation: Professional Education, Health Promotion (state and regional centres), Illawarra Centre, Clinical, Information and Referral (Healthline, website and library) and Research.

An action plan outlines strategies recommended for consideration in business plans for 2006-2009.

GOAL

Improved sexual and reproductive health of people with a disability in NSW to be achieved by Family Planning NSW by:

- Being a leading source of education, information and resources about the reproductive and sexual health needs of people with a disability for health workers, clinicians, disability workers and teachers
- Having a profile within the disability and health sectors for advocating with, and on behalf of, people with a disability in relation to their reproductive and sexual health needs
- Providing clinical services that are inclusive of people with a disability and offer a high level of expertise on disability specific reproductive and sexual health issues
- Having staff who are knowledgeable and supportive of the reproductive and sexual rights of people with a disability
- Being in long term strategic partnerships that enable a more effective response to the needs of people with a disability.

PRIORITY AREAS OF DEVELOPMENT

- Developing professional education services in partnership with NSW Department of Education and Training and NSW Department of Ageing Disability and Home Care.
- Implementing health promotion activities, including resource development, that respond to HIV and STI risk for people with intellectual disabilities and people with mental health issues – focusing on marginalised groups.

- Increasing the service delivery role of the Illawarra centre.
- Establishing a professional development clinical group to coordinate and plan ways to enhance the knowledge and skills of Family Planning NSW clinical staff, including Healthline staff.
- Increasing the professional development role of the two State Senior Health Promotion Officers (SHPO's) to support Family Planning NSW regional centres to respond to local needs for education and information.
- Building the library's disability collection.
- Building long-term partnerships with key disability and health agencies to support health promotion and advocacy work
- Engaging in research and publishing and presenting findings.

RESOURCE IMPLICATIONS

A moderate level of investment in the immediate future by increasing staffing in the State Health Promotion Unit and a future review of staffing needs in the library and the regional centres, will result in a more sustainable and effective response to the sexual and reproductive health needs of people with a disability.

INTRODUCTION

The purpose of this document is to describe a direction for Family Planning NSW in relation to disability issues in sexual and reproductive health for the years 2006 to 2009. The foundations for this plan are the experience gained by the organisation over the past 20 years in delivering disability related services, a sound evidence base drawn from Australian and international literature and the knowledge and vision of staff across the organisation.

Family Planning NSW has a history and reputation for being committed to advocating for the sexual and reproductive health rights of people with a disability. The plan aims to build on this and to promote a shared purposeful commitment among Family Planning NSW staff to supporting people with a disability.

This is important work because people with a disability are significantly disadvantaged in relation to their health care generally. In particular they face barriers in accessing sexual and reproductive health services. (Stinson 2002; Leeder 2005)

Importantly, NSW Health AIDS and Infectious Diseases Branch has identified people with an intellectual disability and people with mental health issues as being population groups vulnerable to contracting HIV and STIs. NSW Health has identified Family Planning NSW as the lead agency in addressing the needs of these groups. (NSW HIV/AIDS Strategy 2006-09)

All the managers consulted for this plan described their commitment to responding to the needs of people with a disability. The plan acknowledges current work for each unit in the organisation – Professional Education, Health Promotion (state and regional centres), Illawarra Centre, Clinical, Information and Referral (Healthline, website and library) and Research. It describes a set of goals and possible strategies for achieving those goals based on the information gained in the consultations.

This plan requires support at all levels in the organisation, identifying disability as a priority population for Family Planning NSW and inclusion of disability issues in strategic and business plans.

This document includes an Action Plan outlining strategies that are recommended for consideration in business plans over the next three years.

GOAL

Improve the sexual and reproductive health of people with a disability in NSW by:

- Being a leading source of education, information and resources about the reproductive and sexual health needs of people with a disability for health workers, clinicians, disability workers and teachers.
- Having a profile within the disability and health sectors for advocating with, and on behalf of, people with a disability in relation to their reproductive and sexual health needs.
- Providing clinical services that are inclusive of people with a disability.
- Having staff who are knowledgeable and supportive of the reproductive and sexual rights of people with a disability.
- Being in long term strategic partnerships that enable a more effective response to the needs of people with a disability.

PRINCIPLES

Family Planning NSW adopts the following principles:

- That people with a disability have a right to be actively supported to have positive, safe and healthy relationships.
- That people with a disability should have the same access to sexual and reproductive health services as other people in the community.
- That supporting these rights should be the role of everyone across the whole organisation.
- That our work is informed by the lived experiences of people with a disability.
- That Family Planning NSW should have a public profile in responding to and, where needed, advocating on behalf of the sexual and reproductive health needs of people with a disability.
- That our work needs to be based on working in partnership with others and having strong links to the disability field.

KEY ACHIEVEMENTS 2003-2006

While many staff members are involved in disability related work, in 2004 FPNSW renewed and expanded its commitment to this area of work, resulting in:

- Establishment of a centre in Wollongong to focus on disability issues in the Illawarra staffed by a part-time Senior Health Promotion Officer and supported by the State Health Promotion Unit.
- Building the capacity of the SHPU with the employment of two Senior Health Promotion Officers with expertise in the area of disability (one full time equivalent) with responsibility for developing and delivering professional education, managing health promotion activities, creating partnerships, advising on organisational direction and being a point of consultation for other staff members. An additional health promotion officer has also been supported to develop skills and knowledge in the disability area.
- Reorienting Healthline and the library to be more responsive to disability needs, especially for people in rural areas.
- Continued development and delivery of unique and highly valued accredited professional education courses.
- Surveying all NSW sexual health clinics to determine support they require to enable them to provide clinical services to people with a disability. The two highest priorities were low literacy resources and access to up-to-date information. The reorienting of Healthline was one response to this need.
- Developing and implementing of *Sex Safe and Fun* across the state. This important sexuality resource and the workshops, which trained participants in using the resource, aimed to increase capacity of service providers to talk about sexuality issues and to also increase the profile and reputation of FPNSW in the disability sector.

