

Access to Health Services for Women with Disabilities

Women with Disabilities Victoria (WDV) repeatedly hear about our members' experiences of inadequate and non-responsive health services: not feeling respected; not being involved in the decisions that affect their health care and treatment; not being able to get onto the examination table; or the recurrent focus on their disability, rather than their health concerns.

This review was commissioned to identify what current research and literature can tell us about ways to improve access to health services for women with disabilities. The absence of evidence on the health experiences of women with disabilities in Australia is stark. In itself, this lack of research is an indicator of the depth of discrimination and the invisibility of women with disabilities within health research, policy and priorities. Key barriers and areas for action are identified and summarised below. Women with disabilities make up 20% of women. Whether we are from Cobram, or a community residential unit in Coburg; whether we are an Aboriginal woman, or were born in Afghanistan; whether we are lesbian, or heterosexual, we are women first. Our health and wellbeing is critically important to us, and to the health of the whole community.

We call on policy makers and health practitioners to respond to the facts presented and to address the policy failures that put our health at risk.

Authors

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Contents:

- Barriers to Access for Health Services
- Key Areas for Action
- Supporting Evidence
- Appendix 1: UN Convention of the Rights of a Person with a Disability
- References

Definition

People with a disability are defined in the United Nations declaration as 'those who have long-term physical, mental, intellectual or sensory impairments which, in interaction with various

barriers, may hinder their full and effective participation in society on an equal basis with others'. In addition, Article 6 states that 'women and girls with disabilities are subject to multiple discrimination'. As a signatory to the convention, Australia has agreed to 'take measures to ensure the full and equal enjoyment by them [women and girls with disability] of all human rights and fundamental freedoms' [1].

Demographics

Australian census surveys report that one in five Australians have a disability - 14.7% a physical disability, which places limitations on the extent and range of movement or activity; 2.2% a psychiatric disability; 2.1% a sensory or speech disability; and 0.8% an intellectual disability. Profound or severe core activity restriction is experienced by 7.1% of women compared with 5.5% for men [2]. Indigenous people overall were twice as likely as non-Indigenous people to have a profound/severe core activity limitation [3].

Barriers to Access for Health Services

Women with disabilities are not able to access the health services they need to optimise their health and well-being. They are not involved in decision-making about their own health. The following outlines key socio-economic, policy and practice barriers to achieving this basic human right:

Women with disabilities are not able to access the health services they need to optimise their health and well-being. They are not involved in decision-making about their own health. The following outlines key socio-economic, policy and practice barriers to achieving this basic human right:

- ❖ Higher rates of **poverty** and housing stress and lower levels of education and employment are experienced by women with disabilities, compared with men with disabilities, or women without disabilities.
- ❖ Lower levels of **health knowledge** among some women with disabilities may contribute to delays in obtaining treatment and lower participation in health promotion and prevention services.
- ❖ **Health information** is not provided in a range of accessible formats for women with disabilities.
- ❖ **Primary carers and health care providers** who do not see beyond the woman's disability, who fail to recognise her holistic health needs, or who do not adjust their care and services to meet those needs, exclude women from mainstream health services.
- ❖ **Gender based violence** is experienced by women with disabilities up to two to three times more often than women without disabilities, with lower rates of access to justice and health systems.
- ❖ Higher rates of **mental health problems** co-exist with having a disability and are exacerbated by the higher rates of violence, socio-economic factors and lack of adequate mental health support and prevention services.
- ❖ Women with disabilities remain poorly served by health services in relation to their **sexual and reproductive health** needs and entitlements. Community attitudes and perceptions of disability, sexuality and gender contribute to the lack of appropriate information and accessible services.
- ❖ Access to **health promotion** initiatives, including **screening** is as important for women with disabilities as for women in general. However these programs, including those for mammography and Pap screening, are not currently meeting their service obligations for this group of women.
- ❖ International, national and state **policies** enshrine the rights to health, freedom, respect, equality and dignity. However, **discrimination** on the basis of disability was the most common cause of complaint in Victoria in 2009/2010. These principles need to be translated into equitable and accessible services. Significant practical, attitudinal and organisational barriers to inclusive services for women with disabilities remain.
- ❖ The lack of Australian **research** on the health service needs of women with disabilities contributes to the maintenance of these barriers.

Key Areas for Action

“The idea that people with disability can be more disadvantaged by society’s response to their disability than the disability itself is leading to a greater focus on policies that seek to remove these barriers.” (National Draft Disability Policy, 2010-2020).

Women with disabilities experience a significant amount of discrimination, much of which is based in a lack of knowledge and sensitivity about disability among health care providers; the physical layout and paucity of appropriate equipment in health services; and a lack of appropriate policies, guidelines and information resources.

International literature and limited Australian research indicates that **equitable access and uptake** of treatment and preventative health services and full participation in **decision-making** by women with disabilities requires:

- ❖ **Further research** about the barriers faced by women with disabilities in accessing health services. This includes data collection describing women’s use of health services and research protocols that mandate the inclusion of women with disabilities.
- ❖ **Professional development** for health service providers that addresses attitudes and prior assumptions. Gaps in knowledge and skills have been shown to result in a reluctance to provide health services to women with disabilities. Evidence demonstrates that training by women with disabilities is most effective in improving knowledge and skills.
- ❖ **Health information** which is clear and concise with appropriate health messages about treatment, screening and lifestyle issues. **Multimedia** methods of disseminating health information are required. Use of reminders, recall systems or other mechanisms to ensure women receive the necessary information and feel included as part of the program are also required.
- ❖ **Multi-disciplinary teams and cooperation between services**, practice nurses, social workers, disability workers and others can facilitate continuity of care and advocacy. This may require the development of **inter-agency policies and procedures** such as domestic violence, sexual assault, justice, housing and health services (treatment and preventative), which respect the privacy of clients.

More accessible health services require:

- ❖ Removing **cost** as barrier to access of services through providing supports such as the free, accessible transport.
- ❖ **Physical access** including ramps, clear signage to assist navigating the environment, the building and the office, disability accessible facilities and examination table.
- ❖ **Effective communication, informed and competent staff** who are knowledgeable about the additional burdens that women with disabilities may face. Talking directly to the woman and where women do not have the capacity involving a designated family member or carer.
- ❖ **Additional time and resources**, including flexible, longer and multiple appointments if necessary to gain a full understanding of the information and health needs of women, particularly those with intellectual and communication disabilities.
- ❖ Acknowledging the important role of **carers, family and friends**, but not to the exclusion of primary decision-making resting with women themselves (except if this not possible).
- ❖ A **holistic** approach to health care for women with disabilities requires services that recognise women’s broader health needs beyond those related to their specific impairment, and the recognition of their **rights** to live full sexual and reproductive lives.

Supporting Evidence - Disability, Disadvantage and Discrimination

Introduction

Optimal health and well-being are government goals for all Australians. However, there is evidence that women with disabilities are disadvantaged in relation to the delivery, access and uptake of health care services they need, and have a right to receive.

The 'right to health' (as enshrined in the *International Covenant on Economic, Cultural and Social Rights* and to which Australia is a signatory) relies on a range of services including those that provide health promotion, prevention, screening, and treatment. Access to health maintenance programs in the community e.g. fitness programs, swimming centres is also intrinsically linked to achieving optimal health outcomes.

