



PapScreen
Victoria

Screened out!

women with disabilities and cervical screening



SCREENED OUT!

**WOMEN WITH DISABILITIES AND
CERVICAL SCREENING**

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October 2002



Screened Out! Women with Disabilities and Cervical Screening

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ISBN 0 947283 74 9

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Cover Illustration
Artist: Lisa Reid
Year: 2002
Thank you to Arts Project Australia

TABLE OF CONTENTS

Acknowledgements	4
Executive summary (plain English)	5
Recommendations	8
Chapter 1 – Cervical screening and women with disabilities: current context	11
Part 1 – Women and cervical screening	25
Chapter 2 – Disability ... it’s a social problem	29
Chapter 3 – Strong women	39
Chapter 4 – Barriers: Subjectivity.....	48
Part 2: Service provider perspective	61
Chapter 5 – Recognising barriers: Organisational perspective	62
Chapter 6 – A community of women: Pap test providers.....	71
Chapter 7 – Auditing Pap test services	83
Conclusion	93
References	99
Appendix 1 Reference Group members.....	103
Appendix 2 Cervical screening and women with disabilities access audit.....	104

ACKNOWLEDGEMENTS

Many people have contributed their time, skills and experience to this project. We would first like to thank the women with disabilities who shared their experiences with us and who gave permission for their accounts to be used to assist others. We would also like to thank the reference group for assisting in the design and implementation of the study. The members include: Ms Liz Alexander (Family Planning Victoria), Ms Kerry Burns (Women's Health Goulburn North East), Ms Danielle Elisha (SANE), Ms Helen Freris (Blind Citizens Australia), Ms Janice Florence (ParaQuad), Ms Sue Giffney (Women's Health in the North), Ms Amanda Hiscoe (Consultant), Ms Lee Kewish (Consultant), Ms Jeanette Lee (Yooralla), Dr Liz McDonald (MS Society), Ms Effie Meehan (ADEC), Ms Andrea Morrow, (Royal Women's Hospital), Ms Karleen Plunkett, (Latrobe City Council), Ms Katy Ragheb (CHECK), Ms Anne Ridowski, (Family Planning Victoria), Ms Naomi Schwarz (*PapScreen Victoria*), Ms Di Siebold, (Vision Australia) Ms Janice Slattery (Consultant), Ms Angela Steele (Royal Women's Hospital), Ms Georgina Sutherland (Centre for Developmental Disabilities Health).

Disability service providers, advocacy organisations and Pap test providers assisted us greatly in both talking about the issue and in putting us in contact with women who were willing to participate.

At the Australian Research Centre in Sex Health and Society we would like to thank Georgi Cahill, Jacqui Randall and Diane Shannon for providing support for the project.

The work was funded by *PapScreen Victoria* which has demonstrated a continuing commitment and interest in the project throughout its development. Thank you to Rachel Haagsma for coordinating the production of this report.

EXECUTIVE SUMMARY (PLAIN ENGLISH)

Screened Out! was a six month study funded by *PapScreen Victoria* which was undertaken by the Australian Research Centre in Sex Health and Society at La Trobe University. The project arose from concerns that women with disabilities are less likely than other women in the community to have regular cervical screening (Pap tests). This is a matter of concern because cervical screening has been found to be a very effective means of lessening the number of women who develop cervical cancer. In the project we aimed to discover the barriers that women with disabilities met when they had cervical screening. We began the study with a series of consultations with key organisations that provided services for women with disabilities or advocated with them. We then held interviews with 25 women who had sensory, intellectual, psychiatric or physical disabilities. We talked with other women in small groups. Finally we met with cervical screening providers and discussed how they saw the barriers for women with disabilities. We found that while some women did not have any problems in having Pap tests, other women found it very difficult.

The Barriers

We found that the barriers that women with disabilities encountered in having Pap tests fell into three broad groups.

1. Social Barriers. These included issues such as transport difficulties and the lack of access to buildings. For example some services did not have moveable beds or hoists to assist women with physical disabilities. We also found that some health professionals were not sensitive to women's needs. Some did not think that women with disabilities were likely to have (or have had) active sexual lives. Therefore they did not think that Pap tests were necessary.

Sometimes staff working with women with disabilities did not know about cervical screening themselves or did not think that the women they worked with needed to have it.

We also found that there was a lack of accessible information for women. There was a need for more plain English information and for information to be available in many different forms like videos or sound tapes.

2. Life Circumstances. Like other women in the community, women with disabilities lead very different life styles from each other. Some live alone, some live in supported accommodation, some work and some are in relationships and are parents. Many are on low incomes. But as well as dealing with these issues, women with disabilities also have to manage issues which arise from the disability itself. Some of these things make it difficult for them to have regular Pap tests. For some women Pap tests were very painful because of their physical disability. Others had very bad experiences with doctors in the past and this made it difficult for them to have Pap tests. Sometimes just managing the professionals who supported the woman with disabilities was time consuming and tiring. In this situation women sometimes found it just too difficult to have Pap tests as well. Some women moved often and so did not have a regular doctor or they did not receive reminder letters about Pap tests. Women who come from culturally and linguistically diverse cultures sometimes found it difficult to have Pap tests because of the way others viewed them or because it was difficult for them to talk about their sexual lives.

For some women the shock of having a disability when they were adults meant that they did not have the energy or the time to think about other health matters. Finally we found that when women had

to spend long periods of time in institutions health professionals did not talk with them about general health care.

3. Subjectivity (How women see themselves). This was an important issue for some women with disabilities. It was mentioned less often by service providers. We found that some women with disabilities were not treated as women because of their disability and this made it difficult for them to have Pap tests. Some women did not have very much privacy and Pap tests made them feel as if they did not have control over their own bodies. Finally we found that Pap tests and sexuality were closely linked for some women. Sometimes the experience of Pap tests reminded women of very bad sexual experiences in the past and sometimes it reminded them too of a sexual life which they no longer had. However some women did see Pap tests as an important part of being a woman and were offended when health professionals told them that they did not need to have the Pap test.

The people we consulted during this study wanted to make changes so that it would be easier for women with disabilities to get access to cervical screening. There was a need for more accessible information, better education and training for health professionals and staff working with women with disabilities and better networks between health and disability professionals.

We found that some Pap test providers are working very hard to make their service accessible to women with disabilities. However more changes need to be made. We hope that this report will help this to happen.

RECOMMENDATIONS

Recommendation 1

PapScreen Victoria should develop a state-wide strategy over two years for assisting women with disabilities to access regular cervical screening. This strategy should include the development of accessible information, education and training for health service professionals, Pap test providers and disability staff and should involve women with disabilities in its development, implementation and evaluation.

Recommendation 2

That cervical screening be promoted holistically as a part of a well women's health check with a particular focus on sexual health.

Recommendation 3

PapScreen Victoria should establish a group of 'cultural consultants' who are women with disabilities to advise on the development of resources and provide advice and support to disability organisations and Pap test providers.

Recommendation 4

Information about cervical screening for women with disabilities should be developed through consultation with women with disabilities, organisations which provide services to them or advocate with them and with Pap test providers. Such information should be provided in a range of formats including plain English, clear graphics, video and audiotapes.

Recommendation 5

Information about cervical screening should be disseminated widely through disability organisations, community health centres and Pap test providers.

Recommendation 6

Resources should be sought from Government to reduce the social barriers encountered by women in accessing cervical screening. This should include: the provision of hoists and moveable beds in services on a submission basis and the wide dissemination of the *PapScreen Victoria* "Listing of Community Pap Test Services Across Victoria".

Recommendation 7

The development of outreach services through disability networks by Pap test providers and *PapScreen Victoria* should be encouraged and this should be accompanied by the further development of peer education.

Recommendation 8

PapScreen Victoria should offer the opportunity for Pap test providers to undertake an annual audit of their service. Women with disabilities (peer educators) should be employed to undertake the audit and those services which have been audited should be noted in *PapScreen Victoria's* "Listing of Community Pap Test Services Across Victoria" each year.

Recommendation 9

The health issues of women with disabilities should be explicitly included in preservice and inservice training for nurses and other health professionals.

Recommendation 10

PapScreen Victoria should identify major institutions offering total care to women with disabilities, and education and training on women's sexual and general health needs should be given to staff at such institutions. Such institutions should include psychiatric hospitals and nursing homes.

Recommendation 11

PapScreen Victoria should undertake an action-based consultation with key disability organisations with a particular focus on working with women with sensory disabilities to identify the best ways of providing accessible information to them.

Recommendation 12

PapScreen Victoria should work with major service providers for women with disabilities to increase their understanding of the importance of cervical screening as part of women's general health and to provide support and information to such organisations.

Recommendation 13

PapScreen Victoria should hold discussions with the Royal District Nursing Service and women's health nurse Pap test providers to explore the possibility of women with disabilities having cervical screening undertaken in their homes when needed.

Recommendation 14

That training and education for disability workers about women's health should be developed as a matter of urgency to ensure that they are aware of the need for cervical screening and can explain it clearly to users of their services

Recommendation 15

In order to counteract the prevailing attitudes and views about women with disabilities which deny their sexuality and therefore their need for cervical screening, a campaign similar to *PapScreen Victoria's* "Lesbians Need Pap Tests Too", should be implemented.

CHAPTER 1 - CERVICAL SCREENING AND WOMEN WITH DISABILITIES: CURRENT CONTEXT

Background

Women with disabilities often have less access to breast and cervical screening programs and services than any other group of women. Even if a woman with disabilities schedules a mammogram or Pap smear, the vast majority cannot receive the service because of economic, social, psychological and cultural barriers that impede or preclude their access to breast health and cervical screening services.

(Frohman, 2002)

This statement summarises some of the concerns of women with disabilities in relation to access to preventative health measures such as cervical screening.¹

However, there is currently little qualitative research in Australia which explores how women with disabilities themselves see the tests and the barriers. *Screened Out! Cervical Screening and Women with Disabilities* was a six month study funded by *PapScreen Victoria* which aimed to increase understanding of the lived experience of women with a disability in relation to this health issue and to ascertain the physical and psycho-social barriers they face in accessing cervical screening services.

Why the study was undertaken?

The success of a screening program is dependent on it being used by people who are thought to be at risk. In relation to cervical screening this would mean all women aged between 18 and 70 years who have ever had sex should be routinely screened every two years. The current project, *Screened Out!* arose from particular concerns about the accessibility of cervical screening for women with disabilities.

These were:

1. *Cervical Screening has proved to be a successful means of early diagnosis of cervical cancer.*

Cervical cancer is the 14th most common cause of cancer death in Australia

¹ Pap tests which involve the testing of cervical cells for evidence of abnormalities is used as a means of identifying precancerous cell growth in the cervix. This test is particularly useful because of the long latency period for cervical cancer (10 years or more).

and accounted for 269 deaths in 1998 (The Cancer Council Australia, 2001, p.68). Cervical screening has proved to be a successful means of reducing the incidence of cervical cancer both in Australia and overseas. For example in the United States and some European countries there has been a 20-60% reduction in death rates since its introduction. In Australia there has been a decline in deaths from cervical cancer of 40% between 1986 and 1998. This decline is attributed to the introduction of co-ordinated cervical screening and improved follow-up of screening programs (The Cancer Council 2001). If women with disabilities find it more difficult than other women to access this service they may be more vulnerable to illnesses which could be prevented or treated through early detection.

2. *Cervical Screening is less accessible for some groups of Australian women.*

A co-ordinated cervical screening program began in Australia in 1991. Figures obtained from the cervical cytology registers in Australia reveal that between 1997-1998, 64% of women aged between 20-69 years participated in cervical screening. However over a three year time interval the participation rate is more than 80%. Table 1 shows participation rates across different age groups.

Table 1. Participation rates in National Cervical Screening Program by age group, Australia, 1997-1998

Age group	20-24	25-29	30-34	35-39	40-44	45-49	50-54	55-59	60-64	65-69
%	50.6	66.5	69.0	70.7	69.8	69.4	72.5	62.9	54.9	43.4

(AHW, Breast Screen and NCSP 1999 cited in The Cancer Council Australia, 2001, p.70)

The overall figures for Australia are very similar to those recorded in overseas research which suggest a take up rate of approximately 80% for all women. For example, the Centre for Research on Women with Disabilities (1999) estimates 73% of women in the USA without disabilities have two yearly Pap tests. In spite of this take up rate there are some groups of women who are less represented among those who regularly access the services. These women include women from culturally and linguistically diverse backgrounds, Koori women and women with disabilities (*PapScreen Victoria 2000*). If screening is to provide an equitable means of assisting women to care for

their health then barriers which prevent some groups from using it need to be identified and where possible removed.

3. *Evidence that women with disabilities are less likely than other women to have regular cervical screening.*

Both Australian and overseas research has shown that women with physical and intellectual disabilities are less likely than other women to have regular cervical screening. However there has been little research with women with either sensory or psychiatric disabilities. There is also a need to explore with women their lived experience in relation to cervical screening and to develop strategies which will provide them with better access.

4. *There is a lack of research in relation to women with disabilities and cervical screening in Australia.*

There are no national or state statistics available on the number of women with disabilities in Australia who have regular cervical screening. However a recent state wide consultation with women with disabilities on health and well being issues revealed that 'sexuality, relationships and reproductive health' was one of the key priorities which needed to be addressed by government policies and strategies (Victorian Women's Health and Well-being, 2001). Our literature search revealed some studies undertaken with women with intellectual and psychiatric disabilities in Australia (Family Planning Victoria, 1998; 2000; Sutherland, 2002). While these studies make an important contribution to our knowledge of women with disabilities and cervical screening they were restricted to working with one group of women rather than across disability groups and they relied on questionnaires rather than on attempting to see how women experience cervical screening in the context of the rest of their lives. The present study sought to work with women with disabilities to explore their experiences of cervical screening.

5. *A recognised need for a strategy to work with women with disabilities.*

PapScreen Victoria has developed a number of strategies to work with women with disabilities in relation to cervical screening. For example it has partially funded a peer education program at Women's Health West where women with disabilities are employed to undertake education with other women with disabilities on Pap tests and breast self examination. The present study is part of a developing strategy to be implemented by 2005 (*PapScreen Victoria*, 2000).

The recently published Victorian State Disability Plan (2002) establishes a ten year vision for government action within the disability field and makes special comment about the health needs of women with disabilities.

The Government will also improve access to important health screening programs (such as breast, bowel, Pap and prostate screening tests) and to sexual and reproductive health services for women with a disability.

(Victorian State Disability Plan, 2000, p.42)

How the study was undertaken

Screened Out! was a six-month qualitative research project which involved working with women with differing disabilities to explore their experiences of cervical screening. In addition consultations were held with Pap test providers and with organisations which work with or advocate for people with disabilities. An audit of four cervical screening services was undertaken by one of the researchers who has a disability, to look at accessibility issues and to identify good practices. The project was advised by a reference group which met three times during the six months of the project.

Aims

Screened Out! aimed to increase understanding of the lived experience of women with a disability in relation to cervical screening and to ascertain the physical and psycho-social barriers they face in accessing cervical screening services. More particularly the research aimed to:

- Interview 30 women with intellectual, physical, psychiatric and sensory disabilities to identify common concerns and barriers about cervical screening.
- Identify by interviews differences in the experience of individual women in relation to the experience of cervical screening.
- Through consultation with key service providers, identify issues and problems encountered by cervical screening agencies in providing a service for women with a disability.
- Recommend changes to agencies and means of support to women with a disability which will increase their access and use of cervical screening tests.

Research strategies

1. Development of reference group

A reference group for the project was seen as an important first step because participating organisations could:

- Contribute experience and expertise to the project.
- Assist in the design of the research.
- Provide access to women with disabilities.
- Disseminate the results of the research.

Key organisations representing women with disabilities or providing services to them were contacted to assess their interest in participating in the project. Invitations were also sent to selected services providing Pap tests to women with disabilities. Organisations were invited to a consultation meeting at the Australian Research Centre in Sex Health and Society. This was followed by two further meetings.

There was a great deal of interest in this project by a wide range of organisations working with women with disabilities and this was sustained over the life of the project. This interest reflected concerns by participating organisations and individuals that women with disabilities often did not have access to preventative health services, that issues relevant to sexual health and expression were often disregarded or ignored by health professionals, and that staff working with women and women with disabilities did not have a voice about these issues.

2. Preparation of interview schedules and checklists

The following interview schedules and checklists were developed and used during the project. All of them were discussed by the Reference Group and then amended on its advice.

- An interview schedule for use as a basis for discussions with women with disabilities about their experiences of cervical screening.
- A list of questions for key service providers and organisations working with women with disabilities.
- An audit checklist and accompanying questions which were used to assess good practice and service accessibility.