RESOURCE IMPLICATIONS

Many of the recommendations made in this report are based on existing resources of staff and funds. This will allow us to maintain our current response to disability issues.

Capacity within current resource levels

The organisation will implement two disability-related health promotion projects each year, conduct professional education for up to 100 service providers and manage the current level of enquiries to Healthline and the library. The Illawarra Centre will continue to receive support from the State SHPOs, however, the other regional centres will not have any increase in support.

With additional resources, Family Planning NSW has opportunities for growth. This would include building sustainable relationships with State Government agencies including NSW Department of Ageing Disability and Home Care and NSW Department of Education and Training and long term partnerships with other agencies. This will positively impact on our capacity to be effective in addressing the needs of people with a disability.

In addition, further staffing resources would allow Family Planning NSW to respond to the needs of the broader disability sector, focusing on small sub-populations of people with an intellectual disability and those with mental health issues; extend out to take up new areas of work, such as research, further health promotion and professional education activities.

Increasing capacity in disability services

Additional resources would provide the capacity of the State Health Promotion Unit over the next three years to:

- Engage more proactively with external partners to implement health promotion activities. For example, development of a relationships booklet and DVD with DADHC and DET as partners; working with DADHC and other partners for the further development of State wide sexuality guidelines and policies
- Research the need for the development of sexuality resources for people with a physical disability
- Work with the boarding house sector to identify strategies for working with people who have both an intellectual disability and a mental health issue
- Increase the support provided to our regional centres to build their capacity to respond to the needs of people with a disability
- Expand our professional education role in rural areas
- Participate in research project with universities.

PRIORITY AREAS OF DEVELOPMENT

- Developing professional education services in partnership with NSW Department of Education and Training and NSW Department of Ageing Disability and Home Care.
- Implementing health promotion activities, including resource development, that respond to HIV and STI risk for people with intellectual disabilities and people with mental health issues – focusing on marginalised groups.
- Increasing the service delivery role of the Illawarra Centre.
- Establishing a professional development clinical group to coordinate and plan ways to enhance the knowledge and skills of FPNSW clinical staff, including Healthline staff, in working with people with a disability.

- Increasing the professional development role of the two State SHPOs to support FPNSW regional centres to respond to local needs for education and information regarding disabilities.
- Building the disability library collection.
- Building long term partnerships with key disability and health agencies to support health promotion and advocacy work.
- Engaging in research and publishing and presenting findings.

CURRENT PRACTICE & FUTURE DIRECTIONS

This section reports on the literature review and consultations with senior staff and makes recommendations for future work. Each unit is considered separately: Professional Education, Health Promotion, Clinical, Illawarra Centre, Information and Referral Services, Research.

1. PROFESSIONAL EDUCATION

What the literature says

Good practice in HIV and sexual health education for people with a disability is inferred from a review of the literature from UK and Australia. Education should be:

- Conducted within a broader sexuality framework than just a biological framework. This framework should be based on human rights and social justice and include a focus on relationships, feelings and self advocacy.
- Explicitly inclusive of diversity especially same sex attraction.
- Addressing discrimination, negative values and attitudes that see people with a disability as asexual or sexually dangerous.
- Including strategies for education of parents who have significant power in the lives of people with a disability.

What the consultations revealed

- All managers prioritised the continuation of professional education as a key area of work for Family Planning NSW. Education needs to be provided to a range of people including disability workers, teachers, doctors and nurses.
- A need for the SHPU to regularly update clinical, health promotion, reception and administration staff on contemporary disability issues.
- The FPA Health Certificate in Sexual and Reproductive Health for Nurses course to include a module on disability related issues.
- The need to provide education to service providers who support people with a physical disability.
- Targeting service providers who work with marginalised young people with a disability, including people from a CALD background and those living in boarding houses.
- The need for regional centres to be able to offer education directly to people with a disability and their carers.
- It was felt that given the amount of new information GPs receive, disability is not a high priority. Family Planning NSW medical updates are not always well attended and GPs may not be interested in disability updates. There is not much scope in the SH&FPA Certificate in Reproductive and Sexual Health (Doctors Course) to offer specific training about disability. Disability training that is targeted at clinicians whose primary area of work is disability may be more successful.
- There are a few medical conferences where disability issues could be introduced: eg Women's Hormone Conference in 2007.

What Professional Education does

Family Planning NSW has a long-standing reputation as a provider of quality education for service providers in the area of HIV, reproductive and sexual health and people with an intellectual disability. We receive requests from disability and non disability NGOs and Government Departments from all over NSW. There are no other organisations in NSW that invest as much in this type of education. Our courses provide advanced standing in community service related courses from Certificate III to Advanced Diploma level.

Illawarra, Dubbo, the Warehouse and Newcastle centres as well as SHPU receive requests for short information sessions and community education. Each of the units respond to these in varying ways depending on their capacity. Fairfield and Ashfield clinics do not receive a lot of requests and refer to SHPU when they do.