This paper describes the gaps that exist between the rhetoric and the inclusion of women with disabilities by these services. The *barriers to access* and *areas requiring action* described above have been drawn from the available published literature with a focus on Australian research, when available. Based on these findings, Victorian women with disabilities will only achieve the 'right to health', if health services' culture changes and encompasses the principles of self-determination and equal opportunity. Four women who live with disabilities have also contributed to this report by providing brief insights into their personal experiences with health services.

Socio-Economic Disadvantage

Social and economic factors disproportionately affect the health of women with disabilities, and the occurrence of one factor increases the risk of the presence of others, as described below. For some women the existence of one form of disability can be related to multiple disabilities, or may co-exist with other health problems. This is Jane's experience.

Jane: *Being a woman born with a disability is not easy. I had convulsions and a cerebral haemorrhage at birth that has affected me with an Acquired Brain Injury causing a legally blind vision impairment, and fine motor co-ordination issues, among other things.*

At the age of 18, and after years of having "women's issues", I was told I have Turners Syndrome. Turners Syndrome is a chromosomal condition that usually means not developing (functioning) ovaries, which means I can't have my own children, I can have heart and kidney problems and am more susceptible to diabetes among other things.

Just because people have situations preventing them from working and earning money doesn't mean we should live in poverty and do it hard. Sometimes situations are out of our control and we shouldn't be punished or penalised for it, it's not our fault.

Relative Poverty

Women living with disabilities are more likely than those without disabilities to experience social and economic disadvantage and poverty. Contributing factors include lower levels of education and employment (46.9% compared with 59.9% for men with disabilities and 64.9% for women without disabilities) [4]. Lower income contributes to significantly more housing stress [5, 6], food insecurity, poorer nutrition and higher rates of obesity and chronic disease [7, 8].

Health Literacy

Lower levels of literacy and education also impact directly on health. It results in a poorer understanding of the way the body functions and the relationship between prevention and

disease and early access to health services for treatment [9]. This may be exacerbated by psychological factors e.g. low self-esteem, depression; cognition problems such as memory and organizational skills (Broughton & Thomson, 2000; Kopac et al., 1998; McRae, 1997) page 143 [10].

Proactive development of health information is needed using a range of formats (including print and emerging electronic technologies). The delivery of education / information must be paced to match the specific disability needs women have. Education needs to be delivered and repeated, if necessary, through all stages of women's lives. Women with disability need to be involved in the development of these resources.

Dependency and Isolation

Many people with disabilities rely on carers - family members and service providers - for intimate physical care as well as access to services. Women with these needs are in a particularly vulnerable position [9, 11]. De-institutionalization has meant that people with disability now have a physical presence in the community, however, access to externally provided support and opportunities is essential and the low expectations of others, including health service providers, can act as significant barriers. The Victorian Auditor General's audit of services for people with disability found "few services [they visited] were providing clients with adequate or appropriate support to achieve community participation and integration" [12].

Jane: Even today, as a mature woman, my parents still to an extent control my life and some of the decisions that are made for me, and I feel it is time to move out of home and find a way to break away from their stranglehold. This is compounded by my lack of an independent income. If I could find employment then I could gain the income I need to rent and live an independent life. But I have found finding and keeping a job very hard. I believe having a disability really affects employers' attitudes.

As I said, my disabilities mean I have had great trouble finding work. This has impacted on my ability to live independently and it really makes a difference to how I can manage my disability and the costs associated with it.

I have chronic back and neck and body pain. Also since birth I have had bad headaches which never go away. I can't afford to pay \$30 to \$70 odd going to a chiropractor, osteopath or physiotherapist or massage or other similar modality.

Gender-based Violence

Women with disabilities are more likely to experience violence compared to other women, or to men with disabilities. While there are discrepancies between the reported rates, in part because of variable definitions used across studies, the proportion of women affected is always high [11, 13-16]. Australian police data indicates that 'just over a quarter of all (sexual assault) victims were identified as having a disability [17, 18]. A NSW Department of Health study found that people with intellectual disability were two to three times as vulnerable to sexual abuse as people without disabilities (Carmody, 1991) [10]. It is believed that these prevalence figures are underestimates of the level of violence that is actually occurring because of under-reporting and problems across disability care, police/justice and support service systems, including their ability to collect data, 'potential victims are extremely powerless and any abuse may not be recognized, reported, recorded, responded to or remembered' page 160 [10].

The gendered pattern of sexual violence persists across diverse ability groups, but particularly among women with intellectual, communication and psychiatric disabilities and across the lifespan, including women in residential aged care settings [17, 19].

High levels of dependency, cognitive and communication disabilities place women at higher risk of violence. Perpetrators are often known to women, they can be carers, residents or other providers of assistance. They may also be partners or family members [13, 17, 20]. In addition, Hassouneh-Phillips et al. found that 'women with high degrees of physical impairment are more likely to perceive themselves as sexually inadequate and unattractive than women with mild impairment'. Negative self-perceptions, when combined with a strong desire to be partnered, increased women's vulnerability to getting into, and staying in abusive relationships over time'[21]. Conversely, Brown et al found that 'Partners of women with disabilities were more likely to engage in patriarchal domination as well as possessive and jealous behaviors' and intimate partner violence [22].

The high rate of violence experienced by women with disabilities co-exists with and low rates of reporting to police. Even when disclosure does occur, adequate responses to meet the support needs of victims/survivors (including counselling) are often lacking [10, 11, 13-16]. There are additional unmet service needs for women who live in rural areas and for Indigenous women [17].

Camilleri [23] analysed the elements that contributed to successful prosecution of a single case of sexual assault of a victim/survivor who had cognitive impairment. She concluded three essential elements were present in this case: 'a strong and determined advocate'; an experienced, competent police officer who 'took an active interest in the case from beginning to end'; and the victim's courage and 'ability to communicate verbally'. Systematic problems result in justice being inaccessible and non inclusive for many people with disability. Continuity was crucial in this case, however it is unusual. Police and health service response systems have become increasingly specialised and often work in silos. It is rare for a victim/survivor to have the support of a single person from the beginning of the process to the end. The second crucial element in this case study was the determination of the advocate, victim and police officer to seek justice. Adversarial systems of justice, such as Victoria's, 'sets one against another, not necessarily to seek the truth but to create doubt and to find and exploit weakness' which makes some women with disabilities particularly vulnerable in this system. Victims who have cognitive and / or communication problems 'remain in the first instance, beyond belief and consequently beyond justice' [23].

The Victorian Law Reform Commission report (2004) concluded that 'the criminal justice system offers people with cognitive impairment very limited protection against sexual assault'. Hugh de Kretser from the Federation of Community Legal Centres in Victoria describes a proposed pilot project to increase the reporting, prosecution and deterrence of sexual assault [24]. If successful, this project will reinforce the message that women with intellectual disability have a right not to be sexually assaulted. Initiatives and research are also needed to improve: sexuality education for women with disabilities including reproductive and sexual health education within a context of sexual rights and consent; professional development of all staff across agencies; organisational policies, guidelines and practical tools to promote prevention, protection and responses to sexual abuse; co-ordinated information, advocacy and support services for victims/survivors in a range of formats. The involvement of women with disabilities will provide perspectives previously missing and avoid the risk of developing well-meaning but paternalistic initiatives [17].