3. Recruitment

A number of strategies were used to recruit participants in the study. These included:

- *Use of Radio.* The researchers with a representative from *PapScreen Victoria* provided two radio broadcasts, one with 3CR and one with 3RBH. Both programs focused on a listening audience with disabilities. Basic information about cervical screening was given during the programs and women were encouraged to contact us if they wanted to discuss cervical screening.
- *Newsletters.* Short articles were prepared for organisations participating in the reference group and seven articles were placed. Again some information about cervical screening was provided and women were asked to participate in the study.
- *Discussions with Participating Organisations.* Participating organisations were consulted by the researchers on how they see the barriers for women with disabilities. Several indicated that they believed a forum for their members would be of use, both to provide them with information about Pap tests and to identify the issues through discussion. Two forums were held in country Victoria as a result of these consultations.
- *Workshop and Conference Attendance.* We attended both the MS conference and the Vicserv conference providing information and seeking participants to the study.
- *Web Page.* The project was placed on the Women with Disabilities Australia web page.

Consultations with existing organisations, our presence at conferences and informal networks and the web page proved to be the most successful ways to involve women with disabilities in the project. Newsletters and radio programs, while extremely useful in disseminating information, were not successful forms of recruitment.

4. Working with the women

At the commencement of the project we believed that, because of the sensitivity of the issues, individual interviews would be the best means of giving women a voice. However, some women preferred to meet in groups and in some instances it was not possible to undertake individual interviews. For example, deaf women required an Auslan interpreter in order to be involved in the project. The cost of this was

beyond the budget of the project for individual interviews. Women from non-English speaking backgrounds chose to meet together to discuss the issues.

Twenty five interviews were undertaken individually. In addition, discussions were held with the following groups:

- Two groups of women with intellectual disabilities. One of these consisted of a group of ten women with intellectual disabilities, two women with physical disabilities and a woman with hearing impairment and intellectual disabilities in a country area. The second consisted of a group of women with intellectual disabilities who were members of a women's group in the city.
- One group of three deaf women.
- A workshop with approximately ten women with psychiatric disabilities who were attending a conference.

Recruitment of women with disabilities is always time consuming. This project did not prove to be different in spite of the enthusiasm of participating agencies. It took time to make contact with some organisations and there were cultural and political issues which required time and sensitivity. For example, many deaf women do not identify as having a disability. However they were included as a group in the study. This created problems in their inclusion which need to be met in a different way in future work. Some women with disabilities from culturally and linguistically diverse backgrounds were not 'allowed' to meet with us without their carers being present. This could not occur for confidentiality and privacy reasons.

5. Consultations with agencies

Consultations were held with representatives from 16 organisations which worked with or represented people with disabilities.² Discussions were also held with four groups of staff (20 people) who provided cervical screening services.

Contact with organisations proved to be the most successful way of reaching women with disabilities. This suggests that they have an unintentional gate-keeping role. The importance of developing relationships with specific organisations over time was extremely important. In some instances it took several visits to negotiate access to a group of women. For example in working with women from

² To preserve the anonymity of informants we have not named the representatives or organisations.

culturally and linguistically diverse backgrounds, staff contacted women and their carers, and at times needed to do this through an interpreter.

Interviews and focus groups were held with five groups of Pap test providers in both country and city areas. Again, networks of people in local areas or relevant associations proved to be the best means of contacting this group.

6. Audit of Pap test agencies

Audits of four Pap test services were undertaken by one of the researchers who has a disability. These services included a hospital, two community health centres and a large organisation providing Pap testing services. Audits involved a checklist which began with a phone call to make an appointment and proceeded to an actual visit and discussions with staff. Each agency involved received a brief report of the audit findings.

Literature review

A literature review was undertaken and a draft paper summarising the research into barriers and Pap testing for women with disabilities was presented to the reference group. The literature revealed that while a considerable amount of research has been undertaken with women with physical and intellectual disabilities both in Australia and overseas there was none which has involved women with hearing or vision impairments or women with acquired brain injury. Little overseas research appears to have been done with women with psychiatric disabilities although Family Planning Victoria undertook two studies with this group in Victoria (1998; 2000). We found no research which looks comprehensively at the barriers experienced by women across disability groups.

The literature survey carried out for this study focused on women with disabilities. However we believe it is also important to examine what barriers have been identified for women generally in the community.

Barriers to cervical screening for women not labelled as having disabilities

Research both overseas and in Australia has revealed that women who are not labelled as having a disability may experience a number of barriers in undertaking regular cervical screening. These include:

- The need for GPs to prompt a woman to have cervical screening or to discuss it with her (Cockburn et al, 1991).
- Lack of access to information about cervical screening or about the sites where it could be carried out (Campbell, McDonald and McKiernan, 1996).
- A belief that the woman was not eligible for screening (Orbell et al, 1995).
- A belief by the woman that she was at lower risk of cervical cancer than others or did not need cervical screening (Orbell et al, 1995).
- Negative feelings about having a Pap test. Such feelings could be related to the nature of the test itself, previous bad experiences of Pap testing, or negative experiences sexually which impacted on the woman's view about Pap testing (Fernbach, 1999; Hirst, 1988; Moore et al, 2000).
- No access to a woman GP or nurse (Fernbach, 1999; Hirst, 1988; Moore et al, 2000).
- Concern about the results of Pap tests (Orbell et al, 1995; Fernbach, 1999).
- Lack of time or forgetting about the test (Fernbach, 1999).
- Not being sexually active (Fernbach, 1999).
- Alienation and powerlessness, a sense of not belonging in the wider community and a sense of not having control over one's own destiny (Community Development in Health, 1988).
- Cost of the service (Hirst, 1988).

Barriers to cervical screening for women with disabilities

All of the studies identified in our literature search focused on one particular group of women with disabilities. We believe this can create problems because women with disabilities who access cervical screening are generally seen by generic health professionals. Such professionals need clear guidelines and education which will assist them to work with a wide range of individuals in the community. Focusing on one disability group may provide support for specialists but it does not, in our view, assist the wider inclusion of women with disabilities into the community.

Further, the literature search revealed that there was a strong emphasis in working with women with physical and intellectual disabilities. There was much less literature available in relation to women with psychiatric or sensory disabilities.

Women with intellectual disabilities

Research with women with intellectual disabilities in the UK and Australia has revealed that they are less likely than women without disabilities to have regular cervical screening. For example Stein and Allen (1999) audited cervical screening for women with an intellectual disability in one English health district. Out of 389 women with an intellectual disability identified from community health records as eligible for cervical screening, only 13% had a record of a smear test in the previous five years. Four percent had received inadequate smear tests and one woman had received a follow up of a previously abnormal result. This coverage was markedly below that for the general regional population which had a screening rate of 88% in a comparable period. Similar regional research by Mencap revealed that only 8% of women with intellectual disabilities underwent cervical screening compared with 85% of women who did not have disabilities (Cambridgeshire County Council, 2002).

A state wide database is currently being developed by the Centre for Developmental Disabilities Health in Melbourne (2002 Sutherland, unpublished data). The preliminary database involved 243 women and revealed provisional data relevant to the present study. Results for the entire sample ($n = 243$) indicated that 10% of women with an intellectual disability were involved in cervical screening during the previous 12 month period. However 82% of them visited a general practitioner for a medical check-up at least once during the same time frame. Only 8% of the youngest age group (18-35years) had participated in cervical screening. 14% of women aged 36-50 and 13% of women aged over 50 years indicated that they had participated. Sutherland (2002) commented that the older subset of women was much smaller and therefore results should be viewed with caution.

The main barriers which women with intellectual disabilities experience in having cervical screening have been identified as:

- *Living arrangements.* Results from the Victorian study (Sutherland, 2002) showed 13% of women living in supported accommodation settings participated in cervical screening in comparison to 5% of women living in the family home. Unfortunately the number of women in the sample who stated that they were living independently was too small to be included in the sample.

- *Pain and difficulty with the procedure.* A regional health study in the UK revealed that the procedure was experienced as painful and difficult by many women with intellectual disabilities. The study does not reveal why this was the case (Broughton and Thompson, 2000).
- *Failure to offer cervical screening.* Stein and Allen (1998) report that health professionals fail to offer cervical screening to women with intellectual disabilities and there was a low demand from this group. This may be due to assumptions by families, staff and health professionals that women with intellectual disabilities are not sexually active (Johnson et al, 2001). Such assumptions should be seen in the context of the high rate of sexual abuse and exploitation experienced by this group of women. For example, overseas research suggests that approximately 86% of women with intellectual disabilities experienced some form of sexual abuse in their lives (McCarthy, 1999).
- *Difficulties in obtaining informed consent.* Lack of information about health matters may exacerbate the difficulties of obtaining consent from women with severe intellectual disabilities. Further there is a reluctance among family and health professionals to provide routine gynaecological health maintenance to these women. Such reluctance seems to be based on a view that they could not tolerate breast and pelvic examinations, that it would be too traumatic for them, would take up too much time or simply be a 'waste of time' (Witmeyer, 1998).
- *Inadequate training and communication skills of GPs* in working with people with intellectual disabilities (Stein and Allen, 1998).
- *Access difficulties.* Of particular concern in the literature were the pressures of competing demands from other patients on the medical services and difficulties by some women in using an appointment system or the only available waiting room (Stein and Allen, 1998).

Women with physical disabilities

There is evidence from overseas research that women with physical disabilities are less likely than other women to have regular screening or other sexual health screening. Evidence has been collected from the National Study of Women with Physical Disabilities in the United States about rates of screening, both for breast and cervical cancer (Nosek and Howland, 1997). This was a case comparison study in which women with a variety of physical disabilities were compared with a group of women without disabilities. A total of 843 women completed the survey, 450

with a disability and 393 of their nondisabled friends. The most common primary disability types were spinal cord injury (26%), polio (18%), neuromuscular disorders (12%) multiple sclerosis (10%) and joint and connective tissue disorders (8%). Twenty two percent of the women were judged to have severe functional limitations, 52% had moderate disability and 26% had mild disability. Women with a disability were less likely than women without a disability to receive pelvic examinations on a regular basis and this was especially the case for women with more severe disabilities. A study of 220 women with Multiple Sclerosis (MS) found that 50% of them did not have regular preventive checkups, and 11% had not had a Pap test in the last five years, while 25% did not have regular pelvic examinations (Shabas and Weinreb, 2000). There is also evidence that the more severe the physical disability the less likely women are to have regular cervical screening (Centre for Research on Women with Disabilities 1999; McConnell, 2001).

A range of barriers to women with physical disabilities accessing regular cervical screening has been identified in the literature. In summary these barriers are:

- *Attitudes of health professionals.* Women with physical disabilities are frequently seen by those around them as 'asexual' (Seymour, 1998; Scullion, 1999). Consequently they may not be told about cervical screening or advised on how to have it. Health professionals may also decide that the woman's physical disability and possible life expectancy does not warrant screening (McConnell, 2001).
- *Access.* Transport issues and access to buildings were reported as difficulties which prevented women with disabilities from having regular cervical screening. Lack of moveable beds or hoists were experienced as particular difficulties. Some women also required an attendant to assist them in taking the test or needed extra time. These needs were often unmet (Nosek et al, 1997).
- *Personal issues.* Some women with physical disabilities reported that lack of time to take the test, their inability to find a doctor who suited them and the embarrassment they experienced in taking the test were obstacles to regular cervical screening (Nosek et al, 1997).
- *Lack of information* about the need for, and the nature of, cervical screening were also experienced as problems by some women (Nosek et al, 1997).
- *Lack of money.* Poverty was a factor for some women with physical disabilities (Nosek et al, 1997).

- *Negative previous medical experiences.* Childhood and adult experiences with the medical profession which may have been negative for some women with physical disabilities could lead them to rejecting screening options in adulthood (Nosek, et al, 1995).

Women with psychiatric disabilities

A recent study (Family Planning Victoria, 2000) involved a consumer survey of ninety one women with a psychiatric disability in Victoria. The ages of the respondents were between teens and seventy with almost all being aged between 20 and 60 years. Many of the barriers to having regular Pap tests stated by women with psychiatric disabilities were similar to those expressed by other women. Women stated that the following were barriers or issues of concern to them:

- *Previous negative experiences.* These included previous sexual abuse, discomfort or pain (though 70% of women said that they were happy with the whole experience).
- *Access.* Included under this label were difficulties in getting to the service and the need for extended consultations.
- *Finding a suitable doctor.* Eighty percent of respondents preferred a woman to attend to sexual and reproductive health needs. Women also reported that many doctors did not provide them with a prompt when cervical screening was due.
- *Issues of informed consent.*
- *Cost* (This was an issue for only a small minority of women).
- *Lack of support from others.*
- *Need for increased information.*

The study also involved a survey with health care providers and made recommendations for changes which included better training for health care providers and support for women with psychiatric disabilities.

Our search of the literature has so far revealed little other literature on Pap tests and women with psychiatric disabilities.

Women with sensory disabilities

We were unable to locate any research literature which involved an exploration of cervical screening and women with sensory disabilities.

Summary

The literature suggests that women with disabilities are less likely to have regular Pap tests than other women in the community. A large number of barriers to cervical screening for these women have also been identified. These have three main characteristics: they involve the nature of the test itself with possible interactions with the previous experience of the woman, the experiences of the women and how they see themselves and their health, and structural issues which include poverty, characteristics of the medical services and the way in which particular groups of women are viewed by those around them.

Conclusion

The response to this project was overwhelming. Agencies gave time and resources to assist in recruitment of women with disabilities and to discuss the issue. Cervical screening was perceived to be an important concern in relation to the health of women with disabilities. Some organisations were concerned because there had been little research undertaken with their members. Others were concerned because they believed that action is urgently needed to ensure that their constituents have regular Pap tests. This research is a small step in meeting their concerns.

The rest of this report provides an account of the consultations and interviews undertaken with women with disabilities, disability organisations and Pap test providers. It is divided into two parts. The first part focuses on the experiences of women with disabilities. The second part is concerned with the responses of disability organisations and Pap test providers.

PART 1 - WOMEN AND CERVICAL SCREENING

I don't mind them (Pap tests) actually, because it makes you, like if you are going to have cancer, you know, the doctor can see if you're gonna have cancer and it's on the safe side that's how I see it.

(woman with an intellectual disability)

It's torture.

(woman with a physical disability)

Women with disabilities have a wide range of often strongly held views and feelings about cervical screening. Generally they also have clear views about its place in their lives and the barriers they experience in accessing it. Part 1 focuses on how women with disabilities see the experience of cervical screening in their lives, the barriers that they encounter in accessing it and the factors which can make it easier for them to do so.

In our discussions, women with disabilities identified three broad clusters of issues which they saw as presenting barriers to regular cervical screening. Many of these are similar to those noted in the literature for other women who do not have disabilities.

- Social barriers, for example, cost, transport and access.
- Factors relating to the woman's particular life circumstances, for example pain, frequent moves in location, lack of support from others, issues relating to a particular disability.
- Subjectivity or the way women see themselves, their bodies and their own sexuality.

These clusters occurred across all disability groups and for this reason we have not discussed the women's views in specific disability groupings although we did in relation to the literature search. Each chapter in Part 1 deals with one of these clusters.

Quotations from the interviews with the women will be used throughout this chapter. We are conscious in doing this that the women's stories are fragmented. The comments they make are powerful but the stories which they told are even

more so. We decided not to use the stories in total because we wanted to show a range of different views and because we did not have the women's permission to do so. We have identified each woman by disability type in order to show the extent to which the factors they identified cross disability barriers. We are somewhat uncomfortable at doing this as it perpetuates the labelling which women experience.

Who were the women?

I try not to overdo it too much now because of my health at the moment, but I do crocheting I do I watch TV and I go on my computer and I go and visit the community house sometimes and you know just odds and ends.

(woman with an intellectual disability)

I'm semi-reclusive...what I do is I try and occupy myself with my interests and one of my interests is writing so I spend a lot of time doing that and that helps keep me steady.

(woman with a psychiatric disability)

I work with theatre and concert bookings... I work on the telephones, answering calls. I live with John. John's my partner. I've been with him ten years. We get on really good together, we have a lot of fun.

(woman with a sight impairment)

I live here on my own so I live independently with carers coming in the morning and at lunch-time and the evenings. So the carers in the morning help me get out of bed and shower and dressed, and the carers at lunch time just make sure I've had something to eat and the carers that come at night time undress me and put me to bed or help me get undressed and they put me to bed. But other than that I'm living independently.

(woman with a physical disability)

The lives of the women we interviewed were very different from each other. Some lived alone in the community, others were in relationships or lived with family

members. Those who were employed worked in a variety of settings and their interests and concerns were diverse.