Nurse Education also receives requests from nursing staff.

Medical Education has not received specific requests for disability related training from doctors. Disability issues are covered in the National SH&FPA Doctors Certificate course.

There are currently three staff members in SHPU who can deliver the two accredited courses, half-day workshops and customised training.

Information provided in Professional Education courses reflects good practice in the delivery of information about sexuality, relationships, HIV and STI prevention. Our experience in delivering sexuality education has informed educative themes based on positive messages and emphasising mutual consent, safety, fun, caring, and privacy. Reflection on the real life stories of people with a disability is an integral part of all the education we provide.

Some UK research, and our own experience, indicates that staff who work with people with a disability have shifted in their attitudes over the last 20 years to be more supportive of the sexual needs and rights of people with a disability. However they are not always equipped with the knowledge, resources and confidence to put this into practice. They also need to be supported in this work by their organisation through policy direction, education and supervision.

We therefore focus on educating service providers, both disability and mainstream, and supporting agencies in areas of policy development. We are also currently focusing on professional education courses for teachers because an updated PDHPE syllabus for years 7-10 has been introduced by NSW Department of Education and Training.

Some of the regional offices provide limited education directly to people with a disability on request.

Professional education has had a more limited role in providing professional education on the sexual and reproductive health needs of people with other disabilities such as physical disability and mental health issues. However there may be opportunities for partnerships in these areas with other agencies. The needs of people with mental health issues are not known.

What Professional Education could do

GOALS:

- To demonstrate best practice in the area of disability and sexuality education through the development, delivery and evaluation of accredited professional education courses.
- To continue to enhance the status and reach of our professional education courses through articulation into a range of tertiary institutions.
- To build partnerships that support education being offered in fields of mental health and physical disability.
- To take up opportunities for building professional development of GPs by publishing journal articles, offering targeted education and presenting at medical conferences.
- To build the capacity of mainstream services including sexual health clinics, youth health services and women's health nurses to better meet the needs of people with a disability.
- To build the professional development of nurses by including a disability module in the Family Planning NSW Certificate in Sexual and Reproductive Health (Nursing).
- To identify where to invest future professional education.

TIME FRAME	STRATEGIES
2006/07	<ul style="list-style-type: none"> • Work in partnership with NSW Department of Education and Training to build teachers' capacity to deliver the Life Skills component of the PDHPE syllabus. • Assess the educational needs of service providers who work with people with a mental health issue and determine if there is role for FP NSW in developing or delivering professional education programs. • Research feasibility DADHC as partner/funder of professional education for DADHC staff. • Provide staff forum on law, consent and guardianship. • Presentation by doctors on women with a disability and menopause at two medical conferences.
2007/08	<p>Articulate our accredited courses into at least one new educational institution.</p> <ul style="list-style-type: none"> • Assess the educational needs of service providers who work with a marginalised group of people with a disability eg boarding house staff . • Work with Nurse Education to develop a disability module for the Family Planning NSW Certificate in Sexual and Reproductive Health (Nursing) • Work in partnership with doctors to write article for medical journal. • Identify possible medical audiences to which we can deliver disability related education. • Review feasibility of employing HPO/Educators with disability expertise in each of the regional centres.
2008/09	<ul style="list-style-type: none"> • Review feasibility of possible partnerships to support education of service providers who support people with a physical disability.

2. HEALTH PROMOTION

STATE UNIT AND REGIONAL CENTRES

What the literature says about HIV and STI prevention

The literature states that people with an intellectual disability are a group that is vulnerable to high rates of STI and HIV because of risky sexual behaviours that may result from deficits in socio sexual behaviour and skills, openness to coercion or exploitation, unequal status in sexual relations, learned compliance, and lack of assertiveness. (Cambridge 1997, 1999) Some men with an intellectual disability engage in relatively higher HIV risk sexual behaviour than men without an intellectual disability. (Cambridge 1997, 1999)

Research recommends that HIV and STI prevention work for people with an intellectual disability needs to be provided in a holistic context and cannot focus simply on messages of condom use and safe sex. (Cambridge 1997, 1999). Resources should show an understanding that men with an intellectual disability who have sex with men do not necessarily identify as homosexual. Explicit work on same sex attraction should be integrated into health promotion and education.

Priority groups within the disability population identified in the literature.

- People on the fringe of the sex industry. They tend not to be organised, are vulnerable and lack self-esteem.
- Men who have sex with men but do not identify as homosexual. They may be homophobic; they may not understand health messages. UK research confirms that men with learning difficulties who have sex with men engage in high risk behaviours. (Cambridge 1997, 1999)
- People with mild disabilities are more at risk than those with severe disabilities because they have greater opportunities for being sexually active but do not have access to health education and information.
- People in prisons.
- CALD groups.
- People who are Aboriginal.

Service providers who are considered a priority for education include:

- Outreach workers who access beats but do not understand the needs of men with an intellectual disability.
- Youth workers, especially those working with marginalised, at risk young people who have disabilities.

What the literature says about sexuality education

There is a lack of positive representation of people with a disability in a sexual context. Even when positive images are displayed, they can still be seen as improper or perverted by the community.

Despite more relaxed and supportive attitudes towards sexuality by service providers, the reality is that relationships are still not generally facilitated and developed. There is still a tendency towards protection and safety. People with a disability frequently lead lonely lives devoid of intimacy primarily because of limited support and opportunities to meet with others. People with a disability are dependent on the moral code and good will of the organisation or staff. Sexual expression is often limited to what can be supervised, therefore to what occurs in public. Continuous group living rarely enables anyone to have satisfying intimate relationships.