Intersectional Disadvantage

Women with disabilities are not a homogenous group and represent a diverse range of physical and cognitive abilities and vulnerabilities [17]. As reflected in the general community, they may also be lesbian, Indigenous, from a culturally and linguistically diverse community and experiencing multiple forms of discrimination and exclusion. Services and organisations tend to be developed and operate as silos, but this does not reflect the diversity and lived reality of many people. Clare (1999) cited in Mann et al, describes this complexity as follows:

Gender reaches into disability; disability wraps around class; class strains against abuse; abuse snarls into sexuality; sexuality folds on top of race . . . everything finally piling into a single body.

Meeting health and wellbeing needs challenges existing organisational structures, normative beliefs and ways of working [25]. Inclusive services are sensitive to this diversity and provide services and information in formats that are accessible to specific needs and types of disability.

In its submission to the Australian Government's consultation for the National Disability Strategy, the Victorian Equal Opportunity & Human Rights Commission stressed consideration in policy development of the complex intersections between for example, 'race and disability, gender and disability, age and disability, disability and sexual orientation'. In particular The Commission noted 'the high correlation between Indigenous status and disability and the unique lived experience of members of this community.' The intersectional issues - legal, economic, social, physical and cultural need to be addressed to ensure that the human rights of all people with disability are promoted and protected.' page 9, [26].

Mental Health

Women with disability are more vulnerable to mental health problems due to the social and economic disadvantage described above and women with psychiatric conditions are particularly vulnerable to abuse and violence, both within health services and more generally in society. Australia's 2007 National Survey of Mental Health and Wellbeing found that 43% of people who had a profound or severe core-activity limitation experienced symptoms of a mental disorder in the 12 months prior to the survey, compared with 20% in the general population [27].

A 2010 UK study identified six inter-related risk factors as potential causes for the people with an intellectual disability developing a mental illness and these were: 'being female, unmet expectations, dysfunctional family upbringing, unstable relationships/loss of children, domestic violence and negative life experiences.' Resilient/protective factors included being proactive, greater community participation, early recognition and provision of mental support services [28].

Experience of violence and sexual abuse are known risk factors for developing mental health problems. Research has shown the proactive identification and provision of individual and group therapy for women with disabilities is beneficial for women and important for prevention of secondary mental health problems (McCarthy 1999)' page 69 [10].

Sexual and Reproductive Health

Mainstream cultural perceptions of 'disability', 'sexuality' and 'gender' and the intersection of these contributes to the lack of effective reproductive services for women with disability. Current issues (and controversies) with particular resonance for women with disability include sterilization, abortion and fertility. Consideration of the rights of women with disability to have, or not have babies and to raise children is particularly important.

The limited available Australian research indicates a lack of appropriate information and education about sexual and reproductive health for women with disabilities, including contraceptive choices and compliance, and recognition of the early signs of pregnancy. The results for women with disability who presented with unplanned or unwanted pregnancies to a Melbourne hospital Pregnancy Advisory Service (PAS) in 2005-2007 were compared with all women who presented in 2006 to the same hospital and were found to be:

- younger (75% were aged 25 or younger, compared with 44%);
- they recognised that they were pregnant at a later stage of gestation, and presented to the hospital later (45% contacted PAS at 12 weeks gestation or later, compared with 20%); and

- 25% of the women with disability, presented too late for the abortion that they wanted, compared with almost 2%;
- 50% of women with intellectual disability proceeded with an abortion, compared with 80% of other women.

These women were found to be more vulnerable to external pressure because of their dependence on assistance from others to access services, and they were more likely to experience violence including sexual coercion [9].

Women with mild or moderate intellectual disabilities are able to give informed consent for an abortion, however when the disability is more severe permission for the abortion must be sought from the Victorian Civil and Administrative Tribunal [29] and this is likely to contribute to further delay.

Researchers surveying all family planning clinics in Northern Ireland concluded that these clinics were 'landscapes of exclusion' for people with disability because they were largely inaccessible both physically and the lack of suitable information and services provided [30].

Many women with disabilities are denied or 'sheltered' from the significant life experiences of sexual relationships, marriage and procreation, either deliberately or by omission. The voices of young women with intellectual disability in particular are missing from the research literature, although qualitative research with older women with intellectual disabilities describes their feelings of 'bitterness and regret' about having been sterilized at an early age, page 91[10]. In the US women with physical disabilities have been reported as undergoing hysterectomies at a significantly higher rates than their peers, the odds of surgically induced menopause for women with physical disabilities was double that of women without physical disabilities [31].

Lesbian women with disability challenge normative values of sexual identity and can experience 'double prejudice' and isolation from gay and lesbian services and disability organisations as well as mainstream services. Issues identified by Victorian disabled gay and lesbian people in a 2006 study included concerns about confidentiality (particularly in rural communities), lack of knowledge of relevant sexual health services, and primarily the effects on their mental health as a result of 'discrimination, violence exclusion and invisibility' experienced in their everyday lives [25].

Sexual and reproductive education, which addresses the social reality experienced by many women with disabilities needs to be available in an accessible format and importantly needs to be provided from 'a rights-based approach which continually reinforces their rights to make choices and not be subjected to violence or sexual coercion' [9].

Jane: . . . it was soon after I'd turned 18 that I got my first boyfriend. We were at the point where we decided we wanted to have sex and it wasn't working. We couldn't figure out why and I talked to Mum and she told me to relax that I was probably too tense. On numerous occasions of trying we weren't any closer to achieving it and I had to discuss it with my gynaecologist.

I should have had Mum in the room too as I hadn't prepared myself to hear what he said. To my horror and disgust, he tells me I have a very small vagina. . . and I need to have surgery so I can more easily have vaginal sex. He had known me since I was young, had known about this problem for years and had done nothing about it. He had given me currettes and other surgeries but hadn't prepared me to be able to have sex!

He took it upon himself to decide.

As if that's not bad enough, it was an extremely hard and humiliating way to find out for

myself when I became sexually active that I couldn't do it. Even then the doctor and my mother decided that I am to wait until the end of the year, when I have finished year 12 to have the surgery. I was not included in this discussion.

As an adult I should have been allowed to make that decision myself. Me being so innocent and naive, I didn't really know my rights and didn't do anything about it. Apparently doctors can refuse surgery and although there were no other local gynaecologists, I should have found someone else to do it for me or at least found out my legal rights.

The thing is at that time I didn't even know who to go to for information. I've never forgiven him or my parents for taking away my adult decision of when to have surgery and taking away what would have been 8 more months of an active love life.

Maternal Health

Rogers describes the social bias against women with disabilities who become parents and as in other areas of health care the lack of accessible necessary equipment (examination tables, scales, communication aids, inaccessible offices) and the research needed to improve service delivery for these women during pregnancy, labour and delivery [32]. Gaps in knowledge exist relating to:

- Physical disabilities and their affect on the management of pregnancy and vice versa (e.g. Caesarean section, use of spinal anaesthesia, neuromuscular, circulatory, respiratory, urinary problems); and
- Postpartum recovery and associated complications; and importantly
- The effect of the attitudes of staff on meeting the care needs of pregnant women with disabilities.