Five of the women lived in country Victoria and the rest lived within the Melbourne metropolitan area. Three came from culturally and linguistically diverse backgrounds. Eleven women with physical disabilities were interviewed. Four of these women had their disability from birth or childhood, the rest had experienced the disability in adulthood. Six women with psychiatric disabilities were interviewed. Two women with sight impairments and three deaf women were interviewed. Two women in the group had multiple disabilities.

The age range of the women was from 26 to 59 years. The average age of the women was 46 years. Fourteen of the women were unemployed though a number of them were keenly interested in paid work. One worked voluntarily. Only two of the women were in full time work. The majority received some form of pension. Five were caring for small children. Fourteen women lived with a partner or family member and twelve lived alone.

All of the women in the group had experienced at least one Pap test. It is perhaps hardly surprising that women who had not had Pap tests did not volunteer to talk with us. Twelve of the women stated that they had Pap tests irregularly while the remaining fourteen had Pap tests every two years.

Talking with the women

Interviews were carried out with the women at a time and place that suited them. Sometimes we met at the University. Other women found it difficult to travel and so interviews were carried out either at their workplace or in their homes. Most interviews went for approximately one hour.

In addition to the interviews, four focus groups were carried out. One of these was in a country region and involved a group of ten women with disabilities, eight of whom had intellectual disabilities and two of whom had physical disabilities. Generally these women were younger than those who were interviewed. A workshop was held as part of the Vicserv conference. The workshop involved both people with psychiatric disabilities and staff from across Victoria. Twenty women attended the workshop with about eight self-identifying as consumers. A discussion was held with a group of eight women with disabilities at a community centre in

Melbourne. Most of these women had an intellectual disability. Finally a focus group was held with a group of peer educators who work with other women with disabilities. Their views are also included later in the report.

CHAPTER 2 - DISABILITY.... IT'S A SOCIAL PROBLEM

"Disability," I write, "it's a social problem,
a problem of access and acceptance.
People can enable or disable.
They can include or exclude."
Disability is that, and more.

Disabled people struggle
in a world not made for us, limited
by bad design, bureaucracy,
attitudes and assumptions
and (yes) by our own bodies and minds....

Ria Strong

This chapter is concerned with women's views about the social barriers which confront them when they seek cervical screening. As noted in the Introduction, much of the available literature on barriers to women accessing such screening has revealed that many of these barriers are ones imposed by the society. In this chapter we outline briefly the social model of disability and health as a theoretical background against which one cluster of the women's responses can be seen.

The social model of disability

Over the past decade the social model of disability has gained increasing influence in discussions about disability and the development of policy and practices affecting the lives of people with disabilities. The social model of disability arose from the disabled people's movement in the UK (Finkelstein, 1993; Oliver, 1996).

The key concerns of the social model are summed up below:

Rather than focusing on the individual's limitations, the social model sees disablement as inherent in society. The barriers to participation, inclusion and full citizenship by people with impairments are many and complex. At the simplest level, this translates into the need for ramps and hearing loops to overcome physical barriers in the built environment. At a more complex level, social model theorists have found barriers in the way paid

work is structured, the pre-eminence given in societal values to youth, beauty and physical perfection (Hevey 1998), and the close association between impairment and evil in much Western literature (like Long John Silver, Captain Hook etc) (Keith 2001).
(Walmsley and Johnson, in press)

It follows from this model that it is the responsibility of the society and its various organisations to remove the barriers which lead to the disablement of any of their members. In relation to cervical screening, the focus of intervention should be on the removal of barriers of access and attitudes, rather than on the attempt to adjust the person with a disability to existing structures and processes or to focus on their impairment as the cause of reduced regular screening among this group.

In talking with the women in this project, it became apparent that many of the barriers which they identified in accessing cervical screening on a regular basis were the result of societal barriers and attitudes. We believe that these particular responses fit well within the social model of disability. Placing them within this framework is important because it leads to a shift in mind set away from the nature of a particular impairment to one where energy, creativity and resources are directed at changing social structures.

Social barriers

When we began this project we believed that social barriers would be the main obstacles for women in gaining access to Pap tests. These were certainly the issues which were most often documented in the literature (see Chapter 1). We found that they are extremely important but they are not the only issues and certainly not the most important for some women. This chapter outlines the main social barriers which women have raised.

Access to buildings and to suitable beds and hoists

Physical access to buildings was not an overwhelming problem for most women with whom we talked. However, often service providers believe that once a ramp is in place then the building is accessible. This is not always the case. For example, some rooms within the building were experienced as too small to manoeuvre a wheel chair and the building layout could present real difficulties. One woman with a sight impairment commented:

It's a bit difficult because when you are in the waiting room and the reception's not straight there. You have to go round a corner and into another room and the people are behind a huge desk which comes up to sort of my chest height, and they're sitting behind that, so they're a bit inaccessible.

(woman with a sight impairment)

The major access problem experienced by women was the lack of adjustable beds and hoists in most surgeries. This was particularly the case for women with physical disabilities who were not able to weight bear and so were dependent on either suitable equipment or the presence of an attendant who could lift them. The consequences of this for women were varied. Their choices of doctor or services were limited to those who had accessible technology. For example one woman was forced to change her long term doctor in order to find an accessible service.

Now I've had to ring around trying to find somebody with a height adjustable bed, there was no one that I could source. So it was a case I just spent the morning ringing around different gynaecologists. That's how I found that one.

(woman with a physical disability)

Two women had asked their doctor to do cervical screening for them at home. One woman was extremely happy with this solution.

I don't mind having it at home because I have a bed that moves up and down and, as I said, I know the nurses really well and I know my doctor really well.

(woman with a physical disability)

This solution was dependent on the woman having a doctor who was willing to do the test at home. And for at least one woman, the experience was intrusive and demeaning.

It was a little uncomfortable being in my bedroom and he couldn't...my light wasn't bright enough and so he borrowed my little desk lamp and sort of put it right on the spot so that he could

see and it was like, oh gee, this is really intimidating, but anyway we got through it and yeah, it came out all clear.

(woman with a physical disability)

Cost

While some cervical screening services are free, others require payment. This can range from \$6.80 to \$80, depending on the practitioner. In some country areas there were no doctors who bulkbilled so a woman was forced to make an up front payment.

Well there was one doctor who bulkbilled... But the others (doctors) ran her out of town.

(woman with a physical disability)

There are also hidden costs involved in travelling to the service or claiming money back afterwards. If this were combined with a payment to the doctor the cost of a Pap test could be more than \$100. Most of the women to whom we spoke were on pensions or low incomes. A Pap test was something that had to be budgeted for.

Well I had to go to the(hospital across town) which means more cabs and stuff and originally a friend had offered to take me but it wasn't school holidays and I knew if I kept putting it off and putting it off, I was already a couple of months beyond what I should have done, I thought I'll never do it. So I just went. So it's a cost thing that you know, there's taxis and stuff. It's not the hour procedure that most people can pop in and out and do.

(woman with a physical disability)

The costs increased further if the woman needed an attendant to assist her in moving from a wheel chair to the bed. One woman with a physical disability reported that the Transport Accident Commission had refused to pay for such an attendant. This meant that she had to change unwillingly to a doctor with more accessible facilities.

Transport

While this was not a problem for all women, some of whom drove their own cars or had support, it was a difficulty for others. Frequent mention was made of taxis which failed to come on time, were ill equipped or left a woman stranded at the service after the test.

And some of the attitudes of the drivers. There was one driver about six months ago, he didn't know how to get his ramp down. He didn't know how to get the ramp down to even wheel me on board.

(woman with a physical disability)

Sometimes doctors failed to realise the difficulties which women had in reaching the service. One woman with a physical disability walked two and a half kilometres each time she went to the doctor because she could not afford the transport to get there.

Information

There is a lack of plain English information available to women about cervical screening. A majority of the women interviewed knew the main purpose of cervical screening, however some did not. This was particularly the case for women with intellectual disabilities and women who were deaf. Little information goes out to women through organisations to which they belong and they saw little information about cervical screening at their health services. Most had been advised to have a Pap test by their doctor although some had heard about it through friends.

No, you don't see very much at all, not even in the doctor's rooms, like you don't see anything about Pap tests. Some people with a disability, not myself, some people with a disability mightn't know what sex means, some might just think if you're holding hands, that's having sex, so it's very hard for, a person that hasn't got a knowledge of sexual activities, what to do.

(woman with an intellectual disability)

Some women had been given no information at all about cervical screening. Friends suggested that they should have it and they did.

I think it's something that happened in, when I was a teenager...and it was something that I was told to have, but there was no, you know, explanation of what it was or anything about it that I was aware of.

(woman with a sight impairment)

Attitudes of health professionals

Women's views about health professionals and their attitudes were complex and varied. Some women had established a comfortable and trusting relationship with their doctor, others relied on assertiveness and their capacity to change doctors to ensure that they got the service they wanted.

I don't necessarily have a regular doctor. Whilst I say I choose doctors carefully, I tend to also avoid them like the plague. I find I tend to know more about medicine than they do on a number of occasions.

(woman with a physical disability)

Some women believed that health professionals saw them as asexual and therefore did not raise issues about Pap tests. This view was held by women across disability groups.

It's the old communication thing. They ask: "And why are you having it?"

(woman with a physical disability)

Such attitudes may express the doctor's negative view about disability.

I had a family doctor... and he just turned around and...when I first got married he wanted me to have me tubes cut and tied and I said "no way" ...he turned round and said to my mother it would be a good idea if we get her tubes cut and tied because she's spastic.

(woman with an intellectual disability)

Some women saw specialists regularly because of their disability. Women reported that specialists did not raise general health issues with them or suggest referrals for screening procedures.

My psychiatrist years ago...he said you're bringing up these problems (physical health issues) with me and I'm here to help you with your mind you know, not your body.

(woman with a psychiatric disability)

They focus mainly on the MS (multiple sclerosis). I mean my new neurologist. He was just basically into neurology you know but he was a very nice doctor and was interested in how I was coping on my own and pointed out a few things but he wasn't really into it.

(woman with a physical disability)

It should not be expected nor would it be advisable for specialists to undertake women's health checks, however there did seem to be a view that a comment or a referral about general health issues would be useful. This was particularly so for women who saw a specialist regularly but did not have a regular GP.

Women practitioners

Having a choice about who carried out cervical screening was very important to the majority of women (though not all). Most indicated a strong preference for a woman to do the test, though others felt comfortable with a man doing so. Women in country areas had few choices about who undertook Pap tests. And it was being able to exercise a choice that was important.

Nope I don't like women doctors.

(woman with an intellectual disability)

It's embarrassing...I wouldn't have a man doctor do it, I'd like a woman to do it. That's why I have a woman instead of a man.

(woman with a psychiatric disability)

Lack of sensitivity by health professionals

A failure to check what supports a woman might need in accessing cervical screening was apparent in reports of some women when talking about service providers. For example, a failure to offer support in getting onto the bed or to question whether a woman knew what the test was for and how it was done.

Sometimes I stand for a few minutes in front of the steps (leading to the bed) and try to figure out how to get myself up them. There isn't even a rail. He never offers to help.

(woman with a physical disability)

Because you don't get told what they're doing Kelley. Like they never explain to you, and like I was, even when I had to have 'em done, it's like I don't want to go and have 'em done because it's likeyou're opened up, and they're putting on these instruments, but they don't explain it to you, what they're doing to you, and for a person with a slight disability that's scary but what about people who have got more a disability, they don't know what these instruments are going inside their private parts.

(woman with an intellectual disability)

Gate keepers

Most of the women with whom we consulted were living independently in the community. However even for this group of women it was clear that gate-keeping by those around them could present barriers to gaining access to information about cervical screening or indeed to the test itself. Two examples highlight these issues.

Attempts to talk with women from culturally and linguistically diverse backgrounds were made difficult in this study because carers and family members did not want the women to hear about cervical screening or to be interviewed about it without their presence.

Discussions with women with intellectual disabilities at a women's group revealed that many of them knew nothing about cervical screening and comments from support staff revealed a view that none of the women in the group would have had

sexual experiences. Therefore staff believed that they did not need to know about cervical screening.

Discussion

"The health and wellbeing of women is related to the social context in which they live. Health and wellbeing is influenced by economic position, access to employment and education, housing and transport; and other critical factors including gender, culture, age, race, disability and geographical location".

(Department of Human Services, 2002, p.9)

The social model of health outlined in the report on Victorian women's health and wellbeing (Department of Human Services, 2002) resonates strongly with the social model of disability discussed earlier in this chapter. Like this, the social model of health encourages a view which focuses on the barriers to women in gaining access to health services. We believe that linking these two models may provide a useful framework for future discussion and action by health services which are responsible for women's access to cervical screening. The comments from women in this chapter reveal a struggle to obtain access to services which can provide adequate support and access to women who are seeking preventative health care.

The women who talked with us revealed a range of different social barriers which made it difficult for them to access cervical screening. However many of these had little to do with them or their disability. In fact a comparison with the barriers experienced by women generally in gaining access to cervical screening reveal similar kinds of barriers: attitudes, access, cost and lack of accessible information are all commonly experienced barriers. Women with disabilities are not a group apart from other women. Their disability provides an additional overlay to concerns experienced by many other women.

The women to whom we spoke were clear about some of the kinds of strategies that they thought would assist them. Of primary importance were changes in attitudes of both disability organisations which could provide needed support and information and the health professionals. Clear accessible information in a variety of forms was also stressed as important. Women suggested the need for material that could be taken away and studied. Videos, sound tapes, Braille and clear, plain English information with graphics were all mentioned. Some women were also

interested in the development of forums where women's health issues could be discussed.

Improving access to health services was also seen as important. Women with disabilities wanted to see more services which provided accessible beds and hoists. They wanted to be able to discuss their needs for such things with the health service professionals and to see some action taken about them.

CHAPTER 3 - STRONG WOMEN

You see
a strong woman,
independent. I bluff.
I've learnt to hide my pain behind
a smile.

Alone
I struggle on.
My friends have their own lives,
and my family-- their abuse
cuts deep.

Ria Strong

Life for women with disabilities is as variable as it is for other women in the community. They may live alone or with partners, be in paid employment or work at home, they may find that their disability is a major factor in their lives or one around which they are able to manage. We found that the particular life circumstances of individual women had a profound effect on their access to regular cervical screening.

Many of the issues raised by women about their life circumstances focused on the impact of the disability on their lives. Some of them expressed great anger and frustration at these issues. Others saw them as ones which they had to manage. In addition there was also a cluster of issues which related more to general factors within a woman's life, her geographical location, her relationship status and her income which may have been influenced by her disability but could also be seen as broader life circumstance issues.

Impact of disability

The way women saw the impact of their disability on their lives varied with the extent of the disability rather than its kind. But the implications of the disability often had a direct influence on their decisions about having regular cervical screening, others were more subtle.

Pain

There was nothing subtle about the pain experienced by some women when having cervical screening. Interestingly this does not receive a great deal of attention in the research literature where it is named but not explored. For some women with cerebral palsy (though not all) there was extreme pain, or "torture" caused by muscular spasms.

Well it took me a long time to work out why it was torture and I used to have a previous GP, woman GP, who basically when I started screaming didn't understand why it was hurting me so much and at that stage I could still get up on the ...table they've got and my memory of it is now that it hurts much more, but that could be knowledge as well.

(woman with a physical disability)

Efforts by more sympathetic and knowledgeable practitioners had failed to reduce this woman's pain. The use of Valium to relax her muscles left her with a 'hangover' for three days, making the Pap test even more of an ordeal.

Pain was also experienced by other women with physical disabilities.

I've got...more intense in certain areas and I find that particularly now, it becomes more painful.

(woman with a physical disability)

The experience of pain was not restricted to women with physical disabilities. It was also raised by two women with intellectual disabilities who made the following comments:

It was the plastic instruments that hurt the most. The other instrument didn't hurt as much because they warmed it up and that, but by God, I tell you what, that other one, you know.

(woman with an intellectual disability)

It's just if you move the wrong way, the metal keeps, between where it sits in your disc, in your disc line of your bones, ...if you move the wrong way the metal moves as well, and they can't get a

clear scrape so they force the metal back into you. They force the clamps into you as well, and the clamps is like "I want the clamps out. I want 'em out now you know.

(woman with an intellectual disability)

For one deaf woman the pain experienced in one Pap test could not be expressed. As she and her doctor relied on written messages for communication she felt unable to tell the doctor of the pain because of the difficulties of communicating with him.

I thought if I tried (to tell him) it would all take longer. I just wanted it to be over.

(deaf woman)

Not all women in the group experienced pain. Although none saw the Pap test as a positive experience, some saw it as a necessary discomfort. However there is a need for sensitivity on the part of health professionals in order to identify where a woman may experience more than discomfort.