Parents have a lot of power in lives of a family member with a disability and they often are ignorant of, disinterested in, or fearful of the sexuality of their family member.

People with a disability have less access to sexuality education and sexual and reproductive services including health care.

What the consultations revealed

- Staff spoke positively about the resources that Family Planning NSW has developed and felt that there was still a need for more resource development.
- Specialist skills are required to do disability work and employing disability HPOs at the regional centres would be an effective strategy in meeting the needs of local service providers.
- Support provided by the Senior HPOs at the SHPU was valued.
- The need to work with those who support people from CALD and Aboriginal backgrounds and people with a physical disability.
- The need to provide ongoing updates for staff about disability issues.

What the Health Promotion Unit does

Family Planning NSW is funded by the AIDS and Infectious Diseases Branch of NSW Health to address the needs of people with an intellectual disability and people with mental health issues in relation to the prevention of HIV.

In 2004 we made a significant contribution to the NSW Health HIV Strategic Planning process advising on needs and good practice in this area. We also employed two part time (onexFTE) disability specific State SHPOs and also established a centre in the Illawarra staffed by a part time SHPO whose role is to develop a regional centre focusing on the disability population.

These actions indicated a renewed focus on the needs of people with an intellectual disability by Family Planning NSW.

All resource development work is informed by, and tested with, people with a disability to ensure that it reflects their experiences and meets their needs. The SHPU will increase the involvement of people with a disability in its health promotion activities.

The State SHPOs provide consultation, supervision, professional development, and information to other units in the organisation regarding disability issues. The limited hours worked by these officers constrains the amount of support they are able to offer.

What the Health Promotion Unit could do

GOALS:

- To establish partnerships to support health promotion activities with peak disability agencies, Area Health Services, NSW Department of Ageing Disability and Home Care, NSW Department of Education and Training.
- To develop innovative effective resources that support educative and clinical work and promote positive sexuality.
- To increase the focus of work on marginalised groups such as men who have sex with men, people from CALD and Aboriginal backgrounds, people living in boarding houses, people who are transgender and people on the margins of the sex industry.
- To support the capacity of the regional centres to respond to the information and education needs of people with a disability, carers and service providers.

TIME FRAME	STRATEGIES
2006/07	<ul style="list-style-type: none"> • Write quarterly articles for staff newsletter to inform Family Planning NSW staff about disability related issues. • Evaluate the impact of <i>Sex Safe and Fun</i> resource and workshops – publish results. • Launch <i>Love and Kisses</i> poster series. • Develop <i>Relationships</i> booklet (partnership with DADHC and young people with a disability) and DVD. • Ensure participation by all Family Planning NSW centres in International Day of Disability – promotion of activities in DADHC <i>Connections</i> (their statewide newsletter). • Promote and disseminate a resource developed and tested by practitioners in the field such as; the <i>Social Story About Masturbation</i>. • Conduct assessment of need of service providers who work with people who have a mental health issue. • Provide professional development opportunities and information to regional HPOs to enable them to respond to needs of local community. • Review feasibility of employing one additional FTE state health promotion officer to focus on disability work.
2007/08	<ul style="list-style-type: none"> • In partnership with Touching Base Inc, People With a Disability Inc, Spastic Centre and Royal Ryde Rehab Centre, negotiate with DADHC to develop state wide policies and guidelines regarding sexuality, relationships and sexual health. • Research need for resources that support the sexual and reproductive health needs of people with physical disabilities, in consultation with people with a physical disability. • Conduct assessment of needs of service providers who support people with intellectual disability living in boarding houses. • Collaborate with women’s health nurses in one regional centre to improve access to pap smears, based on model developed in Illawarra.
2008/09	<ul style="list-style-type: none"> • Develop resource for women with a physical disability on cervical screening (possible partnership with cervical screening program). • Develop resources that address risk issues associated with men having sex with men in public places and sex workers who are working on the margins, possible partnerships with ACON and SWOP. • Assess needs of people with an intellectual disability from CALD communities: possible partnership with Multicultural Disability Advocacy Association (MDDA).

3. ILLAWARRA CENTRE

What we do at the Illawarra Centre

The Illawarra project was initiated in November 2004 to develop a model of regional service delivery to meet the needs of people with a disability.

The primary functions of the SHPO is to develop the capacity of disability service providers to address the needs of the people they support and to increase access to Family Planning NSW services by people with a disability and their carers in the Illawarra.

A service delivery function is also being developed. The SHPO is developing a model based on consultation and brokerage that may be applicable to other regional areas. The centre is increasingly becoming the first port of call in Illawarra for assistance with the sexual and reproductive health of people with a disability.

The outcome of this project has been the establishment of a regional centre with a part time Senior Health Promotion Officer who has been undertaking community development and promoting Family Planning NSW services. Health promotion activities have been inclusive of people with a disability.

A review of this model at 12 months identified the need for a regional centre to have a service delivery function. It is not feasible at this time to provide clinical services so the focus will be on providing community education to people with a disability and their families and professional education to service providers. This will require up-skilling of the SHPO and support by the state SHPOs. The outcome will be an increased profile for Family Planning NSW and a more relevant service to the local community.