The Royal Women's Hospital, Melbourne within its maternity services program provides a Women's Individual Needs (WIN) Clinic for women with intellectual disability and learning difficulty. The clinic provides extra support throughout the woman's pregnancy and up to six weeks post delivery. Information about the clinic is provided to women who either identify or present as having intellectual disability or learning difficulties and attendance is voluntary. Support is provided by midwives and social workers. WIN aims to increase the mothers' confidence and competence and may include individualised childbirth and parenting skill development sessions. Burgen in her unpublished report describes the following issues and concerns of 30 women (15 with intellectual disability and 15 with learning disability) who attended this clinic:

- Almost half did not present for pregnancy care until they were more than 20 weeks pregnant, many did not recognised the pregnancy related changes in their bodies and relied on partners or families to identify their pregnancy and make appointments for them.
- Many women were reluctant to become involved with any service because of their fear of Protective Services and the potential removal of their babies. The provision of 'accessible, flexible and supportive responses will become even more critical' in the future to ensure women do not avoid medical and pregnancy care altogether.

It is believed that WIN is the only clinic in Australia set up to specifically meet the needs of this group of women [33].

Data collection and research that enables the monitoring and evaluation of maternity service outcomes for women with all types of disabilities is urgently needed.

Parenting

Research demonstrates the association between psychiatric and intellectual disability and prevalence of 'statutory protection proceedings' [34]. In Burgen's study one of the fifteen women with learning difficulty who delivered their babies with WIN Clinic support had her baby removed (7%). Compared with twelve of the fifteen women registered with intellectual disability who delivered their babies through the WIN Clinic, seven of these women (60%) had their babies removed soon after birth by Protective Services, by six weeks a seventh mother relinquished care, and her baby was removed [33]. The latter group of mothers were particularly disadvantaged with nearly a half having experienced homelessness and domestic violence; one third did not have a supportive partner or family member; and one third experienced inadequate parenting and foster-care [33].

Burgen notes that few professionals have been trained to work with people with intellectual disability and so lack the skills needed to provide education and support to help these women develop parenting skills and prevent problems. It is often only when a crisis develops that they become involved. She concludes that the labelling of these women as 'intellectually disabled' together with the lack of provision of appropriate support contributed to the discrepancies described between mothers who had a 'learning disability'. She quotes Booth (2003) 'failure to provide appropriate assessment and responses ultimately becomes a rights and equality issue'. Burgen notes that the shortcomings in service provision are often perceived as shortcomings in the parents themselves [33].

Some work that seeks to develop parents' skill levels exists. Llewellyn et al. sought to help parents with intellectual disability provide a healthy and safe environment for their children and to address current service gaps in this area. The home-based intervention targeted parents with intellectual disability aiming to promote child health and home safety in the preschool years. A total of 63 parents were recruited for the study with 45 parents (40 mothers and 5 fathers) from 40 families completing the project. The research design permitted comparison between the intervention and three alternative conditions with all parents receiving the intervention in an alternating sequence over the life of the project. The intervention was effective regardless of parental health, literacy skills, and IQ. This form of home-based intervention promotes a healthy and safe environment which is a prerequisite to continuing parental custody [35].

Tarlton et al. sought to map the issues and experiences of parents with intellectual disabilities who took part in 'positive practice initiatives' in the UK. Ongoing, proactive practical and emotional support was provided to the parents and the author's concluded that 'with appropriate help from services parents can be enabled to support each other, to develop confidence, and to engage more positively with the professionals and systems responsible for safeguarding the welfare of their children' [36].

Protection Services have removed fewer babies born to WIN Clinic mothers in subsequent years. However more research is needed to describe flexible and innovative ways of supporting parents with intellectual disability, over the longer term. The alternative is to continue the system abuse response and confront the consequences of another population of stolen children [33].

Jane believes it is not only women with intellectual disabilities who are denied the right to become parents.

Jane: . . . I have other friends with Turners Syndrome . . . My friends are married and have used IVF to have children. They only have that health issue and have normal love lives with husbands, and kids through IVF and using a family members' donor egg...

I am supposed to feel comfort, support and relief knowing there are other women in the situation I am in but due to my other disabilities, I sometimes feel worse because no

specialist is going to allow me to go through IVF. There are judgements and preconceived ideas that society decides people such as me are not equipped to have children and would possibly put them at risk. This is not true. I get so angry that people who don't seem to care for their kids are able to have them and people who could make great parents aren't supported to have them.

Health Promotion – Screening and Prevention

Being healthy and having a disability can co-exist. However, governments, service providers and individuals need to act to protect and enhance health status. The US Surgeon General in the Call to Action states “Persons with disabilities must have accessible, available and appropriate health care and wellness promotion services. They need to know how to—and to be able to—protect, preserve and improve their health in the same ways as everyone else.” Health care providers are urged to “see and treat the whole person, not just the disability; educators to teach about disability; a public to see an individual’s abilities, not just his or her disability; and a community to ensure accessible health care and wellness services for persons with disabilities.” [37]

Physical Fitness and Well-Being

The benefits of physical exercise on aerobic and cardiovascular responses, weight control, prevention of some chronic conditions and promoting longevity and psychological benefits has been demonstrated in people without disability. Specific information in relation to women with disabilities is however limited [32].

Individualised programs that are specific to each person’s health promotion needs are required together with programs that aim to promote health and feelings of well-being generally. Gerber cited in Krotoski et.al. calls for research and evaluation about what, when and how to structure programs which aim to help women with disabilities reach their maximum potential and also reduce the risk of chronic diseases and co-morbidities. In particular, guidelines based on research are needed for individual conditions e.g. spinal cord injury, arthritis, neuromuscular diseases, brain injury, secondary osteoporosis etc. The relationships between specific treatment programs and outcomes as well as secondary prevention initiatives and disability, particularly physical disability needs to be explored, documented and disseminated to inform future development in this area [32].

Mainstream gymnasiums and health equipment are generally inaccessible for women with physical disabilities. Together with the lack of outcome information on the benefits of exercise for specific disabilities, this can result in psychological and environmental barriers to interventions that have the potential to enhance many women’s lives.

Below is an example of how relatively simple practical changes have increased the level of independence and autonomy for Cathy who has a physical disability. Cathy is also able to actively contribute to her own health maintenance which in turn contributes to her physical health and sense of well-being. This organisation has demonstrated respect for the dignity of disabled people and met their obligations to the community by providing equity of access.

Cathy: *Being a manual wheelchair user, the challenge is how to stay fit and without putting too much stress on my shoulder muscles – as you get older those stalwart muscles can pack it in from overuse. Swimming is highly recommended but the problem with most pools is that they are either inaccessible to get into, or the change rooms are inaccessible or it's only the hydrotherapy pool that is accessible – and it's too hot for laps. So I was delighted when the local city council refurbished the indoor pool and in the process built a ramp into the pool and an accessible change room and installed a plastic wheelchair. I*

can get myself in and out of the pool unassisted and can swim laps regularly. As the ad says - I feel (so much) better now.