Previous medical experiences

For some women a decision to have a Pap test is complicated by previous experiences of medical treatment. In some instances this led women to avoid doctors "like the plague." Other women experienced the medical situation as one of powerlessness which was exacerbated when they did not know about the nature or purpose of cervical screening.

I mean often someone will say something to you and then there'll just be silence, or they'll up and walk off or something and you'll have no sense of how you're meant to react or whether they're asking you or telling you....They've told you you're going to have a Pap smear, but then you think well what is that going to involve and you know you don't know if it's going to be lying down or what are you going to lie down on , you know, because you wouldn't know if there is a bed in the room.

(woman with a sight impairment)

Some women's previous experiences were restricted to adult life but for others the childhood experiences of being treated for a disability remained vivid and impacted on their current decision making.

I'm a person who's gone through the medical system from as long as I can remember....I can remember the Children's [Hospital] and all that sort of stuff and it was lovely because you'd go in there and get to eat in the canteen, and that was a treat, but you'd have physio and doctors would do this and they'd do this thing and you know doctors would come in and pat you on the head...and everything is medicalised.

(woman with a physical disability)

Management of health and disability

Some women's lives were taken up with the management of carers or specialist staff. Sometimes their working and social lives depended on the presence of an attendant carer to assist them. Ensuring the attendants arrived on time or at all was an important part of the woman's life and could be very time consuming. As well some women received regular physiotherapy, home help, district nursing services and also had to go to a specialist on a regular basis. The management issues were sometimes difficult and complex.

I do have attendant care mornings and evenings through an agency. Tonight is not a good night to ask about it. Tomorrow morning is not covered. Who knows what will happen?

(woman with a physical disability)

[If the attendants don't come] I press my alarm, one of those little button things, emergency things and I just ask the girls.... I think it's Medipacks, the company that runs this one and they're very good and they just get on, who do you want us to ring. And they've got a list of three people plus my case management. So you just get them to ring the case manager and then the case manager chases it up.

(woman with a physical disability)

While both of these women managed to have regular Pap tests, it is not surprising that in a situation where the woman was confronting multiple management issues on a daily basis cervical screening could sink to the bottom of the list of priorities.

The shock of disability

Some women had acquired a disability in adult life. Two of them reported that the shock and disruption caused by the advent of the disability led them to abandon preventative health measures for some time.

Yes it was gone in the blink of an eye, my whole life, well, as I had known it. It just sort of disappeared. I hadn't been sick up until that stage. The only time that I bothered with doctors was either to have my children...if they were ill you know.... Was fairly fit...There were a lot more health issues and that one [Pap tests] got pushed to the bottom of the pile.

(woman with a physical disability)

A disruption to having regular cervical screening could also occur when a disabling condition worsened.

I went through a stage where I didn't have one at all, because when I lost the ability to weight bear I couldn't quite see how my doctor was going to conduct the Pap smear because I couldn't get onto his bed, because I can't stand up and weight bear.

(woman with a physical disability)

In neither of these cases did medical professionals provide advice or reassurance in relation to having cervical screening.

Institutional life

Many of the women to whom we spoke had spent extended periods of time living in institutions. These included general hospitals, psychiatric hospitals and nursing homes and institutions for people with intellectual disabilities. These women reported that staff at such institutions did not provide preventative health care reminders or discuss general women's health with them. Neither was there general health information available. One woman who spent a long time in a general

hospital after an accident commented that staff did not show concern about her sexual health in the same way that they did for men. In fact they seemed to either disregard or ignore the issue.

*The men were given plenty of help, you know, but you're fine
...women become second rate...Whether they've changed now
because that's 13 years ago, but I would doubt it, um, it's always
men, it's always - - tends towards their function, everything and
women are just supposed to lie there.*

(woman with a physical disability)

The failure of institutional staff to consider broader preventative health measures had particularly horrific consequences for one woman who lived in institutional care for some years. No reminders about sexual health were given and there was no support offered for her to have checks. She finally requested tests and was found to have uterine cancer.

Institutional life was also seen by some women as disempowering, making it difficult for women to say what they wanted or needed.

*Well you learn...when you're in a institution, you couldn't say what
you want to say and that, see I can remember when I used to go
to the doctor and the doctor was there and the nurse was there
and you couldn't even say what you want to say,...the nurse was
the one that was saying things.*

(woman with an intellectual disability)

Life circumstances

Among the issues raised by women about their life circumstances were poverty, the degree of support they had from others around them, geographical location and cultural issues.

Poverty

Most women we interviewed were either in part time employment or were not in paid work at all. Most were on pensions and found it difficult to manage. Cervical screening in this situation had been weighed against other priorities. For some

women having a free service was extremely important in ensuring that they undertook regular Pap tests. Others commented that they would have the Pap test even if they had to pay because "you only have one life". The issue of cost has been discussed previously in Chapter 1.

Disrupted lives

Some women moved around in order to obtain either a better quality of life or access to needed services. Others moved because of issues relating to their disabilities. Such movements meant that they did not have a regular doctor or health service and did not receive reminder letters about cervical screening (even if they were on the register).

Where I've been homeless and I didn't know where to go and I've had those shelter places that I've been to and that...[It was] very painful being left out in the cold and when you've children it's really hard...I didn't have a stable life.

(woman with psychiatric disability)

In this situation it is hardly surprising that this woman said that she had not had Pap tests during her time of instability.

Support

It was clear from the interviews and discussions with women that having a supportive partner or network was really important to them in maintaining regular health checks. Sometimes this support took the form of assisting a woman physically to attend for screening. However emotional support was seen as critical for some women, as it assisted them overcome their fears about screening processes as well as supporting them in their lives more generally.

If I was on my own here, I don't know how I'd look after [myself]. Whether I could cope if Roger died. I don't know. You know it would be something I'd have to look at.

(woman with a psychiatric disability)

As long as my husband's in the room I feel safe.

(woman with an intellectual disability)

Someone to be with me all the time. It would make me a lot easier to have one of the family members in there. Basically it'd be a lot easier to have someone in front of me, right someone who could keep watch or someone by my side.

(woman with an intellectual disability)

For some women it was important that doctors or Pap test providers be sensitive to their need to have a trusted other person present during the test.

Cultural issues

As noted earlier in this report we found it difficult to discuss the issues of cervical screening with women from culturally and linguistically diverse backgrounds. The sensitivity of the issue for some of these women was clear in the refusal of some carers to let us speak alone with women with disabilities about the issue.

The women to whom we did speak raised a number of issues which they believed could prevent women from their culture from accessing cervical screening. The lack of English language skills could either prevent women from accessing tests or restrict their choice of practitioner since they felt more comfortable with someone from their own culture.

Because of cultural differences and experiences with health professionals they may experience increased anxiety about the results of the test, making it difficult for them to take the first step. Such anxieties may increase if the woman does not have regular Pap tests.

In some cultures virginity in women who were not married was highly valued. Younger women could be prevented from going to a doctor for cervical screening either because it involved disclosing their sexual activity or because they were afraid that by doing so other members of their community might find out about it.

Discussion

The life circumstances of the women had a profound impact on their access to cervical screening. In discussing these issues women were clear about the changes they would want to make in order to make such access easier. For some women this involved a more woman sensitive approach to their situation by the health professional. It was important that their needs were heard and listened to. It was also important that health professionals should be sensitive to possibly negative past experiences with medical practitioners without requiring the woman to provide a history.

Some women were extremely angry at the failure of support staff in institutions to provide them with health care and guidance in relation to general health matters. The lack of information available to them in institutions (or indeed in the community) was an additional problem for these women.

The need to ensure that cervical screening is available to women free or at a very small cost was highlighted again as women spoke of the difficulties of managing their lives on often small incomes.

For some women, the support of a trusted friend or partner was important in helping them to deal with anxiety about cervical screening. However health professionals do need to be careful too that the presence of staff members does not disempower their patient.

Given the strong statements from some women about the pain experienced during Pap tests, it is important that health professionals be alerted to this issue and that they be willing to talk with women about it and to suggest possible ways in which it can be alleviated. Where possible such discussions should happen prior to the test rather than after the women has experienced it.

In conclusion, it seems to us to be important that cervical screening be promoted as part of a necessary well women's check that will enable health professionals and women with disabilities to manage some of the circumstances in their lives and reduce the anxieties which some of them experience in relation to the screening.

CHAPTER 4 - BARRIERS: SUBJECTIVITY

I still

Sometimes miss her,

The woman I once was -

But I'm proud of the woman

I become

Ria Strong - Rebuilding

Background

Ria's poem both celebrates the woman she is and mourns the woman she was. It encapsulates the complexity of views which women in this study had about their subjectivity. In our interviews and discussions with them we found that they held a wide range of views about themselves as women, their bodies, their sexuality and their disabilities. These views and feelings found some expression in the way women regarded cervical screening. This chapter explores how subjectivity impacted on the women's decisions about cervical screening.

Subjectivity in this chapter is defined as:

'the conscious and unconscious thoughts and emotions of the individual, her sense of herself and her ways of understanding her relation to the world.

(Weedon, 1987, p.32)

This definition focuses on a woman's inner experience of self: how she sees herself as a unique person and her awareness of that self. The definition also recognises that subjectivity is not fixed 'self regard' but is partially dependent on how the woman is perceived and known by those around her and how they behave towards her (Henriques et al, 1984).

We found that little has been written about the relationship between subjectivity and the experience of cervical screening. As noted in the introduction, when it is mentioned it occurs in terms of overall categories such as 'fear', 'embarrassment', or 'shyness' which do not reveal the underlying complexity, strength and subtlety of the experience of individual women.

However the importance of subjectivity has been explored by feminist writers, particularly those within the disability field. They provide a broader context for the responses of some of the women with whom we spoke. In particular the literature stresses the denial of gender issues which can occur when a woman has a disability, the effects of current social emphasis on the nature of the 'body' as an important issue in subjectivity and the denial of the wider issue of an inner life for some people with disabilities (Deegan and Brooks, 1985; Fine and Asch, 1988; Johnson, 1998; Traustadottir and Johnson, 2000; Atkinson et al, 2001).

Denial of an internal life

Some people with disabilities are supported strongly by their own sense of themselves and by those around them. However others are forced to struggle against the view by others that they do not have an internal life (especially an internal sexual life) of their own. This is particularly the case for people with intellectual disabilities but may also occur in relation to other individuals with disabilities where the individual is constituted almost entirely by the observer's view of their disability. The effects of the denial of an inner life have been documented by some theorists in terms of the development of secondary disabilities designed as responses to societal reactions to the person's disability (Sinason, 1992; Johnson, 1998) which may involve self hatred, self injury, depression or despair.

Denial of gender issues

One particular aspect to subjectivity which has been repeatedly documented in the literature has been the denial of gender issues among women with disabilities.

The income earning opportunities of women with disabilities are severely constrained. So, too, are their opportunities to be nurtured and to nurture, to be lovers and be loved, to be mothers if they desire. Women with disabilities are less likely than non-disabled women or disabled men to fulfil roles customarily reserved for their respective sexes. Exempted from the 'male' productive role and the 'female' nurturing one, having the glory of neither, disabled women are arguably doubly oppressed....

(Asch and Fine, 1992, p.151)

Feminist writers (often disabled women) have over the past ten years repeatedly described the way in which gender issues can be camouflaged, ignored and screened out of consideration by family, services providers and other community members in relation to women with disabilities (Keith, 1994; Morris, 1991; 1996). Such exclusion is difficult to resist and some women have documented powerfully the struggle to have their issues as women heard by those around them.

The denial by others of the womanhood of some women with disabilities has an effect on the way they see themselves. Some women have struggled to assume roles as independent people, parents, lovers and workers (Traustadottir and Johnson, 2000, Morris, 1996). Others have been unable to resist their exclusion (Johnson, 1998).

The reactions of women with disabilities to the denial of their gender is varied. Some mourn the loss of roles and desires which seem much more difficult to achieve than prior to a disability, others accept the position in which they are placed by society and others react by struggling against societal policies and practices. Each of these positions was represented by some women in our study.

The body and subjectivity

Modern consumer society invites us to celebrate the possibilities of pleasure derived from a cultivated and enhanced embodiment. The principal challenge to this comes from aging, death and disability.....aging and disability...are increasingly regulated, medicalised and controlled by legal regimes (Seymour, 1998, p.vi).

The focus on a 'normalised' and 'idealised' body in the general society has effects not only on the way people with disabilities are viewed but also how they view themselves. A study of the responses by individuals to spinal cord injury (Seymour, 1998) showed that they reacted very differently to the alteration in their body's appearance and functions. Some sought to "explore new and exciting possibilities of bodily experience and practice" (Seymour, 1998 p.178), while others expressed the "desire to be as much like other people as possible in terms of bodily appearance and activities" (Seymour, 1998; p.178). The nature of the response a woman makes to her disability will have an impact on the way in which she views practices such as cervical screening.

Subjectivity: How the women saw cervical screening

Women's views about cervical screening varied widely. None saw it as a positive experience although some commented that it was reassuring to get a result which showed no abnormalities. For some it was a minor intrusion in their lives,

Cervical screening doesn't particularly phase me. It's not something I find particularly invasive.

(woman with a physical disability)

For others as noted in Chapter 2, it was a source of physical pain:

I just had to bear it. It's like the catheter change, you just have to bear it because there was nothing they could do because my legs were in so much spasm they couldn't...the muscles wouldn't relax enough to let the legs flop.

(woman with a physical disability)

Others saw it as something so unpleasant or disturbing that they would not have it. Some of these women did not seem to understand the reasons for cervical screening. Others knew the risks and were willing to take them in order to avoid the test.

Yuck. I'd never have one of those.

(woman with intellectual disabilities)

I don't do it....And...fear of dying from it if you don't, if you don't do the steps....to make sure it doesn't happen to you.... The hating of it [cervical screening] must outweigh the fear, otherwise I would be able to do it.

(woman with a psychiatric disability)

Subjectivity: An issue in decision making

The decision by a woman to have a Pap test or not was mediated by a range of social and life circumstance issues discussed in earlier chapters. However to understand fully the various views which women held about cervical screening and

their subsequent decisions, we believe it is important to explore their experience of subjectivity.

This proved to be a powerful and difficult area to discuss with women and it raised issues which were not considered at the commencement of the project. We believe that it is vitally important that they be considered in thinking about preventative health. The issues about subjectivity which were raised by women who participated in this study included: views about themselves as women, issues of privacy, the lived experience of sexuality, sexual abuse and the fears attached to cervical screening.

Views about self as a woman

Some women were able to continue or develop their lives as women. They were workers, lovers, partners and parents, or independent lone women.

I live on my own. When I'm not working, I spend quite a lot of time climbing...surfing, body boarding....the odd bit of partying here and there.

(woman with a physical disability)

We've been married fourteen years.

(woman with an intellectual disability)

Some women struggled to achieve their desires and dreams as a woman:

I've had to make all me own dreams and find a way to achieve them. You know, when I was a kid it was...I'd rattle on about when I grow up and have kids....and it was kind of like, yeah, yeah, isn't that sweet darling, you've got your dreams. Or it was like, just be realistic and realise that you're never going to achieve that....I've been self made basically.

(woman with a physical disability)

Others gained a positive view of themselves as women by minimising or turning away from a 'disabled identity'. One woman commented:

...The blind live in a small world...I don't know why. But they do live in a different world, it's really strange and I had to get out of it. And get into living. It's too closed....I was advised you know, get out, get into the world and get on with your own life.

(woman with sight impairment)

With one exception, the women who had a positive view of themselves as women had experienced few difficulties with cervical screening.

Other women experienced far greater issues in terms of their view of themselves as women. Some women did not see themselves as women following the impact of the disability on their lives.

I just didn't feel like a woman. I never ever, I didn't look at my face, at my face in the mirror for seven years....After my illness, yeah, I never looked at myself`. I felt ugly. I felt asexual. I felt all sorts of things relating to not being a woman...

(woman with a physical disability)

It is not surprising that this woman did not consider the possibility of cervical screening for herself over a long period of time. It was a painful reminder of what she saw herself as having lost.

Other women found that that the experience of cervical screening could raise issues about themselves as women. One woman learned that her muscular spasms would have made it very difficult for her to have children.

And for a couple of days there I went I'm not female....it suddenly hit me that it wasn't a choice about having children for me. There was no choice....all of a sudden the disability was taking over everything...

(woman with a physical disability)

Other women had to sustain their sense of themselves as women in the face of relationship breakdown following their disability.

I think every relationship has to be worked at, but I mean, my relationship broke up, most of the women I know with MS their

relationships have broken up. There's only a few guys that have hung in there....