What we could do through the Illawarra Centre

GOALS

- To develop a service delivery function provided by the Illawarra Centre to people with a disability and their families in Illawarra.
- To establish long-term partnerships to implement health promotion projects.
- To increase access to Family Planning NSW services by people with a disability and their carers in the Illawarra.

TIME FRAME	STRATEGIES
2006/07	<ul style="list-style-type: none">• Illawarra SHPO to develop skills to provide an educational service for people with a disability and parents and carers.• Continue partnership with Altogether Drama, the Illawarra Disability Trust drama group, as a strategy for promoting sexual health messages.• Develop tip sheet for nurses on supporting women with an intellectual disability to have a pap smear, an outcome of Illawarra project.• Develop resources/Fact Sheets on menstruation management for Family Planning NSW website.• Provide community education to people with a disability and their carers.
2007/08	<ul style="list-style-type: none">• Develop resource to support learning about puberty.• Develop a resource for use by GPs when assessing a woman with an intellectual disability for a pap smear (would include issue of consent and communication) based on outcomes of the Illawarra project.

4. CLINICAL SERVICES

What the literature says

There are more reports on the clinical needs of women's sexual and reproductive health than on men. The focus on men tends to be more on inappropriate socio sexual behaviour including inappropriate behaviour such as: masturbation in public; exploitative and abusive sex with women or less powerful men; and touching people inappropriately.

There has been some reporting of the needs of men in terms of HIV prevention and testing, particularly in relation to their education needs and the use of health resources.

In general it is reported that in Australia, adults with an intellectual disability have reduced access to sexual and reproductive health care.

There is considerable discussion in the literature on issues relating to Pap smears for women with intellectual disabilities. Women with intellectual disabilities are under-represented in those having Pap smears. (Stinson 2002) The barriers to women receiving screening include GPs lack of awareness of need for Pap smears and concerns re consent and the extra time needed to prepare a woman for a Pap smear. Given these issues, GPs tend to err on the side of not doing Pap smears.

There is limited information in the literature on other specific clinical issues. Some examples include: reports that breast cancer deaths occur three times more commonly in women with cerebral palsy (Beange 1999), that women with a disability are predisposed to osteoporosis due to physical immobility, use of anti epileptic medication especially Dilantin, indoor lifestyles and use of long term progestin to prevent menses, leading to hypo oestrogenism and a pseudo-menopausal state. (Kowal 2004)

In general, women with disabilities have reduced access to services in comparison with women who do not have disabilities. They do not receive the same number of education or health messages about their bodies and their rights to health care. Services are physically inaccessible, health workers assume people are asexual or not sexually active and women may be anxious about examinations with the result that it is easier not to provide health care. A neglected area of research is how menopause affects women with an intellectual disability. (Martin 2001) This is of concern because of the ageing population.

Women with an intellectual disability experience inadequate access to gynaecological health care, limited choices regarding reproductive issues, lack of sex education and negative and conflicting stereotypes: eg, that they are perpetual children.

Inadequate health care not only puts women at risk but also devalues their reproductive and sexual health needs.

What the consultations revealed

There was a commonly stated aim to provide best practice clinical services to people with a disability.

It was reported that Family Planning NSW clinicians do not have particular expertise or the service capacity to meet the needs of people with moderate or severe disabilities. This specific area of work requires a significant investment of time by a clinician, including longer and repeated appointments and consultations with carers.

Family Planning NSW does not want to be perceived as the expert provider of clinical services to people with a disability. This is a role that could never be fulfilled due to demand

but also would undermine the work of other mainstream service providers, such as GP's, sexual health clinics and women's health nurses.

The Warehouse has a three year commitment to improving access to clinical services for young people with disabilities. They are currently consulting the community about the issue and plan to audit the service to determine future practice. This work enables the organisation to focus on one priority group with the disability population.

Rather than being a major provider of clinical services, Family Planning NSW could identify opportunities with other agencies. For example, the Centre for Developmental Disability Studies (CDDS) and the NSW Council on Intellectual Disability are proposing to NSW Government that specialist disability clinics be established in a major teaching hospital. This is in response to the relatively poor health outcomes of adults with an intellectual disability. There may be an opportunity for Family Planning NSW to be consulted about sexual health needs.

Family Planning NSW clinicians, who have experience in meeting the needs of people with a disability, could provide a planned and coordinated role in the professional development of other clinicians in the agency.

There needs to be greater promotion of clinical services to people with a disability and those clinics that are not physically accessible should be improved. In particular, the need to make Pap smears more accessible to women with a disability was raised. This requires a higher level of support for the women and access to teaching resources. For Family Planning NSW to have a whole of organisation approach to women with a disability, our clinical services need to be supported to provide an actively inclusive service.

More resources and information for disabled clients, covers and service providers is required to support clinicians in this role. Of particular note was information about how to respond to requests about managing inappropriate sexual behaviours by people with an intellectual disability.

What our Clinical Services provide

While people with a disability access our clinics, numbers of overall presentations are low. The Warehouse and Ashfield and Fairfield clinics are physically accessible. All clinics can access Auslan interpreters.

Family Planning NSW has a number of clinicians with experience and understanding of the needs of people with an intellectual disability. They provide consultation to staff and clients eg through Healthline.

The Illawarra centre has a partnership with local women's health nurses to increase access to sexual health screening and pap smears for women with an intellectual disability. The outcomes of this project will inform further work around the state.

The Warehouse has prioritised improving access for young people with a disability, including developing networks with local agencies and consulting with young people.