Screening

International studies have found that the rates of screening, including Pap smears and mammography, for women with disabilities are lower than those for women in general [10, 38, 39]. This places women with disabilities at higher risk of delayed diagnoses of breast or cervical cancer [40]. Women with disabilities are not mentioned in BreastScreen Australia's monitoring report or in BreastScreen Victoria's 2008-2009 Annual Report and so their participation rate in these screening programs remains unknown [41, 42].

Cervical screening

Noonan Walsh [10] summarised the following research findings on possible reasons for lower screening rates:

- Health care professionals, family members and legal guardians failing to prioritise the sexuality and gender-related needs of this group in relation to their day-to-day needs (McCarthy, 1998b; Sundram & Stavis, 1994).
- Women's negative feelings about previous health service experiences, including significant pain associated with pelvic examinations.
- Examinations conducted without their consent and other difficulties related to their disability.
- Socio-economic factors, e.g. poverty and poor literacy skills (Broughton & Thomson, 2000; Kopac et al., 1998; McRae, 1997).

Research shows that women who have experienced sexual assault are reluctant to access screening programs and require sensitive care [43].

Mammography screening

BreastScreen Australia [44] commissioned a qualitative study in 2006 which included women with disabilities. Researchers found the majority of participants wanted to have regular screening mammograms, but they described 'practical and psychological barriers' such as:

- Concern that the facilities would not be appropriate for them, or staff would not be able to cope with their condition. Women reported being extremely tired of having to explain their particular circumstances and needs to staff whenever they used a new service and that staff often under-estimated the level of the woman's need before they saw her.
- Not receiving an invitation letter from BreastScreen Australia to attend.
- General practitioners not mentioning mammograms. GPs reported that they 'sometimes do not recommend screening mammography to patients who are struggling with other conditions'.
- Expectations that the process would be too difficult and that staff would not understand if appointments would not always be able to be kept.
- Previous experience of pain which lasted for some time after the procedure. For one woman the procedure involved lifting her arm above shoulder height which is something she could not normally do unaided. An ultrasound was a possible alternative, but the woman expected this too would be painful and so she did not intend to arrange for this 'in the near future'.

The authors concluded that because BreastScreen programs operate in isolation from women's 'familiar' services, this maybe a barrier for women with disability. There are a number of

assumptions by both the service providers and potential clients in the report that are not tested or explored.

Possible ways to address some of the concerns raised by women in this report include a more proactive approach including for example:

- Improved communication between the staff and the women about the physical requirements of undergoing a mammogram, and assessment of the woman's particular needs, at the time of making an appointment.
- Consideration of alternative screening options that could include ultrasound if standard mammography equipment is not able to be used.
- Ensuring letters of invitation are suitable and provided to all eligible women, either directly or indirectly through their general practitioners, or other health care provider organisations.

There are time and resource implications if services are to be provided in a more pro-active and inclusive manner. However, a flexible and sensitive response could help women with disability feel as though they are legitimately part of the target group for mammography screening and with adequate information and support they could then make an informed decision about their participation.

Two women not receiving mammography services described their experiences and possible options not currently available:

There are time and resource implications if services are to be provided in a more pro-active manner. However, a flexible and sensitive response could help women with disability feel as though they are legitimately part of the target group for mammography screening and with adequate information and support they could then make an informed decision about their participation.

Two women not receiving mammography services described their experiences and possible options not currently available:

Annie: *"I have advanced Ankylosing Spondylitis (AS) and in recent years the mammogram machines can no longer accommodate my posture, due to the kyphosis and fusion in my spine. Kyphosis is the exaggerated forward curvature of the thoracic region of the spinal column, resulting in a rounded upper back. In my case the spinal areas affected are very stiff or fused, and consequently I cannot move or turn my head away from the equipment to allow the x-ray image to be taken of the breast area. These days this proves to be a very painful experience for me and more time-consuming and frustrating for the equipment operator*

I have a strong family history of breast cancer and within my age group I am classified as high-risk. My own breast surgeon has explained that the mammogram is the preferred image as a screening test. An ultra-sound may be required if an anomaly is highlighted, and more importantly, it is a more appropriate test to check on a specific area."

Ellen: *"My sister Vicki and I are of the same opinion [regarding mammograms]. Having had such a painful experience during our own mammograms, Vicki 17 years ago and I about 20 years ago, neither of us have had one since. We would however welcome a mammogram ultrasound tomorrow if it was offered."*

Secondary Prevention

Menopause

Dormire and Becker [31] reported that women with physical disabilities experience the same symptoms at menopause as women in the general population. However they can be at increased risk of secondary complications - osteoporosis, cardio-vascular disease, thrombosis, sexual health, urinary, kidney and skin problems. The increased risk could be related to physical conditions, earlier menopause, surgically induced menopause and interactions between medications used to manage particular disabilities e.g. cortisone and anti-epileptic drugs and hormone replacement medication.

Women wanted quality information and personalised advice to support their decisions about managing their symptoms, including whether or not their particular disability would be exacerbated by recommended treatment options. They also wanted information and access to facilities that promote healthy lifestyles such as nutritious diet, weight management and 'creative exercise strategies' including resistance training [31].

Older women

Women with intellectual disabilities in the US are living longer, but life expectancy is still less than for women in general. The average age is 67 years for women with mild to moderate disabilities, 57 years for women with Downs syndrome compared with 79 years for women in the general population [10].

A recent Australian Bureau of Statistics report summarised the related issues of an aging population and increased rates of disability. The rate of disability at younger ages remained stable during the period 1998 to 2003, however the rate of disability for people aged 60 years and over is much higher than for younger people, and this proportion of the population is increasing. In 2003, women aged 80 years and over had a much higher rate of profound or severe core-limitation than men in the same age group (52% compared with 34%) [45].

The health service related experiences of older women reported by (Walsh et al., 2000) were consistent with the findings of other studies for women of all ages and stages of their lives, women reported:

- they had inadequate information about the physical changes associated with ageing and related health issues;
- their experiences in health care settings were often confusing, frightening and uncomfortable;
- their ability to practice preventive health behaviours was compromised by lack of support, information and options, page 147 [10].

Policy context

Government policy initiatives need to reflect an awareness of gender and disability as determinants of outcomes across all related areas including justice, education, housing, employment as well as health.

The rights of people with disability are enshrined in current policies at the international, national and state level; however, related and necessary policy development at health service level remains largely unaddressed.

The *Victorian Charter of Human Rights and Responsibilities* protects the rights to 'freedom', 'respect', 'equality' and 'dignity' for all Victorians and places comprehensive obligations on public health service providers. In addition the new *Victorian Equal Opportunity Act*, which comes into force in August 2011, places a greater emphasis on the prevention of discrimination, the

promotion of equal opportunity and the identification of systemic barriers to equal opportunity [46].

The *Victorian State Disability Plan* outlines the Victorian Government's vision for disability and together with the implementation plans 'reaffirms the rights that people with a disability have to live and participate in the community on an equal footing with other citizens of Victoria'. Specifically Objective 5 of the Plan commits the government to improving the health and wellbeing by ensuring that 'Access to health services for people with a disability will be improved by ensuring that doctors, nurses, and other health professionals are better placed to respond to the health needs of people with a disability, at all stages of life.' This includes improved access to screening programs, to sexual and reproductive health services, mental health and wellbeing and sport and recreation programs [47].