(woman with physical disabilities)

While it was not stated, cervical screening may have brought back recollections for these women of relationships and a way of life which they now saw as lost and which was extremely painful for them.

Some participants developed a strong and positive view of themselves as women. Others found this a much more precarious enterprise and one which experiences such as cervical screening could put at risk. And for some, the experience of disability led to a negative image of themselves as women which led them to exclude issues such as cervical screening from their lives.

...that part of the epicentre of my evil is my vagina. So it's like there's a contaminant in me and in that part of my body. And I'm not comfortable about people...exploring that part of my body in any sort of way 'cause of this lingering feeling that they'll be contaminated by me. It's a really horrible feeling. It's not very nice.

(woman with a psychiatric disability)

Most women found the Pap test embarrassing or intrusive. Some were better able to manage this than others. Some women objected to undressing or to having their bodies touched by others.

Privacy

Some women lived their lives open to the public gaze. For example they needed attendants to assist them with intimate care. In these kinds of circumstances, sometimes the women felt that the only privacy remaining to them was within their own bodies. Any intrusion into this area was seen as a gross violation.

I did menstruate irregularly and there was this one nurse that insisted that I used tampons but I couldn't insert them myself so she did it for me and I felt so invaded....it's kind of like the last, your last bastion of privacy and dignity was totally gone....

(woman with a physical disability)

Many women spoke of the invasiveness of the test which for some was heightened by the nature of their disability.

I mean there's nothing worse than somebody standing over you sort of with a vice like grip holding your legs apart with somebody else putting one of those do-dahs up you to have a look.

(woman with a physical disability)

Retaining a sense of dignity and self respect were important issues for many women. Cervical screening which involved an intimate examination of private parts and sometimes what felt like the use of physical force in order to achieve it, was an attack on the identity of the woman and her sense of control over her own body.

Sometimes insensitive medical practices also alienated women who were referred for cervical screening. One woman reported that mention of her psychiatric disability was included in a referral letter by her doctor to the hospital where she had cervical screening. She felt this was unnecessary and an invasion of her privacy.

Lived experience of sexuality

We found that there was a close link between sexuality and cervical screening for many women. A number were anxious that they may not be eligible for inclusion in the study because it had been a long time since they had had sex. Others were uncertain about their inclusion because their current sexual orientation was lesbian, although they had experienced heterosexual sex in the past. In many of the interviews, the discussion moved from a discussion of cervical screening to one which included sexuality and relationship issues. The relationships between sexuality and cervical screening were complex and difficult. Women were asked prior to having cervical screening if they had been sexually active. A negative answer led the provider to inform the woman that she did not need to have a Pap test.

Cervical screening was seen very much as women's business. Some women thought that to exclude women from the test was a form of negation of them as women. The close link between sexuality and identity as a woman became very clear. One woman commented:

I had a turn on the bed when I was having the Pap test. The doctor said, 'don't worry you don't need to have it any more'. He didn't tell me why. I felt just awful. Not like a woman.

(woman with an intellectual disability)

Another woman argued that cervical screening should not be dependent on a woman having had sex. She argued that some nuns develop cervical cancer and that the issue of screening should be 'unhooked' from sexuality.

I would like to see it [cervical screening] unhooked because...I think there is a lesser risk...once you've been sexually active you've got a higher risk, but that does that mean if you've had sex once you've got a higher risk or does it mean you've have to...

(woman with a physical disability)

Some women had not experienced sexual relationships as positive experiences. One woman found that cervical screening reactivated these memories making it more difficult for her to undertake screening.

I've never been great about sex - heterosexual sex or even lesbian sex. I mean I've enjoyed lesbian sex more than heterosexual sex but I mean I hated heterosexual sex. I hated it. So it all just reminds me of that in a way, the invasion of your body.

(woman with a psychiatric disability)

The link between sexuality and cervical screening was fraught with anxiety for some women because it necessitated them admitting to having a sexual life. Previous research has revealed that many women with intellectual disabilities lead secret sexual lives (McCarthy, 1999, Johnson et al, 2001) in part because of the strong prohibitions about their sexuality which are held by those around them. These women are also often subjected to close supervision by staff and families. They consequently have particular difficulties in asking for cervical screening since this is tantamount to a statement that they do have or have had a sexual life.

The problem was raised by some women with intellectual disabilities in focus group discussions and was explored by both service providers and an activist with a physical disability.

The medical profession have this control thing, you know and they see us as being unable to make decisions for ourselves and they talk about things like this with our parents and carers and partners...the whole issue about parents and what say they've got in it, you know that should not even be an issue. You know we don't need doctors going to our parents and saying do I have permission to tell your daughter about Pap smears you know.

(woman with a physical disability)

Sexual abuse

Overseas research suggests that up to 86% of women with intellectual disabilities will have experienced some form of sexual assault or abuse in their lives (McCarthy, 1999). For women who had previously experienced sexual assault or abuse, cervical screening was a painful reminder of the experience. In this situation it could also become the site for fantasies and confusion between the assault and the medical intervention. This led some women to refuse to have Pap tests or to be extremely hesitant about them.

The scariness [of Pap tests] is because I was raped.

(woman with an intellectual disability)

They get these four or five guys...look like body guards and hold you down and it's horrible.

(woman with an intellectual disability)

This experience of sexual abuse was not restricted to women with intellectual disabilities. It was also raised by some women with physical and psychiatric disabilities.

It's this feeling of powerlessness and I suppose for me it reminds me of sexual abuse in a way because that was a powerless feeling...and you feel as though you have no control over the situation. It's not very nice.

(woman with a psychiatric disability)

There appears to be little doubt that such an experience makes it much more difficult for women to subject themselves to an intrusive medical test which resonates with previous negative experiences.

Fears

It is clear from the above discussion, that fears relating to cervical screening could come from a number of sources. However women also had fears about the results of the tests. In some instances these fears led them to undertake regular cervical screening. Three women commented that abnormal results from a Pap test had led them to be very careful about taking them regularly. One woman who experienced Pap tests as extremely painful still had them regularly because of fear that if an abnormality occurred she would have to have them more frequently. However fear of pain and of the discovery of cancer also led some women to avoid cervical screening.

The fear with which cervical screening was viewed by women was connected with the strongly held view that it was linked with the diagnosis of cancer. Almost all of the women in the group gave this as the primary reason for cervical screening.

Cervical screening: Taboo topic

The anxieties and fears which women experienced in relation to cervical screening were heightened by the lack of discussion about it. A number of women commented that it was not something that was discussed even among close friends. Rather it was something which a woman had to deal with alone.

It's a taboo subject. Like many years ago homosexuality used to be taboo and to be a homosexual you used to be considered quite a bad person.

(woman with a psychiatric disability)

I mean it's just not a thing that women talk about a great deal, is your Pap smear.

(woman with a physical disability)

The reticence of women in discussing the issue may lead to an increase in anxiety and fear. There is little opportunity among peers to talk about or to resolve these issues.

Discussion: What did women want?

Subjectivity is a highly personal and often difficult topic to discuss. The women with whom we spoke were open in their accounts of how cervical screening related both to their views of themselves and their past experiences. Some women made it clear that regardless of the risk that they ran in not taking the test, their fears and anxieties were overwhelming. We need to take account of the fact that for some women cervical screening in its current form will be too intrusive for them to bear. However some women were also clear on things which they believed might lessen the impact of cervical screening. Some of these have been canvassed in previous chapters, particularly the need for clear and accessible information and for women sensitive health practitioners. Two further issues can now be added.

The need to unhook cervical screening from sexuality

A number of women strongly recommended that questions relating to sexuality should not be asked by health professionals in relation to cervical screening. Information which included the risk factors associated with sexual activity and cervical screening should be made available to women in an accessible form and the choice as to whether or not they wanted to undertake the test should then be left to them. Of course there are problems in this approach. Some women are not able to give consent to cervical screening independently and some women may not understand the risk factors involved in not having the test. Alternative arrangements through the use of independent advocates may be needed in this situation.

Taking the focus away from cervical screening

A number of women stated plainly that cervical screening should be a part of a general women's health check. This would give time for the woman and her health practitioner to know each other better, and would take the emphasis off cervical screening as a separate health issue. This may reduce some of the anxieties about the intrusive nature of this particular test.

Conclusion

Part 1 of this report has revealed that the views of women about cervical screening are complex and subtle. It is the responsibility of service providers and health professionals to address these issues through a removal of the social barriers which confront women with disabilities in relation to cervical screening and to provide a safe and woman sensitive environment in which the screening can occur.

PART 2: SERVICE PROVIDER PERSPECTIVE

In this report, we have privileged the voices of women with disabilities by placing their information first in the report. However they did not provide the only information in this study. Part 2 explores how service providers viewed issues around cervical screening for women with disabilities. Chapter 5 is concerned with the perspective of representatives from organisations which provide services or are advocates for women with disabilities. Interviews were carried out with 16 organisations which work with women or represent their interests. Chapter 6 focuses on the views of Pap test providers. Focus groups were carried out with five different groups involved in providing cervical screening services or education to women with disabilities. One of the focus groups was undertaken in a country area and the other three were with service providers in Melbourne. Focus groups included representatives from a family planning clinic, a well women's clinic in a metropolitan hospital and a community health centre and an association representing nurses working in community health. A group of peer educators working with women with disabilities also participated. A further five individual interviews were undertaken with selected Pap test providers in Melbourne. This is not a representative sample of Pap test providers but it does represent a range of different views about cervical screening. Significantly all of the Pap test providers included in the consultation were women. Chapter 7 consists of an account of a Pap test audit of four services undertaken by a researcher with a disability during the project. The services volunteered for the audit and were provided with feedback about its results.

CHAPTER 5 - RECOGNISING BARRIERS: ORGANISATIONAL PERSPECTIVE

Recognising the barriers that women with disabilities face in accessing Pap tests is a first step to taking action about them. This paper explores perceptions of barriers by 16 representatives from organisations which work with people with disabilities. These organisations consisted of those who provided services and advocacy to people with specific disabilities. They included organisations which worked with people with psychiatric, physical, sensory, and intellectual disabilities. Discussions with these representatives focused on ways to find women who would like to participate in the study but also included a discussion of perceived barriers to them receiving Pap tests.

This chapter aims to:

- Describe the perceived barriers to women with disabilities accessing Pap tests.
- Report on some ways that such representatives believe that the barriers can be removed.

It became clear from these discussions that organisations working with women with disabilities saw barriers to cervical screening in similar clusters to the women themselves, that is in terms of social barriers, ones which were related to women's particular life circumstances and less frequently, subjectivity.

Social barriers

The key social barriers which were perceived to make it difficult for women with disabilities to access cervical screening included:

- Access issues
- Transport
- Information
- Attitudes
- Cost

Access issues

Access issues were seen as a particular problem for some women with physical disabilities. These included the difficulties of negotiating wheelchair access to buildings, toilets and rooms. However they also included the lack of adjustable tables and hoists which were needed for women to transfer from wheelchairs.

In some instances women found it difficult to wait for attention, either because they did not want to be with others, because the environment was strange or because of physical or psychological distress or restlessness. Many medical services did not provide separate spaces where these women could wait more comfortably and privately.

But for some women physical access issues were not the problem. Advocates in the deaf community commented that there was a lack of doctors who sign and subsequent difficulties in communicating with a doctor.

There are fewer than five signing doctors in Melbourne.

Problems of accessing a doctor were also experienced by women from culturally and linguistically diverse cultures where the importance of being able to speak to a doctor about the issues or to ask questions in the woman's first language were seen to be important. Sometimes this proved difficult or impossible to achieve.

Access to a suitable time frame for the consultation was also a problem. For some women with disabilities a longer consultation time was needed but finding a time that suited staff, the woman and the doctor could be difficult.

Sometimes access issues were due to the failure of services to have adequate supports for a woman. The problems of accessing services if a woman was deaf were stressed by one representative:

Services may not know about this [interpreting service]. May not know where to go to get interpreters. Deaf people may not ask for an interpreter. And it is not offered. First question asked of deaf person should be: How do you want me to communicate with you? This gives the person a choice and they can say that they want an interpreter.

Transport

Many women with disabilities relied on taxis or public transport to get to services which offer cervical screening. Some organisations working with women with physical disabilities expressed concern at the difficulties of obtaining maxi taxis at specified times in order to get to appointments or for a return trip home.

Information

There was a lack of accessible information for women with disabilities. Some organisational representatives commented that they had not thought of the importance of cervical screening for the people who were members or to whom they offered services. One person commented:

We've done a lot of work on breast self examination but I hadn't thought of Pap tests until we heard from you.

Many organisations, with whom we consulted across all disability groups, commented on the lack of accessible information about cervical screening for women with disabilities. This was seen as leading some women to develop myths about Pap tests or to have inaccurate information which posed barriers. For example a worker with deaf women commented that some women with whom she had worked had no knowledge at all about Pap tests, one had said that "Pap tests were about 'cleaning her out 'inside'. She did not think that she needed it." Other women thought that Pap tests were only needed once they were married and others believed that they were only needed if something was wrong or there was a crisis.

There was also a lack of knowledge about where these organisations could send women who had access needs. *PapScreen Victoria's* "Listing of Community Pap Test Services Across Victoria" was not known by these organisations and some workers commented that they found it very frustrating that there were so few services which could accommodate women who could not weight bear.

Women with intellectual disabilities sometimes knew little about their own bodies or body parts, making it extremely difficult for health professionals to explore issues like cervical screening with them.

Attitudes of health professionals

There was a very common perception that health professionals were not supportive of women with disabilities in regard to Pap tests. A major concern across disability organisations was the view that doctors tended to see women with disabilities as asexual. This led to a neglect of cervical screening as a health issue.

However there were other concerns. The disability experienced by the women could lead to a focus on treating it, screening out other health concerns. For example the experience of Multiple Sclerosis may "swamp all other health issues." Alternatively, effects of the disability may in themselves become so important that preventative health is not considered. For example:

Women who require a catheter may experience an increased risk of bladder infections and people become preoccupied with this.

This was also the case for some women with psychiatric and intellectual disabilities where the focus was on their mental health or accompanying physical disabilities, rather than on physical health.

There were reports from some representatives that specialists focused exclusively on their area of expertise and did not take a holistic view of women's health.

Representatives working with women with psychiatric disabilities reported that they had a problem of credibility. Doctors sometimes interpreted general health complaints or requests through the lens of psychiatric illness and disregarded the woman's comments.

Attitudes of disability staff and care givers

There seemed to be a lack of attention given to women's health issues by disability staff who worked with women with disabilities in supported accommodation. This was particularly the case in relation to women with disabilities but was also raised by representatives working with women with physical disabilities and women with sight impairments. The reasons for this lack of focus were varied but included:

- Lack of knowledge by staff about cervical screening and its importance for the women with whom they worked.
- A belief by staff that the women they worked with did not have any sexual experiences.
- Where a woman was dependent on staff to take her to the doctor for cervical screening, difficulties could arise in relation to staff rosters. Staff had to be available to work with an individual woman. Some supported accommodation services did not see this kind of work as part of the role of their workers.

Cost

Some service providers saw cost as an issue for women, not necessarily for the cervical screening itself but for assistance in accessing it. For example:

Services often do not provide interpreters. Question becomes "Who pays for it?" even though through the equal opportunity law people are not supposed to be discriminated against because of disability.

Life style barriers

As noted in Chapter 2, these barriers are in part social ones. However they did relate specifically to the issues which confronted women in the way they lived their lives.

The main life style barriers raised by representatives in our consultation were:

- Isolation.
- Frequent moves.
- Effect of disability on the woman's life.

Isolation

It was recognised by many organisational representatives that women with disabilities often lead very isolated lives. They may live in supported accommodation or alone. This prevents them from having contact with other women from whom they may get needed health information or from other more

formal means of information. Such isolation may also prevent them from knowing where to go in order to access needed services.

Some women with disabilities (particularly women with intellectual disabilities or those with high support needs) had little choice about where or with whom they live. This may restrict their access to publicly available information or services.

Transitory life style

Because of lack of choice in other areas of their lives, women with disabilities may move accommodation frequently. This was seen as being particularly common for women with psychiatric disabilities. Such moves mean that a woman may not have a regular doctor (or indeed any doctor at all) and even if she is on the register for cervical screening, letters informing her of the need for a Pap test may not reach her.

Effect of disability on the woman's life

For many women with disabilities, the disability itself or its treatment were seen as posing a direct barrier to them accessing cervical screening. Women with psychiatric and physical disabilities were often perceived to be tired and/or depressed. In this situation managing to make an appointment for a Pap test, remembering the appointment and managing to get to the appointment could be just too difficult. Sometimes tiredness or other physical symptoms were caused by the medication used to treat the disability or mental health problem.