Nursing staff and the SHPU develop disability FAQs for the website with the aim of increasing disability related content on the site.

What our Clinical Services could do

GOALS:

- To improve access by young people with a disability to one Family Planning NSW clinic.
- To promote clinical services in a way that is actively inclusive of people with a disability.
- To build the capacity of Family Planning NSW clinical staff to provide high quality inclusive services to people with a disability.
- To promote the clinical needs of people with a disability to other clinicians through newsletters, journals and conference papers.

TIME FRAME	STRATEGIES
2006/07	<ul style="list-style-type: none"> • The Warehouse to commence project to increase access and services for young people with a disability, to serve as a model to inform other mainstream youth services. • Establish a professional development group of internal interested and experienced clinicians that can offer a planned and coordinated program for upskilling of FPNSW clinical and Healthline staff. This could include internal forums, articles in staff newsletters. • Disseminate information to Family Planning clinics gained from the women's health project being conducted in the Illawarra.
2007/08	<ul style="list-style-type: none"> • Inform provision of Pap smears at FPNSW clinics based on the model being developed in Illawarra. • Ensure physical access at all clinics and promote this as a feature of the clinics. • Publish and promote good clinical practice by joint authorship with clinical staff of papers for journals and conference presentations.
2008/09	<ul style="list-style-type: none"> • Disseminate information from The Warehouse model of increasing access by young people with a disability to regional clinics.

5. INFORMATION & REFERRAL SERVICES

1. Healthline and Website

What the consultations revealed

A commitment to increasing access to Family Planning NSW services by people with a disability and their carers has been demonstrated by Healthline's work in promoting its service.

Significant promotion to service providers has occurred through professional education delivered by the SHPOs. The Illawarra SHPO promotes Healthline to disability service providers through her networks and the local media.

Healthline staff require up to date information on a regular basis to enable them to respond to enquiries appropriately. There is significant staff expertise experience in disability.

What Healthline does

In 2004 it was determined that Healthline would be reoriented to better meet the needs of people with a disability and their carers. Since then, staff receive regular updates about key disability issues and new resources and the disability referral database has been enhanced. This has enabled Healthline to be a more responsive service to people with a disability and their carers.

Staff currently respond to about 10 calls a month, generally from workers or parents, about the needs of people with an intellectual disability, including managing inappropriate sexual behavior.

2. Library

What the consultations revealed

The disability collection will continue to grow and new teaching resources will continue to be purchased. There needs to be more promotion of the collection through organisational newsletters, expos etc. The breadth of stock needs to be increased to include resources that respond to the needs of people with a physical disability and mental health.

What the Library does

Disability related borrowings have been the most frequent type of borrowings in the general library. In the last two years, the library was restructured to create a specific disability collection within the general library collection. This collection is promoted separately to service providers across the state and borrowings are steadily increasing, especially from workers in rural areas. Further promotion would increase usage. The librarian is a key source of knowledge about the collection, what is contained in the various resources and acts as a point of information and referral.

Main topic areas requested include menstruation, sexual behaviour and relationships, especially the Circles program.

3. Family Planning NSW Website

What the consultations revealed

The FPNSW website is considered an important source of information for people with a disability, their carers and service providers. There is a small range of information that could be enhanced. The site needs to be made more accessible for people with a disability.

What the Website does

FAQs and fact sheets are written for website by State HPU, Healthline staff and the Illawarra SHPO.

The website provides information about Professional Education courses.

It will also be used to promote resources that have been developed by practitioners in the field.

What Information Services could do

GOALS:

- To increase access to Healthline, the library and website by people with a disability, their carers and service providers.
- To develop website content and accessibility for people with a disability and their carers and service providers.
- To continue to build the disability collection stock so that it remains comprehensive, relevant and up to date.

TIME FRAME	STRATEGIES
Ongoing	<ul style="list-style-type: none"> • Continue updates for Healthline staff including strategies to respond to inappropriate behaviours, including masturbation issues. • Increase promotion of Healthline, website and library to service providers and people with a disability. • Maintain and develop the disability referral database. • Increase resources in the disability collection about sexual health issues for people with a physical disability. • Increase resources in the collection that reflect emotional experience rather than just sexual activity. • Identify more Australian resources to be included in the collection.
2007/08	<ul style="list-style-type: none"> • Development of a prompt checklist to support assessment of need of disability calls. • Write Disability Fact Sheets for the website, including menstruation and Pap smears. • Review website for accessibility by people with sensory and physical disabilities.
2008/09	<ul style="list-style-type: none"> • Develop promotional materials that are relevant specifically to people with a disability. • Write Disability Fact Sheets for the website including puberty, mammograms and menopause. • Review need for library assistant.

6. RESEARCH

What the literature says

The literature identifies a number of areas where research, both social and clinical is required, including, but not limited to:

- effects of menopause for women with intellectual disabilities.
- effectiveness of sexuality education programs delivered to people with an intellectual disability.
- effects of long term use of Depo Provera on women with a disability.
- the perceptions of people with an intellectual disability about their own sexuality needs.
- the rates of HIV/AIDS in people with a disability.
- impact of sexuality education on staff practices.

What Research does

The main methods of research have been to conduct needs assessments and review literature to inform new project work. We also regularly evaluate satisfaction with professional education courses and short-term achievements of health promotion projects. This has tended to focus more on process and short-term impact rather than longer-term impact and outcome studies.