The consultation summary for the development of the *Victorian Women's Health and Wellbeing Strategy 2010 – 2014* includes a focus on applying a 'gender and diversity lens' to the identified priority areas (chronic disease and injury, violence against women, mental health, and sexual and reproductive health). Women with disability are not mentioned specifically, however, sub populations at particular disadvantage are to be targeted. Relevant ways of working include taking a holistic view of health that includes physical health as well as quality of life, consideration of the social determinants of health and empowering women through improved health literacy, education initiatives and involvement in decision making and choices about managing their own health [48].

At the national level, the Government has committed to a *National Disability Strategy* (Commonwealth of Australia 2008) and released the draft strategy in 2010 [49] and a *Social Inclusion Agenda* in 2009 [50].

In addition to Australia's obligations to provide the 'right to health' under the *International covenant on Economic, Cultural and Social Rights (ICECSR)* the *UN Convention on the Rights of Persons with Disabilities* emphasizes 'the importance of mainstreaming disability issues as an integral part of relevant strategies of sustainable development' and 'the importance of accessibility to the physical, social, economic and cultural environment, to health and education and to information and communication, in enabling persons with disabilities to fully enjoy all human rights and fundamental freedoms' [1].

The overlapping relationships between disability, health, gender, violence and social inequalities have also recently attracted greater attention at an international policy level. The WHO Commission on the Social Determinants of Health, in its report, *Closing the Gap in a generation* [51], has emphasised that disability is largely missing from evidence on health inequities. This represents an important shift in thinking about disability which has traditionally been conceived as an indicator of poor health rather than as a social determinant of health and a driver of health inequities.

Discrimination

The rights of full citizenship for people with disability are clearly the goal, however 19% of all complaints made to the Victorian Equal Opportunity & Human Rights Commission in 2009/10 were for discrimination on the basis of disability or impairment and this was the most common reason for complaints they received. The majority related to employment [52].

Women with disabilities experience higher levels of disadvantage and discrimination because of the intersection between their disability and gender, and for some women this is exacerbated because of their race, sexuality and age [46].

“Disability hate crimes are a global problem. They are often violent and hyper-aggressive, with life-changing effects on victims, and they send consistent messages of intolerance and bigotry.” Author and advocate Mark Sherry’s latest book focuses on the US (the FBI hate crime database is the longest-running and most comprehensive database on disability hate crime in the world) and UK situation, but is relevant to Australia. Sherry states that “more effective policies and practices can and must be developed to respond and prevent them [hate crimes and there is a need for] . . . legislative recognition of disability hate crimes, improved reporting of incidents and assistance for individual victims of hate crimes, as well as the need to address the social exclusion of disabled people and the negative attitudes surrounding their condition” – the antecedents for disability hate crimes [53]. The need for legislative change is currently the subject of a review in Victoria [54].

Health Services

At a forum held by the Victorian Equal Opportunity & Human Rights Commission in 2009, Indigenous women participants reported their sense of frustration at the lack of progress in delivering meaningful change to improve the experiences of Indigenous women, including their experiences with health services, in spite of ‘well-meaning policies and laws’, such as the Charter of Human Rights page 40, [52]. Indigenous people are twice as likely as non-Indigenous people to have a disability that results in profound/severe core activity limitation [3] and this may contribute to their levels of frustration.

The Victorian Commissioner, Dr Helen Szoke in a talk to Deakin medical students in September 2010 recognised this lag between high level policy commitments and local application. She stated that the experience of the Commission was that ‘the health sector is still coming to understand its obligations in relation to the Victorian Charter of Human Rights and Responsibilities and in particular, the interface between the Charter with the obligations of health service providers.’

She went on to say that under Charter and other policy obligations health services ‘must have special regard for the needs of groups in the community who experience disadvantage’, including women with disabilities to ensure that all health consumers can participate equally and attain the highest standard of health and well-being [46]. Human rights and non-discriminatory based approaches empower health consumers; health care provision becomes a negotiated process based on consent; and is tailored to the needs of the individual.

Mainstream and specialist services may not actively discriminate against women with disability or other ‘hard to reach groups’ but that does not mean they are inclusive.

It is one thing not to do bad things but it is another to make people feel welcome. You need a more active approach that makes it clear that gay and lesbian [and disabled Indigenous and CALD] people are welcome in this service. And this organisation is there for all members of the community [25].

Jane: *I am a person and should be respected as such. I haven’t always felt like I’ve been treated with dignity and respect and had my integrity intact.*

I use my 5 enhanced primary care visits within the first 2 months of the year as I need to see a chiropractor or similar modality every 2 weeks or so or the pain is chronic. Well It’s chronic anyway but worse if I don’t get treatment. It’s been 3 months since treatment already as I can’t afford more visits and am on 5 month waiting list for physiotherapy.

I get my doctor to prescribe me with panadeine forte regularly due to being in constant pain. . . people in chronic pain all the time such as myself, require unlimited enhanced primary care visits per year. The government seems to consider physical therapy

modalities as extra's, or luxury items. What the government fails to recognise is that for too many Australians, treatments such as chiropractic and osteopathy are a necessity for our health and wellbeing. . . . In the end it would be cost effective to prevent further problems and health costs.

Research – Knowledge Gaps

Women with disability are systematically excluded from general health research in Australia, or rendered invisible through the non-gendered nature of substantive disability-related data.

Research is needed to monitor and evaluate the contribution of disability (and types of disability) as drivers of socio-economic disadvantage and health inequities, including:

- Analyses of existing data; these analyses should be disaggregated by gender as gender is both a determinant of disability and the socio-economic disadvantage that occurs as a consequence of having a disability.
- The development of instruments that capture the experiences of people living with a range of disabilities. Current questions on disability are limited to capturing information on severity and functional impairment. The Survey of Disability, Ageing and Carers should be expanded to include questions about economic and social exclusion (while these questions are asked of older people and carers, the questions are not asked of people with disabilities).
- The inclusion of questions on disability in all routine data collection systems and in research projects, where appropriate.
- The development of standardised disability definitions.
- Monitoring service delivery and compliance with legislation.
- Quality assurance for hospitals and other state funded services.
- The involvement of women with disabilities in research, using as an example of best practice the model used for Indigenous research.
- Health services research, including audits of agency policies and service responses regarding people with a disability, including those who experience sexual assault and abuse. The audits could be cross-sectoral, examining agencies across health, disability, aged care, sexual assault, family violence, justice and disability advocacy services.
- Targeted health promotion and secondary prevention initiatives for women with disability, supported by cost-benefit analyses are needed. These include the development and evaluation of initiatives that promote fitness, exercise and feelings of well-being.
- Research is needed to explore the interactions between complex physical, mental health problems and their treatments.

Proactive initiatives are required by major health research funding bodies [e.g. NHMRC] and relevant government departments to provide the necessary research infrastructure that will enable research gaps to be addressed. Evidence is needed to translate policy to practice and ultimately to the lived experiences of women with disabilities.