In some instances the nature of the disability will have had effects on the woman, which prevent her from accessing information easily. This was so for women with intellectual disabilities but was also the case for many deaf women.

About 40% of women who were deaf would not receive education because their parents did not sign, don't talk about sex with them. Often at school they are excluded from this kind of information because of communication barriers.

A consequence of this was a lower literacy rate for these women and exclusion from needed education.

Subjectivity

Perhaps not surprisingly, organisational representatives did not focus on issues relating to the subjectivity of women with disabilities. However there were some exceptions to this.

One person commented that women who acquired a physical disability in adult life seemed better able to get the kind of services that they wanted and needed. This was seen as being much more difficult for women who had always had a disability.

People with spinal cord injuries are more independent. Their injury often happens after they have been able bodied so they are more likely to seek to be treated like other people. People with Polio require more support.

The culture surrounding a disability was also seen as important, particularly so for deaf women. There are differences among the deaf community in terms of how people perceive themselves. Some groups of women do not see themselves as having a disability but rather see the society itself as disabled. However some other groups of women may not hold this view. Women who identify strongly with deaf culture may not have access to information available to other women unless information is framed within that cultural context.

The experience of sexuality was mentioned as an issue which could prevent women with disabilities from accessing cervical screening. For example, some women with intellectual disabilities were seen as leading secret sexual lives making it difficult for them to say to family members or to health professionals that they want a Pap test.

Breaking down barriers

Representatives from disability organisations focused on two issues in relation to removing barriers to cervical screening for women with disabilities: information and training.

Information

All organisations regarded the provision of accessible information as extremely important for women with disabilities. They strongly advocated clear, plain English

pamphlets with pictures and the use of videos and sound tapes for women who had difficulties with literacy. There was a strong feeling that these organisations should be involved in the production of such material so that the needs of their constituents could be taken into account and the resulting material would be relevant. For example, it was seen as particularly important that information for deaf women be produced in plain, clear English and that information sheets used bright colours and graphics.

Such information also needed to take into account that some women had more than one disability, for example, some women were blind and deaf.

Training for service providers and for medical staff

There was a perceived need for much better information and training to be given to all those who work with women with disabilities. This included the practitioners within the generic health system but also organisations working directly with these women.

Concerns were expressed particularly about the lack of training for staff working with women with intellectual disabilities.

Some organisations believed strongly that they needed to take the initiative in becoming more aware themselves about the needs of their constituents in relation to preventative health care. The need for better in-service training and more awareness of the issue were canvassed by some representatives.

Conclusion

The representatives from organisations with whom we have spoken indicated a high degree of interest and concern about the issue of cervical screening for women with disabilities. There seem to be a number of reasons for this. Firstly, the issue is one which specifically relates to women's issues and therefore provides a means for women to voice their concerns. Historically, women with disabilities have often not been heard. Secondly, there is a concern that health issues often take a lower priority than other issues which may be of concern to this group of women.

Finally, the issue of cervical screening leads into a broader discussion about sexuality and gynaecological health issues. In some instances concerns were expressed by representatives about these wider issues.

CHAPTER 6 - A COMMUNITY OF WOMEN: PAP TEST PROVIDERS

If you are different from the white Anglo Saxon reasonably well educated woman who lives in the middle suburbs, every step away from that you are, the harder it is to access a service.

The cervical screening service providers to whom we spoke with in this study saw the issues confronting women with disabilities in relation to cervical screening as part of their marginalisation within the wider community. Disability was seen as an issue which further complicated the access issues for women generally.

This chapter outlines the concerns expressed during consultations with Pap test providers and also describes briefly some of the strategies and initiatives which they are currently undertaking to reduce barriers to cervical screening by women with disabilities.

Perceived barriers

Cervical screening providers were very aware of many barriers experienced by women with disabilities in accessing Pap tests. In some instances this awareness was accompanied by a sense of frustration at not being able to address these adequately within current resources available to their services.

Absence of women with disabilities

All of the providers we consulted had worked with women with disabilities. All were aware that this group of women was less likely than many other women to have regular cervical screening. Almost of all the services we consulted had tried to develop strategies to encourage women with disabilities to access their service. But it was difficult.

Women with hearing impairments are really isolated. We put TTY³ in but hardly ever use it. Children may be linked into health through education. But once that is finished they disappear and don't tend to access the services.

³ Telephone Typewriter – for people with hearing and speech difficulties

In one country service the Pap test provider commented:

...I've had people with psychiatric disabilities and that is fine. Never had people with intellectual disabilities. I have had women with sensory disabilities but it has never been an issue.

One worker with young women in day centres for people with intellectual disabilities commented:

Most of them don't have them done. Pap tests haven't even entered our thinking when we think about that. People aren't even allowed to have relationships let alone exploring stuff around sexual health. There are huge barriers. Very, very few of them would have had a Pap test.

A health educational program with young women with disabilities revealed that few of them had Pap tests although most were sexually active.

Some of the young women have indicated that they are sexually active and they haven't had a Pap test. And they have said that they are not going to have a Pap test with their mum there. Combine that with the fact that mum always is there.

Attitudes and knowledge of carers

Some Pap test providers were concerned at both the attitudes and the lack of knowledge of carers or disability staff working with women with disabilities. For example those involved in education about cervical screening for this group noted that they had found that staff in supported housing sometimes did not know about cervical screening themselves or saw it as irrelevant to the people whom they supported. Similar concerns were expressed by people providing cervical screening services.

[If women with disabilities are] ...to be treated as one of a community of women then carers are fundamental.

Something that we discovered with 'Paps I Should' was that carers didn't know about cervical screening.

However, lack of knowledge was not the only barrier presented by carers. Some Pap test providers expressed concern about women with disabilities who lived at home with parents. They thought that this might make it more difficult for women to access services, either because of parental attitudes towards sexuality or because of a reluctance on the part of a woman to discuss the issue if a parent (usually a mother) was present. Such concerns were supported by particular experiences.

We don't know what happens for women who are at home with their families. There may be more chances for them to access the service if they are in supported housing.

We have sometimes found it difficult to get access to women with disabilities to tell them about cervical screening because staff are anxious that parents won't approve.

Women's Health West tried to organise a [peer facilitation] session with women [with intellectual disabilities] who are over 21. Women's Health West strongly encouraged women to have a session on their own. So we don't have a session. The mothers said there was no way they would let them have the session alone. And their explanation for that was that their daughter needs their care and needs them to help understand things.

On the other hand some mothers who were supportive of cervical screening for their daughters found that health professionals were hesitant or dismissive.

The mothers who have spoken to me about it [cervical screening] often wind up in tears about it. Fear of how their daughter would experience Pap test. Way too hard.

Doctors often knock back the idea of Pap test. Mother being told not to worry about it.

The service providers were concerned at the variation in attitudes of disability staff towards the sexuality of women with disabilities (particularly women with intellectual disabilities). Sometimes they saw women with disabilities as asexual

and therefore cervical screening was irrelevant to them. However sometimes they believed women with disabilities were sexually active when they in fact were not, leading to unnecessary stress for the woman.

Carers assume that they have sexual active lives. One woman came in and after a lot of time with her it was clear that she had never had sex. But the carer was quite definite about it.

Pap test providers believed strongly that disability staff had a responsibility to engage with issues around the sexual health of their clients.

The idea of supporting women for gynaecological care is not just an issue to be addressed by the medical profession. It should be also a concern for attendant carers and support networks.

Lack of information

As with the women and the disability organisations, Pap test providers expressed great concern at the lack of information available to women with disabilities about cervical screening. Some saw the use of peer facilitators as a useful way of developing knowledge and information for this group.

The work peer educators have done about prejudice and assumptions. [This] could be built on.

Others were concerned at the lack of information in accessible formats and at the lack of information given to women about the nature of Pap tests.

I have had training to provide women with information. Often they are quite surprised about this because they have never had this from their GP. "I've never known what you used, I've just got up on the couch".

A lot of women, especially older women have no idea what is being done to them.

Particular concern was expressed about the lack of information available to women about cervical screening services which would be sensitive to their needs and which would be accessible to them.

How do women find out about services like women's health nurse Pap test providers or ones that offer transport? Or even an outreach service? Or in a community setting?

The concern about lack of information extended to the service providers too. They expressed a need for better information about other available services. In this context it is significant that none of the cervical screening providers knew of the *PapScreen Victoria* "Listing of Community Pap Test Services Across Victoria" which provides some information on physical access and the availability of women practitioners for cervical screening services across the state. One Pap test provider suggested that there needed to be a:

Listing of women's health nurse Pap test providers [and a] better database available to workers and women.

The nature of cervical screening

All of the Pap test providers to whom we spoke were aware that cervical screening posed particular problems for women generally, but particularly for women with disabilities. Some of these issues were seen as relating to the nature of the test itself and others to the experiences of women with disabilities. The close link between cervical screening and sexuality was noted by a number of providers.

Secrecy in cervical cancer was related to promiscuity. Stigma. Brings up all those issues.

Others commented on the reaction of women with disabilities to an intrusive test. One woman working with women with intellectual disabilities said:

Mainly they said they haven't had a Pap test. Of the couple who had, one experienced it as traumatic. Again she didn't have the process explained to her and she didn't understand it and she didn't get feedback on the results. The other said no because it is scary.

Incest and sexual assault are things that a large number of people have experienced. Not there with breast cancer.

Attitudes of health professionals

There was general agreement among cervical screening providers that medical staff, particularly GPs, experienced both reluctance and barriers to providing Pap tests for women with disabilities. Some of these issues related to the attitudes of the health professionals and some were seen as training and resource issues.

Women with disabilities (particularly psychiatric and intellectual disabilities) were seen as 'clinical challenges' requiring extra time, expertise and a 'level of comfort' by the practitioner working with this group of women.

The challenges included difficulties sometimes in obtaining a history from a woman who might be confused or unable to articulate her past experiences. Cervical screening was seen as a presenting issue which camouflaged a multitude of other health and psychological needs. In this situation there was a need to have an ongoing relationship which could be time consuming and difficult to manage.

[You] need to break things down into manageable treatment bits. As soon as they've found someone who is prepared to listen you get everything quickly.

Some women also presented difficult ethical issues. If they were unable to cope with the anxieties associated with cervical screening, health professionals then had to make a difficult decision about whether or not to use medication or a general anaesthetic in order to undertake the test or to abandon the procedure altogether.

With my patients at Kew [large institution for people with intellectual disabilities] if they don't let me I don't do it. Some people sedate people or giving a general anaesthetic I don't do that. They're are the hard things. Too hard.

I've seen a couple of women who have had general anaesthetic and Pap tests and I have worked through the issues and they have been able to have them [without general anaesthetic].

These issues were difficult and time consuming for health professionals to manage within private practice particularly if they became known as skilled in working with women with disabilities.

The issues of medical management of patients like this are very time consumptive and extraordinarily difficult for doctors to manage more than a few and keep their practice viable.

Cervical screening service providers stressed the need for Pap testing to be seen as one aspect of women's health. They felt that it should not be separated out but should be seen as one among many other women's health checks. It was felt that this would reduce anxiety for women about cervical screening and also allow for more holistic assessment and practice.

Pap smear is just the one flag. It's the whole thing about their health. They could be having a Pap smear but everything else may be neglected. Well women's clinic is a vehicle is a permission giving. You often find someone asking questions about the rest of their life. We find that time again. It's a safe place to explore those [issues]. And quite often the actual Pap test would be abandoned because it wasn't the main issue for the woman on that day, it might be domestic violence issues or another issue that comes up.

It should be a well women's check. Koori community has taught us about that. Well women check. Top to toe.

The need for networks

Strong views were expressed by the Pap test service providers about the need for much better links between different services. For example, it was felt that psychiatric assessments should include questions about general health issues. There needed to be better links between disability services and health services so that issues could be discussed and mutual training organised.

[There needs to be] education for providers or carers. Need to work with women and carers because they will solve problems for you.

We need more training for [disability] workers and women's health nurse Pap test providers.

Some informants also thought that *PapScreen Victoria* and Breast Screen needed to work more closely together in encouraging preventative health for women with disabilities.

In one service which was attached to a large hospital, service providers highlighted the opportunities this offered for them to provide support for women through other parts of the system through advocacy and advice.

In at least two instances, services had created links with disability services which had proved useful and positive. In one, the initiative had come from a mental health service which had created a link with a Pap test provider. Women with psychiatric disabilities then had opportunities to go to the service, receive education and (if they were willing) have a Pap test.

In another instance, work with community based services such as supported accommodation services had led to an effective outreach service which provided education to women with disabilities about cervical screening and other health issues and had also enabled them to access the health service directly. Creating these links took time and resources.

Access to the service

While some Pap test providers thought that their service was accessible to women with disabilities, others expressed frustration at the lack of resources to provide things like a hoist or a moveable bed.

We just have an ordinary old bed. People with physical disabilities may not be able to lie flat.... You really need a special couch. We don't have a hoist. We don't have the resources to get this. But we need to find ways to get that equipment.

Some providers expressed the view that there might be creative ways of solving problems such as these. Mention was made of residential services which might have underutilised hoists and beds. The need for links between services to identify these resources was noted. One service provider had explored the possibility of the Royal District Nursing Service carrying out cervical screening in women's homes when they were unable to access an outside service. This idea had not been taken up at the time. But it was felt that now with more public recognition of women's health nurse Pap test providers it might be a possibility.

There were limits for all services in the extent to which they could provide Pap tests for women geographically. Some were restricted to women coming to the service itself. Others were able to engage in outreach work within a specified area. However there was general recognition that the need was greater than they could meet.

Initiatives

A number of initiatives and innovations were being trialed by Pap test providers to whom we spoke. Others were involved in projects which aimed to increase access to cervical screening for women with increased needs. This section briefly outlines these initiatives.

Women and sexual assault

CASA House is currently conducting a small pilot study with 20 women to look at the effect of sexual assault on women having Pap tests. It was hoped that this would be expanded into a larger project. Pap test providers were conscious that women with disabilities are more likely than other women to have experienced sexual assault or abuse and that this might be a barrier for them in undertaking an intrusive test.

Family Planning Victoria

In addition to providing cervical screening for women generally, Family Planning has a long history in working with women with disabilities on sexual health issues. This includes one to one counselling and education. Much of this work has been concerned with women with disabilities but educational programs have also been undertaken with organisations working with deaf women and children.

Women's Health in the North

Arising from the work of the women's health nurse at Women's Health in the North, an action research project had been developed by Women's Health in the North which sought to increase links between mental health services and cervical screening providers working in the context of Well Women's Services. Of particular concern was the lack of information amongst mental health services about the importance of screening for their clients and the need for them to have clearer information about how to work with them. The project has involved interviews with mental health services, Women's Health Nurses and women with psychiatric disabilities. A resource kit is expected to become available to service providers as a result of this project.

Women's Health West

Women's Health West has run a peer facilitation project for women with disabilities since 1993. This has employed women with disabilities on a casual basis as peer facilitators who provide information and education to women with disabilities about cervical screening and breast self-examination. Currently Women's Health West is exploring how this program might be broadened to look at these issues as part of the holistic issue of women's health.

Women's Health Goulburn North East

Over the past twelve months an action research project has been conducted by the women's health service to look at sexuality and the sexual health needs of women with intellectual disabilities in the region. Among other initiatives, a women's health group, Groovy Chicks, was established with young women with intellectual disabilities. Over a ten-week period the women explored a range of health issues including cervical screening. Education was provided in conjunction with the local community health centre.

Inner South Community Health Service

This community health centre runs a clinic one morning a week for women with disabilities. The service was developed from concerns by staff at the community health centre and at supported accommodation services about the lack of access to cervical screening and women's health by women with disabilities who were living

in the Port Phillip region. Extended time is allowed for women in relation to cervical screening and specialist nurses are on duty at this time. An outreach service which provides general and sexual health information also operates with nurses going to accommodation and day services to provide education and opportunities for cervical screening in a more informal environment. The outreach service has been successful in both providing information and encouraging women to use the service at the centre. Transport is provided for women who need it to access the health centre.

Discussion: What did Pap test providers want?

Pap test providers were very aware of many of the barriers experienced by women with disabilities in accessing cervical screening. They also had clear views about some of the things that were needed to improve the situation.

An integrated campaign

There was a sense of fragmentation in the work that was being done in promoting and developing accessible Pap test services. Much good work was locally based and was not known by others. It was felt by some people that funding small projects did not change the overall system and was tokenistic. However it was also recognised that the development of a more integrated approach required political decision-making and an allocation of more resources.

What I am talking about is statewide money to develop a system that is sustainable. Bit more money that will enable organisations to get together and do something on a statewide basis.