We have presented at national conferences on resource development, health promotion issues and some clinical issues.

What Research could do

GOALS:

- To develop a partnership with a university, DADHC or CDDS that will support conducting of and reporting on research that informs practitioners about the sexual and reproductive needs of people with a disability
- To include disability in the statewide needs assessment to be conducted by the agency in 2006.

TIME FRAME	STRATEGIES
2006/07	<ul style="list-style-type: none">• Provide input into Family Planning NSW Strategic Plan 2006-2009.• Provide questions on sexual and reproductive health needs of people with a disability for state wide needs assessment.• Report on evaluation of impact of <i>Sex Safe and Fun</i> resource and workshops.• Partnership with clinical staff to review practice and write journal article.
2007/08	<ul style="list-style-type: none">• Create partnerships with key academic agencies to identify and research questions relating to disability and sexual and reproductive health.

Strategies	Activities	Timeframe	Responsibility
Professional education			
<p>4. To take up opportunities for building professional development of GPs by publishing journal articles, offering targeted education, presenting at conferences.</p>	<ul style="list-style-type: none"> • Research feasibility of DADHC being a partner/funder of professional education for DADHC staff. • Provide staff forum on law, consent and guardianship. • Presentation by doctors on women with disability and menopause at one medical conference. 	2007/08	Education & Training Manager
<p>5. To build the capacity of mainstream services including sexual health clinics, youth health services, women's health nurses to better meet the clinical needs of people with a disability</p>	<ul style="list-style-type: none"> • Work with Nurse Education to develop a disability module for the Family Planning NSW Certificate in Sexual and Reproductive Health (Nursing). 		Education & Training Manager
<p>6. To build the professional development of nurses by including a disability module in the Family Planning NSW Certificate in Sexual and Reproductive Health (Nursing).</p>	<ul style="list-style-type: none"> • Articulate our accredited courses into at least one new educational institution. 		Education & Training Manager
<p>7. To identify where to invest future professional education</p>	<ul style="list-style-type: none"> • Assess the educational needs of service providers who work with a marginalised group of people with a disability eg boarding house staff – include talking with people living in boarding houses. • Work in partnership with doctors to write article for medical journal. • Identify possible medical audience to deliver disability related education . • Review feasibility of employing HPO/Educators with disability expertise in each of the regional Centres. • Assess feasibility of supporting the education of service providers who support people with a physical disability. 	2008/09	SHPU Education & Training Manager, Medical Director
			Education & Training Manager, Medical Director, HR Manager, Director Operations
			Education & Training Manager

Strategies	Activities	Timeframe	Responsibility
Health Promotion			
<p>1. To establish partnerships to support health promotion activities with peak disability agencies, Area Health Services, NSW Department of Ageing Disability and Home Care, NSW Department of Education and Training.</p> <p>2. To develop innovative effective resources that support education and clinical work and promote positive sexuality.</p> <p>3. To increase the focus of work on marginalised groups who are at most risk of HIV and STIs such as men who have sex with men, people from CALD and Aboriginal backgrounds, people living in boarding houses, people who are transgender, people on the margins of the sex industry.</p> <p>4. To support the capacity of the regional centres to respond to the information and education needs of people with a disability, carers and service providers.</p>	<ul style="list-style-type: none"> • Write quarterly articles for staff newsletter to inform staff about disability related issues . • Evaluate the impact of <i>Sex Safe and Fun</i> resource and workshops – publish results. • Launch of <i>Love and Kisses</i> poster series. • Develop relationships booklet and DVD (partnership with DADHC and young people with a disability). • Participation by all FPNSW centres in International Day of Disability – promotion of activities in DADHC <i>Connections</i> (statewide newsletter). • Promote and disseminate a resource developed and tested by practitioners in the field ie the social story about masturbation. • Conduct assessment of need of service providers who work with people who have a mental illness – include talking with people with a mental illness. • Provide professional development opportunities and information to regional HPOs to enable them to respond to the needs of local community. • Review feasibility of employing an additional state health promotion officer to focus on disability work. 	<p>2006/07</p> <p>2007/08</p>	<p>SHPU, Education & Training</p> <p>SHPU</p> <p>SHPU, Education & Training Manager</p> <p>SHPU, Illawarra Centre, All FPNSW Centres</p> <p>SHPU, Education & Training Manager</p> <p>SHPU</p> <p>Education & Training Manager</p> <p>Education & Training Manager, HR Manager, Director Operations</p>

Strategies	Activities	Timeframe	Responsibility
<p>Health Promotion</p>	<ul style="list-style-type: none"> In partnership with Touching Base Inc, People With a Disability Inc, Spastic Centre and Royal Ryde Rehab Centre, negotiate with DADHC for the further development of state wide policies and guidelines regarding sexuality, relationships and sexual health. Research need for resources that support the sexual and reproductive health needs of people with physical disabilities. Conduct assessment of needs of service providers who support people with intellectual disability and mental health issue living in boarding houses. Collaborate with women's health nurses in one regional centre to improve access to pap smears – based on model developed in Illawarra. Develop resources that address risk issues associated with men having sex with men in public places and sex workers who are working on the margins – possible partnerships with ACON and SWOP. Assess needs of people with an intellectual disability from CALD communities – possible partnership with MDAA. Develop resource for women with a physical disability on cervical screening (possible partnership with cervical screening program). 	<p>2008/2009</p>	<p>SHPU</p> <p>SHPU</p> <p>Illawarra Centre, SHPU</p> <p>SHPU</p> <p>SHPU</p> <p>Illawarra Centre, SHPU</p>