NB The Victorian Department of Health is currently analysing the results of the Victorian Population Health Survey for People with an Intellectual Disability 2009 and results will be posted to their web site when available: www.health.vic.gov.au/healthstatus/vphsid2009.htm

Summary

Jane's story illustrates the complexity of factors that impact on her life and in particular, the interrelationship between socio-economic disadvantage, disability and physical and mental ill health. Jane writes she cannot adequately care for herself because is unable to find work to relieve her disadvantage and consequently lives in pain, is aware of her 'differentness', believes her life is controlled by others and struggles with her self esteem. Her story tells of other people thinking they know best about decisions that are fundamental to Jane's sense of dignity, autonomy and her sexuality. This situation is mirrored by the experiences of many other women with disabilities [55].

Equity of access and uptake of health services and women with disabilities' right to health requires systemic changes within health care settings, and at a minimum service providers need to address the following three areas:

Communication - staff attitudes and prior assumptions, clear health messages and appropriate educational materials;

Administration - flexible appointments, provision of reminders, and transportation options;

Physical accessible - examination rooms, examination tables, toilets, clear signage [10].

Inclusive service providers are proactive and this requires more than not actively discriminating against women with disabilities, it requires removing the barriers to access described above.

Living with disability should not preclude the achievement of optimal health and wellbeing and life choices, nor does it mean screening and health maintenance programs are not needed, in fact the reverse may be true, however services need to be innovative and develop programs that meet the individual needs of each woman.

Data, evaluation and research are needed to contribute evidence for supporting and directing change including:

- Information about disability as a social determinant of health, and a driver of health inequities in the Australian context;
- Victorian health and related service audits of agency policies and service responses;
- Targeted health promotion and secondary prevention initiatives supported by cost-benefit analyses;

Funding is needed to translate policy and strategy commitments to service delivery and demonstrable health outcomes for women with disability. The experience of living with the range of disabilities needs to inform future work in the above areas through the active participation of women with disabilities.

Appendix I

UN Convention on the Rights of a Person with a Disability [1]

In signing the UN Convention on the Rights of a Person with a Disability, Australia committed to the following in relation to health:

Article 25 – Health

States Parties recognize that persons with disabilities have the right to the enjoyment of the highest attainable standard of health without discrimination on the basis of disability. States Parties shall take all appropriate measures to ensure access for persons with disabilities to health services that are gender-sensitive, including health-related rehabilitation. In particular, States Parties shall:

- Provide persons with disabilities with the same range, quality and standard of free or affordable health care and programmes as provided to other persons, including in the area of sexual and reproductive health and population-based public health programmes;
- Provide those health services needed by persons with disabilities specifically because of their disabilities, including early identification and intervention as appropriate, and services designed to minimize and prevent further disabilities, including among children and older persons;
- Provide these health services as close as possible to people's own communities, including in rural areas;
- Require health professionals to provide care of the same quality to persons with disabilities as to others, including on the basis of free and informed consent by, inter alia, raising awareness of the human rights, dignity, autonomy and needs of persons with disabilities through training and the promulgation of ethical standards for public and private health care;
- Prohibit discrimination against persons with disabilities in the provision of health insurance, and life insurance where such insurance is permitted by national law, which shall be provided in a fair and reasonable manner;
- Prevent discriminatory denial of health care or health services or food and fluids on the basis of disability.

References

1. United Nations. *Convention on the Rights of Persons with Disabilities*. 2008 May [cited 6 September 2010]; Available from: www.un.org/disabilities/convention/conventionfull.shtml.
2. Australian Bureau of Statistics (ABS), *Disability, Ageing and Carers: Summary of Findings, Australia, 2003*. 2004, Commonwealth of Australia: Canberra.
3. Australian Institute of Health and Welfare, *The Health and Welfare of Australia's Aboriginal and Torres Strait Islander Peoples*. 2008, AIHW: Canberra.
4. Australian Bureau of Statistics (ABS), *2006 Year Book Australia*. 2006.
5. Beer, A. and D. Faulkner, *21st century housing careers and Australia's housing future*. 2009, Australian Housing and Urban Research Institute, Southern Research Centre.
6. Beer, A. and D. Faulkner, *The housing careers of people with a disability and carers of people with a disability*. 2008, Australian Housing and Urban Research Institute, Southern Research Centre.
7. Drewnowski, A. and S.E. Specter, *Poverty and obesity: the role of energy density and energy costs*. . N Engl J Med in press in press.
8. Foley, W., et al., *An ecological analysis of factors associated with food insecurity in South Australia, 2002-7*. Public Health Nutr, 2009. **13**(2): p. 215-21.
9. Burgen, B., *Women with Cognitive Impairment and Unplanned or Unwanted Pregnancy: A 2-Year Audit of women Contacting the Pregnancy Advisory Service*. Australian Social Work, 2010. **63**(1): p. 18-34.
10. Noonan Walsh, P. and T. Heller, *Health of Women with Intellectual Disabilities*. 2002, Oxford UK: Blackwell Publishing.
11. Grossman, S.F. and M. Lundy, *Double jeopardy: a comparison of persons with and without disabilities who were victims of sexual abuse and/or sexual assault*. J Soc Work Disabil Rehabil, 2008. **7**(1): p. 19-46.
12. Auditor General Victoria, *Services for people with an intellectual disability 2000*, Government Printer for the State of Victoria: Melbourne.
13. Smith, D.L., *Disability, Gender and Intimate Partner Violence: Relationships from the Behavioral Risk Factor Surveillance System Sexuality and Disability*, 2008. **26**(1): p. 15-28.
14. McCarthy, *Sexuality and Women with Learning Disabilities*. 1999, London: Jessica Kingsley Publications.
15. McCarthy, M. and D. Thompson, *A Prevalence Study of Sexual Abuse of Adults with Intellectual Disabilities Referred for Sex Education*. Journal of Applied Research in Intellectual Disability, 1997. **10**(2): p. 105-122.
16. Brownbridge, D.A., *Partner violence against women with disabilities: Prevalence, risk and explanations*. Violence against women, 2006. **12**(9): p. 805-822.
17. Murray, S. and A. Powell, *Sexual assault and adults with disability: enabling recognition, disclosure and a just response*. 2008, Australian Institute of Family Studies: Canberra.
18. Women with Disabilities Australia (WWDA), *Forgotten sisters: a global review of violence against women with disability*, in *Resource manual on violence against women with disabilities*. 2007, WWDA: Hobart.