Integrated services

There was a strongly held view that cervical screening should be seen as part of a well women's check rather than being seen as something separate. This was seen as requiring increased links between organisations such as *PapScreen Victoria* and Breast Screen. It also needed to involve women's health services and well women's clinics. The use of a single hotline number for both information and booking appointments for breast and cervical screening was raised by one group of Pap test providers to reduce the difficulties some women had in making appointments.

Information and training

The need for accessible information was seen as extremely important as was the general promotion of women's preventative health. However, Pap test providers also believed that there was a need for increased information and training about disability for service providers. Better networking between disability and health services was seen as one way of promoting this.

Conclusion

Although Pap test providers were conscious of the difficulties confronted by women with disabilities in accessing cervical screening and were sometimes frustrated by their limits in supporting such women, there was a sense of optimism and purpose in the discussions. Initiatives were being tried and the Pap test providers to whom we spoke were enthusiastic about developing new strategies and practices. The time seems right for change.

CHAPTER 7 - AUDITING PAP TEST SERVICES

In this chapter we consider the results of four case studies of Pap test services which were audited during the project. An audit checklist and a set of accompanying questions were designed and approved by the Reference Group for the project (See Appendix 2). One of the researchers who has a disability then undertook the audits. Four services which offer Pap testing to women volunteered for the audit and received a feedback report. They are not named in this chapter.

The services which volunteered were:

- A large metropolitan hospital
- A specialist women's health clinic for women with disabilities, based in a community health service
- A generalist family planning clinic
- A community health centre in regional Victoria

The researcher obtained permission from management at each service to undertake the audit. She made an appointment to visit and then went through the process of making an appointment and going to the clinic as if she were intending to have a Pap test. She did not undertake the test but looked at access issues and held an interview with staff at each clinic.

There was some interest by other services in being audited (three other services indicated an interest during the project). This suggests that a voluntary audit modelled on the ones carried out for this study may be a useful approach to improving service quality.

Generally, the four audited organisations offered very positive and sensitive Pap test services for women with disabilities. However there were also issues which could be addressed further in each service. These were:

- Issues relating to making and keeping appointments
- Transport issues
- Physical access issues
- Communication issues
- Information issues
- Culture of the service

Issues relating to making and keeping appointments

All services could be contacted reasonably easily by phone. However when a service used a central appointments system there were difficulties in actually accessing the Pap test service. Sometimes I was left on hold for a considerable time (in one instance for 15 minutes). Prolonged on-hold times make the appointments process inaccessible to many women, including those with anxiety conditions, and those who (because of physical disabilities) cannot easily hold a phone. There was also a problem in that although I indicated that I had a disability none of the services followed this up on the phone in order to arrange an appointment that would meet my individual needs. At times, this lack of practice was not consistent with the actual policy which was explained to me by staff. For example according to the staff member I interviewed at one service, reception staff ask no questions about disability or other special needs.

If women do disclose a disability, however, they are asked if they have particular problems; they are then referred to the triage nurse to discuss their support needs. My own experience of the appointments system did not quite match that. I was certainly asked no initial questions about special needs I may have. When I then said I had a disability, and couldn't get up onto a high bench, the receptionist booked the adjustable table for my "appointment". There was no discussion of any other support needs I may have had (I may, for example, have also needed a longer appointment). I was not referred to the triage nurse. There was a gap between theory and practice.

Some services had one or two staff who were specially trained for sensitive approaches to intake. However if these staff were not available other staff did not know of the procedure. For example at one service I twice attempted to make an "appointment", only to be told that the duty worker was not available. On each occasion, I left a phone number and was told the duty worker would call me back. On the first occasion, my call was not returned at all. On the second occasion, I called back late that afternoon, not having received a call. I was told the duty worker was off sick, and that I would be called the next day. A day or two later, a relief duty worker left a message for me while I was absent. She gave me an appointment. Not having spoken with her, I did not have a chance to say I had a disability, or discuss my support needs. It is important that all staff who are likely to be responding to phone appointments are trained and available.

While some services did have an appointment reminder system, others did not. This is particularly important for some women with disabilities who may have memory difficulties.

Transport issues/transport access

All metropolitan services were well serviced by public transport, train, bus and tram. Train access is important, as other forms of public transport remain inaccessible to many people using wheelchairs. There is a bus in the rural town where I audited a service, but it runs very infrequently.

All services had parking - including reserved disability specific parking - at or near the front door.

One service can pick people up for appointments if transport is a barrier. Two services can provide taxi vouchers. One does so relatively frequently, the other at the manager's discretion, negotiable on an individual basis. The staff member I interviewed indicated that she had "done it in the past".

One service solves the transport problem by using an outreach model. The staff member I interviewed said, "if people come to the [clinic], they have chosen to come to the [clinic]. Many women choose to have the service at a day centre, respite house, CRU or SRS (if they have individual rooms)". This outreach service is more commonly provided for groups of women than for individuals.

At a second service, the Sexual Health Nurse can also do home visits (though this is not usual). It was indicated that the Nurse would visit a woman with a severe physical disability, given the lack of appropriate facilities (i.e. adjustable table and hoist) at the service site.

Physical access issues

All buildings were generally accessible although some had minor problems, for example one service had an extremely heavy door. However there was sufficient room in all services for wheelchair access and accessible toilets were available.

The major problem was the lack of hoists and adjustable beds. Only one service had a fully adjustable bed and hoist. One service did have an adjustable bed and

access to a hoist but there was a lack of clear policy on how to ensure that it was available on the day that it was needed. One service did have an adjustable bed but did not have a hoist. One service had neither. The lack of easily accessible equipment is a major barrier for women with physical disabilities.

Communication issues

Generally these services were supportive and sensitive to women patients arriving for a Pap test. However some women would have experienced real difficulties in communicating with staff. This is particularly so for women who are deaf. Two services had a TTY. However in one instance staff did not know that their service had this facility and did not know how to use it. The other two services did not have TTY and were completely unfamiliar with the National Relay Service which allows people using TTYs to communicate with people using ordinary telephones. When I asked a staff member at one of these services how she communicated with women who were deaf, and what strategies staff used to work with women who were deaf, I was told "I can show women things. I look at them all the time. I ask if they can lip read. I can write things down. I have nothing else to offer". She did not know how to book interpreters. In contrast with this situation, one service did have a staff member who spoke Auslan.

Some services did not promote the accessibility of TTY or email addresses or fax through their pamphlets. Yet for some women, these means of communication are extremely important if they are to access the service. The need for such promotion is particularly important for women with speech difficulties or for those who are deaf.

Information issues

Information access focuses on two issues: accessible information about cervical screening and the information available to women about the specific service. I found that most services had information about both but the quality, accessibility and promotion of the information was variable.

All services had pamphlets about their own service. However such pamphlets did not always include information about TTY or other information which would support women with disabilities in using their service.

Further, not all of this information was readily accessible in terms of format, for example large print, audiotape, Braille, plain English with pictures. This was also true for the information about Pap tests. Written material was the main means of promotion both for the service and cervical screening.

One of the main problems was that while information in a variety of forms might be available on site it was not possible for women to take it home and use it there. On request, staff were happy to discuss issues around Pap testing and several had the *Paps I Should* Video. However these were not available for borrowing. Women have to get to the service in order to access the information.

All services were involved to some extent in community education with women with disabilities. However there was often a lack of resources to fund this in a comprehensive way. Three services had a specific brief (sometimes with a co-located program) to work educatively with women with disabilities and a fourth had become involved in a locally initiated program for women with disabilities. In all cases staff commented favourably on the need for more work of this kind.

Two services had web sites but these did not meet the generally recognised standards for website accessibility (for example, WAI Accessibility Guidelines, W3C Web Content Accessibility Guidelines).

Services acknowledged a need for better plain English information and one service had developed a draft pamphlet for use by its users. One has actively promoted itself to disability service providers, directly to women with disabilities, and in articles in the local press.

Culture of the service

In all services I encountered real concern about the need to respond sensitively to the needs of women with disabilities. Staff were willing to provide longer consulting time, stressed the importance of developing trust between patient and service provider and provided opportunities for women to touch or to be told about the instruments used in the test.

However there were some difficulties. In general these difficulties seem to arise because of the lack of regular consultation by service providers with women with disabilities.

For example there is a risk that women with disabilities will be segregated from the general population of women in an attempt to provide a service which meets their needs. I think it is very important that wherever possible women with disabilities should be integrated into mainstream services but their individual needs should be noted.

In another instance when I asked if clinic staff knew (and used) alternative positions for Pap tests, I was told "we only do it with the women lying on her back with a pillow under her hips. Doing it on the side is an old male thing, it allows doctors to sneak up from behind". For women with significant physical disabilities, it can be difficult to find a comfortable position in which to proceed with a Pap test. Indeed, it may be necessary to experiment with a variety of positions to find one in which a test is possible.

Some women with disabilities find it difficult to spread their legs wide enough for their cervix to be viewed. Others find that lying on their back increases spasticity. For these women, the side-lying position may be the only practical way to do a Pap test.

These are not intentional insensitivities, but rather arise from a failure to consult both with individual women patients about their preferences or to have an advisory group of women with disabilities available to the service to discuss issues which concern them.

Case study: A community health centre

This case study has been included as an example of how an audit can be used to assist a service providing Pap tests to women with disabilities. Any identifying information has been removed.

This case study involved a community health centre which was undergoing renovation and the audit was sought to assist staff to make sure the new clinic was accessible.

Areas of good practice

The community health centre uses a "well women's check" model - looking at, for example, breast health and continence issues as well as Pap tests.

Other workers within the community health centre refer women for Pap tests when appropriate. Referrals come from the continence nurse, drug and alcohol worker, and family planning.

Pap tests can be provided by a woman GP or nurse. The GP bulk-bills; the nurse usually costs \$5, but this cost can be waived.

The service is available four days and one evening per week.

Physical access

The building has a ramped entrance. The waiting area was very tight for wheelchairs - but I was told chairs could be moved. There are no structural barriers to access within the building itself. The examination rooms are physically accessible and large enough for a wheelchair user to move around in. There is a wheelchair accessible toilet.

At the time of my visit, the corridor was partly blocked by boxes moved due to renovation work, and the final effect of the renovations was difficult to ascertain. It will, however, clearly be positive.

Communications access

The Community Health Centre has a fax number and email address; the Sexual Health Nurse also has an individual email address.

Appointment reminders

People can ask for appointment reminders - an important consideration for some people with (for example) memory difficulties. When people have a history of not appearing for appointments, the nurse asks them if they want a reminder.

Home visits

The Sexual Health Nurse can do home visits (though this is not usual). It was indicated that the Nurse would visit a woman with a severe physical disability, given the lack of appropriate facilities (i.e. adjustable table and hoist) at the Community Health Centre.

Information access

Information about Pap tests is available in print or video formats. Explanations can also be made using pictures and/or dolls. Women can see/touch the Pap test instruments.

Areas for improvement

Physical access

The entrance door is somewhat narrow and heavy (a problem which will be resolved when the current renovations are complete - wider, automatically opening doors are being installed). The waiting room area is too small for people in wheelchairs to move around in.

Adjustable bed and hoist

The community health centre doesn't have an adjustable bed, or a hoist.

Communications Access - TTYs and the National Relay Service

The Sexual Health Nurse was unfamiliar with TTYs. She was also unfamiliar with the National Relay Service. This service can enable people with hearing or speech difficulties, including those using TTYs, to communicate by phone. For a service like the community health centre, without a TTY, familiarity with the Relay Service is essential.

Communications Access - Sign Interpreters

Asked what strategies staff used to work with women who were Deaf, I was told "I can show women things. I look at them all the time. I ask if they can lip read. I can write things down. I have nothing else to offer".

The Sexual Health Nurse didn't know how or where to book sign interpreters. She had done a course in working with (spoken) language interpreters, but not sign interpreters. She had never used interpreters.

Recommendations

A number of clear recommendations emerged from these audits. These are listed below and are also incorporated into the general recommendations at the beginning of the report.

1. Appointment systems need to be regularly reviewed by each service to ensure that staff are trained in working with women with disabilities and that the policy guiding appointments is being implemented.
2. Pap test services should have equipment that will enable women with disabilities to use the service easily. TTY should be available, or if not then the National Relay Service (Call 1800 555 660 or see www.aceinfo.net.au for more information) should be included as part of staff orientation. If the service does have TTY, staff need to know how to use it and the phone number needs to be publicised.
3. Web sites should be designed and checked for accessibility using, for example Bobby (see www.cast.org/bobby).
4. Information about Pap tests should be available in waiting areas. Further, women with disabilities should be able to borrow accessible information either from the service or from *PapScreen Victoria*. It is important that such information be in a range of accessible formats.
5. While we recognise that hoists and adjustable beds are expensive, there is a real need for them to be available in Pap test services. If it is not possible for all services to have these then they at least need a list of regional services which do have them.
6. We think it is very important that services have access to women with disabilities as cultural consultants who can assist in the development of information and also advise on service delivery.

7. That reminder calls should be given on request or when there is some evidence that a woman may have difficulties in remembering appointments. A staff member should be delegated to make these calls.
8. Staff at Pap test services should be familiar with how to book sign interpreters who can be booked from VicDeaf: (03) 9657-8111. They need to be booked well in advance.

Conclusions

The four services which volunteered for the audit were generally accessible and sensitive to the needs of women with disabilities. However even the best services can have aspects which make it difficult for some women to access them. Following the audits we would strongly recommend that services which work with women with disabilities extensively should consider the development of a small group of cultural consultants who can offer advice and support for service development and who can undertake regular audits.

CONCLUSION

When we began this study we believed that the issues around barriers to cervical screening for women were relatively straightforward and could be conceptualised in terms of societal barriers. They fitted within a social model of health and the social model of disability. To some extent this view was validated by the research evidence. However it also became clear that the issues were much more complex. For some women cervical screening by its very nature is a difficult issue which raises questions about the way they see themselves as women and the way they see their disability. One of the key and understated issues in other research therefore relates to the connection between women's subjectivity and cervical screening.

We also found in undertaking the research that the difficulties in overcoming the barriers experienced by women resonated with the actual research process. In this conclusion we want to note these issues and relate them to the broader issues of how strategies may be developed to encourage more women with disabilities to undertake cervical screening.

1. A widespread concern

As we discussed in earlier chapters, organisations which work with or advocate for women with disabilities were very concerned about the barriers they experience in accessing cervical screening. There was a widespread response from disability organisations to our request for reference group membership and great willingness to share experiences and to assist us in gaining access to women with disabilities. The concerns they expressed seemed to be due to a number of factors. Some organisations were aware that women who used their services had difficulties in gaining access to services. However organisational representatives were unclear about what they could do to help. Few of them had information about accessible services and none carried good information for women about cervical screening. Some were concerned at the lack of voice which women with disabilities had in their lives. Cervical screening was one element of this perceived voicelessness. Others commented that they had not really given much consideration to cervical screening as other issues had been the main focus of attention. Some organisational representatives made the link between cervical screening and sexuality. They believed that attitudes of women with disabilities were closely linked to the negative or patronising way in which their sexuality was regarded by those around

them. In this kind of culture, cervical screening was not seen as something that was relevant or important to women with disabilities. Finally some organisations also believed that the woman's disability became the main source of concern of the women themselves, service providers and health professionals.

It became clear during the project that many of the organisations which serve women with disabilities were willing and indeed eager to assist in the promotion of cervical screening for their members or service users. For example staff were willing to give time to assist in the development of information resources or to help in organising educational forums for women. This suggests that there is a great opportunity for *PapScreen Victoria* to use the concern and the enthusiasm of service providers to assist in the development of strategies to assist women with disabilities.

2. Developing trust

This project had a short time line of six months. We learned again that it takes time to work with women with disabilities. Many lead lives which are isolated from the mainstream community. Consequently it takes a variety of strategies to contact them in the first place. We found that using organisations which provide services for women or which advocate for them was the most effective means of contacting them. However we are also aware that in this study women who were largely unconnected with these organisations were not able to access the study. Further, for some women cervical screening is not an easy issue to discuss for the reasons explored earlier in this report. Some women were not willing to talk with us. For example repeated efforts by a representative from an organisation for people with vision impairments found that the women with whom she raised the topic were not willing to talk about it. They stated that they had no problems with cervical screening. This may well be the case. However it may also be that for some women the issue is too embarrassing or too anxiety provoking to discuss easily. Time needs to be given to building trust with women around issues which are sensitive and difficult for them to manage.

In developing strategies to support women with disabilities to undertake cervical screening we believe it is important that sufficient time be allocated to enable trust to be developed. We believe this is particularly important in relation to Pap test providers and the women they see but it is also an important consideration for an organisation co-ordinating strategies.