Strategies	Activities	Timeframe	Responsibility
Illawarra			
1. To develop a service delivery function provided by the Illawarra centre to people with a disability and their families in Illawarra	Illawarra SHPO to develop skills to provide an educational service to people with a disability, parents and carers.	2007/2007	Illawarra Centre
2. To establish long term partnerships to implement health promotion projects	<ul style="list-style-type: none"> • Continue partnership with Altogether Drama the Illawarra Disability Trust drama group as a strategy for promoting sexual health messages. 		Illawarra Centre, SHPU
3. To increase access to Family Planning NSW services by people with a disability and their carers in the Illawarra.	<ul style="list-style-type: none"> • Develop tip sheet for nurses on supporting women with an intellectual disability to have a pap smear – outcome of Illawarra project. • Develop resources/Fact Sheets on menstruation management for FPNSW website • Provide community education to people with a disability and their carers. • Develop resource to support learning about puberty. 	2007/2008	Illawarra Centre
	<ul style="list-style-type: none"> • Develop a cue card (or similar resource) for use by GPs when assessing a women with an intellectual disability for a pap smear (would include issue of consent and communication) – based on outcomes of the Illawarra project. 		Illawarra Centre, SHPU

GOAL 2:

To provide clinical services that are actively inclusive of people with a disability

Strategies	Activities	Timeframe	Responsibility
Clinical			
<ol style="list-style-type: none"> To improve access by young people with a disability to one Family Planning NSW clinic To promote clinical services in a way that is actively inclusive of people with a disability To build the capacity of Family Planning NSW clinical staff to provide high quality inclusive services to people with a disability To promote the clinical needs of people with a disability to other clinicians through newsletters, journals, conference papers 	<ul style="list-style-type: none"> The Warehouse to commence a project to increase access and services for young people with a disability – to serve as a model to inform other mainstream youth services. Establish a professional development group of internal interested and experienced clinicians that can offer a planned and coordinated program for upskilling of FPNSW clinical and Healthline staff. This could include internal forums, articles in staff newsletters. Disseminate information to FPNSW clinics gained from the women’s health project being conducted in the Illawarra. Inform provision of Pap smears at FPNSW clinics based on model being developed in Illawarra. Ensure physical access at all FPNSW clinics and promote this as a feature of the clinics. Publish and promote good clinical practice in journals and conference presentations. Disseminate information from The Warehouse model of increasing access by young people with a disability to regional FPNSW clinics. 	<p>2006/2007</p> <p>2007/2008</p> <p>2008/2009</p>	<p>The Warehouse</p> <p>Education & Training, clinicians, Healthline, Centres</p> <p>Illawarra Centre</p> <p>Illawarra Centre</p> <p>Centres, Ashfield Clinic</p> <p>Centres, Ashfield Clinic</p> <p>The Warehouse</p>

GOAL 3:

To have staff who are knowledgeable and supportive of the reproductive and sexual health rights of people with a disability

Strategies	Activities	Timeframe	Responsibility
Information & Referral Services			
<ol style="list-style-type: none"> To increase use of Healthline, the library and website by people with a disability and their carers and service providers. To develop website content and accessibility for people with a disability and their carers and service providers. To continue to build the disability collection stock so that it remains comprehensive, relevant and up to date. 	<ul style="list-style-type: none"> Continue with updates for Healthline staff including strategies to respond to inappropriate behaviours such as masturbation issues. Increase promotion of Healthline, website and the library to service providers and people with a disability . Maintain and develop the disability referral database. Increase resources in the library about sexual health issues for people with physical disabilities. Increase resources in the library that reflect emotional experience rather than just sexual activity . Identify more Australian resources to be included in collection. Write Disability Fact Sheets on menstruation and pap smears on to the website. Develop a prompt checklist to support the assessment of need of disability calls to Healthline. Review the website for accessibility by people with sensory and physical disabilities. 	<p>Ongoing</p> <p>2006/2007</p> <p>2007/2008</p> <p>2008/2009</p>	<p>Education & Training,</p> <p>Healthline, Information Services</p> <p>Healthline, SHPU, Library</p> <p>Library</p> <p>Library</p> <p>Illawarra Centre, SHPU</p> <p>SHPU</p> <p>Information Services</p>

Strategies	Activities	Timeframe	Responsibility
Information & Referral Services	<ul style="list-style-type: none"> Develop promotional materials that are relevant specifically to people with a disability. Load up Disability Fact Sheets on puberty, mammograms, menopause on to the website Review need for a library assistant . 		<p>Communications</p> <p>SHPU, Illawarra Centre Manager, Information Services, HR Manager, Director Evaluation</p>

GOAL 4:

To establish and maintain long term strategic partnerships that enable a more effective response to the needs of people with a disability.

Strategies	Activities	Timeframe	Responsibility
Research	<ul style="list-style-type: none"> Provide questions on sexual and reproductive health needs of people with a disability for state wide needs assessment. Report on evaluation of impact of <i>Sex Safe and Fun</i> resource and workshops . Partnership with clinical staff to review practice and write journal article. Create partnerships with key academic agencies to identify and research questions relating to disability and sexual and reproductive health. 	<p>2006/2007</p> <p>2007/2008</p>	<p>SHPU, Education & Training</p> <p>SHPU</p> <p>Education & Training Manager</p>

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