19. Heenan, M. and S. Murray, *Study of Reported Rapes in Victoria 2000-2003*. 2006, Department for Victorian Communities, The Office of Women's Policy - Statewide Steering Committee to Reduce Sexual Assault: Melbourne.
20. Healey, L., et al., *"Building the Evidence; A report on the status of policy and practice in responding to violence against women with disabilities in Victoria"*. 2008, Women with Disabilities Victoria: Melbourne.
21. Hassouneh-Phillips, D. and E. McNeff, *"I Thought I was Less Worthy": Low Sexual and Body Esteem and Increased Vulnerability to Intimate Partner Abuse in Women with Physical Disabilities* *Sexuality and Disability*, 2005. **23**,(4): p. 227-240.
22. Brownridge, D.A., J. Ristock, and D. Hiebert-Murphy, *The high risk of IPV against Canadian women with disabilities*. *Medical Science Monit*, 2008. **14**((5)): p. 27-32.
23. Camilleri, M., *Enabling Justice*, in *National Victims of Crime Conference: New Ways Forward - Pathways to Change*. 2008: Adelaide.
24. de Kretser, H., *Advancing justice for sexual assault victims with a cognitive impairment*, in *Violence & Disability Newsletter*. 2010.
25. Mann, R., et al., *Swimming Upstream: Making Places Welcoming - A Report on the Needs of Gay, Lesbian and Bisexual People in 'Hard to Reach' Groups*. 2006, La Trobe University: Melbourne.
26. Victorian Equal Opportunity & Human Rights Commission, *Submission to Australian Government's consultation on developing a National Disability Strategy*. 2008, State of Victoria.
27. Australian Bureau of Statistics. *4326.0 - National Survey of Mental Health and Wellbeing: Summary of Results, 2007*. 2008 [cited 2010 31 August 2010]; Available from: <http://www.abs.gov.au/AUSSTATS/abs@.nsf/Latestproducts/4326.0Main%20Features32007?opendocument&tabname=Summary&prodno=4326.0&issue=2007&num=&view=>.
28. Taggart, L., R. McMillan, and A. Lawson, *Staffs' knowledge and perceptions of working with women with intellectual disabilities and mental health problems*. *J Intellect Disabil Res*, 2010. **54**(1): p. 90-100.
29. Victorian Office of the Public Advocate. *Guardianship - Making personal and lifestyle decisions for an adult with a decision-making disability*. 2010 [cited 2010 7 October 2010]; Available from: <http://www.publicadvocate.vic.gov.au/file/file/Guardianship/Guardianship%20290909.pdf>.
30. Anderson, P. and R. Kitchin, *Disability, space and sexuality: access to family planning services*. *Soc Sci Med*, 2000. **51**(8): p. 1163-73.
31. Dormire, S.L., H. Becker, and C.J. Lin, *Menopause healthcare for women with physical disabilities*. *Nurse Pract*, 2006. **31**(6): p. 42-5, 47-50.
32. Krotoski, D.M., M.A. Nosek, and M.A. Turk, *Women with Physical Disabilities: Achieving and Maintaining Health and Well-Being*. 1996, Baltimore: Paul H Brookes Publishing Co.
33. Burgen, B., *Still not accepted: When women with intellectual disabilities choose to become mothers*. Unpublished, 2006.
34. Llewellyn, G., D. McConnell, and L. Ferronato, *Prevalence and outcomes for parents with disabilities and their children in an Australian court sample*. *Child Abuse Negl*, 2003. **27**(3): p. 235-51.
35. Llewellyn, G., et al., *Promoting health and home safety for children of parents with intellectual disability: a randomized controlled trial*. *Res Dev Disabil*, 2003. **24**(6): p. 405-31.

36. Tarleton, B. and L. Ward, "*Parenting With Support*": *The Views and Experiences of Parents With Intellectual Disabilities*. *Journal of Policy and Practice in Intellectual Disabilities*, 2007. **4**(3): p. 194-202.
37. US Surgeon General Department of Health and Human Services, *The Surgeon General's Call to Action to Improve the Health and Wellness of Persons with Disabilities*. 2005.
38. Parish, S.L. and J. Huh, *Health Care for Women with Disabilities: Population-Based Evidence of Disparities*. *Health & Social Work*, 2006. **31**(1): p. 7-15.
39. Barr, J.K., et al., *Understanding Barriers to Participation in Mammography by Women with Disabilities*. *American Journal of Health Promotion*, 2008. **22**(6): p. 381-385.
40. Nosek, M.A. and C.A. Howland, *Breast and Cervical Cancer Screening Among Women With Physical Disabilities*. *Arch Phys Med Rehabil* 1997. **78**(Suppl 5): p. S39-S44.
41. Australian Institute of Health and Welfare (AIHW), *BreastScreen Australia monitoring report 2006–2007 and 2007–2008*. 2010, Australian Government.
42. BreastScreen Victoria, *Annual Report 2008–2009*. 2009, Department of Health: Melbourne.
43. Carlson, K., *Barriers to Cervical Screening Experienced by Victim/Survivors of Sexual Assault - a Pilot Study*. 2002, CASA House, Royal Women's Hospital: Melbourne.
44. BreastScreen Australia, *BreastScreen Australia Evaluation – Participation Qualitative Study* 2008.
45. Australian Bureau of Statistics. *1370.0 - Measures of Australia's Progress, 2010* 2010 15 September 2010 [cited 2010 20 September 2010]; Available from: [http://www.abs.gov.au/ausstats/abs@.nsf/Lookup/by%20Subject/1370.0~2010~Chapter~Living%20with%20a%20disability%20\(4.1.6.5\)](http://www.abs.gov.au/ausstats/abs@.nsf/Lookup/by%20Subject/1370.0~2010~Chapter~Living%20with%20a%20disability%20(4.1.6.5)).
46. Victorian Equal Opportunity & Human Rights Commission. *Human Rights and Public Health Medical Students, Deakin University*. 2010 [cited 20 September 2010]; Talk by the Commissioner, Dr Helen Szoke, to Deakin University medical students on 14 September 2010]. Available from: <http://www.equalopportunitycommission.vic.gov.au/news%20and%20events/speeches/20100914.asp>.
47. Victorian Department of Human Services. *State Disability Plan 2002 - 2012*. 19 May 2009 [cited 2010 15 October 2010]; Available from: http://www.dhs.vic.gov.au/disability/state_disability_plan.
48. Victorian Department of Health, *Victorian Women's Health & Wellbeing Strategy 2010-2014: Consultation Summary May to July 2010*. 2010, Victorian Government: Melbourne.
49. Australian Government, *Draft National Disability Strategy 2010-2020 - An initiative of the Council of Australian Governments*. 2010.
50. Australian Social Inclusion Board, *Social inclusion: A compendium of social inclusion indicators*. 2009, Commonwealth of Australia.
51. WHO Commission on the Social Determinants of Health, *Closing the gap in a generation: Health equity through action on the social determinants of health, Final report*. 2008, World Health Organisation: Geneva.
52. Victorian Equal Opportunity & Human Rights Commission, *Annual Report 2009/10*. 2010, State of Victoria: Melbourne.

53. Sherry, M., *Disability Hate Crimes: Does Anyone Really Hate Disabled People?* 2010, United Kingdom: Ashgate and Gower.
54. Victorian Department of Justice. *Review of Identity Motivated Hate Crime in Victoria* 2010 January 2010 [cited 2010 7 October 2010]; Available from: [http://www.justice.vic.gov.au/wps/wcm/connect/justlib/doj+internet/home/the+justice+system/community+consultation/justice+-+review+of+identity+motivated+hate+crime+in+vicoria+++\(focus+on\).](http://www.justice.vic.gov.au/wps/wcm/connect/justlib/doj+internet/home/the+justice+system/community+consultation/justice+-+review+of+identity+motivated+hate+crime+in+vicoria+++(focus+on).)
55. Howe, K., *Submission to The Consultation on the National Women's Health Policy* 2009, Victorian Women with Disabilities Network: Melbourne.