3. The diversity of disability

There does seem to be a tendency in the community and among health professionals to view all women with disabilities 'as the same'. While many of the issues we identified as barriers in this report are common to many women with disabilities (and to other women in the community) it is also important to recognise the diversity of people with a disability. Some women with disabilities experience few problems in relation to cervical screening, for others it is an issue of both physical and psychological stress. Services and information which are accessible to some women may be viewed as patronising by others. Further there are diverse cultures within the disability field. For example some deaf women do not identify themselves as having a disability and therefore are reluctant to be included in this group. Sensitivity to difference both for individuals and in relation to disability cultures is needed when developing strategies to work with women with disabilities.

4. The need for information

There was an overwhelming expressed need for information about cervical screening by all groups involved in this research. Most women whom we interviewed made a link between cervical screening and the detection of cancer (which sometimes increased their anxieties about it). However many did not have a clear view about why they should undertake regular screening or an understanding of the process itself. We found that we were often asked for this information. We were also asked for information about where women might find accessible Pap test services. We used current information sheets and the directory developed by *PapScreen Victoria* to provide this. However we were very aware that the sheets were not useful for some women. Some found the language used in the information sheet difficult to follow, others needed clear accompanying graphics. For some women it was clear that videos or sound tapes would be a better approach. While women's health nurse Pap test providers were engaging in educational activities with women with disabilities about cervical screening, there needed to be more support for this approach and more information available which women could take away with them.

5. Anxieties about cervical screening

The interviews and consultations revealed that cervical screening is a source of anxiety for some women because of its intrusive nature, their past experiences or

because of the links with cancer detection. This was certainly not the case for all women. But the prevalence of stated anxieties suggests that a new approach is needed to promoting cervical screening. There were repeated recommendations that Pap tests needed to be included in a wider concept of well women with a focus on women's sexual health. This would enable women to undertake Pap tests (or to find out about them) as part of a more generalised and less anxiety creating well women's health check. The need for trust between service providers and women patients would be enhanced by this approach giving women time to talk about the issues which concern them and to resolve (if possible) some of the anxieties relating to Pap tests.

Linking Pap tests with a broader view of women's health would in our view be a positive step towards reducing anxiety and promoting a more positive view of them.

6. Links between services

We found in the study that there were difficulties for women in accessing cervical screening because of the lack of networking between health services and disability service providers. Sometimes the latter are gatekeepers to women with disabilities. If they do not know about cervical screening or are unaware of the need for it then the information is not passed on and service users are not encouraged to engage with cervical screening. The need for networks between service providers has been recognised by Women's Health in the North which is currently undertaking an action research study designed to bring mental health service providers and Pap test providers together. Peer facilitators working with women with disabilities across the state in the 'Paps I Should' program spoke of the need to educate disability service providers about cervical screening.

Some service providers also commented that there was a need for *PapScreen Victoria* and Breast Screen to work more closely together.

Strategies designed to increase the possibility of women with disabilities undertaking regular cervical screening need to include education and networking of both health professionals and disability service providers.

7. Cervical screening and sexuality

Cervical screening is promoted for women who have been sexually active at some point in their lives. It became clear that this was a difficult issue for some women either because of negative views about their sexuality because of their disability or because of cultural issues. The perceived link between sexuality and cervical screening also in some cases prevented women with disabilities getting direct information about cervical screening. Families or service providers tended to see the tests as irrelevant because of assumptions that the women with disabilities would not have engaged in sexual activity. This was particularly the case for women with intellectual disabilities but the issue was not restricted to this group. We believe it is important that women obtain clear and accessible information about cervical screening and that they be then able to make the choice about whether or not to undertake it. Questions about a woman's sexual life are anxiety creating (particularly if the woman is accompanied by someone else). Practitioners need to be aware of this and to be sensitive to the issue.

8. A voice

In a limited way this study has provided some women with disabilities with a voice about cervical screening. We are conscious that because of the nature of the study and its time line we are likely to have heard primarily from the most articulate and confident women. During interviews and focus groups it became evident that women did have clear views about what they wanted in the way of supports to undertake cervical screening. Peer facilitation can be an important way of providing women with disabilities with a voice and may also be a positive and empathic way for some women with disabilities to hear about cervical screening.

There is a need for women with disabilities to have a stronger voice in the way services are designed and implemented. We believe that the use of women with disabilities as 'cultural consultants' in the development of information and service provision of women's health services may provide a useful means of disseminating information and providing a safe forum for women to discuss wider health issues.

9. Access issues

In this study we found by experience how difficult access issues can be for women with disabilities. In many instances women were unable to travel to us for

interviews and most of them were conducted in the women's homes. Access issues to services were a source of anger and frustration to many of these women. The lack of hoists and moveable beds was a particular concern as was the lack of a range of possibilities which would enable women to exercise choices of service providers. Some women would prefer to undertake cervical screening at home but at present this is conditional on finding a sympathetic service provider. We believe that a new approach to the Royal District Nursing Service to explore the possibility of some nurses becoming Pap test providers may be a useful strategy. However some women do not want to use home based services. There is a need for increased resources to be available to services in order to provide hoists and moveable beds in some community health centres. Further discussion is also needed about the provision of efficient transport. More important however is the need for outreach services which will provide women with information about their health generally but which will also enable them to make contact with Pap test providers in a safe and anxiety reduced environment.

Conclusion

Cervical screening is an important means for women to safeguard their health. The difficulties which women with disabilities encounter in accessing it provide a challenge to remove societal barriers and to develop more women sensitive practices generally. We believe following this study, that if such services are more generally available in a non-threatening way, then many of the specific concerns of women with disabilities will be addressed without the need to consider them as a separate group. However we are also conscious that much work needs to be done to ensure that women with a variety of special needs receive the support and access to services that is their right. Having said that, we also believe it is important to stress that finally the choice about having Pap tests is that of an individual woman. It is the responsibility of services and Pap test providers to make sure that women have the information that will enable them to make an informed decision and that the services they attend provide sensitive and holistic approaches to health care.

REFERENCES

- Armstrong, D. (1983). *Political Anatomy of the Body. Medical Knowledge in Britain in the 20th Century*. Cambridge: Cambridge University Press.
- Armstrong, D. (1984). The patient's view. *Social Science and Medicine* 18 (9) 737-44.
- Asch, A. and Fine, M.(1992). Beyond pedestals: revisiting the lives of women with disability. In M. Fine (Ed). *Disruptive Voices. The Possibilities of Feminist Research*. Ann Arbor: University of Michigan Press. 139-70.
- Atkinson, D. McCarthy, M.,Walmsley, J. et al. *Good Times Bad Times*. Kidderminster: BILD.
- Broughton, S. and Thompson K. (2000). Women with Learning Disabilities Risk Behaviour and Experience of Cervical Screening. *Journal of Advanced Nursing*. 32, 4. 905-12.
- Cambridgeshire County Council, (2002) *Joint Investment Plan for Adults with Learning Disabilities*. Internet.
- Campbell, H., MacDonald, S and McKernan, M. (1996). Promotion of cervical screening uptake by health visitor follow-up of women who repeatedly failed to attend. *Journal of Public Health Medicine*. 18, 1. 94-7.
- Centre for Behavioural Research in Cancer (2001). *PapScreen Victoria Evaluation Report. Volume 1. 1997-2000*. Melbourne: Anti-Cancer Council of Victoria.
- Center for Research on Women with Disabilities, (1999). *National Study of Women with Physical Disabilities*. Houston: Baylor College of Medicine.
- Cockburn, J., White, V., Hirst, S and Hill, D. (1991). Response of older rural women to a cervical screening campaign. *Health Promotion Journal of Australia*, 1, 1. 29-34.
- Community Development in Health (1988). *Health and Illness in a Social Context*. Preston: Community Development in Health.
- Deegan, J. and Brooks, N. (1985). *Women and Disability. The Double Handicap*. New Brunswick: Transaction Books.
- Department of Human Services (2002). *Victorian Women's Health and Wellbeing Strategy. Policy Statement and Implementation Framework*. Melbourne: Department of Human Services.
- Family Planning Victoria (1998). *Broadening Gazes: Pap Screening for Women with Psychiatric Disabilities*. Melbourne: Family Planning Victoria.
- Family Planning Victoria, (2000). *Moving Shadows. Psychiatric Disability: No Barrier to Physical Health*. Melbourne: PapScreen Victoria, Anti-Cancer Council Victoria, Family Planning Victoria.

- Fernbach, M. (2000). Barriers to Cervical Screening *PapScreen Victoria* Evaluation Report. Vol. 1. 1997-2000 Melbourne. Anti Cancer Council of Victoria.
- Fine, M. and Asch, A. (1988). *Women with Disabilities. Essays in Psychology, Culture and Politics*. Philadelphia: Temple University Press.
- Finkelstein, V. (1993). Disability: a social challenge or an administrative responsibility. In J. Swain, V. Finkelstein, S. French, and M. Oliver, *Disabling Barriers- Enabling Environments*. London: Sage.
- Frohman, C. (2002) "There is no Justice – Just US!" *The status of women with disabilities in Australia*. Prepared for Women With Disabilities Australia (WWDA). Published by WWDA, Tasmania.
- Henriques, J., Hollway, C., Urwin, V. and Walkerdine, C. (Eds). (1984). *Changing the Subject. Psychology, Social Regulation and Subjectivity*. London: Methuen.
- Hirst, S. (1988). *Anti-Cancer Council of Victoria Cervical Screening Campaign Mallee Loddon Campaspe Region*. Melbourne: Anti-Cancer Council of Victoria.
- Johnson, K. (1998). *Deinstitutionalising Women. An Ethnographic Study of Institutional Closure*. Melbourne: Cambridge University Press.
- Johnson, K., Hillier, L., Harrison, L., Frawley, P. (2001). *People with Intellectual Disabilities. Living Safer Sexual Lives*. Melbourne: Australian Research Centre in Sex, Health and Society.
- Keith, L. (1994). *Mustn't Grumble. Writing by Disabled Women*. London: Women's Press.
- McCarthy, M. (1999). *Sexuality and Women with Learning Disabilities*. London: Jessica Kingsley Publishers.
- McConnell, D. (2001). Prevention services lag for American women disabled by Multiple Sclerosis. *British Medical Journal* 323, 968-9.
- Moore, S., Gridley, H. Taylor, K. and Johnson, K. (2000). Women's views about intimate examinations and sexually inappropriate practices by their general practitioners. *Psychology and Health*. 15, 71-84.
- Morris, J. (1991). *Pride against Prejudice. Transforming Attitudes to Disability*. London: Women's Press.
- Morris, J. (1996). *Encounters with Strangers: Feminism and Disability*. London: Women's Press.
- NHSBSP (2000). *Good Practice in Breast and Cervical Screening for Women with Learning Disabilities. NHSBSP Publication No. 46, NHSCSP Publication No 13*. Sheffield: NHSCSP Publications.
- Nosek, M. A. Young, M., Rintela, D. Howland, C., Foley, C. and Bennett J. (1995). Barriers to reproductive health maintenance among women with physical disabilities. *Journal of Women's Health*. 4, 5, 505-18.

- Nosek, M.A. and Howland, C.A. (1997) Breast and cervical screening among women with physical disabilities *Archives of Physical Medicine and Rehabilitation*. 78. 12, (Suppl.5) 539-44.
- Oliver, M. (1996). *Understanding Disability. From Theory to Practice*. London: Macmillan.
- Orbell, S, Crombie, I, Robertson, A. Johnston, G. and Kenicer, M. (1995). Assessing the effectiveness of a screening campaign: who is missed by 80% cervical screening coverage? *Journal of the Royal Society of Medicine*. 88, 389-94.
- PapScreen Victoria (2001). *Evaluation Report Vol 1. 1997-2000* Melbourne: Anti-Cancer Council of Victoria.
- PapScreen Victoria, The Cancer Council Victoria, Listing of Community Pap Test Services Across Victoria (2002).
- Scullion, P. (1999). Disability in the nursing curriculum. *Disability and Society*. 14, 4, 539-559
- Seymour, W. (1998). *Remaking the Body. Rehabilitation and Change*. London: Routledge.
- Shabas, D. and Weinreb, H. (2000). Preventative health care in women with M.S. *Journal of Women's Health Gender Based Medicine*. 9,4, 389-95.
- Sinson, V. (1992). *Mental Handicap and the Human Condition*. London: Tavistock Press.
- Stein, K. and Allen, N. (1999). Cross sectional survey of cervical cancer screening in women with learning disabilities. *British Journal of Learning Disability*. 23. 56-8.
- Sutherland, G. (2002 unpublished). Preliminary Results - Living Well Research Project. Melbourne: Centre for Developmental Disability Health Victoria (CDDHV).
- The Cancer Council Australia (2001). *National Cancer Prevention Policy. 2001-2003*. Sydney: The Cancer Council Australia.
- Traustadottir, R. and Johnson, K. (2000). *Women with Intellectual Disabilities. Finding a Place in the World*. London: Jessica Kingsley.
- Victorian health and Well Being (2001) *Stage 1 Consultation Report Women with Disabilities*. Melbourne: Department of Human Services.
- Victorian State Disability Plan 2002-2012. (2002) Melbourne: Disability Services. Department of Human Services.
- Walmsley, J. and Johnson, K. (in press) *Inclusive Research with People with Learning Disabilities*. London: Jessica Kingsley.
- Weedon, C. (1987). *Feminist Practice and Poststructuralist Theory*. Oxford: Basil Blackwell.

Witmeyer, S. (2001). GYN exam and mammogram for women with developmental disabilities. *Exceptional Medicine Newsletter*. Quarterly Newsletter of the UNM Health Sciences Centre for Developmental Disabilities Network. 1, 1, 1-10.

APPENDIX 1 REFERENCE GROUP MEMBERS

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Ms Karleen Plunkett, Latrobe City Council
Ms Katy Ragheb, Inner South Community Health Service Inc
Ms Anne Ridowski, Family Planning Victoria
Ms Naomi Schwarz, *PapScreen Victoria*
Ms Di Siebold, Vision Australia
Ms Janice Slattery, Consultant
Ms Angela Steele, Royal Women's Hospital
Ms Ria Strong, ARCSHS
Ms Georgina Sutherland, Centre for Developmental Disabilities Health

APPENDIX 2 CERVICAL SCREENING AND WOMEN WITH DISABILITIES ACCESS AUDIT

QUESTIONS	OBSERVATIONS
<p>1. General</p> <ul style="list-style-type: none"> ? How much does the service cost? ? Is a woman doctor/nurse available? ? How often is the service available? ? What is the referral procedure? 	
<p>2. Finding out about the service</p> <p>How do you advertise your service?</p> <ul style="list-style-type: none"> <input type="checkbox"/> Phone book <input type="checkbox"/> Front of building <input type="checkbox"/> Pamphlets <ul style="list-style-type: none"> <input type="checkbox"/> Plain English <input type="checkbox"/> Community languages <input type="checkbox"/> Alternative formats <input type="checkbox"/> Distributed to disability services <input type="checkbox"/> Disability newsletters <input type="checkbox"/> Media—radio, newspapers, etc. <input type="checkbox"/> Other 	<ul style="list-style-type: none"> <input type="checkbox"/> Is the service clearly signposted from the street? <input type="checkbox"/> Are pamphlets advertising the service available in the waiting room?
<p>3. Asking for a test – whose responsibility???</p> <ul style="list-style-type: none"> ? Whose responsibility is it to ask for a Pap test? The woman's or ??? ? Do (appropriate) staff within the service ask about Pap screening as a matter of course, when they see someone and refer women where appropriate? ? What proportion of clients come through referral? From whom? ? What proportion of clients come as self-referral? 	
<p>4. Making an appointment</p> <ul style="list-style-type: none"> ? How easy is it to make an appointment <ul style="list-style-type: none"> fi Ring service. Ask to have a Pap test. What happens? fi Ask someone with speech difficulties to ring. What happens? ? How long is a standard appointment? Can longer appointments be made? 	

<p>5. Disclosing disability-related needs</p> <ul style="list-style-type: none"> ? Is information sought on disability or other special needs when someone is making an appointment? If so, how? ? If a woman discloses a disability/ disability related needs, how is this information responded to? ? Would you <i>expect</i> a woman to disclose her disability before she came to her appointment? ? If a woman with a disability came for a Pap test, without warning, what would you do? <p>fi Suggest a couple of scenarios.</p>	<ul style="list-style-type: none"> <input type="checkbox"/> Do reception/telephone staff have training in responding to people who have telephone difficulties? <input type="checkbox"/> Is there a TTY number? <ul style="list-style-type: none"> <input type="checkbox"/> Can staff use the TTY? <input type="checkbox"/> If no TTY, are staff familiar with the relay service? <input type="checkbox"/> Is there a fax? <input type="checkbox"/> Is there email?
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